

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

GOOD

POOR

DON'T KNOW

Your cognitive problems

GOOD

POOR

DON'T KNOW

The effects of the illness on you

GOOD

POOR

DON'T KNOW

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*)

YES

NO

DON'T KNOW

Emotional: (eg. *Counselling*)

YES

NO

DON'T KNOW

Social needs: (eg. *Getting out, contact with people*)

YES

NO

DON'T KNOW

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

Payroll assistance - wages, tax etc	YES	NO
Employment - recruitment and interviewing	YES	NO
Paper work (contracts etc.)	YES	NO
No Support Received	YES	NO

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?

Social Services	YES	NO
Occupational Therapy	YES	NO
Privately Paid Staff (inc. care agencies)	YES	NO
Direct Payments	YES	NO

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?

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

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 | YES | NO |
| b) Short break services (respite), where the person with ME stays in a care home for a short time. | YES | NO |
| c) Other service (please specify) _____ | | |

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

0-4 YRS **5-9 YRS** **10-20YRS** **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