


Scottish Good Practice Statement on ME-CFS

A guide for GPs to use
in the consulting room
First edition

 Proof copy for media launch
Scottish Parliament, 14 May 2009

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Introduction

"ME was known to run a chronic course and patients had disabilities due to persistent symptoms of pain, fatigue and loss of endurance to normal physical activities with conspicuous deterioration of symptoms after exercise (post exertional malaise)." Scottish Short Life Working Group¹

The purpose of this Scottish Good Practice Statement on ME-CFS is to provide general practitioners with a simple, straightforward document that can be easily used in the consulting room.

It is hoped that this will be the first in a series which will inform health professionals on the management of ME-CFS until there is the research evidence available to qualify for a guideline by the Scottish Intercollegiate Guidelines Network (SIGN). It is a living document and will be revised as research reports are published which will influence clinical practice.

In parallel with this Statement of Good Practice the Scottish Public Health Network has undertaken a Needs Assessment on ME-CFS which will help inform the NHS in Scotland on future service design and provision for people with ME-CFS.

Myalgic Encephalomyelitis/Encephalopathy (M.E.) is a chronic, fluctuating illness, often referred to as Chronic Fatigue Syndrome (CFS) and sometimes as Post Viral Fatigue Syndrome (PVFS).

It causes significant ill health and disability in a substantial number of adults, young people and children². It can affect anyone, at any age, from any ethnic group. Epidemiological evidence for Scotland is lacking but a population prevalence of at least 0.2% - 0.4% is widely accepted³, and over 20,000 people in Scotland may be affected⁴. It has characteristic features which are highly variable among patients. It is also highly variable in its duration and severity.

At present diagnosis is made from recognising symptom patterns. There is currently no definitive test available on the NHS to confirm the diagnosis.

ME/PVFS is classified as a neurological illness by the World Health Organisation (WHO) (ICD 10 at 93.3) and both the UK and Scottish Governments follow the classifications set out in ICD 10. Chronic Fatigue Syndrome is a non-specific term encompassing people suffering from various syndromes of chronic fatigue.

National and international debate is ongoing as to appropriate terminology but for the purposes of this Statement we will use the composite ME-CFS, the term recommended by the Scottish Public Health Network in the Scottish Needs Assessment (2009).

The NHS has recognised that the symptoms of ME/PVFS are real and of a physical nature. They can be as disabling, for example, as multiple sclerosis, systemic lupus erythematosus, rheumatoid arthritis, congestive heart failure and other chronic conditions and the illness places a substantial burden on people with the condition, their families and carers, and on society⁵.

Prognosis is extremely variable. Most patients have a fluctuating course of illness, some with relapses while others do not experience remission.

Health and functioning rarely return completely to the individual's previous levels⁶; most of those who feel recovered stabilise at a level of functioning lower than they had before the illness.

Overall, there is a wide variation in duration of illness, with some people recovering, or improving significantly, in less than two years, while others remain ill for several decades. Any recovery is not necessarily permanent and relapses can still occur⁷.

ME-CFS causes a range of symptoms and it is necessary to adopt an holistic approach to symptom control and care. Holistic is used here in its fuller sense, ie. as having regard not only for the illness and its treatment but also for the impact of the illness on the patient, their carers, family and on work and social life⁸.

Empathetic listening is vital as with all chronic illnesses. Mutual respect and shared decision-making between the person with ME-CFS and healthcare professionals is essential during diagnosis and all phases of care⁹.

Healthcare professionals should remember that - like all people receiving care in the NHS - people with ME-CFS 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 care¹⁰.

All efforts should be made to investigate the patient's symptoms, particularly if there are changes in presentation, as one would with any chronic illness.

During the very early stages, especially in acute onset, post infection, the clinical presentation is likely to involve symptoms such as hypersomnia and severe post infection fatigue. These may change in severity or nature as time goes on and consequently require a differing approach to certain aspects of management especially activity and sleep disturbance.

There is also a need for early and accurate diagnosis where possible, with consideration of making the provisional diagnosis by three to four months into the illness.

It is important to actively consider ME-CFS as a diagnosis in patients presenting with these symptoms. It focuses relevant investigation and allows symptom and energy management to begin. GPs should be able to alleviate symptoms in most patients with ME-CFS, as with many other chronic conditions. Shared care with specialists, for diagnosis or development of a management plan, will help with problems that are complex, severe or prolonged.

At present the diagnosis of ME-CFS remains clinical, based primarily on symptom recognition, much as Parkinson's disease was in the past, before the development of specific investigations. As the research base develops, it is expected that in time specific investigations will be available to positively support diagnosis. It is vitally important that Scotland has a mechanism for bringing together researchers, practising clinicians and people with ME-CFS to drive the research agenda. This will in turn lead to improved clinical practice in the NHS.

Please note: At present there are investigations, medications and management strategies available privately eg. mitochondrial testing (see p 25).

Clinical presentation

"The normal fatigue/pain pattern directly related to felt causal action and adjusted by activity/rest rhythms is broken in ME-CFS. As a result there are cumulative physical and cognitive fatigue/pain and 'crashing' patterns." Canadian Consensus Document¹¹

Precipitative factors

Some form of infection, typically but not always viral, is a common precipitating factor eg. flu-like illness, glandular fever, viral hepatitis (particularly hepatitis C), enteroviruses, meningitis or encephalitis, labyrinthitis, herpes viruses including cytomegalovirus and herpes zoster and parvovirus B19. In the region of one in ten to one in eight people may be affected by ME-CFS after contracting the Epstein Barr Virus (EBV). Other infections such as Coxiella Burnetii/Q fever and bacterial meningitis can also precipitate ME-CFS. Patients commonly describe themselves as never having fully recovered from the infection.

The role of trauma, surgery, certain vaccinations, toxins, pesticide exposure and/or stressful major events as triggers is possible, but less well established. In a minority of cases, the onset can be more insidious with no identifiable precipitating factor, and here the diagnosis can be harder to make in the early stages.

For most adults, six weeks from the onset of abnormal fatigue and other recognised symptoms is a time to be considering ME-CFS as a differential working diagnosis. By six months, if symptoms persist, a provisional diagnosis can usually be confirmed. The National Institute for Health and Clinical Excellence (NICE) and the Canadian Consensus Document (CCD)¹² suggest these timescales are shortened to three months for children. Further guidance on children and young people is presented on p 12.

Criteria

No one set of criteria for the diagnosis of ME-CFS has been universally agreed. Most criteria have been developed for research purposes.

The Scottish Public Health Needs Assessment document recommends the use of the CCD for the diagnosis of ME and the NICE guideline for the diagnosis of CFS.

The CCD says patients with ME will meet the criteria for fatigue, post-exertional malaise and/or fatigue, sleep dysfunction, and pain; have two or more neurological/cognitive manifestations and one or more symptoms from two of the categories of autonomic, neuroendocrine and immune manifestations; and adhere to item 7 below.

1. **Fatigue:** the patient must have a significant degree of new onset, unexplained, persistent, or recurrent physical and mental fatigue that substantially reduces activity level.
2. **Post-exertional malaise and/or fatigue:** there is an inappropriate loss of physical and mental stamina, rapid muscular and cognitive fatigability, post exertional malaise and/or fatigue and/or pain and a tendency for other associated symptoms within the patient's cluster of symptoms to worsen. There is a pathologically slow recovery period - usually 24 hours or longer.
3. **Sleep dysfunction:** there is unrefreshed sleep or sleep quantity or rhythm disturbances such as reversed or chaotic diurnal sleep rhythms.
4. **Pain:** there is a significant degree of myalgia. Pain can be experienced in the muscles and/or joints and is often widespread and migratory in nature. Often there are significant headaches of new type, pattern or severity.

5. **Neurological/cognitive manifestations:** two or more of the following difficulties should be present: confusion, impairment of concentration and short-term memory consolidation, disorientation, difficulty with information processing, categorising and word retrieval, and perceptual and sensory disturbances - eg. spatial instability and disorientation and inability to focus vision.

Ataxia, muscle weakness and fasciculations are common. There may be overload phenomena: cognitive, sensory - eg. photophobia and hypersensitivity to noise - and/or emotional overload, which may lead to 'crash' periods and/or anxiety.

6. At least one symptom from two of the following categories:
- a. **Autonomic** manifestations: orthostatic intolerance - neurally mediated hypotension (NMH), postural orthostatic tachycardia syndrome (POTS), delayed postural hypotension; light-headedness; extreme pallor; nausea and irritable bowel syndrome; urinary frequency and bladder dysfunction; palpitations with or without cardiac arrhythmias; exertional dyspnea.
 - b. **Neuroendocrine** manifestations: loss of thermostatic stability - subnormal body temperature and marked diurnal fluctuation, sweating episodes, recurrent feelings of feverishness and cold extremities; intolerance of extremes of heat and cold; marked weight change - anorexia or abnormal appetite; loss of adaptability and worsening of symptoms with stress.
 - c. **Immune** manifestations: tender lymph nodes, recurrent sore throat, recurrent flu-like symptoms, general malaise, new sensitivities to food, medications and/or chemicals.
7. The illness persists for at least six months: It usually has a distinct onset, although it may be gradual. Preliminary diagnosis may be possible earlier. Three months is appropriate for children.
- The symptoms must have begun or have been significantly altered after the onset of this illness.
 - It is unlikely that a patient will suffer from all symptoms in 5 and 6.
 - The disturbances tend to form symptom clusters that may fluctuate and change over time.
 - Children often have numerous prominent symptoms but their order of severity tends to vary from day to day.
 - There is a small number of patients who have no pain or sleep dysfunction, but no other diagnosis fits except ME-CFS.
 - A diagnosis of ME-CFS can be entertained when this group has an infectious illness type onset.
 - Some patients have been unhealthy for other reasons prior to the onset of ME-CFS and lack detectable triggers at onset or have more gradual or insidious onset.

An overview of the CCD can be downloaded from: www.cfids-cab.org/MESA/me_overview.pdf

The NICE clinical guideline 53, *Chronic Fatigue Syndrome / Myalgic Encephalomyelitis (or encephalopathy): Diagnosis and management in adults and children*, (published 2007) may be downloaded from: www.nice.org.uk/guidance/CG53*

*The current advice from NHS Quality Improvement Scotland on NICE guidelines is that these have no formal status in Scotland, as SIGN has responsibility to produce clinical guidelines for NHS Scotland. Guidelines help healthcare professionals in their work, but they do not replace their knowledge and skills.

Symptoms and signs

Making a firm, or provisional, diagnosis of ME-CFS is an essential first step in active symptom management.

It removes uncertainty, reduces anxiety and provides an explanatory model that justifies appropriate changes in a person's lifestyle and expectations. **The diagnosis is based on pattern recognition of a range of recognised symptoms and on how they relate to activity.**

It is important to separate the primary symptoms of the illness from the secondary symptoms such as anxiety or depression which can occur with severe chronic illness. Although there is as yet no validated diagnostic test available on the NHS, a diagnosis of ME-CFS can and should be a positive diagnosis, with other conditions excluded as appropriate.

ME-CFS is characterised in many patients by severe, disabling physical and mental fatigue, both of which are exacerbated by relatively minor amounts of exertion. The fatigue is accompanied by post-exertional malaise whereby there is a delayed impact so that coexisting symptoms are worse following activity any time from a few hours later to days later.

The way in which fatigue is described in ME-CFS is very different to normal everyday tiredness. (The MS Society's observation that: "Some people say that their power plug has suddenly been pulled out," is one that ME patients would recognise.) However, fatigue may not be the patient's worst symptom.

Rating scale

When a patient presents to a GP with symptoms consistent with ME-CFS it is valuable to ask the patient to fill out a rating scale (see p 32). Severely affected patients may require help and support from a clinician in carrying this out. The completed rating scale, as well as aiding diagnosis, will guide the symptom management plan.

Key symptoms:

- Activity-induced muscle fatigue.
- Post-exertional malaise (see p 31).
- Cognitive dysfunction: problems with short-term memory, concentration and memory span.
- 'Brain fog' which affects the ability to read, think, process information and understand the simplest of language. Patients experience problems with short-term memory. Cognitive difficulties are more pronounced when the person is dealing with complex issues. Spatial awareness can also be greatly affected.
- Pain is present in the majority of patients and is often persistent and difficult to control. Pain is often muscular but can also be rheumatic, neuropathic or fibromyalgic.
- Muscle weakness and muscle fasciculations.
- Sleep disturbance eg. insomnia, early morning waking, unrefreshing sleep, disturbed sleep/wake cycle.
- A general feeling of ongoing malaise.
- Orthostatic intolerance which can present as 'funny turns,' faints or feeling dizzy even when standing for short periods.

The adverse effect of exercise should be noted particularly on the cardiovascular system including decreased cerebral blood flow (see p 31).

Other symptoms to look for:

- Disequilibrium
- Autonomic dysfunction
- Disturbed thermoregulation, night sweats and heat sensitivity
- Sensory disturbances
- Hyperacusis
- Headaches of new onset, type, pattern or severity
- Arthralgia but not including swelling, redness or joint deformity
- Irritable bowel-type symptoms (eg. nausea, loss of appetite, indigestion, excessive wind, bloating, abdominal cramps, alternating diarrhoea and constipation, food intolerance)
- Alcohol intolerance, drug and chemical sensitivities
- Eye problems (photophobia, nystagmus, blurred vision, difficulty focussing and dry eyes).

Clinical signs

- Postural Orthostatic Tachycardia Syndrome (POTS)
- Recurrent sore throats, including faucial injection
- Tender cervical and/or axillary lymph nodes
- Elevation of radial pulse rate to 20% above normal when patient stands up
- Positive Romberg's sign
- Hypersensitivity to vibration
- Abnormal tandem gait
- Abnormal fatiguing on serial 7 subtraction.

Referral for specialist assessment

At present services throughout Scotland are not uniform. GPs may not have a designated consultant to refer patients to. It would be appropriate for GPs to refer patients to consultants with expertise of the clinical symptoms that dominate in a particular patient eg. cardiovascular assessment for patients with predominantly cardiovascular symptoms and neurological assessment for patients with predominantly neurological symptoms.

Clinical assessment and diagnosis

"As the primary diagnostician, the GP should be aware of the range of illnesses that require to be assessed before a diagnosis can be made." Editorial on the CCD¹³

As the crucial tool in diagnosis is the clinical history, sufficient time should be allowed for patients to give a narrative account of their illness experience. At present there is no confirmatory test available on the NHS.

Fatigue is a symptom of many conditions, therefore investigation should be geared to making a positive diagnosis and to exclude other illnesses.

The following tests should be undertaken for evaluation and to exclude other conditions; additional tests may be needed to further evaluate specific symptoms or features:

- Full blood count
- ESR
- C-reactive protein <CRP)
- Blood biochemistry including creatinine, urea and electrolytes, calcium, liver enzymes and glucose
- Thyroid function tests
- Urinalysis
- Serum creatine kinase
- Blood pressure in upright and supine positions
- ECG (in adults)
- Epworth sleepiness score¹⁴.

Depending on the results of the initial tests and the patient's progress and if symptoms suggest that any of the following are likely, appropriate investigations or specialist referral should be carried out:

- | | |
|--|--------------------------|
| • Adrenal insufficiency | • Organic pain disease |
| • Anaemia | • Primary sleep disorder |
| • Coeliac disease | • Rheumatic diseases |
| • Hepatitis serology | • Somatisation disorder |
| • Immunodeficiency | • Thyroid disease |
| • Malignancy | • Heavy metal poisoning |
| • Multiple sclerosis | • Mood disorders |
| • Identifiable chronic infection (particularly Lyme Disease) | • Myasthenia gravis, |

Dependent on clinical presentation and symptoms, examples of further tests on patients could include;

- Chest x-ray
- Rheumatology and autoantibody screen
- Tissue transglutaminase antibody for coeliac disease
- Serum B12
- Serum 25-hydroxyvitamin D
- Serum oestradiol and FSH
- Serum prolactin and neuroradiology investigations
- Lyme serology
- Infectious disease screen if there is any possibility of chlamydia, hepatitis B/C, HIV, mycoplasma, Q fever etc.

Dependent on the results of these investigations, referral to a specialist for elucidation of diagnosis would be appropriate at this point.

The following tests have been used in research studies and clinical assessment:

- Autonomic function tests
- Infectious disease screen
- MRI scan of the head
- Muscle biopsy
- Fat biopsy test for volatile organic compounds, particularly for those patients exposed to organophosphates, pesticides etc
- Short synacthen (ACTH test)
- Gastric biopsy
- Tilt-table testing*
- SPECT scans.

Please see Professor Newton's paper, p 24. Patients presenting with symptoms consistent with POTS should be referred for tilt table testing.

Investigations not available on the NHS include mitochondrial testing (see p 25)

Monitoring course and assessing severity

The severity of specific symptoms will vary from patient to patient and for an individual patient over time. As part of the ongoing evaluation of the clinical course the practitioner may find it helpful to periodically assess the relative severity and impact of a patient's symptoms using the rating scale set out on p 32

Children and young people

"A significant problem in the literature is the lack of both a pediatric definition of ME-CFS and a reliable instrument to assess it." Leonard A. Jason¹⁵

It is recognised that the diagnosis and management of ME-CFS in children and young people is an area which needs to be developed in a specific Good Practice Statement. However, the following is intended to provide guidance in the interim.

Children can be as profoundly affected by ME-CFS as adults. Symptoms may have similar severity to adults but the fluctuation in severity can be much more dramatic. Severe exhaustion, weakness, pain and mood changes make life very challenging for children (as well as adults) with ME-CFS.

The limited evidence available suggests that young people with ME-CFS are more likely to recover than adults.

Studies with extended follow up show 60-80% partial or complete recovery with an average duration of illness of 37.5 - 49 months, with about 20% of cases remaining incapacitated, some for many years¹⁷.

The principles of care in children and young people are common to many chronic conditions. Most of the issues covered for adults also apply to children. Some need different emphasis.

This can impact upon a child's development and affect family life adversely. It is therefore crucial that the child and their parent/guardian are listened to.

Speedy diagnosis is important to allay fears of other serious illness eg. leukaemia, to protect the patient from undue pressure and to allow symptom control and appropriate management to begin. This should prevent further deterioration in many, but not all, cases. Management should be geared to the condition of the child and agreed with the parents/carers.

Differentiation from school phobia

In one UK study 51 % of pupils with long-term school absenteeism suffered from ME-CFS¹³. However, unlike school phobia, pupils with ME-CFS spend most of their time incapacitated or having to rest¹⁹. They tend to do worse in mathematics and analytical subjects such as science. They are often classified as having school phobia²⁰. Severely affected young people may be bedbound and the impact on the other members of the family, particularly other vulnerable children and adults, should be recognised.

Clinical presentation in children

The CCD says- "Children can be diagnosed with ME-CFS if symptoms last more than three months. They tend to have numerous symptoms of similar overall severity but their hierarchy of symptom severity may vary from day to day. Severe, generalised pain is a common feature. Children may become dyslexic, tearful, physically weak and exhibit exhaustion or profound mood changes."

- **Loss of energy/fatigue**
The loss of energy and weakness may be so profound as to make the child bedbound. Post-exertional fatigue and weakness will affect the ability of the child to undertake exercise or sport. The severity of symptoms will affect the ability of the child to attend school.
- **Cognitive problems**
Slowing of thought processes - work involving abstract thought is difficult to perform in all cases. Even if the child usually starts a task well a rapid deterioration in cognitive abilities often takes place, which may be accompanied by exacerbations of other symptoms.
Impairment of short term memory - poor retention and recall eg. lack of recollection of magazine articles read only a few minutes previously.

Cognitive abilities deteriorate particularly in topics requiring analysis, multi-task activities, fast-paced and confusing environments and with physical, mental and emotional fatigue²¹.

- **Disordered sleep pattern**

- **Weight loss**

There are reports that this can be significant in the early stages. Shepherd and Chaudhuri²² recommend that height and weight charts be maintained in all paediatric cases of ME-CFS where laboratory tests may not be possible.

- **Gastro-intestinal disorders**

Children may be diagnosed with ME-CFS when symptoms have lasted for more than three months. A working diagnosis can be given after a much shorter time.

Care needs

A child can be so profoundly affected that the family may require practical help and support. This may take the form of aids prescribed by a community OT. Care packages may need to be drawn up for those more severely affected.

Referral

GPs would consider this an area of specialist expertise and refer these patients to the paediatric service. Referral to a community OT could also be valuable - and would contribute to the specialist assessment. It could be useful in more severely affected cases where there are muscle problems and problems with mobility. Again, there may be a need for appropriate training in ME-CFS for relevant staff.

Schooling

As a result of physical and mental activity levels being reduced, pupils have difficulty at school or are unable to maintain a full school programme. The school may require a supportive letter from the pupil's doctors (GP and/or paediatrician) outlining the patient's medical condition and the limitations this imposes, and advising on accommodations the school can make to take account of the impact of the illness on the child. Good and open communication between the school and the pupil's doctors is helpful.

For those not able to attend, schools have a responsibility to provide home tuition. Arrangements should be responsive to the child's condition and take advantage of times when the child has more energy. Children attending school may not be able to undertake a full day and appropriate rest breaks in appropriate facilities should be organised.

Children in Scotland runs Enquire, a telephone helpline for advice on educational support needs. Tel: 0845 123 2303. E-mail: info@enquire.org.uk

Child protection issues

There have been concerns that misunderstanding and lack of information about ME-CFS in education and social services has led to inappropriate initiation of child protection procedures²³. There are reports of child protection procedures being initiated because of disagreements between families and health and education professionals over treatment plans.

The report of the Working Group on ME-CFS to the UK's Chief Medical Officer (2002), said: "Neither the fact of a child or young person having unexplained symptoms nor the exercising of selective choice about treatment or education for such a child constitutes evidence of abuse."

As noted elsewhere in this document, much controversy remains over the place of graded exercise and CBT in the management of this condition.

Adults and children who are more severely affected

"Estimates suggest that up to 25% of people with CF5/ME are so seriously affected that they are unable to perform most basic personal tasks and are confined to bed or spend the majority of the day in bed." Working Group Report, 2002²⁴

it is recognised that the diagnosis and management of severe ME is an area which needs to be developed in a specific Good Practice Statement. However, the following is intended to provide guidance in the interim.

No definitive studies have been carried out in the UK to determine the prevalence of severe ME-CFS. Estimates range from 10% to 25%²⁵ of those affected.

At some stage in the illness many patients may fall into the category of severe ME.

The quality of life of ME patients shows marked diminution. However, there is a spectrum of severity. Broadly speaking, up to 25% may be termed severely affected ie. severely restricted in mobility and ability to carry out essential daily tasks and attend to personal care.

At its most extreme, patients may be totally bedbound and report constant pain, inability to tolerate movement, light or noise and certain scents or chemicals (including prescribed drugs). They will often spend periods of time bedbound, housebound or wheelchair-bound. Neurological symptoms can be extreme - with, for example, difficulty swallowing, temporary paralysis.

It is important to check for intercurrent illness such as chest infection.

There is concern that GPs may not be aware of the clinical conditions of the most severely affected patients, making it difficult for their needs to be addressed. Patients may suffer severe debility from the intensity of one prominent symptom or from a cluster of symptoms such as sore throat, swollen glands and flu-like symptoms. Some may become bedbound because of fatigue per se or from, for example, post-exertional fatigue.

Individualised approach

The care and support of such severely affected patients requires a very individualised approach, with care being delivered in the patient's own home as much as possible. It is vital for clinicians to be aware that there is very little research evidence on management of such patients and that simple extrapolation from other patient groups is usually inappropriate. Such patients can only manage physical or cognitive tasks for very short periods, if at all, and this will need to be reflected in consultations.

Expectations must be realistic and discussed with the patient to focus their very limited energy on things that are meaningful for them. Severe effects may prevail for many years before any improvement or stabilisation is seen.

The primary care team is crucial for supporting severely affected patients. Where provision exists, severely affected patients should be referred to a specialist, experienced in severe ME-CFS, immediately²⁶. Where there is no specific provision it would be appropriate to refer to the consultant physician most capable of dealing with the patient's particular clinical needs.

There should be understanding and agreement between clinicians and patients as to what are an individual's most important goals. It may be an agreement to achieve modest increases in self-care or activities of daily living.

Medication can still be useful to help with symptoms such as pain, sleep and secondary anxiety, muscle spasms and cramps, and nausea - see p 18. Many experts have advised that very low doses of medication be used initially (liquid formulations can help with this).

Respite care may be helpful if desired, but ideally should be in settings that have experience with people with severe ME-CFS, and that are adapted to their particular needs.

Carers are especially important in supporting patients, and their own needs must be considered.

Many patients, especially those who live alone, will lose the means to manage their home circumstances, including finances, and effectively seek help and support during their time of incapacity. Anecdotal evidence suggests that the longer it takes to receive medical and practical assistance, the longer the patient's recovery time and the greater the likelihood of chronicity.

It is hoped that aligning the care of those people severely affected, with long-term conditions planning in Health Boards, will allow a full assessment of the needs of those people and allow appropriate management and support plans to be developed.

Assessment by community nursing, community OT and community physiotherapy would also be valuable, depending on the specific needs of the patient. This is predicated upon community staff being able to access appropriate education and training.

Symptom management

"Patient support and well-being are the top priorities." CCD²⁷

The aim of this section is to inform the GP of management strategies that have been made available in the NHS. Management strategies not available in the NHS will be dealt with in the Research section on p 24.

Clinical background

At present there is no uniform care pathway in Scotland. It is important for GPs to involve other professionals in the care and support of people with ME-CFS. GPs need to be aware of management strategies that have been employed in the NHS and to be fully aware of the debate and controversy particularly around Graded Exercise Therapy (GET) and Cognitive Behavioural Therapy (CBT).

- **It is important to give advice/help early on, even whilst waiting for a firm diagnosis.**
- **It is vital to understand the importance to patients of having a name for their condition, to inform the patient of the possible duration and impact of the illness and the uncertainties with which it is associated.**
- **A number of consultations will be required to establish a positive diagnosis and to agree and monitor treatment.**
- **The symptoms of ME-CFS fluctuate in their severity and nature over time, from day to day and can fluctuate hour to hour.**
- **What works for one patient may not work for another and a number of different approaches may need to be tried.**

Services should be delivered in ways that are suitable for the individual patient. This may sometimes mean domiciliary services. This is particularly important for the severely affected who often experience extreme barriers to accessing all forms of care and treatment.

Clinicians should adopt an holistic" approach in treating the symptoms of ME-CFS.

- Acknowledge the biological and pathophysiological reality, impact and heterogeneity of ME-CFS and its symptoms.
- Share decision-making with the patient.
- Be explicit about diagnosis and co-morbidity (if relevant).
- Explain the possible causes, nature and course of the illness, together with possible management options (benefits/risks), as outlined in this guide, taking account of the person's age and the stage, severity and variability of their illness.
- Explore the range of management options that can be utilised, as appropriate to the particular patient's condition.
- Offer information on other sources of support (eg. national charities, local groups and services). Please see p 26.

Discussion with patients with a working diagnosis of ME-CFS should cover:

- Diagnosis (clear diagnosis can be very therapeutic - recognising the heterogeneity of the condition)
- Acceptance (patients will find it hard to make changes if they don't accept that they have the illness).
- Energy levels (management of limited energy levels with pacing to avoid 'boom and bust' because if patients exceed their energy envelope too often or by too much this can cause severe or long-term relapses).
- Adjustment (this can be hard, and it is OK to have help).
- Symptom control (reducing burden and stopping vicious cycles).
- Support and monitoring (listening, interpreting, guiding).
- Possibility of setbacks (not uncommon).
- Support strategies with appropriate literature.

No single treatment has yet been shown to be consistently effective in alleviating the underlying disease process. Various rehabilitative approaches have often been found to be potentially beneficial in modifying symptoms of this illness, and assisting the recovery process, especially in less severely affected patients. While a variety of drug treatments have been suggested for people with ME-CFS, few have been subjected to well organised, randomised controlled trials (RCTs).

Rating scale

A completed rating scale (see p 32) can guide the symptom management plan by indicating:

- Which symptom(s) predominate for an individual patient.
- Which symptoms can be more readily managed by medication.

Repeating the rating scale at regular intervals gives insight into how the illness fluctuates in an individual patient over time.

Care pathway

Different care pathways and services need to be developed for groups with particular requirements such as children and young people; those severely affected; housebound and bedbound patients; and those living in remote or rural areas. Where the patient group is small, such as in remote and rural areas, it may be necessary to develop services for ME-CFS integrated with the management of other chronic diseases, or to work in partnership with other NHS Boards.

Each health Board will have or will develop its own care pathway – see Needs Assessment online at www.healthscotland.com/resources/networks/scotphn/projects/CFSME.aspx

Pharmacological treatments

Reducing the most unpleasant symptoms can help the patient to regain a sense of control, as well as stop vicious cycles, eg. with sleep or mood disturbance. They can be especially useful whilst the patient adjusts to the illness and whilst longer term strategies are developed that may reduce the drive to symptoms (eg. through attempting over-activity). Medication and non-drug treatment can help. Some agents can help several symptoms, so choices may reflect what combination of symptoms the patient wishes most to control. Many patients have reported the value of meditation and relaxation techniques.

People with ME-CFS are often very sensitive to the side-effects of drugs, particularly anti-depressants, anaesthetics and those which act on dopaminergic transmission (eg. metoclopramide). However, these agents can be efficacious at lower doses in such patients. Consequently, it is normally desirable to commence at a low dose, followed by gradual increases, if necessary and tolerated. This may require the use of liquid preparations. Some agents are especially poorly tolerated, including beta-blockers, and the more activating anti-depressants (paroxetine, fluoxetine, venlafaxine).

- ### Pain relief

The value of heat and gentle massage should be considered. Simple analgesics should be tried first, including paracetamol, co-codamol or NSAIDs, topical or systemic. The gastric side-effects of NSAIDs must be particularly noted. Should these prove ineffective, treatment focused on the type of pain can help. There are reports of patients requiring opiates to control their pain.

For neuropathic pain (burning, shooting, dysaesthesia, fibromyalgia), a very low dose of a sedating tricyclic, such as amitriptyline or nortriptyline can be tried initially, especially if there is also sleep disturbance. If of value the dose can be slowly increased. If tricyclics are ineffective, insufficient or not tolerated, gabapentin or pregabalin, or else valproate, can be useful. A TENS machine or acupuncture can be useful for some patients.

Muscle pain is sometimes accompanied by twitching, fibrillation, cramps and spasm. Cautious use of a centrally acting muscle relaxant (such as baclofen) may be helpful in selected cases to reduce unwanted or unco-ordinated muscle activity. Diazepam is licensed for muscle spasm but there are concerns about its use in this condition, particularly regarding pronounced side effects and risk of withdrawal.

- ### Sleep disturbance

The importance of a good sleep pattern should not be underestimated. Hypersomnia is a well recognised problem, particularly in the early stages of the illness. It is appreciated that many mild to moderately affected patients rely on daytime and weekend sleep to allow them to work or undertake other essential activities. Relaxation and meditation techniques can be very useful.

If medication is required, then use of a low dose of a sedating tricyclic, such as amitriptyline, nortriptyline, or trazodone, should be tried, as these can help re-establish sleep rhythm. Non-sedating agents should be used if the patient has early morning wakefulness, but no problem initiating sleep. It is important to explain that these agents are being used to treat sleep, as patients may know them as 'anti-depressants.' A hypnotic should only be used in the short term. Melatonin is awaiting SMC approval.

Some patients find that sleep may be helped by low doses of non-activating SSRIs (taken in the morning), especially if there is associated anxiety.

The pros and cons of daytime napping is an area that remains controversial.

- **Headache**
If migrainous in nature, standard treatments for migraine should be tried, including triptans if appropriate. If frequent, then prophylaxis with amitriptyline, nortriptyline, pizotifen, gabapentin or valproate should be tried, but beta-blockers should be avoided.
- **Abdominal symptoms**
People with ME-CFS often suffer from symptoms of irritable bowel syndrome. This should be treated using conventional medication, such as ispaghula husk and antispasmodics (eg. mebeverine, alverine). A low dose of a sedating tricyclic at night may also be useful, such as amitriptylene.
- **Disorders of balance**
This is common, especially after viral labyrinthitis. Exercises are often ineffective or not tolerated, but some patients can reduce the unpleasant symptoms with betahistine or cinnarizine.
- **Effects on mood**
For patients with co-existent clinical depression and/or anxiety, pharmacological treatment with an anti-depressant may be appropriate. Treatment should be started in a low dose and monitored for effect, being gradually increased if necessary and tolerated. Patients with ME-CFS tend to do better on the less activating agents such as citalopram, sertraline, trazodone or mirtazapine. Choices and combinations of agents should be tailored to patient circumstances, especially the presence of sleep disturbance. Some patients prefer to use St John's Wort, which can also be helpful in some cases.

When appropriate, patients should be offered anxiety management or psychotherapy.

Other pharmacological treatments:

- **Amantadine**
There is no firm evidence of the value of this drug at present.
- **Antifungal drugs**
Antifungal drugs should only be prescribed when there is a proven fungal infection. There is no scientific evidence to support the hypothesis that Candida is involved in ME-CFS.
- **Antiviral drugs**
As yet there is no firm evidence to prescribe these medications. As noted earlier a wide range of viruses and other infectious agents have been investigated but findings are mixed and there is no conclusive support for any one pathogen. At present, there is limited evidence of persistent viral infection. This is an area of ongoing research.
- **Calcium antagonists**
Nimodipine has been suggested as a possible treatment on the basis that there is evidence of cerebral hyperperfusion. Some patients have reported great benefit - further research needs to be done as nimodipine does not have SMC approval.
- **Central nervous system stimulants**
Drugs such as methylphenidate should not be used to treat fatigue as this controlled drug is not licensed by the MHRA for the treatment of ME-CFS.
- **Complementary therapies**
Although unproven by clinical trials, patients' reports suggest that acupuncture may help to relieve pain and other therapies may have a role to play in improving well-being.

The Royal College of Paediatrics and Child Health says that if patients and families express an interest in trying complementary therapies they should be encouraged to find out the details of the proposed therapy and therapist. This should include the extent of the therapist's previous experience with ME-CFS, the risks and proposed benefits, the costs and whether or not it would conflict with, or interfere with current treatment. They should also be advised to avoid trying too many things at the same time or persisting with something that is either not helping or apparently causing adverse effects²⁹.

- **Dietary regimes**

There has been some research into the efficacy of particular dietary regimes - a recent study reported that following an anti-candida diet (low sugar and low yeast) did not show any measurable differences on the assessment of levels of fatigue, mood swing or quality of life measures. Some patients have reported benefits from an anti-candida diet.

Sensitivities and intolerances to various foods are often experienced by people with ME-CF5 and may contribute to gastrointestinal problems.

A diet which maximises energy levels and health is to be encouraged. As part of a healthy diet suggest avoiding caffeine and alcohol, limiting sugar intake and balancing blood sugar by taking more, smaller meals and having healthy snacks available.

- **Hormonal treatments**

Hydrocortisone - studies have shown conflicting results.

Dehydroepiandrosterone - one study found raised levels suggesting that supplementation could be harmful.

Thyroxine - not to be prescribed in patients with normal thyroid function.

- **Low dose naltrexone**

Low dose naltrexone has been advocated by a Scottish GP. Further research needs to be undertaken.

- **Vitamins and minerals**

Patients should keep up to their Recommended Daily Allowances (RDAs) for essential nutrients, especially if they are restricting their diet for some reason.

Some people with ME-CFS need supplements because of a restricted dietary intake or nutritional deficiencies³⁰.

There is little evidence from clinical trials that vitamin B or magnesium³¹ supplements are of value but some patients have reported benefit from taking B12 for fatigue.

As for all women contemplating pregnancy, women with ME-CFS should be advised to take folic acid. If their diet is poor or they are on medications such as gabapentin, then please see British National Formulary (BNF) for the recommended dose.

Some anecdotal patient reports say vitamins C and B are helpful.

Consider the possibility of vitamin D deficiency in patients who are housebound, or who are on a severely restricted diet.

Non-pharmacological management

Although the Cochrane Collaboration found some evidence in support of CBT and GET³², there is debate about the limitations of trial designs and these treatments are controversial. In 2008, a survey of over 2760 people with ME-CFS, undertaken by Action for M.E., found that 82% of respondents had found pacing most helpful. 50% found CBT helpful and 45% of those who said they had received graded exercise therapy (GET) or graded activity found it beneficial (compared to 7% for CBT and 34% for GET in 2001). However, 34% of patients who said they had received GET or graded activity and 12% of those who said they had received CBT since 2005 reported that they felt worse after these treatments³³.

Each individual is best managed according to a unique flexible management plan, in which specific strategies and therapies are tailored to his or her particular circumstances.

All clinical interventions carry a potential risk of harm, especially if applied incorrectly; for ME-CFS in particular, imposed, rigid programmes can be actively harmful³⁴.

It has been reported that ME-CFS patients have a different physiological response to exercises than those who are healthy or depressed (see p 31)³⁵.

At present it is difficult to be didactic about this advice. It is intended that a programme for education and training will aid GPs in acquiring appropriate skills in this area.

In most cases the aim for management will be re-enablement or rehabilitation in terms of regaining function, according to the patient's needs and circumstances. Re-enablement should encompass cognitive, emotional and social aspects as well as physical aspects.

Any rehabilitation or increase in activity should start from an agreed, stable and possibly very low, baseline and should be gradual³⁶. Keep goals small and achievable.

Although a return to previous levels of functioning in the short to medium term is often unrealistic, patients can be encouraged to set goals that involve steadily increasing both physical and mental activities once their condition has started to stabilise and increases in activity have been maintained consistently.

If it is felt that management strategies supervised by a therapist, experienced in ME-CFS, such as activity management and cognitive behavioural therapy (CBT) may be beneficial, the choice of programme, its components and progression must be agreed by the patient and therapist and that patient and therapist are viewed as a partnership.

'Rehabilitation' does not necessarily have to mean 'exercise' - it may refer to any activity. Progress must be regularly monitored.

A relapse must trigger a reassessment of the management plan.

Fluctuations in the condition are natural and may include natural plateaux which may last for years, setbacks or more substantial relapses. Such fluctuations would indicate a need to reassess the management plan or for activity levels to be slowed down.

Not all patients may benefit from activity strategies and some may even have been harmed.

Other aspects are also important, particularly in young people eg. education and training, development etc. Adults may also not be able to undertake their original job and may need careers advice and re-training.

People with ME-CFS are as potentially disabled as those with other chronic conditions and are therefore entitled to apply to the Department for Work and Pensions for the full range of sickness and disability benefits, including the new Employment and Support Allowance (ESA) - see p 26.

Energy management

Activity management or pacing is a way of managing the reduced 'energy envelope' of people with ME-CFS. Gaining the balance between activity and rest can be difficult. It will vary from patient to patient and also during the course of the illness in any patient. It is important to avoid periods of 'boom and bust' in energy expenditure, both physical and mental. Adequate and good quality rest is crucial, especially in early stages and during relapses.

- **Activity management** is an approach that is customised to the needs of the person with ME-CFS. It is based on an understanding that all activities have physical, emotional and cognitive components and on identification of those components.
- **Pacing** is largely a self-management technique with the underlying approach being to establish sustainable activity levels. A safe, consistent and often low baseline of activity (mental as well as physical) should be established which avoids setbacks (including delayed reaction). A diary may help to establish patterns of activity. This is widely considered by patients to be the most helpful intervention. Appropriate, good quality, literature is essential. Setbacks and relapses are crucial reasons to re-evaluate the management plan. Support can be obtained from literature from ME charities eg. the Action for M.E. booklet on Pacing (contact details on p 28).
- **Graded exercise therapy (GET)** is intended to redress decline in physical fitness due to inactivity. **Not all ME-CFS patients become deconditioned** and some patients have said that GET has worsened their symptoms.

GET makes use of an exercise programme involving a **gradual** increase in exercise/activity. **It must be delivered by a suitably trained GET therapist with experience in ME-CFS** ideally on a one-to-one basis.

Some patients with ME-CFS report that exercise programmes have been applied inflexibly at times, without consideration of individual circumstances and goals, sometimes with significant adverse responses. **It is essential that agreement and negotiation are at the very centre of any GET programme.**

Counselling

As with any chronic illness, counselling from a trained counsellor/nurse can be very useful, particularly in the early stages of the illness, in supporting patients as they learn to manage the consequences of ME-CFS.

Cognitive behavioural therapy (CBT) is a psychological intervention usually undertaken on a one-to-one basis. Research so far has failed to differentiate between the effectiveness of CBT on people with neurological conditions and those with other fatigue states. However, CBT is being provided in England to help people with ME-CFS to cope with their illness.

The essence of the treatment is to examine difficulties as they relate to events in an individual's life and identify patterns of expectation which may be unhelpful to coping with being unwell for a prolonged time. CBT can be used, as in other chronic physical medical conditions, as a tool to aid people develop better ways of coping with symptoms such as fatigue, pain and sleep disturbance.

CBT would be of value to patients when their symptoms have led to a psychological response that has compounded their problems.

CBT and GET have been shown in some studies, mainly in mild to moderately affected patients, to produce varying degrees of benefit in some people with ME-CFS³⁷. However, as ME-CFS is a very heterogeneous condition other patients report that these approaches are of no help at all or may even be harmful in the case of GET. Pacing is widely used and is currently the subject of a formal clinical trial, together with CBT and GET (see p 24).

Telemedicine is an area which may play a part in treatment in the future, especially for patients in remote areas. For further information see: www.scot.nhs.uk/publications/Telemed%20Report.pdf
Healthcare professionals interested in reading about ME-CFS from the perspective of a GP with the illness may be interested to read: *ME-CFS/PVFS An exploration of the key clinical issues*, (ME Association, September 2008) and *Living with ME* (Vermillion, 1999) both by Dr Charles Shepherd.

Research

There is much research being undertaken at present in the field of ME-CFS.

Current research covers a number of areas of importance including the biological basis of the condition, the development of specific tests into the condition and looking at appropriate treatments. The aspiration is that, in time, the outcomes of such research can be translated into clinical practice.

It is important that in Scotland we have a mechanism which brings together researchers, practising clinicians and people with ME-CFS to drive the research agenda. This will lead to improved clinical practice in the NHS.

This section cannot be exhaustive but the links provided will allow GPs to access up to date details on research projects.

Examples of current research

- *Postural orthostatic tachycardia syndrome is an under-recognized condition in chronic fatigue syndrome*, A Hoad, G Spickett, J Elliott and J Newton, QJM 2008 101(12):961-965; doi:10.1093/qjmed/hcn123 and *Symptoms of autonomic dysfunction in chronic fatigue syndrome*, Newton J.L et al, Q J Med 2007; 100:519-526. Professor Julia Newton, Newcastle University, has been investigating the effect of low blood pressure on fatigue. She reports on tilt-table testing where 52% of people with ME-CFS exhibit orthostatic hypotension with 27% exhibiting positional orthostatic tachycardia syndrome. She advises treatment regimes of home hypostatic training and the prescription of midodrine.
- *Gene expression subtypes in patients with chronic fatigue syndrome/myalgic encephalomyelitis*. Kerretal. Journal: J Infect Dis. 2008 Apr 15; 197 (8): 1171- 1184.
- *Role of enterovirus in chronic fatigue syndrome*, J K S Chia, Journal of Clinical Pathology 2005; 58:1126-1132; *Chronic Fatigue Syndrome is associated with chronic enterovirus infection of the stomach*, J K S Chia, A Y Chia, Journal of Clinical Pathology 2008; 6V. 43-48.
- PACE trial: The Medical Research Council has supported the PACE trial, which includes a study in Lothian Health Board. PACE is a UK randomised controlled trial of adaptive pacing, CBT, graded exercise and usual medical care for chronic fatigue syndrome which is currently underway. Findings expected 2010.
- FINE trial: UK randomised controlled trial of nurse-led self-help treatment for primary care patients with chronic fatigue syndrome.
- *Use of valganciclovir in patients with elevated antibody titers against Human Herpes 6 (HHV-6) & Epstein-Barr virus (EBV) who were experiencing central nervous system dysfunction including long-standing fatigue*: randomised, placebo-controlled and double blind study at Stanford University (awaiting publication -www.vicd.info/clinicaltrial.html).

- *Chronic fatigue syndrome: inflammation, immune function and neuroendocrine interactions*, Klimas NG, and Koneru A, Current Rheumatology Reports, Vol. 9, #6, pp 482-487, Dec. 2007.
- *ME-CFS and mitochondrial dysfunction*, Dr S Myhill, N E Booth & J McLaren Howard ; International Journal of Clinical and Experimental Medicine, January 2009 (online), www.ijcem.com/812001A.html. This paper outlines a test that has been developed at a private clinic. Depending on the outcome of the test the authors would prescribe dietary supplement, drugs and detoxification. The test is not available on the NHS. This research has not yet been independently validated.

This list represents a very small sample of current work. Seventy trials were reviewed in Effective treatments for CFS/ME, CRD Report 35 Summary Report, University of York, 2006 and the charity, ME Research UK, has a research publications database which lists papers back to 1956 (see below).

Further information

New research is routinely posted on www.co-cure.org

In Scotland, the charity, ME Research UK (MERUK) is supporting biomedical research, both by direct financial support and through holding international conferences. www.mereseearch.org.uk

Further websites:

The CFS Research Foundation website: www.cfsrf.com The

MEA Ramsay Research Fund:

www.meassociation.org.uk/images/stories/Ramsay%20Research%20Fund%20explained.pdf

Invest in ME: www.investinme.org/index.htm

www.meactionuk.org.uk/research_references_update_Dec_08.htm www.name-us.org/researchpages.research.htm

Support for patients

GPs primarily provide medical advice but can also support patients with day to day living (including help with benefits, social care and employers) including referral to appropriate agencies eg. Citizens Advice Bureau and social work.

Services should be delivered in ways that are suitable for the individual patient; this may sometimes mean domiciliary services. This is particularly important for the severely affected who often experience extreme barriers to accessing all forms of care and treatment.

Welfare benefits

People with ME-CFS are as potentially disabled as those with other chronic conditions and are therefore entitled to apply to the Department for Work and Pensions for the full range of sickness and disability benefits, including the new Employment and Support Allowance (ESA).

Further guidance may need to be produced following the welfare reforms currently underway.

In order to qualify for benefits the claimant has to provide sufficient medical evidence to support the claim. The GP's input is essential for a claim to succeed. The fluctuating nature of the condition needs to be taken into account when assisting with welfare benefits applications.

ME-CFS is an illness that can be covered by the Disability Discrimination Act.

Useful contacts for patients

People with ME-CFS can contact Citizens Advice Bureau www.cas.org.uk and www.adviceguide.org.uk or one of the main charities (p 28) for advice on welfare benefits, housing, transport issues etc.

Local authorities often have benefits/money advice centres - see local phone directory. Centres for Inclusive Living give information and advice on a wide range of issues including benefits and money eg. Grapewine and Lothian Centre of Inclusive Living.

There are also local welfare benefit advice organisations and information is available from local support groups (see p 29). The following organisations provide useful contacts and resources for patients:

Action for M.E. Welfare Rights Line

Factsheets on ESA, DLA etc plus a Welfare Rights Line for people with ME.

Tel: 0845 123 2380 for opening times

www.afme.org.uk

Citizens Advice

The local Citizens Advice Bureau may be able to help patients to fill in the forms. See the phonebook for the nearest bureau, or www.cas.org.uk

Disability Alliance

Free factsheets are available to download from their website. They also produce a guide, *ESA - Employment and Support Allowance*, price £7 (£2 for people on benefits). The guide can be ordered by telephoning 020 7247 8776 (please note that this is not an advice line).

www.disabilityalliance.org

DWP

Benefit Enquiry Line for people with disabilities, plus downloadable factsheets from the website, which links to further information at Jobcentre Plus.

Tel: 0800 882 200, Mon-Fri 8.30am-6.30pm and Sat 9am-1pm.

www.dwp.gov.uk/esa

Jobcentre Plus

How to claim and further information.

www.jobcentreplus.gov.uk

DIAL UK

Some Disability Information Advice Line offices help with Welfare Rights issues. Check your local phone directory to see if there is a DIAL UK office near you. The national office number is 0130 2310 123.

Benefits and Work

The Benefits and Work website contains plenty of information about benefits. Membership of £18.95 a year gives unlimited access to their guides for claimants and members forum.

www.benefitsandwork.co.uk

Social care

Social care is vital, especially for people who are severely affected. Depending on the level of disability, people with ME-CFS may be unable to undertake their own personal care, domestic tasks such as shopping, cooking, laundry, deal with money issues, etc.

Provision of adequate support will require a partnership of health and social care. Early recommendation for a community care assessment will be helpful.

Allocation of a key worker or contact responsible for ensuring adequate and appropriate input to the patient's home can work well.

NB, Many people with ME-CFS rely heavily on a family member for daily care, who may themselves require support, advice, information or a care assessment. Carers Scotland has a useful website for carers at www.carerscotland.org

Emotional support

There is still some stigma associated with ME-CFS and it is important to recognise that, as well as experiencing debilitating symptoms and loss of income/work/educational/social opportunities unsupportive attitudes amongst family, friends and professionals can increase the sense of isolation and emotional impact on patients.

A recent survey of 168 ME-CFS patients in Lothian highlighted the importance of listening to patients and providing continuity of help and support³⁸.

As previously mentioned, counselling from a trained counsellor/nurse can be very helpful where patients report difficulties adjusting to long term illness

As well as offering support through regular monitoring, the GP should put the patient in touch with relevant charities, which offer helplines, a wide range of publications and online links to local support groups.

NHS patient information is available at: www.nhs24.com

Appendix 1

Useful resources and contacts

Resources

1. *Myalgic Encephalomyelitis/chronic fatigue syndrome: clinical working case definition, diagnostic and treatment protocols*, Carruthers et al; Journal of Chronic Fatigue Syndrome, January 2003 (Canadian Consensus Document).
2. *ME-CFSIPVFS An exploration of the key clinical issues*, Dr Charles Shepherd and Dr Abhijit Chaudhuri for the ME Association, September 2008
3. *Living with ME-CFS*, Dumfries & Galloway ME Network (see opposite)
4. *Pacing for people with M.E.*, Action for M.E. 2007
5. As well as the *Pacing* booklet, Action for M.E. has a series of articles by medical professionals and others, together with a number of factsheets, available to download free from its website, www.afme.org.uk
6. The ME Association's publications list is also available online at www.meassociation.org.uk

National charities

Action for M.E.

Booklets including *Pacing for people with M.E.*, plus factsheets, volunteer supportline, welfare rights helpline.

Tel: lo-call 0845 123 2380

www.afme.org.uk

ME Association

Factsheets and volunteer helpline. Tel: 0870

444 1836 www.meassociation.org.uk

Association of Young People with ME (AYME)

For children and young people up to 25 Tel: 08451

23 23 89 www.ayme.org.uk

25% Group

For people who are severely affected Tel:

01292 318611 www.25megroup.org

Young ME Sufferers Trust (Tymes Trust)

Tel: 0845 003 9002

www.tymestrust.org

Local support groups

ME and You Aberdeen

Gregor McAbery
Tel: 01224 581162
E-mail: Gregor.mcabery@mac.com
www.meandyouaberdeen.co.uk

Cathcart ME Group

John McKnight Tel: 0141 632 2486
E-mail: peter.cathcartmegroup@ntlworld.com

ME East Kilbride [MEEK] Group

Maisie Karrick Tel: 01355 233369

Dumfries & Galloway ME Network

Norma and Denis Turner
Tel: 01576 204129
E-mail: dennor@btinternet.com
www.dgme.co.uk

Edinburgh Mesh Group

E-mail: convenor@edmesh.org.uk www.edmesh.org.uk

ELMESH (East Lothian ME Self Help)

Dr Marilyn McNeill Tel: 01620 880651
E-mail: Marilyn@rowansdrem.plus.com

Falkirk ME Self Help Group

Neil Swinnerton
Tel: 01506 842599
E-mail: Neil@swinnerton.net

ME Support Fife

Catherine Lewis Tel: 01334 653202
E-mail: Catherine@claremont-cupar.freemove.co.uk

Glasgow West

Ewan Dale
Tel: 0141 332 8115
E-mail: ewandale@yahoo.co.uk

Glasgow ME-CFS Meet-up Group

Anna Wood
Tel: 01419452682
E-mail: anna.k.wood@talktalk.net
www.meetup.com/glasgow-me

Inverness ME / Fibromyalgia/CFS Support Group

Brenda Fraser
Tel: 01463 238533
E-mail: Glenesk.brenda@yahoo.com

Lanarkshire ME Support Group

Jane Giakoumakis
Tel: 01698817114
E-mail: janeyannis@talktalk.net

Oban

Adrian A Lauder
Tel: 01631 720262
E-mail: adrian.lauder@gmail.com

Paisley & District ME Support Group

Theresa Bates
Tel: 0141 561 3426
E-mail: Theresa@mepaisley.co.uk

Perth ME Group

E Moncrieff
E-mail: e.mon@tiscali.co.uk

MESKYE (Isle of Skye)

Mike Wotton
Tel: 01470 592369

ME Support (Stirling)

Alexandra Russell Tel: 01786 816478

Other useful organisations

Long Term Conditions Alliance Scotland

Tel: 0141 404 0231 www.ltcas.org.uk

Carers Scotland

www.carerscotland.org

Citizens Advice Scotland

www.cas.org.uk

Thistle Foundation

Tel: 0131 661 3366 www.thistle.org.uk

Children in Scotland

Enquire helpline for advice on educational support needs.
Tel: 0845 1232303
E-mail: info@enquire.org.uk

Appendix 2

Response to exercise

Table from Canadian Consensus Document

Response to exercise	Healthy people	ME-CFS patients
Sense of well-being	Invigorating, anti-depressant effect	Feel malaise, fatigue and worsening of symptoms
Resting heart rate	Normal	Elevated
Heart rate at maximum workload	Elevated	Reduced heart rate
Maximum oxygen uptake	Elevated	Approximately 1/2 of sedentary controls
Age-predicted target heart rate	Can achieve it	Often cannot achieve it, and should not be forced
Cardiac output	Increased	Sub-optimal level
Cerebral blood flow	Increased	Decreased
Cerebral oxygen	Increased	Decreased
Body temperature	Increased	Decreased
Respiration	Increased	Breathing irregularities: shortness of breath, shallow breathing
Cognitive processing	Normal, more alert	Impaired
Recovery period	Short	Often 24 hours but can last days or weeks
Oxygen delivery to the muscles	Increased	Impaired
Gait kinematics	Normal	Gait abnormalities

Appendix 3

Severity rating scale

The Canadian Consensus Document has been used as a source document in the compilation of the Scottish Good Practice Statement. The following guide is well recognised and used by practitioners on an international scale. It was designed to assist GPs in assessing severity and duration of symptoms and is **to be completed by the patient**.

Rank your symptoms in order of severity (1 being your most severe) in the left column. Rate severity of symptoms by putting a check mark in appropriate column to the right of the symptoms.

Rank	Symptom	0 Absent	1 Mild	2 Moderate	3 Severe
	Post-exertional fatigue: loss of physical and mental stamina, fatigue made worse by physical exertion				
	Long recovery period from exertion: takes more than 24 hours to recover to pre-exertion activity level				
	Fatigue: persistent, marked fatigue that substantially reduces activity level				
	Sleep disturbance: non-restorative sleep, insomnia, hypersomnia				
	Pain: Pain: in muscles, joints, headaches				
	Memory disturbance: poor short term memory				
	Confusion and difficulty concentrating				
	Difficulty retrieving words or saying the wrong word				
	Gastrointestinal disturbance: diarrhoea, IBS				
	Recurrent sore throat				
	Recurrent flu-like symptoms				
	Dizziness or weakness upon standing				
	Change in body temperature, erratic body temperature, cold hands and feet				
	Heat/cold intolerance				
	Hot flushes, sweating episodes				
	Marked weight change				
	Breathless with exertion				
	Tender lymph nodes: especially at sides of neck and under arms				
	Sensitive to light, noise, or odours				
	Muscle weakness				
	New sensitivities to food/medications/chemicals				
	Total check marks in Column				
	Column Total				

Total Score: -----Overall symptom severity: mild _____ moderate _____ severe

(**Mild**- occurring at rest, **moderate** - symptoms that occur at rest become severe with effort, unable to work, and **severe** - often housebound or bed-bound).

Other Symptoms

Aggravators

Change in symptoms

How good is your sleep on a scale of 1-5? (5 = good restorative sleep, 1 = no sleep)

How do you feel today on a scale of 1-10? (10 = terrific, 1 - totally bedridden)

Appendix 4

Sleep and pain profile

Adapted from Canadian Consensus Document

Name _____ Date _____ to _____

Complete this chart for the week before your next appointment

Day	Awakening time	Temp a.m.	Time slept	Sleep quality	Pain a.m.	Pain p.m.	Temp p.m.	Energy level	Bed time	Minutes to fall asleep
Week Average										

Name _____ Date _____ to _____

Temp a.m.: Take your temperature as soon as you awaken, while you are still lying down.

Also indicate if you feel cold (C), had cold feet (CF), or cold hands (CH), and if you were stiff (S).

Time slept: Indicate approximate number of hours and minutes you slept.

Sleep quality: Good, fair, or poor. Also indicate the number of times you woke during the night including waking up much too early, eg. if you woke up twice (W2). Indicate if you know why you woke up - eg. to urinate, muscle cramps, nasal congestion, etc.

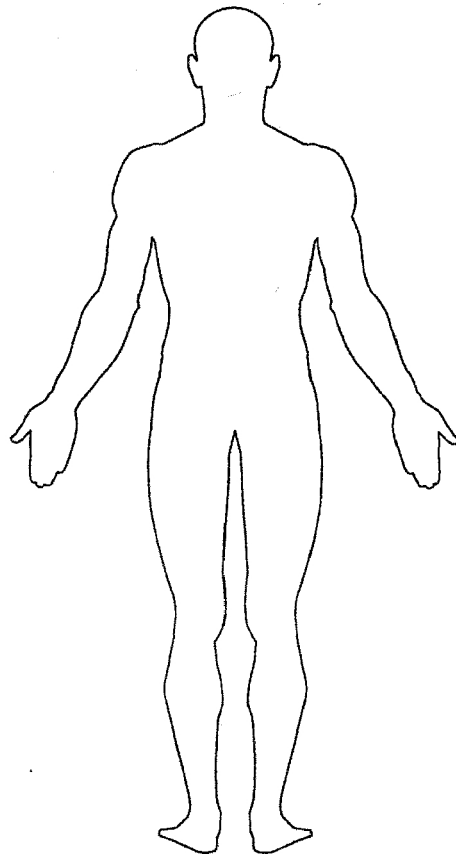
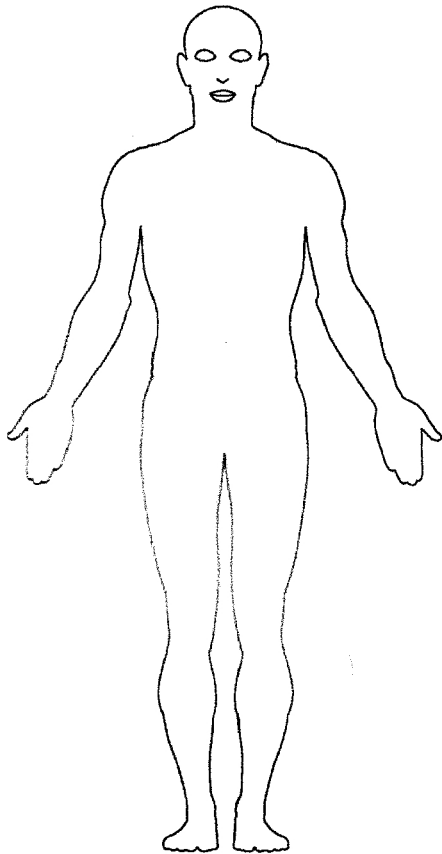
Pain: 0 to 10, **0 being no pain**, 10 being the worst pain you have experienced.

Energy level: Indicate your average energy level for the day - **0 being bedridden**, 10 full of energy.

Temp p.m.: Take your temperature before going to bed. Indicate if you feel cold.

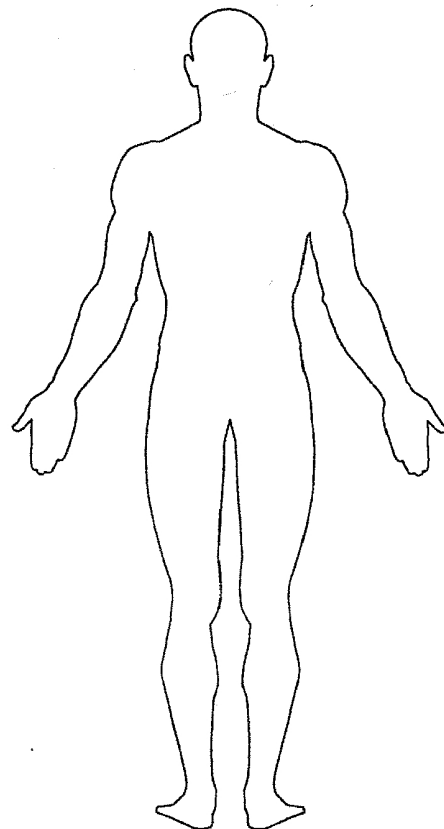
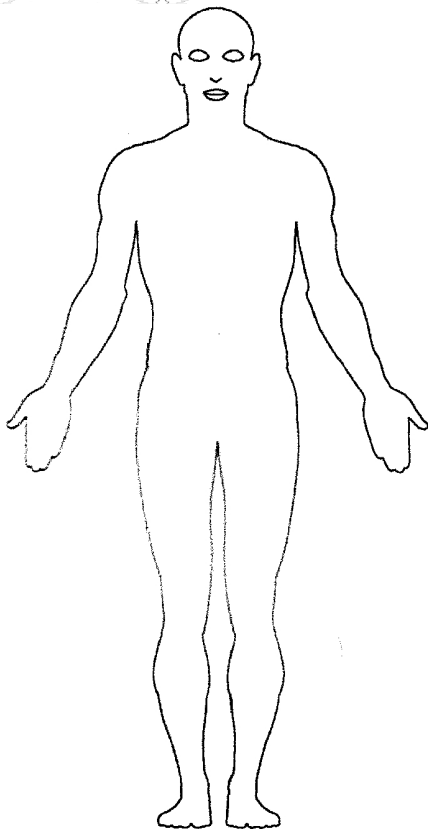
Minutes to fall asleep: Indicate as best you can how many minutes it took you to fall asleep.

Was anything in particular bothering you this week, eg. family crisis?



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8. References

- 1 *Outline for development of services for CFS/ME in Scotland*. Report of the Scottish Short Life Working Group, December 2002
- 2 Scottish Short Life Working Group, December 2002
- 3 *Report of the CFS/ME working Group*: report to the Chief Medical Officer of an Independent Working Group. 2002. London, Department of Health.
- 4 Based on Gallacher et al, Journal of the Royal Society of Medicine, December 2004
- 5 *Diagnosis and management of chronic fatigue syndrome/myalgic encephalomyelitis (or encephalopathy) in adults and children*, National Institute for Health and Clinical Excellence (NICE), 2007
- 6 CFS/ME Working Group Report, 2002
- 7 *ME diagnosis delay harms health*: A report from the ME Alliance, 2005
- 8 Evidence was taken to the Cross Party Group (CPG) on ME in 2009 to show that holism could mean that it was not necessarily central to care to diagnose a physical illness. This definition was rejected by the CPG, which supported what clinicians would understand as holistic care.
- 9 NICE guideline, 2007
- 10 NICE guideline. Quick Reference Guide, 2007
- 11 Carruthers et al; *Myalgic Encephalomyelitis/Chronic fatigue syndrome: clinical working case definition, diagnostic and treatment protocols*. Journal of Chronic Fatigue Syndrome, January 2003 (Canadian Consensus Document)
- 12 Carruthers et al, 2003
- 13 Editorial on the Canadian ME-CFS guidelines: Journal of Chronic Fatigue Syndrome, Vol. 11(1) 2003 pp. 1-6
- 14 www.stanford.edu/~dement/epworth.html
- 15 *A pediatric case definition for ME and CFS*, Jason et al, www.cfids-cab.org/MESA/Jason-1.a.pdf
- 16 *Evidence based guideline for the management of CFS/ME in children and young people*, Royal College of Paediatrics and Child Health, December 2004
- 17 *Thirteen-year follow-up of children and adolescents with chronic fatigue syndrome*. Bell DS, Jordan K, Robinson M. Pediatrics, May 2001.
- 18 *Long-term sickness absence due to ME-CFS in UK schools: an epidemiological study with medical and educational implications*. Dowsett EG, Colby J. Journal of CFS, 1997
- 19 Carruthers et al, 2003
- 20 Carruthers et al, 2003
- 21 Carruthers et al, 2003
- 22 *ME-CFS/FVFS An exploration of the key clinical issues*, ME Association, September 2008
- 23 *The diagnosis and management of (CFS/ME) - child protection guidance for professionals working in health, social services and education*, AYME and Action for M.E., 2006
- 24 CFS/ME Working Group Report, 2002
- 25 CFS/ME Working Group Report, 2002
- 26 NICE Quick Reference Guide, 2007
- 27 Carruthers et al, 2003
- 28 See ref 8 above
- 29 Royal College of Paediatrics and Child Health, 2004
- 30 NICE Quick Reference Guide, 2007
- 31 *Magnesium and chronic fatigue syndrome*. Cox IM, Campbell MJ, Dowson D, Davies S, Walden RJ., Lancet 1991; 337:1295
- 32 *Exercise therapy for chronic fatigue syndrome*, Edmonds M, McGuire H, Price J. Cochrane Database of Systematic Reviews. 2004 Issue 3 and Price JR, Mitchell E, Tidy E, Hunot V. *Cognitive behaviour therapy for chronic fatigue syndrome in adults*. Cochrane Database of Systematic Reviews 2008, Issue 3. Art. No.: CD001027. DOI: 10.1002/14651858.CD001027.pub2.
- 33 *M.E. 2008: what progress?* Action for M.E., 2008, published online at: www.afme.org.uk/res/img/re5ources/Survey%20Summary%20Report%202008.pdf
- 34 CFS/ME Working Group Report, 2002
- 35 Carruthers et al, 2003
- 36 CFS/ME Working Group Report, 2002
- 37 *Effective treatments for CFS/ME*, Centre for Reviews and Dissemination, University of York, 2006. http://www.york.ac.uk/inst/crd/CRD_Reports/crdreport35_summary.pdf
- 38 *Believe in ME: patient experiences of accessing and using services in Lothian to treat ME-CFS/PVFS. A patient involvement initiative*. Anne-Marie Comber, Edinburgh CHP, Liz Simpson, South Central LHP, May 2009

Acknowledgements

The publication of this document has been led by Dr Gregor Purdie, Clinical Lead for ME, NHS Dumfries & Galloway and co-ordinated by Action for M.E., on behalf of the Scottish Government Health Directorates. It has been produced in consultation with Scottish medical practitioners, people with M.E. and their representatives, ME charities and support groups and professionals in health, social care and research.

Dr Purdie, Action for M.E. and the Scottish Government Health Directorates would like to thank everyone who participated in the consultation. Without your help this document would not have been produced.



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