

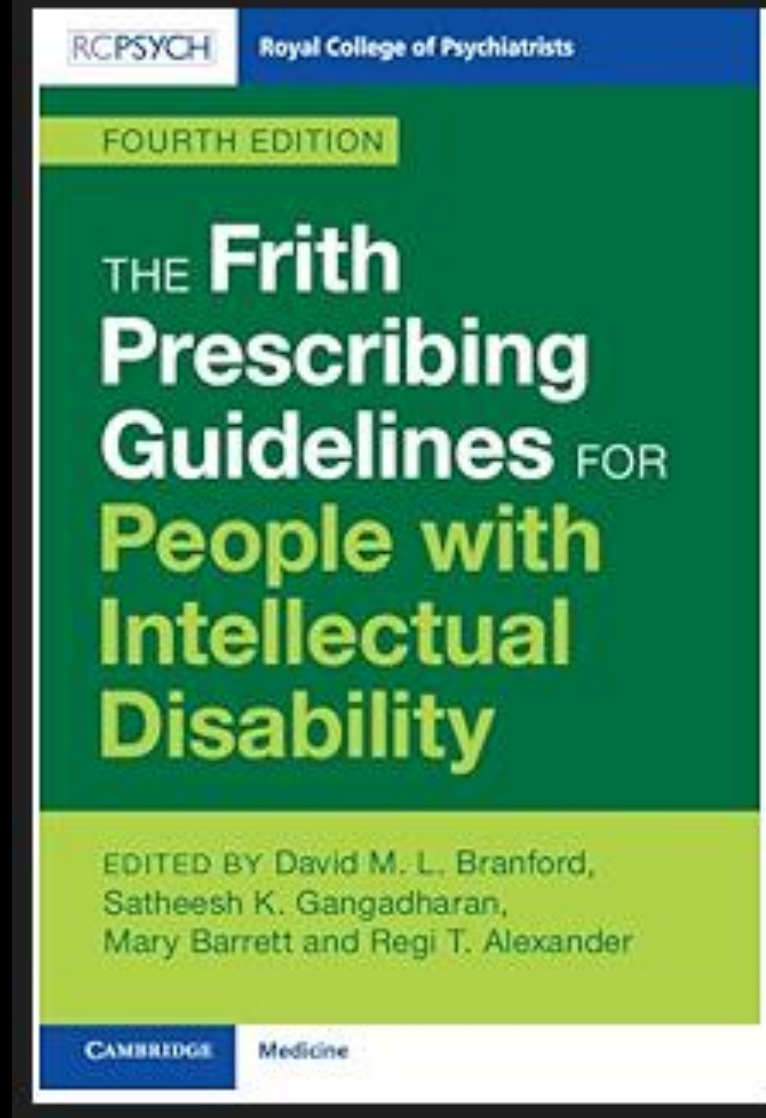
Treatment of sleep disorders in intellectual disability (ID)

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Rebecca Dodds & Laura Korb (2024): Sleep Disorders, The Frith Prescribing Guidelines for People with Intellectual Disability, 4th Edition, Royal College of Psychiatrists, Cambridge University Press (in press, to be released in August 2024)

Overview

What are sleep disorders?

How are sleep disorders different in people with ID ?

How do we identify sleep disorders?

Frith Treatment Guideline for sleep disorders in people with ID.

Sleep disorders

- Insomnias
- Sleep related breathing disorders
- Central disorders of hypersomnolence
- Circadian disorders of sleep-wake cycle
- Parasomnias
- Sleep –related movement disorders
- Other sleep disorders

(ICSD, 3rd Ed American academy of Sleep Medicine 2014)



Insomnias

Complaint of persistent difficulty with sleep initiation, duration, consolidation or quality that occurs despite adequate opportunity and circumstances (ICD-11)

Some form of daytime impairment (WHO 2022)

Daytime impairment including fatigue, depressed mood or irritability, general malaise, cognitive impairment (BNF 2021)

Sleep disorders in people with ID

Multifactorial

Usually secondary

Circadian Rhythm dysfunction, abnormal melatonin levels

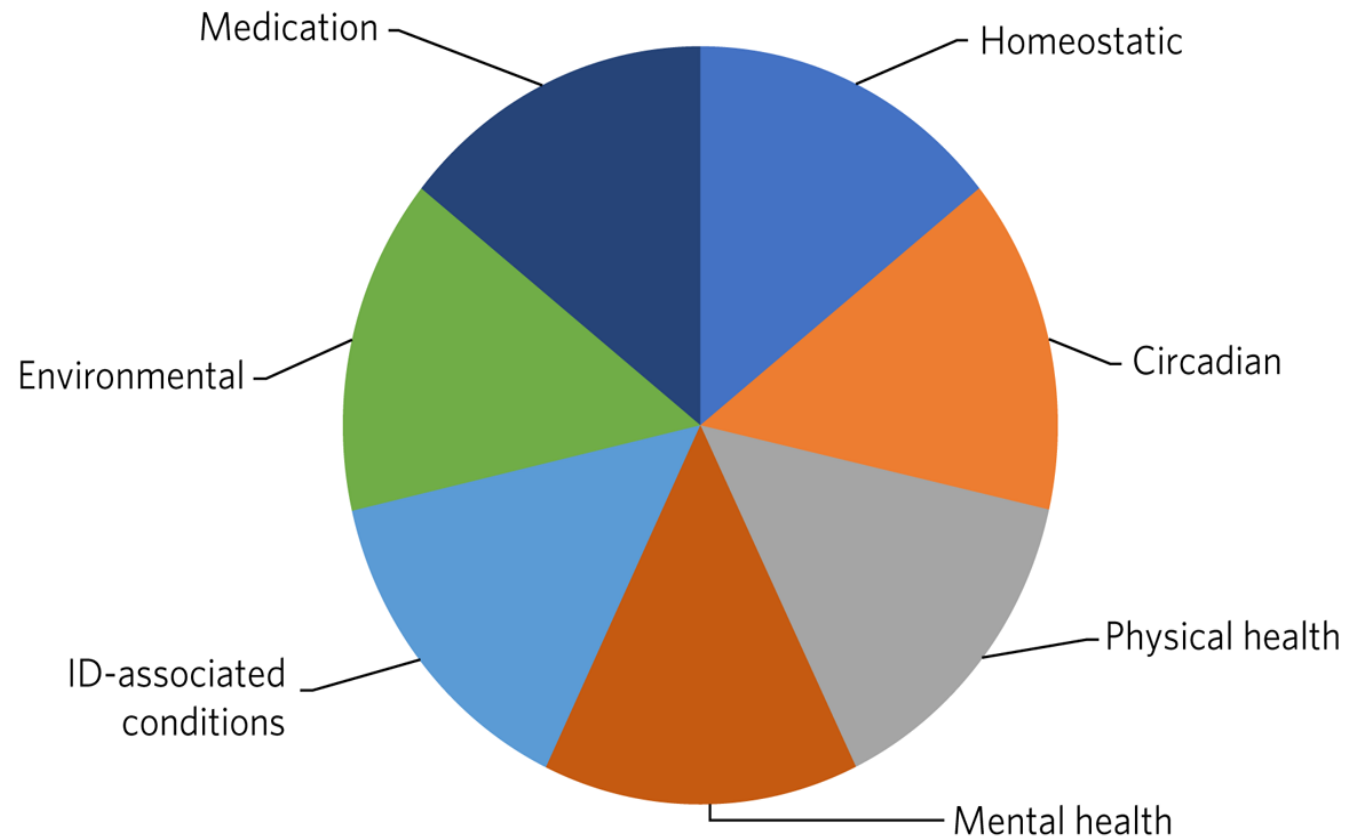
Challenging behaviour could be a cause or result of insomnia

Poor sleep can add to carer stress/ family stress

Increase service requirement (Wiggs 2001)

Causes of insomnia

- Physiological
- Circadian
- Homeostatic
- psychiatric
- Stress
- Medical conditions and symptoms
- Iatrogenic
- Lifestyle
- Environmental



Why should we treat insomnia?

- Short term and long term consequences
- Short term consequences include poor concentration and memory impaired learning and communication skills behavioural problems
- Long term consequences include worsening of hypertension, type 2 diabetes, cardiovascular disease, dyslipidemia, metabolic syndrome, colorectal cancer
- Genetic syndromes, epilepsy, ADHD, autism : associated with sleep problems



Identification of sleep disorders in people with ID



Barriers: communication difficulties



Carers would take into granted, poor sleep as a usual presentation of people with ID



A comprehensive assessment

Sleep assessment



Sleep history



Sleep diary



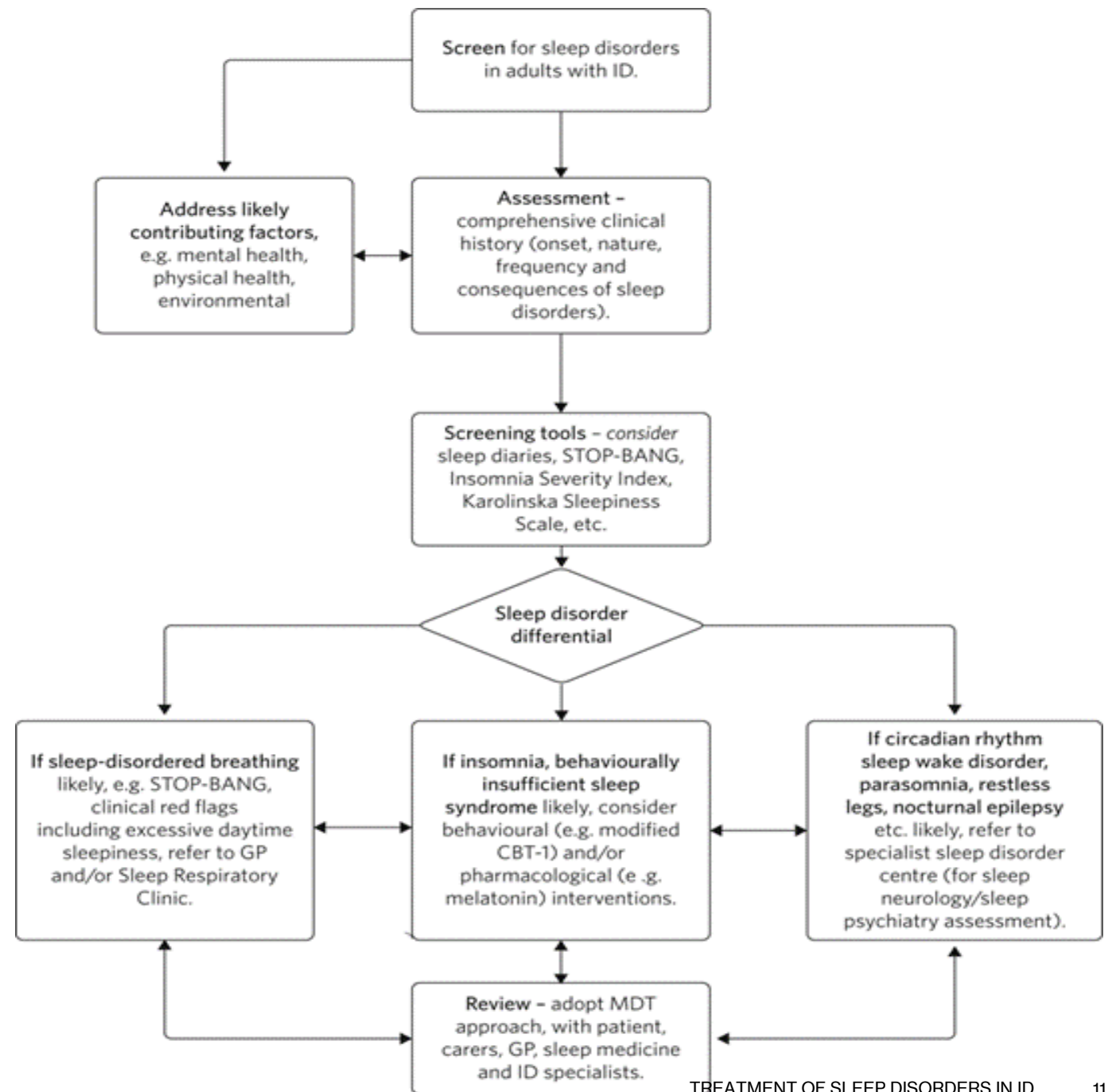
Appropriate screening tools



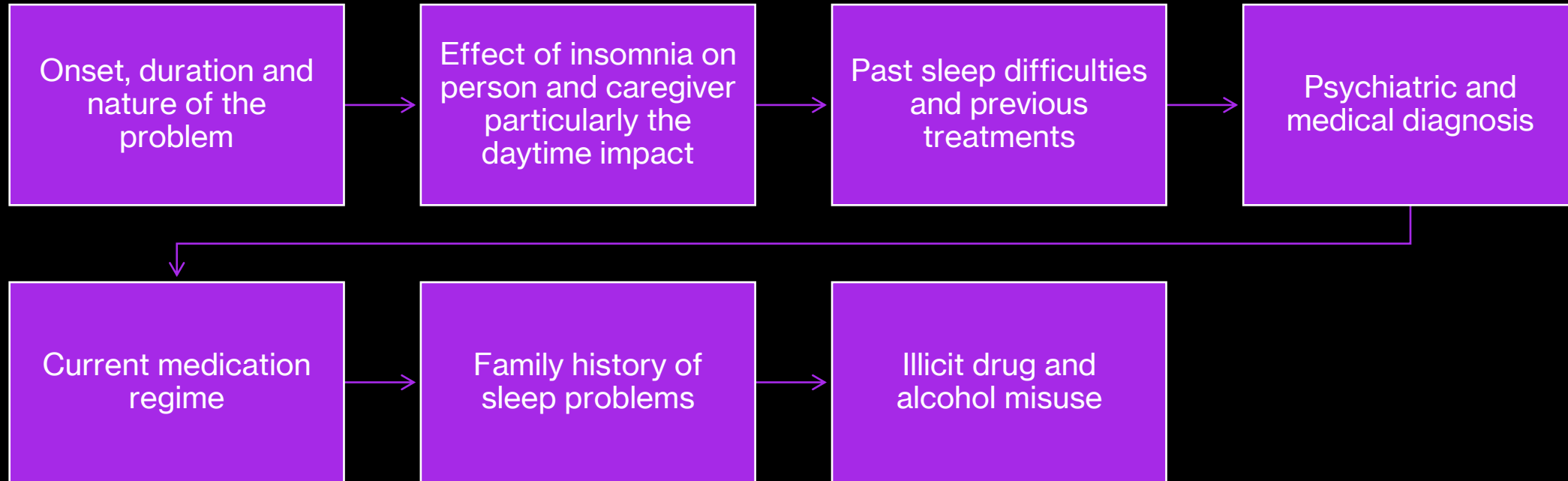
If not insomnia, referral to specialist
sleep disorder clinic

Flowchart for screening, assessing and managing sleep disorders in adults with ID.

GP, psychiatrist, MDT



Sleep history



Sleep Diary

Use this sleep diary to record the quality and quantity of your sleep; your use of alcohol and caffeinated drinks; and how sleepy you feel during the day. Bring the diary to your next appointment with your doctor.

Sleep Diary

Fill out before going to bed	Today's date:	June 13*							
	Number of caffeinated drinks (coffee, tea, cola) and time when I had them today:	1 drink, 8 p.m.							
	Number of alcoholic drinks (beer, wine, liquor) and time when I had them today:	2 drinks, 9 p.m.							
	Nap times and lengths today:	3:30 p.m., 45 minutes							
	Exercise times and lengths today:	None							
	How sleepy did I feel during the day today? 1—So sleepy I had to struggle to stay awake during much of the day 2—Somewhat tired 3—Fairly alert 4—Alert	1							
Waking	Today's date:	June 14*							
	• Time I went to bed last night:	11 p.m.							
	• Time I got out of bed this morning:	7 a.m.							
	• Hours spent in bed last night:	8							

- Helpful to note the time taken to fall asleep times of meals alcohol and caffeine and significant daytime events such as exercise or stress
- Rating of sleep quality each night on a scale of 1 to 5

• Google for templates!

Screening tool: **STOP-BANG** questionnaire

do you **SNORE** loudly (louder than talking or loud enough to be heard through closed doors)? (Yes/NO)

do you often feel **TIRED**, fatigued, or sleepy during the daytime?

has anyone **OBSERVED** you stop breathing during your sleep?

do you have or are you being treated for high blood **PRESSURE**?

BMI more than 35kg/m²?

AGE over 50 years old?

NECK circumference > 16 inches (40cm)?

GENDER: male?

- *high risk of obstructive sleep apnea (OSA): yes to 6-8 questions*
- *intermediate risk of OSA: yes to 3-5 questions*
- *low risk of OSA: yes to 0-2 questions*

Further investigations

Actigraphy

Ambulatory circadian monitoring

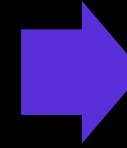
Polysomnography

Not necessary to diagnose insomnia

Used when insomnia is poorly
responsible to conventional treatments

The Frith Treatment Guidelines for Sleep disorders people with ID

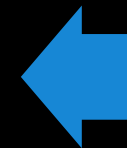
Management is complex given the heterogenicity of the underlying causes



If investigations are not tolerated pragmatic trials of treatment may be necessary



Important to consider medication rationalisation, optimal control of epilepsy if any, regular health checks



Initial management targets identification and mgmt. of modifiable factors and physical health conditions

Non medication approaches



First choice



Although many interventions may be difficult to implement, studies shows benefit.



Sleep hygiene techniques: A comforting sleeping environment and health sleeping habits



Behavioural techniques: to be implemented gradually



Educational training for caregivers

Sleep hygiene

Encourage	Encourage daily exercise during daytime
Avoid	avoid daytime napping
Avoid	avoid large meals caffeine tobacco nicotine alcohol before bedtime
Use	use bedroom for sleep
Set	Set a regular routine of sleeping and waking
Ensure	ensure sleeping environment uncomfortable, quiet, dark and at right temperature

Behavioural strategies



Behavioural extinction and stimulus control



Chronotherapy for sleep phase disorders



sleep restriction therapy



changing daily routine

Cognitive behavioural therapy for insomnia (CBT-I)



Recommended by nice guidelines for chronic insomnia



Include psychoeducation common behavioural strategies, cognitive therapy and relaxation training



Modified CBT-I can be useful for people with ID

Table 2: Modified CBT-I for Individuals with intellectual disabilities

Technique	Aim	Method	General Advice
Anchoring the day	To optimise the homeostatic sleep drive.	Setting a latest fixed rising time that is maintained 7 days a week, no matter how tired or little the individual has slept.	This is easier to achieve with the aid of carers, and if there is something to get up for i.e. structured daytime activity. We recommend setting an alarm so that the anchor time is kept constant.
Daylight exposure	To optimise the circadian rhythm	We recommend a minimum of 20 minutes natural daylight exposure within 2 hours of rising.	This is easier to achieve if there is structured daytime activity, and regular breakfast times (which also helps regulate the biological clock).
Stimulus Control	To re-establish the connection in the mind that the bed and bedroom are places for sleep as opposed to places for wakeful activities. (This technique is based on classical conditioning).	Ideally, the bed and bedroom are used for: sleep, sex and getting dressed only. Any other activity should be undertaken outside of the bed and bedroom.	If the individual only has access to one room, then try to make the bed and bedroom look different in the day and in the night e.g. using a different bed cover for the day, and/or placing a plant in the room, and taking it away at night. The more cues we can give the brain to let it know whether the room is in day or night mode will strengthen this technique.
Buffer Zone	To reduce arousal pre-bed.	This is a period of at least 90 minutes before bed, where the brain and body are moved to a state of relaxation ready for sleep.	We advise beginning the buffer zone with a bath (if safe to do so; a shower can be trialled too), and afterwards keeping the room dimly lit, and encouraging relaxing (non-stimulating) activities until it is time for bed.
Sleep Scheduling	To optimise the internal sleep drive (in conjunction with anchoring the day), and to reduce hyperarousal.	In this technique the total sleep time is closely matched to the total time in bed (judged by keeping sleep diaries, and/or actigraphy).	This often requires carer education, as individuals with intellectual disabilities often have bedtimes that are too early for them. The technique should be used with caution and under expert behavioural sleep medicine supervision, in individuals with co-morbidities which could be made worse by temporary sleep loss e.g., epilepsy, or bipolar affective disorder.
Other	To promote optimisation of zeitgebers i.e., those signals which feed into the biological clock.	Structured daytime activity. Regular mealtimes. Discourage eating during the night if the individual cannot sleep or giving extra attention at this time. Engagement in regular exercise (ideally, getting out of breath).	All of the techniques outlined in this table require patience and perseverance in order to be effective. Initially, sleep may worsen as usual routines are being changed, which can increase anxiety. To circumnavigate this risk, trialling one technique at a time may be advisable for some individuals.

Adapted from [2]

Medication

- Limited evidence base
- Often used as temporary adjuncts
- Melatonin, hypnotics, other medication with sedative effects
- A meta-analysis by Braam et al (2009) in people with ID, the use of melatonin decreases sleep latency and the number of wakes per night and increases the total sleep time.
- At present, the pharmacological management of non-insomnia disorders in ID tend to follow the same pathways as those for the general population.



Melatonin

Naturally occurring hormone

Sleep-wake cycle disturbances, ASD, visual impairment

Used for insomnia in people with ID under specialist supervision.

Not licenced in the UK for this group, licenced only for adults with insomnia > 55years age for 13 weeks

Long terms effects and safety are still unknown

BNF advices modified release tablets, starting 2mg, increase to 4 to 6mg, max 10mg/day

S/E: arthralgia, headaches, infections, pain

No tolerance, rebound insomnia or dependency

Caution: renal impairment, autoimmune disease, hepatic impairment, pregnancy, breast feeding, elderly

Hypnotics

“A medication used to induce sleep”

Benzodiazepines and Z-drugs (Zolpidem, Zopiclone, Zaleplon)

Considered in severe insomnia, where other measures have failed

If prescribed; lowest effective dose and shortest duration possible (max 4 weeks)

Ideally “as required” medication

Risk of dependency, tolerance, rebound insomnia, withdrawal sx

Other medication with sedative effects

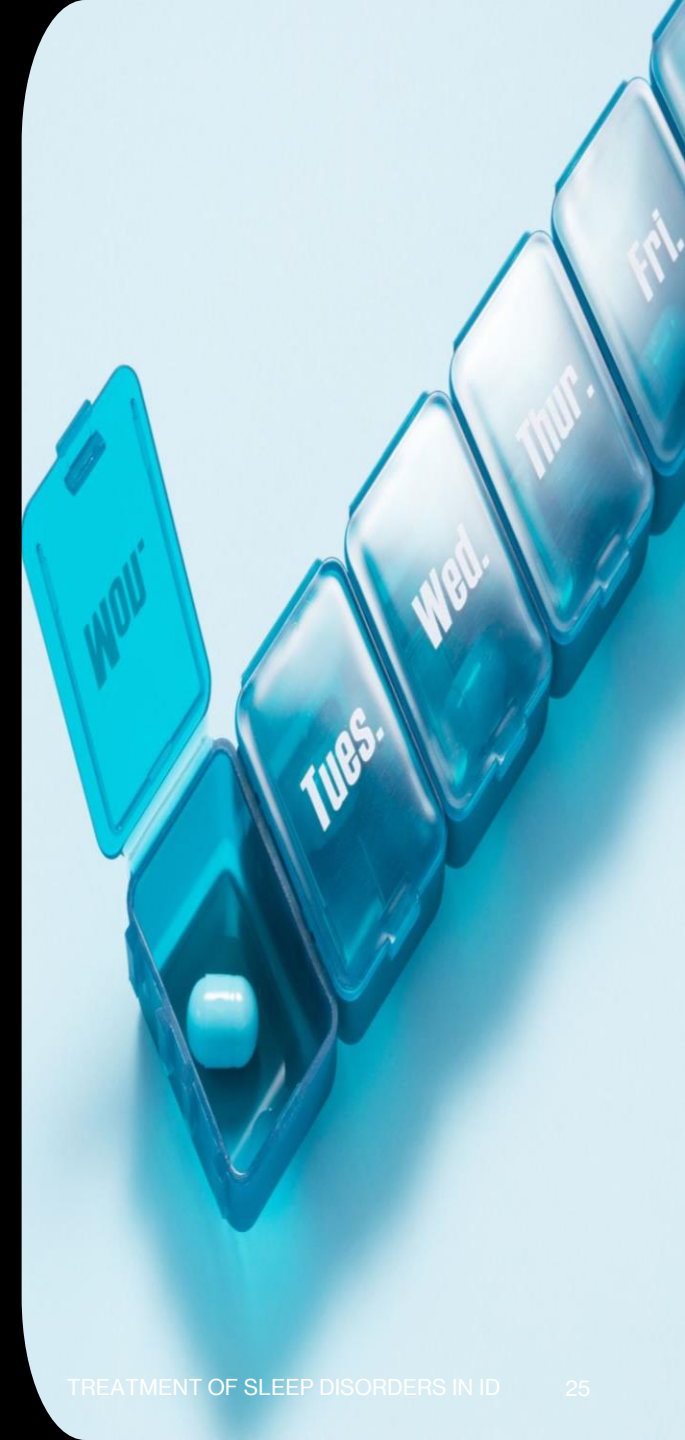
Antihistamines like promethazine

- Prescription/over the counter, but not recommended for treatment
- No lasting benefits, side-effects like “morning hang over” sleepiness due to long half-life

Antidepressants:

- If insomnia secondary to depression- medication of choice
- Mirtazapine/ clomipramine

- Antipsychotics:
- Sedation as a side-effect
- If the individual requires antipsychotics for another indications and has insomnia



Long-term management

Do not issue further prescriptions without review

Over-the-counter treatments not recommended

A follow-up appointment to be scheduled in 4 week's time after initiating hypnotic

Melatonin requires regular review with documentation of any benefits and side-effects

Can continue if there are clear benefits, clearly documented, with ongoing efforts to reduce the dose and stop or find the minimum effective dose

If we need a diagnostic clarification or treatment failed, then refer to the specialist clinic

Withdrawal of medications

Benzodiazepines

Discussion with individual or carers

Tapered and stopped gradually

Consider prolonged withdrawal symptoms including anxiety, depressive sx, nausea, perceptual changes, rebound insomnia

Key points

• Sleep disorders are common in adults with intellectual disabilities.

• Sleep disorders can adversely affect the overall health and quality of life of adults with intellectual disabilities.

• Sleep disorders are often treated as a part of a mental disorder rather than specifically screened for and managed.

• More research into the assessment and management of sleep disorders in adults with intellectual disabilities is required.

Further reading:

- Korb, L., O'Regan, D., Conley, J., Dillon, E., Briggs, R., Courtenay, K., & Perera, B. (2023). Sleep: the neglected life factor in adults with intellectual disabilities. *BJPsych Bulletin*, 47(3), 139–145. doi:10.1192/bjb.2021.122
- Dodds R. & Korb, L. (2024) Sleep Disorders, *The Frith Prescribing Guidelines for People with Intellectual Disability*, 4th Edition, Cambridge University Press (in press)

Thank you!

- Contact me:

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