Bacme

British Association of Clinicians in ME/CFS

Working Group on Severe and Very Severe ME/CFS

Shared Clinical Practice Document

Version 3 October 2023

Document history

Year	Format/changes made
2017	Document first developed
2019	Minor amendments to Autonomic Dysfunction section and links updated
2022/2023	CFS/ME changed to ME/CFS. Reviewed in accordance with the NICE Guideline 2021. This is a living guide which will be updated in response to developments in research and clinical practice.

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Section 1: Authors and Development Process

The first edition of this document was compiled in 2017 by the severely affected working group of the British Association for CFS/ME (BACME) with help from the BACME executive and other contributors, listed in Appendix A. The final version incorporated feedback provided by BACME Patient and Public Involvement representatives, GP's and Allied Health Professionals, also listed in Appendix A.

In 2019 minor revisions were made to the section on autonomic dysfunction to reflect research developments and web links were updated.

In 2022/2023, this document was revised to be NICE compliant and updated to reflect clinical and research developments.

Definitions and Abbreviations

BACME: British Association of Clinicians in ME/CFS

CBT: Cognitive Behavioural Therapy

GP: General Practitioner

ME/CFS: Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome

NICE: National Institute for Health and Care Excellence

NHS: National Health Service

WHO: World Health Organisation

Section 2: Introduction

This document has been produced by the British Association of Clinicians in ME/CFS (BACME) working group on severe ME/CFS. This group includes specialist clinicians involved in the diagnosis and management of people living with severe and very severe ME/CFS and patient and carer representatives with current and past experience of severe and very severe ME/CFS.

This document is designed to help all practitioners involved in the care and support of people living with severe ME/CFS, to better understand the condition, and effectively support and work with the people living with severe ME/CFS and their support networks 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 specialist services across the UK on ways of working together with people with severe ME/CFS 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 to helpful materials and information for health professionals assessing and supporting people living with severe ME/CFS and their carers.

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

- NICE Guideline: ME/CFS Diagnosis and Management https://www.nice.org.uk/guidance/ng206/chapter/Recommendations
- British Association of Clinicians in ME/CFS (BACME) clinical resources available to download from www.bacme.info :
    - BACME An Introduction to Dysregulation in ME/CFS
    - BACME Guide to symptom management
    - BACME Guide to therapy
    - BACME Primary Care Guide
    - BACME Care and Support Plan guidance
    - BACME Dysautonomia- a Guide for ME/CFS

2.1 Defining severe and very severe ME/CFS

ME/CFS is an illness characterised by disabling persistent fatigue, post-exertional malaise, unrefreshing sleep, cognitive dysfunction and other symptoms such as orthostatic intolerance, temperature dysregulation, gastrointestinal symptoms, sensory sensitivities and pain. A full description of the illness and criteria for diagnosis can be found in the NICE Guideline 1.2 to 1.4.

The 2021 NICE guideline defines severe and very severe ME/CFS as follows:

Severe ME/CFS: People with severe ME/CFS are unable to do any activity for themselves or can carry out minimal daily tasks only (such as face washing or cleaning teeth). They have severe cognitive difficulties and may depend on a wheelchair for mobility. They are often unable to leave the house or have a severe and prolonged after-effect if they do so. They may also spend most of their time in bed and are often extremely sensitive to light and sound.

Very severe ME/CFS: People with very severe ME/CFS are in bed all day and dependent on care. They need help with personal hygiene and eating and are very sensitive to sensory stimuli. Some people may not be able to swallow and may need to be tube fed.

This document focuses primarily on the assessment and management of adults due to the scope of the group producing it. Children and young people can develop ME/CFS and can be severely and very severely affected and it is recommended that any clinician involved in the care of a child or young person who is severely affected seeks guidance from a specialist service with experience with this age group. Appendix D at the end of this document also includes some resources relevant for children and young people.

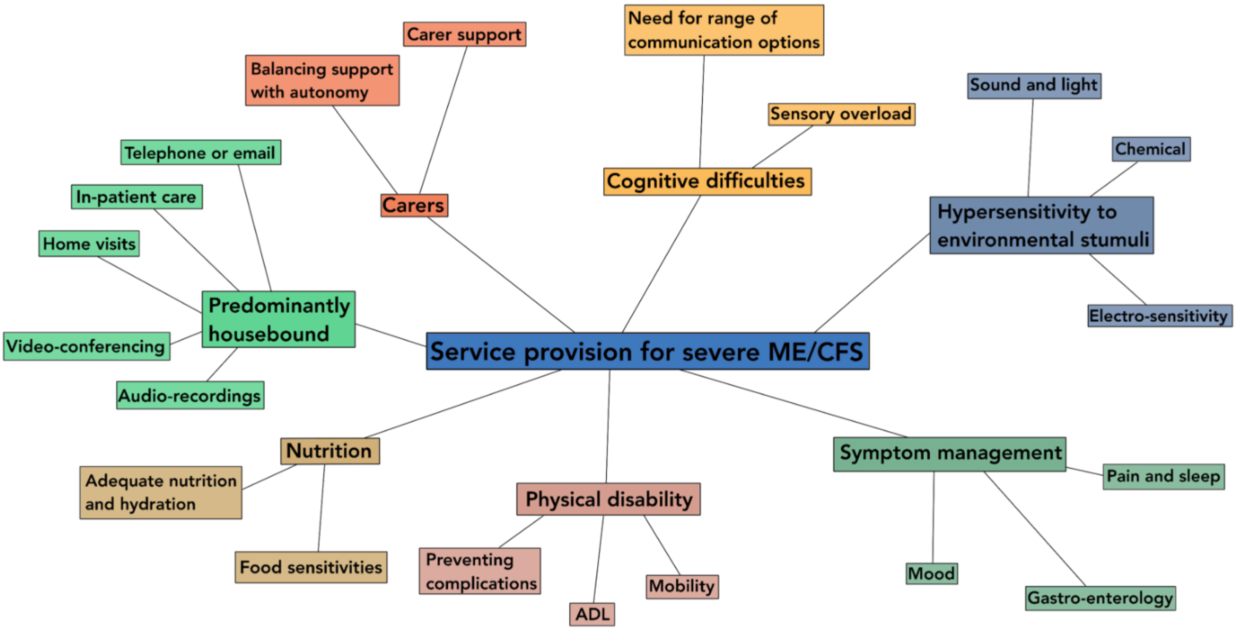
2.2 Health needs of patients with severe ME/CFS

People with severe ME/CFS are housebound, may use a wheelchair and some will be bed-bound and dependent on family and carers for many or all basic activities of daily living. The illness results in some people who are severely affected being profoundly disabled for many years, although others return to a better level of health after a period of more severe illness.

People who are house/bed bound have difficulty accessing health services for management of their ME/CFS along with the management of co-existing health problems or routine health screening.

People with severe ME/CFS have complex needs due to the multisystem nature of the illness and high incidence of co-morbidities. ME/CFS affects many areas of a person’s life (see mind map in Figure 1 below). It is likely that the person living with severe ME/CFS will need help and support from a range of different people, from family, carers, friends and specialist professionals experienced in working with people living with ME/CFS in primary, secondary and tertiary care, social care and the voluntary sector.

Figure 1: Mind map of needs of people with severe CFS/ME



ADL =activities of daily living

Primary care would normally be the first contact for people living with severe ME/CFS. It can be difficult for patients and professionals 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. Primary care staff can provide options for ways to communicate including home visits, telephone calls, video calls and email along with liaising with formal and informal carers with the permission of the patient.

Where it is possible, patients living with severe and very severe ME/CFS should be offered intervention by a secondary or tertiary care specialist ME/CFS service that has experience of working with people who are severely affected. Where such services are not easily accessible, it may be necessary for local primary and secondary care services to seek advice from specialist ME/CFS services in other areas who may be able to provide guidance to local staff. Ideally ME/CFS specialist services would, with the consent of the patient involved, liaise and provide information about ME/CFS or seek information from those outside the specialist team about their involvement so that the most effective, individualised interventions can be offered in the most appropriate setting. This would usually be in the patient's home if this can be facilitated.

Practitioners need to adapt their approach and expectations from usual clinical practice as working with people severely affected by ME/CFS requires a slow and consistent approach. Improvement usually occurs in small increments over a long period of time, including periods of ‘plateau’ where there is no discernable change. Sudden or prolonged deterioration always needs further exploration and may necessitate investigations being done.

The patient will need a thorough clinical assessment (section 3). This may require a number of contacts to gather all the required information and the demand of attending appointments and talking can cause an escalation in symptoms which needs to be accommodated for. 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. Be aware of symptoms outside those normally reported.

There may be situations where a person severely affected by ME/CFS requires admission to hospital either due to the severity of their ME/CFS symptoms and secondary complications such as nutritional compromise, or because of other health conditions requiring hospital treatment. If admission to hospital is required, the person’s needs should be identified, discussed and carefully planned and documented in their Care and Support Plan which should be made available to all staff caring from them. Sensitivity to light, noise, different temperatures and movement can make being in any hospital setting very difficult. Spoken and written language difficulties make communicating specific needs and difficulties a significant challenge. Provision of a single room on a ward is recommended. Providing continuity of care from a carer/care worker who knows the person well is important.

Section 3: Making a diagnosis: assessment and comorbidities

The starting point for a health professional in working with an individual with severe ME/CFS is to ensure that the patient has been fully assessed by a doctor, and multidisciplinary team where possible, to establish diagnosis, identify key medical issues and make sure that co-morbidities have been identified and are treated appropriately. A thorough medical history, physical examination, mental status examination, and laboratory tests are necessary. Assessment can be a challenging process if the patient is unable to attend the GP Surgery or outpatients and has difficulty tolerating contact even at home. Assessment may need to take into consideration: location, duration, tolerability and environment. It is often necessary to obtain history from others (with the patient's consent) or from medical records. Direct patient assessment needs to take into account how long an individual can tolerate talking, whether they are sensitive to stimuli (noise, light, movement) and may need to be carried out on more than one visit. Other modes of contact can be considered including telephone, video calls and written information/email. If the individual cannot tolerate diagnostic tests to exclude other conditions, it would not be possible to reach a clear diagnosis, and other treatable conditions may be missed. The pros and cons of tests need careful discussion with the patient and their carers, including the risk of not being able to carry out these tests. If investigations require attendance at a hospital, the receiving facility may need information about the difficulties the patient has in attending so appropriate adjustments 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 ME/CFS Service

3.1 History

ME/CFS is a condition defined by a specific pattern of symptoms which can be explained by dysregulated responses in multiple dynamic physiological systems. The pathophysiology of ME/CFS is not fully understood but there is evidence of altered function in various systems including the immune system, autonomic nervous system and endocrine systems. The consequence of the altered physiology is that mitochondrial function is impacted resulting in problems with energy production.

The physiological abnormalities that occur in ME/CFS do not show up on standard medical tests. Diagnosis currently relies on detailed history taking to identify the characteristic clinical features including Post-Exertional Malaise. The history also needs to explore whether there are other factors or illnesses that may be contributing to the symptom patterns that may warrant further investigation or alternative treatment pathways.

The reasons why some people develop more severe forms of ME/CFS are not yet fully understood. Some people living with ME/CFS progress rapidly to a more severe state early in the illness whereas other people may have had more mild or moderate ME/CFS for some time before deteriorating and becoming more severely affected.

ME/CFS is a dynamic, fluctuating condition that can change over time. Some people become more severely affected and may then improve over time, whereas other people may remain severely affected for many years.

ME/CFS is a condition where energy production in the body is abnormal. People with severe ME/CFS have extremely low energy levels. This means that any physical, emotional, social or environmental demands can use up their very limited energy supply and result in an exacerbation of symptoms. It can be helpful to explore what factors may be having the most impact on energy usage as that may help identify the reasons for the illness becoming more severe and will also be useful information to start prioratising management strategies.

3.2 Physical examination and emotional wellbeing

There are no diagnostic physical signs that positively identify ME/CFS. However, in patients with severe ME/CFS, 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 postural tachycardia or a postural drop in blood pressure, but this may not be practical or necessary if the history is highly suggestive.

Assessing psychological well-being is a crucial part of any initial assessment. Pressures of living with severe ME/CFS can lead to psychological difficulties such as low mood and anxiety and some people may experience suicidal thoughts. It is important to consider whether there is a primary mental health condition that is causing or contributing to the fatigue issues before confirming a diagnosis of ME/CFS. Conditions such as severe Depression, Anxiety Disorders including

Red flags in ME/CFS diagnosis

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

In particular, the following features should be investigated :

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

PTSD and Obsessional Compulsive Disorder and Eating Disorders can be a cause of persistent fatigue symptoms and low function. It is possible that patients with ME/CFS 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.

3.3 Investigations

The purpose of biomedical investigations is to exclude alternative diagnoses since there are currently no consistent biomarkers that can be used to diagnose ME/CFS.

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

NICE Guidance recommends:

- Medical including physical assessment
- Assess impact of symptoms on psychological and social wellbeing
- Bloods to exclude other diagnoses:
    - full blood count
    - urea and electrolytes
    - liver function
    - thyroid function
    - erythrocyte sedimentation rate or plasma viscosity
    - C-reactive protein
    - calcium and phosphate
    - HbA1c
    - serum ferritin
    - coeliac screen
    - creatinine kinase

- urinalysis for protein, blood, glucose

- Use clinical judgement to decide on additional investigations, for example, vitamin D, vitamin B12

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 diagnosis may not be clear cut at the beginning. In such situations, the person's difficulty with chronic disabling fatigue should still be recognised and the person offered appropriate intervention, while other diagnoses / comorbidities continue to be reviewed.

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

Common comorbidities and contributory factors in ME/CFS include;

- specific physical symptoms e.g. atypical facial pain, migraine, functional neurological symptoms
- constellations of physical symptoms e.g. abdominal symptoms/Irritable Bowel Syndrome
- medication side effects (patients with severe ME/CFS often report more reactions to medications)
- medication burden e.g. high dose opiates, polypharmacy for symptom management
- autonomic dysfunction e.g. PoTS or postural hypotension
- medical complications secondary to severe ME/CFS, such as nutritional deficiencies and/or weight loss and musculoskeletal problems (e.g. contractures or muscle wasting)
- mental illness: e.g. severe anxiety, depression, obsessional compulsive disorder, PTSD. Patients can feel suicidal due to the severity of their illness.
- Hypermobility: patients who are hypermobile can develop increasing problems with joint laxity and subluxations along with increased pain.
- Neurodiversity e.g. Autism Spectrum Disorder, Attention Deficit Hyperactivity Disorder
- there may be other coexisting medical problems, unrelated to ME/CFS, which may have greater impact on a person severely affected e.g. suboptimally treated Thyroid Disorder or Diabetes

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

Section 4: Therapeutic approach

Providing care to patients who are housebound or bed bound requires different consideration to outpatient care. Delivery of care to patients in their own home poses logistical challenges, particularly as those who are severely affected by ME/CFS 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.

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, skills and strategies, tailored to individual need and based in long term conditions professional training and experience.

A patient with severe ME/CFS 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 ME/CFS can experiment with to find out what helps them.

Support from therapists can help with exploring these at their own pace.

4.1 Key principles

ME/CFS 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 individual’s quality of life and develop an individual management plan. Intervention may include offering current understanding of the condition, mitigating the effects of physical and cognitive disability, and maximising independence and quality of life through rehabilitative strategies. A problem-solving approach that looks to make very small changes gradually over time will be most helpful.

4.1.1 Instilling hope

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

Addressing and making therapeutic changes with the person who is severely affected is a sensitive task. Some support may be declined initially when the person is first unwell, for example;

- Where the expectations are that the illness will resolve within a few months
- Where the person has been ill for a long time, and experienced disappointments/ frustrations with therapies that haven't worked
- Where a person feels highly experienced in managing their situation yet is not seeing improvement.

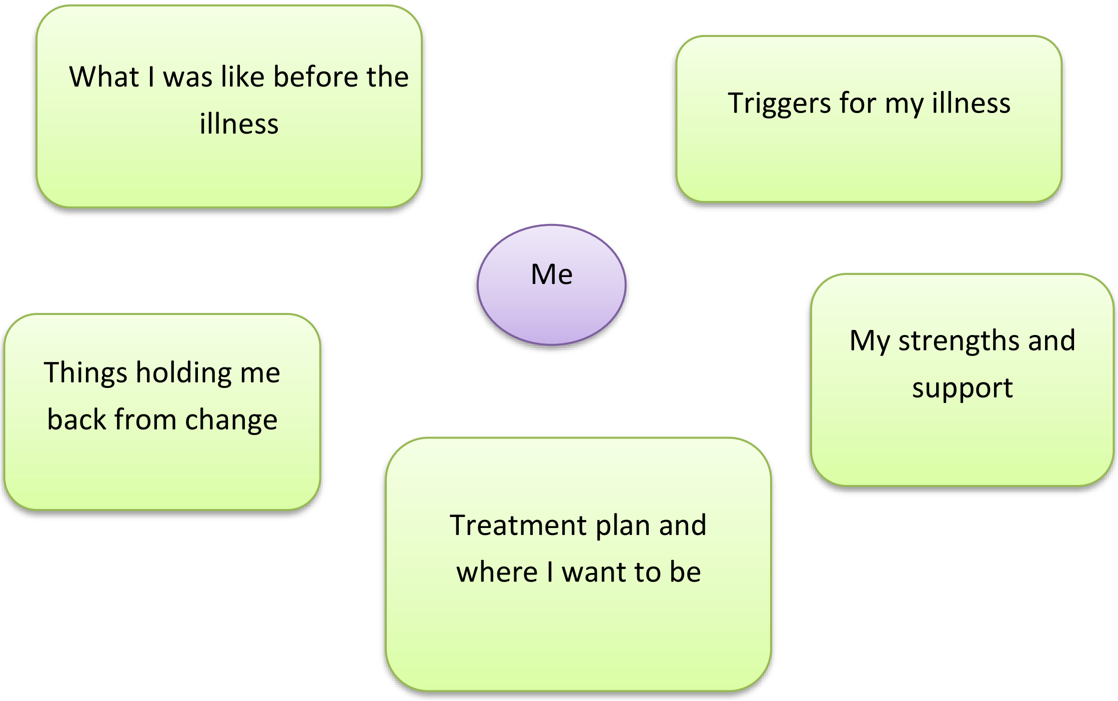
Some people may be in a place where it is difficult to make the smallest change for a variety of reasons. It is possible they may be in a different situation at a future time so is important to maintain a good therapeutic relationship and optimism while being mindful of unrealistic expectations in both patients and clinicians.

4.1.2 Establishing a working relationship

Patients have told us that a crucial aspect of initial assessment is to be enabled to tell their story. This leads to them feeling they have been listened to and understood and validates their experiences of what has led to their current situation and allows exploration of issues concerning them. Their concerns usually go beyond physical symptoms and may include financial hardship, their living situation, relationships, personal care needs, sleep difficulties, social isolation and cognitive difficulties. 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 in 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. 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 shared understanding of the needs of the patient, not only the physical symptoms and diagnosis, but other factors too 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 understanding can be referred to as a formulation and can clarify the therapists and patients understanding of the 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 **timeline** 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 ME/CFS, and their families, can feel completely confined and trapped by the illness. They cannot see a way forward as even very small amounts of activity or external stimulation can feel like an enormous overload and cause a significant increase in symptoms that may appear disproportionate 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 require significant adjustment in how these are carried out. This may mean obtaining some of the illness history through others (with the patient's permission), being creative in how contact is made with the patient (see Section 5) and carrying out assessments on more than one visit.

Interventions and goals to be agreed will also need discussions regarding the priorities for the patient and the pace at which any changes will 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 essential members of the support /management team with their valuable knowledge, insight and experience of how the illness is affecting the person living with ME/CFS and what the person was like pre-illness. 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 involved can become caught in a reactive cycle where the person with severe ME/CFS 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 to find a way to alleviate symptoms, however due to the nature of ME/CFS, 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/care workers so all can share an understanding of the therapeutic approach.

4.2 Overall Treatment Approach

Pacing Strategies

As indicated previously, there is no clear evidence base for the treatment of severe ME/CFS and most specialist services will adapt their approach to individual need. The initial 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. If stability is achieved, this in due course can be followed by a slow stepwise upward grading to achieve sustainable and meaningful change, while monitoring for any change in symptoms.

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 ME/CFS does counts as an ‘activity’. Things that we might take for granted can be demanding if you have ME/CFS and this is greatly amplified when the individual is severely affected. 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.

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

Activities, at the level the person can manage, can be organised 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 activities, one activity at a time, and then take a rest break between each activity.

Some people find a simple recurring pattern can be helpful to minimise the need to think about what they should be doing. 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 plan is to focus 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 do for a few repetitions in the day. This should be trialed, and adjustments made to make sure the baseline is stable. Then individual components can be gradually and gently increased, it may be initially by seconds. The speed at which increases can be made needs to be judged on an individual basis. If there is an increase in symptoms or other factors impacting e.g. acute illness, then any planned increases should be paused and it may be necessary to reduce back to achieve stability again.

An example (for illustrative purposes only) could be:

10 minutes lying flat in silence

5 minutes sitting up supported.

10 minutes lying flat listening to audio book/music.

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

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

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

3 minutes lying down practising breathing.

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

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!

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 ill for some time afterwards.

Having a conversation is an activity that can have high energy demands as you must 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. Successful interaction depends on doing it in the way the person can currently manage.

It can be helpful to limit the time you talk with the person severely affected by ME/CFS and ensure you do not talk when another activity is being carried out such as meal times or when 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 severe ME/CFS have a sensitivity to all stimuli: taste, smell, light, sound, touch, temperature, alcohol and food they may previously have enjoyed. Therapists and carers need to understand that these stimuli place demands on the body to cope with.

Ms D has been severely affected by ME/CFS 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 pacing

- 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 e.g. visitors, change of environment, change of routine etc. 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

4.3 Addressing specific problems

4.3.1 Sleep and re-establishing a diurnal rhythm

Disturbed sleep is universally seen by patients with ME/CFS as having an impact 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 disorders should be excluded at the assessment stage.

Re-establishing a good sleep pattern is very important in the overall management of ME/CFS. The first step is to understand the general pattern of sleep, then find 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. The quantity of sleep does not equate to the quality of sleep. For those who spend long periods asleep, or in a half asleep, half awake state, it may become necessary to very carefully shorten total sleeping time. This can be achieved by gradually reducing sleep duration, by small amounts, such as 15 or 30 minutes. The cycle needs to be adjusted over days or weeks. The initial aim would be to have one period of long sleep equivalent to nighttime sleep. The pros and cons of daytime naps need to be judged on an individual basis. If daytime naps are needed, then it is helpful to establish a regular routine. Long naps and naps taken later in the day are more likely to have a negative impact on nighttime sleep quality so it is worth experimenting with shorter naps. If the goal is to reduce the amount of daytime sleep, once a routine has been established then small 10-15minute reductions can be made gradually over time.

Conventional advice for sleep encourages not staying in bed outside 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, sitting out of bed for short periods, which alongside increasing light exposure, will help to start to set a 24 hour routine.

Most people find that a clear routine each night 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 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.

General principles (adapted to severely affected)

- keep regular bedtimes and rising times
- reduce long 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
- avoid large meals before bed
- try keeping a diary to help identify routine

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 (e.g. laptops, smartphones) in bed during 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.

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

4.3.2 Improving the quality of rest

Due to the severity of their symptoms, people with severe ME/CFS 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, 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 busy 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 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, others can be used to reduce or calm the nervous system. For example, sometimes silence can 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 or soft blanket) 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 practised 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, these techniques 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 support their use consistently. 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

People 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.

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.

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

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

Many people with severe ME/CFS have gastrointestinal symptoms and food intolerances and this can lead to them cutting 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. People with severe ME/CFS may also have 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.

BAPEN (British Association for Parenteral and Enteral Nutrition) has a Malnutrition Self-Screening Tool designed to help combat malnutrition. The web-based Tool MUST, 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 the height and weight of people 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.

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

MUST is a validated, reliable and practical way of screening for nutritional risks in 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.

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 the 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 reinstitution of nutrition to patients who are severely malnourished. Those with severe ME/CFS who have very poor appetites and intake are potentially at risk when they resume eating.

Patients at High Risk of Refeeding syndrome

Any of the following:

- BMI<16kg/m^2
- 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/m^2
- 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/m^2, unintentional weight loss >5% within the last 3-6 months) is at risk of refeeding syndrome.

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

Disordered Eating

Some degree of disordered eating is commonly reported by people with severe ME/CFS. Marked changes in food preferences and restricted range of foods chosen are more evident. Regular reviews and watchful waiting is helpful. Patients can 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 uncomfortably 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 about an eating disorder referral to an Eating Disorder team is advised.

Medical Emergencies in eating disorders (MEED) is a document drawn up by Royal College Psychiatrists and is endorsed by the Academy of Medical Royal Colleges (replaces MARSIPAN). 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.

Weight Gain

Some people with severe ME/CFS may gain significant amounts of weight which may be due in part to substantially reduced mobility, changed eating patterns, and energy expenditure. 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.

Resources

NICE Guideline Adult Nutrition Support
www.**nice**.org.uk/Guidance/CG**32**

BAPEN Malnutrition Universal Screening Tool
www.bapen.org.uk/pdfs/must/must_full.pdf

SCOFF questionnaire -screening tool for eating disorders
Morgan JF, Reid F, Lacey JH. The SCOFF questionnaire. The Western journal of medicine. 2000 Mar 1;172(3):164.
https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1070794/

NICE Guidelines Eating disorders recognition and treatment
https://www.nice.org.uk/guidance/ng69

Medical emergencies in eating disorders (MEED) Guidance on recognition and Management
https://www.rcpsych.ac.uk/improving-care/campaigning-for-better-mental-health-policy/college-reports/2022-college-reports/cr233

Case studies of life-threatening malnutrition in people with very severe ME/CFS
Baxter H, Speight N, Weir W. Life-threatening malnutrition in very severe ME/CFS. InHealthcare 2021 Apr 14 (Vol. 9, No. 4, p. 459). MDPI.
https://www.mdpi.com/2227-9032/9/4/459

The Association of UK Dieticians Food Facts for ME/CFS
https://www.bda.uk.com/resource/chronic-fatigue-syndrome-diet.html

4.3.4 Autonomic dysfunction

People with ME/CFS have a high prevalence of autonomic symptoms, particularly orthostatic intolerance with postural dizziness and in some cases episodes of fainting/loss of consciousness. Other symptoms of altered autonomic function can include temperature dysregulation, changes in sweating patterns, palpitations and inappropriate heart rate responses, gastrointestinal and bladder symptoms. People who are severely affected by ME/CFS are equally affected by dysautonomia symptoms. Symptom escalation can be provoked by a wide range of physiological demands including orthostatic demand which may, for example, occur simply with sitting up. Other triggers that can escalate dysautonomia symptoms include dehydration, physical and cognitive demand, emotional responses, changes in environmental temperature, and sudden sensory stimuli such as loud noises. People with severe ME/CFS can be very sensitive to any of these demands and symptoms can change rapidly.

Screening questions that can identify those at increased risk relate to asking about: symptoms that change in response to posture change; body temperature regulation and sweating; typical gastrointestinal problems related to altered gut motility; and symptoms changing in response to eating and/or fasting. Detecting specific dysautonomia conditions such as Orthostatic Hypotension and Postural Tachycardia Syndrome (PoTS) may lead to additional treatment options that may reduce symptom severity and lead to improved function.

Currently the main test available to look for these conditions is a tilt table test. However, this is not widely accessible and people with severe ME/CFS are likely to be significantly impacted by the demand of attending for a tilt table test. Additionally, this test may not be suitable for someone who is bedbound.

If the person is able to stand up for at least for 10 minutes it is possible to screen for autonomic dysfunction by performing a Stand Test. This involves measuring pulse and blood pressure while lying down and during a 10minute period of standing still. The patient needs to lie flat for 10 minutes prior to starting the test. Pulse and BP are then measured with the patient lying down. They are then asked to stand up and pulse and BP are measured after 2minutes, 5 minutes and 10 minutes, noting any symptom change and colour change such as hands/feet becoming discoloured or mottled. If a patient has significant autonomic dysfunction they may faint during the test so it is essential it is conducted in an environment where the patient can easily abandon the test and lie down if they feel unwell. A diagnosis of PoTS is made if there is a greater than 30 beat per minute rise in pulse as a result of standing (or 40 bpm in teenagers). It is useful to also look for a drop in blood pressure which can sometimes occur towards the end of the 10minute stand. More information regarding this can be found in the ‘PoTS for medics’ section of the POTSuk website: http://www.potsuk.org/gp_guide

If someone is physically unable to participate in a stand test, examining for a haemodynamic response to lesser manoeuvres such as sitting might be of value if they are positive and associated with symptoms.

Recent research has demonstrated that applying an orthostatic stress using a tilt table results in a reduction in cerebral flow in most people with ME/CFS. The reduction in cerebral blood flow has been shown to be greater in people who are hypermobile and in people with ME/CFS diagnosed with psychogenic syncope. The orthostatic stress of a tilt table has been shown to induce post-exertional malaise symptoms and results in changes in memory function and pain symptoms. A small study demonstrated that in people with severe ME/CFS, sitting up can provoke a reduction in cerebral blood flow.

Studies have shown that the haemodynamic changes that occur in people with ME/CFS are not caused by deconditioning. However, spending long periods of time lying horizontal in bed will lead to reduced tolerance to orthostatic (gravity) stress along with loss of muscle strength and fitness. This means that people with severe ME/CFS who are bedbound will have a higher symptom burden related to dysautonomia issues. It is therefore important to explore ways to gradually improve sitting tolerance and increase muscle tone, this needs to be done very gradually. A starting point may be to establish small movements that can be done while lying in bed such as drawing the feet up towards the bottom and squeezing a pillow or cushion between the knees. Orthostatic tolerance can be improved by spending short periods of time propped up into a slightly head elevated position. When this can be tolerated on a regular basis then increase the degree to which they are sitting.

There are additional strategies that can be considered, if tolerated, that can reduce the impact of dysautonomia symptoms. Strategies include; regular fluid intake of at least 2.5 litres of water per day and where there is no evidence of systolic hypertension we recommend increasing salt intake, as a guide, a level teaspoon a day. Use of compression garments can reduce pooling of blood in the legs so can be worn during the day or when doing any upright activities and then removed at night. It is important to review medications to identify any that may aggravate dysautonomia issues.

Prescribing medications for dysautonomia problems is a specialised area and may be of benefit to people with severe ME/CFS if available locally.

Further information regarding dysautonomia symptoms and management strategies is available from the BACME Dysautonomia Guide and Symptom management guide.

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 clinically applicable.

Resources

BACME Dysautonomia- A Guide for ME/CFS

BACME ME/CFS Guide to Symptom Management

www.potsuk.org

https://heartrhythmalliance.org/stars/uk/

http://www.dysautonomiainternational.org/

Modified Orthostatic Symptom Grading Scale

The Composite Autonomic Symptom Score (COMPASS-31)

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4.3.5 Cognitive difficulties

People with ME/CFS 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. This presents a significant limitation for people who are severely affected and further increases isolation and impacts on self-confidence.

People with ME/CFS 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 be slow to initiate speaking and slow in speech, which helps them hold onto what they intend to say but can affect conversation fluency. They can experience word finding difficulty and find it challenging to express themselves. Interruptions and coping with multiple people speaking make the situation more challenging so should be minimised.

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

> “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). For people with very severe cognitive difficulties they may need to rely on pictures rather than words.

Cognitive difficulties can lead to loss of social contacts, difficulty maintaining hobbies and interests and can mean there is very limited capacity for meaningful mental activities. It can affect contact with family, friends and therapists, and may impact on their ability to retain information discussed with a clinician and make use of therapeutic input.

Strategies that can support communication include:

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

- One person speaking at a time
- Speaking slowly and softly
- Use short sentences and leaving longer pauses
- Making short recordings of important conversations that can be re-run at another time
- If the word the person is struggling to retrieve is obvious, saying it for them can help
- Written content needs to be grammatically simple, short and spaced out on a page
- Strategies that are used for conditions like Dyslexia may help such as simple fonts, large font size, coloured background/paper or using coloured lenses

4.3.6 Managing the emotional impact of the condition

When asked what has changed for them since becoming ill - most people say everything but their inner self. ME/CFS impacts 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 wellbeing, 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 and can sometimes have a negative impact on their condition.

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. Mental illness can become a barrier to them being able to implement changes 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 that can contribute to the rehabilitation strategies.

4.3.7 Symptom management including pain

Any care package for a patient with severe ME/CFS 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 ME/CFS clinician who is experienced in working with severely affected patients. Many people with severe ME/CFS develop sensitivities or intolerances to medications and drug metabolism can be altered. This means medications should be kept to a minimum where possible and all medications should be reviewed regularly to ensure only agents that are having a positive impact are continued. If there is evidence of medication sensitivity then medications that allow for very small dose increments are preferable including considering use of liquid preparations. Dosage should be started very low and titrated up slowly while monitoring carefully for benefits and side effects.

Further guidance on symptom management is available in:
BACME ME/CFS Guide to Symptom management.

4.3.8 Stimulus sensitivities

Many patients with severe ME/CFS 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, engaging in 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 clinician 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. Patients 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 were 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 and having access to a quiet waiting area demonstrates a depth of understanding before even meeting the patient. When visiting patients at home, one may need to respect the fact that they need to be seen in a darkened room for their comfort.

At the same time, feedback from people with personal experience of getting better from ME/CFS, 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 patients with experience of getting better from severe ME/CFS highlights the importance of providing mobility aids and adaptations to patients with physical disability. Support from carers to assist with activities of daily living is beneficial. 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.

Where aids and adaptions are needed in the home they can be used to optimise available energy capacity and improve quality of life. Clinicians should carefully consider the message this might give the patient about their prognosis as some people may improve sufficiently to gradually reduce their use of equipment. Therapists should 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

- If the equipment is provided to help with physical limitations (e.g. 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 limitations as a whole.

> 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.

- 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.

- 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 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.

- If the patient has a regular carer, include them in the consultation with the patient's agreement, since they can help to explain what the patient can manage, if the patient has limited stamina for talking.

- 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 autonomic dysfunction and compounded by deconditioning and consequently potential increased risk of osteoporosis, cardiovascular disease or diabetes. It will be important to consider these issues if the patient continues to be severely affected.

As patients may not be able to attend the doctor's surgery, they may miss out on routine health screening such as cervical smears and mammography or some may become concerned about the impact routine vaccinations may have on their condition. 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 was unable to attend hospital outpatients. The GP photographed the skin, and sought advice from the local Dermatology Service regarding what treatments could be tried at home.

When people develop new symptoms which warrant 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 that can be made for the appointment e.g. 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. The 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

Prior to the Covid-19 pandemic, home visits were the most commonly reported means of delivering care by ME/CFS services to housebound patients (McDermott et al 2014), combining the advantages of face-to face therapy with accessibility. 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.

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

We recommend that the 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.

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

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.

One service asks individuals to suggest a simple, non-verbal way that they will let the therapist know they have had enough (e.g. 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 respect 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 maximise 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, although others have reported that they prefer telephone sessions and find them less tiring, which emphasises the need to fit therapy to individual needs. The lack of visual contact may mean 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. Telephone calls give less opportunity for contact with formal and informal carers and family members.

5.3 Video-consultations

Video-consultations potentially offer a low-cost option, combining visibility with flexibility. The Covid pandemic created a demand for improved access to remote methods of consultation which led to many health care services being able to offer this mode of contact. There may be significant advantages for people with severe ME/CFS accessing care via this route as it removes the additional demand of travel or anxieties about having new people in the home. If they can access the technology required, they can engage in consultations while lying down which may mean they have greater capacity to talk. However, some people with ME/CFS find this method of communication more fatiguing and not everyone is confident in using computer technology. Some areas of the UK do not have good internet services and financial restrictions may limit this option for some people. It is important that healthcare services can offer a range of options to suit individual need.

5.4 Written communication

Emailing and texting can offer a means of supporting and staying in contact with patients. Feedback from individuals with severe ME/CFS suggests that even limited contact with a supportive health professional can be very much valued, in preference to feeling left to cope alone. Patients can construct emails in their own time with the support of others if needed. Receiving information in a written format allows time to process it and they can refer back to it when needed and share it with family and carers if relevant.

5.5 Audio/video recordings

For patients too severely affected to cope with direct face to face, phone or video consultations, audio or video 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. on their mobile phone), the carer sends the recording to the therapist, who then records a response and sends this back to the patient.

A key advantage of 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.

5.6 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 ME/CFS, 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. All professionals involved need to be aware of the effect of severe ME/CFS, its impact and symptoms.

Acute Hospital Admissions

Patients with severe ME/CFS may require admission to acute hospital wards either as a result of their ME/CFS symptoms or because of other conditions. An acute hospital environment can be extremely challenging for someone with severe ME/CFS due to the environmental challenges of noise, lights, airborne chemicals, movement around them all of which will be extremely stressful and potentially exacerbate their ME/CFS symptoms. Patients who are very unwell may struggle to communicate their needs and even if they do, they may not be met in such a busy environment. It is always worth considering if there is any appropriate alternative to admission. If a patient does need hospital admission, it will help to have information provided by a health care professional regarding the severity of their ME/CFS and the importance of respecting their need for rest and for a quiet or darker environment whenever possible. Family members and carers will be able to provide valuable information and may be able to provide certain aspects of care while the person is in hospital. If an admission is known about in advance or if a patient is known to be at risk of admission in the future it would be helpful to provide a written document that the patient can take with them to help them communicate their needs in the hospital environment which can include information regarding their care needs which will need to be provided while in hospital.

Specialist ME/CFS Admissions

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 gradual changes that can lead to substantial improvements across a range of aspects. There are some concerns that patients raise when contemplating 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 ME/CFS for other reasons, staff may wish to contact an ME/CFS specialist for advice on how to manage such an admission, which will give all parties confidence.

5.7 Service pathways in out-patient services

The BACME 2023 National Services Survey shows that around 70% of specialist ME/CFS services provide care for people who are severely affected but only 61% of them are able to offer home visiting.

There are a number of ways in which existing community based services provide care to people who are severely affected:

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, practice nurse or a community therapy team. This may be supplemented by periodic contact between the specialist service and the patient via telephone. Therapists should contact their local ME/CFS service, or BACME to find therapists who can offer this service.

Reference

BACME 2023 National Services Survey

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)

The BACME 2023 National Services Survey shows that there is a wide range of outcome measures being used in specialist services. Many services continued using tools included in the National Outcomes Database established in 2006, despite this central collection of data no longer being operational. Commonly used measures include:

SF36
Chalder Fatigue Scale
Pain severity measure
Clinical Global Impression Scale (CGI)
Hospital Anxiety and Depression Scale (HADS)
pHQ9 Depression Questionnaire
EQ5D 5L
Self-efficacy measure

BACME is involved in a project which is seeking to develop ME/CFS specific outcome measures which will allow for improved standardisation across services.

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 a therapist or carer (for example, to read out questions and to write down answers)

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 which 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.

Therapy Outcome Measures for Rehabilitation Professionals 3rd ed Pam Enderby and Alexandra John. J&R Press
https://www.jr-press.co.uk/therapy-outcome-measure-user-guide.html

6.4 Patient satisfaction

It is also important for patients to be able to give feedback on the service they have received. The friends and family test which has been used in a range of NHS services provides 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 very few questions, and care needs to be taken to ensure that the questionnaire burden does not take up energy which is needed for other tasks
- A sensitive and pragmatic approach is recommended to balance patient needs.

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Appendix B: Diagnostic criteria

2021 NICE Guideline Diagnostic Criteria

When to suspect ME/CFS:

All of these symptoms should be present:

- **Debilitating fatigue** that is worsened by activity, is not caused by excessive cognitive, physical, emotional or social exertion, and is not significantly relieved by rest.
- **Post-exertional malaise** after activity in which the worsening of symptoms:
  - is often delayed in onset by hours or days
  - is disproportionate to the activity
  - has a prolonged recovery time that may last hours, days, weeks or longer.
- **Unrefreshing sleep** or sleep disturbance (or both), which may include:
  - feeling exhausted, feeling flu-like and stiff on waking
  - broken or shallow sleep, altered sleep pattern or hypersomnia.
- **Cognitive difficulties** (sometimes described as 'brain fog'), which may include problems finding words or numbers, difficulty in speaking, slowed responsiveness, short-term memory problems, and difficulty concentrating or multitasking.

Be aware that the following symptoms may also be associated with, but are not exclusive to, ME/CFS:

- orthostatic intolerance and autonomic dysfunction, including dizziness, palpitations, fainting, nausea on standing or sitting upright from a reclining position
- temperature hypersensitivity resulting in profuse sweating, chills, hot flushes, or feeling very cold
- neuromuscular symptoms, including twitching and myoclonic jerks
- flu-like symptoms, including sore throat, tender glands, nausea, chills or muscle aches
- intolerance to alcohol, or to certain foods and chemicals
- heightened sensory sensitivities, including to light, sound, touch, taste and smell
- pain, including pain on touch, myalgia, headaches, eye pain, abdominal pain or joint pain without acute redness, swelling or effusion.

Suspect ME/CFS if:

- the person has had all of the persistent symptoms in box above for a minimum of:
  6 weeks in adults and
  4 weeks in children and young people **and**

- the person's ability to engage in occupational, educational, social or personal activities is significantly reduced from pre-illness levels **and**
- symptoms are not explained by another condition.

Diagnose ME/CFS in children, young people and adults if:

- other causes of the symptoms have been confidently excluded and the symptoms in box above have persisted for over 3 months

The 2021 NICE guideline defines severe and very severe ME/CFS as follows:

Severe ME/CFS: People with severe ME/CFS are unable to do any activity for themselves or can carry out minimal daily tasks only (such as face washing or cleaning teeth). They have severe cognitive difficulties and may depend on a wheelchair for mobility. They are often unable to leave the house or have a severe and prolonged after-effect if they do so. They may also spend most of their time in bed and are often extremely sensitive to light and sound.

Very severe ME/CFS: People with very severe ME/CFS are in bed all day and dependent on care. They need help with personal hygiene and eating and are very sensitive to sensory stimuli. Some people may not be able to swallow and may need to be tube fed

Appendix C: Inpatient services

National Inpatient Centre for Psychological Medicine (NICPM)

previously known as the Yorkshire Centre for Psychological Medicine (YCPM), Leeds

https://www.leedsandyorkpft.nhs.uk/our-services/national-inpatient-centre-psychological-medicine-nicpm/

This service takes referrals from all across the UK, i.e. 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 and very severe ME/CFS 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 ME/CFS 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 ME/CFS 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: Severe ME/CFS Resources

General Clinical Resources

NICE Guideline: ME/CFS Diagnosis and Management
https://www.nice.org.uk/guidance/ng206/chapter/Recommendations

British Association of Clinicians in ME/CFS (BACME) clinical resources available to download from www.bacme.info :

- BACME An Introduction to Dysregulation in ME/CFS
- BACME Guide to symptom management
- BACME Guide to therapy
- BACME Primary Care Guide
- BACME Care and Support Plan guidance
- BACME Dysautonomia- a Guide for ME/CFS
- BACME map of specialist services

Video resources about severe ME/CFS
https://www.dialogues-mecfs.co.uk/films/severeme/

Therapy Outcome Measures for Rehabilitation Professionals 3rd ed Pam Enderby and Alexandra John. J&R Press
https://www.jr-press.co.uk/therapy-outcome-measure-user-guide.html

Other relevant NICE Guidelines:

- NICE guideline on multimorbidity
- NICE guideline on depression in adults with a chronic physical health problem
- NICE guideline on depression in adults
- NICE guideline on depression in children and young people
- NICE guideline on generalised anxiety disorder and panic disorder in adults
- NICE guideline on common mental health problems.

Resources for Children and Young People with ME/CFS

Action for M.E. under 18's
https://www.actionforme.org.uk/18-and-under/how-we-can-help/support-for-18-and-under/
Action for M.E. ME/CFS in children and young people
https://www.actionforme.org.uk/uploads/pdfs/MECFS-in-children-and-young-people-Sep-2020.pdf

Key Features of a Multi-Disciplinary Hospital-Based Rehabilitation Program for Children and Adolescents with Moderate to Severe Myalgic Encephalomyelitis/Chronic Fatigue Syndrome ME/CFS
https://www.mdpi.com/1660-4601/19/20/13608

Severe myalgic encephalomyelitis/chronic fatigue syndrome in children and young people: a British Paediatric Surveillance Unit study
https://adc.bmj.com/content/archdischild/early/2022/11/30/archdischild-2022-324319.full.pdf

Management of chronic fatigue syndrome/myalgic encephalopathy (CFS/ME)
https://ep.bmj.com/content/90/2/ep46

Medical emergencies in eating disorders (MEED) Guidance on recognition and Management
https://www.rcpsych.ac.uk/improving-care/campaigning-for-better-mental-health-policy/college-reports/2022-college-reports/cr233

Services that see Children and Young people with ME/CFS can be found via BACME website services map: https://bacme.info/services-map/

Nutrition Resources

NICE Guideline Adult Nutrition Support
www.**nice**.org.uk/Guidance/CG**32**

BAPEN Malnutrition Universal Screening Tool
www.bapen.org.uk/pdfs/must/must_full.pdf

SCOFF questionnaire -screening tool for eating disorders
Morgan JF, Reid F, Lacey JH. The SCOFF questionnaire. The Western journal of medicine. 2000 Mar 1;172(3):164.
https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1070794/

NICE Guidelines Eating disorders recognition and treatment
https://www.nice.org.uk/guidance/ng69

Medical emergencies in eating disorders (MEED) Guidance on recognition and Management
https://www.rcpsych.ac.uk/improving-care/campaigning-for-better-mental-health-policy/college-reports/2022-college-reports/cr233

Case studies of life-threatening malnutrition in people with very severe ME/CFS
Baxter H, Speight N, Weir W. Life-threatening malnutrition in very severe ME/CFS. InHealthcare 2021 Apr 14 (Vol. 9, No. 4, p. 459). MDPI.
https://www.mdpi.com/2227-9032/9/4/459

The Association of UK Dieticians Food Facts for ME/CFS
https://www.bda.uk.com/resource/chronic-fatigue-syndrome-diet.html

Hypermobility Resources

Hypermobility Syndromes Association:
www.hypermobility.org

RCGP Ehlers Danlos Syndromes Toolkit (includes information about Mast Cell Activation Syndrome)
https://www.rcgp.org.uk/clinical-and-research/resources/toolkits/ehlers-danlos-syndromes-toolkit.aspx

The Ehlers-Danlos Society
https://www.ehlers-danlos.com/ehlers-danlos-info/

Dysautonomia Resources

BACME Dysautonomia- A Guide for ME/CFS

BACME ME/CFS Guide to Symptom Management

Modified Orthostatic Symptom Grading Scale

The Composite Autonomic Symptom Score (COMPASS-31)

PoTSuk website
www.potsuk.org

STARS Syncope Trust And Reflex anoxic Seizures website
https://heartrhythmalliance.org/stars/uk/

Dysautonomia International website
http://www.dysautonomiainternational.org/

The Dysautonomia project
www.thedysautonomiaproject.org

Patient and Carer Resources

Action for M.E.
https://www.actionforme.org.uk/

ME Association
https://meassociation.org.uk/

ME Association severe ME/CFS Guide
https://meassociation.org.uk/wp-content/uploads/SEVERE-MECFS-HELPING-YOU-COPE-FEBRUARY-2020.pdf

Book: Severe ME/CFS: A Guide to Living By Emily Collingridge
https://www.severeme.info/

Hannah Radenkova website blog about living with severe ME/CFS
http://superpooped.blogspot.com/

Stickman communications – communication aids
https://stickmancommunications.co.uk/

Book: Chronic Fatigue Syndrome/ME: Support for family and friends Elizabeth Turp

Book: The Selfish Pig's Guide to Caring Hugh Marriot

Disability Assessment Resources

Benefits and Work website: www.benefitsandwork.co.uk/

Citizens' Advice How to fill in your claim form:
https://www.citizensadvice.org.uk/benefits/sick-or-disabled-people-and-carers/pip/help-with-your-claim/fill-in-form-pip/

Disability Rights UK Personal Independence Payment (PIP) guide to making a claim
https://www.disabilityrightsuk.org/resources/personal-independence-payment-pip

7 Tips for Claiming Disability Benefits with M.E. A.Innes
https://meassociation.org.uk/2019/08/top-7-tips-for-claiming-disability-benefits-with-me-by-anne-innes-14-august-2019/

Action for M.E. Welfare benefits factsheets
www.actionforme.org.uk/get-support-now/info-and-support-resources/welfare-benefit-factsheets/

ME Association leaflet Personal Independence Payment – A Guide to Applications
www.meassociation.org.uk/product/personal-independence-payment-guide-to-applications/