



Understanding narcolepsy

Henry Nicholls looks at narcolepsy and the effects it can have on education.

I consider myself fortunate to have developed narcolepsy in my early 20s rather than at school, as I was old enough to be able to recognise the changes that were taking place in my brain, explain them clearly to a doctor and get referred to a sleep specialist in less than two years.

Those who develop narcolepsy when they are children are not always in a position to do this and a diagnosis can be many years, even decades in coming. A young person living in this diagnostic limbo is at a significant risk of being bullied, labelled as stupid or lazy, and leaving school with miserable memories, poor grades and rock-bottom self-esteem. An early diagnosis, access to medication and, crucially, the

support of family, friends and teachers, can mitigate many of these outcomes.

Narcolepsy is reckoned to affect one in 2,500 people, which makes it about as common as cystic fibrosis. This means that in a large secondary school, there's a reasonable chance there will be a least one student with narcolepsy. In a career spanning 20 years, a teacher will almost certainly have had a pupil with narcolepsy. If not, it's

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not because they weren't there, it's just that nobody had spotted the signs.

There are, after all, plenty of other explanations for sleepiness. During puberty, the brain changes the way it responds to light such that a teenager can shift from being a morning lark to a night owl. Going to bed late and getting up early for school every day of the week results in chronic sleep deprivation, a phenomenon that probably accounts for the vast majority of sleepiness in teens. But in and amongst these, there may be one or two with a genuine sleep disorder like narcolepsy.

One of the most common causes of narcolepsy is an autoimmune attack, in response to an infection, which can wipe out a tiny population of neurons in the brain that are crucial for the regulation of sleep. This autoimmune attack can strike at any age, though adolescents appear to be particularly vulnerable, with the average age of onset being around 15. Once the cells have gone, they've gone, so narcolepsy is a lifelong, incurable disorder.

The loss of these neurons affects everyone differently, but it always results in what clinicians refer to as 'excessive daytime sleepiness', an irresistible need to sleep during the day. For some, these bouts of sleep can be quite sudden, but often there will be an excruciating internal battle to stay awake that can last for tens of minutes. This time can be filled with micro-sleeps, where the person with narcolepsy appears to be awake and even continues with routine activities like writing, but their brains are flitting in and out of consciousness and they will have little or no recollection of what has been going on around them. It takes some practice to spot the signs, but if a student frequently has dead eyes, languid eyelids, slurred speech, fails to follow even basic instructions and the quality of their written work sometimes drifts over the course of a sentence, it may be a case of narcolepsy.

The underlying cause of the condition — the loss of these sleep-regulating neurons — also explains several other add-on symptoms that frequently accompany the sleepiness. These may not be obvious in the classroom but, being that bit more unusual, it is these extra symptoms that are often the key to diagnosis.



BIO 

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As with other disabilities, supporting a student with narcolepsy involves knowing the individual and responding to their individual needs.



Around 75% of people with narcolepsy also experience cataplexy, where an emotion (most often mirth, though also anger, fear and stress) causes paralysis of muscles, just as occurs during the rapid eye movement (REM) stage of sleep. The strength of these REM attacks varies from mild (with barely perceptible twitching of muscles around the mouth) to strong (where knees buckle and there is a full-on collapse). A cataplectic seizure looks a lot like sleep, except that there is no loss of consciousness. A child with cataplexy quickly learns that isolation from social situations where laughter is common, is the most effective way to prevent an attack; a coping strategy that can have devastating psychological consequences.

Many people with narcolepsy will also experience sleep paralysis i.e. waking up in the night only to find they cannot move, their muscles paralysed once more by remnants of REM. This unsettling experience is frequently accompanied by the fourth symptom, hypnagogic hallucinations, in which there is a perception of something or someone in the bedroom, often with murderous and or sexually abusive intentions. The fifth and somewhat paradoxical feature of narcolepsy is fractured night-time sleep, broken by such frequent bouts of REM that deep, restful sleep is simply unobtainable. These last three symptoms all contribute to serious sleep deprivation, which may go some way to accounting for the utter exhaustion during the day, every day. Although intellectual capacity is unaffected, without help many of these children will simply be unable to achieve their academic potential.

With a diagnosis, there are medications that can help which include stimulants as well as sedatives to consolidate night-time sleep and improve cataplexy. The dose and timing of these treatments is very important and many students, particularly younger ones, will need help from staff to ensure they can access and take their medications at the right time. These drugs, however, are often only partially effective.

Lifestyle changes can be just as effective as medication, if not more. Being in a bright, sunlit classroom is beneficial for all students but especially those with narcolepsy, with the wavelengths of light emitted during the day having a direct, alerting effect upon the brain. If the room is too warm, however, this will quickly drive a person with narcolepsy to sleep; this can be a particular problem in winter when the radiators go on!

If a child does fall asleep in class, it's usually best to leave them for around 10 minutes before gently waking them up and helping them to rejoin the lesson. Some pupils with narcolepsy may want to be near the back so that if sleep strikes they will not draw too much attention, while others prefer to be at the front as the more interactive the lesson the less likely sleep becomes. Even if there is no obvious sleep, the micro-sleeps and dips in consciousness mean that it is extremely helpful to differentiate

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by providing written instructions for any complex tasks or activities. Given the opportunity, most students with narcolepsy will work hard to catch up on anything they have missed so a take-home summary of the lesson is useful too.

For many people with narcolepsy, a key lifestyle change is to build a nap into their routine, at the same time every day if possible. The duration will vary from one person to the next, but 10-30 minutes is usually sufficient. These have an immediate beneficial effect, increasing alertness and the ability to resist further sleep attacks. Ideally, a young person with narcolepsy would have access to a quiet, safe and discreet environment in which to take these scheduled naps, though some will resist the attention that this affords. When it comes to exams, it is helpful if the school can negotiate additional time to allow for planned naps and arrange for a member of staff to be on hand to prompt them should they fall asleep.