



# Multiple sclerosis (MS) and fatigue

This information sheet from Great Ormond Street Hospital (GOSH) explains about the fatigue that is a common feature of multiple sclerosis (MS). As well as describing what we know about fatigue, it also gives some suggestions to manage it.

## What is fatigue?

Fatigue is an overwhelming sense of tiredness and exhaustion that can affect both body and mind. Fatigue is a very common symptom for adults, teenagers and children with multiple sclerosis (MS), and most people with MS will experience fatigue in some way at some time.

When young people with MS have fatigue, it can be very difficult to do things like concentrate in school and take part in sports or activities. Fatigue can affect their feelings too. When fatigue gets in the way of the things they like to do, or the things they used to be able to do, it's normal to sometimes feel sad or frustrated.

Over the past three years researchers at GOSH and Kings College London have been working on a large project to help understand fatigue in paediatric MS. This has included reviewing fatigue research, undertaking interview studies and doing questionnaires with young people with MS and their parents. The aim of this study was to help understand thoughts, feelings and actions that might be linked to fatigue and in the long term to develop a treatment programme for fatigue that was specific to children and teenagers with MS.

## Why does my child have fatigue?

We don't yet fully understand why fatigue starts, but we think it begins because of the inflammation and demyelination that happens in the body because of MS.

After fatigue starts, there are many things that might keep it going, like the actions we take to try to control fatigue, or the thoughts or worries we have about fatigue. Without having the information and support your child needs to help them to understand and manage their fatigue, coping can be difficult.

## What can my child do to help their fatigue?

As fatigue is an 'invisible' symptom, it can often be misunderstood or misinterpreted by other people like family, friends or teachers. Therefore, it is important that your child tells an adult like their doctor or nurse when they have fatigue so that they can try to help you.

## Some tips to manage fatigue

Some of the things that we do to try to help us sleep actually reduce our chances of falling asleep easily. Sleep hygiene is a term that is used to describe 'tidying up' our sleeping routines and habits. Here are some tips to help your child manage fatigue:

- Have rest breaks during the day but do not go to sleep.
- Try to stick to a routine, getting up and going to bed at the same time each day, including weekends and holidays.
- Make sure the bedroom is used only for sleeping and not for homework, games or television.
- Develop a relaxing bedtime routine, for example a bath, chat or reading.
- Your child should not use any screens (including smart phones) for at least 30 minutes before bed. This helps 'switch off' the most active part of our brains.
- They should not expect to fall asleep straight away, this happens for very few people and as we get older will happen less and less.

- The more we worry, the harder it is to fall asleep so try to avoid pressure to sleep.
- If they are struggling to sleep, they could occupy their brain with another task such as some relaxation techniques, audio books or gentle music.
- If they really cannot sleep after an hour then they should get out of bed and do something quiet and sedate for 15 minutes.
- And finally..... no matter how badly they have slept or what time they went to sleep, they should get up at the usual time the next morning.

Learning to manage fatigue takes considerable effort on the part of the individual, and support with this is available at GOSH through the psychology department and with special fatigue management programs through occupational therapy. Please ask for a referral.