

Who are we and what is M.E.

1. Action for M.E. is the UK's leading charity for children and adults affected by Myalgic Encephalomyelitis (M.E.). We take action to end the ignorance, injustice and neglect faced by people with M.E. We do this by meeting need now to improve the lives of people with M.E. while taking action to secure change for the future. Alongside providing information, support and advice to children and adults to help improve their health and well-being, we work with professionals to enhance the care and support that people with M.E. receive, and fund research projects to advance knowledge of the illness.

2. M.E. is a chronic neurological condition that causes symptoms affecting many body systems, commonly the nervous and immune systems. M.E. affects around 250,000 people in the UK. People with M.E. experience severe, persistent fatigue associated with post-exertional malaise (the body and brain's inability to recover normally after expending any energy), causing a flare-up in symptoms including chronic pain. There is a spectrum of severity: around one in four people with M.E. are so severely affected that they are unable to do any activity for themselves, or can carry out minimal daily tasks only.

Fabricated or Induced Illness (FII)

3. Action for M.E.'s survey (2017) of families with children affected by the Neurological condition M.E. shows that one in five who responded have faced accusations of fabricated/induced illness, abuse or neglect, leading to child protection referrals. Parents often give up work to care for their child with M.E., and can often face barriers in accessing appropriate medical care and educational support.

4. This problem is more acute in Wales due to the lack of specialists who can offer supportive information to social workers and detail the effect the condition can have on a child.

5. The 2017 survey found that:

- 96% of respondents felt that a lack of understanding of M.E. negatively impacted on the support that they receive
- 90% agreed they were concerned that professionals involved with their child did not believe them
- one in five (22%) said a safeguarding/child protection referral had been made against them
- nearly half of these referrals related to claims of fabricated/induced illness or FII (previously known as Munchausen's by Proxy), which occurs when a parent or carer exaggerates or deliberately causes symptoms of illness in the child; this heightened frequency of FII claims sits widely outside the national prevalence rate
- a smaller number of the claims were of neglect (17%) or emotional (10%) or physical (2%) abuse
- 70% of all cases were dropped within a year.

Who is making these allegations?

6. When children and young people become ill with M.E., we all too often see their experience being misinterpreted by teachers and peers, resulting in them being accused of being lazy, anxious or depressed. What our survey shows is that this can wrongly lead to their families being suspected of fabricating their illness, or neglect or abuse. Half (53%) of the families subject to child protection proceedings told us these were instigated by a teacher; nearly three quarters of these (70%) said FII was a factor.

7. The lack of knowledge of Social Workers is also an issue. One family which Action for M.E. supports in Wales had issues where their first social worker did not understand M.E. or the way it affected their child. This had an impact on the support they received and they often faced questions of neglect.

8. The news that so many families are being subjected to FII claims is deeply alarming, adding as it does to the already considerable pressures faced by these very sick children, their parents and their siblings as a result of this challenging condition. We are not disputing the importance of a system which picks up on potential safeguarding and child protection risks, rather questioning why the proportion of FII is so high when it comes to M.E. It is clear that some professionals still do not understand the uniquely complex impact of M.E. This must change.