



# Norfolk & Waveney Autism/ADHD Support Service May 2023 Newsletter

Welcome to our May 2023 newsletter.

One of the subjects which comes up regularly when we talk to parents and carers about their children, is SLEEP. Lack of engagement or co-operation with a bedtime routine, difficulty getting to sleep, getting up through the night, waking up far too early and not wanting to get up for school because they are still so tired are just some of the problems we hear about. And it is very true that when there are difficulties around sleep, when it is a battle every night, when sleep is disturbed....nobody in the family is entirely ready for what the next day is going to throw at them.

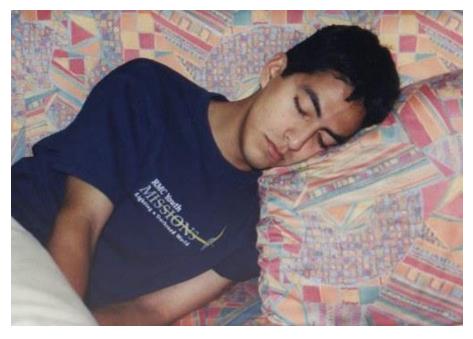
So, in this edition of the newsletter.....Let's talk about sleep.

The newsletter contains this month:

- Let's Talk About Sleep
- Technology to Support Sleep
- SEND Events in Norfolk
- Upcoming Courses, Workshops and Support Groups
- Family Action FamilyLine
- About our Service contact details

Just as every child is unique, every family's situation is different. We in the Norfolk and Waveney Autism/ADHD Support Service speak to many families with children of differing needs. Some of the information contained in this newsletter is anecdotal and some from respected websites. We hope you find the following interesting and helpful.

# Let's Talk About Sleep



#### Sleep and Autism/ADHD

We know that children with neurodiversity are more likely to experience sleep difficulties, in fact twice as likely as their neurotypical peers. As many as 80% of children with Autism or ADHD will experience problems falling asleep at some point. This does not mean that there aren't things we can do to help.

#### **Sleep Environment**

We all need slightly different things to help us fall asleep. Some of us must have the window open for fresh air and others need it shut to reduce road or bird noise. Some like to wear socks because

we get cold feet and others get too hot if wearing anything at all in bed. Some like three pillows and some prefer to be completely flat. Some of us curl up in a tiny ball and others lie like a starfish taking up all the space. I need a firm mattress which you may find unbearable.

The first thing to talk about with your child or young person who has difficulty with sleep is the fact that we are all different and that is okay. Begin a conversation about what helps to sleep and what definitely interrupts your sleep such as the noise of the television in the sitting room, needing the loo, the dawn chorus or next door's cockerel crowing and what you can do about these things. NB: No bird life was harmed in the writing of this newsletter. This will help your child to appreciate that just as everybody is different, we all have differing sleep needs. When you have a child or young person who is autistic or has ADHD, sleep may be impacted also by anxiety, sensory processing differences, difficulty switching off busy thoughts, difficulty transitioning from daytime 'me' to night-time 'me' or a lack of understanding of social cues so not making a link between other people getting ready for bed and that also being the right thing for you to be doing now.

Some children might like to have a parent or carer's physical presence when falling asleep, or a whole zoo of cuddly animals and some may enjoy being in a small enclosed space. Some children like weighted blankets as they provide pressure and sensory stimulation. Some charities will hire out weighted blankets for you to try. Wheat bags can sometimes provide the same weighted reassurance and can be heated up or put in the fridge in order to provide temperature stimulation. You could also consider tents and canopies, which can make the physical sleeping space smaller. These sleep environments should always be set up safely.

Encourage your child or young person to come up with their own ideas and to take some ownership of setting up their bedtime environment so that they feel in control of the process. You might even compile a list, and ticking off the components can become a familiar and comforting part of their bedtime routine.



#### Creating a bedtime routine

We already know that routines in general are important to most neurodiverse children and young people. Knowing what is happening now and will happen next helps them to feel in control, feel safe and feel less anxious and that is exactly how we want them to feel at bedtime. But we want to

encourage healthy rather than unhealthy routines. You may have to introduce changes gently because you have a child who will be quite attached to the routine they already have even if it is not a good one! They probably love falling asleep on the sofa and being carried upstairs or slipping into unconsciousness with their iPad still playing YouTube videos if that is the current norm. So with some children you will be able to create a new bedtime routine all at once and for others you may have to introduce and remove elements gradually.

Having a bath, brushing our teeth, reading in bed or having a story read to us are all helpful and common routines followed before bed. Pre-bed routines should ideally be time-limited, calm and carried out at the same time every night. Certain foods do have sleep inducing qualities so a banana or a milky drink about an hour before bedtime can be a useful part of a routine. Switching off technology (there are notable exceptions - see the next section on technology to help you sleep) and creating a period of low sensory arousal before bed time is generally agreed to be beneficial. Some children have a need to move around before bed or when first in bed by fidgeting, pacing or stretching to give a few examples, and remember that some have a real need for movement. Deciding upon some time-limited routines together might fulfil this need to move around before settling to sleep. This could be doing some yoga, packing a school bag for the next day, laying out uniform, writing a to-do list for the next day or similar. Set clear times by which these activities need to be completed and encourage your child to choose activities which can mostly be done without help. Be wary of steps in the night time routine which are actually designed by the child to avoid or prolong the process. Saying goodnight and kissing each member of the family is fine, having to say goodnight and kiss every member of the family three times and then go out to the garden to say goodnight to the rabbit is probably avoidance.

Some children want to talk about their day and what might be happening the next day when they are settling down in bed. You know your child best. If you feel that getting this off their chest is helpful, allow it. If they only want to talk about worries, it may be worth having a planned time for talking about worries which is not at bedtime. 'I will put that in the worry jar and we will talk about it when you get home from school tomorrow.' But then do make sure you make the time to speak about it the next day. It can be quite unhelpful for children to talk about difficult feelings just before we turn out the light and leave them alone to mull these over. And sometimes, telling you about a worry is just an avoidance technique.

You may also want to have wider conversations, but not at bedtime, about what will or won't happen in your house at night. Some children can have very specific anxieties about what "could" happen so try and help them to express these and talk about what "will" happen instead. These discussions should happen at a time when a child is relaxed, they don't have to happen all at once and might be easier talked about while doing something else – perhaps when you are driving or whilst walking or cooking together so that it feels relaxed for all of you. If they have a very specific worry about something which they think lives in their wardrobe after dark then routinely checking the wardrobe before leaving the room would be appropriate although you should be aiming to move from every night to every other night to once a week and so on.



### **Sensory Difficulties**

Think about light - make sure the curtains are suitable or use black out blinds.

Think about noise - is the door shut fully, is there a gap at the bottom which could be filled with a draught excluder, can you still hear a television elsewhere in the house? You may want to think about ear plugs or allowing your child or young person to listen to music for a time.

Think about smells - are cooking smells getting into the room? Could you use an airfreshner or scented oil which your child finds relaxing.

Think about temperature - consider whether they need the window open or closed, would a fan be useful? The white noise made by a fan is also soothing to some children and young people.

Think about touch - experiment with the texture of different sheets and quilts. For some children the silkier the better. Think also about weight, they may feel safer and more comfortable with old style heavy blankets on top of them rather than a light quilt. You can buy weighted blankets or compression sheets but think about whether the weight is the right weight for them.

Think about distractions - even bright colours on the walls, lots of pictures or just a messy and disordered environment can make a bedroom less calm.

Think about sensory aids - a lava lamp, a sensory projector playing shapes on the ceiling can be soothing for many but overstimulating for some.

Think about stimulants - sugary foods, fizzy drinks and exciting computer games are a no-no just before bed.

Any of the above might cause a "sensory overload" which can cause a child to struggle to fall or stay asleep.



### **Sleep and Adolescence**

Falling asleep can be much harder for children experiencing adolescence. Melatonin, the hormone responsible for making us feel sleepy, is produced differently in teenagers and might not be produced until later in the evening than it would in a younger child or an adult. This doesn't mean that adolescents should go to bed at midnight! There are ways to stimulate melatonin production such as avoiding artificial light at night which means no screens for a couple of hours before bed or if you choose to use a meditation app or if a child needs to use a screen to do school work, you can turn on the blue light filter. You should try and have them turned off by the same time each day. Try and have bedrooms dimly lit if you can. Overhead lights and bright bulbs should be avoided.

A healthy diet contains natural melatonin, and being outside during the day will help encourage serotonin production which we need in order to encourage melatonin production. This is harder at some times of the year, particularly in the UK but some time outside each day will help. You can also consider warm baths or showers, avoiding caffeine and sugar and also, exercise or mediation might help.

The important things to remember are:

Pick your battles – focus on what is most important. It is a marathon, not a sprint.

Be consistent with whatever you do. It can take weeks to change a behaviour.

### Involve your child in the decisions about what you do if possible.

Sometimes a child struggles with sleep to the extent that they might need specialist help or in some cases, medication. These decisions must be made by a health professional. You can keep a sleep

diary and note down things as you try them. Should it become necessary, you can use this diary to show a health professional what you have tried and to identify patterns as you spot them.

For more information or particularly complex difficulties around sleep, please contact local sleep experts NANSA - <u>https://www.nansa.org.uk/sleep-service/</u> or Sleep East - <u>http://www.sleepeast.com/</u>

See also:

https://www.circadiansleepdisorders.org/

https://www.sleepadvisor.org/get-an-autistic-child-to-sleep/

# Technology to Support Sleep



There are some amazing devices, smartphone apps and YouTube resources out there to help a child or young person who struggles with sleep. Whilst we can't recommend any of these products directly, we have included technologies and apps that have been discussed on various autism and ADHD forums. Some of the products are free, or free to try. Others can be very expensive. Before you spend any money, take advantage of any free trials to test out the product and most importantly, do your own research to see how others rate the effectiveness of the item.

It is also important to check that any products are deemed suitable for your child or young person's age group.

### Devices

There are several devices out there that claim to improve sleep.

<u>Dodow</u> is a small, bedside device that projects a a pulsing light onto a ceiling. Your breathing follows the light – as the light gets brighter, you breathe steadily in, as it dims, you breathe out. The inventors claim that the Dodow helps to calm the flow of thoughts and puts your brain in a state of rest.

<u>DreamPad</u> produce special under-pillow speakers that convert music to gentle vibrations to help induce a peaceful "rest and digest" response.

<u>Smart speakers</u>, like <u>Alexa</u>, can play "<u>Sleep Sounds</u>" - a variety of soothing sounds reproducing the sound of the ocean, white noise or a thunderstorm, for example. You can ask Alexa to turn off Sleep Sounds after a certain time period. Alexa also works with many of the smartphone apps we discuss below.

### YouTube

YouTube has many recordings of sounds and stories to help children and young people of different ages sleep. Try searching YouTube for "sleep meditation" or "sleep calm stories for children" and try a few out with your child or young person.

<u>Sleepy Cat Meditations</u> on YouTube produce immersive bedtime stories, guided meditations, and sleepy audiobooks. Their Harry Potter sleep stories have been recommended to us!

### **Smartphone Apps**

There are numerous Smartphone apps available for both Android and Apple phones that claim to improve sleep. Advice around promoting good sleep hygiene recommends turning off your smartphone well before you go to bed (even 30 minutes before can help to promote sleep) – however most sleep apps require your smartphone to be on and nearby.

Luckily, most smartphones allow you to turn off any distractions by switching the phone onto silent or airplane mode and turning it over on the bedside table or on the floor. Many apps can also be played through a smart speaker such as Alexa (for example, Headspace). Amazon have some <u>guidance on finding relevant Alexa skills</u>.

<u>Headspace</u> offers breathing exercises and meditations for better sleep, including <u>content for children</u> and <u>young people</u>. They also offer a 30-day sleep course to subscribers, although check that it is suitable for your child or young person first.

Calm provides a variety of meditations, sleep stories and sounds. They have a dedicated section for "<u>Calm Kids</u>".

<u>Endel</u> creates soundscapes that change depending on time of day, weather, heart rate and location – they use the science behind sleep in their app (circadian rhythms and psychoacoustics) and developed their app with sleep experts.

<u>Chilloutz</u> is a mindfulness app directed specifically at children, using stories to teach mindfulness techniques.

BetterSleep have developed sounds, music, meditation, and stories specifically for younger listeners – there is a "For kids" filter in the app.

<u>Pzizz</u> employs psychoacoustic and clinical principles in their "dreamscapes" to help people fall asleep, stay asleep and wake refreshed. <u>Research in the journal Cognitive Technology</u> concluded that Pzizz was more effective at improving sleep quality than traditional relaxation music.

<u>Insight Timer</u> provides a large library of meditation, sleep, and relaxation content, including evening meditations, body scans and deep breathing exercises specifically for <u>children and young people</u>.

<u>Relax Melodies and Sleep Sounds</u> apps provide sounds and melodies specifically designed to improve sleep by employing techniques such as white noise, nature sounds, ASMR (autonomous sensory meridian response – those "chills" created by certain sounds) and binaural beats (an emerging technology to help combat anxiety and stress).

So there we are, a snapshot of some of the technologies out there to help improve sleep. I'm now feeling very, very, sleepy!

### Resource for Parents and Carers



Essex County Council, in partnership with NHS and local SEND agencies has produced a resource for parents and carers

SUPPORTING YOUR NEURODIVERSE CHILD click on this link

We think it is comprehensive and accessible and wanted to share it with you.

# Making Sense of SEND - King's Lynn Event



Family Action's Norfolk and Waveney Autism/ADHD Support Service will be participating in the next

### FAMILY VOICE - Making Sense of Send Event

### Thursday 18 May 2023 (Discovery Centre, King's Lynn)

Making Sense of SEND events give you the chance to:

- Visit information stands from a range of services
- Listen to a presentation on a specialist subject
- Ask questions
- Meet like-minded parents and carers

These free events are exclusively for parents and carers who have a child with SEND. They are coproduced with Family Voice Norfolk and supported by the following organisations:

- Norfolk SENDIASS
- Norfolk SEN Network
- SENsational Families

### Book your place

Go to Eventbrite to book your free place.



### AND ANOTHER DATE FOR YOUR DIARY......17 JUNE 2023



1 - HERE IS WHAT FAMILY VOICE SAY ABOUT THE SENDfest EVENT

### Last chance to book a place at SENDfest- Easton College on Saturday 17th June 2023

SENDfest will bring together children, young people and their families offering a full day 'festival' style event.

SENDfest is an event for young people under the age of 25 and will feature multisport activities, musical workshops, vocational opportunities PFAL workshops and keynote speakers for families, children and young people with SEND.

A trade area, live demonstrations and even a fully functioning railway will mean the day will be one not to forget!

Our 'Proms in the Park' event over lunchtime will feature a live orchestra and a surprise guest on the Main Stage within the Garden area of Easton College, which will provide a centre point for the day.

Food will be available to purchase from stalls on-site or feel free to bring your own picnic. Sing along with the stars during this inclusive performance celebration!

With designated quiet spaces available this really is a day not to be missed.

A link will be sent to you to sign up to the workshops of your choice prior to the event so you can plan your day.

Booking closes 10th May so do secure your place for this, it should be a lovely event.

BOOK YOUR FREE PLACES HERE

### SENDIASS ADVICE CLINICS



The purpose of the advice clinics is to give parent/carers and young people the opportunity to go through paperwork with one of our trained advisers, something that isn't always easy to do over the phone.

When you book an advice clinic appointment, we will contact you to check what paperwork it is you want to discuss. It's important that if you are attending an advice clinic appointment you have the paperwork to bring with you. If you book an advice clinic appointment but don't have paperwork to bring with you or go through, you will be asked to book a telephone call with an adviser.

Keep an eye on our website and social media to book an appointment at our upcoming advice clinics, these are:

Visit our website to book your place.

- 16th May Great Yarmouth
- 21st June Costessey

**BOOK NOW** 

## **OUR Upcoming Courses, Workshops and Support Groups**



**Drop-in support groups** - **Come along and meet other parents/carers to share similar experiences.** 

Friendly and informal, No need to book. Just come along for a tea/coffee, meet other parents and members of our team.

### **KING'S LYNN**

### DOBBIES, next to TESCO HARDWICK, KING'S LYNN PE30 4WQ

*Come along and join us on......* Tuesday 2nd May - 9.30 am - 11.00 am, FIND US IN THE COMFY, SOFA AREA.

RING 01760 725801 or EMAIL <a href="mailto:swaffham@family-action.org.uk">Swaffham@family-action.org.uk</a> FOR MORE INFORMATION

### SWAFFHAM

### UPSTAIRS IN COSTA COFFEE, MARKET PLACE, SWAFFHAM

Come along and join us in the quiet, upstairs room in Costa Coffee on **Wednesday 3rd of May** - 9.30 am - 11.00 am.

RING 01760 725801 or EMAIL <a href="mailto:swaffham@family-action.org.uk">Swaffham@family-action.org.uk</a> FOR MORE INFORMATION

EAST NORFOLK AND WAVENEY DROP-IN

There will be no East Norfolk and Waveney drop-in in May while we welcome two new team members. They are busy planning sessions for June onwards so look out for news in our June newsletter!

WE ARE SO LOOKING FORWARD TO WELCOMING YOU TO ONE OF OUR SUPPORT SESSIONS IN THE NEAR FUTURE - Family Action's Norfolk and Waveney Autism/ADHD Support Service Team.

PLAN BEE



2 - When a flower is not growing, you fix the environment in which it grows, not the flower. AD Heijer

### Plan Bee – Understanding and supporting your child or young person with additional needs

'Plan Bee' is a FREE 3 week course (2hrs per week) written by two Clinical Psychologists working in Norfolk and is aimed at parents or carers of children or young people with additional needs including suspected or diagnosed Autism or ADHD.

During the three week course, we will explore:

- Behaviour as communication.
- Understanding the full range of needs your child may have.
- Developing a plan to support behaviour in difficult situations which can then be shared with grandparents, schools and others.
- Strategies for creating an environment in which your child or young person can thrive.
- Sharing experiences, challenges and successes with other parents experiencing similar issues and learning from these.

Our popular Plan Bee course is now fully booked for Swaffham in May and Wymondham in June. Keep an eye on the newsletter for any additional courses organised.

We are planning a zoom version of the course in August during the school holiday and the next newsletter will contain details.

Puffins Autism Programme - for parents/carers of children or young people with a *diagnosis* of Autism



Family Action is working with Norfolk Community Health and Care to run the Puffins ASD Programme for Parents/Carers of children or young people **with a diagnosis of Autism.** This is a free, comprehensive, four week course with sessions led by Speech and Language and Occupational Therapy professionals from within the Neurodevelopmental Service and by the Autism Specialist Educational Team.

The Puffins course running in Wymondham in May is now fully booked.

### PLACES STILL AVAILABLE

What? Puffins Autism Programme - June 2023

Where? Swaffham Community Centre, The Campingland, Swaffham, PE37 7RB

When? Mondays 5th, 12th, 19th and 26th 9:30 am to 12:30 pm (apart from first session 9.30 am - 1.00 pm)

Contact? Swaffham 01760 725801/720302 or email swaffham@family-action.org.uk

### **CYGNETS** Course

A 6 week course for parents/carers with children with an autism diagnosis who live in the East Norfolk/Waveney area.

The course running on Friday 12th, 19th, 26th May and 9th, 16th, and 23rd June at the Newberry Clinic is now fully booked. Please call 01493 650220 if you would like to be placed on the waiting list.

*If you wish to join our closed Facebook group, go to Facebook and to the Family Action page and then search for Norfolk and Waveney Autism and ADHD Support Service.* 

You can still access the online videos of our Positive Behaviour Strategies course (now Plan Bee) on the NHS for Norfolk website, Just One Norfolk.

Just click here: <u>https://www.justonenorfolk.nhs.uk/child-development-additional-needs/behaviour-sleep/norfolk-positive-behaviour-strategies-pbs/</u>

### West Suffolk Neurodevelopmental Support Service



Here are some events being run by the **West Suffolk Neurodevelopmental Support Service**. If you have any queries about this events please **call 01284 636655** or **email wsuffolk@family-action.org.uk**.





# **Family Action FamilyLine**



# FamilyLine

Supporting adult family members via telephone, text, email and web chat

FamilyLine is a service for adult family members that aims to:

- provide both immediate and long-term support
- help with practical information and guidance
- provide emotional and listening support
- help with understanding and accessing relevant services and information
- provide regular one-to-one befriending
- support to service users feeling isolated

- access to short term telephone counselling
- a referral into our many projects across England and Wales, where relevant.

Family members aged 18 years old and over from anywhere in England, Wales and the Isle of Man can get in touch with the service for free via telephone, text message, web chat or email, using the details below.

**Opening times:** Monday to Friday, 9am to 9pm

Contact details: Telephone: 0808 802 6666

Text message: 07537 404 282

Email: <a href="mailto:family-action.org.uk">familyline@family-action.org.uk</a>

### Live web chat

### **Contacting FamilyLine out of hours**

Do you need FamilyLine but it's out of our operation hours? You can either call back in our opening hours, leave a message on our voice mail for a call back in our operation hours or if you're in crisis you can contact our crisis line to get in touch with a trained professional.

### **Text FAMILYACTION to 85258**

Our crisis messenger text service provides free, 24/7 crisis support across the UK. We know that getting the correct support at the correct time is so beneficial which is why we've introduced our crisis line. This service is delivered in partnership with <u>Shout</u>.

### **About our Service - Contact Details**



To contact us for advice and support, or to book a place on one of our courses or information sessions, please use the details below.

Phone Swaffham 01760 725801/720302 or email <a href="mailto:swaffham@family-action.org.uk">swaffham@family-action.org.uk</a>

Phone Gorleston 01493 650220 or email gorleston@family-action.org.uk

For North and South Norfolk and Norwich please ring the Swaffham number above or email <u>central@family-action.org.uk</u>

Unsure which area to contact? Use any of the above – we are all here to help you.