THE DRAFT NICE CLINICAL GUIDELINE FOR ME/CFS (2020/21)

ESSENTIAL EXTRACTS
FROM THE GUIDELINE

AUGUST 2021

THE ME ASSOCIATION

THE DRAFT NICE CLINICAL GUIDELINE FOR ME/CFS (2020/21)

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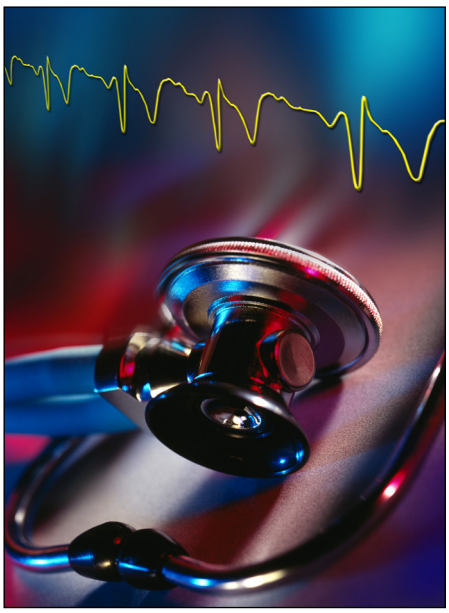

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OVERVIEW

THE CURRENT SITUATION

In 2017, the National Institute for Health and Care Excellence (NICE) finally agreed to review the important clinical guideline on ME/CFS. The guideline had been in place since 2007 and was not fit for purpose - it did not reflect what people needed from health and social care services.

After 4 years of hard work and a thorough evidence-based review, the guideline committee - experts, clinicians, and lay members - submitted their recommendations to NICE and a draft guideline was sent to stakeholders for consultation in November 2020.

The committee then spent months working through all the stakeholder comments and updating the recommendations where it was felt appropriate. The final draft guideline was sent to stakeholders on 04 August ahead of publication on 18 August 2021.

The ME Association is a member of the steering group at Forward-ME - a collaboration of charities and groups across the UK - and we prepared a press release and statement about the new guideline that we sent in good faith to journalists on 17 August. It made it clear that we were in support of the final guideline - and heralded it as a new beginning for people with ME/CFS - although we had some concerns with certain aspects of it.

Within hours of final publication - on the afternoon of the 17 August - NICE announced it was suspending publication because it seems certain Royal Colleges were not happy to see the recommendation for graded exercise therapy removed and threatened not to implement the guideline recommendations.

The process of review was evidence-based and followed the NICE protocols to the letter. It is unprecedented that pressure can be applied this late in the day based on the opinion of a few clinicians. We know that many other clinicians supported the new guideline recommendations and that some ME/CFS specialist services were already starting to make positive changes based on the draft guideline.

As at 23 August, we are waiting to hear from NICE about how we can resolve the matter and get the guideline - that so many deserve - published. We will update this booklet as and when we learn more.

The guideline recommends that GPs refer people with ME/CFS to specialist services who can help people who are struggling to cope.

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You can follow developments, read the press release and statement from Forward-ME, and the news-media reports here:

https://meassociation.org.uk/about-what-is-mecfs/nice-clinical-guideline/

You can access the full draft guideline here:
https://tinyurl.com/aatcs5t3

The guideline is designed to provide recommendations that are also relevant to social care professionals.

BACKGROUND

The National Institute for Health and Care Excellence has provided an important framework of clinical recommendations about ME/CFS for use by health and social care services in England, Wales, and Northern Ireland.

The devolved nations determine the extent to which the recommendations are adopted. Unfortunately, this has meant that the ME/CFS specialist services network in England has not been replicated elsewhere, restricting secondary referral options for a lot of people.

In this booklet we have provided essential extracts from the guideline that will help you to understand the help and support that should be available from your local health and social care services.

NHS PRIMARY CARE

Accessing appropriate healthcare can be a negotiation but establishing a good relationship with your GP is often essential. The guideline establishes that:

- GPs are the primary healthcare providers overseeing care and management plans and are also gatekeepers to secondary care referrals, e.g., ME/CFS specialist services.
- GPs can provide initial and subsequent medical assessments, can make an early and accurate diagnosis, and carry out recommended tests to exclude other possible causes for initial (or new) symptoms.
- GPs can prescribe medications aimed at symptom relief, but there is no list of recommended drugs for ME/CFS because of a lack in research evidence (see section 1.11.30 below).
- GPs and/or ME/CFS specialist services should support applications (or reviews) for welfare benefits, social care applications, needs assessments, and disability aids provided by the NHS.

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NHS SECONDARY CARE

The person with ME/CFS can be referred by a GP to secondary care and the ME/CFS specialist services that have been established across England (and in some parts of Wales). Efforts continue to try and establish similar clinical networks elsewhere in the UK although implementation has been problematic.

- The guideline recommends that GPs refer people with ME/CFS to specialist services who can help people who are struggling to cope and who can support them with individualised approaches to illness management.
- ME/CFS specialist services aim to provide a multi-disciplinary approach to healthcare, are hospital-based, and offer outpatient appointments that should be accessible.
- Specialist services are advised not to discharge patients who have been unable to keep appointments because symptoms have become worse.
- Specialists consist of clinicians (GPs with a special interest or consultants in related areas e.g., neurology or immunology), occupational therapists, psychologists, physiotherapists, and dietitians.
- Services should provide suitable provision for people who are severely and very severely affected by working closely with GPs and social care services and making home visits or providing remote access when required.
- The new guideline recommends:

- energy management as the key approach.

- exercise therapy is not recommended due to reported harms and lack of research evidence.

- CBT is to be used if patients need help with the understandable mental health problems that life with ME/CFS can bring.

A court judgement in 2014 established that commissioners cannot refuse to implement NICE guideline recommendations simply because they disagree with them.

SOCIAL CARE

The guideline is designed to provide recommendations that are also relevant to social care professionals. Social care consists of practical assistance because of illness or disability and is provided by your local authority. Applications can be made direct or by referral from a GP.

A needs assessment will be required which will involve someone from the local authority making a home visit and a determination of your requirements. It will also take into account your ability to contribute to the cost of care. Then a personal

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budget will be established which can be used to pay for the services you require.

Types of social care include, help at home from a paid carer, meals on wheels, having a home adapted, equipment and household gadgets, personal alarms, and home security systems so a person can call for help (for instance, if they were to fall), and help with different types of housing, such as sheltered housing and care homes.

DO HCPS HAVE TO FOLLOW THE NICE GUIDELINE?

"Healthcare and other professionals are expected to take the clinical guidelines fully into account when exercising their professional judgement.

"However, the guidance does not override the responsibility of healthcare professionals and others to make decisions appropriate to the circumstances of each patient.

"These decisions should be made in consultation with, and with the agreement of, the patient and/or their guardian or carer. Healthcare professionals and others should record their reasons for not following clinical guideline recommendations."

Source: **About The NICE Guidelines:**

https://tinyurl.com/265wmur7

WHAT ABOUT THE COMMISSIONERS OF HEALTHCARE?

If you find that you don't have reasonable healthcare or a secondary care specialist service in your area, you might want to approach the local clinical commissioning group (or other commissioning authority) and/or your MP to ask why this is the case.

A court judgement in 2014 established that commissioners cannot refuse to implement NICE guideline recommendations simply because they disagree with them:

"The court judgement does mean that if organisations refuse to put NICE clinical guidelines in place because they disagree with them, this could leave them open to challenge."

Source: **NICE: Court Judgement: what it means for commissioners and providers:**

https://tinyurl.com/f6re3992

The draft NICE Guideline (November 2020) is aimed primarily at health and social care professionals but is also an important resource for people with ME/CFS, carers and family members.

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USING THE NICE GUIDELINE

The guideline can be employed as a personal reference tool to help you understand ME/CFS and the support that is available. It can also be used to establish a good relationship with a GP or social care professional, and to develop a care or management plan, based on evidence-based recommendations.

Should you need to raise the issue of reasonable adjustments when trying to access health and social care services as a disabled person then the guideline can help to support your needs e.g., arranging for home visits, flexible appointments, remote access etc. (see section 1.8.1 below).

THE NICE GUIDELINE FOR ADULTS WITH ME/CFS

The draft NICE Guideline (November 2020) is aimed primarily at health and social care professionals but is an important resource for people with ME/CFS, carers and family members as well. We suggest that you take some time to study it and we will update this booklet when the final guideline is published - hopefully by the end of September 2021.

https://tinyurl.com/aatcs5t3

Please note: the clinical guideline is applicable to children, young people, and adults with ME/CFS, but as we are a charity primarily aimed at helping adults, we have chosen only to include recommendations for adults below.

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THE DRAFT NICE CLINICAL GUIDELINE FOR ME/CFS (2020/21)

1: INTRODUCTION

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.

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.

ABOUT ME/CFS

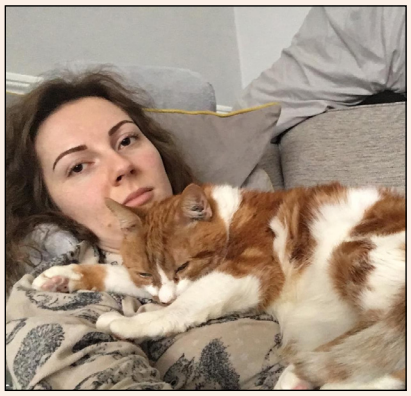
1.1.1: BE AWARE THAT ME/CFS:

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

2: APPROACH FOR DELIVERING CARE

1.1.3: HEALTH AND SOCIAL CARE PROFESSIONALS SHOULD:

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



ILLNESS SEVERITY DEFINITIONS

MILD ME/CFS

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

MODERATE ME/CFS

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

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- use a person-centred approach to assess people's needs,
- involve family members and carers (as appropriate) in discussions and care planning if the person with ME/CFS chooses to include them.

1.1.4: RECOGNISE THAT PEOPLE WITH ME/CFS NEED:

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

RIGHT TO DECLINE CARE

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

AWARENESS OF SEVERE OR VERY SEVERE ME/CFS AND ITS IMPACT

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

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

ILLNESS SEVERITY DEFINITIONS

SEVERE AND VERY SEVERE ME/CFS

People with severe ME/CFS are unable to do any activity for themselves or can carry out minimal daily tasks only (such as face washing or cleaning teeth). They have severe cognitive difficulties and may depend on a wheelchair for mobility.

They are often unable to leave the house or have a severe and prolonged after-effect if they do so. They may also spend most of their time in bed and are often extremely sensitive to light and noise.

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

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

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

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

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

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

Personal care and support for people with severe or very severe ME/CFS should be carried out by health and social care practitioners who are known to the person and their family members or carers wherever possible.

3: SYMPTOMS & DIAGNOSIS

1.2: SUSPECTING ME/CFS

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

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

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

1.2.3: Suspect ME/CFS if:

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

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

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

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

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

1.2.7: Primary healthcare professionals should consider seeking advice from an appropriate specialist if there is uncertainty

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 Malaise 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 known as 'brain fog'

- including problems finding words,
- temporary dyslexia or dyscalculla,
- slurred speech
- slowed responsiveness
- short-term memory problems,
- confusion, disorientation, and,
- difficulty concentrating or multitasking.

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about interpreting signs and symptoms and whether a referral is needed.

1.5: ASSESSMENT AND CARE PLANNING BY A SPECIALIST ME/CFS TEAM

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

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

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

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

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- details of the health and social care professionals involved in the person's care, and how to contact them.

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

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

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

PEOPLE WITH SEVERE OR VERY SEVERE ME/CFS

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

4: INFORMATION AND SUPPORT

COMMUNICATION

1.6.1: Provide information to people with ME/CFS and their families and carers in a variety of formats (for example, written materials, electronic and audio) that can be used both at home and in the clinical setting.

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

INFORMATION ABOUT ME/CFS

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

1.6.4: Explain that ME/CFS:

- is a fluctuating medical condition that affects everyone differently, in which symptoms and their severity can change a lot over a day, week or longer,

ME/CFS is a fluctuating medical condition that affects everyone differently, in which symptoms and their severity can change a lot over a day, week or longer.

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

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

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

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

SOCIAL CARE

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

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

SUPPORTING FAMILIES AND CARERS OF PEOPLE WITH ME/CFS

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

https://tinyurl.com/y2jhn8tr

1.7: SAFEGUARDING

1.7.1: Safeguarding assessments in people with confirmed or suspected ME/CFS should be carried out or overseen by health

Social care can benefit the person living with ME/CFS as well as provide a route to support for families and carers through a formal carer's assessment.

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and social care professionals who have training and experience in ME/CFS.

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

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

1.8: ACCESS TO CARE

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

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

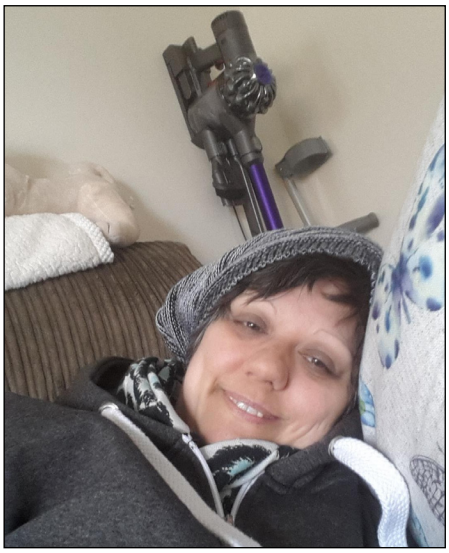
1.8.2: Do not discharge someone who misses appointments because their symptoms have worsened. Contact them to explore why they could not attend and how to support them.

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

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

PEOPLE WITH SEVERE OR VERY SEVERE ME/CFS

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



Debilitating symptoms, fear of relapse or post-exertional symptom exacerbation may often prevent people from leaving their home.

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5. HOSPITAL CARE

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

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

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

PEOPLE WITH SEVERE OR VERY SEVERE ME/CFS

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

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

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

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6: MAINTAINING INDEPENDENCE

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

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

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

AIDS AND ADAPTATIONS

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

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

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

Aids and adaptations are vital to ensure that people can carry out activities of daily living and maintain their quality of life.

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7: WORK, EDUCATION, AND TRAINING

1.9.1: Advise people with ME/CFS that:

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

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

Some people find that going back to work, school or college worsens their symptoms.

8. MULTIDISCIPLINARY CARE

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

- self-management strategies, including energy management,
- symptom management,
- managing flares and relapse,
- activities of daily living,
- emotional wellbeing, including family and sexual relationships,
- diet and nutrition,
- mobility, avoiding falls and problems from loss of dexterity, including access to aids and rehabilitation services,
- social care and support,
- support to engage in work, education, social activities, and hobbies.

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

1.10.3: Give people with ME/CFS (and their family members and carers, as appropriate) a named contact in their primary care

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and/or specialist team to coordinate their management plan, help them access services and support them during periods of relapse.

1.11: MANAGING ME/CFS

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

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

ENERGY MANAGEMENT

1.11.2: **Discuss with people with ME/CFS the principles of energy management, its role in supporting them to live with their symptoms, the potential benefits, and risks and what they should expect. Explain that it:**

- is not curative,
- is a self-management strategy led by the person themselves but with support from a healthcare professional,
- can be applied to any type of activity,
- helps people understand their energy envelope so they can reduce the risk of overexertion worsening their symptoms,
- recognises that each person has a different and fluctuating energy limit, and they are the best judge of their own limits,
- can include help from a healthcare professional to recognise when they are approaching their limit,
- uses a flexible, tailored approach so that activity is never automatically increased but is progressed during periods when symptoms are improved and allows for the need to pull back when symptoms are worse
- is a long-term approach
- it can take weeks, months or sometimes even years to reach stabilisation or to increase tolerance or activity,
- does not assume that deconditioning is the cause of ME/CFS.

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

- cognitive activity,
- mobility and other physical activity,
- ability to undertake activities of daily living,

Help people with ME/CFS to develop an energy management plan with realistic expectations and goals that are meaningful to them.

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- emotional demands,
- social activity, including relationships,
- rest and relaxation (both quality and duration),
- sleep quality and duration,
- anything else that is important to the person.

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

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

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

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

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

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

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

PEOPLE WITH SEVERE OR VERY SEVERE ME/CFS

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

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

Establish an individual activity pattern within the ME/CFS patient's current energy envelope so that it minimises their symptoms.

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THE DRAFT NICE CLINICAL GUIDELINE FOR ME/CFS (2020/21)

PHYSICAL MAINTENANCE

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

- joint mobility,
- muscle flexibility,
- postural and positional support,
- muscle strength and endurance,
- bone health
- cardiovascular health.

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

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

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

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

PHYSICAL ACTIVITY

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

1.11.16: Do not offer people with ME/CFS:

- any therapy based on physical activity or exercise as a treatment or cure for ME/CFS,

Give families and carers (if appropriate) advice and support on how to help the person with ME/CFS follow their management plan in relation to physical maintenance and mobility.

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

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

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

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

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

- establish their physical activity baseline at a level that does not worsen their symptoms,
- start by reducing the person's activity to within their energy envelope,
- be possible to maintain it successfully before attempting to increase physical ability,
- use flexible increments for people who want to focus on improving their physical abilities while remaining within their energy envelope,
- recognise a flare or relapse early and outline how to manage it (see recommendations 1.11.21 and 1.11.22),
- incorporate regular reviews.

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

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

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

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

Rest periods are part of all management strategies for ME/CFS.

9: SYMPTOM MANAGEMENT

REST AND SLEEP

1.11.23: Advise people with ME/CFS:

- on the role of rest in ME/CFS,
- that rest periods are part of all management strategies for ME/CFS,
- how to introduce rest periods into their daily routine, including how often and for how long, as appropriate for each person,
- that relaxation techniques at the beginning of each rest period could be helpful.

MANAGING ORTHOSTATIC INTOLERANCE

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

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

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

MANAGING PAIN

1.11.27: Refer to the following for advice on treating pain:

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

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MANAGING NAUSEA

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

MEDICINES

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

MEDICINES FOR SYMPTOM MANAGEMENT

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

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

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

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

10. DIETARY MANAGEMENT

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

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

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

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

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

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

PEOPLE WITH SEVERE OR VERY SEVERE ME/CFS

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

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

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

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

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

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

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

11: PSYCHOLOGICAL SUPPORT

COGNITIVE BEHAVIOURAL THERAPY

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

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

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

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

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

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

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

- developing a shared understanding with the person about the main difficulties and challenges they face
- exploring their personal meaning of symptoms and illness, and how this might relate to how they manage their symptoms
- working together to adapt and refine self-management strategies to improve the person's functioning and quality of life, for example their sleep, activity, and rest
- developing a self-management plan

Work together to adapt and refine self-management strategies to improve the person's functioning and quality of life.

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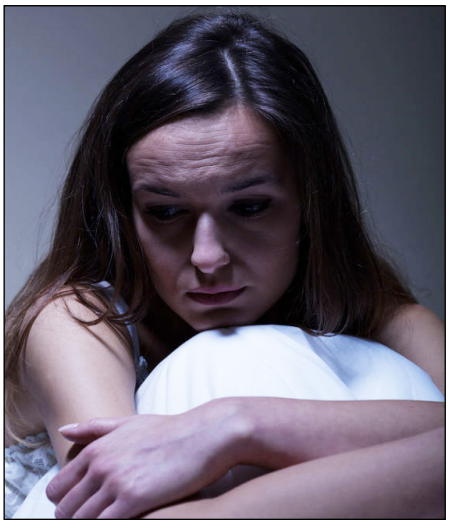
- reviewing their plan regularly to see if their self-management strategies need to be adapted, for example if their symptoms or functioning change
- developing a therapy blueprint collaboratively with their therapist at the end of therapy.

PEOPLE WITH SEVERE OR VERY SEVERE ME/CFS

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



Healthcare professionals delivering CBT to a person with severe or very severe ME/CFS should adjust the process and pace of CBT to meet the person's needs.

12. MANAGING COEXISTING CONDITIONS

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

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

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

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

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

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

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13. MANAGING FLARES AND RELAPSE

FLARES

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

1.13.2: Respond promptly to a flare in symptoms by:

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

RELAPSE

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

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

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

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

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

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

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

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

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

14. HEALTHCARE REVIEWS

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

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

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

- their condition, including any changes and the impact of these, including what can and cannot be achieved
- symptoms, including whether they have experienced new symptoms
- self-management
- ask about activity management strategies
- who is helping them and how they provide support
- emotional and social wellbeing
- any future plans
- ask if the person is considering any changes or if they have any challenges ahead.

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

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

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

When undertaking a review in primary care, ensure you have access to the person's management plan and (if relevant) discharge letter from the specialist ME/CF team.

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