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Quick reference guide

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Chronic fatigue syndrome/myalgic encephalomyelitis (or encephalopathy)

Diagnosis and management of CFS/ME in adults and children

NICE clinical guideline 53
Developed by the National Collaborating Centre for Primary Care

About this booklet

This is a quick reference guide that summarises the recommendations NICE has made to the NHS in 'Chronic fatigue syndrome/myalgic encephalomyelitis (or encephalopathy): diagnosis and management of CFS/ME in adults and children' (NICE clinical guideline 53).

Who should read this booklet?

This quick reference guide is for GPs, other staff in primary care, and specialist healthcare professionals who care for people with CFS/ME.

Who wrote the guideline?

The guideline was developed by the National Collaborating Centre for Primary Care, which is based at the Royal College of General Practitioners. The Collaborating Centre worked with a group of healthcare professionals (including consultants, GPs, occupational therapists, clinical psychologists and physiotherapists), patients and technical staff, who reviewed the evidence and drafted the recommendations. The recommendations were finalised after public consultation.

For more information on how NICE clinical guidelines are developed, go to www.nice.org.uk

Where can I get more information about the guideline?

The NICE website has the recommendations in full, reviews of the evidence they are based on, a summary of the guideline for patients and carers, and tools to support implementation (see inside back cover for more details).

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This guidance is written in the following context

This guidance represents the view of the Institute, which was arrived at after careful consideration of the evidence available. Healthcare professionals are expected to take it fully into account when exercising their clinical judgement. The guidance does not, however, override the individual responsibility of healthcare professionals to make decisions appropriate to the circumstances of the individual patient, in consultation with the patient and/or guardian or carer.

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Introduction

Chronic fatigue syndrome/myalgic encephalomyelitis (or encephalopathy) (CFS/ME) is a relatively common illness: a general practice with 10,000 patients is likely to have up to 40 patients with CFS/ME. The physical symptoms can be as disabling as multiple sclerosis, systemic lupus erythematosus, rheumatoid arthritis and other chronic conditions.

CFS/ME involves a complex range of symptoms that includes fatigue, malaise, headaches, sleep disturbance, difficulties with concentration and muscle pain. The pattern and intensity of symptoms vary between people, and during the course of each person's illness. People often have symptoms for many years before CFS/ME is diagnosed.

The causes and disease processes of CFS/ME are still not understood, but this guideline provides practical recommendations that can help people to manage the condition, with the aim of maintaining and – if possible – extending their physical, emotional and cognitive capacity. Different combinations of approaches will be helpful for different people.

Key elements of management include:

- working in partnership with the person with CFS/ME
- identifying and managing symptoms early
- making an accurate diagnosis and considering alternative diagnoses and comorbidities.

Words printed in **bold** are defined in the key to terms on pages 21 and 22.

Managing severe CFS/ME is difficult and complex, and specialist advice is needed. Recommendations specifically for people with severe CFS/ME are highlighted in green.

Key priorities for implementation

General principles of care

- Shared decision-making between the person with CFS/ME and healthcare professionals should take place during diagnosis and all phases of care. The healthcare professional should:
  - Acknowledge the reality and impact of the condition and the symptoms.
  - Provide information about the range of interventions and management strategies as detailed in this guideline (such as the benefits, risks and likely side effects).
  - Provide information on the possible causes, nature and course of CFS/ME.
  - Provide information on returning to work or education.
  - Take account of the person's age (particularly for children younger than 12 years), the severity of their CFS/ME, their preferences and experiences, and the outcome of previous treatment(s).
  - Offer information about local and national self-help groups and support groups for people with CFS/ME and their carers (see also the NHS Expert Patients Programme[1]).
- Healthcare professionals should be aware that – like all people receiving care in the NHS – people with CFS/ME have the right to refuse or withdraw from any component of their care plan without this affecting other aspects of their care, or future choices about care.
- To facilitate effective management of the condition, healthcare professionals should aim to establish a supportive and collaborative relationship with the person with CFS/ME and their carers. Engagement with the family is particularly important for children and young people, and for people with severe CFS/ME.
- Healthcare professionals should provide diagnostic and therapeutic options to people with CFS/ME in ways that are suitable for the individual person. This may include providing domiciliary services (including specialist assessment) or using methods such as telephone or email.

Diagnosis and initial management

- Advice on symptom management should not be delayed until a diagnosis is established. This advice should be tailored to the specific symptoms the person has and be aimed at minimising their impact on daily life and activities.
- A diagnosis should be made after other possible diagnoses have been excluded and the symptoms have persisted for:
  - 4 months in an adult
  - 3 months in a child or young person; the diagnosis should be made or confirmed by a paediatrician.

[1] For more information see www.expertpatients.nhs.uk or www.eppwales.org

- Healthcare professionals should proactively advise about fitness for work and education, and recommend flexible adjustments or adaptations to work or studies to help people with CFS/ME to return to them when they are ready and fit enough. This may include, with the informed consent of the person with CFS/ME, liaising with employers, education providers and support services, such as:
  - occupational health services
  - disability services through Jobcentre Plus
  - schools, home education services and local education authorities
  - disability advisers in universities and colleges.

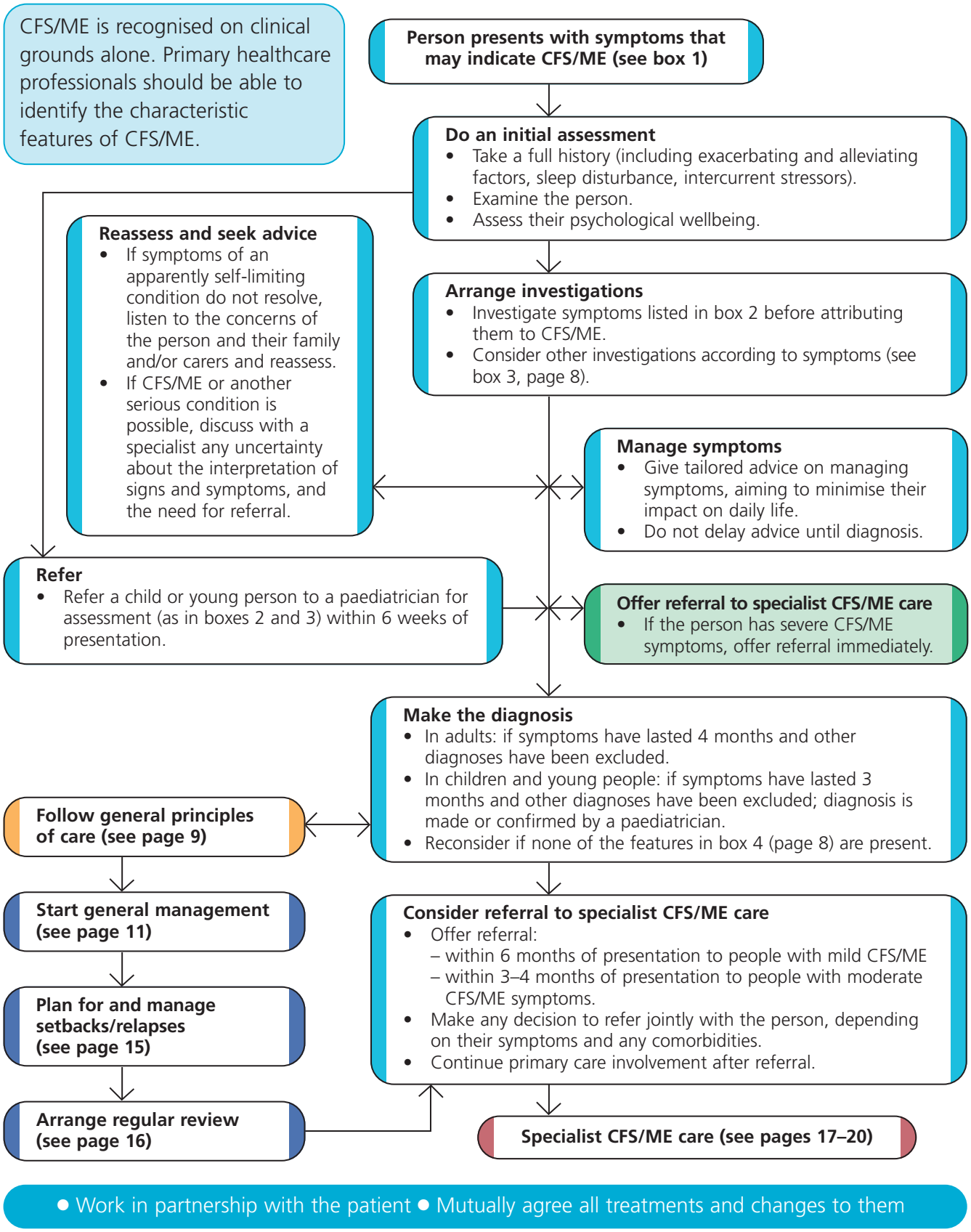
Specialist CFS/ME care

- Any decision to refer a person to specialist CFS/ME care should be based on their needs, the type, duration, complexity and severity of their symptoms, and the presence of comorbidities. The decision should be made jointly by the person with CFS/ME and the healthcare professional.
- An individualised, person-centred programme should be offered to people with CFS/ME. The objectives of the programme should be to:
  - sustain or gradually extend, if possible, the person's physical, emotional and cognitive capacity
  - manage the physical and emotional impact of their symptoms.
- Cognitive behavioural therapy and/or graded exercise therapy should be offered to people with mild or moderate CFS/ME and provided to those who choose these approaches, because currently these are the interventions for which there is the clearest research evidence of benefit.

Patient-centred care

Treatment and care should take into account patients' individual needs and preferences. Good communication is essential, supported by evidence-based information, to allow patients to reach informed decisions about their care. Follow Department of Health advice on seeking consent if needed. Where appropriate, and if the patient agrees, families and carers should have the opportunity to be involved in decisions about treatment and care. Transitional care should be planned and managed as described in 'Transition: getting it right for young people' (available from www.dh.gov.uk).

Presentation, diagnosis and pathway of care



Box 1 Symptoms that may indicate CFS/ME

Consider the possibility of CFS/ME if a person has:

- fatigue with all of the following features:
  - new or had a specific onset (that is, it is not life long)
  - persistent and/or recurrent
  - unexplained by other conditions
  - has resulted in a substantial reduction in **activity** level characterised by post-exertional malaise and/or fatigue (typically delayed, for example by at least 24 hours, with slow recovery over several days)

and

- one or more of the following symptoms:
  - difficulty with sleeping, such as insomnia, hypersomnia, unrefreshing sleep, a disturbed sleep–wake cycle
  - muscle and/or joint pain that is multi-site and without evidence of inflammation
  - headaches
  - painful lymph nodes without pathological enlargement
  - sore throat
  - cognitive dysfunction, such as difficulty thinking, inability to concentrate, impairment of short-term memory, and difficulties with word-finding, planning/organising thoughts and information processing
  - physical or mental exertion makes symptoms worse
  - general malaise or 'flu-like' symptoms
  - dizziness and/or nausea
  - palpitations in the absence of identified cardiac pathology.

The symptoms of CFS/ME fluctuate in severity and may change in nature over time.

Box 2 Consider other diagnoses or comorbidities before attributing clinical features to CFS/ME

In particular, investigate these 'red flag' features:

- localising/focal neurological signs
- signs and symptoms of inflammatory arthritis or connective tissue disease
- signs and symptoms of cardiorespiratory disease
- significant weight loss
- sleep apnoea
- clinically significant lymphadenopathy.

Follow 'Referral guidelines for suspected cancer' (NICE clinical guideline 27) or other NICE guidelines as the symptoms indicate. See www.nice.org.uk for details.

● Be prepared to reassess the diagnosis ● Investigate significant symptoms

Box 3 Investigations

These tests should usually be done:

- 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
- random blood glucose
- serum creatinine
- screening blood tests for gluten sensitivity
- serum calcium
- creatine kinase
- assessment of serum ferritin levels (children and young people only).

Use clinical judgement to decide on additional tests to exclude other diagnoses.

Do not do:

- tests for serum ferritin in adults, unless other tests suggest iron deficiency
- tests for vitamin B_{12} deficiency or folate levels, unless a full blood count and mean cell volume show a macrocytosis
- serological testing, unless there is an indicative history of an infection; if so, consider tests for:
  - chronic bacterial infections, such as borreliosis
  - chronic viral infections, such as HIV or hepatitis B or C
  - acute viral infections, such as infectious mononucleosis (heterophile antibody tests)
  - latent infections, such as toxoplasmosis, Epstein–Barr virus or cytomegalovirus.

Do not do the following tests routinely:

- the head-up tilt test
- auditory brainstem responses
- electrodermal conductivity.

Box 4 Reconsider the diagnosis of CFS/ME

- Reconsider the diagnosis if the person has none of the following symptoms:
  - post-exertional fatigue or malaise
  - cognitive difficulties
  - sleep disturbance
  - chronic pain.

● Work in partnership with the patient ● Mutually agree all treatments and changes to them

General principles of care

Shared decision-making

- Share decision-making with the person with CFS/ME during diagnosis and all phases of care.
  - Acknowledge the reality and impact of the condition and the symptoms.
  - Provide information about the range of interventions and management strategies covered in this guideline, including their benefits and risks.
  - Take account of the person's **age** (particularly for children younger than 12 years), the **severity** of their CFS/ME, their preferences and experiences, and the outcome of previous treatment(s).
- For children and young people, follow the national service frameworks for children for England (www.dh.gov.uk) or for Wales (www.wales.nhs.uk).
- Be aware that people with CFS/ME have the right to refuse or withdraw from any component of their care plan without this affecting the provision of other aspects of their care or future choices about care.
- Recognise that the person with CFS/ME is in charge of the aims of the overall management plan, and mutually agree the pace of progression through any intervention.
- Provide diagnostic and therapeutic options in ways that are suitable for the individual person; for example:
  - domiciliary services (including specialist assessment)
  - using telephone or email.

Support and information

- Establish a supportive and collaborative relationship with the person with CFS/ME and their carers. This is particularly important for children and young people, and for people with severe CFS/ME.
- Assign a named healthcare professional to be responsible for coordinating the person's care.
- Provide accurate information at all stages, from when a diagnosis is first being considered.
- Tailor information to the person's circumstances, including the **stage** and duration of the condition, symptoms, and personal and social factors.
- Make information available in a variety of formats if appropriate (printed copy, electronic and audio).
- Information should cover:
  - possible causes, nature and course of CFS/ME
  - returning to work or education
  - local and national self-help and support groups for people with CFS/ME and their carers
  - the NHS Expert Patients Programme (see www.expertpatients.nhs.uk or www.eppwales.org).

● Be prepared to reassess the diagnosis ● Investigate significant symptoms

Information about CFS/ME

- Give honest, realistic information about CFS/ME at diagnosis. Encourage cautious optimism.
  - Most people with CFS/ME will improve over time and some will recover and be able to resume work and normal activities.
  - However, others will continue to experience symptoms or relapse and some people with severe CFS/ME may remain housebound.
  - The prognosis in children and young people is more optimistic.

Provision of care

- Healthcare professionals caring for people with CFS/ME should have appropriate skills and expertise in the condition.
- Offer every person diagnosed with CFS/ME:
  - acceptance and understanding
  - help negotiating the healthcare, benefits and social care systems
  - help with occupational activities, including work and education if appropriate (see page 12).
- Develop an individualised management plan with the person, and their carers if appropriate, including:
  - relevant symptoms and history
  - plans for care and treatment, including managing **setbacks/relapses**
  - information and support needs
  - any education, training or employment support needs
  - details (and contact details) of the healthcare professionals involved.
- Review the plan at each contact and document any changes.

Additional principles of care for people with severe CFS/ME

- Specialist expertise is needed when planning and providing care for people with severe CFS/ME.
- Diagnosis, investigations, management and follow-up care should be supervised or supported by a specialist in CFS/ME.
- People with severe CFS/ME may need to use community services including nursing, occupational therapy, dietetics, respite care, psychology and physiotherapy (see the 'National service framework for long-term conditions'; www.dh.gov.uk). A named professional should coordinate this.
- Offer a summary record of every consultation to people with severe CFS/ME because of their cognitive difficulties.
- Most people with CFS/ME will not need hospital admission. However, a planned admission may be useful, for example, if an assessment or series of investigations would require frequent visits to the hospital. The decision to admit should be made with the person and their family.

● Work in partnership with the patient ● Mutually agree all treatments and changes to them

General management strategies after diagnosis

Symptom management

- Manage symptoms of CFS/ME as in usual clinical practice.
- If a person with CFS/ME is concerned about adverse/side effects of drug treatment, consider starting at a lower dose than usual, and increasing this gradually, in agreement with the person. (However, no research evidence was found of greater drug intolerance or more severe adverse/side effects among people with CFS/ME.)
- Specific drug treatment for children and young people should be started by a paediatrician. It may be continued in primary care, depending on the preferences of the child or young person and their carers, and local circumstances.
- Manage nausea conventionally, with advice on eating little and often, snacking on dry starchy foods and sipping fluids. Consider anti-emetic drugs only if the nausea is severe.
- Exclusion diets are not generally recommended for CFS/ME, but many people find them helpful in managing symptoms, including bowel symptoms. If a person with CFS/ME undertakes an exclusion diet or dietary manipulation, seek advice from a dietitian because of the risk of malnutrition.

Function and quality-of-life management

Sleep management

- Provide tailored sleep management advice about:
  - the role and effect of disordered sleep or sleep dysfunction in CFS/ME
  - common changes in sleep patterns seen in CFS/ME that may exacerbate fatigue (such as insomnia, hypersomnia, sleep reversal, altered sleep–wake cycle and non-refreshing sleep)
  - sleep hygiene
  - introducing changes to sleep patterns gradually.
- Review the advice regularly.
- If sleep and rest do not improve, consider the possibility of an underlying sleep disorder or dysfunction, and provide interventions if required.
- Do not encourage daytime sleeping and naps. Explain that excessive daytime sleep or frequent napping may further disrupt the sleep–wake cycle without improving physical or mental functioning.

Rest periods

- Advise people with CFS/ME on the role of rest, how to introduce **rest periods** into their routine, and their frequency and length. Advice may include:
  - limiting the rest periods to 30 minutes at a time
  - introducing 'low level' physical and cognitive activities (depending on the severity of symptoms)
  - using relaxation techniques (see below).
- Review the use of rest periods regularly.

● Be prepared to reassess the diagnosis ● Investigate significant symptoms

Bed rest for people with severe CFS/ME

- When making decisions about prolonged bed rest, seek advice from a specialist experienced in the care of people with severe CFS/ME, and take into account the physical risks (such as postural hypotension, deep venous thrombosis, osteoporosis, pressure sores and **deconditioning**), and the psychological risks.
- Explain the risks to the person, and monitor them.

Relaxation

- Offer relaxation techniques for managing pain, sleep problems and comorbid stress or anxiety. Techniques such as guided visualisation or breathing techniques can be incorporated into rest periods.

Diet

- Emphasise the importance of:
  - a well-balanced diet in line with 'The balance of good health' (www.food.gov.uk/multimedia/pdfs/bghbooklet.pdf)
  - eating regularly
  - including slow-release starchy foods in meals and snacks.
- Work with the person to develop strategies to minimise problems caused by nausea, swallowing problems or sore throat, or difficulties with buying, preparing and eating food.

Equipment to maintain independence

- For people with moderate or severe CFS/ME, consider providing or recommending equipment and adaptations (such as a wheelchair, blue badge or stairlift).
- This should be as part of an overall management plan, taking into account the risks and benefits for the individual patient, to help them to maintain their independence and improve their quality of life.

Education and employment

Having to stop work or education is generally detrimental to people's health and well-being. Address each person's ability to continue in education or work early, and review it regularly.

- Proactively advise about fitness for work and education, and recommend flexible adjustments or adaptations to help people to return to them when they are ready and fit enough.

Employment

- With the person's informed consent, liaise with:
  - employers and occupational health services
  - disability services through Jobcentre Plus.

• Work in partnership with the patient • Mutually agree all treatments and changes to them

- If possible, discuss employment issues with occupational health professionals, who will communicate with the person's manager or human resources representative. Otherwise, liaise with the employer directly[2].
- If the person is able to continue in or return to work, ensure (with the person's informed consent) that employers and occupational health staff have information on the condition and the agreed management plan.

Education

- Follow guidance from the Department for Children, Schools and Families (see www.dcsf.gov.uk) on education for children and young people with medical needs, or equivalent statutory guidance.
- With the person's informed consent, work with social care and education services (including home education services, local education authorities and disability advisers in universities and colleges) to ensure a common understanding of the person's goals.
- Discuss a flexible approach, including home tuition and using equipment that allows a gradual reintegration into education.
- Ensure educational institutions have information on CFS/ME and the agreed management plan.
- Do not use time in education as a sole marker of progress of CFS/ME, and ensure a balance between education and home and social activities.

Strategies that should not be used for CFS/ME

Do not offer people with CFS/ME:

- advice to undertake unsupervised, or unstructured, vigorous exercise (such as simply 'go to the gym' or 'exercise more') – this may worsen symptoms
- specialist management programmes (see page 17) delivered by practitioners with no experience in the condition.

- Do not use the following drugs for the treatment of CFS/ME:
  - monoamine oxidase inhibitors
  - glucocorticoids (such as hydrocortisone)
  - mineralocorticoids (such as fludrocortisone)
  - dexamphetamine
  - methylphenidate
  - thyroxine
  - antiviral agents.

[2] NHS Plus guidance on the occupational aspects of the management of CFS/ME is available from www.nhsplus.nhs.uk (search for 'chronic fatigue syndrome'). NICE is developing guidance on the management of long-term sickness and incapacity; publication is expected in December 2008 (details available from www.nice.org.uk).

● Be prepared to reassess the diagnosis ● Investigate significant symptoms

Other management approaches for CFS/ME

Treatment approach	Recommendation
• Cognitive behavioural therapy. • Graded exercise therapy. • Activity management.	• See pages 17–20.
• Encouraging maintenance of activity levels at substantially less than full capacity to reserve energy for the body to heal itself (the 'envelope theory'). • Encouraging complete rest (cognitive, physical and emotional) during a setback/relapse.	• There is considerable support for these approaches among people with CFS/ME, particularly when symptoms are severe. There is no evidence of benefit from controlled trials.
• Prolonged or complete rest or extended periods of daytime rest in response to a slight increase in symptoms. • An imposed rigid schedule of activity and rest.	• These strategies should not be used.
• **Pacing**.	• People with CFS/ME have reported pacing to be helpful in self-management. • There is not enough research evidence on the benefits or harm of pacing.
• Complementary therapies.	• Not recommended: there is not enough evidence they are effective. • However, some people find them useful for symptom control.
• Supplements such as vitamin B_{12}, vitamin C, co-enzyme Q10, magnesium, NADH (nicotinamide adenine dinucleotide) or multivitamins and minerals.	• Do not prescribe for symptoms: there is not enough evidence they are effective. • However, some people with CFS/ME report finding supplements helpful. • Advise people using supplements not to exceed the safe levels recommended by the Food Standards Agency (see www.food.gov.uk). • Some people with CFS/ME need supplements because of a restricted dietary intake or nutritional deficiencies. Seek advice from a dietitian about any concerns.

● Work in partnership with the patient ● Mutually agree all treatments and changes to them

Managing setbacks/relapses

Preparing for a setback/relapse

- Advise people with CFS/ME that setbacks/relapses are to be expected.
- Develop a plan with each person with CFS/ME for managing setbacks/relapses, so that skills, strategies, resources and support are available when needed. This plan may be shared with the person's carers, if they agree.

During a setback/relapse

- In discussion with the person, try to identify the cause(s) of a setback/relapse – for example, unexpected or unplanned activities, poor sleep, infection or stress – but recognise that this may not always be possible.
- When managing a setback/relapse, review the person's management plan. Discuss and agree a course of action, taking into account:
  - the person's experience
  - possible causes of the setback/relapse
  - the nature of the symptoms
  - the severity and duration of the setback/relapse
  - the current management plan.
- Put into place strategies that:
  - include relaxation and breathing techniques
  - maintain activity and exercise levels if possible, by alternating activities with breaks and pacing activities, as appropriate
  - involve talking to families and carers, if appropriate
  - recognise distressing thoughts such as 'this means I'll never get better', but encourage optimism
  - involve reconsidering and revising the levels and types of symptom control.
- It may be necessary to reduce, or even stop, some activities and increase the frequency and/or duration of rest periods to stabilise symptoms and re-establish a baseline activity level. Discuss this with the person.
- Advise the person to minimise daytime sleep periods, but recognise that this is not always possible.

After a setback/relapse

- Review the person's activity levels to re-establish a baseline, and review the management plan. Encourage a gradual return, when possible, to previous exercise and functional routines.
- Advise the person on:
  - slowly decreasing the frequency and duration of rest periods
  - continuing the use of relaxation techniques, even when they feel better.
- Together with the person, review the experience to determine, if possible, whether triggers can be managed in the future, and put strategies in place to do this.

● Be prepared to reassess the diagnosis ● Investigate significant symptoms

Review and ongoing management

- Do a regular, structured review of management, including, if appropriate:
  - assessing improvement or deterioration in symptoms
  - assessing any adverse or unwanted effects of therapy
  - ongoing investigations
  - considering the need to repeat investigations (for children and young people, consider repeating investigations if there is no improvement after 1 year)
  - reviewing the diagnosis, especially if signs and symptoms change (see pages 6–8)
  - considering referral to **specialist CFS/ME care**
  - reviewing equipment needs
  - assessing any additional support needs (see pages 9–12).
- The timing should depend on the severity and complexity of symptoms, the effectiveness of any interventions, and the needs of the person.

● Work in partnership with the patient ● Mutually agree all treatments and changes to them

Specialist CFS/ME care

- After referral, do an initial assessment to confirm the diagnosis.
- Continue any general management strategies that the person finds helpful.

Choosing the treatment

- Offer an individualised, person-centred programme that aims to:
  - sustain or gradually extend, if possible, the person's physical, emotional and cognitive capacity
  - manage the physical and emotional impact of their symptoms.
- Explain the rationale and content of the different programmes, including their potential benefits and risks, and that no single strategy will be successful for all people with CFS/ME, or at all stages.
- Recognise that the person is in charge of the aims of the programme. Agree together the choice of programme, its components, and progression through it, based on:
  - the person's age, preferences and needs
  - the person's skills and abilities in managing their condition, and their goals (such as improving their symptoms or treating deterioration, preventing relapse, or maintenance)
  - the severity and complexity of symptoms
  - physical and cognitive functioning.
- Offer **cognitive behavioural therapy** (CBT) and/or **graded exercise therapy** (GET) to people with mild or moderate CFS/ME, and provide them for those who choose them, because these are the interventions for which there is the clearest research evidence of benefit.
- If a full CBT or GET programme is inappropriate or not available, offer components of CBT or GET, either individually or (more effectively) together with:
  - **activity management** strategies (see page 20)
  - sleep management and relaxation techniques (see page 11).
- Review the choice of programme, its components and progression through it regularly, and agree other approaches as necessary.
- Advise the person with CFS/ME to contact you if they experience an increase in symptoms that lasts for longer than a few days after starting the programme, or if symptoms are severe or distressing.

People with severe CFS/ME

- Offer people with severe CFS/ME an individually tailored activity management programme as the core therapeutic strategy. This may:
  - be delivered at home, or using telephone or email if appropriate
  - incorporate the elements listed on page 20, and draw on the principles of CBT and GET.
- Review the programme regularly and frequently.

● Be prepared to reassess the diagnosis ● Investigate significant symptoms

Cognitive behavioural therapy (CBT)

- A course of CBT should be delivered:
  - by a healthcare professional with appropriate training in CBT and experience in CFS/ME, under clinical supervision, and with close adherence to protocols
  - one-to-one if possible.
- Plan CBT for a person with CFS/ME according to the usual principles of CBT, and include:
  - Acknowledging and validating the person's symptoms and condition.
  - Explaining the CBT approach in CFS/ME, such as the relationship between thoughts, feelings, behaviours and symptoms, and the distinction between causal and perpetuating factors.
  - Discussing the person's attitudes and expectations.
  - Developing a supportive and collaborative therapeutic relationship.
  - Developing a shared formulation and understanding of factors that affect CFS/ME symptoms.
  - Agreeing therapeutic goals.
  - Tailoring treatment to the person's needs and level of functioning.
  - Recording and analysing patterns of activity and rest, and thoughts, feelings and behaviours (self-monitoring).
  - Establishing a stable and maintainable activity level (baseline) followed by a gradual and mutually agreed increase in activity.
  - Challenging thoughts and expectations that may affect symptom improvement and outcomes.
  - Addressing complex adjustment to diagnosis and acceptance of current functional limitations.
  - Developing awareness of thoughts, expectations or beliefs and defining fatigue-related cognitions and behaviour.
  - Identifying perpetuating factors that may maintain or exacerbate CFS/ME symptoms to increase the person's self-efficacy (sense of control over symptoms).
  - Addressing any over-vigilance to symptoms and related checking or reassurance-seeking behaviours by providing physiological explanations of symptoms and using refocusing/distraction techniques.
  - Problem solving using activity management and homework tasks to test out alternative thoughts or beliefs, such as undertaking pleasure and mastery tasks (tasks that are enjoyable and give a sense of accomplishment).
  - Building on existing assertion and communication skills to set appropriate limits on activity.
  - Managing sleep problems, for example by addressing any unhelpful beliefs about sleep, behavioural approaches to sleep disturbance, stress management, and/or relaxation training (see page 11).
  - Treating any associated or comorbid anxiety, depression or mood disorder according to NICE clinical guidelines on these conditions (see page 23).
  - Offering information on managing setbacks/relapses (see page 15).

Graded exercise therapy (GET)

- GET should be delivered:
  - by a suitably trained GET therapist with experience in CFS/ME, under appropriate clinical supervision
  - one-to-one if possible.

● Work in partnership with the patient ● Mutually agree all treatments and changes to them

- Base GET on the person's current level of activities and frequency of setbacks/relapses, emotional factors, vocational or educational factors and individual goals, identified from an activity diary. Include sleep and relaxation strategies (see page 11).
- When planning GET:
  - Do an activity analysis to ensure that the person is not in a **'boom and bust' cycle**.
  - Discuss ultimate goals that are important to the person, for example a twice daily short walk to the shop, a return to cycling or gardening, or, for people with severe CFS/ME, sitting up in bed to eat a meal.
  - Take into account that it can take weeks, months or even years to achieve some goals, and set short- and medium-term goals.
  - Explain symptoms and the benefits of exercise.
- When starting GET:
  - Assess the person's current daily activities to determine their baseline.
  - Agree a level of additional low-intensity exercise that is sustainable, independent of daily fluctuations in symptoms, and does not lead to 'boom and bust' cycles; for example, sitting up in bed or brushing hair for people with severe CFS/ME, or gentle stretches or a slow walk.
  - Encourage the person to undertake this exercise for at least 5 days out of 7, or build up to this level.
  - Explain that symptoms (such as stiffness and fatigue) may increase slightly for a few days, explain why this may occur and discuss strategies to mitigate it.
  - Offer information on managing setbacks/relapses (see page 15).

Progressing with GET

- When the person can sustain the low-intensity exercise for 5 days out of 7 (usually with a reduction in perceived exertion), review the duration and increase it, if appropriate, by up to 20%. For example, a 5-minute walk becomes 6 minutes, or a person with severe CFS/ME sits up in bed for a longer period, or walks to another room more often. Aim to reach 30 minutes of low-intensity exercise.
- When the person is able to do 30 minutes' exercise, consider increasing the intensity gradually up to an aerobic heart rate zone. A rate of 50–70% of maximum heart rate is recommended. Use a heart rate monitor so that the person knows they are within their target zone.
- If the person meets agreed goals and wants to progress, and with their agreement, exercise duration and intensity may be increased further, if other daily activities can also be sustained.

Maintaining exercise

- When a person completes a GET programme, continue working with them to develop and build on strategies to maintain exercise.
- Provide support to help the person reinforce the changes made and continue GET beyond discharge.

● Be prepared to reassess the diagnosis ● Investigate significant symptoms

Activity management

- Activity management is a goal-oriented and person-centred approach tailored to the needs of the person with CFS/ME. It should include:
  - Understanding that activities have physical, emotional and cognitive components, and identifying these components.
  - Keeping a diary that records cognitive and physical activity, daytime rest and sleep. This will help to set baseline levels of activity (a stable and sustainable range of functioning), identify patterns of over- and underactivity, and develop an activity/exercise strategy.
  - Establishing a baseline; specific activities may need to be increased or decreased while this is happening.
  - Gradually increasing activity above the baseline in agreement with the person.
  - Planning daily activities to allow for a balance and variety of different types of activity, rest and sleep. This may include making a weekly activity schedule.
  - Spreading out difficult or demanding tasks over the day or week.
  - Splitting activities into small achievable tasks according to the person's level of ability/functioning, followed by gradual increases in the complexity of the tasks.
  - Monitoring, regulating and planning activities to avoid a 'boom and bust' cycle.
  - Goal setting, planning and prioritising activities.
  - Explaining the role of rest in CFS/ME and helping the person work out how to build in rest periods and achieve a productive day (see page 11).
  - Regularly reviewing activity levels and goals.
  - Offering information on the management of setbacks/relapses (see page 15).

Pharmacological interventions for symptom control

- Consider referral to a pain management clinic if pain is a predominant feature.
- Consider offering a low-dose tricyclic antidepressant (amitriptyline) for poor sleep or pain – but not if the person is already taking a selective serotonin reuptake inhibitor (SSRI) because of the potential for serious adverse interactions.
- Melatonin may be considered for children and young people with CFS/ME who have sleep difficulties, but only under specialist supervision because it is not licensed in the UK.

Key to terms

Activity Any task or series of tasks that a person performs. A task may have physical, emotional, cognitive and social components.

Activity management A person-centred, goal-directed approach to managing a person's symptoms. It uses activity analysis and graded activity to enable people to improve, evaluate, restore and/or maintain their function and well-being.

Age

- Adult: aged 18 years and older.
- Young person: aged between 12 and 17 years.
- Child: aged between 5 and 11 years.

The age at which care is transferred between child and adult health services varies between 16 and 19 years, depending on the young person and their family's preferences and local circumstances.

'Boom and bust' cycles Cycles of fluctuating activity levels and symptoms, which are a common feature of CFS/ME.

Cognitive behavioural therapy (CBT) An evidence-based psychological therapy that is a collaborative treatment approach. When it is used for CFS/ME, the aim of CBT is to reduce the levels of symptoms, disability and distress associated with the condition. The use of CBT does not assume or imply that symptoms are psychological or 'made up'. A course of CBT is usually 12–16 sessions.

Deconditioning Loss of physical fitness as the general physiological response to, for example, a prolonged period of inactivity.

Graded exercise therapy (GET) An evidence-based approach to improving a person's CFS/ME symptoms and functioning, aiming towards recovery. The first step is to set a sustainable baseline of physical activity, then the duration of the activity is gradually increased in a planned way that is tailored to the person. This is followed by an increase in intensity, when the person is able.

Pacing In this guideline, pacing is defined as energy management, with the aim of maximising cognitive and physical activity, while avoiding setbacks/relapses due to overexertion. Many of the principles are included in this guideline's recommendations on CBT, GET and activity management. The keys to pacing are knowing when to stop and rest by listening to and understanding one's own body, taking a flexible approach and staying within one's limits; different people use different techniques to do this.

However, in practice, the term pacing is used in different ways. One understanding of its meaning is as adaptive pacing therapy, facilitated by healthcare professionals. Another understanding is that pacing is a self-management strategy, without intervention from a healthcare professional. People with CFS/ME generally support this approach.

Rest periods Short periods when a person is neither sleeping nor engaged in physical or mental activity.

Setback/relapse An increase in symptoms above the usual daily fluctuations, which may result in a reduction in function for a time.

Severity

- People with **mild CFS/ME** 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, and often take days off.
- People with **moderate CFS/ME** 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. Their sleep at night is generally poor quality and disturbed.
- People with **severe CFS/ME** are unable to do any activity for themselves, or can carry out minimal daily tasks only (such as face washing, cleaning teeth). They have severe cognitive difficulties and 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.

Specialist CFS/ME care A service providing expertise in assessing, diagnosing and advising on the clinical management of CFS/ME, including symptom control and specific interventions. Ideally this is provided by a multidisciplinary team, which may include GPs with a special interest in the condition, neurologists, immunologists, specialists in infectious disease, paediatricians, nurses, clinical psychologists, liaison psychiatrists, dietitians, physiotherapists and occupational therapists.

Stage There are different stages in the natural course of CFS/ME: acute illness, maintenance or stabilisation, and recovery.

Implementation

NICE has developed tools to help organisations implement this guidance (listed below). These are available on our website (www.nice.org.uk/CG053).

- Slides highlighting key messages for local discussion.
- Implementation advice on how to put the guidance into practice and national initiatives that support this locally.
- Audit criteria to monitor local practice.
- Costing tools:
  - costing report to estimate the national savings and costs associated with implementation
  - costing template to estimate the local costs and savings involved.

Further information

Ordering information

You can download the following documents from www.nice.org.uk/CG053

- A quick reference guide (this document) – a summary of the recommendations for healthcare professionals.
- The NICE guideline – all the recommendations.
- 'Understanding NICE guidance' – information for patients and carers.
- The full guideline – all the recommendations, details of how they were developed, and reviews of the evidence they were based on.

For printed copies of the quick reference guide or 'Understanding NICE guidance', phone the NHS Response Line on 0870 1555 455 and quote:

- N1302 (quick reference guide)
- N1303 ('Understanding NICE guidance').

Related NICE guidance

Published

- Nutrition support in adults. NICE clinical guideline 32 (2006). Available from www.nice.org.uk/CG032
- Referral guidelines for suspected cancer. NICE clinical guideline 27 (2005). Available from www.nice.org.uk/CG027
- Depression in children and young people. NICE clinical guideline 28 (2005). Available from www.nice.org.uk/CG028
- Depression. NICE clinical guideline 23 (2004, amended 2007). Available from www.nice.org.uk/CG023
- Anxiety. NICE clinical guideline 22 (2004, amended 2007). Available from www.nice.org.uk/CG022

Under development

- Irritable bowel syndrome in adults: diagnosis and management of irritable bowel syndrome in primary care. NICE clinical guideline (publication expected February 2008).
- Management of long-term sickness and incapacity. NICE public health programme guidance (publication expected December 2008).

Updating the guideline

This guideline will be updated as needed, and information about the progress of any update will be posted on the NICE website (www.nice.org/CG053).

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