

# Understanding Sleep & Autism



EMOTIONAL WELLBEING TEAM KENT  
EMOTIONAL SUPPORT TEAM  
MEDWAY



# Why is sleep important?

- Sleep is important for the wellbeing of children & young people (CYP), and their parents and caregivers.
- The amount of sleep needed will generally differ depending on the age of the child.
- Lack of sleep impacts upon us in many ways including our physical health, emotional wellbeing & mental health, educational attainment, and decision making ability.

# Significance for Sleep



The average under 5 spends half of their time asleep



Sleep problems are high on the list of concerns to paediatricians



Sleep problems can have an impact on a child's development and the well-being of the family.

# Activity

Why do you think  
sleep is  
important?

What do you  
notice when your  
child doesn't get  
enough sleep?



# Functions of Sleep



To restore and refresh



Bolster Immunity



Brain Functioning



Memory & Thinking



Manage our mood and emotions



# Recommended Sleep Time by Age

Your child's age	Recommended sleep time in 24 hours
Infants 4 to 12 months	12 to 16 hours including naps
Children 1 to 2 years	11 to 14 hours including naps
Children 3 to 5 years	10 to 13 hours including naps
Children 6 to 12 years	9 to 12 hours
Teenagers 13 to 18 years	8 to 10 hours

# Preparing to Sleep

Tired

Circadian rhythm /  
body clock

Dark

Quiet

Familiar

Temperature

Not too  
hungry/too full

Relaxed- rather  
than experiencing  
pain, stress,  
anxiety

Melatonin release



# Differences in attitudes towards Sleep

Culture

Family Values

Individual Preferences

Timings

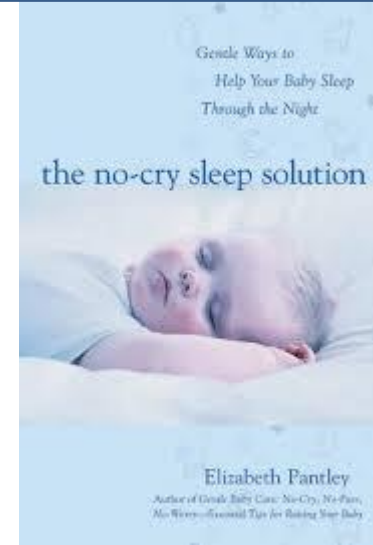
Co-sleeping/Room Sharing

Different contexts

If it works for you then 😊



# Early Childhood Approaches



Extinction

Controlled  
Crying

Gradual  
retreat

Pick up, put  
down

Co-sleeping

Parent led

Child led



# Sleep and Autism

*“Sleep was not a secure place. Sleep was a place where darkness ate you alive. Sleep was a place without colour or light. In the darkness you could not see your reflection. You couldn’t get ‘lost’ in sleep. Sleep just came and stole you beyond your control. Anything that robbed me of total control was no friend of mine.”*

**Somebody somewhere, Donna Williams via NAS website**



# Autistic children commonly experience sleep difficulties

An estimated **40-83%** of autistic individuals have some form of sleep disturbance (1).

Research found that autistic children slept **17-43 mins** less than same age peers (2) and experienced poorer sleep quality (3).

Comorbidities such as **ADHD** alongside Autism can also contribute to sleep difficulties (4).

The prevalence of insomnia in autistic children has been researched to be around **60–86%**, which is two to three times greater than typically developing (TD) children (5).

1) Schwichtenberg et al. (2022) 2) Humpheries et al. (2014) 3) Tse et al. (2020) 4) NHS – ADHD 5) Souders et al. (2017)



# Autism & Sleep

*See Carmassi et al. (2019) for review*

Poorer sleep  
quality

Difficulties  
falling asleep

Restless sleep

Wake earlier

Wake more  
frequently in  
the night

Shorter sleep  
duration

Daytime  
sleepiness

Nightmares



# What are sleep difficulties?

- Some CYP have difficulty relaxing and falling asleep
- Some CYP need less sleep than others; however, some CYP may be “over-tired” making it more difficult for them to relax and fall asleep.
- Some CYP may find it difficult to stay asleep (e.g., frequent night-time waking)
- During childhood there a number of different factors that may contribute towards sleep difficulties.

# Types of Sleep Disorder

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Insomnias- not sleeping enough

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Hypersomnias- sleeping too much

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Parasomnias- unusual experiences during sleep

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Circadian Rhythm Disorders- internal body clock problems

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Sleep related breathing disorders

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Sleep related movement disorders



# Sleep Hygiene

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Dark, quiet, cool bedroom

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No screens

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Consistent bedtime

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Falling asleep alone

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Daytime exercise

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Calming down in the hours before bedtime

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School aged children-shouldn't have naps



# Falling Asleep & Sensory Associations

Sense	Strategy example
Sounds	Play the same calming music before going upstairs/ read Harry Potter to them before bed
Smells	Spray lavender on PJs
Sights	Have bedroom organised in the same way before bed, have the same duvet etc
Texture	Have the same PJs/duvets etc
Tastes	Sleepy foods like bananas before going upstairs to bed



# Activity

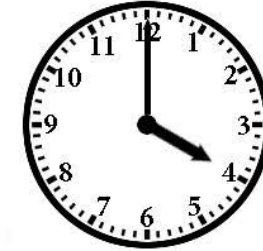
What strategies  
do you / your  
child use to fall  
asleep?



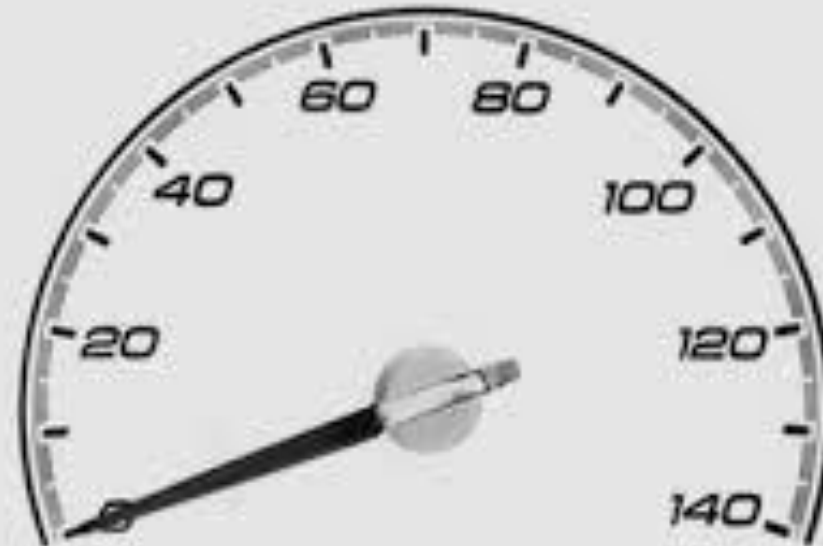
# How fast is your motor going?



Organising activities:  
learning, talking,  
helping, eating



Calming activities:  
Bathing, resting,  
listening to stories, sleeping



Alerting activities:  
running,  
jumping,  
chasing, dancing



.....'s Bedtime Routine



Playing



Dinner



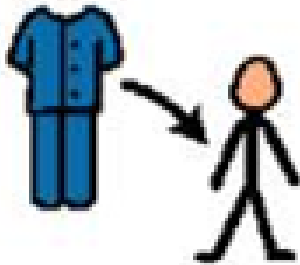
Quiet time



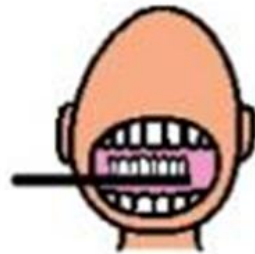
toilet



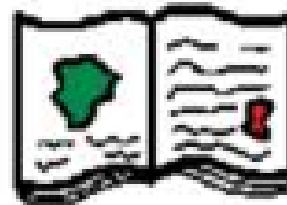
bath



Pyjamas



Brush teeth



Story



Sleep



# Social Stories

## Bedtime

My name is Rosa and I am 6 years old. After dinner, mummy or daddy can say 'it's bath time'. Then we will go and have bath time.

Mummy or daddy will be there with my bath toys.

After I have had a bath and dry off, I can put on my PJs and brush my teeth.

Then I can choose a story for mummy or daddy to read.

When the story is finished I can lie on my bed.

Mummy or daddy can give me a cuddle and say 'goodnight'. I will see them in the morning

I can close my eyes and wait to fall asleep, it may take some time to fall asleep, but that's ok. If I don't fall asleep right away I can think about Peppa Pig, until I fall asleep.





When it is time for bed, mom and dad will let me know. It will be time for me to go to my



room and put on my pajamas. Then I need to go to the bathroom and brush my teeth. It is important



to keep your teeth clean so that they are healthy. Mom or dad will read me a book then I will close

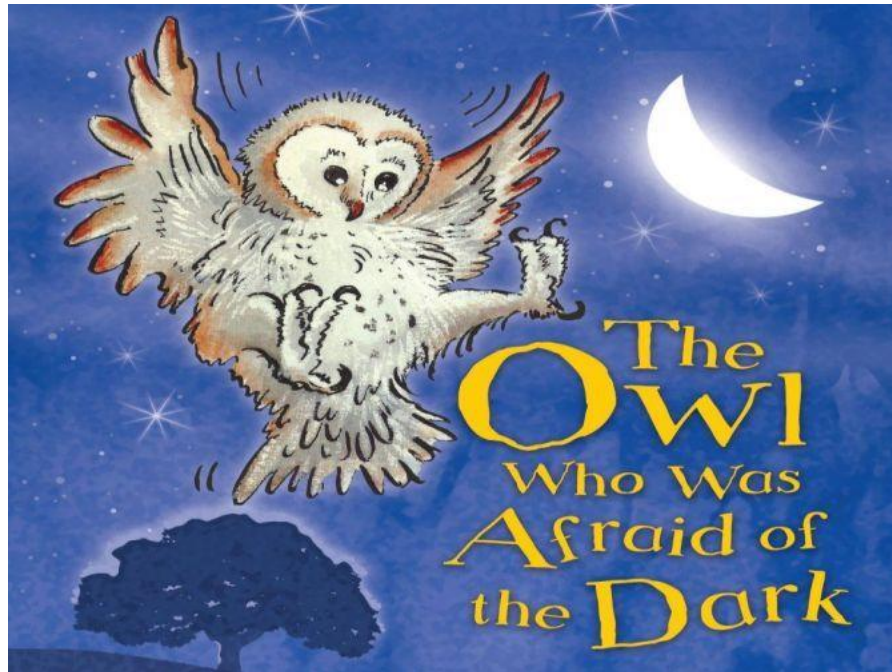


my eyes and go to sleep.

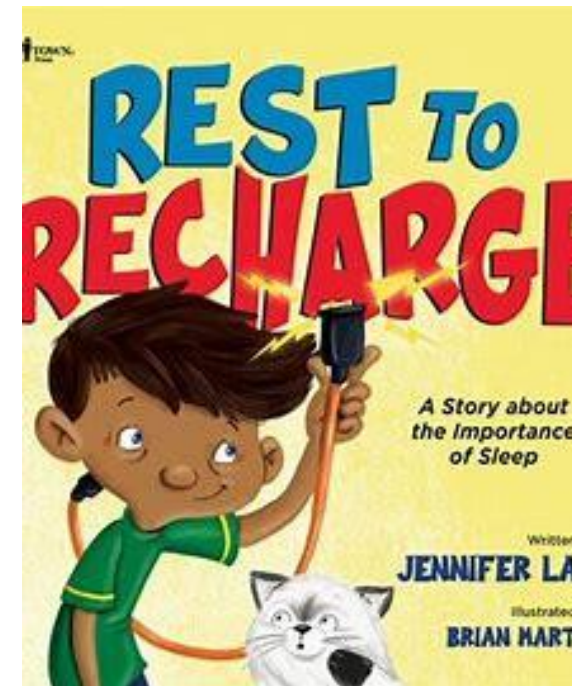


# Books to check out

The Owl Who was Afraid of the Dark by *Jill Tomlinson*



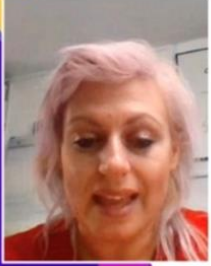
Rest to Recharge by *Jennifer Law*



a GOOD NIGHT'S SLEEP

Learning from Autistic Young People





# Background



UCL researcher  
Dr Georgia Pavlopoulou

Asked 54 autistic adolescents, aged 12 to 17 years, to generate their own photos and use objects and words to introduce subjects and ideas that are meaningful and important to them, around the following themes:

The place they sleep and its surroundings  
activities or objects that are related to their sleep habits  
activities

Objects or people that show situations that are related to  
daytime and night-time activities that help them to fall or  
stay asleep

Objects, people or drawings that show or are related to the  
bedtime thoughts and activities that help them to fall asleep

Objects, drawings or actions that show how they feel or  
think about their sleep.

The results identified  
four key factors that  
may play a role in the  
sleep experiences of  
autistic young people:

**focused interests**  
**physical activity**  
**sensory autonomy**  
**during bedtime**  
**having more control**  
**and choice in their**  
**daily lives.**



# Some of the original data

## Complete preferred meal routine

It's about the expected color, the expected taste



## Knowing the outcome of completed homework

To know = worry less, not to have to stay up worrying



## Playing a table game with clear set of rules with family member

Cards game is fun, I know the rules, what can go wrong



## Favorite activity before night time

Playing with Lego, reaching a point of effortless satisfaction



## Bed modifications to feel sensory safety

Important to create visual edges around bed



## Sensory autonomy

Being able to choose the smell, the texture, the volume



## Checking notes to self and items that remind me of past or future good times

Feeling good about life, thinking that there is a happy life for me.



## Sitting quietly next to family member, non-verbal interaction before going to bed

Being in their company but not too close, not having to put too much effort or thought.



## Rehearsing what will happen tomorrow with mother in bedroom

Asking her about things and giving me specific answers back, like a game. Like lyrics of a song.



## Repetitive reading of focused interest books, audio books or movies' dvds

Reading encyclopedic books, enjoying reading something very familiar, almost automatic reading.



## Engage with play station games that have calming repetitive music and slow motion

Non-action games with no surprises, just relaxing moving bubbles.



## Engage online with teams that present facts about my focused interests

Harrow Bus Enthusiasts group is relaxing me when at bed.

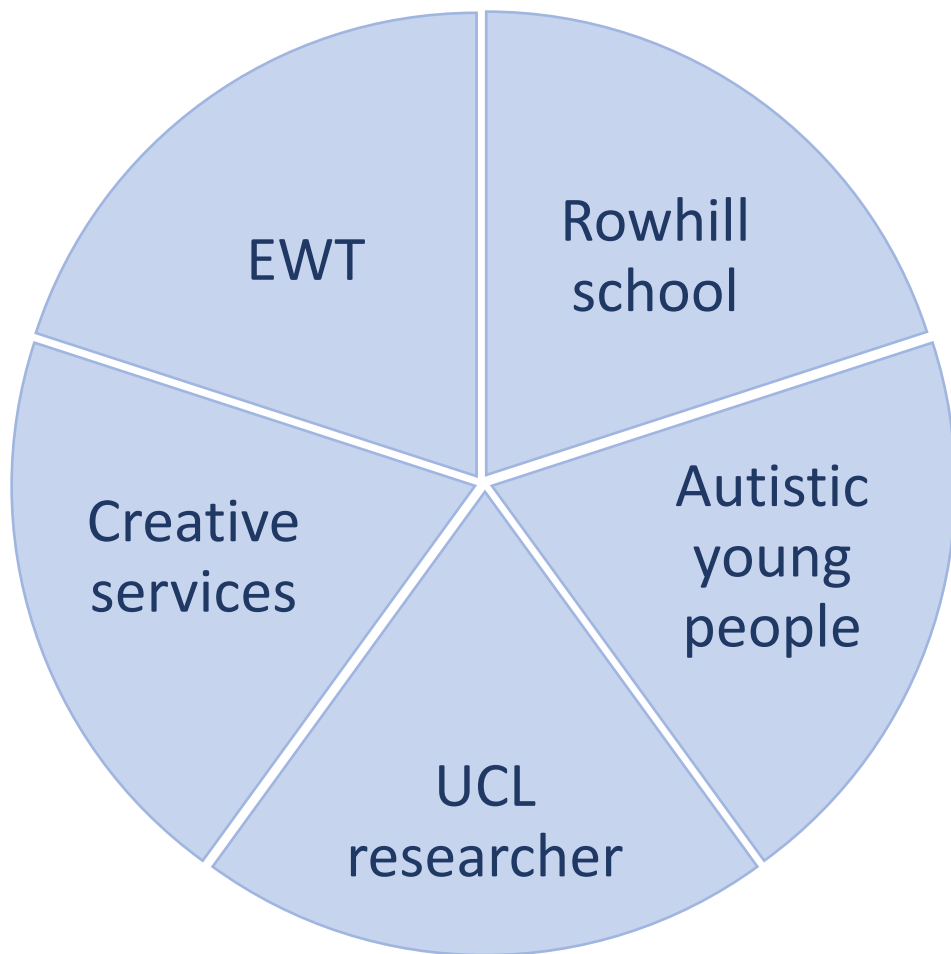


# Results of the research

[Frontiers | A Good Night's Sleep: Learning About Sleep From Autistic Adolescents' Personal Accounts | Psychology \(frontiersin.org\)](#)

“Our results highlight that sleep should be treated *individually* and in relation to the *environmental and personal factors* that affect each autistic person.”

# Our co-production team



# Overview of the co-production process

- UCL researcher, Dr Georgia Pavloupoulou, joined the co-production team to share and discuss the findings of the original research
- Young people discussed the findings of the research and gave feedback that the finding of the original research made sense to them and reflected some of their own personal experiences
- The co-production team worked together to create a leaflet and two animations.
- Additional resources were then created: lesson plan for schools and guided self-help materials for young people.



# Co-produced animation (04:01 mins)



<https://youtu.be/y6dviuVRkbA> - Top tips for helping children with autism to get a good night's sleep



# Leaflet

## Sleep is important

It affects how we feel and what we do when we are awake. It affects how we learn at school. Our body and our brain need sleep. No one is exactly sure what work the brain does when you're sleeping, but some scientists think that the brain sorts through and stores information, replaces chemicals, and solves problems while we snooze.

### Lots of autistic people have difficulty sleeping.

They might find it hard to fall asleep.

They might wake up a lot in the night.

They might sleep for less time than other people.

There is a lot of advice about how to get a 'good night's sleep' but we don't know whether it is helpful for autistic people. The first line of advice for many autistic young people who struggle to fall asleep, or to stay asleep during the night, is introducing general sleep rules, for example not viewing screens before bed and making sure a bedroom is dark. For some autistic young people this might feel like one more pressure to comply with rules written by, and for, non-autistic people.

To find out more, a researcher worked with 54 autistic young people to understand what helped them sleep. They worked together using photo taking, talking, writing, and drawing to understand their sleep-related activities during the day and before bedtime that contributed to a good night's sleep.

Full research paper:  
<https://www.frontiersin.org/articles/10.3389/fpsyg.2020.583868/full>



If you need to talk to someone, these organisations can help:

**Samaritans:** call 116123

**Shout:** text SHOUT to 85258

**Childline:** children & young people call 0800 1111

**For mental health advice and support in Kent & Medway,** please contact **NELFT** Single Point of Access (SPA):

**Call:** 0800 011 3474

**Email:** nem-tr.kentchildrenandyoungpeoplehealthservices@nhs.net

**Website:** [www.nelft.nhs.uk/single-point-of-access-referral](http://www.nelft.nhs.uk/single-point-of-access-referral)

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Scientific Support: Dr Georgia Pavlopoulou, Dr Virginia Lumsden, Prof Richard Mills.

Co-production leads: Helen Thomas, Tabitha Collumbell.

Illustration: Joshua Knowles.

Design: Briony Campbell.



## A GOOD NIGHT'S SLEEP

### LEARNING ABOUT SLEEP FROM AUTISTIC YOUNG PEOPLE



Recommendations made with and for autistic young people, and for all supporters of autistic young people.



### AUTISTIC YOUNG PEOPLE MADE TWO TOP RECOMMENDATIONS

1. It is important to work out sleep routines that work for you, even if that is different from the general sleep advice. Maybe your parents/carers and supportive adults can work out with you what will help you sleep.
2. It is important to consider the following daytime and bedtime "feelgood" factors that may have an impact on the quality and quantity of sleep.

#### Focussed interests

Many autistic young people said that they feel happier and more relaxed when they focus on their special interests (themed books, animation, playing an instrument, chatting about favourite movie characters or nature). Time spent on special interests helps them sleep. Some said they plan some time for special interests in the day and at bedtime. They prefer to have a visual agreement with parents/carers on when it is time to stop doing favourite activities, and a few reminders so that they don't get interrupted suddenly.

#### Physical activity

Lots of autistic young people said it helps to exercise or play sports. Choosing a time and way that feels alright was important to them (playing basketball alone, being able to change clothes or join a group as much or as little as you want).

#### A chance to choose

Lots of autistic young people said that being able to choose how to spend some of their time at home/school helped them sleep. This helped make a balance between things they have to do and things they like to do. They slept better after talking through problems or just sharing their favourite hobbies or achievements with people who listen to them. Being able to make choices at bedtime was also important

#### Being kind to your senses

Autistic people can be sensitive to what they see, smell, taste, touch and hear. Many autistic young people said that before bedtime they get rid of things that feel bad (uncomfortable labels, unwanted noise) and choose things that feel good (creams that smell good, familiar food, soft clothes).

## Things that help in the evening & at bedtime

#### Personalised sleep routine

Choosing things that feel, taste, smell, and sound good helped some autistic young people to feel relaxed and safe before they went to bed. For example: special smells from clothes, toys, oils, or body creams; eating certain foods; wearing comfortable clothes; putting things along the edge of the bed; blocking out noises, for example, by turning on a fan.

#### Relaxing before bed

Many autistic young people felt more relaxed when they had time to themselves to choose what to do. Some said they find it easier to sleep on days that they do not have extra clubs and activities. Relaxing activities included: listening to music; watching familiar videos; using a self-help exercise; taking a bath; meditating.

#### Spending time with family

Spending time with people in a way that is comforting and supportive helped many young people sleep. For example: relaxing in the same room; playing a rule-based game; talking about the day; planning the next day; having familiar bedtime conversations.



## Things that help during the day



#### Physical activity

Some autistic young people said that physical activities during the day helped them to feel happier at bedtime. Activities included: swimming; riding a bike; doing gymnastics; or having a short drumming session. They like to do this in a way that feels comfortable (e.g. riding a bike alone to have a feeling of freedom).

#### Things that make you feel good

Many autistic young people said they sleep better when there are things that make them feel good during the day. It helped to: plan nice activities for the future; see what interesting lessons they have the next day; talk through schoolwork so they know they can do it; have a good relationship with a teacher; prepare for activities; attend a club they have set up; talk about good things that have happened.

#### Focused interests

Spending time on special interests helped many autistic young people relax so that they slept better. It helped to: spend some time doing activities that they enjoy; talk about their favourite topics with family; plan time for their special interest the next day.





# Additional resources



## A GOOD NIGHT'S SLEEP

When we make a sleep routine it is important to see if it is working.  
 Try your routine for two weeks and track your sleep to see if it works.  
 After two weeks you can choose to use the routine or make changes to improve it.



### My Sleep Tracker

Put an x on the line to show how well you slept each day	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
5. I had a great night's sleep	-----						
4. I slept most of the night	-----						
3. I woke up a bit but i did sleep	-----						
2. I slept a bit but woke up a lot	-----						
5. I was awake most of the night	-----						
What did you do in the day and before bed to help you sleep?							





## A GOOD NIGHT'S SLEEP

When we have trouble sleeping it can be useful to think about what helps us feel relaxed and ready to fall asleep.

These worksheets will consider what helps you sleep and put those ideas into your own personalised sleep routine.

**Stick pictures of things you like in this box**

### What are your interests?

Spending time doing things that interest you can help you get a good night's sleep. Write down some of your interests on the lines below:

1. \_\_\_\_\_

2. \_\_\_\_\_

3. \_\_\_\_\_

### How do you stay active?

Some physical activity in the day can help us sleep at night. We all stay active in different ways. Some people like sports or yoga, others prefer to take a walk. Write down some ways that you like to get active on the lines below:

1. \_\_\_\_\_

2. \_\_\_\_\_

3. \_\_\_\_\_

### Things that make you feel good

Many autistic people said they sleep better when there are nice things to enjoy during the day: perhaps a club they like, favourite lesson or teacher, time with a friend or pet. Write three things you look forward to.

1. \_\_\_\_\_

2. \_\_\_\_\_

3. \_\_\_\_\_

### A chance to choose

There are lots of things we have to do, so it is important to plan how we do them. It helps to save some time for the things we want to do too!

Who can help you plan and solve problems?

\_\_\_\_\_

When can you have some free time?

\_\_\_\_\_

Who can you discuss your day with?

\_\_\_\_\_



## ★ Being kind to your senses

Our senses are important. They tell us about the world around us. Being kind to our senses can help us feel happy and calm so we can get a good night's sleep.

What do you like looking at?	What smells do you like?
What don't you like looking at?	What smells don't you like?
What do you like to touch/feel?	What tastes do you like?
What don't you like to touch/feel?	What tastes don't you like?
What do you like to listen to?	There are two extra senses that people often forget. We sense how we are moving and balancing. We also sense where our body is and what it is doing without looking. The activities below use our extra senses.
What do you like to listen to?	

Circle any that you enjoy. Cross out any that you don't like.

a big squeeze/hug   sit under a heavy blanket   massage   yoga  
 move something heavy (e.g. weights)   balance  
 hang upside-down   swinging   jump   pull a stretchy band  
 scooter/skate   rocking chair   bounce (e.g. on a yoga ball)

Are there any other sensory activities you enjoy?



## A GOOD NIGHT'S SLEEP

When we have trouble sleeping it can be useful to think about what helps us feel relaxed and ready to fall asleep.

These worksheets will consider what helps you sleep and put those ideas into your own personalised sleep routine.

### How do you relax?

Feeling relaxed can help us get a better night's sleep. For example, might do something we enjoy, take a bath or listen to music. What do you do to relax before bed?

1. \_\_\_\_\_
2. \_\_\_\_\_
3. \_\_\_\_\_

### Time with family

Spending time with people in a way that is comforting and supportive helped many young people sleep, like playing games or planning the next day. How do you like to spend time with people?

1. \_\_\_\_\_
2. \_\_\_\_\_
3. \_\_\_\_\_



## My Personalised Sleep Routine

Stick or draw pictures

What I will do




# Relevant Services

## Autism & ADHD Support & Resources (office.com)

- National Autistic Society: [National Autistic Society \(autism.org.uk\)](https://www.autism.org.uk)
- Kent Autistic Trust [The Kent Autistic Trust \(kentautistictrust.org\)](https://www.kentautistictrust.org)
- Cygnet Group through Early Help: [Early Help \(support for families\) - Kent County Council](#)
- [Medway Small Steps Service - Family Action \(family-action.org.uk\)](https://www.family-action.org.uk)
- IASK for help with education: [Information, Advice and Support Kent \(IASK\) - Kent County Council](#)
- The Autism Apprentice CIC: [Autism Apprentice](#)



# Online Support Intervention (OSI)



## OSI COULD HELP YOU

OSI (Online Support and Intervention) is an online platform designed to help parents to learn tools and techniques to help their child (aged 5 to 12 years old) to overcome difficulties with anxiety.

Parents work through weekly online modules that contain videos, quizzes, and interactive worksheets. Parents are also supported by a weekly telephone/videocall appointment with a clinician.

You can access OSI at a convenient time for you using any electronic device!



My son's anxiety has noticeably declined, and I feel much more confident...we worked together on a specific goal and I have to say it was life changing. I can say that it worked for her too.



## GET IN TOUCH:

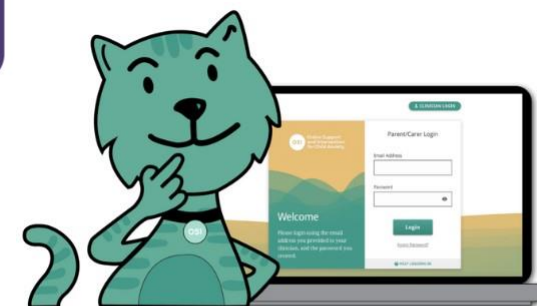
Scan the QR code for more information on OSI.  
If your child attends one of our schools, and you are interested in learning more about OSI and whether this is the right support for you, please email our team at:  
[EWTanDESTenquiries@nelft.nhs.uk](mailto:EWTanDESTenquiries@nelft.nhs.uk)  
Currently available until end of October half-term 2023

[EWTanDESTenquiries@nelft.nhs.uk](mailto:EWTanDESTenquiries@nelft.nhs.uk)



# Online Support Intervention (OSI)

- OSI is an online platform that supports the delivery of a parent-led intervention for child anxiety problems (aged 7 – 12).
- Modules are completed by the child's parent/carer.
- There is weekly telephone support from a practitioner/clinician.



**Parents can now self-refer via our website.**

<https://osiresearch.org.uk/osi/the-parent-carer-role/resources-for-parents/>

Best care by the best people



# Countywide online workshops

These are the workshops we run for **primary** school parents/carers:

Introduction to Autism

Understanding ADHD

Understanding your child's behaviour

Understanding Anxiety

Me and My Child: Understanding resilience

Sleep and Autism

[Link to Primary  
School Workshops  
Terms 3 & 4  
Poster](#)



# Countywide online workshops

These are the workshops we run for **secondary** school parents/carers:

Understanding the Amazing Teenage Brain

Understanding ADHD

Less Stress Guide to Exams

[Link to Secondary  
School Workshops  
Terms 3 & 4 Poster](#)



# We welcome your feedback!

Your feedback helps us improve these workshops and enables us to host them more.

## ***From previous feedback we:***

- Have added extra content and created new workshops in line with parent requests.
- Considered the timing of the workshops and time to talk within them.





# Thank you for listening



Best care by the best people



# Disclaimer

The purpose of this workshop is to share information about local resources/support. The Emotional Wellbeing Teams/Emotional Support Teams cannot comment on the suitability/quality of these resources and whether it would meet the needs of your family.

If there are additional sources of support that you would recommend, that are not listed here, please email us at:

[ewtandestenquiries@nelft.nhs.uk](mailto:ewtandestenquiries@nelft.nhs.uk)

We would love to hear about them.

