ME (chronic fatigue syndrome) overview

NICE Pathways bring together everything NICE says on a topic in an interactive flowchart. NICE Pathways are interactive and designed to be used online.

They are updated regularly as new NICE guidance is published. To view the latest version of this NICE Pathway see:

http://pathways.nice.org.uk/pathways/me-chronic-fatigue-syndrome
NICE Pathway last updated: 29 October 2021

This document contains a single flowchart and uses numbering to link the boxes to the associated recommendations.

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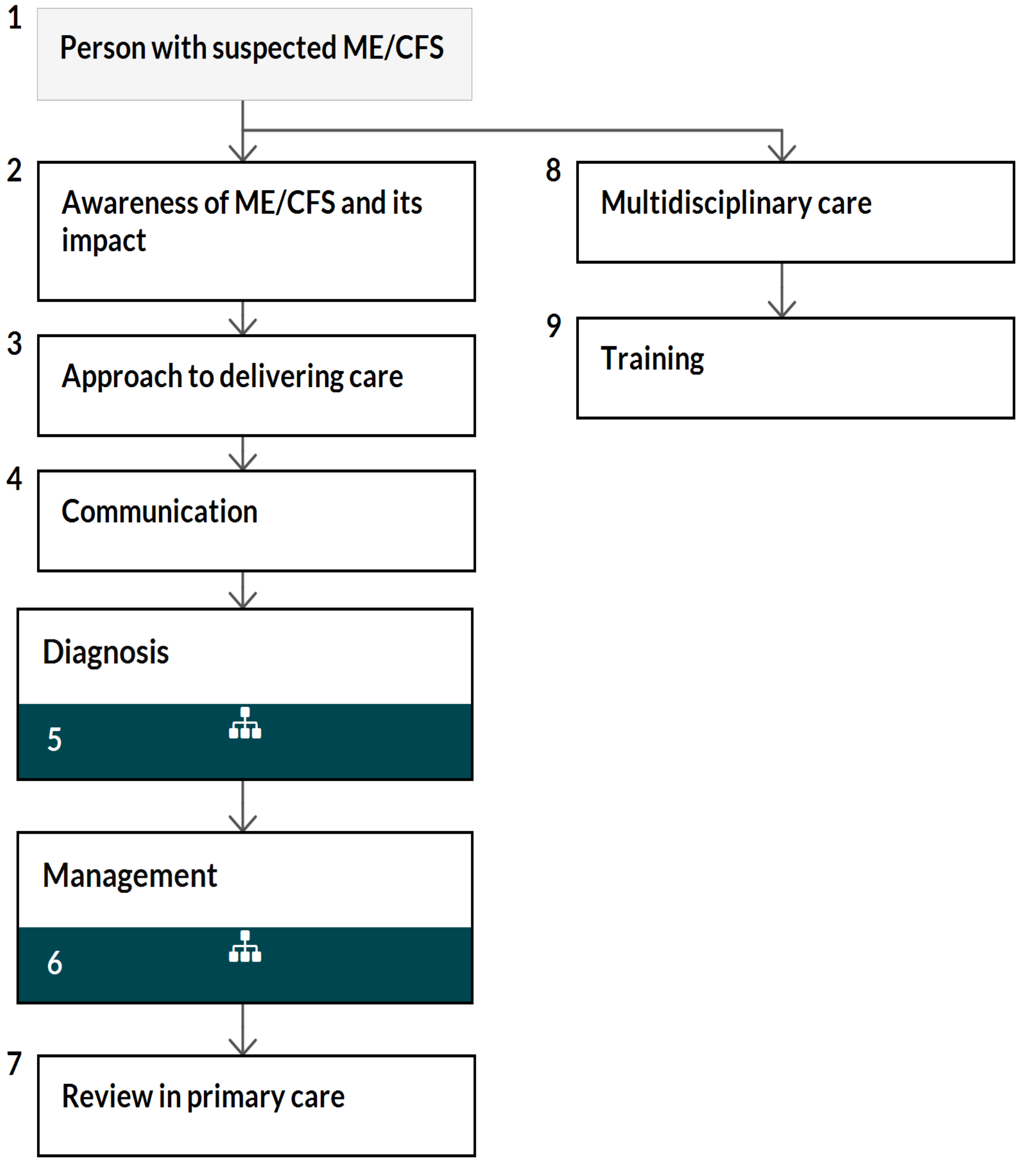

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1 Person with suspected ME/CFS

No additional information

2 Awareness of ME/CFS and its impact

Be aware that ME/CFS:

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

See the NICE guideline to find out why we made this recommendation and how it might affect practice.

Be aware that ME/CFS symptoms can be managed but there is currently no cure (non-pharmacological or pharmacological) for ME/CFS. See the NICE guideline to find out why we made this recommendation and how it might affect practice.

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

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

See the NICE guideline to find out why we made this recommendation and how it might affect practice.

Severe or very severe ME/CFS

Be aware that people with severe or very severe ME [See page 12] may experience some of

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the following symptoms that significantly affect their lives, including their mobility, emotional wellbeing and ability to interact with others and care for themselves:

- severe and constant pain, which can have muscular, arthralgic or neuropathic features
- hypersensitivity to light, noise, touch, movement, temperature extremes and smells
- extreme weakness, with severely reduced movement
- reduced ability or inability to speak or swallow
- cognitive difficulties that limit the person's ability to communicate and take in written or verbal communication
- sleep disturbance such as unrefreshing sleep, hypersomnia and altered sleep pattern
- gastrointestinal difficulties such as nausea, incontinence, constipation and bloating
- neurological symptoms such as double vision and other visual disorders, dizziness
- orthostatic intolerance [See page 11] and autonomic dysfunction, such as POTS and postural hypotension.

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

- need a low-stimulus environment, for example a dark quiet room with interaction at a level of their choice (this may be little or no social interaction)
- are housebound or bedbound and may need support with all activities of daily living, including aids and adaptions to assist mobility and independence in activities of daily living (for example, a wheelchair)
- need careful physical contact when supported with activities of daily living, taking into account possible sensitivity to touch
- cannot communicate without support and may need to choose someone to be their advocate and communicate for them
- are unable to eat and digest food easily and may need support with hydration and nutrition (see dietary management and strategies)
- have problems accessing information, for example because of difficulty with screens, sound and light sensitivity, headaches affecting their ability to read, or brain fog affecting their concentration.

See the NICE guideline to find out why we made these recommendations and how they might affect practice.

3 Approach to delivering care

Health and social care professionals should:

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

Recognise that people with ME/CFS need:

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

See the NICE guideline to find out why we made these recommendations and how they might affect practice.

Give adults, children and young people with ME/CFS (and their family or carers (as appropriate) a named contact in their primary care and/or ME/CFS specialist team to coordinate their care and support plan, help them access services and support them during periods of relapse. See the NICE guideline to find out why we made this recommendation and how it might affect practice.

Additional considerations for children and young people

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

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

See the NICE guideline to find out why we made this recommendation and how it might affect practice.

Provide children and young people with ME/CFS and their family or carers (as appropriate) with

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details of a named professional in the ME specialist team [See page 11] who they can contact with any concerns about their child's health, education or social life.

For young adults with ME/CFS moving from children's to adults' services, manage transitions in line with the NICE Pathway on transition from children's to adults' services.

See the NICE guideline to find out why we made these recommendations and how they might affect practice.

Severe or very severe ME/CFS

Personal care and support for people with severe or very severe ME [See page 12] should be carried out by health and social care practitioners who are:

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

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

See the NICE guideline to find out why we made these recommendations and how they might affect practice.

4 Communication

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

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

Follow the principles on communication, information giving and shared decision-making in the NICE Pathways on patient experience in adult NHS services: enabling patients to actively participate in their care, people's experience in adult social care services and shared decision making.

See the NICE guideline to find out why we made this recommendation and how it might affect

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practice.

Additional considerations for children and young people

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

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

See the NICE guideline to find out why we made this recommendation and how it might affect practice.

5 Diagnosis

See ME (chronic fatigue syndrome) / Diagnosing ME (chronic fatigue syndrome)

6 Management

See ME (chronic fatigue syndrome) / Managing ME (chronic fatigue syndrome)

7 Review in primary care

What to review

When carrying out a review in primary care, ensure you have access to the person's care and support plan and any clinical communications from the ME specialist team [See page 11] (including their discharge letter, if relevant).

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

- their condition, including any changes in their illness and the impact of this
- symptoms, including whether they have experienced new symptoms

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- self-management – ask about their energy management plan and (if relevant) their physical activity [See page 12] or exercise programme
- who is helping them and how they provide support
- psychological, emotional and social wellbeing
- any future plans – ask if the person is considering any changes or if they have any challenges ahead.

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

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

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

See the NICE guideline to find out why we made these recommendations and how they might affect practice.

Frequency of reviews

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

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

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

Additional principles for children and young people

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

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

- their developmental stage

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

Also see approach to delivering care [See page 4] for guidance on ensuring the child's voice is heard and on involving their parents or carers.

See the NICE guideline to find out why we made these recommendations and how they might affect practice.

8 Multidisciplinary care

Provide care for people with ME/CFS using a coordinated multidisciplinary approach. Based on the person's needs, include access to health and social care professionals with expertise in the following as a minimum, with additional expertise depending on symptoms:

- medical assessment and diagnosis
- developing personalised care and support plans
- self-management strategies, including energy management
- symptom management, including prescribing and medicines management
- managing flare-ups [See page 11] and relapses [See page 12]
- activities of daily living (including dental health)
- psychological, emotional and social wellbeing, including family and sexual relationships
- diet and nutrition
- mobility, avoiding falls and problems from loss of dexterity, including access to aids and rehabilitation services
- social care and support
- support to engage in work, education, social activities and hobbies.

Care for people whose ME/CFS is managed in primary care should be supported by advice and direct clinical consultation from an ME specialist team [See page 11].

See the NICE guideline to find out why we made these recommendations and how they might affect practice.

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9 Training

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

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

See the NICE guideline to find out why we made this recommendation and how it might affect practice.

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Flare-up

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

ME/CFS specialist team

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

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

Orthostatic intolerance

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

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Physical activity

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

Relapse

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

Severe ME/CFS

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

Very severe ME/CFS

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

Glossary

Advocate

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

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Care and support plan

(the personalised collaborative care and support plan is developed by the ME/CFS specialist team based on a holistic assessment; it is the basis for other assessments and plans in areas such as social care, energy management, physical activity, physical functioning and mobility, CBT and dietary management)

Care and support plans

(the personalised collaborative care and support plan is developed by the ME/CFS specialist team based on a holistic assessment; it is the basis for other assessments and plans in areas such as social care, energy management, physical activity, physical functioning and mobility, CBT and dietary management)

Carers

(in this guidance, a carer refers to someone who provides unpaid care and support to a family member, partner or friend with ME/CFS; this is distinct from care workers who are employed to provide support)

CFS

chronic fatigue syndrome

Energy management

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

Exercise

(planned, repetitive, and purposeful activity focused on improvement or maintenance of 1 or more components of physical fitness; exercise is a subcategory of physical activity)

ME

myalgic encephalomyelitis (or encephalopathy)

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POTS

postural orthostatic tachycardia syndrome

Unrefreshing sleep

(means sleep that is non-restorative, even after a full night's sleep, people do not feel refreshed; people with ME/CFS often report waking up exhausted and feeling as if they have not slept at all, no matter how long they were asleep)

Sources

Myalgic encephalomyelitis (or encephalopathy)/chronic fatigue syndrome: diagnosis and management (2021) NICE guideline NG206

Your responsibility

Guidelines

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

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

Commissioners and providers have a responsibility to promote an environmentally sustainable health and care system and should assess and reduce the environmental impact of

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implementing NICE recommendations wherever possible.

Technology appraisals

The recommendations in this interactive flowchart represent the view of NICE, arrived at after careful consideration of the evidence available. When exercising their judgement, health professionals are expected to take these recommendations fully into account, alongside the individual needs, preferences and values of their patients. The application of the recommendations in this interactive flowchart is at the discretion of health professionals and their individual patients and do not override the responsibility of healthcare professionals to make decisions appropriate to the circumstances of the individual patient, in consultation with the patient and/or their carer or guardian.

Commissioners and/or providers have a responsibility to provide the funding required to enable the recommendations to be applied when individual health professionals and their patients wish to use it, in accordance with the NHS Constitution. They should do so in light of their duties to have due regard to the need to eliminate unlawful discrimination, to advance equality of opportunity and to reduce health inequalities.

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

Medical technologies guidance, diagnostics guidance and interventional procedures guidance

The recommendations in this interactive flowchart represent the view of NICE, arrived at after careful consideration of the evidence available. When exercising their judgement, healthcare professionals are expected to take these recommendations fully into account. However, the interactive flowchart does not override the individual responsibility of healthcare professionals to make decisions appropriate to the circumstances of the individual patient, in consultation with the patient and/or guardian or carer.

Commissioners and/or providers have a responsibility to implement the recommendations, in their local context, in light of their duties to have due regard to the need to eliminate unlawful discrimination, advance equality of opportunity, and foster good relations. Nothing in this

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interactive flowchart should be interpreted in a way that would be inconsistent with compliance with those duties.

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

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