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NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

Guideline

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

Draft for consultation, November 2020

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

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

Who is it for?

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

What does it include?

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

- the guideline context.

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

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

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

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1 Recommendations

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

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

2 1.1 Principles of care for people with ME/CFS

3 Awareness of ME/CFS and its impact

4 1.1.1 Be aware that ME/CFS:

- 5 • is a complex, chronic medical condition affecting multiple body systems
6 and its pathophysiology is unclear
- 7 • can have a significant impact on people's (and their families and
8 [carers'](#)) quality of life, including their activities of daily living, family life,
9 social life, emotional wellbeing, work and education
- 10 • affects each person differently and varies widely in severity – in its most
11 severe form it can lead to substantial incapacity (see recommendations
12 1.1.8 and 1.1.9)
- 13 • is a fluctuating condition in which symptoms can change unpredictably
14 in nature and severity over days, weeks or longer – ranging from being
15 able to carry out most daily activities to severe debilitation.

16 1.1.2 Recognise that people with ME/CFS may have experienced prejudice and 17 disbelief and feel stigmatised by people who do not understand their 18 illness. Take into account:

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

1 **Approach to delivering care**

2 1.1.3 Health and social care professionals should:

- 3
- 4 • acknowledge to the person the reality of living with ME/CFS and how symptoms could affect them
 - 5 • take time to build supportive, trusting and empathetic relationships
 - 6 • use a person-centred approach to assess people's needs
 - 7 • involve family members and carers (as appropriate) in discussions and
 - 8 care planning if the person with ME/CFS chooses to include them.

9 1.1.4 Recognise that people with ME/CFS need:

- 10
- 11 • early and accurate diagnosis so they get appropriate care for their symptoms
 - 12 • regular monitoring and review, particularly when their symptoms are
 - 13 worsening or changing (see the [section on managing flares and](#)
 - 14 [relapse](#)).

15 1.1.5 Explain to people with ME/CFS and their family or carers that they have

16 the right to decline or withdraw from any part of their [management plan](#)

17 and it will not affect other aspects of their care. They can begin or return

18 to an intervention if they feel able to resume.

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

20 1.1.6 Be aware of the impact on [children and young people](#) with ME/CFS who

21 have experienced prejudice and disbelief by people they know and who

22 do not understand the illness (family, friends, health and social care

23 professionals and teachers). Health and social care professionals should

24 understand this experience may result in a breakdown of the therapeutic

25 relationship, lack of trust and hesitation to engage further in health and

26 social care services.

27 1.1.7 Ensure the voice of the child or young person is always heard by:

- 28
- 29 • taking a child-centred approach, with the communication focusing on them

[appendix 2: people with severe ME/CFS](#). Other supporting evidence and discussion can be found in [evidence review B: information for health and social care professionals](#) and [appendix 1: children and young people](#).

1 1.2 Suspecting ME/CFS

2 1.2.1 Explain to people presenting with possible symptoms of ME/CFS that
3 there currently is no diagnostic test for ME/CFS and it is recognised on
4 clinical grounds alone.

5 1.2.2 If ME/CFS is suspected carry out an assessment, which should include:

- 6 • a comprehensive clinical history
- 7 • a physical examination
- 8 • psychological wellbeing assessment
- 9 • baseline investigations to exclude other diagnoses.

10 1.2.3 Suspect ME/CFS if:

- 11 • the person has had all of the persistent symptoms (see box 1) for a
12 minimum of 6 weeks in adults and 4 weeks in [children and young
13 people](#)
- 14 • the person's ability to engage in occupational, educational, social or
15 personal activities is significantly reduced from pre-illness levels
- 16 • symptoms are new and had a specific onset.

17 Box 1 Symptoms for suspecting ME/CFS

- Debilitating [fatigability](#) that is not caused by excessive cognitive, physical, emotional or social exertion and is not significantly relieved by rest **and**
- [Post-exertional symptom exacerbation](#) after [activity](#) that:
 - is delayed in onset by hours or days
 - is disproportionate to the activity
 - has a prolonged recovery time lasting hours, days, weeks or longer **and**
- [Unrefreshing sleep](#), which may include:

- feeling exhausted, flu-like and stiff on waking
- broken or shallow sleep, altered sleep pattern or hypersomnia **and**
- Cognitive difficulties (sometimes described as ‘brain fog’), including problems finding words, temporary dyslexia or dyscalculia, slurred speech, slowed responsiveness, short-term memory problems, confusion, disorientation and difficulty concentrating or multitasking.

1

2 1.2.4 Be aware that the following symptoms may also be associated with, but
3 are not exclusive to, ME/CFS:

- 4 • [orthostatic intolerance](#) and autonomic dysfunction, including dizziness,
5 palpitations, fainting, nausea on standing or sitting upright from a
6 reclining position
- 7 • temperature hypersensitivity resulting in profuse sweating, chills, hot
8 flushes, or feeling very cold
- 9 • neuromuscular symptoms, including twitching and myoclonic jerks
- 10 • flu-like symptoms, including sore throat, tender glands, nausea, chills or
11 muscle aches
- 12 • intolerance to alcohol, or to certain foods, and chemicals
- 13 • heightened sensory sensitivities, including to light, noise, touch and
14 smell
- 15 • pain, including pain on touch, myalgia, headaches, eye pain, abdominal
16 pain or joint pain without acute redness, swelling or effusion.

17 1.2.5 Do not delay making a provisional diagnosis of ME/CFS. As soon as
18 ME/CFS is suspected, based on the criteria in recommendation 1.2.3,
19 give the person advice about symptom management (see the [section on](#)
20 [managing ME/CFS](#)).

21 1.2.6 When ME/CFS is suspected, continue with any tests needed to exclude
22 other conditions and explain to people that this does not affect their
23 provisional diagnosis of ME/CFS.

1 1.2.7 Primary healthcare professionals should consider seeking advice from an
2 appropriate specialist if there is uncertainty about interpreting signs and
3 symptoms and whether a referral is needed.

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

5 1.2.8 When ME/CFS is suspected in a child or young person based on the
6 criteria in recommendation 1.2.3:

- 7
- 8 • refer them to a paediatrician for further assessment and investigation
9 for ME/CFS and other conditions
 - 10 • write to the child or young person's place of education or training to
advise about flexible adjustments or adaptations.

For a short explanation of why the committee made these recommendations see the [rationale and impact section on suspecting ME/CFS](#).

Full details of the evidence and the committee's discussion are in [evidence review D: diagnosis](#).

11 **1.3 Advice for people with suspected ME/CFS**

12 See [section 1.11 for recommendations on managing specific symptoms](#). This
13 guideline does not cover all the symptoms that can occur in ME/CFS and refers to
14 other NICE guidance in section 1.12.

15 1.3.1 When ME/CFS is suspected, give people personalised advice about
16 managing their symptoms. Also advise them:

- 17
- 18 • not to use more energy than they perceive they have – they should
19 plan their daily [activity](#) to stay within their [energy envelope](#) and not
20 push through activity
 - 21 • to rest as they need to
 - to maintain a healthy balanced diet, with adequate fluid intake.

22 1.3.2 Explain to people with suspected ME/CFS that their diagnosis can only be
23 confirmed after 3 months of persistent symptoms. Reassure them that

1 they can return for a review if they develop new or worsened symptoms,
2 and ensure they know who to contact for advice.

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

Full details of the evidence and the committee's discussion are in [evidence review E: strategies pre diagnosis](#).

3 **1.4 Diagnosis**

4 **Making a diagnosis**

5 1.4.1 Diagnose ME/CFS in a child, young person or adult who has the
6 symptoms in recommendation 1.2.3 that have persisted for 3 months.

7 1.4.2 After a diagnosis, refer adults directly to a specialist team experienced in
8 managing ME/CFS to develop a [management plan](#).

9 1.4.3 If ME/CFS is diagnosed in a child or young person after assessment by a
10 paediatrician (based on the criteria in recommendation in 1.2.3), refer
11 them directly to a paediatric specialist team experienced in ME/CFS to
12 develop a management plan.

For a short explanation of why the committee made these recommendations see the [rationale and impact section on diagnosis](#).

Full details of the evidence and the committee's discussion are in [evidence review D: diagnosis](#).

13 **1.5 Assessment and care planning by a specialist ME/CFS** 14 **team**

15 1.5.1 After confirming a diagnosis of ME/CFS, carry out and record a holistic
16 assessment. This should include:

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

1 1.5.3 Recognise that the person with ME/CFS is in charge of the aims of their
2 management plan. The plan should be mutually agreed and based on the
3 person's:

- 4 • preferences and needs
- 5 • skills and abilities in managing their condition
- 6 • hopes, plans and priorities
- 7 • symptom severity
- 8 • physical and cognitive functioning.

9 1.5.4 Give the person (and their family members or carers, as appropriate) a
10 copy of their management plan and share a copy with their GP.

11 **People with severe or very severe ME/CFS**

12 1.5.5 Offer home visits to people with [severe or very severe ME/CFS](#) to carry
13 out their holistic assessment and develop their management plan.

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

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

14 **1.6 Information and support**

15 **Communication**

16 1.6.1 Provide information to people with ME/CFS and their families and carers
17 in a variety of formats (for example, written materials, electronic and
18 audio) that can be used both at home and in the clinical setting. Follow the
19 principles on communication, information giving and shared decision
20 making in the [NICE guidelines on patient experience in adult NHS](#)
21 [services](#) and [people's experience in adult social care services](#).

1 1.6.2 When providing information for [children and young people](#) with ME/CFS,
2 take into account their age and level of understanding, any disabilities or
3 communication needs. Use interactive formats such as:

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

8 **Information about ME/CFS**

9 1.6.3 Give people and their families and carers (as appropriate) up-to-date
10 information about ME/CFS starting from when ME/CFS is suspected.
11 Tailor information to people's circumstances, including their symptoms,
12 the severity of their condition and how long they have had ME/CFS. Ask
13 people regularly if they would like more information or to revisit
14 discussions.

15 1.6.4 Explain that ME/CFS:

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

1 1.6.5 Explain to children and young people with ME/CFS and their parents and
2 carers that although long-term outcomes are different for everyone, the
3 outlook is usually better in children and young people than in adults.

4 1.6.6 Give people (and their families and carers, as appropriate) information
5 about:

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

9 1.6.7 Give families and carers of people with ME/CFS information about the
10 condition and ways they can help the person.

11 **Social care**

12 1.6.8 Discuss sensitively with the person and their family members or carers
13 how social care may benefit them. Explain that it can help the person
14 living with ME/CFS as well as provide a route to support for families and
15 carers through a formal carer's assessment.

16 1.6.9 Explain to people and their families and carers how to self-refer for a
17 social care needs assessment from their local authority. Offer to make the
18 referral for them if they prefer.

19 1.6.10 Advise children and young people with [moderate ME/CFS](#) to [severe or](#)
20 [very severe ME/CFS](#) and their parents or carers that they may be entitled
21 to support from children's social care as children in need because of their
22 disability.

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

24 1.6.11 Follow recommendations in the [NICE guideline on supporting adult carers](#)
25 on identifying, assessing and meeting the caring, physical and mental
26 health needs of families and carers.

27 1.6.12 Advise families and carers about the right to assessment and support for
28 their own needs, as follows:

- 1 • parents or carers of children and young people under 16 with ME/CFS,
2 according to the [Children and Families Act 2014](#)
- 3 • young carers, according to the [Young Carers \(Needs Assessment\)](#)
4 [Regulations 2015](#).

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

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

5 **1.7 Safeguarding**

6 1.7.1 Safeguarding assessments in people with confirmed or suspected
7 ME/CFS should be carried out or overseen by health and social care
8 professionals who have training and experience in ME/CFS.

9 1.7.2 Recognise that people with ME/CFS, particularly those with [severe or very](#)
10 [severe ME/CFS](#), are at risk of their symptoms being confused with signs
11 of abuse or neglect.

12 1.7.3 If an assessment under the [Mental Health Act 1983](#) or the [Mental](#)
13 [Capacity Act 2005](#) is needed, involve health and social care professionals
14 who have training and experience in ME/CFS. This should be done within
15 24 hours in an emergency.

16 **Children and young people**

17 1.7.4 Be aware that recognising and responding to possible child abuse and
18 neglect (maltreatment) is complex and should be considered in the same
19 way for [children and young people](#) with confirmed or suspected ME/CFS
20 as with any child with a chronic illness or disability. Follow the [NICE](#)
21 [guidelines on child maltreatment](#) and [child abuse and neglect](#).

1 1.7.5 Using a child-centred approach, listen to the child or young person and
2 support them to express their wishes and feelings. Follow the principles of
3 the [Children Acts 1989](#) and [2004](#) that the welfare of the child is paramount
4 and that children are best looked after within their families, with their
5 parents playing a full part in their lives, unless compulsory intervention in
6 family life is necessary (see [the Department for Education's statutory](#)
7 [guidance on working together to safeguard children](#)).

8 1.7.6 Recognise that the following are not necessarily a sign of abuse or
9 neglect in children and young people with confirmed or suspected
10 ME/CFS:

- 11 • physical symptoms that do not fit a commonly recognised illness
12 pattern
- 13 • more than 1 child or family member having ME/CFS
- 14 • disagreeing with, declining or withdrawing from any part of their
15 [management plan](#), either by the child or young person or by their
16 parents or carers on their behalf
- 17 • parents or carers acting as an [advocate](#) and communicating on behalf
18 of the child or young person
- 19 • reduced or non-attendance at school.

For a short explanation of why the committee made these recommendations see
the [rationale and impact section on safeguarding](#).

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

20 **1.8 Access to care**

21 1.8.1 Service providers should ensure people with ME/CFS can access health
22 and social care services by:

1 1.8.5 Discuss with people who need inpatient care whether any aspects of
2 where their care will be provided could cause problems for them,
3 including:

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

8 ***People with severe or very severe ME/CFS***

9 1.8.6 When planning hospital care for people with severe or very severe
10 ME/CFS:

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

1 **Maintaining independence**

2 1.8.7 If a person with ME/CFS needs support at home, conduct a social care
3 assessment, record and provide information and support on:

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

17 1.8.8 Give families and carers information on how to access training and
18 resources about how to care for the person with ME/CFS.

19 ***Aids and adaptations***

20 1.8.9 Provide aids and adaptations identified in the person's management plan
21 without delay, so that people can carry out activities of daily living and
22 maintain their quality of life as much as possible.

23 1.8.10 Enable prompt assessment for funding for home adaptation. If the person
24 is not eligible for funding, continue to offer information and support in
25 arranging home adaptations.

26 1.8.11 For people with [moderate ME/CFS](#) or severe or very severe ME/CFS,
27 consider providing or recommending aids and adaptations (such as a
28 wheelchair, blue badge or stairlift) that could help them maintain their
29 independence and improve their quality of life, taking into account the
30 risks and benefits. Include these in the person's management plan.

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

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

1 **1.9 Supporting people with ME/CFS in work, education and**
2 **training**

3 1.9.1 Advise people with ME/CFS that:

- 4
- 5 • there may be times when they are unable to continue with work or
 - 6 education
 - 7 • some people find that going back to work, school or college worsens
 - 8 their symptoms
 - 9 • they may be able to access reasonable adjustments or adaptations (in
 - 10 line with the Equality Act 2010) to help them continue or return to work
 - or education.

11 1.9.2 Offer to liaise on the person's behalf (with their informed consent) with
12 employers, education providers and support services. Give them
13 information about ME/CFS and discuss the person's agreed [management](#)
14 [plan](#) and any adjustments needed.

15 1.9.3 Health and social care professionals should follow the [Department for](#)
16 [Education's guidance on supporting pupils at school with medical](#)
17 [conditions](#) or equivalent statutory guidance.

18 1.9.4 Health and social care professionals should work with training and
19 education services to:

- 20
- 21 • provide information about ME/CFS and the needs and impairments of
 - 22 [children and young people](#) with ME/CFS, including the need for a
 - balance of activities in their life

- 1 • discuss the child or young person’s management plan so that everyone
2 has a common understanding of their priorities, hopes and plans
3 • discuss a flexible approach to training and education – this could
4 include adjustments to the school day, online or home schooling and
5 using assistive equipment.
- 6 1.9.5 Give parents and carers information about education, health and care
7 plans and how to request one from their local authority.
- 8 1.9.6 Advise children and young people with ME/CFS (and their parents and
9 carers) that:
- 10 • training or education should not be the only [activity](#) they undertake
11 • they should aim to find a balance between the time they spend on
12 education or training, home and family life, and social activities.

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

Full details of the evidence and the committee’s discussion are in [evidence review A: information for people with ME/CFS and appendix 1: children and young people](#).

13 **1.10 Multidisciplinary care**

- 14 1.10.1 Provide care for people with ME/CFS using a coordinated multidisciplinary
15 approach. Based on the person’s needs, include health and social care
16 professionals with expertise in the following:
- 17 • self-management strategies, including [energy management](#)
18 • symptom management
19 • managing flares and [relapse](#)
20 • activities of daily living
21 • emotional wellbeing, including family and sexual relationships
22 • diet and nutrition

- 1 • mobility, avoiding falls and problems from loss of dexterity, including
2 access to aids and rehabilitation services
- 3 • social care and support
- 4 • support to engage in work, education, social activities and hobbies.
- 5 1.10.2 Care for people whose ME/CFS is managed in primary care should be
6 supported by advice and direct clinical consultation from a specialist team.
- 7 1.10.3 Give people with ME/CFS (and their family members and carers, as
8 appropriate) a named contact in their primary care and/or specialist team
9 to coordinate their [management plan](#), help them access services and
10 support them during periods of relapse.

11 **Children and young people**

- 12 1.10.4 Provide parents and carers of [children and young people](#) with ME/CFS
13 with details of a named professional in the specialist team who they can
14 contact with any concerns about their child's health, education or social
15 life.

16 **Moving into adults' services**

- 17 1.10.5 For young adults with ME/CFS moving from children's to adults' services,
18 manage transitions in line with the [NICE guideline on transition from
19 children's to adults' services for young people using health or social care
20 services](#).

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

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

1 **1.11 Managing ME/CFS**

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

4 1.11.1 Be aware there is no current treatment or cure (non-pharmacological or
5 pharmacological) for ME/CFS.

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

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

6 **Energy management**

7 1.11.2 Discuss with people with ME/CFS the principles of [energy management](#),
8 its role in supporting them to live with their symptoms, the potential
9 benefits and risks and what they should expect. Explain that it:

- 10 • is not curative
- 11 • is a self-management strategy led by the person themselves but with
12 support from a healthcare professional
- 13 • can be applied to any type of [activity](#)
- 14 • helps people understand their [energy envelope](#) so they can reduce the
15 risk of overexertion worsening their symptoms
- 16 • recognises that each person has a different and fluctuating energy limit,
17 and they are the best judge of their own limits
- 18 • can include help from a healthcare professional to recognise when they
19 are approaching their limit ([children and young people](#) in particular may
20 find it harder to judge their limits and can overreach them)
- 21 • uses a flexible, tailored approach so that activity is never automatically
22 increased but is progressed during periods when symptoms are
23 improved and allows for the need to pull back when symptoms are
24 worse

1 1.11.8 Refer people with ME/CFS to a specialist ME/CFS physiotherapy or
2 occupational therapy service if they:

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

8 ***People with severe or very severe ME/CFS***

9 1.11.9 Refer people with [severe or very severe ME/CFS](#) to a specialist ME/CFS
10 physiotherapy or occupational therapy service for support on developing
11 energy management plans.

12 1.11.10 Be aware when agreeing energy management plans with people with
13 severe or very severe ME/CFS (and their families and carers as
14 appropriate) that changes in activity should be smaller and any increases
15 (if possible) much slower.

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

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

16 **Physical maintenance**

17 1.11.11 Include [physical maintenance](#) in the [management plan](#) for people with
18 ME/CFS. Think about including the following:

- 19 • joint mobility
- 20 • muscle flexibility
- 21 • postural and positional support
- 22 • muscle strength and endurance

- 1 • use flexible increments for people who want to focus on improving their
2 physical abilities while remaining within their energy envelope
- 3 • recognise a [flare](#) or [relapse](#) early and outline how to manage it (see
4 [recommendations 1.11.21 and 1.11.22](#))
- 5 • incorporate regular reviews.
- 6 1.11.21 Agree with the person how to adjust their physical activity after a flare or
7 relapse. This should include:
- 8 • providing access to support from the specialist ME/CFS physiotherapy
9 service
- 10 • reducing physical activity within the person's current energy envelope
11 to stabilise their symptoms
- 12 • only once symptoms stabilise and the person feels able to resume
13 physical activity, establishing a new physical activity baseline.
- 14 1.11.22 Advise people with ME/CFS after a flare that the time it takes to return to
15 the level of physical activity they had before the flare varies from person to
16 person.

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

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

17 **Rest and sleep**

- 18 1.11.23 Advise people with ME/CFS:
- 19 • on the role of rest in ME/CFS
- 20 • that rest periods are part of all management strategies for ME/CFS
- 21 • how to introduce rest periods into their daily routine, including how
22 often and for how long, as appropriate for each person

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

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

Full details of the evidence and the committee's discussion are in [evidence review G: non pharmacological management](#).

3 **Managing orthostatic intolerance**

- 4 1.11.24 Be aware that people with ME/CFS may experience [orthostatic](#)
5 [intolerance](#), such as postural orthostatic tachycardia syndrome (POTS),
6 orthostatic hypotension or neurally mediated hypotension.
- 7 1.11.25 Medicine for orthostatic intolerance in people with ME/CFS should only be
8 prescribed or overseen by a healthcare professional with expertise in
9 orthostatic intolerance.
- 10 1.11.26 Refer people with orthostatic intolerance to secondary care if their
11 symptoms are severe or worsening, or there are concerns that another
12 condition may be the cause.

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

Full details of the evidence and the committee's discussion are in [evidence review G: non pharmacological management](#).

13 **Managing pain**

- 14 1.11.27 Refer to the following for advice on treating pain:
- 15 • [NICE guideline on neuropathic pain in adults](#)
16 • [NICE guideline on headaches in over 12s](#).

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

Full details of the evidence and the committee's discussion are in [evidence review G: non pharmacological management](#).

1 **Managing nausea**

- 2 1.11.28 Encourage people with ME/CFS who have nausea to keep up adequate
3 fluid intake and advise them to try to eat regularly, taking small amounts
4 often.

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

Full details of the evidence and the committee's discussion are in [evidence review G: non pharmacological management](#).

5 **Medicines**

- 6 1.11.29 Do not offer any medicines or supplements to treat or cure ME/CFS.

7 ***Medicines for symptom management***

- 8 1.11.30 Offer people with ME/CFS a medication review in line with the [NICE](#)
9 [guidelines on medicines adherence](#) and [medicines optimisation](#).

- 10 1.11.31 Take into account when prescribing that people with ME/CFS may be
11 more intolerant of drug treatment and have more severe adverse effects.

12 Consider:

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

- 15 1.11.32 Drug treatment for the symptoms associated with ME/CFS for children
16 and young people should only be started under guidance or supervision
17 from a paediatrician.

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

Full details of the evidence and the committee's discussion are in [evidence review F: pharmacological management](#).

1 **Dietary management and strategies**

- 2 1.11.33 Emphasise to people with ME/CFS the importance of adequate fluid
3 intake and a well-balanced diet according to the [NHS eat well guide](#).
- 4 1.11.34 Work with the person (and their family members or carers, as appropriate)
5 to find ways of minimising complications caused by nausea (see
6 recommendation 1.11.28), swallowing problems, sore throat or difficulties
7 with buying, preparing and eating food.
- 8 1.11.35 Refer people with ME/CFS for a dietetic assessment by a dietitian who
9 specialises in ME/CFS if they are losing weight and at risk of malnutrition,
10 or they have a restrictive diet.
- 11 1.11.36 Be aware that people with ME/CFS may be at risk of vitamin D deficiency
12 because they spend a lot of time indoors, especially those who are
13 housebound or bed-bound. For advice on vitamin D supplementation, see
14 the [NICE guideline on vitamin D](#).
- 15 1.11.37 Explain to people with ME/CFS that there is not enough evidence to
16 support routinely taking vitamin and mineral supplements as either a
17 treatment for ME/CFS or for managing symptoms. If they are advised to
18 take a supplement it should be a multivitamin and mineral supplement and
19 they should stay within the recommended daily amount. Explain the
20 potential side effects of taking higher doses of vitamins and minerals.
- 21 1.11.38 Refer children and young people with ME/CFS who are losing weight or
22 have faltering growth or dietary restrictions to a paediatric dietitian who
23 specialises in ME/CFS.

1 1.11.39 For advice on food allergies in children, see the [NICE guideline on food](#)
2 [allergy in under 19s](#).

3 ***People with severe or very severe ME/CFS***

4 1.11.40 Refer people with severe or very severe ME/CFS for a dietetic
5 assessment by a dietitian who specialises in ME/CFS.

6 1.11.41 Monitor people with severe or very severe ME/CFS who are at risk of
7 malnutrition or unintentional weight loss because of:

- 8
- 9 • restrictive diets
 - 10 • poor appetite linked with altered taste and smell
 - 11 • food intolerances
 - 12 • nausea or difficulty swallowing and chewing.

12 Follow the recommendations on screening for malnutrition, indications for
13 nutrition support, and education and training of staff and carers related to
14 nutrition, in the [NICE guideline on nutrition support for adults](#).

15 1.11.42 Consider advice to support people with severe or very severe ME/CFS,
16 which could include:

- 17
- 18 • eating little and often
 - 19 • having nourishing drinks and snacks, including food fortification
 - 20 • finding easier ways of eating to conserve energy, such as food with
21 softer textures
 - 22 • using modified eating aids, particularly if someone has difficulty
23 chewing or swallowing
 - oral nutrition support and enteral feeding.

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

Full details of the evidence and the committee's discussion are in [evidence
review G: non pharmacological management](#).

1 **Psychological support: cognitive behavioural therapy**

2 1.11.43 Only offer cognitive behavioural therapy (CBT) to people with ME/CFS
3 who would like to use it to support them in managing their symptoms of
4 ME/CFS and to reduce the psychological distress associated with having
5 a chronic illness. Do not offer CBT as a treatment or cure for ME/CFS.

6 1.11.44 CBT should be only delivered by a healthcare professional with
7 appropriate training and experience in CBT for ME/CFS, and under the
8 clinical supervision of someone with expertise in CBT for ME/CFS.

9 1.11.45 Discuss with the person the principles of CBT, its role in supporting them
10 to adapt to and manage the impact of symptoms of ME/CFS and the
11 potential benefits and risks. Explain that CBT for people with ME/CFS:

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

21 1.11.46 Explain what CBT involves so people know what to expect. Tell them that
22 it:

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

30 1.11.47 CBT for people with ME/CFS should include the following components:

- 1 • developing a shared understanding with the person about the main
- 2 difficulties and challenges they face
- 3 • exploring their personal meaning of symptoms and illness, and how this
- 4 might relate to how they manage their symptoms
- 5 • working together to adapt and refine self-management strategies to
- 6 improve the person's functioning and quality of life, for example their
- 7 sleep, activity and rest
- 8 • developing a self-management plan
- 9 • reviewing their plan regularly to see if their self-management strategies
- 10 need to be adapted, for example if their symptoms or functioning
- 11 change
- 12 • developing a [therapy blueprint](#) collaboratively with their therapist at the
- 13 end of therapy.

14 ***Children and young people***

15 1.11.48 Only consider CBT for a child or young person with ME/CFS if they and

16 their parents or carers have been fully informed about its aims and

17 principles and any potential benefits and risks.

18 1.11.49 If CBT is considered for children and young people with ME/CFS:

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

22 ***People with severe or very severe ME/CFS***

23 1.11.50 Healthcare professionals delivering CBT to a person with severe or very

24 severe ME/CFS should adjust the process and pace of CBT to meet the

25 person's needs. This might include shorter, less frequent sessions and

26 longer-term goals.

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

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

1 **1.12 Managing coexisting conditions**

2 1.12.1 Take into account the recommendations in the [section on principles of](#)
3 [care for people with ME/CFS](#) and [section on access to care](#) when
4 managing coexisting conditions in people with ME/CFS.

5 1.12.2 Be aware that other conditions may coexist with ME/CFS and should be
6 investigated and managed in accordance with best practice.

7 1.12.3 For recommendations on multimorbidity, thyroid disease and coeliac
8 disease refer to the:

- 9 • [NICE guideline on multimorbidity](#)
- 10 • [NICE guideline on thyroid disease](#)
- 11 • [NICE guideline on coeliac disease](#).

12 1.12.4 For recommendations on identifying and treating associated or comorbid
13 anxiety, depression or mood disorders see the:

- 14 • [NICE guideline on depression in adults](#)
- 15 • [NICE guideline on depression in adults with a chronic physical health](#)
16 [problem](#)
- 17 • [NICE guideline on depression in children and young people](#)
- 18 • [NICE guideline on generalised anxiety disorder and panic disorder in](#)
19 [adults](#)
- 20 • [NICE guideline on common mental health problems](#).
- 21

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

Full details of the evidence and the committee's discussion are in [evidence review D: diagnosis](#).

1 **1.13 Managing flares and relapse**

2 **Flares**

3 1.13.1 Recognise a [flare](#) in symptoms of ME/CFS when there is a sustained
4 exacerbation of symptoms to a level greater than the person's usual day-
5 to-day variation, which usually lasts a few days.

6 1.13.2 Respond promptly to a flare in symptoms by:

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

14 **Relapse**

15 1.13.3 Recognise a relapse when there is a sustained and marked exacerbation
16 of ME/CFS symptoms lasting longer than a flare and needing substantial
17 and sustained adjustment of [energy management](#).

18 1.13.4 When a person with ME/CFS has a relapse, review their [management](#)
19 [plan](#) with them and discuss and agree a course of action, taking into
20 account:

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

- 1 1.13.5 During a relapse, discuss and agree with the person with ME/CFS (and
2 their family members or carers, as appropriate):
- 3 • reducing, or even stopping, some activities
 - 4 • increasing the frequency or duration of rest periods
 - 5 • re-establishing a new [energy envelope](#) to stabilise symptoms.
- 6 1.13.6 If a flare or relapse cannot be managed using the person's self-
7 management strategies outlined in their management plan, advise the
8 person to contact their named contact in the primary care or specialist
9 team for review.
- 10 1.13.7 Once a flare or relapse has resolved or stabilised, discuss with the
11 person:
- 12 • whether their management plan needs to be reviewed and adjusted to
13 reflect their current symptoms and energy envelope, because this may
14 be different from before the flare or relapse (for people participating in
15 [physical activity](#) programmes see [recommendations 1.11.21 and](#)
16 [1.11.22](#))
 - 17 • their experience of the flare or relapse to determine, if possible,
18 whether strategies can be put in place to manage potential triggers in
19 the future
 - 20 • investigate any new symptoms that may have caused the flare or
21 relapse.

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

Full details of the evidence and the committee's discussion are in [evidence review G: non pharmacological management](#).

1 **1.14 Review**

2 1.14.1 Offer adults with ME/CFS a review of their care and [management plan](#) in
3 primary care at least once a year (see recommendation 1.14.3 for what to
4 review).

5 1.14.2 Arrange more frequent primary care reviews for people with ME/CFS as
6 needed, depending on the severity and complexity of their symptoms, and
7 the effectiveness of any symptom management.

8 1.14.3 When undertaking a review in primary care, ensure you have access to
9 the person's management plan and (if relevant) discharge letter from the
10 specialist ME/CF team. As part of the review, discuss with the person with
11 ME/CFS (and their family members and carers, as appropriate) and
12 record as a minimum:

- 13 • their condition, including any changes and the impact of these,
14 including what can and cannot be achieved
- 15 • symptoms, including whether they have experienced new symptoms
- 16 • self-management – ask about [activity](#) management strategies
- 17 • who is helping them and how they provide support
- 18 • emotional and social wellbeing
- 19 • any future plans – ask if the person is considering any changes or if
20 they have any challenges ahead.

21 1.14.4 Refer the person with ME/CFS to their named contact in the specialist
22 team if there are any new or deteriorating aspects of their condition.

23 1.14.5 Consider seeking advice from an appropriate specialist if there is
24 uncertainty about interpreting signs and symptoms and whether a referral
25 is needed.

26 **Children and young people**

27 1.14.6 Offer [children and young people](#) with ME/CFS a review of their care and
28 management plan at least every 6 months (see recommendation 1.14.3
29 for what to review).

1 1.14.7 When deciding on how often reviews or reassessment might be needed
2 for children and young people with ME/CFS, take into account:

- 3
- 4 • their developmental stage
 - 5 • transitions, such as changing schools or exams
 - 6 • the severity and complexity of symptoms
 - 7 • the effectiveness of any symptom management.

7 1.14.8 Ensure reviews are carried out or overseen by a paediatrician with
8 expertise in ME/CFS. Involve other appropriate specialists as needed.

9 Also see [recommendation 1.1.7 on ensuring the child's voice is heard and on](#)
10 [involving their parents or carers](#).

For a short explanation of why the committee made these recommendations see the [rationale and impact section on review](#).

Full details of the evidence and the committee's discussion are in [evidence review J: review of care](#).

11 **1.15 Training for health and social care professionals**

12 1.15.1 Health and care providers should provide access to training that reflects
13 current knowledge in ME/CFS (including understanding what ME/CFS is,
14 diagnosis and management) for all health and social care staff who deliver
15 care to people with ME/CFS.

16 1.15.2 Ensure that training programmes on ME/CFS:

- 17
- 18 • provide evidence-based content and training methods (developed and supported by specialist services with input from people with ME/CFS)
 - 19 • are run by trainers with relevant skills, knowledge and experience
 - 20 • include monitoring, using relevant competency frameworks or
 - 21 assessment for the area of training
 - 22 • represent the experiences of people with ME/CFS, using video and
 - 23 other resources.

- 1 1.15.3 Health and social care professionals who provide care for people with
2 ME/CFS should undertake training that reflects current knowledge and
3 maintain continuous professional development in ME/CFS relevant to their
4 role so that they provide care in line with this guideline.

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

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

5 **Terms used in this guideline**

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

9 **Activity**

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

12 **Advocate**

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

18 **Carers**

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

1 **Children and young people**

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

4 **Energy envelope**

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

7 **Energy management**

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

10 **Exercise**

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

14 **Fatigability**

15 Fatigability in ME/CFS has the following features:

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

25 **Flare**

26 A flare is a worsening of symptoms, more than would be accounted for by normal
27 day-to-day variation, that affects the ability of the person to perform their usual
28 activities. Flares may occur spontaneously or be triggered by another illness,
29 overexertion or stress of any kind. The worsening of symptoms is transient and flares

1 typically resolve after a few days (1 to 3 days), either spontaneously or in response
2 to temporary changes in energy management or a change in treatment.

3 **Management plan**

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

9 **Mild ME/CFS**

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

14 **Moderate ME/CFS**

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

20 **Orthostatic intolerance**

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

27 **Physical activity**

28 Physical activity is defined as any bodily movement produced by skeletal muscles
29 that results in energy expenditure. Physical activity should not be confused with
30 [exercise](#) which is a subcategory of physical activity. Physical activity in daily life can

1 be categorised into occupational, sports, conditioning, household, or other activities,
2 and can be done during leisure time, to get around or as part of a person's work. For
3 many people, physical activity has a health benefit but in people with ME/CFS
4 physical activity may make their symptoms worsen. See the [World Health
5 Organization advice on physical activity](#).

6 **Physical maintenance**

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

18 **Post-exertional symptom exacerbation**

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

23 **Relapse**

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

1 **Severe or very severe ME/CFS**

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

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

11 **Therapy blueprint**

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

17 **Unrefreshing sleep**

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

21 **Recommendations for research**

22 The guideline committee has made the following recommendations for research.

23 **Key recommendations for research**

24 **1 Diagnostic tests**

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

For a short explanation of why the committee made this recommendation see the [rationale section on diagnosis](#).

Full details of the evidence and the committee's discussion are in [evidence review D: diagnosis](#).

1 **2 A core outcome set**

2 What core set of relevant health outcome measures should be used for trials of
3 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](#).

4 **Other recommendations for research**

5 **Diagnostic criteria**

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

For a short explanation of why the committee made this recommendation see the [rationale section on diagnosis](#).

Full details of the evidence and the committee's discussion are in [evidence review D: diagnosis](#).

8 **Self-monitoring management strategies**

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

For a short explanation of why the committee made this recommendation see the [rationale section on energy management](#).

Full details of the evidence and the committee's discussion are in [evidence review G: non pharmacological management](#).

1 **Sleep management strategies**

- 2 What is the clinical and cost effectiveness of sleep management strategies in
- 3 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](#).

4 **Dietary strategies**

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

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

Full details of the evidence and the committee's discussion are in [evidence review G: non pharmacological management](#).

7 **Rationale and impact**

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

10 **Principles of care for people with ME/CFS**

11 [Recommendations 1.1.1 to 1.1.11](#)

12 **Why the committee made the recommendations**

- 13 Common themes across the qualitative evidence showed a lack of belief about
- 14 ME/CFS as a real condition by health and social care professionals, and a lack of
- 15 understanding about what it is and the impact it has. The committee used this

1 evidence to make recommendations to raise awareness about ME/CFS. One strong
2 theme showed how experiencing a lack of understanding and prejudice can lead to
3 people losing trust in health and social care services. The committee agreed that
4 health and social care professionals need to take into account the impact of not
5 being believed when building relationships with people with ME/CFS and their
6 families. The committee considered this particularly relevant to children and young
7 people and made separate recommendations highlighting communication with
8 children.

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

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

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

22 **How the recommendations might affect practice**

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

25 [Return to recommendations](#)

26 **Suspecting ME/CFS**

27 [Recommendations 1.2.1 to 1.2.8](#)

1 **Why the committee made the recommendations**

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

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

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

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

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

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

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

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

16 **How the recommendations might affect practice**

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

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

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

30 [Return to recommendations](#)

1 **Advice for people with suspected ME/CFS**

2 [Recommendations 1.3.1 and 1.3.2](#)

3 **Why the committee made the recommendations**

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

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

13 **How the recommendations might affect practice**

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

17 [Return to recommendations](#)

18 **Diagnosis**

19 [Recommendations 1.4.1 to 1.4.3](#)

20 **Why the committee made the recommendations**

21 ***Making a diagnosis***

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

27 Reflecting the common theme across the evidence about a lack of knowledge of
28 ME/CFS and evidence that non-specialists in ME/CFS are not confident about

1 diagnosing and managing ME/CFS, the committee recommended referring people
2 with ME/CFS to a ME/CFS specialist team at 3 months to confirm their diagnosis and
3 develop a management plan.

4 ***Diagnostic criteria***

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

16 ***Diagnostic tests***

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

25 **How the recommendations might affect practice**

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

29 The duration of symptoms before diagnosis can take place has been reduced but the
30 criteria are now stricter, requiring that 4 different sets of symptoms are all present in
31 order to suspect ME/CFS. The impact therefore will not necessarily be an increase in

1 referrals but for people to receive their diagnosis earlier, which will bring forward their
2 assessment and care plan. Earlier access to appropriate advice and care could
3 prevent disease progression and therefore reduce resource use in the longer term.

4 [Return to recommendations](#)

5 **Assessment and care planning by a specialist ME/CFS team**

6 [Recommendations 1.5.1 to 1.5.5](#)

7 **Why the committee made the recommendations**

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

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

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

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

1 **How the recommendations might affect practice**

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

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

13 [Return to recommendations](#)

14 **Information and support**

15 [Recommendations 1.6.1 to 1.6.12](#)

16 **Why the committee made the recommendations**

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

21 The evidence showed people with ME/CFS and their families and carers valued
22 general information about ME/CFS that they could use themselves and share with
23 others (families, friends, employers and practitioners), particularly around the time of
24 diagnosis and the early stages of ME/CFS. This enabled them to develop accurate
25 expectations about the future, relieve distress caused by the general lack of
26 information and educate others. The evidence suggested people with ME/CFS
27 wanted realistic information about what ME/CFS is and how it might affect them in
28 the future, and this formed the basis of the recommendations outlining the key
29 characteristics of ME/CFS. The recommendation noting that the long-term outlook

1 can be better in children and young people was based on the committee's
2 experience.

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

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

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

18 **How the recommendations might affect practice**

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

22 [Return to recommendations](#)

23 **Safeguarding**

24 [Recommendations 1.7.1 to 1.7.6](#)

25 **Why the committee made the recommendations**

26 The committee recognised that safeguarding is a particular issue in ME/CFS in a
27 way that is different from other chronic illnesses and disabilities because people with
28 ME/CFS commonly report that they are not believed. No evidence was identified on
29 safeguarding in ME/CFS, but the committee agreed it was very important to make

1 recommendations based on consensus. The recommendations address some of the
2 misconceptions on this topic and highlight the need for expertise in ME/CFS when
3 carrying out safeguarding assessments.

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

7 **How the recommendations might affect practice**

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

10 [Return to recommendations](#)

11 **Access to care**

12 [Recommendations 1.8.1 to 1.8.11](#)

13 **Why the committee made the recommendations**

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

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

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

1 address this, the committee highlighted the flexibility and specific support needed by
2 people with severe or very severe ME/CFS.

3 ***Maintaining independence***

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

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

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

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

19 **How the recommendations might affect practice**

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

25 [Return to recommendations](#)

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

27 [Recommendations 1.9.1 to 1.9.6](#)

1 **Why the committee made the recommendations**

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

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

15 **How the recommendations might affect practice**

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

18 [Return to recommendations](#)

19 **Multidisciplinary care**

20 [Recommendations 1.10.1 to 1.10.5](#)

21 **Why the committee made the recommendations**

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

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

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

10 **How the recommendations might affect practice**

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

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

25 [Return to recommendations](#)

26 **Managing ME/CFS**

27 [Recommendation 1.11.1](#)

1 **Why the committee made the recommendations**

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

9 ***Core outcomes in ME/CFS***

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

18 **How the recommendations might affect practice**

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

21 [Return to recommendation](#)

22 **Energy management**

23 [Recommendations 1.11.2 to 1.11.10](#)

24 **Why the committee made the recommendations**

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

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

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

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

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

19 ***Self-monitoring techniques***

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

1 **How the recommendations might affect practice**

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

7 [Return to recommendations](#)

8 **Physical maintenance**

9 [Recommendations 1.11.11 to 1.11.14](#)

10 **Why the committee made the recommendations**

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

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

21 **How the recommendations might affect practice**

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

25 [Return to recommendations](#)

26 **Physical activity**

27 [Recommendations 1.11.15 to 1.11.22](#)

1 **Why the committee made the recommendations**

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

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

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

21 **How the recommendations might affect practice**

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

27 [Return to recommendations](#)

28 **Rest and sleep**

29 [Recommendation 1.11.23](#)

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

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

11 **How the recommendations might affect practice**

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

14 [Return to recommendation](#)

15 **Managing orthostatic intolerance**

16 [Recommendations 1.11.24 to 1.11.26](#)

17 **Why the committee made the recommendations**

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

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

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

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

4 **How the recommendations might affect practice**

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

7 [Return to recommendations](#)

8 **Managing pain**

9 [Recommendation 1.11.27](#)

10 **Why the committee made the recommendation**

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

15 [Return to recommendation](#)

16 **Managing nausea**

17 [Recommendation 1.11.28](#)

18 **Why the committee made the recommendation**

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

23 **How the recommendation might affect practice**

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

26 [Return to recommendation](#)

1 **Medicines, including medicines for symptom management**

2 **Why the committee made the recommendations**

3 [Recommendations 1.11.29 to 1.11.32](#)

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

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

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

20 **How the recommendations might affect practice**

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

23 [Return to recommendations](#)

24 **Dietary management and strategies**

25 [Recommendations 1.11.33 to 1.11.42](#)

26 **Why the committee made the recommendations**

27 There was not enough evidence to make a recommendation for any dietary strategy
28 for ME/CFS. However, the committee agreed some general recommendations to

1 ensure that people with ME/CFS receive appropriate support related to diet. This
2 included guidance on when to refer someone to a dietitian who specialises in
3 ME/CFS. The committee also referred to other NICE guidance that was relevant.

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

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

16 **How the recommendations might affect practice**

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

19 [Return to recommendations](#)

20 **Psychological support: cognitive behavioural therapy**

21 [Recommendations 1.11.43 to 1.11.50](#)

22 **Why the committee made the recommendations**

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

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

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

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

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

20 **How the recommendations might affect practice**

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

24 [Return to recommendations](#)

25 **Managing coexisting conditions**

26 **Why the committee made the recommendations**

27 [Recommendations 1.12.1 to 1.12.4](#)

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

5 **How the recommendations might affect practice**

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

7 [Return to recommendations](#)

8 **Managing flares and relapse**

9 [Recommendations 1.13.1 to 1.13.7](#)

10 **Why the committee made the recommendations**

11 In the committee's experience, flares and relapse are a common part of ME/CFS.

12 The committee considered it important to give people information about what a flare
13 is, how to recognise one and how they can lead to a relapse if activity is not
14 monitored and adjusted.

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

20 **How the recommendations might affect practice**

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

23 [Return to recommendations](#)

24 **Review**

25 [Recommendations 1.14.1 to 1.14.8](#)

1 **Why the committee made the recommendations**

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

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

13 **How the recommendations might affect practice**

14 There is variation in practice and some people with ME/CFS, including those with
15 severe and very severe ME/CFS, do not get a clinical review routinely, so for some
16 this will be a change in practice. These recommendations are in line with other long-
17 term conditions and support equity of access to care for people with ME/CFS.

18 Routine follow-up might not be present everywhere but most people with ME/CFS
19 already have regular contact with their primary care teams, so there is not expected
20 to be a large resource impact.

21 [Return to recommendations](#)

22 **Training for health and social care professionals**

23 [Recommendations 1.15.1 to 1.15.3](#)

24 **Why the committee made the recommendations**

25 A strong theme in the evidence was the lack of knowledge, understanding and up-to-
26 date training that health and social care professionals have about ME/CFS. This was
27 reflected in the committee's experience so they recommended that all health and
28 social staff who deliver care to people with ME/CFS should be trained so they are
29 able to provide the care in this guideline. The evidence showed that training

1 programmes in ME/CFS are often out of date, so the committee made a
2 recommendation highlighting what a training programme should look like.

3 **How the recommendations might affect practice**

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

8 [Return to recommendations](#)

9 **Context**

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

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

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

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

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

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

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

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

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

25 **Finding more information and resources**

26 To find out what NICE has said on topics related to this guideline, see the [NICE](#)
27 [webpage on ME/CFS](#).

28 For details of the guideline committee see the [committee member list](#).

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