

Walking With You Parent Support Group (Oxfordshire) Newsletter 22

The Theme for WWY in November was on Sleep

General Themes

- A lack of sleep can be draining. It is really important for parents to focus on their own sleep as well as their children's sleep.
- There are many things is society that make it difficult to sleep e.g. constant stimulation through mobile devices, light weight duvets rather than heavier blankets, doing things late at night that you don't have time to do during the day.
- Sleep is a fundamental basic need. However some children naturally need less sleep than others.
- Is it normal for children to take high doses of Melatonin –
 Children who are neurodivergent have different levels of
 sensitivity to many things including medication. Some children
 may need a lower dose, some may need a higher dose.
- Going to bed is a transition and can be hard. Activities e.g. reading stories that are part of a bedtime routine can make the transition harder for some children.
- Interoception feeling sensations inside the body that tell us we need to e.g. eat, drink. Some children are not able to recognise when they are tired and when they need to sleep. This will have to be taught.
- If you are in bed and struggling to get to sleep after 15 minutes, get up and do something else. Staying in bed when you cannot sleep is not helpful.

Situations parents shared

- Parents unable to sleep because their child would not let them
- Parents unable to sleep due to concerns about their child you were having intrusive thoughts and was at risk of self-harming.
- Switching of at the end of the day is hard and makes sleep difficult.
- Having a child who has Autism and a PDA Profile. A large part of this is wanting to control other people. If they don't want to sleep, they don't want anyone else to sleep.
- Having a child who functions well during the day even when they go through the night without any sleep.
- Severe nightmares, waking up and finding it difficult to know what is real / unreal.
- Difficulties within school and the lack of support are causing a lot of anxiety which is influencing sleep.
- There is a need to find alternatives to talking therapies. Talking doesn't work for everyone.
- Their child is now being home schooled due to high levels of anxiety. Home schooling is hard and challenging but has been worth it. Their child is much calmer and less anxious.
- Decompressing after school is really important and their child stays on the sofa with a weighted blanket. It isn't until bedtime that they then want to talk. Being able to talk is really important

Autism Oxford – If you are on the NDC Pathway Waiting list you can access resources and support through the Autism Oxford Website. Ask the NDC Team for a code – this releases the resources.

https://onhs.autismoxford.com/?pass word-

protected=login&redirect_to=https% 3A%2F%2Fonhs.autismoxford.com% 2F

SENDIASS

Sendiass provide support up to the age of 25yrs.

https://sendiassoxfordshire.org.uk/contact/

CEREBRA A national charity that offers a sleep Advice Service. You can self refer for support from a Sleep Practitioner. They also have a range of online resources.

https://cerebra.org.uk/get-advicesupport/sleep-adviceservice/?gclid=CjoKCQiA4aacBhCUA RIsAI55maEv4x53mCMPtIfXH00mA 96lYigfrg1B2En7xwZdSZ14-2SKYhL_cMsaAiWhEALw_wcB

The Sleep Charity

A national award winning charity - one of the leading independent expert voices on sleep issues.

https://thesleepcharity.org.uk/

The Teen Sleep Hub

A one stop shop for all things sleep. They offer a National Sleep Helpline as well as a range of online resources.

Home - Teen Sleep Hub

<u>National Sleep Helpline - The Sleep</u> Charity

Oxford Health Leaflet on coping with poor sleep

https://www.oxfordhealth.nhs.uk/wp

content/uploads/sites/13/2020/12/Sl

but it is difficult to manage when the focus should be on getting to sleep.

If you, your child or any member of your family are experiencing significant difficulties with sleeping it is important to seek specialist help

If you are receiving support from CAMHS, makes sure you tell your clinician that you are having difficulties with sleep and ask to be referred to a specialist sleep clinic. This can sometimes be overlooked.

Top Tips parents shared on getting themselves to sleep

- watching something familiar on the TV that you don't have to think about really helps them to get to sleep.
- Think of a happy memory or sound you find relaxing e.g. water running, waves, wind, sound of rain.
- Weighted blankets.
- Pillow spray
- Keeping the windows open to cool down the bedroom.
- No screen time before going to sleep / turning on do not disturb at 10pm.
- Listening to podcasts / music

Top Tips From parents on getting your child to sleep

- Finding ways to negotiate to give your child some level of control in when they sleep.
- Sleep itself is non-negotiable. You need it in the same way as food and drink but when you sleep can be negotiable.
- Parents may need to train their child to want to go to sleep.
- If your child is taking Melatonin and it is having little effect, talk to a psychiatrist about the possibility of adding anxiety medication. Parents shared that a combination of Melatonin, Anxiety meds and Psychoeducation can be helpful.
- Helping your child if they are hearing intrusive voice one parent shared how she challenges her child about what the voices are saying and talking to them directly... that's an interesting thought, lets challenge that... see if you can find some solutions together.
- One parent shared that she brought her children Dreamcatchers when they were having nightmares. She explains that the dreamcatchers would take away their bad dreams. She cannot explain why but these really helped her children settle at night.
- If your child is anxious but doesn't want to talk, try to communicate using Voice notes on Whats App. This can be used to help dump whatever is on their minds.
- If you have the space having different areas for different activities is helpful. Try to keep the bed free for sleeping.

Challenges in School that are impacting on Sleep:

- You do not need to wait for school to assess the need for an EHCP and put one in place. You can complete a Parent Application.
- Collect as much evidence as you can of the support that has



Do you know what help and support is available in Oxfordshire?

Do you know if you are entitled to access any benefits or grants?

Check out these links to get more information.

Family Information Directory

http://www.oxfordshire.gov.uk/familyinformation

Family Benefits
Advice - Family Support
Information

www.familysupportni.gov.uk/Support/17/family-benefits-advice

been put in place and what has not worked.

- Word everything as an education need
- SENDIAAS can support you with a Parent Application. You can book a meeting with a SEND Consultant.
- If you are considering home schooling, it is important to discuss this with the school / SENDIAAS. If you take your child off the school roll then you will be totally responsible for all funding related to their education. If you remain on the school roll you will be entitled to support and funding. Please refer to guidance form SENDIAAS on Elective Home Schooling.
- One parent shared how their child has recently started drawing again to express how they felt. This had previously been really helpful but something that their child had stopped.
 Unfortunately, when they built up the confidence to start drawing again they were told them off by their teacher.
- Please refer to Newsletter 21 for links to resources around Elective Home Schooling.

Basic Sleep Techniques: It is important to think about the basics of sleep hygiene

- Make sure the environment is not too hot or too cold.
- Open the windows to let the temperature to drop.
- Block out noise or use white noise i.e. recordings of sounds / a fan
- Blackout Blinds to reduce light stimulation
- Keeping your bedroom tidy to protect space for sleep, make sure it is a comfortable space to be in.
- Keep sleep times regular
- Develop a regular routine to prepare for sleep.
- Be more active earlier in the day / evening and less active in the evening.
- Avoid napping during the day unless this is part of a treatment plan
- Process the day, wind down and get ready for the evening.
- No time on mobile devices / TV before going to bed
- If you are not asleep in bed, get out of bed.

For guidance on good sleep habitats follow the link below

Dimitri Gavriloff - Teen sleep during COVID-19 - YouTube

Please note the Tips in this Newsletter are from Parents and not recommendations from CAMHS.



