

Narcolepsy

Narcolepsy is a chronic neurological disorder caused by the brain's inability to regulate sleep-wake cycles normally. At various times throughout the day people with narcolepsy experience fleeting urges to sleep. If the urge becomes overwhelming, patients fall asleep for periods lasting from a few seconds to several minutes. In rare cases, some people may remain asleep for an hour or longer.

In addition to daytime sleepiness, three other major symptoms frequently characterize narcolepsy:

- **cataplexy**, or the sudden loss of voluntary muscle tone.
- vivid **hallucinations** during sleep onset or upon awakening;
- brief episodes of total **paralysis** at the beginning or end of sleep.

Narcolepsy is not rare, but it is an under recognised and under diagnosed condition. There are no indications that narcolepsy is inherited. But familial clusters are known to occur. Factors, such as infection, immune-system dysfunction, trauma, hormonal changes or stress, may also be present before the disorder develops.

Experts have also begun to recognize that narcolepsy sometimes contributes to certain childhood behavioral problems, such as attention-deficit hyperactivity disorder, and must be addressed before the behavioral problem can be resolved. If left undiagnosed and untreated, narcolepsy can pose special problems for children and adolescents, interfering with their psychological, social, and cognitive development and undermining their ability to succeed at school. For some young people, feelings of low self-esteem due to poor academic performance may persist into adulthood.

Developmental Areas

Children may display some of the following characteristics

Social and Emotional Development

- May become easily upset and frustrated with her/himself or others
- May exhibit inappropriate behaviours that result in a negative reaction from peers
- May have low self esteem
- May be withdrawn and go unnoticed
- May require help with 'self-help' tasks

Physical Development

- May experience difficulty with visual-motor integration
- May have poor motor co-ordination
- May have delays in fine motor skills

Language and Communication Development

- May experience difficulties in producing some speech sounds
- May have difficulty in keeping up with a two way conversation
- May have poor listening skills
- May have lack of attention
- May not be able to follow simple instructions

Cognitive Development

- May have had limited concrete experience with the environment
- May have developmental delay due to increased hospital visits
- May act impulsively without considering the consequences
- May have learning difficulties
- May be unable to stay at a task for long enough to complete
- May find new tasks frustrating

Narcolepsy Inclusion Strategies

Each child diagnosed with **Narcolepsy** will be different and individual. It is important to gain information from the parents as to what characteristics of **Narcolepsy** their child displays. It is important to work closely with the parents as well as any additional support specialists e.g. therapists who may be involved with the child. It is also important to gain an understanding from the parent as to what is the most important aspect of their child's needs when attending your service. What is it that parents hope to gain from using your service? The following inclusion strategies are just some examples which may be applied to support the inclusion process. This list is only the start and it is dependant on a variety of factors such as environment, length of time child is in care, child's interest, likes, dislikes and skills already achieved. The strategies are divided into developmental areas; however some strategies overlap and assist in a variety of developmental areas.

Social and Emotional Development

- Encourage and plan for positive social experiences e.g. small group experiences.
- Provide activities that enable each child to achieve within their own personal best.
- Provide activities that identify the limits and rules of the service.
- Provide activities that assist in developing a child's self help skills.

Physical Development

- Provide some fine motor and gross motor activities.
- Make the physical activities achievable for each individual child. Identify ways that activities can be modified.

Language and Communication Development

- Provide activities that allow the child to practice sounds to assist in developing stronger fine motor muscles.
- Label pictures with words/symbols to assist a child's response in communication.
- Provide activities that enable the child to develop listening skills e.g. provide sounds with musical instruments, ask the children to make the sound they have heard.
- Give instructions and activities in single steps i.e. one at a time.

Cognitive Development

- Utilise activities that provide a cause and effect response to develop an understanding of considering the consequences.
- Ensure tasks are able to be achieved by the child considering the complexity of the task in relation to the child's skills.

Reference

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Kozma, C. & Stock, J. (1993) **Caring for every child—Ideas to meet diverse needs in Child Care**. Funded by the Commonwealth department of Human Services and Health : Sydney

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