

## M.E./CFS in children and young people

This guidance has been produced by UK charity Action for M.E., in collaboration with Children and Families Social Workers.

A lack of understanding about myalgic encephalomyelitis (M.E.) and its impact means that families living with this illness, sometimes diagnosed as chronic fatigue syndrome (CFS, or M.E./CFS), still face considerable challenges in accessing appropriate care and support.

This resource for Children and Families Social Workers aims to improve this situation, by offering information and practical advice for Children and Families Social Workers, so they can better support their clients, and work more effectively with other health and care professionals.

You should start with the quick guide, before moving to the more detailed information section, which expands on this.

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## QUICK GUIDE

### What is M.E./CFS? An overview

- Around one in 200 children and young people are estimated to have M.E./CFS.<sup>1</sup>
- M.E./CFS can cause symptoms ranging from mild (where young people can maintain some level of school or work) to severe (where any activity is near impossible).<sup>2</sup>
- There is currently a lack of paediatric specialists in the condition, meaning specialist medical help and support for families is frequently inaccessible.<sup>3</sup>
- When families come into contact with social services, it is often due to inappropriate referrals which place concerns in a child protection context, rather than recognising that young people with M.E./CFS are children in need. This is often due to a lack of understanding of the severity of the impact and fluctuating nature of the illness.<sup>4</sup>
- While there is a poor access to treatment and appropriate care and support, young people can be supported with the right social work intervention, supporting parents and young people in their right to choice.
- One in five families of young people with M.E./CFS have faced accusations of fabricated or induced illness (FII), abuse or neglect, leading to child protection referrals.<sup>5</sup>

### When might social care professionals come into contact with young people with M.E./CFS?

- M.E./CFS is a relatively common disease and the family may need the same range of services and support offered to any young person with a disability.
- M.E./CFS may also be seen alongside other concerns which necessitate social care involvement.
- Schools may be considering legal action due to a lack of attendance and/or medical evidence of a diagnosis from a specialist.
- Health professionals, where there is a lack of awareness and understanding of the illness, may suggest parents are neglecting their child and/or causing the condition, and use the term FII.

### What practice guidance should social workers keep in mind when working with young people with M.E./CFS and their families?

- Begin by understanding the range of symptoms (see Appendix II on p 15) including the fluctuating nature of the condition.
- Understand the levels of severity and how this may present, eg. a young person at the most severe end of the spectrum may have no medical support and be in bed all day in a darkened room, whereas a mildly affected young person may initially present with poor school attendance due to fatigue.
- Explain your role and responsibilities and the process, leaving literature for parents to read following your visit.
- Acknowledge the difficulties of having a non-visible illness.
- Validate the young person's experience of the illness, symptoms and impact, by listening and asking clarifying questions. Remember that M.E./CFS is a fluctuating condition and symptoms can change over time.

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<sup>1</sup> Collin SM et al (2016) Chronic fatigue syndrome at age 16 years. *Pediatrics*. 137:e20153434

<sup>2</sup> <https://www.nhs.uk/conditions/chronic-fatigue-syndrome-cfs/symptoms>

<sup>3</sup> Action for M.E. (2017) *Spotlight on specialist services: UK healthcare for people with M.E.*

<sup>4</sup> Action for M.E. (2017) *Families facing false accusations: results of Action for M.E.'s survey*

<sup>5</sup> *ibid.*

- Avoid too many questions: listen and clarify only when essential. Accept that parents may frequently need to speak on the young person’s behalf.
- Allow time over several visits to get to know and understand the individual; energy levels vary from person to person.
- Ask how long the young person can meet for and, if severely affected, accept you may not meet the young person for your first few visits if they are having a bad day.
- Before your initial visit, ask what level of severity the young person is experiencing and what his/her worst symptoms are. For example, if they are highly sensitive to smell you should avoid wearing aftershave or perfume, if sensitive to noise don’t ring the doorbell but knock quietly and speak softly throughout. Ask what else you may need to consider.

Issues to look out for and signpost for help and support:

- Parents may be struggling to come to terms with the impact on the young person’s life: *“I feel as though I have lost the child I know.”*
- Coping with financial stress of a parent having to give up work
- Social isolation for parent and young person.

Being heard and then signposted to the right support can be a lifeline to families coping with a long-term condition, particularly one that is invisible, frequently misunderstood and underdiagnosed (see p 10 for more information on advocacy).

### How does an M.E./CFS diagnosis differ from neglect/FII? How can social workers explore this?

If we consider the indicators of FII highlighted by the Royal College of Paediatrics and Child Health (RCPCH), we can gain understanding into how concerns about M.E./CFS may arise.

<b>Indicators which should alert professionals to the possibility of FII, taken from RCPCH guidance<sup>6</sup></b>	<b>Possible explanations where M.E./CFS is either diagnosed or presents as potential diagnosis</b>
A carer reporting symptoms and observed signs that are not explained by any known medical condition.	The wide range of M.E./CFS symptoms are frequently misunderstood and underdiagnosed in primary care, which may lead to excessive testing initiated by the GP but later may reflect poorly on the parent – or symptoms being dismissed.
Physical examination and results of investigations that do not explain symptoms or signs reported by the carer.	Investigations resulting in a ‘nothing wrong’ outcome is a relief for the practitioner but adds to the parent’s concerns due to the levels of pain and fatigue the young person is presenting with.
The young person having an inexplicably poor response to prescribed medication or other treatment, or intolerance of treatment.	It is acknowledged by specialists in the medical profession and National Institute for Health and Care Excellence (NICE) guidance that intolerance to medication is seen in patients with M.E./CFS

<sup>6</sup> RCPCH (2009) Fabricated or Induced Illness by Carers A Practical Guide for Paediatricians. [www.rcpch.ac.uk/resources/fabricated-or-induced-illness-fii-carers-practical-guide-paediatricians](http://www.rcpch.ac.uk/resources/fabricated-or-induced-illness-fii-carers-practical-guide-paediatricians)

<p>Acute symptoms that are exclusively observed by/in the presence of the carer.</p>	<p>Young people want to be at school, with their friends and will use all of their available energy and ability to participate. This frequently results in a ‘crash’ when they arrive home – unseen by those other than the parent. Following exertion, symptoms can be exacerbated through post-exertional malaise (see p 5-6), and further compounded when poor sleep is experienced.</p>
<p>On resolution of the child’s presenting problems, the carer reporting new symptoms or reporting symptoms in different children in sequence.</p>	<p>Some young people experience the wide range of M.E./CFS symptoms some of the time, and others all of the time, with these fluctuating throughout the period of their illness. It is recognised that there is a genetic link and in some families, we see more than one child and wider family members diagnosed with M.E./CFS.</p>
<p>The young person’s daily life and activities being limited beyond what is expected due to any disorder from which they are known to suffer, for example, partial or no school attendance and the use of seemingly unnecessary special aids.</p>	<p>If those concerned have a lack of expertise in the condition (eg. have only known mildly affected young people), the limitations of someone more severely affected can lead to concern. School attendance is frequently affected and a lack of diagnosis, which for some takes months or years due to the paucity of specialist services, can exacerbate these concerns. A reasonable adjustment might be attending only part of the day, or with regular rest breaks. A wheelchair used appropriately, can enable a young person to attend school saving valuable energy for time with peers and lessons, as opposed to ‘giving the young person an image of themselves as disabled.’ Some young people will be too ill to attend school at all.</p>
<p>The carer seeking multiple opinions inappropriately.</p>	<p>Seeing their child in pain, fatigued and unable to participate in activities they love, one parent supported by Action for M.E. told us: “I will search and continue to search and we won’t leave any stone unturned until I have an answer – how can that be explained as me harming my child?” After 12 months and intervention by the charity, this parent secured an appointment with a specialist, and their child was diagnosed with M.E./CFS.</p>

### What about parents who refuse a particular treatment/management option?

It should be noted here that there is no proven treatment or cure for this illness, so parents may refuse to proceed with management offered, as might happen with any illness.

NICE says it expects healthcare professionals “to take our guidance into account, but people also have the right to be involved in discussions and make informed decisions about their care.”<sup>7</sup> Offering support at this time should be considered and may be all that is required. **Refusal of treatment alone is not sufficient reason for a referral to Social Services for investigation.**<sup>8</sup>

<sup>7</sup> [www.nice.org.uk/about/nice-communities/nice-and-the-public/public-involvement/making-decisions-about-your-care/your-care](http://www.nice.org.uk/about/nice-communities/nice-and-the-public/public-involvement/making-decisions-about-your-care/your-care)

<sup>8</sup> RCPCH (2009) Fabricated or Induced Illness by Carers A Practical Guide for Paediatricians. [www.rcpch.ac.uk/resources/fabricated-or-induced-illness-fii-carers-practical-guide-paediatricians](http://www.rcpch.ac.uk/resources/fabricated-or-induced-illness-fii-carers-practical-guide-paediatricians)

## MORE DETAILED INFORMATION

### M.E./CFS in more detail

M.E./CFS is a chronic, fluctuating, neurological condition that impacts on many body systems, more commonly the nervous and immune systems. M.E./CFS affects an estimated 250,000 people in the UK, including young people.

In some young people it appears to be triggered by a virus such as glandular fever, but for many it is impossible to pin-point what the trigger was, if anything.

Young people with M.E./CFS experience debilitating pain, fatigue and a range of other symptoms associated with **post-exertional malaise**, the body and brain's inability to recover after expending even small amounts of energy.

Not everyone will experience the same symptoms so it's important not to compare one young person with another. Young people with M.E./CFS vary enormously in their experience of the illness, and how long their symptoms last. Some make good progress and recover, while others remain ill for several years. Some young people find that they don't get back to the way they felt before they became ill but recover sufficiently to lead happy and fulfilling lives. **Some remain severely affected despite the involvement of specialist management. This is similar to many other chronic illnesses.**<sup>9</sup>

### Degrees of severity

NICE states that the physical symptoms of M.E./CFS can be as disabling as multiple sclerosis, systemic lupus erythematosus, rheumatoid arthritis, congestive heart failure and other chronic conditions. Other research in adults shows that people with M.E./CFS score lower overall on health-related quality of life tests than most other chronic conditions.<sup>10</sup>

The Functional Ability Scale<sup>11</sup> details the impact of mild, moderate and severe M.E. (see Appendix I on p 13).

**Even in its mildest form, M.E./CFS has a significant impact on a young person's life, and not just on their health.** A lack of understanding and awareness of M.E./CFS means young people experience stigma, disbelief and even discrimination, from friends, family and professionals.

### Key symptoms of M.E./CFS

Each young person's condition will follow a different pattern, and symptoms and severity can vary, fluctuate and change over time.

**M.E./CFS is not "feeling tired"** and it is distressing for a young person when faced with analogies from friends and professionals who refer to their own personal experiences eg. feeling exhausted after a game of football or a night out.

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<sup>9</sup> [www.actionforme.org.uk/what-is-me/introduction](http://www.actionforme.org.uk/what-is-me/introduction)

<sup>10</sup> Hvidberg et al (2015) The Health-Related Quality of Life for Patients with M.E./CFS. *PLOS ONE*

<sup>11</sup> [www.actionforme.org.uk/functional-ability-scale](http://www.actionforme.org.uk/functional-ability-scale)

Simple physical or mental activities, or combinations of activities, leave young people feeling utterly debilitated. They can also experience an increase in other symptoms, eg. pain, as a result.

The impact of this may be felt immediately but can typically take a day or even longer before being felt and is not significantly improved by rest. **This is a key feature of M.E./CFS and is known as post-exertional malaise (sometimes referred to as 'payback').**

While it's important to find out more about the range of symptoms experienced by a young person with M.E./CFS, it is also important to understand that some young people may only experience a few of them, at varying levels of severity; others may have all of the symptoms, all of the time. Any new symptom should be reviewed by a doctor, as it may be unrelated to M.E./CFS.

Along with post-exertional malaise, young people with M.E./CFS may experience a range of symptoms, listed in Appendix II (see p 15).

As a consequence of having to cope with the impact of their condition and its symptoms frustration, anxiety, low mood and depression are sometimes experienced by young people with long-term health conditions, M.E./CFS is no exception. **This does not mean that M.E./CFS is a mental health condition and should not be treated as such.**

### Impact of M.E./CFS on young people and their families

It's hard to put an accurate number on just how many young people have M.E./CFS.; prevalence rates vary widely, up to as high as 3%. It affects young people from all social classes and ethnic groups and is the biggest cause of long-term health-related school absence,<sup>12</sup> having a profound effect on every aspect of a young person's life.<sup>13</sup>

Parents are often forced to give up work to care for their child, affecting household income; accessing information and support in applying for benefits can alleviate this.

**M.E./CFS does not just affect teenagers.** The RCPCH recognises that children of any age can develop M.E./CFS,<sup>14</sup> and Action for M.E. has worked with children as young as three years old who have been diagnosed. Young people experience most of the same symptoms as adults, but they can be particularly prone to tummy aches, pain in their limbs, nausea, loss of appetite or weight gain. Girls may find that symptoms worsen at different times in their menstrual cycle.

Young people may become sensitive to light, sound and touch, exacerbating the reported social isolation not just from friends, but family as well. In the most severely affected, what should be a comforting hug becomes painful, and personal care can be difficult or impossible to maintain to a standard they would want. Many young people become sensitive to medication and as a result are unable to gain relief from their symptoms.

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<sup>12</sup> Dowsett and Colby (1997) Long Term Sickness Absence due to M.E./CFS in UK Schools: An Epidemiological Study with Medical and Educational Implications. *Journal of Chronic Fatigue*

<sup>13</sup> Geraghty and Charles (2019) The Importance of Accurate Diagnosis of ME/CFS in Children and Adolescents: A Commentary. *Frontiers in Pediatrics*

<sup>14</sup> Royal College of Child Health and Paediatrics (2004) *Evidence based Guideline for the Management of CFS/ME in children and young people*

Recognising and accepting the illness early on maximises the potential for improvement and recovery.<sup>15</sup> Though more studies are needed, most experts agree that young people with M.E./CFS have a better chance of full or partial recovery than adults.<sup>16</sup>

Perhaps the hardest outcome families are forced to face is disbelief and accusations (see Appendix III on p 17). Instead of offering help and support, professionals who haven't seen the condition or who lack understanding, awareness and belief, accuse parents of neglecting their child or causing their condition, ie. FII.

Schools may consider taking legal action because of poor or no attendance. Health professionals, due to the lack of availability of paediatric M.E./CFS specialist services, may be reluctant to diagnose in young people. In some cases, this leads to a deterioration in symptoms and functional ability.

Social Services can become involved for a variety of reasons and families with M.E./CFS are over-represented in child protection interventions, which are often not appropriate and increase stress and pressure on the family. This has led to a reluctance in some families to seek the help both they need.

It is understandable that, for some professionals, seeing a severely affected young person for the first time, in bed, in a darkened room, in extreme pain and isolated from their family and peers, can be alarming, particularly when they aren't able to access primary care support. Getting support to understand M.E. and its impact will allay this initial response and enable professionals to identify the support required.

### **The impact on education**

M.E./CFS introduces profound biographical disruption through its effects on young people's ability to socialise, perform in school and how they see their future.<sup>17</sup>

Every young person with a long-term health condition, including M.E./CFS, is entitled to an education that meets their individual needs.

The amended Children Act 2014 places a duty on local authority schools to make their Medical Conditions Policy available, and acts as good practice guidance for Academies and Public Education provision.

An Individual Health Care Plan (IHCP)<sup>18</sup> can be put in place to support joined-up working. The IHCP is a collaborative document, informed by the young person and their parents, with input from health professionals, facilitated and informed by education professionals. It should be reviewed regularly – at least termly, or at a time of significant change.

Young people with M.E./CFS need appropriate support from their teachers, school and other education services. Some may only be able to attend school part-time, and some not at all; for others, long irregular absences may occur.

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<sup>15</sup> ME Alliance (2005) ME Diagnosis: Delay Harms Health. [www.tymestrust.org/pdfs/me\\_diagnosis\\_report.pdf](http://www.tymestrust.org/pdfs/me_diagnosis_report.pdf)

<sup>16</sup> Centers for Disease Control and Prevention (2018) Presentation and Clinical Course of ME/CFS. [www.cdc.gov/me-cfs/healthcare-providers/presentation-clinical-course/prognosis.html](http://www.cdc.gov/me-cfs/healthcare-providers/presentation-clinical-course/prognosis.html)

<sup>17</sup> Parslow et al. (2017) Children's experiences of chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME): a systematic review and meta-ethnography of qualitative studies. *BMJ Open*.

<sup>18</sup> Health Conditions in Schools Alliance. [www.medicalconditionsatschool.org.uk](http://www.medicalconditionsatschool.org.uk)

Initially the family GP should be able, with the family's permission, to write to school and offer guidance on what is a suitable level of attendance for a young person or they may defer to the parent. If they feel a home tutor or online education would be better at this stage of the young person's condition this must be provided. Once under the care of a specialist M.E. service, managing the young person's education provision becomes part of the young person's overall care and management.

Health and education should work in partnership, with the young person and their family being at the centre of all plans and decisions.

### The impact on managing health

The family GP should be the best contact in terms of managing the young person's condition on a day-to-day basis. It should be recognised that there are poor levels of research, and limited treatment options for managing this complex condition, particularly in young people.

The NICE guideline for M.E./CFS states that, after three months without improvement, a young person should be referred to a paediatrician and after six months – or in the case of the young person becoming severely affected, immediately – to a specialist M.E./CFS paediatric service. However, as previously mentioned, there are very few specialist services available. Referral out of area may result in long delays waiting for funding, and long journeys to the service, which young people may not be able to manage.

When a diagnosis of M.E./CFS is confirmed, care can be co-ordinated and guidance made available for any educational and social issues that arise. Other healthcare professionals may be needed to provide support the young person's care. This will depend on the extent and stage of their illness and circumstances.

Health professionals may include occupational therapists, physiotherapists, social workers, nurses, dieticians and mental health professionals. All of these should work under the direction of the specialist service to avoid symptoms being exacerbated.

It should be noted here that there is no proven treatment or cure for this illness, so parents may refuse to proceed with management offered, as might happen with any illness. NICE says it expects healthcare professionals "to take our guidance into account, but people also have the right to be involved in discussions and make informed decisions about their care."<sup>19</sup>

Offering support at this time should be considered and may be all that is required. **Refusal of treatment alone is not sufficient reason for a referral to Social Services for investigation.**<sup>20</sup>

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<sup>19</sup> [www.nice.org.uk/about/nice-communities/nice-and-the-public/public-involvement/making-decisions-about-your-care/your-care](http://www.nice.org.uk/about/nice-communities/nice-and-the-public/public-involvement/making-decisions-about-your-care/your-care)

<sup>20</sup> RCPCH (2009) Fabricated or Induced Illness by Carers A Practical Guide for Paediatricians. [www.rcpch.ac.uk/resources/fabricated-or-induced-illness-fii-carers-practical-guide-paediatricians](http://www.rcpch.ac.uk/resources/fabricated-or-induced-illness-fii-carers-practical-guide-paediatricians)

## The impact on social life

M.E./CFS can make any kind of social interaction challenging and, for some, impossible. This can have a major impact on a young person's life, affecting school, hobbies and friendships. They might have to stop doing all the things they enjoy or do them less often.

It can be hard for friends to understand what they are going through, leaving them with feelings of no-one understanding what it's like to have M.E./CFS.

With the resulting isolation from peers, it is perhaps unsurprising that 97% of young people with the illness who engaged with Action for M.E.'s 2019 Big Survey said they feel socially isolated because of their condition.<sup>21</sup>

Introducing young people with M.E./CFS to Action for M.E.'s Young Person's Community, free to join for anyone aged 18 or under, can provide the much-needed social contact these young people ask for; services include a safe online forum, pen pals and a buddy scheme.

In addition, with the young person's permission, ensuring friends and classmates understand the fluctuating nature and range of symptoms can help to maintain contact and enable them to understand the confusing picture they see. School can help by ensuring young people are included in all information about school life even when unable to attend, newsletters, parents' evenings etc.

## Financial support

A personal budget is the amount of money a local authority allocates for care, based on its assessment of needs. It is possible for parents to be put in charge of this budget either by informing the local authority how they would like it spent, or by the council giving the money to the family so they can directly pay for care (a direct payment – see below).

It could also be given to a separate organisation (such as a user-controlled trust) that will spend the money on the young person's care as seen fit, if this is the family's preference. These are commonly known as Individual Service Funds.

Additionally, a combination of the above (for example, a direct payment with some council-arranged care and support) can be offered, often called a mixed package.

With the recognition of personal budgets in the law, every individual is legally entitled to a personal budget that must be incorporated in every care and support plan (or support plan for carers) – unless the individual is just getting intermediate care or re-enablement support to meet their identified needs. Legally, the young person has a right to advocacy support if they require help to have their say about his or her individual care needs.

An NHS personal health budget is an amount of money to support identified health and wellbeing needs, planned and agreed between the patient and local NHS team. The aim is to give people with long-term conditions and disabilities greater choice and control over the healthcare and support they receive.

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<sup>21</sup> [www.actionforme.org.uk/big-survey](http://www.actionforme.org.uk/big-survey)

Personal health budgets work in a similar way to the personal budgets that some people with M.E./CFS may already be using to manage and pay for their social care.

Together with the NHS team (such as a GP), a care plan should be developed. The plan sets out:

- personal health and wellbeing needs
- the health outcomes the patient wants to achieve
- the amount of money in the budget
- how the patient wants to spend it.

A personal health budget can be used to pay for a wide range of items and services, including therapies, personal care and equipment. This allows more choice and control over the health services and care received. A personal health budget cannot be used for emergency care or primary care services, eg. dental treatment.

### Rights and responsibilities

*“Every child has the right to say what they think in all matters affecting them and to have their views taken seriously.” (Article 12, UN Convention on the Rights of the Child)*

In circumstances where their parents are unable to do so, independent advocacy can be a much-needed process which ensures the voice of a young person with M.E. can be heard. Independent organisations (see useful contacts on p 12) can support young people in a range of situations including those with a disability; but every local authority should provide an advocacy service for young people.

If a young person is not able to communicate or instruct an advocate or does not have the capacity to understand the issues or consequences of choices, then non-instructed advocacy may be used.

*“Non-instructed advocacy is taking affirmative action with or on behalf of a person who is unable to give clear direction of their views or wishes in a specific situation. The non-instructed advocate seeks to uphold the person’s rights; ensure fair and equal treatment and access to services; and make certain that decisions are taken with due consideration for their unique preferences and perspectives.”<sup>22</sup>*

This type of advocacy ensures that the best interests, the rights of the young person and their views are included in decisions which affect their lives.

In non-instructed advocacy, the advocate’s actions will be based upon observations and their perception of the young person’s preferences and needs. Non-instructed advocacy should only be used when the young person is unable to instruct.

There may also be some situations where a parent, carer or guardian of a young person wishes their voice to be heard. It may be appropriate for an issues-based advocate (who works with adults, from an organisation such as Action for Advocacy – see useful contacts on p 12) to raise these concerns with professionals with direction from the parent, carer or guardian. This is not the same as legal advocacy.

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<sup>22</sup> Henderson, R. (2007) Non-instructed Advocacy in Focus. Action for Advocacy

If the advocate is advocating on behalf of the parent, carer or guardian then it is *their* views which will be amplified. It is important that the views and wishes of the young person do not get overlooked and that an appropriate person is sought to represent the young person in the situation if they are not able to do this themselves.

If an advocate is representing a parent, carer or guardian, this does not replace the need of the child to have their own views, wishes and needs heard and included (the young person may have differing views from that of their parent, carer or guardian).

The local authority has a duty to provide an independent advocate for any child or young person who feels they need someone independent to share their views and each local authority will have a different provider. Social workers can find out more about accessing advocacy for children and young people by contacting their local authority.

Action for M.E. can also offer advocacy for young people, supporting them to have their voice heard when engaging with education, health and social care services.

## Useful contacts

### **Action for M.E.**

*Information and support for young people, parents and professionals in the UK, including advocacy for young people and families*

42 Temple Street, Keynsham BS31 1EH

Tel: 0117 927 9551

Email: [questions@actionforme.org.uk](mailto:questions@actionforme.org.uk)

[www.actionforme.org.uk/children](http://www.actionforme.org.uk/children)

[www.actionforme.org.uk/parents](http://www.actionforme.org.uk/parents)

### **Action for Advocacy**

*Independent advocacy in England and Wales*

The Oasis Centre, 75 Westminster Bridge Road, London SE1 7HS

Tel: 0207 921 4395

Email: [info@actionforadvocacy.org.uk](mailto:info@actionforadvocacy.org.uk)

[www.actionforadvocacy.org.uk](http://www.actionforadvocacy.org.uk)

### **Coram Voice**

*Enabling children and young people in the UK to hold to account the services that are responsible for their care*

Coram Campus, 49 Mecklenburgh Square, London WC1N 2QA

Tel: 0808 800 5792

Email: [help@coramvoice.org.uk](mailto:help@coramvoice.org.uk)

[www.coramvoice.org.uk](http://www.coramvoice.org.uk)

### **National Youth Advocacy Service**

*Rights-based charity operating across England and Wales for children, young people and adults*

Tower House, 1 Tower Road, Birkenhead CH41 1FF

Tel: 0808 808 1001

Email: [help@nyas.net](mailto:help@nyas.net)

[www.nyas.net](http://www.nyas.net)

### **Who Cares? Scotland**

Professional, independent advocacy for young people in most local authority areas in Scotland.

Tel: 0141 226 4441

Email: [hello@whocaresscotland.org](mailto:hello@whocaresscotland.org)

[www.whocaresscotland.org](http://www.whocaresscotland.org)

## Appendix I: Action for M.E. functional ability scale

*The functional ability scale<sup>23</sup> can help young people describe and measure how much they can do. There are times when they will stay at the same level, and times when they may go up and down, sometimes slowly, and sometimes in a jump. An individual may be in different places physically and mentally on the scale.*

### 100% FUNCTIONAL ABILITY

**FULLY RECOVERED** No symptoms, even following physical or mental activity. Able to study (or work) full time without difficulty, and enjoy a social life.

### 95% FUNCTIONAL ABILITY

**VIRTUALLY RECOVERED** No symptoms at rest. Mild symptoms following physical or mental activity – tire rather easily but fully recovered next day. Able to study or work full time without difficulty, but social life is slightly restricted.

### 90% FUNCTIONAL ABILITY

**MILDLY AFFECTED** No symptoms at rest. Mild symptoms following physical or mental activity - tire easily. Study/work full time with some difficulty. Social life rather restricted with gradual recovery over two/three days.

### 80% FUNCTIONAL ABILITY

**MILDLY AFFECTED** Mild symptoms at rest, worsened to moderate by physical or mental activity. Full time study at school/college is difficult, as is full-time work, especially if it is a crowded, noisy or busy environment. Home tuition or part-time study without difficulty.

### 70% FUNCTIONAL ABILITY

**MODERATELY AFFECTED** Mild symptoms at rest, worsened to severe by physical or mental activity. Daily activity limited. Part time study at school/college is very tiring, and may be restricting social life. Part time work may be possible for a few hours in the day. With careful pacing of activities and rest periods, you may discover windows of time during the day when you feel significantly better. Gentle walking or swimming can be beneficial.

### 60% FUNCTIONAL ABILITY

**MODERATELY AFFECTED** Mild to moderate symptoms at rest. Increasing symptoms following physical or mental activity. Daily activity very limited. Study with others or work outside the home difficult unless additional support is available (such as use of a wheelchair/quiet room for a rest period). Short (1-2 hours) daily home study/work may be possible on good days. Quiet, non-active social life possible.

### 50% FUNCTIONAL ABILITY

**MODERATE TO SEVERELY AFFECTED** Moderate symptoms at rest. Increasing symptoms following physical or mental activity. Midday rest may still be needed. Simple, short (1hr) home study/home activity possible, when alternated with quiet, non-active social life. Concentration is limited. Not confined to the house, but may be unable to walk much beyond 100-200m without support. May manage a trip to the shops in the wheelchair.

### 40% FUNCTIONAL ABILITY

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<sup>23</sup> Action for M.E. (2019) Symptoms, energy and rest.

[www.actionforme.org.uk/functional-ability-scale](http://www.actionforme.org.uk/functional-ability-scale)

**MODERATE TO SEVERELY AFFECTED** Moderate to severe symptoms following any activity. Care must be taken not to overdo anything at this stage. Not confined to the house, but unable to walk much more than 50- 100m, usually requiring aids such as walking stick/crutches. May manage a wheelchair trip to the shops on a quiet day, and 3 or 4 regular rest periods are needed during the day. Only one 'large' activity possible per day – eg. a friend dropping by, or doctor's visit, or short home study (half hour at a time), with space usually requiring rest day/s between.

**30% FUNCTIONAL ABILITY**

**SEVERELY AFFECTED** Moderate to severe symptoms at rest. Severe symptoms following any physical or mental activity. Usually confined to the house but may occasionally take a quiet wheelchair ride or very short, gentle walk in the fresh air. Most of the day resting. Very small tasks possible but mental concentration poor and home study difficult.

**20% FUNCTIONAL ABILITY**

**SEVERELY AFFECTED** Fairly severe symptoms at rest. Weakness in hands, arms or legs may be restricting movement. Unable to leave the house except very rarely. Confined to bed/settee most of the day but able to sit in a chair for a few, short periods. Unable to concentrate for more than one hour a day but can read for about five to 10 minutes at a time.

**10% FUNCTIONAL ABILITY**

**VERY SEVERELY AFFECTED** Severe symptoms following any activity. Weakness and pain in arms or legs. In bed most of the time but feeling more stable and less dizzy. No travel outside the house. Concentration very difficult indeed. A friend can be seen for ten minutes or so.

**5% FUNCTIONAL ABILITY**

**VERY SEVERELY AFFECTED** Severe symptoms almost continuously, but may be possible to be propped up in bed for very short periods. Weakness and pain in arms or legs can give rise to paralysis; dizziness and nausea. Small, personal care may be possible (eg. if washing equipment placed on the bed it may be possible to wash some parts of the body). As with 0%, sudden jerking movements can be a problem and what may be described as panic attacks are felt. No TV is possible but a little quiet music or audio book may be listened to for a few minutes. A friend can be seen for a minute for a hug and a few words.

**0% FUNCTIONAL ABILITY**

**VERY SEVERELY AFFECTED** Severe symptoms on a continuous basis. In bed constantly, feeling extremely ill even with permanent rest. Severe dizziness makes it almost impossible to be propped up in bed for longer than a few minutes at a time. Light and noise are very painful to the eyes and ears - curtains are closed and earplugs are needed. Severe pain almost anywhere in the body with the skin feeling very cold and extremely sensitive to touch. Unable to care for self at all; washing needs to be done a tiny bit at times throughout the day. Nausea and severe fatigue make eating extremely difficult. Liquid based food preferred– little and often. Occasionally, nasal feeding tubes are required when the energy to chew is completely spent. Any stimulus worsens the feeling of being severely ill, with no movement in the bedroom preferred. Any visitor to the room is almost impossible. Talking, even to the carer/family, is often impossible. This is often misread as being “selective mute.” Severe adrenaline rushes felt with heightened sensitivity; sleep pattern often completely reversed.

## Appendix II: Symptoms of M.E./CFS

While it's important to find out more about the range of symptoms<sup>24</sup> experienced by a young person with M.E./CFS, it is also important to understand that some young people may only experience a few of them and at varying levels of severity and others, all of the symptoms, all of the time. However any new symptom should be reviewed by a doctor, as it may be unrelated to M.E./CFS.

Along with post-exertional malaise, young people with M.E./CFS may experience a range of symptoms, as follows.

### Feeling generally unwell

- Having flu-like symptoms (often called “general malaise” by doctors)
- Recurrent sore throat, with or without swollen glands.

### Pain, such as:

- aching muscles
- aching joints
- nerve pains or pins and needles
- headache or migraine
- twitching muscles or cramps
- abdominal pain (stomach or bowel problems)
- chest pain
- back pain.

If pain, especially muscle pain, is more of a problem than fatigue, fibromyalgia may be considered as a diagnosis.

### Sleep disturbance, such as:

- unrefreshing sleep
- difficulty getting off to sleep
- waking for long periods in the early hours
- light, dreamy, restless sleep
- sleep reversal (for example sleeping from 4am till midday)
- hypersomnia (sleeping for a long time).

### Problems with concentration, thinking and memory (often referred to as “brain fog”), such as:

- reduced attention span
- short-term memory problems
- speech and language problems, including word-finding difficulties
- inability to plan or organise thoughts
- loss of concentration.

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<sup>24</sup> Action for M.E. (2019) Symptoms. [www.actionforme.org.uk/what-is-me/symptoms](http://www.actionforme.org.uk/what-is-me/symptoms)

**Problems with the nervous system, such as:**

- poor temperature control
- dizziness on standing or sitting up
- hyper-sensitivity to light and sound
- sweating
- loss of balance
- poor circulation.

**Digestive problems, such as:**

- nausea
- loss of appetite
- indigestion
- excessive wind/bloating
- cramps
- alternating diarrhoea and constipation
- Irritable Bowel Syndrome.

**Intolerance and increased sensitivity to:**

- bright lights
- noise
- touch
- odours
- some foods (for example dairy or wheat)
- some medications
- alcohol.

As a consequence of having to cope with the impact of their condition and its symptoms frustration, anxiety, low mood and depression are sometimes experienced by young people with long-term health conditions, M.E./CFS is no exception. **This does not mean that M.E./CFS is a mental health condition, and should not be treated as such.**

### Appendix III: Families facing false accusations

Action for M.E.'s 2017 survey of 270 families<sup>25</sup> with children affected by M.E./CFS shows that one in five who responded have faced accusations of fabricated/induced illness, abuse or neglect, leading to child protection referrals.

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.

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 Action for M.E.'s 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 said these were instigated by a teacher; nearly three quarters of these (70%) said FII was a factor.

One parent reported: "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 reported: "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 Action for M.E.'s 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.

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<sup>25</sup> Action for M.E. (2017) Families facing false accusations: results of Action for M.E.'s survey. [www.actionforme.org.uk/uploads/pdfs/families-facing-false-accusations-survey-results.pdf](http://www.actionforme.org.uk/uploads/pdfs/families-facing-false-accusations-survey-results.pdf)