

PATIENT QUESTIONNAIRE

APPG INQUIRY INTO NHS SERVICES FOR PEOPLE WITH M.E. / CFS

Please respond to each of the following questions. Answers should be in the format of a self-contained memorandum and the entire response should be no more than 3,000 words.

Respondents typing their submission may answer by filling in this questionnaire and including any detailed answers immediately after each question. If the response is hand-written, each question should be clearly re-stated in the response, with answers immediately following each particular question.

The document must include a very brief executive summary about yourself of approximately 200-300 words. Once submitted, your submission becomes the property of the APPG. The APPG will expect to publish the written evidence it receives. Please notify us if you wish your statement to be anonymous.

Please ensure that your questionnaire is submitted by the **20th of July 2009** to either turnerd@parliament.uk or

Dr Desmond Turner MP
House of Commons
London
SW1A 0AA

ABOUT YOU

1. Your age:

- Adult
- Adolescent up to 18 years
- Child under the age of 12

2. Your sex:

- Male
- Female

3. How long have you had ME/CFS?

ABOUT THE NHS CLINIC/SERVICE YOU ATTEND/ATTENDED

4. Which service have you used/are you using? Please supply the name of the service and the town/city where it is located.

5. In which year/s were you seen?

6. Approximately how long did it take to obtain an appointment following the GP referral?

7. Were you referred for:

- Diagnosis
- Management
- Both

8. What treatments were you offered?

9. Which of the following health professionals have been/are involved in your care?

- cognitive behaviour therapist
- counsellor
- dietician
- general practitioner with special interest
- nurse practitioner
- occupational therapist
- paediatrician
- physician
- physiotherapist
- psychiatrist
- psychologist
- other

10. Which of the following aspects of management were/are being covered by either consulting room advice or the provision of information

- benefits
- cognitive behaviour therapy
- counselling
- domiciliary service (home visits)
- graded exercise therapy
- nutrition
- occupational health
- pacing
- symptom relief
- other

11. After your initial appointment were you seen again?

- Yes
- No

If yes, approximately how many times?

OUTCOME AND SATISFACTION

12. What advice were you given on symptom management?

13. Overall, how do you rate the service provided. Please give further details if relevant.

- very helpful
- helpful
- neutral
- not helpful
- very unhelpful

14. Are there any aspects of the service that you found/find particularly helpful?

15. Are there any aspects of the service that you found/find particularly unhelpful?

16. Did you feel that you were properly consulted and informed about the way in which management decisions were taken?

- Yes
- No

Please give further details

17. Was there any coercion to take part in any specific aspects of management?

- Yes
- No

18. Overall, what effect do you feel that attending the service has had on your health:

- major improvement
- some improvement
- no change
- made worse
- made much worse

19. Is there anything else that you would like to tell the Inquiry about this service?

20. Has it ever been suggested by your GP or specialist, that you approach an ME support Group?

ENDS