

Submission to Health Select Committee on Petition of Marsha Mackie for Diabetes New Zealand: Diabetes Petition

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1. Introduction

1. Diabetes New Zealand is the leading national organisation supporting people with all types of diabetes. Our role is to lead initiatives and advocate for people with diabetes to improve their health and well-being. We do this by increasing access to, and effectiveness of, information and resources to provide support, promote better understanding and enhance self-management to reduce long-term health complications. Support and education are provided for people with diabetes via an 0800-phone line, website, social media, quarterly magazine, monthly Connect e-newsletter and all activities during Diabetes Action Month in November.
2. Diabetes NZ is a Charitable Trust and as such is not a 'member' organisation. The organisation is led by the Trustees, Advisory Council and CEO; national administration and financial functions of the organisation are provided by National Office in Wellington. At local and regional level, Diabetes NZ has branches and regional representatives offering local advocacy, support and education.
3. The petition taken to Parliament in November was as a result of dissatisfaction and feedback from people with diabetes over the last year on social media channels and via email. This petition asked: "That the House of Representatives urge Pharmac to fund Continuous Glucose Monitors (CGM), GLP1 agonists including Bydureon, Byetta, Lyxumia, and Victoza, SGLT2 inhibitors including Forxiga and Jardiance, and DPP-4 inhibitors including Januvia, Onglyza, and Trajenta".
4. There are approximately 260,000 people with diabetes in New Zealand. Of these 10% have type 1 diabetes including approximately 2,000 children and young people. Due to people with type 1 diabetes being diagnosed young, it means that the long-term complications of diabetes occur when they are much younger. This in turn can lead to earlier mortality for those who do not have good control of their blood glucose levels. They need to prick their fingers multiple times a day to test their blood glucose level and adjust their doses of insulin and this is often difficult to achieve. Fingers get sore and this is a barrier to good management of diabetes. Long-term complications can be preventable by good control of diabetes including regular monitoring of blood glucose and appropriate doses of insulin. Continuous Blood Glucose Monitors and Flash Glucose Monitors measure blood glucose without the need for pricking a finger.
5. The Ministry of Health invited Allen and Clark in 2018 to report on understanding diabetes in youth. This report outlined: "a consistent theme of our interviews was the strong benefits that better access to better technology would provide. Interviewed participants thought that current funding arrangements discouraged and limited the ability of young people to effectively manage their diabetes".
6. "Continuous glucose monitors and insulin pumps make diabetes management easier, and many young people and their families will remain unhappy as long as these devices are unfunded/tightly controlled" (Cam Vannisselroy, Josh Williams, Jacqui Haggland, 2018).

7. For the 90% of people who are diagnosed with type 2 diabetes there are a range of oral medications that provide control of blood glucose. Long-term complications from poorly controlled diabetes has a high health cost due to additional medications, regular screening, hospitalisation for various medical and surgical needs, outpatient appointments, and much more. If other classes of medication were available for people with type 2 diabetes the risk and cost of these long-term complications would be reduced.

2. Background to petition

1. Pharmac restrict their funding of Diabetes related devices and medications. In our petition we highlighted the need for Continuous Glucose Monitors that are essential for people with Type 1 diabetes and drew attention to the valuable new classes of medication available overseas for people with type 2 diabetes.
2. A device known as the 'Freestyle Libre' which is a flash glucose monitor, often referred to as intermittently viewed CGM, has a sensor that is placed into the skin on the back of the arm and a reader that is swiped over it to give a blood glucose reading. One sensor will stay in place up to 14 days. This means no finger pricking and a parent can swipe the reader over their child's arm during the night without waking them. If the parent finds the child is having a hypo by swiping their arm during the night, they can wake them to treat them. If the child does not suffer with hypoglycaemia (low blood glucose levels [hypos]) overnight, they will have a solid night's sleep and wake up in the morning being functional for a productive day at school. The child themselves can swipe the reader during the day while they are school. The reader will then send data to the 'cloud' and a parent can download this via a smart phone app so that they can phone the school and advise the teacher aide if the child is about to have a hypo so that it can be prevented through an agreed care plan. This minimises the disruption to the child's schooling through suffering the side effects of a hypo: headache or confusion; pins and needles on lips or tongue; thumping heart; hungry; weak knees, shaky hands; pale and sweaty; and/or blurred vision.

The reader for a Freestyle Libre is \$105 inc GST for a one-off cost, but a sensor lasting up to 14 days also costs \$105 inc GST. This ongoing cost is impossible for most young families. Some families have two children with type 1 diabetes which means over \$200 per week ongoing cost to help the family have a near normal life. This is not a luxury to them, it is essential. In many instances, adults with type 1 diabetes have funded this device and found their previous poor control of diabetes and multiple admissions to hospital with high and/or low blood glucose levels has been turned around with the use of a Freestyle Libre.

3. There are also Continuous Glucose Monitors that continuously update a device from a sensor without the need for scanning. One of these devices is known as a Dexcom. The difference between Freestyle Libre and Dexcom is that the Dexcom has real time alarms that will alarm on the users or parents' phone. For example, if a person was sleeping and went low with a Libre no alarm would go off and that person would sleep through the hypo and potentially die. With a Dexcom the alarm goes off and wakes them up. The technology in this device is more superior especially in low blood glucose settings and will alert people to potentially serious life-threatening events automatically, without the person having to be awake already and scanning as with the Freestyle Libre. This enables the person wearing a Dexcom to prevent these events by treating a hypo early or by giving themselves an additional dose of insulin if their blood glucose is rising. The Dexcom automatically tests the blood glucose continuously. The sensor is linked by Bluetooth to either a device or an app on a smart phone. Through secure wireless connections, the Dexcom CGM System allows remote viewing of glucose levels, trends and data between the person with diabetes and their spouse, grandparent or other loved ones from their compatible smart device. The Dexcom also links directly to Tandem pumps that are funded in NZ and will in future have Basal IQ which will cut off the

insulin in the pump when it knows you will go low. Also Control IQ which has just been released in the US will automatically adjust insulin based on the Dexcom readings. This will be life changing.

4. **Mother's perspective (names changed)**

- a. *Mother: "I can't ever put into words how traumatic it is for a child, or anyone, to realise that for the rest of their lives they will need to prick their fingers every few hours and have multiple injections every day. Someone once said to Jack "you're so brave I'm afraid of injections" and Jack said, "I am afraid of them too".*
- b. *Another mother: "The Libre has made a significant difference to Mia's (and our) quality of life. Removing the need for routine use of needles greatly reduces the number of medical interventions we have to make every day. The ability to easily scan to get a reading of glucose levels makes it easier for Mia in all aspects of her daily life. It's much less obtrusive than finger pricking. As parents it's easy for us to check on her levels when she's sleeping. A quick scan is all it takes".*
- c. *"Having a CGM for our seven-year old son has changed his life and ours. He is having far less painful prick tests, he's less upset and we have been able to manage his levels far easier with the increased information. It literally saved his life one night when it identified a massive drop which we could treat before he fell into a deeper sleep. He's able to focus more on his education without the huge interruption of having to do finger prick tests all the time. We're all finally getting more sleep - I can't put into words how wonderful it is to have access to this life saving and life changing device."*

5. **A seven-year old's words**

- a. *"I love my libre. It gives me freedom. It makes me feel like I'm like everyone else. It makes me be able to be like all the other kids and sometimes I can even pretend I don't have diabetes. I wish everyone could have this if they have diabetes".*

6. **A young adult with type 1 on Freestyle Libre**

- a. *"I've had type 1 diabetes for almost a decade now and there have been many highs and lows, but nothing has ever changed my life with diabetes quite as much as the Freestyle Libre".*
- b. *"This ease of checking my glucose has completely transformed my way of living with diabetes. Whether I'm on the run, in the middle of a meeting, travelling, exercising or partying – with one swift move I can check my glucose. Fast, easy and pain-free. To me, that's incredible!"*
- c. *"Before, I dreaded checking my glucose and never did it often enough. Today, I check my levels between 10 and 20 times per day. To me, this is unbelievable".*
- d. *"Whenever I am without a sensor for a few days, I feel like I'm back in the stone ages. A single glucose reading? What am I supposed to do with that? Without the glucose graph and the trend arrows I feel lost".*

7. **A young adult with type 1 on a Dexcom**

- a. *"Having a Dexcom has allowed me to have a baby safely while looking after a young child. Now as a single mum I can go to sleep at night knowing that if I go low overnight my Dexcom will alarm and wake me and I won't die in my sleep. My greatest fear is that my kids will find me one morning dead having had a dangerous low overnight. With Dexcom I know this won't happen. Unfortunately, the cost of Dexcom has now become*

unaffordable for me which leaves me in a difficult position. It's why I'm so passionate about funding. Buying sensors from Australia will cost me \$300 for a box of 4 delivered compared to \$540 for the same box in New Zealand from the same company. NZMS can definitely provide Dexcom cheaper in NZ."

8. In the above cases, people have chosen to seek funding for a device themselves. For most people, this cost is prohibitive. In Southland, 103 people with type 1 diabetes were admitted to hospital with ketoacidosis in the year 2016/17 (Coppell et al, 2019) at a cost of NZ\$349,892. Ketoacidosis occurs either at diagnosis of people with type 1 diabetes or with very poor blood glucose control. Poor control can be changed through regular blood glucose testing and a plan of action with insulin dose changes. Coppell et al (2019) identified that 7% of admissions had a primary diagnosis of diabetes of which 31% had type 1. Complications from poor control of type 1 diabetes were also costed by Southland hospitals and the total including ketoacidosis was NZ\$609,335 for the year (Coppell et al, 2019). If blood glucose testing becomes more appealing using devices such as FGMs and CGMs it is likely there will be significantly less hospitalisation and overall less cost to the health budget. We ask government to urge Pharmac to provide funding for **both** FGM and CGM devices.
9. Until 2018, when Vildagliptin was funded by Pharmac for people with type 2 diabetes there had been no new medications for type 2 diabetes for 14 years. It is excellent that Pharmac are now funding Vildagliptin, a new class of medication for diabetes, however, there are other classes of medication that have additional proven health benefits than Vildagliptin. We feel that people with diabetes should be funded for a variety of the new classes of medication that offers them best health outcomes according to international evidence and guidelines. We are aware that Pharmac has recently issued a Request for Proposals (RFP) for the supply of anti-diabetic agents, including SGLT-2 inhibitors and GLP-1 agonists (as well as DPP-4 inhibitors). In the RFP, Pharmac are looking to fund at least one SGLT-2 inhibitor and/or GLP-1 agonist. If they reach an agreement with a supplier, they will publicly consult on the proposal to fund one or more of these medicines.
10. Vildagliptin, and other DPP4 inhibitors, are weight neutral, but have not yet been shown to improve cardiovascular outcomes. The classes of medications such as GLP1 agonists and the SGLT2 inhibitors have a known positive effect on weight loss (Shah & Vella, 2014; Cai et al, 2018) which improves blood glucose levels, control of diabetes and reduces long-term complications, but most significantly, recent research has provided evidence of additional benefits for cardiovascular health (Zinman et al, 2015; Jia et al, 2018). Cardiovascular disease has significant health cost implications and this class of medication has been proven to reduce this.
 - a. "A significant part of the additional cost for patients with diabetes is due to longer stays, as we demonstrated in this study for admissions where coronary artery disease was the primary diagnosis (Coppell et al, 2019)".
11. All these new classes of medication offer a low risk of hypoglycaemia (low blood glucose levels) to people not on insulin or older diabetes medications. This signifies that all the new classes of medication are valuable for the treatment of people who have poorly controlled blood glucose levels on the older oral hypoglycaemic agents. Hypoglycaemia has a detrimental effect on concentration and causes confusion in many; this can significantly impact work, school, sports, driving and all other activities.
12. We ask government to urge Pharmac to remember the other classes of medication, GLP1 agonists and the SGLT2 inhibitors, that evidence reveals has exceptional health advantages over Vildagliptin. **Both** these classes of medication should be funded as well as Vildagliptin for people with type 2 diabetes.

3. Recommendations

The Health Committee should write an expectation to Pharmac for the following recommendations:

1. Pharmac should provide funding for **both** CGM and FGM for all people with type 1 diabetes without exception to enable them to lead as normal life as possible with significant reduction of the risk of long-term complications from diabetes and the personal as well as health cost of regular hospitalisation.
2. Pharmac should provide funding for **all** other classes of medication for people with type 2 diabetes to aid reduction in the risk of cardiovascular disease which increases mortality in people with diabetes as well as increase weight loss. Pharmac has suggested they might fund one or other of these classes of medication. Please urge Pharmac to fund both SGLT2 inhibitors and GLP1 agonists.

4. References

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