NICE National Institute for Health and Care Excellence

Chronic fatigue syndrome/myalgic encephalomyelitis (or encephalopathy)

Diagnosis and management of CFS/ME in adults and children

Issued: August 2007

NICE clinical guideline 53

guidance.nice.org.uk/cg53

Contents

Introduction

Chronic fatigue syndrome (CFS)/myalgic encephalomyelitis (or encephalopathy) (ME) is a relatively common illness. The physical symptoms can be as disabling as multiple sclerosis, systemic lupus erythematosus, rheumatoid arthritis, congestive heart failure and other chronic conditions. CFS/ME places a substantial burden on people with the condition, their families and carers, and hence on society.

There is a lack of epidemiological data for the UK, so population estimates are based on extrapolations from other countries. Overall, evidence suggests a population prevalence of at least 0.2–0.4%. This means that a general practice with 10,000 patients is likely to include up to 40 people with CFS/ME; half of these people will need input from specialist services.

Many different potential aetiologies for CFS/ME – including neurological, endocrine, immunological, genetic, psychiatric and infectious – have been investigated, but the diverse nature of the symptoms can not yet be fully explained. The World Health Organization (WHO) classifies CFS/ME as a neurological illness (G93.3), and some members of the Guideline Development Group (GDG) felt that, until research further identifies its aetiology and pathogenesis, the guideline should recognise this classification. Others felt that to do so did not reflect the nature of the illness, and risked restricting research into the causes, mechanisms and future treatments for CFS/ME.

CFS/ME comprises a range of symptoms that includes fatigue, malaise, headaches, sleep disturbances, difficulties with concentration and muscle pain. A person's symptoms may fluctuate in intensity and severity, and there is also great variability in the symptoms different people experience. CFS/ME is characterised by debilitating fatigue that is unlike everyday fatigue and can be triggered by minimal activity. This raises especially complex issues in adults and children with severe CFS/ME.

CFS/ME, like other chronic conditions for which the causes and disease processes are not yet fully understood, poses significant problems for healthcare professionals. It can cause profound, prolonged illness and disability, which has a substantial impact on people with CFS/ME and their carers. Uncertainties about diagnosis and management, and a lack of clinical guidance for healthcare professionals, have exacerbated this impact.

The recommendations in this guideline emphasise the importance of early symptom management, making an accurate diagnosis, ensuring that significant clinical features are investigated, and working in partnership with people with CFS/ME to manage the condition. Different combinations of approaches will be helpful for different people.

Definitions used in this guideline are provided in Appendix D.

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. For children and young people with CFS/ME, this will depend on their age and capacity to make decisions. It is good practice for healthcare professionals to involve the young person's parent(s) or guardian(s) in the decision-making process.

If patients do not have the capacity to make decisions, healthcare professionals should follow the Department of Health's advice on consent and the code of practice that accompanies the Mental Capacity Act. In Wales, healthcare professionals should follow advice on consent from the Welsh Government.

Good communication between healthcare professionals and people with CFS/ME is essential. All healthcare professionals should have a high standard[1] 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 socioeconomic status, culture, cognitive ability and any specific needs.

Communication should be supported by evidence-based written information tailored to the person's needs. Treatment and care, and the information people with CFS/ME (and their families and carers as appropriate) are given about it, should be culturally appropriate. It should also be accessible to people with additional needs such as physical, sensory or learning disabilities, and to people who do not speak or read English.

Carers and relatives should have the opportunity to be involved in decisions about the patient's care and treatment, unless the patient specifically excludes them.

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

Adult and paediatric healthcare teams should work jointly to provide assessment and services to young people with CFS/ME. As part of the transition process from paediatric to adult services,

diagnosis and management should be reviewed and, throughout, there should be clarity about who is the lead clinician to ensure continuity of care.

Transitional care should be planned and managed according to the best practice guidance described in Transition: getting it right for young people.

[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.

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[2]).
- 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.
- 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.

[2] For more information see Expert Patients Programme or Education Programme for Patients Wales

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).

1.1 General principles of care

1.1.1 Shared decision-making

1.1.1.1 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[3]).

1.1.1.2 When providing care for children and young people, healthcare professionals should follow best practice as described in the national service frameworks for children for England or for Wales[4].

1.1.1.3 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.

1.1.1.4 Healthcare professionals should recognise that the person with CFS/ME is in charge of the aims and goals of the overall management plan. The pace of progression throughout the course of any intervention should be mutually agreed.

1.1.1.5 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.

1.1.2 Support and information

1.1.2.1 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.

1.1.2.2 A named healthcare professional should be responsible for coordinating care for each person with CFS/ME.

1.1.2.3 Healthcare professionals should provide accurate information to people at all stages of CFS/ME, starting from when a diagnosis is first being considered. This should be tailored to the person's circumstances, including the stage and duration of the condition, symptoms experienced and relevant personal and social factors.

1.1.2.4 Information should be available in a variety of formats if appropriate (printed copy, electronic and audio), which people with CFS/ME and their carers can refer to at home and in the clinical setting.

1.1.3 Provision of care

1.1.3.1 Healthcare professionals responsible for caring for people with CFS/ME should have appropriate skills and expertise in the condition.

1.1.3.2 Every person diagnosed with CFS/ME should be offered:

- information about the illness (see section 1.1.2)
- acceptance and understanding
- assistance negotiating the healthcare, benefits and social care systems
- assistance with occupational activities including work and education if appropriate (see section 1.4.5).

1.1.3.3 An individualised management plan should be developed with the person with CFS/ME, and their carers if appropriate. The plan should be reviewed and changes documented at each contact. It should include:

- 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 of the healthcare professionals involved in care and their contact details.

1.2 Presentation

1.2.1 Presenting symptoms suspicious of CFS/ME

1.2.1.1 CFS/ME is recognised on clinical grounds alone. Primary healthcare professionals should be familiar with and be able to identify the characteristic features of CFS/ME.

1.2.1.2 Healthcare professionals should 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 lifelong)
  - 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.

1.2.1.3 Healthcare professionals should be aware that the symptoms of CFS/ME fluctuate in severity and may change in nature over time.

1.2.1.4 Signs and symptoms that can be caused by other serious conditions ('red flags') should not be attributed to CFS/ME without consideration of alternative diagnoses or comorbidities. In particular, the following features should be investigated[5]:

- 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.

1.2.2 History, examinations and investigations

1.2.2.1 A full history (including exacerbating and alleviating factors, sleep disturbance and intercurrent stressors) should be taken, and a physical examination and assessment of psychological wellbeing should be carried out.

1.2.2.2 A child or young person who has symptoms suggestive of CFS/ME should be referred to a paediatrician for assessment to exclude other diagnoses within 6 weeks of presentation.

1.2.2.3 The following 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).

Clinical judgement should be used when deciding on additional investigations to exclude other diagnoses.

1.2.2.4 Tests for serum ferritin in adults should not be carried out unless a full blood count and other haematological indices suggest iron deficiency.

1.2.2.5 Tests for vitamin B_{12} deficiency and folate levels should not be carried out unless a full blood count and mean cell volume show a macrocytosis.

1.2.2.6 The following tests should not be done routinely to aid diagnosis:

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

1.2.2.7 Serological testing should not be carried out unless the history is indicative of an infection. Depending on the history, tests for the following infections may be appropriate:

- chronic bacterial infections, such as borreliosis

- chronic viral infections, such as HIV or hepatitis B or C
- acute viral infections, such as infectious mononucleosis (use heterophile antibody tests)
- latent infections, such as toxoplasmosis, Epstein–Barr virus or cytomegalovirus.

1.2.3 Advice on symptom management before diagnosis

1.2.3.1 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.

1.2.4 Re-assessment before diagnosis

1.2.4.1 If symptoms do not resolve as expected in a person initially suspected of having a self-limiting condition, primary healthcare professionals should listen carefully to the person's and their family and/or carers' concerns and be prepared to reassess their initial opinion.

1.2.4.2 If considering the possibility of CFS/ME or another serious alternative condition, primary healthcare professionals should consider discussion with a specialist if there is uncertainty about the interpretation of signs and symptoms 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 if symptoms are unusual.

1.3 Diagnosis

1.3.1 Making a diagnosis

1.3.1.1 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.

1.3.1.2 When a diagnosis of CFS/ME is made, healthcare professionals should provide honest, realistic information about CFS/ME and encourage cautious optimism.

- Most people with CFS/ME will improve over time and some people 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.

1.3.1.3 The diagnosis of CFS/ME should be reconsidered if none of the following key features are present:

- post-exertional fatigue or malaise
- cognitive difficulties
- sleep disturbance
- chronic pain.

1.4 General management strategies after diagnosis

1.4.1 Symptom management

1.4.1.1 There is no known pharmacological treatment or cure for CFS/ME. However, symptoms of CFS/ME should be managed as in usual clinical practice.

1.4.1.2 No research evidence was found to support the experience of some people with CFS/ME that they are more intolerant of drug treatment and have more severe adverse/side effects. However, if people with CFS/ME have concerns, healthcare professionals may consider starting drug treatment for CFS/ME symptoms at a lower dose than in usual clinical practice. The dose may be increased gradually, in agreement with the patient.

1.4.1.3 Specific drug treatment for children and young people with CFS/ME should be started by a paediatrician. However, prescribing may be continued in primary

care, depending on the preferences of the patient and their carers, and local circumstances.

1.4.1.4 If a person experiences nausea as part of CFS/ME, this should be managed conventionally, including giving advice on eating little and often, snacking on dry starchy foods and sipping fluids. The use of anti-emetic drugs should be considered only if the nausea is severe.

1.4.1.5 Although exclusion diets are not generally recommended for managing CFS/ME, many people find them helpful in managing symptoms, including bowel symptoms. If a person with CFS/ME undertakes an exclusion diet or dietary manipulation, healthcare professionals should seek advice from a dietitian because of the risk of malnutrition.

1.4.2 Function and quality-of-life management

Sleep management

1.4.2.1 Healthcare professionals should provide tailored sleep management advice that includes:

- Explaining the role and effect of disordered sleep or sleep dysfunction in CFS/ME.
- Identifying the common changes in sleep patterns seen in CFS/ME that may exacerbate fatigue symptoms (such as insomnia, hypersomnia, sleep reversal, altered sleep–wake cycle and non-refreshing sleep).
- Providing general advice on good sleep hygiene[6].
- Introducing changes to sleep patterns gradually.
- Regular review.

1.4.2.2 If sleep management strategies do not improve the person's sleep and rest, the possibility of an underlying sleep disorder or dysfunction should be considered, and interventions provided if needed.

1.4.2.3 Sleep management strategies should not include encouraging daytime sleeping and naps. People with CFS/ME should be advised that excessive sleep does not generally improve physical or mental functioning, and excessive periods of daytime sleep or frequent napping may further disrupt the sleep–wake cycle.

Rest periods

1.4.2.4 Restperiods are a component of all management strategies for CFS/ME. Healthcare professionals should advise people with CFS/ME on the role of rest, how to introduce rest periods into their daily routine, and the frequency and length appropriate for each person. This may include:

- Limiting the length of 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 recommendation 1.4.2.6).

1.4.2.5 Healthcare professionals should review the use of rest periods regularly as part of the patient's management plan.

Relaxation

1.4.2.6 Relaxation techniques appropriate to the person with CFS/ME should be offered for the management of pain, sleep problems and comorbid stress or anxiety. There are a number of different relaxation techniques (such as guided visualisation or breathing techniques) that can be incorporated into rest periods.

Pacing

1.4.2.7 People with CFS/ME have reported pacing to be helpful in self-managing CFS/ME. However, healthcare professionals should advise people with CFS/ME that, at present, there is insufficient research evidence on the benefits or harm of pacing.

1.4.3 Diet

See also recommendations on managing nausea (1.4.1.4) and bowel symptoms (1.4.1.5), and use of supplements (1.4.7.2–4).

1.4.3.1 Healthcare professionals should emphasise the importance of a well-balanced diet in line with 'The balance of good health'[7]. They should work with the person with CFS/ME to develop strategies to minimise complications that may be caused by nausea, swallowing problems, sore throat or difficulties with buying, preparing and eating food.

1.4.3.2 Healthcare professionals should emphasise the importance of eating regularly, and including slow-release starchy foods in meals and snacks. The physiological consequences of not doing so should be explained to the person with CFS/ME.

1.4.4 Equipment to maintain independence

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

1.4.5 Education and employment

1.4.5.1 Having to stop their work or education is generally detrimental to people's health and well-being. Therefore, the ability of a person with CFS/ME to continue in education or work should be addressed early and reviewed regularly.

1.4.5.2 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.

1.4.5.3 For people with CFS/ME who are able to continue in or return to education or employment, healthcare professionals should ensure, with the person's informed consent, that employers, occupational health or education institutions have information on the condition and the agreed management plan.

Education

1.4.5.4 Healthcare professionals should follow the guidance from the Department for Children, Schools and Families[8] on education for children and young people with medical needs, or equivalent statutory guidance.

1.4.5.5 Healthcare professionals should work closely with social care and education services to ensure a common understanding of the goals of the person with CFS/ME. The use of a flexible approach should be discussed, including home tuition and use of equipment that allows a gradual reintegration into education.

1.4.5.6 Time in education should not be used as a sole marker of progress of CFS/ME, and education should not be the only activity a person undertakes. There should be a balance between time spent attending school or college and doing homework, and time spent on home and social activities.

Employment

1.4.5.7 If possible, and with the informed consent of the person with CFS/ME, healthcare professionals should discuss employment issues with occupational health professionals, who will communicate with the person's manager or human resources representative. If there is no access to occupational health services, the responsible clinician should liaise with the employer directly[9].

1.4.6 Strategies that should not be used for CFS/ME

1.4.6.1 The following drugs should not be used for the treatment of CFS/ME:

- monoamine oxidase inhibitors
- glucocorticoids (such as hydrocortisone)
- mineralocorticoids (such as fludrocortisone)
- dexamphetamine
- methylphenidate
- thyroxine
- antiviral agents.

1.4.6.2 The following strategies should not be offered to people with CFS/ME:

- Advice to undertake unsupervised, or unstructured, vigorous exercise (such as simply 'go to the gym' or 'exercise more') because this may worsen symptoms.
- Specialist management programmes (see section 1.6) delivered by practitioners with no experience in the condition.

1.4.6.3 Although there is considerable support from patients (particularly people with severe CFS/ME) for the following strategies, healthcare professionals should be aware that there is no controlled trial evidence of benefit:

- Encouraging maintenance of activity levels at substantially less than full capacity to reserve energy for the body to heal itself (sometimes known as the envelope theory).
- Encouraging complete rest (cognitive, physical and emotional) during a setback/ relapse.

1.4.6.4 Strategies for managing CFS/ME should not include:

- 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.

1.4.7 Complementary and supplementary therapies

1.4.7.1 There is insufficient evidence that complementary therapies are effective treatments for CFS/ME and therefore their use is not recommended. However, some people with CFS/ME choose to use some of these therapies for symptom control, and find them helpful.

1.4.7.2 There is insufficient evidence for the use of supplements – such as vitamin B_{12}, vitamin C, co-enzyme Q10, magnesium, NADH (nicotinamide adenine dinucleotide) or multivitamins and minerals – for people with CFS/ME, and therefore they should not be prescribed for treating the symptoms of the condition. However, some people with CFS/ME have reported finding these helpful as a part of a self-management strategy for their symptoms.

1.4.7.3 People with CFS/ME who are using supplements should be advised not to exceed the safe levels recommended by the Food Standards Agency[10].

1.4.7.4 Some people with CFS/ME need supplements because of a restricted dietary intake or nutritional deficiencies. Healthcare professionals should seek advice from a dietitian about any concerns.

1.5 Referral to specialist CFS/ME care

1.5.1.1 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.

1.5.1.2 Referral to specialist CFS/ME care should be offered:

- within 6 months of presentation to people with mild CFS/ME

- within 3–4 months of presentation to people with moderate CFS/ME symptoms
- immediately to people with severe CFS/ME symptoms.

1.6 Specialist CFS/ME care

1.6.1.1 After a patient is referred to specialist care, an initial assessment should be done to confirm the diagnosis.

1.6.1.2 If general management strategies (see section 1.4) are helpful for a person with CFS/ME, these should be continued after referral to specialist CFS/ME care.

1.6.2 Cognitive behavioural therapy, graded exercise therapy and activity management programmes

Choosing and planning treatment

1.6.2.1 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.

1.6.2.2 The rationale and content of the different programmes, including their potential benefits and risks, should be fully explained to the person with CFS/ME. Healthcare professionals should explain that no single strategy will be successful for all patients, or during all stages of the condition.

1.6.2.3 Healthcare professionals should recognise that the person with CFS/ME is in charge of the aims of the programme. The choice of the programme, its components, and progression throughout the programme should be mutually agreed and based on:

- the person's age, preferences and needs

- the person's skills and abilities in managing their condition, and their goals (such as improvement or treatment of deterioration of symptoms, prevention of relapse or maintenance)
- the severity and complexity of symptoms
- physical and cognitive functioning.

1.6.2.4 Cognitive behavioural therapy (CBT) and/or graded exercise therapy (GET) 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.

1.6.2.5 If a full CBT or GET programme is inappropriate or not available, components of CBT or GET should be offered, either individually or more effectively in combination with:

- activity management strategies (see 1.6.2.22)
- sleep management (see 1.4.2.1–3)
- relaxation techniques (see 1.4.2.6).

1.6.2.6 The choice of programme, its components and progression through it should be reviewed regularly, taking into account the goals and abilities of the person with CFS/ME, and other approaches agreed as necessary.

1.6.2.7 Healthcare professionals should advise people with CFS/ME to contact them if they experience an increase in symptoms that lasts for longer than a few days after starting the specialist programme, or if symptoms are severe or distressing.

Cognitive behavioural therapy (CBT)

1.6.2.8 A course of CBT should be delivered only by a healthcare professional with appropriate training in CBT and experience in CFS/ME, under clinical supervision. The therapist should adhere closely to empirically grounded therapy protocols.

1.6.2.9 CBT should be offered on a one-to-one basis if possible.

1.6.2.10 CBT for a person with CFS/ME should be planned according to the usual principles of CBT, and should 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 recommendations 1.4.2.1–6).
- Treating any associated or comorbid anxiety, depression or mood disorder according to NICE clinical guidelines on these conditions (see section 6).
- Offering information on managing setbacks/relapses (see section 1.7).

Graded exercise therapy (GET)

1.6.2.11 GET should be delivered only by a suitably trained GET therapist with experience in CFS/ME, under appropriate clinical supervision.

1.6.2.12 GET should be offered on a one-to-one basis if possible.

1.6.2.13 People with mild or moderate CFS/ME should be offered GET that includes planned increases in the duration of physical activity. The intensity should then be increased when appropriate, leading to aerobic exercise (that is, exercise that increases the pulse rate).

1.6.2.14 GET should be based on the person's current level of activities (such as physical activity, daily routines, sleep patterns and frequency of setbacks/ relapses) and emotional factors, vocational or educational factors and individual goals (details of these may be obtained from an activity diary). The programme should also include sleep and relaxation strategies (see recommendations 1.4.2.1–6).

1.6.2.15 When planning GET, the healthcare professional should:

- Undertake an activity analysis to ensure that the person with CFS/ME is not in a 'boom and bust' cycle before they increase the time spent in exercise.
- Discuss with the person the ultimate goals that are important and relevant to them. This might be, for example, a twice-daily short walk to the shops, a return to a previous active hobby such as cycling or gardening, or, for people with severe CFS/ME, sitting up in bed to eat a meal.
- Recognise that it can take weeks, months or even years to achieve goals, and ensure that this is taken into account in the therapy structure (for example, by setting short- and medium-term goals).
- Explain symptoms and the benefits of exercise in a physiological context.

1.6.2.16 When starting GET, the healthcare professional should:

- Assess the person's current daily activities to determine their baseline.
- Agree with them 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. This may be sitting up in bed or brushing hair, for example, for people with severe CFS/ME, or gentle stretches or a slow walk.
- Encourage them to undertake this exercise for at least 5 days out of 7, or build up to this level if and when possible.
- Advise them that this level of exercise may mildly increase symptoms for a few days (for example, a mild to moderate increase in stiffness and fatigue), explain why this may occur and discuss strategies to mitigate it.
- Offer information on the management of setbacks/relapses (see section 1.7).

Progressing with GET

1.6.2.17 When the low-intensity exercise can be sustained for 5 days out of 7 (usually accompanied by a reduction in perceived exertion), the duration should be reviewed and increased, 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. The aim is to reach 30 minutes of low-intensity exercise.

1.6.2.18 When the duration of low-intensity exercise has reached 30 minutes, the intensity of the exercise may be increased gradually up to an aerobic heart rate zone, as assessed individually by a healthcare professional. A rate of 50–70% maximum heart rate is recommended.

1.6.2.19 Exercise intensity should be measured using a heart rate monitor, so that the person knows they are within their target heart rate zone.

1.6.2.20 If agreed GET goals are met, exercise duration and intensity may be increased further if appropriate, if other daily activities can also be sustained, and in agreement with the person with CFS/ME.

Maintaining exercise

1.6.2.21 After completing a GET programme, the healthcare professional and the person with CFS/ME should continue working together to develop and build on strategies to maintain exercise. Support should be available, if needed, to enable the person to reinforce the learning and lifestyle changes made and continue GET beyond discharge.

Activity management

1.6.2.22 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 recommendations 1.4.2.1–6).
- Regularly reviewing activity levels and goals.
- Offering information on the management of setbacks/relapses (see section 1.7).

1.6.3 Pharmacological interventions for symptom control

1.6.3.1 If chronic pain is a predominant feature, healthcare professionals should consider referral to a pain management clinic.

1.6.3.2 Prescribing of low-dose tricyclic antidepressants, specifically amitriptyline, should be considered for people with CFS/ME who have poor sleep or pain. Tricyclic antidepressants should not be offered to people who are already taking selective serotonin reuptake inhibitors (SSRIs) because of the potential for serious adverse interactions.

1.6.3.3 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.

1.7 Management of setbacks/relapses

1.7.1 Preparing for a setback/relapse

1.7.1.1 People with CFS/ME should be advised that setbacks/relapses are to be expected as part of CFS/ME.

1.7.1.2 Healthcare professionals and people with CFS/ME should develop a plan for managing setbacks/relapses, so that skills, strategies, resources and support are readily available and accessible when needed. This plan may be shared with the person's carers, if they agree.

1.7.2 During a setback/relapse

1.7.2.1 Setbacks/relapses may be triggered by factors such as unexpected/unplanned activities, poor sleep, infection or stress. Healthcare professionals, in discussion with the person with CFS/ME, should try to identify the cause(s) of a setback/relapse, but it should be recognised that this may not always be possible.

1.7.2.2 When managing a setback/relapse, the management plan should be reviewed. Healthcare professionals should discuss and agree an appropriate course of action with the person with CFS/ME, taking into account:

- the person's experience
- possible causes of the setback/relapse, if known
- the nature of the symptoms
- the severity and duration of the setback/relapse
- the current management plan.

1.7.2.3 When managing setbacks, healthcare professionals should put strategies in place 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 about setbacks/relapses such as 'this means I'll never get better', but encourage optimism.
- Involve reconsidering and revising the levels and types of symptom control.

1.7.2.4 In some setbacks/relapses, 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. This should be discussed and agreed with the person with CFS/ME.

1.7.2.5 People with CFS/ME should be advised to minimise daytime sleep periods. However, healthcare professionals should recognise that this is not always possible, depending on the severity of a person's symptoms and the setback.

1.7.3 After a setback/relapse

1.7.3.1 After a setback/relapse, healthcare professionals should review the person's activity levels to re-establish a baseline and review the management plan. A gradual return, when possible, to previous exercise and functional routines should be encouraged. Activity should be increased gradually.

1.7.3.2 Healthcare professionals should advise on:

- Slowly decreasing the frequency and duration of rest periods.
- Continuing the use of relaxation techniques, even when the person with CFS/ME is beginning to feel better.

1.7.3.3 After a setback, healthcare professionals and people with CFS/ME should review the experience to determine, if possible, whether triggers can be managed in the future, and put strategies in place to do this.

1.8 Review and ongoing management

1.8.1.1 Regular, structured review should be undertaken for all people with CFS/ME. The review should include, 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, repeating investigations should be considered if there is no improvement after 1 year).
- Reviewing the diagnosis, especially if signs and symptoms change (see recommendation 1.2.1.4).
- Considering referral to specialist CFS/ME care.
- Reviewing equipment needs.
- Assessing any additional support needs (see sections 1.1 and 1.4).

1.8.1.2 The timing of the reviews should depend on the severity and complexity of symptoms, the effectiveness of any interventions, and the needs of the person with CFS/ME.

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

1.9.1 General principles of care

1.9.1.1 Management of severe CFS/ME is difficult and complex and healthcare professionals should recognise that specialist expertise is needed when planning and providing care for people with severe CFS/ME.

1.9.1.2 Diagnosis, investigations, management and follow-up care for people with severe CFS/ME should be supervised or supported by a specialist in CFS/ME.

1.9.1.3 People with severe CFS/ME may need to use community services at times. These services may include nursing, occupational therapy, dietetics, respite care, psychology and physiotherapy (see the 'National service framework for long-term conditions'[11]). The input of different professionals should be coordinated by a named professional.

1.9.1.4 People with severe CFS/ME should be offered a summary record of every consultation because of their cognitive difficulties.

1.9.1.5 Most people with CFS/ME will not need hospital admission. However, there may be circumstances when a planned admission should be considered. The decision to admit should be made with the person with CFS/ME and their family, and be based on an informed consideration of the benefits and disadvantages. For example, a planned admission may be useful if assessment of a management plan and investigations would require frequent visits to the hospital.

1.9.2 Rest

1.9.2.1 When making decisions about prolonged bed rest, healthcare professionals should seek advice from a specialist experienced in the care of people with severe CFS/ME. The significant physical and psychological risks associated with prolonged bed rest should be taken into account.

1.9.2.2 Healthcare professionals working with people with severe CFS/ME who are in bed most (or all) of the time, should explain the associated risks (such as postural hypotension, deep venous thrombosis, osteoporosis, pressure sores and deconditioning) and monitor these.

1.9.3 Management approaches

1.9.3.1 People with severe CFS/ME should be offered an individually tailored activity management programme (see recommendation 1.6.2.22) as the core therapeutic strategy, which may:

- be delivered at home, or using telephone or email if appropriate

- incorporate the elements of recommendation 1.6.2.22 and draw on the principles of CBT and GET (see recommendations 1.6.2.1–21).

1.9.3.2 An activity management programme should be reviewed regularly and frequently.

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[3] For more information see Expert Patients Programme or Education Programme for Patients Wales

[4] Available from the Department of Health (England; this framework includes an exemplar pathway for CFS/ME) and NHS Wales.

[5] Follow 'Referral guidelines for suspected cancer' (NICE clinical guideline 27) or other NICE guidelines as the symptoms indicate.

[6] For general advice on sleep hygiene, see the NHS Direct website.

[7] Food Standards Agency (2006) 'The balance of good health'. London: Foods Standards Agency.

[8] See Department for Education

[9] NHS Plus has produced guidance on the occupational aspects of the management of CFS/ME (search for 'chronic fatigue syndrome').

[10] See Food Standards Agency

[11] Available from the Department of Health.

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.

This guideline addresses the diagnosis, treatment and management of CFS/ME in adults and in children aged 5 years and older, in primary and secondary care and in specialist centres and teams. The guideline is also relevant to the work of occupational health services, social services, educational services and the voluntary sector, although it does not make recommendations for them directly.

The guideline does not cover the management of comorbidities, highly specialised procedures, service provision or models of care.

How this guideline was developed

NICE commissioned the National Collaborating Centre for Primary Care 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 about how NICE clinical guidelines are developed on the NICE website. A booklet, 'How NICE clinical guidelines are developed: an overview for stakeholders, the public and the NHS' is available.

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.

- 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 that 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.

The aetiology of CFS/ME was outside the scope of the guideline and therefore a systematic search of the area was not carried out. For that reason, the GDG has not made a research recommendation about the causes of CFS/ME, but it recognises that research in this area would be very helpful.

4.1 Extrapolating use of intervention strategies

Are intervention strategies that have been shown to be effective in mildly to moderately affected adults also effective in children and in people (adults and children) with severe CFS/ME?

Why this is important

There is limited evidence for the use or effectiveness of strategies recommended in this guideline in these two patient groups. Population data suggest that these groups constitute a significant percentage of the population with CFS/ME. Some patient experience suggests that some of these interventions may be harmful and/or not effective.

4.2 Delivery of standard methods of care

Are there more efficient ways of delivering standard methods of care? For example, what is the most efficient way of delivering domiciliary care for people with CFS/ME?

Why this is important

Randomised controlled trials, with adequate power, are needed to compare different methods of delivering standard methods of care, and whether outcomes differ depending on whether they are delivered in primary or secondary care. Subgroup analysis may clarify which approach is most efficient (that is, cost effective without decreasing efficacy) in different groups of people with CFS/ME (for example, people who are severely affected).

4.3 Prevalence and course of the illness

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

Why this is important

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

We recommend that these questions are answered using a mixture of:

- cross-sectional population studies, including people with different levels of disease severity from all ethnic groups and social classes
- longitudinal cohorts of people with CFS/ME, and population cohorts to assess the incidence and prognosis of CFS/ME in a previously normal cohort.

4.4 Measuring outcome

What is the best way of measuring outcome in research studies?

Why this is important

There is a lack of studies in this area. Knowing what is important to people with CFS/ME is crucial for designing future studies. It is not known how best to measure improvement scientifically for people with CFS/ME, and how much of an improvement is significant. More information is needed on functional outcomes such as return to work or education, return to normal family life or social activities, or increased self-esteem, to inform future estimates of the cost effectiveness of treatment.

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.

5.2 Information for the public

NICE has produced information for the public explaining this guideline.

We encourage NHS and voluntary sector organisations to use text from this information in their own materials.

6 Related NICE guidance

Nutrition support in adults: oral nutrition support, enteral tube feeding and parenteral nutrition NICE clinical guideline 32 (2006).

Referral guidelines for suspected cancer. NICE clinical guideline 27 (2005).

Depression in children and young people: identification and management in primary, community and secondary care. NICE clinical guideline 28 (2005).

Depression: management of depression in primary and secondary care. NICE clinical guideline 23 (2004, amended 2007). [Replaced by NICE clinical guideline 90]

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 22 (2004, amended 2007). [Replaced by NICE clinical guideline 113]

Irritable bowel syndrome. NICE clinical guideline 61 (2008).

Management of long-term sickness and incapacity. NICE public health programme guidance 19 (2009).

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

Chair: Professor Richard Baker
Head of Department, Department of Health Sciences, University of Leicester

Mr Richard Eddleston
Patient Representative, Nottingham

Mrs Ute Elliott
Patient Representative, Sheffield

Ms Tanya Harrison (resigned August 2007)
Patient Representative, Norfolk

Ms Jessica Bavinton
Physiotherapist, London

Dr Esther Crawley
Consultant Paediatrician, Bath

Dr Tony Downes
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Dr Richard Grünewald
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Dr William Hamilton
General Practitioner/Researcher, Bristol

Mrs Judith Harding
Dietitian, Essex

Dr Frederick Nye
Infectious Disease Consultant Physician, Liverpool

Ms Amanda O'Donovan
Clinical Psychologist, London

Dr Alastair Santhouse
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Dr Julia C Smedley
Consultant Occupational Health Physician, Southampton

Dr David Vickers
Consultant Paediatrician, Cambridge

Mrs Gillian Walsh
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Ms Carol Wilson
Occupational Therapist, Falmouth

Dr Philip MD Wood
Consultant Immunologist, Leeds

Members of the GDG from the National Collaborating Centre for Primary Care (NCC-PC)

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Chief Executive and Project Lead, NCC-PC

Ms Elizabeth Shaw
Deputy Chief Executive and Reviewer, NCC-PC

Mr Gary Britton
Health Services Research Fellow (from August 2006), NCC-PC

NCC-PC technical team

Miss Nicola Costin
Project Manager and Researcher (until June 2006), NCC-PC

Ms Sarah Dunsdon
Project Manager and Researcher (from August 2006 until February 2007), seconded to the NCC-PC

Mr Richard Norman
Health Economist (until July 2006), NCC-PC

Ms Stefanie Kuntze
Health Economist (from December 2006), NCC-PC

Ms Yolanda Jozephs
Administrator (until August 2006), NCC-PC

Mrs Karina Ramos

Administrator (from March 2007), NCC-PC

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.

Professor Mike Drummond (Chair)
Professor of Health Economics, Centre for Health Economics, University of York

Ms Karen Cowley
Practice Development Nurse, York Health Services NHS Trust

Mr Barry Stables
Patient/Lay Representative

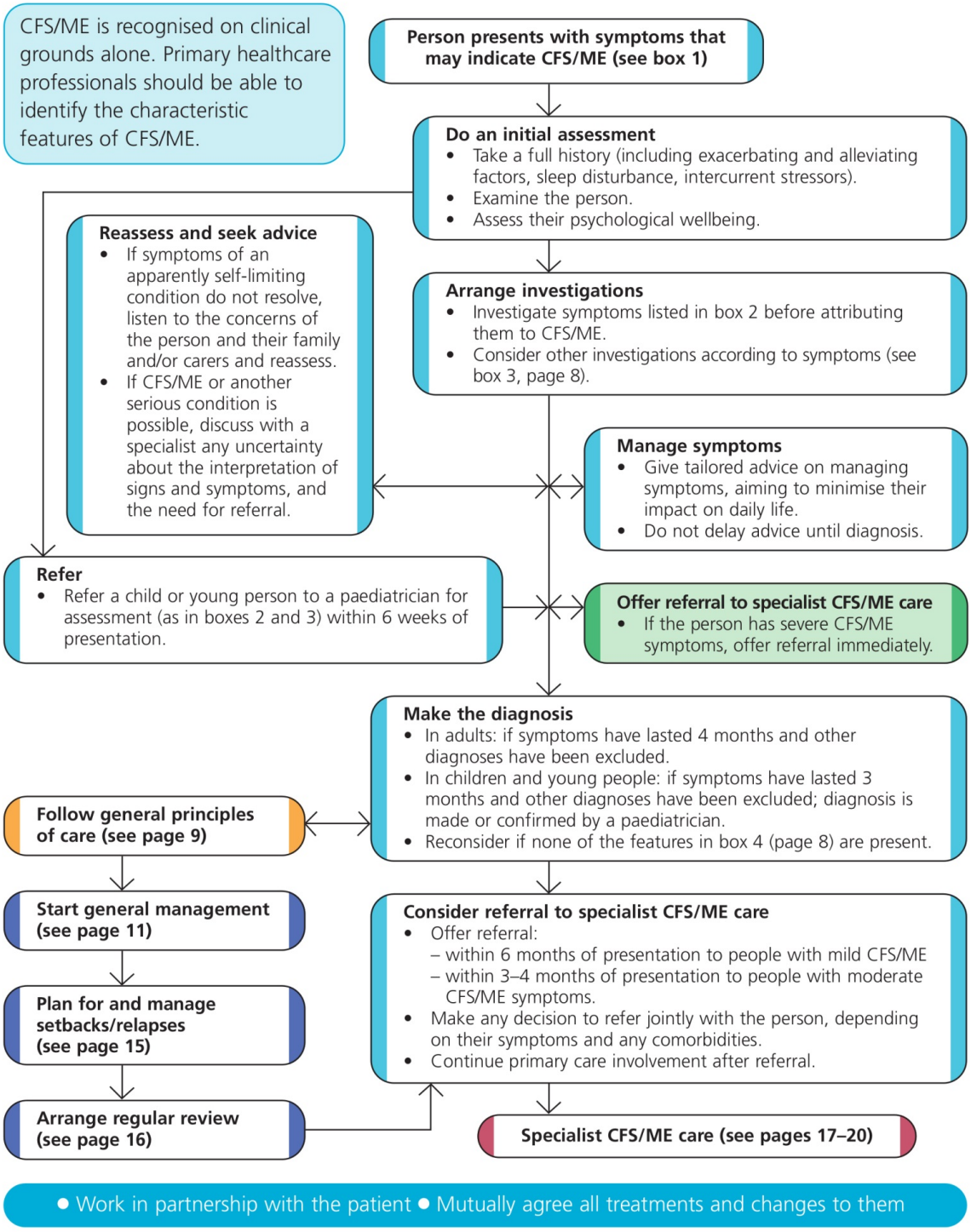
Dr John Harley
Clinical Governance and Prescribing Lead, North Tees PCT

Dr David Gillen
Medical Director, Pfizer Ltd

Appendix C: The algorithms

Care pathway

Presentation, diagnosis and pathway of care



Appendix D: Definitions used in this guideline

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 approach to managing a person's symptoms by using activity. It is goal-directed and uses activity analysis and graded activity to enable people to improve, evaluate, restore and/or maintain their function and well-being in self-care, work and leisure.

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. Boom and bust cycles can happen when a person with CFS/ME is overactive when they are feeling better, which may lead to an increase in symptoms and a decrease in function.

Cognitive behavioural therapy (CBT)

An evidence-based psychological therapy that is used in many health settings, including cardiac rehabilitation and diabetes management. It is a collaborative treatment approach. When it is used for CFS/ME, the aim is to reduce the levels of symptoms, disability and distress associated

with the condition. A course of CBT is usually 12–16 sessions. The use of CBT does not assume or imply that symptoms are psychological or 'made up'.

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 CFS/ME that involves physical assessment, mutually negotiated goal-setting and education. 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, taking into account their preferences and objectives, current activity and sleep patterns, setbacks/relapses and emotional factors. The objective is to improve the person's CFS/ME symptoms and functioning, aiming towards recovery.

Pacing

The report of the Chief Medical Officer's working group[12] defined the principles of pacing, and these are supported by people with CFS/ME and patient groups. Many of the principles are included in this guideline's recommendations on CBT, GET and activity management. Examples include spreading activities over the week, breaking tasks down into small manageable parts, interspersing activity with rest and setting appropriate, realistic goals for increasing activity.

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. 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 differently by different groups of people. One understanding of its meaning is as adaptive pacing therapy, which is facilitated by healthcare professionals, in which people with CFS/ME use an energy management strategy to monitor and

plan their activity, with the aim of balancing rest and activity to avoid exacerbations of fatigue and other symptoms.

Another understanding is that pacing is a self-management strategy, without specific 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. Rest periods are a core component of all management approaches for CFS/ME.

Setback/relapse

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

Severity

The degree to which CFS/ME affects a person's functioning and daily life[13].

- 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. They often take days off, or use the weekend to cope with the rest of the week.
- 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, school or college and need rest periods, often sleeping in the afternoon for 1 or 2 hours. 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.

[12] Department of Health (2002) *A report of the CFS/ME working group: report to the Chief Medical Officer of an independent working group*. London: Department of Health.

[13] These definitions were agreed by the GDG and have been derived from definitions in:

- Royal College of Paediatrics and Child Health (2004) Evidence-based guideline for the management of CFS/ME (chronic fatigue syndrome/myalgic encephalopathy) in children and young people.

- Department of Health (2002) *A report of the CFS/ME working group: report to the Chief Medical Officer of an independent working group*. London: Department of Health.

- Cox DL, Findley L (1998) Management of chronic fatigue syndrome in an inpatient setting: presentation of an approach and perceived outcome. British Journal of Occupational Therapy 61: 405–9 (this approach was adopted in the CFS/ME working group's report to the Chief Medical Officer, see footnote 12).

About this guideline

NICE clinical guidelines are recommendations about the treatment and care of people with specific diseases and conditions in the NHS in England and Wales.

The guideline was developed by the National Collaborating Centre for Primary Care. The Collaborating Centre worked with a group of healthcare professionals (including consultants, GPs and nurses), patients and carers, and technical staff, who reviewed the evidence and drafted the recommendations. The recommendations were finalised after public consultation.

The methods and processes for developing NICE clinical guidelines are described in The guidelines manual.

We have produced information for the public explaining this guideline. Tools to help you put the guideline into practice and information about the evidence it is based on are also available.

Changes after publication

January 2012: minor maintenance

November 2013: minor maintenance

Your responsibility

This guidance represents the view of NICE, 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. However, the guidance does not override the individual responsibility of healthcare professionals to make decisions appropriate to the circumstances of the individual patient, in consultation with the patient and/or guardian or carer, and informed by the summary of product characteristics of any drugs they are considering.

Implementation of this guidance is the responsibility of local commissioners and/or providers. Commissioners and providers are reminded that it is their responsibility to implement the guidance, in their local context, in light of their duties to avoid unlawful discrimination and to have regard to promoting equality of opportunity. Nothing in this guidance should be interpreted in a way that would be inconsistent with compliance with those duties.

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