

25% ME Group Adult Social Services Survey

THE COMMUNITY CARE ASSESSMENT

This is an extract the findings from a survey of adult members of the 25% ME Group, asking about their social care needs and their experiences of attempting to access care from social services. The survey was carried out in the autumn of 2008.

We present feedback obtained from 66 respondents regarding the conduct of their Community Care Assessments.

- **Do you feel the Social Worker/Care Manager took on board all your care requirements in order to properly assess your daily care needs?**
Just over half [56%] answered 'no'.
- **Was the Community Care Assessment explained clearly to you?**
Almost half of the relevant respondents felt that the assessment process had *not* been clearly explained. Only 39% were confident that the assessment process *had* been clearly explained.
- **Were you allowed to be fully involved in the CCA?**
Just under half said that they had been allowed to be fully involved. Some of those who replied in the negative said that they had simply been too ill - others would have wished more involvement.
- **Did you feel that your particular disabilities/illness were recognised?**
Around two thirds felt that their particular disabilities / illness had not been recognised during the assessment process.
- **What level of understanding did you feel that the assessor had of ...**
 - ... **M.E. in general?** Three-quarters felt that the assessor's understanding of M.E. in general had been poor
 - ... **The effects of the illness on you?** Almost as many [70%] felt that understanding had been similarly lacking in respect of how the illness was impacting on them
 - ... **Your cognitive problems?** There was a particularly poor level of understanding among assessors regarding cognitive problems [80% 'poor']
 - ... **The variability and fluctuating nature of symptoms?** 75% felt that the assessor's understanding of the characteristic variability and fluctuating nature of symptoms had been poor

Feedback on Community Care Assessment

- *"Rationed care for everyone. No understanding of the impact of ME on my needs and disbelief at what I said. Poor communication between departments & with me."* [Perthshire]
- *"Since my daughter has gone into adult services not been treated that well. No information on meeting held. No letters what happen at these meetings. We sent assessment papers back with alteration made to them but never heard any more. That was over a month ago. Can't ring social worker as gives my daughter nightmares when she sees her and lady shouts when she goes in my daughter's room."* [Carer of a young adult in the East Midlands].

BALANCE OF ATTENTION IN THE ASSESSMENT PROCESS

Asked - **Which of these areas did you feel needed to be met the most? Physical, Emotional, Social Domestic -**

- respondents overwhelmingly replied that assistance with *physical care needs* was most important
- next highest priority was accorded to *domestic needs*
- assistance to meet *social needs* and *emotional needs* took a much lower profile

It is interesting to compare this feedback with the perceived emphasis placed by social services on the various areas of need when conducting Community Care Assessments: /

Did you feel that the correct amount of attention was given to these areas of need ?

Area of Need	Yes	No	Don't Know	Total
PHYSICAL (eg. Personal Care/ Mobility)	31	29	4	64
EMOTIONAL (eg. Counselling)	8	48	8	64
SOCIAL (eg. Getting out, contact with people)	15	43	6	64
DOMESTIC (eg. Essential Household Chores)	23	38	3	64

- **Physical Needs** Respondents were fairly evenly divided as to whether or not appropriate attention had been focussed on the high priority area of *physical care needs*, with approximately half saying 'yes', and half 'no'. The need for assistance to get out of the house to conduct necessary business may have been variably considered as physical (entails help with mobility) or social (involves getting out);
- **Domestic Needs** Respondents were less likely to feel that the correct amount of attention had been given to *domestic needs* (38%), which followed physical in respondents' priority rankings.
- **Social Needs** Approximately a quarter (26%) felt that the correct amount of attention had been paid to *social needs*. This was a relatively low priority area for respondents, so it is more likely that they felt that too much emphasis had been placed on this rather than too little. Responses relating to 'Social needs' apparently reflected carers' needs for a break to socialise in some cases.
- **Emotional Needs** The lowest incidence of satisfaction was with the degree of priority that had been accorded to *emotional needs* (14%). Notably, this was also a low priority area for respondents, so it would appear that social services tend to over emphasise emotional needs when conducting Community Care Assessments for people with severe M.E.

Feedback on Balance of Attention in Assessment Process

- "Focussed too much on Social Needs not understanding that I was unable to go out and how little strength I had to talk or socialise (too weak)."

COPING WITH COMMUNITY CARE ASSESSMENT

- Several respondents had been too ill to be involved in the assessment any way, and had been represented in the course of their assessment by family or an advocate.
- Around half of those who had been involved in their assessment had had someone with them while being assessed. In about half of these cases, that person had felt that they were listened to by the assessor.
- Only a few of those who had been assessed felt that they had been well enough to cope *during* the assessment [12/66 patients; 18%].
- Responses indicate that *all* of those who had participated in the assessment had been exhausted *afterwards*.
- Very few got over the adverse impact of participating in the assessment in a day or two. The vast majority had taken 3 days or longer to recover from the adverse impact of the assessment process, with around a quarter taking over a month.

25% ME Group

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