

Living with Severe M.E. in Scotland

Report on Members' Consultation, Autumn 2011

Your Illness & Best Management



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INTRODUCTION: About This Feedback

The 25% ME Group is a UK charity that specifically supports and represents severely affected myalgic encephalomyelitis patients. We are committed helping ground the NHS and other services in the lived experiences of people with severe ME, so that together we can focus on addressing the issues that are impacting on people's daily lives.

With this in mind, in autumn 2011 we undertook a feedback exercise among our 77 members in Scotland. We wanted to find out about their experiences, needs and wishes. A postal enquiry was sent to members in Scotland and elicited 37 responses. This means that almost half participated, which is remarkable given the effort required from people with severe ME.

The intention was to give people with severe ME and their carers scope to raise the issues that matter to them, with the freedom to identify their own issues and to respond on them in their own words. Obtaining direct qualitative feedback was fundamental to our approach, illuminating situations that people with severe ME and their families are facing and the action they would like to see taken.

The topics highlighted included:

- *Your Experiences of the NHS and what we can learn from them;*
- *Your Illness & Best Management;*
- *Your Care Needs;*
- *Access to Disability Benefits – Obtaining Medical Evidence*

All feedback reports are available on request from the 25% ME Group (contact details on front page).

This report provides feedback on topics around management, particularly activity and rest, and the input obtained from healthcare professionals. We also provide feedback on members' positive vision for the NHS in Scotland

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YOUR ILLNESS - Origins, Course & Severity

The most commonly reported trigger was some form of viral illness. There were also cases where vaccinations had appeared to trigger the illness.

The majority of respondents described variations in severity; however some had been consistently severely affected from the outset.

Many felt that their ME had been exacerbated by bad advice they had received in the earlier stages of the illness - to get back to work, keep active and 'push through'.

Experiences included:

"Severe attack of glandular fever in January 1985. Severe ME followed this and has been unremitting since."

"OP poisoning / vaccinations / poor diet / bouts of food poisoning while working overseas. Slow onset but now severe – had it 16 years now."

"Caught Coxsackie B virus from colleague at work. Severity increased when I developed arterial fibrillation"

"My mother had illness like it for 20 years – but she died when I was 23 and before I had it. Daughter contracted it after several bouts of tonsillitis and infection while she was on holiday. After 7 years she is much improved. I still have it after 18 years."

"I came down with an unidentified bacterial infection 23 years ago and have had ME ever since. It was severe from the start but has followed a relapsing-semi remitting course. My current severe relapse began out of the blue six years ago. I was only diagnosed in 2007 by Prof Findlay."

"Illness began 18 years ago following respiratory virus. Only reached current severity after bad neck strain and subsequent osteopathic treatment, approx 12 years ago." "[I got] Cox B4 infection: was told I had ME but was encouraged back to work too soon."

"Began with influenza flu. It was not severe in the beginning and had I been advised/diagnosed correctly I believe I would be much better than I am today."

"Sore throats one after the other. Very bad pain at back of neck. I worked through all these and kept on exercising – gymnastics and ice-skating until I could no longer. Then I was housebound and then bedbound for years."

"Catalyst was viral bronchitis. Life was very stressful and difficult – single parent with 3 sons. Probably working too hard and very run-down. The first year (2002) was very difficult, with no help or care, even though I was quickly diagnosed with ME."

"I had gastro-enteritis following a possible viral infection at 26 years I developed my current experience of ME 37 years ago. I continued working for 18 mths as it grew worse and worse. I was unable to get a diagnosis for 4 years (the ME was chronic and severe and still is.)"

WHAT WORKS BEST FOR YOU - *Symptomatic Relief*

People with severe ME have real problems accessing effective symptomatic relief on the NHS. Only a limited number of the symptoms experienced appear to be readily helped by accessible medications.

The impact of medications and other therapies can be variable from patient to patient.

Stomach intolerance of medications makes treatment very difficult in some patients, including access to basic pain relief.

All respondents have become experts on their ME and in particular how to keep their symptom level down in order to maximise the level of activity they can manage.

They have developed their own coping strategies and instinctive pacing – sometimes in the face of lack of information or understanding from GPs and other Health Professionals

According to the feedback received most people with severe ME find it very difficult to access effective symptomatic relief through the NHS.

In many cases it was ultimately the patient's own knowledge of their illness and abilities that had aided symptomatic relief.

Experiences included:

"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 had a great experience in the Homeopathic Hosp in Glasgow in the past but they can no longer take me due to the long waiting list for in-patient services. I still receive support through phone-calls and remedies sent by post but I feel I'd benefit more from an in-patient stay."

"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."

WHAT WORKS BEST FOR YOU - *Approaches to Activity and Rest*

People with severe ME in Scotland have learned to listen to their bodies and follow the approaches to activity and rest that work best for them.

Flexible pacing was found to be vitally important. Some would appreciate advice on this subject, however support is not always available, and such advice as was provided not always helpful.

Many of the respondents said that they believe their ME was exacerbated by the bad advice they received in the earlier stages of the illness. Namely to get back to work, keep active and push through.

Can you tell us about what has worked best to keep your symptom level down and maximise the level of activity you can manage? Have you had advice with activity and rest and if so have you found it helpful or not?

It is very clear from the feedback received from respondents that they have, over time and through necessity, learned to listen to their bodies and to adhere to their own activity/rest regimes. However limits could be 'difficult to gauge' and some would appreciate suitable help with this. Pacing was found to be vitally important and some of the respondents who had had advice (from OT etc.) on this had felt the benefit. However support is not always available, and such advice as was provided not always helpful.

Feedback included:

"I would love help with pacing and more care e.g. someone to shop/clean/ help when needed."

"Pacing is helpful, but difficult to gauge. Having husband available as carer allows better quality of life."

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

"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."

"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."

"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."

"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. Need to conserve energy so cannot be very social."

"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."

"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."

“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.”

“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.”

Several respondents stressed that treatments for ‘chronic fatigue’ and what is appropriate for a person with ME are two completely different things. ME is not ‘fatigue syndrome’ and does not amount to suffering from chronic fatigue. The NHS tends to view ‘CFS’ as chronic fatigue without a medical basis, and ‘CFS’ is the diagnostic label presently applied to people with ME. The results can be extremely detrimental.

Feedback Included:

“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.”

“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.”

The latter quote is in keeping with feedback from many other respondents who felt that following poor advice to push on in the early stages had adversely impacted on the course of their illness.

WHAT WORKS BEST FOR YOU - *Experiences of Allied Health Professionals*

Most respondents had seen allied health professionals – such as occupational therapists, physiotherapists, and nurses. Feedback produces mixed reviews. The intervention of physiotherapists in particular was frequently found to be unhelpful.

It would be helpful to have a central database of allied healthcare professionals who have been properly trained in severe M.E. and are contracted to make domiciliary visits.

We would be interested to know if you have seen a physiotherapist, occupational therapist or another allied health professional. For example:

Who did you see? When? Did you wish to be referred? How did you find this service – was it helpful or unhelpful? How might it be improved?

Overview

There was an issue of lack of follow-up on the part of some of the professionals discussed, which undoubtedly impacted upon the overall experience and its impact on the patient. Keeping in touch to find out how the patient was faring with the advice or equipment provided and offering a further or alternative form of support where required would have been welcome.

The issue of training and understanding of severe ME was identified as key to the helpfulness (or otherwise) of the service provided. A general view clearly emerged that it would be helpful to have a central database of allied healthcare professionals who have been properly trained in severe ME and are contracted to make domiciliary visits.

Occupational Therapists:

Many had seen an Occupational Therapist (OT), which had generally been useful in order to gain practical help with equipment etc.

Physiotherapists:

Around one-third of respondents had seen a Physiotherapist; the great majority had found this most unhelpful. Many of these referrals to Allied Health Professionals had been made at the patient's request. Some were still awaiting appointments when we consulted them about this.

Feedback on Referrals to Occupational Therapists and Physiotherapists

"Referred to Physio in early 2008 – no appointment despite chasing up. ENT consultant referred me to continence service – very helpful, Continence Nurse referred me to OT at Disabled Living Centre – absolutely wonderful!"

"Rehab Consultant (Jan 2010) recommended I see a Physio and OT – still waiting for appointments and condition has deteriorated. I now need a hoist which means I need 2 carers 6 times a day – a huge increase in my care package. Even if I did see a Physio now it's unlikely I'd regain my ability to transfer independently. I don't think I'd have lost my independence if I'd seen the Physio last year when it was recommended."

"Saw OT when sick and trying to continue working – an abusive experience. I pushed on and became chronic and severe."

A Positive Vision – what you would like from the NHS?

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

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?

Respondents had a clear idea of what they would like from the NHS in Scotland, based on their experience of what currently happens when they seek to have their needs met and the barriers they face to accessing the help and treatment they require. A positive vision of the NHS would provide truly patient-centred services – and a start would be listening to what people with severe ME are saying that they would like to see from the NHS:

- Immediate investigations leading to prompt diagnosis
- Treatment congruent with the disease process, which may differ from patient to patient
- Appropriate referrals to Consultants from a range of specialisms
- Reduced waiting times for outpatients appointments, access to appointments later in the day, quiet waiting area, room with daylight rather than bright artificial light
- Hospital in-patient stays with quiet, single rooms, and proper knowledge of the special care considerations for ME

A positive vision for the NHS in Scotland

“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.”

“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.”