

25% M.E. Group Adult Social Services Survey Summary

The 25% M.E. Group exists to represent the estimated 1 in 4 people with M.E. who are severely affected. People with severe M.E. are severely restricted in mobility and ability to carry out essential daily tasks and attend to personal care. At its most extreme, sufferers are totally bedbound, in constant pain, unable to tolerate movement, light or noise and certain scents or chemicals - including prescribed drugs.

In September 2008 the 25% M.E. Group sent a questionnaire to adult members asking about their social care needs and their experiences of attempting to access care from social services. What comes over loud and clear from this survey is both the pressing need for care services and the existence of various barriers to people with severe M.E. attempting to access appropriate provision.

Overview of Responses

100 people with severe M.E. ranging in age from young adults to pensioners and resident in locations throughout the UK responded to the survey.

35 were receiving care from social services. This group comprised:

13 who were broadly satisfied with the care provided;

21 who expressed dissatisfied with the level and/or quality of care received;

1 who gave no indication regarding satisfaction with the care received.

34 wished to receive care and had applied to local authority social services for care in the past, but were presently receiving no care via social services.

Barriers to Meeting Care Needs Included:

- ◆ **limits on the type and level of care services provided;**
- ◆ **the cost of care to the person requiring care;**
- ◆ **lack of awareness on the part of care services regarding the nature and impact of severe M.E.;**
- ◆ **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 that care services may be available.**

SOCIAL SERVICES CARE

Around one third of respondents [35] were receiving care from social services at time of survey.

- *This group included 6 severely affected M.E. patients who had had their care package reduced on review even though their care needs had not lessened.*
- *It is notable that as many had been refused care from social services or had had their care package stopped as were currently receiving care from social services.*

LOSING CARE ON REVIEW

Of particular concern is the high proportion of those who were initially granted care but who later 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.*

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. The majority stated that they were dissatisfied with quality of their care from social services.

THE COMMUNITY CARE ASSESSMENT

Coping with the Assessment Process

Findings clearly indicate that the Community Care Assessment process is not geared to the needs of people who are severely affected by M.E. It would appear that this process had adversely impacted on *all* of the relevant respondents:

- *less than 1 in 5 of those who had been assessed felt that they had been well enough to cope during the assessment [12/66; 18%];*
- *several had been too ill to be involved in any way, and had been represented for CCA purposes by family or an advocate; all of those who had participated in the assessment had been exhausted afterwards;*
- *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.*

Assessment of Care Needs

Survey findings reflect considerable disjunction between the care needs experienced and social services assessment of same.

The vast majority prioritised the need for assistance to meet fundamental physical care needs – such as personal care and mobility needs – and domestic care needs in the form of essential household chores. However, most felt that the Community Care Assessment process had got the balance wrong between addressing these needs and any emotional and/or social needs.

Health Care Staff and Access to Social Care Services

It would appear that people with severe M.E. who have had a community care assessment (CCA) are far less likely to have been referred by health professionals than the client population in general.

- *Over one-third of people having a CCA are referred for the assessment by health professionals (according to figures presented a recent government Green Paper), This compares to just 17% among people with severe M.E. who participated in our care survey.*
- *This finding is in keeping with feedback provided in a prior members' survey, which indicated that a sizeable minority of severely affected M.E. patients - around one third - had no contact with healthcare professionals whatsoever. (This was largely due to the reluctance of general practitioners to make home visits.)*
- *Furthermore, responses to our care needs survey illustrated that poor experiences of the health service can operate as a barrier to accessing appropriate social care.*

CONTACT WITH SOCIAL SERVICES STAFF

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

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.

VOLUNTARY CARE

Seven out of ten respondents [70] were receiving voluntary care, mostly from family and friends. In over half of these cases [38] this was the person's sole form of care support.

NO CARE

Seven respondents were receiving no care at all.

- *This group included 5 severely affected M.E. patients 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.*