

Submission for continued (and increased) Insulin Pump Subsidy.

Date: 13/02/2013.

Without the subsidy I could not afford to access an insulin pump. Even with the subsidy it was still a considerable cost that was difficult to meet. If I had waited longer before applying, I would not have qualified for the highest rate of the subsidy, and I would not be able to access a pump at all. Without the government subsidy, the up front cost of an insulin pump would have required me to take out a personal loan and I would not have been able to secure a loan from a financial institution because I don't meet their lending criteria. I can't afford full private health insurance. Even if I could, the waiting time for accessing appliances on cover with existing medical conditions is anywhere from 12-24 months and the health funds do not provide 100% of the cost of the pump- I would still have to find a considerable amount to cover the difference. This would have put me in severe financial difficulties. Without at least half to 3/4's of the maximum subsidy given, I would not have my son's pump. Thankfully, I was granted the full amount of subsidy available and only needed to find \$1600 to buy the (Medtronic) insulin pump for my son. If the subsidy was not available, (and remembering: I can't afford private health insurance), it would be up to me to find the money to buy the pump and it would take me years to save the money. If I relied on the generosity of family and friends, or the community to raise the money, it would seem as though they are providing the health care requirements to my son, when it should be part of the national health system.

The co-payment meant I didn't have to wait as long to access a pump, getting a pump was more affordable, but more importantly, it did not push me into financial difficulties. Having a child with a life threatening disease doesn't just affect them, or the immediate family, it also affects extended family, friends and the community as a whole. Apart from the extra cost to me to buy supplies, insulin and make more thoughtful food choices for my family, these considerations are a cost over and above what most families have. It is a cost that inevitably passes indirectly to other family and friends as they too have to choose differently diet wise to what they might have when my son is visiting. Many foods more suitable for persons with diabetes are sometimes 3 times more expensive than the 'normal' food equivalent. This extra cost is over and above the cost of a pump and would have meant I could not afford to get a pump for my son without the government subsidy. Although I worry sometimes how I will be able to afford the cost to keep the pump, I would never have been able to do it at all if the subsidy was removed or reduced.

My son doesn't have a choice about having Type 1 Diabetes, he would die without treatment, but his life would be much poorer without good, accurate and long term health care. The insulin pump has not only made his life more 'normal' by allowing more accurate control over the insulin delivery to his unique needs and requirements in real time rather than administering insulin via injection and hoping it matches his needs; it has enabled me to relax a little for the first time since my (now 14 year old) son was first diagnosed as a 7 month old baby. My son finds the ability to live more like "everyone else" much more relaxing, empowering and less "abnormal" than he ever felt before he had his pump. He rarely complains about feeling "different" anymore. He knows his needs are not the same as everyone else's, but it no longer feels quite so obvious. Sure, he is a typical teenager, but the flexibility in routine particularly, has meant he now feels much more comfortable. When he was injecting, he had to eat whether he wanted to or not, even if he was sick. With the pump, if he isn't hungry, or he has gastro- he doesn't have to eat AND he doesn't have to worry so much about having to go to hospital for treatment to control insulin and blood glucose levels like he did before his pump. The timing of his switch to a pump could not have been more fortuitous, on the cusp of puberty, just as his body was beginning to become a hormonal mess, the pump meant we had tight, accurate and immediate control over his needs for insulin. The pump enables flexible but detailed and effective control around all aspects of daily life. Everything from illness, physical activity, food intake and hormonal changes influence his blood sugar and insulin needs are able to be monitored and adjusted incredibly quickly with the pump. This is something we did not have as much control over with injections. The type of pump my son has is also able to be used as a continuous blood glucose monitor- we have used a pump for this twice before he got his for insulin delivery and it is of such value in seeing what's happening between separate BGL (blood glucose level) checks with his BGL machine, that I just wish I could also afford the sensors and transmitter to use it at home whenever we wanted to instead of having to book in a 6 day testing period through the hospital to use the ones available through there, and wait months to do so. At last check they are not subsidised through the NDSS and cost upwards of \$1200 for one transmitter (reusable) and approximately \$700 for 10 sensors. Each sensor lasts approximately 6 days and is not reusable. The ability to use this function on the pump more regularly would make management even more efficient and beneficial, something that in the longer term would most likely show lower burden on the healthcare system through the health of my son being better as a result of early, sustained excellent health care!

In 2012, my son grew 30cm taller. For the whole of 2012 he was on the insulin pump. Not only was his HbA1c very reasonable, it did not fluctuate wildly and he has had no health complications develop in that time. In fact it appears he has no signs of any development of the common circulatory, renal, visual or neurological degeneration that develop in long term poor control of diabetes. I believe he can only continue to maintain this level of care and success with an insulin pump.

My son's quality of life is undoubtedly better. The pump enables accurate, realtime monitoring and adjustment of needs. He has shown remarkable growth in the past 12 months and despite the changes to his body because of this, his health has been incredibly good, his Endocrine doctor always compliments my son on his continued efforts and say the results are excellent. The ability to have an accurate but flexible insulin delivery method means mealtimes are no longer a regimented affair. It makes mealtimes less a major focus on my son and his needs and more like the family gathering with equal focus on everyone. We do spend quite a lot of time correctly calculating his carbohydrates, but when he eats it is no longer fixed, inflexible and can be tailored to match exactly what he eats and we know he's getting the correct amounts of insulin. Our whole family is more relaxed, extended family included, because they know that the pump is able to adjust to my son's needs quickly and accurately and quite easily too. They don't fear having to give him injections or draw up insulin, figure out how to calculate the dose or what to do with the associated needles and rubbish that goes with injections. We don't have to worry if a syringe gets dropped by mistake, and the baby picks it up and gets hurt, sharps containers are a thing of the past! Everyone is more relaxed about the specific needs of my son without feeling they don't know what to do or can't figure it out. When it comes to school camps and excursions, there is still the ongoing time consuming organisation of how he will attend and what his needs are whilst away that takes up not just my time but that of the school too, but the flexibility of control means he can more easily fit into the same routine as everyone else, with much smaller interruption to the daily activities planned and menu's on offer do not pose as much of a problem as before because he is getting the insulin he needs at the time he needs it. Life is more relaxed, more streamlined, much less a hassle and battle to maintain good control and good compliance with treatment.

Although the ongoing cost of the pump's consumable components is considerably more than when my son was injecting insulin, the benefits outweigh this cost. It is still a cost I would like to see reduced through higher subsidy of the pump consumables on the NDSS. It does make a difference to our family's budget-something I wish we didn't have to pay for, but the health of my son is so much better with a pump. I would be devastated if we had to buy him another one, since I would no longer qualify for the full grant as it is assessed now, and with more children to support than before and I am no longer single, I don't know if we could replace his pump. I would strongly encourage the Government to consider full subsidy of the cost of the pump to commence pump therapy and replacement of pumps ongoing for those already using one.

Living with someone with Type 1 Diabetes means life is not simple. It's more time consuming, costly, emotionally and physically draining, and not just for the person who has Diabetes, the whole family deal with more responsibility, concern and

thoughtfulness than most families. Having a pump for my son means we all get to experience a much more flexible approach to dealing with Diabetes as a part of the family. We can make faster decisions about a last minute changes in activity plans, meals or even go out without anywhere near as much worry about how we will manage. It allows my son to feel more like 'everyone else'. While many families might be considering where their next holiday will be- Bali or the Gold Coast for example, our family dreams we might be able to go on a holiday to a different state and stay at a hotel or resort- for us- we can't afford it because the choice we have to accept is that health comes first and it is at the sacrifice of many other activities and experiences that many other families take for granted and don't even consider what it might be like to have to miss out on.

Without a pump, my son feels like he sticks out, that he's different and not in a good way. He doesn't like attracting attention to himself, he doesn't want to feel 'different', he wants to look and behave just like every other healthy young man his age. A pump allows him the closest opportunity to do this, with the exception of a cure and since this is not an option available to anyone at the moment, the pump is the best treatment of his Diabetes available at the current time. Without significant subsidy and support for allowing my son to access insulin pump therapy, he would probably be resistant, defiant, depressed and in a much poorer state of health because he would want to ignore having Diabetes. We would rue the day that the Government might decide that my sons health doesn't deserve having the opportunity to make the most of, and have the best possible chances at a healthy, productive and successful life because the treatment was too expensive to access without Government subsidy and everyone's family situation is different. I firmly believe that the subsidy should apply to EVERYONE, not just a sliding scale according to income. Especially since the income level where the subsidy is of such a small amount as to not be of any benefit, is far lower than what most families need to remain above the poverty line and therefore the current subsidy inaccurately reflects the ability for families to 'afford' the treatment and maintain the treatment. Having a pump is not a luxury, it is not a treatment that only those families who should have a higher disposable income may access and it certainly should not be assessed according to income. It should be assessed according to the benefit directly to the person who uses it to treat their disease and society as a whole that contains a healthier and more able member for a longer period of time. There should be no distinction between those that can afford the pump and those that can't. No one is refused medical treatment because they cannot afford it in Australia, nor should anyone be refused access to better treatment because they can't afford it.

Thank you for your time reading this submission.
