



Campaign toolkit for M.E. in Scotland



Foreword

To successfully overcome the challenges that people with M.E. face, influencing key people in local communities, decision-makers, policy makers and politicians is vital.

No one individual or charity can achieve this on their own. Working with people with M.E., we have developed this toolkit with ideas and templates that can support individuals and groups to campaign locally.

The idea came out of discussions at Action for M.E.'s open meetings in Glasgow and Lockerbie in October 2014. Developing the toolkit was one of six key activities taken forward from the meetings as part of our *Hear me, influence M.E.* project, funded by a Big Lottery, Awards for All Scotland grant. We are very grateful to the Big Lottery for funding this work and enabling us to realise the ideas raised during the meetings.

People participating told us about local issues they'd like to address but also said they were already stretched sustaining local support networks. Some people with M.E. told us that knowing where to start or having something to work with would be of real benefit. Others with more campaigning experience said they'd like a resource bringing together key information about M.E. and services in Scotland for easy reference.

The result is this toolkit, which caters for a range of needs, and takes into account different levels of experience.

The more local influencing and campaigning work that takes place, the louder the voice; the stronger the voice, the faster and greater the likelihood that, together, we can achieve positive change.

Please use the ideas and templates, adapting them in whatever way you wish to support you to add your voice. And don't forget, please do let me and the Action for M.E. team know what you think, how you have used the toolkit and what difference it's made. I wish you great success.



Sonya Chowdhury
Chief Executive
Action for M.E.

Contents

Introduction	4
Campaigning: what is campaigning and why is it important?	5
Tool one: Target decision makers	7
The Scottish Government	7
NHS Scotland	12
Welfare and social care	15
Tool two: Use the media	16
Online media	16
Traditional media	18
Tool three: Community engagement	19
Tool four: Be creative	22
Resources	24
Campaign checklist	28
Appendix: template letter to MSP	29

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Introduction

If you are reading this you likely have M.E. or care about someone who has M.E., and want to campaign to help them secure the care and support they need. Thank you.

Action for M.E.

Action for M.E. is an organisation led by people with M.E., for people with M.E. Our mission is empowering people with M.E. to fulfil their potential and secure the care and support they need, while working towards a greater understanding of the illness and ultimately a cure.

What is M.E.?

M.E. (Myalgic Encephalomyelitis) affects an estimated 250,000 men, women and children in the UK, including 20,000 in Scotland.

A key symptom is post-exertional malaise. A period of intense exhaustion can typically take a day or two to kick in following physical or mental activities. Additional symptoms may include muscle and joint pain, sleep disturbance, problems with concentration, thinking and memory, problems with the nervous system, digestive difficulties and increased sensitivity to light and sound. M.E. affects different people in different ways and symptoms can fluctuate and change over time.

M.E. is defined by the World Health Organisation as a neurological condition. It may be diagnosed as Chronic Fatigue Syndrome (CFS) or Post Viral Fatigue Syndrome (PVFS). This should not be confused with chronic fatigue, which is a common symptom of many conditions.

About this guide

This toolkit is designed to cover the basic needs of those campaigning at all levels from organising local community events to writing to your MSP. Due to the nature of M.E., many people are too unwell to become involved in traditional campaigning activities. However, we find that direct contact with MSPs from constituents is the best way to achieve a real impact.

As the internet continues to evolve it is providing greater access to information and increasing the ability of those with M.E., their families and friends to participate.

Campaigning

What is campaigning?

Campaigning is the act of trying to influence decision-makers, so they can create change that improves peoples' lives and leads to a better society. Campaigning can take many forms, from contacting your MSP, to raising awareness at events and demonstrations, to online campaigning and publicity stunts. Ultimately, these are all ways of achieving the same thing – empowering people with M.E.

If you have ever worn a red ribbon on World Aids Day, had a chat with your friends about climate change or added Fairtrade tea to your shopping list, then you are already a campaigner.

Why is it important to campaign?

Campaigners want to change practices, policies, attitudes or even beliefs. They believe a different world is possible. Your actions can change the lives of people with M.E.

We understand that many people with M.E. are often too unwell to take part in high-energy action, so this guide also focuses on low-energy activities. We will show that every action, big or small, can make a difference. No experience is necessary.

Most importantly, people campaign because it works.

Change can only occur when people believe that lives can be transformed and their voices heard. By contributing to a campaign, you will be part of the collective effort to change the lives of people with M.E.

What does a successful campaign look like?

At the start of 2015 the Scottish First Minister Nicola Sturgeon announced that the Scottish Government would double the number of NHS nurses specialising in Motor Neurone Disease (MND). This decision was directly influenced by Scot Gordon Aikman, who has MND, and his powerful campaign *Gordon's fightback* (www.gordonsfightback.com), to improve care and treatment for people with MND in Scotland.

The combination of his persuasively told personal story, the backing of national charity MND Scotland, strategic use of the internet and effective use of opportunities to communicate key messages to decision-makers achieved remarkable success in a short time frame.

What can I do?

You can add your voice to the growing call for change in support and care for people with M.E. For example, you could campaign by sending a tweet, an email or a letter to your MSP, local councillor or Health Board. You could also spread the word on the internet. There are many things you can do to push for change, either as an

individual or a group. If you have M.E and are too unwell to campaign or lobby, getting your friends and family to help is a great way to contribute.

Persistence and patience will make all the difference.

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.

What do I want to achieve?

You must first identify the issue (or issues) that will be the core motivation of your campaign. What significant thing do you want to change or raise awareness about? You'll need a clear key message to get across to as many people as possible.

For example, your own campaign could be about:

- lack of specialist NHS M.E. services in your area
- GPs lacking a proper understanding of M.E.
- lack of access to social care support for people with M.E.
- fragmented health and care services
- cuts to welfare benefits causing financial problems for people with M.E.
- not enough investment in M.E. research
- the need for specialist education and employment support
- urgent care needed for those with severe M.E.

How will I achieve it?

It is important to think about how your problem could be solved. Whether it is a short-term or long term goal, you should aim for something that is achievable. The grid below can be used to brainstorm ideas, with an example to show how this might work.

Issue	Goal	Solutions
GP lacks knowledge of M.E.	Better informed GPs	Contact health board
		Distribute leaflets to GPs
		Deliver GP training sessions

How will I know I've succeeded?

Evaluating your campaigns progress is important for ensuring you are always on the right track. You should

- keep up to date with relevant political and social news and how it may affect your campaign; it can help you to identify new opportunities, too
- record key outcomes of your campaign, eg. Twitter followers, Facebook likes, MSP responses, media coverage
- report these outcomes to your followers and supporters
- ask for feedback from your followers, supporters and fellow campaigners.

Tool one: Target decision makers

Whether they're your elected MSP or health board member, decision makers are the gatekeepers to change.

You, family and friends, local support groups and the general public are the key that can open these doors to change.

The rights of people with M.E.

In Scotland people with M.E. have health and social care, disability and wider human rights which have been written in law to support them. This can be vital information to use when influencing decision-makers.

See the resources section on p 24 for a list of organisations and legislation you can refer to.

Who should I target?

What we know as 'the system' is actually made up of varying organisations of different shapes and sizes. They often do not share information, have different priorities and are constantly evolving. This is exacerbated by current budget pressures.

Don't be put off by any delays or by someone you encounter who is not very helpful. In the next chapters we detail information about the most likely organisations you will contact, followed by their key decision makers and guidance on how to contact them.

The Scottish Government

Under the Scotland Act of 1988 that established the Scottish Government, law-making powers for health, social care, housing and education policies were devolved to Holyrood.

This means that local social work departments and health boards are ultimately accountable to the Scottish Government. Local Authorities themselves negotiate with the Government collectively through the Convention of Scottish Local Authorities (COSLA). Because COSLA is the collective voice for all local authorities in Scotland, it is also a significant player in social care policy in Scotland.

The key decision makers you should contact are:

- the Scottish Government First Minister
- Scottish Government Ministers with responsibility for an area relating to your campaign eg. Minister for public health
- Opposition spokesperson for an area relating to your campaign
- Leaders of opposition parties
- your local Member of the Scottish Parliament (MSP).

Main political parties in Scotland include:

- Scottish National Party
- Scottish Labour Party
- Scottish Liberal Democrats
- Scottish Conservative Party
- Scottish Greens.

It is best to contact parliamentarians in writing in the form of a letter or email. You should provide summary background information on M.E. and give clear, concise details explaining exactly what you are looking for from the parliamentarian.

As time is a major factor for MSPs it will be easier to get them on board if they can see exactly what is required up front. Writing a letter also requires them to write a formal response to you.

Everyone in Scotland is represented by eight MSPs: one for their constituency and seven for the larger region in which they live. You can decide which of these eight MSPs you would prefer to contact. For example, you may wish to contact an MSP from a particular party or one you have heard of locally.

For more information on who your local MSPs are, MSP interests, questions asked in Parliament and committees they sit on, visit www.scottish.parliament.uk/msps

How to write to your MSP

We have produced a template letter (see p 29) and some simple guidelines to get you started:

- 1 Include your address so they know where to respond.
- 2 Address your MSP correctly, ending with 'MSP' after their name, eg. Joe Bloggs MSP. Are they a Mr, Mrs or Dr?
- 3 Tell the MSP who you are, eg. "I am a member of your constituency and I have M.E."
- 4 Inform the MSP about M.E. You probably have a lot to say about your own experience but it is best to keep it short so that the MP is more likely to take what you say on board. You can find information about M.E. at www.actionforme.org.uk or call us on 0117 927 9551
- 5 Tell them your specific concern and present the causes and/or evidence. What is your personal connection to it?
- 6 Suggest a potential solution.
- 7 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 Cabinet Secretary?"
- 8 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."

Meeting your MSP

If all goes well, you could have a meeting set up with your MSP. You should:

- have a simple set of goals that you wish to achieve when you meet them, as your time will be limited
- always ask them for a quick and easy action that demonstrates their support, such as a signature on a petition or pledge, or being photographed
- ask whether the MSP could ask a Parliamentary question on the issue for you; this is a way of getting a written or oral response from the Scottish Government in Parliament.

Ideally, you are trying to build a partnership with your MSP. It is important to be persuasive but not confrontational, as you want them to be an ally. Most MSPs will be happy to talk to you, but don't be disappointed if they don't respond or if you only hear from one of their researchers. Their researchers do a lot of their leg work.

Research your MSP:

- Are they your local MSP? Check first on www.theyworkforyou.com
- What party do they belong to? Are they a minister?
- What committees do they belong to?
- Find out information on their voting habits at www.theyworkforyou.com
- Read up on the campaign messages you want to make.
- Prepare to answer any arguments they may have against your case.

During the meeting:

- introduce yourself and summarise the reason for your meeting
- be positive and listen to your MSP
- use specific facts to support your argument
- use your own words and experiences for the most powerful argument
- don't be afraid to take notes in the meeting
- ask your MSP to take action on your behalf, such as writing to the Cabinet Secretary
- be realistic about what you ask your MSP.

After the meeting:

- write to thank your MSP and include a summary of the key points made
- make sure you follow up on any promises you made, eg. sending them some specific information.

Submit a petition to Parliament

You can submit a petition to Parliament with at least one signature (more is better) to raise an issue with your elected representatives in Parliament. It will be considered by the Public Petitions Committee, who meet fortnightly and decide if it can be taken forward. Sometimes they may ask for oral evidence as well.

To submit a petition online and more information visit
www.scottish.parliament.uk/gettinginvolved/petitions/HowToPetition.aspx

Scottish Parliamentary Questions and motions for debate

Parliamentary questions can be asked by any MSP to the Scottish Government. The questions provide a means for MSPs to obtain factual and statistical information from the Scottish Government. Parliamentary questions can be in oral or written form. Oral questions are answered at Question Time and First Minister's Question Time.

Motions are used by MSPs as a device to initiate debate or propose a course of action in Parliament. Other MSPs can sign up in support of motions that have been lodged. Visit www.scottish.parliament.uk/parliamentarybusiness/32115.aspx

Parliamentary reception

Your MSP can sponsor a Parliamentary reception. These events provide a platform in which to speak to and discuss your issue in front of invited MSPs.

Organising a reception is a big undertaking and can be expensive if you wish to provide refreshments for your guests. Action for M.E. usually organises a Parliamentary event during M.E. Awareness week in May, in partnership with other individuals and organisations. Please contact us (see p 30) if you would like to explore opportunities for linking your campaign in with the event.

If you do wish to organise your own parliamentary reception, things to consider include:

- a photo opportunity, which helps attract MSPs, as the image can be sent to the press to highlight their work
- timing: it's best to avoid the times that Parliament is sitting as you will limit the number of parliamentarians able to attend
- do not expect MSPs to be able to be at the event for a long time and be flexible as they may be delayed
- it's best to avoid times near elections as MSPs will be devoting their diaries to political campaigning

Parliament also hosts themed exhibitions of artwork, photography and other displays periodically.

To set up an event or exhibition you need an MSP to formally sponsor you, then contact the Events and Exhibition team at the Scottish Parliament on 0131 348 6933 or email eventsandexhibitions@scottish.parliament.uk

Freedom of information (FOI) requests

The Freedom of Information (Scotland) Act 2002 gives you the right to ask for information from a Scottish public authority. You can use this to find out information to support your campaign.

FOI requests are most effective if used sparingly and when the information cannot be obtained by other means. A lot of information is already available through public bodies or may be voluntarily supplied on request, so it's worth checking first. You may get more information through less formal routes.

If you do make a FOI request, be courteous and to the point. Be aware that your request may be handled by someone whose expertise is in FOI requirements rather than by the person who knows most about the subject area. For further information visit www.itspublicknowledge.info/YourRights/WhatAreMyRights.aspx

NHS Scotland

Legislation about the NHS is made by the Scottish Parliament. The Cabinet Secretary for Health and Wellbeing has ministerial responsibility in the Scottish Cabinet for the NHS in Scotland and has a budget of approximately £11.9 billion at the time of writing.

The Scottish Government sets national objectives for the NHS which are directed to the 14 NHS Boards in Scotland. NHS Boards plan, commission and deliver NHS services and take overall responsibility for the health of their populations.

This includes hospital and community health services such as GPs, dentists, community pharmacists and opticians. Local Health Boards are supported by a number of non-geographical Special Health Boards (see p 13) providing national services.

See p 14 for information about Local Community Health Partnerships (CHPs),

NHS Health Boards

To find your local health board, and its website and contact details, visit www.nhsinform.co.uk/nhs-in-your-area

If the issue you want to raise is relevant across the Health Board, write to the Chief Executive: their contact details can be found on the relevant health board website.

Try and use NHS language to communicate with NHS Boards. You can refer to current strategic planning and guidance available on their websites. For example, if campaigning on the lack of specialist M.E. services in your area, you may wish to refer to care pathways for M.E. patients and relate what you know is happening in practise to any existing planning documents or guidance for professionals.

Special NHS Boards

Special NHS Board	Aim and purpose	Website
NHS Education for Scotland	Ensures that patients and their families get the best healthcare possible from a well-trained and educated staff	www.nes.scot.nhs.uk
NHS Health Scotland	Promotes ways to improve the health of the population and reduce health inequalities	www.healthscotland.com
NHS Inform	A national health information service providing quality controlled health information to the public. Provides information on health services in Scotland, how to make a complaint and patient rights	www.nhsinform.co.uk/rights/usingnhs
NHS 24	Service providing health advice and information 24/7 via its website and helpline	www.nhs24.com/
Healthcare Improvement Scotland	Responsible for overseeing the quality and safety of healthcare. Aims to ensure the delivery of high quality, person-centred care	www.healthcareimprovementscotland.org
NHS National Waiting Times Centre	Aims to ensure prompt access to treatment	www.nhsgoldenjubilee.co.uk

Local Community Health Partnerships (CHPs)

There are 34 CHPs in Scotland (www.chp.scot.nhs.uk), covering the 14 NHS Health Boards and 32 local councils. A CHP is a committee which develops local community health services in partnership with local authority partners. Their main purpose is to ensure that primary and community health and social care services are fully integrated.

In some areas, CHPs are called Community Health and Care Partnerships (CHCPs) and Community Health and Social Care Partnerships (CHSCPs). There is no single CHP model and each CHP has a degree of freedom to develop as required to meet local needs.

The Scottish Government has highlighted the importance of involving local people within the work and services managed by the CHPs. Local communities, voluntary sector representatives, patients and carers are able to be kept informed and get involved in CHP work on local health and social care issues through Public Partnership Forums (PPFs). A list of PPF contact details can be found on the Scottish Health Council's website (www.scottishhealthcouncil.org).

Current national priorities for CHPs are:

- better access to Primary Care Services
- taking a systematic approach to long term conditions
- anticipatory care
- supporting people at home
- preventing avoidable hospital admissions
- more local diagnosis and treatment
- enabling discharge and rehabilitation
- improving specific health outcomes
- improving health and tackling inequalities.

There is also an umbrella organisation, the Association of Community Health Partnerships (ACHP) in Scotland (www.achp.scot.nhs.uk).

Welfare and social care

Department for Work and Pensions (DWP)

At the time of writing, the Department for Work and Pensions (DWP) in Westminster is responsible for welfare, pensions and child maintenance policy. It administers the state pension and a range of working age, disability and ill health benefits.

You can write to:

- Secretary of State for Work and Pensions
- Minister of State for Disabled People
- Minister of State for Employment.

Further information can be found at:

www.gov.uk/government/organisations/department-for-work-pensions

NB: It is expected that the Scottish Government will take over responsibility in Scotland from DWP for Disability Living Allowance, Personal Independence Payments, Carer's Allowance, Attendance Allowance and Severe Disablement Allowance in 2017. For details see www.smith-commission.scot

Local social care services

Your local council is responsible for providing care needs assessments, special equipment and homecare. It also runs services such as supported accommodation and housing services, and administers the council tax reduction scheme, housing benefit and the Scottish Welfare Fund for individuals in financial difficulties (www.gov.scot/Topics/People/welfarereform/scottishwelfarefund).

Local councils can also provide support for carers, including respite care.

Welfare Reform Committee

The Scottish Parliament Welfare Reform Committee was established in January 2012. The committee's role is to keep under review the passage of the UK Welfare Reform Act 2012 and monitor its implementation as it affects welfare provision in Scotland and to consider relevant Scottish legislation.

You can contact the committee Clerk on 0131 348 5228 or by email at WelfareReformCommittee@scottish.parliament.uk

Tool two: Use the media

Action for M.E. is always looking for people who are willing to become media case studies. This means speaking to a journalist about your experience of M.E., and it's a brilliant way to raise awareness of the condition.

If you would like to be a media case study for us, we ask you to fill out a media case study questionnaire and send us a photo. We can then use this to write a press release and ask journalists if they are interested in your story.

We won't give out your name and contact details to any journalist until you give us permission, and we can talk you through the sort of questions they'll ask so you feel well prepared.

Interested? You can complete a media case study questionnaire on our website or contact us for a paper copy.

Promoting your campaign

If you are promoting a specific campaign, you can promote it using online and traditional media.

With the power of the internet at your fingertips, it is now even easier to become an online activist. It is also cheap, a low energy activity and a great way to promote your campaign to a large audience.

Online media

Facebook (www.facebook.com) provides a free, ready-made platform to publicise your campaign.

If you are new to Facebook, setting up a profile is really easy: just follow the simple steps from the homepage.

If you are already using Facebook, you can set up a group or event page to post details of upcoming campaign events and activities, including uploading photographs, videos and links to relevant news articles, websites and blogs. Remember to ask people's permission if you wish to post photographs or films of them online.

Use Facebook to share information, contacts and networks that could benefit your campaign. Simple ideas include:

- like Action for M.E.'s Facebook page at www.facebook.com/actionforme
- like, share and comment on posts by Action for M.E. and other relevant groups
- ask people on your own event or group page their opinion on something: people love to discuss and debate online
- start a poll to get people talking about your campaign
- don't just use words: pictures, cartoons, info-graphics and films, including links to YouTube, can really boost your interactions.

Twitter is an online social networking service that enables users to send and read short 140-character messages called tweets. You can tweet up-to-the-minute updates of your campaign to your supporters, including sharing images and video content.

Simple ideas include:

- follow Action for M.E. on Twitter at www.twitter.com/actionforme and retweet our tweets to your followers
- target specific organisations, celebrities or groups that share your campaigns aims
- tweet your local councillor or MSP to bring M.E. to their attention; you could include links to information about M.E. from www.actionforme.org.uk
- use a hashtag specifically for your campaign, eg. #MEaware
- add a link to your Facebook page so people can access more content
- search for hashtags such as #MECFS or #chronicillness to find people talking about M.E.-related topics; join in with their discussions and draw attention to your campaign, and get more followers.

Other social networks

Other social networking sites you might wish to explore include:

- YouTube (www.youtube.com) is a video sharing website that you can link to from Facebook, Twitter or your own blog (see below). For example, you could share an awareness-raising film from Action for M.E.'s YouTube channel (www.tinyurl.com/actionformeyoutube)
- Tumblr (www.tumblr.com), which attracts a younger demographic who post images and ideas: good for awareness raising
- LinkedIn (www.linkedin.com) for business and professional networking
- Instagram (www.instagram.com) for sharing images and video with comments
- Flickr (www.flickr.com) for sharing images.

Blogging

A blog is a discussion site you create, where you can write articles that followers can read and comment on. Use free resources such as www.blogger.com or www.typepad.com to set up your own blog site.

Remember to post links to your blog on Facebook and Twitter, if you're using them. Use blogs as a way to write about your campaign events and activities. Also 'tag' key words in your blog to maximise the chances of people finding it online.

Traditional media

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. 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 as a press release (see below) and ready to email. Build good working relationships with individual journalists and be even-handed with rival media. Keep the campaign in the public eye with follow-up events and/or photo opportunities.

You could also try writing to the "Letters to the Editor" section and encourage supporters to do the same to get a debate going.

Find your local newspaper at www.newspapersoc.org.uk

Local radio and TV

Local radio is often keen to promote local interest stories, especially if there is someone they can interview for a 20-30 second sound bite. 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. Contact the programme editor or producer.

Stations like STV Edinburgh (www.edinburgh.stv.tv) have just started, so this is a good time to engage with local television. 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. Contact the programme editor or producer.

Find your local radio stations at www.radio-now.co.uk

Writing a short press release

- 1 Start with a catchy headline
- 2 The first paragraph should summarise the key facts of your story (who, what, where, when and why) in about 50 words: make sure you mention the local connection.
- 3 In the second paragraph, explain a bit more about the story you have outlined.
- 4 The 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 eg. 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.

Tool three: Community engagement

To raise awareness of M.E. and your campaign, reaching a wider audience in your local community is vital. The following ideas are simple ways to broaden your reach.

Campaign stall

This is a simple but effective way to talk face-to-face with members of the public, and introduce new people to M.E. Stalls are easy to plan and don't need large numbers of volunteers to set up. They can be used as an area to collect signatures, showcase your campaign or start a discussion.

Good locations include a town centre, local event or festival and shopping centres. Check you have permission from the land/premises owner or manager. For public spaces, your local Council can advise you about any regulatory requirements.

It is important to seek permission/advice in advance if you intend to set up a very large stall, sell goods to raise money or serve any kind of food or drink as you may need a license and/or insurance for some activities. You will always need to ask permission to use an indoor venue.

Don't let this put you off – shopping centres often give their permission for local charitable groups to set up stalls and have been used by local M.E. support groups during M.E. Awareness Week (see p 21).

Think about what kind of people will go through the area. Are they commuters or shoppers? Areas which are too busy are not suitable. You want a spot with enough people passing by, but quiet enough so they can notice you, stop and engage with you.

Also consider whether you can manage an outdoor stall or will need to be indoors if the weather is poor. Be prepared to answer general questions, refer people to the website if needed and always offer people the chance to get more involved.

Organise a local campaign event

An event can raise awareness of your campaign and give the opportunity for others to get involved and learn more about M.E.

Ask your local M.E. support group, family and friends to help organise your event. Tell Action for M.E. about your plans and we can help publicise your event through our news channels.

Allow yourself and your helpers plenty of time to plan ahead. Make your event interesting and creative to capture people's attention – and make it more fun for you.

The five W-words are important when organising your event:

- 1 Why are you holding the event and what do you aim to achieve? Think about a realistic goal.
- 2 What will your event involve?
- 3 Who are the key people involved? How many are needed? Who is your audience?
- 4 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?
- 5 When will your event take place? Set a date so as many people as possible can join in.

Publicise your event:

- promote your event online through social media (see p 16)
- contact local media (see p 18) to publicise your campaign and raise awareness of the issues
- create posters and leaflets (see below) for your event.

Posters and leaflets

Posters and leaflets are an effective way to raise awareness of your campaign. Posters can go up in small shop windows, health shops, doctor's surgeries, and your friends and family members' 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 or leaflets.

You could also hand leaflets out to people in the street. 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 family to help you.

You can download our M.E. awareness posters and leaflets to use from our Online M.E. Centre at www.actionforme.org.uk – just look in the 'Publications' section.

Family and friends

Action for M.E.'s *M.E. Time to deliver* report (www.actionforme.org.uk/timetodeliver) found that 84% of people with M.E. are cared for by a family member and the condition clearly has a big impact on their lives as well.

If you are a relative of someone with M.E., or a friend, your help with all aspects of campaigning is vital both in terms of supporting the person with M.E., but also using your own stories and situation to tell others about the wider impact of M.E.

Local support groups

Local M.E. support groups can be an invaluable source of information. They are run by volunteers, with many having M.E. themselves. To find local support groups go to: www.actionforme.org.uk/services-directory

M.E. Awareness Month

Action for M.E. supports international M.E. Awareness Month, which takes place in May each year. International M.E. Awareness Day is 12 May, and M.E. Awareness Week is the Sunday to Saturday that includes 12 May.

This can be a good time to have your campaign beginning or ending, as media and political awareness of the illness is heightened.

Tool four: Be creative

Advertising and promoting your campaign is the key to attracting new supporters and growing awareness of your campaign, but there are many worthwhile campaigns all competing for attention. Be creative to stand out from the crowd.

New technology

Cameras, videos and mobile phones are changing the way we campaign online. The days of heavy camcorders are over. Now just using your mobile phone you can become a filmmaker or photographer.

Short and simple ideas include:

- record some quick interviews on your mobile phone with people who are campaigning with you or attended your event.
- record short films showing how much you are getting out of campaigning.
- film a short, simple and powerful 15 second message to supporters.
- check out existing online campaigns for ideas.

Videos can be easily uploaded onto Facebook, Twitter, YouTube, Tumblr and other sites. Most computers, cameras and mobile phones come with simple editing software.

You can see examples of campaigning videos made by Action for M.E. at www.tinyurl.com/actionformeyoutube

Digital storytelling

Professional storyteller Michael Williams says everyone has a story to tell, but others don't always listen. Action for M.E. has worked with him to help people with M.E. make short films about their experience of M.E., which were screened at the Scottish Storytelling Centre during M.E. Awareness Week 2014.

You can watch these films at www.tinyurl.com/MEstorytelling and have a go at making your own by using Action for M.E.'s storytelling toolkit.

This provides a step-by-step guide to telling your own M.E. story simply, affordably and effectively. The toolkit guides you through the process of making your own digital films, outlining what equipment you need, how best to use it and providing tips on film-making.

The toolkit is designed to enable people affected by M.E. to work at their own pace while managing their symptoms. Read and/or download it at www.actionforme.org.uk/digitalstorytelling

Writing and other creative approaches

Some people with M.E. find sharing their story through poetry, traditional prose or online personal blogs helps them come to terms with living with the illness. It can also be a great way of reaching out to others and illustrating the realities of the condition in your campaign.

Visit the following webpages for a few (of many) examples:

- search for 'Poetry corner' at www.actionforme.org.uk
- www.severeme.info
- www.samandme.org

Other creative approaches can include using photography, art work, comedy or drama.

Whatever approach you choose, the important thing is that you are able convey your message effectively and that it captures people's interest and makes them want to engage with your campaign.

Resources

Action for M.E. would really like to keep up-to-date with your campaign's progress. If you have any success stories, including responses from MSPs or goals that you've reached, please let us know.

We can post about your campaign on our website and in our Scottish Hub newsletter to inspire and inform other people with M.E.

If you would like to use the Action for M.E. logo on your campaign, please contact our Communications and Policy and Campaigns Officer on 0117 937 6620 or by email at policy@actionforme.org.uk

Key facts

As M.E. diagnoses are not consistently recorded, the following statistics are commonly used estimates:

- 250,000 people in UK have M.E.
- this includes 20,000 people in Scotland
- 25% of patients are severely affected (housebound or bedbound)

Our [M.E. Time to deliver in Scotland](http://www.actionforme.org.uk/timetodeliver) (www.actionforme.org.uk/timetodeliver) report presents key findings from the people with M.E./CFS in Scotland (out of 2,081 total UK respondents) who took part in Action for M.E.'s 2014 health, welfare, employment and education survey. The report found that:

- 31% of people with M.E./CFS in Scotland hadn't seen their GP in the past year
- 74% said having a better informed GP would make a real difference to their healthcare
- 73% had not attended a specialist M.E./CFS clinic in the past five years
- 81% not had a social care assessment in the past five years.

Health and social care

The purpose of the 2010 [Scottish Good Practice Statement on ME-CFS](http://www.show.scot.nhs.uk/GoodPracticeStatementonME-CFSforGeneralPractitioners.aspx) (www.show.scot.nhs.uk/GoodPracticeStatementonME-CFSforGeneralPractitioners.aspx) is to provide GPs with guidance on differential diagnosis and clinical management of M.E.

Building on the Good Practice Statement, Action for M.E. produced its booklet [Managing ME-CFS: a guide for GPs in Scotland](#) (Tel: 0117 927 9551. www.actionforme.org.uk) in 2014. Copies were distributed to each GP practice in Scotland.

The Scottish Public Health Network published a [Healthcare Needs Assessment](#) (www.scotphn.net/projects/previous_projects/care_needs_for_those_experiencing_me_cfs) of people with M.E. in Scotland in 2010. This is a useful source of evidence of need at local and national level. You may also wish to refer to the report's recommendations for service development.

All GPs in Scotland must be registered with the [General Medical Council \(GMC\) Scotland](http://www.gmc-uk.org) (Tel: 0131 525 8700. www.gmc-uk.org). It oversees medical training and set standards that doctors must follow. The GMC website contains guidance on what you can expect from your GP and on making a complaint.

[Social Care and Social Work Improvement Scotland](http://www.scswis.com) (Tel: 0345 600 9527. www.scswis.com) is responsible for regulating social services, and ensuring that people receive high quality care and ensure that services promote and protect their rights.

[Healthcare Improvement Scotland](http://www.healthcareimprovementscotland.org) (Tel: 0131 623 4300 or 0141 225 6999. www.healthcareimprovementscotland.org) supports and empowers people to have an informed voice in managing their own care and shaping how services are designed and delivered

The [National Health and Wellbeing Outcomes Framework](http://www.gov.scot/Publications/2015/02/9966/downloads) (www.gov.scot/Publications/2015/02/9966/downloads) sets out the outcomes integrated health and social services should be striving for, with a focus on individual needs.

The Neurological Alliance of Scotland's 2011 [health service experience survey](http://www.scottishneurological.org.uk/content/res/NAS_Health_Experience_Survey_Report.pdf) (www.scottishneurological.org.uk/content/res/NAS_Health_Experience_Survey_Report.pdf) shows a contrast between the experiences of M.E. patients and those with other neurological conditions.

Published in 2009 by local support group Edmesh, [Believe in M.E.](http://www.nhslothian.scot.nhs.uk/MediaCentre/Publications/SupportAndAdvice/Documents/BelieveInME.pdf) (www.nhslothian.scot.nhs.uk/MediaCentre/Publications/SupportAndAdvice/Documents/BelieveInME.pdf) reports on the experiences of patients using M.E./CFS services in Lothian. It was reported on by STV news (www.news.stv.tv/scotland/97393-nhs-lothian-to-improve-service-for-me-patients)

For further NHS Scotland national information, statistics and publications
www.healthscotland.com (Tel: 0141 414 2762)
www.show.scot.nhs.uk (Tel: 0131 275 6665)

For information about Scottish Government publications and public consultations
www.gov.scot (Tel: 0300 244 4000)

Severe M.E.

You could link to Action for M.E.'s film [My life is over: the pain of severe M.E.](http://www.tinyurl.com/painofsevereME) (www.tinyurl.com/painofsevereME) on your social media site, or share our 2014 report, "[My life stopped...](http://www.actionforme.org.uk)" (Tel: 0117 927 9551. www.actionforme.org.uk)

Public screenings of severe M.E. documentary [Voices from the shadows](http://www.voicesfromtheshadowsfilm.co.uk) (www.voicesfromtheshadowsfilm.co.uk) have been organised by local groups and individuals around the UK.

Welfare benefits

In January 2015, leaders of the main political parties formally agreed in broad terms the **Smith Commission** (www.smith-commission.scot) plans for the devolution of welfare powers to the Scottish Parliament.

Under these plans, the Scottish Government is set to take over full responsibility for some, though not all, benefits, and will also have discretionary powers to create new benefits. The full legislation required to take forward this further devolution of powers will be developed by the new UK government after the May 2015 election.

Carers

Carers Scotland (Tel: 0800 808 7777. www.carersuk.org/scotland) offers information and support for carers, and campaigns on policy issues affecting carers.

Scotland's carers: statistical report for Scotland (www.gov.scot/Resource/0047/00473691.pdf), published in March 2015, brings together statistical analysis and research on caring.

Support and signposting

Citizens Advice Scotland (Tel: 0808 800 9060. www.adviceguide.org.uk/scotland) offers free, confidential, face-to-face advice on everything from consumer rights to welfare benefit payments. They run the national Patient Advice and Support Service for NHS service users in Scotland through their network of local offices. Appointments need to be booked in advance as early as possible as waiting times can be long.

The rights of people with M.E.

The **Equality Act 2010** (www.equalityhumanrights.com/legal-and-policy/legislation/equality-act-2010/what-equality-act) is a wide-ranging piece of legislation that brings together equalities related legislation under one Act, including protection from discrimination due to disability caused by long term health conditions.

The **Scottish Human Rights Commission** (Tel: 0131 240 2989. www.scottishhumanrights.com) is responsible for promoting and protecting human rights for everyone in Scotland.

The **United Nations convention on the rights of people with disabilities** (www.un.org/disabilities/convention/conventionfull) sets out in detail the rights of persons with disabilities and how to promote policies and laws which change the perception of disability and ultimately stop discrimination.

Patients' Rights (Scotland) Act 2011 (www.gov.scot/Topics/Health/Policy/Patients-Rights) gives a right to patients to have their needs considered and for them to take part in discussions about their health and wellbeing. It also provides patients the right to give feedback on the healthcare they have received.

MSPs and parliamentary activities

Find out about your local MSP, their activities and Committee work at www.scottish.parliament.uk/msps.aspx

Find out background information about your local MSP at www.theyworkforyou.com

Campaign support

Action for M.E. (Tel: 0117 927 9551. www.actionforme.org.uk) produces awareness-raising posters and leaflets, plus has lots of information about M.E. and its impact that you could use in your campaign.

The **Sheila McKechnie Foundation** (Tel: 020 7697 4040. www.smk.org.uk) supports campaigners who are new to campaigning, are marginalised, have few resources and cannot get the support they need elsewhere.

Scottish Council for Voluntary Organisations (Tel: 0131 474 8000. www.scvo.org.uk) is a membership organisation for around 1,500 Scottish charities, voluntary organisations and social enterprises. Its website is a good source of information about the practicalities of creating a formal organisation and on issues such as insurance required for events.

Health and Social Care Alliance Scotland, known as the ALLIANCE (Tel: 0141 404 0231. www.alliance-scotland.org.uk) is the national umbrella organisation for more than 900 health and social care organisations, including small, volunteer-led groups and individuals who are disabled, living with long term conditions or providing unpaid care. Members are invited to share information about their activities, campaigns and events.

A smaller membership organisation with a similar remit to the ALLIANCE, **Voluntary Health Scotland** (Tel: 0131 474 6189. www.vhscotland.org.uk) looks at health inequalities, health and social care integration, and strengthening engagement between the NHS and the voluntary sector. It offers resources for organisations and community groups and invites members (including individuals) to share information about their activities.

The Neurological Alliance of Scotland (Tel: 0141 332 3903. www.scottishneurological.org.uk) is an umbrella, membership organisation representing people living with or affected by a neurological condition. It shares patient stories on its website and runs the Neurological Voices training programme for patients.

Inclusion Scotland (Tel: 0131 281 0860. www.inclusionscotland.org) is a national network of disabled people, their organisations and allies.

Disability Rights UK (Tel: 020 7250 8181. www.disabilityrightsuk.org) produces high quality information, products and services developed by and for disabled people.

Campaign checklist

- ☐ Have you decided which issue you will campaign on?
- ☐ Have you done some research so you are well informed about your issue?
- ☐ Have you set your campaign aims?
- ☐ Have you decided who is your target audience or decision-maker?
- ☐ What type of campaign activity will best highlight your issue?
- ☐ How much time can you give – can you balance it with work or other commitments?
- ☐ Do you need a team to help you?
- ☐ Have you checked to see what help and material Action for M.E. can give you?
- ☐ Have you thought about advertising or publicity?
- ☐ Do you need to set up your own social networking site or can you join in with others?
- ☐ Have you got feedback on your campaign so you can improve future activity?
- ☐ Have you come across others who could use this toolkit?
- ☐ 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 will you do differently or carry on doing?

Promoting your campaign

- ☐ Create a Twitter account
- ☐ Create a Facebook page
- ☐ Make a YouTube video for your campaign
- ☐ Arrange a meeting with your MSP/Local councillor
- ☐ Organise an event

Low energy checklist

- ☐ Follow and retweet Action for M.E.
- ☐ Tweet your local MSP and councillor
- ☐ 'Like' Action for M.E.'s Facebook page and share posts relevant to your campaign
- ☐ Download a poster to put in your house window
- ☐ Write a letter to your MSP by using the template letter below

Appendix: template letter to MSP

[Your address]

[MSP's name
Address 1
Address 2
Address 3
Postcode]

[Date]

Dear [MSP's name],

I am a member of your constituency and I have M.E.

I am writing to ask for your help with progressing, in [local authority name or area]. I would also like to arrange a meeting with you to discuss this issue.

The *M.E. Time to deliver in Scotland* report, published in May 2014, sets out clearly the problems people with M.E. face in diagnosis, treatment and social support. Using this report we wish to set out key actions and recommendations to be taken forward by the NHS and/or local authorities in order to improve outcomes for people with M.E., and the support that they and their families receive.

[Say something here that describes why you are interested in the M.E. strategy being implemented, including if you have M.E., a family member with M.E. or another connection.]

[Tell your MSP what your main concern(s) about support for people with M.E. are in your area. For example, these might be about getting a diagnosis, accessing social care or about training for professionals. Try to keep this short, with just one or two main points.]

Would you be able to write to our NHS Board or local authority to find out what progress they are making on delivering services for people with M.E.? [You may wish to refer your MSP to relevant recommendations of the 2010 National Needs Assessment for ME-CFS in Scotland].

I would very much like to meet you to discuss this matter further. Please could you contact me to arrange a suitable time?

You can contact me at [email] or [telephone]. Thank you for your help with this matter, I look forward to your response.

Yours faithfully,
[Your name]

Contacting Action for M.E.

For publications, information and signposting,
contact general enquiries

Tel: 0117 927 9551

Email: admin@actionforme.org.uk

For campaigning in Scotland, contact our
Scottish Project Co-ordinator

Tel: 0117 927 9551

Email: scotland@actionforme.org.uk

For details of our M.E. policy work, contact
our Communications and Policy Officer

Tel: 0117 937 6620

Email: policy@actionforme.org.uk

Find us on social media

 www.facebook.com/actionforme

 www.twitter.com/actionforme



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