

# Living with Severe M.E. in Scotland

Report on Members' Consultation, Autumn 2011

## ***PART 2. Your Illness & Best Management***



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## INTRODUCTION: About This Feedback Report

The 25% ME Group is a UK charity that specifically supports and represents severely affected myalgic encephalomyelitis patients. We are committed helping ground the work of the Cross Party Group 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 Illness – Origins, Course & Severity; and What Works Best? – Symptomatic Relief & Approaches to Activity and Rest*. Feedback on these forms the focus of this report.

There are further reports providing members' feedback on:

- *Your Experiences of the NHS and what we can learn from them*; (NB this complements the present report)
- *Your Care Needs*; and
- *Access to Disability Benefits – Obtaining Medical Evidence*

Copies of these reports are available from the 25% ME Group.

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### ***YOUR EXPERIENCE OF M.E. and WHAT WORKS BEST FOR YOU***

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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 over the course of their illness; 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'.**

**Can you point to anything that triggered your illness?** Not surprisingly, no one trigger was identified by all respondents. The most common trigger was some form of viral illness, including Influenza, Coxsackie virus, viral bronchitis, and respiratory virus etc. There were also cases where vaccinations had appeared to trigger the illness and low/defective immune system. Prior experience of polio, food poisoning and poor diet as well as bacterial infections and post-operative infections were also cited. Often it was a combination of things and/or repeated infections which triggered the onset of the ME.

**Can you say something about how you came to develop severe ME – or has your ME been severe from the start?** One in six of respondents told us their ME had been severe from the start while the remainder describe variations in speed of onset and severity.

### Experiences included:

*“Severe attack of glandular fever in January 1985. Severe ME followed this and has been unremitting since (27 years ago).”*

*“My illness was triggered by a virus and within 3months I was severely affected – bedridden.”*

*“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 A.F. [arterial fibrillation]”*

*“I think it's genetic as I see mild ME in my family – for me I pushed myself so worsened it. Over 20 years it has deteriorated.”*

*“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.”*

Notably, 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...

### Experiences included:

*“[I got] Cox B4 infection in Crete: [was] told I had ME (1984) 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."*

*"In the year preceding my collapse I had a notable virus for 6 weeks which was not tested or diagnosed. But referred to in hindsight, first 18 months moderately affected then caught influenza virus and became severely affected."*

*"I had gastro-enteritis following a possible viral infection at 26years. I think I had earlier episodes of ME which weren't diagnosed and I recovered. I developed my current experience of ME 37 years ago. I continued working for 18 months 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.)"*

*"I suspect [my son] had a low immune system prior to contracting an infection/virus which he ignored."*

#### **U's EXPERIENCE**

*I first became ill with ME when I was working as a student gardener. We had been clearing out the ponds and at one stage I had fallen in the mud. I don't know if I had caught a virus then. I had completed my first year at college and stress fluctuated greatly as I experienced the independence of working/living away from home for the first time. My general health also took a beating when I decided to lose weight and lost 2 stone within 6 months. This included calorie-counting as well as double (if not triple) the amount of exercise I was used to as well as the practical work for a horticulture diploma. I reckon this, in turn, made my immune system very weak and whilst working I was exposed to autumn weather as well as many soil and airborne viruses. I experienced flu-like illness at the start which left me with extreme exhaustion and soreness throughout my whole body. It took nearly 8 years to recover to an almost normal state with careful pacing and help with practical things by just family and friends. The NHS did not help much at the start because I was living between home and college during which time I was going through all the usual tests. In 2000 I managed to get a full-time job which was stressful in itself but not too taxing on the body as it was a desk job. Other stresses at home were going on and my body just gave out. Then I got paid off because I wasn't doing too well at work and I think something in my brain triggered a major relapse of ME. It was as if my immune system had given up fighting. I did not get the flu-like illness this time but the aches and pains and the exhaustion was even worse than the first time. It has taken 10 years to get to an almost good (but not normal) state of health which has good spells, very good spells (rarely), bad spells and really awful spells (when I'm bedbound); the latter getting shorter and less frequent as time goes on and stress and activity is managed better.*

#### **T's EXPERIENCE**

*After vaccinations developed severe flu-like illness, went blue from head to toe. In 1997 caught flu, bedridden for 5 years, spoon-fed for 2. It's been severe from start but in early days had remission to the degree of being able to function for 8-9 hrs tops. But sleep, sleep, sleep to power up. Always felt a degree of ghastly. Was underweight – stomach, memory, balance issues etc. I'd also like to say it should be notifiable in schools as I went from B+ in Physics to D-. You do not have the cognitive function or energy to take in knowledge or energy to clamber up and down stairs.*

## WHAT WORKS BEST FOR YOU

### *Symptomatic Relief*

People with severe ME in Scotland 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.

In the absence of information or understanding from GPs and other Health Professionals they have developed their own coping strategies and instinctive pacing.

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

In terms of dealing with symptoms, respondents variously identified the following as having helped them:

- Good quality sleep / rest
- Pacing
- Homeopathic Remedies
- Family support/carer support
- Herbal treatments
- B12
- Massage
- Diet
- Relaxation
- Lack of stress

The message was clear that not one thing works in isolation. Rather, while the need for family support, good quality sleep/rest, pacing and lack of stress run throughout the course of the illness, other treatments, dietary considerations etc. must combine to alleviate symptoms and promote quality of life for the person with ME.

Pacing was identified as being very helpful by many respondents (more on pacing at '*Activity and Rest*' below). A number of respondents spoke about how important it is to have good nutrition in order to help stem the weight loss suffered.

The effectiveness of a therapy or medication could vary from patient to patient - for example, while massage might be found helpful by some patients, it may be found completely unhelpful when tried by others. (Though there are of course different forms of massage.) Impact could also vary depending on the stage of a person's illness, and whether they were experiencing a relative remission (albeit fluctuation with better spells is sadly not generally characteristic among people with severe ME) or a flare up in intensity at the time.

#### *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. Myhill [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."*

*"Homeopathic and Bach flower remedies seem to give support when well but nothing helps once ill."*

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

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

According to the feedback received most people with severe ME find it very difficult to access effective symptomatic relief through the NHS and have had to work out for themselves what is most helpful in terms of dealing with symptoms. Medications available on the NHS are limited in effectiveness and while several people reported some help with sleeping there appears to be little success with pain relief.

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

In terms of complementary therapy, acupuncture was found by several respondents to help with pain relief. One member spoke of having a series of 6 sessions on the NHS a number of years ago which but once these had finished it was *"out the door regardless of whether I was still in pain."* Other members do pay privately for treatment but this can also be expensive.

Low Dose Naltrexone (LDN) medication accessed through private doctor has helped to stabilise symptoms for some respondents who felt that too many GPs offer to prescribe 'antidepressants' only. Many respondents stated that the best help came from private doctors with an interest in environmental medicine who use complex homeopathic remedies (classical homeopathic remedies for exhaustion were found to be unhelpful), food allergy testing, vitamin and mineral testing and oral supplements.

In many cases it was ultimately the patient's own knowledge of their illness and abilities that had aided symptomatic relief. Respondents had been able to access helpful information and advice through knowledgeable websites and other publications.

#### Experiences included:

*"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."*

### X's EXPERIENCE

*After vaccinations, I developed severe flu-like illness and went blue from head to toe.*

*It should be noticed in schools – I went from B+ in Physics to a D-. You do not have the cognitive function or energy to take in knowledge or energy to clamber up and down stairs.*

*In 1998 saw Prof. Behan, ME specialist at Glasgow Southern General who gave me certain drugs that woke me gradually. In 2001 I saw Dr John Richardson, Newcastle ME Research who confirmed I had classical ME (neurological) - he said it was Posterior Polio...*

*In 2005 at the Wellness Clinic I was told I didn't want to get better and I had to exercise to health!*

*In 2009 I had acupuncture, 6 sessions and then out the door regardless of whether I was still in pain.*

*That same year a consultant told me I could not have an MRI as I was imagining I was ill but saw an Osteopath who stated that all my muscles were in spasm which was confirmed by a Consultant Pain Clinic Doctor who told me I had neuropathic pain which I've had since 1998!*

*I listen to my body – I have no option as I'm always fighting infection, sore throats, feeling fluey. In the past I have forced myself on but the relapses were so severe I ended up bed-ridden for 5 years and spoon-fed for 2. I take pain medication and rest for as long as it takes till I 'power-up'. You cannot predict the level of functioning from hour to hour, day to day. You have to keep warm [because of] problems with circulation, if body kicks off you have to lie down to it, when able you feel as if you are drunk / hung-over with legs like lead weights. It is hard at times to sit upright as blood feels as if it drains from brain.*

*It is disgusting the way people with severe ME are expected to live. It is an existence as opposed to a life and in my view the support is very fragile. If you can push a button, or occasionally get out they call it independent living. 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. Having this illness is a case of damage limitation until we get proper medical treatments i.e. anti(retro)virals, immune modulators etc. I have found anything you can do to calm the immune system is best e.g. Antihistamines, finding out what your newly developed food and chemical allergies are (after getting ME) and avoiding them... Avoid stress if you can... Do not push yourself; fatigue is a protective measure – your body telling you to stop. The less I do the better I feel, giving a chance for the inflammation in my body/brain to settle down. I now plan to pay for tests/an assessment and to get some LDN because I can't stand the way I have to live my life anymore without treatment. I'm very angry I will have to fund this from my own low income – If I had a self-inflicted illness/was a drug addict for example, I would get to see a consultant and get prescribed medication like LDN for free.*

## WHAT WORKS BEST FOR YOU

### *Approaches to Activity and Rest*

Over time and through necessity, 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 all respondents that they have, 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.

#### **Y's EXPERIENCE**

***I became ill after what was most likely a Coxsackie B infection in July 1968. I had malaise and various neurological problems through my teens but became worse after recurring bouts of flu.***

***I was moderately affected for years, managing to bring up a family as long as I had plenty of rests and help. When my youngest child was young he had health problems and life was difficult. I was given no help with him despite my disabilities and his problems. He started nursery: my husband dropped him off in the morning but I had to pick him up at lunch time if no one else was available. This involved a bus journey and a climb up a steep hill. As the weeks passed, I began to get fitter and manage the hill much more easily. I thought I was cured, it was wonderful. Then one Wednesday afternoon in April 1990 my legs would hardly move as we came home from the library. I had to drag myself home hanging on the railings and have not walked outside the house since then.***

***The exercise had made me fitter, but all that did was to mask the underlying disease so I passed to the severe form. My neurological symptoms became much worse until I needed help to feed myself. I began to get episodes of blindness and I was often confined to bed or lying on the settee. Hyperbaric O2 has helped the neurological problems so they have eased a little... Now my family are grown and I have less to do but I now have diabetes, eye problems that require constant tending and stop me sleeping much, psoriasis and the start of arthritis. These are all taking a toll on the ME even if just by the activity required to deal with them!***