

Following message sent on Sunday, 12 July to Dr Des Turner, Chair of APPG (All Party Parliamentary Group) Inquiry on NHS Service Provision for people with ME/CFS.

I would like to again thank you, for inviting the Worcestershire ME Support Group to be involved in the Oral Hearing last week.

Just to confirm, during the meeting I mentioned ... ..

I gave a submission to the Inquiry on behalf of the Worcestershire ME Support Group. Since then I have collated more information received from our members, and on Wednesday 8 July I attended the Herefordshire & Worcestershire CFS/ME LMDT Steering Group meeting.

People with ME want more help locally from the GPs and their practice. This means more training and understanding for all health professionals, social services, and carers/domiciliary help.

One member had proactive support from a GP many years ago which helped, but that GP retired so the help ceased, and she has relapsed.

Another had a few months at the ME Centre in Essex many years ago which helped. She has recently relapsed and the Worcestershire LMDT is not able to give the support she needs, so she is back at the ME Centre again.

At the Steering Group meeting our LMDT Clinical Lead said - The service does not have the capacity for people with severe ME. If the patient has severe ME and there are complex disabilities, it is outside our sphere. He also stated that all GPs must appreciate that the onus relies on them.

The document from our group handed to you at last week's meeting is attached. *[this is below]* I also handed to you some information received from the Worcestershire CFS/ME Service that I was given last Wednesday, 8 July.

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## **Following was handed to members of the APPG on ME at the Oral Hearing on 9 July.**

The current NHS Service for people with ME, is inadequate, frequently not suitable, and in some situations it can be dangerous.

I am the Co-ordinator of the Worcestershire ME Support Group and a carer of a person with ME, speaking on behalf of people with ME in Worcestershire. The Worcestershire CFS/ME Service is part of the Herefordshire & Worcestershire CFS/ME Local Multi-Disciplinary Team.

We emphasise the fact that M.E. becomes much worse if treated inappropriately. Provision needs to reflect the needs of the particular patient. The current Worcestershire CFS/ME service offers a limited service to those with severe ME. We are told that owing to a large catchment area, and limited capacity the service cannot offer as many interventions as needed, in the home, by all the MDTeam. We understand, help by telephone, and support to carers, as well as a limited number of home visits is offered.

A patient who was diagnosed in July 2008 is still on a waiting list to see a psychologist.

People force themselves to the two plus hour group therapy sessions feeling that they ought to go, even though they could be spending the next couple of days in bed. This is also apparent with the new pathways to work and benefit procedures whereby people feel they have to attend the sessions, or their benefits will be stopped.

It is essential for GPs to be more aware of the illness, to be able to diagnose, and proactively support people with ME. Our members would like to see information available from their GP as soon as a diagnosis is confirmed, including the local services available, how to obtain benefits, and local support groups. It is felt that this should be given to the M.E. sufferer and their carer.

We would like to see ME to be included in basic training and not as an optional extra, so 'they' know it is physical, and there is something out of balance in the body. This should be for medical, nursing, and social welfare training. Plus, all GPs, Social Services, and Educational Establishments to be kept up to date with ME knowledge.

These awareness and training requests were emphasised at meetings our group held in 2004 prior to the LMDT being formed.

Health warnings are not given about the potential damage done to pwme by over exertion/exercise. We still hear from pwme whose GPs tell them to go for long walks, or the gym. All health professionals should be receiving proper education and training in ME, but many are not. The NHS services are failing in this area. This is some of the information that should be included in the national training conferences. The training and education programme for health professionals put forward by the CFS/ME Clinical & Research Network & Collaborative (CCRNC) is, in our opinion, entirely inappropriate. Recent conferences at Milton Keynes show a distinct bias towards the psychological approach for ME/CFS.

One member said - the impression created was that everything is due to **deconditioning**, and if you manage your life properly you will become okay.

Also, the Worcestershire Service handout states:

Interventions include: Self management advice to minimise **deconditioning** through too little activity, and Goal Setting for greater quality of life.

The Canadian Guidelines refers to the Bazelman (2001) research -  
"Failing to find any statistically significant differences in maximum exercise performance

between ME/CFS patients and the controls, Bazelmans et al. (147) **concluded that deconditioning was not a perpetuating factor in ME/CFS.**"

Also : Bazelmans E, Bleijenberg, G., van der Meer, JWM and Folgering, H.

**Is physical deconditioning a perpetuating factor in chronic fatigue syndrome?**

A controlled study on maximal exercise performance and relations with fatigue, impairment and physical activity. Psychological Medicine, 2001, 31, 107-114.

Since posting the Patient Questionnaire to over 430 people with ME (group members, and people who have contacted in the group in the last five years), our Chairman Ian Logan has spoken to nearly 20 people who have completed their forms. One of the points they all mention is the lack of support from their GPs' practice. Only one of these people had proactive support from her GP, and this was many years ago - antibiotics were prescribed for a number of years which improved her health, but when this GP retired the other GPs in the practice would not prescribe antibiotics despite the fact that they helped her - so she relapsed.

A few of the messages received during the last ten days:

I have depressingly come to the position that GPs and their staff first need to have minds open to ME, because although there is a lot more information available now than there was 20 years ago, hostile attitudes do not seem to have changed.

(I heard an account a very few years ago, from a reputable source, of a group of GPs meeting the evening before they were to interview applicants for a place in the practice - one said "well of course the first interview question should be "do you believe in ME?"" - this was met by gales of laughter.)

My GPs are based at Corbett Medical Practice, Droitwich and I have found them particularly unhelpful. In fact if it wasn't for the support group I do not know how I would have got through the early days. Sue Gordon Saner first visited me 8 months after my diagnosis. My NHS experience has been pretty depressing. I even had one Dr tell me that if I wanted to be diagnosed with CFS and have a sleep on the way to work then he would do that!!! Not the support I wanted.

I also found the occupational health at the West Midlands Police, unhelpful and was diagnosed with stress amongst other things.

A carer said - the sad thing is that not much seems to have improved over the years and there is still a great need for doctors to be trained in the illness, information to be widely disseminated to hospitals and GPs and the general public as with other illnesses.

EARLY diagnosis is still paramount so clinics staffed appropriately and available are needed.

And remedial treatments are needed eg acupuncture for pain relief instead of swallowing pain killers

Fortunately our GP is supportive but lacks appropriate support from others in NHS as they do not address the needs of the severely affected.

The interventions offered from the Worcestershire CFS/ME service are self-serving, written as if they are making a difference and in fact are inappropriate unless you are already in the recovery phase of the illness.

There is an inadequate domiciliary support. Dr Roberts does not visit patients at home unless they pay him money. Comparing notes with others who have called on him privately

to see if he has had any beneficial effect reveal the same story. Dr Roberts is inappropriate for the role of lead clinician for this area and prejudiced in his approach, unobservant and insensitive towards the severely affected. He seems to be following the psychosocial model and makes comments that the symptoms are self-inflicted. After a visit from Dr Roberts patients are left feeling invalidated. A waste of money.

I have attended 5 of the 8 Group sessions so far. I'm not sure what to make of them. The 2 hours are indeed heavy going and tend to overrun; so it makes me ill afterwards. The 2 Sue's are very well informed and kindly - probably much better informed than any doctors I've seen - and I am grateful for that. I am interested in the explanations given. I still feel we need a neurologist involved in the team somewhere, though.

I don't think I can cope with the homework of finding a base line of activity and then increasing by 10% after 2 weeks and so on.

I have just realised, in writing this, that perhaps there is too much emphasis on psychology in the sessions.

The service throughout the country was created on a shoestring. The NHS are finding that more services are needed, and not just psychological. People with ME want their condition treated and would like to see biomedical research carried out via the CNCCs and LMDTs.

Finance desperately needs to go into training right across the health profession and care services.

**The original draft bid for a LMDT for the two counties requested (totalling £203,000):**

2 x Grade A Psychologist	(0.5 wte)
2 x Occupational Therapist, senior 1	(whole time)
2 x Occupational Therapy assistants	(whole time)
2 x Dietician	(0.2 wte)
2 x Physiotherapist, Senior 1	(0.2 wte)
1 x Clinical/Research assistant	(1.0)

**The two counties were successful with a bid, after it was cut back to (totalling £119.350):**

2 x Grade A Psychologist	(0.2 wte)
2 x Occupational Therapist, senior 1	(whole time)
2 x Dietician	(0.2 wte)
2 x Physiotherapist, Senior 1	(0.2 wte)

**The Worcestershire LMDT is currently:**

Service Co-ordinator / Occupational Therapist F/T

Physiotherapist (0.2 wte)

Psychologist (0.2 wte)

Dietician - sessional for the groups (people with ME can only see her at one of the group sessions. Otherwise people need to pay and see her privately. The Group wrote to her a couple of times, after which I was told that any more questions and I would be charged!).