DIABETES CANADA

Submission to Senate Standing Committee on Social Affairs, Science and Technology

Ongoing challenges experienced by Canadians with diabetes in accessing the Disability Tax Credit and Registered Disability Savings Plan

Diabetes Canada
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Overview

Diabetes Canada is very proud to represent the estimated 11 million people living with diabetes or pre-diabetes. We are committed to helping those at risk of diabetes avoid developing this condition and to helping those who have it live well.

Diabetes is a challenging and expensive disease to manage. Programs such as the Disability Tax Credit (DTC) and Registered Disability Savings Program (RDSP) provide important financial security to people struggling with diabetes or other conditions. Yet in 2017 a procedural change made by CRA employees caused most adults with type 1 diabetes to be deemed ineligible for these programs, even where they had previously qualified. This development caused significant concern for Diabetes Canada's stakeholders.

Diabetes Canada is very pleased to note that the Canada Revenue Agency, with the encouragement of officials from all political parties, has reversed that procedural change and granted more than 400 adults with type 1 diabetes the DTC (and, consequently, the RDSP). However, the events of 2017 highlighted some ongoing challenges with respect to the operations of these programs which the government should hasten to address in order to ensure these programs meet their intended purpose of supporting Canadians with disabilities.

Type 1 diabetes is serious and complex

Type 1 diabetes is an incurable chronic auto-immune condition affecting nearly 300,000 Canadians. While no one knows the exact cause of type 1, we do know there is nothing anyone can do to cause himself to get it or to avoid developing it. At some point, usually in childhood or young adulthood, the person's immune system destroys the cells that produce insulin – a hormone we all rely on to live – giving that person type 1 diabetes.

People with type 1 diabetes depend on multiple daily injections or infusions of insulin for the rest of their life. To determine the dose of insulin required, individuals must test their blood glucose six or more times a day, and make complex calculations accounting for such things as what time of day it is, the amount and type of food they are eating, the activity they plan to do in the coming hours, how much stress they are under and whether they are fighting a cold or not.

Managing type 1 diabetes has been likened in complexity to flying a plane, by a study that found it can take up to 600 steps *each day* to contend with all that goes into living

with the disease.[1] And while technological advancements such as insulin pumps offer people with diabetes a better chance at blood sugar control, it does not make managing the disease less complex or time-consuming.

Canadians with type 1 diabetes are at constant risk of dangerously high blood sugar, which can lead to complications, or dangerously low blood sugar, which can result in a coma or death. Diabetes is the leading cause of amputations, blindness, kidney and heart disease, and other debilitating conditions. Canadians with type 1 diabetes can expect to develop at least one of these complications within 25 years of diagnosis, and their life span to be shortened by 5 to 10 years. In every sense of the word, it is a disability.

Type 1 diabetes is costly

The costs of managing this challenging disease are significant and increasing. Those using insulin pumps and continuous glucose monitoring may face out-of-pocket costs of more than $15,000 per year. Many critical supplies are only covered by supplemental health insurance programs, and some (for example, continuous glucose monitoring systems or insulin pumps and supplies) may not even be covered by those. Studies show that these costs adversely affect the ability of some with type 1diabetes to follow their prescribed treatment protocol, at significant negative impact to their long-term health and at significant cost to the Canadian health care system.

The DTC helps, but can be difficult to obtain

The DTC is an important tool for many in managing these out-of-pocket costs. Some persons with diabetes have been approved for the DTC and found relief from these unavoidable expenses.

For many Canadians, the process is too complex, and rates of utilization of the program are low. According to a recent report published by the University of Calgary's School of Public Policy, only 40 per cent of the 1.8 million Canadians who live with severe disability in Canada use the DTC.[2] Unclear applications processes and opaque assessment practices are cited as some of the reasons why, and anecdotal evidence Diabetes Canada has gathered supports this finding.

[1] https://www.ncbi.nlm.nih.gov/pubmed/19820281
[2] http://theprovince.com/opinion/op-ed/dr-jennifer-zwicker-and-stephanie-dunn-why-is-the-canada-revenue-agency-denying-the-disability-tax-credit-to-those-who-need-it-most

While approximately 300,000 Canadians live with type 1 diabetes, and a large portion of those can be assumed to meet the eligibility criteria for the DTC, a small fraction accesses the DTC or RDSP. Unfortunately, the CRA does not currently track applications by the applicants' underlying condition, but only by category of application. Under the category of Life-Sustaining Therapy, which is made up primarily of people requiring kidney dialysis or living with cystic fibrosis, since 2014 the CRA has granted the DTC to only 50,000 people. Very few of those 50,000 can be assumed to live with diabetes.

Diabetes Canada has heard clearly from both patients and clinicians that the application process is far too unclear and cumbersome. Many clinicians, frustrated and uncertain of how to apply, refuse outright to certify a patient's application. It should be noted that this is not often due to a belief that their patient doesn't "deserve" the credit, or even that their patient doesn't meet the stated eligibility criteria, but rather because they don't believe that the application will be approved no matter what they say. Those who are willing to complete applications on behalf of their patients must take significant time out of their clinical practice to complete paperwork, and still frequently receive non-specific requests for "more information" from the CRA which they struggle to respond to. This is not an effective use of the time and expertise of doctors and nurses or of our health care dollars.

Furthermore, clinicians are currently asked to certify activities that they cannot witness. For example, a doctor certifying the application of a patient with type 1 diabetes has to certify that their patient is spending more than 14 hours per week testing her blood sugar, administering insulin, etc. However, these activities are not performed in a clinical setting (i.e. with the doctor present), which makes some doctors uncomfortable with certifying these activities. This is not to say that they don't necessarily believe that their patient is spending that time; simply that they cannot attest to it having not observed it. This causes some practitioners to refuse to certify any applications, preventing many Canadians who otherwise qualify for the DTC and RDSP from accessing it.

Even when clinicians do certify the applications of their patients' applications are sometimes denied, with no clear explanation, which inhibits applicants from filing an informed appeal. The subjective and inequitable application of eligibility criteria is unfair to Canadians.

The current process is designed for the medical practitioner to determine if their patient meets the criteria. The determination is made based upon their detailed understanding of this disease and its management, as well as based upon a personal knowledge of their patient's self-management practices. They are best positioned to opine on whether the patient is actually spending the minimum of 14 hours per week

on applicable activities. Yet the process that is designed by CRA is not respected as the clinical certification is not always accepted. This practice of rejection questions the knowledge and/or integrity of the certifying clinician and is unacceptable.

Diabetes Canada's recommends that the Canada Revenue Agency accept the certifications of medical professionals regarding their patient's individual circumstances and grant access to the DTC to people with diabetes who rightfully qualify.

The RDSP is valued and must be protected

A major concern with losing the DTC is the related impact on the ability of those with type 1 diabetes to access or maintain their Registered Disability Savings Plans (RDSP).

The RDSP is a savings plan that is intended to offer Canadians who are eligible for the DTC increased long term financial security. Only those who are eligible for the DTC may contribute to an RDSP. Contributions may be eligible for government matching through the Canada Disability Savings Grant (CDSG) and/or the Canada Disability Savings Bond (CDSB). The amounts of this matching can be significant: there is a $70,000 lifetime limit for the CDSG and a $20,000 lifetime limit for the CDSB.

Once an individual is no longer eligible for the DTC, he or she no longer qualifies for the RDSP. At that point, CRA requires that the RDSP be closed and liquidated AND it claws back the contributions that have already been made by the government under the CDSG and CDSB.

To quantify the impact, here are some data. Given that many people with type 1 diabetes apply and qualify for the DTC many years after their initial diagnosis, and given that the DTC and RDSP are granted retroactively up to 10 years, the average RDSP would contain $10,000 of contributions, government grants and bonds in the first year of opening. Some Canadians have been amassing 9 years' worth of their own and government contributions since the RDSP was introduced in December 2008.. This means that those people with type 1 diabetes are at risk of losing tens of thousands of dollars in the next year due to the change in interpretation of the DTC by CRA agents. If just 10 % of the 150,000 people with type 1 who may be eligible for the DTC have RDSPs, the claw back could amount to $150 million taken back from Canadians living with diabetes.

This can be a significant financial blow for a person with type 1 diabetes who ceases to qualify for the DTC, not because their disease has changed, nor because its management has changed, but simply because interpretations of eligibility criteria

have changed by CRA agents. While we appreciate the recent decision to revert to previous practices in accepting DTC applications, we must protect Canadians from future practices that are enforced without consultation or oversight.

Recommendations on the DTC

The solutions Diabetes Canada proposes mirror those of the School of Public Policy and of the Senate Standing Committee on Banking, Trade and Finance's own 2014 study[3].

Diabetes Canada offers the following recommendations regarding the DTC:

1) Permit the time spent on all activities related to administering insulin (e.g. counting carbs; treating and recovering from low and high blood sugars; meal planning related to time activity profile of insulin used) to be counted toward the 14 hours per week criteria under Life-Sustaining Therapy.
2) Modernize and amend eligibility criteria in the Income Tax Act such that the language reflects that doctors and nurse practitioners can certify that their patient has type 1 diabetes and is following their prescribed regimen, but does not require certification of activities performed by the patient in a non-clinical setting.
3) Clarify and streamline the application process AND reasons given when applications are disallowed in order to make the program more straightforward and understandable for eligible Canadians to access.
4) Ensure that comprehensive stakeholder consultations are performed prior to the CRA changing its interpretation of the Income Tax Act so that the full consequences of those changes can be assessed.

Recommendations on the RDSP

1) People with type 1 diabetes should not lose their RDSP just because they cease to be deemed eligible for the DTC. T1D is an incurable, progressive disease and people need to be able to rely on this form of savings. Contributions made to the RDSPs of people with type 1 diabetes while they were deemed eligible for the DTC should not be withdrawn if and when eligibility criteria are changed. These Canadians *must* be able to rely on funds already invested in these savings vehicles.

[3] https://sencanada.ca/content/sen/Committee/412/banc/rep/rep03mar14-e.pdf

2) Take measures to ensure that all Canadians with disabilities are aware of the existence of the RDSP program. A 2014 Senate Study found that only 15 per cent of eligible Canadians with disabilities have RDSPs, and lack of awareness is one of the major reasons why.[4]

Conclusion

Type 1 diabetes is unquestionably a costly and lifelong disability, the likes of which the DTC and RDSP were designed to help address. Diabetes Canada is appreciative of the government's recent steps to rectify the issues experienced by Canadians with type 1 diabetes trying to access the DTC in 2017, but work remains to be done.

Diabetes Canada shares the assessment of the School of Public Policy that the recent reinstatement of the Disability Advisory Committee, bringing together stakeholders and CRA officials, is a "promising step,"[5] and government must support and enable this Committee in its work by bringing the resources and urgency required to ensure the system surrounding the DTC and RDSP is comprehensively reviewed and changed quickly.

[4] https://sencanada.ca/content/sen/Committee/412/banc/rep/rep03mar14-e.pdf
[5] http://theprovince.com/opinion/op-ed/dr-jennifer-zwicker-and-stephanie-dunn-why-is-the-canada-revenue-agency-denying-the-disability-tax-credit-to-those-who-need-it-most