



1. Who is the Association of Young People with M.E.?

The Association of Young People with M.E. ([AYME](#)) is a UK charity that provides support for children and young people aged up to 26 who have M.E. AYME also offers help and support to parents, carers and professionals in health, education and social care.

2. Who is Action for M.E.?

[Action for M.E.](#) takes action to end the ignorance, injustice and neglect faced by people with M.E. Along with providing information, support and advice to people to help improve their health and well-being, Action for M.E. works with professionals to enhance the care and support that people with M.E. receive and funds pilot research projects to advance knowledge of the illness.

3. Why are AYME and Action for M.E. coming together in this way?

The Boards of Trustees of both charities have decided to take this course of action because they wholeheartedly believe that it will benefit children, young people, adults and families affected by M.E.

We believe it will allow us to support more people more effectively; to work more efficiently; and to speak with one voice to end the ignorance, injustice and neglect experienced by people with M.E.

4. I am a member of AYME – what does this mean for me?

Your membership of AYME will transfer so that you become a Supporting Member of Action for M.E., unless you choose to opt out. Details of how to do this are included in the email you have received from AYME. However, we really do hope you choose to stay on this journey with us.

If you are under 18 (there is no lower age limit), it will be free to be a Supporting Member of Action for M.E.

If you are over 18, the membership fee you have already paid will be extended to the end of April 2018, bringing you in line with Action for M.E.'s Supporting Membership year and giving you an additional four months membership free. You will be contacted in March 2018 then about renewing your Supporting Membership, which costs £21 per year. For those experiencing financial hardship, Action for M.E. may be able to offer a waiver.

Data protection

If you become a Supporting Member of Action for M.E., the data that AYME currently holds about you, such as your name and contact details, will instead be stored by Action for M.E., effective from Monday 3 April.

If AYME holds sensitive data about you or your family relating to a case active within the past 12 months (ie. since 14 March 2016), you will be contacted asking for permission to transfer this data to Action for M.E., where it will be stored securely in accordance with its Data Protection policy. If you choose to opt out, then your data will be deleted.

Member services

We can reassure you that the services and support you have received in the past will still be available to you.

If you are under 18, this includes Forward letters, Bunting, Penpal Emate, Notebook, being a Buddy Writer, contributing to and/or viewing Cheers magazine, leading or taking part in a Local Contact Group, getting a birthday card, and having access to a moderated forum (see question 13).

If you are over 18, you will have access to Action for M.E.'s full range of services and support, including:

- a range of [booklets](#) and [factsheets](#) covering most aspects of living with M.E., employment and education, caring for somebody with M.E. and welfare benefits. These can be ordered by post or read/downloaded online free of charge.
- its friendly peer-support forum, [M.E. Friends Online](#)
- a confidential [Welfare Advice and Support Service](#), which offers information on all aspects of the benefits system including what benefits are available, how to apply for them and what to do if you want to appeal against a decision.
- its lively membership magazine, *InterAction*, published three times a year, featuring latest campaign news, readers' experiences, informative articles, research, letters, book reviews, giveaways and more.

5. I am a Supporting Member of Action for M.E. – what does this mean for me?

We can reassure you that the services and support you have received in the past will still be available to you. While Action for M.E. is extending its work to include children and families, it remains committed to supporting adults affected by M.E., and its policy position has not changed. Action for M.E. will not change the information it gives to people with M.E., nor its work to secure better understanding of M.E. and support for people living with the condition.

6. Where should children and young people, and their parents and carers, now go to access information, advice and support?

Between now and Sunday 2 April, they should contact AYME by phone or email, or visit www.ayme.org

From Monday 3 April, information for children and families affected by M.E. will be available on Action for M.E.'s [website](#), including further contact details. Or call the Action for M.E. office on 0117 927 9551 and they will be directed to the appropriate team.

7. Can I belong just to the Children's Services team, but not Action for M.E.?

The Children's Services Team will be part of Action for M.E. so, to access all the support you are used to receiving, you need to become a Supporting Member of Action for M.E. We will automatically transfer your membership unless you tell us you want to opt out (as explained in question 4).

We want to keep supporting you, and we understand that it might be difficult to hear that AYME will no longer operate from Monday 3 April.

We can reassure you that the services and support you have received in the past will still be available to you. You will still be in contact with many of the same people: Mary-Jane Willows will lead Action for M.E.'s Children's Team Services, and we are undertaking consultation with AYME staff regarding their transfer to Action for M.E.

We are confident that, by delivering services for children and adults, we will create better value for money and be better able to secure additional resources to increase the work we do.

8. Who can I speak to about these changes?

If you are a member of AYME, please phone the information and support line on 0330 221 1223 (Mon to Fri 10am to 2pm until Monday 3 April – see question 6). AYME staff will be able to talk you through the changes and reassure you that every child, young person, parent and carer who currently makes use of these services can continue to do so.

You can also contact Action for M.E. by email, phone or letter. You can find contact details at www.actionforme.org.uk/contact

9. How did you decide to close AYME and launch Action for M.E.'s Children's Services Team, and what did you do to ensure that it was the right thing for people with M.E.?

The idea was raised in December during a meeting between the Chairs and Chief Executives of Action for M.E. and AYME to explore how both charities could better deliver services for children and adults affected by M.E.

Both Boards followed a due diligence process, supported by their own independent legal advisors. This ensured that they independently considered the benefits and possible disadvantages for the people affected by M.E. that they support.

However, following the due diligence process, both Boards are confident that we will improve continuity of support, and ensure that people affected by M.E. can access the information and support they need, at the time they need it most.

Based on the business case presented on 2 March, both Boards took a decision that we could better meet the needs of children and adults by working together to close AYME, and launch Action for M.E.'s Children's Services Team.

10. Were members of Action for M.E. and AYME consulted about this decision?

There was no specific consultation with the individuals who use the services and support provided by Action for M.E. and AYME, as discussions were necessarily confidential. Both Boards of Trustees followed a due diligence process and independently considered the benefits and possible disadvantages for people affected by M.E. and especially for their own members.

NB. The legal definition of Action for M.E.'s and AYME's members under company law refers only to their Trustees. Neither Action for M.E. Supporting and Lifelong Members, nor AYME Supporters, AYME Parents & Carers and AYME Graduates are members of Action for M.E. or AYME as a company law matter. As a consequence, they do not have voting powers or legal responsibility as company members. Decisions of this kind must be taken by the "members" under company law.

11. Why did you choose this M.E. charity to merge with, and not a different one?

Action for M.E. and AYME have worked closely together for a number of years, and collaborated on occasion, eg. our *Your child and M.E.* booklet. By supporting both children and adults in this way, we can create more opportunities to raise the profile of M.E. and its impact.

12. Which of AYME's services will instead be offered by Action for M.E.'s Children's Services Team?

All of the services that have up to now been provided by AYME will continue to be offered by Action for M.E.'s experienced Children's Services Team and dedicated volunteers. Every child, young person, parent and carer who currently makes use of these services can continue to do so.

13. What will happen to the AYME website?

The valuable information and support resources on AYME's website will be moved to Action for M.E.'s website. Redirects will be set up so that anyone who has AYME pages bookmarked will be automatically sent to the correct page on Action for M.E.'s website. The AYME website will be taken down on Monday 3 April.

With regards to AYME's forums, we are currently exploring some complex technical issues with transferring these to Action for M.E.'s website; the work and ensuing cost is very high and it looks very unlikely that this will be possible. We are therefore looking at providing dedicated forum space for AYME forum users on the Action for M.E. website.

For under 18s, this will be a separate, dedicated, moderated forum, with all the existing security and protections in place. For young adults (18-26 years), we hope to provide a dedicated space within [M.E. Friends Online](#). For parents/carers of children with M.E., we understand the need for a secure space that enables them to

talk freely, knowing that their child won't have access to the discussion, and are looking at the best way to make this happen.

For each forum, we are assessing options around preserving existing forum content that users tell us they find useful; this includes looking at what costs may be incurred to do this. We have limited funds available and need to use them as effectively as possible, so please bear with us while we work out the best way forward.

14. What will happen to AYME staff and Trustees?

There are legal processes that determine what must happen when two organisations choose to take the action that we have. We are working within these to ensure that services for children and adults with M.E. continue to be provided, with a view to extending them further in the future.

AYME Trustees Colin Batten and Eric Mercer have been appointed to the Action for M.E. Board of Trustees from Monday 3 April. They will work with Action for M.E. to ensure that children's services are an integral part of our work.

15. Who will Action for M.E.'s Medical Advisors be from Monday 3 April?

Action for M.E.'s current Medical Advisers are Prof Julia Newton and Dr Gregor Purdie. This will not change as a result of AYME closing or the launch of Action for M.E.'s Children's Services Team.

16. How will this affect the information and advice you give about living with M.E.?

Action for M.E., including its Children's Services Team, will continue to provide information and support that empowers people to make informed decisions about living with the impact of M.E.

Action for M.E. does not recommend any treatment for people with M.E. as its staff are not medically trained. Instead, they offer information about treatment that people with M.E. may be offered. Action for M.E. also provides information about the experiences of people with M.E. who have tried different treatments (including information from surveys carried out by Action for M.E. and other M.E. charities).

17. I support AYME by raising and/or donating money: can I still do this and what will happen to my donation?

From Monday 3 April, all donations will go to Action for M.E. If you have already committed to raising money for AYME, you can request that your donation is used for a specific area of Action for M.E.'s work – such as children's services or research.

We want to make sure that every penny raised to support children and adults affected by M.E. goes as far as it possibly can. We are confident that, by delivering services in this way, we create better value for money and be better able to secure additional resources to increase the work we do.