

Supporting the Student's Graduated Independence in Diabetes Care

Crystal C. Jackson

Anastasia Albanese-O'Neill, PhD, ARNP, CDE

The gradual progression to self-management is a critical milestone for children/adolescents with diabetes. This article provides recommendations to facilitate collaboration between the student's family, diabetes healthcare provider, and school nurse to support and implement a plan that enables the child/adolescent to acquire the skills and knowledge necessary to successfully transition to independent management of diabetes.

Keywords: diabetes; independence; self-management; transition; support

Diabetes is a chronic illness for which the preponderance of the daily care is provided by the person with diabetes, the family, or other caregiver (Chiang, Kirkman, Laffel, & Peters, 2014). Because effective diabetes care depends on self-management, each person with diabetes ultimately becomes responsible for all aspects of routine care, including blood glucose monitoring, insulin/medication administration, the recognition and prompt treatment of hypo- and hyperglycemia, and carbohydrate counting. Once more basic aspects of self-care are mastered, the

person with diabetes advances to an understanding of how to balance food and medication intake with physical activity and other variables that affect blood glucose levels. For children and adolescents, an appropriate level of responsibility for self-management must be considered and permitted for the many hours spent in the school setting (Jackson et al., 2015).

Diabetes Medical Management Plan

An individualized Diabetes Medical Management Plan (DMMP), also known as healthcare provider orders, is recommended for every student with diabetes (National Diabetes Education Program [NDEP], 2010). This plan should be developed by the student's treating diabetes healthcare provider in collaboration with the parent/guardian and student, as appropriate (AADE, 2016). The DMMP "contains the medical orders that are the basis for the student's health care and educational plans" (NDEP, 2010, p. 5) and should include an assessment of the student's level of independence in his or her self-management, describe any related need for supervision or assistance with diabetes care, and include provisions for the following:

- blood glucose monitoring by meter;
- continuous glucose monitoring (CGM) and specifications for confirming CGM readings by fingerstick before correcting hyperglycemia or treating hypoglycemia;
- insulin administration—dosing, drawing insulin in syringe, priming pen, choosing injection site, injecting/administering insulin;
- pump skills, including appropriate bolus administration, setting a temporary basal, changing batteries, disconnecting pump, inserting infusion set, preparing reservoir and tubing, and so on;
- keytone monitoring;
- recognition of hypoglycemia and hyperglycemia treatment of mild to moderate symptoms;
- carbohydrate counting and calculation; and
- data sharing technology from meters, CGM, and insulin pumps.

The school nurse, in collaboration with the student's diabetes healthcare provider and family, develops the Individualized Health Care Plan (IHP) to implement the student's DMMP in the school setting (NDEP, 2010). The IHP includes specification for the coordination and training of school personnel necessary to

provide the needed level of supervision and assistance. This ensures that the student with diabetes is well supported in the school setting. As children/adolescents mature, they should be encouraged and given the support to perform diabetes care on their own at home and at school (NDEP, 2010). Parents/guardians, healthcare providers, and school nurses should partner together to look for opportunities to teach skills, share diabetes knowledge, and provide support to empower students on the trajectory to self-management. The ultimate goal is independent self-management; normal growth, development, and learning; and full and safe participation in the school setting.

Age-Appropriate Self-Management

Each child/adolescent is different. There are few hard rules on what age a child/adolescent with diabetes will have the skills and ability to take responsibility for self-management. Self-management capability is variable and dependent on the individual student's physical ability, motor skills, maturity, knowledge, and willingness to do so. Although some children/adolescents are competent in self-management skills, parental/guardian involvement and guidance is critical throughout childhood and adolescence regardless of the student's self-management level (Silverstein et al., 2005). As such, parents/guardians, healthcare providers, and school personnel should be aware that prematurely transferring self-management to the child/adolescent can result in nonadherence, put the student at risk for diabetes burnout, and have an adverse impact on glycemic control (American Diabetes Association, 2016). Keeping in mind that every student's self-management capability is unique to that individual, an aged-based summary of when children/adolescents "typically" take responsibility for various aspects of self-management follows:

- **Preschooler:** Children in this age group lack the skills to perform self-care and are often unable to recognize hypoglycemia. These

children are completely dependent on preschool staff, and the staff members must have appropriate training so they are prepared to provide all diabetes care (Siminerio et al., 2014).

- **Elementary school-aged children:** Many early elementary school-aged children will be able to perform their own blood glucose monitoring but will need an adult to help administer insulin. Most children in this age group should be able to recognize the onset of hypoglycemia and alert an adult for intervention, although some suffer from hypoglycemic unawareness. Older elementary school-aged children may be able to administer their own insulin and possess other self-management skills. Again, an assessment of each student's self-management capability should be included in the DMMP.
- **Middle/high school-aged children/adolescents:** If noted in the DMMP, older children/adolescents should be able to provide all of their own diabetes care anywhere, anytime without assistance or supervision. However, these students will always need help when experiencing hypoglycemia or at other times when blood glucose levels are out of target range. While most adolescents are capable of performing self-management tasks, sometimes they may need help with decision making, especially during illness and when ketones are detected. Some students in this age range may require support and supervision, especially if they are newly diagnosed or lack adequate support at home. Including the student and parent/guardian in the development and annual update of the IHP keeps everyone on the same page and provides an opportunity for the school nurse to create a plan that provides for both independence in care and safety. For example, the middle school student and nurse might agree on a daily time to touch base (e.g., lunch time) as this facilitates the school nurse's ability to assess the student's self-management

skills and to get to know the student better. As the student gains self-confidence, this daily time to touch base might only be needed for the first couple of weeks of school. Older and more mature students may only need to seek out the school nurse in the event of a diabetes management challenge.

Legal Protections

Federal laws, including Section 504 of the Rehabilitation Act of 1973 and the Americans with Disabilities Act, prohibit discrimination against students with disabilities, including diabetes, in the school setting. Schools are required to provide students with diabetes with the access to the care they need to be safe at school and to fully participate in all school-related activities with as little disruption to the routine as possible. Many states have laws and/or guidance that require schools to permit capable students to self-manage their diabetes anywhere, anytime (American Diabetes Association, 2015b). The ultimate goal is to ensure that diabetes-related disruptions to the student's classroom learning and participation in extracurricular activities are minimized. These accommodations should be documented in the student's Section 504 plan or other written education plan (American Diabetes Association, 2015a; Jackson et al., 2015).

Timely and Gradual Transition Is Critical

Ultimately, all care and planning will shift from parental/guardian responsibility to the adolescent/emerging adult. New responsibilities extend beyond the ability of performing self-care to making one's own medical appointments, securing and financing health insurance, to self-advocacy to avoid discrimination in the workplace, school, and community. Planning for this eventual transition is an ongoing process that is necessary to ensure a seamless and smooth transition from childhood to adulthood (NDEP, 2016; Peters, Laffel, & American Diabetes Association

Transitions Working Group, 2011). Transitioning from teenage years to adulthood can be stressful for teens with diabetes and their families. School nurses can encourage students and their families to explore the National Diabetes Education Program's (niddk.nih.gov) Transitions: From Pediatric to Adult Health Care web resource, which contains a number of helpful resources, including a Transition Planning Checklist and a Pediatric to Adult Diabetes Care Clinical Summary form that is completed with the pediatric care team and provided to the adult care team. With proper support from the student's family and school, the transition to independence can be successfully achieved. ■

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Crystal C. Jackson
Director, Safe at School Initiative
American Diabetes Association
Alexandria, VA

Crystal C. Jackson is the director of the American Diabetes Association's Safe at School Initiative in Alexandria, Virginia, and a type 1 diabetes parent.

Anastasia Albanese-O'Neill,
PhD, ARNP, CDE
Assistant Professor
University of Florida, College of Nursing
Gainesville, FL

Anastasia Albanese-O'Neill, PhD, ARNP, CDE is assistant professor, University of Florida, College of Nursing, Gainesville, Florida, the American Diabetes Association's Safe at School Working Group Co-Chair, and a type 1 diabetes parent.