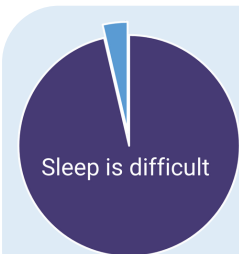


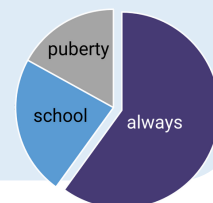


## Sleep & PDA – survey responses

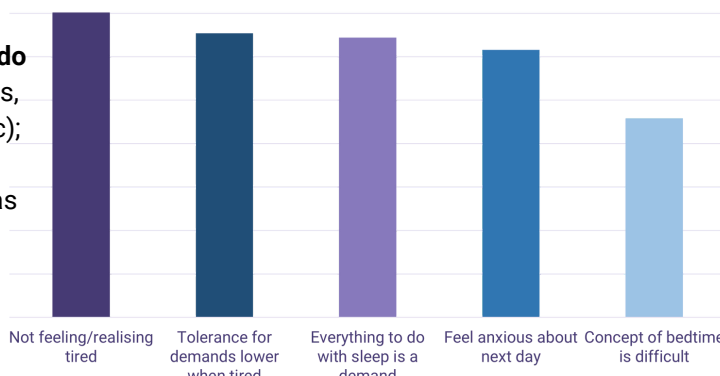
A survey undertaken by the PDA Society in November 2021 had 569 responses and revealed that sleep is a significant issue for many PDA people ...



- **85% of respondents reported that sleep was an issue** for them or their child. Of the few who said sleep itself wasn't difficult, 70% said that everything to do with going to bed was a demand. Although as always, for a few it's not an issue at all and one person mentioned that sleep was great because it was a good way to escape from demands!
- **60% said sleep had been difficult** from birth, with around a quarter saying sleep became harder on starting school and 17% saying it got worse around puberty.



- For most respondents, **professional advice and conventional approaches for sleep hygiene** (including consistent routines) **had been unhelpful for the most part**. 60% had had some professional input, but only 8% of these had found it helped, with a further 28% saying it had partly helped.
- The **top 4 areas of difficulty** were: getting to sleep, going to bed, getting up & getting going in the morning, and staying asleep.
- The most frequently mentioned difficulty was individuals **not feeling or realising that they were tired**, with several mentions of there being no 'gradual feeling of tiredness', just a sudden realisation that they were tired.
- The next most frequently mentioned difficulties were: **tolerance for demands is lower when tired; everything to do with going to sleep feels like a demand** (stopping activities, going upstairs, brushing teeth, changing into nightwear etc); and **anxiety about the next day**. And for many, the very **concept of 'bedtime'** was difficult – because it was seen as being rather arbitrary or because different bedtimes for different family members felt unfair.
- 10% responses indicated a **circadian** rhythm difference of some sort – delayed sleep phase, advanced sleep phase or non-24.\*
- A quick analysis of **bedtimes** showed that this varied widely across the board, with younger children perhaps going to bed slightly later than average, but also a noticeable number of individuals of all ages having random or no bedtimes.
- Looking at **sleep onset**, this seemed to be long on the whole, again varying widely but in the majority of cases seeming to take an hour or more, in many cases 2-4 hours.



## Other difficulties frequently mentioned:

**Anxiety** from the current day and the need to process this; worries about the next day (one respondent said "anxiety about the next day prevents sleep because if I sleep the next day will arrive faster"); and also worries about being alone.

**Regular night-time waking**, nightmares and very vivid dreams, with individuals then finding it very difficult to go back to sleep.

**Night time incontinence** was mentioned by several respondents, as was some form of **rhythmic movement disorder**.

**Problems 'switching brain off'** or seeming to not need much sleep. Also **difficulties with self-soothing**, and the need for physical contact with others on settling to sleep.

**Fear of sleep**. One parent said "there are so many factors not within her control: dreams, the day coming to an end, the way falling asleep feels, not being in control while asleep etc." An adult said "I don't want my body to be in control of me, it generates panic. Sleep takes control away from our consciousness."

And for some sleep is seen as being **boring** or a waste of time whilst others seem more naturally nocturnal or have a **preference for night time**\*. One respondent said "night time and darkness is seen as a quiet, restorative time with low demands, for instance showers often happen in the early hours when there is less pressure to do anything".



**What helps** The top 10 things that respondents said helped, in order of priority, were:

- 1 Reading/listening/watching something until fall asleep** – whilst first line sleep recommendations are to have no screens in the hour/hours before bedtime, removing screens was a big trigger for many PDAers who found that going to bed for another purpose other than sleep (i.e. watching or listening to something) was most helpful. Also see point no.7.
- 2 Flexibility** – as with all helpful approaches for PDA, being open-minded and adaptable is often key.
- 3 Routine of own making** – whether that's brushing teeth at a different time of day or sleeping in your work clothes or, as one person said, having an espresso at bedtime rather than a milky drink!
- 4 Co-sleeping** – This was mentioned frequently. One respondent said: *"When we started co-sleeping his sleep changed for the better. Our therapist advised that this is OK and in many cultures it's the norm."*
- 5 Not following sleep hygiene recommendations, or adapting them considerably** – for instance, using subtle signals to suggest bedtime (like dimming lights or closing curtains) or using other indirect ways to let someone know it's bedtime (e.g. using their phone alarm or sending them a message/GIF) and embedding some flexibility into the bedtime process (e.g. choice of washing options or being able to skip a wash).
- 6 Not worrying about it/trusting sleep will come** – as one parent said *"Introducing yet more demands just because it's some arbitrary 'bedtime' makes everyone miserable. Once we stopped trying to control it, my son's sleep got better."*
- 7 Not mentioning/thinking about sleep** – for instance, going to bed for another purpose (e.g. watching YouTube or chatting with a friend) and sleep coming when ready.
- 8 Different options on where to sleep** – this might be spaces that are already created (such as a cosy/dark tent or area under a cabin bed, or a lighter cooler area) or the options of a different bedroom or someone else's bed (subject to household arrangements) or even the sofa ...
- 9 Sleep hygiene recommendations** – although several respondents said things on these lines: *"Having a consistent sleep schedule helps, but my demand avoidance makes me refuse the routine of this."*
- 10 Pets** – not just in terms of the presence and company a pet provides, but also the sensory feedback of a pet lying on or alongside you. One respondent said: *"My cat gets annoyed when we go to bed really late, and equally gets annoyed when I stay up on my phone in bed – I don't want to disappoint her!"*

## Other things that helped included ...

**Medication** – melatonin\* had a significant benefit for a lot of respondents, with many mentions of it being the only thing that has made any difference. Some said melatonin wasn't effective at all, or the effect wore off, or it was too much of a demand to take it. Those with co-occurring ADHD noted some sleep benefits once ADHD medication was working well.

Trial and error and **following gut instinct** rather than the 'usual advice' had worked for many, as had listening to others in the PDA community and knowing they weren't alone with sleep difficulties.

**Reducing anxiety**, both around bedtime and in the daytime, had a big impact for all family members.

In terms of **sensory adaptations**, this was highly individualised ... for some low lighting, black-out blinds, a weighted blanket, cooler temperatures in the bedroom, fans or other white noise worked wonders, and for others the opposite was true!

**Autonomy**: the more control or sense of control someone has over bedtime and sleep, the better it tends to go. As one parent said *"Letting her do it her own way worked best – it may not sound like great advice but fighting it made it worse"*. Another suggestion was to have a 'rhythm' to bedtime rather than a routine, i.e.. there were things that happened in the lead-up to sleep but they didn't need to happen in a particular way or order.

\* also see the Sleep & the circadian clock section

## Further advice from The Sleep Charity



The results of the survey show how 'gold standard' sleep practices may not always be helpful for PDA people, and this is also reflected in the professional experience of sleep practitioners trained by The Sleep Charity.

Most recommended interventions around sleep involve altering behaviours and having consistent routines, both of which are quite demand-heavy. So, as a starting point, it's important that everyone involved (PDA people, families, partners and professionals) adopts a **bespoke and flexible approach**.

For instance, although it's often recommended to wake at the same time each morning, this may not work for PDA people – not only because the rigid routine may trigger demand avoidance but also because of possible circadian sleep disorders\*.

Whilst some of the many helpful pointers highlighted in the survey responses may seem unconventional, it's important to **try a variety of approaches** and do **'whatever works'** to a certain degree – the priority is always to try and enable sufficient sleep. It is definitely OK to do things differently to the sleep strategies traditionally suggested.

If anyone is concerned about any **unusual movements or breathing** in relation to sleep, it's essential to speak with a healthcare professional about this. The charity ERIC provides a range of information and support around **night-time incontinence**.



These additional suggestions may be helpful:

- It's really important to bear in mind that **tackling sleep difficulties can be very challenging**, and can also sometimes result in sleep patterns getting worse before they get better. It may be worth thinking about whether now is the best time to address things, or whether another time (e.g. a settled period or a particular time of year) may be best.
- Really try to work out **what specific factors are impacting on sleep** – maybe think through the themes from the survey results above and see which of these (there may be several) are relevant for you/your child. Helpful approaches to working on sleep issues will depend on what the underlying causes may be.
- Sleep can't be controlled – this can be a difficult concept for anyone and may be particularly tricky for PDA people. Using **'distress tolerance' techniques** – including distraction, relaxation techniques, doing an activity, engaging senses etc. - can help with managing this and enable sleep to come once someone is feeling calmer.
- Also enabling some level of **control or choice** relating to sleep can be useful – so providing yourself/your child with options on where and when to sleep (within reason), what to wear (a fireman's suit is OK ;-)) ... and knowing that there is no one 'right' way to sleep ...
- For parents or family members of a PDA person, **reducing the demands around bedtime** by altering the way things are worded or by **using more indirect 'signals'** can be really helpful. For instance, saying something like *'your pyjamas are on the bed'*, or sending someone a yawning GIF, or communicating via a favourite toy rather than saying *'it's bedtime'*.
- **Thinking about the day as a whole** rather than just focusing on sleep is usually helpful. For instance, thinking about how to **manage sensory inputs throughout the day** so that a PDA person is neither over nor under stimulated when it comes to bedtime. Where possible, **addressing wider, holistic factors** including mental and physical health and the home environment, is likely to be beneficial for sleep. One respondent to the PDA Society survey said: *"by far the most effective way of solving the sleep problems was for school to learn how to support him and make it more acceptable to him."*
- Sometimes **accepting and working round** sleep difficulties, especially for circadian sleep disorders (see overleaf), may be necessary. One respondent to the PDA Society survey said: *"When he can sleep to his own natural cycles he's happier, more relaxed and more able to tolerate demands"*
- Coping with your own, or your child's, sleep difficulties can feel very isolating, so if possible **try to have a support network around you** whether that's a family member, partner, professional, pet or online community.

\* also see the Sleep & the circadian clock section

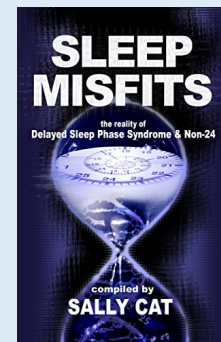
## Sleep & the circadian clock – extracts from 'Sleep Misfits' by Sally Cat

10% of the PDA Society survey respondents mentioned a circadian sleep disorder\*\* of some form: delayed sleep phase syndrome (DSPS), advanced sleep phase syndrome or non-24.

\*\* A majority of DSPS and Non-24 people consider their condition to be a disorder.

Adult PDAer Sally Cat has DSPS and has published a book called Sleep Misfits:

<https://smile.amazon.co.uk/Sleep-Misfits-reality-Delayed-Syndrome/dp/B09YQJFZPB> (with the royalties kindly donated to the PDA Society). The book explores DSPS and non-24 through the words of those who experience them. The aim of the book is to tackle the prejudice towards people whose body clocks prevent them from waking and sleeping at socially-approved hours by increasing empathy. The book also serves as a manual for those whose sleep is impacted by their circadian rhythm. The information below is taken from this book.



In addition to Sleep Misfits Sally Cat has also published an engaging fairy tale book about DSPS for children called **Stella Noctella**: <https://smile.amazon.co.uk/Stella-Noctella-Nighttime-Sally-Cat/dp/B0B1BZTPW3/>

### Definitions

- **DSPS** causes someone's sleep-wake cycle to be later than the 'norm' – it could be delayed by a few hours (for instance, sleeping from midnight to 8 am) or by a much more significant amount (for instance, sleeping from midday to 8pm).
- **Advanced sleep phase syndrome** is the 'opposite' to DSPS, where someone's sleep-wake cycle is much earlier than the 'norm'.
- **Non-24** is related to DSPS and causes someone's sleep-wake cycle to be longer than 24 hours, meaning sleeping and waking shifts later each day. Sometimes DSPS switches to non-24.



Illustration of a 25 hour/non-24 body clock that's out of sync with the night-day cycle.

### Origins

These sleep disorders are controlled by the internal body clock. Most people have a 24 hour body clock, where their internal systems, including hormone production and temperature, are aligned in a cycle called a 'circadian rhythm', which also regulates sleep-wake timing.

Research suggests that these sleep disorders are neurological in origin and that they frequently co-occur with autism and ADHD.

### Impacts

Circadian sleep disorders can make 'normal life' – working, attending school, arranging appointments, maintaining relationships and enjoying leisure time – very tricky because society is almost entirely geared towards the conventional sleep-wake patterns of the majority. Sleep deprivation is prevalent amongst people whose natural sleep cycle differs from the norm. Extended sleep inertia (the period after waking when cognitive and motor abilities are impaired) is common for DSPS and non-24 people, so they need quiet space for an hour or more after waking. Demand tolerance may be very low at this time.

All this can have a major impact on mental and physical wellbeing.

*"It feels like chronic jet lag."*

*"My AM and PM are backwards."*

*"People think you're lazy because your sleep schedule doesn't conform. It's so lonely."*

*"It affects every aspect of my life."*

*"It's not a choice or a preference, it's the only way we can sleep."*

### What helps

Research indicates that circadian sleep disorders aren't helped by standard sleep hygiene recommendations or by using 'chronotherapy' (gradually trying to shift the sleep-wake cycle towards the social 'norm') which can actually trigger non-24.

Some success has been achieved with the use of:

- morning bright light therapy (30-90 minutes of exposure can help speed up the circadian clock)
- blue light blocking in the evenings (although the causal role of blue light in delaying sleep is now being questioned)
- melatonin (research suggests that very small doses taken several hours before the desired sleep time may be effective and that higher doses may have a negative impact)

Many people who experience circadian sleep disorders find that sleeping to their own natural cycle, and putting in place as many adaptations and accommodations as possible (for instance requesting afternoon appointments; working shifts or freelance; dividing parenting responsibilities according to the time of day; online schooling ...), are what helps most.

### Further information

The **Circadian Sleep Disorders Network** [www.circadiansleepdisorders.org](http://www.circadiansleepdisorders.org) provides extensive information with descriptions, definitions, Q&As for professionals, up to date research, details on diagnosis and sleep specialists, sleep logs and groups to join etc.