

Action for M.E. Young People's Services Steering Group and Workshop volunteer pack



Background and overview

Action for M.E. offers a range of services for children and young people with ME/CFS aged up to and including 18 years. Our [Young People's Community](#) is free to join and gives members access to:

- Cheers, a monthly e-magazine written especially for and by young people with ME/CFS
- our lively Young People's Forum, moderated by brilliant volunteer Peer Support Moderators
- a pen pal service that connects young people by email and/or post
- a buddy service for more severely affected members
- handwritten cards on their birthday every year.

We also offer free monthly [Breaking Isolation workshops](#) for games and discussions.

In spring 2024, thanks to funding from the National Lottery Community Fund, we launched a free Counselling service for young people with ME/CFS/CFS. It's really important that young people have a say in how we deliver this service to make sure we are getting it right!

We have extended our existing Young People's Steering Group (set up help us run our Breaking Isolation workshops) to shape all our services for people aged up to and including 18 years. The Steering Group takes a leading role in deciding how and where we promote our services and help us measure the difference these services make.

What we ask of all Action for M.E. volunteers

We ask you to make a commitment to us for 12 months if you can. We understand that this isn't always possible and will explore the best options available with you. We also ask you to:

- treat fellow volunteers and the people that use our services with respect and compassion
- tell us if you are not clear about your role or activities that you are involved in so we can help you understand them better
- let us know if you are not able to complete tasks or come to work when agreed
- act in a professional way when volunteering on behalf of Action for M.E. or talking about us and our work
- make sure you do not discriminate against another person or exclude people.

What all Action for M.E. volunteer can expect from us

People volunteer for all kinds of reasons and we want to ensure that you get something back as well as giving you time and commitment. We will work with you to ensure that we get the balance right. We will:

- treat you with respect and compassion
- ensure you are clear about your role and responsibilities
- provide you with support through regular contact and meetings that fit with your work and your needs as well as ours
- offer you honest and fair feedback on your volunteering and achievements
- listen to, and act on, feedback that you share with us
- value the role you play in our team and the contribution you make to our work.

Role description

Team:	Support Services
Key contact:	Keely Amor, Family Support Officer
Location:	Home-based
Hours:	REQUIRED Attend online Steering Group meetings via Zoom, every two months, for up to an hour (including breaks), ideally for a minimum of 12 months but we are always willing to be flexible. OPTIONAL You also have the option to get involved in co-facilitating monthly Breaking Isolation workshops (1.5 hours long), to be agreed with Keely.

Main tasks and activities

Steering Group meetings

With support from the staff team, you will help us:

- design the content and materials we use to promote our services, like social media posts and printed posters/leaflets
- develop a plan to advertise our services as widely as possible to young people with ME/CFS
- decide how we make sure our counselling service is working well for the clients that use it
- check in with the wider ME/CFS community to get input on what other kind of support young people need and how Action for M.E. might help.

This will involve taking part in online Zoom meetings every two months. We will make sure meetings work for everyone in the Steering Group, eg. sending out information to think about in advance, having scheduled breaks, and offering a range of ways to input thoughts/feedback.

Co-facilitating Breaking Isolation workshops

1. Offer up ideas and support to attendees in the workshops, typically:
 - offering up conversation starters, if attendees are a little nervous or reluctant to share
 - joining in with conversations to keep it flowing
 - offering up own experiences and tips for managing ME/CFS – if you feel comfortable and its appropriate
 - being first in line to complete the ‘getting to know each other’ games – e.g. 2 truths and a lie, guess the object (yes or no question game) to get the game going so the attendees feel comfortable and know the rules of the game
2. Supporting with administration, typically:
 - Supporting Keely with keeping on top of reading out comments from attendees as some only communicate through the chat function, so we read out their comments to allow their voices to be in the room.

The workshops are 1.5 hours long, starting at 4pm and running until 5.30pm, with up to 12 attendees. We have a full schedule of workshops that you can choose from to co-facilitate up to May 2025. More information here: www.actionforme.org.uk/breaking-isolation

What you will get out of this role

This role offers you:

- a way of meeting new people and making a real difference to your peers and workshop attendees
- the chance to shape valuable support services for young people with ME/CFS
- experience of volunteering in the charity sector
- space to develop new and existing skills in areas including planning, creativity, marketing and impact; plus potentially facilitation and workshop development.

What next?

- Please email Keely on familysupport@actionforme.org.uk to set up an informal chat, including going over what is expected of you (and what you can expect from us!) in the Steering Group and, if you are interested, co-facilitating Breaking Isolation workshops.
- Keely will make sure you have our Steering Group and co-facilitator sign up form, please send this back to Keely on familysupport@actionforme.org.uk
- For the workshops - your first workshop that you help facilitate you can take it easy, and get the feel of the workshops, and you always have the option of joining a workshop with another peer facilitator first to get more of an understanding of how everything works.
- If you are under 16, we will need to speak to your mum, dad or carer to make sure they are happy for you to volunteer with us (we will get back in touch to ask for their details).
- Keely will send out Steering group meeting polls to choose dates, and send out all info and agendas, along with the zoom link you will meet on
- You are very welcome to ask any questions or if you would like any more information, then please email Keely on familysupport@actionforme.org.uk



Action for M.E., 42 Temple Street, Keynsham BS31 1EH. Tel: 0117 927 9551.

Registered charity in England and Wales: 1036419. Registered in Scotland: SC040452.

Company limited by guarantee, registered in England no. 2906840.

To learn more about how we collect, store and process your information, please view [our privacy policy](#).