

## Case Study

**Sara, 36**

**Autism, Dystonia, Parkinsonism, Developmental Delay, NBIA & BPAN  
Involuntary movement in bed causing frequent night waking**

### **Referral/presenting issues**

Sara is 36 years old. She has several medical diagnoses including Autism, Dystonia, Parkinsonism and Developmental Delay. She was diagnosed with an unknown form of Neurodegenerative Brain with Iron Accumulation (NBIA) in 2008, aged 25. The diagnosis came after Sara started having increased issues with involuntary movement. The Dystonia was causing her severe sleep disturbances, and her mother reports that she would wake in the night, screaming in pain. In 2012, when Sara was aged 29, researchers discovered the de novo gene and the mutated gene was named Beta-propeller Protein-Associated Neurodegeneration (BPAN).

Before the year 2000, (age 17), Sara had regularly slept through the night. As her mobility issues increased, Sara began to move around much more in bed. Her mother advises that she had to get a bed rail to keep her from falling out of bed. Whilst in bed, her increased involuntary movement would mean that she would end up sideways or upside down in bed, often kicking off her blankets in the process. Her mother would wake up two to three times a night to reposition her in bed and replace her covers. Sara has a monitor in her room that alerts her mother when she rolls around in bed. Sara is non-verbal but is vocal when she moves. Sara's mother has tried weighted blankets and Sara has also been prescribed numerous different sleep medication, but none have been effective. Sara's mother discovered Fidgetbum, having tried many other sleep aids without success, to support the family with a new plan of intervention.

### **Background Information**

Sara lives with her mother, who is her full-time carer, her step-father and her 16 year old cousin (her mother's nephew). Sara's mother reports that Sara's quality of sleep is poor, due to an increase in movement, leaving her in uncomfortable positions in bed and cold, from kicking her covers off throughout the night. Sara's frequent night waking and sleep disturbance would often require her mother to come into her room throughout the night, rearrange her position in bed and put the covers back on the bed.



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### Assessment

After carrying out observations on Sara's nocturnal habits, it was observed that she was very restless in bed and would stay asleep for approximately three hours before waking herself up and alerting her mother, who is exhausted due to the constant broken sleep. She has a bed guard on the bed to stop her from falling out of bed at night.

### Plan

Due to Sara's increased movement and her restlessness in bed, Sara's mother had tried various sleep aids, including a bed guard and weighted blankets to help keep her in place. The bed guard stopped her from falling out, but nothing she had tried was effective in stopping Sara from moving around the bed, kicking her covers off and waking throughout the night. Sara's mum discovered Fidgetbum online in a Facebook group for those living with BPAN and trialled it with Sara to see whether it would help.

### Intervention

Sara trialled the Fidgetbum. Her mother was hoping that it would keep her covers in place. The first two nights using FIDGETBUM, her mother reports that Sara was quiet, but she still woke (out of habit) to check on her. Each time she checked on Sara, she was in the same position as when she went to bed. The Fidgetbum had kept her from moving around the bed and disturbing her sleep. On the third night, Sara's mother didn't wake out of habit during the night. Instead, she woke in a panic around 6am to find Sara still sound asleep.

Sara's mother reports that the Fidgetbum keeps Sara secure enough that she doesn't move around involuntarily in bed anymore and keeps her covers in place (without restricting her too much).

### Summary

Fidgetbum has improved Sara's sleep quality and intake. Her involuntary movement has been massively reduced, is now under control and she stays secure and asleep all night. Her mother reports that Sara also goes to a group home one weekend a month for respite care and takes her Fidgetbum with her. The caregivers there have also reported a dramatic improvement in her sleep quality: they do bed checks every two hours and have reported that Sara has been asleep every time and hadn't changed her position in bed. Sara's mother says: "I'm so pleased that we tried Fidgetbum. It has worked far better than I ever imagined possible. Sara sleeps so well now. I had been waking up throughout the night for her for 18 years and now, suddenly, I don't need to anymore. It's changed our lives."