All-Party Parliamentary Group on ME

Inquiry into NHS Service Provision for ME/CFS

March 2010

Contents

Foreword	3
Introduction	4
Limitations of the Inquiry	4
Review of Current Treatments	4
Review of Adult Services	9
Review of Children's Services	12
Training	14
Research	16
Disability and Benefits	16
Conclusion	17
Recommendations	18
Appendix 1: APPG Inquiry on NHS service provision for people with ME: Terms of reference	21
References	24

Foreword

The All Party Parliamentary Group on M.E. (Myalgic Encephalomyelitis) strives to support the improvement of health and social care of all people with M.E. in the UK.

The APPG accepts the WHO Classification of M.E. (ICD G93.3) as a neurological condition and welcomed the recognition by the Department of Health that M.E. is a long term neurological condition.

Department of Health funding in 2004/05 and 2005/06 resulted in the establishment of 13 Clinical Network Coordinating Centres and some 50 Local Multidisciplinary Teams. However subsequent changes in NHS organisation and budget setting arrangements have since made it far more difficult to establish the level of investment into the care of these patients. It has also become apparent that some of these newly established secondary services are having to cope with significant reductions in funding. As a result, some have either closed or are under threat of closure.

Patient group surveys and letters to MPs and members of the House of Lords continue to identify high levels of patient concern about the services which are being provided and further concerns about the way in which the recommendations contained in the 2007 guideline on ME/CFS from NICE could result in an inflexible approach to management.

The APPG therefore decided to conduct an inquiry into NHS services for patients with M.E. in England, recognising that responsibility for delivering NHS services in Scotland, Wales and Northern Ireland is delegated to the National Assemblies.

Our report makes 11 key recommendations that are vital and urgent for the long overdue improvement in the Government's support to the 250,000 people with M.E. in the UK and their carers.

I place on record my sincere thanks to all those who gave written or oral evidence to this inquiry, to those who have analysed the large volume of data that it produced and to my Parliamentary colleagues who formed this group with me, namely the Countess of Mar, Peter Luff MP, Andrew Stunell MP and Tony Wright MP for Great Yarmouth.

Des Turner MP
10 March 2010

Introduction

This inquiry arose as a result of long-term concerns that the National Health Service (NHS) provision for people with ME/CFS was not meeting their needs.

As stated in the terms of reference, the overall goal of the inquiry was to obtain information from key individuals and groups involved with ME/CFS, including patients, carers, charities and service providers. The terms of reference seek to determine if the current service provisions offered are fit for purpose and what areas need to be improved.

ME/CFS is an extremely complex disease covering a range of symptoms and clinical presentations. There is currently no scientifically proven cause or cure. Treatments and coping strategies are largely designed to enable patients to manage their symptoms. It is therefore important that patients receiving treatment are able to access the best possible care and support in a multidisciplinary setting. It is also vital that these services are of the highest quality across all primary care trusts (PCTs) within England.

The APPG issued an open call for written evidence requesting submissions from patients, carers, charities and service providers, in particular PCTs. Evidence was sent to the APPG through tailored questionnaires for patients and PCTs. The patient questionnaire was published on the APPG on ME's website and was also distributed to patients through the ME patient groups. In total, more than 400 responses were received. The number of submissions and the number of people wishing to remain anonymous persuaded the APPG not to list the names of those who submitted written evidence.

Limitations of the Inquiry

This Inquiry had very scant resources with which to collate and analyse data from the large volume of information that was submitted. We have made no attempt to write up everything in this report. Rather we have satisfied ourselves that the main issues that arise for adults and children with ME/CFS have been included and that the evidence that we quote is representative. The most important part of the report is the section on our conclusions and recommendations.

Review of Current Treatments

According to the NHS, the main symptom of ME/CFS is severe fatigue following almost any mental or physical activity[1]. This does not go away with sleep or rest and limits usual activities[2].

The fatigue experienced by patients is mental as well as physical and can been described in the following ways;

- It is a different type of tiredness from what the patient has experienced before
- After sleeping patients do not feel refreshed
- It is not due to exhaustion
- It is not caused by a loss of motivation, which people with depression often experience
- Exercising beyond individual limitations will make symptoms worse[3]

According to evidence to the Group and from the Gibson Inquiry; the Independent ME/CFS Working Group Report to the Chief Medical Officer (CMO); and the NICE guidelines, there are numerous therapies on offer to patients. The most common are listed below;

Treatment	In detail
Symptom Management	This therapy typically focuses on the management of pain, exhaustion, nausea, food intolerance, light and noise sensitivity and other distressing symptoms[4]
Function and Quality of Life Management	Function and quality of life management includes help to cope with sleep problems and advice on energy and rest management[5]
Cognitive Behavioural Therapy (CBT)	CBT is an evidence-based psychological therapy that is a collaborative treatment approach. When it is used for ME/CFS, the aim of CBT is to reduce the levels of symptoms, disability and distress associated with the condition. A course of CBT is usually 12-16 sessions.[6]
Nutrition and diet	People with ME/CFS experience digestive problems, such as Irritable Bowel Syndrome (IBS), and it appears to be relatively common to develop intolerances to certain foods such as wheat or dairy.[7] Some people appear to obtain improvement or relief of their symptoms when they use dietary supplements or alter their diet.
Graded Exercise therapy (GET)	GET is an evidence-based approach to improving a person's ME/CFS symptoms and functioning, aiming towards recovery. The first step is to set a sustainable baseline of physical activity, then the duration of the activity is gradually increased in a planned way that is tailored to the person.[8] This is followed by an increase in intensity, when the person is able.
Pacing	Pacing is an important way of controlling ME/CFS symptoms. It involves a balance between activity and rest and avoiding large bursts of exercise that may cause relapses.[9]
Complementary Therapies	There are a wide range of complementary therapies however most of which are not available from the NHS. Some people find them useful for symptom control[10]

As part of the call for evidence, the Group received patient surveys from a number of ME/CFS support groups as a part of their written evidence. These surveys indicate that the majority of interventions were deemed to be helpful to some degree. Space allows only three to be listed here: one local area and two national.

Table 1 Norfolk & Suffolk ME/CFS Service – 2009 Patient Survey p27

Intervention	No. of respondents	Helpful %	No change %	Not helpful %
Pacing	164	77	12	6
Rest	161	76	17	4
Pain Meds	128	62	19	13
Change Diet	129	59	22	9
Sleep Meds	130	54	17	22
Nausea Meds	80	47.5	17.5	14
CBT	85	20	21	40
GET	86	13	10	58

Table 2 Action for M.E. and AYME joint report "M.E. 2008: What progress" – page 13. 2763 people responded to the survey

Intervention	Helpful %	No change %	Made worse %
GET	45	21	34
CBT	50	38	12
Pacing	82	15	3
Rest inc bed rest	86	13	1
Pain medication	74	22	4
Sleep medication	76	17	7
Dietary changes	68	30	2
Supplements	61	37	2
Medication to help mood	64	22	14
Other medication to help nausea	71	23	6
Acupuncture	56	34	10
Herbal remedies	58	36	6
Reiki	63	32	5
Lightning therapy	53	31	16
Reverse/Mickel therapy	45	34	21

Table 3 Q 15 pp7 2008 MEA survey of 4,217 individuals (3,494 on-line; 723 on paper). Preliminary survey results were published in the MEA magazine in Spring 2009

Answer Options	Response Count	Greatly Improved	Improved	No Change	Slightly Worse	Much Worse	Worse + Much Worse
Graded Exercise Therapy(GET)	906	3.4%	18.7%	21.4%	23.4%	33.1%	56.5%
Physiotherapy	862	3.5%	27.0%	36.7%	17.2%	15.7%	32.8%
Drug – modafinil/Provigil	81	14.8%	22.2%	33.3%	16.0%	13.6%	29.6%
Yoga	812	4.2%	34.9%	32.9%	20.8%	7.3%	28.1%
Hydrotherapy	275	4.0%	37.5%	32.0%	13.5%	13.1%	26.5%
Reverse therapy	107	8.4%	21.5%	45.8%	16.8%	7.5%	24.3%
Drug – inosine pranobex/Imunovir	62	8.1%	17.7%	50.0%	16.1%	8.1%	24.2%
Corticosteroid eg. hydrocortisone	323	10.5%	32.5%	35.3%	10.8%	10.8%	21.7%
Lightning Process (LP)	101	25.7%	18.8%	34.7%	7.9%	12.9%	20.8%
Cognitive Behavioural Therapy (CBT)	997	2.8%	23.1%	54.6%	11.6%	7.9%	19.6%
Massage	1037	5.4%	43.9%	31.3%	12.7%	6.7%	19.4%
NADH	358	3.4%	16.5%	63.4%	12.3%	4.5%	16.8%
Osteopathy & Chiropractic	774	9.8%	41.1%	33.3%	10.1%	5.7%	15.8%
Perrin technique	115	13.9%	37.4%	37.4%	7.0%	4.3%	11.3%
Thyroxine	414	8.7%	30.4%	50.0%	6.0%	4.8%	10.9%
Counselling (other than CBT)	984	2.6%	26.8%	60.1%	6.1%	4.4%	10.5%
Homoeopathy	1100	5.5%	24.4%	59.9%	7.1%	3.2%	10.3%
L Carnitine	318	2.8%	28.0%	62.9%	3.8%	2.5%	6.3%
Advice (to help me to cope)	2147	3.3%	39.5%	50.9%	3.7%	2.6%	6.3%
Oil of Evening Primrose (OEP)	1231	2.6%	25.8%	66.3%	3.7%	1.6%	5.4%
Pacing	2137	11.6%	59.6%	24.1%	3.5%	1.2%	4.7%
Eicosapentaenoic acid (EPA) Omega 3 oil	1217	3.2%	33.1%	59.7%	2.9%	1.1%	3.9%
Allergy treatments	686	9.5%	41.7%	45.2%	2.2%	1.5%	3.6%
Vitamins and supplements	2370	3.7%	31.9%	61.9%	1.8%	0.8%	2.5%
Meditation or Relaxation techniques	1675	6.1%	47.6%	44.3%	1.6%	0.4%	2.0%

These surveys suggest that pacing is arguably the best current form of therapy as, when successful, it allows patients to, in at least some aspects, be able to manage their lives. This fits with the written responses that the APPG received and many patients recognised pacing as an effective method to enable them to exert an element of control in their lives.

The APPG also found that much of the evidence suggested that CBT and GET were viewed with concern. Much anecdotal evidence suggested that in a number of situations, both treatments have made patients' conditions worse. This result seems to fit with the results of the independent patient surveys which both noted a disturbingly high number of patients who found the treatments unhelpful and sometimes even counter-productive.

While the APPG recognises that it is impossible for all treatments in any disease area to be side-effect free, if CBT and GET were licensed medication, this number of patients claiming devastating side effects would undoubtedly have led to a review by NICE. The same standards should apply to CBT and GET.

However, it was noted in the oral evidence sessions, that concerns around CBT and GET may be due to the competence of the practitioner and not the treatments themselves. This was the assertion from Dr Esther Crawley, who is a consultant paediatrician and the clinical lead at the Bath ME/CFS Service. In Dr Crawley's oral evidence, she stated that evidence suggests long term strategies of CBT were successful and that it is dangerous to only accept patient evidence and not detailed scientific studies.

It was suggested by Dr Crawley and in a number of patient and carer surveys that some failures in the CBT treatment could be caused by practitioners who are without the proper training in ME/CFS. She stated it was vital that all treatments, including CBT, GET, pacing etc. should be offered by specialists who have received specialist training with ME/CFS patients. The issue of training will be dealt with in greater detail further on in the report.

The Group heard evidence regarding the Lightning Process during the oral evidence sessions. This treatment, as far as the APPG is aware, is still only considered to be complementary. While the APPG has received both written and oral evidence that the Lightning Process can be very effective, it is also very expensive. According to the organisation that offers the programme's website, it costs £560 for the three day session[11] and none of this cost can be claimed on the NHS. The APPG would also point out that, like many CFS/ ME treatments, it is not suitable or effective for all patients but the Group suggest that further investigation of its efficacy might be undertaken. It is important to note that the Group has received anecdotal evidence of people who have chosen to spend £560 on this therapy but have gained no benefit at all.

What is clear to the Group is that there is no magic bullet and most of the treatments outlined above only offer patients a way to manage their lives as normally as possible. None provides a scientifically proven cure.

Review of Adult Services

The evidence painted a clear but damming picture of the current state of adult services. In particular, the three adults with ME/CFS who attended the first oral evidence session described their own experiences of the illness. They had all encountered very serious problems in getting referred to specialist clinics for treatment. One witness, Sally Philippe told the Inquiry:

We do not have a specialist clinic or a designated service in Teesside. There is nowhere for my GP to send me. I have never been referred to anybody and I have had no help and I am very angry about that on behalf of all those people in the country that do not have a dedicated service in their area. I am expressing their anger as well. I have been severely ill for 12 years and had no help.

The witnesses also highlighted their experiences of doctors failing to understand ME/CFS and the impact of that failure on patients' lives. Jo Birdsey said:

I had to educate my doctors because they actually did not know anything, and they admitted that while at medical school they had 15 minutes training. So I would like to see doctors educated how to look for the signs of ME. Most importantly, it is actually educating doctors what to look for. I know a lot of doctors would need to be re-educated.

Concerns were also raised by the patient group representatives. Christine Harrison of BRAME described the continuing difficulty in persuading the local PCT to restore the specialist service which had been lost three years ago in East Anglia following the retirement of the lead clinician.

Sir Peter Spencer of Action for M.E. summarised the main conclusions from a very large survey of over 2700 respondents in 2008. Key concerns included:

the attitude of a significant proportion of GPs; the way in which the current system fails the severely affected; the difficulty that many people have in even getting to specialist services and the lack of availability; diagnostic times have improved very slightly over the last 6 years but are still far too long; the fact that Graded Exercise Therapy demonstrated an alarmingly large percentage of people who reported that it had given them a setback and the need for further work; lack of ongoing support once people have been through their package of treatment.

Dr Charles Shepherd of the ME Association echoed concerns about GPs and quoting results from a 2009 MEA survey of just over 4,000 respondents stated that

53% of people are still waiting a year or more to get the diagnosis, in many cases it is often even longer, because GPs do not have the skills or the practical training to either diagnose this illness or make the most crucial decisions on management, both in the very early stages and in the chronic stages... There is an urgent need for undergraduate training because that is where general practitioners are coming from, postgraduate training in general practice, and this is just not happening.

Doris Jones of the 25% Group aired concerns about treatments such as CBT and GET and stated:

The work and ideologies of some key professionals in influential positions on policies adopted by state agencies such as the NHS, NHS Plus, the Department for Work and Pensions, NICE and the MRC are likely to have devastating effects on the future availability of essential benefits for serious ME patients if these ideologies and proposals are implemented.

Jill Pigott representing the Worcestershire ME Support Group stated that she had recently attended a meeting of the Herefordshire and Worcestershire LMDT steering group.

At that meeting the lead clinician said: "The service does not have the capacity for people with severe ME. If there are complex disabilities and people with severe ME, it is outside our sphere. All GPs must appreciate that the onus relies on them". So that is a statement that we received yesterday.

Also this information I have here says people with ME want more help locally from GPs and from practice nurses, anything from their practice centre. This means more training in understanding for all health professionals, social services and carers, domiciliary help etc."

Over the period of the call to evidence, the Group has also received a great deal of written evidence to show that the effectiveness of service provision is patchy at best. The APPG sent written questionnaires to all PCTs in England and Wales and while a number of PCTs offered some exceptional services, lamentably, this is not the situation universally.

In total, the APPG wrote to 133 different PCTs. The below table outlines the APPG's review of the responses.

Ranking	Number	Percentage
Good to Excellent	12	28.57
Average to Fair	14	33.33
Poor to non-existent services	16	38.01
No response	91	n/a

The APPG rated 61.9% of those who responded as average to excellent. This shows that there is a will within some sectors of the health community to address this illness. With the assistance of experts such as Dr Esther Crawley, some PCTs are making a significant effort to try and help patients. PCTs such as the Ashton, Leigh and Wigan PCT have quite detailed ME/CFS treatment programmes and all PCTs with similar programmes should be commended.

However, the APPG was deeply concerned that 38% of PCTs offered poor to non-existent services. Examples of responses from such PCTs include;

XXX PCT currently does not commission services specifically for this group of patients. Patients with ME in our catchment area do have some clinical services provided for them but these would not be considered to be specialist services

Also;

...we do not have one commissioner who is specifically responsible for ME and chronic fatigue syndrome.

Other responses were patchy or answered with little detail.

Another serious concern is the extremely high number of PCTs which did not respond to the letter of inquiry. Whilst there may be extenuating circumstances in some instances, through anecdotal evidence, the Group can only assume that there is a lack of interest or concern amongst a significant number of PCTs. Therefore the high level of service provision from some PCTs may not be entirely representative of the current situation. This is worthy of future discussion and investigation.

Number of PCTs contacted	Number of PCT responses	Number of PCTs that did not respond
133	42	91

A postcode lottery has been a significant blight on services for some time and has led to patients not having access to uniform services. The option of referring a patient to another PCT or treating hospital has been suggested to the group as a means of getting PCTs to offer full services. This is a long-term strategy, as PCTs should inevitably set-up their own services when they realise the cost savings would be significant. The cost of referring patients to external areas would be high in comparison. The annual audit of PCT accounts would demonstrate the cost effectiveness of local provision.

There is the argument however that PCTs, in particular PCTs which have no visible or inadequate services should be forced to offer not only the full range of services, but a full range of specialists. Minister of State for Health, the Rt Hon Mike O'Brien MP said during oral evidence that it was important that local PCTs understand the issues behind the disease and see the need for offering the service rather than being forced. Mr O'Brien stated that it is not up to the Government and Whitehall to dictate terms to PCTs, however, he recognised that it is up to the NHS to convince PCTs that funding is required to treat this disease. The Group understands Mr O'Brien's point of view, however, it feels that Government and Whitehall must ensure that DoH and NICE guidelines on service provision are adhered to by the PCTs. Currently, ME/CFS falls under the National Strategic Framework (NSF) for Long Term Conditions and under the regulations, PCTs are obliged to treat ME/CFS patients and offer specialist treatment.

Dr Esther Crawley praised the NICE guidelines for requiring patients to be offered a range of treatments suitable to the patient[12]. Patients are also obliged to receive specialist care as soon as possible. Below is the relevant section of the NICE guidelines;

Referral to specialist ME/CFS care should be offered:

- Within 6 months of presentation to people with mild ME/CFS
- Within 3-4 months of presentation to people with moderate ME/CFS symptoms
- Immediately to people with severe ME/CFS symptoms[13]

As stated, patients should be referred for immediate assessment by an experienced ME/CFS specialist if the symptoms are deemed severe.

During oral evidence, Mr O'Brien, backed up Dr Crawley's point stating it was important that ME/CFS patients are offered and understand the full range of therapies. According to the NICE guidelines, patients have to be offered a range of treatments, enabling them to choose the most suitable and effective treatment. Patients also have the right to refuse certain treatments or receive more than one.

When asked about a specific NSF for ME/CFS, Mr O'Brien stated that ME/CFS sits within the NSF for Long Term Conditions as treatment, education, support for employment were as important to ME/CFS patients as they were for patients with other long term disease and it is useful for patients and carers from a number of disease areas to work together. He said that it wasn't viable for there to be a specific ME/CFS framework as that would mean the need for a framework for every disease.

The APPG understands the necessity for streamlining, but we feel that if accurate patient cohort numbers could be obtained, there would be an acknowledgement for a need for a NSF. With this in mind, we feel that the DoH should initiate a proper investigation into the numbers of patients with ME/CFS. For a PCT to not offer services because there isn't a significant enough demand whilst, according to their responses to the Group, they do not have actual figures to determine the demand, is somewhat baffling.

The Group has heard a number of reasons why patients will not be referred to specialist services thereby not allowing for accurate patient cohort data including – patients are confined to bed and cannot see a GP; the GP does not recognise the disease and therefore will not refer the patient; the GP is unaware of the services; the patient has given up on the NHS and is either dealing with the disease themselves or is accessing treatment through private means; services are closed due to lack of funding or over demand as is the case in Cornwall. The Group believes these excuses don't justify ignoring the problem and generally show an endemic problem with the services and funding provided. Therefore, the lack of national patient cohort numbers is inexcusable, as is the lack of a National Service Framework.

Review of Children's Services

Many services only offer treatments to patients 16 and over, therefore children are left stranded. The Group received written evidence from a number of patients and / or carers detailing the problems faced by children who have this disease. Whether the problems are due to lack of diagnosis, lack of access to services or the cost of treatment as parents are forced to seek private health care because of the lack of services, children are clearly being neglected.

The Group heard oral evidence from Madeline Lawrence, currently 25, who has had ME/CFS since the age of 9. Originally she was told her illness was psychosomatic by the NHS consultants. It wasn't until Madeline was 15 that she finally received a diagnosis from the NHS. Previously, she had been unsuccessfully treated through private care. Madeline's is a good news story and she has been receiving CBT from St Bartholomew's Hospital. This has apparently enabled her to lead a relatively normal life. Unfortunately, this is not a story the APPG regularly hears.

Tanya Harrison who also gave oral evidence said that she *"had ME since I was 10. I have been severely affected and bed bound and wheelchair bound since I was 15. It took me 5 and a half years from starting to show symptoms to get any kind of diagnosis and it was not until I was to the point where they thought I was dying, I was in such a terrible condition that I was then referred to a consultant who specialised in ME and I was diagnosed with ME.... 3 years ago I lost my consultant and since then I have had no care for ME whatsoever. We do not have many GPs in our area, I do not have a GP, and the GPs in my local surgery do not believe in the illness anyway. They do not believe that people with ME have pain, they do not think people have neurological symptoms. So I do not have basically any medical support whatsoever for my condition now for the last three years."*

Mary-Jane Willows of the Association for Young People with ME said:

GPs across the country, as you have heard, are completely ignorant of services. We took 2,381 helpline calls last year and the majority of those have now been supported in accessing specialist services by using the NICE guidelines because what we say to patients is you take the NICE guidelines to your GP, you tell him you are entitled to services and you say if there are not any in the county, you insist on going out of county. What we have been told is that it is only by making them pay for out of county referrals, the bill will get so high they will then set up services. That is how we got the Hertfordshire service re-established, because Great Ormond Street charged Hertfordshire for every single patient they saw.

According to Dr Crawley's oral evidence, only 15% of children have access to ME/CFS services across to the UK. Dr Crawley analysed data from 6,793 mothers with children currently aged 13 from her area in Bristol and Bath and she found the percentage of housebound children from that cohort is 0.1% which equates to 7 children, none of them were known to her and therefore she hypothesised that none of them had been referred to any treatment services. If this number of 0.1% equates across the UK, there is, potentially, a significant number of school aged children who are housebound without proper treatment due to ME/CFS.

When a child is ill, a parent becomes the lead carer, meaning that they are unable to work. The child is denied the right to receive a full-time education and also loses out on many important aspects of childhood including social skills. This in itself is a huge issue that needs to be addressed. The lack of services provided to children is especially regrettable.

There was agreement on the part of all the witnesses giving evidence about service provision for children that there was a great deal of ignorance among teachers and social services about the impact of ME/CFS on children.

Training

Adequate training is vital to every aspect of this disease, from the moment the patient first sees the GP, to the cognitive and behavioural therapist, physiotherapist and every other specialist who treats the patient.

The NICE guidelines state "Healthcare professionals responsible for caring for people with ME/CFS should have appropriate skills and expertise in the condition".[14]

Similarly, in the Report of the ME/CFS Working Group to the Chief Medical Officer, published in 2002, recommendation 2 in section 6.2 states that;

Healthcare professionals should have sufficient awareness, understanding, and knowledge of the illness to enable them to recognise, assess, manage, and support the patient with ME/CFS. Healthcare workers who feel they need extra skills should seek and receive help from those experienced in this area.[15]

Many of the issues that were referenced in that landmark report were also included and addressed by the NICE guidelines, but adherence to the recommendations is yet to be fully observed.

Many GPs, despite their lack of knowledge and training in this condition, are extremely supportive and for that they should be commended. However, some submissions from patients have raised issues regarding the education and awareness of ME/CFS amongst GPs. To quote one respondent "my GP said look at the internet, I can't help you". This is, of course, unacceptable. Further examples include:

My GP is very sympathetic and would love to know how to advise and help me but what can he say, I now know more than him.

The APPG wrote to the Royal College of General Practitioners and the Royal College of Physicians to determine the level of training that student doctors receive on the treatment of ME/CFS. The APPG received a reply from the Royal College of Physicians which referred the answer to the Royal College of General Practitioners. To the best of the APPG's knowledge, the Group has received no reply to the original letter. The Group finds this lack of acknowledgment a disturbing mirror of the situation as it stands.

The Group also received a letter from the Dean of the Brighton and Sussex Medical School, Professor Dean Cohen, who stated that he would expect qualifying medical students to be aware of the condition through exposure during their primary care attachments, medical clinics or infections disease rotations. The disease "would be on the radar" of most medical students and doctors, but there would be few that would have a detailed understanding of the disease. The Group feel that it is essential there is increased training for medical students and junior doctors.

Lack of awareness is also common amongst secondary care staff. One respondent who wished to remain anonymous stated.

My confidence was lost with the OT [Occupational Therapist] and physio when we were told that everyone benefits from increased exercise...

Minister of State for Health, Mr O'Brien MP stated that doctors and GPs who don't recognise the disease were often from the older generation, whereas many newer doctors now believe that this disease is real and an issue, thanks mostly to the Independent Report to the CMO and the NICE Guidelines. This is possibly true as the

majority of written evidence submissions were from patients who have had the disease for at least 5-10 years and many would have been treated prior to the publication of the Report to the CMO. However, it does not excuse older doctors who should be receiving continued training and not relying on outdated methods of diagnosis and treatment. That is a concerning situation for not just ME/CFS patients, but also for patients with other diseases where treatments have improved rapidly overtime.

It is important to note that the NICE guidelines explicitly state that *"Every person diagnosed with ME/CFS should be offered acceptance and understanding".*[16] Far too frequently the evidence showed that some GPs and healthcare professionals still advised patients that the disease was "all in their head". This is of course incorrect and has been proven by numerous studies. This disease is real and is recognised by the CMO, DoH, NICE and the WHO, therefore diagnosing the illness as psychosomatic is unprofessional, inept and callous to the patient.

Healthcare professionals should also *"Acknowledge the reality and impact of the condition and the symptoms"*.[17] Furthermore, *"Primary healthcare professionals should be familiar with and be able to identify the characteristic features of ME/CFS."*[18] It is therefore vital that these guidelines are thoroughly adhered to.

There are positive stories worth highlighting as it shows there is a significant number of doctors and service providers who do an excellent job. One patient stated;

I would just like to say that for me my GP and the people at Oxford have been wonderful. I have read and heard of some people not being so lucky as me. I can't praise them enough.

But the Group is concerned that there are not enough of these positive stories.

Mike O'Brien, MP, Minister of State for Health said during oral evidence that part of the reason why there had been protracted issue with the care and treatment of patients with ME/CFS was because of the lack of recognition of the disease being real within the Department of Health. However, he stated that now there is significant demand to ensure that ME/CFS must be addressed clinically through effective services.

Mr O'Brien assured the Group that the NHS is working internally and with other organisations to ensure that patients with ME/CFS are treated correctly by skilled and experienced specialists. He also went on to state that there is recognition that the service provision is indeed patchy and that this is an issue that must be addressed.

It is with these thoughts in mind, that the APPG reviewed the Report to the CMO and were disappointed to find that almost all recommendations in section 6.4 are yet to be met to a completely satisfactory degree[19]. Currently, patients are still stigmatised and referred to as 'lazy' and the disease is often called 'yuppie flu'. These are divisive terms and the need to educate medical specialists and the general public is vital for the dignity and respect of the patients and their families.

Research

There have been many false hopes over the years in the search for a cause and cure for ME/CFS. Currently, there is no clear cause of the disease but it is vital that one is found.

Considerable clinical and epidemiological research into once controversial diseases such as AIDS and MS raised the level of understanding of their aetiology and gave the impetus for the development of treatments. The APPG feel that there should be significantly more funded research into the disease which affects an estimated 250,000 people[20].

Currently, there are very few studies ongoing into ME/CFS especially those funded by the Medical Research Council (MRC), the organisation best positioned to fund research into this disease. It must be said however that the APPG is aware that the MRC has convened an expert group to consider research strategies surrounding ME/CFS and the Group is very glad to see there may be positive movement in this area.[21]

Dr Esther Crawley said in her oral evidence, that she expects the MRC to have a number of applications for research grants into the field. Dr Crawley pointed out that as more doctors and specialists become interested in the area, there will be more grant applications, thereby increasing the research funding. The Group recognises that this is a catch-22 situation. More research and publicity into the area, will lead to more interest and a will to be involved. However, without this will, there is no funding. This is an endemic problem and can only really be addressed by increased funding into training as discussed earlier.

At the time of writing this report, the Group was very heartened by research that has come out of the USA. Recently, in the journal Science, there is significant reason to suggest the retrovirus XMRV may play a role in the disease. According to the research, this retrovirus is present in 67% of ME patients, versus only 4% of the general population[22].

This research is only very preliminary and has yet to be replicated in other laboratories. It is, however, wise to be cautious as ME/CFS patients' hopes for a cause and therefore a cure have been raised and then dashed in the past. At the very least, it should spur further research.

Disability and Benefits

It has been a long term complaint that patients and carers suffering from ME/CFS have severe difficulty in receiving disability benefits and other financial and social support. Over the years, the APPG has met with a number of different Secretaries of State for Work and Pensions and it is clear that this is one of the most emotive and frustrating consequences of the disease.

In some instances, it is impossible for many people with ME to work and they are therefore reliant on disability payments by the government. However, due to the nature of the disease and the lack of knowledge surrounding it, it is very difficult for those affected to get the support they need. This was an issue that came across noticeably in the patient submissions.

Due to the fluctuating nature of the disease, patients are often able to perform the tests on the day of their medical examination by the ATOS doctor. These doctors are employed by ATOS Healthcare on contract to the DWP to carry out medical and disability assessments in relation to DWP benefit applications. They advise decision makers as to whether a patient should receive benefits[23]. No account seemed to be taken of the fact that patients could not sustain the activity over time or that their symptoms would be exacerbated by the effort. Little account appeared to be taken of GP or consultant reports. This would result in the application for benefit being disallowed, followed by an appeal to the tribunal where it was highly likely that the decision would be reversed. This failure to appreciate the nature of ME/CFS results in a serious waste of resources and the imposition of unwarranted stress on patients.

The NICE guidelines also state that *"Every person diagnosed with ME/CFS should be offered...assistance negotiating the healthcare, benefits and social care systems."*[24] The Group is not entirely sure that this is the case. Many patient groups offer support to patients, as do MP's offices and the Citizens' Advice Bureaux. It seems extraordinarily perverse that lack of awareness of ME/CFS persists in the community.

Conclusion

There is a very messy picture of service provision given the size of the patient cohort and economic impact on society. Only a concerted national effort can address the lack of provision and the development of evidence based therapies.

Compared with diseases such as cancer, ME/CFS is less expensive to treat. It is certainly less expensive than the cost of complacency. The cost to society by paying benefits and providing social care; the cost of lost taxes and income and the cost to the patients, both financial and emotional, is far more expensive than the cost of adequate research, diagnosis and treatment. This is an issue that must be addressed.

Minster of State for Health, the Rt Hon Mike O'Brien MP stated that some PCTs are better than others when it comes to service provision, while Dr Crawley reminded us that in England only 15% of children and 65% of adults with ME/CFS have access to treatment. These statistics are disappointing.

It appears that some patients suffer at the hands of their GPs and specialists due to inadequate training. This is possibly why treatments such as CBT and GET are ineffective in some circumstances. The APPG notes Dr Crawley's statement that these treatments do work, but we also note the concerns about adverse effects of these therapies reported by so many patients. We believe that in some instances the competence of practitioners may need to be reviewed and that this must be a fact given serious consideration by NICE when it reviews Guideline 53.

It is obvious to the Group, that there have been improvements since the report to the CMO and the publication of the NICE guidelines. However, these improvements have been too little and too few. The APPG feels that urgent improvements are needed to be made across the fields of research, education, training, awareness and practice. The Group has therefore put together a number of recommendations.

Recommendations

Recommendation 1

There were a significant number of submissions from PCTs stating that they do not have accurate patient numbers. PCTs who do offer adequate services could only supply numbers of how many people are using their particular service. There will also be an unknown number of other sufferers within the community.

The Department of Health should undertake research to accurately determine the numbers of patients with ME/CFS.

Recommendation 2

It is clear from the evidence that there are probably sufficient numbers of patients involved and sufficient uncertainties about the nature and availability of services to justify a measure in addition to the NICE Guidelines.

A national service framework should be created to complement the NICE Guidelines.

Recommendation 3

The APPG felt that many of the concerns and experiences submitted as evidence by patients, carers and patient organisations would have been addressed had the Independent Working Group Report to the Chief Medical Officer (CMO) of 2002 had been acted upon adequately.

The DoH should revisit the report to the CMO and ensure that the recommendations relating to service provision are adequately addressed and are implemented promptly.

Recommendation 4

Currently, there appears to be a lack in consistency in treatment options offered to patients in different PCTs. The Group has ascertained this from the evidence supplied by PCTs and patients. The APPG finds the degree of variation in the availability and access to services unacceptable. Patient evidence also indicates people want services that are physician led, multidisciplinary, and are situated in locations that are easily accessible to those with significant mobility problems.

The APPG recommend the DoH take steps to remedy the variation and ensure that each PCT offers a full range of services promptly – a process that should involve meaningful consultation with local patients or patient support groups.

Recommendation 5

Through the evidence supplied to the Group, it is clear that there is a significant lack of services available for children and adolescents. Many services only offer treatment options to patients over 16, which has led to many children not receiving adequate care. This is unacceptable and can lead to tragic consequences.

The APPG therefore call on PCTs, Strategic Health Authorities and the DoH to undertake a detailed review of current services for children and adolescents to ensure that all receive adequate care and that all decisions are made in conjunction with personal carers, education authorities and social services where appropriate.

Recommendation 6

From correspondence with the Royal College of Physicians and the Royal College of General Practitioners, the Group is not convinced that medical students receive sufficient training on ME/CFS, including how to clinically assess and diagnose these patients and advise on appropriate forms of management.

The Group recognises that ME/CFS does not have the same obvious impact as cardiovascular disease or cancer, but that it is necessary for medical students to receive adequate training in ME/CFS. The relevant Royal Colleges should ensure that students receive training in this disease.

Recommendation 7

There were a large number of submissions from patients that stated their experience with GPs was poor due to lack of awareness of the disease amongst primary care givers.

GPs should receive ME/CFS awareness training as part of their continuing professional development and ensure they are able to adequately recognise the symptoms of ME/CFS and deliver a correct diagnosis. They should also be aware of the various management pathways.

Recommendation 8

The Group noted evidence that there were serious concerns about acceptability, efficacy and safety with some treatments such as cognitive behaviour therapy (CBT) and graded exercise therapy (GET). This may be due to the lack of training given to professionals but evidence was given that it was in part due to fixed attitudes about causation by some health professionals. The Group feel that it is inadequate for professionals to treat patients with ME/CFS when they have not been fully trained in the particular characteristic of this disease.

It is essential that all healthcare professionals i.e. dieticians, nurses, occupational therapists, physiotherapists and psychologists, involved in treatment should have adequate training in ME/CFS and the relevant professional bodies should ensure this occurs as a matter of real urgency.

NICE should carry out a detailed review of their management guidance on ME/CFS, in particular the mounting evidence for the need to broaden the range of appropriate therapies beyond CBT and GET, and to specify that all such therapies should be delivered by specifically ME/CFS trained professionals.

Recommendation 9

To date research in the field of ME/CFS has produced little substantive progress but there are a number of encouraging findings e.g. the XMRV research, which need to be pursued. As noted in the Gibson report, there has also been far too much emphasis in the past on psychological research and insufficient attention to biomedical research. The Group welcomes the recent MRC initiative to attract new researchers and new technologies in to this area.

However, the Group is sure that it is vital that further biomedical research is undertaken to help discover a cause and more effective forms of management for this disease.

Recommendation 10

It is clear from the evidence submitted to the Group that currently, ME/CFS patients receive little assistance in the complicated process of application for benefits and that refusal rates are worryingly high. Applying for benefits is an extremely prolonged and strenuous task, especially if patients are forced to appeal the original decision where their application was denied.

The Department of Work and Pensions should review its guidance to decision makers to increase the awareness of the specific difficulties faced by ME/CFS sufferers. Furthermore the Group recommends that ATOS Healthcare staff should also receive increased training to ensure that they are fully aware of ME/CFS and the limitations that it places on patients

Recommendation 11

The APPG is aware that many patients who are severely affected by this disease are receiving either inadequate care or no NHS care at all, which is clearly inconsistent with the NICE Guidelines.

Specialist referral services must ensure that high priority is given to the needs of the severely affected, especially in relation to domiciliary services and in-patient facilities for assessment and management.

Appendix 1

APPG Inquiry on NHS service provision for people with ME: Terms of reference

Background

The 2002 CMO report recommendations, which were accepted by the government, raised expectations in some quarters of major improvements in the provision of primary and secondary healthcare services for patients with M.E. (Myalgic Encephalomyelitis).

M.E. is classified as a neurological illness under the World Health Organisation classification (ICD G93.3). However the NHS largely uses the term Chronic Fatigue Syndrome instead of M.E. or else adopts the hybrid CFS/M/E. in diagnosing and treating patients. Terminology is a contentious matter. It has some bearing on this inquiry because to use only the precise WHO classification of M.E. above will impede access to information from the NHS that is crucial to the success of this inquiry.

A central 'ring fenced' budget of £8.5 million was announced in 2003 with the specific aim of developing new secondary referral services for people with ME in England. The Department of Health funding was released in two phases in 2004/05 and 2005/06. This resulted in the establishment of 13 Clinical Network Co-ordinating Centres and some 50 Local Multidisciplinary Teams.

Subsequent changes in NHS organisation and budget setting arrangements have since made it far more difficult to establish the level of investment into the care of these patients. It has also become apparent that some of these newly established secondary services are having to cope with significant reductions in funding. As a result, some have either closed or are under threat of closure – an issue that was discussed by the APPG at its meeting on 12 July 2007.

Patient group surveys continue to identify high levels of patient concern about the services which are being provided and further concerns about the way in which the recommendations contained in the 2007 guideline on ME/CFS from NICE could result in an inflexible approach to management.

Aim

The inquiry will evaluate the extent to which the NHS is providing care for people with M.E. (Myalgic Encephalomyelitis) in England, particularly in primary and secondary care, and in specialist centres/teams.

Specific areas of enquiry

The inquiry will focus on collecting data from each Strategic Health Authority (SHA) and Primary Care Trust (PCT). It will also collect data from specialist treatment centres, directors of Public Health, patients and patient groups. Questions will inquire about:

Their service framework for caring for people with M.E., including children with M.E. and those severely affected by M.E.

The funding they had available in 2007-2008 for caring for people with M.E., what they will have in the budget to provide services for people with M.E. in 2008-2009.

Their estimate of the number of people with M.E. living in their area of responsibility; of these how many are severely affected and how many are children; what is their estimate of the annual funding needed to provide adequate health care services for these patients.

Their plans for the establishment of new clinical services where no such service currently exists.

What currently happens to people with ME where a secondary referral is required but no local service currently exists.

The ways in which patient outcomes are measured and seeing how this compares with how patients measure outcomes.

It will also consider:

The extent to which the National Service Framework for Long Term Neurological Conditions addresses the generic issues affecting the management of the illness, sets standards for treatment and care and supports health and social care professionals to deliver high quality services.

What diagnostic criteria are being used.

How well the reality and impact of the condition and its symptoms are acknowledged in primary and secondary care and in specialist centres/teams.

How well health professionals in primary care, secondary care and in specialist centres/teams provide information about the range of interventions and symptom management strategies available, including benefits, risks and likely side effects

The extent to which health professionals in primary care, secondary care and in specialist centres/teams receive appropriate professional training in the range of interventions and symptom management strategies available, including benefits, risks and likely side effects.

Whether health professionals in primary care, secondary care and in specialist centres/teams provide adequate information on the possible causes, nature and course of M.E.

The extent to which health professionals in primary care, secondary care and in specialist centres/teams take account of the:

- age of the person with M.E., particularly for children younger than 12 years
- the severity of the patient's M.E.
- patients' preferences and experiences and the outcome of previous treatments
- the stage of the illness

Provide diagnostic and therapeutic options to people with M.E. in ways that are suitable for the individual, including providing domiciliary services (including specialist assessment), or using methods such as telephone or e-mail.

The extent to which health professionals in primary care, secondary care and in specialist centres/teams share decision-making with the person with M.E., establish a supportive and collaborative relationship with that patient and their carer(s) and recognise their right to refuse or withdraw from any component of their care plan without affecting other aspects of their care or future choices about care.

Evidence

Organisations and individuals are invited to submit written evidence. The strong preference is for written evidence to be in Word format-not PDF format-and sent by e-mail to info@appgme.org.uk

However it recognised that many people with M.E. will not have the use of computers or internet facilities and so typewritten scripts and legible hand written scripts will also be accepted.

The body of the e-mail or covering letter must include a contact name, telephone number and postal address. The e-mail/covering letter should also make clear if the submission is from an individual or on behalf of an organisation. The deadline is 30 June 2009.

Submissions must address the terms of reference. They should be in the format of a self-contained memorandum and should be no more than 3,000 words. Paragraphs should be numbered for ease of reference, and the document must include an executive summary. Submissions should be original work, not previously published or circulated elsewhere, though previously published work can be referred to in a submission and submitted as supplementary material. Once submitted, your submission becomes the property of the APPG. The APPG will expect to publish the written evidence it receives

References

1 Symptoms of chronic fatigue syndrome, NHS, http://www.nhs.uk/me/symptoms/, accessed 25/11/09

2 Symptoms of chronic fatigue syndrome, NHS, http://www.nhs.uk/me/symptoms/, accessed 25/11/09

3 Symptoms of chronic fatigue syndrome, NHS, http://www.nhs.uk/me/symptoms/, accessed 25/11/09

4 National Institute of Health and Clinical Excellence, 2007, NICE Clinical Guideline 53 Diagnosis and Management of ME/CFS in Adults and Children, London, pp 13

5 *Ibid*., pp 11

6 *Ibid*., pp 11

7 *Ibid*., pp 14

8 *Ibid*., pp 18

9 Treating chronic fatigue syndrome, http://www.nhs.uk/conditions/chronic-fatigue-syndrome/pages/treatment.aspx, accessed on 26/9/09

10 NICE, *op.cit*., pp 14

11 How much does The Phil Parker Lightning Process™ cost? http://www.lightningprocess.com/what-does-it-cost.aspx accessed on 17/11/09

12 Turnbull N, Shaw EJ, Baker R, Dunsdon S, Costin N, Britton G, Kuntze S and Norman R (2007), Chronic fatigue syndrome/Myalgic encephalomyelitis (or encephalopathy): diagnosis and management of chronic fatigue syndrome/myalgic encephalomyelitis (or encephalopathy) in adults and children, London, Royal College of General Practitioners, pp 28

13 *Ibid*, pp 183

14 Turnbull N, Shaw EJ, Baker R, Dunsdon S, Costin N, Britton G, Kuntze S and Norman R (2007), Chronic fatigue syndrome/Myalgic encephalomyelitis (or encephalopathy): diagnosis and management of chronic fatigue syndrome/myalgic encephalomyelitis (or encephalopathy) in adults and children, London, Royal College of General Practitioners, pp 32

15 ME/CFS Independent Working Group (2002), *A Report of the ME/CFS Independent Working Group – Report to the Chief Medical Officer*, pp68

16 Turnbull N, Shaw EJ, Baker R, Dunsdon S, Costin N, Britton G, Kuntze S and Norman R (2007), Chronic fatigue syndrome/Myalgic encephalomyelitis (or encephalopathy): diagnosis and management of chronic fatigue syndrome/myalgic encephalomyelitis (or encephalopathy) in adults and children, London, Royal College of General Practitioners, pp 33

17 *Ibid*, pp 35

18 *Ibid*, pp 33

19 ME/CFS Independent Working Group (2002), *A Report of the ME/CFS Independent Working Group – Report to the Chief Medical Officer*, pp68

20 Action for ME,2006, *ME: More than you know – Facts and Figures*, Bristol, pp 3

21 Our Research Chronic Fatigue Syndrome/Myalgic Encephalomyelitis, http://www.mrc.ac.uk/Ourresearch/ResearchFocus/CFSME/index.htm, accessed 17/11/09

22 ME virus discovery raises hopes http://news.bbc.co.uk/1/hi/8298529.stm, accessed 18/11/09

23 DWP Health and Work; ATOS Healthcare http://www.dwp.gov.uk/healthcare-professional/guidance/atos-healthcare/ accessed17/11/09

24 Turnbull N, Shaw EJ, Baker R, Dunsdon S, Costin N, Britton G, Kuntze S and Norman R (2007), Chronic fatigue syndrome/Myalgic encephalomyelitis (or encephalopathy): diagnosis and management of chronic fatigue syndrome/myalgic encephalomyelitis (or encephalopathy) in adults and children, London, Royal College of General Practitioners, pp 33