Factsheet

Narcolepsy

british society of pharmacy sleep services

Definition

Narcolepsy is a rare (approx 1 in 2,000), disabling long-term brain disorder that can result in excessive daytime sleepiness, sleep attacks, cataplexy, sleep paralysis, excessive dreaming and disturbed nocturnal sleep.

Symptoms

There are two types of Narcolepsy.
Narcolepsy Type 1 (NT1) and Narcolepsy Type 2 (NT2).

Excessive Daytime Sleepiness (EDS) is the most common symptom in most cases. Sleepiness can be overwhelming especially during monotonous situations and can be accompanied by performance deficits.

Sleep attacks can occur in more severe cases and can occur when the patient is engaged in active states e.g. driving, eating, walking etc, These episodes can be short but tend to be refreshing.

Patients can often present with automatic behaviours e.g. carrying on writing when they've drifted off to sleep, because sleep periods can invade wake periods.

Fatigue and tiredness are frequent.

Cataplexy is the only specific symptom of narcolepsy. Cataplexy is sudden episodes of bilateral, short-lasting loss of muscle tone and usually triggered by sudden emotions such as laughing. Consciousness is reserved throughout the attack. The attack can range from a mild jaw drop, tongue protrusion (in children), eyelid closure (partial attack) to falls (complete attack). The frequency of these attacks can vary from several per day to a few per year and can last from seconds to a few minutes.

The British Society of Pharmacy Sleep Services is a Charitable Incorporated Organisation. Reg.: 1198553 | For more information visit https://bspss.org/

Narcolepsy

Symptoms (contd.)

Sleep paralysis and hallucinations are also common features occurring in 50% - 60% of cases.

Nocturnal sleep is fragmented and disturbed with recurring wake periods.

Sleep disordered breathing (SDB), periodic limb movements (PLMS) and REM sleep behaviour disorders (RBD) are frequently seen in conjunction with narcolepsy.

Overall quality of life is greatly impaired with cognitive and metabolic disturbances common as well as psychiatric and psychological problems.

It should be noted that the clinical presentation is similar in both types of narcolepsy (NT1 and NT2). However, in patients with NT2 cataplexy is absent, EDS tends to be milder as well as decreased frequency of sleep paralysis and hallucinations.

Investigations / Assessment

Classification of both Narcolepsy type 1 (NT1) and Narcolepsy type 2 (NT2) is based on criteria as per International Classification of Sleep Disorders (ICSD) 3.

Patients should be referred to a sleep specialist when the diagnosis is based on their clinical history. Misdiagnosis is not uncommon.

Epworth Sleepiness Scale (ESS) is usually 18 or more.

Correct identification of cataplexy is crucial as it is the only specific sign of narcolepsy (NT1 only). A validated tool for diagnosing cataplexy does not exist. The Swiss Narcolepsy Scale can be used and has a high sensitivity rate for the diagnosis of NT1.

The British Society of Pharmacy Sleep Services is a Charitable Incorporated Organisation. Reg.: 1198553 | For more information visit https://bspss.org/

Narcolepsy

Investigations / Assessment (contd.)

The Multiple sleep latency test (MSLT) is the most common test used to help make the diagnosis of narcolepsy. This should be done in conjunction with nocturnal polysomnography (PSG). The MSLT is used to measure mean sleep latency and assess for the presence of SOREMS (sleep onset REM).

The most sensitive and specific test for narcolepsy is measurement of hypocretin 1 (orexin) in cerebrospinal fluid (CSF). Decreased levels of hypocretin 1 (orexin) is found in 95% of cases with cataplexy.

Possible treatments available

Treatment can be complex but treatment objectives should include control of sleepiness and other sleep related symptoms if present. Management of narcolepsy (NT1 and NT2) relies on several classes of drugs as well as behavioural interventions.

Pharmacological treatment options for adult patients with narcolepsy as per the American Academy of Sleep Medicine (AASM) 2021 guidelines, include:

- Modafinil
- Pitolisant
- Sodium Oxybate
- Solriamfetol
- Armodafinil
- Dextroamphetamine
- Methylphenidate

Pharmacological treatment options for paediatric patients with narcolepsy as per AASM 2021 include:

- Modafinil
- Sodium Oxybate

About The British Society of Pharmacy Sleep Services

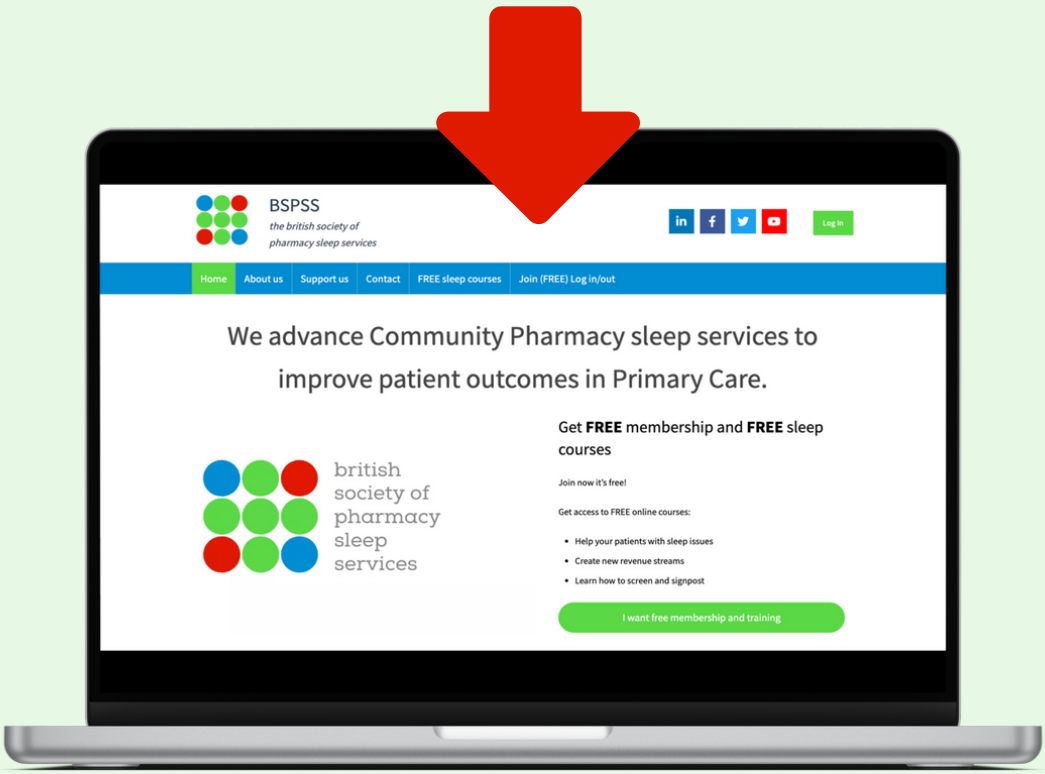
Our independent research established that the general public 'often' to 'very often' consult a community pharmacist about suspected sleep disorders.

We aim to empower the community pharmacist to assess, screen and recognise these individuals in order to help patients progress rapidly to appropriate care.

The BSPSS was established in 2021 to plug the disconnect between sleep expertise and the public, and in 2022 we became a registered charity.

We recognise the community pharmacist as the front-line healthcare professional.

Click here to take your learning further with free BSPSS membership, training and support



The British Society of Pharmacy Sleep Services is a Charitable Incorporated Organisation. Reg.: 1198553 | For more information visit https://bspss.org/