

Living with Severe M.E. in Scotland

Report on Members' Consultation, Autumn 2011

PART 4. Meeting Care Needs



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INTRODUCTION: About This Feedback Report

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

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

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

The topics highlighted included: Personal Care – Meeting Care Needs. Feedback on this issue is the focus of this report. There are further reports covering members' feedback on:

- *Your Experiences of the NHS and what we can learn from them;*
- *Your Illness & Best Management (Symptomatic Relief; Approaches to Activity & Rest);* and
- *Access to Disability Benefits – Obtaining Medical Evidence*

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

PERSONAL CARE: Meeting 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

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 21st 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