

INFORMATION FOR SCHOOLS

NARCOLEPSY & CATAPLEXY: CHILDREN IN SCHOOL

This note is intended to provide information for schools on the condition for Narcolepsy and to provide some guidance for schools on the possible accommodations which can be made for children suffering from this condition in schools.

1. ABOUT NARCOLEPSY

- It is a neurological condition, which causes a malfunction of the sleep/wake mechanism in the brain. Sufferers go into dream (REM) sleep within minutes of falling asleep.
- It is an embarrassing condition.
- It is relatively rare.
- It neither shortens the lifespan nor impairs a child's inherent mental and physical capabilities. However, this condition impacts on educational and social aspects of life.
- Narcolepsy sufferers feel every day, as if they have been awake for 36 hours.

2. THE MAIN SYMPTOMS OF NARCOLEPSY ARE:

- **DAYTIME SLEEPINESS** – this is not due to lack of interest, but simply because the child cannot resist the urge to sleep. This may last for a few seconds or a few minutes. The urge to sleep is very powerful. It does not normally happen during physical activity but will happen if he/she is sitting or not fully involved in an activity. Triggers may be certain temperatures, subjects, and teaching styles.
- **CATAPLEXY** – this is a momentary loss of muscle tone and comes in the form of slight tremors, eyelids drooping, head slumping and lolling to the side, jaw dropping and slightly slurred speech. He/she can also get some leg buckling if he/she laughs a lot. It looks as if he/she is drunk – many adult narcoleptic sufferers are wrongly accused of either being drunk or under the influence of drugs. Cataplexy can occur without cause, but is often brought about by strong emotions, the main ones being surprise, laughter and fear.

He/she is aware of what is happening when he/she has a cataplexy attack, he/she can have many of these every single day. He/she will recover very quickly – within seconds. He/she is unlikely to be harmed by cataplexy unless he/she was in an unsafe environment.

- **AUTOMATIC BEHAVIOUR** – narcoleptics are unaware of automatic behaviour. He/she may appear to be concentrating or studying when in fact he/she is not really “with it”. He/she may find when he/she comes out of it that he/she has doodled or carried on writing something that does not make sense.
- **DISTURBED NIGHT TIME SLEEP** – it is wrong to think that narcoleptics are so sleepy that they will sleep well every night. In fact the opposite is true. He/she may wake several times every single night. Narcoleptics often suffer from

nightmares and hallucinations, either on falling asleep or on waking. Nightmares and hallucinations do not occur every night but are not unusual. These can understandably be very frightening. Poor night-time sleep contributes to more sleepiness next day.

CHILDREN WITH NARCOLEPSY CAN SUFFER WITH SOME OF ALL OF THE ABOVE SYMPTOMS.

3. POSSIBLE ACCOMODATIONS IN SCHOOL.

- 1 Please allow him/her to move around in his/her chair – he/she may need to “stretch” or move his/her legs a lot, in order to try to keep himself/herself awake.
- 2 Please do not make him/her feel responsible for making up for work he/she may have missed or be slower at. He/she wants to keep up.
- 3 Please do not keep him/her in at break times to catch up on work. He/she needs his/her break time to move around and wake himself/herself up.
- 4 He/she may need to leave the lesson to have a 5-10 minute nap. He/she will feel very refreshed after just 10 minutes. It would be helpful if schools had a rest room or rest area.
- 5 Please consider a buddy system whereby other pupils can take notes of a good standard for him/her.
- 6 Extra academic support may be required. Schools may make provision for extra learning support for children with narcolepsy from their General Allocation Model provisions or Learning Support allocations.
- 7 He/she may “fight” sleep and endeavour to stay awake. He/she may tell you he/she is not sleepy, but that does not mean however that he/she is fully alert and ready to function in class. If he/she falls asleep at his/her desk please allow him/her to have 5-10 minutes and gently wake him/her. This can be very embarrassing for him/her and he/she may wake in the middle of a dream.
- 8 Please be aware of his/her condition when testing him/her, either formally or informally. To test him/her late in the morning or at the end of the day would be like asking an adult to do a test at 3am.
- 9 He/she can be extremely tired at the end of the school day; to do homework may be very taxing for him/her.
- 10 Where a child with narcolepsy has been absent for a significant proportion of the school year due to their medical condition, application may be made for home tuition support for such a child under the terms of Department of Education and Skills Home tuition scheme. (DES Circular supp
- 11 Where a child with Narcolepsy is participating in a state exam and may require additional supportive accommodations, schools may apply to the State Exams Commission under the Scheme of Reasonable Accommodations for such accommodations.

4. OTHER CONSIDERATIONS

In class he/she may miss anything from a few seconds to a few minutes without this being obvious. If however this is key information it will render the rest of the lesson bewildering and meaningless.

Some days are very different to others; sleepiness occurs at random times.

Narcolepsy sufferers have difficulty remembering information given to them when they are sleepy.

Over time the child with unmanaged narcolepsy demonstrates academic deterioration, falling grades, difficulty completing assignments and memory problems (Wise and Lynch: Seminars in Paediatric Neurology, Dec 2001).

5. WHAT TO DO

Where it has been identified to a school that a child is suffering from the condition of Narcolepsy, please make all members of staff who are dealing with this child aware of this condition and bring this information note to the attention of those staff.

Where a school considers that a child may be displaying symptoms of narcolepsy but where a diagnosis of narcolepsy has not been brought to the attention of the school, the school should raise their concerns with the child's parents/guardians, so that they may seek the advice of their GP.

Schools may, if necessary, seek guidance from their National Educational Psychological Services Psychologist or National Council for Special Education Special Educational Needs Organiser regarding accommodations that they can make for children with narcolepsy.