

# Living with Severe M.E. in Scotland

Report on Members' Consultation, Autumn 2011



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*25% ME Group*

*Report to Cross Party Group on ME at the Scottish Parliament*

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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, including their thoughts on NHS and local authority service provision and how this is – or is not - working to improve the lives of people with severe ME in Scotland.

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. With this in mind, the pro forma questionnaire was prefaced by this guidance:

*The following headings are intended to give you scope to raise issues that matter to you, and to describe your own experience in your own words. This is really important since you are the best person to explain about concerns and share successes from your own experience. We have given you some prompts about points you may wish to cover – please do not feel that you have to confine yourself to these, nor that you have to address them all.*

The topics highlighted were:

- *Your Experiences of the NHS and what we can learn from them*
- *What Works Best for You – dealing with symptoms; approaches to activity & rest*
- *Your Care Needs - meeting care needs, care services*
- *Welfare Benefits – access to supporting medical evidence*
- *Your Illness – triggers and severity*

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. It is also important to acknowledge the strength of feeling among the remaining members, some of whom let us know that they would have wished to add their voices but found themselves once again silenced by the illness. There is no doubt that the will to participate is there.

We have structured this report using headings relating to the above topics. There is inevitably a degree of overlap – for example, between discussion of symptomatic relief and feedback on experience of the NHS – and so the feedback set out in this report is best viewed in the round. However we have on occasion repeated an illustrative example where this relates to more than one topic, to avoid key experiences being 'lost' if focusing solely on the topic in question.

This report indicates the overall thrust of responses in quantitative terms. However, 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.

Ultimately we hope that the findings will make a very positive contribution to the work of the CPG in the forthcoming year and that the impact will spread both locally and nationally to increase understanding and help keep focus on the issues that matter most to people living with ME in Scotland.

# EXPERIENCES OF THE NHS AND WHAT WE CAN LEARN FROM THEM

## 1. You and Your General Practitioner (GP)

**Many people with severe ME in Scotland rarely or never see their GPs.**

**This is partly due to GP reluctance to make home visits, and partly due to people with severe ME actively avoiding seeing their GPs due to lack of GP understanding of their illness.**

**Some did find their GPs pleasant and willing to help, but lacking in the knowledge and understanding of ME required to assist patients, or even positively misinformed.**

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

It appears that most people with severe ME in Scotland do not see their GPs often, and that when they do this may be for help with other illnesses and not regarding ME.

Around a quarter had check-ups or reviews once or twice a year and a similar proportion saw their GP every two or three months. None saw their GP more frequently than this. Around half had minimal contact with a doctor, or none at all, perhaps only seeing their GP or Practice Nurse only at specific clinics (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 and certainly it appears that many do 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 M.E.

### ***Experiences included:***

*“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.”*

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

There is a clear split in whether or not members in Scotland find the service they get from their GP helpful – with responses fairly evenly divided.

According to the negative responses received, there appears to be a worrying tendency towards a projection of disbelief and unwillingness to accept the symptoms described by the severe ME patient, with a minimising or trivialising response from the GP. Feedback in response to this question again indicates that people with severe ME in Scotland may actively choose not to involve their GP with their ME. This emerges through feedback on a number of different GPs in different surgeries and across different areas of Scotland.

### Experiences Included:

*"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."*

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

*"I get support for med reports but not much else – how can he treat me when I know more about the illness than he does? He 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?"*

*"I think my GP would treat me if he could but I do not know if any health practitioners have any knowledge of how the disease actually affects us. If they have a patient with arthritis or MS they have a mental picture of what it involves but not with ME. Changing that would be a giant step forward for us even if there is still no cure or treatment."*

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

Home visits where required were clearly seen by 25% ME Group members in Scotland as key to improving the GP service to people with severe ME. However, there appears to be a 'lottery' in terms of variation across surgeries as to whether or not GPs provide home visits to such patients. Only one-third of our respondents confirmed that they can get home visits with an equal number saying this service was not available to them. Most of the others did not know, possibly because they had not sought out a home visit, given the reluctance on the part of some to consult their GP in view of the possible response. Some relied on telephone consultations.

The lack of access to home visits from doctors is consistent with the findings of UK survey research involving people with ME. As many severe ME patients simply cannot travel to the surgery to consult with a GP, the result is that many people with severe ME are receiving no healthcare and that medical professionals can be quite unaware of the presentation of this illness, particularly in its most severe form.

### Experiences re GP Home Visiting included:

*"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."*

*"No home visits. I feel home visits are necessary. Often I am unwell and need to see my GP; consequently 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'! He is not aware of ME-CFS."*

*"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 but 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."*

*"I have been unable to get to my GP surgery for the past 12 years and home visits [from emergency doctor] mean that the attending Doctor does not have my notes to hand. I have paid for a copy of my notes which amounts to a massive record because I have had a lot of investigations and treatment over the years. This means it would be very difficult for any new doctor to see clearly what has happened to me... An Emergency doctor is only able to have a brief visit, subject to other call-outs – this doesn't allow for much discussion of what is*

*happening and it follows that if the notes do not accurately reflect what is happening for me then what I describe to the next doctor is met with disbelief and the assumption is that I have got it wrong."*

#### **A's EXPERIENCE**

***I see my GP as little as possible... the service I get from him is dire, dangerous and deliberately callous. I have been disbelieved, lied to, mocked, labelled mentally ill, accused of making things up, playing games, seeking attention etc. I was put at serious risk when he had my care package stopped – almost overnight (5 days notice) without my knowledge or permission. Without friends, family and ex care-staff (working for free) to support me I firmly believe I would not still be alive. I was left without food or water and no help to get out of bed.***

***My GP has said in front of me and my advocate that he did not believe that ME/CFS was a neurological illness – in his opinion it was a mental aberrance, and should be treated as a psychological problem. I cannot convey how much harm this man and his closed mindset has done. People just kept on saying this can't be happening, not in the UK, not in the 21<sup>st</sup> Century, we are a civilised society etc.***

***Well it DID – it happened to me – and I am STILL fighting with my local authority to have my care restored.***

***I have seen two physios and three different OTs over a six month period during 2010. I did not want to see them but was given no choice. They were unhelpful to the point of doing me real harm. ... I was not believed – and my helpers, flat mate, family and friends were also ignored.***

#### **What a different experience means!**

***I was hospitalised for emergency surgery to correct a twisted intestine related to my IBS. I was in intensive care – then the high dependency unit and finally the general surgical ward, all in all I was in hospital for just under two weeks. My treatment there was very practical and person-centred. My ME/CFS was recognised as a neurological illness and hospital staff ... understood that I knew my body and abilities best, and I was involved 50-50 in all aspects of my care and treatment. .... Everything was just how it should be, as were all of my follow-up out-patient appointments.***

#### ***Is your GP aware of the 'Scottish Good Practice Statement on ME-CFS'? Has this been helpful?***

Few respondents knew whether or not their GP is aware of the Scottish Good Practice Statement (SGPS) on ME-CFS. Where patients knew that their GP was aware of the SGPS, this was because they had passed on the document to their GP themselves.

#### **Observations included:**

*"Yes GP aware of Scot Good Practice Statement and NICE Guidelines but little advice specific to severe ME in either."*

*"She was unaware of the SGPS on ME. However, between the telephone conversation to make the appointment and her attending my home, she had done some research and agreed on my suggestion to review me annually."*

*"He admits he wants to learn more so I have given him a copy of the International Consensus Criteria... GP didn't mention Scottish Good Practice Statement when I gave him the ICC so don't know if he has received it / read it."*

*"I gave the draft version of the SGPS on ME-CFS to my GP and he found it useful.\* I didn't give him the final version because it was a terrible document..."*

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\* The SGPS went through various drafts. The version being referred to here is the 'first edition - proof copy for media launch at Scottish Parliament 14<sup>th</sup> May 2009'. This 'launch' proved the prelude to a further draft, which in turn was replaced by the version finally circulated in the NHS. Published August 2010, this comprises a full SGPS, a quick reference guide, and a patient leaflet. Please note that the full SGPS was revised November 2010, to take account of feedback from the 25% ME Group regarding the misleading way that statistics on the numbers of patients involved in

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

Respondents provided a number of suggestions for improving the GP service to people with severe ME. Most revolve around increasing awareness and understanding of illness and treating patients with dignity and respect. There is also a strong sense that GPs have no appropriate or useful procedures to follow, no recourse to investigative tests that reveal the known abnormalities, and no treatment to provide. This leaves the patient with no option but to seek private care and costly investigations.

*Suggestions included:*

*“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.”*

*“It would be helpful if there was a central base for every county (based within NHS building) 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 to recovery... 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, so I will have to pay a private doc to get this.”*

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Cochrane reviewed studies had been presented (inflated by the amalgamation of studies on people with ‘CFS’ and studies on fibroyalgia, where the numbers involved are much greater, thus lending undue weight to the relevance of the conclusions to ‘CFS’).

## 2. 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.

The issue of training and understanding of severe ME was identified as key to the helpfulness (or otherwise) of the service provided. 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?*

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 – but not all - of the referrals to Occupational Therapists and Physiotherapists had been made at the patient's request. Some were still awaiting appointments when we consulted them about this.

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.

### Feedback on Referrals to Occupational Therapists and Physiotherapists included:

*"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."*

*"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."*

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

*"I accept the use of physical aids such as a wheelchair and stair-lift and perching stool, electric scooter when I can manage it."*



### **A's EXPERIENCE**

*I have seen two physios and three different OTs over a six month period during 2010. I did not want to see them but was given no choice. They were unhelpful to the point of doing me real harm. They collectively refused to recognise the pain I was in, or the obviously visible injuries I had (I took photographs). They refused to accept that repetitive movements have for me a negative accumulation. I explained that I may do a thing once (say transfer from my bed into my wheelchair), when I was not too tired or sore, however, I could not do it every time without putting myself or my health at risk. They refused to recognise that pain could also be accumulative and worsened by activity, that I could do as they asked – but then I would be ill and in pain for the next three or four days (or longer). I was not believed – and my helpers, flat mate, family and friends were also ignored.*

Other Allied Health Professionals: As well as NHS services, some took the opportunity to comment here on Health Professionals seen privately. Those consulted include Osteopath (there was a call to have Osteopathy made available on the NHS), Community Psychiatric Nurse, Psychologist, Counsellor, Acupuncturist, Dietician and District Nurse.

There was a wide variety of feedback on the involvement of this group of professionals, particularly since some were found to have been variously helpful and unhelpful at different stages of a person's illness. For example, acupuncture might be found initially helpful yet later experienced as painful and lacking any positive effect. Herbal medicine worked for some but there were also reports of how it resulted in an upset stomach and made general symptoms worse. Counselling was found by some to be helpful to a degree, but this also varied in effectiveness.

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.

### **B's EXPERIENCE**

*Our son has seen the district nurse and physiotherapist. We have had a wheelchair provided but he cannot currently use it. GP sent referrals on our request. Unfortunately these services are not a lot of use when our son is totally bedbound, light and sound-sensitive... There are absolutely no specialist services provided in Tayside whatsoever. A total dearth of information and help.*

*Our son has private medical insurance and has had to see a totally disbelieving psychiatrist. This was very damaging and exhausting for him.*

*It would be helpful to try some of the lesser known treatments that have proved efficacious in some patients and also it would be very helpful to obtain a list of possible alternative conditions that hospitals could test for and rule out or in.*

### **U's EXPERIENCE**

*At the beginning of my major relapse in 2000 I had to find my own counselling service which was quite helpful. But it was only when I became suicidal that action by the NHS started and an OT was sent out to see me over several months. I was referred to a doctor who was in a hospital on the other side of the city but because I had to find my own transport I was so exhausted with the travelling that the appointment wasn't very productive. The doctor asked so many questions and did tests which I didn't understand that I was even more tired afterwards. It could have been helpful if I had continued to visit but I was too ill to go out.*

### ***3. Hospital Stays***

Respondents stated quite clearly that they would go to great lengths to avoid hospital admission. This goes far beyond the hospital environment being quite different from one's own home, rather it is experienced as a dangerous place for the person with ME when there is little or no knowledge or understanding of the needs of patients with the illness, whatever the reason for their admission.

***We would be interested to hear about your experiences as a hospital in-patient. For example: Where were you admitted to and for how long? How did you find the experience? How did it impact on you - at the time and in the longer term? Was your admission related to ME or some other health problem?***

Almost all respondents had experienced hospital admission at some time. Not all admissions related directly to ME, however the stays were described as having been negatively impacted by having ME, and conversely their ME was exacerbated by the experience of a hospital environment. Words used by severely affected ME patients to describe their stays in hospital included:

- “Frightening”
- “Awful”
- “Stressful”
- “Nightmare”
- “Hostile”
- “Traumatic”
- “Horrendous”
- “Unbearable”

Responses covered a period of some 20 years and named a range of hospitals including Glasgow Southern General, Raigmore Hospital Inverness, Stirling Royal Infirmary, Edinburgh Western General, Ninewells Hospital, Edinburgh Royal Infirmary, Victoria Infirmary, Inverclyde Royal, the Homeopathic Hospital, and Perth Royal Infirmary.

Once again the issue of variability in staff's knowledge and understanding of ME was highly relevant to the resultant experience. There appears to be lack of knowledge on the part of hospital staff of the special care considerations that having severe ME necessitates.

*Experiences included:*

*“I was admitted 2 years ago for a suspected heart attack – it was reflux caused by medication for A.F. [arterial fibrillation]. Nurses good, overnight doctors good. Doctor in charge AWFUL – laughed in my face when shown material relating to heart problem in ME patients produced by Prof. Cheney (USA). Was put on warfarin and statin without discussion – liver function went haywire.”*

*“Was put in respite home for the elderly (aged 41). It was frightening and the staff woke me at 7am and had no idea about ME. Bells rang through the night and I felt insecure.”*

*“Infectious Diseases Ward: Usually 3-5 days – Ward Staff have no understanding of what makes my illness worse, strong lights, noise, smells – made me physically worse and staff (nursing in particular, when I saw one) had little compassion or understanding. I'd rather not go into hospital – it makes me more ill and have warned my family not to let it happen unless I need resuscitation!”*

*“Went through an incredibly painful and unnecessary operation due to ignorance about how the illness (ME) manifests itself. The fact I had ME was completely ignored/disregarded. I ended up having severe complications and could have died. No protocol regarding my pain relief/type of anaesthetic in relation to me having ME was adhered to. Again it's hardly surprising that they had no specific info on the special medical needs I would require....”*

*"Admitted September 2010 with severe chest pains. Tested for heart attack. Sent home very ill but told it was ME-related and they could not help me – no Consultant!"*

*"It was horrendous due to a complete lack of knowledge of my symptoms. The impact was that I hoped never to be admitted to hospital again. At the time I was referred to a neurologist and was referred for a CT and MRI scan, both helpful."*

*"I found the experience absolutely unbearable because of the staff's ignorance and disrespect concerning ME... Basically I was treated as if I'm mad (which I'm not). Glaring lights and noise didn't help either. Eventually I discharged myself against medical advice because the hospital was making me even more ill than I was already."*

*"Consultants sceptical regarding the existence of ME. I had a difficult time in both hospitals. I was forced to see a psychiatrist in both hospitals."*

*"Most of the doctors seem to think that the ME is psychological and I'm frequently asked when I last saw a psychiatrist."*

People with severe ME consistently report distress when approached and treated as if they have mental health problems rather than a neurological illness. To have psychiatric intervention forced upon people with neurological illness is humiliating and distressing.

#### **C's EXPERIENCE**

*I was taken as an inpatient to a neurology ward in 1995. I was there for 9 days and I still feel traumatised. I get agitated even thinking about it and my health was adversely affected.*

*I thought I was going to be assessed, to have someone see what my symptoms were actually like. Instead I was asked to walk between two handrails for ten minutes each day and when I did not improve each day I was told my 'behaviour was too entrenched for changing.'*

*I was desperate for improvement so when they said to try walking to the toilet instead of using my chair I realised there was a long bench and I walked a bit rested, till I got there. My efforts were not noticed or appreciated and when I was too exhausted to try again I was left in bed trying not to wet myself until visitors arrived to take me. During the night I still tried to go myself, but did not have the strength to open the door when I finally got back. I ended up lying on the floor for over an hour and they still did not think I was trying to walk.*

*The nurses were not sympathetic, my pills were left where I could not reach them, and my water was removed despite a sicca syndrome. A lot of it was done with a look rather than anything you could complain about and I became totally demoralised.*

*I was blinded, literally, one morning when the light was suddenly switched on as I was looking at it. They would not tell a doctor and I was given no help at all even trying to eat breakfast by touch.*

*One nurse said that sick patients were having to go hungry while they dealt with the fuss I was causing. When I asked for a cup with large handles I could hold they said they were for other patients and again I had to get help from visitors...*

*Eventually I was given a diagnosis of 'entrenched psychological inability to walk superimposed on a mild ME condition' [I love that 'mild.']. My husband was told there was nothing wrong with me.*

Given the general lack of understanding of ME, and particularly severe ME, the need to take due cognisance of ME when treating concurrent illnesses – whether in hospital or in the community - could give rise to considerable apprehension.

Experiences included:

*“I am frequently admitted to hospital because of my severe asthma. Each admission has a detrimental effect on my ME because of the environment and routines.*

*“I use patient transport for appointments. Even if my appointment is at 11.30am I still have to be ready for 8.30am in case they come for me early. I frequently have to go ‘round the houses’ while we collect other patients and then wait hours to be taken home. Often a 15min appointment means I’m out of the house for 4+ hours. A specific time for picking me up and dropping me off would save me huge amounts of energy. It can take me almost a week to recover from a hospital appointment purely because of transport issues.”*

*“I am currently concerned as I have been offered toxic drugs for another medical condition and am concerned that the specialist cannot judge how these can affect my severe ME although he thinks he ‘knows’ about ME.”*

However there was at least one experience of appropriate care in hospital:

**A’s EXPERIENCE**

***I was hospitalised for emergency surgery to correct a twisted intestine related to my IBS. I was in intensive care – then the high dependency unit and finally the general surgical ward, all in all I was in hospital for just under two weeks. My treatment there was very practical and person-centred. My ME/CFS was recognised as a neurological illness and hospital staff (from ward assistants right through to my anaesthetist and my consultant) understood that I knew my body and abilities best, and I was involved 50-50 in all aspects of my care and treatment. I was treated with respect and dignity, my pain management was excellent. Not one person disbelieved me – doubted what I said or devalued my experiences. Everything was just how it should be, as were all of my follow-up out-patient appointments.***

## 4. Experience of 'CFS' Services

Most respondents had not been referred to any such service. However, it is notable that most of those who had accessed the service provided did not find it particularly helpful.

*Have you been referred to a service intended specifically for people with 'CFS'? For example, the specialist nurse in Fife, the 'Wel' clinic in Glasgow. We would be interested to know, for example: Which service? How would you describe the service on offer and its impact on you? Did you feel that those providing the service understood ME and how it affects you?*

Most respondents had not been referred to any such service, either because there are none provided within their local authority area or because they do not feel the service provided is appropriate to the needs of people with ME / severe ME.

Some did have experience of these services. It is notable that most of those who had accessed the 'specialist' service provided did not find it particularly helpful. The concern was expressed that an impression is being created that something is being done for people with ME when in fact it is not what is required to truly support patients or to define and treat the disease.

It should also be noted that the closure of the ME clinic at the Southern General Hospital in Glasgow, where groundbreaking research had been conducted and clinical consultations offered, was a matter of great regret. Some patients in the Greater Glasgow area had been left unable to access medication or other professional help for their ME on the NHS.

### Feedback included:

*"There was no acceptance of, or interest in, any symptoms other than 'fatigue'... The appointment was an hour and ten minutes – too long for me; no concessions were made... I felt the underlying agenda was to appear to be doing something for patients with ME without actually doing anything other than to create the impression that this severe neurological disease is nothing other than a minor mental health problem, born of sheer laziness, depression and a lack of motivation. Nothing could be further from the truth."*

*"Because I had to find my own transport I was so exhausted with the travelling that the appointment wasn't very productive. The doctor asked so many questions and did tests which I didn't understand that I was even more tired out afterwards. It could have been helpful if I had continued to visit but I was too ill to go out."*

*"Was at Wellness ['Wel'] Clinic ... Other individuals there were not as disabled, most having part time jobs... [The message was] we have suppressed 'issues', that we do not address - totally dismissed virus or genetic predisposition. Clinic I was told I didn't want to get better and I had to exercise to health! I could say more – if you want ME patients to get sicker send them to [t]his clinic!"*

### **D's EXPERIENCE**

*I heard via word of mouth of the 'Mindfulness' Clinic at the homeopathic hospital Glasgow five years ago and I asked my GP to refer me. I attended the hospital for an assessment to discover the clinic service was 3 hours long in a lecture theatre. I explained that I could not sit for this length of time and was basically told I was therefore not well enough to attend. I felt marginalized and isolated once again from the health service. [NOTE: This feedback relates to the 'Wel' clinic, which offers 'mindfulness meditation' as one aspect of the programme.]*

## 5. 'Patient Centred' Services?

This question elicited strong opinions. Issues were raised about both in-patient and out-patient services and a general feeling across all respondents that services are not currently delivered in a 'patient centred' manner.

*The Scottish Health Department is advocating 'patient centred' services – which means services that are delivered in a way that is designed around patients and their needs.*

*Please tell us about anything that has made it more difficult for you to access the NHS, or anything about access that has been detrimental to you e.g. having to travel, waiting times in public spaces with bright lights, noise etc.*

*Do you have any ideas / suggestions about what might help overcome these barriers? e.g. home visits, specific transport arrangements, locally based provision.*

This question elicited strong opinions from all respondents. Answering individually, they were unanimous in stating that as severe ME sufferers their access to services was detrimentally affected by having to travel to appointments and then having to tolerate waiting times in public spaces with bright lights, noise etc.

There were issues raised about both in-patient and out-patient services and a general feeling across all respondents that the services provided are currently not 'patient-centred'. Needing to travel 'flat' (i.e. lying down) causes many problems in terms of arranging transport in what appears to be a system which is certainly not 'joined-up' and this is only one instance where stress and vulnerability is experienced by people who are housebound or even bed-bound and needing to attend appointments. Everyone should have access to essential services.

### Perspectives included:

*"It would be fabulous if home visits, transport arrangements, locally based provisions etc... I suppose if government poured money into NHS these suggested services would be implemented. Also [need] to educate consultants into the real state of play regarding ME and not to dismiss us as surplus to requirements... How can you access help from NHS if there are no bio-medically trained neurological ME consultants..."*

*"Travelling and everything in examples [cited on the questionnaire – see above]. Home visits and where appropriate telephone consultations would be wonderful. From my own experience I know my body and symptoms and if not stressed could easily pass them on by phone or self but by the time I travel and sit in public in bright lists etc I'm lost – forget everything and can't ask for the help I need."*

*"There is a problem travelling to hospitals and also inside hospitals. I don't think the mobility needs of ME patients are understood and the impact these visits have on the severity of ME, and recovery time required afterwards."*

*"A good starting point would be to actually have staff educated about the pathophysiology of the illness. That would be truly amazing and with true understanding the rest would naturally follow. I currently medically neglect myself as I know I won't be able to travel to outpatient appointments, cannot sit for hours waiting to be seen, too ill to cope with it all and know I have no hope of getting home visits."*

## E's EXPERIENCE

*The instant I sit up from the prone position my blood pressure drops dramatically. It will continue to drop the longer I remain upright and/or move around. This is very disabling for me... causes lots of problems. Having to remain lying down means that I am unable to integrate with the world rendering me desperately vulnerable in situations outside of my own home e.g. in the case of hospital admission. Because the effects are to the brain, I am unable to communicate properly what is happening at a time when it is most important to be able to do so and get the assistance I need. To minimize the danger it is very important to be in control of the environment as far as possible.*

*One example of the lack of patient centred service is my experience of trying to organise to have my routine smear test. I received my referral letter along with details of who to phone to organise transport etc. Upon calling to explain my predicament I was told 'we can do that' but when it came to discussing the appointment time the problems began to surface. I had been given a 4pm appointment but the transport service only operates until 3pm for a 4pm finish. As the discussion progressed I was told I was 'being very awkward' and later informed that I couldn't be transported as 'we don't service this clinic'. It is very frustrating – they are still battling me about from A to B and I should be able to have a smear test like any other woman but I can't make the necessary arrangements.*

*It is also a problem that trolleys are not routinely available for outpatients but only for in-patients. The fact that I need a trolley to be available on arrival at a hospital/clinic is met with derision by rude porters who insist that the only way for this to be available is for me to be booked in. The whole system is a mess which contributes to my difficulty in getting to see a consultant. Because we have only one small hospital locally and certain health problems are treated at specific hospitals on the mainland (chiefly Central Belt locations) this makes travel and distance a particular issue. For example I must travel to Glasgow for treatment in relation to my heart condition. One consultant did visit me at home and stated that I need to have tests done but couldn't get me to Glasgow to have them.*

*The system can't cope with someone as ill as I am and row upon row just makes me more ill.*

*I have been unable to get to my GP surgery for the past 12 years and home visits mean that the attending Doctor does not have my notes to hand. I have paid for a copy of my notes which amounts to a massive record because I have had a lot of investigations and treatment over the years. This means it would be very difficult for any new doctor to see clearly what has happened to me if GPs can't come with my notes.*

*An Emergency doctor is only able to have a brief visit, subject to other call-outs – this doesn't allow for much discussion of what is happening and it follows that if the notes do not accurately reflect what is happening for me then what I describe to the next doctor is met with disbelief and the assumption is that I have got it wrong.*

By contrast, A's experience of hospital care shows that it is possible for the NHS in Scotland to deliver some aspects of a patient centred approach to a person with severe ME (see page 12).



## 6. 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 – 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.”*

*“NHS use of mitochondrial testing would dispel misconceptions.”*

*“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.”*

### **Y’s PERSPECTIVE**

***It is strange having ME. It has left me disabled, unable to look after myself, in constant pain but it is never discussed medically. I read about research that is being done but have no idea if I have any of the problems they find with the heart or the immune system or whatever. I can’t get B12 injections or even a Vitamin D test despite never being out in sunshine. It is like a strange elephant in the room. I think my GP would treat me if he could but I do not know if any health practitioners have any knowledge of how the disease actually affects us. If they have a patient with arthritis or MS they have a mental picture of what it involves but not with ME. Changing that would be a giant step forward for us even if there is still no cure or treatment.***

## WHAT WORKS BEST

### 7. 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.*

## 8. 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. There is more on this at section 11 below.

#### **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!***

## 9. PERSONAL CARE: *Meeting Personal Care Needs*

Respondents identified a range of care needs – most needing help with bathing, shopping and preparing meals, making drinks, getting to the toilet etc.

More than a third rely on partners/family as primary care providers.

The view is that there are not enough formal carers who have knowledge and understanding of the needs of people with severe ME. Individuals may do their best but they are too often poorly paid and poorly trained.

### ***Can you tell us how your care needs are being met - for example, do you have help with bathing, meals, getting to the toilet?***

Almost all respondents identified needing assistance to care for themselves. Some found that the level of care assistance required fluctuated, depending on the course of the illness.

More than a third were relying on their spouse / partner or other family as primary or sole carer. Reliance on family, for those who have access to this support, is a worry for many of our members. However, the situation is even bleaker for those without family support.

Most used the services of personal assistants, cleaners or other paid support staff. It is notable that a quarter of respondents were paying for support staff from their personal income, no matter how limited, because lacking access to appropriate level of funded care support.

#### *Experiences included:*

*"I have a cleaner. I can't prepare meals so use ready meals. My sister cooks batches of soup etc. for freezer and shops."*

*"I currently receive care from 2 private care companies and my husband helps daily."*

*"My husband has to do all the housework, laundry and most of the food shopping. Occasionally he also has to make the meals (normally my job) and do the washing up (normally shared job). At times he has had to support me in getting to the toilet, but this is not usual as I can crawl if I can't stand!"*

*"I employ personal assistants via Direct Payments. I require assistance bathing, hair-washing, meal preparation, and with medication."*

*"My husband does it all as well as working full-time, a worry as his health is not brilliant."*

*"My parents make meals and bring them upstairs – I can't get downstairs. They empty my commode which is in my room. I can now shower fairly frequently. I have Direct Payments for 24 hours a month to give parents respite."*

*"My husband and myself - retired parents - meet all care needs: reading mail, washing clothes, washing dishes, shopping for fresh food etc. and provide safe, warm home in family house for our 32 year old son."*

*"I worry about asking for help when that time arrives... I wonder if my explanations will be believed, or the severity of my condition understood. I tend to be cheerful and it can be misleading."*

### ***Is there anything you would like to say about local authority or private care services?***

The perception of local authority care is that they believe people with other illnesses/disabilities are more in need of their services.

Less than 10% of respondents were in receipt of local authority care/support. However, around a quarter of respondents had had some experience of local authority care and there was a clear perception that the needs of people with severe ME are not understood.

Direct payments are a 'life-saver' for those who can access them – many of the respondents who are using direct payments to employ personal assistants did try direct Local Authority care but found this to be unsatisfactory and stressful because of the lack of flexibility in approach to arranging times for visits, the staff members' lack of knowledge and understanding of ME and ever-present threat of service cuts.

Personal Assistants can be employed where a person is eligible for a certain level of care and chooses to arrange for their care using Direct Payments, although difficulties in accessing benefits has been identified as a barrier for more than one third of respondents.

Feedback included:

*"LA services are awful. I had a woman coming in for 15mins at tea-time to make a smoothie. I stopped it as she was unhygienic and left the kitchen in a mess. They are poorly paid and poorly trained."*

*"I tried Local authority but had to give it up. The staff had no idea re. ME! They were loud; turned up at unexpected times and knew nothing about special diets."*

*"Local authority budget could run to only 4 hours care per week, contracted privately. I paid the remainder myself. Frequent changes of personnel was tiring and stressing. My partner (now retired) cares for me full time."*

*"I use direct payments to have a combination of agency and PA carers. I have found most of the agencies to provide a poor level of care plus the Social Work Dept doesn't provide enough money through direct payments to employ the good agencies i.e. they give £12.50 per hour but most agencies cost £15 per hour and I can't afford the difference."*

*"Without the services I would be dead. I am not washed every day and the itch is so bad I tear my skin. Even with bathing every day, itch can still be bad. Evenings and nights without money to pay private care I would be in hell."*

*"Would rather go unwashed than put up with abuse from Home Help Service (have heard such awful reports from others who have used this 'service'). You are constantly assessed/disbelieved and made to feel an undeserving burden to them. No privacy and totally humiliating. In Glasgow the quality of the staff is appalling. They won't even do housework or food shopping anymore and I'm too ill to be disturbed/ woken up to deal with an unsympathetic person. I pay for someone to come in and help me out of my own benefit money. At least that way, I won't be abused but I can't afford to have them as often as I need to."*

*"21 hours per week is not enough and carers are not paid for nights waking or sleeping over. I live rural for health reasons – most of their pay goes on diesel or petrol, it is very unfair."*

*"I have help with everything. I have carers in 6 times a day. My care package is 55hrs per week."*

*"My Care Services were recently stopped, even though I am no better. I had been receiving help at home from the local authority for over 20 years. I am now paying privately for home care. It is just as well that a suitable care support worker crossed my path at just the right time or a horrendous experience would have been even worse."*

This feedback from members in Scotland regarding their care need and experiences of care services complements the findings of the 25% ME Group's social services survey, conducted three years previously among the UK membership. The survey findings can be downloaded from the Group's website: [www.25megroup.org/info\\_group\\_publications.html](http://www.25megroup.org/info_group_publications.html)



### **Z's EXPERIENCE**

***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... My GP is far more supportive with regards to my diabetes and severe asthma than he is over my ME***

***I saw a rehab consultant in Jan 2010 who recommended that I see a Physio and occupational therapist to help me to do standing transfers and I am still waiting for an appointment. Since then my condition has deteriorated so much that I can no longer transfer into my wheelchair myself and now need a hoist which means that 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.***

***I have help with everything. I have carers in 6 times a day. My care package is 55 hours per week. 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.***

Sadly medics, rather than providing assistance to access care services, could be positively unhelpful in this regard:

### **A's EXPERIENCE**

***I was put at serious risk when he [my GP] had my care package stopped – almost overnight (5 days notice) without my knowledge or permission. Without friends, family and ex care-staff (working for free) to support me I firmly believe I would not still be alive. I was left without food or water and no help to get out of bed.***

***I cannot convey how much harm this man and his closed mindset has done. People just kept on saying this can't be happening, not in the UK, not in the 21<sup>st</sup> Century, we are a civilised society etc. Well it DID – it happened to me – and I am STILL fighting with my local authority to have my care restored.***

The Long Term Conditions Alliance Scotland (LTCAS) has initiated a social services workstream initiative among members, and the 25% ME Group is participating in this via our representative in Scotland, Helen Brownlie. You can find out more about this by contacting Helen on 0141 570 2938 or by e-mail at [HelenB-25megroup@ntlworld.com](mailto:HelenB-25megroup@ntlworld.com)

## 10. 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.*

## 11. 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.*