ME in children and young people: A guide for social workers

Updated: March 2025

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Introduction

A lack of understanding about myalgic encephalomyelitis (ME) and its impact means that families living with this illness, sometimes diagnosed as chronic fatigue syndrome (CFS, or ME/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, so that Children and Families Social Workers can better support their clients and work more effectively with other health and care professionals.

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

A note on ME and long Covid

The term 'long COVID is commonly used to describe signs and symptoms that continue or develop after infection with SARS-CoV-2. It includes both ongoing symptomatic COVID-19 (from 4 to 12 weeks) and post-COVID-19 syndrome (12 weeks or more).

In children and young people, "the overlap of symptoms between long COVID and ME is substantial and includes fatigue, post-exertional malaise, cognitive impairment, sleep disturbance and lightheadedness," says research published in the Paediatric Infectious Disease Journal in 2022.[1]

Initial findings from an NIHR-funded paediatric study into long Covid, the Clock Study showed that 14% of children can go on to develop long Covid.[2]

A meta-analysis published in 2022[3] found that the prevalence of long Covid in children was 25.24% although others have reported lower figures. Whatever the exact rate, it is widely accepted that for a proportion of people of all ages, multiple symptoms may develop and/or persist following acute COVID-19 infection.

The information and guidance in this resource may also be applied to families of children and young people living with long Covid.

Acknowledgements

This resource was first produced in 2019 then reviewed in detail and updated in May 2024 by Action for ME in collaboration with Dr Emma Reinhold and Prof Andy Bilson. It will be reviewed regularly, and feedback is welcome (please send to infosupport@actionforme.org.uk).

Quotations in boxes throughout are taken from Explaining ME/CFS,[4] a resource developed and written by young people with ME supported by Action for ME.

What is ME? An overview

Around one in 200 children and young people are estimated to have ME.[5]

The 2021 National Institute for Health and Care Excellence (NICE) guideline for ME6 highlights that ME/CFS is a complex, chronic, fluctuating medical condition that affects everyone differently, with symptoms (see p 14) that can change unpredictably in nature and severity over a day, week or longer, affecting activities of daily living, family life, social life, emotional wellbeing, work and education.

There is currently a lack of paediatric specialists in the condition, meaning specialist medical help and support for families is frequently inaccessible, and there is often a delay in even getting a diagnosis.[7]

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 ME 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.

One in five families of young people with ME have faced unfounded accusations of fabricated or induced illness (FII), abuse or neglect, leading to child protection referrals.[8]

While there is poor access to medical management and appropriate care and support, young people can be helped with the right social work interventions, supporting parents and young people in their right to choose, in navigating health, education and social care systems, and in coping with the impact of having a child/young person with a profoundly debilitating long-term condition.

When might social care professionals see young people with ME?

ME 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/long-term condition.

Schools may be, often inappropriately, concerned or even considering legal action due to a lack of consistent attendance.

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 or perplexing presentation.

What practice guidance should social workers keep in mind when working with young people with ME and their families?

Begin by understanding post-exertional malaise and the serious impact it can have (see p 16) alongside additional symptoms, and the fluctuating nature of the condition. To avoid triggering PEM, people with ME are advised to practice energy management, sometimes called “pacing.”

It means planning activities which use physical or mental energy and not doing too much at one time, or on one day/week as well as constantly listening to your body. This is not easy, and you may be able to support a family in learning how to pace.

> *"Trying to push through ME/CFS is like trying to run up an escalator that's going down. You can try as hard as you can, but you will inevitably end up crashing down at the bottom. You can determinedly sprint up that escalator again and again but you will fall harder every time."*

Understand levels of severity of ME and how this may present, e.g. 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, and even requiring tube feeding, whereas a mildly affected young person may initially present with poor school attendance.

Explain your role and responsibilities and the process, leaving literature for parents to read following your visit.

Acknowledge the difficulties of having an “invisible illness.” Validate the young person’s experience of the illness, symptoms and impact, by listening and asking clarifying questions. Remember that ME is a fluctuating condition and symptoms can change over time.

Avoid too many questions: listen and clarify only when essential. Accept that parents may frequently need to speak on the young person’s behalf, both because it can be difficult to describe the bodily experiences, and because such conversations can be exhausting in themselves.

Allow time over several visits to get to know and understand the individual and their family; energy levels vary from person to person and from day to day.

Ask how long the young person can meet for and if there is a better time of day for your visit, and, if severely affected, accept you may not meet the young person for your first few visits if they are having a bad day.

Consider first meeting with the young person but give them permission to withdraw if they run out of energy and continue speaking with their parents/carers.

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.

Children experiencing significant pain may need to distract themselves by listening to music or playing games on an electronic device. Ask what else you may need to consider.

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

Parents may be struggling to come to terms with the impact on the young person's life and possibly coping with the financial and other stresses of having to give up work to be at home with their child. Ensure the family are aware of any welfare benefits or other financial support they may be entitled to.

Social isolation for the young person with ME and their parent(s) can be hard. Consider whether there may be aids or adaptations which might help the individual or their family. This may include the use of wheelchairs, application for a blue badge and other equipment for the home eg. shower chairs.

Feeling heard and then being signposted to the right support (see useful contacts on p 22) can be a lifeline to families coping with a long-term condition, particularly one that is invisible, frequently misunderstood and underdiagnosed.

Key advice from the NICE guideline for ME/CFS

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.

Refusal of treatment alone is not sufficient reason for a referral to Social Services for investigation.

The NICE guideline for ME/CFS[6] states (section 1.7.4): "Recognise that the following are not necessarily signs of abuse or neglect in children and young people with confirmed or suspected ME/CFS:

- physical symptoms that do not fit a commonly recognised illness pattern
- more than 1 child or family member having ME/CFS
- disagreeing with, declining or withdrawing from any part of their care and support plan, either by them or by their parents or carers on their behalf
- parents or carers acting as advocates and communicating on their behalf
- reduced or non-attendance at school."

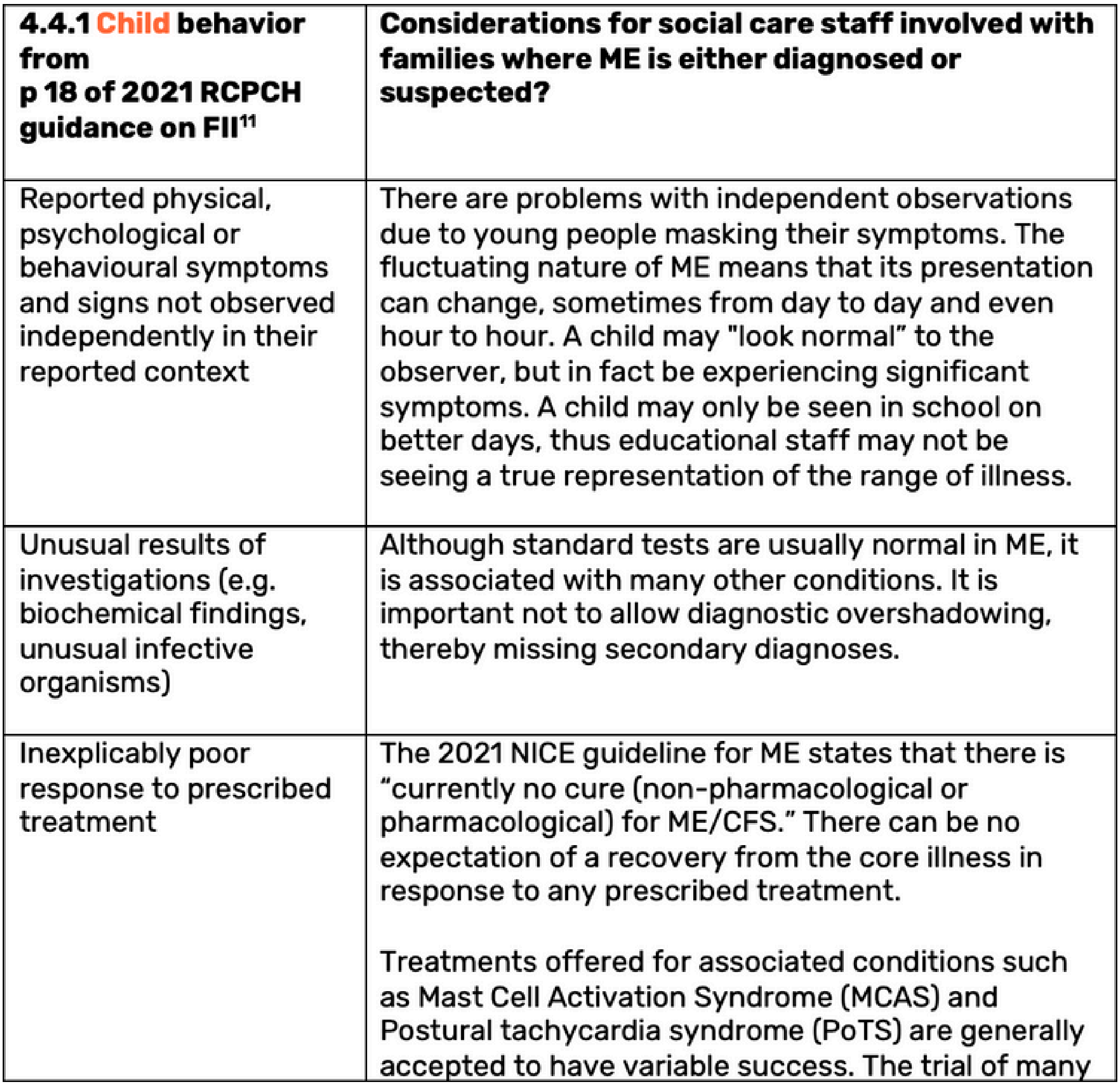
The 2021 NICE guideline on babies, children and young people's experience of healthcare[9] offers useful guidance on the principles of shared decision-making.

How the FII alerting signs can lead to misidentification of FII in cases of ME/CFS

There is a high rate of children with ME being misidentified as having been the subject of FII (see Appendix II). The alerting signs for FII have no research base and have not been tested for specificity and sensitivity.[10]

In the case of children who have ME many of the alerting signs will arise from the child's illness and parent's natural responses to it rather than because of fabrication. This will particularly be the case in the many cases where ME is still undiagnosed, and parents are struggling to get their child's illness identified. Social workers need to be able to distinguish between FII and ME.

The two tables below (child behaviour from p 6 to 7, then parent behaviour from p 8 to 12) shows how misidentification of FII can occur because the alerting signs of FII are present due to ME and not fabrication.



4.4.1 Child behavior from p 18 of 2021 RCPCH guidance on FII[11]	**Considerations for social care staff involved with families where ME is either diagnosed or suspected?**
Reported physical, psychological or behavioural symptoms and signs not observed independently in their reported context	There are problems with independent observations due to young people masking their symptoms. The fluctuating nature of ME means that its presentation can change, sometimes from day to day and even hour to hour. A child may "look normal" to the observer, but in fact be experiencing significant symptoms. A child may only be seen in school on better days, thus educational staff may not be seeing a true representation of the range of illness.
Unusual results of investigations (e.g. biochemical findings, unusual infective organisms)	Although standard tests are usually normal in ME, it is associated with many other conditions. It is important not to allow diagnostic overshadowing, thereby missing secondary diagnoses.
Inexplicably poor response to prescribed treatment	The 2021 NICE guideline for ME states that there is “currently no cure (non-pharmacological or pharmacological) for ME/CFS.” There can be no expectation of a recovery from the core illness in response to any prescribed treatment. Treatments offered for associated conditions such as Mast Cell Activation Syndrome (MCAS) and Postural tachycardia syndrome (PoTS) are generally accepted to have variable success. The trial of many

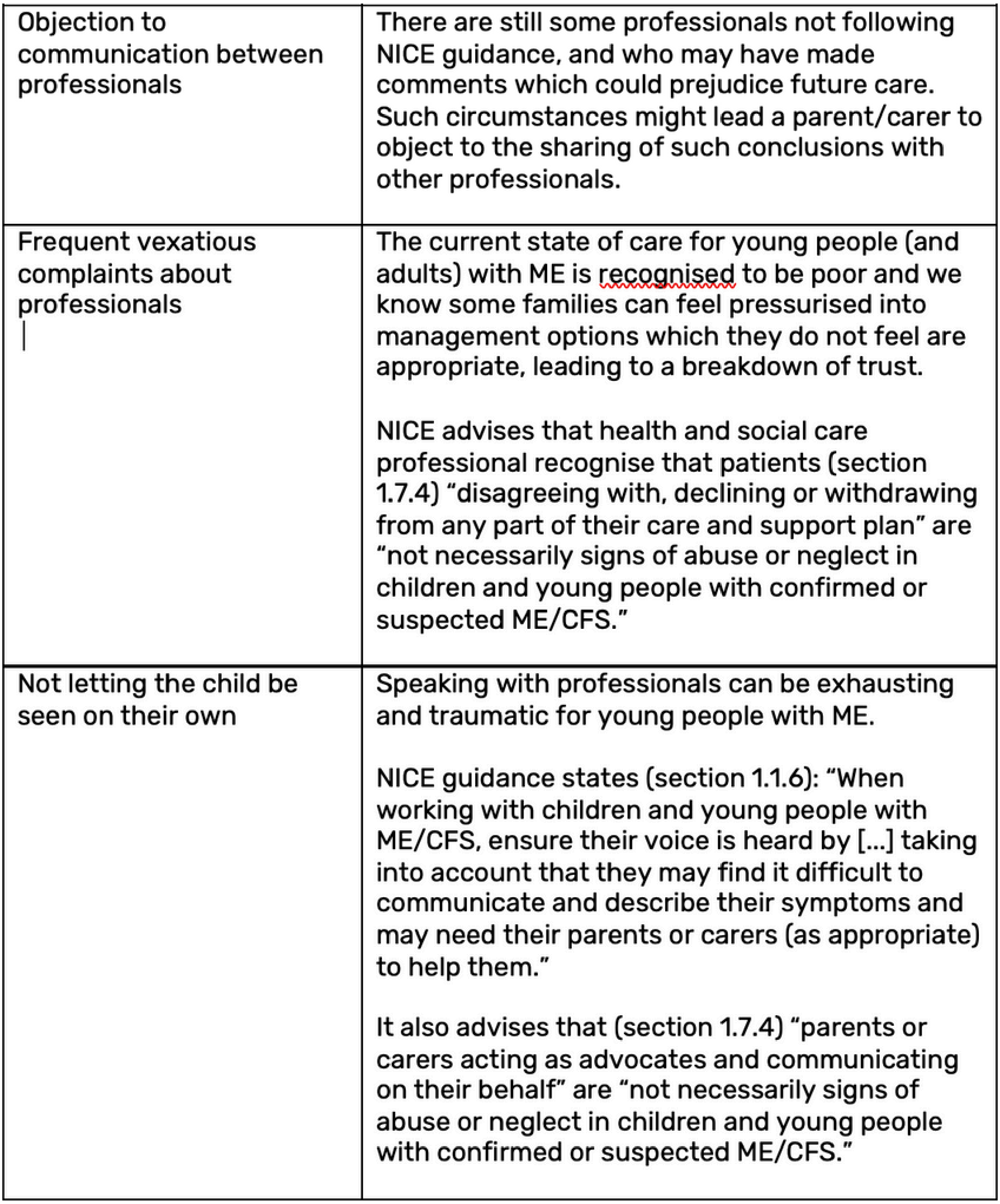
	combinations of drugs is commonplace, with some conferring no benefit to the individual and therefore being stopped. Additionally, it is acknowledged by specialists in the medical profession and the 2021 NICE guideline for ME/CFS (sections 1.12.15 to 1.12.18) that intolerance to medication is seen in patients with ME/CFS.
Some characteristics of the child's illness may be physiologically impossible eg. persistent negative fluid balance, large blood loss without drop in haemoglobin	Social workers should be encouraged to maintain professional curiosity not only about families, but also the opinion of medical professionals.
Unexplained impairment of child's daily life, including school attendance, aids, social isolation	ME is a complex, fluctuating condition, meaning that attendance at school or other activities may be erratic. The NICE guideline highlights (section 1.7.4) "that the following are not necessarily signs of abuse or neglect in children and young people with confirmed or suspected ME/CFS: […] reduced or non-attendance at school." It also advises highlighting to people with ME that (section 1.9.2) "there may be times when they are unable to continue with work or education" and that children and young people with ME (section 1.9.6) should be advised that "training or education should not be the only activity they undertake; [and] they should aim to find a balance between the time they spend on education or training, home and family life, and social activities." It gives clear guidance about how best to support children and young people to access appropriate educational and social activities tailored to their individual needs, capabilities and wishes. This may include the use of aids and equipment (section 1.8.8): "For people with moderate ME/CFS or severe or very severe ME/CFS, consider providing or recommending aids and adaptations (such as a

	wheelchair, blue badge or stairlift) that could help them maintain their independence and improve their quality of life, taking into account the risks and benefits.”

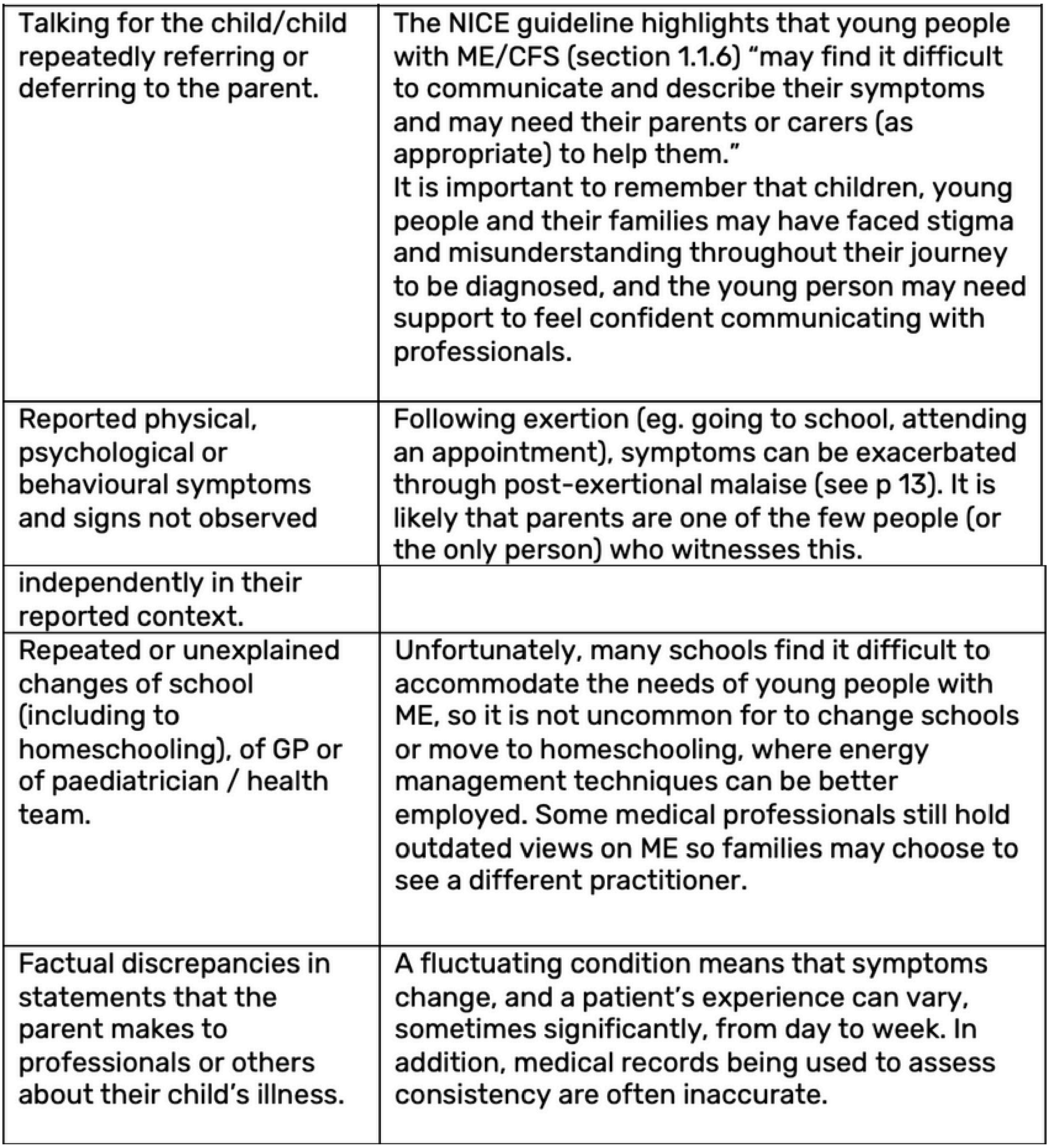
4.4.2 Parent behaviour from p 18 of 2021 RCPCH guidance on FII[11]	**Possible explanations where ME is either diagnosed or presents as potential diagnosis**
Parents’ insistence on continued investigations instead of focusing on symptom alleviation when reported symptoms and signs not explained by any known medical condition in the child	The wide range of ME symptoms are frequently misunderstood and underdiagnosed in primary care, which may lead medical professionals to undertake further investigations. As ME is also associated with other conditions, it may be advisable to continue investigations for these, whilst also attempting to alleviate symptoms in parallel. Although ME can manifest in many ways, it is also important that families report atypical symptoms in order that additional diagnoses are not missed.
Parents’ insistence on continued investigations instead of focusing on symptom alleviation when results of examination and investigations have already not explained the reported symptoms or signs	Standard diagnostic test results are usually “normal” in ME. Care must be taken in explaining that this does not mean that the medical team are saying there is nothing physically wrong. It is a widely held belief that there must be a test for all medical conditions. On the contrary, there are still medical conditions which rely solely on a clinical diagnosis. At the onset of symptoms of ME, it is not possible to make a definitive diagnosis, as this requires symptoms to be ongoing for a three-month period.
Repeated reporting of new symptoms.	ME symptoms (see p 13) are multiple and varied and commonly fluctuate over time. At initial appointments, often under time pressure, young people may not list every symptom, focusing on the most important. It is entirely expected that new symptoms can develop over time with ME. NICE recommends that people with ME/CFS

	need (section 1.1.4) “regular monitoring and review, particularly when their symptoms are worsening, changing or are severe.”
Repeated presentations to and attendance at medical settings including Emergency Departments.	Some parents have found they have to go through multiple GP appointments before being believed. A young person with orthostatic symptoms [a form of low blood pressure that happens when standing after sitting or lying down] might present to A&E if they have fainted, or if they are really poorly a parent may end up seeking help via A&E.
Inappropriately seeking multiple medical opinions.	It’s important to consider what circumstances would lead seeking answers to be considered “inappropriate” here – have the parents and child been involved in shared decision making up to this point? RCPH guidance on seeking second[12] says: “Children with complex care needs are often under the care of multiple specialist teams, which can mean that families have difficulty navigating the decision-making process. It is always important to hear the voice of the child. Sometimes families report that their experience of their child’s life is not given sufficient weight in informing treatment decisions.” The first phase of the introduction of Martha's Rule is being implemented in the NHS from April 2024. Once fully implemented, patients, families, carers and staff will have round-the-clock access to a rapid review from a separate care team if they are worried about a person's condition.
Providing reports by doctors from abroad which are in conflict with UK medical practice.	The UK is not at the forefront in managing ME well, so it’s important to remain open to new information about this condition. In addition, there are comorbid conditions for which it is extremely difficult to get assessments in the UK.

Child repeatedly not brought to some appointments, often due to cancellations.	Some young people with ME, particularly those with a more severe disease, may be unable to attend appointments or consultations at short notice. This may be due to a flare up, relapse, post-exertional malaise (see p 13) or other factors related to their health. The NICE guideline says (section 1.8.1): "Health and social care organisations should ensure that people with ME/CFS can use their services by: • adapting the timing, length and frequency of all appointments to the person's needs • taking into account physical accessibility, such as how far the person has to travel, whether there is suitable transport and parking, and where rooms are for appointments • taking into account sensitivities to light, sound, touch, pain, temperature extremes or smells • providing care flexibly to the person's needs, such as by online or phone consultations or making home visits."
Not able to accept reassurance or recommended management, and insistence on more, clinically unwarranted, investigations, referrals, continuation of, or new treatments (sometimes based on internet searches).	NICE recognises that there are no curative treatments for ME/CFS, and that symptoms management focuses on pacing, or energy management. However, we also know that people with ME are prone to many comorbid conditions, which may be overlooked. Parents/carers, seeing their child in obvious physical and psychological distress, may seek further investigations or treatments in a genuine attempt to help their child. Professionals should not feel threatened by this natural search for answers and improvements. Parents of children with long term conditions, including ME, will often become experts, keeping up with the latest research.



Objection to communication between professionals	There are still some professionals not following NICE guidance, and who may have made comments which could prejudice future care. Such circumstances might lead a parent/carer to object to the sharing of such conclusions with other professionals.
Frequent vexatious complaints about professionals	The current state of care for young people (and adults) with ME is recognised to be poor and we know some families can feel pressurised into management options which they do not feel are appropriate, leading to a breakdown of trust. NICE advises that health and social care professional recognise that patients (section 1.7.4) "disagreeing with, declining or withdrawing from any part of their care and support plan" are "not necessarily signs of abuse or neglect in children and young people with confirmed or suspected ME/CFS."
Not letting the child be seen on their own	Speaking with professionals can be exhausting and traumatic for young people with ME. NICE guidance states (section 1.1.6): "When working with children and young people with ME/CFS, ensure their voice is heard by [...] taking into account that they may find it difficult to communicate and describe their symptoms and may need their parents or carers (as appropriate) to help them." It also advises that (section 1.7.4) "parents or carers acting as advocates and communicating on their behalf" are "not necessarily signs of abuse or neglect in children and young people with confirmed or suspected ME/CFS."



Talking for the child/child repeatedly referring or deferring to the parent.	The NICE guideline highlights that young people with ME/CFS (section 1.1.6) “may find it difficult to communicate and describe their symptoms and may need their parents or carers (as appropriate) to help them.” It is important to remember that children, young people and their families may have faced stigma and misunderstanding throughout their journey to be diagnosed, and the young person may need support to feel confident communicating with professionals.
Reported physical, psychological or behavioural symptoms and signs not observed independently in their reported context.	Following exertion (eg. going to school, attending an appointment), symptoms can be exacerbated through post-exertional malaise (see p 13). It is likely that parents are one of the few people (or the only person) who witnesses this.
Repeated or unexplained changes of school (including to homeschooling), of GP or of paediatrician / health team.	Unfortunately, many schools find it difficult to accommodate the needs of young people with ME, so it is not uncommon for to change schools or move to homeschooling, where energy management techniques can be better employed. Some medical professionals still hold outdated views on ME so families may choose to see a different practitioner.
Factual discrepancies in statements that the parent makes to professionals or others about their child’s illness.	A fluctuating condition means that symptoms change, and a patient’s experience can vary, sometimes significantly, from day to week. In addition, medical records being used to assess consistency are often inaccurate.

ME in more detail

ME is a chronic, fluctuating, neurological condition that impacts on many body systems, more commonly the nervous and immune systems. There are an estimated 1.3 million people, including young people, living in the UK with ME or ME-like symptoms.

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

Young people with ME experience debilitating pain, fatigue and a range of other symptoms associated with post-exertional malaise.

This is the body and brain’s inability to recover after expending even a small amount of cognitive, physical, emotional or social activity. Individuals may find their symptoms worsen 12 to 48 hours after the activity and can last for days or weeks, sometimes leading to a relapse. Post-exertional malaise can have a significant impact on a children or young person’s life.

> *"Having ME/CFS feels like something constantly needs repairing but you're never quite fixed."*

Not everyone will experience the same symptoms so it's important not to compare one young person with another.

Young people with ME vary enormously in their experience of the illness, and how long their symptoms last.

Symptoms of ME in young people can include (but aren’t limited to) “orthostatic intolerance and other signs of autonomic dysfunction, and cognitive problems, as well as by unrefreshing sleep, headache, and other pain symptoms.”[13]

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.

"Prioritising activities that are most important to you is essential (eg. choosing to limit social time to focus on exams, or focusing on physical wellbeing rather than schoolwork). Also, having the self discipline to stop yourself from overdoing things is really important with pacing (this can be hard!). There is a lot of support out there, so to anyone with ME/CFS, remember there is an awesome community out there to support you and you are not alone!"

Degrees of severity

ME affects every person differently and the degree of severity of symptoms varies from person to person. Some people with ME have mild symptoms and can participate in some activities, whereas others with severe ME are bedbound.

Research in adults[5] shows that people with ME score lower overall on health-related quality of life tests than most other chronic conditions.

The 2021 NICE guideline for ME/CFS[6] offers definitions for mild, moderate, severe and very severe ME (see “Box 1 Severity of ME/CFS” on p 8 of the guideline). It is important to remember that even with these definitions of severity, it is not clear cut because individual symptoms vary.

Even in its mildest form, ME has a significant impact on a young person’s life, and not just on their health.

The 2021 NICE guideline for ME/CFS[6] offers definitions for mild, moderate, severe and very severe ME (see “Box 1 Severity of ME/CFS” on p 8 of the guideline). It is important to remember that even with these definitions of severity, it is not clear cut because individual symptoms vary.

A lack of understanding and awareness of ME means young people experience stigma, disbelief and even discrimination, from friends, family and professionals.

Key symptoms of ME

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

ME 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. The fatigue experienced by a person with ME is debilitating and prevents them from participating in normal daily activities.

Simple physical or mental activities, or combinations of activities, leave young people feeling utterly debilitated. They can also experience an increase in other symptoms 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 ME and is known as post-exertional malaise (sometimes referred to as ‘payback’).

Post-exertional malaise can make it difficult for a young person or child to participate in normal activities, especially as it may take a significant amount of planning to accommodate any ‘payback’ they may experience afterwards. Post-exertional malaise can make symptoms worse for days or even months, and can sometimes lead to a relapse.

This makes it a key barrier to learning and accessing health and social care.

Many people with ME manage their limited energy using a strategy called pacing. This means keeping activity levels within a certain range with the aim of preventing an increase in symptoms. Professionals can support pacing by agreeing to keep appointments short, and/or taking breaks, being led by the young person with ME and their family.

> *“What helps with managing symptoms? ‘Having the love and support of family and friends who can bolster me up.' 'Pacing and planning.' ‘Reading and music.' ‘Regular rest/sleep."*

While it’s important to find out more about the range of symptoms experienced by a young person with ME, 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 ME.

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, ME is no exception.

This does not mean that ME/CFS is a mental health condition and should not be treated as such.

Action for ME offers support and services (see useful contacts on p 22) to help children and young people who may be feeling isolated, are worried about friendships or struggling to get others to understand the impact of ME.

Impact of ME on young people and their families

It’s hard to put an accurate number on just how many young people have ME.; 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,[14] having a profound effect on every aspect of a young person’s life.[15]

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.

ME does not just affect teenagers. The RCPCH recognises that children of any age can develop ME[16] and Action for ME 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.

Recognising and accepting the illness early on maximises the potential for improvement and recovery.[17] Though more studies are needed, most experts agree that young people with ME have a better chance of full or partial recovery than adults.[9]

Perhaps the hardest outcomes that some families are forced to face are disbelief and accusations. Instead of offering help and support, professionals who haven't seen the condition or who lack understanding accuse parents of neglecting their child or causing their condition, i.e. FII.

> *"ME/CFS is not a mental illness and the main goal of someone with ME/CFS is to become as well as possible. ME/CFS is not a choice."*

Schools may consider taking legal action because of poor or no attendance. Health professionals, due to the lack of availability of paediatric ME/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 ME are over-represented in child protection interventions, which increase stress and pressure on the family. This has led to a reluctance in some families to seek the help 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 patients aren't able to access primary care support.

Getting support to understand ME and its impact will allay this initial response and enable professionals to identify the support required.

The impact on education

ME introduces profound biographical disruption through its effects on young people's ability to socialise, perform in school and how they see their future.[10]

Every young person with a long-term health condition, including ME, 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) 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 ME 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.

> *When asked what education support they wanted, young people said: "Having better systems in place for students who are too severe to attend school in person (e.g. online zoom calls)," and "A better understanding of the illness and appreciate the difficulty of managing both education and a chronic illness."*

Section 1.9 of the 2021 NICE guideline for ME/CFS6 offers key guidance for professionals on supporting young people and adults with ME in work, education and training, including signposting to the Department for Education's Guidance on supporting pupils at school with medical conditions.[18]

The NICE guideline also highlights that school attendance should not be the sole goal for young people with ME/CFS (section 1.9.6): "Advise children and young people with ME/CFS and their parents or carers (as appropriate) that:

- training or education should not be the only activity they undertake
- they should aim to find a balance between the time they spend on education or training, home and family life, and social activities.

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.

Section 1.2.7 of the 2021 NICE guideline for ME/CFS6 states that any young person with suspected ME/CFS should be referred to a paediatrician for further assessment and investigation, and that professionals should "start to work with the child or young person's place of education or training to support flexible adjustments or adaptations."

A diagnosis does not need to be confirmed for a support plan to be put in place. Sometimes diagnosis can take many more months than it should, so care should not be delayed on this basis.

Guidance should be made available for any educational and social issues that arise. Other healthcare professionals may be needed to 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.

The RCPCH briefing on the 2021 NICE guideline16 highlights the "inclusion on the regularity of assessments for children, in section 1.7.6 on safeguarding. This notes that children and young people should be seen at six-monthly intervals and more frequently if needed, depending on the severity and complexity of their symptoms."

For children and young people who are so severely affected that they cannot even tolerate getting out of bed, home visits should be considered a basic reasonable adjustment.

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.

Refusal of treatment alone is not sufficient reason for a referral to Social Services for investigation.

The impact on social life

ME 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, particularly when they experience post-exertional malaise (see p XX) following activity.

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 ME.

With the resulting isolation from peers, it is perhaps unsurprising that 97% of young people with the illness who engaged with Action for ME's 2019 Big Survey[19] said they feel socially isolated because of their condition.

A diagnosis does not need to be confirmed for a support plan to be put in place. Sometimes diagnosis can take many more months than it should, so care should not be delayed on this basis.

Introducing young people with ME to Action for ME'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

According to the Equality Act 2010, you are disabled if you have a physical or mental impairment that has a substantial or long-term effect on your ability to do normal activities.

This means that some young people with ME will quality for disability-related welfare benefits.

Families should be signposted to appropriate information and advice about their entitlements, including Disability Living Allowance (Child Disability Payment in Scotland).

A child with ME may also be entitled to a personal budget based on 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 reablement 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.

NHS personal health budgets work in a similar way to the personal budgets that some people with ME use to manage and pay for their social care. Together with the NHS team (such as a GP), a care plan can be developed to set 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 (but not emergency or primary care services, eg. dental treatment). This allows more choice and control over the health services and care received.

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 ME can be heard.

Independent organisations (see useful contacts on p 24) 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.

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 24) to raise these concerns with professionals with direction from the parent, carer or guardian. This is not the same as legal 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.

Useful contacts

Action for ME
Free support services for young people with ME and their parents.
Unit 2.2 Streamline, 436-441 Paintworks
Bristol, BS4 3AS
Tel: 0117 927 9551 (Mon to Fri 10am to 4pm)
Email: infosupport@actionforme.org.uk
www.actionforme.org.uk

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
www.actionforadvocacy.org.uk

Coram Voice
Supporting children and young people in care and care leavers through advocacy and other services.
Coram Campus, 49 Mecklenburgh Square, London WC1N 2QA
Tel: 0808 800 5792
Email: help@coramvoice.org.uk
www.coramvoice.org.uk

Health Conditions in Schools Alliance
Guidance and tools for schools who are looking after children with health conditions.
www.medicalconditionsatschool.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
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
www.whocaresscotland.org

Appendix I: families facing false accusations

Action for ME's 2017 survey[8] of 270 families with children affected by ME shows that one in five who responded have faced accusations of fabricated/induced illness, abuse or neglect, leading to child protection referrals.

- 96% of respondents felt that a lack of understanding of ME 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 (11%) or physical (2%) abuse.
- 70% of all cases were dropped within a year.

When children and young people become ill with ME, we all too often see their experience being misinterpreted by teachers and peers, resulting in them being accused of being lazy, anxious or depressed. Action for ME's survey shows 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 ME. 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 ME’s survey are frequently challenged on school attendance and the validity of their child’s ME diagnosis (despite this being confirmed in many cases by at least one specialist) by professionals who do not understand the complexities of ME.

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