

Scottish Good Practice Statement on ME-CFS

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1 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 Group.¹

Purpose

The purpose of this Scottish Good Practice Statement is to provide general practitioners with simple and straightforward guidance that can be used to assist with the diagnosis and clinical management of patients with ME-CFS. It contains more detailed information and underpins two other summary documents, prepared at the same time. (1) Scottish Good Practice Clinical Guidance on Adults with ME-CFS and (2) A Patient Guide for Adults on Adults with ME-CFS. This Good Practice Statement is also *primarily* about the Care of Adults with ME-CFS, but in the absence yet of a separate Good Practice Statement on Children with ME-CFS, interim guidance on the management of children with ME/CFS is offered in Section 3.

It is hoped that these documents will be the first of a series which will inform health professionals on the management of ME-CFS.

These documents are primarily based on the synthesis of best available current evidence. As such, they are living documents and will be subject to periodic review as research is published which will influence clinical practice.

The guidance provided should not be regarded as prescriptive; such general advice will always need to be modified in line with the needs of any individual patient.

In parallel with the development of this Statement, 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 service provision for people with ME-CFS.

There has been much national and international debate over the terminology for this illness. ME-CFS is a composite term for a range of chronic, fluctuating conditions characterized by persistent symptoms of fatigue, pain and loss of endurance to normal activities associated with conspicuous deterioration after exercise. These conditions have been referred to as ME, CFS or PVFS.

It causes significant ill health and disability in a substantial number of adults, young people and children.¹ It can affect anyone, at any age, from any ethnic group.

Epidemiological evidence is lacking in Scotland but a population prevalence of at least 0.2% - 0.4% is widely accepted,² and over 20,000 people in Scotland may be affected.³ It has characteristic features which can be variable among patients. It is also variable in its duration and severity.

At present, the diagnosis of ME-CFS remains clinical, based on recognizing specific symptom patterns. Currently there are no specific tests available to confirm the presence of the condition. There is, however, high quality scientific evidence that the diagnosis can be made accurately.

The WHO has classified Post viral fatigue syndrome, including Benign Myalgic Encephalomyelitis under disorders of the nervous system ICD 10 G93.3. Chronic Fatigue Syndrome is classed separately in ICD 10 within F48.0: neurasthenia, under mental and behavioural disorders. A number of other attempts have been made to define the condition(s), none of which are universally accepted. From a clinical neuroscience perspective, any separation of mind and brain is outdated. The crucial point is that the NHS recognizes that the condition is real, associated with altered neural functioning and causes significant disability. As such, it places a substantial burden on people with the condition, their families and carers and on society.⁴

The prognosis is extremely variable. Most patients have a fluctuating course of illness with some people recovering, or improving significantly, in less than two years, while others remain ill for several decades.² Some patients will have a relapsing remitting course of illness while others do not experience remission.⁵

ME-CFS causes a range of symptoms and it is necessary to adopt a holistic approach to care and symptom control 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 life.⁶

The normal general practice principles of empathetic listening, mutual respect and shared decision making between a person and ME-CFS and health care professionals are essential during all phases of care in the NHS.⁴ People with ME-CFS have a right to refuse or withdraw from any component of their care plan without affecting other aspects of their care, or future choices about care.⁷

There is also the need for early and accurate diagnosis where possible, with consideration of making the provisional diagnosis by three to four months into the illness. Relevant investigations should be completed in this timeframe and symptom management should begin. GPs should be able to help alleviate symptoms in most patients with ME-CFS, as with many other chronic conditions. Shared care with specialists, for diagnosis and/or development of a management plan, will help with problems that are complex, severe and prolonged.

It is vitally important that Scotland develops effective mechanisms 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 in Scotland.

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2 Clinical assessment and diagnosis

INITIAL PRESENTATION OF ME-CFS

This may be sudden or gradual. It may follow an infection, typically but not always viral for example: flu-like illness, glandular fever, viral hepatitis and labyrinthitis. 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 burnetti/Q fever can also precipitate ME-CFS. Patients commonly describe themselves as never having fully recovered from the infection.

The role of trauma, surgery and stressful major life events as trigger factors is possible, but less well established. Toxin and pesticide exposures have also been suggested, but there is no published evidence at present to substantiate this. 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.

As with any long term condition, early and accurate diagnosis brings significant benefits. For most adults, six weeks from the onset of abnormal fatigue is a time to be considering ME-CFS as a differential working diagnosis. The aim should be to make a diagnosis 3-4 months into the illness. Further guidance on children and young people is presented in **Section 3**.

Making a diagnosis is an essential first step in active management of the condition. It removes uncertainty, reduces fear and provides an explanatory model that justifies appropriate changes in a person's lifestyle and expectations. Like many neurological disorders, the diagnosis is based on clinical evaluation and there are no confirmatory diagnostic tests. The diagnosis should be a positive one based on pattern recognition of a range of recognized symptoms, with other conditions excluded as appropriate.

SYMPTOMS

The illness usually presents with a combination of persistent or recurrent fatigue and myalgic pain in the absence of swelling or redness. The myalgic pain can be migratory. The characteristic However, fatigue may not be the patient's worst symptom. Symptoms are provoked by physical or mental exertion. Post-exertional malaise lasting for more than 24 hours is commonplace. There is a substantial reduction in activity levels.

History

It is helpful to create a list of all current symptoms as “polysymptomatology” is a significant diagnostic clue.

- Activity induced muscle fatigue
- Post exertional malaise
- Cognitive impairments, particularly slowed speed of processing, poor attention and disturbances of anterograde memory – almost always present.
- Recurrent flu like symptoms of sore throat, painful swollen lymph nodes.
- Sleep disturbance – hypersomnia, insomnia and unrefreshing sleep
- Headaches
- Arthralgia without swelling, redness or joint deformity.
- Peri-oral and peripheral paraesthesia
- Postural light headedness, dizziness, palpitations
- Nausea
- Irritable bowel symptoms
- Feeling of fever and shivering
- Altered appetite
- Urinary frequency and urgency

It is important to ask about recent travel, tick bites, “odd infections” drug and alcohol use. Review current medication, if applicable.

EXAMINATION

A full physical examination must be performed.

- Height and weight (severe obesity can cause fatigue)
- Supine and erect blood pressure (to exclude significant postural hypotension which can mimic ME-CFS or be sign of Addison’s disease)
- General medical examination including looking for signs of anaemia, tanning in unusual sites (for Addison’s) enlarged or tender lymph nodes and organomegaly
- Skin and Joints for evidence of systemic inflammatory diseases – note any peri-articular tenderness typical of fibromyalgia.
- Neurological examination to exclude neurological abnormalities such as obvious wasting, ptosis, upper motor neurone signs, ataxia, fasciculations, absent reflexes. **Note:** Muscle twitches and spasms are common occurrences in ME-CFS and some give way weakness is also common because of pain and fatigue, but normal power is usually possible even if only for a few seconds with encouragement.

Mental state examination should be carried out to identify patients with major depressive disorder and panic disorder with agoraphobia. This can be the sole cause of persistent fatigue or present as important and reversible co-morbid disorders. Somatisation disorder needs also to be excluded.

INVESTIGATIONS

All patients

- Full blood count (FBC)
- Urea, electrolytes and creatinine (U&Es)
- Liver function tests, including albumin (LFTs)
- Thyroid function tests (TFTs)
- Glucose (random)
- Erythrocyte Sedimentation Rate (ESR)
- C-reactive protein (CRP)
- Calcium studies
- Creatine kinase
- Urinalysis

When indicated by history or examination

- Antimitochondrial antibodies (AMA) (if minor alterations in LFTs)
- Antinuclear antibody test (ANA)
- Cytomegalovirus (CMV)
- Coeliac serology (if diarrhoea, weight loss or history of autoimmune disorders)
- Epstein-Barr Virus (EBV)
- Extractable Nuclear Antigens (ENA)
- Human Immunodeficiency Virus (HIV)
- Hepatitis B and C
- Lyme serology
- Q Fever
- Toxoplasma
- Electrocardiogram (ECG) if any cardiological symptoms

Investigations not currently indicated in clinical practice

Laboratory tests:

- Vitamin B12 & folate (where normal FBC)
- Candida albicans
- Ferritin
- Fibrinogen

- Lactate dehydrogenase
- Mitochondrial testing
- Platelet activation
- Protein electrophoresis
- Prothrombin fragment 1&2
- Soluble fibre monomer
- Thrombin-antithrombin complexes
- Xenotropic murine leukaemia virus-related virus (XMRV) serology.

Other investigations:

- Magnetic Resonance Imaging (MRI) brain scan (in the absence of objective neurological signs)
- Tilt table testing (in the absence of other clinical indications)
- Auditory brainstem responses
- Electroencephalography (EEG)
- Electrodermal activity
- Positron emission tomography (PET) imaging
- Single Photon Emission Computed Tomography (SPECT) imaging

RATING SCALES

When a patient presents to a GP with symptoms consistent with ME-CFS, it may be helpful to ask the patient to fill out a rating scale and complete a body pain map. These documents allow a lot of clinical information to be communicated succinctly. This may aid diagnosis and management (see also **Section 5 - Interventions, Management and Rehabilitation**). They can also be used in ongoing monitoring of the clinical condition. A severity rating scale is provided in **Appendix 2**. A sleep and pain profile is provided in **Appendix 3**. Both are adapted from the Canadian Consensus Document.⁸

3 Children and young people

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. A significant problem in the literature is the lack of both a paediatric definition of ME-CFS and a reliable instrument to assess it.⁹

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,¹⁰ some for many years.¹¹

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, for example 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-CFS.¹² However, unlike school phobia, pupils with ME-CFS spend most of their time incapacitated or having to rest.⁸ Other differences have been reported, potentially leading to misclassification. 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

Children may 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 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 fatigue.⁸

- **Disordered sleep pattern**

- **Weight loss**

- **Gastro-intestinal disorders**

Children may be diagnosed with ME-CFS when symptoms have lasted for more than three months. A working diagnosis may be made 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. 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. www.childreninscotland.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 procedures.¹³ Concerns have also been raised that child protection procedures have been initiated because of disagreements between families and health and education professionals over treatment plans. In addressing this area, the report of the Working Group on ME-CFS to the UK's Chief Medical Officer (2002), noted: *"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."*² Nonetheless, children with ME-CFS may suffer harm and this should be considered as a possibility when preparing the differential diagnosis. As for other aspects of children's care, it is important to listen to the child, as well as to family members and patient/carers, to respect their experiences, and to give due weight to their views, especially the child's.¹⁴

Further information

Further information on the management of children with ME-CFS is available from the Royal College of Paediatrics and Child Health,¹⁰ and in the relevant NICE Guidance.^{4,7}

4 People who are more severely affected

The Report of the 2002 Chief Medical Officer (England) CFS/ME Working Group noted that not enough was known about severe forms of the condition, “*that are reported to affect up to 25% of patients*”.² A search of the scientific literature, as part of the development of this good practice statement, has not been able to validate this estimate, or provide a robust alternative. No definitive studies have been carried out as yet in the UK, to determine the prevalence of severe ME-CFS. Recognizing the heterogeneity and complexity of this area, research studies are therefore urgently required on: (1) the prevalence and impact of severe disease; (2) the pathways to chronicity and to becoming severely affected, and (3) strategies that would benefit such individuals.²

It is clear however, at some stage in the illness, that many patients may fall into the category of severe ME-CFS, with specific care needs.

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:

The quality of life of ME patients shows marked diminution. However, there is a spectrum of severity. Those who are severely affected have severe restrictions in their 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.

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

There is concern that some 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, immediately.⁷ 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. 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 NHS 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.

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5 Interventions, management and rehabilitation

General Principles

All patients will benefit from the general skills of good medical practice including being treated with respect, being listened to with empathy, and having the opportunity to build a rapport with their general practitioner. All treatment should be collaborative and there is no place for a coercive approach.

In general clinicians should adopt a holistic approach in treating the symptoms of CFS/ME. No single treatment has yet been shown to be consistently effective. However, various rehabilitative approaches have often been found to be beneficial in modifying symptoms of this illness, and assisting the recovery process. While a variety of drug treatments have been suggested for people with CFS/ME, the results have generally been disappointing when they have been subjected to well organised, randomised controlled trials (RCTs).

A standard approach to management will involve:

- Acknowledge the reality of the patient's symptoms and the impact on their life.
- 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), 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 **Appendix 1** for further guidance.

The following are usually helpful areas to discuss:

- **Diagnosis:** A clear diagnosis, with an explanation of why the diagnosis has been made in the particular patient's case, can be very therapeutic.
- Facilitate discussion about the patient's acceptance of the diagnosis and the attitudes of other people in their life to the diagnosis.

- Suggest keeping a diary of activity levels over a four week period. Look for evidence of a 'boom and bust' approach to activity cramming lots into the 'good days' and 'paying for it' afterwards. Recommend a more consistent approach to activity planning.
- Acknowledge the difficulties in adjustment to coping with the symptoms.
- Offer advice on control of specific symptoms.
- Offer support and monitoring; listening, interpreting, guiding.
- Discuss the possibility of setbacks and plan for how they might best be coped with.
- Support strategies with appropriate literature when available.

Pharmacological interventions

Treatment for associated clinical conditions, such as tension headache, irritable bowel syndrome or depression should follow standard clinical practice. Pain symptoms are often problematic. Avoid excessive use of opiate analgesics and consider 'atypical' analgesics like tricyclics, gabapentin and duloxetine. Be alert to the problems of polypharmacy and stop medications that are not producing substantive benefits. Patients with CFS-ME are often very sensitive to the side-effects of medication. In general terms it is usually beneficial to start with very low doses and then steadily increase over time. Side effects are often particularly bad during the first few weeks of exposure so try to avoid frequent changes to medication particularly between drugs in the same therapeutic class.

Other interventions

At the current time the strongest graded scientific evidence is in support of rehabilitative strategies: cognitive behavioural therapy (CBT) and graded exercise therapy. The summary data from the Cochrane collaboration reviews, based on randomized controlled trial (RCT) data on 3655 patients, which support these treatments, is provided below.¹⁵ Such treatments are in line with standard neuro-rehabilitation principles. It is often assumed that the efficacy of such treatments suggests that the underlying condition must be 'psychological'. This is not the case and there is now high quality evidence that CBT leads to demonstrable changes in brain functioning and structure.

However, such management strategies will not be effective for all patients and remain controversial for some. 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 (see below). 50% found CBT helpful and 45% of those who said that they received graded

exercise therapy (GET) which is designed to redress decline in physical fitness due to inactivity helpful. 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.¹⁶

There is no place for coercing patients into accepting unwanted treatments in this area anymore than any other branch of medicine; patients have an unequivocal right to choose whether or not to accept a treatment and this must be respected.

If a patient wishes to explore this form of treatment it is important that such treatments are supervised by therapists working in teams with specific expertise in CFS-ME. The choice of program, its components and progression must be agreed by the patient and therapist and that patient and therapist are viewed as a partnership.

The use of such rehabilitative treatments should not be confused with non-specific advice to be 'more active', or to go to the gym and 'do some exercise'. Such approaches are usually highly unproductive.

Many patients express a preference for pacing. Pacing is largely a self-management technique with the underlying approach being to establish sustainable activity levels. A consistent and often low baseline of activity (mental as well as physical) should be established which avoids setbacks (post-exertional malaise and related symptoms). A diary may help to establish patterns of activity. This is widely considered by patients to be the most helpful intervention. Support can be obtained from literature from ME charities eg: the Action for M.E. booklet on Pacing (contact details in **Appendix 1**). This approach is currently being tested in a large randomized trial, which has now finished recruiting, and more will be known of its effectiveness in the near future

Evidence levels for interventions:

The grading of level of evidence has been made in accordance with the SIGN Guidelines approach.¹⁷ In keeping with recent SIGN developments, due weight is also given to people's experience of living with the condition. Further details are available at: <http://www.sign.ac.uk/guidelines/fulltext/50/annexb.html>

Interventions that benefit some, but not all:

Level 1 evidence

- Cognitive Behavioural Therapy (when delivered in centres with specific expertise in treating CFS/ME)

- Graded Exercise Therapy (when delivered in centres with specific expertise in treating CFS/ME). Graded exercise therapy may be particularly effective in treating related fibromyalgic pain symptoms.¹⁸

Interventions that may benefit some, but not all:

Level 4 evidence

- Acupuncture
- Gabapentin
- Pacing
- 'Step 1' analgesics
- Transcutaneous Electrical Nerve Stimulation (TENS)
- Tricyclic antidepressant drugs (starting with low dose)

Interventions that possibly work and are unlikely to do harm:

(Level 2- evidence)

- Acetyl-L-carnitine and propionyl-L-carnitine supplements
- Essential fatty acid supplements
- Massage therapy
- Melatonin

Interventions that may do more harm than good

(Level 4 evidence)

Amantidine, antifungal drugs, baclofen, benzodiazepines, methylphenidate, naltrexone, nimodipine, thyroxine (except where low T4 levels), non specific advice on activity (eg "go to the gym and do some exercise").

Interventions that do more harm than good

(Level 2- evidence)

Immunoglobulins, oral NADH, Staphylococcus toxoid.

Interventions for which trials have shown a lack of benefit

(Level 2- evidence and above)

Acyclovir, acyclicidine, alpha interferon, amino acids, ampligen, clonidine, dexamphetamine, fludrocortisones, fluoxetine, galantamine, ganciclovir, general supplements, growth hormone, homeopathy, hydrocortisone, inosine pranobex, interferon, liver extract, low sugar/low yeast diet, magnesium, medicinal mushrooms,

moclobemide, osteopathy, phenelzine, pollen extracts, selegiline, sulbutiamine, terfenadine, topical nasal corticosteroids.

RATING SCALES

As indicated in **Section 2 – Clinical Presentation**, use of severity rating scale (**see Appendix 2**) and completion of a body pain map (**see Appendix 3**) may aid management. They can also be used in ongoing monitoring of the clinical condition.⁸

REFERRAL FOR SPECIALIST ASSESSMENT

Care Pathway

At present services throughout Scotland are not uniform. It is hoped that the Scottish Public Health ME-CFS Needs Assessment [*to add finalized reference here*] and subsequent Health Board responses will help clarify this. Referrals may need to be made to designated clinical services, for assistance with the management of patients in those whom the diagnosis has been made or to appropriate medical specialty in situations where there is diagnostic doubt.

A diagnostic, management and referral algorithm has been incorporated into the accompanying summary clinical guidance: *Scottish Good Practice Clinical Guidance on Adults with ME-CFS*, and is reproduced again below, for ready reference.

Further Information on Clinical Management

Further information on the management of adults (and children) with CFS, is available in relevant Guidance from NICE,^{4,7} and the guidance made available to GPs in England by Action for M.E.

Key Guiding Principles:

- **WORK IN PARTNERSHIP WITH THE PATIENT**
- **MUTUALLY AGREE ALL TREATMENTS**

Patient presents with symptoms that may indicate ME-CFS

Do an initial assessment

- Take history (including exacerbating and relieving factors, sleep disturbance, inter-current stressors)
- Conduct physical examination
- Look for signs of depression and/or agoraphobic symptoms

Reassessment and interim advice

- Remain vigilant for newly emerging symptoms suggestive of alternate diagnoses.
- Maintain relationship and encourage discussion of mood state. Be particularly vigilant for somatic symptoms of depression and agoraphobic symptoms.
- Encourage early rehabilitation. In particular encourage activity based on rehabilitation principles. Suggest use of a diary & planned activity, *within abilities*, setting achievable goals. Be alert for, and caution against, a 'boom and bust' approach such as doing all the week's housework on a 'good day' then collapsing the next day

Arrange Investigations

- FBC, U&Es, creatinine, LFTs (inc albumin), TFTs, ESR, CRP, calcium, creatine kinase, random glucose, urinalysis.
- Consider whether any other investigations are indicated by history

Make provisional diagnosis

- In adults if symptoms have lasted 4 months and other diagnoses have been excluded
- Reconsider diagnosis if any 'red flag' symptoms/signs are present

ME-CFS diagnosis not supported at this stage: Consider referral to appropriate medical or psychiatric clinic

- If specific diagnostic query (such as possible MS)
- If substantial pre-existent co-morbidity

If ME-CFS suspected -

- and symptoms have lasted more than four months and not improving
- or presentation is severe - **consider referral to Specialist Clinic/ Treatment Centre for:**
 - assessment
 - further investigation as appropriate
 - management advice
 - referral for specific treatments if appropriate
 - an expert intervention package tailored to the needs of each individual patient.

Maintain general practice involvement after specialist referral and follow general principles of good medical care

Review management plans and progress

- Remember to seek out positive features, such as goals met and achievements

Help manage setbacks and relapses

6 Research

Ongoing research is required into ME-CFS to help us understand the causes of the condition and also to guide our current management approaches. Research is made more difficult in the absence of a definitive diagnostic test for the condition concerned, and studies of sufficient size (power) are required to achieve compelling results. It is unlikely that there will be a complete understanding of the mechanisms underpinning the condition within the next decade. It is therefore important that we do not 'stand still' and make robust progress in investigating and testing treatments, in the interim. A specific urgent need for research into the epidemiology of the severity of ME-CFS and its management has already been highlighted in **Section 4 – People who are more severely affected**.

Government Sponsored Research

The Chief Scientist Office (CSO), of the Scottish Government Health Directorates, which has responsibility for encouraging and supporting research into health and health care needs in Scotland, is collaborating with the Medical Research Council (MRC) on the implementation of its research strategy into ME-CFS. CSO has contributed funding to the PACE (Pacing, graded Activity and Cognitive behaviour therapy: a randomised Evaluation) trial which has been set up in order to provide a systematic evaluation of these therapies. The value of the award for the PACE trial was £2.8m, of which £250k was provided by CSO. The trial is expected to report later in 2010.

Although not presently funding (at April 2010) any research specifically related to the biological effects of ME-CFS, the MRC and CSO remain committed to funding scientific research into all aspects of ME-CFS including evaluations of other treatments and studies into the biological basis of the condition. The MRC and CSO do not have set budgets for specific illnesses, so support of the existing ME-CFS studies does not mean that money is not available for other proposals that meet the scientific standards set by the peer review process. CSO is always willing to consider soundly-based proposals for research, which are then subject to rigorous peer review.

ME-CFS is a strategic priority area for the MRC and they are continuing to promote research in this area and encourage applications for funding. Research proposals in all areas compete for the funding available. While research excellence continues to be the primary consideration in funding decisions, and the MRC does not as a rule earmark funds (nor does it commission research) for particular topics, when appropriate, high quality research in the areas the Council is promoting may be given priority in competition for funds.

In 2008, a new Expert Group was set up by the MRC to consider how best to encourage new high-quality research into ME-CFS and to bring researchers from associated areas into the field. In addition, the MRC held a ME-CFS workshop in November 2009 and a note of the discussions will be published on their website (www.mrc.ac.uk) in due course.

Charity Supported and other Research

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). ME Research UK also holds a large research publications database.

Other charities supporting research are:

The CFS Research Foundation website: www.cfsrf.com

Action for M.E. website: www.afme.org.uk

The MEA Ramsay Research Fund:

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

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

Information about ME-CFS research

In addition to MEDLINE, OVID and other academic reference databases, other sources of information on research are available from other databases, and ME-CFS charities including:

www.meactionuk.org.uk/research_references_update_Dec_08.htm

www.mereseearch.org.uk

www.name-us.org/researchpages.research.htm

It is important that research on ME-CFS is conducted to the highest standards and subject to robust scientific peer review, as exemplified in the reviews undertaken by the Centre for Reviews and Dissemination, University of York,¹⁵ and by the Cochrane Collaboration Reviews.^{18,19}

Supporting participation in research studies

Research studies, however novel and well designed, will only be successful if enough patients are recruited into them. We must all play our part in pulling together, patients, clinicians and researchers, to aid recruitment into studies. It is imperative that in Scotland we have effective structures which bring together researchers, practising clinicians and people with CFS-ME to facilitate future research into the condition.

7 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 assistance is essential for this process. 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 (see Appendix 1) 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. Grapevine and Lothian Centre for Inclusive Living. Tel: 01314752370. www.lothiancil.org.uk/whatwedo/grapevine/grapevine.php

There are also local welfare benefit advice organisations and information is available from local support groups (see Appendix 1). 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 for 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 support.²⁰

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.

Further NHS patient information is available at the NHS 24 website: www.nhs24.com

8 References

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www.sehd.scot.nhs.uk/mels/hdl2003_02report.pdf
- 2 *Report of the CFS/ME Working Group*. Report to the Chief Medical Officer of an Independent Working Group. Department of Health, London, 2002.
www.dh.gov.uk/en/publicationsandstatistics/publications/publicationspolicyandguidance/browsable/DH_4095249
- 3 Based on: Gallacher AM, Thomas JM, Hamilton WT, White PD. Incidence of fatigue symptoms and diagnoses presenting in UK primary care from 1990 to 2001. *Journal of the Royal Society of Medicine* 2004;97: 571-5.
- 4 *Diagnosis and management of chronic fatigue syndrome/myalgic encephalomyelitis (or encephalopathy) in adults and children*. National Institute for Health and Clinical Excellence (NICE), London, 2007. www.nice.org.uk/guidance/CG53
[Please note: 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].
- 5 *ME diagnosis delay harms health*. A report from the ME Alliance, 2005.
www.afme.org.uk/res/img/resources/me%20diagnosis%20report%20master.pdf
- 6 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.
- 7 Quick Reference Guide, *Diagnosis and management of chronic fatigue syndrome/myalgic encephalomyelitis (or encephalopathy) in adults and children*. National Institute for Health and Clinical Excellence (NICE), London, 2007.
www.nice.org.uk/guidance/CG53
- 8 Carruthers BM, Jain AK, De Merleier KL *et al*. Myalgic encephalomyelitis/chronic fatigue syndrome: Clinical Working Case Definition, Diagnostic and Treatment Protocols. (Canadian Consensus Document) *Journal of Chronic Fatigue Syndrome* 2003;11(1):7-116.
See: www.cfids-cab.org/MESA/
- 9 Jason LA, Jordan KA, Miike T *et al*. A pediatric case definition for ME and CFS. *Journal of Chronic Fatigue Syndrome* 2006;13:1-44.
- 10 *Evidence based guideline for the management of CFS/ME in children and young people*. Royal College of Paediatrics and Child Health, London, 2004
www.rcpch.ac.uk/research/ce/rcpch-guidelines
- 11 Bell DS, Jordan K, Robinson M. Thirteen-year follow-up of children and adolescents with chronic fatigue syndrome. *Pediatrics* 2001;107, 994-8.

- 12 Dowsett EG, Colby J. Long-term sickness absence due to ME-CFS in UK schools: an epidemiological study with medical and educational implications. *Journal of Chronic Fatigue Syndrome* 1997;3:29-42.
- 13 *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. www.ayme.org.uk
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- 15 Bagnall AB, Hempel S, Chambers D, Orton V, Forbes C. *The treatment and management of chronic fatigue syndrome/myalgic encephalomyelitis in adults and children*. Centre for Reviews and Dissemination, University of York, 2007. www.york.ac.uk/inst/crd/CRD_Reports/crdreport35.pdf
- 16 *M.E. 2008: what progress?* Action for M.E., 2008, published online at: www.afme.org.uk/res/img/resources/Survey%20Summary%20Report%202008.pdf
- 17 Evidence levels for interventions. The grading of level of evidence in this guidance has been made in accordance with the SIGN Guidelines Approach. In keeping with recent SIGN developments due weight is also given to people's experience of living with the condition. See: www.sign.ac.uk/guidelines/fulltext/50/annexb.html
- 18 Larun L, McGuire H, Edmonds M, Odgaard-Jensen J, Price JR. Exercise therapy for chronic fatigue syndrome. *Cochrane Database of Systematic Reviews* 2004, Issue 3. Art. No.: CD003200. DOI: 10.1002/14651858.CD003200.pub2. www.cochrane.org/reviews/en/ab003200.html
- 19 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. www.cochrane.org/reviews/en/ab001027.html
- 20 Comber A-M, Simpson L. *Believe in ME: patient experiences of accessing and using services in Lothian to treat ME-CFS/PVFS. A patient involvement initiative*. Edinburgh and South Central Community Health Partnerships, NHS Lothian, 2009. www.nhslothian.scot.nhs.uk/news/publications/believe%20in%20ME.pdf

Appendix 1

Useful Contacts

- **Action for M.E.**
Welfare Rights Line for people with ME. 0845 123 2380
- **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
- **Centres for Inclusive Living** give information and advice on a wide range of issues including benefits and money eg. Grapevine and Lothian Centre of Inclusive Living.
- **Citizens Advice Bureau** www.cas.org.uk and www.adviceguide.org.uk or one of the main charities for advice on welfare benefits, employment rights, housing, transport issues etc. The local **Citizens Advice Bureau** may be able to help patients to fill in benefits forms. Also see the phonebook for the nearest bureau.
- **Department for Work and Pensions**
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
- **Disability Alliance:**
Free factsheets are available to download from their website. They also produce an annual guide called "Disability Rights Handbook (Disability Alliance)". The 34th edition is for the year April 2009-April 2010. There are separate publications on ESA (Employment and Support Allowance) and DLA (Disability Living Allowance). These guides can be ordered by telephoning 020 7247 8776 (please note that this is not an advice line) or through the website www.disabilityalliance.org
- **Jobcentre Plus**
How to claim and further information. www.jobcentreplus.gov.uk
- **Local authorities** often have benefits/money advice centres - see local phone directory.
- There are also **local welfare benefit advice organisations** and information is available from local support groups.

Further Resources

1. Shepherd C, Chudhuri A. CFS/ME/PVFS. An exploration of the key clinical issues. ME Association, October 2009
2. Living with CFS/ME – leaflet produced by Dumfries and Galloway M.E. Network. February 2009
3. Pacing for people with M.E., Action for M.E. 2010
4. All about M.E., Action for M.E. 2010
5. Your Child and M.E., Action for M.E. 2010
6. 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
7. The ME Association's publications list is available online at www.meassociation.org.uk
8. Ho-Yen D. *Better Recovery from Viral Illnesses*, Dodona Books, 2008, ISBN 0-9511090-7-3
9. Carruthers J et al. Myalgic Encephalomyelitis/chronic fatigue syndrome. (Canadian Consensus Document: rating scales section). *Journal of Chronic Fatigue Syndrome* 2003;11(1):7-116. www.cfids-cab.org/MESA/

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: 0844 576 5326
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
Margaret Williams
E-mail: margaret.williams@icscotland.net
- Dumfries & Galloway ME Network
Norma and Denis Turner
Tel: 01576 204129
E-mail: dennor@btinternet.com
www.dgme.co.uk
- Edinburgh M.E. Self-Help Group (edmesh)
Membership Enquiries to: 0845 625 2025 or email: membership@edmesh.org.uk
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.freereserve.co.uk
- Glasgow West
Ewan Dale
Tel: 0141 332 8115
E-mail: ewandale@yahoo.co.uk

- Glasgow CFS/ME 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: 01698 817114
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 organizations

- Neurological Alliance of Scotland
Tel: 07540 643545
www.scottishneurological.org.uk
- Long Term Conditions Alliance Scotland
Tel: 0141 404 0231
www.ltcas.org.uk
- Carers Scotland
www.carerscotland.org
0141 445 3070

- Citizens Advice Scotland
www.cas.org.uk
- Thistle Foundation
Tel: 0131 661 3366
www.thistle.org.uk
- Children in Scotland
www.childreninscotland.org.uk
- Enquire helpline for advice on educational support needs
Tel: 0845 1232303 E-mail: info@enquire.org.uk
- Princess Royal Trust for Carers
f.burke@carers.org
Tel: 0141 221 5066

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Appendix 2

Severity rating scale

The Canadian Consensus Document has been used as a resource document in the compilation of the Scottish Good Practice Statement. The following guide is 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 Symptoms: 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: 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)

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Appendix 3

Sleep and pain profile

Adapted from Canadian Consensus Document

Please complete this chart for the week before your next appointment

Name _____ Date _____ to _____

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?

Body pain diagram

Pain Visual Analog Scale (Pain VAS), Body Pain Diagram

Please indicate the amount of pain you have had in the last 48 hours by marking a "/" through the line.

0 _____ 1 _____ 2 _____ 3 _____ 4 _____ 5 _____ 6 _____ 7 _____ 8 _____ 9 _____ 10
No pain Excruciating pain

On the following diagrams, please indicate your areas of:

Aching: ===

Burning pain: xxx

Stabbing pain: ///

Pins and needles: ooo

Other pain: ppp

Describe: _____

[Please note: Original body diagram to be re-instated here].

Appendix 4

Group Process

[This section still to be added/finalised]

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Acknowledgements

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