NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

Guideline

Myalgic encephalomyelitis (or encephalopathy)/chronic fatigue syndrome: diagnosis and management

Draft for consultation, November 2020

This guideline covers diagnosing and managing myalgic encephalomyelitis (or encephalopathy)/chronic fatigue syndrome (ME/CFS) in children, young people and adults. It aims to improve awareness and understanding about ME/CFS and when to suspect it, so that people are diagnosed earlier. It also includes recommendations on assessment and care planning, safeguarding, access to care and symptom management.

This guideline will update NICE guideline CG53 (published August 2007).

Who is it for?

- Health and social care professionals, including those working or providing input into educational and occupational health services
- Commissioners
- People with suspected or diagnosed ME/CFS, their families and carers and the public

What does it include?

- the recommendations
- recommendations for research
- rationale and impact sections that explain why the committee made the recommendations and how they might affect practice

- the guideline context.

Information about how the guideline was developed is on the guideline's webpage. This includes the evidence reviews, the scope, details of the committee and any declarations of interest.

The recommendations in this guideline update were developed based on evidence reviewed before the COVID-19 pandemic. We have not reviewed evidence on the effects of COVID-19, such as fatigue, so it should not be assumed that these recommendations apply to people who have fatigue after COVID-19.

NICE is working jointly with SIGN (The Scottish Intercollegiate Guidelines Network) and the Royal College of General Practitioners to develop a guideline on the long-term effects of COVID-19, including fatigue, which we expect to publish by the end of the year.

Contents

Recommendations

People have the right to be involved in discussions and make informed decisions about their care, as described in making decisions about your care.

Making decisions using NICE guidelines explains how we use words to show the strength (or certainty) of our recommendations, and has information about prescribing medicines (including off-label use), professional guidelines, standards and laws (including on consent and mental capacity), and safeguarding.

1.1 Principles of care for people with ME/CFS

Awareness of ME/CFS and its impact

1.1.1 Be aware that ME/CFS:

- is a complex, chronic medical condition affecting multiple body systems and its pathophysiology is unclear
- can have a significant impact on people's (and their families and carers') quality of life, including their activities of daily living, family life, social life, emotional wellbeing, work and education
- affects each person differently and varies widely in severity – in its most severe form it can lead to substantial incapacity (see recommendations 1.1.8 and 1.1.9)
- is a fluctuating condition in which symptoms can change unpredictably in nature and severity over days, weeks or longer – ranging from being able to carry out most daily activities to severe debilitation.

1.1.2 Recognise that people with ME/CFS may have experienced prejudice and disbelief and feel stigmatised by people who do not understand their illness. Take into account:

- how this could affect the person with ME/CFS
- that they may have lost trust in health and social services and be hesitant about involving them.

Approach to delivering care

1.1.3 Health and social care professionals should:

- acknowledge to the person the reality of living with ME/CFS and how symptoms could affect them
- take time to build supportive, trusting and empathetic relationships
- use a person-centred approach to assess people's needs
- involve family members and carers (as appropriate) in discussions and care planning if the person with ME/CFS chooses to include them.

1.1.4 Recognise that people with ME/CFS need:

- early and accurate diagnosis so they get appropriate care for their symptoms
- regular monitoring and review, particularly when their symptoms are worsening or changing (see the section on managing flares and relapse).

1.1.5 Explain to people with ME/CFS and their family or carers that they have the right to decline or withdraw from any part of their management plan and it will not affect other aspects of their care. They can begin or return to an intervention if they feel able to resume.

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.

Awareness of severe or very severe ME/CFS and its impact

1.1.8 Be aware that people with severe or very severe ME/CFS may experience some of the following symptoms that significantly affect their emotional wellbeing, communication, mobility and ability to interact with others and care for themselves:

- severe and constant pain, which can have muscular, arthralgic or neuropathic features
- hypersensitivity to light, noise, touch, movement, temperature extremes and smells
- extreme weakness, with severely reduced movement
- reduced ability or inability to speak or swallow
- cognitive difficulties, causing a limited ability to communicate and take in written or verbal communication
- sleep disturbance such as unrefreshing sleep, hypersomnia, altered sleep pattern
- gastrointestinal difficulties such as nausea, incontinence, constipation and bloating
- neurological symptoms such as double vision and other visual disorders, dizziness
- postural orthostatic tachycardia syndrome (POTS) and postural hypotension.

1.1.9 Recognise that symptoms of severe or very severe ME/CFS may mean that people:

- need a low-stimulus environment, for example a dark quiet room with interaction at a level of their choice (this may be little or no social interaction)
- are housebound or bed-bound and may need support with all activities of daily living
- need careful physical contact when supported with activities of daily living, taking into account possible sensitivity to touch
- need aids such as wheelchairs
- cannot communicate without support and may need someone else they have chosen to be their advocate and communicate for them
- are unable to eat and digest food easily and may need support with hydration and nutrition (see the section on dietary management and strategies)
- have problems accessing information, for example because of difficulty with screens, noise and light sensitivity, headaches affecting their ability to read, or brain fog affecting their concentration.

1.1.10 Personal care and support for people with severe or very severe ME/CFS should be carried out by health and social care practitioners who are:

- known to the person and their family members or carers wherever possible
- aware of the person's needs.

1.1.11 Risk assess each interaction with a person with severe or very severe ME/CFS in advance to ensure its benefits will outweigh the risks to the person (for example, worsening their symptoms). For people with very severe ME/CFS, think about discussing this with the person's family or carer on their behalf.

For a short explanation of why the committee made these recommendations see the rationale and impact section on principles of care for people with ME/CFS.

Full details of the evidence and the committee's discussion are in evidence review A: information for people with ME/CFS and evidence review C: access to care and appendix 2: people with severe ME/CFS. Other supporting evidence and discussion can be found in evidence review B: information for health and social care professionals and appendix 1: children and young people.

1.2 Suspecting ME/CFS

1.2.1 Explain to people presenting with possible symptoms of ME/CFS that there currently is no diagnostic test for ME/CFS and it is recognised on clinical grounds alone.

1.2.2 If ME/CFS is suspected carry out an assessment, which should include:

- a comprehensive clinical history
- a physical examination
- psychological wellbeing assessment
- baseline investigations to exclude other diagnoses.

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
- the person's ability to engage in occupational, educational, social or personal activities is significantly reduced from pre-illness levels
- symptoms are new and had a specific onset.

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.

1.2.4 Be aware that the following symptoms may also be associated with, but are not exclusive to, ME/CFS:

- orthostatic intolerance and autonomic dysfunction, including dizziness, palpitations, fainting, nausea on standing or sitting upright from a reclining position
- temperature hypersensitivity resulting in profuse sweating, chills, hot flushes, or feeling very cold
- neuromuscular symptoms, including twitching and myoclonic jerks
- flu-like symptoms, including sore throat, tender glands, nausea, chills or muscle aches
- intolerance to alcohol, or to certain foods, and chemicals
- heightened sensory sensitivities, including to light, noise, touch and smell
- pain, including pain on touch, myalgia, headaches, eye pain, abdominal pain or joint pain without acute redness, swelling or effusion.

1.2.5 Do not delay making a provisional diagnosis of ME/CFS. As soon as ME/CFS is suspected, based on the criteria in recommendation 1.2.3, give the person advice about symptom management (see the section on managing ME/CFS).

1.2.6 When ME/CFS is suspected, continue with any tests needed to exclude other conditions and explain to people that this does not affect their provisional diagnosis of ME/CFS.

1.2.7 Primary healthcare professionals should consider seeking advice from an appropriate specialist if there is uncertainty about interpreting signs and symptoms and whether a referral is needed.

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.

> For a short explanation of why the committee made these recommendations see the rationale and impact section on suspecting ME/CFS.
>
> Full details of the evidence and the committee's discussion are in evidence review D: diagnosis.

1.3 Advice for people with suspected ME/CFS

See section 1.11 for recommendations on managing specific symptoms. This guideline does not cover all the symptoms that can occur in ME/CFS and refers to other NICE guidance in section 1.12.

1.3.1 When ME/CFS is suspected, give people personalised advice about managing their symptoms. Also advise them:

- not to use more energy than they perceive they have − they should plan their daily activity to stay within their energy envelope and not push through activity
- to rest as they need to
- to maintain a healthy balanced diet, with adequate fluid intake.

1.3.2 Explain to people with suspected ME/CFS that their diagnosis can only be confirmed after 3 months of persistent symptoms. Reassure them that they can return for a review if they develop new or worsened symptoms, and ensure they know who to contact for advice.

For a short explanation of why the committee made these recommendations see the rationale and impact section on advice for people with suspected ME/CFS.

Full details of the evidence and the committee's discussion are in evidence review E: strategies pre diagnosis.

1.4 Diagnosis

Making a diagnosis

1.4.1 Diagnose ME/CFS in a child, young person or adult who has the symptoms in recommendation 1.2.3 that have persisted for 3 months.

1.4.2 After a diagnosis, refer adults directly to a specialist team experienced in managing ME/CFS to develop a management plan.

1.4.3 If ME/CFS is diagnosed in a child or young person after assessment by a paediatrician (based on the criteria in recommendation in 1.2.3), refer them directly to a paediatric specialist team experienced in ME/CFS to develop a management plan.

For a short explanation of why the committee made these recommendations see the rationale and impact section on diagnosis.

Full details of the evidence and the committee's discussion are in evidence review D: diagnosis.

1.5 Assessment and care planning by a specialist ME/CFS team

1.5.1 After confirming a diagnosis of ME/CFS, carry out and record a holistic assessment. This should include:

- a full history (including relevant symptoms and history, comorbidities, overall physical and mental health, anything that is known to

exacerbate or alleviate symptoms, sleep quality and other causes of physical or emotional stress)
- physical functioning
- the impact of symptoms on psychosocial wellbeing
- current and past experiences of medicines (including tolerance and sensitivities), vitamins and mineral supplements
- dietary assessment (including weight history before and after their diagnosis of ME/CFS, use of restrictive and alternative diets, and access to shopping and cooking).

1.5.2 Develop a personalised management plan with the person with ME/CFS (and their family members or carers, as appropriate) informed by the holistic assessment. Based on the person's needs, include in the plan:

- information and support needs (see section 1.6 on information and support)
- support for activities of daily living (see recommendation 1.8.7 on maintaining independence)
- mobility aids and adaptations to increase or maintain independence (see recommendations 1.8.9 to 1.8.11 on aids and adaptations)
- education, training or employment support needs (see section 1.9 on supporting people with ME/CFS in work, education and training)
- self-management strategies, including energy management (see recommendations 1.11.2 to 1.11.10 on energy management)
- physical maintenance (see recommendations 1.11.11 to 1.11.14 on physical maintenance)
- symptom management (see recommendations 1.11.27 to 1.11.50 on managing symptoms)
- guidance on managing flares and relapse (see section 1.13 on managing flares and relapses)
- details of the health and social care professionals involved in the person's care, and how to contact them.

1.5.3 Recognise that the person with ME/CFS is in charge of the aims of their management plan. The plan should be mutually agreed and based on the person's:

- preferences and needs
- skills and abilities in managing their condition
- hopes, plans and priorities
- symptom severity
- physical and cognitive functioning.

1.5.4 Give the person (and their family members or carers, as appropriate) a copy of their management plan and share a copy with their GP.

People with severe or very severe ME/CFS

1.5.5 Offer home visits to people with severe or very severe ME/CFS to carry out their holistic assessment and develop their management plan.

For a short explanation of why the committee made these recommendations see the rationale and impact section on assessment and care planning.

Full details of the evidence and the committee's discussion are in evidence review G: non pharmacological management and evidence review A: information for people with ME/CFS.

1.6 Information and support

Communication

1.6.1 Provide information to people with ME/CFS and their families and carers in a variety of formats (for example, written materials, electronic and audio) that can be used both at home and in the clinical setting. Follow the principles on communication, information giving and shared decision making in the NICE guidelines on patient experience in adult NHS services and people's experience in adult social care services.

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

1.6.3 Give people and their families and carers (as appropriate) up-to-date information about ME/CFS starting from when ME/CFS is suspected. Tailor information to people's circumstances, including their symptoms, the severity of their condition and how long they have had ME/CFS. Ask people regularly if they would like more information or to revisit discussions.

1.6.4 Explain that ME/CFS:

- is a fluctuating medical condition that affects everyone differently, in which symptoms and their severity can change a lot over a day, week or longer
- often involves periods of remission and relapse, although it is less common to have long periods of remission (see the section on managing flares and relapse)
- varies in long-term outlook from person to person – although a small proportion of people recover or have a long period of remission, many will need to adapt to living with ME/CFS
- can have a major impact on people's lives, including their daily activities, family and social life, and work or education, so they may need to adjust how they live
- can be worsened by particular triggers, for example new infections, physical injury or stressful events, including childbirth
- may be self-managed with support and advice (see the section on energy management).

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.

1.6.6 Give people (and their families and carers, as appropriate) information about:

- self-help groups, support groups and other local and national resources for people with ME/CFS
- advice about financial support, including applying for benefits.

1.6.7 Give families and carers of people with ME/CFS information about the condition and ways they can help the person.

Social care

1.6.8 Discuss sensitively with the person and their family members or carers how social care may benefit them. Explain that it can help the person living with ME/CFS as well as provide a route to support for families and carers through a formal carer's assessment.

1.6.9 Explain to people and their families and carers how to self-refer for a social care needs assessment from their local authority. Offer to make the referral for them if they prefer.

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

1.6.11 Follow recommendations in the NICE guideline on supporting adult carers on identifying, assessing and meeting the caring, physical and mental health needs of families and carers.

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.

For a short explanation of why the committee made these recommendations see the rationale and impact section on information and support.

Full details of the evidence and the committee's discussion are in evidence review A: information for people with ME/CFS. Other supporting evidence and discussion can be found in evidence review B: information for health and social care professionals, evidence review C: access to care and appendix 1: children and young people.

1.7 Safeguarding

1.7.1 Safeguarding assessments in people with confirmed or suspected ME/CFS should be carried out or overseen by health and social care professionals who have training and experience in ME/CFS.

1.7.2 Recognise that people with ME/CFS, particularly those with severe or very severe ME/CFS, are at risk of their symptoms being confused with signs of abuse or neglect.

1.7.3 If an assessment under the Mental Health Act 1983 or the Mental Capacity Act 2005 is needed, involve health and social care professionals who have training and experience in ME/CFS. This should be done within 24 hours in an emergency.

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 1 child or family member having ME/CFS
- disagreeing 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.

For a short explanation of why the committee made these recommendations see the rationale and impact section on safeguarding.

Full details of the evidence and the committee’s discussion are in evidence review B: information for health and social care professionals. Other supporting evidence and discussion can be found in evidence review A: information for people with ME/CFS and appendix 1: children and young people.

1.8 Access to care

1.8.1 Service providers should ensure people with ME/CFS can access health and social care 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, noise, touch, pain, temperature extremes or smells
- providing care flexibly, such as by phone or video conferencing or making home visits.

1.8.2 Do not discharge someone who misses appointments because their symptoms have worsened. Contact them to explore why they could not attend and how to support them.

1.8.3 Be aware that people with ME/CFS are unlikely to be seen at their worst because:

- debilitating symptoms, fear of relapse or post-exertional symptom exacerbation may often prevent people from leaving their home
- cognitive difficulties may often mean people wait until they feel they can speak and explain clearly before contacting services.

People with severe or very severe ME/CFS

1.8.4 Service providers should be proactive and flexible in delivering services to people with severe or very severe ME/CFS, who may have particular difficulty accessing services and articulating their needs. This could include home visits, online consultations, written communication, and supporting their applications for aids and appliances.

Hospital care

For improving access to hospital outpatient care for people with ME/CFS, see recommendation 1.8.1.

1.8.5 Discuss with people who need inpatient care whether any aspects of where their care will be provided could cause problems for them, including:

- where a bed is situated on a ward (if possible, aim to provide a single room)
- the accessibility of toilets and washrooms
- environmental factors such as lighting, noise, heating and smells.

People with severe or very severe ME/CFS

1.8.6 When planning hospital care for people with severe or very severe ME/CFS:

- discuss with the person (and their family members or carers, as appropriate) what to expect when they come into hospital
- aim to minimise discomfort and post-exertional symptom exacerbation during transfer to hospital, for example by planning the route in advance, avoiding noisy areas and admitting them straight to the ward on arrival
- discuss the person's management plan with them, including information on comorbidities, intolerances and sensitivities, to plan any reasonable adjustments that are needed
- aim to provide a single room if possible
- keep stimuli to a minimum, for example by:
  - seeing them one-to-one
  - using calm movements and gestures
  - not duplicating assessments
  - being cautious about the pressure of touch
  - keeping lights dimmed
  - reducing noise
  - keeping a stable temperature
  - minimising strong smells.

Maintaining independence

1.8.7 If a person with ME/CFS needs support at home, conduct a social care assessment, record and provide information and support on:

- activities of daily living
- mobility, including transferring from bed to chair, access to and use of the toilet and washing facilities, use of stairs, and access to outside space
- dexterity and poor balance, including avoiding falls
- their home, including environmental controls to avoid glare from lights, loud noise, and temperature fluctuations
- the feasibility of equipment and adaptations
- access to technology, including online access
- where to get financial support and advice, for example signposting to advice on money management and making personalised arrangements with banks or the Post Office to access personal finances, and how to claim carers' and disability benefits and grants.

1.8.8 Give families and carers information on how to access training and resources about how to care for the person with ME/CFS.

Aids and adaptations

1.8.9 Provide aids and adaptations identified in the person’s management plan without delay, so that people can carry out activities of daily living and maintain their quality of life as much as possible.

1.8.10 Enable prompt assessment for funding for home adaptation. If the person is not eligible for funding, continue to offer information and support in arranging home adaptations.

1.8.11 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. Include these in the person’s management plan.

For a short explanation of why the committee made these recommendations see the rationale and impact section on access to care.

Full details of the evidence and the committee's discussion are in evidence review C: access to care. Other supporting evidence and discussion can be found in evidence review A: information for people with ME/CFS and appendix 2: people with severe ME/CFS.

1.9 Supporting people with ME/CFS in work, education and training

1.9.1 Advise people with ME/CFS that:

- there may be times when they are unable to continue with work or education
- some people find that going back to work, school or college worsens their symptoms
- they may be able to access reasonable adjustments or adaptations (in line with the Equality Act 2010) to help them continue or return to work or education.

1.9.2 Offer to liaise on the person's behalf (with their informed consent) with employers, education providers and support services. Give them information about ME/CFS and discuss the person's agreed management plan and any adjustments needed.

1.9.3 Health and social care professionals should follow the Department for Education's guidance on supporting pupils at school with medical conditions or equivalent statutory guidance.

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.

For a short explanation of why the committee made these recommendations see the rationale and impact section on supporting people with ME/CFS in work, education and training.

Full details of the evidence and the committee's discussion are in evidence review A: information for people with ME/CFS and appendix 1: children and young people.

1.10 Multidisciplinary care

1.10.1 Provide care for people with ME/CFS using a coordinated multidisciplinary approach. Based on the person's needs, include health and social care professionals with expertise in the following:

- self-management strategies, including energy management
- symptom management
- managing flares and relapse
- activities of daily living
- emotional wellbeing, including family and sexual relationships
- diet and nutrition

- mobility, avoiding falls and problems from loss of dexterity, including access to aids and rehabilitation services
- social care and support
- support to engage in work, education, social activities and hobbies.

1.10.2 Care for people whose ME/CFS is managed in primary care should be supported by advice and direct clinical consultation from a specialist team.

1.10.3 Give people with ME/CFS (and their family members and carers, as appropriate) a named contact in their primary care and/or specialist team to coordinate their management plan, help them access services and support them during periods of relapse.

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.

For a short explanation of why the committee made these recommendations see the rationale and impact section on multidisciplinary care.

Full details of the evidence and the committee's discussion are in evidence review I: multidisciplinary care, evidence review C: access to care. Other supporting evidence and discussion can be found in evidence review A: information for people with ME/CFS and appendix 1: children and young people with ME/CFS.

1.11 Managing ME/CFS

Refer to relevant NICE guidance for managing symptoms associated with ME/CFS that are not covered in this section.

1.11.1 Be aware there is no current treatment or cure (non-pharmacological or pharmacological) for ME/CFS.

For a short explanation of why the committee made this recommendation see the rationale and impact section on managing ME/CFS.

Full details of the evidence and the committee's discussion are in evidence review F: pharmacological management and evidence review G: non pharmacological management.

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:

- is not curative
- is a self-management strategy led by the person themselves but with support from a healthcare professional
- can be applied to any type of activity
- helps people understand their energy envelope so they can reduce the risk of overexertion worsening their symptoms
- recognises that each person has a different and fluctuating energy limit, and they are the best judge of their own limits
- 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)
- uses a flexible, tailored approach so that activity is never automatically increased but is progressed during periods when symptoms are improved and allows for the need to pull back when symptoms are worse

- is a long-term approach − it can take weeks, months or sometimes even years to reach stabilisation or to increase tolerance or activity
- does not assume that deconditioning is the cause of ME/CFS.

1.11.3 Carry out an assessment to help people with ME/CFS develop an energy management plan with realistic expectations and goals that are meaningful to them. Discuss and record the person's:

- cognitive activity
- mobility and other physical activity
- ability to undertake activities of daily living
- emotional demands
- social activity, including relationships
- rest and relaxation (both quality and duration)
- sleep quality and duration
- anything else that is important to the person.

1.11.4 Based on the person's assessment, establish an individual activity pattern within their current energy envelope that minimises their symptoms. For example:

- reduce activity as the first step
- plan periods of rest and activity, and incorporate the need for pre-emptive rest
- alternate and vary between different types of activity and break activities into small chunks.

1.11.5 Agree how often to review the person's energy management plan with them and revise it if needed.

1.11.6 Advise people with ME/CFS to reduce their activity if increasing it triggers symptoms, or if they have fluctuations in their daily energy levels.

1.11.7 Make self-monitoring of activity as easy as possible by taking advantage of any tools the person already uses, such as an activity tracker, phone heart-rate monitor or diary.

1.11.8 Refer people with ME/CFS to a specialist ME/CFS physiotherapy or occupational therapy service if they:

- have had reduced physical activity or mobility levels for a long time
- are ready to progress their physical activity beyond their current activities of daily living
- would like to incorporate a physical activity programme into the management of their ME/CFS.

People with severe or very severe ME/CFS

1.11.9 Refer people with severe or very severe ME/CFS to a specialist ME/CFS physiotherapy or occupational therapy service for support on developing energy management plans.

1.11.10 Be aware when agreeing energy management plans with people with severe or very severe ME/CFS (and their families and carers as appropriate) that changes in activity should be smaller and any increases (if possible) much slower.

For a short explanation of why the committee made these recommendations see the rationale and impact section on energy management.

Full details of the evidence and the committee's discussion are in evidence review G: non pharmacological management. Other supporting evidence and discussion can be found in evidence review A: information for people with ME/CFS and appendix 2: people with severe ME/CFS.

Physical maintenance

1.11.11 Include physical maintenance in the management plan for people with ME/CFS. Think about including the following:

- joint mobility
- muscle flexibility
- postural and positional support
- muscle strength and endurance

- bone health
- cardiovascular health.

1.11.12 Assess people with severe or very severe ME/CFS at every contact for:

- areas at risk of pressure ulcers (see the NICE guideline on pressure ulcers)
- deep vein thrombosis
- risk of contractures.

1.11.13 Give people and their families and carers (as appropriate) advice and support on how to recognise and prevent possible complications of long-term immobility, including contractures, pressure ulcers (see the NICE guideline on pressure ulcers), deep vein thrombosis (see the NICE guideline on venous thromboembolic diseases) and osteoporosis (see the NICE guideline on osteoporosis).

1.11.14 Give families and carers (if appropriate) advice and support on how to help the person with ME/CFS follow their management plan in relation to physical maintenance and mobility. This may include bed mobility, moving from lying to sitting to standing, transferring from bed to chair, use of mobility aids, walking, joint mobility, muscle stretching, muscle strength, balance, and going up and down stairs.

For a short explanation of why the committee made these recommendations see the rationale and impact section on physical maintenance.

Full details of the evidence and the committee's discussion are in evidence review G: non pharmacological management.

Physical activity

1.11.15 Do not advise people with ME/CFS to undertake unstructured exercise that is not part of a supervised programme, such as telling them to go to the gym or exercise more, because this may worsen their symptoms.

1.11.16 Do not offer people with ME/CFS:

- any therapy based on physical activity or exercise as a treatment or cure for ME/CFS
- generalised physical activity or exercise programmes – this includes programmes developed for healthy people or people with other illnesses
- any programme based on fixed incremental increases in physical activity or exercise, for example graded exercise therapy
- structured activity or exercise programmes that are based on deconditioning as the cause of ME/CFS
- therapies derived from osteopathy, life coaching and neurolinguistic programming (for example the Lightning Process).

1.11.17 Only consider a physical activity programme for people with ME/CFS who are ready to progress their physical activity beyond their current activities of daily living, or would like to incorporate physical activity into the management of their ME/CFS.

1.11.18 A physical activity programme, if offered, should only be delivered or overseen by a physiotherapist or occupational therapist with training and expertise in ME/CFS.

1.11.19 Tell people about the risks and benefits of a physical activity programme. Explain that some people with ME/CFS have found that physical activity programmes can make their symptoms worsen, for some people it makes no difference and others find them helpful.

1.11.20 If a physical activity programme is agreed with the person with ME/CFS, it should be personalised and should:

- establish their physical activity baseline at a level that does not worsen their symptoms
- start by reducing the person’s activity to within their energy envelope
- be possible to maintain it successfully before attempting to increase physical ability

- use flexible increments for people who want to focus on improving their physical abilities while remaining within their energy envelope
- recognise a flare or relapse early and outline how to manage it (see recommendations 1.11.21 and 1.11.22)
- incorporate regular reviews.

1.11.21 Agree with the person how to adjust their physical activity after a flare or relapse. This should include:

- providing access to support from the specialist ME/CFS physiotherapy service
- reducing physical activity within the person's current energy envelope to stabilise their symptoms
- only once symptoms stabilise and the person feels able to resume physical activity, establishing a new physical activity baseline.

1.11.22 Advise people with ME/CFS after a flare that the time it takes to return to the level of physical activity they had before the flare varies from person to person.

For a short explanation of why the committee made these recommendations see the rationale and impact section on physical activity.

Full details of the evidence and the committee's discussion are in evidence review G: non pharmacological management, evidence review A: information for people with ME/CFS and appendix 1: children and young people.

Rest and sleep

1.11.23 Advise people with ME/CFS:

- on the role of rest in ME/CFS
- that rest periods are part of all management strategies for ME/CFS
- how to introduce rest periods into their daily routine, including how often and for how long, as appropriate for each person

- that relaxation techniques at the beginning of each rest period could be helpful.

For a short explanation of why the committee made this recommendation see the rationale and impact section on rest and sleep.

Full details of the evidence and the committee's discussion are in evidence review G: non pharmacological management.

Managing orthostatic intolerance

1.11.24 Be aware that people with ME/CFS may experience orthostatic intolerance, such as postural orthostatic tachycardia syndrome (POTS), orthostatic hypotension or neurally mediated hypotension.

1.11.25 Medicine for orthostatic intolerance in people with ME/CFS should only be prescribed or overseen by a healthcare professional with expertise in orthostatic intolerance.

1.11.26 Refer people with orthostatic intolerance to secondary care if their symptoms are severe or worsening, or there are concerns that another condition may be the cause.

For a short explanation of why the committee made these recommendations see the rationale and impact section on orthostatic intolerance.

Full details of the evidence and the committee's discussion are in evidence review G: non pharmacological management.

Managing pain

1.11.27 Refer to the following for advice on treating pain:

- NICE guideline on neuropathic pain in adults
- NICE guideline on headaches in over 12s.

For a short explanation of why the committee made this recommendation see the rationale and impact section on managing pain.

Full details of the evidence and the committee's discussion are in evidence review G: non pharmacological management.

Managing nausea

1.11.28 Encourage people with ME/CFS who have nausea to keep up adequate fluid intake and advise them to try to eat regularly, taking small amounts often.

For a short explanation of why the committee made this recommendation see the rationale and impact section on managing nausea.

Full details of the evidence and the committee's discussion are in evidence review G: non pharmacological management.

Medicines

1.11.29 Do not offer any medicines or supplements to treat or cure ME/CFS.

Medicines for symptom management

1.11.30 Offer people with ME/CFS a medication review in line with the NICE guidelines on medicines adherence and medicines optimisation.

1.11.31 Take into account when prescribing that people with ME/CFS may be more intolerant of drug treatment and have more severe adverse effects. Consider:

- starting drug treatments at a lower dose than in usual clinical practice
- gradually increasing the dose if the drug is tolerated.

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.

For a short explanation of why the committee made these recommendations see the rationale and impact section on medicines, including medicines for symptom management.

Full details of the evidence and the committee's discussion are in evidence review F: pharmacological management.

Dietary management and strategies

1.11.33 Emphasise to people with ME/CFS the importance of adequate fluid intake and a well-balanced diet according to the NHS eat well guide.

1.11.34 Work with the person (and their family members or carers, as appropriate) to find ways of minimising complications caused by nausea (see recommendation 1.11.28), swallowing problems, sore throat or difficulties with buying, preparing and eating food.

1.11.35 Refer people with ME/CFS for a dietetic assessment by a dietitian who specialises in ME/CFS if they are losing weight and at risk of malnutrition, or they have a restrictive diet.

1.11.36 Be aware that people with ME/CFS may be at risk of vitamin D deficiency because they spend a lot of time indoors, especially those who are housebound or bed-bound. For advice on vitamin D supplementation, see the NICE guideline on vitamin D.

1.11.37 Explain to people with ME/CFS that there is not enough evidence to support routinely taking vitamin and mineral supplements as either a treatment for ME/CFS or for managing symptoms. If they are advised to take a supplement it should be a multivitamin and mineral supplement and they should stay within the recommended daily amount. Explain the potential side effects of taking higher doses of vitamins and minerals.

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.

People with severe or very severe ME/CFS

1.11.40 Refer people with severe or very severe ME/CFS for a dietetic assessment by a dietitian who specialises in ME/CFS.

1.11.41 Monitor people with severe or very severe ME/CFS who are at risk of malnutrition or unintentional weight loss because of:

- restrictive diets
- poor appetite linked with altered taste and smell
- food intolerances
- nausea or difficulty swallowing and chewing.

Follow the recommendations on screening for malnutrition, indications for nutrition support, and education and training of staff and carers related to nutrition, in the NICE guideline on nutrition support for adults.

1.11.42 Consider advice to support people with severe or very severe ME/CFS, which could include:

- eating little and often
- having nourishing drinks and snacks, including food fortification
- finding easier ways of eating to conserve energy, such as food with softer textures
- using modified eating aids, particularly if someone has difficulty chewing or swallowing
- oral nutrition support and enteral feeding.

For a short explanation of why the committee made these recommendations see the rationale and impact section on dietary management and strategies.

Full details of the evidence and the committee’s discussion are in evidence review G: non pharmacological management.

Psychological support: cognitive behavioural therapy

1.11.43 Only offer cognitive behavioural therapy (CBT) to people with ME/CFS who would like to use it to support them in managing their symptoms of ME/CFS and to reduce the psychological distress associated with having a chronic illness. Do not offer CBT as a treatment or cure for ME/CFS.

1.11.44 CBT should be only delivered by a healthcare professional with appropriate training and experience in CBT for ME/CFS, and under the clinical supervision of someone with expertise in CBT for ME/CFS.

1.11.45 Discuss with the person the principles of CBT, its role in supporting them to adapt to and manage the impact of symptoms of ME/CFS and the potential benefits and risks. Explain that CBT for people with ME/CFS:

- is not curative
- is designed to improve wellbeing and quality of life
- aims to improve functioning and reduce the psychological distress associated with having a chronic illness
- does not assume people have ‘abnormal’ illness beliefs and behaviours as an underlying cause of their ME/CFS, but recognises that thoughts, feelings, behaviours and physiology interact with each other
- takes a non-judgemental, supportive approach to the person's experience of their symptoms and the challenges these present.

1.11.46 Explain what CBT involves so people know what to expect. Tell them that it:

- is a collaborative, structured, time-limited intervention that focuses on the difficulties people are having at that time
- involves working closely with their therapist to establish strategies that help the person to work towards meaningful goals and priorities that they have chosen themselves
- takes into account how symptoms are individual to the person, can fluctuate in severity and may change over time.

1.11.47 CBT for people with ME/CFS should include the following components:

- developing a shared understanding with the person about the main difficulties and challenges they face
- exploring their personal meaning of symptoms and illness, and how this might relate to how they manage their symptoms
- working together to adapt and refine self-management strategies to improve the person's functioning and quality of life, for example their sleep, activity and rest
- developing a self-management plan
- reviewing their plan regularly to see if their self-management strategies need to be adapted, for example if their symptoms or functioning change
- developing a therapy blueprint collaboratively with their therapist at the end of 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.

People with severe or very severe ME/CFS

1.11.50 Healthcare professionals delivering CBT to a person with severe or very severe ME/CFS should adjust the process and pace of CBT to meet the person's needs. This might include shorter, less frequent sessions and longer-term goals.

For a short explanation of why the committee made these recommendations see the rationale and impact section on psychological support: cognitive behavioural therapy.

Full details of the evidence and the committee's discussion are in evidence review G: non pharmacological management and appendix 2: people with severe ME/CFS.

1.12 Managing coexisting conditions

1.12.1 Take into account the recommendations in the section on principles of care for people with ME/CFS and section on access to care when managing coexisting conditions in people with ME/CFS.

1.12.2 Be aware that other conditions may coexist with ME/CFS and should be investigated and managed in accordance with best practice.

1.12.3 For recommendations on multimorbidity, thyroid disease and coeliac disease refer to the:

- NICE guideline on multimorbidity
- NICE guideline on thyroid disease
- NICE guideline on coeliac disease.

1.12.4 For recommendations on identifying and treating associated or comorbid anxiety, depression or mood disorders see the:

- NICE guideline on depression in adults
- NICE guideline on depression in adults with a chronic physical health problem
- NICE guideline on depression in children and young people
- NICE guideline on generalised anxiety disorder and panic disorder in adults
- NICE guideline on common mental health problems.

For a short explanation of why the committee made these recommendations see the rationale and impact section on managing coexisting conditions.

Full details of the evidence and the committee's discussion are in evidence review D: diagnosis.

1.13 Managing flares and relapse

Flares

1.13.1 Recognise a flare in symptoms of ME/CFS when there is a sustained exacerbation of symptoms to a level greater than the person's usual day-to-day variation, which usually lasts a few days.

1.13.2 Respond promptly to a flare in symptoms by:

- identifying possible triggers, such as acute illness or overexertion (in some cases there may be no clear trigger)
- temporarily reducing activity levels
- monitoring symptoms, recognising that although flares are transient, some will develop into a relapse
- not increasing activity levels until the flare has resolved (see the relapse section if flare is prolonged).

Relapse

1.13.3 Recognise a relapse when there is a sustained and marked exacerbation of ME/CFS symptoms lasting longer than a flare and needing substantial and sustained adjustment of energy management.

1.13.4 When a person with ME/CFS has a relapse, review their management plan with them and discuss and agree a course of action, taking into account:

- possible causes of the relapse, if known
- the nature of the symptoms
- the severity and duration of the relapse (bearing in mind this can be years).

1.13.5 During a relapse, discuss and agree with the person with ME/CFS (and their family members or carers, as appropriate):

- reducing, or even stopping, some activities
- increasing the frequency or duration of rest periods
- re-establishing a new energy envelope to stabilise symptoms.

1.13.6 If a flare or relapse cannot be managed using the person's self-management strategies outlined in their management plan, advise the person to contact their named contact in the primary care or specialist team for review.

1.13.7 Once a flare or relapse has resolved or stabilised, discuss with the person:

- whether their management plan needs to be reviewed and adjusted to reflect their current symptoms and energy envelope, because this may be different from before the flare or relapse (for people participating in physical activity programmes see recommendations 1.11.21 and 1.11.22)
- their experience of the flare or relapse to determine, if possible, whether strategies can be put in place to manage potential triggers in the future
- investigate any new symptoms that may have caused the flare or relapse.

For a short explanation of why the committee made these recommendations see the rationale and impact section on managing flares and relapse.

Full details of the evidence and the committee’s discussion are in evidence review G: non pharmacological management.

1.14 Review

1.14.1 Offer adults with ME/CFS a review of their care and management plan in primary care at least once a year (see recommendation 1.14.3 for what to review).

1.14.2 Arrange more frequent primary care reviews for people with ME/CFS as needed, depending on the severity and complexity of their symptoms, and the effectiveness of any symptom management.

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/CF 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.

1.14.4 Refer the person with ME/CFS to their named contact in the specialist team if there are any new or deteriorating aspects of their condition.

1.14.5 Consider seeking advice from an appropriate specialist if there is uncertainty about interpreting signs and symptoms and whether a referral is needed.

Children and young people

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.

For a short explanation of why the committee made these recommendations see the rationale and impact section on review.

Full details of the evidence and the committee’s discussion are in evidence review J: review of care.

1.15 Training for health and social care professionals

1.15.1 Health and care providers should provide access to training that reflects current knowledge in ME/CFS (including understanding what ME/CFS is, diagnosis and management) for all health and social care staff who deliver care to people with ME/CFS.

1.15.2 Ensure that training programmes on ME/CFS:

- provide evidence-based content and training methods (developed and supported by specialist services with input from people with ME/CFS)
- are run by trainers with relevant skills, knowledge and experience
- include monitoring, using relevant competency frameworks or assessment for the area of training
- represent the experiences of people with ME/CFS, using video and other resources.

1.15.3 Health and social care professionals who provide care for people with ME/CFS should undertake training that reflects current knowledge and maintain continuous professional development in ME/CFS relevant to their role so that they provide care in line with this guideline.

For a short explanation of why the committee made these recommendations see the rationale and impact section on training for health and social care professionals.

Full details of the evidence and the committee's discussion are in evidence review B: information for people with health and social care professionals. Other supporting evidence and discussion can be found in evidence review A: information for people with ME/CFS and appendix 2: people with severe ME/CFS.

Terms used in this guideline

This section defines terms that have been used in a particular way for this guideline. For other definitions see the NICE glossary and the Think Local, Act Personal Care and Support Jargon Buster.

Activity

Activity is any effort that uses energy and includes cognitive, emotional and social activity, as well as physical activity.

Advocate

In this guideline, the role of an advocate in health and social care is to support a vulnerable or disadvantaged person and ensure that their rights are being upheld in a healthcare context. They are chosen by the person with ME/CFS and can include family members, carers, friends or an independent advocate. They make sure that the person with ME/CFS is heard.

Carers

In this guideline, a carer refers to someone who provides unpaid care and support to a family member, partner or friend with ME/CFS.

Children and young people

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

Energy envelope

The amount of energy a person has to do all activities without triggering an increase in their symptoms.

Energy management

A self-management strategy that involves managing a person's activities to stay within their energy envelope.

Exercise

Exercise is planned, structured, repetitive and purposeful activity focused on improvement or maintenance of one or more components of physical fitness. Exercise is a subcategory of physical activity.

Fatigability

Fatigability in ME/CFS has the following features:

- sick or 'flu-like' fatigue, especially in the early days of the illness
- 'wired but tired' fatigue, or restless fatigue (it may also include hypervigilance during sleep)
- low energy or a lack of physical energy to start or finish activities of daily living and the sensation of being 'physically drained'
- cognitive fatigue that worsens existing cognitive difficulties
- rapid muscle fatigue in which strength or stamina are lost quickly after starting an activity, causing sudden weakness, clumsiness, lack of coordination, and being unable to repeat physical effort consistently.

Flare

A flare is a worsening of symptoms, more than would be accounted for by normal day-to-day variation, that affects the ability of the person to perform their usual activities. Flares may occur spontaneously or be triggered by another illness, overexertion or stress of any kind. The worsening of symptoms is transient and flares typically resolve after a few days (1 to 3 days), either spontaneously or in response to temporary changes in energy management or a change in treatment.

Management plan

The personalised management plan is developed by the specialist team after the confirmation of a diagnosis of ME/CFS and a holistic assessment. It is the basis for other assessments and plans such as social care assessments, energy management, physical maintenance, physical activity, cognitive behavioural therapy (CBT) and dietary management.

Mild ME/CFS

People with mild ME/CFS are mobile, can care for themselves and can do light domestic tasks with difficulty. Most are still working or in education, but to do this they have probably stopped all leisure and social pursuits. They often take days off or use the weekend to cope with the rest of the week.

Moderate ME/CFS

People with moderate ME/CFS have reduced mobility and are restricted in all activities of daily living, although they may have peaks and troughs in their level of symptoms and ability to do activities. They have usually stopped work, school or college and need rest periods, often resting in the afternoon for 1 or 2 hours. Their sleep at night is generally poor quality and disturbed.

Orthostatic intolerance

The inability to regulate blood pressure and cerebral blood flow when upright, usually when standing, but it can also occur when sitting. It may lead to postural tachycardia, hypotension and alterations in consciousness (such as fainting). This may include postural orthostatic tachycardia syndrome (a significant rise in pulse rate when moving from lying to standing) and postural hypotension (a significant fall in blood pressure when moving from lying to standing).

Physical activity

Physical activity is defined as any bodily movement produced by skeletal muscles that results in energy expenditure. Physical activity should not be confused with exercise which is a subcategory of physical activity. Physical activity in daily life can be categorised into occupational, sports, conditioning, household, or other activities, and can be done during leisure time, to get around or as part of a person's work. For many people, physical activity has a health benefit but in people with ME/CFS physical activity may make their symptoms worsen. See the World Health Organization advice on physical activity.

Physical maintenance

Physical maintenance is the process of incorporating into daily activity a level of movement that does not exacerbate symptoms and ensures that joint and muscle flexibility does not deteriorate further than that caused by the condition so far. For many people with ME/CFS, this will be to ensure as much independence as possible in activities ranging from personal hygiene to daily living, working and social interactions. For the most severely affected, it may only be passive movements, which aim to maintain joint flexibility and gently stretch muscle groups to avoid contractures developing. For some people with ME/CFS it can include physical activity which additionally assists bone health, posture and muscle strength. Such activity is undertaken within the person's energy envelope and avoids pushing through boundaries of tolerance.

Post-exertional symptom exacerbation

The worsening of symptoms that can follow minimal cognitive, physical, emotional or social activity, or activity that could previously be tolerated. Symptoms typically worsen 12 to 48 hours after activity and can last for days or even weeks. This is also referred to as post-exertional malaise.

Relapse

A relapse is a sustained and marked exacerbation of symptoms lasting longer than a flare and needing a substantial and sustained adjustment to the person's energy management. It may not be clear in the early stages of a symptom exacerbation whether it is a flare or a relapse. The person's symptoms and level of disability may be similar to illness onset. Relapses can lead to a long-term reduction in the person's energy envelope.

Severe or very severe ME/CFS

People with severe ME/CFS are unable to do any activity for themselves or can carry out minimal daily tasks only (such as face washing or cleaning teeth). They have severe cognitive difficulties and may depend on a wheelchair for mobility. They are often unable to leave the house or have a severe and prolonged after-effect if they do so. They may also spend most of their time in bed and are often extremely sensitive to light and noise.

People with very severe ME/CFS are in bed all day and dependent on care. They need help with personal hygiene and eating and are very sensitive to sensory stimuli. Some people may not be able to swallow and may need to be tube fed.

Therapy blueprint

This summarises the therapy and provide a basis for future independent self-management. The blueprint may include the therapy formulation, strategies that have been helpful, 'warning signs' and triggers of flares and how to manage them, and goals for the future. It is important that the therapy blueprint is led by the person themselves and is in their own words, supported by guidance from the therapist.

Unrefreshing sleep

Unrefreshing sleep is described as a light sleep. Even after a full night’s sleep people do not feel rested. People with ME/CFS often report waking up exhausted and feeling as if they have not slept at all, no matter how long they were asleep.

Recommendations for research

The guideline committee has made the following recommendations for research.

Key recommendations for research

1 Diagnostic tests

What diagnostic tests are clinically and cost effective in people with suspected ME/CFS?

For a short explanation of why the committee made this recommendation see the rationale section on diagnosis.

Full details of the evidence and the committee's discussion are in evidence review D: diagnosis.

2 A core outcome set

What core set of relevant health outcome measures should be used for trials of treatments for ME/CFS and managing symptoms of ME/CFS?

For a short explanation of why the committee made this recommendation see the rationale section on managing ME/CFS.

Full details of the evidence and the committee's discussion are in evidence review G: non pharmacological management.

Other recommendations for research

Diagnostic criteria

In people with suspected ME/CFS, what criteria should be used to establish a clinical diagnosis?

For a short explanation of why the committee made this recommendation see the rationale section on diagnosis.

Full details of the evidence and the committee's discussion are in evidence review D: diagnosis.

Self-monitoring management strategies

What is the clinical and cost effectiveness of self-monitoring techniques in guiding energy management in ME/CFS?

For a short explanation of why the committee made this recommendation see the rationale section on energy management.

Full details of the evidence and the committee's discussion are in evidence review G: non pharmacological management.

Sleep management strategies

What is the clinical and cost effectiveness of sleep management strategies in managing ME/CFS?

For a short explanation of why the committee made this recommendation see the rationale section on rest and sleep.

Full details of the evidence and the committee's discussion are in evidence review G: non pharmacological management.

Dietary strategies

What is the clinical and cost effectiveness of dietary strategies in managing ME/CFS?

For a short explanation of why the committee made this recommendation see the rationale section on dietary management and strategies.

Full details of the evidence and the committee's discussion are in evidence review G: non pharmacological management.

Rationale and impact

These sections briefly explain why the committee made the recommendations and how they might affect practice.

Principles of care for people with ME/CFS

Recommendations 1.1.1 to 1.1.11

Why the committee made the recommendations

Common themes across the qualitative evidence showed a lack of belief about ME/CFS as a real condition by health and social care professionals, and a lack of understanding about what it is and the impact it has. The committee used this evidence to make recommendations to raise awareness about ME/CFS. One strong theme showed how experiencing a lack of understanding and prejudice can lead to people losing trust in health and social care services. The committee agreed that health and social care professionals need to take into account the impact of not being believed when building relationships with people with ME/CFS and their families. The committee considered this particularly relevant to children and young people and made separate recommendations highlighting communication with children.

The evidence showed this loss of trust can be compounded when people with ME/CFS have negative experiences of healthcare services if they decline treatments that have been offered to them. This was a strong theme in the evidence for children and young people. The committee agreed that declining a specific treatment should not affect other areas of the person's care.

The qualitative evidence also showed that one of the barriers to good ME/CFS management was a late diagnosis and a lack of monitoring, and this reflected the committee's experience.

Evidence relating to people with severe ME/CFS reinforced the committee's experience that this group of people are often neglected, and the severity of their symptoms misunderstood. The committee made recommendations on the symptoms experienced by people with severe or very severe ME/CFS and what this means when providing care.

How the recommendations might affect practice

These overarching principles will improve consistency of best practice and do not need any additional resources to deliver.

Return to recommendations

Suspecting ME/CFS

Recommendations 1.2.1 to 1.2.8

Why the committee made the recommendations

The committee took into account both the lack of evidence on diagnostic tests and the evidence that people value realistic advice about ME/CFS (particularly around diagnosis) when making the recommendation to explain how the condition is recognised.

In outlining key areas for assessment, the committee agreed that although they could not give a list of standard tests, it was important to carry out baseline investigations to exclude other potential diagnoses, although this should not affect a provisional diagnosis of ME/CFS.

The committee acknowledged there is ongoing discussion in the ME/CFS community about which diagnostic criteria should be used to diagnose ME/CFS. Based on both the evidence and their experience, the committee agreed that the Institute of Medicine’s 2015 criteria had the best balance of inclusion and exclusion of all the reviewed criteria, but it needed to be adapted for optimal use. In particular, the committee felt that the 6-month delay should be reduced so that management could start earlier, and that fatigue and post-exertional symptom exacerbation should be defined clearly to make it easier to interpret the revised criteria.

Based on their experience, the committee decided that people should be given a provisional diagnosis of ME/CFS if they have all the 4 key symptoms (debilitating fatigability, post-exertional symptom exacerbation, unrefreshing sleep and cognitive difficulties) for a minimum of 6 weeks in adults and 4 weeks in children and young people. The committee agreed it would be unusual for an acute illness, including a viral illness, to persist longer than 6 weeks in an adult and 4 weeks in a child or young person with all 4 key symptoms. They emphasised it is the combination and interaction of the symptoms that is critical in distinguishing ME/CFS from other conditions and illness.

In addition to the 4 key symptoms, the committee noted that many of the criteria used to define ME/CFS also include other symptoms that are commonly experienced by people with ME/CFS. They agreed that although these symptoms are not crucial to a diagnosis, they are important for understanding ME/CFS and helping to manage symptoms, so they made a recommendation to raise awareness of them.

The evidence and the committee's experience suggested that managing symptoms early may prevent them getting worse and the person's health deteriorating. To reflect this the committee recommended advice on symptom management for people as soon as ME/CFS is suspected.

The committee discussed the non-specific nature and common presentation of some ME/CFS symptoms (for example, cognitive difficulties such as brain fog), which make it difficult to diagnose and distinguish from other conditions. This has led to misdiagnosis, missed diagnosis, and delays in the diagnosis of ME/CFS and of other conditions. Because of this, the committee agreed it is important that when a healthcare professional suspects ME/CFS, they should also consider alternative explanatory diagnoses or coexisting conditions. They should appropriately investigate these and refer to a specialist if they are unsure.

The committee agreed that to avoid any disruption to education, once ME/CFS is suspected in a child or young person their place of education should be contacted to advise about flexible adjustments or adaptations.

How the recommendations might affect practice

There is variation in practice, and no one set of criteria is used clinically, with a 'mix and match' approach used alongside clinical experience. These recommendations will standardise practice and it is not believed they will have any impact on resource use or training.

The recommendations aim to raise awareness of symptoms and associated conditions that should raise suspicion of ME/CFS, particularly among healthcare professionals with limited knowledge about ME/CFS. This could increase the number of people with suspected ME/CFS who are then referred to a specialist service but will help to ensure they get appropriate care and substantially better outcomes.

The recommendation that children and young people with suspected ME/CFS should be referred to a paediatrician after 4 weeks is earlier than current practice. However, referring earlier for further assessment will help children and young people with ME/CFS to get appropriate care sooner, improving their outcomes.

Return to recommendations

Advice for people with suspected ME/CFS

Recommendations 1.3.1 and 1.3.2

Why the committee made the recommendations

There was limited clinical evidence on management strategies for people with suspected ME/CFS. The qualitative evidence and the committee's experience suggested that managing symptoms early may prevent them getting worse and the person's health deteriorating. To reflect this, the committee made a recommendation to give people advice on symptom management drawn from their own knowledge and experience.

The qualitative evidence suggested this can be an anxious time for people with suspected ME/CFS and the committee agreed it was important for people to know who to contact if their symptoms change.

How the recommendations might affect practice

Providing the advice in these recommendations would not impose a significant cost on the NHS. If this advice leads to fewer people with deteriorating symptoms, the recommendations would be highly cost effective.

Return to recommendations

Diagnosis

Recommendations 1.4.1 to 1.4.3

Why the committee made the recommendations

Making a diagnosis

The committee agreed that although a 6-month delay before diagnosis is built into the Institute of Medicine criteria, the criteria could be safely amended by reducing this period to 3 months. The committee saw removing this delay as useful because it might enable earlier management and could potentially improve longer-term outcomes.

Reflecting the common theme across the evidence about a lack of knowledge of ME/CFS and evidence that non-specialists in ME/CFS are not confident about diagnosing and managing ME/CFS, the committee recommended referring people with ME/CFS to a ME/CFS specialist team at 3 months to confirm their diagnosis and develop a management plan.

Diagnostic criteria

The committee made a recommendation for key symptoms based on the evidence review of the current diagnostic criteria but no one criteria was agreed to be better overall. There is an ongoing discussion in the ME/CFS community about which diagnostic criteria are best and which should be used in the identification and diagnosis of ME/CFS. The factors influencing these discussions are the broadness of the inclusion criteria, the definition of some of the symptoms, and the usability of the criteria as a clinical tool. There are concerns that many of the existing criteria do not accurately identify people with or without ME/CFS. Currently there is no validated diagnostic criteria for ME/CFS, and this leads to confusion about which criteria to use. The committee agreed to make a recommendation for research on diagnostic criteria to inform future guidance.

Diagnostic tests

No evidence was identified for any tests or specific signs and symptoms as predictors of a later diagnosis of ME/CFS. Accurate diagnostic tests that correctly identify ME/CFS will support healthcare professionals to identify people who have ME/CFS and rule out those who do not. The committee decided to make a recommendation for research on diagnostic tests to help identify effective diagnostic tests for ME/CFS that will facilitate early diagnosis and potentially lead to better outcomes for people with ME/CFS. They hoped this research would inform future guidance.

How the recommendations might affect practice

There will be no change to the current practice of diagnosing ME/CFS based on clinical assessment and history and performing tests for differential diagnoses as appropriate.

The duration of symptoms before diagnosis can take place has been reduced but the criteria are now stricter, requiring that 4 different sets of symptoms are all present in order to suspect ME/CFS. The impact therefore will not necessarily be an increase in referrals but for people to receive their diagnosis earlier, which will bring forward their assessment and care plan. Earlier access to appropriate advice and care could prevent disease progression and therefore reduce resource use in the longer term.

Return to recommendations

Assessment and care planning by a specialist ME/CFS team

Recommendations 1.5.1 to 1.5.5

Why the committee made the recommendations

The committee agreed that the key to managing ME/CFS symptoms successfully is having a personalised management plan, which should be developed as soon as the person’s diagnosis is confirmed. A copy of this plan can be shared with primary care and a copy held by the person themselves and it can be referred to in situations such as planning an admission to hospital. In the committee’s experience, this approach to assessment and planning is common in specialist ME/CFS services.

The committee outlined key areas to assess what support might be needed, based on their experience. The committee noted that the key areas to assess and the support needed will depend on the person’s severity of ME/CFS, the impact of their symptoms and their needs. Someone with mild ME/CFS will not need as much support as someone with severe or very severe ME/CFS. Once the overall management plan is agreed, it then provides a basis for the more detailed assessments and plans outlined in specific interventions in the guideline, such as social care assessments, energy management, physical maintenance, CBT and dietary management. Each of these assessments and plans outlines the important considerations for each person in these areas of care.

Based on the evidence about problems with accessing services, the committee made a recommendation for home visits to people with severe and very severe ME/CFS to carry out the assessment.

The qualitative evidence highlighted the importance of a collaborative relationship between the person with ME/CFS and their healthcare professional, and the committee made a recommendation to emphasise this.

How the recommendations might affect practice

Carrying out a holistic assessment and developing a management plan are already current practice in specialist services, although there may be more referrals and people to develop plans for. However, having a management plan will facilitate people's care and lead to better outcomes. If assessment is carried out early and a care plan is implemented, it could reduce resource use in the longer term by preventing progression of disease.

There may be an increased number of home visits for people with severe or very severe ME/CFS. However, this will provide equity of access to care for this group who are usually housebound. The emphasis in this guideline on early diagnosis and referral to a specialist team for a personalised care plan has the aim of minimising the number of people who may progress to severe ME/CFS.

Return to recommendations

Information and support

Recommendations 1.6.1 to 1.6.12

Why the committee made the recommendations

Qualitative evidence showed that people with ME/CFS valued information from health and social care practitioners in formats that took into account the way symptoms such as 'brain fog' affected their capacity to take in and remember information. The committee highlighted formats that were reported as useful.

The evidence showed people with ME/CFS and their families and carers valued general information about ME/CFS that they could use themselves and share with others (families, friends, employers and practitioners), particularly around the time of diagnosis and the early stages of ME/CFS. This enabled them to develop accurate expectations about the future, relieve distress caused by the general lack of information and educate others. The evidence suggested people with ME/CFS wanted realistic information about what ME/CFS is and how it might affect them in the future, and this formed the basis of the recommendations outlining the key characteristics of ME/CFS. The recommendation noting that the long-term outlook can be better in children and young people was based on the committee's experience.

The evidence supported the committee's view that information about ME/CFS and advice about other support is not easily available from health and social care services, and they agreed that people would benefit from information from local and national support groups.

Evidence suggested that people with ME/CFS needed practical support both for themselves and their carers. The committee considered that some people may have reservations about engaging with social care, after experiencing disbelief about their illness and the impact it has on their day-to-day functioning. For this reason, the committee emphasised the need for sensitivity when talking to people and their families about social care support.

The committee made recommendations signposting to different assessments and support that could be helpful. In their experience, health and social care professionals were not always aware what support is available to families and carers of people with ME/CFS, so the committee also referred to the NICE guideline on supporting adult carers.

How the recommendations might affect practice

The recommendations are in line with the general principles for providing information already established in the existing NICE guideline on patient experience in the NHS and so were not considered likely to have any additional impact on practice.

Return to recommendations

Safeguarding

Recommendations 1.7.1 to 1.7.6

Why the committee made the recommendations

The committee recognised that safeguarding is a particular issue in ME/CFS in a way that is different from other chronic illnesses and disabilities because people with ME/CFS commonly report that they are not believed. No evidence was identified on safeguarding in ME/CFS, but the committee agreed it was very important to make recommendations based on consensus. The recommendations address some of the misconceptions on this topic and highlight the need for expertise in ME/CFS when carrying out safeguarding assessments.

The committee noted that although safeguarding is not solely about children and young people, most of the concerns they were aware of related to children and young people with ME/CFS, so they made separate recommendations for this group.

How the recommendations might affect practice

The recommendations will improve consistency of best practice and do not need any additional resources to deliver.

Return to recommendations

Access to care

Recommendations 1.8.1 to 1.8.11

Why the committee made the recommendations

The evidence showed that people with ME/CFS can have difficulty using healthcare services, particularly because of physical accessibility and the time constraints of appointments. This can make it more difficult to get the support and treatment they need. The committee was also aware that common sensitivities in ME/CFS, such as to light and noise, can make it challenging to travel to and attend appointments and to receive inpatient care. The committee made recommendations to improve access to care based on these potential barriers.

The committee discussed the unpredictable and fluctuating nature of ME/CFS and the risk that people will be discharged from a service if they miss appointments when their symptoms worsen. They agreed to make a recommendation based on consensus to address the lack of awareness about this in health and social care services.

The committee was aware that difficulties accessing care are intensified in people with severe or very severe ME/CFS, particularly when they need hospital care. The evidence showed that, as a result of this, some people with severe or very severe ME/CFS have little contact with and support from health and social care services. To address this, the committee highlighted the flexibility and specific support needed by people with severe or very severe ME/CFS.

Maintaining independence

There was limited evidence directly addressing the barriers and facilitators to accessing social care. However, the committee agreed this was an important area of care and they could draw conclusions from the evidence on healthcare and use their own experience to make recommendations.

ME/CFS can affect a person's ability to carry out activities of daily living and maintain their independence and quality of life. The committee agreed that everyone with ME/CFS should be asked how their symptoms affect their independence and then a social care assessment carried out if needed. Using their experience, the committee outlined the topics for assessment and discussion.

The committee also made further recommendations based on their own knowledge and experience, including that:

- many families and carers do not know the most appropriate ways to support someone with ME/CFS and need advice on this
- people with ME/CFS often have difficulty getting the equipment they need to support their activities of daily living and maintain their quality of life.

How the recommendations might affect practice

Some of these recommendations might need extra staff time or other healthcare resource use, for example to offer flexible appointments and home visits, make adjustments during inpatient stays and provide aids and adaptations. However, for equity reasons, people with ME/CFS need the same access to healthcare and support as other NHS patients that is commensurate with the severity of their illness.

Return to recommendations

Supporting people with ME/CFS in work, education and training

Recommendations 1.9.1 to 1.9.6

Why the committee made the recommendations

The evidence showed a lack of support with education and training for children and young people with ME/CFS and their families and carers, and this can result in some children or young people leaving education. This reflected the committee's experience and they agreed that many of the themes in the evidence could also be applied to people in work.

The common theme of lack of knowledge and understanding about ME/CFS was echoed in this evidence with a lack of awareness about the impact that a high-stimulus environment (such as a school) can have on someone with ME/CFS. There was a lack of understanding about the need for a flexible approach to education with possible adjustments. The committee agreed that better communication between health and social care professionals and training and education services is key to develop a shared understanding of the needs and impairments of people with ME/CFS and how to provide them with appropriate educational support.

How the recommendations might affect practice

The recommendations will improve consistency of best practice and do not need any additional resources to deliver.

Return to recommendations

Multidisciplinary care

Recommendations 1.10.1 to 1.10.5

Why the committee made the recommendations

There was limited evidence on the composition of a multidisciplinary team, but based their experience, the committee agreed that good care for people with ME/CFS results from access to an integrated team of health and social care professionals who are trained and experienced in managing ME/CFS. The fluctuating nature of ME/CFS means that people's support needs can change, so access to different expertise is needed at different times. The committee agreed to make recommendations on providing a coordinated multidisciplinary approach and to identify the expertise that should be available.

In the committee's experience, care for most people with ME/CFS can be managed in primary care after their diagnosis is confirmed and they have a management plan agreed. However, the committee acknowledged the lack of confidence that non-specialists can have in managing ME/CFS and they recommended support from a ME/CFS specialist team.

The qualitative evidence showed that people with ME/CFS valued continuity of care and the committee agreed that having a single point of contact in their care team would avoid needing to have contact and appointments with multiple professionals which, for some people, could worsen their health.

How the recommendations might affect practice

The recommendations on the specialist multidisciplinary team, providing a named contact and giving support to primary care services may need resources. Current provision of specialist teams is very uneven across the country and increased staffing may be needed in some areas if there are more referrals. The specialist team will need to cover different areas of expertise, but most people will only need access to some elements and only at specific times. However, faster access to diagnosis and appropriate care will lead to better symptom management and to substantially better outcomes for people with ME/CFS and so might reduce health and care costs in the longer term.

Allocating a single point of contact to the person with ME/CFS is not routine practice across the NHS. This could be implemented differently in different regions according to local service structures and may not necessarily need the addition of new staff. It could improve the efficiency of care for people with ME/CFS by reducing the burden of repeated appointments.

Return to recommendations

Managing ME/CFS

Recommendation 1.11.1

Why the committee made the recommendations

Overall, the evidence for non-pharmacological and pharmacological interventions for ME/CFS was heterogenous and inconclusive, with limited evidence for any one intervention, and this supported the committee's experience. The committee was aware of claims that have been made about cures for ME/CFS and that there is often a financial cost to people with ME/CFS when they pursue these. To address this, the committee agreed to raise awareness in the recommendations of the current lack of treatment or cure for ME/CFS.

Core outcomes in ME/CFS

There is considerable controversy over the outcome measures used in trials of treatments for ME/CFS and managing symptoms. Inconsistency in outcomes used and concerns over the validity of some outcome measures in an ME/CFS population make it difficult to combine and compare results from different trials, limiting the ability to draw conclusions on the clinical and cost effectiveness of interventions. The committee made a recommendation for research on core outcome sets to enable the direct comparison of treatments for ME/CFS and symptom management and shape and optimise ME/CFS trial design.

How the recommendations might affect practice

The recommendations reflect current practice so no impact on resources is anticipated.

Return to recommendation

Energy management

Recommendations 1.11.2 to 1.11.10

Why the committee made the recommendations

The committee discussed how the controversy over graded exercise therapy had resulted in confusion over what support should be available to safely manage physical activity in people with ME/CFS. They agreed it was important to provide clarity and clear guidance around activity.

Based on their experience, the committee agreed that energy management is one of the most important tools that people with ME/CFS have to support them in living with the symptoms of ME/CFS. Energy management is not a physical activity or exercise programme, although the principles of energy management do apply to physical activity programmes.

The committee listed the components of energy management and what an assessment and plan would include, noting that the key component is understanding the principle of the ‘Energy envelope’. They recommended a detailed assessment that takes into account all areas of current activity and evaluation of rest and sleep, to establish an individual activity pattern within the person’s current energy envelope.

To avoid potential harms through energy management being wrongly applied to people with ME/CFS without adequate support and expertise, the committee recommended that in specific circumstances people with ME/CFS should be referred to a specialist ME/CFS physiotherapy or occupational therapy service.

The committee agreed that if energy management strategies are inappropriately applied in people with severe or very severe ME/CFS this will increase the potential for harm. To reflect this, they recommended specialist advice and additional care in this group.

Self-monitoring techniques

Although there was a lack of effectiveness evidence on tools to support people to monitor activity management, the committee considered the qualitative evidence and their experience about benefits in using tools to monitor activity alongside the potential harms of increasing the burden on the person and causing them additional anxiety about their activity levels. The committee decided to recommend that activity recording should be as easy as possible, and people should take advantage of tools they are already using. The committee also decided to make a recommendation for research on self-monitoring management strategies to help determine which techniques are effective.

How the recommendations might affect practice

The energy management plan forms part of the overall personalised management plan and is a usual part of specialist care. Appropriate energy management supports people to stay within their energy envelope and aims to prevent their symptoms from worsening and to support them to increase their activity if possible. If people maintain or improve their health this will be highly cost effective.

Return to recommendations

Physical maintenance

Recommendations 1.11.11 to 1.11.14

Why the committee made the recommendations

The committee discussed that people with ME/CFS can have reduced or limited mobility and, in their experience, this can lead to health problems. Physical maintenance should therefore be assessed and included in the person's management plan.

The committee agreed that people with ME/CFS who are immobile need information to help them recognise and prevent the possible complications of long-term immobility such as bone health and skin problems. In the committee's experience, families and carers are given limited information about these areas of care (for example, how to transfer someone from a bed to a chair) and it would have helped them.

How the recommendations might affect practice

These recommendations are already established in other NICE guidance and should not impose a significant cost on the NHS. If they lead to fewer people with deteriorating symptoms they will be highly cost effective.

Return to recommendations

Physical activity

Recommendations 1.11.15 to 1.11.22

Why the committee made the recommendations

Because of the harms reported in the qualitative evidence, as well as the committee's experience of the effects when people exceed the limits of their energy envelope, the committee recommended that people with ME/CFS should not undertake a physical activity or exercise programme unless it is delivered or overseen by a physiotherapist or occupational therapist who has training and expertise in ME/CFS. The committee reinforced there is no therapy based on physical activity or exercise that is effective as a treatment or cure for ME/CFS.

In developing more specific recommendations on the content, approach and delivery of physical activity management, the committee considered the benefits and harms associated with graded exercise therapy that had been identified in the qualitative evidence and their own experiences of these types of interventions. They recommended not to offer any programme based on fixed incremental physical activity or exercise, for example graded exercise therapy or structured activity or exercise programmes that are based on deconditioning as the cause of ME/CFS.

In the committee's experience, people with ME/CFS have had varying results from physical activity programmes and they thought it was important to discuss this with people with ME/CFS and talk to them about the possible risks and benefits. The committee outlined what a personalised physical activity plan should look like based on their experience.

How the recommendations might affect practice

These recommendations should prevent inappropriate or unstructured physical activity or exercise programmes from worsening people's symptoms. The referral to a specialist physiotherapist or occupational therapy service may need increased resources; however, this should not impose a significant cost on the NHS and if it leads to fewer people with deteriorating symptoms, it will be highly cost effective.

Return to recommendations

Rest and sleep

Recommendation 1.11.23

The committee considered that giving advice on planning rest and activity was a fundamental part of any management strategy. In their experience, understanding the role of rest and how to introduce rest periods was important in successful energy management.

There was a lack of evidence for sleep management, but the committee recognised that difficulty with sleep was an area of concern for many people with ME/CFS. The committee discussed making consensus recommendations for providing advice for people with ME/CFS, but they agreed it was hard to be confident in recommending any advice when there was not any evidence and a lack of consensus in the area so they made a recommendation for research on sleep management strategies.

How the recommendations might affect practice

This recommendation should not impose a significant cost on the NHS and if it leads to fewer people with deteriorating symptoms it will be highly cost effective.

Return to recommendation

Managing orthostatic intolerance

Recommendations 1.11.24 to 1.11.26

Why the committee made the recommendations

Orthostatic intolerance is identified as one of the symptoms commonly associated with but not exclusive to ME/CFS (see the section on suspecting ME/CFS). In the committee’s experience, although not everyone with ME/CFS experiences orthostatic intolerance, it is very common and the symptoms can be hard to differentiate from other ME/CFS symptoms.

Based on consensus, the committee made recommendations to raise awareness that people with ME/CFS may experience orthostatic intolerance, and to clarify when people with orthostatic intolerance should be referred to secondary care.

The committee did not make any recommendations on managing orthostatic intolerance because this can involve advice on diet, daily activities and activity support and needs to be tailored to each person, taking into account their other ME/CFS symptoms.

The committee recommended that medicines should only be prescribed or overseen by a clinician with expertise in orthostatic intolerance because the medicines that are usually prescribed can worsen other symptoms in people with ME/CFS.

How the recommendations might affect practice

The recommendations should not impose a significant cost on the NHS and if they lead to fewer people with deteriorating symptoms they will be highly cost effective.

Return to recommendations

Managing pain

Recommendation 1.11.27

Why the committee made the recommendation

The committee agreed that pain is a common symptom in people with ME/CFS and is particularly intense in people with severe and very severe ME/CFS. The lack of evidence meant they could not recommend any interventions, but they did refer to the NICE guidelines on neuropathic pain and headaches.

Return to recommendation

Managing nausea

Recommendation 1.11.28

Why the committee made the recommendation

In the committee’s experience, many people with ME/CFS have nausea and this can impact on maintaining a healthy diet. In the absence of evidence, the committee made a consensus recommendation with advice to manage nausea based on their own experience.

How the recommendation might affect practice

This recommendation should not impose a significant cost on the NHS and if it leads to fewer people with deteriorating symptoms it will be highly cost effective.

Return to recommendation

Medicines, including medicines for symptom management

Why the committee made the recommendations

Recommendations 1.11.29 to 1.11.32

The evidence for any pharmacological interventions for ME/CFS was inconclusive with limited evidence for any one medicine and this supported the committee's experience. The committee was aware of claims that have been made about cures for ME/CFS and there is often a financial cost to people with ME/CFS when these are pursued. The committee considered it was important to highlight that medicines or supplements should not be offered as a cure for ME/CFS.

The committee recognised that medicines can be useful for people with ME/CFS to manage their symptoms. The committee agreed that people with ME/CFS may be more intolerant of drug treatment and have more severe adverse effects than people who do not have ME/CFS, so they decided to raise awareness of this. To reduce the risk of harm, the committee discussed using a cautious approach to medicines prescribing, which includes starting the medicine at a lower dose than in usual clinical practice and monitoring how the person responds before adjusting the dose.

The committee discussed medicines management for children and young people, noting the potential for harm, which led them to recommend that prescribing should be initiated under the supervision of a paediatrician with expertise in ME/CFS.

How the recommendations might affect practice

The recommendations should not impose a significant cost on the NHS and if they lead to fewer people with deteriorating symptoms they will be highly cost effective.

Return to recommendations

Dietary management and strategies

Recommendations 1.11.33 to 1.11.42

Why the committee made the recommendations

There was not enough evidence to make a recommendation for any dietary strategy for ME/CFS. However, the committee agreed some general recommendations to ensure that people with ME/CFS receive appropriate support related to diet. This included guidance on when to refer someone to a dietitian who specialises in ME/CFS. The committee also referred to other NICE guidance that was relevant.

The committee considered that people with severe or very severe ME/CFS are particularly at risk of problems associated with eating and are likely to need additional support and referral to a dietitian who specialises in ME/CFS. The committee also used their own experience to recommend some general dietary advice that could be helpful for people with severe or very severe ME/CFS.

There was a lack of evidence for dietary strategies, but the committee recognised that difficulties with diet and nutrition was an area of concern for many people with ME/CFS. The committee discussed making consensus recommendations for providing dietary strategies for people with ME/CFS but they agreed it was hard to be confident in making recommendations when there was not any evidence and a lack of consensus in the area, so they made a recommendation for research on dietary strategies.

How the recommendations might affect practice

The recommendations should not impose a significant cost on the NHS and if they lead to fewer people with deteriorating symptoms they will be highly cost effective.

Return to recommendations

Psychological support: cognitive behavioural therapy

Recommendations 1.11.43 to 1.11.50

Why the committee made the recommendations

The quantitative and qualitative evidence was mixed, and this reflected the committee’s experience. Based on criticisms in the qualitative evidence of CBT being used as a ‘treatment’ for ME/CFS, the committee considered it was important to highlight that CBT is not a cure for ME/CFS and should not be offered as such, but that it is a type of supportive psychological therapy which aims to improve wellbeing and quality of life and may be useful in supporting people who live with ME/CFS to manage their symptoms. It should therefore only be offered in this context.

The qualitative evidence showed that people with ME/CFS have found CBT useful when delivered by a therapist who understands ME/CFS, but also that there is the potential for harm when it is inappropriately delivered. To avoid this, the committee made the recommendation about who should deliver CBT and the clinical supervision they should have.

The committee also made recommendations based on their experience to explain the principles of CBT for people with ME/CFS and what people should expect if they decide to consider CBT.

There was limited evidence in children and young people for the committee to make specific recommendations. After reflecting on their own experience, they decided to recommend that CBT is only considered for children and young people with ME/CFS who have been fully informed (along with their parents and carers) about the principles and aims of CBT and that their cognitive and emotional maturity is taken into account.

None of the clinical evidence included or reflected the needs of people with severe ME/CFS, and the qualitative evidence was mixed, with some people reporting benefit and others harm. The committee recognised that CBT could be supportive for people with severe ME/CFS but because of the severity of their symptoms it is important to be more flexible and adapt the delivery of CBT to accommodate people's limitations.

How the recommendations might affect practice

CBT is currently provided for people with ME/CFS in specialist services. These recommendations clarify when CBT should be offered to people with ME/CFS. They should not have an impact on NHS resource and costs.

Return to recommendations

Managing coexisting conditions

Why the committee made the recommendations

Recommendations 1.12.1 to 1.12.4

The evidence on the diagnostic criteria identified that some conditions are common in people with ME/CFS and this reflected the committee's experience. The committee made a recommendation to highlight this and referred to relevant NICE guidance.

How the recommendations might affect practice

The recommendations should not impose a significant cost on the NHS.

Return to recommendations

Managing flares and relapse

Recommendations 1.13.1 to 1.13.7

Why the committee made the recommendations

In the committee's experience, flares and relapse are a common part of ME/CFS. The committee considered it important to give people information about what a flare is, how to recognise one and how they can lead to a relapse if activity is not monitored and adjusted.

The committee discussed the importance of recognising when a flare has moved to a relapse and that it needs to prompt a review of the person's management plan. It is also possible that a relapse may lead to someone moving to a more severe form of ME/CFS. Part of the review of the management plan is to consider what the causes of relapse might have been and to consider this when revising the plan.

How the recommendations might affect practice

The recommendations should not impose a significant cost on the NHS and if they lead to fewer people with deteriorating symptoms they will be highly cost effective.

Return to recommendations

Review

Recommendations 1.14.1 to 1.14.8

Why the committee made the recommendations

The evidence showed that people with ME/CFS did not always receive follow up or review of their care, but those who did valued this. This reflected the committee's experience, so they recommended at least annual reviews for adults. The committee outlined areas for discussion during the review, including asking people how much support they had to carry out their activities of daily living. This was because, in the committee's experience, this is an area often overlooked and the input of family and carers is often not acknowledged. The committee noted that if any problems are identified advice should be sought from an appropriate specialist.

The committee agreed that children and young people need more frequent review to take into account changes in their ME/CFS as they develop. They also wanted to highlight the importance of involving a paediatrician.

How the recommendations might affect practice

There is variation in practice and some people with ME/CFS, including those with severe and very severe ME/CFS, do not get a clinical review routinely, so for some this will be a change in practice. These recommendations are in line with other long-term conditions and support equity of access to care for people with ME/CFS. Routine follow-up might not be present everywhere but most people with ME/CFS already have regular contact with their primary care teams, so there is not expected to be a large resource impact.

Return to recommendations

Training for health and social care professionals

Recommendations 1.15.1 to 1.15.3

Why the committee made the recommendations

A strong theme in the evidence was the lack of knowledge, understanding and up-to-date training that health and social care professionals have about ME/CFS. This was reflected in the committee's experience so they recommended that all health and social staff who deliver care to people with ME/CFS should be trained so they are able to provide the care in this guideline. The evidence showed that training programmes in ME/CFS are often out of date, so the committee made a recommendation highlighting what a training programme should look like.

How the recommendations might affect practice

Training and education in ME/CFS are not widespread and this will be a change in practice, so there will be a resource impact from the cost of providing this training. Improving knowledge and awareness about ME/CFS will support identifying ME/CFS earlier, which should improve people’s care and lead to better outcomes.

Return to recommendations

Context

The terms ME, CFS, CFS/ME and ME/CFS have all been used for this condition and are not clearly defined. There is little pathological evidence of brain inflammation, which makes the term 'myalgic encephalomyelitis' problematic. Many people with ME/CFS consider the name 'chronic fatigue syndrome' too broad, simplistic and judgemental. For consistency, the abbreviation ME/CFS is used in this guideline.

Recent data from the UK Biobank suggests that there are over 250,000 people in England and Wales with ME/CFS, with about 2.4 times as many women affected as men. It is a complex, multi-system, chronic medical condition that has considerable personal, social and economic consequences and a significant impact on a person’s emotional wellbeing and quality of life.

Everyday life for people with ME/CFS, their family and carers is disrupted and unpredictable. Many people with the condition are unemployed, and less than a fifth work full-time. Approximately 25% have severe disease and are housebound or bed-bound. The quality of life of people with ME/CFS is lower than that of many people with other severe chronic conditions, including multiple sclerosis and some forms of cancer.

It is not clear what causes ME/CFS. In many cases, symptoms are thought to have been triggered by an infection, but it is not simple post-illness fatigue. It lasts longer and even minimal mental or physical activity can make symptoms worse.

There is no diagnostic test or universally accepted definition for ME/CFS. People with the condition report delays in diagnosis, and many healthcare professionals lack the confidence and knowledge to recognise, diagnose and manage it. Fatigue associated with another chronic disease may be confused with ME/CFS and some practitioners are reluctant to positively diagnose ME/CFS when no other causes are found.

People with ME/CFS report a lack of belief and acknowledgement from health and social care professionals about their condition and related problems, which may lead them to be dissatisfied with care and to disengage from services. There are added issues for children and young people if illness makes school attendance difficult, bringing families to the attention of educational and social care services.

NICE produced a guideline on CFS/ME in 2007. That guideline made recommendations on cognitive behavioural therapy and graded exercise therapy. Both treatments are controversial for this condition, and there are disagreements and uncertainty about their effectiveness among both people with ME/CFS and health providers. The evidence for the effects of other commonly prescribed therapies has also been questioned and there is a need to review the evidence for these interventions.

Further evidence is likely to emerge from major studies that have started recently. When they are completed NICE will review the evidence to see whether another guideline update is needed in future.

There is unequal access to specialist services across England and Wales with some areas reporting very limited access. It is important this inequity of access is addressed.

Finding more information and resources

To find out what NICE has said on topics related to this guideline, see the NICE webpage on ME/CFS.

For details of the guideline committee see the committee member list.