# Campaign for a Very Severe ME Service

## Parliamentary Advocacy Guide

## Meeting with your MP

#MEAction UK has developed this guide to give you the basic tools to help you to feel comfortable meeting with your Member of Parliament (MP) either in person or virtually. 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 4 easy steps for meeting with your MP.

### 1. Find your MP

To find your MP's contact details, enter your postcode on the parliament website here.

### 2. Research your MP (optional)

This step is optional, jump to the next stage if you have limited energy! Researching your MP will help you prepare for the meeting, as you can find out their interests and if they've previously spoken about ME.

i) The parliament website shows your MP's records on: select committees they are on/have been on, their written parliamentary questions, Early Day Motions they've signed, their voting record and spoken questions on Hansard (you can search the Hansard record using keywords).

ii) Have a look at your MP's website, Facebook or Twitter feed. These will help you understand your MP's current priorities.

iii) TheyWorkForYou provides a good overview of your MP's voting record and registered interests.

**3. Book an appointment with your MP**

MPs hold regular sessions called surgeries where they meet constituents to discuss issues relevant to them. Surgery dates are normally listed on your MP’s website. You will usually need to book an appointment at one of these surgeries, either in person or virtually. 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. If meeting an MP as a group, please be aware they may have a maximum number of people they see at one time.

i) **Use our email template** in Appendix 2 to request a meeting 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.

ii) Follow-up a week later with a phone call to your MP’s constituency office if you haven’t received a response.

**4. Meeting Preparation, Meeting and Follow-up**

When meeting with your MP they will want to know - **What actions do constituents want me to take?** and **Why should I take action?**

i) Write an email to your MP beforehand, outlining everything you want to say during your meeting. Include your ‘Ask', what you’d like to discuss and factsheets/information about ME.

The ‘Ask’ is the action you are requesting the MP to take, and **we have provided an example of asking for a service for very severe ME patients in** Appendix 1.

There are general actions listed that your MP can take in order to increase their knowledge of ME, if they express interest which will make them more likely to support any specific campaigns, such as a main chamber debate at Westminster. It’s important to decide on which 1-2 ‘Asks’ you will be putting to your MP.

ii) Explain brain-fog/cognitive impairment/sensory sensitivities. If you are writing to your MP in advance of the meeting you may find it useful to explain these things at this point. Do ask how long the appointment is likely to be and plan accordingly. Ask if you can meet online to conserve your energy.

iii) Make a checklist of points you wish to cover to refer to during the meeting. **We have provided the key message in** Appendix 1.

**Meeting**
A good rule of thumb for a 15 minute meeting is:

- 5 minutes for introduction/basic facts
- 3-5 minutes for your personal story
- 5 minutes for the 'Ask' and closing

i) Take fact sheets/information about ME with you and leave these factsheets behind for MP.

ii) Tell your personal story. Succinctly describe your history and the impact ME has had on you and, as appropriate, loved ones. Given the time constraints, it's critical to stay focused and, as best as possible, relate your story to the Ask.

iii) Be very clear about the action that you want your MP to take (your Asks).

iv) Ask for a likely time frame within which these actions will be completed.

v) Ask to be kept informed of what action has been taken and copied in on any responses etc.

vi) Take a photo with your MP to share on social media.

Be positive, and stay focused on your message. If your MP or their assistant says something offensive or inaccurate, gently correct them, i.e. let me explain why ME is not a matter of simply feeling sleepy at times, or forcing yourself to push through.

Don't be afraid to ask questions. Also, it's okay to say that you don't know the answer to their questions. Just say you'll get back to them with an answer. Email us at admin@meaction.org.uk if you need any assistance.

**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.

ii) **Use our email template** in Appendix 3 to send a ‘Thank you for meeting me email’ a couple of weeks after the meeting. This also allows you to check on progress, if any has been made regarding your Asks.

iii) Even if you’ve been given a “no” to your Asks, stay in touch! It’s important to make sure that your MP remembers you and knows that you are not going away. Send periodic emails to the office to keep the momentum going! A good excuse to email them is to include a recent article/news clip/scientific finding that you can tell them about.

iv) Write an article for your local newspaper about your meeting and include a photo from the meeting if you took one. (Email admin@meaction.org.uk if you’d like help with the article)

# Appendix 1

## ‘Asks’- Actions your MP can take

### Setting up a service for the very severe

There is no NHS service for the very severe ME patient to be referred to. The setting up of this service is in the gift of 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 severe and very severe with ME.

**This service will take years to make a difference even if it is started today so, if you live in England, you can also ask your MP to:**

Lobby your local Integrated Care Board (ICB) for the immediate setting up of a virtual ward system and inclusion in their Joint Forward Plan.
https://www.england.nhs.uk/contact-us/about-nhs-services/contact-your-local-integrated-care-board-icb/

A virtual ward allows patients to receive acute, hospital-level care in their own homes, care homes, or hospices rather than a hospital bed. It uses technology—such as apps, wearables, and monitoring devices—combined with regular, multidisciplinary team visits (nurses, doctors, therapists) to monitor conditions, prescribe medication, and provide treatments like oxygen or fluids.

If your MP is willing to help please email admin@meaction.org.uk as we are happy to provide more information.

## Other things to discuss with your MP

1. ME receives a tiny percentage of the research funding awarded to other chronic illnesses. For example, ME has been shown to be more disabling than MS and yet receives at least 20 times less research funding in the UK. We urgently need a commitment to funding biomedical research commensurate to disease burden and to compensate for decades of under investment.

2. Even after the updated NICE guideline on ME/CFS there is no effective treatment for ME and GPs receive little or no training into the disease. Many patients report being disbelieved by their doctors. You could ask your MP to lobby to make training on ME mandatory for doctors and direct them to this CPD accredited module and this NHS elearning on ME.

## Ideas for engaging your MP

- Watch Unrest on Apple TV or YouTube
- Watch the short "I got a virus" film
- Watch Jen Brea's Ted Talk
- Read our ME resources
- Issue a statement on social media, in support of ME patients and biomedical research
- Appear in a photograph of the meeting to allow constituents to publicise the work being.done
- Pledge to support people with ME in parliament by:

    - Attending the APPG on ME
    - Agree to be notified of future EDMs and campaigns supporting people with ME
    - Write to the relevant minister
    - Ask a parliamentary question. If you would like help thinking of a question prior to meeting your MP email us at admin@meaction.org.uk.
    - Pledge to attend debates about ME
    - Sponsor a Ten Minute Rule Bill
    - Share information on ME with party colleagues and appropriate agencies

Give your MP the opportunity to choose which of the parliamentary actions suggested they are willing and able to do. You are of course free to make up your own Ask or to adapt an Ask to the specific interests/experience of your MP.

# Appendix 2

## Requesting an appointment: 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 affecting over 700,000 people in the UK. ME causes profound neurological, immunological and metabolic dysfunction.

In the UK there is no NHS service for the very sickest people with ME. It is estimated that up to 175,000 people 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 would welcome the chance to meet with you to discuss the current situation for very severely ill people with ME in your constituency. *The decision to set up this service* *lies with the Secretary of State for Health and Social Care so I am asking you to set up a meeting and present the urgent case for healthcare for the very sickest people who have the least help.(please use your own wording if possible).* Please let me know when you are available.

***(If you live in England you can ask your MP to contact your local Integrated Care Board:)***

Setting up a specialised service for the very severely ill with ME will take years. You can help relieve suffering now by lobbying our Integrated Care Board (ICB) and ask for the immediate setting up of a virtual ward system and inclusion in their Joint Forward Plan.
https://www.england.nhs.uk/contact-us/about-nhs-services/contact-your-local-integrated-care-board-icb/

A virtual ward allows patients to receive acute, hospital-level care in their own homes, care homes, or hospices rather than a hospital bed. It uses technology—such as apps, wearables, and monitoring devices—combined with regular, multidisciplinary team visits (nurses, doctors, therapists) to monitor conditions, prescribe medication, and provide treatments like oxygen or fluids.

Thank you for your attention,

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

# Appendix 3

## Thank you for meeting me: email example

**Subject:** Thank You for Meeting Regarding Myalgic Encephalomyelitis (ME)

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

I am writing to thank you for meeting with me on *[insert the date of your meeting]* to discuss Myalgic Encephalomyelitis (ME).

We discussed *[insert a very brief summary of what you discussed]*. I requested that you take the following actions:

- *[state the ‘Asks’ here, bullet points are good if there are more than one.]*

I appreciate your interest in this matter, and would be very grateful if you could keep me updated on any progress and developments with these actions.

Thank you for taking the time to meet with me and for your interest in this very important issue,

*[Your Name]*
*[Your Contact Info - contact phone number, address with postcode]*