Sheffield sleep service
and
Management options for insomnia

Janine Reynolds

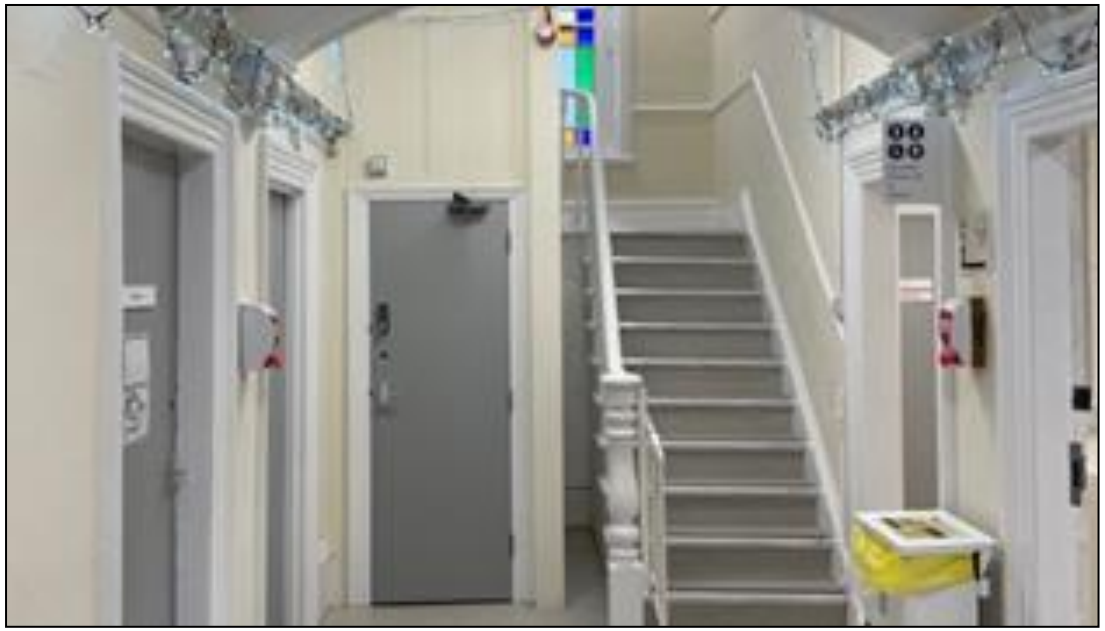
Will Daw

Sheffield Children's NHS
NHS Foundation Trust


JOIN THE
MARCH
TIME 1915
DAY
DATE JAN
200
200
when Peter (WMGM) Tripp has been
awake 200 HOURS he will
ring this bell to start the
March of Dimes Mothers March
WMGM
WMGM
POLIO

Sleep Team

Sheffield Sleep Service

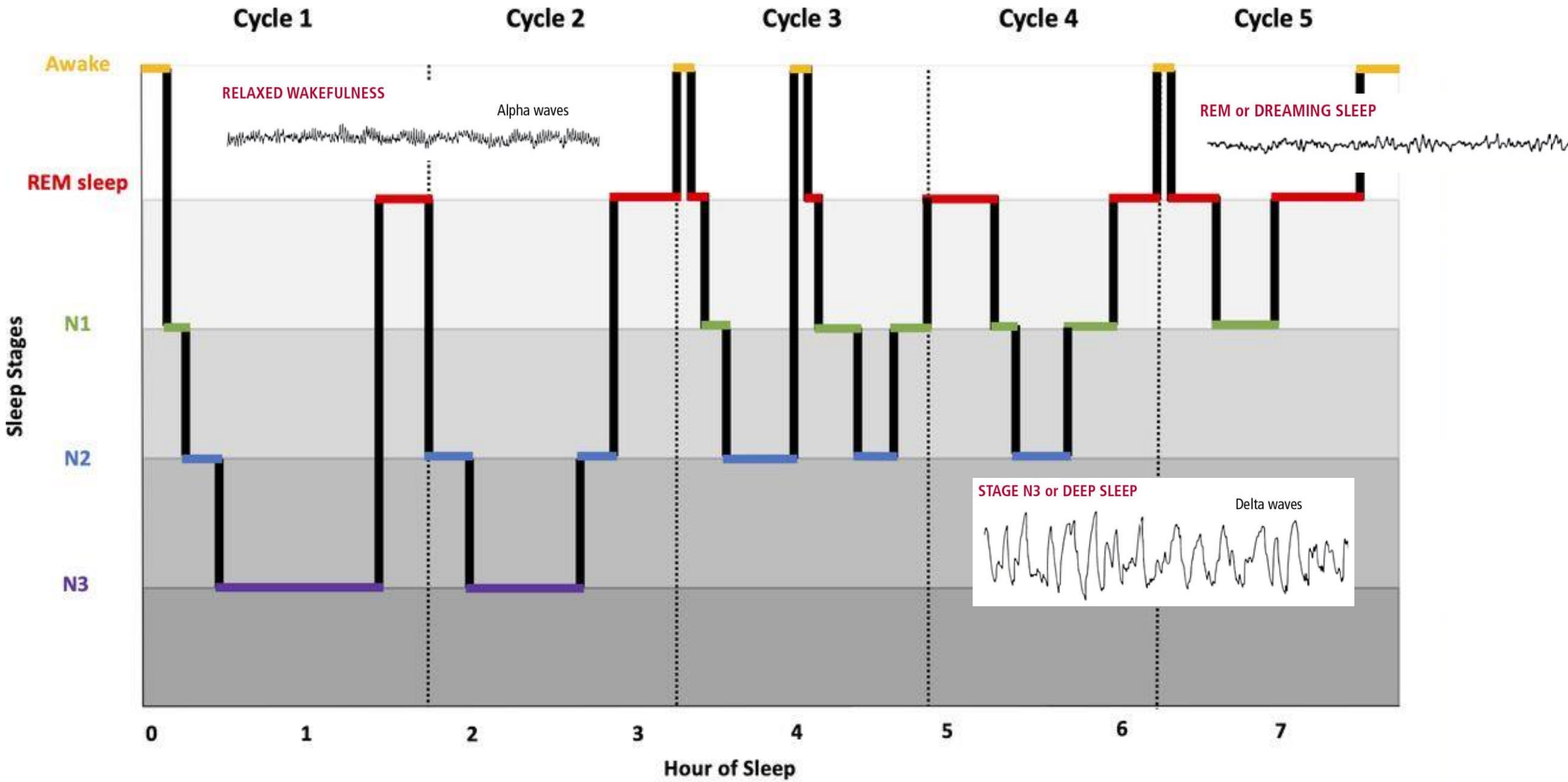


5 Consultants
5 nurses and 5 practitioners
Sleep House

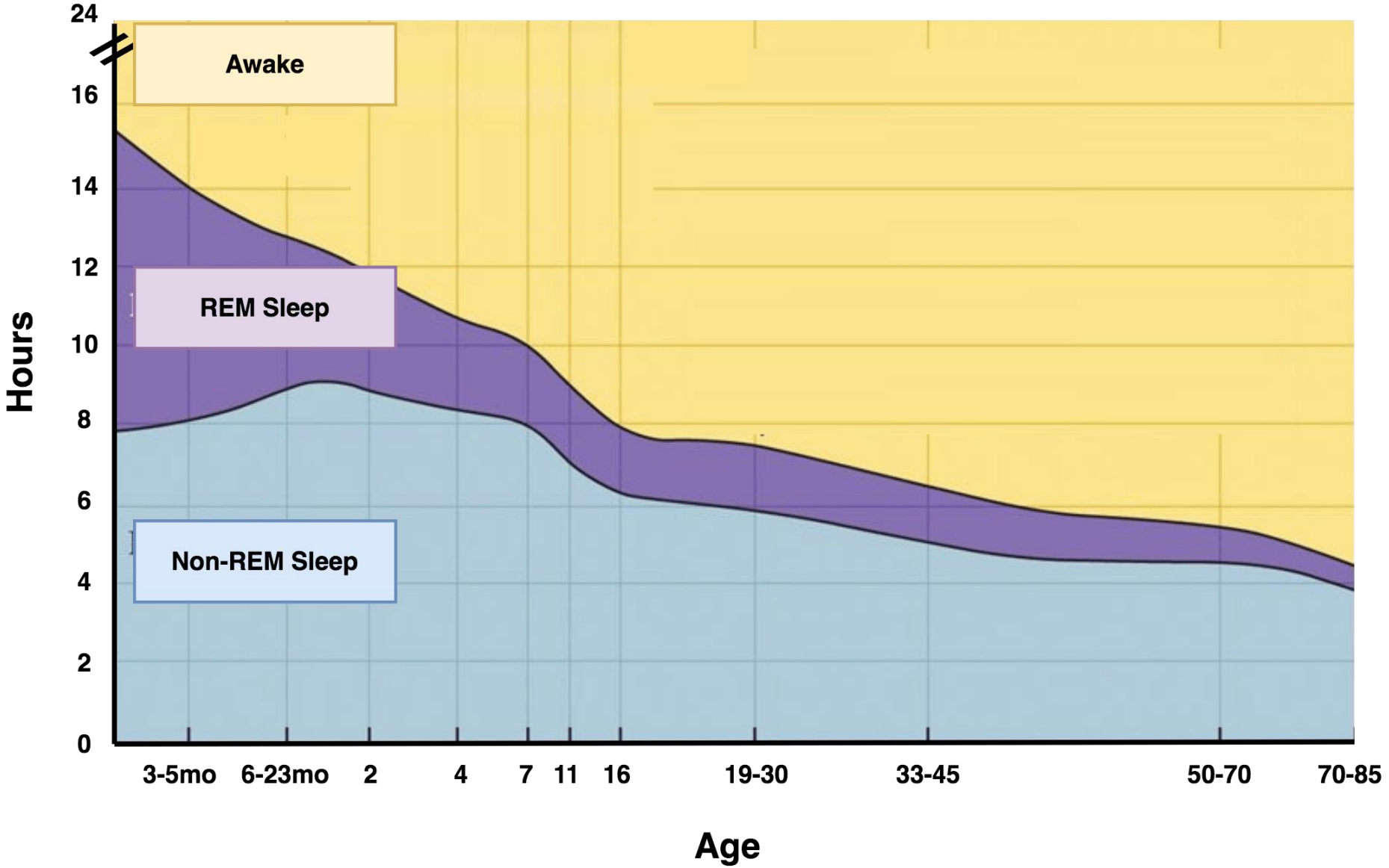
Sleep studies
Narcolepsy service
Home oximetry service
Home ventilation service

Overview

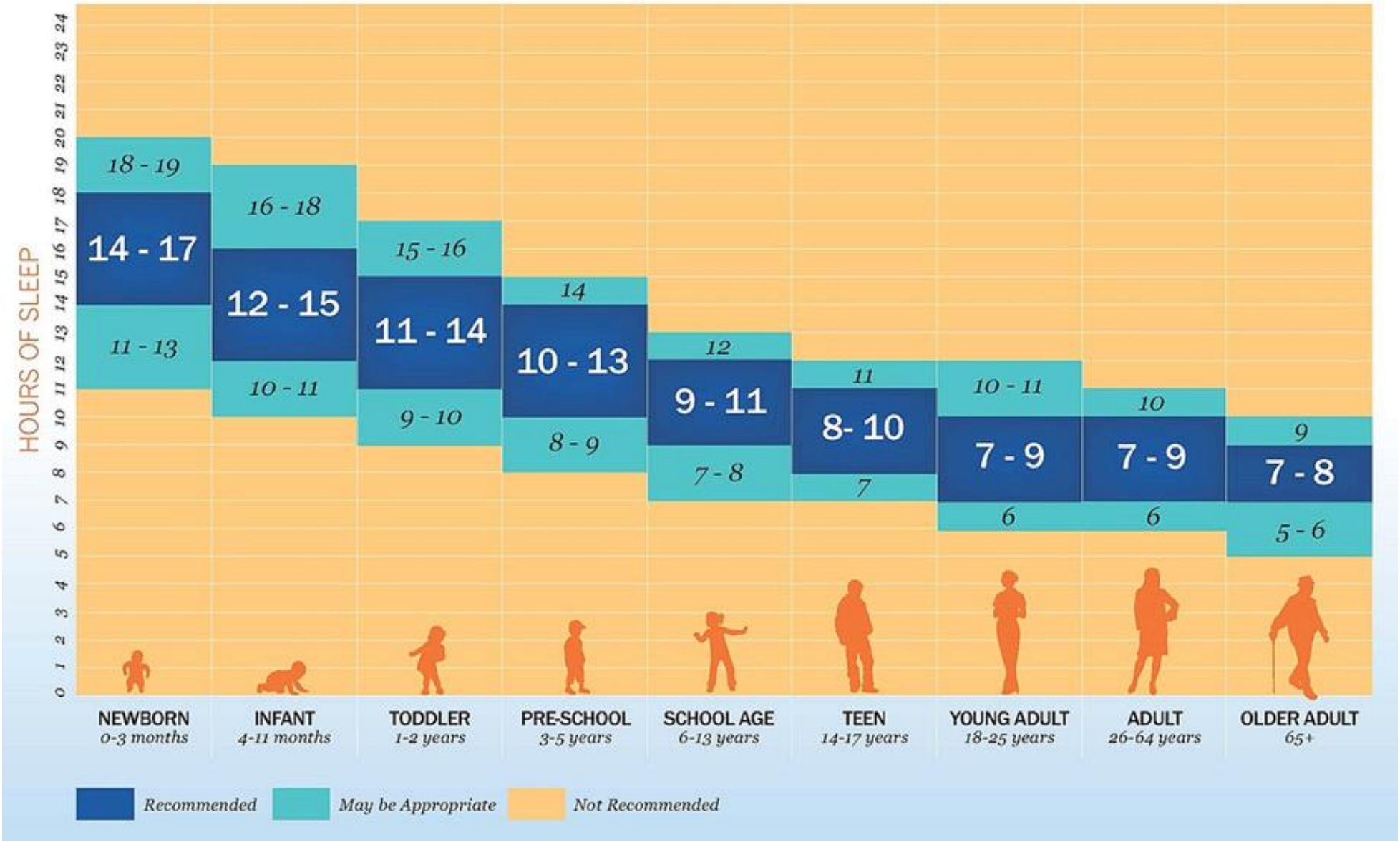
- What is sleep
- Sleep disorders
- Behavioural insomnia
- Nurse-led sleep clinic
- Melatonin
- Updates


Cycle 1
Cycle 2
Cycle 3
Cycle 4
Cycle 5
Awake
REM sleep
N1
N2
N3
Sleep Stages
RELAXED WAKEFULNESS
Alpha waves
REM or DREAMING SLEEP
STAGE N3 or DEEP SLEEP
Delta waves
0
1
2
3
4
5
6
7
Hour of Sleep

Sleep pattern changes with age



Sleep duration recommendations



AMAZING BREAKTHROUGH!

Scientists have discovered a revolutionary new treatment that makes you live longer.

- It enhances your memory and makes you more creative.
- It makes you look more attractive.
- It keeps you slim and lowers food cravings.
- It protects you from cancer and dementia.
- It wards off colds and the flu.
- It lowers your risk of heart attacks and stroke, not to mention diabetes.

You'll even feel happier, less depressed, and less anxious.

Are you interested?

Sleep disorders divided into 6 major categories:

1. Sleep-related breathing disorders
2. **Insomnia**
3. Hypersomnia's of central origin
4. Circadian rhythm sleep disorders
5. Parasomnias
6. Sleep-related movement disorders

Estimated prevalence in Childhood

Insomnias 30%

Parasomnias 25%

Circadian rhythm disorders 7%

Sleep related movement disorders 1–2%

Sleep related breathing disorders 2–3%

Hypersomnias 0,01–0,02%

Diagnostic criteria for chronic insomnia (ICSD III)

Following present for ≥ 3months for ≥ 3 days a week

- Sleep initiation or maintenance problems
- Adequate opportunity and circumstances to sleep
- Daytime consequences
- Exclusion of other sleep disorder

- **Behavioural insomnia**
  Commonest cause of chronic insomnia
  - Limit-setting type
  - Sleep onset association type
- **Psycho-physiological insomnia**
  Anxiety at bedtime and preoccupation with failure to fall asleep.
- Insomnia **secondary** to another chronic physical or mental health condition

- **B** – Bedtime issues
- **E** – Excessive daytime sleepiness
- **A** – Awakenings during the night
- **R** – Regularity and duration of sleep
- **S** – Snoring

BMJ Paediatrics Open

Pilot study of an integrated model of sleep support for children: a before and after evaluation

Heather E Elphick ,[1] Candi Lawson,[2] Ann Ives,[2] Sue Siddall,[2] Ruth N Kingshott,[1] Janine Reynolds,[1] Victoria Dawson,[3] Lorraine Hall[2]

To cite: Elphick HE, Lawson C, Ives A, *et al*. Pilot study of an integrated model of sleep support for children: a before and after evaluation. *BMJ Paediatrics Open* 2019;**3**:e000551. doi:10.1136/bmjpo-2019-000551

► Additional material is published online only. To view please visit the journal online (http://dx.doi.org/10.1136/bmjpo-2019-000551).

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ABSTRACT

Objective Despite the success of behavioural sleep support interventions in the third sector, sleep support is not universally available for families in the UK. The aim of the study was to provide evidence of efficacy and to propose a delivery model for integrated sleep support for families of vulnerable children.

Design and setting A sleep support intervention was carried out in Sheffield Local Authority evaluated using a preintervention and postintervention study design by Sheffield Children's National Health Service (NHS) Trust.

Participants Fifty-six children aged 6–16 years with significant sleep problems were recruited; 39 completed the intervention and evaluation.

Interventions Basic sleep education and an individualised programme was delivered by a sleep practitioner. Follow-on telephone support was provided to empower the parent (and/or young person) to carry out the

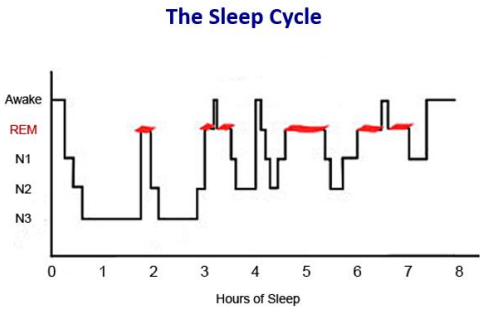
What is known about the subject?

- Sleep deprivation due to behavioural insomnia has an impact on physical, mental and emotional health and well-being for the child and family.
- Intensive sleep support interventions are effective but access to support is patchy and, in most areas, offered only by the voluntary sector.
- Integrated multiagency working is a National Health Service priority area.

What this study adds?

- Cross-agency sleep support delivered via an integrated delivery model has shown efficacy and can be implemented by integration into the existing

Behavioural Sleep Intervention



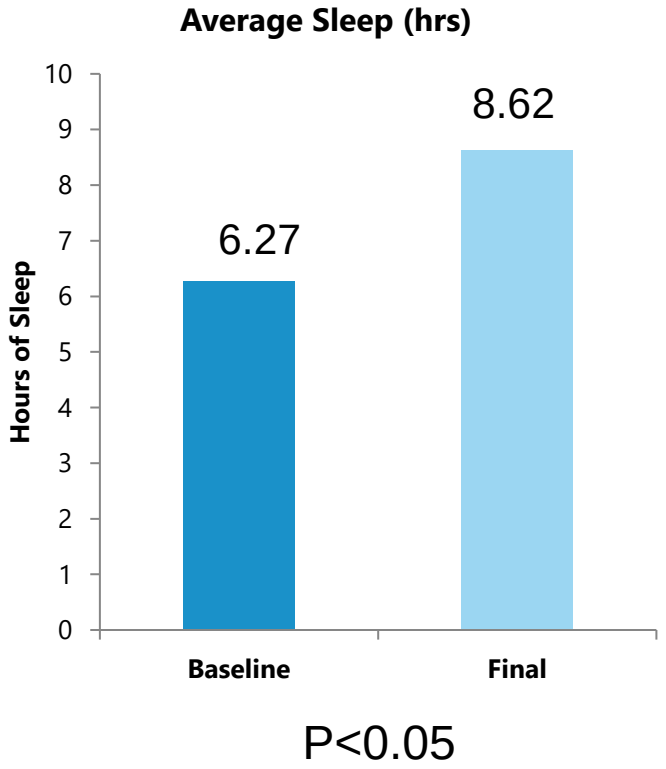
- Sleep Routine information
- 1-1 support to develop an individualised plan
- Follow up telephone support from
- a Sleep Practitioner

Case examples

7 years old with ADHD
+4 hours to fall asleep, up 4-5 times a night
Sometimes no sleep for 36 hours

- Damages property
- Steals food
- Impact on Dad's ability to drive

15 year old in residential home
4-5 hours sleep, up during the night
Impacting on other children in home
Very challenging behaviour
At risk to himself and others
Waking night staff employed



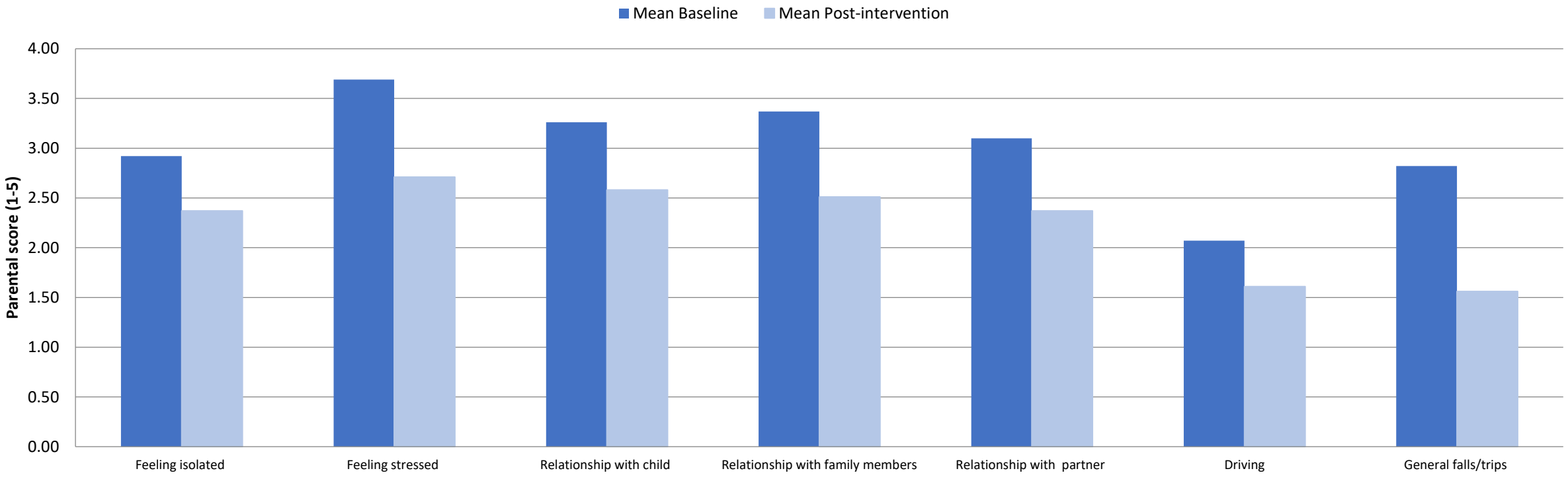
P<0.05

Children gained on average an extra

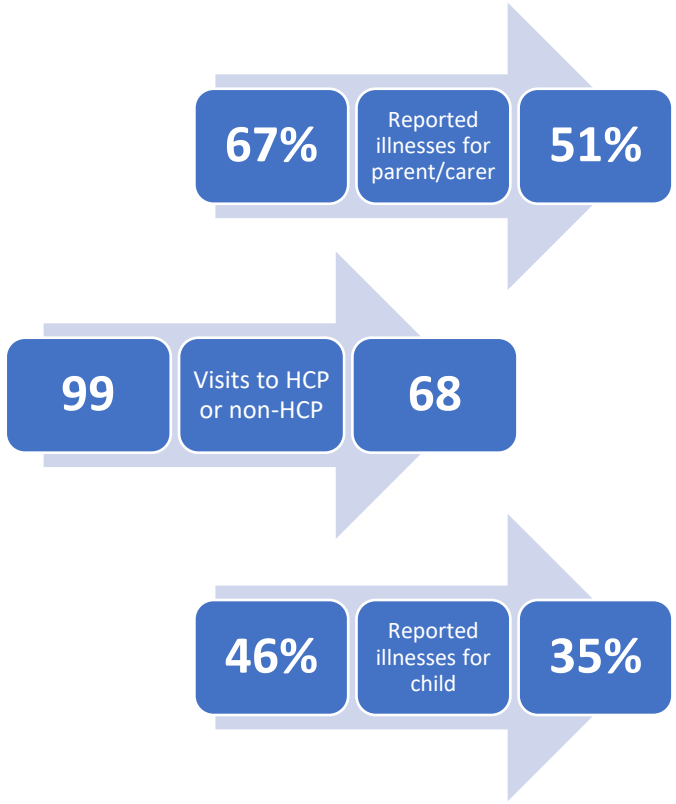
2.4 hours sleep a night = nearly **2 nights extra sleep a week!**

Mood of the Child on Wakening

Impact on Parental Wellbeing

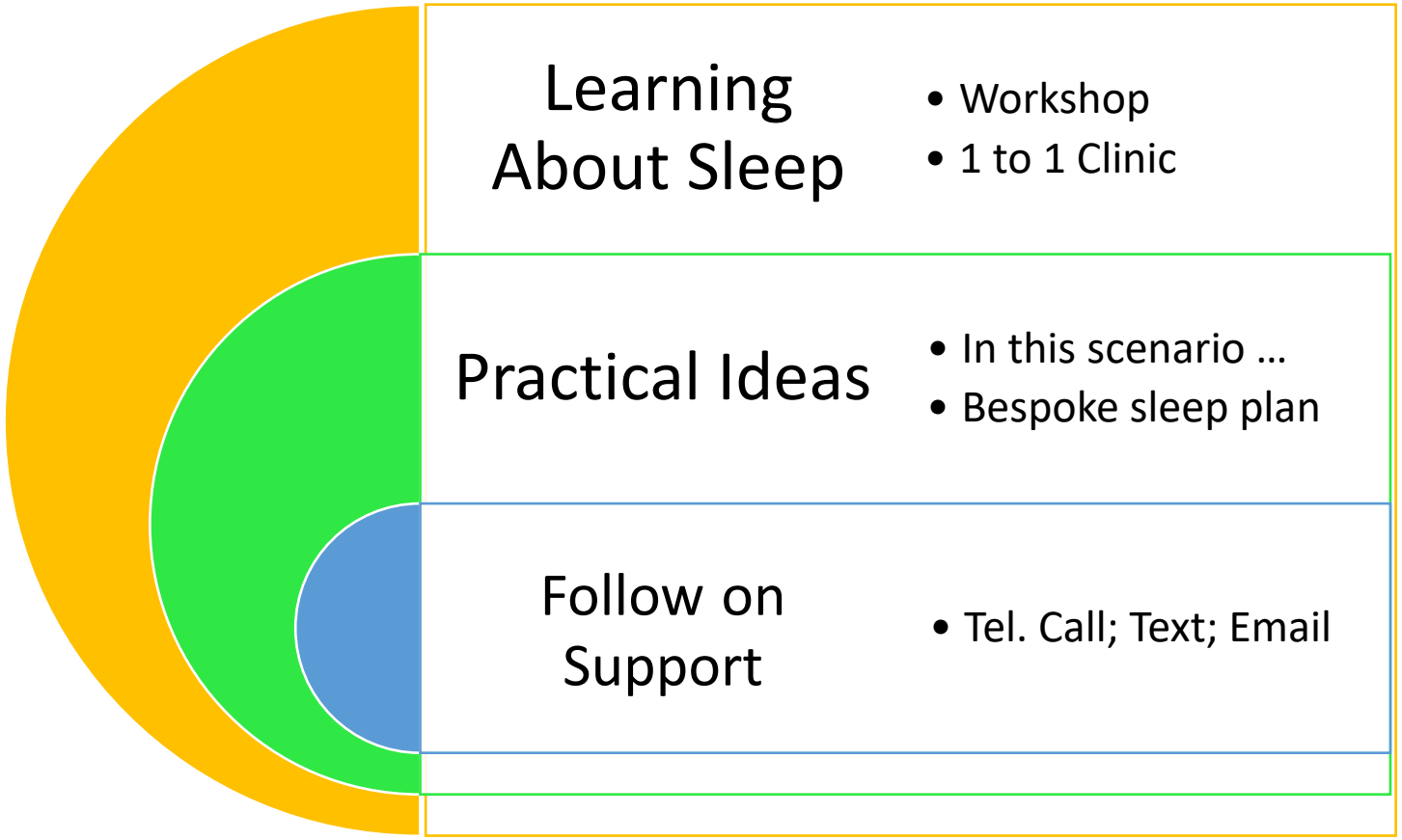


WIDER VALUE



- Value for patient:
  - Seeing appropriate specialist and receiving the right support
  - Holistic approach
  - Inter-agency communication
- Value for money:
  - Consultant time savings
  - Waiting list targets
  - Potential to reduce placement breakdown, improve engagement, reduce contact with other services

WHAT HELPED PARENTS



Our Vision across NHSE

Jarvis K, et al. Arch Dis Child 2024;0:1–7. doi:10.1136/archdischild-2023-326120

Resource Gaps

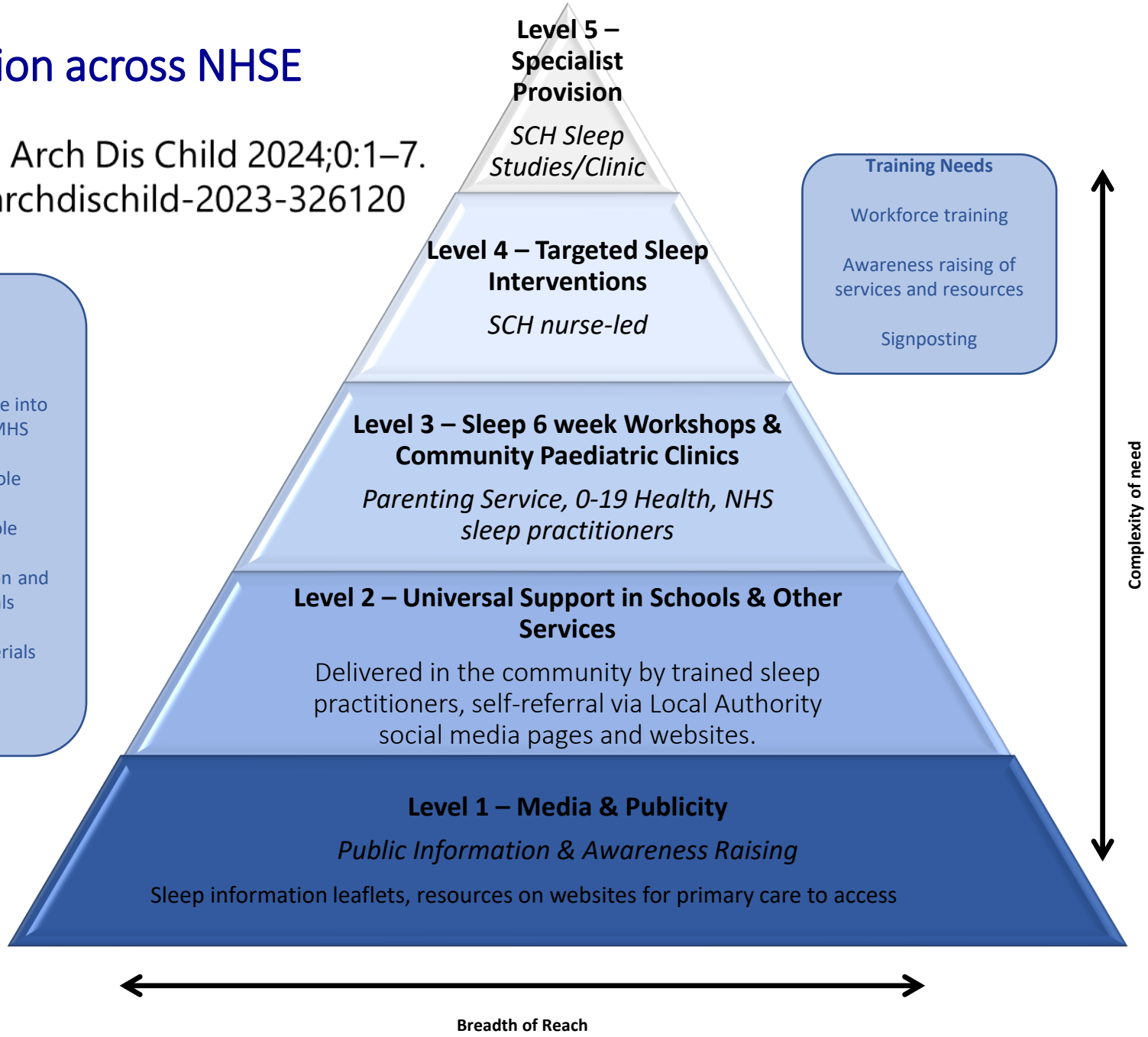
Expansion of SCH service into Neurodisability / CAMHS

Sleep Coordinator Role

Time within usual role

Training, implementation and mentorship materials

Leaflets, website materials



Training Needs

Workforce training

Awareness raising of services and resources

Signposting

NEW NURSE LED SERVICE

- A Specialist Service for those patients who have:
    - Limit Setting Insomnia (e.g. delaying bedtime, curtain calls)
    - Sleep Onset Association Insomnia (e.g. dummy, rocking, lighting, TV)
    - Psychophysiological Insomnia (e.g anxiety at bedtime)
    - Insomnia Secondary to another chronic physical or mental health condition
    - Sleep Maintenance issues (e.g. self-settles to sleep ok, but wakes in the night)
    - Early Morning Wakings (e.g. issues of regularly waking before 06:00am)

When parents report a sleep problem – baseline assessment

Important to establish their concern….

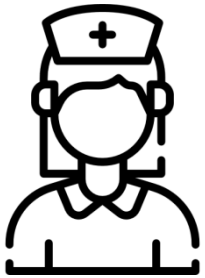
- Not enough sleep
  - Falling asleep?
  - Staying asleep?
  - Waking up too early?
- Excessive total sleep
- Daytime sleepiness or is it excessive tiredness?
- Things that happen in sleep (e.g. snoring/ noisy breathing / bed-wetting/sleep walking/sleep terrors/environmental factors)
- Other comorbidities- Asthma/ Eczema/Reflux/ ADHD/ASD/ genetic syndromes

WHAT WE DO

Referrals

- From across the region
- Rapid increase in referrals
- Filtered by consultants
- Direct referrals into service

Baseline Assessment



- 20 page assessment with Sleep Nurse & Practitioner
- Detailed history and plan prescribed by Nurse
- Sleep Practitioner takes the plan forward with daily/weekly calls

Tel clinics

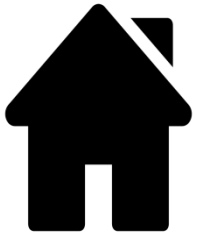
- Sleep nurse/ Sleep practitioner check in with calls needed
- Discuss cases at weekly nurse MDT
- Discuss cases at consultant MDT

Discharge

- Referred back to the Nurse for successful / unsuccessful discharge
- Referral back to consultants if needed
- Back to original referrer

FURTHER INTERVENTIONS

BLOODS



HOUSING

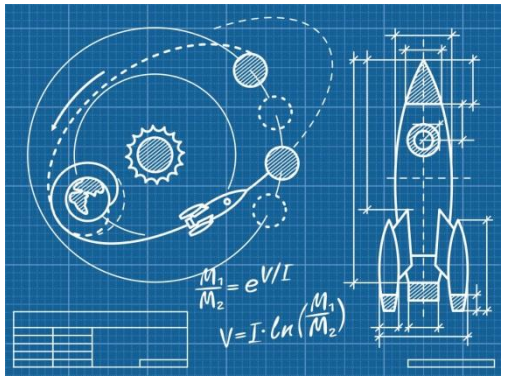
ONWARD REFERRAL

SOCIAL CARE / MAST

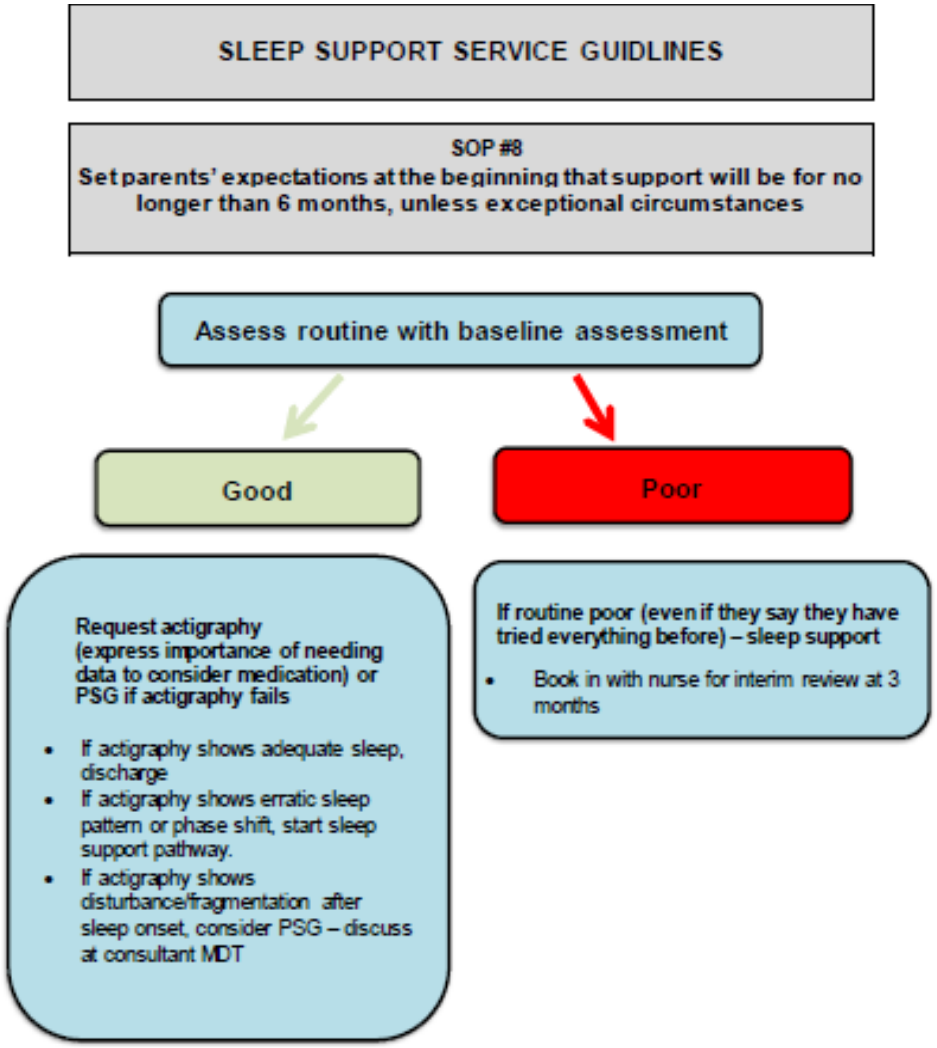
SCHOOL CONTACT EHCP SUPPORT

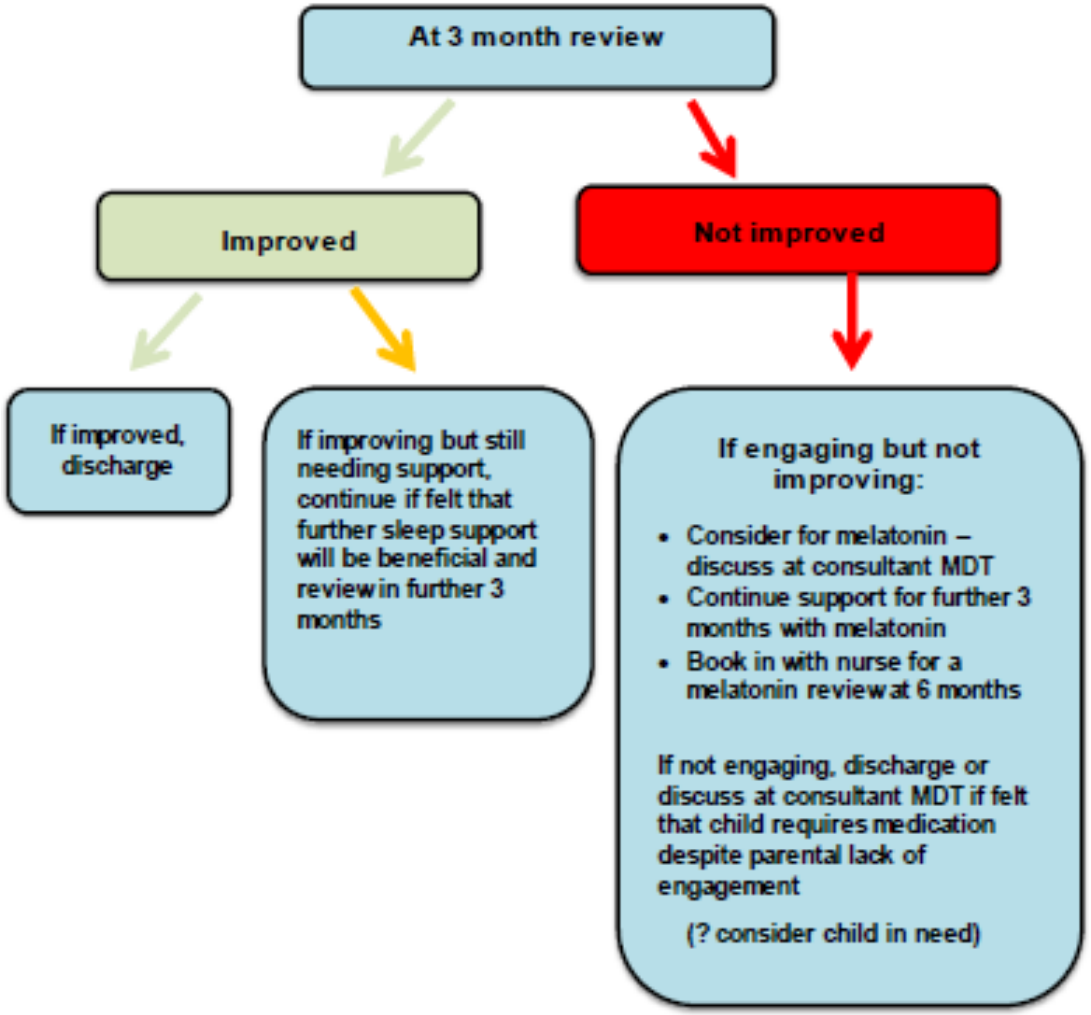
SAFE GUARDING

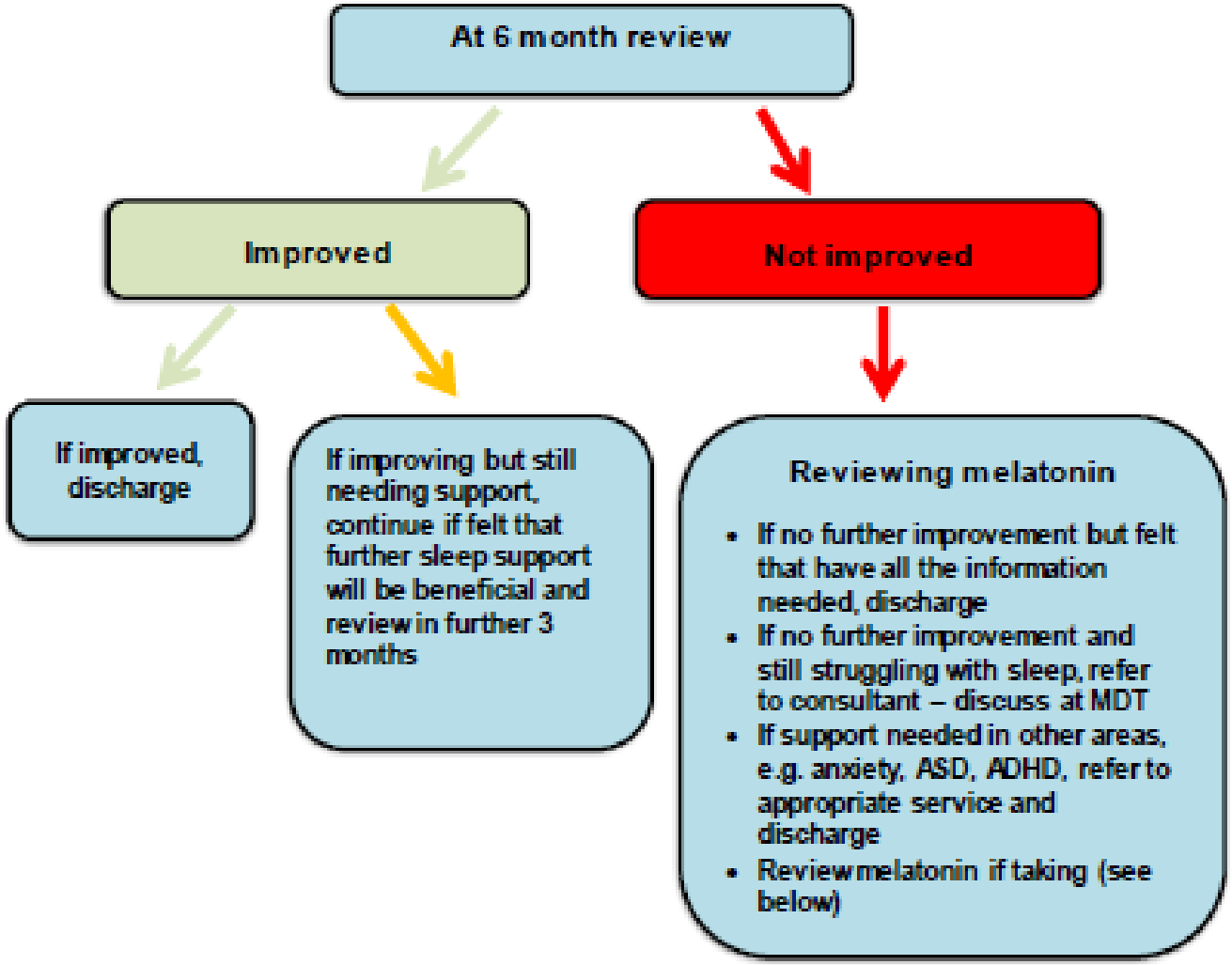
IT’S NOT ROCKET SCIENCE

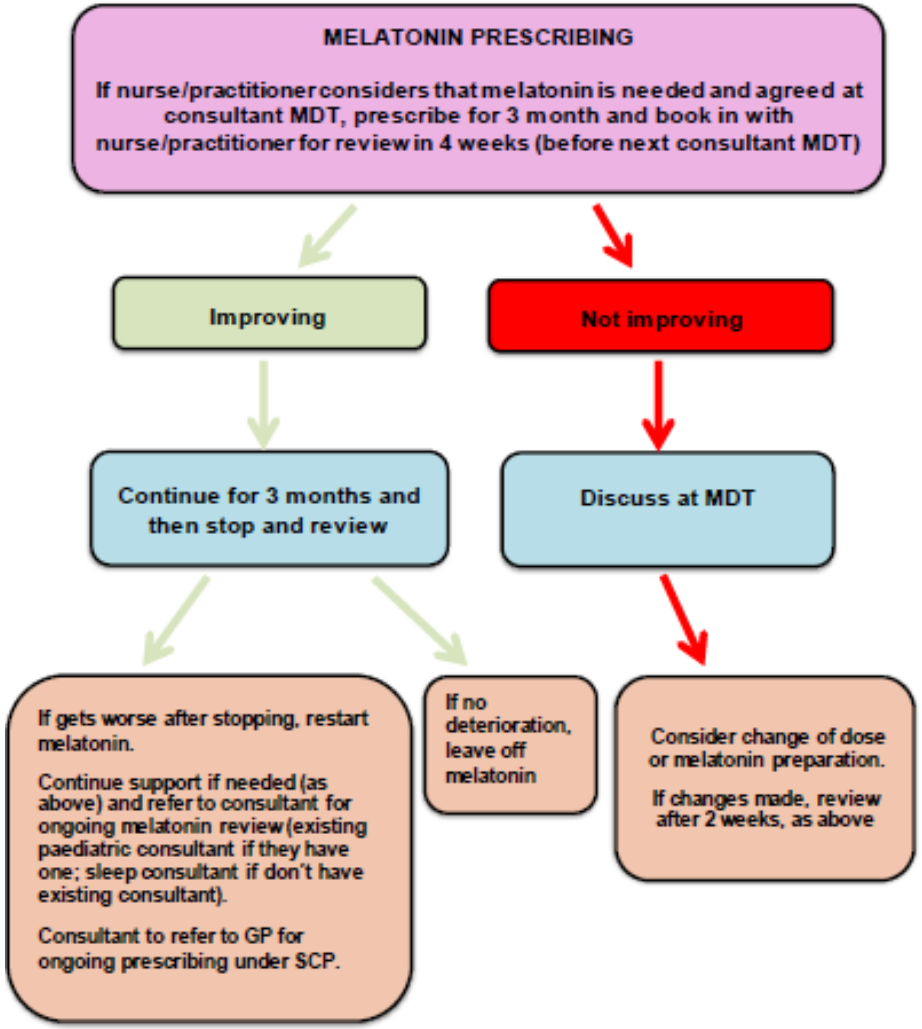


“If I wanted to get there,
I wouldn’t start from here!”

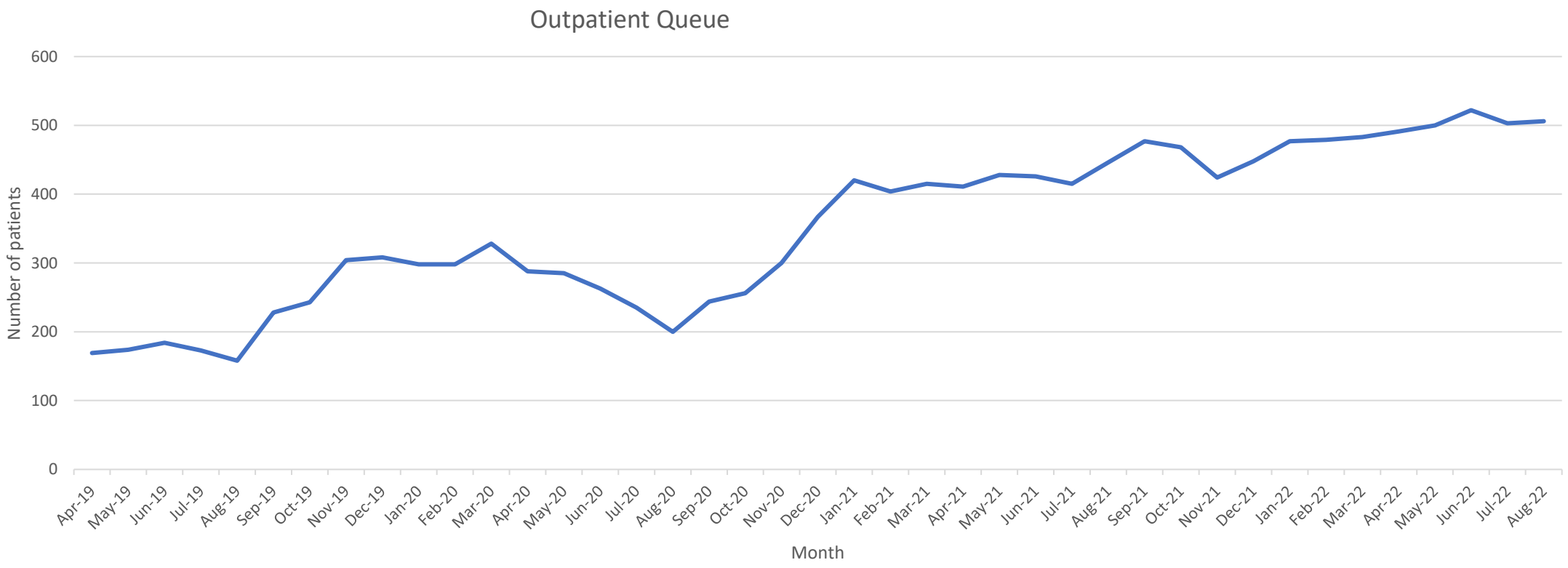

SLEEP SUPPORT SERVICE GUIDLINES
SOP #8
Set parents' expectations at the beginning that support will be for no longer than 6 months, unless exceptional circumstances
Assess routine with baseline assessment
Good
Poor
Request actigraphy (express importance of needing data to consider medication) or PSG if actigraphy fails
If actigraphy shows adequate sleep, discharge
If actigraphy shows erratic sleep pattern or phase shift, start sleep support pathway.
If actigraphy shows disturbance/fragmentation after sleep onset, consider PSG – discuss at consultant MDT
If routine poor (even if they say they have tried everything before) – sleep support
Book in with nurse for interim review at 3 months


At 3 month review
Improved
Not improved
If improved, discharge
If improving but still needing support, continue if felt that further sleep support will be beneficial and review in further 3 months
If engaging but not improving:
• Consider for melatonin – discuss at consultant MDT
• Continue support for further 3 months with melatonin
• Book in with nurse for a melatonin review at 6 months
If not engaging, discharge or discuss at consultant MDT if felt that child requires medication despite parental lack of engagement
(? consider child in need)


At 6 month review
Improved
Not improved
If improved, discharge
If improving but still needing support, continue if felt that further sleep support will be beneficial and review in further 3 months
Reviewing melatonin
If no further improvement but felt that have all the information needed, discharge
If no further improvement and still struggling with sleep, refer to consultant – discuss at MDT
If support needed in other areas, e.g. anxiety, ASD, ADHD, refer to appropriate service and discharge
Review melatonin if taking (see below)


MELATONIN PRESCRIBING
If nurse/practitioner considers that melatonin is needed and agreed at consultant MDT, prescribe for 3 month and book in with nurse/practitioner for review in 4 weeks (before next consultant MDT)
Improving
Not improving
Continue for 3 months and then stop and review
Discuss at MDT
If gets worse after stopping, restart melatonin.
Continue support if needed (as above) and refer to consultant for ongoing melatonin review (existing paediatric consultant if they have one; sleep consultant if don't have existing consultant).
Consultant to refer to GP for ongoing prescribing under SCP.
If no deterioration, leave off melatonin
Consider change of dose or melatonin preparation.
If changes made, review after 2 weeks, as above

Out-patients waiting times



Clinic entry and discharge criteria

- Completion of 2 weeks sleep diary – to prove engagement
- Primary care referrals – Sheffield only
- GP or paediatrician referrals only
- Encouraging first step in referral pathway to parenting, 0-19s teams

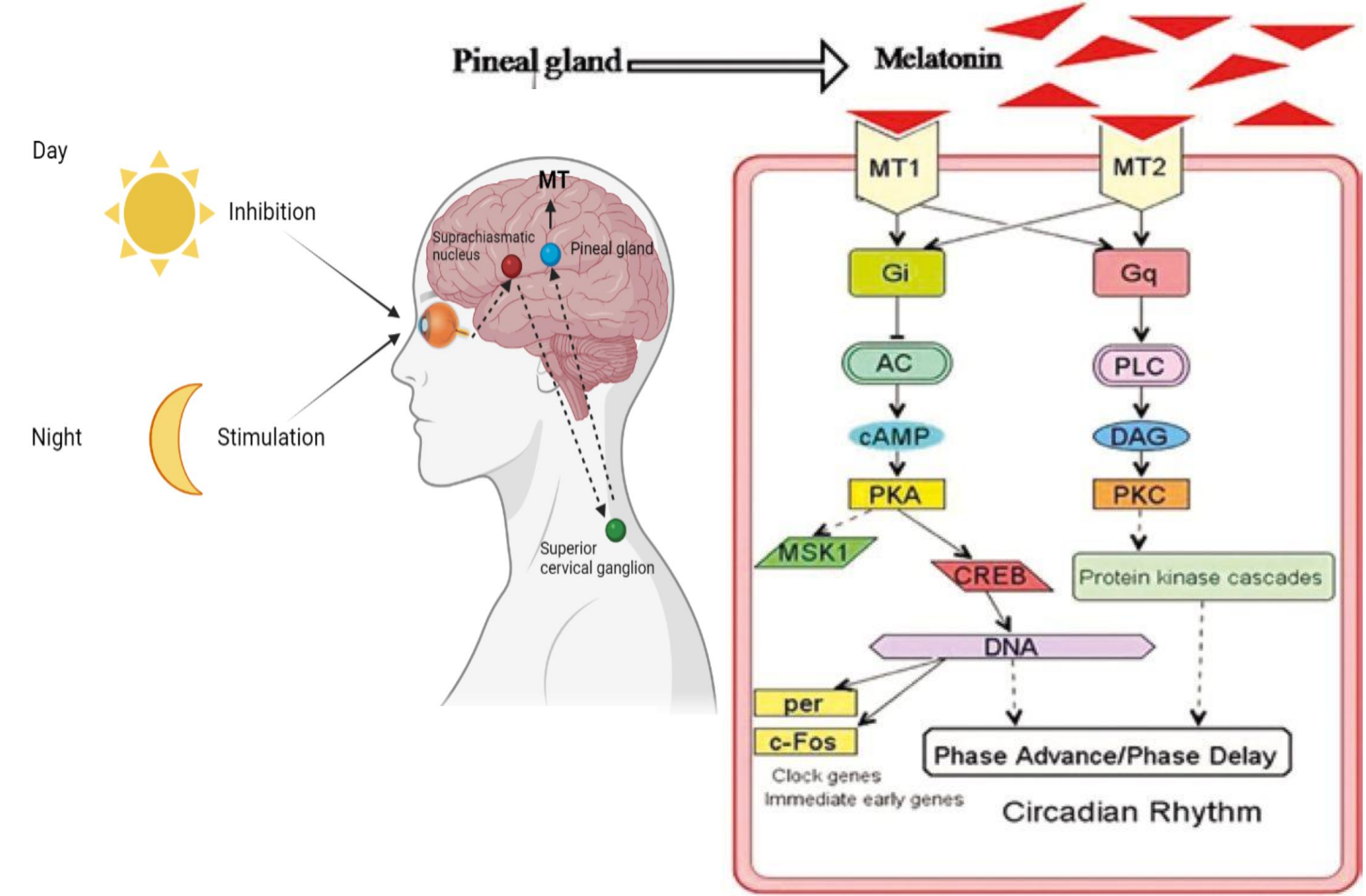
- Discharge after max 6 months
- MDT discussion prior to staring melatonin

Referral Criteria to SCH Nurse-led clinic

- Under 16 years at point of referral and one or both of the below
    - Sleep latency (time taken to fall asleep after getting into bed) - more than 60 minutes
    - Total sleep time - less than 8 hours if <10 years/less than 6 hours if >10 years
- Please provide evidence of engagement with community sleep service or sleep hygiene advice given in DGH /community clinic
- Parents of all children referred are expected to have completed a paper sleep diary for 2 weeks prior to being added to the waiting list or submit data via SnappD app
- Please ensure they have an open or FU appointment in DGH/ community consultant clinic
    - Non Sheffield GP referrals are not accepted into the Sleep service

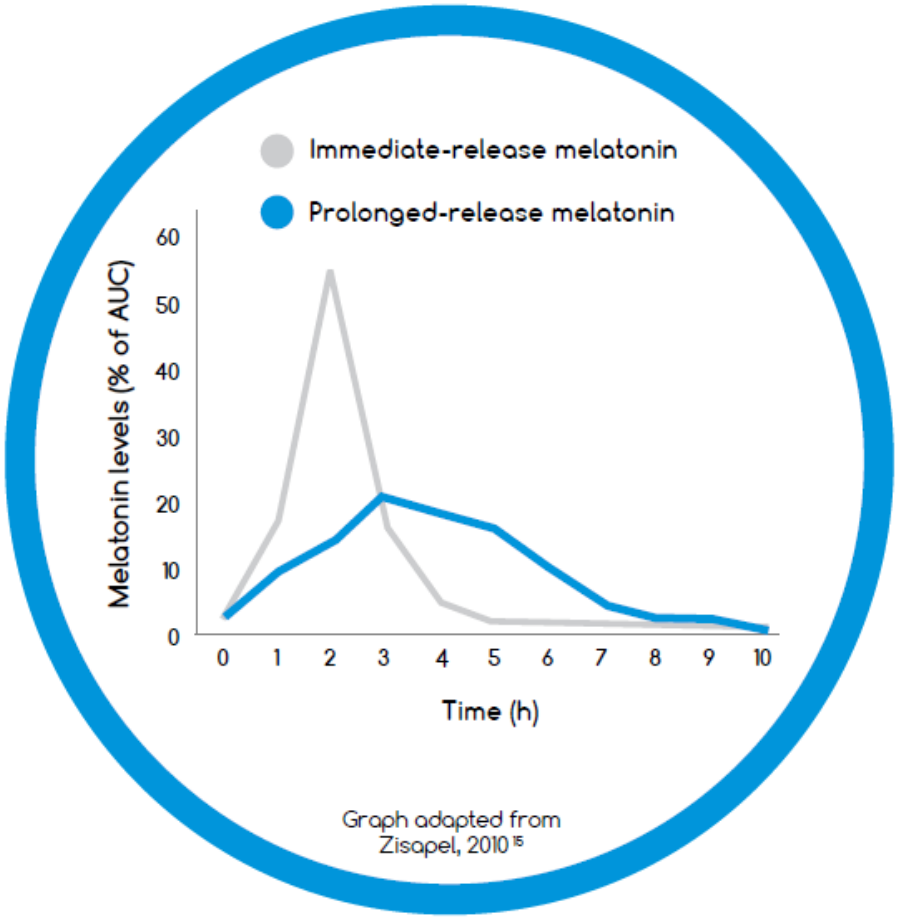
- Back to Will

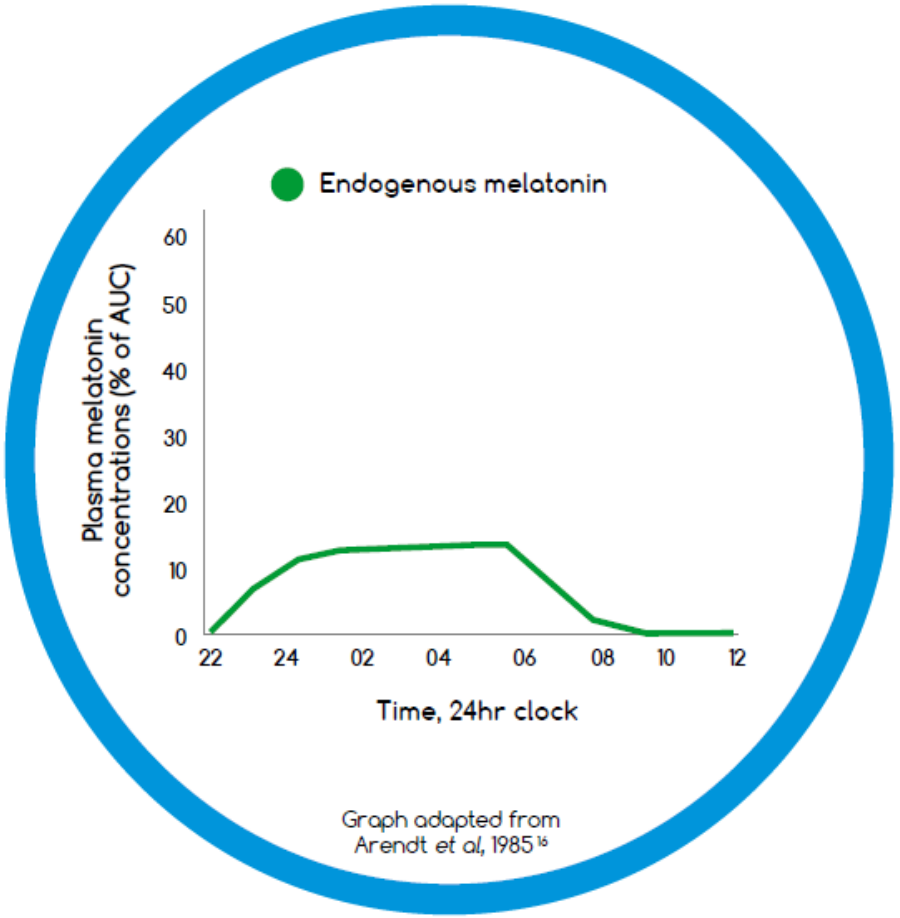

SLEEP SUPPORT
Melatonin
Extra Strength
5 mg
Timed Release
Fall Asleep, Stay Asleep
60 Tablets


Pineal gland
Melatonin
Day
Inhibition
Night
Stimulation
MT
Suprachiasmatic nucleus
Pineal gland
Superior cervical ganglion
MT1
MT2
Gi
Gq
AC
PLC
cAMP
DAG
PKA
PKC
MSK1
CREB
Protein kinase cascades
DNA
per
c-Fos
Clock genes
Immediate early genes
Phase Advance/Phase Delay
Circadian Rhythm

adaflex®
MELATONIN

Profiles of immediate versus prolonged-release Melatonin





- **Immediate Release melatonin** has a rapid onset to high levels followed by a rapid decline
- **Prolonged Release melatonin** mimics the endogenous release profile of melatonin

Randomized Controlled Trial > BMJ. 2012 Nov 5;345:e6664. doi: 10.1136/bmj.e6664.

Melatonin for sleep problems in children with neurodevelopmental disorders: randomised double masked placebo controlled trial

P Gringras [1], C Gamble, A P Jones, L Wiggs, P R Williamson, A Sutcliffe, P Montgomery, W P Whitehouse, I Choonara, T Allport, A Edmond, R Appleton, MENDS Study Group

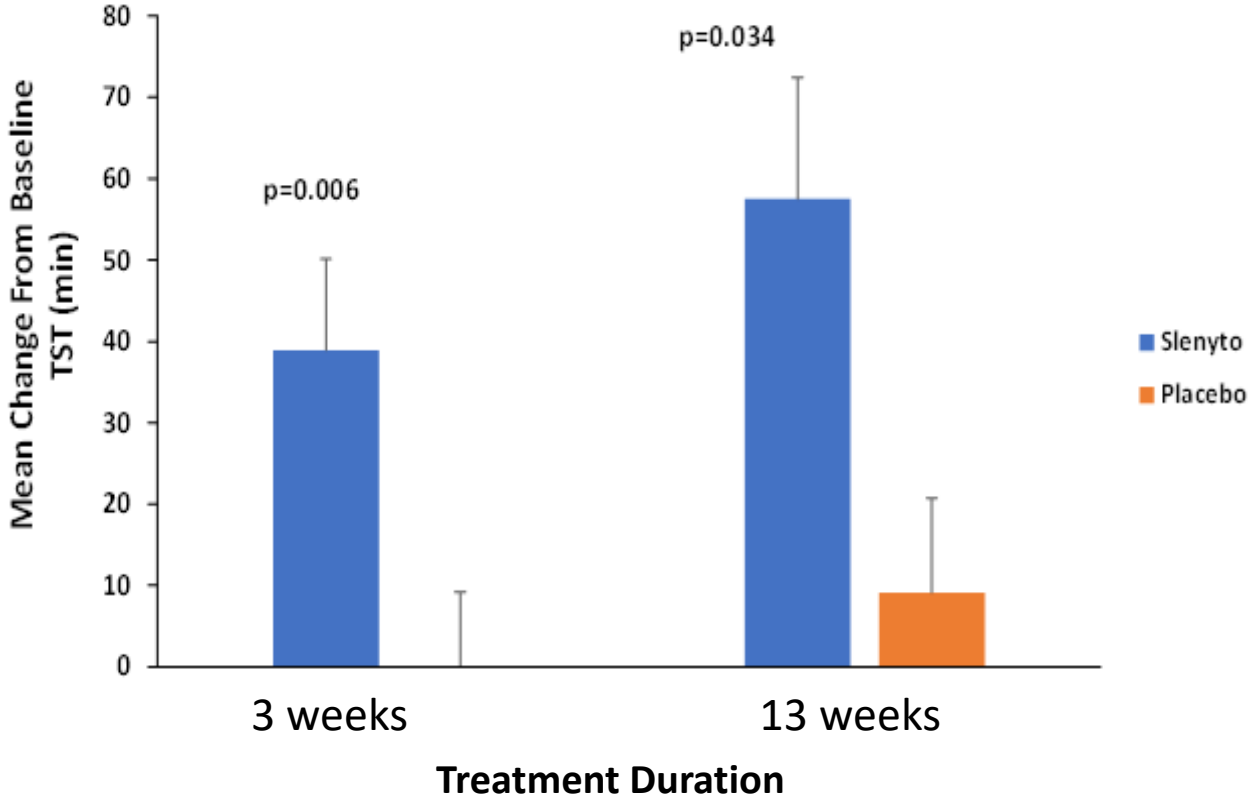
- N= 146, aged 3-16 years
- **Immediate-release melatonin** v **placebo** for 12 weeks

- Fell asleep significantly faster but gained little additional sleep
- Child behaviour and family functioning outcomes did not significantly improve

- N=125, aged 2−17.5 years; whose sleep failed to improve on behavioural intervention alone
- **Prolonged Release Melatonin** v **Placebo** for 13 weeks
- 96.8% ASD, 3.2% Smith-Magenis syndrome [SMS]

Mean change from baseline in mean total sleep time

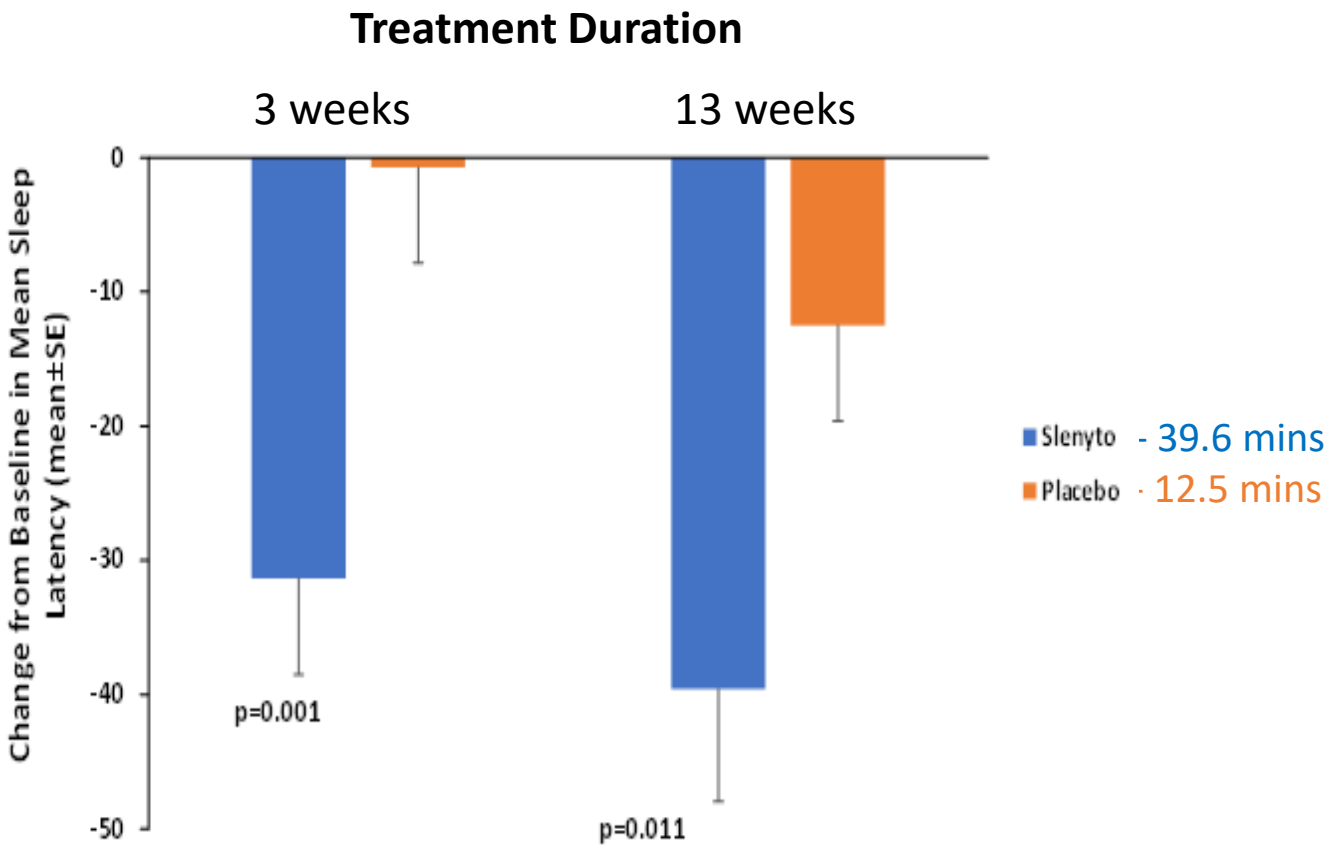
Clinical response pre-defined as increase of ≥ 45 mins in TST



Slenyto treated children slept an average of 58 minutes longer after 13 weeks treatment

Change in Sleep Latency (SL)

Clinical response pre-defined as decrease of ≥ 15 mins in SL



Slenyto treated children fell asleep an average of 40 minutes earlier after 13 weeks treatment

Review > Pharmacotherapy. 2017 May;37(5):555-578. doi: 10.1002/phar.1920.

Effectiveness of Sleep-Based Interventions for Children with Autism Spectrum Disorder: A Meta-Synthesis

Belinda M Cuomo [1], Sharmila Vaz [1], Elinda Ai Lim Lee [1 2], Craig Thompson [1 2], Jessica M Rogerson [1], Torbjorn Falkmer [1 2 3 4]

Affiliations – collapse

- Melatonin, behavioural interventions and parent education interventions most effective

ipsa
international pediatric sleep association

www.pedsleep.org

Studies support the use of melatonin for special needs paediatric populations (ASD, NDD)

Should only be undertaken with medical supervision – need for continued use; side effects

Only if behavioural measures haven't worked and other medical conditions/sleep disorders have been ruled out

Behavioural therapy should be used alongside melatonin

Use with caution < 2 years

Administration recommended 30-60 minutes before desired bedtime

Indiscriminate use of OTC melatonin should be discouraged

Long term data reports few adverse effects up to 104 weeks, but exercise caution if using for more than a few months

- **New York Times survey 2020**
- 933 parents – 1 in 6 had given their child melatonin in the last year

- **Lelak et al 2022**
  - 2012-2021 260,000 reports of unintentional OTC melatonin overdosage at home
  - 14.7% hospitalised; 2 died

- **Cohen et al 2023;30 brands of US melatonin –**
  - Content ranging from 74% - 347%
  - Could contain 1.3-13.1mg per gummy
  - 12% were within 10% of the dose stated on the label

- Presence of **serotonin** contamination found in 26% products

Practical guide to the use of medicines in paediatric sleep disorders

Heather E Elphick , Moira Gibbons, Hemant Kulkarni

BMJ Group

Elphick HE, *et al*. *Arch Dis Child Educ Pract Ed* 2024;**0**:1–6. doi:10.1136/archdischild-2024-327011

RCPCH

SCAN ME

Share Care Protocol for Melatonin and Slenyto

ALIMEMAZINE SHARED CARE PROTOCOL

- Back to Janine

SLEEP AND THE GLOBAL MENTAL HEALTH CRISIS

- **Sleep problems are linked with the brain areas that control emotional processes and risk taking**

Sleep loss impacts

- **“Emotion centre of the brain”**
- **Degree of emotional response**
- **Control of emotions**
- **Sleep as overnight therapy**
- **Reward related decision making**
- **Perceive fewer negative consequences**
- **Take fewer greater risks**
- **Impulsivity**

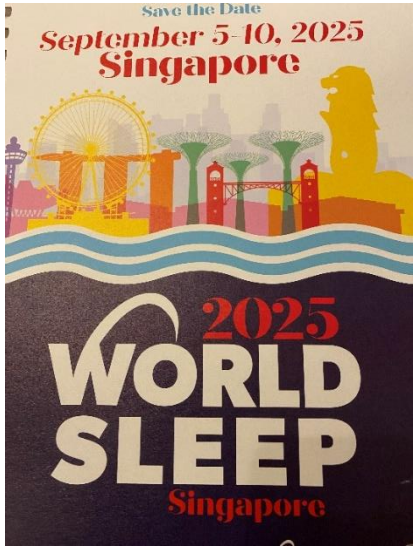
Life’s Essential 8™

- **“The new metric of sleep duration reflects the latest research findings: sleep impacts overall health, and people who have healthier sleep patterns manage health factors such as weight, blood pressure or risk for Type 2 diabetes more effectively,” said American Heart Association President Donald M. Lloyd-Jones,**
  - **Diet (updated):**
  - **Physical activity (no changes):**
  - **Nicotine exposure (updated):**
  - **Sleep duration (new):**
  - **Body mass index (no changes):**
  - **Blood lipids (updated):**
  - **Blood glucose (updated):**
  - **Blood pressure (no changes):**


Life's
Essential 8™
LIPIDS

What is Sleep Health

- Some things to keep in mind when thinking about getting good, healthy sleep are:
- Q**uantity** (Are you getting optimal hours?),
- Q**uality** (Are you getting the right amounts of restorative NREM & REM sleep?)
- T**iming** (Is your sleep schedule in sync with your body's circadian clock's rhythm?



“

- **Developing practices to improve hospitalized patient sleep is a top priority because sleep is fundamental to health and recovery. Hospital leaders recognize the importance of improving patient sleep, but few have existing sleep-friendly institutionalized practices. Most institutions have no sleep health equity practices currently despite widespread agreement among hospital leader-ship on its importance in the hospital. Clinicians and hospital leaders should promote improved sleep quality for hospitalized patients by building sleep-friendly hospital cultures, addressing sleep health equity within the hospital, and establishing best practices for patient sleep**

”

Janine Reynolds
Paediatric Sleep Disorders
Nurse Specialist

Email: scn-tr.sleepnurses@nhs.net

Solid book review.