

Worcestershire M.E. Support Group

for people affected by M.E. (Myalgic Encephalomyelitis), CFS (Chronic Fatigue Syndrome), PVFS (Post Viral Fatigue Syndrome) and FMS (Fibromyalgia Syndrome)

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Dr Desmond Turner MP
House of Commons
London
SW1A 0AA

APPG (All Party Parliamentary Group) Inquiry into NHS Services for People with M.E. / CFS

Support Group Submission to the APPG Inquiry from:

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Yours sincerely,

Jill Pigott
Co-ordinator
Worcestershire ME Support Group

Hon. President:	Betty Hughes, MBE
Patron:	Peter Luff, MP for Mid-Worcestershire

APPG INQUIRY INTO NHS SERVICES FOR PEOPLE WITH M.E. / CFS Worcestershire ME Support Group

The Worcestershire ME Support Group's submission gives information on:

- NHS Service for people with ME in Worcestershire
 - Diagnosis
 - The Herefordshire and Worcestershire Chronic Fatigue Syndrome/ Myalgic Encephalomyelitis (CFS/ME) Local Multi-Disciplinary Team (LMDT).
 - Prevalence in the LMDT area - information from the PCT's bid dated 2004.
- Worcestershire Chronic Fatigue Syndrome / Myalgic Encephalomyelitis (CFS/ME) Service *[HANDOUT]*
- Information extracted from our Support Group's questionnaire - membership year September 2008 to August 2009
 - Members were asked how they would rate their current medical care
 - Primary Care involvement - regular check-ups
 - Diagnosis - members gave name of consultant and/or GP who gave initial diagnosis
 - The Worcestershire Service within the LMDT, including improvement (or otherwise) of their condition
 - Comments received from members via the questionnaires
- Response from people after the LMDT group therapy sessions
- Herefordshire & Worcestershire CFS/ME LMDT general information, and Steering Group meetings
 - Waiting Lists
 - Group therapy sessions
 - More support required
 - The Herefordshire CFS/ME Service contacted all Hereford GPs
 - Recent messages received by our Group
 - Finally

1. NHS Service for people with ME in Worcestershire

1.1. Diagnosis

Dr Mark Roberts, Specialist in Infectious Diseases Worcestershire Acute Hospital NHS Trust, is the Lead Clinician of the Herefordshire and Worcestershire Chronic Fatigue Syndrome/Myalgic Encephalomyelitis (CFS/ME) Local Multi-Disciplinary Team (LMDT).

Dr Roberts holds CFS/ME Clinics in Kidderminster, Worcestershire, for a new diagnosis, or when further support is required. Dr Roberts has held this position since October 2005. (Dr Roberts also holds clinics in Hereford for people in that county).

1.2. The Herefordshire and Worcestershire Chronic Fatigue Syndrome/ Myalgic Encephalomyelitis (CFS/ME) Local Multi-Disciplinary Team (LMDT).

The Worcestershire CFS/ME service consists of:

1 full time Occupational Therapist
1 part time Physiotherapist (2 days a week)
1 part time Psychologist (1 day a week)
A dietician attends one of the group therapy sessions.

The majority of the Worcestershire CFS/ME Service is given as group therapy sessions, rather than individual. If people want to see a dietician, other than at the one group therapy session, they have to pay privately. A Dietician should be part of the LMDT and available free to people with ME/CFS.

The Worcestershire Paediatric CFS/ME OT Service is part of the Herefordshire and Worcestershire CFS/ME Local Multi-Disciplinary Team. The bid for ME/CFS LMDT services dated 2004, gave the name of a lead paediatric clinician, but there is not now a specialist CFS/ME Paediatrician in Worcestershire or Herefordshire. Worcestershire Paediatricians refer children to the Worcestershire Paediatric CFS/ME OT service. We also understand some GPs in the Malvern area (south Worcestershire) refer children to a Paediatrician in Cheltenham who are then referred to the Bath CFS/ME Paediatric Service.

The Worcestershire Paediatric CFS/ME OT service's literature states they take an individualised approach to treatment for children who are referred to this service including: Lifestyle management, - including balancing of rest and activity, graded activity and goal setting; Healthy Living Principles - including sleep, relaxation and diet, plus challenging unhelpful thoughts, if needed.

1.3. Prevalence in the Herefordshire & Worcestershire CFS/ME LMDT area

The bid for ME/CFS LMDT services, dated 2004 stated:

The exact prevalence of ME/CFS patients within the 4 PCTs across Herefordshire and Worcestershire is not known but the likely prevalence is as follows:

Redditch & Bromsgrove PCT:	}	495 - 660	<i>Now Worcestershire PCT</i>
Wyre Forest PCT		330 - 440	
South Worcestershire PCT		780 - 1040	
Herefordshire PCT		approx 400	

2. Worcestershire Chronic Fatigue Syndrome / Myalgic Encephalomyelitis (CFS/ME) Service [HANDOUT]

The Worcestershire CFS/ME Team offers a multi professional service to those adults who have a primary diagnosis of chronic debilitating fatigue for which there is no alternative diagnosis. Patients must have been previously screened for a differential diagnosis, and fulfil the criteria for CFS/ME. Those young people who suffer CFS/ME are seen by specialist Occupational Therapists in the Paediatric Community Teams.

The team includes:

- Consultant in Infectious Diseases P/T
- Service Co-ordinator / Occupational Therapist F/T
- Physiotherapist P/T
- Psychologist P/T
- Dietician - sessional for the groups

General Practitioners refer people to the consultant physician for a new diagnosis, or when further support is required.

Referrals to the team are accepted primarily through the consultant physician, but also from General Practitioners who have completed the diagnostic screening, and are certain of the CFS/ME diagnosis.

The team provides both individual and group interventions for those patients fulfilling the criteria.

The service adopts a model of care which encourages patients to learn physical, psychological and practical self management techniques to improve functional ability, and quality of life.

The service provides a specialist assessment to ascertain predisposing, precipitating and perpetuating factors of the illness, and the needs of the individual patients.

The interventions include:

- Understanding symptoms of CFS/ME, and how to manage Setbacks.
- Self management advice to minimise deconditioning through too little activity, and Goal Setting for greater quality of life.
- Grading activity, Pacing of activity, and Lifestyle management.
- Stress Management and Relaxation.
- Stabilising Sleep and Rest.
- Help with pain management.
- Help with memory and concentration.
- Help to return to exercise.
- Help to return to work.
- Help with Communication and Relationships.
- Help to regain optimism and self confidence.

The Worcestershire CFS/ME Team can be contacted at: 01527 488316

3. Following uses information extracted from our Support Group's questionnaire - membership year September 2008 to August 2009

Information given by members who have received a diagnosis of ME/CFS

3.1. Members were asked how they would rate their current medical care

Of the 84 who responded to this question -

- 3 Excellent
- 20 Good
- 18 Average
- 5 Poor
- 4 Very poor
- 34 Not receiving medical care

43 out of the 84 were either poor, very poor, or not receiving NHS medical care.

3.2. Primary Care Involvement - Regular Check-Ups

Of the 93 who responded to this question - 62 said they had not been receiving regular check ups, so just 32 had been receiving regular check-ups. 24 of the 93 who had responded, received a diagnosis since 2005.

The NICE Clinical Guideline's 'Quick Reference Guide' states that CFS/ME is recognized on clinical grounds alone, and Primary healthcare professionals should be able to identify the characteristic features of CFS/ME. It gives a guideline on the 'presentation, diagnosis and pathway of care' - giving advice on managing the symptoms before official diagnosis, and arranging continuing primary care involvement with regular reviews after diagnosis.

3.3. Diagnosis

Of the 24 diagnosed since 2005, 19 of these patients have been diagnosed by -	
Dr Mark Roberts, Specialist in Infectious Diseases Worcestershire Acute Hospital NHS Trust & the Lead Clinician of the Herefordshire and Worcestershire CFS/ME LMDT from October 2005	9
Dr Alastair Miller, Specialist in Infectious Diseases Worcestershire Acute Hospital NHS Trust, & the Lead Clinician of the Herefordshire and Worcestershire CFS/ME LMDT until May 2005, plus pneumonia doctor at Worcester Hospital	1
Dr Stephen Sturman, City Road Hospital, Birmingham	1
Professor Kendall, Selly Oak Hospital	1
Dr Dyer, Worcester Royal Hospital	1
Dr Jenkins, Worcester Royal Hospital	1
GP at Northumberland House Surgery, Kidderminster	1
Dr Williams, GP in Kidderminster	1
Dr McCarthy, GP in Malvern	1
Dr Love, GP in Halesowen	1
Dr J Brammal, GP in Stourbridge	1

Of the 9 patients who received a diagnosis from Dr Roberts, 5 stated they had also received a diagnosis from their GP. Dr Morgan Worcester, Dr Martyn Kidderminster, Dr Dow Redditch, Dr Wilkinson Kidderminster, Dr Lewis Droitwich.

3.4. The Worcestershire Service within the LMDT

Out of the 84 who gave their decade of onset, none of those diagnosed before the 1990s have been referred to the LMDT.

3.4.1. Members were asked whether they had improved, worsened, or were the same, since the LMDT therapy, plus similar question for their condition during the last year

None of the members who had had either group or individual sessions considered that they had improved during the last year.

15 said that they had had individual sessions. 9 said they had had group sessions. Of those who answered both questions, double were the same or worse since individual sessions compared to those who had improved. For group sessions 1 out of the 9 said they had improved since the sessions.

3.5. Comments received from members via the questionnaires

My GP recently diagnosed ME. I have been informed there are no local services specific to my condition *[Evesham]*

NHS not offering specialized help for my illness. I have to push to get blood tests and any help. I feel abandoned by the system.

Quite disappointed with surgery's response to person moving to area with known CFS. They prefer to think of ME as depressed. 3 appointments to get GP to read my notes and have sensible discussion. I will self-manage disease with little help from them.

Contradictory information leads to confused medical staff and patients.

Even when bedridden (few days at a time) or housebound (recurrent and many months for several years) I found that consulting GPs was exhausting and pointless. When I needed symptomatic help, I learned not to mention ME.

With all the effort going into providing information for GPs it is a shame they are not starting to be better informed.

Occupational Therapist and Physiotherapist within the Worcestershire CFS/ME LMDT Service, are very dedicated but it is not what is really wanted. Pain control, immunology, allergy advice needed, not psychiatry.

Sleep clinic for people with ME/CFS could be provided as part of the Worcestershire CFS/ME service.

My GP and his partners and staff were/are unaware and unconcerned about the service. No offers to refer.

4. Response from people after the LMDT group therapy sessions

These group therapy sessions are run to a strict programme - people need individual help so advice can be flexible. Group therapy sessions mean that more people can be seen - but the reaction from our members is not good:

“... .. the disappointing thing is that out of the possible 9 or 10 who started the course only 4 of us finished it. Either that is because it wasn't suitable or of no value to some or those who have had the condition for so long thought the effort to get there outweighed the benefit. It was however a good place to meet and very quiet. I didn't learn anything particularly new.”

A member told the group that the sessions are not promoted with sufficient duty of care, and are 'Downright Dangerous'. He pointed out that forcing yourself up to a higher base line is dangerous and with him caused periods of faintness. He conscientiously tried to follow advice, and eventually collapsed and was taken to hospital.

Attended first two sessions so far - I am very confused. Information being received at group therapy is very contradictory - one minute we are being told it is all in the mind, the next minute it isn't.

I am concerned the LMDT is unaware of the basic ME definition and treatment protocol, ie the World Health Organisation's definition of ME as a physical-neurological condition.

I recommend people attend the groups for information, but the impression created was that everything is due to deconditioning, and if you manage your life properly you will become okay.

Group sessions disappointing. Assumption that people in group had been 'living wrong'. Waste of time/energy receiving inappropriate information due to group sessions. Two hour sessions far too long - long periods of concentration demanded without a break.

The regime of graded exercise was far too strenuous for me, and I was forced to abandon her style and develop my own at a more suitable pace. With the group graded exercise regime I was relapsing frequently. It is obvious that each ME sufferer, whilst having correlating symptoms with other sufferers, experiences this illness in an individual manner, and this was the consultant's belief. However those individual needs are not noticed by the LMDT. My needs were most definitely ignored.

5. Herefordshire & Worcestershire CFS/ME LMDT Steering Group meetings and general information

In February 2004 the Worcestershire ME Support Group held three meetings to discuss the proposed bid for services.

The Worcestershire ME Support Group has been represented at all CFS/ME LMDT stakeholder and steering group meetings since 2004.

The four Primary Care Trusts (PCTs) of South Worcestershire, Redditch & Bromsgrove, Wyre Forest and Herefordshire, made a joint bid for services to enhance the service for people in the two counties of Hereford and Worcestershire. In July 2004 the bid was accepted for £120,000 to commence a Herefordshire and Worcestershire Local Multi-Disciplinary Team (LMDT) in April 2005.

5.1. Waiting Lists

In October 2008 we were informed that the LMDT waiting list is 30 weeks and 6 months for psychology. We heard from a member who saw the consultant in 22 July 2008, and waited till 5 February 2009 to see the Co-ordinator/Occupational Therapist. This is not the only situation.

In November 2008 a new system was put in place whereby the Co-ordinator/ Occupational Therapist sees newly diagnosed ME/CFS patients directly after their appointment with the consultant. This is welcome when it happens. They are then placed on the waiting list for either group therapy or individual sessions.

We also heard of a ME/CFS patient who has waited for 11 months to see a ME/CFS psychologist. She has been referred by the consultant and Co-ordinator/Occupational Therapist but it still waiting. I understand that the current ME/CFS psychologist commenced with the Worcestershire service in the Autumn of 2007 but she has not as yet attended any of the LMDT Steering Group meetings, and looking through our members' questionnaire forms - none of our members have yet had an appointment with her.

At the beginning of 2009 the Worcestershire CFS/ME service did not have any clerical support, so with the therapists doing their own admin, the waiting lists became longer. As from the middle of March this service was reinstated for one day a week. Discussions have taken place for this to be increased.

5.2. Group therapy sessions

Group sessions for people with ME are held in various locations in Worcestershire, but they are only practical for people with mild to mild/moderate ME. People with severe and moderate ME are not able to attend these two hour sessions.

5.3. More support required

Worcestershire definitely needs more care for people with ME/CFS, including a dietician to be part of the team, and more support for people with severe M.E. With the limited funding, the LMDT do not have the time to visit many people with severe M.E.

5.4. The Herefordshire CFS/ME Service contacted all Hereford GPs

Rob Cunningham, Director of Specialist Services Herefordshire PCT had meetings with three members of the Herefordshire CFS/ME/FMS Group, and the Herefordshire CFS/ME Team Occupational Therapist and Team Leader. The discussions at these meetings resulted in a letter being produced, plus a questionnaire and the Herefordshire & Worcestershire CFS/ME Therapy Service Referral Pathway.

Discussions took place with Judy Richards, Worcestershire PCT Commissioning of Long Term Conditions, with a view to a similar exercise taking place in this county, but due to lack of funding, and the feeling that GPs would not respond, this has not happened.

5.5. Recent messages received by our Group

One person mentioned ME to her GP, and as soon as she said ME, he shouted "get out" - this person was so shaken she left the Malvern surgery.

A person who had an appointment with Dr Roberts was told on entering the consulting room - before we start, I need to let you know that I am only able to see you for one appointment as we do not have funding for more.

Another had seen Dr Roberts and requested help with pain - but nothing has happened.

People are told that their ME is evolving but there are no suggestions/help with the symptoms being experienced.

People are being left in limbo, and when GPs have referred their patients to Dr Roberts the GPs feel something is happening. We hear that people are referred to the management team if they already know that it exists. If they see Dr Roberts without having any knowledge of the LMDT, it is more than likely that a referral is not made - and yet the GP thinks they are receiving help.

5.6. Finally

M.E. becomes much worse if treated inappropriately, so provision needs to reflect the needs of the particular patient.

All medical professionals and the Social Services in Worcestershire, need more information on ME/CFS, and the local services available.

Our group's response to the NICE Draft Guidelines, and our group's presentation at the Parliamentary Inquiry on Scientific Research into M.E., both contained the wish for a Register of ME/CFS patients and the need for regular check ups.

We believe all people with ME/CFS should receive regular check-ups with their GPs. This could then involve regular monitoring by the GPs, with more blood tests carried out annually - monitoring and collating the findings to assist with biomedical research.

People with ME/CFS hear of new facilities/services via our newsletters, our website, and the local press, but they would not know otherwise - we believe GPs/ Practice managers should inform their patients of new services available, including support groups, benefit information and national ME charities. This would be possible if regular check-ups were carried out.