

## Diabetes Care & Education Specialists Working with Persons with Type 1 Diabetes Over The Lifespan

The diabetes care & education specialist (DCES) plays a pivotal role in providing education to individuals with type 1 diabetes. This includes but is not limited to the disease process and treatment strategies as well as providing guidance and continued support and education on the potential utilization of technologies, such as meters, insulin pumps and sensors. The diabetes care & education specialist must be part of the team educating, enhancing problem solving skills and supporting family, school personal, coaches and employers. The need for education and support continues throughout the continuum of life as a child with type 1 diabetes enters school, adds organized sports, transitions to college, enters a career, chooses pregnancy, develops possible complications and enters the older years with potential for assisted living.

In 2017, it was estimated that 1.5 million people in the United States have type 1 diabetes,<sup>1,2</sup> due to the partial destruction or ineffectiveness of the beta cells of the pancreas, resulting in minimal or no insulin production. The diagnosis of type 1 diabetes is based on the clinical signs of hyperglycemia as a result of insulin deficiency (excessive thirst, frequent urination, marked weight loss generally in the presence of historically appropriate BMI, and ketosis) and reliance on insulin vs oral agents to lower blood glucose (BG) values. There is considerable variability in adults presenting with a more gradual onset of symptoms in which they are often misdiagnosed with type 2 diabetes, classified as latent autoimmune diabetes of the adult (LADA)<sup>4</sup>. With the increase in weight in the overall population, using lean habitus as a marker for type 1 vs type 2 diabetes can no longer be as suggestive of type 2 vs type 1 diabetes. Family history can remain a strong risk factor.

Pancreatic autoantibodies are indicative of type 1 diabetes and can be utilized to help diagnose type 1 vs type 2 diabetes along with assessing the c-peptide values although there is a potential for false positive and false negative results<sup>5</sup>.

Type 1 diabetes requires constant vigilance to obtain and maintain BG levels within a safe and healthy range. In addition to all the prediction equations, type 1 diabetes BG 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 certainly adds to a level of tedium unknown in any other medical condition. In addition, forms of discrimination can occur throughout the lifespan in school, sports, and the workplace.

In the minds of many individuals, type 1 diabetes and type 2 diabetes are so distinct from one another, there has been movement over the years to have a completely different label<sup>6</sup>, though in “diabetes”, regardless of etiology, the overall marker is hyperglycemia. It is important that diabetes care & education specialists understand the unique challenges of type 1 diabetes that may not be noted in persons with type 2 diabetes including early age of diagnosis, BG volatility, and heightened risk of hypo and hyperglycemia even when applying management techniques.

Recently, JDRF (Juvenile Diabetes Research Foundation) formed a committee of leading diabetes organizations to develop a consensus statement on clinically meaningful outcomes for type 1 diabetes aside from HbA1c lab values. The full document can be found at <http://care.diabetesjournals.org/content/40/12/1622>. These defined outcomes include hypoglycemia, hyperglycemia, time in range, diabetic ketoacidosis and patient-reported outcomes. The committee recommends these outcomes to be used in research, development and evaluation of type 1 diabetes therapies as well as future insurance reimbursement.

### **The Initial Diagnosis:**

#### ***Inpatient:***

Thirty percent of persons at initial diagnosis with type 1 diabetes are in diabetic ketoacidosis (DKA)<sup>7</sup>. Frequently, the individual is hospitalized in the intensive care unit (ICU) to resolve the DKA and the diabetes care & education specialist called upon to start the teaching process of managing type 1 diabetes at home. Particularly in the case of a child diagnosed, the parent(s) or caregiver will be present during the hospital stay and the educational process can begin. Families are often overwhelmed with the diagnosis and reassurance that most everything in life is still achievable with frequent blood glucose monitoring and insulin adjustments is needed. The educator should assure families that continued support through the medical team is available as needed when questions and concerns arise beyond the hospital stay and provide appropriate contact information and resources.

Survival skills are initially taught: how to use an insulin pen (or syringe and vial) and how that may differ from the hospital pen needles, how to follow the insulin plan provided, what to do if BGs start to drop, when to call the health care provider/DE for adjustments and the initial blood glucose goals during the transition to home. A healthy lifestyle including food and activity should be discussed and carbohydrate counting may be initiated. The nursing staff can also be called upon to help with the education process. A glucose meter is generally provided with education to the individual and family and teach back encouraged to assure understanding of the operation of the glucose meter. The educator should also include treatment

of hypoglycemia and hyperglycemia and encourage teach back to assure understanding of these important principles.

#### ***Outpatient:***

As health care providers (HCP)'s, parents and individuals have become more informed in regard to recognizing signs and symptoms of diabetes, early recognition provides an opportunity to start the education process for newly diagnosed type 1 diabetes as an outpatient. The diabetes care & education specialist is an essential part of the diabetes team to provide education, support and problem solving initially and for ongoing care. The same topics that are covered inpatient will need to be covered at the outpatient appointments, which may be scheduled daily or weekly depending on the individual needs of the individual and family. Twenty-four-hour availability of the diabetes team is essential to support individuals and families as they learn how to manage this challenging disease.

#### ***Transition to home:***

As the individual and/or family gets ready for discharge, or in the event of a diagnosis and treatment without hospitalization, the tools to help manage diabetes must be available to the patient. Insulin pens and pen needles, glucose meter kit with prescription for a minimum of 6-8 strips per day (prior to each meal, HS, periodic 0200 check, prior to sport, and more frequent monitoring when ill or feeling "off"), glucose tablets, carbohydrate counting sheet or menu plans to help start the process of understanding the role of nutrition in diabetes management. In addition, making sure the patient has access to supplies utilizing their insurance or a local community clinic if needed, along with appropriate contact information and resources. The diabetes care & education specialist can alert the social worker, case manager, or care coordinator to the needs of the patient so they may assist in obtaining financial assistance and social supported if needed for ongoing care and supplies.

Frequent initial visits with the diabetes care & education specialist can be reassuring as the family learns how to incorporate the tasks of diabetes management into their daily routine. Reviewing timing of glucose testing as well as adding ketone checks as needed and the how to and when to use a glucagon kit should be discussed. More time can be spent on discussing the etiology of type 1

diabetes and the overall management goals to reduce acute or chronic complications.

Depending on the family/individual, introducing the concept of insulin pump therapy and continuous glucose monitor (CGM) options can also be included early on in the education session. When the choice is made to utilize an insulin pump or CGM, the education on how to use the tools should fall to the educator who is trained in insulin pump and CGM 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<sup>8</sup>.

Overarching themes throughout the lifespan includes components of the AADE7™ Self Care Behaviors; Healthy eating, being active, monitoring (frequency), taking medication (adjustments or potentially different types and concentrations of insulins), problem solving, reducing risks and healthy coping.

### **Type 1 Diabetes Throughout The Lifecycle**

At each stage of life, the management of type 1 diabetes needs to be incorporated into the individual's daily routine. The diabetes care & education specialist must be an integral part of the team in coaching the individual and family members how to maximize blood glucose management. For an excellent reference for type 1 diabetes throughout the lifespan refer to the American Diabetes Association (ADA) paper titled type 1 diabetes through the lifespan: A position statement<sup>5</sup>.

### **Toddlers and Preschoolers**

An annual increase in the diagnosis of type 1 diabetes has been reported with the greatest increase in children < 5 years of age relative to all children diagnosed<sup>10,11</sup>.

Persons diagnosed in early childhood with history of significant hyper and hypoglycemia are at increased risk of problems later in life with working memory and attention<sup>9</sup>. Diabetes education in childhood and adolescence has a positive impact of glycemic control and psychosocial outcomes. The International Society for Pediatric and Adolescent Diabetes (ISPAD) Clinic Practice Consensus Guidelines in 2014 recommend that structured

education is available to all young people with diabetes<sup>12</sup>.

The adult must provide most, if not all of the diabetes care to the young child. The diabetes care & education specialist plays a critical role in providing education on prevention of hypoglycemia, avoiding extreme blood glucose fluctuations, continuing the support and education for the family, and helping the family to educate other caregivers (day care, baby sitters, and grandparents) in regard to diabetes management<sup>13</sup>.

### **Grade School and Middle School**

When children with diabetes start school the diabetes care & education specialist can be the primary contact between the school, parent/guardian and diabetes health care team. The diabetes care & education specialist can facilitate the writing of the medical management plan from the health care provider, making sure parents are aware of the 504 plan. The 504 Plan is a plan developed to ensure that a child who has a disability identified under the law and is attending an elementary or secondary educational institution receives accommodations that will ensure their academic success and access to the learning environment. The Diabetes care & education specialist can be an integral part of helping to educate the school nurse and staff to the needs of the individual child<sup>14</sup>.

School and extra-curricular sports can impact blood glucose with both hyper and hypoglycemia challenges. The diabetes care & education specialist can help coach the child and family on suggested insulin adjustments for activities, as well as contributing 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 exercise<sup>15</sup> indicating the need for further education in this regard.

In a recent study utilizing focus groups in children ages 11-14 and 15-16, young people felt exercise helped them manage their diabetes and had a positive impact. However, they reported a lack of knowledge and understanding among school staff and other young people in this regard<sup>16</sup>.

Most studies support diabetes camps as having a positive impact on diabetes acceptance and potential for improved management<sup>17</sup>. The diabetes care & education specialist 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<sup>18</sup>."

Working with persons with Type 1 diabetes and their families to help define appropriate diabetes tasks for the child as they continue through their developmental stages is an important role of the diabetes care & education specialist. Challenges can be anticipated and discussed to help maintain optimal management of diabetes and maximize outcomes<sup>19</sup>. An excellent review of the developmental stages and their impact on diabetes management is included in the paper by Chiang<sup>5</sup>.

Although some parents prefer simple language broken down into key points and hands on teaching<sup>20</sup>, other methods of delivering diabetes education have also successfully been incorporated including mobile technology<sup>21</sup>, tablet based apps<sup>22</sup> and online professional and peer support<sup>23</sup>.

### High School

As the child with Type 1 diabetes continues through the lifecycle, physiological as well as social changes will continue to create more challenges that can be reviewed for problem solving with the diabetes care & education specialist. More autonomy as the teen spends more time with friends and less time with the parent(s) or caregiver. Eating out may become common, and the teen should not only be aware of the carbohydrates in food, but be comfortable checking blood glucose levels and giving insulin at meal time with friends present. Diabetes care & education specialists play an important role in continued education, support and safety for the adolescent.

Traveling with sports, debate team or band can enrich and complicate the life of a teen with diabetes. Helping to educate the coach, music teachers, peers can also be part of the role of the diabetes care & education specialist. Encouraging teens to bring a close friend to an appointment may be beneficial to enhance support. Females

starting their menstrual cycle may find variations in blood glucose levels that require a cyclic change in insulin dosing. A second basal rate may be an option for those on insulin pumps which can be discussed with the diabetes care & education specialist.

Access to and experimentation with alcohol, drugs and sex become more common creating new challenges. The diabetes care & education specialist must be a part of the information system working with the student in regard to the risks of mixing alcohol and diabetes, and the options available to lessen the risks if they are chosen rather than to ignore the fact that alcohol may become a part of their lives. In a recent survey of substance abuse among American adolescents (not specific to diabetes) among individuals aged 12 and older, 52% had consumed alcohol and 24% had binged on alcohol. In addition, 6.5% had used marijuana<sup>23</sup>. In a recent self-reported assessment of 29,630 patients with type 1 diabetes (median age 17 years), 10.8% reported regular alcohol consumption<sup>24</sup>.

A recent study in Norway collecting data on adolescents aged 16-19 years suggests that type 1 diabetes did not increase the incidence of psychosocial problems as previously described. A refreshing addition to the literature on teens with type 1 diabetes<sup>25</sup>. It does not discount, however, the high incidence of challenges in teens in general as they progress to more independence<sup>26</sup>.

Education about the risks of child bearing, in particular risks to the infant when BG values are highly variable and/or consistently elevated, also needs to be addressed. Educating young women in regard to A1C goals prior to pregnancy must be part of the educational sessions during the teen years – while strongly encouraging excellent BG's overall and a family support system prior to conception. Teenage pregnancy is generally unplanned and teenagers with type 1 diabetes are a high-risk group for poor pregnancy outcomes<sup>27</sup>.

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 must be considered in discussions. These include interaction with peers, emotional well-being, grades, family interactions and interactions with others such as teens<sup>28</sup>.

As a teenager with diabetes, the transition to adulthood creates yet another opportunity for the diabetes care & education specialist to help coach the individual and family. Challenges include a new social structure, ordering insulin and other supplies in a timely manner, and the potential for changes in insurance plans. Will there be a new diabetes team as the child leaves the pediatric world and transitions to adulthood sometimes very abruptly? These conversations must be started early (at least 1 year prior to leaving home and perhaps as early as middle school) so the teen and family can start preparing for this challenging but exciting time in the life of a young person with diabetes. One of the biggest transitions throughout the lifecycle in relationship to diabetes management is when the adolescent leaves the world of pediatrics and moves to adult diabetes care<sup>29</sup>. A recent study by Egan et al<sup>30</sup> suggests that prior to leaving home, joint visits with the pediatric provider and new adult provider, along with a transition coordinator improved follow up and reduced distress.

### Transition to Adulthood

Although findings from recent studies on improving transition to adult care suggest that interventions may be effective to help maintain glycemic control, however, the most effective program types have yet to be elucidated.<sup>31</sup> Young adults with a history of lapses in care may benefit from a structured diabetes education transition program<sup>32</sup>. Other models of transition include transition navigators, attendance at a young adult bridge clinic or joint visits with pediatric and adults care providers<sup>33</sup>. Identifying current and future self-management concerns of individuals and their families can help facilitate the development of individual diabetes education interventions<sup>34</sup>. An ADA position statement titled *Diabetes care for emerging adults: recommendations for transition from pediatric to adult diabetes care systems*, provides recommendations for transition from pediatric to adult diabetes care systems which may assist the diabetes care & education specialist in determining a successful path for enhancing diabetes education during this phase of life<sup>35</sup>.

As the individual with diabetes enters adulthood, conversations need to continue in regard to coping with and taking care of diabetes in a more solo environment. Working through how to educate a

roommate to recognize signs and symptoms of hypoglycemia, reviewing access to supplies and health care appointments, are just some of the key conversation topics that are essential. A college student may benefit from the diabetes care & education specialist's support in obtaining support services at the university for taking tests when BG values are within goal range to maximize their testing outcomes. Some universities and colleges have a support group such as the College Diabetes Network that provides support throughout the college years.

### Adulthood

Young adulthood is a critical time for the development of lifelong management skills. Only 17% of young adults aged 18-25 and 30% aged 26-30 meet the American Diabetes Association glycemic goal of <7% A1C<sup>36</sup>. Inconsistent routines, changes in diet and exercise patterns, involvement in romantic relationships, and establishing a family are all challenges in general, but more so when also needing to manage type 1 diabetes<sup>37</sup>.

Pregnancy is an exciting time, but also one in which insulin requirements change dramatically. In addition, the importance of strict BG goals is stressed in order to maximize the health of the mother and baby<sup>37</sup>. An A1C goal of <6% prior to conception reduces the fetal risks of congenital malformation such as cardiac and neural tube defects<sup>37</sup>. Diabetes care & education specialists are an integral part of educating women about pre-conception blood glucose goals and understanding the importance of maintaining healthy eating prior to and during pregnancy. Frequent contact with the mother is important not only to review BG's, but to provide added support, particularly when a positive relationship has been established over the years of working with the individual<sup>37,38</sup>.

Complications from hyperglycemia can arise during adulthood. Problem solving with individuals not only on how to obtain optimal blood glucose management, but addressing coping with diagnosis of co-morbidities is a key role for diabetes care & education specialists. For example, if peripheral neuropathy is impacting manual dexterity, what glucometers and lancet devices are easiest to use? If the individual has been giving injections, is it time to revisit insulin pump therapy for easier management during dialysis vs non-dialysis days?

Is exercise more challenging and is there a way to facilitate consistent exercise? As years advance, risk of hypoglycemia unawareness rises and a discussion about utilizing a continuous glucose monitor should be considered. Has the PWD been referred for screenings related to vision, hearing, podiatry, cardiology, or nephrology as early intervention can help to reduce or prevent complications. As part of the diabetes team, a diabetes care & education specialist can work with the primary care physician to refer individuals with additional needs to physical therapy, psychology, and social workers.

### Advancing Years

Treatment regimens must often be modified to adapt to the changes often observed with aging<sup>39</sup>. Vision and hearing loss may challenge management. Decreased manual dexterity may make simple tasks such as retrieving glucose strips from the container difficult. Accurately drawing the appropriate doses into insulin syringes, pens and insulin pumps may become challenging. Reduced joint mobility may reduce the ability and desire to exercise, influencing not only overall health, but may significantly change insulin requirements. A person with diabetes may not only need to take care of their own diabetes but may also have the role of being a caretaker for their spouse or loved one. Interventions including diabetes-related education, organizing pharmacy delivery to a home, assisting with transportation, working with social services<sup>39</sup> and incorporating the diabetes education session along with their provider visits may help to reduce diabetes distress.

Nursing home transition can be a major challenge<sup>39</sup>, particularly for the person who historically has been very independent in managing his or her diabetes. Autonomy is often lost. The ability to count carbohydrates and remember to administer insulin may be an insurmountable task and blood glucose values become compromised. The diabetes care & education specialist can help with the transition and may be familiar with facilities that are better trained in diabetes management and care. Fixed dose insulin for meals may be necessary with correctional scales provided to the nursing home. Working with the primary care provider to develop a plan for insulin dosing in the nursing home and presenting the

plan in a thoughtful and effective way can be enhanced by the presence of the diabetes care & education specialist. In-services for the nursing home staff may help with the individual's transition and provide the staff with confidence about when and who to call if questions arise regarding caring for the new resident with type 1 diabetes

Over the lifespan, the AADE7™ concepts must be reinforced. The primary focus of appointments is often blood glucose management via insulin adjustments, so revisiting the basics can be neglected. When revisiting the AADE7™ self-care behaviors with people with diabetes, consider addressing the following questions:

### Healthy Eating

Are healthy foods still a part of the daily life of the individual with type 1 diabetes? Is carbohydrate counting still a tool for insulin dosing or should the system be altered based on stage of life (fixed dose insulin for residential living for example). Are the calories appropriate to reduce the risks of obesity and insulin resistance? Has the individual been screened for celiac disease? Is a referral to a dietitian appropriate?

### Being Active

Is exercise being incorporated into the daily life of the individual? Are appropriate insulin adjustments and recommended carbohydrate intakes for various physical activities being used? Are appropriate treatments for low blood glucose within easy access during activities? Is an exercise partner that is familiar with treating hypoglycemia part of the exercise routine? If not previously adopted, would a CGM be helpful if the individual is exercising in more extreme environments (running in the country, mountain climbing, exercising in extreme heat)?

### Monitoring

How frequently are blood glucose values checked, and is it sufficient? Are new glucose meters and lancets available that would enhance persistence with frequent BG checks? Would the addition of a continuous glucose monitor help to reduce glucose variability and hypoglycemia? How often is their blood sugar being managed vs their HgbA1c level managed? Have BG goals changed due to co-morbidities or hypoglycemia unawareness. Should

a continuous glucose monitor be incorporated into the diabetes management plan?

As with the recommendations of the Desk Reference, monitoring is more global and goes beyond that of checking blood glucose. What is the PWD's smoking status? Are they monitoring their blood pressure and cholesterol? Monitoring for microvascular and macrovascular complications; vision, hearing, periodontal exams?

### **Taking Medications**

Is medication being delivered in the correct way? Are sites of insulin injections and infusion sets being rotated? Is there evidence of lipohypertrophy at the injection sites? If insulin syringes are being used, would insulin pens be more precise and insulin injections more frequently administered due to convenience? Is an insulin pump a better option for more precise insulin delivery and improved quality of life? Is new sensor augmented insulin pumps a viable option that would enhance outcomes?

### **Problem Solving**

Working through barriers to taking insulin or checking BG may be magnified during adolescence. Insurance benefits may change over time, creating a challenge for the person with diabetes to be able to obtain adequate supplies. Complications from diabetes or other co-morbid conditions may create greater challenges for managing diabetes and need to be addressed.

### **Reducing Risks**

Are short and long-term potential complications discussed a periodically throughout the lifetime of the individual? Are concerns addressed including psychological and physical barriers to BG management? Are they up to date with immunizations; flu, pneumonia, hepatitis B, shingles? Are they able to seek preventative care for complications, such as dental and podiatry visits? Do you smoke? What type of birth control

are you using? Have low blood glucose values been a frequent problem? Would the individual benefit from a higher BG goal to avoid hypoglycemia? A continuous glucose monitor? An intense class in hypoglycemia awareness? Do blood glucose goals need to be changed based on the stage of life and/or comorbidities?

### **Healthy Coping**

Is the family overwhelmed with the diagnosis, and are other family members feeling left out when a sibling has type 1 diabetes? Has depression become an issue, reducing the desire to self-manage diabetes. Are complications overwhelming? What are you seeking to help cope with the ins and outs of care? Do you have a source of peer support? The role of the diabetes care & education specialist is to recognize and start the conversation regarding how individuals and families are coping with diabetes and suggest an appropriate referral.

### **Conclusion**

As diabetes care & education specialists working with individuals and families with type 1 diabetes, the challenges are never over and the need for education, understanding and support never extinguished. The biggest task is to keep informed about all aspects of care for the person with type 1 diabetes, including medication options for treating diabetes, the action of all insulins that may be incorporated into their care, meters and lancet devices and their appropriateness for the individual, and keeping up with new technology, pumps and sensors. Diabetes care & education specialists will continue providing education and advocating for access to their services for all. Type 1 diabetes is unique in its ongoing and relentless requirements for assessment and minute by minute decision making. Diabetes care & education specialists belong on the front lines of care for people with Type 1 diabetes and their caregivers and are well versed in the uniqueness of this complex and tedious disease.

**Further readings on specific topics related to type 1 diabetes management**

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