



The Bedtime Story of Sleep Deprivation

A TALE OF LOVE, HOPE, SURVIVAL, MYSTERY, SUSPENSE, AND THE ULTIMATE TEST OF PATIENCE.

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Meet Lily...



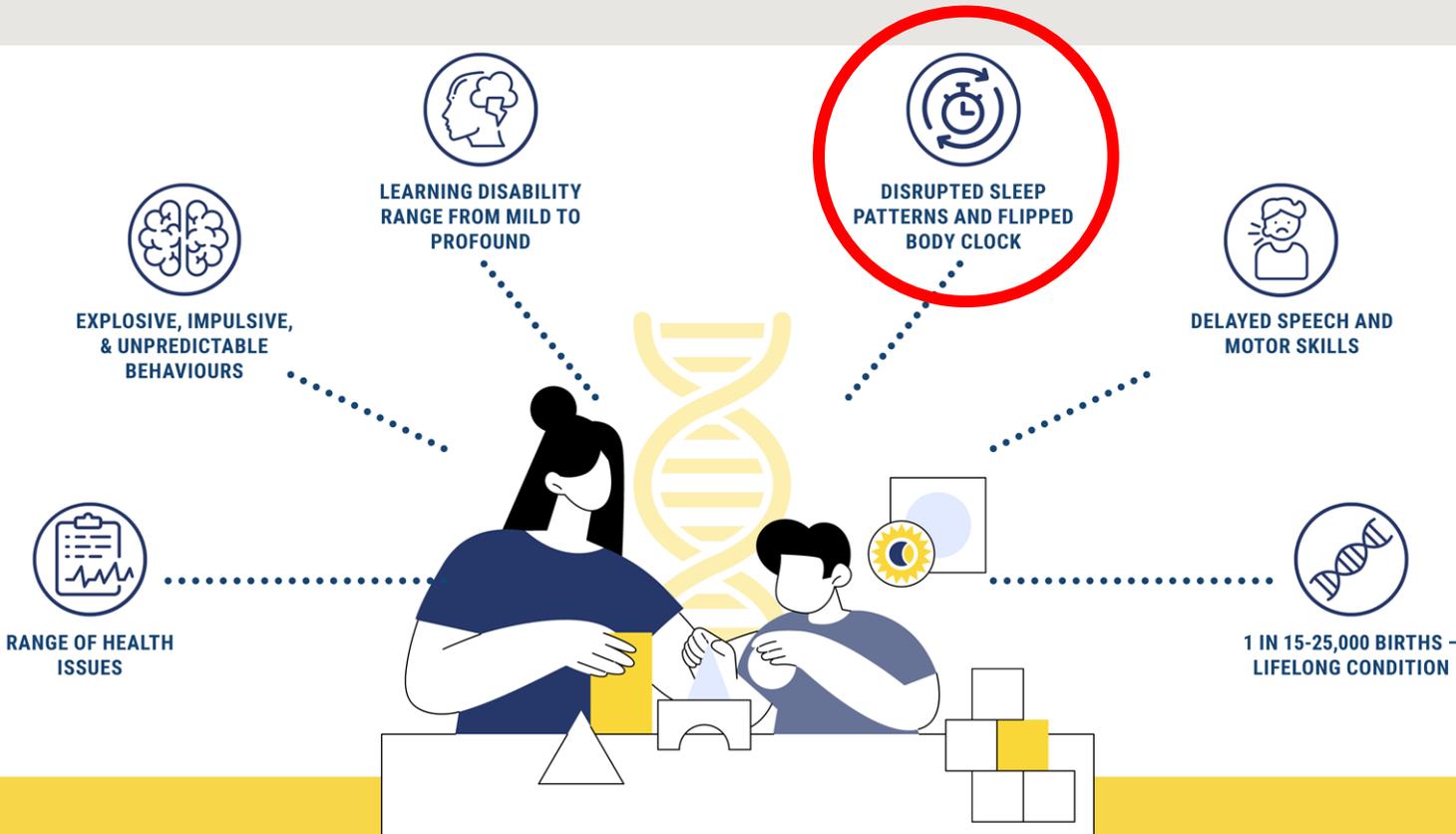
Early Signs

- Very poor sleep at night
- Excessive sleeping during day
- Failed hearing tests, repeated infections
- Delayed speech (no babbling etc)
- Delayed crawling

Widening Gaps

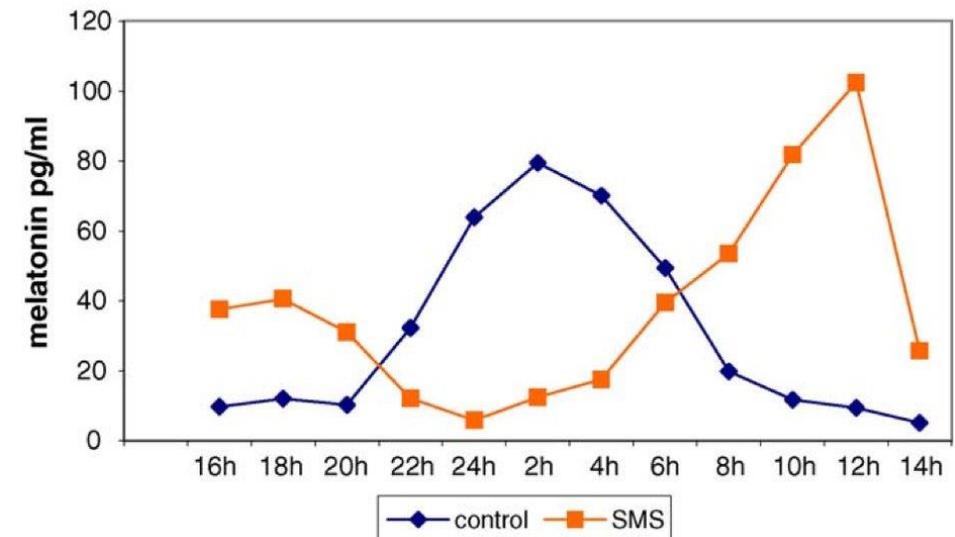
- Health issues (ear & chest infections)
- Delayed communication
- Delayed gross and fine motor skills
- Atypical behaviours
- Severely disrupted sleep pattern

What is Smith-Magenis syndrome?



Smith-Magenis Syndrome (SMS) is a rare genetic condition that occurs once in every 15-25,000 births. People with SMS have complex needs and behaviours, along with a learning disability that can range from mild to profound.

It is lifelong, individuals with SMS will always need extra support.



The Twilight Zone



How did this impact our family?

- Lily awoke frequently through the night, **every night**
- Sleep was erratic - each night was different
- Attempts to transition to a bed had been disastrous
- She couldn't be left alone - we were up all night with her

- We were exhausted and desperate

Before I go to Sleep

- No i-pad, gadgets, or TV before bed
- Consistent timings
- Calming bedtime story, warm bath and milk
- Aromatherapy, organic essential oils
- No stimulating toys or gadgets from her room
- Plenty of daytime exposure to light (lightbox)
- **NOTHING** placed in reach of her cot!

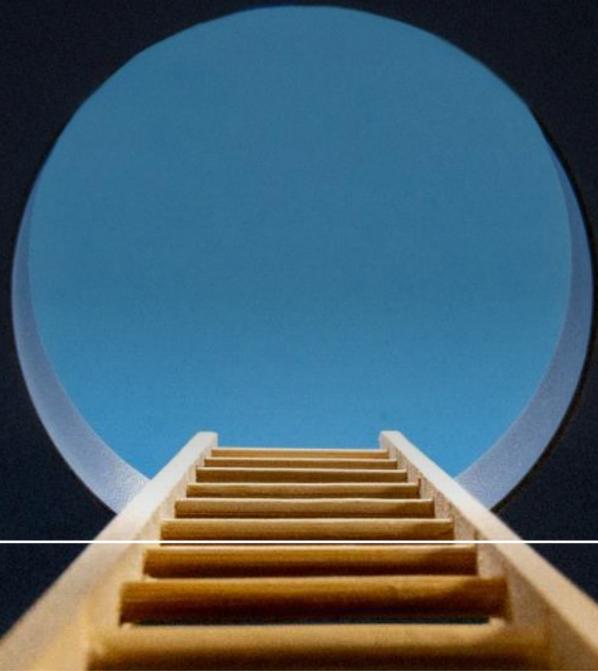


The Great Escape



- She had become an escape artist!
- She didn't stay asleep and awoke **frequently** every night
- She was able to roam the house at night
- Another baby was on the way
- We needed practical solutions!

Escape Plan



	SMS	Parents	
Lily had discovered freedom and escaped every night	1	0	😱
We adapted her cot (frame around the top)	0	1	😞
Until one night she found a foothold and climbed out again	1	0	😱
We made the frame higher	0	1	😏
Challenge accepted, she adapted her escape route	1	0	😱
We lined the frame to eliminate footholds	0	1	👉

Bedknobs and Broomsticks



- Options were expensive £3k+
- We negotiated on prices
- Dropped unnecessary extras
- Designed a bed around her needs
- Reached out to charities for support



Paranormal Activity



- Toaster was used to make breakfast
- The iron turned on and burning a hole through the ironing board
- A bottle of alcohol from a high up shelf was on the floor
- Hack saw used to saw Lily's desk



We needed a holistic 'problem solving' approach

Armageddon



Timer safe for gadget
and drink/snack



Lockable medicine
cabinet



Locked doors and
alarms
Useful for holidays too!



Simple baby monitor
so we could hear when
she woke up



Gro clock to indicate
time for sleep and
wake up

From Dusk Till Dawn

- Child locks on wardrobe doors and drawers
- No valuables left out or access to keys (house and car)
- Nothing potentially dangerous (scissors, irons etc) left around
- Scheduled daily naps (including school!)
- Light exposure during the day
- Black out blinds - outside shutters
- Aromatherapy - electric diffusers
- White/pink/brown noise (or noise of a fan!)
- Weighted blanket (although Lily wasn't keen on that)
- Lock-down routine every night
- Regular review of health and medications - melatonin/acebutolol
- Managing her anxiety



Happily Ever After

- Sleep has improved (somewhat!)
- She still wakes through the night
- She understands rules and boundaries (not up before 5am)
- She can self-manage most of the time
- Sometimes she goes back to sleep
- She will slam and bang doors deliberately to wake us up
- She still sleeps **a lot** during the day
- Tiredness has a huge impact on her behaviour



Safe Sleeping with Smith-Magenis syndrome



With thanks to film students Edinburgh Napier University (2021)

Outtakes

