

Experience of a Parent and Parent's Perspectives of Raising a Child with Diabetes

Lorraine Pitman

Education and self-management is a powerful position to be in with any condition; it is the starting point and foot hold you need to guide you through those periods of change and transition.

No matter what age you are diagnosed it is never an ideal time to 'get type 1 diabetes'. Let's face it, nobody wants to get it but you have to try and understand it to manage it or it will manage you.

Our son Tom was diagnosed at 2 years old, so now ten years on we can reflect on what he has gone through at a range of different stages, ages and fazes. We have a wonderful health care team who have supported us as a family, providing proper guidance, education and self-management tools. However, no-one knows Tom's diabetes like him and our family.

While our diabetes educator and endocrinologist are very well informed and keep us up to date with current therapies, they can't always know everything about Tom and our family's lifestyle so it is important to work together and not be afraid to speak up and share our needs and concerns.

Over the years Tom has led and guided me, enabling me to support him with his health management. It has certainly been a lifelong condition for Tom which has involved making

certain life, treatment and management changes along the way.

The challenges of achieving optimal BGL's and HbA1c's is taxing at times as they are governed by a range of activities, emotional states and the food he eats. It is important to recognise that there is type 1, and type 1 in the individual. It is exactly that, an individual's set of circumstances which are unique to the individual. It is important as a carer, person with type 1 and health professional to recognise the constant considerations that you have to make in every activity of everyday life. It's hard work!

Every stage and age can feel like a new frontier, with discoveries, challenges and at times victories. Trying to stay connected and planning ahead has helped us prepare for obstacles that presented along the way. Keeping information relevant has been a good coping mechanism, not looking too far ahead but recognising the importance of accessing the right information at the right time.

We have been through preparing for kindergarten and supporting him in the school setting, managing common misconceptions and social stigma, fear and exclusion and a lack of understanding of type 1 by family and friends, but I would have to say the most challenging period to date is pre-teen. There are so many things to consider that it feels like you are losing control. The funny thing is that

control doesn't really exist in the world of type 1. Management and influencing outcomes are a better way of looking at type 1.

As we find ourselves in the pre-teen years there has been a period of change and transition for both myself and Tom. There has been a gradual handover that has occurred in roles and responsibilities in his health management. With the support of his health management team we have been gradually equipping, enabling and empowering him to take the lead in his health outcomes.

I realised early on that I can't watch him every minute and I don't want to cramp his style, he needs to be kid, so I have worked with him to ensure he has strategies and an understanding that will keep him safe.

He recently went on a school camp which involved a lot of water sports, so prior to going away he discussed the option of going on needles as opposed to his current insulin pump therapy regime. Inside I was reluctant but chose to keep my concerns to myself and work with his endocrinologist to support his decision instead. The benefit of following his choice has shown him he does have a real choice and is empowered to have the flexibility in his health management. He also ultimately made the decision for himself that he preferred the insulin pump over the needles.

I have always encouraged discipline in the way he manages his diabetes and insist on the same commitment for blood glucose monitoring, food intake and exercise. Establishing good self-care habits has always been a priority, as it has set the foundation that will enable him to develop the confidence to become independent and take responsibility for his own care. This was proven on his recent camp, and he expressed how good it made him feel. With support he achieved one of those little type 1 victories!

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