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Contact Hours: **5**

# Diabetes in Children and Adolescents

## Symptoms and Management

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**LEARNING OUTCOME AND OBJECTIVES:** Upon completion of this continuing education course, you will have increased your understanding of the impact of diabetes on children and adolescents. Specific learning objectives to address potential knowledge gaps include:

- Review the prevalence of type 1 and type 2 diabetes in children and adolescents.
- Describe the diagnosis of diabetes in children and adolescents.
- Summarize diabetes treatment and management strategies in youth.
- Explain the medical complications associated with diabetes in children and youth.
- Outline the common challenges facing children with diabetes and their families.
- Explain the issues faced by adolescents with diabetes.
- Discuss the transition from pediatric to adult diabetes care.

## INTRODUCTION

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Clinicians in all care settings are encountering children with diabetes, and the number of children with type 1 and type 2 diabetes is increasing. **Type 2 diabetes (T2D)**, once considered a disease of older adults, is on the rise in children of all age groups and disproportionately among racial minorities and low-income families. Research has found that children and adolescents who are obese are at the greatest risk for developing type 2 diabetes between the ages of 10 to 18 years. As of 2021, around 13.7 million children and youth in the United States are obese (Tamborlane, 2021; CDC, 2021a).

**Type 1 diabetes (T1D)** is one of the most frequently found conditions among children. T1D is on the increase worldwide. No one cause has been pinpointed for this increase, but some of the

areas that are being researched include changes in lifestyle and environmental factors (Mobasseri et al., 2020; Tamborlane, 2021).

According to the CDC, around 1 in every 5 youths between the ages of 12–18 years also have prediabetes. (Prediabetes is a condition diagnosed when fasting glucose levels are elevated in the range of 101–125 mg/dL on more than one occasion.) Research findings show that among adolescents, the rate of prediabetes is higher in young males and those who are obese. Prediabetes places children at high risk for developing type 2 diabetes, but this can be reversed by lifestyle modifications such as decreased calorie intake and increase levels of exercise (CDC, 2020c, 2019).

While diabetes affects children of all ages, impacts of diabetes vary among different age groups. Clinicians must therefore be equipped with a wide range of knowledge in order to provide care to children and their families. For instance, parents of toddlers with diabetes may have to deal with the erratic eating habits of their children when trying to dose insulin. Parents of grade schoolers may be worried about managing diabetes in their children who want to play sports.

Likewise, coping with diabetes can present many challenges for adolescents, especially those who are newly diagnosed with the condition. Many youths find it difficult to adjust to a diagnosis of a chronic condition they see as curtailing their freedom and choices—one that sets them apart from their peers during a time when peer acceptance is essential to their well-being. The role of the clinician is also pivotal in fostering the development of positive coping skills for the adolescent patient with diabetes and for their families.

## Prevalence of Diabetes among Children and Youth

According to the National Diabetes Statistics Report, around 210,000 children and youth under the age of 20 years in the United States had a diagnosis of diabetes as of 2018. Of this group, 187,000 were diagnosed with type 1 diabetes, making T1D the most prevalent form of diabetes in children and adolescents (CDC, 2020c; ADA, 2020).

During 2014–2015, the approximate yearly number of newly diagnosed cases of diabetes in the United States included:

- 18,291 children and adolescents younger than 20 years of age with type 1 diabetes
- 5,758 children and adolescents between the ages of 10–19 years with type 2 diabetes (CDC, 2020c)

### SEARCH FOR DIABETES IN YOUTH STUDY

This study began in 2000. It is funded by the CDC, with support from the National Institute of Diabetes and Digestive and Kidney Diseases. The purpose of the study is to investigate the considerable knowledge gap that exists in the understanding of childhood diabetes. Five centers across the country are involved in the SEARCH study, and to date it is the biggest and most diverse research investigation of diabetes among youth in the United States. More than



20,000 youths are participating in the study, drawn from diverse racial and ethnic backgrounds (SEARCH, 2021).

The SEARCH for Diabetes in Youth study identified the following trends among youth and adolescents:

- During 2002–2015 there was a significant total increase in the numbers diagnosed with type 1 diabetes.
- During 2002–2010 the most significant increase in type 1 diabetes was among Hispanic children and adolescents.
- During 2011–2015, non-Hispanic Asian and Pacific Islander children and adolescents had the biggest significant increase in type 1 diabetes.
- For the time period 2002–2015, there was a significant overall increase in type 2 diabetes in youth 10–19 years.
- During the time frames 2002–2010 and 2011–2015, the rates of T2D among youth 10–19 years did not change among non-Hispanic Whites, but there was a notable increase for all other groups, particularly non-Hispanic Blacks.

(SEARCH, 2021)

## DIAGNOSING DIABETES IN CHILDREN AND YOUTH

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The symptoms of diabetes in children, youth, and adults are similar. However, as the American Diabetes Association (ADA) has pointed out, children are not “little adults,” and diabetes in children has its own unique pathophysiology and development issues that require care and interventions tailored to meet those needs (ADA, 2018a).

### Diagnosing Type 1 Diabetes

Type 1 diabetes was previously known as *juvenile diabetes*, since it was believed that this form of diabetes occurred only in children. However, when it became clear that this form of diabetes can occur across the lifespan, the terminology was changed to *type 1 diabetes*. However, there is ongoing debate over whether the terms *type 1* and *type 2* fully encapsulate the characteristics of both forms of diabetes and clearly differentiate between them (Hoskins, 2020).

Type 1 diabetes is a complex disease. Autoimmune destruction of the insulin-producing beta cells in the pancreas results in complete insulin deficiency or the production of minute amounts of insulin that are insufficient to meet the needs of the body. It is theorized that viral infections have a role in initiating the autoimmune response in genetically at-risk persons that results in the destruction of beta cells and the consequent development of T1D (Tamborlane, 2021).

Type 1 diabetes is considered to have both a genetic and environmental component, although a family history of the condition is frequently not found at the time of diagnosis. However, the



presence of a family history of other autoimmune conditions such as Grave's disease or Hashimoto's thyroiditis has been noted at the time of diagnosis of T1D. Research studies based on twin and family data suggest that in monozygotic twins (twins who share 100% of their genes), when one of the twins has T1D, the risk of the other twin developing the disease is around 50%.

The most frequent period of onset of T1D is during childhood. Childhood onset of the disease is postulated to be more probably genetic in origin than when the disease develops in later adult years. However, more research is needed to fully understand the genetic impact related to the development of T1D (NIDDK, 2018).

T1D can be diagnosed at any age, but for children, the **two peak periods** are from the ages of 5–6 years and 11–13 years. The initial signs and symptoms of T1D can include:

- Thirst
- Increased urination
- Onset of bedwetting in children who have already gained continence
- Increased appetite
- Weight loss

(AAP, 2020; Basina, 2020)

In around one third of children, the first presenting sign of T1D is diabetic ketoacidosis (ADA, 2020a) (see also “Diabetic Ketoacidosis” later in this course).

**Missed diagnosis** for T1D in children is common. Many times, when a child is brought to the pediatrician's office with listlessness, weight loss, increased thirst, nausea, and possible vomiting, the initial diagnosis may be “stomach flu.” It is important to be aware that these flu-like symptoms are also the symptoms of T1D.

Further assessment at this point can include either a simple finger-stick blood glucose test or a ketone stick test of the patient's urine. These tests in themselves do not confirm a diagnosis of T1D, but positive results may indicate the need for further testing. For example, a random blood glucose test that shows a blood glucose level of 200 mg/dL or higher is highly suggestive of diabetes and will require more detailed investigation (Whittemore et al., 2018; Mayo Clinic, 2020).

Beyond a random blood glucose test, **diagnostic testing** for T1D includes a glycosylated hemoglobin (A1C) test. An A1C of 6.5% or greater on two separate tests is indicative of T1D. A fasting blood glucose test may also be done after the child has fasted overnight, with a level of 126 mg/dL or greater supporting a diagnosis of T1D (Mayo Clinic, 2020).

At the time of diagnosis of T1D, approximately 25% of children have thyroid auto-antibodies, which is an indicator of **thyroid malfunction**, most frequently hypothyroidism. Therefore, once a diagnosis of T1D has been confirmed, the child should also be screened for autoimmune



thyroid disease. If the first test shows a “slightly abnormal” result, it is recommended to repeat the test once the child’s glycemic targets have been met and are maintained (ADA, 2020a).

**Celiac disease** is also more common in those with T1D than in the general population. The ADA recommends the following screening protocol for children with T1D:

- Soon after the diagnosis of T1D is established, screen for celiac disease by assessing IgA tissue transglutaminase (tTG) antibodies.
- Repeat the screening test within 2 years of the T1D diagnosis and again after 5 years.
- For children exhibiting symptoms of celiac disease or who have a first-degree relative with the condition, screen more frequently.

Patients who have a biopsy-confirmed diagnosis of celiac disease are started on a gluten-free diet and will benefit from a referral to a dietitian experienced in diabetes and celiac disease (ADA, 2020a).

## Diagnosing Type 2 Diabetes

In type 2 diabetes there is a relative, rather than complete, lack of insulin due to the body not secreting enough insulin or not using insulin well (i.e., insulin resistance). Like T1D, T2D has genetic and environmental components. Several genes have been linked to the development of T2D, but their precise role in the development of the disease has yet to be determined. Studies indicate that high numbers of those diagnosed with type 2 diabetes have a first- or second-degree relative with the condition, with figures ranging from 74% to 100%. Of the environmental components associated with T2D, the most significant is obesity (Tamborlane, 2021).

Approximately 40% of children with T2D have no obvious symptoms, and the condition is often diagnosed during routine physical examinations. The **ADA recommends screening** for prediabetes and T2D in children and adolescents who:

- Are overweight or obese
- Have a first- or second-degree relative with T2D
- Identify as Native American, African American, Latino, Asian American, or Pacific Islander
- Exhibit signs of insulin resistance or have disorders related to insulin resistance, such as acanthosis nigricans (dark discoloration and thickness of skin in skin folds and creases), hypertension, dyslipidemia, or polycystic ovary syndrome (ADA, 2020a)

T2D in children and youth is associated with obesity. Obesity is increasingly diagnosed in children and adolescents (FDA, 2018). Data from 2015–2016 indicate that almost 1 in every 5 youth (18.5%) between the ages of 2 and 19 years is obese (Hales et al., 2017).



Exams of children who are overweight should include questions about the following **signs and symptoms**:

- Thirst
  - Frequent urination
  - Tiredness
  - Blurred vision
  - Frequent infections
- (Mayo Clinic, 2017)

While conceding that there is minimal data to support using A1C measurement to diagnose T2D in children and adolescents, the ADA continues to recommend using A1C as the diagnostic criteria in this group (ADA, 2020a).

#### **ANSWERING PARENT/PATIENT QUESTIONS**

**Q: What is juvenile diabetes and what causes it?**

**A:** *Juvenile diabetes* is an older term for what is now referred to as type 1 diabetes in children. It is caused when the pancreas is no longer able to produce insulin. Common symptoms include increased thirst, increased urination, and weight loss. Bed wetting in a child who is already successfully potty trained is another symptom to be aware of. Children who have a first-degree relative with type 1 diabetes (such as father, mother, brother, or sister) have a greater risk for developing type 1 diabetes (Tamborlane, 2021).

**Q: What is the difference between type 1 and type 2 diabetes?**

**A:** In type 1 diabetes the body is unable to produce insulin due to the destruction of the insulin-producing cells in the pancreas. In type 2 diabetes, the body is still producing insulin, but the cells in the body are unable to use the insulin the way they should. This is referred to as *insulin resistance*.

**Q: What is prediabetes?**

**A:** In prediabetes the blood sugar level is higher than what it should normally be, but it has not reached the upper limit at which diabetes will be diagnosed. In other words, the individual does not have diabetes, but they are at increased risk of developing it.

**Q: If a child or adolescent has prediabetes, does this mean they will develop diabetes?**

**A:** No. Although the risk of developing diabetes is high when prediabetes exists, it is not a certainty. There is much that parents and caretakers can do to reverse prediabetes in children. This includes encouraging and practicing healthy eating in the home and increasing the child's



level of activity. Parents should set a goal of 60 minutes of physical activity for their child on a daily basis (CDC, 2019).

**Q: How do I know if my child has diabetes?**

**A:** The most obvious signs of diabetes that parents and caregivers should be aware of are increased thirst, increased urination, and weight loss. These findings should be reported to the child's pediatrician, and further testing can be done to determine if the child has diabetes.

## DIABETES MANAGEMENT IN CHILDREN AND ADOLESCENTS

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The overarching goal for treating and managing diabetes in children is centered around maintaining normal physical growth and positive psychosocial development by establishing good glycemic control and preventing acute and chronic complications as far as possible (ADA, 2017a).

### Pharmacotherapy

**Insulin therapy** is the primary treatment for type 1 diabetes and also often implemented for type 2 diabetes. The discovery of insulin in 1921 was a turning point in the treatment of type 1 diabetes. Prior to the introduction of insulin therapy, the life expectancy of children with type 1 diabetes was around one year from the time of diagnosis (Tamborlane, 2021).

Insulin needs for children will fluctuate significantly as the child grows. When children are first diagnosed with type 1 diabetes, the most common treatment requirement is 0.5–0.8 units of insulin per kilogram of body weight per day. However, when the child with T1D enters puberty, the need for insulin therapy sharply increases to 1.0–1.5 units/kg/body weight daily. During growth spurts children may need two to three insulin dose adjustments on a weekly basis (ADA, 2017a).

Insulin pumps with continuous glucose monitoring are becoming more popular and work well for children. In toddlers and preschool-age children it has been shown that using an insulin pump delivers a more dependable dose of basal insulin (ADA, 2017a; ADA, 2020a). (See also “Monitoring Blood Glucose” below.)

### HONEYMOON PERIOD

Approximately 62% of children with T1D may experience partial remission, sometimes referred to as a *honeymoon period*. The duration of the remission varies from 6 weeks to 2 years. During remission, the pancreas continues to produce some insulin, decreasing and sometimes eliminating the need for treatment. However, once the “honeymoon period” ends there is an increased need for insulin therapy. Family education on what is happening during



this period is important so that families are aware that the diabetes has not gone away and they are prepared for the time when insulin treatment will need to be increased (ADA, 2017a).

### ACCESS TO INSULIN

Insulin is not just another medication; it can be the difference between life and death for a person with diabetes. Since the year 2002, the cost of insulin has almost tripled. In 1996 a vial of Humalog insulin cost \$21; in 2019, it cost \$255 (Roberts, 2019). At each appointment, the clinician must inquire as to whether the patient is having any problems gaining access to their insulin or diabetes supplies. Patient assistance programs may be offered by pharmaceutical companies as well as state and federal agencies. (See “Resources” at the end of this course.)

For children with type 2 diabetes, treatment is frequently started with the oral **anti-hyperglycemic medication** Metformin. Presently Metformin is approved for children 10 years of age and older (ADA, 2017a). However, Metformin does not achieve therapeutic outcomes in many children with T2D, and these children need to start on insulin therapy soon after diagnosis (Curry, 2016).

### ANSWERING PARENT/PATIENT QUESTIONS

**Q: Can diabetes be cured? Does it eventually go away?**

**A:** At this time diabetes cannot be cured nor will it go away. However, it is a condition that can be successfully managed and treated.

**Q: What are the treatments for diabetes?**

**A:** Insulin is the primary treatment for type 1 diabetes. Type 2 diabetes can be controlled by diet and sometimes will require either oral medications or insulin depending on the severity of the disease.

## Monitoring Blood Glucose

The recommendation for children with T1D is for blood glucose checks before meals and at bedtime. This necessitates that some blood glucose checks be done while the child is at school or for preschool-age children while at daycare (ADA, 2017b). Children with T2D will also require several blood glucose checks on a daily basis, especially if they start on insulin therapy (FDA, 2018).

Blood glucose monitoring for young children requires the use of fine-gauge lancets and adjustable ends on the lancing machine. Clinicians must teach parents and guardians of young children how to choose the superficial-depth setting on the lancet device, to use the side of the child’s fingers for testing, and to observe the sites for soreness and bruising (ADA, 2017a).



The ADA recommends **continuous glucose monitoring (CGM)** for children and youth with T1D, whether they are being managed by insulin injections or by continuous subcutaneous insulin infusion. CGM can be used for children as young as 2 years. Research has also shown that CGM improves the quality of life for adolescents with T1D and decreases levels of diabetes distress (ADA, 2020a; NIDDK, 2017; Spero, 2018).

While strong evidence exists for the use of CGM in those with T1D, less evidence exists for its use in T2D. However, the evidence available does demonstrate that CGM offers similar benefits to patients with T2D as to those with T1D (Lin et al., 2021).

A continuous glucose monitor will automatically screen blood glucose levels. The monitor may be a stand-alone device or part of an insulin pump. A small sensor is placed under the patient's skin; typical sites are the belly or arm. The sensor measures the glucose in the interstitial fluid under the skin. A transmitter wirelessly relays that information to a monitor, and the monitor converts the reading to a blood glucose number. An alarm rings when the blood glucose levels are out of range.

Some monitors transmit information directly to a smartphone or tablet and to a second individual's smartphone, such as a parent's, if a child's blood glucose levels move out-of-range. The sensor performs glucose testing every few minutes, making it possible for the patient or caretaker to see the blood glucose level at a glance, at any given time, including overnight. Apart from reducing the number of finger sticks, continuous glucose monitoring allows for more accurate decision-making regarding balancing food, exercise, and medications (Spero, 2018; NIDDK, 2017).

CGM requires a physician's prescription. Most insurance plans cover the cost, but there may still be considerable copayments. Clinicians must oftentimes guide the patient to seek help through partnerships with patient advocates who speak to the insurance carrier on behalf of families.

Parents and caregivers must be made aware of the learning curve involved in switching to CGM from fingersticks, and the patient's diabetes management team must assess the family's willingness and motivation to invest the time and effort needed to successfully use CGM. Also, it is important for the clinician to inform parents and caregivers that fingersticks are still required to calibrate the device and to confirm an out-of-range glucose reading before instigating treatment.

To successfully use CGM, the clinician must ensure that the child and parents are trained on the following points:

- The low alerts on the CGM must be turned on.
- The alert onset must be set above the point where hypoglycemia develops.
- Every low alert signal must be addressed immediately and consistently. (Scheiner, 2020)



## CGM DEVICES AND TREATMENT DECISIONS

Clinicians should be aware that some, but not all, CGM devices have been approved by the FDA for the purpose of making treatment decisions. This means that it is acceptable to make treatment decisions based solely on the results provided by FDA-approved devices. For all other CGM devices, out-of-range readings must be correlated by a fingerstick check before initiating treatment. However, in all instances, patients, parents, and caretakers must be instructed that if presenting symptoms do not match the CGM reading, a finger-stick must be done before taking any action, regardless of the device being used.

Given the ongoing advances in technology, the diversity of CGM devices will continue to change, and clinicians must stay abreast of new developments. The recommendation from the American Diabetes Association is for a young person's diabetes management plan to be checked in all instances before using CGM results to make treatment decisions (ADA 2018b, Spero, 2018; NIDDK, 2017).

## Preventing Hypoglycemia

Hypoglycemia is a common occurrence in type 1 diabetes; it can also occur in those with type 2 diabetes but usually to a lesser degree (Worldwide Diabetes, 2021). Hypoglycemia is a major concern for children with diabetes, especially hypoglycemia occurring during the night.

Accurately pinpointing the exact rate of occurrence of hypoglycemia is difficult since asymptomatic hypoglycemia frequently occurs in children with type 1 diabetes and is often not recognized. Studies have shown that severe hypoglycemia is much more likely to occur in younger children between the ages of 2–6 years as compared to those in the 18–26 age range (Tamborlane, 2021).

**Symptoms** of hypoglycemia include:

- Shakiness, which may manifest as slight shaking or trembling
- Sweating on the face and over the body, comparable to the sweating that occurs with exercising
- Feeling of hunger, often developing suddenly and felt more intensely the lower the blood glucose levels
- Fast heartbeat
- Inability to concentrate
- Dizziness or lightheadedness
- Irritability or moodiness
- Anxiety or nervousness



- Headache
- Paleness, clammy feeling  
(Mayo Clinic, 2019; Diabetes Care Community, 2021)

Preventing episodes of hypoglycemia is best achieved by monitoring blood glucose levels before meals and at bedtime.

Doing blood glucose checks before, during, and after exercise or sports indicates how these activities affect a child's blood glucose levels and may indicate the need for a snack before or after exercise or playing sports. Changes in insulin dosing may also be required on days when the child is more active (Kelly & Gilliland, 2018).

The ADA cautions that when establishing individualized blood glucose ranges, attention must be given to the danger of hypoglycemia based on the age of the child. Children under the age of 6 are usually not able to identify hypoglycemia, express what they are feeling to others, or manage the condition themselves (ADA, 2020a).

The ADA points out that individualized A1C targets are attainable in children, even those under the age of 6, without amplifying the risk of severe hypoglycemia. The ADA advises lowering and maintaining blood sugar levels in children in a series of distinct stages (ADA, 2020a).

## **NOCTURNAL HYPOGLYCEMIA**

Nocturnal hypoglycemia is frequent in children with diabetes, usually occurring in the earlier part of the night. It correlates with bedtime blood glucose values of <150 mg/dL (ADA, 2017a). For children with nocturnal hypoglycemia, middle-of-the-night blood glucose monitoring is advisable.

Testing at midnight and again at around 3 a.m. on a weekly basis can help parents recognize a pattern in their child's nocturnal blood glucose levels and assess whether changes to a child's diabetes management are successful or not. For instance, middle-of-the-night testing may indicate the need for a bedtime snack and whether such a snack was adequate or not (Kelly & Gilliland, 2018).

Parents are also encouraged to perform a middle-of-the-night blood glucose test after a child has participated in strenuous exercise or sporting activities because a child with diabetes can develop hypoglycemia several hours after the activity or exercise is over.

Young children are not always able to express in words what they are feeling, and a child refusing to sleep, showing signs of irritability, and/or crying may be experiencing hypoglycemia. Parents are instructed to perform a blood glucose check to determine if hypoglycemia is the cause of such behaviors (ADA, 2017a).



**ANSWERING PARENT/PATIENT QUESTIONS****Q: How do I know if my child has a low blood sugar level (hypoglycemia)?**

**A:** Very young children may become irritable, fussy, and refuse to sleep. Other signs to look for are complaints of dizziness, light-headedness, and headaches. Look closely at the child's physical appearance; pale, clammy skin, tremors, or slight shakiness are all signs of low blood sugar. The child may also complain of feeling hungry. If any of these signs are present, it is important to check the child's blood sugar level.

**TREATING HYPOGLYCEMIA IN CHILDREN*****Consuming Carbohydrates***

Hypoglycemia in children is treated by consuming 15 grams of carbohydrates. Good sources for children are 4-ounce juice boxes, regular soda, nonfat milk, and raisins. Parents are instructed to wait for 15 minutes and then recheck the child's blood sugar. If it is still low (<70 mg/dL), the child is treated with a second 15 grams of carbohydrates.

Foods containing fats, such as chocolate, should not be used to treat hypoglycemia, since the fat content can hinder the action of the carbohydrates and thus extend the acute hypoglycemic episode.

***Glucagon Administration***

Glucagon is a hormone produced by the alpha cells in the islets of Langerhans in the pancreas; it is also available as a medication to treat episodes of hypoglycemia. When administered, glucagon activates the release of glucose into the blood stream. It normally takes 10–15 minutes after the administration of glucagon for blood glucose to return to a safe level.

Glucagon is indicated when the individual is exhibiting signs and symptoms of hypoglycemia and cannot safely swallow food or fluids, is unconscious, or is having seizure activity (Children with Diabetes, 2021; NCH, 2020). Glucagon can be administered in the presence of nasal congestion or a cold, and it can be used in children ages 4 years and older.

Parents and caregivers of children with diabetes are instructed on when and how to administer glucagon for severe hypoglycemia. Traditional glucagon comes in a kit that includes a powder and a liquid that must be mixed together prior to injection. Glucagon shots can be administered in the upper arms, thighs, or buttocks. Glucagon is injected in the same way as insulin. Other forms of glucagon therapy have received FDA approval, including a premixed autoinjector and a nasal powder (Baqsimi), which can be administered even to a patient who is unconscious since it does not need to be actively inhaled but is absorbed through the nasal tissue (ADA, 2020a, 2017b; Pietrangelo, 2021; Werner, 2019; Children with Diabetes, 2021).



Precautions include:

- After administering glucagon, do not leave the child alone. Call 911 for further assistance.
- Keep the child on their side since vomiting is a side-effect of glucagon administration. (Other side effects can include headache, flushing, and a rapid heartbeat.)
- Once the child is alert and can safely swallow, provide oral carbohydrates to treat hypoglycemia; this can be in the form of fruit juice or non-diet soda.

### **HYPOGLYCEMIA UNAWARENESS**

Hypoglycemic unawareness happens when the individual fails to recognize the warning symptoms that precede an episode of hypoglycemia (see above). It can result from frequent episodes of severe hypoglycemia.

A considerable number of children with T1D experience hypoglycemic unawareness. Very young children are more profoundly affected by repeated episodes of hypoglycemia since their central nervous system is still in the process of maturing. These children are at greater risk for cognitive deficits and behavioral problems (Szadkowska et al., 2018).

Hypoglycemic unawareness in children is usually treated by changing the child's blood glucose range to a higher level for several weeks. This is achieved by performing at least four blood glucose checks during the day. Blood glucose checks at night may also be recommended. The goal is to help the child recover an awareness of their typical sensations of low blood glucose levels. It is critical that parents understand the importance of preventing episodes of hypoglycemia from occurring during this time period (Kelly & Gilliland, 2018).

### **DIABETES ALERT DOGS**

Use of a trained diabetes alert dog (DAD) to recognize an impending episode of hypoglycemia is a recent trend in diabetes management. These dogs are particularly useful for those with hypoglycemic unawareness. How this works is not completely understood, but it is recognized that the DAD employs its heightened sense of smell to detect certain odors produced by the human body during an episode of hypoglycemia. Once the DAD perceives this odor, they warn their owner by initiating certain behaviors such as placing their paws on the owner's lap, jumping up on their lap, touching their nose, or alerting other family members that the patient needs help.

DADs have been found to be of special benefit to children with diabetes, especially in detecting nighttime episodes of hypoglycemia and alerting parents to the child's condition. However, many agencies that provide DADs do not serve children due to the complexities of having to train the dog to meet the needs of both the child with diabetes and their family. There is also concern that children under the age of 12 years are not capable of independently



managing a dog outside of the home. In some states, a child who wants to bring a DAD to school must pay for the cost of a handler to assist with the dog (Fachetti, 2018).

## Medical Nutritional Therapy

Individualized medical nutritional therapy is an indispensable part of a treatment plan to manage diabetes in children and youth. At the time of diagnosis with diabetes, the child is referred to a registered dietitian with experience in managing children with diabetes. Yearly follow-up visits are included in the child's comprehensive plan of care (ADA, 2020a).

Medical nutritional therapy is geared toward the child's age and stage of development. Meal planning must take into consideration the number of calories a child needs for growth. The goal is to help the child reach and maintain a healthy weight. Strategies may include:

- Teaching parents and children about portion control
  - Aiming for three meals and three snacks daily
  - Planning each meal to contain the same amount of carbohydrates
  - Including healthy fats in the diet
  - Not regarding a particular food as “off-limits,” while teaching how different foods affect blood glucose and how and when certain foods, especially treats, should be included into the meal plan
  - Working with parents to set a goal for the whole family to gradually replace soda and other sugary drinks (e.g., juices, sports drinks) with plain water or low-fat milk
  - Teaching parents and children about the importance of reading food labels and how to understand what they mean
- (NIH, 2021)

Meal planning for **toddlers and preschoolers** can take skill and patience. Toddlers in particular are prone to reject foods that add variety to their diet. Parents are advised that young children require morning, afternoon, and bedtime snacks to ensure a ready source of glycogen (ADA, 2017a). However, very young children may not complete a meal or snack, which makes it extremely difficult for parents of children with T1D to safely dose insulin prior to meal times. In these instances, rapid-acting insulin analogs given after a meal are recommended. Parents are instructed to determine the insulin dose based on what the child actually ate (ADA, 2017a).

For **school-age children**, medical nutritional therapy must take into account meals at school, afterschool events, sporting activities, parties, eating out, sleepovers at friends' houses, the child's changing food tastes, etc. (ADA, 2017a). Clinicians encourage parents and school-age children to work together to develop meal plans, assisting children to acquire the skills they need



to become more independent by learning about carbohydrate counting and planning their own food choices and portion sizes.

**Adolescents** can be more involved in their own care by monitoring their carbohydrate intake and individualizing their meal plan based on greater awareness of their food preferences (ADA, 2020a).

The diabetes management team, along with the child and family, formulate a dietary plan that is adaptive to the needs of the family. The clinician must take into account the child and family's dietary habits, cultural or religious considerations, financial resources, and mathematical ability to successfully count carbohydrates (ADA, 2020a).

For many children with diabetes, it is important to ensure they are not singled out as needing “special foods” or missing out on the treats enjoyed by siblings or peers. For example, the dietitian may suggest limiting dessert to once a week or adopting certain foods for the entire family. With guidance from the dietitian, the parents and child can discover when it is possible to incorporate more flexibility into the diet plan and when adjustments can be made (Lebow, 2019).

#### **MINDFUL EATING**

Mindful eating is an approach that is becoming more popular as a means to avoid overeating and to achieve a healthy weight. The basis of this approach is to help the child identify what is prompting them to eat: are they bored, in need of emotional support (e.g., a hug), or truly hungry for food? Mindful eating also encourages children not to focus on what they cannot eat and to enjoy mealtimes (Stevelos, 2017).

### **Sick-Day Planning**

Illness increases stress, leading to an increase in blood glucose levels. Vomiting and diarrhea can cause dehydration, and an inability to keep food down can result in the body utilizing fat for energy. This may in turn lead to ketoacidosis due to above-normal levels of ketones, which is a serious and possibly fatal condition (see also “Diabetic Ketoacidosis” later in this course).

It is important for children with diabetes and their parents to understand how illness, including minor colds and infections, affects diabetes. Having a practical and workable plan for sick-day management is essential and must be put in place as soon as diabetes is diagnosed. This also reduces fear and anxiety for the child and their parents (ADA, 2017a).

Important **elements of a sick-day plan** include:

- Never stopping taking insulin or diabetic medications
- Maintaining fluid intake (since dehydration can lead to DKA)
- When vomiting occurs, considering it to be a sign of insulin deficiency until confirmed differently



- Treating the underlying condition
- Implementing more frequent blood glucose checks (every 2 to 4 hours)
- Checking for ketones in urine  
(Beebe et al., 2017; Laffel, 2018)

The intake goal is 15 grams of carbohydrates per hour. Typically, the child is encouraged to drink small amounts of fluids, around 1/2 cup every hour, slowly and without taking large mouthfuls. Recommended **foods to avoid hypoglycemia** when sick include:

- Jello
- Saltines
- Apple sauce
- Bananas
- Toast
- Graham crackers
- 1/2 cup ice cream
- 1/4 cup sherbet  
(Hess-Fischl, 2020)

Families are instructed on when they should **call for medical help** and provided with 24-hour contact information for medical assistance, preferably someone on the diabetes management team. They are instructed to call their provider or emergency contact if the child has several episodes of vomiting, diarrhea, refuses to take fluids, has blood glucose levels that remain out of range, becomes lethargic, or develops deep, rapid respirations. Other reasons to seek emergency care include:

- When it is unclear what the causative condition is, if fever persists, or if the child or family feel a need to reach out for help for any reason
- If blood glucose levels are not staying within range (either too high or too low)
- If blood sugar levels continue to rise despite administering extra doses of insulin
- If there is a fruity breath-smell that persists or increases
- If urine ketone levels continue in large amounts despite extra insulin dosing and hydration
- If the child becomes exhausted, starts hyperventilating, shows signs of confusion, or develops acute abdominal pain
- If the child or family do not have adequate supplies to monitor blood glucose levels or insulin to provide treatment  
(Hess-Fischl, 2020; ADA, 2017a; Laffel, 2018)



**Sick-day supplies** that should always be kept on hand may include:

- Chicken soup, clear broths, and hydration drinks containing water and salt to prevent dehydration
  - Glucose tablets, jelly beans, and dried fruits to treat hypoglycemia
  - Easily digested sources of carbohydrates (e.g., crackers, noodles, rice, yogurt) to main blood glucose levels
- (Laffel, 2018)

## MEDICAL COMPLICATIONS ASSOCIATED WITH DIABETES IN CHILDREN

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Children with both types 1 and 2 diabetes are at risk for several complications. Data indicates that 1 in 3 adolescents with type 1 diabetes and around 3 in 4 adolescents with type 2 diabetes exhibit symptoms of at least one diabetes-associated complication. However, diabetes complications in children and youth have not been well studied.

While the same effects of diabetes are common to all age groups, one of the important factors in the development and severity of diabetic complications is the length of time diabetes is present. Young children diagnosed with diabetes have a potentially greater risk for microvascular complications as they proceed into their adult years, compared to their peers without a diagnosis of diabetes.

The types of complications are also similar between forms of diabetes, but there is a difference in prevalence rates. For example, retinopathy can occur more frequently in youth with type 1 diabetes, whereas microalbuminuria and hypertension occur more often in youth with type 2 diabetes. It has also been found that diabetic-related complications occur at a younger age in youth with type 2 diabetes compared to those with type 1 diabetes.

The presence of diabetes is a major risk factor for earlier mortality related to cardiac disease. Research shows that the risk of cardiac disease and acute myocardial infarction has a 30-times increase in those who diagnosed with type 1 diabetes before the age of 10 (ADA, 2018; NIDDK, 2018; Tamborlane, 2021).

### Complications and Type 1 Diabetes

#### DIABETIC KETOACIDOSIS (DKA)

One of the most serious complications for children with T1D is diabetic ketoacidosis. When the body is unable to utilize glucose for energy due to a lack of insulin, it turns instead to its fat stores as an energy source, and the byproducts of this process are ketones (fatty acids), which alter the serum and urine pH and eventually result in DKA (ADA, 2017a).



The condition can develop slowly, but without treatment it is fatal. DKA is the most pervasive cause of mortality in children with T1D (ADA, 2017a). DKA has also been proven to result in serious consequences for brain development and function (ADA, 2020a).

**Signs** of DKA include:

- Excessive thirst
- Dry mouth
- Weakness
- Lethargy
- Fruity breath-smell
- Nausea
- Vomiting
- Abdominal pain
- Difficulty breathing

Once vomiting occurs, the child's condition can quickly deteriorate to full-blown DKA within a matter of a few hours. A child with DKA requires immediate medical treatment to correct dehydration and bring blood glucose levels back down to normal. Acute kidney injury can occur in children during episodes of DKA; research has found that this can lead to slight cognitive impairment, which includes short-term memory loss and decreased IQ scores (Weiner & Karlya, 2017; Zolot, 2021).

## **CARDIOVASCULAR DISEASE**

Clinicians may not consider cardiovascular disease as a problem in children and youth, however current data indicates that 14%–45% of children with T1D develop two or more atherosclerotic cardiovascular diseases (ADA, 2020a). Cardiovascular disease risk factors are highest among minority youth, and girls are at higher risk than boys.

ADA recommendations for screening of cardiovascular disease in children and youth with T1D include:

- Blood pressure measurement at each visit using an appropriate-size cuff for a child
- Lipid evaluation shortly after diagnosis with T1D

Treatment interventions focus primarily on lifestyle modifications, with emphasis on dietary modifications and exercise (ADA, 2020a).



## RETINOPATHY

Retinopathy is another major medical complication associated with T1D. Current data indicate a small risk of developing retinopathy in children before the age of 12. Problems with retinopathy most frequently occur after the start of puberty and after the presence of T1D for 5 to 10 years.

ADA recommendations for retinopathy screening include a comprehensive eye examination, along with dilation, for a child who is at least 11 years of age or older or who has reached puberty and is 3 to 5 years postdiagnosis with T1D, whichever happens first. Once a baseline exam has been conducted, a comprehensive eye exam with dilation is advised every two years. This may be extended to every four years on the advice of an eye care specialist.

Clinicians must educate parents and youth on the importance of eye exams. Parents should seek out an eye specialist with expertise in diabetic retinopathy and who is well versed in counseling families and youth in prevention measures and the signs and symptoms to observe for in order to ensure early detection (ADA, 2020a).

## NEUROPATHY

Diabetic neuropathy is not commonly found in children with T1D before puberty, or within the first 1 to 2 years following onset of diabetes. The ADA recommends a yearly foot examination beginning at the onset of puberty or at 10 years of age or greater, whichever occurs first. The ADA also recommends a complete clinical foot inspection during each routine visit as a means to educate the young person on the importance of foot care (ADA, 2020a).

## Medical Complications in Type 2 Diabetes

Compared to youth with T1D, medical complications are higher in youth with T2D. Likewise, studies show that T2D is a more severe disease in children than in adults. When adults are diagnosed, complications may not arise for a considerable length of time, often up to 10 years. However, in children with T2D, complications start developing within a few years of diagnosis.

The rates of T2D are higher in racial/ethnic minorities, many of whom live in environments in which diabetes self-care, health management, and lifestyle changes can be challenging. Youth with T2D may already have other health conditions present at the time of diagnosis, similar to those discussed above for T1D. Other problems unique to T2D must also be taken into account.

## COMPLICATIONS OF TYPE 2 DIABETES

**Kidney disease** is a frequent complication of T2D in children (Curry, 2016). The evidence shows that in youth with T2D, there is a faster ongoing deterioration in beta-cell function than in adults with T2D.

The development of **vascular defects**, including ischemic heart disease and stroke, seems to be more prominent in youth with T2D compared to youth with T1D with a similar duration since diagnosis.



Micro- and macrovascular changes are among the most serious medical complications of T2D in this population, which heightens their risk of cardiovascular disease and death at a younger age when compared to those diagnosed with T2D at later stage in life. It is believed that this increased susceptibility to adverse cardiovascular events is due to the greater lifetime exposure to hyperglycemia and other variants associated with T2D, such as insulin resistance, dyslipidemia (abnormal blood lipid levels), high blood pressure, and chronic inflammation (ADA, 2020a).

**Other complications** include:

- Polycystic ovary disease (a hormonal condition resulting in irregular or extended menstruation)
- Hyperandrogenism (a higher-than-normal level of male sex hormones)
- Sleep apnea
- Hepatic steatosis (a build-up of fat in the liver)  
(ADA, 2020a)

## SCREENING RECOMMENDATIONS

ADA recommendations for screening youth who are newly diagnosed with T2D include:

- Screening for retinopathy at the time of diagnosis or shortly thereafter
- Evaluation for nonalcoholic fatty liver disease at the time of diagnosis, using AST and ALT measurements, and follow-up testing yearly
- Screening for symptoms of sleep apnea, snoring restless sleep, and morning headache at each visit and, if necessary, referral to a pediatric specialist for further evaluation
- For adolescent girls with T2D, assessing for menstrual problems and, if warranted, for polycystic ovary disease
- Lipid screening once glycemic control has been established, and then repeated yearly
- Baseline foot exam at the time of diagnosis and on a yearly basis to monitor for neuropathy  
(ADA, 2020a)

## CHALLENGES FACING CHILDREN WITH DIABETES AND THEIR FAMILIES

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There are many challenges facing children with diabetes and their families. For instance, parents often ask, “What can my child do (or not do), and how can we keep our child safe?” Another area of concern for families of children with diabetes is physical activity. The clinician must be ready to address these and other challenges when caring for pediatric patients.



## Managing Diabetes in School Settings

Starting daycare and then school is an exciting and challenging time for children and their parents. For children with diabetes, there are extra challenges to overcome and concerns to be addressed during this transition. Clinicians who work with young children with diabetes are aware of these challenges and provide support, encouragement, and education.

### DAYCARE AND DIABETES

An important concern for parents of very young children with diabetes is whether their child can attend and be safe in daycare. Therefore, the clinician ensures that the child's healthcare team and parents develop a written plan of care for the child and that the parents then review the plan with the daycare administration and staff.

All the staff working with the child must have basic diabetes education, be able to recognize high and low blood glucose levels, and know whom to call for assistance. It is essential that there is always at least one daycare staff member present who has been trained to perform blood glucose checks and to administer insulin if needed.

It is the responsibility of the parents to provide the daycare facility with all the diabetes supplies that their child will need, as well as the prescribed insulin and snacks (ADA, 2017b).

### DIABETES AND DISCRIMINATION LAWS

Federal and state laws protect against discrimination against children with diabetes. Children with diabetes have the same right to attend daycare as any other child. The legal protections against discrimination for children with diabetes are covered under the Americans with Disabilities Act and section 504 of the Rehabilitation Act of 1973.

The role of the clinician is not to know all the details about these laws but to alert parents and children that such laws exist and to provide them with related resources, such as contact information for the American Diabetes Association, which will be able to provide specific details of the laws in their state (ADA, 2017b).

### DIABETES CARE AT SCHOOL

During the school day, students must perform blood glucose checks based on their plan of care, follow a healthy diet, and self-administer insulin or manage an insulin pump. These activities are carried out with assistance and supervision from the school nurse.

In their position statement "Diabetes Management in the School Setting," the National Association of School Nurses (2017) stresses the importance of school nurses having current knowledge and competency in coordinating and providing care to children with diabetes. In conjunction with the family and the child, the school nurse develops an individualized healthcare plan (IHP) for the child. The IHP is based on the primary healthcare provider's orders for



diabetes management for the child and the nurse's assessment. The IHP includes instructions on how the child's diabetes will be managed in the school setting and who will be involved in the care.

The school nurse is also responsible for developing an emergency care plan (ECP) based on the primary healthcare providers orders and outlining how to recognize hypoglycemia and hyperglycemia, including which actions must be taken to correct these conditions. The nurse ensures that all school personnel having accountability for the child during the school day or during afterschool activities are provided with copies of the ECP and know how to act upon its instructions (NASN, 2017).

However, the school nurse may not always be available to assist and monitor each individual student. School-based occupational therapists, in collaboration with school nurses, are part of the interdisciplinary team and promote and maintain self-management skills and address the mental health concerns of children dealing with diabetes in the school setting (Polo & Cahill, 2017).

It is also important that parents play a supportive role in their child's school diabetes management plan. Parent interventions include meeting with the child's teachers and discussing with them the specific signs and symptoms their child may exhibit when their blood glucose level is dropping, such as becoming irritable or nervous or complaining of feeling hungry or dizzy. When teachers are aware of what to look for in children with diabetes, they can intervene more quickly (CDC, 2021b).

## Physical Activity for the Child with Diabetes

Exercise is good for children with diabetes. Participating in sports promotes physical and psychological well-being and helps to maintain blood glucose control. Children with diabetes indicate that being involved in sports and other extracurricular activities helps them to cope with having a chronic condition and allows them to "feel normal," but fewer children with diabetes participate in sporting activities and other extracurricular activities compared to those without diabetes. Participation is exceptionally low in children from poorer families contrasted to children from middle-class backgrounds (Beebe et al., 2017).

Fear of hypoglycemia is the main deterrent to participating in sports (Beebe et al., 2017). It is important that the diabetes management plan devised for each child includes recommendations for physical activities and also ways to prevent, detect, and treat episodes of hypoglycemia, such as more frequent blood glucose checks and adjusting insulin doses, meals, and snacks on days when the child participates in physical activities and sports (ADA, 2017a). Awareness is essential of these steps needed to prevent and treat hypoglycemia before and after physical activities.

The ADA and the American Academy of Pediatrics recommendations for children with diabetes include at least 60 minutes of moderate to strenuous physical activities every day. Further ADA physical activity recommendations include:

- Ensure that the child has a pre-exercise glucose level of 90–250 mg/dL.



- Ensure that the child has access to sources of carbohydrates before beginning physical activity or participation in sports.
  - Prepare a kit for the child to take to physical activity (e.g., team practices and games) that has snacks, glucose tablets, fruit juices, water, and medications recommended by the diabetes management team.
  - For organized sports activities, ensure that coaches are aware that the child has diabetes. Many school sports coaches have experience with children with diabetes, but it is still the parents' responsibility to explain the child's unique experience with diabetes to the coach and what interventions will be needed if a problem arises related to diabetes.
  - Ensure children with diabetes wear medical identification bracelets during all physical activities and sports events to alert others to the child's condition, especially in an emergency situation.
  - Educate the child on the importance of taking a break from activities, even in the middle or near the end of a game, if they start to feel that something is wrong. Parents and coaches must re-emphasize this point with the child.
  - Determine how the insulin dosage for the meal prior to the physical activity should be reduced.
  - Include a bedtime snack after physical activity.
  - Frequently monitor blood glucose levels before, during, and after physical activity regardless of whether or not CGM is employed, which is essential to identify out-of-range blood glucose levels occurring with physical activity.
- (ADA, 2020a; Hess-Fischl, 2019)

#### **ANSWERING PARENT/PATIENT QUESTIONS**

**Q: What should my child with diabetes be instructed to do if they start experiencing low blood sugar while participating in sports?**

**A:** It is important that children understand that they must stop the activity immediately and not ignore how they are feeling. They should tell their coach or supervisor about how they are feeling and eat a snack. If possible, they should check their blood sugar. They should not be left alone at any time.



## DIABETES SUMMER CAMPS

Summer camps play an important role in the lives of many children. They provide a time to make new friends, learn new skills, or experience living independently away from home. However, for children with diabetes, parents may mistakenly think that summer camps are out of the question.

Clinicians must acknowledge parents' concerns, such as: Will the child remember to check their blood sugar level? What will occur if they run out of diabetes supplies at camp? Is there a medically trained person on the camp staff who has experience dealing with diabetes? Will they be able to care for the child 24-hours a day?

The American Diabetes Association offers camps for children with diabetes, located in most states. Physicians, nurses, and counselors experienced in treating diabetes are on staff and provide 24-hour supervision for the children. These camps provide physical and emotional benefits to children with diabetes as well as improve their skills in diabetes self-management. A 2019 survey to assess the effectiveness of the ADA camp curriculum found that at least 70% of the children who participated in the camps acquired or improved their existing skills in a minimum of one diabetes activity. These activities involved drawing up insulin, self-administering insulin shots, or changing their insulin pump sites (Fawcett, 2020).

## Addressing Emotional and Psychosocial Issues

Clinicians must recognize the emotional burden that diabetes management places on the family and the child with diabetes. Quality of life can be compromised, and mental health issues can develop. In addition to dealing with the day-to-day burden of managing the condition, the physiology of diabetes can directly affect emotions. The emotional health of children with diabetes and their families must be taken into consideration by the healthcare team. Establishing a nurturing, trusting relationship with the child and the family is the first step in achieving positive outcomes. The ADA recommends including mental health professionals skilled in the area of childhood diabetes as part of the diabetes management team.

## CHILDREN'S COMMON EMOTIONAL REACTIONS

Children at different ages and stages of development have varying reactions to living with diabetes. **Preschoolers and children in the early school years** have a tendency for “magical thinking,” which can lead them to believe that insulin shots will make their diabetes go away or, conversely, that the shots are a punishment for misbehaving. Other common fears in young children with diabetes include having “holes” left in their skin from shots or having no more blood left due to regular glucose monitoring (Perez, 2016).

Role-playing is an important way for young children to express their fears and concerns about their condition. For example, using role-playing with a teddy bear in their interactions with young children with diabetes, clinicians can ask the child to show them how “Teddy” reacts when he gets a shot. This provides far greater insight into children's thought processes than asking them how they feel about getting insulin shots (Perez, 2016).



It is important for parents and caregivers to be cognizant of the language they use regarding blood glucose levels. The terms *bad* and *good* are not useful descriptors of blood glucose levels and can imply to children, especially small children, that an out-of-range blood glucose level means that the child themselves is bad (Lebow, 2019).

**School-age children** (7–8 years) struggle with the reality of requiring insulin shots for the rest of their lives. Children at this age may ask themselves, “What bad thing did I do to cause this, and what can I do to make it right?” Children may not vocalize these thoughts to their parents or the diabetes care team, but clinicians must be aware that such thinking exists and gauge their responses to explain that diabetes is not the result of bad behavior (Lebow, 2019).

Another common concern for school-age children with diabetes is feeling different from other children, leading to social isolation, for instance, stating, “No one will want to play with me if they know I have diabetes.” To offset such fears, children may deny that they have diabetes or believe that it will go away. While this may be a natural protective reaction at the time of diagnosis, clinicians must understand that, left unaddressed, such thinking may lead to serious consequences, such as the child not taking their insulin or refusing to follow dietary recommendations (Lebow, 2019).

### DIABETES DISTRESS

*Diabetes distress* is a term used to describe a sensation of being overwhelmed or a feeling of failure or frustration in the person with diabetes. It is an increased level of emotional distress related to the specific burdens of living with diabetes and its treatment. The strain of living every hour of the day and night with diabetes is often heightened in families where divorce has happened and where there are economic and cultural barriers. Young women with diabetes are more susceptible to diabetes distress compared to their male counterparts (Hood et al., 2018; NIDDK, 2018; Tamborlane, 2021).

Research also indicates that interventions put in place before symptoms of psychological distress begin are effective in preventing the development of diabetes distress in children and adolescents. These interventions include resilience promotion by developing positive problem-solving skills, developing social supports, and fostering a sense of hopefulness (Gutierrez-Colina et al., 2020).

Research findings suggest that children and youth with diabetes have higher rates of anxiety, depression, and psychological distress compared to children who do not have diabetes.

**Depression** is the most frequently occurring mental health condition in children and adolescents with diabetes. Family conflict over management of diabetes is another source of emotional distress for children and adolescents with diabetes. Research shows that **suicidal thoughts** are common among adolescents with type 1 diabetes (Tamborlane, 2021).

Research has also found that children and youth with poorly controlled diabetes and recurring episodes of DKA are at a higher risk for underlying psychosocial problems or psychiatric illness than their counterparts who have good diabetes control.



Children who developed diabetes prior to the age of 5 years and with a history of poorly controlled diabetes should be closely monitored in school to identify learning difficulties. If problems are identified, these children will require a referral for psycho-educational or neuropsychological evaluations (Delamater et al., 2018).

The ADA recommends screening for symptoms of depression and diabetes distress beginning at ages 7 to 8 years for children with diabetes (ADA, 2020a). Symptoms of depression in children can include:

- Poor performance in school
  - Reluctance to go to school
  - Complaints of body pains and hurting not related to injury
  - Irritability
  - Clinginess
- (CDC, 2020d)

#### ANSWERING PARENT/PATIENT QUESTIONS

**Q: Are mood swings and depression common in youth with diabetes?**

**A:** Mood swings and depression are commonly found in youth with diabetes. The stress of having to constantly live with diabetes—there are no “days off”—can be overwhelming for children and adolescents with diabetes. This sometimes manifests as what is called *diabetes distress*.

#### PARENT AND FAMILY STRESS

Diabetes care requires a round-the-clock, full-time commitment, and a diagnosis of diabetes in a child can be devastating for parents. First reactions include fear, concern, and guilt. Examples of parents’ questions include:

- “What will happen to our child, and will they be okay?”
- “Is our child’s diagnosis a result of something we did or didn’t do?”
- “How will this affect the other children in our family?”
- “Will we be able to manage our child’s care?”

It is vital that the healthcare team address these and other concerns not just initially but on an ongoing basis and to acknowledge parents’ efforts to successfully cope with the challenges of diabetes care for their child (ADA, 2017a).

Studies show that parents of children with T1D are at high risk for depression and anxiety. Parents of children with a chronic health condition such as diabetes often focus their energy and



attention on the child's healthcare needs to the detriment of their own well-being. Clinicians must be constantly on the alert for caregiver burnout and help parents understand that maintaining their own physical and emotional health is essential for their child's well-being (Whittemore et al., 2018).

Another problem parents may face is a child who is uncooperative with diabetes care. This may happen more often with older children who, despite the best efforts of their parents, rebel against treatment and insist on making their own decisions. This can be physically and emotionally exhausting for parents. In these instances, the child and parents are referred to a mental health professional on the diabetes management team.

The needs of other children in the family must also be acknowledged and receive attention. How siblings react to diabetes can vary. Common reactions include fear that they too will develop diabetes, resentment about the extra time and attention the child with diabetes receives, protectiveness of their sibling with diabetes, and a desire to be involved in the care of the child with diabetes. As far as possible, all children in the family are included in diabetes education and a family treatment plan (ADA, 2017a). Older siblings can be an important resource in supporting and encouraging the child with diabetes in standing up for themselves and educating others about their sibling's diabetes (Children with Diabetes, 2019).

(See also "Issues Facing Adolescents with Diabetes" and "Transition to Adult Care" later in this course.)

#### CASE

James is eight years old and was diagnosed with T1D when he was four. He lives with his mother, Margot, who is a single parent, and his 9-year-old sister. James's mother was devastated when he was diagnosed but was determined to learn how to manage her son's care.

At his scheduled appointment today, James is quiet and clearly unhappy, and his mother looks anxious and exhausted. The clinician notices that Margot snaps several times at her son. Relying on the trusting relationship that she has developed with the family, the clinician asks Margot if she may speak with James alone. His mother agrees, and once she leaves the room, the clinician asks James if he has anything he wants to tell her. "I want to play soccer, but my mom won't let me. I hate this stupid diabetes!" he responds.

The clinician then asks James to wait in the playroom while she speaks with his mother: "Are you having a difficult time at the moment? What can I do to help?" Margot bursts into tears, sobbing, "James wants to play soccer, but no matter how often I tell him it's too dangerous, he won't listen."

The clinician discusses with James and his mother the positive benefits of exercise and explains that participating in team sports such as soccer is possible for children with diabetes. At the same time, the clinician acknowledges Margot's fears and hesitation. As a first step, she suggests they prepare a list of questions and concerns. Then, Margot can meet with the soccer coach and discuss the possibility of James joining the team.



When they meet with the soccer coach a few days later, the coach tells Margot that he has had several children with diabetes on his teams over the years and that he understands her fears. Although she is still concerned about the risk of hypoglycemia, Margot agrees to let James start soccer practice twice a week. She and the coach review all the pertinent details of James's condition and management plan. James is overjoyed and excitedly tells his mother, "I'm going to be like all the other kids!"

## Developing Patient Independence in Diabetes Self-Management

As children get older, it is important that they learn to actively participate in their own diabetes care and that the parents' role in their child's diabetes care evolves from that of caretaker to coach (ADA, 2017a). This can be a challenging time for parents and children, and some parents can become overprotective, leading to a strained relationship with the child or the entire family (Lebow, 2019).

The clinician's role during this developmental phase is to provide education, support, and reassurance and to help everyone recognize the need for the child to be able to safely self-manage their diabetes care by the time they are old enough to leave home or live independently.

How quickly a child will become independent in most or all of their diabetes self-management differs from child to child. Transfer of care to the child is best achieved in small, manageable steps. The clinician closely monitors and assesses the child's readiness to learn new skills and their proficiency in performing each skill, such as drawing up and administering their own insulin (ADA, 2017a).

Advice that can be given to parents and families during this transition phase includes:

- Maintain open communication, allow the child to express their concerns, and avoid telling the child how they should feel.
- Ensure that the child knows they can reach out to their parents regardless of any problem, whether at home or at school, without fear of the parent's anger or censure.
- Nurture the child's self-confidence while providing them with emotional and practical support.
- Strive for balance between taking care of the child and allowing them to take care of themselves. For example, when traveling, parents can carry a backup blood-testing kit and insulin supplies in case the child forgets to bring them.
- Listen to the child's needs and make adjustments where possible while maintaining the rules that are in place to keep the child safe. If this becomes an area of contention between the child and the parents, the best course is to discuss it with the diabetes team, ensuring that the child is allowed to express their thoughts and have them validated.



- Continue to advocate for their child, while teaching the child the skills and knowledge needed to advocate for themselves.
- Remember to do fun things with the child on a regular basis, individually and as a family.
- Do not allow the responsibility of managing diabetes to become the dominant force in the child's life; make time for hobbies, laughter, and a balanced life.

(Lebow, 2019)

## Addressing Medical Neglect

A clinician may encounter a child in which parental involvement is less than optimal for diabetes care, and type 1 diabetes is one of the most common conditions related to medical neglect of children reported to Child Protective Services. The priority in such cases is the child's well-being and safe management of their diabetes.

It is important for clinicians to identify children at risk for medical neglect. Including a social history in the initial assessment and inquiring about any new problems during follow-up visits are crucial in getting to know families and their circumstances. Interventions that can be put in place to help families include contact with social and community services and more frequent clinical visits with the child and family.

The reasons for medical neglect can be complex and not easily fixed. Factors may include parental psychiatric illness, substance abuse, and domestic violence. Other obstacles to ensuring adequate care for a child with diabetes include difficulty with transportation, lack of a caretaker for other children in the family, financial problems, difficulty understanding the complexity of care, and lack of caretaker motivation (Fortin et al., 2016).

In some cases, parents or caretakers of children with diabetes are juggling many other responsibilities, such as other children in the family, careers, and aging parents who may need their assistance. These demands on a parents' time may mean that the child with diabetes will have multiple caretakers who may not all be properly educated in diabetes management.

Leaving a child with diabetes in the care of a person who has not received diabetes education and/or who is not provided with the supplies and medications to care for the child is considered medical neglect. The diabetes management team must emphasize to the parents that it is the parent's responsibility to ensure that everyone who provides care for the child is educated in diabetes management. Clinicians can supply education materials that parents can use to train babysitters and other caretakers in providing safe care. They can also role-play teaching sessions between parents and other caretakers (Fox et al., 2018).

Another "red flag" for medical neglect in a child with diabetes is recurrent admissions for DKA, together with the claim that the child has been sneaking food as the cause. Such an explanation by parents or a caretaker points to the possibility of medical neglect or, at the minimum, substandard attention to and/or poor understanding of diabetes management (Fox et al., 2018).



Clinicians must also be attentive to the difficulties families may have in navigating the healthcare system. For example, obtaining health insurance may be difficult for some due to the complexity of the process or the financial burden. Coordination with pharmacies, sometimes more than one, for diabetic supplies and insulin can also be an overwhelming task for families and inadvertently lead to medical neglect (Fortin et al., 2016; CDC, 2021c).

## ISSUES FACING ADOLESCENTS WITH DIABETES

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Adolescence can be a difficult time in the best of circumstances, and for those with diabetes, it can be especially challenging. Issues can arise related to independence and “becoming one’s own person”; the hormonal and maturational changes that occur at puberty; and concerns about peer relationships. For instance, worries in some young people about how friends perceive their diabetes can lead to diminished adherence to diabetes management, erratic metabolic control, and diabetic complications (Justus, 2018). Or young adults may become distressed upon the realization of what a chronic, lifelong condition means, and clinicians must be aware that these patients are at high risk for diabetes burnout and depression.

Positive communication between parents and adolescents is important to navigating these issues. Clinicians can support parents in meeting the challenges of relinquishing responsibility for care to their adolescent child and evolving into the role of “coach” (ADA, 2017a). Likewise, adolescents can be educated in ways to “vent” their anger and frustration and assisted in developing a plan to better manage their condition.

### **Being Diagnosed with Diabetes during Adolescence**

The reaction to a diabetes diagnosis is highly individualized. However, a broad distinction can be made between those adolescents who were diagnosed with diabetes as children and those who are newly diagnosed in their teen years. A 15-year-old who was first diagnosed with diabetes as a 4-year-old will likely have a much different mindset about the condition than a 14-year-old who was diagnosed three months ago. For instance, the former may think that “diabetes sucks,” but they will not remember a life without diabetes and are accustomed to it as part of their day-to-day existence.

The newly diagnosed adolescent may experience an acute sense of loss, seeing their choices curtailed, their independence restricted, and spontaneity of actions reduced. A sudden diagnosis of a lifelong chronic condition can be devastating for an adolescent. Research has shown that such a diagnosis can produce emotions akin to grief, negatively impact the individual’s self-concept, and evoke a significant feeling of being different from one’s peers. The strong desire for acceptance can cause adolescents with diabetes to deny their condition, neglect diabetes management, and skip insulin injections. The consequences of this behavior can be serious, such as recurring hospital admissions with diabetic ketoacidosis (Robinson, 2015).

An important goal of care is to help such an adolescent accept a new normal in their lives and develop the belief that it is possible for them to manage diabetes. Research shows parental participation and support of family and friends to be the primary source of positive adjustment to



diabetes among adolescents. Conversely, a lack of or limited parental involvement correlates with poorly controlled diabetes. Participation in support groups for young adults with diabetes is also linked to positive outcomes for adolescents with diabetes.

The healthcare team also plays a critical role in the adjustment process for adolescents diagnosed with diabetes. How an adolescent is informed of the diagnosis of a chronic health condition is vitally important. Sensitivity, caring, and a patient-centered approach are key factors in how well the young adult begins to process what is happening. Adolescents with diabetes have reported a positive impact of having choices in setting treatment goals and of regular appointments with the same members of the diabetes healthcare team (Robinson, 2015).

## **Puberty and Diabetes**

The physiologic changes of puberty may be impacted by diabetes. Uncontrolled diabetes can delay the onset of puberty. Insulin resistance will increase, and more frequent blood glucose checks are required. This can be a further source of frustration for the adolescent and a source of worry for the parents (ADA, 2017a).

Girls with diabetes have a higher prevalence of weight gain during puberty than their peers who do not have diabetes. They are also at a higher risk for polycystic ovary disease (Justus, 2018). Patient education for young girls and their parents includes a discussion of how blood glucose levels may increase in the days preceding menses and decrease in the days immediately after menses. This requires more frequent blood glucose checks, adjustments in insulin dosage, and possible changes to the meal plan. Hormone fluctuations in the early stages of puberty can also make it more difficult for adolescent girls to maintain optimum glucose control (ADA, 2018).

For adolescent boys, blood glucose control is more difficult in the later stages of puberty. Research shows that one fourth of adolescent males with T1D have diminished levels of testosterone. Poorly controlled diabetes can also result in lower-than-normal weight, height, and BMI in young males (Justus, 2018).

## **Sexual Counseling**

Sexual activity, contraception, and pregnancy should be discussed openly and nonjudgmentally. This is a conversation that most young people will not initiate, whether out of embarrassment, fear, or simply not knowing how to begin. It is up to the clinician to include these topics as part of the overall education plan for the patient with diabetes. It is important to assure the young person that their privacy will be respected. It may also be an opportune time for a clinician to introduce to parents the need for private conversations between their adolescent child and healthcare providers without parents being present.

Sex is a physical activity, and similar to all other physical activities, it can impact a patient with diabetes. Lower blood glucose levels may occur during and following sexual activity. Therefore, preventing hypoglycemia associated with sex is part of an adolescent's self-management plan (ADA, 2020a).



Girls with diabetes are educated that pregnancy during their teen years can result in serious health problems related to their age and to diabetes.

## PRECONCEPTION COUNSELING

Many young people may have concerns that diabetes will prevent them from having a normal pregnancy and a healthy baby. The clinician can assure them that once they are ready to have a baby, a healthy pregnancy is possible and that the key to this is preconception counseling (ADA, 2018). Female adolescents with diabetes can also be referred to OB/GYNs, since these professionals provide in-depth preconception counseling. Preconception counseling begins as soon as a girl starts menstruation and continues as an ongoing conversation at every visit with the diabetes management team.

Awareness of the importance of the consistent and correct use of **contraception** in the prevention of unwanted pregnancies is something that must be reinforced with adolescents who have diabetes. Recommendations for contraceptives include the use of long-acting reversible contraception (LARC) such as intrauterine devices and subdermal hormonal implants. However, studies find that healthcare providers infrequently provide counseling on LARC use.

Clinicians must also discuss the importance of planned pregnancies and achieving and maintaining optimal blood glucose levels prior to becoming pregnant in order to decrease the risk of adverse outcomes for the mother and baby. Unplanned pregnancy, especially if blood glucose levels are not well controlled, can put the expectant mother at risk for several complications, including preeclampsia (a condition characterized by hypertension and leading to damage to organ systems, most notably the kidneys and liver). Preconception counseling therefore focuses on ensuring the patient has attained optimal glycemic control and overall good health prior to becoming pregnant (Disney et al., 2020).

Although the ADA recommends preconception counseling as part of the education process for all adolescent girls with diabetes, studies indicate that this may not be happening. As advocates for their patients, clinicians can be instrumental in incorporating preconception counseling into the diabetes management program. Other considerations for preconception counseling include expanding the program to include adolescent males and ensuring the program is sensitive to cultural and religious values (Peterson-Burch et al., 2018; ADA, 2020a).

## Driving with Diabetes

Driving with a low blood sugar increases the possibility of having an automobile crash. While having diabetes does not preclude an adolescent from obtaining a driver's license, under the law, all drivers can be held accountable for keeping their blood glucose at safe levels while driving (ADA, 2017a; ADA, 2020a). Therefore, part of responsible behavior for an adolescent with diabetes is to ensure that their blood glucose level is within a set target range prior to driving.



Driving education for an adolescent with diabetes includes the following points:

- Check blood sugar levels prior to driving, every time.
- Treat a low blood glucose level even if it means being late to one's destination.
- Do not start driving until blood glucose is within the target range. (It is okay to call a friend for a ride or to tell others that one is going to be late.)
- Keep a supply of nonperishable snacks and fast-acting sugars in the car or carry some along if traveling in a friend's car.
- Never leave insulin and test strips in the car; hot and cold temperatures damage them.
- If beginning to feel unwell or noticing that blood sugar is dropping, pull over immediately. Do not tell yourself, "I'm nearly there; I can make it."
- Once pulled over, check blood glucose, treat a low level, wait 15 minutes, and then recheck.
- Never leave home without a medical alert ID bracelet or necklace. (ADA, 2017a; ADA, 2020a)

## **Alcohol, Smoking, and Recreational Drug Use**

Although the legal drinking age in most jurisdictions is 21 years, a conversation about alcohol, smoking, and drug use must begin during adolescence. Using alcohol and drugs can have an instantaneous effect on blood glucose levels. These substances can also adversely impact an individual's awareness of and capacity to treat a low blood glucose level.

### **ALCOHOL AND DIABETES**

Knowledge that drinking alcohol can be dangerous to those with diabetes may not prevent an adolescent from this activity, particularly in the presence of peers who are drinking. The clinician must educate the adolescent and their parents on its safe use.

Research shows that it takes the liver between one to one-and-a-half hours to process a single drink, and it is during this time that those with diabetes are most at risk for developing low blood glucose levels (Demitz, 2017). Consuming two alcoholic drinks prolongs the risk of hypoglycemia for two to three hours, and the more alcoholic drinks consumed, the greater the amount of time one is at risk for hypoglycemia.

Actions to keep safe when drinking include:

- Eat before taking the first drink and eat carbohydrate snacks such as chips while drinking.
- Remain in the company of a reliable friend who is aware one's diabetes and who knows how to treat hypoglycemia if it occurs.



- Between alcoholic drinks, consume water or a sugar-free drink to prevent dehydration.
- Test blood sugar at least every hour, or have a friend test it. If the blood sugar level drops and one starts vomiting and cannot keep anything down, have someone call 911. Ensure that there is at least one friend with you who knows what to do in these circumstances because it is an emergency.
- After a night of drinking, eat a meal that contains both fat and protein. Since alcohol remains in the body for a period of time after one stops drinking, it is possible that hypoglycemia can occur while sleeping.
- Since the symptoms of hypoglycemia mimic those of being drunk, always wear a diabetes ID necklace or bracelet so that, in the event of a hypoglycemic episode, others will not presume the individual is merely drunk.

(Demitz, 2017)

### **ANSWERING PARENT/PATIENT QUESTIONS**

#### **Q: Is it safe to drink alcohol if you have diabetes?**

**A:** Drinking alcohol is not safe for those with diabetes, as it can severely lower blood sugar levels. If you are going to drink alcohol, there are some important precautions to take such as eating carbohydrate snacks prior to drinking, limiting alcohol intake, and having along at least one reliable companion who knows that you have diabetes and how to treat low blood sugar levels if that occurs.

### **SMOKING AND DIABETES**

Smoking rates are considerably higher among youth with diabetes than among their peers without diabetes (ADA, 2020a). Education for adolescents with diabetes regarding smoking includes the fact that nicotine damages small blood vessels and can result in kidney and nerve disease. Smoking also heightens the risk for albuminuria.

The best advice a clinician can give to an adolescent with diabetes is: “If you haven’t started smoking, don’t. And if you have, we can work together on helping you stop.” Advising against cigarette smoking also includes advising against the use of e-cigarettes (ADA, 2020a).

### **RECREATIONAL DRUGS AND DIABETES**

Substance abuse and nonprescription drug use can lead to impaired judgment, irregular diabetes management, infrequent blood glucose checks, and erratic insulin administration. This puts the adolescent at risk for short- and long-term complications. Adolescents with diabetes are taught that this is a dangerous and possibly lethal practice (Yale School of Medicine, 2019).



Different types of illicit drugs can affect people with diabetes in the following ways:

- **Marijuana** is the most commonly used substance by youths with T1D. Those with diabetes consider marijuana to have fewer negative consequences when compared to drugs such as cocaine or heroin. However, the impact of marijuana on cognitive and physical functioning can lead to grave problems for those with diabetes. Negative effects include:
  - Greater appetite, which can cause overeating, and hyperglycemia
  - Short-term memory problems, which can lead the individual to forget to take insulin or diabetes medications
  - Impaired hand-eye coordination, which can lead to incorrect administration of insulin or diabetes medications
  - Symptoms of depression with regular use
  - Severe damage to the kidneys and heart when combined with alcohol
- **Stimulants:** Those who take stimulants frequently experience low blood glucose levels due to stimulants breaking down carbohydrates at a faster rate than normal.
  - Ecstasy is a stimulant drug that may contain poisonous substances. It can be particularly hazardous for persons with diabetes. Serious side effects of ecstasy use include kidney damage leading to kidney failure and an irregular heartbeat, which can prove fatal.
  - Cocaine is an extremely addictive stimulant that can cause hypertension and a subsequent heightened risk for strokes and heart attacks. Cocaine use also leads to loss of appetite. Those who use cocaine on a regular basis are predisposed to eating fewer balanced meals and an increase in the intake of fatty foods. Irregular eating habits and poor food choices can be damaging to those with diabetes.
  - Methamphetamines are extremely dangerous for those with diabetes. They interfere with the activity of insulin and hormone production, causing the release of excessive glucose and subsequent high blood glucose levels. If taken consistently, methamphetamines can cause decrease in appetite, depression, and memory problems.
- **Heroin** is a very dangerous, highly addictive depressant. It causes erratic eating patterns and hormone production, impairing the person's ability to maintain blood glucose levels within a set range.
- **Hallucinogens** (PCP, LSD, ketamine, mescaline, "magic mushrooms") result in hallucinations, which can lead to paranoia, bizarre behavior, and panic attacks. These behaviors can decrease awareness of fluctuating blood glucose levels and the need for interventions to stabilize blood glucose levels.



Since some adolescents will experiment with illicit drugs, those with diabetes must be educated about their safer use and the dangerous outcomes that can result. Important points to emphasize include:

- Check blood glucose levels every 2–3 hours.
- Check for ketones if the blood glucose level is  $>300$  mg/dL.
- Implement a sick-day plan when needed.
- Work with the healthcare team to eliminate problematic drug use.
- Only take an illicit or new drug in the presence of someone else who knows what the drug is and who knows you have diabetes; this will help ensure that necessary care will be sought if serious complications occur.
- Do not stop taking insulin or other diabetes medications, since this can lead to high blood glucose levels and organ damage.
- Have readily available sources of quick-acting carbohydrates in case symptoms of hypoglycemia develop after taking an illicit drug.
- Avoid mixing illicit drugs or combining them with alcohol, since this can be a deadly combination.
- Always wear a diabetes identification bracelet.
- Develop friendships in which peer pressure to engage in high-risk activities is not present.

(Yale School of Medicine, 2019; Vieira, 2020)

## Privacy about Diabetes Diagnosis

It is an adolescent's decision about whom to share their diagnosis with. Confiding in close friends usually is not a problem, but sharing this information with someone they start dating and want to impress may not be so easy. Frequently, parents want everyone, or nearly everyone, their child is friends with to know about their condition. Adolescents can find this annoying and may complain about it to members of their diabetes management team. The clinician empathizes with their need for privacy, at the same time explaining that parents are motivated by concern for their child's welfare. The clinician also explains to parents that it is up to their adolescent child to decide when and whom to tell about their condition.

Regardless of whether an adolescent decides to tell the person they are dating about their condition, they are reminded by clinicians of the importance of wearing a medical alert bracelet at all times. Also, they are encouraged to think ahead about situations such as eating out on a date or playing sports—for instance, what snacks to eat (or avoid) at the movies or how to manage an out-of-range blood glucose level, either too high or too low, while on a date?



A question the clinician may be asked is, “How do I tell someone new that I have diabetes?” The clinician can suggest keeping it simple and using language that is most comfortable for the adolescent. It is usually wiser to tell a new partner about diabetes early on in the relationship. The clinician can remind the youth that a caring person will be supportive and that someone who does not want to be in a relationship with a person with diabetes is probably someone the youth would rather not be around in any case.

The clinician can also discuss with the youth that it may be awkward for a new or existing partner to ask questions about diabetes. They can be concerned about saying something that sounds foolish or ignorant. The youth with diabetes should not take silence as a lack of caring. For the young person with diabetes, it is a matter of inviting those they care about into their personal space: talk to others about what they experience living with diabetes, what it feels like to have a hypo- or hyperglycemic episode, and what a partner can do to help in these situations (CDN, 2019a).

#### **ANSWERING PARENT/PATIENT QUESTIONS**

##### **Q: Whom do I need to tell that I have diabetes?**

**A:** There are no rules about whom you should confide in about your diagnosis. However, it is wise to consider safety issues. For instance, it is advisable to have at least one or two people in your work, school, and friend circles who are aware that you have diabetes and how they should intervene if you need help. It is also common to be concerned when starting a new relationship about the “right” time to talk about diabetes. This is an individual choice. Being able to safely manage diabetes on dates or activities usually makes it a better option to discuss diabetes at the beginning of the relationship.

## **Disordered Eating Behaviors**

Disordered eating behavior (DEB) can be a problem in young people with type 1 diabetes. Research data shows that females with T1D are 2.4 times more likely to develop an eating disorder than females who do not have diabetes. Risk factors for developing DEB among adolescents with diabetes include depression and the desire to curb weight gain. Although eating disorders are more common in females with diabetes, they can also occur in males (Weiner, 2017).

**Diabulimia** is an eating disorder behavior in which insulin use is intentionally restricted to lose weight. It is estimated that 30%–40% of young females with T1D reduce insulin therapy to lose weight, with the highest incidence of this behavior in those between the ages of 15–30 years (Weiner, 2017; ADA, 2020b). Adverse side effects associated with diabulimia include:

- Dehydration
- Loss of lean body mass
- In severe cases, development of DKA (ADA, 2020b)



Eating disorders also occur in young people with type 2 diabetes. In one study, over 50% of the surveyed youth with T2D had an eating disorder, and over 30% were willing to sacrifice diabetes control and insulin dosing to lose weight (Weiner, 2017).

It is vital for clinicians to educate young patients with diabetes that this is both an unsafe and potentially life-threatening practice. Adolescents may have a hard time acknowledging problems with eating to a clinician, including whether they are skipping insulin doses. Clinicians must maintain a nonjudgmental, supportive attitude. Patients with an eating disorder will most likely be referred to a mental health professional with experience in eating disorders (ADA, 2017c).

## TRANSITION TO ADULT CARE

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Transitioning from pediatric to adult care providers can be a vulnerable time for the patient and family. It may be extremely difficult to leave caretakers whom they have come to know and trust. Many providers are flexible and do not require all patients to transfer to adult care once they turn 18 in order to allow for a more gradual transition. Pediatric clinicians can help prepare an adolescent and family for differences they may encounter when they transition to adult care providers. For instance, the nurturing atmosphere characteristic of pediatric care in many instances may be replaced by a faster pace and less interaction time in adult services.

Clinicians working in adult diabetes management must likewise be aware that young people transitioning from pediatric services may require assistance and greater attention to integrate successfully into the practice. Clinicians in both pediatric and adult diabetes care can explore with the patient and family what barriers exist to the patient moving successfully into the adult setting. The diabetes management team can also work with the patient and family to develop goals and interventions to help ensure the patient's ability both physically and psychologically to take responsibility for diabetes self-management.

The shift from pediatric to adult healthcare presents a high risk for loss of cohesion in the delivery of services and is a period when many young people no longer receive adequate health care. Others may never take ownership of their diabetes and remain over-reliant on their parents for diabetes management. This transition phase is linked with worsening glycemic stability, higher rates of acute complications, and the beginning of chronic complications associated with poor diabetes control (ADA, 2020a).

The clinician therefore advises parents to permit the adolescent to attend medical appointments alone during at least the last six to nine months of their pediatric care. This step fosters independence and allows the young person to practice describing their symptoms, answering provider questions, posing their own questions, and planning implementation steps that may result from the appointment. Initially, parents may not react well to this suggestion. In this case, the clinician can provide parents with a summary at the end of the appointment (Roemer, 2016; Ramchandani, 2019).



**ANSWERING PARENT/PATIENT QUESTIONS**

**Q: How can young people become more independent in diabetes self-management before moving away from home?**

**A:** Working with the diabetic management team to assist young people to take ownership of their diabetes self-management is important. Young people with diabetes should be assessed for their readiness to become independent in diabetes self-care, and any concerns need to be addressed. The most important areas to be considered are the young person's level of diabetes knowledge, their ability to self-manage insulin, and their nutrition and health behaviors.

**Moving Away from Home**

Young people moving away from their family home or leaving to attend college is often stressful and may introduce unique issues related to diabetes care.

Patients will have new providers involved in their care, and so a priority for the diabetes care team is to assist the young person and their family in locating new providers who have experience in managing diabetes (see above). For those attending college, the young adult and parents are encouraged to contact the college's health center.

Insurance and financial considerations for healthcare coverage are an important issue. The Affordable Care Act allows for continued coverage under parents' healthcare policies until the age of 26 years (ADA, 2020a). Parents are advised to contact the insurance provider in advance to learn how coverage may be affected if their child with diabetes moves to a different part of the state or out of state.

Adapting to college or work schedules, making new friends, and socializing can all push diabetes care into the background for the young adult. Parental supervision and the support of childhood friends may no longer be available. The diabetes care team therefore works to ensure that diabetes self-management remains a top priority in the patient's life. If attending college, the student and family can inquire about care and support groups offered by the college to students with diabetes. College health officials and at least a small group of new acquaintances should be informed about the student's diabetes, including roommates, dormitory supervisors, and other appropriate college staff members (Roemer, 2016).

(See also "Resources" at the end of this course.)

**PARENTS' ROLE IN PREPARING THEIR CHILD TO MOVE AWAY FROM HOME**

Parents often confide to the clinician their fears and anxieties about their child with diabetes moving away from home. On one hand, they want their child to be independent and pursue their own dreams and goals; on the other hand, they may worry about "what if" horror scenarios associated with diabetes. Clinicians can remind parents that their involvement in the move can be a great support. For instance, they can help ensure their child has new healthcare



providers in place, prepare sick-day supplies for their child's new home, and confirm their child has renewable prescription orders and monthly reminders set up at a nearby pharmacy.

The diabetes management team discusses various issues with the young adult and their parents and reviews strategies for possible problem scenarios that may occur when living independently or with a new roommate. Examples include:

- How will you manage low blood sugar during the night?
- What will you do if you run out of insulin late at night?
- Who will be your point of contact for emergencies?
- What will you do if checking your blood sugar and administering insulin conflicts with class time or work shifts?
- What approaches will you use to deal with stress, such as exams?
- What action will you take if you find a cut or sore on your foot that is not healing?
- What will you do if you do not like your new healthcare provider?

(Roemer, 2016)

The list of possible situations introduced by diabetes care team members may trigger further questions from the young adult and/or family. The most important issues to address are those posed by the young adult, and the best interventions are those that are practical and workable in each unique patient situation.

An important teaching point the clinician emphasizes to the patient is to take all their insulin doses at the scheduled times. Another important recommendation is for the patient to keep a glucagon emergency kit with them at all times and to teach others how to use it. Following these steps can alleviate many potential problems (CDN, 2019b).

#### CASE

Kevin is 17 years old and was first diagnosed with type 1 diabetes when he was 6. He's now a senior in high school and plans to go to college in a few months. During a routine visit, the clinician pays special attention to the pattern of behavior that has typified Kevin's visits and diabetes management.

Kevin is polite, enjoys talking about school and sports, and keeps his blood glucose readings up to date on his smart phone. He has been independent in administering insulin since his early teens. However, his parents take responsibility for all other aspects of diabetes management, such as meal preparation, calorie counting, sick-day management, and collecting insulin prescriptions from the pharmacy. When the clinician asks what preparations Kevin and his parents have made for managing his diabetes at college, Kevin looks to his parents, who respond, "We haven't thought about it yet."



The clinician is aware that, although Kevin is independent in checking his blood glucose and administering insulin, he has not yet taken ownership of full management of his diabetes. This is an important step that must be achieved if he is to live safely away from home when he moves away to attend college. The clinician makes several recommendations in this regard:

- That Kevin start attending his appointments for diabetes care on his own. His parents may be apprehensive about this, but the clinician can explain this will allow Kevin to develop self-advocacy skills. The clinician can also point out that, as a 17-year-old young man, Kevin may wish to discuss issues with his provider that he will not raise in front of his parents.
- That Kevin attend a consultation with the dietitian to review mechanisms for calorie counting and how that best can be accomplished living in a dorm and when selecting a college meal plan.
- That Kevin read up about the College Diabetes Network and list at least three recommendations he finds on their website that he will follow up on.

The clinician provides Kevin's parents with time to talk about their fears and concerns and acknowledges that it is a challenging time for them also. The clinician points out there are several steps they can take to ensure college is a safe and positive transition for Kevin. The clinician helps the parents to put together a plan that includes the following steps:

- Check with their healthcare carrier to ensure their present policy will continue to cover Kevin when he moves away from home.
- Meet with the social worker on the diabetes management team to identify providers close to Kevin's intended college who have experience working with college students with diabetes.
- Set up a meeting with the college healthcare center for themselves and Kevin in order to learn about available services and programs he could benefit from, such as a diabetes support group for students.
- Help Kevin put together an emergency contact list he can call on once he moves to college.
- Put together sick-day supplies Kevin can keep in his dorm room.

The clinician also explains to Kevin and his parents that preparation for transitioning to college is not a one-time event; it is a process that takes several months to successfully complete.



## CONCLUSION

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The numbers of children and youth with diabetes are increasing. Providing care to young patients with diabetes can be a unique and challenging experience in all settings. Clinicians must take into consideration the child's developmental stage in order to create a holistic approach to diabetes care. In many instances, a clinician will work with pediatric patients with diabetes over the course of several years and build up a close, therapeutic relationship with these children and their families. In this way, the clinician advocates for the patient's needs and offers support and encouragement to them and their caregivers from childhood through adolescence and as they transition to independent self-management.



## RESOURCES

Access and affordability resources (Association of Diabetes Care and Education Specialists)  
<https://www.diabeteseducator.org/practice/practice-tools/app-resources/affordability-resources>

College Diabetes Network  
<http://collegediabetesnetwork.org>

Diabetes and youth (CDC)  
<https://search.cdc.gov/search/?query=diabetes%20and%20child&dpage=1>

Financial help (Diabetes Foundation)  
<https://diabetesfoundationinc.org/services/financial-assistance/>

Financial help for diabetes care (NIDDK)  
<https://www.niddk.nih.gov/health-information/diabetes/financial-help-diabetes-care>

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## TEST

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1. Which is a **correct** statement about the prevalence of type 2 diabetes in youth?
  - a. It is found only in adolescents.
  - b. It is more common in female than male youth.
  - c. It is related to a genetic mutation.
  - d. It is found in both children and adolescents.
  
2. Diabetic ketoacidosis is the first presenting sign of type 1 diabetes in:
  - a. A very small percentage of children.
  - b. Approximately one third of children.
  - c. Approximately one half of children.
  - d. Over two thirds of children.
  
3. Disorders related to insulin resistance seen in children with type 2 diabetes may include acanthosis nigricans, hypertension, polycystic ovary syndrome, and:
  - a. Addison's disease.
  - b. Asthma.
  - c. Dyslipidemia.
  - d. Food allergies.
  
4. The overarching goal for treating diabetes in children can best be described as:
  - a. Ensuring regular attendance at school and academic achievement.
  - b. Maintaining normal physical growth and positive psychosocial development.
  - c. Encouraging nonstressful daily activities and personal interests.
  - d. Preparing the child and family for the drawbacks and everyday problems with chronic illness.
  
5. The partial remission that can occur in children diagnosed with type one diabetes, known as the "honeymoon period," will result in a temporary:
  - a. Decrease or elimination of the need for exogenous insulin therapy.
  - b. Regeneration of all insulin-producing beta cells in the pancreas.
  - c. Appetite stimulation and weight gain for children.
  - d. Lethargy or mood swings in children.



- 6.** When instructing the parents of a toddler with nocturnal hypoglycemia, the clinician recommends:
- Lowering the child's blood glucose range for several weeks.
  - Monitoring for increased thirst, appetite, and urination.
  - Providing the child with 45 grams of carbohydrate prior to bedtime.
  - Performing a blood glucose check at 12 a.m. and again at 3 a.m.
- 7.** Patient education about managing diabetes during sick days includes which important consideration?
- Never stop taking insulin completely
  - Limit fluid intake
  - Decrease carbohydrate intake if a fruity breath-smell develops
  - Increase pain medication for headache and nausea
- 8.** Diabetic ketoacidosis is a serious complication of type 1 diabetes and the most pervasive cause of:
- Mortality in children with type 1 diabetes.
  - Destruction of insulin-producing pancreatic beta cells.
  - Increased insulin sensitivity in children.
  - Hypoglycemia in children and young adults.
- 9.** The recommendations from the American Diabetes Association and the American Academy of Pediatrics regarding physical activity for children with diabetes include:
- Participating in sporting activities only on weekends and vacation time.
  - Engaging in at least 60 minutes of moderate to strenuous physical activity every day.
  - Limiting any strenuous physical activity due to the risk of hypoglycemia.
  - Ensuring the parent or guardian is present during all strenuous physical activities.
- 10.** When helping a child to begin developing independence in diabetes self-management, the transfer of care is best achieved:
- Quickly so that the child will not continue to rely on support from the parents and other family members.
  - When the child enters high school, since they are not mature enough before then.
  - In small, manageable steps, with assessment of the child's readiness to learn new skills.
  - When the child reaches the age of 18 and transitions from a pediatric to an adult-oriented primary healthcare provider.



- 11.** Preconception counseling for the female patient with diabetes should begin when the:
- Patient or her family request it.
  - Patient is preparing to leave for college.
  - Healthcare provider decides the patient is ready.
  - Patient starts menstruation.
- 12.** What is an important point the clinician must stress to an adolescent with diabetes who has just obtained their driver's license?
- There must be at least one other person in the vehicle who is not a diabetic.
  - Check blood glucose level prior to driving, every time.
  - Restrict driving to daylight hours only.
  - Avoid driving in areas of heavy traffic.
- 13.** Many young females with type 1 diabetes improperly use insulin restriction to:
- Increase their ability to exercise.
  - Diminish daytime drowsiness.
  - Conceal the fact that they have diabetes.
  - Lose weight.
- 14.** Beginning to attend healthcare visits without their parents present helps young adults with diabetes by:
- Fostering independence and patient self-advocacy skills.
  - Decreasing the amount of time required for their appointments.
  - Relieving their parents from the responsibility of monitoring their care.
  - Cutting down on the number of questions they will ask the clinician.
- 15.** To support a young adult's move out of the family home to attend college, the clinician encourages the parents to:
- Request the young adult to call home at a set time each day to report their blood glucose levels.
  - Confirm that the young adult has renewable prescriptions at a pharmacy close to the college.
  - Remove the young adult from the parents' health insurance coverage once they reach the age of 18.
  - Suggest to the young adult that they choose a college close to home.

