



Campaign for a Very Severe ME Service

Parliamentary Advocacy Guide

Contacting your MP

Guide for the very severe who can't meet in person

#MEAAction UK has developed this guide to give you the basic tools to contact your Member of Parliament (MP). MPs are there to represent YOU, and your personal story is your most important asset.

We are asking MPs to lobby the Secretary of State for Health and Social Care. There is no specialised service for very severe ME patients to be referred to. The decision to set up this service lies with the Secretary of State for Health and Social Care so ask your MP to set up a meeting and present the urgent case for healthcare for the very sickest people who have the least help.

Here we take you through some easy steps for contacting your MP.

1. Find your MP

To find your MP's contact details, enter your postcode on the parliament website [here](#).

2. Book a phone call or online call with your MP

If you are well enough to book a call read this, if you are not please skip to point 3.

Some MPs may be able to speak to you outside of their surgery times, and may agree to speak to you on the telephone or via video conference (e.g. Zoom), or to visit you at home if you are unable to get to the surgery.

i) **Use our email template** in [Appendix 1](#) to request a call with your MP. If you have a personal connection, be sure to add that to your request. You must **provide your address, including your postcode**, as MPs are only required to respond to people who live in their constituency. You should alter the email template to explain any accommodations you need to ensure the meeting is accessible, including if you need to do it by phone/video conference or at your own home.

3. Sending a message to your MP if you are unable to meet

Use our email template in [Appendix 2](#) to send a message to your MP explaining that you are too ill for a phone or video call. If you have a personal connection, be sure to add that to your request. You must **provide your address, including your postcode**, as MPs are only required to respond to people who live in their constituency.

Follow-Up

i) Email us at admin@meaction.org.uk to let us know who you are, who you met with, and what came out of the meeting. And let us know if you need help handling the follow-up or responding to questions. Please keep us updated on any information you receive which could be useful for campaigning.

[Appendix 1](#)

Requesting a phone call or online meeting: email example

This is a basic sample email. Feel free to alter it and use your own words, but try to keep it short.

Subject: Request for Meeting Regarding Myalgic Encephalomyelitis (ME)

Body: Dear *[insert your MP's name]*,

My name is _____ and I am one of your constituents, my postcode is *[insert postcode]*. I have *[had ME/cared for someone with ME for ? years]*. Myalgic Encephalomyelitis (ME) is a complex, debilitating, and chronic disease. Following the Covid epidemic there are 1.35 million people in the UK with ME which causes profound neurological, immunological and metabolic dysfunction.

In the UK there is no NHS service for the very sickest people with ME. Of the 1.35 million with ME, 25% or 337,500 are severely ill. This means that there are an estimated 2,000 people with ME in your constituency, and 500 will be severely ill.

The very severely ill in this cohort are suffering at home or in hospital, bedbound, tube fed and paralysed, with no specialist service to call on.

The DHSC ME/CFS Delivery Plan promised to start the process of commissioning a service for the very severely ill ME sufferer in England. The start of this process has now been pushed back until April 2027 at the earliest while the very frail are left with no service, no specialists and nowhere to go.

[Add personal or local information that will help illustrate the issues you are concerned about. Make it as personal as you are comfortable with.]

I am too ill to come to your surgery to meet with you to discuss the current situation for very severely ill people with ME in your constituency so request an online meeting or phone call so I can present the urgent case for healthcare for the very sickest people who have the least help. The decision to set up this service lies with the Secretary of State for Health and Social Care. Please let me know when you are available.

Thank you for your attention,

[Your Name]

[Your Contact Information - contact phone number, address with postcode]

[Appendix 2](#)

Sending a message to your MP if you are unable to meet

This is a basic sample email. Feel free to alter it and use your own words, but try to keep it short.

Subject: Request for Support Regarding Myalgic Encephalomyelitis (ME)

Body: Dear *[insert your MP's name]*,

My name is _____ and I am one of your constituents, my postcode is *[insert postcode]*. I have *[had ME/cared for someone with ME for ? years]*. Myalgic Encephalomyelitis (ME) is a complex, debilitating, and chronic disease. Following the Covid epidemic there are 1.35 million people in the UK with ME which causes profound neurological, immunological and metabolic dysfunction.

In the UK there is no NHS service for the very sickest people with ME. Of the 1.35 million with ME, 25% or 337,500 are severely ill. This means that there are an estimated 2,000 people with ME in your constituency and 500 will be severely ill. The very severely ill in this cohort are suffering at home or in hospital, bedbound, tube fed and paralysed, with no specialist service to call on.

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[Add personal or local information that will help illustrate the issues you are concerned about. Make it as personal as you are comfortable with.]

I am too ill to come to your surgery to meet with you to discuss the current situation for very severely ill people with ME in your constituency or to talk on the phone/or via a video call, so ask you to read the information in this email and message me.

My situation illustrates how urgent the case for healthcare is for the very sickest people with ME who have the least help. The decision to set up this service lies with the Secretary of State for Health and Social Care. Please lobby and represent how urgent the situation is for those of us who are too ill to campaign on our own behalf.

Thank you for your attention,

[Your Name]

[Your Contact Information - contact phone number, address with postcode]