

Living with Severe M.E. in Scotland

Report on Members' Consultation, Autumn 2011

PART 1. Experiences of the NHS & what we can learn from them



25% M.E. Group
21 Church Street,
Troon,
AYRSHIRE
KA10 6HT
TEL: 01292 318611

25% M.E. Group

Feedback from Members in Scotland 2011

EXPERIENCES OF THE NHS AND WHAT WE CAN LEARN FROM THEM

1. You and Your General Practitioner (GP)	3
2. Experience of Allied Health Professionals	6
3. Hospital Stays	8
4. Experience of CFS Services	10
5. 'Patient Centred' Services?	11
6. A Positive Vision – what would you like from the NHS?	12

Introduction

In autumn 2011 the 25% ME Group, the UK charity that supports and represents people who are severely affected by myalgic encephalomyelitis, approached the Group's 77 Scottish members seeking feedback. This included asking for thoughts and experiences on service provision and how this is – or is not - working to improve the lives of people with ME in Scotland.

Our postal enquiry elicited 37 responses. This amounts to a 48% return, 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.

This type of approach is fundamentally about in-depth qualitative feedback, rather than number crunching. The strength of the exercise lies in illuminating the situations that people with severe ME and their families in Scotland are facing and the action they would like to see taken, giving a voice to people who are all too often voiceless.

This report presents a summary of the responses regarding experiences of the NHS.

There are further reports covering members' feedback on:

- *Your Illness and Best Management – Symptomatic Relief; Approaches to Activity & Rest* (NB This complements the present report as it touches on ability to access 'What Works Best' on the NHS)
- *Your Care Needs*; and
- *Access to Disability Benefits – Obtaining Medical Evidence*

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

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.

“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.

“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?”

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

“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.”

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.

“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...”*

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.

“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.”

* The SGPS went through various drafts. The version being referred to here is the ‘first edition - proof copy for media launch at Scottish Parliament 14th 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 Cochrane reviewed studies had been presented (inflated by the amalgamation of studies on people with ‘CFS’ and studies on fibromyalgia, 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.

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 of these referrals to Allied Health Professionals had been made at the patient's request. and some were still awaiting appointments when we consulted them about this.

Feedback on Referrals to Occupational Therapists and Physiotherapists

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

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

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

Other Allied Health Professionals:

Although this question was presented under the heading 'Your Experiences of the NHS' understandably some took the opportunity to comment here on Allied Health Professionals seen privately.

Other Allied Health Professionals seen include Osteopath (there was a call to have Osteopathy made available on the NHS), Community Psychiatric Nurse (CPN), 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.

Overview

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

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

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

"I was admitted 2 years ago for a suspected heart attack – it was reflux caused by medication for A.F. 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 as there are no guidelines published regarding this.”

“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 was in a Neurology Ward for 9 days in 1995 and I still feel traumatised. I get agitated even thinking about it and my health was adversely affected...”

Patients consistently report distress at being 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, according to the experiences of the respondents in this exercise. And totally unfounded.

“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.”

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

“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.”

4. Experience of Chronic Fatigue Syndrome (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.

There are no specialist services in Scotland specific to people with ME. Because of this, we asked about services for chronic fatigue syndrome (CFS), which is the diagnostic label that is commonly applied to people with ME in Scotland at present.

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 respondents 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.

"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 Clinic 2005... 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. I could say more – if you want ME patients to get sicker send them to [t]his clinic!"

5. 'Patient Centred' Services?

This question elicited strong opinions from all respondents. 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'.

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

"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."

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 – and the NHS needs to be prepared to work with us as equal partners and to learn from us, not fall back on assumptions and prejudices. Above all we need a multidisciplinary service made up of open-minded doctors and support staff...”

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

“A proper ME Unit with fully trained staff supplied on the NHS.”

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