

**Chronic fatigue syndrome/myalgic
encephalomyelitis (or encephalopathy):
diagnosis and management of CFS/ME in
adults and children**

NICE guideline

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If you wish to comment on this version of the guideline, please be aware that all the supporting information and evidence is contained in the full version.

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Introduction

CFS/ME is a relatively common illness that places a substantial burden on patients, carers and families, and hence on society. It comprises a range of symptoms including fatigue, malaise, headaches, sleep disturbances, difficulties with concentration, and muscle pain. Symptoms may fluctuate in intensity and severity. It is characterised by debilitating fatigue that is unlike everyday fatigue and can be triggered by minimal activity. It raises especially complex issues in severely affected adults and children.

Overall, the evidence suggests a population prevalence of at least 0.2–0.4% which means that a general practice with a population of 10,000 patients is likely to have up to 40 patients with CFS/ME, half of whom will need input from specialist services. However there is a lack of epidemiological data for the UK, which means that population estimates are based on extrapolations from other countries. The estimated annual prevalence is approximately 4000 cases per million of the population.

CFS/ME, like other chronic illnesses with no certain disease process, poses real problems for healthcare professionals. CFS/ME can cause profound, prolonged illness and disability, which has a substantial impact on patients and their families. Uncertainties about diagnosis and management, and a lack of clinical guidance for healthcare professionals has exacerbated this impact.

Patient-centred care

This guideline offers best practice advice on the care of people with CFS/ME.

Treatment and care should take into account patients' individual needs and preferences. People with CFS/ME should have the opportunity to make informed decisions about their care and treatment. Where patients do not have the capacity to make decisions, healthcare professionals should follow the Department of Health guidelines – 'Reference guide to consent for examination or treatment' (2001) (available from www.dh.gov.uk).

Good communication between healthcare professionals and patients is essential. All health care professionals should have a high standard¹ of consultation and communication skills and use a consulting style that enables people with CFS/ME (and their families and/or carers as appropriate) to participate as partners in all decisions about their healthcare, taking fully into account their ethnicity, socio-economic status, culture and any specific needs.

Communication should be supported by the provision of evidence-based information offered in a form that is tailored to the needs of the individual patient. The treatment, care and information provided should be culturally appropriate and in a form that is accessible to people who have additional needs, such as people with physical, cognitive or sensory disabilities, and people who do not speak or read English.

Unless specifically excluded by the patient, carers and relatives should have the opportunity to be involved in decisions about the patient's care and treatment.

Carers and relatives should also be provided with the information and support they need.

¹ The standards detailed in the video workbook 'Summative assessment for general practice training: assessment of consulting skills – the MRCGP/summative assessment single route' are a good example of standards for consulting skills.

Definitions used in this guideline

Activity management	A person centred and collaborative approach to managing symptoms. It is goal directed and promotes the skills of activity grading and analysis to enable patients to improve and or maintain their function and sense of well-being in self care, work and leisure roles.
Cognitive behavioural therapy (CBT)	CBT is an evidence based treatment for CFS/ME. CBT is a psychological therapy and collaborative treatment approach which aims to reduce the levels of symptoms, disability and distress associated with CFS/ME. CBT or psychological approaches to CFS/ME do not imply that symptoms are psychological, 'made up' or in the patient's head. It is used in many health settings including cardiac, cancer, diabetes and chronic pain as well as with mood disorders such as anxiety and depression.
Graded exercise therapy (GET)	GET is an evidence-based self-management approach to CFS/ME involving appropriate physical assessment, mutually negotiated meaningful goal setting and education. It involves setting an achievable baseline of physical activity, followed by individually tailored and planned increases in duration of exercise. This is followed by an increase in intensity when able; taking into account a patient's preferences and objectives, current activity patterns, sleep, setbacks, and emotional factors; with the objective of improving CFS/ME symptoms and functioning aiming towards recovery.
Specialised care	Provides expertise in the assessment, diagnosis and advice on clinical management of CFS/ME, including symptom control and specific interventions. Ideally this will be provided by a multidisciplinary team and members may include general practitioners with a special interest,

neurologists, immunologists, liaison psychiatrists, specialists in infectious disease, paediatricians, clinical psychologists, dietitians, physiotherapists, occupational therapists and nurses.

This glossary will be expanded in the published version. Please see the full guideline for an interim glossary.

Age

These definitions were agreed by the GDG and have been derived from definitions in the National Service Framework for Children, Young People & Maternity Services: Core Standards².

- Adult: 19 years and above.
- Child: children and young people covers all up to their 19th birthday. However after their 16th birthday young people will have the option of transition to adult services, depending on their maturity and wishes.

Severity

These definitions were agreed by the GDG and have been derived from definitions in the Royal College of Paediatrics and Child Health Guidelines³ and the CMO report⁴:

- mild CFS/ME: individuals are mobile, can care for themselves and can do light domestic tasks with difficulty. The majority will still be working. However, in order to remain in work they will probably have stopped all leisure and social pursuits, often taking days off. Most will use the weekend to cope with the rest of the week.
- moderate CFS/ME: individuals have reduced mobility and are restricted in all activities of daily living, often having peaks and troughs of ability,

² Department of Health. National Service Framework for Children, Young People & Maternity Services: Core Standards, London: Department of Health; 2004.

³Royal College of Paediatrics and Child Health. Evidence based guideline for the management of CFS/ME (Chronic Fatigue Syndrome / Myalgic Encephalopathy in Children and Young People), December 2004.

⁴ Department of Health. A report of the CFS/ME working group: report to the chief medical officer of an independent working group. London: Department of health; 2002.

dependent on the degree of symptoms. They have usually stopped work and require rest periods, often sleeping in the afternoon for one or two hours. Sleep quality at night is generally poor and disturbed.

- Severe/very severe CFS/ME: will be able to carry out minimal daily tasks only (for example, face washing, cleaning teeth) or are unable to mobilise and do any of these for themselves. Have severe cognitive difficulties and be wheelchair dependent for mobility. These people are often unable to leave the house except on rare occasions with severe prolonged after-effect from effort. They may also be in bed for the majority of the time and are often unable to tolerate any noise, and are generally extremely sensitive to light.

Key priorities for implementation

- When the adult or child's main goal is to return to normal activities then the therapies of first choice should be CBT or GET because there is good evidence of benefit for this condition in mild to moderately affected adults and some evidence in mild to moderately affected children.

- Shared decision-making between an adult or child and healthcare professionals should take place during diagnosis and all phases of care. To facilitate shared decision-making the healthcare professional should:
 - acknowledge the reality and impact of the condition and the symptoms
 - provide information about the range of therapies and management strategies as detailed in this guideline
 - provide information on the aetiology, nature, course and approaches towards CFS/ME, including the use of any therapy (such as benefits, risks, likely side effects), and returning to work or education
 - provide information, if appropriate, on recovery after viral infection
 - consider patient preference, experience and outcome of previous treatment(s)
 - offer information about access to self-help groups and support groups for adults and children, families and carers (see www.nhsdirect.nhs.uk, and also the NHS Expert Patient Programme www.expertpatients.nhs.uk/)
 - be aware that all adults and children with CFS/ME have the right to refuse any component of a care plan without detriment to the provision of other aspects of care.

- An individualised multi-component programme should be agreed with the adult or child with CFS/ME. The objectives of the programme are to:
 - sustain or gradually extend, if possible, the person's physical, emotional, cognitive capacity and
 - manage the physical and emotional impact of their symptoms.

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- A diagnosis of CFS/ME in an adult should be made after symptoms have persisted for 4 months, and after other likely causes of the symptoms have been ruled out. The diagnosis of a child should be made by a general paediatrician after symptoms have persisted for 3 months and other likely causes of the symptoms have been ruled out.
- Adults and children who are severely affected should be able to access the same diagnostic and therapeutic options as those who are not severely affected, as appropriate.
- When an acute infection is followed by excessive fatigue, the adult or child should receive advice on how to promote recovery. The advice should focus on sleep management, risks of prolonged bed rest (for example, deterioration in muscle function), and a gradual return to a normal daily routine.
- Healthcare professionals should aim to establish a supportive and collaborative relationship with the adult or child with CFS/ME, family, and carers to facilitate their effective management.
- Referral to specialised care for adults and children with CFS/ME should be based on the person's needs and symptoms, the duration and severity of symptoms, and the decision should be made in partnership.
- In the absence of a definite diagnosis and/or while waiting for referral, advice and symptom management should not be delayed until a diagnosis is made.

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- Healthcare professionals should be proactive in advising about fitness for work and education, and recommend adjustments or adaptations to work or studies to enable rehabilitation of adults and children with CFS/ME. This includes liaising (with the person's consent) with employers, education providers and support services e.g:
 - occupational health services
 - disability services through Jobcentre Plus
(<http://www.jobcentreplus.gov.uk/JCP/Customers/Helpfordisabledpeople/index.html>)
 - Connexions for schools
 - disability advisers in universities and colleges

1 Guidance

The following guidance is based on the best available evidence. The full guideline ('CFS/ME: diagnosis and management of adults and children') gives details of the methods and the evidence used to develop the guidance (see section 5 for details).

The methods were based on those of the National Institute for Health and Clinical Excellence (NICE) in 'Guideline Development Process – Information for National Collaborating Centres and Guideline Development Groups' (available at www.nice.org.uk). Consensus development methods were also used in addition to the usual guideline development processes.

1.1 *General principles of care*

1.1.1.1 Shared decision-making between an adult or child and healthcare professionals should take place during diagnosis and all phases of care. To facilitate shared decision-making the healthcare professional should:

- acknowledge the reality and impact of the condition and the symptoms.
- provide information about the range of therapies and management strategies as detailed in this guideline.
- provide information on the aetiology, nature, course and approaches towards CFS/ME, including the use of any therapy (such as benefits, risks, likely side effects), and returning to work or education.
- provide information, if appropriate, on recovery after viral infection.
- consider patient preference, experience and outcome of previous treatment(s).
- offer information about access to self-help groups and support groups for adults and children, families and carers. (see

www.nhsdirect.nhs.uk, and also the NHS Expert Patient Programme www.expertpatients.nhs.uk/)

- be aware that all adults and children with CFS/ME have the right to refuse any component of a care plan without detriment to the provision of other aspects of care.

1.1.1.2 Healthcare professionals who are responsible for the care of an adult or child with CFS/ME should have the appropriate skills and expertise in the condition.

1.1.1.3 Adult and paediatric teams should work jointly to provide assessment and services to young people with CFS/ME.

1.1.2 Transition process in transfer of care

1.1.2.1 As part of the transition process, diagnosis and management should be reviewed.

1.1.2.2 Throughout the transition process there should be clarity about who is the lead clinician to ensure that there is continuity of care.

1.1.3 Information

1.1.3.1 Consistent and universally understood definitions of treatments and medical terminology should be applied throughout CFS/ME care (such as those in this guideline. See glossary).

1.1.3.2 Healthcare professionals should provide validated, accurate information to adults and children, tailored to their individual circumstances (including stage and duration of the condition, symptoms experienced, relevant and personal and social factors), at all stages of their illness starting from when a diagnosis of CFS/ME is first being considered. The 'Understanding NICE guidance' document which accompanies this guideline is a good starting point and is freely available from the NHS response line (phone 0870 1555 455 and quote reference XX). **[[Note: this document will be available at publication of this guideline.]]**

- 1.1.3.3 Information should be available in a variety of formats (hard copy/electronic/audio) to allow access by adults or children and carers at home and in the clinical setting.
- 1.1.3.4 Paediatricians should follow the guidance from the Department for Education and Skills (www.des.gov.uk) on education for children and young people with medical needs or equivalent statutory guidance.
- 1.1.3.5 Where adults and children with CFS/ME are able to continue at, or return to work or school, the healthcare professional should ensure that, with the patient's informed consent, employers, occupational health or education institutions have information on the condition and the agreed management plan.
- 1.1.3.6 Healthcare professionals should be proactive in advising about fitness for work and education, and recommend adjustments or adaptations to work or studies to enable rehabilitation of adults and children with CFS/ME. This includes liaising (with the person's consent) with employers, education providers and support services for example:
- occupational health services
 - disability services through Jobcentre Plus (<http://www.jobcentreplus.gov.uk/JCP/Customers/Helpfordisablepeople/index.html>)
 - Connexions for schools
 - disability advisers in universities and colleges.

1.1.4 Support

1.1.4.1 A documented, individualised management plan should be developed with the adult or child with CFS/ME, and the carer, where appropriate to include:

- relevant symptoms and history
- plans for care
- information and support needs
- education or employment plans
- details of the healthcare professionals involved in care and their contact details.

The management plan should be reviewed and documented at each contact.

1.1.4.2 A designated healthcare professional should be identified who is responsible for coordinating care for each adult or child with CFS/ME.

1.1.4.3 Healthcare professionals should aim to establish a supportive and collaborative relationship with the adult or child with CFS/ME, family, and carers to facilitate their effective management.

1.1.4.4 Support that should be considered for any adult or child with, or suspected to have, CFS/ME are:

- information concerning the illness (see information recommendations)
- acceptance and understanding
- assistance negotiating the healthcare, benefits and social services systems
- availability of care regardless of ability to travel to services
- assistance with social activities including work and education.

1.2 *Making a diagnosis of CFS/ME*

1.2.1 The diagnostic process

1.2.1.1 CFS/ME is recognised on clinical grounds alone. Primary healthcare professionals should be familiar with the presenting features of CFS/ME, and be able to identify these features when adults and children consult.

1.2.1.2 CFS/ME should be considered if an adult or child has fatigue that is all of the following:

- persistent and/or recurrent, and
- unexplained by other conditions, and
- results in substantial reduction in previous activity level, and
- characterised by post-exertion malaise and/or fatigue (often delayed with slow recovery),

AND one or more of the following symptoms:

- difficulty with sleeping (for example,, insomnia, hypersomnia, unrefreshing sleep, disturbed sleep/wake cycle)
- muscles and/or joint pain(multi-site without evidence of inflammation)
- significant headaches of new type, pattern or severity
- painful lymph nodes without pathological enlargement
- sore throat
- cognitive dysfunction, for example difficulty thinking, inability to concentrate, impairment of short-term memory, word-finding difficulty, difficulty to plan/organise thoughts, difficulty with information processing
- physical or mental exertion making symptoms worse
- recurrent flu-like symptoms
- dizziness, nausea and palpitations.

1.2.1.3 CFS/ME may present with symptoms also seen in common self-limiting conditions. The primary healthcare professional should be

ready to review the initial assessment in an adult or child in whom symptoms do not resolve as expected.

1.2.1.4 Some serious underlying diseases might present with similar symptoms and signs as CFS/ME. The following should be regarded as 'red flags', indicating a higher index of suspicion of serious underlying pathology.

- Abnormal neurological signs.
- Features of cardiovascular problems.
- Weight loss.
- Features of sleep apnoea.
- Features of anxiety and depression (please refer to the NICE guidelines on anxiety, depression and depression in children and young people)

1.2.1.5 Primary healthcare professionals should listen carefully to parents' and/or carers' concerns and be willing to reassess their initial opinion, or to seek a second opinion from a colleague if a child fails to recover as expected.

1.2.1.6 A child who has symptoms suggestive of CFS/ME or disabling fatigue should be referred to a general paediatrician for assessment to exclude a diagnosis within 6 weeks of presentation.

1.2.1.7 Discussion with a specialist should be considered if there is uncertainty about the interpretation of symptoms and signs, and whether a referral is needed. This may also enable the primary healthcare professional to communicate their concerns and a sense of urgency to secondary healthcare professionals when symptoms are unusual.

1.2.1.8 As with other potentially chronic conditions, before progressing to a diagnosis of CFS/ME, medical examination and assessment of mental health (both targeted according to the presenting symptoms) should be carried out.

- 1.2.1.9 In the absence of a definite diagnosis and/or while waiting for referral, advice and symptom management should not be delayed until a diagnosis is made.
- 1.2.1.10 When an acute infection is followed by excessive fatigue, the adult or child should receive advice on how to promote recovery. The advice should focus on sleep management, risks of prolonged bed rest (for example, deterioration in muscle function), and a gradual return to a normal daily routine.
- 1.2.1.11 Primary healthcare professionals should provide general practical advice for self management of symptoms to adults and children (and their families) in whom a diagnosis CFS/ME is being considered. This should be tailored to the specific symptoms of the individual and aim to minimise their impact on daily life and activity.

1.2.2 Investigations to aid diagnosis

- 1.2.2.1 Investigations should be tailored to the history, and signs and symptoms of the adult or child, taking into account other possible diagnoses.
- 1.2.2.2 Before progressing to a diagnosis of CFS/ME, investigations should be carried out to exclude other diagnoses that would explain the symptoms. Such tests could include the following, but clinical judgment should be used.
- Urinalysis for protein, blood, glucose.
 - Full blood count.
 - Assessment of blood ferritin levels (children only).
 - Urea & electrolytes.
 - Liver function tests.
 - Thyroid function tests.
 - Erythrocyte sedimentation rate / plasma viscosity.
 - C-reactive protein.
 - Random blood glucose.

- Serum creatinine.
- Screening blood tests for gluten sensitivity.
- Serum calcium.
- Creatinine kinase (children only).

1.2.2.3 The following tests should not be done routinely.

- The head-up tilt test.
- Auditory brainstem responses.
- Electrodermal conductivity.
- Serology testing for chronic bacterial infections (for example, borelliosis) in the absence of any indicative history.
- Serology for chronic virus infections: HIV, hepatitis B and C, in the absence of any indicative history.
- Serology for general viruses (for example, heterophile antibody tests for infectious mononucleosis) in the absence of any indicative history.
- Serology testing for latent infections: toxoplasma, EBV (Epstein Barr virus), CMV (cytomegalovirus) in the absence of any indicative history.
- Folate levels.

1.2.3 Arriving at a diagnosis

1.2.3.1 A diagnosis of CFS/ME in an adult should be made after symptoms have persisted for 4 months, and after other likely causes of the symptoms have been ruled out.

1.2.3.2 The diagnosis of a child should be made by a general paediatrician after symptoms have persisted for 3 months and other likely causes of the symptoms have been ruled out.

1.2.3.3 When a diagnosis is made, a prognosis of cautious optimism should be conveyed. With appropriate management, most children and adults, but not all, will have some improvement and some will recover fully.

1.2.4 Referral to specialised CFS/ME care

1.2.4.1 Referral to specialised care for adults and children with CFS/ME should be based on the person's needs and symptoms, the duration and severity of symptoms, and the decision should be made in partnership.

1.2.4.2 The GDG considered that generally, in the absence of an earlier referral:

- adults and children with mild CFS/ME symptoms should be offered referral to specialised care within 6 months of presentation
- adults and children with moderate CFS/ME symptoms should be offered referral for specialised care within 3-4 months of presentation
- adults and children with severe CFS/ME symptoms should be offered referral immediately.

1.2.4.3 The GDG considered that when seen in the early stages of illness, it is reasonable to observe adult patients for a few weeks before specialist referral as some patients will improve spontaneously. The view of the GDG is that no adult should wait for more than 6 months for a referral.

1.3 Management

1.3.1 CBT, GET, activity management and other self-management strategies

General Principles

1.3.1.1 An individualised programme should be offered to all adults and children with CFS/ME and agreed with them.

1.3.1.2 The programme should be the choice of the adult or child with CFS/ME and mutually developed, after the rationale has been fully explained. During the programme the patient should be in control of

their goals, has the right to refuse any component of the programme and can withdraw at any time.

1.3.1.3 When the adult or child's main goal is to return to normal activities then the therapies of first choice should be CBT or GET because there is good evidence of benefit for this condition in mild to moderately affected adults and some evidence in mild to moderately affected children.

1.3.1.4 If a comprehensive, evidence-based programme, such as CBT or GET, is not appropriate, the programmes or components which appear helpful for this condition (and which are also components of GET or CBT) which should be offered individually or more effectively in combination are:

- activity management strategies (see recommendations below)
- sleep management (see recommendations below)
- relaxation techniques (see recommendations below).

1.3.1.5 The choice of components of strategies, at any given time, should be made based on:

- patient preferences and needs
- their skills, abilities and goals for managing their condition
- the severity of their symptoms
- physical and cognitive functioning.

1.3.1.6 The objectives of the individualised programme are to:

- sustain or gradually extend, if possible, the person's physical, emotional and cognitive capacity
- manage the physical and emotional impact of their symptoms.

1.3.1.7 The choice of programmes or components should take into account the aims of the individual (for example, prevention of relapse, maintenance, treatment of deterioration or improvement of symptoms) and should be reassessed if these aims change.

1.3.1.8 For adults and children with moderate or severe symptoms, provision of equipment and adaptations (for example, a wheelchair, blue badge or stairlift) to allow individuals to improve their independence and quality of life should be considered, if appropriate and as part of an overall management plan.

1.3.1.9 Strategies that are not recommended for adults and children with CFS/ME are:

- advice to undertake unstructured, often vigorous exercise (for example, go to the gym or exercise more) as this may worsen symptoms.
- management programmes delivered by practitioners with no experience in the condition.

1.3.1.10 Health professionals should be aware that there is no evidence for the following strategies:

- those which encourage maintenance of activity levels at substantially less than full capacity in order to have reserve energy for the body to heal itself (can be known as the envelope theory) as there currently is no evidence of benefit. However, there is considerable patient support for this (particularly for adults and children with severe symptoms of CFS/ME), and research is currently being undertaken to evaluate the effectiveness of this approach
- those which encourage complete rest (cognitive, physical and emotional) during significant increases in symptoms (a 'set-back').

Cognitive behaviour therapy (CBT)

1.3.1.11 CBT should be individual or group therapy depending on the individual circumstances.

1.3.1.12 A programme of CBT should include:

- acknowledgement and validation of the patient's symptoms and condition
- acknowledgement of the patient's existing skills and abilities
- explanation of the CBT model for CFS/ME and therapy rationale, for example, the relationship between thoughts, feelings, behaviours and symptoms, and the distinction between causal and perpetuating factors
- discussion of the patient's attitudes and expectations
- development of a supportive and collaborative therapeutic relationship
- development of a shared model of understanding and therapeutic goals
- tailoring to the patient's needs and level of activity.

1.3.1.13 A programme of CBT may also include:

- developing awareness of thoughts or expectations, or beliefs and defining fatigue-related cognitions and behaviour
- self-monitoring to record patterns of activity and rest, and thoughts, feelings, and behaviours
- establishing a stable and maintainable level of functioning, followed by a gradual, and mutually agreed, increase/decrease in activity
- challenging cognitions which may adversely affect rehabilitation and/or symptom management, for example, fear of activity and perfectionist beliefs
- addressing complex adjustment to diagnosis and acceptance of illness limitations, for example, grief, anger and guilt-evoking beliefs and expectations such as 'I should be able to do more' or 'I can't do what I used to do'

- identifying perpetuating factors that increase, maintain or exacerbate CFS/ME symptoms to facilitate the patient's self-efficacy and sense of control over symptoms
- decreasing somatic attributions and addressing symptom over-vigilance and/or checking 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. For example, activity as a therapeutic tool, pleasure and mastery tasks
- building on existing assertion and communication skills in order to set appropriate limits on activity
- management of sleep problems, such as establishing a consistent sleep routine by challenging unhelpful beliefs about sleep, behavioural approaches to sleep disturbance, stress management, and/or relaxation training
- treatment of any associated or comorbid anxiety, depression or post-traumatic stress disorder (refer to NICE guidelines)
- development of setback management or relapse prevention, such as encouraging and building on self-management skills, identifying potential triggers to relapse, problem solving, normalising fluctuations in symptoms.

Graded exercise therapy (GET)

1.3.1.14 Adults with mild or moderate CFS/ME should be offered a programme that includes planned increases in duration of physical activity/exercise followed by increases in intensity leading to aerobic exercise (that is, exercise which increases the pulse rate) such as GET.

1.3.1.15 A GET programme should:

- be based on current activities such as physical activity, daily routines, sleep patterns, emotional factors, vocational or

educational factors, and individual goals. Details of these may be obtained from an activity diary

- be meaningful and focused upon functional goals, vocational goals, related to work, hobbies, or social activities
- explain symptoms and benefits of exercise in a physiological context
- include effective sleep and relaxation strategies.

1.3.1.16 When planning a programme of GET the healthcare professional should:

- discuss with the patient ultimate goals that are important and relevant to them. This may be, for example a 2 x 15 minutes daily brisk walk to the shop, a return to previous active hobby such as cycling or gardening, or, if more severely affected, sitting up in bed to eat a meal.
- recognise that it may take weeks, months, or even years to achieve goals, and it is essential that the therapy structure takes this pace of progress into account.

1.3.1.17 In **starting** a GET programme:

- an initial assessment of current daily activity should be undertaken
- a baseline of low intensity exercise, in addition to the person's normal activity, should be agreed. The baseline should be set at a level which is sustainable independent of daily fluctuations in symptoms and avoiding 'boom and bust' cycles. This may start at a very low level such as gentle stretches or a slow walk. For people who are severely affected brushing hair or sitting up in bed may be a good starting point
- patients should be encouraged to undertake their baseline exercise for at least 5 days out of 7, or build up to this level if and when possible

1.3.1.18 This level of exercise may mildly increase symptoms for a few days (eg mild to moderate increase in stiffness and fatigue). If the symptoms persist for more than a few days or if they are severe or distressing then the exercise or activity levels should be reviewed and reduced if necessary.

1.3.1.19 Progression: When the baseline level of exercise at low intensity can be sustained for 5 out of 7 days a week, (usually accompanied by a reduction in perceived exertion):

- the duration should be renegotiated and increased, if appropriate, by up to 20% (for example, a 5 minute walk becomes 6 minutes, or for people who are more severely affected, they may be able to sit up in bed for a longer period, or walk more frequently to another room) with the aim of reaching 30 minutes of low-intensity exercise.
- when the duration of low-intensity exercise has reached 30 minutes, the intensity of the exercise may then be increased from their current level, gradually up to an aerobic heart rate zone as assessed individually by an appropriately trained professional.

If agreed GET goals are met, exercise duration and intensity can be increased further if, and when, appropriate and if other daily activities can also be sustained and if the patient would like to progress further.

1.3.1.20 Managing setbacks: During a setback, when there is an increase in CFS/ME symptoms or symptoms are exacerbated, exercise or physical activity should be maintained if possible to avoid the negative affects of de-conditioning and withdrawal from activity. If activity decreases significantly at this time, a gradual return, when possible, to previous exercise and functional routines is important.

1.3.1.21 Maintaining exercise: Toward the end of the formal GET programme, the healthcare professional should utilise their therapy

alliance skills to maximise self-efficacy and enable patients to continue their GET beyond discharge, working with the patient should together continue to develop and build on strategies to maintain exercise after being discharged. Support should be available, if needed, to enable the patient to reinforce the learning and lifestyle changes made and which they continue to make.

Activity management

1.3.1.22 Activity management should include:

- identifying and establishing a stable and sustainable range of functioning (baseline). (This may involve increases or decreases in specific activities whilst the baseline is established)
- establishment of baseline, followed by a gradual, and mutually agreed, increase in activity over a period of time
- a goal-oriented and patient-centred approach tailored to individual needs.

1.3.1.23 Activity management may include:

- identifying and understanding that activities have physical, emotional and cognitive components
- planning daily activities to allow for a balance and variety of different types of activity, rest and sleep
- identifying activity in order to spread out difficult or demanding tasks over the day/week
- analysing activities into component parts and breaking into small achievable tasks according to the patient's level of ability/functioning. This should be followed by gradual increases in task complexity
- monitoring, regulating and planning activities to avoid over-activity on days when there are not many symptoms which may then result in an exacerbation of symptoms followed by a period of under activity ('boom/bust' cycle)
- goal setting, planning and prioritising activities

- keeping a diary/schedule which records cognitive and physical activity, daytime rest and sleep will help to set baseline levels of activity and identifying patterns of over- and under-activity and develop an activity/exercise strategy
- explanation of role of rest in CFS/ME, such as tasks which have low demand on physical and cognitive activity. Advice and guidance on the type and length of rest appropriate for the individual. This could include advice to rest not sleep, or to limit rest periods (for example, to 20 minutes maximum at any one time, where possible)
- problem solving around building in rest periods and achieving a productive day, for example, planning, setting limits, appropriate rest activities
- regular review of levels of activity and goals
- during setbacks, maintaining usual activities when possible and incorporating gentle stretching and relaxation. Increasing rest should be avoided but may be appropriate if symptoms are severe
- following a setback, review activity levels and gradually return to previously established levels of activity and rest.

1.3.1.24 Activity management should not include:

- prolonged/complete rest or extended periods of day-time rest in response to an increase in symptoms, unless absolutely necessary
- rigidly adhering to a fixed schedule or activity plan.

1.3.2 Individual components of a self-management strategy which may also be components of CBT, GET or activity management

Sleep management

1.3.2.1 Sleep management should include:

- an explanation about the role and effect of disordered sleep or sleep dysfunction with CFS/ME
- identification of the common changes in sleep seen in CFS/ME which may exacerbate fatigue symptoms
 - unrefreshing sleep
 - insomnia
 - hypersomnia/over-sleeping
 - restless sleep/increased awakenings
 - sleep reversal
 - disturbance in sleep–wake cycle, for example excessive daytime sleeping
- advice on establishing a normal sleep-wake pattern. Excessive sleep doesn't generally improve physical or mental functioning in patients with CFS/ME and excessive periods of daytime sleep or frequent napping may further disrupt the sleep-wake cycle
- specific intervention if there is a concurrent primary sleep disorder (for example, sleep apnoea)
- regular review.

1.3.2.2 Sleep management may include:

- limiting (or reducing to 30 minutes) daytime naps, particularly if affecting night-time sleep
- introduction of a sleep routine:
 - waking at the same time each day, where possible
 - getting out of bed at the same time each day, where possible
 - going to bed at the same time each night, where possible

- establishing a ‘wind-down’ period before going to bed and doing something relaxing (for example, warm bath, reading, listening to music, gentle stretching, if appropriate)
- avoiding stimulating activities prior to going to bed (for example, watching TV or computer games)
- keeping a sleep diary
- keeping the bed and bedroom for night-time sleep where possible
- reduce amount of time in bed when you’re not sleeping, for example, get up after 15 minutes if awake during the night and doing something relaxing, do a boring task, or have a hot milk drink
- ensuring that the bedroom is conducive to sleep, such as a comfortable temperature, dark, quiet, appropriate mattress
- avoiding caffeine and stimulants prior to going to bed (including coffee, tea, cola, some over the counter medications, nicotine)
- avoid excessive alcohol prior to going to bed as this reduces the quality of sleep, with a tendency to wake more frequently
- advice on coping strategies to reduce thoughts or worries that may prevent falling asleep (for example, writing a list, setting aside ‘worry time’)
- use of relaxation techniques.

1.3.2.3 Sleep management should not include:

- encouragement of day-time sleeping and naps
- marked or rapid changes in sleep pattern; any changes should be introduced gradually.

1.3.2.4 If sleep management strategies do not result in improved sleep and rest, the possibility of an underlying sleep disorder or dysfunction should be considered.

Relaxation

1.3.2.5 Relaxation techniques are appropriate for the management of sleep problems and comorbid stress, anxiety or pain. Relaxation techniques can also be incorporated into periods of rest.

1.3.2.6 Relaxation may include the use of relaxation techniques such as:

- progressive muscle relaxation
- passive muscular relaxation
- breathing techniques (7/11 breathing, diaphragmatic breathing)
- autogenic technique
- imagery/guided visualisation
- mindfulness and body scanning
- meditation.

1.3.3 Management of setbacks

1.3.3.1 There should be a written plan for managing setbacks in place, so that skills, strategies, resources and support are more available when needed. This should be shared with carers and supporters.

1.3.3.2 The advice for the management of setbacks may vary according to the cause. The healthcare professional should ascertain the cause of the setback which may be as a result of unexpected/unplanned activities, an active infection, following a viral infection or other illnesses or stress.

1.3.3.3 Management should also take into account the severity and duration. For clarity, these are separated into 'mild/moderate' and 'severe' setbacks. Setback plans will need to be adjusted to specific circumstances, but general guidelines in advising patients are:

Mild/moderate setbacks

- Do not panic – panic can cause an increase in anxiousness, tenseness and tiredness. Setbacks are a normal part of CFS/ME and are to be expected.

- Put strategies into place:
 - relaxation and breathing techniques
 - maintain usual activity levels or implement a gentle reduction in levels of activity and exercise
 - continue activity management by alternating activities with breaks and pacing activities
 - increase rest periods or frequency of rests as appropriate
 - talk to supporters/family/friends
 - challenge distressing thoughts about setbacks such as ‘this means I’ll never get better’
 - if setback is primarily due sleep problems or low mood maintain usual exercise and activity
 - problem solving around particular strategies for each symptom eg sleep disturbance, muscle aches, low mood.
- resume usual activity and normal living as soon as possible in a structured way with guidance from the CFS/ME team.
 - A couple of days later gradually build up activities.
 - Slowly begin to decrease frequency and length of rest periods.
 - Keep using relaxation, even when beginning to feel better.
 - Contact any people / appointments that have been cancelled and rebook.
 - Ensure that the setback plan is kept somewhere easily accessible.

Severe Setbacks

- Follow setback plan – contact support, put strategies into place.
- Review activity/exercise programme with CFS/ME team.
- Reduction of some activities may be necessary initially to re-establish a baseline and stabilise symptoms.
- Ensure that a rest/activity programme is in place using good-quality rest periods and relaxation techniques.

- Increasing the frequency of rest periods may be required, increasing the duration of rest periods may be appropriate depending on the severity of symptoms – this should be discussed with the CFS/ME team initially.
- Activity levels should be increased as CFS/ME symptoms stabilise and improve.

Following a setback

- Review current activity levels and management programme.
- Gradually increase activity again in a structured with guidance from the CFS/ME team.
 - Review current activity levels to re-establish baseline.
 - Gradual structured increase in activity levels with advice.
 - Slowly begin to decrease frequency and length of rest periods.
 - Keep using relaxation, even when beginning to feel better.
 - Contact any people/appointments that have been cancelled and rebook when able.
- Ensure that the setback plan is kept somewhere easily accessible.

Competencies

1.3.3.4 CBT should be delivered only by a suitably trained CBT therapist with appropriate clinical supervision who can demonstrate that they adhere closely to empirically grounded therapy protocols preferably with experience in CFS/ME, or other chronic conditions or medically unexplained symptoms.

1.3.3.5 A GET programme should be delivered by an appropriately trained professional with experience of GET with CFS/ME.

1.3.4 Pharmacological interventions

1.3.4.1 There is no known pharmacological treatment or cure for CFS/ME. Symptoms should be managed conventionally (that is, as per usual

clinical practice), and within the following principles of drug treatment for adults and children with CFS/ME.

- 1.3.4.2 Adults and children with CFS/ME may experience greater intolerance and more severe adverse/side effects from drug treatment. Where appropriate, drug treatment used for symptom control should therefore be initiated at a lower dose than in usual clinical practice, and should be increased gradually.
- 1.3.4.3 Drug treatment for children should be initiated by a general paediatrician, but prescribing may be continued in primary care depending on the preferences of the child and their family/carer and local circumstances.
- 1.3.4.4 Prescribing of thyroxine should only be considered for adults and children who have low thyroxine levels or for children when standard biochemical tests indicate that they are hypothyroid. Thyroxine should not be prescribed when the adult or child is biochemically euthyroid.
- 1.3.4.5 Prescribing of gut anti-spasmodics (such as mebeverine, alverine, and peppermint oil) should be considered for adults and children with bowel symptoms, such as cramp or bloating.
- 1.3.4.6 Prescribing of skeletal anti-spasmodics (such as baclofen or benzodiazepines) should only be considered for adults who have significant muscle pain, cramps, or twitching.
- 1.3.4.7 Melatonin may be considered for children with sleep difficulties but only under specialist supervision as it is currently not licensed in the UK.
- 1.3.4.8 Prescribing of low-dose tricyclic antidepressants specifically amitriptyline should be considered for adults or children who have poor sleep or pain symptoms, unless they are already taking SSRIs.

1.3.4.9 The following treatments are not generally recommended for the management of CFS/ME.

- The use of thyroxine where the individual has NORMAL thyroid function tests.
- The use of monoamine oxidase inhibitors.
- The use of glucocorticoids (such as hydrocortisone).
- The use of mineralocorticoids (such as fludrocortisone).
- The use of dexamphetamine.
- The use of methylphenidate.
- The use of anti-viral agents.

1.3.5 Nutritional/dietary support

1.3.5.1 Healthcare professionals should emphasise the importance of a well balanced diet in line with 'The Balance of Good Health'⁵, and work with the adult or child to develop strategies to minimise complications that may be caused by nausea; sore throat; or additional physical limitations (such as food purchasing, preparation and eating).

1.3.5.2 Adults or children who experience severe weight loss should be referred to a dietitian for assessment, advice and nutritional support, which in extreme cases may include tube feeding. (please refer to the NICE nutrition support in adults guideline).

1.3.5.3 Where an adult/child experiences nausea or severe bowel symptoms, these should be managed conventionally. Exclusion diets are not generally recommended for the management of CFS/ME. However where an exclusion diet is undertaken for the investigation and treatment of bowel symptoms, it should be clinically supervised by a dietitian because of the risks of a severely limited diet.

⁵ Food Standards Agency. The Balance of Good Health, London: Foods Standards Agency; 2006.

1.3.6 Complementary/supplementary

1.3.6.1 There are no complementary therapies that treat CFS/ME for adults and children and their use is not recommended. However, people may choose to access some of these therapies for symptom control and find them helpful.

1.3.6.2 If accessing complementary therapies it is important that the therapist is registered appropriately and has both a good understanding of CFS/ME and experience of the use of the therapy with this condition.

1.3.6.3 There is no evidence on the use of supplements for adults and children with CFS/ME (for example, vitamin B₁₂, vitamin C, co-enzyme Q10, magnesium, NADH, or multivitamins and minerals), and therefore they are not generally recommended for the treatment of the symptoms of CFS/ME. However some individuals find these supplements helpful as part of a self-management strategy for their symptoms. Adults should be advised not to exceed the levels for safety as recommended by the Food Standards Agency.

1.3.7 Ongoing management and review

1.3.7.1 The timing of the reviews will be dependent on the severity of symptoms, the effectiveness of any interventions, and patient need.

1.3.7.2 Regular, structured review of management should be undertaken for all adults and children with CFS/ME. The review should include, if appropriate:

- assessment of improvement or deterioration in symptoms
- assessment of any adverse or unwanted effects of therapy
- ongoing investigations
- a review of the diagnosis especially if signs and symptoms change

- consideration of referral to specialised care
- review of aids and advice of allowances.

1.3.7.3 For children, the healthcare professional should consider repeating selected investigations if there is no improvement at 1 year.

1.3.7.4 For adults, the healthcare professional should consider repeating selected investigations if there is no improvement, particularly in the severely affected as comorbid conditions can be wrongly attributed.

1.3.7.5 The investigations for adults and children who are severely affected should be done under the supervision or with the support of a specialist in CFS/ME.

1.4 Key principles of care for people with severe CFS/ME

1.4.1.1 Adults and children who are severely affected should be able to access the same diagnostic and therapeutic options as those who are not severely affected, as appropriate.

1.4.1.2 Adults and children who are severely affected should be offered an individually tailored programme based on activity management which may be delivered at home (and/or by telephone if appropriate).

1.4.1.3 For severely affected patients having activity management, GET may be an appropriate addition to help patients to develop their physical capacity and functioning.

1.4.1.4 Activity management should be the core therapeutic strategy but elements of CBT may be suitable for some adults and children.

1.4.1.5 Great care must be taken in devising the programme to ensure that it is set at the right level for the adult or child, taking into account

the severity of the illness. The programme needs to be reviewed regularly and frequently.

1.4.1.6 Adults and children who are severely affected may need to access, at various times, community services such as nursing, physiotherapy, psychology and occupational therapy (ref NSF long term conditions). The input of various professionals should be coordinated by a named professional and those involved in care need to be trained in the management of CFS/ME.

1.4.1.7 As they may have cognitive difficulties, adults or children with severe symptoms may find it useful to have a summary record of every consultation for them to refer to.

1.4.1.8 The majority of adults and children with CFS/ME will not need hospital admission. However, there may be circumstances when an admission is helpful. This may be when, for example, assessment of a management plan and investigations would require frequent visits to the hospital or the impact of travel would be detrimental to the adult or child's condition.

2 Notes on the scope of the guidance

NICE guidelines are developed in accordance with a scope that defines what the guideline will and will not cover. The scope of this guideline is available from www.nice.org.uk/NICEtoaddetails.

The guideline is of relevance to those who work in or use the National Health Service in England and Wales:

- Healthcare professionals who have direct contact with, and make decisions concerning, the care of people with CFS/ME.
- Adults and children (from 5 years and upwards) who are mildly, moderately or severely affected by the condition.

The guideline is also relevant to the work, but does not cover the practice, of those working in:

- occupational health services
- social services
- educational services
- the voluntary sector.

The guideline does not cover:

- the management of people for whom CFS/ME has been excluded as a diagnosis
- the management of comorbidities
- highly specialised procedures and procedures that are pilot/exploratory studies
- service provision or models of care.

How this guideline was developed

NICE commissioned the National Collaborating Centre for [add full name] to develop this guideline. The Centre established a Guideline Development Group (see appendix A), which reviewed the evidence and developed the recommendations. An independent Guideline Review Panel oversaw the development of the guideline (see appendix B).

There is more information in the booklet: 'The guideline development process: an overview for stakeholders, the public and the NHS' (second edition, published April 2006), which is available from www.nice.org.uk/guidelinesprocess or by telephoning 0870 1555 455 (quote reference N****).

3 Implementation

The Healthcare Commission assesses the performance of NHS organisations in meeting core and developmental standards set by the Department of Health in 'Standards for better health', issued in July 2004. Implementation of clinical guidelines forms part of the developmental standard D2. Core standard C5

says that national agreed guidance should be taken into account when NHS organisations are planning and delivering care.

NICE has developed tools to help organisations implement this guidance (listed below). These are available on our website (www.nice.org.uk/CGXXX).
[NICE to amend list as needed at time of publication]

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

4 Research recommendations

The Guideline Development Group has made the following recommendations for research, based on its review of evidence, to improve NICE guidance and patient care in the future. The Guideline Development Group's full set of research recommendations is detailed in the full guideline (see section 5).

4.1 Are current intervention strategies that have been shown to be effective in mild to moderately affected adults effective in a) children and b) those who are severely affected (adults and children)?

There is no evidence for the use or effectiveness of these strategies in these two patient groups. Population data suggests that these groups are a significant percentage of the population. Patient experience suggests that some of these interventions may be harmful and/or not effective. Denying these two patient groups access to appropriate and effective care increases inequality.

4.2 *Are there more efficient (cost effective without decreasing efficacy) ways of delivering standard methods of care? For example a) group versus individual CBT or GET or b) telephone or computer CBT or GET?*

Randomised controlled trials, with adequate power, should be used to compare different methods of delivering standard methods of care. Sub-group analysis (if appropriate) may clarify which approach is most effective in different groups of patients (for example, people who are severely affected).

4.3 *What is the prevalence and incidence of CFS/ME in different populations? What is the natural course of the illness?*

We recommend that these questions are answered using a mixture of the following methods: a) cross-sectional population studies which ensure that patients from all ethnic groups, social class and disease severity are included, b) longitudinal cohorts of patients with CFS/ME as well as population cohorts to assess the incidence and prognosis of CFS/ME in a previously normal cohort.

We need reliable information on prevalence and incidence of this condition to plan services. This will require well constructed epidemiological studies across different populations to collect longitudinal data needed to predict outcome, and to calculate the economic impact due to loss of work/education.

4.4 *What is the best way of measuring outcome in research studies? Which outcomes accurately reflect functional ability, which outcomes are important to patients and how much change in outcomes are clinically significant?*

There is a lack of studies in this area. Knowing what is important to patients is crucial for designing future studies. It is not known how much improvement is

important for patients with CFS/ME. Future research studies to investigate cost effectiveness of treatment require functional outcomes such as return to work.

5 Other versions of this guideline

5.1 Full guideline

The full guideline, 'Chronic fatigue syndrome/myalgic encephalomyelitis (or encephalopathy): diagnosis and management of CFS/ME in adults and children', contains details of the methods and evidence used to develop the guideline. It is published by the National Collaborating Centre for Primary Care, and is available from [NCC website details to be added], our website (www.nice.org.uk/CGXXXfullguideline) and the National Library for Health (www.nlh.nhs.uk). **[Note: these details will apply to the published full guideline.]**

5.2 Quick reference guide

A quick reference guide for healthcare professionals is available from www.nice.org/CGXXXquickrefguide

For printed copies, phone the NHS Response Line on 0870 1555 455 (quote reference number N1XXX). **[Note: these details will apply when the guideline is published.]**

5.3 'Understanding NICE guidance'

Information for patients and carers ('Understanding NICE guidance') is available from www.nice.org.uk/CGXXXpublicinfo

For printed copies, phone the NHS Response Line on 0870 1555 455 (quote reference number N1XXX). **[Note: these details will apply when the guideline is published.]**

6 Related NICE guidance

Anxiety: management of anxiety (panic disorder, with or without agoraphobia, and generalised anxiety disorder) in adults in primary, secondary and community care. *NICE clinical guideline* no. 22 (2004). Available from www.nice.org/CG022

Depression: management of depression in primary and secondary care. *NICE clinical guideline* no. 23 (2004). Available from www.nice.org/CG023

Depression in children and young people: identification and management in primary, community and secondary care. *NICE clinical guideline* no. 28 (2005). Available from www.nice.org.uk/CG028

Nutrition support in adults: oral nutrition support, enteral tube feeding and parenteral nutrition *NICE clinical guideline* no. 32 (2006). Available from www.nice.org.uk/CG032

Post-traumatic stress disorder: Management of post-traumatic stress disorder in adults in primary and secondary care no. 26 (2005). Available from www.nice.org.uk/CG026

7 Updating the guideline

NICE clinical guidelines are updated as needed so that recommendations take into account important new information. We check for new evidence 2 and 4 years after publication, to decide whether all or part of the guideline should be updated. If important new evidence is published at other times, we may decide to do a more rapid update of some recommendations.

Appendix A: The Guideline Development Group

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Appendix B: The Guideline Review Panel

The Guideline Review Panel is an independent panel that oversees the development of the guideline and takes responsibility for monitoring adherence to NICE guideline development processes. In particular, the panel ensures that stakeholder comments have been adequately considered and responded to. The Panel includes members from the following perspectives: primary care, secondary care, lay, public health and industry.

[NICE to add]

[Name; style = Unnumbered bold heading]

[job title and location; style = NICE normal]

Appendix C: The algorithms

Care pathway for adults and children



