



Cerebra

Positively Different

UNDERSTANDING AND SUPPORTING CHILDREN'S SLEEP

Name – Sleep Practitioner

New brand

We're the charity that works with families who include children with brain conditions. We listen to them, we learn from them, we work with them. We carry out research, we design and innovate, we make and share. What we discover together makes everyone's life better. Join us on our journey, and who knows what we could find?

Aims of this session

- To raise awareness of the sleep processes
 - To look at why good sleep is essential and the effects of disturbed sleep
 - To think about the modern barriers to good sleep
 - To look at sleep management techniques
 - To look at tools which can aid sleep
 - To be familiar with what Cerebra sleep service offers, along with the charity as a whole
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The role of the sleep practitioner

- To help parents of children aged 0-16 yrs, who have a neurological condition, learning difference or developmental delay.
 - To offer information and guidance to families, by post, telephone, email or face to face.
 - To set up and run sleep clinics across the country, offering one to one appointments.
 - To offer sleep workshops and talks to groups of parents/carers/teens or professionals, to raise awareness about sleep related issues.
 - Services offered by Cerebra are FREE to parents.
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What we don't do

Move in or offer overnight or early morning visits

Provide medical advice or prescriptions

Provide equipment – although you can borrow a weighted blanket from our library

Offer 24 hour support

Manage severe anxiety or other mental health issues

Use cameras/video links/webcams or actigraphy



Definition of Sleep

Sleep may be defined as a behavioural state characterized by the following:

- Reduced motor activity
- Decreased interaction with and responsivity to the environment
- Specific postures (e.g. lying down, eyes closed)
- Easy reversibility

A Clinical Guide to Pediatric Sleep – J.A. Mindell & J.A. Owens



Why is sleep essential?

- Sleep is still a biological enigma, it is still not fully understood, but we do know it is essential to life
- Growth hormones are released, usually during deep sleep
- Consolidation of newly learned tasks and information during REM sleep
- The immune system and vital hormone systems are at work in deep sleep
- Essential to emotional well being
- Good concentration and behaviour



Sleep Disturbance in Developmental Disorders

- Sleep disturbance is serious enough for the population at large, but worse for children with disorders of development of a physical or psychiatric nature, in whom sleep problems seem to be particularly common.

Ref: Sleep disturbance in Children and Adolescents with Disorders of Development: its significance and Management Edited by Gregory Sores and Luci Wiggs



How the sleep-wake cycle usually works

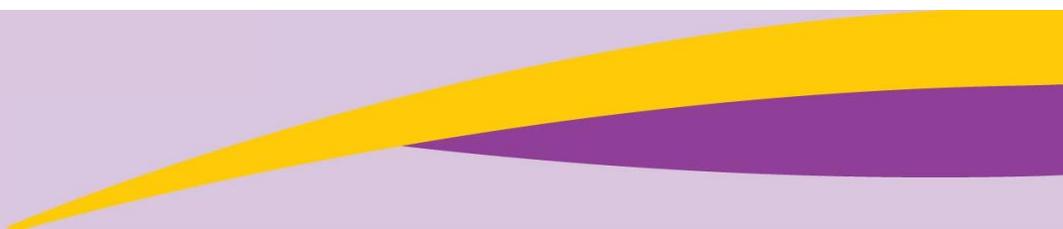
- Circadian rhythms are biological cycles that repeat about every 24 hours
 - They include patterns of sleeping, waking, activity, rest and eating
 - A person's ability to fall asleep and stay asleep is very much linked to the timing of their body clock, which is reset each day by the use of cues i.e. Meal times, bed and waking time.
 - The body clock uses signals like sunlight and darkness to know when to produce and shut down sleep hormones
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Melatonin

- Melatonin is a hormone that primarily induces sleep
 - It is produced and released by the pineal gland in the brain during darkness
 - It is suppressed by bright, natural or artificial light
 - It is not the only aspect that controls sleep
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The two different stages of sleep

NREM Sleep – Non Rapid Eye Movement

- **Stages 1** – a light sleep, person easily woken
 - **Stage 2** – slow rolling eye movements, partial relaxing of voluntary muscles; deeper sleep but still quite easily woken. Sleep jerks can occur
 - **Stage 3 & 4** - deep slow wave sleep, blood pressure, heart rate and breathing slow down, very difficult to wake and confused if woken
 - Each stage of NREM sleep has its own recognisable electrical brain wave patterns. NREM takes up the largest portion of the sleep cycle
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The two different stages of sleep

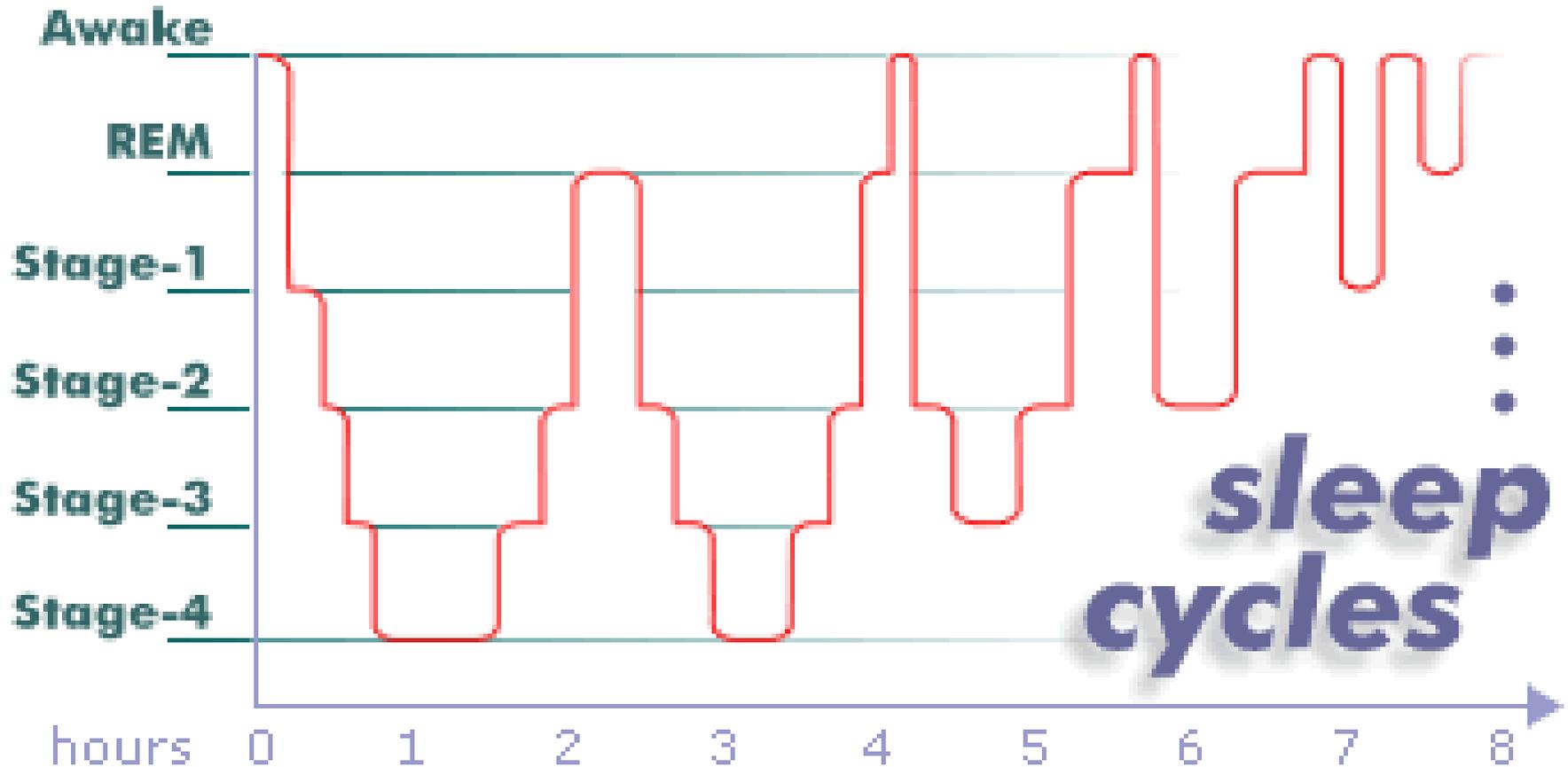
REM Sleep – Rapid Eye Movement

- Normally characterised by intense brain activity and dreaming, our eyelids usually flicker ‘REM’
- An inability to use our muscles, with the exception of our eye muscles and our diaphragm (to enable us to breathe)
- REM occurs several times during the second half of the nights sleep, but comprises the smallest portion of our sleep cycle



Nightly sleep cycles

Diagram taken from: <http://library.thinkquest.org>



Sleep Disorders

- Sleep Onset Association Disorder
 - Nightmares
 - Parasomnias – sleep terrors/sleep walking/sleep talking/bruxism (usually occur in NREM)
 - Obstructive Sleep Apnoea
 - Narcolepsy (REM disorder)
 - Enuresis (Bedwetting)
 - Rhythmic Movement Disorder
 - Nocturnal Epilepsy
 - Sleep Phase Delay
 - Advanced Sleep Phase
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What do you want to change about
your child's sleep?



The 4 common sleep problems

Difficulty Settling

Night Waking

Difficulty Sleeping Alone

Early Rising

Difficulty Settling

? Unsuitable Bedroom

? Unsuitable Bedtime

? Ineffective Routine

Bedroom Environment

An advisable bedroom environment:

- ✓ Plain neutral walls, carpet and duvet cover, minimal furniture
- ✓ No toys or other stimulating objects in the room, or for toys to be out away in cupboards, boxed up or at least covered over at bedtime
- ✓ Black out blinds to ensure that the room is dark. If you use a night light, consider using one on the red spectrum as it does not interfere with Melatonin.

Bedtime

- ✓ Have realistic expectations
- ✓ Putting a child to bed when they are physically tired is going to be the right time for that child
- ✓ Signs of being tired are the rubbing of eyes, yawning and 'grumpy' behaviour
- ✓ If a child is in bed for a longer period than 15 minutes, and they are not going to sleep, they are probably not tired.

Bedtime routine

A structured routine is very important. A routine should include a set waking up time every morning and a set going to bed time.

An ideal bedtime routine would include: (depending on individual receptiveness to interactions)

- Calm activity (TV off)
- Have a light snack/drink (avoiding caffeine)
- Take a bath ensuring that it is relaxing rather than stimulating
- Brush Teeth
- Put on bedclothes
- Hand/foot massage
- Read a short story
- Into bed
- Make sure the room is dark (red based night light if needed), quiet and/or use soothing music, introduce smell and ensure the room is a comfortable temperature
- Say goodnight and leave the room

Worth considering.....

- If you put your child into their PJ's just after tea and then they watch TV and play before going to bed, they will not recognise getting ready for bed as a trigger or cue to bedtime.
 - A lot of children need help in recognising these cues, i.e. A child with visual impairment may not see darkness fall.
 - When having a bath, try using battery operated lighting rather than keeping the bright main light on.
 - A consistent bedtime routine helps the child to understand what is expected of them, it can make them feel safe and secure.
 - Pain, discomfort, allergies and intolerances can all impact on sleep. It can be hard to know in children with communication difficulties.
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Night Waking

- ? Ineffective Routine
- ? Sleep Onset Association Disorder
- ? Difficulty sleeping alone
- ? Terrors/Nightmares/Pain/Bedwetting
- ? Reinforced Waking

Sleep onset association disorder

Needing something or someone in order to get to sleep:

- Gradual withdrawal technique.
- Gradual withdrawal of an object (e.g bottle or person)
- Removing parent - start off next to your child and gradually move away from your child over a period of time, remaining in each position for 3-4 days at a time.
- Removing a bottle - either dilute the milk gradually or you can reduce the amount of milk gradually.

Scheduled waking technique

Terrors/nightmares

- This involves waking your child sometime prior to a sleep waking episode, generally when the child is waking up at the same time each night
- Determine the time or times when the child tends to wake during the night(use a sleep diary if required)
- Wake the child approximately 15 minutes before typical waking time. Do not fully wake the child, just gently touch them or speak to them until they become slightly roused and then let them fall straight back to sleep.
- If the child fully wakes up, alter the timing the next night to approximately 25 minutes before their normal wake time. Continue with this until the child is no longer fully waking, and then gradually remove the scheduled waking.

Scheduled waking technique

Bedwetting

- If your child is regularly wet at a certain time, you can try waking 15 minutes before and get them to go to the toilet.
- Speak to your GP/ health visitor or school nurse, may need referral to enuresis clinic.
- For more information contact ERIC: www.eric.org.uk

Reinforced waking

- **Robotic Parenting Technique:** After you have said goodnight, become 'robotic' by keeping conversation, eye contact and cuddles to an absolute minimum or even better to zero!
- **Behaviour Including the ABC model:** A parent's response to a child once they have said goodnight to a child is crucial, as without even realising it, a parent can create and maintain an unwanted behaviour in their child.



Pain

- Research has shown that sleep problems increase when pain is present in young people with physical and intellectual disabilities.
- How is your child expressing their pain? Settling, anxiety, nightmares/terrors, sleep disordered breathing etc

Early Rising

- ? Lack of Understanding
Your child may not realise that they should stay in bed or what you expect of them when they wake up
- ? If it is light outside the child may believe it is morning, if they wake up and feel alert they may also assume it is morning and time to get up

Lack of Understanding

✓ **Tools**

There are bed time tools on the market that can aid in helping your child to understand that it is still bedtime, such as clocks that show when to stay in bed and when they can get up.

✓ **Rewards**

These can include praise, stickers, toys, money or food, to name a few. Or you could implement a reward chart. Try to remember that what a child finds rewarding can change regularly, so make sure your child is motivated for their reward.

Alex

***Alex is 9 years old, he has Aspergers and is Hypersensitive**

- Alex has never slept well or alone from birth
- Settling issues – would not settle without mum, would shout, scream and run after mum when leaving the room
- Frequent night waking – mum up and down all night, swapping beds, younger sibling would then get in with dad –Musical beds!
- Verbal aggression on being woken for school
- Behaviour was very negative
- Family relationships starting to breakdown
- Younger , neuro typical sibling imitating behaviour of brother

* Name changed for anonymity

Alex

After completion of a sleep questionnaire and a consultation the parents agreed to follow the advice/suggestions given which were:

- **Introduce wind down activity** – Alex loved to draw, this became his wind down activity, tea time news turned off to decrease some anxiety
 - **Introduce new clear bedtime routine at set times** – in bed for 8.30 pm and waking up himself at 7.30 (once established) no aggression towards mum on morning waking
 - **Use of visual prompt cards** – immediately after wind down time, for supper, bath, teeth, bed, story, goodnight
 - **Follow graduated extinction technique** – and robotic parent
 - **Lots of praise for positive behaviour during routine**
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Alex

Parents consistent effort over 9 nights resulted in

- Both children settling
 - Self soothing back to sleep during the night
 - Up in time for school and in a pleasant mood
 - Big improvements with behaviour and attention at school
 - Family relationship improved
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Ben

I attended a sleep presentation recently. My little boy *Ben has autistic traits and is **nearly 4 years old**. I am so grateful for all the advice and support given at that workshop, and as a result, in addition to the 5mg melatonin he has, I was able to try lots more things, we got a **bubble fish light** he loves as he did seem afraid of the dark as his nightlight wasn't giving enough light, but his old lamp was too bright, a **heavy lavender filled cuddly which can be warmed in the microwave**, **gradual retreat** from his room onto the landing, and we have now **managed to get regular full night's sleep** and **Ben settles well**, which is amazing for Ben and our family. I couldn't have contemplated returning to work before, but now I have been able to start a new job as well.

I am so grateful to you and your staff for providing such a great support, what a huge difference your help makes to families.
Thanks again

*name changed for anonymity



Charlie

Charlie is 15 years old and has A.D.H.D.

- He has **trouble settling** every night and doesn't tend to fall asleep until around 5am. This is called a delayed sleep phase and is common in teenagers.
 - He therefore has **trouble waking in the morning** and sleeps in until about midday, missing most of school.
 - Professionals have become concerned about his attendance.
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Charlie

After completion of a sleep questionnaire and diary and a 1:1 home visit. The family followed the recommendations:

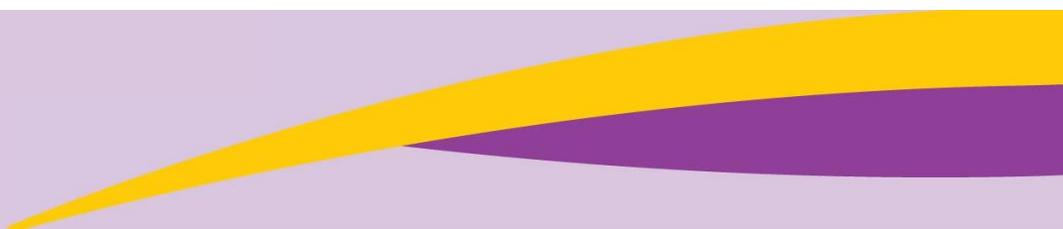
- Parents to follow a technique called Chronotherapy which involves moving bedtime forward, by a few hours each day (example below)
 - 1st night: sleep at 4 a.m., wake at 12 midday
 - 2nd night: sleep at 7 a.m., wake at 3 p.m.
 - 3rd night: sleep at 10 a.m., wake at 6 p.m.
 - 4th night: sleep at 1 p.m., wake at 9 p.m.
 - 5th night: sleep at 4 p.m., wake at 12 p.m.
 - 6th night: sleep at 7 p.m., wake at 3 a.m.
 - 7th night: sleep at 10 p.m., wake at 6 a.m.
 - The hour before sleep time would include a set bedtime routine
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Charlie

- Once the family reached a bed time of 10pm, they then stayed at this time and still encouraged him to wake at 6am to maintain the new sleep pattern.
- Please note, this technique is ideally completed during a school holiday as the timings would miss school.
- This is an intense technique, which usually involves you staying up with the child, so make sure you are prepared for it and have support if needed.

Sleep management

Things to consider before starting a sleep programme:

- ? Are you willing to complete a sleep diary and questionnaire if required
 - ? Physical activity – is it too early/too late/getting enough
 - ? Is your child eating a healthy/balanced diet
 - ? Timings of medication – could they complicate new changes
 - ? Is this the right time to start a sleep programme
 - ? Are you using appropriate communication that your child understands
 - ? Are you ready/able to give consistent messages
 - ? Are there any sensory issues
 - ? Have you considered the needs of the whole family
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Who to contact:

For further information:

- Call or email your local sleep practitioner:
Name:
Tel No:
Email:
- Complete our online contact form at www.cerebra.org.uk
- Call or email our Head Office 0800 3281159
sleep@cerebra.org.uk

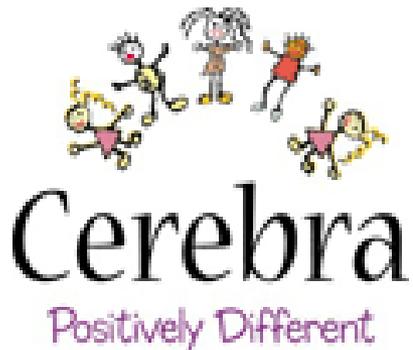
Contact Cerebra:

FREEPHONE 0800 3281159

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Thank you

Any Questions?

