

Working Together to Support a Child with Autism Spectrum Disorder Experiencing Sleep Disturbance

Georgie is six years old. She has a diagnosis of autism spectrum disorder (ASD). She also has epilepsy, well managed with medication, and is being investigated for a possible diagnosis of ADHD. She has annual appointments with her developmental paediatrician and paediatric neurologist.

She sees the family's GP on occasion for general health issues, but is usually quite well. Today she has presented at the clinic with an ear infection.

The GP knows the family and that Georgie lives with her Mum (Jan), Dad (Graham) and two older siblings, Tom 10 and Jess 12. Jan works weekdays from 9 – 2.30pm at a local delicatessen. Jan is very busy with after-school activities for Tom and Jess, who are both involved in basketball and tennis. Graham is a fly-in-fly-out worker with a 21 days on and 7 days off roster. He admits that he struggles with Georgie's diagnosis and leaves a lot of the parenting to Jan. Tom and Jess are pre-occupied by their involvement in local sport, but often complain that they 'miss out on things because of Georgie'. Jan admits that family conflict has escalated recently and she feels that everyone has been 'at each others' throats'.

Georgie attends her local primary school (five days a week). She is supported by a team of therapists both at school and home, focusing on her mobility, hand skills, high-level language skills and her independence in age-appropriate activities of daily living. An Aide (0.5 FTE) is employed to help out in the classroom. The aide liaises with the principal, program consultant, integration specialist, teacher and Georgie's mum on a regular basis. An adult volunteer also helps out one day per week. Additionally, Georgie is seen by the special continence management team, for help with her toilet training, constipation and chronic bed wetting. Georgie uses a night nappy, but it often leaks and the bed ends up wet.

A quick look at the notes prompts the GP to ask if Georgie's sleeping has improved at all. "Not really," answers Jan, "we went to the initial consultation at the sleep school, but I found getting to appointments really difficult with my job, after-school activities and the commitments we already have for Georgie. She still wakes two or three times most nights – calls out, screams at times, and will only settle if I take her into our bed and she has her special baby blanket. Once she's in bed with us, she wriggles about, pinches and kicks me, wanting to play," says Jan.

Jan continues, "I seem to spend most of the night trying to re-settle Georgie and when I finally get to sleep, it's nearly time to get up!" "I've also noticed she gets very hot and sweaty during the night, especially around her head, and her snoring can sometimes disturb Jess, who shares a room with Georgie." Jan also notes that Georgie's sleep and behaviour seem even worse when she is constipated.

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She goes on to say that Georgie has 'no trouble at all' settling to sleep initially. "We have a nice routine. She sits with me each night on the lounge, drinking her favourite chocolate milk, while I watch TV. I stroke her legs until she nods off and once she's in a deep sleep I carry her to her bed." She states that it is difficult to put Georgie to bed if she is still awake and she will often get up relentlessly, before finally settling. Putting her to bed when she is fast asleep has been the key and gives the family a much needed break from noise and disruption.

Jan notes that Georgie is difficult to wake for school and her teachers say that on most days she is inattentive and uncooperative. When tired, she becomes very 'hyped up', with increased behaviour difficulties such as fighting with her siblings, throwing toys, refusing to sit at the table for dinner, refusing to get into the bath etc.

Sometimes Georgie falls asleep on the lounge chair after school. On weekends she sleeps until 9.00-9.30am. The family looks forward to these mornings.

After discussing the sleep difficulties Jan breaks down and says that she is exhausted. "I don't need this; I didn't ask for this; I just can't handle it anymore."

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This is a de-identified vignette.

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