

Submission to the Parliamentary Inquiry into Diabetes: Suggestions towards consultative policies for the health, safety and human rights of Australians with type 1 diabetes

This submission responds to three of the inquiry's five terms of reference with regard to the type 1 diabetes community, with the specific terms of reference being listed under each heading.

*Please note, I only give my consent for this submission to be published as a **Name withheld submission**.*

Hospitals

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

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

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

The negative impacts of the health system on people living with diabetes in turn has impacts on our health system and economy. This inquiry should have happened a long time ago, before I'd spent years of my adult life experiencing the way people with type 1 diabetes are treated by the health system. We are not told the role of an endocrinologist or credentialed diabetes educator (CDE) in the public system or why we might seek their services; our access to services is instead determined by our HbA1c, which is unreliable.

Endocrinologists' reliance on HbA1c to assess a patient's glycaemic control can lead to poor health outcomes for the patient. It's up to the patient to demand testing for blood disorders that affect HbA1c and advocate for alternatives to the HbA1c to be used, like the fructosamine test and continuous glucose monitoring (CGM)/ Flash glucose monitoring (Flash GM) data. In my experience, CDEs in the public system tend to expect patients to meet unrealistic targets, giving unrealistic advice presumably to tick boxes or discharge their hospital of legal responsibility for what happens to the patient, which can also lead to poor health outcomes and disengagement with the system. It would be good to see an outcomes-based approach taken up by the public health system in its delivery of specialised services to patients with type 1 diabetes.

Hospital policies for inpatient care often seem rigged against the health and safety of patients with type 1 diabetes in every way. The ridiculous "diabetic menu" in hospitals, which usually offers inappropriate high glycaemic index (GI) foods, high levels of artificial sweeteners, less choice than a normal menu and little if any carbohydrate information (the only thing that would actually make a menu appropriate for patients with type 1 diabetes) is forced on patients, with it being left to the patient to figure out how to get put on a normal menu. The diabetic menu seems to exist because it's the cheapest way hospitals can pretend they care about our health and safety – instead of recruiting and training more CDEs, properly training doctors and nurses to care for patients with type 1 diabetes, and making hospital policies that allow patients with type 1 diabetes to self-manage except in circumstances where there is a *proven risk* of self-harm. This is a system where doctors may

arbitrarily remove patients with type 1 diabetes from their insulin pumps or remove their access to insulin and all the other equipment they need to function and survive, where few doctors or nurses know what CGM or Flash GM or insulin pumps are or how they work, and where nobody knows how people with type 1 diabetes work out how to “titrate” their insulin. People with type 1 diabetes can learn about bolusing (administering insulin for carbohydrates) and many other aspects of managing type 1 diabetes at a two-day seminar such as the **Baker Heart and Diabetes FlexIT** course <https://baker.edu.au/health-hub/education-services/flexit> so why can't healthcare professionals? Also, whether a patient's type 1 diabetes is described as “well controlled” or “poorly controlled” depends more on the expertise of the person making the statement and their understanding of *clinical realities* as opposed to *clinical targets*, than on any evidence actually relating to the patient's type 1 diabetes management. It shouldn't be hard to educate all doctors and nurses on the clinical realities of type 1 diabetes.

The trauma of discrimination, ignorance and the need for relentless self-advocacy we experience in hospital stays with us for life. What does the **Australian Charter of Healthcare Rights** <https://www.safetyandquality.gov.au/publications-and-resources/resource-library/australian-charter-healthcare-rights-second-edition-a4-accessible> offer us, when hospital policies obviously have no concern for our health and safety or human rights. Policies always seem to be made with consideration for lowest costs, manufacturing the appearance of care and absolving the hospital of legal responsibility for when things go wrong. Inadequate inpatient care has a negative impact on physical and mental health, which is counterproductive for the recovery of hospital patients. It leads to people leaving hospital before they should (as I have done previously, because I was scared I would die if I stayed), or else having a longer admission than necessary due to medical mismanagement of their diabetes. The impact of inadequate inpatient care on our physical and mental health and trust for the health system is to the detriment of the health system and economy.

It would be good to see hospital policies that affect patients with type 1 diabetes actually developed in consultation with us, and healthcare professionals given appropriate levels of training to make them aware of type 1 diabetes and how to care for patients with type 1 diabetes. Refer to this **UK report** <https://www.diabetes.org.uk/professionals/resources/improving-inpatient-care-programme/report-hospitals-safe> many of whose insights are relevant to the Australian context as well. To fix the massive problems with inpatient care for people with type 1 diabetes, the federal government would do well to conduct an investigation of its own. You will find no shortage of Australians with type 1 diabetes with lived experienced of this system's failings to share. With proper training and policies in place, I hope we will one day have a health system where patients with type 1 diabetes are not labelled “non-compliant” for having to educate staff and fight for our right to be healthy and safe in hospital.

Type 1 diabetes in the context of normalised healthcare inequality

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The lack of government and public interest in people with type 1 diabetes was no more obvious than in the type 1 community's decade-long campaign for CGM access, where many members of our community spent their life savings on this essential equipment, and some people who couldn't afford it died. The battle was finally won on Easter Sunday, 2022, with announcements from both major parties that subsidised CGM and Flash GM would finally be available to ALL Australians with type 1 diabetes regardless of age, gender, ethnicity or income (the criteria previously used to exclude the majority of people who needed this technology from accessing it). This announcement was made without fanfare, and the media didn't really care. It was for the type 1 community and our allies to celebrate, as our human right to healthcare had never been a matter of "public interest", despite the savings to the health budget that access to CGM will bring, which benefits the economy and all taxpayers.

Even with access to subsidised CGM, there are still a lot of expenses involved in living with type 1 diabetes. Silver or gold level health insurance is required to access an insulin pump, which is the only suitable method of insulin delivery for many people with type 1 diabetes. There is also inequality between people who can afford access to private services and those forced to make do with public services. Like people with other chronic illnesses, people with type 1 diabetes do not get any transport assistance to get to appointments if they don't have a driver's licence and a car, unlike NDIS participants, many of whom receive transport funding despite having both driver's licence and car! People with type 1 diabetes have even had to **crowdfund to pay for car repairs** in order to get to their essential medical appointments, as in this instance <https://www.yourlocalexaminer.com.au/dialysis-patients-long-journey-to-hospital/> I am not suggesting that the NDIS include people with type 1 diabetes unless they have a qualifying disability, I am simply pointing this out as an example of normalised inequality affecting people with type 1 diabetes.

The lack of mental health services for people with type 1 diabetes community is well known within our community, though it's worth mentioning as it may not be well known by government. There is a lack of mental health professionals aware of the massive mental health burden of living 24/7 with a life-threatening, life-long chronic illness that requires daily life-or-death decision making and on average **180 extra decisions per day according to this research by Stanford University** <https://scopeblog.stanford.edu/2014/05/08/new-research-keeps-diabetics-safer-during-sleep/> and subsequent mental health conditions like "diabetes burnout." Important work has been done on the impact of type 1 diabetes on mental health by **Dr Christel Hendrieckx** <https://acbrd.org.au/christel-hendrieckx/> including this **handbook entitled Diabetes and Emotional Health** <https://www.ndss.com.au/wp-content/uploads/resources/diabetes-emotional-health-handbook.pdf> However, the reality of ignorance among mental health professionals coupled with the high price of seeing a mental health professional often means people with type 1 diabetes are unable to seek professional help for type 1 diabetes-specific issues like diabetes burnout and are reliant on their access to the type 1 community for peer support instead.

There is normalised inequality in the treatment of people with type 1 diabetes in public institutions such as prisons and aged care. When asked to take part in protests and sit-ins

for good causes, I have always declined because I know that I can't get arrested or go to jail. Since medical neglect of people with type 1 diabetes is pervasive and normalised in the health system, what more should we expect from the prison system where staff are obviously not healthcare professionals and where medical neglect of prisoners with diabetes is well known. Even if prisons are the responsibility of state governments, the federal government should still take an interest in how people with medical needs are treated in public institutions.

These institutions include aged care facilities. I would expect the federal government to take a great interest in the wellbeing of our type 1 seniors, who according to **NDSS Snapshot data** <https://www.ndss.com.au/about-diabetes/diabetes-facts-and-figures/diabetes-data-snapshots/> are much more numerous than children with type 1 diabetes. We have an ageing population – what are the federal government and aged care providers doing to ensure the health and safety, and human rights, of the most vulnerable members of the type 1 community – the elderly? Do all healthcare professionals and care and support workers understand that older people can actually have type 1 diabetes instead of type 2 diabetes and that this is a different disease? I've seen it suggested within the type 1 diabetes community that free community CDEs should be available to seniors with type 1 diabetes, as breast cancer nurses are freely available to people who need them in the community – sadly, type 1 diabetes is not an illness that has received saturation-level publicity as breast cancer has, and it would take serious government investment to make this a reality.

Low-carb diets

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Low-carb diets are not the be all and end all of living well with type 1 diabetes. There are a multitude of **factors that affect blood glucose**, 42 of which are outlined in this useful chart <http://www.diatrube.org/42FactorsExplained> Government should take a balanced view of low carb diets. While they are appropriate and effective for some, they are not appropriate or effective for everyone. Government should be aware of the potential mental health impacts on individuals from being exposed to unrealistic lifestyles and being shamed for wanting to live a normal life. Common sense would suggest that even current best practice for type 1s (planning everything we do and measuring everything we eat) would have mental health consequences, so how much more would extreme lifestyles? Government would do well to read Dr Bernstein's book themselves with input from experts who are not necessarily low-carb lifestyle advocates. Perhaps if it became standard practice for specialised healthcare professionals to discuss low carb lifestyles with patients early in their journey this would benefit patients and make it less likely they will see them as a "solution" that has been "hidden" from them.

Policies for the workplace, public spaces, and education

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

Discrimination against people with type 1 diabetes has an impact on the economy as it affects our mental health, productivity, and willingness to engage in work and civic duties. I try to avoid situations and workplaces where I have to constantly advocate for myself and my right to exist and be included. I shouldn't have to do this. The rules for all workplaces, public spaces and educational settings, jury service in a courtroom, and any other no-phones environment, should be written to include as many people as possible, including people with a disability or chronic illness. Why should "universal design" not apply to policy, too? It should not be on us to "request" exemptions to discriminatory rules, on us to constantly prove we are allowed to exist somewhere, that we are allowed to have our essential medical devices and access to them via our phones. Although people with chronic illness are supposedly protected by the federal *Disability Discrimination Act (1992)*, in reality this is of little help to us. The usefulness of legislation to protect us "from" things, is always of less value than being included to begin with.

What can government do?

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We live in a society where the word "diabetes" is used as an insult, as a shorthand way to refer to people who are overweight, impoverished, lazy, greedy, and ignorant. The word "diabetes" is not used as a shorthand to refer to elite athletes, newborn babies, busy professionals, active seniors, OR people trapped in a dysfunctional health system, victims of workplace discrimination, or someone who died in their sleep from hypoglycaemia because they had not been given access to CGM. The ignorance in society adds to the existing mental health burden of living with this relentless, life-threatening disease that demands hundreds of decisions from us each day, every day, without a break, for life. Whose responsibility is it to change this ignorance? Diabetes peak bodies and the type 1 diabetes community have a responsibility to engage in advocacy, but government ultimately has the role of making policies that can improve our lives and reduce the impact of diabetes on our health system and economy.

What government can do is *ask us* what we need, more often. Give us more opportunities to provide feedback, and you will receive more feedback and make better policies. I propose that if government actually asks us how we are going and what we need more often (i.e. more than once in a lifetime), more people with diabetes will end up living a better quality of life and thus the economy and society will benefit. A Parliamentary Inquiry is a start, but there are limitations to this form of investigation, especially in terms of who will and won't be at the table. Who *aren't* you going to hear from? Most Australians with diabetes, since they either won't know this inquiry exists or will feel too daunted by the prospect of writing a submission. The federal government should think of innovative ways to consult with the type 1 diabetes community (and Australians with all types of diabetes) in order for us to inform the policies that affect us. This will benefit our health system and economy, and can make Australia the world leader in diabetes policy that it has the potential to be.