

Case Study

Madi, 16, Quadriplegic Cerebral Palsy.

Madi also has Epilepsy, Reflux, Dystonia and other related conditions

Madi is 16 years and 3 months old and has been diagnosed with severe Quadriplegic Cerebral Palsy. Madi also has Epilepsy, Reflux, Dystonia and other related conditions. Madi's Dystonia causes Madi to move a lot and constantly. This can be small movements in the hands and fingers to extremely large and strong movements in the arms, trunk and legs. Madi is in a profiling bed, with a sleep system. It has been instructed that Madi must sleep at an angle due to an overnight gastrostomy feed. Madi has a high daily amounts of drugs to take:

- Gabapentin – 20mls X 3 daily
- Epilim – 7mls X 2 daily
- Omepraole – 10 mg once daily and 20mg once daily
- Glycopyrronium Bromide – 1 X 1 mg tablet X 2 daily and 2 X 1mg tablet X 1 Daily
- OptiFibre – 5 scoops daily
- Paed Movicol and Paracetamol as required.
- Elemental 28 Enteral Feed
- Cutimed cream for skin care
- Sofradex for Stoma care.
- Buccal Midazolam – Emergency seizure meds after a seizure lasting 4 mins.

Referral/presenting issues

Madi has struggled to get to sleep at night for years due to severe dystonic movements. Regular care and support is required to keep Madi within her bed system every night with the covers staying on. Madi is unable to re-position herself or put on/remove her own bed covers.

Background Information

A weighted blanket was recommended and tried, but Madi's Dystonia causes Madi to be very hot and the weighted blanket contributed to Madi getting even hotter. Not only was this uncomfortable for Madi but this also put her at a higher risk of seizures.

Then the idea of a single flat sheet used length ways around the bed to allow for it to be tucked in tightly each night was carried out. This was time consuming and physically awkward, as it needed re-tucking both sides of the bed every night and was only about 65% effective.



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Plan / Assessment

After carrying out observations on Madi's current bedtime routine, evidence was gathered by professionals in seeing how challenging Madi's bedtime behaviour had changed. Madi's mother had read about the Fidgetbum and the positive outcomes it was providing so many children around the country. It was agreed to trial a Fidgetbum for Madi.

Intervention

The Fidgetbum arrived in quick time and was quick and easy to put in place. Madi's parents were amazed at how well it stayed insitu and it uses just a simple zip which ensures it stays in place each night.

Summary

The Fidgetbum allows Madi to move, but to a much lesser degree to her previous bedtime behaviour. It provides Madi the comfort of not being too restrictive but it is restrictive enough that Madi stays in the correct position in her bed system. It also ensures that Madi's covers stay in place. The Fidgetbum has the added benefit that when in hotter climates it can be used without Madi's other covers.

It is soft and luxurious to the touch and therefore can be used just like a sheet on a hot summer's day/evening whilst maintaining Madi's position within her bed system. We are extremely pleased that we made the decision to try Fidgetbum, Madi's bedtime routine is less stressful, less time consuming, we have no physical issues such as back ache when using the Fidgetbum, it has taken all the frustration out of Madi's bedtime routine and overall she is much calmer at bedtime resulting in a better nights sleep.