1. At what age were you first diagnosed?
2. How long have you had ME/CFS?
3. Have you received a firm diagnosis of ME/CFS?
4. - Was this from a GP, specialist or other - specify?
5. How long did it take you to get a diagnosis?
6. Did your illness start suddenly, or gradually worsen over time?
7. What was your experience of getting a diagnosis (please detail)?
8. What factors do you feel helped you get a diagnosis?
9. Did any factors delay your diagnosis?
10. Did your primary care doctor/GP agree with a diagnosis of ME/CFS and offer you appropriate support?
11. Is your illness relatively stable, have you experienced any periods of improvement or remission?
12. Would you classify yourself as mild, moderate or severe ME/CFS currently?
13. Did or does your illness prevent you from:
14. …Attending school or college/university/training or work?
15. …Participate in social events?
16. Are you able to get outside your home to shop or undertake outside activities?
17. Do you receive support from family members?
18. Do you have a carer or care assistant? (how often per week)
19. Have you been prescribed any drugs by your doctor or a specialist specifically for your ME/CFS or related symptoms – list?
20. Have these helped improved symptoms? – please specify
21. Have you been offered any other treatments for your illness?
* Cognitive Behavioural Therapy (CBT)
* Graded Exercise Therapy (GET)
* Pacing Therapy (Adapted Pacing Therapy – APT)
* Physiotherapy
* Other therapies (please specify)
1. For each treatment or therapy undertaken, please detail if this therapy helped, made no difference, or made symptoms worse?
2. Have you ever refused to undertake a specific therapy or treatment (please specify which ones and your reasons for not undertaking)?
3. Have you ever required specialist support such as tube feeding, IV fluids, speech therapy - please list?
4. Have you ever tried any alternative treatments or therapies (not offered by your doctor or the NHS) y/n – please specify which ones? Eg massage, supplements, psychotherapy, and so on.
5. Did any of these alternative treatments or therapies help improve your symptoms, did any make things worse?
6. Does your GP visit you at home, if you are unable to attend a GP practice/surgery?
7. Are you able to attend hospital appointments or appointments with specialists?
8. Do GPs/specialists offer any alternative arrangements if you are unable to attend?
9. Are hospital staff aware of your condition and do they accommodate your needs on hospital visits?
10. Have you had any hospital in-stays – how many per year or since you developed the illness?
11. Do you make decisions about your care, do you feel you are able to make choices about the types of care you receive?
12. Do doctors consult you and take your views on board during treatment?
13. Have you had any support from a social worker/social services?
14. What type of support or care do you receive from them?
15. Did you receive any Government disability of sickness benefits?
16. Do you use mobility aids or a mobility scooter?
17. Have you encountered any difficulties in accessing social care and or sickness benefits – please specify any issues?
18. Has your illness and symptoms remained relative stable or changed since it began – specify if it has remained relatively the same, has worsened over time, has improved over time, or fluctuates frequently?
19. Have you been able to return to work, study if prevented to previously?
20. Have you received any special medical or social care assistance that has helped you undertake work or education/training?
21. Have you been able to take part in social activities recently if prevented previously?
22. What types of medical or social support have been most useful to you in managing your illness - please specify?
23. Is your ME/CFS regularly monitored by either a GP or hospital specialist, if so who and how often?
24. Do you feel your illness receives adequate ongoing medical support?
25. What more do you feel your doctors or care support workers could do to assist you living with ME/CFS?
26. Do you feel there is enough information or educational material available relating to your illness?
27. How accessible is this information or educational material?
28. Where did you go to get or access information or educational material – please detail?
29. Are you a member of an ME/CFS patient organisation or support group – please detail which ones?
30. What information or educational material have you found most useful to you in dealing with your illness?
31. Is the material you used tailored for your needs?
32. Is there material available tailored to family members and carers?
33. Is or was your primary care doctor or hospital specialist knowledgeable about ME/CFS – please detail?
34. If you feel their knowledge or awareness was lacking in any way, what could be done to improve raising awareness of the illness among health and social care professionals?
35. When visiting your GP or hospital were you able to convey any special needs or requirements to staff, were these needs accommodated eg quiet area, short waiting time, and so on?
36. Were you treated with respect and empathy/understanding by health and social care professions – please detail any response?
37. What do health and social care professionals need to specifically take into account when dealing with patients with severe ME/CFS – please detail any response?
38. Is there any other relevant information you wish to share that is not covered in the questions above – please feel free to detail in this section?

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