

**Submission to the House of Representatives Standing Committee on Health, Aged Care and Sport  
regarding Diabetes**

Thank you for instigating the *Inquiry into Diabetes*. I acknowledge the hard work done to establish such an inquiry and believe it to be both sorely needed and overdue. In this submission I will be addressing Points 2, 3, and 5 of the Terms of Reference. It is my expectation and hope that information provided herein may benefit this inquiry and people living with diabetes in Australia.

I am a young Australian living with type one diabetes (T1D), having been diagnosed in my late teens in 2017. I have primarily relied on multiple daily injections (MDI) of fast-acting insulin for treatment and used Freestyle Libre products for management. I have previously used insulin pumps (both Cellnovo and then later the Accu-Check Solo). I am also considered to be in the 'honeymoon period' of T1D, in that I currently do not require any long-acting (basal) insulin and rely solely on fast-acting insulin to manage high blood sugars. In a professional context, I have a Masters of Public Health and currently work in the public health sector. I believe this combination of factors positions me well to prepare this submission from a place of both personal and professional interest. I take every opportunity I can to provide feedback into processes which are working and which could be improved, hence this submission.

Australians benefit from well-developed health infrastructure and a robust public health system. I'd like to recognise the efforts of countless advocates in their work to secure better outcomes for people with diabetes (PWD). This includes but is not limited to PWD, healthcare professionals, public servants in the health sector, medical researchers, and charities. While these efforts must be recognised and applauded, we must also consider what pitfalls exist in diabetes management, treatment, and prevention in Australia.

My submission to the inquiry will discuss the following topics:

2. New evidence-based advances in the prevention, diagnosis and management of diabetes, in Australia and internationally

- Australia's place in the global efforts to treat or otherwise cure diabetes
- Limited access to modern medicine and technology for management of T1D in Australia

3. The broader impacts of diabetes on Australia's health system and economy;

- Barriers to accessing and benefiting from healthcare
- Economic and environmental impact

5. The effectiveness of current Australian Government policies and programs to prevent, diagnose and manage diabetes.

- A culture of blame and shame leading to stigma and discrimination

## 2. New evidence-based advances in the prevention, diagnosis and management of diabetes, in Australia and internationally

### **Australia's place in the global efforts to treat or otherwise cure diabetes**

Australia is far from first place when it comes to developing new treatments for diabetes, especially T1D. While promising research is published at regular intervals, there is a lack of meaningful work being done. Some studies seem to have little actual benefit for those living with T1D and instead only satiate scientific curiosity and provide insights that will only be useful to a limited percentage of the T1D community. If a study is done to measure the changes in blood sugar when people are put in outlandish situations, it begs the question of who the study will help. It would be great to know how floating in zero gravity impacts on blood sugar levels, but it would be much greater to understand how we can reverse the destruction of beta cells that leads to T1D in the first place. While it cannot be considered wholly unethical, it seems inappropriate and extravagant to perform research on a group of people that will not benefit them.

The lack of curative or other treatment research in Australia compounds with the lack of modern supports in the interim. With the removal of fiasp from the PBS we are moving backwards and losing access to contemporary treatments for T1D, while there is a dearth of work being done to cure T1D.

#### **Recommendation 1**

Commit to funding at least one curative avenue for T1D on an annual basis. While a cure is often considered a pipe dream, it is true that without T1D there would be a drastic improvement to patients quality of life along with economic benefits for the nation due to reductions in hospital admissions and increased productivity. Similarly, a cure for lack of insulin production could also benefit those with type two diabetes (T2D), gestational diabetes, cystic fibrosis related diabetes, and other types of diabetes.

#### **Recommendation 2**

Impose some sort of ethical research restriction where research done on people with T1D would have some sort of actionable benefit for the community. Otherwise, propose a comprehensive research plan for the future that can map out the research that must be done to improve patient outcomes and allocate healthcare resources and funding in the most effective way possible.

### **Limited access to modern medicine and technology for management of T1D in Australia**

Something that has been a significant concern for me since my diagnosis in 2017 is the slow pace that Australia has when it comes to accessing and distributing new medical devices and treatments.

When I first heard about fiasp insulin, the new ultra rapid insulin available overseas, I was so excited for it to arrive in Australia so I could benefit from it, but waited years for it to be approved. When the Freestyle Libre 2 became available overseas I was once again excited to benefit from the newest and improved flash glucose monitor, yet this was also delayed by years. The story continues with numerous medical devices and some medications. It's the same story for the Dexcom G6 and now the Dexcom G7, the same for the Eversense, for the Freestyle Libre 3, for the new teplizumab the only medication released to date that can impact the progression and management of T1D that isn't insulin. I should note that when the inquiry was first announced I watched the informative video that accompanied it, and was confused by the inclusion of a video of someone using a Freestyle Libre 3, as Australians do not have access to this technology due to the aforementioned delays. Though this was a simple mistake, the bigger issue is why do we not have access to this modern technology? How

much could we stand to gain by bringing it to Australia? How much do we stand to lose by delaying its introduction? I am pleased that when I contacted the relevant party regarding the discrepancy in the video, I was treated kindly and the mistake was remedied, which is rarely the case when similar errors are pointed out in other areas across Australia (such as asking a café to stop promoting their pastries with the diabetes hashtag, for example).

Hearing that the long anticipated and regularly used fiasp was to be removed from the PBS was painful. It still hurts to think that a lifesaving medication can so swiftly and simply be deleted from the national system and removed from the country. The various insulins are not the same, and I have tried novorapid, Humalog, apidra, and fiasp, with fiasp bringing me the most benefit. It is exhausting to think about changing to another insulin and having to adjust all of my management protocols, even more exhausting to think that Australia's newest insulin is now over a decade old. I fear this could be a starting point, that maybe the next move is to remove the CGM subsidy. Removing fiasp is a stark reminder of how little control we have over our own healthcare and bodies, and is incredibly disempowering.

Many PWD turn to DIY methods of managing diabetes, typically looping or otherwise hacking the existing technology to improve it. This further goes to show just how dissatisfying our current options are, that we are willing to take matters into our own hands and reconfigure the technology available to us (often to great success).

**Recommendation 3**

Fast track the approval of medical devices and medications that have been introduced in other countries with comparable standards such as Europe and America. This can be done by establishing a pathway of registration for new technology and medication so we don't have to wait more than 6 months to access these.

**Recommendation 4**

Renegotiate to keep fiasp on the PBS.

**Recommendation 5**

Introduce teplizumab rapidly as an option for those newly diagnosed with T1D.

### 3. The broader impacts of diabetes on Australia's health system and economy;

#### **Economic impact**

There are numerous financial costs associated with diabetes. At a national level there are costs associated with preventable hospital admissions and productivity losses. At the individual level there are many costs due to diabetes, including the ongoing cost of the following:

- Insulin pumps (including private health insurance which often requires the highest level of cover to receive any significant support in accessing an insulin pump)
- Insulin pump consumables
- Continuous or flash glucose monitors (more so for those who do not have access to the subsidy)
- Purchasing and disposal of sharps containers

- ‘Hypo snacks’ – any food purchased for the sole purpose of treating hypoglycaemia (e.g., jelly beans, juice boxes)
- GP appointments to get a new script for insulin (a confusing concept, as for those with T1D you are unlikely to suddenly stop needing insulin)
- GP appointments when you need to go back to them to change an allocation on a chronic illness management plan
- Numerous allied health appointments to manage the comorbidities and complications of diabetes, such as psychology appointments which are limited to the 10 Medicare funded sessions
- If following a low or no carbohydrate diet, then the associated premium cost for food
- The loss of work time and associated wages due to attending appointments related to diabetes or taking unpaid leave to manage especially difficult days due to stubborn high or low blood sugars
- Any cost associated with additional purchases to support the above such as parking for appointments, and adhesives for medical devices

**Recommendation 6**

Allow PWD to change the allocations on the chronic management plan to save money time and energy, and free up GP appointments for those in need

**Recommendation 7**

Inform people with T1D about potential benefits of low carb eating but do not endorse as a solution for all. Provide funding and support to boost low carb food options in Australia. If there is any national pursuit of low carbohydrate diets to assist in management of T1D then introduce supports for this such as a subsidy or card to access low carbohydrate foods at a more affordable rate, or similar strategies.

**Recommendation 8**

Standardise the process for purchasing and disposing sharps. Make this free if you want hazardous materials to be disposed of correctly.

**Recommendation 9**

Allow extra personal leave days for PWD. This allows us to attend appointments or take a day off to contend with persistent high or low blood sugars.

**Recommendation 10**

For those with a concomitant chronic management plan and mental health care plan, expand the number of Medicare subsidised sessions from 10 to 15+. This will help address the well-known association of diabetes and poor mental health.

**Recommendation 11**

Continue the CGM subsidy for people with T1D and consider introducing it for people with CFRD, type 3 diabetes, and those with type 2 diabetes. Prioritise those who are dependent on insulin.

### **Environmental impact of T1D**

Newer technologies such as the Libre 3 and Dexcom G7 are much smaller than previous versions and use less packaging. As climate change continues many of us want to reduce our environmental impact and live more sustainably, but this is hard to accomplish when we regularly have to dispose of pump consumables, disposable insulin pens, glucose monitor packaging, insulin vials, used lancets, test strips among other medical consumables. As mentioned above, disposal of sharps containers is also a point of confusion, and another form of waste associated with insulin dependent diabetes. It is hard not to feel a sense of guilt when discarding these materials, which brings another burden to the mental health of PWD.

In addition to this is the waste and carbon footprint of low value care provided to PWD. A personal example is a blood test I had earlier this year. A GP had given me a pathology form for usual T1D bloods, and during my phone call appointment with an endocrinologist, I was told that they also wanted me to get a blood test for them. I suggested that they contact the GP for the results but was told the system 'doesn't work like that' and that it would be better to just get them both done. Frustratingly, the tests were almost identical and I now regret having got both done as the second blood test was redundant. The phlebotomist taking my blood told me we had to take close to the maximum amount of blood and asked me not to bring that many pathology forms again, especially as they were essentially the same thing for two different people. I agree – this was a waste of my time, the phlebotomists time, the other patients time, and the time of the medical scientists who analyse these samples.

#### **Recommendation 12**

Plan and implement appropriate infrastructure for pathology tests for PWD. Determine what pathology tests should be done by PWD and at what frequency.

#### **Recommendation 13**

Consider ways to reduce carbon emissions and waste associated with managing and supporting PWD.

### **Barriers to accessing and benefiting from healthcare**

While medical professionals have a clear role in improving and sustaining the health of PWD, there are many pitfalls that this group fall into when assisting us.

I have had too many poor experiences in the health system due to T1D. When doctors find out I have T1D during an otherwise unrelated consult, I find they often bend over backwards trying to link the condition to T1D, even when it becomes nonsensical. There is also an inconsistency in the way we are treated at different clinics. I've noticed that a HbA1c of 7.2 is appalling, according to the local GP clinic, and amazing, according to the public hospital clinic. We know that it is best to have a HbA1c below 7, but the comments provided by these two clinics are so conflicting that it leaves me confused about where to go from there. Furthermore, when health professionals' comment on my blood sugars being high, they never follow up to ask me why. They never ask how they can help or what I might need or strategize how to improve it, but simply tell me it isn't good enough.

When this isn't the case it is the opposite, and I present with a T1D related concern which is then brushed off as something else. I developed a red mark on my shin 18 months ago, something I assumed was a scar from some mosquito bites. I got it checked out by several GPs who shrugged it off until I explicitly requested a dermatology referral. To my surprise the dermatologist could

diagnose it without seeing me as it is an uncommon manifestation of T1D called necrobiosis lipoidica. While considered a 'complication' it is not connected to blood sugar control and has an approximate prevalence of 0.3% in people with T1D. It is upsetting to realise that I had this mark on my skin that could have easily been identified by googling 'type one diabetes red mark on shin'. If one of the GPs had googled it then we would have figured it out much earlier. Luckily, it isn't an overtly dangerous condition, but it is concerning to me that front line health professionals could miss a condition so overwhelmingly associated with T1D, while simultaneously trying to link every other symptom I experience to T1D. It is truly bizarre, and increasingly frustrating.

During the COVID-19 pandemic there was reduced access to insulin and medical consumables due to fears of hoarding, but this became very frustrating to navigate through, especially for those who used to be able to pick up supplies every few months and now had to shift their schedule to pick them up more regularly. This only increases the mental burden of diabetes and was made more difficult for those who have additional conditions such as ADHD and found it harder to adapt.

There should also be more support provided for PWD to access affordable and regular dental care, due to the associations of diabetes and periodontal disease. A clear example here is for those who experience hypoglycaemia. When you have a hypo at midnight and wake feeling confused and groggy and sick, you treat it as best you can and often fall asleep again before brushing your teeth, which is not ideal. If you do get up to brush them then by the time you return to bed you are wide awake and its more difficult to fall back to sleep.

**Recommendation 14**

Support PWD to access affordable dental care.

**Recommendation 15**

Support healthcare professionals to upskill and learn more about T1D and associated conditions and presentations.

**Recommendation 16**

Encourage and support more people with T1D to study and gain employment in health disciplines. It would make such a difference in my life to attend an appointment with a health professional who not only understands T1D but has lived experience of it.

## 5. The effectiveness of current Australian Government policies and programs to prevent, diagnose and manage diabetes.

### **A culture of blame and shame leading to stigma and discrimination**

I was devastated when I was diagnosed with T1D, not only due to the need for insulin injections, but because I knew what people would think of me. I didn't truly believe I could have diabetes because I was healthy, I exercised and ate a good diet, I was a normal weight, I took care of myself. As far as I was aware, you only got diabetes if you didn't look after your health. This was and continues to be the one consistent message spread about diabetes, from the media to medical professionals, to shop owners and friends and family. This has led to stigma, from which comes discrimination and a culture of blame and shame. You see it now even, at cafes with a 'type 2 shake' or that advertise their goods with the diabetes hashtag. There is a myth that PWD cannot take care of ourselves, and there is a clear need for patient advocacy.

Unfortunately, some of the least informed individuals seem to be medical professionals. Many make offhand comments about 'poor control' without engaging us in a respectful two-way conversation about our treatment goals or asking us if we want to discuss our diabetes during the consult which we have often booked for another reason. It is incredibly disheartening to make an appointment for something entirely unrelated to diabetes and still have it called in to question. Those of us with T1D know how to handle it and have survived as long as we have through our own efforts. 99% of the time we are solely responsible for the decisions made on our own treatment and yet are still treated as though we don't know much about diabetes. Our concerns and queries are disregarded in favour of yet another explanation on how insulin works, and we are told off for high blood sugars and criticised for low blood sugars. Indeed, as soon as we seem to hit a happy middle ground it is my experience that the goalposts shift yet again to ensure we are never quite good enough. You can't shame someone into perfect blood sugar control. It scares me how little the various medical professionals seem to know about T1D, and I've really lost such a staggering amount of trust in doctors since my diagnosis. The current programs are clearly not working well, and any benefit that could be provided through management from health professionals is mitigated by poor communication and lack of meaningful support.

One of my clearest memories of discrimination was at a local university bar. I was at a quiz night and went to get a rum with coke zero. I asked the bartender for this and she made a snide comment about how coke zero is just as bad as coke and I gave her the benefit of the doubt by mentioning that it was because I have T1D. Her response was to question whether I should really be drinking then. I regret not reporting her for that, because of how entirely inappropriate it was. Firstly, she is working at a bar where she is expected to serve alcohol, if this goes against her values then she shouldn't work there. Secondly, technically no one should be drinking alcohol. Lastly, I had not booked a consult with her to discuss my health concerns, she was not a medical professional nor someone I had asked for advice on whether I should be drinking or not. I've never forgotten this, and as a result I make sure not to mention to people I don't know that I have diabetes. Because this always happens. People say horrible and uninformed things. At a previous job I was injecting insulin and someone joked that I was injecting something that everyone else made naturally, this was entirely unprovoked. When I first told this person I had T1D they commented that I had to look after my eyes and feet so I didn't lose them, which was an upsetting thing to remind someone of. I've had colleagues offer everyone a home baked cookie only to pull the tray away from me saying they forgot I couldn't eat them. More recently, I overheard work colleagues laughing about how they were 'drinking diabetes' by having instant hot chocolate. I was so angry that I couldn't focus on my work. The worst part is I feel so powerless to make a change, there was no one I could report them to for spreading misinformation and for making discriminatory jokes and comments. This goes to show that there is significant work that needs to be done to improve the health literacy of Australians on diabetes. Though the terms of reference focus on the medical treatment, the fact is there is so many aspects of life that impact on our health and impact on our outcomes as PWD that must be considered when developing and implementing new policies. These cannot be developed in silos separated from the reality of daily life and social experiences of those with T1D and other forms of diabetes.

Another important point is the limitations of knowledge and support across the different health professionals. Several acquaintances who have T1D as well as myself aren't interested in seeing an endocrinologist nowadays due to the lack of benefit in attending these appointments. A typical appointment for me would include them explaining how insulin works for the umpteenth time, then finding my worst day in the previous 3 months and asking me questions about it. I have never left an endocrinology appointment feeling more secure in my management, it is typically the opposite.

Personally, I have never found any benefit from seeing an endocrinologist and have actually found it to be a harmful experience in the past. This is due to a combination of factors, mainly the culture of shame and blame, and the fact that the conversation is ruled by numbers on a screen determining how the appointment will go. The language use is also quite cruel though this is not only an issue for endocrinologists. Telling someone who is struggling with stubborn high blood sugars that they are 'poorly controlled' is off putting, and incredibly unhelpful. In my experience, the best people for T1D's to see about their diabetes are credentialled diabetes educators.

There is little space for PWD outside their homes and the clinic. Sharps containers are a good example of this. My work doesn't have any sharps containers and I use MDI, so I have three options. One option is I can bring my own sharps container for my desk, which I won't do because I don't want people to ask probing questions about it or tell me I can't have it there as it is a safety hazard. A second option is I can bring a mini portable sharps container, and this is something I have previously done. A third option is I can just re-use needles a couple times. I know the third option is not ideal and I would really rather not reuse needles but that is what ends up happening.

On a similar note, a common question asked in T1D support groups is whether or not we should disclose it in job applications. If there are protections against medical discrimination for us then they aren't well known and are shadowy at best. I like to think it would be illegal to not hire us due to T1D, but I know there are exceptions so I wouldn't be surprised if there are no repercussions for organisations that do so.

Due to the stigma around diabetes, I have found myself compelled to hide the fact that I have it. Of all things, I struggled the most with public transport. I have had so many hypos on the bus because I would often sit behind the sign that tells you not to eat or drink on the bus. I took it literally and very seriously I avoided eating so to not get in trouble, at the expense of my own health as I would push myself through a hypo and ignore it as best as I could. The fact is that sometimes we get called out for eating in class or at work or on the bus, and have to carefully navigate the situation to avoid a poor outcome. I don't want to have to discuss my health with the bus driver, the same way I don't want everyone in my university tutorial to know why I am not sharing my jelly beans.

I also want to raise that diabetes is also a point of control in the context of family and domestic violence. People who perpetrate such violence may use it to deflect or gaslight their partner who has diabetes. The phrase, "can you check your blood sugars for me? You are acting like you are low..." is a good example of how abusers adopt the language of diabetes and use it as a mechanism of control.

Which would be safer, to be driven home by someone having a hypoglycaemic episode, or someone who is over the legal limit for alcohol? This was a frightening and legitimate question I had to ask myself several months ago, when I attended an event with my partner. I was the designated driver while they (also someone with T1D) could have a few drinks. I did all the right things, I bought hypo snacks along and monitored my blood sugars. But sometimes things go wrong no matter what you do and towards the end of the night my blood sugars started to drop suddenly. I was reassured by the fact that some first aid officers were at the event and knew they would have fast acting glucose for those experiencing hypoglycaemia. My CGM said I was around 6 and trending straight down, and 20 minutes earlier I had been sitting around 11. I had been dancing, and the exercise would drop my blood sugars faster. I hadn't been drinking, but I hadn't eaten recently apart from my hypo snacks. I was quickly disappointed to find that not only would they refuse to provide me any assistance until my blood sugar was under 4, but they would also require me to do a separate finger prick to 'confirm' I was low. I wish I was surprised. Though we have modern technologies there is still a reliance on finger pricks, and a disregard for what PWD have to say about their own bodies and healthcare. We know how it feels to drop low, please trust us with knowing what is best when it



comes to high and low blood sugars. The story didn't end there, and I went to purchase a soft drink from the bar at the event. My stomach dropped when I saw they had closed up for the night as the event was nearing its end. I saw some people were still closing up, and I checked my blood sugars again to find they were lower than before and still dropping. I was scared. I went up and tried to clearly and calmly inform them that I was having a medical emergency (because no one knows what hypoglycaemia means) and that I desperately needed to purchase a soft drink or I could become very unwell. They brushed me off at first as they were likely used to people trying to buy more alcohol. I felt terrified and embarrassed, and I ended up starting to cry and panic with the realisation that if I couldn't get anything sugary from them then my only option was to start asking strangers if they had anything sugary I could buy from them, or begging or bribing the first aid officers, or otherwise waiting while everyone left the event until my blood sugars dropped low enough for the first aiders to be satisfied that I could receive treatment. But then I thought, once the event ends they will leave and then what will I do – I couldn't drive with low blood sugar so my partner would have to, but they had been drinking...so surely I should drive? What would you do? Luckily, my sobbing and promise to pay \$20 for a lemonade attracted the attention of a younger bar tender, who came over and found a lemonade for me. I felt so vulnerable and overcome with fear. I do find it interesting that while we promote prevention when it comes to illness, there is a culture of wait and treat rather than prevent when it comes to things such as hypos.

**Recommendation 17**

Allow PWD to change our allocations on our chronic illness management plans to reduce unnecessary GP appointments and empower us in our own health management.

**Recommendation 18**

Support PWD to access patient advocacy services to ensure they receive supportive and appropriate care.

**Recommendation 19**

Clarify what protections exist to protect and assist PWD experiencing discrimination due to their diabetes.

**Recommendation 20**

Develop strategies to engage people with T1D who have become disillusioned with the medical system, with a focus on patient empowerment.

Thank you for reading this submission and taking my experiences and recommendations into consideration. I'd like to heavily emphasise the fact that no one deserves to have diabetes, and that we should be blaming the disease rather than blaming those who suffer from it. I'd like to remind the reader that I am but one person with T1D and my views will not reflect that of the entire community. I will also acknowledge the privilege I have in that I have a high level of health literacy and an understanding of how the public sector works. There will no doubt be PWD who could provide valuable information to the committee who will not have the opportunity to share their views. I am happy to discuss any information enclosed in this document further if requested.

Thank you.

Kind regards.