



# Action for M.E. campaign toolkit



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## About this guide

This guide is designed to offer ideas and tips for a selection of campaigning and lobbying activities. We realise that due to the nature of M.E., many people are too unwell to become involved in campaigns and lobbying. However, we find that direct contact from constituents is the best way to achieve impact.

Therefore, we have created this guide for anyone who would like to get involved in campaigning for M.E. whether it is by sending a letter to an MP, taking action with a local group, long-term or short-term. We hope it may also be useful to friends, families or carers of people with M.E. who would like to campaign.

## What is campaigning?

Campaigning is the act of trying to influence decision-makers, so they can create change for a better and more just society.

Campaigning takes many forms of actions. Internal campaigning includes lobbying members of Parliament, ministers and civil servants, responding to department consultations, and working with organisations in order to influence their decisions. Other methods of campaigning involve protests, marches and sit-ins.

However, we understand that most people with M.E. are too unwell to take part in this high energy action, so this guide focuses on low-energy tactics which can be just as worthwhile.

## Why do people campaign?

People campaign for many different reasons and causes, but they all want to *change* something. Campaigners want to change practices, policies, attitudes or even beliefs. They believe a different world is possible. They want to make their voices heard. Most importantly, people campaign because it works!

By contributing to a campaign, you will be part of the collective effort to change the lives of people with M.E. Furthermore, no experience is necessary.

## **Campaigning for M.E.**

### **What can I do?**

You can add your voice to the growing call for change about M.E. You could campaign by sending a tweet, an email or a letter to your MP, local councillor or primary care trust (PCT) and more. You could also spread the word on the internet. There are many things you can do to force change, either as an individual or a group. We realise that many people with M.E. are too unwell to campaign or lobby, so getting your friends and family to help is a great way to contribute to the cause.

You could join our Time for Action campaign which seeks to end the ignorance, injustice and neglect of M.E., which stems from Government, through the NHS, local authorities, the public, right down to your friends and families. You can find this in our Online M.E. Centre at [www.actionforme.org.uk/time-for-action](http://www.actionforme.org.uk/time-for-action)

It is important to remember that while many campaigns won't always reach their ultimate goal, most achieve some change that is still valuable for people living with M.E., such as increasing awareness of the condition.

If you would like to use the Action for M.E. logo on your campaign, please contact our Communications and Policy team on [policy@actionforme.org.uk](mailto:policy@actionforme.org.uk) or 0117 937 6620.

### **Identify the issue**

You must first identify the issue as this will be the core motivation of your campaign. What significant thing do you want to change or raise awareness about? It is a good idea to have a key message which you will try to get across to as many people as possible.

Your own campaign could be about something more specific or local issue, for example:

- there are no specialist NHS M.E. services in your area
- your GP lacks a proper understanding of M.E.
- the cuts to benefits are causing unjust and disproportionate financial problems for people with M.E.

Action for M.E. has identified these key areas for campaigning: health, welfare eg. benefits, research, employment, social care, education and carers.

## **Identify the solution and goals**

Next, it is important to think about how to solve your problem. You may have a very clear idea of how to do this, or the solution may be long and complicated. You may not even know the solution yet, but make sure you know what you want your campaign to achieve. Your goal could be short-, medium- or long-term, or a few small goals, but try to make sure it's achievable.

## **Who is involved in campaigning?**

The campaign process will include your allies and your potential opponents. Who is for the change and who is against the change? You need to identify these and then work out what their viewpoint or arguments may be.

Decision-makers or power-holders are the key people that you will try to lobby and influence. These include ministers, your MP/MSP, your local councillor, medical professionals or decision-makers in social services. Your MP and councillor may be able to influence more power-holders in Government. You can find your local MP on the Parliament website at [www.findyourmp.parliament.uk](http://www.findyourmp.parliament.uk)

Contact people who can influence the public and promote your campaign, such as local radio DJs, news reporters, journalists, and newspaper editors.

Recruiting fellow campaigners and volunteers will add to your cause. These could include your family, friends, local M.E. support group members, doctors, nurses, colleagues or employers.

## **Gather your evidence**

People with the power to make decisions are most likely to listen to your campaign if you have evidence to back it up. You could use your personal experiences (qualitative evidence) or statistics and figures (quantitative evidence). You can include survey results, interviews and case studies.

Evidence can be gathered from people with M.E., carers of people with M.E., and anyone else who has experienced M.E. in some way. Local support groups would be good places to gather evidence.

We have factsheets and publications you can use in your campaign in our Media Centre in our online M.E. Centre well as our consultations and survey reports at [www.actionforme.org.uk/time-for-action](http://www.actionforme.org.uk/time-for-action)

If you would like to use the Action for M.E. logo on your campaign, please contact our Communications and Policy team on [policy@actionforme.org.uk](mailto:policy@actionforme.org.uk) or 0117 937 6620.

## Let's take action

### Your MP and you

Your MP works on behalf of you and your constituents. In order to make your voice heard in Parliament, your MP needs to know what you want to say. Most MPs will be happy to talk to you, but don't be disappointed if your MP doesn't respond or if you only hear from one of their researchers. Their researchers do a lot of their leg work.

When lobbying your MP, it is important to be persuasive, not confrontational - you want your MP to be an ally. Do not lobby on a party political basis as charity campaigning must be politically neutral i.e. try not to pit one party against another.

### Write to your MP

Writing a personal letter or email to your MP is an effective campaigning tactic. We have set out a step-by-step guide to writing your letter or email. We have also put some template letters on our Online M.E. Centre for you to personalise; research shows that a direct and personal approach gets the best result.

Steps to writing your letter or email:

1. Include your address so they know where to respond.
2. Address your MP correctly, finishing with 'MP'; are they a Dr, Mrs, Rt Hon? You can find out on the parliament website at [www.findyourmp.parliament.uk](http://www.findyourmp.parliament.uk)
3. Tell the MP who you are eg. "I am a member of your constituency and I have M.E."
4. Inform the MP about M.E. You can find information about M.E. at [www.actionforme.org.uk](http://www.actionforme.org.uk)
5. Tell them your concern and present the causes and evidence.
6. Inform them about your personal connection to the issue.
7. Inform the MP of a potential solution.

8. Let them know what you want them to do about it. Your 'ask' should be very clear and concise. For example:
  - "Please could you write to the relevant Secretary of State"
  - "I urge you to join the All Party Parliamentary Group for M.E."

You could include bullet points for more than one 'ask.'

9. Thank them for their time and consideration and let them know you would like a response. You could say "I look forward to hearing from you."

### **Arrange a meeting with your MP**

MPs hold regular surgeries so their constituents can talk to them about almost anything. Your MP might not know much about M.E. so it is a great opportunity to bring the issue onto their agenda, or even to increase their awareness.

To find out when your MP holds surgeries, contact your local constituency office. To arrange the date, it is best to send a letter or email to your MP, and ask when they are available to meet with you. If you do not receive a response in a long time, make sure to chase them up with a further email or letter.

Things to do before the meeting:

- Research your MP. What party do they belong to? Are they a minister? What Committees do they belong to? Find out information on their background and voting habits at [www.theyworkforyou.com](http://www.theyworkforyou.com)
- Read up on your campaign messages and be familiar with the arguments you want to make.
- Prepare to answer any arguments they may have against your case.

At the meeting:

- introduce yourself and summarise the reason for your meeting
- don't feel you have to cover a broad range of issues and arguments, narrow it down
- use your own words and experiences for the most powerful argument.
- don't be afraid to take notes in the meeting
- be positive and listen to what your MP has to say, but don't let them dominate the conversation (and vice versa)
- ask your MP to take action on your behalf, such as writing to Secretaries of State
- be realistic about what can be achieved; your MP won't be able to change the system overnight!

And after the meeting:

- write to thank your MP and include a summary of the key points made
- make sure you follow up on any promises made.

Action for M.E. would really appreciate it if you let us know how your campaign is progressing, including responses from MPs. This helps our campaigns team make an impact nationally. You can contact our Communications and Policy team on [policy@actionforme.org.uk](mailto:policy@actionforme.org.uk) or 0117 937 6620.

### Use the internet

The internet is a cheap and easy way to promote your campaign to a large audience, so if you or someone you know has internet access, it can be a very useful tool. You can also use the internet to ask other people to get on board.

Low energy, quick and simple tactics using the internet:

- ‘Like’ our Facebook page at [www.facebook.com/actionforme](http://www.facebook.com/actionforme) and then repost any of our posts which you find interesting.
- Follow us on Twitter at [www.twitter.com/actionforme](http://www.twitter.com/actionforme) and retweet our tweets to your followers.
- Tweet your local councillor or MP to bring M.E. to their attention. You could even include links to information about M.E. on our website.

How you can use social media for your own campaign:

- Facebook is a great way to raise awareness of your campaign and to get support. Create a Facebook page and invite everyone you know to join. You can post campaign updates and interesting information, photos, videos and more. Start a poll or discussion group to get people talking about your campaign.
- Twitter is also a quick and reliable way to post updates about your campaign and promote your concerns. Follow as many people as possible relevant to your campaign and this will encourage them to follow you. You can also add a link to your Facebook page.
- On Twitter search for terms like #MECFSS to find people talking about M.E. related topics; join in with their discussions and draw attention to your campaign, and get more followers.

Be as creative and interesting as you can when using social media so that you stand out from the crowd. Interact with your followers and campaign supporters regularly to keep them engaged.

## Organise a campaign event

An event can raise awareness of the issue of your campaign and give the opportunity for others to get involved and learn more about M.E. Ask your local M.E. group, family and friends to help organise your event.

The five 'W's are important when organising your event:

- Why are you holding the event and what do you aim to achieve? Think about a realistic goal.
- What will your event involve?
- Who are the key people involved? How many are needed? Who is your audience?
- Where will you hold your event? Think about where your audience will be and find out if you need to inform the police or get permission from your local council. Will it cost any money?
- When will your event take place? Set a date so as many people as possible can join in. Allow yourself and your helpers plenty of time to plan ahead.

Publicise your event:

- If you have access to the internet, you can promote your event through Facebook, Twitter and YouTube.
- Contact your local media to publicise your event, your campaign and M.E.
- Create posters and leaflets for your event.
- Make your event interesting and creative to capture people's attention, and to make it more fun for you!

## Spread the word

Much of your campaigning activity will naturally get people talking about M.E. and your concerns. However, there are more ways to get your voice heard and to promote your campaign, which are included in this section of the campaign guide.

## Your local newspaper

Try to get your campaign or message published in your local newspaper as it will reach a large audience and raise awareness.

Local journalists are always on the lookout for local interest stories, so don't be shy about getting in touch. Contact the newsdesk. Larger regional papers may have a specific health correspondent.

It's best to phone but it can help to have the information ready to hand, typed up in a press release, ready to email if you can.

Build good working relationships with individual journalists. Be even-handed with rival media. Keep the campaign in the public eye with follow-up events and/or photo opportunities.

Write to the "Letters to the Editor" section and encourage supporters to do the same. Try to get a debate going.

If you can communicate the 'what, when, where, who, how and why' of your event or activity, concisely, in three or four short paragraphs, under a catchy headline, you have the basis of a press release.

An outline template would be:

1. Catchy headline.
2. First paragraph summarising the key facts of your story (who, what, where, when and why) in about 50 words.
3. Second paragraph explaining a bit more about the story you have outlined.
4. Third paragraph could be a quote from you or someone central to the story, saying more about the reasons for the campaign and/or event.
5. The last paragraph should provide extra relevant information e.g. how people can get involved, get more info, or sponsor you.
6. On a new line, type the word "Ends" to indicate the end of the press release.

7. Leave a line then put your name and contact details, so that journalists can get in touch if they need more information.

8. 'Notes for editor' is an optional extra section which goes at the end, if there is further relevant detail to which a journalist can refer if they decide to write a longer article. For example, you could add a final paragraph which says: "For further information about M.E. contact Action for M.E. [www.actionforme.org.uk](http://www.actionforme.org.uk)"

### **Your local radio**

Local radio is often keen to promote local interest news, especially if there is someone they can interview for a 20-30 second soundbyte. This can be live or pre-recorded, which allows for re-takes. Try to contact the station as far in advance as possible and again the day before.

The advice in the 'Your local newspaper' section also applies to local radio. Contact the programme editor or producer.

### **Regional TV**

Remember all TV news is picture-led. Again, they will be looking for somebody to interview and for a 'case study' willing to be filmed. Broadcasters are unlikely to commit to an event more than a day in advance.

### **The internet**

Use the internet to spread the word about your campaign to a large audience. You could start a blog, using websites such as [www.blogger.com](http://www.blogger.com), create a website or use social media sites such as Facebook and Twitter to reach a larger audience. You could also make a film about M.E. or your concerns and upload it to YouTube. M.E. forums on M.E. websites may be a good place to promote your campaign to relevant people.

However you choose to use the internet, try to be creative, unique, eye-catching, interesting and informative.

### **Posters and leaflets**

It is important to make your campaign visible and to capture people's attention. Posters and leaflets are often an effective way to raise awareness of your concern.

Posters can go up in small shop windows, health shops, Doctor's surgeries, schools and colleges, and your friends and families house windows.

Leaflets can also be left in Doctor's surgeries, health shops, colleges and universities. Just make sure you ask first, as some places may not allow posters and leaflets.

You could also hand leaflets out to people in the streets. This type of campaigning is more effective if you capture a person's attention by asking them a question; making sure they know you won't sell them anything; and having a friendly conversation about your topic. It can be very tiring, so make sure you take plenty of breaks, and ask friends and families to help you.

You can download our ready-to-go M.E. awareness posters and leaflets from our Online M.E. Centre at [www.actionforme.org.uk](http://www.actionforme.org.uk)

There are helpful hints and tips for creating your own posters at [www.artskills.com/poster-help](http://www.artskills.com/poster-help)

## Your campaign's progress

Evaluating your campaign progress is an important part of the campaigning cycle, for ensuring you are always on the right track. Here are some tips:

- Keep up to date with relevant political and social news and think about how this may affect your campaign.
- Identify new opportunities.
- Record key outcomes of your campaign, e.g. Twitter followers, Facebook likes, MP responses, media coverage etc.
- Report these outcomes to your followers and supporters.
- Ask for feedback from your followers, supporters and fellow campaigners.

Evaluate your campaign:

- What impact has your campaign had so far?
- Have you got the results you wanted or expected?
- Have you tried anything that hasn't worked? Why not?
- What would you do differently or carry on doing?

## Share your achievements

We would really like to keep up to date with your campaigning progress. If you have any success stories, including responses from MPs or goals that you've reached, please let us know. We may be able to post about your campaign on our website to inspire and inform other people with M.E.

Please contact our Communications and Policy team on [policy@actionforme.org.uk](mailto:policy@actionforme.org.uk) or 0117 937 6620.

## Useful websites

Action for M.E.'s Online M.E. Centre for information and campaigning resources  
[www.actionforme.org.uk](http://www.actionforme.org.uk)

Find out about your local MP, their background and whether they are on a Committee  
[www.parliament.uk](http://www.parliament.uk)

Find your local MP  
[www.findyourmp.parliament.uk](http://www.findyourmp.parliament.uk)

Find out background information about your local MP  
[www.theyworkforyou.com](http://www.theyworkforyou.com)

Find your local radio stations  
[www.radio-now.co.uk](http://www.radio-now.co.uk)

Find your local media  
[www.newspapersoc.org.uk](http://www.newspapersoc.org.uk)

Disability campaigning organisation  
[www.disabilityrightsuk.org](http://www.disabilityrightsuk.org)

Support and resources for e-campaigning  
[www.louder.org.uk](http://www.louder.org.uk)

Sheila McKechnie Foundation, set up to inform, connect and support campaigners  
[www.smk.org.uk](http://www.smk.org.uk)

## Checklist

### Low energy

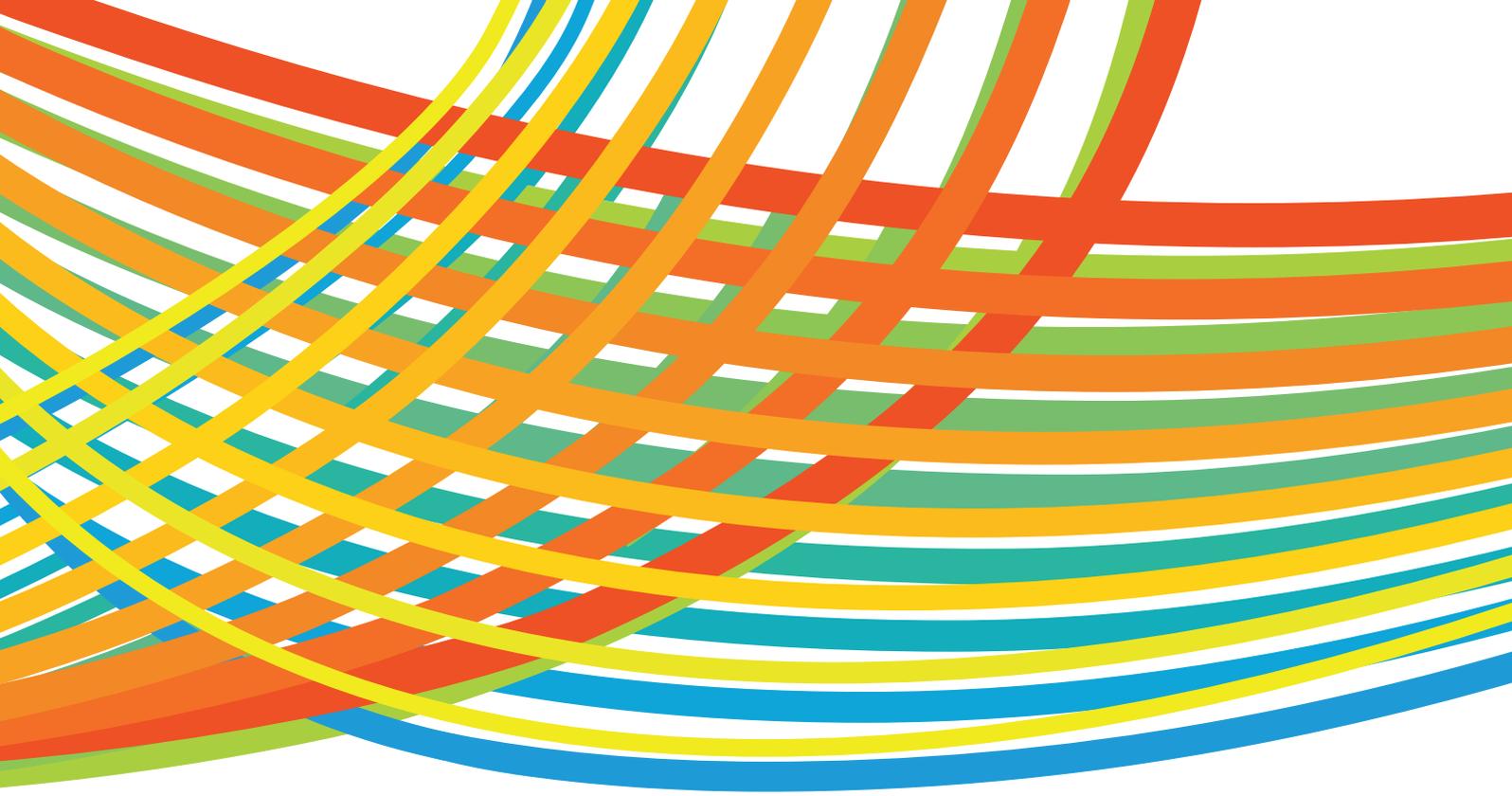
- Follow and retweet Action for M.E.
- Tweet your MP and councillor
- 'Like' Action for M.E.'s Facebook page and share our campaign posts
- Download our poster to put in your house window
- Write a letter to your MP or use our template letters

### Your campaign

- Create a twitter account for your campaign and follow people
- Create a Facebook page for your campaign
- Make a YouTube video for your campaign
- Arrange a meeting with your MP/Local councillor
- Organise an event

### Spread the word

- Write a press release
- Contact local journalists, including print, radio and T.V.
- Put up posters
- Hand out leaflets
- Use the internet
- Join discussion forums
- Share your achievements



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