

Free independent advocacy for children and young people

Thank you for contacting **Action for M.E.'s Children and Young People'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 Children and Young People's Advocacy service is free, and can provide support and advocacy on issues you are concerned about, as well as helping you to overcome barriers to accessing services relating to M.E./CFS.

What is advocacy?

Advocacy is a process which is led by you and makes sure that you are listened to when decisions are being made about you. Our Children and Young People's Advocate will enable and support you to understand your rights, and have your views, wishes and interests included in decisions which effect you.

Advocacy is often used when people have difficulties getting the support or services they are entitled to from medical professionals (such as doctors), schools/colleges, and local authority services, such as Children's Services.

We provide instructed advocacy; which is when you tell the advocate what you want to achieve and decide what action will be taken.

What is self-advocacy?

Self-advocacy is when someone advocates for themselves. This means the person represents themselves when dealing with an organisation or an individual.

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 represents you and is not connected to organisations providing health, education, care or other services.

Advocates support and encourage individuals to be able to achieve their goals and how much advocates are involved depends on what is confirmed in 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 what you can do 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 approaches you can take or things you can do✓ Communicate your decisions if you tell them to✓ Talk to health professionals, teachers, social workers, other professionals/ agencies, or family members about what you want✓ Make a complaint or start an appeal if you ask them to✓ Take a stand against discrimination and challenge negative views about people with M.E./CFS✓ 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✓ Help to make sure that people listen to you and promote your interests, wishes and needs	<ul style="list-style-type: none">✗ Make decisions for you✗ Give you legal advice✗ Give you medical advice✗ 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 or Personal Assistant 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 and/or your parents/carers can leave feedback by completing a short survey even if you have only worked with us over a very short period of time. You can choose to be anonymous if you prefer.

- Survey for young people: <https://forms.gle/pNsVWzHLbLRa2si77>
- Survey for parents: <https://forms.gle/21ZHsZ6pmLhtQt6C8>

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.