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The case for better NHS services for people with ME/CFS

Submission of The ME Association to the All Party Parliamentary Group on ME Inquiry into NHS services: submission dated 29 June 2009

EXECUTIVE SUMMARY

1 ME/CFS covers a wide range of clinical presentations and severity. This has to be appreciated when planning NHS service development and the training of those involved – doctors, nurses, occupational therapists, physiotherapists – in the clinical assessment and care of patients.

2 Everyone with ME should be able to receive an early and accurate diagnosis, normally through the primary care system, along with access to a local hospital-based specialist service for further advice on either diagnosis or management, where necessary.

3 The severely affected group require home-based management and designated in-patient beds for assessment and management.

4 The MEA submission describes serious deficiencies and omissions in all of the above key aspects of assessment and care.

5 The 2002 Chief Medical Officer's report into ME/CFS made a number of specific and helpful recommendations regarding service development. The subsequent injection of ring-fenced funding from the Department of Health resulted in a number of new services opening. However, some parts of England still have no local specialist service to whom patients can be easily referred and some of the existing services are experiencing serious problems with funding.

6 The MEA submission highlights positive aspects of the CMO report that have still not been acted on by those responsible for funding and providing NHS services.

7 The 2007 NICE guideline on ME/CFS forms the new basis for clinical assessment, diagnosis and management of ME/CFS patients. Almost all of the charities representing people with ME/CFS believe that the NICE guideline has made the management situation worse because of their 'one size fits all' approach, which involves only recommending cognitive behaviour therapy and graded exercise therapy. This approach fails to take into account the fact that large numbers of people with ME/CFS report that these two treatments are either ineffective or cause a worsening of their condition – but this is all that is being offered in the way of management to significant numbers of people.

8 The MEA submission explains why the recommendations on management in the NICE guideline are a major stumbling block when it comes to providing services for people who are not going to be helped by CBT or GET.

THE ME ASSOCIATION (MEA)

1.1 The MEA is the oldest charity in the UK for people with ME/CFS. We produce an extensive range of information for sufferers, carers and health professionals. Our telephone and email service – ME Connect – deals with over 5,000 enquiries per year. We campaign on issues of concern – in particular benefits, research and service provision. Our Ramsay Research Fund supports biomedical research into the underlying cause of ME/CFS and effective forms of management.

1.2 We actively campaign for services based on the biomedical model of ME/CFS and strongly oppose services that are based on the psychosocial model. We fully accept that, as with any other chronic and disabling illness, some people will experience emotional problems and psychiatric complications during the course of their illness and that these need to be managed by referral to an appropriate clinical service.

COLLECTION OF EVIDENCE

2.1 In order to monitor existing and developing NHS services, we encourage feedback from people with ME/CFS and their carers. We regularly ask people to pass on their experiences through our website, magazine, and ME Connect.

2.2 In 2008 we conducted a comprehensive on-line and paper questionnaire on management issues. There were 3,494 on-line responses and 723 paper responses. The data from these questionnaires is still being statistically analysed but some of the preliminary findings are referred to here and a summary of results will be forwarded separately to the Inquiry. We also carry out monthly surveys on management issues using the MEA website.

2.3 When we asked on our website in February 2009 about people's overall view on NHS services for ME/CFS, we received 1,096 responses as follows:

- 562 (51%) - very poor
- 223 (20%) - poor
- 170 (15%) - no longer used NHS
- 74 (7%) - average
- 39 (4%) - good
- 28 (3%) - excellent

2.4 In response to a question in the management questionnaire which asked whether the person's medical adviser is sufficiently aware of the range of therapies available for ME/CFS, replies were as follows:

- 1,403 (53%) – no
- 832 (32%) - partly
- 386 (15%) – yes

2.5 In response to a website question in May 2009 about how much money people had spent on treatments for ME/CFS in the past year that are not available on the NHS, we received 606 responses:

- 155 (26%) - £100 to £500
- 135 (22%) - nothing
- 115 (19%) - £1000 to £5000
- 92 (15%) - £500 to £1000
- 71 (12%) - less than £100
- 23 (4%) - £5000 to £10000
- 15 (2.5%)- £10000 or more

2.6 These three extracts provide a rough indication of satisfaction with current NHS services and suggest that significant numbers of people are spending large sums of money outside the NHS as a result of being inadequately served by it. The MEA believes that one reason for doing so is the NICE guideline on ME/CFS. This is referred to in more detail in 4.3 .

THE MEA SUBMISSION

3.1 In accordance with the Terms of Reference, our submission relates to various aspects of NHS service provision:

- NICE guidance on ME/CFS
- General Practitioners and Primary Care
- Nurses
- Occupational Therapists and Physiotherapists
- 2002 Chief Medical Officer's Report
- Services for children and adolescents
- Tertiary Referral Services
- Services for severe ME/CFS

3.2 The MEA and Action for ME have assisted the APPG in the preparation stages of the Inquiry. This included assistance in preparing the questionnaires, Terms of Reference, and timetable. We have no role in the analysis of evidence or writing the report.

NICE GUIDANCE ON THE CLINICAL ASSESSMENT AND MANAGEMENT OF ME/CFS

4.1 The NICE guidance on clinical assessment, diagnosis and management forms the foundation for NHS service delivery. Unfortunately, many health professionals view this guidance as an instruction on how to deal with ME/CFS patients rather than advice.

4.2 The MEA has consistently opposed some key recommendations and conclusions in the NICE guideline. We believe the NICE guideline is unfit for purpose and needs to be rewritten because it:

- fails to recognise the heterogeneity of clinical presentation and pathology in patients who come under the ME/CFS umbrella
- has widened the clinical definition of what constitutes ME/CFS
- places far too much emphasis on cognitive behaviour therapy (CBT) and graded exercise therapy (GET) – treatments that have been shown to be ineffective or harmful to significant numbers of patients in several large surveys of patient opinion.
- fails to deal with symptom control, and a range of other key management issues, in a sufficiently detailed and balanced manner.
- fails to deal with key issues relating to management in primary care – in particular the early, accurate diagnosis and management during the first few weeks and months of this illness.

4.3 In relation to CBT, 997 reported on this treatment in our 2008 management questionnaire as follows:

- 54.6% - no change
- 23.1% - improved

- 11.6% - slightly worse
- 7.9% - much worse
- 2.8% - greatly improved

4.4 In relation to GET, 906 reported as follows:

- 33.1% - much worse
- 23.4% - worse
- 21.4% - no change
- 18.7% - improved
- 3.4% - greatly improved

4.5 The MEA has supported the recently published guidance for Scottish General Practitioners – the Scottish Good Practice Statement (SGPS) – on the basis that this takes full and balanced note of patient, clinical and research evidence. We believe the SGPS provides a far more acceptable and balanced view of illness management and is something that should be used elsewhere in the NHS as a basis for management for people with ME/CFS

GENERAL PRACTITIONERS AND PRIMARY CARE SERVICES

5.1 The March 2009 MEA website survey asked whether GPs had the necessary knowledge and skills to care for people with ME/CFS. Feedback was as follows:

- 439 (40%) – No, sympathetic but needs more education
- 250 (23%) – No, not interested in ME/CFS
- 176 (16%) – Yes, to some extent
- 151 (14%) – No, knows nothing about ME/CFS
- 68 (6%) – Yes, very much so

5.2 These results are roughly in line with feedback we regularly receive on GP services. Some GPs provide an excellent service regarding both diagnosis and management. More would like to do so but lack of information and skills that are acquired from post-graduate education and practical experience of dealing with ME/CFS patients. A minority of GPs remain unhelpful and even hostile.

5.3 In July 2008, The MEA had a meeting with the Royal College of General Practitioners to discuss concerns relating to postgraduate medical education on ME/CFS. Our points were well received and acknowledged. However, this has not resulted in any steps being taken to improve the current situation.

5.4 We are very concerned at how supportive GPs often lack information about the availability of local referral services and the information/support provided via the charity sector.

5.5 The MEA believes that GPs and other primary care staff, have a key role to play in this illness, especially regarding early and accurate diagnosis; early stage management before hospital referral takes place; and long- term monitoring of patients no longer being seen at referral centres.

NURSES

6.1 The MEA believes that nurses, in both primary and secondary care, should play a role in the multidisciplinary management of people with ME/CFS. In the few cases where nurses are involved in a specialist service, the feedback we receive is generally positive.

6.2 Unfortunately, as a recent paper in BMC Nursing illustrates [1] most nurses currently have insufficient knowledge or skills. Replies given by practice nurses indicate a significant number hold discriminatory or hostile views.

6.3 Following publication of this paper, The MEA was instrumental in setting up a meeting at the House of Lords at which the Forward ME Group of ME/CFS charities heard a presentation from a Royal College of Nursing representative. The meeting looked at ways in which the RCN could improve both theoretical and practical knowledge of managing people with ME/CFS.

[1] **Chew-Graham CA et al. Practice Nurses' views of their role in the management of chronic fatigue syndrome/myalgic encephalomyelitis: a qualitative study.** ***BMC Nursing 2009*****, 8:2**

OCCUPATIONAL THERAPISTS AND PHYSIOTHERAPISTS

7.1 Most new multidisciplinary teams employ occupational therapists (OTs) and physiotherapists – sometimes in senior or pivotal roles. The feedback we receive ranges from extremely positive (especially where sensible and realistic advice is given about activity management) to extremely negative. Two problems in particular have emerged:

7.2 Firstly, many lack the training to undertake a detailed medical assessment and clinical examination. Consequently, certain aspects of medical management and investigation – eg when to request further investigations and the prescription of drugs involved in various aspects of symptom control – are outside their expertise or remit. However, in some cases the initial (and sometimes only) clinical assessment appears to be their responsibility, with referral to a physician being the exception. The MEA believes that all hospital-based services should be physician-led and that patients should generally have a comprehensive medical assessment from a physician before being passed to other members of the multidisciplinary team. This view is supported by feedback obtained in the 2008 management questionnaire.

7.3 Second is where OTs or physiotherapists appear to have been directed into following a psychosocial model of illness whereby problems with fatigue are largely or wholly attributed to inactivity and deconditioning – despite there being sound research evidence to question the role of deconditioning as a prime cause of muscle fatigue in ME/CFS. As a result, there may be recommendations, or even coercion, to take part in activity management programmes that are inappropriate and may even be harmful.

7.4 In some cases, where a more active programme of graded exercise is being implemented with increasing aerobic activity, the NICE guideline recommendation that this should be accompanied by cardiac monitoring does not always appear to be followed.

2002 CHIEF MEDICAL OFFICER'S (CMO) REPORT AND HEALTH SERVICE PLANNING

8.1 Prior to publication of this report there were very few hospital-based services. These were mainly operated by clinicians with considerable interest in the illness, who came from a variety of medical disciplines. Some services were based on little more than a consultant-led out-patient clinic. Others were multidisciplinary in nature and saw a considerable number of patients, including out-of-area referrals. Few had in-patient facilities and home-based services were unusual. Despite these limitations, most services, especially those that were physician-led, were well thought of by patients.

8.2 The 2002 Chief Medical Officer's Report into ME/CFS made a number of specific recommendations regarding service development. Among the key points in section 6:3 were:

- Service networks should be established to support patients in primary care and community settings.
- Health service commissioning must ensure that local provision for these patients is explicitly planned and properly resourced, and that health professionals are aware of the structure and scale of provision.
- Each Strategic Health Authority should make provision for secondary and tertiary care for people with ME/CFS, based on an annual prevalence rate of approximately 4,000 cases per million.
- People who are so severely affected that their disability renders them house-bound or bed-bound have needs that must be met through appropriate domiciliary services.

8.3 These recommendations have been acted upon to varying extent in some parts of the country. In other areas there has been little or no action.

8.4 Following the CMO report, there was an injection of £8.5 million ring-fenced money from the Department of Health over the period 2004 - 2006. As a result, a series of 13 Clinical Network Co-ordinating Centres and around 50 Local Multidisciplinary Clinics (LMDTs) emerged throughout England. A full list of NHS Services, including those that are not linked to the CNCC network, can be found on the MEA website.

8.5 We supported a model of service development based on centres of clinical excellence that theoretically co-ordinate and supervise the work of peripheral clinics.

8.6 However, we are not happy with certain aspects of the outcome – in particular the way some services appear to dogmatically follow the NICE guideline's conclusions and recommendations regarding patient management. Consequently, management is often dominated by almost automatic referral for cognitive behaviour therapy (CBT) and/or graded exercise therapy (GET).

8.7 Publication of the 2007 NICE guideline also meant everyone with ME/CFS in England and Wales should now have access to local hospital-based service for advice on diagnosis and management. Surprisingly, since publication, there appears to have been very little development of new clinical services in places where no local service exists. We are also aware of instances where existing clinical services have closed or had funding reduced. This means that there are still significant areas of England where there is no local referral service for people with ME/CFS, and we are aware of people in such areas having great difficulty in obtaining out-of-area referrals.

8.8 Problems relating to the funding of existing services were referred to at an APPG meeting on 12 July 2007 where problems with the East Anglia service were discussed at length with the lead clinician, Dr Terry Mitchell. We understand local people are still very unhappy with what has happened to this service.

8.9 Where new services have been proposed or introduced, the MEA has received further negative feedback – especially regarding ones that do not appear to be physician-led and may not therefore offer a diagnostic service. Instead, the service appears to work on the basis of managing patients with already diagnosed ME/CFS. Management advice is then dominated by CBT and GET.

8.10 One further concern relates to the way in which some categories of patients – children, adolescents, severely affected – are not properly catered for by existing services. Some clinics also operate discriminatory referral exclusions – eg not normally seeing people who are significantly overweight.

SERVICES FOR CHILDREN AND ADOLESCENTS

9.1 There are two charities for children and adolescents with ME/CFS: The Association for Young ME and The Tymes Trust. The MEA does not actively work with this age group and instead refers enquiries to the Tymes Trust.

9.2 We are however concerned at the overall lack of specialist services for children and adolescents. As a result, they often have to travel long distances to see a paediatrician with expertise in diagnosis and management. This and other concerns will no doubt be referred to in submissions from these two charities.

TERTIARY REFERRAL SERVICES

10.1 Despite the recommendation in the CMO report, the number of tertiary referral centres having both expertise and in-patient facilities to deal with complex or severe cases remains very unsatisfactory and in some areas non-existent.

10.2 The MEA believes that there must be a number of dedicated specialist services that have (a) in-patient beds/rooms designed to meet the needs of severely affected ME/CFS patients, (b) properly trained staff to care for them, and (c) a home-visiting service providing clinical assessment, on-going support, and regular liaison with the person's primary care team.

10.3 These centres should also be closely linked to centres involved in biomedical research and they should take part in clinical trials of treatments.

SERVICES FOR THE SEVERELY AFFECTED

11.1 It is generally accepted that

around 25% of people with ME/CFS fall into the severely affected category at some stage in their illness – meaning that they are wheelchair-bound, house-bound or bed-bound. This obviously creates difficulties, especially in relation to accessing hospital-based services, domiciliary (home visiting) services, and in-patient facilities for assessment and management (which may require a prolonged hospital admission).

11.2 We are aware of major difficulties in all the areas referred to above and it is disturbing to note that, when a new clinical service is being established, priority is seldom being given to the group with the most needs. In fact, in some cases the development of a domiciliary service is given low priority. We believe this is unacceptable.

11.3 We assume the 25% Group, which represents the needs of the severely affected, will be sending in a submission. Consequently, the MEA will not enlarge on these concerns.

WHAT DO PEOPLE WITH ME/CFS WANT FROM NHS SERVICES?

12.1 Much of this submission has dealt with feedback on existing and proposed services. The final section briefly deals with what people tell us they want from NHS services. This information has been obtained from answers given in the on-line version of the management questionnaire (ie covering both members and non-members of the MEA) that was carried out in 2008.

12.2 When asked who people want to co-ordinate their care, 2,547 replied as follows:

- GP – 634
- GP + Consultant Physician – 598
- Consultant physician – 248
- Consultant neurologist – 246
- GP plus Practice Nurse – 222
- Nurse Specialist – 159
- Alternative therapist - 121
- Occupational therapist – 62
- Psychologist – 21
- Psychiatrist - 20
- Practice nurse - 18
- Physiotherapist – 15
- Other – 168

12.3 When asked where their care should be co-ordinated, 2547 replied as follows:

- Specialist ME Centre - 1408
- Primary care/GP – 907
- Local NHS hospital – 127
- Other place – 93

12.4 When asked what sort of approach would be preferred, 2499 replied as follows:

- Individual sessions – 1590
- Group sessions covering different topics – 83
- Mixture of both – 753
- Other - 66

CONCLUSIONS AND RECOMMENDATIONS

13.1 The MEA submission highlights a number of serious concerns, based on long-term interaction with people with ME/CFS, relating to areas where we believe existing services are failing.

13.2 We make a number of practical recommendations as to how the current situation should be improved.

13.3 We hope that the Inquiry will use the Oral Hearings to follow up these concerns with representatives of service providers and the Department of Health and make appropriate recommendations when the report is published.

13.4 We would welcome the opportunity to discuss our submission during one of the Oral Hearings.

The ME Association
7 Apollo Office Court
Radclive Road
Gawcott
Buckinghamshire MK18 4DF

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