

PO Box 6021
Parliament House
CANBERRA
Canberra ACT 2600

RE: Inquiry into Diabetes.

To whom it may concern,

To begin with I would like to thank the committee for reading all submissions offered to this inquiry, and for opening up a dialogue about Diabetes in our community. This submission will offer the perspective of my lived experience with Type 1, and the ways it has impacted my life. My strong belief is that there needs to be reform around education, and accessibility to mental, physical, and professional resources available both at diagnosis and continuously through the patient's life, pursuant to their personal needs.

I was diagnosed with Type 1 in May 2017, at 16. I had just entered year 11, was studying ATAR courses, and had big aspirations for the next two years of my high school life and the opportunities they would offer me post-graduation.

My diagnostic story was less than ideal, as is the case with most patients.

I was misdiagnosed with Type 2 Diabetes in November 2016- I was run of the mill insulin resistant, but still had some pancreatic function present, so was given a prescription for Metformin and sent on my way. The resources offered to me from the outset of this misdiagnosis were next to none. A BSL machine, a prescription and a quick "keep checking your sugars and try to limit carbohydrate intake" was the instruction.

In May the following year I had fallen very ill, and started running a BSL around 20mmol/L, 12mmol/L higher than that of a non-compliant type 2. I was instructed to attend an emergency department which I did. After 3 days in the first hospital, while being prescribed and having had insulin administered during my stay, I was given a referral to a private endoscopist for suspected stomach ulcers, which we told doctors we could not afford. They gave me one last shot of Novorapid insulin and 4 hours post dose, I was discharged to the care of my terrified parents.

The following day, I tested my blood sugars and returned a reading of 27.3 mmol/L. I scheduled an urgent appointment with my GP and was sent to a different emergency department. 4 hours later I was informed that my GAD antibody levels, which are a key indicator of T1D, was 25 times the highest end of normal, and that the team could simply not believe the other hospital had overlooked this. 3 days later, with an overwhelming amount of information that I didn't truly understand, I was discharged and told they'd make an appointment for me in the outpatient clinic, but it might be a while since the clinic I was attending only runs once every 3 months.

I had just received a life altering diagnosis, and had a spanner thrown in my dreams. I was chronically exhausted, I couldn't do my first round of ATAR mock exams, I lost friends, and I wound up in a situation with my family where they could simply only worry.

I was completely isolated from the people I cared about, I felt like an alien in my own skin, and I was shamed by my peers for my need to inject a necessary drug. It was horrifyingly alienating for me as a young woman to have to hide to survive, so I made the subconscious decision that instead I would pretend that nothing was wrong; that I would not need to hide if I simply believed I did not need to take my medication.

When I attended my first outpatient appointment, I had done some research and realised a pump was an option, but I failed to realise that I had missed the cut off for a subsidised pump by a measly five months, as my 16th birthday was the December prior to my diagnosis. This led to a deep resentment for myself and the system that failed me in November. It also resulted in a string of serious hospitalisations due to Diabetic Keto-Acidosis, which prior to my first hospitalisation post-diagnosis, I had no information on, nor understanding of. My parents could not afford the insurance coverage that would allow me to be issued an insulin pump, much less the outright cost of a pump without any assistance.

In the process of my denial and alienation, I do wish there were mental health resources provided. At 16 I had just started entering into life, and by 16 and a half, I felt I didn't deserve it, because I was made to feel like a burden to the system. I was bullied in school, called "obese" despite a normal BMI, and a "junkie" for my need to inject insulin. I was told I was "faking it" to get more time in exams, and made to feel like my disease was just in my head. I don't blame my peers for this; they didn't know any better, and I barely did either. My physical health was at an all-time low, and my mental health was no better. We could not afford the additional psychology sessions I required outside what my GP had provided as part of a mental health care plan. My psychologist wanted to see me once every week or fortnight, and at the best time I was able to go once every month which was completely insufficient for my needs at the time.

The education and stigma around diabetes is absurd. I was left in a situation in my young life where I was training supervisors in my work about how to manage any emergencies that may occur, because despite being qualified to provide first aid, they knew nothing about emergency management of this disease. The lack of knowledge about T1D which impacts 5% of Australians is astounding to me and prior to my diagnosis I was part of the ill-informed. There most certainly needs to be a change to the understanding of the public about the disease.

At 18 I almost lost my life to DKA. I spent a week in the High Dependency Unit, I and lost 3 days, which I still cannot remember. The last thing I remember before those 3 days was my older sister holding my hand, crying, and telling me "You got this." And my reply being "I don't think I do", then hearing the nurse telling my family to prepare for the worst. This still frequently plays on my mind because the first thing I remember after finally coming to was two nurses talking. They were saying how they were shocked I was still alive. Hearing this struck a chord with me that makes me both thankful and deeply fearful.

After this, I made the decision to invest in Private Health Insurance. I was making less than \$35,000 P.A, and had to cut down my social life in my young adult years to almost nothing because after the cost of medication, insurance, and other living expenses, I was left with about \$100 a week to get by. I could not afford the luxury of the therapy I desperately needed after a severely traumatic event, and despite this still had to wait a 12 month waiting period to be eligible for my pump, then an additional 3 months for an appointment in my clinic.

Now seven years post diagnosis, I am very lucky to have an insulin pump, but the cost of supplies and medication is still difficult when the time rolls around. Between the cost of living sky rocketing and wage growth being minimal, I have found myself in a similar situation as prior despite making much more. However in a worse situation in some ways because getting into my clinic is harder than ever, as it only operates in standard hours- sacrifice a day of work and lose the money I need for supplies, or miss appointments that will provide me resources I need like pump updates, medication changes or access to CGM?

The truth is this disease doesn't end, and these decisions will look me in the face and laugh at me into my old age. But the difference could be my opportunity to laugh, to look at these decisions and make them mine instead of being their martyr. And this unfortunately does not lie only in my hands. In some ways I have the opportunities to make a change; I could get a better job, though I can't afford a

tertiary education. Or, there could be changes to the system in favour of us, the people who are faced with the choice of food or medication, appointments or paying the bills. This starts with education, not just for the general public, but in the health care sector; and changes to the cost and accessibility of desperately needed resources that we simply don't have. I implore the committee to investigate the need for mental health assistance for those with chronic health diagnoses, understanding and mitigating the cost for people with diseases, especially since low socioeconomic people are the most impacted by it, and to ensure a reform to education both in schools and workplaces, in favour of those who day to day need understanding to feel human.

Thank you for your consideration of this submission.

Yours Sincerely,

Nicola Hames.