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Complications

KRKT:T1DE · KRKT's Type 1 Diabetes Education

In an emergency. Someone with type 1 who is confused, very drowsy, can't swallow or is unconscious: call 911.

Education, not medical advice. Every dose, ratio and target belongs with your own diabetes team.

Complications

What the long-term risks of type 1 actually are, how far they have fallen, and what the evidence says you can do about them.

This is the part of type 1 many people dread most. There are no photographs of wounds or amputations and no worst-case stories. The aim is to make an existing fear the right size, not to add a new one. Four things before you start:

- **These are risks, not destinies.** Nothing here is something that *will* happen to you. Every number describes a group of people over decades, and every one of those numbers has fallen.
- **The numbers online are old.** Most published rates come from people diagnosed between 1950 and 1990, before A1C testing, modern insulins, pumps and sensors. They are not a forecast of your life.
- **Complications are not a verdict.** They happen to people who did everything asked of them. Biology, access, cost, other illnesses and luck all play a part.
- **You are probably already worried.** Worry about future complications is the most commonly reported problem among people living with type 1. These pages are here to make that fear accurate, not bigger.

Tone matters here: hopeful information given at diagnosis still shapes how people manage their diabetes one to five years later.

Sources: Diabetes Canada Clinical Practice Guidelines · DCCT (New England Journal of Medicine 1993)

What the DCCT showed, and what it cost

The 1983–1993 trial that proved managing glucose lowers the risk of complications, the 30-year follow-up, and the trade-off it came with.

Does the daily work of managing type 1 actually change what happens decades later? That question was settled in a randomised trial about forty years ago. This page explains what the trial found, what the 30-year follow-up added, and why the trade-off it came with looks very different today.

The trial

From 1983 to 1993, the **Diabetes Control and Complications Trial (DCCT)** followed 1,441 people with type 1 diabetes, split into two groups. One group got the standard care of the day. The other got intensive management: more injections, far more monitoring, constant adjustment.

It was a randomised trial, not an observation of people who happened to do things differently, and it is the reason the modern model of type 1 care exists.

After six and a half years, the difference between the two groups came down to one thing: an average A1C of about **7%** against about **9%**. That gap of two percentage points was the entire experiment. It is also the most important thing anyone with type 1 has ever been given: proof that the daily effort buys something real.

What those two points bought

Compared with conventional therapy, over a mean of 6.5 years, intensive management gave:

76%
lower risk of developing eye disease

60%
lower risk of nerve damage at five years

54%
lower risk of protein leaking into the urine

53%
lower risk of nerve damage affecting the heart

These are the largest effect sizes in the whole of diabetes medicine, and they came from managing glucose, nothing else. Note what they are: large reductions in risk. None of them abolishes the risk, and that honest distinction matters for everything that follows.

Thirty years of follow-up

When the trial ended, everyone was offered intensive management, and the two groups' A1C levels converged. A follow-up study called **EDIC** kept tracking them anyway. The gap that opened in those first six years never fully closed.

42%
fewer cardiovascular events at about 17 years, and still 30% fewer at 30 years

57%
fewer heart attacks, strokes and cardiac deaths

33%
lower risk of dying over 27 years (this difference took about 15 years to show up)

65%
of all participants still had no advanced eye disease at 30 years

That last figure is the one worth dwelling on. Two-thirds of the people in a 1980s cohort, using 1980s tools, reached thirty years without advanced eye disease.

Your body remembers the good stretches too

Researchers call this **metabolic memory**. A period of near-normal glucose keeps paying off for years afterwards, *even if* the numbers later rise again. In the four to eight years after the trial ended, when both groups had the same A1C, the original intensive group still had **72% less** eye disease progression and **84% less** new protein leakage from the kidneys.

And it works the other way too

The effect fades after about ten years. Researchers call that metabolic amnesia.

So a difficult year, a rough adolescence, or a period when life made diabetes impossible to manage is **not** a permanent sentence. The body forgets in both directions.

Both halves matter. People who have had a hard stretch often conclude that their future is already fixed. The evidence says otherwise: it is never a case of "the damage is already done".

What the trial cost, and why your version is different

The honest price in 1993

Intensive management came with **two to three times** the rate of severe hypoglycemia. That was the real trade-off, and it was a serious one. The DCCT was not a free win.

Stating that openly is what makes the rest of the numbers believable. But the people in the trial had no continuous glucose monitors, no alarms, no modern insulin analogues and no automated insulin delivery. Lower glucose and fewer severe lows are no longer opposing goals in the way they were then. Today's tools were built specifically to break that trade-off.

It is also worth remembering that every risk figure in these pages comes from people managing type 1 with the technology of decades ago.

Sources: DCCT (New England Journal of Medicine 1993) · EDIC (New England Journal of Medicine 2005) · EDIC (JAMA 2015) · EDIC (Diabetes Care 2016) · Understanding Metabolic Memory, Diabetes Care 2021

Eyes, kidneys and nerves

What happens to eyes, kidneys and nerves in type 1, how common it is, how far the rates have fallen, and what can improve.

The eyes, kidneys and nerves are affected by damage to small blood vessels, which is why they are often grouped together. This page explains, plainly, what can happen to each one and how common it is. But first, context: what has been happening to these numbers over the last few decades. Context first, then detail. The reverse order tends to produce fear rather than understanding.

The rates have already fallen, a lot

This is the most under-told part of the whole subject.

−77%

annual incidence of advanced eye disease in type 1, 1980 to 2007. Vision impairment fell 57% over the same period.

21%

eye disease at 15 years in a Belgian national registry in 2022, down from 36% in 2001

3–4%

kidney failure at 25 to 30 years across recent Swedish, Norwegian, Finnish and Japanese population studies

Kidney failure sits in the low single digits, not the figure people imagine. There is an honest caveat, though: early markers are falling faster than hard endpoints, and one Swedish registry found no clear drop in kidney failure since 2001. The direction is good, but it is not uniform.

Eyes

What happens. The tiny blood vessels in the retina, at the back of the eye, get damaged. In later stages, fragile new vessels can grow and bleed. Fluid can also collect at the centre of vision, and that is the more common cause of sight loss.

How common. Diabetes Canada puts advanced eye disease at about 23%, and fluid at the centre of vision at about 11%, among people with type 1. Those rates have been falling steadily for four decades.

> ### Why screening matters most here
>
> Eye disease is completely silent until it is advanced, and highly treatable when caught early. You cannot feel it coming and you will not notice it in a mirror.

Can it improve? Yes. Early changes can and do regress: improvement was seen in 18% of participants in the largest long-term study. Advanced disease is treatable with laser and injections, and sight is usually preserved.

Clinically meaningful eye changes are rare in the first five years after diagnosis, which is why Canadian screening starts at that point. If you take one action from this section, make it booking the annual eye appointment. It is the highest-value hour in the calendar.

Kidneys

Start with this: in a long-running Boston study, **58%** of people with early protein leakage saw it **go back to normal** over six years. Kidney disease is what people fear most after blindness, and it is the complication on this list most likely to genuinely reverse in its early stage.

It moves slowly, in stages. It usually takes five years or more to pass through each stage. Slow means there is time to act, as long as someone is looking.

Early changes are not rare. Around 15% of people show some protein leakage by 15 years, and 30% by 25 years. These figures come from people who lived with the tools of earlier decades, and early markers like this are the ones falling fastest. Either way, protein leakage is a marker to act on, not a diagnosis of kidney failure.

Kidney failure is the rare end. Roughly 3 to 4% at 25 to 30 years in recent population studies. Dialysis is not the expected destination.

What makes it regress. Blood pressure at target, glucose in range, lower cholesterol, and catching it early. Most of that is medication, not willpower.

> Diabetes Canada updated its chronic kidney disease chapter in 2025. The kidney figures and screening details here follow the guideline's stable structure; please confirm the current recommendations with your diabetes team.

Nerves

Longest nerves first. Nerve changes usually start in the feet, then the legs, then the hands. They can show up as burning or shooting pain, or as numbness. Numbness matters more, because losing protective sensation is what makes foot injuries possible.

Read the number carefully. Diabetes Canada says nerve changes are *detectable on examination* within 10 years in 40 to 50% of people with type 1. "Detectable" is a much wider category than painful or troubling, and symptoms are uncommon in the first five years. Like every rate on this page, it describes people who lived with older tools, and in the DCCT, intensive management lowered the risk of nerve damage at five years by 60%.

Nerves that run the body. The same process can affect the nerves that control heart rate, the bladder and the stomach. Slow stomach emptying (gastroparesis) affects roughly 5% of people over ten years, usually after other complications have appeared.

An honest point. Nerve damage is prevented far better than it is reversed, and slow stomach emptying in particular does not reliably improve even when glucose is in range afterwards. Gastroparesis is the complication most often blamed on the person who has it, and the evidence does not support that blame. Anyone told it is their fault has been told something untrue.

Nerve pain itself is treatable: several medications routinely reduce it by a third to a half.

Sources: Diabetes Canada Clinical Practice Guidelines (Ch. 29, 30, 31) · NIH/NCBI Diabetes in America · Belgian IQED registry · Frontiers in Nephrology 2023 · Swedish National Diabetes Register · Perkins/Joslin regression data · Diabetes Spectrum

Heart, feet, DKA and lost hypo warnings

Heart disease, foot care, diabetic ketoacidosis and hypoglycemia unawareness: what matters most, and how much of it can be prevented or reversed.

Eyes, kidneys and nerves get most of the attention. This page covers four things that matter at least as much: the heart and blood vessels, the feet, diabetic ketoacidosis (DKA), and losing the warning signs of a low. Each one comes with good news about what can be done.

Heart and blood vessels: the one that matters most

Cardiovascular disease is what actually accounts for most of the difference in life expectancy for people with type 1. In Scottish national data, ischaemic heart disease alone explained about a third of that difference.

Heart events are rare in young adulthood, but risk builds quietly from diagnosis onward. That is the whole argument for paying attention to cholesterol and blood pressure in your twenties, when nothing hurts. And this risk has already been shown to move: in the long-term DCCT/EDIC follow-up, intensive glucose management was linked to 42% fewer cardiovascular events at about 17 years.

> ### And it is the most modifiable
>
> This is the complication where things other than glucose do most of the work: blood pressure, cholesterol, not smoking, and staying active.
>
> Most of that is a once-daily tablet and a pair of shoes, not another mental load on top of the twenty decisions a day diabetes already asks for.

You may come across relative risk figures for heart disease in type 1 in research papers. They look alarming because they compare against a very low baseline in young people. They are real, but in everyday terms they can mislead badly, which is why none appear here.

Feet: the cheapest prevention in diabetes care

The chain is well understood and it runs in one direction: **loss of sensation → an injury that goes unnoticed → an ulcer → infection**. Almost every amputation is preceded by an ulcer, and almost every ulcer is preceded by a foot that stopped reporting pain.

Foot problems are less common in type 1 than in type 2, and the lifetime risks published online mostly lump both together.

> **Which is why this chain is breakable**
>
> An annual foot exam costs nothing and catches the first link. Looking at your own feet takes ten seconds a day.
>
> Numb feet do not report blisters, badly fitting shoes or a stone. If sensation is reduced, your eyes do the job your nerves used to do.

In Canada, the recommendation is a foot examination at least once a year, more often if anything has already been found. No technology, no cost, no burden: just a look.

DKA: the one that matters most in young adults

Most patient material spends its time on complications that take decades and skips the one that can become an emergency this weekend. In Scotland's national type 1 data, the largest single share of years of life lost before age 50 (around a quarter) came from **diabetic ketoacidosis (DKA) and diabetic coma**, not from eyes, kidneys or nerves.

DKA is an acute, fast-moving and preventable emergency. Reported death rates range from under 1% to around 3%, and delay in treatment is what drives the higher end. That is why acting early matters so much.

What sets it off:

- illness and infection
- a pump failing (with no long-acting insulin in the body, DKA can develop quickly)
- insulin not taken: it ran out, it was unaffordable, the person was too unwell to dose, or they were avoiding it

In research, "insulin omission" covers all of those causes. It does not mean carelessness.

> This is why sick-day rules and ketone strips are not an optional extra. They are the part of diabetes education that saves the most years of life. The Emergencies section covers sick days and the signs of DKA.

Losing the warning signs of a low, and getting them back

Repeated lows can train the body to stop reacting to them. The shaking and pounding heart that used to arrive at around 3.5 mmol/L stop appearing, and the first sign of a low becomes confusion, or nothing at

all. This is called hypoglycemia unawareness.

It is a complication in its own right, and the one that most limits everything else. It makes tight targets unsafe, and it feeds the fear that shapes daily decisions.

The good news: **it is reversible**. Strictly avoiding lows for anywhere from a couple of days to three months has been shown to bring the warning symptoms back, at least partly. Diabetes Canada's advice is to deliberately **loosen** targets for up to three months to do it. Recovery is often partial rather than complete: sensors help restore some symptoms without fully restoring the body's hormone response.

So if someone is told by their team to run higher for a while, that is good medicine. It is not backsliding, and nobody should treat it as such. It is a useful reminder that lower is not always better.

Sources: Livingstone et al., Scotland · Swedish National Diabetes Register · Diabetes Canada Clinical Practice Guidelines (Ch. 14, 15, 32) · NIDDK workshop, Diabetes Care 2022

Screening, targets and the five levers

The Canadian screening schedule for type 1, what guideline-level success really looks like, and the five risk factors that shape long-term outcomes.

This is the practical page: the checks to book, the targets that define success, and the five things that together shape long-term risk. If you leave having booked one overdue appointment, this page has done its job.

The Canadian schedule: the actual to-do list

What	When it starts	How often	What it involves
Eyes	5 years after diagnosis, age 15+	Annually	An optometrist or ophthalmologist looks at the retina
Kidneys	After 5 years' duration	Annually	A urine sample and a blood test
Nerves	5 years after puberty ends	Annually	A nylon filament and a tuning fork on the feet
Feet	From diagnosis	At least annually	Someone looks at them properly, shoes and socks off

What	When it starts	How often	What it involves
Cholesterol	At diagnosis	Annually if untreated	A blood test, fasting or not
Blood pressure	From diagnosis	Every visit	Target below 130 over 80

Notice that every screen for the small blood vessels (eyes, kidneys, nerves) begins at **five years**. Canadian guidelines do not expect a newly diagnosed person to have anything to find.

> Diabetes Canada updated its chronic kidney disease chapter in 2025. The kidney screening interval above follows the guideline's stable structure; please confirm it with your diabetes team.

What success actually looks like, and it is not 100%

These are the time-in-range targets from the 2019 international consensus, plus Diabetes Canada's A1C target. They apply to most non-pregnant adults; children, older adults and pregnancy have their own targets, so check yours with your team.

>70%
time in range, 3.9 to 10.0 mmol/L: about 17 hours of the day

<4%
below 3.9 mmol/L: about an hour a day, and under 1% below 3.0

<25%
above 10.0 mmol/L: roughly six hours, and under 5% above 13.9

≤7.0%
A1C, for most adults: Diabetes Canada's target

Read the first two together. **Success, as the guidelines define it, includes roughly seven hours a day outside range and about an hour low.** If every high reading feels like a failure, the target itself says otherwise. Perfectionism drives burnout, and the guideline is the best argument against it.

Glucose is the biggest lever. It is one of five.

Swedish registry research models outcomes by how many of five risk factors are on target, and risk rises step by step for each one that is not. This is genuinely good news that is rarely told: four of the five are handled at an appointment, not at every meal.

Glucose. A1C at or under 7.0%, time in range over 70%. This is the one that takes constant attention.

Blood pressure. Under 130 over 80. Usually one tablet, checked at every visit.

Cholesterol. LDL under 2.0 mmol/L, or halved. A statin is indicated from age 40, or from age 30 with 15 years' duration of diabetes.

Kidney protection. An ACE inhibitor or ARB where indicated. It is the strongest kidney intervention there is, and it works independently of glucose.

Not smoking, and moving regularly. Both sit in the same model as the other four.

> ### Ask about the four levers that aren't glucose
>
> Blood pressure, cholesterol, kidney protection and smoking. Most people with type 1 have never been walked through them. Whether any of these medications is right for you is a decision for you and your diabetes team.

There is an honest limit here: even with all five on target, kidney risk in type 1 stays above that of the general population. Managing these risk factors roughly halves the extra risk rather than erasing it. That is still a very large effect, and most of it does not depend on moment-to-moment effort.

Sources: Diabetes Canada Clinical Practice Guidelines (Ch. 8) · Battelino et al., Diabetes Care 2019 · Rawshani et al., Diabetes Care 2022

A complication is not a verdict on effort

Why complications happen to people who did everything asked of them, how cost and access shape care in Québec, and why diabetes distress is normal.

When a complication appears, the first question people often ask, of themselves or of someone they love, is "what did I do wrong?" This page explains why that question has the evidence backwards, what really shapes care in Canada and Québec, and why the emotional weight of type 1 deserves to be named.

A complication is not a verdict on how hard someone tried

People develop diabetes-related complications having done everything they were asked to do. Genetics, blood pressure, other health conditions, age at diagnosis, what technology they could get, and plain luck are all part of the picture. Effort is one input among many.

It is also the only input anyone ever gets blamed for, and there is direct evidence that blame makes every other input worse. People who experience stigma have higher A1C, more variable glucose, and are **less likely to come back for follow-up care**.

Which means shame is not a harmless motivational tool that happened not to work. **It is a risk factor.**

If you are a family member reading this, this may be the most important sentence on the site for the person with diabetes to hear you understand.

Why care goes wrong, even with public healthcare

Public healthcare does not mean everything is covered. Concrete, checkable figures:

$18,306

a year: what out-of-pocket costs can reach for someone with type 1 in parts of Canada, according to Diabetes Canada

Over half

face costs above 3% of family income, or cannot follow the treatment their doctor recommended. That is a Canadian figure.

In Québec specifically, the public insulin pump program covers **people under 18 only**. An adult diagnosed at 25 gets no public pump funding, so whether they use one depends on private insurance, not on clinical need.

The sensor paradox. The RAMQ covers glucose sensors for adults only if their A1C is above target, or if they have frequent or unrecognised lows. So doing well can disqualify you from the very tool that helped.

Add depression, which affects people with diabetes at roughly three times the general rate, and it becomes clear why what gets called "improper care" is usually a description of circumstances, not of character.

Diabetes distress is a normal reaction, not a weakness

Between **1 in 4** and as many as **2 in 5** adults with type 1 report high levels of diabetes distress: the emotional weight of relentless daily management. The research describes it as an expected response to living with diabetes. It is not a mental health disorder.

What it is about. The most frequently reported source of that distress is **worrying about the future and the possibility of serious complications**, the very subject of this section.

It travels with harder numbers. Distress is associated with higher A1C and with doing less of the daily management, roughly as strongly as depression is. Adding fear does not improve either.

Numbers in range don't guarantee peace either. Some people reach their targets through intense, unsustainable effort that costs them everywhere else. An A1C tells you nothing about what it took.

> ### Say it out loud if it feels heavy
>
> Distress, and burnout (exhaustion and detachment from the whole thing), are common, treatable and routinely go unmentioned in appointments. Bring them up with your diabetes team the way you would a blood result.

If you recognise yourself here, that recognition is the point. You are not alone, and there is help.

Sources: Diabetes Canada out-of-pocket costs report · Québec Insulin Pump Access Program · RAMQ via Diabète Québec · MILES-2 · ADA/NDSS Diabetes and Emotional Health

Disordered eating, and what families can say

How fear of complications can feed insulin restriction, and the words that help or hurt when you support someone with type 1.

Information about complications is meant to help, but delivered badly it can cause harm of its own. This page covers one risk that talks about complications can create, and then the words that help, or hurt, when you are supporting someone who lives with type 1.

The risk that talk about complications can create

Around **a quarter** of people living with insulin-treated diabetes screen positive for disordered eating, and roughly **one in five** report skipping or reducing insulin, often to influence their weight. These are screening-questionnaire results rather than diagnoses, but they show how common the problem is.

It is a foreseeable consequence of a condition where the medication that keeps you alive also affects your weight, and where numbers are discussed as if they were grades.

Reducing insulin is linked to eye and kidney damage more often than other weight-control behaviours are, and it raises the risk of diabetic ketoacidosis (DKA).

Why does this belong in a section about complications? Because telling someone that high glucose harms their eyes, while insulin is also the thing that adds weight, builds exactly the kind of thinking that

leads to insulin restriction. Talking about complications while ignoring this is not neutral.

If this sounds familiar

It is a conversation to have with a clinician, not something to manage alone. It is common, treatable and not shameful. If someone you love recognises themselves here, offer to help them find support rather than pressing for detail.

For families: the words that do damage, and what to say instead

The sentences below are drawn from published lists of language to avoid, not from anyone's personal opinion. If you recognise one you have said, you are in very good company. It is not a rebuke, just a place to start.

Avoid

- "You'll go blind / lose a foot / end up on dialysis"
- "My grandmother had diabetes and she..."
- "Is your sugar *good* today?"
- "Should you be eating that?"
- "You just need more discipline"
- "What did you do?" after a high reading

Try instead

- "How are you doing with it?"
- "What would actually help right now?"
- "That looks like a lot of work."
- "Tell me a bit more about what worries you."
- Or nothing at all about the number on the screen.

Across international surveys, 96% of people with diabetes find the word "sufferer" unacceptable, and 83% reject "good" and "bad" applied to blood sugar.

Worth knowing

Nobody caused it. Type 1 is autoimmune. It was not caused by diet, by parenting, or by sugar.

Judgement leads to hiding. People under-report readings they expect to be judged for, and hidden numbers are a safety problem. A calm, neutral response to a number keeps it visible.

The help that is wanted is usually quiet. Learning how to give glucagon, knowing the sick-day rules, driving to appointments, not making a scene at dinner.

Sources: Eating Behaviors 2024 (systematic review and meta-analysis) · dStigmatize · ADA 2017 · Diabetes Canada Language Matters · Diabetes Australia

KRKT's Type 1 Diabetes Education (KRKT:T1DE), from the KRKT Library.

Education, not medical advice. Every dose, ratio and target belongs with your own diabetes team.