

GUIDE TO ADULT CARE

Transitioning to Adult Health Care with T1D





What's Inside

The Guide to Adult Care features four sections, each containing tips, important information, and downloadable tools designed to help you through your transition to adult care. To access a specific section, click the title below.

About the Guide

Learn more about why the Guide was written and the team behind it.

Preparing for Transition

Information to help you gauge what you know, what you need to know and how to choose the best adult care option for you.

Starting Adult Care

Everything you need to know about navigating the adult health care setting, including what to expect at appointments and tips on how to make sure you are ready for your appointments.

Taking Control of Your Health

Information to help you become a strong self-advocate to ensure you are receiving the care you need to manage your diabetes.

Using the Guide

<u>Underlined</u> Text

Indicates a live link you can use to get more information from external resources.



Link to downloadable forms and resources related to the topic. All downloads are also available at www.diabeteshopefoundation.com.



Click the back arrow to return to the What's Inside page.

DISCLAIMER

The information in the Guide to Adult Care is intended as guidance only and is not intended to be used for medical advice or planning. Please talk with your health care team about your personal diabetes management plan before making any changes to your health care. Information in the Guide is not exhaustive - your care team and the linked referenced materials should be used to enhance your knowledge.

Welcome to the Guide to Adult Care!

DHF is excited to offer you a collection of resources, reading materials, and practical tips to support you as you transition from pediatric to adult care. Written by T1Ds for T1Ds, the Guide to Adult Care was designed to provide you with important information that will help you prepare for receiving care as an adult with T1D. The Guide is filled with tip sheets and downloadable tools, including topics such as knowing your rights, exploring technology options, differences in adult care, establishing boundaries, finding your ideal healthcare team... and so much more!

Along with the Guide to Adult Care, be sure to explore DHF's other programs and resources, including:

- The <u>HOPE Connects Program</u> matches students in grade 12 or first- and second-year college/university with a peer mentor, allowing them to talk to someone who knows first-hand what it's like to manage T1D while at post-secondary school.
- The <u>T1D Campus Connect</u> Discord server provides a virtual connection to T1D students across Canada. Each channel focuses on something different, such as tech talk, high & low tricks, general conversation, questions, and pet pictures!
- The <u>Student Transition Planner</u> is a comprehensive resource that contains all the information you need to successfully navigate post-secondary school with T1D.

All of DHF's programs are created in collaboration with youth living with T1D to help you navigate your transitions!

Wishing you all the best in your diabetes journey, and welcome to the DHF Community!

The Hope Connects Team

Message from the Authors





Heather Janine, Hope Connects Facilitator

This guide has been thoughtfully designed to help you navigate the unique aspects of adult care and address the key challenges that come with it. Throughout its development, we drew on our personal experiences and research to create a practical and insightful resource specifically tailored to your needs.

As I worked on creating the guide, I often reflected on how invaluable such a resource would have been during my own journey of finding the right adult care team. Now, as I approach my 10-year diaversary, I'm beyond thrilled to share a resource that can help youth better navigate their healthcare experiences and empower them to become more active, informed patients.



Abbi Cloth, Hope Connects Facilitator

When I transitioned from pediatric to adult care, I quickly realized there were significant gaps in the information I was given. Much of what I learned came through trial and error or by scouring countless type 1 diabetes (T1D) blogs and articles.

This guide was created to help bridge those gaps. It is filled with practical resources, helpful tips, and key talking points to support you through this important transition. Whether you are navigating new healthcare provider options, managing prescriptions, or exploring diabetes technology, this guide is designed to make the shift to adult care smoother and more empowering.

You are not alone in this journey - this guide is here to help you feel informed, confident, and prepared.

Special Thanks

We would like to thank the following people for supporting the *Guide to Adult Care* through providing invaluable insights, suggestions, and edits.

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PREPARING FOR TRANSITION

www.diabeteshopefoundation.com/transition-resource-hub

Differences in T1D Care

Diabetes 101: Transition Review

Transition Readiness Check-List

Establishing New Boundaries

Topics to Review with Parents/Caregivers

<u>Finding Your Ideal</u> <u>Healthcare Team</u>

Personal Pump Settings



Differences in T1D Care

PEDIATRIC DIABETES CLINIC

VS

ADULT DIABETES CARE

Parents and caregivers are actively involved in your appointments, including decision-making. Gradually, this responsibility will shift to you.

WHO TAKES
THE LEAD?

You will be expected to take full responsibility for your appointments, including raising concerns and answering questions about your diabetes management.

Typically appointments involve your whole family, with longer visits to address growth, insulin needs, and school-related concerns.

APPOINTMENT STRUCTURE

Appointments are usually shorter and focused on individual health concerns, including diabetes management, work, lifestyle, and other health conditions.

Appointments often involve meeting with a full multidisiplinary team (endocrinologist, nurse, dietitian, and sometimes a social worker or psychologist).

HEALTHCARE
TEAM &
COORDINATION

You will typically only see your endocrinologist, with patients often needing to book separate visits for other members of your team (e.g. dietitian, mental health support).

More frequent appointments to monitor your growth and insulin needs, typically every 3 to 4 months. Bloodwork is often completed on the day of your appointment, either at the hospital's outpatient lab or with your healthcare team.

FREQUENCY OF APPOINTMENTS

Visits may be less frequent, typically occurring every 6 to 8 months, unless there is a change in your care plan. You are required to complete bloodwork before appointments. Book your next appointment and request your requisition form before leaving!

Waiting rooms are typically filled with children and families and feature colourful decor with toys and books.

CLINIC ENVIRONMENT

Patients may be a mix of ages, including older adults and those with type 2 diabetes or other conditions.



Once you have transitioned to adult care, your parents or caregivers will need your consent to speak with your care team, access your records, or attend appointments with you.

Source: Children and Adolescents: Standards of Medical Care in Diabetes-2022

Diabetes 101: Transition Review

Before you transition to adult care, consider revisiting different elements of diabetes management with your pediatric team. Use the <u>Personal Transition Readiness List</u> to find out where your knowledge gaps are and remember: **there are no silly questions!** Your team is there to support you in managing your diabetes in the best way possible, which includes refreshers if/when you need them. You can also ask your new adult care team whenever you are unsure or need a reminder!



HOW CAN I IMPROVE MY CARB COUNTING SKILLS?

- Ask for resources or apps to help with accurate carb counting.
- Review carb counting basics including portion sizes and the glycemic index.



HOW CAN I HANDLE A DIABETES EMERGENCY IN DIFFERENT SITUATIONS?

- Review signs of severe hypo- and hyperglycemia.
- Ask about emergency glucagon options and how to use them.
- Develop an action plan for different emergencies.



WHAT SHOULD I DO IF I GET SICK?

- Review insulin adjustments for illness.
- Learn when to check for ketones and when to seek medical help.
- Co-create a step-by-step sick day plan.



HOW CAN I MANAGE MY BLOOD SUGAR DURING EXERCISE?

- Learn how different types of activity impact glucose levels.
- Discuss insulin and snack adjustments for workouts.



HOW CAN I ADJUST MY INSULIN BETWEEN CLINIC VISITS?

- Ask how to spot patterns that may indicate insulin adjustments.
- Review how food, exercise, stress, and illness impact insulin needs.



HOW CAN I MEAL PLAN MORE EFFECTIVELY WITH NUTRITIOUS FOODS?

- Ask how to balance meals for a more stable blood sugar and overall nutrition.
- Review how different foods affect energy levels and blood sugar control.
- Learn strategies for meal prepping to save time and maintain a healthy diet.



HOW CAN I MANAGE T1D WHEN DRINKING OR USING RECREATIONAL DRUGS?

- · Learn to recognize severe lows while intoxicated.
- Discuss how alcohol may impact insulin and medications (e.g., glucagon).
- · Ask how alcohol and substances affect blood sugar and ways to prevent issues.



HOW MIGHT T1D IMPACT MY SEXUAL HEALTH?

- Learn how to adjust insulin or medications before or after sexual activity.
- Ask how T1D can affect sexual health and blood sugar management.



Transition Readiness Check-List

The Transition Readiness Checklist is a tool designed to help individuals assess their diabetes management, and ensure that all key aspects of diabetes care are understood as they move from pediatric to adult care. By using this checklist, you can identify areas where you may need additional support and gain confidence in managing your health as you transition to adulthood.

For each statement, please select the response that best reflects your management knowledge:	I Don't Know This Yet	I Know Some Of This	I Am Well Aware Of This
I know how to carb count.			
I know what to do in the event of a severe low/high glucose. My family/friends know where my glucagon is kept and how to use it.			
I know how to communicate with my care team (email, text, phone).			
I know the names of the medications I take.			
I know when and how to reorder medications before they run out.			
I can call my doctor's office to make or change an appointment.			
I make a list of questions to ask my healthcare team before attending appointments.			
I organize and keep track of my health information (appointments, medications, <u>pump settings</u> , follow-ups, etc.).			
I know how to share my CGM results with my healthcare team.			
I know the importance of asking about new technologies in diabetes care.			
I understand how lifestyle choices can affect my blood glucose (e.g. sleep, alcohol, drugs, food, temperature).			
I understand the rules about driving with type one diabetes.			
I understand how pediatric clinics differ from adult clinics.			
I understand how to adjust my insulin regimen on sick days, respond to ketones, and go to the ER when necessary			
I know how pregnancy and birth control can impact diabetes.			

(Continued....)

For each statement, please select the response that best reflects your management knowledge:	I Don't Know This Yet	I Know Some of This	I Am Well Aware Of This
I know how to get blood work done and check my results online.			
I know the impact of alcohol and drugs on my glucose levels, as well as how alcohol impacts the use of glucagon.			
I know how to advocate for myself at doctor's appointments.			
I can describe my diabetes to others and explain my healthcare needs.			
I know where the closest pharmacy to my school/home/work is.			
I know how to understand my blood glucose readings (e.g. what your AGP, time in range, & GMI represents).			
I know the impacts of drugs and alcohol on my diabetes and how to responsibly prepare for a night out.			
I can comfortably disclose my needs to family members, friends, educators, and coworkers when experiencing diabetes-related episodes.			
I can explain my insulin regimen and how to adjust doses based on food or activity.			
I am comfortable navigating health insurance options and understanding my coverage for diabetes-related needs.			
I can handle my diabetes supplies, ensuring I have everything needed at all times.			
I know how to manage my diabetes during travel, including insulin storage and adjustments.			
I can recognize the signs and symptoms of high and low blood sugar and know how to treat them.			
I can explain my medical history and current diabetes management plan to new healthcare providers.			
I can identify when I need help managing my diabetes and feel comfortable reaching out for support.			
I understand the importance of regular eye exams, dental check-ups, and foot care for diabetes management.			
I have spoken with my parents/caregivers about taking on more responsibilities and how they can support me.			



Establishing New Boundaries

When you start adult care, it will be a big shift for your entire family. It is important to talk with family and friends to **clarify what kind of support you want and need for your diabetes management**. Try to have these conversations before you transition to your new care team and establish clear boundaries to help make the transition easier for everyone. Remember, boundaries are fluid and can change over time!

Setting Boundaries

As you transition to adult care you will likely also be taking on more responsibility around your diabetes management or your family may become less involved. As you navigate this change, keep in mind:



Boundaries are about what you are going to do, not about telling others what to do.



Boundary setting can be uncomfortable but it helps clarify roles & expectations.



Stating your feelings and intentions early prevents resentment and confusion later.



Remember to use
I-statements
when sharing
feelings and
focus on moving
forward together.

The biggest thing your supporters want to know is that you are okay. Talk about how often they can ask about your diabetes and what language to use. Think about where you want and need support, and what that support looks like. Consider the following questions:

- Do you want reminders about doctor's appointments?
- Do you want anyone to accompany you to your appointments?
- Who will order your supplies?
- Will your caregivers continue to follow your CGM?
- If a low alarm goes off, at what point should others get involved and what steps should they take? Who can your parents/caregivers call if they can't reach you?
- How often can your supporters ask about your T1D and what is the best way to ask?

You Don't Have to Do It Alone

Let your supporters know that you are both a responsible person capable of taking the lead on your own T1D management and that you may still need support in some areas. Openly communicating your T1D needs will help clarify for others how they can help you and will ensure healthy relationships that prioritize your physical and mental health.



Topics to Review with Your Parents/Caregivers

As you begin transitioning to adult life with T1D, it is important to talk about different aspects of diabetes management with your parents/caregivers. Their lived experiences can offer valuable insights and practical advice on how to navigate everyday challenges as you gain more independence. Your caregivers know your diabetes almost as well as you do and can help you find the strategies that will work best for you. Having open conversations will help ensure you are set up for success as you take on new responsibilities.



ORDERING PRESCRIPTIONS AND MANAGING SUPPLIES

- Learn how to manage refills and avoid running out of supplies.
- Ask about emergency backup plans for supply shortages.
- Discuss options for automatic refills or reminders.



NAVIGATING HEALTH INSURANCE AND MANAGING COSTS

- Ask about navigating insurance coverage for insulin, supplies, and devices.
- Learn how to budget for diabetes-related expenses and explore <u>financial</u> <u>assistance options</u>.
- Discuss what to do if coverage changes or claims are denied.
- Learn about what disability tax credits or savings accounts they have set up for you and when to transfer them to your name.



ACCESSIBILITY ACCOMMODATIONS

- Ask about accommodations at school or work and how to set them up.
- Learn how to request and advocate for necessary adjustments.
- Discuss where to get help if accommodations are denied.



BALANCING DIABETES WITH SOCIAL LIFE AND INDEPENDENCE

- Ask about managing diabetes in social situations, like dining out or drinking.
- Learn tips for disclosing diabetes to friends, partners, or employers.
- Establish new boundaries that balance caregiver support around your health with shifting responsibilities around your diabetes management.



TRAVELLING WITH T1D

- · Ask about packing essentials, including backup supplies and prescriptions.
- Learn how to handle airport security, time zone changes, and long trips.
- Discuss emergency planning for travel, including finding insulin and medical care abroad.

Finding Your Ideal Healthcare Team

Rely on your pediatric team to assist you in finding the right fit based on your individual care needs and preferences. They will begin working with you on transitioning when you turn 16 (or sometimes even earlier!), so let them know what is important to you using the Adult Care Team Checklist.

Adult Care Team Checklist

STAFFING	Very Important	Somewhat Important	Not At All Important
A clinic care team with various clinicians available to meet with you at one location			
A stand-alone endocrinologist's office			
A healthcare clinic that has a dietician			
A healthcare clinic that has a diabetes educator			
A healthcare clinic that has a registered nurse			
A healthcare clinic that has a social worker			
A care team that is stand-alone from your endocrinologist or main healthcare provider			
A clinic that is involved in research opportunities			
CLINIC ENVIRONMENT	Very Important	Somewhat Important	Not At All Important
A care team that values what works best for your diabetes management			
A care team that has an inclusive and comfortable environment			
A healthcare team that understands your goals			
A healthcare team that understands your lifestyle			
A healthcare team that focuses on diabetes-related care that is specific to your life		(Continu	ed)

APPOINTMENT ACCESSIBILITY	Very Important	Somewhat Important	Not At All Important
A care team that offers virtual appointments			
A care team that allows you to book appointments online			
A care team that meets in-person			
A care team that is located close to your place of work/school/home			
A care team that has a pharmacy on-site			
A care team that has an on-call number			
A care team that can book you in at various times (e.g. morning, afternoon, evening)			
A care team that meets with you every 3 months			
TECHNOLOGY KNOWLEDGE	Very Important	Somewhat Important	Not at All Important
A care team that prioritizes communication and exploring new methods of diabetes management			
A care team that you can share your glucose levels with before appointments through CGM data or other formats			
A care team that is well-rounded in both injection and pump management (certified for pump training)			
A care team that is familiar with new technology, different forms of glucagon, and insulin options			



Asking for a Referral

While you shouldn't be too quick to judge your new healthcare team (it takes time to get to know your new team!) if it doesn't feel like a good fit after approximately four appointments, ask your current provider about referral options. You can also ask for a referral if your care needs change over the course of your life. Make sure to research prospective care teams ahead of time to determine if they are able to meet your care needs.

Personal Insulin Pump Settings

Insulin Settings:

Be sure to update this chart with your new pump settings when you make changes or modifications, and bring it to your appointments to make sharing the info with your team easier.

(mmol/L)	High Range			
Blood Glucose Target Range (mmol/L) Units: g, mmol/L	Low Range			
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)r		
(mmol/L per U) n Time (h:mm):	Sensitivity Factor		
(mmol/L per U) Active Insulin Time (h:mm):	Start Time		

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Carbohydrate Ratio (g/U) Maximum Bolus Rate:	H	Start I ime				
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Updated on: _

CGM Settings:

In case of a pump malfunction, record your individual CGM settings here to make replacement pump set-up easier.

Notes:

Document adjustments you make on your own (and why) to share with your team at your next appointment.

Basal Rates Maxiumum Basal Rate:

Start Time

STARTING ADULT CARE

www.diabeteshopefoundation.com/transition-resource-hub

Your Adult Healthcare Team

What to Expect at Your Adult Care Appointment

Roles and Expectations

<u>Arriving Prepared for</u>
<u>Your Appointment</u>

<u>Keeping Track of Medical</u> <u>Appointments and Tests</u>

<u>Appointment Follow-Ups</u>

Blood Work Requisition 101

Managing Prescriptions



Your Adult Healthcare Team

Moving to adult care often means that your diabetes care is no longer a one-stop shop where you meet with your entire team at once. In some cases, you will need to build your own team through referrals to ensure you are getting the care you need. **Below are the key medical professionals who provide specialized care to support overall health and diabetes management.** Not all medical professionals listed here require regular visits, so be sure to talk with your endo about your specific medical needs to determine who is best suited to support your health.

Endocrinologist

For ongoing diabetes management and insulin adjustments.



Recommended follow-up frequency: Every 3-6 months.

Eye Doctor (Optometrist or Ophthalmologist)

Screen for diabetic retinopathy or other vision issues.

Recommended follow-up frequency: Once a year.



Dentist

Monitor for gum disease, cavities, and other oral health issues.

Recommended follow-up frequency: Every 3-4 months.

Primary Care Physician (Family Doctor)

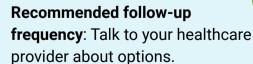
For general health and vaccinations (e.g., flu shot).

Recommended follow-up frequency: As needed.



Certified Diabetes Educator

For support with carb counting, insulin dosing, and lifestyle tips. 53





Registered Dietitian

For individualized nutrition advice, especially if eating habits change.



Recommended follow-up frequency: Talk to your healthcare provider about options.

Mental Health Professional

Support for managing diabetes distress or burnout.



frequency: Talk to your healthcare provider if this would benefit you.

Podiatrist/Chiropodist

For individuals experiencing neuropathy or foot issues.

Recommended follow-up frequency:

Talk to your healthcare provider if you have concerns and need a referral.

What to Expect at Your Adult Care Appointment



When visiting your first adult diabetes clinic, you will likely notice that the experience differs quite a bit from your pediatric care. You will most likely only see one member of your multidisciplinary team at a time, and your appointments with your endocrinologist are shorter than what you are used to. Before your first visit to the adult clinic, it is helpful to prepare for what your appointment will likely include.

FEET CHECK-UPS

During your appointment, your doctor or care team may ask to take a <u>look at your feet</u> to make sure that everything looks healthy and there is no numbness or pain. This may not be something that you have experienced before, but it is perfectly normal. Make sure to wear easily removable socks and shoes before leaving for your appointment!

BLOOD PRESSURE & WEIGHT CHECKS

It is common to have your <u>blood pressure</u> and weight checked during your appointment, and may have your waist measured. You can also ask not to get weighed. Ensure you wear a shirt or sweater that has short or loose-fitting sleeves that roll up for your blood pressure check.

CHECK-IN ON BLOOD SUGARS AND INSULIN DOSAGE

Your lead healthcare provider will review your recent blood glucose levels and refresh themselves on your insulin dosage. For this part of the appointment, it is always helpful to share your CGM data beforehand if you use one - make sure your passwords are all up to date! One week before your appointment, take note of details about your insulin use. Make a note of how much insulin you use per day, what your correction factor is, what your carb ratio is, and what times you typically give insulin. You can also make note of any times or situations that you find difficult to stay in range.

5-10 MINUTE APPOINTMENTS

Appointments with your endocrinologist can be *very* quick. This may seem alarming at first, but it is perfectly normal. Having your <u>bloodwork</u> done before your appointment is also helpful so you can go over any questions or concerns with your care team. However, if you don't get it done, it is okay - don't cancel your appointment!

SELF-DIRECTED CARE

In adult care team appointments, the healthcare you receive is much more self-directed. Although there will be common topics at each appointment (i.e. how to improve blood glucose time-in-range) you need to be prepared to initiate conversations based on your individual needs. For some people, it is helpful to bring a list of questions you would like to address at each appointment.

Roles and Expectations

Adult care appointments tend to be more independent*, with you taking on more responsibility in guiding the conversation and choosing which topics to address. To ensure you are getting the most out of your appointment, it is important to recognize the your role as a patient and what you can reasonably expect from your health care provider.

PATIENT ROLES & EXPECATIONS

- **Bringing your medical history:** Be ready to provide information on your medical history, including any other health conditions or medications.
- **Bloodwork:** Make sure you get your bloodwork taken at least one week before your appointment. If you cannot do this, make sure to continue to attend your appointment and put a reminder on your calendar for next time!
- **Monitoring your blood sugar:** You are responsible for checking and recording your blood sugar levels as instructed by your healthcare team.
- **Tracking medication usage:** Ensure that you take medications or insulin as prescribed and report any issues or side effects.
- **Tracking irregularities:** Keep track of any irregularities you may experience, such as unusual blood sugar fluctuations.
- **Communicating lifestyle changes:** Be prepared to discuss changes in diet, exercise habits, or stress levels, as these can impact blood sugar control.
- Asking questions: Ask about anything you don't understand or want to learn more about, or concerns; also ask to have required <u>forms</u> filled out and bring them with you! (i.e. Disability Tax Credit, Assistive Devices Program, etc.)
- Following up on recommendations: After the appointment, make sure to follow through on any blood work tests, medication changes, or lifestyle adjustments discussed. Don't forget to book your next appointment before you leave!

*While it is expected that you attend your appointments on your own, it is your right to have a support person come with you. Make sure you clarify how you would like them to support you ahead of time, and discuss it with your health care team before youre appointment. You will need to sign documentation if you want others to have access to your medical records.

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Roles and Expectations

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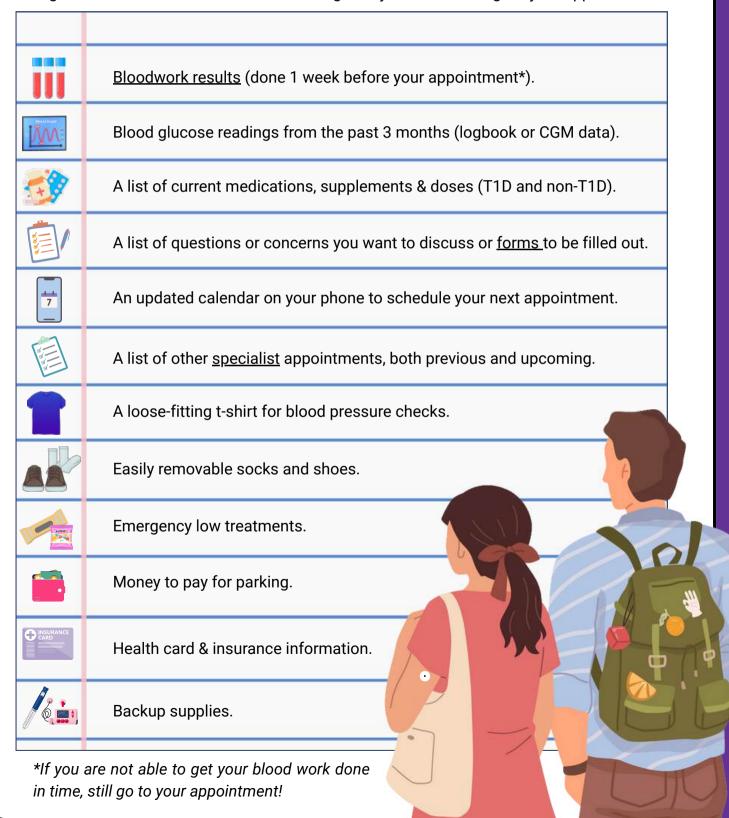
CLINICIAN ROLES & EXPECATIONS

- **Review your medical history:** The endocrinologist will review your current and past medical conditions and treatments.
- Assess your diabetes management: They will evaluate your blood sugar logs, insulin use to learn more about how you are managing your diabetes and what adjustments may need to be made to meet your target time in range.
- <u>Monitoring long-term health</u>: The doctor may check for early signs of diabetes-related complications. This may include checking your feet, taking your blood pressure, and checking that you are using different injection sites (for insulin pen users).
- **Provide education:** The endocrinologist will educate you on managing diabetes effectively, discussing lifestyle changes, insulin use, and healthy habits*.
- Adjust medications: Based on your current health and blood sugar trends, they may
 adjust your insulin doses or prescribe other medications to help you achieve your
 targeted time in range.
- Offer guidance on technology: They may assess and advise on the use of diabetes management technology (e.g., insulin pumps, CGMs).
- **Order tests**: Blood work may be ordered to assess overall health and they will give you the requisition form for blood work to complete before your next appointment.
- **Set goals:** They will work with you to set realistic goals for your diabetes management and provide the support needed to achieve them.
- Collaborate with other specialists: If necessary, your team may refer you to other healthcare providers, such as dietitians or ophthalmologists.

*If you are unclear about what is happening during your appointment or about recommendations your clinician makes, ask for more information! Most adult clinics don't have after-hours info lines to call, so make sure you fully understand what is being recommended before you leave.

Arriving Prepared for Your Appointment

As an adult, it is important to show up prepared for your appointments! These are some things to take into consideration and/or bring with you when leaving for your appointment.



Keeping Track of Medical Appointments and Tests

Text and Email Reminders

Sign up for automated clinic reminders and set personal alerts.

Set Reoccurring Appointments

Schedule follow-ups consistently (i.e., same day/time each appointment).

Family and Friends

Let your friends and family know about your appointments so they can offer a gentle reminder.

Centralized Health Folder

Organize appointment info and medical records in one place, either in a physical file folder or a digital folder.

Appointment Reminder Apps

Check out the App
Store or Google Play for
apps that can alert you
and track medical
appointments.

MISSED AN APPOINTMENT? MAKE SURE TO ...

- Contact the doctor's office as soon as possible: Call or email to let them know what happened and apologize for missing your appointment.
- Check the clinic's policy: Review and ask about policies on missed appointments to avoid penalties and find out how to reschedule next time if needed.
- Reflect on why it was missed: Identify the cause and make a plan in case it happens
 again (i.e., anxiety, too busy, forgot, uncomfortable with your health care provider). If you
 are feeling anxious about getting blood work done or attending appointments, find
 someone to talk to about it (i.e. social worker, diabetes educator, or mental health
 professional).
- Reschedule!! Book a new appointment promptly to maintain consistent care.

NOTE: If you do not get your bloodwork done ahead of your appointment, STILL GO! There are other important things to discuss with your team, and you can use your CGM, logbook or glucometer to share information about your management trends.

Appointment Follow-Ups

While preparing for appointments ensures that healthcare providers can make informed decisions when you meet wit them, following up on recommendations after appointments is essential to ensure any new strategies or adjustments to your treatment plans are adopted. Consistent follow-up leads to better diabetes management habits!

Schedule follow-up appointments and lab work as soon as possible so you don't forget about it. Be sure to set a reminder in your calendar!
Follow up on any additional referrals you may have been given (e.g. with a dietitian, diabetes educator, or for mental health provider).
A month before your next appointment, make sure it still fits in your schedule. If you have a conflict with your appointment (i.e exams or assignment due), reschedule for your earliest convenience.
Make adjustments in your care plan or medications as directed, and document how it's going. Also document the impact of any adjustments you make to your care plan to review at your next appointment.
Fill out any forms or paperwork your healthcare team has given you to work on (e.g. carb counting tracking sheets, food/insulin tracking sheets).
Review any resources you may have been given (e.g. <u>glycemic index</u>) and make a note of any questions you might have for your next appointment.
Talk with your supporters about how the appointment went and share any challenges or successes you've had! This can include parents/caregivers, friends, partners or mentors.

Utilize Your Support Network

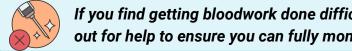
It is important to lean on your support network during difficult times. After appointments with your care team, you may need extra support when making changes to your diabetes management plan. Do not hesitate to talk to trusted friends and family during this time to lighten the load.

Blood Work Requisition 101

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V.	Ontario Ministry of Health and Long-Term Care										
Laboratory Requisition Requisitioning Clinician / Practitioner											
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Blood Work Requisition Legend

- **Glucose**: Checks the current level of glucose in the bloodstream. FASTING GLUCOSE TEST: Measured after an overnight fast to help assess how well the body regulates glucose without the influence of food. RANDOM GLUCOSE TEST: Measured at any time, typically after eating, to evaluate how the body handles glucose after meals.
- **HbA1c (A1c)**: Measures average blood sugar levels over the past 2-3 months. IMPORTANCE: HbA1c levels above target ranges for long periods of time have been linked to negative long-term health outcomes.
- Creatinine: Measures the level of creatinine in the blood a waste product produced by muscles and filtered out of the blood by the kidneys. IMPORTANCE: T1D can increase your risk of kidney damage.
- Potassium: Measures potassium levels, essential for muscle and nerve function, fluid balance, and heart rhythm. IMPORTANCE: Diabetic ketoacidosis (DKA) and kidney issues may cause potassium imbalances.
- ALT: Measures liver enzyme levels, helping to assess liver function and detect liver damage or inflammation. IMPORTANCE: T1D can increase your risk of liver issues.
- Lipid Assessment: Measures levels of cholesterol and triglycerides, including total cholesterol, LDL (bad cholesterol), HDL (good cholesterol), and triglycerides, to assess heart health. IMPORTANCE: T1D can increase your risk of cardiovascular diseases.
- Albumin/Creatinine Ratio (ACR) Urine: Measures the amount of albumin (a protein) relative to creatinine in urine. IMPORTANCE: Helps detect early kidney damage.
- CBC (Complete Blood Count): Measures various components of blood, including red blood cells, white blood cells, hemoglobin, platelets, and thyroid levels, to assess overall health and detect infections, anemia, or other blood disorders. IMPORTANCE: T1D can increase your risk of infections, which may impact blood cell counts.
- Key information about who else will receive your results (i.e. family doctor), whether fasting is required, if a urine sample is needed, and any additional tests your doctor has ordered.



If you find getting bloodwork done difficult due to needle anxiety and/or phobia, reach out for help to ensure you can fully monitor and manage your diabetes.

Managing Prescriptions



As you take on more responsibility for your diabetes care, managing your prescriptions is an essential skill you'll need to learn. If you haven't already, get your parents/caregivers to provide you with a list of where you get your prescription filled (i.e. at a pharmacy or online through the manufacturer or an online supplier) and learn when and how to order supplies so that you always have what you need to manage your diabetes.

Be sure to find out how to order replacement supplies if you have a pump or CGM failure, including who to contact, what information they will ask for, and how long you typically need to wait before replacements arrive.

DID YOU KNOW...

Most pharmacies across Canada have at least one pharmacist who is also a Certified Diabetes Educator (CDE). They are a valuable resource that you can access between medical appointments for a number of diabetes-related questions or concerns. Here are some ways a CDE pharmacist can help you:

- Pharmacists can review your prescriptions and medications, explain how they interact, and discuss their potential impact on your blood glucose levels.
- Pharmacists can discuss potential side effects you may experience, such as sun sensitivity, nausea, and others.
- Pharmacists have access to your medical history and insurance information, making them a valuable resource for clarifying your coverage.
- Pharmacists can explain the differences between name-brand and generic medications and help determine which is best for you based on your coverage options.
- Pharmacists can help you create a medication schedule that fits your routine and provide information on new diabetes technology.
- Pharmacists can assist with obtaining new sharps bins and safely disposing of old sharps or unused prescriptions.
- Visiting your pharmacy before tax season can be helpful, as they can provide a list of your prescriptions with price and coverage details.

TAKING CONTROL OF YOUR HEALTH

www.diabeteshopefoundation.com/transition-resource-hub

Taking Control of Your Health

T1D Mindset Matters

Know Your Rights

Managing T1D Over Time

Navigating Medical Conversations

Exploring Tech Options

Mental Health Resources

Financial Assistance Programs

Resources



Taking Control of Your Health

Advocating for your health is one of the most important actions you can take for yourself. Self-advocacy in the healthcare system involves prioritizing your needs, understanding your goals, and actively seeking the resources and support you need to achieve them. By advocating for your long-term health, you ensure that your healthcare team helps you focus on sustainable habits, preventative care, and achieving your goals over time.

Prepare For Appointments. This can include making a list of questions, as well as what personal successes and challenges you want to share around your T1D management. Be sure to bring your log/share CGM data and get yout blood work done a week ahead of time.

Communicate openly with your care team. Ensure there is a clear and open dialogue about what your goals are in diabetes management, and establish what will work best for you based on your personal history and needs.

Address mental and emotional health. Living with diabetes can impact your mental and emotional well-being, and it's important to acknowledge feelings of stress, frustration, or burnout. Your healthcare team can connect you with resources like counsellors, support groups, or strategies to help manage the emotional aspects of diabetes care.

Leverage technology. Research new technology or upgrades to the technology you're currently on, and ask if a trial run is available at your care team's office. Take advantage of modern tools to manage your diabetes effectively. From continuous glucose monitors and insulin pumps to mobile apps for tracking nutrition and activity, there are options for everyone! Discuss these options with your healthcare team to find tools that align with your needs and lifestyle.

Engage as a partner. Think of your diabetes care as a collaboration. This can mean sharing your experiences, setting goals together, and working toward solutions that fit your life. This partnership empowers you to take control of your health while benefiting from expert guidance.

Evaluate your care team & advocate for long-term health. Your care team should align with your needs and support your journey toward better health. Regularly assess whether your team listens to your concerns, respects your input, and provides clear guidance.

Source: 7 Strategies for Self-Advocacy in Diabetes Care



T1D Mindset Matters

When you visit your endocrinologist, it is essential to remember that the numbers they review - such as your blood sugar levels, A1C, and insulin usage - are simply data points and not a reflection of you as a person. These numbers help guide your care, but they do not define you. Below are a few things to keep in mind when visiting your healthcare provider(s) to ensure your appointments are as productive and supportive as possible.

YOU ARE NOT YOUR DIABETES

Remember, your healthcare team is not there to judge you but to help you with managing T1D. Your blood glucose levels do not reflect who you are as a person, and transparency with your healthcare team about your levels leads to improved care.

T1D IS A MARATHON, NOT A SPRINT



Diabetes management is not a linear journey. Celebrate the successes and learn from the challenges with the help of your team. Keep your focus on your long-term health, not a single A1c and remember, change takes time!

THERE IS NO PERFECTION WITH T1D



Living with T1D means embracing the reality that perfection is unattainable. Instead of striving for flawless blood sugar levels, aim for balance, understanding that change is an inevitable part of T1D. Focus on learning, adapting, and continuously growing in the face of challenges.

IT'S OKAY TO NOT BE OKAY



Asking for help is a part of everyone's T1D journey. Asking and receiving help demonstrates strength, independence, and growth. Remember - you're not alone in your journey. <u>Build your community</u> and reach out to supporters during tough times because that is what they are there for.

Know Your Rights

Whether or not you choose to personally identify as a person with a disability is **100% your choice**, and this choice should always be respected. You should know that the Government of Canada officially recognizes Type 1 Diabetes as a <u>disability</u> due to its impact on lifestyle, the constant monitoring of blood sugar levels, and the potential risks associated with the condition. This recognition ensures that people with diabetes have certain **protections afforded to them under the law**, both in Canada and internationally.

Your legal rights:

Canadian Charter of Rights and Freedoms:

• Section 15 ensures equality, irrespective of race, gender, sexuality, and *disability*. The CCRF was signed into law in 1982.

Canadian Human Rights Act:

 An extension of the Charter, the Canadian Human Rights Act ensures that everyone is treated equally and justly, regardless of age, gender or disability.

United Nations Convention on the Rights of Persons with Disabilities:

• This International Human Rights Treaty is intended to protect the rights and dignity of people with disabilities.

The Patient Bill of Rights

When you are accessing care, your patient rights ensure you are treated with respect and dignity. Each hospital/clinic will have policies aroud the key rights listed below, as well as procedures regarding what to do if you feel you have had your rights violated.

- 1) The right to be treated with respect for one's dignity and privacy.
- 2) The right to receive care that is free from discrimination and bias.
- **3)** The right to be **informed** about one's health status and treatment options.
- 4) The right to **participate actively** in healthcare decisions that affect one's well-being.
- 5) The right to access one's medical records and to have them kept confidential.
- **6)** The right to **voice concerns** and to **seek resolution** when expectations are not met.

For more detailed information on your rights as a patient, visit the <u>Canadian Patient's Bill of Rights</u>. Want a more detailed breakdown of the Bill of Rights? Check out this <u>blog</u>. If you're looking to review the original text, you can access the <u>Patient Bill of Rights Charter here</u>.

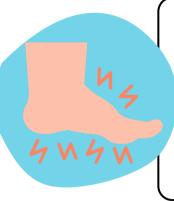


Recognizing Clinician Rights

Remember, clinicians have the right to be treated with respect and professionalism. Abusive language or behavior towards healthcare staff is never acceptable, and it's important to maintain a professional and respectful dialogue for the best care experience.

Managing T1D Over Time

Thinking about potential long-term T1D complications can be overwhelming, but it is important to be informed about them. As you transition into adult care, your team will be more actively monitoring for potential complications and will work with you to manage your time in range to help prevent them. Below is an overview of potential long-term complications associated with T1D. Be sure to discuss any concerns you have with your healthcare team so you can better understand your risks and take proactive steps to prevent or address them.



Diabetic Peripheral Neuropathy

- Prolonged periods of high blood sugar can damage the nerves, preventing essential nutrients from reaching these areas.
- Nerve damage, also known as neuropathy, can affect the feet, hands, arms, and legs.
- Screening for common symptoms such as tingling, burning, throbbing, and numbness is ongoing.

Learn more: Diabetic Peripheral Neuropathy

Kidney Disease

- High glucose levels over a long period of time can damage the kidneys, preventing them from functioning properly.
- Your kidney function is monitored regularly through your bloodwork.

Learn more: Kidney Disease -Diabetes Canada





Diabetic Retinopathy

- High glucose levels or rapid changes in glucose levels can damage the blood vessels in the retina.
- Diabetic retinopathy usually develops slowly, which is why ongoing monitoring is necessary to catch early warning signs.

Learn more: Retinopathy - Diabetes Canada

Heart Disease & Stroke

- High glucose levels, high blood pressure, and high cholesterol can increase your risk of heart disease as you get older.
- Your team will monitor these risk factors regularly through bloodwork and checking your blood pressure at appointments.

Learn more: ABCDEs of diabetes management



Navigating Medical Conversations

An essential part of managing your diabetes is **advocating for your needs during appointments**. Below are some key topics to consider discussing at your next visit with your healthcare provider, along with sample questions to guide your conversation.

EMERGENCY PLANNING	PHYSICAL HEALTH				
 How should I handle a severe low blood sugar episode if I am alone? What are the signs of diabetic ketoacidosis (DKA), and when should I seek emergency care? How should I communicate my diabetes needs to emergency responders or hospital staff? 	 How can I adjust my insulin for different levels of physical activity? What should I do if I experience frequent low/high blood sugars? What should I do to manage my diabetes when sick? How does diabetes impact my sexual health and pregnancy? 				
MENTAL HEALTH	PRESCRIPTIONS				
 What resources are available beyond my core healthcare team? (i.e. community programs, support groups and/or resources) What are the signs of diabetes distress or burnout? What do I do if I am experiencing diabetes distress/burnout? How can I build a positive mindset around diabetes self-care? 	 What should I do if my insulin prescription changes or becomes unavailable? Are there alternative medications or insulins if my current prescription isn't working well? How will other medications I take (i.e. birth control, ADHD meds, etc.) impact my diabetes care? Are there any new insulins that I should consider to help with my management? 				
TECHNOLOGY	FINANCIAL				
 How do insulin pumps and multiple daily injections compare? Are there any new diabetes technologies or apps that could help with management? What do I need to know if my tech fails? (i.e. manual pump mode) 	 How can I get forms completed for financial assistance programs & is there a charge? Can I access free or subsidized programs for any of my medical devices? If my current diabetes medication is no longer covered by my insurance, what are some alternative biosimilars? 				





Change is a **constant** in diabetes management. Depending on how long you have had your diagnosis, you may feel comfortable with your current method of care and may not feel the need to explore newer options. However, it is important to reassess your diabetes management every **five years** to ensure you are living your best life with type 1 diabetes. Whether you're thinking about switching to a new CGM, trying a different pump, returning to injection pens, or simply staying informed about advancements in **diabetes technology**, the first step is starting a conversation with your healthcare provider.

When to Ask About New Technology

- Anytime is a good time to ask about new technology! If you feel ready for a change or are curious about your options, make a point of bringing it up at your next appointment.
- Reasons for wanting to explore new options can include issues you are experiencing
 with your current tech or wanting to explore ways to have more control over your blood
 glucose levels.

Do Your Research

- Once you learn about a few different diabetes technologies that you're interested in trying, narrow it down to what best fits your needs and goals. A couple of questions to ask your endocrinologist are: "What technology do you recommend?" and "What do you hear from other patients about which technology is the best to use?"
- Areas of consideration in making a decision include cost (health insurance and/or provincial coverage options and guidelines, and if there are subsidy programs available), whether your pharmacy carries the technology, the quality of tech support available, and whether the new tech is compatible with your current CGM/pump.
- You can also go online to read other people's experiences with various pumps and CGMs, including Reddit and <u>blog forums</u>.

Test-Driving Your Technology

- Ask your healthcare team if they are registered to deliver diabetes tech training. If they
 aren't, they should be able to reach out to a tech company representative. Trials typically
 last between 7 to 10 days, and some pumps even have demo apps for you to use.
- You can try out a few different diabetes technologies before committing to one, so make the most of the experience!

Overcoming Fear of Technology

- Something that may scare people away from trying new technology is the fear of having to inject their body in a different and potentially more painful way than they are used to or a lack of confidence in the new system.
- Make sure to do your research and use tips to help overcome your fears around injections and sharps.

Mental Health Resources

Distress Lines Across Canada

https://thelifelinecanada.ca/suicide-prevention-crisis-centre-contact-information/crisis-centres/canadian-crisis-centres/

Search this site for local distress lines.

9-8-8 Crisis Helpline

https://988.ca/

Call or text 9-8-8 to connect with a trained responder who is there to listen and support you.

Kids Help Phone

https://kidshelpphone.ca

Call 1-800-668-6868 (toll-free) or text CONNECT to 686868. Available 24 hours a day, 7 days a week to Canadians aged 5 to 29 who want confidential and anonymous care from trained responders.

Access Open Minds

https://accessopenminds.ca/

Mental health hubs for youth, up to age 25. Visit their site to find in-person centres across Canada where youth can access mental health supports.

Mental Health + Diabetes Directory

https://directory.breakthrought1d.ca/

Find a mental health provider who has completed the Mental Health + Diabetes Training Program, a collaboration between Breakthrough T1D and Diabetes Canada.

Good2Talk

https://good2talk.ca/

Free, confidential support services for post-secondary students in Ontario and Nova Scotia.

Healing in Colour (BIPOC)

https://www.healingincolour.com/

A directory of BIPOC therapists who are committed to supporting BIPO, in all our intersections.

Hope for Wellness Hotline

https://www.hopeforwellness.ca/

Call 1-855-242-3310 or visit their website for an online chat. The Hope for Wellness Helpline is available to all Indigenous people across Canada. Experienced and culturally competent counsellors are reachable by telephone and online 'chat' 24 hours a day, 7 days a week.

National Eating Disorder Information Centre (NEDIC)

https://nedic.ca

Call 1-866-633-4220

A bridge between community and care for people affected by eating disorders in Canada, NEDIC offers information, resources, referrals and support to individuals living with an eating disorder.



Financial Assistance Programs

Managing diabetes comes with certain costs, including insulin, syringes, pump/CGM supplies, blood glucose monitors, test strips, etc. Below is a list of programs available for Canadians that offer financial assistance for medical costs across Canada.

NATIONAL PROGRAMS	CONTACT INFO
Canadian Dental Plan	1-833-537-4342
Canadian Disability Tax Credit*	1-800-959-8281
<u>Pharmacare</u>	1-866-225-0709
Registered Disability Savings Plan	1-866-204-0357
Non-Insured Health Benefits for First Nations and Inuit	1-800-567-9604
ONTARIO PROGRAMS	CONTACT INFO
Ontario Trillium Drug Plan	1-800-575-5386
OHIP Plus – under 25	1-800-267-8097
Ontario Assistive Devices Program (ADP)	1-800-268-6021
QUEBEC PROGRAMS	CONTACT INFO
Régime d'assurance maladie du Québec or RAMQ – under 18	1-800-561-9749
Quebec Assistive Devices Program (ADP)	1-800-575-5386
SASKATCEHWAN PROGRAMS	CONTACT INFO
Saskatchewan Drug Plan	1-800-667-7581
Saskatchewan Children Drug Plan – under 15	dpeb@health.gov.sk.ca
Saskatchewan Insulin Pump Program (SIPP)	info@health.gov.sk.ca

*Disability Tax Credit Info

- Speak with your parents/caregivers about when and now to transferr the DTC to your name.
- Eligibility for the DTC can be paid retroactively up to 10 years from the date the CRA receives your application.

 (Continued....)

ALBERTA PROGRAMS	CONTACT INFO
Alberta Aids to Daily Living (AADL)	310-0000 then 780-427-0731
Alberta Health Care Insurance Plan	310-0000 then 780-427-1432
MANITOBA PROGRAMS	CONTACT INFO
Manitoba Pharmacare Program	1-800-297-8099
Manitoba Health, Seniors and Long-Term Care	1-800-392-1207
BRITISH COLUMBIA PROGRAMS	CONTACT INFO
BC Fair PharmaCare Program	1-800-663-7100
BC Ministry of Health's Home and Community Care Program	1-855-412-2121
NOVA SCOTIA PROGRAMS	CONTACT INFO
Nova Scotia Pharmacare	1-800-544-6191
Insulin Pump Program	1-855-306-6360
NEW BRUNSWICK PROGRAMS	CONTACT INFO
New Brunswick Prescription Drug Program (NBPDP)	1-800-332-3692
The New Brunswick Insulin Pump Program (IPP)	1-855-655-5525
NEWFOUNDLAND AND LABRADOR PROGRAMS	MORE INFO
Newfoundland and Labrador Prescription Drug Program (NLPDP) – under 25	1-888-859-3535
Newfoundland and Labrador Insulin Pump Program (NLIPP)	1-888-246-4888



PRINCE EDWARD ISLAND PROGRAMS	MORE INFO
PEI Pharmacare Program	1-877-577-3737
PEI Health Plan – under 25	1-877-577-3737
<u>Diabetes Drug Program</u>	1-877-577-3737
NUNAVUT PROGRAMS	MORE INFO
Nunavut Drug Formulary	1-800-580-0950
Nunavut Health Care Plan	1-800-661-0833
NORTHWEST TERRITORIES PROGRAMS	MORE INFO
NWT Prescription Drug Program	1-800-661-0830
NWT Health Care Plan	1-855-846-9601
YUKON TERRITORIES PROGRAMS	MORE INFO
Yukon Pharmacare Program	1-800-661-0408
Chronic Disease and Disability Benefits Program	1-800-661-0408

Tips and Reminders:

- Download any forms that require medical verification before your next doctor's appointment, and check ahead about potential fees to have forms completed.
- Many universities and colleges have student health insurance plans that cover medication and supplies - find out what is covered by your school's plan in the <u>DHF</u> <u>Transition Guide</u>.
- The National Pharmacare program is relatively new, so if it is not available for your province/territory yet, make sure to follow the news for announcements about if/when it becomes available for you.
- The Government of Canada also offers a <u>non-refundable tax credit</u> for medical expenses, and many provinces and territories also have medical expense credits. Check out <u>Type 1 Better's</u> Blog for more information about Canadian financial supports and benefit programs.

External Resources

Topics to Review with Parents/Caregivers

Academic and Campus Accommodations for Students Living with Diabetes

Personal Transition Readiness List

• Transition Readiness Checklist for the Person with Epilepsy

Differences in T1D Care

• Children and Adolescents: Standards of Medical Care in Diabetes—2022

Appointment Follow-Ups

• Glycemic Index Food Guide

Managing T1D Over Time

- <u>Diabetic Peripheral Neuropathy</u>
- Kidney Disease Diabetes Canada
- Retinopathy Diabetes Canada
- ABCDEs of diabetes management

Taking Control of Your Health

• 7 Strategies for Self-Advocacy in Diabetes Care

Know Your Rights

- Federal Disability Reference Guide
- Canadian Charter of Rights and Freedoms
- Canadian Human Rights Act
- <u>United Nations Convention on the Rights of Persons with Disabilities</u>
- Canadian Patient's Bill of Rights
- Patient Bill of Rights and Responsibilities
- Patient Bill of Rights Charter

Exploring Tech Options

• TU Diabetes Forum

Overcoming a Fear of Needles

• How to Overcome the Fear of Giving Yourself a Needle Injection

Financial Aids

- DHF Transition Guide
- Young Adult Transition Guide
- Taxes and type 1 diabetes: learn about the credits and benefits you may qualify for!



DHF Resources

The following resources mentioned in the Guide are available for download at the <u>DHF Transition Resource Hub</u>, along with a number of other tools and resources to help youth living with T1D navigate the transition to adult care and post-secondary school.

Tavelling with T1D

 Helpful tips and tricks to help make your travels smoother, including information on packing, navigating security and managing your T1D during your time away.

Transition Readiness Checklist

A checklist designed to help you prepare for transitioning to adult care.

T1D Communication Agreement

 A checklist to help you decide what is most important to you when looking for you adult care team.

Finding Your Ideal Healthcare Team

 A checklist to help you decide what is most important to you when looking for you adult care team.

Personal Pump Settings

 A tool to help track changes to your pump settings between health care appointments.

Overcoming a Fear of Needles

 A resource guide that provides strategies and tips for overcoming a fear of needles, specifically to help individuals with T1D manage injections and blood work with more confidence.

Exercise and T1D

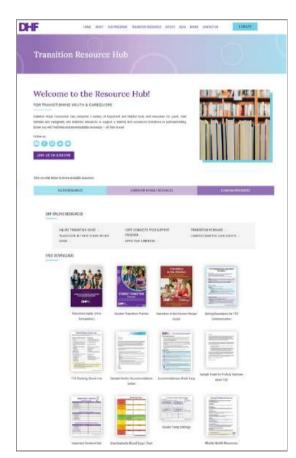
 A resource that offers guidance on exercising with T1D including tips for blood sugar management, preventing lows, and staying active safely.

Mental Health Resources

 A resource listing national and provincial programs that offer financal support to people living with diabetes.

Financial Assistance Programs

 A resource listing national and provincial programs that offer financal support to people living with diabetes.



www.diabeteshopefoundation.com

HOPE CONNECTS

PEER SUPPORT FOR YOUTH LIVING WITH T1D





CONNECT HOWEVER WORKS FOR YOU

- 1:1 Peer Mentorship ✓
- Virtual and In-Person Drop-ins ❷
 - Campus Club Events ≥
- T1D Campus Connects on Discord

 ✓

WHY CONNECT?

- Judgment-free support
- Tips & tricks for living with T1D from folks who know
 - Get the inside scoop on college & university
 - A community of support that's there when you need it

Learn more today!











The HOPE Connects Program is funded by:



DIABETES HOPE **FOUNDATION** www.diabeteshopefoundation.com





The Guide to Adult Care was generously funded by:



