Parliamentary Advocacy Toolkit
Meeting with your MP

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#MEAction has developed this guide to give you the basic tools to help you to feel comfortable meeting with your Member of Parliament (MP). MPs are there to represent you, and your personal story is your most important asset. The next time your MP comes across something about myalgic encephalomyelitis (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.

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

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 (find these here). These will help you understand your MP's current priorities.

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

iv) Ask your #MEAction regional Facebook group (see Appendix 4) for details on any previous support your MP has shown for our campaigns.

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. 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 Skype, or to visit you at home if you are unable to get to the surgery. If meeting MPs as a group, please be aware they may have a maximum number of people they see at one time.

i) **Use our email template (Appendix 2)** to request a meeting with your MP. 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 accomodations you need to ensure the meeting is accessible, including if you need to do it by phone/skype or at your own home.

ii) Follow-up a week later with a 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?**

Preparation

i) Write an email to your MP 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 MP to take, and **we have provided examples in Appendix 1**. These are general actions your MP can take in order to increase their knowledge of ME, which will make them more likely to support any specific future 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.

iii) Make a checklist of points you wish to cover to refer to during the meeting. **We have provided the key messages 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 (find some here), 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 uk@meaction.net if you need any assistance.

Follow-Up

i) Please fill out this survey 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 (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 uk@meaction.net if you'd like help with the article)

5. Using Social Media for Advocacy

Social media is another critical tool you can use to influence MPs without having to leave your home! Learn about strategies for using Facebook, Twitter and Instagram - and what to us when - in order to reach your MPs.

Read the Social Media Toolkit here.

Appendix 1

'Asks:' Actions your MP can take

- Watch Unrest on Netflix, Amazon Video, Vimeo, Google Play or iTunes.
- Read our ME fact sheet and the S4ME summary of the PACE trial controversy.
- Watch Jen Brea's Ted Talk.
- Issue a statement on social media in support of ME patients and biomedical research.
- Appear in a picture 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 EDMs and campaigns supporting people with ME
  - Write to the relevant minister
  - Ask a parliamentary question. A list of recently asked questions is here. (If you'd like help thinking of a question prior to meeting your MP email us at uk@meaction.net)
  - 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.

N.b. Some MPs might suggest a meeting with CCGs or local health boards. This is a very demanding activity on energy levels. If suggested and you feel unable to take part it is okay to say so, and to divert attention back to the Asks above.

Key points to discuss with your MP

1. Immediate action must be taken to end the use of CBT and GET as treatments for ME. These treatments are based on debunked trials, are ineffective and potentially harmful, and contribute to the hostile environment of disbelief and neglect that people with ME encounter.

2. 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 commitment to funding biomedical research commensurate with the disease burden, and to compensate for decades of under investment.

3. Commissioning bodies must ensure medical, welfare and care services are accessible to people with ME, specifically including home visiting for those who are severely affected. Twenty-five percent of patients are housebound or bed-bound, some of whom have been

that way for decades.

4. There are no universally effective treatment for ME, and GPs receive little or no training about the disease. Meanwhile, the National Academies of Science in the US has reported that people with ME have lower quality of life measurements (pg. 1 and 31-32) than those with other disabling illnesses such as multiple sclerosis, heart disease, and end-stage renal disease.

5. 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 practices.

Appendix 2

Request 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 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 roughly 250,000 people in the UK. 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 UK government currently spends approximately 50 pence per patient per year), there are no effective treatments available to people with ME from the NHS.

[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 be taking. 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 about 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]

Appendix 4

#MEAction Regional Facebook groups

You can find a listing of all #MEAction groups at www.meaction.net/groups

Scotland: https://www.facebook.com/groups/175392066302063/

Wales: https://www.facebook.com/groups/2098153813739090/

Northern Ireland: https://www.facebook.com/groups/228736971224556/

London: https://www.facebook.com/groups/218708485387254/

South East: https://www.facebook.com/groups/314683952398771/ (Berkshire, Buckinghamshire, East Sussex, Hampshire, Isle of Wight, Kent, Oxfordshire, Surrey, West Sussex)

South West: https://www.facebook.com/groups/457694154686290/ (Bristol, Gloucestershire, Somerset, Wiltshire, Dorset, Devon, Cornwall)

West Midlands: https://www.facebook.com/groups/910797942432520/ (Herefordshire, Shropshire, Staffordshire, Warwickshire, West Midlands, Worcestershire)

North West: https://www.facebook.com/groups/257493764993299/ (Cheshire, Cumbria, Greater Manchester, Lancashire and Merseyside)

North East: https://www.facebook.com/groups/174190006532829/ (Northumberland, Tyne and Wear, Durham, North Yorkshire)

Yorkshire & the Humber: https://www.facebook.com/groups/233721820723436/ (South Yorkshire, West Yorkshire, North Yorkshire, East Riding and Lincolnshire)

East Midlands: https://www.facebook.com/groups/162480141271246/ (Derbyshire, Nottinghamshire, Lincolnshire, Leicestershire, Rutland, Northamptonshire)

East of England: https://www.facebook.com/groups/127113918161445/ (Bedfordshire, Cambridgeshire, Essex, Hertfordshire, Norfolk, Suffolk)