NICE National Institute for Health and Care Excellence

Royal College of Physicians

NICE guideline

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

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Your responsibility

The recommendations in this guideline represent the view of NICE, arrived at after careful consideration of the evidence available. When exercising their judgement, professionals and practitioners are expected to take this guideline fully into account, alongside the individual needs, preferences and values of their patients or the people using their service. It is not mandatory to apply the recommendations, and the guideline does not override the responsibility to make decisions appropriate to the circumstances of the individual, in consultation with them and their families and carers or guardian.

Local commissioners and providers of healthcare have a responsibility to enable the guideline to be applied when individual professionals and people using services wish to use it. They should do so in the context of local and national priorities for funding and developing services, and in light of their duties to have due regard to the need to eliminate unlawful discrimination, to advance equality of opportunity and to reduce health inequalities. Nothing in this guideline should be interpreted in a way that would be inconsistent with complying with those duties.

Commissioners and providers have a responsibility to promote an environmentally sustainable health and care system and should assess and reduce the environmental impact of implementing NICE recommendations wherever possible.

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Overview

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 includes recommendations on diagnosis, assessment and care planning, safeguarding, access to care and managing ME/CFS and its symptoms.

These recommendations were developed based on evidence reviewed before the COVID-19 pandemic. We have not reviewed evidence on the effects of COVID-19, so it should not be assumed that these recommendations apply to people diagnosed with post-COVID-19 syndrome. NICE has produced a guideline on managing the long-term effects of COVID-19.

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

This guideline was commissioned by NICE and developed at the National Guideline Centre which is hosted by the Royal College of Physicians.

This guideline updates and replaces NICE guideline CG53 (published August 2007).

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Recommendations

People have the right to be involved in discussions and make informed decisions about their care, as described in NICE's information on 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.

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Box 1 Severity of ME/CFS

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Unless stated otherwise, these recommendations apply to everyone with myalgic encephalomyelitis (or encephalopathy)/chronic fatigue syndrome (ME/CFS) regardless of symptom severity. There are also additional considerations in the section on care for people with severe or very severe ME/CFS.

Definitions of severity are not clear cut because individual symptoms vary widely in severity and people may have some symptoms more severely than others. The definitions below provide a guide to the level of impact of symptoms on everyday functioning.

Mild ME/CFS

People with mild ME/CFS care for themselves and do some light domestic tasks (sometimes needing support) but may have difficulties with mobility. Most are still working or in education, but to do this they have probably stopped all leisure and social pursuits. They often have reduced hours, take days off and 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 or education, and need rest periods, often resting in the afternoon for 1 or 2 hours. Their sleep at night is generally poor quality and disturbed.

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 sound.

Very severe ME/CFS

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.

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1.1 Principles of care for people with ME/CFS

Also see the section on care for people with severe or very severe 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 still being investigated
- affects everyone differently and its impact varies widely – for some people symptoms still allow them to carry out some activities, whereas for others they cause substantial incapacity
- is a fluctuating condition in which a person's symptoms can change unpredictably in nature and severity over a day, week or longer
- can affect different aspects of the lives of both people with ME/CFS and their families and carers, including activities of daily living, family life, social life, emotional wellbeing, work and education.

1.1.2 Recognise that people with ME/CFS may have experienced prejudice and disbelief and could feel stigmatised by people (including family, friends, health and social care professionals, and teachers) who do not understand their illness. Take into account:

- the impact this may have on a child, young person or adult with ME/CFS
- that people with ME/CFS may have lost trust in health and social care services and be hesitant about involving them.

Approach to delivering care

1.1.3 Health and social care professionals should:

- take time to build supportive, trusting and empathetic relationships
- acknowledge to the person the reality of living with ME/CFS and how symptoms could affect them

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- use a person-centred approach to care and assessment
- involve families and carers (as appropriate) in discussions and care planning if the person with ME/CFS chooses to include them
- be sensitive to the person's socioeconomic, cultural and ethnic background, beliefs and values, and their gender identity and sexual orientation, and think about how these might influence their experience, understanding and choice of management.

1.1.4 Recognise that people with ME/CFS need:

- timely and accurate diagnosis so they get appropriate care for their symptoms
- regular monitoring and review, particularly when their symptoms are worsening, changing or are severe (see the section on managing flare-ups in symptoms and relapse and review in primary care).

1.1.5 Explain to people with ME/CFS and their family or carers (as appropriate) that they can decline or withdraw from any part of their care and support plan and this will not affect access to any other aspects of their care. They can begin or return to this part of their plan if they wish to.

1.1.6 When working with children and young people with ME/CFS, ensure their voice is heard by:

- taking a child-centred approach, with the communication focusing on them
- discussing and regularly reviewing with them how they want to be involved in decisions about their care
- taking into account that they may find it difficult to communicate and describe their symptoms and may need their parents or carers (as appropriate) to help them
- recognising that they may need to be seen on more than 1 occasion to gain trust (with or without their parents or carers, as appropriate).

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For a short explanation of why the committee made these recommendations and how they might affect practice, 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, education and support for people with ME/CFS and their families and carers
- evidence review C: accessing health and social care services
- appendix 2: involving adults with severe ME/CFS.

Other supporting evidence and discussion can be found in evidence review B: information, education and support for health and social care professionals and appendix 1: involving 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 Suspect ME/CFS if:

- the person has had all of the persistent symptoms in box 2 for a minimum of 6 weeks in adults and 4 weeks in children and young people **and**
- the person's ability to engage in occupational, educational, social or personal activities is significantly reduced from pre-illness levels **and**
- symptoms are not explained by another condition.

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Box 2 Symptoms for suspecting ME/CFS

All of these symptoms should be present:

- Debilitating fatigue that is worsened by activity, is not caused by excessive cognitive, physical, emotional or social exertion, and is not significantly relieved by rest.
- Post-exertional malaise after activity in which the worsening of symptoms:
  - is often delayed in onset by hours or days
  - is disproportionate to the activity
  - has a prolonged recovery time that may last hours, days, weeks or longer.
- Unrefreshing sleep or sleep disturbance (or both), which may include:
  - feeling exhausted, feeling flu-like and stiff on waking
  - broken or shallow sleep, altered sleep pattern or hypersomnia.
- Cognitive difficulties (sometimes described as 'brain fog'), which may include problems finding words or numbers, difficulty in speaking, slowed responsiveness, short-term memory problems, and difficulty concentrating or multitasking.

1.2.3 If ME/CFS is suspected, carry out:

- a medical assessment (including symptoms and history, comorbidities, overall physical and mental health)
- a physical examination
- an assessment of the impact of symptoms on psychological and social wellbeing

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- investigations to exclude other diagnoses, for example (but not limited to):
  - urinalysis for protein, blood and glucose
  - full blood count
  - urea and electrolytes
  - liver function
  - thyroid function
  - erythrocyte sedimentation rate or plasma viscosity
  - C-reactive protein
  - calcium and phosphate
  - HbA1c
  - serum ferritin
  - coeliac screening
  - creatine kinase.

  Use clinical judgement to decide on additional investigations to exclude other diagnoses (for example, vitamin D, vitamin B12 and folate levels; serological tests if there is a history of infection; and 9am cortisol for adrenal insufficiency).

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

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- heightened sensory sensitivities, including to light, sound, touch, taste 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 Primary healthcare professionals should consider seeking advice from an appropriate specialist if there is uncertainty about interpreting signs and symptoms and whether an early referral is needed. For children and young people, consider seeking advice from a paediatrician.

1.2.6 When ME/CFS is suspected:

- continue with any assessments needed to exclude or identify other conditions
- give the person advice on managing their symptoms in line with the section on advice for people with suspected ME/CFS.

Referring children and young people with suspected ME/CFS

1.2.7 When ME/CFS is suspected in a child or young person based on the criteria in recommendation 1.2.2 and the assessment in recommendation 1.2.3:

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

For a short explanation of why the committee made these recommendations and how they might affect practice, 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: identifying and diagnosing ME/CFS.

1.3 Advice for people with suspected ME/CFS

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

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- not to use more energy than they perceive they have – they should manage their daily activity and not 'push through' their symptoms
- to rest and convalesce as needed (this might mean making changes to their daily routine, including work, school and other activities)
- 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 before that if they develop new or worsened symptoms, and ensure that they know who to contact for advice.

For a short explanation of why the committee made these recommendations and how they might affect practice, 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: management strategies before diagnosis.

1.4 Diagnosis

1.4.1 Diagnose ME/CFS in a child, young person or adult who has the symptoms in recommendation 1.2.2 that have persisted for 3 months and are not explained by another condition.

1.4.2 Primary healthcare professionals should consider seeking advice from an appropriate specialist if there is uncertainty about interpreting signs and symptoms at 3 months and whether further investigations are needed.

1.4.3 Refer adults directly to an ME/CFS specialist team (see box 3) to confirm their diagnosis and develop a care and support plan.

1.4.4 Refer children and young people who have been diagnosed with ME/CFS after assessment by a paediatrician (based on the criteria in recommendation 1.2.2) directly to a paediatric ME/CFS specialist team (see box 3) to confirm their diagnosis and develop a care and support plan.

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Box 3 ME/CFS specialist team

Specialist teams consist of a range of healthcare professionals with training and experience in assessing, diagnosing, treating and managing ME/CFS. They commonly have medically trained clinicians from a variety of specialisms (including rheumatology, rehabilitation medicine, endocrinology, infectious diseases, neurology, immunology, general practice and paediatrics) as well as access to other healthcare professionals specialising in ME/CFS. These may include physiotherapists, exercise physiologists, occupational therapists, dietitians, and clinical or counselling psychologists.

Children and young people are likely to be cared for under local or regional paediatric teams that have experience of working with children and young people with ME/CFS in collaboration with ME/CFS specialist centres.

For a short explanation of why the committee made these recommendations and how they might affect practice, see the rationale and impact section on diagnosis.

Full details of the evidence and the committee's discussion are in evidence review D: identifying and diagnosing ME/CFS.

1.5 Assessment and care and support planning by an ME/CFS specialist team

Also see the section on care for people with severe or very severe ME/CFS.

1.5.1 Carry out and record a holistic assessment to confirm the person's diagnosis of ME/CFS and inform their care and support plan. This should include:

- a medical assessment (including relevant symptoms and history, comorbidities, overall physical and mental health, anything that is known to exacerbate or alleviate symptoms, and sleep quality)
- physical functioning
- the impact of symptoms on psychological, emotional and social wellbeing

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- 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 and agree a personalised care and support plan with the person with ME/CFS and their family or carers (as appropriate) informed by their holistic assessment. Include the following, depending on the person's needs:

- information and support needs (see the section on information and support)
- support for activities of daily living (see the section on access to care and support and recommendation 1.6.8 on accessing social care)
- mobility and daily living aids and adaptations to increase or maintain independence (see the recommendations on aids and adaptations)
- education, training or employment support needs (see the section on supporting people with ME/CFS in work, education and training)
- self-management strategies, including energy management (see the recommendations on energy management)
- physical functioning and mobility (see the recommendations on physical functioning and mobility)
- managing ME/CFS and symptom management, including medicines management (see recommendations 1.12.1 to 1.12.26 on managing symptoms)
- guidance on managing flare-ups and relapses (see the section on managing flare-ups in symptoms and relapses)
- details of the health and social care professionals involved in the person's care, and who to contact (see recommendation 1.10.3).

1.5.3 Recognise that the person with ME/CFS is in charge of the aims of their care and support plan.

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

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For a short explanation of why the committee made these recommendations and how they might affect practice, see the rationale and impact section on assessment and care and support planning by an ME/CFS specialist team.

Full details of the evidence and the committee's discussion are in evidence review G: non-pharmacological management of ME/CFS and evidence review A: information, education and support for people with ME/CFS and their families and carers.

1.6 Information and support

Communication

1.6.1 Ensure information is provided to people with ME/CFS and their family or carers (as appropriate):

- in a variety of formats, such as written materials, electronic and audio, and suitable for their needs (for example, in their preferred language or an accessible version)
- both in person in clinical settings and for them to use at home.

  Follow the principles on communication, information giving and shared decision making in the NICE guidelines on patient experience in adult NHS services, people's experience in adult social care services and shared decision making.

1.6.2 When providing information for children and young people with ME/CFS, take into account their age and level of understanding, symptoms and 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 with ME/CFS and their family or carers (as appropriate) up-to-date

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information about ME/CFS as soon as it 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 over a day, week or longer
- varies in long-term outlook from person to person – although a proportion of people recover or have a long period of remission, many will need to adapt to living with ME/CFS
- varies widely in its impact on people's lives, and can affect their daily activities, family and social life, and work or education (these impacts may be severe)
- can be worsened by particular triggers – these can be known or new triggers or in some cases there is no clear trigger
- can be self-managed with support and advice (see the section on energy management)
- can involve flare-ups and relapses even if symptoms are well managed, so planning for these should be part of the energy management plan.

1.6.5 Explain to children and young people with ME/CFS and their parents or carers (as appropriate) that the outlook is better in children and young people than in adults.

1.6.6 Give people with ME/CFS and their family or carers (as appropriate) information about:

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

Social care

1.6.7 Discuss sensitively with the person and their family or carers (as appropriate) how social care may benefit them. Explain that it can help the person living with

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ME/CFS as well as provide a route to support for families and carers through a formal carer's assessment. Also see recommendations 1.8.5 and 1.8.6 on maintaining independence.

1.6.8 Explain to people with ME/CFS and their family or carers (as appropriate) how to self-refer for a social care needs assessment from their local authority. Offer to make the referral for them if they prefer.

1.6.9 Advise children and young people with moderate ME/CFS or severe or very severe ME/CFS and their parents or carers (as appropriate) 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

1.6.10 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.

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

- parents and 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.

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For a short explanation of why the committee made these recommendations and how they might affect practice, 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, education and support for people with ME/CFS and their families and carers.

Other supporting evidence and discussion can be found in:

- evidence review B: information, education and support for health and social care professionals
- evidence review C: accessing health and social care services
- appendix 1: involving children and young people.

1.7 Safeguarding

1.7.1 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.

1.7.2 If a person with confirmed or suspected ME/CFS needs a safeguarding assessment, directly involve health and social care professionals who have training and experience in ME/CFS as soon as possible.

1.7.3 If a person with confirmed or suspected ME/CFS needs to be assessed under the Mental Health Act 1983 or the Mental Capacity Act 2005, directly involve health and social care professionals who have training and experience in ME/CFS as soon as possible.

1.7.4 Recognise that the following are not necessarily signs of abuse or neglect in children and young people with confirmed or suspected ME/CFS:

- physical symptoms that do not fit a commonly recognised illness pattern
- more than 1 child or family member having ME/CFS

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- disagreeing with, declining or withdrawing from any part of their care and support plan, either by them or by their parents or carers on their behalf
- parents or carers acting as advocates and communicating on their behalf
- reduced or non-attendance at school.

1.7.5 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.

1.7.6 Offer children and young people with ME/CFS a review of their care and support plan at least every 6 months, and more frequently if needed, depending on the severity and complexity of their symptoms.

For a short explanation of why the committee made these recommendations and how they might affect practice, see the rationale and impact section on safeguarding.

Full details of the evidence and the committee's discussion are in evidence review B: information, education and support for health and social care professionals.

Other supporting evidence and discussion can be found in evidence review A: information, education and support for people with ME/CFS and their families and carers and appendix 1: involving children and young people.

1.8 Access to care and support

Also see the section on care for people with severe or very severe ME/CFS.

1.8.1 Health and social care organisations should ensure that people with ME/CFS can use their services by:

- adapting the timing, length and frequency of all appointments to the person's needs

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- taking into account physical accessibility, such as how far the person has to travel, whether there is suitable transport and parking, and where rooms are for appointments
- taking into account sensitivities to light, sound, touch, pain, temperature extremes or smells
- providing care flexibly to the person's needs, such as by online or phone consultations or making home visits.

1.8.2 If a person with ME/CFS misses an appointment:

- do not discharge them for not attending because it could be due to their symptoms worsening
- discuss why they could not attend and how the multidisciplinary team can support them.

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

- debilitating symptoms or the risk that their symptoms will worsen may 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.

Hospital care

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

1.8.4 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, sound, heating and smells.

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Maintaining independence

Also see the recommendations on social care and supporting families and carers of people with ME/CFS.

1.8.5 If a person with ME/CFS needs support at home, carry out a social care needs assessment. As a minimum, record and provide information and support on:

- activities of daily living
- mobility, including transferring from bed to chair, access to and use of toilet and washing facilities, use of stairs, and access to outside space
- dexterity and balance, including avoiding falls
- their home, including environmental controls to reduce light levels, sound levels and temperature fluctuations
- the feasibility of equipment and adaptations
- access to technology, including internet 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.

1.8.6 Give families and carers information on how to access training and resources about caring for the person with ME/CFS (see the NICE guideline on supporting adult carers).

Aids and adaptations

1.8.7 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.

1.8.8 For people with moderate ME/CFS or severe or very severe ME/CFS, consider providing or recommending aids and adaptations (such as a wheelchair, blue badge or stairlift) that could help them maintain their independence and improve their quality of life, taking into account the risks and benefits. Include these in the person's care and support plan.

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1.8.9 Provide aids and adaptations identified in the person's social care needs assessment without delay, so that people with ME/CFS can carry out activities of daily living and maintain their quality of life as much as possible.

For a short explanation of why the committee made these recommendations and how they might affect practice, see the rationale and impact section on access to care and support.

Full details of the evidence and the committee's discussion are in evidence review C: accessing health and social care services.

Other supporting evidence and discussion can be found in evidence review A: information, education and support for people with ME/CFS and their families and carers and appendix 2: involving adults with severe ME/CFS.

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

1.9.1 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 care and support plan and any adjustments needed.

1.9.2 Advise and discuss with people with ME/CFS that:

- 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
- 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.

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:

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- 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 care and support 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 learning or education at home and using assistive equipment.

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

1.9.6 Advise children and young people with ME/CFS and their parents or carers (as appropriate) that:

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

For a short explanation of why the committee made these recommendations and how they might affect practice, 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, education and support for people with ME/CFS and their families and carers and appendix 1: involving 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 access to health and social care professionals with expertise in the following as a minimum, with additional expertise depending on symptoms:

- medical assessment and diagnosis
- developing personalised care and support plans

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- self-management strategies, including energy management
- symptom management, including prescribing and medicines management
- managing flare-ups and relapses
- activities of daily living, including dental health
- psychological, emotional and social 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 an ME/CFS specialist team.

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

1.10.4 Provide children and young people with ME/CFS and their family or carers (as appropriate) with details of a named professional in the ME/CFS specialist team who they can contact with any concerns about the child or young person'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.

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For a short explanation of why the committee made these recommendations and how they might affect practice, 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 and evidence review C: accessing health and social care services.

Other supporting evidence and discussion can be found in evidence review A: information, education and support for people with ME/CFS and their families and carers and appendix 1: involving children and young people.

1.11 Managing ME/CFS

1.11.1 Be aware that ME/CFS symptoms can be managed but there is currently no cure (non-pharmacological or pharmacological) for ME/CFS.

For a short explanation of why the committee made this recommendation and how it might affect practice, 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 interventions and evidence review G: non- pharmacological management of ME/CFS.

Energy management

Also see the section on care for people with severe or very severe ME/CFS.

1.11.2 Discuss with people with ME/CFS the principles of energy management, 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 with support from a healthcare professional in an ME/CFS specialist team
- includes all types of activity (cognitive, physical, emotional and social) and takes into account overall level of activity

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- helps people learn to use the amount of energy they have while reducing their risk of post-exertional malaise or worsening their symptoms by exceeding their limits
- recognises that each person has a different and fluctuating energy limit and they are experts in judging 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 maintained or adjusted (upwards after a period of stability or downwards 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.

1.11.3 Help people with ME/CFS develop a plan for energy management as part of their care and support plan. Support them to establish realistic expectations and develop goals that are meaningful to them. Discuss and record the following in the plan along with anything else that is important to the person:

- cognitive activity
- mobility and other physical activity
- ability to undertake activities of daily living
- psychological, emotional and social demands, including family and sexual relationships
- rest and relaxation (both quality and duration)
- sleep quality and duration
- effect of environmental factors, including sensory stimulation.

1.11.4 Work with the person to establish an individual activity pattern within their current energy limits that minimises their symptoms. For example:

- agree a sustainable level of activity as the first step, which may mean reducing activity
- plan periods of rest and activity, and incorporate the need for pre-emptive rest

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- 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 how to manage flare-ups and relapses (see the section on managing flare-ups in symptoms and relapse).

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 physiotherapist or occupational therapist working in an ME/CFS specialist team if they:

- have difficulties caused by reduced physical activity or mobility (also see the sections on physical functioning and mobility and care for people with severe or very severe ME/CFS) **or**
- feel ready to progress their physical activity beyond their current activities of daily living (see the section on physical activity and exercise) **or**
- would like to incorporate a physical activity or exercise programme into managing their ME/CFS (see the section on incorporating physical activity and exercise).

For a short explanation of why the committee made these recommendations and how they might affect practice, 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 of ME/CFS.

Other supporting evidence and discussion can be found in evidence review A: information, education and support for people with ME/CFS and their families and carers and appendix 2: involving adults with severe ME/CFS.

Incorporating physical activity and exercise

1.11.9 Do not advise people with ME/CFS to undertake exercise that is not part of a

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programme overseen by an ME/CFS specialist team, such as telling them to go to the gym or exercise more, because this may worsen their symptoms.

1.11.10 Only consider a personalised physical activity or exercise programme for people with ME/CFS who:

- feel ready to progress their physical activity beyond their current activities of daily living **or**
- would like to incorporate physical activity or exercise into managing their ME/CFS.

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

1.11.12 If a physical activity or exercise programme is offered, it should be overseen by a physiotherapist in an ME/CFS specialist team.

1.11.13 If a person with ME/CFS takes up the offer of a personalised physical activity or exercise programme, agree a programme with them that involves the following and review it regularly:

- establishing their physical activity baseline at a level that does not worsen their symptoms
- initially reducing physical activity to be below their baseline level
- maintaining this successfully for a period of time before attempting to increase it
- making flexible adjustments to their physical activity (up or down as needed) to help them gradually improve their physical abilities while staying within their energy limits
- recognising a flare-up or relapse early and outlining how to manage it.

1.11.14 Do not offer people with ME/CFS:

- any therapy based on physical activity or exercise as a cure for ME/CFS
- generalised physical activity or exercise programmes – this includes programmes developed for healthy people or people with other illnesses

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- any programme that does not follow the approach in recommendation 1.11.13 or that uses fixed incremental increases in physical activity or exercise, for example, graded exercise therapy (see box 4)
- physical activity or exercise programmes that are based on deconditioning and exercise avoidance theories as perpetuating ME/CFS.

Box 4 Graded exercise therapy definition

Graded exercise therapy is a term used in varying ways by different services supporting people with ME/CFS.

In this guideline, graded exercise therapy is defined as first establishing an individual's baseline of achievable exercise or physical activity, then making fixed incremental increases in the time spent being physically active. This definition of graded exercise therapy reflects the descriptions given in the evidence that was reviewed, and it is this approach that the guideline says should not be undertaken.

An individualised approach that should be taken for people with ME/CFS who choose to undertake a physical activity or exercise programme is described in recommendations 1.11.10 to 1.11.13.

Flare-ups and relapse

1.11.15 Agree with the person how to adjust their physical activity during a flare-up or relapse. This should include:

- providing access to review and support from a physiotherapist in an ME/CFS specialist team
- stabilising their symptoms by reducing physical activity to within their current energy limits
- only once symptoms stabilise and the person feels able to resume physical activity, establishing a new physical activity baseline.

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

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For a short explanation of why the committee made these recommendations and how they might affect practice, see the rationale and impact section on incorporating physical activity and exercise.

Full details of the evidence and the committee's discussion are in:

- evidence review G: non-pharmacological management of ME/CFS
- evidence review A: information, education and support for people with ME/CFS and their families and carers
- appendix 1: involving children and young people.

1.12 Symptom management for people with ME/CFS

Refer to relevant NICE guidance for managing symptoms that are not covered in this section, taking into account the recommendations in the sections on principles of care for people with ME/CFS, access to care and support and energy management.

Rest and sleep

1.12.1 Advise people with ME/CFS:

- about 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.

1.12.2 Give people with ME/CFS personalised sleep management advice that includes:

- explaining the role and effect of sleep disturbance in ME/CFS
- identifying the common changes in sleep patterns seen in ME/CFS (such as broken or shallow sleep, altered sleep pattern or hypersomnia)

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- developing good sleep habits
- taking into account the need for rest in the day, and balancing this against how the person is sleeping at night
- introducing changes to sleep patterns gradually.

1.12.3 If sleep management strategies do not improve the person's sleep and rest, think about the possibility of an underlying sleep disorder or dysfunction and whether to refer to an appropriate specialist.

1.12.4 Review the use of rest periods and sleep management strategies regularly as part of the person's care and support plan.

For a short explanation of why the committee made these recommendations and how they might affect practice, 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 of ME/CFS.

Physical functioning and mobility

1.12.5 Include strategies to maintain and prevent deterioration of physical functioning and mobility in the care and support plans of people with ME/CFS. These strategies may need to be carried out in small amounts and spread out throughout the day. Think about including the following:

- joint mobility
- muscle flexibility
- balance
- postural and positional support
- muscle function
- bone health
- cardiovascular health.

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1.12.6 Assess at every contact people with severe or very severe ME/CFS or those with prolonged periods of immobility for:

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

1.12.7 Give people with ME/CFS and their family or carers (as appropriate) information, advice and support on how to recognise and prevent possible complications of long-term immobility.

1.12.8 Give families and carers information, advice and support on how to help people with ME/CFS follow their care and support plan in relation to physical functioning and mobility. This may include:

- bed mobility
- moving from lying to sitting to standing
- transferring from bed to chair
- using mobility aids
- walking
- joint mobility
- muscle stretching
- muscle strength
- balance
- going up and down stairs.

For training to provide care and support, see NICE's guideline on supporting adult carers.

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For a short explanation of why the committee made these recommendations and how they might affect practice, see the rationale and impact section on physical functioning and mobility.

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

Orthostatic intolerance

1.12.9 Be aware that people with ME/CFS may experience orthostatic intolerance, including postural orthostatic tachycardia syndrome (POTS).

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

1.12.11 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 and how they might affect practice, 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 of ME/CFS.

Pain

1.12.12 Be aware that pain is a symptom commonly associated with ME/CFS.

1.12.13 Investigate and manage the person's pain according to best practice, referring to specialist pain services if appropriate.

1.12.14 Refer to the following for advice on treating neuropathic pain or headaches:

- NICE's guideline on neuropathic pain in adults

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- NICE's guideline on headaches in over 12s.

For a short explanation of why the committee made these recommendations and how they might affect practice, see the rationale and impact section on pain.

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

Medicines

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

Medicines for symptom management

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

1.12.17 Take into account when prescribing that people with ME/CFS may be more intolerant of drug treatment. Consider:

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

1.12.18 Drug treatment for the symptoms associated with ME/CFS for children and young people should only be started under guidance or supervision from a medical professional trained and experienced in paediatric prescribing.

For a short explanation of why the committee made these recommendations and how they might affect practice, see the rationale and impact section on medicines.

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

Dietary management and strategies

Also see the section on care for people with severe or very severe ME/CFS.

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

1.12.20 Work with the person and their family or carers (as appropriate) to find ways of minimising complications caused by gastrointestinal symptoms (such as nausea), changes to appetite, swallowing difficulties, sore throat or difficulties with buying, preparing and eating food.

1.12.21 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. Explain that not eating or drinking may increase their nausea.

1.12.22 Refer people with ME/CFS for a dietetic assessment by a dietitian with a special interest in ME/CFS if they are:

- losing weight and at risk of malnutrition
- gaining weight
- following a restrictive diet.

1.12.23 Be aware that people with ME/CFS may be at risk of vitamin D deficiency, especially those who are housebound or bedbound. For advice on vitamin D supplementation, see the NICE guideline on vitamin D.

1.12.24 Explain to people with ME/CFS that there is not enough evidence to support routinely taking vitamin and mineral supplements as a cure for ME/CFS or for managing symptoms. If they choose to take a vitamin or supplement, explain the potential side effects of taking doses of vitamins and minerals above the recommended daily amount.

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

1.12.26 For advice on food allergies in children, see the NICE guideline on food allergy in under 19s.

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For a short explanation of why the committee made these recommendations and how they might affect practice, 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 of ME/CFS.

Lightning Process

1.12.27 Do not offer the Lightning Process, or therapies based on it, to people with ME/CFS.

For a short explanation of why the committee made this recommendation and how it might affect practice, see the rationale and impact section on the Lightning Process.

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

Cognitive behavioural therapy

Also see the section on care for people with severe or very severe ME/CFS.

1.12.28 Discuss cognitive behavioural therapy (CBT) with adults, children and young people with ME/CFS (and their parents or carers, as appropriate). Explain:

- its principles, including that it may help them manage their symptoms but it is not curative (see box 5) and
- any potential benefits and risks.

Box 5 Cognitive behavioural therapy

The committee wanted to highlight that cognitive behavioural therapy (CBT) has sometimes been assumed to be a cure for ME/CFS. However, it should only be offered to support people who live with ME/CFS to manage their symptoms, improve their functioning and reduce the distress associated with having a chronic illness.

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1.12.29 Only offer CBT to adults, children and young people with ME/CFS if, after discussing it (see recommendation 1.12.28), they would like to use it to support them in managing their symptoms.

1.12.30 For children and young people with ME/CFS who would like to use CBT:

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

Also see the section on principles of care for people with ME/CFS (including the additional principles of care for children and young people with ME/CFS).

1.12.31 CBT should only be 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.

1.12.32 Explain that CBT for people with ME/CFS:

- aims to improve their quality of life, including functioning, and reduce the 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.

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

- takes a non-judgemental, supportive approach to the person's experience of their symptoms and the challenges these present
- 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 to work towards goals and priorities that they have chosen themselves
- takes into account how symptoms are individual to each person, can fluctuate in severity and may change over time.

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1.12.34 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 the personal meaning of their symptoms and illness, and how this might relate to how they manage their symptoms
- developing a self-management plan
- 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
- 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.

For a short explanation of why the committee made these recommendations and how they might affect practice, see the rationale and impact section on cognitive behavioural therapy.

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

1.13 Managing coexisting conditions

1.13.1 Be aware that other conditions may coexist with ME/CFS and should be investigated and managed according to best practice.

1.13.2 When managing coexisting conditions in people with ME/CFS, take into account the recommendations in the sections on principles of care for people with ME/CFS, access to care and support and energy management.

1.13.3 For recommendations on multimorbidity, thyroid disease and irritable bowel syndrome in adults, refer to the:

- NICE guideline on multimorbidity

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- NICE guideline on thyroid disease
- NICE guideline on irritable bowel syndrome in adults.

1.13.4 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 and how they might affect practice, 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: identifying and diagnosing ME/CFS.

1.14 Managing flare-ups in symptoms and relapse

1.14.1 Explain that flare-ups and relapses can happen in ME/CFS even if the person's symptoms are well managed.

1.14.2 Tell people with ME/CFS that:

- they are likely to be having a flare-up if they experience a worsening of their symptoms beyond their normal day-to-day variation, which lasts a few days
- a relapse is when there is a sustained and marked exacerbation of ME/CFS symptoms lasting longer than a flare-up and needing substantial and sustained adjustment of energy management.

1.14.3 Include guidance on managing flare-ups and relapses in the person's care and support plan.

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1.14.4 Evaluate and investigate any new symptoms or a change in symptoms and do not assume they are caused by the person's ME/CFS.

1.14.5 Discuss and agree self-management strategies with the person with ME/CFS to help them respond promptly if they have a flare-up or relapse, and record these in their care and support plan. This should include:

- For a flare-up:
  - identifying possible triggers, such as acute illness or overexertion (in some cases, there may be no clear trigger)
  - temporarily reducing their activity levels
  - monitoring symptoms, recognising that although flare-ups are transient, some will develop into a relapse
  - not returning to usual activity levels until the flare-up has resolved.
- For a relapse:
  - reducing, or even stopping, some activities
  - increasing the frequency or duration of rest periods
  - reassessing energy limits to stabilise symptoms.

1.14.6 If a flare-up or relapse cannot be managed using the person's self-management strategies outlined in their care and support plan or they are worried about new symptoms or a change in symptoms, advise the person to contact their named contact in primary care or the ME/CFS specialist team.

1.14.7 When a person with ME/CFS has a relapse, review their care and support plan with them (if needed), 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).

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After a flare-up or relapse

1.14.8 Once a flare-up or relapse has resolved or stabilised, discuss with the person:

- whether their care and support plan needs to be reviewed and adjusted to reflect their current symptoms and energy limit if this is different from before the flare-up or relapse (for people participating in physical activity or exercise programmes, see recommendations 1.11.15 and 1.11.16)
- their experience of the flare-up or relapse to determine whether strategies can be put in place to manage potential triggers in the future.

For a short explanation of why the committee made these recommendations and how they might affect practice, see the rationale and impact section on managing flare-ups in symptoms and relapse.

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

1.15 Review in primary care

1.15.1 Offer adults with ME/CFS a review of their care and support plan in primary care at least once a year.

1.15.2 Offer children and young people with ME/CFS a review of their care and support plan at least every 6 months.

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

1.15.4 When carrying out a review in primary care, ensure you have access to the person's care and support plan and any clinical communications from the ME/CFS specialist team (including their discharge letter, if relevant).

1.15.5 As part of the review, discuss with the person with ME/CFS (and their family or carers, as appropriate) and record as a minimum:

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- their condition, including any changes in their illness and the impact of this
- symptoms, including whether they have experienced new symptoms
- self-management – ask about their energy management plan and (if relevant) their physical activity or exercise programme
- who is helping them and how they provide support
- psychological, emotional and social wellbeing
- any future plans – ask if the person is considering any changes or if they have any challenges ahead.

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

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

1.15.8 Evaluate and investigate whether new symptoms, or a change in symptoms, are due to the person's ME/CFS or whether they are due to another condition.

Additional principles for children and young people

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

1.15.10 When deciding 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.

Also see recommendation 1.1.6 on ensuring the child's voice is heard and on involving their parents or carers.

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For a short explanation of why the committee made these recommendations and how they might affect practice, see the rationale and impact section on review in primary care.

Full details of the evidence and the committee's discussion are in evidence review J: monitoring and reviewing people with ME/CFS.

1.16 Training for health and social care professionals

1.16.1 Health and social care providers should ensure that all staff delivering care to people with ME/CFS receive training relevant to their role so they can provide care in line with this guideline. Training should include:

- helping them to understand what ME/CFS is and its diagnosis and management
- the experiences of people with ME/CFS.

For a short explanation of why the committee made this recommendation and how it might affect practice, 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, education and support for health and social care professionals.

Other supporting evidence and discussion can be found in evidence review A: information, education and support for people with ME/CFS and their families and carers and appendix 2: involving adults with severe ME/CFS.

1.17 Care for people with severe or very severe ME/CFS

This section supplements the rest of the guideline with additional considerations for people with severe or very severe ME/CFS.

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

Also see the main section on principles of care for people with ME/CFS.

1.17.1 Be aware that people with severe or very severe ME/CFS may experience the

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following symptoms that significantly affect their lives, including their mobility, emotional wellbeing 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, sound, touch, movement, temperature extremes and smells
- extreme weakness, with severely reduced movement
- reduced ability or inability to speak or swallow
- cognitive difficulties that limit the person's ability to communicate and take in written or verbal communication
- sleep disturbance such as unrefreshing sleep, hypersomnia and altered sleep pattern
- gastrointestinal difficulties such as nausea, incontinence, constipation and bloating
- neurological symptoms such as double vision and other visual disorders, dizziness
- orthostatic intolerance and autonomic dysfunction, such as postural orthostatic tachycardia syndrome (POTS) and postural hypotension.

1.17.2 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 bedbound and may need support with all activities of daily living, including aids and adaptations to assist mobility and independence in activities of daily living (for example, a wheelchair)
- need careful physical contact when supported with activities of daily living, taking into account possible sensitivity to touch
- cannot communicate without support and may need to choose someone 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 recommendations on dietary management and strategies)

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- have problems accessing information, for example because of difficulty with screens, sound and light sensitivity, headaches affecting their ability to read, or brain fog affecting their concentration.

1.17.3 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 or carers wherever possible
- aware of the person's needs.

1.17.4 Risk assess each interaction with a person with severe or very severe ME/CFS in advance to ensure its benefits will outweigh the risks (for example, worsening their symptoms) to the person. For people with very severe ME/CFS, think about discussing this with the person's family or carers on their behalf (if appropriate), while keeping the focus of the engagement on the person with ME/CFS.

Assessment and care and support planning by an ME/CFS specialist team

Also see the main section on assessment and care and support planning by an ME/CFS specialist team.

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

Access to care and support

Also see the main section on access to care and support.

1.17.6 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 or phone consultations, supplying written communication, and supporting their applications for aids and appliances.

Hospital care

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

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- discuss with the person (and their family or carers, as appropriate) what to expect when they come into hospital
- aim to minimise discomfort and post-exertional malaise 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 care and support 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 sound
  - keeping a stable temperature
  - minimising smells.

Managing ME/CFS

Also see the main section on managing ME/CFS.

Energy management

Also see the main section on energy management.

1.17.8 Refer people with severe or very severe ME/CFS to a physiotherapist or occupational therapist working in an ME/CFS specialist team for support on developing energy management plans.

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1.17.9 When agreeing energy management plans with people with severe or very severe ME/CFS (and their family or carers, as appropriate), take into account the need to make any changes in activity smaller and any increases (if possible) much slower.

Symptom management

Also see the main section on symptom management for people with ME/CFS.

Dietary management and strategies

1.17.10 Refer people with severe or very severe ME/CFS for a dietetic assessment by a dietitian with a special interest in ME/CFS.

1.17.11 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, for example linked with altered taste, smell and texture
- food intolerances
- nausea
- difficulty swallowing and chewing.

Follow the recommendations on screening for malnutrition and indications for nutrition support, in the NICE guideline on nutrition support for adults.

1.17.12 Give 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.

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Cognitive behavioural therapy

1.17.13 Healthcare professionals delivering CBT to people 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 and how they might affect practice, see the rationale and impact section on care for people with severe or very severe ME/CFS.

Full details of the evidence and the committee's discussion are in:

- evidence review A: information, education and support for people with ME/CFS and their families and carers
- appendix 1: involving children and young people
- evidence review B: information, education and support for health and social care professionals
- evidence review C: accessing health and social care services
- evidence review G: non-pharmacological management of ME/CFS
- evidence review I: multidisciplinary care
- evidence review J: monitoring and reviewing people with ME/CFS.

Other supporting evidence and discussion can be found in evidence review A: information, education and support for people with ME/CFS and their families and carers and appendix 2: involving adults with severe ME/CFS.

Terms used in this guideline

For other definitions, see the NICE glossary and the Think Local, Act Personal Care and Support Jargon Buster.

Activity

Any effort that uses energy, which includes cognitive, emotional and social activity as well as

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physical activity. Different activities combine and interact to cause a cumulative impact for the person.

Advocate

In this guideline, the role of an advocate is to support a vulnerable or disadvantaged person with ME/CFS and ensure that their rights are being upheld in a health and social care context. They are chosen by the person with ME/CFS and could be a family member, carer, friend or an independent advocate. They make sure that the person is heard.

Care and support plan

The personalised collaborative care and support plan is developed by the ME/CFS specialist team based on a holistic assessment. It is the basis for other assessments and plans in areas such as social care, energy management, physical activity, physical functioning and mobility, cognitive behavioural therapy and dietary management.

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. This is distinct from care workers who are employed to provide support.

Children and young people

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

Energy limit

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

Energy management

A self-management strategy that involves a person with ME/CFS managing their activities to stay within their energy limit, with support from a healthcare professional.

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Exercise

Exercise is planned, structured, repetitive and purposeful activity focused on improvement or maintenance of 1 or more components of physical fitness. Exercise is a subcategory of physical activity.

Fatigue

Fatigue in ME/CFS typically has the following components:

- feeling flu-like, especially in the early days of the illness
- restlessness or feeling 'wired but tired'
- 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 difficulties
- rapid loss of muscle strength or stamina after starting an activity, causing for example, sudden weakness, clumsiness, lack of coordination, and being unable to repeat physical effort consistently.

Flare-up

A worsening of symptoms, more than would be accounted for by normal day-to-day variation, that affects the person's ability to perform their usual activities. Flare-ups may occur spontaneously or be triggered by another illness, overexertion or other triggers. Flare-ups usually occur as part of post-exertional malaise but it is possible for other symptoms, such as pain, to flare-up without post-exertional malaise. The worsening of symptoms is transient and flare-ups typically resolve after a few days, either spontaneously or in response to temporary changes in energy management or a change in treatment. A relapse lasts longer than a flare-up.

Graded exercise therapy

In this guideline, graded exercise therapy is defined as establishing a baseline of achievable exercise or physical activity and then making fixed incremental increases in the time spent being physically active. It is a therapy based on the deconditioning and exercise avoidance theories of ME/CFS. These theories assume that ME/CFS is perpetuated by reversible physiological changes of deconditioning and avoidance of activity. These changes result in the deconditioning being maintained and an increased perception of effort, leading to further inactivity. This definition of

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graded exercise therapy reflects the descriptions of it included in evidence review G: non-pharmacological management of ME/CFS.

ME/CFS specialist team

These teams consist of a range of healthcare professionals with expertise in assessing, diagnosing, treating and managing ME/CFS. They commonly have medically trained clinicians from a variety of specialisms (including rheumatology, rehabilitation medicine, endocrinology, infectious diseases, neurology, immunology, general practice and paediatrics) as well as access to other healthcare professionals specialising in ME/CFS. These may include physiotherapists, exercise physiologists, occupational therapists, dietitians, and clinical or counselling psychologists. Children and young people are likely to be cared for under local or regional paediatric teams that have experience working with children and young people with ME/CFS in collaboration with ME/CFS specialist centres.

Orthostatic intolerance

A clinical condition in which symptoms such as light-headedness, near-fainting or fainting, impaired concentration, headaches, dimming or blurring of vision, forceful beating of the heart, palpitations, tremulousness and chest pain occur or worsen on standing up and are improved (although not necessarily resolved) by sitting or lying down. Orthostatic intolerance may include postural orthostatic tachycardia syndrome (POTS), which is a significant rise in pulse rate when moving from lying to standing, and postural hypotension, which is a significant fall in blood pressure when moving from lying to standing. People with severe orthostatic intolerance may find they are unable to sit up for any length of time.

Physical activity

Any bodily movement produced by skeletal muscles that results in energy expenditure. It should not be confused with exercise. 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. See World Health Organization advice on physical activity. Physical activity has a health benefit for most people and many conditions, but in people with ME/CFS, physical activity may make their symptoms worsen.

Physical functioning and mobility

The process of incorporating into daily activities a level of movement that helps to maintain joint and muscle flexibility without worsening symptoms of ME/CFS. This aims to support people to have

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as much independence as possible in their activities, ranging from personal hygiene to activities of daily living, working and social interaction. Such movement is undertaken within the person's energy limits and avoids pushing through their boundaries of tolerance.

Post-exertional malaise

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

Relapse

A sustained and marked exacerbation of symptoms lasting longer than a flare-up 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-up or a relapse. Relapses can lead to a long-term reduction in the person's energy limits.

Special interest in ME/CFS

A special interest in ME/CFS refers to a healthcare professional who is not working in an ME/CFS specialist team service but has knowledge and experience in this area.

Therapy blueprint

This summarises the therapy and provides a basis for future independent self-management. The blueprint may include the therapy formulation, strategies that have been helpful, 'warning signs' and triggers of flare-ups 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 means sleep that is non-restorative. Even after a full night's sleep, people do not feel refreshed. 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.

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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 myalgic encephalomyelitis (or encephalopathy)/chronic fatigue syndrome (ME/CFS)?

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

Full details of the evidence and the committee's discussion are in evidence review D: identifying and diagnosing ME/CFS.

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 of ME/CFS.

3 Diagnostic criteria

In people with suspected ME/CFS, how effective is the NICE 2021 consensus-based diagnostic criteria in identifying people with ME/CFS?

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

Full details of the evidence and the committee's discussion are in evidence review D: identifying and diagnosing ME/CFS.

Other recommendations for research

Self-monitoring management strategies

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

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 of ME/CFS.

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 of ME/CFS.

Dietary strategies

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

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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 of ME/CFS.

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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 1.1.6

Why the committee made the recommendations

Common themes across the qualitative evidence showed a lack of belief about myalgic encephalomyelitis (or encephalopathy)/chronic fatigue syndrome (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.

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

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Suspecting ME/CFS

Recommendations 1.2.1 to 1.2.7

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.

Criteria

The committee acknowledged there is ongoing discussion in the ME/CFS community about which diagnostic criteria should be used to identify and diagnose ME/CFS. The committee made a recommendation for key symptoms based on the evidence review of the current diagnostic criteria, but no 1 set of criteria was agreed to be better overall. 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. 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 malaise should be defined clearly to make it easier to interpret the revised criteria.

Based on their experience, the committee decided that a diagnosis of ME/CFS should be suspected if people have all 4 key symptoms (debilitating fatigue, post-exertional malaise, unrefreshing sleep or sleep disturbance [or both], 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 this in someone who has 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.

Currently, because there are no validated diagnostic criteria for ME/CFS, 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.

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.

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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.

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 made 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.

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 investigations to exclude other potential diagnoses. They listed some examples of tests that could be done to exclude reversible conditions with similar symptoms to ME/CFS and that are often missed.

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 investigate these and refer to an appropriate specialist if they are unsure. The committee also agreed that diagnosis can be reviewed if symptoms change or new symptoms emerge.

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 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 single set of criteria is used clinically, with a 'mix and match' approach used alongside clinical experience. These recommendations will standardise practice and

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it is not believed they will have any impact on resource use or training.

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 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 an ME/CFS specialist team, but it will help to ensure they get appropriate care and 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 in current practice. However, referring earlier for further assessment will help children and young people to get appropriate care sooner by identifying and excluding other conditions as well as ME/CFS, 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 from 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.

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Diagnosis

Recommendations 1.4.1 to 1.4.4

Why the committee made the recommendations

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 an ME/CFS specialist team at 3 months to confirm their diagnosis and develop a care and support plan.

How the recommendations might affect practice

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 might lead to some resource savings in the longer term.

Return to recommendations

Assessment and care and support planning by an ME/CFS specialist team

Recommendations 1.5.1 to 1.5.4

Why the committee made the recommendations

The committee agreed that the key to managing ME/CFS symptoms successfully is having a collaborative personalised care and support plan. This should be developed based on a holistic

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assessment as soon as the person's diagnosis is confirmed. The committee agreed that a medical assessment should be part of this assessment, typically requiring access to a medically trained clinician. A copy of the care and support 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 ME/CFS specialist teams.

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. Once the care and support 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 needs assessments, energy management, physical functioning and mobility, cognitive behavioural therapy (CBT) and dietary management.

How the recommendations might affect practice

Carrying out a holistic assessment and developing a care and support plan is already current practice in ME/CFS specialist services, although there may be more referrals to the specialist service resulting from these recommendations. However, having a care and support plan will facilitate people's care and may 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.

Return to recommendations

Information and support

Recommendations 1.6.1 to 1.6.11

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

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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 did not always know 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.

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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

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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 emphasised the need for frequent review of children and young people with ME/CFS (in line with recommendations 1.15.2 and 1.15.3). The importance of appropriate review is also highlighted in the NICE guidelines on child maltreatment and child abuse and neglect.

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 and support

Recommendations 1.8.1 to 1.8.9

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 were also aware that common sensitivities in ME/CFS, such as to light and sound, 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 made a recommendation based on consensus to address the lack of awareness about this in health and social care services.

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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 needs assessment carried out if necessary. 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 access to 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

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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 on 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 diagnosing and 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 that medical assessment and diagnosis would typically require access to an ME/CFS specialist physician or a GP with a special interest in ME/CFS. The committee agreed to make recommendations on providing a coordinated multidisciplinary approach and to identify the expertise that should be available.

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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 care and support plan agreed. However, the committee acknowledged the lack of confidence that non-specialists can have in managing ME/CFS and they recommended support from an 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 ME/CFS specialist multidisciplinary team, providing a named contact and giving support to primary care services may need resources. Current provision of ME/CFS 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 should 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 people 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 recommendation

Overall, the evidence for non-pharmacological and pharmacological interventions for ME/CFS was heterogenous and inconclusive, with limited evidence for any single intervention, and this supported the committee's experience. The committee were 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

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the current lack of a 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 makes 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 to shape and optimise ME/CFS trial design.

How the recommendation might affect practice

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

Return to recommendation

Energy management

Recommendations 1.11.2 to 1.11.8

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 people with ME/CFS to safely manage their level of activity, including physical activity or exercise. They agreed it was important to provide clarity of information and clear guidance around energy management, physical activity and exercise to people with ME/CFS. The committee also agreed people need clear information about services available to them to support the development of energy management plans.

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. They agreed that people with ME/CFS should have access to support from an ME/CFS specialist team to develop a plan for energy management.

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 using energy in a way to minimise post-exertional malaise. They recommended a detailed assessment that takes into

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account all areas of current activity and evaluation of rest and sleep, to establish an individual activity pattern within the person's current energy limit. The committee noted that energy management is not a physical activity or exercise programme, although the principles of energy management do apply to physical activity and exercise programmes.

To avoid potential harms by 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 physiotherapist or occupational therapist in an ME/CFS specialist team.

Self-monitoring strategies and techniques

There was a lack of effectiveness evidence on strategies and tools to support people to self-monitor activity management. The committee considered the qualitative evidence and their own experience of the benefits of using strategies and 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 strategies and techniques are effective.

How the recommendations might affect practice

The energy management plan forms part of the care and support plan and is part of ME/CFS specialist care. Appropriate energy management supports people to stay within their energy limits and aims to prevent their symptoms from worsening. It also supports them to increase their activity if possible. If this helps people maintain or improve their health this will be highly cost effective.

Return to recommendations

Incorporating physical activity and exercise

Recommendations 1.11.9 to 1.11.16

Why the committee made the recommendations

The committee agreed that clarity of information and clear guidance on energy management in relation to all activity should be available to people with ME/CFS. The committee also agreed that people need clear information about services available to them, and particularly the specific

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circumstances in which a personalised physical activity or exercise programme could be considered by a person with ME/CFS.

In the committee's experience, people with ME/CFS have had varying results from physical activity and exercise programmes. The committee agreed it was important to discuss this with people with ME/CFS and to explain to them the possible risks and benefits.

Because of the harms reported by people with ME/CFS in the qualitative evidence, as well as the committee's experience of the effects when people exceed their energy limits, the committee recommended that people with ME/CFS should not undertake a physical activity or exercise programme unless it is overseen by a physiotherapist who has training and expertise in ME/CFS.

The committee outlined what a personalised physical activity or exercise programme should, and should not, include. In developing recommendations on the content, approach and delivery of physical activity and exercise programmes, the committee considered the benefits and harms associated with graded exercise therapy that had been reported with ME/CFS across the quantitative and qualitative evidence, alongside their own experiences. They recognised that different definitions of the term 'graded exercise therapy' are used, and as a result the content and application of graded exercise therapy programmes differ. This has resulted in confusion. Taking into account descriptions of graded exercise therapy in the evidence they reviewed, the committee included a definition in this guideline to clarify what graded exercise therapy is intended to mean in the recommendation.

The committee concluded any programme using fixed incremental increases in physical activity or exercise (for example, graded exercise therapy), or physical activity or exercise programmes that are based on deconditioning and exercise avoidance theories, should not be offered to people with ME/CFS. The committee also wanted to reinforce that there is no therapy based on physical activity or exercise that is effective as a cure for ME/CFS.

For people with ME/CFS who do choose to take part in a physical activity or exercise programme, this should follow the principles set out in this section and the energy management section.

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 physiotherapist or occupational therapist in an ME/CFS specialist team 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

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will be highly cost effective.

Return to recommendations

Rest and sleep

Recommendations 1.12.1 to 1.12.4

Why the committee made the recommendations

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 recommendations based on consensus for providing advice for people with ME/CFS and agreed they could recommend general advice for sleep management. They noted that there are common sleep patterns in people with ME/CFS that need to be considered when giving advice about sleep management. In addition, they made a recommendation for research on sleep management 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

Physical functioning and mobility

Recommendations 1.12.5 to 1.12.8

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 functioning and mobility should therefore be assessed and included in the person's care and support plan.

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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, for example in relation to bone health and skin problems. In the committee's experience, families and carers are given only 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

The 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

Orthostatic intolerance

Recommendations 1.12.9 to 1.12.11

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.

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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

Pain

Recommendations 1.12.12 to 1.12.14

Why the committee made the recommendations

Pain is identified as one of the symptoms commonly associated with, but not exclusive to, ME/CFS (see the section on suspecting ME/CFS). The committee agreed that pain is a common symptom in people with ME/CFS and is particularly intense in people with severe or 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. The committee also made consensus-based recommendations to raise awareness about pain in ME/CFS and what action to take.

How the recommendations might affect practice

The recommendation referring to other NICE guidance should not have a resource impact as those recommendations are already established. The other recommendations should not impose a significant cost on the NHS and if they lead to fewer people deteriorating then they would be highly cost effective.

Return to recommendations

Medicines

Recommendations 1.12.15 to 1.12.18

Why the committee made the recommendations

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 were 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

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to highlight that medicines or supplements should not be offered as a cure for ME/CFS.

Medicines for symptom management

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, 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's symptoms respond 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 1.12.19 to 1.12.26

Why the committee made the recommendations

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

The committee recognised that difficulties with diet and nutrition was an area of concern for many people with ME/CFS. They discussed making consensus-based 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 no evidence and a lack of consensus in the area, so they made a recommendation for research on dietary strategies.

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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

Lightning Process

Recommendation 1.12.27

Why the committee made the recommendation

The committee discussed the limited evidence on the Lightning Process. They acknowledged that although some benefit was demonstrated and aspects of it, such as goal setting, practical examples and applications and peer support, were found to be helpful, the qualitative evidence on people's experiences of the therapy varied and raised some concerns. In the qualitative evidence, some people reported negative experiences to do with the confusing nature of the educational component, the intensity of the sessions, and the secrecy surrounding the therapy. While in the SMILE trial children under 16 were accompanied by parents, the committee were particularly concerned about the reported secrecy of the Lightning Process in the qualitative evidence and the lack of public information on the implementation of the process in practice. The committee agreed the transparency of any intervention is important and noted that in the qualitative evidence it was reported that people had been specifically encouraged not to talk about the therapy. The committee agreed this was an inappropriate and unusual message to give, particularly to children and young people.

The committee discussed concerns that the Lightning Process encourages people with ME/CFS to ignore and 'push through' their symptoms and this could potentially cause harm. In the qualitative evidence, some participants reported they had received advice they could do what they wanted. The committee noted they had made clear recommendations on the principles of energy management and this advice appears at odds with these principles.

Overall, the committee considered there was a lack of clarity around the implementation of the Lightning Process in practice and some concerning issues raised in the qualitative evidence. As a result, the committee agreed the Lightning Process should not be offered to people with ME/CFS.

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How the recommendation might affect practice

The Lightning Process is not offered as part of current practice so this recommendation will maintain current practice.

Return to recommendation

Cognitive behavioural therapy

Recommendations 1.12.28 to 1.12.34

Why the committee made the recommendations

The quantitative and qualitative evidence was mixed for adults, children and young people, and this reflected the committee's experience. Based on criticisms in the qualitative evidence of cognitive behavioural therapy (CBT) being described as a 'treatment' (cure) 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. Instead, it aims to improve wellbeing and quality of life, and may be useful in supporting people who live with ME/CFS to manage their symptoms and reduce the distress associated with having a chronic illness. It should therefore only be offered in this context, and after people have been fully informed about its principles and aims. The committee agreed if a child or young person would like to use CBT, it was important to adapt the therapy taking into account their cognitive and emotional maturity.

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.

How the recommendations might affect practice

CBT is currently provided for people with ME/CFS in specialist ME/CFS services. The 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

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Managing coexisting conditions

Recommendations 1.13.1 to 1.13.4

Why the committee made the recommendations

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 recommendations 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 flare-ups in symptoms and relapse

Recommendations 1.14.1 to 1.14.8

Why the committee made the recommendations

In the committee's experience, flare-ups and relapse are a common part of ME/CFS. The committee considered it important to give people information about what a flare-up 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-up has moved to a relapse and that it needs to prompt a review of their care and support 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 care and support 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

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Review in primary care

Recommendations 1.15.1 to 1.15.10

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 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.

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.

How the recommendations might affect practice

There is variation in practice and some people with ME/CFS, including those with severe or 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

Recommendation 1.16.1

Why the committee made the recommendation

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

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experience, so they recommended that all health and social care staff who deliver care to people with ME/CFS should be trained so they are able to provide the care in this guideline.

How the recommendation 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 recommendation

Care for people with severe or very severe ME/CFS

Recommendations 1.17.1 to 1.17.13

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

People with severe or very severe ME/CFS were named as a group for special consideration in the guideline scope. 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, and with every recommendation the committee considered whether different or additional recommendations were needed for this group. The rationale and impact sections for these recommendations are below. These additional considerations for people with severe or very severe ME/CFS were placed in a separate section to make sure they could be easily found within the guideline.

Return to recommendations

Assessment and care and support planning by an ME/CFS specialist team

Why the committee made the recommendation

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

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How the recommendation might affect practice

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.

Return to recommendation

Access to care and support

Why the committee made the recommendations

The committee were 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 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.

How the recommendations might affect practice

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. Some of these costs may be offset by the ability to provide online consultations when appropriate. The emphasis in this guideline on timely diagnosis and referral to an ME/CFS specialist team for a personalised care and support plan aims to minimise the number of people who may progress to severe ME/CFS.

Return to recommendations

Energy management

Why the committee made the recommendations

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 physiotherapy advice and additional care for people with severe or very severe ME/CFS who have chosen to develop an energy management plan.

How the recommendations might affect practice

The energy management plan forms part of the care and support plan and is a usual part of ME/CFS

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specialist care. Appropriate energy management supports people to stay within their energy limits and aims to prevent their symptoms from worsening. It also supports them to increase their activity if possible. If this helps people maintain or improve their health, this will be highly cost effective.

Return to recommendations

Dietary management and strategies

Why the committee made the recommendations

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 has a special interest 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.

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

Cognitive behavioural therapy

Why the committee made the recommendation

None of the clinical evidence included or reflected the needs of people with severe or very 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 or very severe ME/CFS in some circumstances, 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 recommendation might affect practice

CBT is currently provided for people with ME/CFS in specialist ME/CFS services. The 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 recommendation

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Context

The terms myalgic encephalomyelitis (ME; or encephalopathy), chronic fatigue syndrome (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. Myalgic encephalomyelitis is classified under diseases of the nervous system in the SNOMED CT and ICD10 (G93.3). 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 suggest 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. ME/CFS can affect people of all ages. 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 quality of life, including their psychological, emotional and social wellbeing.

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 bedbound. 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.

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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.

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

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Finding more information and committee details

You can see everything NICE says on this topic in the NICE Pathway on ME (chronic fatigue syndrome).

To find NICE guidance on related topics, including guidance in development, see the NICE webpage on ME/CFS.

For full details of the evidence and the guideline committee's discussions, see the evidence reviews. You can also find information about how the guideline was developed, including details of the committee.

NICE has produced tools and resources to help you put this guideline into practice. For general help and advice on putting our guidelines into practice, see resources to help you put NICE guidance into practice.

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Update information

This guideline updates and replaces NICE's guideline on chronic fatigue syndrome/myalgic encephalomyelitis (or encephalopathy): diagnosis and management, published in August 2007.

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