

# Nothing about M.E. without me:

A self-advocacy resource for people with M.E.



# Self-advocacy

Action for M.E. supports people affected by M.E. to live life to their full potential. We do this by providing a wide range of information and resources, and increasing awareness and understanding of the illness and its impact.

But of course it's also vital for people with M.E. to have their own voices heard, in order to represent their needs for care and support. We've created this self-advocacy resource to help you do just that.

According to the charity Mind, self-advocacy is about "learning skills and building confidence to have a stronger voice for yourself."

For more information on advocacy, please see p 11.

This resource is a work in progress, and addresses the needs of people with M.E. in England, as rights and entitlements can differ in the devolved nations. We will be building on this to ensure that we include information and signposting relevant to Scotland, Wales and Northern Ireland.

## How to be a self-advocate

People with M.E. have told us they can struggle to communicate their concerns and needs effectively:

*"It is difficult to get social services, the NHS and the care agency to listen to or understand my needs. It feels like a constant struggle and it affects my health adversely."*

This resource includes guidance to enable you to overcome such challenges and help yourself.

To be a successful self-advocate you need to think about:

1. Your rights – including what support you might be eligible for
2. What is the issue – and what are your goals?
3. Effective communication – how to express yourself clearly.

The following sections explain these points in more detail.

---

Because of the cognitive dysfunction experienced by many people with M.E., we have endeavoured to make this resource as clear and easy-to-use as possible. However, it may be useful to ask a friend or family member to help you work through this booklet.

If you have any feedback, please do let us know.

---

# 1 Your rights

People with M.E. have told us they have been deterred from asking for help by anxiety that others won't understand M.E. or won't believe that they are genuinely disabled and deserving of help or support:

*"I feel that my condition isn't seen as a disability by social services, ie. I look fine."*

However, a number of important guidelines and documents support the reality of the situation – that M.E. is a genuine, disabling illness that deserves recognition:

*"The physical symptoms can be as disabling as multiple sclerosis, systemic lupus erythematosus, rheumatoid arthritis, congestive heart failure and other chronic conditions. CFS/M.E. places a substantial burden on people with the condition, their families and carers, and hence on society."*

The NICE guideline for M.E./CFS.<sup>1</sup>

*"A disability can arise from a wide range of impairments which can be: impairments with fluctuating or recurring effects such as rheumatoid arthritis, myalgic encephalitis (M.E.), chronic fatigue syndrome (CFS), fibromyalgia, depression and epilepsy."*

The Equality Act 2010's 'Guidance on matters to be taken into account in determining questions relating to the definition of disability' (Paragraph A5).<sup>2</sup>

Even in its mildest form, M.E. can have a significant impact on an individual's life. It may affect your relationships, employment or education. It is important that everyone involved in decisions about you understands the debilitating nature of the illness, how it affects you, and why you might be eligible for support.

Self-advocacy is about ensuring you are clear about your rights and able to speak up for yourself to achieve your goals.

Areas where self-advocacy may come in useful include:

- healthcare
- social care
- welfare benefits
- housing
- employment.

On the next pages we explain some situations where you might benefit from self-advocacy, as well as where to find out about your rights for that area, and where to go for more advice or information, or to complain or appeal.

For details of the resources, and contact details for the organisations listed, please see p 14.

Situation	Your rights are set out in:	Where to go for more advice/information
<p>Healthcare eg. a medical appointment</p>	<p><b>The NICE guideline for M.E./CFS<sup>1</sup></b> This advises the NHS on caring for people with M.E./CFS and the treatments they should receive</p> <p><b>The NHS Constitution<sup>3</sup></b> This sets out rights to which patients, public and staff are entitled, and pledges that the NHS is committed to achieving.</p>	<ul style="list-style-type: none"> <li>• <b>NHS complaints procedure</b> – the first step for any complaint. There are also NHS complaints advocacy services. Contact your local authority to find out who your advocacy provider is.</li> <li>• <b>Patient Advice and Liaison Service (PALS)</b> – help with health-related questions and advice about the NHS complaints procedure.</li> <li>• <b>Parliamentary and Health Service Ombudsman</b> – if you are unhappy with the outcome of an NHS complaint you can refer the matter here.</li> </ul>
<p>Social care eg. requesting social care support</p>	<p><b>The Care Act 2014 (England)<sup>4</sup></b> This states that a person will have eligible needs if they meet all of the following:</p> <ul style="list-style-type: none"> <li>• they have care and support needs as a result of a physical or mental condition</li> <li>• because of those needs, they cannot achieve two or more of the outcomes specified</li> <li>• as a result, there is a significant impact on their wellbeing.</li> </ul>	<ul style="list-style-type: none"> <li>• <b>Your local adult social services or social work department</b> – to find out about assessment arrangements and what support might be available.</li> <li>• <b>In Control</b> – national charity working for an inclusive society where everyone has the support they need to live a good life and make a valued contribution.</li> <li>• <b>Disability Rights UK's personal budgets helpline</b> – info on how to access social care funding in the light of the Care Act.</li> <li>• <b>Equality Advisory Support Service</b> – advice on issues relating to equality and human rights.</li> </ul>

Situation	Your rights are set out in:	Where to go for more advice/information
<p>Welfare benefits eg. making a claim</p>	<p>The 'A-Z of medical conditions' guide DWP staff<sup>5</sup> This medical guidance for decision-makers includes information about M.E./CFS, including:</p> <ul style="list-style-type: none"> <li>• the disabling effects</li> <li>• typical problems with daily living activities for people with M.E.</li> <li>• useful sources of further evidence.</li> </ul>	<ul style="list-style-type: none"> <li>• <b>Action for M.E.'s Welfare Advice and Support Service</b> – confidential information and advice on welfare benefits, disability discrimination, employment and insurance issues. Action for M.E.'s <i>Guide to welfare benefits and other support</i> provides a brief overview of the benefits that people with M.E. may be eligible for.</li> <li>• It is a good idea to get a complete benefit check done – your local council and/or Citizens Advice service may employ welfare rights workers who can do this.</li> </ul>
<p>Housing</p>	<p><b>The Equality Act 2010<sup>6</sup></b> This legally protects people from discrimination in the workplace and in wider society. It replaced previous anti-discrimination laws with a single Act, making the law easier to understand and strengthening protection in some situations. It sets out the different ways in which it's unlawful to treat someone, including in relation to disabilities, such as M.E.</p>	<ul style="list-style-type: none"> <li>• <b>Shelter</b> – a housing and homelessness charity offering practical advice and support online, in person and by phone.</li> <li>• <b>ACAS</b> – information, advice, training, conciliation and other services for employers and employees to help prevent or resolve workplace problems.</li> </ul>
<p>Employment eg. a dispute at work</p>		

## 2 What is the issue – and what are your goals?

To be an effective self-advocate you need to identify the issue and how it is affecting you, and then work to identify your goals and the actions to achieve them.

Think about these questions	Write your thoughts and plans here
What is the issue? What is your biggest concern?	Eg. I am too unwell to cook or wash myself.
How is the issue affecting you? How are you feeling?	Eg. I am not eating or bathing properly. This makes me upset and depressed, and is affecting my stress and energy levels.
What can be done to change the situation? What are your goals?	Eg. I need a carer to come in a few times a week to help me wash and to provide meals.
Who or what can help? Who can you ask for support or information?	Eg. The adult social care team at my local authority. Action for M.E. may also have some advice.
What are the actions you and other people can take?	Eg. Arrange for a social care assessment. Ensure relevant information is available (ie. ask GP for medical evidence).

For other examples to do with accessing healthcare, welfare benefits etc, please contact us (see p 16).

We have included a blank version of this table at the end of the booklet for you to complete. You could ask a friend or family member to help you if needed. Please contact us (see p 16) for more copies.

### 3 Effective communication

Once you have identified what the problem or issue is, what changes you would like to see, and who can help, you then need to communicate your needs clearly and assertively – whether you are speaking in a meeting or on the phone, or writing an email or letter.

#### Speak up and be heard

One potential problem for self-advocates is not being listened to. It can be frustrating to speak up and not be heard.

You should always plan what you want to say – write a list of your key points and read from it when you're at a meeting or on the phone, or include them in your email or letter (this will keep you on track and may also make it easier for others to follow you).

When you're in a meeting or on the phone make sure you:

- take a few moments to prepare yourself before you speak – remember you have the right to ask for this support
- feel confident to speak up if the person you are talking to interrupts you – say something like “Please let me have my say” or “Please could you repeat that/speak more slowly.”

When you're in a meeting it can also help to use positive body language to support your messages – sit or stand up straight and tall if you can; keep your body language 'open' (don't cross your arms across your body); try to look and feel calm.

#### Listen

When you listen closely to others, they are more likely to listen to you. You will also understand more about the situation.

Make sure you:

- let others have their say – try not to interrupt
- ask them questions about what they are saying
- use good body language (nod, “mirror” them), and use eye contact
- acknowledge their point of view (even if you don't agree with it)
- recognise that they might not be authorised to give you what you want at that point in time – but it's still useful to have the conversation.

## Methods of communication

There are many methods of communication, so try to think about the best one for your situation, and which one you feel most comfortable with.

	Pros	Cons	Tips
<b>Face to face meetings</b>	<ul style="list-style-type: none"><li>• As time is precious, meetings can often be productive and efficient.</li><li>• Everyone can have their say.</li><li>• You can bring along notes and/or supporting documents.</li></ul>	<ul style="list-style-type: none"><li>• Meetings can seem daunting.</li><li>• It can be impossible to get to a meeting if you are house/bedbound. However, you can ask for some meetings to be relocated to your home, or take part via conference call</li></ul>	<ul style="list-style-type: none"><li>• Ensure the meeting is organised for a day and time that suits you and tell the meeting organisers about any accessibility needs you have.</li><li>• You can ask a friend or family member to come with you if you want support. They can also help by taking notes while you listen and speak.</li></ul>
<b>Telephone calls</b>	<ul style="list-style-type: none"><li>• Phone calls can be a quick and easy way to get answers to your questions or problems.</li><li>• They can be made from virtually anywhere.</li></ul>	<ul style="list-style-type: none"><li>• Some phone numbers are more expensive to call than others.</li><li>• You may be kept on hold while you wait to speak to an appropriate person, which can be frustrating.</li></ul>	<ul style="list-style-type: none"><li>• Make the call in a quiet place where you won't be disturbed, and have your notes with you.</li><li>• Take notes while you're on the phone, to help you remember what was said. Include the date to help you monitor the progress after the call.</li></ul>



**Remember:** always plan what you want to say beforehand, think about your issue, and be clear about the changes you would like to see.

	Pros	Cons	Tips
<b>Emails</b>	<ul style="list-style-type: none"><li>• You can re-read what you've written before you press send. You can also save your email as a draft and come back to it later.</li><li>• Sending and receiving emails provides you with a written record of the 'conversation.'</li></ul>	<ul style="list-style-type: none"><li>• You need regular access to your emails so you can check for replies or chase up your email if you haven't heard back.</li><li>• Some people with M.E. can find that using a computer makes their symptoms worse – a smartphone/tablet might be better as they are handheld and can be used in bed.</li></ul>	<ul style="list-style-type: none"><li>• For letters and emails – explain why you're writing, then state what you want/need, and what you want the recipient to do</li><li>• For emails – keep them short and to the point and use an informative subject line.</li><li>• For letters – make sure you sign and date them and keep a copy in your files.</li><li>• If you struggle to type emails or letters, have you considered using voice-recognition software? Options include:<ul style="list-style-type: none"><li>– Dragon Naturally Speaking</li><li>– Siri (on iPhone and iPad).</li></ul></li></ul>
<b>Letters</b>	<ul style="list-style-type: none"><li>• You can take your time and really think about and prepare what you are going to say.</li><li>• You can enclose copies of other documents with your letter if needed.</li></ul>	<ul style="list-style-type: none"><li>• You might need to make a phone call to find out where to send your letter.</li><li>• Letters can be a slow method of communication, and require going to a post box (which can be a struggle for people with M.E.)</li></ul>	

## Why we've created this resource

At Action for M.E.'s Severe M.E. Symposium in November 2014, the need for advocacy for people with M.E., especially severe M.E., came up time and again.

*“There is no advocacy for us, this is something that Action for M.E. should focus on: organising a system for us to access help and support, or signposting us to the relevant people.”*

While we know that some third sector disability agencies provide advocacy for people with M.E., this is limited by available funds and fragmented geographical provision.

In addition, in 2015 Action for M.E. surveyed 850 people with M.E. about their social care and advocacy needs. Detailed information has been published in our interim report, *Close to collapse*.<sup>7</sup>

A key finding is that adult social care services across the UK are failing to meet the support needs of people affected by M.E.:

- 97% percent of respondents met the potential eligibility threshold for statutory care and support.
- Only 16% had engaged with care processes.
- Only 6% had received a care package from their local authority.

The interim report also identifies some of the probable causes for this gap between care needs and service provision for people with M.E. These include:

- a lack of information about social care process and entitlements
- cognitive difficulties acting as a barrier to self-representation.

Linked to this, the need for advocacy also emerges as an issue:

- Three quarters of respondents believed their situation would be “a little better” (25%) or “a lot better” (50%) if they had someone to represent them.
- Nearly four in five respondents had not accessed advocacy; for 60% of those the reason for this was not being able to find a suitable service.

## Where to go for more help

It is important to understand that if a meeting, phone call, email or letter does not have the desired effect, it is not necessarily the end of the matter. You can seek further help, make a complaint or lodge an appeal.

See the table on p 4-5 for organisations that may be able to help you depending on the situation. Their contact details are shown in the 'useful contacts' section on p 14.

### The Care Act and advocacy

Chapter seven of the Department of Health's Care and Support Statutory Guidance (issued under the Care Act 2014) states:

"Local authorities must arrange an independent advocate to facilitate the involvement of a person in their assessment, in the preparation of their care and support plan and in the review of their care plan, if two conditions are met. The aim is to provide assistance; first, to people who have substantial difficulty in being fully involved in these processes and second, where there is no one appropriate available to support and represent the person's wishes."

If you think that you, or someone you are supporting, might need advocacy, contact your local authority.

## What is advocacy?

According to the charity SEAP, advocacy in all its forms seeks to ensure that people, particularly those who are most vulnerable in society, are able to:

- have their voice heard on issues that are important to them
- defend and safeguard their rights
- have their views and wishes genuinely considered when decisions are being made about their lives.

However, people with M.E. have told us they have encountered barriers in accessing advocacy, such as a lack of knowledge about M.E. and inaccessible services. We also know that the community advocacy sector is under increasing strain.

*"Whenever I could have done with an advocate, I have found they don't know enough about the condition to be of any real use."*

This resource focuses on self-advocacy, but we are also currently seeking funding to establish a national advocacy service to directly support individuals.

## Table: What is the issue – and what are your goals?

---

Think about these questions

Write your thoughts and plans here

---

What is the issue?

What is your biggest concern?

---

How is the issue affecting you?

How are you feeling?

---

What can be done to change the situation?

What are your goals?

---

Think about these questions

Write your thoughts and plans here

---

Who or what can help?

Who can you ask for support or information?

---

What are the actions you  
and other people can take?

We have included this blank table for you to complete. You could ask a friend or family member to help you if needed. Please contact us (see p 16) for more copies.

## Useful contacts

### ACAS

Help and advice for employers and employees

Tel: 0300 123 1100

[www.acas.org.uk](http://www.acas.org.uk)

### Action for M.E.'s Welfare Advice and Support Service

Confidential information and advice on welfare benefits, disability discrimination, employment and insurance issues

Tel: 0800 138 6544

[www.actionforme.org.uk](http://www.actionforme.org.uk)

### Citizens Advice

Free, independent, confidential and impartial advice to everyone on their rights and responsibilities

#### **Citizens Advice England and Wales**

Tel: 03444 111 444 (England) or 03444 77 20 20 (Wales)

[www.citizensadvice.org.uk](http://www.citizensadvice.org.uk)

#### **Citizens Advice Scotland**

Tel: 0808 800 9060

[www.cas.org.uk](http://www.cas.org.uk)

#### **Citizens Advice Northern Ireland**

[www.citizensadvice.co.uk](http://www.citizensadvice.co.uk)

### Disability Rights UK – personal budgets helpline

Information and advice on social care funding

Tel: 0300 555 1525

Email: [personalbudgets@disabilityrightsuk.org](mailto:personalbudgets@disabilityrightsuk.org)

[www.disabilityrightsuk.org](http://www.disabilityrightsuk.org)

### Dragon Naturally Speaking

Speech recognition software for PC and Mac

Tel: 0162 849 1600

[www.nuance.co.uk/dragon](http://www.nuance.co.uk/dragon)

### Equality Advisory Support Service

Advice on issues relating to equality and human rights

Tel: 0808 800 0082

[www.equalityadvisoryservice.com](http://www.equalityadvisoryservice.com)

### In Control

A national charity working for an inclusive society where everyone has the support they need to live a good life and make a valued contribution

Tel: 01564 821 650

[www.in-control.org.uk](http://www.in-control.org.uk)

### NHS complaints procedure

The first step for any complaint

Email: [england.contactus@nhs.net](mailto:england.contactus@nhs.net)

[www.nhs.uk/choiceintheNHS/Rightsandpledges/complaints](http://www.nhs.uk/choiceintheNHS/Rightsandpledges/complaints)

## The Parliamentary and Health Service Ombudsman

Final decisions on complaints that have not been resolved by the NHS in England (and UK government departments/UK public organisations)

Tel: 0345 015 4033

[www.ombudsman.org.uk/make-a-complaint](http://www.ombudsman.org.uk/make-a-complaint)

## Patient Advice and Liaison Service (PALS)

Confidential advice, support and information on health-related matters

To find of your nearest PALS, ask your GP surgery or local hospital, or search [www.nhs.uk/service-search](http://www.nhs.uk/service-search)

## SEAP (Support, Empower, Advocate, Promote)

An independent charity that specialises in the provision of advocacy (services across the south of England; information also available online)

Tel: 0330 440 9000

[www.seap.org.uk](http://www.seap.org.uk)

## Shelter

Practical housing advice and support – free and confidential

Tel: 0808 800 4444

[www.shelter.org.uk](http://www.shelter.org.uk)

## References

- 1 National Institute for Health and Care Excellence (2007) NICE clinical guideline 53: diagnosis and management of CFS/M.E. in adults and children.  
[www.nice.org.uk/guidance/CG53](http://www.nice.org.uk/guidance/CG53)
- 2 Equality Act 2010 'Guidance on matters to be taken into account in determining questions relating to the definition of disability'  
[www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/85010/disability-definition.pdf](http://www.gov.uk/government/uploads/system/uploads/attachment_data/file/85010/disability-definition.pdf)
- 3 The NHS Constitution for England  
[www.gov.uk/government/publications/the-nhs-constitution-for-england](http://www.gov.uk/government/publications/the-nhs-constitution-for-england)
- 4 The Care Act 2014  
[www.gov.uk/government/publications/care-act-2014-statutory-guidance-for-implementation](http://www.gov.uk/government/publications/care-act-2014-statutory-guidance-for-implementation)
- 5 The 'A-Z of medical conditions' guide for DWP staff  
[www.gov.uk/government/publications/medical-guidance-for-dla-and-aa-decision-makers-adult-cases-staff-guide](http://www.gov.uk/government/publications/medical-guidance-for-dla-and-aa-decision-makers-adult-cases-staff-guide)
- 6 The Equality Act 2010  
[www.legislation.gov.uk/ukpga/2010/15/contents](http://www.legislation.gov.uk/ukpga/2010/15/contents)
- 7 Action for M.E. (2015) Close to collapse: An interim report on access to social care and advocacy for people with M.E./CFS  
[www.actionforme.org.uk](http://www.actionforme.org.uk)

## With thanks to:

Advocacy for Inclusion, an Australian charity that works to improve life for people with disabilities.

Action for M.E.'s Patient and Carer Reference Group.

Action for M.E. is the UK's leading charity for people affected by M.E.

We offer invaluable information and support – and we have been at the forefront of the campaign for more research, more effective treatments and better services since 1987.



42 Temple Street  
Keynsham  
BS31 1EH

T 0117 927 9551

E [admin@actionforme.org.uk](mailto:admin@actionforme.org.uk)

[www.actionforme.org.uk](http://www.actionforme.org.uk)

 [www.facebook.com/actionforme](https://www.facebook.com/actionforme)

 [www.twitter.com/actionforme](https://www.twitter.com/actionforme)

**Registered charity**

Registered charity in England and Wales no. 1036419

Registered in Scotland no. SC040452

Company limited by guarantee, registered in England no. 2906840

©Action for M.E. November 2015

**Join us as a Supporting Member for as little as £2 a month**