

Type 1 Diabetes

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



**Ontario
Health**

Ontario Health is committed to improving the quality of health care in the province, in partnership with patients, health care professionals, and other organizations.

To do that, Ontario Health develops quality standards that set out important steps to treat conditions like type 1 diabetes. These standards are based on current evidence and input from an expert committee that includes patients, health care professionals, and researchers.

If you're interested in learning more about the quality standard on type 1 diabetes, see page 13 of this guide. It has a summary of the top five areas to improve care for people with type 1 diabetes. You can also download the complete [quality standard here](#).



Managing type 1 diabetes





Diabetes develops when your body can't adjust sugar—or glucose—levels in your blood. Blood sugar is your main source of energy: it comes from the food you eat. A hormone (a chemical) called insulin helps you use this energy.

With type 1 diabetes, your body produces little or no insulin. Because of this, your body can't manage your blood sugar on its own. Type 1 diabetes is usually diagnosed in children or young adults, but it 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 type 1 diabetes. But it can help you talk with your care team about living with type 1 diabetes and its common challenges. It supports those conversations with questions about:

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

If you don't have time to go through the entire guide, use this checklist when you talk with your care team. The more you talk with them, the more help you can get managing your type 1 diabetes.

*"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 support you and your child with your diabetes 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.



Resources for children and adults

- [AboutKidsHealth Diabetes Resource Centre](#) shares information for children, youth, and their families about diabetes—from symptom recognition, diagnosis, and treatment, to long-term complications.
- The [Clinic Conversation Guide](#) from the Type 1 Think Tank Network can help you to talk with your health care providers and ask for the support you need.
- [Connected in Motion](#) offers diabetes education and sport and outdoor adventure opportunities for youth and adults with type 1 diabetes.
- [Diabetes at School](#) provides resources and tools for families, schools, and caregivers to support children and youth with type 1 diabetes in schools.
- [Diabetes Canada](#) shares information about diabetes, providing tools and resources for you and your family, such as fact sheets, recipes, interactive tools, videos, webinars, and local programs and events (including camps for children with diabetes).
- [I Challenge Diabetes](#) offers education programs, workshops, and other opportunities to support, empower, and connect people of all ages living with type 1 diabetes.
- [JDRF Canada](#) provides support and resources for people of all ages living with type 1 diabetes and their families.



Staying healthy with type 1 diabetes

You do a lot to stay healthy with type 1 diabetes, including checking your blood sugar, eating a healthy, balanced diet, staying active, and taking insulin. It takes time and effort to handle each part of your care 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 with 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 with about the stress of handling everything?
- ☐ What resources and community 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
- ☐ If your diabetes routine that used to work isn't keeping your blood sugar levels in your target range anymore
- ☐ If you need help managing type 1 diabetes in a new situation: for example, while travelling, if you're under stress, if you're feeling depressed or anxious, or if you're planning to become pregnant



Write it down

It can help to take notes as your symptoms, or your child's symptoms, develop and change. Having notes with these details will help you describe things clearly when you talk with your care team.

At visits with your care team, a friend or family member can take notes for you. That can make it easier for you to remember your discussions with your care team.

If your child has type 1 diabetes



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

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 my child's diabetes safely? 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 in coping with the stress of managing their diabetes?
- ☐ Where can I find resources or support for me? Where can I find groups for parents of children with type 1 diabetes in my community or online?



"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



"Everybody is different, and everyone needs different management strategies for their type 1 diabetes."

PERSON WITH TYPE 1 DIABETES



Where can I find support?

JDRF offers the [Talk T1D](#) program, which provides one-on-one peer support to families and individuals living with type 1 diabetes.

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

The Diabetes Hope Foundation offers a [Peer Support Program](#) for teens ages 13 to 18 living with type 1 diabetes. Its [HOPE Connects Program](#) provides mentorship for postsecondary students living with type 1 and 2 diabetes.



Checking your blood sugar

Checking your blood sugar levels and keeping them within a healthy range can be challenging, even when you're trying your best.

What you eat, your activity level, and your insulin doses all affect your blood sugars.

Things like stress, hormones, and growth influence your levels, too. 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 targets for another test called an A1C (see box). They will also help you create a routine that helps you stay in this range as much as possible.



The A1C test

At least twice a year, your care team will do a test called a glycated hemoglobin, or A1C, test. The A1C result shows you and your care team how well your diabetes management plan has been working over the past 2 to 3 months.

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



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 blood sugars?
- ☐ How do I avoid low and high blood sugars before and after exercise?
- ☐ Are there any tools or technologies that can help me stay in range? How do I use the information they provide?



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 child's 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



See page 13 (quality statement 3) for more information on setting goals for your blood sugar and A1C ranges.



How diabetes technology can help

Different devices can help you manage your type 1 diabetes. For example, blood glucose monitors can check your blood sugar, and other tools can help you take your insulin.

Talk with your care team about the different devices out there and whether to try something new. Your team 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 can:

- Measure your blood sugar
- Help you to see how food, exercise, insulin, and other factors affect your blood sugar levels
- Help you and your care team decide whether to make changes to your insulin doses or daily routines

Depending on the device you choose, it may also show information about blood sugar patterns and trends. Some tools, like continuous glucose monitors, offer alerts when blood sugars are too high or too low.



Insulin delivery devices

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

Depending on your device, it may:

- Measure and deliver insulin
- Show a history of your doses and the timing
- 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)



See page 13
(quality statement 1) for
more information on type 1
diabetes self-management
and support.



Ask your care team:

- ☐ What type of device (glucose monitor or insulin delivery device) 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 delivery device) or supplies? Are there any programs that can help me pay for them? If so, what are the initial and ongoing requirements for those programs?
- ☐ What training and support is available to teach me (or my child) to use the device (glucose monitor or insulin delivery device) and act on the results?
- ☐ What are the newest glucose monitoring or insulin delivery 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 develop type 1 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.

This 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, leaving home, or working at the same time 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 type 1 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.



See page 13 (quality statement 5) for more information on the transition from pediatric to adult diabetes care.



For your reference: The quality standard in brief

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

Below is a summary of the top five areas to improve care for type 1 diabetes. To read more, you can download the [quality standard here](#).

Quality Statement 1: Diabetes Self-Management Education and Support

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

Quality Statement 2: 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.

Quality Statement 3: 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.

Quality Statement 4: 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 referred to a health care professional with expertise in mental health for further assessment and treatment.

Quality Statement 5: 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'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 only a starting point.

You may have other topics you want to cover with your care team. It's important to speak with 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@ontariohealth.ca or 1-866-623-6868.

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