

AN ME ASSOCIATION SUMMARY OF THE 2021 NICE CLINICAL GUIDELINE FOR ME/CFS

ESSENTIAL INFORMATION
FROM THE NEW NICE GUIDELINE

DECEMBER 2021

NICE National Institute for
Health and Care Excellence



The ME Association is delighted that the guideline has been published and we fully support the recommendations that it contains.



AN ME ASSOCIATION SUMMARY OF THE 2021 NICE CLINICAL GUIDELINE FOR ME/CFS

INTRODUCTION

The National Institute for Health and Care Excellence (NICE) recently published a new clinical guideline about ME/CFS (NG206) for use by the NHS and social care services in England, Wales, and Northern Ireland. It is also recognised in Scotland.

The ME Association is delighted that the guideline has been published and we fully support the recommendations that it contains. It has also been supported by the British Association of CFS/ME (BACME) – the organisation for health professionals who work in ME/CFS specialist services – and widely welcomed by the patient community.

People with ME/CFS had to live with a previous guideline that was unfit for purpose – because it recommended treatments that were often inappropriate, ineffective, or harmful. After a very thorough review of all the evidence – from clinical trials, experts, and patients – we now have a guideline that has properly recognised this complex medical condition and recommends improvements to the level of service that patients can expect from the NHS and social care services.

There will now be a period of implementation, which could take several years as we work collaboratively with colleagues in the NHS and social care to ensure positive change is brought to existing patient pathways and new services are introduced to help more people with ME/CFS.

Implementation will involve:

- training health and social care professionals on how to employ the new recommendations,
- establishing a UK-wide network of hospital-based ME/CFS specialist services,
- making all NHS services accessible and capable of providing personalised ongoing care and support,
- ensuring that NHS and social care provision is monitored and regularly reviewed.

OVERVIEW

The NICE clinical guideline for ME/CFS provides a framework of recommendations to health and social care professionals about the pathway of patient care and it is a useful resource for patients, their carers, and families. It includes information about:



An ME Association Summary of the 2021 NICE Clinical Guideline for ME/CFS, has been written by Dr Charles Shepherd, Hon Medical Adviser, ME Association and Member of the NICE guideline committee 2019 – 2021.

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DISCLAIMER

We recommend that the medical information in this leaflet is discussed with your doctor. It is not intended to be a substitute for personalised medical advice or treatment. You should consult your doctor whenever a new symptom arises, or an existing symptom worsens. It is important to obtain medical advice that considers other causes and possible treatments. Do not assume that new or worsened symptoms are solely because of ME/CFS.



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NHS services and what patients can expect:

- shared decision-making,
- early symptom recognition,
- the diagnostic process,
- how to access secondary care specialist services and the kind of help available to better understand, cope with, and manage this complex and chronic medical condition.

It aims to improve awareness and understanding so that health and social care professionals are better informed and know what to do when someone with suspected symptoms needs an accurate diagnosis, or when someone with a diagnosis needs ongoing care to help them live with ME/CFS.

The guideline is appropriate for children, young people, and adults – and includes specific recommendations for people with severe and very severe ME/CFS, an addition that is especially welcome.

The guideline also includes recommendations that cover:

- monitoring and ongoing reviews,
- recognising and managing relapses,
- dealing with education and employment,
- recognising safeguarding concerns,
- the provision of disability aids and adaptations,
- needs assessments and social care.

We realise that not everyone can follow or absorb a lot of information, so we have featured key recommendations from the guideline in this booklet.

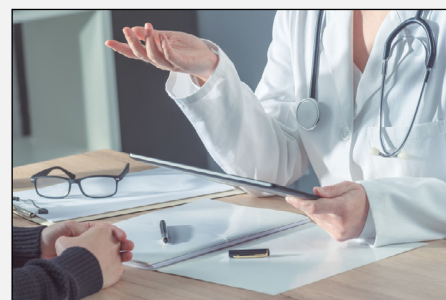
We also suggest that you refer to relevant sections from the guideline when you have an appointment with your GP or an ME/CFS specialist service.

We recommend that people with ME/CFS and those who care for them become familiar with the guideline, because its content will affect the services that should be available in England, Wales and Northern Ireland - once the recommendations are implemented.

The complete clinical guideline covers 87 pages. You can download the complete version of the clinical guideline from the NICE website:

<https://www.nice.org.uk/guidance/ng206/chapter/Recommendations>

- or you can review the key information that we have selected from the guideline, below.



“We now have a guideline that has properly recognised this complex medical condition and recommends improvements to the level of service that patients can expect from the NHS and social care services”

Please note: The information on the pages that follow are extracts taken from the clinical guideline and may not entirely reflect the ME Association’s position on certain issues.

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THE NICE CLINICAL GUIDELINE FOR ME/CFS

The recommendations contained in this clinical guideline are applicable to anyone with ME/CFS regardless of symptom severity. It also contains additional considerations in the section on care for people with severe or very severe ME/CFS.

The following definitions of illness severity are not clear cut because individual symptoms vary widely in severity and people may have some symptoms more severely than others. These definitions provide a guide to the level of impact that symptoms can have on everyday functional ability.

ME = Myalgic Encephalomyelitis or Encephalopathy

CFS = Chronic Fatigue Syndrome

MILD ME/CFS

People with mild ME/CFS care for themselves and do some light domestic tasks (sometimes needing support) but may have difficulties with mobility. Most are still working or in education, but to do this they have probably stopped all leisure and social pursuits. They often have reduced hours, take days off and use the weekend to cope with the rest of the week.

MODERATE ME/CFS

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

SEVERE ME/CFS

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

VERY SEVERE ME/CFS

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

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FEATURED EXTRACTS FROM THE 2021 NICE CLINICAL GUIDELINE FOR ME/CFS (NG206).

A. GENERAL INFORMATION

AWARENESS AND IMPACT

Be aware that ME/CFS:

- is a complex, chronic medical condition affecting multiple body systems. The pathophysiology is still being investigated,
- affects everyone differently – 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.

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. Health professionals must take into account:

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

APPROACH TO DELIVERING CARE

Health and social care professionals should:

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



“Recognise that people with ME/CFS may have experienced prejudice and disbelief and could feel stigmatised by people who do not understand their illness”

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PEOPLE WITH ME/CFS NEED:

- a 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.

ACCESS TO CARE AND SUPPORT

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

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

If a person with ME/CFS misses an appointment:

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

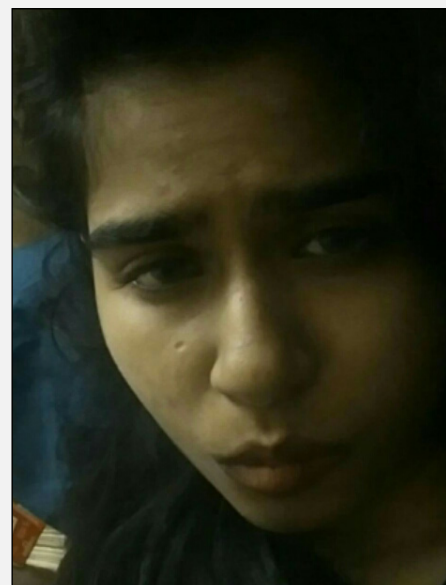
BE AWARE THAT PEOPLE WITH ME/CFS ARE UNLIKELY TO BE SEEN AT THEIR WORST BECAUSE:

- debilitating symptoms or the risk that their symptoms will worsen may prevent people from leaving their home
- cognitive difficulties may often mean people wait until they feel they can speak and explain clearly before contacting services.

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,



“Be sensitive to the person’s socioeconomic, cultural, and ethnic background, beliefs and values, and their gender identity and sexual orientation”



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

HOSPITAL CARE

Also see section below about severe and very severe ME/CFS.

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

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

B. SYMPTOMS AND DIAGNOSIS

SUSPECT ME/CFS IF:

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

ALL OF THE FOLLOWING FOUR SYMPTOMS SHOULD BE PRESENT:

- Debilitating fatigue that is worsened by activity,
- Post exertional malaise/symptom exacerbation,
- Unrefreshing sleep and/or sleep disturbance,
- Cognitive dysfunction.



“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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OTHER SYMPTOMS THAT MAY BE PRESENT INCLUDE:

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

INVESTIGATIONS TO EXCLUDE OTHER DIAGNOSES:

- urinalysis for protein, blood, and glucose,
- full blood count,
- urea and electrolytes,
- liver function,
- thyroid function,
- erythrocyte sedimentation rate or plasma viscosity,
- C-reactive protein,
- calcium and phosphate,
- HbA1c,
- serum ferritin,
- coeliac disease screening,
- creatine kinase.

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



“Doctors should use their clinical judgement to decide on additional investigations to exclude other diagnoses”

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ADVICE FOR PEOPLE WITH SUSPECTED ME/CFS

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

- not to use more energy than they perceive they have - they should manage their daily activity and not 'push through' their symptoms,
- to rest and convalesce as needed - this might mean making changes to their daily routine, including work, school, and other activities.

Explain to people with suspected ME/CFS that their diagnosis can only be confirmed after three months of persistent symptoms. Reassure them that they can return for a review before that if they develop new or worsened symptoms and ensure that they know who to contact for advice.

DIAGNOSIS

Diagnose ME/CFS in a child, young person or adult who has the above 4 symptoms where they have persisted for 3 months and are not explained by another condition.

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

Refer adults directly to an ME/CFS specialist team to confirm their diagnosis and develop a care and support plan.

Refer children and young people who have been diagnosed with ME/CFS after assessment by a paediatrician directly to a paediatric ME/CFS specialist team to confirm their diagnosis and develop a care and support plan.

C. REFERRAL TO AN ME/CFS SPECIALIST TEAM

Also see section below about severe and very severe ME/CFS.

ASSESSMENT, CARE, AND SUPPORT PLANNING BY AN ME/CFS SPECIALIST TEAM

Carry out and record a holistic assessment to confirm the person's diagnosis of ME/CFS and inform their care and support plan and which should then be used to create an individual care and support plan. This should include:



“Rest and convalesce as needed - this might mean making changes to daily routines, including work, school, and other activities”

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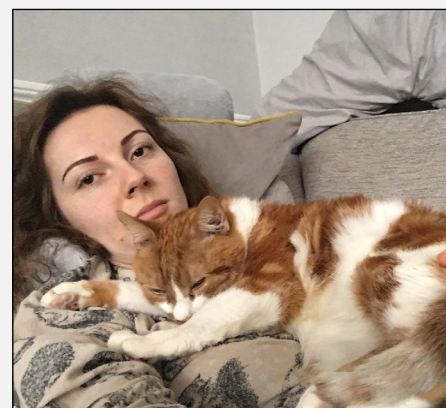
- a medical assessment (including relevant symptoms and history, comorbidities, overall physical and mental health, anything that is known to exacerbate or alleviate symptoms, and sleep quality),
- physical functioning,
- the impact of symptoms on psychological, emotional, and social wellbeing,
- current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

Develop and agree a personalised care and support plan with the person with ME/CFS and their family or carers informed by their holistic assessment. This should include the following, depending on the person's needs:

- information and support needs,
- support for activities of daily living,
- mobility and daily living aids and adaptations to increase or maintain independence,
- education, training, or employment support needs,
- self-management strategies, including energy management
- physical functioning and mobility,
- managing ME/CFS and symptom management, including medicines,
- guidance on managing flare-ups and relapses,
- details of the health and social care professionals involved in the person's care, and who to contact.

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

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



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

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THE ME/CFS SPECIALIST TEAM

Specialist teams [should] consist of a range of healthcare professionals with training and experience in assessing, diagnosing, treating, and managing ME/CFS.

They [should] 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.

■ To find an ME/CFS specialist service near to where you live, visit the ME Association website, and enter your postcode or location:

<https://meassociation.org.uk/nhs-me-cfs-specialist-services/>

Please note: ME/CFS specialist services are not available in all areas – especially those outside of England – although we hope this will improve as the guideline is implemented.

■ Your GP should know more about suitable referrals in your area or be able to provide ongoing care and support themselves.

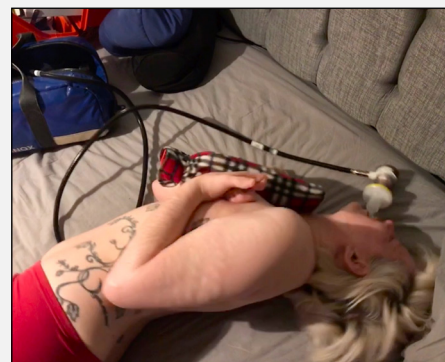
■ You can be referred to a specialist service outside of your area, providing of course that you are able to travel without it affecting your health.

■ Some services are providing home visits for people severely and very-severely affected, and remote access to some elements of the service, but this is not a widespread practice at present.

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 and relapses,
- activities of daily living, including dental health,
- psychological, emotional, and social wellbeing, including family and sexual relationships,
- diet and nutrition,



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- 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/CFS specialist team.

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.

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

PRIMARY CARE REVIEWS

- Offer adults with ME/CFS a review of their care and support plan in primary care at least once a year,
- Offer children and young people with ME/CFS a review of their care and support plan at least every 6 months,
- 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.

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

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 their symptoms, including whether they have experienced new symptoms,
- self-management - ask about their energy management plan and (if relevant) their physical activity or exercise programme,
- who is helping them and how they provide support,



“Care for people whose ME/CFS is managed in primary care should be supported by advice and direct clinical consultation from an ME/CFS specialist team”



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- 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.

D. MANAGEMENT

Also see section below about severe and very severe ME/CFS.

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

ENERGY AND ACTIVITY MANAGEMENT

Health professionals should discuss the principles of energy management, the potential benefits and risks and what people with ME/CFS should expect. Explain that this:

- is a self-management strategy led by the person themselves with support from a healthcare professional in an ME/CFS specialist team,
- includes all types of activity (cognitive, physical, emotional, and social) and takes into account overall level of activity,
- helps people learn to use the amount of energy they have while reducing their risk of post-exertional malaise or worsening their symptoms by exceeding their limit,
- recognises that each person has a different and fluctuating energy limit and they are experts in judging their own limits,
- can include help from a healthcare professional to recognise when they are approaching their limit - children and young people in particular may find it harder to judge their limits and can overreach them,



“Health professionals should discuss the principles of energy management, the potential benefits and risks and what people with ME/CFS should expect”

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- uses a flexible, tailored approach so that activity is never automatically increased but is maintained or adjusted - upwards after a period of stability or downwards when symptoms are worse,

- is a long-term approach - it can take weeks, months or sometimes even years to reach stabilisation or to increase tolerance or activity.

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

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

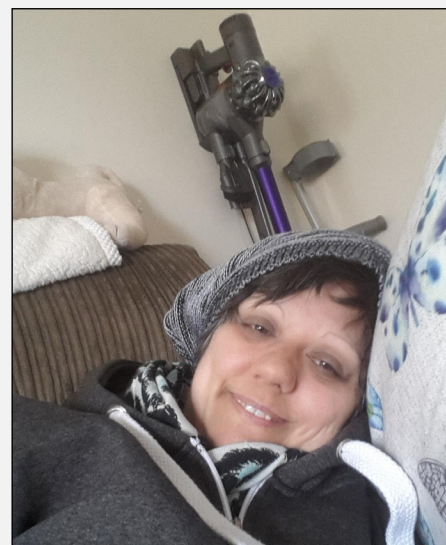
Work with the person to establish an individual activity pattern within their current energy limits that minimises their symptoms. For example:

- agree a sustainable level of activity as the first step, which may mean reducing activity,
- plan periods of rest and activity and incorporate the need for pre-emptive rest,
- alternate and vary between different types of activity and break activities into small chunks.

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

Advise people with ME/CFS how to manage flare-ups and relapses.

Make self-monitoring of activity as easy as possible by taking advantage of tools such as an activity tracker, phone heart-rate monitor or diary.



“Help people with ME/CFS develop a plan for energy management as part of their care and support plan”



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Refer people with ME/CFS to a physiotherapist or occupational therapist working in an ME/CFS specialist team if they:

- have difficulties caused by reduced physical activity or mobility
- feel ready to progress their physical activity beyond their current activities of daily living or
- would like to incorporate a physical activity or exercise programme into managing their ME/CFS.

INCORPORATING PHYSICAL ACTIVITY AND EXERCISE

Do not advise people with ME/CFS to undertake exercise that is not part of a programme overseen by an ME/CFS specialist team, such as telling them to go to the gym or exercise more, because this may worsen their symptoms.

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

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

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

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

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

- Establishing their physical activity baseline at a level that does not worsen their symptoms,
- initially reducing physical activity to be below their baseline level,
- maintaining this successfully for a period of time before attempting to increase it,



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

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- making flexible adjustments to their physical activity (up or down as needed) to help them gradually improve their physical abilities while staying within their energy limits,
- recognising a flare-up or relapse early and outlining how to manage it.

DO NOT OFFER PEOPLE WITH ME/CFS:

- any therapy based on physical activity or exercise as a cure for ME/CFS,
- generalised physical activity or exercise programmes – this includes programmes developed for healthy people or people with other illnesses,
- any programme that does not follow the approach in this guideline or that uses fixed incremental increases in physical activity or exercise, for example, graded exercise therapy,
- physical activity or exercise programmes that are based on deconditioning and exercise avoidance theories as perpetuating ME/CFS.

SYMPTOM MANAGEMENT FOR PEOPLE WITH ME/CFS

As with many other NICE guidelines, information on the management of specific symptoms such as orthostatic intolerance, pain, and sleep disturbance is largely by way of referral to another NICE guideline covering this symptom.

REST AND SLEEP

Advise people with ME/CFS:

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

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

- explaining the role and effect of sleep disturbance in ME/CFS,



“Advise people with ME/CFS that rest periods are part of all management strategies for ME/CFS”



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- identifying the common changes in sleep patterns seen in ME/CFS, such as broken or shallow sleep, altered sleep pattern or hypersomnia (= increased sleep requirements),
- developing good sleep habits,
- taking into account the need for rest in the day, and balancing this against how the person is sleeping at night,
- introducing changes to sleep patterns gradually.

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

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

PHYSICAL FUNCTIONING AND MOBILITY

Include strategies to maintain and prevent deterioration of physical functioning and mobility in the care and support plans of people with ME/CFS.

These strategies may need to be carried out in small amounts and spread out throughout the day. Think about including the following:

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

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

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

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



“Give people with ME/CFS and their family or carers information, advice, and support on how to recognise and prevent possible complications of long-term immobility”

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

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

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

MEDICINES

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

MEDICINES FOR SYMPTOM MANAGEMENT

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

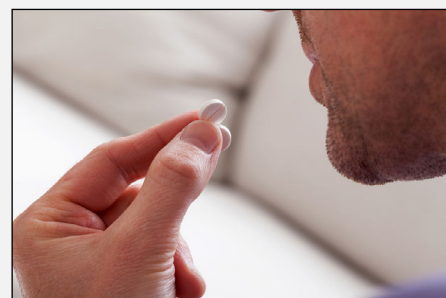
- starting medicines at a lower dose than in usual clinical practice
- gradually increasing the dose if the medicine is tolerated.

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

DIETARY MANAGEMENT AND STRATEGIES

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

Work with the person and their family or carers (as appropriate) to find ways of minimising complications caused by



“Be aware that people with ME/CFS may be at risk of vitamin D deficiency, especially those who are housebound or bedbound”

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gastrointestinal symptoms (such as nausea), changes to appetite, swallowing difficulties, sore throat, or difficulties with buying, preparing and eating food.

Encourage people with ME/CFS who have nausea to keep up adequate fluid intake and advise them to try to eat regularly, taking small amounts often. Explain that not eating or drinking may increase their nausea.

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

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

Be aware that people with ME/CFS may be at risk of vitamin D deficiency, especially those who are housebound or bedbound.

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

LIGHTNING PROCESS

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

COGNITIVE BEHAVIOUR THERAPY

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

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

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

- involve parents or carers (as appropriate) in the therapy wherever possible



“CBT should only be offered to support people who live with ME/CFS to manage their symptoms, improve their functioning, and reduce the distress associated with having a chronic illness”



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- adapt the therapy to the child or young person's cognitive and emotional stage of development.

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

EXPLAIN THAT CBT FOR PEOPLE WITH ME/CFS:

- aims to improve their quality of life, including functioning, and reduce the distress associated with having a chronic illness
- does not assume people have 'abnormal' illness beliefs and behaviours as an underlying cause of their ME/CFS, but recognises that thoughts, feelings, behaviours, and physiology interact with each other.

E. CARE FOR PEOPLE WITH SEVERE AND VERY SEVERE ME/CFS

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

ADDITIONAL SYMPTOMS

Be aware that people with severe or very severe ME/CFS may experience 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, sound, touch, movement, temperature extremes and smells,
- extreme weakness, with severely reduced movement,
- reduced ability or inability to speak or swallow,
- cognitive difficulties that limit the person's ability to communicate and take in written or verbal communication,
- sleep disturbance such as unrefreshing sleep, hypersomnia and altered sleep pattern,
- gastrointestinal difficulties such as nausea, incontinence, constipation, and bloating,
- neurological symptoms such as double vision and other visual disorders, dizziness,



“People with severe or very severe ME/CFS may experience symptoms that significantly affect their lives, including their mobility, emotional wellbeing, and ability to interact with others and care for themselves”



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■ orthostatic intolerance and autonomic dysfunction, such as postural orthostatic tachycardia syndrome (POTS) and postural hypotension.

SYMPTOM IMPACT

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

- need a low-stimulus environment, for example a dark quiet room with interaction at a level of their choice (this may be little or no social interaction),
- are housebound or bedbound and may need support with all activities of daily living, including aids and adaptations to assist mobility and independence in activities of daily living (for example, a wheelchair),
- need careful physical contact when supported with activities of daily living, taking into account possible sensitivity to touch,
- cannot communicate without support and may need to choose someone to be their advocate and communicate for them,
- are unable to eat and digest food easily and may need support with hydration and nutrition,
- 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.

PERSONAL CARE AND SUPPORT

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

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

Risk assess each interaction with a person with severe or very severe ME/CFS in advance to ensure its benefits will outweigh the risks (for example, worsening their symptoms) to the person.



“Symptoms of severe or very severe ME/CFS may mean that people are housebound or bedbound and may need support with all activities of daily living”

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For people with very severe ME/CFS, think about discussing this with the person's family or carers on their behalf (if appropriate), while keeping the focus of the engagement on the person with ME/CFS.

ASSESSMENT, CARE, AND SUPPORT PLANNING BY AN ME/CFS SPECIALIST TEAM

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

ACCESS TO CARE AND SUPPORT

Service providers should be proactive and flexible in delivering services to people with severe or very severe ME/CFS, who may have particular difficulty accessing services and articulating their needs.

This could include home visits, online or phone consultations, supplying written communication, and supporting their applications for aids and appliances.

HOSPITAL CARE

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

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



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



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- keeping lights dimmed,
- reducing sound,
- keeping a stable temperature,
- minimising smells.

MANAGING ME/CFS

Also see the main section on managing ME/CFS.

ENERGY MANAGEMENT

Also see the main section on energy management.

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

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

SYMPTOM MANAGEMENT

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

DIETARY MANAGEMENT AND STRATEGIES

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

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

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



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

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

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

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

COGNITIVE BEHAVIOURAL THERAPY

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

F. MAINTAINING INDEPENDENCE AND SOCIAL CARE

MAINTAINING INDEPENDENCE

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

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



“If a person with ME/CFS needs support at home, carry out a social care needs assessment. Discuss sensitively with the person and their family or carers how social care may benefit them”



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AIDS AND ADAPTATIONS

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.

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

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

SOCIAL CARE

- Discuss sensitively with the person and their family or carers (as appropriate) how social care may benefit them. Explain that it can help the person living with ME/CFS as well as provide a route to support for families and carers through a formal carer's assessment.
- Explain to people with ME/CFS and their family or carers (as appropriate) how to self-refer for a social care needs assessment from their local authority. The healthcare professional should offer to make the referral for them if they prefer.
- Advise children and young people with moderate ME/CFS or severe or very severe ME/CFS and their parents or carers (as appropriate) that they may be entitled to support from children's social care as children in need because of their disability.

G. SAFEGUARDING CHILDREN, YOUNG PEOPLE, AND ADULTS WITH ME/CFS

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.

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



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

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

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

- physical symptoms that do not fit a commonly recognised illness pattern
- more than 1 child or family member having ME/CFS
- disagreeing with, declining, or withdrawing from any part of their care and support plan, either by them or by their parents or carers on their behalf
- parents or carers acting as advocates and communicating on their behalf
- reduced or non-attendance at school.

Be aware that recognising and responding to possible child abuse and neglect (maltreatment) is complex and should be considered in the same way for children and young people with confirmed or suspected ME/CFS as with any child with a chronic illness or disability.

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

H. SUPPORTING PEOPLE WITH ME/CFS IN WORK, EDUCATION, AND TRAINING

Offer to liaise on the person's behalf (with their informed consent) with employers, education providers and support services.

Give them information about ME/CFS and discuss the person's care and support plan and any adjustments needed.

Advise and discuss with people with ME/CFS that:

- they may be able to access reasonable adjustments or adaptations (in line with the Equality Act 2010) to help them continue or return to work or education
- there may be times when they are unable to continue with work or education



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



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

Health and social care professionals should follow the Department for Education's guidance on supporting pupils at school with medical conditions or equivalent statutory guidance.

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

- provide information about ME/CFS and the needs and impairments of children and young people with ME/CFS, including the need for a balance of activities in their life,
- discuss the child or young person's care and support plan so that everyone has a common understanding of their priorities, hopes and plans,
- discuss a flexible approach to training and education – this could include adjustments to the school day, online learning or education at home and using assistive equipment.

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

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

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

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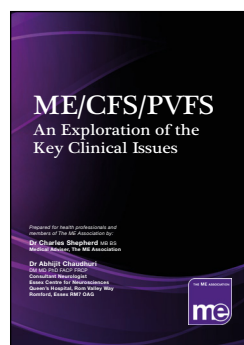
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