

A FREE SLEEP RESOURCE FOR 22Q HOUSEHOLDS

Seven Nights

Before you change anything, look at what is actually happening at night.

You may know the feeling. The evening comes, and before anything has happened you are already wondering what kind of night it will be. Sleep difficulties are common in 22q at every age. They can have many causes: breathing, the inner clock that tells the body when to sleep and when to wake, discomfort in the body, worry, and, in our clinical experience, a nervous system that needs more time to calm down. Which of these matters most is different in every home.

The sheet on page 3 helps you see your own pattern. It asks for two minutes each morning, for up to seven mornings. There are no right answers. **Three nights is enough to start seeing something.**

How to use it

1. Print the sheet on page 3, or copy the questions into a notebook or onto your phone.
2. Fill it in the next morning, not during the night. When you wake at night, there is no need to look at the clock. A rough guess in the morning is enough.
3. Skip anything you do not know. If you miss a morning, simply continue the next day.
4. There is also a row for your own sleep. Your rest matters too.
5. When you are ready, after three nights or seven, turn to page 4.



What research tells us

Every question on the sheet is there because of what studies of people with 22q have found.

2 in 3

children at a US 22q clinic were sleepy during the day, the most common sleep problem of all.

Ingram et al., 2023

60%

of young people with 22q had sleep problems, compared with 23% of their own brothers and sisters.

Moulding et al., 2020

1 in 2

adults with 22q who had a sleep test had sleep apnoea. Parents of adults report snoring more than any other sleep problem.

Cancelliere et al., 2023 · Leader et al., 2023

Getting to sleep, staying asleep

In a US study, 85 of 100 children had sleep scores that point to a real sleep problem. In a study from Cardiff University (UK), sleep problems took two main forms: restless sleep, and trouble falling or staying asleep.

Ingram et al., 2023 · Moulding et al., 2020

Tired, even after a full night

In a small University of Geneva study (37 people with 22q), deep sleep did less of its recovery work, and the brain still showed a need for sleep in the morning. This went with daytime sleepiness and more difficulty with attention and speed of thinking. Enough hours in bed do not always mean rested.

Reich et al., 2025

Breathing

The shape and tone of the throat can narrow the airway in sleep. In a French study, almost half (46%) of children checked with a sleep test had some sleep apnoea, mostly mild. Surgery to help speech (pharyngoplasty) can also change the airway, and a University of Toronto study linked it, with other factors, to adult sleep apnoea.

La Regina et al., 2025 · Crockett et al., 2014 · Cancelliere et al., 2023

The body

In 149 children and teenagers with 22q, stomach and bowel problems went together with sleep problems. Discomfort at night does not always show itself clearly. It can look like restlessness or waking for no reason.

Leader et al., 2020

The next day

Children who slept worse showed more behaviour that is hard to manage, and young people who slept poorly had more anxiety and low mood. In our clinical experience it works both ways: a hard day can lead to a hard night, and the other way round.

Leader et al., 2020 · Moulding et al., 2020 · O'Hora et al., 2022

Adults with 22q

Sleep problems do not always pass with age. Parents of 101 adults with the 22q11.2 deletion reported sleep problems that went together with anxiety and low mood.

Leader et al., 2023

The 22q11.2 duplication

Children, young people and adults with the duplication also sleep less well than people without it, at a similar level to those with the deletion.

O'Hora et al., 2022

Your own night

Research in 22q has mostly looked at the person with 22q, and very little at the parents. In our clinical experience, many parents sleep lightly for years, and the tension can start before the night does. That is why your sleep has its own row.

What helps

Families and studies do not agree on this. What helps seems to depend on what keeps this person awake, and the sheet can start to show you that.

Ingram et al., 2023 · Arganbright et al., 2020



The sheet

Each morning	Night 1	Night 2	Night 3	Night 4	Night 5	Night 6	Night 7
Evening routine started at the first step, for example bath or pyjamas							
In bed at, asleep at two rough times							
Woke up in the night how many times, and for about how long							
Breathing and body snoring, gasping, pauses in breathing, restless legs, stomach pain, unusual sleeping position							
What helped them calm down anything at all, however small							
Got up in the morning at and how getting up went							
The next day tiredness, mood, big reactions: 1 (a hard day) to 5 (a good day)							
Anything different that day illness, a change, an outing, medication, screens late in the evening							
Your own night how you slept: 1 (badly) to 5 (well). Were you awake for a long time after they fell asleep?							

If you are an adult with 22q and use this sheet for yourself, fill in the questions about your own nights. You can use the last row for someone you live with, or leave it empty.



Looking back

Read what you wrote once, slowly. Look for anything that repeats. These questions may help.

- What was hardest most often: getting to sleep, staying asleep, or waking too early?
- Was there a time of night that was hardest? Was it the same most nights?
- Did the harder nights follow particular days?
- What helped, even once? And what did you try that made no difference?
- What was the next day like after a harder night?
- And your own nights: did you sleep when they slept, or did you stay awake, waiting for them to wake again?

You may finish with a clearer picture. You may also finish with a new question you did not have before. Both are useful.

Worth raising with your doctor

Some sleep difficulties in 22q have a physical cause that a sleep study can check. If you noticed any of the following, it is worth mentioning to your own or your child's doctor:

- regular snoring, gasping, or pauses in breathing during sleep
- sleeping with the head tipped far back, or sitting up
- signs of reflux (acid coming up) or stomach pain at night
- being very tired during the day, even after enough hours of sleep
- any of the above in someone who had surgery to help their speech (pharyngoplasty). This surgery helps speech, and it can also change the airway over the years, so a sleep check-up later on is part of good follow-up care.

Bring what you noticed

In the webinar *Better Sleep, Better Days*, Linda Campbell and Sasja Duijff explain why sleep can be so hard in 22q, from childhood to adulthood, and what families find helps. Watch the recording first, then bring your own questions to a 60-minute live Q&A. The Q&A is not recorded. There are 50 places, and you choose one session.



Scan to book

Q&A with Linda

Sunday 11 October, 12 pm (noon) AEDT
Saturday 10 October
6 pm California · 7 pm Colorado

Q&A with Sasja

Sunday 11 October, 5 pm CEST
4 pm London · 11 am New York

● 22qminded.com/product/webinar-better-sleep-better-days

Sources: Arganbright et al. (2020) *Mol Genet Genomic Med* · Cancelliere et al. (2023) *Sleep Med* 104 · Crockett et al. (2014) *Front Pediatr* · Ingram, Rajé & Arganbright (2023) *J Clin Sleep Med* 19(1) · La Regina et al. (2025) *Am J Med Genet A* · Leader et al. (2020) *Res Dev Disabil* 104 · Leader et al. (2023) *Res Dev Disabil* 136 · Moulding et al. (2020) *Psychol Med* 50 · Reich et al. (2025) *Psychiatry Res* 347 · O'Hara et al. (2022) *J Neurodev Disord* 14:41. This sheet helps you observe. It does not give a diagnosis and does not replace advice from your doctor.