NHS

Chronic Fatigue Syndrome and ME
Northern Clinical Network

Guidance Notes on the Medical Assessment of Adult Patients with Suspected Chronic Fatigue Syndrome/ME

2nd Edition 2013

www.cfsmenorth.nhs.uk

Contents

Introduction

The purpose of these guidance notes is to raise awareness in healthcare practitioners, who may see adults with suspected CFS/ME, of the full breadth of the potential differential diagnosis and to clarify the conditions that can and should be referred to the local NHS CFS/ME services in the North of England. This guidance explains the purpose and value of full medical assessment prior to initiation of therapy, which should be carried out by a medical practitioner with experience in the diagnosis of CFS/ME. The guidance will also be a valuable guide to therapists who in some areas undertake the initial screening of patients referred from primary care, and to GPs who will be making decisions about referral. It will also be of value to trainee doctors who may be asked to see or review patients with fatigue.

Purpose of medical assessment

Medical assessment of patients referred with suspected CFS/ME is essential, as local studies have shown that between 20-74% of patients may have other identifiable causes for fatigue. Therapy services are limited and it is important that the resource is targeted at those most likely to benefit. Patients with other functional disorders and non-CFS/ME diagnoses should be redirected to other appropriate services, for example mental health and chronic pain services. It is essential that all therapy teams, where the local pathway involves GP to therapist referral, have access to experienced physicians who can review the patients to confirm or refute the diagnosis. The ideal standard should be that all patients with suspected CFS/ME (adults and children) should be reviewed by a consultant-led medical team with experience of the diagnosis and management of CFS/ME and of the differential diagnostic possibilities. This should be before a therapeutic programme is initiated, wherever possible.

CFS/ME is a clinical diagnosis, and the current definition (for therapy purposes) is based on the Fukuda critieria, which are essentially symptom based and exclusion based. There are however variants of CFS/ME whose predominant symptoms may not be identified in this set of criteria and conversely the advances in understanding of the aetiology of CFS/ME will enable more precise identification of patients fulfilling the physiological, if not the classification criteria.

Fatigue is a common symptom, and is not by itself specific for CFS/ME. The associated symptoms are also not specific. Broad medical knowledge is required to formulate a correct diagnosis. Medical assessment comprises two elements, firstly an initial screen of the referral letter and The Nice Guideline 53 recommends screening blood test results, which should accompany the referral, for obvious pointers to alternative diagnoses, and secondly an outpatient consultation with a full history and physical examination. This will take about 45-60 minutes. It should not be necessary to repeat the screening blood tests carried out in primary care and other tests should only be done against specific clinical indications.

The NICE Guidelines recommend blood screening as part of the primary care evaluation before referral. It is essential that all these results are available to the medical screeners. Referrals with abnormal screening bloods should not be accepted unless the medical screener is satisfied that these have been explained and/or are not relevant to a diagnosis of CFS/ME.

Patients applying to the DWP will require evidence of a medical consultant review, as GP reports are now unlikely to be accepted.

Once medical screening has been undertaken and a clear diagnosis made, long-term medical follow-up in secondary care is not appropriate, with the exception of children and adolescents in transition, where specific needs in relation to education will usually require a period of follow-up in addition to therapy input.

Diagnostic features of CFS/ME

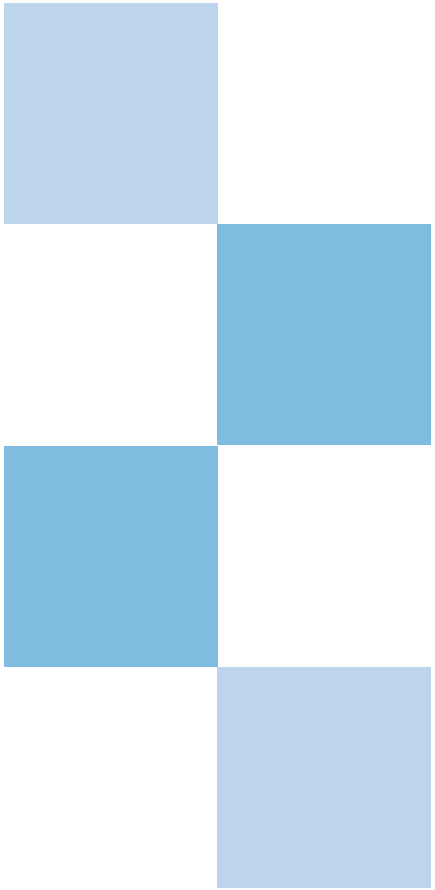
Patients may have used resources such at the Internet to research their own symptoms. This makes obtaining an uncontaminated history difficult, and patients will often present their symptoms in a way that confirms their theory that they have CFS/ME.

Two types of CFS/ME are identifiable, those with a definable starting point for their symptoms, usually following infection, and a group with a gradual onset. It is unclear at the present whether these groups are physiologically distinct.

Key symptoms are:

- Prolonged debilitating fatigue (not tiredness), affecting their functional capacity, made worse by activity.
- Generalised muscular and joint pains without evidence of joint swelling, made worse by exercise. Identify how much physical activity is required.
- Reduced memory and concentration (obtain specific examples).
- Disturbance of sleep and/or feeling unrefreshed by sleep.
- Headache – usually generalised (distinguish focal headache, migraine).
- Intolerance of light and loud noise.
- Dizziness (non-rotational); shakiness (not tremor)
- Increased frequency of sore throats and swollen glands.
- Temperature disturbance (usually hot when others are cold and vice versa)..
- Evidence of 'boom and bust' cycles of activity followed by inactivity due to worsening symptoms.
- Irritable bowel symptoms (nausea, bloating, abdominal discomfort/ cramps, diarrhoea or constipation or alternating bowel habit)
- Autonomic features: pre-syncope, syncope, positional tachycardia, abnormal sweating (check for postural BP drop and postural tachycardia)

Other features that are strongly associated with CFS/ME include atypical facial pain and temporomandibular joint disorder and irritable bladder syndrome. Psychosocial stressors are usually increased in the period preceding the onset of fatigue (bereavement, divorce, redundancy etc) and should be noted. Abnormal bereavement reactions and post-traumatic stress disorder should be identified and referred NICE approved treatments through other channels, if this is identified as the major source of symptoms.



It is important during the history and examination to identify non-CFS features, in particular:

- Evidence of a primary sleep disorder (excessive or inappropriate somnolence): sleep diary may be helpful
- Evidence for sleep apnoea (typical neck and pharyngeal shape, documented excessive snoring, apnoeic spells); Epworth score may help but is not specific. Insomnia, circadian rhythm disorder and other primary sleep disorders.
- Evidence for a primary psychiatric or psychological disorder: depression, severe anxiety, including health anxiety, obsessive-compulsive disorder, psychosis and somatisation (as secondary depression and anxiety can accompany CFS/ME this can be difficult – if there is doubt discuss with psychologist/psychiatrist in therapy team)
- Evidence for primary neurological disorder (muscle wasting, tremor, abnormal tone)
- Evidence for arthritis (swollen tender joints with restricted movement) or joint hypermobility.
- Evidence for documented organ-based disease (chronic lung, cardiac, liver, renal and musculoskeletal disorders)
- Contributory drug therapies
- Evidence of endocrine disorder (changes in menstruation, libido etc.).

CFS and Fibromyalgia

Fibromyalgia (FM) is a syndrome of muscular pain, associated with marked point tenderness, in the absence of raised inflammatory markers or other markers of autoimmune or structural joint or muscle disease. Like CFS/ME, it is a diagnosis principally of exclusion. When the CFS/ME services were funded, DH made it clear that they viewed primary FM as *excluded* from the remit of the teams.

However, there is considerable overlap of CFS/ME with FM. It is unclear at the moment whether these conditions are part of a continuous spectrum or discrete illnesses with different aetiologies. For the time being it is safest to view them as two ends of a spectrum. It is possible to identify CFS/ME patients where there is little or no muscle pain, and FM patients with no significant fatigue. In between there are patients with varying levels of fatigue and pain.

At medical assessment, patients with minimal fatigue and predominant FM symptoms should be referred back to their GP with advice about the use of alternative analgesic agents (amitryptiline, gabapentin, pregabalin, sodium valproate, duloxetine) and the advice to refer to pain management services if not well controlled. Pain services usually use similar therapeutic models to CFS/ME services.

Patients where fatigue is the major problem but where there is fibromyalgic pain as well may legitimately be referred to the CFS/ME therapy teams. The assessing clinician should provide the GP with advice on symptom control, as for fibromyalgia.

Joint hypermobility is more frequent in patients with fibromyalgia. In patients with marked joint hypermobility, the possibility of Ehlers-Danloss Syndrome should be considered. Some patients (Type III) with EDS may have multiple symptoms resembling CFS/ME.

CFS/ME related syndromes

Positional orthostatic tachycardia syndrome (POTS)

This is an autonomic dysfunction syndrome that is strongly associated with chronic fatigue syndrome, although it may occur in the absence of fatigue. It is commoner in young patients and is characterised by an abnormal tachycardia on changing from lying to standing (either a rise of >30 bpm, or a rate > 120 bpm). Symptoms may include postural dizziness and/or tachycardia. It is important to identify these patients as drug therapy will control the heart rate and improve symptoms. Patients with POTS as well as CFS/ME will usually not notice dramatic improvements in their fatigue from therapy and referral to CFS/ME therapy teams is required for fatigue management. Diagnosis should be undertaken by a falls and syncope service with access to tilt table testing. Professor Julia Newton (Falls & Syncope Service, Royal Victoria Infirmary) can advise on further investigation and management.

Recurrent vasovagal syncope (young patients) with fatigue

This is the blood pressure equivalent of POTS and is also an autonomic dysfunction syndrome, but where there is marked and inappropriate postural hypotension, often associated with syncope. Diagnosis and management through a falls and syncope service with access to tilt table testing is required. Drug therapy may improve the syncopal tendency, but will not resolve the fatigue.

It is particularly important to identify postural autonomic syndromes as patients with these syndromes in association with chronic fatigue are more likely to become bed-bound, as getting up makes them feel much worse. Deconditioning and worsening of the postural symptoms then follows. Postural exercise training can be used to supplement drug therapy. Encouraging fluid intake, avoidance of caffeinated drinks, and increasing salt intake can be helpful.

DEMS with polyalgia

DEMS stands for dry eyes and mouth syndrome. These patients have features suggest of Sjögren's syndrome, with dry eyes and mouth and non-specific generalised aching and debilitating fatigue. Blood tests show that, unlike true Sjögren's syndrome, these patients do not have elevated inflammatory markers, elevated immunoglobulins or positive autoantibodies. Published evidence suggests that they should be managed as CFS/ME.

Reactive hypoglycaemia

Some patients with CFS/ME who follow unusual diets with inadequate carbohydrate content may develop secondary insulin oversensitivity, leading to late reactive hypoglycaemia 2-4 hours after carbohydrate intake, with symptoms of dizziness, faintness, nausea and sweating. This often reinforces the impression that they are intolerant of carbohydrate, which they reduce still further, increasing the symptoms! The diagnosis is made by a four hour glucose tolerance test, which will demonstrate late hypoglycemia. Management is by regular small meals of complex carbohydrate, avoidance of refined sugars, and management of the CFS in the normal way.

Irritable bowel syndrome

Almost all patients with CFS/ME have symptoms of irritable bowel syndrome. If the patient has a prior diagnosis of IBS, the source of the diagnosis should be checked, including verification of the investigations carried out. Patients should be advised to follow the BDA/NICE guidance on dietary management of IBS. Symptoms of nocturnal diarrhoea or blood in the stools suggest inflammatory bowel syndromes and require further investigation. CFS/ME therapy intervention is not appropriate until such investigations have been completed and confirmed as normal. Baseline bloods recommended by NICE include a serological test for celiac – this should be done early in the illness. A positive result is an indication for referral for endoscopy and duodenal biopsy.

Irritable bladder syndrome

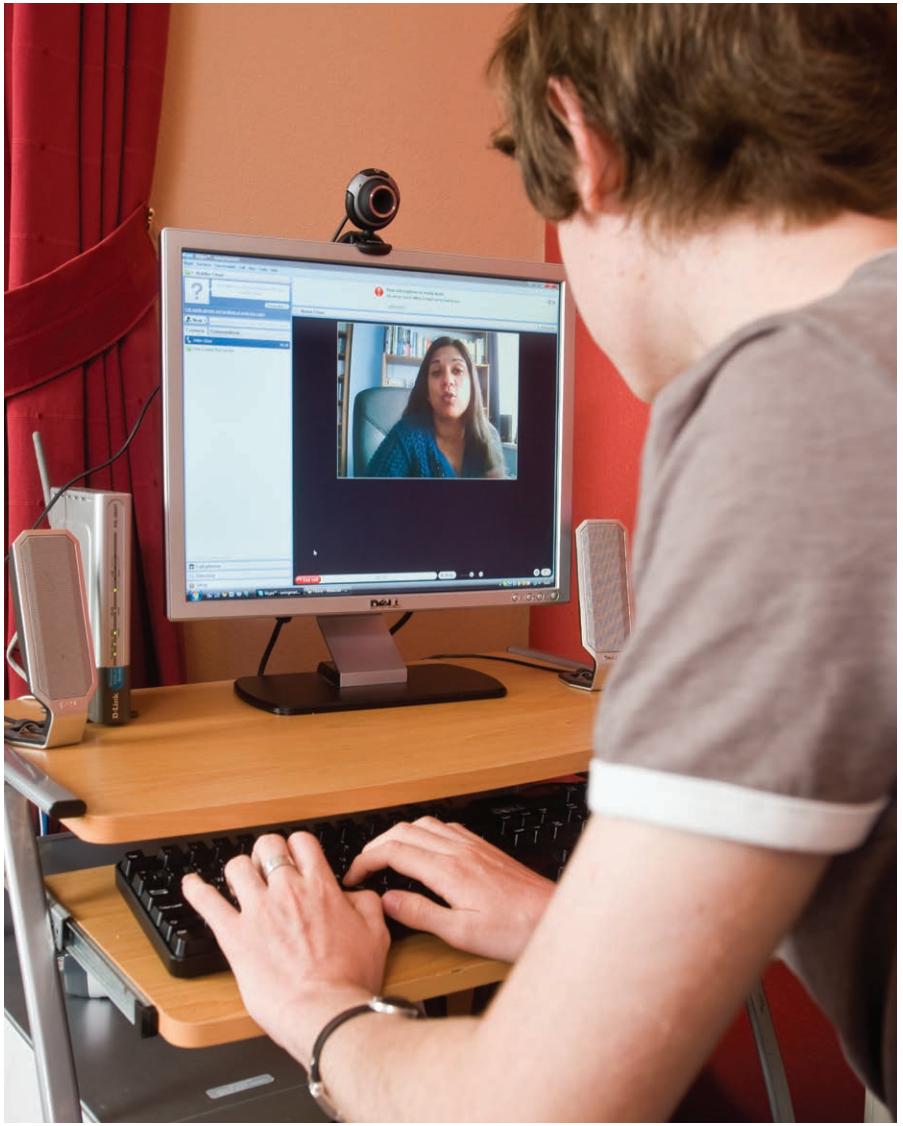
A smaller proportion of patients with CFS/ME complain of irritable bladder syndrome, with frequency and dysuria. This may overlap with interstitial cystitis.

Restless legs

Patients with CFS/ME may complain of marked restless legs at night. Sometimes this may be of a severity that causes daytime fatigue due to sleep deprivation making it difficult to be certain about the primary diagnosis. Ropinirole and pramipexole may be helpful in reducing symptoms and improving sleep.

Patients with mild and/or recovering CFS/ME

These patients can usually be managed with simple graded activity with pacing advice in the clinic and reassurance. Referral to the CFS/ME therapy team may not be appropriate and may actually make the problem worse when they encounter severely affected patients in group sessions, leading to increased health anxiety. An appropriate self help guide is the book 'Fighting Fatigue' by Sue Pemberton & Catherine Berry.



Non-CFS/ME syndromes

Patients with these syndromes should *not* be referred to CFS/ME therapy teams, but should be either directly referred to an appropriate service or referred back to the GP with advice about an appropriate care pathway.

Vitamin and mineral deficiency

Deficiency of iron (ferritin <20 mcg/l) may cause fatigue even if the haemoglobin is not significantly reduced. Low MCV may be an indicator on the screening FBC and should be investigated with serum iron and ferritin (transferrin saturation and zinc protoporphyrin may also be used). Ferritin is an acute phase reactant and will be elevated in line with CRP. A diagnosis of CFS/ME should not be made until the patient is fully iron replete and symptoms have been documented not to have improved.

Vitamin D deficiency may cause fatigue, muscle weakness and bone pain. Up to 30% of the population in the North of England may be vitamin D deficient due to lack of sun exposure during the summer. As this is a treatable cause of fatigue, it is wise to check vitamin D levels and ensure replacement. Levels <25 ng/ml may be associated with symptoms.

Morbid obesity

Under the Fukuda criteria, morbid obesity with a BMI >40 is an exclusion criterion for CFS/ME. Such patients will be fatigued and have significantly raised risk factors for other fatiguing co-morbidities such as sleep apnoea, chronic cardiac disease, fatty liver etc. Patients should be referred back to the GP for community based management with emphasis on dietetic input and assessment for drug therapy and gastric banding.

Coeliac disease (unless there is evidence of good compliance with GFD, with negative tTG antibody)

Patients in whom coeliac disease has been identified on blood screening and confirmed by biopsy, as part of the work-up for fatigue, should not be referred to CFS/ME therapy teams until there has been confirmation that the disease has been controlled on a gluten-free diet. It may take 1-2 years for the fatigue to disappear completely, where the disease has been longstanding. It is essential that that the tTG (tissue transglutaminase) or endomysial antibody is monitored. These antibodies will disappear in GFD-compliant patients: if it is still present then there is gluten in the diet and the patient may have active disease. Patients with known coeliac disease and good compliance should be assessed for CFS/ME on their individual merits, but with emphasis on a careful search for complications of coeliac disease (vitamin and mineral deficiencies, small bowel lymphoma).

New diagnosis or poorly controlled endocrine syndromes (diabetes, Addison's thyroid)

Patients should not be evaluated for CFS/ME until there is evidence of stable control of the metabolic/endocrine syndrome over a period of one year without resolution of fatigue. Discussion with the responsible endocrinologist or diabetologist may be required, and further investigation for associated diseases may be required (e.g. coeliac disease in Type I diabetes; Addison's disease in patient with thyroid disease and pernicious anaemia). For patients whose fatigue persists, evaluation for CFS/ME should be undertaken in the normal way and referral on to the therapy team considered if it is clear that there is no evidence for untreated medical disease.

Because thyroid disease is common, the development of intercurrent thyroid disease in a patient with known CFS is not uncommon, but the diagnosis is often delayed because symptoms are attributed to a relapse of the CFS. Therapy with thyroxine, or T3 or thyroid extracts in patients with normal thyroid function is suggested by some alternative practitioners as being valuable as treatment for CFS/ME. This is on the basis that NHS thyroid function tests do not reliably diagnose sub-clinical hypothyroidism and that thyroid extracts or T3 are better than standard thyroxine. Hypothyroidism due to pituitary failure will be missed if TSH alone is used as a screening test. However, clinical history and examination should identify other features of pituitary insufficiency. Thyroid replacement is only indicated in patients with persistent biochemical evidence of hypothyroidism. Some patients do feel better with combined T4 and T3 replacement. Advice from a thyroid specialist should be sought.

Addison's disease may present with fatigue to CFS/ME services and may be difficult to diagnose clinically. Weight loss, nausea and non-specific malaise are additional features Pigmentation of non-sun-exposed areas (palmar creases, buccal mucosa) is highly suggestive. There may be postural hypotension. Electrolytes may show raised potassium and reduced sodium. A random cortisol >550 nmol/L excludes the diagnosis. If there is doubt consider a short synacthen test.

Patients with polycystic ovarian syndrome (PCOS) may experience fatigue as part of the metabolic syndrome. This may be compounded by a raised BMI, which is a common feature. Discussions with an endocrinologist may be required concerning the management of the metabolic problem.

Inflammatory arthritis (including early RA) and connective tissue diseases

In inflammatory arthritides and connective tissue diseases, the NICE recommended screening tests should identify evidence of raised inflammatory markers. History and examination should identify specifically symptoms of morning stiffness and joint swelling. Anti-CCP antibodies are a more sensitive and specific test for early rheumatoid arthritis than rheumatoid factor, where there is a high pre-test probability. Fatigue is also a significant and often presenting feature in other connective tissue diseases such as systemic lupus erythematosus, Sjögren's syndrome and seronegative arthritides (ankylosing spondylitis, psoriatic arthropathy etc). The fatigue will respond to the treatment of the underlying illness and the patient should be referred on to an appropriate specialist. Referral to the CFS Therapy team is not appropriate

Vasculitis (consider PMR, GCA – may occur in over 40s)

As above, the inflammatory markers should be elevated. Platelet count is also usually increased. Careful consideration should be given to the possibility of polymyalgia rheumatica in the older population of patients presenting with 'fatigue', and of temporal/giant cell arteritis (GCA) in those presenting with fatigue and headache. Occasional patients with these conditions have normal inflammatory markers. While usually considered as disorders of the elderly (>60), both diseases may occur, rarely, in patients in the age range 40-60.

Allergy

Chronic allergic inflammation is usually accompanied by fatigue. Patients with perennial rhinosunisitis may present to CFS/ME services. Headache, disturbed sleep, dizziness and fatigue are major features. Fatigue may be exacerbated by daytime use of chlorphenamine (Piriton®), a sedating anti-histamine. Some third generation 'non-sedating' anti-histamines may also cause sedation and dizziness. Referral to the Allergy Service for further investigation and management is appropriate and patients should not be referred to CFS/ME therapy services until optimal management of the allergy has been obtained.

Evidence of active infection

Evidence of active chronic infection is an exclusion criterion for a diagnosis of chronic fatigue syndrome and patients should *not* be referred to therapy teams until it is clear that fatigue persists despite curative anti-infective therapy.

50% of patients with CFS/ME have a sudden onset with an infective sounding illness. Unless patients are seen in the early phase (when it is not possible anyway to make a diagnosis of CFS/ME) aggressive investigation to identify the type of infection is not useful. Exceptions are those patients whose employment or social background puts them at risk of chronic infections (Lyme Disease, Toxoplamosis, Brucellosis, TB), who should be investigated on merit. Fatigue is a common symptom of chronic hepatitis C (even in the absence of severe liver disease) and HIV infection. Patients with a history that could be consistent with possible contact with these viruses (intravenous drug use, use of anabolic steroid injections, sexual contacts with high risk groups, multiple sexual partners) should be tested for these viruses and referred on to appropriate services if positive.

There is a perception in some groups of patients with CFS/ME that all CFS is due to a variant of borreliosis. Evidence to support this conclusion and the corollary that prolonged courses of antibiotics are helpful is lacking. This group of patients base their assumption on tests carried out outside the NHS, usually in the USA.

Another popular view is that CFS/ME is due to chronic CMV infection, and that treatment with oral valganciclovir is appropriate. 40-60% of the population have evidence of CMV infection by the time they reach adulthood. The role of CMV in CFS/ME is not proven in CFS is not proven and valganciclovir, which is a toxic drug, is not justified without evidence of active current infection. Advice can be obtained from the Infectious Disease Services at the Royal Victoria Infirmary, Newcastle upon Tyne and James Cook University Hospital, Middlesbrough.

"Candida overgrowth" is a popular explanation advanced by patients for their fatigue, promoted by some alternative practitioners. There is no convincing evidence for this and the use of anti-fungals is not recommended in the absence of documented fungal infection. Anti-candida diets may improve irritable bowel type symptoms in CFS/ME patients as they reduce the intake of resistant starches. Chronic mucocutaneous candidiasis is an immune dysregulation syndrome, often with autoimmune features and having a genetic basis. It is rare and typical features include oral and nail candidiasis: patients with these features should be referred to clinical immunology for formal evaluation.

Primary sleep disorders (insomnia, narcolepsy, idiopathic hypersomnolence)

Primary sleep disorders are usually distinguishable by virtue that the primary problem is not fatigue but inappropriate sleeping (too much or too little). Such patients should be referred on to a specialist in sleep disorders, usually a neurologist, for further investigation and management. Referral to the CFS/ME therapy teams is not appropriate. Dr. Kirstie Anderson, (Consultant Neurologist, Royal Victoria Infirmary) is able to advise.

Circadian sleep disorder

This disorder is due to abnormalities of the 'body clock' when sleeping takes place at the incorrect time of day or may not be on a 24 hour cycle (irregular). This may be extrinsic due for example to shift working (see below) or intrinsic (several variants recognised). Sleep diaries will help identify these patients. The disorder is treatable and patients should be referred to a sleep specialist.

Secondary sleep disorders (sleep deprivation)

Sleep deprivation with consequent daytime somnolence and fatigue may occur for example in mothers with children with sleep disturbance (night terrors, nocturnal head banging etc) and those unable to sleep due to changing shift patterns (Shift-work disorder). Management of the underlying problem or the secondary cause may be required to solve the problem. Referral to the CFS/ME Therapy team is not appropriate.

Sleep apnoea

Sleep apnoea is commonly confused with CFS/ME, as the daytime symptoms are similar, with headache, sore throats, fatigue and malaise. Pointers tend to be increased body mass index, short neck, increasing collar size or absolute collar size (17 or above), and evidence of a narrow pharynx with bulging side walls on inspection (Mallampati Grade III or IV). The Epworth sleep score should be used and any patient with a score of 12 or above should be referred for sleep studies. Sleep apnoea is a risk factor for stroke and myocardial infarction. Patients with sleep apnoea who do not respond well to optimised CPAP should be evaluated for CFS/ME (they can co-exist!). Referral to a therapy team should not take place until there has been an effective trial of CPAP.

Mental Health/Psychiatric disorders

It is important to consider psychiatric illness in all patients presenting with fatigue. There may be an overlap between depression, anxiety and CFS/ME which can make diagnosis difficult. One third of patients with CFS/ME have co-morbid depression. The HADS score is useful screening tool (included in the national CFS/ME Minimum Data Set for patient evaluation). If there is doubt, formal evaluation by an experienced psychologist or liaison psychiatrist should be sought *prior* to making a diagnosis of CFS/ME.

Many patients with CFS/ME have co-existing mental health problems, including depression and anxiety. This requires treatment but does not preclude referral to the therapy team, as treatment of the underlying CFS will help improve mood and treatment of the depression may reduce fatigue, if this is as a result of developing CFS/ME. Short-term (4-6 months) use of anti-depressants is helpful in the first instance; if depression is recurrent then longer term treatment may be appropriate. SSRIs are the preferred drugs, although fluoxetine and paroxetine may be poorly tolerated in patients with CFS/ME; citalopram and venlafaxine seem to be better tolerated, although the latter should only be used with specialist advice.

It is important to identify patients whose fatigue is secondary to a primary mental health disorder, usually depression or sever anxiety. Such patients will have the cardinal feature of low mood, with other symptoms such as loss of interest, loss of pleasure, loss of confidence, self-reproach or guilt, agitation or retardation, as well as reduced concentration, change in appetite and sleep. There may be diurnal variation of symptoms including fatigue. Suicide risk needs to be explored. Where this is identified, patients should be referred back to their GP for appropriate management, unless there is immediate concern about suicide risk, in which case referral to the crisis team should be initiated.

Factitious or exaggerated illness is more difficult to identify without corroborative evidence from other sources. Anxiety over benefits may contribute to over-estimation of the severity of symptoms and functional capacity. If in doubt, seek advice from liaison psychiatry before proceeding to referral to therapy teams.

Post-traumatic stress disorder

A number of patients have been referred for medical assessment of fatigue where it is clear that the fatigue is part of a post-traumatic stress disorder. There is some evidence that previous abuse (physical, mental, sexual) can be a predisposing factor for fatigue. Where this is identified for the first time, patients should be referred through their GP for appropriate counselling or primary care psychology and not to the chronic fatigue therapy teams.

Fatigue related to organ-specific disease (lung, heart, liver, kidney) or its treatment

Fatigue as a consequence of chronic or sub-acute organ-based illness is common and its severity usually mirrors that of the primary disorder. Even moderate COPD is associated with significant fatigue. Renal impairment is associated with fatigue at quite modest elevations of serum creatinine. Primary biliary cirrhosis is very strongly associated with fatigue, but autoimmune hepatitis is not. Referral to the CFS/ME therapy teams is not appropriate for organ-based fatigue. Fatigue should be managed as part of the ongoing illness by the organ-based specialist.

Neurological disease

The most important neurological disorder to consider is multiple sclerosis. Fatigue can be a prominent feature of chronic MS. Usually the history includes symptoms occurring in different anatomical locations at different times. Where there is doubt, review by a neurologist should be obtained.

In older patients, consider early onset Parkinson's disease. Tremor may be present in CFS/ME but is usually coarse and easily stopped by distraction. Patients with early Alzheimer's disease may also present in CFS/ME clinics. Features of concern would include predominance of memory problems (short term, with preservation of long-term), loss of navigational skills (getting lost going to shops), unexplained deterioration in work performance.

None of these patients should be referred to therapy teams.

Chronic fatigue has also been noted in patients who have recovered from Guillain-Barré syndrome (GBS). As GBS is usually infection driven and autonomic dysfunction is a well recognized feature in the acute phase, it is not unreasonable to consider fatigue in this context as being identical to CFS/ME and appropriate to refer for therapy. Fatigue is also seen in chronic demyelinating neuropathies, but here there is an active inflammatory process that is usually undergoing active management, and this group is unlikely to benefit from referral.

Migraine

Migraine is one of the commonest neurological problems. Patients with a past history of migraine who develop CFS/ME may see an increase in frequency of migraine, which should be addressed. However severe chronic migraine with >15 attacks/month (transformed migraine) is strongly associated with fatigue, brain fog and sensory intolerance. Analgesic induced headache (codeine derivatives) may be a complication. CFS/ME should not diagnosed until migraine has been well controlled with appropriate preventative treatments have been introduced and analgesic withdrawal has been undertaken. Propranolol should be used with care as a migraine preventative as it may increase fatigue. Specialist advice should be sought for severe chronic migraine from a neurologist (Dr Paul Dorman, Dr. Kirstie Anderson and Dr. Paul Goldsmith, Consultant Neurologists, Royal Victoria Infirmary are happy to advise).

Post-MI/stroke syndromes

Patients who have had major coronary events with arrest or peri-arrest situations often have suffered a degree of cerebral hypoxia which causes fatigue, poor memory and concentration and this is often accompanied by severe depressive illness, especially in younger males who lose their jobs as a result, or where the illness came out of the blue. Good cardiac rehabilitation may help. CFS/ME therapy is unlikely to help as this is a neurological insult which will recover only slowly. Psychological input through community psychology services or through cardiac rehab services is most appropriate. Similar problems are seen in patients post stroke, and are likely to increase as more patients undergo thrombolysis and have less residual motor deficit.

Fatigue secondary to malignancy and/or chemo/radiotherapy

Malignancy and chemo/radiotherapy for its treatment are all strongly associated with chronic fatigue, which may persist long-term (up to 10 years) even when the primary tumour has been fully treated. It is important in medical screening to be alert to the possibility of occult malignancy, seeking specifically evidence for unexplained localised symptoms/ signs such as bone pain, new skin rashes, unexplained recurrent venous thrombosis and other paraneoplastic phenomena. Depressive illness following a diagnosis of cancer will complicate matters. This is most appropriately dealt with through community psychology services. Palliative care services may also be able to advise on other avenues of support, as may cancer-specific patient support groups. Referral to CFS/ME therapy teams is unhelpful.

Fatigue when other illness have been treated

There will be a small number of patients with fatigue-inducing organ-based disease where there is a clear medical diagnosis and where optimum treatment does NOT improve fatigue, for example thyroid disease and obstructive sleep apnoea. Each of these cases must be evaluated on their merits and discussion with an appropriate specialist is required.

Dangers of diagnostic labels

Patients are very keen for diagnostic labels, but once applied become almost impossible to remove. Accordingly it is crucial that a label of CFS/ME should not be applied unless there is clear evidence that the diagnostic criteria are met and that there is no possibility of a confounding illness. Patients may have increased anxiety when given a label of CFS/ME, fuelled by media misinformation: in these circumstances giving a diagnostic label early may increase symptoms. Patients do however have an expectation that the doctors in the medical assessment service will be able to give them a clear diagnosis and management plan.

Once a patient has acquired a label of chronic fatigue (or any other chronic diagnosis) there is a medical tendency to subsequently attribute any new symptoms to the existing diagnosis, rather than evaluate the patient fully. This is extremely dangerous and may lead to coincidental serious pathology being missed. All new symptoms in patients with CFS/ME should be investigated on their merits.

Advice

Members of the local CFS/ME therapy teams are happy to advise on local pathways for medical assessment. The medical assessment team in Newcastle are happy to advise on general issues and on complex cases.

Contact details for your nearest service can be found at www.cfsmenorth.nhs.uk or www.bacme.info

Acknowledgements

I am grateful to Dr. D.A.Price, Consultant in Infectious Disease, Royal Victoria Infirmary, Professor J.Newton, Falls & Syncope Service, Royal Victoria Infirmary, Dr.K.Anderson, Neurology Royal Victoria Infirmary, Dr. M.Firth & Dr. A.Kelly, Health Psychology, Royal Victoria Infirmary and Dr. K.Lindsley, Consultant Psychiatrist, for critical comment on this Guidance.

Dr.G.P.Spickett
Consultant Clinical Immunologist
Clinical Champion for CFS/ME
Northern CNCC
Royal Victoria Infirmary
Newcastle upon Tyne
NE1 4LP

Telephone 0191 2825517

Email gavin.spickett@nuth.nhs.uk

March 2013

NHS

Chronic Fatigue Syndrome and ME
Northern Clinical Network

www.cfsmenorth.nhs.uk