

**Action for M.E. summary of the National Institute for Health Excellence (NICE) guideline for M.E./CFS, draft for consultation, November 2020**

**Summary of guidance relating to children and young people with M.E./CFS**

Most sections of the draft NICE guideline for M.E. give specific guidance relating to children and young people, which we summarise below, and share in full on pages 3 to 7. Please note this should be considered in the context of the overall guideline.

In the guideline, children and young people are aged under 18 (adults are 18 and above).

**Key messages for taking an empathic, child-led approach**

- As with adults, any professionals working with children and young people with M.E. should be aware of the impact of “prejudice and disbelief” from people who do not understand the illness.
- A child-centred approach must be taken to ensure that the voice of the child or young person is always heard.
- When sharing information with children and young people, their age, level of understanding, any disabilities and communication needs must be taken into account.

**Key messages for diagnosing children and young people**

- M.E. should be suspected if a child or young person has all of the persistent symptoms – see p 3 – for four weeks. This should prompt a referral to a paediatrician, and a letter from the doctor to their school to advise on flexible adjustments and adaptations.
- Children and young people and their parents/carers should be advised that, although different for everyone, the outlook is usually better in children and young people than in adults.

**Key messages for symptom management**

- Energy management: children and young people in particular may find it harder to judge their limits and can overreach them; support from a healthcare professional may be useful.
- Medicines for symptom management should only be started under guidance or supervision from a paediatrician.
- Children and young people who are losing weight should be referred to a paediatric dietitian who specialises in ME/CFS.

- Cognitive behavioural therapy should only be considered for a child or young person if they and their parents or carers have been fully informed about its aims and principles and any potential benefits and risks.
- GPs are advised to review children and young people’s management plans at least every six months, with clear guidance on what the review should include, overseen by an appropriate specialist with expertise in M.E.

### **Key messages around care, support and safeguarding**

- Children and young people with moderate, severe or very severe ME/CFS and their parents/carers should be advised that they may be entitled to social care support, and signposted to government regulations on this.
- Parents should be given details of a named professional in the specialist team.
- There is detailed guidance on working with the school to support the child or young person’s symptom-management plan, with clear advice that “training or education should not be the only activity they undertake.”
- When moving to adult services, refer to the [NICE guideline on transition from children's to adults' services for young people using health or social care services.](#)
- Clear advice on safeguarding states that “physical symptoms that do not fit a commonly recognised illness pattern” and other common causes for concern, including reduced school attendance, “are not necessarily a sign of abuse or neglect in children and young people with confirmed or suspected ME/CFS.”

Copied and pasted from each section of the draft NICE guideline, for ease of reference

From section 1.1 Principles of care for people with ME/CFS

**Additional principles of care for children and young people with ME/CFS**

1.1.6 Be aware of the impact on children and young people with ME/CFS who have experienced prejudice and disbelief by people they know and who do not understand the illness (family, friends, health and social care professionals and teachers). Health and social care professionals should understand this experience may result in a breakdown of the therapeutic relationship, lack of trust and hesitation to engage further in health and social care services.

1.1.7 Ensure the voice of the child or young person is always heard by:

- taking a child-centred approach, with the communication focusing on them
- discussing and regularly reviewing with the child or young person how they want to be involved in decisions about their care (taking into account that their parents or carers may act as advocate)
- taking into account that children and young people may find it difficult to describe their symptoms and may need their parents or carers to help them.

From section 1.21 Suspecting ME/CFS

1.2.3 Suspect ME/CFS if:

- the person has had all of the persistent symptoms (see Box 1) for a minimum of 6 weeks in adults and 4 weeks in children and young people.

Box 1 Symptoms for suspecting ME/CFS

- Debilitating fatigability that is not caused by excessive cognitive, physical, emotional or social exertion and is not significantly relieved by rest **and**
- Post-exertional symptom exacerbation after activity that:
  - is delayed in onset by hours or days
  - is disproportionate to the activity
  - has a prolonged recovery time lasting hours, days, weeks or longer **and**
- Unrefreshing sleep, which may include:
  - feeling exhausted, flu-like and stiff on waking
  - broken or shallow sleep, altered sleep pattern or hypersomnia **and**
- Cognitive difficulties (sometimes described as ‘brain fog’), including problems finding words, temporary dyslexia or dyscalculia, slurred speech, slowed responsiveness, short-term memory problems, confusion, disorientation and difficulty concentrating or multitasking.

## **Referring children and young people with suspected ME/CFS**

1.2.8 When ME/CFS is suspected in a child or young person based on the criteria in recommendation 1.2.3:

- refer them to a paediatrician for further assessment and investigation for ME/CFS and other conditions
- write to the child or young person's place of education or training to advise about flexible adjustments or adaptations.

## **From section 1.6 Information and support**

### **Communication**

1.6.2 When providing information for children and young people with ME/CFS, take into account their age and level of understanding, any disabilities or communication needs. Use interactive formats such as:

- one-to-one or group discussion
- written materials and pictures
- play, art and music activities
- digital media, for example video or interactive apps.

### **Information about ME/CFS**

1.6.5 Explain to children and young people with ME/CFS and their parents and carers that although long-term outcomes are different for everyone, the outlook is usually better in children and young people than in adults.

### **Social care**

1.6.10 Advise children and young people with moderate ME/CFS to severe or very severe ME/CFS and their parents or carers that they may be entitled to support from children's social care as children in need because of their disability.

### **Supporting families and carers of people with ME/CFS**

1.6.12 Advise families and carers about the right to assessment and support for their own needs, as follows:

- parents or carers of children and young people under 16 with ME/CFS, according to the Children and Families Act 2014
- young carers, according to the Young Carers (Needs Assessment) Regulations 2015.

## **From section 1.7 Safeguarding**

### **Children and young people**

1.7.4 Be aware that recognising and responding to possible child abuse and neglect (maltreatment) is complex and should be considered in the same way for children and

young people with confirmed or suspected ME/CFS as with any child with a chronic illness or disability. Follow the NICE guidelines on child maltreatment and child abuse and neglect.

1.7.5 Using a child-centred approach, listen to the child or young person and support them to express their wishes and feelings. Follow the principles of the Children Acts 1989 and 2004 that the welfare of the child is paramount and that children are best looked after within their families, with their parents playing a full part in their lives, unless compulsory intervention in family life is necessary (see the [Department for Education's statutory guidance on working together to safeguard children](#)).

1.7.6 Recognise that the following are not necessarily a sign 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 child or family member having ME/CFS
- is agreeing with, declining or withdrawing from any part of their management plan, either by the child or young person or by their parents or carers on their behalf
- parents or carers acting as an advocate and communicating on behalf of the child or young person
- reduced or non-attendance at school.

### **From section 1.9 Supporting people with ME/CFS in work, education and training**

1.9.4 Health and social care professionals should work with training and education services to:

- provide information about ME/CFS and the needs and impairments of children and young people with ME/CFS, including the need for a balance of activities in their life
- discuss the child or young person's management plan so that everyone has a common understanding of their priorities, hopes and plans discuss a flexible approach to training and education – this could include adjustments to the school day, online or home schooling and using assistive equipment.

1.9.5 Give parents and carers information about education, health and care plans and how to request one from their local authority.

1.9.6 Advise children and young people with ME/CFS (and their parents and carers) 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.

### **From section 1.10 Multidisciplinary care**

#### **Children and young people**

1.10.4 Provide parents and carers of children and young people with ME/CFS with details of a named professional in the specialist team who they can contact with any concerns about their child's health, education or social life.

## **Moving into adults' services**

1.10.5 For young adults with ME/CFS moving from children's to adults' services, manage transitions in line with the NICE guideline on transition from children's to adults' services for young people using health or social care services.

## **From section 1.11 Managing ME/CFS**

### **Energy management**

1.11.2 Discuss with people with ME/CFS the principles of energy management, its role in supporting them to live with their symptoms, the potential benefits and risks and what they should expect. Explain that it:

- can include help from a healthcare professional to recognise when they are approaching their limit (children and young people in particular may find it harder to judge their limits and can overreach them).

### **Medicines for symptom management**

1.11.32 Drug treatment for the symptoms associated with ME/CFS for children and young people should only be started under guidance or supervision from a paediatrician.

### **Dietary management and strategies**

1.11.38 Refer children and young people with ME/CFS who are losing weight or have faltering growth or dietary restrictions to a paediatric dietitian who specialises in ME/CFS.

1.11.39 For advice on food allergies in children, see the [NICE guideline on food allergy in under 19s](#).

### **Psychological support: cognitive behavioural therapy**

#### **Children and young people**

1.11.48 Only consider CBT for a child or young person with ME/CFS if they and their parents or carers have been fully informed about its aims and principles and any potential benefits and risks.

1.11.49 If CBT is considered for children and young people with ME/CFS:

- involve parents or carers in the therapy wherever possible
- adapt therapy to the child or young person's cognitive and emotional stage of development.

## **From section 1.14 Review**

### **Children and young people**

1.14.3 When undertaking a review in primary care, ensure you have access to the person's management plan and (if relevant) discharge letter from the specialist ME/CFS team. As part of the review, discuss with the person with ME/CFS (and their family members and carers, as appropriate) and record as a minimum:

- their condition, including any changes and the impact of these, including what can and cannot be achieved
- symptoms, including whether they have experienced new symptoms
- self-management – ask about activity management strategies
- who is helping them and how they provide support
- emotional and social wellbeing
- any future plans – ask if the person is considering any changes or if they have any challenges ahead.

1.14.6 Offer children and young people with ME/CFS a review of their care and management plan at least every 6 months (see recommendation 1.14.3 for what to review).

1.14.7 When deciding on how often reviews or reassessment might be needed for children and young people with ME/CFS, take into account:

- their developmental stage
- transitions, such as changing schools or exams
- the severity and complexity of symptoms
- the effectiveness of any symptom management.

1.14.8 Ensure reviews are carried out or overseen by a paediatrician with expertise in ME/CFS. Involve other appropriate specialists as needed.

Also see recommendation 1.1.7 on ensuring the child's voice is heard and on involving their parents or carers.