MNIS - OXON
Medical Needs in Schools

Oxfordshire Hospital School
Ofsted Outstanding Provider

Chronic Fatigue Syndrome Toolkit

1 Definition:

Chronic Fatigue

CFS (Chronic Fatigue Syndrome) is also known as ME (Myalgic Encephalomyelitis) It is sometimes referred to as CFS/ME. The condition is long-term and can affect anyone. The main symptom of CFS is extreme tiredness though other symptoms may also be experienced. These can include

- Feeling generally unwell or having flu like-symptoms
- Sleep problems
- Muscle or joint pain
- Headaches
- Sore throat
- Problems thinking and concentrating
- Memory problems
- Dizziness
- Sickness
- Palpitations

Symptoms might be broadly grouped into 4 categories

Muscular symptoms and Pain - tummy, headaches, muscular, joints, low tolerance for exercise, worse after physical activity, often chronic

Central nervous system and cognitive symptoms – dizziness and fainting, heart palpitations,, reduced mobility, some young people may experience visual disturbance, headaches and migraines; ‘brain fog’ (concentration, memory and information processing difficulties)

Fatigue – generalised tiredness or extreme tiredness after little effort, rest may not help much, lack of concentration, variability in how much an individual can do at different times, Apparent abnormalities in **immune system function** – sore throats, enlarged glands, temperature dysregulation, flu-like symptoms, headaches

Approximately one third of children and young people with CFS/ME will also experience mental health difficulties e.g. anxiety and/or depression. Often these can develop after, and in response to, their CFS/ME. Anxiety and/or depression can complicate recovery from CFS/ME and young people may need help in understanding the links between their symptoms and feelings. (Anxiety and Depression are common responses in any individual, child or adult, who is diagnosed with a significant illness of any kind and therefore not unusual.)

Over-exercising (including cognitive activity) tends to make symptoms worse.

There is no single test for CFS, so a diagnosis is made by exclusion, and includes assessment of current symptoms and health history. A battery of screening blood tests are done to rule out any other underlying difficulties. The symptoms are similar to other common illnesses that have to be eliminated first, so the diagnosis of CFS may take a while to be given. Doctors might consider diagnosing CFS if tiredness has lasted a long time or keeps coming back, if the child or young person can't do what they used to do, if the tiredness worsens after even gentle activity and if the symptoms have lasted for more than three months.

It's not known what causes CFS but some common triggers include

- Viral and bacterial infection (like glandular fever or pneumonia)
- Problems with the immune system
- Hormone imbalance
- Stress or emotional trauma
- Genes

There are three treatments recommended by NICE which aim to relieve the symptoms and bring recovery. They include

- Activity Management
- Cognitive Behaviour Therapy
- Graded Exercise Therapy

Some young people may be given medication to help the management of some of their symptoms, e.g. pain relief for chronic headaches or short-term medication to help in resetting sleep onset. However there is little solid research yet on the benefits of these medications in CFS/ME so a Paediatrician always has to assess carefully.

The recovery rates for CFS/ME in children and young people are better than for adults; we do not yet know why but it is thought that biology may play a role (the young person's body is more able to recover more quickly) and it can be easier for a child to make changes to their activity levels and to reduce e.g. school attendance, compared to an adult who may have work and childcare commitments.

When someone has Chronic Fatigue it is common:

- To see lots of different doctors and have lots of examinations before reaching a confirmed diagnosis
- For X-rays and scans (e.g. gastro assessments) to show up as normal
- For the level of fatigue to change throughout the day or from day to day
- For people not to understand what it is
- To feel sad and worried about being ill

Many young people find their own ways to live with their condition and some recover without specialist treatment (approximately 8%). Recovery rates are much better when young people are seeing a specialist service. Recovery rate for those in specialist treatment with a CFS/ME service are approximately 60% after 6 months of treatment and 85% at 1 year of treatment.

Chronic Fatigue is unlikely to be "cured" in the short-term and the child or young person will instead be supported in "managing" the symptoms. A key concept is that a young person should not allow their tiredness to dominate their lives. Focusing on the fatigue, or other symptoms, can make it harder for a young person to recover. They can acknowledge it and yet still engage in an appropriate level of activity as advised by a clinician. Gradually increasing and controlling levels of activity can help to build stamina. Levels of stress are always likely to have an impact on the level of fatigue experienced by the pupil and it is very likely that there will be points in the journey when the child or young person seems to go backwards. But an effective rehabilitation programme can be successful.

It is very important that children and young people who have chronic fatigue should attend school. This will usually involve attending a part-time timetable which gradually increases as the pupil's stamina increases. The aim will usually be for them to build up to returning there full-time and to sustain this, but this is likely to be a long-term goal, usually taking months or even years.

2 Key Points:

For pupils who are diagnosed with CFS, it is important to accept that the conditions are likely to be chronic and long-term. It is also important to say that the course of illnesses such as these will be different for each individual and there will be much variation between them. Therefore any plan that is put in place needs to be “bespoke” rather than “generic”.

The relapsing and fluctuating nature of CFS/ME can make it difficult to plan for in schools. The variability in the severity with which the symptoms present from day to day and even within the same day is to be expected and is a part of the usual course of the condition. It is crucial that the pupil feels believed about their symptoms and that the evidence base of accepted best practice is used as a basis for planning (not personal judgement).

Having accepted that CFS/ME is likely to be chronic and long-term, the focus for schools should be on the management of the pupil’s access to learning during this time. Once a bespoke plan has been made for an individual, it is important to stick to it and to remember that doing too much can be as much of a problem as doing too little, with the impact of too much activity being felt later. Realistically, the plan for meeting the needs of the pupil may need to include arrangements for days when the pupil is too ill to attend school, days when they can manage only some time in a learning base and days when they can attend some or all lessons as usual alongside their peers. The plan will need to be very flexible and responsive and there will need to be good communication (probably daily) between school and home in deciding what to aim for on any particular day. Because of this, it is useful to allocate an individual worker in school who will be the single point of contact.

Try to work within a non-confrontational relationship with the pupil and the parents.

General approaches

Take the chronic feelings of fatigue seriously. It is reasonable to make demands of children and young people but it is unhelpful to dismiss the feeling of tiredness or exhaustion. Acknowledge the feeling, but encourage the young person to move beyond a focus on it by directing their attention elsewhere. Encourage the pupil to try to stick with the planned level of activity, whether this means supporting them to persist or stopping them when they have achieved it.

The ultimate aim is to manage full school attendance, but there will usually be a graded plan in place for long periods of time.

Be aware that pupils may have a number of medical appointments with different specialists and that in itself this can be stressful.

Consult with parents and the young person as to what they want other pupils to know. Pupils with CFS/ME can find it helpful for teachers (and sometimes peers too) to have some level of understanding. This helps the pupil to feel understood by those around them, and reduces the fear of peers asking questions about where they have been, or making comments which can feel challenging or upsetting, e.g. “you’re so lucky, you get to go home early”.

Try to allow children with chronic fatigue to manage their own condition, lead a full school life and be included in activities and normal social interaction with their peers as far as possible, though be mindful of the negative impact of over-activity when things are going well and the temptation is to do too much. Keeping in touch with peers and having some ‘normal’ social contact can have a really positive impact on the young person’s overall wellbeing.

Pupils leaving schools at an unscheduled time is undesirable so it may be useful to identify resting places in school if a pupil needs it. This is more likely to be needed once the pupil is attending for more extended periods of time.

Please read information from the CFS national service about learning challenges

3 Information and Assessment to inform planning for the individual

Home School:
Relevant information regarding past attendance, achievement, behaviour and future targets. Any SEND needs in addition to Chronic Fatigue Syndrome
Clinicians:
Likely length of treatment
Advice about appropriate levels of activity
Effects on attendance & learning, including any mobility, appearance, mood issues, from diagnosis & treatment
Care Plan/ general information about therapeutic approach and the language used
Updates from formal meetings when held eg TAF, and from any other professionals involved
Other sources of information:
Royal College of Psychiatrists
NHS (nhs.uk/conditions/chronic-fatigue-syndrome-cfs/)
Action for m.e (actionforme.org.uk)
Oxford University Hospitals (www.ouh.nhs.uk/chronic-fatigue/)
ME association (www.meassociation.org.uk) Nasen
Bath Specialist CFS/ME service (www.ruh.nhs.uk/cfs)

4 Impact of Condition on Learning

Tiredness and worrying about being tired and focusing on it instead of on their learning
Inability to concentrate and to block out background noise/distractions
Memory difficulties
Difficulties processing information and ‘taking it in’
Avoidance of activities that cause anxiety, including school or lesson attendance
Anxiety in trying new things and reduced self-confidence in abilities
Feeling frustrated and irritable
May be particularly sensitive to perceived criticism
May be self-critical and experience loss of self-esteem
Loss of interest and motivation
Feelings of isolation/impacts of less social contact
Difficulty making decisions

5 Interventions

Support strategies/Interventions	How this might be recorded in IHP
The pupil is not fit to have contact with school or to learn. You have been asked by the health professionals involved to remove all pressure. This will be very rare.	The school will provide a choice of simple activities for home which will only be offered to the pupil if they request them. Parents will keep in touch with the school weekly to say whether or not other resources are needed. A meeting will be arranged once health professionals advise us that the pupil is ready to have more contact with school.
Allocate individual worker to build relationship. Schedule regular meetings. Might begin contact at home, neutral location then into school. Work to be sent home and collected/feedback given by teachers.	X will be allocated (name) as an individual support worker who will meet with X weekly to begin with. Work at an appropriate level from subject teachers will be provided and completed work collected in this meeting and feedback given. The individual worker will communicate with the parents/carers regularly and involve them in planning.
Try on uniform/pack school bag. Visit school out of hours for a walk round eg have meeting with individual worker at end of school day. Come in to collect and return work at the end of the school day.	X will visit the school after the end of the school day and re-familarise/de-sensitise herself to the school site by walking around it with the support of parent/member of school staff. X will meet with (individual worker) after school to collect work from teachers and return completed work and receive feedback. X will wear school uniform when on the school site.
Agree a graded return to school programme if the pupil has been out of school for some time. Consult with the child, parents and medical professionals.	X will attend school for 2 hours a day (from 10am until 12 pm) for the first 2 weeks of the plan, with the aim of gradually increasing to full time. The plan will be reviewed regularly and decisions as to the pace of reintegration made in the light of current progress.
This might begin by doing work set by subject staff in learning base, building up amount of time gradually eg an hour a week, an hour a	X will have work set by subject staff and be given support to work on it for 2 hours each day in the learning base. Subject staff will supply

day, 2 hours a day. Think about getting to and from the learning base (or lessons at a later stage) NB Some pupils will be ready to go straight into lessons and this should be encouraged. Initially, the routine of being in school to build up stamina may be more important than learning.	other work that can be done independently at home. X will be met at the school reception at an agreed time by a member of staff and walked over to the learning base. A member of staff will take her back to the school reception at the end of the session.Staff are aware that at this stage the primary objective is to encourage school attendance and start to build up some physical stamina.
Prepare for returning to lessons	We will organise a meeting for X to meet her new form tutor and also encourage her to reconnect with her friends, initially by text.
Identify a starting point for attending lessons with other students – best subject or teacher/a group with a friend - and gradually increase the time spent in lessons. May need support from individual worker to do this (in the lesson/sitting with/sitting apart, just outside the classroom, to be found in an appointed place if they are particularly anxious e.g. after a long absence.)	X will begin to start some lessons with other students. We will start with Art as this is her favourite subject and she has a supportive relationship with the teacher. We will add in other subjects in negotiation with X as she feels able to do more.
Review and agree next stage of plan at appropriate intervals.. Accept that progress will be slow and that for some periods (maybe often) the plan will remain the same. Give time to talking about how new things are likely to happen/think about eventualities and make plans for them/counting down “In ten minutes we’re going to…” “ In two week’s time it’s going to be …”	X’s timetable will be reviewed monthly and in negotiation with her. A flexible part-time timetable will be agreed with some time in school and some time working independently at home. We will work with X to make sure that she knows what to expect and to flag up extracurricular events she may wish to be included in.
Make some reasonable allowances for activities the pupil may find particularly tiring	Staff are aware that X’s handwriting may be untidy when she is tired and that this does not mean that she is being careless. She will be encouraged to take her time. Staff will help with longer note-taking work by providing photocopies.

Think about any adjustments that are needed for exams eg using a laptop rather than handwriting	X will be offered rest breaks and 25% extra time in exams, as well as the option to take the exam in a smaller, quieter room.
Some flexibility or adaptation may be needed around PE lessons	X will be responsible for pacing herself during PE lessons but will try to participate when possible. X will inform staff if she needs to rest and staff will be aware that this may be the case. Staff will encourage X to participate in other ways if the physical activity is too much e.g. by refereeing or keeping score where possible, or by adapting the activity for her.
Do not be quick to send a young person who is tired home, if being in school at that time is expected. Agree a management plan with the child, parents or medical team.	X is particularly fatigued in school she can approach staff to request time out in the medical room. She is to be allowed 30 minutes (?) rest and should then return to class. If X is unable to return to class after 30 minutes parents are to be called and X is to be taken home for the rest of the day (and to continue with the agreed timetable for the next day).
Ask the pupil/family to make a personal "Distraction Box" which includes things to use to self-soothe at times when the they are struggling (make a nice box, allow ipod, puzzles, mindful colouring, sensory or fiddle toys, handcream...etc). It’s important for the pupil to take responsibility for choosing and supplying what it contains. This will be useful if the pupil needs “time out” in school	X will make herself a Distraction Box including activities to do if she is experiencing bad pain. It will be stored in the medical room and X will be given access to it if “time out” in school has been needed.
Work on specific problems that inhibit progress - seek advice from clinicians if the problems require it or seem intractable.	We will seek clinical advice about… or X has been working on managing to participate in PE in school. We will support the way of working her consultant has suggested (give details if possible)

Think about incentives and rewards - these could come from school or family and should be individually tailored.	X is to have a reward when she has managed to attend her individualised programme for a week. She has chosen to have a trip to the swimming pool with her cousin.
Using praise and reflection	Staff will give praise at appropriate times to reinforce effort and attainment, particularly to recognise when X has pushed through her fatigue, remained in school or persisted with schoolwork
As time in school increases and includes break or lunch make a plan for these unstructured times if needed. Arrangements to be as normal as possible to encourage social interaction and foster independence and self-confidence. It should be rare that special arrangements are needed.	X will come to the learning support base at break and lunch time if she is in school at those times. She will be encouraged and supported to socialise with other students (Circle of Friends) in the learning base.
Teachers should be made aware of how the pupil might present at difficult times. Fatigue and anxiety may cause changes in behaviour, including withdrawal, poor concentration and frustration or aggression. The pupil and the teacher may need a quick means of communication that can be used easily in lessons.	Staff will be made aware of how X's fatigue may sometimes lead to changes in her behaviour and be sensitive to this where appropriate. Staff will be aware that she has a time out plan (and how it works) and may ask for medication. Staff will give positive feedback when X has done well. X has written a list of things for staff that are helpful or not helpful to her in lessons (What I want my Teachers to Know). This will be communicated to staff. X will carry traffic light cards to indicate to staff how she is feeling. (Green - all well, Amber – might need support, Red – needs to leave lesson and go to medical room to rest)

It would be helpful for school staff to use a common language with the pupil, especially if they are having "talking" therapy by linking in with therapist e.g. thinking about ‘high’ vs ‘low’ level activities; not focusing on symptoms; settings goals for gradually re-building school etc; focusing on activity rather than symptoms; keeping a stable ‘baseline’ of activity across the week; avoiding a ‘boom and bust’ cycle of doing too much and then crashing out.	Staff will try to use language that is accessible and familiar to X in school, drawing on the words and terms she is using in CBT or other.
There may be particular arrangements that need to be considered about exams, PE, visits and trips	X has been working on managing to participate in PE in school. We will support the way of working her consultant has suggested (give details if possible)

6 Scripts

“We understand that you are tired and that school is sometimes difficult for you. But we have worked with pupils like yourself in the past and we can support you. We can make a plan with you that will help you get back to where you need to be. (Reassurance/normalising the situation/building confidence)

I can see that you’re looking tired – we’ll try to carry on but you’ll have to let me know if it gets worse…

I’m really sorry you had a bad night…how about we look at this and see how it goes?

What would help you right now? How about a bit of a stretch? A walk round? A glass of water? A minute’s break?

“What helped you get through this last time?”

Let’s try to take your mind off things and see how it goes…

“I know you’re worried about wearing yourself out, but that might not happen…we won’t know unless you try – can you think of a way of doing this differently that might be better? Let’s just do a couple of minutes…”

“Let’s make a plan and see how it goes – if it doesn’t work, we’ll think about it together again”

Let’s just try just the next step...”

“I can see that this is too much for you right now…can you think of a better time to try it?”

“Let’s try 5 minutes, and if it’s still too much, talk about it and try again tomorrow”.

“You’ve done the time/amount of minutes we agreed. That’s terrific. You’ve worked really hard to keep going. Well done.

It’s great that you’ve managed to do that despite not feeling so good – how did you manage to keep going? Let’s try to remember that…

“I can see this is too much for you today - let’s take some time out and think again. Sometimes we have to try lots of times before we succeed, so let’s try to keep going and come back to this another time”

“It was really good that you managed to (do more) than last time. What made it different? Let’s remember that so you can try it again”.

“What do you think we should aim for next?”

“I know you’re feeling poorly, let’s do something together to try and take your mind off it!”

“Well done, you’re doing so well, I know you’re tired, but you are doing amazingly well! Let’s keep going…”

I’m going to say it’s time to finish now, you’ve done really well but let’s stick to the plan. I don’t want you to wear yourself out and I think you need a break. I want to leave you with enough energy for the evening and tomorrow.”

7 Progress

Indicators of success/Identifying further development

What might achievement and progress look like?

Able to attend most lessons and to learn.
Able to manage some social time
Continuing to work on remaining challenges. May still need to have some time in learning base or similar as part of their routine.
Good pupil/family/support worker communication established but needing less frequent contact.
Pupils will be able to use a range of strategies to reduce/manage their fatigue in most situations and will be becoming increasingly independent.
When unable to remain in lessons, the pupil will use their rest space and be able to manage them self or to approach staff for extra support.

N.B. Update the IHP - keep copies of previous versions or a rolling log so there is a record of the interventions you have put in place and their outcomes. Note the positives/achievements as well as on-going difficulties. Put in more support at points of transition eg ends and starts of years, changes of staff, exams, trips and visits.

Accept that this will be a longer-term recovery and that there are likely to be periods of regression along the way and that this does not necessarily mean failure.

The CFS Progress Grid below may help with assessment.

Name

Colour	Date

Not able to come to school at all Needs to be with an adult at all times, to be accompanied on and off the school site	Needing an adjusted timetable (up to 25%) In learning base all the time Unable to work elsewhere	Needing an adjusted timetable (attending up to 50% of full timetable) Mainly in learning base, but attending some classes Needs support for moving around the school	Managing almost a full timetable(Up to 75%of the full timetable) Mainly in lessons/small amounts of time in learning base Managing most transitions by self	Managing a full timetable Up to 100% In lessons Managing transitions independently
Not able to be present with any other students, needs to be in a separate space	Can be around other students in learning base, can see other students and be seen, but avoiding all interaction	Can be around other students in social time in a protected space.	Can attend lessons with extra support in or outside the classroom	Can attend lessons without extra support and manage social time
Unable to form social relationships with peers	Has some contact with one or more friends, in or out of school	Is forming connections with other peers in a protected setting	Able to work with others in the context of a lesson	Maintaining friendships
Not ready for contact with school staff Able to acknowledge the presence of school staff through their body language	Can communicate with staff if directly spoken to	Forming good relationships with one or more members of staff eg mentor	Will engage with and respond to most adults Able to work with a larger number of staff	Has formed positive relationships with most members of staff who teach them
Unable to show interest or motivation in learning Unable to focus at all due to fatigue Working on personalised/engagement activities	Can begin work with 1-1 support Able to focus for about 15 minutes Working on bespoke work/project approach	Can learn independently Can focus for an hour at a time Accessing selected parts of the curriculum, with some additional support	Can learn independently and also small groups Can focus for 2-3 hours during the day Accessing most of the curriculum, with less individual support	Can learn alongside others in a class setting Can focus for most of a school day Accessing the whole curriculum
Too much pain to attempt to come in to school Unable to challenge pain Has no skills and strategies to use	Can access school with a lot of individual support Understands that pain needs to be challenged Can sometimes manage their pain with intensive support from an adult	Has periods of time in school where pain is not an issue Can make a plan to challenge pain and begin to execute it Has learnt some skills and strategies that can help and can sometimes use them	Managing most routine things in school though will still have occasional difficult times Can identify skills and strategies that are helpful Can mostly use skills and strategies with success	Can manage unpredictable or unusual events – visits, tests Uses skills and strategies independently Knows what to do to manage self in most situations