DecodeME Second Questionnaire

This is a copy of the DecodeME second questionnaire that is for information only.

Please DO NOT post it to us, your responses won't be processed. Please complete the online questionnaire if you want to participate.

If you require a paper version of the questionnaire, please contact us at info@DecodeME.org.uk or 0808 196 8664, and we will post you all the documents.

Please answer the questions below.

I am providing information on behalf of another person:

- ☐ Yes
- ☐ No *(Skip to the next page)*

If you answered "Yes", are you the other person's:

- ☐ Parent or legal guardian
- ☐ Child
- ☐ Sibling
- ☐ Partner
- ☐ Other family member
- ☐ Friend
- ☐ Other

Please give your name here: ______________________

Physical Functioning

1. The following questions are about activities you might do during a typical day. Does **your health now limit you** in these activities? If so, how much: (Select one option on each line).

	Yes, limited a lot	Yes, limited a little	No, not limited at all
Vigorous activities, such as running, lifting heavy objects participating in strenuous sports	☐	☐	☐
Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	☐	☐	☐
Lifting or carrying groceries	☐	☐	☐
Climbing **several** flights of stairs	☐	☐	☐
Climbing **one** flight of stairs	☐	☐	☐
Bending, kneeling, or stooping	☐	☐	☐
Walking **more than a mile**	☐	☐	☐
Walking **several hundred yards**	☐	☐	☐
Walking **one hundred yards**	☐	☐	☐
Bathing or dressing yourself	☐	☐	☐
Household responsibilities	☐	☐	☐
Maintaining friendships	☐	☐	☐
Community joining	☐	☐	☐
Work/education	☐	☐	☐

IF you are a parent, guardian or carer:
(Please skip this question if it's not applicable to you)

	Yes, limited a lot	Yes, limited a little	No, not limited at all
Caring responsibilities	☐	☐	☐

Symptoms

2. For each of these 3 symptoms, indicate the level of severity **over the past week**.

	No problem	Slight or mild problems: generally mild or intermittent	Moderate: considerable problems; often present and/or at a moderate level	Severe: pervasive, continuous, life disturbing problems	Prefer not to answer
Fatigue	☐	☐	☐	☐	☐
Waking unrefreshed	☐	☐	☐	☐	☐
Cognitive symptoms *For example, problems with memory, thinking skills and/or concentration.*	☐	☐	☐	☐	☐

3. During the **past 6 months** have you had any of the following symptoms?

	Yes	No	Prefer not to answer
Pain or cramps in the lower abdomen	☐	☐	☐
Depression	☐	☐	☐
Headache	☐	☐	☐

Pain

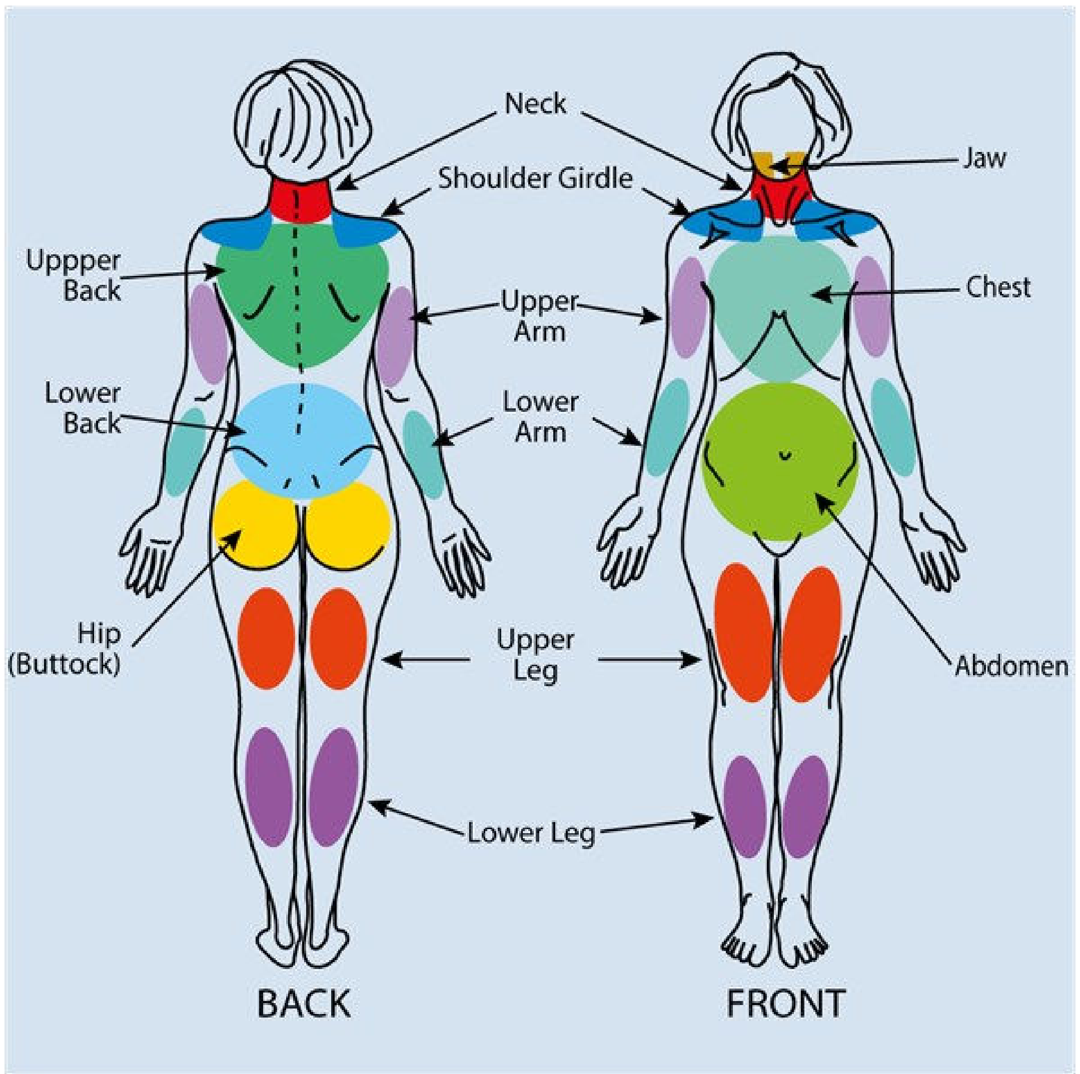
4. Are you troubled by pain or discomfort, either all the time or on and off, that has been present for **more than 3 months**?
   - ☐ Yes
   - ☐ No *(Skip to Question 8)*
   - ☐ Do not know *(Skip to Question 8)*
   - ☐ Prefer not to say *(Skip to Question 8)*

5. How long have you been suffering with this pain or discomfort?
   - ☐ 3-12 months
   - ☐ 1-5 years
   - ☐ More than 5 years
   - ☐ Do not know
   - ☐ Prefer not to say

6. Thinking about **the last 24 hours**, how would you rate your pain on a 0-10 scale, where 0 is ‘no pain’ and 10 is ‘pain as bad as it could be’?

0	1	2	3	4	5	6	7	8	9	10
☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

7. Please indicate if you have had pain or tenderness during the past week in each of the areas listed below.



☐	Jaw, left	☐	Jaw, right
☐	Shoulder girdle, left	☐	Shoulder girdle, right
☐	Upper arm, left	☐	Upper arm, right
☐	Lower arm, left	☐	Lower arm, right
☐	Hip (buttock), left	☐	Hip (buttock), right
☐	Upper leg, left	☐	Upper leg, right
☐	Lower leg, left	☐	Lower leg, right
☐	Neck	☐	Chest
☐	Upper back	☐	Abdomen
☐	Lower back	☐	None of these areas

Post-Exertional Malaise

8. Do you experience post-exertional malaise (PEM)?
   ⓘ PEM is described as a worsening of your ME/CFS symptoms, or development of new symptoms, after you do more physical or mental activity than usual (exceed your energy limit).

   If you pace your energy, we want you to think about what would have happened if you didn't.
   - ☐ Yes
   - ☐ Sometimes
   - ☐ No *(Skip to Question 14)*

9. How likely are the following types of exertion to trigger your PEM?

	Not very likely	Somewhat likely	Very likely
Physical	☐	☐	☐
Emotional	☐	☐	☐
Cognitive	☐	☐	☐
Sensory	☐	☐	☐

10. Whilst experiencing PEM, how likely is it for the following symptoms to become worse or develop?

	Not very likely	Somewhat likely	Very likely
Fatigue	☐	☐	☐
Cold or flu-like symptoms	☐	☐	☐
Muscle/joint pains	☐	☐	☐
Sensitivities/intolerances	☐	☐	☐
Gut symptoms (nausea, heartburn, irritable bowel, etc.)	☐	☐	☐
Headaches	☐	☐	☐
Cognition (brain fog, understanding, decision making, etc.)	☐	☐	☐
Sensation/movement (coordination, balance, speech problems, etc.)	☐	☐	☐
Sleep disturbance	☐	☐	☐
Automatic body functions (dizziness, heart palpitations, sweating, bladder problems etc.)	☐	☐	☐
Appetite/problems eating	☐	☐	☐
Mood	☐	☐	☐

11. On average, how long does it take for your symptoms to worsen, or develop, after exertion?
    - ☐ Less than 6 hours
    - ☐ Between 6 and 12 hours
    - ☐ Between 12 and 24 hours
    - ☐ Between 24 and 48 hours
    - ☐ More than 48 hours

12. On average, how long from the onset of PEM does it take to return to your baseline level of symptoms?
    - ☐ Less than 24 hours
    - ☐ 1-3 days
    - ☐ 3-7 days
    - ☐ 7-28 days
    - ☐ Over 28 days

13. Does your level of functioning worsen whilst experiencing PEM?
    - ☐ Yes, my level of functioning severely worsens during PEM
    - ☐ Yes, my level of functioning is somewhat worsened during PEM
    - ☐ My level of functioning remains unchanged during PEM

Pacing

14. Since you became ill with ME/CFS have you tried pacing?
    ⓘ *Pacing is a way of carefully managing physical, mental and emotional activity and rest to reduce or avoid post-exertional malaise.*
    - ☐ Yes
    - ☐ No *(Skip to Question 15)*

14a. How did it affect your ME/CFS symptoms?
    - ☐ Pacing has improved/reduced my symptoms
    - ☐ Pacing has made no difference to my symptoms
    - ☐ Pacing has worsened my symptoms
    - ☐ Not sure

Treatments and Therapies

15. What drugs/therapies/interventions have you tried? You can list up to 10.
    For each of these treatments/therapies please tell us whether it made your ME/CFS worse or better, as well as how long this effect lasted.
    If you haven't tried any, please skip to Question 16.

Treatment/Therapy 1: ………………………………….

Effect on your ME/CFS	Much worse	Somewhat worse	About the same	Somewhat better	Much better
	☐	☐	☐	☐	☐

How long did this effect last?	0-6 months	6 months – 1 year	1-3 years	More than 3 years but the effect stopped	More than 3 years and the effect is ongoing
	☐	☐	☐	☐	☐

Treatment/Therapy 2: ……………………………………

Effect on your ME/CFS	Much worse	Somewhat worse	About the same	Somewhat better	Much better
	☐	☐	☐	☐	☐
How long did this effect last?	0-6 months	6 months – 1 year	1-3 years	More than 3 years but the effect stopped	More than 3 years and the effect is ongoing
	☐	☐	☐	☐	☐

Treatment/Therapy 3: ……………………………………

Effect on your ME/CFS	Much worse	Somewhat worse	About the same	Somewhat better	Much better
	☐	☐	☐	☐	☐
How long did this effect last?	0-6 months	6 months – 1 year	1-3 years	More than 3 years but the effect stopped	More than 3 years and the effect is ongoing
	☐	☐	☐	☐	☐

Treatment/Therapy 4: ……………………………………

Effect on your ME/CFS	Much worse	Somewhat worse	About the same	Somewhat better	Much better
	☐	☐	☐	☐	☐
How long did this effect last?	0-6 months	6 months – 1 year	1-3 years	More than 3 years but the effect stopped	More than 3 years and the effect is ongoing
	☐	☐	☐	☐	☐

Treatment/Therapy 5: ……………………………………

Effect on your ME/CFS	Much worse	Somewhat worse	About the same	Somewhat better	Much better
	☐	☐	☐	☐	☐
How long did this effect last?	0-6 months	6 months – 1 year	1-3 years	More than 3 years but the effect stopped	More than 3 years and the effect is ongoing
	☐	☐	☐	☐	☐

Treatment/Therapy 6: ……………………………………

Effect on your ME/CFS	Much worse	Somewhat worse	About the same	Somewhat better	Much better
	☐	☐	☐	☐	☐
How long did this effect last?	0-6 months	6 months – 1 year	1-3 years	More than 3 years but the effect stopped	More than 3 years and the effect is ongoing
	☐	☐	☐	☐	☐

Treatment/Therapy 7: ……………………………….

Effect on your ME/CFS	Much worse	Somewhat worse	About the same	Somewhat better	Much better
	☐	☐	☐	☐	☐
How long did this effect last?	0-6 months	6 months – 1 year	1-3 years	More than 3 years but the effect stopped	More than 3 years and the effect is ongoing
	☐	☐	☐	☐	☐

Treatment/Therapy 8: ……………………………….

Effect on your ME/CFS	Much worse	Somewhat worse	About the same	Somewhat better	Much better
	☐	☐	☐	☐	☐
How long did this effect last?	0-6 months	6 months – 1 year	1-3 years	More than 3 years but the effect stopped	More than 3 years and the effect is ongoing
	☐	☐	☐	☐	☐

Treatment/Therapy 9: ……………………………….

Effect on your ME/CFS	Much worse	Somewhat worse	About the same	Somewhat better	Much better
	☐	☐	☐	☐	☐
How long did this effect last?	0-6 months	6 months – 1 year	1-3 years	More than 3 years but the effect stopped	More than 3 years and the effect is ongoing
	☐	☐	☐	☐	☐

Treatment/Therapy 10: ……………………………….

Effect on your ME/CFS	Much worse	Somewhat worse	About the same	Somewhat better	Much better
	☐	☐	☐	☐	☐
How long did this effect last?	0-6 months	6 months – 1 year	1-3 years	More than 3 years but the effect stopped	More than 3 years and the effect is ongoing
	☐	☐	☐	☐	☐

Sleep

16. How many hours sleep do you get in every 24 hours? (please include naps)

    ⓘ *If the time you spend sleeping varies a lot, give the average time for a 24 hour day in the last 4 weeks.*

    Number of hours: ___________________

17. Do you consider yourself to be?
   ⓘ *If this varies a lot, answer this question in relation to the last 4 weeks.*
   - ☐ Definitely a 'morning' person
   - ☐ More a 'morning' than 'evening' person
   - ☐ More an 'evening' than a 'morning' person
   - ☐ Definitely an 'evening' person
   - ☐ Do not know
   - ☐ Prefer not to answer

18. Do you have trouble falling asleep at night **OR** do you wake up in the middle of the night?
   ⓘ *If this varies a lot, answer this question in relation to the last 4 weeks.*
   - ☐ Never/rarely
   - ☐ Sometimes
   - ☐ Usually
   - ☐ Prefer not to answer

19. Does your partner or a close relative or friend complain about your snoring?
   ⓘ *If you are unsure, please provide an estimate or select "Do not know".*
   - ☐ Never/rarely
   - ☐ Sometimes
   - ☐ Usually
   - ☐ Do not know
   - ☐ Prefer not to answer

20. How likely are you to doze off or fall asleep during the daytime when you don't mean to? (e.g. when working, reading or driving)
   ⓘ *If you are unsure, please provide an estimate or select "Do not know".*
   - ☐ Never/rarely
   - ☐ Sometimes
   - ☐ Often
   - ☐ Do not know
   - ☐ Prefer not to answer

21. Do you have a nap during the day?
   ⓘ *If this varies a lot, answer this question in relation to the last 4 weeks.*
   - ☐ Never/rarely
   - ☐ Sometimes
   - ☐ Usually
   - ☐ Prefer not to answer

22. Do you sleep more or less while you are experiencing post-exertional malaise (PEM)? **Only answer this question if you answered "Yes" in Question 8.**
   - ☐ I sleep more whilst experiencing PEM
   - ☐ I sleep less whilst experiencing PEM
   - ☐ There is no change

23. Does your sleep quality change while you are experiencing post-exertional malaise (PEM)? **Only answer this question if you answered “Yes” in Question 8.**
   - ☐ Yes, my sleep is less refreshing whilst experiencing PEM
   - ☐ Yes, my sleep is more refreshing whilst experiencing PEM
   - ☐ There is no change

Depression and Anxiety

Some questions in this section discuss topics that may be upsetting. If you find you need support for any of the questions asked, take a look at our support page online: https://www.decodeme.org.uk/faqs/where-can-i-find-mental-health-support/.

24. **Over the last few weeks**, how often have you been bothered by the following problems?

	Not at all	Several days	More than half the days	Nearly every day
Little interest or pleasure in doing things	☐	☐	☐	☐
Feeling down, depressed, or hopeless	☐	☐	☐	☐
Thoughts that you were better off dead or hurting yourself in some way	☐	☐	☐	☐
Feeling nervous, anxious or on edge	☐	☐	☐	☐
Not being able to stop or control worrying	☐	☐	☐	☐
Worrying too much about different things	☐	☐	☐	☐
Trouble relaxing	☐	☐	☐	☐
Being so restless that it is hard to sit still	☐	☐	☐	☐
Becoming easily annoyed or irritable	☐	☐	☐	☐
Feeling afraid as if something awful might happen	☐	☐	☐	☐

25. Did you experience prolonged periods of low mood or were diagnosed with depression **before you had ME/CFS**?
   - ☐ Yes, I experienced periods of low mood but wasn't diagnosed with depression
   - ☐ Yes, I was diagnosed with depression
   - ☐ No

26. Have you experienced prolonged periods of low mood or have been diagnosed with depression **after your ME/CFS began**?
- ☐ Yes, I experienced periods of low mood but haven't been diagnosed with depression
- ☐ Yes, I was diagnosed with depression
- ☐ No *(Skip to Question 27)*

26a. Please select which of the following applies to you:
- ☐ The main reason for my low mood/depression is the impact that ME/CFS has on my life
- ☐ Other issues than ME/CFS are the main reason for my low mood/depression
- ☐ I'm not sure what is the main reason for my low mood/depression

27. Did you experience prolonged periods of feeling anxious or were diagnosed with generalised anxiety disorder **before you had ME/CFS**?
- ☐ Yes, I experienced periods of feeling anxious but wasn't diagnosed with anxiety
- ☐ Yes, I was diagnosed with generalised anxiety disorder
- ☐ No

28. Have you experienced prolonged periods of feeling anxious or were diagnosed with generalised anxiety disorder **after your ME/CFS began**?
- ☐ Yes, I experienced periods of feeling anxious but haven't been diagnosed with anxiety
- ☐ Yes, I was diagnosed with generalised anxiety disorder
- ☐ No *(Skip to Question 29)*

28a. Please select which of the following applies to you:
- ☐ The main reason for my anxiety is my ME/CFS (the symptoms and impact of the illness on my life)
- ☐ ME/CFS is not the main reason for my anxiety although it may still impact the way I feel
- ☐ I'm unsure if my ME/CFS is the main reason for my anxiety or not

Bedbound/Housebound

29. **In the last 6 months**, how often have you been **bedbound** by your illness?
- ☐ 100% of the time
- ☐ Between 75% and 99% of the time
- ☐ Between 50% and 74% of the time
- ☐ Between 25% and 49% of the time
- ☐ Up to 24% of the time
- ☐ I've not been bedbound by my illness in the last 6 months.

30. **In the last 6 months**, how often have you been **housebound** by your illness (not necessarily confined to bed, but limited to your home)?
    - ☐ 100% of the time
    - ☐ Between 75% and 99% of the time
    - ☐ Between 50% and 74% of the time
    - ☐ Between 25% and 49% of the time
    - ☐ Up to 24% of the time
    - ☐ I've not been housebound by my illness in the last 6 months.

Triggers

31. What do you believe may have been the trigger for your ME/CFS? (You can select multiple answers)
    - ☐ Viral infection
    - ☐ Bacterial infection
    - ☐ Physical trauma
    - ☐ Emotional/psychological trauma
    - ☐ Stress
    - ☐ Vaccination
    - ☐ Surgery
    - ☐ Exposure to toxins/chemicals
    - ☐ Pregnancy
    - ☐ Heart attack
    - ☐ Other: ________________
    - ☐ Not sure
    - ☐ There wasn't a trigger

32. Do you believe any of the following to have caused a worsening of your symptoms at any point during your illness? (You can select multiple answers)
    - ☐ Viral infection
    - ☐ Bacterial infection
    - ☐ Physical trauma
    - ☐ Emotional/psychological trauma
    - ☐ Stress
    - ☐ Vaccination
    - ☐ Surgery
    - ☐ Exposure to toxins/chemicals
    - ☐ Pregnancy
    - ☐ Heart attack
    - ☐ Other: ________________
    - ☐ Not sure
    - ☐ None of the above

Other Conditions

33. If a health professional has **ever** told you that you had any of the conditions below, please select all that apply. If the conditions don't apply to you, please do not select any box. Please mark:

    Active – If the condition has given you symptoms in the past 6 months.
    Not active – If the condition has not given you symptoms in the past 6 months, either because it has died down or treatment has controlled it.

Active	Not active	
☐	☐	Asthma
☐	☐	Attention deficit hyperactivity disorder (ADHD)
☐	☐	Autism
☐	☐	Cardiovascular disease
☐	☐	Ehlers-Danlos syndrome (EDS)
☐	☐	Other hypermobility syndromes
☐	☐	Endometriosis
☐	☐	Functional neurological disorder
☐	☐	Hernia
☐	☐	High blood pressure
☐	☐	Long Covid
☐	☐	Osteoarthritis
☐	☐	Polycystic ovary syndrome (PCOS)
☐	☐	Post-traumatic stress disorder (PTSD)
☐	☐	Postural tachycardia syndrome (PoTS)
☐	☐	Vitamin D deficiency

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