

## Fatigue Management

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### What is fatigue?

Fatigue in general is not just an ordinary tiredness, it can be described as an overwhelming and extreme sense of tiredness, which includes both physical and emotional energy and motivation, often with no obvious cause. Individuals suffering with fatigue may:

- feel extremely tired after very little activity
- wake up feeling as tired as you did when you went to sleep
- describe their limbs as feeling heavy
- experience other symptoms, such as difficulties with balance, vision or concentration, which might also get worse temporarily.

The fatigue may be severe, fleeting or persistent and can form a vicious circle, as the tired individual is unlikely to exercise and without exercise can become lethargic. Whilst it is important to try to be more active, a balance between exercise and rest is important to restore energy. When fatigue is severe, it is a tiredness that is rarely improved with rest and can last for some considerable time. It could be triggered by certain activities or stress and can lead to frustration and then sometimes to periods of depression, especially when the fatigue is significantly interfering with life plans.

### Who might experience fatigue?

Whilst most people have fatigue at one time or another in their lives, children and young people with physical disabilities and complex medical needs may experience this regularly due to conditions such as:

- Chronic Fatigue Syndrome, Ehlers-Danlos Syndrome, Lupus, Juvenile Idiopathic Arthritis (JIA)
- degenerative conditions such as Duchenne Muscular Dystrophy or Spinal Muscular Atrophy
- certain types of cancer and the treatment they will be receiving for them.
- Traumatic and acquired brain injuries (ABI) will also cause fatigue.

For some vulnerable children, fatigue may become chronic. Chronic fatigue occurs when symptoms of exhaustion or lack of energy last over 6 months and is a symptom of many chronic conditions. It often results from sleep disturbances, usually insomnia, in combination with chronic pain, poor diet and depression. Suffering from chronic fatigue because of a disability or illness is not the same as Chronic Fatigue Syndrome.

### Chronic Fatigue Syndrome (CFS/ME)

[Chronic fatigue syndrome](#) is a state of fatigue that has lasted for at least 6 months, and that can be so severe that it gets in the way of normal daily activities, at home and at school. Rest and sleep do not seem to help. Children and young people with CSF may find that physical activity can leave them feeling worse, typically the next day, a condition called post-exertional malaise. They will tend to awaken almost every morning feeling as if they did not get enough sleep, and can often wake up a lot at night, for no apparent reason. A student with CSF will have trouble concentrating and multi-tasking, they can often feel worse after standing and remaining on their feet.

## Fatigue Management

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The condition is rare in children, but girls are more likely to develop it than boys, and the illness most often begins in teenagers between the ages of 13 and 15.

The top ten symptoms of CFS are likely to be found in children and young people with a number of conditions which cause chronic fatigue. Symptoms include:

- **Cognition difficulties:** such as brain fog. Children and adults with CFS often find that their short-term memory weakens making them feel like their thoughts often dissolve in their head. They find it hard to express their thoughts clearly in a cohesive manner and at times also face difficulty in talking and understanding speech.
- **Muscle and joint pain:** Most people with chronic fatigue syndrome experience acute or chronic pain, stiffness and soreness in their muscles and joints. The extent and severity of the pain depends on the pain tolerance of the sufferer. The pain is generally intermittent in nature, starts randomly and subsides on its own in time. It generally lasts for some weeks but can even persist for months in certain cases.
- **Erratic sleep:** An erratic sleep pattern is another common symptom of CFS. Despite feeling tired and worn out throughout the day, these individuals find it difficult to sleep at night. Some chronic fatigue syndrome patients find it difficult to wake up without feeling extremely irritated. Most people with chronic fatigue syndrome sleep only during certain times of the day, generally morning or midday, causing a reversal of their sleeping hours in the long run.
- **Vertigo:** is one of the common symptoms of CFS. Vertigo is a condition which affects a person's sense of direction and stability making it tough for them to carry out their day to day activities, normally. Vertigo patients tend to experience disorientation, dizziness, nausea, tinnitus and blurred vision. These individuals tend to fall and bump into things very often.
- **Sensitivity to external stimuli:** CFS sufferers are specifically sensitive to external stimuli such as certain smells and sounds. For example, a loud noise or a bright visual can cause extreme irritation, anger, headaches and even vomiting in chronic fatigue syndrome patients.
- **PEM: Post-exertional malaise** or PEM is characterized by a generalized state of weakness. PEM is a classic, and also one of the most debilitating, symptoms of CFS. In PEM, patients tend to experience symptoms after prolonged exertion. The complaints often include fatigue, pain, sore throat and swelling in the lymph nodes. These usually follow an intense period of mental or physical activity, like taking an exam or sporting activities.
- **Weakened immunity:** Weakening of the immune system is a long-term symptom appearing in people with CFS. Proper sleep is essential for maintaining the health of the immune system of the body. Due to lack of adequate sleep, CFS patients feel weak and drowsy and tend to lose their ability to fight infections and diseases effectively. They fall sick more often and face greater risk of developing autoimmune disorders.
- **Paraesthesia:** This symptom appears randomly in CFS individuals. Paraesthesia is a condition wherein the person experiences abnormal sensations like tingling, tickling, numbness or burning of the skin without any physical cause. It can be acute or chronic.
- **Gastrointestinal problems:** People with CFS often encounter difficulties in digesting certain foods. Some will experience intense stomach pain and bloating on eating raw

## Fatigue Management

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vegetables, while some get nauseated after consuming meat. Excruciating pain in the gut, stomach upset, indigestion, rashes and such gastrointestinal problems too are one of the common symptoms of CFS.

- **Orthostatic Intolerance:** is the inability to remain upright for long durations. It is one of the most problematic of the 10 symptoms of CFS. Usually those experiencing orthostatic intolerance often feel like sitting or lying down. This occurs as the blood pressure falls when one stands up and fails to regain stability instantly. This makes them feel dizzy and lightheaded.

### Lupus (SLE)

[Paediatric Lupus](#) is an autoimmune condition which has many presentations but mainly affects joints (arthritis and muscle pain), skin (rash on face, neck and scalp), kidneys, heart and lungs with fatigue being a significant factor. The average age for diagnosis is 12 and girls are 4 times as likely to have Lupus than boys.

There are a lot of problems that may be experienced by children after a diagnosis of Lupus eg trying to keep up with school and friends when they are feeling tired and unwell, coping with body image problems such as skin rashes and drug side effects like weight gain can be especially difficult. Lupus can cycle between flare into active disease which in children may be triggered by infections, sunlight, stress and/or exhaustion, and periods of remission.

### Ehlers Danlos Syndrome (EDS)

[EDS](#) is not a single syndrome, but rather an inherited group of conditions that affect connective tissue such as the skin, bones, cartilage, tendons, blood vessels, and more. It is important to note that there is a wide spectrum of symptoms that may occur in people with EDS. Some people are diagnosed quickly as young children, whereas others are unaware of the syndrome until they become adults. EDS can be as mild as "loose joints" or severe enough to be life-threatening.

### Neuromuscular diseases

People with neuromuscular diseases, such as: [Myasthenia Gravis](#), [Spinal Muscular atrophy](#) (SMA), Myotonic disorders, Metabolic disorders (such as McArdle's and Tarui's diseases) and Mitochondrial diseases are subject to all types of fatigue, and particularly muscle fatigue caused by their disorders. This is not the same as muscle weakness, which is more or less a constant condition caused by the neuromuscular disease. Muscle fatigue can occur any time the child makes greater demands than their muscles can handle. Fatigue also plays a huge role in the lives of those with many of the muscular dystrophies as muscles weaken and require greater energy to perform the same activities. Children with neuromuscular diseases like [Duchenne Muscular Dystrophy](#) are reportedly more concerned by their fatigue than they are by muscle weakness.

Causes of fatigue in children with neuromuscular diseases can be due to depression, boredom, stress, sleep difficulties and heart and respiratory problems. If children are not breathing easily their body has to work harder to receive the oxygen it needs which may cause the child to feel tired. Heart and lung problems may lead to fatigue. Weakened

## Fatigue Management

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respiratory muscles may lead to lowered oxygen levels during deep sleep, which in turn is likely to leave the child groggy, dull, apathetic and depressed during the day.

### Childhood cancer

Fatigue is a common and often debilitating side-effect of cancer treatment or sometimes of the cancer itself. The teenage and young adult age group are affected by this more so than younger children. Cancer-related fatigue may cause a child or young person to tire rapidly, with less physical activity than normal and this tiredness is usually not relieved by rest or sleep. The psychological effects of a cancer diagnosis, such as pain, anxiety, stress, and disturbed sleep pattern, can result in a child's feelings of fatigue.

The different types of fatigue related specifically to cancer are:

- Normal – where there is an identifiable cause.
- Pathological – where it is caused by disease process
- Situational – where it is related to stress
- Psychological – where it is related to anxiety.

### Strategies to support inclusion at school

School attendance and participation can become very challenging for learners with fatigue, which in turn can lead to mental health difficulties brought about by isolation, poor self-esteem and missing friends. The following recommendations should be considered as '*reasonable adjustments*' to support inclusion and educational progress:

- Put the **student at the centre** of planning and work around their needs
- Ensure **good communication** routes between school/student/home. This might be via email, regular telephone contact between named person at school and family, video links – review support plans at least once every 3 months
- Identify a named member of staff that the student can **liaise** with over any difficulties or worries – plan to have at least weekly contact if not daily
- Recognise that the student's fatigue levels are likely to be **variable**, ie not the same every day. This could be seasonal or vary from day to day or week to week. Support may need to be offer flexibly
- Understand that students will often push themselves beyond their limits to try to keep up with their peers. This **Boom and Bust** cycle of fatigue can lead to a flare of symptoms which mean more time out of school and low self-esteem
- Managing activity levels is recommended by helping the student to pace their activity. This is well described in the **Spoon Theory** where a student has a finite amount of energy that they can expend during the day (say 12 spoons) before they have to stop. Each activity they do will use up a certain number of spoons, eg 1 to eat breakfast, 2 to have a shower, 1 to go to school, 3 to do the work and socialise until break time. 12 spoons are very quickly used up and the student will not have any energy left by lunchtime
- Help students manage their energy levels in class by making adjustments to **reduce the amount of writing** they are required to produce, eg write a detailed essay plan rather than the whole essay, make a list rather than write in sentences – ask for quality rather than quantity

## Fatigue Management

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- Introduce and support the use of **assistive technology** to support recording, eg word prediction software for longer pieces of writing, voice recognition software for homework, screen reader to listen to information on headphones. Assistive technology is another skill for the student to learn to use see [Assistive Technology; when, where and how this can be used](#)
- Provide **support in class** to help with notetaking and in practical subjects to physically support the student
- Avoid **information overload** and be prepared to simplify language when giving information and instructions if the student is feeling fatigued
- **Part-time timetable** can either be attending school for part of the day, or part of the week. It can also mean being in school all day but not attending all lessons and having a rest break during the day, eg before lunch
- If the student is going to need to **rest during the day**, try to find a quiet and private place where they can lie down and relax. They may need to sleep for a while to recharge their energy levels
- Plan for how the student will **access the curriculum**. Part-time attendance, particularly in secondary school, can mean that the student is only working on core subjects and all of the 'fun' foundation subjects are removed. Try to keep some 'fun' lessons on the timetable to help the student feel positive about their schoolwork
- Reduce the amount of carrying the student has to do by giving them **an extra set of books** to use at home
- Give them **extended exams with rest breaks** if this is helpful. A chance to step out of the exam room and walk about or sit in a comfy chair for 15 minutes can be really helpful. Advice on exam access arrangements can be found on the [JCQ website](#)
- **Provide printouts** of worksheets and powerpoints used in lessons to reduce the need to write and allow the student to focus on their learning by just annotating their handouts
- Help to **reduce stress** by being flexible about deadlines for work. A student may need an extension on key homework if they are not well. Teachers should be ready to reassure students about which homeworks are essential and which are desirable but could be missed out if necessary
- Think carefully about how you will support the student to keep up with **missed lessons**. This could be through emailing work home, providing a topic overview, home tutoring, use of [AV1 telepresence robot](#) in lessons
- Offer and encourage the use of organizers, planners, and other tools for **time management**
- Discuss with the student about whether they want to **join in with PE**, whether it needs to be modified or use the PE lesson time for independent study, or rest
- Try to **be patient** with the student, especially during morning hours or following lunch time when symptoms are often worse
- Support **emotional wellbeing** through opportunities to talk about how things are going. It can be very challenging for high achievers to accept that they physically cannot keep up with their peers – referral for counselling may be appropriate
- Many students with chronic illnesses are encouraged to learn [CBT \(Cognitive Behaviour Therapy\)](#) techniques to help them manage the negative feelings that their condition bring

## Fatigue Management

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up. Try to pair students with chronic fatigue with a member of staff who can informally reinforce CBT strategies to help them think through their challenging times

- Do not expect the student to tell you that they are struggling without prompting. It can be really difficult for students to admit that something that they could do easily before is now too difficult or exhausting.
- It can be really helpful to have a **regular meeting** time at the end of the day to talk about what has gone well and why it was good as well as what was challenging and what could have been done to make it easier. Record what the student says and feedback to relevant teachers so that they can **adapt their planning** as necessary
- **Keep parents/carers informed** so that they can support from home and reassure the student about what teachers are expecting them to produce for homework or independent work when they are absent.
- **Review regularly with parents/student** so that any changes of need are quickly identified and adjustments to the provision plan can be amended

### Useful links

Spoon theory – a concept developed by Christine Miserandino to help people understand her fatigue caused by Lupus <https://butyoudontlooksick.com/articles/written-by-christine/the-spoon-theory/>

CBT – Cognitive Behaviour Therapy – a talking therapy that aims to help you manage your problems by changing the way you think and behave.

<https://www.nhs.uk/conditions/cognitive-behavioural-therapy-cbt/>

AV1 Telepresence Robot – the robot for children with long-term illness

No Isolation <https://www.noisolation.com/uk/av1/>