Combining Research and Storytelling: A Carer's Perspective of Thriving to Surviving

Authors: Neish, M[1] and Neish, E

TAFE NSW[1], Sydney Children's Hospital Network[1]

Background – The search for information is often fueled by something. Anyone who has children will understand that in any one day, you can be asked hundreds of impossible questions. Kids just need to know things.
Why isn't ice-cream a breakfast food? Do penguins have knees? How is a blackhole made?
Why do I sweat so much? Is it normal to see only black sometimes? Why am I so thirsty all the time? Why don't the doctors know what's wrong with me? Will I ever drive? Am I going to die?
Questions of our sons and our own, fueled my quest for information and the countless hours spent searching for something I didn't know existed. Amazingly, the doctors we saw for first 12 years of our son's life clearly didn't know either.

Methods – This document is based on our son's condition and our time spent caring for him. By combining what I learnt through research and in telling the carers version of his story (with permission) the story of Ethan's experience with Dysautonomia came to life.

Results – A resource for people who want to know more about what life with Dysautonomia can include and some ways to live with the challenges that arise. For clinicians, this guide may enhance their understanding of the experiences of their patients and the patient's families. For patients and their families, this guide may provide comfort both in the strategies discussed and the awareness of shared experiences.

Conclusions – Practical resources to support the daily life of people living with Dysautonomia, particularly rare subtypes, are limited. We couldn't find any that helped us, so I wrote one.

Disclosure of Interest Statement: The information presented in this presentation forms part of our family's story of Ethan's condition and the experiences we have shared since he became unwell. The full story has been self-published as a book that is available for purchase on Amazon. This resource has also been distributed for free to people living with Dysautonomia and their loved ones.

<< Please ensure you delete all <instructions> and the text in the document header prior to submission. Abstracts not submitted in the correct format will be returned for correction >>