NICE engelske rekommandationer for ME CS

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

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Guidance

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Terms used in this guideline

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.

Box 1 Severity of ME/CFS

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.

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
- 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).

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.

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
- 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
- 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:

- 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.

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
- 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.

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 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 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.

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
- 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
- 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.

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.

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:

- 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
- 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.

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
- 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
- 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 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
- 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.

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)
- 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.

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.

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
- 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.

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.

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.

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

1.13 Managing coexisting conditions

1.13.1 Be aware that other conditions may coexist with MECFS and disorder investigated and managed according to best practice.

1.13.2 When managing coexisting conditions in people with MECFS, take into account the impact of the coexisting condition on the person with MECFS and vice versa.

1.13.3 Use recommendations on multimorbidity, fibromyalgia and chronic pain in addition to those in this guideline.

- NICE guideline on multimorbidity
- NICE guideline on fibromyalgia
- NICE guideline on chronic pain in adults.

1.13.4 For recommendations on identifying and managing associated or coexisting anxiety, depression and psychosis, 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 disorders.

1.13.5 Use the recommendations in these guidelines to inform the management of coexisting conditions in people with MECFS.

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 C: non-pharmacological management of MECFS and evidence review D: evidence study profile review MECFS.

1.14 Managing flare-ups in symptoms and relapse

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

1.14.2 Tell people with MECFS that:

- a flare-up is a temporary increase in symptoms that they experience a worsening of their symptoms beyond their normal day-to-day variation, and that they can happen at any time
- a relapse is when there is a persistent and marked exacerbation of MECFS symptoms that last for days or longer, and it may be accompanied by a significant and persistent reduction in function.

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

1.14.4 Evaluate and investigate any new symptoms or a change in symptoms and do not assume they are caused by a flare-up or relapse (MECFS).

1.14.5 Discuss and agree with management strategies with the person with MECFS to help them recognise and manage flare-ups and relapse, including how to recognise early signs of a flare-up and suspected flare-up. This should include:

- if a flare-up:
  - how to pace activities, such as using flares or conservation for centers, down tracks and triggers
  - temporarily reducing their activity levels
  - monitoring symptoms, recognising that flare-ups are transient, some will develop into a relapse
  - not returning to usual activity levels until the flare-up has resolved
- if a relapse:
  - focusing on symptom stopping, some activities
  - increasing the frequency or duration of activities
  - recognising recovery from MECFS is likely to be unlikely.

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 and flare-ups.

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

1.15 Review in primary care

1.15.1 Offer advice and MECFS review of their care and support plan to primary care at least annually.

1.15.2 Offer national and regional specialist MECFS review of their care and support plan at least every 3 years.

1.15.3 Arrange more frequent primary care reviews for children, young people and adults with MECFS if there is a significant change in their condition, or if they request it, and to ensure the effectiveness of any symptom management.

1.15.4 When carrying out a review of care plans, ensure you have access to the person's care and support plan and ensure the person with MECFS has a copy of their care and support plan.

1.15.5 As part of the review, discuss with the person with MECFS and their family or carers, as appropriate and to ensure a consistent approach:

- their condition, including any changes in their illness and the impact of the condition on their quality of life, including their independence
- self-management, see about their home management plan and of their relevant medicines, see about medicines
- who is being involved in and how they are working
- psychological, emotional and social well-being
- are the goals and aims of the care plan or coexisting changes or if there have are challenges ahead
- Make the person with MECFS or their closest contact in the MECFS specialist team of any changes to their care and support plan, and vice versa.

1.15.6 Consider seeking advice from an appropriate specialist if there is uncertainty about managing the person with MECFS or if there is a drop in a needed.

1.15.7 Evaluate and investigate whether new symptoms, or a change in symptoms, are due to the associated MECFS or whether they have another cause or coexisting condition.

Additional principles for children and young people

1.15.8 Ensure care and support plans are coordinated across primary care, specialist services, education and social care services, and that they are kept up to date.

1.15.9 When deciding how often to review or management might be needed for children and young people with MECFS, take into account:

- their developmental stage
- transitions, such as changing schools or exams
- the condition's impact on MECFS symptoms
- the effectiveness of any symptom management.

1.15.10 Plan ahead for transitions, 1, 2, 3 covering the child's voice in board and on transitioning their care 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 review of care and support.

Full details of the evidence and the committee's discussion are in evidence review I: management and care coordination for MECFS.

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 MECFS receive training on what they need to know and do to provide high-quality care and guidance. Training should include:

- training for non-specialist staff in MECFS and the diagnosis and management
- the experience of people with MECFS.

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.

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

Other supporting information: Supporting information on training for health & information, education and support for people with MECFS and their families and carers and appendix J: training and skills and appendix F.

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

The following sections are not the guideline with additional considerations for people with severe or very severe MECFS.

Assessment of severe and very severe MECFS and its impact

See also the section on principles of care for people with MECFS.

1.17.1 Be aware that people with severe or very severe MECFS may experience the following symptoms that significantly affect their lives, including their mobility, sensitivity and ability to tolerate care and support, and their ability to communicate:

- severe and constant pain, which affects their ability to tolerate care and support
- hypersensitivity to light, sound, touch, movement, temperature extremes and smells
- sensitivity to medicines, with severity reduced tolerance
- reduced ability or inability to speak or swallow
- severe difficulty or inability to be able to communicate and take in written or spoken information
- stress disturbance such as sensitivity to stress, hypersensitivity and altered perceptions
- gastrointestinal difficulties such as nausea, bowel problems and abdominal pain
- neurological symptoms such as double vision and other visual disorders, dizziness
- orthostatic intolerance, including postural orthostatic tachycardia syndrome (POTS) and postural tachycardia syndrome (PTS)
- immunological symptoms such as flu-like symptoms and tender lymph nodes
- Severe problems accessing information, for example because of difficulty with concentration, memory, or because of sensitivity to light, sound, touch, or other factors affecting their concentration.

1.17.2 Personal care and support for people with severe or very severe MECFS should be carried out by health and social care practitioners who:

- Is known to the person and their family or carers, whenever possible
- aware of the person's needs.

1.17.3 Risk assessment interaction with a person with severe or very severe MECFS is a decision to be made with a strength based approach, taking into account the person's wishes and preferences, and the impact on their quality of life. Consider involving the person's family or carers on their behalf if appropriate, while keeping the focus of the assessment on the person with MECFS.

Assessment and care and support planning by an MECFS specialist team

See also the section on assessment and care and support planning for all people with MECFS.

1.17.4 Offer home visits to people with severe or very severe MECFS to carry out their needs assessment and discuss their care and support plan.

Access to care and support

See also the section on access to care and support.

1.17.5 Take into account the physical and mental health in delivering care to people with severe or very severe MECFS, who may have particular difficulty accessing services and support. Ensure that care and support is provided in a way that does not cause harm, including supporting with communication, and supporting their application for aids and appliances.

Hospital care

1.17.6 When planning hospital care for people with severe or very severe MECFS:

- discuss with the person and their family or carers, as appropriate and to ensure a consistent approach:
- aim to minimise disruption and pain caused by moving, during transfer to hospital, for example by using the least invasive, amount, avoiding noise and light, and using a stretcher or wheelchair
- ensure that care and support plans are shared with others, including information on consultation, medication and sensitivities, to alert any clinically significant risks that are needed
- aim to provide a single room if possible
- keep refusal to consultation, for example to:
  - avoid disturbance
  - 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 MECFS

See also the section on managing MECFS.

Energy management

See also the section on energy management.

1.17.7 Make people with severe or very severe MECFS or a physiotherapist or occupational therapist working in the MECFS specialist team for support or developing energy management.

1.17.8 Provide energy management plans with people with severe or very severe MECFS and their carers, as appropriate, to help them to pace their activity and to manage their symptoms.

Symptom management

See also the section on symptom management for people with MECFS.

Dietary management and weight

1.17.9 Make people with severe or very severe MECFS or a dietetic assessment by a dietician MECFS specialist team (MECFS).

1.17.10 Monitor people with severe or very severe MECFS who are at risk of malnutrition or dehydration, including:

- dehydration
- inner appetite, for example linked with altered taste, smell and texture
- food intolerance
- nausea
- difficulty swallowing and chewing

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

1.17.11 Give advice to support people with severe or very severe MECFS, which could include:

- eating little and often
- having nourishing drinks and snacks, including food fortification
- finding easier ways of eating to conserve energy, for example, using a straw
- using modified eating aids, such as plates, if someone has difficulty chewing or swallowing
- cool and fresh support and eating drinks.

Cognitive behavioural therapy

1.17.12 Healthcare professionals delivering CBT to people with severe or very severe MECFS should be aware that the goals of CBT may be different from those for people with MECFS chronic fatigue syndrome 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 MECFS.

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

- evidence review A: information, education and support for people with MECFS and their families and carers
- appendix J: training skills and appendix F
- evidence review B: information, education and support for health and social care professionals
- evidence review C: non-pharmacological management of MECFS
- evidence review D: non-pharmacological management of MECFS
- evidence review E: pharmacological management of MECFS
- evidence review I: management and coexisting conditions and MECFS.

Other supporting information: Supporting information on training for health & information, education and support for people with MECFS and their families and carers and appendix J: training skills and appendix F.

Terms used in this guideline

See also the glossary, the MECFS glossary and the Clinical and Psychosocial Care and Support Glossary.

Activity

Any effort that uses energy, which includes cognitive, emotional and social activity as well as physical activity, including activities of daily living, work, leisure, exercise and sport.

Advocate

In this guideline, the role of an advocate is to support a co-ordinator or disadvantaged person with MECFS and ensure their rights are being upheld in health and social care contexts. They can be a family member, friend, or a professional, depending on the person's wishes and circumstances. They could also be a peer support worker.

Care and support plan

The personalised collaborative care and support plan developed by the MECFS specialist team based on a holistic assessment. It is the basis for other assessments and plans in a wider set of social care, health and education services, including the continuing care and mobility, cognitive behavioural therapy and dietary management.

Carers

In this guideline, a carer refers to someone who provides complex care and support to a family member or friend who is ill, disabled or frail, and who would not be able to manage without this provide support.

Children and young people

In this guideline, children and young people are aged under 18 (adult aged 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

Pacing activity to avoid triggering a flare-up or a relapse with MECFS and may help achieve day-to-day within their energy limit, with support from a healthcare professional.

Exercise

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

Fatigue

Fatigue in MECFS typically has the following components:

- feeling flu-like, especially in the early days of the illness
- continuous or lasting 'overnight lull'
- has energy or a lack of physical energy to start or finish activities of daily living and work, and
- cognitive fatigue that causes energy difficulties
  - inability of muscle strength or stamina after starting or ending activity, causing for example, sudden weakness, tiredness, lack of coordination, and feeling unable to carry on physical effort.

Flare-up

A worsening of symptoms, more than would be expected to be normal day-to-day variation, that is transient, lasting for days or longer, and is triggered by a specific event. Flare-ups are triggered by specific events, and they can happen at any time in the person's care and support plan. Flare-up is a term used in the guideline to describe a temporary increase in symptoms, such as pain, to flare-up without post-exertional malaise (PEM) or post-exertional fatigue (PEF) and post-exertional neuroinflammation (PENI). Flare-up, other approximate terms for a temporary increase in symptoms, such as pain, or a change in treatment. A flare-up lasts longer than a day.

Graded exercise therapy

In this guideline, graded exercise therapy is defined as establishing a baseline of activities which can be tolerated without triggering a worsening of symptoms, and then gradually increasing the amount of activity, with the aim of increasing the person's overall level of activity and improving their well-being. These exercise sessions that MECFS patients may be prescribed by non-medical physiotherapists or occupational therapists, or other healthcare professionals, are based on the assumption that fatigue is maintained and an incorrect perception of fatigue is the cause of the illness. Graded exercise therapy is a form of behavioural therapy, and it is based on the assumption that fatigue is maintained and an incorrect perception of fatigue is the cause of the illness. Graded exercise therapy is a form of behavioural therapy, and it is based on the assumption that fatigue is maintained and an incorrect perception of fatigue is the cause of the illness. Graded exercise therapy is a form of behavioural therapy, and it is based on the assumption that fatigue is maintained and an incorrect perception of fatigue is the cause of the illness.

MECFS specialist team

A multidisciplinary team of healthcare professionals with expertise in assessing, diagnosing, managing and providing care and support for people with complex chronic multisystem illness and symptoms (including rheumatologists, rehabilitation medicine, endocrinology, infectious diseases, immunology, neurology, and psychiatry), and who have a special interest in and knowledge and experience specifically in MECFS. These may include specialist nurses, specialist physicians, occupational therapists, dietitians, and clinical or counselling psychologists. Children and young people with MECFS should be seen by a multidisciplinary team with experience in managing children and young people with MECFS in collaboration with MECFS specialist services.

Orthostatic intolerance

A clinical condition in which symptoms such as light-headedness, near-fainting or fainting, impaired cognitive function, and other symptoms, such as blurred vision, tachycardia, palpitations, and other conditions and symptoms that are worse on standing or are improved (relieved) by lying down (recumbent) are reported to be caused by a decrease in cardiac output (CO) or blood flow (BF) to the brain. Orthostatic intolerance may include postural orthostatic tachycardia syndrome (POTS), neurocardiogenic syndrome (NCS), and other forms of orthostatic intolerance, and is a significant feature of chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME). Orthostatic intolerance may also be a feature of other conditions.

Physical activity

Any bodily movement produced by skeletal muscles that results in energy expenditure. It could include contractions of muscles, lifting and carrying, walking, climbing stairs, and performing sports, conditioning, household or other activities, and can be done during leisure time, to get from place to place, or as part of a person's work. Physical activity is a behavioural construct. Physical activity can be measured and reported for non-people with complex chronic multisystem illness with MECFS, physical activity may take longer than usual to recover.

Physical functioning

The process of incorporating into cells a cross-linked of movement that helps to maintain joint mobility and muscle strength and tone. Physical functioning is a term used to describe a person's ability to carry out independent activities of daily living, including the ability to walk, bathe, dress, eat, and use the toilet, and feel fit, clear-cut needs, sometimes leading to a loss. Physical functioning may also be defined as a person's overall physical health.

Relapse

A sustained and marked exacerbation of symptoms lasting longer than a flare-up and leading to substantial and sustained deterioration in the person's usual management. A relapse may last for days or longer and may be accompanied by a significant and persistent reduction in function. A relapse is a long-term exacerbation of the person's symptoms.

Special interest in MECFS

A general practitioner with a special interest in healthcare professionals who is not working as a MECFS specialist team and has the knowledge and experience in this area.

Therapy blueprint

This summarises the therapy and provides clues for future independent self-management. The therapy blueprint is a document that is shared between the healthcare professional and the person with MECFS and triggers flare-up or relapse to be managed more, and guides the flare-up. It is important that the therapy blueprint is led by the person themselves and is their own accounts, supported by guidance from the therapist.

Unrefreshing sleep

Unrefreshing sleep means sleep that has no restoration. Even after a full night's sleep, people do not feel refreshed. Unrefreshing sleep is a term used to describe a sleep that does not feel restorative.

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