



Living with severe M.E.

Action for M.E.'s Big Survey: two-page explainer

What is M.E.?

- Myalgic Encephalomyelitis (M.E.) is a long-term, fluctuating, neurological condition affecting many body systems.
- Within the NHS, it is diagnosed as chronic fatigue syndrome (CFS) or M.E./CFS.
- Everyone who experiences M.E. has a different pattern of illness, and symptoms and severity fluctuate and change over time.
- People with M.E. experience debilitating pain, fatigue and other symptoms linked to post-exertional malaise, a cardinal symptom of M.E.
- **Around one in four people with M.E. are severely affected by the condition, ie. bed-and/or house-bound.**

"I'm 17 and my mum has had to give up work to be my full-time carer. I live in an alternative universe. My school said no education unless in school for one hour at 9am. When I couldn't do this the school reported us for non attendance." Tom, Brighton

"It is life-changing and not in a good way. It is utterly limiting in that I can't go out and can only concentrate on visitors, etc for 30 mins to an hour on a good day." Mark, Anglesey

"Due to being housebound it's virtually impossible to access the doctors so other worries or concerns that could be serious that are not to do with M.E. are not looked at." Jayne, Liverpool

"M.E. has had a dramatic effect on my life. I lost my hobbies, then my job, then my friends. My boyfriend tried to be there for me but eventually couldn't handle the illness once I became housebound. I am 34 yet I have to live with my parents and, even though their health isn't great, they are my main carers." Susan, Cambridge

What did adults and young people with severe M.E. tell our Big Survey?

- Less than one in five (14%) with severe M.E. received a diagnosis within six months.
- Almost all (99%) have stopped or reduced social contact and work.
- Four out of five (79%) with severe M.E. said they require full/part time care.
- Nearly three quarters (73%) said they are no longer able to leave home independently
- More than a third (35%) said it has affected their decision to have children
- One in five (20%) have seen their GP more than 7 times about their M.E.
- Two thirds (64%) of respondents under 18 with severe M.E. said they are not accessing any education. Nearly half (46%) are in touch with other young people with M.E. online.

What is Action for M.E.'s Big Survey?

- Between May and August 2019, UK charity Action for M.E. surveyed more than 4,000 children, young people and adults with M.E.
- We asked about diagnosis, education and employment, health and social care, symptom management and Universal Credit.
- Nearly two thirds of respondents were 40 years or older; 5% were under 18.
- There was a ratio of one to five male to female respondents; nearly 90% had been ill for four years or more.
- 99% said they experience post-exertional malaise either always, usually or sometimes.
- 96% were White British, Irish or other. 82% of respondents were from England, 12% from Scotland, 5% from Wales and 2% from Northern Ireland.

We asked: what would make a real difference to your healthcare?

78% said a better informed GP



56% said joined-up health and social care



67% said home visits



42% said accessing consultations via video conference



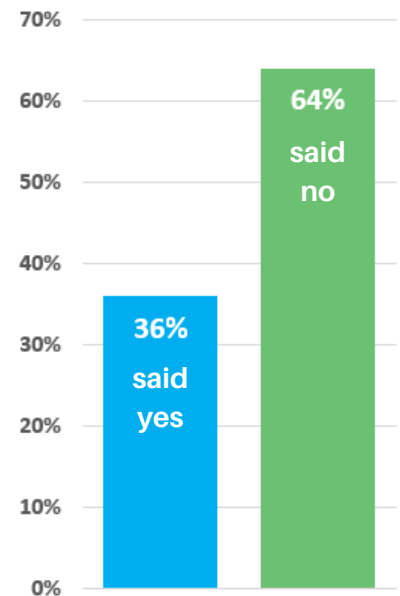
65% said more effective medication



38% said having more of a say in their treatment

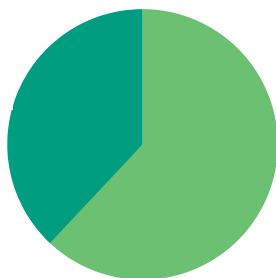


We asked: Have you had a social care assessment since August 2014?



We asked: how confident are you that your GP understands M.E.?

38% said reasonably or fully confident



62% said not very or not at all confident

We asked: what barriers have you experienced in accessing NHS services for severe M.E.?

- 78% said they were too ill.
- 49% said there was no specialist NHS services in their area.
- 47% said it was a lack of follow-up/ongoing care.
- 43% said that the distance and/or travel time to the service was a barrier; 15% cited cost of transport.
- 31% said long waiting times for treatment or referral.
- 15% said they didn't want to use any of the services on offer.

Respondents who said yes had the following outcomes:

- 11% said they received no support at all.
- 20% were allocated a Personal Budget.
- 27% got help with domestic care (eg. cleaning, shopping).
- 36% got help with personal care (eg. washing)
- 52% were given aids and adaptations to their home.
- Other respondents said they received help through a Personal Assistant, information on self-care or support for a family carer.

Action for M.E. takes action to end the ignorance, injustice and neglect faced by people with M.E. We meet need now to improve lives while taking action to secure change for the future.

www.actionforme.org.uk | Tel: 0117 927 9551 | Email: questions@actionforme.org.uk