

The Standing Committee on Health, Aged Care and Sport
House of Representatives, Australia
Re: Inquiry into Diabetes

To the Honourable Members of the Committee,

I was diagnosed with type 1 diabetes at the age of 33, in June 2020. It involved a short stay in Hospital, where my blood sugars were brought under control. It was determined that my immune system had developed a high level of antibodies, attacking endocrine systems relating to insulin production.

Upon discharge from hospital, I was provided with a chiller box full of two types of insulin, a manual (“finger-prick”) glucose monitor with test strips, and a number of pamphlets about different aspects of my treatment. The total out-of-pocket charge for me was simply the cost of filling my prescriptions during the stay. Follow-up appointments with an endocrinologist and a diabetes educator were booked through the public clinic at the hospital.

As much as I was unlucky in developing diabetes as an autoimmune disease, I do feel very lucky that I am an Australian. The NDSS and PBS subsidies—for glucose and ketone test strips, and insulin—that are in place have made my treatment affordable. I am able to access a fully subsidised continuous glucose monitor through the NDSS, which would otherwise cost close to \$350 per month. The CGM (initially Dexcom G5, now Dexcom G6) has improved my quality of life immeasurably, as I am able to monitor changes to my blood glucose caused by eating, drinking, activity, and rest.

However, there are major aspects of my treatment and management that have gone wholly unsupported by the NDSS and Diabetes Australia.

In 2020, I was receiving JobSeeker, as I had taken a hiatus from studying while the pandemic was developing.

After developing diabetes, my mental health plummeted. I was no longer able to simply *enjoy* any meal; now every item of food or drink I take in involves an additional process of planning insulin injections.

To begin with, I was weighing every meal and calculating the carbohydrate content. This meant if I ever wanted to eat a meal out, or purchase a take-away, I would either need to look up the nutritional information—if it was available at all—or I would have to simply guess. My estimates have become more accurate over time, however it continues to weigh on my mental health.

If I should inject too much insulin, by miscalculation, mistake, or by not correctly accounting for physical activity, I need to eat something sugary to compensate. An act that had been considered an enjoyable treat for 32 years of my life suddenly became a punishment; a suggestion or reminder that I was not careful enough with my condition.

I am aware of the DAFNE program, but I am concerned that it is a 5 day intensive course, when I would much rather spend my time (and my life) with my diabetic treatment in the back of my mind, and not the forefront.

The impact of diabetes, and its treatment, on my mental health was so intense that, at one point, I was on the verge of attempting suicide by insulin overdose. I have since applied for, and now receive, the Disability Support Pension, awarded for my mental health. In the process of receiving mental health treatment and diagnosis leading up to the application, I was diagnosed

with ADHD. One unforeseen complication is that there is no moment that my mind does not spend at least some energy on my diabetes. Another is that the ongoing chore of weighing every meal I made at home was unsustainable.

Despite these challenges, and due to a greater understanding of how my brain operates, psychological treatment, and a change to my antidepressants, I have been able to return to study, albeit in a greatly reduced capacity. Although my diabetes educator assured me that I would be able to return to a normal life after my diagnosis, I am constantly aware that I have a reduced capacity for exertion, whether physical or strictly mental, as any activity—and even changes in mood—affects my blood sugars.

The NDSS, Diabetes Australia, and the diabetes/endocrinology clinics I have attended seem completely ill-equipped to handle the mental health challenges I have faced, and continue to face. The vast majority of resources for type 1 are catered towards juvenile diabetes, and the parents of juvenile patients. There is remarkably little support specific to adults who develop type 1.

It seemed to me that the general attitude is that, if one is an adult with type 1, one should already know all about it, and be fully responsible for one's own treatment. This simply, and trivially, isn't the case for adult-onset type 1 diabetes. There are many questions and challenges which are unique to adult-onset type 1 diabetes, that have gone unanswered by the specialists and clinic appointments which have been organised for me.

Furthermore, as part of my ongoing endocrinology check-ups, I am expected to have regular medical checks on my eyes, feet, and blood. The blood tests are fully covered by Medicare, and I see ophthalmologists and opticians at Specsavers, who are also funded by Medicare. However, podiatry is an Allied Health specialty, which would incur fees that are only partially covered by Medicare, and only under a Chronic Health Management Plan set up by a GP. The endocrinologists at the clinic are unable to assist with this.

I have been unable to secure a place in any public podiatry clinics in the 3 years since my diagnosis. There is a podiatrist supplied by my current endocrinology clinic at Hospital, however I am—and have been since my diabetes developed—outside the age bracket for referral to them. I am only fortunate that my blood sugars have been well enough controlled that I have not suffered any issues with my feet.

Podiatry is a medically essential part of diabetes management and treatment, and it is baffling that the NDSS does not provide any subsidies or assistance to access it.

I have also needed dental work since developing diabetes, and my dentist made me aware of ongoing research into the impact of diabetes on teeth, gums, and oral health. It is not altogether unsurprising that there is a link; diabetes is a disease which affects every system in the body. This is one of many reasons to consider the inclusion of dentistry and dental hygiene treatments in Medicare coverage, especially for patients with diabetes, or other conditions/diseases that have impact on oral health.

As it stands, especially as someone living solely on the DSP, every expense related to my health—from filling prescriptions to specialists such as dentists or podiatrists—feels like a punishment for developing a disease that could not be foreseen or prevented.

I thank the Committee for taking the time to read my submission, and hope that my experience helps to inform recommendations in the future. I have requested that my submission be kept confidential due to the inclusion of aspects of my medical history, however on condition that details that could identify me are redacted, I do consent to this submission being published, and/or quoted in the report.

27th June, 2023