

6th July 2023

Dear Minister for Health and Aged Care, the Hon Mark Butler MP, and the The House of Representatives Standing Committee on Health, Aged Care and Sport

Re: Submission relating to the Parliamentary Inquiry into Diabetes in Australia

Thank you for the opportunity to provide a submission into this pivotal inquiry. I would like to address Terms of Reference 5 of this inquiry, namely *“The effectiveness of current Australian Government policies and programs to prevent, diagnose and manage diabetes.”*

I am a 53-year-old male living with the chronic Genetic disorder of **Cystic Fibrosis (CF)**.

Cystic Fibrosis (CF)

For some of you, this life limiting medical condition may be foreign to you, and for others, you may know a great deal about it. Regardless, those of us who suffer from CF are impacted daily from this condition in all aspects of our lives. From spending 2 hours a day nebulising medication, to taking upwards of 17 different medications a day, no two days are the same for me. Each day is a focused fight to stay fit and healthy, and live a fulfilling life.

There are too many struggles, barriers, challenges to overcome daily, and elaborating on them could take more than the allotted 10 pages for this submission to highlight their impact and effects on me – so I won't go there but will rather focus on the Diabetes aspect.

CF is an inherited life-threatening disorder that damages the lungs and digestive system. Cystic fibrosis affects the cells that produce mucus, sweat and digestive juices. It causes these fluids to become thick and sticky, which then plug up tubes, ducts, and passageways in many organs, including the Pancreas. This intern results in significant health issues requiring major, frequent hospitalisations and a diverse array of highly specialised treatments and medications. There is no cure for CF!

Like all CF sufferers, I was just unlucky to get the two mutated copies of the CFTR gene from my parents at conception, which resulted in me being born with CF. I guess I never had a choice in the matter... thanks folks, not 😊!

One of the key organs affected by CF is the **pancreas**, which is a thin, 15 cm long organ that lies behind the stomach and under the liver. It is a vital organ with two crucial roles — helping the body to digest food and making **hormones (including insulin) that control blood sugar levels**.

My whole life I have faced a daily struggle to exist, but most importantly to succeed in everything I can and to be as “normal” as possible. As someone who has always been fanatical about their health, diet, and rigorously exercises 3-5 times a week, I could not stem the steady decline of my problematic pancreas (defective since conception basically), which resulted in me being diagnosed in 2010 with a specific form of Diabetes, which is neither Type 1, nor Type 2.

My Diabetes is well documented and is classed as **Cystic Fibrosis-Related Diabetes (CFRD)**. This diabetes is specifically caused by cystic fibrosis and develops with age, and

the median age at diagnosis is 21 years. In majority of CF sufferers, it is a matter of time until you develop it.

Cystic Fibrosis-Related Diabetes (CFRD).

For someone who has been an extremely compliant CF patient my whole life, only to develop Cystic Fibrosis-Related Diabetes CFRD, it came as a yet another significant health blow to me. Not only learning how to manage, cope, and control a new and complex co-morbidity, but dealing with the fact that yet again, here was another condition impacting me that would further increase the relative risk of an even earlier death - as if CF never caused enough issues on that front!

Within a short period of time, I had to begin injecting Insulin with every meal to control my escalating Blood Glucose Levels (BGLs). Failing to get this under control leads to even more debilitating healthcare consequences, incurs higher costs for the Government and myself, as well as increased hospitalisations and a rapidly declining Quality of Life, to name a few things.

As it relates to this last point, most of this information, data, clinical stats, cost to an individual's productivity, mental health, healthcare expenditure impact etc etc will no doubt be elaborated extensively upon by other submissions. Once again, I will focus on my experience as it relates to the Government's policies and programs to prevent, diagnose, and manage diabetes.

Challenges Of CFRD

One of the real challenges in using insulin is trying to figure out how much medication to inject with a meal, as it really depends on how your pre-meal blood glucose levels are tracking, and the amount or type of carbohydrates you plan on eating with that meal. To do this, you need to use a manual blood glucose testing kit, which involves pricking your finger before and after the meal and testing the blood to obtain a blood glucose level reading.

The drawbacks of this finger prick method from my experience are numerous:

- Painful to do this 6-10 times/day, excluding injecting too!
- Messy as you invariably have blood on your finger which finds its way everywhere
- Discarding the lancets/bloody test strip is often very difficult
- Complex as there is no fewer than 4 separate parts to do the test EVERY time
- Time consuming as well
- Not exactly the most hygienic process
- Worst of all, the impact on your ability to do it discreetly as you need the kit with you wherever you go e.g., Restaurant, work, friends, travelling on a bus/plane etc. So, trying to find somewhere to do it in private is not easy or even possible.
- These things caused me, and others with any form of Diabetes that requires insulin treatment, to become non-complaint with checking your BGL manually. Ultimately resulting in much worse glucose control for me which is the last thing you want due to the costly complications that arise.

Continuous Glucose Monitoring (CGM) Devices & Benefits

Personally, using insulin is a little akin to a game of “Russian Roulette”.

Too little insulin with a meal results in very high blood glucose levels, which over time, high blood glucose levels can damage the body's organs. Possible long-term effects include damage to large (macrovascular) and small (microvascular) blood vessels, which can lead to heart attack, stroke, and problems with the kidneys, eyes, gums, feet, and nerves.

However, from a patient's perspective, worst of all in my experience is when you have too much insulin and you suffer a hypoglycaemic event. This is not only extremely unpleasant and terrifying, because it can lead to you passing out and requiring immediate medical assistance. Trying to do a manual blood glucose test in this situation is near impossible, especially if not at home and or your test kit is not on you. Then again if you have passed out as the onset is rapid, it's a moot point.

In the initial years of injecting Insulin, I estimate that I had conducted several hundred finger prick tests, to the point I had callouses on all my main fingers.

After a few years, I was told about the novel CGM device from Abbott, the Freestyle Libre sensor system... a true Game Changer!

Unfortunately, at the time, this CGM device was not funded via the NDSS, but the **benefits** for me were clear from the outset.

- NO finger pricks! A small but significant thing...
- Instant glucose readings via a scan of your mobile device, discreetly. No more rushing off to the carpark, toilet, or other unpleasant places to test via a finger prick test
- Simple, accurate, non-invasive, real-time data that tells you if you are within your target BGL range
- A data reading that indicates if your BGLs are trending up or down, approaching the danger zones
- As well as a cumulative 8-hour view of your full BGLs and more data analytics to support a patients care, progress in managing the condition
- Advance indication of a hypoglycaemic event about to eventuate based on the data. Meaning I can proactively mitigate dangerously low blood glucose levels. Or manage excessively high BGLs.
- Overall, improved glucose and diabetes management, better quality of life and overall improved long term health outcomes.
- Keep in mind that higher BGLs for me with CF also has a more detrimental impact on my lungs and associated chest infections, hospitalisations, mental health and QoL

So, given the incredible benefits the Freestyle Libre CGM provided, I took on the extra burden of costs associated with purchasing these sensors. Which as you can appreciate has caused further economic difficulties by adding >\$200/month to my already hefty medical bills and out of pocket expenses. As you can appreciate, spending another \$2,500/pa on this alone is a significant barrier and financial burden, given the excessive costs of all my other related medications, physician care, OTC medications, supplements, and injecting consumables, to name a few.

When I heard that the NDSS/Government agreed to fund the use of CGM devices for Diabetic patients in July 2022 I was incredibly excited. This would alleviate the cost pressures I face daily for my CF and diabetes management, often foregoing other items as I

do my best to prioritise my health and stay working fulltime, contributing to the economy. A CGM also ensures increased compliance for me, while having some peace of mind in not worrying about the cost and making tough trade-offs.

Not Eligible For CGM Funded Devices

Unfortunately, I soon realised via my Endocrinologist that I was not eligible for the NDSS funded CGM devices because I have CF-related-diabetes (CFRD), not Type 1 classified diabetes.

You can understand that this news was devastating and since then, I have had to personally fund these devices every month, in addition to all the other health costs I face with CF and my CFRD. Honestly, I find the Government policy pretty discriminating to be excluded through no fault of my own. Mine is not a lifestyle induced disease, but one that I would end up with ultimately, because of my CF. Living with CF is a daily grind and literally a fight to live. Having CFRD as well, I don't wish it on anyone (even those across the Political isle)!

Furthermore, one would argue that my CFRD is more complex to manage than Type 1 Diabetes. The cost of my healthcare complications arising from uncontrolled CF-related-diabetes (CFRD) would be far greater than those of a Type 1 patient, and ultimately cause a higher impact on State and Government healthcare budgets if left unmanaged properly – when taken on a per individual basis. Because all my CF issues are exacerbated by poor glucose control. Not least my quality of life, ability to be a healthy husband, a fully functioning member of society, and be productive tax paying citizen through my fulltime employment.

Finally.....

The better I and other CF patients with CFRD are controlled, the better the overall health outcomes and containment of healthcare cost for all stakeholders.

The most impactful and beneficial mechanism for doing this, is via changing the Government policy and expanded access to publicly funded CGM devices like the Freestyle Libre system, and other CGM devices for patients like me, with CF-related-diabetes. This will afford us the same benefits as Type 1 patients, but with peace of mind knowing we don't have to spend the exorbitant amount of >\$2,500/pa on this expensive device. Additionally, we could rather use that money to help our families meet the excessive rising costs of living and investing it in better health opportunities like gym membership, exercise, and diet management plans.

All of which will see us live more healthy and productive lives, being employed longer term and paying our share of taxes without being a drain on the healthcare expenditure.

I thank the Committee for considering my submission in good faith and truly hope that you will support a policy change for expanded access to CGM devices for CFRD patients and other non-Type 1 sufferers.

I ask the Committee to consider my submission as a ***Name withheld submission***, and am fine with you making my submission public via redacting my name.

Your faithfully

CF & CF-Related Diabetes Patient