Sleep

A Guide for Parents

CEREBRA

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Thank you.

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Introduction

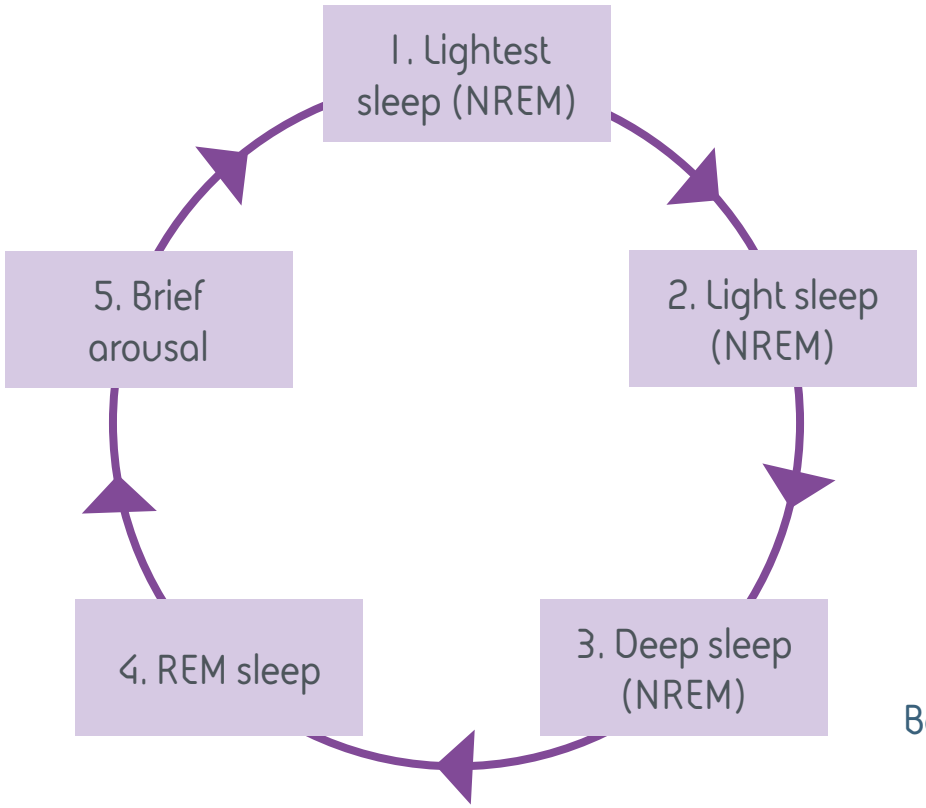
This guide has been developed to help parents understand the nature of sleep problems in children with intellectual disability and what can be done to improve sleep. Part one describes common sleep problems in individuals with intellectual disability and how these sleep problems are assessed. Part two gives a brief overview of sleep problems in specific genetic syndromes. Part three outlines some strategies which may help to reduce or improve sleep problems. A glossary of key terms (highlighted in blue) and list of useful resources are provided at the end of this guide.

Part One

What is sleep?

Sleep, rather than just being a time when the brain 'switches off', is actually an active process essential for survival. Both the brain and body are active during sleep and are involved in vital processes and functions, ranging from resisting infection through to consolidating memories. In children, sleep is important for growth, with certain stages of sleep associated with the release of growth hormones[1]. Poor sleep can result in irritability the next day, as well as poor memory, low mood and impaired concentration in both children[2] and adults[3]. Equally, good quality sleep is important for ensuring good physical and mental health.

Sleep is made up of four different stages, which cycle several times throughout the night (see Box 1). Each cycle ends with a 'brief arousal', which may only last a few seconds. These brief arousals are not usually remembered the next day.



Box 1. The stages of sleep

Sleep begins with light non-rapid eye movement (NREM) sleep (Stage 1 in the diagram overleaf). During lightest sleep, we feel as though we are awake but we are drifting off to sleep. After this, NREM sleep becomes progressively deeper and when in the deepest stage (sometimes called 'slow wave sleep') it is difficult for others to wake us up. After that we enter a brief period of rapid eye movement (REM) sleep. During this stage of sleep, our breathing and heart rate tend to be less regular than in NREM sleep and we may experience dreaming. A brief arousal then occurs before we go through gradually deepening stages of NREM sleep and then more REM sleep, as the cycle is repeated. The length of time spent in each stage changes as the cycles continue.

The amount of sleep an individual requires to feel refreshed varies between different children (regardless of their stage of development) but also changes with age. The American Academy of Sleep Medicine[4] has suggested the following guidelines for typically developing children. There is significant natural variation in the amount of sleep that healthy, typically developing children require. Nonetheless, these guidelines are also likely to be relevant to children with intellectual disability:

Age	Amount of sleep recommended per 24 hour period
4-12 months	12-16 hours (including naps)
1-2 years	11-14 hours (including naps)
3-5 years	10-13 hours (including naps)
6-12 years	9-12 hours
13-18 years	8-10 hours

What is a 'sleep problem'?

A good night's sleep does not necessarily mean uninterrupted sleep for the recommended number of hours. In individuals with and without an intellectual disability, it is normal to wake up a few times in the night. This only becomes problematic if the individual is unable to go back to sleep. In children and adults with intellectual disability this may also have an effect on other members of the family. See page 12 on "What impact do sleep problems have?" for more information about the impact of sleep problems on other members of the family.

Individual differences are also important to consider because some people feel refreshed after only five or six hours of sleep, whereas others feel tired even after ten. Importantly, even though the amount of sleep one child needs may differ to the amount of sleep another child needs, each child's own need for sleep seems to remain constant[5]. For example, someone who needs eight hours of sleep is likely to need about eight hours every night in order to feel refreshed.

How sleepy or awake an individual feels varies within the 24 hour period, according to the internal 'body clock' (circadian rhythm). Generally, we feel sleepy during the earliest hours of the morning and most alert in the early evening[1]. Levels of sleepiness also fluctuate during the day, so that most people will feel tired in the early afternoon too[1]. However, there are individual differences. Some people may prefer to be awake later into the evening and sleep in later the following morning ('night owls'). 'Morning larks', on the other hand, tend to wake up earlier than others and become tired earlier in the evening[6]. It is important to remember these individual differences when thinking about what constitutes a sleep 'problem'. Remember that if your child's sleep pattern is affecting him/her or you/your family, then it is worth thinking about in order to identify some possible solutions.

Sleep problems can be divided into several categories:

- **Insomnia**

  This refers to problems such as having difficulty settling to sleep, waking early in the morning or during the night and not being able to return to sleep. This occurs despite the individual having adequate opportunity for sleep (e.g. spending ten hours in bed). Some researchers and clinicians would also include sleeping for an adequate amount of time but not feeling refreshed in this category of sleep problem. Unlike people who feel refreshed after just a short sleep, those who experience insomnia find that these difficulties impact their ability to function day to day. The majority of this guide will focus on describing insomnia and some strategies which may be helpful in reducing it.

- **Excessive daytime sleepiness**

  This is where an individual lacks energy and feels sleepy throughout the day, despite apparently sleeping adequately the night before. The individual feels either less alert or sleepier than would be expected from the normal population. This is not the same as 'laziness'. Sometimes individuals who experience Excessive daytime sleepiness do actually fall asleep in the day. Younger children may be over-active or restless and struggle to concentrate when experiencing Excessive Daytime Sleepiness.

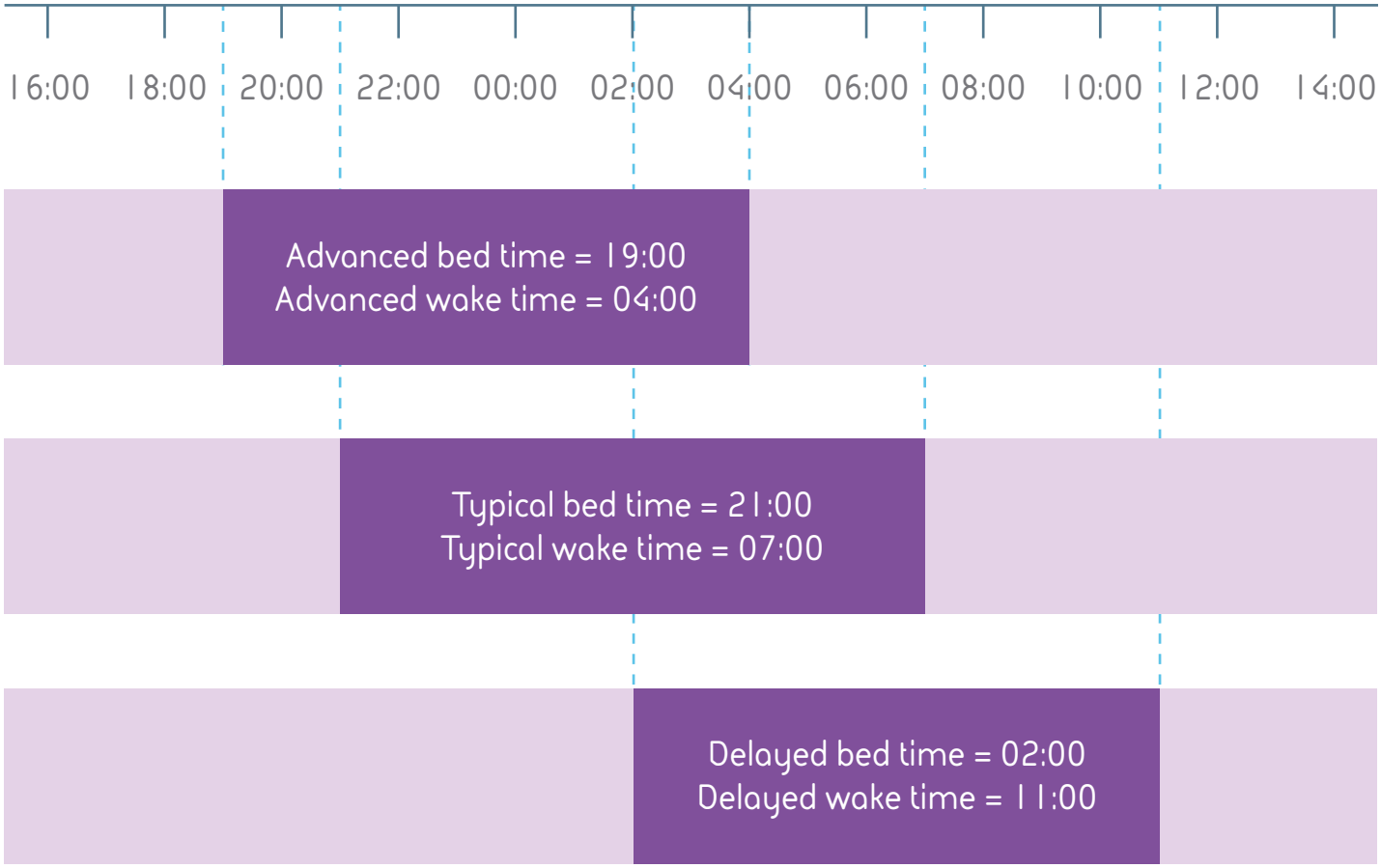
- **Parasomnias**

  Parasomnias refer to unusual movements or behaviours which can happen at any stage of NREM or REM sleep. Examples include sleep-walking, nightmares and sleep paralysis.

Other types of sleep problems include sleep-related movement disorders (such as nocturnal head banging), sleep-related breathing disorders (such as sleep apnoea) and circadian rhythm sleep-wake disorders.

Sleep-related breathing disorders are more common in certain genetic syndromes associated with intellectual disability (particularly those with characteristic cranial-facial differences, see Part Two on page 16) than in the general population. When we sleep, the muscles in our upper airways relax slightly and breathing becomes more difficult than when we are awake. This is normal but can be more problematic for some people and they will experience lots of brief arousals due to these breathing difficulties. The most common sleep-related breathing disorder in children with intellectual disability is obstructive sleep apnoea (OSA)[7]. Individuals with OSA experience brief periods during sleep where the airway is obstructed by this relaxation of the muscles for 10 seconds or more, causing them to wake. These brief obstructions interrupt the sleep cycle described in the "Stages of sleep" diagram in Box 1 on page 4, and so although the wakings are not usually remembered, individuals who experience OSA do not feel refreshed even after long periods of time in bed[8].

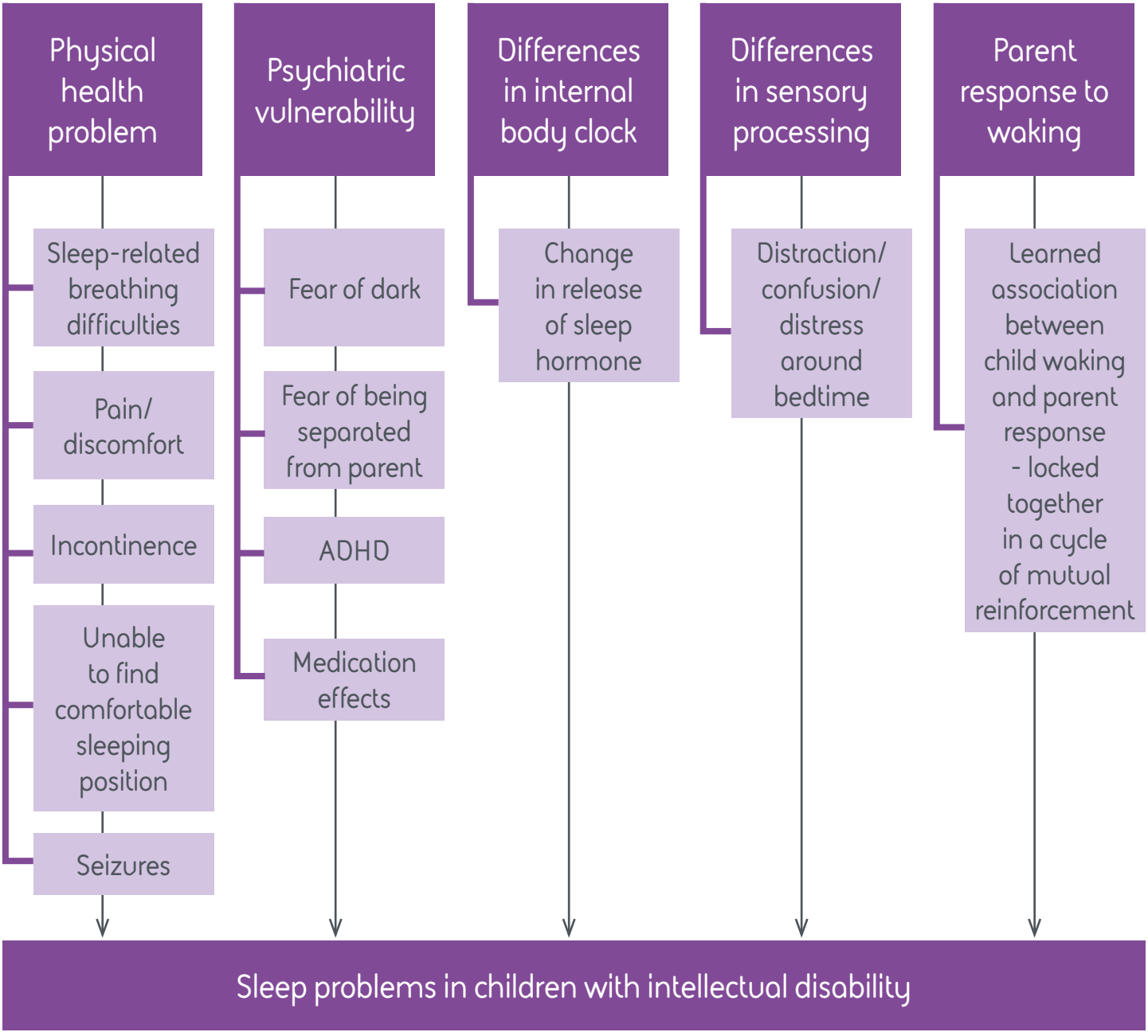
Circadian rhythm sleep-wake disorders refer to a group of sleep problems linked to the internal 'body clock' (see 'Differences in internal body clock' on page 10). For some individuals, this means that sleep patterns typical for their age are either advanced or delayed by several hours (see Box 2 below). For example, if an individual has advanced sleep-wake disorder they will fall asleep much earlier than most other people. This means their sleep needs are likely to be met before other people naturally wake up[1]. In delayed sleep-wake disorder, individuals fall asleep much later than other people. Chronotherapy[9] is often a last-resort treatment for delayed sleep phase circadian rhythm disorder because it involves keeping an individual awake later and later in the day. The idea is that by shifting an individual's bedtime to progressively later (for example by three hours a day), the sleep schedule will eventually advance to the desired sleep time. However, this is obviously practically very difficult to stick to, and so other strategies are recommended first (see Part Three on page 19).



Box 2. A pattern of bedtime and morning wake time characteristic of circadian rhythm sleep-wake disorders, compared to a typical bedtime and morning wake times, for a 14 year old child.

How common are sleep problems?

In the general population, fewer than 3 out of 10 children are estimated to experience sleep problems[10]. This figure is even greater (about 8 out of 10[11]) among children with an intellectual disability, whose sleep problems also tend to be more severe and persistent. Very few research studies have looked at why this is the case but there are certain aspects of health and behaviour that are known to be more common in children with intellectual disability. The following section presents some ideas about how these characteristics could be associated with a sleep problem in children with intellectual disability (Box 3).



Box 3. Pathways to problems with sleep in children with intellectual disability, explained below.

Physical health problems

Children with intellectual disability often experience physical health problems associated with pain and discomfort. Being in pain and/or uncomfortable can interfere with sleep, particularly if the health problem restricts clear breathing as in obstructive sleep apnoea. Asthma can also disrupt sleep because of narrowing airways and frequent coughing and wheezing[12]. Many children with sleep problems are also reported to have eczema, suggesting they may be kept awake because of the itching/burning sensations[13]. Other health problems (such as epilepsy, severe allergies, muscular problems, gastro-oesophageal reflux, dental problems, middle ear infections) may also prevent the individual from finding a sleeping position which is comfortable[14] and may be treated with medications which also affect sleep (for example, anti-epilepsy medication[15]).

Given the high rate of both sleep and physical health problems in individuals with intellectual disability, it is very important to seek medical advice if your child/the child you care for is experiencing reduced or disturbed sleep. This should help to rule out any underlying physical cause. Further information about assessing whether the individual may be experiencing pain can be found in the "How are sleep problems assessed?" on page 13 and in Cerebra's Pain guide, which is listed in the Resources section on page 26.

Psychiatric vulnerability

Mental health difficulties such as anxiety and depression are common in individuals with intellectual disability and may be linked to sleep problems. Although everyone experiences worry and low mood from time to time, when these emotions occur persistently they may start to impact everyday life and sleep. Many children who experience anxiety have difficulty settling to sleep and wake frequently during the night[16], possibly due to fears around being alone or the dark. These problems can become more severe in children with intellectual disability who may not be able to communicate their anxiety in the same way as children without an intellectual disability. For some children, waking in the night to find things different to the way they were when they went to sleep can trigger anxiety. For example, if a child falls asleep with a parent in their bed and a certain song playing, if they wake later in the night and the parent and music are not still there this can be anxiety provoking. This may make it difficult for them to get back to sleep again. For further information on anxiety in individuals with intellectual disability, read Cerebra's Anxiety Guide, which is referenced in the Resources section on page 26.

Additionally, many children with intellectual disability also have Attention Deficit Hyperactivity Disorder (ADHD). ADHD is associated with insomnia, excessive daytime sleepiness and parasomnias[17].

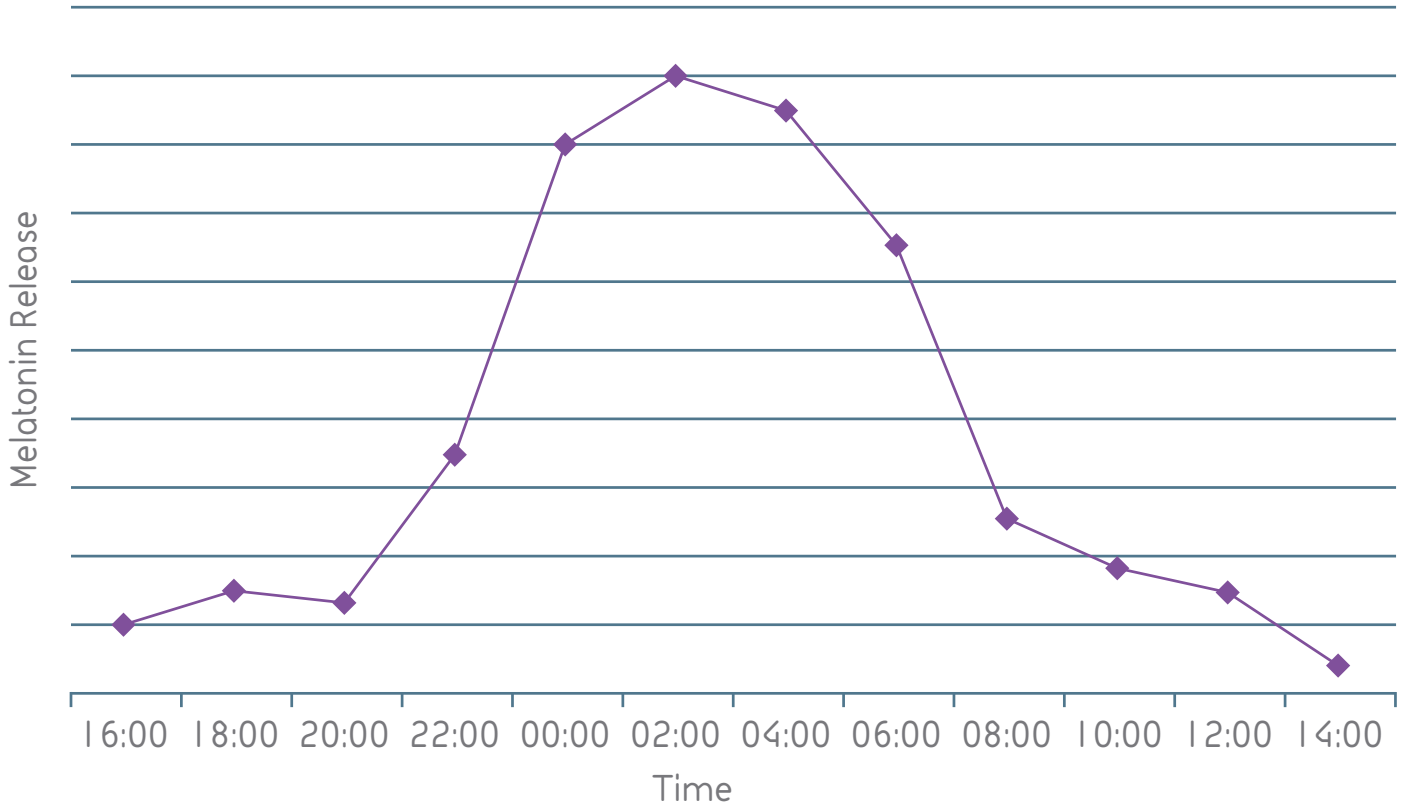
Some medications prescribed for anxiety, depression and ADHD may influence sleep. For example, ADHD may be treated with stimulant drugs which can cause insomnia or hyperactivity close to bedtime[17] whereas some antidepressants have been linked to sleepwalking and other parasomnias[1].

Differences in sensory processing

Some children with intellectual disability also experience differences in the way they process sensory input (e.g. flavours, smells, sights, sounds, textures) compared to children of the same age without an intellectual disability. This can sometimes make them more sensitive to certain sensations, which may lead to distraction, distress, fear or confusion around bedtime and sleeping[18]. For example, some children may be irritated by the texture of a label in their pyjamas. Removing unwanted sensory input and taking extra care over developing a bedtime routine and other aspects of sleep hygiene (see Part Three on page 19) may be helpful for children who have sensory difficulties.

Differences in internal body clock

Individuals with intellectual disability may also have differences in the internal 'body clock' which controls sleep and wakefulness (circadian rhythm). This internal body clock is guided by the individual's environment which indicates time, such as meal times, social contact and the 24 hour light-dark cycle. Melatonin is a hormone released by the brain to promote sleep in response to decreasing light in the afternoon and evening (see Box 4).



Box 4. The typical release pattern of melatonin.

Some children with intellectual disability may be less sensitive to these indicators[7] or may experience them differently to children without an intellectual disability – resulting in a sleep pattern which may not conform to the typical 24 hour period. This may be a particular problem for children who are born blind, because their internal body clock cannot be guided by indicators from the light-dark cycle. Instead they will need to rely on other indicators to train their circadian rhythm. In some genetic syndromes, notably Smith-Magenis syndrome, the circadian rhythm may be inverted[19]. This means that the hormone which initiates sleep (melatonin) is released at the 'wrong' time so that individuals are sleepy in the day and alert during the night. For more information on sleep difficulties in specific genetic syndromes, see Part Two on page 16.

Parent response to waking

As in children without an intellectual disability, sleep problems in children with intellectual disability can also be influenced by parent response to waking. Due to understandable concern about their children's welfare, all parents may unintentionally reinforce the behaviours their children show when they wake up. For example, by allowing a crying child who has woken in the night to come into their bed (something the child may find rewarding i.e. something they are likely to want to access again) or providing them with long periods of physical or verbal comfort. For children who enjoy adult interaction, even being 'told off' for waking up and making noise can be rewarding. This means that the child learns an association between crying when they wake and accessing

the attention/comfort/reprimand again. This is not a conscious process, and may initially occur because children cannot (rather than will not) find any other way to settle themselves back to sleep. As a parent or carer of a child with an intellectual disability you may be more concerned about your child's waking than other parents might be, perhaps because of their associated health problems or challenging behaviours and this makes this problem more difficult than it is for a typically developing child.

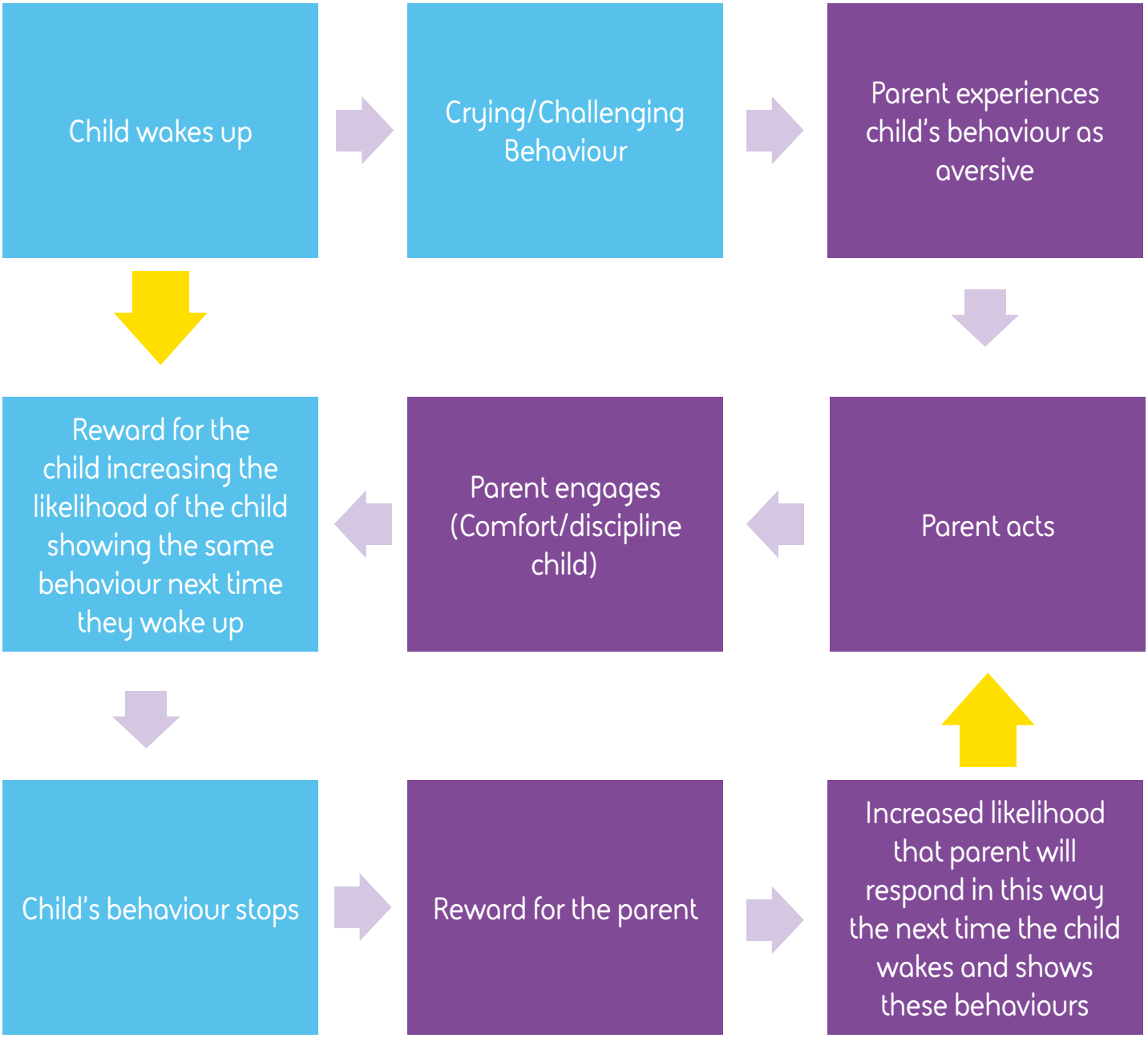
Although a child's sleep problem may have initially started because of one of the factors listed above, it may be maintained by these interactions with concerned parents which unintentionally reinforce the behaviour shown when waking. This means it is more likely to continue. For example, if a child wakes up in the middle of the night and cries out, resulting in their parent waking, entering their room, providing comfort and singing to them until they fall back to sleep, the child is likely to associate their waking with these rewarding parent behaviours. This is called a learned association. This means that over time the child associates waking with the immediate soothing presence of the caregiver, and so does not learn to re-settle themselves to sleep.

Waking problems may also occur when children do not learn to fall asleep independently. Often children fall asleep whilst feeding, or in bed with a certain caregiver – meaning they learn to associate falling asleep with the presence of that adult. If, during the brief arousal between sleep cycles, they fully awaken and the adult is not there, they may struggle to self-soothe (i.e. fall back to sleep by themselves). Instead they may cry out until their parent returns to settle them off to sleep again. By responding to these cries, the child's behaviour after waking is unintentionally reinforced by the parent's presence and this creates a learned association (that the adult must be there for them to fall asleep).

This learning is a two-way process. On the child's part, if parent responses are not immediate, the child may continue to cry and may start to show other unwanted behaviours until the reinforcing response is provided. Once the response is provided, the child is more likely to show these crying and unwanted behaviours when they next wake because these behaviours are effective in gaining the parent's attention. This is not a conscious process on the child's behalf but an unintended learned association.

For the parent, if the child's crying becomes louder and more distressed and if other unwanted behaviours emerge, the parent may find this increasingly difficult to ignore. Eventually, they might go in to engage with the child. This may be to comfort, reprimand, offer something or remove something. Eventually, the child's distress and behaviour reduces and they return to sleep. When the child returns to sleep, the parent is also reinforced (by a sleeping quiet child!) and therefore the next time child wakes and cries out, the parent is more likely to go in to them. Again, this is not a not a conscious process but an unintended learned association.

Over time, these two cycles of reinforcement can lock together making it challenging to break the learned associations. This is the process of mutual reinforcement, best explained in Box 5 on the next page, with child behaviour and reinforcement in blue and parent behaviour and reinforcement in purple.



Box 5. The mutual reinforcement process.

Parenting a child with an intellectual disability can be very challenging, and when parents' own sleep is affected by their children's sleeping problems, it may be more likely that parents will do whatever it takes to get their child to return to sleep. However, it is important to consider how your behaviour as a parent or caregiver may be unintentionally reinforcing your child's sleep problem in order to put into practice the intervention ideas suggested in Part Three on page 19.

What impact do sleep problems have?

Although the odd night of poor sleep may not affect daily abilities, persistent sleep problems can have a huge impact on individuals with and without intellectual disability and their friends, families, colleagues and carers. For all individuals, lack of sleep is associated with problems with mood, learning, memory and behaviour.

Learning

Importantly, poor sleep affects motivation and concentration[20], which means that individuals who are experiencing sleep problems may make more errors at school/work, particularly on repetitive tasks. This means that if your child is struggling on 'easier' tasks at school (which are often repeated until they are ready to move on to harder tasks) it is worth speaking to their teacher, who may be under the impression that they are struggling because of their intellectual disability, rather than the sleep issues[21]. Sleep is also vital to a process called memory consolidation[22], where memories from the day (e.g. memory of what is learned at school) are strengthened. If sleep is disrupted these memories may not be stored properly, making it harder for children to use what they have already learned during the next day at school.

Challenging behaviour

Poor sleep may also reduce an individual's ability to cope with changes in their routine. You may notice that your child shows more challenging behaviour (for example, self-injury, aggression, destruction) when they have not slept well the night before[23]. This is common in children with intellectual disability and also in children and adults of typical development! We are all more irritable when we have not slept well and are therefore more likely to show behaviours which indicate that we would like certain tasks to end or situations to change. Since individuals with intellectual disability may have limited ways to communicate their feelings and preferences, challenging behaviour can be a very effective way of indicating needs or desires (for example for a task to be taken away). It is natural for parents/carers/teachers to want to respond quickly to the challenging behaviour, which means that it is more likely to occur again the next time they want a task to be removed. For more information on mutual reinforcement of challenging behaviour, see "Parent response to waking" on page 10, and also Cerebra's guide on Self-injurious behaviour which is listed in the Resources section on page 26.

Parents of children with intellectual disability therefore have a lot to do: comforting children with sleeping problems, acting as an advocate for their child's learning and health, and managing challenging behaviour. Often parents and family members experience a loss of sleep themselves, which can make managing these aspects of parenting more difficult and may even contribute to low mood[24] and impaired concentration. It may feel as though your child's sleep problem is out of your control or that you do not have the time/resources to invest in fixing it. However, after thorough assessment, there are some simple intervention strategies available in Part Three on page 19 which can help to improve sleep.

How are sleep problems assessed?

The previous sections have described some of the different types of sleep problem and possible factors which may contribute to their development. Since sleep is clearly much more complicated than just 'switching your brain off', tailored intervention for each type of sleep problem is very important. You may be tempted now to skip straight to the end of this guide and get started on fixing the problem! However, it is really important to assess sleep problems thoroughly before attempting any of the intervention strategies described in Part Three on page 19. This helps us to understand the likely root of the sleep problem and the best way to tackle it.

The first step in assessing an individual's sleep would be to complete a sleep diary (see Box 6), and answer some questions about the individual's sleep habits, settling and waking behaviours. This allows caregivers and professionals to see how long the child sleeps for, what happens when they wake (for example any challenging behaviour) and the general pattern of waking.

Sleep Diary

Child's Name: Parent/ carer's Name:

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Date							
Time of waking in morning							
Mood upon waking							
Times of naps during the day							
Time started preparing for bed							
What time did the child go to bed?							
What time did the child get to sleep?							
Time(s) of waking during the night (e.g. 2:30am, 4am etc...)							
What did you (parent/ carer) do?							
Length of time(s) taken to fall asleep again							
Total no. of hours sleep							

Box 6. An example sleep diary, used by Cerebra's sleep practitioners. For more on the work of Cerebra's sleep service, see page 25.

However, sometimes parents are not exactly sure when their child actually falls asleep (this may be much later than when they are put to bed, which could indicate a "settling to sleep" problem) or what behaviour children show in their own bedrooms after the lights have been turned out. In these cases, some parents find using a video camera in their child's bedroom helpful. This helps them to ensure that the child is safe, and also to see what behaviours they do show when they wake up. This may be particularly useful for parents who suspect their child may be experiencing parasomnias.

Live or video behavioural observation could also be used to identify whether children may be experiencing pain which could be affecting their sleep. An important part of assessment of sleep problems is ruling out any possible underlying medical factors. Since we know that children who are in pain or discomfort have more sleep problems (see "Physical health problems" on page 9), it may be that health difficulties are preventing a good night's sleep. Although some children with intellectual disability may be able to communicate verbally that they are in pain, in others it may be more difficult to tell.

Box 7 outlines the Face, Legs, Activity, Crying and Consolability (FLACC) Pain Scale – which any parent or caregiver can use to look for non-verbal indicators of pain in their child. You simply have to watch your child for ten minutes and then score them on each FLACC subscale. A score of zero on each of the subscales refers to no pain-related behaviour (e.g. face subscale includes 'No particular expression or smile') and a maximum score of two on each subscale refers to behaviours which are indicative of high levels of pain (e.g. face subscale includes 'Frequent to constant quivering chin, clenched jaw'). These scores are added together to produce a total from zero to

ten. A total score of zero indicates that this child shows no or few behavioural indicators of pain, while higher scores represent a greater number of behavioural indicators of pain. For further guidance on use of the FLACC, see Cerebra's Pain guide, which is listed in the Resources section on page 26.

The FLACC Pain Scale

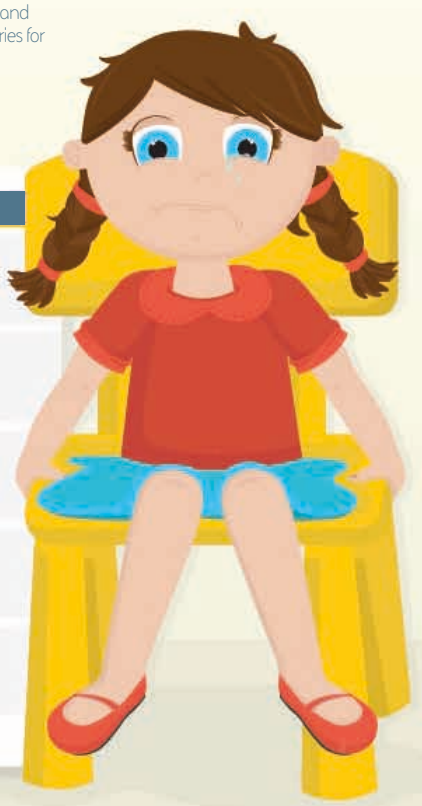
Sometimes it is difficult to assess pain in children who are non-verbal. The FLACC Pain Scale is a system that can help parents and professionals assess pain levels in children who have limited or no expressive communication. The diagram shows the categories for scoring. Zero, one or two points are given to each of the five categories: Face, Legs, Activity, Cry and Consolability.

Interpreting the Behaviour Score
Each category is scored on the 0-2 scale, which results in a total score of 0-10

0	relaxed and comfortable	4-6	moderate pain
1-3	mild discomfort	7-10	severe discomfort of pain or both

Categories ▼	Score Zero ▼	Score One ▼	Score Two ▼
Face F	No particular expression or smile	Ocasional grimace or frown, withdrawn, disinterested	Frequent to constant quivering chin, clenched jaw
Legs L	Normal position or relaxed	Uneasy, restless, tense	Kicking or legs drawn up
Activity A	Lying quietly, normal position moves easily	Squirming, shifting back and forth, tense	Arched, rigid or jerking
Cry C	No crying (awake or asleep)	Moans or whimpers, occasional complaint	Crying steadily, screams or sobs, frequent complaints
Consolability C	Content, relaxed	Reassured by occasional touching, hugging or being talked to, distactable	Difficult to console or comfort

If a child is showing these behaviours, it doesn't necessarily mean that they are in pain, as some of the behaviours measured by the FLACC scale can happen for other reasons. However, parents are advised to follow up high scores with a professional.



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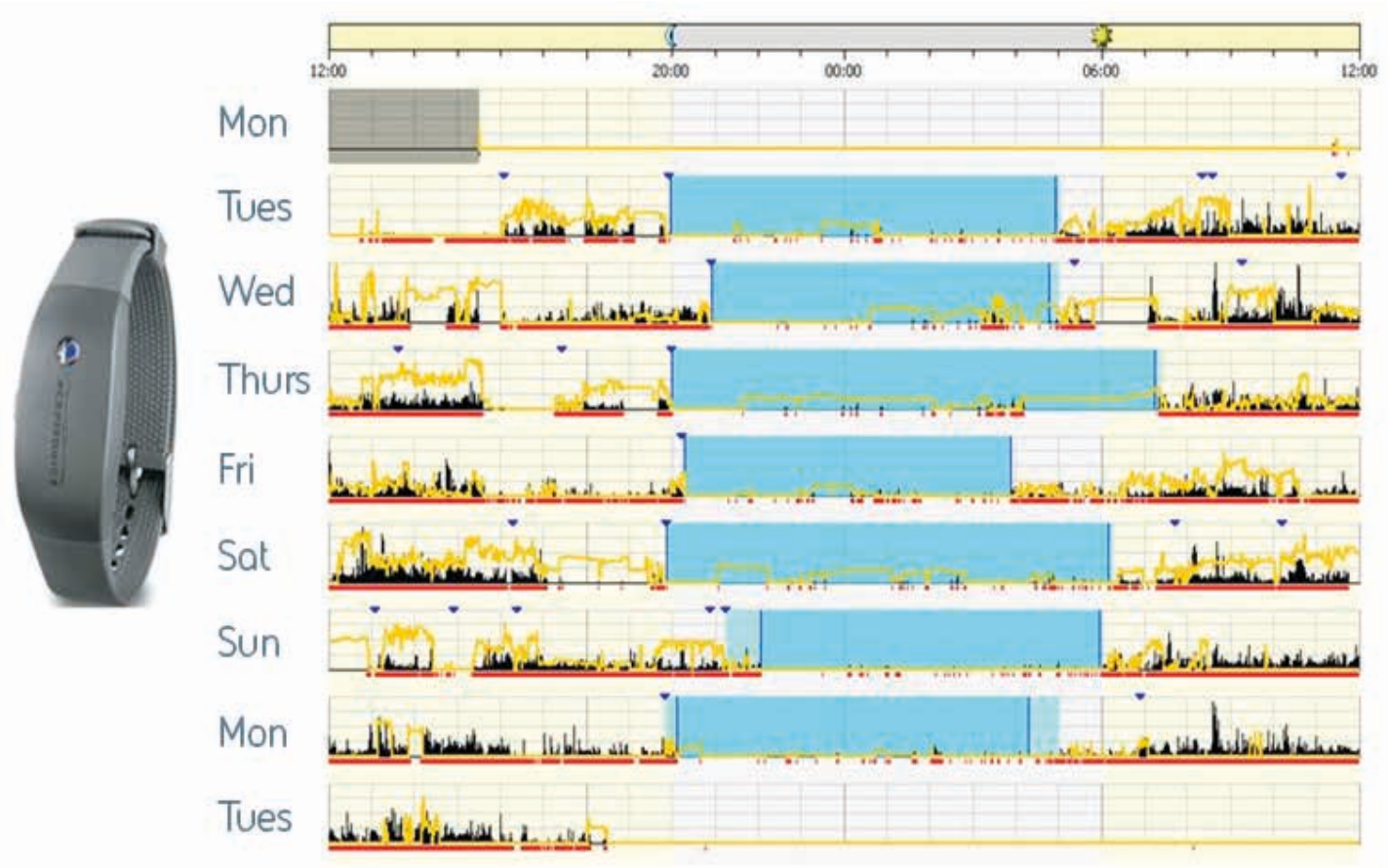
REFERENCE Merkel, S.I., Voepel-Lewis, T. Shayevitz, J.R., and Malviya, S. (1997). The FLACC: A behavioural scale for scoring postoperative pain in young children. *Pediatric Nursing, 23(3), 293-297.*

Box 7. The FLACC assessment of pain-related behaviour.

Where sleep-related breathing disorders are suspected, polysomnography (PSG) is recommended. This involves sleeping for at least one night (preferably more) in a sleep laboratory. The individual's brain wave activity, leg, eye and muscle movements, oxygen levels and breathing effort are monitored alongside other specific biological measurements whilst they sleep. From these measurements, recommendations for certain sleep problems can be made. However, this approach relies on the assumption that children are able to sleep in a sleep laboratory whilst attached to various wires and monitors, and also that this night's sleep will be typical for them despite all of the changes to their environment.

Actigraphy studies are useful for investigating whether circadian rhythm sleep-wake disorders are suspected. In these studies, children wear an actigraph (see Box 8), around either their wrist or their ankle. This is a small device which measures an individual's activity levels and estimates sleep onset, morning wake time and any night time wakings shown in an actigram (see Box 8). Actigraphy can be cross-referenced with parental sleep diaries and gives a useful insight into what parents may not be aware of in terms of their children's waking and nightime activity.



Box 8. An actigram and the output it produces, taken from a study funded by Cerebra. The light blue interval shows where the child is asleep and the black lines indicate activity. From this and a sleep diary, researchers can identify the time the child went to sleep, any wakings after sleep onset and the overall sleep efficiency (time spent asleep divided by time in bed).

Part Two

Sleep in genetic syndromes

As outlined in Part One, there are a variety of sleep problems commonly experienced by children with intellectual disability. Recent research funded by Cerebra suggests that the cause of a child's intellectual disability can be an important factor in contributing to the pattern of sleep problems they may experience, though it is important to recognise that these patterns are not inevitable for all individuals with these syndromes. Therefore, Part Two gives a brief overview of sleep problems in some specific genetic syndromes, where published research is available. These are listed in alphabetic order.

Angelman syndrome

Angelman syndrome (AS) occurs when the genetic material on chromosome 15 (inherited from the mother) is missing or altered. The exact prevalence of AS is unknown, but estimates suggest that it occurs in between 1 in 10,000 and 1 in 40,000 people[25]. Sleep problems are common, particularly early waking, night time waking and difficulty settling to sleep[26]. Other behaviours such as night time teeth grinding, sleep walking, sleep-disordered breathing and sleep paralysis are also reported[27]. Sleep problems in AS may be linked to epilepsy, which occurs very frequently in individuals with AS[28].

Cornelia de Lange syndrome

Cornelia de Lange syndrome (CdLS) is most commonly caused by deletions to the NIPBL gene, but can also be caused by changes to other genes. It affects approximately 1 in 40,000 people. Around 50% of children with CdLS[29] are reported to experience sleep problems, usually problems with falling asleep or waking in the night. Daytime sleepiness and falling asleep in the daytime are also common in children with CdLS[29], and sleep disordered breathing occurs more in CdLS than in the general population[30]. Gastro-oesophageal reflux and epilepsy also occur frequently in CdLS, which may be linked to the sleep problems (see Part One for further explanation of the links between physical health conditions and disrupted sleep).

Cri du Chat syndrome

Cri du Chat syndrome (CdC) occurs in 1 in 37,000 to 50,000 live births. It is caused by a missing piece of genetic information on chromosome 5. Sleep difficulties are reported in 50% of children with CdC, with problems falling asleep and frequent night wakings the most common[31]. A small percentage of children with CdC also wake early and struggle to return to sleep. Snoring is very common in CdC, as is anxiety around going to sleep, meaning that many children with CdC insist on a complicated bedtime routine or ritual and need a security object before going to sleep[32].

Down syndrome

Down syndrome (DS) is a relatively common genetic syndrome, occurring in 1 in 700 births[17]. It is caused by trisomy 21 – a third copy of the chromosome 21 (typically developing individuals have one pair of each chromosome, one inherited from their mother and one from their father). This copy of the chromosome may be full or incomplete. Sleep problems are relatively common in DS, particularly difficulty with settling to sleep and waking frequently in the night[33]. Obstructive sleep apnoea is also common in DS (affecting 31 – 100% of children[33]), possibly due to the characteristic craniofacial features of the syndrome[17].

Fragile X syndrome

Fragile X syndrome (FXS) is a genetic syndrome which results in changes to a specific protein (FMRP). FXS occurs in around 1 in 2,500 to 5,000 males and 1 in 6,000 females, and around half of individuals with FXS are reported to experience significant sleep problems[34]. The most commonly reported sleep problem in individuals with FXS is difficulty settling to sleep, as well as frequent night wakings. These night wakings tend to reduce as individuals get older. For some people with FXS, daytime sleepiness and restless sleep are also problematic.

Kleefstra syndrome

Kleefstra syndrome (KS) is an extremely rare genetic syndrome (prevalence estimated at 1 in 200,000) which is caused by a deletion of the genetic material on chromosome 9. According to very early research, sleep patterns seem to vary in children with KS, but early waking and waking in the night are common problems. A small group of children with KS have sleep-related breathing disorders.

Prader-Willi syndrome

Prader-Willi syndrome (PWS), which affects 1 in 20,000 to 1 in 25,000 live births, occurs when information is missing on the copy of chromosome 15 which is inherited from the individual's father. Sleeping problems are relatively common in PWS[35], particularly excessive daytime sleepiness which continues into adulthood[36]. This may be linked to sleep-related breathing disorders, which are common in PWS[37]. The REM stage of sleep is also believed to be reduced in individuals with PWS.

Smith-Magenis syndrome

Smith-Magenis syndrome (SMS) is caused by a deletion, or in some cases an alteration, of parts of the genetic material on chromosome 17. SMS occurs in roughly 1 in 15,000 to 25,000 live births[38]. Sleep problems are very common

in SMS with 88% of individuals reported to experience them[39]. In particular, difficulties with settling, night and early waking and excessive daytime sleepiness are noted. These sleep difficulties have been linked to a change to the normal sleep-wake patterns[40] seen in individuals with SMS – instead of releasing the hormone melatonin at night, the amount of melatonin naturally produced may peak during the day so that individuals with SMS may feel tired at different times to individuals without SMS. For this reason, many children with SMS may have earlier bedtimes than other children of the same age[40], and wake earlier.

Tuberous sclerosis complex

Tuberous sclerosis complex (TSC) is caused by a change in one of two genes, located on chromosomes 9 and 16. These changes can result in various growths developing in different areas of the body, including the eyes, brain and skin. Some individuals are affected so mildly that they do not know that they have TSC, whilst others are more severely affected. It is estimated that TSC occurs once in every 6,000 births[41]. Children and adults who are more severely affected are reported to have more sleep problems. Research into sleep in TSC is still in its early stages but there is some evidence that children with TSC have problems settling and wake frequently in the night[42]. Individuals with TSC may also wake early and experience excessive daytime sleepiness[42]. Epilepsy is particularly common in TSC (affecting up to 90% of individuals at some point in their lifetime[43]), which may be linked to the sleep problems.

Williams syndrome

Williams syndrome (WS) is caused by deletion of many genes on the long arm of chromosome 7. The syndrome affects 1 in 7,500 individuals[44] and although there is little research conducted on sleep difficulties in WS, available studies suggest that the rate of sleep disturbance is high[45] including problems settling (such as bedtime resistance and sleep anxiety[45]) and night waking. Excessive daytime sleepiness has also been reported in individuals with WS, even when they appear to have had a good amount of sleep the night before[46]. Many individuals with WS also experience bed-wetting[47].

As the above sections demonstrate, although there are specific types of sleep problem which may be associated with certain genetic syndromes (such as very early morning waking in Smith-Magenis syndrome), there are also lots of similarities between syndromes. In most of the syndromes (with the exception of Kleefstra and Prader-Willi syndromes), for example, problems with settling and frequent night waking are the primary concern. This suggests that although some sleep problems have specific causes within each syndrome, others may have a shared cause across syndromes. These shared causes may include common health difficulties, cranial-facial differences, sleep-related breathing disorders, bedtime anxiety, a combination of these factors or any other factor which makes children with intellectual disability more likely to experience a sleep problem (see "How common are sleep problems?" on page 8).

If there are shared causes of sleep problems, intervention strategies which target some of these behaviours are likely to be effective for children with different genetic syndromes who are experiencing the same type of sleep problem. Crucially, this means that though having a child with a particular syndrome associated with a specific sleep problem may put them at greater risk for that problem; it's still possible that changing some of the other risk factors could lead to vast improvements. Therefore careful assessment of the sleep problem is vital before attempting intervention strategies in Part Three. This should involve some combination of the steps outlined in Part One, taking into account some of the common difficulties reported in your child's genetic syndrome.

Part Three

Intervention for sleep problems in individuals with intellectual disability

There are two main types of intervention for insomnia: behavioural and pharmacological (medical). For some children, medical prescription of melatonin, a naturally occurring hormone which makes you feel tired, can help them get to sleep faster and for longer, and reduce night wakings[48] but for others it is not so effective[49]. Overall, parents tend to report that melatonin helps their child to get to sleep, but not to stay asleep[50]. Importantly, melatonin must be used alongside other strategies to ensure that conditions are appropriate to promote sleep. For example, melatonin won't be very effective for a child who is drinking a coke and playing video games at midnight, but it may help a child who is able to be calmed in a dimly lit bedroom. Melatonin is not licensed for children's use in the UK, but may be prescribed 'off-label' by your GP alongside sleep hygiene and other strategies[51].

For other sleep problems, such as obstructive sleep apnoea, other approaches would be more appropriate – for example Continuous Positive Airway Pressure (CPAP), or surgery.

This guide focuses on a few key behavioural intervention techniques, largely adapted from a book by Mark Durand. This book is included in the Resources section on page 26. These interventions may improve sleep in individuals with intellectual disability. Of course, there may be other techniques that you may come across and would like to try (e.g. chronotherapy, relaxation techniques etc.) but these are beyond the scope of this guide.

Before starting any of the intervention strategies described in this section, it is important to take into account the type of sleep disturbance experienced by the individual. Keep a sleep diary for at least two weeks prior to beginning intervention (see the example diary provided in Part One). Thorough assessment is needed before starting any intervention and you may wish to consult with a health professional who knows your child before you begin. It is important to ensure thorough assessment and treatment of any painful physical health problems before beginning any behavioural interventions as pain may be causing or maintaining the sleep problems (as discussed in Part One). Some strategies are more appropriate for certain types of sleep problem, while others can be used (with some adaptations) for multiple problems. Some are likely to be effective more quickly than others, while others take longer but may be 'easier'. Choose whatever works for you, your child and your family, and be prepared to trial a few options. Above all, do not give up! It may take some time but research shows that these strategies can be effective[52].

Sleep hygiene

Good sleep hygiene is important for good quality sleep in all adults and children. Sleep hygiene refers to good habits which help an individual to get regular, good quality sleep[53]. You may have tried some of these techniques before but don't skip this section! Some aspects of sleep hygiene are likely to be more relevant to you and your child than others but it is important to consider the following list, regardless of the type of sleep problem they are experiencing:

- ### Routine

  For many children (with and without an intellectual disability), a 30-60 minute bedtime routine can be a helpful way of signalling that 'play time' has transitioned into 'sleep time'. This should be directed by the parent, but can involve activities that the child prefers and finds soothing. For example, you may choose to include a bath in the bedtime routine, but if your

child finds water very stimulating this may not be a helpful soothing activity. Common steps in the routine might include changing into pyjamas, brushing teeth, reading bedtime stories. Ensure that you end the routine with a phrase or action (e.g. a special goodnight song) which indicates that it is now time for sleep. Importantly, this must be something that could be completed again if the child wakes up in the night. You may wish to complement the bedtime with a visual schedule to show the child the order of activities. Keep the order and timing of the routine the same each night, and avoid the temptation to extend the routine to just one more story! One important exception to this should be made for children with Autism Spectrum Disorder (ASD) or ASD characteristics. These children may become very fixed in their routine and then not be able to sleep unless the full routine is completed. For these children, consider allowing variation in the order of aspects of the routine to prevent the routines from becoming too rigid (e.g. Day 1: bathtime, then brushing teeth, Day 2: brushing teeth, then bathtime).

- ## Caffeine

  Although a bedtime snack can sometimes be a helpful aspect of the bedtime routine, chocolate and drinks such as tea, coffee and several fizzy drinks contain caffeine which can interfere with sleep. Make sure that these are not consumed 6 hours before bedtime.

- ## Exercise

  Do not be tempted to provide lots of activity as part of the bedtime routine to 'tire children out'. Exercise raises the internal temperature of the body and can prevent us from feeling drowsy at bedtime. Instead try and limit energetic activity in the final hour before bedtime and instead engage in calming activities with your child. Exercise can be helpful throughout the day so try scheduling it 4-6 hours before bedtime. This will lead to the body temperature dropping again at just the right time for your child to feel drowsy.

- ## Timing

  Putting your child to bed and waking them at the same time each day can also be helpful. Work out how many hours of sleep your child needs (using the recommendations in Part One of this guide and your sleep diary), and what time they need to be awake for school. Count the recommended number of hours of sleep backwards from the ideal wake time to work out the ideal bedtime.

- ## Bedroom environment

  Ensure that a child's bed is associated with sleeping, not with playing; so if possible do not keep toys in the bedroom (or put them away in cupboards as part of the bedtime routine). This strategy is called "stimulus control", where the bed, bedroom and bedtime routine all signal sleep. If your child is awake in bed for more than 20 minutes, they will associate being in bed with being awake, rather than with being asleep. Consider moving them downstairs until they feel sleepier. Be careful not to engage in energetic activities in this period. Check your child's bedroom for noise levels, temperature, light or anything else which might be disturbing their sleep. For example, extended hours of daylight in summer can cause problems with settling and early waking, so fitting blackout blinds may be helpful.

- ## Sleep associations

  Ensure that, as far as possible, the environment that your child falls asleep in is the same as it would be if they were then to wake during the night because this will be reassuring for them when they wake. For example, if your child settles to sleep with a night light on, do not turn that off once you have checked they are asleep. This should be a particular priority for children who experience anxiety around bedtime.

- **Screen time**

  It is also important to try and limit use of devices which emit bright light (such as televisions, computers and tablets) close to bedtime. This is because just 10 minutes of light exposure interferes with the brain's production of the 'sleepy' hormone, melatonin[53]. The Sleep Council's 'Good Night Guide for Children', which is listed in the Resources section on page 26, recommends turning off all screens in the hour before bedtime. If the use of a tablet is an essential, non-negotiable part of your child's bedtime routine before bed or upon waking during the night, you could install an application to filter out blue light (the particular 'wave' of light which interferes most with melatonin). These can be downloaded from the app store on iOS or on Android devices.

If, once you feel confident about your child's sleep hygiene and bed time routine, the sleep problem persists, consider trialling one (or more) of the following strategies. Bear in mind that your child may show some challenging behaviour in response to these techniques (see Cerebra's Self-injurious Behaviour guide, included in the Resources section on page 26) – and this behaviour may seem to get worse at first. This is normal – keep going. It is usually best to try one strategy at a time, ensuring you are being as consistent as possible.

What should I do when my child just will not go to sleep?

Often settling problems can be caused by a lack of bedtime routine or perhaps the bedroom being associated with activities other than sleep. However, even after establishing a calming bedtime routine, it may be that your child does not want to go to sleep and cries out to you. This may be distressing for you as a parent to hear and your natural reaction may be to go back into your child's bedroom. As described in Part One, this may be contributing to the problem, and so the next step for intervention would be to stop reinforcing the settling problem.

This may require 'ignoring' your child's cries, which is known as extinction. However, this can be very difficult for parents and children, so graduated extinction is recommended[54].

Agree a set amount of time (e.g. 2 minutes) that you will allow your child to cry for, before briefly checking on them.

1. When your child has been crying for the 2 minutes, go in and check them. This checking should only be to reassure yourself that the child is alright and to tell them to go back to bed. When you check on them, do not offer physical interaction, music, or any other aspect of the bedtime routine.
2. Leave the room and wait the agreed time before repeating the checking procedure.
3. You may have to repeat this many times before your child eventually falls asleep, so it's a good idea to start on a Friday night or another evening where no one has school or work the next day.
4. The next night, gradually increase the amount of time you allow before checking on your child (e.g. from 2 minutes to 4 minutes), and continue to keep the checking procedure brief.
5. Repeat this until the child's crying at settling reduces.

If the suggested times here are too long, try just waiting for one minute before checking and then gradually increase the time by 30 seconds each night. Eventually your child will learn to settle themselves to sleep without you there.

What can I do if I cannot leave my child to cry?

If graduated extinction does not seem appropriate or possible in your situation (maybe because as well as crying out when you leave, your child also shows challenging behaviour

which may harm them, someone else or the environment, or your child has a history of seizures) then you can try bedtime fading[55]. This involves keeping your child awake later than usual so that they become so tired that they fall asleep by themselves. For example, if you usually put your child to bed at 8:30pm, but they struggle to settle at this time, try keeping them awake until 11pm. If at this temporary bedtime they are able to fall asleep by themselves, then you can 'fade' bedtime back to a more acceptable time very gradually.

When selecting the temporary bedtime, consult the sleep diary you completed at the assessment stage for times when your child fell asleep by themselves (e.g. when they were late going to bed because of a family party) and then add 30 minutes. This is likely to be quite late, but should be when your child is so tired that they go to bed without trouble. If you are unsure, experiment by allowing your child to stay up late and seeing when they naturally fall asleep.

1. Complete the bedtime routine for 30-60 minutes before the new bedtime.
2. Do not allow your child to fall asleep until they are in their bed. Also ensure that they are not awake in bed for more than 20 minutes. If your child is still awake at this point, get them out of bed for another hour before putting them to bed. Avoid energetic activities, but keep them awake (for example by reading stories, putting toys away). It is vital that they fall asleep in bed. If your child is napping during the day, they may not be tired until later in the evening, and so trying to reduce napping may be necessary first (see "What should I do if my child naps for long periods of the day?" on page 24).
3. Once your child has fallen asleep within 20 minutes for 2 consecutive nights at the late bedtime, you can begin to move bedtime (and the start of the bedtime routine) earlier by 15 minutes each night.
4. Repeat this until you reach the bedtime you want or until your child no longer falls asleep within 20 minutes.
5. Bear in mind that children may need different amounts of sleep at different ages or compared to other children (see the recommendations on page 5), and so the 'ideal' bedtime you choose should be appropriate for their individual needs. You will also need to stay up until this strategy is effective, which may take a few weeks. Graduated extinction may be quicker (sometimes only a few days), but may be harder in other ways[56]. Choose whatever works best for you, your child and your family.

What can I do if my child needs me to be there in order for them to sleep?

For some children, falling asleep without an adult with them seems impossible. Perhaps your child is used to you sleeping in bed with them, or on a chair in the corner of their room. Although your presence may help them settle to sleep initially, if these same conditions are not in place when they wake up in the middle of the night, they may struggle to settle themselves back to sleep. In order to help your child learn to fall back to sleep by themselves, you could try gradual withdrawal.

If, for example, you usually sleep in the same bed as your child, try sleeping on the floor next to them. After three nights, move slightly further away. After three more nights, you could sleep on a chair next to the bed. Then try moving to the corner, then outside the room. If your child cries and tries to get you to come into bed with them be firm. Avoid conversation and eye contact if possible. This may be very difficult at first but eventually your child will learn to fall asleep without you there.

What should I do if the settling problem comes back?

With each of the strategies described above, seemingly 'cured' settling problems can return after anything that causes a change in the routine. This might be an illness or a family holiday. Think ahead about how you might be able to preserve your child's bedtime routine, even in the midst of these events, for example by taking the items needed for their bedtime routine on holiday. If disruptions to the routine are unavoidable, be consistent as soon as things return to normal.

What can I do if my child has problems with settling AND night waking?

Many children who do not sleep through the night also have settling problems[57], and these can aggravate the night wakings. For example, if children fall asleep with the light on, whilst being held or sung to by a parent, they may never learn to settle themselves to sleep independently (self-soothing). This means that when they experience a brief arousal in the night (see Box 1 on page 4), they do not have strategies to put themselves back to sleep. This causes them to cry out for the parent, who is likely to respond and probably make the child more alert. This reinforces the waking behaviour and so the pattern of not falling asleep independently is continued, as explained in Part One on page 4. Therefore, for children with multiple sleep problems it is best to target the settling problem first. Once the child can settle themselves, night waking sometimes decreases[57]. If the night waking does not reduce spontaneously you can use the same strategies for settling your child to sleep in the evening, described above, to help your help to settle back to sleep after a night waking.

My child wakes in the night or early in the morning but does not wake me... What should I do?

When children wake they are not always disruptive, some may be content to lie awake in bed or wander around the house, play with toys etc. Although they do not necessarily disturb anyone else, this disrupted sleep can cause daytime sleepiness for them and interfere with their learning the next day. Graduated extinction is not necessary because they are not crying out, so a strategy known as sleep restriction can be useful[55]. Sleep restriction involves reducing the amount of time a child is in bed to the amount of time that they are actually asleep. This will probably involve putting your child to bed later to make them really tired, so that they sleep more soundly.

1. Use your child's sleep diary to work out how long they are actually asleep for (not time in bed – so subtract the time it takes them to settle and all waking times) on average throughout the week.
2. Then multiply the number of hours by 0.9 to restrict that sleep time to 90%.
3. Adjust either bedtime or wake time to restrict your child's sleep to new number of hours. Do not restrict to less than 4 hours. For example, if your child usually sleeps for an average of 7 and a half hours a night, multiply this by 0.9 to work out 90% (7.5 x 0.9 = 6.75). 90% is therefore 6.75 hours (i.e. 6 and hours, 6 hours 45 minutes). This is the new amount of time you should restrict your child's sleep to, by shifting the bed time to roughly 45 minutes later or wake time to roughly 45 minutes earlier.
4. If your child is ever awake in bed for more than 20 minutes, get them out of bed and have them do something quiet and soothing downstairs for 15-30 minutes.

5. After one week without night waking on this new schedule of restricted sleep, begin to move to the previous schedule by about 15 minutes. This means either letting your child go to bed 15 minutes earlier, or sleeping in 15 minutes longer each week.

Sleep restriction by waking the child earlier is recommended, because once you start to adjust the schedule it is easier to sleep for 15 minutes longer in the morning than go to bed earlier in the evening[58]. Daytime napping should also be restricted, using the procedure explained below.

My child wakes in the night or early in the morning and wakes EVERYONE.... What can we do?

Some children who experience night waking may show disruptive or challenging behaviours, crying, entering their parents' bedroom etc., which may wake parents and other family members. If this is the case, graduated extinction is likely to be more appropriate than sleep restriction. Using this procedure, parents should wait for gradually increasing amounts of time (for example 2 minutes, 4 minutes, 6 minutes, 8 minutes, 10 minutes etc) before checking on the child when they wake up and cry out. This technique, fully outlined in the "What should I do when my child just will not go to sleep?" on page 21 is useful when a bedtime routine with regular sleep-wake times and good sleep hygiene is already in place. When children's behaviour is so disruptive that they cannot be ignored, even for just a few minutes, sleep restriction may be more appropriate.

Another strategy for night waking involves gently waking your child in the 30 minute period before they usually wake up[59]. Due to the sleep stages outlined in Part One on page 4, it is possible that your child will have fairly consistent wake times (check the sleep diary you completed in the assessment stage).

Gently wake your child 30 minutes before their typical wake time, (do not fully awake them, but just gently touch them so that they open their eyes briefly) and then allow them to fall back to sleep. You may need to try several different scheduled awakening times to see what works best for your child. If your child wakes fully and cannot go back to sleep, try waking them 15 minutes earlier the next night. Once you have found the right time to wake your child, repeat the scheduled awakening until they sleep for seven full nights without waking. Then skip one night per week (i.e. don't do the scheduled awakening). If your child has night wakings again, go back to using scheduled awakening each night. Then slowly reduce the number of scheduled awakening nights each week. This technique has the advantage of preventing night wakings without allowing the child to be disruptive, but can be difficult for the parent whose own sleep is very much disrupted by having to conduct the scheduled awakenings. Again, choose whatever works best for you, your child and your family!

What should I do if my child naps for long periods of the day?

Although napping can be beneficial for some children, if your child has fallen into a pattern of napping during the day, and wakes frequently or has trouble settling at night, it is possible that they are not tired enough at bedtime[21]. Therefore, reducing nap time could be critical to improving sleep. This should be done gradually, for example by waking your child up from a nap 5 minutes earlier each week until napping stops altogether. If it is easier to wake the child at a set time (for example in time to pick up a sibling from school in the car, an activity they may enjoy), consider delaying the nap by five minutes each week, rather than waking them earlier. Since many children nap on the journey to and from school, and/or when they are there, you may need to talk to your child's teacher to ensure this strategy is enforced consistently.

What can I do if these strategies don't work or my child has a sleep problem which is not listed here?

Sleep is not an exact science, and it may take various attempts at different strategies to work out which one is best for you and your child. If you need help implementing any of these strategies, or any other advice on sleep, consider contacting Cerebra's Sleep Service on 01267 244210 or sleep@cerebra.org.uk.

Resources

For general information about sleep in children and adults, The Sleep Council is a very useful resource. Their leaflet 'The Good Night Guide for Children' is not specific to children with intellectual disability, but is very relevant. It can be downloaded from their website here: http://www.sleepcouncil.org.uk/helpful-leaflets

For more detailed information about sleep in specific genetic syndromes, check out the FIND website, run by the team at the Cerebra Centre for Neurodevelopmental Disorders at the University of Birmingham: www.findresources.co.uk

The syndrome support group relevant to the individual you care for may also be able to provide more detailed information about sleep in that specific syndrome.

Cerebra has guidance, freely available on their website (https://cerebra.org.uk/get-advice-support/parent-guides/) on factors that may affect sleep. These include:

- Anxiety: A Guide for Parents–https://cerebra.org.uk/download/anxiety-guide-a-guide-for-parents/
- Pain: A Guide for Parents–https://cerebra.org.uk/download/pain-a-guide-for-parents/
- Self-injurious behaviour in children with intellectual disability -https://cerebra.org.uk/download/self-injurious-behaviour-in-children-with-intellectual-disability-2/

For more detailed information about the intervention strategies introduced in this guide, Mark Durand's 2014 book 'Sleep better. A guide to improving sleep for children with special needs' can be purchased online.

Glossary

Bedtime resistance: A term used to describe the behaviours an individual shows rather than settling to sleep, when asked to do so at bedtime. This may include attempting to delay or extending the bedtime routine, challenging behaviour, or calling out to parents once they have left the room. Children who show bedtime resistance are sometimes described as having 'settling problems'.

Brief arousal: A normal waking in the night which occurs between sleep cycles and as an individual transitions between stages of the sleep cycle.

Challenging behaviour: Any behaviour that could potentially cause injury to the individual (self-injurious behaviour) or to those around them (aggressive behaviour), or impact on the individual's day to day life by disrupting activities or restricting which activities are available.

Circadian rhythm: Biological processes which occur within a day, including the sleep-wake cycle. This can be thought of as an 'internal body clock' which tells us when we feel sleepy and awake, based on external cues from the light/dark cycle, social opportunities and meal times.

Excessive daytime sleepiness: A type of sleep problem where an individual has a consistent lack of energy and feels sleepy throughout the day, despite apparently sleeping adequately the night before.

Gastro-oesophageal reflux disorder: A disorder caused by stomach acid leaking from the stomach up into the oesophagus (the tube from the mouth to the stomach), potentially causing discomfort and pain which could lead to disturbed sleep.

Insomnia: A term used to describe a range of sleep problems common in children with intellectual disability, including problems with settling to sleep, waking during the night, and waking early in the morning.

Learned association: A term used to describe the association between an individual's behaviour and a specific consequence, when over time that consequence is reliably provided in response to the behaviour.

Melatonin: A hormone, involved in sleep and wakefulness, which occurs naturally in the brain and is sometimes prescribed 'off-label' for children with sleep problems. Melatonin production may be different in different genetic syndromes.

NREM: The first three stages of sleep are referred to as non-rapid eye movement (NREM) sleep.

Parasomnias: A broad range of unusual movements or behaviours which can happen at any stage of NREM or REM sleep, such as sleep-walking, nightmares, sleep paralysis and nocturnal head-banging.

Reinforcement: A behaviour is reinforced when there is a response to it which acts as a reward of some kind. This reward makes the behaviour more likely. For example when a child experiences social contact as rewarding, if a parent provides this in response to a night waking, the night waking is more likely to continue (i.e. it is reinforced).

REM: Rapid-eye movement sleep is the fourth stage of sleep in the sleep cycle. It is the stage of sleep where most dreams occur.

Self-soothe: A term used to describe an individual's ability to settle themselves back to sleep after waking in the night, rather than needing a parent or specific environment in order to settle to sleep.

Sleep-related breathing disorder: A physical problem which affects sleep when an individual's breathing becomes laboured and they wake up several times in the night. These wakings are not usually remembered the next day but seem to disrupt sleep quality.

Sleep paralysis: A type of parasomnia, where an individual briefly feels that they cannot speak or move immediately upon waking up or just before falling asleep. This feeling lasts for a few minutes at most, and is not harmful, but can be quite frightening for the individual.

Typically developing: A term used to describe children without an intellectual disability or neurodevelopmental disorder.

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