



Action for M.E. is the only UK charity supporting people with M.E. of all ages.

We offer a range of services supporting children, young people and adults living with M.E. We work collaboratively to improve access to appropriate services and support, and to accelerate much-needed biomedical research.

This leaflet shares key information about M.E., and how Action for M.E. can help. You can also access advice and support at www.actionforme.org.uk/families

We are Action for M.E.



Information and support for families living with M.E.



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What is M.E.?

M.E. stands for Myalgic Encephalomyelitis. It is a chronic neurological condition that affects 25,000 children and young people in the UK.

The condition affects children and young people of all ages, and from all social and ethnic backgrounds. We don't yet know what causes M.E., although in children and young people it most commonly follows persistent viral infection.

There is no single medication that you can take specifically for M.E., but with careful management and appropriate support from experienced, specialist professionals, children and young people can significantly improve their lives, even to the point where they are completely better.



What do young people say about having M.E.?

Everyone's energy reserves – their batteries, if you like – are different. Having M.E. means that yours might vary from day to day, and even hour to hour – that's why M.E. is known as a fluctuating condition.

Children and young people with M.E. can experience a range of symptoms. These symptoms may come and go and it can be difficult, especially when first diagnosed, but remember we are here to help and support you.

- Hannah: "The most challenging thing for me is fatigue as it limits my energy; muscle pain get really sore, and with the brain fog I can't remember simple things or take in basic information."
- Oliver: "I use a wheelchair for school and avoid the busy, noisy times when classes are changing, going in before the class starts and leaving before it finishes."
- Verity: "If you have just been diagnosed or are struggling, my advice would be to take things day by day, pace yourself and listen to your body as much as you can."

Action for M.E. is here to help.

You don't need a diagnosis to get in touch. Under 19s can join our Children and Young People's Community for free, to get access to:

- our safe, friendly online forum for young people with M.E.
- our lively monthly digital magazine, Cheers
- a fully customisable penpal service
- Christmas (if you are severely affected) and birthday cards
- a buddy scheme for those in need of extra support.

Action for M.E.'s experienced Children and Young People's Services Team also offers:

- one-to-one information and advice for parents/carers on accessing education, healthcare and social services, and a dedicated online forum for parents
- support and skills for teachers, doctors, social workers and other professionals working with families affected by M.E.

You are not alone.

Visit www.actionforme.org.uk/families or call us on 0117 927 9551.



"I tried to push myself and do a lot more than I was really capable of. It was a natural reaction for me, but now I realise that it wasn't brave. If you do that, you end up feeling worse than when you started. Then I learned to manage my activity and tried to avoid the urge to complete a task in one sitting. I alternated small mental tasks with small physical ones because I soon learned that it was as important to rest my brain as it was my body."