

descriptions

a patient-led description of ME

Why are we running this survey?

We are sharing this survey to invite people living with M.E. to describe their experience of the disease. The responses will be used by Alec Finlay, an internationally-recognised artist and poet, to create a collective patient-led description of the illness.

Alec will use your responses to create a description in your own words. The final text will be a found poem – Alec will use the most expressive of your phrases, without altering them. Descriptions will be published in a book and made available online, as a downloadable PDF, and an audio recording.

None of the responses will be attributed to individuals – they will all remain anonymous. However, everyone who sends a response and supplies their name will be credited as a contributor.

There are a wide variety of questions, but please note that we don't expect you to answer them all. They are intended as a prompt for your descriptions. The questionnaire allows you to start answering, then pause, and return when you are ready to answer more questions.

The questions are arranged in different categories. You don't need to answer in any particular order.

Please contribute to the extent that you are able; every submission will be valued. We hope that the result will help convey your experiences to society and the medical system.

There are 35 questions in these categories:

Before you had M.E.

Diagnosis and at the beginning

Relationships

Impact on your life

Medical treatment and Self Management

Describing M.E. and its impact on your life

M.E. and what needs to be addressed by others.

You can answer as many or as few as you want or are able.

Submitting form

Once you have finished and want to submit this form then please email it to:

avril.mclean@actionforme.org.uk.

Please include your name, but remember that, while all the contributors will be credited, none of the text will be identified with an individual. The deadline is 31 December 2021.

Before you had M.E.

1. If you were aware of ME before you became ill how did you perceive it?

Diagnosis and at the beginning

2. What age were you when you first become ill with ME?

3. In a few sentences can you describe the onset of your ME (the first few weeks)?

4. In a few sentences can you describe the first six to nine months of your ME and what the impact was on your life?

5. If you could speak to yourself as the person who first became ill is there one piece of advice you would give?

Relationships

6. Does anyone else in your extended family have ME? What relation are they to you?

7. In a few sentences can you describe how ME has affected your family relationships?

8. In a few sentences can you describe how ME has affected your friendships?

Impact on your life

9. How long have you had ME?

10. In a few sentences can you describe how ME has affected your life, in the long term?

11. What is your worst symptom and how do you describe it? Please use your own descriptive language and imagery to convey your experience?

12. What one thing do you most miss being able to do and why?

13. What things do you do when you are able, or even if you are not able, despite the cost in terms of pain or energy, and what is the typical effect on you?

14. How has your sense of travel and journeys changed since you became ill?

15. How has your experience of work changed since you became ill? (Do you continue to work, have had to reduce your working hours, or are you unable to work?)

16. Has your diet been affected since you became ill with ME; please describe how?

17. Has your sleep quality and/or sleep pattern been affected and how?

18. What has your experience of the benefits system been?

Medical treatment and self management

19. In a few sentences can you describe what helps alleviate your ME symptoms, if anything?

20. In a few sentences can you describe your experiences of medical professionals in terms of your ME?

21. In a few sentences can you describe the treatment you have been advised to follow by your GP, any specialist medical help your ME, or any alternative/natural remedies, and what the effect of these have been?

22. What else do you do to recover from a flare or a crash, or enact self-care –what gives you a sense of healing or alleviating your symptoms?

23. What are the worst and what is the most helpful things that has been said to you in relation to ME? Please include the quote as you remember it, but do not include any personal names.

Describing M.E. and its impact on your life

24. Can you describe how it feels to live with fluctuating health, and what this means for your life?

25. Can you describe how a relapse feels? Again, please use your own descriptive language and imagery to convey the experience.

26. Do you feel that you understand your illness and, if you do, using your own words and imagery, how would you describe the way ME works? (We understand that your knowledge is not that of a professional medical expert, and are interested in your own description).

27. Have you been affected in terms of a particular sense – hearing, sight, touch, etc. – and can you describe an example of this in your own words?

28. Is there a particular piece of writing, art, music, or film, that speaks to your experience of illness and which has helped you? How has it helped?

29. We're making a visualisation of symptoms from a list of descriptive pair words. Rather than medical terms we're interested in the vivid and

forceful words you use to express feelings of pain and fatigue. Some examples: ‘beyond tired’, ‘sleep thief’, ‘woozy head’.

30. We’re collecting lists of ten words that describe ME. We will collect these from PWME and people who treat ME, as a way to gather as complete a lexicon as we can, and to see how they compare and where they differ.

31. We’re collecting images and metaphors for this illness: some people have a name for their illness, others think of it as a character, like a Bond villain, or a figure from mythology – if you have any imagery you can share please do.

M.E. and what needs to be addressed by others

32. Do you think the understanding of ME has changed –improved or worsened – in the past 2-3 years, and, if so, why?

33. What makes you most hopeful in terms of a cure for ME?

34. What makes you feel most disappointed, upset, or angry in terms of the perception and treatment of ME?

35. Please include your name with your response. We would prefer to credit every contributor who submits a response, however, if you would like not to be credited please say so. If you would be happy for us to possibly contact you in the future about following up on your comment

then please leave an email address or phone number where you can be reached

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To learn more about how we collect, store and process your information, please view our privacy policy. <https://www.actionforme.org.uk/get-information/about-us/our-privacy-policy/>