



Working Group on Severe CFS/ME

Shared Clinical Practice Document

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Section 1 Authors and development process

The first edition of this document was compiled by the Severely Affected Working Group of the British Association for CFS/ME with help from the wider executive and other contributors. Contributors are listed in Appendix A.

The final version incorporates feedback provided by our Patient and Public Involvement representatives, GP's and allied professionals who have offered to read it as a non-CFS/ME specialist, also listed in Appendix A.

Definitions and Abbreviations

BACME: British Association for CFS/ME

CBT: Cognitive Behavioural Therapy

CDC: Center for Disease Control (United States of America)

CFS/ME: Chronic Fatigue Syndrome/Myalgic Encephalomyelitis

GET : Graded Exercise Therapy

GP: General practitioner

NHS: National Health Service

NICE: National Institute for Health and Care Excellence

CCG: Clinical Commissioning Group

WHO: World Health Organisation

Section 2 Introduction

This document has been produced by the British Association for CFS/ME (BACME) National Working Group on Severe CFS/ME. Our working group includes experienced clinicians involved in the diagnosis and management of patients with severe CFS/ME, patient representatives with current and past experience of severe CFS/ME, and carers.

This document is designed to help practitioners, working with people severely affected by CFS/ME, to feel able to better understand the condition, and find guidance for how to work with the individual and their support network to find a way forward in managing this complex condition. Its aims include:

1. To **highlight the particular health needs** of this group of patients
2. To **share practical ideas contributed from services across the UK** on ways of working together with people with severe CFS/ME and their carers to improve quality of life, health and well-being.
3. To provide a **resource for those who are considering setting up new services**
4. To **signpost helpful materials and information** for health professionals seeing people with severe CFS/ME and carers.

Whilst this working group acknowledges the brief principles on severe CFS/ME outlined in the 2007 NICE guidelines, we also recognise the limitations of these guidelines and seek to expand on these brief principles by sharing good practice, contributed from the accumulated experience of health professionals, patients and carers across the UK. Some of the experience shared by both clinicians and patients in the process of producing this document have been highlighted in text boxes.

More general information on the diagnosis and management of CFS/ME can be found in:

- NICE Guideline Section 1.9 Key principles of care for people with CFS/ME www.nice.org.uk/guidance/cg53/chapter/1-guidance
- Therapy and Symptom Management in CFS/ME produced by the British Association for CFS/ME (BACME) from www.bacme.info
- Scottish Good Practice Statement on ME/CFS (2010), www.scot.nhs.uk/scottish-good-practice-statement-on-me-cfs/

2.1 Defining severe CFS/ME

CFS/ME is an illness characterised by disabling persistent fatigue, pain, cognitive dysfunction and other symptoms. A full description of the illness and criteria for diagnosis can be found in the NICE Guideline, Section 3 and Appendix B. For the purposes of this document, we will define severe CFS/ME in adults as a level of CFS/ME in which the person is **housebound, unable to mobilise without a wheelchair, or bedridden** (The level descriptors were originally defined in Cox (1998), and Cox & Findley (1998) and adopted by NICE 2007).

The first edition of this document has had to focus primarily on the assessment and management of adult patients due to the scope of the group. We have signposted sources of information for children and young people with CFS/ME in . It is recommended that readers also seek advice from services specialising in assessment and management of patients in this age group which can be obtained from BACME website: www.bacme.info

References

Cox DL (1998) Management of CFS: development and evaluation of a service. *British Journal of Therapy and Rehabilitation*. 5(4):205-209

Cox DL, Findley LJ (1998) The management of chronic fatigue syndrome in an inpatient setting: presentation of an approach and perceived outcome. *British Journal of Occupational Therapy*. 61(9):405-409

2.2 Health needs of patients with severe CFS/ME

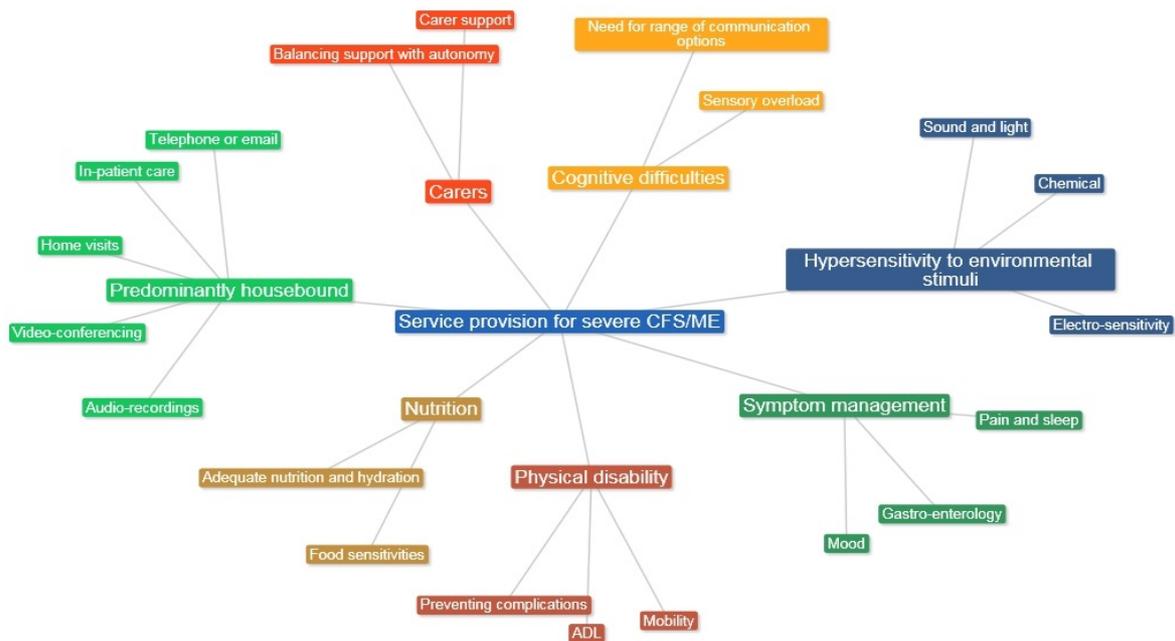
Chronic fatigue syndrome, also known as myalgic encephalomyelitis (CFS/ME), is an illness characterised by debilitating physical and mental fatigue, pain and other symptoms. At its most severe, CFS/ME can lead to individuals becoming housebound, wheelchair user or bed-bound and dependent on family and carers for many or all basic activities of daily living. The illness can leave some severely affected individuals profoundly disabled for many years, although others return to health within a much shorter time.

Patients who are house/bed bound will also have difficulty accessing other health services, for any co-existing health problems or routine health screening in primary care. If they

require admission to a hospital, the often busy hospital environment can become extremely stressful and distressing. Those who are sensitive to light and noise would find both outpatients and inpatient areas difficult, and with additional cognitive difficulties, communicating their needs and difficulties can become a huge challenge.

People who are severely affected by CFS/ME inevitably have needs that are beyond the condition itself, as it will affect many areas of their lives as summarised in the Mind map in Figure 1 below. It is likely that they need help and support from a range of different people, from family / carers/ friends, professionals from primary and secondary care, social care and the voluntary sector.

Figure 1: Mindmap of needs of patients with severe CFS/ME



ADL =activities of daily living

Primary care would normally be the first port of call for these patients, but due to the severity and or complexity of the patients’ problems, it can be difficult for both patients and professionals to start to clarify how to best meet the needs of the individual. However, appropriate intervention can lead to significant improvement in the person’s condition, function and quality of life, enabling greater independence and reduction of burden of care.

Where it is possible to access Specialist services offering input to patients severely affected by CFS/ME, patients may be offered intervention between primary and secondary care. Where such services are not easily accessible, it may be necessary for local services to seek advice from specialist service in other areas, in providing the much needed intervention nearer the patient’s home. Ideally CFS/ME Specialist Services would, with the consent of the patient involved, liaise and provide information about CFS/ME or seek information from those outside the specialist team about their involvement so different intervention can be coordinated.

Most practitioners will need to adapt their approach and expectations from their usual clinical practice as working with people severely affected by CFS/ME requires a gentle, steady approach as improvement takes considerable time and there is no quick fix.

In the first instance the patient will need a thorough clinical assessment (section 3). This may require a number of visits and we have included guidance for managing those appointments in limited time slots as well as taking account of the main symptoms that are likely to affect the patient and how you might adapt your approach.

Section 3 Making a diagnosis : assessment and comorbidities

The starting point for any health professional in working with an individual with severe CFS/ME, is to ensure that the patient has been fully assessed by a doctor to check their diagnosis, to identify key medical issues and make sure that any co-morbidities (other medical conditions occurring alongside the CFS/ME) have been identified and given appropriate treatment. A thorough medical history, physical examination, mental status examination, and laboratory tests are necessary. This can be a challenging process if the patient is unable to attend GP Surgery or outpatients and have difficulty tolerating contact even at home. Assessment may need to take into consideration : location, duration, tolerability, environment. It is often necessary to obtain history from others (with patient's consent) or medical records. Direct patient assessment needs to take into account how long an individual can tolerate, whether they are sensitive to stimuli (noise, light, position) and may need to be carried out on more than one visit. If the individual cannot tolerate diagnostic tests to exclude other conditions, it would not be possible to reach a clear diagnosis, and also risk missing other treatable conditions. The pros and cons of tests would need careful discussion with the patient and their carers as to the risk of not being able to carry out these tests. If this includes investigations that requires attendance at a hospital, the receiving facility may need to be given information about the difficulties the patient has in attending and see if appropriate adjustment can be made to enable the patient to attend.

I sometimes have to assess an individual in a darkened room with double blackout curtains and whisper due to extreme noise and light sensitivity.

Consultant in a CFS/ME Service

3.1 History

CFS/ME represents a constellation of persistent physical symptoms without a single identifiable pathology. The diagnosis is a clinical one based entirely on history.

The most commonly used diagnostic criteria is the CDC/Fukuda 1994 (www.cdc.gov/cfs/case-definition/1994.html). For consideration on other diagnostic criteria, see Appendix B.

The diagnosis is made by identifying characteristic clinical features and the absence of red flags that point to potential missed pathology. If post-exertional fatigue / malaise (payback), sleep disturbance, persistent pain and cognitive disturbance (brain fog) are absent, it is important that the diagnosis of CFS/ME is reconsidered. If there are additional pathology, these should be properly assessed/treated before the diagnosis is considered. In the presence of other comorbidities, it is possible that these patterns may not be classically seen (further conditions that exclude or need not exclude CFS/ME see Appendix B).

3.2 Physical examination and psychological well being

There are no diagnostic physical signs that positively identify CFS/ME (whereas fibromyalgia has characteristic allodynia or tenderness of soft tissues). However, in patients with severe CFS/ME, it will be important to ensure that examination includes weight and nutritional state, range of joint movements, pressure areas and psychological

well-being. Many patients experience dizziness on upright posture, and if tolerated, one may consider looking for a postural drop in blood pressure, but this may not be practical or necessary, if history is highly suggestive.

Assessing psychological well-being is a crucial part of any initial assessment. Pressures of living with severe CFS/ME can lead to psychological difficulties, such as low mood and anxiety. It is important to note that some (though not all) diagnostic criteria for CFS/ME require the exclusion of psychiatric diagnoses, so this point needs careful consideration before making a diagnosis. Conditions such as severe Depression, Anxiety Disorders including Obsessive Compulsive Disorder and Eating disorders can be a cause of persistent fatigue symptoms and low function. It is also possible that patients with CFS/ME also suffer from psychological conditions as an additional diagnosis, which can become a significant barrier to recovery, unless they are addressed in their own right.

Red flags in CFS/ME diagnosis

Clinical features that can be caused by other serious conditions should not be attributed to CFS/ME without consideration of alternative diagnoses or comorbidities.

In particular, the following features should be investigated :

- Localising/focal neurological signs
- Clinical features of inflammatory arthritis or connective tissue disease
- Clinical features of cardiorespiratory disease
- Significant weight loss
- Sleep Apnoea
- Clinically significant lymphadenopathy

Source : Nice guidelines (CG53) and Scottish good practice statement in ME-CFS (SGPS) for GP's

3.3 Investigations

NICE guidance (CG53) suggest the following in adults to ensure they are normal :

Blood tests

Full blood count, ESR or CRP

Urea, creatinine, electrolytes, liver function

Thyroid function, glucose (more commonly HbA1c)

Coeliac screen, Calcium and CPK

Urinalysis

The purpose of biomedical investigations is to exclude other alternative diagnoses since there are currently no consistent proven biomarkers for CFS/ME.

In people who are severely affected, we recommend testing for Vitamin D due to poor sun exposure, and B12, folate, ferritin levels if the patient has eating difficulties or poor nutrition.

3.4 Difficulties reaching a diagnosis

It is important that a clear diagnosis is made at the earliest opportunity where possible to facilitate effective intervention. However, it is possible that due to complex combinations of difficulties in someone who is severely affected, the diagnoses may not be clear cut at the beginning. In such situations, the person's difficulty with chronic disabling fatigue should still be recognised and offered appropriate intervention with a rehabilitative focus, while diagnoses / comorbidities continue to be reviewed.

It is important that other conditions that the patient is presenting with is effectively addressed.

Comorbidities are common in CFS/ME, including;

- specific physical symptoms e.g. atypical facial pain, migraine,
- constellations of physical symptoms e.g. abdominal symptoms/Irritable bowel syndrome
- medication side effects (patients with severe CFS/ME often report more reactions to medications)
- medical complications which are secondary to severe CFS/ME, such as nutritional deficiencies and/or weight loss, autonomic dysfunction (e.g. POTS syndrome or postural hypotension) and musculoskeletal problems (e.g. contractures or muscle wasting)
- mental health : severe anxiety, depression, obsessional compulsive disorder can become a significant barrier to rehabilitation.
- there may be other coexisting medical problems, unrelated to CFS/ME, which may have greater impact on a person severely affected.

Sometimes the most intrusive symptoms may be the biggest barrier to improvement and may need to be the focus of intervention initially, regardless of the order in which the problems arose. For instance, if a person has become low weight or nutritionally deficient due to difficulty eating, it will be difficult to improve function before they can gain weight and correct nutritional deficiencies.

Section 4 Therapeutic approach

Providing care to patients who are housebound or bed bound requires different consideration from outpatient care. Delivery of care to patients in their own home poses logistical challenges, particularly as those who are severely affected by CFS/ME may not be able to tolerate the clinical contact that is normally taken for granted. Approaches that are helpful, from the experience of services involved, are collated here, and the logistics of how to deliver the care is considered in Section 5.

A patient with severe CFS/ME contributing to this report suggested that the most important role of therapeutic intervention is to offer a 'toolbox' with a wide range of interventions and strategies that a patient with severe CFS/ME can experiment with to find out what helps them, with support from therapists in exploring these at their own pace.

As a working group, we recognise that particular interventions may help some patients and not others. In the absence of specific research evidence about what is most likely to be helpful in this patient group, most services take a pragmatic approach, offering a range of therapeutic tools and strategies, tailored to individual need.

4.1 Key principles

CFS/ME is a complex illness which, for those that are severely affected, completely impacts on their life and the lives of those who care for them. Patients and carers need clear, consistent and constructive information to build up their understanding of what can be done to improve the affected individuals quality of life and develop a recovery

pathway. Intervention may include offering understanding of the condition, mitigating the effects of physical disability, and maximising independence and quality of life through rehabilitative strategies.

4.1.1 Instilling hope

There is currently a lack of research evidence on interventions for severe CFS/ME. However, the limited research evidence available, combined with reports from experienced clinicians, and patients themselves, suggest that a multi-disciplinary, patient-centred approach, tailored to the needs of the individual can lead to improvement, and even recovery in some. It is possible to enable positive change and improvements for people with severe CFS/ME despite the situation seeming to be overwhelming for all. However this takes time and requires all involved parties to work together and develop an individualised care plan shared by all concerned which may need to be sustained over a long period.

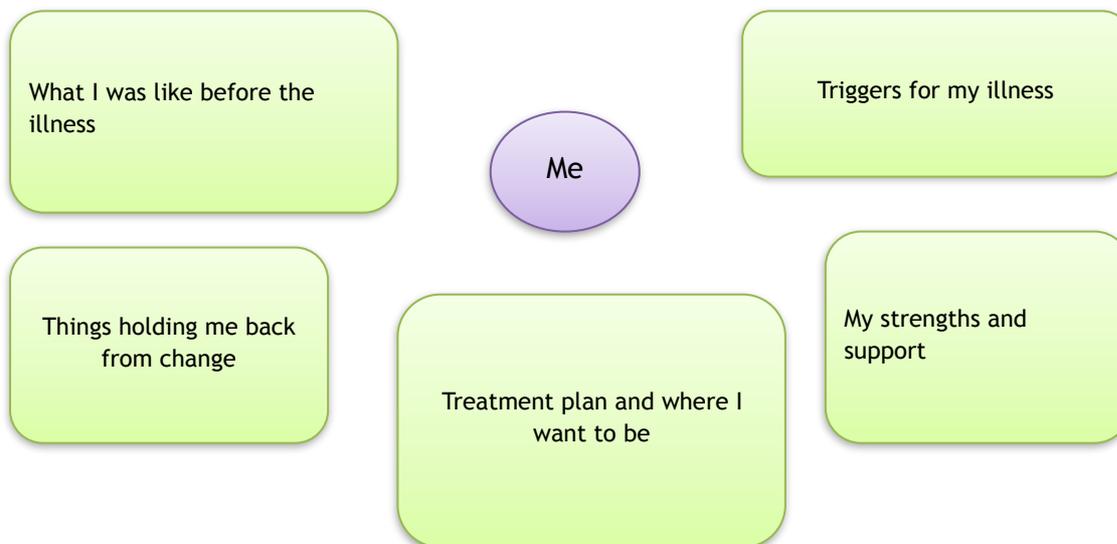
Addressing making therapeutic changes with the person who is severely affected is a sensitive task. Some support may be rejected initially when the person is first ill where expectation is that the illness will resolve within a few months; or, where the person has been ill for a long time, and experienced disappointments with therapies that haven't worked, or they feel highly experienced in managing their situation yet not seeing improvement. Some people may be in a place where it is difficult to make even the smallest change, for a variety of reasons, but it is possible that they may be in a different situation at a future time, so it is important to maintain therapeutic optimism whilst at the same time guarding against unrealistic expectations.

4.1.2 Establishing a working relationship

Our patients have told us that a crucial aspect of initial assessment is to be enabled to tell their story, if they are able, and to feel that they have been listened to and understood. This validates the individual's experiences of what has led to their current situation and allows exploration of the issues that are concerning them. Their concerns go beyond the physical symptoms and may include financial hardships, living situation, relationships, personal care needs, social isolation and cognitive difficulties. The listening is part of the process of establishing a therapeutic relationship between the therapist and the patient and their family. Understanding what changed for the person as a result of the illness, and supporting the person to find ways to bring about therapeutic change is an important aspect of the therapeutic approach. Trust of the therapist and establishing a partnership is vital in effecting change that a person can encompass and that they see is of benefit. This relationship may need to be sustained over a long period of time and not giving up is vital as many patients talk of therapists 'arriving full of hope and positivity then giving up when change doesn't happen'.

Ideally, it would be helpful to reach a point of a shared understanding of the wider needs of the patient, that covers not only the physical symptoms and diagnosis, but also other factors that may be impacting on their current condition, factors that may potentially impede changes they would like to see, as well as strengths they have to move towards improvement. This is sometimes called a formulation, which can help clarify to both therapists and patients that they share the understanding of the patient's present position and what specific issues need to be addressed.

An example of a formulation may be:



Some people also find it helpful to create a **time line** to make sense of how they got to where they are. This may look something like:

- Xx years What I was like, what life was like
- Xx years Triggers for illness and what was happening in my life at the time
- Xx years What happened after becoming ill
- Xx years Where I am now
- Xx years Where I want to be in the future

4.1.3 Flexible and collaborative approach

Many people severely affected by CFS/ME, and their families, can feel completely confined and trapped by the illness and cannot see a way forward as even tiny amounts of activity or external stimulation can feel like an enormous overload and cause an increase in symptoms that may appear disproportionately extreme to others. Patients will vary in the degree to which they can tolerate contact with clinicians so making contact, carrying out the assessment and working on a rehabilitative strategy may all require significant adjustment in how these are carried out. This may mean obtaining some of the illness history through others (with patient's permission), being creative in how contact is made with the patient (cf Section 5) and carrying out assessments on more than one visit, as mentioned previously.

Interventions and goals to be agreed would also need negotiations regarding the priorities for the patient and the pace at which any changes would be attempted, in a flexible and collaborative manner. Showing understanding of the limitations the patient faces and negotiating an agreed approach can be crucial in making progress in the longer term.

4.1.4 Involvement of family and carers

Family member(s) and carers are an essential member of the support /management team with their valuable knowledge, insight and experience of how the illness is affecting the person living with CFS/ME and it is important that they are involved in all aspects of assessment and treatment where there is permission from the patient to do so.

All parties involved can sometimes be caught in a reactive cycle where the person with severe CFS/ME has a crisis or develops a new symptom. Practitioners / carers want to find

a solution to try and help make things better at that time and search for another intervention or feel they need to respond to well meaning but not necessarily productive advice from the wider circle of family and friends. Understandably, people are wanting to help and find a way to alleviate intrusive symptoms, however due to the nature of CFS/ME, it can often be more helpful to take a more considered response as maintaining consistency and routine can be far more helpful to all in the longer term.

It is important that there is good communication between the clinicians/therapists, the patient and the family and carers so that all can share the understanding of the therapeutic approach.

Helpful information may be obtained via Specialist CFS/ME Services, where available, and via national and/or local charities and support groups such as:-

- www.bacme.info/local_services
- www.ayme.org.uk
- www.actionforme.org.uk/Resources/Action%20for%20ME/Documents/get-informed/caring-for-somebody-with-me.booklet.pdf

4.2 Overall Treatment Approach

Incremental Pacing and Grading up activities

As indicated previously, there is no clear evidence for treatment of CFS/ME patients who are severely affected, and most specialist services will adapt their approach to individual need, which will incorporate incremental pacing and grading of activities to aid rehabilitation. The goal is to enable individuals to find ways to better balance their activity and quality rest within their immediate limitations to establish more predictable and maintainable patterns of activity. This in due course can be followed by a slow stepwise upward grading to achieve sustainable a meaningful change.

Initially the therapist will need to develop a picture of what the individual is doing on a daily basis and find a way to create a balanced pattern of activity. The individual may feel as if they are doing nothing but by sensitively gathering information from the individual, as well as family and carers it is possible to help the individual begin to see that even the smallest movements or activity during the day have a purpose.

Everything the person with CFS/ME does counts as an 'activity'. Things that we might take for granted can be demanding if you have CFS/ME and this is greatly amplified when the individual is severely affected - so the therapist needs to help the individual consider the impact of activities such as:- talking, texting, looking, listening, washing, worrying, thinking, changing position, eating, drinking.

Activities, at whatever level this means for the individual, can be reorganised over the day so that they are in small chunks interspersed with rest breaks. It is better to do tiny amounts of a number of different things, one activity at a time, and then take a rest break between each activity.

Value of marginal gains

The tiniest changes, in different areas added together over time, can add up to something substantial and make a big difference

Lesson from the Olympic Team

So the individual doesn't have to think about what they should be doing, some people find a simple recurring pattern can be helpful. These need to be individually designed and tailored. The best way is to start with an idea of what the person can do at this time, then try and put small amounts of each activity and rest into a simple pattern. Often the initial

An example (for illustrative purposes only) could be:

10 min lying flat in silence

5 min sitting up supported.

10 min lying flat listening to audio book/music.

15 min free rest (as we used to rest before)

5 min sitting doing cognitive activity (iPad, puzzle, social media)

1-min physical activity (go to toilet, walk to window, do stretches).

3 min lying down practicing breathing.

Tip : to avoid getting fixed into a rigid routine, it can be helpful to have more than one routine to alternate

plan is to focused on increasing tolerance to gravity and increase relaxed state in the body.

It is important to work with the person to establish a pattern that they feel they can sustain or can do for a few repetitions in the day. This should be trailed and adjustments made to make sure it is a stable baseline. Then individual components can be increased gently, so it may initially be by seconds. Each level is usually sustained for a few days before increasing again. Using this method can reduce recording as the initial plan is recorded and then just how many times the person could achieve it that day or any changes to the plan need noting.

It is important to recognise that dealing with external stimuli may also feel demanding, and ensure these are also given consideration, e.g. it may be difficult for the individual to manage listening to two people talking so it's better for one person to take responsibility for a conversation. At the same time, avoidance of external stimuli can make matters worse in the long run and it is important that it is graded not avoided (see section on stimulus sensitivity) .

Helpful thoughts

- It is possible to do things despite the person feeling unwell with careful planning and timing
- Thinking 'smaller' and changing big ideas into smaller more achievable ones
- Tasks can be broken down with mini-breaks, to reduce the impact of an activity. Breaks might mean switching activity rather than complete rest, depending on the severity.
- Putting one toe forward and keeping it there is better than taking a step and falling backwards.
- Progress will have small or large setbacks on the way, but it doesn't mean things won't move forward over time with patience and perseverance
- Having a way of recording achievements, no matter how small, is essential as tomorrow it may be forgotten. Once recorded it can never be taken away!
- It is important for the families and carers to see that positive change can happen with person specific management plans including practical support and management techniques tailored to the person's current capacity and rate of change, allowing for relapse and plateau

Example 1

Dealing with more than one thing at a time can have a huge impact and lead to increased symptoms leaving the individual feeling very poorly for some time afterwards.

Having a conversation is an activity that can have high energy demands as you have to talk, listen and think all at the same time. Visual processing i.e. following facial signals and lip movement is often limited alongside auditory or written language processing. It can feel very difficult to limit conversation as most of us find this pleasant at the time and we can feel 'rude' to the other person if we do not get involved in the conversation. But successful interaction depends on doing it in the way the person can currently manage.

It can be very helpful to limit the time you talk with the person severely affected by CFS/ME and ensure you do not talk when another activity is being carried out such as:

- meal times
- washing

The individual may find it difficult asking you not to talk so your support in minimising conversation can be very helpful. Sometimes a sign on the bedroom door to remind people can be helpful for any visitors or carers coming into the home.

Example 2

Most people with CFS/ME are extremely sensitive to all stimuli: taste, smell, light, sound, touch, temperature, alcohol and food they may previously have enjoyed. So therapists and carers need to understand that these stimuli place demands on the body to cope with

Ms D has been severely affected by CFS/ME and was mostly bed- or sofa-bound but has very gradually introduced a range of activities into her routine, initially in very small amounts. Intolerance to noise was a big problem so family members tried to be very quiet around the house to prevent Ms D withdrawing to her bedroom. Initially this approach was useful when Ms D was very unwell but it had the effect of increasing her sensitivity to sound over time.

Together we discussed a plan to very gradually increase Ms D's tolerance to noise, based on her priorities and interests. Initially she tried out introducing listening to music and found that single instruments, playing one at a time, was more tolerable. She also tried talking to people for short periods but this wasn't always easy to control. At a point when Ms D felt stable enough she also wanted to try to use an electric toothbrush but found the noise barely tolerable. Together we worked out a very gradual way of re-introducing the noise where Ms D just turned on the toothbrush for a few seconds every day but did not put it anywhere near her mouth. She built this time up over weeks to a point where she was able to gradually introduce the toothbrush into her mouth, and then build up her tolerance, over time, to start to brush her teeth. Ms D now cleans her teeth twice daily using her electric toothbrush.

Ms D has used this approach to reintroduce other activities into her routine in the same very gradual way.

Summary

Strategies for incremental pacing and grading

- Planning ahead with the individual so each day is consistent and unexpected events are minimised as much as possible
- Breaking all activities into much smaller manageable parts
- Carefully planning the duration of all activities / interventions.
- Doing one action / task at any one time
- Alternating each task / part of task with planned rest breaks

Difficulties may include:

- Coping with anything unexpected or out of the ordinary....whether visitors, change of environment, change of routine and it is useful to work out ways of dealing with this in the general care plan
- Fear and anxiety about 'what might happen' having had negative experiences in the past as above

4.3 Addressing different problems

4.3.1 Sleep and re-establishing a diurnal rhythm

Disturbed sleep is universally seen by patients with CFS/ME as impacting on other daytime symptoms. Patients report broken sleep, difficulty getting off to sleep, or needing to sleep excessively. Additionally, if patients have become highly sensitive to light, they may be in a darkened room day and night, which results in loss of diurnal rhythm further impacting on their sleep pattern and quality. As previously mentioned, primary sleep disorder should be excluded at the assessment stage.

Re-establishing a good sleep pattern is very important in the overall treatment and management of CFS/ME. The first step is to understand the general pattern of sleep, then finding a way to establish a diurnal rhythm of sleep and awake periods in a 24 hour period. This may also be helped by gradually introducing daylight into the bedroom, (see sensitivity section) to enable the brain to re-establish the circadian rhythm.

It is also important to recognise that excessive sleep is as problematic as too little sleep, and for those who spend long periods asleep, or in a half asleep, half awake state, it may become necessary to start to shorten their total sleeping time. This will be achieved by gradually reducing the sleep duration, in small steps, such as 15 or 30 minute steps, and it needs to be adjusted over days or weeks. The initial aim would be to have one period of long sleep equivalent to night time sleep. Although daytime napping is discouraged generally, in the early stages, this also needs to be tackled in small steps, reducing any 'daytime sleep' in say 10 or 15 minute steps, aiming for a maximum of 30 minute naps in the daytime.

The conventional advice for sleep encourages not staying in bed outside the sleep time, which is not practical for those who are bed bound. However, tackling sleep may go hand in hand with a very gradual programme of starting to sit a little, or sitting out of bed for

short periods, which alongside increasing light exposure, will all help to start to set a 24 hour routine.

Most people find that by sticking to a clear routine each night, it acts as a trigger for the body to move into 'sleep mode'. If the person wakes in the night and can't get back to sleep after about 20 -30 minutes, it may help to establish a mini routine where they get out of bed (if able), do something relaxing until they feel sleepy and then return.

For those who have difficulty falling asleep, identifying and addressing factors that get in the way of sleep such as worry or pain would need to be tackled. Patients may also be using electronic devices (eg laptops, smartphones) in bed in their waking hours. They would be advised to limit their use in the hour or two before bed time, changing to a different bed time routine.

General principles (adapted to severely affected)

- keep regular bedtimes and rising times
- reduce daytime napping in steps
- morning exposure to daylight
- establish bedtime routine - 'wind down' avoid dwelling on problems in bed
- avoid stimulants, alcohol and cigarettes, bright lights and screen usage pre bed
- comfortable bed: not too warm or too cold
 - try keeping a diary to help identify routine
 - avoid large meals before bed

Much of this work has been shown to be beneficial in chronic pain
www.sciencedirect.com/science/article/pii/S1389945710000146

More resources for patients can be found at the Australian self help site

www.sleephealthfoundation.org.au/pdfs/Chronic-Fatigue.pdf

www.sleephealthfoundation.org.au/pdfs/Good-Sleep-Habits.pdf

4.3.2 Improving the quality of rest

Due to the severity of their symptoms those people with severe CFS/ME will spend the majority of their time resting, or in some cases sleeping. Because doing any activity may increase symptoms, people see rest as a helpful state. However, it is the quality of the rest that is important. It is not just muscles that use energy, but cognitive activity uses energy as do all the other systems in the body. Many people with severe symptoms feel too unwell to move, but still have overactive minds. Some people describe it like their brains are running all the time and the more stress or stimulation they are exposed to the worse this feels. Therefore, early in the therapy process it is important for the patient to understand the importance of increasing relaxation/restorative rest. Simple breathing control, supporting lowering of heart rate can be used or there are lots of free resources available through electronic devices to enable people to try different methods for enhancing the relaxed state in their body.

Soothing the sensory system

The state of arousal in the body can also be affected by sensory experiences. If someone goes into too high a state of sensory arousal they can experience a state of 'shutdown', when it feels like neither the body or brain will function. So just as some sensory experiences, such as conversations or bright light can increase sensory alertness, other can be used to reduce or calm the nervous system. So for example sometimes silence can actually be perceived by the brain to be a threat as it is more aware of any small noises or

is listening out to what may be going on around you. The brain may not be able to tolerate talking or music but it may find natural sounds, like rain, wind, trees moving, etc calming. There are resources on line or apps that can be used to access different natural sounds to find which work for that individual. Everybody's sensory system is different but it is common to find sounds, certain light frequencies, application of heat/cold, textures (like stroking a pet) and deep pressure have a calming effect. Activating particular sensory signals can also help pain, such as when we bang a limb we rub it to create heat and pressure, which helps reduce the pain.

Following being given a device that monitored heart rate a young girl with severe ME was shocked to find that the device showed her heart rate reflected 9 hours of high cardiac activity, when she had laid down all day. She practiced using breathing to slow her heart rate down once every hour and also if she had to get up. She got the reading down to 15 minutes and was more able to start doing activity.

Using the sensory system can help with increasing relaxation. As the person doesn't have to think or act, they can be accessible to many patients with severe symptoms. Carers can help with this. Firstly, work out which sensory stimuli are calming and can be tolerated and then helping to make sure they are used consistently. So for example putting on the desired sounds, applying heat pad, using gentle stroking or a pressure pad, for the person at particular times of day. (see Stimulus Sensitivity)

4.3.3 Nutrition

Those who are severely affected are more at risk from poor or inadequate nutritional intake. This can lead to substantial weight loss and can be a significant concern to family, carers and/or health professionals. The adverse consequences of malnutrition are well reported and include: impaired immune response with increased risk of infection; decreased muscle strength; apathy, depression, self-neglect.

Conversely, due in part to substantially reduced mobility, changed eating patterns, and energy expenditure, some people who are severely affected gain significantly amounts of weight. This can compromise any recovery strategies, as being heavier impedes mobility and can also impact on emotional wellbeing. To manage weight gain encourage a reduction in high fat/high sugar processed foods and drinks especially snacks such as biscuits, crisps, sugary drinks, pastries, cakes. Instead replacing these with more vegetables, fruit and fluids low in calories.

An inadequate intake may happen for a number of reasons such as:

- Poor appetite
- Being too exhausted to chew and eat food
- Carers needed to help with shopping/food preparation/feeding
- Disrupted meal patterns due to poor sleep
- Sensitivity to smells, taste and texture of foods.
- Food hypersensitivities
- Sore throat that affects and limits food choices
- Financial impact of illness -less money for food
- Nausea and vomiting

Practical Tips

- Eating smaller meals and more often can help
- When bedbound check for a “safe swallow”. If needed refer to a Speech and Language therapist for assessment
- Feeding position is important and the more upright the better. If bedbound and sitting up is difficult, prop up with good head and neck support. Using a straw can help with fluids.
- Choosing foods that are easier to chew and swallow is helpful. These include softer textures, more sauces, pureed foods and soups.
- Using nourishing milky drinks. Homemade is cheaper and often more palatable, but commercial nutritional drinks such as Complan can be convenient when eating is difficult.
- Regular weight checks where possible or alternative measures- see BAPEN link above are important to monitor progress.

Many with severe CFS believe they have intolerances, and cut out more and more basic food items which is likely to make them at higher risk of nutritional inadequacy. Assumptions of having food allergy and intolerance require further clinical questioning to ensure the diet is not unnecessarily compromised. Also in the severely affected there are often marked changes in food preferences, and sensitivities such as texture, taste, and temperature that cannot be explained. This can be distressing for the patient and carers and a supportive, empathetic approach is vital to achieve best outcome.

Assessing nutritional risk : the Malnutrition Universal Screening Tool (MUST)

MUST is a validated, reliable and practical way of screening for adults, even if they are obese. It is a four step process developed by a multi-disciplinary group of health professionals. It is produced by BAPEN (British Association for Parenteral and Enteral Nutrition)

Step 1 BMI

Score : 0 if over 20, 1 if 18.5-20, 2 if under 18.5

Step 2 Unplanned Weight Loss in last 3-6 months (% body weight)

Score : 0 if less than 5, 1 if 5-10, 2 if more than 10%

Step 3 Add scores from 1,2

0= low risk 1=medium risk 2 or more = high risk

Step 4 Management plan

- Record overall risk score, agree and document a care plan and advice given
- Patients with high or medium risk typically require some form of intervention - referral to a dietician or implementation of local policies on food fortification together with re-screening after a month in community setting or a week in hospital.

BAPEN (British Association for Parenteral and Enteral Nutrition) has launched a new Malnutrition Self-Screening Tool designed to help combat malnutrition. The web-based Tool, which is free to use, is designed to help adults living in the community to identify their own risk of malnutrition. Individuals identified as being at risk of malnutrition, can download a dietary advice sheet that gives them basic information and suggestions for improving their nutritional intake, until they receive further advice from a healthcare professional.

Copies of the 'MUST' materials and the 'MUST' Explanatory Booklet - a guide to the use of 'MUST' are available to view and download in PDF format free of charge.

It may not always be possible to measure height and weight those who are severely affected. BAPEN have written guidance and considerations in these circumstances. Further details can be found on alternative measurements such as estimating height from ulna, knee height or demispan, and using mid upper arm circumference, in the "MUST" explanatory booklet.

Supporting those with poor nutritional intake

First line: Use Food First

With a MUST score of 2 or more (check your local policy as this may vary) refer to a dietitian for assessment to give tailor-made advice such as modifying texture and fortifying foods. In some circumstances this fails to give an adequate intake, nutritional supplements may be prescribed.

Enteral Feeding

Despite trying all these approaches the patient may still continue to lose weight to a level that poses serious risk to the person's overall health. Enteral feeding may need to be considered in such situations, i.e. feeding via a nasogastric (NG) tube, nasojejunal (NJ) tube or PEG (percutaneous endoscopic gastrostomy). This needs the assessment and intervention from a specialist team involving doctors and a specialist dietitian in nutritional support.

Considerations for enteral feeding:

1. Swallowing difficulties affecting oral intake substantially
2. If oral intake is absent or likely to be absent for a prolonged period
3. If patient is unable to meet nutritional requirements adequately via oral food and nutritional supplementation therefore at risk of severe weight loss.
4. Early instigation of enteral feeding may be needed in severely malnourished patients.

Risk of Refeeding Syndrome

Refeeding syndrome consists of metabolic disturbances that occur as a result of reinstatement of nutrition to patients who are starved or severely malnourished. Those with Severe CFS/ME who have very poor appetites and intake are potentially at risk when they resume eating / food intake.

Patients at High Risk of Refeeding syndrome

Any of the following: BMI < 16 kg/m²

- Unintentional weight loss > 15% within the last 3-6 months
- Very little or no nutrition for > 10 days
- Low levels of potassium, magnesium or phosphate prior to feeding

Or 2 or more of the following BMI < 18.5 kg/m²

- Unintentional weight loss > 10% within the last 3-6 months
- Very little or no nutrition for > 5 days

- Any patient who has had very little food intake for > 5 days especially if already undernourished (BMI<20kg/m², unintentional weight loss >5% within the last 3-6 months) is at risk of Re feeding syndrome.

Please follow local protocol for treatment for those identified at high risk.

Disordered Eating

In the severely affected some degree of disordered eating is commonly reported. Marked changes in food preferences and restricted range of foods chosen are more evident. Regular reviews and watchful waiting is helpful. They should be encouraged to keep on retrying food being avoided as the changes may be temporary. Psychological intervention to help the person regularise their eating pattern may also be effective if it is accessible.

When to suspect an eating disorder?

Though not diagnostic, a score of two or more from the questions below (SCOFF questionnaire) should raise your index of suspicion.

1. Do you ever make yourself sick because you feel uncomfortable full?
2. Do you worry you have lost control over how much you eat?
3. Have you lost more than 1 stone in a 3 month period?
4. Do you believe yourself to be fat when others say you are too thin?
5. Would you say that food dominates your life?

If there is concern of an eating disorder referral to an Eating Disorder team is advised (NICE guidelines CG9 2004 last updated 2015).

Marsipan (Management of Really Sick Patients with Anorexia Nervosa) Guidance (www.rcpsych.ac.uk/pdf/CR189_1.pdf) is a document drawn up by Royal Colleges of Pathologists, Physicians and Psychiatrists. It has guidance for primary care and secondary medical care clinicians in assessing and managing disordered eating/eating disorder where there is serious risk to health.

References

NICE Clinical Guideline 32 Adult Nutrition Support Feb 2006 www.nice.org.uk/Guidance/CG32

NICE Clinical Guidelines 9 Eating disorders in over 8s-management www.nice.org.uk/guidance/cg9/resources

MARSIPAN(Management of Really Sick Patients with Anorexia Nervosa) www.rcpsych.ac.uk/pdf/CR189_a.pdf

SCOFF questionnaire www.kcl.ac.uk/ioppn/depts/pm/research/eatingdisorders/resources/THESCOFFQUESTIONNAIRE.pdf

4.3.4 Autonomic dysfunction

Those with CFS/ME have a high prevalence of autonomic symptoms, particularly postural dizziness and episodes of faintness/loss of consciousness. Those who are severely affected by CFS/ME are equally affected by significant symptoms related to problems of the autonomic nervous system. Without further research it remains unclear whether the absolute prevalence of autonomic dysfunction is higher in those with severe CFS/ME and whether autonomic dysfunction could be a primary precipitant for the symptoms (i.e. as we see in Postural Tachycardia Syndrome, POTS) or whether the inactivity and deconditioning that occurs in those who are house, chair or bedbound, are the aggravating

factors for continuation of symptoms. Either way it is important that autonomic dysfunction is managed appropriately, investigated and identified in those with CFS/ME.

Particular screening questions that identify those at increased risk relate to postural dizziness and episodes of faintness/loss of consciousness. Detecting conditions such as Orthostatic Hypotension and POTS are important as both have treatments that may ultimately allow individuals to be less symptomatic and as a result function better, These can be tested formally using a tilt table.

However, formal testing of autonomic function may not be accessible to a patient who is bed or housebound. If the person is able to stand up at least for 10 minutes, it is possible to screen for autonomic dysfunction by measuring pulse and blood pressure at the bedside. They rest supine for 10 minutes. At that time they are asked to stand as quickly as possible with support if necessary for up to 2 minutes in the first instance. During that time the clinician is looking for any changes in blood pressure that might be consistent with orthostatic hypotension (a drop in systolic blood pressure of greater than 20 mm/hg or diastolic of greater than 10mm/hg). In addition to blood pressure we monitor heart rate looking for POTS (ie. where there is an increase in heart rate by more than 30 beats per minute on assuming the upright position, or to above 120 beats per minute).

If people who are physically unable to participate in a stand then examining for a haemodynamic response to lesser manoeuvres such as sitting might be of value if they are positive and associated with symptoms, although there are no guidelines or evidence to underpin this.

For those who are completely bed bound and unable to sit up, they are likely to experience postural dizziness due to inactivity and deconditioning regardless of autonomic function. It will be important to help the person understand the negative impact of lying horizontally for long periods of time and start to introduce postural change aiming in the first instance to a sitting position in small gradual steps.

If individuals are found to have problems with their autonomic nervous system - management includes; encouraging fluid intake of at least 2.5 litres of water per day, where there is no evidence of systolic hypertension we recommend increasing salt intake, as a guide, a level teaspoon a day. If possible we encourage individuals to wear graduated elastic hosiery to reduce pooling of blood in the legs, in the daytime, taking them off at night. It is important to withdraw or reduce any vasoactive medications. Guidance for POTS self management can be found at www.stars.org.uk/patient-info

Very occasionally, medication targeted at autonomic dysfunction may be considered (see BACME symptom management document)

Objective assessment of the severity of the autonomic symptoms can be obtained using validated scoring systems such as the Orthostatic Grading Scale or the Composite Autonomic Symptom Scale. These tools have specific thresholds for symptoms consistent with orthostatic intolerance and orthostatic hypotension and are very clinically applicable.

References

Tilt table testing : Parry Heart Newcastle Protocols Heart 2009;95:416-420

Orthostatic Grading Scale Schrezenmaier C, Gehrking JA, Hines SM, et al. Mayo Clin Proc 2005;80:330-333

Composite Autonomic Symptoms Scale David M, Sletten BA, Gillermo A, et al Mayo Clinic Proceedings 2012: 87:1196-1201

4.3.5 Cognitive difficulties

Patients with CFS/ME frequently report difficulties with concentration, short term memory and word finding difficulties. Processing and production of written and spoken language is significantly affected alongside short term memory function. Although this all generally improves with recovery it presents a significant limitation when severely affected and further increases isolation and impacts on self-confidence.

People have difficulty following normal conversation, as they struggle to take in the whole of the sentence, and have difficulty picking up non-verbal cues. They may become slow in speech, which helps them hold onto what they intend to say, but ordinary conversational turn taking can be difficult. They may also find it difficult to focus on the conversation when multiple people are speaking at the same time.

“Not being able to follow what someone was saying , having trouble talking and forgetting anything I did understand made me think I had dementia”

People may find it difficult to initiate speech or find words to express themselves.

“I used to read a book every night now I flick through a picture book”

Similar difficulties arise with written language (writing and reading) and numerical sequences (often reversed or mis-sequenced). At its worst, they may need to rely on pictures rather than words.

For those who are severely affected, they may also have lost contact with their friends or have had difficulty maintaining their hobbies and interests, and may have limited capacity or opportunity for meaningful mental activities.

All these problems affect contact with family and therapists, or ability to retain information discussed with a clinician, that enable them to make use of therapeutic input.

It will help communication by others speaking slowly and softly, with short sentences, leaving longer pauses to allow a response and making a very short written or recorded edit of the important parts of the conversation to re run at another time. If the word the person is struggling to retrieve is obvious, saying it for the person can help. Written content needs to be grammatically simple, short, spaced out on a page and preferably in 14pt type. Sometimes a coloured background, coloured type or using coloured lenses aids the reading process. (many of the approaches used for people with dyslexia, which these written language difficulties mimic , can be useful)

“at times I have to sit and wait for the brain to reboot”

Section 5 on providing accessible services give some ideas of how communication can be facilitated in more detail.

4.3.6 Managing the emotional impact of the condition

When asked what has changed for them becoming ill - most people say everything but their inner self. It impacts on relationships, roles, finance, independence etc. In the words of a young teenager, “My life moved from a round to a flat football”. Similarly the principal carers, be they family or friends experience many changes in all these areas. These would naturally impact on the person’s emotional and psychological well being, some people become hopeless, helpless and depressed, some become anxious and stressed, and some in the effort to regain control, may become preoccupied with what may improve their condition in search for a cure. They (and/ or their families and friends) may look for anything that will improve their situation, the most commonly investigated area is nutrition/diet but people look for hope in a range of interventions. They become

vulnerable to trying out interventions which may be costly and have little research to support them.

Clinical depression and anxiety are common conditions in people experiencing chronic illness, especially those that have a huge impact on their function, and may require treatment in their own right. They can become blocks to making changes mentioned above, that can lead to improvement in their condition. This may mean considering the use of antidepressants for either depression or anxiety, or if the person is able and can access psychological therapies, to see this as one of the tools for the rehabilitation strategy.

4.3.7 Symptom management including pain

Any care package for a patient with severe CFS/ME needs to consider medical management of symptoms, such as pain, poor sleep, nausea or other gastroenterological symptoms, low mood or anxiety. Ideally these should be managed in collaboration between the patient's GP and a CFS/ME clinician who is experienced in working with severely affected patients. This may not always be the case. To assist GP's BACME have recently produced Good Practice Guidelines on symptom management (www.bacme.info).

4.3.8 Stimulus sensitivities

Many patients with severe CFS/ME experience hyper-sensitivity to sound, light, motion and other environmental stimulation. For those experiencing this, 'ordinary' levels of noise or light can feel overwhelming, causing great distress, and making concentration very difficult. These difficulties become a significant barrier to receiving medical care, day to day activities, family life and intimate relationships. Clinicians need to be aware that light and noise levels which may feel normal to them, may be greatly amplified to a patient with these symptoms. Poor tolerance of movement may limit ability to travel and also increase nausea and dizziness.

Some patients also report sensitivity to chemicals (e.g. perfume or scented toiletries), or to electrical devices such as mobile phones. Discussion at initial consultation can enable the therapist to be aware of these issues. Patients may also appreciate it if their attending clinician avoids using perfumes or strongly-scented deodorants, and wearing plain (non-patterned) clothes. Patient report they found it most helpful for the therapist to find a balance between validating the individual's current (sometimes overwhelming) experience, and encouraging optimism that environmental hypersensitiveness can improve, or even resolve completely over time, and that, as with noise and light, very careful and gradual exposure can support this process.

Two of the patients helping us with this chapter, who had previously been profoundly severely affected by light sensitivity, reported that they had found that by getting their carer to hang many layers of dark grey muslin over the window to exclude light, and then removing layers gradually over a number of weeks/ months, they was gradually able to cope with increasing light levels. Additionally early evening light is far kinder to those with sensitivity.

Patients highlight the crucial importance of listening to and validating the patient's first-hand experience in this aspect, and in finding ways of assisting people to cope with this distressing symptom. Showing empathy for this in clinics, for those able to attend in wheelchairs, by having lights that dim, having access to a quiet waiting area demonstrates a depth of understanding before even meeting the patient. Or visiting patients at

home, one may need to respect the fact that they need to be seen in darkened room for their comfort.

At the same time, feedback from people with personal experience of getting better from CFS/ME, suggests that building up exposure to sound and light gently and slowly can often facilitate gradual improvement. Sensory modulation is a technique that can be usefully applied by occupational therapists in addressing some of these difficulties.

4.3.9 Physical disability and use of aids and adaptations

Feedback from current and previous patients with experience of getting better from severe CFS/ME highlights the importance of providing mobility aids and adaptations to patients with physical disability, as well as carers to assist with activities of daily living as needed. This feedback suggests that maximising independence by these means can improve quality of life, lift mood, build confidence, and make it easier for patients to start rebuilding their lives, and regaining health.

Physiotherapy (including passive physiotherapy for those most severely affected) may also play a key role both in preventing medical complications from immobility (e.g. contractures and bedsores), and in assisting patients to regain physical mobility, flexibility and strength.

However, if providing aids and adaptations (particularly permanent changes to the home), clinicians should carefully consider the message this might give the patient about their prognosis, and the potentially limiting influence they may have longer-term on recovery. Depending on the circumstances, therapists should encourage the patient to view such aids as potentially temporary to assist them now, and not necessarily permanent. Therapists should also consider whether there is a review process in place to ensure these remain appropriate should the patient's condition improve.

Assistance may need to include

- Occupational therapy input to assess activities of daily living
- Home adaptations (e.g. ramps, stair-lifts, showering facilities) to maximise independence
- Providing relevant equipment and disability aids (e.g. wheelchairs, bathing or kitchen aids)
- Organising for paid or unpaid carers to support patients in domestic tasks, or personal care
- Providing training, mentoring or support for paid or unpaid carers
- Social care package to allow respite for carers and parents

Some issues to bear in mind when assessing for aids and adaptations

1. If the equipment is provided to help with physical limitations (eg poor mobility), does the patient have any other symptoms which might make it difficult for them to use the equipment. For example, if a manual wheelchair is provided, do they have pain in their arms which would make self-propelling the chair difficult or exhausting. If a stair lift is considered, do they have problems with balance or sensitivity to motion which might make them unable to use it. Consider the patient's strengths and

I had a patient who was given a stair lift and lots of equipment, but she can't operate them herself and doesn't have the tolerance for the movement, but no-one thought to ask her about that. So it all sat there and she stayed in bed.

limitations as a whole.

2. For some patients, starting to use mobility aids, such as a wheelchair can lead to fears that the illness will lead to life-long disability. It may be important to talk this over with them, and explain that using appropriate aids, when needed, can leave more energy free for them to increase their quality of life and range of activities, which can support improvement and hopefully in due course, recovery.

3. Being aware that the patient tires quickly and may have severe sensitivity to light, sound or movement can help in making a consultation easier for the patient and more fruitful for the therapist. If it is important that the patient demonstrates what they can do, or tries out different pieces of equipment, if at all possible, keep this as short and as simple as possible as the patient may tire very quickly. Keeping light and noise levels quiet and gentle, is likely to make things much easier for the patient.

4. If the patient has a regular carer, it may be helpful to include them in the consultation since they can help to explain what the patient can manage, if the patient has limited stamina for talking.

5. Appropriate equipment can make a big difference to an individual's quality of life, and is highly valued by most severely affected patients so it is worth taking the time and thought to match the equipment to the individual's particular needs and limitations.

4.3.10 Access to routine healthcare

Severely affected/ house bound individuals may be at increased risk of additional health problems e.g. muscle weakness leading to increased risk of falls, postural hypotension/postural tachycardia syndrome due to disuse and deconditioning or autonomic dysfunction and consequently potential increased risk of osteoporosis, cardiovascular disease or diabetes if there is significant weight gain and deconditioning. It will be important to consider these issues if the patient continues to be severely affected

As patients may not find it easy to attend the doctor's surgery, they may miss out on routine health screening such as cervical smears and mammography or some may also become anxious about routine vaccinations. For patients who are unable to attend surgery for healthcare, home visits from a GP and/or a nurse to address these issues would be important.

Access issues may also mean problems accessing dental and eye care. Domiciliary dental and optician services may go part way to assessing this where they are funded and accessible.

A bed bound patient had severe skin problems that required a Dermatology opinion but unable to attend hospital outpatients. The GP photographed the skin, and sought the advice from the local Dermatology Service regarding what treatments can be tried at home.

When people develop new symptoms or red flags which would require further investigation, they may find it difficult to access secondary care investigations and assessments, due to their mobility or stimulus sensitivity. It may be facilitated by discussing any adjustments made for appointment (timing, waiting area, transport). Where further investigations are difficult to negotiate an individual risk assessment of the pro and cons of not pursuing such tests may need to be discussed by all concerned.

Section 5 Providing accessible care to housebound patients

Providing care to patients who are housebound requires different consideration from outpatient care. Delivering care in a domiciliary setting poses logistic challenges, and those who are severely affected may not be able to tolerate the clinical contact that is normally taken for granted in a clinic setting. The working group have tried to highlight issues or solutions that are particularly pertinent in delivering care to this group of patients. Logistics of delivering care is addressed in Chapters 2 and 3 whereas therapeutic approaches that need to be considered in severely ill patients are considered in Chapter 4.

5.1 Home visits

Home visits are the most commonly reported means of delivering care by CFS/ME services to housebound patients (McDermott et al 2014), combining the advantages of face-to face therapy with accessibility.

For severely affected patients, talking can be very tiring and the ideal duration of session may initially be short, sometimes only a few minutes.

Patient with severe CFS/ME report that they find it difficult to tell a therapist when they need to stop, because they feel embarrassed to say so.

For this reason, we recommend that initial length of session should be discussed and agreed at the outset between clinician and patient, ideally before the first visit. For very severely affected patients, length of session may need to be discussed with the carer first, and then verified with the patient themselves. It may be helpful to ensure that a clock is clearly visible. One service asks individuals to suggest a simple, non-

Experienced clinicians have also emphasised the importance of watching for signs that the patient is beginning to tire, such as facial pallor, change in expression, voice or posture. They suggest that demonstrating awareness of when a patient is beginning to tire, and responding to this supportively can be a valuable means of building trust and rapport, and may in the long term give the patient confidence that they can cope with therapy sessions.

verbal way that they will let the therapist know they have had enough (eg raising a hand), which can make it easier for patients to signal when they tire, without feeling that they are interrupting the therapist. Whether the signal to stop is verbal or non-verbal, it is important to this request to ensure that the patient gets the best outcome of the session, without getting overtired.

The logistical challenges involved in providing home visits had led to a range of creative approaches to maximising resources.

One NHS service reported that they are able to minimise travel required through “closer to home” outpatient appointments where mild to moderate patients are seen at community hospitals or GP practices closer to their homes and then severely affected patient home visits are included on days when a therapist is in their location.

5.2 Telephone consultations

A key advantage of phone sessions is that several short phone sessions can take place in equivalent time to that which would be used by one home visit. This may be of benefit for both patient and therapist. However some patients with cognitive symptoms may find it harder and more tiring to talk by phone than face-to-face, although others have reported that they prefer telephone sessions and find them less tiring, emphasising the need to fit therapy to individual needs. In addition, the therapist and patient cannot see each other

over the phone, sometimes the therapist may miss out on valuable non-verbal communication; but for some patients the lack of face-to-face contact can feel positive and allow them to speak more openly. A home visit also offers the opportunity for the therapist to speak with carers and assess the home environment, as well as the patient, which may be an important aspect of care and support.

5.3 Video-consultations

Video-consultations potentially offer a low-cost option, combining visibility with flexibility. However, there are two main limitations to video-consultations at the current time. Firstly, cognitive symptoms can make using a computer tiring, and some severely affected patients may be unable to use computers at all. Secondly, in order to ensure patient confidentiality, it may be necessary to conduct video-consultations via technology capable of providing a higher level of data-protection than is currently possible over unprotected broadband. This protective technology can be expensive to set up. Services interested in this approach should consult their NHS trust for guidance on Trust policy. Nevertheless, progress in technology may make video-consultations a promising option in the future for those patients who are able to use a computer, tablet or smartphone. For further reading on the subject, the following report by Steel et al (2011) describes a pilot project conducted in Cumbria to explore this approach.

Emailing and texting can also offer a means of supporting and staying in contact with patients. Feedback from individuals with severe CFS/ME suggests that even limited contact with a supportive health professional can be very much valued, in preference to feeling left to cope alone.

References

Chronic Fatigue Syndrome and ME Northern Clinical Network (2009) Video-consulting for delivery of CFS/ME interventions at home: Tele-rehabilitation. Systematic Review: Final Report - source www.cfsmenorth.nhs.uk/reources-and-downloads

Telerehabilitation in North Cumbria www.ruralhealthlink.co.uk/activities/list/telerehabilitation-in-north-cumbria

Steel et al (2001) Therapeutic videoconferencing interventions for the treatment of long term conditions. J Telemed Telecare 17:109-117.

5.4 Audio-recordings

For patients too severely affected to cope with direct face to face conversation, phone or computer, audio-recordings may offer a route into communication which would otherwise not be possible. Recordings can be played by the patient at times when cognitive symptoms are less severe, and listened to in segments, as brief as the patient can cope with at a time.

These recordings can be

- Standardised (e.g. recordings explaining aspects of the illness, or describing strategies for managing symptoms, or providing therapies such as relaxation or mindfulness)
- Personalised (the therapist may make an audio-recording talking about specific issues of relevance to an individual patient)
- Interactive (the patient can record the questions they want to ask the therapist using an audio-recorder (e.g. digital MP3 recorder), the carer sends the recording to the therapist, who then records a response and sends this back to the patient).

A key advantage of audio-recordings is that patients can play and re-play them in their own time, when they feel ready, and listen to as much or as little at a time as they

choose. This makes the approach very accessible to patients with severe symptoms, who may only have short periods when they are able to do cognitive tasks.

5.5 Inpatient care

For some patients, their condition may involve a level of complexity and severity which needs inpatient care. Patients may have a number of complicating factors in addition to their symptoms of severe CFS/ME, such as other physical symptoms and illness, stressful social or interpersonal situations, and the secondary physical consequences of their illness and impaired function. In addition, the consequences of medical treatments, other additional medical conditions, and psychological or emotional factors may make it difficult to provide effective home-based treatment and may require specific attention.

Typically, packages of care offered by specialist inpatient units allow the patient to stay for periods of weeks or several months. The team in such a service will make the detailed assessments which become possible on a 24/7 inpatient basis and aim to deliver, in parallel and at the same time, the range of interventions which can be offered by a multidisciplinary team, on an individualised and rehabilitation/recovery-focused basis. In general the goal will be to alter the “trajectory” which the patient is on, and to make very substantial improvements across a range of aspects. There are some concerns that patients raise when contemplating an inpatient admission. The inpatient unit may be a long way away from home. They may worry that they would feel pressured to increase activity more quickly than they feel able, even if this is not the case. It is important to allow patients to voice these concerns, and discuss with the involved therapist, so that pros and cons of admission can be discussed openly. It may be helpful to put the patient in touch with the inpatient unit in advance so that these discussions can take place with the admitting team to facilitate the admission process.

An inpatient stay needs to be followed up by community-based support once the patient has returned to their own home to maintain progress, which would need to be addressed by good liaison between the inpatient team and local services, in advance of and at the point of discharge.

Further information about the inpatient service available in the NHS at present is in Appendix C, which includes a case example of what may be involved in an inpatient admission.

If patients need admission in a unit that does not specialise in CFS/ME for other reasons, staff may wish to contact a CFS/ME specialists for advice on how to manage such an admission, which will give all parties confidence.

5.6 Service pathways in community

A scoping exercise on service provision for severe CFS/ME patients conducted in 2013 found that just over half of the NHS specialist services in England provided face to face therapy and support for severely affected CFS/ME patients (McDermott et al 2014). The availability of these service has reduced since the survey was carried out.

There are a number of ways in which existing services provide this care :

Direct MDT input

Home visits : Clinicians to visit the patient at home for assessment and treatment. This has the advantage of direct contact but distance and therapist time can make it expensive in time and cost. Once a direct contact is established, there are options to use video-consulting or other communications tools to supplement this. Medical assessment may be provided by the patient’s GP or a medical member in the Specialist Service such as a GP

with Special Interest, who may offer the initial assessment and ongoing medical support to the multidisciplinary team.

Closer to Home : A variation on this model is the “Closer to Home” arrangement - in Dorset, and Cornwall therapists run regular sessions out of “satellite” bases across the county in a variety of community hospitals or GP practices to reduce travelling time for patients where travel to the Team base would be considered detrimental. Use of these satellite bases also allows for appointments for severely affected patients in the same area to be booked on days where travel can be managed more effectively by the therapist.

Consultation model

Some services offer a ‘consultation model’, in which the service provides training, supervision and advice alongside consultation for established health professionals who already have a relationship with the patient, such as GP or practice nurse. This may be supplemented by periodic contact between the specialist service and the patient via telephone. Therapists should contact their local CFS/ME service, or BACME to find therapists who can offer this service.

Reference

McDermott C, Al Haddabi A, Akagi H, Selby M, Cox D, Leith G. What is the current NHS service provision for patients severely affected by chronic fatigue syndrome/myalgic encephalomyelitis? A national scoping exercise. *BMJ Open*, July 2014, 1-6.

Section 6 Outcome measures

6.1 Why use outcome measures?

- As a therapeutic tool, to allow therapist and patient to track and reflect back on any improvements in the individual’s recovery process
- To evaluate the benefits of service input, for example, to produce data to feed back to commissioners
- To generate health economic data to inform decision makers within the NHS
- To provide evidence to funders

It is important to recognise that completing questionnaires can take a lot of mental effort for a patient who might be only able to tolerate a few minutes conversation at one time or who may have 'brain fog' which makes reading and writing difficult. Nevertheless, for the reasons given above, we suggest that all services should consider incorporating basic outcome measures into their work with severely affected patients wherever possible.

Outcomes may be recorded by patients themselves (Patient reported outcome measure - PROM) or by Clinicians (Clinician reported outcome measure - CROM), though the latter can be carried out with the patient.

6.2 PROM (Patient reported outcome measure)

Since 2006, PROMs used in the majority of adult CFS/ME services in England have been the Minimum Dataset agreed by the services across England, The baseline measures are Hospital Anxiety and Depression scale (HADS), Chalder fatigue scale, Pain Visual Analogue scale, Physical Function SF36, Self Efficacy Scale, EQ-5D, Epworth Sleepiness Scale. All

baseline measure are repeated at follow-up, with the addition of the Clinical Global Impression of Change. These are used at before treatment (baseline) and at follow-up. With cessation of National Outcomes Database service, some services are reviewing the PROMs they use.

Some services reported using additional questionnaires including

- Work and Social Adjustment Scale
- Pittsburgh Sleep Index

Services reported a range of strategies to make it easier for severely affected patients to complete questionnaires including allowing patients to complete the questionnaires over several weeks, rather than on the same day and assistance from therapist or carer (for example, to read out questions and to write down answers)

Nevertheless, severely affected patients vary greatly in their level of function and their initial therapeutic goal, it is not always possible to measure meaningful change using a standard PROM and some services consider an individually agreed goal as a measure of achievement is more meaningful for the patient and the clinician.

6.3 CROM (Clinician reported outcome measure)

There is a CROM developed in rehabilitation settings (TOMS : Therapy outcome measure Therapy Outcome Measures for Rehabilitation Professionals 3rd ed Pam Enderby and Alexandra John. J&R Press) allows clinicians to describe relative abilities and difficulties of a patient/client in the four domains of impairment, activity, participation and wellbeing in order to monitor changes over time. This allows for an assessment of change in function and role, without significant burden on answering questions on the part of the patient. It is a measure that can also be used in collaboration with the patient. There is a new version of TOM specific to patients with CFS/ME in preparation at present.

6.4 Patient satisfaction

It is also important for patients to be able to give feedback on the service they have received. Friends and family test which has been used in a range of NHS services provide a simple structure of enabling patients to provide feedback on the service they have received, and may be accessible for patients with limited communication ability to still provide feedback.

In Summary

- Severely affected patients are likely to need additional support in completing outcome measures
- The most severely affected patients may only be able to answer a very few questions, and care needs to be taken to ensure that questionnaire burden does not take up energy which is needed for other tasks
- A sensitive and pragmatic approach is recommended, to balance patient needs.

Section 7 Setting up a service

7.1 Who are your commissioners and how do they work

Clinical commissioning in England is provided by the clinical commissioning groups. In Scotland and Wales this is by regional health boards. Northern Ireland has a local commissioning group for each health board.

For example each clinical commissioning group (CCG) in England is typically divided services are you in to several clinical commissioning programs (CCP)

Every year each CCG will typically re-commission all services they provided in the previous year. Additionally each year they will go through a commissioning cycle to consider what new services need to be commissioned under the scrutiny of the relevant CCP. You want the commissioners to understand that there is a commissioning need and to put out a call for tender for the necessary service provision ideally through approaching the relevant CCP.

If this cannot be achieved by direct representation to the clinical commissioning group (and specific CCP lead) you may want to prepare a full business case. To do this you need to do a needs assessment identifying the magnitude of the problem, the resources that are currently spent, and the services that patients may currently access and those that may be being denied access to treatment if there is a lack of e.g. domiciliary support/input. It would be useful to know how much money is being spent on private and out of area NHS referrals. You can find this out by submitting a freedom of information request directly to your commissioners.

When preparing a business case you want as much support as possible from clinicians and patient groups/charities (*And a possible exemplar of difference in costs/outcome of GP only intervention and specialist service plus GP etc.?*). Cite all national guidance and care quality standards where appropriate.

Resources

Who is the commissioner I need to approach?

Look up your location on the map of clinical commissioning groups/health boards.

England-

www.england.nhs.uk/wp-content/uploads/2014/02/ccg-map-Feb2014.pdf

Scotland-

www.scotland.gov.uk/Topics/Health/NHS-Workforce/NHS-Boards

Wales-

www.wales.nhs.uk/ourservices/directory

Once you know your CCG/Health Board look up their contact details, generally available on their website, and decide which people you wish to approach.

7.2 Document the service need (needs assessment)

The NICE clinical guidelines are a good bench mark of what should be provided. But, there is no statutory obligation for these to be commissioned or funded except for NICE Health technology assessments www.nice.org.uk/guidance/CG53

Section 1.9 'Key principles of care for people with severe CFS/ME' highlights the need for 'special expertise' and access to an 'individually tailored activity management programme'.

You can refer to what services are already available and their limitations by using the published scoping exercise showing the postcode lottery of availability of current services.

bmjopen.bmj.com/content/4/6/e005083.full?sid=643d58c-f6ee-470e-a7d2-8ed30dee6ffa

The Chief Medical Officer's report into CFS/ME noted that 'individuals severely affected by the condition tend to be overlooked and under-represented in research, service development, and policy' and that the 'severely affected are particularly vulnerable from lack of medical attention, understanding, and home attention'

www.mereseach.org.uk/wp-content/uploads/2013/05/WorkingGroupReport.pdf

And there is also the wider health economic context of effect on family carer's health.

Findings from a survey of the severely affected in the UK noted that:-

- More than half are unable to attend their GP surgery, yet only a minority of these ever get a GP home visit
- One third waited longer than 18 months for formal diagnosis
- Many feel suicidal because of their illness

www.mereseach.org.uk/our-research/ongoing-studies/severely-affected-me-patients

General feedback from people with the illness (and their carers) is that patients may be denied access to normal health checks etc. because they are wrongly considered to be capable of attending GP surgeries/clinics.

Useful descriptions on how to plan for setting up a new service:-

The first is a referenced description outlining the components required in a needs assessment, and the components of a business case

careers.bmj.com/careers/advice/view-article.html?id=20000452

The second is a 10 step guide to setting up a new, in this case nurse led, service.

www.nursingtimes.net/nursing-practice/specialisms/management/nurse-led-clinics-10-essential-steps-to-setting-up-a-service/1931644

Business case point to consider including

Intervention in the severely affected has the potential to lead to savings in future total care needs and cost (healthcare and social care). A new severely affected service may release other expensive resources used to treat and support these individuals.

Such a new service can provide access to treatment that has key features including consistency, continuity, support and reassurance as well as being flexible to an individual's needs for such cases. Lack of these tends to be common problems with the care of isolated severely affected cases.

This is a long term condition and enhancing the quality of life of such individuals is a priority of the NHS see www.england.nhs.uk/resources/resources-for-ccgs/out-frwrk/dom-2/

The need to help identify this group of patients who are sometimes/typically excluded from healthcare as a consequence of their illness and maybe under recognised or identified as a consequence

In working with other agencies the need is to enable them to work better with these clients - there is a need for understanding of fatigue, limitations of stamina, intolerances/ sensitivities that most care professionals will not be used to

Before the business case for a new service is submitted it would be helpful to know what current service provision is provided. Even if there is no clinical service there may be individual funding arrangements for specific cases. These may be considerable in cost and not necessarily the most efficient way of supporting only a small proportion of the severely affected.

Alternatively if no funded service can be secured then applying for individual funding from the commissioners may enable resources to be released for this group.

Appendix A Authorship and acknowledgements

(Alphabetical order)

BACME Severely Affected Working Group contributors

Dr Hiroko Akagi, Leeds and West Yorkshire CFS/ME Service (retired)

Ms Dorrett Erskine, Birmingham CFS/ME Service

Ms Sue Luscombe Nutrition and Dietetic Dept. Bedford Hospital and BACME executive

Dr Clare McDermott, Department of Primary Care and Population Science, University of Southampton

Ms Anne Nichol, CFS/ME Service for South Yorkshire and North Derbyshire

Ms Hilly Quigley (previous member) Oxfordshire CFS/ME Service (retired)

Dr Selwyn Richards Dorset CFS/ME Service

Ms Ceri Rutter Plymouth and District CFS/ME group, BACME executive

Ms Michelle Selby, Dorset CFS/ME Service

Ms Mary Jane Willows, Chief Executive AYME and BACME executive

We would also like to acknowledge and thank additional contributions/feedback from :

BACME executive members

Ms Jessica Bavington, Vitality 360, BACME Executive

Prof Diane Cox, University of Cumbria, Lancaster

Prof Esther Crawley, University of Bristol

Ms Emma Cross, BSc Univeristy of Leeds

Dr Lesley Godfrey, Priory Medical Group, York

Ms Hilary Hogg, RD Lead Community Dietitian, Plymouth

Dr Christine Johnson, Priory Medical Group, York

Dr Hazel O'Dowd, Bristol CFS/ME Service

Prof Julia Newton, Newcastle University and Royal Victoria Infirmary, Newcastle-upon-Tyne

Dr Sue Pemberton, Yorkshire Fatigue Clinic, York

Mr Russel Saxby, National Inpatient Centre for Psychological Medicine, Leeds (retired)

Dr Peter Trigwell, National Inpatient Centre for Psychological Medicine, Leeds

Dr Vikki McKeever, Leeds CFS/ME Service, BACME Executive

Ms Carol Wilson, Cornwall and Isles of Scilly CFS/ME Service

Appendix B Diagnostic issues

CDC/Fukuda 1994 criteria

See www.cdc.gov/cfs/case-definition/1994.html

The individual has severe chronic fatigue for 6 or more consecutive months that is not due to ongoing exertion or other medical conditions associated with fatigue (these other conditions need to be ruled out by a doctor after diagnostic tests have been conducted)

The fatigue significantly interferes with daily activities and work

The individual concurrently has four or more of the following symptoms:

- post-exertional malaise lasting more than 24 hours
- unrefreshing sleep
- significant impairment of short-term memory or concentration
- muscle pain
- pain in the joints without swelling or redness
- headaches of a new type, pattern, or severity
- tender lymph nodes in the neck or armpit
- a sore throat that is frequent or recurring

These symptoms persisted or recurred during 6 or more consecutive months of illness and they cannot have first appeared before the fatigue.

Conditions that Exclude a Diagnosis of CFS

1. Any active medical condition that may explain the presence of chronic fatigue, such as untreated hypothyroidism, sleep apnea, and narcolepsy, and iatrogenic conditions such as side effects of medication.
2. Some diagnosable illnesses may relapse or may not have completely resolved during treatment. If the persistence of such a condition could explain the presence of chronic fatigue, and if it cannot be clearly established that the original condition has completely resolved with treatment, then such patients should not be classified as having CFS. Examples of illnesses that can present such a picture include some types of cancers and chronic cases of hepatitis B or C virus infection.
3. Any past or current diagnosis of:
 - major depressive disorder with psychotic or melancholic features
 - bipolar affective disorders
 - schizophrenia of any subtype
 - delusional disorders of any subtype
 - dementias of any subtype
 - anorexia nervosa
 - bulimia nervosa
4. Alcohol or other substance abuse, occurring within 2 years of the onset of chronic fatigue and any time afterwards.
5. Severe obesity is defined as having a body mass index equal to or greater than 45. [Body mass index = weight in kilograms ÷ (height in meters)². Body mass index values vary considerably among different age groups and populations. No "normal" or "average" range of values can be suggested in a fashion that is meaningful. The range of 45 or greater was selected because it clearly falls within the range of severe obesity.

Any unexplained abnormality detected on examination or other testing that strongly suggests an exclusionary condition needs to be resolved before attempting further classification. Considerations of exclusionary conditions are important in research studies attempting to identify causes or evaluate therapies specific for CFS. Exclusionary

conditions are important clinically because they are often treatable. However, once all exclusionary conditions have been fully treated, if the patient still meets criteria for CFS, they would be managed clinically as a CFS patient.

Conditions that Do Not Exclude a Diagnosis of CFS

1. Any condition defined primarily by symptoms that cannot be confirmed by diagnostic laboratory tests, including fibromyalgia, anxiety disorders, somatoform disorders, nonpsychotic or melancholic depression, neurasthenia, and multiple chemical sensitivity disorder.
2. Any condition under specific treatment sufficient to alleviate all symptoms related to that condition and for which the adequacy of treatment has been documented. Such conditions include hypothyroidism for which the adequacy of replacement hormone has been verified by normal thyroid-stimulating hormone levels, or asthma in which the adequacy of treatment has been determined by pulmonary function and other testing.
3. Any condition, such as Lyme disease or syphilis that was treated with definitive therapy before development of chronic symptoms.
4. Any isolated and unexplained physical examination finding, or laboratory or imaging test abnormality that is not enough to strongly suggest the existence of an exclusionary condition. Such conditions include an elevated antinuclear antibody titer that is inadequate, without additional laboratory or clinical evidence, to strongly support a diagnosis of a discrete connective

Alternative criteria

The NICE Criteria

The National Institute for Health and Clinical Excellence (NICE) in England and Wales published a multidisciplinary *clinical practice guideline* in 2007 in which the following criteria are employed.

- fatigue that is new, persistent and/or recurrent, not explained by other conditions and has resulted in a substantial reduction in activity level characterised by post-exertional malaise and/or fatigue (typically delayed, for example by at least 24 hours, with slow recovery over several days) *and*
- one or more of the following list of symptoms: difficulty with sleeping, muscle and/or joint pain at multiple sites without evidence of inflammation, headaches, painful lymph nodes that are not pathologically enlarged, sore throat, cognitive dysfunction, worsening of symptoms by physical or mental exertion, general malaise, dizziness and/or nausea and palpitations with no identifiable heart problem.

The diagnosis should be reconsidered if none of the following symptoms remain: post-exertional fatigue or malaise, cognitive difficulties, sleep disturbance, chronic pain

The guideline requires fatigue to have been present for 4 months in an adult or 3 months in a child. It expects a diagnosis in a child to be made by a paediatrician. The guideline states that a referral to a CFS/ME specialist should be offered immediately to the severely ill

Many other criteria have been proposed but are rarely used in clinical practice.

These include the complex multidomain approach of the *Canadian Criteria*: the full text can be found at

www.name-us.org/DefintionsPages/DefinitionsArticles/ConsensusDocumentFull.pdf

More recently the National Institute of Health in the USA have suggested a new name and diagnostic criteria. They called their new simpler criteria

Systemic exertion intolerance disease (NIH criteria)

iom.nationalacademies.org/Reports/2015/ME-CFS.aspx

It remains unclear at present if these will replace use of the Fukuda criteria.

Proposed Diagnostic Criteria for ME/CFS (Institute of Medicine, www.iom.edu/ME/CFS)

Diagnosis requires that the patient have the following three symptoms:

1. A substantial reduction or impairment in the ability to engage in pre-illness levels of occupational, educational, social, or personal activities, that persists for more than 6 months and is accompanied by fatigue, which is often profound, is of new or definite onset (not lifelong), is not the result of ongoing excessive exertion, and is not substantially alleviated by rest, and
2. Post-exertional malaise, * and
3. Unrefreshing sleep*

At least one of the two following manifestations is also required :

1. Cognitive impairment* or
2. Orthostatic intolerance

* Frequency and severity of symptoms should be assessed. The diagnosis of ME/CFS should be questioned if patients do not have these symptoms at least half of the time with moderate, substantial or severe intensity.

Appendix C Inpatient services

National Inpatient Centre for Psychological Medicine (NICPM)

previously known as the Yorkshire Centre for Psychological Medicine (YCPM), Leeds
www.leedspft.nhs.uk/our_services/Specialist-LD-Care/YPCM
www.leedspft.nhs.uk/our_services/Specialist-LD-Care/NICPM

This service takes referrals from all across the UK, ie from multiple commissioners and on a cost per case basis, and provides expert multidisciplinary biopsychosocial assessment and treatment in an inpatient ward in a general hospital setting.

Case example from NICPM

This case example is intended to give referrers and potential patients an idea of what is provided by this service and how things tend to go for people who are admitted. We would want to stress that all care plans are tailored to each individual, that progress is of course also individual to each person, and that a key feature of the approach on the ward is a recognition that what needs to be addressed to make progress, and what helps, may be different from one person to another.

We hope that the case example illustrates several things; that we take care to understand the person at the beginning of the admission, that the pace of rehabilitation is set collaboratively and adjusted according to individual needs, and also that a multidimensional rehabilitation approach can make a huge difference.

Sarah (name changed for this case example) was admitted to the NICPM following several years of illness with severe CFS/ME and in the context of significant deterioration in her level of functioning. She suffered extreme sensitivity to light, sounds and, in particular, perfumes/scents. She was virtually bed bound, otherwise entirely wheelchair bound, and required an intense level of support from her husband and local services, upon whom she was almost entirely dependent. She had become very anxious in relation to her physical health difficulties. Her GP was also very concerned about her presentation and, despite their best efforts, local CFS/ME services had been unable to arrest this decline.

Multidisciplinary approach

Sarah settled into the ward environment and engaged in a period of assessment undertaken by the occupational therapy, physiotherapy, medical and nursing staff. After being on the ward for a week, Sarah appeared to understand the concept of grading and pacing very well and describe her mood as “more hopeful”. Her admission blood tests were all within the normal ranges and an admission ECG was also normal. As always, a detailed, individualised and biopsychosocial approach to both assessment and commencing treatment was taken by the multidisciplinary team.

Collaborative plan of care involving the patient and the whole team

In the initial few weeks the focus was on arriving at a collaborative set of care plans, across Sarah’s range of needs. She was engaging fully in her (paced and graded) daily plan and had also been noted to be “very positive regarding staff input.” She continued to be supported by her husband on visits and reported a reduced frequency of her energy levels dipping. Over time she started to sit out in a chair from her bed. She was also able to tolerate normal light levels without sunglasses and was walking independently to the ward toilet. She had also noted some reduction in her anxiety levels, and also begun to receive input from the hospital chaplain. She had chosen to set a goal of being able to mobilise to the hospital chapel during her admission.

Multidimensional rehabilitation

As the care plans progressed over several weeks, Sarah was feeding herself at all meal times, had taken 2 baths and began to socialise with other patients. She spoke openly of her concern for her husband, the impact her illness and recovery had on him, and how she would like to support him. Staff suggested that he attend MDT and Sarah was keen for this to happen. She continued to feel that she was benefitting from medication in terms of reduced anxiety levels and had noted no side effects. After several weeks of inpatient stay, Sarah was virtually independent in terms of her personal hygiene care and had been preparing meals and eating in the dining room with other patients on a regular basis. She also requested a haircut and had met all of her goals as per her graded care plan. The NICPM team discussed with Sarah the various aspects of care delivered (medication, occupational and physiotherapeutic work, psychological work to address anxiety, etc) and how each was contributing in an important way to her rehabilitation. It was also discussed that some of the physical sensations that she found disturbing may be related to the physical de-conditioning of her body and she was able to recognise that this could be a contributory factor given the progress she was now making.

Sarah continued to engage well in 1:1 sessions with nursing staff, and although she continued to experience vibration sensations she did not allow this to prevent her from completing her goals. She was able to attend the nursing station if she needed assistance from staff instead of using her room buzzer. She had revised her activity plan several times and, with ongoing support, continued to display excellent motivation to progress with her rehabilitation.

A couple of months into admission, she identified three further areas she wished to tackle before leaving the NICPM; increasing her mobility further, managing a flight of stairs safely, and improving her activities of daily living such as cooking and cleaning. Her key and overall aim was to increase her level of independence. She also had a formal CBT assessment with the CBT therapist. Anxiety was identified as a significant factor making her rehabilitation process more difficult. She described “worrying about the anxiety, and a loss of control.” She was able to accept that there was an interaction between her physical symptoms and the intense anxiety symptoms which she experienced, and was willing to explore this further as part of her ongoing rehabilitation work. She made excellent progress in all of these areas over the three remaining weeks on the unit.

Transferring progress made to home / the real world

A plan was made for Sarah to go on a period of home leave which went very well. On her return to the ward she spoke about sitting in her lounge for the first time in 20 months and feeding her chickens, all of which she described as “bliss“, and she had been able to spend time with a friend for the first time in two years. Sarah has also found that she was able to maintain her activity plan, and further discussion around her discharge took place.

Continuing progress and recovery

By the end of the admission at the NICPM Sarah was able to attend a local branch of Tesco’s independently from the ward and was able to reach the hospital chapel (on the other side of the building) unaided. She was fully self-caring regarding hygiene, etc, and in many ways now independent, including being able, to her delight, to wear scented body products. She was in very good spirits upon leaving the unit.

Sarah made excellent use of the treatment and support offered at the NICPM, and her improved physical functioning was very clear. She was able to socialise, to make meals, and carry out coordinated tasks independently. She had also made significant progress

with regard to her anxiety management, and was no longer overwhelmed by anxiety about her difficulties and the impact of it. She left the unit keen to continue with CBT work, alongside her ongoing occupational and physical rehabilitation, and now able to benefit from attending her local CFS/ME service to build upon the progress she had made at the NICPM.

Independent sector services

There are also services that offer inpatient rehabilitation in the independent sector. When considering referral to these units, the referrer would need to take into consideration the therapeutic approach, service quality, and clinical governance arrangements, and would also require funding from the patient's Commissioners who would need to be satisfied of the same.

Appendix D Children and Young People with CFS/ME

The Royal College of Paediatrics defines 'severe CFS/ME' in children and young people as '**effectively housebound**' and 'very severe' as '**effectively bedridden**' for a period of at least 3 months.

Royal College of Paediatrics : www.rcpch.ac.uk/system/files/protected/page/RCPCH%20CFS.pdf

Evidence based guidelines for the management of CFS/ME in children and young people (2004) www.rcpch.ac.uk/system/files/protected/page/RCPCH%20CFS.pdf

Patient support organisation for young persons with CFS/ME

ayme.org.uk/documents/10228/11022/Your%20child%20and%20M.E..pdf

Services that see Children and Young people with CFS/ME can be found via BACME website www.bacme.info