

# **Taking a Stand**

## **Advocacy Position Statements on the issues facing people with diabetes in Canada**

**August 2011**

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**Overview****An Agenda for Diabetes Action**

The diabetes world is exploding, not only in numbers of people being diagnosed but also in the development and release of new treatment options and resources for diabetes management. Each time a new drug or device is introduced, there is the opportunity for a person with diabetes to live a healthier and longer life, but only if they can obtain and afford those new treatments.

Diabetes is a unique disease. While it often leads to other related illnesses, it is also very responsive to early care and treatment. However, to meet the needs of those living with diabetes in Canada, the health-care system of the future will need to:

- 1. Recognize and be prepared to meet the ongoing medical, financial and support needs of those with chronic illnesses, such as diabetes.**
  - People with chronic illnesses such as diabetes not only live with difficult health issues on a daily basis but also bear significant financial burdens. Also, the emotional impact on individuals and families is difficult to calculate but impossible to ignore. Adequate financial coverage for and easier access to medications and supplies, no matter where a person lives in Canada, will help ensure that people are able to manage their disease and reduce their medical and financial burdens.
- 2. Provide quick and effective treatment and ongoing education to those diagnosed with diabetes, particularly because early diagnosis and treatment often delays or prevents costly complications.**
  - Timely access to medication at an affordable price is vital for those with diabetes. A more effective drug review process and more responsive formulary systems will help to ensure that new drug therapies with proven efficacy are available across the country quickly.
- 3. Move beyond a purely medical model to encourage and support initiatives focuses on primary prevention, improved health education, and lifestyle change. The incidence of type 2 diabetes can be markedly decreased by positive lifestyle changes such as improved diet and increased exercise.**
  - Primary prevention initiatives must become a priority, with increased support for community-based initiatives aimed at creating healthier communities. Health is linked to educations, social status, economic status, and spiritual and mental well-being.

Governments need to consider the health implications of tax policies and spending decision across departments such as finance, educations, social services, housing and the environment.

Bridging the gaps among effective care, barriers to service and treatment and a renewed health-care system requires a commitment to action within defined parameters. The ongoing development and review of organizational position statements brings increased clarity to the actions required of the Canadian Diabetes Association to meet its mission.

### **Barriers to effective care**

At present, there are many barriers in place which prevent the health care system from meeting the needs of people with diabetes.

### **Barriers to obtaining diabetes medication, supplies, and medical devices:**

- *Drug coverage programs* which offer widely different levels of financial support across the country (very high deductible or co-payment requirements/restrictive age or income requirements), or which provide no coverage for many therapies that could improve the quality of life for those with diabetes.
- *Formulary systems* which create unequal levels of access across the country, often imposing product restrictions that render them virtually inaccessible.
- *Drug review systems* which are slow to test and approve new therapies, and which lack adequate accountability for updates to current and new drugs.
- *Reference-based pricing systems* which focus primarily on cost reduction rather than patient health and well-being.
- *Limited recognition of the extraordinary financial burdens* faced by people with chronic illnesses, which could be alleviated, in part, by a system of enhanced tax credits.

### **Barriers to accessing diabetes services and education:**

- *Long waiting lists* for diabetes education programs and services (especially those newly diagnosed patients), and difficult access for those living outside urban areas.
- *Limited diabetes-specific training* at professional institutions and associations, and corresponding lack of recognition of the need for the person with diabetes to be an active participant in his or her own health care.

### **Barriers to full participation in many areas of life:**

- *Assuming diabetes automatically implies disability.* Outdated assumptions about diabetes and limited awareness of the improvements for treatment and control often leads to ongoing discrimination against people with diabetes in areas such as employment, driving, insurance and participation in school, sports or other activities.

## Position statement development

In February 2000, the Canadian Diabetes Association brought together volunteers, members and employees at an Advocacy Leadership Forum. Their task was to identify some of the most important issues facing people who have diabetes. This information became the starting point for the ongoing development of organizational position statements.

Most of the position statements address the fact that many people with diabetes do not have access to required medication, treatment and services, at affordable prices, and in reasonable periods of time, regardless of where they live in Canada. The lives of all Canadians with diabetes will be dramatically improved when these issues are addressed.

In addition to offering a broad summary of where the CDA stands, the position statements also:

- provide a specific advocacy focus;
- represent a public commitment to making substantive changes in policy; and
- enhance the Association's ability to present a clear, comprehensive and unified message to both government and industry.

The National Advocacy Council (NAC), working closely with the National Office of Public Policy and Government Relations, is responsible for steering the development, consultation, review, and dissemination phases of the position statement process. The National Board of Directors provides final approval. Once position statements have been approved, staff and volunteers are invited and expected to use them as widely as possible in their advocacy efforts.

Position statements are reviewed annually and revised if necessary by the National Advocacy Council. Revisions are approved by the National Board of Directors.

## Summary

People with diabetes face many issues that have serious and long-term effects on their physical, emotional and financial quality of life. The Canadian Diabetes Association works to prevent diabetes and to improve the quality of life for those affected through research, education, service and advocacy. It encourages a healthy lifestyle as the best method of prevention, and represents the interests of those with diabetes to government, business, and the public.

An effective diabetes health-care plan requires a multi-faceted approach that attacks barriers of cost, access and education/information with equal force. These position statements offer a starting point for effective action.

Feedback and comments are welcome. They may be sent to:  
National Office of Public Policy & Government Relations [advocacy@diabetes.ca](mailto:advocacy@diabetes.ca)

## **Section A**

### **Diabetes Medication, Supplies and Medical Devices** **Easing the Burdens of Access and Cost**

People with diabetes experience heavy medical and financial burdens. To ease these burdens, to ensure an optimal quality of life, and to possibly prevent or delay costly and devastating complications, people with diabetes deserve equal and timely access to the best possible medication, supplies and medical devices at an affordable cost, regardless of where they live in Canada.

It is in the best interests of the Canadian health-care system, the local community, the individual with diabetes and his or her family to ensure that issues of access and cost are never barriers to effective diabetes management.

## **Access to Diabetes Medication, Supplies and Medical Devices**

### ***Position Statement***

**People with diabetes should have timely access to medication, supplies and medical devices that can improve their immediate quality of life and that may decrease the likelihood of future interventions which are often more costly and less effective.**

**Federal, provincial and territorial governments should commit to the development of an effective formulary system (or systems), which is (are) mindful of products providing the best outcomes based on sound medical evidence, and which do not create additional barriers to access.**

**New products with proven efficacy should be listed in a timely fashion.**

### ***Definitions***

A **formulary** is a list of drug benefits available under government drug insurance plans, specifying who is covered (i.e. seniors, people receiving social assistance), which drugs and medical devices (such as syringes, lancets, blood glucose test strips or insulin pumps) are paid for and at what percentage of the cost.

Each provincial and territorial government has its own formulary. The federal government also maintains formularies that apply to Aboriginal people, veterans, Royal Canadian Mounted Police force, and others.

Once a new drug is approved by Health Canada, the drug manufacturer makes a submission to health officials in each jurisdiction for the drug to be listed on the respective formularies. An expert advisory committee reviews the therapeutic benefits and/or economic impact of the drug on the province/territory and makes a recommendation to the relevant Ministry of Health. Treasury Board approval may be required. Listing a drug on the formulary determines its accessibility through the public drug insurance plan. Private sector drug plans may develop their own drug benefit policies; however, some follow provincial formularies and pricing policies.

**Medication, supplies and medical devices** are broadly defined to include all currently-accepted therapies, as well as newer technologies such as insulin pumps. Herbal remedies and alternative therapies that are not included on drug plans are not included.

**Background and Rationale**

There is great variation as to the medication, supplies and medical devices listed on federal, provincial and territorial formularies. Access to these items depends as much on where someone lives in Canada as it does on their income or their health status.

Often, new drug treatments are not listed on provincial or territorial drug formularies in a timely manner, or they are listed with limited or restricted access. This makes them, for all intents and purposes, unavailable to the majority of people who might benefit from them. To prescribe a “limited” or “restricted use” drug, a physician (often a specialist) usually must undertake a detailed and time-consuming application process. These variations in how formulary drugs are listed and prescribed have a profound effect on consumer access and ultimately, consumer health.

People with diabetes need timely access to medication, supplies and devices that can improve their quality of life and potentially reduce or delay the onset of serious complications. This has the potential to save the health-care systems millions of dollars by way of fewer doctor visits, medical interventions and hospital stays.

One proposal for addressing this vital aspect of diabetes care and treatment is the development of a single, national drug formulary and a common review process for new drugs. Proponents of such a system outline the following potential benefits:

- Elimination of the pressuring of one province to add a new drug to its formulary simply because a neighbouring province has done so.
- Enhanced ability to research the benefits of a new drug by conducting the research at a national level.
- Lower drug purchase prices for public plans.

Some of the concerns expressed about a common review and formulary system are:

- The system as a whole may fall to the lowest common denominator, with only the least expensive therapeutics being listed.
- Additional barriers to timely access may be created by adding a new layer of co-ordinating bureaucracy to the review.
- Regional disparities may not be addressed if every region still maintains its own autonomy.
- A national formulary may further hinder the ability for provinces and territories to consider drug therapy expenditure within the larger context of health spending as a whole.

Ultimately, the success of any changes to current formulary systems will depend on the extent to which the changes ensure that needs of people with chronic health problems re the primary focus.

## **Cost of Diabetes Medication, Supplies and Medical Devices**

### ***Position Statement***

**Federal, provincial and territorial governments should commit to a strategy such that the cost to the individual of diabetes medication, supplies and medical devices, as well as the costs associated with diabetes-related complications, are not a barrier or a burden to managing the disease.**

### ***Definition***

**Medication, supplies and medical devices** are broadly defined to include all currently-accepted therapies, as well as newer technologies such as insulin pumps. Herbal remedies and alternative therapies that are not included on drug plans are not included.

### ***Background and Rationale***

A person with diabetes usually incurs medical costs which are much higher than those of a person without diabetes, including:

- Diabetes management supplies such as syringes, glucose testing meters, test strips and insulin pumps.
- Insulin and/or other diabetes drugs and therapeutics.
- Other medication to lower cholesterol, blood pressure, etc.
- Frequent medical visits and diagnostic tests.
- Specialized home care visits, and rehabilitation or permanent residential care should debilitating complications arise.

People with diabetes face these costs no matter where they live in Canada. However, government drug plan coverage to help with this financial burden varies greatly across the country. Some plans cover almost all costs for all the medication, supplies and devices which are needed to adequately manage diabetes, while other jurisdictions provide little or no coverage for these same items.

Coverage levels are often subject to very high deductibles or cost sharing formulas, meaning that even those who qualify for government programs may still be unable to benefit from them. In addition, the level of financial assistance based on income or age also varies widely across the country. For instance, although the cost of insulin for people on social assistance is covered in almost all jurisdictions, in some areas the cost of the syringes needed to administer the insulin is not.

#### Advocacy Position Statements

Many proposals for addressing these disparities have been suggested, including a nationally-coordinated drug coverage system, a national pharmacare program, or the inclusion of all drugs under the Canada Health Act. Presently, there are many more questions than answers about what system would best meet the current need. Would everyone be covered or only those with high drug costs and/or low income? Would all therapeutics be covered? Would it be a single payer, publicly financed plan or a combined public/private plan? And, of course, how would such a program be financed?

## Government Efforts to Control Drug Costs

### Position Statement

**Government efforts to control drug costs should not be undertaken in ways that restrict patient access to therapeutics which could improve long-term health and improve quality of life, increase costs borne by the patient, or restrict physicians' options to prescribe.**

### *Background and Rationale*

Pharmaceutical costs have been rising steadily in Canada and account for an ever-increasing percentage of total health-care costs. Each provincial and territorial government has a prescription drug plan providing some public support for the cost of prescription drugs because prescription drugs are recognized as being medically necessary.

To reduce the cost of prescription drug plans, some governments have implemented or are considering the implementation of programs such as “reference based pricing”, wherein a public drug plan reimburses a patient for the cost of the lowest priced drug within a designated therapeutic category. (British Columbia claims that reference-based pricing has reduced public expenditures for prescription drugs by as much as \$50 million in one year). However, patients, physicians and pharmaceutical companies are concerned that programs like reference-based pricing focus primarily on reducing drug and diagnostic product costs without a corresponding regard for optimal patient care.

Some of the criticisms of government cost-containment programs include concerns that they:

- impose higher drug costs on patients who wish to use a higher priced drug and who must pay the difference between the cost of a drug covered by a government plan and the cost of the drug they wish to use.
- do not recognize the needs of patients to access a variety of therapies and treatments.
- restrict physicians' ability to prescribe the drugs they believe are most beneficial for their patients.
- impose additional administrative burdens on physicians, which can be a barrier to access.

## Drug Review Process

### ***Position Statement***

**People with diabetes should have timely access to new and appropriate treatments at an affordable price.**

**The government of Canada should allocate the necessary resources and implement more stringent measures of accountability to create a drug and medical device review process which is timely, transparent and incorporates a functional post-market surveillance system.**

### ***Definition***

**Post-market surveillance** is the process of monitoring a new drug once it has been approved and introduced into the market to ensure that unfavorable effects are reported, documented and addressed.

### ***Background and Rationale***

The government of Canada is responsible for the review and approval of new drugs and medical devices. The current system has been criticized for being slow, overly-complicated, under-resourced, and lacking a sufficient focus on product review and evaluation (particularly in comparison with other countries). As a result, there is concern that pharmaceutical companies are discouraged from introducing new drugs into the Canadian market. While it is vital to ensure that new treatments for people with diabetes are safe and efficacious prior to approval, access to new treatments should be available without undue delay, particularly if the delay is clearly a result of the process being under-resourced.

## Means Testing

### ***Position Statement***

**Where governments choose to use means testing, the means test criteria must be set at a level which ensures that the cost of caring for diabetes is not a barrier or a burden.**

### ***Definition***

**Means testing** is a process whereby an individual's access to products or services is dependent on that person's financial circumstances falling within pre-set criteria. If those criteria are exceeded, the person is found to be "financially ineligible" and must pay for the products or services.

### ***Background and Rationale***

Due to the high cost of caring for diabetes, the issue of means testing is of particular importance for people with diabetes, particularly those with reduced incomes. Often, people with diabetes who do not satisfy the means test criteria will still be unable to afford to pay for their diabetes supplies. Traditionally, means test criteria set by governments for other purposes such as welfare or legal aid have been set so low that many of those who "fail" the means test are left unable to properly care for themselves.

In addition, means testing can be viewed as an invasion of privacy as well as disrespecting the dignity of individuals. This is particularly true when they must undergo the testing process simply to try to access essential and necessary care. Given that deductibles and co-payments are already set very high in many jurisdictions, means testing is another barrier to people with diabetes who need proper care and treatment, regardless of their circumstances.

Long term costs to the medical system of improper preventative care and management of diabetes, as well the savings in the face of good quality care are well-documented. In addition, administrative and infrastructure costs associated with implementing any means testing system will offset any potential savings.

## **Discontinuation of Diabetes Medication and Products**

### ***Position Statement***

**Where a diabetes treatment option is being discontinued, people who are dependent on that treatment option should continue to have access to that treatment, or to an alternative which is viable for them, without extraordinary measures (financial or otherwise) being borne by the person with diabetes.**

**Where a pharmaceutical company declares its intent to discontinue a safe and effective diabetes product for which there is still demand, the pharmaceutical company and the federal government should work together to ensure appropriate solutions are readily available for those who find that they are unable to make the transition.**

**Consumers and health professionals should have access to a network of medical expertise to assist with the transition process when a product for which there is still demand is discontinued.**

### ***Background and Rationale***

As new diabetes-related drugs are developed and marketed, manufacturers are correspondingly discontinuing old product lines. (For example, with the introduction of human/genetic insulin, the production of most animal insulin was discontinued). This can be a concern for people who have relied on a specific medication or product over the course of many years. Although medical evidence may suggest that the new product is actually more efficacious, the consumer who is doing well on a particular drug can find its discontinuation devastating.

People with diabetes have a right to access medication or other treatment options with sound medical and clinical evidence of providing effective treatment of diabetes and its complications. The fact that most people with diabetes are responsible for their own primary care makes personal perceptions and experiences even more important.

## Section B

### **Diabetes Education and Health Services** **Ensuring access to the best possible care**

Managing diabetes is a time-consuming process. The requirements for self-care and self-knowledge are very high; people with diabetes must be aware of their condition at all times, and make decisions about the management of their disease on a daily basis.

To make informed choices about their health, people with diabetes need accurate and up-to-date information and education. Making appropriate decisions, with support from a qualified health-care team, may lead to a better personal quality of life and the prevention or delay of complications.

Inappropriate decisions may play a part in leading to devastating and potentially deadly complications that include heart attack, stroke, blindness, kidney disease or lower limb amputations.

## Access to Health Services

### ***Position Statement***

**People with diabetes have a right to timely, affordable and ongoing diabetes education and comprehensive treatment services provided with seamless coordination by a Diabetes Health Care Team and other specialists as specified in the Canadian Diabetes Association's current *Clinical Practice Guidelines for the Prevention and Management of Diabetes in Canada* and *Standards for Diabetes Education in Canada*.**

**Upon diagnosis, physicians should refer patients with diabetes to a diabetes education program, with waiting periods not to exceed those specified in the Canadian Diabetes Association's current *Standards for Diabetes Education in Canada*.**

### ***Background and Rationale***

Diabetes is one disease where a modest up-front investment can result in significant future savings to the health-care system. Although continuing education is vital to understanding and managing diabetes, long waiting lists often mean that many people with diabetes never receive appropriate education about diabetes and self-care. Although diabetes management requires a sustained commitment on the part of the individual with diabetes and timely, effective and coordinated care on the part of the providers, the benefits can be great, as effective management can delay or even prevent the onset of complications.

## Health Professionals

### ***Position Statement***

**Educational institutions, professional associations, and employers engaged in the initial training and ongoing education of health professionals should ensure the provision of comprehensive and current programs of diabetes prevention, information and care.**

**Where possible, such programs should be delivered by knowledgeable individuals and include representation from all members of the Diabetes Health Care Team, as well as people living with diabetes.**

### ***Background and Rationale***

Diabetes is one of the most complex diseases to manage and treat. It is not one disease; there are different types requiring varied management strategies. Also, diabetes can affect an individual person differently at different times. It can lead to a wide range of complications requiring specialized treatment. Many health-care professionals often receive a “bare minimum” of diabetes training in their curriculum, possibly due to this very complexity.

Diabetes management and treatment also must recognize the person with diabetes as a pivotal member of the health-care team, more so than other diseases. This can be a challenge for a health-care professional with minimal diabetes-specific training, one which could be addressed through better and ongoing training and education.

## Smoking

### ***Position Statement***

**Health professionals should inform their patients with diabetes of the unique risks incurred by smoking or by exposure to smoke, emphasize the benefits of quitting, and review available treatment options.**

**Smoking cessation products should be covered on provincial formularies for high-risk patients such as those with diabetes.**

**Governments should enact legislation to protect citizens from exposure to tobacco smoke in public places, and support programs in schools that have proven to be effective in convincing young people not to start smoking.**

### ***Background and Rationale***

People with diabetes face unique risks from exposure to tobacco smoke. However, nearly one third of people with diabetes smoke, despite studies showing that smoking greatly increases the risk of developing diabetes-related complications. Smokers who have diabetes need the full support of their health professionals and governments to quit smoking.

No matter how long an individual has smoked, health improvements will occur after quitting.

## Food Security\*

### Position Statement

**Healthy food choices are essential to good diabetes management and to help prevent type 2 diabetes. All Canadians should have access to affordable, sufficient, safe and nutritious food.**

**For people living in remote or northern communities, or those with below average income, the affordability of healthy food choices should not be a barrier.**

**Governments should work together to develop and implement social policies and programs, including educational programs, to ensure all Canadians have food security.**

### *Definition*

**Food security** exists when all people, at all times, have physical and economic access to sufficient, safe and nutritious food to meet their dietary needs and food preferences for an active and healthy life.

### *Background and Rationale*

Food security is a key social determinant of health and is a public health issue that affects many Canadians living with or at risk of developing diabetes.

Diabetes can often be prevented or well-managed with proper nutrition. Individuals living with food insecurity often consume low-cost foods which may be calorically dense and nutritionally inadequate. To support people in choosing healthy food, it must be affordable and readily available in the local community.

It is equally important that people are educated about healthy eating, including meal planning, food budgeting, and food preparation.

(\*Replaces position statement on Nutrition)

## Diabetes Care in Institutional Settings

### Position Statement

**People with diabetes should receive care that promotes the highest quality of life regardless of the setting.**

**People with diabetes have a right to timely, affordable and ongoing diabetes education and comprehensive treatment services provided with seamless coordination by a Diabetes Healthcare Team and other specialists as specified in the Canadian Diabetes Association's *current Clinical Practice Guidelines for the Prevention and Management of Diabetes in Canada* and *Standards for Diabetes Education in Canada*.**

### *Definition*

**Institutional Settings:** Where residents require care and services provided by various certified/licensed service and care providers. These settings may include nursing homes/long term care facilities, group homes, hospitals and correctional facilities.

### *Background and Rationale*

People with diabetes may receive inadequate diabetes care when living in institutional settings. A prison, for instance, may not provide the residents with diabetes education, healthy food choices or the freedom to self-monitor.

## Diabetes and Mental Health

### ***Position Statement***

**Psychological issues related to the diagnosis and/or self-care demands of diabetes often have a negative affect on many aspects of diabetes management and glycemic control. As such:**

**Individuals with diabetes should be regularly screened by their healthcare team for psychological distress and psychiatric disorders<sup>1</sup>.**

**Access to mental health professionals and community support should be timely, affordable and ongoing.**

**Diabetes self management education should incorporate strategies to prevent and/or manage psychological distress related to the diagnosis and management of diabetes.**

### ***Definitions***

**Psychological Distress** is a term that includes a range of negative feelings and emotions that people experience in reaction to adversity. Ongoing or persistent negative moods such as sadness, frustration and anxiety can be mild or severe and may affect quality of life.

**Psychiatric Disorders** are mental illnesses which may include conditions such as major depression, severe anxiety and eating disorders. Unmanaged psychological distress may trigger or worsen existing psychiatric conditions.

### ***Background and Rationale***

People with diabetes are often overwhelmed or frustrated by the, burdensome demands of managing their chronic disease. They may feel angry, guilty, frightened, discouraged, depressed and unmotivated and their relationships may be strained.

People with diabetes are at greater risk of mental illness and people with some mental illnesses are at greater risk of diabetes. Depression is more common in people with diabetes compared to the general population and major depression is present in approximately 15% of people with diabetes<sup>2</sup>.

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<sup>1</sup> CDA 2008 Clinical Practice Guidelines for the Prevention and Management of Diabetes in Canada p. S82

<sup>2</sup> Ibid.

Depression is associated with poorer self-care, poorer blood glucose control, health complications, decreased quality of life and psychological well being, increased family problems and higher health care costs. It is important that physicians and other members of the diabetes healthcare team consider or address the psychological aspects of living with diabetes.

Diabetes self-management education and follow-up is vital to understanding and managing diabetes, thereby helping to reduce psychological stress related to the diagnosis and management of diabetes. However, long waiting lists at diabetes clinics and poor access in rural areas are often barriers to accessing required education and ongoing support.

## Section C

### **Diabetes and Discrimination** **Respecting individual rights and privileges**

While diabetes has the potential to be disabling, it affects people in very different ways, and can usually be well managed with diet, exercise, and/or medication.

People with diabetes have the right to be assessed on an individual basis to determine their fitness for work, insurance, driving, or participation in school or other activities.

## Disability

### ***Position Statement***

**People with diabetes have a right to be assessed on an individual basis to determine if their diabetes constitutes a disability as defined within the specific context.**

### ***Background and Rationale***

With proper care and treatment, most people with diabetes can achieve an optimal quality of life. Although diabetes can be a potentially disabling disease, particularly if complications ensue, it does not in and of itself constitute a disability.

## Employment

### ***Position Statement***

**A person with diabetes should be eligible for employment in any occupation for which he or she is individually qualified.**

**In being considered for employment in safety-sensitive positions, a person with diabetes has the right to be assessed for specific job duties on his or her own merits based on reasonable standards applied consistently.**

**Employers have the duty to accommodate employees with diabetes unless the employer can show it to cause undue hardship to the organization.**

### ***Definition***

**Undue hardship** arises as part of the legislative requirement that employers must change workplace policies, rules, practices and operations that result in discrimination, as well as provide individual accommodation unless it would lead to “undue” or unreasonable hardship on the part of the employer.

The question of what constitutes undue hardship varies; however, courts have made it clear that employers must expect to experience some cost in eliminating barriers and providing accommodation. Questions arise over *when* the threshold of undue hardship has been reached. The *Canadian Human Rights Act* provides that undue hardship must be assessed considering “health, safety and cost.” The mere fact that some cost, financial or otherwise, will be incurred is insufficient to establish undue hardship. (Source: A Place for All: A Guide to Creating an Inclusive Workplace, The Canadian Human Rights Commission)

### ***Background and Rationale***

People with diabetes may face discrimination in the workplace simply because they have diabetes. Most people with diabetes can perform their job duties with minimal accommodation by the employer, such as nutrition breaks, time for glucose level testing, and/or injection of insulin.

Employers have terminated, demoted or denied positions to employees with diabetes without having adequate knowledge of the disease and without reasonable investigation into individual circumstances. Individual assessment tools tailored specifically for the job circumstances and developed jointly by the employer, employee, and health care practitioner can minimize such occurrences.

## Insurance

### ***Position Statement***

**People with diabetes should be able to access adequate insurance coverage of all types at a reasonable cost.**

### ***Background and Rationale***

People with diabetes often face discrimination when seeking insurance, simply on the basis of their diagnosis. Some people are immediately denied insurance; others are compelled to pay extraordinarily high premiums.

Some insurance companies remain unaware of the many advances in diabetes management and care and still tend to automatically view diabetes as a life-threatening condition. This inevitably compromises the risk-assessment process and the individual's ability to secure insurance at a reasonable cost.

## Driving and Licensing

### ***Position Statement***

**People with diabetes have the right to be assessed for a license to drive a motor vehicle on an individual basis in accordance with Canadian Diabetes Association guidelines for private and commercial driving.**

### ***Background and Rationale***

People with diabetes often face discrimination when being assessed for a driver's license simply on the basis of their diagnosis. In fact, most people with diabetes can drive safely provided they are adequately informed about their condition and its management, and take the necessary precautions.

In consultation with a number of experts, the Canadian Diabetes Association has developed recommended guidelines for diabetes and private and commercial driving. These guidelines also refer to safety-sensitive situations where individual assessment is required.

## Children in School

### ***Position Statement***

**Children with diabetes have the right to be full participants in all aspects of school life.**

**School personnel or other caregivers of children should possess basic knowledge about diabetes and be able to recognize and respond to hypoglycemia and hyperglycemia.**

**Where requested, the Canadian Diabetes Association will work with school boards, administrators, teachers and parents to ensure the delivery of accurate and current information about diabetes, and to assist with the development of policies and programs addressing diabetes management.**

**On an ongoing basis, parents or guardians should take a pro-active role in educating their child's teacher(s) and, if possible, classmates, about diabetes and the specific needs of their child, thus helping to ensure their own comfort with the school's ability to keep their child safe and minimizing anxiety on the part of teachers and students.**

### ***Background and Rationale***

Children with diabetes are sometimes denied the opportunity to participate in school activities, and also may not be adequately accommodated while attending school. These situations usually occur because of the lack of knowledge about diabetes.

Diabetes requires ongoing monitoring and attention. Children with diabetes must manage their disease by knowing the warning signs associated with their condition, test their blood glucose levels and take prompt action, when necessary, to treat their condition. This can be a challenge, especially for very young children, but not impossible.

As a result, teachers and other school personnel must have adequate education, direction and resources in order to assist their students with diabetes. A broader understanding of the disease enables schools to better safeguard the health of students as well as minimize the anxiety of parents/guardians and school personnel. The Canadian Diabetes Association offers The Kids with Diabetes in Your Care resource kit to people who provide care to children with diabetes including parents/guardians, school staff, childcare workers, coaches, youth workers and camp staff.

## Diabetes Self-Care in Public Places

### ***Position Statement***

**When in public places, people with diabetes must be allowed to do what is necessary to prevent or treat hypoglycemia and hyperglycemia, including:**

- **Self-monitor blood glucose levels,**
- **administer insulin,**
- **carry food and beverage supply, and**
- **consume food and beverage.**

**People with diabetes are responsible for disposing of sharps and related materials in the safest possible manner.**

### ***Definitions***

**Self-monitoring of blood glucose (SMBG)** is performed by piercing the skin to obtain a drop of blood to place on a test strip that is inserted into a meter. The meter then provides a measurement of the level of glucose (sugar) in the blood.

**Hypoglycemia** is low blood glucose.

**Hyperglycemia** is high blood glucose.

**Sharps** are syringes, needles and lancets.

### ***Background and Rationale***

As part of their self-care, people with diabetes need to be able to test their blood glucose levels, often several times a day, to obtain information necessary for making appropriate adjustments to diet, activity and medications (including insulin). Regular blood glucose testing is critical to avoid and/or identify either hyperglycemia (high blood glucose) or hypoglycemia (low blood glucose); conditions which may require immediate treatment.

The treatment of mild to moderate hypoglycemia includes consuming food or drink containing carbohydrate (i.e. sugar). People with diabetes must immediately treat hypoglycemia in order to prevent more serious reactions.

People with diabetes who use insulin may be required to administer it several times a day by various devices including syringe, insulin pen or pump.

It is important that everyone using sharps work with and dispose of them safely and responsibly.

## **Section D**

### **Diabetes and Canadian Public Policy Encouraging Government Accountability**

## Enhanced Tax Credits for People with Diabetes

### ***Position Statement***

**The government of Canada should institute a system of enhanced tax credits wherein people with diabetes would be eligible for consideration for a non-refundable tax credit or a refundable payout specifically designed to reduce the burden of higher medical and treatment costs.**

### ***Definition***

The **Disability Tax Credit (DTC)** is a non-refundable tax credit applied to reduce the amount of income tax owing. Eligibility includes individuals with severe and prolonged disabilities or those who need life-sustaining therapy on an ongoing basis.

### ***Background and Rationale***

Canadians with diabetes, as well as other chronic diseases, face very high costs for medical care and treatment. An enhanced tax credit to assist with these costs would directly contribute to the health of Canadians and ultimately alleviate long term costs to the health care system. For those with diabetes, such a credit would reduce the financial burden of supplies and medication needed to manage diabetes and possibly prevent or delay the onset of complications.

Unlike the Disability Tax Credit, the enhanced tax credit would specifically address the economic burden of living with and managing a chronic condition, regardless of whether or not the condition has actually created a disability. The current Disability Tax Credit is limited to people who meet specific eligibility criteria based on severe physical and mental impairments. Most people with diabetes do not qualify to receive the Disability Tax Credit; however, they still face very high medical costs. As a result, some people with diabetes are forced to make decisions about their illness based on financial considerations rather than on the best care for their situation. With a disease such as diabetes, additional financial support can be the critical factor that may prevent or delay the development of potentially disabling complications.

## **Tax Incentives for Charitable Gifts**

### **Position Statement**

**To encourage more and larger philanthropic gifts, the government of Canada should implement charitable tax incentives equal to those allowed for political contributions.**

### ***Background and Rationale***

Health organizations such as the Canadian Diabetes Association rely on charitable gifts to fulfil their missions. They also play a vital role in sustaining the health of a community. In the face of dwindling health-care dollars and increased demand, it is important that Canadians are given every possible incentive to continue to support health organizations. This will be increasingly necessary as government asks that health organizations assume even more responsibility for the well-being of Canadians.

Canadians are encouraged to participate in the democratic process through political contributions which offer very generous tax incentives. An equal incentive for charities should be strongly encouraged.

## Disposal of Sharps

### Position Statement

**As an environmental issue, it is the responsibility of government to ensure a system for the safe and convenient disposal of household generated sharps, and to assume costs of such disposal.**

### *Background and Rationale*

Effective diabetes management requires blood glucose monitoring and, for some individuals, the injection of insulin. Both procedures generate items requiring special disposal (for example, sharps, lancets, et cetera). People with diabetes should not have to bear extraordinary costs for waste disposal associated with their disease.

## Organ Donor Registry

### ***Position Statement***

**A national organ donor registry should be developed, implemented and promoted in such a way that the maximum number of usable organs will be available for transplantation.**

**People with diabetes have a right to be assessed on an individual basis in determining transplant eligibility.**

### ***Background and Rationale***

People with diabetes often require organ transplants if severe complications ensue. The hallmarks of an organ donor system should include 'ease' (to encourage people to register) and 'proactiveness' (including educational efforts to promote awareness of such a system). As in all instances, eligibility should be determined on a case-by-case basis; one's diabetes should not be an impediment.