

Thank you for reviewing our draft patient guide. We greatly appreciate your time and insights.

Once we collect all feedback, our writers and designer will edit the guide based on what we hear. This can include making it shorter and easier to read. To see an example of a designed guide, please see our draft patient guide for [Diabetes in Pregnancy](#). (Note: All guides may look different.)

When you're finished reading the draft patient guide, please fill out [this survey](#) by **October 10, 2019**.

**Health Quality
Ontario**

Let's make our health system healthier

Ontario 

IMAGE TBD

Type 1 Diabetes

What to discuss with your care team to help you receive high-quality care

Managing type 1 diabetes

Diabetes happens when there's too much sugar—or glucose—in your blood. Blood sugar is your main source of energy. It comes from the food you eat, and a hormone (a special chemical) called insulin helps your body use this energy.

With type 1 diabetes, your body doesn't produce insulin and can't manage your blood sugar on its own. It's usually diagnosed in children or young adults but can appear at any age. It is a serious, lifelong condition.

You might have a new diagnosis, or you might have had type 1 diabetes for a while but still have questions about how to manage it from day to day.

This guide doesn't tell you everything you need to know about diabetes. But it can help you talk to your care team about living with type 1 diabetes and ways to handle common challenges. It supports those conversations with questions on:

- Staying healthy with type 1 diabetes
- Checking your blood sugar
- How diabetes technology can help
- Making the transition to adult diabetes care

If you don't have time to go through the entire guide, use this checklist as a quick reference when you talk to your care team.

The questions included in this guide are optional, and some may not apply to you. You might have other questions to ask, too. The more you talk with your care team, the more help you can get managing your diabetes.

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*"I didn't want people to think of me as someone with an illness. I just wanted them to think of me as the person I was before the diagnosis.
... I didn't want the diagnosis or the illness to define me."*

PERSON WITH TYPE 1 DIABETES

If your child has type 1 diabetes

If your child has type 1 diabetes, this guide will highlight questions that might come up for parents or other caregivers.

You and your family aren't in this alone. Your care team will build a trusting relationship with you and your child and support you both through your routines.

Type 1 diabetes can run in the family, and you might know how to manage it for yourself or another adult. However, diabetes in children is different, and your role in managing it will be different, too. Your child's care team will help you learn how to handle their diabetes and feel more confident in your role.

"I had type 1 diabetes for 40 years but didn't worry until my daughter was diagnosed."

PERSON WITH TYPE 1 DIABETES

Learn more

[AboutKidsHealth Diabetes Resource Centre](#) shares information for children, youth, and their families about diabetes, from symptom recognition, diagnosis and treatment, to long-term complications.

[Clinic Conversation Guide](#)—this guide from the Type 1 Diabetes Think Tank Network can help you to talk with your health care providers and ask for the support you need

[Diabetes at School](#) provides resources and tools for families, schools, and parents to support children and youth with type 1 diabetes in schools

[Diabetes Canada](#) shares a range of information about diabetes, including tools and resources for you and your family (fact sheets, recipes, interactive tools, videos, webinars)

[I Challenge Diabetes](#) offers education programs, workshops, and other opportunities to support, empower, and connect people of all ages living with type 1 diabetes

Staying healthy with type 1 diabetes

Managing your diabetes involves looking at different things—your blood sugar, your diet, how active you are, and the insulin you take—to stay healthy. It takes time and effort to handle each part and to understand how they interact with each other.

Putting all the pieces together can be tough emotionally, too. Don't hesitate to check in with your care team about how you're feeling. Talking to others with type 1 diabetes can help, too.

Ask your care team:

.....
How often do I need to see my care team if I'm doing well?

Is there someone I can talk to about the stress of handling everything?

What resources and support services (locally or online) can help me?

Tell your care team:

.....
If you're having trouble managing day-to-day diabetes care

If you need emotional support

"You have to be adaptable and figure out what works best for you."

PERSON WITH TYPE 1 DIABETES

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If your diabetes routine that used to work isn't keeping you in your target range anymore

If you need help managing diabetes in a new situation; for example, while travelling, if you're under stress, or if you're planning to become pregnant

My endocrinologist sees me as the person in the driver's seat and asks what I need from her ... [My care team] are my pit crew; they're not the driver."

PERSON WITH TYPE 1 DIABETES

If your child has type 1 diabetes

Parents for children with type 1 diabetes are always on alert. Monitoring your child's health and ensuring that their care continues at school or during activities outside your home takes a lot of effort.

The care and time managing your child's condition and gradually helping them learn to manage it on their own can be stressful. But there is support out there for you, too.

Ask your child's care team:

- How can I work with my child's daycare or school to manage their diabetes safely while they're there? What supports are available to help me?
- At my child's age, how can I help them be more involved in managing their diabetes? How can I help them manage their diabetes at school or when they are with friends?
- What can I do to help and support my child to cope with the stress of managing their diabetes?
- Where can I find resources or support for me? Where can I find groups for parents with type 1 children in my community or online?

Where can I find support?

[Talk T1D](#) provides one-on-one peer support to families and individuals living with type 1 diabetes.

[Diabetes Canada](#) provides resources to support parents of people with type 1 diabetes.

The Diabetes Hope Foundation offers a [Peer Support Program](#) for teens ages 13 to 18 living with type 1 diabetes, and the [HOPE Connects Program](#) is a mentorship for post-secondary students living with type 1 and 2 diabetes.

Checking your blood sugar

Checking your blood sugar levels and staying within a healthy range can be challenging, even when you're doing all the right things.

Keeping your levels in range takes a careful balance between what you've eaten, how active you are, and the amount of insulin you give yourself. It can take time to figure out what works for you.

You and your care team can work together to set your target blood sugar range and target glycated hemoglobin (A1C). They will also help you create a routine that helps you stay in this range as much as possible.

Ask your care team:

.....
What information will we use to see if I'm in my target range?

I'm following my plan, but my blood sugars aren't in range, what can I do?
Could something else be affecting my sugars?

How do I stop low and high blood sugars before and after exercise?

Are there any tools or technology that can help me stay in range? How do I use the information they provide?

The A1C test

At least twice a year, your care team will do a test called a glycated hemoglobin, or A1C. This measures your average blood sugar levels for the past two to three months, which lets you and your care team know if your diabetes management plan is working well.

Your A1C number isn't a test to pass or fail—you're aiming for the healthiest range for you, which can help reduce or prevent diabetes complications.

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Tell your care team

.....
If you don't feel involved in setting your targets

If there are things that make it hard to reach your targets

If your child has type 1 diabetes

Ask your care team:

- How important is the A1C test for children?
- What factors might make the test results different in children?

“Meeting targets [is] about me being satisfied with outcomes and management. I don't pay much attention to whether I'm meeting a [standard] goal or not; it's whether I'm meeting my personal goal for targets and A1C.”

PERSON WITH TYPE 1 DIABETES

How diabetes technology can help

You use devices to help manage your diabetes, including glucose monitors to check your blood sugar and other tools and technology to take insulin.

It's helpful to talk with your care team about the different devices that are out there and whether it makes sense to try something new. They can help you choose the tools that meet your needs, preferences, and budget.

No matter what devices you use, it's important to get training and education on how to use them properly—you should be comfortable using them and have ongoing support to solve any problems or questions.

Glucose monitors

Blood glucose meters, continuous glucose monitors, and flash glucose monitors:

- Measure whether your blood sugar is low or high
- Help you to see how food, exercise, and insulin affect your levels
- Help you and your care team decide whether to make changes to your insulin or routines

Depending on your device, it may provide more information on glucose patterns and trends. Some tools, like continuous glucose monitors, offer alerts when sugars are too high or low.

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Insulin devices

You can inject insulin with a syringe, pen, or pump. Your care team can help you choose the device and needles that suit you and suggest different needles if your skin gets sore or irritated.

Depending on your device, it may:

- Measure and inject insulin (“smart” pen)
- Show a history of your doses and the timing (smart pen)
- Deliver insulin continuously throughout the day (an insulin pump)
- Adjust your insulin automatically based on monitor readings (a pump that works with a continuous glucose monitor)

Ask your care team:

What type of device (glucose monitor or insulin) would be best for me (or for my child)?

What are its pros and cons? What are the risks?

Will I have to pay for my device (glucose monitor or insulin) or supplies? Are there any programs that can help me pay for them?

What training and support can teach me (or my child) to use the device (glucose monitor or insulin) and act on the results?

What are the newest glucose monitoring or insulin devices available in Ontario? Would any of them be good for me (or my child)?

What tools or apps are available for me and my family to see my or my child’s blood sugar data remotely on a smartphone, tablet, or computer?

Making the transition to adult diabetes care

If you have diabetes as a child or a teenager, your care will change as you get older. At a certain age (usually 18 years old), you'll leave your child-focused diabetes team for an adult diabetes clinic.

The transition is a big step for both teens and parents, who are balancing practical, emotional, and financial changes at this stage in life. Teenagers might be going to college or university or leaving home as they're moving to adult diabetes care.

Your care team will work with you before the transition to help keep the move to adult care smooth. They'll assess how prepared you are to move into adult care, and whether there are things you still need to learn about diabetes.

Learn more

- The Diabetes Hope Foundation offers transition resources, including a [Transition Resource Guide](#) and a [Peer Support Program](#)
- [Got Transition](#) offers resources and tools to help with transitions, including questions to ask your care team about your transition, videos, and checklists

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For your reference: the quality standard in brief

Health Quality Ontario is committed to helping patients, health care providers, and organizations improve the quality of health care in Ontario.

We know that not everyone across the province receives the right care, every time. So, to help address gaps in care, we produce quality standards that outline **what quality care looks like** for specific conditions and situations, such as type 1 diabetes. Quality standards are based on current best evidence and input from patients, caregivers, and health care providers.

This patient guide accompanies the quality standard on type 1 diabetes.

If you're interested in the quality standard, below is a summary. To read more, you can download it [here](#).

Diabetes Self-Management Education and Support

People with type 1 diabetes and their family and caregivers are offered an individualized, structured self-management education and support program at diagnosis and on an ongoing basis.

What this means for you

Starting from the time of diagnosis, you and your family and caregivers should be offered education and support to help you learn about type 1 diabetes and ways to manage it effectively. Your needs are unique and change throughout your life, and the education and support you receive should address your individual needs and involvement in your own care.

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If you are a parent or caregiver of a child with type 1 diabetes, you will have a greater role in managing their diabetes. Education and support will be tailored to you and your needs during this time. As children grow up and become more independent, they will increasingly take over responsibility for their care and self-management, and education and supports should shift accordingly.

Access to an Interprofessional Care Team

People with type 1 diabetes have access to an interprofessional diabetes health care team with training in type 1 diabetes.

What this means for you

- You should have access to a care team with expertise in type 1 diabetes care. This team may include doctors, nurses, a social worker, a pharmacist, and others
- You and your family should be included as important members of your care team. Your questions, concerns, observations, and goals should be discussed and incorporated into your care plan
- You should be supported to play an active role in your own care

Setting and Achieving Glycemic Targets

People with type 1 diabetes, in collaboration with their health care team, set individualized glycemic targets, including glycated hemoglobin (hemoglobin A1C) and other available measures of glycemia. All available data are used to assess whether individualized glycemic targets are achieved and to guide treatment decisions and self-management activities.

What this means for you

Your diabetes care team should work with you to determine your target hemoglobin A1C value and target glucose range (before meals and after

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meals). Staying within target will help reduce complications. You should be offered treatment and support to help you reach and stay at your targets.

Please see page 9 for more information about checking your blood sugar.

Identifying and Assessing Mental Health Needs

People with type 1 diabetes are screened for psychological distress and mental health disorders on a regular basis using recognized screening questions or validated screening tools. People who screen positive for a mental health disorder are assessed by a health care professional with expertise in mental health.

What this means for you

Managing your diabetes is demanding, and it can affect your emotional well-being and quality of life. It is normal to sometimes feel burnt out or tired of managing your diabetes. Maintaining your mental and emotional health is important to help you take care of yourself and your diabetes. Your health care professional should ask about your mental health and how diabetes is impacting you and offer you treatment and support, if you need it.

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Transition from Pediatric to Adult Diabetes Care

People with type 1 diabetes experience planned, coordinated, and supported transitions from pediatric to adult diabetes care.

What this means for you

When you are preparing for the transition to adult care, your care team should:

- Start working with you early to ensure a smooth transition
- Give you care that's appropriate to your age and individual needs
- Make sure that you and any new team members have the right information
- Make sure you receive the information and services you need

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What's next?

Remember, everybody is different.

The support you need and the care plan you develop with your care team will be unique to you.

This conversation guide is meant as only a starting point.

You may have other topics you want to cover with your care team. It's important to speak to them about any other questions or concerns.

Need more information?

If you have any questions or feedback about this guide, please contact us at qualitystandards@hqontario.ca or 1-866-623-6868.

For more reading on type 1 diabetes, read the quality standard at: hqontario.ca/qualitystandards

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