

Social Services Survey Report

25% ME Group – Social Services Survey Report

by Associate Member, Helen Brownlie

Last September the 25% ME Group sent a questionnaire to members asking about their social care needs and their experiences of attempting to access care from social services.

Social services are a potential source of much needed immediate practical support to people with ME, and I've long felt that more could be done to focus on this. So I was pleased to be asked to take a look at the findings.

Responses were received from 100 members throughout the UK, ranging in age from young adults to pensioners.

What comes over loud and clear is both the pressing need for care services and the existence of various barriers to accessing appropriate provision. For example:

- * limits on the nature of the care services provided
- * the cost of care to the patient
- * lack of awareness on the part of social services regarding the nature and impact of severe ME
- * the practical difficulties for a sick person in arranging care under the Direct Payments scheme
- * the difficulty of providing appropriate care from outwith close family when a patient is *very* severely affected
- * lack of awareness on the part of some patients that care services may be available

Type of care received:

- Seven out of ten respondents [70] were receiving voluntary care, mostly from family and friends. In over half of cases these cases [38] this was the patient's sole form of care.
- Around one third [35] were receiving care from social services.
- A similar proportion were receiving care from a privately paid worker.
- Seven were receiving no care at all, including five who had applied for care from social services but had been refused care on initial assessment or had had their care package stopped on review.

Social Services Summary (100 patients surveyed)

- 13 patients were receiving care from social services and were broadly satisfied with this.
- 21 patients were presently receiving care via social services but were dissatisfied with some aspects, including 6 patients who had had their care package reduced on review even though their care needs had not lessened.
- 34 patients wished to receive care from social services and had applied for care at some point, but were presently receiving none.
 - As many patients had been refused care or had their care package stopped [34] as were currently receiving care from social services [34].
- 21 patients appeared to need care support but for various reasons had not approached social services to meet their needs. This group covers a variety of scenarios, including patients whose care needs were being adequately met by family and others who would have wished service but were unaware that care may be available or did not know how to go about applying for care.
- 4 patients appeared to have low care needs at the time and had stated that they were able to live without assistance in their own home.
- The situation in respect of the remaining 6 patients was unclear in some respect.

Occupational Therapy Summary (100 patients surveyed)

- 62 patients had had an Occupational Therapy (OT) assessment carried out.
- Around one third of those assessed [31%] felt that the Occupational Therapist had not taken on board their disability requirements, or had done so only partially.
- The majority had received some OT assistance following the assessment, but 7 patients had been refused any service and a further 4 had been refused some aspects of the help that they felt to be required. One patient had had their request for referral for OT assessment refused.

Reasons referred to in respect of refusal of service commonly related to lack of funds. There were also some instances of the Occupational Therapist feeling insufficiently qualified to assess the patient, or of the • patient being too debilitated to be able to benefit from provision of OT service.

- Around three quarters indicated satisfaction with the OT service, while around a quarter were dissatisfied.

Some Key Points:

THE COMMUNITY CARE ASSESSMENT

Two thirds of patients [66] had had a Community Care Assessment at some point.

- Asked: *Do you feel the Social Worker/Care Manager took on board all your care requirements in order to properly assess your daily care needs?* the majority of these patients [56%] answered 'no'.
- Three quarters felt that the assessor had had a poor level of understanding of ME in general and a similarly high proportion [70%] felt that understanding had been similarly lacking in respect of how the illness was impacting on the patient. There was a particularly poor level of understanding regarding the impact of cognitive problems [80%].
- Few of those who had been assessed felt that they had been well enough to cope *during* the assessment [12 patients; 18%]. And the indications were that all of those who had participated in the assessment had been exhausted *afterwards* (a few patients had been too ill to be involved in any way, and had been represented by family or an advocate). The vast majority had taken 3 days or longer to recover from the adverse impact of the assessment process, with some taking over a month.

LOSING CARE ON REVIEW

Of particular concern is the number of patients who had had their care package reduced or stopped altogether on review, even though their condition had not improved. This applied to around half of those who had been granted care, many of whom were told at the review stage that they did not fit social services criteria.

ONGOING CONTACT WITH SOCIAL SERVICES

Levels of ongoing contact were low: Around half of those who were currently receiving care from social services had [47%] had seen a social worker or care manager three times or less in the previous five years.

SATISFACTION WITH QUALITY OF CARE

Approximately a third of those who were currently receiving care from social services [37%] indicated that they were satisfied with the quality of care received.

FORMAL COMPLAINTS

A surprisingly high proportion of those who had had

dealings with social services care had made a formal complaint at some time [38%]. Most of these complaints had been upheld, fully or in part. A number of others had wished to make such a complaint, but had been prevented because they were too ill to do so.

CARERS

Around half of the questionnaires [51] included a completed carers' section.

Only 15 had received a carer's assessment.

- 13 had been provided with assistance, but two had subsequently received no respite support.

One carer who was refused respite from social services now receives help from a voluntary organisation, so 14 carers in all were receiving some form of support.

➤ However, only four indicated that they felt that they were receiving all the help that was needed.

The remainder [37] were shouldering the responsibility for care without any form of carers' support.

➤ This group illustrated a range of expressed needs, from ten carers who indicated that they did not feel that they needed any support, to a similar number who indicated dissatisfaction that there was no service – or, at least, no suitable service – available to meet their needs.

➤ Family care scenarios ranged from parents caring for sick children who had grown into young adults to elderly spouses coping with their own deteriorating health as well as attempting to provide adequate care to a severely affected ME patient. (Lack of awareness of the possible availability of patient care and carers' support services was particularly to be found among elderly people.) There were also instances of young people looking after sick relatives:

“I am 18 years old. I’ve looked after my auntie every night for 5 years. My auntie asked social services for respite for me to have a break but they said there was no funding for this purpose. I dare not leave my auntie (who is very severely affected) in case she falls over. She can’t do things for herself. I feel my auntie is treated bad and is invisible to most people.”