

## In Brief

To develop individualized goals of therapy for youth with diabetes, an awareness is needed that diabetes both affects and is affected by normal child and adolescent growth and development, as well as by family functioning and dynamics. However, it takes more than the health care team and family members to succeed at managing a child's or adolescent's diabetes. This article offers ideas to empower the families of young people with diabetes through multidisciplinary community support from schools, camps, health care teams, and research-driven programs.

# It Takes a Village: Helping Families Live With Diabetes

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The results of the Diabetes Control and Complications Trial (DCCT)<sup>1-3</sup> and the Epidemiology of Diabetes Interventions and Complications (EDIC) trial<sup>4,5</sup> outline the importance of optimal glycemic control for individuals living with diabetes. The sustained risk reduction in microvascular complications reported in the EDIC trial supports intensive treatment of diabetes.<sup>5</sup> Continued research has shown that the earlier the initiation of intensive therapy, the greater the risk reduction for future complications.<sup>6,7</sup>

However, intensive management resulting in optimal glycemic control remains challenging in adolescent and pediatric populations. Two multicenter studies of pediatric populations reported that only 34 and 33% of patients, respectively, achieved a hemoglobin A1c (A1C) < 8.0%.<sup>8-10</sup> Also, hypoglycemia still remains a major limiting factor in intensive treatment, especially in young children.

To obtain optimal glycemic control, individuals with diabetes must pay attention to multiple diabetes management tasks. These tasks include blood glucose monitoring, tracking blood glucose fluctuations and patterns, making insulin and/or medication adjustments, following a healthy meal plan, incorporating exercise/activity into the daily schedule, and problem-solving when the management plan does not work as intended.<sup>11-13</sup>

In addition to the medical aspects of diabetes, psychosocial factors play a role in the family management of diabetes. The report of the Psychosocial Therapies Working Group<sup>14</sup> noted the considerable demands that diabetes places on youth and their families, which in turn make managing diabetes difficult in this population. This report showed that regimen adherence, glycemic control, and family dynamics all may be negatively affected by

adverse psychosocial functioning of the child and family.

Family involvement is necessary to adhere to the rigorous demands of these diabetes management tasks.<sup>15,16</sup> However, even with family involvement, there are several obstacles to obtaining optimal glycemic control during the childhood and adolescent years. Optimal glycemic control is challenged by both physical factors,<sup>17-21</sup> such as growth and development, and psychosocial factors, including diabetes-specific conflict within the family, diabetes-related burnout, and negotiation and maintenance of positive family involvement.<sup>22-25</sup> Therefore, a comprehensive support system needs to be in place for children and adolescents living with diabetes and their families.

With the prevalence of both type 1 and type 2 diabetes in children and adolescents increasing at an alarming rate, we need to search for strategies to support these children and adolescents and their families.<sup>26-35</sup> These supports must include children, their families, their health care teams, school personnel, and the community—all creating the “village” that will help families live effectively with diabetes.

### Diabetes and School

Families with children or adolescents with diabetes often need help with issues that arise at school or day care centers. Children and adolescents spend most of their waking hours at school or day care, so schools and center personnel must become part of the “village” in caring for students with diabetes. In order to provide a safe environment, school and center personnel need to understand current treatment plans for diabetes management and the issues that affect school-age children with diabetes. The family, health care team, and school or center staff must work together to ensure a safe learning environment for young people with diabetes.

The American Diabetes Association (ADA) position statement, “Care of Children With Diabetes in the School and Day Care Setting,”<sup>36</sup> is available online at [http://care.diabetesjournals.org/cgi/content/full/26/suppl\\_1/s131](http://care.diabetesjournals.org/cgi/content/full/26/suppl_1/s131). It summarizes the laws protecting children with diabetes, general diabetes care guidelines, and responsibilities and expectations of all involved parties. The key recommendation is that students with diabetes

need a written plan. The development of a written individualized Diabetes Health Care Plan, or a “504 plan,” which meets the requirements of section 504 of the Rehabilitation Act of 1973, is necessary for all students with diabetes to ensure that they will have a safe environment and will be included in all school or center activities.<sup>36</sup> Information on school issues and diabetes and the development of such a plan can be found at <http://www.diabetes.org/community/advocacy/504plan.jsp>

The National Diabetes Education Program, in recognition of the unique challenges that diabetes poses to children and adolescents, has recently published a guide titled “Helping the Student with Diabetes Succeed: A Guide for School Personnel.” Available online at <http://ndep.nih.gov/materials/pubs/schoolguide.pdf>, this guide is a resource for school personnel to ensure a safe learning environment and equal access to educational opportunities for all students with diabetes.

Through the years, families of children with diabetes have faced numerous school- and day care-related problems. At one time, students with diabetes were not allowed to go on field trips without an accompanying parent, to carry a source of fast-acting carbohydrate in case of hypoglycemia, to eat in the classroom, or to leave the room to go to the bathroom to check their blood glucose or take insulin. Further, hypoglycemic students were sent alone to the school nurse’s office. Based on feedback from a 1993 needs assessment questionnaire completed by more than 350 school nurses, students with diabetes, and the students’ parents in the Commonwealth of Massachusetts, the ADA and the Joslin Diabetes Center established an annual diabetes education program for school nurses.

The program curriculum changes each year to reflect the changing needs of both students with diabetes and school personnel. In recent years, the focus has expanded to include information about insulin pump therapy, diabetes health care plans and 504 forms, the ADA’s position statement on the management of diabetes in school,<sup>36</sup> and guidelines regarding type 2 diabetes in children and adolescents.<sup>31</sup> Families have responded positively to this program. With education, school nurses and other school personnel have become more knowledgeable about diabetes and more

supportive of students with diabetes and their families.

We all have the same goal: healthy, happy students with diabetes. Through accommodation and support of diabetes self-management tasks at school, students with diabetes will be afforded the ability to safely succeed in their diabetes management, academics, and development of evolving social skills. Parents and diabetes professionals need to ensure that school staff members become knowledgeable and have the necessary tools to feel comfortable and be able to help students with diabetes-related tasks.

### Diabetes Camps and Family Programs

In 1925, just four short years after the discovery of insulin, the first diabetes camp opened. Early diabetes camps offered a camp experience to children who might not otherwise have had the opportunity to attend camp. Today, approximately 20,000 campers with diabetes each year are afforded a diabetes camp experience that has fun as its primary goal.<sup>37</sup>

Campers benefit from meeting other children and staff with diabetes, sharing a commonality of living with diabetes, learning about new ways to manage diabetes, and being exposed to new tools and therapies. Health care professionals gain diabetes research and clinical experience by participating in camps. Campers’ parents receive a welcome vacation from the daily tasks of diabetes management.

For children and adolescents with diabetes, 50–51 weeks a year are spent in the “real world,” where diabetes self-management tasks are not the norm among their peers. For one or two weeks a year, these youths have the rare opportunity of being in the majority, being the norm, and sharing experiences with others who live with diabetes.

Family diabetes camps have become increasingly popular. Recognizing that diabetes affects the entire family, family camps offer an opportunity to share a fun and supportive environment with other families living with diabetes. Family camps come in all sizes, seasons, and lengths of time. Some family camps are weekend programs, and others provide a week-long summer experience. Programs often include diabetes education workshops and discussion groups, activities for children or teens, family games and

activities, and shared cooking and clean up duties.

Joslin retreat-type support programs, such as Youth Leadership, Diabetes Youth Weekend Retreats, and Life After High School, offer young people additional opportunities to gain support and knowledge. A key example is the Life After High School program developed by youths and professionals reacting to both parents' and adolescents' concerns about "leaving the nest" for the first time, either for college or for a more independent lifestyle in a new job or a new living situation. Most problem-solving and preparation for one of life's most dramatic lifestyle changes is guided by those who are still going through the process—the young adults living with diabetes who are heading out on their own. Some parents say that they wish such a program were available for their teens who do not have diabetes.

A list of diabetes camping resources can be found in Table 1. Whether children or adolescents go to a residential, day, or family camp, or to a weekend or week-long support program, all family members benefit from meeting both other families or young people living with diabetes and diabetes professionals. Ensuing support grows into the "village."

### Health Care Programs

Ongoing clinical research is necessary to create a support system for children and families living with diabetes. However, research projects should be driven by our clinical encounters with children with diabetes and their families. The children and their families are continually teaching us how to maintain and strengthen the "village." The Joslin has been offering several clinical programs to the pediatric population and their families. The following programs can be used as a model for other pediatric diabetes programs.

### Joslin's Young Children's and School Age programs

These programs are comprehensive outpatient programs offered monthly. They serve children ages 0–8 and 8–12, respectively.

The Young Children's Program was developed in response to the unique needs of young children with diabetes and their families. The program strives to offer parents and young children with diabetes an integrated medical and psychosocial support system. The program has four tiers:

- Individual medical appointments with a pediatric endocrinologist or diabetes nurse educator
- A parent group facilitated by members of the medical and psychosocial teams
- A children's group facilitated by an early childhood educator/certified diabetes educator (CDE) and a child life specialist
- Other medical appointments with specialists in nutrition, mental health, exercise physiology, and ophthalmology

The initial parental needs assessment for the Young Children's Program identified the following issues of concern: collision between diabetes treatment and normal childhood behavior, differentiating symptoms of hypoglycemia from normal behavior and mood swings, and the impact of diabetes on family relationships.<sup>11,38</sup> Fear of hypoglycemia surfaced as the primary parental concern.

In a program evaluation, it was found that those classified as "attenders" (attendance in the program three or more times during a 33-month interval) were seven times more likely to receive regular diabetes medical or nursing care during the 3-year follow-up period.<sup>38</sup> Attendance in the comprehensive program of integrated medical and psychosocial care

by families with a young child with type 1 diabetes predicted that the child would receive follow-up diabetes care in later childhood and have a decreased risk of poor glycemic control (A1C > 9.9%) as compared to those in the "nonattender" group.

In recognition of the clinical benefits of this integrated model, the second developmental-based program, the School Age Program, which started as the children progressed to the next age group, was a natural outgrowth of the Young Children's program.

### Parents of Teens support group

This is a psycho-educational support group that meets six times a year in the evenings. Parents are welcome to attend as many group meetings as they would like. Each meeting is moderated by a mental health clinician (psychologist or social worker) and a pediatric endocrinologist or CDE. The group covers topics such as coping with the stress of diabetes, parental support of diabetes management, fear of diabetes complications, eating and weight issues, and research and technology updates. Incorporating teens into support programs requires sensitivity to the need for teens to be active versus sitting and talking, as in our Parents of Teens model.

### Celiac and Diabetes support group

Celiac disease is an autoimmune disorder that has an increased incidence in the type 1 diabetes population.<sup>39–41</sup> Individuals with celiac disease must follow a gluten-free diet, which excludes all foods made wheat, rye, and barley. This diet must be strictly followed to avoid further damage to the intestines.<sup>42</sup> Therefore, children living with diabetes and celiac disease must pay tremendous attention to their meal plan. In some cases, the entire family follows a gluten-free diet.

Because of these increased demands, the Joslin has initiated a support program for families coping with diabetes and celiac disease. Our Celiac and Diabetes support group is facilitated by members of the health care team, including a registered dietitian with expertise in both diabetes and gastrointestinal nutrition. The focus of the support group is on healthy nutrition, recipes and cooking tips, school and food issues, psychosocial support, and eating out.

This group is available for individuals with celiac disease and their families. A separate play group is offered

**Table 1. Diabetes Camp Resources**

- The **Diabetes Camping Association (DCA)** was established in 1997 to promote communication, provide education, share resources, and serve as a worldwide voice to advance diabetes camping programs. More information, including a directory of diabetes camping programs, can be obtained from the DCA Web site: (<http://www.diabetescamps.org/what.html>)
- The **ADA** is an excellent source of information on diabetes camping programs. More information is available at: [http://www.diabetes.org/main/community/outreach/youth/camp2.jsp?WTLPromo=SEARCH\\_camp](http://www.diabetes.org/main/community/outreach/youth/camp2.jsp?WTLPromo=SEARCH_camp)
- The **Children with Diabetes** Web site (<http://www.childrenwithdiabetes.com/camps/>) has information on diabetes camping programs and is an excellent Internet-based reference.

for children who do not wish to participate in the support group.

### *Insulin pump program*

The prevalence of insulin pump therapy, or continuous subcutaneous insulin infusion (CSII), has grown exponentially over the past few years, especially in the pediatric population. To ensure successful pump therapy initiation, Joslin has established an insulin pump protocol.

The evaluation process is completed by an endocrinologist, a nurse educator, a registered dietitian, and a mental health clinician (psychologist or social worker). The main goals of the pump evaluation are to provide information about CSII, review the challenges and opportunities of CSII, perform an assessment of the family's readiness for CSII implementation, and discuss the most appropriate timing for CSII initiation.

The psychosocial component is critical to the pump assessment process. The psychosocial assessment evaluates realistic expectations to help ensure appropriate implementation of and follow-up for CSII. The psychosocial component also focuses on the importance of family involvement before and after pump initiation. Butler et al.<sup>16</sup> found that greater family involvement after pump initiation was associated with increased frequency of blood glucose monitoring and improved glycemic control.

After the evaluation process is completed, the CSII initiation period takes 3 weeks. The first week is meant as an adjustment period, during patients wear the pump with a saline infusion. During the second week, insulin infusion begins. A follow-up appointment is made for the third week to continue making insulin adjustments.

### *Care ambassador model*

Research has shown that assigning a "care ambassador" to families living with diabetes can reduce the risk of acute diabetes-related complications for children.<sup>38,43,44</sup> A care ambassador is a college graduate who is trained to help families navigate the health care system and ensure that families are coming to their regularly scheduled appointments as prescribed by their health care team. The care ambassador meets with families at each health care visit and directs families between visits to the resources that they need. Laffel et al.<sup>43</sup> found that patients with a care ambassador came

to significantly more clinic visits, experienced significantly fewer episodes of severe hypoglycemia, and had significantly fewer emergency room visits and hospitalizations than did those without a care ambassador.

Joslin has incorporated the care ambassador model into a new program called Jump Start. This multidisciplinary approach provides newly diagnosed youngsters and families with the opportunity to get off to a good start with their diabetes care. Research shows that children and adolescents with diabetes who develop good diabetes management skills early in their disease are more likely to enjoy a lifetime of better health. The goal of Jump Start is to help families fit diabetes into their lives, rather than molding their lives around diabetes, through medical care, education, and support of the family.

The care ambassador model is one of the key features of Jump Start. The care ambassador meets with families at each visit and proactively telephones them monthly. If a family member raises a medical or psychosocial concern during a phone call, the care ambassador makes the appropriate referral to a member of the child's or adolescent's health care team.

### *Internet resources*

The role of technology is rapidly

expanding. There are many Internet resources for families living with diabetes. Although it is beyond the scope of this article to provide a comprehensive list of all online diabetes resources, Table 2 offers some key Web sites.

The Pediatric and Adolescent Unit at the Joslin has recently set up its own Internet resource ([www.joslin.org/managing/pedi\\_discussion.shtml](http://www.joslin.org/managing/pedi_discussion.shtml)) for Joslin patients and other families living with diabetes. The pediatric discussion boards on the Joslin Web site provide medical information and psychosocial support for all teens (13 years of age and older) with diabetes and for parents. The pediatric discussion boards are based on the Joslin discussion boards developed for adults living with diabetes and their families. Zrebiec and Jacobson<sup>45</sup> found that the discussion boards are a widely used resource for adult individuals with diabetes and their families to gather information about diabetes and to obtain emotional support.

The pediatric discussion boards are designed to offer teens and parents a safe place to ask questions that they may be too embarrassed to ask of their own health care team or that they may not have time to ask during a regular clinic or office visit. The boards are also designed to reach a larger audience than the Joslin patient

**Table 2. Web Sites for Diabetes Information**

Web site address	Site of:
<a href="http://www.childrenwithdiabetes.com">www.childrenwithdiabetes.com</a>	Children With Diabetes
<a href="http://www.joslin.org">www.joslin.org</a>	Joslin Diabetes Center
<a href="http://www.diabetes.org">www.diabetes.org</a>	American Diabetes Association
<a href="http://www.jdrf.org">www.jdrf.org</a>	Juvenile Diabetes Research Foundation
<a href="http://www.niddk.nih.org">www.niddk.nih.org</a>	National Institute of Diabetes and Digestive and Kidney Diseases
<a href="http://www.animascorp.com">www.animascorp.com</a>	Animas (insulin pump company)
<a href="http://www.disetronic.com">www.disetronic.com</a>	Disetronic (insulin pump company)
<a href="http://www.minimed.com">www.minimed.com</a>	MiniMed (insulin pump company)
<a href="http://www.aventispharma-us.com">www.aventispharma-us.com</a>	Aventis (insulin company)
<a href="http://www.lilly.com">www.lilly.com</a>	Eli Lilly (insulin company)
<a href="http://www.novonordisk.com">www.novonordisk.com</a>	Novo Nordisk (insulin company)
<a href="http://www.medisense.com">www.medisense.com</a>	Abbott MediSense (meter company)
<a href="http://www.amiramed.com">www.amiramed.com</a>	Amira (meter company)
<a href="http://www.ascensia.com/us/index.html">www.ascensia.com/us/index.html</a>	Bayer (meter company)
<a href="http://www.lifescan.com">www.lifescan.com</a>	LifeScan (meter company)
<a href="http://www.diabetes.roche.com">www.diabetes.roche.com</a>	Roche (meter company)
<a href="http://www.therasense.com">www.therasense.com</a>	TheraSense (meter company)
<a href="http://www.mendosa.com/mag.htm">www.mendosa.com/mag.htm</a>	Online Diabetes Resources (columnist Rick Mendosa)
<a href="http://www.diabetesmonitor.com">www.diabetesmonitor.com</a>	The Diabetes Monitor
<a href="http://www.afdr.ab.ca/main.htm">www.afdr.ab.ca/main.htm</a>	Alberta Foundation for Diabetes Research
<a href="http://www.nal.usda.gov/fnic/foodcomp/index.html">www.nal.usda.gov/fnic/foodcomp/index.html</a>	US Dept. of Agriculture Nutrient Database



population. However, the discussion boards are not meant to be a substitute for medical or mental health advice, diagnosis, or treatment, and individuals should contact their health care team immediately in any emergency situation or urgent problem.

Clinicians from the Joslin Pediatric and Adolescent Unit moderate the free discussion boards, to which postings can be made anonymously. This “virtual village” supports children and adolescents with diabetes and their families.

## Conclusion

Diabetes care professionals must continue in the quest to help families by assessing, developing, and maintaining methods of support for families of children and adolescents living with diabetes. As in life, there is no one-size-fits-all approach to diabetes management, and there is no one program or therapy to fit every patient's or family's needs. Therefore, multiple forms of support must be available.

To support children and families living with diabetes, the whole “village,” including grandparents, aunts, and uncles; teachers; health care providers; bus drivers; little league and gymnastics coaches; playmates; and classmates must lend their support. By combining improved therapies and technologies with psychosocial support for families living with diabetes, many obstacles to optimal glycemic control can be made more manageable. This should be the goal of the entire “village.”

## Acknowledgments

The authors would like to acknowledge the support and guidance of Lori Laffel, MD, MPH, and Barbara Anderson, PhD; the contributions of the Pediatric and Adolescent Unit at the Joslin Clinic; and the research expertise of Lisa Volkening. The authors' time for this project was supported by a grant (DK-46887) from the National Institute of Diabetes and Digestive and Kidney Diseases and grants from the Charles H. Hood Foundation and the Katherine Adler Astrove Youth Education Fund.

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*Note of disclosure: The authors are employed by the Joslin Diabetes Center, whose programs are discussed at length in this article.*