

Inquiry into Diabetes

Submission by

**/Name withheld/
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Dear Committee Members,

I am writing to address several significant issues related to my daughter's Type 1 Diabetes management under the care of a public endocrinologist. These issues not only impact patient care and outcomes but also impose substantial financial burdens on families like ours as we had to switch to a private team. Additionally, I want to emphasise the importance of advocating for the adoption of low-carbohydrate dietary strategies, which had proven extremely effective for our daughter, and the need to introduce modern technologies that are currently not available in Australia.

1. Outdated Diabetes Management Strategies

During our visits to the public endocrinologist, we received diabetes management strategies that relied on outdated practices from the pre-continuous glucose monitoring (CGM) era. While medical science has made significant advancements in diabetes care, these outdated strategies neglected the benefits of modern technologies, such as CGM devices, insulin pumps, and data-driven personalised treatment plans. As a result, my daughter's diabetes management was not optimised to achieve the best possible outcomes.

When my daughter was diagnosed with Type 1 diabetes and admitted to the hospital, we were not provided with a continuous glucose monitoring (CGM) device. It was only one month later that we were able to obtain a CGM, despite its recognised benefits in managing blood glucose levels effectively. During her hospital stay, medical professionals attempted to stabilise her blood glucose levels using finger pricks every two hours, both day and night. This approach proved to be ineffective and extremely taxing for my daughter, who endured significant pain and disrupted sleep during this process. I believe that all newly diagnosed individuals should have access to Dexcom G6 or similar continuous glucose monitoring from day one, as it can greatly improve their diabetes management, making life easier and safer.

Additionally, the healthcare team relied on carb counting as the sole method for determining insulin doses. However, carb counting alone is an outdated and incorrect approach, as protein and fat intake can also significantly impact blood sugar levels. The disregard for these essential factors led to erratic blood sugar fluctuations, with my daughter experiencing dangerously high readings of up to 30 mmol/L and dangerously low readings as low as 1.2 mmol/L.

Furthermore, our public endocrinologist insisted on specific meal timings and limited insulin injections to three times a day. This was extremely difficult to achieve by my daughter who never had to follow rigid meal schedules. He also did not allow giving any insulin corrections between meals and that resulted in extremely high blood glucose levels especially at school.

Moreover, when my daughter and I expressed interest in using an insulin pump to manage her condition more effectively our endocrinologist insisted that we should continue with injections and "learn the basics" for at least a year before considering a pump. My daughter was a brave little warrior but experienced soreness from frequent injections due to her slender build as she lost a lot of her weight at diagnosis but our doctor's response was to suggest holding her down and administering the injections instead. I strongly believe that an insulin pump is more than just a tool; it is a vital means to achieve better blood glucose control and an enhanced quality of life. The pump allows for precise insulin delivery of small doses of insulin, reducing the frequency of painful injections and offering more flexibility in managing diabetes.

Reflecting on our experience, I am astounded by how poorly equipped our hospital was in assisting newly diagnosed kids with type 1 diabetes in terms of information and equipment. It is disheartening to realise that the care provided fell short of what is actually possible during such a crucial time. As a parent, I believe that newly diagnosed families

should receive comprehensive education and have access to the necessary equipment to effectively manage their child's T1D from the beginning.

The only silver lining during our hospital stay was the presence of a wonderful playroom, staffed by two caring play therapists. Their presence and support made this otherwise stressful time much more manageable and comforting for my daughter. Engaging in playful activities and receiving the attention of these compassionate therapists provided a much-needed respite during our stay, brightening our overall experience amidst the challenges of managing diabetes in the hospital environment.

When we were discharged from the hospital we were only equipped with a matrix provided by our public endocrinologist. Intended to calculate insulin dosing based on carb amounts, the matrix failed to work effectively, leaving us feeling scared to leave home. As a result, my daughter missed so much of her school days, causing us great concern and uncertainty. Her HbA1c was 9.7%.

Our doctor restricted the number of insulin injections in our school plan, leaving us with no choice but to manage corrections on our own. Unfortunately, the infrequency of buses forced me to stand in front of the school for all 6 hours, burdened with the responsibility of caring for my one-year-old toddler alongside. Despite the urgency for a pump to improve our situation, our doctor informed us of significant wait times, citing that others needed it more urgently.

Switching to the self-education path was a turning point for us. As we took charge of learning and understanding diabetes management ourselves, things started to improve. It empowered us to make informed decisions, find effective tools, and gain greater control over the condition. Upon reflection, we found that everything we were initially taught at the hospital during the time of diagnosis turned out to be false and, at times, even harmful.

2. Access to Modern Tools and strategies

I feel disappointed and somewhat frustrated that my public endocrinologist didn't mention certain tools that could have made our diabetes management more effective and less painful. Interestingly, I happened to learn about these tools through Facebook groups, which surprised me as I expected to receive comprehensive information from my medical appointments.

Firstly, I came across reusable half unit pens that allow for more precise insulin dosing, making BGL corrections easier and more frequent. Curious about its benefits, I asked my public endocrinologist about it during our appointment. To my surprise, they dismissed the idea, stating it wasn't necessary for our treatment plan. It was our GP who helped us obtain Novopen Echo insulin cartridges for short acting insulin and Sanofi Junior Star cartridges for long acting insulin. The pens themselves were provided to us for free by the manufacturers.

Secondly, I stumbled upon another useful tool called TickleFlex. This simple yet innovative device is designed to improve the insulin injection process by making it less painful and more comfortable. Unfortunately, TickleFlex was never brought up in my discussions with my endocrinologist.

Additionally, my journey led me to discover another remarkable tool called Genteel. This innovative device is designed to obtain blood samples for glucose testing with minimal discomfort by using a vacuum and depth control technology. Genteel is a versatile tool that can obtain blood samples for glucose testing from various parts of the body, not just fingers. This feature makes it especially beneficial for individuals who may prefer to test from alternative sites due to finger sensitivity or other reasons. Once again, it was disheartening to find that my endocrinologist never brought up Genteel during our appointments.

Furthermore, my research led me to discover another valuable tool called iPort Advance. This innovative device simplifies insulin delivery by providing a discreet and convenient way to administer multiple injections without repeatedly puncturing the skin. Regrettably, my endocrinologist never mentioned iPort Advance during our consultations, leaving me unaware of this potential option.

I also got to know about xDrip, a cutting-edge diabetes app that revolutionises glucose monitoring. Compatible with continuous glucose monitoring (CGM) systems, xDrip offers real-time data insights, customisable alerts, and even

audibly announces blood glucose levels with each reading. Despite its incredible capabilities, our public endocrinologist never informed us about this app.

Next, I came across AndroidAPS, a groundbreaking open-source app that combines a continuous glucose monitor with an insulin pump (Dexcom G6 and Omnipod Dash in our case). AndroidAPS empowers individuals with diabetes to personalise and automate insulin delivery, resulting in better glucose control and a more flexible lifestyle. Yet again, my endocrinologist did not mention AndroidAPS during our consultations. I was left to discover this transformative tool through my own research and interactions within the diabetes community.

Lastly, I discovered the existence of Fiasp insulin, which acts much faster than Novorapid that was prescribed to us. Fiasp insulin is designed to speed up the insulin absorption process, leading to more rapid reductions in blood glucose levels after meals. Despite this significant advancement, my endocrinologist did not mention Fiasp insulin during our appointments. I express deep disappointment and devastation regarding the recent removal of Fiasp insulin from the Pharmaceutical Benefits Scheme (PBS). This development has had a significant impact on many individuals, my daughter included, who relies on Fiasp for its faster action and improved glucose control.

The value of Fiasp insulin becomes even more pronounced for us, as we rely on AndroidAPS in a full closed loop mode for diabetes management. Fiasp's rapid action aligns perfectly with the real-time data and automation provided by AndroidAPS, enabling tighter glucose control and reducing the risk of complications. The recent removal of Fiasp from the Pharmaceutical Benefits Scheme (PBS) has left us in a state of uncertainty and concern. As users of the AndroidAPS closed loop system, access to Fiasp is integral to maintaining stability in glucose levels and promoting overall well-being.

In addition to the valuable tools and technologies I previously mentioned, I also discovered the "Sugar Surfing" book. This book, written by Dr. Stephen Ponder, is a comprehensive guide to dynamic diabetes management, focusing on a proactive and real-time approach to blood glucose control. Despite its potential benefits, my endocrinologist never mentioned the "Sugar Surfing" book during our appointments. Once again, I had to rely on my own research and connections within the diabetes community to learn about this valuable resource.

The "Sugar Surfing" book has been instrumental in helping individuals like myself gain a deeper understanding of managing diabetes in a flexible and intuitive manner. Its insights on interpreting glucose data from a CGM and making timely adjustments have empowered many to take charge of their diabetes management proactively. I learned how to perform proper basal testing with carbs only dinner and how to keep my daughter in range using microdosing and microcarb-ing. I strongly believe that patients should be informed about effective diabetes management strategies like Sugar Surfing. A proactive approach that integrates knowledge from this book can lead to better glucose control and ultimately improve our overall quality of life.

Our public Diabetes Educator suggested that we do not need to administer insulin for so-called "free foods." However, through my own research and understanding, I have learned that there is no such thing as "free foods" in diabetes management. Every food item, regardless of its carbohydrate content, can impact blood glucose levels and may require careful insulin dosing.

Through my journey of self-education, I also discovered that the Insulin Sensitivity Factor (ISF) tends to be stronger for low Glycemic Index (GI) foods ranging from 5 to 20 in our case as opposed to a set number given to us by our public endocrinologist.

3. Inappropriate Dietary Recommendations

In addition to the outdated management strategies, the public endocrinologist insisted on putting my daughter on a high-carbohydrate diet, claiming that carbohydrates were crucial for her development as a child. However, I later discovered that the body can produce carbohydrates through the process of gluconeogenesis from proteins. The inappropriate dietary recommendations not only affected my daughter's blood sugar levels but also put her at risk of experiencing complications associated with poorly managed diabetes.

Furthermore, in my pursuit of valuable resources for diabetes management, I came across the "Dr. Bernstein's Diabetes Solutions" book. Written by Dr. Richard K. Bernstein, a renowned endocrinologist with diabetes himself,

this book offers a comprehensive guide to achieving better blood sugar control through a low-carbohydrate approach.

To my surprise, my endocrinologist did not mention "Dr. Bernstein's Diabetes Solutions" during our appointments. Once again, I had to rely on my own research and the insights shared within the diabetes community to discover this potentially life-changing resource.

Dr. Bernstein's book provides a wealth of knowledge and practical strategies for managing diabetes through carbohydrate restriction, which can lead to more stable blood sugar levels and improved overall health. This approach has proven beneficial for many individuals, especially those seeking better glucose control and reduced dependence on insulin.

Through Dr. Bernstein's teachings, I learned that normal blood glucose levels for kids should be around 3.9 mmol/L. Additionally, I discovered that steady blood glucose readings up to 3 mmol/L do not necessarily require immediate treatment as a low.

Patient education is a critical aspect of diabetes care, and it is essential for healthcare providers to inform us about effective approaches like the one presented in "Dr. Bernstein's Diabetes Solutions." Armed with this knowledge, individuals can make informed decisions about their dietary choices and tailor their management plan to suit their unique needs.

It is essential to advocate for the incorporation of low-carbohydrate dietary approaches into diabetes management guidelines, as it has proven benefits for individuals with Type 1 diabetes in achieving better blood sugar control and overall health.

4. Financial Impact

Due to the lack of satisfactory care from the public endocrinologist and urgent need for a pump, we had no choice but to switch to a private healthcare team. The financial burden of private healthcare, including consultation fees, diagnostic tests, and medications, has been substantial for our family. While we prioritise our daughter's well-being and will continue to make sacrifices for her care, it is disheartening to face such financial strain while seeking appropriate and updated medical support.

5. Our results

In terms of diabetes management, our proactive self-education efforts, along with the support of our private healthcare team, have resulted in remarkable achievements.

My daughter's HbA1c level is an impressive 4.9%, comparable to that of a non-diabetic individual. She has no risk of developing any diabetes health complications later in life.

She experiences very few low glucose episodes and her blood sugar levels rarely exceed 7 mmol/L. This success is largely attributed to her commitment to a very low carb diet, allowing her the flexibility to eat whenever and whatever she desires.

With the aid of advanced technologies, such as her tubeless pump Omnipod Dash operating in auto mode, she experiences minimal manual input, making diabetes management seamless for her and her teachers. There is no need for carb counting or manual bolusing, the AndriodAPS app gives insulin automatically based on predictions. Her blood glucose levels fluctuate slowly, contributing to stable glucose control. Our sleep is not interrupted by lows or the need for manual corrections. Through trial and error, we have discovered a perfect spot for placing the Dexcom sensor, which has helped us avoid compression lows.

As a parent, I have the privilege of monitoring her blood glucose levels and insulin on board through my phone remotely, while she can also access this information conveniently from her watch. This real-time data empowers both of us to stay informed and make decisions about her diabetes management.

These achievements fill us with immense pride and instill confidence in our ability to effectively manage her diabetes. By continuing to stay proactive and embracing advanced technologies, we strive to maintain this level of success in her diabetes journey, ensuring she can live a healthy and fulfilling life.

Not everyone can afford a private team so many Australian parents and children living with diabetes diligently follow their public endocrinologist's advice for diabetes management for years, and unfortunately their kids' blood glucose levels are like a roller coaster ride, fluctuating dramatically. They experience depression due to a prevailing sense of helplessness caused by the perceived unpredictability of the condition. Insufficient knowledge and support from the public healthcare system lead to high HbA1c levels of 6-7% or even higher and avoidable health complications. Public doctors can be pushy and aggressive in advocating for outdated strategies. Empowering families with education and access to advanced technologies can provide greater control, improve their mental health and quality of life and help prevent unnecessary health issues.

6. Innovative Diabetes Technologies Unavailable in Australia

Looking towards the future of diabetes management, there is a world of innovative technologies and advancements that remain beyond our reach in Australia.

Insulin Lyumjev, an innovative rapid-acting insulin analog, stands as one of the unavailable advancements in diabetes care within Australia. Developed to provide even faster insulin action compared to existing rapid-acting insulins, Insulin Lyumjev could hold immense potential in post-meal glucose control and flexibility in insulin dosing. However, as of now, it remains beyond our reach, leaving patients unable to benefit from its promising features.

Dexcom G7, the much-awaited next-generation continuous glucose monitoring (CGM) system, promises to be a game-changer in diabetes management. With a mere 30-minute warmup time and a smaller, more discreet design, Dexcom G7 revolutionises how individuals with diabetes track their glucose levels. Size matter greatly for us as my daughter gets chemical burns from the adhesive. By embracing Dexcom G7, Australia can enhance diabetes care, providing patients with greater convenience, comfort, and improved overall health outcomes.

Libre 3, the latest FreeStyle Libre CGM, redefines diabetes care. Unlike Libre 2, it offers seamless glucose data without manual scanning. With a 60-minute warm-up time, it provides real-time readings, empowering users to make informed decisions effortlessly. Its compact design ensures comfort, revolutionizing diabetes management and enhancing overall well-being. Embracing Libre 3 in Australia can bring unprecedented advancements to diabetes care, fostering optimal glucose control and healthier lives.

Eversense is a groundbreaking long-term continuous glucose monitoring (CGM) system, worn for up to 90 days, offering continuous glucose data and avoiding frequent sensor replacements. It features a smart transmitter communicating real-time readings to a mobile app, empowering users with comprehensive glucose insights and minimizing compression lows. Embracing Eversense in Australia can transform diabetes management, fostering better control and improved quality of life.

Omnipod 5, a cutting-edge diabetes management system, revolutionizes insulin delivery with its tubeless and wearable design. Featuring a built-in closed-loop function with a Continuous Glucose Monitor, Omnipod 5 automates insulin dosing based on real-time glucose data, eliminating the need for setting up a DIY closed loop app that is currently not supported by most medical professionals in public system. By embracing Omnipod 5 in Australia, the healthcare system can elevate diabetes care, supporting patients in achieving optimal glucose control

and improved well-being. The integrated closed-loop system with a CGM sets a new standard in diabetes management, offering users a transformative tubeless solution for a healthier and more fulfilling life.

7. Actions to take

I urgently request that the government committee takes decisive action by implementing the following measures:

A. **Mandatory Continuing Education:**

Implement comprehensive and ongoing training programs for public healthcare professionals, specifically focused on the latest advancements in diabetes management. These programs should emphasise the importance of incorporating modern technologies, such as CGMs and insulin pumps, and evidence-based treatment protocols into clinical practice.

B. **Improved Access to Modern Tools**

Advocate for improved access to modern diabetes management tools to enable patients to choose the most suitable treatment options based on their preferences and needs.

C. **Updated Clinical Guidelines**

Collaborate with leading diabetes experts and professional organisations to develop and disseminate updated clinical guidelines that align with current best practices in diabetes care. These guidelines should promote the integration of advanced technologies and personalised treatment plans for better patient outcomes.

D. **Regular Performance Evaluation**

Implement mechanisms for evaluating the performance of healthcare professionals to ensure adherence to updated guidelines and the use of modern diabetes management strategies. Regular evaluations can help identify areas where improvement is needed and ensure a higher standard of care.

E. **Affordable Access to Quality Care**

Explore avenues to provide affordable access to quality diabetes care, including support for families facing financial constraints due to necessary private healthcare expenses.

F. **Advocacy for Low-Carb Approaches**

Encourage research and promote the benefits of low-carbohydrate dietary strategies for individuals with Type 1 diabetes, recognising its potential in achieving normal blood sugars and overall health.

G. **Put Fiasp back on PBS**

Reinstate Fiasp on the PBS. Not only is Fiasp unaffordable without PBS coverage, but there is also a real risk of it disappearing entirely from pharmacies. It is crucial to maintain access to insulin medications that are instrumental in supporting modern diabetes management techniques like closed loop systems.

H. **Approve unavailable innovative diabetes technologies**

Urgently approve innovative diabetes technologies, such as Insulin Lyumjev, Omnipod 5, Dexcom G7, Libre 3 and Eversense for use in Australia.

By addressing these issues, we can not only improve diabetes care but also alleviate the financial burden on families seeking appropriate medical support. Moreover, advocating for the incorporation of low-carbohydrate approaches into diabetes management guidelines will provide patients with more effective options to manage their condition.

Thank you for your attention to this matter. I trust that, with your leadership and commitment, we can bring about positive change in diabetes care and support the well-being of those affected by this condition.

Sincerely,

/Name withheld/

References:

1. Sugar Surfing: How to Manage Type 1 Diabetes in a Modern World by Stephen W. Ponder, M.D., FAAP, CDE - Published in 2015.
2. Dr Bernstein's Diabetes Solution: A Complete Guide To Achieving Normal Blood Sugars, 4th Edition - Published in 2011.