UNIVERSAL CARE*

* some exceptions apply

Alberta's 150,000 diabetics are at risk for blindness, stroke, kidney failure and amputations—and their treatments aren't covered.

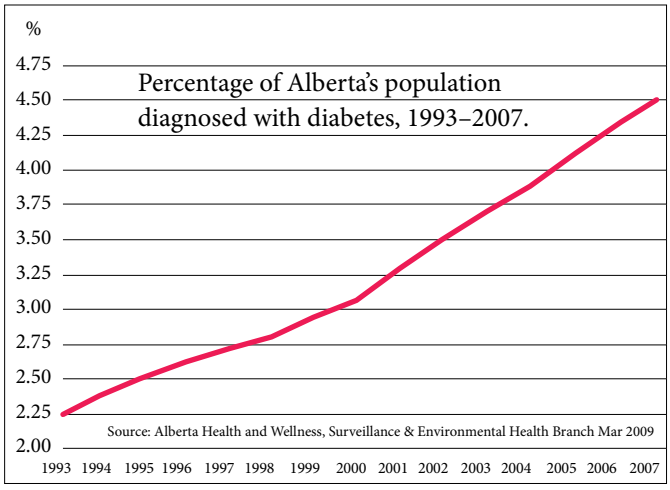
By GREG FLANAGAN

MY UNCLE, HARALD SKJEI, WAS BORN IN 1899 AND died from diabetes at the age of 14. A diagnosis of diabetes meant almost certain death before the historic work of Canadian doctors Frederick Banting, Charles Best, John Macleod and James Collip. The major work of isolating and synthesizing insulin was accomplished by Banting and his assistant Best in 1921 (with help from Collip, all overseen by Macleod). For the discovery, Banting and Macleod shared a Nobel Prize in 1923. The Canadian government gave Banting a lifetime annuity to work on his research; King George V knighted him in 1934, making him "Sir" Frederick Banting. In 2004, the doctor finished in fourth place in the CBC's "Greatest Canadian" contest.

The accolades heaped on Banting point to the major impact of the disease in the early 20th century. But it has only grown more serious in the ensuing decades. Today, it is a global epidemic affecting 250 million people. Diabetes is the fourth leading cause of death in the world, the sixth leading cause in Alberta.

Diabetes has no cure, only treatment. However, people with the disease can take control, lower the risk of complications and lead normal, productive lives. One might assume that most treatments for diabetics are covered by Alberta's healthcare system, whose purpose, after all, is to keep Albertans healthy and prevent future health problems. However, most treatments and methods of prevention for this chronic disease are not covered.

BY 2006, SOME TWO MILLION CANADIANS HAD BEEN diagnosed with diabetes. Diabetes affects 7 per cent of all Canadians aged 20 years or older and prevalence increases with age: from about 2 per cent in individuals in their 30s to over 20 per cent in people aged 75–79. About one-half of Canada's diabetics are aged 65 or greater. Most alarmingly, the rate of diagnosed diabetes has been rising steadily for all Canadians:



from 4.2 per cent of the national population in 2001 to 5.9 per cent in 2006, a 40 per cent increase over just five years.

In 2007, Alberta had over 150,000 diabetics. More than 12,000 new cases are diagnosed each year in Alberta, and the seniors cohort is expected to double by 2027.

Diabetes can lead to serious complications, including blindness, kidney failure, nerve damage, heart disease and stroke. Four out of every five diabetics die of heart disease. A person's risk of a stroke doubles after being diagnosed with type 2 diabetes. Diabetes is a leading cause of adult blindness; 20 per cent of diabetics will become blind. Adult diabetics are hospitalized 24 times more often for lower limb amputations, seven times more often for chronic kidney disease, four times more often for hypertension or heart failure and three times more often for heart attacks and strokes. Death rates in 2005–2006 for adults aged 20 and older were twice as high for diabetics. Diabetics in the 25–39-year-old cohort, for example, have a nine-year reduction in life expectancy.

Diabetes is a chronic condition where the body is unable to produce or properly use insulin. The body needs insulin to process sugar. There are many different forms of diabetes, although only two main classifications, type 1 and type 2.

Insulin pumps improve self-care, but aren't covered in Alberta.

Type 1, which cannot be prevented, accounts for less than 10 per cent of diagnoses in Canada; the other 90 per cent are type 2, for which one can take preventive measures. "Pre-diabetes"—that is, higher than normal blood glucose levels—is a warning sign. Millions of overweight, inactive Canadians likely have pre-diabetes. The risk of developing type 2 diabetes is significantly lower in people who maintain a healthy diet and weight, participate in regular physical activity, do not smoke and do not drink alcohol excessively.

Type 1, known as juvenile diabetes or insulin-dependent diabetes, is an autoimmune disorder where insulin-producing islet cells in the pancreas are destroyed. Without insulin, glucose accumulates in the blood. Almost all type 1 diabetics must take insulin to regulate blood sugar levels. Type 2 diabetes occurs when the body fails to use insulin properly and produces a declining quantity of insulin. Type 2 diabetes is also regulated with insulin injections, but therapies vary with severity.

Insulin is administered either with multiple daily injections (MDI) using a syringe or injection pen, or by pump—a small pager-like device that mechanically injects fast-acting insulin. It requires the setting of basal rates and the calculation of various insulin-to-food ratios, but allows diabetics to match insulin to carbohydrate intake.

Pump therapy can liberate diabetics, offering freedom, flexibility and microcontrol of insulin delivery. It's the method most recommended by many doctors. But an insulin pump is expensive, costing $6,000–$7,000 up front and $2,000 for supplies per year. Syringes, glucose testing meters, test strips, insulin, other diabetes drugs and additional medications to lower cholesterol and blood pressure are also expensive.

Treatment for diabetes (like that for many chronic ailments) falls to the discretion of the provinces, and there's a huge variation; the eligibility conditions and reimbursement criteria for different provincial plans differ widely. Some plans cover almost all costs for medication, supplies and devices; others provide little or no coverage. Ontario, for example, provides free insulin pumps and supplies to all Ontarians with type 1 diabetes. Alberta covers the relatively small cost of insulin, but doesn't cover pumps, syringes, glucose testing meters, test strips and many other treatments and equipment.

Where costs are largely borne by diabetics themselves—as in Alberta—self-management and control of the disease is limited. Some 57 per cent of diabetic Albertans say they aren't complying with their doctor's orders for treating their diabetes; 24 per cent of Canadian Diabetes Association members say they can't afford the cost of medications and supplies. Two out of every three Albertans with type 2 diabetes say they can't afford the food their doctor recommends for managing their diabetes effectively. More than 50 per cent of Canadians with type 2 diabetes are not at recommended target levels for their blood glucose levels, putting them at high risk of serious complications. Many do not get recommended tests, such as regular blood pressure checks, A1C and lipid tests, eye exams, foot exams and assessments to check for early signs of kidney disease.

The cost of diabetes to an individual Canadian not only depends on the province in which they reside, but on how old they are, how much they earn, where they work and who they live with. This is a long way from the principle of universal access upon which our healthcare system is founded. And Alberta has strayed as far from this principle as any province in Canada.

I MET SHERRY HAYWARD WHILE CAMPAIGNING AS A candidate during the 2008 provincial election. She brought to my attention the lack of financial support our healthcare system provides for the day-to-day needs of Alberta's diabetics. Sherry is a highly qualified and experienced nurse and has had type 1 diabetes for 50 years. As chair of a diabetes support group, she invited me to meet a number of Albertans—to hear their stories, successes and frustrations.

S.H. says she has difficulty affording her treatments. Her insulin pump cost $7,000; her out-of-pocket costs for test strips and injection pen tips are $3,000 annually. Only her insulin is covered by Alberta healthcare, a cost of about $500 per year.

R.B. has been diagnosed with type 1 for 20 years and injects insulin. His costs are about $3,500 per year. His wife's health plan covers all but 20 per cent of that, paying for pump supplies but not the initial cost of the pump. He also pays $100 to renew his driver's licence every year, a requirement for insulin-dependent diabetics. He's concerned that his wife's plan will expire when she retires.

J.P., type 1 for 55 years (since the age of 14), depends on multiple daily insulin injections. He was covered by a health plan at work, but as a retiree he depends on Blue Cross. His plan pays 70 per cent of the cost of drugs, such as an insulin called NPH which gives low control. However, J.P.'s doctor recommends that he uses Lantus insulin, which acts evenly and predictably. Lantus is not on Blue Cross's approved list, so J.P. pays $825 monthly—where NPH had cost him $100 per month.

G.T. has been diagnosed diabetic for over 30 years. His employment benefits cover 100 per cent of his costs. He notes that there are non-medical costs associated with diabetes, though, such as unpaid time spent seeing his family doctor and endocrinologists. He estimates he misses at least one hour of work every month to take fasting blood sugar levels, and another two hours every month for doctor appointments. Before he went on an insulin pump, G.T. spent 30 minutes a day testing

and injecting. He notes the cost to his supervisors in finding and managing replacements for him at work. G.T. says his pump gives much better control and confidence and eliminates many of these work-related costs. He argues that insulin pumps should be provided to all type 1 diabetics. He's concerned that diabetics' financial burden leads to poor control, complications and ultimately increased physician visits and hospital costs.

Ten years ago, at age 32, P.H. was diagnosed with type 1 diabetes. Her erratic disease meant numerous tests every day, frequent injections and a lot of expensive test strips, syringes and pen tips. Finding the right regime was difficult. P.H.'s doctor recommended an insulin pump, which relieved her concerns about getting appropriate amounts of insulin, especially during the night. The pump, however, cost $7,000 and was only expected to last four years; supplies cost $2,000 annually. Her variability required frequent testing, at a cost of over $4,000 per year for test strips. Her doctor recommended that she use a continuous glucose monitor for her blood sugar, which didn't eliminate testing but reduced the frequency from 16 tests per day to five. Her annualized costs for these two machines range from $10,000 to $12,500. As high as these costs are, P.H. notes that they're nothing compared to the social, economic and healthcare costs of not managing her diabetes. She's fortunate to have a good employee health plan, which pays 90 per cent of her expenses. But she too worries about how she'll cope once she retires.

E.J., an immigrant from Germany, said it most bluntly: How can Alberta claim to have universal medicare when certain individuals bear the costs of managing and treating a chronic disease?

As these accounts attest, the proper management of diabetes is expensive. Some fortunate Albertans receive financial support through workplace health plans. But many diabetic Albertans bear most of the costs themselves.

THE HEALTHCARE SYSTEM INCURS CONSIDERABLE costs from diabetes as well. The Alberta Diabetes Surveillance group reports that individuals with diabetes visit their doctor two to three times more often than non-diabetics, visit emergency departments twice as often and spend three times as many days in hospital. This is necessary to treat the complications of diabetes, but much of it is due to our failure to fund preventive treatments in the first place. The Public Health Agency of Canada estimates that the cost of these visits could be reduced by up to 50 per cent through better management and self-treatment.

Alberta's current approach to diabetes exposes serious flaws in our healthcare system. In accordance with the Canada Health Act, Alberta's publicly funded healthcare system guarantees that Albertans will receive "universal access to medically necessary hospital and healthcare services." Treatment for type 1 diabetes is absolutely medically necessary: without treatment, death is certain. However, most of the necessary treatments are not included under our provincial plan.

Alberta does provide some financial assistance to low-income diabetics. Alberta Health & Wellness funds the Alberta Monitoring for Health Program (administered by the Canadian Diabetes Association), Alberta Employment & Immigration funds Alberta Works Health Benefits, and Alberta Seniors & Community Supports funds the Alberta Seniors Benefit (Blue Cross) and the Assured Income for the Severely Handicapped program. However, any financial support is limited to the provincial "formulary," a list of drugs and medical devices available under government insurance plans. Even though it helps some seniors and people on social assistance, many medium-income earners get almost no help at all.

> Over half of Alberta's diabetics don't comply with doctor's orders, often because they can't afford to.

The Alberta government should commit to the following:

- Include diabetes medication, supplies and devices in medicare so that their costs are not a barrier or burden to managing the disease. (Of course, a nationally coordinated drug coverage system under the Canada Health Act would be preferable.)
- Decrease the number of Albertans with undiagnosed diabetes in order that management might begin before serious and costly complications arise.
- Expand team-based primary healthcare clinics, especially for diabetics, for the best possible management of the chronic illnesses—again saving the costs of much more expensive interventions down the road.
- Promote self-management training for diabetics.
- Develop a single formulary system which includes the best products based on medical evidence and doctor recommendations (e.g., insulin pumps). New products with proven efficacy should be listed in a timely fashion.
- Provide no-cost access to drugs, supplies, devices and assistance that improve diabetics' quality of life and encourage proper management of the disease. This will reduce or delay the onset of serious complications and reduce doctor visits, medical interventions and hospital stays—again, saving the healthcare system millions of dollars.

The discovery of insulin in 1921 is credited with saving 16 million lives this century. Tragically, the discovery did not come soon enough for my Uncle Harald and his family—and for the thousands of others diagnosed with diabetes before Banting & Co.'s momentous work. But this discovery was surely better late than never. So it should be with reforms to our healthcare system that allow everyone to be treated as equals, save our healthcare system money, free up space in our hospitals—and further normalize life for all of Alberta's diabetics. ■

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