

# CBT for CFS Therapist Manual

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*Note:* This manual is not intended to be prescriptive. It aims to summarise current practice, which is individualized for each young person depending on their needs, formulation, developmental stage, interests and context. Individual therapists also have their own styles and preferences, so this is intended to be used flexibly but with fidelity. We also include links to some of our own resources and information sources, as well as some of other reputable organisations.

## General CBT Principles

Cognitive Behaviour Therapy (CBT) is one of the three current NICE recommended treatments for Chronic Fatigue Syndrome (CFS/ME). CBT aims to help a person change their feelings through changes in thinking and doing; changing the way patients think or respond to their symptoms or experiences can help bring positive change in how they feel. It assumes that feelings and actions arise from thoughts and attributions (i.e. the meaning given to a situation).

The core features of CBT are:

- *Based on theory* – CBT is based on testable models of links between thoughts-feelings-behaviour which inform how and where to make changes, based on evidence.
- *Collaborative partnership* – Young people are empowered to be active within the therapeutic relationship. Rather than assuming that the therapist is the expert who will ‘do’ things to ‘fix’ the problem, the therapist and young person both bring expertise to the table. The therapist knows the CBT principles for building recovery from CFS/ME and what works generally, and the young person knows themselves and their lives. Through a collaborative partnership, they bring this expertise together to find what works to overcome problems for that young person at that time.
- *Scientist-discoverer* – The work of CBT is about testing out different ways of thinking and doing, and about assessing how things change as a result. It is about actively learning from experience. The evidence for and against thoughts may be weighed up, and behavioural experiments may be carried out to test whether beliefs are true or whether there may be other ways of looking at things. Together the therapist and young person set out to find new information about the young person and their experiences, with the overall aim of helping that young person to make positive changes and to get better.
- *Here-and-now*- CBT focuses on the present. It aims to address problems in the here-and-now, and to change ways of interacting with the world going forwards. This does not mean it completely ignores the past; the past is explored where it is relevant to what is happening now. But it is particularly helpful for the young person to be empowered in setting and working towards goals in the present and future.
- *Time-limited* – CBT is a relatively brief therapy, and typically lasts for  $\leq 16$  sessions. The aim is to develop skills which the young person can continue to use beyond

the end of therapy, and even to come back to later down the line, if they need. Therefore, rather than the therapeutic relationship being the vehicle for change (as in some other therapeutic modalities), the skills learned are the vehicle for change. The therapeutic relationship is considered to be necessary but not sufficient for change.

- *Structured* – The process of CBT begins with an assessment. Following this, a shared understanding (formulation) of the problem is developed with the young person which includes identifying how thoughts-feelings-behaviours (and how they interconnect) are keeping the problem going. The therapist works with the young person to develop skills to manage thoughts, and to respond in more helpful ways. Progress and change are evaluated using rating scales, and goals set at the outset are regularly reviewed. Each session is also structured, starting with a check-in, then agreeing together a shared agenda (key things to talk about in that session), covering these items with reference to the goals and formulation, and use of periodic summaries (by both the young person/therapist) to consolidate learning and check for understanding,

CBT is based on the work of Aaron Beck and his daughter, Judith Beck (see Cognitive Therapy: The Basics and Beyond).

The main differences in the delivery of CBT when working with young people and families (compared to when delivering the therapy with adults) are:

- Parents are more likely to be involved (as facilitators/co-therapists/co-clients).
- Greater use of creative methods
- Adaptation to developmental level, including developing emotional literacy, where needed.

See Stallard's Think Good Feel Good and Fuggle, Dunsmuir & Curry's CBT with Children, Young People and Families for more detailed descriptions.

## INTRODUCING CBT TO PATIENTS & FAMILIES

CBT typically begins by explaining what CBT is and what it will involve to a young person and their family, known as 'socialising' to the model. See information sheets:

- [https://www.ruh.nhs.uk/patients/services/clinical\\_depts/paediatric\\_cfs\\_me/documents/CFSCBT.pdf](https://www.ruh.nhs.uk/patients/services/clinical_depts/paediatric_cfs_me/documents/CFSCBT.pdf)
- Stallard's Think Good Feel Good & Clinicians' Guide to Think Good Feel Good.

The key messages are:

- Cognitive Behavioural Therapy (CBT) can be helpful for young people with CFS/ME.
- CBT looks at the links between the way you think, how you feel and what you do.

- It helps by creating new ways of managing difficult thoughts and feelings.
- CBT involves a series of one-to-one sessions with a healthcare professional trained in mental health, e.g. a psychologist.
- CBT is typically delivered in 1hour (maximum) sessions with the young person, which take place either weekly or every other week depending on clinic availability and what is most appropriate for the young person.
- After an assessment session, the therapist and patient will commonly plan a block of sessions (e.g. 6) after which a review is held. The review helps to track the progress of treatment more formally in relation to the patient's goals, and to consider whether (or how many) further sessions are needed.
- CBT is time-limited and a young person may have on average something like 12-15 CBT sessions. CBT aims to develop tools for the young person to use even beyond the end of the work together.

## CBT for CFS/ME

What follows in the subsequent sections is a detailed description of the components of CBT for CFS/ME. As a preface to this, here are some ways in which CBT for CFS/ME may be different to CBT more broadly.

### Acknowledging that fatigue is real

It is important to acknowledge with the young person that the fatigue is real. CFS/ME unfortunately carries with it a history of being misunderstood (and even sometimes disbelieved); even today's patients are affected by this. They might report a sense of others suggesting it isn't real, or that (and this is a terrible phrase) it is "all in their head". The challenges of an invisible illness can be multiple, complex, and highly distressing. The therapist has a key role here in acknowledging that the fatigue is very much a real and present experience, and that whilst there may not be a medical 'cure' it is possible to use non-pharmacological methods such as behavioural and psychological strategies to helpfully bring about change and improvement. This is an important and subtle distinction to address with the young person and those supporting them.

### Adjustment to a CFS/ME diagnosis, building acceptance and engaging in treatment

Young people, and their families, can react to a diagnosis of CFS/ME in different ways. For some the diagnosis comes as a huge relief, after a period of uncertainty. As CFS/ME is diagnosed by excluding other possible explanations for fatigue, a young person may have had a long journey to reaching a diagnosis. This can lead to a great sense of confusion, uncertainty and frustration for the young person and their family. In addition to this, families often report a sense of not being understood (or worse: not believed) by others around them that something is wrong. CFS/ME is one of many invisible illnesses and it can pose great challenges for the sufferer in this way.

CBT can therefore be particularly important here for supporting the young person, and their family, to process the new diagnosis. It also helps to build a shared understanding together of the aims and goals of CBT treatment within the recovery journey. Adjustment, acceptance, and engagement are key processes of therapy which must be considered and explored at the outset of therapy but are also likely to recur later on as the therapeutic work progresses.

### Exploring beliefs about illness and recovery

It is particularly important in CBT for CFS/ME to give the young person space to recognize and become familiar with their thoughts and beliefs about CFS/ME. Many young people might not have voiced (or even consciously accessed) these prior to starting therapy. Some young people can need encouragement and even permission to open these conversations.



The therapist plays a key role in normalizing and validating any such feelings that the young person may present.

Curiously exploring the thoughts or beliefs that significant others hold about illness and recovery can be particularly helpful too. This can include friends, family, and perhaps even others who have a caring or supportive role such as school staff. The recovery journey in CFS/ME is certainly not something done by the young person alone but with support of the therapist and the wider, multi-layered systems around them. Therefore, eliciting and exploring all beliefs held within these systems is crucial. It might be for example that a parent feels helpless or doubtful about the prospect of the young person's recovery; this is really important to explore and address.

### **Finding new ways of managing symptoms e.g. pain or disrupted sleep**

CBT provides a range of methods or skills for managing symptoms. These might be quite practical and familiar (e.g. learning good sleep hygiene methods), or perhaps newer to the young person (e.g. physical relaxation methods and controlled breathing exercises). It is about giving the young person new ways of coping with and responding to their symptoms. CBT creates the opportunity to bring about behavioural change through cognitive and behavioural methods. For example, the therapist can support the young person to conduct cost-benefit analyses of a current behaviour and use this to consider the benefits of new or different behavioural responses to their symptoms. The young person is gently guided to consider new ideas and to try new things out, in an 'experimental' approach. The aim here is always about helping the young person to move towards their own therapeutic goals for recovery.

### **Re-building self-confidence and enjoyment of activities**

As a young person progresses through treatment it is possible to shift focus not just to the rebuilding of activities themselves but also to the enjoyment of them. CBT for CFS/ME can give the young person opportunities to explore why activities are important to them, and to reflect on themes such as their sense of self and identity. As a young person returns to old favoured activities (or indeed begins new ones) it is important to scaffold the rebuilding of their self-confidence; something which is likely to have taken several knocks during the course of their illness.

### **Learning to manage setbacks**

CBT for CFS/ME has a central focus of building a young person's skills in recognising, understanding, and managing their symptoms and experiences. These skills are key in each stage of the recovery process, including the management of flare-ups (temporary recurrence or worsening of symptoms) or other setbacks during the recovery journey. It is important to discuss the possibility of flare-ups and for the young person to feel clear on which skills and strategies they would employ from their toolkit if needing to. In this way

the young person can finish CBT sessions armed with knowing what to do later down the line if symptoms recurred or worsened after therapy had ended.

### Working with fatigued patients

Doing CBT with young people who are struggling with fatigue is likely to require adaptations to CBT practices to account for the symptoms of CFS/ME, particularly concentration and 'brain fog'. This may include:

- Keeping sessions shorter
- Taking breaks during sessions
- Repeating material/revising key concepts more often
- Providing written material to supplement in session discussion
- Keeping key concepts and written material simple
- Capturing the key points of each session by writing these down (ideally, getting the young person to do this)
- Offer some sessions by videoconference, particularly if the young person lives a considerable distance from the clinic location as travelling can be particularly tiring
- Including parents more to aid the retention of information and to enable them to provide reminders in between sessions.
- Remember that symptoms are variable, so what a young person can do on one day may be different from another.

Note, at the end of this manual, we have included a general guide about treatment sequencing in behavioural approaches, CBT for CFS/ME and CBT for CFS/ME with co-morbid anxiety and/or depressive symptoms. This guide is not intended to be prescriptive.

# What is CFS/ME?: Psychoeducation about CFS/ME

## Definitions and diagnosis

Chronic Fatigue Syndrome (CFS), sometimes referred to as Myalgic Encephalomyelitis (ME), is a health condition characterized by extreme tiredness. Like other syndromes, CFS/ME has core symptoms, which must be present for a diagnosis to be made. It can also include a number of other symptoms which not everyone with CFS/ME will have, or has to differing extents. This means that there is individual variation in how CFS/ME presents.

To be diagnosed with CFS/ME a young person would need to meet the following four key criteria:

- Persistent fatigue, that is not life-long but has been ongoing for at least 3 months.
- The fatigue is not just due to exertion (instead, it is there in the background a lot of the time) and is not substantially improved by resting.
- Post-exertional malaise; the fatigue is worsened after increased activity. This can show itself 1-2 days after the busy time and can take a few days to recover from.
- Fatigue that is severe enough to significantly disrupt all areas of daily life e.g. going to school, hobbies or clubs, time with friends or family, etc.

In addition, some other symptoms of CFS/ME include sleep disturbance, muscle and joint pain, headaches and sore throats, cognitive dysfunction (including attention, processing and memory difficulties), dizziness, nausea, and heart palpitations, amongst others. Some young people may also experience increased sensory sensitivity e.g. to touch, noise, or light. A substantial minority of young people with CFS/ME also experience problems with mood and anxiety. This may be due to feelings of sadness, worry, or frustration about their illness and its impact, amongst other things.

## Onset and maintenance of CFS/ME

CFS/ME is complex and we do not always know what causes or triggers it. Often, young people with CFS/ME will report a history of having an acute illness (e.g. a bad virus, or glandular fever), and a sense that they never really recovered afterwards. For others, the trigger could have been a highly stressful or traumatic event, however this is less common and less well understood.

Whereas the trigger or onset of CFS/ME can be unclear, we know more about what can keep CFS/ME going. The evidence points towards behavioural maintenance factors (activity patterns, sleep) and cognitive maintenance factors (thoughts and beliefs about fatigue). And this is where we can helpfully apply evidence-based treatments, including CBT, to enable the young person to make changes and work towards recovery from their CFS/ME. There is no medicine or 'cure' for CFS/ME. Instead, treatments use largely behavioural methods to bring about changes and improvements, e.g. starting with regulating sleeping patterns and activity levels. This will be explained later in this manual.

## Recovery in CFS/ME

The good news is that recovery rates from CFS/ME in young people are very good. A Dutch study looking at recovery found that approximately 85% of young people were recovered (absence of severe fatigue) at 1 year after starting active CFS/ME treatment (internet based CBT for fatigue). This data can be compared to a 27% recovery rate for those who were not in active treatment, after 1 year (see Nijhof, S. L., Bleijenberg, G., Uiterwaal, C. S., Kimpfen, J. L., & van de Putte, E. M. (2012). Effectiveness of internet-based cognitive behavioural treatment for adolescents with chronic fatigue syndrome (FITNET): a randomised controlled trial. *The Lancet*, 379(9824), 1412-1418).

This data shows us a few things:

1. The recovery journey takes a matter of months, or a year, or perhaps longer. It is not something completed in weeks.
2. It suggests that most young people with CFS/ME will be recovered after 1 year of CBT.
3. But this will not be the case for everyone; for some, the journey may be slightly over 1 year but also for some it could be significantly longer.
4. Even without active treatment, there is some natural recovery in young people with CFS/ME, but CBT can speed up this process.

Much less is known about treatments for those who are most severely affected by CFS/ME.

## Assessment

### Diagnostic Assessment

The diagnostic assessment of CFS/ME is generally conducted either by community paediatricians or highly trained clinicians working in specialist CFS/ME services, including Doctors and Clinical Psychologists, amongst others. Diagnosis involves several sources of information which are collated and synthesized. Patients with a queried CFS/ME presentation are required to have a set of screening blood tests completed, in line with NICE treatment guidelines for CFS/ME, prior to assessment. These blood tests are to rule out any other underlying health difficulties which could be relevant.

The diagnostic assessment interview includes taking a thorough medical and developmental history, and asking about the current symptom presentation, including considering the results of blood tests. A symptom checklist may be used to structure this. It can be informative to gather information on the family and wider family health history too. A good biopsychosocial assessment in CFS/ME would aim to build a picture of all aspects of the child's functioning at present, including sleeping patterns, school attendance, engagement in hobbies or social activities, diet, mental health, and any other pertinent information presented by the family. All possible alternative explanations for fatigue need to be explored before a diagnostic conclusion can be reached.

The assessment process is helpfully supported by use of questionnaires, typically completed by the young person prior to the diagnostic assessment in clinic. At a basic level these questionnaires aim to assess current levels of fatigue and its impact on functioning, as well as screening of mental health difficulties (anxiety and depression). Other, more detailed psychological measures can be also conducted e.g. assessing cognitive and behavioural responses to fatigue, or the extent of general negative thinking patterns.

Note that where mental health problems like anxiety or depression are the primary problem that explains the fatigue, a diagnosis of CFS/ME would not be made. However, a young person may have mental health problems AND CFS/ME, where the fatigue meets the diagnostic criteria for CFS/ME and is not fully explained by the mental health problem(s) alone.

### CBT Assessment

At the first CBT session, a more detailed exploration of thoughts, feelings, behaviours and physical symptoms, and the links between these, is likely to be explored. This will feed into the initial formulation. It is also likely to include an exploration of the key problems, which may form a 'problem list'. A more detailed consideration of mood and anxiety, particularly where there are indications that this might be part of the picture, may also be undertaken. Assessment is likely to be iterative and ongoing, and may be revisited as therapy progresses.

Questionnaires that may be useful for aiding assessment and for progress tracking during therapy are:

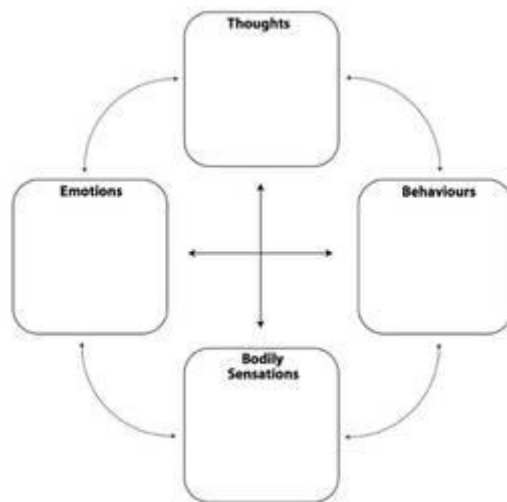
Focus	Questionnaire	No of items	Clinical cut-off/scoring
Fatigue	Chalder Fatigue Questionnaire	11	Items scored as 0 (less than usual) to 3 (much more than usual). 7 items pertain to physical fatigue and 4 to mental fatigue. Higher scores indicate greater fatigue. Scores of $\geq 19$ indicate clinically significant fatigue
Physical functioning (disability)	SF36 Physical Functioning Subscale	10	Items scored as 0 (yes, a lot)/5 (yes, a little) /10 (not at all). 0-100 (where 100 is better functioning).
Anxiety and Depression	Revised Children's Anxiety and Depression Scale – (RCADS)	10 items depression 37 items anxiety (separated into GAD, Social Anxiety, Panic, OCD and Separation Anxiety)	Child and parent versions. Each item is scored 0 (never) to 3 (always). Higher scores indicate greater psychopathology. RCADS-depression $>14-15$ likely indicates probable depression, and RCADS-anxiety (total) $> 37-38$ likely indicates a likely Anxiety Disorder.
Cognitive and behavioural responses to fatigue	Cognitive and Behavioural Responses to Symptoms Questionnaire (CBRQ)	18 items (also a 40-item version) Subscales: (symptom focusing, fear avoidance, embarrassment avoidance, catastrophizing, damage beliefs, all-or-nothing behaviour, avoidance/rest).	For the cognitive items, 0 = strongly disagree, 4 = strongly agree. Higher scores indicate more unhelpful beliefs about symptoms. For the behavioural items, 0 = never, 4 = all the time. Higher scores indicate more unhelpful responses to symptoms.
General negative thinking patterns	Children's Negative Cognitive Errors Questionnaire (CNCEQ-R)	16 (5 subscales: (underestimation of coping ability, personalising without mindreading, mindreading, selective abstraction, overgeneralizing)	Each item presents a scenario and a distorted thought. Respondents are required to indicate how similar their thinking would be to the given thought on a 5-point scale from 'not at all like I would think' (1) and 'almost exactly like I would think' (5). Higher scores indicate more negative thinking patterns.

Note: this is not intended to be a definitive list. These are examples which have been used in adolescents with CFS/ME, but others may be more clinically useful in a particular case. Idiosyncratic measures such as 0-10 or 0-100 rating scales may also be useful and may be more appropriate to decrease the burden of filling in extensive measures.

## Formulation – Our road map

The formulation can be thought of as the shared understanding of the problem and what is keeping it going. It may also include the shared understanding of how the problem started.

Most typically, the formulation describes the links between aspects of thinking, feeling and doing. In the paediatric setting, it most likely also includes physical symptoms. A relatively basic formulation is Padesky's hot cross bun, as seen below. The multiple and bidirectional arrows demonstrate that all of these elements interact with each other and can make each other worse. Understanding these links is crucial for trying to reduce unhelpful cycles and to bring about new, helpful cycles between thoughts, feelings, behaviour, and fatigue.



The formulation is constantly evolving. It guides intervention by highlighting what needs to change for things to be different. Whilst we often can't change the situation, or our feelings directly, by making changes in thinking and doing, the feedback loops lead to changes in feelings. In paediatric settings, the emphasis is often on living the best life you can alongside physical symptoms, rather than necessarily seeking to change the physical symptoms themselves directly.

There are more specific formulation templates that can be used for specific problems (e.g. social anxiety disorder) or completely idiosyncratic approaches may be worked on together in therapy. [www.psychologytools.com](http://www.psychologytools.com) and [www.getselfhelp.co.uk](http://www.getselfhelp.co.uk) are good sources of printable worksheets of a variety of models.

The therapist may develop a more detailed formulation of the problem than is necessarily shared with the young person/family, particularly for patients with complex presentations where to share the formulation in its entirety could be overwhelming or confusing. Ideally, the formulation should be as detailed but as simple as possible (parsimony). The

therapist can use any additional (more complex) formulations to sensitively guide their thinking during the therapy and in supervision, and may draw on some parts of it as therapy continues.

### Formulations in CBT for CFS/ME

A key task in CBT for CFS/ME is to build a shared understanding (formulation) of the young person's experiences, symptoms and situation. It is a way of looking at what is going on for them, and how their thoughts, feelings and behaviour connect with each other, and with their fatigue. It also helps to highlight areas which may be particularly important to work on during CBT sessions.

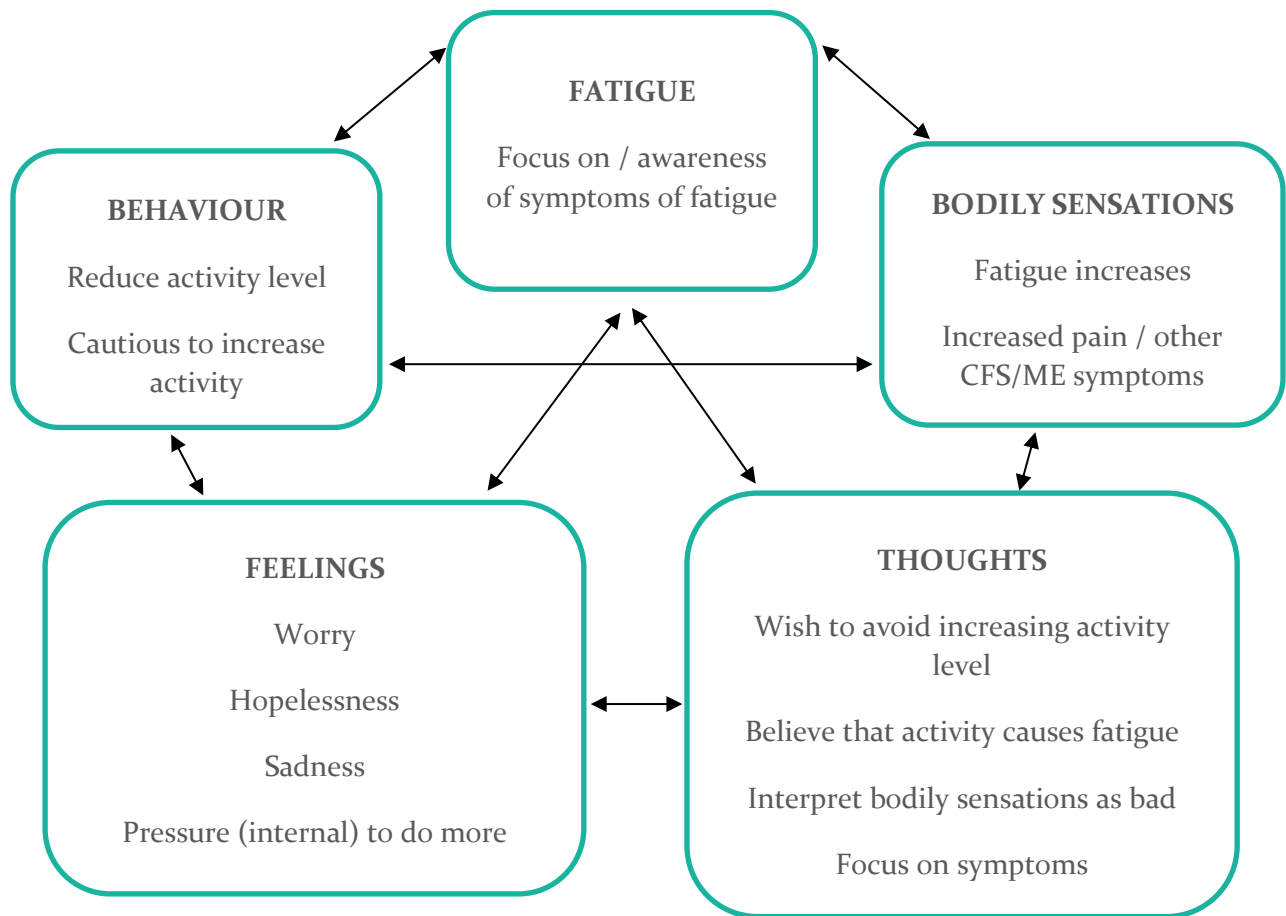
To illustrate, here are some examples of some of the common thoughts-behaviours-fatigue links, for a young person with CFS/ME.

A young person with CFS/ME may be prone to focus on their physical symptoms. If aware of feeling particularly tired or in pain, a young person is likely to be cautious and behave differently e.g. reduce their activity level. This may mean not going into school, resting more, or even sleeping more. As an unhelpful consequence, this reduced activity level can lead to increased disability and worsened fear about reinstating activities, making it harder for the young person to then resume activities. It is important to notice these sorts of links carefully and sensitively.

Similarly, young people with CFS/ME may be extra aware of symptoms or feelings in their body and more likely to detect small changes in how they physically feel. If a young person then interprets these feelings as 'bad', they may 'blame' activity as the cause of these symptoms. As a result, they may find themselves reducing their activity level or engaging in other precautionary "safety behaviours" in an attempt to prevent their fatigue from worsening, which can in fact cause them further difficulties and build barriers in reaching their goals.

Another challenge for young people with CFS/ME can be the role of thoughts and their influence on behaviour. A young person who has been unwell for some time may have reduced self-efficacy or be hyper-sensitive to the perceived opinions or reactions of others. Young people with CFS/ME can feel a great pressure to do their best, or a sense of needing to be seen to do well, in the context of having lost physical strength or perhaps not doing as well at school as they used to, for example. These thoughts and worries too can lead to the young person finding it hard to re-increase activities and becoming somewhat stuck. Aiming for perfection is very daunting. This reduced activity level combined with increased anxiety can worsen fatigue itself and the 'stuck' circle can continue.





In these ways, it is hugely important to help the young person recognize the links between their own thoughts, feelings, behaviour, and symptoms of fatigue. Having a better understanding of how these things connect enables the young person, with the support of their therapist, to identify areas to work on in CBT sessions. This might be about setting activity-related goals or working on managing particular thoughts or feelings; in this way CBT for CFS/ME can encompass a range of key skills and learning.

The formulation(s) are continually reviewed and adapted as treatment progresses. It is important to come back to the formulation during treatment and consider what changes have occurred so far; updating the formulation and revising the patient's next goals to focus on. It is an iterative process, of looking back at the formulation and goals.

## Goals - what do we want to achieve together?

After completing the assessment and formulation stages in CBT, it is important to establish the young person's goals for their treatment and recovery journey. Goals can be identified early within assessment but often become clearer, and more specific, through formulation. Similarly, goals can continue to be reviewed and revised throughout the whole of the treatment.

It is crucial to set goals for the young person's recovery, at the outset of treatment because:

1. It gives the young person a clear message that they are now in the great position of being able to work towards recovery. They have a diagnosis; a name for their symptoms and experiences, and with that comes a treatment to bring about improvement and recovery.
2. It helps the young person to now look forwards with optimism.
3. It helps both the young person and the therapist to track progress during therapy. As with other complex illnesses, it can be hard for the young person to notice positive change and improvement. This is particularly the case when the ultimate goals for full recovery can feel like a long way away for the young person. Use of measurable goals helps the young person to track steps towards them, however small.
4. Having goals also helps the young person and therapist together to recognize when the goals have been achieved and therefore when the time has come to appropriately end therapy.

We usually try to set goals that are SMART:

- Specific
- Measurable
- Achievable
- Realistic
- Time-limited.

Goal based outcome sheets can be helpful - <https://www.corc.uk.net/outcome-experience-measures/goal-based-outcomes/>

Regular progress reviews include a review of these goals, usually at least every 6<sup>th</sup> session, and may also include completing other questionnaires to track symptoms and functioning.

## Examples of goals

Each young person's goals will be different and unique to them. However, there are often common themes that arise, when young people with CFS/ME are asked what they would like to work towards within their recovery journey. Here are some examples:

- School:
  - To be able to manage 3 hours in school every day by the end of term (shorter-term goal)
  - To be able to return to school full-time by the end of the school year (longer-term goal)
  - To complete my GCSE exams next year in 8 subjects (longer-term goal)
- Social (friends / families)
  - To text my friend Sarah once a week (shorter-term goal)
  - To go to my cousin's birthday party in a month (shorter-term goal)
  - To be able to have a sleepover for my 16<sup>th</sup> birthday next Spring (longer-term goal)
  - To spend one hour with my family every evening rather than be in my room.
- Hobbies / other activities
  - To restart my yoga stretches for 10 minutes, once per week (shorter-term goal)
  - To get back to competing with my swimming team by next summer (longer-term goal)
  - To restart helping out at Brownies for 1 hour every Tuesday

## Components of Treatment

### SLEEP

Sleep is generally the first treatment target within any of the three NICE recommended treatments for CFS/ME. This is because it is very common for sleep patterns and/or timings to have become dysregulated for young people with CFS/ME. It might be that the young person has begun a pattern of having long naps each day due to their fatigue. Others can drift into a pattern of getting up late in the mornings, and as a result find it hard to feel tired at bedtime and so end up falling asleep very late or even in the early hours of the morning. At the most extreme end of this, young people with CFS/ME can become nocturnal. Whatever the precise pattern, it is commonly seen in clinic for there to be at least some change or disruption to the 'normal' sleeping pattern that might have been in place prior to CFS/ME.

Addressing sleep early on (if not first) in treatment is important both for reinstating more adaptive sleeping patterns and improving quality of sleep for the young person, and also boosting their chances of being able to cognitively engage in the fairly demanding therapeutic process of CBT for CFS/ME.

Therapeutic work on improving sleep includes advice about sleep restriction to the appropriate amount for their age, anchored sleep and wake up times, appropriate use of rests (but not naps) during the day, and good sleep hygiene.

The following bullet points summarise key guidance on sleep to be shared with the young person and their family. It is important to share this psychoeducation to give the rationale for making changes to sleeping patterns. This section of treatment can feel quite information-heavy and so it is a challenge for clinicians to try and keep some elements of Socratic discussion which enable the young person to draw on their own knowledge and experience, as per usual CBT practice.

#### How much sleep/sleep restriction

- This varies for each person.
- For general guidance, see [www.nhs.uk/Livewell/Childrenssleep/Pages/howmuchsleep.aspx](http://www.nhs.uk/Livewell/Childrenssleep/Pages/howmuchsleep.aspx).
- There is an optimum amount of sleep. Importantly, sleeping more than needed will compound tiredness because it reduces the sleep quality.
- We recommend trying to stick as close to the recommended sleep as possible.
- Trying to stop tiredness in CFS/ME by sleeping more usually makes things worse.
- So, the key points are:
  - You need to sleep no more than your friends

- At first you will feel much worse, because you will be having less sleep – after a couple of weeks you should be sleeping better at night and most young people start to feel better.

### Timing of sleep

- Day/night reversal is common in young people with CFS/ME.
- Treat it like jet lag:
  - Wake up 30 to 60 minutes earlier each day until you're waking up between 7am and 8am
  - The most important thing to set is your wake-up time, which should be anchored. It is important that your brain gets the right stimulation to tell it if it is day or night. Try to stay awake during the day so that you see daylight – this helps the brain get into the correct day/night routine.

### Daytime rests/naps

- Different types of rest: Most rest doesn't involve sleeping and can include sitting quietly or zoning out whilst listening to restful music or a relaxation CD. If possible, this should not happen in your bedroom.
- If you really need a sleep, make sure it is less than 30 minutes, before 3pm and in a light room with the curtains open. This is to stop you going into deep sleep, as this could damage your nighttime sleep.

### Sleep Hygiene

- Sleep routine/wind-down - This helps your brain get ready for sleep by giving it lots of signals to go to sleep.
  - E.g. warm bath, warm drink (milk is helpful, but not hot chocolate as it is a stimulant).
  - Don't do things just before bed that send confusing signals and stimulate your brain, such as TV, computer games and certain books (e.g. scary ones).
  - Try to do the same thing every evening – your brain will learn to start getting ready to sleep.
  - Some people find lavender oil helps, or listening to gentle music.
  - Avoid anything with caffeine in the afternoon – caffeine is a stimulant and is found in coffee, tea and soft drinks such as Coca Cola, Red Bull, Pepsi and in chocolate.
- What if I can't get to sleep? Wait 20 minutes and then get up, go out of the bedroom and perhaps get yourself a drink. Avoid tossing and turning. When you do this you may need to repeat it a few times but after a few days you should find yourself getting off to sleep easier. You could also try some relaxation exercises (see later section on this).

This advice is summarized in the Sleep and Relaxation Leaflet

[https://www.ruh.nhs.uk/patients/services/clinical\\_depts/paediatric\\_cfs\\_me/documents/P\\_CFS004\\_Sleep\\_Relaxation.pdf](https://www.ruh.nhs.uk/patients/services/clinical_depts/paediatric_cfs_me/documents/P_CFS004_Sleep_Relaxation.pdf)

## ACTIVITY MANAGEMENT

Activity Management is, as a standalone intervention, another of the three NICE recommended treatments for CFS/ME (the third being Graded Exercise Therapy (GET) which will not be covered in this manual). Activity Management is also encompassed within CBT for CFS/ME – most notably the regulation, monitoring and steady increase of activity levels.

Activity management fundamentally recognizes that the activity levels and patterns of a young person with CFS/ME are important to address. How much activity a young person does, and how it is spread out across the day or week, can have a direct and significant impact on their symptoms of fatigue. Typically, before starting treatment a young person will report highly dysregulated activity levels with great variation in what they do from day-to-day.

### The boom and bust cycle

A known perpetuating factor in CFS/ME is the so-called ‘boom-bust’ cycle. This is where a young person with CFS/ME will push themselves to do as much as they can on a ‘good day’ or when they perceive themselves to have more energy. They might even be able to sustain this high ‘boom’ level of activity for a little while e.g. a few days or more. However, typically the total amount of activity is higher than they can actually continue to sustain and so it leads to a flare (or worsening) in symptoms and a crash (or ‘bust’) in activity levels. For example, a young person may push themselves to be at school for the whole day on Monday and Tuesday but then experiences significant, increased fatigue and be unable to get into school for the rest of the week. Or this pattern may play out over longer timeframes, e.g. getting through the whole school week but then ‘crashing’ at the weekends, or even managing a half-term but then having a big flare up in symptoms during the holidays.

We know that neither extreme here (the ‘boom’ nor the ‘bust’ levels of activity) are good for a young person with CFS/ME and indeed see-sawing between these two states can keep the fatigue going. Therefore, an important first step in Activity Management is to establish an appropriate ‘baseline’ for the young person. This means an amount of activity that they can sustain comfortably every single day and one which does not lead to a worsening of their symptoms of fatigue.

## Categorising activities

The activity baseline is calculated by using activity diaries to first monitor and categorise activities. An example of the diary used can be seen at [https://www.ruh.nhs.uk/patients/services/clinical\\_depts/paediatric\\_cfs\\_me/documents/CSActivityRestSleepdiary.pdf](https://www.ruh.nhs.uk/patients/services/clinical_depts/paediatric_cfs_me/documents/CSActivityRestSleepdiary.pdf) and the supporting information leaflet at [https://www.ruh.nhs.uk/patients/services/clinical\\_depts/paediatric\\_cfs\\_me/documents/CSEnergyManagement.pdf](https://www.ruh.nhs.uk/patients/services/clinical_depts/paediatric_cfs_me/documents/CSEnergyManagement.pdf).

When completing the diaries, young people can use a colour-code to capture the different activities they complete. Activities are categorized into colours according to their level of intensity or demand as follows:

- The most demanding (or fatiguing) activities are coloured as **red**. These high energy 'red' activities can be one of three things; cognitive activity (e.g. school work, computer use, reading, watching TV), physical activity (e.g. walking, cycling, participating in P.E), or emotional (high energy laughter and fun, or also times of particular anxiety or interpersonal conflict). 'Red' activities are by no means bad, but are those which take the most energy from young people and are those activities which they self-report they cannot do for very long, compared to some less-demanding activities.
- The next level of activity (which could be seen as moderate) is coloured as **yellow**. These lower-level 'yellow' activities are times when the young person is still engaged in doing something, but not so demanding as the 'red' counterparts. For example, the young person might be playing in a relaxed way with a pet, flicking through a magazine, doing bits of food preparation or craft activity, or watching something they have seen before. To the onlooker the young person is engaged in an activity, but it is not one which requires so much cognitive concentration or physical or emotional energy.
- The next level of activity (low) is coded as **green**. This really denotes the absence of active activity. 'Green' time is real relaxation or 'chill out' time. It can include lying down peacefully (as one would before falling asleep at night and on waking in the morning), or perhaps following simple relaxation, meditation or breathing exercises. For some it could be having bath or listening to relaxing music. It is a calm and quiet state with no interaction with others and no real demands being placed on the young person. Needless to say it is not something that is seen a great deal in the diaries of young people, when often there is a natural preference for more active (and interactive) states of being.

Sleep is also important to record on the diaries and this is coloured as **blue**.

It is important to note that what is categorized into each kind of activity is individual and may change at different points of the illness. For example, at the worst point of CFS/ME, a young person might find getting dressed or combing their hair to be highly demanding of

energy, and would categorize this as 'red' activity. However, as they begin to recover, this may become less demanding and may then be 'yellow' or even 'green'.

### Calculating the Activity baseline

After 1 to 2 weeks of tracking activity levels through completing activity diaries (or using an app), the baseline can be calculated. The baseline is typically the median time spent doing 'red' (high energy) activities each day, when looking at the variation across a couple of weeks. This baseline (for example it could be 4 hours' 'red' activities per day) then becomes an aim for the young person; they are asked to now aim for this amount of activity each day, without falling below it on 'bad' days nor exceeding it on 'good days'. The young person will be asked to maintain this level typically for 2 weeks until the next appointment, and to continue using the diaries to track and record this. Guidance is given on how to spread out the baseline amount across the day and it is typically recommended that school activity is no more than half of the baseline (therefore in this example school or school-work would not exceed 2 hours per day).

Recording activity at home in between appointments is important in helping young people to notice their patterns of activity and to understand whether they are doing the same each day or varying their activity. It also helps with gauging whether the baseline has been set at the correct level. Occasionally it can need some tweaking in the early stages of activity management.

### Increasing the activity baseline

When a young person has managed to sustain the baseline level of activity consistently for 2 weeks, they can then be instructed to increase this by 10-20% every week or two. Therefore, using the above example, a baseline of 4 hours' 'red' activity would then increase to something in the region of 4 ½ - 5 hours.

The aim is to continue gradually increasing the baseline activity level in this step-wise fashion until the young person can comfortably manage at least 8 hours' high energy activity per day. At this point the young person will be working towards full-time school attendance again and will have enough in their allowance to begin reinstating other activities outside of school. Importantly, at this point the young person will also be skilled in the process of monitoring and regulating their activity levels and so the need for this close monitoring within therapy sessions becomes less great.

Throughout the process therapists will discuss problems encountered by participants and provide possible solutions. Managing setbacks is also discussed (for example, how much to reduce school and other activities by, in the context of a worsening in symptoms, and for how long).



## Activity Scheduling – valued activities

Activity management entails a close focus on the key, repeated activities within the young person's daily life and weekly pattern. Invariably, school is a big focus both in terms of time spent but also importance and value attributed to it. Therefore school, and everything related to attending school whilst recovering from CFS/ME, is an important topic to be covered within sessions. We have written a separate section with information pertaining specifically to school.

However, it is important to remember that other activities outside of school are relevant and very important in the recovery journey for a young person with CFS/ME. Some will have given up previous hobbies due to their poor health or reduced energy levels, and others may have fallen out of love with a previous interest due to now doubting their own abilities or competence. When discussing treatment goals, it is helpful to explore which activities a young person would like to (re)instate as they re-gain strength and energy during their recovery journey.

For many young people with CFS/ME, recovery is not about a 'going back' to who they used to be, but a 'going forwards' to a new version of themselves whom has been through what is often reported as an enriching and developing experience, and who has progressed developmentally too. Young people will commonly report struggles in the journey, of course, but also a sense that through it they have learnt a great deal about themselves and what they can cope with, or what is important to them. They often report a sense of becoming a new person after illness.

In this way it is important to explore valued activities for the young person and to consider how they can build these into their day and week. As well as exploration of the activities in question, therapy can helpfully support the young person in considering how they can best manage their time. CBT for CFS/ME often addresses the need for achieving balance between times of productivity and times of rest; 'allowing' themselves time to 'switch off' and enjoy the simple things – whatever that may mean for them. It is not about being at full capacity all the time.

## De-Regulating

Activity management requires close monitoring of activity levels and patterns. As treatment progresses and the young person can increase their total activity level, regularity is still encouraged, including regular sleeping patterns and consistent activity levels across the week. A key process which comes later in activity management (and is important too in the recovery journey) is what we call deregulating. This is about supporting the young person to move away from the strict regularity they have been keeping and indeed to deliberately bring more 'natural' variation back again. For example in terms of sleep, this could mean a young person returning to having an occasional

sleepover with their friends which would no doubt entail a later and/or shorter nights' sleep, but also is an event which only happens from time-to-time. Therefore, the natural, occasional variation is reintroduced to the pattern of the week or month.

Deregulating is important for many reasons:

1. It may be part of the young person reaching some of their goals for example attending sleepovers or participating in infrequent events such as the school sports' day or attending a big family celebration.
2. It can be a visible marker of having come a long way and achieving particular milestones.
3. It builds confidence in being more flexible with timings and patterns; helping them to see that their body can again now cope with variation and that it is not damaging. Confidence is hugely significant when it comes to reinstating activities and returning to previous or new, higher, activity levels in the CFS/ME recovery journey.

Starting the process of deregulating with the support of the therapist helps the young person to move out of the therapy or treatment mode or towards a sense of 'normal life'. This can also help the young person to feel confident in working towards ending sessions and continuing life beyond therapy.

### **Activity management with younger CFS/ME patients**

Activity management with younger children is invariably more challenging than working with older children or adolescents. CBT for CFS/ME overall is a demanding treatment process and requires a reasonable level of emotional literacy, understanding and recognition of symptoms and experiences, planning ahead, and the cognitive abilities to communicate these things in treatment. It also requires other key abilities driven by cognitive development including self-monitoring, self-regulation and inhibitory control. It is hard for a young child to keep in mind their activity schedule and to stop an activity early, particularly when they are having fun and their peers can continue taking part.

Therefore, CBT for CFS/ME with younger children needs to bring in extra support, in order for these young patients to benefit as much as possible. Typically, this means a greater level of parental involvement and that of other key adults including teachers. The system around the child must take more ownership for leading and supporting the treatment process. Therapists must therefore work carefully with these adults and support networks, and regular joint review meetings can be particularly helpful. As well as shared communication, another key aim of working together is to keep the child and their voice at the centre of the process.

When completing activity management with younger children, creative and visual methods work well. Pictures can be used to represent activities, when showing a child the difference between high- and low-energy activities. In terms of using activity diaries, a few simple changes can be made. When appropriate, parents can complete the diaries on the young person's behalf, to the best accuracy possible. It can also really help to employ more creative methods. Coloured cards, balls, bracelets or marbles can be used to represent the child's available activity baseline. The child can be encouraged to 'trade in' an item with a parent each time they complete a high energy activity, helping them to visually track their allowance. Timers can also be a helpful tool for tracking time limits on activities. Rest breaks can be planned into the child's day in advance, to make them more likely to happen.

Generally, visual tools work best for younger children and so therapists should be creative in producing these with the young person. Perhaps the child has a name for their fatigue or imagines it as a monster or a being with a certain shape. The therapist can support the child in using their own terminology or imagery to track and communicate their experiences of fatigue. Narrative methods, such as comic book ideas, can also be drawn on to capture the young person's experiences. These sorts of tools can then be helpfully shared with others including school staff, so they too can encourage communication with the child about their fatigue and activity levels.

A secondary advantage of these creative approaches is to build some sense of ownership of treatment for the young person at the centre. It can be too easy for CBT for CFS/ME with young children to fall into another set of 'rules' planned by adults (parents, teachers, doctors etc) that the child must follow. This perceived dynamic can be really hard for the young person who then might well want to rebel against the process and reject what is being suggested or asked of them. It can be hard for parents too, who feel like 'the bad guy' and may struggle to follow the treatment recommendations closely due to not wanting to upset their young child. This will likely affect engagement in treatment and ultimately can jeopardise the process of recovery. It is important therefore, particularly for primary school aged children, to have some age-appropriate level of involvement in their treatment, at every stage possible.

## COGNITIVE WORK: THOUGHTS THAT ARE UNHELPFUL

It is common, and completely understandable, for young people to have difficult thoughts about their illness, their situation, or even their chances of making things better. CFS/ME is a challenging illness in that it often brings about change in many areas of life, such as reduced time in school, less contact with friends, loss of hobby or extra-curricular activities due to reduced energy, amongst others. CBT can help here in supporting the young person to become more familiar with their thinking patterns.

Unhelpful thoughts are often negative, exaggerated or distorted, to the exclusion of other positive information, and sometimes 'all or nothing' in totality. Perhaps the young person has some recurring, negative thoughts about certain topics which make it really hard for them to work towards their goals. Perhaps there are certain things they particularly worry about, such as going back to school. Whilst these negative thoughts may be grounded in truth, they are often distorted and useful counter-evidence may be overlooked.

Common unhelpful themes in the thoughts of a young person with CFS/ME may include:

- A focus on symptoms or even looking out for them when they are not present
- Negative interpretation of symptoms, either predicting worsened fatigue and/or 'blaming' activity for the presence of symptoms
- Negative view of the self or one's ability to cope
- Negative predictions about upcoming events or perceived challenges
- A belief of needing to keep struggles to oneself rather than 'burden' others
- A wish to present oneself as 'coping' and to conceal true thoughts or feelings
- High pressure or standards for oneself

To illustrate these are some examples of specific unhelpful thoughts that a young person with CFS/ME may present in therapy:

- "It's my fault I'm ill"
- "No-one understands me, there's no point talking about it"
- "When will I have another flare?"
- "I'm a burden on my family"
- "Maybe I can just hide it and pretend it's all ok"
- "I've got to do the best I can at school; it's all I've got"
- "If I don't do my best, people will think I'm a failure"
- "I'm no good at anything anymore"
- "Everyone else can cope fine – why can't I?"
- "People are talking about me all of the time"
- "If people see me out during the school day they'll judge me for not being in school"
- "I won't be able to cope with my exams because of my fatigue"

Key cognitive tasks therefore include helping the young person to recognize unhelpful thoughts and negative thinking patterns, to notice the effects of these thoughts, and ultimately to learn more helpful ways of thinking.

Some examples of common, helpful cognitive strategies can be found in the below:

- Paul Stallard's 'Think Good Feel Good' books
- <https://www.psychologytools.com/resource/unhelpful-thinking-styles/>
- <https://www.psychologytools.com/resource/prompts-for-challenging-negative-thinking/>
- <https://www.psychologytools.com/resource/simple-thought-challenging-record/>

### More helpful ways of thinking

Once the unhelpful thoughts and themes have been identified, the young person and therapist together can then use common CBT cognitive strategies for exploring and evaluating these thoughts. The following techniques and themes are particularly helpful:

#### *Evidence for and against*

This is a central cognitive strategy for working on negative thoughts in CBT for CFS/ME. The main idea is to identify negative thoughts, consider how valid these are, and to come up with more realistic or helpful alternatives.

The young person may hold a strong, negative belief about what could happen in a pending situation. For example they may believe that on returning to school, "I will be so exhausted that I won't be able to cope and everyone will notice and comment". There are various metaphors which can be used to guide the young person through considering the evidence for and against their thought. For example, the court case metaphor: The therapist here guides the young person to act like a judge in court; to consider evidence for and against the thought, and to come to a conclusion.

In this example, evidence *for* the thought could include "my fatigue is always worse at school" or "people have commented before" and evidence *against* could include "I'm much better now than I was before" and "my friends are really supportive and wouldn't say anything mean". After considering this sort of 'evidence', (many more pieces of 'evidence' are normally encouraged) the young person is then supported to generate a more realistic or rational alternative to the original thought. In this example, the young person may postulate: "I'm much better than I was before and I will be fine. Even if I do feel tired I can have a break and my friends will be supportive."

### *Positive evidence: positive self-talk, self-compassion, and positive data logs*

In the face of often negative or distorted thoughts, positive self-talk can be a powerful cognitive strategy for supporting behavioural change, increasing confidence and self-efficacy, and lifting mood. A young person completing CBT for CFS/ME can be encouraged to notice and collate positive 'evidence' of their achievements and capabilities, and to use this as an encouraging reminder in challenging times. For example, a young person who is feeling particularly anxious could remind themselves of recent achievements which they might not have previously thought possible, back when their fatigue was at its worst. The therapist can encourage the creation of a positive data log for capturing this important information. This can also help to boost self-efficacy.

It is particularly important for the young person to be kind to themselves and encourage themselves forwards, rather than the (somewhat common) pattern of easily noticing 'failure' or struggles. When struggling with difficult thoughts and feelings it is too easy for the brain to generate unkind thoughts or focus. Self-kindness and self-compassion can be helpfully explored and encouraged within sessions. It is often a somewhat challenging (and unfamiliar) practice for young people, and so must be explored with sensitivity. Young people with CFS/ME can be encouraged to notice the positives and at the same time acknowledge that they are in a tough situation but are working hard to try and make things better. It is not about being overly positive or dismissive of struggles, but about being kind to themselves.

Another helpful form of positive self-talk is to shift to an approach of focusing on what *has* been achieved, as opposed to what *hasn't*. This could be in many areas that inherently include gradual progress, for example with shifting sleep patterns, amount of schoolwork or revision completed so far, or progress towards therapeutic goals. Focusing on, and appreciating, progress made so far is a much better incentive for further therapeutic progress compared to allowing the mind to focus on what is yet to be done. Staring at a long 'to-do list' is daunting and can halt therapeutic progress. The young person can helpfully be encouraged to remind themselves of their progress.

### *Positive/coping imagery*

Alongside the more verbal strategies for managing unhelpful thoughts can be the successful use of imagery. Imagery is a powerful method for connecting with emotion and soothing difficult feelings. Positive or coping imagery could include use of imagining a favourite or safe place, to boost positive feelings. The young person can transport themselves mentally, no matter where they are, and use the image for comfort and encouragement. Or perhaps imagining success ahead of time, for example the young person can picture themselves standing up and giving their presentation at school, successfully, in a similar way to use of imagined rehearsal.

## *Surveys*

This technique can be particularly helpful when a young person has thoughts about how others may think or behave, or indeed makes predictions about others' experiences. These predictions typically compare the young person with CFS/ME negatively, relative to their peers. In addition to using some of the strategies above, surveys can be used to actively challenge and 'test out' a young person's cognitions.

The young person and therapist together will generate a survey to ask others' opinions on the most pertinent questions to be explored. The survey is then given out (typically to the young person's peers, although this can vary) and the collected responses are explored in therapy and discussed, often bringing unexpected information or new perspectives for the young person. There is great therapeutic value in seeking and becoming aware of others' perspectives, particularly in relation to things like anxiety. Surveys conducted with peers can often be really effective in helping to shift a young person's cognitions; there is something powerful about seeking information from a peer group that is also a neutral third-party, outside of the therapy room.

## *Behavioural experiments*

Behavioural 'experiments' are a way of setting out to test a theory or hypothesis, through a scientific approach. The idea is to choose a particular thought or cognition of the young person's, which is predictive in nature, and to test it out with curiosity. This can be a highly effective in bringing about cognitive change as the young person is encouraged to pose a question and to then go and find out the answer. They play an active role in seeking out the new information, which has inherently a slightly different feel to the more 'purely' cognitive discussions held with the therapist in some other cognitive techniques.

An experiment is carefully designed between the young person and therapist to test a measurable and specific prediction. The currently held expectations are laid out, and the method of testing them is planned. The young person is encouraged to attend to, and record, what *actually* happens in the experimental situation. This information is then discussed back together with the therapist and is used to consider whether it supported, or disproved/disputed the original prediction. In a similar way to surveys, gathering new information in this way helps to weaken previously held negative predictions and to build a bank of new, perhaps more rational information.

## *Mindfulness*

Mindfulness can be described as a 'third-wave' psychological or therapeutic approach which some might see as a stand-alone therapy or others might place within part of wider therapies, cultural practices, or religions. It is something that has grown hugely in understanding and popularity in recent times. In referring to mindfulness here we are

thinking simply about the basic idea of helping the young person moving from a 'doing' mode to a 'being' mode.

Being 'mindful' is about allowing the mind to focus fully on what the person is currently experiencing, in a helpful way. Allowing the young person to focus just on what they are doing in that moment; not other things that they may need to do soon, or other things they may be worrying about. Nor focusing on symptoms or predicting how the day may go e.g. based on how their night's sleep was. But just to focus on the specific task or experience at that time.

It is about focusing on the present moment (often to the exclusion of other thoughts or worries attached to other time-points) and engaging in the present, fully. This can also help with breaking tasks into steps. For example, if a young person is worried about going into school, perhaps they can first focus on having breakfast mindfully – focus on what it tastes like! Then focus on brushing their hair and getting dressed. Then focus on the music that's playing in the car on the way to school; and so on, moving through the morning routine. Before they know it, the young person is at school and can become immersed in the rhythm of the day without feeling worried about it.

There are many examples available of 'mindful' activities. Here are some initial ones for familiarization:

- Finding ways to:
  - o notice thoughts and to see these as thoughts, not facts
  - o sit with strong emotions instead of responding automatically to them
- e.g. Leaves on a stream - <https://www.mindfulnessmuse.com/wp-content/uploads/2011/09/Cognitive-Defusion-Exercise-1.pdf>
- e.g. for younger children:
  - o Mindful posing as superman/wonderwoman.
  - o Spidey-senses – tune in to smell, sight, hearing, taste and touch (like spiderman)
  - o Mindful safari – an everyday walk is becomes a safari – spot birds, bugs, animals – focus all their senses on finding them.
- Further information and examples can be found at [www.getselfhelp.co.uk/mindfulness](http://www.getselfhelp.co.uk/mindfulness).



## MANAGING FEELINGS

The behavioural and cognitive elements of CBT for CFS/ME discussed so far aim ultimately to improve how the young person feels, in a holistic sense. Therefore these strands of treatment, whilst not focusing directly on managing emotions, can lead to an improvement in emotional distress. However these strategies can take time, over several sessions. Therefore it is also important within CBT for CFS/ME to explicitly focus on direct strategies for managing difficult feelings in the moment. Accessible, simple methods for managing feelings when they arise are highly valuable in this work.

As with many elements of CBT, it is common for the young person to want to jump to the 'how to do it' part of the process, whereas the therapist must first carefully support an exploration of the 'why do we need to do it?' and also establishing 'what do we need to do?'.

### The foundations: Emotional literacy and emotional regulation

The first step in learning to manage emotions is a check-in of the young person's emotional literacy. How familiar are they with identifying emotions? Do they notice when experiencing different feelings? Can they use words to describe them? These steps, which may seem simple at first glance, can in fact be new and challenging for some young people, especially those who are younger or for developmental (or other) reasons are less well-versed in emotional literacy. Helpful prompts can be used to assess and establish emotional literacy, including use of pictures and pairing typical bodily sensations (e.g. shakiness, tummy pain etc) to common emotions.

As well as assessing emotional literacy, preparatory work for building strategies in emotional regulation also entails a fair bit of psychoeducation. It can be helpful to explain the role of physiological symptoms within emotions, and how they interrelate. For example, the 'fight or flight' response, which underpins many body-emotion links including (but not limited to) those within anxiety or panic. If the young person can understand why they feel certain physical symptoms, they can make better sense of then applying the strategies below for controlling the symptoms.

A lot of these strategies have been developed into mobile phone 'apps' and other audio versions. These can be greatly helpful in therapy for introducing the methods and making them even more accessible for young people, particularly for practicing them further at home. Some great examples can be found on the apps Mindshift, SAM, and Chill Panda, amongst others.

## Calm Breathing

The breath is a hugely powerful entity. It is a fundamental yet completely accessible part of how our bodies work and is closely connected with both the mind and body. Various emotional states can lead to changes in breathing patterns and it is a fantastically simple but effective strategy therefore to learn how to control or alter the breath.

One example (and there are many to choose from) is a simple controlled breathing exercise. The basic idea is to bring focus on the breathing. This can be done anywhere and a great advantage is that onlookers won't even notice what you are doing. When using this method, the young person learns to slowly draw in a deep breath, hold it for 5 seconds and then very slowly let it out. As you breathe, they can also say to themselves "Relax!" Doing this a few times will help the young person to feel calmer.

A similar idea is called square breathing where, in a similar way to the above, the young person is encouraged to focus on their breathing. This time they hold the image of a square in their mind. When taking the in-breath, the young person can imagine going up the left-hand vertical side of the square. They then hold their breath for a moment, imagining moving along the horizontal. The out-breath goes with the image of descending the right-hand vertical side and holding the breath travels back along the bottom horizontal side of the square.

The aim in both of these methods is to bring focus to the breath, indirectly also likely slowing it down and simultaneously moving focus away from other, less helpful things such as negative thoughts or physical feelings of anxiety. It is very hard for the mind and body to feel both anxious/agitated and calm at the same time.

## Relaxing place imagery

As mentioned briefly earlier, imagery can be a powerful and effective method for bringing change in how people feel in the moment. It can be applied to feelings of anxiety, fear, low mood, and many others. In CBT for CFS/ME, imagery can be used to help manage physical feelings of the illness (e.g. fatigue itself, or pain, amongst others) as well as emotional experiences such as frustration or anxiety.

The young person can be prompted with a script, for example: "Think about a special place that you find restful. Think about your dream place. It could be somewhere you have been, or a pretend place. Imagine a picture of it and make the picture as real as you can. Think about: the noise of the waves crashing on the beach or the sound of the wind blowing in the trees, or the smell of the sea or the scent of pine forests, or perhaps the warm sun shining on your face or the wind blowing in your hair." As with the other strategies above, the use of imagery here aims to shift the young person's physical and emotional experiences in the moment from that of discomfort or suffering to a more comfortable and calm place.

## Muscle Relaxation

Building on the physiological links between the mind and body as discussed above under 'calm breathing', physical relaxation methods are used to explicitly relax the muscles of the body itself. This can be highly effective and helpful for managing both physical discomfort and emotional difficulty. The aim of physical relaxation methods such as progressive muscle relaxation exercises, is to bring a new focus to the physical experience in the moment and thereby bring improvement or change in emotions. An example simple script to use with a young person could be: "When we are tense or worried, our muscles become tight. Practice tensing and relaxing different groups of muscles. Enjoy the feeling of being completely relaxed." Again, many Apps have accessible audios for progressive muscle relaxation exercises and young people with CFS/ME can be encouraged to try these exercises within their daily routine such as before going to bed.

## Grounding Techniques

Grounding techniques are a set of strategies for helping the young person to reconnect with their immediate surroundings. This is used across many different psychological disciplines and for many different difficulties, including dissociation, trauma and flashbacks. In CBT for CFS/ME, grounding techniques can be particularly helpful for enabling the young person to reconnect with their immediate, physical surroundings; to the exclusion of focusing on symptoms of fatigue, or on thoughts or worries stemming from their fatigue. It is in some ways similar to mindfulness, but doesn't require the young person to be *doing* anything, rather just bringing a focus to their physical *being*. The aim is that this present, physical focus allows a sense of comfort and security.

One example of a beautifully simple yet effective grounding technique is to use 5-4-3-2-1:

- Encourage the young person to tune into their senses, and notice:
  - 5 things you can see
  - 4 things you can touch around you
  - 3 things you can hear
  - 2 things you can smell
  - 1 thing you can taste

## School and CFS/ME

School is such a big part of life for children and young people. School is discussed at every stage of CBT for CFS/ME as it is a hugely relevant and important part of the picture. It is therefore important for healthcare professionals and education providers to ensure good communication between themselves, with families' consent, in order to best support the needs of the young person with CFS/ME as they work through treatment. Regular reviews and joint meetings can be particularly helpful.

This section aims to outline some of the key considerations about school, when working with young people who have CFS/ME.

### Activity Management and time in school

School time must be calculated within the activity management element of treatment. Typically, when young people with CFS/ME are engaged in treatment they will be encouraged to reduce their school attendance and begin some form of reduced timetable plan if they have not already done so. This is part of the wider process (discussed earlier) of moving from a boom-bust pattern of activity to a more sustained, manageable one. For example, attending school every day just for 2 hours is better than attending for the full day on Monday and Tuesday, and then needing the rest of the week off due to increased fatigue. Once the young person can manage the new reduced timetable consistently, it is reviewed and gradually increased (in line with overall, gradual increases in activity level), working back towards full-time attendance.

School time (meaning time in school, any school work completed at home through home tuition or other means, and also homework or revision) should equate to no more than roughly half of the young person's activity baseline. This is particularly important when the young person is earlier on in treatment and/or has a relatively low baseline. For example, a young person with a baseline of 4 hours' high energy activity per day should do no more than 2 hours per day of school-related activity. This is important in ensuring there is enough high energy activity time left for other activities outside of school.

### Supporting a young person with CFS/ME in school

Clinicians working with young people with CFS/ME can make recommendations for teachers and school staff. It is often helpful to discuss these with school staff in order to boost a collaborative approach between services and to address any queries.

- Rest breaks
  - Rest breaks away from the classroom and learning can be effective; something like 10 minutes per school hour tends to be enough.
  - Ideally these regular rest breaks are away from the classroom environment and in a quiet place.

- It can be particularly helpful for younger children if these are scheduled into the daily timetable.
- 'Time out' (or 'medical') cards – These can be used to enable older pupils to indicate to teachers those times when they feel they need a break, and to access it without having to draw particular attention during the lesson.
- Concentration
  - Concentration is often impaired for young people with CFS/ME and it can be helpful to work in chunks of no more than 30-45 minutes; severely affected students may only be able to sustain concentration for 15 – 20 minutes.
  - Students often have increased sensitivity to everyday sounds and are likely to be more easily distracted in the classroom environment.
  - Students may experience 'brain fog' i.e. difficulty processing information – it can be helpful to provide written instructions and memory aids.
- Exams
  - Young people with CFS/ME benefit from being allowed to sit exams in a room on their own, or with few other students.
  - They should be allowed to get up and move around for timed rest breaks.
  - We would also advise that they are allowed 25% extra time in exams.
  - Some young people also benefit from access to a laptop, a scribe, or a reader in exams depending on their needs.

Further related guidance can be found at the following websites:

[https://www.ruh.nhs.uk/patients/services/clinical\\_depts/paediatric\\_cfs\\_me/documents/P\\_CFS011\\_Info\\_for\\_Schools\\_and\\_Colleges.pdf](https://www.ruh.nhs.uk/patients/services/clinical_depts/paediatric_cfs_me/documents/P_CFS011_Info_for_Schools_and_Colleges.pdf)

[https://www.ruh.nhs.uk/patients/services/clinical\\_depts/paediatric\\_cfs\\_me/documents/P\\_CFS019\\_Learning\\_Challenges.pdf](https://www.ruh.nhs.uk/patients/services/clinical_depts/paediatric_cfs_me/documents/P_CFS019_Learning_Challenges.pdf)

<https://www.wellatschool.org/chronic-fatigue-syndrome>

### Extra support available

Some young people may need a greater, more individualized level of support in school due to their CFS/ME and associated health needs. There are various assessments and support plans which can be completed for a young person, particularly if their needs are more complex. These can include Individual Healthcare Plans (IHP) or an Education and HealthCare Plan (EHCP), amongst others. Schools are the best placed to apply for such assessments and plans, given their familiarization with both the young person and also the

remit of the different forms of support. Healthcare professionals can play a role in providing supporting information from the clinical side, when requested by schools or families, as well as signposting families to helpful information sources.

The following websites provide a good starting point for further information:

<https://www.wellatschool.org/resources>

<http://medicalconditionsatschool.org.uk/>

### When a child cannot attend school

If a young person struggles to attend school due to the extent of their CFS/ME and its associated challenges (e.g. severity of other CFS/ME symptoms, or associated anxiety, amongst others), it is appropriate to consider alternative methods of accessing their education. A common alternative is to work with the local Hospital Education and Reintegration Service (or similarly named service). These services offer home tuition, online education options, and sometimes the option to attend schooling at a smaller, specialist unit often called a Hospital School. The exact provision available of course varies between counties and depends on what the service has available at that time, as well as what is deemed most appropriate for the educational needs of the young person in question.

The young person's mainstream school can refer pupils to the appropriate local alternative education provider, and are highly experienced in doing so. Medical teams and CFS/ME clinicians can often help the process by writing a letter of support to accompany the school's referral, or sometimes completing the referral form direct. Medical and healthcare professionals can also help to inform the process by giving approximate recommendations for example of how much schooling the young person can currently manage, based on their activity levels and current health.

### The social side of CFS/ME and school attendance

Young people with the illness can feel different from their peers; socially isolated, left out, and can struggle with the sense of peers not understanding their situation. Patients in our clinic often recount unthinking comments from friends, generally made with good intentions, but often with damaging emotional impact. For example "you're so lucky you get to go home early", or "I get tired too", or "I wish *I* didn't have to do homework". Young people with CFS/ME have to navigate these such social-emotional challenges within school, on top of their fatigue management. It can be hard work. Some young people may think about ways of helpfully sharing information about CFS/ME with their friends, class or even year group, in order to boost understanding of the illness.

Attending school on a reduced timetable clearly has the potential for social consequences for children and young people with CFS/ME. It is already hard to feel different from peers, and potentially to feel 'left out' due to not being able to do as much as them. But the very practical reality of not having as much time with friends in school can be really hard.

For this reason, it is important to ensure that children and young people who are on a reduced timetable of some sort can keep some contact with their friends. For example, if in school for 2 hours per day, this could include a lesson and some non-lesson time such as break, lunch or tutor time. Attending school isn't just about the educational aspects and so, ideally, a reduced plan should try to include as many of the elements held within a fuller school day as is possible.

Unfortunately, it can be the case that CFS/ME can disrupt school attendance for anything between 6 months and a few years. As we know from epidemiological research there is a peak in CFS/ME prevalence within adolescence – an already complex developmental period. It is possible to suggest that less time in school during childhood and/or adolescence can have an impact on the development of social skills and related areas including problem-solving skills, self-confidence, and assertiveness, amongst others.

Another important consideration to keep in mind are the key transition stages held within the school years including moving from primary to secondary school, the major exam years, and other key points such as end of year performances, school trips, competitions, or formal events. The impact of missing such events can be hard emotionally for children and young people with CFS/ME. Thought should always be given to how at least some participation can be kept.

### **The emotional side: school-related anxiety or stress**

Children and young people with CFS/ME can experience increased anxiety; notably this tends to be increased separation anxiety in younger children and both social anxiety and generalised anxiety in adolescents. After a prolonged absence, returning to school can be anxiety provoking. Therefore, it is important for education and healthcare teams to keep an awareness of the young person's emotional state and to consider how best to support and alleviate anxiety where possible. CBT for CFS/ME can offer a great deal for managing anxiety within the illness; this will be covered in more detail in a later section.

Stress is another important consideration. For a young person who has had to reduce their school-time, perhaps give up hobbies and cut down on things they used to enjoy, school can suddenly seem a much bigger focus. Particularly as re-building time in school is often a key goal for CBT treatment. It becomes a tangible measure of progress and young people with CFS/ME can all too easily feel pressure (often internally driven) to therefore do their best. School might move from being an ordinary part of life pre-illness to a very central focus during illness where very high standards 'must' be achieved. This can play out

during key times of stress such as exams, but can also underpin general and ongoing worries. It is helpful to explore these issues within CBT for CFS/ME.

### Supporting younger children with CFS/ME in school

CFS/ME is less common (in terms of diagnosis rates) in children under the age of 12. However, we know that those younger children with CFS/ME require greater differentiation and support within school due to their age and earlier stage of development in key areas including emotional literacy. A young child with CFS/ME is likely to need a great deal more help in the school environment to manage their physical, practical and emotional needs in relation to CFS/ME, compared to an older child.

Young children will often struggle particularly with regulating their activity levels. They are more likely to be driven by impulse and desire, and to overlook what they are being asked to do within CBT for CFS/ME. For example, a young child will find it hard not to run around at break time with friends, or to remember to take rest breaks during the day. Younger children may well be less aware of when they are running out of energy and may push themselves beyond what they can comfortably manage. It can be helpful therefore for members of staff to prompt and remind the child about their individualized plan. For this to be successful, meetings between CFS/ME healthcare professionals, the family, and school staff are essential and should be regular. Ideally a child would have a clear personalized timetable for the day which includes pre-determined rest breaks and any other needs identified by the team. Times of potential high-energy activity (P.E., break and lunch for example) should be carefully thought through in advance.

In addition, younger children with CFS/ME are more likely to struggle with anxiety, as well as their understanding and communication of it being more naïve. It can be helpful for those supporting the child to use age-appropriate supports and prompts for talking about emotion and opening up these conversations. Some of the best tools are the simplest, such as a traffic light system of coloured cards, for the child to indicate whether they are feeling fine, slightly unsure, or when something is wrong.



## What can get in the way of making changes?

Although making behavioural changes to sleep and activity might appear simple, these can often be very difficult in practice. This can be for a number of reasons:

- When the young person may have been in their current patterns for a long time. Habits are hard to break, and perhaps too they could feel fearful of moving away from what they have become used to. Or perhaps the young person may have tried to change their patterns unsuccessfully before starting CBT and therefore they have reservations about making change now.
- Systemic factors can make change more challenging for the young person. For example, in some families a relative or friend may have had CFS/ME and this can bring prior experience or expectations of what the journey may be for the young person now in question. Clearly in some cases this could be helpful. But for others, and particularly when those prior experiences have been hard, this could bring unhelpful thoughts or beliefs for example about what the young person's own recovery journey may be.
- Practical barriers can get in the way. For example, a reduced timetable plan at school can only really work if the family is able to accommodate the different drop-off and pick up times, alongside other childcare commitments and parental working hours. Or perhaps the family work patterns include night-shifts and it is hard therefore to have the same systemic teamwork in supporting the child's sleep-wake plans, as the parent and child may not have the same amount of time available together during the day.

As can be seen, there can be many reasons why young people can find treatment challenging and it is important firstly to normalize and acknowledge this with them. CBT for CFS/ME is a demanding treatment which asks a lot of the patients, including making several changes in different areas of their lives. Motivational interviewing and problem-solving can help to identify and overcome these barriers.

## MOTIVATIONAL INTERVIEWING

Motivational interviewing is a helpful strategy for improving engagement in, and adherence to, treatment. This approach recognizes that as humans we can struggle to get 'on board' with something. We might have a sense of procrastinating, or avoidance, or ambivalence about what we want to do. This can be for a number of reasons, including lack of information or understanding about what's being asked or required, or perhaps anxiety about the possibility of trying and getting it wrong. Or many other reasons.

The aim of motivational interviewing within CBT for CFS/ME is to help the young person make behavioural change particularly when they feel unsure about doing so. The key idea here is about having a non-judgmental conversation with the young person in therapy,

exploring where they are now, what they think about that, and where they might like to be. Motivational interviewing allows space to talk about cognitive dissonance, ambivalence, fear of change and any other barriers to moving forwards in therapy. It introduces the idea that change is possible, and helps the young person move towards it.

- Some key steps in motivational interviewing are as follows: Start by listening and seeking to understand where the young person is at in relation to change (assessing readiness to change), by use of:
  - o Open ended questions
  - o Reflective listening
  - o Acknowledging the dilemma/struggle
  - o Clarifying and summarising
  - o Looking for successes in changing behaviour and building on those
- Exploring the pros and cons of change vs no change (e.g. see <https://www.psychologytools.com/resource/motivation-and-ambivalence/>)
- Considering what change would mean for the young person, in relation to working towards their therapy goals.
- Building the young person's confidence in making steps towards change.

## PROBLEM SOLVING

Problem solving aims to help gently move the young person from a 'stuck' position (often accompanied by a lack of hope or self-efficacy) to one of making an active choice to improve the given situation. It helps the young person to move through a barrier and to move forwards in treatment.

Problem solving is done together between the therapist and young person, working collaboratively through a series of logical steps. Firstly, the current 'problem' is identified; then possible options or solutions are considered, before selecting the best one and establishing how to act in line with this plan. This process, like many others within CBT for CFS/ME, aims to 'skill up' the young person in thinking through the current situation and also then applying the same strategy by themselves, both between appointments and after therapy has ended. It is a useful skill for the young person to have in their 'toolbox'.

The following example illustrates how problem solving might be used in CBT for CFS/ME:

- Where particular problems have arisen in making behavioural changes (e.g. "I can't wake up in the morning because I don't have an alarm clock"), this presents an opportunity to build problem solving skills by scaffolding the young person to work through the following steps:
  - o Step 1: Specify the problem
  - o Step 2: Why is this a problem?
  - o Step 3: What are the possible ways to solve this?

- Step 4: Advantages and disadvantages of each possible solution?
- Step 5: Try out the best solution
- Step 6: Check – did it work?

(see <https://www.getselfhelp.co.uk/docs/ProblemSolvingWorksheet.pdf> for example)

Thinking in these ways with patients can enable them to move from a 'stuck' position to one in which they can see and choose different possible actions, in order to move forwards. It is an important and empowering process, particularly for this patient group where it can be common to feel a sense of helplessness or lack of self-efficacy.

By breaking challenges into steps and encouraging a focus on just one step at a time, the young person can begin to see solutions and ways out of the initial problem. It can often be helpful to involve parents in these discussions, for a number of reasons, but one being that the parent can then model some of these problem-solving strategies with the young person at home in between appointments, if challenges arise.

# Adapting CBT for CFS/ME when there are concurrent Mental Health Problems

## ANXIETY

Anxiety is common in young people with CFS/ME. Anxiety is, itself, an energy sapping activity. Some young people with CFS/ME will not report any particular worries, or not to a greater extent than the general population. Others may report some low-level worries relating to their illness and perhaps attending school, or coping with their symptoms. These sorts of low-level worries can helpfully and effectively be addressed using the CBT techniques discussed earlier. We often see reduction in anxiety as the young person moves towards recovery in the CFS/ME treatment journey.

However, some children and young people with CFS/ME will struggle with anxiety to a much greater extent. We know from recent research that approximately one-third of young people with CFS/ME also meet the diagnostic criteria for an anxiety disorder (See **Loades, M.E., Read, R., Smith, L., Higson-Sweeney, N., Laffan, A., Stallard, P., Kessler, D., & Crawley, E. (2020).** How common are Depression and Anxiety in adolescents with Chronic Fatigue Syndrome (CFS) and how should we screen for these mental health comorbidities? A clinical cohort study. *European Child and Adolescent Psychiatry*. doi:10.1007/s00787-020-01646-w). The most common anxiety disorders are generalized anxiety disorder and social anxiety disorder. Many young people who meet the criteria for one anxiety disorder diagnosis also meet the criteria for another anxiety disorder diagnosis and/or depression. Some of these young people may have had anxiety prior to their CFS/ME and it has since become compounded or exacerbated. Others report that their anxiety began after their CFS/ME, and in some instances, this may be because they have (or perceive themselves to have) fallen behind academically and or socially as a result of CFS/ME. In this situation resuming normal activities on the journey towards recovery can be anxiety provoking.

Anecdotally in clinic, we commonly see increased symptoms of panic amongst the more anxious patients, who particularly report physiological anxiety symptoms such as fast breathing and shakiness. Young people with CFS/ME may be more hypervigilant for physical symptoms generally, including those which may arise from anxiety. A young person with CFS/ME may also have had a protracted period of time (prior to diagnosis) where there was a great focus on trying to understand and identify their symptoms, again perhaps contributing to a heightened awareness of physiological symptoms. Therefore, the principles applied to shifting the focus away from symptoms generally may be helpful.

## Additional CBT techniques which may be helpful

The core CBT techniques described earlier in this manual such as unhelpful vs. helpful thinking, and tools for managing feelings, remain relevant and appropriate for those also struggling with more significant anxiety. They can be adapted and shaped to include a

greater focus on managing anxiety, and exploring its relationship with CFS/ME. However, anxiety may hinder treatment progress in several ways, including:

- 1) Anxiety, which is a high energy activity, gets in the way of activity management and contributes to ongoing boom and bust patterns
- 2) Anxiety-driven avoidance gets in the way of resuming normal activities.

Therefore, there are some additional techniques which may be helpful when delivering CBT for CFS/ME with more anxious children and young people. The formulation should be used to inform if and when these are utilized.

### *Gradual exposure / goal hierarchy work*

A graded approach to overcoming avoidance and facing feared situations may be helpful when there is a specific situation (or situations) which particularly provokes anxiety. It could be something like giving a presentation in school, or talking to someone new at a youth club. Typically the target behaviour or action will be something of importance to the young person; something they would love to be able to do, but currently feel unable to due to their anxiety. The idea here is to break the goal into steps, and to work towards it.

The therapist supports the young person in first generating a list of potential steps; actions or behaviours which also induce some anxiety, but less so than the target one. They are then placed in order, starting with the easiest (least anxiety provoking) and working towards the main goal. The therapist can help the young person to consider any safety behaviours (precautions) that they are taking, which in their mind prevent the feared catastrophe. These safety behaviours in fact keep anxiety going as they prevent the young person from discovering that the feared catastrophe actually does not happen. Therefore safety behaviours need to be dropped in order for the young person to fully engage in the anxiety-provoking situation and to see that they can cope. It is also helpful to think about rewards or anything to help boost the young person's motivation for trying each step.

Each action or behaviour (or step in the ladder) then provides an opportunity to face an anxiety-provoking situation, to test out related fears about what might happen, to practice anxiety management in the moment (e.g. through breathing exercises, or other strategies as discussed earlier), and to gather new evidence about what actually happened. Each step, if successful, should increase the young person's confidence in completing the next, and anxiety should gradually reduce.

See Stallard, P. (2014). *Anxiety: Cognitive behaviour therapy with children and young people* (book) for further information. Useful resources including anxiety ladders can be found in the final chapter of this book, in Stallard's *Think Good Feel Good* book, and at <https://www.psychologytools.com/professional/problems/anxiety/> for instance.

### *Worry time (worry postponement)*

This strategy brings together many different strands of CBT because it is essentially both a cognitive and behavioural method which also enables an increased management of emotions in the moment. Put simply, ‘worry time’ is a method for postponing any worries to an allocated (delayed) time, typically in the evening or before bed. For example, a young person may be given the following instruction: “Scan through your mind and see if there are any busy thoughts or worries. If there are any, write them down and make a note to deal with them at a specific, dedicated worry time. If something is really bothering you, plan to talk to someone you trust.”

The idea here is to learn that worries do not have to be dealt with necessarily in the moment but that it is possible to put them to one side with the plan of addressing them later. This method is often done jointly with parents, as they can be helpfully involved in sharing the ‘worry time’ with the young person when the worries are then talked through. It can be particularly helpful for younger children. The child or young person is encouraged to write down or record their worry in some way, for discussion later. In the short term this enables them to free their mind of the worry until the designated time, and in some ways to learn the ability to ‘sit with’ the emotion.

Often, by the time of the allocated ‘worry time’ the young person may notice feeling less worried about the issue in question, as time has passed and the intensity of the feelings may well have reduced. This too is a helpful experience for the young person to notice and should be picked up on in therapy.

### *Building tolerance of uncertainty*

Because we can’t see into the future, uncertainty is unavoidable. Tolerance of uncertainty can be thought of a bit like an allergy. For most people, uncertainty, like pollen, for instance, provokes mild discomfort at most. For some people though, even a little pollen (or uncertainty) provokes high levels of discomfort; it provokes high levels of worry and anxiety. It is particularly typical of those who have Generalised Anxiety Disorder. There are ways in which a young person can build up their tolerance of uncertainty. Some ideas can be found here <https://www.psychologytools.com/resource/intolerance-of-uncertainty/>

### *Treating anxiety in younger CFS/ME patients*

As with other elements of CBT for CFS/ME, anxiety work with younger children generally requires slightly different ways of working. This is partly due to the less matured cognitive and emotional abilities of the younger child. CBT for anxiety with younger children, outside of CFS/ME treatment specifically, has been found to be most effective when

delivered with and through the child's parents. The therapist's role therefore is to 'train' parents in delivering CBT with the child in the home environment. For example, skilling the parent in helping the child to identify and communicate times of feeling anxious, as well as facilitating the delivery of key cognitive and behavioural strategies to manage the anxiety. Another key part of this work can be helping the parent themselves to recognize any contribution of their own anxiety, and to learn ways of managing it constructively. Cathy Creswell and Lucy Willets' 'Helping your child with fears and worries: a self-help guide for parents' (2019) is an excellent resource for further information. There are a number of self-help guides for anxiety in young children, which again can be 'delivered' by the parents. Examples include:

- *'What to do when you worry too much: A kids' guide to overcoming anxiety'* by Dawn Huebner (for children aged 6-12 years)
- *'Starving the anxiety gremlin: A cognitive behavioural therapy workbook on anxiety management for young people'* by Kate Collins-Donnelly (for children aged 10+)

Paul Stallard's *'Think good feel good'* resources include ideas for helping young children with managing anxious thoughts and feelings. Additional tools for anxiety work within CBT for CFS/ME, may include:

- Body mapping
- Emotion cards
- Idiosyncratic assessment/monitoring tools such as visual rating scales
- Parent only sessions to be considered

## DEPRESSION

Low mood and depression is also common in young people with CFS/ME. This can compound fatigue because fatigue is a somatic symptom of depression, as are problems with sleeping, appetite and concentration. Depression is characterized by negative thinking, hopelessness and anhedonia (lack of interest in and enjoyment of activities) which can get in the way of engaging in treatment for CFS/ME and being able to live life to the fullest.

Feeling frustrated and sad about not being able to do the things that a young person wants to is a reasonable response to having a disabling and prolonged illness. Low mood and depression are negatively reinforced by not being able to engage in activities which give us a sense of enjoyment and/or pleasure. For many young people, their mood may improve as they begin to re-engage in the activities they want to do on the journey towards recovery from CFS/ME.

However, some children and young people with CFS/ME will struggle with their mood to a much greater extent. Around one in five young people with CFS/ME also meets the diagnostic criteria for Depression, and many of these young people will also have difficulties with anxiety (See **Loades, M.E., Read, R., Smith, L., Higson-Sweeney, N., Laffan, A., Stallard, P., Kessler, D., & Crawley, E. (2020).** How common are Depression and Anxiety in adolescents with Chronic Fatigue Syndrome (CFS) and how should we screen for these mental health co-morbidities? A clinical cohort study. *European Child and Adolescent Psychiatry*. doi:10.1007/s00787-020-01646-w).

### Additional CBT techniques which may be helpful

The core CBT techniques described earlier in this manual such as unhelpful vs. helpful thinking, and tools for managing feelings, remain relevant and appropriate for those also struggling with more significant mood problems.

#### *Behavioural Activation*

Within activity management, an increased focus on doing more valued activities (those that have meaning for the young person), including activities that bring a sense of achievement, closeness and enjoyment, could be useful where low mood is evident. Drawing on the principles of Behavioural Activation Treatment for Depression (BATD) can be helpful. It is important to help the young person to identify enjoyable activities that are low energy, so that their activity management baseline does not preclude them from engaging in mood-boosting activities. With these young people, it might also be particularly important to focus the available high energy time available on the most meaningful and mood-boosting activities for the young person rather than those that are 'important' but perhaps not mood-boosting.



See Lejuez, C. W., Hopko, D. R., Acierno, R., Daughters, S. B., & Pagoto, S. L. (2011). Ten year revision of the brief behavioral activation treatment for depression: revised treatment manual. *Behavior modification*, 35(2), 111–161. <https://doi.org/10.1177/0145445510390929>

### *General as well as fatigue-specific negative thoughts*

Young people with CFS/ME who are also low in mood tend to experience more negative, distorted thoughts in general as well as unhelpful fatigue-specific thoughts. The cognitive techniques discussed above for addressing unhelpful thoughts should be more applied more broadly in those with concurrent mood problems so that general negative thoughts are also addressed. If these are not addressed, general negative thinking can form a barrier to making changes that can help with CFS/ME (e.g. thinking ‘Nothing is going to help’ may make a young person less likely to make changes to sleep and activity patterns).

### *Core Beliefs*

Core beliefs are deeply held beliefs about ourselves, other people, or the world. They can determine how we perceive things and respond to our experiences. Sometimes in CBT for CFS/ME it may be appropriate (and indeed necessary) to explore the young person’s core beliefs. This can be particularly helpful if the therapist sees that certain core beliefs are key to the formulation and, perhaps, inhibiting the young person’s progress throughout therapy.

See Verduyn, C., Rogers, J., & Wood, A. (2009). *Depression: Cognitive behaviour therapy with children and young people*. Routledge for further information and helpful worksheets.

## **WHEN MORE HELP FOR MENTAL HEALTH PROBLEMS IS NEEDED**

There are of course some instances where a young person’s mental health needs become greater than can be appropriately supported within a CFS/ME service. At these times the clinician needs to consider whether the young person would be better served by accessing CBT (or other evidence-based treatment) for their anxiety within a mental health service, such as CAMHS (Child and Adolescent Mental Health Services).

It is important for this need to be correctly identified, primarily to best support the mental health of the child or young person, and also to consider most efficient use of specialist CFS/ME clinicians’ time. There are very few paediatric CFS/ME services in the country and so it is important to ensure clinicians in this service are able to provide support to children and young people which they cannot otherwise access elsewhere.

The following points are useful to consider, when deciding where a young person’s mental health needs are most appropriately supported:

- Primary issue – What does the young person feel is their main difficulty at the current time? If mental health related, and not CFS/ME, it could be appropriate to refer outwards.
- Longevity of the mental health problems – Does the young person feel their anxiety/mood is long-standing? Is it something they have always struggled with, and never previously had professional support for it? Are their longer term issues which may need exploring in a different modality e.g. through Art Therapy or Family Therapy?
- Maintenance formulation – What is keeping the young person stuck currently from working towards their CFS/ME goals? Is mental health the main barrier to progressing with their CFS/ME treatment programme? If so, is the mental health inter-related to their CFS/ME or is it somehow separate?
- Severity and complexity – There are some mental health problems for which specialist input is indicated at the outset, including PTSD, and Eating Disorders as these require management and specialist therapy from appropriately trained mental health clinicians.
- Risk management – Any young people presenting with significant levels of risk (e.g. self-harming behaviours and/or suicidal ideation) must be supported within mental health services.

## Relapse Prevention and Managing Setbacks

Another key stage of CBT for CFS/ME is preparing the young person for how to manage after the time that active treatment has ended. There are two key processes here; relapse prevention, and building a therapeutic 'blueprint' for managing setbacks if they do occur.

Relapse prevention is about helping the young person know what they need to keep going with, after therapy has ended, to prevent further fatigue. This does not necessarily mean a strict monitoring of activity levels, but perhaps keeping going with some elements of the treatment journey that have been particularly helpful for them. This can often link to specific events. For example, many young people will come to reflect that stress (such as that brought about during exam periods) can be unhelpful through disrupting their sleep, making it harder to concentrate at school, and ultimately impeding their exam performance. Therefore, the young person can help to prevent future difficulty in this area by being clear on what helps them to manage or minimize stress if it does arise, before it can cause more difficulty and potentially lead to increased fatigue. Consideration should also be given to what the early warning signs would be if difficulties did emerge again.

Having a clear plan of helpful behaviours or actions helps the young person to recall what has helped them previously. This information is what is held within the therapeutic blueprint. If the young person's fatigue does re-increase (following a particular trigger e.g. illness or cause of stress, for example), the blueprint can be used as a personalized self-help guide to know how to then best manage this setback. In terms of activity levels, it might be appropriate for example to temporarily reduce school attendance slightly again, and to gradually re-build it in the same way as was done before. Having these ideas planned out in advance gives the young person security in knowing they are skilled to manage any setbacks if they arise, without needing to return to active treatment with a therapist.

Of course, there are times when previous patients may be re-referred to a CFS/ME service, particularly if health or circumstances have changed more significantly for them during the interim time. But at these times the therapist would keenly take a clear focus on revisiting previous strategies and exploring with the young person what they can do to manage; it would not be a case of starting again in full therapy. We might think of this as having a few 'top up' CBT sessions.

**Treatment Sequence for Behavioural Approaches vs CBT-F vs CBT-F with co-morbid anxiety and depression** (indicative time frames) - Note: This is a general guide and is not intended to be used prescriptively. The idiosyncratic formulation would inform in a specific instance.

	Behavioural Approaches (e.g. Energy/Activity Management, GET)	CBT-F	CBT-F + depression &/anxiety
<b>Assessment &amp; formulation</b>			
Assessment	Usually 1 90-minute session, and may include filling in questionnaires and collecting information from others (e.g. teachers, especially for primary school age children)		
What is CFS/ME? Psychoeducation about CFS/ME	Usually covered briefly during the assessment session, with information leaflets to take away, and revisited as needed, particularly at the early stages of treatment.		Also include psychoeducation about mood and anxiety e.g. fight-flight response
Formulation	✓	✓	✓ including how mood/anxiety link to fatigue
Goal setting	Usually covered at the end of the assessment, revisited at the beginning of treatment. Focus on goals related to overcoming fatigue.		Would include goals relevant to mood and anxiety as well as overcoming fatigue.
<b>Treatment sessions</b>			
Sleep	Sessions 1-2	Sessions 1-2	Sessions 1-2
Setting an activity baseline	Sessions 1-6 (GET focuses on physical activity only; Energy/ Activity management focuses on cognitive and social activities too)	Sessions 1-3	Sessions 2-5 Likely to take longer - include consideration of mood boosting activities by: (1) Identifying low energy enjoyable activities (2) Making sure that some of high energy time is spent on fun activities (activity scheduling for depression).
Gradually increasing activity levels by 10-20% every 1 -2 weeks as tolerated	Session 3 onwards when baseline is established and stable	Session 3 onwards when baseline is established and stable	Sessions 3 onwards when baseline is established and stable If specific fears and worries identified may need to use graded hierarchy for exposure to overcome those fears (e.g. a graded hierarchy of social situations)
Cognitive work: Thoughts that are unhelpful		✓ About fatigue specifically – often later in therapy, particularly if thoughts about fatigue are getting in the way of making progress.	✓ Broader (i.e. general negative thoughts as well as fatigue specific) and may be introduced earlier in therapy
Managing feelings		May introduce relaxation strategies if needed.	As soon as needed e.g. where anxiety is a key part of the problem, relaxation might be introduced early on
Risk management	Only if indicated	Only if indicated	-Throughout-
School and CFS/ME	✓ throughout	✓ throughout	✓ throughout
What can get in the way of making changes?	As needed	As needed	As needed
Reviewing progress	Approx. every 6 sessions	Approx. every 6 sessions	Approx. every 6 sessions
Relapse prevention & Managing setbacks deregulating	Towards end of therapy		

