

25% ME Group – Social Services Survey Report Part II

Last September the 25% ME Group sent a questionnaire to members asking about their social care needs and experiences. A summary of the main findings appeared in the last issue of The Quarterly. Here is a recap of the overview picture:

One hundred members participated in the survey

35 were receiving care from social services:

- 13 were broadly satisfied;
- 21 were dissatisfied with the level and/or quality of care received;
- 1 gave no indication of whether or not they were satisfied with the care received.
- *(Eagle eyed readers may have noticed that the earlier article presented overview information on just 99 patients: this person's response had been inadvertently omitted).*

34 wished to receive care from social services and had applied for care at some point, but were presently receiving none.

21 required care support but had not approached social services to meet their needs.

6 were unclear as to whether or not they were presently receiving care from social services:

- 3 were satisfied with their present situation
- 3 wished to have some or more care from social services

4 had relatively low care needs at time of survey.

This article provides a more in-depth look at some of the findings, drawing on the comments that many respondents provided to illustrate their circumstances. This element of the survey was optional, as it was not felt appropriate to require severely affected ME patients and/or their carers to take the time and effort to do this. Nonetheless, a rich resource of illustrative material emerged.

In particular, we'll consider some of the barriers experienced by people with severe ME in seeking appropriate social care to meet their needs, with a focus on issues relating to the financing of care. Firstly though, there are several points to be aware of relating to the distinction between social services staff and privately paid workers, which is not always clear cut:

- Patients may employ agency staff, with funding through the social services Direct Payments scheme.
- Local authorities may use agency staff to supply social services.
- Patients may be asked to pay some or all of the cost of care supplied by social services.

Barriers to Accessing Appropriate Social Care Provision

Limits on the level and nature of the care services provided

A number of respondents highlighted issues regarding the restricted nature of the service that social services provide to physically disabled adults. Some had been receiving care services in the past, which had ceased after social services withdrew from the area of provision required. For example:

- *“Our social services only provide personal care (bathing, dressing). You must pay privately for everything else. Social services won't even provide meals. ... Social services provide very little in the way of care.”*
- *“Package no longer delivered what I needed or my spouse so it was stopped.”*

- *“My daughter was sent a form to fill out – ‘a care assessment’ eventually a social worker called on the phone. We never saw her. She said she could offer ‘personal care’ but not going shopping or cleaning house which is what we needed.”*
- *“They’re not allowed to lift a lightweight wheelchair in the boot/car so I can’t go out when I’m up to it – not very often. Due to Health & Safety blanket ban on wheelchairs.”*
- “There is a huge difference in support from social ➤ services for learning difficulties adults and physically disabled adults. Only one scheme caters for physically disabled adults and it’s very limited by funding shortage/ staff shortage.”*
- *“Had to have bath/shower 10.30 a.m. Mondays. Too early for me and not always well enough.”*

In at least one area, social services were planning to withdraw their staff from care services entirely and to provide all long term social care through the Direct Payments method, which involves providing a sick or disabled person with funds to employ their own carers. One respondent, presently receiving care from social services and without family support, articulated serious concern for her future in the light of these proposed changes:

“I am very worried about the fact that social services Home Care Support Workers are going to cease to exist as social services are planning to give all future care work to the PRIVATE agencies. Social services will be only running a 6 week care package for clients who can be rehabilitated. They are called re-enablement workers. I’ve had private care before and it was dreadful and though I can get Direct Payments I’m not well enough to do all the business side of employing my own carers. I am very frightened about my future.”

We’ll return to the issues around Direct Payments below.

Funding Constraints

A number of patients highlighted funding constraints as having been cited as reasons for the failure of social services to provide the level and nature of care service required. For example:

- *“I have 6 hrs a week & did have 9 but 3 taken away 2½ years ago due to lack of funds.”*
- *“I have never had any care services, despite being seriously ill for 13 years. I was assessed over the phone in 1997. Requested CC package – told me there was no funds...” (This patient receives high level care component of DLA and is paying privately for care.)*
- *“Care was stopped because my youngest child had just turned 4 therefore I no longer need help! Plus lack of funds. The M.E. did not stop simply because our son reached school age. We asked again several times, but were refused as there were ‘no children involved’. So who did they think would do the school runs, shopping, washing, cleaning – a 4 year old should walk home alone and prepare his own meals because his mother was ill in bed! We paid for private child minder, and still pay for private domestic help. The carer has to hold down a full time job.”*

A number of patients noted that they had had their social services care package reduced, or withdrawn altogether, or had found that some aspects of the care required were not provided on assessment, due to lack of funds. There were also instances of patients being refused care on the basis of lack of funds *without* a Community Care Assessment having been conducted. This could happen in the course of a single visit from a social worker, or even over the telephone.

Such restrictions commonly resulted in severely affected ME patients and their families paying for private domestic and care services from their own funds. In these circumstances it is particularly important that the patient receives any benefits to which they may be entitled, including the correct level of DLA care component, in order to have the resources to be able to fund the care required. Yet there were examples of bedbound patients, paying privately for care following refusal of care from social services, who had been assessed to receive only low level DLA care component.

The cost of care to the patient

Not only were some patients requiring to pay for care privately due to restrictions on the social services care provided, several pointed out that *social services* were levying charges for care at a level that they were unable to afford. For example:

- Stopped social services care because *“I was too ill – couldn’t afford it.”* (This patient is mainly bedbound. She has family care support but now pays privately for some care services.)
- Social services *“recently cancelled, can’t afford.”*
- *“I get no [financial] help whatsoever as my pension is £2.60 over the limit to get help assessed at 3 hours minimum @ £17 per hour. I get help now privately and sometimes I have a lodger and pay them for help. I never see a social worker as, I am told, I am ‘intelligent enough’ to help myself!”* Asked if able to live at home without assistance, this patient replied: *“No, but I have to”*.
- “My wife receives a care package of 63 hours a week + I care for her during evenings + get up at night to care for her as required until day carer arrives. This costs £174 per week contribution to the Independent Living Fund (ILF) + Social Services financial package. There is no funding to increase my wife’s care package.”* This couple are required to pay towards the cost of care from social services, topping up the funding provided by the local authority. So the same care staff are paid by a combination of social services funding and the client’s own money. They have also spent many thousands of pounds on mobility equipment and adaptations as Occupational Therapists *“only deal with inside (the home)”*.
- *“Because we have too much savings it is cheaper to employ private people anyway.”*
- *“We wanted access to Direct Payments”* but discovered that this *“would end up costing us out of our own pocket.”*

Practical difficulties for a sick person in arranging care under the Direct Payments Scheme

Most of those who had received a care package from social services had been informed about the Direct Payments option, which entails providing the patient with funding to employ carers. However, just over half of these respondents (54%) felt that they hadn’t been fully informed about the advantages and disadvantages of the Direct Payments scheme.

Fourteen respondents were receiving Direct Payments, this figure representing around four in ten of those who were receiving care from social services (40%). All but two had received some form of support to manage the scheme. This could take the form of payroll assistance (10), help with recruitment (9), or help with paperwork such as contracts (7). However, it was by no means clear that Direct Payment recipients were receiving all the help needed in this regard. Indeed, one *very* severely affected patient, who was entirely dependent on for her social care on arrangements made via Direct Payments, elaborated on how difficult managing this system was for her:

“(Began to receive Direct Payments) End of 2007 after years of trying + planning. All support partial only but very inadequate. Paperwork a HUGE problem still.”

And several others, who were *not* currently receiving Direct Payments referred to the inherent difficulties of administering this system for a very sick person as presenting significant barriers to this route to social care:

- *“I didn’t receive any help, not even when I contacted social services with a query/problem. They knew less than I did! Was satisfied with the finance itself, when I had it, but not any support.”*
- *“No Support (to administer) when I previously had them.”*
- *“ ... someone visited us to explain what was involved with Direct Payments. ... too complicated for someone with ME”*

- *“I really need Direct Payments, but, I would need some support hours allocated to help me manage this and none are allowed.”*
- *“ ... though I can get Direct payments I'm not well enough to do all the business side of employing my own carers.”*

In conclusion, this approach is unsuitable to the most severely affected patients, particularly those who live alone and lack the ability to make the necessary arrangements for themselves. The ironic result is that people with high social care needs and without a family member to provide some care support are at the same time most dependent on social care services and least able to organise the employment of staff through Direct Payments.

Further Issues

A number of other areas of concern emerged from the findings. These include:

- Deficiencies in the quality of care service provided
- Refusal of care from social services and difficulties in appealing decision
- Delays in the assessment process/ provision of care and impact on patient

- *Lack of awareness on the part of social services about the nature and impact of severe ME*

- *Experiences in the NHS deflecting patient from accessing appropriate social care*

- *Barriers to accessing suitable occupational therapy service*
- Barriers to carers accessing appropriate support

We hope to have a look at these in the next issue of the Quarterly and/or to post a discussion of relevant findings on the Group's website in the New Year.

We will also be drawing on the findings of the social services survey to inform the 25% ME Group's response to the UK government's consultation on the future of care services in England (see advocacy page for more on this).

Many thanks to Helen Brownlie for her all hard work on this analysis.

(Full report available soon on group website.)