Action for ME's Big Survey, 2025

Action for ME runs their Big Survey every five years, and the data produced informs all aspects of the charity's work to improve the lives of people with ME. The aim of the 2025 Big Survey is to illustrate the impact of ME. This year, the survey is being produced in collaboration with Durham University's Institute for Medical Humanities, and postdoctoral researcher Dr Katharine Cheston will work with Action for ME's research team to analyse the survey data.

This survey is for **adults in the UK who live with ME** or **who live with Long Covid and experience ME symptoms** (debilitating fatigue, post-exertional malaise, sleep disturbance, cognitive difficulties), **whether or not they have a diagnosis of ME**. If you are unable to fill out the survey, a carer is welcome to fill it out on your behalf.

The survey has 46 questions, but not all may apply to you. We know that this is a huge undertaking for people with ME and Long Covid. Each question has been carefully designed to give us meaningful data that strengthens our advocacy. The survey has also been co-produced with a Patient and Public Involvement (PPI) group drawn from the wider ME and Long Covid communities (including, but not limited to, members of Action for ME).

Every question on this survey is optional. You can skip questions and whole sections. Every piece of information you give us is valuable and is hugely appreciated. Please note that the survey asks about topics, such as experiences of healthcare, that may be upsetting.

You can exit the survey and come back to it later. The survey saves your progress whenever you click to go forward to the next page, or back to the previous page. (Please note that the save and return function does not work if you use a private browser.) If you start the survey but later decide that you no longer want to take part, you can exit the survey and your responses will not be shared with us. Please note that once you complete the survey and submit your responses, they cannot be withdrawn, so make sure you are comfortable with the information you provide before finishing the survey.

By completing the survey, you are giving your consent for your anonymised responses to be used by Action for ME, and their research collaborators, in their work. This includes using anonymised quotations from the text shared in the survey, in which any identifying information will be removed. Survey data will be used in outputs, which may include (for example) policy reports, publications, briefings, presentations, and factsheets.

Anonymised survey data will be shared with Dr Audrey Ryback, University of Edinburgh, who will use the data to study the age of ME onset, triggers, and heritability. If you provide additional consent and opt in, your anonymised survey data may later be shared with other researchers studying the impact of ME and with other organisations working with people with ME and Long Covid. Applications to access the anonymised

Big Survey data, of those who provided their additional consent, will be reviewed by Action for ME’s Research Subcommittee.

No identifying information will be shared, at any point, and all data will be handled in line with data protection best practices. You can read Action for ME’s Privacy Policy for more information on how we handle your personal data.

The deadline for completing the survey is 27 January 2026. Please ensure that you have finished the survey before this date, if you would like to share your responses with us.

If you have any questions about the survey and how your data will be used, please contact Action for ME’s Research Team: research@actionforme.org.uk.

Thank you so much for your time and energy.

Do you consent for your anonymised data to be shared, pending approval by Action for ME’s Research Subcommittee, with other researchers and organisations?

☐ Yes
☐ No

You and ME

All questions on this survey are optional. You can skip questions and whole sections. Please prioritise your health and stop when you need to.

1. Which country do you live in?
    - ☐ England
    - ☐ Northern Ireland
    - ☐ Scotland
    - ☐ Wales

2. Which region do you live in?

ENGLAND
- ☐ North East England
- ☐ North West England
- ☐ Yorkshire and the Humber
- ☐ East Midlands
- ☐ West Midlands
- ☐ East of England
- ☐ London
- ☐ South East England
- ☐ South West England

NORTHERN IRELAND
- ☐ Antrim
- ☐ Armagh
- ☐ Down
- ☐ Fermanagh
- ☐ Londonderry
- ☐ Tyrone

SCOTLAND
- ☐ Highlands & Islands
- ☐ North East
- ☐ Perthshire
- ☐ Borders, South and South West
- ☐ Central Belt

WALES
- ☐ North Wales
- ☐ Mid Wales
- ☐ West Wales
- ☐ South Wales

3. What year were you born?

4. Which of the following best describes your gender?
   - ☐ Woman
   - ☐ Man
   - ☐ Non-binary
   - ☐ My gender is not listed
   - ☐ Prefer not to say

5. What is your ethnicity?
   - ☐ Asian or Asian British
   - ☐ Black, Black British, Caribbean or African
   - ☐ Mixed or multiple ethnic groups
   - ☐ White (British, Irish, or other)
   - ☐ Other ethnic group

6. What year did you become ill with ME?

7. Do you associate the start of your illness with a particular event?
   - ☐ Glandular fever or infectious mononucleosis
     Was this infection confirmed by a test?
     - ☐ Yes
     - ☐ No
     - ☐ I don’t know
   - ☐ Covid-19
     Was this infection confirmed by a test?
     - ○ Yes
     - ○ No
     - ○ I don’t know
   - ☐ Other infection
     Please specify which infection you had (e.g., ‘flu, cold) ______________________
     Was this infection confirmed by a test?
     - ☐ Yes
     - ☐ No
     - ☐ I don’t know
   - ☐ Accident / injury / surgery
   - ☐ Psychologically traumatic life event
   - ☐ Vaccine
   - ☐ Pregnancy / birth
   - ☐ I do not associate the start of my illness with any particular event
   - ☐ Other (please specify)

8. Was the onset of your illness gradual or sudden?
   - ☐ Gradual
   - ☐ Sudden
   - ☐ Unsure

9. Do you have any blood relatives who have, or have had, ME? (Please select ‘yes’ even if you are unsure if they have had a formal diagnosis or if they suspected that they had ME but were never diagnosed.)

- ☐ Yes
- ☐ No

10. (If yes) Please indicate how many of your relatives have/had ME and how they are related to you, by writing the number of relatives with ME in the box next to the relevant relative. For example, if you have one brother and two cousins with ME, you would fill in Sibling [1], Cousin [2] and leave the other boxes blank.

- ☐ Parent
- ☐ Sibling (e.g., brother, sister)
- ☐ Child
- ☐ Grandparent
- ☐ Aunt/Uncle
- ☐ Cousin (your aunt’s or uncle’s child)
- ☐ Niece/Nephew (your sibling’s child)
- ☐ Other blood relative (please specify relation and number)

  ____

11. Which description most closely matches how severe your ME has been **over the past three months**?

- ☐ **Mild**: People with mild ME care for themselves and do some light domestic tasks (sometimes needing support) but may have difficulties with mobility. Most are still working or in education (often with reduced hours) but to do this they have probably stopped all leisure and social pursuits.
- ☐ **Moderate**: People with moderate ME have reduced mobility and are restricted in all activities of daily living. They have usually stopped work or education, and need rest periods, often resting in the afternoon for 1 or 2 hours.
- ☐ **Severe**: People with severe ME are unable to do any activity for themselves or can carry out minimal daily tasks only (such as face washing or cleaning teeth). They may depend on a wheelchair for mobility, are often unable to leave the house, and may spend most of their time in bed.
- ☐ **Very severe**: People with very severe ME are in bed all day and dependent on care. They need help with personal hygiene and eating, and are very sensitive to sensory stimuli.

12. Do you experience the following symptoms? Please select any that apply.

- ☐ **Debilitating fatigue** that is worsened by activity, is not caused by excessive cognitive, physical, emotional or social exertion, and is not significantly relieved by rest.
- ☐ **Post-exertional malaise** (PEM). This means that your symptoms get worse after (physical, cognitive, emotional) activity, and the reaction is out of proportion to what you did. PEM is often delayed in onset by hours or days. It has a prolonged recovery time that may last hours, days, weeks or longer.

- ☐ **Unrefreshing sleep** and/or **sleep disturbance**. For example, feeling exhausted or flu-like when you wake up, experiencing broken or shallow sleep, or an altered sleep pattern.
- ☐ **Cognitive difficulties** (sometimes described as **'brain fog'**). These may include problems finding words or numbers, difficulty in speaking, short-term memory problems, and difficulty concentrating or multitasking.

13. What diagnoses have you received? Please select all statements that apply.
    - ☐ I have a diagnosis of ME (or ME/CFS, CFS/ME, or CFS)
    - ☐ I do not have a diagnosis, but I suspect that I have ME
    - ☐ I have a diagnosis of Long Covid (or post-Covid syndrome)
    - ☐ I do not have a diagnosis of Long Covid (or post-Covid syndrome), but I suspect that I have Long Covid

<u>The impacts of ME</u>

All questions on this survey are optional. You can skip questions and whole sections. Please prioritise your health and stop when you need to.

14. How does your ME affect your day-to-day life? Please select all that apply.
    - ☐ I have stopped or reduced paid work
    - ☐ I have stopped or reduced education
    - ☐ I have stopped or reduced caring roles
    - ☐ I have stopped or reduced household tasks
    - ☐ I have stopped or reduced social contact
    - ☐ I have stopped or reduced sports and hobbies
    - ☐ I have stopped or reduced voluntary roles
    - ☐ I'm unable or less able to provide emotional/practical support to others
    - ☐ It has affected my decision to have children
    - ☐ It has affected my career choices/development
    - ☐ It has affected my emotional wellbeing
    - ☐ I have reduced/lost capacity to drive
    - ☐ I need full-time care
    - ☐ I need part-time care
    - ☐ I have reduced/lost capacity to leave my home independently
    - ☐ I have to spend all day in bed
    - ☐ I often/always can't speak
    - ☐ I often/always can't tolerate light or sound
    - ☐ I often/always struggle to eat enough to maintain my weight
    - ☐ All of the above
    - ☐ None of the above

15. Due to your ME, have you experienced a reduction in, or a loss of, any of the following? Please select all that apply.
    - ☐ Independence
    - ☐ Spontaneity
    - ☐ Freedom

- ☐ Security
- ☐ Privacy
- ☐ Being believed and/or understood by others
- ☐ Trust in institutions (e.g., NHS, DWP)
- ☐ Self-worth and/or confidence

16. We'd like to learn about other people's attitudes to ME, and their impacts. Please select all statements that apply.

- ☐ I feel believed and supported by my family
- ☐ I feel believed and supported by my friends
- ☐ When I tell people that I have ME, I feel that they understand what this means
- ☐ If I had to tell a stranger that I had ME, I would worry they would judge me
- ☐ In some situations, I hide my ME from others
- ☐ I have lost friendships and/or relationships because of people's attitudes to ME

17. Do you feel socially isolated because of your ME?

- ☐ Yes
- ☐ No

18. In your own words, please tell us a little about the impact having ME has had on your life.

Access to healthcare

All questions on this survey are optional. You can skip questions and whole sections. Please prioritise your health and stop when you need to.

19. In the past year, have you been able to access a home visit from your GP, if you have needed one?

- ☐ Yes
- ☐ No
- ☐ Not applicable

20. Have you experienced any barriers in accessing NHS services for ME (GP/consultant/specialist clinic)? Please select any that apply.

- ☐ Too ill to attend
- ☐ No NHS specialist ME service in my area
- ☐ My local ME specialist clinic does/did not accept people with severe or very severe ME
- ☐ Home visits not available
- ☐ Lack of virtual options for consultations (telephone, video call)
- ☐ Lack of infection-control measures (e.g., masking)
- ☐ Appointments offered were too long and/or at unsuitable times
- ☐ I have not experienced any barriers
- ☐ Other (please specify)

21. Because of your ME, do you currently experience barriers in accessing other NHS services? Please select any that apply.

- ☐ No, I do not currently experience any barriers
- ☐ I cannot access cervical screening (the “smear” test)
- ☐ I cannot access breast screening
- ☐ I cannot access abdominal aortic aneurysm screening
- ☐ I cannot access diabetic eye screening
- ☐ I cannot access dental care
- ☐ Yes, I experience other barriers (please specify)

22. Do you feel that having ME affects the care you receive from the NHS?
- ☐ Yes, I receive **better** care
- ☐ Yes, I receive **worse** care
- ☐ No, it does not affect the care I receive

Experiences of NHS healthcare

All questions on this survey are optional. You can skip questions and whole sections. Please prioritise your health and stop when you need to.

23. Do you feel supported by the NHS?
- ☐ Yes
- ☐ No

24. Does your NHS GP and/or specialist team offer you any ongoing support or follow-up care for your ME? Please select any statements that apply.
- ☐ Yes, I have regular monitoring and/or review with my specialist team
- ☐ Yes, I have regular monitoring and/or review with my GP
- ☐ Yes, I have an annual review with my GP
- ☐ No

25. Thinking about the NHS GP you see most often, or that you saw most recently, how confident are you that they understand ME?
- ☐ Fully confident
- ☐ Reasonably confident
- ☐ Not very confident
- ☐ Not at all confident
- ☐ I do not see an NHS GP about my ME
- ☐ I don’t know

26. We are interested in understanding more about experiences of seeking NHS healthcare for ME. Please select any statements that apply.
- ☐ An NHS healthcare professional has believed what I have told them about my ME
- ☐ I have been treated with respect by an NHS healthcare professional
- ☐ An NHS healthcare professional has learned more about ME so they can support me better
- ☐ An NHS healthcare professional has treated me just like any other patient
- ☐ I have been disbelieved by an NHS healthcare professional about my ME
- ☐ I have had an experience of NHS healthcare, related to my ME, that I would describe as ‘traumatic’ or ‘traumatising’
- ☐ An NHS healthcare professional made me feel as though my ME was my own fault
- ☐ I have felt upset after an NHS appointment because of the way I was treated about my ME

27. If you consider yourself to have had at least one **positive** experience of NHS healthcare for your ME, did this (or did any of these) happen recently?

- ☐ Yes, in the past year
- ☐ Yes, in the past two years (since 2023)
- ☐ Yes, in the past five years (since 2020)
- ☐ No, not within the past five years.
- ☐ Unsure

28. If you consider yourself to have had at least one **negative** experience of NHS healthcare for your ME, did this (or did any of these) happen recently?

- ☐ Yes, in the past year
- ☐ Yes, in the past two years (since 2023)
- ☐ Yes, in the past five years (since 2020)
- ☐ No, not within the past five years.
- ☐ Unsure

29. Have your past experiences changed how you approach the NHS? Please select any statements that apply.

- ☐ I avoid seeking NHS healthcare, where possible
- ☐ I have stopped seeking NHS healthcare completely
- ☐ I have not told a healthcare professional about my ME diagnosis
- ☐ I have felt scared or worried before an NHS appointment
- ☐ I have lost trust in the NHS
- ☐ I am more likely to seek help from the NHS when I need it
- ☐ I feel less anxious about attending NHS appointments
- ☐ I feel more comfortable discussing my ME with NHS healthcare professionals
- ☐ No, my approach to the NHS has not changed

30. What would improve your experience of NHS healthcare for your ME? Please select any statements that apply.

- ☐ Follow-up care with GP and/or specialist medical team
- ☐ Being believed
- ☐ Home visits
- ☐ Having an ME specialist service in my area
- ☐ Online or telephone consultations
- ☐ Better informed GP or specialists
- ☐ Other (please specify)

31. Is there anything else you would like to tell us about your experiences of NHS healthcare?

Social care

All questions on this survey are optional. You can skip questions and whole sections. Please prioritise your health and stop when you need to.

32. A social care assessment, sometimes called a needs assessment (in England/Wales), community care assessment (Scotland) or assessment of need (NI) is an assessment by your local council to see if you are eligible for support with personal care, aids and adaptations and other support. Have you had one of these assessments?

- ☐ Yes
- ☐ No
- ☐ I'm waiting to be assessed

33. (If 'yes') What was the outcome of this assessment?

- ☐ Practical help from a paid carer
- ☐ Adaptations to my home
- ☐ Equipment or aids
- ☐ I was given a Personal Budget/direct payments to organise my own support
- ☐ I was told I did not qualify for care/support
- ☐ Other (please specify)

34. We are interested in understanding more about experiences of seeking social care for ME. Please select any statements that apply.

- ☐ I was offered the support I needed in a timely manner
- ☐ Adult social care believed what I told them about my ME
- ☐ I was treated with respect
- ☐ Adult social care did not understand ME
- ☐ I had to educate social care professionals about ME
- ☐ I was accused of self-neglect

35. Do you feel that your care needs are currently being met?
- ☐ Yes (please skip to question 38)
- ☐ No (please consider questions 36 and 37)
- ☐ Not applicable (please skip to question 38)

36. Why are your care needs not currently being met? Please select any statements that apply.
- ☐ I can't afford to pay for care/support and my local council will not provide it
- ☐ I cannot afford the financial contribution to my care that social services have assessed me as being able to pay
- ☐ I cannot find a carer/personal assistant who understands ME
- ☐ My local council does not support me to manage my direct payments or Personal Budget
- ☐ I am still shielding from Covid-19
- ☐ My previous experience in seeking support from my local council has put me off seeking further help
- ☐ Other (please specify)

37. How does this impact you? Please select any statements that apply.
- ☐ It makes my ME worse
- ☐ I can't get the rest I need
- ☐ I can't prepare nutritious food for myself
- ☐ I can't eat enough to maintain my weight
- ☐ I don't have the support I need to maintain a clean, comfortable environment
- ☐ I can't maintain my personal care to the standard I would want
- ☐ Other (please specify)

38. Is there anything else you would like to tell us about your experiences of social care?
[Text box]

The cost of ME

All questions on this survey are optional. You can skip questions and whole sections. Please prioritise your health and stop when you need to.

39. Can you currently do any paid work?
    - ☐ Yes, I work 35 hours per week
    - ☐ Yes, I work 20-34 hours per week
    - ☐ Yes, I work 1-19 hours per week
    - ☐ No, my ME is too severe
    - ☐ No, I took early retirement because of ill health
    - ☐ I am retired (not due to ill health)

40. Please read the statements below and select any that apply.
    - ☐ Returning to work or increasing my hours would make my ME worse
    - ☐ I could return to work if I could find accessible employment (e.g., part-time remote work, self-employment)
    - ☐ I can't increase my hours as this will affect my disability benefit claim, which I need to be able to afford to live
    - ☐ I am concerned that a new or different employer would not understand my ME and how it impacts me
    - ☐ I am concerned I would be treated badly by an employer because of my ME
    - ☐ I have experienced discrimination at work because I have ME
    - ☐ Having a manager/employer willing to provide flexibility and/or make reasonable adjustments has helped me stay in work

41. Do you receive disability benefits?
    - ☐ Yes
    - ☐ No

42. (If 'no') If you do not currently receive disability benefits, but would benefit from this financial support, can you tell us why this is? Please select any statements that apply.
    - ☐ I don't think I'm eligible
    - ☐ I am too ill to complete the application
    - ☐ The application process would make me more ill
    - ☐ The application process would be harmful to my wellbeing
    - ☐ I cannot get the medical evidence I need for the application
    - ☐ My last application was unsuccessful
    - ☐ I am appealing the outcome of my application
    - ☐ Other (please specify)

43. Has having ME had a significant impact on your finances?
    - ☐ Yes
    - ☐ No

44. Has your household spending, in the following categories, increased due to your ME? Please select any that apply.

- ☐ Food
- ☐ Care
- ☐ Housing costs (e.g., rent)
- ☐ Mobility aids (purchase or maintenance)
- ☐ Energy bills
- ☐ Private healthcare

45. Have any of your family or friends had to stop or reduce paid work outside the home to provide care or support for you?

- ☐ Yes
- ☐ No

46. Is there anything else you would like to tell us about the cost of ME?

Further information

47. In your view, what does Action for ME do well, and what could it do better to support people with ME and drive meaningful change?

48. We may wish to clarify some of the information you have given us in this survey, in order to get a fuller picture of the issues faced by people with ME. If we need to do this, would you be willing to provide contact details at the end of this section so that we can follow up with you?

- ☐ Yes
- ☐ No

49. Would you like to be involved in Action for ME's work? If so, please select from the list below the areas that you would be interested in hearing more about, and provide your email address at the end of this section.

- ☐ Sharing my lived experience to shape research studies on ME (e.g., as part of a Public and Patient Involvement (PPI) group)
- ☐ Volunteering for Action for ME (for example, support with fundraising, partnerships development, research communications, campaigning and/or other direct research tasks such as data analysis)
- ☐ I have ME and would like to be informed of any future opportunities to participate in research studies
- ☐ I have Long Covid and would like to be informed of any future opportunities to participate in research studies
- ☐ I would like to share my personal story of ME and be a case study for use in media, awareness, and fundraising work
- ☐ I would like to volunteer to help with All-Party Parliamentary Group work and/or take part in campaigns

50. Would you like to subscribe to Action for ME's newsletter to receive email updates on our latest activities, news, and campaign information? If so, please select 'yes' to consent, and provide your name and email address at the end of this section.

- ☐ Yes
- ☐ No

51. As per the questions above, please provide your name and/or email address below and we will be in touch. We will only use your name and email address for the purposes outlined in questions 48, 49, and 50.
Name:

Email address:

Thank you so much for taking part in Action for ME's Big Survey 2025.

We are very grateful to you for spending your time and energy in this way. The information you have provided will inform our work to improve the lives of people with ME.

We look forward to sharing the results of our Big Survey with you, in Spring 2026, via our website. You can also receive updates by subscribing to our newsletter, by filling out the form at the bottom of this webpage.

If taking part in this survey has raised any issues for you, and you feel that you need information or support, **you can call Action for ME's Information & Support service on 0117 927 9551 (choose option one) to request a call-back**, between 10.30am and 3pm, Monday to Thursday (excluding bank holidays). Please leave your name, number and a brief description of how we can help. If you give us an idea of when it's best to reach you, we will do our best to call then. You can also email us: infosupport@actionforme.org.uk. Please note that this service is not 'live', but we get back to everyone who leaves us a request for a call-back or sends an email, within five working days (Monday to Friday excluding bank holidays) and often much sooner.

If you need support now, you can contact any of the following organisations, by phone, email, or text:

Samaritans
Call 116 123, at any time
Email jo@samaritans.org

Campaign Against Living Miserably (CALM)
Call 0800 58 58 58, 5pm to midnight every day
You can also use the Live Chat service via the website

You can also message a text line by texting SHOUT to 85258.
This service is open 24 hours a day, every day.

If you have any questions about the survey itself or how we will use your data, please contact Action for ME's Research Team via email: research@actionforme.org.uk.