



# Living with the impact of 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.

*"The hardest part is the psychological impact of knowing that no-one (family, friends & colleagues) understands what it means for me personally to live with M.E./CFS."* Mark, Brighton

*"If teachers and doctors had more knowledge on realistic life with M.E., things would be so much easier. It was heartbreaking to hear someone who is supposed to understand me the most dismiss my symptoms."*

Young person, London

*"I had to hide severity from my employer at first as it was difficult to get them to understand without having a diagnosis. It was so much easier with diagnosis as there is clarity on the condition and limitations."*

Phillip, London

*"Learning to listen to your body, to trust what it tells you and to act in a responsible way to its messages, enables more than simple activity; it allows you to feel more in control, have greater self respect and self worth."*

Julie, Worcestershire

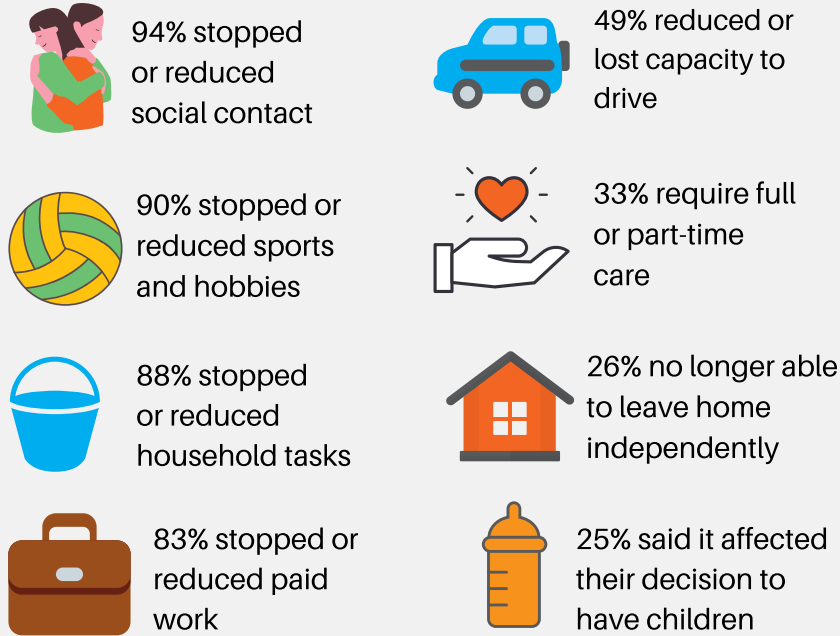
### What did our Big Survey find?

- One in four survey (25%) respondents said they were severely affected, with 62% saying moderately affected and 13% saying mildly affected.
- Just 7% of children and young people and 16% of adults are obtaining a diagnosis within the NICE guideline timescale of three months and four months respectively. Almost one in five adults (18%) waited more than six years for a diagnosis.
- Three quarters (77%) said they are unable to work because of the impact of M.E.
- Of those respondents who said they are supported by a carer, almost all (89%) said the carer was a family member, most of whom (84%) receive no financial support at all. One in ten respondents (10%) pay privately for care.

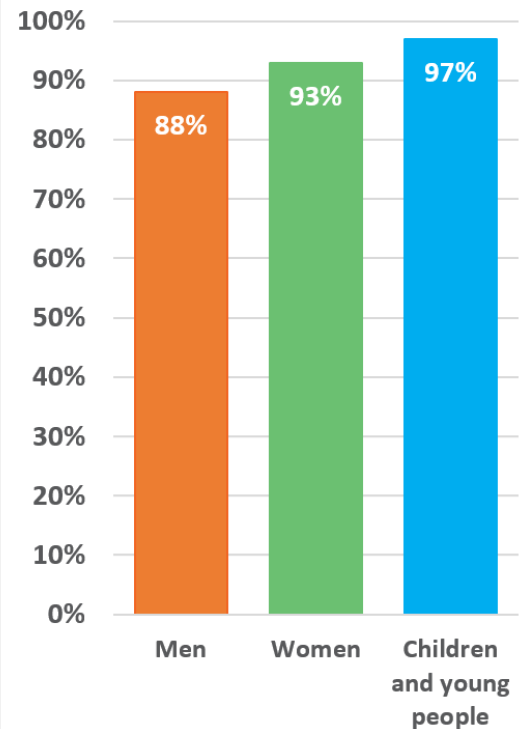
### What is Action for M.E.'s Big Survey?

- Between May and August 2019, UK charity Action for M.E. surveyed more than 4,000 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.

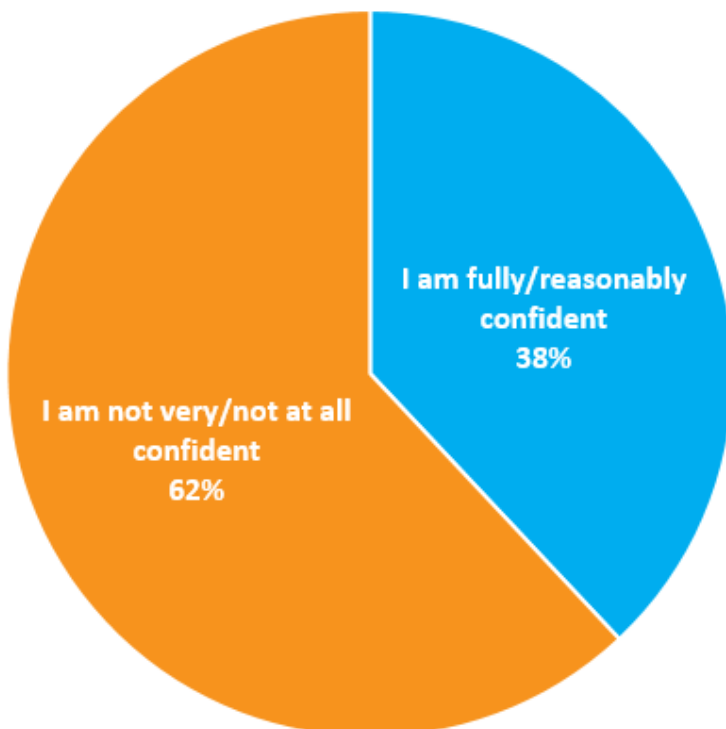
## We asked: what impact has M.E./CFS had on your life?



## Those who said they feel socially isolated because of their condition



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



Respondents who said they **don't** feel socially isolated were more likely to have mild (30%) or moderate (66%) M.E.

## What support is needed?

- Three in four people said that they are in need of support to access more appropriate or different health or social care services.
- Almost half need support to challenge a decision relating to welfare benefits.
- one in five need support to have their views represented to their employer to make work more accessible for them.

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.

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