



Free independent advocacy for adults with M.E.

Thank you for contacting **Action for M.E.'s Independent Advocacy Service**. This information pack aims to provide you with key information about our service and the next steps.

Please note that this service is primarily delivered through email, phone and video call with some postal and face to face support available. Face to face support is limited and the need for this will be assessed on a case by case basis, dependent upon availability of resources and in response to the needs of those with severe M.E. If you have any further questions please don't hesitate to contact us using the details included in this pack on page 3.

Our service

Our specialist Independent Advocacy service is free and can support you to advocate on issues, and/or address barriers to accessing services, that directly relate to your M.E./CFS.

Action for ME is independent of statutory organisations and therefore free from influence or conflicts of interest so that we can represent the individuals for whom we advocate.

What is advocacy?

Advocacy is a process led by you which amplifies your voice and empowers you to champion your rights and have your views, wishes and interests included in decisions which affect you.

Issues which are common to advocacy include; advocating with medical professionals, employers, educational bodies and local authority services (such as social care) to gain improvements, entitlements or changes to services. We provide instructed advocacy; which is when the client tells the advocate what they want to achieve and directs the course of action taken.

What is self-advocacy?

Self-advocacy is when an individual advocates for themselves. This could be when a person complains about the service they are receiving or it could be when a person explains to a decision maker or a carer that they do not want to be treated in a certain way. Self-advocacy is all about standing up for yourself and making decisions which reflect your interests, wishes and needs.

What is an advocate?

An advocate is someone who is independent and able to represent the interests, wishes and needs of a client. Advocates empower their clients to achieve their goals and the extent to which an advocate is involved will vary depending upon the advocacy agreement.

Roles and responsibilities

Advocates maintain a professional role when they work with you. The role of the advocate is mainly to support you to identify your issue and strategies to overcome this and then to work with you on an action plan that helps you achieve your outcomes.

Your role is to work with your advocate to complete an advocacy agreement (this sets out what you will do and what your advocate will do) and to complete actions as agreed in partnership with your advocate.

If we stop hearing from you

There are limits to the time we can keep your case open if we are not actively working with you. If we have committed to undertake work with you then we will do our best to honour this. If we have no direct contact from/with you for 30 days or more, and your case is not requiring active work by your advocate, we will check if support is still required before closing your case.

This is to make sure we offer a fair service and are able to support as many people as possible. If you do get back in touch and require further support at a later date, we will ask you to wait until an advocate becomes available.

What advocates can and can't do

Can do	Can't do
<ul style="list-style-type: none">✓ Help by researching your issue✓ Present you with options and offer potential strategies✓ Communicate your decisions with your instruction✓ Talk to health professionals, employers, other professionals, agencies, family members about what you want✓ Make a complaint or start an appeal with your direction✓ Take a stand against discrimination and challenge stigma✓ Work with you to problem solve✓ Find out about and help you access health and social care services and support✓ Speak up for your human rights✓ Amplify your voice and champion your interests, wishes and needs	<ul style="list-style-type: none">✗ Make decisions for you✗ Give you legal advice✗ Give you medical advice✗ Work on an issue where another advocate/advocacy provider is involved✗ Help you apply for benefits and entitlements✗ Help to claim compensation✗ Provide befriending, coaching, counselling or mentoring✗ Provide an emergency support service✗ Provide general support with administration/PA tasks✗ Provide general, ongoing advocacy support

Contacting us

If you have any questions, please contact your advocate for more information.

You can email us at advocacy@actionforme.org.uk, call us through the Information and Support line on 0117 927 9551, or write to us at Advocacy, Action for M.E., 42 Temple Street, Keynsham, BS31 1EH.

Leaving feedback or making a complaint

We hope that you will feel that you received a good quality service and we welcome your feedback whether this be positive or negative. You can leave feedback by completing a short survey even if you have only worked with us over a very short period of time. Completing this survey is your opportunity to honestly tell us what you thought of our service. You can choose to be anonymous if you prefer. Complete the survey at: <https://forms.gle/dntfQFSvp9uiX7Kq7>

You can also send your feedback or complaint to advocacy@actionforme.org.uk or Advocacy Coordinator, Action for M.E., 42 Temple Street, Keynsham BS31 1EH.