

Families facing false accusations: results of Action for M.E.'s survey

June 2017

Action for M.E.'s survey of families with children affected by the neurological condition Myalgic Encephalomyelitis (M.E.) shows that one in five who responded have faced accusations of fabricated/induced illness, abuse or neglect, leading to child protection referrals.

What is M.E. and how does it affect families?

M.E. (sometimes known as chronic fatigue syndrome or CFS/M.E.) is a neurological condition affecting an estimated 250,000 people in the UK, including around 25,000 children and young people.

M.E. has a profound effect on every aspect of a child's life, with many missing a considerable amount of school. Parents often give up work to care for their child with M.E., and can often face barriers in accessing appropriate medical care and education support.

What did our survey find?

With 270 families responding to our Children's Services Team survey, which ran for three months from February to April 2017, results indicate 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?

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.

One parent told us: “We were told by the Head of our child’s school that he had referred us to safeguarding for failing to ensure that our child attended school regularly.”

However, it’s not only teachers and education professionals that need support to better understand M.E. Nearly a third (29%) of the families subject to child protection proceedings had these instigated by a health professional; more than half of these (56%) said FII was a factor.

One parent told us: “I was accused of not supporting the program set by the hospital, putting my own illness onto my child and stopping them getting better. The outcome of the investigation was that I was just trying to get appropriate help for my child, that there was no evidence to support the accusation, and that the hospital failed in its communication.”

In addition to accusations of FII, the families that responded to our survey are frequently challenged on school attendance and the validity of their child’s M.E. diagnosis (despite this being confirmed in many cases by at least one specialist) by professionals who do not understand the complexities of M.E.

What needs to happen?

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.

In response to these findings, Action for M.E. will take action by:

- sharing our survey results with policy-makers and professionals, including parliamentarians and the Chief Social Worker for Children and Families
- asking them to work with us to increase understanding of M.E. among frontline staff, and reduce the number of families subjected to false accusations
- highlighting our survey findings in the press, including sharing them with BBC File on 4 for its investigative programme, [Children with M.E.](#)

We will also continue to:

- share accurate information and support about M.E. and its impact via our Online M.E. Centre,, targeting [education professionals](#) and [health professionals](#), and through our Webinars for GPs series
- offer direct support to professionals working with children and families affected by M.E. through our Children’s Services Team.

To contact Action for M.E. for information and support, or to work with us to improve the lives of children, families and adults affected by M.E., visit www.actionforme.org.uk