25% ME GROUP

ADULT SOCIAL CARE QUESTIONNAIRE

SEPTEMBER 2008

Please circle the answer you wish to give

Please refrain from writing extra notes on questionnaire, unless requested. Thank you.

GENERAL SECTION

1. Geographical area i.e. County/Region

2. Age: 18-30 31-45 46-55 56-64 65+

3. Gender: Male Female

4. How long have you been ill with ME? 0-4YRS 5-9YRS 10-20YRS 20+

5. Level of severity: Mainly Wheelchair User Mainly Housebound Mainly Bedbound

6. Are you able to live without assistance in your home? YES NO

7. Do you currently receive Disability Living Allowance (DLA) benefit? YES NO

8. If YES, what level of DLA CARE component do you receive?

Low Medium High

9. Do you receive Care Services of any kind in your home?

   Family/friends/voluntary YES NO

   Social Services YES NO

   Privately paid worker YES NO

10. Did you arrange to be assessed to receive care services yourself? YES NO

11. Did someone else arrange for you to be assessed to receive care services? YES NO

12. If YES to Q11, who was this? Circle an option below if applicable:

   General Practitioner Advocacy service

   Occupational Therapist Family Member

   Friend Hospital Specialist

   Other, please state ________________________________
13. How long did you have to wait to get contact from Social Services?

- less than 1 month
- 1-3 months
- 4-6 months
- 6months +

14. Are you in a Care Home or hospital due to your ME?

- YES
- NO

SOCIAL SERVICES SECTION

15. Have you ever asked for a Community Care Assessment (CCA) in order to receive care services from your local Social Services Department?

- YES
- NO

16. If YES, do you have a dedicated Social Worker/Care Manager?

- YES
- NO

17. How long did you have to wait to be assessed by Social Services?

- 1 week
- 2-4wks
- longer than 4 weeks

18. If you had a Community Care Assessment, do you feel the Social Worker/Care Manager took on board all your care requirements in order to properly assess your daily care needs?

- YES
- NO
- DON’T KNOW

19. Was the Community Care Assessment explained clearly to you?

- YES
- NO
- DON’T KNOW

20. Were you allowed to be fully involved in the CCA?

- YES
- NO
- DON’T KNOW

21. Did you receive a care package following the Community Care Assessment?

- YES
- NO

22. At the assessment by Social Services, what level of understanding did you feel that the assessor had of the following:

- ME in general
- Your cognitive problems
- The effects of the illness on you
- The variability & fluctuating nature of symptoms

- GOOD
- POOR
- DON’T KNOW

23. Did you feel that your particular disabilities/illness were recognised?

- YES
- NO

24. Did you feel that the correct amount of attention was given to the following four areas?

- Physical : (eg. Personal Care/Mobility Needs)
- Emotional: (eg. Counselling)
- Social needs: (eg. Getting out, contact with people)
- Domestic Needs : (eg. Essential Household Chores)

- YES
- NO
- DON’T KNOW
25. Which of the following did you feel needed to be met the most?  
*(Please rate the following in order of importance from 1-5. 1 being highest priority)*

Physical: (eg. Personal Care/Mobility Needs) 1 2 3 4 5
Emotional: (eg. Counselling) 1 2 3 4 5
Social needs: (eg. Getting out, contact with people) 1 2 3 4 5
Domestic Needs: (eg. Essential Household Chores) 1 2 3 4 5

26. Did you feel that during the assessment you were well enough to cope?  
YES NO

27. Did the process of being assessed leave you exhausted?  
YES NO

28. If YES, how long did it take to recover from this?  
less than a day 1-2 days 3-6 days 1wk - 4wks longer than 4 weeks

29. Did you have anyone with you while being assessed?  
YES NO

30. If YES, did they feel they were listened to?  
YES NO

**COMMUNITY CARE ASSESSMENT REVIEWS**

31. How often have you seen a Social Worker/Care Manager in last 5 years?  
NEVER 1-3 (times) 4+ (times)

32. Has your care package ever been reduced or stopped at a Community Care Assessment Review, although your condition remained the same or had deteriorated?  
YES NO

33. If YES, was it due to any of the following, please tick more than one option, if applicable:

- Assessed as not requiring services
- Lack of funds
- Do not fit Social Work criteria
- Other, please state: __________________________

34. If your care package was reduced or stopped after Community Care Assessment Review, were you told that you could appeal against the decision?  
YES NO DON'T KNOW

35. Have you ever needed to make a formal complaint about any aspect of social work involvement?  
YES NO
36. If YES, to what extent was your complaint upheld?

FULLY  PARTIALLY  NOT AT ALL  ONGOING

OCCUPATIONAL THERAPY SECTION

37. Have you ever asked for an Occupational Therapy Assessment?  YES  NO

38. Has a Social Worker/Care Manager ever offered to send out an Occupational Therapist as part of a Community Care Assessment?  YES  NO

39. If a referral was made, how long did you have to wait before seeing an Occupational Therapist?

1 – 4 weeks  4 – 8 weeks  more than 2 months

40. If you have had an Occupational Therapy Assessment carried out, how often have you seen an Occupational Therapist in the last 5 years?

NEVER  1-3 (times)  4+ (times)

41. If you have been assessed by an Occupational Therapist, did you feel that they took on board your disability requirements?  YES  NO  DON'T KNOW

42. Were you refused Occupational Therapy services after an assessment?  YES  NO

43. If YES, was it due to any of the following, please tick more than one option, if applicable:

Assessed as not requiring services  Lack of funds
Do not fit Occupational Therapy criteria
Other, please state ________________________________

44. If you received services from the OT Dept, did you also receive a follow up in order to check if the equipment etc. was appropriate for your needs or if you required other support?

YES  NO  N/A

DIRECT PAYMENTS SECTION

45. If you received a Care Package following a CCA, were you also told about the Direct Payments Scheme (to enable you to employ your own carers/PAs, if you wished)?  YES  NO  N/A

46. If YES, were you fully informed about the advantages/disadvantages of the Direct Payments Scheme?

YES  NO  N/A

47. Do you receive Direct Payments?  YES  NO

48. If YES, do you employ your own carers/PAs?  YES  NO
49. If YES to Q48, do you receive support to manage your carers efficiently in any of the following areas?

<table>
<thead>
<tr>
<th>Area</th>
<th>YES</th>
<th>NO</th>
</tr>
</thead>
<tbody>
<tr>
<td>Payroll assistance - wages, tax etc</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Employment - recruitment and interviewing</td>
<td></td>
<td></td>
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<tr>
<td>Paper work (contracts etc.)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No Support Received</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

50. Have you ever been refused Direct Payments?  YES  NO

**QUALITY**

51. Are you satisfied with the quality of the care that you receive in the following areas?

<table>
<thead>
<tr>
<th>Area</th>
<th>YES</th>
<th>NO</th>
</tr>
</thead>
<tbody>
<tr>
<td>Social Services</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Occupational Therapy</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Privately Paid Staff (inc. care agencies)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Direct Payments</td>
<td></td>
<td></td>
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</tbody>
</table>

**CARERS SECTION**

Please complete the following questions ONLY if you are an unpaid/voluntary carer (e.g. relative/partner of the person with ME)

52. Have you received a carers’ assessment?  YES  NO

53. How long did you have to wait for respite/help from the carers’ assessment stage?

<table>
<thead>
<tr>
<th>Duration</th>
<th>YES</th>
<th>NO</th>
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<tbody>
<tr>
<td>1 – 4 weeks</td>
<td></td>
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<tr>
<td>4 – 8 weeks</td>
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<tr>
<td>more than 2 months</td>
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54. Do you as carer of the person with ME currently receive any services?  YES  NO

55. Do you receive all the help that is needed?  YES  NO

56. Do you receive some help but not as much as you would like?  YES  NO

57. Do you receive no help as you don’t meet the criteria as set out by the local authority?  YES  NO

58. Do you receive no help as you feel you don’t need any support as a carer?  YES  NO
59. For each service that you receive as carer, please answer the questions in the list below.

*Only fill out information for services that are received.*

*Tick the type of service received.*

a) Short break services (respite) in the home

b) Short break services (respite), where the person with ME stays in a care home for a short time.

c) Other service (please specify) ____________________________________________________________

60. For how many years have you been receiving the service?

- 0-4 YRS
- 5-9 YRS
- 10-20 YRS
- 20+
- N/A

61. Are you satisfied with the quality of the service that you receive?

- YES
- NO

62. Do you think that you have had enough information about care services that are available to help you?

- YES
- NO
- DON’T KNOW

63. Do you have any comments on the quality of the service you receive?

________________________________________________________________________________________
________________________________________________________________________________________
________________________________________________________________________________________
________________________________________________________________________________________

We hope to collate the findings from this questionnaire and use them to highlight any problem areas to MP’s/MSP’s, Social Work Directors and possibly, other agencies, during ME Awareness Week 2009.

**Please send all completed Questionnaires no later than 15th November 2008 to:**

The 25% ME Group, 21 Church Street, Troon, Ayrshire, KA10 6HT.

*Please return in an A5 envelope (ie. same size envelope that this questionnaire was posted in) as postage will then only cost you 1 x second class stamp (27p). Thanks*

Thank you for your in co-operation in completing this questionnaire.