

## Make a difference

Having the right information at the right time can make a crucial difference to those trying to find the best way to live with M.E.

UK charity Action for M.E. provides one-to-one information, advice and support to help children, young people and adults make informed decisions about their care; and safe, friendly peer-support forums to help thousands of people with M.E. be better connected.

We equip teachers, doctors, social workers and other M.E. professionals with experience and knowledge to better support people with M.E., and invest time and money in biomedical research.

We are here to help – and we need your support to reach even more children, young people and adults with M.E.

Find out how you can make a difference at [www.actionforme.org.uk/make-a-difference](http://www.actionforme.org.uk/make-a-difference)

*“Thank you so much. In the ten years I have suffered with my health, this is the best information I have been given. I will look into all of this and hopefully be able to get back on track.”*

Information and Support Service user

*“It can be very lonely coping with chronic health problems. Action for M.E. is a valuable resource and it’s reassuring to know that there are wonderful people like you who care and are doing as much as they can to help others.”*

Elaine, who called us for support



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## Are you missing M.E.?



## What is M.E.?

Myalgic Encephalomyelitis (M.E.), also diagnosed as chronic fatigue syndrome (CFS, or M.E./CFS) is a disabling neurological condition that affects at least 250,000 children, young people and adults in the UK.

People with M.E. experience debilitating pain, fatigue and a range of other symptoms associated with post-exertional malaise, the body and brain's inability to recover after expending even small amounts of energy; this may be delayed by up to a day or two.

Around one in four children, young people and adults with M.E. are so severely affected that they are house or bed bound, often unable to care for themselves.

Action for M.E.'s 2019 Big Survey of more than 4,000 people with M.E. found that:

- 90% have stopped working or reduced hours because of M.E.
- 33% require full or part-time care
- one in three children and young people with M.E. are not accessing any education at all.

*"I am lucky to have supportive family and friends. My husband's career means that he is not always able to care for me, or our child, when I am having a bad spell. No matter how well you understand the condition, M.E. impacts on everything you do and everyone you love."*

Big Survey respondent, Maria

## Living with M.E.

*"I was diagnosed with M.E. aged 14 after six months of going backwards and forwards to the doctors and trying to be in school. At my worst I was largely bedbound/housebound, making it out roughly once a month in my wheelchair. I struggled to read and couldn't watch TV because all the movement and noise was too much and no longer made any sense to me. Action for M.E. really did become my lifeline through my teens as my friends at school struggled to understand."*

Helen, who took part in our Big Survey

People with M.E. can vary enormously in their experience of the illness, and also how long their symptoms last. Some make good progress and may recover; some can remain ill for a number of years and may not get better.

Even in its mildest form, M.E. can have a significant impact on an individual's life, and not just on their health.

Children and adults with M.E. still face ignorance, injustice and neglect from those who don't understand its impact. At the very least this leads to isolation and stigma. For those put under pressure to do too much, to return to school or work too soon, the consequences can be devastating.

While there might not be a proven pharmaceutical cure for M.E./CFS yet, some treatment approaches can help people with M.E. manage their symptoms.

We need more research to add to our knowledge of M.E., helping us move towards improved diagnosis, more effective treatments and, one day, a cure.

## You are not alone

If you have M.E., or care for someone who does, Action for M.E. is here to help. We offer a range of services and support for children, young people and adults with M.E., plus the family, carers, friends and professionals supporting them.

Visit our Online M.E. Centre or contact us to find out more about:

- diagnosis and symptom management
- how to access health and social care
- applying for welfare benefits for you or your child with M.E.
- staying in, going back to or leaving work
- education that meets your child's needs
- talking to family and friends about M.E.
- coping as a carer
- finding support in your local area
- joining one of our friendly, peer-support forums for children, parents or adults affected by M.E.

*"This forum has been an extremely useful and valued resource in my journey so far. It has given me a way to connect with others who understand, a way to learn more about symptom management, somewhere to come on the bad days when I feel isolated and lonely."*

Action for M.E. forum user