Sleep disorders are extremely common in children with neuromuscular disorders. The main sleep problems that occur are hypoventilation, sleep fragmentation and poor quality sleep, obstructive sleep apnoea, obstructive hypoventilation and behavioural sleep disorders.

Muscle weakness causes a number of problems during sleep. The most problematic is impaired gas exchange due to muscle weakness, leading to low oxygen levels and high carbon dioxide levels during sleep (hypoventilation). Hypoventilation is important to recognize as it usually first appears during sleep and progresses to daytime hypoventilation, respiratory failure and death. The symptoms of hypoventilation are non-specific and include tiredness, fatigue, headaches (especially when waking) and nausea. Low oxygen levels can also cause poor weight gain and learning difficulties. Unfortunately, these symptoms can be difficult to detect, particularly in children who may not be able to describe symptoms. Many of these symptoms are also caused by the underlying neuromuscular disorder and may not be recognized as a consequence of hypoventilation. Patients who do not normally hypoventilate can develop hypoventilation during a lower respiratory tract infection due to increased lung collapse (atelectasis) and increased secretions. Lower respiratory tract infections are very common in children with neuromuscular disorders due to weak and ineffective cough, oro-motor problems and restrictive lung disease.

Impaired gas exchange during sleep causes the brain the briefly wake during sleep (arousal) to restart breathing. This interrupts the sleep cycle and when it occurs repeatedly during the night it leads to poor quality sleep from sleep fragmentation. As a consequence, sleep is often disrupted in neuromuscular disorders and affected patients feel very sleepy during the day. It is important to monitor sleep quality as daytime tiredness may be the first clue to impaired gas exchange during sleep and hypoventilation.

Another common cause of sleep disruption in neuromuscular disorders is night care, particularly in those that are non-ambulant. Patients will often require turning during the night to avoid pressure areas and skin breakdown, which is very disruptive. Leg pain due to muscle damage is another common cause of waking at night, and this is exacerbated by pathological bone fractures from osteoporosis. If overnight gastrostomy feeds are required, this can further interrupt sleep.

Due to low muscle tone, patients with neuromuscular disorders are at risk of obstructive sleep apnoea. This occurs due to collapse of the weak airway muscles during sleep, particularly in REM (dreaming) sleep. When the airway becomes collapsed and blocked,
there will be a pause in the breathing. The brain will partially awaken (arousal) to start breathing again. Long airway collapses (more than a few seconds) can also impair gas exchange, lowering oxygen levels and increasing carbon dioxide levels. This can be severe enough to cause hypoventilation from repeated airway obstruction during sleep. Older children are also at risk of obstructive sleep apnoea due to growth of the tonsils with age, and weakness of facial muscles can exacerbate airway narrowing with growth.

Behavioural sleep disorders are common in children of all ages, and extremely common in children with neuromuscular disorders. Sleep onset association disorder (where children are unable to fall asleep without a certain condition, often comforting from a parent or a bottle) often occurs when children have a prolonged hospital admission and their routine is disrupted. Behavioural sleep disorders can be very difficult to treat, and parents may be reluctant to address these problems due to the complexity of the medical needs of the child. Anxiety is a common co-morbidity in children with neuromuscular disorders, particularly those with learning disorders or intellectual impairment (for example Duchenne Muscular Dystrophy). As anxiety can exacerbate behavioural sleep disorders, it is important to specifically enquire about worrying and difficulty with sleep initiation in these patients. It is common for behavioural sleep disorders to masquerade as medical sleep disorders, and if there is any doubt a sleep study should be arranged to exclude hypoventilation or obstructive sleep apnoea.

Circadian sleep disorders (especially delayed onset sleep phase) is common in adolescents, and late sleep time may have a significant impact upon a teenager who already has poor quality sleep from hypoventilation or obstructive sleep apnoea. Disruption of the sleep wake cycle is also very common in patients with visual impairment or after a prolonged hospital admission. Melatonin can be useful in treating circadian disorders, but a sleep study should always be performed before prescribing any medications with the potential to impact upon sleep to avoid worsening hypoventilation or obstructive sleep apnoea.

The combination of hypoventilation, sleep disruption from medical care, obstructive sleep apnoea, impaired gas exchange during sleep, behavioural sleep disorders and circadian disorders can cause significant sleep fragmentation and daytime fatigue in patients with neuromuscular disorders. Even though patients with neuromuscular disorders may sleep for long periods of time, it is not unusual for them to experiencing poor quality sleep due to all of the above factors. Unfortunately, sleep disorders are often poorly recognized in these disorders, particularly as many of the symptoms can also be caused by the underlying disorder. It is imperative that all patients with neuromuscular disorders are regularly reviewed by a respiratory specialist with an understanding of sleep disorders. As poor sleep has a significant impact upon the quality of life, sleep problems must be routinely asked about and monitored.