

The Role of the Diabetes Care & Education Specialists in Pediatric Diabetes: The Etiology of the Diagnosis

Reviewed on behalf of the Professional Practice Committee

Utilizing projection studies based on the SEARCH for Diabetes in Youth study (SEARCH) and the US Census Bureau population demographic projections, Imperatore et al¹ suggests the incidence of youth with type 1 diabetes will triple by 2050 to 203,382 persons and youth with type 2 diabetes will quadruple to 84,131 persons. Diabetes is one of the most common and costly chronic conditions in the pediatric population.¹ Diabetes care & education specialists play a vital role in the education process for children and families with all types of diabetes, including but not limited to type 1, type 2, maturity onset diabetes of youth (MODY) and secondary diabetes related to cystic fibrosis, steroid utilization and pancreatectomy. It is critical that the educator understand the unique requirements of working with children who have diabetes. Even though the mechanisms for developing the diseases are similar within each category of diagnosis, the educational approach differs based on the developmental stages of the child, family dynamics and healthy literacy.

This paper will address each form of diabetes independently, rather than approaching them as one disease. Some of the educational strategies may be the same, but they are different diseases with the same manifestation of elevation in blood glucose levels. At times, differentiating between type 1 and type 2 diabetes in children may be challenging.² The requirements and diligence needed to care for the condition varies considerably from one form to another.

Type 1 Diabetes

The incidence of type 1 diabetes has been steadily rising. Data from the SEARCH study revealed an increased incidence from 2002-2003 to 2011-2012 of 1.4% annually.³ There were 17,900 persons under 20 years of age diagnosed with type 1 diabetes in 2011-2012.⁴ Over 50% of youth are hospitalized at diabetes onset, and approximately 30% of newly

diagnosed children present in diabetic ketoacidosis (DKA).⁵

Pancreatic autoantibodies are indicative of type 1 diabetes and along with assessing the C-peptide values, can be utilized to help diagnose type 1 vs type 2 diabetes. However, there is a potential for false positive and false negative results.⁵ Few environmental risk factors have been identified in type 1 diabetes, with genetics playing the major role.⁶

Type 1 diabetes requires constant vigilance to obtain blood glucose (BG) and/or interstitial glucose levels within a safe and healthy range. While multiple options for prediction equations are available, type 1 diabetes glucose values are not always predictable and result in frequent episodes of glucose variability requiring "on the go" insulin adjustments. This balancing act can result in frustration and adds to a

level of tedium rarely seen in any other medical conditions.

The management of children and adolescents has proven to be challenging with less than 30% achieving glycemic goals within an endocrinology setting based on data from the T1D exchange clinic registry. Of note, children less than 6 years of age were more likely to meet A1C targets than those in the adolescent age group (64% vs 21%).⁷

Treatment

One key factor in the treatment of children diagnosed with type 1 diabetes is the requirement for exogenous insulin administration at onset. The matching of insulin to activity, food intake, growth, illness and stress varies over the course of a lifetime requiring frequent adjustments. Even with careful monitoring and fine tuning, there generally remains a considerable amount of glucose variability with risks of both hyperglycemia and hypoglycemia. Celiac disease occurs in approximately 10% of children with type 1 diabetes and, if diagnosed, must also be considered in the treatment strategy.⁸

The Initial Diagnosis

Frequently, the individual is hospitalized in the ICU to resolve the DKA and the diabetes educator is called upon to start educating the family about managing type 1 diabetes at home. Generally, the parent(s) or caregiver(s) will be present during the hospital stay and the educational process can begin. Families are often overwhelmed with the new diagnosis. Reassurance that almost everything in life is still achievable with frequent glucose monitoring and insulin adjustments is comforting. The educator should inform families that continued support through their diabetes care team is available as needed when questions and concerns arise beyond the hospital stay. Due to the many questions and problems that arise during afterhours and on weekends, staff contact information should be provided.

The initial education usually covers what is called "survival skills", which typically includes the action of insulins, how to use an insulin pen or syringe, how their equipment may differ from the hospital's, how to follow the insulin plan provided, what to do if BG starts to drop, when to call the healthcare provider/diabetes care & education specialists for adjustments and the initial blood glucose goals during the transition to home. In addition, the

individual and family are taught how to use a blood glucose meter they can take home with them. Teach-back is encouraged to assure understanding of the operation of the meter. Because of the reliance on insulin and the potential danger of DKA, instruction on ketone testing via urine or meter is also provided, with clear instructions on interpreting the results and when and what action is required. All members of an interdisciplinary team can also be called upon to help with this education process.^{9,10}

Another area of learning to ensure safety involves the treatment of hypoglycemia and hyperglycemia and how to use glucagon in case of a severe hypoglycemic reaction. The family or individual is encouraged to call when questions arise; encouraging open communication between the family and diabetes care team (healthcare provider, diabetes care & education specialists, nursing staff, social worker and endocrinologist).

Carbohydrate counting may be initiated depending on the individual and family and their ability to grasp the information provided. This requires ongoing support and education to fully understand the importance of evaluating carbohydrate intake as well as potentially the role of other macronutrients.^{11,12} Fats and protein, although playing a minor role, can impact glucose outcome whether eaten alone or with carbohydrates.

For a child diagnosed with type 1 diabetes who is medically stable, a hospital admission is generally unnecessary and the individual and family can be successfully educated in the clinic setting. Each child and family should be evaluated for this approach independently.¹³

Transition to home:

As the individual and/or family gets ready for discharge, or in the event of a new diagnosis and treatment without hospitalization, the tools to help manage diabetes must be made available. These include:

- Insulin pens/vials and pen needles/syringes
- Blood glucose monitoring kit with prescription for 6-8 strips per day (prior to each meal, bedtime [HS], periodically in the middle of the night, prior to sports, and any time the child does not feel well)
- Glucose tablets

- Carbohydrate counting sheets and resources or menu plans (to help start the process of understanding the role of nutrition in diabetes management)
- Prescription for glucagon and ketone strips
- Phone numbers of persons to contact for clarification/questions

It is important to make sure caregivers have access to supplies. Insurance and a local community clinic should be considered as needed. The diabetes care & education specialists should alert the social worker to the needs of the child and family to assist in obtaining financial assistance if needed for ongoing care and supplies. A social worker can also help ease the transition back to school and provide psychological support to the family as needed.

Frequent initial visits and/or close phone and email communication with the diabetes care & education specialists can be re-assuring as the family learns how to incorporate the tasks of diabetes management into their daily routine. Communication should include reviewing timing of glucose checks, adding ketone checks/sick day guidelines as needed and the how to/when to use a glucagon kit. More time can also be spent on discussing the etiology of type 1 diabetes and the overall management goals to reduce any acute or chronic complications.

Depending on the family/individual, introducing the concept of insulin pump therapy can also be included in an initial education session. The option of a continuous glucose monitoring (CGM) system should be discussed and encouraged when financially feasible. When the choice is made to utilize an insulin pump or sensor, the education on how to use these devices should go to an educator who is well versed in insulin pump and sensor therapy. The content and pace of the education process should be determined on an individual basis. An excellent review of educational topics to be covered over time with families is provided in the National Institute for Health and Care Excellence (NICE) guidelines.¹⁴

An effective framework for providing education throughout the individual's lifespan includes components of the AADE 7 Self-Care Behaviors™: healthy eating (a well-balanced approach), being active (all children should be active), monitoring of BG or ketone checks (frequency), taking medication (adjustments or potentially different types and

concentrations of insulins), reducing risks (particularly acute risk at this juncture), problem solving (how to adjust for exercise for example) and healthy coping with diabetes (how to work with challenges).¹⁵

Toddlers and Preschoolers

Looking further at the annual increase in the diagnosis of type 1 diabetes, the greatest increase has been reported in children under 5 years of age relative to all children diagnosed.^{16,17} Quality education is critically important in children of this young age, especially with a history of significant hyperglycemia and hypoglycemia, because they are at an increased risk for problems later in life related to working memory and attention.¹⁸ The International Society for Pediatric and Adolescent Diabetes (ISPAD) Clinic Practice Consensus Guidelines in 2018 recommend that structured education be available to all young people with diabetes.⁹ Since many children this age are cared for outside of the home, it's important to know that any childcare facility receiving federal funds must comply with Section 504 laws; a written, legal document that specifies reasonable accommodations for children with disabilities, which includes diabetes. The diabetes care & education specialists can assist in the development of the 504 plan and plays a critical role in providing continuing support for the family and helping the family to educate other caregivers (daycare, baby sitters, grandparents) regarding safe diabetes management.^{19,20}

Grade School and Middle School

When children with diabetes start school, the diabetes care & education specialists can be the primary contact between the school, parent/guardian and diabetes care team. The diabetes care & education specialists can facilitate development of the medical management plan from the healthcare provider, educate parents and school nurses about 504 plans, and communicate with the school nurse and staff about the needs of the child.²⁰

Three federal laws that address a school's responsibility to provide care to students with diabetes are:

1. Section 504 of the Rehabilitation Act of 1973 (also known as Section 504)

2. The Americans with Disabilities Act of 1990 (ADA) and the ADA Amendments Act of 2008
3. The Individuals with Disabilities Education Act (IDEA)

Any school that receives federal funding must comply with Section 504 laws. Initiating a 504 plan is a legal written document specifying what “reasonable” accommodations the school must provide. Examples would include, but are not limited to, access to water, bathrooms and more time for testing.

School and extra-curricular sports can impact blood glucose with both hyperglycemia and hypoglycemia challenges. The diabetes care & education specialists can teach the child and family about insulin adjustments for activities based on collaborative agreements or recommendations by the healthcare provider, as well as contribute to the education of the coach in helping to enhance the child’s safety while under their watch. A recent study demonstrated many youths are not adjusting insulin for exercise despite the frequency of hypoglycemia during and after exercise²¹ indicating the need for further education.

Although some parents prefer simple language broken down into key points and hands on teaching,²² other methods of delivering diabetes education such as mobile technology,²³ tablet-based apps, and online professional and peer support have also successfully been incorporated.²⁴

High School

As the child with diabetes continues through the lifecycle, physiological as well as social changes will continue to create more challenges that the diabetes care & education specialist is trained to help problem-solve. As the teen spends more time with friends and less time with the parent(s) or caregiver(s), this increased autonomy may lead to more eating out, necessitating a need for more awareness of the carbohydrates in food and guidance on becoming comfortable checking glucose levels and giving insulin at meal time with friends present.

Traveling with sports teams, debate teams or band can enrich and complicate the life of a teen with diabetes. Helping to educate the coach, music

teachers and peers can also be part of the role of the diabetes care & education specialists.

Girls and young women with diabetes have their own unique needs and challenges that will need to be addressed. Girls starting their menstrual cycle may find variations in blood glucose levels that require a cyclic change in insulin dosing.²⁵ For those on insulin pumps, the diabetes care & education specialists can help determine if a second basal rate pattern would be beneficial.

Educating young women about A1C goals prior to pregnancy should be part of the educational sessions during the teen years while strongly encouraging target glucose management overall and a family support system prior to conception. Teenage pregnancy is generally unplanned and teenagers with type 1 diabetes are considered a high-risk group for poor pregnancy outcomes.²⁶ Therefore, education about the risks of child bearing, particularly the risks to the infant when BG values are highly variable and/or consistently elevated, should also be included when working with this age group.

Risky behaviors are more common in all teens but present unique challenges in teens with diabetes. In a recent self-reported assessment of 29,630 people with type 1 diabetes (median age 17 years), 10.8% reported regular alcohol consumption.²⁷ In a recent survey of substance abuse among American adolescents (not specific to diabetes) aged 12 years and older, 52% had consumed alcohol and 24% had binged on alcohol. In addition, 6.5% had used marijuana.²⁸ The diabetes care & education specialists should be a part of the information system for the teen with diabetes; educating the adolescent about the risks of mixing alcohol and diabetes as well as other options available to lessen the risks if they choose to drink alcohol.

An evaluation of two major diabetes online forums from 2011-2013 suggests that although teens expressed concern about their blood glucose values, other outcomes also mattered to them that should be considered in discussions. These outcomes include interaction with peers, emotional well-being, grades, family interactions and interactions with others such as teens.²⁹ Adolescents should be screened for potential depression as well as eating disorders.

Diabetes Camps

Most studies support diabetes camps as having a positive impact on diabetes acceptance and potential for improved management.³⁰ The diabetes care & education specialists can encourage children to attend diabetes camp, help connect families with funding opportunities if needed and become involved in camp by volunteering. Using the active camping environment as a teaching opportunity is an invaluable way for children with diabetes to gain skills in managing their disease within the supportive camp community.³¹

Transition throughout the lifecycle

Care and close supervision of diabetes management are shifted from parent or caregiver to the youth with diabetes throughout childhood and adolescence. During this transition phase, several major concurrent transitions are also taking place which may include moving away to attend college; engagement in serious relationships; being sexually active; learning to drive; experimentation with alcohol, smoking cigarettes and/or marijuana, and possibly taking illegal drugs. Comprehensive and coordinated planning that begins in early adolescence or at least one year prior to transition is necessary to facilitate a seamless transition to adult diabetes care. New responsibilities in self-management may include finding a new provider, making medical appointments, ordering supplies and medications, and finding a medical plan suitable for their needs. This shift occurs abruptly as the older teen enters the next developmental stage referred to as "emerging adult."³²

The years immediately following high school have been associated with a lapse in health care, deterioration in glycemic management, an increased occurrence of acute complications, psychosocial, emotional and behavioral challenges as well as the emergence of chronic complications. In college, it is the student's responsibility to make their disability known and to request special accommodations if they so choose. Working with the resource center to complete any necessary paperwork will be essential to help protect the student with diabetes. Some of the accommodation requests may include nutritional data from the food service, extra time during exams if glucose values are out of acceptable range and excused absences if needed for medical appointments. Informing and training the resident assistant (RA) and roommates about glucagon administration for severe hypoglycemia is important.

Having a separate refrigerator for insulin and snacks could also be helpful.

Transition from pediatric to adult-centered care often occurs concurrently with the development of adolescent independence which focuses on the development of personal identity. Seeking independence may take precedence over self-care, making transition difficult. Not all individuals move through developmental stages at the same pace, thus transition plans need to be individualized. Contemporary thinking is that young adulthood may not immediately follow adolescence but begins when youth are in their late 20s or early 30s. This phase is referred to as "emerging adulthood."³²

Psychiatric issues are more common in emerging adults with type 1 diabetes, similar to children that have other chronic medical conditions. Individuals in this transition period may experience sleeping disturbances, compulsions and depressive moods. Anxiety disorders, the most frequently diagnosed psychiatric disorder in the general population, can complicate diabetes self-management. Depression or the presence of depressive symptoms is a well-known comorbidity of diabetes and is a barrier to effective diabetes self-management. It is linked to poor glycemic management and diabetes complications.³⁴ Females in this age range are at a 2.4 times greater risk for disordered eating.³⁵ Potential for unwanted pregnancies and sexually transmitted diseases need to be addressed as well as the need for reproductive planning in order to optimize the outcomes of the person with diabetes who becomes pregnant. Individuals need to be informed about the maternal and fetal risks of pregnancy and the need for good glycemic management in order to conceive and give birth to a healthy child.³⁶

Rates of clinically apparent diabetes complications are usually low in adolescents, although there is evidence that approximately 10% of persons with type 1 diabetes³⁷ and up to 30% with type 2 have microalbuminuria.³⁸ Cardiovascular risk factors are greater in youth with type 2 diabetes rather than those with type 1. Elevated lipid profiles in type 1 diabetes may be related to poor glycemic management. According to the SEARCH a multicenter study funded by the Centers for Diabetes Control and Prevention (CDC) and National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) to learn more about type 1 diabetes and type 2 diabetes in children and young

adults in the United States, fatty liver disease and dyslipidemia is more common amongst obese children with insulin resistance and type 2 diabetes.

This transition period is considered a high-risk period for a person with diabetes during which interruption of care is likely for several reasons; leaving the comfort of pediatric care, financial stressors, poor glycemic management, high risk behaviors such as smoking, drug and/or alcohol abuse, and uncertainty regarding health insurance coverage. Eight areas of focus from pediatric to adult care differences include poor glycemic management, loss to follow up care, acute complications, psychosocial issues, reproductive health issues, substance use and abuse and chronic complications. Resources and guidelines related to the transition period are available, including The NDEP (National Diabetes Education Program) transition planning checklist and the American Diabetes Association position statement "Diabetes Care for Emerging Adults: Recommendations for Transition from Pediatric to Adult Diabetes Care Systems".³⁹

The American Diabetes Association recommends that pediatric healthcare providers work closely with parents and family to provide diabetes self-management care directed to the teen and emerging adult with a gradual transfer of responsibilities to the teen from the parent or guardian. Both pediatric and adult providers should ensure that people with diabetes receive ongoing primary and preventive health care that is separate from their ongoing diabetes specialty care.

Type 2 Diabetes in Youth

Incidence

Type 2 diabetes in youth is a relatively new, and growing, clinical and public health concern. Findings from the SEARCH study, indicate that the prevalence of type 2 diabetes in youth is increasing. It is estimated that type 2 diabetes accounts for 10-11% of diabetes in youth under the age of 20 years old.^{40,41} Additionally, the study estimates that there are approximately 3,700 youth diagnosed with type 2 diabetes annually.⁴²

Members of racial minority groups have the highest rates of new type 2 diabetes cases in youth. Similar to adults, type 2 diabetes disproportionately affects youth of ethnic and racial minorities. Studies indicate that in minority adolescents, type 2 diabetes

approaches or exceeds 50% of all cases of new onset diabetes.^{40,41} Native American youth have the highest incidence of type 2 diabetes, followed by non-Hispanic Black, Hispanic, and non-Hispanic White respectively. Additionally, youth from socioeconomically challenging backgrounds with high rates of poverty and low parental education attainment have higher rates of type 2 diabetes than youth with higher socioeconomic status.⁴²

Type 2 diabetes in youth and adolescents appears to be different from not only type 1 diabetes but also type 2 diabetes in adults. Some youth with type 2 diabetes appear to experience more rapid decline in beta cell function and earlier onset of diabetes-related complications than typically seen in adults with the same diagnosis.⁴²⁻⁴⁵

Etiology

Type 2 diabetes is associated with insulin resistance combined with beta cell dysfunction and relative insulin deficiency. Unlike type 1 diabetes, there is no identified autoimmune process leading to insufficient insulin secretion.⁴² Over the past several decades, the number of cases of youth with type 2 diabetes has risen along with the increasing number of youths that are overweight or obese.⁴⁶

Risk factors associated with type 2 diabetes in the pediatric population are a BMI-for-age greater than the 85th percentile, the onset of puberty, female gender, racial minority, a family history of type 2 diabetes and low socioeconomic status.^{42,46} Puberty is associated with decreased insulin sensitivity in approximately 50% of lean, healthy children. The onset of puberty is a high-risk time for the development of type 2 diabetes for those that are already at increased risk.⁴⁷ Additionally, adolescent girls have a 60% higher prevalence rate of type 2 diabetes than adolescent boys.^{44,46}

Diagnosis

Given the number of youths that are overweight or obese, differentiating between type 1 diabetes and type 2 diabetes in youth can be challenging. Determining an accurate diagnosis is essential, as treatment, educational needs and methods, nutrition advice and outcomes differ between the two diagnoses.⁴⁴ It is recommended that type 2 diabetes in youth be diagnosed using the American Diabetes Association diagnostic criteria. Following diagnosis, autoantibody testing should be considered in youth with diabetes in order to better determine the type

of diabetes and ensure appropriate treatment.⁴⁸⁻⁵⁰ It is possible, but not likely, that youth with type 2 diabetes present in DKA at diagnosis.⁵¹

Treatment

To date, there have been limited studies completed regarding type 2 diabetes in youth. Consequently, minimal guidance is available from which to develop best practice guidelines specific to youth with type 2 diabetes. More research is needed to better understand type 2 diabetes in the pediatric population.⁴⁵

At present, the general BG target goals for youth with type 2 diabetes are the same as those for youth with type 1 diabetes.⁴³ Initial treatment should address blood glucose management and management of comorbidities such as obesity, dyslipidemia, hypertension and other microvascular complications.⁴⁸ From a management standpoint, youth with type 2 diabetes present a unique challenge to the diabetes care team. Individual-level lifestyle interventions are most likely not sufficient and may not be developmentally appropriate for youth with type 2 diabetes.⁴³ The diabetes educator should be aware that a family-centered approach to education, medical management and lifestyle modification is essential for children with type 2 diabetes. Individuals and their families must work toward recommended lifestyle modifications together and diabetes educators are a source of knowledge and ongoing support.⁴⁸ Encouraging regular exercise and working with the family to develop healthy eating plans that are financially acceptable and encourage moderation in portion sizes can be effective in reducing the reliance solely on medication to achieve target glucose levels.

Medications

Until recently, medical management options for youth with type 2 diabetes was limited to lifestyle

modifications and two medications that are FDA approved for those under the age of 18; insulin and Glucophage (Metformin).^{43,48} Liraglutide is the most recent medication to receive FDA approval for use in T2D patients aged 10 and older, approved for use in June, 2019.⁵²

Metformin

Recommendations for initial treatment of youth with type 2 diabetes include the use of Metformin combined with lifestyle changes. Metformin is taken orally in pill or liquid form, has a low risk of hypoglycemia, requires less blood glucose monitoring and is associated with weight loss or weight neutrality.⁵³ Because Metformin is a low burden therapy, youth with type 2 diabetes may have higher rates of persistence to therapy with metformin vs insulin therapy.⁵⁴ Families should be given education regarding how to administer the drug, how to titrate the dose as directed, adverse side effects, and how to minimize gastro-intestinal side effects.

Insulins

Insulin is typically required if the individual is not metabolically stable or if glycemic management goals are not achieved with metformin and lifestyle changes alone. Educational needs for safe insulin administration in youth with type 2 diabetes are the same as those for youth with type 1 diabetes. Although hypoglycemia is very uncommon in youth with type 2 diabetes, they should still receive education regarding signs/symptoms and appropriate treatment of hypoglycemia when insulin therapy is initiated. Additionally, weight gain with insulin can be substantial in this population. It is therefore important that the educator emphasize the continued importance of nutrition management and exercise while using insulin therapy.⁴⁹ The ISPAD Clinical Practice Guidelines outline the use of insulin in this population, as seen in Table 1.

Table 1. ISPAD 2018 Clinical Practice Guidelines* for youth with type 2 diabetes⁵⁵

Initial Diagnosis	A1C <8.5; no symptoms	A1C > 8.5% or Ketosis/ketonuria/ketoacidosis	Failure to reach A1C<7.0% in 4 months
Treatment	Lifestyle and Metformin	Lifestyle basal insulin and Metformin (may able to d/c insulin after 4-6 weeks)	Add bolus insulin to regimen

*At the time of publication, there are no clinical practice guidelines published on the use of Liraglutide for youth with type 2 diabetes.

Liraglutide

Liraglutide is a daily, injectable GLP-1 receptor agonist. It is associated with reduced fasting and post-prandial blood glucose, reduced A1C, weight loss and low risk of hypoglycemia. Liraglutide can be used in combination therapy with diet, exercise, Metformin and/or basal insulin.⁵² Families should be given education regarding how to administer the drug, how to escalate the dose as prescribed, adverse side effects and how to recognize and treat hypoglycemia.

Other Agents

Though there are many different classes of drugs used to manage type 2 diabetes in adults. Use of agents other than metformin, insulin and Liraglutide are not recommended for youth with type 2 diabetes outside of clinical trials at this time.

Bariatric surgery

Studies on weight-loss surgery in adolescents who are obese have found improvements in body weight, insulin resistance, type 2 diabetes management or remission of type 2 diabetes following Roux-en-Y gastric bypass and sleeve gastrectomy. Weight-loss surgery may be considered a treatment option for morbidly obese youth with type 2 diabetes.^{56,57} Individuals and families of youth with type 2 diabetes who meet criteria for bariatric surgery should be informed of the availability, risks and benefits of surgical weight loss so that they are aware of all treatment options available and can make informed decisions about their care.

Lifestyle changes

Healthy lifestyle changes are the foundation of treatment of type 2 diabetes. However, type 2 diabetes in youth most often occurs in complex psychosocial and cultural environments where implementing and achieving lasting lifestyle changes can be difficult due to multiple barriers. Because most of the youth with type 2 diabetes are obese, improved dietary habits and increased physical activity to reduce BMI and improve glycemic management is recommended by both the American Academy of Pediatrics (AAP) and the American Diabetes Association.^{48,53}

Overweight and obese youth with type 2 diabetes and their family should be provided with developmentally appropriate comprehensive lifestyle education that is integrated with diabetes management in order to achieve 7 to 10% decrease in excess weight.⁴⁸ Success in making lifestyle changes and achieving treatment goals requires initial and ongoing education of the individual, his/her caregivers and support systems.⁵³

Dietary management

A single best meal plan for adults or youth with type 2 diabetes has not been established. However, there have been numerous studies conducted regarding effective weight management strategies for overweight children and adolescents. Current nutrition recommendations for youth with type 2 diabetes are based on The Academy of Nutrition and Dietetics (formerly the American Dietetic Association) Pediatric Weight Management Evidence-based Nutrition Practice guidelines. Nutrition education for youth with type 2 diabetes should focus on healthy eating principles and emphasize increasing intake of quality, nutrient dense foods while decreasing intake of calorically dense, nutrient poor foods—especially sugar sweetened beverages. Individuals and their families should be referred to a Registered Dietitian with experience and expertise in the needs of youth with type 2 diabetes for medical nutrition therapy (MNT) and other nutrition-related diabetes self-management education and support (DSMES).^{48,49}

Common dietary recommendations to reduce calorie intake and promote weight loss in children and adolescents include:^{48,49}

- Eliminating sugar/calorie containing beverages. The exception being low fat milk
- Limiting fruit juice to no more than 1 cup per day
- Eating regular meals and snacks
- Limiting frequency of snacks
- Increasing fruit and vegetable intake
- Consuming 2 to 3 servings of fat-free or low-fat dairy per day

- Reducing intake of processed, prepackaged convenience foods
- Reducing intake of foods high in refined sugar
- Reducing intake of high fat foods
- Portion control
- Reducing number of meals eaten away from home
- Substituting whole grains for refined grains as much as possible
- Changing family diet behaviors to those that promote and support healthy eating

In addition to weight management, education regarding carbohydrate counting or a scheduled meal plan may be necessary for youth with type 2 diabetes using bolus or split-mixed insulin as part of their diabetes management plan.

Physical activity

Youth with diabetes, like all children, should be encouraged to decrease sedentary behavior and participate in at least 60 minutes of moderate to vigorous physical activity per day and strength training at least 3 days per week.⁴⁸ Activity may be completed in shorter segments throughout the day. Children and adolescents with type 2 diabetes should be encouraged to meet these recommendations in order to reduce BMI and improve glycemic management. In addition to increasing daily physical activity, nonacademic screen time should be limited to no more than 2 hours per day in order to reduce sedentary time.^{48,49,53}

Youth with type 2 diabetes and their families should be educated regarding the positive impact of regular physical activity on weight management, BG management and improved insulin resistance. Exercise safety should also be discussed, especially if insulin therapy is required. Families may need guidance and support in starting an exercise routine as well as tips for incorporating more physical activity into their daily lives.

Monitoring

Studies evaluating the value of frequent finger-stick blood glucose (FSBG) monitoring have not been conducted in children and adolescents with

type 2 diabetes. However, blood glucose monitoring can provide insight to understand the impact of eating, exercise, stress and illness on BG levels when integrated into the broader self-management plan. Current American Diabetes Association recommendations for FSBG monitoring apply to most youth with type 2 diabetes and are as follows.⁵³ Individuals using intensive insulin regimens should assess glucose levels using self-monitoring of BG (or CGM) fasting, prior to meals and snacks, at bedtime, occasionally postprandially, prior to exercise, when they suspect low blood glucose, after treating low blood glucose until they are normoglycemic and prior to critical tasks such as driving. For individuals using less frequent insulin injections, oral or other non-insulin injectable agents, or lifestyle interventions alone, FSBG may be a useful guide to the success of therapy.

The AAP suggests that all newly diagnosed youth with type 2 diabetes, regardless of therapy, perform FSBG before meals and at bedtime until reasonable metabolic management is achieved. Frequency of monitoring can then be adjusted depending on the needs of the individual's diabetes care regimen and whether they are achieving glycemic goals. Youth with type 2 diabetes treated with insulin therapy will require continued frequent FSBG monitoring, while those treated with metformin and lifestyle management, or lifestyle modifications alone, may not need to test as frequently.⁵⁴

The Role of the Diabetes Educator

All youth with type 2 diabetes, their parents or guardians, and other care providers should receive comprehensive DSMES that is specific to the youth with type 2 diabetes. Given that many youths with type 2 diabetes come from ethnic minorities, DSMES should be culturally sensitive.⁵⁹ It is recommended that DSMES be provided by a multidisciplinary team that includes a physician, diabetes nurse educator, registered dietitian, and psychologist or social worker and other members of the health care team who are knowledgeable about type 2 diabetes in youth and the continually changing needs of the pediatric population.^{48,60}

DSMES is recommended at diagnosis; annually for assessment of education, nutrition and emotional needs; when new complicating factors arise that impact self-management; and when transitions in

care occur.⁶¹ Initial and ongoing DSMES for type 2 diabetes should focus on food intake and physical activity changes as well as on the administration of metformin, insulin administration, signs/symptoms and treatment of hypoglycemia, and BG monitoring as needed.⁴⁸ Not only do individuals need to know the correct technique when monitoring, but they also need to understand how to evaluate BG data and identify when an adjustment in therapy may be needed.⁵³

Because youth with type 2 diabetes typically do not present in DKA at diagnosis, initial diabetes education will most likely take place in the outpatient setting. Limited finances, transportation issues and difficulty taking time off work are all common barriers to appointment attendance and persistence to care in this population and should be considered when designing type 2 diabetes classes or educational programs.

Youth with type 2 diabetes frequently have a family history of type 2 diabetes and may already be familiar with how other family members manage their diabetes. Youth with type 2 diabetes most often come from socially vulnerable demographics that are associated with poorer outcomes and often are familiar with the long-term complications of poorly managed diabetes.⁶² As part of initial DSMES, the diabetes care & education specialists must reassure families that, with proper management, children and teens with type 2 diabetes will be able to live a healthy life.

Onset of type 2 diabetes in youth before puberty is rare, therefore most youth with type 2 diabetes are middle school and high school aged. Age-specific education considerations and concerns for youth with type 2 diabetes in these age groups are

similar to the education needs described for their same-age peers with type 1 diabetes. Working with the school, as with type 1 diabetes, and developing a 504 plan will help provide the support the child needs within the school setting.¹⁶

Throughout the education process and through various stages of the child's life, the diabetes care & education specialists should be sensitive to the challenges that are common in youth with type 2 diabetes.⁴⁸ The diabetes care & education specialists should tailor DSMES to help individuals and families better meet challenges and overcome barriers to adherence to their medical care, helping to ensure the best possible outcomes.

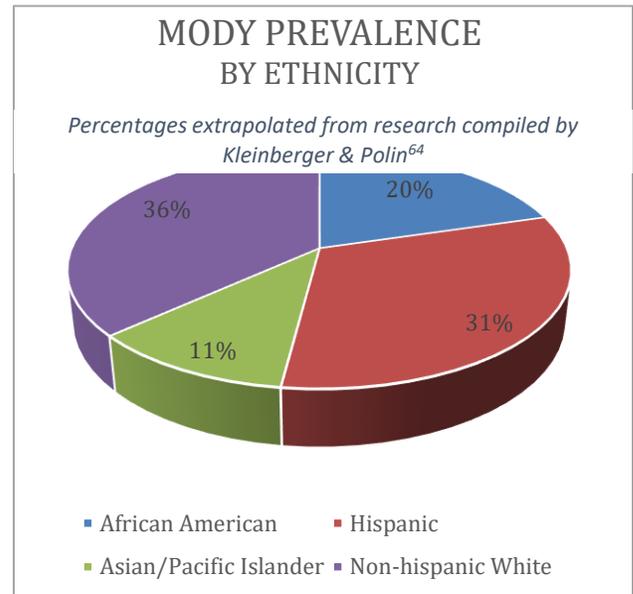
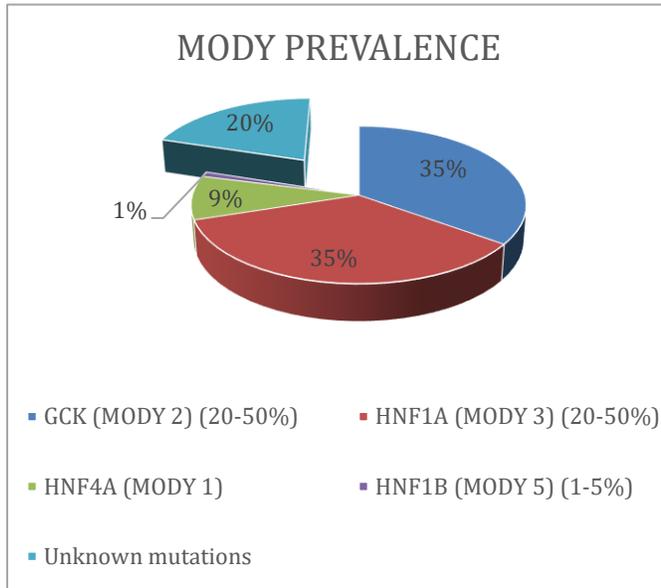
Participating in a camp program is another role the diabetes care & education specialists can play in helping children and families at risk. Some day camps are now being organized specifically for type 2 diabetes prevention for children at risk.

MODY (mature-onset diabetes of the young)

Mature-onset diabetes of the young (MODY), a monogenic form of diabetes, accounts for at least 1% of all cases of diabetes and is frequently characterized by onset of hyperglycemia at an early age (classically before age 25 years in lean individuals, although diagnosis may occur at older ages). MODY is most often characterized by impaired insulin secretion with minimal or no defects in insulin action (in the absence of coexistent obesity). It is inherited in an autosomal dominant pattern with abnormalities in at least 13 genes on different chromosomes identified to date. These mutations lead to pancreatic beta cell dysfunction and ultimately, elevated glucose levels.⁶

Figure 1. Prevalence of MODY

The most commonly reported forms of MODY are GCK-MODY (MODY2), HNF1A-MODY (MODY3), and HNF4A-MODY (MODY1)⁶⁵.



*Study of the frequency of MODY at the Barbara Davis Center among antibody-negative subjects with diabetes onset <25 and conserved C-peptide*⁶

Presentation of MODY

Clinically, individuals with GCK-MODY exhibit mild, stable, fasting hyperglycemia and do not require antihyperglycemic medications. These individuals might present with symptoms such as polyuria/polydipsia and weight loss, but rarely accompanied by DKA. Persons with HNF1A- or HNF4A-MODY usually respond well to low doses of sulfonylureas, which are considered first-line therapy. Mutations or deletions in HNF1B are associated with renal cysts and uterine malformations (renal cysts and diabetes [RCAD] syndrome). Other extremely rare forms of MODY have been reported to involve other transcription factor genes including PDX1 (IPF1) and NEUROD1.^{63,64}

Proper Clinic Diagnosis

Though there is often an overlap with type 1 and type 2 diabetes, the clinical diagnosis for MODY has been based upon the following criteria: family

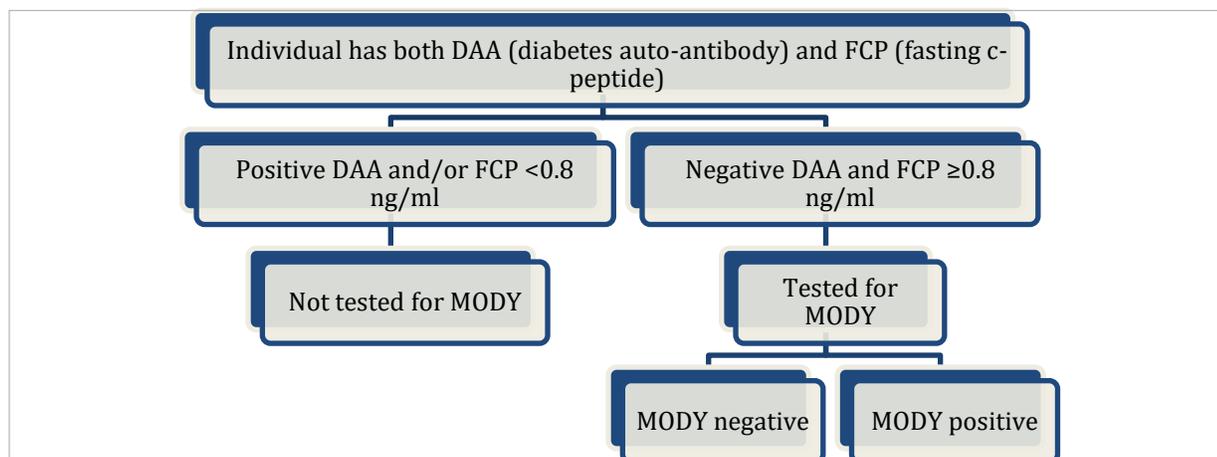
history of diabetes, insulin independence and onset by age²⁵. Researchers on this subject generally agree that a proper diagnosis needs to be established in affected individuals, as treatment options may vary widely. Some estimate that 95% of MODY cases in the US are misdiagnosed.⁶⁵

The American Diabetes Association Standards of Care suggest that a diagnosis of monogenic diabetes should be considered in children with the following characteristics:⁶³

1. Diabetes diagnosed in the first 6 months of life
2. Family history of diabetes without type 2 diabetes risk factors (non-obese, low-risk ethnicity)
3. Mild fasting hyperglycemia if young and non-obese
4. Diabetes with negative autoantibodies and without signs of obesity or insulin resistance

Figure 2. MODY diagnosis criteria

The researchers for the SEARCH study recommend the following algorithm to ensure that a proper diabetes diagnosis is obtained:



For individuals with a FCP level of ≥ 0.8 ng/mL and negative results for selected DAA, test for the 3 most common forms of MODY: HNF1A, HNF4A, and GCK.⁶⁶

Medication Treatment Options

Treatment is chosen based on the form of MODY. In HNF1A & HNF4A, oral sulfonylurea medication vs injected insulin is recommended; in GCK, possibly no treatment is necessary.⁵⁰

Lifestyle modification: The role of the diabetes care & education specialists

As with other forms of diabetes, the role of the educator is to help empower the individual to maximize their self-management skills. Healthy eating and an appropriate weight, regular exercise, taking medications as prescribed, and the proper administration of medication(s) and possible side effects should be discussed. A review of the frequency of monitoring as directed by the medical staff along with monitoring techniques, avoiding long term complications, appropriate coping skills and problem-solving challenges that may contribute to more challenging management should be incorporated into the diabetes education sessions with the individual and supporting family members as appropriate.

Secondary forms of diabetes

Cystic Fibrosis Related Diabetes:

Cystic fibrosis-related diabetes (CFRD) is the most common co-morbidity linked to cystic fibrosis (CF) and is reported in 20% of adolescents and 40–50% of adults with cystic fibrosis.⁶³ Advances in the clinical care of CF have increased life expectancy and the likelihood of seeing CFRD.⁶⁷ Early detection of CFRD and aggressive insulin therapy have narrowed the gap between mortality in individuals with and without diabetes and has eliminated the sex difference mortality.⁶⁸ The main goal of insulin therapy is to preserve lung function and maximize nutritional status.⁶⁹ High BG levels may also promote thickened secretions and subsequent bacterial colonization which may lead to infection and further compromise lung function.⁷⁰

Severe insulin deficiency is the primary defect in CFRD. There is also marked glucagon deficiency and variable insulin resistance secondary to illness and medications such as glucocorticoids.⁷¹ DKA is

rare and for this reason, individuals with CFRD do not routinely need to learn ketone testing.⁷²

Insulin therapy is recommended for the treatment of CFRD in order to achieve BG targets recommended by the American Diabetes Association.⁷³ CFRD with fasting hyperglycemia is typically treated with basal/bolus insulin therapy either via multiple daily insulin injections of rapid-acting insulin and long-acting insulin or through insulin pump therapy.⁷³ Treatment of CFRD without fasting hyperglycemia has been shown to benefit from pre-meal rapid-acting insulin due to the anabolic effect of insulin and ability to improve nutritional state.⁷⁴ Multiple insulin injections have benefits including flexibility with timing of dose and amount of food consumed. Some families may resist multiple injections and are able to be managed on a regimen of 70/30 insulin or only require insulin during overnight feeds.⁷⁵ Overnight continuous feeds may require a combination of regular insulin and NPH with insulin doses titrated based on BG checks four hours into the feeding and end of the feed.⁷⁶ NPH or insulin detemir is typically given at the start of the nighttime continuous feed. Insulin pump therapy has been shown to be effective and safe in management of CFRD⁷⁷ and yet, for unknown reasons, is often underutilized.⁷⁸ More clinical studies are

desperately needed to determine the best and most effective insulin regimen for managing CFRD.⁷⁹

CGM devices are closer to becoming part of the standard management for type 1 diabetes and has been validated in terms of being reliable, reproducible and repeatable in children and adolescents with CFRD.^{80,81} A prospective monocentric cross-sectional cohort study conducted from March 2009 through September 2012 concluded CGM reveals early abnormalities of glucose tolerance in people with CF who have normal oral glucose tolerance test and is associated with worse lung function and a higher prevalence of *P. aeruginosa* colonization.⁸² Continued research will help determine the role of CGM in CF and CFRD.

It is essential for diabetes care & education specialists working in pediatrics to keep abreast of new guidelines associated with the management of CFRD. In Table 2 are some key recommendations for diabetes care guidelines in CFRD. Refer to ISPAD clinical practice consensus guidelines 2014 compendium: definition, epidemiology and classification of diabetes in children and adolescents.⁸³

Table 2. Diabetes Care Guidelines for Management of CFRD in Pediatrics

Annual screening for CFRD	Annually starting at age 10 for those not diagnosed with CFRD (2-hour 75G OGTT)
Diabetes medication	Insulin only Oral agents not recommended
Blood glucose goals	Obtain same goals as recommended for all individuals with diabetes, targets are individualized based on needs
A1C	Quarterly
Blood glucose monitoring	Minimum of three times a day but may be needed much more depending on insulin therapy, meal pattern, intestinal concerns, etc.
Routine follow-up	Seen quarterly by diabetes multidisciplinary team and CF multidisciplinary team
DSMES	Ongoing education from education program that meets national standards
Nutrition	Essential to be followed by a dietitian knowledgeable in CF Usually requires 120-150% (or more) of normal caloric intake for age and gender to prevent underweight <ul style="list-style-type: none"> • Fat 40 % of total energy • Total carbohydrate 45-50% of total energy • No protein or salt restriction
Screening	Annual monitoring for microvascular disease starting 5 years after diagnosis Blood pressure checked at each visit Lipid profile annually for individuals with exocrine insufficiency and CFRD or if any of the following risk factors present: obesity, family history or coronary artery disease. Treatment as per American Diabetes Association recommended guidelines for all individuals with diabetes

*Adapted from ISPAD Clinical Practice Consensus Guidelines for management of CFRD: 2014 Compendium in pediatrics management of cystic fibrosis-related diabetes in children and adolescents.*⁸³

The diabetes care & education specialists is a vital part of the individual’s healthcare team. Initial education will focus on diabetes self-care skills related to initiation of insulin therapy. Comprehensive DSMES should be provided to the person and family based on individualized assessment of needs (see Table 3).

Table 3. Diabetes self-management education and support topics⁸⁴

- Overview of diabetes care team
- What is diabetes and overview of CFRD (causes, caused health problems, symptoms)
- Importance of glycemic management and insulin therapy in improving health outcomes
- Treatment of CFRD (insulin, BG monitoring)
- Home blood glucose monitoring (how to check, target, frequency of testing)
- Insulin therapy and administration, insulin calculations (if using basal/bolus insulin therapy) or insulin pump therapy
- Nutritional counseling and instruction on carbohydrate counting – coordinate with CFRD
- Signs, symptoms and treatment of hypoglycemia including use of glucagon
- Signs, symptoms and treatment of hyperglycemia
- Sick day management
- Activity guidelines and insulin therapy
- Prevention of long-term complications (microvascular, macrovascular)
- Driving, alcohol information (if applicable)
- Driving guidelines (if applicable)
- Importance of preconception planning (if applicable)

It is essential the diabetes care team, CF care team and the individual/family have clear, open and honest communication to best coordinate care to ensure that optimal outcomes are achieved.

Medication-Induced Diabetes

Medication-induced diabetes is a common condition causing referral from the medical provider for DSMES during an inpatient hospitalization. The majority of medication-induced diabetes in children is related to glucocorticoid therapy.⁸⁵ A 2014 meta-analysis evaluating the incidence of hyperglycemia induced by glucocorticoid therapy reported the development of glucose-induced hyperglycemia or diabetes to be 32.3% and 18.6% respectively.⁸⁶ A 2010 Canadian two-year prospective surveillance pediatric study of 56 children with medication-induced diabetes reported that 98% were associated with glucocorticoid therapy.⁸⁷

Glucocorticoids alter glucose metabolism by causing a reduction of insulin production and secretion (dose related), a reduction of insulin sensitivity and an increase in glucose production.⁸⁸ Glucocorticoids can cause new onset hyperglycemia or worsen insulin resistance in someone with established diabetes.⁸⁹

Treatment

Although high-dose steroids are frequently utilized in pediatrics (oncology, transplantation, rheumatology) there are no national or international guidelines for managing steroid-induced hyperglycemia.⁹⁰ Different gluco-corticoid agents have different impacts on carbohydrate metabolism.⁹¹ Early recognition and treatment of children with glucocorticoid-induced diabetes is important to reduce morbidity associated with hyperglycemia.⁹² DKA is not a common side effect of steroid-induced diabetes, however, there have been reports of DKA in children and adolescents receiving glucocorticoid therapy.^{93,94}

The 2018 Diabetes Care in the Hospital: Standards of Medical Care in Diabetes recommends insulin therapy for treatment of persistent hyperglycemia for BG value greater or equal to 180 mg/dL.⁹⁵ Insulin is generally recommended if serum glucose is greater than 200 mg/dL for medication-induced hyperglycemia with management being individualized regarding lifestyle modification and alternative diabetes medication.⁹⁶ Insulin and metformin are the only diabetes medications approved for pediatric use at this time. Glucocorticoid-induced diabetes typically presents as fluctuations in postprandial hyperglycemia with minimal impact on fasting glucose.⁹⁷ The insulin regimen is directed at maintaining glycemic

management in response to glucocorticoid dosing through monitoring of blood glucose and titration of insulin therapy.⁹⁸

Role of the Educator

The educator's role is to balance the demands of managing BG levels with the physical and emotional demands of the individual's underlying condition. DSMES will be individualized based on needs at discharge. Education should address healthy eating, being active as tolerated, glucose monitoring as prescribed and healthy coping. It is essential to provide the family with a plan for insulin titration that matches titration of glucocorticoid therapy in order to prevent acute complications such as hypoglycemia.

Total Pancreatectomy with Islet Autotransplantation (TPIAT)

Children who experience debilitating pain from chronic pancreatitis and for whom medical measures and/or endoscopic management have not been successful, may be candidates for a procedure called total pancreatectomy with islet autotransplantation (TPIAT).^{99,100} The aim is for the pancreatectomy to relieve pain from chronic pancreatitis and auto islet transplantation (from self) to help prevent or reduce the severity of hyperglycemia post-pancreatectomy. Individuals/families must be willing to accept diabetes in the event islet autotransplantation is not successful.¹⁰¹

In 2012, Sutherland¹⁰² reported 53 children ages 5 to 18 years of age, including 356 adults with chronic pancreatitis, underwent TPIAT from February 1977 to September 2011. At three years post-transplant, one third were insulin independent, including one quarter of the adults and half of the children.

Hyperglycemia has been found to negatively impact beta cell survival in mice.¹⁰³ In order to improve beta cell outcomes following the TPIAT procedure, tight glucose management is maintained by using continuous insulin infusion drip titration.¹⁰⁰ In a small study involving nine individuals who underwent a TPIAT, Elder¹⁰⁴ found continuous glucose monitoring was an effective tool to help achieve glucose range of 70-140 mg/dL in first 5 days post-operatively. Experts have recommended the need for continued research studies on pancreas and islet cell transplantation, the creation of pediatric centers of excellence, and pancreas-focused clinics to help ensure optimal outcomes.¹⁰⁵

Individuals and their families will require extensive diabetes education prior to discharge. Initially, individuals are discharged on exogenous insulin. Exogenous insulin is weaned over time based on insulin production by beta cells. Individuals and families will require DSMES on topics including basic understanding of diabetes, importance of optimal glucose management, carbohydrate counting, insulin dose calculation, insulin administration, BG monitoring, prevention, detection and treatment of hypoglycemia/hyperglycemia and psycho-social support. In addition, individuals may benefit from use of diabetes technology including insulin pumps and CGM devices to keep BG in tight management to maximize outcomes.

Summary

Diabetes presents in many ways in the pediatric population and, as the manifestation of diabetes differs, so does the need for individualized treatment and educational interventions. When diabetes care & education specialists conduct a thorough assessment of the individual and family, understand the requirements for their specific diagnosis and work with individuals and families to establish goals towards maximal health, all involved will benefit and those living with or affected by diabetes will be able to more fully enjoy their lives despite their challenges. As

diabetes care & education specialists, our biggest challenge may be to recognize the variations in etiology for the development of elevated glucose levels and to understand the modifications required in, not only the overall assessment of the needs for the child and family but how to apply the AADE7[®] principles in these very different diseases.



On-line resources for diabetes care & education specialists

<http://www.diabetes.org/living-with-diabetes/parents-and-kids/>

www.jdrf.org/t1d-resources/

<http://www.childrenwithdiabetes.com/>

<https://www.thediabetesCouncil.com/kids-with-diabetes-resources/>

<http://www.diabetes.org/living-with-diabetes/parents-and-kids/children-and-type-2/>

<https://www.uptodate.com/contents/cystic-fibrosis-related-diabetes-mellitus#H17626652>

<https://www.cff.org/Life-With-CF/Daily-Life/Cystic-Fibrosis-related-Diabetes/Managing-CFRD.pdf>

https://www.pedsendo.org/assets/patients_families/transition_toolkit/assets/Planning-Checklist-508.pdf

https://www.jdrf.org/wp-content/docs/JDRF_School_Advisory_Toolkit.pdf

<http://www.diabetes.org/living-with-diabetes/parents-and-kids/diabetes-care-at-school/>

Additional resources

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