Transitions in T1D Care: From Adolescence to Adulthood

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Adolescents and young adults with type 1 diabetes (T1D) require special attention when transitioning from pediatric to adult diabetes care. As they grow older, adolescents with T1D begin to rely less on parental involvement and more on their own decision making.[1] This transitional period is a critical time when adolescents and young adults may have unique concerns about a variety of challenges, including[1,2]:

- Psychosocial issues related to T1D and interactions with family members, friends, and coworkers
- Diabetes distress
- Depression and anxiety
- Disordered eating
- Sexual health, contraception, and preconception care
- Emergence of risk factors (eg, smoking, alcohol use, obesity, hypertension) for chronic diabetes-related complications
- Alcohol and drug use with adverse effects on glucose levels (eg, risk of hypoglycemia, diabetic ketoacidosis)
- Maintaining optimal glycemic management

Healthcare providers play a crucial role in providing necessary information to adolescents and young adults on these topics so they can successfully navigate the transition from pediatric to adult T1D care.[2] They also educate patients about the effects of T1D on typical activities of young adulthood, such as driving, attending college, and having a job.[2]

This handout highlights the challenges that adolescents with T1D may experience when transitioning to adult diabetes care. It also provides strategies and resources for helping adolescents and young adults through this transitional time in their lives from the perspectives of both the adult care provider and pediatric care provider.

CONSISTENCY OF CARE: A TOP PRIORITY

Most young people with T1D transition from pediatric to adult care by 18 years of age.[3] There is no single best strategy or optimal age for making this transition, but an organized approach based on individual needs and preferences is encouraged for patients over 12.[4] Consistent diabetes care during this period is the key priority; chaotic transitions from pediatric to adult diabetes care contribute to care fragmentation and an increased risk of adverse outcomes.[5,6]

TRANSITION STRATEGIES: PEDIATRIC PROVIDER PERSPECTIVE

The transition process begins with assessing patient readiness through direct discussions with the patient, as different individuals will have different needs.[3,7,8]

Broadly, the Diabetes Canada Clinical Practice Guidelines (CPG) and the International Society for Pediatric and Adolescent Diabetes (ISPAD) offer the following suggestions for transition of care[2,4]:

- **Start preparing youth for a coordinated transition in early adolescence** by collaborating with the patient and family members at around 12 years of age
- **Emphasize diabetes self-management skills** (eg, self-monitoring of blood glucose, administering insulin, scheduling appointments, maintaining medications/supplies), with a gradual transfer of diabetes-related care responsibilities from the parent to the adolescent
- **Review differences between pediatric and adult systems and health-care navigation**
- **Provide the patient and adult care provider with a written summary** of medications, past glucose levels, diabetes-related comorbidities, referrals during pediatric care, and an active problems list

- **Provide support and resources,** including psychosocial, vocational, and educational resources, as well as resources that can help them connect to the diabetes community and peer support and to reconnect to diabetes care if they become lost to follow-up
- **Recommend different educational resources to help engage the patient,** such as age-appropriate written materials, text messaging, online resources, social media, peer involvement, and group learning
- **Offer culturally sensitive and non-judgmental information** on the effects of T1D on employment, driving, sexual health and contraception, and alcohol and drug use
- **Recommend future visits** to assess glycemic levels and screen for diabetes-related complications
- **Cultivate regular collaboration** with healthcare providers in adult care settings
- **Keep parents and guardians involved** in care transitions, especially during adolescence

BENEFITS OF A STRUCTURED TRANSITION PROGRAM

Structured transition programs, such as GET-IT-T1D, aim to provide integrated group-based education and peer support for adolescents moving to adult care. The goal is to facilitate improvements in glycemic stability and psychosocial well-being.[9] Key components of the GET-IT-T1D program include[9]:

- Group-based educational modules for adolescents on diabetes basics and technology use, navigating the adult healthcare system, interpersonal relationships with both peers and parents, other life transition activities (driving, moving out, traveling, school/work), managing stress, and the use of alcohol and recreational drugs.
- Group-based education sessions that coincide with routine clinic visits
- Patient-driven, facilitator-mediated discussions with a certified diabetes educator (nurse, dietitian, social worker).
- Ability to directly receive peer support during group sessions
- Requiring no additional in-person visits beyond routine clinic visit commitments

TRANSITION STRATEGIES: ADULT CARE PROVIDER PERSPECTIVES

The "receivership" role of adult care providers is critical in ensuring a successful transition, but it is often underappreciated.[10] The following are key components of successful receivership care.[10]

Communicating and Coordinating Care with the Patient's Pediatrician

Young patients with T1D often form strong emotional bonds with their pediatric providers.[10] Maintaining a good working relationship between pediatric and adult care providers is the key to navigating challenges that may arise during the transition process.[10]

Assessing the New Patient's Needs, Knowledge, and Skill Levels

Adult care providers may wrongly assume that assessing transition readiness is the sole responsibility of the referring pediatric care provider.[10] In fact, ongoing assessment of self-management skills is an important aspect of diabetes care. Available assessment tools include[11-15]:

- Readiness Assessment for Emerging Adults with Diabetes Diagnosed in Youth (READDY)[11]
- TR(x)ANSITION scale[12]
- Self-Management Skills Assessment Guide (SMSAG)[13]
- Transition Readiness Assessment Questionnaire (TRAQ)[14]
- On TRAck Transition Readiness Assessment[15]

Building Rapport and Long-Term Relationships

A strong patient-provider relationship lays the groundwork for effectively helping young adults manage glycemic levels and prevent diabetes-related complications.[10] Adult care providers can start building these relationships with new patients by taking the time to listen to them and involve them in management decisions.[10] In addition, adult care providers may want to consider using telemedicine to improve patient engagement, especially for young adults who have difficulties coming in for regular visits due to work or school commitments.

TELEMEDICINE EXAMPLE

The Colorado Young Adults with Type 1 Diabetes (CoYoT1) Clinic is a care model that uses web-based videoconferencing to facilitate clinic visits with a healthcare provider and group visits with other young adults with T1D.[16] Individuals who participated in this care model reported high levels of satisfaction with the virtual clinic visits and high levels of perceived support from the peer interactions.[16] They also increased their number of clinic visits from the previous year.[17]

Addressing the Psychosocial Needs of Young Adults

Depression, common in both adults and adolescents with diabetes, is associated with glycemic instability. In addition, adolescents with T1D have significantly higher rates of anxiety, diabetes-associated distress, and disordered eating than their peers who do not have diabetes.[1] Patients with psychosocial difficulties may benefit from a prompt referral to experienced mental health providers.[1]

Using a Team-Based Approach

Diabetes care during the transition period can be optimized by a healthcare team that includes physicians, nurses, registered dietitians, certified diabetes educators, social workers, and others.[10] This collaborative approach can more effectively address a range of patient-specific needs and facilitate the timely delivery of support and resources. Some evidence suggests that enlisting a transition coordinator or care navigator can improve patient engagement and glycemic stability better than less-structured approaches.[10]

HELPING PATIENTS NAVIGATE COVERAGE FOR MEDICATIONS / DEVICES AND OTHER FINANCIAL BENEFITS

Maintaining continuity of health insurance is critical for young people with T1D. In Canada, there are federal, provincial, and private plans that may contribute to healthcare coverage. It is important for teens to discuss with their parents or caregivers to find out what they are currently covered for, and how that may change as they turn 18 (if at all).

Depending on a person's location or income, provincial or territorial public insurance coverage may cease after a certain age and would need to be supplemented with private insurance through colleges, universities, or employers. Individuals approaching adulthood should review their province or territory's insurance program months in advance to learn which diabetes medications, supplies, and devices will continue to be covered.

TIPS FOR YOUNG PEOPLE WITH T1D:

- **Federal:** as of June 2022, all Canadians living with T1D automatically qualify for the disability tax credit (DTC). If a young person with T1D's parents/caregivers have already applied on their behalf, the person with T1D can claim this credit once they file income taxes. The parents/caregiver may retain this credit if they are still financially supporting the young person with T1D.
- **Federal:** those eligible for the DTC are also eligible for a Registered Disability Savings Program (RDSP). A beneficiary can only have one RDSP at any given time; therefore, the young person with T1D should confirm with their parents/caregivers if a plan already exists in their name.
- **Federal:** the Canada Disability Act passed in June 2023, which allows the government to create and deliver a new benefit to working-age persons with disabilities in Canada. Those living with T1D will be deemed as automatically qualifying. Details of this new benefit are still under development.
- **Federal:** the Non-Insured Health Benefits (NIHB) program provides eligible First Nations and Inuit Canadians with coverage for a range of health benefits including medical supplies and equipment, and drug coverage.
- **Provincial:** coverage of medical devices (including continuous glucose monitors, flash glucose monitors, and insulin pumps) is regulated provincially. A coverage map across Canada is available on JDRF Canada's website.
- **Provincial:** some provincial drug plans cover the cost of insulin depending on private health coverage and household income. The amount of coverage or the required deductible may change as the person with T1D turns 18 or 24 years of age, depending on the province.
- **Private:** private insurance may cover diabetes supplies or other insurance products with limitations up to the age of 18, or in some cases the age of 24. It is important that individuals are aware of their private insurance eligibility criteria and apply for continuing or extended coverage where necessary.

CASE STUDY - A young adult with T1D is resisting making the transition to adult care. What steps would you take to help your patient take the next steps in her healthcare?

Emily is a 17-year-old adolescent who was diagnosed with T1D when she was 10 years old. As an adolescent, she has struggled with body image and feeling awkward at school because of her T1D needs (eg, wearing an insulin pump and continuous glucose monitor). She has generally maintained glycemic levels within target, but as she has become more independent, she has not been self-monitoring her blood glucose regularly or following her dietitian's advice. Her parents still assist her with her insulin pump maintenance.

She lives with her parents, attends a local high school, and expects to attend a local university following graduation next year. She plans to stay on her family's private healthcare plan for the time being. Over the last 2 years, her pediatric care provider has suggested several times to both her and her parents that they start to consider transitioning Emily to adult care providers. Although her parents were open to the idea, Emily seemed sad and voiced considerable resistance, saying, "Why do I need to do that? You're my favourite doctor!"

What's your plan?

- The most important thing to do right now is to suggest that she continue to see you for the time being and encourage her to start writing down some health-related goals for herself
- Explain that an adult care provider will be able to better address her T1D medical needs as well as her non-T1D health issues as she moves into adulthood
- Refer her for a few sessions with a diabetes educator to become more familiar with using and maintaining the insulin pump as well as advice on nutrition management
- Ask your nurse coordinator to set up an initial appointment with a primary care provider with expertise in T1D who works with both younger people and adults
- Begin coordinating with her specialty care team (if she has one)
- Explain to Emily that your office and the new doctor will work together to help coordinate her care for a while
- Reassure her that, if she doesn't like the new doctor, you will refer her to another provider

ADDITIONAL RESOURCES

We hope you found this to be a useful summary of information to help you manage transitions in care for young individuals with T1D. To access resources that your patients with T1D may find helpful during and after this transition in care, including online and community support, please visit:

- JDRF: www.jdrf.ca/resources
- The Diabetes Link: https://thediabeteslink.org/
- Diabetes Hope Foundation Transition Guide: https://diabeteshopefoundation.com/transition/
- I Challenge Diabetes: https://ichallengediabetes.org/

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