

Parliamentary Toolkit Meet your MSP

#MEAction Scotland has developed this guide to help you feel confident engaging and meeting with Members of the Scottish Parliament (MSP). Responsibility for the delivery of health services and policy decisions in Scotland is <u>devolved</u> to the Scottish Parliament, so MSPs have the power to make change for people with ME in Scotland.

Your personal story is your most important asset. The next time your MSP comes across something about ME or there is a specific 'Call to Action', we want them to remember you and your story and the stories of others in their constituency affected by ME.

You can engage with your Member of Parliament (MP) for the UK as well, particularly if you wish to raise an issue about a reserved matter. If you are unsure whether a matter is devolved or reserved, you can find out by contacting <u>Public Information</u>.

Here we take you through four simple steps for engaging with your MSP:

Stage 1: Find your MSP(s)

To find out who your MSPs are and their contact details, enter your postcode on the Scottish Parliament website.

You are represented by eight MSPs – one for your constituency and seven for the larger parliamentary region that includes your constituency. Constituency and regional MSPs have the same powers to represent you, and you are free to contact any of your eight MSPs. For example, you may choose to contact an MSP because they belong to a particular party or because you know that they have an interest in the topic you want to discuss.

Your constituency MSP has a particular duty to respond to you so we recommend contacting them first.

Stage 2: Research your MSP

This step is optional - jump to Stage 3 if you have limited energy!

Researching your MSP is helpful, as you can find out their interests and if they've previously shown an interest in supporting people with ME. It is good to know which

political party they are in - for example if they are in the Government's party, they may know a relevant Government Minister.

- Your MSP's profile on the <u>Scottish Parliament website</u> shows your MSP's records on parliamentary committees they are on/have been on, their written parliamentary questions and what they have said in parliament.
- Have a look at your MSP's website and social media activity. Again, there should be links to these in their profile on the <u>Scottish Parliament website</u>. This will help you understand your MSP's current priorities.
- The website <u>They Work For You</u> provides a good overview of your MSP's voting record and registered interests.
- Ask in the <u>#MEAction Scotland Facebook group</u> for details on any previous support your MSP has shown for our campaigns.

Stage 3: Get in contact with your MSP

MSPs hold regular sessions called surgeries where they meet constituents to discuss issues relevant to them. This is a good way to meet with your MSP and surgery dates should be listed on their website. You may need to book an appointment at one of these surgeries. If meeting MSPs as a group, please be aware they may have a maximum number of people they see at one time.

If your MSP is not currently holding surgeries or you are not comfortable/able to meet them face to face, you can ask to speak to them over the phone or via video call.

- 1. Email your MSP. We have provided a template below (<u>Appendix 2</u>) to request a meeting with your MSP. If you have a personal connection, be sure to add that to your request. You must **provide your address**, **including your postcode**, as MSPs are only required to respond to people who live in their constituency. You should alter the email template to explain any accomodations you need to ensure the meeting is accessible, including if you need to do it by phone, video call or at your own home.
- 2. Follow-up two weeks later with a call or email to your MSP's constituency office if you haven't received a response.

Stage 4: Meeting Preparation, Meeting and Follow-up

When meeting with your MSP the key things they will want to know are:

- What actions do constituents want me to take?
- And why should I take action?

Preparation

- Write an email to your MSP beforehand, outlining everything you want to say during your meeting. Include your 'asks' - what you'd like to discuss and factsheets/information about ME.
 - The 'ask' is the action you are requesting the MSP to take, and we have provided examples in <u>Appendix 1</u>. These are general actions your MSP can take in order to increase their knowledge of ME, which will make them more likely to support any specific future campaigns. It's important to decide on which asks you will be putting to your MSP.
- Explain brain-fog/cognitive impairment/sensory sensitivities. If you are writing to your MSP 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.
- Make a checklist of points you wish to cover to refer to during the meeting. We have provided the key messages in <u>Appendix 1</u>.

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 your asks and closing
- Take <u>factsheets/information</u> about ME with you, and leave them behind for your MSP.
- 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.
- Be very clear about the action that you want your MSP to take your asks.
- Ask for a likely time frame within which these actions will be completed.
- Ask to be kept informed of what action has been taken and copied in on any responses etc.
- If possible, take a photo with your MSP to share on social media.
- Be positive, and stay focused on your message. If your MSP 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 scotland@meaction.net if you need any assistance.

Follow-Up

- Please fill out this <u>survey</u> 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.
- Use our email template (<u>Appendix 3</u>) 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.
- Even if you've been given a no to your asks, stay in touch! It's important to make sure that your MSP 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.
- Write an article for your local newspaper about your meeting and include a photo
 from the meeting if you took one. Email <u>scotland@meaction.net</u> if you'd like help.

Appendix 1

'Asks'- Actions your MSP can take

- Watch 'I got a Virus' short video
- Watch Unrest on Netflix, Amazon Video, Vimeo, Google Play or iTunes
- Watch Jen Brea's Ted Talk
- Read our <u>Factsheet on ME in Scotland</u> and the <u>S4ME summary of the PACE trial</u> <u>controversy</u>
- Issue a statement on social media, in support of your constituents with ME and highlighting the need for funding 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:

- Agree to be notified of future Members' Motions and campaigns supporting people with ME
- Write to the relevant minister
- Ask a parliamentary question. If you'd like help thinking of a question prior to meeting your MSP email us at scotlant@meaction.net)
- Pledge to attend debates about ME
- Sponsor a Members' Debate
- Share information on ME with party colleagues and appropriate agencies

Give your MSP 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 MSP.

Key things to discuss with your MSP

- 1. Immediate action must be taken to end the use of Graded Exercise Therapy as a treatment for ME. This treatment is based on debunked trials, is ineffective and potentially harmful, and contributes to the hostile environment of disbelief and neglect that sufferers face.
- 2. The high number of people post COVID-19 who are suffering from an ME type illness makes it even more essential that action to end Graded Exercise Therapy is taken immediately.
- 3. 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.
- 4. We are fighting to compel all commissioning bodies to ensure medical, welfare and care services are accessible to people with ME, specifically including home visiting for those who are severely affected. 25% of patients are housebound or bed-bound, some of whom have been that way for decades.
- 5. 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. There is an urgent need to update training of GPs and medical professionals so that they are equipped with clear guidance on diagnosis of ME and appropriate management advice to reflect international consensus on best practice.

Appendix 2

Requesting an appointment: email example

This is a basic sample email. Feel free to alter it, but try to keep it short.

Subject: Request for Meeting Regarding Myalgic Encephalomyelitis (ME)

Body: Dear [insert your MSP'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 roughly 25,000 people in Scotland. That equates to roughly 400 people within your constituency. ME causes profound neurological, immunological and metabolic dysfunction. Due to scarcity in biomedical research funding, the cause of the disease is unknown and there is currently no effective treatment.

[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 people with ME in your constituency, where we need to get to and what actions you can take. These include *[insert your 'asks' here]*. 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 3

Thank you for meeting me: email example

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

Body: Dear [insert your MSP'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]