

Living with Severe M.E. in Scotland

Report on Members' Consultation, Autumn 2011

PART 3. Access to Disability Benefits: Obtaining Medical Evidence



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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: Welfare Benefits – access to supporting medical evidence. Feedback on this issue is the focus of this report. There are further reports covering members' feedback on:

- *Your Experiences of the NHS and what we can learn from them;*
- *Your Illness & Best Management (Symptomatic Relief; Approaches to Activity & Rest)*
- *Your Care Needs.*

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

WELFARE BENEFITS: Access to Disability Benefits: Medical Evidence

Many people with severe ME in Scotland struggle to obtain medical evidence for benefits claims.

Respondents described the 'battles' they have had, sometimes over a number of years, trying to get benefits they are entitled to and which are essential for them to be able to access the care and support they need.

Have you attempted to obtain medical evidence for benefits claims? Was this made readily available to you? Have you been refused benefits because you were unable to provide supporting medical evidence?

It had been a struggle for most to obtain supporting medical evidence for benefits claims.

Many people living with ME do not have a medical diagnosis, people with severe ME may not see medical professionals (partly through the reluctance of GPs to carry out home visits – see above), also because we do not have many health professionals routinely dealing with ME there is a dearth of people who can help with providing supporting evidence.

Half of our respondents described having had battles trying to access benefits they were entitled to, with more than a third of all respondents having to go to an appeal tribunal - sometimes on several occasions over a number of years. Such perseverance is born out of desperation and causes untold stress to people with severe ME.

There also appears to be a significant inconsistency in how the benefits are assessed, since while many people are being turned down because of lack of medical evidence, other members tell us that they are not experiencing the same problems. Around a sixth of respondents say that medical evidence was made readily available to them and this made a huge difference.

Experiences included:

"Yes, was knocked back twice. I had to apply again. Got medical advice from my GP and had an independent doctor twice to my home. Could not get out of bed for the first four years – [the experience] is still very raw."

"The benefits system is a minefield – had to go to 2 tribunals to get benefits. Since 2007, my ME has been severe, more evident so easier to get proof. Even so, I was made to jump through hoops, which is demeaning and stressful."

"I have had to fight every time for DLA, even though I have had ME for over 20 years. Sometimes twice in one year, one time two tribunals in 6 weeks. I find filling forms hard and without DLA I cannot then pay for private health. Benefits offices still do not understand how serious ME is and that the breakdown of the brain and body leave you so unlike what you were before that depression sets in making things even worse."

"I was initially refused DLA but on appeal without any extra evidence I got high mobility and middle care – I didn't even attend the appeal."

"I did not try to obtain medical evidence for my recent benefits claim but I still retained my benefits."

"I've been very fortunate, all the GPs I've had have all supported my claims..."

"I've never attempted to claim benefits. The claim forms are not designed to reflect the severity or scope of ME."

"Currently receive Incapacity Benefit. Was refused DLA even on (supported) appeal because lacked medical evidence to support my claims."

"My then GP felt if I could do something once, e.g. get out of a chair that meant I had no problem even if I could only do it once a day! So not useful. Consultant said I was in a wheelchair because of my psychological problems so they tried to claim back 10 years of mobility benefits, nightmare!!"

Around a quarter of respondents had found themselves having to pay privately for tests in order to provide the required evidence for the benefit claim. This has been a great strain for many and of course many others are simply not able to pursue this avenue for help and support.

Experiences included:

"I had problems initially in getting DLA. I have had a photomicrograph of my blood done in NZ (Dr Les Simpson). I have also had 2 sets of bloods down in local surgery for metabolic tests. I was awarded DLA at high level because of overt neurological signs and visual/spatial processing deficit."

"The medical evidence given by a private ME specialist was necessary when I had to go to appeal. I have been awarded DLA mobility (High) care (Middle) indefinitely after being refused!"

"I mentioned [to GP] that I have heard that a positive mitochondrial dysfunction test could help with DLA. My GP refuted this – said the test was unavailable on the NHS, I could pursue it privately but that in his opinion it would be in no way helpful for DLA. As there are no services and no access to a specialist clinician, I have no supporting evidence at all."

"I have obtained medical evidence in support of my claim through a private doctor. This has been accepted. I think my GP has supported my claim but medical evidence per se doesn't seem to be available via the NHS. I have not been refused benefits so far... The difficulty lay in obtaining an accurate diagnosis in the first place."

Given the difficulties experienced to date, there is a fair amount of trepidation around amongst people with severe ME with regard to forthcoming changes to the benefits system.

Feedback included:

"I have full DLA but it took years of fighting and was detrimental to my overall health (poor as it was/is) to get. I despair at what lies ahead."

"I was refused IB initially – partly because my (then) GP said I had depression – I'm house / bed bound so of course I'm depressed. I had to appeal and it took a year. I dread the new medicals."

"My DLA will be coming up in June 2012. I am concerned about this as I only have my GP. I am not under anyone from a hospital as when I was no longer a child there was no neurologist on the NHS to take over from Dr. McWilliam (children's neurologist) so not under anyone for last 7 years. Don't have anyone apart from GP to write medical report so not sure what will happen."

W's EXPERIENCE

Thank goodness I have a relatively supportive doctor – I have to give him detailed information so he can do an accurate report for me. Otherwise he has no other medical evidence to go on. There are no test results, consultants' letters etc. to help him. The system is deliberately set up so I can't get specialised medical test to prove I'm ill... I have been refused benefits on many occasions despite providing supportive medical reports! Having to appeal/ask for reconsiderations is the norm.

Worrying about refusal of benefits I am more than legally entitled to, is beyond distressing – each struggle affecting my health severely... It is the single most distressing thing that makes my illness worse – living in a state of permanent fear subject to constant assessments...

Tell the MSPs if they're not going to offer us real treatment or give us access to tests to prove the serious nature of our illness then at least don't make our lives more hell than they are in the meantime with this abuse/harassment that makes up the current benefits situation. It has made me feel suicidal on many occasions.

V's EXPERIENCE

I applied for and was refused DLA numerous times – through appeals etc. This hinged on the doctor's assertion that I could manage to walk 200 yards (which was not my actual experience).

Fortunately I was finally able to get the help I really needed through the ME Association who provided paperwork to advise on how to complete the DLA application forms. Even then it took approximately 4 months for me to fill in the form one step at a time.

The system works against people who have problems with such complex forms and the time and effort it takes to complete them. Despite requesting more time to complete the form(s) and clearly outlining the reason for the request (perfectly in line with the rationale of the benefit/allowance in question) I was refused which led to severe consequences for my family.

Outside of major cities there are not the same facilities for assistance in completing benefit forms and I have had to do a considerable amount of searching to find help for my husband who is also disabled. I have now managed to get some assistance from Age Concern who will help in the case of people over the age of 50. The stress involved in dealing with the process of applying for the help and support you need without any help and support in doing so only serves to exacerbate my health problems.

In terms of the doctor providing inaccurate medical information on my DLA form (about my ability to walk 200 yards) – I was too tired by the end of the process to go through the form with him and requested that we do so at a later date. He did not return so even though I had not signed the form to confirm its accuracy it was still submitted and my application was refused. My benefits had been stopped causing me to experience a number of personal losses including my children and my home.

I paid privately for mitochondrial tests to be carried out by Dr. Forsyth and travelled to London three years ago to have these done. I strongly believe that these should be made available on the NHS as there is an issue around access to benefits and the 'proof' of condition provided by such tests. I got my benefits back because I had had the tests done but had to absorb the costs (financial and health-wise) of going through this process.