

ILLNESS MANAGEMENT REPORT: CBT, GET, AND PACING

“NO DECISIONS ABOUT ME, WITHOUT ME”

**Results and In-depth Analysis of the 2012 ME Association
Patient Survey Examining the Acceptability, Efficacy,
and Safety of Cognitive Behavioural Therapy, Graded
Exercise Therapy and Pacing, as Interventions used as
Management Strategies for ME/CFS**

The ME Association, May 2015

EXECUTIVE SUMMARY

A summary of our report on the acceptability, efficacy, and safety of Cognitive Behaviour Therapy (CBT), Graded Exercise Therapy (GET) and Pacing, as interventions used as management strategies for patients with ME/CFS.

This relates to the use of CBT, GET and Pacing by health professionals when delivered to patients on either a one-to-one basis or in a group setting.

We are publishing this report to coincide, as closely as is possible, with ME Awareness Week 2015. Printed versions will also be made available to order from the website shop.

INTRODUCTION

Evidence from patient surveys reporting experiences of the three main therapeutic approaches to management of ME/CFS have produced results which differ significantly to that promoted by some healthcare practitioners and claimed by the published research evidence.

In 2012 we decided that a new and more detailed patient survey was required to seek to explain the factors that might contribute to patient reported outcomes.

When large numbers of patients consistently report that currently employed management approaches are not as acceptable, effective, or safe as has been claimed they ought to be, we see it as our responsibility to investigate these reports, attempt to substantiate them, and then lobby for change in respect of clinical recommendations.

It is our hope that this new evidence might persuade the National Institute for Health and Care Excellence (NICE) to improve the current clinical guideline on ME/CFS (CG53), and also provide clearer guidance to NHS specialist services and private health

practitioners on ways in which illness management advice can be made more suitable for all those affected by this illness; thus leading to improved patient reported outcomes.

METHOD

Our survey was launched online in May 2012 and operated until August 2012. It was open to anyone with myalgic encephalomyelitis, chronic fatigue syndrome or post-viral fatigue syndrome, which we have called ME/CFS.

We asked about management courses and self-management which employed CBT, GET or Pacing approaches and we also canvassed the views of those who had not been offered a course, had been refused a course, or had not taken up a course recommendation.

The survey was split into three sections, one each for CBT, GET and Pacing, asked 228 questions in total and was completed by 1428 respondents (though not every question was completed by every respondent).

Part 1 of the report is concerned with responses from those who had received a positive diagnosis from a health professional, had undertaken one-to-one or group courses (whether or not they had fully completed the recommended number of sessions) and had indicated the severity of their illness before and after their courses, and whether or not their courses were appropriate to their needs.

Of these respondents, 493 had been on a CBT course, 233 on

a GET course and 226 on a Pacing course. Some had been on separate courses for one or more of the interventions; others had been on courses comprising multiple interventions.

Part 1 comprises 120 pages of quantitative analysis (looking at the data from various perspectives), 10 pages of conclusions and recommendations, and is accompanied by 130 pages of qualitative data (non-numerical data which relates to the written descriptions of respondents' experiences).

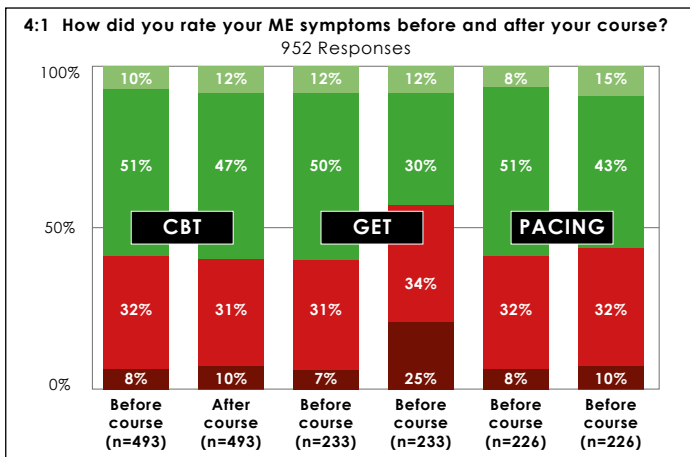
RESULTS

We examined the effect courses were deemed to have had on illness severity, symptoms (overall and individually), disability benefits, employment and education, the appropriateness of courses in relation to individual patient needs and the effect CBT has on anxiety, depression and stress.

We also considered course availability within the NHS, suitability of session length, reasons why courses were not completed in full, the provision of course information to patients, the impact NICE Guideline CG53 (2007) has had on delivery, effectiveness of courses delivered by specialists versus non-specialists, and we compared our results against previous patient surveys.

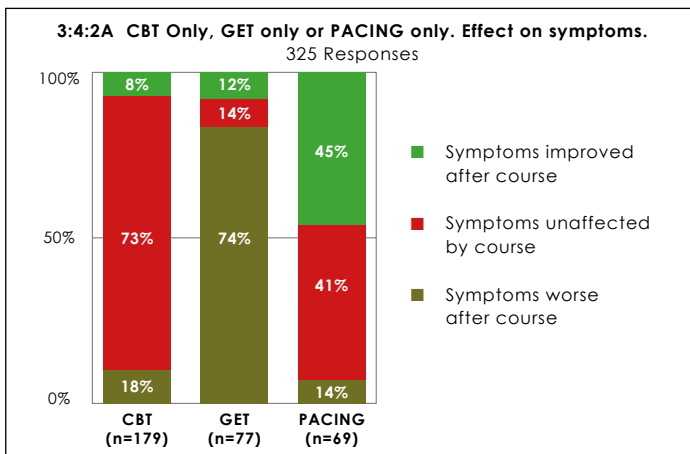
For this executive summary, we provide some examples – complete results and full analysis can be read later in the report:





Example A:

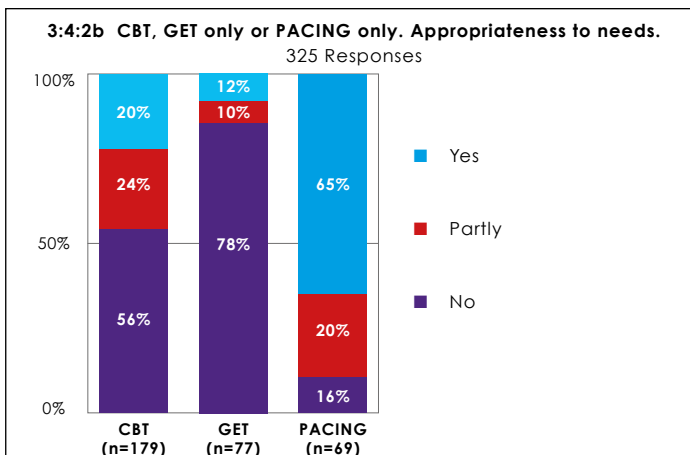
With regard to the effect courses had on illness severity, we found that GET resulted in the most significant change with more patients who attended such courses reporting their illness had become more severe as a result (see Section 3, Key Findings 3:3 and chart at Appendix 2 Section 4, 4:1).



Example B:

Where patients attended a CBT, GET or Pacing course which had no overlapping elements of the other two interventions, more reported an improvement in symptoms following their Pacing course than did those who attended either of the other courses.

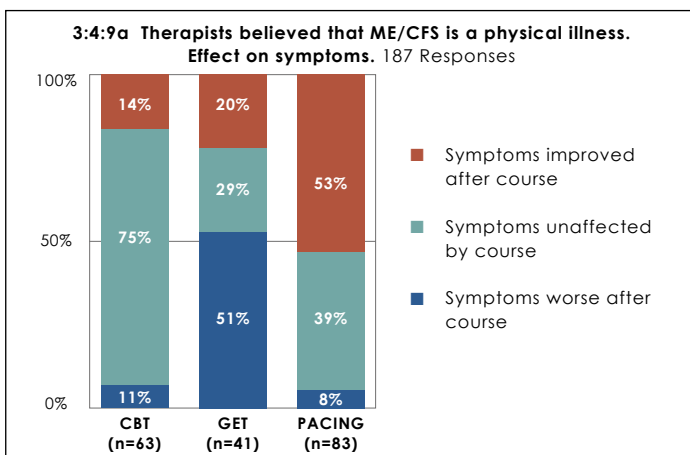
CBT resulted in 91% of participants feeling their ME/CFS symptoms were unaffected or made worse, GET 88%, and Pacing 55% (see Section 3, Key Findings 3:4, chart: 3:4:2a)



Example C:

It was clear that the majority of patients attending Pacing courses with no overlapping elements found this management approach more appropriate to their needs than did those who attended either CBT only or GET only courses.

Only a small minority of GET and CBT courses were appropriate to needs (see Section 3, Key Findings 3:4, chart: 3:4:2b).

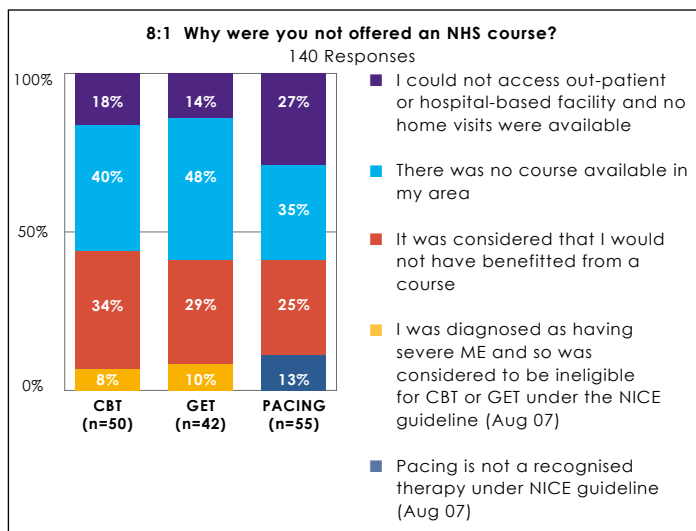


Example D:

Symptoms were reported as having improved or as remaining unaffected by more patients where therapists leading a course recognised ME/CFS to be a physical illness than where therapists believed the illness was psychological.

Symptoms were deemed to have been made notably worse where courses were led by therapists holding this psychological belief even for Pacing (see Section 3, Key Findings 3:4, charts: 3:4:9a and 3:4:11a).

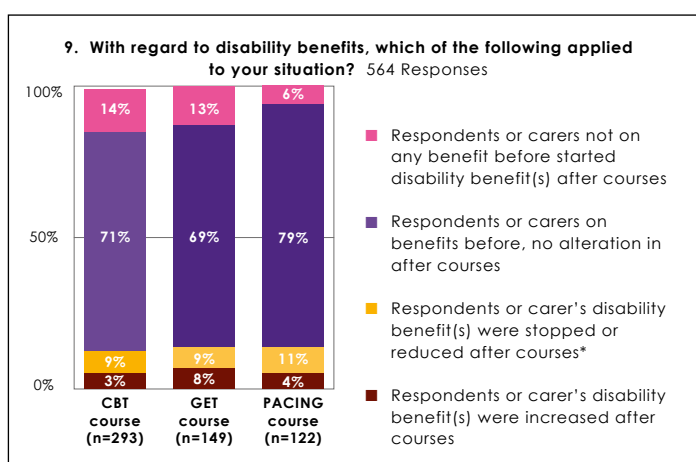




Example E:

Patients who were not offered or who were refused courses reported the main reason as being that no courses were available in their area.

The second reason was judged to be that many patients were considered unlikely to benefit from the offered courses, and also of note was a lack of access to courses and no available home-visit option (see Key Findings, Section 3:11 and Chart at Appendix 2, Section 8).



Example F:

For those who were on benefits, it was most notable that irrespective of the course undertaken, claims remained largely the same with few reducing or stopping their benefits.

However, net overall increases were seen in benefits following courses in CBT and GET compared to a slight decrease from those attending Pacing courses (see Key Findings, Section 3:12 and Chart at Appendix 2, Section 9).

CONCLUSIONS AND RECOMMENDATIONS

We conclude that CBT in its current delivered form should not be recommended as a primary intervention for people with ME/CFS.

CBT courses based on the model that abnormal beliefs and behaviours are responsible for maintaining the illness, have no role to play in the management of ME/CFS and increase the risk of symptoms becoming worse. The belief of some CBT practitioners that ME/CFS is a psychological illness was the main factor which led to less symptoms improving, less courses being appropriate to needs, more symptoms becoming worse and more courses being seen as inappropriate.

Our results indicate that graded exercise therapy should form no part of any activity management advice employed in the delivery of CBT, as this also led to a negative impact on outcomes.

There is a clear need for better training among practitioners. The data indicates that lack of knowledge and experience had a direct effect on outcomes and remained a key factor, even where courses were held in specialist clinics or elsewhere given by therapists with an ME/CFS specialism.

However, our results did indicate that, when used appropriately, the practical coping component of CBT can have a positive effect in helping some patients come to terms with their diagnosis and adapt their lives to best accommodate it.

CBT was also seen to have a positive effect in helping some patients deal with comorbid issues – anxiety, depression, stress – which may occur at any time for someone with a long-term disabling illness.

An appropriate model of CBT – one that helps patients learn practical coping skills and/or manage comorbid issues such as those listed

above – could be employed, where appropriate, for ME/CFS as it is for other chronic physical illnesses such as multiple sclerosis, Parkinson's disease, cancer, heart disease, and arthritis etc.; and we recommend all patients should have access to such courses as well as access to follow-up courses and/or consultations as and when required.

GRADED EXERCISE THERAPY (GET)

We conclude that GET should be withdrawn with immediate effect as a primary intervention for everyone with ME/CFS.

One of the main factors that led to patients reporting that GET was inappropriate was the very nature of GET itself, especially when it was used on the basis that there is no underlying physical cause for their symptoms, and that patients are basically ill because of inactivity and deconditioning.



A significant number of patients had been given advice on exercise and activity management that was judged harmful with symptoms becoming worse or much worse and leading to relapse. And it is worth noting that despite current NICE recommendations, a significant number of severe-to-very severe patients were recommended GET by practitioners and/or had taken part in GET courses.

The other major factor contributing to worsening symptoms was the incorrect belief held by some practitioners that ME/CFS is a psychological condition leading to erroneous advice that exercise could overcome the illness if only patients would 'push through'.

We recognise that it is impossible for all treatments for a disease to be free from side-effects, but if GET was a licensed medication, we believe the number of people reporting significant adverse effects would lead to a review of its use by regulatory authorities.

As a physical exercise-based therapy, GET may be of benefit to a sub-group who come under the ME/CFS umbrella and are able to tolerate regular and progressive increases in some form of aerobic activity, irrespective of their symptoms. However, identifying a patient who could come within that sub-group is problematic and not possible at present.

Some patients indicated that they had been on a course which had a gentle approach of graded activity rather than a more robust and structured approach of graded physical exercise. There were some reports that patients were told they should not exercise when they felt too unwell to do so. These led, for some, to an improvement in symptoms or to symptoms remaining unaffected.

However, we conclude that GET cannot be regarded as a safe and effective form of treatment for the majority of people with ME/CFS. The fact that many people, including those who consider themselves severely affected, are being referred to specialist services for an

intervention that makes them either worse or much worse is clearly unacceptable and in many cases dangerous.

GET should therefore be withdrawn by NICE and from NHS specialist services as a recommended treatment with immediate effect for everyone who has a diagnosis of ME/CFS. This advice should remain until there are reliable methods for determining which people who come under the ME/CFS umbrella are likely to find that GET is a safe and effective form of management.

PACING

Pacing was consistently shown to be the most effective, safe, acceptable and preferred form of activity management for people with ME/CFS and should therefore be a key component of any illness management programme.

For some, improvement may be a slow process so, whilst they may be somewhat better by the end of a course, the improvement is not enough to take them into a better category of severity for some time, perhaps not until they have self-managed their illness for a few years.

The benefit of Pacing may relate to helping people cope and adapt to their illness rather than contributing to a significant improvement in functional status. Learning coping strategies can help make courses more appropriate to needs even if they do not lead to immediate or even longer term improvement in symptoms. Importantly, it can prevent symptoms from becoming worse.

Pacing can be just as applicable to someone who is severely affected, as to someone who is mildly or moderately affected, although additional measures need to be taken to ensure that a person who is severely affected has equal access to services.

As with CBT, there must be better training for practitioners who are to deliver such management courses. Proposed increases in activity, both mental and physical, must be gradual, flexible and individually

tailored to a patient's ability and circumstance and not progressively increased regardless of how the patient is responding and therapists must be taught to recognise that.

All patients should have access to suitable courses, follow-up courses and/or consultations as and when required.

WHAT'S NEXT?

We consider the current NICE guideline on ME/CFS with regard to illness management recommendations to be in need of considerable amendment and for NHS specialist services and private practitioners to be advised of more appropriate management methods.

We will therefore be preparing a paper on illness management that will better reflect the patient experience using evidence that has been obtained in this report, and from our 2010 Management Report, 'Managing my M.E. What people with ME/CFS and their carers want from the UK's health and social services.' This paper will also reflect those aspects of the 2007 NICE guideline that we feel are supported by patient evidence but have not found their way to delivered patient care.

Our paper will detail recommended illness management methods and focus on issues such as a more personalised approach to patient care, improving professional education, course accessibility and home visits, better provision of patient information and shared decision making.

We have already made a start on this work and some of our conclusions and recommendations which directly follow on from the results of this survey are presented in part 1 of the report.

We aim to improve patient reported outcomes with a more encompassing and sympathetic approach to illness management.

Note: Please see Sections 4 and 5 for our full conclusions and recommendations.

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TABLE OF CONTENTS

2	Executive Summary	2	3:4:5	Courses Held by Therapists Specialising in ME/CFS
2	Introduction	2		
2	Method	2	3:4:6	Courses Held by Therapists Not Specialising in ME/CFS
2	Results	2	3:4:7	One-to-one Courses
4	Conclusions and Recommendations	4	3:4:8	Group Courses
5	What's next?	5	3:4:9	Courses held by Therapists who believed that ME/CFS is a Physical Illness
6	Table of Contents	6		
11	Section 1: Introduction			
1:1	Reasons for Survey		3:4:10	Courses held by Therapists who believed that ME/CFS is a Mixture of a Physical and a Psychological Illness
1:2	Intervention Definitions			
	Section 2: About the survey			
2:1	General		3:4:11	Courses held by Therapists who believed that ME/CFS is a Psychological Illness
2:2	Nomenclature			
2:3	Division of Data – Categories of ME/CFS Severity		3:4:12	Courses which did not affect Symptoms – Appropriateness to Needs
2:4	Division of Data – Effect of Courses on Overall Symptoms		3:4:13	Courses Completed in Full
2:5	Report Recipients		3:4:14	Courses Partly Completed
	Section 3: Key Findings			
3:1	Qualitative Data – Reasons for Course Success and Course Failure		3:5	Further Comparisons – Most and Least Beneficial of the Listed Criteria
3:2	Criteria Employed		3:5:1	Cognitive Behavioural Therapy (CBT)
3:2:1	Listed Criteria		3:5:2	Graded Exercise Therapy (GET)
3:2:2	Effect of Courses on Specific Symptoms		3:5:3	Pacing
3:2:3	Factors Influencing Course Effectiveness		3:6	Effect of Courses on Illness Severity
3:3	Effect of Courses on Illness Severity		3:6:1	Effect of Courses on Illness Severity – CBT
3:3:1	Effect of Courses on Illness Severity – CBT		3:6:2	Effect of Courses on Illness Severity – GET
3:3:2	Effect of Courses on Illness Severity – GET		3:6:3	Effect of Courses on Illness Severity – Pacing
3:3:3	Effect of Courses on Illness Severity – Pacing		3:7	Effect on Mental Health and ME/CFS Symptoms – CBT
3:4	Effect of Courses on Symptoms		3:8	Effect of Courses on Specific ME/CFS Symptoms
3:4:1	Overall Data – Total Respondents		3:8:1	Effect of Courses on Specific ME/CFS Symptoms – CBT
3:4:2	Single Intervention Courses		3:8:2	Effect of Courses on Specific ME/CFS Symptoms – GET
3:4:3	Combined Courses – Elements of all Three Interventions		3:8:3	3:8:3 Effect of Courses on Specific ME/CFS Symptoms – Pacing
3:4:4	Combined Courses – Elements of One of the other Two Interventions		3:9	3:9 Self-management

TABLE OF CONTENTS

<p>2 3:9:1 Self-management – CBT</p> <p>2 3:9:2 Self-management – GET</p> <p>2 3:9:3 Self-management – Pacing</p> <p>2 3:10 3:10 Comparison with Previous Patient Surveys</p> <p>4 3:11 Availability of NHS Management Courses</p> <p>5 6 3:12 Disability Benefits Status Following Courses</p> <p>3:13 Effect of Courses on Employment and Education</p> <p>3:14 Length of Course Sessions</p> <p>3:15 Provision of Information about Courses</p> <p>3:16 Effect of the 2007 NICE Guideline on Course Outcomes</p> <p>3:16:1 Introduction</p> <p>3:16:2 Effect of the 2007 NICE Guideline on Course Outcomes – CBT</p> <p>3:16:3 Effect of The 2007 NICE Guideline on Course Outcomes – GET</p> <p>3:16:4 Effect of The 2007 NICE Guideline on Course Outcomes – Pacing</p> <p>Section 4: Conclusions</p> <p>4:1 General</p> <p>4:2 Conclusions – Cognitive Behavioural Therapy (CBT)</p> <p>4:3 Conclusions – Graded Exercise Therapy (GET)</p> <p>4:4 Conclusions – Pacing</p> <p>4:5 Conclusions – Position Following The 2007 NICE Guideline</p> <p>4:5:1 4:5:1 Position Following The 2007 NICE Guideline – CBT</p> <p>4:5:2 Position Following The 2007 NICE Guideline – GET</p> <p>4:5:3 Position Following The 2007 NICE Guideline – Pacing</p> <p>Section 5: Recommendations</p> <p>5:1 General</p> <p>5:2 Recommendations – CBT</p> <p>5:3 Recommendations – GET</p> <p>5:4 Recommendations – Pacing</p>	<p>2 5:5 Recommendations – Health Professional Training – Safety and Adverse Effects</p> <p>2 5:6 Recommendations – Practical Considerations Course Planning</p> <p>2 5:7 Recommendations – Provision of Patient Information</p> <p>4 5:8 Recommendations – Follow-up Courses and Consultations</p> <p>5 5:9 Recommendations – The 2007 NICE Guideline for ME/CFS (CG53)</p> <p>5:10 Recommendations – Patient Involved Decision Making</p> <p>Section 6: Report Caveats</p> <p>Section 7: Acknowledgements</p> <p>7:1 7:1 Report Authors</p> <p>7:1:1 7:1:1 Principle Authors</p> <p>7:1:2 7:1:2 Contributors</p> <p>7:2 7:2 Author's Note</p> <p>Appendix 1: Qualitative Data – Additional Comments about Course99</p> <p>1:1 Courses Taken by Mild to Moderate Sufferers</p> <p>1:1:1 Courses taken by Mild to Moderate Sufferers – CBT</p> <p>1:1:2 Courses Taken by Mild to Moderate Sufferers – GET</p> <p>1:1:3 Courses taken by Mild to Moderate Sufferers – Pacing</p> <p>1:2 1:2 Courses Attended by Severe to Very Severe Sufferers</p> <p>1:2:1 Courses Attended by Severe to Very Severe Sufferers – CBT</p> <p>1:2:2 1:2:2 Courses taken by Severe to Very Severe Sufferers – GET</p> <p>1:2:3 Courses taken by Severe to Very Severe Sufferers – Pacing</p> <p>Appendix 2: Quantitative data – Listed Criteria</p> <p>2:1 2:1 Introduction</p> <p>2:2 2:2 Demographics</p> <p>2:2:1 2:2:1 Who did you receive your positive diagnosis from?</p>
---	---

TABLE OF CONTENTS

<p>2 2:2:2 How old were you when your ME symptoms first started?</p> <p>2 2:2:3 How long have you been ill or, if recovered, were ill?</p> <p>2 2:2:4 What is your gender?</p> <p>4 2:3 Course Specifics</p> <p>5 2:3:1 Did your course contain overlapping elements of CBT and/or GET and/or Pacing?</p> <p>6 2:3:2 For how many years did you have ME before you received the course?</p> <p>2:3:3 Which of the following was your main course practitioner?</p> <p>2:3:4 Was your course held in a clinic or online?</p> <p>2:3:5 Geographically, where did the course take place?</p> <p>2:3:6 If you only attended/completed part of a course, why did you?</p> <p>2:3:7 How long did each course session last?</p> <p>2:3:8 How many course sessions did you take part in?</p> <p>2:3:9 Was your course in a group or one to one?</p> <p>2:3:10 Were you given information about the course?</p> <p>2:3:11 Did your therapist believe that ME/CFS is a physical illness, a mix of a physical and psychological illness, or a psychological illness?</p> <p>2:3:12 Did you receive an entire course or part of a course?</p> <p>2:4 Effect of Courses on ME/CFS Symptoms</p> <p>2:4:1 Did the degree of severity of your ME/CFS symptoms alter after your course?</p> <p>2:4:2 Overall, (irrespective of the Listed Criteria) how were your ME/CFS symptoms after the course compared to how they were before?</p> <p>2:4:3 Overall, how were your ME/CFS symptoms after the course compared to how they were before? Courses which were CBT only, GET only or Pacing only.</p>	<p>2 2:4:4 Overall, how were your ME/CFS symptoms after the course compared to how they were before? Courses which had elements of all 3 interventions.</p> <p>2 2:4:5 Overall, how were your ME/CFS symptoms after the course compared to how they were before? Courses run by therapists stated an ME/CFS specialism.</p> <p>4 2:4:6 Overall, how were your ME/CFS symptoms after the course compared to how they were before? Courses held by therapists not stated to have an ME/CFS specialism.</p> <p>5 2:4:7 Overall, how were your ME/CFS symptoms after the course compared to how they were before? One-to-one courses.</p> <p>6 2:4:8 Overall, how were your ME/CFS symptoms after the course compared to how they were before? Group courses.</p> <p>2:4:9 Overall, how were your ME/CFS symptoms after the course compared to how they were before? Courses where therapists who believed that ME/CFS is a physical illness.</p> <p>2:4:10 Overall, how were your ME/CFS symptoms after the course compared to how they were before? Courses where therapists believed that ME/CFS is a mixture of a physical and a psychological illness.</p> <p>2:4:11 Overall, how were your ME/CFS symptoms after the course compared to how they were before? Courses where therapists believed that ME/CFS is a psychological illness.</p> <p>2:4:12 Overall, how were your ME/CFS symptoms after the course compared to how they were before? Courses completed by respondents.</p> <p>2:4:13 Overall, how were your ME/CFS symptoms after the course compared to how they were before? Courses partly completed by respondents.</p>
--	--

TABLE OF CONTENTS

<p>2 2:5 Courses Appropriate to Needs</p> <p>2 2:5:1 On balance, would you say that the course was appropriate to your needs? Overall data (i.e. irrespective of the Listed Criteria).</p> <p>2</p> <p>2 2:5:2 On balance, would you say that the course you received was appropriate to your needs? Courses which were CBT only, GET only, or Pacing only.</p> <p>6</p> <p>2:5:3 On balance, would you say that the course you received was appropriate to your needs? Courses which had elements of all three interventions.</p> <p>2:5:4 On balance, would you say that the course was appropriate to your needs? Courses which were held by therapists stated to have an ME/CFS specialism.</p> <p>2:5:5 Overall, how were your ME/CFS symptoms after the course compared to how they were before? Courses held by therapists not stated to have an ME/CFS specialism.</p> <p>2:5:6 On balance, would you say that the course was appropriate to your needs? One-to-one courses.</p> <p>2:5:7 On balance, would you say that the course was appropriate to your needs? Group courses.</p> <p>2:5:8 On balance, would you say that the course was appropriate to your needs? Courses where therapists who believed that ME/CFS is a physical illness.</p> <p>2:5:9 On balance, would you say that the course was appropriate to your needs? Courses where therapists believed that ME/CFS is a mixture of a physical and a psychological illness.</p> <p>2:5:10 On balance, would you say that the course was appropriate to your needs? Courses where therapists believed that ME/CFS is a psychological illness.</p> <p>2:5:11 On balance, would you say that the course was appropriate to your needs? Courses which did not affect symptoms.</p>	<p>2 2:5:12 On balance, would you say that the course was appropriate to your needs? Where respondents completed the course.</p> <p>2</p> <p>2 2:5:13 On balance, would you say that the course was appropriate to your needs? Courses partly completed by respondents.</p> <p>4</p> <p>6 2:6 Effect on Mental Health and ME/CFS Symptoms – CBT</p> <p>2:6:1 Overall, how were your anxiety, depression, stress and ME symptoms after your course?</p> <p>2:7 How did your Course Affect Specific ME/CFS Symptoms?</p> <p>2:7:1 Cognitive Behavioural Therapy (CBT)</p> <p>2:7:2 Graded Exercise Therapy (GET)</p> <p>2:7:3 Pacing</p> <p>2:8 Respondents who were Not Offered or were Refused an NHS Course</p> <p>2:8:1 To the best of your knowledge, what do you think was the main reason why you were not offered or were refused the option of attending an NHS course?</p> <p>2:9 Disability Benefits Status Following Courses</p> <p>2:9:1 With regard to disability benefits, which of the following applied to your situation?</p> <p>2:10 Effect of The 2007 NICE Guideline on Course Outcomes</p> <p>2:10:1 Did the severity of your ME/CFS symptoms alter after the course?</p> <p>2:10:2 Overall (irrespective of the Listed Criteria) how were your ME/CFS symptoms after the course compared to how they were before?</p> <p>2:10:3 On balance, would you say that the course was appropriate to your needs?</p>
---	---

TABLE OF CONTENTS

2 2 2 2 4 5 6	Appendix 3: Qualitative Data – Courses with Elements of other Interventions 3:1 CBT Courses with Elements of Other Interventions 3:1:1 CBT Courses with Elements of Pacing (sometimes called 'Activity Management') – no specific mention of Exercise 3:1:2 CBT Courses with Elements of GET 3:1:3 CBT courses with elements of both GET and Pacing 3:2 GET Courses with Elements of CBT and Pacing 3:2:1 GET Courses with Elements of CBT 3:2:2 GET Courses with Elements of Pacing 3:2:2 GET Courses with Elements of both CBT and Pacing 3:3 Pacing Courses with Elements of CBT and GET 3:3:1 Pacing Courses with Elements of CBT 3:3:2 Pacing Course with Elements of GET 3:3:3 Pacing Courses with Elements of both CBT and GET Appendix 4: Qualitative Data – Effect of courses on Employment and Education 269 4:1 Effect of Courses on Employment and Education – CBT 4:2 Effect of Courses on Employment and Education – GET 4:3 Effect of Courses on Employment and Education – Pacing Appendix 5: Quantitative data – Self Management 282 5:1 Was your self-management effective? 5:2 Overall, how were your symptoms after you began self-managing your illness compared to how they were before?	2 5:3 If you had a consultation, did you find it helpful for self-management? 2 2 Appendix 6: Previous Patient Surveys 285 4 6:1 Previous Patient Survey Results – CBT 5 6 6:2 Previous Patient Survey Results – GET 6:3 Previous Patient Survey Results – Pacing Appendix 7: Concerns about the Reporting of RCTs Appendix 8: Questions Asked in Survey – Answers Not Used in Report 8:1 Questions Asked in Survey – Answers not used in Report Appendix 9: References
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SECTION 1: INTRODUCTION

1:1 REASONS FOR SURVEY

This survey into the acceptability, efficacy and safety of the interventions known as Cognitive Behaviour Therapy (CBT), Graded Exercise Therapy (GET) and Pacing (Pacing) as illness management strategies for patients with Myalgic Encephalopathy (ME), also called Myalgic Encephalomyelitis, Chronic Fatigue Syndrome (CFS) and Post Viral Fatigue Syndrome (PVFS) was initiated for the following reasons:

a) We were aware, from the reporting of symptom changes from patient surveys and clinical trials, that some patients found one or more of these interventions to be beneficial. However a substantial number did not. We wanted to find the reasons for this so that steps could be taken to increase the effectiveness of courses and self-management of symptoms.

b) At the same time, we were aware, from the reporting of symptom changes from patient surveys, of the harm which CBT and GET can do to some patients. We were also aware from patient surveys that the degree of harm following Pacing was far less but did exist. We wanted to see if we could give an indication of why this is so that steps could be taken to minimise it.

c) We wanted to gauge the effect of courses on disability allowances, on employment and on education.

d) Together with some other ME/CFS charities we had criticised the 2007 NICE (the National Institute for Health and Clinical Excellence) Guideline CG53. We were aware that, with CBT and GET, there was some (not always consistent) support for their use from randomised controlled clinical trials (RCTs) and this support was reflected in the 2007 NICE guideline. However, we were also aware of criticisms in the reporting of these trials.

For example, in reporting that CBT and GET were beneficial no explicit indication was given as to the type of CBT or GET that was being trialled and whether there is heterogeneity in their components. We felt that if those criticisms were justified it cast doubt on the wisdom of NICE relying on those trial results and that, in any event, what takes place under trial conditions, with therapists having an expert knowledge of ME/CFS, was not what was necessarily taking place in general delivery. We perceived a need to try to ascertain, in detail, patient experience outside trials.

f) We were aware of an RCT involving Pacing, Wallman et al.

g) We were also aware of the PACE trial 2011 and 'adaptive pacing'. However, we believe the conduct and reporting of the PACE trial to be flawed. See note below.

h) We were aware of a considerable amount of evidence about the interventions from patient surveys all of which were ignored by NICE. In the 2007 NICE guideline, Pacing was listed as a management approach with a note that people have reported it to be helpful but that there was not enough research evidence on benefits or harm. That is the only mention of it. It is true that patient surveys produce subjective data and it is true that, with different cohorts of survey respondents and different ways of putting questions, some of the data will differ. However, the ME/CFS patient surveys of which we were aware produced an overall clear and consistent pattern about symptoms following the interventions. We felt that for NICE to ignore the weight of this patient evidence was wrong. We therefore commissioned a survey that was more wide ranging than any previous patient survey in order to obtain further evidence to show why such evidence should be given proper consideration.

i) We had anecdotal evidence that there was sometimes

misunderstanding as to the delivery of the interventions. We were also aware that, aside from what were termed illness/energy/activity management courses, there were large degrees of overlap and interaction between CBT, GET and Pacing, and we believed it could be beneficial if the extent of this overlap was better understood.

j) We were aware that some CBT and GET therapists were of the opinion that ME/CFS is a psychological rather than a physical illness and wanted to give an indication of the extent of that belief and its effect on patient reported outcomes.

k) We were aware of considerable degrees of antagonism and scepticism about CBT and GET among ME/CFS patients and wanted to try to find out whether that antagonism and scepticism was justified.

l) We were aware that many patients were left to self-manage their illness following courses or consultations. We wished to see how well those patients coped with self-management with a view to seeing how this could be improved.

Note:

1. The ME Association's letter dated 23rd October 2013 outlining our opposition to the proposal that a review of the 2007 NICE guideline be placed on hold. That opposition has also been expressed in other reports and communications. See for example:

2. 'Reporting of Harms Associated with Graded Exercise Therapy and Cognitive Behavioural Therapy in Myalgic Encephalomyelitis/Chronic Fatigue Syndrome' at pages 78-83 which expresses concerns about how the data in the PACE trial was collected, interpreted and reported, and;

3. The comments about the PACE trial from nine internationally recognised ME/CFS specialists reported on the website "Paradigm Change". This article largely relates to beliefs that



Cognitive Behaviour Therapy and Graded Exercise Therapy are not suitable interventions for patients with ME/CFS.

4. Six letters criticising aspects of the PACE trial paper published in *The Journal of Psychological Medicine* August (2013).

1:2 INTERVENTION DEFINITIONS

Cognitive Behaviour Therapy (CBT), Graded Exercise Therapy (GET) and Pacing have been used for some time as the three main non-pharmacological interventions widely recommended in the specialist management and/or self-management of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS).

In our 2012 survey we defined these interventions as follows:

COGNITIVE BEHAVIOURAL THERAPY (CBT)

"The aim of CBT is to remove negative attitudes and improve the day-to-day functioning of people with both physical and psychiatric illnesses. It involves addressing negative beliefs and actions that can affect physiological processes. In relation to ME a course of CBT is often based on the idea that the illness is largely maintained by unhelpful psychological beliefs and behaviour."

GRADED EXERCISE THERAPY (GET)

"GET is a form of planned exercise that aims for gradual, progressive increases in aerobic activities such as walking or swimming. It is based on the principle that a main factor maintaining the illness is inactivity, resulting in lack of fitness and stamina (i.e. de-conditioning). Gradual, ever increasing, exercise within the individual's limits is thought also to help improve confidence in physical ability."

PACING

"Pacing is an energy management strategy in which people with ME are encouraged to achieve an appropriate balance between activity and rest. The hypothesis is that if people with ME use their



energy wisely, then their limited energy will gradually increase. The aim is to prevent people entering a vicious circle of over-activity and setbacks (what is known as 'boom and bust')."

Many courses involve a combination of two or more of these interventions, even if they are not labelled as combination courses. Sometimes combination courses are termed graded activity or energy management courses. These courses may also include approaches such as mindfulness or sleep hygiene.

SECTION 2: ABOUT THE SURVEY

2:1 General

This is the one of the most comprehensive surveys ever to be carried out about courses for and self-management of ME/CFS using CBT, GET and Pacing interventions. Both quantitative and qualitative data was collected.

We asked 228 questions of each respondent.

There were 3 sections to the survey questionnaire, one for each of CBT, GET and Pacing. Each section had two sub-sections asking for information about courses and one sub-section asking for information about self-management.

This part of the report (Part 1) is principally based on the findings of respondents who undertook courses or parts of courses. It also includes data about respondents who were not offered or were refused NHS courses and includes such data about self-management as is pertinent to our Part 1 conclusions and recommendations.

1428 respondents took part. For this part of the report, we made a decision to omit data from those respondents;

- who had not had a positive diagnosis from medical specialists, GPs or other health professionals,
- who had not reported on the degree of severity of their ME/CFS before and after their courses,
- who had not reported on the effect of courses on their symptoms or on whether or not they found their courses appropriate to their needs.

This left 493 respondents who had had a CBT course, 233 who had had a GET course and 226 who had had a Pacing course. Some respondents took courses for more than one intervention and were asked to report on not more than one course/part course for each intervention.

556 respondents reported on self-management using CBT principles and practices, 331 reported self-management using GET principles and practices and 634 reported on self-management using Pacing principles and practices.

We received a large amount of data. Data from questions which related to courses and which are not included in this part of the report are detailed in Appendix 8. The full courses data is available on request.

Many survey questions had an option of 'don't know/can't remember' and we have taken the view, except with two sets of responses, that to include those figures is not useful to a NICE guideline review committee, to health authorities or to researchers and have not included them in this report.

Qualitative data giving indications of what, in the opinion of the respondents, made courses succeed or fail, what interventions overlapped with each other and what courses led to an alteration in the respondents' employment or education are set out in Appendices 1,3 and 4.



To find out what made some courses beneficial, some ineffective and some inappropriate or harmful to patients, we have compared the overall quantitative data with the effects of courses on symptoms and on the appropriateness of courses to the respondents' needs with various sets of criteria as shown in 3:2:1 ('The Listed Criteria').

A statistical analysis of Part 1 has been commissioned.

2:2 NOMENCLATURE

Please note that the survey questionnaire asked respondents to complete the questionnaire if they have, or in the past have had, Myalgic Encephalomyelitis (ME) or Chronic Fatigue Syndrome (CFS) or Post Viral Fatigue Syndrome (PVFS).

We refer to all three in this report as 'ME/CFS' because all three names are used by doctors interchangeably and we are unable to verify what the most accurate description/diagnosis is for individual respondents in this type of survey.

2:3 DIVISION OF DATA – CATEGORIES OF ME/CFS SEVERITY

Because the NICE guideline differs according to the degree of ME/CFS severity:

- In Appendix 1 we have split the qualitative data to report on why some courses were appropriate or inappropriate, succeeded or failed for patients who had mild to moderate ME/CFS before their courses and on patients who had severe to very severe ME/CFS before their courses, and

- In Appendix 2 we have split some of the quantitative data to show any differences between the effects of courses and the appropriateness of courses to the needs of patients who had mild to moderate ME/CFS before their courses and on patients who had severe to very severe ME/CFS before their courses

Our Section 3: Key Findings do not show these splits.

2:4 DIVISION OF DATA – EFFECT OF COURSES ON OVERALL SYMPTOMS

In Appendix 2 we have split:

- the degrees of improvement in ME/CFS symptoms following courses into very much better and somewhat better, and
- the degrees to which ME/CFS symptoms became worse following courses into somewhat worse and very worse

Note: The numbers of respondents who felt so much better after courses that they considered themselves well were only 2 (CBT), 3 (GET) and 3 (Pacing) and in Appendix 2 the data about symptom change following courses has been amalgamated with the data about respondents who felt very much better.

In Section 3: Key Findings, averages of symptom improvement and symptoms becoming worse are given.

2:5 REPORT RECIPIENTS

This Report is available via the ME Association website (<http://www.meassociation.org.uk/>) and printed copies will be sent to:

- All UK health authorities,
- All UK CFS/ME services
- NHS England whose task it is to instruct NICE regarding the preparation of new clinical guidelines, with a request that our conclusions and recommendation require their urgent attention.

They will also be sent to:

- All Party Parliamentary Group on ME/CFS (APPG ME/CFS)
- British Association for Chronic Fatigue Syndrome/ME (BACME)
- British Library
- CFS/ME Research Collaborative (CMRC)
- Chief Medical Officer – Dame Sally Davies
- College of Occupational Therapists
- College of Physiotherapists
- National Institute for Health and

Care Excellence (NICE)

- Royal College of General Practitioners (RCGP)
- Royal College of Nursing (RCN)
- Royal College of Physicians (RCP)
- Royal College of Psychiatrists (RCPsych)
- Science Media Centre (SMC)

Copies of the report will also be sent, on request, to ME/CFS patient support groups.

SECTION 3: KEY FINDINGS

3:1 QUALITATIVE DATA – REASONS FOR COURSE SUCCESS AND COURSE FAILURE

We asked an open question at the end of each section of the survey questionnaire, "Is there anything further you would like to tell us?", and received an enormous response affording us a huge insight into patients' views about what makes a course successful or not.

This was important as successful courses were seen as leading to a better ability to manage the illness and, sometimes, to an improvement in symptoms. It also informed us that unsuccessful courses can be damaging to a patients' health and a waste of energy, time and money.

The most useful responses, because they give information not covered by the quantitative data, concern:

- The knowledge and experience that the therapists had about ME/CFS and their ability to empathise with patients, including their ability to listen
- Courses which contained elements that the respondents found useful but other elements that they did not
- Any unfulfilled expectations which the respondents may have been given by



their therapists about the success of their courses – about symptom improvement or about being taught how to cope with the illness better than before

- Therapists who set goals that did not take into account the severity of their patients' illness or their patients' lifestyles and commitments

- Courses that did not teach patients anything they did not already know and so did not help their abilities to self-manage their illness

- Courses that were so time and energy consuming to travel to, that patients were made worse. It will be seen from Appendix 1 that some patients felt obliged to attend courses because they were asked to do so by their employers or because they felt that failure to do so could have led to refusal of applications for disability benefits

- Courses where the sessions were so long that patients were made worse

- The degree of severity of ME/CFS of the other members of the group which sometimes made courses inappropriate

- The respondents' inability to adjust to pacing or their view that a course was not necessary to understand what to do to pace themselves

These responses are in Appendix 1 and the quantitative data key findings should also be read in light of them.

3:2 CRITERIA EMPLOYED

3:2:1 Listed Criteria

To find out what made some courses beneficial, some ineffective and some inappropriate or harmful to patients, we have compared the overall quantitative data (i.e. irrespective of (a) to (l) below (hereafter called the 'listed criteria')), with the effects of courses on symptoms and on the appropriateness of courses to the respondents' needs where:

Listed criteria:

a. Courses were, in the opinion of the respondents, CBT only, GET only, or Pacing only – no overlapping elements of the other two interventions:

By this we mean that CBT courses had no GET or Pacing elements, GET had no CBT or Pacing elements and Pacing had no CBT or GET elements.

We had, for example been aware of a CBT course that was effectively a GET course and a GET course that was effectively a Pacing course.

For example the following comment relates to a GET course:

"It was very good but I believe I was able to follow it successfully because I already had strong understanding of what can get in the way of people adapting to illness and making changes to learn to manage. I was able to deal with the anxiety and low mood that come with possibly losing your job, home and relationships and follow the instructions given. Many of my peers on course weren't and if they had children it was hard for them to prioritize the programme. Looked at how overestimating stamina increases symptoms, how fighting against illness increases symptoms, taught to get in touch with energy and respond accordingly to try to manage limited energy more effectively and smooth out boom and bust patterns."

We also felt it was important to determine whether or not overlapping is a common practice. And we wanted to try to ascertain the value of the interventions per se.

b. Courses had overlaps with one or both of the other two interventions

c. Courses were held by therapists stated to have an ME/CFS specialism

d. Courses were held by therapists not stated to have an ME/CFS specialism

e. Courses were held on a one-to-one basis

f. Courses were held in groups

g. Courses were held by therapists who, in the opinion of the respondents, believed that ME/CFS is a physical illness. It is defined as a physical illness by the World Health Authority

h. Courses were held by therapists who, in the opinion of the respondents, believed that ME/CFS is a mixture of a psychological and a physical illness

i. Courses were held by therapists who, in the opinion of the respondents, believed that ME/CFS is a psychological illness

j. When considering appropriateness to needs courses had no effect on symptoms

k. Entire courses were attended

l. Courses were partly attended:

Appendix 2, 3:6 gives some reasons for part attendance. Many of the responses in Appendix 1 indicate that patients dropped out because their symptoms became worse and/or because of criticisms of their therapists. In addition to these reasons, it will be seen from Appendix 1 that some courses were ongoing at the time of the survey and some therapists realised that respondents had been referred to them inappropriately.

3:2:2 Effect of Courses on Specific Symptoms

The point of the question was to see whether, for example, GET had a greater effect on exercise-induced muscle fatigue, post-exertional malaise and/or muscle pain than it did on other symptoms. In this set of data we compare the percentages of success/failure of courses for each symptom.

For this question we did not separate the categories of severity. These key findings contain brief summaries about these individual symptom percentages. Further data is shown in Appendix 2, section 7.



PERCENTAGE OF RESPONDENTS EXPERIENCING SPECIFIC ME/CFS SYMPTOMS BEFORE COURSES BEGAN:

SYMPTOM	SLIGHT	SIGNIFICANT
Exercise-induced muscle fatigue	10%	87%
Post-exertional malaise (PEM)	7%	92%
Muscle pain	21%	72%
Cognitive dysfunction	18%	80%
Aching joints without swelling or redness	16%	69%
Dizziness or feeling faint on standing	25%	64%
Headaches of type not previously experienced	20%	59%
Inability to cope with temperature changes	22%	70%
Increased sensitivity to light and/or sound and/or smells	24%	65%
Recurrent sore throats and enlarged glands	25%	60%
Sleep disturbance or unrefreshing sleep	10%	88%



3:2:3 Factors Influencing Course Effectiveness

All research data is affected by various factors. In this survey the effectiveness of courses is influenced by factors shown in the qualitative responses in Appendices 1 and 3 and by the listed criteria.

3:3 EFFECT OF COURSES ON ILLNESS SEVERITY

■ See Appendix 2, Section 4, 4:1

Note: The definitions of severity were taken from the 2002 Chief Medical Officer's Report on ME/CFS.

3:3:1 Effect of Courses on Illness Severity – CBT

There was general lack of movement between categories of severity of ME/CFS in CBT:

- Before CBT courses, 60% of the respondents were mild to moderate sufferers and 40% were severe to very severe sufferers
- After CBT courses, 59% of the respondents were mild to moderate sufferers and 41% were severe to very severe sufferers

This suggests to us that:

a) Successful courses were counterbalanced by unsuccessful

ones – see below re symptom improvement and symptoms becoming worse

b) Benefits may relate to helping people cope with the various restrictions imposed by their illness rather than a significant improvement in functional status. Learning those coping strategies can make courses appropriate to needs even if they do not lead to immediate or even longer term improvement in symptoms and,

c) For some, improvement may be a slow process so, whilst they may be somewhat better by the end of the course, the improvement is not enough to take them into a better category of severity for some time, perhaps not until they have self-managed their illness for a few years.

3:3:2 Effect of Courses on Illness Severity – GET

There was significant movement between categories of severity of ME/CFS in GET:

- Before GET courses, 62% of respondents were mild to moderate sufferers and 38% were severe to very severe sufferers
- After GET courses, 41% of respondents were mild to moderate sufferers and 59% were severe to very severe sufferers

This suggests to us that substantial harm was done to many GET participants.

3:3:3 Effect of Courses on Illness Severity – Pacing

There was slight movement between categories of severity of ME/CFS in Pacing:

- Before Pacing courses, 52% of the respondents were mild to moderate sufferers and 48% were severe to very severe sufferers.
- After Pacing courses, 58% of the respondents were mild to moderate sufferers and 42% were severe to very severe sufferers.

This suggests to us that (as with CBT):

a) Successful courses were counterbalanced by unsuccessful ones – also see below re: symptom improvement and symptoms becoming worse.

b) Benefits may relate to helping people cope with managing their illness rather than a significant improvement in functional status. Learning those coping strategies can make courses appropriate to needs even if they do not lead to immediate or even longer term improvement in symptoms, and



c) For some, improvement may be a slow process so, whilst they may be somewhat better by the end of the course, the improvement is not enough to take them into a better category of severity for some time, perhaps not until they have self-managed their illness for a few years.

3:3:4 Effect of Courses on Symptoms

Note:

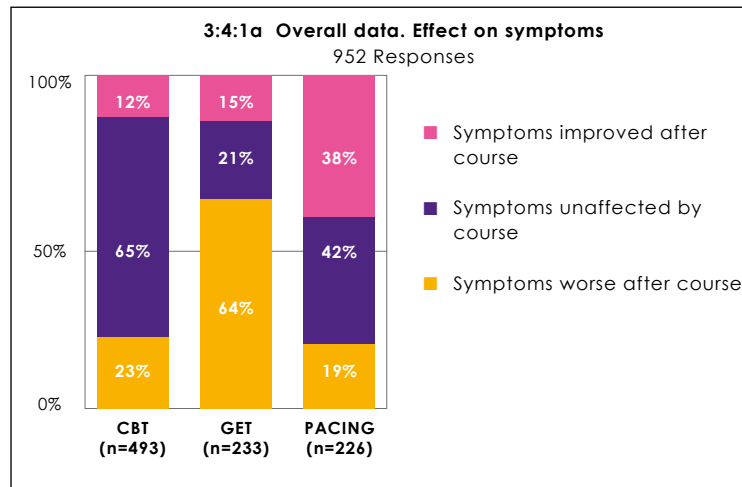
a) The list of criteria considered in 3:4 and 3:5 is set out in 3:2 above.

b) See 3:5 opposite for comparisons of effect of courses on symptoms and comparisons of appropriateness of courses to needs. For example, courses held by those stated to have an ME/CFS specialism are compared with those held by therapists not stated to have an ME/CFS specialism, one-to-one courses are compared to group courses etc.

c) In the graphs opposite n = the number of respondents.

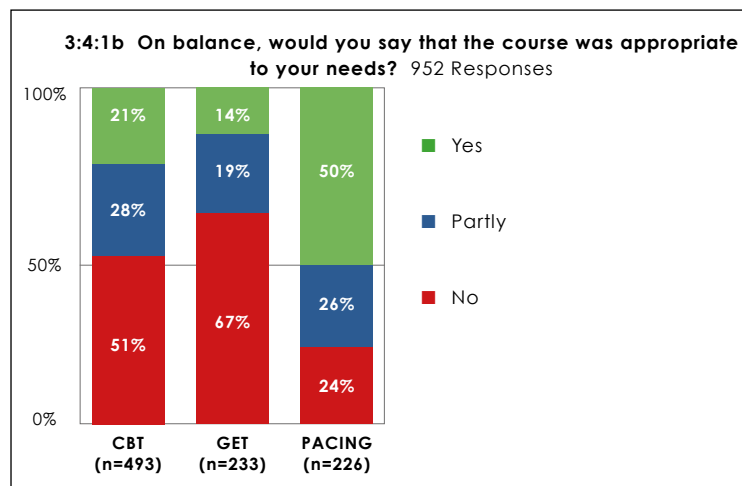
3:4:1 OVERALL DATA – TOTAL RESPONDENTS

3:4:1a Overall, how were your ME/CFS symptoms after the course compared to how they were before?



Further information given in Appendix 2, 4:2

3:4:1b On balance, would you say that the course was appropriate to your needs?

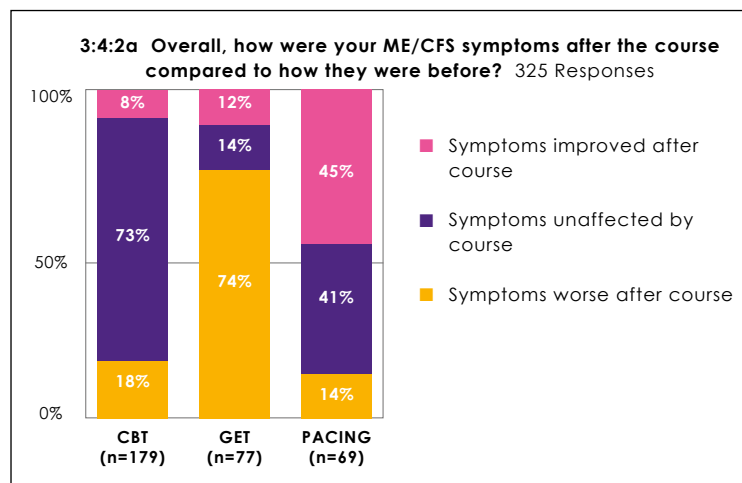


Further information given in Appendix 2, 5:1

3:4:2 SINGLE INTERVENTION COURSES

37% CBT, 34% GET and 32% Pacing courses were stated by respondents to have no overlaps – see Appendix 2, 3:1.

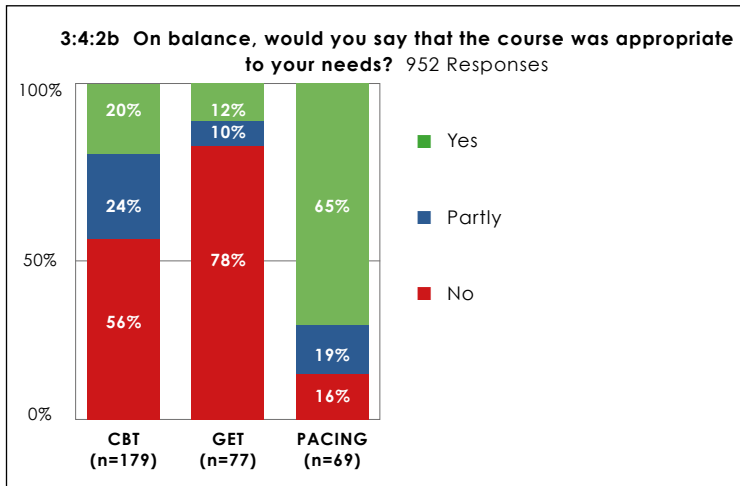
3:4:2a On balance, would you say that the course was appropriate to your needs?



Further information given in Appendix 2, 4:3

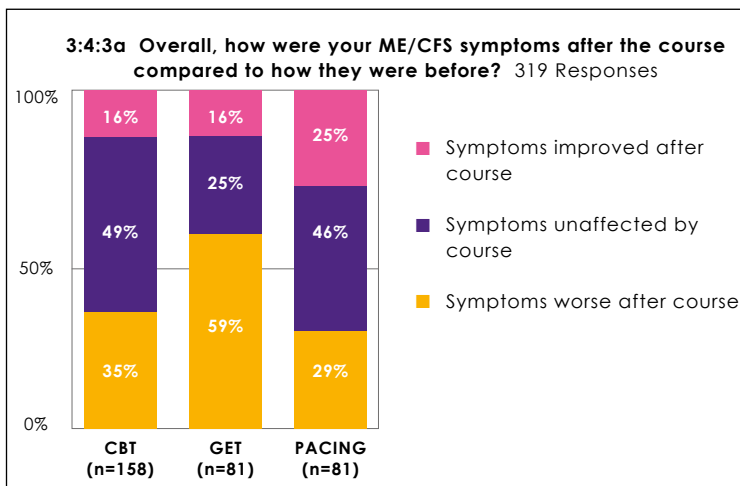


3:4:2b On balance, would you say that the course was appropriate to your needs?



Further information given in Appendix 2, 5:2

3:4:3a Overall, how were your ME/CFS symptoms after the course compared to how they were before?

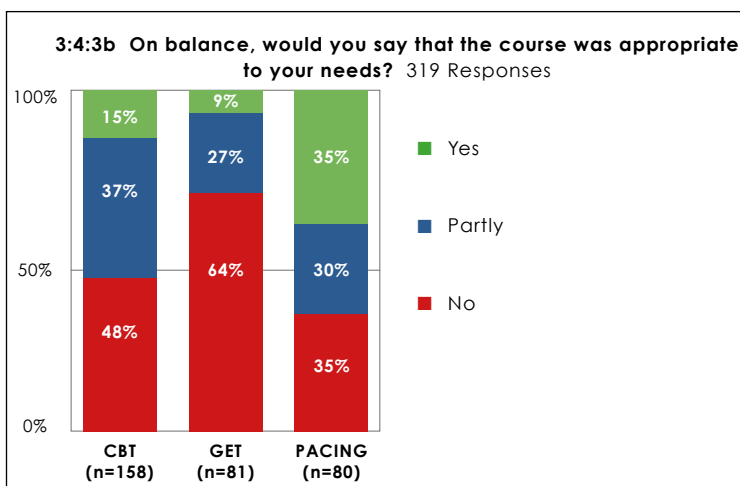


Further information given in Appendix 2, 4:4

3:4:3 COMBINED COURSES – ELEMENTS OF ALL THREE INTERVENTIONS

33% CBT, 36% GET and 37% Pacing courses were stated by respondents to have elements of all three interventions - for further details see Appendix 2, 3:1. Appendix 3 gives examples.

3:4:2b On balance, would you say that the course was appropriate to your needs?



Further information given in Appendix 2, 5:3



3:4:4 COMBINED COURSES – ELEMENTS OF ONE OF THE OTHER TWO INTERVENTIONS

■ CBT courses:

8% had GET elements but no Pacing elements

23% had Pacing elements but no GET elements

■ GET courses:

10% had CBT elements but no Pacing elements

20% had Pacing elements but no CBT elements

■ Pacing courses:

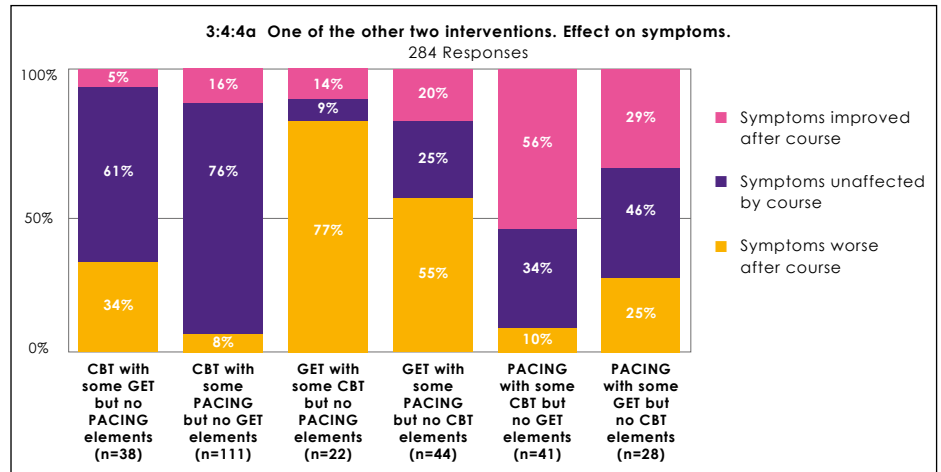
19% had CBT elements but no GET elements

13% had GET elements but no CBT elements

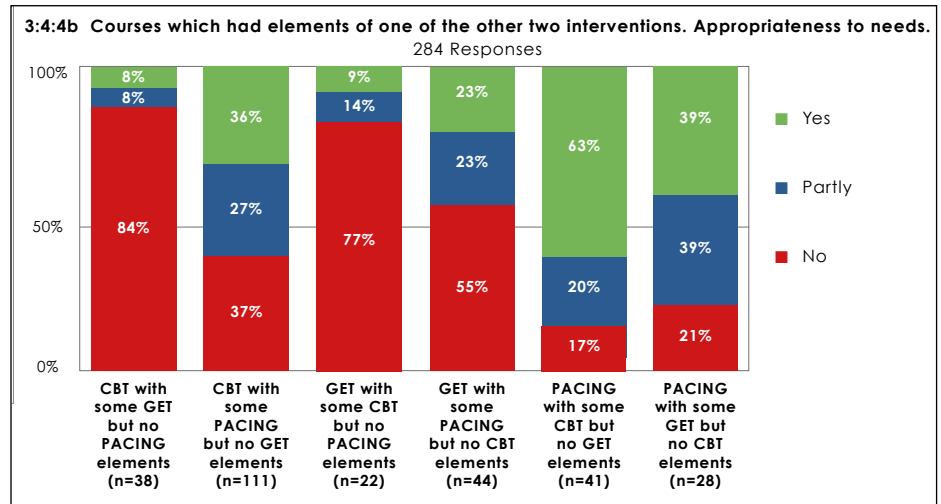
Some of the resulting cohorts were too small to be included in Appendix 2, where they are split into two categories of illness severity (mild/moderate and severe/very severe) and then further split into degrees of symptom improvement (so much better that the respondents considered themselves well/very much better/somewhat better) or symptoms becoming worse (somewhat worse/very much worse).

See Appendix 2, 3:1. Appendix 3 for examples.

3:4:4a Overall, how were your ME/CFS symptoms after the course compared to how they were before?



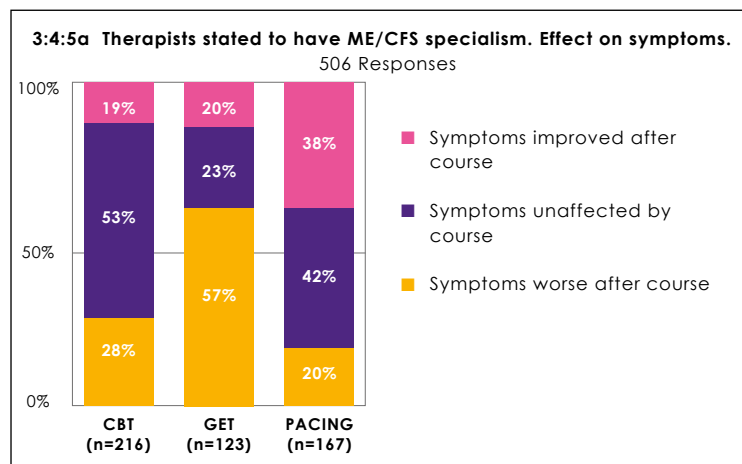
3:4:1b On balance, would you say that the course was appropriate to your needs?



3:4:5 COURSES HELD BY THERAPISTS SPECIALISING IN ME/CFS

46% CBT, 55% GET and 77% Pacing therapists were stated to have an ME/CFS specialism – See Appendix 2, 3:3a.

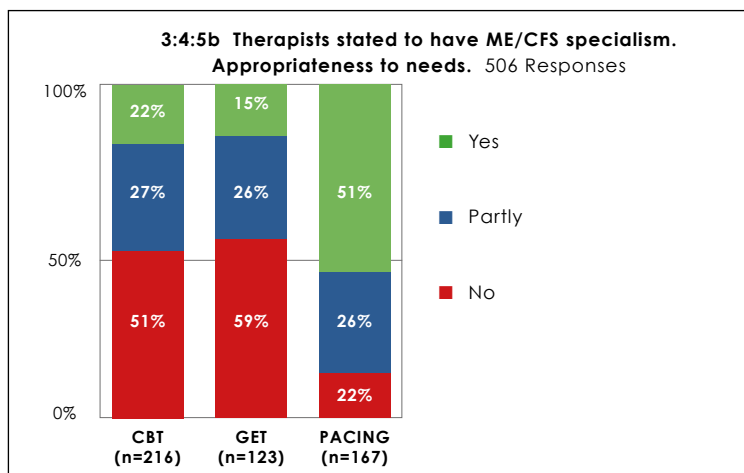
3:4:5a Overall, how were your ME/CFS symptoms after the course compared to how they were before?



Further information given in Appendix 2, 4:5

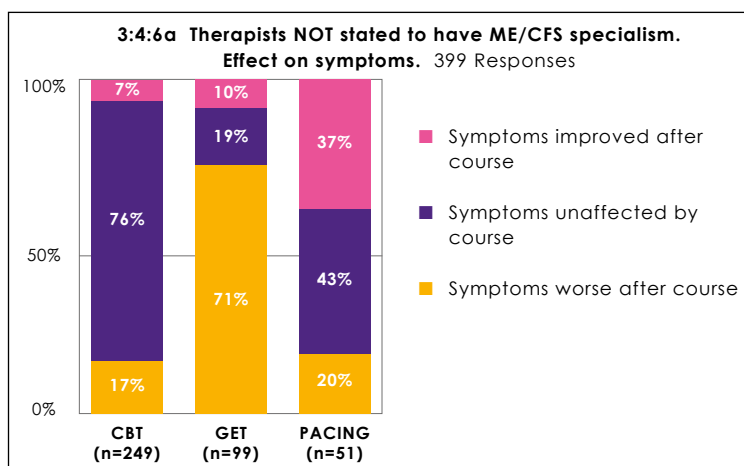


3:4:5b On balance, would you say that the course was appropriate to your needs?



Further information given in Appendix 2, 5:4

3:4:6a Overall, how were your ME/CFS symptoms after the course compared to how they were before?

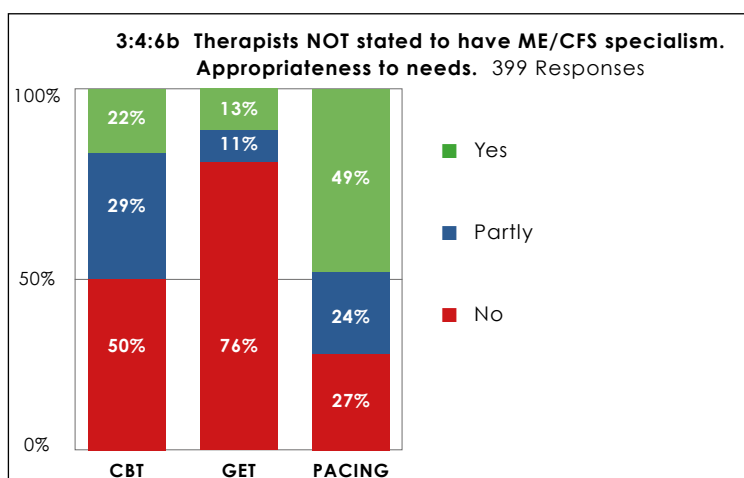


Further information given in Appendix 2, 4:6.

3:4:6 COURSES HELD BY THERAPISTS NOT SPECIALISING IN ME/CFS

54% CBT, 45% GET and 23% Pacing therapists were not stated to have an ME/CFS specialism – see Appendix 2, 3:3b.

3:4:6b On balance, would you say that the course was appropriate to your needs?



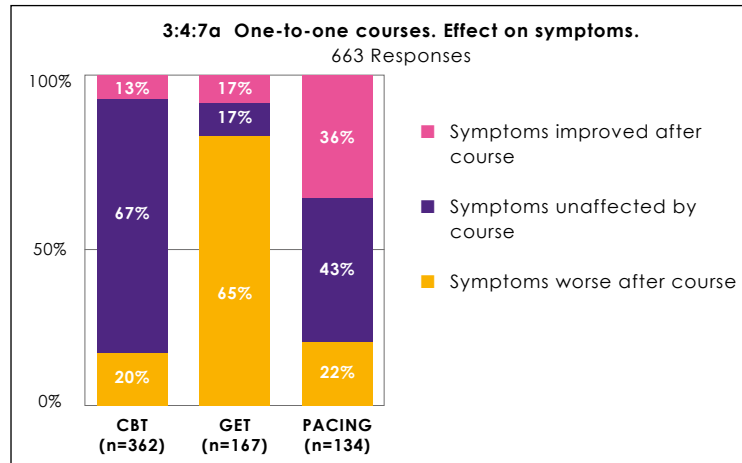
Further information given in Appendix 2, 5:5



3:4:7 ONE-TO-ONE COURSES

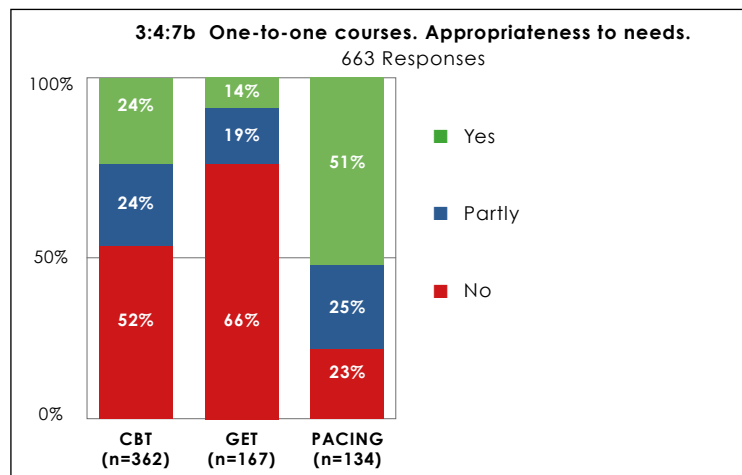
74% CBT, 72% GET and 59% Pacing courses were held on an individual (one-to-one) basis – see Appendix 2, 3:9.

3:4:7a Overall, how were your ME/CFS symptoms after the course compared to how they were before?



Further information given in Appendix 2, 4:7

3:4:7b On balance, would you say that the course was appropriate to your needs?

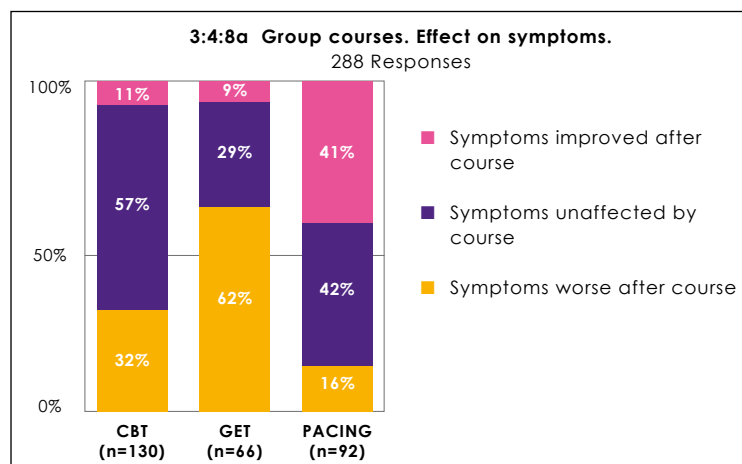


Further information given in Appendix 2, 5:6

3:4:8 GROUP COURSES

26% CBT, 28% GET and 41% Pacing courses were aimed at groups of patients – see Appendix 2, 3:9.

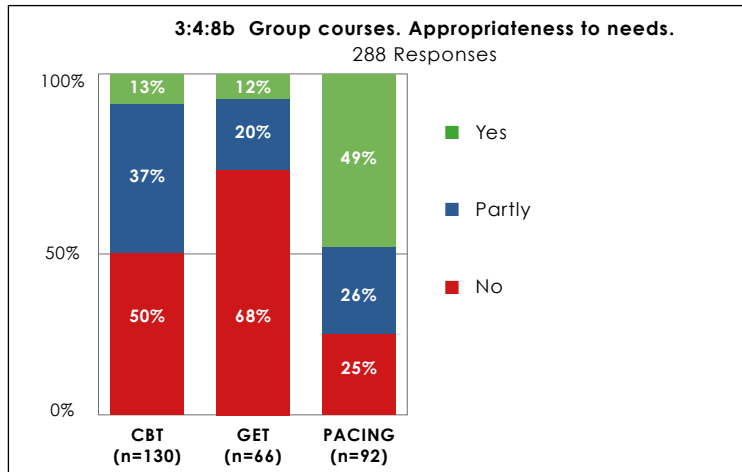
3:4:8a Overall, how were your ME/CFS symptoms after the course compared to how they were before?



Further information given in Appendix 2, 4:8

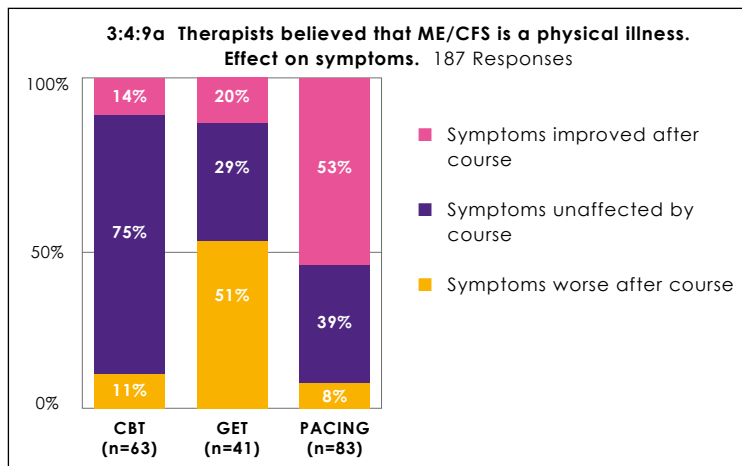


3:4:8b On balance, would you say that the course was appropriate to your needs?



Further information given in Appendix 2, 5:6

3:4:9a Overall, how were your ME/CFS symptoms after the course compared to how they were before?

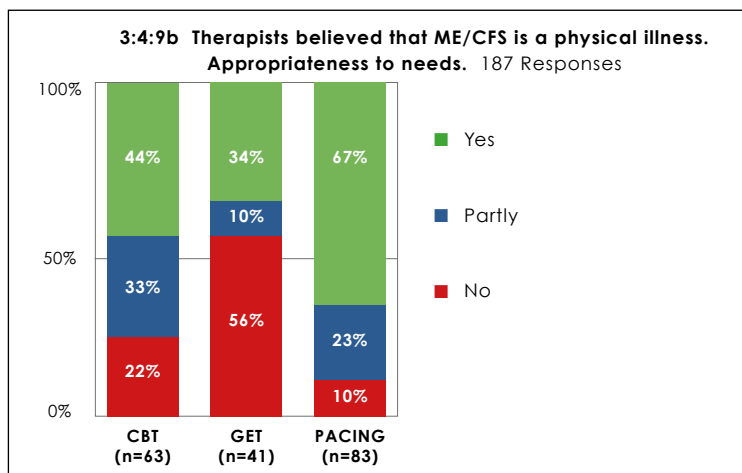


Further information given in Appendix 2, 5:7

3:4:9 COURSES HELD BY THERAPISTS WHO BELIEVED THAT ME/CFS IS A PHYSICAL ILLNESS

19% CBT, 25% GET and 50% Pacing course respondents said their course therapists believed ME/CFS to be a physical illness – see Appendix 2, 3:11.

3:4:9b On balance, would you say that the course was appropriate to your needs?



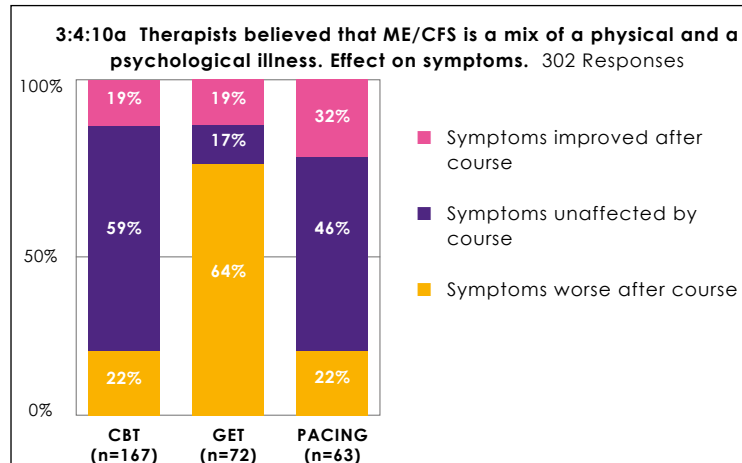
Further information given in Appendix 2, 4:9



3:4:10 COURSES HELD BY THERAPISTS WHO BELIEVED THAT ME/CFS IS A MIXTURE OF A PHYSICAL AND A PSYCHOLOGICAL ILLNESS

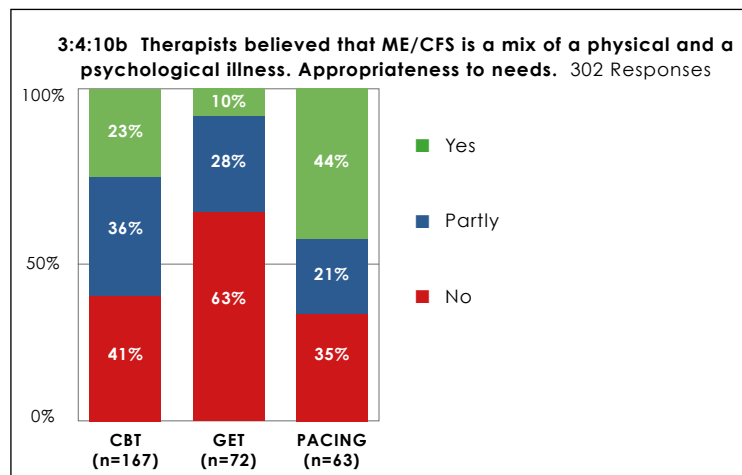
50% CBT, 44% GET and 38% Pacing course respondents said their course therapists believed ME/CFS to be a mixture of a physical and a psychological illness – see Appendix 2, 3:11.

3:4:10a Overall, how were your ME/CFS symptoms after the course compared to how they were before?



Further information given in Appendix 2, 4:10

3:4:10b On balance, would you say that the course was appropriate to your needs?

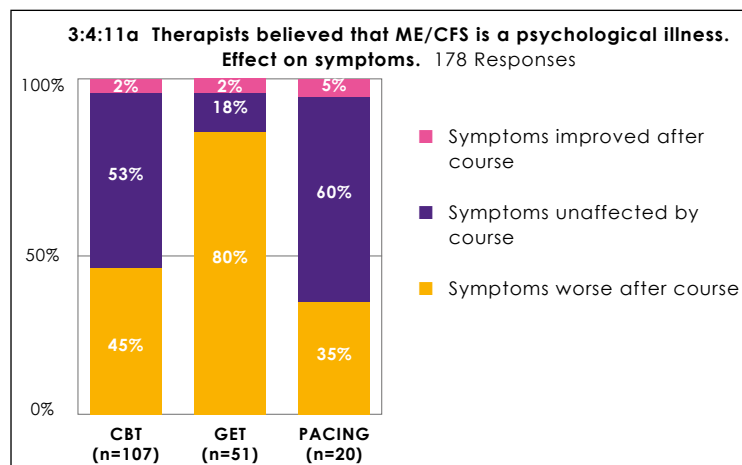


Further information given in Appendix 2, 5:9

3:4:11 COURSES HELD BY THERAPISTS WHO BELIEVED THAT ME/CFS IS A PSYCHOLOGICAL ILLNESS

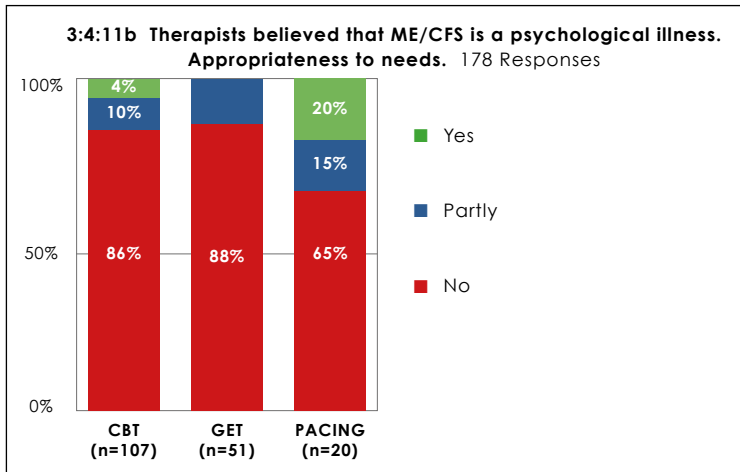
32% CBT, 31% GET and 12% Pacing course respondents said their course therapists believed ME/CFS to be a psychological illness – see Appendix 2, 3:11.

3:4:11a Overall, how were your ME/CFS symptoms after the course compared to how they were before?

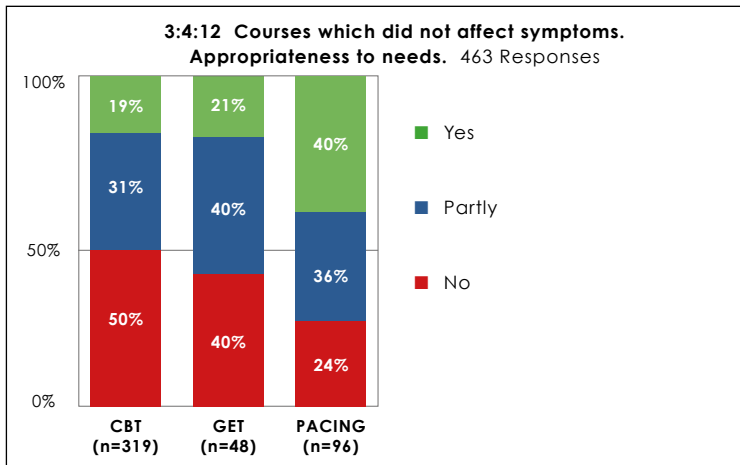


Further information given in Appendix 2, 4:11

3:4:11b On balance, would you say that the course was appropriate to your needs?



Further information given in Appendix 2, 5:10

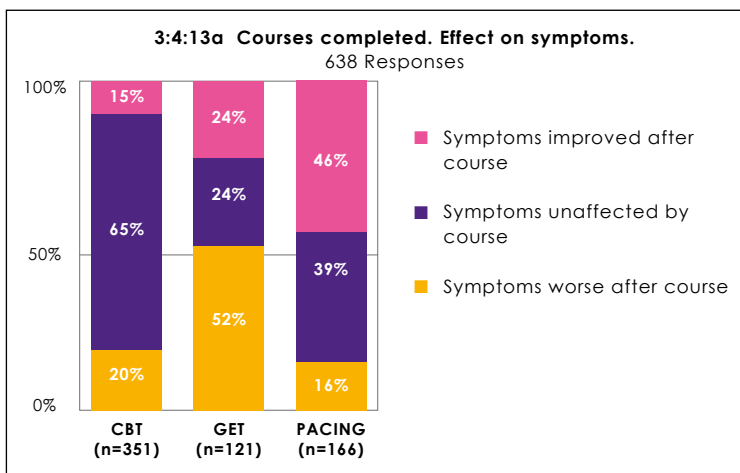


Further information given in Appendix 2, 5:11

3:4:12 COURSES WHICH DID NOT AFFECT SYMPTOMS – APPROPRIATENESS TO NEEDS

65% CBT, 21% GET and 42% Pacing courses had no effect on symptoms (see above at 3:4:1a).

3:4:13a Overall, how were your ME/CFS symptoms after the course compared to how they were before?



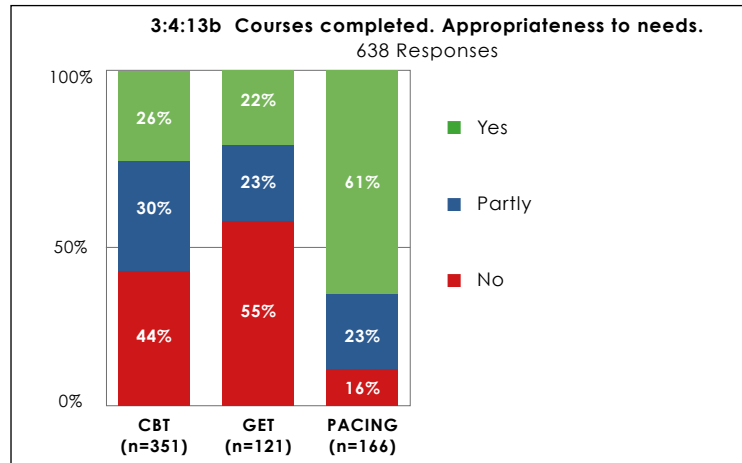
Further information given in Appendix 2, 4:12

3:4:13 COURSES COMPLETED IN FULL

71% of CBT, 52% of GET and 73% Pacing courses were completed in full – see Appendix 2, 3:12.



3:4:13b. On balance, would you say that the course was appropriate to your needs?



Further information given in Appendix 2, 5:12

3:4:14 COURSES PARTLY COMPLETED

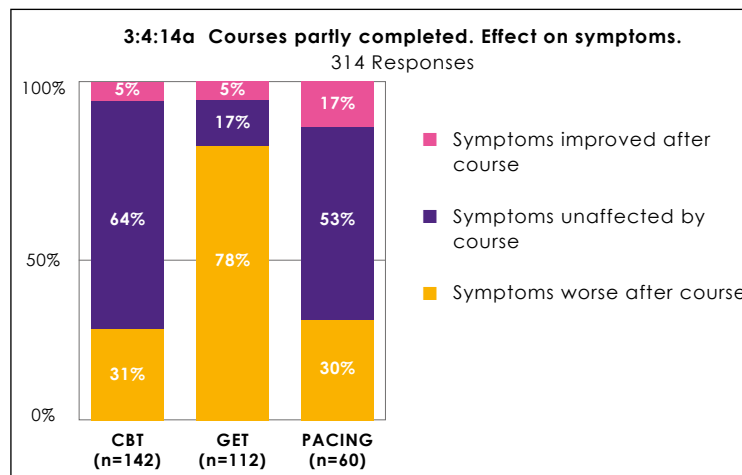
29% of CBT, 48% of GET and 27% Pacing courses were only partly completed – see Appendix 2, 3:12.

Appendix 1 and Appendix 2 at 3:6 give some respondents' reasons for only completing parts of courses. Appendix 2 at 3:8 gives a rough indication of how many sessions respondents took part in.

We asked an open question about how many sessions there were in a course but a substantial percentage of respondents could not remember and so we have not reported on this. Of those who did remember, the variation was substantial.

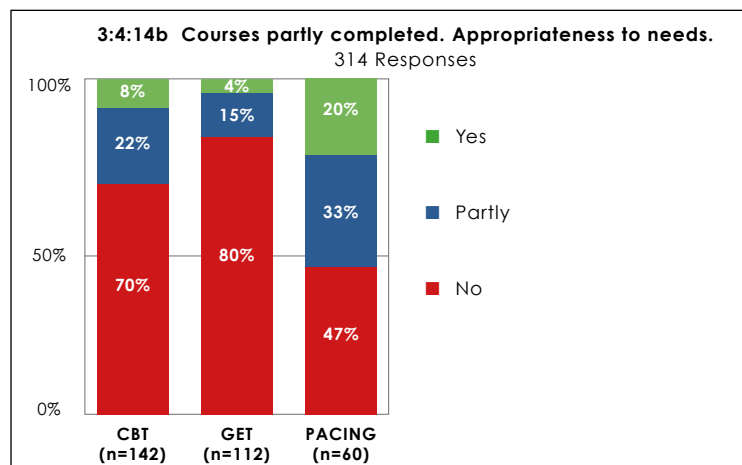
Of those respondents who replied to the question 'How many sessions did you take part in?' (445 CBT, 200 GET and 210 Pacing respondents) only 10% CBT, 22% GET and 8% Pacing patients attended less than half the course sessions – see Appendix 2, 3:8.

3:4:14a Overall, how were your ME/CFS symptoms after the course compared to how they were before?



Further information given in Appendix 2:4:13

3:4:14b On balance, would you say that the course was appropriate to your needs?



Further information given in Appendix 2, 5:13



3:5 FURTHER COMPARISONS – MOST AND LEAST BENEFICIAL OF THE LISTED CRITERIA

3:5:1 Cognitive Behavioural Therapy (CBT)

3:5:1:1 CBT Courses that led to Symptom Improvement

Overall and whichever of the listed criteria was considered, CBT courses brought about improvements for a small minority:

- **0.4%** said they felt so much better that they considered themselves well
- The overall percentage of respondents (i.e. irrespective of the listed criteria) whose symptoms improved was **12%**

In the listed criteria:

CBT courses without overlapping elements – versus – those with overlapping elements:

- CBT courses which were CBT only – no elements of GET or Pacing – symptoms improved for **8%** of respondents
- CBT courses which had elements of GET – but no Pacing – symptoms improved for **5%** of respondents
- CBT courses which had elements of Pacing – but no GET – symptoms improved for **16%** of respondents
- CBT courses which had elements of both GET and Pacing – symptoms improved for **16%** of respondents

CBT courses held by therapists stated to have an ME/CFS specialism – versus – CBT courses held by therapists not stated to have an ME/CFS specialism:

- CBT courses held by therapists stated to have an ME/CFS specialism, symptoms improved for **19%** of respondents
- CBT courses held by therapists not stated to have an ME/CFS specialism, symptoms improved for **7%** of respondents

CBT one-to-one courses – versus – CBT group courses:

- CBT one-to-one courses, symptoms improved for **13%** of respondents

- CBT group courses, symptoms improved for **11%** of respondents

Note: very little difference here, but see below, the courses where symptoms became worse and courses which were appropriate/not appropriate to needs percentages.

CBT courses held by therapists with differing beliefs about the nature of ME/CFS:

- CBT courses held by therapists who believed that ME/CFS is a physical illness, symptoms improved for **14%** of respondents
- CBT courses held by therapists who believed that ME/CFS is a mixture of a psychological and a physical illness, symptoms improved for **19%** of respondents
- CBT courses held by therapists who believed that ME/CFS is a psychological illness, symptoms improved for **2%** of respondents

CBT courses attended in full – versus – those only partly attended:

- Where respondents attended a whole CBT course, symptoms improved for **15%**
- Where respondents attended part of a CBT course, symptoms improved for **5%**

Example comment:

ME moderate before CBT course, became mild after course. Symptoms were very much better after. Course appropriate to needs.

"It helped me to accept the illness. I am forever grateful. The therapist taught me some very useful techniques. He helped me reduce the stress (partly caused by fear of not coping) and gave me some really useful advice about coping. He helped me communicate with my family, or accept their failure to listen and help. He also helped me to understand depression and to make choices about my treatment options. He basically had a lot of the Whys and Wherefores that you need to understand when sick and that in turn helps you learn how to look after yourself when you have ME. I don't feel it was at all

negative nor had any negative effects".

3:5:1:2 CBT Courses that led to harm

With one exception, more respondents were made worse by CBT than improved, often substantially more so:

- The overall percentage (i.e. irrespective of the listed criteria) of respondents who became worse from CBT was **23%**

In the listed criteria:

CBT courses without overlapping elements – versus – those with overlapping elements:

- CBT courses which were CBT only – no elements of GET or Pacing – symptoms worsened for **18%** of respondents
- CBT courses which had elements of GET – but no Pacing – symptoms worsened for **34%** of respondents
- CBT courses which had Pacing elements – but no GET – symptoms worsened for **8%** of respondents
- CBT courses which had elements of both GET and Pacing – symptoms worsened for **35%** of respondents

CBT courses held by therapists stated to have an ME/CFS specialism – versus – CBT courses held by therapists not stated to have an ME/CFS:

- CBT courses held by therapists stated to have an ME/CFS specialism made symptoms worse for **28%** of respondents
- CBT courses held by therapists not stated to have an ME/CFS specialism made symptoms worse for **17%** of respondents

CBT one-to-one courses – versus – CBT group courses:

- CBT group courses symptoms became worse for **32%** of respondents
- CBT one-to-one courses symptoms became worse for **20%** of respondents

CBT courses held by therapists with differing beliefs about the nature of ME/CFS:



■ CBT courses held by therapists who believed that it is a physical illness, the symptoms became worse for **11%** of the respondents

■ CBT courses held by therapists who believed that ME/CFS is a mixture of a psychological and a physical illness, symptoms became worse for **22%** of the respondents

■ CBT courses held by therapists who believed that ME/CFS is a psychological illness, symptoms became worse for **45%** of the respondents

CBT courses attended in full – versus – those only partly attended:

■ Where respondents attended part of a CBT course, symptoms became worse for **31%**

■ Where respondents attended a whole CBT course, symptoms became worse for **20%**

The exception, where less respondents were made worse than improved, was in CBT courses held by therapists who believe that ME/CFS is a physical illness where the symptoms of **11%** of respondents became worse (**14%** improved).

Example comment:

ME moderate before CBT course, became very severe after course. Symptoms were very much worse after. Course not appropriate to needs.

"The practitioner of the course seemed to think that all of my symptoms were largely psychological in nature, and really refused to listen to what I was telling her about how certain symptoms had developed and the physical nature of the illness. This made family members think that my illness was psychological because the practitioner was to them a specialist in M.E and therefore couldn't be wrong. I'm afraid the practitioner was highly ignorant of the illness confounded by her ignoring almost everything I was telling her about what I was experiencing."

3:5:1:3 CBT Courses that had No Effect on Symptoms

Overall (i.e. irrespective of the listed criteria), CBT courses did not affect the symptoms of a substantial majority i.e. 65% of respondents.

In the listed criteria:

CBT courses without overlapping elements – versus – those with overlapping elements:

■ CBT courses which were CBT only – no GET or Pacing elements – the symptoms of **73%** of respondents were unaffected

■ CBT courses which had some GET – but no Pacing elements – the symptoms of **61%** of respondents were unaffected

■ CBT courses which had some Pacing – but no GET elements – the symptoms of **76%** of respondents were unaffected

■ CBT courses which had elements of both CBT and GET – the symptoms of **49%** of respondents were unaffected

CBT courses held by therapists stated to have an ME/CFS specialism – versus – CBT courses held by therapists not stated to have an ME/CFS:

■ CBT courses held by therapists stated to have an ME/CFS specialism had no effect on the symptoms of **53%** of the respondents

■ CBT courses held by therapists not stated to have an ME/CFS specialism had no effect on the symptoms of **76%** of the respondents

CBT one-to-one courses – versus – CBT group courses:

■ CBT one-to-one courses the symptoms of **67%** of respondents remained unaffected

■ CBT group courses the symptoms of **57%** of respondents remained unaffected

CBT courses held by therapists with different beliefs about the nature of ME/CFS:

■ CBT courses held by therapists who believed that ME/CFS is



a physical illness, symptoms remained unaffected for **75%** of the respondents

■ CBT courses held by therapists who believed ME/CFS is a mixture of a psychological and a physical illness, symptoms remained unaffected for **59%** of the respondents

■ CBT courses held by therapists who believed that ME/CFS is a psychological illness, symptoms remained unaffected for **53%** of the respondents

CBT courses were attended in full – versus – those which partly attended:

■ When respondents attended a whole CBT course, symptoms remained unaffected for **65%**

■ When respondents attended part of a CBT course, symptoms remained unaffected for **64%**

Example comment:

ME moderate before CBT course, remained moderate after course. Symptoms were the same after. Course appropriate to needs.

"I think it was hugely beneficial. At no point was it ever suggested that it would cure me. It was about teaching my mind to deal with emotions and thoughts in a way that would cost less energy and so make living with ME easier. I have only just finished the course. I feel calmer and less wound up and I am confident that what I have learnt will help me manage my ME and my life better and cope with the mental problems of living with a chronic illness better. It has resulted in no change in symptoms, but I feel happier and less distressed. I think it will help me improve my quality of life."



3:5:1:4 CBT Courses Appropriate to Needs

Whichever of the listed criteria was considered, CBT courses were appropriate to the needs of a minority:

The overall (i.e. irrespective of the listed criteria) percentage of those who thought the course was appropriate to their needs was **21%**

In the listed criteria:

CBT courses without overlapping elements – versus – those with overlapping elements:

- CBT courses which were CBT only – no elements of GET or Pacing – were appropriate to the needs of **20%** of respondents

- CBT courses which had elements of Pacing – but no GET elements – were appropriate to the needs of **36%** of respondents

- CBT courses which had elements of both GET and Pacing – were appropriate to the needs of **15%** of respondents

- CBT courses which had elements of GET – but no Pacing – were appropriate to the needs of **8%** of respondents

CBT courses held by therapists stated to have an ME/CFS specialism – versus – CBT courses held by therapists not stated to have an ME/CFS specialism:

- CBT courses held by therapists stated to have an ME/CFS specialism were appropriate to the needs of **22%** of respondents

- CBT courses held by therapists not stated to have an ME/CFS specialism were also appropriate to the needs of **22%** of respondents

CBT one-to-one courses – versus – CBT group courses:

- CBT one-to-one courses were appropriate to the needs of **24%** of respondents

- CBT group courses were appropriate to the needs of **13%** of respondents

CBT courses held by therapists with differing beliefs about the nature of ME/CFS:

- CBT courses held by therapists who believed that ME/CFS is a physical illness were appropriate to the needs of **44%** of respondents

- CBT courses held by therapists who believed that ME/CFS is a mixture of a psychological and a physical illness were appropriate to the needs of **23%** of respondents

- CBT courses held by therapists who believed that ME/CFS is a psychological illness were appropriate to the needs of **4%** of respondents

CBT courses which had no effect on symptoms:

- **19%** of courses were appropriate to the respondents' needs

CBT courses attended in full – versus – those only partly attended:

- When respondents attended whole CBT courses, **26%** found them to be appropriate to their needs

- When respondents attended part of a CBT course, **8%** found them to be appropriate to their needs

Example comment:

ME moderate before CBT course, remained moderate after course. Symptoms were the same after. Course appropriate to needs.

"CBT helped me to come to terms with chronic illness and to take measures to stop fighting it and be at peace with my condition. It did not cure my ME and my therapist did not try to cure my ME but recognised and identified coping strategies."

3:5:1:5 CBT Courses Not Appropriate to Needs

With one exception, more respondents considered their CBT courses were not appropriate to their needs than considered they were appropriate, often substantially more:

- The overall (i.e. irrespective of the listed criteria) percentage of those who thought the CBT course was not appropriate to their needs was **51%** In the listed criteria:

CBT courses without overlapping elements – versus – those with overlapping elements:

- CBT courses which were CBT only – no elements of GET or Pacing – were not appropriate to the needs of **56%** of respondents

- CBT courses which had elements of GET – but no Pacing – were not appropriate to the needs of **84%** of respondents

- CBT courses which had elements of Pacing – but no GET – were not appropriate to the needs of **37%** of respondents

- CBT courses which had elements of both GET and Pacing – were not appropriate to the needs of **48%** of respondents

CBT courses held by therapists stated to have an ME/CFS specialism – versus – CBT courses held by therapists not stated to have an ME/CFS specialism:

- CBT courses held by therapists stated to have an ME/CFS specialism were not appropriate to the needs of **51%** of respondents

- CBT courses held by therapists not stated to have an ME/CFS specialism were not appropriate to the needs of **50%** of respondents

CBT one-to-one courses – versus – CBT group courses:

- CBT one-to-one courses were not appropriate to the needs of **52%** of respondents

- CBT group courses were not appropriate to the needs of **50%** of respondents

CBT courses held by therapists with differing beliefs about the nature of ME/CFS:

- CBT courses held by therapists who believed that ME/CFS is a physical illness were not appropriate to the needs of **22%** of respondents

- CBT courses held by therapists who believed that ME/CFS is a mixture of a psychological and a physical illness were not appropriate to the needs of **41%** of respondents

- CBT courses held by therapists who believed that ME/CFS



is a psychological illness were not appropriate to the needs of **86%** of respondents

CBT courses attended in full – versus – those only partly attended:

■ When respondents attended part of a CBT course, **70%** found it to be not appropriate to their needs

■ When respondents attended a whole CBT course, **44%** found it to be not appropriate to their needs

The exception was in CBT courses held by therapists who believed that ME/CFS is a physical illness where **22%** thought they were not appropriate and **44%** thought they were appropriate.

Example comment:

ME moderate before CBT course, remained moderate after course. Symptoms were the same after. Course not appropriate to needs.

"There was no real understanding of my condition particularly post exertion malaise. They encouraged us to do more and when we said we couldn't they didn't really believe us. The course overall did nothing for me and just left me depressed afterwards when I realised that my physical illness was not really being taken seriously, and since there was nothing after this, and this didn't help, I felt cut off with little chance of any improvement."

3:5:1:6 CBT Courses Partly Appropriate to Needs

Overall and in six of the twelve sets of listed criteria, when percentages of CBT courses which respondents considered were appropriate and those which respondents considered were partly appropriate, were added together, they were less than the percentages of respondents who found courses to be not appropriate. In two sets these percentages were equal.

The overall (i.e. irrespective of the listed criteria) percentage of those who thought the course partly appropriate to their needs was **28%**

In the listed criteria:

CBT courses without overlapping elements – versus – those with overlapping elements:

■ CBT courses which were CBT only – no elements of GET or Pacing – were partly appropriate to the needs of **24%** of respondents

■ CBT courses which had elements of GET – but no Pacing – were partly appropriate to the needs of **8%** of respondents

■ CBT courses which had elements of Pacing – but no GET – were partly appropriate to the needs of **37%** of respondents

■ CBT courses which had elements of both GET and Pacing – were partly appropriate to the needs of **37%** of respondents

CBT courses held by therapists stated to have an ME/CFS specialism – versus – CBT courses held by therapists not stated to have an ME/CFS specialism:

■ CBT courses held by therapists stated to have an ME/CFS specialism were partly appropriate to the needs of **27%** of respondents

■ CBT courses held by therapists not stated to have an ME/CFS specialism were partly appropriate to the needs of **29%** of respondents

CBT one-to-one courses – versus – CBT group courses:

■ CBT group courses were partly appropriate to the needs of **37%** of respondents

■ CBT one-to-one courses were partly appropriate to the needs of **24%** of respondents

CBT courses held by therapists with differing beliefs about the nature of ME/CFS:

■ CBT courses held by therapists who believed that ME/CFS is a physical illness were partly appropriate to the needs of **33%** of respondents

■ CBT courses held by therapists who believed that ME/CFS is a mixture of a psychological and a physical illness were partly appropriate to the needs of **36%** of respondents

■ CBT courses held by therapists who believed that ME/CFS is a psychological illness were partly appropriate to the needs of **10%** of respondents

CBT courses which had no effect on symptoms:

■ **31%** of CBT courses were partly appropriate to the respondents' needs

CBT courses attended in full – versus – those only partly attended:

■ When respondents attended a whole CBT course, **30%** found them to be partly appropriate to their needs

■ When respondents attended part of a CBT course, **22%** found it to be partly appropriate to their needs

Example comment:

ME moderate before CBT course, became severe after course. Symptoms were somewhat worse after. Course partly appropriate to needs.

"At the time I believed in it, but sometime later I realised it was all making me worse. The data they collected was from self-assessment forms, before and after treatment. They taught us positive mental attitude, so it was impossible to report back the truth without being accused of negativity."



3:5:2 Graded Exercise Therapy (GET)

3:5:2:1 GET Courses that led to Symptom Improvement

Overall and whichever of the listed criteria was considered, GET courses brought about improvements for a minority:

- **1.3%** said they felt so much better that they considered themselves well
- The overall (i.e. irrespective of the listed criteria) percentage of those for whom symptoms improved was **15%**

In the listed criteria:

GET courses without overlapping elements – versus – those with overlapping elements:

- GET courses which were GET only – no elements of CBT or Pacing – symptoms improved for **12%** of respondents
- GET courses which had elements of CBT – but no Pacing – symptoms improved for **14%** of respondents
- GET courses which had elements of Pacing – but no CBT – symptoms improved for **20%** of respondents
- GET courses which had elements of both CBT and Pacing – symptoms improved for **16%** of respondents

GET courses held by therapists stated to have an ME/CFS specialism – versus – GET courses held by therapists not stated to have an ME/CFS:

- GET courses held by therapists stated to have an ME/CFS specialism improved the symptoms of **20%** of respondents
- GET courses held by therapists not stated to have an ME/CFS specialism improved the symptoms of **10%** of respondents

GET one-to-one courses – versus – GET group courses:

- GET one-to-one courses symptoms improved for **17%** of respondents
- GET group courses symptoms improved for **9%** of respondents

GET courses held by therapists with differing beliefs about the nature of ME/CFS:

- GET courses held by therapists who believed that ME/CFS is a physical illness, symptoms improved for **20%** of the respondents
- GET courses held by therapists who believed that ME/CFS is a mixture of a psychological and a physical illness, symptoms improved for **19%** of respondents
- GET courses held by therapists who believed that ME/CFS is a psychological illness, symptoms improved for **2%** of respondents

GET courses attended in full – versus – those only partly attended:

- Where respondents attended a whole GET course, symptoms improved for **24%**
- Where respondents attended part of a GET course, symptoms improved **5%**

Example comment:

ME moderate before GET course, became mild after course. Symptoms so much better after that respondent considered himself/herself to be well. Course appropriate to needs.

"It was very good but I believe I was able to follow it successfully because I already had strong understanding of what can get in the way of people adapting to illness and making changes to learn to manage. I was able to deal with the anxiety and low mood that come with possibly losing your job, home and relationships and follow the instructions given.

Many of my peers on course weren't and if they had children it was hard for them to prioritise the programme. Looked at how overestimating stamina increases symptoms, how fighting against illness increases symptoms, taught to get in touch with energy and respond accordingly to try to manage limited energy more effectively and smooth out boom and bust patterns."

3:5:2:2 GET Courses that led to Harm

GET made ME/CFS symptoms worse for the majority:

- The overall (i.e. irrespective of the listed criteria) percentage of respondents whose symptoms became worse was **64%**

In the listed criteria:

GET courses without overlapping elements – versus – those with overlapping elements:

- GET courses which were GET only – no elements of CBT or Pacing – symptoms became worse for **74%** of respondents
- GET courses which had elements of CBT – but no Pacing – symptoms became worse for **77%** of respondents
- GET courses which had elements of Pacing – but no CBT – symptoms became worse for **55%** of respondents
- GET courses which had elements of both CBT and Pacing – symptoms became worse for **of** respondents

GET courses held by therapists stated to have an ME/CFS specialism – versus – GET courses held by therapists not stated to have an ME/CFS specialism:

- GET courses held by therapists stated to have an ME/CFS specialism made symptoms worse for **57%** of respondents
- GET courses held by therapists not stated to have an ME/CFS specialism made symptoms worse symptoms for **71%** of respondents

GET one-to-one courses – versus – GET group courses:

- GET one-to-one courses, symptoms became worse for **65%** of respondents
- GET group courses, symptoms became worse for **62%** of respondents

GET courses held by therapists with differing beliefs about the nature of ME/CFS:

- GET courses held by therapists who believed that it is a physical



illness, symptoms became worse for **52%** of respondents

- GET courses held by therapists who believed that ME/CFS is a mixture of a psychological and a physical illness, symptoms became worse for **64%** of respondents

- GET courses held by therapists who believed that ME/CFS is a psychological illness, symptoms became worse for **80%** of respondents

GET courses which were attended in full – versus – those which were only partly attended:

- Where respondents attended part of a GET course, symptoms became worse for

- Where respondents attended a whole GET course, symptoms became worse for **52%**

Example comment:

ME mild before GET course, became very severe after course. Symptoms very much worse after. Course not appropriate to needs.

“GET is dangerous and has completely ruined my life, I do not see any other illness offered GET. I am not an idiot and as an advanced personal trainer if you were depressed GET would help you for CFS. But not for ME as like when you have a virus and train in the gym it will make you worse. If I had the knowledge about ME when I first got it I would never have done it. Someone should be held accountable for destroying my life and thousands of others

I am in constant pain on pain killers to ‘try’ to help but to no avail as I am not offered any proper medications or treatment for ME as no doctor knows enough about it. You had to have GET no matter how you felt, told you to pace yourself after doing something and rest in between Told me to have a part of the day to lay in silence, could not understand severe ME and how I do that most of the day to cope with this damn illness.”

3:5:2:3 GET Courses that had No Effect on Symptoms

- Overall (i.e. irrespective of the listed criteria), GET courses did not affect the symptoms of **21%** of respondents

In the listed criteria:

GET courses without overlapping elements – versus – those with overlapping elements:

- GET courses which were GET only – no CBT or Pacing elements – the symptoms of **14%** of respondents were unaffected

- GET courses which had some CBT – but no Pacing elements – the symptoms of **9%** of respondents were unaffected

- GET courses which had some Pacing – but no CBT elements – the symptoms of **25%** of respondents were unaffected

- GET courses which had elements of both CBT and Pacing – the symptoms of **25%** of respondents were unaffected

GET courses held by therapists stated to have an ME/CFS specialism – versus – GET courses held by therapists not stated to have an ME/CFS specialism:

- GET courses held by therapists stated to have an ME/CFS specialism had no effect on the symptoms of **23%** of the respondents

- GET courses held by therapists stated to have an ME/CFS specialism had no effect on the symptoms of **19%** of the respondents

GET one-to-one courses – versus – GET group courses:

- GET one-to-one courses, the symptoms of **17%** of respondents remained unaffected

- GET group courses, the symptoms of **29%** of respondents remained unaffected

GET courses held by therapists with differing beliefs about the nature of ME/CFS:

- GET courses held by therapists who believed that ME/CFS is a physical illness, symptoms

remained unaffected for of the respondents

- GET courses held by therapists who believed that ME/CFS is a mixture of a psychological and a physical illness, symptoms remained unaffected for **17%** of respondents

- GET courses held by therapists who believed that ME/CFS is a psychological illness, symptoms remained unaffected for **18%** of respondents

GET courses which were attended in full – versus – those which were only partly attended:

- When respondents attended a whole GET course, symptoms remained unaffected for **24%**

- When respondents attended part of a GET course, symptoms remained unaffected for **17%**

Example comment:

ME moderate before GET course, remained moderate after course. Symptoms the same after. Course partly appropriate to needs.

“During the GET course I had to increase my use of painkillers to deal with post-exertional pain. The course was partly successful as I became a lot fitter - i.e. slimmer, better breathing, less food cravings - but I was just spending my time walking and resting, even after several months of keeping to the regime, so I had to sacrifice my already minimal social life and other hobbies such as art.

My illness comes in ‘flares’ when I am bed-bound for several days, and take a few weeks to recuperate from. These knock me back to square one physically so I have to build up the activity again afterwards, so there is no real possibility of GET having a long-term effect. Having said that, I was already using my own version of GET to up my activity levels in the period after a flare - I have always known of the risks of deconditioning.”

3:5:2:4 GET Courses Appropriate to Needs

Overall and whichever of the listed criteria was considered, GET courses were appropriate to the needs of a minority:

- The overall (i.e. irrespective of the listed criteria) percentage of respondents who thought their courses were appropriate to their needs was **14%**

In the listed criteria:

GET courses without overlapping elements – versus – those with overlapping elements:

- GET courses which were GET only – no elements of CBT or Pacing – were appropriate to the needs of **12%** of respondents

- GET courses which had elements of CBT – but no Pacing elements – were appropriate to the needs of **9%** of respondents

- GET courses which had elements of Pacing – but no CBT – were appropriate to the needs of **23%** of respondents

- GET courses which had elements of both CBT and Pacing – were appropriate to the needs of **9%** of respondents

GET courses held by therapists stated to have an ME/CFS specialism – versus – GET courses held by therapists not stated to have an ME/CFS specialism:

- GET courses held by therapists stated to have an ME/CFS specialism were appropriate to the needs of **15%** of respondents

- GET courses held by therapists not stated to have an ME/CFS specialism were appropriate to the needs of **14%** of respondents

GET one-to-one courses – versus – GET group courses:

- GET one-to-one courses were appropriate to the needs of **14%** of respondents

- GET group courses were appropriate to the needs of **12%** of respondents

GET courses held by therapists with differing beliefs about the nature of ME/CFS:

- GET courses held by therapists who believed that ME/CFS is a physical illness, were appropriate to the needs of **34%** of respondents

- GET courses held by therapists who believed that ME/CFS is a mixture of a psychological and a physical illness, were appropriate to the needs of **10%** of respondents

- GET courses held by therapists who believed that ME/CFS is a psychological illness, were appropriate to the needs of **0%** of respondents

GET courses which had no effect on symptoms:

- **21%** of GET courses were appropriate to the respondents' needs

GET courses attended in full – versus – those only partly attended:

- When respondents attended whole GET courses, **22%** found them to be appropriate to their needs

- When respondents attended part of a GET course, **4%** found it to be appropriate to their needs

Example comment:

ME moderate before GET course, remained moderate after course. Symptoms somewhat better after. Course appropriate to needs.

"This gave me exercises that I can still do in my home that are gentle enough. If the muscle spasms get bad, I can work on some exercises. Taught to pay attention to our bodies and find what was enough for each of us to do. Sometimes still get it wrong".

3:5:2:5 GET Courses Not Appropriate to Needs

With one exception, the majority of respondents found their courses were not appropriate to their needs:

- The overall (i.e. irrespective of the listed criteria) percentage of respondents who found their courses were not appropriate to their needs was **67%**

In the listed criteria:

GET courses without overlapping elements – versus – those with overlapping elements:

- GET courses which were GET only – no elements of CBT or Pacing – were not appropriate to the needs of **78%** of respondents

- GET courses which had elements of CBT – but no Pacing – were not appropriate to the needs of **77%** of respondents

- GET courses which had elements of Pacing – but no CBT – were not appropriate to the needs of **55%** of respondents

- GET courses which had elements of both CBT and Pacing – were not appropriate to the needs of **64%** of respondents

GET courses held by therapists stated to have an ME/CFS specialism – versus – GET courses held by therapists not stated to have an ME/CFS specialism:

- GET courses held by therapists stated to have an ME/CFS specialism were not appropriate to the needs of **59%** of respondents

- GET courses held by therapists not stated to have an ME/CFS specialism were not appropriate to the needs of **76%** of respondents

GET one-to-one courses – versus – GET group courses:

- GET group courses were not appropriate to the needs of **68%** of respondents

- GET one-to-one courses were not appropriate to the needs of **66%** of respondents

GET courses held by therapists with differing beliefs about the nature of ME/CFS:

- GET courses held by therapists who believed that ME/CFS is a physical illness, were not appropriate to the needs of **56%** of respondents

- GET courses held by therapists who believed that ME/CFS is a mixture of a psychological and a physical illness, were not appropriate to the needs of **63%** of respondents

■ GET courses held by therapists who believed that ME/CFS is a psychological illness, were not appropriate to the needs of 88% of respondents

GET courses which had no effect on symptoms:

■ 40% of courses were not appropriate to the respondents' needs (the exception)

GET courses attended in full – versus – those only partly attended:

■ When respondents attended a whole GET course, 55% found it to be not appropriate to their needs

■ When respondents attended part of a GET course, 80% found it to be not appropriate to their needs

Example comment:

ME moderate before GET course, became very severe after course. Symptoms very much worse after. Course not appropriate to needs.

"The time that my OT opposed me getting a walker was the last time I saw her. I felt like she was more worried about me becoming dependant on a walker than the fact that I was bedridden and unable to get out of the house at all. I did get the walker, through my GP, and it did improve my quality of life. I really resent the way she treated me, and am appalled that I put up with it for so long. There was a lot of talk about illness beliefs and deconditioning, and the form of "pacing" that she wanted me to use, was to do the same amount of activity every day, no matter how I felt. I did not feel this was appropriate, as some days I am barely able to get out of bed and go as far as the toilet, and I think trying to do more on those days would be harmful for me".

3:5:2:6 GET Courses Partly Appropriate to Needs

■ The overall (i.e. irrespective of the listed criteria) percentage of respondents who thought their course partly appropriate to their needs was 19%

In the listed criteria:

GET courses without overlapping elements – versus – those with overlapping elements:

■ GET courses which were GET only – no elements of CBT or Pacing – were partly appropriate to the needs of 10% of respondents

■ GET courses which had elements of CBT but no Pacing – were partly appropriate to the needs of 14% of respondents

■ GET courses which had elements of Pacing – but no CBT – were partly appropriate to the needs of 23% of respondents

■ GET courses which had elements of both CBT and Pacing – were partly appropriate to the needs of 27% of respondents

GET courses held by therapists stated to have an ME/CFS specialism – versus – GET courses held by therapists not stated to have an ME/CFS specialism:

■ GET courses held by therapists stated to have an ME/CFS specialism were partly appropriate to the needs of 26% of respondents

■ GET courses held by therapists not stated to have an ME/CFS specialism were partly appropriate to the needs of 11% of respondents

GET one-to-one courses – versus – GET group courses:

■ GET one-to-one courses were partly appropriate to the needs of 19% of respondents

■ GET group courses were partly appropriate to the needs of 20% of respondents

GET courses held by therapists with differing beliefs about the nature of ME/CFS:

■ GET courses held by therapists who believed that ME/CFS is a physical illness, were partly appropriate to the needs of n of respondents

■ GET courses held by therapists who believed that ME/CFS is a mixture of a psychological and a physical illness, were partly appropriate to the needs of 28% of respondents



■ GET courses held by therapists who believed that ME/CFS is a psychological illness, were partly appropriate to the needs of 12% of respondents

GET courses which had no effect on symptoms:

■ 40% of courses were partly appropriate to the respondents' needs

Example comment:

ME moderate before GET course, remained moderate after course. Symptoms somewhat worse after. Course partly appropriate to needs.

"Despite it becoming very clear that extra physical activity, even introduced very gently, eventually hits a level when I suddenly got worse, the clinicians would not accept this, I even got myself a pedometer and showed them the rough break point, but they would not accept it. They could not see that mental activity relating to my work restricted my physical activity".

3:5:3 Pacing

3:5:3:1 Pacing Courses that led to Symptom Improvement

Overall and whichever of the listed criteria was considered, except in Pacing courses which had elements of CBT but no GET elements (where 56% improved) and courses held by therapists who believed that ME/CFS is a physical illness (where 53% improved), Pacing courses brought about improvements for a minority; the percentages were considerably higher than the CBT percentages but nevertheless were a minority.

- 1.3% said they felt so much better that they considered themselves well

- The overall percentage of respondents whose symptoms improved (i.e. irrespective of the listed criteria) was 38%

In the listed criteria:

Pacing courses without overlapping elements – versus – those with overlapping elements:

- Pacing courses which were Pacing only – no CBT or GET – symptoms improved for 45% of respondents

- Pacing courses which had elements of CBT – but no GET – symptoms improved for 56% of respondents

- Pacing courses which had elements of GET – but no CBT – symptoms improved for 29% of respondents

- Pacing courses which had elements of both CBT and GET – symptoms improved for 25% of respondents

Pacing courses held by therapists stated to have an ME/CFS specialism – versus – Pacing courses held by therapists not stated to have an ME/CFS specialism:

- Pacing courses held by therapists stated to have an ME/CFS specialism improved the symptoms of 38% of the respondents

- Pacing courses held by therapists not stated to have

an ME/CFS specialism improved the symptoms of 37% of the respondents

Pacing one-to-one courses – versus – Pacing group courses:

- Pacing one-to-one courses, symptoms improved for 36% of respondents

- Pacing group courses, symptoms improved for 41% of the respondents

Pacing courses held by therapists with differing beliefs about the nature of ME/CFS:

- Pacing courses held by therapists who believed that ME/CFS is a physical illness, symptoms improved for 53% of respondents

- Pacing courses held by therapists who believed that it is a mixture of a psychological and a physical illness, symptoms improved for 32% of respondents

- Pacing courses held by therapists who believed that ME/CFS is a psychological illness, symptoms improved for 5% of respondents

Pacing courses attended in full – versus – those only partly attended:

- Where respondents attended part of a Pacing course, symptoms improved for 17%

- Where respondents attended a whole Pacing course, symptoms improved for 46%

Example comment:

ME moderate before Pacing course, became mild after course. Symptoms were very much better after. Course appropriate to needs.

“It was a multi component programme to teach sufferers of ME about the illness and how best to try and cope with it or even improve. Pacing and CBT has completely turned my illness around, although I am still unwell I can function much better than I could before and can actually get out of bed more often than not which is good. My level of activity has increased enough to allow me to do some jobs at home but sadly

I am still not able to return to work just yet.”

3:5:3:2 Pacing Courses that led to Harm

Although the percentages of those who were made worse were overall and in most of the listed criteria data less than the CBT percentages, harm was done to some Pacing respondents:

- The overall (i.e. irrespective of the listed criteria) percentage of respondents who became worse was 19%

In the listed criteria:

Pacing courses without overlapping elements – versus – those with overlapping elements:

- Pacing courses which were Pacing only – no CBT or GET – symptoms became worse for 14% of respondents

- Pacing courses which had elements of GET – but no CBT – symptoms became worse for 25% of respondents

- Pacing courses which had elements of CBT – but no GET – symptoms became worse for 10% of respondents

- Pacing courses which had elements of both CBT and GET – symptoms became worse for 29% of respondents

Pacing courses held by therapists stated to have an ME/CFS specialism – versus – Pacing courses held by therapists not stated to have an ME/CFS specialism:

- Pacing courses held by therapists stated to have an ME/CFS specialism made symptoms worse for 20% of respondents

- Pacing courses held by therapists not stated to have an ME/CFS specialism made symptoms worse for 20% of respondents

Pacing one-to-one courses – versus – Pacing group courses:

- Pacing one-to-one courses, symptoms became worse for 22% of respondents



■ Pacing group courses, symptoms became worse for **16%** of respondents

Pacing courses held by therapists with differing beliefs about the nature of ME/CFS:

■ Pacing courses held by therapists who believed that ME/CFS is a physical illness, symptoms became worse for **8%** of respondents

■ Pacing courses held by therapists who believed that ME/CFS is a mixture of a psychological and a physical illness, symptoms became worse for **22%** of respondents

■ Pacing courses held by therapists who believed that ME/CFS is a psychological illness, symptoms became worse for **35%** of respondents

Pacing courses which were attended in full – versus – those which were only partly attended:

■ Where respondents attended part of a Pacing course, symptoms became worse for **30%**

■ Where respondents attended a whole Pacing course, symptoms became worse for **16%**

Example comment:

ME mild before Pacing course, became moderate after course. Symptoms were somewhat worse after. Course partly appropriate to needs.

“Pacing was a mixed bag. It was definitely better than GET, as it taught me to listen to my body and not ignore symptoms and I gradually began to see the link between exercise/activity and delayed fatigue, which I hadn't done beforehand. That was crucial in slowing down my deterioration. But I wish someone had said 'if you are experiencing symptoms you should rest' – the message was, 'you can get worse briefly but symptoms should then go again'. I kept waiting for them to go and they never did. Then I had a massive relapse which I have not recovered from. Pacing is not very satisfactory – it is full of confusing contradictory messages 'rest – but bed rest is BAD' (when I had

bed rest I actually improved most rapidly), 'increase activity – but not too much' – how much is too much? I felt the emphasis was too heavily on increasing activity – I should have been told to rest.”

3:5:3:3 Pacing Courses that had No Effect on Symptoms

■ Overall (i.e. irrespective of the listed criteria), **42%** of respondents found their courses had no effect on their symptoms

In the listed criteria:

Pacing courses without overlapping elements – versus – those with overlapping elements:

■ Pacing courses which were Pacing only – no CBT or GET – the symptoms of **41%** of respondents were unaffected

■ Pacing courses which had some GET – but no CBT – the symptoms of **46%** of respondents were unaffected

■ Pacing courses which had some CBT – but no GET – the symptoms of **34%** of respondents were unaffected

■ Pacing courses which had elements of both CBT and GET – the symptoms of **46%** of respondents were unaffected

Pacing courses held by therapists stated to have an ME/CFS specialism – versus – Pacing courses held by therapists not stated to have an ME/CFS specialism:

■ Pacing courses held by therapists stated to have an ME/CFS specialism had no effect on the symptoms of **42%** of respondents

■ Pacing courses held by therapists not stated to have an ME/CFS specialism had no effect on the symptoms of **43%** of respondents

Pacing one-to-one courses – versus – Pacing group courses:

■ Pacing one-to-one courses, the symptoms of **43%** of respondents remained unaffected

■ Pacing group courses, the symptoms of **42%** of respondents remained unaffected

Pacing courses held by therapists with differing beliefs about the nature of ME/CFS:

■ Pacing courses held by therapists who believed that ME/CFS is a physical illness, symptoms remained unaffected for **39%** of respondents

■ Pacing courses held by therapists who believed that ME/CFS is a mixture of a psychological and a physical illness, symptoms remained unaffected for **46%** of respondents

■ Pacing courses held by therapists who believed that ME/CFS is a psychological illness, symptoms remained unaffected for **60%** of respondents

Pacing courses which were attended in full – versus – those which were only partly attended:

■ When respondents attended part of a Pacing course, symptoms remained unaffected for **53%**

■ When respondents attended a whole Pacing course, symptoms remained unaffected for **39%**

Example comment:

ME moderate before Pacing course, remained moderate after course. Symptoms were the same after. Course appropriate to needs.

“I felt it validated my need to rest and made me more aware when I was overdoing things and pushing into the 'danger zone'.”

3:5:3:4 Pacing Courses that were Appropriate to Needs

■ The overall (i.e. irrespective of the listed criteria) percentage of those who thought their courses were appropriate to their needs was **50%**

In the listed criteria the percentages were:

Pacing courses without overlapping elements – versus – those with overlapping elements:

■ Pacing courses which were Pacing only – no CBT or GET – were appropriate to the needs of **65%** of respondents



■ Pacing courses which had elements of CBT – but no GET elements – were appropriate to the needs of **63%** of respondents

■ Pacing courses which had elements of GET – but no CBT – were appropriate to the needs of **39%** of respondents

■ Pacing courses which had elements of both CBT and GET – were appropriate to the needs of **35%** of respondents

Pacing courses held by therapists stated to have an ME/CFS specialism – versus – Pacing courses held by therapists not stated to have an ME/CFS specialism:

■ Pacing courses held by therapists stated to have an ME/CFS specialism were appropriate to the needs of **51%** of respondents

■ Pacing courses held by therapists not stated to have an ME/CFS specialism were appropriate to the needs of **49%** of respondents

Pacing one-to-one courses – versus – Pacing group courses:

■ Pacing one-to-one courses were appropriate to the needs of **51%** of respondents

■ Pacing group courses were appropriate to the needs of **49%** of respondents

Pacing courses held by therapists with differing beliefs about the nature of ME/CFS:

■ Pacing courses held by therapists who believed that ME/CFS is a physical illness, were appropriate to the needs of **68%** of respondents

■ Pacing courses held by therapists who believed that ME/CFS is a mixture of a psychological and a physical illness, were appropriate to the needs of **44%** of respondents

■ Pacing courses held by therapists who believed that ME/CFS is a psychological illness, were appropriate to the needs of **19%** of respondents

Pacing courses which had no effect on symptoms:

■ **40%** of courses were appropriate to the respondents' needs

Pacing courses attended in full – versus – those only partly attended:

■ When respondents attended part of a Pacing course, **20%** found them to be appropriate to their needs

■ When respondents attended whole Pacing courses, **61%** found them to be appropriate to their needs

Example comment:

ME very severe before Pacing course, improved to severe after course. Symptoms somewhat better after. Course appropriate to needs.

"Pacing works. My instinct always told me so but the psychobabblers derailed me for years, I needed one short course to confirm what I knew. Pacing works."

3:5:3:5 Pacing Courses not Appropriate to Needs

■ The overall (i.e. irrespective of the listed criteria) percentage of those who thought their courses were not appropriate to their

needs was **24%**

In the listed criteria the percentages were:

Pacing courses without overlapping elements – versus – those with overlapping elements:

■ Pacing courses which were Pacing only – no CBT or GET – were not appropriate to the needs of **16%** of respondents

■ Pacing courses which had elements of GET - but no CBT – were not appropriate to the needs of **21%** of respondents

■ Pacing courses which had elements of CBT – but no GET – were not appropriate to the needs of **17%** of respondents

■ Pacing courses which had elements of both CBT and GET were not appropriate to the needs of **35%** of respondents

Pacing courses held by therapists stated to have an ME/CFS specialism – versus – Pacing courses held by therapists not stated to have an ME/CFS specialism:

■ Pacing courses held by therapists stated to have an ME/CFS specialism were not appropriate to the needs of **22%** of respondents

■ Pacing courses held by therapists not stated to have an ME/CFS specialism were not appropriate to the needs of **27%** of respondents

Pacing one-to-one courses – versus – Pacing group courses:

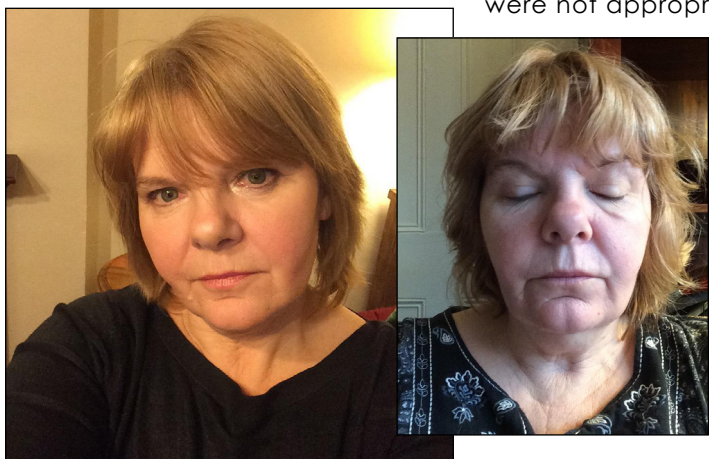
■ Pacing one-to-one courses, were not appropriate to the needs of **23%** of respondents

■ Pacing group courses, were not appropriate to the needs of **26%** of respondents

Pacing courses held by therapists with differing beliefs about the nature of ME/CFS:

■ Pacing courses held by therapists who believed that ME/CFS is a physical illness, were not appropriate to the needs of **9%** of respondents

■ Pacing courses held by therapists who believed that ME/CFS is a mixture of a psychological and a physical illness, were not appropriate to the needs of **35%** of respondents



■ Pacing courses held by therapists who believed that ME/CFS is a psychological illness, were not appropriate to the needs of **67%** of respondents

Pacing courses which had no effect on symptoms:

■ **24%** of courses were not appropriate to the respondents' needs

Pacing courses attended in full – versus – those only partly attended:

■ When respondents attended part of a Pacing course, **47%** found it to be not appropriate to their needs

■ When respondents attended a whole Pacing course, **16%** found it to be not appropriate to their needs

Example comment:

ME moderate before Pacing course, remained moderate after course. Symptoms were somewhat better after. Course not appropriate to needs.

"I think it's really bad that the only treatment offered to me is to try to live within a much reduced 'life'. I was in the top sets at school and did a lot of dance and sport before becoming ill. Now I miss a lot of school and can't do much sport or dance, although I do keep trying. I'm sick of feeling ill and no-one seems to be able to help."

3:5:3:6 Pacing Courses Partly Appropriate to Needs

■ Overall (i.e. irrespective of the listed criteria), **26%** of Pacing courses were partly appropriate to respondents' needs.

In the listed criteria the percentages were:

Pacing courses without overlapping elements – versus – those with overlapping elements:

■ Pacing courses which were Pacing only – no CBT or GET – were partly appropriate to the needs of **19%** of respondents

■ Pacing courses which had elements of CBT – but no GET – were partly appropriate to the need of **20%** of respondents

■ Pacing courses which had elements of GET – but no CBT – were partly appropriate to the needs of **39%** of respondents

■ Pacing courses which had elements of both CBT and GET were partly appropriate to the needs of **30%** of respondents

Pacing courses held by therapists stated to have an ME/CFS specialism – versus – Pacing courses held by therapists not stated to have an ME/CFS specialism:

■ Pacing courses held by therapists stated to have an ME/CFS specialism were partly appropriate to the needs of **26%** of respondents

■ Pacing courses held by therapists not stated to have an ME/CFS specialism were partly appropriate to the needs of **24%** of respondents

Pacing one-to-one courses – versus – Pacing group courses:

■ Pacing one-to-one courses were partly appropriate to the needs of **25%** of respondents

■ Pacing group courses were partly appropriate to the needs of **26%** of respondents

Pacing courses held by therapists with differing beliefs about the nature of ME/CFS:

■ Pacing courses held by therapists who believed that ME/CFS is a physical illness, were partly appropriate to the needs of **23%** of respondents

■ Pacing courses held by therapists who believed that ME/CFS is a mixture of a psychological and a physical illness, were partly appropriate to the needs of **21%** of respondents

■ Pacing courses held by therapists who believed that ME/CFS is a psychological illness, were partly appropriate to the needs of of respondents

Pacing courses which had no effect on symptoms:

■ **36%** of Pacing courses were partly appropriate to the respondents' needs

Pacing courses attended in full – versus – those only partly attended:

■ When respondents attended part of a Pacing course, **33%** found it to be partly appropriate to their needs

■ When respondents attended a whole Pacing course, **23%** found it to be partly appropriate to their needs

Note: Activity Management Courses

Pacing courses containing elements of GET or CBT

Whilst GET is based on an abnormal behaviour model of causation and is applied in a different way, **13%** of respondents attending Pacing courses reported that they contained elements of GET (with no CBT element), and a further **37%** reported that their Pacing courses contained elements of both CBT and GET – see also Appendix 2, 3.1c.

This might suggest that some therapists actually delivered Activity Management (or Graded Activity Management) in addition to Pacing.

Example comments:

"We were told to follow our exercise plan daily no matter how we felt."

"I was then instructed to GET OUT of my wheelchair – that what I really needed was exercise."

"It was called Graded Activity Therapy. A baseline was established. In my case 50 steps to be carried out each day for two weeks then, providing there was no significant increase in symptoms, the 50 steps were to be increased by 10% i.e. to 55 steps. Again this to be followed for two weeks with the same criteria until I crashed!"

3:6 EFFECT OF COURSES ON ILLNESS SEVERITY

■ For full details see Appendix 2, Section 4

Where differences were greater than **15%**



3:6:1 Effect of Courses on Illness Severity – CBT

Mostly, based on the data, no substantial difference was indicated.

CBT courses held by therapists with an ME/CFS specialism:

- 30% mild to moderate and 11% severe to very severe sufferers found their courses to be appropriate to their needs
- 39% mild to moderate and 66% severe to very severe sufferers found their courses to be not appropriate to their needs.

CBT group courses:

- The symptoms of 66% mild to moderate and 40% severe to very severe sufferers remained the same
- The symptoms of 13% mild to moderate and 29% severe to very severe sufferers became somewhat worse
- 45% mild to moderate and 60% severe to very severe sufferers found their courses to be not appropriate to their needs

CBT courses held by therapists who believed that ME/CFS is a physical illness:

- The symptoms of 3% mild to moderate and 19% severe to very severe sufferers became somewhat worse

CBT courses held by therapists who believed that ME/CFS is a mixture of a physical and a psychological illness:

- 33% mild to moderate and 50% severe to very severe sufferers found their courses to be not appropriate to their needs

3:6:2 Effect of Courses on Illness Severity – GET

In addition to the changes in severity of ME/CFS (see 3:4 above), courses with a 15% or more percentage difference between the outcomes of courses on mild to moderate sufferers and severe to very severe sufferers are:

GET courses which were GET only – no elements of CBT or Pacing:

- The symptoms of 19% mild to moderate and 4% severe to very severe sufferers were unaffected
- The symptoms of 37% of mild to moderate and 65% severe to very severe sufferers became very much worse
- 17% mild to moderate and 0% severe to very severe sufferers found their courses to be appropriate to their needs
- 72% mild to moderate and 91% severe to very severe sufferers found their courses to be not appropriate to their needs

GET courses held by therapists with an ME/CFS specialism:

- 22% mild to moderate and 39% severe to very severe sufferers became very much worse
- 50% mild to moderate and 65% severe to very severe sufferers found their courses to be not appropriate to their needs

GET group courses:

- 35% mild to moderate and 13% severe to very severe sufferers became somewhat worse
- 28% mild to moderate and 48% severe to very severe sufferers became very much worse

GET courses held by therapists who believed that ME/CFS is a physical illness:

- 16% mild to moderate and 0% severe to very severe sufferers became very much better
- 16% mild to moderate and 38% severe to very severe sufferers became very much worse
- 44% mild to moderate and 19% severe to very severe sufferers found their courses to be appropriate to their needs
- 48% mild to moderate and 69% severe to very severe sufferers found their courses to be not appropriate to their needs

GET courses held by therapists who believed that ME/CFS is a psychological illness:

- 31% mild to moderate and 14% severe to very severe sufferers became somewhat worse

GET courses which were only partly completed by the respondents (irrespective of criteria):

- 41% mild to moderate sufferers and 26% severe to very severe sufferers became somewhat worse

3:6:3 Effect of Courses on Illness Severity – Pacing

Pacing courses which were Pacing only – no elements of CBT or GET:

- The symptoms of 52% mild to moderate and 32% severe to very severe sufferers remained unaffected

Pacing courses held by therapists not stated to have an ME/CFS specialism:

- The symptoms of 5% mild to moderate sufferers and 50% severe to very severe sufferers became very much better
- The symptoms of 57% mild to moderate sufferers and 33% severe to very severe sufferers remained unaffected

Pacing group courses:

- The symptoms of 28% mild to moderate and 44% severe to very severe sufferers became somewhat better

Pacing courses held by therapists who believed ME/CFS to be a psychological illness:

- The symptoms of 73% mild to moderate and 44% severe to very severe sufferers remained unaffected
- 27% mild to moderate and 11% severe to very severe sufferers found their courses to be appropriate to their needs
- 45% mild to moderate and 89% severe to very severe sufferers found their courses to be not appropriate to their needs
- 27% mild to moderate and 0% severe to very severe sufferers found their courses to be partly appropriate to their needs – but these were very small cohorts

Pacing courses which did not affect symptoms:

■ **15%** mild to moderate sufferers and **34%** of severe to very severe sufferers found their courses to be not appropriate to their needs

Pacing courses which were only partly completed by the respondents:

■ **38%** of mild to moderate sufferers and **57%** of severe to very severe sufferers considered their courses to be not appropriate to their needs

■ **41%** of mild to moderate sufferers and **25%** of severe to very severe sufferers considered their courses to be partly appropriate to their needs

3:7 EFFECT ON MENTAL HEALTH AND ME/CFS SYMPTOMS – CBT

■ See Appendix 2, Section 6

CBT courses brought about greater improvements to the symptoms of anxiety, depression and stress than they did on ME/CFS symptoms with a slightly lower number becoming worse:

■ Mental health symptoms of **34%** of respondents improved compared to a **13%** improvement in ME/CFS symptoms following CBT courses

■ Mental health symptoms of **18%** of respondents became worse compared to a **20%** worsening of ME/CFS symptoms following CBT courses

■ For those respondents who reported that they did not have any anxiety, depression or stress symptoms before their CBT courses, ME/CFS symptoms improved for only **5%** but became worse for **39%**

Example comment – CBT:

“The course was helpful in accepting the physical nature of the disease and the lack of effective medical treatment. The course was most helpful in dealing with the depression accompanying the loss of physical and mental abilities.”

3:8 EFFECT OF COURSES ON SPECIFIC ME/CFS SYMPTOMS

We considered the effect of courses overall (meaning irrespective of the listed criteria) and courses which were CBT only, GET only or Pacing only, on the specific symptoms listed below.

Specific ME/CFS symptoms:

■ Exercise-induced muscle fatigue

■ Post-exertional malaise

■ Muscle pain

■ Cognitive dysfunction

■ Aching joints without swelling or redness

■ Dizziness or feeling faint on standing

■ Headaches of type not previously experienced

■ Inability to cope with temperature changes

■ Increased sensitivity to light and/or sound and/or smells

■ Recurrent sore throats and enlarged glands

■ Sleep disturbance or unrefreshing sleep

■ For further details see Appendix 2, Section 7

3:8:1 Effect of Courses on Specific ME/CFS Symptoms – CBT

Symptom improvement

Following CBT, specific symptom improvements ranged from **3%** to **12%** irrespective of the listed criteria. The overall percentage of symptoms improving as shown at **3:4:1a** and **3:5:1:1** above is **12%**.

CBT courses which were CBT only – no elements of GET or Pacing – demonstrated specific symptom improvements ranging from **2%** to **8%**. The overall percentage of symptoms improving as shown at **3:4:2a** and **3:5:1:1** above is **8%**.

Symptoms becoming worse

Following CBT, specific symptoms becoming worse ranged from **12%** to **20%** irrespective of the listed criteria. The overall percentage of symptoms becoming worse as

shown at **3:4:1a** and **3:5:1:2** above is **23%**.

CBT courses which were CBT only – no elements of GET or Pacing – demonstrated that specific symptoms becoming worse ranged from **7%** to **15%**. The overall percentage of symptoms becoming worse as shown at **3:4:2a** and **3:5:1:2** above is **18%**.

Symptoms remaining unaffected

Following CBT, specific symptoms remaining unaffected ranged from **71%** to **82%** irrespective of the listed criteria. The overall percentage of symptoms remaining unaffected as shown at **3:4:1a** and **3:5:1:3** above is **65%**.

CBT courses which were CBT only – no elements of GET or Pacing – demonstrated that specific symptoms remaining unaffected ranged from **78%** to **90%**. The overall percentage of symptoms that remained unaffected as shown at **3:4:2a** and **3:5:1:3** above is **73%**.

3:8:2 Effect of Courses on Specific ME/CFS Symptoms – GET

Symptom improvement

Following GET, specific symptom improvements ranged from **6%** to **13%** irrespective of the listed criteria. The overall percentage of symptoms improving as shown at **3:4:1a** and **3:5:2:1** above is **15%**.

GET courses which were GET only – no elements of CBT or Pacing – demonstrated specific symptom improvements ranging from **1%** to **9%**. The overall percentage of symptoms improving as shown at **3:4:2a** and **3:5:1:1** above is **12%**.

Symptoms becoming worse

Following GET, specific symptoms becoming worse ranged from **32%** to **62%** irrespective of the listed criteria. The overall percentage of symptoms becoming worse as shown at **3:4:1a** and **3:5:2:2** above is **64%**.

GET courses which were GET only – no elements of CBT or Pacing – demonstrated



that specific symptoms becoming worse ranged from **37%** to **72%**. The overall percentage of symptoms becoming worse as shown at **3:4:2a** and **3:5:2:2** above is **74%**.

In both sets of data and as a result of Graded Exercise Therapy: post exertional malaise, exercise-induced muscle fatigue, muscle pain, aching joints without swelling or redness, cognitive dysfunction and sleep disturbance or unrefreshing sleep – became notably worse for the majority of respondents.

Symptoms remaining unaffected

Following GET, specific symptoms remaining unaffected ranged from **62%** to **25%** irrespective of the listed criteria. The overall percentage of symptoms remaining unaffected as shown at **3:4:1a** and **3:5:2:3** above is **21%**.

GET courses which were GET only – no elements of CBT or Pacing – demonstrated that specific symptoms remaining unaffected ranged from **20%** to **61%**. The overall percentage of symptoms remaining unaffected as shown at **3:4:2a** and **3:5:2:3** above is **14%**.

3:8:3 Effect of Courses on Specific ME/CFS Symptoms – Pacing

Symptom improvement

Following Pacing, specific symptom improvements ranged from **14%** to **36%** irrespective of the listed criteria. The overall percentage of symptoms improving as shown at **3:4:1a** and **3:5:3:1** above is **38%**.

Pacing courses which were Pacing only – no elements of CBT or GET – demonstrated specific symptom improvements ranging from **14%** to **44%**. The overall percentage of symptoms improving as shown at **3:4:2a** and **3:5:3:1** above is **45%**.

Symptoms becoming worse

Following Pacing, specific symptoms becoming worse ranged from **13%** to **19%** irrespective of the listed criteria. The overall percentage of symptoms becoming worse as shown at



3:4:1a and **3:5:3:2** above is **19%**.

Pacing courses which were Pacing only – no elements of CBT or GET – demonstrated that specific symptoms becoming worse ranged from **14%** to **19%**. The overall percentage of symptoms becoming worse as shown at **3:4:2a** and **3:5:3:2** above is **14%**.

Symptoms remaining unaffected

Following Pacing, specific symptoms remaining unaffected ranged from **47%** to **72%** irrespective of the listed criteria. The overall percentage of symptoms remaining unaffected as shown at **3:4:1a** and **3:5:3:3** above is **42%**.

Pacing courses which were Pacing only – no elements of CBT or GET – demonstrated that specific symptoms remaining unaffected ranged from **45%** to **76%**. The overall percentage of symptoms remaining unaffected as shown at **3:4:2a** and **3:5:3:3** above is **41%**.

3:9 SELF-MANAGEMENT

Further details: see Appendix 5.

Full data relating to self-management of ME/CFS will be given in Part 2 of this report, to be published later.

3:9:1 Self-management – CBT

Self-management using CBT principles and practices was found to be effective by **53%** of respondents, whereas **47%** found such self-management ineffective

Self-management using CBT principles and practices resulted in improved symptoms for **26%**, unaltered symptoms for **57%**, and

worsened symptoms for **17%** of respondents

Self-management consultations were found to be helpful for **48%**, but unhelpful for **52%** of respondents

3:9:2 Self-management – GET

Self-management using GET principles and practices was found to be effective by **46%** of respondents, whereas **54%** found such self-management ineffective

Self-management using GET principles and practices resulted in improved symptoms for **28%**, unaltered symptoms for **33%**, and worsened symptoms for **39%** of respondents

GET self-management consultations were found to be helpful for **43%**, but unhelpful for **57%** of respondents

3:9:3 Self-management – Pacing

Self-management using Pacing principles and practices was found to be effective by **70%** of respondents, whereas **30%** found such self-management ineffective

Self-management using Pacing principles and practices resulted in improved symptoms for **56%**, unaltered symptoms for **32%**, and worsened symptoms for **12%** of respondents.

Pacing self-management consultations were found to be helpful for **79%**, but unhelpful for **21%** of respondents

3:10 COMPARISON WITH PREVIOUS PATIENT SURVEYS

Appendix: 6 sets out details of the data on CBT, GET and Pacing from the previous patient surveys that we are aware of.

It is clear that there is a pattern in all previous patient surveys and that the same pattern runs in this survey. The pattern is that Pacing is the most effective intervention and GET is the least effective and may cause harm.



It is acknowledged that different criteria – such as the type listed in **3:1** above – will have led to different results in the previous surveys. To give examples:

- There will have been different degrees to which the three interventions overlapped each other and yet were called CBT or GET or Pacing
- There were different cohorts of respondents with different degrees of severity of ME/CFS
- There will have been different degrees to which respondents were able to concentrate on looking after themselves and not others, this having an effect on the success or failure of their courses
- The questions which were asked will have been differently expressed, even had different terms used in the reporting. We do not always know what is meant by better or worse – whether it means much better or somewhat better or much worse or somewhat worse
- The expertise of therapists involved is mostly unknown
- We do not know the extent to which respondents took part in more than one survey and so possibly duplicated some results
- In most survey's respondents were asked to provide answers to three choices (e.g. symptoms improved/satisfactory, symptoms not effected/partly appropriate, deterioration/not acceptable) but in two surveys only two answers were provided. This, of course, had an effect on the comparison

Nevertheless, the pattern is predominantly the same and should not be ignored: Pacing is the most effective intervention, and GET is the least effective and may cause harm.

3:11 AVAILABILITY OF NHS MANAGEMENT COURSES

- See Appendix 2, Section 9
- **40%** of CBT, **48%** of GET and **35%** of Pacing respondents said there was no NHS ME/CFS management course available in their area
- **18%** of CBT, **14%** of GET and **27%**

of Pacing respondents said they could not access an out-patient or hospital-based facility and no home visits were available

- **34%** of CBT, **29%** of GET and **25%** of Pacing respondents said it was considered they would not have benefitted from such a course
- **8%** of CBT, **10%** of GET said they were diagnosed as having severe ME/CFS and considered to be ineligible for CBT or GET under the 2007 NICE guideline
- Some Pacing respondents said that were not given a course because Pacing is not a recognised therapy under the 2007 NICE guideline

3:12 DISABILITY BENEFITS STATUS FOLLOWING COURSES

- See Appendix 2, Section 9.

Disability benefits information represents an objective measure of recovery, improvement or deterioration. Benefits asked about were Attendance Allowance, Carer's Allowance, Disability Living Allowance, Employment and Support Allowance and Incapacity Benefit. Combined figures are given.

Note: Overall, the percentage of respondents claiming disability benefits both before and/or after courses was: **61%** for CBT courses, **66%** for GET courses and **55%** for Pacing courses.

Cognitive Behavioural Therapy (CBT):

- The disability benefits of **71%** of the respondents remained the same after CBT courses
- The disability benefits of **19%** started or were increased and **9%** were stopped or reduced
- Net increase in benefits of **10%**

Graded Exercise Therapy (GET):

- The disability benefits of **69%** of the respondents remained the same after GET courses
- The disability benefits of **22%** started or were increased and **9%** were stopped or reduced
- Net increase in benefits of **13%**

Pacing:

- The disability benefits of **79%** of the respondents remained the same after courses
- The disability benefits of **10%** started or were increased and **11%** were stopped or reduced
- Net decrease in benefits of **1%**

Note:

This is much the same pattern as the benefit status information reported in the 2012 PACE trial Cost Effective Analysis paper, which noted that "benefit status increased across all four treatments", i.e. adaptive pacing therapy, cognitive behavioural therapy, graded exercise therapy, and specialist medical care.

The information above from our 2012 survey takes into account patients or carers:

- who were on benefits before courses with no alteration after courses
- who were on benefits before courses started and who were granted other disability benefits after courses
- who were not on disability benefits before courses but who started disability benefits after courses
- whose disability benefits were increased after courses
- whose disability benefits were stopped or reduced after courses

Example comments:

"...CBT opened the door to people saying I am suffering from severe anxiety and depression which has caused me nothing but massive problems in appealing DLA, and my works pension. I am now in purgatory."

"Pacing helps with symptom severity and duration as long as I can stay within my personal limits. Unfortunately two medical assessments and a DLA tribunal pushed me past my physical, mental and emotional limits and it was impossible to pace for the medicals, interviews, travelling etc., and I





relapsed dramatically, had to have increased medications and also medications for my mental health which also suffered.

The relapse lasted two and a half years, strict pacing and with the help of the ME Association and the Expert Patients Program has helped me get 'back on track'. Unfortunately my DLA renewal is due, I am having to forego strict pacing also anxiety levels are building and depression deepening (anti-depressant dosage increased). I notice a great difference between effective pacing and not being able to stay within my limits, both in symptom severity and also the amount of medications."

3:13 EFFECT OF COURSES ON EMPLOYMENT AND EDUCATION

Our survey asked for information about status changes with regards to education, training or paid employment as a result of course attendance.

The answers gave us information that is not covered by the quantitative data and which, as with disability benefits, represents an objective measure of recovery, improvement or deterioration:

- Some who were working before their courses gave up work or study because they were taught that they needed to allow their bodies a better chance at recovery
- Some whose courses made their illness worse had to give up work because they were unable to continue
- Some whose courses led to an improvement in symptoms allowed

them to return to work

But for many there was no change because they were not able to work or study before their courses due to ME/CFS and were not able to return to work or study afterwards.

Individual responses are set out in Appendix 4.

3:14 LENGTH OF COURSE SESSIONS

■ See Appendix 2, Section 3, 3:7

■ **41%** CBT, **62%** GET and **39%** Pacing course sessions were held for less than an hour but most were for at least half an hour

■ **39%** CBT, **17%** GET and **30%** Pacing course sessions were held for an hour

■ **20%** CBT, **20%** GET and **32%** Pacing course sessions were held for more than an hour and in some cases were held for over two hours

The qualitative data in Appendix 1 notes that many respondents found the longer sessions exhausting and not suited to their state of health. And many of those who dropped out of their courses did so because they said the courses were too tiring.

3:15 PROVISION OF INFORMATION ABOUT COURSES

■ See Appendix 2, Section 3, 3:10

Although **60%** of respondents reported that they had received verbal information about courses and their objectives, only **20%** received written information and **20%** received no information.

3:16 EFFECT OF THE 2007 NICE GUIDELINE ON COURSE OUTCOMES

■ See Appendix 2, Section 10

3:16:1 Introduction

We have looked at the effects of courses on symptoms and the appropriateness of courses to the respondents' needs before and after the introduction of the NICE guideline in 2007 to try to ascertain whether the guideline has brought about an improvement in patient

reported outcomes. Pacing is not a recommended intervention under the guideline.

Because we did not specifically ask when respondents had attended their courses in this section of the report we have only been able to include data from those respondents who we know had courses before or after the guideline.

The main data course count is 493 CBT, 233 GET and 226 Pacing respondents.

The count in this section is:

■ Pre-2008 124 CBT, 92 GET and 55 Pacing respondents

■ Post-2007 113 CBT, 46 GET and 70 Pacing respondents

So we are only reporting on 48% CBT, 59% GET and 55% Pacing respondents and when comparing data in this section with data taken from the overall data in Section 3 this must be remembered.

In our calculations we made an assumption that the guideline, which was issued in August 2007, had been disseminated to health professionals by January 2008.

3:16:2 Effect of the 2007 NICE Guideline on Course Outcomes – CBT

As with the overall data in 3:3:1 above there was a general lack of movement between categories of severity of ME/CFS following courses both before and after 2007:

■ **Pre-NICE guideline:**

53% of respondents were mild to moderate sufferers before CBT courses and **53%** after courses

47% of respondents were severe to very severe sufferers before CBT courses and **47%** after courses

■ **Post-NICE guideline:**

61% of respondents were mild to moderate sufferers before CBT courses and **60%** after courses

39% of respondents were severe to very severe sufferers before CBT courses and **40%** after courses



Note:**At 3:3:1 above – the overall percentages were:**

■ **61%** of respondents were mild to moderate sufferers before CBT courses and 59% after courses

■ **40%** of respondents were severe to very severe sufferers before CBT courses and **41%** after courses

3% more CBT respondents reported an improvement in symptoms following courses after 2007 than those who had courses before 2008:

■ **Pre-NICE guideline:** the percentage of respondents whose symptoms improved after CBT courses was **13%**

■ **Post-NICE guideline:** the percentage of respondents whose symptoms improved after CBT courses was **16%**

Note:

At **3:4:1:1** above – the overall percentage of respondents whose symptoms improved after CBT courses was **12%**

1% less CBT respondents reported that their symptoms were worse following courses after 2007 than those who had courses before 2008:

■ **Pre-NICE guideline:** the percentage of respondents whose symptoms became worse after CBT courses was **23%**

■ **Post-NICE guideline:** the percentage of respondents whose symptoms became worse after CBT courses was **22%**

Note:

At **3:4:1:2** above – the overall percentage of respondents whose symptoms became worse after CBT courses was **24%**

1% less CBT respondents reported that their symptoms remained the same following courses after 2007 than those who had courses before 2008:

■ **Pre-NICE guideline:** CBT courses did not affect the symptoms of **63%** of respondents

■ **Post-NICE guideline:** CBT courses did not affect the symptoms of

62% of respondents

Note:

At **3:4:1:3** above – the overall percentage of CBT courses that did not affect the symptoms of respondents was **64%**

4% more CBT respondents reported that their courses were appropriate to the respondents' needs after 2007 than those who had courses before 2008:

■ **Pre-NICE guideline:** the percentage of respondents who thought CBT courses were appropriate to needs was **21%**

■ **Post-NICE guideline:** that percentage of respondents who thought CBT courses were appropriate to needs was **25%**

Note:

At **3:4:1:4** above – the percentage of respondents who thought CBT courses were appropriate to needs was **21%**

8% less CBT respondents reported that their courses were not appropriate to the respondents' needs after 2007 than those who had courses before 2008:

■ **Pre-NICE guideline:** the percentage of respondents who thought CBT courses were not appropriate to needs was **55%**

■ **Post-NICE guideline:** the percentage of respondents who thought CBT courses were not appropriate to needs was **43%**

Note:

At **3:4:1:5** above – the overall percentage of respondents who



thought CBT courses were not appropriate to needs was **52%**

8% more CBT respondents reported that their courses were partly appropriate to the respondents' needs after 2007 than those who had courses before 2008:

■ **Pre-NICE guideline:** the percentage of respondents who thought CBT courses were partly appropriate to needs was **24%**

■ **Post-NICE guideline:** the percentage of respondents who thought CBT courses were partly appropriate to needs was **32%**

Note:

At **3:4:1:6** above – the overall percentage of respondents who thought CBT courses were partly appropriate to needs was **27%**

3:16:3 Effect of The 2007 NICE Guideline on Course Outcomes – GET

Before 2008 29% of mild to moderate sufferers became severe to very severe sufferers following GET courses. After 2007 the percentage fell to **15%**. (The overall percentage in **3:3:2** above)

■ **Pre-NICE guideline:** **59%** of respondents were mild to moderate sufferers before GET courses and **30%** after courses

Pre-NICE guideline: **41%** of respondents were severe to very severe sufferers before GET courses and **70%** after courses

■ **Post-NICE guideline:** **78%** of respondents were mild to moderate sufferers before GET courses and **63%** after courses

Post-NICE guideline: **22%** of respondents were severe to very severe sufferers before GET courses and **37%** after courses

Note:

At **3:3:2** above – the overall percentages were:

■ Before GET courses **62%** of the respondents were mild to moderate sufferers and **41%** after courses

■ Before GET courses **38%** were severe to very



severe sufferers and **59%** after courses

25% more GET respondents reported an improvement in symptoms following courses after 2007 than those who had courses before 2008:

■ **Pre-NICE guideline:** the percentage of respondents whose symptoms improved after GET courses was **8%**

■ **Post-NICE guideline:** the percentage of respondents whose symptoms improved after GET courses was **33%**

Note:

At **3:3:2** above – the overall percentage of respondents whose symptoms improved after GET courses was **15%**

27% less GET respondents reported that their symptoms were worse following courses after 2007 than those who had courses before 2008:

■ **Pre-NICE guideline:** the percentage of respondents whose symptoms became worse after GET courses was **75%**

■ **Post-NICE guideline:** the percentage of respondents whose symptoms became worse after GET courses was **48%**

Note:

At **3:3:2** above – the overall percentage of respondents whose symptoms became worse after GET courses was **64%**

4% more GET respondents reported that their symptoms remained the same following courses after 2007 than those who had courses before 2008:

■ **Pre-NICE guideline:** GET courses did not affect the symptoms of **16%** of respondents

■ **Post-NICE guideline:** GET courses did not affect the symptoms of **20%** of respondents

Note:

At **3:3:2** above – the overall percentage of GET courses that did not affect the symptoms of respondents was **21%**

10% more GET respondents

reported that their courses were appropriate to the respondents' needs after 2007 than those who had courses before 2008:

■ **Pre-NICE guideline:** the percentage of respondents who thought GET courses were appropriate to needs was **10%**

■ **Post-NICE guideline:** the percentage of respondents who thought GET courses were appropriate to needs was **20%**

Note:

At **3:3:2** above – the overall percentage of respondents who thought GET courses were appropriate to needs was **13%**

14% less GET respondents reported that their courses were not appropriate to the respondents' needs after 2007 than those who had courses before 2008:

■ **Pre-NICE guideline:** the percentage of respondents who thought GET courses were not appropriate to needs was **79%**

■ **Post-NICE guideline:** the percentage of respondents who thought GET courses were not appropriate to needs was **65%**

Note:

At **3:3:2** above – the overall percentage of respondents who thought GET courses were not appropriate to needs was **68%**

15% more GET respondents reported that their courses were partly appropriate to the respondents' needs after 2007 than those who had courses before 2008:

■ **Pre-NICE guideline:** the percentage of respondents who thought GET courses were partly appropriate to needs was **11%**

■ **Post-NICE guideline:** the percentage of respondents who thought GET courses were partly appropriate to needs was **26%**

Note:

At **3:3:2** above – the overall percentage of respondents who thought GET courses were partly appropriate to needs was **19%**

3:16:4 Effect of The 2007

NICE Guideline on Course Outcomes – Pacing

Before 2008 **13%** of severe to very severe sufferers became mild to moderate sufferers following Pacing courses. After 2007 the percentage fell to **5%**.

■ **Pre-NICE guideline:** **42%** of respondents were mild to moderate sufferers before Pacing courses and **55%** after courses

58% of the respondents were severe to very severe sufferers before Pacing courses and **45%** after courses

■ **Post NICE guideline:** **64%** of the respondents were mild to moderate sufferers before Pacing courses and **69%** after courses

36% of the respondents were severe to very severe sufferers before Pacing courses and **31%** after courses

Note:

In **3:3:2** above – the overall percentages were:

■ Before Pacing courses **52%** of the respondents were mild to moderate sufferers and **58%** after courses

■ Before Pacing courses **48%** were severe to very severe sufferers and **42%** after courses

16% less Pacing respondents reported an improvement in symptoms following courses after 2007 than those who had courses before 2008:

■ **Pre-NICE guideline:** the percentage of respondents whose symptoms improved after Pacing courses was **51%**

■ **Post-NICE guideline:** the percentage of respondents whose symptoms improved after Pacing courses was **35%**

Note:

At **3:3:3** above – the overall percentage of respondents whose symptoms improved after Pacing courses was **38%**

4% less Pacing respondents reported that their symptoms were worse following



courses after 2007 than those who had courses before 2008:

■ **Pre-NICE guideline:** the percentage of respondents whose symptoms became worse after Pacing courses was **20%**

■ **Post-NICE guideline:** the percentage of respondents whose symptoms became worse after Pacing courses was **16%**

Note:

At **3:3:3** above – the overall percentage of respondents whose symptoms became worse after Pacing courses was **19%**

21% more Pacing respondents reported that their symptoms remained the same following courses after 2007 than those who had courses before 2008:

■ **Pre-NICE guideline:** the percentage of respondents who thought Pacing courses did not affect symptoms was **29%**

■ **Post-NICE guideline:** the percentage of respondents who thought Pacing courses did not affect symptoms was **50%**

Note:

At **3:3:3** above – the overall percentage of respondents who thought Pacing courses did not affect symptoms was **42%**

17% less Pacing respondents reported that their courses were appropriate to needs after 2007 than those who had courses before 2008:

■ **Pre-NICE guideline:** the percentage of respondents who thought Pacing courses appropriate to needs was **58%**

■ **Post-NICE guideline:** the percentage of respondents who thought Pacing courses appropriate to needs was **41%**

Note:

At **3:3:3** above – the overall percentage of respondents who thought Pacing courses were appropriate to needs was **50%**

9% less Pacing respondents reported that their courses were not appropriate to needs after 2007 than those who had courses

before 2008:

■ **Pre-NICE guideline:** the percentage of respondents who thought Pacing courses were not appropriate to needs was **15%**

■ **Post-NICE guideline:** the percentage of respondents who thought Pacing courses were not appropriate to needs was **24%**

Note:

At **3:3:3** above – the overall percentage of respondents who thought Pacing courses were not appropriate to needs was **24%**

7% more Pacing respondents reported that their courses were partly appropriate to needs after 2007 than those who had courses before 2008:

■ **Pre-NICE guideline:** the percentage of respondents who thought Pacing courses were partly appropriate to needs was **27%**

■ **Post-NICE guideline:** the percentage of respondents who thought Pacing courses were partly appropriate to needs was **34%**

Note:

At **3:3:3** above – the overall percentage of respondents who thought Pacing courses were partly appropriate to needs was **25%**

SECTION 4: CONCLUSIONS

4:1 GENERAL

The overall data (i.e. irrespective of the listed criteria) comes from fairly large cohorts and we conclude that it is reliable. Our findings need only be weighed against the caveats set out at the end of the report (see Section: 6).

Some of the cohorts which led to key findings based on the listed criteria are small. However, where these findings are reflected time and again when different criteria are considered, we conclude that they become reliable.

Most patients with ME/CFS are individuals who are experts in their experience of the illness

and their needs. They acquire a fund of knowledge as to what works for them and what does not and, whilst many of the courses reported on date back several years, it is clear from the qualitative data that the respondents' memories about their courses remain fresh in their minds.

The evidence of this report coupled with the evidence of previous patient surveys (see Key Findings and Appendices 1- 6) and the perfectly valid concerns about the design, outcome measures and reporting of RCTs (see Appendix 7) involving CBT and GET that are repeatedly expressed in the medical literature; lead us to the conclusion that there must be a change in the position held by NICE where patient evidence is almost completely ignored and the evidence from RCTs is relied on seemingly without question.

Readers are reminded:

- a. Of the Introduction at 1:2, that many courses involve a combination of two or more of these interventions, even if they are not labelled as combined courses. Sometimes combined courses are termed graded activity management or energy management courses, and
- b. Of the caveat about the substantial reporting of heterogeneity of CBT, GET and Pacing

We base the following conclusions on the evidence contained in Section 3: Key Findings above.

4:2 CONCLUSIONS – COGNITIVE BEHAVIOURAL THERAPY (CBT)

We conclude that CBT in its current delivered form should not be recommended as a primary intervention for people with ME/CFS.

CBT courses based on the model that abnormal beliefs and behaviours are responsible for maintaining the illness, have no role to play in the management of ME/CFS and increase the risk of symptoms becoming worse.



The belief of some CBT practitioners that ME/CFS is a psychological illness was the main factor which led to less symptoms improving, less courses being appropriate to needs, more symptoms becoming worse and more courses being seen as inappropriate.

It appeared that, for some, it was acceptable that therapists considered ME/CFS to be a mixture of a physical and a psychological illness but their belief that it was a psychological illness was almost always totally unacceptable. Other criteria had influences, but this was the largest element which, if removed from CBT, would lead to improvements in its delivery.

Our results indicate that graded exercise therapy should form no part of any activity management advice employed in the delivery of CBT, as this also led to a negative impact on outcomes.

There is a clear need for better training among practitioners. The data indicates that deemed lack of knowledge and experience had a direct effect on outcomes and remained a key factor even where courses were held in specialist clinics or otherwise given by therapists with an ME/CFS specialism.

However, our results did indicate that when used appropriately the practical coping component of CBT can have a positive effect in helping some patients come to terms with their diagnosis and adapt their lives to best accommodate it.

CBT was also seen to have a positive effect in helping some patients deal with comorbid issues – anxiety, depression, stress – which may occur at any time for someone with a long-term disabling illness.

An appropriate model of CBT – one that helps patients learn practical coping skills and/or manage co-morbid issues such as those listed above – could be employed, where appropriate, for ME/CFS as it is for other chronic physical illnesses such as multiple sclerosis, Parkinson's disease,

cancer, heart disease, and arthritis etc.; and we recommend all patients should have access to such courses as well as access to follow-up courses and/or consultations as and when required.

We therefore conclude that CBT should be considered as part of illness management programmes where needed and irrespective of the degree of severity of the illness. This report will be followed up with a report on illness management to include the part CBT should play.

Note:

Enhancing recovery rates in IAPT services: Lessons from analysis of the year one data was published in 2013. It talks about the importance of experienced NHS staff and relates to data from 19,395 patients and is relevant to the discussion above.

4:3 CONCLUSIONS – GRADED EXERCISE THERAPY (GET)

We conclude that GET should be withdrawn with immediate effect as a primary intervention for everyone with ME/CFS.

One of the main factors that led to patients reporting that GET was inappropriate was the very nature of GET itself, especially when it was used on the basis that there is no underlying physical cause for the symptoms, and that patients are basically ill because of inactivity and deconditioning.

A significant number of patients had been given advice on exercise and activity management that was judged harmful with symptoms having become worse or much worse and leading to relapse. And it is worth noting that despite current NICE recommendations, a significant number of severe-to-very severe patients were recommended GET by practitioners and/or had taken part in GET courses.

The other major factor contributing to poor outcomes was the incorrect belief held by some practitioners that ME/CFS is a

psychological condition leading to erroneous advice that exercise could overcome the illness if only patients would 'push through' worsening symptoms.

When it comes to prescribing any form of exercise, health professionals should be doing so with the same degree of caution that would apply to a drug intervention. Clearly that does not often happen with GET. A very significant number of patients had been given advice on exercise and activity management that was not appropriate to the extent of their disability and which resulted in harm.

We recognise that it is impossible for all treatments for a disease to be free from side-effects, but if GET was a licensed medication we believe the number of people reporting significant adverse effects would lead to a review of its use by regulatory authorities.

As a physical exercise-based therapy, GET may be of benefit to a sub-group who come under the ME/CFS umbrella and are able to tolerate regular and progressive increases in some form of aerobic activity, irrespective of their symptoms. However, identifying a patient who could come within that sub-group is problematic and not possible at present.

Some patients indicated that they had been on a course which had a gentle approach of graded activity rather than a more robust and structured approach of graded physical exercise. There were some reports that patients were told they should not exercise when they felt too unwell to do so. These led, for some, to an improvement in symptoms or to symptoms remaining unaffected.

However, we conclude that GET, as it is currently being delivered, cannot be regarded as a safe and effective form of treatment for the majority of people with ME/CFS. The fact that many people, including those who consider themselves severely affected, are being referred to specialist services for



an intervention that makes them either worse or much worse is clearly unacceptable and in many cases dangerous.

GET should therefore be withdrawn by NICE and from NHS specialist services as a 'one size fits all' recommended treatment with immediate effect for everyone who has a diagnosis of ME/CFS. This advice should remain until there are reliable methods for determining which people who come under the ME/CFS umbrella are likely to find that GET is a safe and effective form of management.

The concerns about GET as practiced outside research conditions and consistently expressed in this and other patient surveys are well founded (see Key Findings 3:7 and Appendix 6).

4:4 CONCLUSIONS – PACING

Pacing was consistently shown to be the most effective, safe, acceptable and preferred form of activity management for people with ME/CFS and should therefore be a key component of any illness management programme.

The benefit of Pacing may relate to helping people cope and adapt to their illness rather than contributing to a significant improvement in functional status. Learning coping strategies can help make courses more appropriate to needs even if they do not lead to immediate or even longer term improvement in symptoms.

For some, improvement may be a slow process so, whilst they may be somewhat better by the end of the course, the improvement is not enough to take them into a better category of severity for some time, perhaps not until they have self-managed their illness for a few years.

Pacing can be just as applicable to someone who is severely affected, as to someone who is mildly or moderately affected, although additional measures need to be taken to ensure that a person who is severely affected has equal access to services.

However, proposed increases in activity, both mental and physical, must be gradual, flexible and individually tailored to a patient's ability and circumstance, and not progressively increased regardless of how the patient is responding.

There must be better training for practitioners who are to deliver such management courses and all patients should have access to suitable courses, follow-up courses and/or consultations as and when required.

4:5 CONCLUSIONS – POSITION FOLLOWING THE 2007 NICE GUIDELINE

4:5:1 Position Following The 2007 NICE Guideline – CBT

We base these conclusions on 3:16:2 of our Key Findings and Appendix 2, Section: 10.

The data indicates that, despite concerns about the delivery of CBT courses and the slight downward trend in the change of degree of severity after courses, there has been a slight improvement in services delivered after the NICE guideline. However, there is nothing in our data to indicate that our conclusions at 4:2 above are not correct.

4:5:2 Position Following The 2007 NICE Guideline – GET

We base these conclusions on 3:16:3 of our Key Findings and Appendix 2, Section: 10.

The data indicates that despite an increase, after the NICE guideline, in the percentage of respondents reporting improved symptoms after GET courses and an increase in courses that were appropriate to needs, GET is an intervention which still causes harm to 48% of sufferers and is not appropriate to the needs of 54%. There is nothing in our data to indicate that our conclusions at 4:3 above are not correct.

4:5:3 Position Following The 2007 NICE Guideline – Pacing

We base these conclusions on

3:16:4 of our Key Findings and Appendix 2, Section: 10.

The data shows a decrease in the percentage of respondents who improved to being mild to moderate sufferers from severe to very severe sufferers after the NICE guideline. It was a very slight decrease when compared to the percentage of respondents whose courses we know took place before the NICE guideline, but an 8% decrease when compared to the overall data percentage.

The results also show a decrease in the percentage of respondents reporting an improvement in symptoms following course and/or courses which were appropriate to needs. There was an increase in courses which were not appropriate to respondents' needs when compared to the percentage in courses where we know courses took place before the NICE guideline, but after the NICE guideline the percentage was the same as the overall data percentage.

Despite these changes, Pacing remains the most effective, safe, acceptable and preferred of the three interventions. There is nothing in our post-NICE guideline data to indicate that our conclusions at 4:4 above are not correct.

SECTION 5: RECOMMENDATIONS

5:1 GENERAL

We consider the NICE guideline to be in need of considerable amendment and will as soon as possible prepare a paper recommending more appropriate illness management that will include such parts of the guideline as we consider are appropriate.

The recommendations in this report are restricted to evidence arising from our survey and relate to:

- The adoption of Pacing and a more appropriate form of CBT in the recommended management of ME/CFS by NHS Health Authorities and by



private practitioners and improved training of practitioners, most especially those stated to have an ME/CFS specialism

- The removal of GET from the management of ME/CFS by NHS Health Authorities and by private practitioners

- The removal of GET and the adoption of Pacing together with a more appropriate form of CBT in the recommended management of ME/CFS in the NICE guideline

Some of these recommendations may be repeated and/or further recommendations about CBT, GET or Pacing may be included in our paper on illness management.

5:2 RECOMMENDATIONS – CBT

We recommend that CBT should no longer be regarded as a primary form of treatment for ME/CFS. The 2007 NICE guideline recommendation relating to CBT being offered to everyone with mild or moderate ME/CFS should be retracted.

The coping strategy components of CBT, which a significant proportion of respondents found helpful, should be incorporated into multidisciplinary illness management programmes and made use of in the management of people who are having difficulty in coping with the many restrictions imposed by ME/CFS including Pacing and/or any mental health and emotional issues which may arise during the course of their illness.

This 'coping with a chronic illness' component should normally be delivered by a specialist nurse or other health professional who has the necessary skills, knowledge and experience to do so - as is the case for specialist services provided to people with multiple sclerosis, Parkinson's disease, cancer, heart disease, arthritis etc.

When delivered in a mental health setting, the use of CBT should be restricted to people who are having problems with emotional or mental health (anxiety, depression, stress etc.).

Abnormal illness beliefs and behaviours have no role to play in the treatment of ME/CFS.

5:3 RECOMMENDATIONS – GET

GET should be withdrawn with immediate effect from the NICE guideline as an automatic recommendation for everyone with ME/CFS and from use by all health practitioners and not used in any illness management by Health Authorities or private practitioners.

This position should remain until there are reliable methods for determining which people who come under the ME/CFS umbrella are likely to find that GET is a safe and effective form of management.

5:4 RECOMMENDATIONS – PACING

Pacing should play a key role in activity and energy management aspects of illness management programmes. Clearly, from the Pacing findings in this and other patient surveys, such a recommendation will be widely welcomed by the patient community and is likely to be far more effective and safe. Advice on relevant Pacing should be offered to all ME/CFS patients irrespective of degree of severity of their illness.

Any activity and energy management programme must be based on the stage, severity and variability of a person's illness. We recommend that increases in activity, both mental and physical, must be gradual, flexible and within a patient's limitations, and not progressively increased regardless of how the patient is responding.

For those patients who progress and improve, a move to a more active and progressive activity and energy management approach may become appropriate. Any decision to include aerobic exercise should take into account the individual's ability, the stage of illness and the sustainability of recovery.



5:5 RECOMMENDATIONS – HEALTH PROFESSIONAL TRAINING – SAFETY AND ADVERSE EFFECTS

All health professionals involved in the delivery of CBT and/or Pacing must appreciate that this illness is a heterogeneous condition covering a wide spectrum of clinical presentations, disease pathways and severity.

The different clinical presentations almost certainly reflect the presence of different disease pathways which may, or may not, overlap. Consequently it is unrealistic and unhelpful to patients for health professionals to conclude that ME/CFS represents one single clinical entity, but from the qualitative data in this survey it is clear that many therapists adopt this view.

Our data indicates that a substantial percentage of health professionals do not understand the illness and we found it disturbing that the position was not much different when the therapists were believed to have an ME/CFS specialism.

We recommend that health professionals who are involved in the delivery of CBT and Pacing be educated in all aspects of ME/CFS. The relevant professional bodies should ensure that this is occurring. Health professionals should also ensure that they are up to date with new developments, even though this may involve clinical and research information that is outside their specific area of expertise. This is particularly important in relation to health professionals who may only see occasional patients with ME/CFS.



We recommend that therapists are instructed that they should not dogmatically base their approach to management on the view that the same causative factors apply to everyone with ME/CFS. This is particularly important in relation to therapists who believe in the abnormal illness beliefs and behaviour model of ME/CFS and consequently deliver their courses based on this erroneous belief. The adverse effect of so doing is clearly demonstrated in this survey.

A high percentage of respondents reported that they found self-management to be ineffective. Those who did not self-manage consistently reported this was because they did not find the programmes helpful. This indicates a lack of understanding on the part of many practitioners who therefore need to be trained to better impart practical knowledge to their patients.

5:6 RECOMMENDATIONS – PRACTICAL CONSIDERATIONS COURSE PLANNING

When planning times and locations of courses (or consultations), health professionals must take account of the problems experienced by patients in relation to physical and mental fatigue, mobility and access.

We recommend that courses (and consultations) take place in locations that can be easily accessed by patients without risk of deterioration of their symptoms. Courses and appointments should not last for more than one hour but individual needs should also be carefully taken into account. Facilities for people who wish to take rest breaks should also be made readily available.

We recommend that, for patients for whom home-based courses or consultations would be more appropriate, these should be provided.

We strongly recommend that hospital-based referral services are set up throughout the UK so that people at the severe end of the ME/CFS spectrum can properly attend courses and consultations

in environments that are suitable to their needs including, if necessary, in-patient facilities.

5:7 RECOMMENDATIONS – PROVISION OF PATIENT INFORMATION

We recommend that patients are fully informed about their courses before undertaking them so that they are aware of the content and objectives. They should also be told what they will be expected to do regarding self-management during and after courses. This information should be given both verbally and with written information provided to take home.

Patients should be fully aware:

- that symptoms may not improve after courses or consultations and that all they may reasonably expect is to be better able to manage their illness
- that should symptoms improve, some symptoms may benefit more than others from illness management
- that with any form of illness management there are risks attached and patients should be appraised of what those risks might be
- of how to best manage any increase in symptoms following illness management advice

We recommend the use of follow up questionnaires in order that courses and consultations are monitored to help better determine outcomes and to aid in the future development of illness management programmes. Such data should be made freely available.

5:8 RECOMMENDATIONS – FOLLOW-UP COURSES AND CONSULTATIONS

The survey data indicates that only **5%** of respondents felt their courses led to symptoms becoming very much better.

However, if regular follow-up or refresher courses with health professionals experienced in ME/CFS had been provided for the

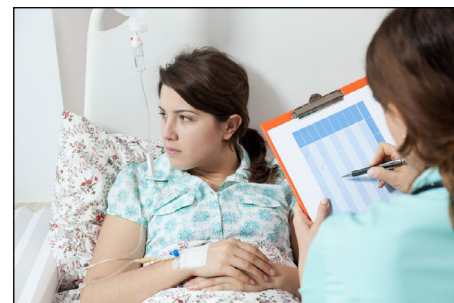
remaining **95%** of respondents, it might have increased the number of improved outcomes. Yet it is clear from our data that such additional course provision is rare.

Follow-up/refresher courses and consultations are almost always essential and we recommend that adequate provision is made for them.

5:9 RECOMMENDATIONS – THE 2007 NICE GUIDELINE FOR ME/CFS (CG53)

The 2007 NICE guideline, while containing some useful recommendations regarding service provision, contains specific recommendations about CBT and GET which, in our opinion, require it to be substantially amended.

We believe that the guideline is reviewed so that it contains recommendations that reflect the conclusions and patient evidence from this report as well as from other patient surveys, in addition to evidence from properly conducted RCTs.



5:10 RECOMMENDATIONS – PATIENT INVOLVED DECISION MAKING

“No decisions about me, without me”

All healthcare professionals and providers should have this message leading its healthcare delivery.

Patients with ME/CFS are individuals who are experts in their experience of their illness as well as their needs. They acquire a fund of knowledge as to what works for them and what does not and they manage their conditions better when they are involved patients.

Critically, it follows that this approach to overall management is better



for the health service. Informed patients use health resources more appropriately and economically. They do not then drop out so frequently from treatment or end up so often in hospital beds, ambulances and Accident and Emergency.

Our qualitative data clearly shows how dissatisfied many ME/CFS patients are with the situation. We urge health service providers to listen to what the patients are saying and deal with the issues they raise. It is a "win-win" situation. Involving the patient brings better healthcare results for them and saves valuable resources for the healthcare provider.

SECTION 6: REPORT CAVEATS

Please note:

- a) Responses to the survey were not compulsory and so the percentages given are the percentages of the respondents who answered a particular question.
- b) Subject to a) respondents whose data is included in this part of the report completed the section about courses. Not all completed the section about self-management.
- c) In a few instances the cohorts are small.
- d) The statements that courses had overlapping elements of the interventions and the statements about the beliefs of therapists about the nature of ME/CFS are the opinions of the respondents.
- e) People with ME/CFS who have recovered, or made a return to near normal health are less likely to take part in such a survey. So we have little data on the use of these three approaches in people who have recovered, or have largely recovered.
- f) Because the survey was carried out by a patient support charity, there is likely to be a bias towards those groups of people who are current members of ME/CFS charities or who utilise charity websites or attend ME/CFS support groups.

Therefore we recognise that patients who have long-term illness and moderate to severe symptoms/disability as well as women are possibly over-represented. Those with short-term and/or less severe illness are possibly under-represented – as are men, children and adolescents.

Only 16 respondents noted they had heard about the survey through young persons' ME/CFS charities. 70% of respondents who answered the question said they heard about the survey through The ME Association, 4% through other national ME/CFS charities, 12% through their local support groups and 9% through online discussion boards/forums. 5% said "person I know who has ME" or "other".

ME/CFS charities, support groups and online discussion boards/forums tend to have a predominance of female members and people with long term and/or more severe ME/CFS.

g) There will be an element of symptoms becoming better or worse despite courses.

h) There is some conjecture even in the patient community that a percentage of patients are incorrectly diagnosed with ME/CFS and that an incorrect diagnosis could be a significant factor when considering the effect of interventions on symptoms.

i) It will be seen that there was a substantial reporting of heterogeneity of CBT, GET and Pacing, often reflecting what had been taught in courses. For example, what might have been termed a CBT course by a respondent or by a therapist may not necessarily just consist of CBT, and the same might be true of other courses and interventions. This report is a record of what were termed CBT, GET and Pacing as delivered. The heterogeneity should be borne in mind when reading this report.

j) The report should not to be taken as advice as to appropriate treatments.

SECTION 7: ACKNOWLEDGEMENTS

The ME Association wishes to thank all those who took part in filling in the questionnaires and contributing the information that forms the basis of this report.

It was a long and difficult survey questionnaire, particularly for people with a depletion of energy and cognitive challenges, and most completed it stoically and without complaint. We hope your hard labours can now be seen to have borne fruit.

This research was funded by the ME Association Ramsay Research Fund.

7:1 REPORT AUTHORS

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2010 MEA report 'Managing my M.E. What people with ME/CFS and their carers want from the UK's health and social services' – and David Thomas DA

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■ And, Gill Briody, Company Secretary, ME Association.

7:2 AUTHOR'S NOTE:

"This report has been a team effort with the contributors. The knowledge about ME/CFS and these interventions and numerous helpful suggestions have come from everyone and my thanks go to them all.

I am the author who has had main responsibility for composing the survey questionnaire, analysing the data and drafting the report. This has involved long hours of work and my thanks goes to my daughter who has ME/CFS and who has had to 'boom' and therefore 'bust' on many occasions to enable me to do it.

I would not have managed this work well without the help of the team but my particular thanks go to Charles Shepherd and Neil Riley who have played a huge part in the construction of this report and without whose help I would not have managed at all."

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APPENDIX 1: QUALITATIVE DATA – ADDITIONAL COMMENTS ABOUT COURSE

At the end of each intervention section of the survey, we asked the following open-ended question:

"Is there anything further that you would like to say about your course? This could be anything from what the course covered that you have not already told us about, whether it was part of a tailor-made multi-component programme, how you felt about the course and the course practitioner, to what effects it had on your health and lifestyle (family/social life/increases or decreases in levels of activity). Please include here any further positive or negative effects that the course had on you in terms of your use of pain killers, or any changes that your doctor made to your medication around the time of your course."

We were inundated with replies and these follow below. They are restricted to those which relate to the appropriateness/inappropriateness and success/failure of courses.

Note:

1. Where a response is an extract this is stated as such
2. Each response is preceded by the respondent's identity number (all respondents are anonymous)
3. This being an anonymous report, any references which might lead to identification have been omitted

1:1 Courses Taken by Mild to Moderate Sufferers

Why some courses are either appropriate, inappropriate, and why they succeed or fail.

1:1:1 Courses taken by Mild to Moderate Sufferers – CBT

#24: ME moderate before course, remained moderate after course.

Symptoms were the same after course. Course appropriate to needs.

"My course practitioner was very flexible and recognised when I had increased stress or a ME setback, this affected my attendance i.e. changed appointments."

#79: ME moderate before course, remained moderate after course. Symptoms were the same after. Course appropriate to needs.

"My therapist did his very best for me and never asked me to do anything I disagreed with. Everything was thoroughly explained and I was always asked for feedback at the next session. I was advised to reduce my previously high level of activity - this helped reduce the severity of my symptoms. The course was tailor made to my individual needs and, although it made very little difference to my CFS/ME long term, I did feel that something was being done to try and help me, which was important as my GP does not have any treatments for me. I also had PTSD and this was greatly helped during my CBT sessions. I am currently on follow-up sessions and am able to email my therapist if I have serious problems. We have a very nice 'therapeutic relationship' and I always feel listened to and respected."

#96: ME moderate before course, remained moderate after course. Symptoms were the same after. Course appropriate to needs. Part only attended.

"The psychologist was a very pleasant woman, but didn't appear to know much about ME. She only claimed to help with symptoms of anxiety and depression, neither of which I suffered with, so we agreed that to continue would be pointless. I was annoyed that I was being offered such an expensive therapy when it clearly wasn't appropriate."

#97: ME moderate before course, remained moderate after course. Symptoms were the same after. Course appropriate to needs.



"I think it was hugely beneficial. At no point was it ever suggested that it would cure me. It was about teaching my mind to deal with emotions and thoughts in a way that would cost less energy and so make living with ME easier. I have only just finished the course. I feel calmer and less wound up and I am confident that what I have learnt will help me manage my ME and my life better and cope with the mental problems of living with a chronic illness better. It has resulted in no change in symptoms, but I feel happier and less distressed. I think it will help me improve my quality of life. There have been no medication changes."

#109: ME moderate before course, remained moderate after course. Symptoms were the same after. Course partly appropriate to needs.

"CBT was part of my Occupational Health assessment and was useful in that it demonstrated very clearly that my ME symptoms were physical and not related to mood. This clarified both my own thinking and that of others around me."

#115: ME moderate before course, remained moderate after course. Symptoms were the same after. Course partly appropriate to needs.

"The course was useful in that it brought one into contact with other sufferers and professionals who understood the nature of the illness. The course provided me with considerable reassurance as to my illness but little in offering any cure."

#116: ME moderate before course, remained moderate after course. Symptoms were the same after. Course partly appropriate to needs.

Extract: "The course was valuable and well-run. For me, it didn't help much because everything they were trying to teach us I'd already taught myself over the previous 11 years of illness. It reinforced my own ideas about self-help, however, and boosted my confidence on that score. But it didn't aid my recovery any further

than I'd already done for myself, instinctively. When handled well, gently, and non-judgementally, CBT can be a useful tool in ME management. It was tiring, however, but I sort-of factored that in to my life for the duration of the course, because I felt that it was important to concentrate on the course. There were no other changes to my regime or medication at that time, nor did I feel that any were necessary."

#119: ME moderate before course, remained moderate after course. Symptoms were somewhat better after. Course appropriate to needs.

"CBT at X was part of a package the therapist called Integrated Psychological Therapy and comprised of Mindfulness, CBT, Pacing and Acceptance and Commitment Therapy (ACT). I can't say we ever addressed 'negative beliefs' and my beliefs about this illness remain unchanged in that I believe this is a predominantly physical illness. This was never challenged, though we did discuss mind/body interaction. However, she did not impose any views on me. I was told at the beginning that therapy was not a cure.

(I started X and have just finished X). Mine did not and was tailored to my needs. Although I have not increased my physical activity, in fact I am now very careful about not doing too much and am doing somewhat less, my mental capacity is continuing to increase and I have less severe physical symptoms.

For me the course has been positively life changing. A combination of Mindfulness and CBT has helped me to look at the way I treat myself and increased my ability to treat myself more kindly. I'm no longer so hard on myself and I have stopped struggling to do more than I am able. I am far more able to acknowledge my needs and to express them. Using mindfulness, I am much more aware of underlying thoughts and feelings and can give them the space to exist, rather than resisting them. I also I have more control over my

illness.

Practically speaking, the therapy was conducted in person and often over the phone when I couldn't make it to the clinic. The first few sessions were every other week and they gradually became more spread out. I found the therapist empathic and genuine and she encouraged me to discuss any discontent/disagreement regarding therapy so we could keep communication really open. In general I feel much better equipped to cope with this illness and my quality of life has significantly improved. This would have been a useful intervention even if I didn't have ME."

#133: ME moderate before course, remained moderate after course. Symptoms were the same after. Course appropriate to needs.

"I learnt to think about my day to day activities and to choose what could potentially make my ME worse and either avoid these activities or do them differently by breaking up tasks with pacing etc."

#135: ME moderate before course, remained moderate after course. Symptoms were the same after. Course partly appropriate to needs. Part only attended. Reason given – it was not working.

"Common sense, not M.E. specific and made no difference but wasted my time and energy."

#137: ME before course moderate. Became severe after course. Symptoms were somewhat worse after. Course not appropriate to needs.

"Totally inappropriate. Two hours a week in a group setting totally exhausted me."

#147: ME moderate before course, remained moderate after course. Symptoms were the same after. Course partly appropriate to needs.

"Main positive from CBT was the reassurance that I was normal for a person with ME and that it's ok to plan rest into lifestyle as well as activity. Medication was



not discussed as part of sessions."

#148: ME moderate before course, remained moderate after course. Symptoms were the same after. Course not appropriate to needs. Part only attended. Reason given – it was not working.

"At various points during the course I was told to completely give up any scepticism I might have about CBT treatment and it was suggested that my problems were partly caused "because I am a scientist", which I found deeply insulting. Overall, I found the therapists to be extremely patronizing. Also, my therapist was changed several sessions into the programme due to maternity leave issues, which was unavoidable, but extremely unhelpful."

#151: ME moderate before course, remained moderate after course. Symptoms were the same after. Course not appropriate to needs.

"Mixture of people there all much older with variety of conditions, no one else was employed or had children. Pacing not that simple when out of your immediate control. Part only attended. Reason given – I did not like the course."

#156: ME mild before course, remained mild after course. Symptoms were somewhat better after. Course appropriate to needs.

"It was great. It pointed out some of my thinking errors, and that allowed me to sustain relationships more easily. Wish I'd done it when I was 16."

#169: ME mild before course, remained mild after course. Symptoms were the same after. Course appropriate to needs.

"The CBT was useful in combating negative thoughts and changing my thought patterns. The CBT has not changed my ME symptoms. The course was done in a group setting I personally do not think individuals can get much out of a group CBT session because some things are very personal. The practitioners were very knowledgeable and have never suggested that CBT would make

ME go away. The CBT was a very small part of the 8 week group sessions."

#172: ME moderate before course, remained moderate after course. Symptoms were somewhat worse after. Course not appropriate to needs. Part only attended. Reason given – it was not working.

"I felt obliged to go and that the course was not relevant to what I was feeling at the time and sometimes felt it difficult to participate. I guess it felt like I needed to perform. I did not find it useful. I had been dealing with M.E. for a long time and have learnt to adapt my life."

#183: ME moderate before course, remained moderate after course. Symptoms were the same after. Course not appropriate to needs.

"The first course was done at the X Hospital by a psychiatrist being supervised by Dr X. I don't believe it benefited my physical or mental health at all. I later had a short course of CBT from a X NHS psychologist and would say it was even less useful, a complete waste of time, as she had no understanding of ME."

#207: ME moderate before course, remained moderate after course. Symptoms were the same after. Course not appropriate to needs.

"I felt that the practitioner did not understand how I felt at all and was prejudging me. I ended up arguing with him continuously."

#240: ME moderate before course, remained moderate after course. Symptoms were the same after. Course appropriate to needs.

"The CBT was never presented as a cure for ME but simply a possible tool to help me manage what had happened better. I think CBT had a positive effect in providing me with a range of tools that I can use at certain low times particularly when depression creeps in. Also to be able to recognise my behaviours tied to anxiety means I have some chance of finding a different perspective and concentrate on altering those behaviours to improve my quality of life. However, CBT has not cured

me of ME but then that never was my expectation."

#248: ME moderate before course, remained moderate after course. Symptoms were the same after. Course partly appropriate to needs.

"Initially for a short period the course did improve my mobility. However after several weeks pursuing the GET did result in a significant relapse in my condition, with significant pain, fatigue and constant infections. I did however find that reflecting on the psychological aspects of the course was worthwhile and is helping me to live with my condition. The CBT component of the course emphasised this at the outset and did not promise any potential improvement in pain and fatigue. I believe that there are positive aspects to be taken from CBT in managing the condition and living day to day with M.E. There is however a clear distinction between cure and marginal improvement in one's mental health."

#252: ME moderate before course, remained moderate after course. Symptoms were the same after. Course not appropriate to needs.

"I did not gain anything from the course of CBT that I received. It was a long way from my home and involved a 2hr round trip (+ hour session) and a day off work for my partner which caused more stress."

#264: ME moderate before course, remained moderate after course. Symptoms were somewhat worse after. Course not appropriate to needs.

"Practitioner admitted he knew nothing about ME/CFS at all so said he didn't know how he could help."

#268: ME moderate before course, became severe after course. Symptoms were somewhat worse after. Course partly appropriate to needs.

"At the time I believed in it, but sometime later I realised it was all making me worse.



The data they collected was from self-assessment forms, before and after treatment. They taught us positive mental attitude, so it was impossible to report back the truth without being accused of negativity."

#274: ME moderate before course, remained moderate after course. Symptoms were the same after. Course partly appropriate to needs. Part only attended. Reason given – it was too tiring.

"Found the stress of getting to appointments made my symptoms worse. I saw 3 different therapists and had to start from scratch each time. Felt that their emphasis was on the psychological side as that was their 'field' of expertise. It was part of a multi component programme but I just felt no benefit at all.

My employer also made it difficult to arrange as he does not allow time off for appointments so had to take unpaid leave therefore had the extra stress of getting less pay. I had to make the appointments during my working week (4 days = Tues to Fri) as the ME clinic was only open 3 afternoons a week which coincided with my work pattern.

I have however found the only way to conserve my energy is to pace myself, however I feel this is just common sense and don't feel that it deserves to be attributed to a therapy called 'pacing'. Surely everyone does what they feel capable of up to their own individual energy levels."

#295: ME moderate before course, remained moderate after course. Symptoms were very much worse after. Course not appropriate to needs. Part only attended. Reason given – it was too tiring.

"I felt that the course dealt with my symptoms as a psychological condition and because of this I felt that there was nothing physically wrong with me. On a positive note I did feel that the pacing element helped slightly."

#301: ME moderate before course, remained moderate after course. Symptoms were very much worse



after. Course not appropriate to needs.

"Practitioner indicated she knew nothing about ME."

#304: ME moderate before course, remained moderate after course. Symptoms were the same after. Course partly appropriate to needs. Part only attended.

"Whilst I have some faith in the concept behind the programme I am fearful of being completely honest with my practitioner as he remains extremely critical of anything short of absolute progression and success and strongly and brusquely implies that it is entirely my fault if only little or no progress is made between sessions.

I feel like a failure and that it is my fault that I am still suffering with ME symptoms and not fully well and back in work. My GP is extremely supportive and encouraging but has nowhere else to refer me if I am dismissed from this course, so I carry on despite feeling remorselessly dejected with every visit."

#331: ME moderate before course, became severe after course. Symptoms were very much worse after. Course not appropriate to needs.

"I was told that my illness could be cured by positively thinking that I was not ill and I should use meditation and stress/anxiety relieving techniques to control

my symptoms and carry on with work and normal activities as much as possible. I had to say to myself "I am not ill, this is just a passing phase, keep going, these symptoms are due to my thoughts, relax".

I was told that when I was not improving, but getting worse it was because I was not doing the relaxation exercises properly, or was not trying to tell myself that it was all in my mind. In other words it was my fault I was feeling so ill. Consequently I tried so hard to work and carry on that I eventually collapsed and was bed bound for over a year and so distressed because I thought it was all my fault and I must be mentally ill."

#333: ME moderate before course, remained moderate after course. Symptoms were the same after. Course appropriate to needs.

"I found the counsellor to be understanding and non-judgemental. She looked at my individual thought processes and helped me to have a better mental approach to what I was experiencing. However the course did not affect my physical condition in any way."

#349: ME moderate before course, remained moderate after course. Symptoms were the same after. Course partly appropriate to needs.

"It helped me to come to terms with the illness as I was recently diagnosed. I learned to stop being so negative with myself as this uses up precious energy, but my course of CBT didn't have a significant effect on the level or severity of my symptoms."

#355: ME moderate before course, became mild after course. Symptoms were somewhat better after. Course appropriate to needs.

Extract: "My 'psychological wellbeing practitioner' was surprisingly good and did her research re ME; I felt she was genuinely 'on my side' wanting to help me live better with it."

#359: ME moderate before course, remained moderate after course. Symptoms



were the same after. Course not appropriate to needs. Part only attended. Reason given – I did not like the course.

"I found the people who ran the course were very caring, and sympathetic, and they made it clear that they did not wish to force or persuade me to participate in the course if I felt it didn't suit me. I was made to feel that I was completely free to participate or drop out of the course at any time, without prejudicing my wider treatment.

The people who ran the course did not seem to be able to adapt the course to my specific life-style when I explained to them that it didn't suit my lifestyle. The expectation of the course was that I would plan all of my activities extremely carefully and methodically.

I could not see how this could practically fit in with anybody's life-styles, and particularly mine. For example, according to the methods we were expected to employ, if I had already carried out a particular day's prescribed activity, then I could not carry out any spontaneous activities, such as going out to buy a pint of milk, or having an unplanned meeting with a friend. The method was completely impractical, especially for someone who lives on their own, and for someone who doesn't like to plan their lives carefully in advance.

I explained this to the people who ran the course, and they were sympathetic but unable to explain how the therapy was practical or helpful."

#376: ME moderate before course, remained moderate after course. Symptoms were the same after. Course partly appropriate to needs.

"It didn't seem specific to CFS/ME and I'm not sure how much the practitioner really knew about it. He failed to acknowledge the effects of a concurrent condition (Hypermobility Syndrome). Overall I believe the course gave me a few more coping techniques but did nothing to relieve any of my symptoms."

#385: ME mild before course, remained mild after course. Symptoms were very much better after. Course partly appropriate to needs. Part only attended.

"It had a huge effect on how I thought about things – and I apply the principles to how I live now – 4 and a half years later."

#395: ME mild before course, remained mild after course. Symptoms were somewhat better after. Course appropriate to needs.

"CBT was a component of a course run by the specialist CFS/ME service (X Hospital). It was useful to receive an introduction to the principals of CBT. This helped me to better manage anxiety and stress which were impeding my recovery from CFS/ME. However, in itself, I do not think that the CBT had a very significant impact on my physical symptoms.

My physical symptoms are much improved but I believe this is due to the use of Pacing rather than attributable to CBT. Pacing has allowed me to carefully manage activity and gradually build up activity. Pacing and CBT have been useful in combination and the CBT helped to provide stress management strategies, but I do not believe this would have been effective as a treatment if offered without the Pacing."

#407: ME mild before course, remained mild after course. Symptoms were the same after. Course not appropriate to needs.

"The course was lovely, with relentlessly positive and kind OTs (2), and it was great to meet others on it, but it seemed fundamentally to be trying to treat a physical illness psychologically. How can that work?"

#421: ME moderate before course, became mild after course. Symptoms were very much better after. Course appropriate to needs.

"It helped me to accept the illness. I am forever grateful. The therapist taught me some very useful techniques. He helped me reduce the stress (partly caused by fear of not coping) and gave me some really useful advice about coping.

He helped me communicate with my family, or accept their failure to listen and help. He also helped me to understand depression and to make choices about my treatment options.

He basically had a lot of the Whys and Wherefores that you need to understand when sick and that in turn helps you learn how to look after yourself when you have ME. I don't feel it was at all negative nor had any negative effects."

#422: ME moderate before course, became mild after course. Symptoms were somewhat better after. Course appropriate to needs.

"Course was excellent, practitioner excellent, very interesting and knowledgeable. Improvement was significant at time of course but when tried to return to work, my condition deteriorated and I became worse than ever and developed fibromyalgia too."

#443: ME moderate before course, became mild after course. Symptoms were the same after. Course partly appropriate to needs. Part only attended.

"Helpful counselling sessions encouraged acceptance of limitations and management of symptoms while trying to remain in employment as a teacher. Helped me to be positive and less negative about myself, helped me to see the illness was not my fault."

#457: ME moderate before course, remained moderate after course. Symptoms were somewhat better after. Course appropriate to needs.

"The CBT was approached as an aid to for unexplained illness, rather than for a psychological or physical illness, and was independent of other treatments by other departments. No other changes were made at the time (would have helped to increase painkillers). Its benefit was in ignoring the symptoms, rather than reducing them."

#459: ME moderate before course, remained moderate after course. Symptoms were somewhat worse



after. Course partly appropriate to needs. Part only attended. Reason given – the course was cancelled.

"I was initially referred to the psychologist by a consultant who thought that I was an "attention seeker" who "disliked school" and was "damaged because I came from a single parent family".

It was between the consultant appointment and seeing the psychologist for the first time that I received the diagnosis from my GP. My psychologist was very unsure how to deal with this diagnosis to begin with and instead started with counselling sessions to find if I had any underlying "issues" that could be causing the illness.

However, once she started doing CBT with me, she decided after only about 3-4 weeks that there was no point in continuing because I was already doing most of what she was teaching me. So I went to see her for quite a long time for sometimes very long sessions (up to 2 hours) and ended up making myself much more ill for her to tell me that there was actually no point in going."

#462: ME moderate before course, remained moderate after course. Symptoms were somewhat worse after. Course not appropriate to needs.

"The course had a negative effect. The pain became worse because of the GET. The practitioner did not appear sympathetic to my concerns and did not appear to fully understand my condition. I feel that he used a "text book approach" rather than a personal programme for me."

#470: ME mild before course, remained mild after course. Symptoms were the same after. Course not appropriate to needs. Part only attended.

"I had not been aware she was supposed to be doing CBT until it came up later on in our sessions. She seemed to have little understanding of ME and the symptoms I may experience. For example, there was a very loud clock in the room, also she sat with

her back to the window, I had to point out that these things were effecting me.

The OT left me thinking that I could control my symptoms, it took me a lot of self-work and with a private therapist that it was more about managing than control (this left me feeling more in control though if you understand what I mean, not as helpless and therefore not as depressed at my situation).

I have some training and use CBT in my work as a social worker, had it been delivered appropriately by someone with experience and understanding I feel it may have been helpful although I can't be certain as this was not my experience.

The only thing I got from the pacing exercises was an understanding of my symptoms which helped me in explaining to others, and of course with understanding who I now was rather than who I had been before I started with ME. However I don't recall the OT helping me with this side of coming to terms with my condition. The ME support line was far more use in this side of things."

#471: ME moderate before course, became mild after course. Symptoms were very much better after. Course appropriate to needs.

"My practitioner was very good and supportive. However, it was misleading to label the course as 'CBT'. CBT only constituted a third of the course, along with pacing and GET.

Pacing was by far the most effective and useful element of the course in helping me to manage my symptoms better and becoming well enough to return to work part-time.

GET was also helpful to stop my muscles deteriorating, but this was because I was a moderate case of ME and some days I was well enough to go a gym (although only limited frequency, and often if I felt too ill on the planned day I would not exercise at all). I can't see it working if I was more severely ill.

The CBT helped with the psychological symptoms of ME, and emotional effects of when my cognitive function is more confused. CBT helps give the discipline needed for pacing.

The clinic leader also once said to me that the course results show a high success rate, and the only people who don't achieve improvement are the more severely ill cases.

I was also given the impression that some patients don't improve because they were not considered to be trying hard enough to apply the techniques and give them a chance. I was also told I would feel worse before I feel better, as a result of following pacing and the course requirements. This was true."

#475: ME moderate before course, remained moderate after course. Symptoms were the same after. Does not say whether or not course appropriate to needs.

Extract: "The 'specialist' seemed very biased and unprofessional, at one point he even rolled his eyes when referring (sarcastically) to people who are bed bound. He actually stated at our first session that he guaranteed he would make me better if I promised to do what he said and stop reading books or the internet and not be part of any support groups.

He was paid via the health insurance I had through work. When I eventually lost my job (and therefore my health insurance) he dropped me like a ton of bricks and offered me no further assistance, saying I had already had more sessions than I would have got on the NHS and his advice was that if I intended to get any further help from the NHS that I should 'lay it on thick' with regards to the psychological effects or I would get someone straight out of university.

My whole experience was appalling and he got paid £150 per session via my insurance. I believe pushing myself to meet the targets set each time, ultimately made



me worse and developed within me a deep sense of mistrust and disillusionment."

#476: ME moderate before course, remained moderate after course. Symptoms were the same after. Course not appropriate to needs.

Extract: "I was happy with the point I had reached in my life, but there was some effort especially by the psychiatrist who assessed me to persuade me 'I was suffering from depression or anxiety'. The counsellor interfered in all areas of my life (including those going well) in an unhelpful way.

There was no consideration as to whether I was well enough to attend the hospital or do the sessions or the work between the sessions. When I told them the sessions had interfered with my ability to do my job there was no suggestion that they would stop the sessions.

When the counsellor caused me distress (by trying to get me to change travel plans) and I reported this back to her at the next session, she said any distress she caused was my problem (and continued to cause me distress right up to the last session).

When I said I had mobility problems and would a wheelchair be helpful (also so I could use my limited energy properly) she felt this was an example of 'hysterical conversion'.

There was at all times attempts to fit the problems to psychiatric illness. I was also accused of somatising my symptoms, however I was subsequently diagnosed with other physical health problems which needed treatment/operations and a lot of the symptoms I complained about turned out to have a physical basis not a somatic one."

#479: ME moderate before course, remained moderate after course. Symptoms were the same after. Course not appropriate to needs. Part only attended. Reason given – I did not like the course.

"The course was far too late as I had already had ME for 10 years. Many components of the course I

had already done myself anyway."

#499: ME moderate before course, remained moderate after course. Symptoms were the same after. Course appropriate to needs.

"It helped me have a better understanding of ME."

#512: ME before course moderate, became severe after. Symptoms were somewhat worse after. Course not appropriate to needs.

"Although my physical and cognitive symptoms got worse during and since my CBT course I do not 'blame' it on the CBT directly, it was more because of what has been happening in my life that has prevented me from being able to look after myself enough.

But this is something that any treatment programme needs to factor in – people have stuff going on in their lives that can get in the way of them being able to follow CBT or Pacing principles or undertake GET. Difficulties with employment, struggling to meet deadlines for filling out lengthy benefits forms, housing issues, or the fact that self-care activities such as preparing meals or having a wash are boom and bust for someone who is moderately or severely affected but have to be done, etc.

Although my practitioner did help me with what she could of these things, I don't think my course of CBT allowed enough for this. So while I could understand how their theories could work for someone who was only mildly affected, or someone who was living in a bubble isolated from the real world, or for someone who had someone else to take on the burden of dealing with a lot of these things for them, but that's not real life, especially when you're living on your own.

In spite of how I feel about the course, I did feel that my practitioner was very supportive and I don't know how I would have got through that time with all its difficulties (and these were things that were happening as a direct result of my ME) without her

support so although my health didn't improve I'm still glad I did it.

I referred to anxiety and stress in the questions about mental health; these came on in the 12+ months between the onset of my illness and starting my CBT course, because I did not understand what was wrong with me and it was having a major impact on my life. I was not suffering from stress or anxiety before the onset of my ME. The CBT did help me deal with these problems.

I do think that the CBT course would have been of greater benefit to me if it hadn't been so long between the onset of my illness and starting the course. I was referred by my GP 4 months after first becoming ill, it then took 3 and a half months to get assessed by X, and it was then a further 5 months before a therapist was available to start the course of CBT. I know other people wait even longer, or don't get referred at all, but I think having help earlier could, in my case, have helped."

#525: ME mild before course, remained mild after course. Symptoms were somewhat worse after. Course not appropriate to needs. Part only attended.

"My therapist had NO idea what M.E. entailed. She was totally on the wrong track and offered NO help what so ever. The sessions were frustrating and a waste of time. She made my health worse because she was so unorganised and we never had time to do any work before the session was over. I learned a lot about her social life!"

#540: ME moderate before course, became very severe after course. Symptoms were very much worse after. Course not appropriate to needs.

"Getting to the course was 2 buses and some standing and walking it really took a lot out of me but I was encouraged to do more and pace myself but I was self-motivated and I led the way as to how much I could do I gradually got more and more ill pushing



through including vomiting with severe headaches for several days afterwards."

#551: ME moderate before course, remained moderate after course. Symptoms were the same after. Course appropriate to needs.

"X Hospital in X has a Psychiatric Liaison Department which specifically deals with helping people with chronic and/or life threatening illnesses to come to terms with their diagnosis and manage their condition. Although the original psychiatrist I saw was clearly of the ME is psychological school of thought, the CBT practitioner wasn't and has been incredibly helpful in helping me liaise with my GP and establishing a care plan for me.

Although I have been pacing for some time on my own, the practitioner's aim was to help me fine-tune what I was doing so that I was beginning to build up consistent reserves of energy rather than using them up all the time. He is very experienced in dealing with people with ME and FMS and made it clear he knows it's a physical illness and he understood the impact it has on people's lives.

He wrote to my doctor regarding my pain levels and sleep problems enabling me to get increased medication which has really helped.

I feel in control of where we go with the sessions, and he helped me develop some strategies for dealing with my "I should" guilt about not doing things when I don't feel up to it. I do feel more empowered to put my needs first now, and I feel more in control about how to manage my pacing.

While my activity levels haven't changed, I haven't felt under pressure from my practitioner to do more or increase them – this has purely been about managing where I am in a more effective way.

Although my symptoms haven't improved, neither he nor I expected them to as he was absolutely clear CBT will not cure

me, it's just another strategy to help manage my symptoms. He's been great, and I know how lucky I've been!"

#553: ME moderate before course, remained moderate after course. Symptoms were somewhat better after. Course appropriate to needs. Part only attended.

"Found some aspects of course useful and made me change how I managed my illness, has made small improvement to life, but pacing is very hard to do when you have a family and commitments. Made me feel more positive about future but also made me realise that I have to restrict areas of my life as well."

#561: ME moderate before course, remained moderate after course. Symptoms were the same after. Course appropriate to needs.

"The course was well organised but it is not appropriate for people with ME/CFS given the effort involved attending the course which for me had a severe detrimental effect.

I now believe that ME/CFS sufferers are the most motivated group of people and this is the problem. This type of approach means they will do their very utmost to participate but sadly and ironically this is the very thing that makes them worse. That is what happened to me and I am a trained nurse and understood all the theory which is presented well, however hard it is for me to believe as a medical person, it is without doubt harmful.

It is like making a cancer patient travel to 12 sessions to enable them to 'manage' their cancer. It is wrong, inappropriate, dangerous and resulted in me losing career and any previous function I had.

I was so so grateful to have been accepted on the course, so ridiculously relieved that someone was taking this seriously I wept with joy and hope. They tell you to only do five minutes at a time but expect you to travel to and attend a long course.

It used to take me all day to get there and back on two buses

because I could no longer drive. In the end it is accepting the ambiguity of the disease that is the key and continuing research in the meantime. As humans both patients and doctors struggle with ambiguity."

#568: ME moderate before course, remained moderate after course. Symptoms were the same after. Course not appropriate to needs.

"The therapist(s) were hostile to the idea that I had a physical illness."

#571: ME moderate before course, became severe after. Symptoms were much worse after. Course not appropriate to needs. Part only attended. Reason given – it was not working.

"Far too exhausting, to me it's not a suitable treatment for M.E. I am on more medication after the course for pain etc. The course caused more stress and anxiety which I was unable to cope with."

#584: ME mild before course, became moderate after course. Symptoms were somewhat worse after. Course not appropriate to needs. Part only attended. Reason given – it was not working

"Sorry but negative view. Endless talking, very slow, and often just stating common sense management strategies which I'd worked out myself in order to cope with day to day life. No use, just very patronising and frustrating...a bit harsh but true."

#588: ME mild before course, remained mild after course. Symptoms were the same after. Course partly appropriate to needs.

"It was a general CBT course not specifically for ME."

#606: ME mild before course, remained mild after course. Symptoms were the same after. Course not appropriate to needs.

"Even though I accept that I have some mental health problems, the course was insensitive, humiliating and hugely damaging to my situation. I have never recovered from the



damage that this, and later, ill-judged therapies inflicted."

#630: ME moderate before course, became mild after course. Symptoms were very much better after. Course appropriate to needs.

"Pacing was the best thing that could have happened to me with having ME. It is easy to think you can't do something for fear of consequences so for people that think this way a psychiatrist etc would need to address the patients mental thought processes before embarking on coaching. Fortunately I did not think this way and was very positive so CBT had the best chance of success.

The sessions were regular at first and then spaced out over longer periods of time. It was a complete lifestyle change at first and you have to be completely committed to doing it or it will fail but over time I have been able to adapt the activity/rest to suit my more active lifestyle. Until a person has completed a pacing course with 100% commitment I really don't think they are in a position to comment on its success!"

#634: ME moderate before course, remained moderate after course. Symptoms were the same after. Course not appropriate to needs. Part only attended. Reason given – it was not working.

"It had no effect, and it was offered to me by the consultant at the ME clinic as the only treatment option. It made me feel the NHS believed my condition was 'in my head' and that they would offer me no real help."

#638: ME mild before course, remained mild after course. Symptoms were the same after. Course appropriate to needs.

"I found the course comforting and the counsellor was lovely! She helped me to calm down and identify my 'unhelpful' thinking patterns, think practically about my work situation and encouraged me to confront relationship issues, even inviting my partner to some sessions. This was very helpful to my state of mind.

She was very keen for me to pace

and regulate my activity. (Pacing has never actually affected my symptoms which remain quite random and beyond my control) So, my actual PHYSICAL SYMPTOMS remained unchanged."

#641: ME moderate before course, remained moderate after course. Symptoms were the same after. Course appropriate to needs.

"My therapist was very easy to get along with and very professional. She was only recently qualified and I believe this contributed to her up to date knowledge around ME/CFS and also her enthusiasm and general attitude. I respected her honesty and she informed me very clearly during my first appointment that the therapy could only offer help in the way of management of symptoms and was certainly not a cure.

I don't honestly think that CBT has changed my condition or level of symptoms, other than perhaps staving off a possible downward spiral of depression due to my circumstances (I'm fairly recently diagnosed and the impact and adjustments to my life have been huge).

So, I think I found it most useful as a general counselling therapy and as an aid to helping me deal with my current circumstances, such as – loss of career/ability to work, loss of independence, subsequent financial difficulties, very poor and at times, positively harmful treatment at the hands of medical professionals (so I have little trust in doctors and am angry and frustrated at the way I have been treated).

CBT has helped being able to talk about my fears regarding my lack of mobility, pain levels etc, but in all honesty, I think I have used CBT as a sort of general counselling therapy and in that respect it has been helpful and positive.

To sum up, I have found CBT useful, but not in the way I anticipated and probably not in the way it was originally intended. I do believe that I might have been on increased doses of anti-depressants by now if I had not attended CBT, but I think this was

due to the therapist recognising how best she could help me and me taking exactly what I required from the sessions. Surely this is what all CBT therapists should be capable of doing?"

#666: ME mild before course, remained mild after course. Symptoms were the same after. Course partly appropriate to needs.

"Helped me cope with having a life-changing chronic illness. Did not change the illness or its progression."

#675: ME moderate before course, remained moderate after course. Symptoms were the same after. Course not appropriate to needs.

"Felt very pressured into being "well" that I should be able to make myself well enough to be back in school by sleeping at proper times and exercising.

At the end felt hostility towards the therapist as I felt she didn't listen to what I was saying and didn't feel she understood (although she was a pleasant and nice enough woman).

I think she believed so strongly that it was a psychological illness (even though she found me to be well adjusted and not show any signs of depression or being a "school avoider" etc. to back up her theory).

She signed me off and wished me well and said she wasn't able to make me well. We left it that.

I believe it is a physical illness which causes psychological effects due to the changes it creates in your life, and she felt it was a psychological illness which created physical manifestations of symptoms.

So in the end we agreed to disagree but in good terms."

#676: ME moderate before course, remained moderate after course. Symptoms were the same after. Course not appropriate to needs.

"The course practitioner didn't understand ME at all. Her suggestion that ME was "part



physical part psychological" was an attempt to brainwash me into believing that I could think myself better.

The practitioner expected improvement in my symptoms just because I was "thinking differently" and pressure was placed on me to claim that they were improved when they were not."

#683: ME moderate before course, remained moderate after course. Symptoms were somewhat better after. Course appropriate to needs.

"X was extremely helpful and although still physically ill I am happy and take every day as it comes! I am now in adult services and had no support from hospital in a year."

#686: ME moderate before course, remained moderate after course. Symptoms were somewhat better after. Course appropriate to needs.

"Helped manage reactions to severe symptoms."

#694: ME moderate before course, remained moderate after course. Symptoms were the same after. Course not appropriate to needs. Part only attended. Reason given – the course was cancelled.

"Although it was called CBT he seemed more keen to get me to do breathing and relaxation techniques than talking. He seemed to think this was how I would recover.

I was stressed out at being ill but understandably because I have a child to care for too. I found a lot of things he suggested completely impractical because when you're a mum you can't just have six weeks off, or do half an hour of activity and then shut yourself away in a back room to meditate for an hour.

I felt they didn't try to understand me, he said he was there to look after my needs not those of my son, but didn't seem to understand I was a struggling single mum.

In the end they cancelled my sessions. I missed one session because my son was off school sick and I left about 6 messages on their phone for another

appointment but I just got a letter saying I'd been discharged back to my GP."

#701: ME moderate before course, remained moderate after course. Symptoms were the same after. Course not appropriate to needs. Part only attended. Reason given – it was not working.

"It was a struggle, when feeling so physically ill, to have to assert that what I was experiencing was not of psychological origin. CBT might have been useful later on in the disease process, as part of the strategy of coming to terms with a chronic illness."

#722: ME moderate before course, became severe after course. Symptoms were somewhat worse after. Course not appropriate to needs. Part only attended. Reason given – I did not like the course.

"I received CBT before my diagnosis of ME as my GP was adamant I was suffering from depression.

The CBT was useless because without the diagnosis neither the GP nor counsellor would accept this was anything more than depression and thus in the CBT I was being treated for depression and lack of motivation when neither of these things were a problem in reality."

#744: ME moderate before course, became severe after course. Symptoms were somewhat worse after. Course partly appropriate to needs.

"I did gather a few coping tips, but the travelling to get there and sitting with a group of other people pushed me into one of the most severe relapses I have ever had."

#752: ME moderate before course, became severe after course. Symptoms were somewhat worse after. Course partly appropriate to needs.

"Even though the sessions were for an hour, mine had to be cut back to half hour sessions as I couldn't cope with an hour.

It was a little helpful in planning my day and trying to pace yourself

properly. Everything else pain killer wise was the same. Though I was more exhausted doing the course."

#756: ME mild before course, remained mild after. Symptoms were the same after. Course not appropriate to needs.

"It was good that it was made available. The group aspect was beneficial. It was not for M.E. patients but for people over 60?"

The 2 nurses were pleasant and positive. We had a useful tea break. It felt like some sort of support in an otherwise isolating existence. Something to go to that was near and not too onerous."

#771: ME moderate before course, remained moderate after course. Symptoms were the same after. Course not appropriate to needs.

"Was geared too much towards depression with little recognition of the impact of M.E. as an illness."

#772: ME mild before course, remained mild after course. Symptoms were the same after. Course appropriate to needs.

"My counsellor on the whole saw the CBT course as a way of giving me tools to help with issues surrounding the illness, like others' perceptions of the illness, coping with own feelings of guilt when couldn't do more, dealing with disappointment, creating helpful and manageable work weeks that would manage my energy levels etc.

She was very clear it was a physical illness and she was helping me to deal with that. It was very positive and I still use many of the CBT tools on a daily basis to deal with it."

#792: ME moderate before course, remained moderate after course. Symptoms were the same after. Course appropriate to needs.

"I was happy with my experience, the CBT helped me to reduce my illness related anxiety and cope better with stress, but I think a refresher course should be offered as I feel I'd benefit from more sessions."



#810: ME moderate before course, became mild after course. Symptoms were the same after. Course partly appropriate to needs.

"It gave me the confidence to realise I did in fact manage my condition very well and it was mainly outside influences e.g. works expectation of what they thought I could or should be able to do."

#811: ME moderate before course, remained moderate after course. Symptoms were the same after. Course not appropriate to needs. Part only attended. Reason given – I did not like the course.

"This course was a complete waste of time and for someone who has had ME since the age of 13 I was not told/advised anything that I didn't already know/was doing myself.

I found the course a little patronising, I have tried pacing and it does not work for me therefore the whole course was a waste of time as no alternative was suggested."

#826: ME mild before course, remained mild after course. Symptoms were the same after. Course not appropriate to needs.

"Complete waste of time. Psychologist appeared sceptical that ME was a physical illness. I persisted as was desperate to get better, but I found the whole thing rather insulting."

#880: ME moderate before course, became mild after course. Symptoms were very much better after. Course appropriate to needs.

"Only needed 4 sessions as made good progress in managing anxiety about returning to school after a year absence."

#881: ME moderate before course, remained moderate after course. Symptoms were the same after. Course not appropriate to needs.

"Course practitioner was a CBT trainee with no understanding of ME. She felt she learnt a lot from me, and although more through study than attending the sessions I did feel better able to cope with having ME."

#886: ME mild before course, remained mild after course. Symptoms were the same after. Course partly appropriate to needs.

"I have previously had CBT therapy years before I had any ME symptoms and was diagnosed with ME – therefore these sessions were more of a refresher for me.

However I did feel that the person taking the course was bit dismissive of the physical elements of ME and although didn't say it I did feel that she thought ME was more psychological than physical.

Also because the sessions were held in a group basis it was difficult to concentrate on individual issues and was covered in a general way as to the basics and principles of CBT."

#905: ME moderate before course, became severe after course. Symptoms were very much worse after. Course not appropriate to needs. Part only attended.

"I felt the psychologist did her best to help me and was prepared to be flexible.

I would like to comment on the FINE trial. It was a mixture of 3 therapies and also included sleep advice. As a model it could be quite helpful but I found the ideas of faulty belief systems and assumption that you weren't as active as possible really offensive at times.

There was a fixed view of what ME was and it was definitely NOT a physical illness. I have a scientific background and it became obvious to me that the sessions were already looking for reasons in your life would explain why their approach hadn't worked but that it was still the right model."

#917: ME moderate before course, became severe after course. Symptoms were very much worse after. Course not appropriate to needs.

"It was clear that the course leaders considered we were mentally ill and had "abnormal illness beliefs". The course encouraged us to IGNORE and PLAY DOWN distressing physical

symptoms, particularly pain and exhaustion, and they kept stressing that what we were experiencing was normal aches and pains and tiredness.

The course leaders took pains to come across as friendly and nice but frequently made inappropriate remarks. The course encouraged me to push beyond my boundaries and I got significantly worse following the course. I then immediately stopped CBT/GET.

The CBT had no effect at all as I realised that the intention of it was to try and make me believe I was not ill. That, together with the fact that I realised at that point that I would get no medical help whatsoever from the NHS, made me more depressed and anxious than I had been before the course!

The course led to a significant worsening of the illness."

#921: ME moderate before course, remained moderate after course. Symptoms were the same after. Course not appropriate to needs.

"I undertook this course a long time ago (2005). At the time I didn't know much about CBT but I had heard it might be helpful and I felt I had reached a plateau in terms of recovery and was desperate to move forward/progress. It was me who went to GP and persisted in asking him if I could attend. He didn't know much about it either.

I attended the sessions and they were useless. It took a great deal of effort for me to continue going there (even though it's only 10 minute drive to venue) and the counsellor seemed to have very little real understanding of M.E.

Afterwards I felt no better and the ways in which I had learnt to manage my condition (on my own) seemed to be all put into question. The whole thing made me unsure and I felt no better.

It made me feel insecure and as if here was another thing I'd tried and failed at. I wish I had never gone and not persisted in pestering the GP."



#938: ME before course moderate, became very severe after course. Symptoms were very much worse after. Course not appropriate to needs.

"X clinic programme had very negative effect as I felt inadequate for not getting better... "continuing to feel ill after illness was over. It is your body playing tricks because your mind still believes you are ill"."

#961: ME before course moderate, became severe after course. Symptoms were somewhat worse after. Course not appropriate to needs. Part only attended. Reason given – it was not working.

"The overall effect of the CBT course was to increase my illness. It was not appropriate to my needs, it drained my time and energy, and the extra exertion over 12 weeks triggered symptom flares and a worsening of the illness from which I have never improved.

It would be better if the medical and psychiatric professions would recognise that ME is not appropriately treated with CBT and that the additional activity of completing such a course only causes symptom flares and worsening of illness.

Requiring ME patients to try CBT is like requiring cancer patients to smoke. We already know that exertion, whether mental, physical or emotional, worsens ME symptoms. CBT and GET are therefore contra-indicated."

#978: ME moderate before course, remained moderate after course. Symptoms were the same after. Course not appropriate to needs. Part only attended.

"It was an ME programme which included a little CBT. CBT part didn't help me as it was too focussed on mental dysfunction and negative thoughts."

#986: ME moderate before course, remained moderate after course. Symptoms were the same after. Course not appropriate to needs. Part only attended. Reason given – it was not working.

"The course of CBT I was given

was part of the Pace Trial. At the time I had no idea of the politics involved and was so desperate for help with CFS that I would just about have accepted any treatment.

However, it soon became apparent to me that the CBT therapist was biased and his only concern was to elicit the desired results pertinent to his research. He could not answer questions I asked him regarding the efficacy of CBT and made false claims about its efficacy (stating it had a 99% success rate in helping people with CFS/ME), he got angry and caused me immense stress whenever I took issue with anything in the pace trial folder by Chalder et al, and he would promise to discuss issues in my life that were affecting my CFS and then refuse to do so etc. etc.

Worst of all, when I told him I was leaving the trial since the CBT was not helping me, he phoned me twice to put pressure on me to stay in the trial – thus confirming that his only concern was for his research results rather than genuinely helping me with my CFS."

#988: ME moderate before course, remained moderate after course. Symptoms were the same after. Course not appropriate to needs.

"What I took from the course could have been condensed into 10 minutes. Don't catastrophize your situation! Try to avoid black and white thinking. But I simply do not rate it as a treatment for ME."

#992: ME before course moderate, became very severe after course. Symptoms were very much worse after. Course not appropriate to needs. Part only attended. Reason given – it was not working.

"The practitioner of the course seemed to think that all of my symptoms were largely psychological in nature, and really refused to listen to what I was telling her about how certain symptoms had developed and the physical nature of the illness.

This made family members think that my illness was psychological because the practitioner was

to them a specialist in M.E and therefore couldn't be wrong. I'm afraid the practitioner was highly ignorant of the illness confounded by her ignoring almost everything I was telling her about what I was experiencing.

As a result of me seeing this psychologist, my GP thought it would be a good idea for me to try anti-depressants (Imipramine and Dothiepin were tried) which had no effect other than making me more drowsy."

#994: ME moderate before course, remained moderate after course. Symptoms were somewhat better after. Course appropriate to needs.

"I found CBT very useful, it helped me to think much more positively and my family noticed a difference in me in quite a short period of time."

#1001: ME moderate before course, remained moderate after course. Symptoms were somewhat better after. Course appropriate to needs.

"In my case the idea that ME is "largely maintained by unhelpful psychological beliefs & behaviour" was never expressed or implied.

CBT gave me practical techniques for dealing both with the illness and the depression it had begun to cause and gave me back a sense of control.

Improvements in symptoms indicated in earlier questions were due to using these techniques. I feel the approach and empathy of the individual therapist is crucial. My NHS therapist was flexible, supportive and encouraging."

#1015: ME before course moderate, became severe after course. Symptoms were very much worse after. Course not appropriate to needs.

"I had two courses of CBT, one with a psychologist and one with an RN therapist. CBT was great for helping with lowering stress, anxiety, negative thinking patterns, etc. Would probably be great for anyone to engage in (healthy or ill).



BUT was not effective at all for treating ME. It was irrelevant for that, except perhaps in that slightly lowered stress was less draining.

At the time, my doctors were convinced that my symptoms must stem from depression, and had convinced me as well. Consequently, I was fully committed to the programme and very motivated to follow their suggestions.

There was no need to discuss false "illness beliefs" because I did not have any. I believed my issues were purely psychological, and treated them as such. I was advised to try to ignore the messages of fatigue that my body was sending me, and to be as active as possible anyway – take walks, see friends, etc.

In retrospect, this was a terrible mistake for me, since it led me to push on in ways that caused a progressive and dramatic decline in my physical functioning. When I got so bad that I was bed bound, I finally received an accurate diagnosis, which explained FAR more of my symptoms than depression ever had.

If I had been only very mildly ill, I could see the lowered stress being helpful, since stress often seems to put extra strain on the body and make symptoms worse, but if I was that mild I don't know how I would have noticed that anything was wrong in the first place.

My level of functioning going into the CBT was not ideal. I had just left work. But at that time I could still drive myself, be independent, care for my own basic needs, etc.

After treatments, I was bed bound and unable to care for myself, feed myself, bathe myself, etc. I got so bad that I had difficulty holding my own head up even temporarily. And false beliefs of illness did not factor into it at all, except in that I had falsely believed the illness to be psychological. I should not have, and wish that I knew then what I know now.

During this time, I was also prescribed some antidepressants,

which also had a negative rather than positive effect."

#1019: ME moderate before course, remained moderate after course. Symptoms were the same after. Course not appropriate to needs.

"I felt the period of the course was too long as the time it took to travel to the venue used a lot of energy, then to sit in the group with three professionals judging what you were saying and then telling you how you should be thinking telling you not to plan things.

I found the last half hour very beneficial were we had coffee and talked amongst ourselves hearing others way of dealing with things and to know I was not alone in the way I was thinking. The amount of us who had all had a virus and can pin point the beginning of our restricted life. None of us were depressed but continually being told we were – very negative."

#1028: ME moderate before course, remained moderate after course. Symptoms were the same after. Course not appropriate to needs. Part only attended.

As I only received two sessions on cbt in my eight week course of treatment it was not very helpful I was then left to self-manage I don't really think cbt has had any impact on my symptoms.

#1037: ME moderate before course, remained moderate after course. Symptoms were somewhat worse after. Course not appropriate to needs.

"I was made to feel like I wasn't trying, my depression was not recognised. More encouragement was given to those who made most progress. I felt more depressed after the course, but felt compelled to say I had enjoyed it, almost too afraid to contradict the therapists."

#1047: ME moderate before course, remained moderate after course. Symptoms were somewhat worse after. Course not appropriate to needs.

"I found the therapies quite

patronising, as they were common sense approaches already applied to my life. And as they did not work in a realistic set up, it significantly reduced my optimism of overcoming the condition, considering it was a take it or leave it approach, if the therapies did not work, it was tough, as there was nothing else that could be offered to help."

#1058: ME moderate before course, remained moderate after course. Symptoms were the same after. Course partly appropriate to needs. Part only attended. Reason given – I did not like the course.

"Was just a counselling session not very relevant so stopped going."

#1088: ME moderate before course, remained moderate after course. Symptoms were the same after. Course not appropriate to needs.

"Just unhelpful. I don't think a single member of the group was well enough to get to all the sessions, and I would need a day to recover after it every week. It was a 'one size fits all' course, not in any way tailored to the patients. There was a general atmosphere of 'if we didn't get better it was our own fault'. One girl was doing the course for the third time – so not cured then..."

#1094: ME moderate before course, remained moderate after course. Symptoms were somewhat better after. Course partly appropriate to needs.

"It was extremely useful, gave me back control of my ability to manage my illness from a mental point of view. The rules for activity we developed there are still useful 5 years later. This is a form of pacing, but was not explored in detail. However, exercise, as opposed to real carefully planned and controlled GET was only mentioned in passing in the last session."

#1100: ME moderate before course, remained moderate after course. Symptoms were somewhat worse after. Course partly appropriate to needs.



"I felt that the course was great at the time as the ONLY source of help I was given and as a group I met others who also were local going through the same if not more or less than myself.

I didn't like the lack of contact once the course had finished and feel that a contact person would be useful to help with anything really as it's a lonely world..... all 3 of our group leaders were fantastic especially the OT who took a lot of time and individual interest which is something you don't receive elsewhere."

#1129: ME before course moderate, became mild after course. Symptoms were somewhat better after. Course appropriate to needs.

"The methodology of how to deal with unhelpful thought loops, and bring reality checks into my real and current situation was useful. I saw that stopping wasteful thought processes does leave me with more energy.

It is not an issue of these processes caused my condition of ME, but that someone with so restricted energy levels can take advantage and get better by reducing any waste of mental energy. Also as confused thoughts and forgetfulness and foggy thinking was a major issue for me with the relapse, bringing back my consciousness to where I am, and choosing to challenge unhelpful thoughts saved me energy.

Relaxation and Meditation has in fact been MUCH more useful than the CBT."

#1147: ME before course mild, remained mild after course. Symptoms were the same after. Course partly appropriate to needs. Part only attended.

"Too spread out 3 month gaps between appts. Not much linking between sessions or follow up on particular aspects that were discussed previously to see if techniques working."

#1163: ME moderate before course, became severe after course. Symptoms were somewhat worse after. Course appropriate to needs.

"I found it of great benefit. At no stage did the hospital suggest that CBT was because ME was "psychological or somatoform or functional illness". They made it very clear that it was used as a means of helping people cope with the impact mentally and emotionally of a chronic and life altering illness and the 'loss' of your life and how you saw yourself as a result of illness.

The fact that I deteriorated so quickly afterwards was because my employers forced me to continue with the phased return to work whilst attending the course at the same time, coupled with the very late diagnosis I received which meant that I pushed through the fatigue and other symptoms for almost 3 years before being diagnosed with ME.

What I learned in CBT has helped me cope with the fact that I'm now severe with highest rates DLA for care and mobility. Disabled facilities grant is providing level access shower in my home, can only go out in a wheelchair which I often have to use in the home now as well, I have a Blue Badge, Disabled Parking Bay and now have been granted a Personal Budget from Social Services for a carer/personal assistant.

I don't know that I would have coped with such a life change in the last 6 months on an emotional and mental level quite as well as I have without CBT training."

#1173: ME moderate before course, became severe after course. Symptoms were very much worse after. Course not appropriate to needs. Part only attended. Reason given – it was too tiring.

"Increase in painkillers, had 3 sessions and then had to stop going and doing what I was asked to do as I had become very much worse."

#1201: ME moderate before course, remained moderate after course. Symptoms were somewhat worse after. Course not appropriate to needs.

"I always felt as if they thought

I wasn't trying hard enough. It was treated much more as a psychological illness. I later discovered that the man I was seeing had helped set up the NICE guidelines.

Initially I saw him and his colleague. When I was talking about how the illness affected me and the symptoms I experienced they seemed surprised. As far as I am aware there was no contact with my GP who is largely unsympathetic.

Dr X wrote to my GP after every meeting with him, making further suggestions to her as to how I could be helped. I think my GP found this vaguely annoying but went along because he was the expert.

I finally had to give up with X. One morning I got a phone call saying that my appointment that day was cancelled. I had not been informed I had an appointment that day. I had two further appointments cancelled on the day.

I had to rest for the weeks of the appointment because I had to travel a long way for them and they'd exhaust me. They also kept changing which health centre in X they'd see me at. I don't know X well so this became stressful. Public transport to X is erratic at best so I was having to get taxis. This was a massive expense for someone living on benefits.

It all became too stressful and exhausting and I was getting very little benefit from their advice. I felt as if I'd given up on myself, and thought my GP and X would believe 'I just didn't want to get better'."

#1206: ME mild before course, remained mild after course. Symptoms were the same after. Course partly appropriate to needs.

"I feel the course of CBT helped my initial diagnosis of depression, and I utilise the tools of CBT continually to help maintain my mental health.



However because I was encouraged to do things, i.e. continue at school as much as possible and engage socially, I feel my M.E. worsened because I was continually pushing myself to do more than my body was really capable of.

I ended up much more ill than before the course. It is impossible to know whether this would have happened anyway."

#1226: ME moderate before course, remained moderate after course. Symptoms were somewhat worse after. Course not appropriate to needs.

"Made me feel worse; too much for me to attend and was a huge effort increased anxiety and fatigue, I couldn't confide in with therapist and he was unprofessional when making inappropriate comments and also provocative.

I hate going there but as it was me who wanted the support I daren't not attend and wondered whether this would go against me. The only benefit I feel I have had is some relaxation techniques and I could have had those from elsewhere."

#1230: ME moderate before course, remained moderate after course. Symptoms were the same after. Course partly appropriate to needs.

"My Doctor started writing anxiety and depression on my sick lines although he knows I have been fighting this condition for 26 years. He did a mental health questionnaire which I answered honestly. He said I was severely depressed.

As I was losing my job at the time and having to sell my house, the stress was massive. Anyone would be severely depressed under those circumstances. He put me on a very strong anti-depressant for 6 weeks. This had no effect on me at all. I decided to stop taking them.

As this went on my medical records and went to a consultant who was deciding if I should get an ill health pension at the same time. I was refused the pension.

I was told my depression would pass with some group therapy and could return to employment in 12 months.

My ME was totally ignored and not even considered. I believe that going to CBT opened up circumstances that weren't an issue before."

#1233: ME moderate before course, remained moderate after course. Symptoms were the same after. Course appropriate to needs.

"It has given me a more accepting attitude towards my illness. Have managed to rid myself of many of the feelings of inadequacy and guilt that my restrictions brought about."

#1242: ME moderate before course, remained moderate after course. Symptoms were the same after. Course not appropriate to needs.

"I've had CFS for over 10 years and really felt this course was not for me, even though I was interviewed by the course leader to assess my suitability prior to joining. All the other people on the course had been recently diagnosed.

The emphasis was on full recovery and I do not think this helped me. We were basically told that if you change how you think, you can get better from CFS, which is essentially the same as saying it is a mental illness and we are 'thinking' ourselves ill. I found this very disheartening.

As a scientist I read a lot of relevant literature regarding CFS studies showing evidence for a biological basis of the illness, so this type of treatment annoys me. In what other chronic illness would 'exercising a bit more' and 'changing how you think' be a treatment?

The pacing advice fine but I already do all that and have done for many years. I have excessive daytime sleepiness and need to sleep for at least an hour every afternoon (this does not interfere with my night time sleep).

I sleep as soon as I get home from

work – if I try not to I am so unwell I cannot get out of bed to eat dinner or watch TV or even speak to my husband!

I was basically told on the course that I have 'trained' myself to sleep during the day and need to gradually stop doing it. I tried so hard during the course to do this, but it made my fatigue symptoms much worse and I just could not sustain it. As soon as the course finished I went back to my normal afternoon nap routine.

I think the course should have supported people with any activity that clearly helped them manage their symptoms (such as daytime napping for me)."

#1243: ME moderate before course, remained moderate after course. Symptoms were very much worse after. Course not appropriate to needs.

"I did not appreciate that the Therapist told me that CFS was in the past (meaning before course started) therefore it DID NOT exist !!!"

#1264: ME moderate before course, remained moderate after course. Symptoms were the same after. Course not appropriate to needs. Part only attended. Reason given – it was not working.

"It sadly and frustratingly wasn't at all useful and didn't help any of my symptoms, in fact having the stress of having to get to the clinic where it was taking place, inevitably worsened all my symptoms.

I've never been offered a Pacing programme by any medical practitioner, but had one been offered, it would have been highly appreciated as it appears to be much more successful in terms of results for ME sufferers."

#1267: ME moderate before course, remained moderate after course. Symptoms were the same after. Course appropriate to needs.

"CBT helped me to come to terms with chronic illness and to take measures to stop fighting it and be at peace with my



condition. It did not cure my ME and my therapist did not try to cure my ME but recognised and identified coping strategies."

#1296: ME moderate before course, remained moderate after course. Symptoms were the same after. Course not appropriate to needs.

"There was no real understanding of my condition particularly post-exertion malaise.

They encouraged us to do more and when we said we couldn't they didn't really believe us.

The course overall did nothing for me and just left me depressed afterwards when I realised that my physical illness was not really being taken seriously, and since there was nothing after this, and this didn't help, I felt cut off with little chance of any improvement."

#1299: ME moderate before course, became severe after course. Symptoms were very much worse after. Course not appropriate to needs.

"The course meant that I could do nothing between sessions except recover. It was all I did outside of the house for three months and left me feeling very ill due to the exertion of going and the concentration involved.

This in itself was very demoralising, especially as some of the things on the course did not apply to me or make sense to me in terms of my illness.

I did also try to go to one-to-one CBT. I went to one session and it was far too much for me to be talking that intensively for an hour. I was not well enough and had to say no."

#1313: ME moderate before course, became severe after course. Symptoms were very much worse after. Course not appropriate to needs. Part only attended. Reason given – it was too tiring.

"The prior interview to the course, half the course, and new monthly ME meetings have all crashed me into continuous ME symptoms. I cannot seem to get back to

where I was before with careful prioritising and pacing/resting."

#1325: ME moderate before course, remained moderate after course. Symptoms were the same after. Course not appropriate to needs.

"It was pathetic, as a response to a devastating illness. They were well meaning but ignorant."

#1331: ME moderate before course, remained moderate after course. Symptoms were the same after. Course not appropriate to needs.

"They didn't understand the illness."

#1341: ME moderate before course, became severe after course. Symptoms were very much worse after. Course not appropriate to needs.

"The course was horrid, no consideration regarding pain, the room was crowded, hot. The dropout rate was massive."

#1343: ME mild before course, remained mild after course. Symptoms were the same after. Course not appropriate to needs. Part only attended. Reason given – it was not working.

"I felt it was simplistic – with repeated use of the same questionnaire. I've always been positive about my condition, avoided wasting energy on anger, accepting that I can no longer do certain things.

This was surprising to them, and I began the course with the kind of mental attitude they hoped to produce at the end of the course!"

#1382: ME moderate before course, remained moderate after course. Symptoms were the same after. Course not appropriate to needs.

"I found getting to the therapy and all the exercises added to the stress of trying to have a life."

#1385: ME moderate before course, remained moderate after course. Symptoms were somewhat better after. Course appropriate to needs.

"I managed to restart and to increase my level of mental activity, but it has since reached a level – a maximum total of three hours a day – from which I cannot progress."

1:1:2 Courses Taken by Mild to Moderate Sufferers – GET

#03: ME mild before course, became moderate after course. Symptoms very much worse after. Course not appropriate to needs. Part only attended. Reason given – it was not working.

"Very rigid, frustrating therapies; very blinkered. I left feeling that it was my fault that it was not working and I could not get up to targets."

#06: ME moderate before course, became severe after course. Symptoms very much worse after. Course not appropriate to needs.

Extract: "The Course, which started in September 2008, included Pacing, CBT and GET. I consider that the GET made me significantly more ill than I had been or need have become. Unfortunately, due to the fact that my follow-up appointment did not take place for some while after starting the GET, I persisted with the prescribed walking exercises for about six weeks, despite feeling more and more ill, as I had been told it would take some while for the benefits to take effect."

#10: ME mild before course, became severe after course. Symptoms very much worse after. Course not appropriate to needs.

"As it was part of the PACE trial, a strict agenda was adhered to with no deviations. Also, the physio was not allowed to comment on any symptoms I may have had between sessions or as a result of treatment. The course was weekly for 4 weeks, fortnightly for 10 sessions and a last one 3 months later."

#15: ME moderate before course, became very severe after course. Symptoms very much worse after. Course not appropriate to needs. Part only



attended. Reason given – it was not working.

“GET made me significantly worse. Before I didn't use a wheelchair, now I use one full time. It caused harm.”

#16: ME moderate before course, remained moderate after course. Symptoms the same after. Course not appropriate to needs. Part only attended.

“Would have damaged my health if I'd joined in with the marching up and down, and if I'd started walking more at home. I explained this to the tutors- they accepted this.”

#24: ME moderate before course, remained moderate after course. Symptoms somewhat worse after. Course not appropriate to needs. Part only attended. Reason given – it was too tiring.

“The course practitioner did not seem to understand how I lived my life since becoming unwell and just wanted to see more physically active e.g. walking FASTER.”

#35: ME moderate before course, remained moderate after course. Symptoms the same after. Course not appropriate to needs.

“At the 'X boot camp' I felt it was a one size fits all approach. I was pushed too hard. There was no adapting to my illness needs.

The 30 mins 5x/week was presented as a new concept for ME patients, which it isn't, it's used for all sorts of illnesses.

At X it is tailored to me and I have now made some progress.”

#40: ME moderate before course, remained moderate after course. Symptoms somewhat worse after. Course not appropriate to needs. Part only attended. Reason given – it was too tiring.

“It caused exhaustion; less social activity.”

#79: ME moderate before course, remained moderate after course. Symptoms somewhat worse after. Course partly appropriate to needs. Part only attended.

“In my case I was told to do LESS exercise and rest more as I was

in a boom and bust cycle. This advice helped greatly but did not cure my illness, which is still about the same 10 years on.”

#84: ME moderate before course, remained moderate after course. Symptoms somewhat worse after. Course not appropriate to needs.

“My GET course was actually called a Fitness for Life programme, and I was told by the therapist that ME was progressive without treatment, which I found very curious when there is no universally agreed treatment.

Personally the therapists were full of empathy and I believe they thought they were helping patients but they were poorly informed on all aspects of ME. They seemed to believe a mind over matter approach was a bona fide treatment, regardless of the after-effects.

I also discovered the reports from the course didn't go back to our consulting physicians, and we weren't informed why and for whom they were being collated.

I was never told it was a GET course, but it was clear this was exactly what it was because all the patients included in the course had either ME or FM.”

#144: ME moderate before course, remained moderate after course. Symptoms somewhat worse after. Course not appropriate to needs. Part only attended. Reason given – it was not working.

“Physio made me feel my symptoms were psychological. Gave me an exercise regime which was unrealistic and made me very ill Gave up after a few sessions.”

#145: ME moderate before course, became severe after course. Symptoms somewhat worse after. Course not appropriate to needs.

Extract: “I felt that I was pushed too far to do much more than I felt I could, which led to relapse. I also felt bullied and threatened that if I did not comply with GET my insurance payments would be stopped.”

#173: ME mild before course, became moderate after course.

Symptoms somewhat worse after. Course not appropriate to needs.

“I found the exercise drained my energy and I deteriorated whilst I continued with it. I improved gradually after I stopped. Told that negative thoughts and beliefs made M.E. worse. Discussed pacing to use limited energy.”

#176: ME mild before course, became severe after course. Symptoms very much worse after. Course not appropriate to needs. Part only attended.

Extract: “Course offered by Dr X at Y in 2005. Dr Z the therapist, explicitly said that ME was not a physical illness and that GET would keep me out of a wheelchair.

The course itself was over the phone with me being told to use an exercise bike three times daily along with other general movement exercises, with her ringing to check on my progress every week.

Course progression was too fast, course practitioner overbearing and didn't listen to my feedback that I was unable to physically tolerate the exercise programme – especially the bike.

Before the course I was able to complete a 40 minute walk with no physical side-effects. After doing GET I could no longer walk for even 5 minutes without extreme breathlessness which lasted for up to three hours at its worst.

I deteriorated so rapidly that my GP gave me an attendant wheelchair as I could no longer walk. Seven years later I still need the wheelchair. GET took away my independence and destroyed my life.”

#215: ME moderate before course, remained moderate after course. Symptoms somewhat better after. Course appropriate to needs. Part only attended.

“After suffering from ME for over 11 years, I was still able to learn from GET and it enabled me to fulfil more in a day with my energy.

I am only not continuing to practice the suggestions used at present as commitments



in my life have changed and I need focus on them, but once I am able to I will get back to GET practice and build myself up.

I had always been wary of the EXERCISE part of GET but I did this mentally, not physically, and nothing was forced on me."

#288: ME mild before course, became very severe after course. Symptoms very much worse after. Course not appropriate to needs. Part only attended.

"GET is dangerous and has completely ruined my life, I do not see any other illness offered GET I am not an idiot and as an advance personal trainer if you were depressed GET would help you for CFS. But not for ME as like when you have a virus and train in the gym it will make you worse.

If I had the knowledge about ME when I first got it I would never have done it. Someone should be held accountable for destroying my life and thousands of others I am in constant pain on pain killers to 'try' to help but to no avail as I am not offered any proper medications or treatment for ME as no doctor knows enough about it.

You had to GET no matter how you felt, told you to pace yourself after doing something and rest in between. Told me to have a part of the day to lay in silence, could not understand severe ME and how I do that most of the day to cope with this damn illness."

#291: ME moderate before course, became severe after course. Symptoms very much worse after. Course not appropriate to needs.

"Graduated exercise was the most unhelpful thing I have done and only succeeded in making my symptoms very much worse!"

#305: ME moderate before course, remained moderate after course. Symptoms somewhat worse after. Course partly appropriate to needs.

"I was put on the course just after my diagnosis after 8 years of people not believing I had anything other than depression. I was so pleased I had a diagnosis and that people believed me I

had the momentum to continue with the therapy for a number of weeks – I was full of hope, adrenaline and belief that they were going to cure me.

After a number of weeks, especially when they introduced the graded exercise I began to get very tired, although I was able to do all the exercises, my home life – housework, visiting friends, amount of time I could stay up all suffered until I was using all me energy walking.

When I was left on my own, I was even worse – the physiotherapist did not understand that I was using all my energy for this alone and I became very upset with her. I do not think she believed me – I think she saw it as an excuse. As far as she was concerned it was supposed to make me more active and improve muscle tone, reduce heart rate etc.

She did not understand that psychologically I had had a 'liff' from someone finally believing me but that my fatigue had now become bad that it had overwhelmed my enthusiasm and the euphoria of finally being believed and getting a diagnosis.

I now use Pacing – which I learnt from a book and it works well most of the time – I do have setbacks and I know what reason they have been caused – excess activity, illness and etc. I still have bouts of good energy but now use them wisely.

Graded Exercise only taught me that I have limited energy and to use it wisely – that was the only benefit. The Psychiatrist offered me CBT but I know that I am not depressed, that what I have is physical and that I have to manage my ME, it no longer manages me."

#315: ME moderate before course, became very severe after course. Symptoms very much worse after. Course not appropriate to needs.

"I was only 13 and was given the exercises by a Physiotherapist at X. Didn't have any understanding of M.E. Six week course of CBT was the main course.

GET was tried as part of the treatment but stopped halfway through because of the reaction I had as a result. School holidays given circuit training. Full relapse."

#317: ME moderate before course, remained moderate after course. Symptoms the same after. Course partly appropriate to needs.

"During the GET course I had to increase my use of painkillers to deal with post-exertional pain. The course was partly successful as I became a lot fitter – i.e. slimmer, better breathing, less food cravings – but I was just spending my time walking and resting, even after several months of keeping to the regime, so I had to sacrifice my already minimal social life and other hobbies such as art.

My illness comes in 'flares' when I am bedbound for several days, and take a few weeks to recuperate from. These knock me back to square one physically so I have to build up the activity again afterwards, so there is no real possibility of GET having a long-term effect.

Having said that, I was already using my own version of GET to up my activity levels in the period after a flare – I have always known of the risks of deconditioning."

#332: ME moderate before course, became severe after course. Symptoms very much worse after. Course not appropriate to needs. Part only attended. Reason given – it was not working.

"It was a terrible, terrible time. I was in more pain, had more problems sleeping, was unable to do anything else each day, felt like my life was over.

My GP had told me it was the only way to get better from ME, so I kept persevering with it but this made me more and more ill and I got very depressed and felt suicidal, because I thought I was never going to feel well again."

#339: ME moderate before course, remained moderate after course. Symptoms somewhat worse after. Course partly appropriate to needs.



"I went into the GET course with high hopes but found the level of increases in walking increased my symptoms. I felt worse as the walking went above 5 minutes and kept coming down with infections.

I found continuing to try this when feeling so ill had a negative impact on my health. Was told to try and pace activities throughout the day."

#344: ME mild before course, became moderate after course. Symptoms somewhat worse after. Course not appropriate to needs.

"Complete waste of time. Seemed to concentrate on coping with ME – e.g. how do you manage your shopping (get it delivered!) with only subsidiary on GET and no individual assessment."

#407: ME moderate before course, remained moderate after course. Symptoms the same after. Course appropriate to needs.

"It was a very gentle course with tiny increases in exercise, far less than everyday activities e.g. bathing, and far less than getting to GET sessions! Made no difference to my health."

#425: ME moderate before course, became very severe after course. Symptoms very much worse after. Course not appropriate to needs. Part only attended. Reason given – it was too tiring.

"The time that my OT opposed me getting a walker was the last time I saw her. I felt like she was more worried about me becoming dependant on a walker than the fact that I was bedridden and unable to get out of the house at all.

I did get the walker, through my GP, and it did improve my quality of life. I really resent the way she treated me, and am appalled that I put up with it for so long.

There was a lot of talk about illness beliefs and deconditioning, and the form of "pacing" that she wanted me to use, was to do the same amount of activity every day, no matter how I felt.

I did not feel this was appropriate, as some days I am barely able to get out of bed and go as far

as the toilet, and I think trying to do more on those days would be harmful for me."

#459: ME moderate before course, became severe after course. Symptoms somewhat worse after. Course appropriate to needs. Part only attended. Reason given – it was too tiring.

Extract: "She tailored the GET programme to suit me. She had seen many people with ME so, thankfully, knew what she was doing.

Her primary concern wasn't that I increased my exercise levels regularly but that I found a baseline that was right for me. When I began to deteriorate, she decreased all of the exercises and made the programme as easy as she could.

Eventually, she discharged me because I showed no sign of reaching a plateau and she suggested that it would not be appropriate for me to continue having GET as long as I was still deteriorating.

She said that she would only agree to anyone in the department to treating me again if I began to show strong signs of improvement."

#470: ME mild before course, became severe after course. Symptoms somewhat worse after. Course not appropriate to needs. Part only attended. Reason given – it was too tiring.

"It made me worse as I was having to increase activity when I was also trying to get into work and this was not considered or tailor made to meet my needs.

It was delivered by OT support staff that did not have the knowledge to deliver this. Some of the practices I experienced were unsuitable.

I think they were training in using the machines and told to increase by a certain amount each time but they did not have any sports or physiological training or understanding."

#537: ME moderate before course, became severe after course. Symptoms very much worse after. Course not appropriate to needs.

"Since this course of GET things have only got worse for me. I need more painkillers, have more problems with headaches, more exhaustion after doing LESS and have needed medication to help me sleep ever since.

All the practitioners I encountered (Psychologists, physiotherapists etc.) all thought they knew everything about my illness (whereas I was deluded about it) and had virtually no understanding of ME or its symptoms and effects.

I wish I'd stood up to them at the time, then maybe I wouldn't have become even more ill. I was TOLD that I was not physically ill, just "deconditioned" with "unhelpful illness beliefs", TOLD to get onto an exercise bike and cycle until I was out of breath.

I suffered somewhat at the time, but suffered a major relapse after this GET with CBT elements. I have never even regained the level of illness I had before doing this i.e. I've been more ill ever since."

#540: ME moderate before course, became severe after course. Symptoms very much worse after. Course not appropriate to needs.

"I had already been through a course of CBT before the GET. I was already keeping up my exercise levels which was doing daily activities at a level which meant I was having less severe symptoms of ME but with frequent headaches being a problem as well as fatigue weakness pain. As I progressed to do more activity I progressively became worse over the years."

#542: ME moderate before course, became very severe after course. Symptoms very much worse after. Course not appropriate to needs. Part only attended. Reason given – it was too tiring.

"It's a wonderful idea if yours is a fatigue condition only BUT mine was not and the GET caused decline in my health that I have never got back."

#556: ME mild before course, remained mild after course. Symptoms somewhat worse after.



Course partly appropriate to needs. Part only attended. Reason given – it was not working.

"I felt the GET element was inappropriate without proper supervision. Group settings have limited use in ME as everyone's symptoms and circumstances differ. It felt like sticking a plaster on an amputation."

#578: ME moderate before course, became severe after course. Symptoms very much worse after. Course not appropriate to needs.

"The main problem was that the referring psychiatrists could not accept that the GET was making my symptoms worse."

#581: ME moderate before course, remained moderate after course. Symptoms somewhat worse after. Course not appropriate to needs. Part only attended. Reason given – the course was cancelled.

"It was a joke. She told me how to do some basic Pilates moves (I have been going to the gym for 10 years before getting ill, I already know how to do core muscle strengthening).

I did the exercises. Relapsed. Attempted again. Relapsed. And so on and so on. Every time I had another go I tried to do everything slower but to no avail. GET is definitely bad for my form of ME."

#584: ME mild before course, became moderate after course. Symptoms somewhat worse after. Course not appropriate to needs. Part only attended. Reason given – it was not working.

"Again not positive as I would love to increase my physical activity to what it used to be but cannot as my legs won't work as they should and I pass out if I stand up too long!

Pushing past muscle weakness doesn't increase stamina as it used to when I used to train in the past, but makes the muscle fatigue and weakness last longer and worse.

Again frustrating treatment as being ex-military I probably had more direct experience of physical training than the person trying to advise me who by their own admission did not."

#589: ME moderate before course, became severe after course. Symptoms very much worse after. Course not appropriate to needs.

"My "course" was to see a neuropsychiatrist monthly. I felt that I had to take part so that I could say that I'd tried it when applying for benefits as it's the recommended management.

When I attended my appts, I had to take my partner as I felt that I was being pressurised into saying that I was depressed or I felt frustrated with life.

I did the course with an open mind but there was an element of "pleasing" the doctor, so continued with plan even when I knew it wasn't doing any good. Eventually I went to my GP to explain that my symptoms esp. pain had become very much worse and it was agreed that I stop the plan.

I was referred by the GP and the neuropsychiatrist to the Pain Clinic, where I have found again that the emphasis is on increasing activity, deconditioning and mood management.

I had my meds changed to help with the change in severity of symptoms. Out of the fire.... establishing a base level of household activities e.g. ironing and a base level of walking and then increasing them."

#616: ME moderate before course, remained moderate after course. Symptoms somewhat worse after. Course not appropriate to needs. Part only attended.

"GET did not work and if it hadn't been for the flexibility of the physiotherapist in changing her approach from GET to Pacing I fear that I may have become so much worse than I am today health wise.

After the physiotherapist conducting the GET realised how detrimental it was, she switched to educating me in the art of pacing – listen to your body was her favourite. I still use that as the cornerstone of my pacing now 12 years later."

#629: ME mild before course, became moderate after course. Symptoms very much worse after. Course not appropriate to needs.

"It was a GP who recommended it to me. She said, "you've probably got depression, but if you haven't it doesn't matter because they're the same treatment (as CFS)".

I increased my activity, ignoring symptoms, believing it would make me better. I went from being a mild sufferer to a moderate sufferer in the space of 18 months – and now I have further deteriorated to severe ME.

My GET was based on the theory of being deconditioned despite physio being surprised at my muscle strength on a 'good' day."

#648: ME moderate before course, became very severe after course. Symptoms very much worse after. Course not appropriate to needs. Part only attended. Reason given – it was not working.

Extract: "The GET 'course' I received should shame any medical professional and its effects run in stark contrast to the Hippocratic oath. "

#655: ME mild before course, became severe after course. Symptoms very much worse after. Course not appropriate to needs. Part only attended.

"During GET course I began to have episodes of paralysis below the waist, because of this my paediatrician stopped the GET.

I have never been able to return to my level of health prior to GET. GET rendered me housebound and triggered off a number of new symptoms as well as worsening the severity of my old symptoms and worsening my overall health, mobility and cognitive ability to severe.

I went from mild/moderate M.E to severe M.E following GET."

#656: ME moderate before course, became severe after course. Symptoms somewhat worse after. Course not appropriate to needs. Part only attended. Reason given – it was too tiring.



"This course was run by a physiotherapist who had developed it herself with no input from anyone else. Since she left the hospital the course has been discontinued.

In the years since taking the course I have learned a bit more about my illness and come to the conclusion that she hadn't researched very thoroughly while putting the course together.

The first half of the course was about pacing and finding your baseline, the second half was about trying to improve through GET."

#666: ME mild before course, became severe after course. Symptoms very much worse after. Course not appropriate to needs. Part only attended.

"Greatly exacerbated my illness progression. Permanently decimated my quality of life, and annihilated my ability to earn a living."

#675: ME moderate before course, became very severe after course. Symptoms very much worse after. Course not appropriate to needs. Part only attended. Reason given – it was not working.

"I feel that I was too ill at the time for GET, I believe that it has its place and purpose if used at the correct stage of the illness. For me it made me much worse and put me back significantly health wise.

I now try to incorporate small gentle exercises into my daily routine as I have muscle tone loss and no core stability or muscle strength due to being so inactive for so long. I used to be a dancer and gymnast and so my body was used to constant exercise prior to falling ill.

I felt the GET I was asked to do was too much, too fast and too soon and inappropriate for me at that time. I didn't gel with the physiotherapist in charge of treating me and she was adamant I didn't use a wheelchair when going out with the family and stated I should stay at home until I could walk distances on my own!"

#676: ME moderate before course, became very severe after course. Symptoms very much worse after. Course not appropriate to needs.

"It was torture, and abuse. Nothing more. The idea that ME can be exercised better when in actual fact it caused me to be much worse is reckless as it put my health at serious risk.

I was made bedbound by GET. I did GET because I trusted the hospital consultant, he made me believe that it would work. Therefore my informed consent to do the course was achieved through coercion – coercion that was based on misinformation, false statistics and unsupported claims directly made by X and X.

This kind of claim is medical fraud, and on balance and abuse of patients' rights. Had I known the truth about GET I never would have done it."

#694: ME moderate before course, became severe after course. Symptoms somewhat worse after. Course not appropriate to needs. Part only attended. Reason given – the course was cancelled.

Extract: "I was told I was not ready for GET when my symptoms worsened and so my course was cancelled. I think he believed I had a psychological barrier to it working.

I tried to explain that after doing all the chores I had to do I was exhausted already and anything extra just gave me a massive setback. I felt like I was wasting his time because I couldn't be positive about it."

#706: ME mild before course, remained mild after course. Symptoms the same after. Course appropriate to needs.

"Sometimes more painkillers had to be taken. Left to patient to set goals."

#771: ME moderate before course, remained moderate after course. Symptoms somewhat worse after. Course not appropriate to needs. Part only attended.

"Useless and potentially damaging, all those who attended

felt worse for several months afterwards. CBT and Pacing elements included general changing negative thoughts to positive, and a little about learning to recognise when to stop and rest before the onset of severe symptoms."

#826: ME mild before course, remained mild after course. Symptoms somewhat better after. Course appropriate to needs.

"The course helped me increase my levels of activity and reduced my fear of relapse, but I still have ME more than 20 years later."

#877: ME mild before course, became moderate after course. Symptoms somewhat worse after. Course not appropriate to needs. Part only attended. Reason given – it was too tiring.

"My health deteriorated to severely affected after the GET (i.e. lower than the moderate I mentioned earlier which was immediately after the course). I believe this wouldn't have happened if I had never done the GET."

#921: ME moderate before course, became severe after course. Symptoms very much worse after. Course not appropriate to needs. Part only attended.

"It was my GP who persuaded me to follow his directions with regard to exercising. This was about 6 months after diagnosis when I was very ill (It has now been confirmed that I have had M.E. for 40 years but at that point, 11 years ago... my GP assumed my condition was 'new').

Foolishly I followed his recommendations and became dramatically worse. I am convinced that, had I listened to my own advice, and rested as much as possible instead of following periods of exercise, that I may have made a better recovery from the catastrophic relapse I had in 2001 when I was diagnosed.

As it is, I have never really recovered and live on a knife-edge in terms of how much I am able to do before



inducing another relapse. I have never been able to return to work or education."

#932: ME moderate before course, became severe after course. Symptoms somewhat worse after. Course not appropriate to needs. Part only attended.

"Totally useless. Had 1 assessment and was baffled as to why I was being asked what I realise now (years later) were psychological Qs. I was given exercise targets to do in my own time (e.g. walking and exercise bike) – but I couldn't do them. It made me worse.

Only got 1 follow-up phone call after 4 weeks – and it was really just left that I should keep trying – and I was to phone the person back myself to report after another month. I was getting stressed because the targets were making me worse. So I just stopped."

#936: ME moderate before course, became very severe after course. Symptoms very much worse after. Course not appropriate to needs. Part only attended. Reason given – it was too tiring.

"I withdrew when the psychiatrist tried to pressure me into self-committing to a psychiatric unit. I would not have been released until 'cured'.

I was also getting worse and worse under GET, but the committal stage was a step too far and as even the psychiatrist admitted I had no mental illness other than his perception of the cause of ME. I would not agree to it."

#939: ME moderate before course, became severe after course. Symptoms very much worse after. Course not appropriate to needs. Part only attended. Reason given – it was not working.

"My first course of GET made me realise the extent of my impairment. Until I got sick, I had been very active, especially in fitness and outdoor activities. GET made me really push myself and I hit a wall.

As someone who used to enjoy taking 7 mile hikes and doing training at the gym, it was humiliating, horrifying, and

depressing to push myself and feel my limits at only 5 or ten minutes on a stationary bike. After two weeks of sessions I felt much worse and my activity levels at home plummeted. It became clear to me that something was really wrong with my body."

#950: ME moderate before course, remained moderate after course. Symptoms the same after. Course partly appropriate to needs.

"Too long, everyone was tired, the room was depressing, the temperature did not suit everyone, the chairs uncomfortable, the practitioner 'fixed' in her ideas e.g. I was too ill to attend a session and asked her to sum up, she wouldn't."

#997: ME moderate before course, became severe after course. Symptoms very much worse after. Course not appropriate to needs. Part only attended. Reason given – it was not working.

"The course was led by a physiotherapist whom I assumed understood ME. It became apparent as the weeks passed that she had no idea.

We were advised to do as many of each exercise as we could. Before the illness I had always enjoyed exercising and was eager to be able to do this again. I pushed myself to do the exercises, however after each session I became more ill.

I had to take painkillers and go to bed, which continued for a number of days. After a few weeks I knew that the therapy was making me a lot worse. Also being sick was causing problems with my job, so I stopped.

At the end of the therapy everyone was given free membership to a gym. I know from speaking to the group that no one benefitted from the therapy or managed to maintain the exercise programme."

#1047: ME moderate before course, remained moderate after course. Symptoms somewhat worse after. Course not appropriate to needs.

"I found the course to be repetitive as Pilates incorporates similar elements to GET based exercise, but is a better work out, as it focuses on building up your core strength.

Although I have always maintained to do these exercises on a regular basis, I've never been able to reach a baseline as the fatigue fluctuates too often, without an apparent reason or cause."

#1050: ME mild before course, became severe after course. Symptoms very much worse after. Course not appropriate to needs. Part only attended. Reason given – it was not working.

"It was a course open to anyone who had need of help with exercise to improve their mobility. It was not tailored to M.E."

#1070: ME moderate before course, remained moderate after course. Symptoms somewhat worse after. Course not appropriate to needs.

"Actually the physical training just hit my confidence quite badly. The pain was so bad I thought I would never be well again and I didn't want to live anymore.

The CBT element to the course was that I had to think more positively about exercise. It was stupid. It was like telling someone with flu to get out more, that it was all in my head. It was really stupid and it hurt more."

#1076: ME moderate before course, became severe after course. Symptoms very much worse after. Course not appropriate to needs. Part only attended. Reason given – it was too tiring.

"The increased migraines caused by the GET course meant increased use of painkillers. It affected family relationships as I became increasingly disabled in my day to day life and had to be cared for.

Socially I could not interact or go out as I had become to physically ill. The GET course was very aggressive and at the



time I was thirteen years old, the unbelievable chest pain and burning in my legs didn't stop for years.

It is the worst treatment I have received for my condition. Both psychologically demeaning and physically damaging."

#1129: ME moderate before course, remained moderate after course. Symptoms somewhat worse after. Course partly appropriate to needs.

"Despite it becoming very clear that extra physical activity, even introduced very gently, eventually hits a level when I suddenly got worse, the clinicians would not accept this. I even got myself a pedometer and showed them the rough break point, but they would not accept it.

They could not see that mental activity relating to my work restricted my physical activity. Pacing – noting the amount of physical activity I was undertaking, putting in more activity very gently, walking a few steps more, etc."

#1130: ME moderate before course, became very much worse after course. Symptoms very much worse after. Course not appropriate to needs.

"The doctor at the pain clinic who prescribed the course of GET said I no longer had ME and I was just unfit.

He said if I wanted to get better I would do the course, insinuating that if I refused to do the course I didn't want to get better.

I dropped out after 6 weeks. When I saw the doctor again he told me he was surprised I lasted that long."

#1158: ME moderate before course, became mild after course. Symptoms so much better after that respondent considered himself/herself to be well. Course appropriate to needs.

"It was very good but I believe I was able to follow it successfully because I already had strong understanding of what can get in the way of people adapting to illness and making changes to learn to manage.

I was able to deal with the anxiety and low mood that come with possibly losing your job, home and relationships and follow the instructions given. Many of my peers on course weren't and if they had children it was hard for them to prioritize the programme.

Looked at how overestimating stamina increases symptoms, how fighting against illness increases symptoms, taught to get in touch with energy and respond accordingly to try to manage limited energy more effectively and smooth out boom and bust patterns."

#1160: ME moderate before course, became severe after course. Symptoms very much worse after. Course not appropriate to needs.

"I found the whole course extremely stressful, the physiotherapist had a very poor understanding of ME in general. I became so much sicker after doing it, we felt a lot of pressure during the course to do the exercise they were suggesting.

It was the first and only time I had the POTS type symptoms. It took me a long time to recover. However, again I thought I'd meet my specialist half way and do the course, then there couldn't be the suggestion that if only I'd do the course I'd get better. I have always tried most things suggested by my specialist.

I became pretty much housebound for the following six months after the GET course. I was to be honest dismayed at the way it was handled. Also the physios were quite flippant about the illness in general.

The physiotherapists would say that my muscle weakness was due to deconditioning, although I still had very large muscles. And my muscle weakness pretty much happened overnight after my pneumonia and has never come back.

The pacing was done by using a journal and writing down rest and activity periods in the day. I was already doing this though before I'd started my course."

#1169: ME moderate before course, remained moderate after course. Symptoms the same. Course appropriate to needs.

"It helped me understand "ME" better and try to conserve my energy better but unfortunately for me it did not make much difference.

In the group some were similar to me others a little better and I think 2 others were virtually cured.

Told about the jug of energy and not to use it all up or the effects of ME will cut in, and try to build oneself back up to maintain a stronger muscle system if possible."

#1261: ME moderate before course, became mild after course. Symptoms so much better after that respondent considered himself/herself to be well. Course appropriate to needs.

Extract: "It was simply an ideal programme for me. The two tutors treated everyone with respect and empathy plus explained all the issues and symptoms of ME.

Following the guidance worked well and also gave me control and understanding of my recovery. The options of walking, swimming and finally jogging also provided an option to the exercise bike, (of which I was never too keen). For someone like me who previously liked exercise it was the ideal treatment with maximum feel good factor in all areas of life. Perhaps a determination in making sure the GET worked for me (to avoid further years of recovery) was an important ingredient.

Pacing tuition included an explanation of the important balance between exercise and rest. Pushing yourself would cause the production of additional adrenalin to complete the task, which had a pay back the next day of fatigue. This could cause further deconditioning and a downward spiral.

The basic idea of the pacing was to change the direction of this spiral to one of slow and steady reconditioning. Even on periods you may be bed



ridden to simply sit on the edge of the bed for several minutes rather than getting straight back into bed. To progress to standing for slightly longer each day.

I was fortunate not to have any relapses and I could follow exercise progression from the start. The pacing of exercise started climbing a few steps every couple of hours, plus a few rotations on an exercise bike with no resistance at first (or walking).

The advice was not to rest for hours at a time but to have more but shorter rest breaks. The activity level should only start at a maintainable level (one which allowed you to do the same level or more the next day).

The climbing of stairs (increasing slightly each day) did appear to become noticeably easier after only several days. This was similar with the other activities walking, swimming etc. The key difference was the slow gradual build up did not result in fatigue, as previous general exercise did.

At 50+ on a GET programme I generally felt fitter each day. We were asked to keep a diary of what we did, how we felt and to look back over the previous months to see review the changes. Although there was some fluctuation on a day by day level in how you felt it became clear how well you had progressed over weeks and months. Although much of what we did appeared to be simple and common sense, it was something I had missed on my first ME illness."

#1313: ME moderate before course, became severe after course. Symptoms somewhat worse after. Course not appropriate to needs. Part only attended. Reason given – it was too tiring.

"Very damaging to me and has set me right back to before my regular self-pacing (and has induced dizziness and unsteadiness on feet and increased muscle pain)."

#1334: ME moderate before course, became severe after course. Symptoms somewhat

worse after. Course not appropriate to needs.

"Initially the GET did realise some improvement in posture and mobility, however after several weeks, my condition deteriorated significantly becoming virtually housebound spending most of my day in bed in significant pain and with extreme fatigue."

#1362: moderate before course, remained moderate after course. Symptoms somewhat better after. Course appropriate to needs.

"This gave me exercises that I can still do in my home that are gentle enough. If the muscle spasms get bad, I can work on some exercises. Taught to pay attention to our bodies and find what was enough for each of us to do. Sometimes still get it wrong."

#1364: ME moderate before course, remained moderate after course. Symptoms the same after. Course not appropriate to needs. Part only attended.

Extract: "I was advised to walk for a certain period of time, for example, whether I felt up to it or not."

During any bad period, I felt much much worse after doing as instructed. I continued with it for the duration of the course but my opinion is that if it does work for some people, it's not a one-size-fits all.

After discontinuing it, I felt returning to my own regime (listening to my body) brought more positive results. Practising GET made me feel like an invalid, no thanks."

#1419: ME moderate before course, became mild after course. Symptoms somewhat better after. Course partly appropriate to needs.

"The course practitioner was good. She listened, encouraged me but never pushed me. The exercises could be broken down in smaller sections throughout the day. E.g. half hour walking on a bad day can be performed in 2 or 3 sections and in each section you could stop or sit down for a little. The clock started again when you started walking."

1:1:3 Courses taken by Mild to Moderate Sufferers – Pacing

#07: ME moderate before course, remained moderate after course. Symptoms were the same after. Course appropriate to needs.

"Some 6 years after becoming ill and about 2 years after finishing the course and 3 years after finishing work, there has been a very slight improvement whilst I continue to self-manage my ME/CFS with a pacing technique."

But that progress has been very slow and somewhat up and down and my ME/CFS symptoms still persist. Pacing taught me not to boom or bust but it is not a quick fix solution. I was in part time employment before my ME but, even with Pacing technique, had to stop work and a capability hearing found me unfit to work."

#09: ME moderate before course, remained moderate after course. Symptoms were the same after. Course appropriate to needs.

"The course helped me in coming to terms with the illness and the effects it has had on my family/ social/work life."

#15: ME moderate before course, became severe after course. Symptoms were very much worse after. Course not appropriate to needs. Part only attended.

"Pacing should not be treated as same as GET. Pacing myself GENTLY helps. The pacing course I received was not gentle."

#16: ME moderate before course, remained moderate after course. Symptoms were somewhat better after. Course appropriate to needs. Part only attended.

"The only useful therapy! The OT really supportive and had some understanding of ME."

#38: ME moderate before course, remained moderate after course. Symptoms were very much better after. Course appropriate to needs.

Extract: "Before I went on the course of pacing therapy I had tried to manage my ME using pacing (which I



had read about) with very little success. The course I went on was an NHS CFS/ME service, specialised therapy lifestyle management programme. It was a multi-component programme which was predominantly about pacing therapy but it also included some CBT and graded activity."

#41: ME moderate before course, remained moderate after course. Symptoms were the same after. Course not appropriate to needs.

"I was not very happy - told not to plan ahead, explained that was what I am a planner, told not good, felt the people taking course did not understand how it felt to have the illness as length of time of sessions in stuffy room - where your opinions were being analysed by 3 professionals with blinkered opinions."

#42: ME moderate before course, remained moderate after course. Symptoms were the same after. Course appropriate to needs.

"It helped to know that my efforts to pace myself before I saw her had been going in the right direction. It has been difficult to follow all the directions because I have responsibilities and it is impossible to get help. Pacing has helped me to accept that it is better to rest when I have to."

#43: ME moderate before course, remained moderate after course. Symptoms were very much better after. Course appropriate to needs.

"We were taught how to tailor-make our own programme if we wished to and felt that it would be helpful. I was able to VERY gradually come off sleeping tablets as I was sleeping better."

#67: ME moderate before course, remained moderate after course. Symptoms were the same after. Course partly appropriate to needs.

"The pacing has been the approach I have tried to use the most but living alone means that it is very hard to do effectively. I do now have help. But my ME has gradually gotten worse over time as I have suffered relapses for different reasons.

The pacing is only an inadequate means of keeping my head above the water and in no way helps make me better. It at best keeps me level. But there are times when I have no choice but to do too much and that does not help."

#77: ME moderate before course, became severe after course. Symptoms were very much worse after. Course appropriate to needs.

"My answers do not really reflect the effects of the pacing. I went through certain life events at the same time - loss of job, house move, divorce and the stress of all this made my condition worse NOT the pacing. On the days when I have been able to pace with all the other stuff going on I have felt a positive benefit."

#130: ME moderate before course, became mild after course. Symptoms were somewhat better after. Course partly appropriate to needs.

"I am of the opinion that M.E. was trivialised. It seemed that we were being told that our former lifestyles, stress levels, work ethic (too much work and no relaxation) were the main reasons why we had burned out!

Basically we "gave ourselves the baffling array of symptoms" and only diet, pacing, attitude would "cure us".

Pain levels and loss of our careers meant nothing to the group leaders really and the general consensus of all attendees that "If we didn't want ME then we didn't have to have it" was astonishingly ignorant.

But I did, however, listen carefully to other aspects of the course material and learned the importance of pacing to help alleviate the more distressing and incapacitating symptoms of the fickle malady that is M.E."

#156: ME mild before course, remained mild after course. Symptoms were the same after. Course appropriate to needs.

"It was useful in that it stopped me getting worse by going into a downward spiral of boom and bust."

#158: ME moderate before course, became mild after course. Symptoms were very much better after. Course appropriate to needs.

"The physiotherapist who treated me worked in an NHS clinic as an M.E. specialist nurse but also in a private capacity and I saw her privately. She had M.E. herself and therefore believed it to be a physical illness and spoke from personal experience."

#169: ME mild before course, remained mild after course. Symptoms were the same after. Course appropriate to needs.

"The pacing course was very good, I used a diary over several weeks to record my activity and rest, then I had to look at how best to manage the activity and rest breaks. I also planned ahead and tried to evenly manage rest and activity.

At times it is not easy to plan ahead. I am able to mentally plan my week without the use of a diary but it is a useful tool especially if I am not managing my activity and rest well."

#204: ME moderate before course, remained moderate after course. Symptoms were somewhat better after. Course appropriate to needs.

"Gave me better understanding of ME and how to avoid boom and bust which did improve my symptoms by learning to conserve energy for important things. So I suppose enabling more stability in symptoms."

#228: ME mild before course, became moderate after course. Symptoms were somewhat worse after. Course appropriate to needs.

"I feel that it was a well-considered course and did help me to manage my available energy levels, though it did not have a direct effect on whether my condition improved/got worse.

I did find it useful as management rather than treatment."

#234: ME moderate before course, remained moderate after course. Symptoms were somewhat better



after. Course partly appropriate to needs.

"I found it hard work to travel to and from the course and to concentrate while there. The hand-outs were very useful to read afterwards and to refer back to. I feel this was the least useful element of the three for me."

#249: ME moderate before course, remained moderate after course. Symptoms were somewhat better after. Course partly appropriate to needs.

"It was part of a whole life readjustment program which was too prescriptive and ultimately unworkable. The pacing element remains helpful to this day."

#254: ME moderate before course, remained moderate after course. Symptoms were the same after. Course not appropriate to needs.

"It was too short, there should be an opportunity to review changes after say 6 months."

#257: ME moderate before course, remained moderate after course. Symptoms were somewhat better after. Course partly appropriate to needs.

"I felt like it was just common sense to begin with, and it took a while for me to realise that I really must slow down. Only when I started doing less that I felt I could, did I begin to see any benefit - I had energy for longer, and relapses became less. I had been on statins prior to my pacing therapy, which I stopped, and I believe these were the cause of my muscle loss in legs and caused me to limp."

#284: ME moderate before course, became severe after course. Symptoms were somewhat worse after. Course partly appropriate to needs.

"Two hours weekly plus travel time was far too much and made my ME much worse during and immediately after the course, the majority of the course content I could have read from a book or from the internet in a fraction of the time and pacing simply hasn't worked for me."

#308: ME moderate before course,

remained moderate after course. Symptoms were somewhat better after. Course appropriate to needs.

"I found pacing a very useful tool that helped manage my illness. My health has got worse since I have let the tools learned slip."

#320: ME moderate before course, remained moderate after course. Symptoms were the same after. Course not appropriate to needs.

"Too much focus on delegating because I have no carer or partner to whom I can delegate."

#321: ME mild before course, remained mild after course. Symptoms were the same after. Course partly appropriate to needs.

"Due to the fact that my M.E. is very intermittent, I find the idea of Pacing whilst it all makes sense not particularly useful as when I am free of symptoms I like to live life 'normally' and enjoy being symptom free. However, when the symptoms start to appear I do apply the Pacing principles. The course did include discussion about vitamins and the use of anti-depressants both of which I take, which led me to make minor adjustments to both."

#383: ME mild before course, remained mild after course. Symptoms were the same after. Course partly appropriate to needs.

"Found the attitude of OT unhelpful. She was too prepared to accept my state of wellbeing as it was whereas I wanted to get better. No encouragement to try and regain what is a more normal life for me - trying to get me to accept what suits others."

If I'd followed her recommendations to the letter I'd be housebound and bored to death by now!

Focus was on allocating energy to work rather than trying to live a more positive balanced life."

#395: ME mild before course, remained mild after course. Symptoms were very much better after. Course appropriate to needs.

"The course run by the specialist CFS/ME service (X Hospital) was run by a multi-disciplinary team specialising in CFS/ME. The principles of pacing which were introduced were extremely useful and I have found pacing to be a key strategy in self-managing my CFS/ME."

Careful activity management through pacing has led to a significant improvement in my CFS/ME symptoms and overall energy levels. This is allowing me to plan for a return to work and has allowed me to increase my social activity and time spent with family."

There have been no negative effects of pacing therapy and I intend to continue to use this even following recovery in order to prevent danger of a relapse in symptoms."

#419: ME moderate before course, became mild after course. Symptoms were somewhat better after. Course appropriate to needs.

"Found it very informative and helpful."

#425: ME moderate before course, remained moderate after course. Symptoms were somewhat better after. Course appropriate to needs.

"The US\$30 I spent for this course has been more helpful than anything the NHS has offered me, either through my GP or the specialist ME clinic."

#442: ME moderate before course, remained moderate after course. Symptoms were somewhat better after. Course appropriate to needs.

"More just chatting with the nurse. However it did help to talk about resting in between bouts of activity to prolong the energy that I do have. I am a "get up and go" person, so have always found it hard to rest when my mind wants to get going. I have learnt to some extent to pace myself, and this has made my illness easier to live with since I had the pacing sessions."

#446: ME moderate before course, became mild after course. Symptoms were the same after. Course not appropriate to needs. Part only attended.



"As I have said before I needed significant more explanation to have carried it out. More frequent support would have been better, especially when I became poorly again and the plan seemed to stop working.

Dr X did all that (and most of the 2 hours was checking the diagnosis). She explained the pain, that I was sleeping about an hour too much and that I increased my activity too much too soon and so my basal energy level went down, but I didn't realise.

The leaflets she gave me also explain it and so are a good support. We talked about pain and the fact I have had it for a long time... that it is more like phantom limb pain, as my glands are no longer swollen, but the body still reacts that way. We talked about when to take painkillers and when not to.

So pacing is good, but not without adequate specialist advice and support. Dr X has drawn up a plan, not for me to manage but to follow.... the idea is to keep my activity levels more or less the same from day to day and gradually increase slowly, reviewing it regularly.

I already feel more awake and have more energy."

#470: ME mild before course, remained mild after course. Symptoms were the same after. Course partly appropriate to needs. Part only attended. Reason given – it was not working.

"It was too directive and from the OT's perspective rather than around my individual symptoms."

#495: ME moderate before course, remained moderate after course. Symptoms were somewhat better after. Course appropriate to needs.

"Following the course I had to alter my lifestyle to avoid the boom and bust cycle I was in. The advice regarding exercise reinforced that from my initial medical consultation."

#530: ME moderate before course, remained moderate after course. Symptoms were somewhat better after. Course appropriate to needs.

"I was unable to answer question 15 ("Which of the following was your main course practitioner?") as the course was run by both an Occupational Therapist and a Clinical Psychologist equally at all sessions.

It was set up under the newly funded ME clinics that appeared across the country in 2006ish I believe that they are now out of funding and have closed down.

The Course title was 'X CFS/ ME Service Treatment Program' though in the first session they confessed there is no treatment and that it should be called a 'management' program.

It was very well thought through and I would recommend it to all sufferers if it were available. They were very understanding though it became apparent on occasions that they had not suffered with ME/CFS themselves.

All patients were assessed before the course by both the specialist GP and or Clinical Psychologist to determine suitability for the course. i.e. ability to attend etc."

#540: ME moderate before course, became very severe after course. Symptoms were very much worse after. Course not appropriate to needs.

"My pacing therapy was self-motivated by obvious pattern of exercise or activity leading to more symptoms immediately during and after activities, with more severe symptoms gradually accumulating over a week to ten days sometimes severe.

I was gradually getting worse attending the course itself left me unwell for a week."

#556: ME mild before course, remained mild after course. Symptoms were the same after. Course partly appropriate to needs. Part only attended.

"Sleep improved greatly. Fatigue has not improved, is worsening but I do not think in response to pacing as I am unable to consistently pace.

Illness disrupts sleep progress and constantly having to start again.

Not sleeping during the day is sometimes impossible to achieve.

I remain working but having little social life. Cutting back activities did help some, but that's not living. I would rather boom and bust than live a dead life."

#581: ME moderate before course, remained moderate after course. Symptoms were somewhat worse after. Course appropriate to needs.

"Pacing was the best thing the NHS did for me. I was too ill to attend the clinic though. It was torture going to the clinic and recovering after. I killed myself going because I was so desperate to get well.

They should do home visits. If only they understood how terribly I was suffering at that time."

#584: ME mild before course, became moderate after course. Symptoms were somewhat worse after. Course not appropriate to needs. Part only attended. Reason given – it was not working.

"PACE idea is just common sense... weeks spent stating the obvious, do what you can, don't overdo it and rest... but not too much or you get weaker. Had amazingly worked that out all by myself over the course of having ME and managing life!"

#600: ME moderate before course, remained moderate after course. Symptoms were the same after. Course partly appropriate to needs. Part only attended. Reason given – it was not working.

"If it has taught me anything it is that I need to heed the warning signs my body gives me and allow myself to rest after periods of activity. If I push myself too hard it will come back to haunt me!"

#616: ME moderate before course, remained moderate after course. Symptoms were the same after. Course appropriate to needs. Part only attended.

"It was tailor made for me and is the most effective treatment I have ever had for my ME, it has allowed me to remain positive most



of the time and helps me through bad patches. With Pacing I can manage without painkillers some of the time."

#629: ME mild before course, became moderate after course. Symptoms were somewhat worse after. Course partly appropriate to needs.

"Pacing was a mixed bag. It was definitely better than GET, as it taught me to listen to my body and not ignore symptoms and I gradually began to see the link between exercise/activity and delayed fatigue, which I hadn't done beforehand. That was crucial in slowing down my deterioration.

But I wish someone had said 'if you are experiencing symptoms you should rest' – the message was, 'you can get worse briefly but symptoms should then go again'. I kept waiting for them to go and they never did. Then I had a massive relapse which I have not recovered from.

Pacing is not very satisfactory – it is full of confusing contradictory messages 'rest - but bed rest is BAD' (when I had bed rest I actually improved most rapidly), 'increase activity - but not too much' – how much is too much? I felt the emphasis was too heavily on increasing activity – I should have been told to rest."

654: ME mild before course, remained mild after course. Symptoms were somewhat worse after. Course not appropriate to needs.

"The course was unhelpful as it was not possible to achieve the starting point of a baseline of activity wherein my symptoms stabilised.

Half way through the course, the practitioner just began repeating the obstacles – which she called maintaining factors – I was already aware of (i.e. my life) but failing to offer any offer any reasonable solution outside of my thinking."

#694: ME moderate before course, remained moderate after course. Symptoms were somewhat worse after. Course appropriate to needs.

"This was the easiest to apply therapy and I liked the sessions. Everything was explained to me and written down for me and all my questions answered.

I was asked to move on and try CBT or GET because I didn't make any real improvement, but I did find elements of it useful and still use it today.

I would go as far as to say that my time spent with the OT had more of a positive effect on my mental state than the CBT course did."

#747: ME moderate before course, became mild after course. Symptoms were very much better after. Course appropriate to needs. Part only attended.

"It was a multi component programme to teach sufferers of ME about the illness and how best to try and cope with it or even improve. Pacing and CBT has completely turned my illness around, although I am still unwell I can function much better than I could before and can actually get out of bed more often than not which is good.

I was on Duloxetine and Pregabalin and at the start of my treatment these were changed to Fluoxetine and Tramadol. My level of activity has increased enough to allow me to do some jobs at home but sadly I am still not able to return to work just yet.

The GET and any increase in physical activity for example running, cycling, swimming etc. renders me too ill to get out of bed so this did not help at all."

770: ME mild before course, remained mild after course. Symptoms were somewhat better after. Course appropriate to needs.

"I was initially extremely sceptical of the Pacing Therapy (I'd lived by it for years, but this was the first time I'd been formally taught about it).

I disliked being told that I "shouldn't" crash/bust, because I've operated for a long time making the decision to do that.

However, when I raised this, they said that as long as I was in control of my energy levels, it was fine to

operate like this. After that I was a lot happier and felt as though I was respected as an individual."

#771: ME moderate before course, remained moderate after course. Symptoms were the same after. Course appropriate to needs.

"I felt it validated my need to rest and made me more aware when I was overdoing things and pushing into the 'danger zone'."

#873: ME moderate before course, remained moderate after course. Symptoms were the same after. Course appropriate to needs. Part only attended.

"It was a tailor-made multi-component programme."

#887: ME moderate before course, remained moderate after course. Symptoms were the same after. Course appropriate to needs.

"Firstly it was just wonderful to meet other people with similar problems. It was also wonderful to be assured that it wasn't all in my head or that I was lazy.

The idea of pacing is extremely sensible and although I wouldn't say it enabled me to increase my levels of activity it gave me the courage to manage things I had to/wanted to do by ensuring I had adequate rest periods."

#968: ME moderate before course, remained moderate after course. Symptoms were somewhat better after. Course not appropriate to needs.

Extract: "I think it's really bad that the only treatment offered to me is to try to live within a much reduced 'life'. I was in the top sets at school and did a lot of dance and sport before becoming ill. Now I miss a lot of school and can't do much sport or dance, although I do keep trying. I'm sick of feeling ill and no-one seems to be able to help."

#1013: ME moderate before course, remained moderate after course. Symptoms were somewhat worse after. Course not appropriate to needs. Part only attended. Reason given – it was too tiring.



"The pacing suggested did not take into account other people I live with or normal living. It required a rigid routine that I cannot keep to."

#1016: ME moderate before course, remained moderate after course. Symptoms were somewhat better after. Course appropriate to needs.

"The art of pacing was explained fully verbally during the initial 3 x one hour sessions and I was given a folder containing all the elements of pacing. This was followed up by six monthly appointments to date (approximately 12) but have now stopped due to cuts."

#1047: ME moderate before course, became severe after course. Symptoms were somewhat worse after. Course not appropriate to needs.

"For all 3 types of therapies, if they have any chance of working I think it is necessary to be tailored made, rather than one explanation to the group. However, I personally don't see any benefit to pacing, if anything, the time consumption of managing the condition by spreading tasks out over a long period of time, only leads to further fatigue, rather than reduction of exhaustion."

#1129: ME moderate before course, became severe after course. Symptoms were very much worse after. Course partly appropriate to needs.

"Looking to improve your physical functionality is important, and doing so systematically and progressively sounds sensible, but unless the clinicians can accept that there are limits that can cause a crash, that other things like mental activity and job routines have an impact that can stop this progress, this is a dangerous and blinkered 'fittest' approach."

#1133: ME moderate before course, remained moderate after course. Symptoms were the same after. Course appropriate to needs.

"As mentioned earlier, although pacing did not lead to an

improvement in my symptoms it did enable me to manage my limited energy better so that I was able to achieve a better work-life balance – I continued to work the same part time hours but was able to have a slightly better (although still very limited) social life."

#1204: ME moderate before course, became mild after course. Symptoms were somewhat better after. Course appropriate to needs.

"My consultant was excellent. I wish she was still working at the centre as I did lose confidence when she left and they have replaced her with lower grade people."

#1226: ME moderate before course, remained moderate after course. Symptoms were the same after. Course appropriate to needs.

"I was given some useful tips and broke down every activity to include rest in between."

#1296: ME moderate before course, remained moderate after course. Symptoms were the same after. Course partly appropriate to needs.

"There were some positive effects of pacing and sometimes I would see improvements but mainly it helped me manage my condition and prevent it from getting worse."

#1299: ME moderate before course, remained moderate after course. Symptoms were the same after. Course appropriate to needs.

"I have answered about my first course of pacing in X, but I also attended the lifestyle management group in Y which was a mixture of pacing CBT and GET.

The X course I experienced was more helpful and supportive, but I was not aware of the ideas behind some of these therapies and was just pleased to be getting seen at last. I did find learning to avoid major boom and bust cycles useful, but I should have had that advice as soon as I got ill, not 2-3 years in once I had pushed myself into the ground without knowing what was happening, or needed physically (REST!).

The second course made me much more ill, and I should not have continued to go as I was not well enough, but it caught me at a vulnerable and desperate time and I thought there might be something of use.

I also felt that if I attended as much as possible no-one could say I had not tried everything offered. I did not want to be seen as uncooperative, to reject help offered or to hold negative beliefs!

Pacing as it was taught I find far too involved and took a lot of admin time (charts and documenting everything) it added too much work to my day and ended up being very confusing as it assumes a baseline that just is not there from one day to the next. Our bodies are not that logical and cannot be managed to the nth degree, nor should we use all our energy focussing on our illness.

In general, when personalised, Pacing is useful and allows more informed choice and self-knowledge about what we can and should not do, and when to break these rules.

I have not experienced any improvement in my health overall as a result (things have generally got worse and worse) but it can make day to day life easier."

#1313: ME moderate before course, remained moderate after course. Symptoms were somewhat worse after. Course not appropriate to needs.

"The "ME Intervention" was insulting, overpowering and awful!"

#1334: ME moderate before course, became severe after course. Symptoms were somewhat better after. Course partly appropriate to needs.

"It was part of the group therapy sessions I attended at the X ME Clinic in 2007/8, which was run by an Occupational Therapist and a Physiotherapist.

It was helpful to meet with others who were having similar health



experiences and share ideas. No strict pacing programme was carried out but the methods were discussed and printed information given out.

We went around the group and discussed how to pace certain difficult activities from our day to day lives. At the time I was a teacher and we discussed how I might pace myself in a lesson but in practice the ideas suggested weren't very practical as classes can vary so much and be unpredictable."

#1364: ME moderate before course, remained moderate after course. Symptoms were the same after. Course not appropriate to needs.

"All of these therapies seem to rely on the proposition that ME is a psychological illness - which is unhelpful. I found Pacing, like GET made me feel like an invalid and was less effective than using my own common-sense."

#1403: ME moderate before course, remained moderate after course. Symptoms were the same after. Course appropriate to needs.

"The course made me reassess my lifestyle and look at ways in which to manage my energy levels more effectively."

1:2 Courses Attended by Severe to Very Severe Sufferers

Why some courses are either appropriate, inappropriate, and why they succeed or fail.

1:2:1 Courses Attended by Severe to Very Severe Sufferers – CBT

#32: ME severe before course, remained severe after course. Symptoms were very much worse after. Course not appropriate to needs.

"I accepted the CBT course because I didn't know what else to do. I was put on a psychiatric ward. I think that I was the only one sane. Was given antidepressant drugs no pain relief at all. My ME got worse when I was discharged."

#44: ME severe before course, remained severe after course. Symptoms were the same after. Course partly appropriate to needs. Part only attended.

"I felt it was rather vague and not covered in enough detail. There was just a group session which explained what CBT was and how to apply it (i.e. stopping negative thoughts).

I did feel the CBT was used in a sensitive way (i.e. to help deal with stress rather than to suggest ME is 'all in the mind')."

#46: ME severe before course, became very severe after course. Symptoms were very much worse after. Course not appropriate to needs. Part only attended. Reason given – it was not working.

"I was so fatigued after the first session of 1hr I was unable to stand after and barely able to speak. My father who accompanies me to therapy was very shocked and thought that I had undergone some terrible treatment. I tried another 2 sessions but gave up as was much worse after."

#54: ME very severe before course, remained very severe after course. Symptoms were very much worse after. Course not appropriate to needs. Part only attended. Reason given – it was not working.

"I was given a book to write everything down-what time I got up-what kind of night I had-how long it took me to shower-how long to make my breakfast-what pain I was in. Because it took all my time to do the things I needed to care for myself I had no time to do all this writing. I also really thought it was focusing too much on how ill I felt."

#59: ME very severe before course, remained very severe after course. Symptoms were very much worse after. Course not appropriate to needs. Part only attended. Reason given – it was too tiring.

"Suffered severe damage from attending the introductory sessions. I was also actually horrified and insulted to find out what this "CBT" actually is.

Positive mental attitude renamed e.g. do you feel worthless? Do you feel useless? Have you lost interest in your appearance? Do you need a kick up the backside to do something (need motivation).

What a cheek! This is very much like a cult, X Cult. Do people actually get paid for preaching and teaching this rubbish does this actually qualify as a job?

I actually worked for a living, hard physical work and used my brain also, if this is all I had done as a so called job I do not think I would ever have reached this state.

Surely this is simply a questionnaire for depression? Would you give this treatment to cancer patients instead of chemo, no? Then why give this crap to ME patients?"

#67: ME severe before course, remained severe after course. Symptoms were the same after. Course appropriate to needs. Part only attended.

"The CBT for me was aimed at helping me to cope emotionally with a physical illness and the counsellor I had accepted my ME as a genuine illness during the first session.

I took her a copy of the Canadian criteria which she took away and read she was very glad to find out more about what ME was and in no way looking at me from the point of changing how I saw my illness but was very supportive and was aiming all we did at helping me cope with my ME and POTS with a positive frame of mind that was helpful but overall it was not helpful in dealing with the Me itself.

But having somebody say I was not mentally ill or making it up and helping me see that I could cope with being ill and was in fact doing that quite well dispute my limitations was good however it did no good to help me physically."

#77: ME severe before course, remained severe after course. Symptoms were the same after. Course not appropriate to needs.

"This course might have



been useful at the start of my illness but I had already been ill for over 10 years and had learnt most of the information given through experience. I had also learned through trial and much error that graded exercise had a negative effect both on my health and my morale.

The only reason I undertook the course was because my employer would not release my pension on health grounds until I had done it. My ME specialist had referred me as a result, but did not think that it would be of help."

#78: ME very severe before course, remained very severe after course. Symptoms were the same after. Course partly appropriate to needs. Part only attended.

"CBT was helpful in the long term but only because the therapist totally understood ME and it was part of a whole support system which included adaptations to my home and round the clock care."

#105: ME severe before course, remained severe after course. Symptoms were somewhat worse after. Course not appropriate to needs. Part only attended. Reason given – I did not like the course.

"Answering all questions is tricky: their approach and their beliefs were quite sophisticated, e.g. they 'told' us their objectives ('ME-sympathetic') but these were quickly revealed as lies (as they switched into 'ME-hostile'). They also moved between Pacing and GET-style approaches with shifty slight-of-hands.

They were overtly 'on-our-side' and hyper-aware of ensuring we felt safe and taken seriously, etc. then would slip in their 'evil'. They also used a lot of psychological techniques (sub-consciously, I'm sure) to manoeuvre the group into their desired state of acceptance of CBT-GET style thinking – like blanking things people said that were counter to their belief-system, or encouraging the group to recognise such things as 'Negative-Illness-Causing-Thinking'.

It was subtle but powerful – like mind-control, like a cult. I studied

cults as a part of my Social Science studies when I was well, before, and there is no distinction between the CBT approaches of these 'clinics' and cults in terms of the way they operate. I believe they are dangerous and unacceptable as a part of any serious medical care system."

#112: ME severe before course, became very severe after course. Symptoms were very much worse after. Course not appropriate to needs. Part only attended. Reason given – it was not working.

"I HAD IT B4 DIAGNOSIS FELT LIKE I WAS TREATED LIKE I WAS SOME SORT OF NUTTER. DEMORALIZING. UNHELPFUL. DAMAGING ."

#131: ME severe before course, became moderate after course. Symptoms were the same after. Course partly appropriate to needs.

Extract: "I think I began to relax my muscles more when I got tired and I was less embarrassed about my inability to do things as before. However I still was crashing out and my GP was in the background helping with pain control and all the other ill effects I was suffering.

It took about a year to get me an assessment. The length of the travel time and the appointments themselves and I was usually at risk of falling asleep midway. I had to get there early enough to rest first and I needed a rest before I could set out on the way home."

#138: ME severe before course, became very severe after course. Symptoms were very much worse after. Course not appropriate to needs.

"All of my CBT/GET took part in Hospital when severely affected. I was denied all medications including pain control, as this was said that this would enforce my belief ME was a physical illness. I was denied any measuring of blood pressure/pulse/respiration as again I was told this was a negative enforcer.

When I relapsed I was told I was trying to ruin the programme of recovery and if I did not improve I would be discharged. When I

failed I was also told I was a useless person who cannot be bothered to make an effort to recover."

#140: ME severe before course, remained severe after course. Symptoms were somewhat worse after. Course not appropriate to needs. Part only attended. Reason given – I did not like the course.

Extract: "Distressing, brainwashing and misinformation which describes what we suffer from as deconditioning and behavioural habits. I had to educate them and I felt I was always on the defence.

One specialist nurse was stubborn and kept referring me to the manual, instead of acknowledging what I said.

Agenda driven, back to work attempts by the government based on erroneous CF and deconditioning has nothing to do with ME. A lot of the 70+ references quoted in the manual were not even supportive of the therapy. Some were on astronauts, the elderly, heart disease patients and athletes!

The complete untruths about the illness not being a virus, no underlying disease process and that we are just deconditioned. If people need support, counselling would be more appropriate, not brainwashing CBT. Totally unethical and damaging. Glad I was able to stand up for myself. Others sadly can't or don't and they suffer more from this unethical therapy."

#178: ME severe before course, remained severe after course. Symptoms were the same after. Course not appropriate to needs.

"I do not enjoy being told what to think. I asked repeatedly for a definition/explanation of what CBT was. I don't think she was trained enough to answer.

She wrote to GP saying I had an unhappy childhood. Rubbish. I got her to retract it. As for thinking differently she couldn't grasp that not expecting to get better was a protection mechanism against daily disappointment but didn't stop me hoping to get better. I don't



expect to win the lottery but buy a ticket. We were not compatible."

#189: ME severe before course, remained severe after course. Symptoms were the same after. Course partly appropriate to needs. Part only attended.

"I was referred to a Pain Management Clinic but after assessment it was decided that I was too ill to take part in group work and therefore I was to have one-to-one sessions with a physio and a psychologist.

I had a few sessions with the physio but felt she gave up on me as no matter what, I just couldn't get up every day at the same time even though that was 2pm! I was seeing a psychologist at the same time for CBT and for depression which I'd developed as a result of ME.

I still take the same dose of painkillers so there's been no change in pain levels or managing pain the only change I feel I've benefit from is recognising unhelpful thoughts that take you on a downward spiral and am more able to nip them in the bud so to speak.

If you have a physical illness no amount of CBT is going to change that, it's your attitude as to how it effects you mentally which can help."

#196: ME severe before course, remained severe after course. Symptoms were the same after. Course not appropriate to needs. Part only attended.

"The Therapist was trained in CBT but not with regard to ME. The course was initially to treat my depression but they moved it to attempting to treat my ME, even though I stated I did not want this."

#197: ME severe before course, remained severe after course. Symptoms were somewhat worse after. Course not appropriate to needs.

"The course leaders were not open and honest about their belief that "CFS" is psychological and we were just deconditioned. I think they knew that if they were honest

about that then people would leave!

After the CBT/GET course I declined from severe to very severe and my pain medications increased vastly. I wish I had not agreed to go on the course.

They should be honest about their beliefs as to the cause of the "syndrome". I was trying to be a good patient to my GP and to "show willing" by agreeing to go, so I was devastated when I realised they were suggesting it was all psychological. I tried hard with the GET and cut back on resting and napping and it all made me worse. Disaster!"

Note: It was confirmed this is a correct report although respondent said the degree of severity of ME remained the same after the course but the remarks indicate otherwise.

#225: ME severe before course, remained severe after course. Symptoms were the same after. Course not appropriate to needs.

Extract: "The OT offered me a place on the CBT course as there was nothing else available to offer, she thought it might be of benefit to me so I agreed to try it. Initially I was meant to be attending a group course.

The first session was held in a morning (the time I usually sleep) so it was really difficult for me to make it there. The hospital doesn't have anywhere suitable for a group so the session was in a hired room at the local MS Society centre. The session went on for over 2 hours, by which time I was feeling absolutely awful.

The group setting also made me uncomfortable, I arrived and found myself sat in a circle of people I'd never met before and was expected to openly announce to the group who I was and my diagnosis (and 'how it made me feel emotionally') and a brief medical history.

I found this really intrusive and uncomfortable and did not enjoy the process at all. It became apparent that I had been ill for a lot longer than anyone else

present (15 years as opposed to 3 years max.) and that I was the only person in the room who hadn't also been diagnosed with clinical depression.

I found the experience to be very disturbing, the other group members didn't seem to know much about ME and appeared depressed, being incredibly negative, wanting to spend the session moaning and crying about how rubbish their lives were and I was left feeling really dragged down by the whole experience.

The OT is a lovely lady, but has only worked for the 'CFS service' for about two years, having previously worked with people with depression. I felt she was sympathetic but didn't really understand."

#272: ME very severe before course, remained very severe after course. Symptoms were the same after. Course not appropriate to needs. Part only attended.

"I attended two sessions where I was told my approach to my illness was very close to CBT anyway and to come back if things changed. I felt no difference as a result of any method I've tried."

#278: ME severe before course, became very severe after course. Symptoms were very much worse after. Course not appropriate to needs.

"Far too many people in group, was unable to leave room to go to toilet as I was unable to enter room with full group, too noisy and mind was totally blank."

#296: ME severe before course, remained severe after course. Symptoms were somewhat worse after. Course not appropriate to needs.

"The programme was intended to teach us to manage our illness. It didn't help in my circumstances. If I had a full time carer it may have been different. I needed all of what energy I had to listen to my son when he came home from school, to get food into the house and to try and cook one a day. I didn't have



any spare energy to spend doing things suggested by the CBT."

#367: ME severe before course, remained severe after course. Symptoms were the same after. Course partly appropriate to needs. Part only attended.

"No change in meds... The person was quite condescending and did not agree with me doing a bible course. She told me to stop study... This was what got me through to where I am now.

I had been bedridden for two and half years with a four year old and no support besides few neighbours. So it was important to me to get well.

She got quite annoyed with me on our second to last session when I refused to agree I was starting to feel better. My body did not feel better. It was still as weak as before.

It became very evident that she was after a statistic for her notes so I did not go back to the final apt. as she was quite bullying.

I would have liked someone to have been in with me but this was not possible. So she could really get away with saying what she did including saying bad comments about Jesus name. Knowing full well that was my belief.

She did not understand. Nor did she want to. Just statistics to say they were doing something!

#374: ME very severe before course, remained very severe after course. Symptoms were the same after. Course not appropriate to needs. Part only attended.

"The psychiatric nurse visited me three times, talked about my mental approach to life and activity, and told me I was well already advanced in CBT techniques (I had done some professional training prior to becoming ill, so applied such techniques naturally); I think he suggested I was a 'perfectionist' and encouraged me to 'lighten up'. But he felt I didn't need any more help after the three sessions."

#438: ME severe before course, improved to moderate after

course. Symptoms were somewhat better after. Course appropriate to needs.

"It helped me to deal with the symptoms."

#461: ME severe before course, remained severe after course. Symptoms were the same after. Course not appropriate to needs.

"The therapist told me that ME was/is a psychological condition and that it was perpetuated by false illness beliefs."

#463: ME severe before course, remained severe after course. Symptoms were the same after. Course not appropriate to needs.

"There seemed to be the assumption that I would improve if I followed what the OT suggested, and there were times when my reactions were mislabelled. For instance, the ME Consultant, during a ward round, told me my prognosis was poor as I had certain symptoms. This was the first time I'd been told about a poor prognosis.

Afterwards, I was upset and the OT, who was passing, asked why. I explained about the Consultant's opinion. Later, when I went for an MRI scan and had to take my hospital notes with me, I noticed the OT had written, 'She expressed negative thoughts about her prognosis and doesn't think she will improve.'

I was really annoyed, as this was the Consultant's opinion, not my negative thoughts. At that time I'd 'only' been severe for 2 years and really hoped I would improve, so this was not my opinion or negative thoughts at all, but my response to a Consultant's words."

#519: ME severe before course, remained severe after course. Symptoms were the same after. Course not appropriate to needs. Part only attended. Reason given – I did not like the course.

"Didn't help, didn't like attitude of physio or implications that if I just did more I would miraculously get better – like it was just through laziness and lack of effort. Second physio I saw said there was nothing wrong with me."

#537: ME severe before course, remained severe after course. Symptoms were the same after. Course partly appropriate to needs.

"I desperately wanted (and still want) to get better, so I believed what I was told by the Clinical Psychologist, that "the illness had left my body" and that it was only my belief that I was ill that stopped me from getting better.

As a result I went back into denial about how ill I was and subsequently suffered a number of major relapses. At the end of the course I had more symptoms and had to use more painkillers. My health has never even got back to my pre- CBT and GET level (using your scale I went from "moderate" to "severe").

My main psychological symptom, dealing with the massive frustration of this illness (which has robbed me of my career, friends, active lifestyle and more) was completely & unhelpfully ignored."

Note: It was confirmed this is a correct report although respondent said the degree of severity of ME and symptoms did not alter after the course but the remarks indicate otherwise.

#542: ME severe before course, became very severe after course. Symptoms were the same after. Course not appropriate to needs.

"CBT did not help my M.E in anyway sadly. Being asked to attend a course once a week for over an hour each time was far too much for me as I have severe M.E and cannot go out that often or sit for that long! I learnt absolutely nothing new or useful."

#587: ME very severe before course, became mild after course. Symptoms were somewhat worse after. Course partly appropriate to needs.

"I felt like a naughty school child being shouted at by a stern and bossy teacher. I missed one day out of the 10 days of the course, due to the effects that the course triggered off in me, which was total



fatigue and bedbound state, and my spine went stiff, I had severe migraine. When I told the physio therapist why I hadn't attended the course, she showed me up and belittled me, in front of the class, which I felt was cruel and unfair.

The extreme stress that was placed on my spine during these exercises was terrible, but I was ordered to work through the pain. I had no sensation in my legs and feet, but I was ignored by the therapist. I had to increase my pain killers while doing the exercises because the spine pain was terribly bad and triggered migraines."

Note: It is confirmed this is a correct report although respondent said the degree of severity of ME was better after the course and the course was partly appropriate to need but also said that the symptoms were somewhat worse after and the remarks are all condemning.

#591: ME severe before course, remained severe after course. Symptoms were the same after. Course not appropriate to needs.

"The psychologist who delivered the CBT seemed disengaged. Privately, the OT in charge said the course wasn't intended for people like myself. My doctor and the consultant psychiatrist both said I do not have psychological issues and CBT would not be appropriate. I needed to attend the course in order to apply for ill-health retirement."

#615: ME severe before course, improved to moderate after course. Symptoms were somewhat better after. Course appropriate to needs.

"Part of tailor made multi programme. Met my own needs and enabled me to have activity and do things to gain self-satisfaction. Fully recommend this model."

#682: ME severe before course, remained severe after course. Symptoms were the same after. Course not appropriate to needs.

"The WORST and most damaging thing was disingenuousness. The

pretence that she believed me fell to pieces when it became obvious that she did not. I think it incredible that this is precisely what the PACE Trial instructed its CBT therapists to do. It is in breach of the Declaration of Helsinki."

#727: ME severe before course, remained severe after course. Symptoms were somewhat worse after. Course not appropriate to needs. Part only attended. Reason given – the course was cancelled.

"I liked the CBT course practitioner and the psychologists very much. In contrast, I found the psychiatrists to be egotistical, rude, un-listening, and unsympathetic, almost to a man. On the other hand, I found female psychiatrists to be more sympathetic and listening, but they were generally over-influenced by their bullying and conceited male counterparts."

#730: ME severe before course, improved to moderate after course. Symptoms were the same after. Course not appropriate to needs. Part only attended.

"I felt they gave me so much to go away and do on my own that I felt overwhelmed and could not manage the things asked of me."

#760: ME severe before course, improved to moderate after course. Symptoms were the same after. Course not appropriate to needs.

"Mandatory to be assessed by a psychiatrist initially (1998) – condition of agreeing to CBT was taking SSRI fluoxetine. I refused as recent research had indicated this was of no value whatsoever, Psychiatrist unaware of this! Agreed to take Sertraline as alternative. No other help with any medication for pain etc. etc.

Completed the course as requested with great difficulty i.e. physically difficult getting there. Great mobility problems.

The psychologist admitted I knew more about ME/CFS than he did and there was nothing more they could do for me. No follow up. The graded exercise component was poor, badly constructed and made me much worse."

#773: ME severe before course, remained severe after course. Symptoms were the same after. Course not appropriate to needs.

"I believe the whole tailored program to be of no use to an ME sufferer. The practitioners believe that ME is solely a psychological disorder that can be cured with a bit of counselling and some pacing of activities."

#782: ME severe before course, remained severe after course. Symptoms were the same after. Course not appropriate to needs. Part only attended.

"The CBT was completely useless as the OT seemed to think that we had an unlimited amount of money and kept on telling my Mum about expensive items we needed to buy such as an anti-glare screen for the television which we could not afford.

I actually got more depressed during the course and was unable to complete my sessions with the OT as she had very little idea of how ME affected me. She basically told me that since I slept for 10 hours throughout the day and during the night that I needed to go to sleep at 10pm every night and wake up at 8am so that I could stay awake all day. That is not possible for me as my sleep varies greatly and when I need to sleep I need to sleep and cannot stay awake.

I did not get on with her at all and could not complete the course because there was not another OT available in the County that I could see so I was discharged and have never received any more treatment."

#784: ME severe before course, improved to moderate after course. Symptoms were the same after. Course partly appropriate to needs.

"My health authority refused to refer me to X and a specialised ME team, because there was a CBT counsellor in my area – who had no experience with ME whatsoever. Such uneducated CBT would have been a disaster if



X hadn't stepped in, and the lack of distinction between CBT and CBT geared towards ME concerns me."

#793: ME severe before course, improved to moderate after course. Symptoms were somewhat better after. Course appropriate to needs. Part only attended.

"My therapist used CBT with mindfulness meditation. The meditation helped with pain as well as anxiety."

#827: ME severe before course, improved to moderate after course. Symptoms were very much better after. Course appropriate to needs.

Extract: "It was very good for me. I have some life, it is very restricted and I do not have a social life but I choose everything that I want to do. I am back in control.

X gave me back the power to control my life. The course had therapists who did relaxation and exercises. They gave a folder and sheets for everything. X gave talks on how to deal with and understand what is happening.

The only problem was that there was supposed to be a nurse and Dr at these sessions. The group had lots of questions regarding treatment with drugs, mainly pain killers and there was no one to ask. We were not referred to a pain clinic as some sufferers are. We just have a GP who does not fully understand and that was the only downside of the course.

I am still on 40mg of citalopram and 100mg of tramadol but I only take them at night. This suits me nicely if I have relapses such as my throat starts first when I start to relapse so I alter the medication increasing pain killers, using sprays, etc."

#839: ME severe before course, remained severe after course. Symptoms were somewhat worse after. Course not appropriate to needs. Part only attended.

"My physical symptoms impacted on my ability to sit through the course. The practitioner acknowledged to me that my

thought processes were positive and that it was my physical symptoms that was affecting my ability to participate."

#866: ME severe before course, remained severe after course. Symptoms were the same after. Course not appropriate to needs. Part only attended. Reason given – it was too tiring.

"The course made me feel as if I was responsible for giving myself M.E and if I was the one stopping myself from getting better and recovering as if I was holding myself back in life. This made me feel more depressed and worthless in society because I was ill. I felt a failure because I could not make myself better with mind over matter."

#890: ME severe before course, remained severe after course. Symptoms were the same after. Course partly appropriate to needs. Part only attended.

"I already had a good pacing strategy in place so the course did not add anything in that respect but might have been useful for others. The stuff about self-perpetuation of the condition and GET seemed to me to demonstrate a complete misunderstanding of what it is like to have ME. I had no changes to medication as a result of the course."

#899: ME very severe before course, improved to severe after course. Symptoms were the same after. Course partly appropriate to needs. Part only attended. Reason given.- it was too tiring.

"I had a positive experience with a psychologist who understood how severe my disease was. She often changed her appointments to fit with my schedule. She was flexible and extremely helpful in getting me into other treatments. She understood the devastating effects of chronic illness on social, mental, emotional and physical wellbeing. She made me feel empowered but the treatments were exhausting. Using my brain and body more than rest was extremely challenging."

#931: ME severe before course,

remained severe after course. Symptoms were somewhat worse after. Course not appropriate to needs.

"Group setting was completely unsuitable for me as I was much more severely affected than anyone else there and had been suffering a lot longer. I was also a wheelchair user, and the group was up stairs. I relied on hospital transport which meant that the CBT session was extended to a day-long outing. All-in-all it did not consider the needs of someone who barely left the house and had already done CBT twice years before!"

#933: ME very severe before course, remained very severe after course. Symptoms were the same after. Course not appropriate to needs. Part only attended. Reason given –it was not working.

"It just seemed like they thought it was my thoughts rather than a genuine illness and didn't seem to understand the illness at all."

#952: ME very severe before course, remained very severe after course. Symptoms somewhat worse after. Course not appropriate to needs. Part only attended. Reason given – it was too tiring.

"A group session was not good as they had people who had minor ME, who exercised every day and who work. Then two people – me being one of them – who had severe ME. And were wheelchair and bed bound. We felt suicidal after being there."

#965: ME severe before course, improved to moderate after course. Symptoms were somewhat better after. Course appropriate to needs.

"The therapist was well trained and experienced in CBT and extremely patient and understanding regarding my condition. The course was structured but with a high degree of versatility – I could input as much or as little as I felt I was able to at any given session.

While it was difficult to begin some of the exercises or cognitive tasks, over the long-



term there was a definite improvement in my physical and cognitive capabilities and an overall increase in activity."

#970: ME severe before course, remained severe after course. Symptoms were the same after. Course not appropriate to needs. Part only attended.

"I was told that I would be discharged after my first session. The reason stated that I already had sufficient coping strategies and could not be taught anything further. I was also told that the clinic could not handle severe and very severe patients and coming to clinic could worsen my condition.

I rang the next day to ask to be re-instated on the sessions as I was not ready to lose support after waiting 7 years for it. I had two telephone sessions where my "therapists" answered my questions to the best of her abilities (not well). At the initial group session, another occupational therapist told me that I would know what had caused my relapse if I really thought about it (this does indicate her belief toward psychological onset)! My attendance to clinic gave me no support whatsoever."

#933: ME very severe before course, remained very severe after course. Symptoms were the same after. Course not appropriate to needs.

"It just seemed like they thought it was my thoughts rather than a genuine illness and didn't seem to understand the illness at all."

#952: ME very severe before course, remained very severe after course. Symptoms were somewhat worse after. Course not appropriate to needs.

"A group session was not good as they had patients who had minor ME, who exercised every day and worked. Then two people me being one of them who had severe ME. And were wheelchair and bed bound. We felt suicidal after being there."

#1002: ME severe before course, remained severe after course.

Symptoms were the same after. Course not appropriate to needs.

"I have had CBT experience twice, I answered for the most recent experience which was 3 years ago. The group was ME specialist clinic in 2002, I received no benefit from it, but was less ill then.

My GP noted that following my severe relapse in 2007 I was experiencing depression. Referral to mental health services resulted in referral for CBT with a psychologist. Who took it upon herself to decide that my symptoms were entirely psychological and would not engage with my day to day experiences.

Attending the sessions was difficult as the psych clinic did not have proper disability access. It was an entirely negative/irritating experience.

My consultant psychiatrist signed me off because we agreed it was a waste of my energy to attend and was doing me no good at all."

#1003: ME severe before course, remained severe after course. Symptoms were the same after. Course not appropriate to needs. Part only attended.

"The CBT worker admitted that he felt out of his depth with me, and not equipped to help. Felt very demoralised by the total mismatch between my illness and this service."

#1033: ME very severe before course, remained very severe after course. Symptoms were somewhat worse after. Course not appropriate to needs. Part only attended. Reason given – it was too tiring.

"The length of time of each meeting was too long. After getting up and ready to get to the appointment I found myself already stressed and fatigued. Then I had to sit in the office and answer questions which I struggled to remember even at the time for another hour. By the time we got to the end I struggled to even get out of the room let alone get home. I don't think the course is suitable to everyone and this needs to be given more thought."

#1036: ME very severe before course, remained very severe after course. Symptoms were somewhat worse after. Course not appropriate to needs. Part only attended. Reason given – I did not like the course.

"I felt even more frustrated that we were being told what to think-brainwashed into believing we are just lazy and this distressed me greatly-everyone in the group had varying degrees of disability and the 'support' should have been tailored to each individual – very disenchanted with the service – I was supposed to receive the second session of the CBT course as I said I couldn't go due to ill health – I am still waiting for the invite as promised me!!! Though I shan't be going!!!"

#1057: ME severe before course, remained severe after course. Symptoms were the same after. Course partly appropriate to needs.

"I felt like it put a psychological emphasis on my condition which made me feel responsible for my own fatigue and therefore had a negative effect on my self-image and self-esteem.

I have subsequently received a pacing/GET programme which has freed me from the feelings of guilt and shame that can be (mistakenly but nonetheless) associated with a psychological condition, particularly one which can appear to the outside world to be "put on".

The CBT forced me to spend a lot of time on introspective reflection which did not allow me to focus on the positives and push forward as best I could within my limits.

The long wait for treatment (over 9 months from initial referral) may also have limited my self-healing as I felt that once I got the treatment they would do the right things when I felt I was probably doing all the wrong things which I later found out was not true."

#1073: ME very severe before course, improved to severe after course. Symptoms were



somewhat better after. Course partly appropriate to needs. Part only attended.

"The one-to-one sessions were helpful in that they gave the opportunity to talk about stresses to an unbiased body, impersonally. It relieved some of the guilt I felt at having to rely on family members and monopolising activities or the energies of those around me."

#1095: ME severe before course, remained severe after course. Symptoms were the same after. Course not appropriate to needs. Part only attended.

Extract: "My own view is that CBT, as it was delivered e.g. 'I collapsed after gardening last week' to be 'reconfigured' in one's mind as something like 'I worry about my symptoms and therefore this worry caused me to collapse after gardening last week', is total rubbish."

#1104: ME very severe before course, remained very severe after course. Symptoms were the same after. Course not appropriate to needs.

"I was not listened to and it was just imposing on my personal affairs that had no relation to my illness."

#1135: ME severe before course, remained severe after course. Symptoms were the same after. Course not appropriate to needs.

"While I can see that CBT may work for some people I found the constant focus that ME is a psychological illness and it being implied that I was depressed and that is what had caused it was very unhelpful (any mild depression was because I was ill and I couldn't get any real help to get better and not the cause).

Furthermore upon treatment in a private clinic I have realised that I had physical problems and that the constant pushing to increase activity was actually making symptoms and the illness worse rather than better and was the wrong advice for me."

#1143: ME severe before course, became very severe after course.

Symptoms were very much worse after. Course not appropriate to needs. Part only attended. Reason given – it was not working.

"Complete waste of time, taught me nothing I wasn't doing myself, relapse are totally physical/viral, flu like symptoms, etc. a silly guess only by medics who won't research."

#1151: ME severe before course, remained severe after course. Symptoms were the same after. Course not appropriate to needs.

"It wasn't great. It was carried out by a psychologist who had no knowledge of M.E. She had bought books about it from the library before my sessions began. These were all over the table when I went for my sessions. However, she said she hadn't had time to read them.

She also questioned my symptoms a lot – over and over like she was trying to catch me out. Sessions were held at local hospital which made my symptoms worse in short-term as had to travel there and walk miles to/from car park/hospital department. Sessions lasted one hour – again, this was too long for someone with M.E."

#1157: ME severe before course, became very severe after course. Symptoms were very much worse after. Course not appropriate to needs.

"Nothing changed – I live on an island where the GPs think ME is just a frame of mind – basically told me they don't believe in M.E."

#1175: ME severe before course, remained severe after course. Symptoms were somewhat worse after. Course not appropriate to needs. Part only attended. Reason given – it was too tiring.

"It was terrible! The councillor had no idea what I was experiencing and just implied I was making it all up! She then suggested I might need further sessions of Private counselling, which I would obviously have to pay for!"

#1208: ME severe before course, remained severe after course. Symptoms were very much worse

after. Course not appropriate to needs.

"She outright told me that ME is classified as a mental health disorder. She had no conception of the physical symptoms and was focused only on psychological problems. She told me she had not trained in CBT.

She suggested that I 'picture a blue bubble around myself' to lessen stress when talking to people I find stressful. She had me feeling the desk as a mindfulness exercise completely oblivious to the extent of the physical pain in my body and that feeling up her desk really wasn't going to do it for me.

She wasn't even a good counsellor which is what she is trained in. She was lacking in empathy and care. She was unable to 'hear' what was said to her because she had already made assumptions about the symptoms and experiences someone with 'CFS' should be having.

Her preconceptions and rigid adherence to the CFS model training got in the way of her ability to interact in a humane way with me. I came away feeling let down, frustrated and traumatised by her.

At the end of the sessions she wrote to my GP saying that I initially had severe malaise and pain but that I had improved as a result of seeing her. This was an outright lie!

She said that I still had 'flare-ups' – either she had misunderstood that my symptoms are constant and just fluctuate a bit or it was another lie!

I feel her letter could affect my benefits claim. She told me that she couldn't write in support of benefits claims because it is a 'conflict of interests'. When I asked her to elaborate on this she refused.

My encounter with her was entirely counter-productive and harmful to me both psychologically and physically."



#1220: ME severe before course, remained severe after course. Symptoms were somewhat worse after. Course not appropriate to needs.

"I found the two courses of CBT I tried (I tried a second as was desperate to succeed and become well) to be quite damaging psychologically as to make me doubt my own illness and severity.

I still have problems with this today. In the end it had no positive effects on my illness. It felt like an attempt at brainwashing me into believing I had no illness."

1221: ME very severe before course, remained very severe after course. Symptoms were very much worse after. Course not appropriate to needs.

Extract: "I consider the treatment to have been deeply abusive. I suffered years of mental abuse and was not allowed to stop the drug treatment which I was assured would definitely work. It didn't. I still have ME. They lied telling me the Prozac had no side effects so I thought the vomiting was part of the illness. After about 6 years I decided to give up the Prozac and felt much better."

#1263: ME severe before course, became very severe after course. Symptoms were very much worse after. Course not appropriate to needs.

"Useless and insulting to one's intelligence. CBT delivered in the least effective way – someone just talking and giving participants patronizing tasks asking about their 'feelings' with no practical relevance. Pathetic."

#1283: ME severe before course, remained severe after course. Symptoms were the same after. Course not appropriate to needs.

"We were told CFS is not progressive and nobody has ever died of it. I felt like I was being brainwashed."

#1280: ME severe before course, remained severe after course. Symptoms were somewhat worse after. Course not appropriate to

needs. Part only attended.

"Being referred on the CBT/GET course gave me some hope that the NHS was trying not giving up on ME patients. I worked extremely hard on the course as my main aim was to have some sort of recovery. I naively thought the course could provide some sort cure.

Although I pushed myself to my limits in order to achieve all that was required of me on the course, looking back, I can safely say, it had absolutely no benefits at all to my health."

#1285: ME severe before course, remained severe after course. Symptoms were the same after. Course not appropriate to needs. Part only attended. Reason given – I did not like the course.

"I only went once, and had one session over the phone when I was too ill to attend. I could barely walk and it was some distance from the waiting room to the treatment room, down lots of corridors. The therapist led the way and quite pointedly did not slow down for me, nor did he make any reference to the fact that I was in some distress trying to keep up with his pace.

I asked lots of questions at the initial session and made it clear that I was sceptical about the programme. During the second session, on the telephone, I queried the benefits of a psychological treatment for a physical illness. He told me, "A lot of people want to cling to the belief that they have a physical illness." That's when I stopped the treatment."

#1293: ME severe before course, remained severe after course. Symptoms were very much worse after. Course not appropriate to needs. Part only attended.

"I was only given one session of CBT as I was told I was 'not co-operating' because I refused to believe that it was all in my mind.

Just getting to the course left me completely exhausted and unable to communicate effectively or think straight, so the whole thing

was a nightmare. The practitioner shouted at me in the end for not co-operating and I never went back to the hospital. It was a really horrible experience.

#1319: ME severe before course, became very severe after course. Symptoms were very much worse after. Course not appropriate to needs. Part only attended. Reason given – I did not like the course.

"It was institutionalised bullying. I felt ripped apart. Course introduced as supporting a physiological condition, but delivered to make us change our beliefs claiming this would make our symptoms disappear.

Belief and debate about the physiological reality of the disease was classed as proof of imbedded psychological error and obsession. Lies, deceit, passive aggressive techniques, psychological bullying, encouraging the group to single out, ignore or negatively judge members who held "beliefs" of physiological causation was the core of their approach.

I approached them with evidence and reports (Chief Medical Examiners, Gibson, etc.) which they had no knowledge of. Tried to engage them in intelligent discussion about causation, treatment and concerns and invited them to speak with the local ME support group – to all of which they had major psychological barriers!"

#1352: ME severe before course, remained severe after course. Symptoms were somewhat worse after. Course not appropriate to needs.

"Felt that the CBT approach my OT used was not tailored towards a CFS/ME sufferer. It was a generic "one size fits all" approach she used and overall not very helpful. I regret having seen her if I am honest."

#1354: ME very severe before course, remained very severe after course. Symptoms were somewhat worse after. Course not appropriate to needs.

"It was a complete waste of time. I felt that



I wasn't being taken seriously, and I felt as though people who don't suffer think that it is all in my head. My pain medication increased threefold, and my depression became more focused and more intense."

#1395: ME severe before course, remained severe after course. Symptoms were somewhat better after. Course partly appropriate to needs.

"My CBT course was given to me at the beginning of my ME because my GP had to rule out that I wasn't suffering from Depression, so it was focused on Depression. I have to say that it was good as, although I wasn't depressed that much, my CBT course helped me to manage stress, which is the main cause of my ME, therefore, it didn't cure me but it stopped getting my symptoms worse and helped to create a foundation for Pacing."

#1397: ME very severe before course, remained very severe after course. Symptoms were the same after. Course not appropriate to needs. Part only attended. Reason given – I did not like the course.

"The psychologist providing the CBT claimed that she had helped to rehabilitate someone who had suffered polyneuropathy (Guillain-Barre Syndrome), and seemed to think that my condition was similar.

I have severe orthostatic intolerance and struggle even to sit upright without tachycardia and severe fatigue afterwards (this symptom has been present from the very start of my illness before any deconditioning took place), something she did not seem to understand, rather believing that it was more to do with deconditioning and that would respond to rehabilitation over time.

I was really looking for help such that I could better cope with my symptoms (particularly pain and fatigue) that cause me a lot of distress, rather than to be rehabilitated. We were concerned at this, and we asked her to contact an ME/CFS specialist with whom we had consulted such that

he could better explain my illness (the psychologist refused to do this).

The psychologists behaviour was questionable, at one point she suggested that I took on a sick role because it meant that I might receive more attention as a result, when in fact my partner has precious little time because of the demands of his employment, our own small business, and menial tasks around our home. The psychologist also seemed to think that if they could somehow convince me that all my symptoms were the result of deconditioning I could then blithely ignore my illness and begin rehabilitation.

For example, I also have sensitivity to light, the psychologist insisted that I have all the curtains in my room opened during the consultation, and then asked if I felt OK? I subsequently explained that it was uncomfortable, but the psychologist said that it would pass. What the psychologist was not there to see that evening (nor could believe or understand in the following week's consultation) was the subsequent pay back in pain and fatigue that occurred that evening and persisted for the next few days.

So much of what the psychologist said seemed trite and hackneyed, like a more formal version of things we had heard when seeing unsympathetic physicians that did not specialise in psychology but would offer advice in this respect in spite of this.

The psychologist also seemed to be more interested in pieces of paper (including a series of tick boxes) that they had in front of her, rather taking time to talk to me, listen to me, and understand my illness.

We ended the consultation after only 5 sessions as I was starting feel more stress as a result of them, and certainly did not feel any benefit."

#1398: ME severe before course, remained severe after course. Symptoms were the same after. Course not appropriate to needs. Part only attended.

"Very misplaced as I was not depressed, anxious or stressed. Got the feeling there was nothing else they could offer/help me with so "had" to provide me with something."

#1402: ME severe before course, remained severe after course. Symptoms were somewhat worse after. Course not appropriate to needs.

"Whilst my CBT practitioner was sympathetic and understanding, I feel that she was put under pressure from her employer to put the demands of my PHI insurer before my health. The whole focus was on getting me back to work, pushing myself and increasing my activity levels to facilitate a return to work. The result is that I crashed and suffered a relapse. I feel that the CBT practitioner's duty of care to the patient was severely compromised by the corporate machine."

#1404: ME severe before course, improved to moderate after course. Symptoms were somewhat better after. Course appropriate to needs.

"It was right for me because of the stage that I was at in my illness. I needed to learn ways to deal with issues in my past that had caused me stress and be given tools to cope with them in future. It worked well for me as I wanted to do it and I chose the course. It decreased my stress levels significantly and I believe it led to a faster recovery from M.E."

#1405: ME severe before course, remained severe after course. Symptoms were somewhat worse after. Course not appropriate to needs. Part only attended. Reason given – it was too tiring.

"There were 4 therapists: ergonomics, relaxation, physical, and psychological. They started off pretending they believed ME was a physical disorder then gradually switched to an obviously psychologically-grounded approach. I doubt I'll ever trust a psychologist again. Opposing the idiocy of the therapists together



has strengthened my relationship with my fiancé."

#1410: ME severe before course, improved to moderate after course. Symptoms were somewhat better after. Course partly appropriate to needs.

"It was part of a programme designed to help people cope better with ME/CFS and manage their symptoms better. I was initially sceptical about the notions of 'false illness beliefs' and 'exercise avoidance', however, during the course of the programme I did find that some of my assumptions were challenged, and I now find it much easier to cope with 'bad days' and negative thoughts thanks to this programme."

#1428: ME very severe before course, remained very severe after course. Symptoms were somewhat worse after. Course not appropriate to needs.

"It was a very personal and painful experience, looking at my past and all the painful things which happened. I believe that it did not help me with ME in any way and led to a deeper depression."

1:2:2 Courses taken by Severe to Very Severe Sufferers – GET

#31: ME very severe before course, remained very severe after course. Symptoms were the same after. Course partly appropriate to needs.

"Over many years (as a teenager and young adult) I was given physio with the clear aim of improving my strength. Elements of it were helpful in preventing contractures etc. As my ME improved it was helpful to have some assistance in regaining muscle strength. But any benefit from GET only came if the ME had improved and my body needed help in gaining some strength.

It has never happened the other way round i.e. GET NEVER improved the ME symptoms, and indeed made them worse if applied too forcefully. I was encouraged to view my extreme muscle weakness, pain etc. as primarily deconditioning. I

was told that the amount of progress I made was dependent on the amount of effort and determination I put in. There was some recognition of the fact I needed to rest and recover from exertion. To an extent this was respected, though I'm not sure what the physical reason for it was."

#32: ME very severe before course, became severe after course. Symptoms were very much worse after. Course not appropriate to needs.

"Too much to think about. Bad experiences."

Note: It was confirmed this is a correct report although respondent said the degree of ME was better following the course (severe from very severe) although the symptoms were somewhat worse, the course was not appropriate to needs and the remarks were negative.

#36: ME severe before course, remained severe after course. Symptoms were the same after. Course not appropriate to needs. Part only attended.

"I felt that my illness was not taken sufficiently seriously by the practitioner. During long periods my increase of activity was accompanied by deteriorating symptoms, which did not concern her at all.

During periods where I slowed the pace of increase, due to pressure from the symptoms, was met with resistance from her and if I refused to do as I was told, because such things had gone wrong before or were bringing up symptoms which caused a relapse, I was greeted with tuts and pulled faces.

In the end, I had greatly increased levels of activity, but my symptoms were much the same, with increased pain, and I was not able to do a wider range of activity, with some very simple lifting having become too painful to do.

I was blamed for my lack of progress, told I refused to do things to spite the practitioner and told I 'wasn't motivated to recover'.

To add some balance, I found it useful to find equilibrium or activity and rest where I could then increase activity from, which I had often been over-ambitious about before, and I took this into my later pacing programme.

However, it would have been far better to have found a level of increase that I could do without making things worse.

What was most surprising and alarming about the practitioner was that, despite her supposed experience, she clearly didn't understand the concept of being severely affected and had never seen anyone who had to stay in bed most of the time."

#72: ME severe before course, remained severe after course. Symptoms were the same after. Course appropriate to needs. Part only attended.

"The physio had the sense to know that I was not well enough for this and wrote to this effect to the Dr after I saw her. She could tell by looking at me that I was not well enough, I didn't have to do anything."

#92: ME severe before course, remained severe after course. Symptoms were very much worse after. Course not appropriate to needs. Part only attended.

"Felt that the GET therapists were not at all understanding they tried to push too hard. They made us do circuit training in a gym, I could barely cope with the warm up and collapsed during the main exercise. The next week they wanted me to do more.

I was asked to leave the course after 3 weeks because they said my objectives did not fit with theirs. I was on a phased return to work, increasing every week and this was vitally important to me.

The GET therapists insisted I had to add social activities to my plan, but I could not cope with any extra activity in addition to that at work. The GET therapists would not accept this and asked me to leave.



I found out through the local support group later that the person in charge of the program was conducting research and it seems likely that I would have produced unfavourable results if I had continued."

#112: ME severe before course, remained severe after course. Symptoms were very much worse after. Course not appropriate to needs. Part only attended.

"GP AGREED IT WAS NOT DOING ME ANY GOOD."

#113: ME severe before course, became very severe after course. Symptoms were very much worse after. Course not appropriate to needs. Part only attended. Reason given – the course was cancelled.

"It made my condition MUCH worse."

#138: ME severe before course, became very severe after course. Symptoms were very much worse after. Course not appropriate to needs.

"GET caused me to relapse into an extreme state, in the hospital. They would wait a few days if I was totally bed ridden then start again, causing me to relapse, and so on. When I permanently relapsed they accused me of sabotaging the programme of recovery for ME patients. If I didn't increase enough, they said I wasn't trying hard enough and would be discharged. Thus making me increase more, and relapse. A level of static activity, was not permitted. You HAD to increase. GET has permanently worsened my mental health due to these experiences."

#140: ME severe before course, remained severe after course. Symptoms were very much worse after. Course not appropriate to needs. Part only attended. Reason given – I did not like the course.

"Lack of honesty about the government's back to work agenda. I have a big problem with them treating everyone with the umbrella term of CFS as the same. Some people have motivation, anxiety/depression issues and not genuine ME.

For some of them, a rigid exercise and activity based programme is good for them, but not for me where any increased activity results in exacerbation of viral infections and muscle weakness, loss of production in energy and cognitive dysfunction.

Telling everybody that they can recover by applying this treatment is very distressing as it denies the very nature of the disease and the limitations and symptom severity.

I felt that the therapists were not acknowledging and listening to the patients but believed everything the official line said in their agenda driven training programmes."

Note: It was confirmed that this response relates to a question about GET courses, despite the reference to CFS.

#178: ME severe before course, became very severe after course. Symptoms were very much worse after. Course not appropriate to needs. Part only attended. Reason given – it was not working.

"Patronising, insulting and harmful. I showed evidence that GET deconditioning wasn't a factor neither low motivation and was asked to leave I was told GET would cure me and I'd be back at work in less than a year. If only."

#208: ME severe before course, remained severe after course. Symptoms were the same worse after. Course not appropriate to needs. Part only attended. Reason given – it was too tiring.

"I was unable to do what was asked of me on the GET part of my me therapy. I thought the attitude of the therapist was surly/stroppy. He lacked empathy. The distance I had to travel effected all of my M.E. treatment. I have just started GET again but have been advised I am too tired to do it and my sleep needs to be controlled first. However the M.E. clinic and my doctor are disagreeing about my medication to help me with this so at the moment I am at stalemate!"

#197: ME severe before course, became very severe after course. Symptoms were very much worse

after. Course not appropriate to needs.

"The course leaders were not open and honest in their belief that ME is a psychological illness. I felt they were trying to trick us into doing the GET and CBT elements."

#258: ME severe before course, became very severe after course. Symptoms were very much worse after. Course not appropriate to needs. Part only attended.

"I was not listened to. I was considered "in denial" and too ashamed to admit my psychological problems. They wanted to stop my medication, but my GP carried on. I was told my behaviour was "entrenched" because I could not increase how far I could walk. My DLA mobility was stopped as they said I had a psychological illness. My life fell to pieces."

#296: ME severe before course, became very severe after course. Symptoms were very much worse after. Course not appropriate to needs. Part only attended. Reason given – it was too tiring.

"I was so excited at being told to exercise on an exercise bike, I'd owned one before and loved it. The physiotherapist was so positive about GET and I really wanted it to work.

After one session near the end of the course I saw my GP immediately after the session and I was so ill he sent me straight to hospital.

There were 10 of us on the course although we were seen individually. 8 people dropped out before me and only one finished the course. The physiotherapist rated the course a success as those of us who dropped out, because we were so ill, he said "didn't want to get better".

I tried GET again at X but after some very light exercise the physiotherapist there said I was far too ill to exercise and told me if I improve I can walk to the garden gate and back.

Glutton for punishment



and so desperate to do SOMETHING to make myself better I tried again at X but immediately became very ill so stopped. I now refuse point-blank to try GET in any shape or form."

#416: ME very severe before course, remained severe after course. Symptoms were the same after. Course partly to needs. Part only attended.

"I think I was lucky in that I was referred to a physiotherapist who a) was able to come out and visit me at home for sessions, and b) was not pushy about my exercise levels/did not mention anything about my illness being anything other than physiological in origin.

The physiotherapist I saw had worked with ME patients before, apparently including one who was bedbound when she began seeing her, but after a year or so had improved to the level where she was able to go out sometimes.

I was encouraged to stick to my limits and never to push myself; in fact, the physiotherapist often advised me to cut back on activity, to help me find a baseline I could stick to all the time. In this respect, I don't consider the treatment I had to be true GET; it was given from a more holistic, person-centred approach. I imagine if I had been given another therapist to provide the treatment, I may have ended up much worse if they had pushed me to levels of activity I was unable to sustain."

#453: ME very severe before course, improved to mild after course. Symptoms were very much better after. Course appropriate to needs.

"Although it was a serious challenge to get started on the course, I clearly had considerable benefit. I continued the exercise programme at a private Gym for a further year which was of great help in that it seemed to assist with the reprogramming of my hormone/chemical control systems.

I now own an exercise bicycle and rowing machine which I bring

into use when I get an occasional relapse in my ME. The key seems to be to carefully monitor exercises and ensure you do not overdo matters.

Exercises were based on a session of Cycling, rowing and walking with gentle warm up and down. BP and pulse monitoring between. Machines set with modest resistance which remained constant throughout exercises. Started with approx. 3min on each machine and held this for a week (3 sessions). Increasing each week by 1 minute.

Reverted when over tired or felt a reaction. After 3 months exercise level reached 40 mins including 5mins. warm up and 5 mins warm down."

#463: ME severe before course, remained severe after course. Symptoms were somewhat worse after. Course not appropriate to needs.

"The assumption was that I would improve and any impediment to improvement lay within my own psychological attitude to my illness and not to problems with the method or the severity of my illness. I was blamed for not improving at all. I was told I was not 'engaging in recovery' when I asked if I could focus on pacing only, as pacing helped but the GET was making me worse. I was not listened to."

#513: ME very severe before course, remained very severe after course. Symptoms were very much worse after. Course not appropriate to needs.

"I was originally confident of doing the course but it was very obvious that the graded exercises were making my condition worse. I felt that, when talking on the arranged telephone interviews that I had to think past the systems, and because I had been a very competitive and active person pre ME, I should be able to press forward.

After 6 months of me trying this daily I was obviously becoming worse, but the practitioner, wasn't happy with me. I put a report in

with the paperwork saying the same. This wasn't a good therapy with my condition, and feel it contributed to me becoming long term disabled as I should have rested as and when in the early days of becoming ill.

I should have listened to a physiotherapist friend of mine, right at the beginning of my illness who recommended I rest my body and not put any pressure on it with exercise. This lady was right.

Also the practitioner, basically said, that I should put myself first and not my young family. This was practically impossible being a single mother of 5 – 4 living with me.

During the same time as doing this course, I sourced types of medication that I took with the support of my own GP, which helped a great deal, along with pacing every part of my physical and mental day, to which I still do to this day."

#591: ME severe before course, remained severe after course. Symptoms were somewhat worse after. Course not appropriate to needs.

"Just attending the course made me sicker but I did manage to get there. The physio was anti-wheelchair usage and one attendee was only allowed to attend as long as she didn't use her wheelchair. At this time I was still having to crawl upstairs on my hands and knees."

#647: ME severe before course, became very severe after course. Symptoms were very much worse after. Course not appropriate to needs. Part only attended. Reason given – it was not working.

"It was a regime made up 'on the spot' by the paediatrician. It was highly inflexible and prescriptive, and I failed it relapsing into severe disability very quickly."

#678: ME severe before course, became very severe after course. Symptoms were very much worse after. Course not appropriate to needs. Part only attended.



"My GET was provided by a physiotherapist while I was an inpatient at St. Mary's Hospital, Paddington. It involved daily sessions, with the physiotherapist attempting to double my activity levels at each session; after two weeks of this treatment I could barely move and was discharged."

#743: ME severe before course, became very severe after course. Symptoms were very much worse after. Course not appropriate to needs.

"GET tailor made by neurologist and physiotherapist when Pyridostigmine bromide significantly increased muscle endurance so I could do GET. Effect permanently very bad on health and lifestyle."

#760: ME severe before course, remained severe after course. Symptoms were somewhat worse after. Course partly appropriate to needs.

"I did not find GET helpful – my symptoms worsened considerably because I was given unrealistic goals and not enough supervision. There was no contact between appointments to discuss setbacks/management. Disappointing."

Note: It is confirmed this is a correct report though respondent said the symptoms were somewhat worse after the course and the remarks were negative but also said the course was partly appropriate to needs.

#840: ME severe before course, remained severe after course. Symptoms were somewhat worse after. Course appropriate to needs.

"This approach to GET was a lifestyle killer if carried out properly, since no activities were permitted other than those prescribed. It was only the carrot of getting better in the end that made me stick with it.

I only deviated from continuous attempts at increases for occasional visits to family or holidays for 7 years, and this was typical of this doctor's patients. Since he has an 85% success rate in terms of returning patients to previous levels of function I felt it

was worth it, but, alas, I was in the 15% who did not benefit."

Note: It is confirmed this is a correct report even though respondent said the symptoms were somewhat worse after the course and the remarks are negative but also said that the course was appropriate to needs.

#886: ME severe before course, remained severe after course. Symptoms were very much worse after. Course not appropriate to needs. Part only attended. Reason given.- it was too tiring.

"The GET had a very negative effect on my M.E as I could not keep increasing my activity levels at all and this made me very de-moralised and I felt as if I was holding back my recovery.

It made me feel depressed and as if I still wanted to stay ill as I could not do what was being asked of me. It made the M.E much worse when I tried to increase my activity levels and therefore the pain was worse and fatigue etc. It meant I was actually spending more time in bed resting following the increased activity.

I felt that the people doing these courses did not fully understand M.E."

#906: ME severe before course, remained severe after course. Symptoms were very much worse after. Course not appropriate to needs. Part only attended.

"Although I only managed to do GET for a very short period of time (approx. 2 weeks) I deteriorated so rapidly and markedly and my functioning became worse.

Before GET I had been able to build up to walking more for a few weeks for 5 or 10mins sometimes (prior to this walking as much more limited), but after the GET I couldn't do this and I have been unable to achieve this since, and it is over 2 and half years since I did it.

I would never do it again, now that I understand more about M.E and I know it made me worse, and did harm rather than good (within 2 weeks I was having trouble

standing and having funny turns which I had previously had when my M.E was worse)."

#926: ME very severe before course, remained very severe after course. Symptoms were very much worse after. Course not appropriate to needs. Part only attended.

"I was in a multi discipline neuro rehab unit as an inpatient following emergency admission the unit had OT and Physio present 8am to 5 pm on my last admission the aim was to at least get me to be able to stand up and poss manual transfer.

We went round in circles – I'd be a bit stronger, we tried to move forward, I'd go backward to the extent of temp paralysis. I got very angry with myself because I couldn't do it. My Consultant call a halt. The physio said he was of the opinion I would never walk or stand again. 7 years later he is still right."

#938: ME severe before course, became very severe after course. Symptoms were very much worse after. Course not appropriate to needs.

"Too strenuous."

#969: ME severe before course, became very severe after course. Symptoms were very much worse after. Course not appropriate to needs.

"I have gone far worse since receiving GET to the extent I haven't been out since my last treatment. I have had no follow up treatment and the physio concerned tried to get the X to take over my case, although neurology and psychiatry have said that it is the responsibility of the local 'CFS' team. The 'CFS' team have been refusing services."

#961: ME severe before course, became very severe after course. Symptoms were very much worse after. Course not appropriate to needs. Part only attended. Reason given – it was too tiring.

"Objectives were



described both verbally and in writing. I was very hopeful that GET might help me. Then, I was very greatly relieved when, GET having proven harmful, my practitioners suggested I should drop GET."

#971: ME severe before course, became very severe after course. Symptoms were very much worse after. Course not appropriate to needs. Part only attended. Reason given – it was too tiring.

"Increased the severity of my symptoms significantly. Was made to feel the symptoms were psychological, not trying etc. A traumatic experience for me."

#984: ME severe before course, remained severe after course. Symptoms were very much worse after. Course not appropriate to needs. Part only attended. Reason given – it was too tiring.

"I'm not sure it falls into the category of GET. My GP called it a "prescription for exercise" and said it was used for people with depression and many other conditions. It just consisted of going to the gym, being assessed by a member of staff for a few minutes, being shown how to use the circuit training equipment and then being left on my own to follow a written list of which machines to use and how many repetitions.

I felt terribly ill afterwards and had to sit in my car for ages each time, too ill to drive the very short distance home. Afterwards, I'd be bedbound and in great pain for days. Thus, I only completed 3 or 4 sessions."

#999: ME very severe before course, remained very severe after course. Symptoms were somewhat worse after. Course not appropriate to needs. Part only attended. Reason given – it was too tiring.

"Instead of my muscle function getting stronger the more I exercised the weaker they became. The physio realised this and stopped the sessions."

#1015: ME severe before course, became very severe after course. Symptoms were somewhat worse

after. Course not appropriate to needs. Part only attended.

"Truly, I think that this is DANGEROUS. Increased physical activity was a primary factor in my ME becoming so severe, and a year and a half later, I have still not recovered anywhere near to my prior level of functioning.

There is a huge difference in the kinds of symptoms that show up as the result of deconditioning and those that come on from overexertion by someone with ME. I don't know how anyone could possibly mistake them."

#1095: ME severe before course, remained severe after course. Symptoms were somewhat worse after. Course not appropriate to needs. Part only attended.

"The GET group sessions were, I felt, inappropriate for the group – given that it was a mixture of depression and ME patients (in the main).

Did not follow Pacing for ME principles. Plus we did some exercises which were simply beyond those with severe or even moderate ME! A lot of standing!

However the one to one sessions I had with the physio were helpful. She was just great and talked to me about my activity levels and trying to very very gradually increase them – strategies, etc."

#1142: ME very severe before course, remained very severe after course. Symptoms were somewhat worse after. Course not appropriate to needs. Part only attended. Reason given – it was too tiring.

"Was done by physiotherapist who hadn't treated M.E. patients before. Very sympathetic but course was offered too soon to be of benefit. It made me worse. If I had been offered GET when in Mild to Moderate phase, I believe it would have given more benefit."

#1154: ME severe before course, remained severe after course. Symptoms were somewhat worse after. Course partly appropriate to needs. Part only attended.

"Stretching exercises are helpful

but unable to progress with GET plan of increase."

#1168: ME severe before course, became very severe after course. Symptoms were very much worse after. Course not appropriate to needs. Part only attended. Reason given – it was not working.

"Being told to gradually increase my exercise made me push myself more and more and each day I would get worse and worse. Instead on days when I was able I would do what I could but on other days I learned to push myself just made me feel more and more ill."

#1175: ME severe before course, became very severe after course. Symptoms were somewhat worse after. Course not appropriate to needs. Part only attended. Reason given – it was too tiring.

"When I told my GP that I couldn't continue he stated "well that proves you have ME then"."

#1221: ME very severe before course, remained very severe after course. Symptoms were very much worse after. Course not appropriate to needs.

"Caused much more pain and he refused to believe me when I told him that, or I was expected to push through the pain barrier. I took a lot more pain killers, to try to counteract the prozac headaches. He also told me I was fatter because I was comfort eating, I wasn't eating any differently it was the amitriptyline."

#1263: ME severe before course, became very severe after course. Symptoms were very much worse after. Course not appropriate to needs.

"Useless, offensive, insulting, patronizing. Had to increase sleeping pills to actually sleep. Increased pain. Permanent deterioration and new symptoms. Almost no cognitive issues before GET, significantly worse.

Continued to decline for 3 years following trying to implement GET programme until completely bedbound



and only able to eat liquid food, needing an eye mask in a dark room as any small amount of light (e.g. for standby lights) would send body to fits/jerks."

#1293: ME severe before course, became very severe after course. Symptoms were very much worse after. Course not appropriate to needs. Part only attended.

"This was the worst so called treatment I have ever taken part in. After my initial assessment my condition worsened, so I was unable to get to the hospital and everything was done over the phone.

I was physically unable to get out of bed without help and could not do what was asked of me, so it just ended up with the therapist shouting at me so much each time I ended up in tears. It was unbelievable for a good hospital like X.

Up until then the service from them had been brilliant, but this Therapist said if I did not start 'co-operating' – her words – I would be thrown out of the clinic. She did not seem to realise it wasn't that I didn't want to do what she was asking, I just couldn't physically do it.

After a couple of months I got the letter I had been dreading. She had got me thrown out of the clinic."

#1397: ME very severe before course, remained very severe after course. Symptoms were somewhat worse after. Course not appropriate to needs.

"The course was administered as part of an in-patient stay at the X Hospital. I was initially seen by a gastro-enterologist specialist (specifically the autonomic aspect) who seemed to have interest dysautonomia and ME/CFS, and who referred me internally within the hospital throughout my stay.

The GET/Pacing was overseen by a physiotherapist who openly admitted that she had no experience with ME/CFS and was used to working with elderly patient who had suffered strokes.

I was pushed too hard, felt increasingly tired and ill throughout the course. The physiotherapist did not seem to understand that the severe orthostatic intolerance from which I suffer has been present from the initial onset of my illness and has not been caused by deconditioning through being bed bound (the orthostatic intolerance caused me to become wheelchair and then bed bound from the very start of my illness. Further, ignoring this symptom and trying to carry on made it worse).

I only had a few sessions of this treatment before I was discharged, and did not seek to continue this treatment at home because on top of the stress of a trip and stay in hospital the physiotherapy had made me feel more symptomatic and utterly exhausted."

#1410: ME severe before course, improved to moderate after course. Symptoms somewhat better after. Course appropriate to needs.

"Increased muscle strength and stamina, increased confidence about improving my muscle strength, extremely valuable advice about what exercises to try and how to do them, and how to monitor progress safely; using fewer painkillers as muscle stretches and posture exercises have helped with headaches."

1:2:3 Courses taken by Severe to Very Severe Sufferers – Pacing

#20: ME severe before course, remained severe after course. Symptoms were the same after. Course appropriate to needs.

"It was generally helpful and supportive."

#23: ME severe before course, remained severe after course. Symptoms the same after. Course appropriate to needs.

"Between 4 and 6, 30 min rest periods per day. At least one of these had to be relaxation and at one point it was increased to 2 or 3 relaxations. The course practitioner was very helpful."

#37: ME very severe before course, improved to severe after course. Symptoms very much better after. Course appropriate to needs.

"I have found pacing therapy to be an absolutely invaluable tool in dealing with my ME. Even though there was no significant improvement in the illness in the first 2 years of pacing, I achieved a level of stability and control that I hadn't had before. It also gave me some knowledge and understanding of my limits which was helpful not only for myself, but also for friends and family. For example, once people knew that I could only talk on the phone for (say) 10 minutes, I had less explaining to do all the time, and they didn't get offended if I had to cut off a conversation. So pacing can improve relationships!

As I've gradually improved, pacing has meant that I am less likely to overdo activity and make myself worse as I so often did in the past. Pacing has allowed steady progress. I also think it was important that my therapist also taught me about relaxation techniques.

I think it would be great if everyone with ME was given the opportunity to learn to pace. Having a sympathetic and encouraging therapist was also hugely helpful.

I must acknowledge that I was very lucky to have been referred to the local CFS/ME service at a time when they had the resources to give me a therapist who could do home visits. Home visits are essential for people who are very severely affected and without them there is really no help at all."

#44: ME severe before course, remained severe after course. Symptoms somewhat better after. Course appropriate to needs.

"I felt the pacing element of the course at X was very good. However I feel there should be follow-up after the course: perhaps a review one-to-one every 6 months for those with severe to moderate illness."



#45: ME very severe before course, improved to severe after course. Symptoms somewhat better after. Course appropriate to needs.

"Given a relaxation tape by the physio. Also factsheets about pacing, relaxation. Managing setbacks (photocopies incl.). Still have fatigue and days when I feel really ill but not the serious relapses that left me bedbound. A very positive experience which increased my confidence and quality of life. Physiotherapist and consultant (X & X) very supportive and encouraging."

#46: ME very severe before course, improved to severe after course. Symptoms somewhat better after. Course appropriate to needs.

"My occupational therapist treated me as a whole person and tailored all advice to how I was at the time. I trusted her completely as she only worked at my level of activity and adjusted straight away if I struggled. She noticed immediately if I was fatigued and stopped consultation. Her name was X at X ME service."

#51: ME very severe before course, remained very severe after course. Symptoms very much worse after. Course appropriate to needs.

"Pacing therapy was useful in so far as it made me realize how truly ill I was and how limited my ability to do what I had previously not thought twice about because I was able to keep weekly diaries of activity and compare and contrast them. It helped me come to terms with the disease."

#93: ME severe before course, improved to moderate after course. Symptoms somewhat better after. Course appropriate to needs. Part only attended.

"I worked one to one with my local OT and found her support on pacing invaluable. I had a tailor made programme designed around me. I found the pacing very difficult at first and hated most of it but over time I experienced a real improvement in my symptoms and I felt back in control again – one of the major benefits to me of pacing."

I am experiencing a severe relapse and am returning back to basics with pacing and hope to see improvements over the coming months. I would not say that pacing cured my M.E. I am also aware that I hit a glass ceiling and did not improve above a certain level – I was never better than moderately effected. But it is still better than I was (or am now)."

#112: ME very severe before course, remained very severe after course. Symptoms very much worse after. Course not appropriate to needs. Part only attended.

"TOTAL WASTE OF TIME MADE ME ILL AND FEEL LIKE SHIT I WAS A LOSER THEY WANTED SUCCESS."

#118: ME severe before course, improved to moderate after course. Symptoms somewhat better after. Course appropriate to needs.

"The practitioner was very helpful and I certainly benefitted from attending the course. I was told that she would be happy to see me again, and if I felt at any time that this was necessary I could be referred by my G.P. As I walked out of the hospital after that final appointment (over a year ago) I felt alone and abandoned to get on with it and still feel that way, which is why I recently joined the M E Association."

#120: ME severe before course, remained severe after course. Symptoms somewhat better after. Course appropriate to needs.

"It was a tailor made program and I was given the knowledge to find out my own personal limit that would not exacerbate existing symptoms."

#145: ME very severe before course, improved to severe after course. Symptoms somewhat better after. Course appropriate to needs.

"It helped me to stop the "boom and bust" that I had been in."

#189: ME severe before course, remained severe after course. Symptoms the same after. Course partly appropriate to needs. Part only attended.

"It was part of a multi-component pain management programme with a physio for Pacing and GET (which didn't work) and a psychologist for CBT to help with depression."

The psychologist took over as the physio gave up on me as I couldn't follow the programme she set out for me – it was far too structured and rigid and ended up with me failing."

#191: ME severe before course, improved to moderate after course. Symptoms very much better after. Course appropriate to needs.

"The pacing course made a huge difference to my life and taught me how to manage my illness."

The course practitioner was very knowledgeable and so supportive. She said she recommends graded activity instead of graded exercise."

Just making a meal for myself became possible due to pacing. I live alone. The course was tailor made to my particular needs, i.e. severely affected, living alone."

#208: ME severe before course, remained severe after course. Symptoms the same after. Course appropriate to needs.

"It helped me to accept my ME and to make things easier by pacing, although it didn't improve my condition overall."

#227: ME severe before course, remained severe after course. Symptoms the same after. Course appropriate to needs.

"I believe the therapist was taught in the psychological view of ME & deconditioning. Although gave good pacing advice."

#238: ME severe before course, remained severe after course. Symptoms the same after. Course not appropriate to needs.

Extract: "It wasn't the pacing therapy I found a complete waste of time; it was the ME/CFS Nurse Specialist. Where I live, they have this policy that ALL sufferers must be assessed in the clinic so I (and a carer and a



wheelchair) dragged myself to the clinic and by the time I got there, I could hardly string a coherent sentence together.

After this first visit, he did home visits. He was all gung ho about treating my insomnia and when he couldn't – he discharged me. He might have been good for newly diagnosed sufferers who were mild to moderate but as a severe sufferer, I found it quite useless."

#430: ME severe before course, remained severe after course. Symptoms the same after. Course not appropriate to needs.

Extract: "You had a choice of what you could take part in and pacing was the only thing I wanted help with, but I came away a year later thinking what a waste of time. I don't think the practitioner had any idea of how difficult life was."

#442: ME severe before course, improved to mild after course. Symptoms very much better after. Course appropriate to needs.

"Pacing was extremely helpful and after doing it for 4 years I went into remission for 3 years. I relapsed 2 years ago after having a Hepatitis B vaccine but have improved from severe to moderate through pacing and taking LDN.

My specialist was the first doctor who properly understood ME. He was not patronising and did not suggest I had a psychiatric problem or school phobia. He suggested medication (amitriptyline) that was very helpful for my insomnia.

I did not have a certain level of activity to do a week (as in GET) but he allowed me to go at my own pace. The most helpful advice was how to avoid the boom and bust cycle by keeping to a low level of daily activity. School hours were not used as a form of increasing activity but were just a result of recovery."

#571: ME severe before course, remained severe after course. Symptoms the same after. Course appropriate to needs.

"The course has been good for me for recognising warning signals

before the symptoms get too bad, also learning about mental as well as physical exhaustion."

#578: ME severe before course, remained severe after course. Symptoms somewhat better after. Course appropriate to needs.

"Pacing hasn't stopped the decline in my health (this was I believed triggered by an inappropriate course of GET when I should have been resting) but pacing does enable me to manage my symptoms much more effectively. Keeping a diary in the early stages was very helpful. Pacing puts me in control of my ME as far as is possible."

#619: ME severe before course, remained severe after course. Symptoms the same after. Course not appropriate to needs.

"I am glad it was a home-visit course, as I could never have managed regular outpatient appointments.

It was good for me to start breaking activities down and taking a rest before I became exhausted. That was a hard lesson for me to learn when I got ME, because I used to be a really active and busy person who pushed myself to the limits.

However, after some months of trying to follow the disciplined daily plans recommended by the therapist, I have started listening to my body more. In particular I now sleep and wake whenever I feel the need, rather than trying and failing to follow a prescribed sleep routine.

I am much happier as a result. I also allow myself to occasionally attend a big event (like a friend's birthday party) knowing that I will "overdo" it and have a setback afterwards, because I missed being a part of other people's lives."

#657: ME very severe before course, improved to moderate after course. Symptoms very much better after. Course partly appropriate to needs.

"Pacing Therapy was extremely helpful but I felt there should

have been a review say 6 months later, then perhaps a year later and or 5 years later to assess any "slide-back" and to feel there was someone I could contact if things got worse."

#776: ME severe before course, remained severe after course. Symptoms somewhat worse after. Course not appropriate to needs. Part only attended.

"I don't think pacing therapy is effective. I am currently in the process of writing a daily diary but see no benefit as it causes cognitive problems as I sometimes forget to fill it in and have to remember what I did yesterday. I believe that going to physio has been more helpful and also talking to people like the physio made me feel like I was a real person again."

#789: ME severe before course, remained severe after course. Symptoms the same after. Course partly appropriate to needs. Part only attended.

"The term course would be stretching it, it was just two one on one sessions with an OT. I could have seen her more, but my health deteriorated and I became housebound."

#843: ME severe before course, remained severe after course. Symptoms the same after. Course not appropriate to needs.

Extract: "The course I attended made absolutely no difference to my illness other than leaving me feeling (for the first time ever!), that ME is caused by 'expecting' to feel exhausted/in pain/ etc and that by setting 'goals', pacing, etc. I would eventually get better and be able to return to work. Frankly I found this offensive."

#866: ME severe before course, improved to moderate after course. Symptoms the same after. Course appropriate to needs. Part only attended.

"I found the course of pacing very useful but did not like the CBT or GET aspects as there were of no use in helping my symptoms of M.E. In fact the CBT and GET made them



worse. The Pacing was useful as I discovered that I was actually doing too much activity and pushing myself too much.

I was taught to switch activities between physical and mental and the most important thing was to incorporate rest periods and relaxation which I found extremely helpful and I also found my quality of sleep improved due to the relaxation aspect. I discovered that I was doing too much activity previously without pacing myself and taking a break which I now know is very important. I also learnt that it's OK not to keep pushing and pushing myself as it will do not me any good in the long run."

Note: It is confirmed this was a correct report even though symptoms said the change from severe to moderate and yet were 'the same afterwards'.

#938: ME very severe before course, remained very severe after course. Symptoms very much worse after. Course not appropriate to needs.

"Pacing element more useful to take away. A full on 3 hr session is not pacing yourself properly. I was allowed a 15 min snooze in order to complete it!"

#964: ME severe before course, remained severe after course. Symptoms somewhat better after. Course appropriate to needs.

"At first my pacing course worked extremely well and I noticed great improvements, however I could not maintain the strict management lifestyle and problems with IBS and getting viruses knocked me back again and again. I now find it too stressful and confining to pace."

#1036: ME severe before course, remained severe after course. Symptoms the same after. Course not appropriate to needs. Part only attended. Reason given – I did not like the course.

"It didn't tell me anything that anyone with half a brain cell wouldn't know – obviously ME sufferers have no choice but to pace themselves – insulting and condescending to imply that

sufferers need to be told this! What a waste of resources!

#972: ME severe before course, remained severe after course. Symptoms the same after. Course not appropriate to needs.

"I was unable to clearly say whether or not the course I went on included CBT or GET components – certainly it touched on mental issues and gave a description of how to calculate and increase physical exercise once equilibrium is achieved.

There was an introduction called Understanding CFS/ME: The Biopsychosocial Model. The sessions were entitled: 1. Outline of CFS/ME, the Boom and Bust Cycle, Activity Diaries, Relaxation. 2. Setting Baseline, Improving Sleep, Relaxation. 3. Activity Diaries, Helpful Thinking, Relaxation. 4. Talking about CFS to family and friends, Relaxation. 5. Balancing Your Life, Goal Setting, Relaxation. 6. How are you? Managing Setbacks, Relaxation.

It was of interest to hear about the main premise to achieve a sustainable balance of activity/rest and the activity classifications of physical, mental and emotional. Previously I tended to think of exertion in physical terms. I didn't think much of the rest of the subject matter covered.

I'm glad I went but the course did not have any effect (I was already instinctively self-regulating and not being capable of much of a 'boom') and I wasn't convinced by a lot of the theory.

I found some of the written notes and delivery patronising. Some aspects were downright cringe-worthy: "Write the helpful thoughts down on a small card and carry them around with you. Get the card out and read them when you find yourself having unhelpful thoughts." Infantile tosh! They hadn't thought the practicalities through either.

However now, although I don't actively follow the recommendations (no cards in my pockets), I do vaguely evaluate activity in 'pacing' terms to try

to balance activity and rest and tentatively say I 'manage' the symptoms where I can but am just so aware that there is too much unpredictability in this disease (as well as life) that defies management.

The kind of pacing I can achieve is just damage limitation and has never achieved sustainability for any reasonable length of time.

#1113: ME severe before course, remained severe after course. Symptoms the same after. Course appropriate to needs.

"The course taught me how to cope with what little energy I have by making better use of it – and to rest considerably more than I was – and not to play "bull in a china shop" between total exhaustion. I believe that without the course I'd now be worse than I am now and may have taken my own life from the despair this horrific illness causes."

#1126: ME severe before course, improved to moderate after course. Symptoms somewhat better after. Course appropriate to needs. Part only attended. Reason given – it was too tiring.

"I have found pacing to be ideal for me, although friends and family have found it difficult to understand. I have been able to reduce the amount of the antidepressant I am taking from 150mg to 50mg daily. I am also feeling confident enough to try to stop smoking after 25 years of 20 a day."

#1151: ME severe before course, remained severe after course. Symptoms somewhat better after. Course appropriate to needs.

"Pacing therapy was good. Physio was understanding. Pacing helped me to better cope with daily activities, such as reading, sitting up to eat meals, etc."

#1182: ME severe before course, improved to moderate after course. Symptoms the same after. Course appropriate to needs.

"Over time my self-management of ME



has improved after I was provided with the information and tools to help me understand where I was going wrong i.e. boom and bust. I had access to help from OT's and physios after the course whenever I needed it (if I hit a set back or exacerbation of the condition from another illness)."

Note: It is confirmed this is a correct report although respondent said the degree of ME was better following the course although the symptoms remained the same (the question having related to improvement of worsening of symptoms).

#1221: ME very severe before course, improved to severe after course. Symptoms somewhat better after. Course appropriate to needs.

"Pacing works. My instinct always told me so but the psychobabblers derailed me for years, I needed one short course to confirm what I knew. Pacing works."

#1231: ME severe before course, remained severe after course. Symptoms the same after. Course appropriate to needs.

"I still use pacing to date as it stops my symptoms from becoming worse, although sometimes worsening is unavoidable on a non-average day of activity. Pacing has not helped my symptoms improve in any way, but it has helped me manage them. It has been the most useful treatment so far."

#1319: ME severe before course, remained severe after course. Symptoms somewhat better after. Course appropriate to needs.

Extract: "The one-on-one session with the OHT included very minimal CBT – just about staying positive – just as I would expect for any other physical condition such as MS. Pacing works better without 'full on' CBT (belief of psychological causation and cure) since its key element is acknowledging your body's limitations and working within it to allow healing to occur if possible – and this HEALING is stated as the causation of cure."



This is empowering and gives permission of the ME sufferer to do what their body is telling them. Add 'full on' CBT and this balance is destroyed, risking negative spiralling into physical and psychological damage as the person is encouraged to work against themselves.

The psychologist-led multi-disciplinary course used Pacing as a foil to deceitfully foist full CBT and GET upon us once our guard had been dropped.

The true Pacing course was immensely beneficial (though not curative for me) and returned my dignity and self-esteem which had been stripped by the years of incompetent CBT forced upon me by the misdiagnosis of depression. It was also the antidote to the years of damaging pushing I'd been encouraged to do as my 'cure' for the non-existent depression."

#1410: ME severe before course, improved to moderate after course. Symptoms somewhat better after. Course partly appropriate to needs.

"It was impossible for the practitioner to explain at what point pacing becomes boom and bust – I was boom and busting severely before I began pacing so it is very hard for me to know whether what I'm doing now is considered boom and bust for other people or not, and I wasn't helped to establish my baseline levels. I learnt more about pacing through my own work prior to the course."

APPENDIX 2: QUANTITATIVE DATA – LISTED CRITERIA

2:1 INTRODUCTION

Notes:

a) The charts and tables set out in Appendix 2, sections 2, 3 and 4 below; contain data collected by our survey. They deal with the responses to those quantitative data questions which the authors consider have the greatest relevance to the reasons why this survey was initiated.

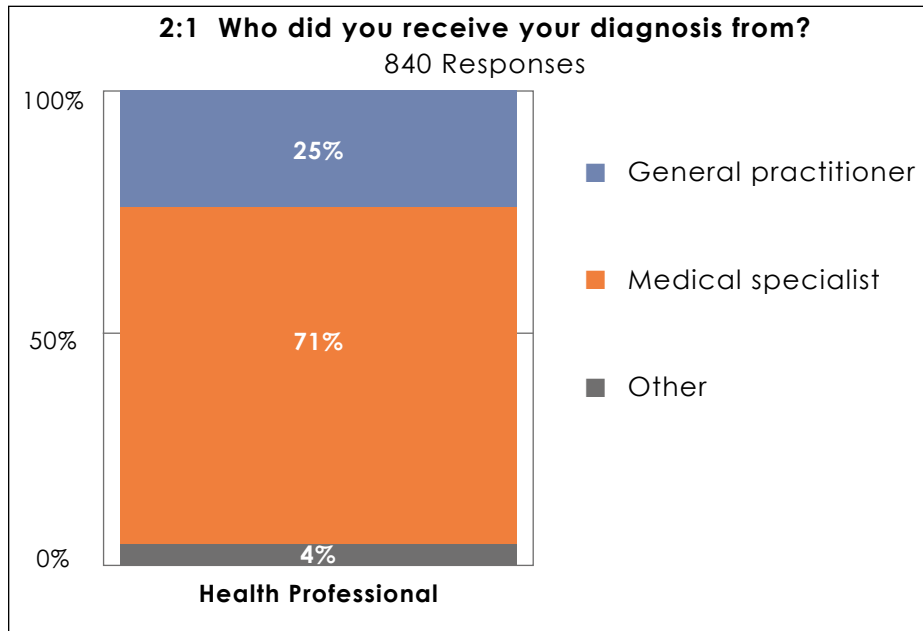
b) As noted in Section 2 of this report ('About this Survey') above, we have included data from those respondents who had received positive diagnoses from medical specialists and who reported on the degree of severity of their ME/CFS before and after their courses, the effects of their courses on their symptoms and whether or not they found their courses appropriate to their needs.

c) Not all respondents whose responses are included knew the answers to all the questions asked, but the percentages used relate to those who did.

d) Qualitative responses have been used sparingly in this Appendix to illustrate a particular point.

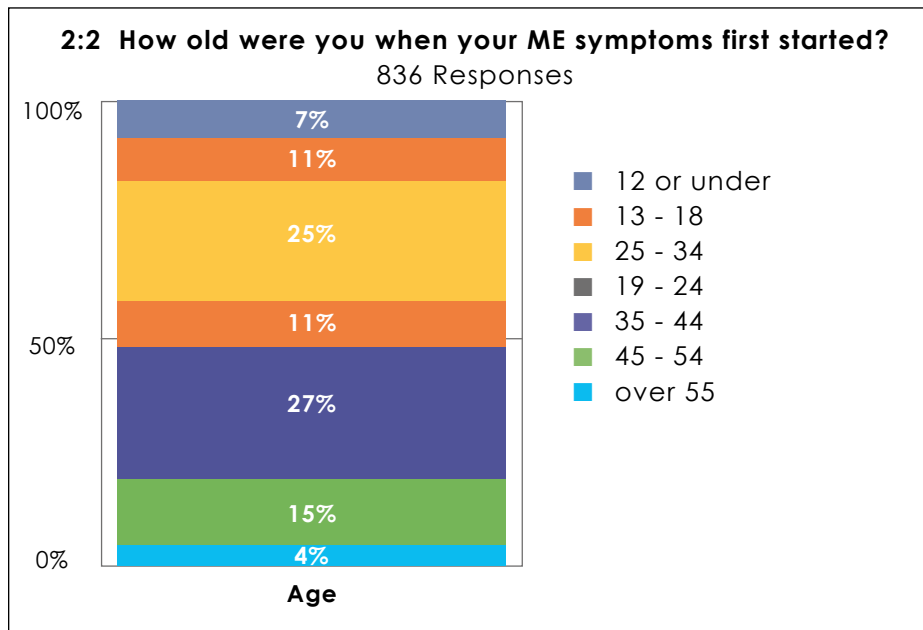
2:2 DEMOGRAPHICS

2:2:1 Who did you receive your positive diagnosis from?



It was important to know that diagnoses came from qualified health practitioners.

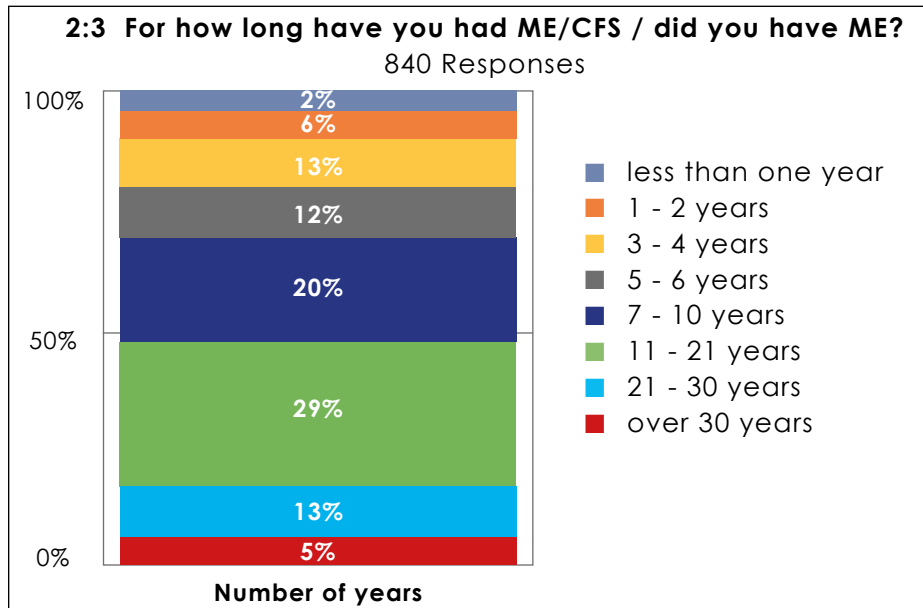
2:2:2 How old were you when your ME symptoms first started?



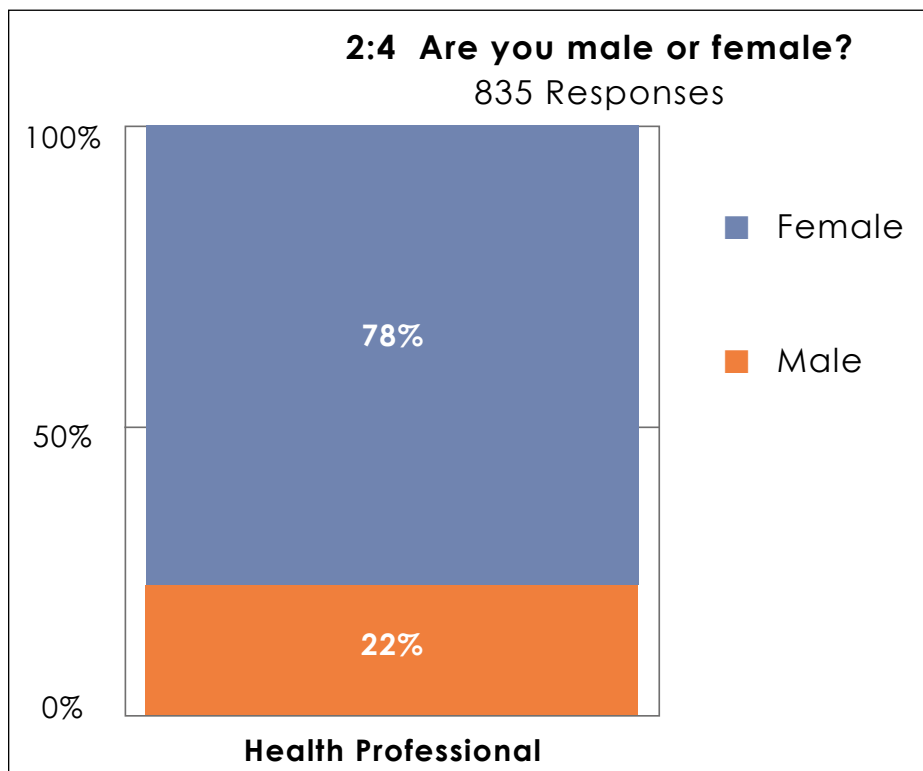
Age at onset is very similar to other current epidemiological evidence, which indicates that the onset of ME/CFS most commonly occurs between the ages of 20 and mid-forties.



2:2:3 How long have you been ill or, if recovered, were ill?



2:2:4 What is your gender?



Epidemiological studies consistently report a female: male sex ratio in ME/CFS in the region of 70:30. However, the figures here are not uncommon. See our caveat in Section 2:4 'About this Survey'.



2:3 COURSE SPECIFICS

Notes:

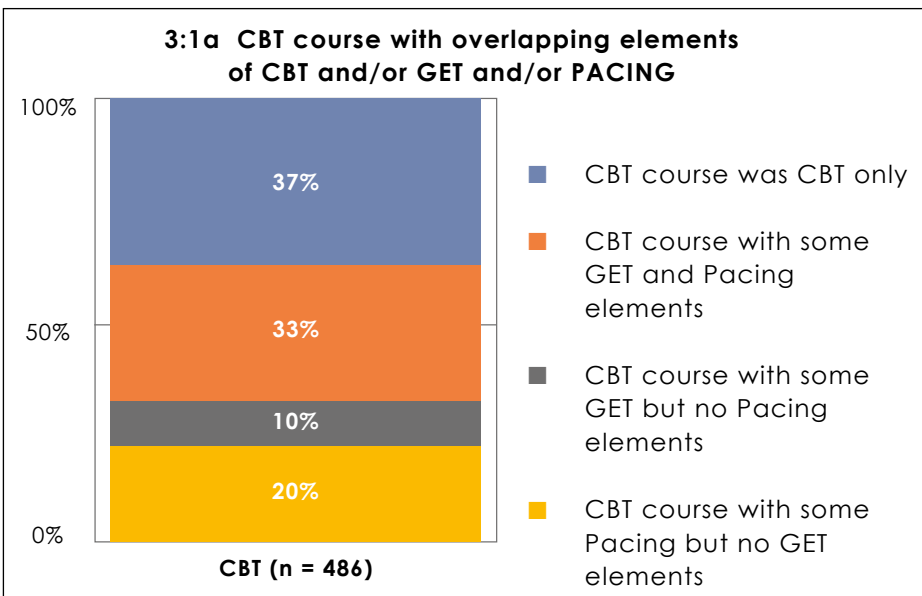
Section 1 of the report (Introduction) at 1:2 gives definitions of CBT, GET and Pacing as used in this survey, but:

a) Examples of CBT might include being taught that your muscle fatigue/weakness was more likely to have a psychological cause, or more likely to be due to being unfit (deconditioned), than having a physical cause; or being taught that there is nothing wrong with the muscles in ME and so it is unhelpful to believe that exercise could make symptoms worse.

b) Examples of GET might include being asked to regularly walk a certain distance each day, or several times a day, and then to progressively increase this activity on a regular basis; or being told to join a gym as part of an exercise programme.

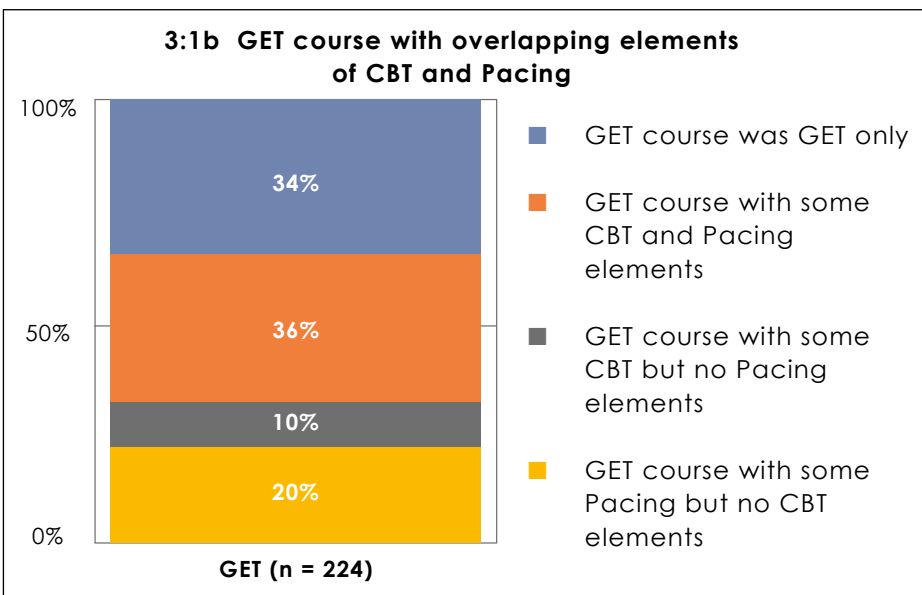
c) Examples of Pacing might include you identifying which activities you were able to do, how often and under what circumstances, and then not increasing those activities until you could manage them without the occurrence of post-exertional malaise; or restricting the number of times you repeat activities which you find demanding or stressful.

2:3:1 Did your course contain overlapping elements of CBT and/or GET and/or Pacing?



CBT course comment:

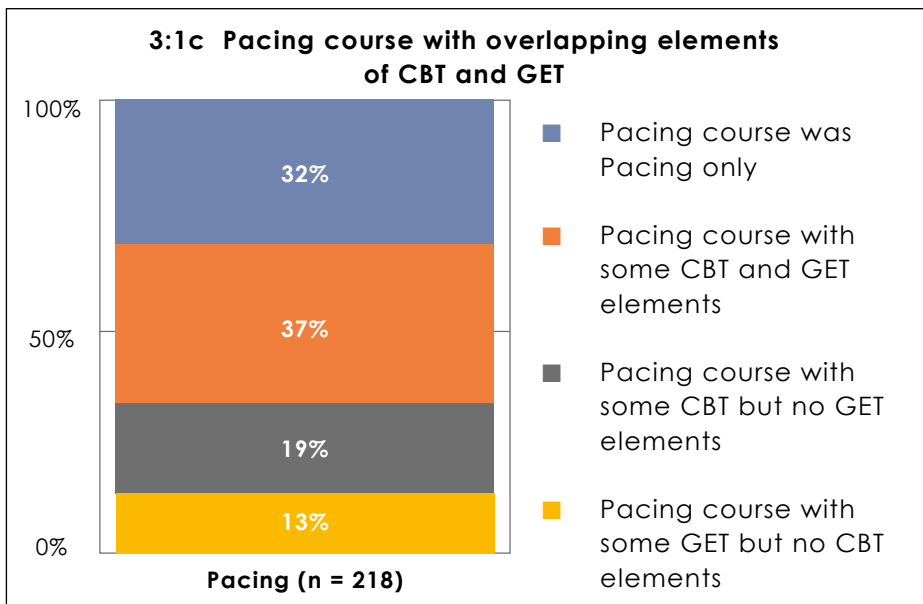
“We set ourselves a target that we wanted to achieve. We were taught to stop an activity before the bust point and to rest totally then to resume activity and to alternate physical and mental activities as well”.



GET course comment:

“The pacing elements were extremely useful and I still use what I learned today. It is all very logical but it is not something I had figured out myself by that stage of my illness”.

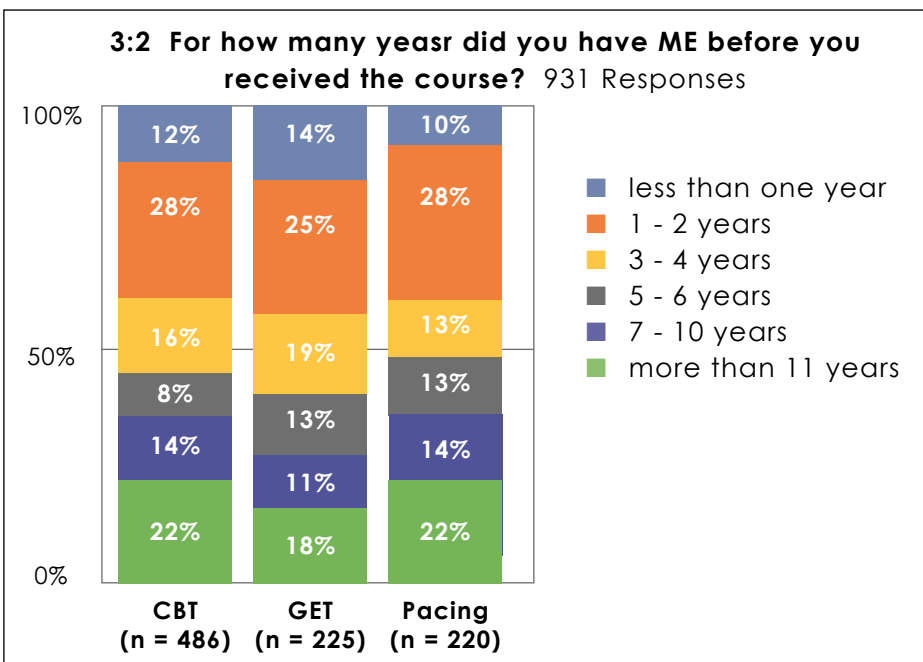




Pacing course comment:

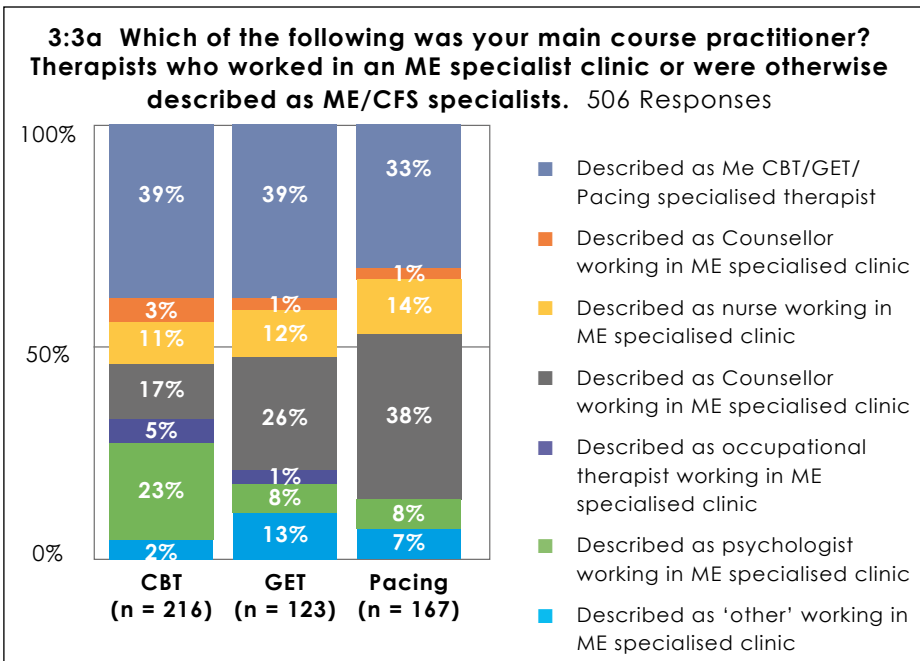
“GET – Light exercises – but from the mind-set that a little gentle exercise is better than none, and then stepping it up gently. CBT – letting us know that negative feeling can have physiological effects but that ME is real and not imagined, but being positive helps”.

2:3:2 For how many years did you have ME before you received the course?



2:3:3 Which of the following was your main course practitioner?

Note: The following two charts are compiled from a combination of two sets of responses.



465 respondents who had taken a CBT course answered this question:

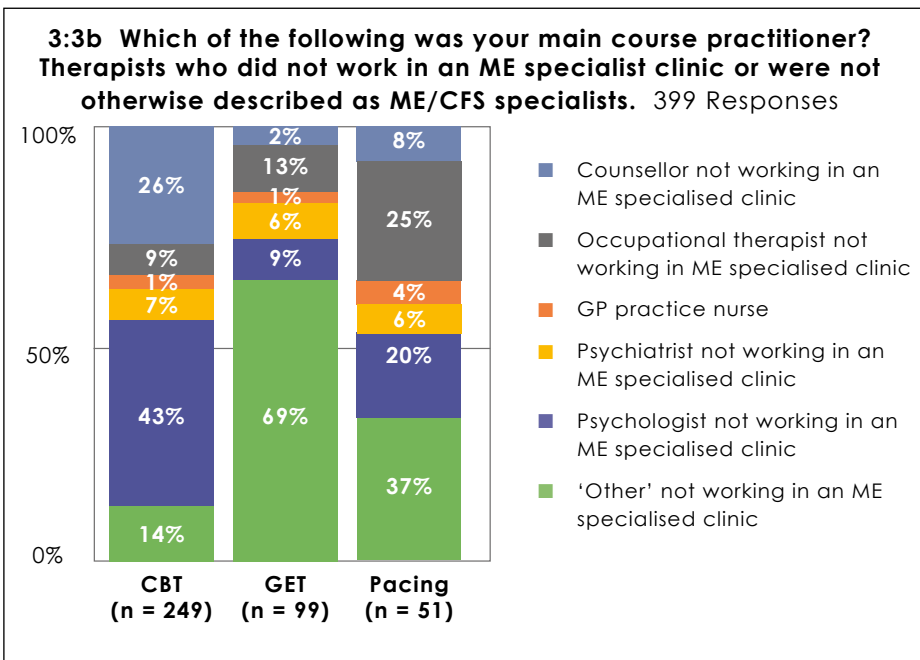
- 46% had courses held by therapists stated to have an ME/CFS specialism
- 54% had courses held by therapists not stated to have an ME/CFS specialism

222 respondents who had taken a GET course answered this question:

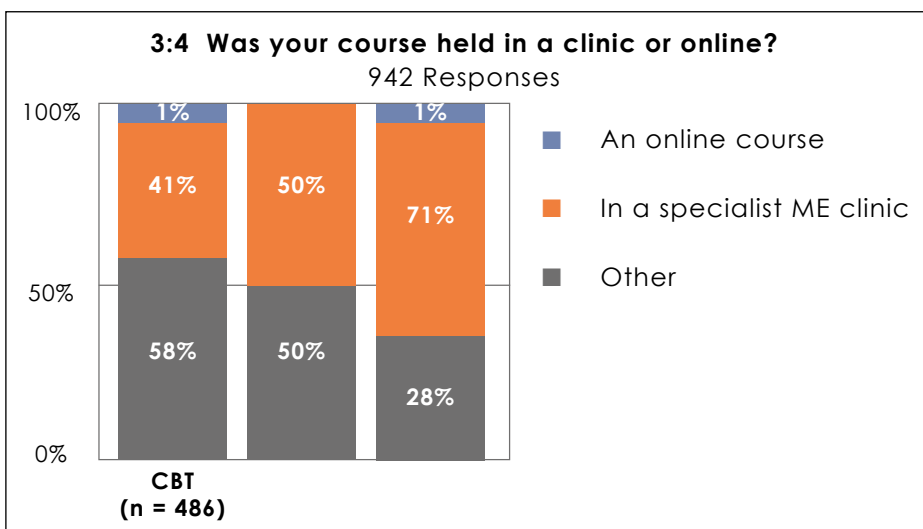
- 55% had courses held by therapists stated to have an ME/CFS specialism
- 45% had courses held by therapists not stated to have an ME/CFS specialism

218 respondents who had taken a Pacing course answered this question:

- 77% had courses held by therapists stated to have an ME/CFS specialism
- 23% had courses held by therapists not stated to have an ME/CFS specialism



2:3:4 Was your course held in a clinic or online?



A total of only 10 respondents reported they had taken an online course and only 1 of them reported taking an online course for GET.

2:3:5 Geographically, where did the course take place?

This question was asked to ensure that there was a wide geographical spectrum of responses.

Cognitive Behavioural Therapy – CBT

There were 453 responses to this question of which 356 responses (79%) gave details of hospitals, clinics and surgeries in a total of 156 cities, towns, counties or countries in the UK (the 58 courses being held in London Boroughs being included as taking place in one city).

There were 9 non UK courses and 4 online courses.

Other responses just said e.g. 'At home', 'In hospital', 'At my GP

surgery', 'in a private clinic' or, in 5 responses, gave no real indication.

Graded Exercise Therapy – GET

There were 209 responses to this question of which 167 responses (80%) gave details of hospitals, clinics and surgeries in a total of 84 cities, towns, counties or countries in the UK (the 34 courses being held in London Boroughs being included as taking place in one city).

There were 4 non UK courses.

Other responses just said e.g. 'At home', 'In hospital', 'At my GP surgery', 'in a private clinic' or, in 10 responses, gave no real indication.

Pacing

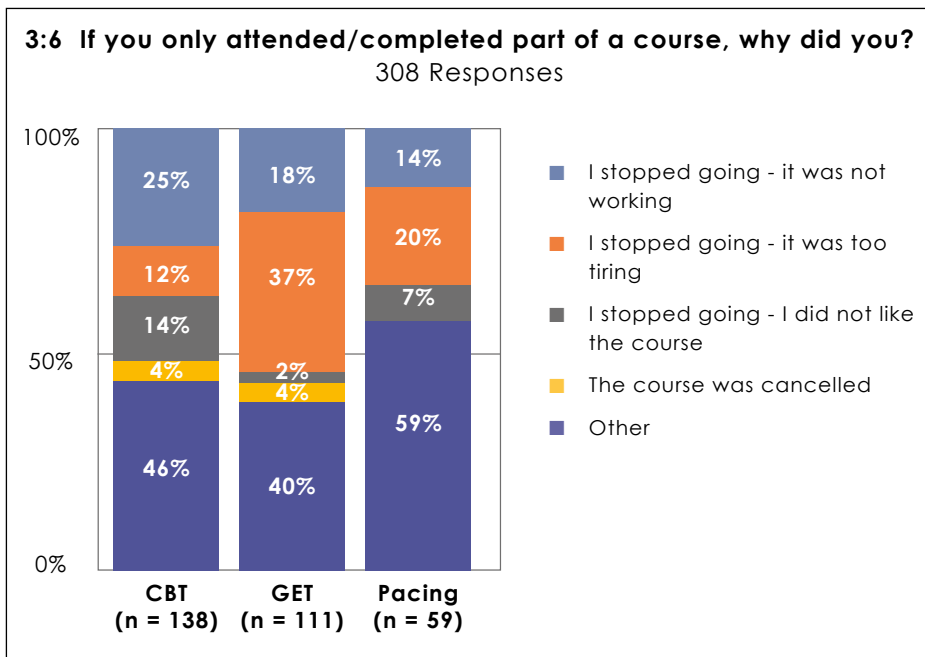
There were 210 responses to this question of which 183 responses (87%) gave details of hospitals, clinics and surgeries in a total of 90 cities, towns, counties or countries in the UK (the 16 courses being held in London Boroughs being included as taking place in one city).

There were 4 non UK courses and 3 online courses.

Other responses just said e.g. 'At home', 'In hospital', 'At my GP surgery', 'in a private clinic' or, in 7 responses, gave no real indication.

2:3:6 If you only attended/completed part of a course, why did you?

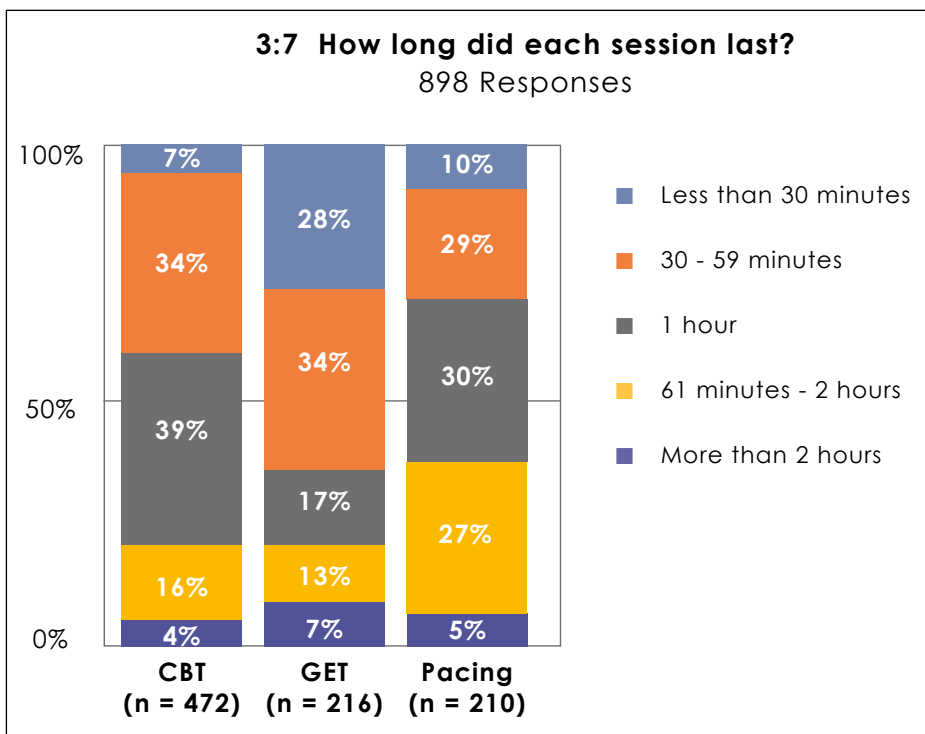
Note: Some of the qualitative responses in Appendix 1 indicate that a course was ongoing at the time of the survey.



CBT course comment:

Extract: "The session went on for over 2 hours, by which time I was feeling absolutely awful. The group setting also made me uncomfortable, I arrived and found myself sat in a circle of people I'd never met before and was expected to openly announce to the group who I was and my diagnosis (and 'how it made me feel emotionally') and a brief medical history. I found this really intrusive and uncomfortable and did not enjoy the process at all."

2:3:7 How long did each course session last?



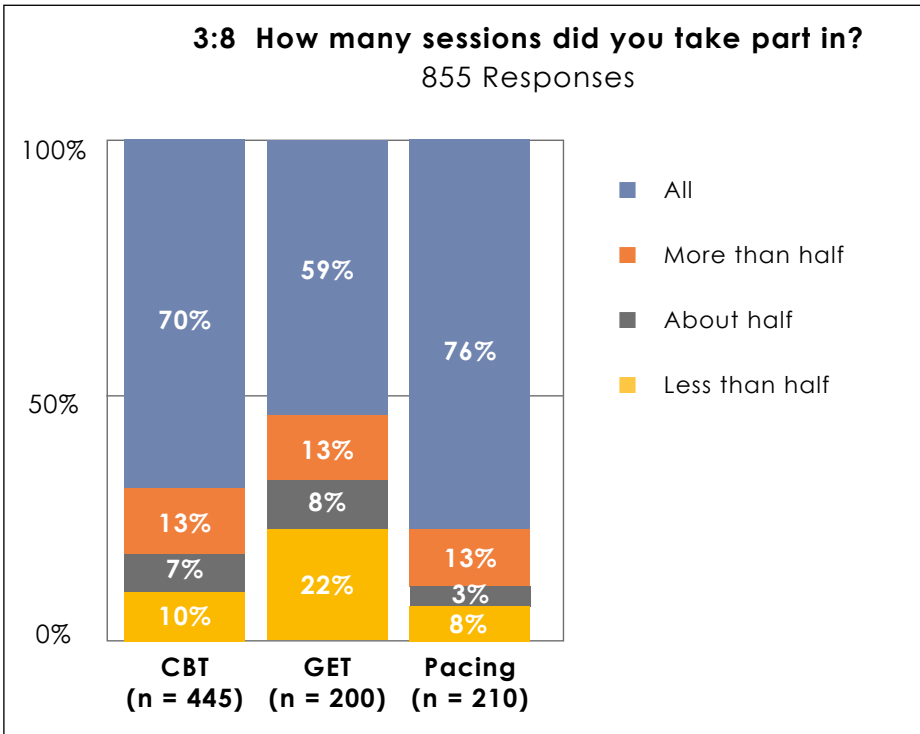
Example comments:

"Totally inappropriate. Two hours a week in a group setting totally exhausted me."

"So I went to see her for quite a long time for sometimes very long sessions (up to 2 hours) and ended up making myself much more ill for her to tell me that there was actually no point in going."

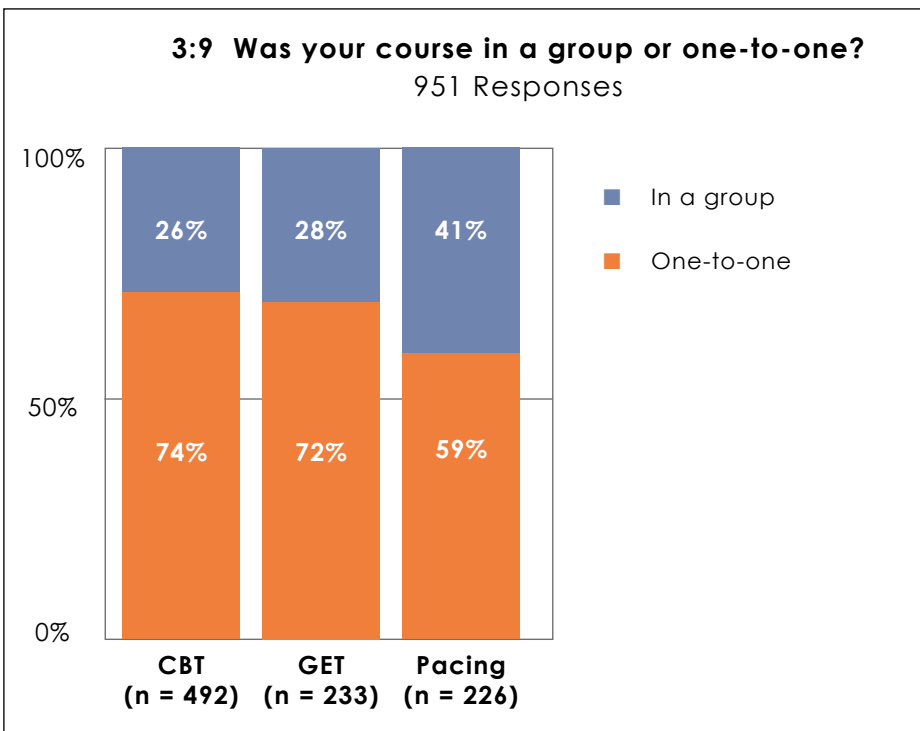


2:3:8 How many course sessions did you take part in?



Note: In another question, respondents were asked whether they attended an entire course or part of a course. The percentages given in that that answer are slightly different to these percentages and are reflected in 3:12.

2:3:9 Was your course in a group or one to one?



Example comments:

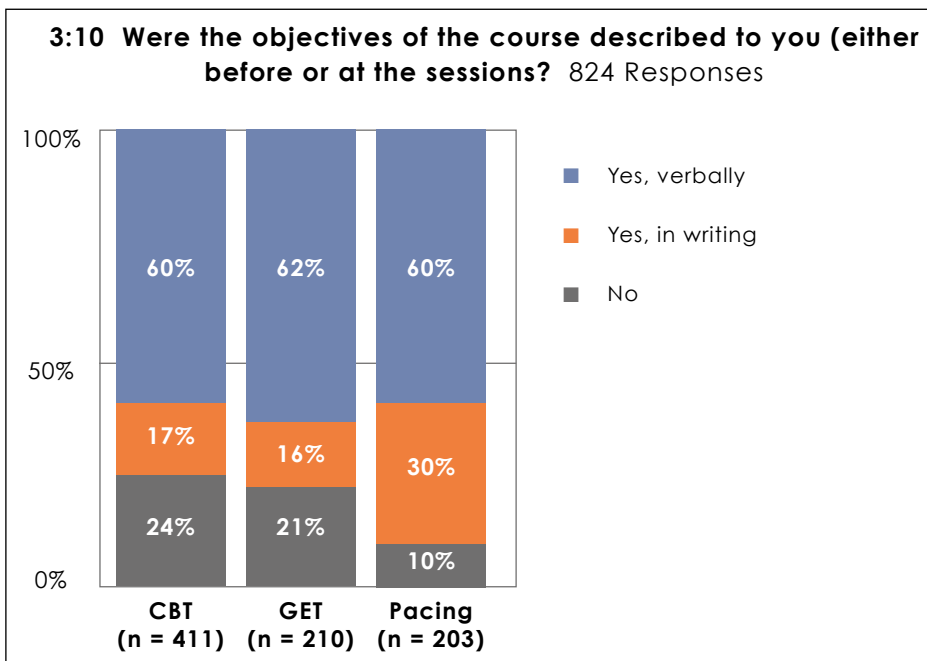
“It was helpful to meet with others who were having similar health experiences and share ideas, but in practice the ideas suggested weren't very practical as classes can vary so much and be unpredictable.”

“It was a ‘one size fits all’ course, not in any way tailored to the patients”.

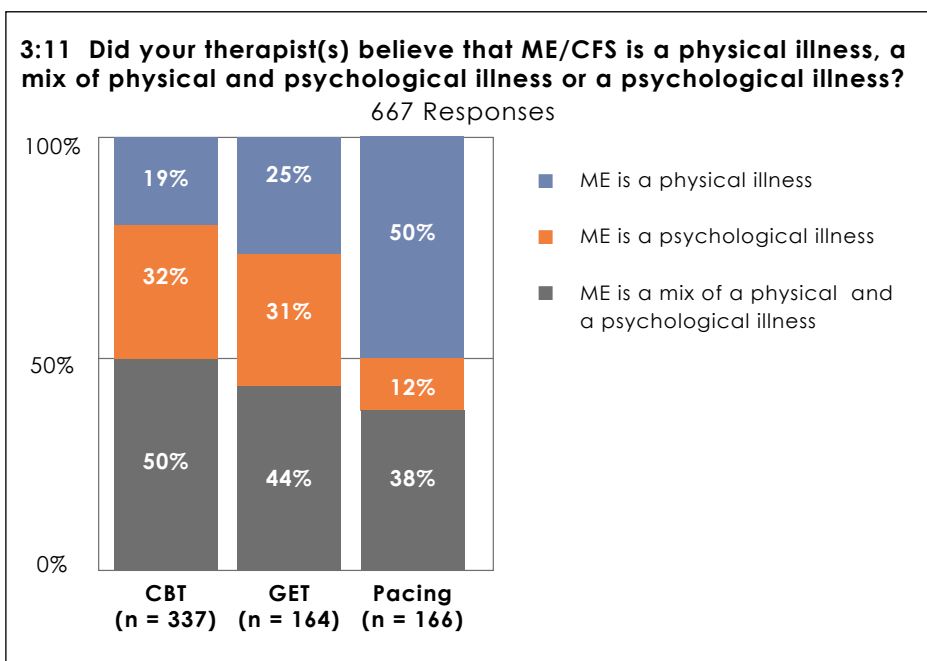
“I found the last half hour very beneficial when we had coffee and talked amongst ourselves hearing others' way of dealing with things and to know I was not alone in the way I was thinking, the amount of us who had all had a virus and can pin point the beginning of our restricted life”.



2:3:10 Were you given information about the course?



2:3:11 Did your therapist believe that ME/CFS is a physical illness, a mix of a physical and psychological illness, or a psychological illness?



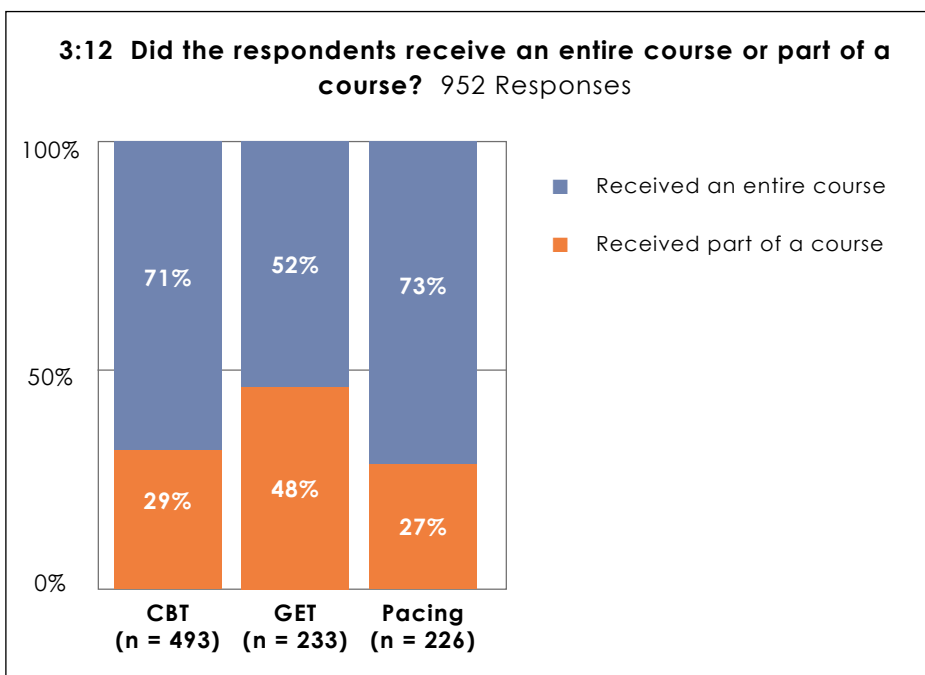
Example comments:

"I found the constant focus that ME is a psychological illness and it being implied that I was depressed and that is what had caused it was very unhelpful (any mild depression was because I was ill and I couldn't get any real help to get better and not the cause)."

"At no stage did the hospital suggest that CBT was because ME was "psychological or somatic or a functional illness". They made it very clear that it was used as a means of helping people cope with the impact mentally and emotionally of a chronic and life altering illness and the 'loss' of your life and how you saw yourself as a result of illness."



2:3:12 Did you receive an entire course or part of a course?



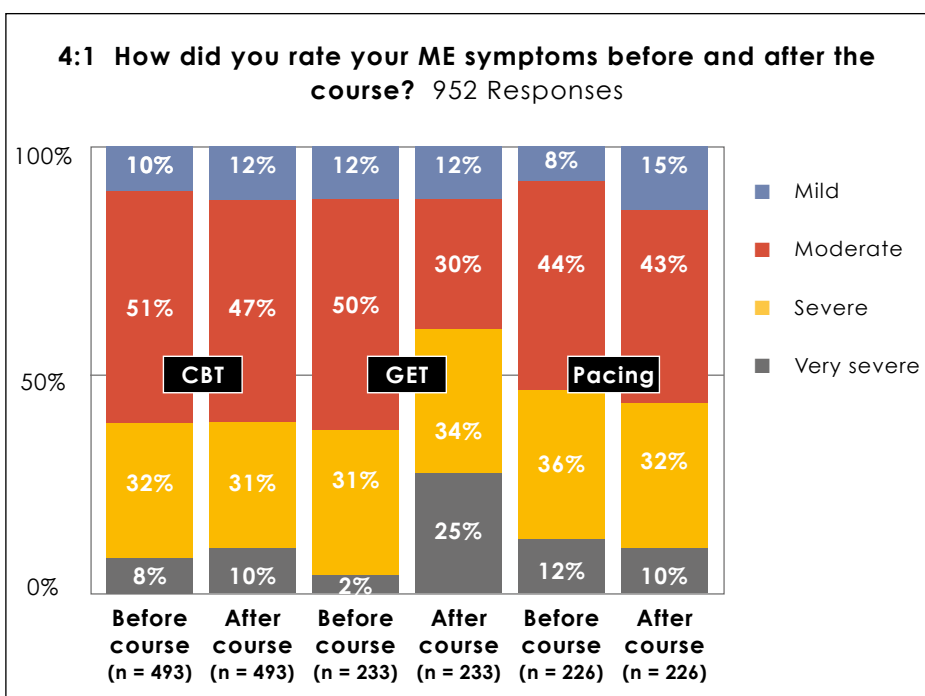
Options were given for respondents to state whether they had received an entire course, more than one course, or part of a course. If they had received more than one course they were asked to choose the one they would most like to report on and then complete that section of the survey, thinking about that course only.

2:4 EFFECT OF COURSES ON ME/CFS SYMPTOMS

Notes:

a) In total only 7 respondents felt so much better that they considered themselves well: 2 (0.4%) following a CBT course, 2 (0.9%) following a GET course and 3 (1.3%) following a Pacing course. In the charts in Appendix 2, these results have been

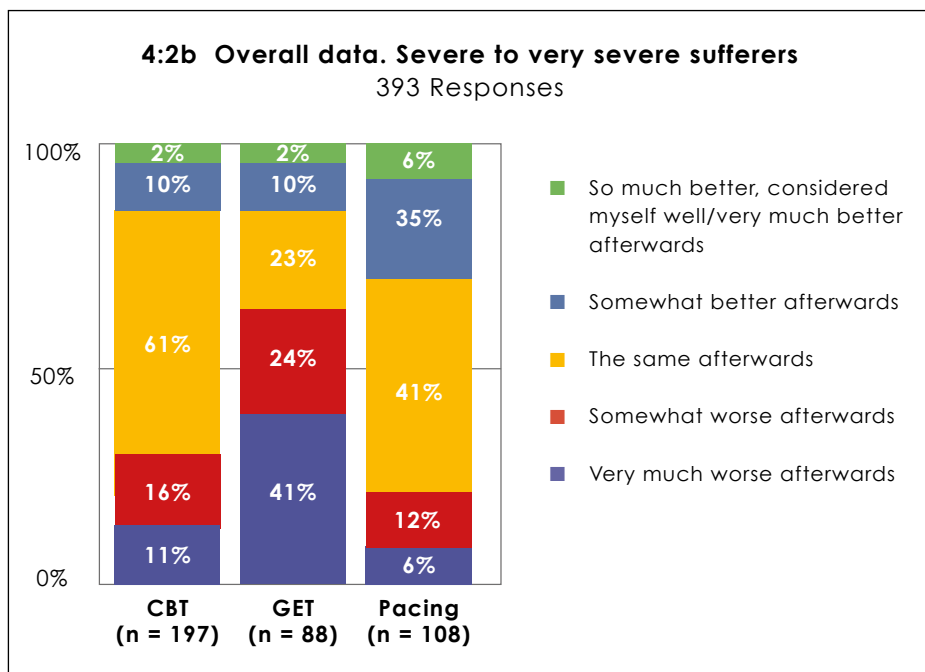
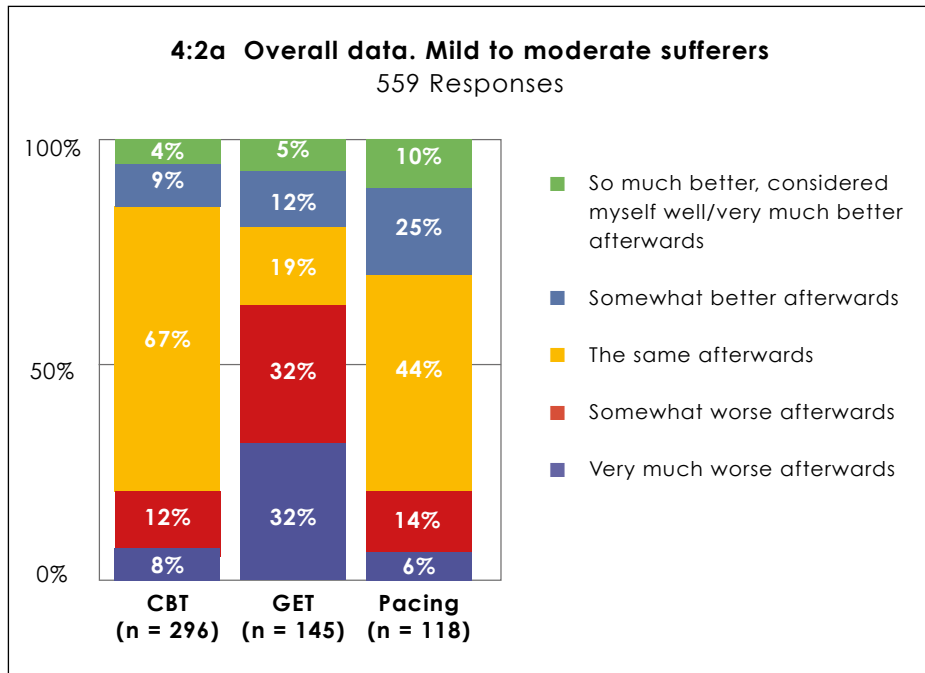
amalgamated with those who considered themselves very much better.
 b) Degrees of illness severity in 4:2 – 4:11 are that stated to have applied before courses began.
 c) We have split the data in 4:2 to 4:10 to show the effect of courses on mild to moderate sufferers and severe to very severe sufferers.



2:4:1 Did the degree of severity of your ME/CFS symptoms alter after your course?



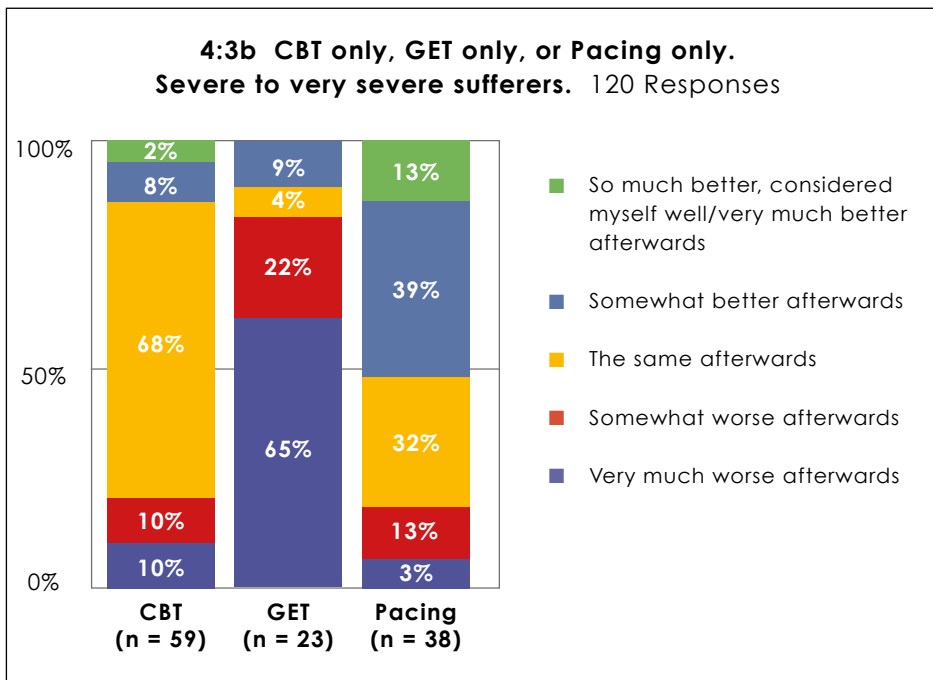
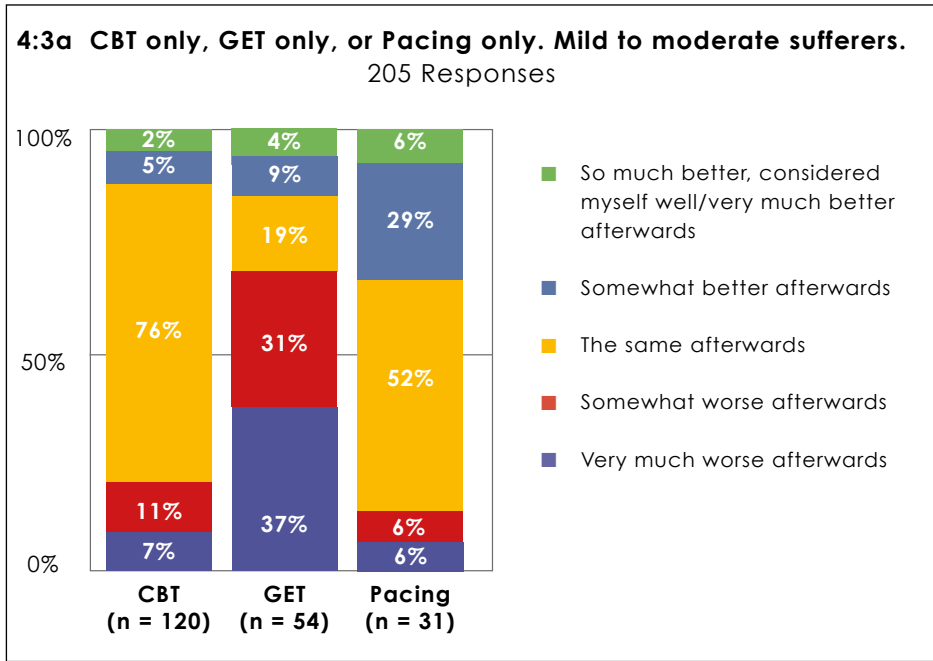
2:4:2 Overall, (irrespective of the Listed Criteria) how were your ME/CFS symptoms after the course compared to how they were before?



2:4:3 Overall, how were your ME/CFS symptoms after the course compared to how they were before? Courses which were CBT only, GET only or Pacing only.

■ See 3:1 above and Key Finding 3:4:2a.

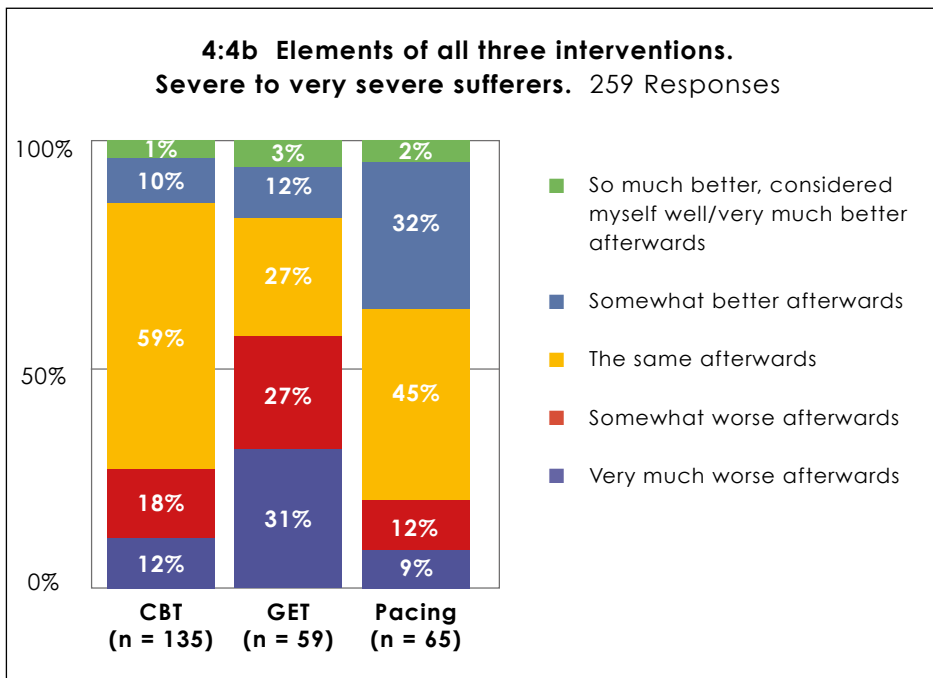
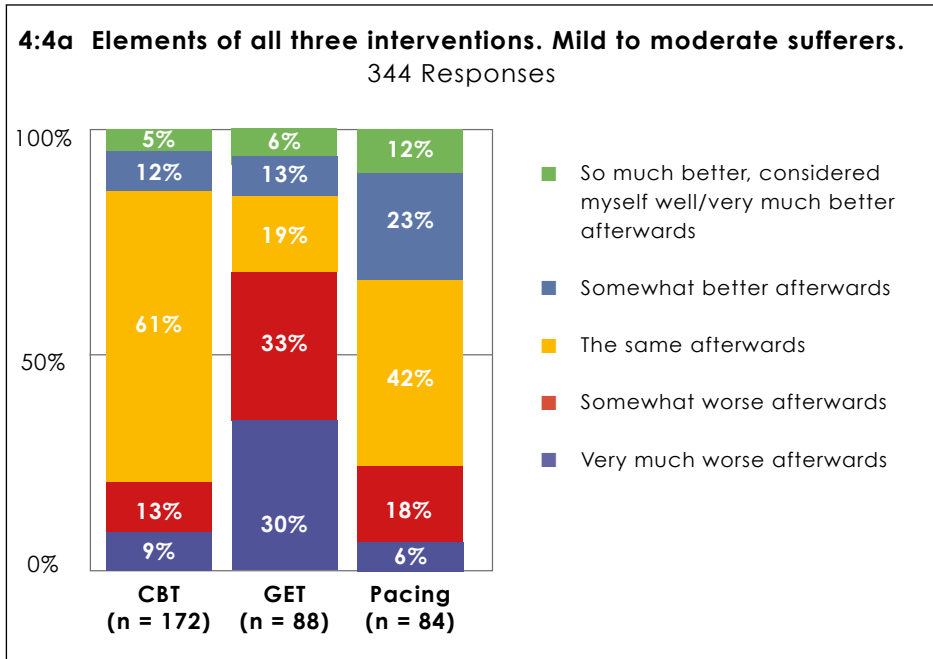
37% CBT, 34% GET and 32% Pacing courses were stated by respondents to have no overlaps.



2:4:4 Overall, how were your ME/CFS symptoms after the course compared to how they were before? Courses which had elements of all 3 interventions.

■ See 3:1 above and Key Finding 3:4:3a.

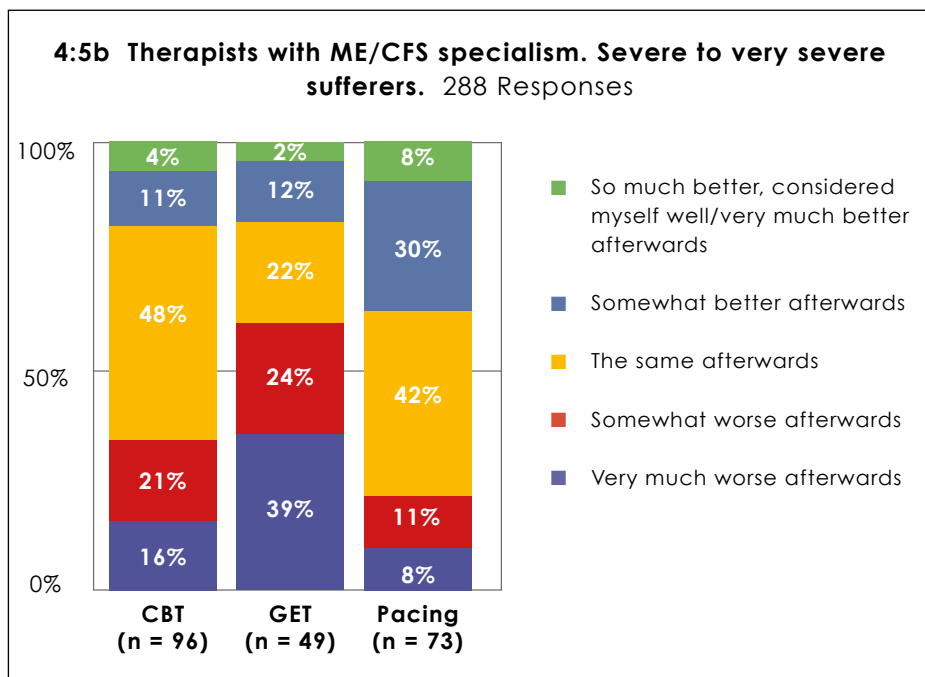
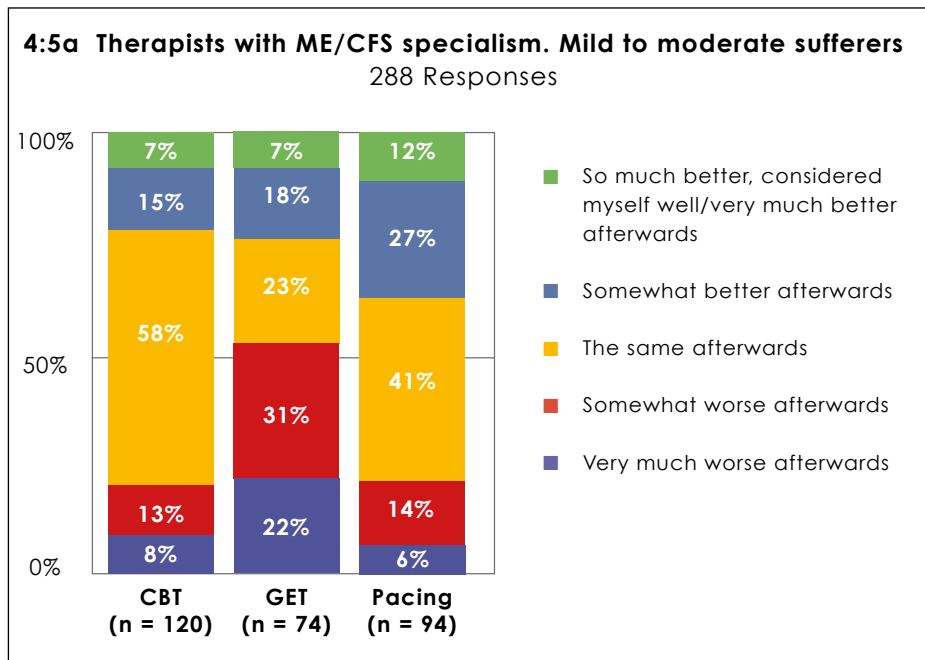
33% CBT, 36% GET and 37% Pacing courses were stated by respondents to have elements of all three interventions. Appendix 3 gives examples.



2:4:5 Overall, how were your ME/CFS symptoms after the course compared to how they were before? Courses run by therapists stated an ME/CFS specialism.

■ See 3:3a. and b. above and Key Finding 3:4:5a.

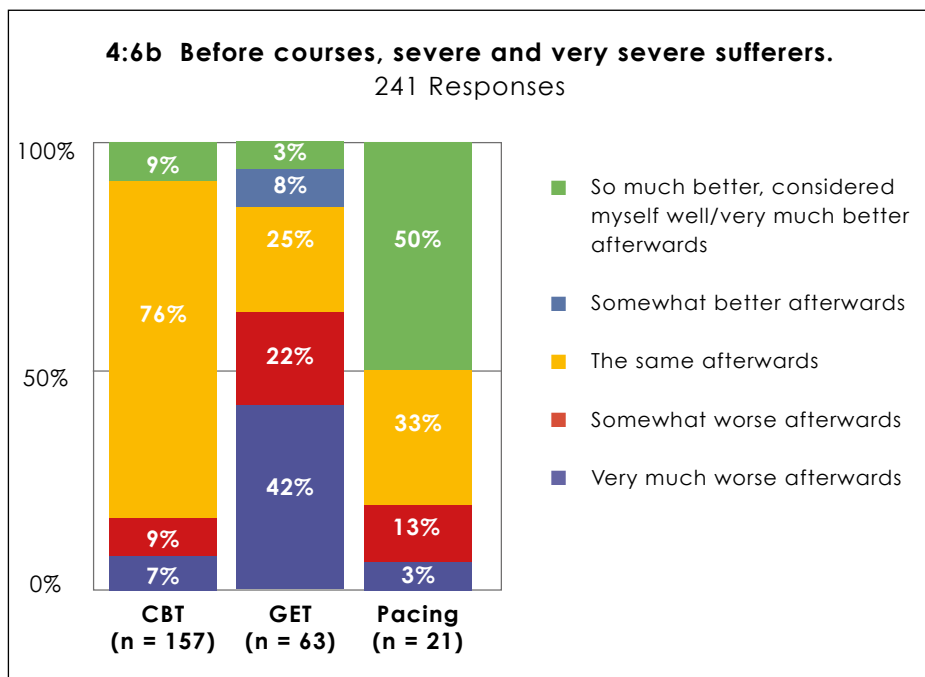
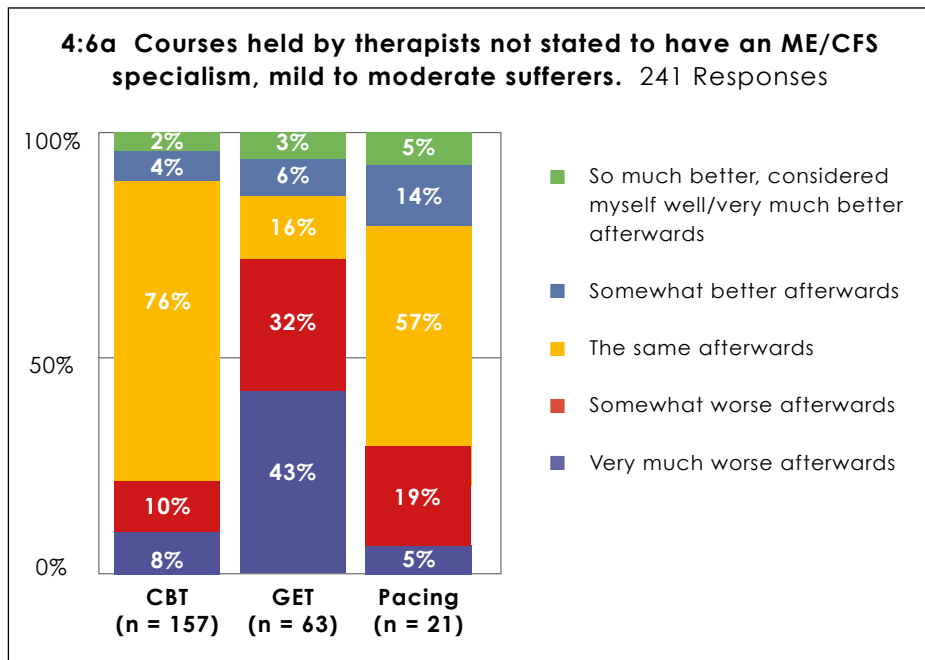
46% CBT, 55% GET and 77% Pacing therapists were stated to have an ME/CFS specialism.



2:4:6 Overall, how were your ME/CFS symptoms after the course compared to how they were before? Courses held by therapists not stated to have an ME/CFS specialism.

■ See 3:3a and 3:3b above and Key Finding 3:4:6a.

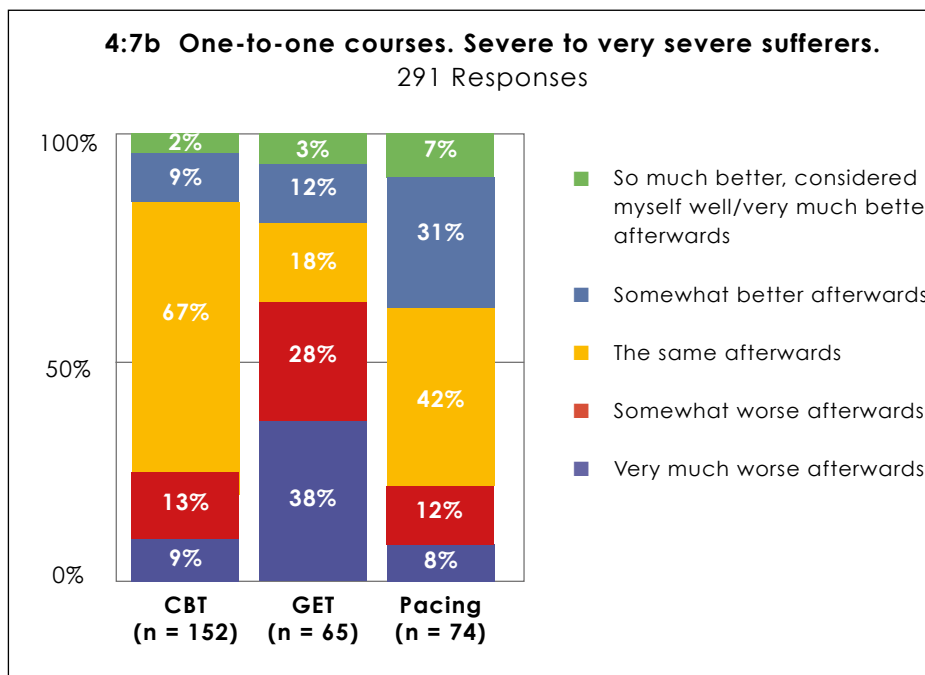
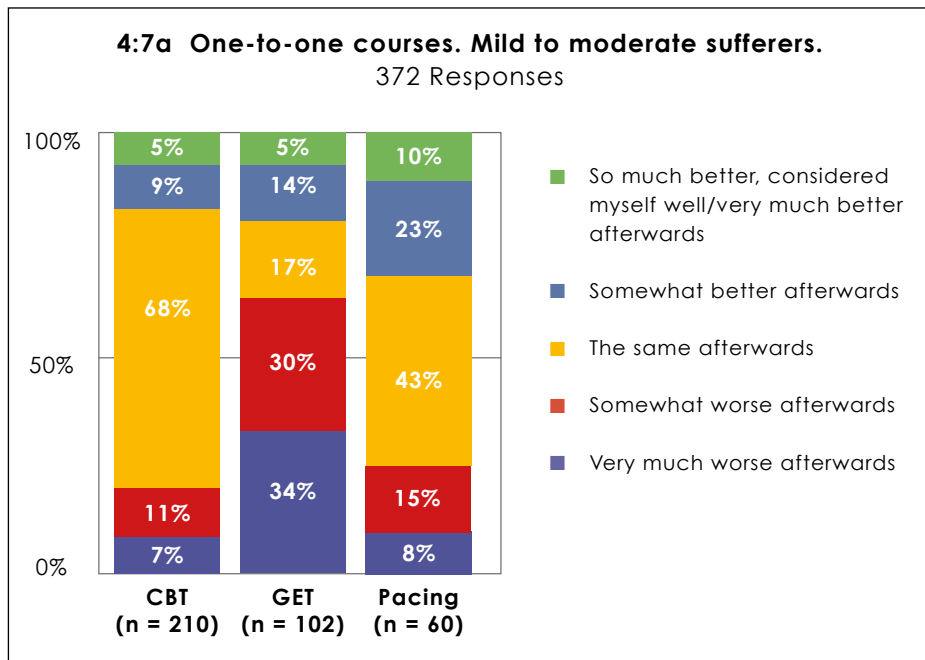
54% CBT, 45% GET and 23% Pacing therapists were not stated to have an ME/CFS specialism.



2:4:7 Overall, how were your ME/CFS symptoms after the course compared to how they were before? One-to-one courses.

■ See 3:9 above and Key Finding 3:4:7a.

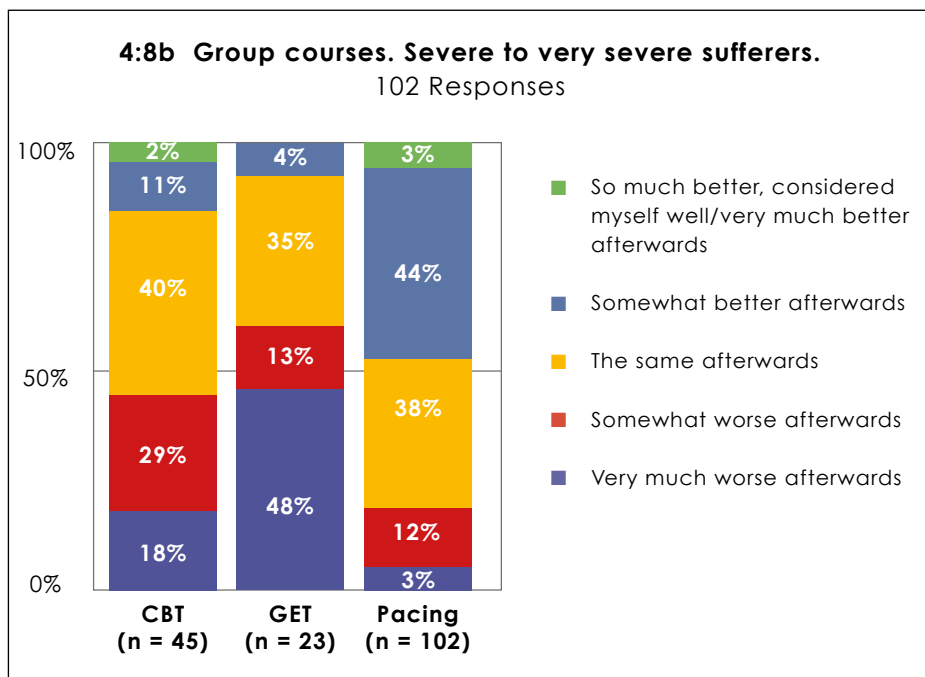
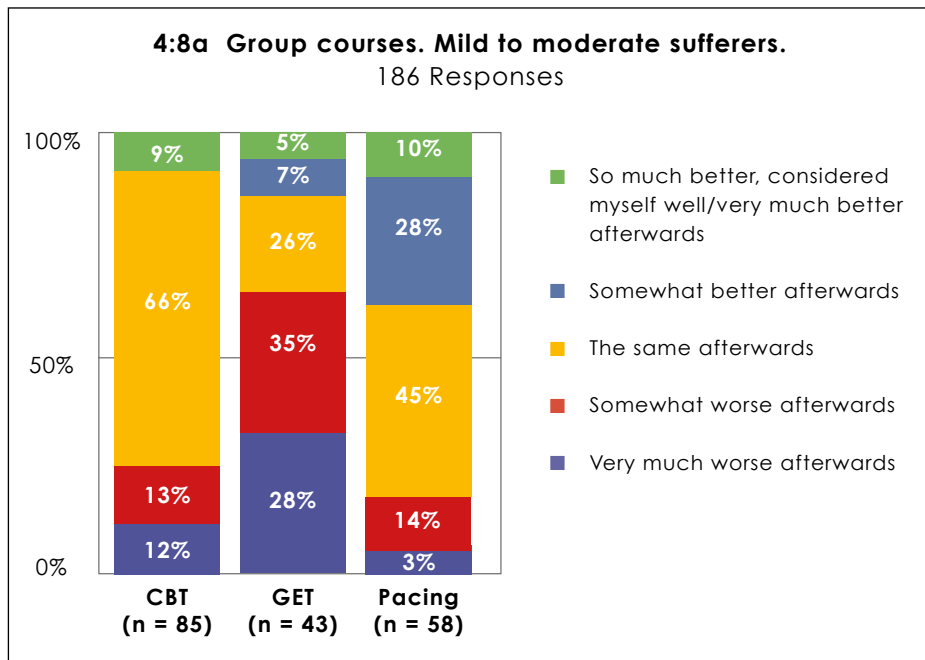
74% CBT, 72% GET and 59% Pacing courses were one-to-one.



2:4:8 Overall, how were your ME/CFS symptoms after the course compared to how they were before? Group courses.

■ See 3:9 above and Key Finding 3:4:8a.

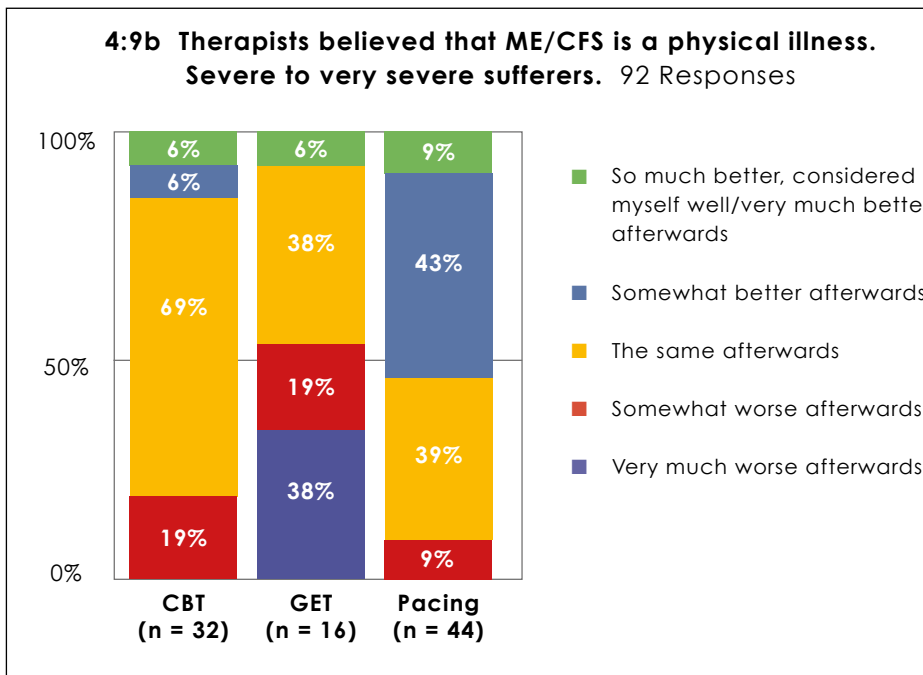
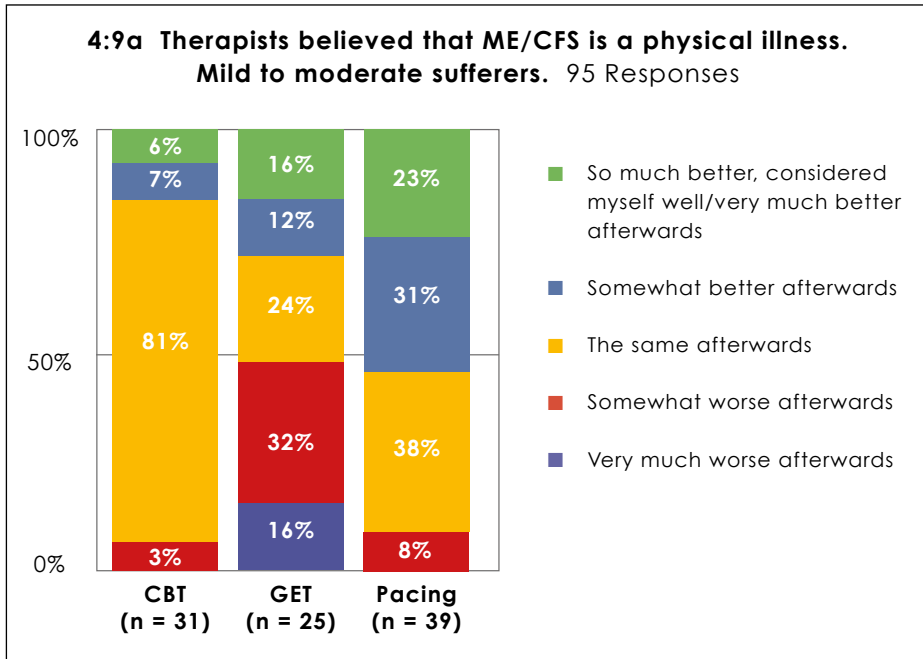
26% CBT, 28% GET and 59% Pacing courses were held in groups.



2:4:9 Overall, how were your ME/CFS symptoms after the course compared to how they were before? Courses where therapists who believed that ME/CFS is a physical illness.

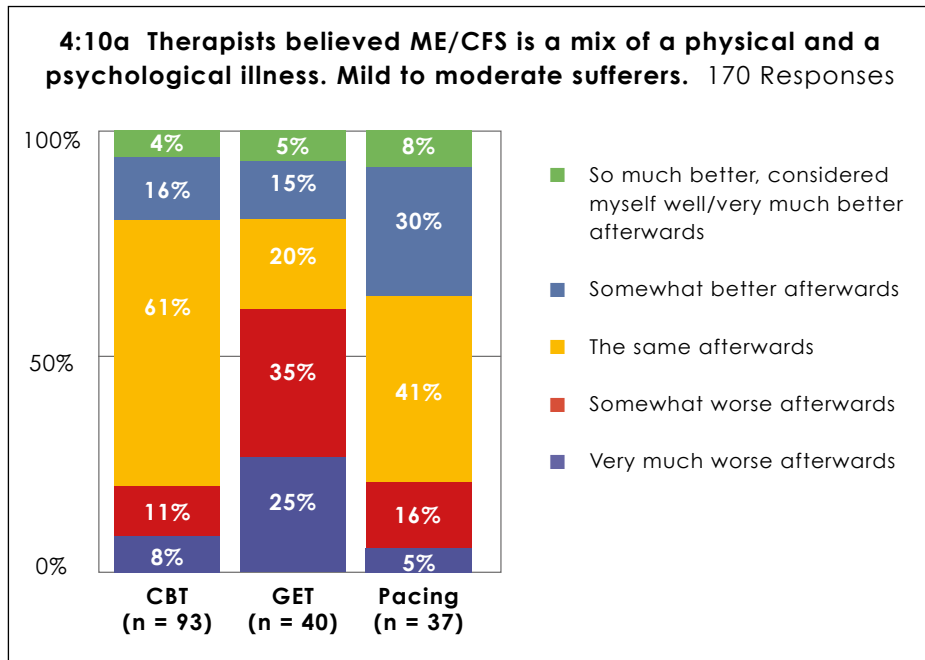
■ See 3:11 above and Key Finding 3:4:9a.

19% CBT, 25% GET and 50% Pacing course respondents said that their course therapists believe that ME/CFS is a physical illness.

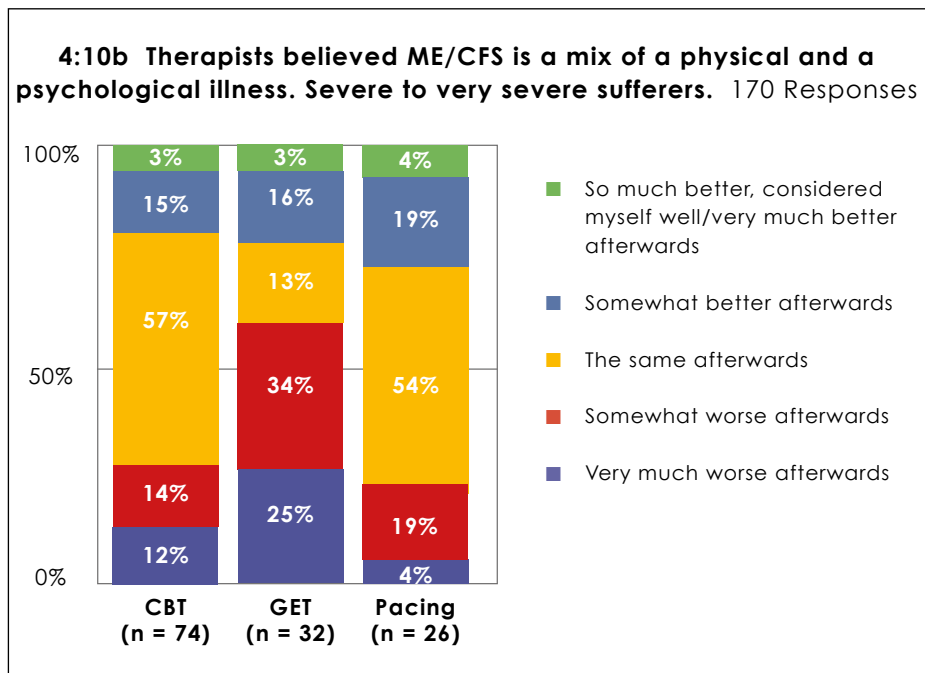


2:4:10 Overall, how were your ME/CFS symptoms after the course compared to how they were before? Courses where therapists believed that ME/CFS is a mixture of a physical and a psychological illness.

■ See 3:11 above and Key Finding 3:4:10a.

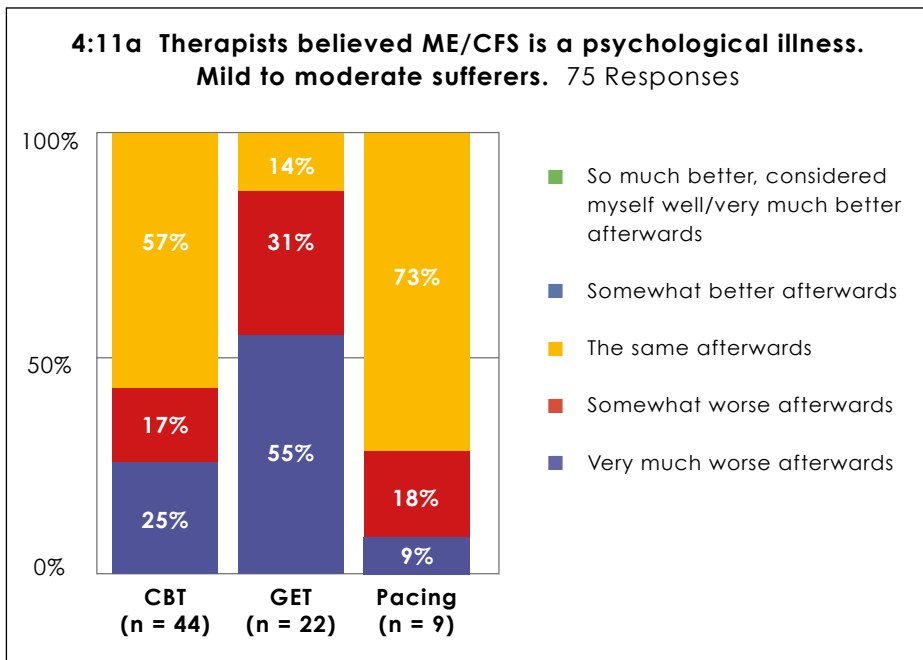


50% CBT, 44% GET and 38% Pacing course respondents said that their course therapists believe that it is a mixture of a physical and a psychological illness.



2:4:11 Overall, how were your ME/CFS symptoms after the course compared to how they were before? Courses where therapists believed that ME/CFS is a psychological illness.

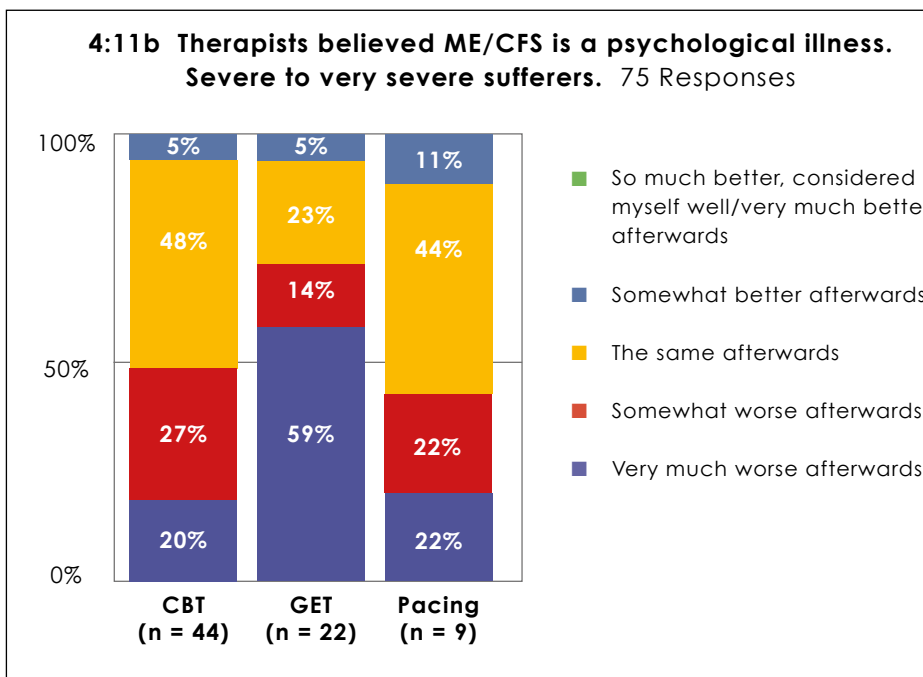
■ See 3:11 above and Key Finding 3:4:11a.



32% CBT, 31% GET and 12% Pacing course respondents said that their course therapists believe that it is a psychological illness.

Example comment:

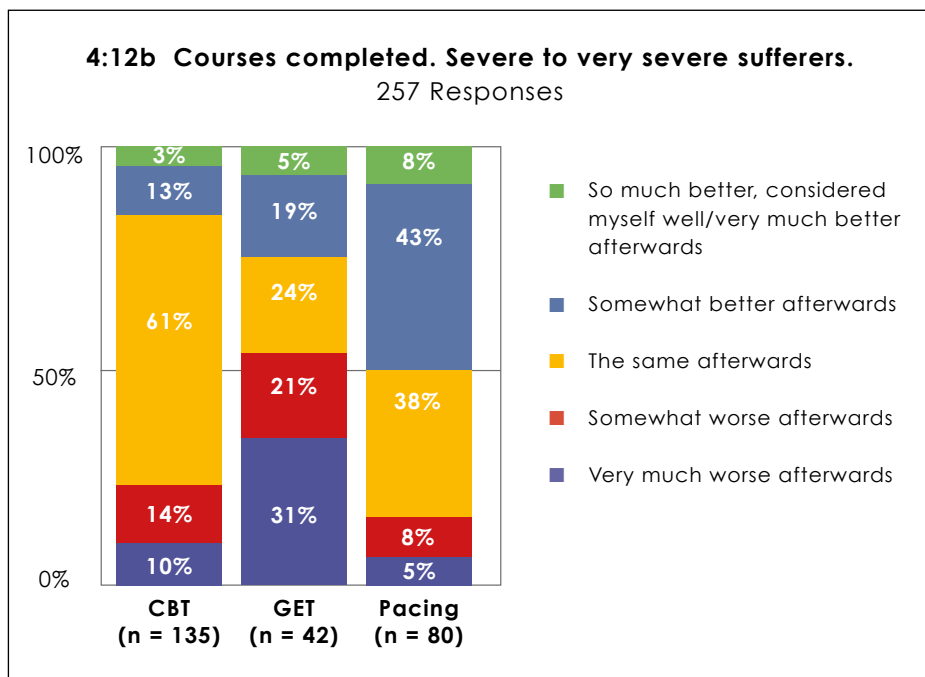
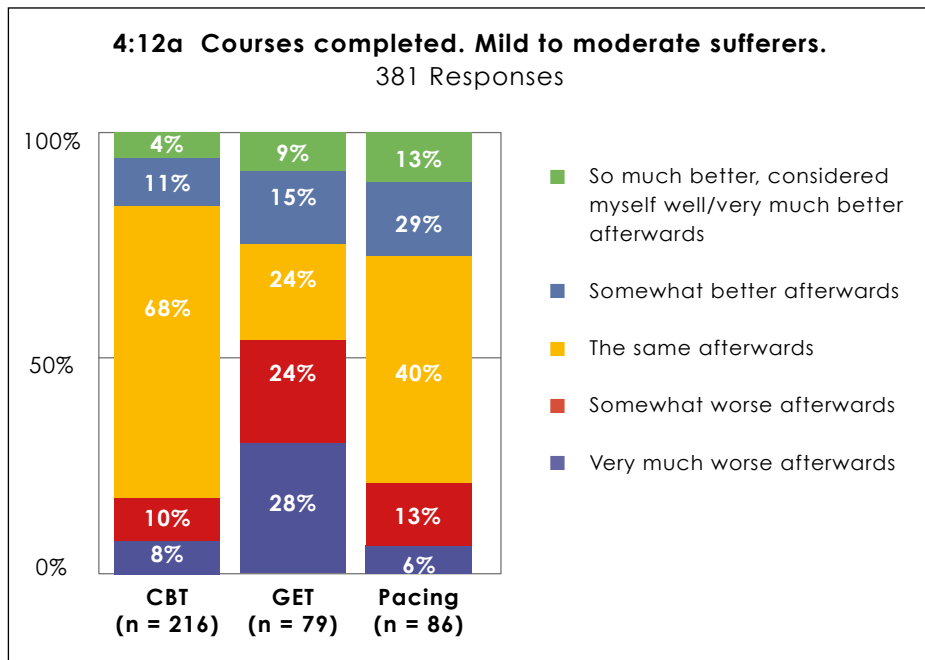
“I was told that my illness could be cured by positively thinking that I was not ill and I should use meditation and stress/anxiety relieving techniques to control my symptoms and carry on with work and normal activities as much as possible. I had to say to myself “I am not ill, this is just a passing phase, keep going, these symptoms are due to my thoughts, relax”. I was told that when I was not improving, but getting worse it was because I was not doing the relaxation exercises properly, or was not trying to tell myself that it was all in my mind. In other words it was my fault I was feeling so ill. Consequently I tried so hard to work and carry on that I eventually collapsed and was bed bound for over a year and so distressed because I thought it was all my fault and I must be mentally ill.”



2:4:12 Overall, how were your ME/CFS symptoms after the course compared to how they were before? Courses completed by respondents.

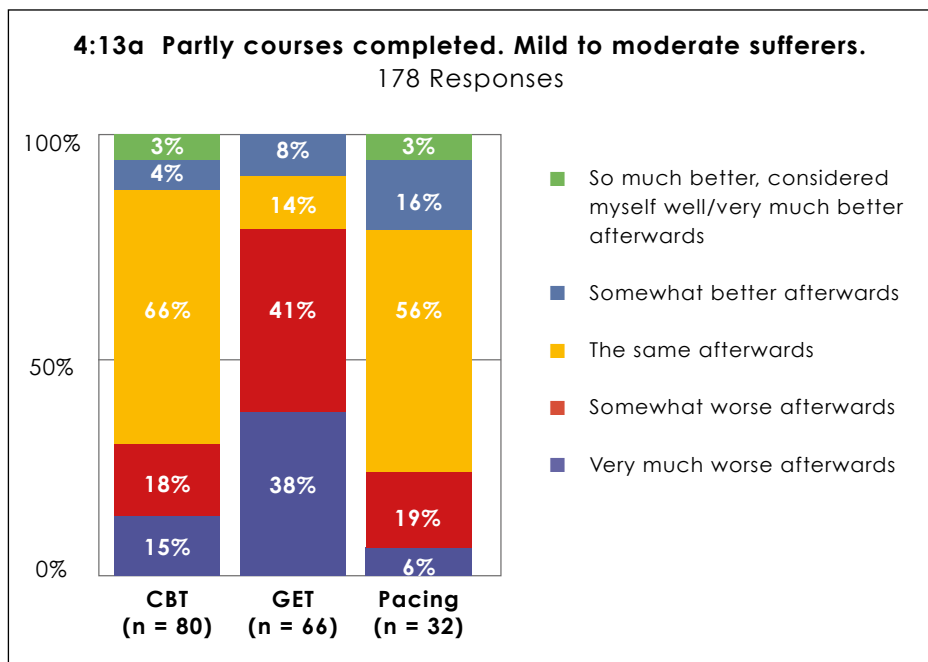
■ See 3:12 above and Key Finding 3:4:13a.

71% of CBT, 52% of GET and 73% Pacing courses were attended in their entirety.



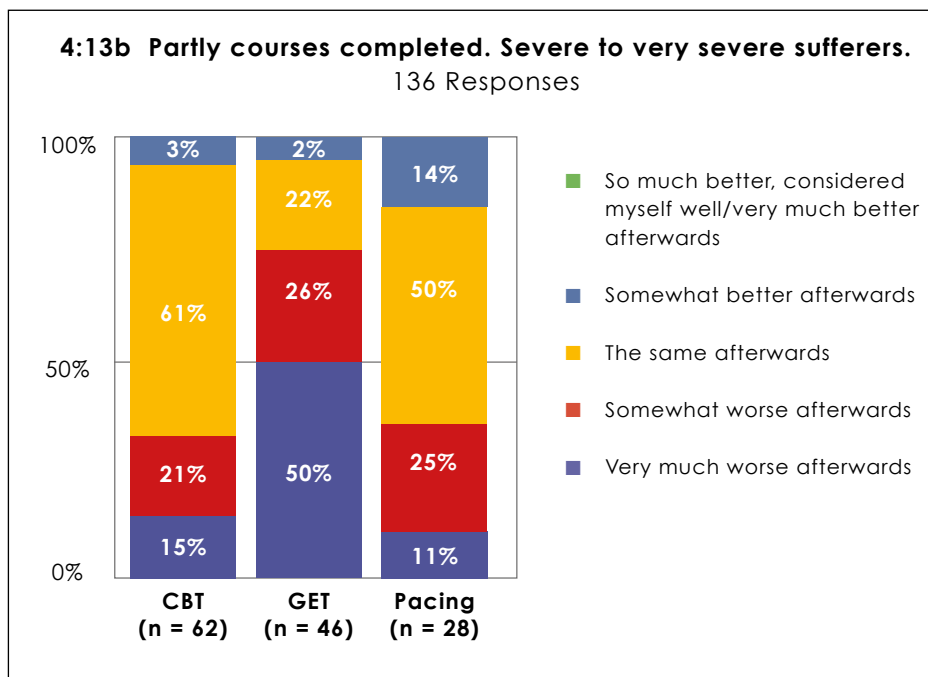
2:4:13 Overall, how were your ME/CFS symptoms after the course compared to how they were before? Courses partly completed by respondents.

■ See 3:12 above and Key Finding 3:4:14a.



29% of CBT, 48% of GET and 27% Pacing courses were only partly attended. Appendix 1 and Appendix 2 at 3:6 give some respondents' reasons for only attending parts of courses.

Of those respondents who answered the question 'How many sessions did you take part in?' (445 CBT, 200 GET and 210 Pacing respondents) 10% CBT, 22% GET and 8% Pacing patients attended less than half the course sessions (see 3:8 above).



2:5 COURSES APPROPRIATE TO NEEDS

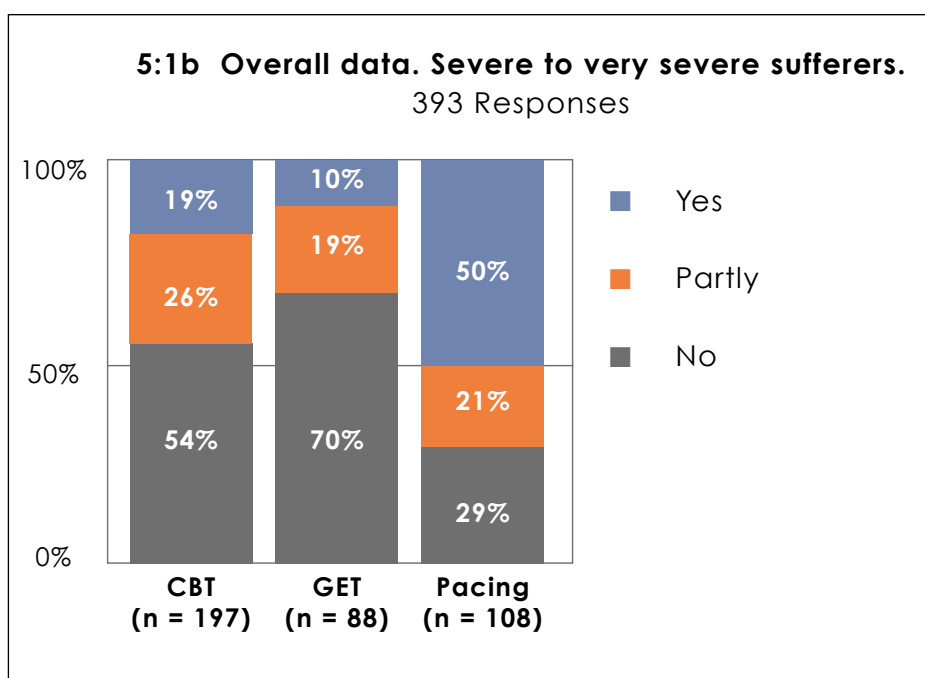
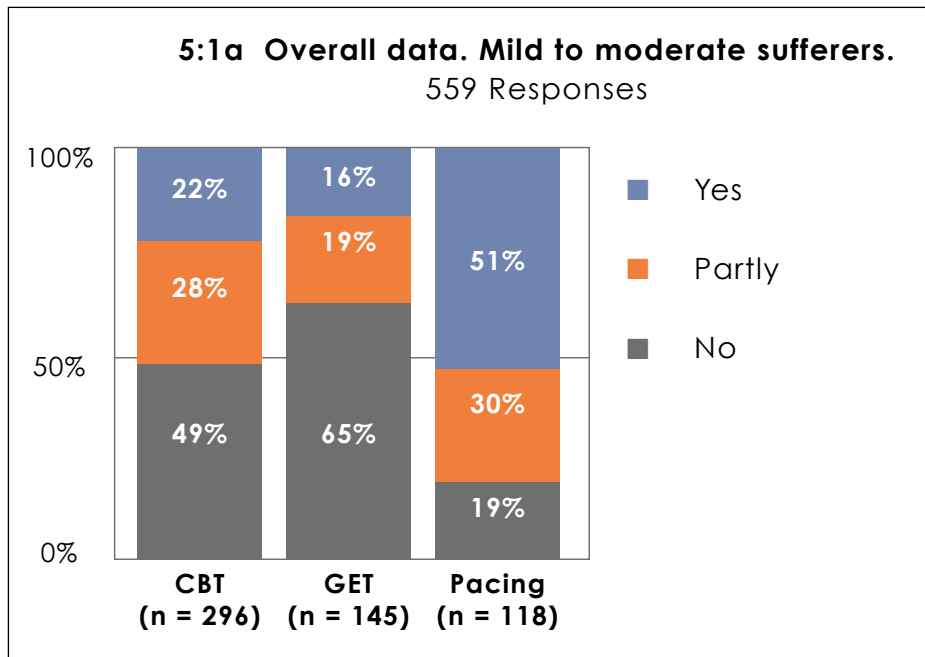
Notes:

a) The stated degree of severity of ME/CFS in questions 5:1 – 5:10 is that before courses.

b) In 5:1 to 5:10 we have split the data to show the effects of courses on mild to moderate sufferers and severe to very severe sufferers.

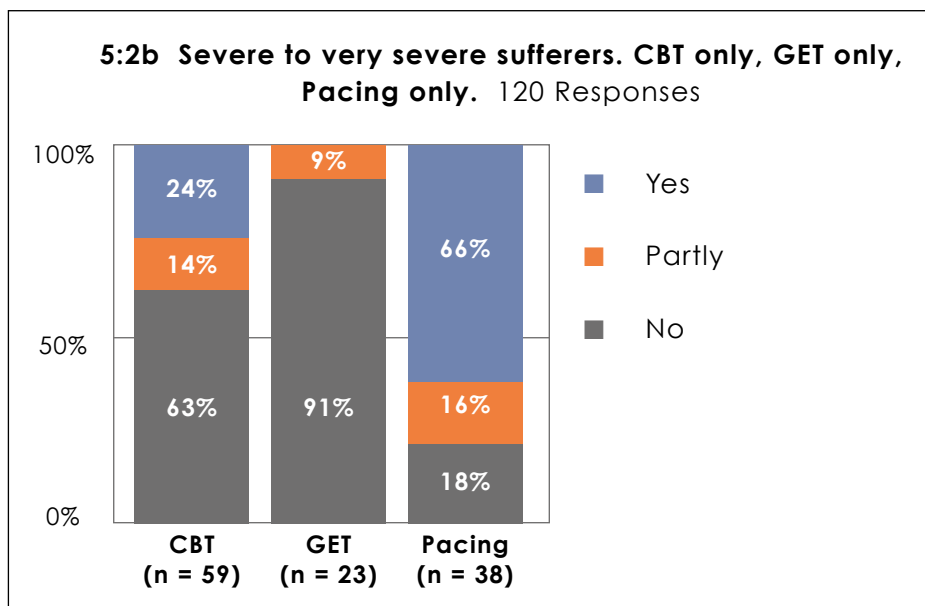
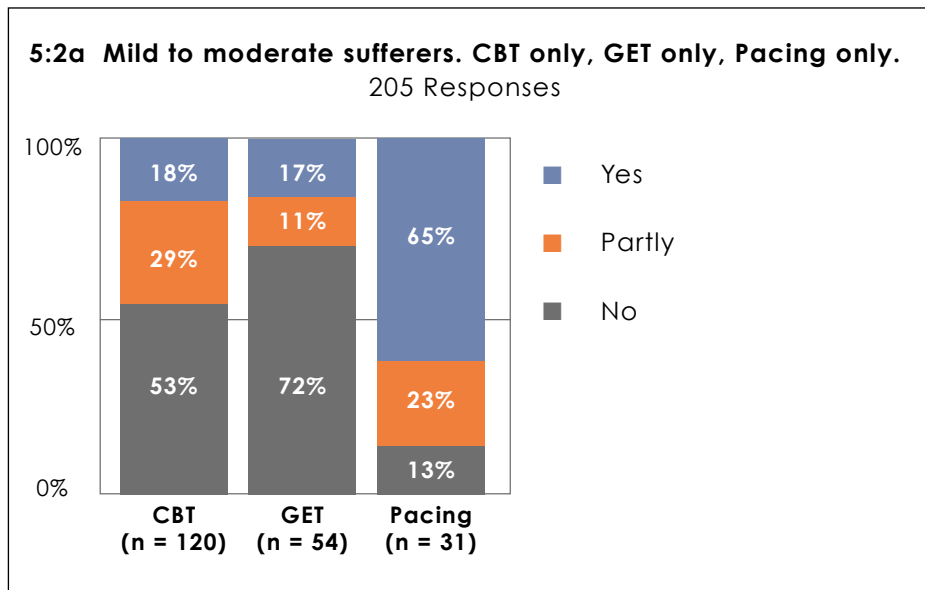
2:5:1 On balance, would you say that the course was appropriate to your needs? Overall data (i.e. irrespective of the Listed Criteria).

■ See Key finding 3:4:1b.



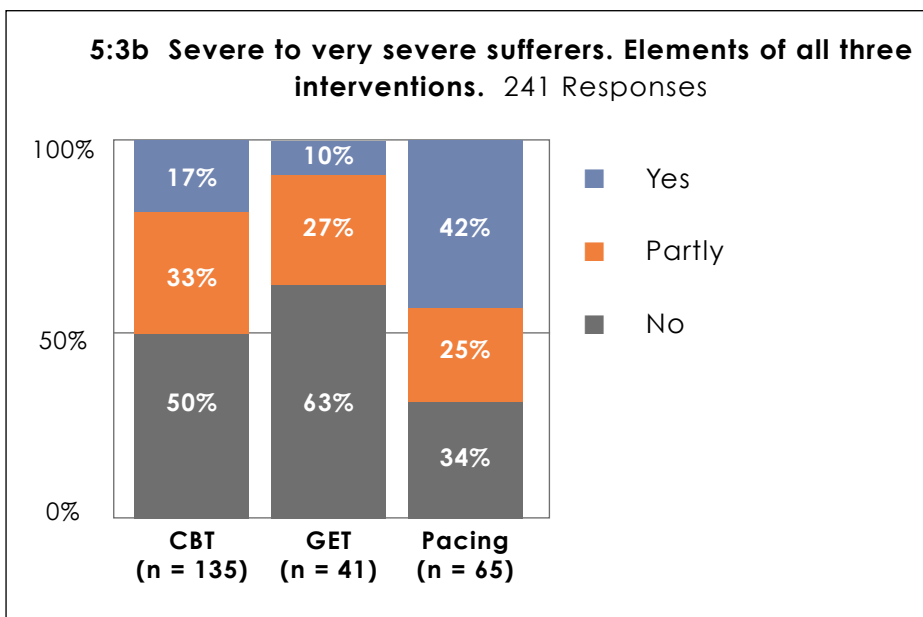
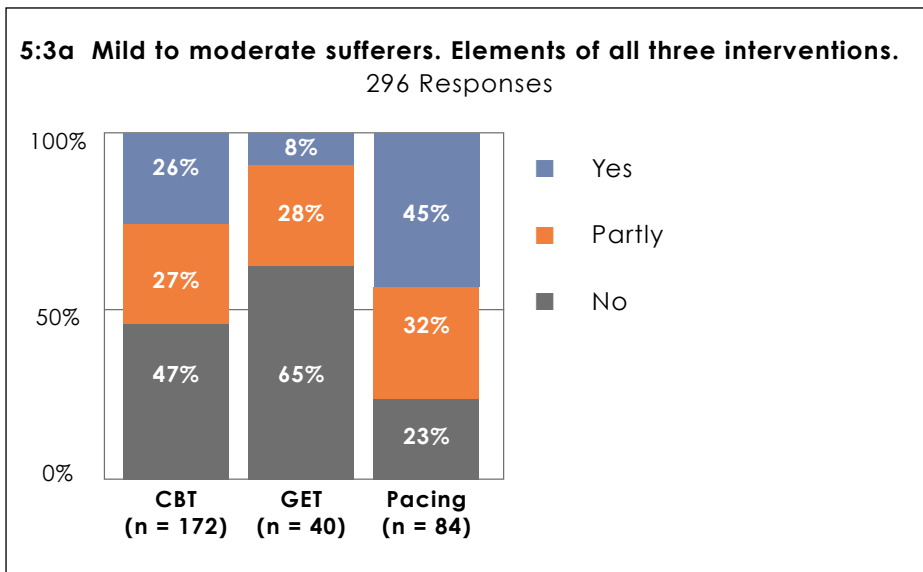
2:5:2 On balance, would you say that the course you received was appropriate to your needs? Courses which were CBT only, GET only, or Pacing only.

■ See 3:1 above and Key Finding 3:4:2b.



2:5:3 On balance, would you say that the course you received was appropriate to your needs? Courses which had elements of all three interventions.

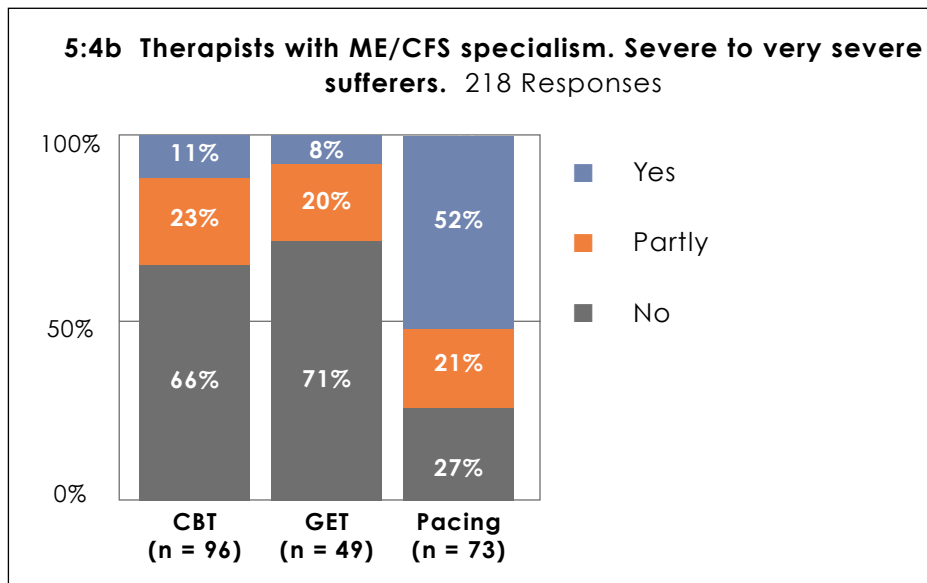
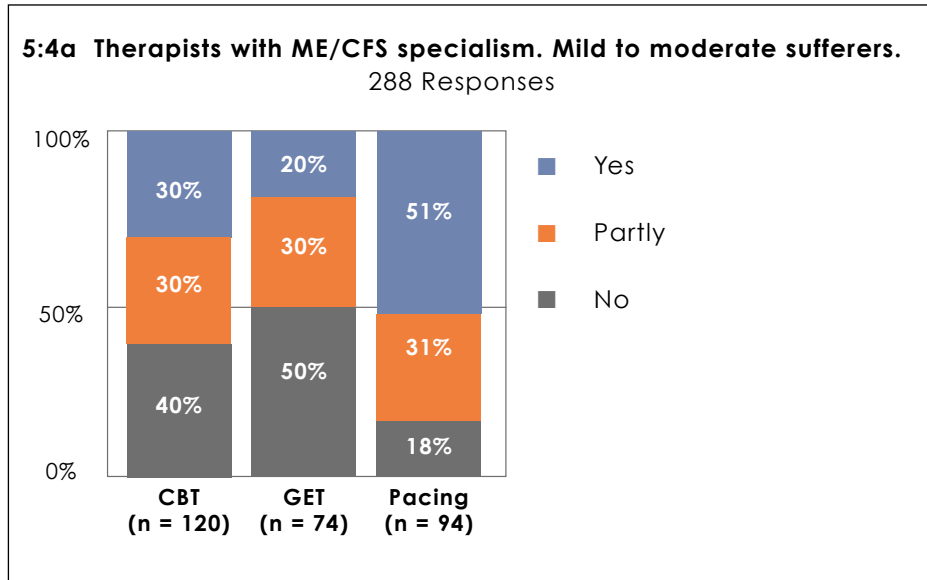
■ See 3:1 above and Key Finding 3:4:3b.



2:5:4 On balance, would you say that the course was appropriate to your needs? Courses which were held by therapists stated to have an ME/CFS specialism.

■ See 3.3a. and 3:3b. above and Key Finding 3:4:5b.

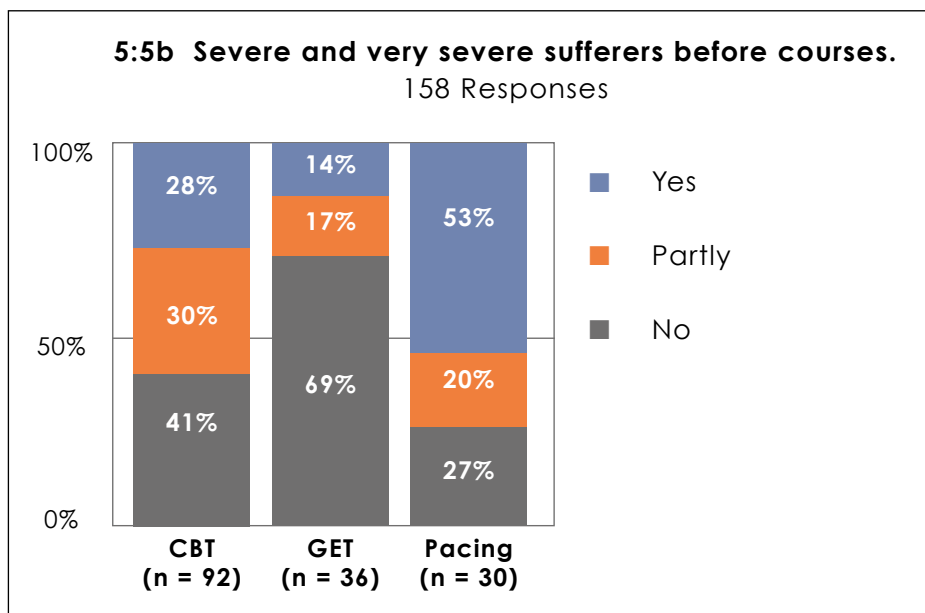
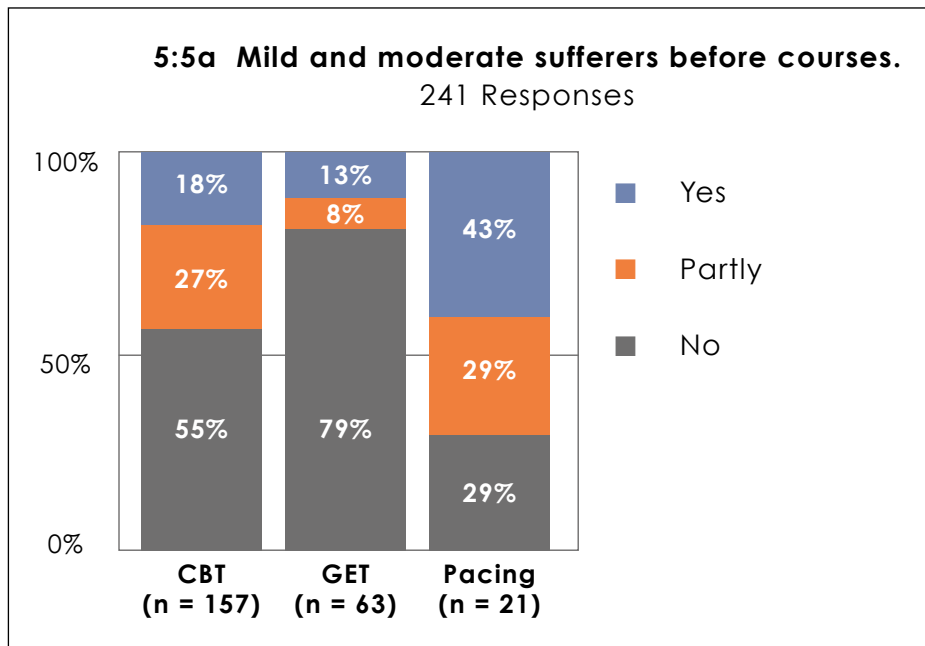
46% CBT, 55% GET and 77% Pacing therapists had an ME/CFS specialism.



2:5:5 Overall, how were your ME/CFS symptoms after the course compared to how they were before? Courses held by therapists not stated to have an ME/CFS specialism.

■ See 3:3a. and 3:3b. above and Key Finding 3:4:6b.

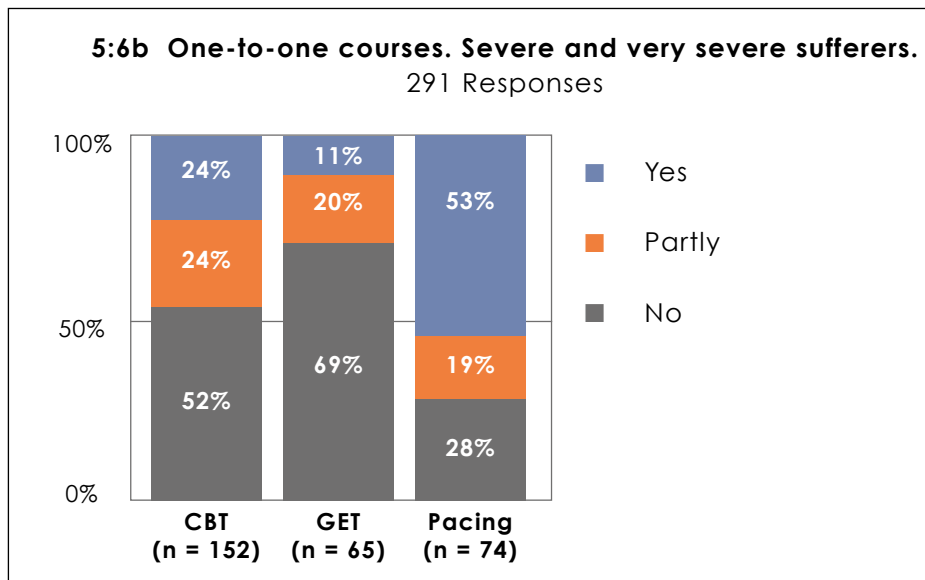
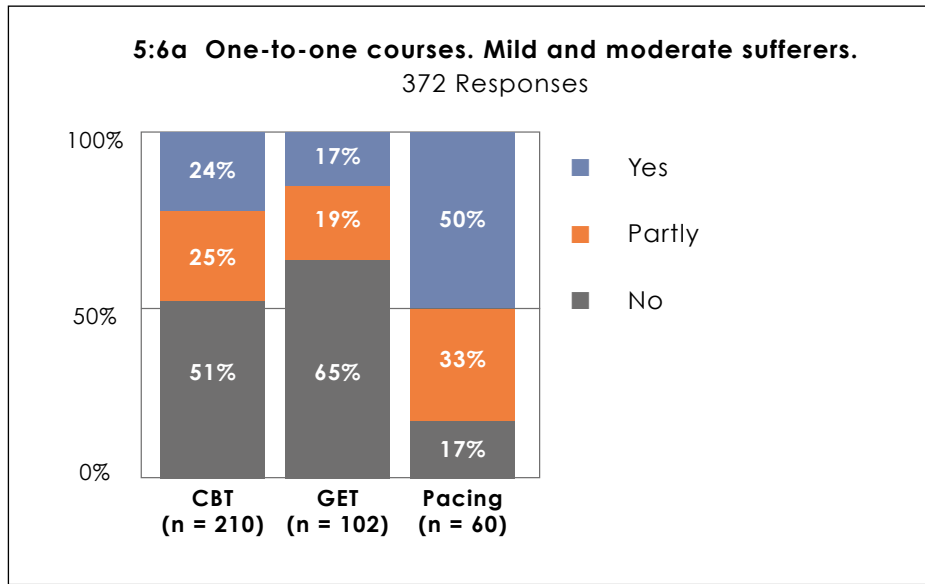
54% CBT, 45% GET and 23% Pacing therapists were not stated to have an ME/CFS specialism.



2:5:6. On balance, would you say that the course was appropriate to your needs? One-to-one courses.

■ See 3:9 above and Key Finding 3:4:7b.

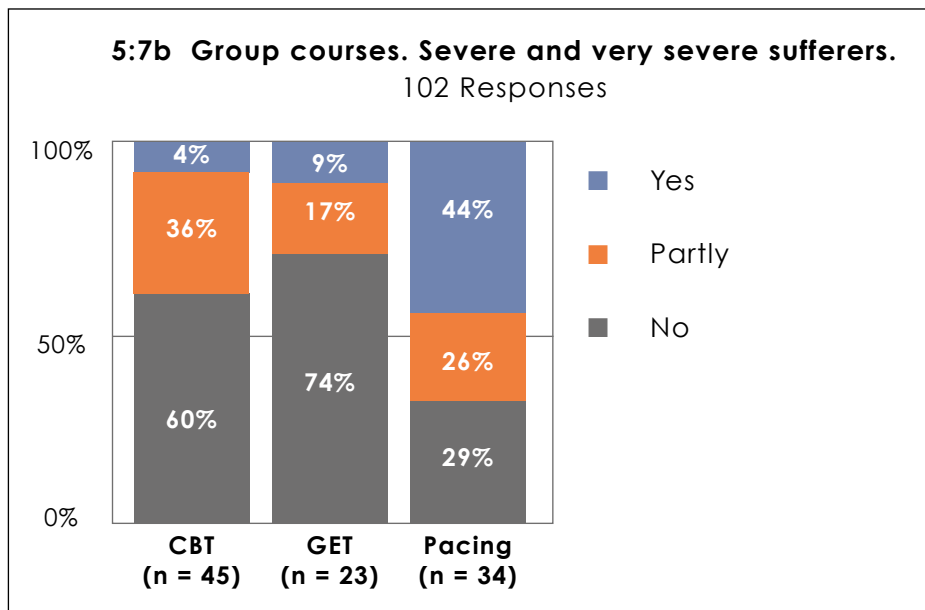
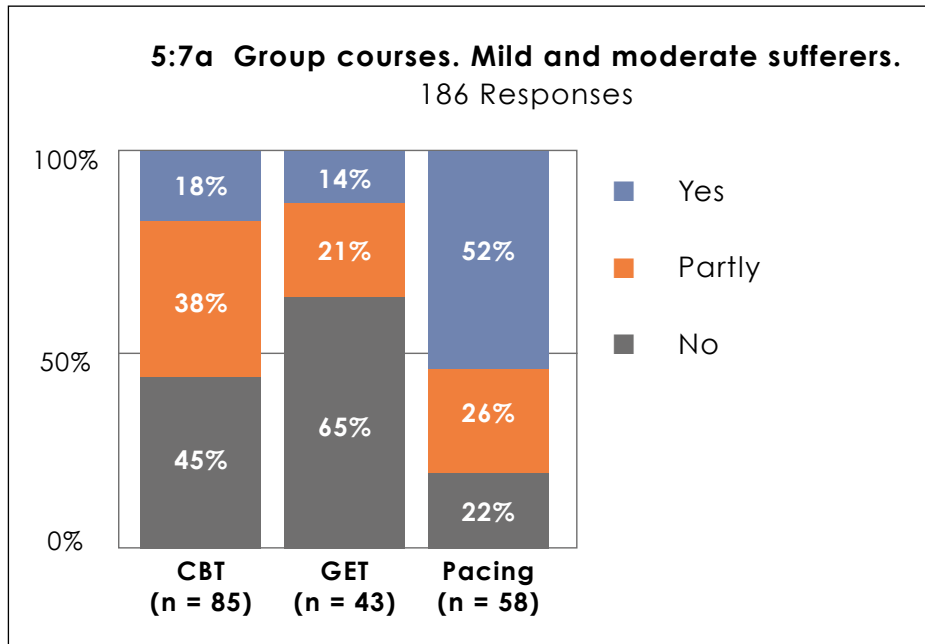
74% CBT, 72% GET and 59% Pacing courses were one-to-one.



2:5:7 On balance, would you say that the course was appropriate to your needs? Group courses.

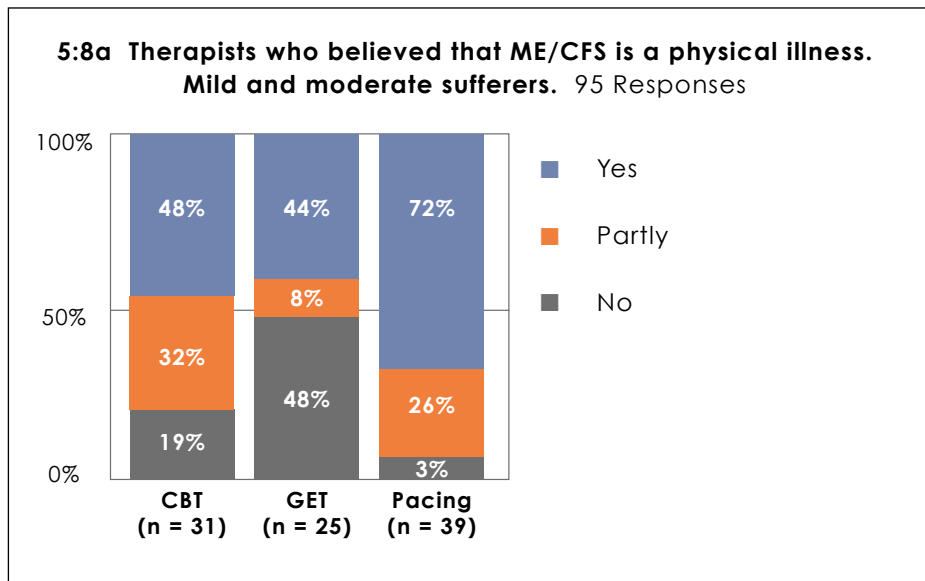
■ See 3:9 above and Key finding 3:4:8b.

26% CBT, 28% GET and 59% Pacing were group courses.

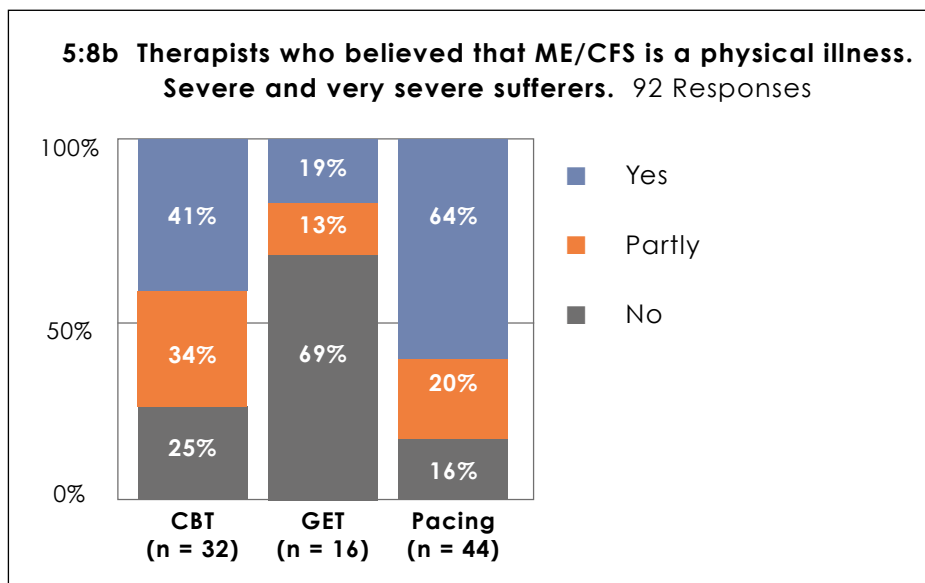


2:5:8 On balance, would you say that the course was appropriate to your needs? Courses where therapists who believed that ME/CFS is a physical illness.

■ See 3:11 above and key finding 3:4:9b.

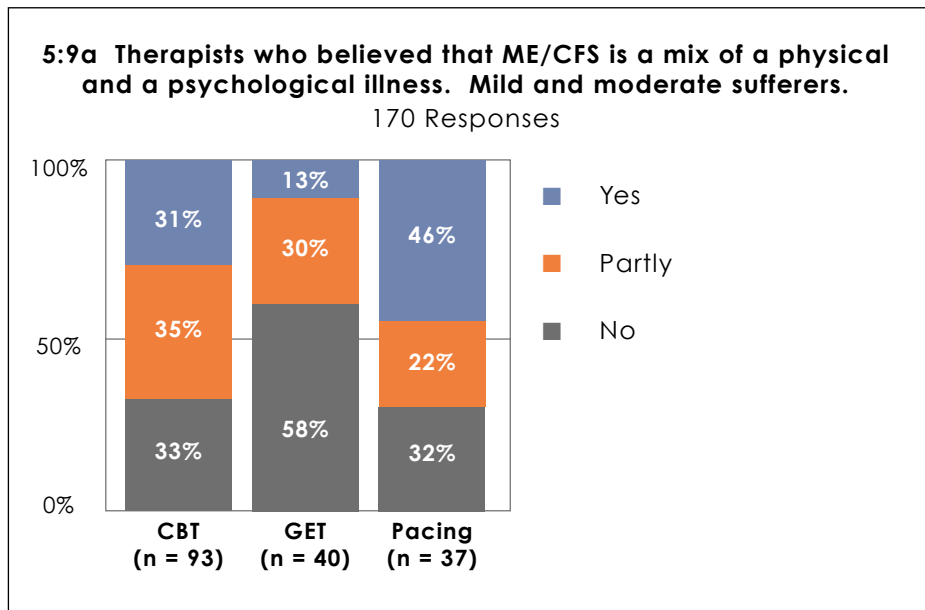


19% CBT, 25% GET and 50% Pacing course respondents said that their course therapists believed that ME/CFS was a physical illness.

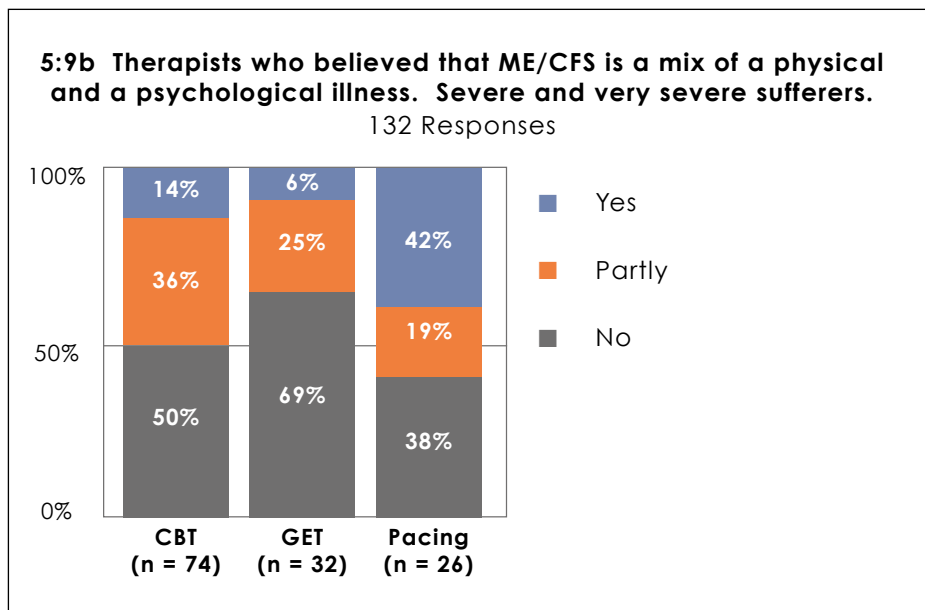


2:5:9 On balance, would you say that the course was appropriate to your needs? Courses where therapists believed that ME/CFS is a mixture of a physical and a psychological illness.

■ See 3:11 above and Key finding 3:4:10b.



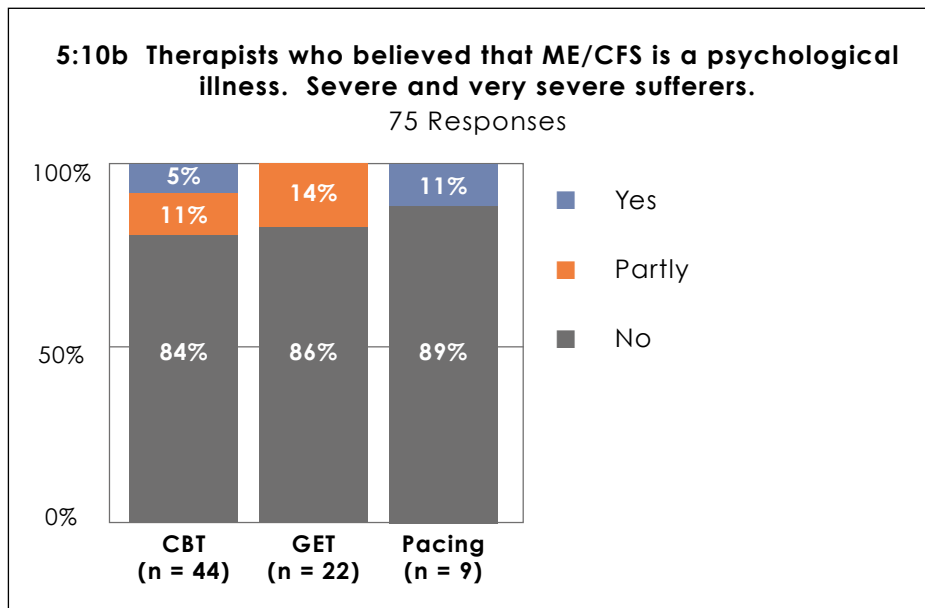
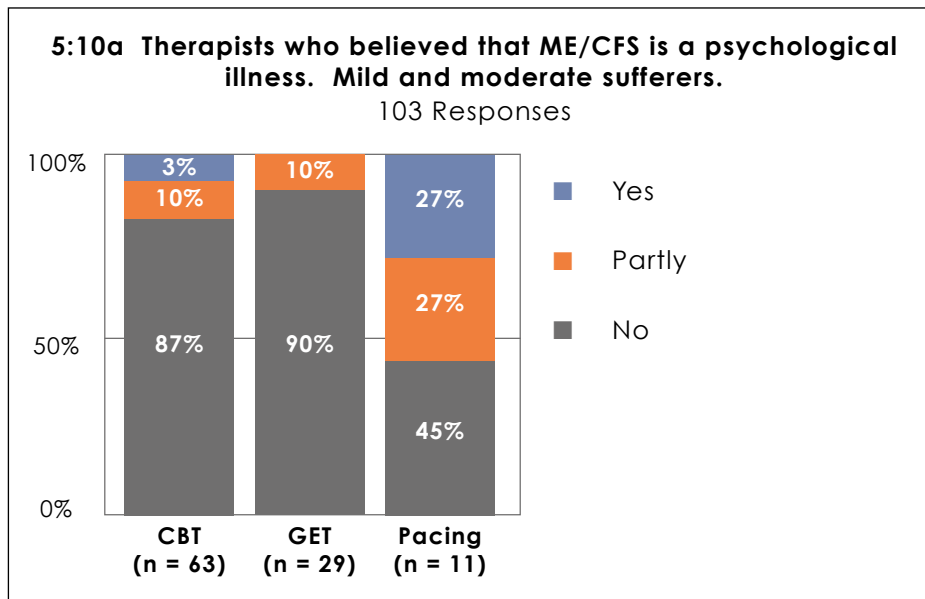
50% CBT, 44% GET and 38% Pacing course respondents said that their course therapists believed that ME/CFS was mixture of a physical and a psychological illness.



2:5:10 On balance, would you say that the course was appropriate to your needs? Courses where therapists believed that ME/CFS is a psychological illness.

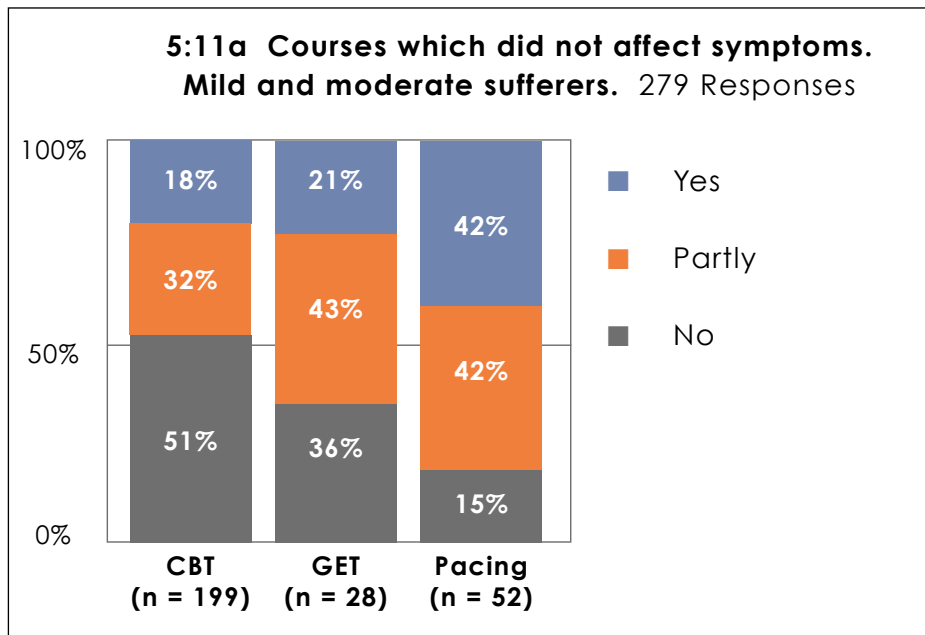
■ See 3:11 above and Key Finding 3:4:11b.

32% CBT, 31% GET and 12% Pacing course respondents said that their course therapists believed ME/CFS was a psychological illness.

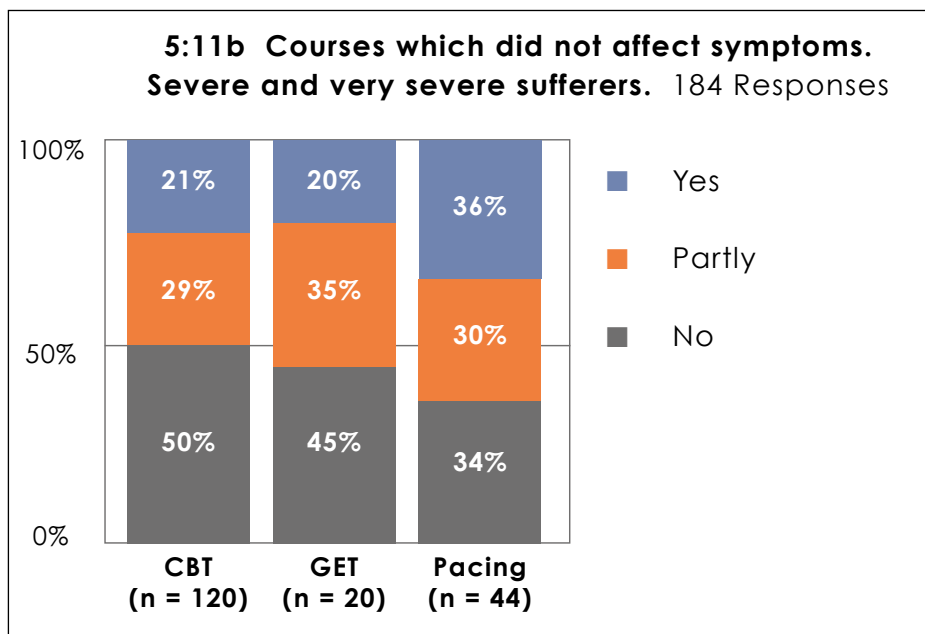


2:5:11 On balance, would you say that the course was appropriate to your needs? Courses which did not affect symptoms.

■ See Key Finding 3:4:12.



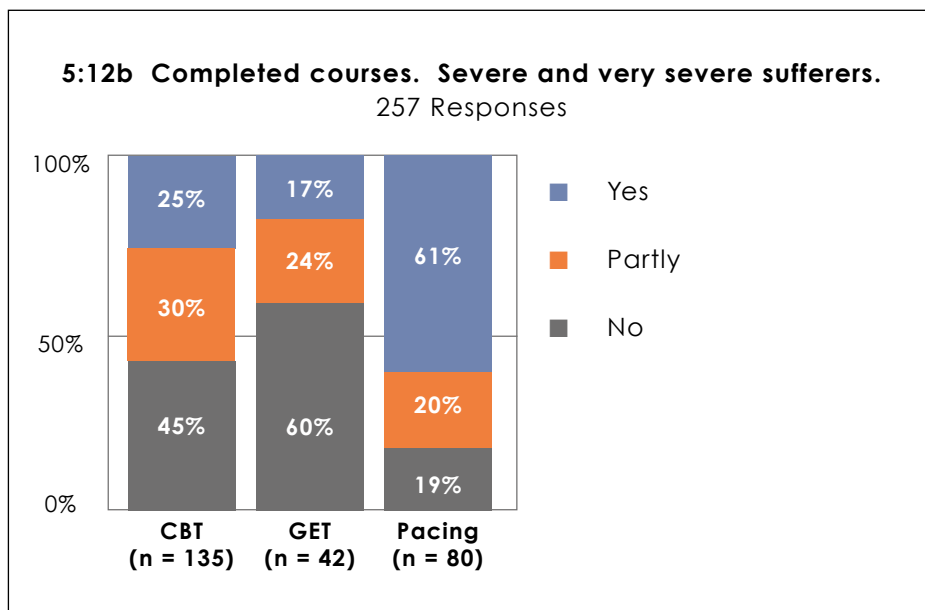
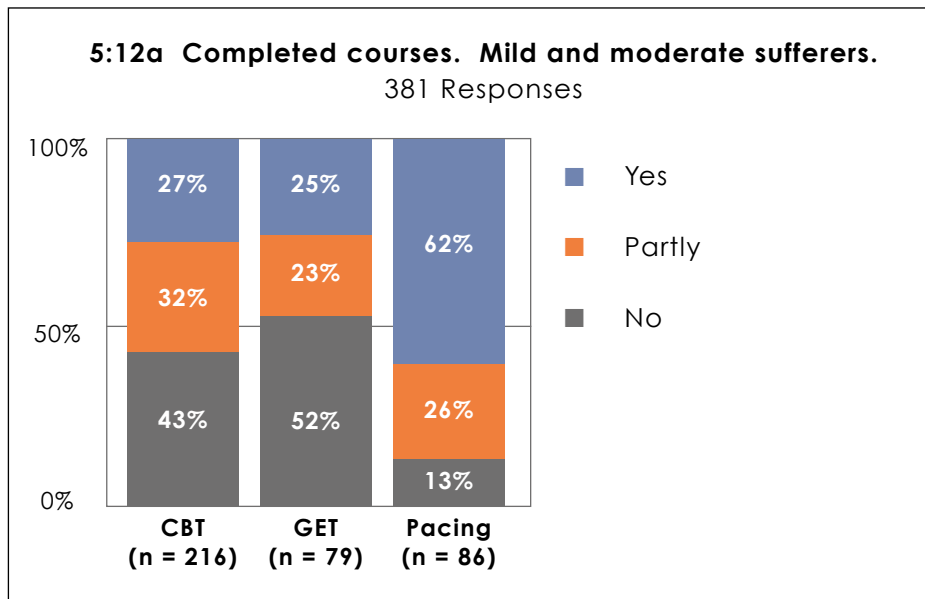
65% CBT, 21% GET and 42% Pacing courses had no effect on symptoms.



2:5:12 On balance, would you say that the course was appropriate to your needs? Where respondents completed the course.

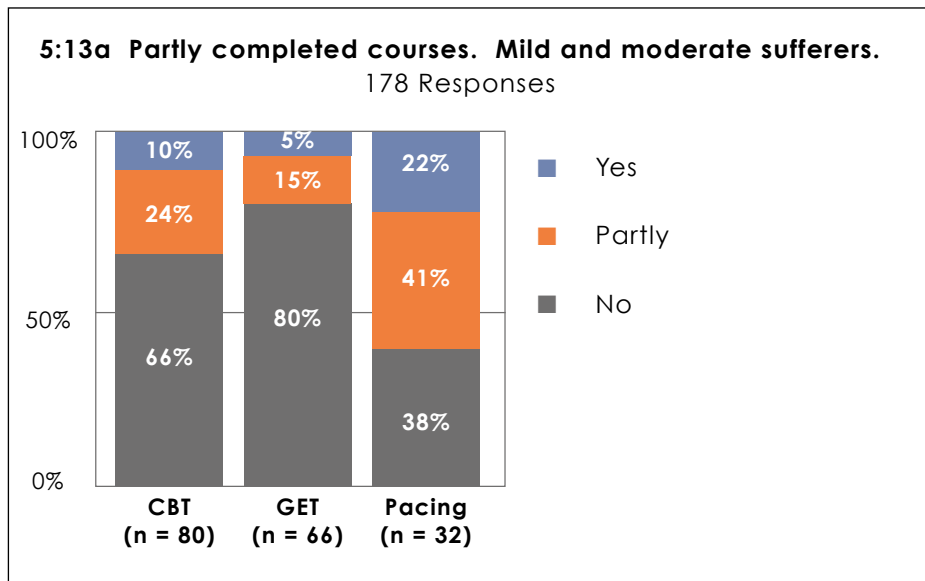
■ See 3:12 above and Key Finding 3:4.13b.

71% of CBT, 52% of GET and 73% Pacing courses were completed in full.



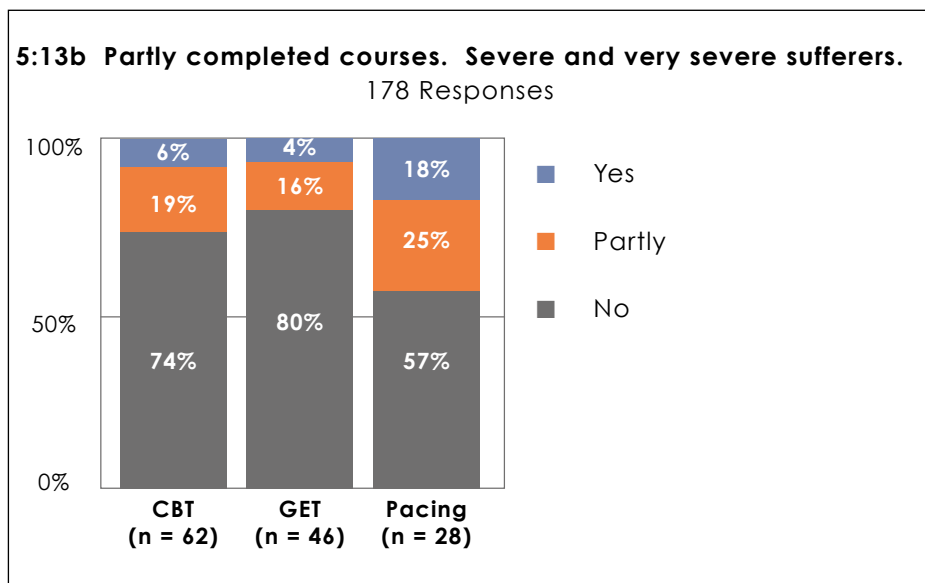
2:5:13 On balance, would you say that the course was appropriate to your needs? Courses partly completed by respondents.

■ See 3:12 above and Key Finding 3:4:14b.



Appendix 1 and 3:6 above give some respondents' reasons for only attending parts of courses.

Of those respondents who completed the question 'How many sessions did you take part in?' (445 CBT, 200 GET and 210 Pacing respondents) 10% CBT, 22% GET and 8% Pacing patients attended less than half the course sessions (see 3:8 above).



2:6 EFFECT ON MENTAL HEALTH AND ME/CFS SYMPTOMS – CBT

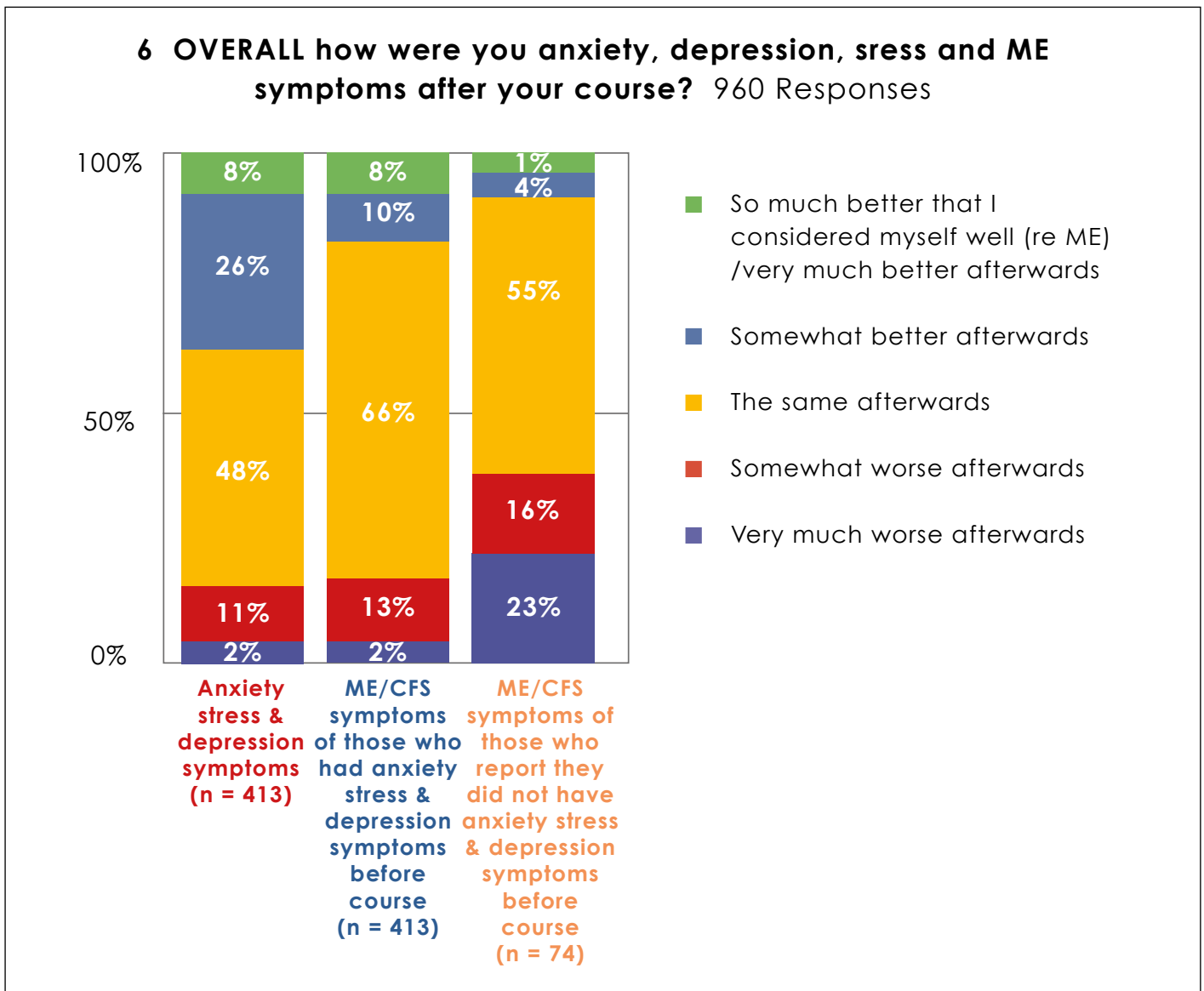
We have combined anxiety, depression and stress data to make a comparison with the data shown about ME/CFS symptoms.

413 of the 493 respondents who had been on a CBT course and whose data we have included in

this report reported the effect their course had on anxiety and/or depression and/or stress symptoms.

In this next graph we compare this 'mental health' data with the data about the effects of their ME/CFS symptoms:

2:6:1 Overall, how were your anxiety, depression, stress and ME symptoms after your course?



2:7 HOW DID YOUR COURSE AFFECT SPECIFIC ME/CFS SYMPTOMS?

We asked the respondents about the effects of their courses on the specific symptoms listed below. The point of the question was to see whether e.g. GET had a greater effect on e.g. exercise-induced muscle fatigue, post-exertional malaise and/or muscle pain than it did on other symptoms. In this set of data we compare the percentages of success/failure of courses for each symptom.

It will be seen that some symptoms are more likely to become better, worse or remain unaffected by the

interventions than are others, aside from the question of whether CBT, GET and Pacing are appropriate or inappropriate interventions.

Note:

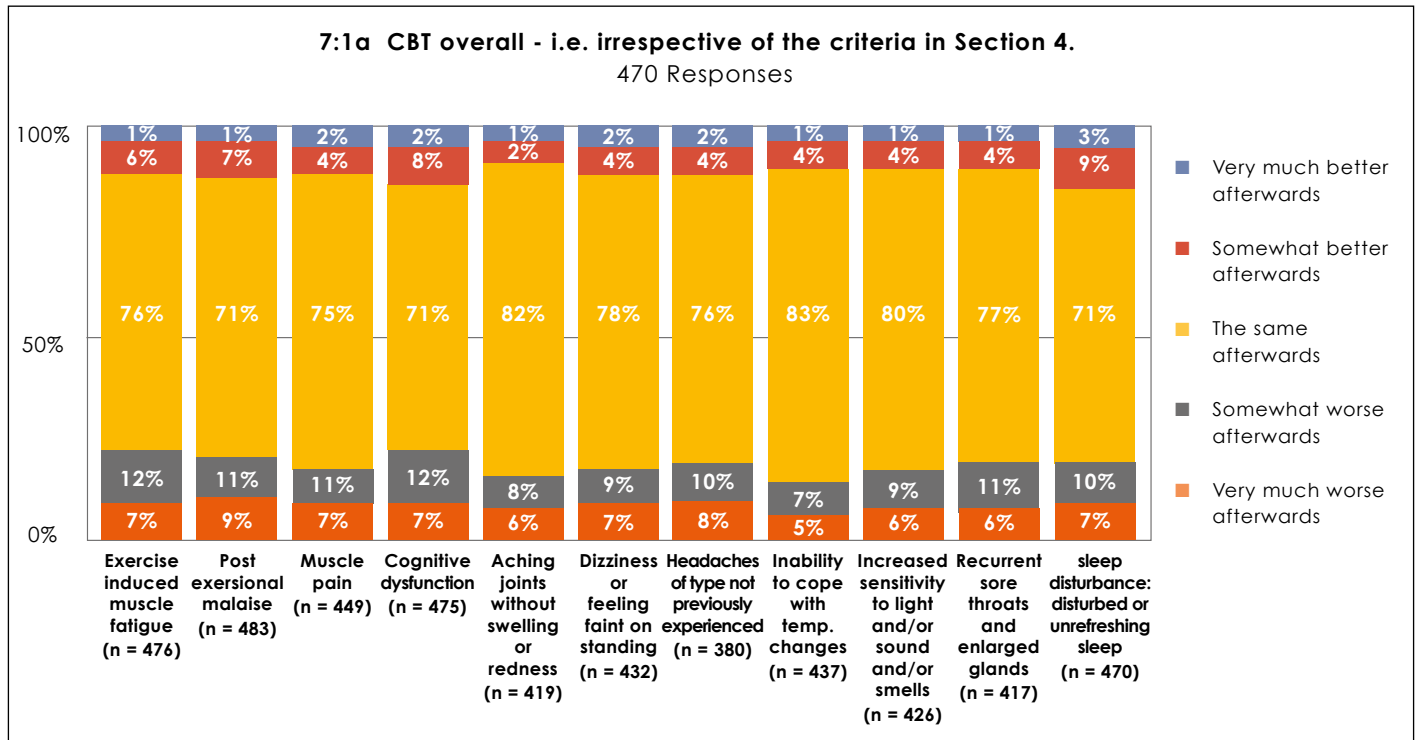
- a) We have not separated the categories of severity.
- b) The figures in brackets below show the percentages of respondents who experienced the symptoms before their courses:

Percentage of Respondents Experiencing Specific ME/CFS Symptoms Before Courses Began:

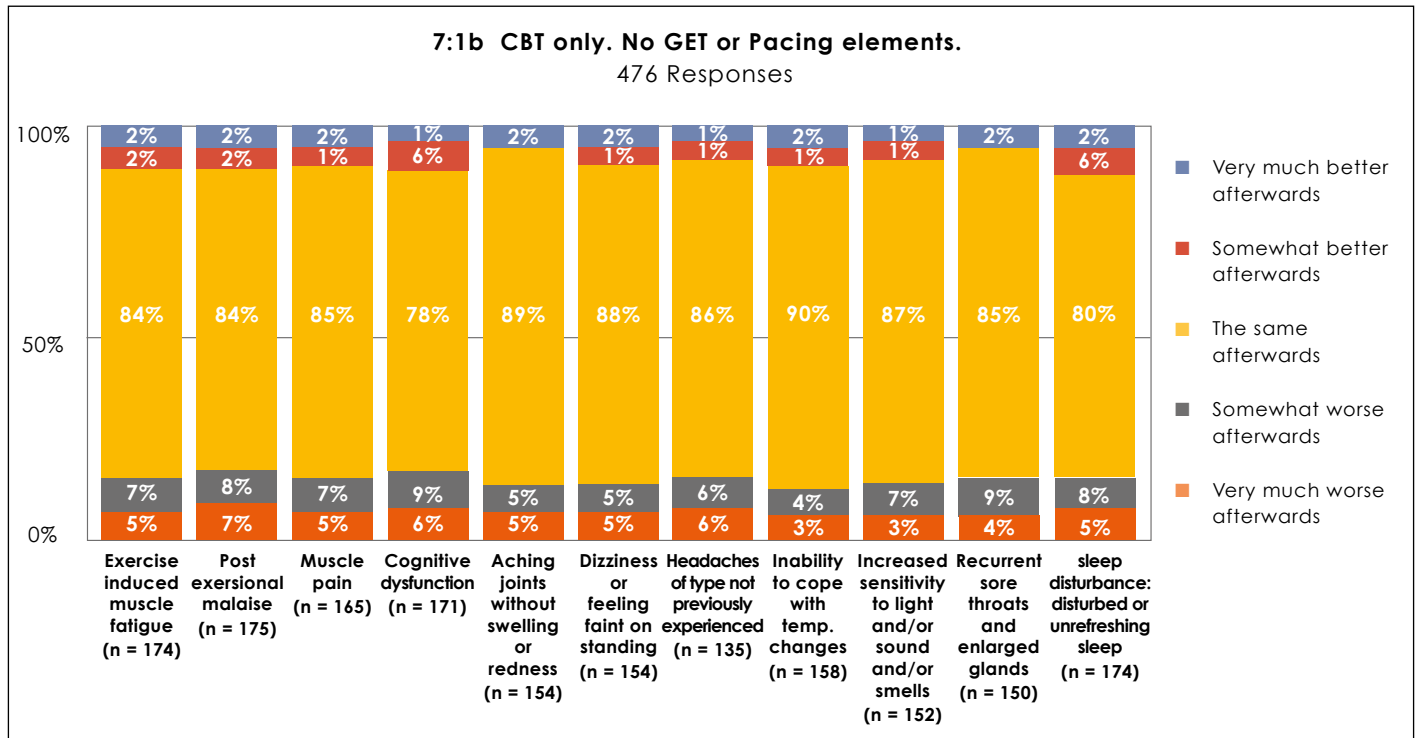
SYMPTOM	SLIGHT	SIGNIFICANT
Exercise-induced muscle fatigue	10%	87%
Post-exertional malaise (PEM)	7%	92%
Muscle pain	21%	72%
Cognitive dysfunction	18%	80%
Aching joints without swelling or redness	16%	69%
Dizziness or feeling faint on standing	25%	64%
Headaches of type not previously experienced	20%	59%
Inability to cope with temperature changes	22%	70%
Increased sensitivity to light and/or sound and/or smells	24%	65%
Recurrent sore throats and enlarged glands	25%	60%
Sleep disturbance or unrefreshing sleep	10%	88%

2:7:1 COGNITIVE BEHAVIOURAL THERAPY (CBT)

2:7:1a Overall (i.e. irrespective of the criteria listed in Section 4) how did your CBT course effect certain ME/CFS symptoms?

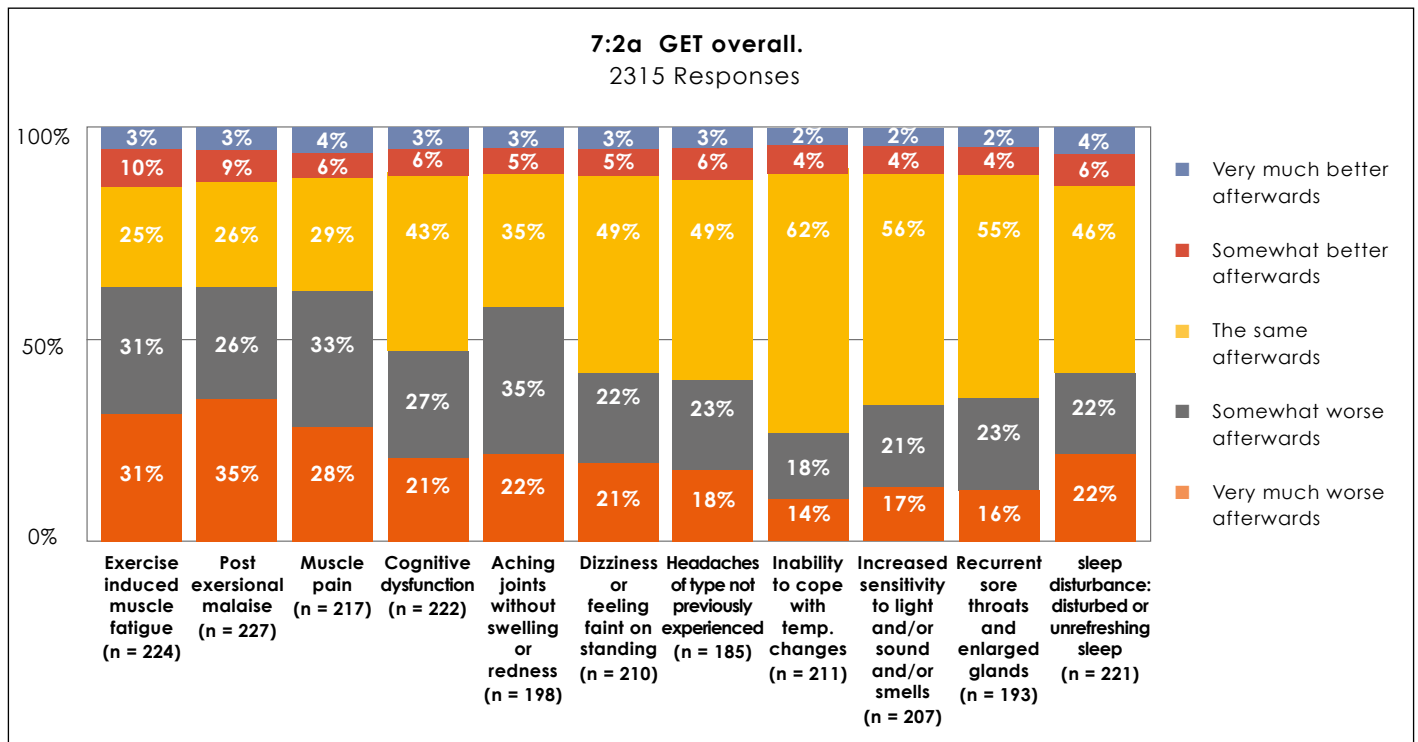


2:7:1b How did your CBT course effect certain ME/CFS symptoms? Courses which were CBT only – no overlapping GET or Pacing elements.

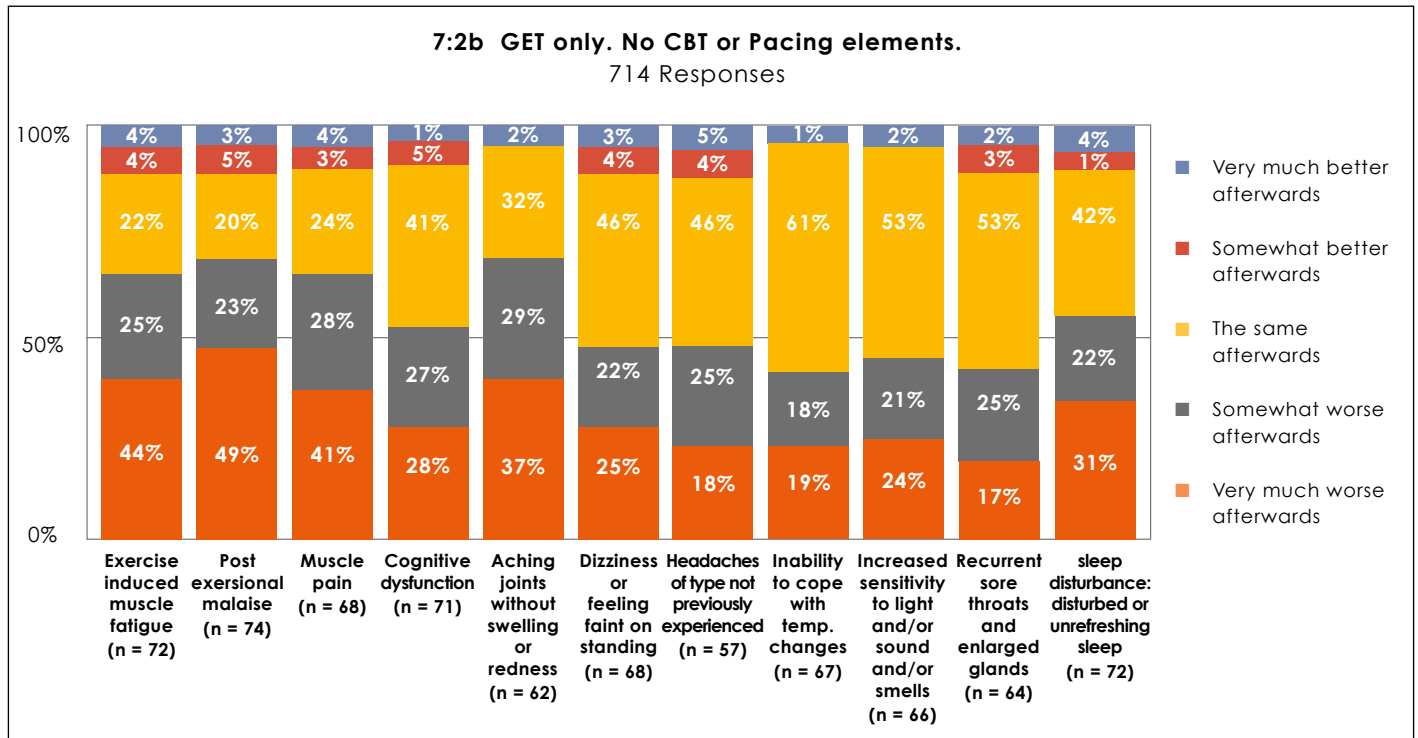


2:7:2 GRADED EXERCISE THERAPY (GET)

2:7:2a Overall (i.e. irrespective of the criteria listed in Section 4) how did your GET course effect certain ME/CFS symptoms?

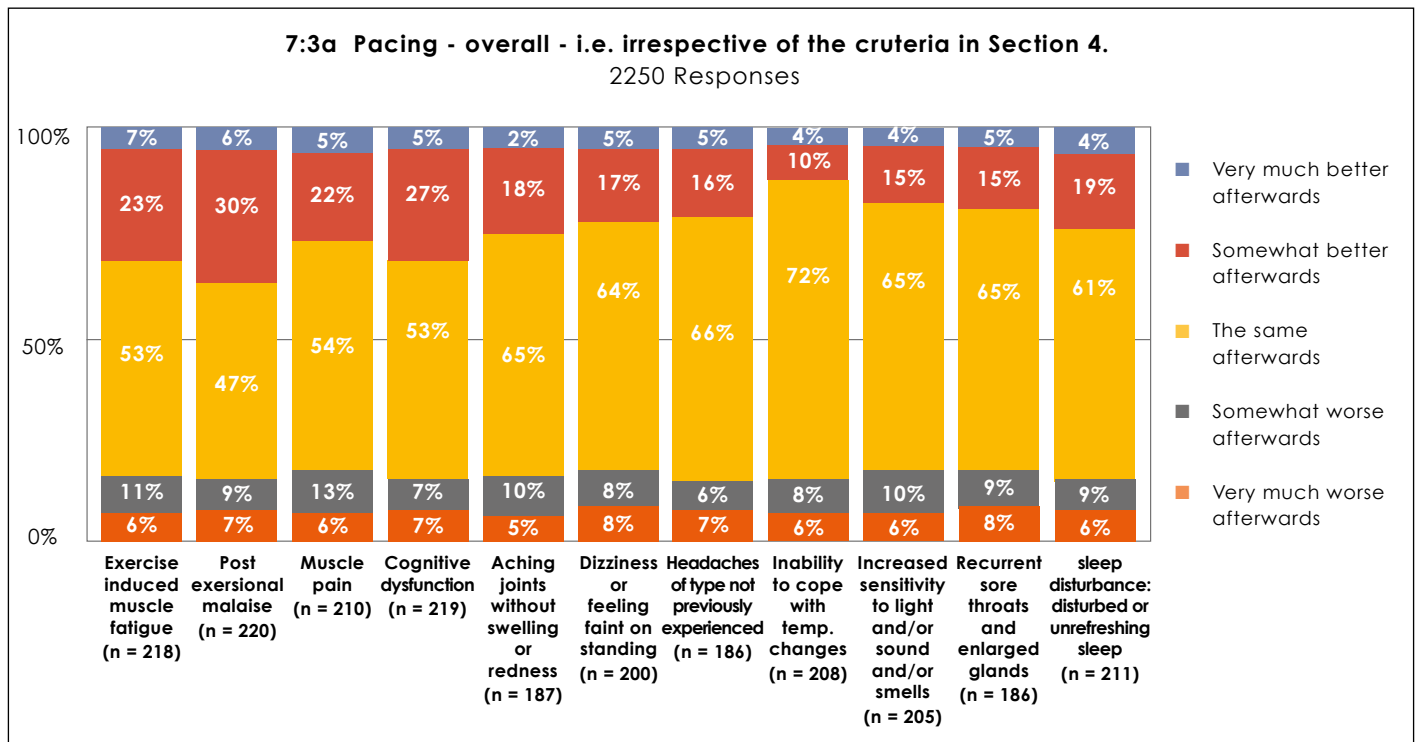


2:7:2b How did your GET course effect certain ME/CFS symptoms? Courses which were GET only – no overlapping CBT or Pacing elements.

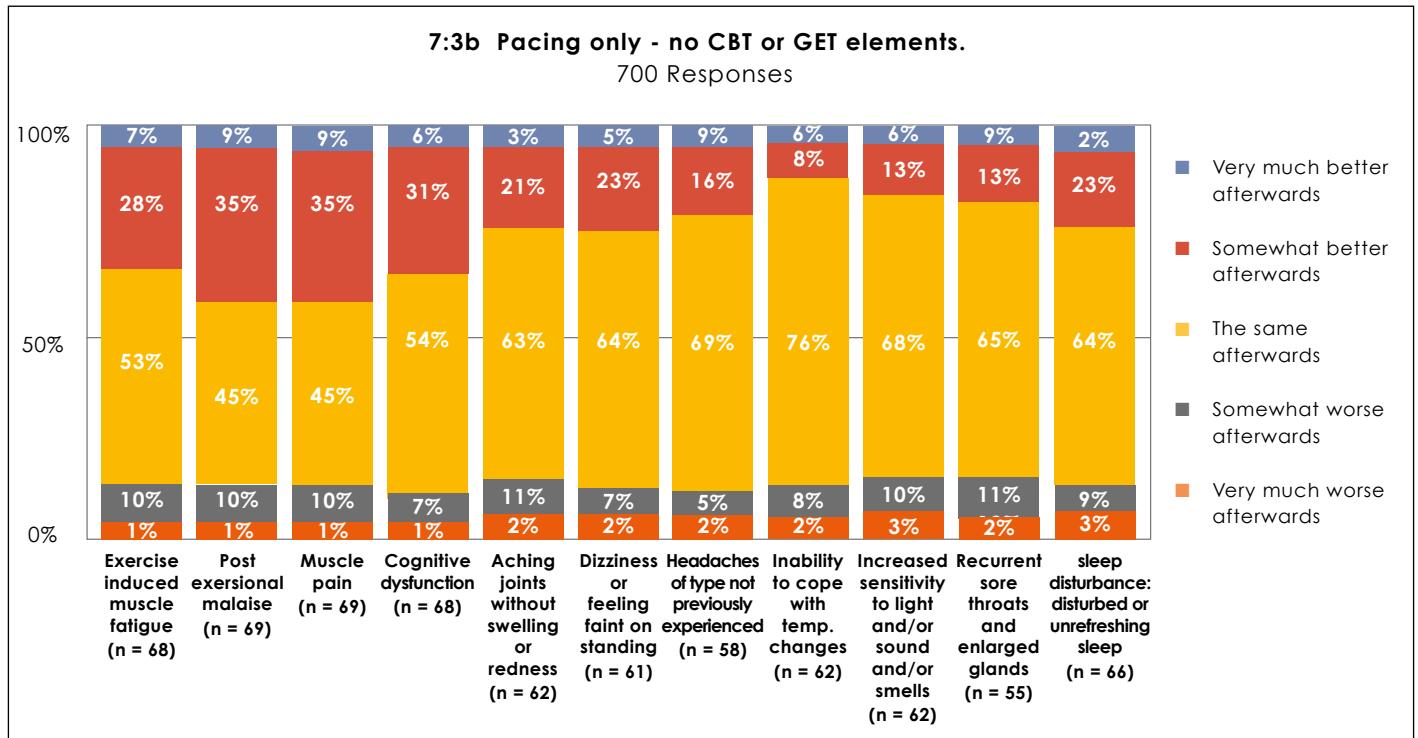


2:7:3 PACING

2:7:3a Overall (i.e. irrespective of the Listed Criteria) how did your Pacing course effect certain ME/CFS symptoms?



2:7:3b How did your Pacing course effect certain ME/CFS symptoms? Courses which were Pacing only – no overlapping CBT or GET elements.



Notes:

a) Comparing the percentages in the charts above with those in the chart in Appendix 2, Section 4, 4:2 – ‘Overall (i.e. irrespective of the listed criteria) how were your ME/CFS symptoms after the course compared to how they were before?’:

The average (i.e. irrespective of degree of severity) overall percentages of respondents whose symptoms improved at 4:2 are 12% CBT, 15% GET and 38% Pacing. When the symptoms are considered individually, one CBT percentage is also 12%. Apart from that percentage, the percentages are less.

The average (irrespective of degree of severity) overall percentages of respondents

whose symptoms became worse at 4:2 are 24% CBT, 64% GET and 19% Pacing. When the symptoms are considered individually apart from a few exceptions, the percentages are less. There is one GET exception and one Pacing exception where the percentages of respondents who became worse are the same 64%/19%. There are six GET exceptions where the percentages of symptoms which became worse are higher than 64%.

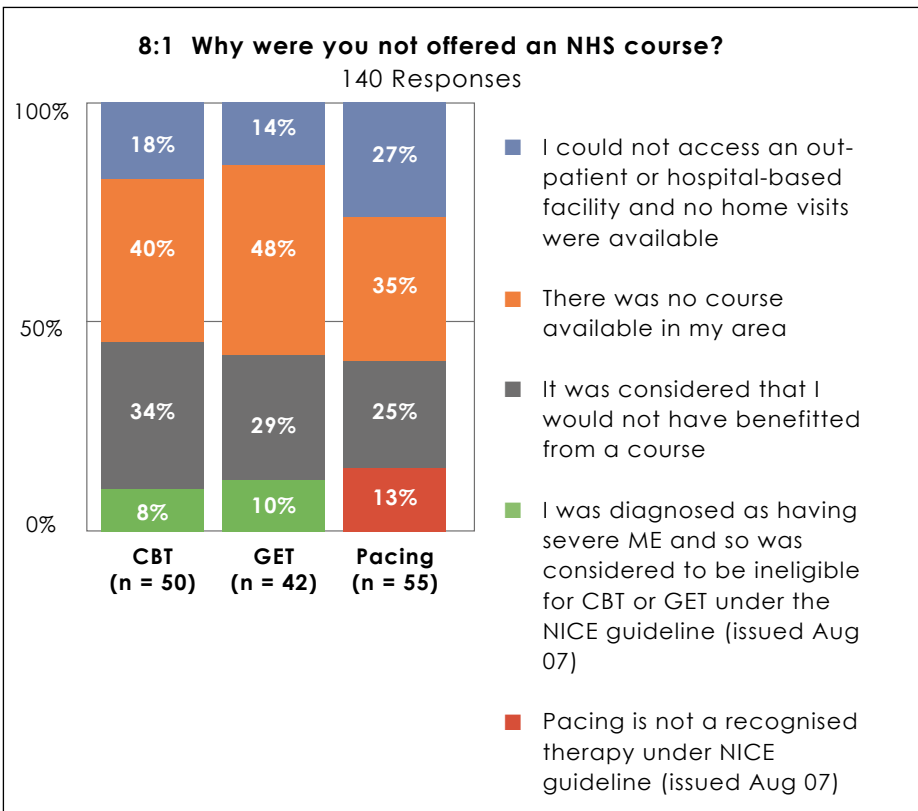
b) Comparing the percentages in the charts above with those in the chart at Appendix 2, Section 4, 4:3 – ‘Overall, how were your ME/CFS symptoms after the course compared to how they were before? Courses which were CBT only, GET only or Pacing only’;

The average (irrespective of degree of severity) percentages of respondents whose symptoms improved at 4:3 are 9% CBT, 11% GET and 44% Pacing. When the symptoms are considered individually apart from two exceptions, the percentages are less. The two exceptions are in Pacing where the percentages of respondents whose symptoms improved are the same 44%.

The percentages of respondents whose individual symptoms became worse are all less than the average (irrespective of degree of severity) percentage of respondents whose symptoms became worse at 4:3. There they are 24% CBT, 64% GET and 19% Pacing.

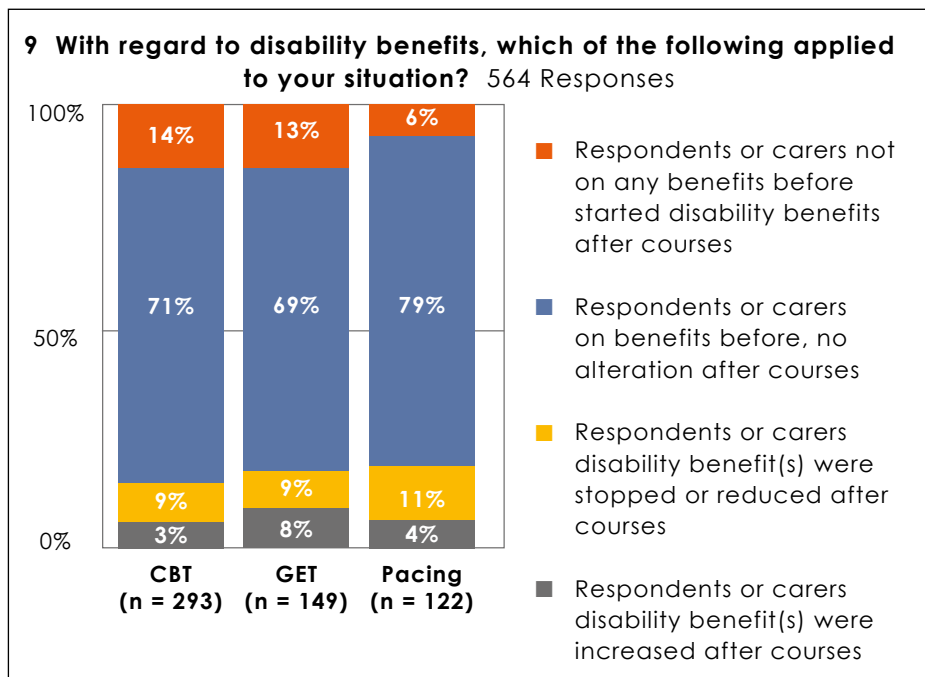
2:8 RESPONDENTS WHO WERE NOT OFFERED OR WERE REFUSED AN NHS COURSE

2:8:1 To the best of your knowledge, what do you think was the main reason why you were not offered or were refused the option of attending an NHS course?



2:9 DISABILITY BENEFITS STATUS FOLLOWING COURSES

2:9:1 With regard to disability benefits, which of the following applied to your situation?



We asked about Attendance Allowance, Carer's Allowance, Disability Living Allowance, Employment and Support Allowance and Incapacity Benefit. The chart below amalgamates all benefits.

61% CBT, 66% GET and 55% Pacing respondents were on disability benefits before and/or after their courses.

Note:

Not shown in the chart above (because too small to be clearly seen) but taken into account; 2% (n7) CBT and 1% GET (n1) respondents on benefit(s) before their course started another benefit(s) after their course.

2:10 EFFECT OF THE 2007 NICE GUIDELINE ON COURSE OUTCOMES

In our survey questionnaire, we had not asked a specific question about the years in which courses were taken – we had asked questions, in bands of years, about the number of years respondents had had ME/CFS and how many years after that they had their courses.

We have assumed that the NICE guideline, published in August 2007, had been disseminated to

health professionals by January 2008. The consequence is, because of our banding, there is a considerable percentage of courses which could have been Pre-2008 or Post-2007 (i.e. Pre-NICE or Post-NICE) and we had to omit data about these from this section.

To give an example of a respondent not included:

He had had ME/CFS for 7-10

years before the survey (one band), so he became ill at some time between 2002 and 2005. He said he had had ME/CFS for 3-4 years before receiving his course (another band), so he could have had his course any time between 2005 and 2009. Consequently, his data will not be included in this section.

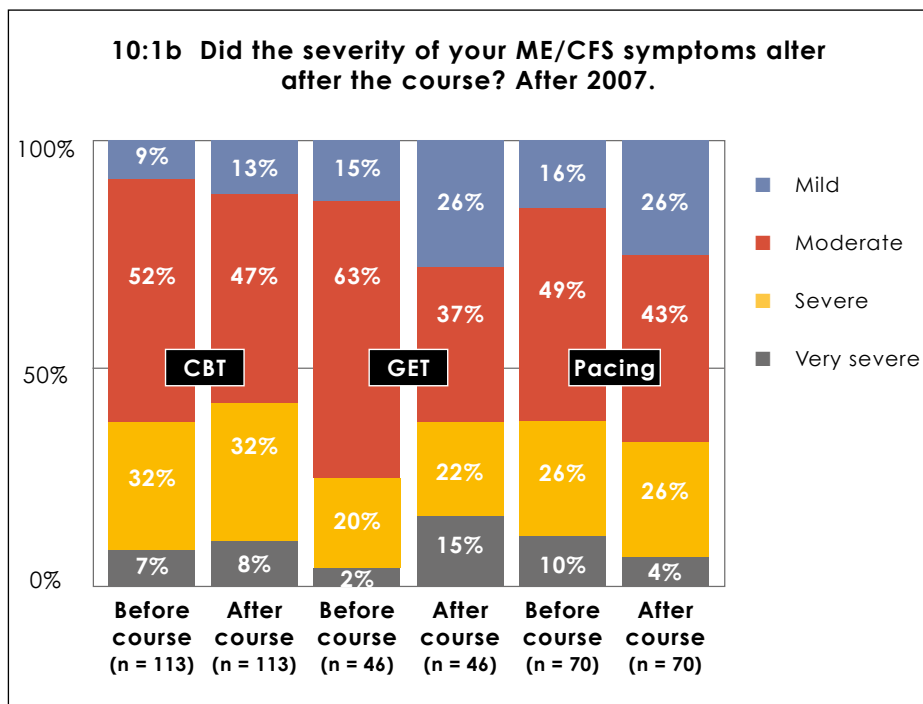
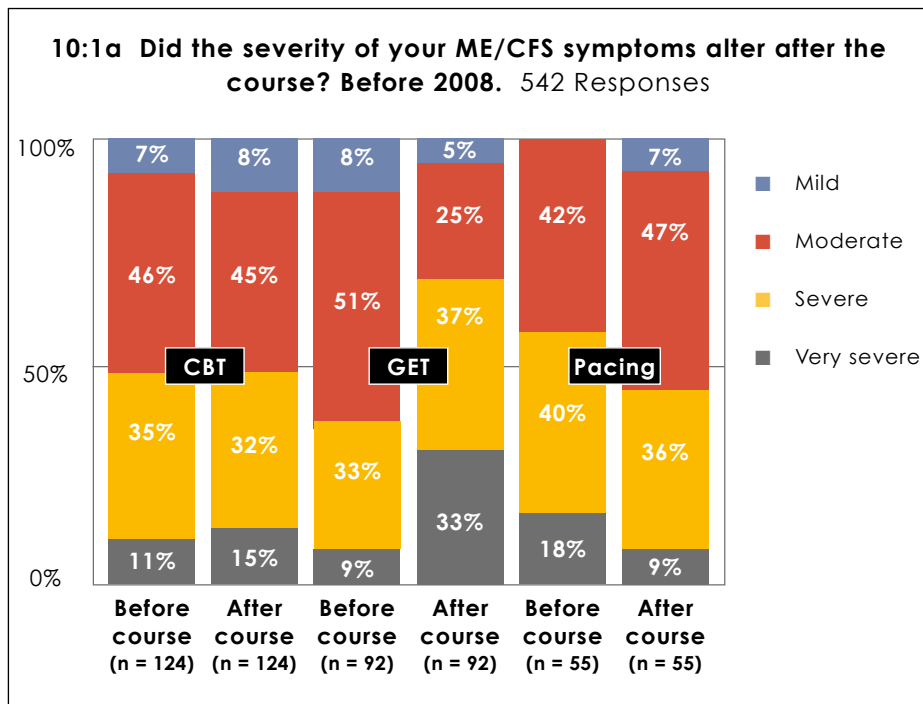
The count for this section of the report is:

	CBT	GET	Pacing	Total	All %
Courses known to be pre 2008	124	92	55	271	54%
Courses known to be after 2007	124	46	70	229	46%
Total	237	138	125	500	100%

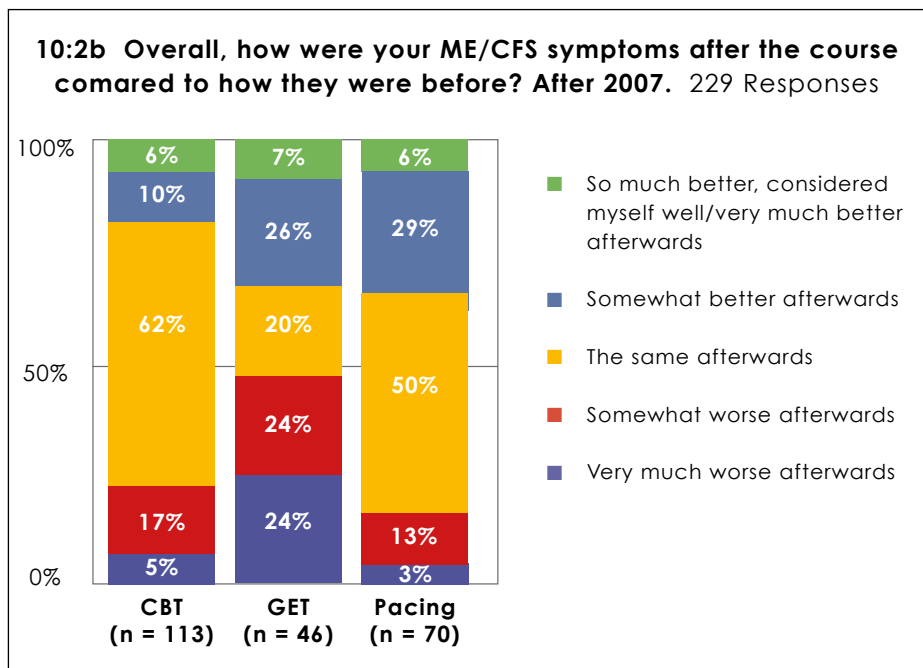
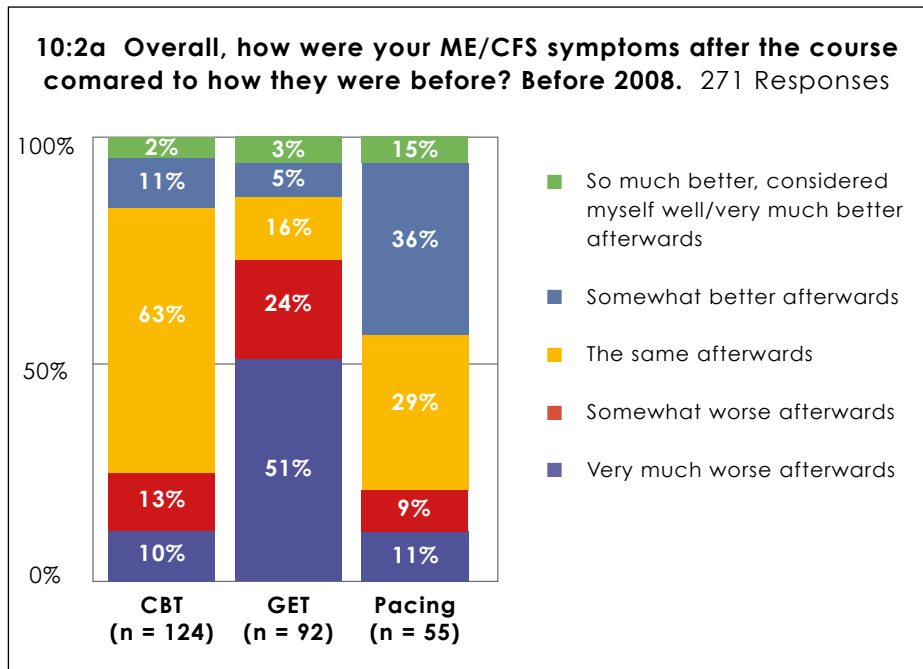
The overall data count based on courses is: 493 CBT, 233 GET and Pacing 226. Therefore, when comparing data in this section with data taken from the overall data in Section 3, this must be remembered.



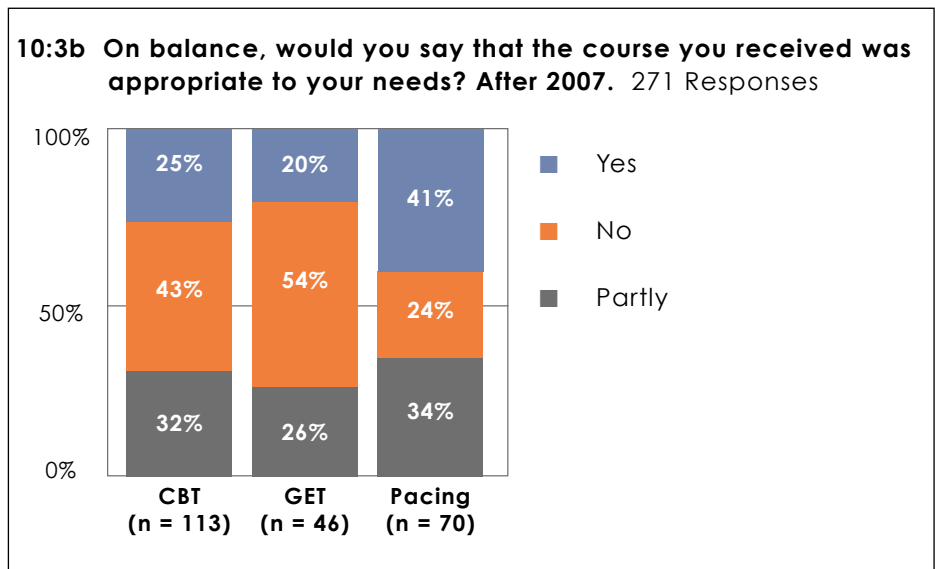
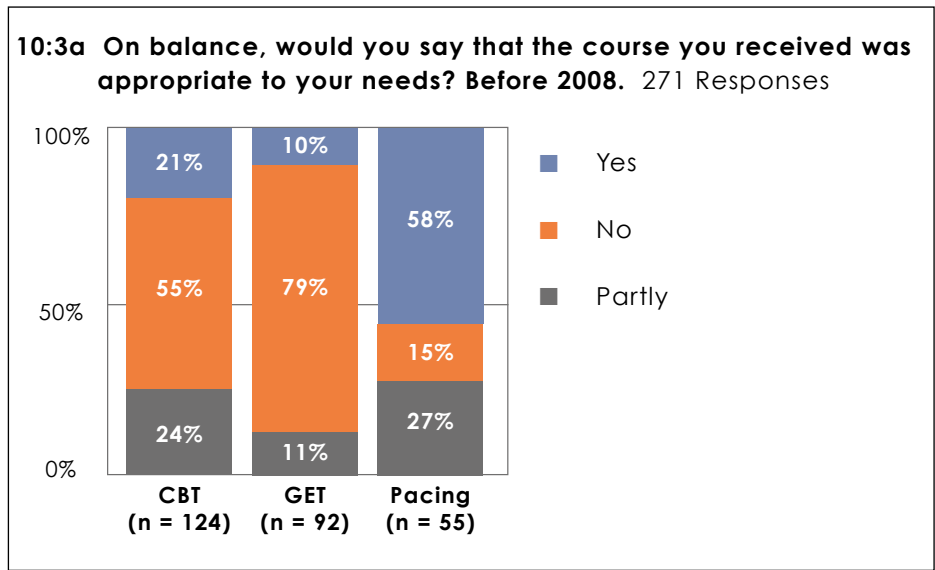
2:10:1 Did the severity of your ME/CFS symptoms alter after the course?



2:10:2 Overall (irrespective of the Listed Criteria) how were your ME/CFS symptoms after the course compared to how they were before?



2:10:3 On balance, would you say that the course was appropriate to your needs?



APPENDIX 3: QUALITATIVE DATA – COURSES WITH ELEMENTS OF OTHER INTERVENTIONS

Experience of patients whose courses contained overlapping elements of CBT, GET and Pacing.

Notes:

a) The survey being an anonymous one, the numbers are respondent ID numbers, specified in case a need arises to link with other answers.

b) A few responses indicate that courses were multi component courses or were referred to as 'Activity management' courses although they are recorded as CBT/GET/Pacing courses.

c) For the purpose of this Appendix, GET is taken to refer to therapy about exercise with no mention of every day activity and Pacing is taken to mean therapy about activity with no specific mention of exercise.

3:1 CBT COURSES WITH ELEMENTS OF OTHER INTERVENTIONS

3:1:1 CBT Courses with Elements of Pacing (sometimes called 'Activity Management') – no specific mention of Exercise

#24.: "Learnt how to break tasks down into small manageable chunks to avoid the ALL or NOTHING scenarios."

#58: "She just explained the theory of pacing and encouraged me to keep a diary."

#72: "She gave me diagrams about pacing and lots of information. When she discovered that I had barely enough energy to get through day to day stuff, she told me to start pacing my hobbies like to read magazines instead of books and only read for x amount of time etc., etc."

#77: "Kept diaries of periods of activity and inactivity and analysed them. Identified activities

that I would like to do and gradually increased the amount of activity week by week."

#78: "I was unable to sit up. So would sit 5 minutes, then rest. This was my starting point."

#82: "We were asked to record our activity and look at this with a view to better managing ourselves by Pacing."

#90: "Diary keeping and identification of exacerbators. Activity planning to enable me to do things that did not make me worse and to look for patterns in my activities that made me feel worse."

#114: "Diary of symptoms and activities."

#115: "Learning to balance activity and rest. Breaking activities into smaller elements. Incorporating rest periods into normal day. Imagining energy levels as a 'battery' and try not to deplete fully before 'recharging'."

#116: "We were encouraged to get up at the same time every day, and to include periods of rest into our day, without going back to bed."

#133: "I was encouraged to break up activities in my day with rest periods e.g. wash up for 10 mins then rest for 10 mins then wash up again for 10 mins etc."

#137: "Find base level (point at which you are symptom free, which I am never so that was impossible) and build activity from there, increasing gradually. Do same on good day as bad."

#147: "In depth advice as to how to self manage GET and Pacing. Provision of time sheets to help record activity and rest. Time sheets reviewed at sessions to identify where more balance needed etc."

#148: "Management of activities requiring different energy levels and structured periods of rest during the day."

#151: "How to break up activity."

#170: "It was part of the fortnightly tasks, I kept records of activity and basic diary for a given period and then we analysed this together."



#180: "I am asked to complete diaries and set myself goals e.g. getting up in the morning at a certain time."

#183: "It was pacing in relation to the usual activities I undertook daily."

#235: "No sleep advice given. Shown how to use an activity management plan."

#238: "She asked me to pace my hobbies. I think she was thinking about graduated exercise elements but realised that I was struggling with day to day life, never mind going out for a walk every day. She then decided to get me to pace my hobbies and day to day life so that I would have enough energy to get through the day without the boom and bust."

#270: "Tried to establish a manageable pattern of activity, to break boom and bust cycle. Then tried to build from this level, slowly."

#273: "How to manage energy and to plan lots of activity interspersed with rest periods."

#296: "We were taught to pace ourselves, to keep some energy at end of day in reserve and to rest between activity. I found it hard to do in real life bringing up a son on my own."

#301: "Advised to rest for 10 minutes after e.g. shopping."

#359: "The emphasis of the course was for the patient to carefully plan their activities, with a view sustaining and increasing activity levels."

#372: "Information on breaking the boom and bust cycle by maintaining a steady level of activity. Activity diary to identify which activities might be causing increased levels of fatigue and discussion about how to manage this."

#388: "I was encouraged to increase my activity although it was called PACING. It appears that individual therapists twist the meaning to suit their own beliefs."

#395: Pacing/Management Activity/CBT course:

"The course was run by the specialist CFS / ME service (X). Pacing and activity management formed the core of the course. There was also an element of CBT. Pacing strategies were introduced and individual pacing plans were discussed within a group and with specialist CFS/ME practitioners (multi-disciplinary team of occupational therapists, psychologists etc.) over the course of 6 weeks."

#406: "Find the right balance for myself in day to day activities."

#407: "We kept a diary of a few days' activities and then were encouraged to look at it to see if we could change things to improve outcomes."

#408: "We set ourselves a target that we wanted to achieve. We were taught to stop an activity before the bust point and to rest totally then to resume activity and to alternate physical and mental activities as well."

#443: "Keeping activity diary, feedback to employers regarding reasonable adjustments and access to work requirements. Available space for lunch time rest period."

#456: "Finding a level of activity that I was able to maintain, with a gradual increase over a long period of time, if I encountered relapses, then reduce the increase."

#463: "I was encouraged to establish a baseline of activities I could do every day, then to build up one activity (physical or mental) at a time in small increments."

#470: "Writing down all my daily activities and looking at where I could balance these out."

#476: "I was told to take an hour's rest for every hour worked."

#479: "Keeping a diary of activity and energy levels and gradually increasing amount of activity."

#485: "Identifying activities as red, green, amber for high, low and medium energy use and planning week so only 1 red per day."

#506: "I was actually told that I was pacing myself well before their advice. Resting very regularly, changing what I do – a short read, short time on PC, refusing phone calls. The course actually taught me nothing. Managing my way of life is the only thing that stops me from losing my speech and becoming very ill."

#512: "I was asked to fill out activity/rest diaries and given advice to split up my activity and rest to avoid boom and bust and not to rest for more than 30 mins at one time."

#551: "I had help with establishing an activity baseline, keeping an activity diary to help reduce episodes of push and crash. I also had to keep a sleep and fatigue level diary. It was made very clear that any increase in activity attempted would be very small, if indeed any was attempted at all, and my symptoms would have to stabilise for a matter of weeks if not months before this we would try this. This course was much more about helping me to cope with the limitations of a chronic physical illness, and in fact ironically this medical professional was the one I expected least of and who turned out to be the most knowledgeable and helpful of all!"

#555: "We have worked on setting baselines for activities and then developing a stable plan of activity in order to stabilise the symptoms - then set new goals to

steadily but slowly increase levels of activity."

#572: "Keeping a diary to identify where one was doing too much or too long."

#599: "Maintaining an activity diary to measure over-exertion and de-conditioning during a 7 day period and as a result help to amend activities accordingly in the following weeks."

#603: "I had to keep a diary of my daily activity for a week or fortnight. Then this was used as a basis for a base line daily routine that I had to stick to. Then activity would be gradually increased."

#615: "Managed activity and rest and relaxation periods."

#617: "Listening to body and pacing accordingly."

#618: "Making a timetable of activity. Assigning points to each activity. Working out a baseline amount of points which can be achieved without crashing. Slightly increasing the activity amount each week."

#630: "Course was mostly pacing with minimal CBT. My programme included activity followed by rest. Times were built up slowly for each over the year."

#634: "Learning to manage daily activity."

#638: "I was encouraged to pace my activities so that every day was about the same."

#641: "I was encouraged to recognise when I needed to rest and to take appropriate rest periods throughout the day."

#695: "Attended psychologist with my mum. She taught me relaxation esp. when I couldn't get off to sleep. She taught me how to set up a weekly routine and then slowly increase every few weeks if my symptoms had not flared. I don't know if it was CBT that I go to or whether it was just good sensible advice from a sensible psychologist. It was really common sense what she discussed, belief that I was OK that could get better look at the



positive things I had in my life set up a good sleep wake cycle."

#707: "Just to try and up activities gradually, in my case it would plateau but then I have always relapsed to a greater or lesser degree."

#713: "Managing activities, booming and busting, sleep hygiene."

#716: "Sleep management, friends only seeing me for a short time. Keeping a record of what I did."

#721: "Like I had stated on the previous pages, it was a good program but I was only there for 4 weeks and practically bed bound and the after care. CBT & physiotherapy wasn't consistent. I have learnt to self help and pace through the treatment but have been pretty much left to get on with it, I have researched many more helpful skills & therapy's since that I'd be happy to share."

#729: "To be honest it put into words what I'd already worked out for myself. Battery always half full... stop before hitting the metaphorical wall. That sort of thing."

#784: "I was asked to set targets for activity and keep a diary to gauge if I was reaching those targets and improving week on week."

#792: "A weekly planner to plan activities, found it helpful."

#811: "We were taught pacing techniques and most of the course centred around this."

#812: "They told me to save my energy. I had to count on "10 pounds sterling of energy instead of 100 like before" I had to spend it wisely and I finally accepted my illness with this example and started pacing. This reduced boom and bust or if I decided to boom (because it was worth it) I was aware that the bust would come and I would be prepared and therefore less sad or upset about it."

#870: "We discussed the impact of trying to do too much on my symptoms and what the real effect of not doing everything I thought

I should do was. Also breaking activities down into smaller units so that they became more achievable."

#886: "The course had more of a pacing element than CBT element. The sessions covered how pacing works, setting baseline etc."

#890: "Pacing was emphasized as a management strategy with the aim to keep a consistent level of activity. We were encouraged to try increasing our activity levels slowly and to try to stick to the new level even on bad days."

#970: "Just told to carry out daily tasks whilst watching for symptoms at which point I should stop for a break."

#977: "How to pace activities housework, ironing etc. small steps understanding the battery of energy."

#978: "Calculating how long I needed to carry out certain tasks. Doing a little each day and try to include minimal increases."

#980: "Teaching me to know my limits and not go beyond them."

#984: "Please note I did GET separately, prescribed by my GP and it was very damaging. Re: pacing, I was asked to keep a detailed note of daily activities and was helped to understand that even watching TV was a tiring activity and stopping in a cafe in the hope of extending a visit to the shops would not necessarily be helpful because being in a busy environment is draining. I realised how taking activities in little bites was so much better and switching between mental and physical activities. I was also taught that going overboard on a high-energy day was a bad idea too. Also stopping an activity just before it became too tiring was good."

#1001: "Planning the day to balance activity and rest. Maintaining a consistent pattern from day to day as far as possible. Dealing with relapses."

#1012: "Writing timetable of what I do in the day and planning rest breaks and breaking up activities."

#1019: "Recording daily activities

for full week, including rest periods and how they used your energy."

#1057: "I was asked to use a diary to record my daily activities with coloured pens to indicate my levels of effort throughout the day. I was encouraged to build upon the daily activities but this is something I would have done as a matter of course anyway. It was not clear when I should be pushing forward and when I should be recovering."

#1094: "I was helped to set up rudimentary activity rules, which governed the number of days (2 per week) I was out of the house or doing a high activity (for me). I specified the number of rest days, or quiet days in between the high activity days. I also made a 3x5 card up of what to do if I crashed while out and set up a kit of dark chocolate, oatcake and husband's phone number, with £10 to get me home if he wasn't available to collect me."

#1098: "The psychotherapist had herself had ME and we discussed ways to slow down and experience less boom and bust."

#1130: "I had to do a task (playing my guitar) and see how long I could do it for each day before I got symptoms so I could find out how long I could do it for without triggering symptoms. I couldn't do it; my condition varies too greatly to find a happy medium."

#1135: "We looked at activities and planned them trying to balance activity and rest and gradually increased periods of activity over a period of time. This increased my symptoms during that time."

#1142: "Energy management, task management."

#1163: "Establishing baseline, switching between activity, rest, goal setting, learning to say 'no' when an activity was outside of capability and how to gradually increase over time, handling setbacks and relapses, looking at how to do things differently and mindfulness."

#1196: "Rest for as long as I do an activity (wash up for 10 mins, rest for





10 mins etc.) get up before 10 every morning."

#1205: "Taught to do things for a set amount of time (e.g. 15mins), then rest for 10mins then another 15 and to stop when didn't recover correctly."

#1227: "Advice on managing my activity."

#1231: "Learning how to do pacing and planning pacing was a big part of my CBT sessions. Pacing helped me to not blow out my limited energy quickly and helped me accept my illness and learn to live suitably within its boundaries with less shame."

#1242: "Detailed information was provided on how to use pacing throughout the day."

#1283: "We were encouraged to monitor our activity & increase it until we relapsed, then rest & start the process again. Not really any different from what usually happens with my disease!"

#1285: "I was supposed to fill out a detailed daily diary about what I did all day. The therapist said we would re-schedule my day to break it up into smaller chunks, with shorter, more frequent rests and activities. The aim was to make me live by a specified schedule rather than do what I felt according to how my body was. Eventually he was going to introduce more physical activities (GET) but we never got to that."

#1288: "Timing how long an activity could be carried out before exhaustion and pain. Noting timings over a course of time. Writing them down. Then in carrying out daily activities stopping before and prior to pain and exhaustion, even if having a rare good day."

#1306: "Suggesting that we always got up at the same time every day; suggesting that we balance activity with rest throughout the day."

#1355: "OT suggested graded activities based on a daily diary I kept and incorporated pacing techniques into my daily routine."

#1366: "Was made to keep a diary with fatigue levels to see how tired I got."

#1368: "To find out what amount of energy I could use without burning myself out and try to do this on a regular basis."

#1385: "Trying to restart and then gradually to increase my mental activity (reading, writing, etc)."

#1394: "The course leaders explained about how to assess your current energy expenditure and how to methodically spread this across the week. We also discussed ways of fitting rest periods into everyday activities."

3:1:2 CBT Courses with Elements of GET

#28: To walk and pace myself each day. This caused exhaustion. To do something - always results in activity-rest-tired-activity circle. To exercise and build up the time each day

#44: "There were several course sessions covering pacing and GET. The GET aspect was sensitively applied: i.e. the focus was on a graded activity as opposed to exercise. Only those who were mildly affected were encouraged to exercise."

#140: "Though the clinic talked about pacing, the reality was that they were asking me to do the same activities interspersed with rest every day, with no flexibility and to do it even if experiencing symptoms."

People with genuine ME have PEM* so there's always fluctuation and an increase in symptoms day(s) after activities. You were told to find your baseline again but this would be constant with people with ME.

This was not energy management pacing, this was a rigid increase

in activity compared to what I was doing with a goal to increase this activity. There was also a 5min aerobic activity that I was supposed to do outside every day, on top of all that. This was with the same goal of increasing until I would be able to do salsa dancing.

No account was taken of my orthostatic hypotension, which is worse during the morning and PEM. The team manager eventually admitted that I shouldn't be exercising with viral infections!"

*Post Exertional Malaise

#197: "They wanted us to pick an activity like walking and gradually increase it. They didn't seem to grasp problems like PEM and OI/POTS. They made us log our activities and wanted us to cut right down on rests and naps."

#288: "GET I had to carry on doing exercises everyday no matter how bad I felt in the belief in time it would make me better."

#295: "Exercise bike, step machine, stretching exercises."

#304: "Multi component programme. As described above: with a very strict expectation of walking for a set time every other day, no more, no less and not walking on the alternate day."

I find this extremely restrictive and feel that my already severely limited life is even more restricted and am finding it almost impossible to remain positive about this programme.

I also feel extremely trapped as there is no other health professional or treatment available to me in my area (or in the whole of X) and if I stop following this restrictive programme I fear I will be thrown off the course as so many of my fellow support group members have been previously and my employers (currently holding my job open for me as I am 'getting help') will terminate my contract if I am no longer deemed to be 'getting help' towards a recovery.



I am frightened about my future and frightened of expressing concerns or doubts to the health professional leading the multi component programme and incredibly frustrated.

#324: "Cycling machine, step machine, mild aerobic exercise."

#367: "The GET was going the Library."

#391: "The whole course seemed to be designed around GET. Each week we would go through my day-to-day activity and each week he would push me to increase it."

#461: "Walking increasing distances."

#462: "Daily walks increased to 2 sessions per day."

#475: "Increasing time spent at work, increases to time spent walking each day."

#537: "I was sent to see a physiotherapist (at Northwick Park & then at Charing Cross). One put me on an exercise bike and forced me to bicycle until I couldn't continue (to establish my "aerobic threshold"). It took me a month to recover, possibly longer (my health deteriorated long term at about this time)."

#540: "I was encouraged to continue my walk each week to the sessions the sessions were weekly with some gaps for meetings or I was too ill unable to attend but I was self-motivated to take a walk each week usually a mile which subsided to once a fortnight during the course."

#569: "The GET was very full on - I was doing pure aerobic activity by the end of the sessions and was struggling with it."

#574: "Balancing: (ergotherapy), relaxation exercises, diet, resting times and choice of activities. Borg: Physiotherapy. Maximum capacity measurement on basis of patient experience measured over a week rather than a one-time absolute maximum capacity test on a good day."

#606: I cannot recall the details, but I was encouraged to try to build myself up physically."



#616: "Tried GET under the supervision of a physiotherapist who quickly realised it was doing more harm than good so effectively concentrated on Pacing elements - "listen to your body" was her expression which I still follow today some 12 years later."

#639: "Encouraged to exercise gently daily."

#675: "I had to walk increasing distances every day, twice a day - 4 lamp posts and back and increase the speed I did it in each time. It started to cause joint and muscle pain and exhaustion, by the end of a week I couldn't get out of bed."

#683: "Walking round the block everyday (very tricky as was exhausted from school) and making sure I had a solid routine so up and dressed and a bath on a night."

#711: "Emphasis on proactively thinking about my symptoms and behaviours to separate normal physical responses to exercise and abnormal responses. Exercise was only what I could do on my worst day."

#883: "Increase with time, even if you are feeling unwell (but also state stop when tired rather contradictory). Use pain relief to

allow for more physical exercise. Physiotherapy used as a way to GET. No concern for posture and other difficulties during exercises."

#917: "Emphasis was on GET - we were given a sheet on "deconditioning" but they were trying to dress it up as "pacing"."

#997: "We had a 4-6 weeks with a physiotherapist. 2-3 weeks in the pool doing basic exercises. We then moved on to the gym for the remaining weeks. At the end of this we were given free membership to a local gym."

#1010: "Physiotherapy and an emphasis on making me stand and walk. I relapsed and became very severely affected and have yet to recover to the illness level I was prior to the CBT and GET, more than a DECADE later!"

#1015: "Encouraged to walk, progressively more over time."

#1033: "I was given written instructions to start exercising and stretching as well as trying to get me to believe I could do things. It also included ways of relaxing and shutting out the world. I was told not to sleep during the day as this will mess up my nights and that is why I wasn't sleeping. This made me very ill."



#1036: "The inference was that if you exercise in a gradual way you would be helping yourself get better which I found very insulting and hence I did not go to the next pace course!!!"

#1104: "Asked to walk a certain distance every day."

#1154: "Stretching exercises and then progressive plan to increase after Programme with feedback to centre in future. Great for the pain-only patients but I knew this was not going to be possible for me."

#1175: "I was simply told to increase my exercise & start walking more."

#1183: "As I was able to breathe better I started with simple up on toes while boiling kettle and expanding these very slowly, I can now walk a little way down the road."

#1202: "I was told to take one step out of my house, and increase this on a daily basis so that I got further away from my front door."

#1230: "Two min very light walking on cross-trainer at home in the morning followed by two min in afternoon. This was to increase to three min the next day and so on. I had to stop after the first week as I could not recover from each session and carried it on to the next."

#1263: "GET and CBT delivered together as one integrated 'pain management' course. Forced to increase every exercise daily."

#1296: "Suggested regular measured walks to stop when start feeling tired."

#1322: "Walking Zumba."

#1331: "Told to start at certain amount of exercise and build up daily."

#1341: "Increase walking by 10% daily."

#1402: "I was asked to start swimming and increase the amount of minutes each week."

#1405: "Encouraged to walk a few minutes per day. Some help in trying to determine current limits."

3:1:3: CBT courses with elements of both GET and Pacing

#49: "We were told to follow our exercise plan daily no matter how we felt. Pacing and CBT were a means of exercising to good health and wellbeing. Group pacing advice: to maintain exercise plan followed by daily living. 1.5 hours instruction, exercise (own pace) relaxation tape."

#79: "Targets were set for walking daily (10 - 20 mins). Energy management plan drawn up with my involvement."

#240: "I looked carefully at my activity and rest patterns by recording this daily with a self-assessment of fatigue and pain. This continued for over 6 months in an attempt to understand my patterns. The Physio helped to assess my baseline level of activity and suggested stretches and exercises which I could do a few repeats with a view of increasing the repeats if no exacerbation of symptoms were caused. However the physio was willing to accept that I could not do these if I also wanted to go for a short walk of ten minutes. She was willing to accept that I was doing as much as I was able and to be able to get out of the house was better for my mental health."

#259: "Encouraged to join in with sport and playtimes at school and have rest periods."

#274: "Given stretches to do on a daily basis and told to increase repetition if no adverse effects felt. The principles of pacing were explained and I was told to keep an activity diary which we then analysed and planned my activities round rest periods – however this was almost impossible to follow through at work because of work pressure and lack of support at work."

#349: "Finding a baseline for activity, keeping a diary that mixed physical and mental activities with rest and relaxation. GET was suggested as a way of building up activities such as walking for one minute one day, then two minutes etc."

#351: "GET – mainly under a different practitioner. Suggestions to walk 5 mins, then increase to 7, then to 10 mins etc. Not very successful."

Pacing – Effective review of activity levels, identifying essential tasks and redistributing other tasks to other people. Not increasing my activity until easily coping with the identified baseline. Still trying to attempt baseline activities on any given day (and baseline only including activities that I could do on my worst days), to maintain activity and routine."

#360: "Was advised to start increasing amount of steps taken in a day/or at a time. Was advised to increase amount of time standing. Pacing was the main part of CBT for me. It included keeping a diary and ensuring regular rest breaks and breaking up of activities."

#369: "Enforced exercise graded to activity level. Discussions of pacing and diary based activities."

#373: "Suggestions of daily walks, building up to further distances each week. Suggestions of staying up in the evenings, later & later each week."

#421: "GET was a physiotherapist, who was utterly useless telling me how to gradually increase my ability to walk further. He couldn't answer my questions or tailor the work to my needs. I think it may have been better with a better therapist."

The pacing was pretty hopeless as it didn't take into account the very real pressures on me as a mother and the lack of options about when and how to modify your energy demands. Great in theory. Hopeless in real life."

#422: "We were taught how to pace ourselves, and discussed GET."

#469: "It was suggested that I tried to walk on the flat for 2 minutes a day and only increase that in increments of 10% when I was able to walk it without any exacerbation of

symptoms for 5 days out of 7. This didn't take into account the fact I could not stop being a parent and having to structure my activities around my child's needs.

I found pacing a more helpful notion. The CBT and as previously mentioned the meeting up with others struggling with the same illness did more to help me see I was normal and doing well to cope at all."

#471: "Encouraged to go for a walk regularly, and massive emphasis on pacing such as having 30min rests at least three times a day, and alternating physical and mental activity, and planning activities each week, keeping a sleep and activity diary."

#519: "I was told to increase my levels of exercise and praised for already pacing, but not told to do pacing particularly."

#560: "The pacing element was introduced before CBT started – keeping a record of activities and tired score and planning activity from the results plus goal setting to increase activity gradually.

The graded exercise was flexible and not encouraged to do exercise no matter what. Guidance notes and advice given and I then decided for myself what exercise to do and when to increase."

#581: "Told to keep a diary & then found baseline. I then paced activities around baseline. GET wasn't guided very well at all. I was just told to do Pilates exercises. But guidance was very vague and they said not to do it if I felt ill."

#587: "Making lists of when to work, and when to rest. Using apparatus to walk up. Cycle on and weights to lift."

#591: "GET was stretching activity and repetitions. Pacing was advocated but we were urged to ignore symptoms and setbacks. I was certainly one of the sickest there. Some people were walking several miles a day and didn't have the symptoms I have e.g. POTS."

#651: "We were told to exercise and build up our resistance to exercise. We received pacing advice and basically everything was pointing to our negative thinking."

#744: "GET gradually increase cycling distance each week. Pacing – throw your washing down the stairs, don't carry it."

#773: "Filling in activity sheets, hourly throughout the length of the course. Pace sheets relating to physical activity."

#810: "Increase exercise in very small amounts, try and pace yourself through the day taking breaks before you need to."

#827: "They discussed GET and left it to the individual if you felt that it was harmful to you then they said it is up to you when you find you starting baseline. I tried walking so far and further the next but it just made me worse so I stopped. I do not believe in GET.

Pacing is a different matter. They said it was boom and bust. You have a good day and you go mad and do everything you needed to do over the last few days when you were ill. Then bust you are ill again and it takes time to get will again and then boom you do it again.

Pacing taught me to prioritise and what is important. What really needs to be done and what are you doing that you can stop. For example, one woman ironed her husband's pants and socks. We all laughed. This taught me to say enough, or no or leave it. I have a list of things I want to do. A small list and if I am OK I may do more. If I am not OK I may do none. It is OK for me to do that.

This is where the cognitive came into place. As a mother you think you have to do everything all the time and you do not."

#938: "Exercise session and chat about previous week re: Pacing and CBT with psych., GP, physio and dietician."

#946: "Gentle exercise increasing slowly in intensity and time management."

#992: "Elements included; gradually walking further each week. Writing ten minutes more a week. Learning to stop an activity when I felt pain or experienced fatigue. Not to over-do a task."

#1013: "If I felt exhausted to first try walking round the garden. If I felt worse to rest, if I felt better to walk round the garden again. Listening to my body and its needs and fitting my life into that."

#1073: "Daily walks around room; different activities for timed periods, such as reading/writing."

#1085: "Course designed to ultimately create a benchmark of physical and cognitive activity that can be sustained on a daily basis."

#1096: "GET – goals set each week – and increased every 2 weeks. Pacing – weekly activity sheets had to be filled in and colour coded – each week an hour was spent going through these."

#1100: "GET – Physio provided a sheet of basic exercises we could try and if we couldn't do then were advised to not continue but to try to walk a little more as part of pacing. Pacing included a diary of what we did and the base levels."

#1118: "Activity planning with meditation and sleeping or rest incorporated. Small daily walks with physio exercises."

#1132: "Most of my sessions with my occupational therapist required setting goals of pacing in a variety of areas of lifestyle i.e. exercise, daily tasks, sleeping. I also attended an exercise programme at the local sports centre to gain strength. The class was tai chi and I also went swimming."

#1225: "Given exercises to do in class and at home. Also taught to pace myself."

#1319: "Pacing: advice good. GET: gentler end of the spectrum. Very gentle start but assumption of definite potential of increase. Assumption that only barrier to increase is the psyche."



Disguised as Pacing – “GET” never mentioned, deceit all round, but approach unmistakable.”

#1334: “Daily pacing advice and daily exercise programme were included within a three-week residential programme.”

#1380: “GET involved going for a walk every day and gradually increasing the length of the walk this led to setbacks, it also involved pacing and rests gradually reducing rest periods.”

X focused more on pacing with physical tasks e.g. ironing counting as activity. There was an acknowledgement that if you lived on your own there was no point in going for a regular walk if it left you absolutely shattered and unable to do important basic tasks for yourself like the shopping and meal preparation all of which counted as activity.”

#1410: “GET involved demonstrating some strengthening exercises and explaining how to implement them, but did NOT suggest keeping going with exercises even if symptoms got worse – was very much within pacing guidelines and felt very safe.”

Pacing advice involved explaining how to pace but wasn't all that helpful – very basic.”

3:2 GET COURSES WITH ELEMENTS OF CBT AND PACING

3:2:1: GET Courses with Elements of CBT

#591: “CBT delivered by psychologist. GET delivered by a physiotherapist who gave the impression that we could gradually return to activity levels of a healthy person. However, when I said I was crashing and bedbound all week after every session and couldn't keep up with the repetitions work she didn't want me to push any further.”

#917: “CBT was main part of the course. They often referred to “pacing” but in fact what they were teaching was GET.”

#946: “Try to change my views about my behaviour and thoughts

and time management.”

#1047: “I found it frustrating to be told to remove the negative outlooks of the condition, as though to sweep the problems under the carpet, when I don't consider my condition to be a psychological condition, but the result of the physical fatigue and pain. As I've maintained doing Pilates prior to and after the diagnosis of ME it is factually incorrect to state that my condition is the result of inactivity. The only thing to ever caused me to be less active is the fatigue caused by this particular condition, and not the other way round.”

3:2:2 GET Courses with Elements of Pacing

#31: “I was encouraged to view my extreme muscle weakness, pain etc as primarily deconditioning. I was told that the amount of progress I made was dependent on the amount of effort and determination I put in. There was some recognition of the fact I needed to rest and recover from exertion. To an extent this was respected, though I'm not sure what the physical reason for it was.”

#36: “I was told that my muscles had nothing wrong with them and that this was a ‘physiological fact’ and that, if I was doing more activity I was therefore better, despite my symptoms being worse. I was encouraged to alternate activity with rest and to ‘listen to what my body told me’. However the better advice only seemed applicable if it agreed with what she thought it should say.”

#77: “Kept and analysed diaries of activity and inactivity. Chose an activity to gradually increase on a weekly basis.”

#288: “You had to GET no matter how you felt, told you to pace yourself after doing something and rest in between. Told me to have a part of the day to lay in silence, could not understand severe ME and how I do that most of the day to cope with this damn illness.”

#711: “Helped to sort out normal from abnormal responses to

exertion. Pacing was done by splitting day into hour chunks and following hard activities by rest/easy activities.”

#840: “I totally was not told either of the explanations for muscle problems given on the previous page as part of CBT – muscle fatigue is centrally mediated rather than due to muscle damage, which is not the same as saying it is a psychological illness.”

The Pacing was designed to ensure that my condition was stable for 2 weeks before I attempted to increase the level of my activities. I did a tiny increase and had to keep at this level for a further 2 weeks and be stable for adding another tiny increase.”

#1095: “As per the CBT, the GET appeared to officially work on the de-conditioning model of ME. However it did stress the need for gradual increases in activity but totally overlooked the rest aspects of Pacing. Therefore whilst the term ‘pacing’ was used, I do not consider it to mean Pacing in the sense that informed members of the ME ‘community’ do.”

#1160: “The physiotherapists would say that my muscle weakness was due to deconditioning, although I still had very large muscles. And my muscle weakness pretty much happened overnight after my pneumonia and has never come back.”

The pacing was done by using a journal and writing down rest and activity periods in the day. I was already doing this though before I'd started my course.”

#1313: “The pacing was very rigid involving writing timed lists and keeping records – all too much overload for me!”

#1364: “Haven't I answered that already? My practitioner agreed that CBT was unnecessary in my case (after questioning me). Gave advice regarding Pacing (which I thought was common-sense and I already practised) like giving maximum times for activities with rest periods in between them.”



3:2:3 GET Courses with Elements of both CBT and Pacing

#03: "CBT was aimed at power of positive thoughts and optimism that could recover provided reassurance and understanding."

Pacing was related to ... activities, providing breaks, changing working arrangements, using adaptations and different ways and doing activities to minimise energy usage."

#44: "The CBT was very general and briefly covered: we had one session covering what CBT was and we talked about 'positive thinking'. We were told how to apply CBT at home. Pacing was covered in considerable detail: filling out activity charts etc."

#49: "Pacing and CBT as support for GET."

#74: "CBT discussed deconditioning/ pacing referred to boom and bust."

#79: "It was an integrated course stressing CBT principles and including energy management via Pacing."

#140: "The course was based on the deconditioning theory. That there is no underlying pathology in ME and that behaviour after an initial viral infection, creates deconditioning."

The pacing was based on gradually increasing activity, doing similar each day but increasing it incrementally, but balanced with short rest periods. NOT PACING.

The CBT had additional descriptions of a typical person with CFS. All of the description plus the deconditioning theory, did not fit with my behaviour, thoughts, personality, exact symptom description and cause, or the precise disease I have."

#173: "Told that negative thoughts and beliefs made M.E. worse. Discussed pacing to use limited energy."

#274: "Talking therapy = CBT. Pacing advice given following an activity diary."

#291: "Charts to fill in about daily

activities to see where pacing could help. CBT and GET were counselling/advice."

#369: "CBT – management of illness and altering views. Pacing – diary based."

#408: "Knowing limits before busting, challenging negative thoughts and learning how to ask for help and say no."

#461: "Increasing exercise, setting achievable goals, being more positive, conserving energy for important tasks."

#771: "General changing negative thoughts to positive, and a little about learning to recognise when to stop and rest before the onset of severe symptoms."

#827: "Boom and bust how to get control of your life back. You are not the illness. You choose what you want to do not the other way around. Pacing to do as much as you are able. Do not push yourself. Take rests in between things."

#866: "The psychologist provided the CBT part of the course and also made references to GET and how it would help me with my M.E. The occupational therapist provided the pacing aspect of the course and also made references to the GET and how it would help my M.E so both advised the GET."

#961: "All elements were combined in an overall Pain Management course lasting three hours per session, 12 weekly sessions."

#1057: "The course encouraged a mix of rest and activity but this was inevitable as that was all I could manage at the time. The course was a talking therapy so inevitably involved some reflection on the psychological factors but suggested practical activities to improve psychological wellbeing, not just introspection as I had experienced on the CBT course."

#1158: "Looked at how overestimating stamina increases symptoms, how fighting against illness increases symptoms, taught to get in touch with energy and respond accordingly to try to manage limited energy more

effectively and smooth out boom and bust patterns."

#1380: "Pacing included taking regular breaks and timing activities to avoid boom and bust. CBT involved looking at behavioural patterns. The people carrying out the course had a preconceived belief that people with M.E. remained ill because being ill had the benefit of other people running round looking after you. I lived on my own and had an elderly mother who relied on me and made no allowances for the fact that I was so ill!"

#1402: "The CBT elements were nothing new to me since I went through the same stuff on the CBT course paid for by my insurer. The pacing elements were extremely useful and I still use what I learned today. It is all very logical but it is not something I had figured out myself by that stage of my illness."

#1410: "Part of an integrated course. CBT involved challenging unhelpful beliefs, how to deal with blips & negative thoughts, etc. Pacing was a brief explanation of how to pace effectively, the theory behind it etc."



3:3 PACING COURSES WITH ELEMENTS OF CBT AND GET

3:3:1 Pacing Courses with Elements of CBT

#38: "During the course of pacing therapy we covered the following CBT elements: we looked at how thoughts, attitudes and beliefs effect the way we feel and behave. We learned about how effective management



of emotional energy can help overall ME management. We looked at how perceptions and interpretations can effect behaviour and we did a situation-response diary. We learned about balancing activity and rest e.g. too much rest will cause lethargy and de-conditioning, too little rest will result in fatigue and an increase in symptoms due to over-exertion. We learned that establishing a routine of rest, activity and sleep will re-programme the body and mind to respond in a more consistent way, so that you gain control over your energy levels and sleep pattern."

#43: "We had a very little info (as far as I can remember) re how to cope with negative attitudes from family and friends etc, and I think prioritising/delegating. Coping with feeling useless due to being so limited. Others in the group could also share how they coped, so it was also a support group and I said that when out I would say to myself 'health not wealth' so I would feel OK about buying food/drink when out to make myself stop for a rest!"

#89: "Positive thinking. Meditation techniques."

#90: "Diary keeping and identification of exacerbators. Activity planning to enable me to do things that did not make me worse and to look for patterns in my activities that made me feel worse. Addressing thinking around what I could and could not do realistically – e.g. helping me to adapt and manage self with confidence."

#168: "It was all about changing negative thoughts into positives."

#234: "The impact of the way you think."

#240: "Looking at my belief systems and any inappropriate behaviours which I'd used successfully as a child but which were no longer appropriate as an adult or after being ill."

#296: "How to avoid negative thoughts, how to cope with depression, to give myself a break and appreciate how well I do cope with the illness."

#350: "It was quite subtle, but things like 'don't research what is wrong with you, because that will make you feel worse,' and when you have established your activity baseline, step up a bit, then keep stepping up until you are much better (not necessarily better)."

#425: "Learning to accept the illness as a long-term part of my life and no longer expecting a miracle cure. Managing grief and mourning the life I had lost."

#704: "CBT elements were not to alter beliefs about illness but used to boost individual's self-esteem or feelings of negativity BECAUSE physically ill."

#914: "Strategies managing feelings."

#940: "The CBT elements were based on looking at beliefs such as thinking we 'should' do things, and to be more realistic about the amount we 'could' do. Also about balance of spending our energy on 'enjoyable' things not just practical things."

#1016: "I was given a pack with an element about how to challenge thoughts and the effect on symptoms that psychological factors can have."

I was also encouraged to find a base line for all physical and mental activities and to try to increase these by 1 minute every 2 weeks, but to listen to my body about any increase. I was monitored every six months."

#1126: "I was given activity sheets to fill in which showed me how I was doing too much in too short a time and it was causing me pain and illness. The CBT showed me how to stop!"

#1153: "Changing mind-set, if it's not in your control; don't worry about it. Amazing the results if you put your mind to it."

#1204: "Only the way I react to stresses etc."

#1394: "The CBT elements were more about ways in which we cope with our illness, such as methods of relaxation/general strategies for organising our day to day living, how to deal with other

people's reaction to ME and our own anxieties by discussing what each of us do already and what we find helpful i.e. pooling/sharing ideas."

#1425: "Allowed to see how all the different aspect impact in different ways on the illness and when used in conjunction they can be of huge benefit."

3:3:2 Pacing Course with Elements of GET

#20: "Suggested trying to walk a bit further without getting fatigued."

#44: "There were several course sessions covering pacing and GET. The GET aspect was sensitively applied: i.e. the focus was on a graded activity as opposed to exercise. Only those who were mildly affected were encouraged to exercise."

#49: "We were told to follow our exercise plan daily no matter how we felt. Pacing and CBT were a means of exercising to good health and wellbeing. Group pacing advice: to maintain exercise plan followed by daily living. 1.5 hours instruction, exercise (own pace) relaxation tape."

#257: "Just told to try and keep active, but at a level that suited me. This was to stop my muscles wasting. It was stressed that I should do slightly less than I felt capable of doing."

#282: Extract: "I was then instructed to GET OUT of my wheelchair – that what I really needed was exercise."

#319: "It was called Graded Activity Therapy. A baseline was established. In my case 50 steps to be carried out each day for two weeks then, providing there was no significant increase in symptoms, the 50 steps were to be increased by 10 % i.e. 55 steps. Again this to be followed for two weeks with the same criteria until I crashed!"

#367: "The GET was going the Library... Boom and Bust. Explanation as to what the body is going through."



#446: "Advice about exercising regularly and gradually increasing it in length of time and intensity."

#495: "These were at my request, being an ex-racing cyclist I needed advice on following an exercise program."

#629: "Just that I was encouraged to specifically focus on improving my walking by cutting down on mental activity and trying to improve the amount I was walking."

#703: "It was recommended to set targets to increase my physical activity (e.g. walking) – but that I should only try to achieve those targets as and when I was well enough to, and not to push to reach those targets if it meant ignoring how ill I was."

#840: "I was told that the muscle problems were centrally mediated, but not psychological; although I did have a positive biopsy showing slight muscle damage, exercise should not be deleterious. The GET was the main object, so once I was stable by doing the same every day for 2 weeks, I added one tiny bit and stayed at that level for 2 weeks before adding another increase."

#910: "It was self-directed, following guidelines to start with a small amount of exercise and increase by increments of 5%, delaying increasing exercise if energy levels were challenged. I found I reached a plateau which was acceptable to the therapist."

#1036: "The inference was that if you exercise in a gradual way you would be helping yourself get better which I found very insulting and hence I did not go to the next pace course!!! Exercise more and you can help yourself and 'cure' ME referred to as chronic fatigue syndrome."

#1180: "Exercise spread out over day – time to recover."

#1182: "Walking for a set number of minutes every day and gradually increasing in accordance with my symptoms (tolerance)."

#1261: "Guided programme of suggested exercises starting

from a very low level. It stated from a maintainable level and the increase was very slow and gradual."

#1371: "I was very ill when I first met with the specialist. She told me not to do any exercise. When I saw her next 2 1/2 months later, she wanted me to start doing 2 minutes at a time on an elliptical. Between that time and the last visit I was too worn out to continue exercising and have to re-think my pacing."

3:3:3 Pacing Courses with Elements of both CBT and GET

#07: "CBT elements – positive thoughts and that it is a physical illness. GET elements – to try to increase activity/exercise. GET increases activity too intensely and too quickly so makes you have relapses. I found that increasing like this made me worse and I then needed to reduce activity/exercise to below baseline pacing level and then very slowly increase to baseline pacing level again."

#23: "Encouraged to take a short daily walk and to gradually increase activity as able. Every time I increased activity I had a short relapse until eventually I had a six week relapse and I stopped trying to increase activity."

#45: "Set myself short-term/long-term goals. Gently/controlled exercise would not make ME worse, positive thinking. How to cope with setbacks. Gentle exercise which was gradually increased. Exercises to strengthen the muscles. Regular rest and relaxation periods."

#79: "Targets were set for walking daily (10 - 20 mins). Energy management plan drawn up with my involvement. CBT – beliefs/targets/negative thoughts. GET – activity levels monitored and tailored to my circumstances."

#140: "The CBT was to get you to change your thoughts and accept that the illness is deconditioning brought on by your habits/behaviour. Plus that you focus on symptoms, over breathe, stay in your nightclothes all day etc. That all you have to do to recover is

follow the GET programme, as CFS is just deconditioning!

The GET went hand in hand with the APT. It wasn't really about managing energy. More about GET balances with short rest, but effectively, you were doing more than your body could do during an illness with immune system dysfunction and/or viral infection/symptoms and mitochondrial dysfunction.

I felt that they didn't fully understand the physiological limitations of genuine ME or understand the differences between CF, CFS (umbrella term), deconditioning and ME.

#273: "How to manage energy and to plan lots of activity interspersed with rest periods. It was a complete treatment covering all elements of CBT pacing and GET."

#274: "Talking therapy = CBT. Stretches for GET."

#360: "CBT = unhelpful beliefs but mainly about the guilt that I had felt in not being able to contribute to family life. Also about blaming myself."

The GET elements were very basic but encouraged me to increase my mobility slowly. Introduce amount of time I could stand up for. Also walking more paces each time."

#383: "Advised to take up some limited exercise daily. Advised to stop trying to get back to how I was before ME, accept it and take up more suitable activities."

#410: "Advised to take regular exercise and "think positively"!!!!"

#695: "Target setting, any barriers to getting better and psychological problems that might get in the way. GET was increase my activity when my symptom were feeling comfortable and increase only just a tiny little bit."

#771: "Altering negative thought patterns and maintaining adequate exercise levels."

#901: "Light exercises – but from the mind-



set that a little gentle exercise is better than none, and then stepping it up gently. CBT – letting us know that negative feeling can have physiological effects but that ME is real and not imagined, but being positive helps."

#964: "Using CBT when feeling low. Using GET to help with exercising and building muscle tone."

#1013: "If I felt exhausted to first try walking round the garden. If I felt worse to rest, if I felt better to walk round the garden again. Listening to my body and its needs and fitting my life into that. They listened to personal issues, and talked about the need for gentle exercise."

#1033: "Positive thinking about recovery. Pushing myself but not too far. Stretching and keeping a pacing chart to show what I was doing and how I was pacing myself."

#1231: "Learning how to do Pacing and planning Pacing was a big part of my CBT sessions. Pacing helped me not blow out my limited energy quickly and helped me accept my illness and learn to live suitably within its boundaries with less shame. CBT and Pacing coincided together, but GET was also encouraged as part of my pacing."

APPENDIX 4: QUALITATIVE DATA – EFFECT OF COURSES ON EMPLOYMENT AND EDUCATION

We asked:

"For some people, their ability to attend work or education alters as result of courses. Please provide any information about changes in your attendance at school, college, university, training or paid work as a result of your course.

For example, you may have changed from part-time to full-time attendance, started part-time having not been for a while, or you may have had to drop to part-time from full-time attendance. Please tell us what happened in your

case, and in particular whether you believe any changes in levels of attendance were a direct result of your course."

Notes:

a) The survey being an anonymous one, the numbers are respondent ID numbers, specified in case a need arises to link with other answers.

b) A few responses indicate that courses were multi component courses or were referred to as 'Activity management' courses though they were recorded as CBT/GET/Pacing courses.

4:1 EFFECT OF COURSES ON EMPLOYMENT AND EDUCATION – CBT

#06: "I attended a CBT course in 2009, the purpose of which was to help with the anxiety/panic which accompanied the deterioration in my condition as a result of the GET. However that 2009 course made matters even worse and I am now a very severe sufferer, being 90% disabled on The ME Association's Disability Rating Scale.

Consequently I have not been able to do, or even contemplate doing, anything work-related."

#32: "I had to leave my paid work as a result of my ... course of CBT."

#79: "I was forced to take early retirement."

#90: "I realised I was making myself worse by thinking that I could work and pressurising myself to try doing so. CBT helped me to realise that I was too ill to work and that I was doing everything I could to help myself get better by Pacing and caring for myself. So, I was still employed when I did the CBT though I was on sick leave. CBT helped me to see that I needed to stop work all together."

#112: "STOPPED WORKING NEVER WORKED SINCE THEN."

#133: "I cut down my work load to part-time then left my previous occupation permanently during my course of CBT which had a beneficial impact on my health as I was physically not pushing

my body to its limits like I was previously."

#137: "I was working 4 days per week pre course (with great difficulty). After course I was unable to work same amount again, now can no longer work at all."

#170: "I reduced hours at work as I had been trying to do too much and I got confirmation that I was too ill to try and keep pushing on. I got confirmation that I wasn't depressed but had a chronic long term illness."

#172: "I received CBT quite some time after I had requested it from my GP. I had been having problems at work because of my symptoms and had had 5 months off. I felt I had already resolved any depression I had experienced and already gone back to work so attending these sessions was putting extra strain on me because of working full time. The only thing they may have resolved was that I decided to go part time."

#175: "Before I had ME, I worked full-time. Following CBT, I dropped to part-time in order to manage."

#240: "I went from initially having to work part-time in an attempt to recover back to full-time work. The CBT helped me realise that even this amount of work was making my recovery less likely so I was encouraged to look to improve my quality of life and ensure I did not worsen and so was encouraged to consider stopping work altogether to enable my body to have some chance of recovery. I feel this was good advice since my physical functioning has improved but not to a level where I can consider returning to work even on a part-time basis.

The CBT help me realise that I was pushing myself too hard to hold onto even part-time work. That I needed to look after myself better to avoid being bed-bound which was strongly suggested could be a consequence if I did not pull back."

#300: "I was attending a college course trying to re-train and after a few



months relapsed whilst attending the CFS clinic since 2006 my symptoms have stopped my life."

#308: "I was working part time during the course. After the treatment I became worse and eventually had to accept medical retirement or redundancy (agreed on medical retirement)."

#315: "Had been put into major relapse by Physiotherapy then sent immediately for CBT, this all resulted in me being housebound and unable to attend school even on the part-time basis in an alternative education base that I was. CBT was a very negative experience."

#317: "As a result of my course I gave up my stressful job in which I was unreliable and performing badly due to ME, and went into higher education, studying Fine Art with a view to becoming a professional artist."

#331: "I was so poorly after the CBT as a result of trying to ignore my illness that I fell asleep for 3 months and had to stop work."

#366: "Could not return to work as all symptoms were made exponentially worse."

#388: "I eventually lost my part time job as a result of attending the CBT course and my health deteriorating. Before CBT I had been able to work on a contract or part time basis when my health allowed it. These periods of slightly better health plummeted."

#395: "Following my course of CBT I am preparing to return to work. Prior to diagnosis with ME I was working full time. I am preparing to make a phased return to full time work starting in the next fortnight."

#421: Extract: "I returned to part time work, ... I think I was the right candidate for CBT and I think it helped me a lot."

#422: "After CBT I returned to work on a phased return but after 5 months my symptoms became worse again, even worse than originally and I have had to take ill health retirement."

#446: "Was less, but not to do with CBT treatment, but more because



we failed to follow the energy management plan carefully enough and didn't recognise the draining effect of the CBT itself (didn't include it in the list of activities)."

#459: "I gradually deteriorated whilst seeing my psychologist, partly because I was having to attend long appointments every week. I had already dropped to part-time at school and very shortly after the course ending I was forced to drop out of school altogether."

#468: "My feelings of anxiety and stress improved after CBT and for that I was able to return to work-full time for 5 months however I am now looking to reduce to part-time hours as I don't have any work life balance."

#475: "CBT encouraged me to push myself further and for longer, when I should have been resting and ultimately left me unable to work at all, having always worked full time. I regret embarking on this course of treatment and wish I had been encouraged to rest instead."

#476: "I was forced to give up my part time job at the end of the course of CBT because I felt I could no longer manage to do my job as well as the CBT. At my assessment I was told my standard had dropped from excellent to good."

The CBT had felt like a 2nd part time job with the keeping of lots of activity charts, at a time when

I could barely manage one job. I couldn't sustain this so I felt I had no choice but to resign."

I did find another part time job about a month after the CBT ended but I was collapsing every afternoon when I came home from work so the CBT did me no favours."

#479: "I have returned to university full time, studying for a masters. My CBT was during my year off from university following my diagnosis halfway through my university course."

#504: "I have had to give up work."

#507: "I stopped a college course after CBT i had already had to give up work."

#545: "I had a phased return to work as a Health Visitor and CBT supported me through a very long process. My confidence as a professional was virtually non-existent and I feel the CBT gave me strategies to cope with work and also the ME."

#561: "Had to resign from work as a direct result of attending the course."

#574: "Started working less hours because maximum capacity for me is less than a normal working day. 18 hrs, or I will get ill. The course helped me to accept this change in perspective."

#606: "I had to suspend my research (towards a PhD) within 1-2 years of the CBT treatment commencing. I was unable to return to university. I have been unable to work since. I think the CBT course contributed significantly to this outcome by confusing matters and damaging my self-esteem, but it was not the only factor."

#631: "Attended University part-time whereas previously I could not."

#638: "I lost my job as a teacher. The CBT helped me to feel less depressed about this."

#663: "Went back to work part time, and five months later full time."



#682: "The part-time study I had always done became impossible. Complete brain-fog."

#711: "Was able to get back to full-time work and part time study. These changes were a direct result of a combined treatment of CBT, GET and pacing."

#772: "Rather than necessarily increasing attendance at work, it helped me to manage expectations of what I was able to do, to be kinder on myself so that I would achieve manageable chunks of the working day without impacting my health too much. So it helped with more sustained, manageable working periods rather than crash and burn."

#784: "Prior to a CBT course I had two hours of home study a week. After the CBT course I managed around two hours of study at college a week. I didn't manage it easily and still felt unwell. The improvement was very slight but there was improvement."

#848: "I had a staged return to work. I have now had a return of the condition after some 2 years relatively clear and am signing off sick. There's a fair degree of stress involved as I am under pressure to go part - time which will not necessarily help at all."

#899: "I was able to attend school 1 hour 5 days a week."

#905: "I was recovering from a relapse and so visiting occupational health when started CBT, had got back to full-time work but then suffered worse flare up including complete shut down just after starting. Not fair to blame CBT was caused by work changes plus other things but CBT was not helpful and the psychologist said I did not need it and was capable of thinking positively etc. already. She used my time for other more helpful therapies."

Since this flare up I have been severely affected and unable to work. I also participated in the FINE trial which included CBT. I think I found some aspects helpful but long term it has had no effect on my symptoms."

#1015: "Was not able to work

following CBT. Condition worsened progressively despite my full compliance and belief that it would help me. Continued activity resulted in a severe worsening of symptoms and becoming bed bound.

Was helpful for minor anxieties, but that level of anxiety was not debilitating at all. It was just a nice bonus to be rid of it. The CBT itself was not damaging in terms of changing mental beliefs. Encouragement to push through when my body was telling me to rest was EXTREMELY detrimental."

#1036: "Had to leave career as a reception teacher."

#1047: "Following the course, it has restricted my ability to work even further, as the CBT did not improve my ME, and all that was preached was to 'reduce what you're doing if you are still feeling exhausted.' As I was still feeling extremely fatigued and run down, when I was only managing to do the basic tasks to get by and survive, I feel trapped to how to get on with my working life etc. and not let the illness rule what I can achieve (or cannot do), considering at baseline I'm still exhausted!"

#1094: Extract: "I had more confidence and knowledge about the ME condition and how manage it. I felt confident to take a part time college course. However, I didn't have enough knowledge to stop overdoing it and crashing from time to time."

#1098: "About a year after the therapy ended I started an afternoon a week of part time study at our local university. The CBT was part of seeing a psychotherapist for 15 months on a weekly basis, and this contributed to me feeling able to take this up. The psychotherapy was not described as CBT, but I understand the therapist used some CBT ideas. I was not informed as to how and when she did this, and only once did she refer to using CBT, so I have completed this whole section on the basis of this slight information."

#1115: "It actually made me re-evaluate my work life balance

and I reduced my hours as had been pushing myself for too many years."

#1142: "Full-time from home with extra university support."

#1163: Extract: "I was in the middle of a phased return to work when I attended the symptom management programme incl. CBT but effort of trying to return to work and attend course was too much and I had a complete relapse within a week of finishing the 6 week course. Have not been able to leave house since except in wheelchair to attend medical appointments. I'm now in 'severe' to 'very severe' category."

#1206: "I was only able to attend school part-time before my course of CBT, and my attendance did not improve after the course. In fact it worsened, and I decreased my hours continually over the next few years until I left school. My initial diagnosis was depression, and whilst the CBT helped this diagnosis, I feel it worsened the underlying fatigue because I was encouraged by myself and others to keep doing things despite how exhausted I was."

#1208: "The psychologist who delivers CBT at X is not trained to do so, so encouraged me to take an adult education course which I did. I managed to attend 4 out of 18 sessions and it made me feel very much more unwell and lowered my mood because it made me aware that I cannot even do that."

When I finished seeing her she wrote a letter saying I had improved and that I have 'flare-ups' – this was a lie – the letter caused me to feel very anxious because it is now on my medical records. In all, my ability to take part in anything has been diminished considerably by attending the psychologist at X CFS service."

#1233: "I have reduced number of hours worked as I wasn't coping. My sick leave is high and due to my ongoing condition my employer is considering ill health retirement."



#1242: "No changes in attendance. My work is flexible and I can work from home when I need to – I was encouraged during the CBT course to gradually do this less and to stay at my place of work for full days (9-5). This made me feel worse so I stopped doing it as soon as the CBT course finished and went back to working from home when my symptoms are bad."

#1248: "My physical symptoms didn't change and I appealed against decision for not getting ill health retirement after completing CBT & pacing showing no improvement and got it."

#1281: "I felt confident enough to work full time. However this turned out to be too much physically."

#1283: "I had to leave my full time education course as I could not keep up while attending the CFS management course."

#1293: "I did not officially change my time on the course, (I was not allowed to do so, even though it was recommended by my GP) but I had to miss so much my tutors marked down what work I had done, openly admitting it was because I had not been in their lectures. Having struggled so much to complete all the work only to find it illegally down marked I was heartbroken. I was told if I appealed I would be failed on everything as I had missed over 20% (but not more than 25%) of the lectures. It was so unfair. If I had had any other problem other than ME I don't believe I would have been treated like this, but with compassion and understanding. Other people on my course with much less severe problems missed far more than me and were given credits."

#1385: "Had to stop full-time work."

#1402: "There wasn't any change in my ability to return to work after the course. Because my CBT was paid for by an insurer I was pressured to enrol in a return to work programme immediately after the course and used up significant energy fighting this."

The actual CBT course made me worse because of the distance I had to travel and the frequency of the sessions. It was simply too much for me and my symptoms worsened. The CBT practitioner I saw even wrote to the insurers and explained the deterioration in my health and recommended my treatment be delayed but the insurers refused and continued to pressure me to return to work.

In conclusion, I cannot be certain whether it was the CBT itself that worsened my symptoms or the pressure I received from the insurers. My personal view is that if the CBT treatment was closer to home such that the travel did not worsen my symptoms, I believe the CBT would have had no effect on my symptoms (rather than a worsening). I don't think it would have improved my symptoms because I am naturally optimistic and positive and most of the CBT recommendations I was doing already."

#1425: "Ability to discuss needs with employer improved. CBT therapist also met employer which had a massive positive effect."

4:2 EFFECT OF COURSES ON EMPLOYMENT AND EDUCATION – GET

#02: "Paid work much more difficult – much more time off."

#06: "I had left university in 2008 with a first-class degree in Engineering, hoping for a career in manufacturing engineering which had been my objective for many years. However, I realised I needed to improve my health as even the moderate ME/CFS from which I was suffering would have prevented me starting such a career."

I was enrolled for an ME/CFS self-management programme by way of a group course provided by the NHS X Chronic Fatigue Service which took place in the later part of 2008.

However, instead of improving my symptoms as hoped, the effects of the GET section of the course were so bad that I have been severely

affected ever since and unable to begin a career."

#32: "Gave up full-time work retired due to ill health."

#74: "It is hard to follow the GET principals and work full time. I did feel better when off work and concentrating on the GET principals but this soon lapsed once back at work. I was still unsure and sometime unable to attend social functions as I 'paid' for them after a couple of days. This makes you not go out as you know what you will feel like a few days after. I love my work and feel I make a difference so believe my work is important so sacrifice my social / weekend life to be able to work. This still takes its toll as some days I need to work from home as I can either use physical or mental energy and not both. Having relatives and professionals who do not believe this syndrome exists doesn't help with your daily life."

#95: "After initially starting to recover from a relapse in 2009, worst relapse I've had in 10 years of ME followed pressure to embark on a back to work by my employer. The GET course was to try to build up stamina to cope with working. The effect on my mobility over a year on is now I've moved from mod to severe ME. I would like to stress the Physio was very responsive to my situation and very quickly adapted the course around me and my capabilities – or lack of them!"

#137: "Had to give up work after course due to increased severity of illness (3 years ago)."

#162: "Part-time home tuition to nothing so far for 2 years except an Art lesson."

#176: "Following GET treatment I have been unable to work again."

#196: "After a year's GET I was able to return to work part-time and after a further six months, full-time."

#223: "I went through a course of treatment based on CBT and GET principles; before this I was working but had reduced to part-time (4 days a



week, no overtime). Because the treatment had no effect on my symptoms, I was able to apply for and was granted ill-health retirement and am now retired."

#291: "Unable to continue my job unfortunately."

#297: "I had slightly less attendance at school after GET; I couldn't cope going every day."

#352: "Reduced to part time hours and a lot of sickness absence."

#366: "Could not go back to work."

#408: "Had to give up working full time and still am unable to work at all."

#446: "Not sure it had any correlation. I was gradually increasing what I did, including number of lessons at school and amount and eventually intensity of exercise. As I increased the intensity of the exercise, that's when my plan stopped working and I started having good and bad days and then missing some times at school. "

#459: "I was forced to drop out of school entirely after GET, whereas before I was able to attend school for at least 2-3 hours per week."

#470: "I was off from work for a couple of prolonged periods."

#490: "I took early retirement; fortunately I had an NHS pension. How you cope otherwise I do not know."

#517: "Not able to work."

#561: "Had to leave work."

#574: "Changed from part-time to even less hours."

#578: "GET resulted in me having to give up work. I was encouraged to exercise more and more over a period of nearly a year and the psychiatrists would not believe me when I told them it was making my symptoms worse.

They discharged me worse than when I started and to this day it makes me angry that they did not listen to me. They were so caught up in their mind-set that 'exercise is good for you' that they could not accept it was doing me harm."

#581: "After my CBT/GET my ME was unbearable and I have not been able to return to work."

#629: "I went from full-time work to four hours a week. Deterioration was gradual as I continued to do the exercise and then I suddenly had a major relapse which has (thus far) caused permanent damage."

#647: "Had to give up school and even home tuition completely."

#655: "Was attending part time school, after GET was unable to continue with education."

#656: "I had to drop out of university because I was no longer well enough to study. I don't think this was entirely the fault of the GET course but it definitely contributed to my decline in health."

#666: "Whilst doing GET I had to keep reducing my work hours due to worsening of ME. Eventually had to give up work entirely, and I have been unable to work ever since."

#704: "I became bed-bound and was unable to do any work or study at all for almost 2 years post-GET."

#706: "In the short term I had to work more flexibly from home as there were days when I could not cope if I had done too much exercise in the pool."

#711: "It allowed me to go from part-time work to full-time, and get back to part-time study."

#743: "Significant and permanent change in level of ability to perform paid work and manage my financial affairs as direct consequence of course of GET."

#877: "Part-time education, to no education. Believe it was the result of GET."

#931: "I gradually had to reduce my hours at school at the time until I left secondary school."

#936: "I was unable to maintain my part-time job and became housebound and largely bedbound too."

#939: "After GET, any hope of

returning to school faded as my symptoms worsened so much."

#950: "Paid work stopped."

#991: "Had graded hours at work at first but was told I had to be working full-time including shifts within 8 months. However, I stalled at 4 hours so I lost my job as a WPC. Changes in my levels of attendance were a direct result of the course of treatment. I felt they were rushing me to be 'cured'. After I left I asked and received my personal file and my concerns were justified."

#1017: "Couldn't attend high school."

#1076: "I had to drop from part-time to around an hour a week, my whole body and mental functions were affected by GET for an extended period of time. In the end I had to drop out."

#1142: "Unable to work or study at all."

#1180: "Had to change to part-time work because my workload was too high. Have a poor employer."

#1221: "I simply changed carer and moved away. I was still bed-bound. Eventually through a year's rest and Pacing I got a little better but that was Pacing and small amounts of swimming – NOT GET. With GET you push yourself. I was always told to do 25 percent more than I felt able to. Completely the wrong advice. With Pacing I managed to regain some functionality by doing tiny fragments on my best day and 25 percent LESS than I felt able."

#1261: Extract: "I continued with the GET programme which allowed me to become well again and to start another career.

I am convinced that the fully guided GET programme on the 2nd occasion prevented the boom and bust cycle, suffered in first ME symptoms, which lasted 7 years.

The GET programme provided greater knowledge of what is happening and a sensible progress (rather than simply doing as much as





possible as I did on the first time with ME).

Presentations from several past programme members who had recovered from ME, assisted in me trusting the slow progress guide. Others on the same programme did not have (or make) the time to follow the guidelines and did not progress at the same rate. It may also not suit everyone.

Since GET treatment I have returned to good health going to university for the first time and becoming a part time teacher. I now attempt to follow the GET guidelines after any viral illness."

#1339: "Found University more difficult. Needed longer to do coursework and more time for exams."

#1402: "GET made my symptoms worse so I was even further away from making a return to work."

#1419: "Have not worked for 3 years due to extreme fatigue. Will start part-time work in September. GET has made me fitter and more confident, as well as taught me to regulate sleep patterns and Pacing. However, it has not cured the ME.

During GET I also took homeopathic treatment and meditation, as well as being careful with food and taking supplements such as magnesium and antidepressants. So I would say that there have been other tools and therapies that have helped alongside the GET.

I think GET on its own may not have enabled me to try to go back to work. I don't know if I will

be able to sustain work for 20 hrs per week and a daily commute. I am a bit anxious. I still have significant memory impairment and cognitive dysfunction. I have applied for a job that is 3 grades below what I used to do, so to keep stress levels and responsibilities low."

4:3 EFFECT OF COURSES ON EMPLOYMENT AND EDUCATION – PACING

#43: "I was able to progress through various training courses, then take on some voluntary work, then do some part-time work gradually increasing the hours in these added up to 13 hrs per week. I then started paid work for 16 hrs a week, experienced stress with ... caught a bad cold/virus, was driving further, had to give up work after 5 weeks, was too ill to return etc."

#137: "Pre-Pacing full-time work. Post-Pacing can no longer work."

#158: "Went from no work to part-time work after following Pacing routine."

#273: "I am no longer able to work."

#291: "Unable to continue to work."

#383: "Given up part-time job I had at that time and now working part-time for myself."

#395: "I am preparing for a phased return to full-time employment following a period of sickness absence due to CFS/ME. Pacing therapy has allowed me to recover sufficiently to prepare for a return to work (in the next fortnight). Pacing therapy has provided the key strategy for managing activity, allowing a gradual return to significantly improved energy levels, and a reduction in most of my CFS / ME symptoms. I will continue to use pacing therapy to manage my return to work within the Pacing model."

#442: "Before Pacing I had to drop all my GCSEs but one that I had to work on from home. During Pacing I managed to do 3 more GCSEs one year and 2 the next. After 3 years of Pacing I went to sixth form college part-time, which became

full-time the next year. I believe this improvement is completely due to Pacing."

#446: Extract: "As I got used to Pacing, I started to be able to do more and had lessons at home, which increased. As I felt better I gradually increased my exercise and activities."

#540: "Dropped a college course of one session a week of 2 and a half hours."

#619: "I continued with part-time study, but was careful to break down study sessions into small, manageable chunks. As I was writing a thesis I had very few contact hours anyway so I could work from home."

#638: "I went self-employed so it is easier to Pace."

#654: "I believe my sick days at work increased as a result of Pacing therapy."

#657: "After the course and with strong analgesics I was able to continue working full-time for some years. However, I was not able to continue with the practice of the Pacing Therapy due to pressures of work and after having being dismissed from one job due to my condition with a somewhat untrue reason but I felt that taking a few minutes morning and afternoon for Time Out and resting became a problem for them.

I am not able currently to continue with the therapy as I need to work but have experienced a massive deterioration in the last 6 months and have been off work for the last 4 months. I plan to return to work in July but I am not sure how this will be achieved but achieve it I must!

The Pacing Therapy was a life saver for me at the time (late 1990s) and enable me to continue working full time and continue living in a reasonable fashion albeit my social life disappeared completely as I was saving my energy for essential tasks."

#695: "I slowly started getting back to school I am now at university full-time. I was



bedbound for three years in late primary/early teens."

#740: "I switched from full-time to part-time. My illness worsened so I took this decision to ensure I was Pacing."

#742: "Had periods of time off before course due to viral relapses. Course helped me stay at work for a couple of years more but further viruses worsened the situation and I left work 15 months ago to get better properly rather. So far this is working and immune system has returned to normal. Have now got autonomic dysfunction in the form of high standing heart rate but this also is slowly improving."

#770: "Pacing (which I worked out before I received proper therapy/training about it) has allowed me to go from extremely poor school attendance, to almost full-time, getting 2 A-levels and 3 AS levels. It's also allowed me to graduate from University (full-time). It only works to a point though. I am now in a one year job which I just can't find my rhythm for, probably because it's just too much for me."

#901: "Stopped work (having previously reduced from full-time to part-time) altogether, having realised just how unwell I was making myself by forcing myself to carry on being "normal" and going to work."

#968: "The only thing that has helped by symptoms has been to reduce the time I spend at school and on activities. I reduced school to 2 hours a day and stopped my dance and athletics groups altogether."

I still have flare-ups and some symptoms are always there still, but at least now, I'm not always feeling ill. I can now manage to do part of my PE and dance classes at school but aerobic exercise always makes me feel ill.

Pacing has helped reduce the frequency and intensity of some of worse symptoms but I don't feel I'm getting better. I want to be able to go to school full-time and do sports and dance again, but every time I try to do more, I'm ill again."

#1013: "I find self-management pacing very useful. I have managed to attend a short college course in the evening. I plan to do nothing else that day or the day after, but Pacing allowed me to attend."

#1016: "Although the Pacing really helped by that time my local authority had decided I was no longer competent to teach and I retired on the grounds of ill health."

#1036: "Had to leave career as reception teacher due to ill health as advised by my G.P."

#1047: "When I incorporated Pacing, my symptoms appeared worse. Due to the time it took to complete every task, it became much more exhausting and strenuous, without feeling as though I was achieving anything. Pacing is definitely not practical or realistic in a working environment."

#1126: "I have applied to study part-time this September which I would not have been able to do without the Pacing information and the CBT."

#1142: "Able to attend full-time university from home with university support."

#1151: "Pacing helped me with my school work, which was part-time and stayed part-time. Previously, I was studying in bed. Pacing helped me to find correct posture, sit up at table while studying, concentrate for short-periods only, etc."

#1153: "I reduced my working days from 4 to 3, doing Mon, Wed, Fri, so I had a day of rest in between. Said no to a lot of sports I used to play and focused on family life managing to do a bit of everything, consistently using the Pacing which is very effective."

#1180: "Went part-time from full-time as could not manage workload. Poor employer and lack of support."

#1231: "I stopped attempting to go back to high school and focused on gently studying courses from home."

#1394: "During the times that I have paced my activities I have done so in a flexible way and began doing it more after I had left my job. I was able to do a small amount of temporary part-time work and study (which involved attendance on two evenings each week for a year)."



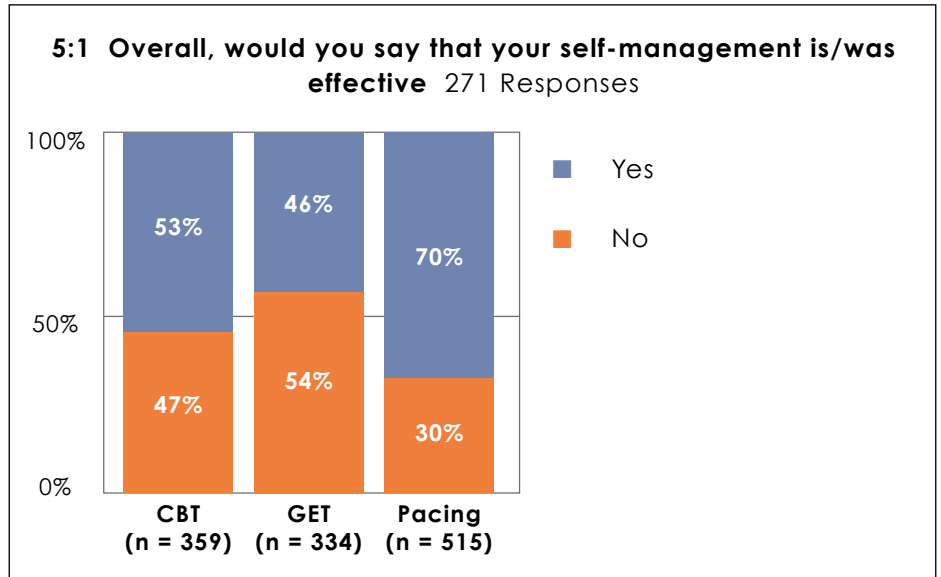
**APPENDIX 5:
QUANTITATIVE DATA –
SELF MANAGEMENT**

Part 2 of this report will contain full details about self-management. In this Appendix we only set out the data gathered about self-management that has informed our recommendations on developing illness management programmes.

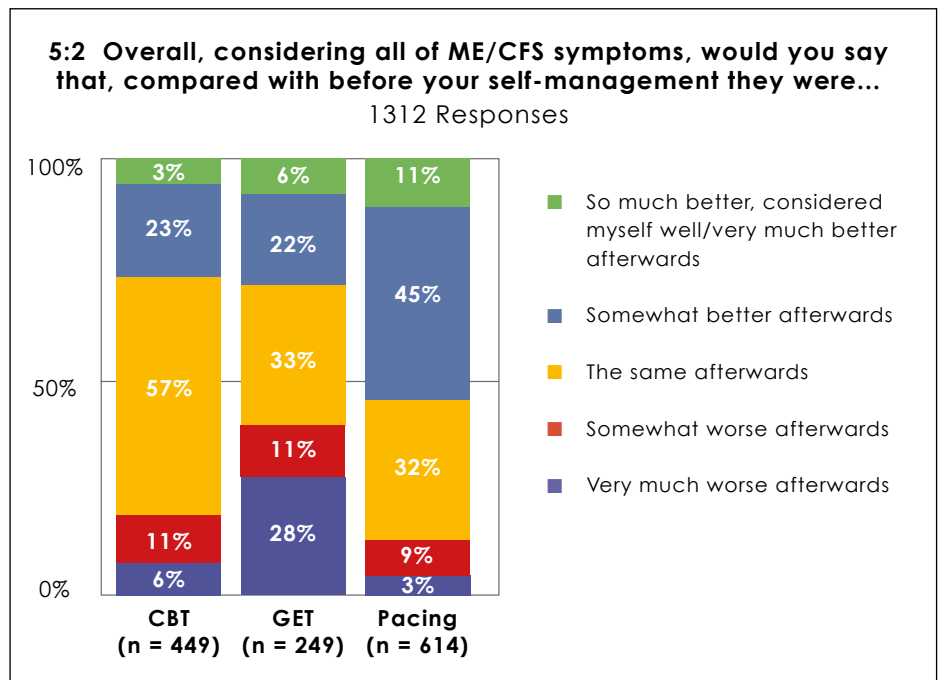
556 respondents reported on self-management of symptoms using CBT principles and practices, 331 on using GET principles and practices and 634 on using Pacing principles and practices.

81% of the respondents reporting on cognitive behaviour had had a CBT course or consultation, 68% of the respondents reporting on graded exercise had had a GET course or consultation and 55% of the respondents reporting on Pacing had had a Pacing course or consultation.

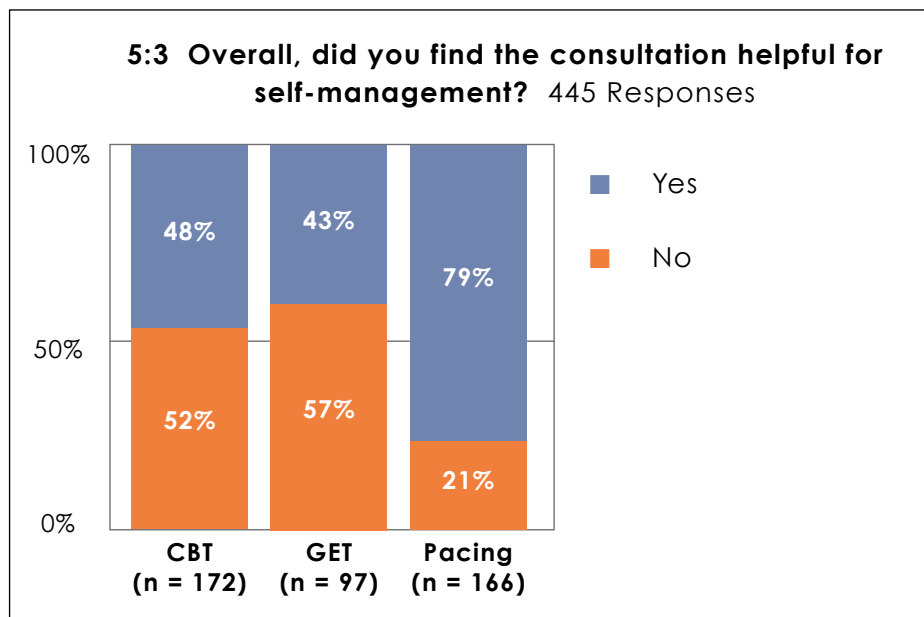
5:1 Was your self-management effective?



5:2 Overall, how were your symptoms after you began self-managing your illness compared to how they were before?



5:3 If you had a consultation, did you find it helpful for self-management?



APPENDIX 6: PREVIOUS PATIENT SURVEYS

Part 2 of this report will contain full details about self-management. In this Appendix we only set out the data gathered about self-management that has informed

our recommendations on developing illness management programmes.

556 respondents reported on self-management of symptoms using CBT principles and practices, 331 on using GET principles and practices and 634 on using Pacing principles and practices.

81% of the respondents reporting on cognitive behaviour had had a CBT course or consultation, 68% of the respondents reporting on graded exercise had had a GET course or consultation and 55% of the respondents reporting on Pacing had had a Pacing course or consultation.

6:1 PREVIOUS PATIENT SURVEY RESULTS – CBT

Note:

a) In 3 of these surveys CBT was shown to have done more harm than good.

CBT Results	Nationality/ Publication Date	Number of Respondents	Terms used; Useful, Helpful, Positive, Improvement, Better, Satisfactory	Terms used; No effect, No change, No impact, Neutral	Terms used; Harmful, Made worse, Dis- improved, Deterioration, Not acceptable
C.F.I.D.S.	USA 1999	160	67%	23.8%	10%
AfME	UK 2001	285	7%	67%	26%
25% ME Group	UK 2004	437	7%	Not stated	93%
AfME Scotland M.E./CFS coping exercise report	UK 2007	160	38.8%	43.7%	17.5%
Koolhaas et al.	Netherlands 2008	100	32%	30%	38%
AfME/AYME: What progress?	UK 2008 (Since 2005)	699	50%	38%	12%
Veer et al.	Netherlands 2008	115	30.4%	42.6%	27%
Bjorkum et al.	Norway 2009	311	56.9%	36%	7.1%
MEA (re symptom change)	UK 2010	997	25.9%	54.6%	19.5%
MEA (re acceptability) ¹⁸	UK 2010	976	62%	Not asked for	38%
Total/Average %		4180	38%	34%	29%

6:2 PREVIOUS PATIENT SURVEY RESULTS – GET

Note:

a) In 6 of these surveys, GET was shown to have caused more harm than good and the overall percentage indicated that more harm is done than good. Conversely in 3 more good was done than harm.

b) The 25% Group report 'March 2004 Severe ME Analysis Report' was on a survey of their members all of whom have severe/very severe ME/CFS and noted that not all members had severe ME before GET and that 82% were made worse by it.

CBT Results	Nationality/ Publication Date	Number of Respondents	Terms used; Useful, Helpful, Positive, Improvement, Better, Satisfactory	Terms used; No effect, No change, No impact, Neutral	Terms used; Harmful, Made worse, Dis- improved, Deterioration, Not acceptable
ME Action	UK 1990	127	37%	13.4%	49.6%
C.F.I.D.S.	USA 1999	462	61%	11%	28%
AfME	UK 2001	1214	34%	15%	50%
25% ME Group	UK 2004	437	5%	Not stated	96%
AfME Scotland M.E./CFS coping exercise report	UK 2007	172	11.6%	14%	74.4%
AfME/AYME: What progress?	UK 2008 (since 2005)	699	45%	21%	34%
Veer et al.	Netherlands 2008	142	43%	23.9%	33.1%
Bjorkum et al.	Norway 2009	620	13.1%	8.2%	78.7%
MEA (re symptom change)	UK 2010	906	22.1%	21.4%	56.5%
MEA (re acceptability)¹⁸	UK 2010	888	47%	N/A	53%
Total/Average %		5667	32%	13%	55%

6:3 PREVIOUS PATIENT SURVEY RESULTS – PACING

Note:

a) All 9 surveys indicated that much more good was done than harm and the average percentage of good was far higher than in any of the CBT and GET survey results.

CBT Results	Nationality/ Publication Date	Number of Respondents	Terms used; Useful, Helpful, Positive, Improvement, Better, Satisfactory	Terms used; No effect, No change, No impact, Neutral	Terms used; Harmful, Made worse, Dis- improved, Deterioration, Not acceptable
C.F.I.D.S.	USA 1999	601	97%	3%	0.2%
AfME	UK 2001 AfME members	2180	89%	9%	1%
25% ME Group	UK 2004	437	70%	Not stated	30%
AfME Scotland M.E./CFS coping exercise report	UK 2007	298	86.5%	9.6%	3.6%
AfME/AYME	UK 2008 (since 2005)	1750*	82%	15%	3%
Veer et al. Management trying to balance between activity and rest	Netherlands 2008	172	57%	33.7%	9.3%
Bjorkum et al.	Norway 2009	804	96.4%	2.1%	1.5%
MEA (re symptom change)	UK 2010	2137	71.2%	24.1%	4.7%
MEA (re acceptability)¹⁸	UK 2010	2047	88%	N/A	12%
Total/Average %		10426	82%	11%	7%

*Total number of respondents estimated to be c.1750. Total survey response 2,763.

APPENDIX 7: CONCERNS ABOUT THE REPORTING OF RCTS

In 2000 and 2008 14 CBT Randomised Controlled Trials (RCTs) had been reviewed by the Cochrane Collaboration, a multinational independent network of medical professionals, researchers and policymakers.

Only one had any data to assess patient acceptability and none of the studies had good quality data related to adverse effects. Drop-out rates averaged 16% across studies but definitions for what constituted "drop-outs" varied and reasons for attrition were not detailed; a third of the studies had drop-out rates over 20%. Concerns were expressed.

In 2006, a systematic review by Chambers and colleagues of the same set of GET trials and most of the same CBT studies echoed similar concerns:

"There is limited evidence about adverse effects associated with behavioural interventions. Withdrawals from treatment in RCTs suggest that there may be an issue but the evidence is often difficult to interpret because of poor reporting."

In 2011, an in-depth exploration of the issue of the harms reported was published, 'Reporting of Harms Associated with Graded Exercise Therapy and Cognitive Behavioural Therapy in Myalgic Encephalomyelitis/Chronic Fatigue Syndrome'.⁵ Using the guidance issued by the Consolidated Standards of Reporting Trials (CONSORT) for the reporting of harms in RCTs, problems were identified with the reporting of harm caused by CBT and GET.

Specific concerns about the reporting of the PACE Trial have been noted in the Introduction to this report at 1 (g) – page 17 – above.

APPENDIX 8: QUESTIONS ASKED IN SURVEY – ANSWERS NOT USED IN REPORT

Notes:

a) We have omitted answers to questions that did not lead to Key Findings.

b) Some answers have been used in narrative or calculations and have not been set out in charts in Appendix 2. For example: 'Do you have ME at the moment?' 'Which of the following statements best applies to you?' Where this is the case we have detailed such questions below.

c) The questions numbers refer to those from the paper version of the survey. The online survey programme is no longer available but in any event, if a respondent chose to skip questions, the number of his next question followed his last.

d) Apart from the first general questions, the survey was split into 3 sections, one for each of the three 3 interventions. Accordingly, the numbering frequently shows three repeat questions.

e) Full responses are available upon request.

8:1 QUESTIONS ASKED IN SURVEY – ANSWERS NOT USED IN REPORT

Q1. "Do you have ME at the moment?"

Note: Responses used in calculations.

Q5. "Have you had a positive diagnosis of ME?"

Note: Those not diagnosed were excluded from the report.

Q7. "To the best of your knowledge, what was the main trigger factor in the onset of your ME?"

Q9, 85, 157. "Which of the following statements best applies to you?"

"I have received an entire course,

or more than one course/I have received part of a course/I have never received a course but I have self-managed my ME using X principles/I have never received a course nor self-managed using X principles, but I would have liked to have been offered a course/ To the best of my knowledge I have never followed X Therapy principles."

Note: Responses Used in calculations.

Q11, 87, 159. "How was the course paid for?"

Q14, 90, 162. "Who recommended the main course practitioner to you?"

Q17, 93, 165. "Thinking in more detail about your particular symptoms, please could you indicate which of the following ME symptoms you experienced before the course, to what extent they affected you and how far they altered after your course."

Note: The report does not include details of the degree to which respondents were affected before courses (i.e. slightly or significantly).

Q19, 95, 167. "On balance, for how long would you say your ME symptoms improved following the course of CBT/GET/Pacing?"

Q20, 96, 168. "On balance, for how long would you say your ME symptoms remained worse following the course of CBT/GET/Pacing?"

Q21, 97, 169. "On balance, for how long would you say your ME symptoms remained the same following the course of CBT/GET/Pacing?"

Note: The purpose of the question was to ascertain whether follow up courses or consultations were needed. Data about this will be covered in part 2 – self management. Other quantitative data gives sufficient evidence for the recommendations made in this report.

Q22. CBT section only:
"Please read the list below which contains



three of the most common types of mental health/psychiatric problems that may occur and indicate which, if any, you experienced before your course of CBT, to what extent they affected you and how far they altered following your course of CBT."

Note: The list was anxiety, depression and stress. The report does not include details of the degree to which respondents were affected before courses (i.e. slightly or significantly).

Q26, 100, 172. "Was the reduction or stoppage of your benefit after you self-managed using CBT practices and beliefs a voluntary decision based on improvement that had occurred in your symptoms?"

Q28, 102, 174. "Did your therapist ever..."

Suggest that there was no need to alter your belief as to the cause of ME/Suggest that you should consider believing that ME is a psychological illness/Suggest that you should consider believing that ME is a mixture of a psychological illness and a physical illness/None of the above/Don't know/can't remember."

Q30, 104, 176. "Please state the name of the online course supplier."

Q31, 105, 177. "How many sessions were in a full course?"

Q34, 108, 180. "Approximately how many other people were in your group, including you?"

Q36, 110, 182. "How frequent were the sessions?"

Q37, 111, 183. "At or around the time of your course/self-management of symptoms using CBT/GET/Pacing principles, if you also underwent any other ME related course of drug treatment or therapy such as a GET/Pacing/CBT course or a complementary therapy course, maybe in courses as part of a tailor-made multi-component programme, please provide details here."

Questions for those who have had a consultation with a health professional but have not been

offered a course of treatment under the NHS or have been offered an NHS course but not taken it up:

Q76, 148, 220. "Have you ever had a consultation with a health professional about X Therapy?"

Q77, 149, 221. "Why did you refuse an NHS course?"

Q78, 150, 222. "How many years had you had ME for before you attended the consultation when CBT was discussed?"

Q79, 151, 223. "Who was the consultation with?"

Q81, 153, 225. "How would you rate your symptoms at the time of your consultation?"

Q82, 154, 226. "Thinking in more detail about your particular ME symptoms, please could you indicate which of the following you experienced at the time of your consultation?"

Note: 11 symptoms were listed.

Q83, 155, 227. "Do you think you could have benefitted from receiving a course?"

Q84, 156, 228. "Please tell us why you feel that a course could have been beneficial and what benefit you think you could have got from the course."

Q44, 118, 190. "Is there anything further that you would like to say about your course? This could be anything from whether your CBT/GET/Pacing is part of a tailor-made multi-component programme, how you felt about CBT/GET/Pacing, the course and the course practitioner, to what effects it had on your health and lifestyle (education/work/family/social life).

Please include here any further positive or negative effects that the CBT/GET/Pacing course had on you in terms of your use of pain killers, or any changes that your doctor made to your medication around the time of your course."

Note: Appendix 1 lists 84 responses only, limited to what makes courses succeed or fail.

Q229. "Please could you tell us where you heard about this survey?"

APPENDIX 9: REFERENCES

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11: Chambers, D. et al. Interventions for the treatment, management and rehabilitation of patients with chronic fatigue syndrome/Myalgic encephalomyelitis: an updated systematic review. J R Soc Med. 2006;99:506-20: <http://www.ncbi.nlm.nih.gov/pubmed/17021301>

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