

My son was diagnosed with type 1 diabetes in November 2021 at the age of 13. At the time we had no idea how this disease would change our lives in the most profound way. In an odd kind of way, I see our family as lucky, as we are equipped to self-educate, and source the best medical help available to us.

Unfortunately, our journey did not start out this way. We were allocated a Diabetic Educator through the hospital he was admitted to and had to end up asking her to leave and not to return. Her level of professionalism was at its minimum, and her treatment of the staff of the hospital was also deplorable. She yelled at my 13-year-old inquisitive son for asking too many questions, choosing to turn her back on him and announce she would be ignoring all his questions because “he was being a smart arse”. Thus began our research into finding a DE that suited our needs. This was self-research, and no help was offered by the attending Paediatrician. Through determination we found the perfect person and have now established an excellent patient/Professional rapport.

The school in which our son attends has been nothing but supportive and accommodating to our needs. Again, we are lucky enough to attend a private school that has a health centre with 2 registered nurses. He has been able to attend excursions, camps and lead a fairly normal life with his friends whilst being at school.

My concerns are about his future. Next year he will turn 16, and this comes with another round of confusing, and unguaranteed paperwork and forms submitted to Centrelink, for what will be an Ex-Carer allowance. I find it hard to believe that most 16-year-olds are self-sufficient enough to have to apply for this allowance which allows them to maintain a health care card and receive the government allowance. We will still be paying his medication, supplies encompassing CGM and pump, and taking him to Doctor, endocrinologist, and DE appointments. This does not change because he is turning 16. However, the process changes! And I ask you why? He is still at school and living at home. The Ex-carers allowance and health care card are not guaranteed for him, yet nothing changes except his age.

Every single parent of a newly diagnosed child should have access to education, parent peer support in hospitals, school support and funding for aides and workplace education.

Without our self-research our journey would have been difficult, and to an extent could have been easier. There is a need for parent support on diagnosis. We need parents with experience in hospitals supporting newly diagnosed parents. There are schools that have no funding to supply an aide to help with blood glucose testing and insulin administration. Education and understanding in the workplace once the parents have returned to work is crucial. I personally have had a very tough time getting my colleagues and managers to understand the need for me to leave at a moments notice, turn up to work after having sleepless night, calling in sick because my Type 1 child is unwell. The lack of understanding has led to workplace bullying, and comments like, “I thought this would be easier by now”, or “can’t he just go the health centre until his levels rise”, or “you are unable to wear a smart watch, as its not uniform approved”.

I am asking you to consider every part of being diagnosed with Type1 diabetes. Its not just about the diagnosis, and here have some insulin. Its about so much more.

Thank you for reading my submission.