Transitions in T1D Care: From Adolescence to Adulthood

Teens 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. This transitional period is a critical time when teens and young adults may have unique concerns about a variety of challenges, including:

- Psychosocial issues related to T1D and interactions with family members, friends, and coworkers
- Depression and anxiety
- Eating disorders (especially common in young women with T1D)
- 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 glycated hemoglobin (HbA1c) and blood glucose goals

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. They also educate patients about the effects of T1D on typical activities of young adulthood, such as driving, attending college, and having a job.

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 patients 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 between 18 and 22 years of age. There is no single best strategy or optimal age for making this transition, but an organized approach based on individual needs and preferences is recommended for all patients. 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.

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. Although transition periods often coincide with major life changes, such as moving away to college or starting a new job, delaying transfer of care until such changes normalize may be beneficial for maintaining visit frequency and glycemic control.

Broadly, the American Diabetes Association (ADA) and the International Society for Pediatric and Adolescent Diabetes (ISPAD) offer the following recommendations for transition of care: Start preparing youth for a coordinated transition in early adolescence by collaborating with the patient and family members at least 1 year before transitioning to adult healthcare. 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. 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 that can benefit the patient, including psychosocial, vocational, and educational resources, as well as resources that can help them reconnect to diabetes care if they become lost to follow-up. Recommend different educational resources to help engage the adolescent patient, such as age-appropriate written materials, text messaging, online resources, social media, peer involvement, and group learning. Offer culturally sensitive information on the effects of T1D on employment, driving, sexual health and contraception, and alcohol and drug use.
• **Recommend future visits** to assess glycemic control 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 Let’s Empower and Prepare (LEAP), aim to provide comprehensive resources and education for young adults moving to adult care. The goal is to facilitate improvements in glycemic control and psychosocial well-being. Key components of the LEAP program include:

- Educational modules on diabetes basics, sick day management, accessing care in the adult healthcare system, contraception/family planning, and use of alcohol and recreational drugs
- Case managers to coordinate transfer care
- Option to transfer to a multidisciplinary young adult diabetes clinic
- Access to carbohydrate counting classes
- Support through a social networking website

### 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. The following are key components of successful receivership care:

#### Communicating and Coordinating Care with the Patient’s Pediatrician
Young patients with T1D often form strong emotional bonds with their pediatric providers. Maintaining a good working relationship between pediatric and adult care providers is the key to navigating challenges that may arise during the transition process.

#### 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. In fact, ongoing assessment of self-management skills is an important aspect of diabetes care. Available assessment tools include:

- Readiness Assessment for Emerging Adults with Diabetes Diagnosed in Youth (READDY)
- TRxANSITION scale
- Self-Management Skills Assessment Guide (SMSAG)
- Transition Readiness Assessment Questionnaire (TRAQ)
Building Rapport and Long-Term Relationships
A strong patient-provider relationship lays the groundwork for effectively helping young adults manage glycemic control and prevent diabetes-related complications. 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. 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.

Addressing the Psychosocial Needs of Young Adults
Depression, common in both adults and adolescents with diabetes, is associated with poor glycemic control. In addition, adolescents with T1D have significantly higher rates of anxiety, diabetes-associated distress, and eating disorders than their peers who do not have diabetes. Patients with psychosocial difficulties should be referred promptly to experienced mental health providers.

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. 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 control better than less-structured approaches.

HELPING PATIENTS NAVIGATE HEALTH INSURANCE CHANGES
Maintaining continuity of health insurance is critical for young adults with T1D. Changing jobs or aging out of a parent’s health insurance plan requires planning to avoid gaps in care. Patients without the option of employer-based insurance can enroll in the Affordable Care Act’s health insurance marketplace. For eligible patients, low- or no-cost healthcare coverage may be available through a state Medicaid program. Additionally, most universities offer student health plans.

HEALTH INSURANCE TIPS FOR PATIENTS
- If aging out of a parent’s health insurance plan, start planning several months in advance
- If changing jobs, start planning before giving notice
- Keep a list or calendar of key dates (eg, when current insurance ends, application deadlines, new insurance start date)
- Gather and organize important information and documentation (eg, medical records, health insurance cards, tax documents, and contact information phone numbers for healthcare providers, insurance companies, employers)
- Research and select a new health insurance plan (consider deductibles, copays, out-of-pocket maximums, waiting periods, in-network providers)
- Keep track of communications with employers, insurance companies, and medical device companies

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. 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. They also increased their number of clinic visits from the previous year.
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 22-year-old young adult 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 (e.g., wearing an insulin pump and continuous glucose monitor). She has generally maintained glycemic control 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 college, and expects to graduate in 2 years. She plans to stay on her family’s 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 favorite 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 counting carbohydrates
✓ 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:

• Juvenile Diabetes Research Foundation: www.jdrf.org/t1d-resources
• College Diabetes Network: www.collegediabetesnetwork.org
REFERENCES


