

# Living with Severe ME

## *Experiences of the NHS - you and your GP*



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***Supporting People with Severe ME***

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## EXPERIENCES OF THE NHS

### *You and Your General Practitioner*

Many people with severe myalgic encephalomyelitis (ME) rarely or never see their general practitioner.

This is partly due to GP reluctance to make home visits and partly due to people with severe ME actively avoiding consulting a GP due to lack of understanding of their illness. Some did find their GP pleasant and willing to help but lacking in the knowledge and understanding of ME required to effectively assist.

The result is that many such patients are receiving no healthcare and that medical professionals, for their part, can remain quite unaware of the presentation of this illness, particularly in its most severe form.

#### ***When did you last see your GP? Roughly how often do you see them?***

Around half had minimal contact with a doctor, or none at all, perhaps only seeing their GP or practice nurse at specific clinics on other matters *e.g.* for diabetes, thyroid, blood pressure or annual flu jabs. Several reported that they had not consulted their GP for a number of years. What's more, it appears that many who *had* seen a GP did not discuss their ME with their GP at all. Indeed, several mentioned that they did not want to upset or "lose the goodwill" of their GP by consulting them about having ME

*"Probably haven't seen GP in a year. Had telephone appointment a few months back – check on repeat prescription Choose not to involve my GP in helping my ME but rather see a private GP."*

*"Last seen 2 years 4 months ago - In past 10 yrs have consulted on other health matters (e.g. osteoporosis) but have learned not to ask specifics about ME and its symptoms as GP simply seems nonplussed and unable to offer help. This contributes to a sense of hopelessness on my part as no health professional seems able or prepared to discuss the illness."*

*"I see GP and Practice Nurse often for diabetes and other conditions. I avoid ME as I do not want to take the chance on falling out as other GPs have not been as good."*

***"Having diabetes has been an advantage as I now get regular health checks that should be done for ME."***

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#### ***How would you describe the GP service? What type of support/help? Was the service in any way unhelpful?***

Reported experiences were fairly evenly divided between 'helpful' and 'unhelpful'. According to the negative responses, there exists a tendency towards disbelief and unwillingness on the part of GPs to accept the symptoms described by the patient: a minimising or trivialising response.

*"My GP is bewildered by ME but is willing to learn. Generally, he takes his lead from me, acknowledging that I know much more about it than he does and we work together to manage the disease on a symptomatic basis. I do the research, he does the admin."*

*"The GPs seem to have no appropriate or useful procedures to follow, no investigative tests which reveal the known abnormalities to offer and no treatment to give... The unhelpful manner 'stone-walls' the patient in a variety of ways..."*

*“GP is extremely good but she doesn’t really understand the condition. She is very receptive to suggestion though. GPs are generally unsure of what is best for ME patients.”*

***“He [my GP] has no clue of the seriousness of the illness, again because doctors tend to trust test results more than patient testimony and I can’t get the relevant tests done so what real proof do I have?”***

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### ***Does your GP make home visits?***

Most severe ME patients simply cannot travel to the surgery, so it is no surprise that home visits were seen as key to improving access to the GP service. However, a ‘lottery’ emerged in this regard, with variation as to whether or not GPs would provide home visits to such patients. Only one-third confirmed that they can access a home visit, with an equal number advising that this was not available to them - some relied on telephone consultations. Most of the others did not know whether or not their GP made home visits, possibly because they had not sought a consultation for some time (see above feedback). This reported lack of access to home visits from GPs is consistent with the findings of UK survey research involving people with ME.

*“GP comes once a year for check up. Although she is pleasant enough – she does not even mention ME and appears to have very limited knowledge of the condition.”*

*“He will do home visits but it has to be for an emergency otherwise it has to be a phone appointment. I have waited 3 weeks for a phone appointment. Could see him that day [at the surgery] if I wasn’t housebound.”*

*“GP is supportive and happy to visit at home... However I don’t ask often as any visits are difficult for me.”*

***“No home visits. I feel home visits are necessary. Often I am unwell and need to see my GP; I have no energy to visit the surgery. I am being denied therefore a GP service. I have been told ‘come in when you feel better!’”***

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### ***Do you have any suggestions for improving the GP service to people with severe ME?***

Respondents provided a number of further suggestions for improving the GP service to people with severe ME. Most revolve around increasing awareness and understanding of this illness and treating patients with dignity and respect. There is also a strong sense that GPs themselves are in a difficult position - with no appropriate or useful procedures to follow, no recourse to investigative tests that would reveal the type of abnormalities emerging on investigation of research subjects and no treatment or effective palliative response to provide. This could leave the patient seeking private care and costly investigations.

*“It would be helpful if there was a central NHS base for every county where a professional could interview a sufferer or potential sufferer and sort out some sort of coping strategy... Having the patient aware that they are not alone is a great aid ... the main thing is to get the patient out of a ‘no-man’s-land’ sort of grief about losing a life of physical ability to a different life of different possibilities as smoothly as possible...”*

*“I like my GP, but how can he do his job when he is getting no information or misinformation about my illness... The drugs I need e.g. low dose Naltrexone, he wouldn’t be willing to prescribe for me, I have to pay a private doc to get this.”*

***“All GPs need to understand the scope of ME and be trained to break ME down into its constituent parts; to analyse test results with an eye for the nuances of ME; and to manage the disease symptomatically. They should also learn to be alert to co-morbidities.”***

## WHAT WORKS BEST FOR YOU?

### *Managing Activity*

People with severe ME have learned to listen to their bodies and follow the approaches to activity and rest that work best for them. Flexibly pacing any activity was found to be vitally important: many had developed their own coping strategies and instinctive pacing.

However limits could be difficult to gauge and some felt the need for advice on this.

Unfortunately NHS guidance had not always been helpful. Some had experienced long term exacerbation of their illness after following advice to keep active and try to 'push through', particularly in the early stages of their illness. Likewise the outcome of trying to maintain or gradually increase activity could be extremely detrimental.

Relatedly, several respondents stressed that interventions aimed at 'chronic fatigue' are completely different to what is appropriate for a person with ME.

#### ***Can you tell us about what has worked best to keep your symptom level down and maximise the level of activity you can manage?***

*"I need to be able to rest as much as I feel I require... One learns to live with an illness like ME. The problem is that everyone else thinks they know better. This causes stress and fear."*

*"The only thing I have found helpful is pacing and energy management which I undertook myself."*

*"Any activity must be followed by rest. I currently manage only two activities a day though always trying to increase both in number and duration. This is my own system; I have had no specific advice."*

*"No advice except to 'try'! If I am well enough to be out of bed I do about 5 mins then lie down for 20 and do a bit more. It can take weeks but I achieve something. Recently I have used a chest heart monitor and found that my heart rate shoots up just reaching for something on days I don't think I can do much. It has given objective measure of my own insight so I trust myself and rest when I feel I need it."*

*"I have read books about pacing, treat energy as money in the bank i.e. do not overspend. Accept the use of physical aids such as a wheelchair and stair-lift and perching stool, electric scooter when I can manage it. Minimise stress! No advice from GP except 'don't overdo it'. Avoid noise, crowds and travel where possible. Winter months are more difficult, cannot keep warm."*

***"Don't ever push beyond your mental/physical limits – whether it be trying to read/watch TV or just sitting up... You can't fight this illness and win. It controls you and not the other way round."***

#### ***Have you had advice with activity and rest? if so have you found it helpful or not?***

*"I have had to do all my own research to find out about my illness and treatments for it, particularly when it comes to not making things worse. Medical staff are trained to treat people with 'chronic fatigue'. This they treat with CBT and GET which makes you worse and is mostly impossible to do anyway as a severe sufferer."*

*"In the past I've had advice from physios about activity and rest but in my experience their starting point for activity is far too high. Their starting exercises that I'm supposed to build upon are just unsustainable never mind increasing the*

*amount. I can't keep up with the basic demands of everyday life let alone trying to incorporate exercise."*

*"After referral to psychiatrist (who disagreed with GP's diagnosis of depression and was helpful and supportive) was asked to keep detailed chart of activities and symptoms. Very useful for determining how many 'energy shots' I could count on most weeks."*

*"My ME was triggered by an untreated severe infection in my abdomen from an ovarian cyst and has become severe over several years. I think it was because I was wrongly advised to keep working and pushing myself. I was not advised to rest."*

***"The only advice I have had re activity and rest is to do more, more... which I did for years, pushing on and now I'm much more ill and disabled because of this advice with little real chance of ever recovering. I am now mostly bed bound."***

### BACKGROUND INFORMATION

It may be helpful to provide some contextual orientation concerning the conditions under which such adverse patient experiences are unfolding.

Firstly, with regard to patient experience, having ME does not amount to a sensation of fatigue. This is a common misperception.

Secondly, in terms of illness classification, ME is a separate disorder to 'fatigue syndrome' - the latter being a behavioural disorder while ME is classified as neurological. It would be fair to say that both medical education establishments and the NHS are routinely failing to appreciate this crucial distinction.

Thirdly, 'chronic fatigue syndrome' (CFS) is the diagnostic label that is presently applied to people with ME on the NHS. In view of the distinction between ME and 'fatigue syndrome', it is unsurprising that introducing a diagnostic label of 'chronic fatigue syndrome' has contributed to the general confusion. It is important to be aware that the World Health Organisation indexes 'CFS' to post-viral fatigue syndrome / myalgic encephalomyelitis in the central nervous system chapter.

In a nutshell, the NHS presently tends to view 'CFS' as amounting to the experience of chronic fatigue, occurring without a medical basis and with or without the concomitant experience of other symptoms. The result is that people with ME are variously misconstrued as experiencing something that is behaviourally induced (*i.e.* a consequence of inactivity) or a conversion disorder.

## WHAT WORKS BEST FOR YOU?

### *Symptomatic Relief*

As there is no known cure for this illness, providing a palliative response is particularly important and greatly appreciated by the patient. However, according to the feedback received, most people with severe ME find it very difficult to access effective symptomatic relief through the NHS.

The impact of medications and other therapies can vary from patient to patient. Also sensitivity to / intolerance of medication - including analgesics - makes alleviating symptoms very difficult for some.

Often it was ultimately the patient's own knowledge, gained through long experience of their illness and abilities, that had helped. Patients themselves learn how best to keep their symptom levels down and thereby help maximise their quality of life.

***Please tell us about what has helped you, and anything that has been unhelpful.***

***Have you been able to access effective symptomatic relief on the NHS?***

***Can you tell us about any involvement of private healthcare providers/ complementary therapists etc.?***

*"Stomach intolerance of most medications makes treatment of pain (worst symptom) impossible. 'Tens' machine merely exacerbates my pain. Temazepam when used very occasionally helps with insomnia."*

*"I currently take anti-spasmodic drugs and painkillers which take the edge off pain and help keep me going."*

*"When you're this ill and have so many serious allergies and hypersensitivities it's very hard to stay healthy in a general sense. That's what Dr X [private doctor] concentrates on: general well-being. Get that right and the ME can't get such a stranglehold on all of our biological systems."*

*"Amitriptyline helps pain and sleep. Tried a warm hydrotherapy pool which made fatigue worse."*

*"I can't get B12 injections or even a Vitamin D test despite never being out in sunshine."*

*"NHS has not helped at all with symptoms. I had expensive phone consults [private] which did not help and cost a fortune..."*

*"I have had some symptomatic relief on the NHS but it is only for a limited number of the symptoms I experience."*

*"I have not been able to access effective symptomatic relief on the NHS. I have regular treatment to loosen muscles and relieve pain with Bowen Treatment – an Australian discovery, it is very good. Some very gentle exercise that moves the muscles treated. Have air purifiers throughout home."*

*"NHS has given me no help at all – it has been all self-learned."*

***"I get painkillers and baclofen and chlorodyne which help my ME symptoms but I have asked for these. No treatments have been offered except psychological years ago (useless!) I buy vitamins and pay for massage and hyperbaric O2 at a MS centre."***

## A POSITIVE VISION

### *What you would like from the NHS?*

Respondents had a clear idea of what they would like from the NHS. This was grounded in experience of what currently happens when they seek to have their needs met and the barriers they face in accessing help and treatment, whether for ME or for a co-morbid condition:

- specialist investigations - as opposed to stopping at basic tests geared to a diagnosis of exclusion
- an approach to management congruent with the disease process
- appropriate referrals to consultants from relevant medical specialism(s)
- reduced time in the waiting room for outpatient appointments, quiet waiting area, room with daylight rather than bright artificial light, access to appointment scheduled for later in the day if required
- when hospital in-patient stay is indicated, a quiet single room and proper knowledge of the special care considerations for a person with ME can make this feasible; otherwise co-morbid conditions can go untreated

### *Is there anything you'd like to say about how your needs could be properly met? What would a helpful NHS response look like? and how would it be provided?*

*"Understand the disease, it's very unique, you can't exercise it away. Medication to help with severe pain... Regular home visits which offer moral support. If tolerated, reflexology, massage, acupuncture or heated pool treatment etc. Podiatry. ME Consultant / Centre for ME where appropriate appraisal can be made for each individual and ongoing monitoring of condition progression. All of these are equally important."*

*"A helpful NHS service would be responsive to international research findings and open and honest about the fact that medicine and medical hypotheses are constantly evolving... In this disease patients are the experts – only we have a proper overview of how ME affects us – and the NHS needs to be prepared to work with us as equal partners and to learn from us, not fall back on assumptions and prejudices. Above all we need a multidisciplinary service made up of open-minded doctors and support staff..."*

*"It simply would be nice to meet doctors and nurses who are knowledgeable about ME and not prejudiced. They need to know that it is a physical, neurological illness and not a psychological one."*

*"A proper ME Unit with fully trained staff supplied on the NHS."*

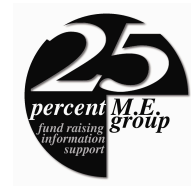
*"To be treated seriously would be a dream come true, not to dread visiting doctors, hospitals etc."*

In 2011 the 25% ME Group asked people with severe ME to share their thoughts and experiences of the NHS. The approach was geared to obtaining in-depth qualitative feedback rather than reductive number crunching.

This booklet gives a flavour of the feedback obtained. It illuminates personal situations and indicates the action that patients would like to see - giving a voice to people who may otherwise be unheard by the medical profession.

*The 25% ME Group is the UK charity that supports and represents people who are severely affected by myalgic encephalomyelitis*

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