

# School Advisory Toolkit for Families

This guide offers collaborative methods for educators and parents of children with diabetes to ensure that every child enjoys the best possible school experience.



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## About the Author and the Goal of this Guide

Harold Wolff is the parent of a son, Michael, who was diagnosed with type 1 diabetes when he was 3½ years old; today, Michael is an active and healthy adult. Harold taught students in grades four through twelve for the first half of his educational career. For the last sixteen years he was a principal of a middle school (grades six through eight) with 1,500 students.

These experiences give Wolff a unique perspective on the issues of school and child/parent relationships as it relates to diabetes management. Although there is currently information available on how to deal with school personnel, this Guide provides a balanced approach to how parents of a child with diabetes and the school can work together to provide a safe, caring, and positive learning environment for the child/student. The goal is for both the parent's and school's points of view to be communicated, heard, and understood and to encourage a cooperative effort to provide the very best school experience for the child with diabetes.

## Manual Overview

As a parent you know that your child spends most of his day in the school setting; in the care of teachers, nurses, and other school personnel. Most parents are comfortable with this environment, as most students' healthcare needs consist of band-aids for the occasional scrape, oral medications, and the occasional ice pack. As the parent of a child with diabetes, however, you know that the day-to-day disease management is intensive and that the school must play an important role in this care.

The Juvenile Diabetes Research Foundation (JDRF) understands the importance of your child's care in the school setting. After receiving several requests from parents for help in their children's schools, JDRF conducted an extensive research report. This report led us to develop this toolkit in conjunction with Harold Wolff and with contributions from Tamara Burns, JDRF Triangle Chapter Volunteer and mother to a child with type 1 diabetes. We hope this guide will equip you for working with your child's school to ensure that proper diabetes care is provided.

For further information or support with diabetes in the school setting please reach out to your local chapter. You can find the chapter closest to you by going to [www.jdrf.org](http://www.jdrf.org) and selecting the Locations tab near the top of the homepage.

## Disclaimer

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Under no circumstances will JDRF be liable for any direct, indirect, special or other consequential damages arising out of any use of this manual.

# Communicating with Schools

- A message to school staff
- A message to parents
- Scenario No. 1 – The cooperative and respectful way
- Scenario No. 2 – The adversarial way
- How to handle difficult situations that may arise



## Communicating with Schools

### A Message to School Staff – Realistic Expectations

Parents have of School Personnel

(parents should read this, too)

You have a child with diabetes enrolled in your school and you want him/her to have the very best school experience possible. You have every reason to expect that the child's parents will work with you in a friendly and cooperative manner and provide as much support and assistance as they are able. You also have every reason to expect that the child's parents will appreciate your efforts to provide a safe and caring learning environment and understand the overwhelming responsibilities that teachers and the school hold. If you make a good faith effort to provide for the child with diabetes' needs, the parents should understand if, occasionally, you ask for their time, help, and support.

Working with parents in a cooperative, friendly, and mutually respectful manner requires that you understand the parent point of view. Parents obviously need to take care of their children, BUT the parents can't do it all. Parents should do their part in providing information, snacks, supplies, emergency directions, etc., but the school needs to understand that even the best and most caring parents can't anticipate all of the school needs of their children. Parents often have jobs, family responsibilities, and stresses that can sometimes be overwhelming.

Now, add to the mix a child with diabetes, and suddenly parents are confronted with the highly emotional task of raising a child with a serious and potentially life-threatening chronic disease. Feelings of guilt, anxiety, and fear are only the tip of the iceberg for these parents. Sleepless nights become a regular occurrence; parents sometimes stay up all night worrying and checking blood sugars to make sure their child doesn't have a serious hypoglycemic reaction. They also must do the following:

- Learn to count carbohydrates and sometimes change their family's diet
- Learn about long and short acting insulin
- Learn to give shots or use an insulin pump
- Learn to check their child's blood sugar and interpret the results
- Understand how exercise, illness, and stress affect blood sugars
- Mediate rivalries and feelings of jealousy between their children
- Build the self-esteem and understand the range of emotions of a child who suddenly is very different from others
- Combat ignorance and prejudice on a daily basis concerning their child's diabetes

...all this while trying to remain the calm, dependable mother or father they have always been.

**School Personnel** – the parents would like you to know that they care about their child and want to do what's best for him, but they can't be everywhere all the time and can't do it all. They need your cooperation, assistance, and understanding of what they are dealing with on a daily basis.

## A Message to Parents – Realistic Expectations You Have of School Personnel

### (school staff should read this, too)

Of course, you want the very best school experience possible for your child. You have every reason to expect that your child will be welcomed at school and that school personnel will happily provide a caring and safe place in which your child learns and grows to the best of his/her ability. It is true that your child's school has legal obligations that mandate certain kinds of services for your child, and if the school does not partner with you in an appropriate manner, pursuing legal means (e.g., a 504 Plan) may be necessary. But please be assured that your child will thrive better if he/she observes you and the school working in a cooperative, friendly, and mutually respectful manner. This requires that you understand the school's point of view in addition to your own.

The school has legal and moral obligations to your child, but the school can't do it all. The school should make a good faith effort to provide for your child with type 1 diabetes, but keep in mind that they are only human. Even the best and most caring teachers and staff can't magically make a nurse appear if one is not available. School personnel are incredibly busy with endless responsibilities. What goes on in a school and in a teacher's classroom on a daily basis is mind-boggling.

A teacher is not only responsible for the medical needs of your child but of other children as well. A teacher is responsible for creating a positive learning environment, planning lessons, delivering effective and interesting instruction, taking attendance, planning field trips, participating in other school activities (coaching, sponsoring clubs, supervising evening activities, etc.), continuing his/her own education, grading papers, communicating with parents and special education teachers, attending faculty meetings, filling out paperwork, meeting State and Federal mandates, and dealing with the social, emotional, physical and intellectual needs of their students.

#### **While instructing, teachers are constantly:**

- observing student reactions and gauging understanding of what is being taught
- monitoring and dealing with student behavior
- adjusting instruction for students' individual needs and styles of learning
- responding to instructions or interruptions from the office

- ensuring the safety of students in the classroom (e.g., science labs)
- making sure that band and orchestra students get to their lessons on time

...and all this while leaving no child behind. The nurse, office staff, and administrators are also working hard at their own jobs and are just as busy as the teachers.

**Parents** – school personnel would like you to know that they care – about your child and want to do what's best for her, but they can't be everywhere all the time and can't do it all. They need your cooperation and understanding of how much they do.

## The Right Approach -The Cooperative and Respectful Way

It's 4 to 5 weeks before school starts. A parent calls the school and communicates to the secretary that her daughter has just been diagnosed with type 1 diabetes. The parent requests a meeting with the Principal (and if possible, the nurse and teacher) when it is convenient. The parent acknowledges that this is a busy time of year for school staff, but explains that it is important that they meet before the start of the school year to work together to come up with procedures to ensure the safety of her daughter.

At the scheduled meeting: The parent acknowledges that the school is a wonderful place, that everyone is busy, and that she will be adding responsibilities. She comments on how much she appreciates what all of the people in the room will be doing for her daughter, as their time is valuable. She expresses her hope that together, she and the school staff will be able to create a plan to provide the best and safest learning environment possible for everyone.

The parent also communicates that she has a full-time job but knows that she, on occasion, will have to help out (e.g., chaperone a field trip or perhaps come to the school to give blood tests and/or shots). The parent provides information to help the school gain an understanding of type 1 diabetes and how to care for a child with diabetes at school. The parent provides information about when the daughter will need lunch, physical education, and snacks. If a physical education class or lunch for the daughter's grade level is not available during these times, the parent understands and asks if they could work together to provide the best schedule that is possible.

The principal, teacher, nurse, and parent all follow through on their agreed upon roles – and not only does the daughter learn and grow in a most positive school environment, she also learns how to work cooperatively and respectfully with others.

## The Wrong Approach – The Adversarial Way

It's registration time at the beginning of the school year. The school is crawling with students and parents and the school administrators, teachers, and secretaries are quite busy. A parent brings her daughter with diabetes into the office, states that her daughter is diabetic, and demands an immediate meeting with the principal, nurse, and teacher.

Somehow, the principal, nurse, and teacher manage to put aside their other pressing duties on this busy Registration Day and meet with the parent and child. The parent is emotional and demands that the school take care of her daughter – letting the daughter come to the nurse's office whenever she wishes and eat snacks whenever she wishes. The parent also tells the school that she “knows her rights” and that the school must provide a full-time nurse to take care of her daughter and that if the nurse is out, the school should hire a substitute nurse. She also says flat-out that she is a busy mother who works and won't be available to go on any field trips or help out in any way.

The principal, nurse, and teacher have an immediate reaction. They are already feeling overwhelmed with all that they have to do – to hear that this student will need to be closely monitored and that low blood sugar is a life-threatening event is dire and frightening news. The teacher feels stress and even fear and wonders if she is capable of handling an emergency of this nature. How will she remember all that she's supposed to for this child?

The “fight or flight” response kicks in and the school staff becomes defensive. The principal tells the parent that her child needs to be home-schooled and that her child can't attend this school unless she is totally independent and can take care of herself. Or, the nurse says that she is too busy; the parent will have to come in four times per day to test the child and give her any necessary insulin shots.

The parent again threatens that she knows her rights and she'll get a lawyer to force the school to cooperate with a 504 plan. A long-term adversarial relationship is begun.

## How to Handle the Difficult Situations That May Arise

Unexpected situations may arise during your child's school years. Many of these situations may take you by surprise. Teachers, administration, rules, or other things may change suddenly or over time. These changes may cause you to jump to conclusions, but try not to react before you have all of the information. Some key things to remember when facing an unexpected challenge are:

- Remain calm
- Take a deep breath
- Gather all the facts
- Offer another way to handle things (seek win-win solutions)
- Seek support (e.g., local JDRF Chapter)

# Diabetes Basics

- What is type 1 diabetes?
- What is type 2 diabetes?
- Type 1 diabetes facts
- Diabetes control & management
- High blood sugar – Definition, Symptoms
- What to do about high blood sugar
- Low blood sugar – Definition, Symptoms
- What to do about low blood sugar levels
- What is glucagon
- Blood glucose testing
- Insulin delivery methods
- Effects of exercise, illness, stress, and growth on blood sugar levels



## What is Type 1 Diabetes?

### (a simplified explanation)

Type 1 diabetes often develops in children, adolescents, and young adults, so it's sometimes called "juvenile diabetes." Diabetes is not contagious. You cannot catch diabetes from someone who has it. Researchers continue to study how and why diabetes occurs in certain children and families. Although diabetes cannot be cured, it can be controlled.

### About Blood Sugar Levels

A healthy pancreas produces insulin, a hormone that the body uses to change glucose in the blood into energy. Glucose in the blood comes from the food and drink a person consumes. A person with type 1 diabetes doesn't produce any insulin. Without insulin, the glucose builds up in the blood, causing high blood sugar, or hyperglycemia. Blood sugar levels that are too high and untreated for long periods of time can lead to ketoacidosis, a very serious condition. Very high blood sugars for an extended period of time can eventually lead to coma and death.

In people without diabetes, the pancreas maintains a "perfect balance" between food intake and insulin. When a person eats, the pancreas puts out the exact amount of insulin needed to turn the glucose into energy. If the person eats a lot, the pancreas puts out a lot of insulin. If the person eats just a little, the pancreas puts out just a little insulin.

### Insulin Needs

Since people with type 1 diabetes can't produce their own insulin, they must put insulin into the blood stream through injections or an insulin pump. If people with type 1 diabetes inject too much insulin (or eat too little) they may have a hypoglycemic reaction. Hypoglycemia (low blood sugar) is the most common problem in children with diabetes. It can be very serious and requires immediate action.

People with type 1 diabetes often struggle to determine how much insulin to inject. In a simple and perfect world, this question would have an easy answer (e.g. always eat a certain amount of food and inject a certain amount of insulin). However, in reality there is no way to know how much insulin to inject with 100% accuracy. Many factors influence how much insulin people need to get to the desired "perfect balance" of glucose and insulin. These factors include foods with different absorption rates as well as the effects of stress, illness, and

exercise. Also, as children grow, their insulin needs change. Since determining how much insulin the body needs to "balance" the amount of glucose is really a best guess, sometimes the guess is inaccurate and high or low blood sugar results.

### Risk of Complications

High blood sugar levels over a number of years can cause serious damage to the body's organ systems. This damage may cause complications affecting the heart, nerves, kidneys, eyes, and other parts of the body. A number of studies, however, have proven that careful monitoring and control of blood sugar levels greatly reduces the threat of these complications. Researchers are also making progress at developing new treatments and technologies to help people with diabetes stay healthy. It's important to remember that people with diabetes can lead active and productive lives, just like anyone else.

**Diabetes is not contagious.** You cannot catch diabetes from someone who has it. Researchers continue to study how and why diabetes occurs in certain children and families. Although diabetes cannot be cured, it can be controlled.

## What is Type 2 Diabetes?

### (a simplified explanation)

People with type 2 diabetes produce some of their own insulin, but the insulin is either insufficient in quantity or ineffective in its ability to stabilize blood sugar levels. Ineffective action of insulin is called insulin "resistance". Many factors can cause insulin resistance; a major cause is known to be obesity. People with type 2 diabetes can sometimes manage their disease with diet and exercise. Some individuals with type 2 can take an oral medication that improves the effectiveness of the insulin, while other type 2's need to inject additional insulin.

Most school age children with diabetes have type 1. Unfortunately, however, as more and more of our nation's children become overweight and sedentary, type 2 diabetes is occurring more frequently in school age children.

## Type 1 Diabetes Facts

### Affects Young Children

Type 1 diabetes strikes children suddenly, makes them dependent on injected or pumped insulin for life, and carries the constant threat of devastating complications. While diagnosis most often occurs in childhood and adolescence, it can and does strike adults as well. Type 1 diabetes is an autoimmune disease in which the body's immune system attacks and destroys the insulin-producing cells of the pancreas. While the causes of this process are not yet entirely understood, scientists believe that both genetic factors and environmental triggers are involved.

### Needs Constant Attention

To stay alive, people with type 1 diabetes must take multiple insulin injections daily or continually infuse insulin through a pump, and test their blood sugar by pricking their fingers for blood six or more times per day. While trying to balance insulin doses with their food intake and daily activities, people with this form of diabetes must always be prepared for serious hypoglycemic (low blood sugar) and hyperglycemic (high blood sugar) reactions, both of which can be life-limiting and life threatening.

### Insulin Does Not Cure It

While insulin allows a person to stay alive, it does not cure diabetes nor does it prevent its eventual and devastating effects: kidney failure, blindness, nerve damage, amputations, heart attack and stroke.

### Difficult to Manage

Despite rigorous attention to maintaining a meal plan, exercise regimen, and injecting the proper amount of insulin, many other factors can adversely affect efforts to tightly control blood sugar levels including: stress, hormonal changes, periods of growth, physical activity, medications, illness/infection, and fatigue.

## Statistics and Warning Signs

- As many as 2-3 million Americans may have type 1 diabetes.
- Each year over 15,000 children are diagnosed with diabetes in the U.S.; that's 40 children per day.
- The prevalence of type 1 diabetes in the US is 1 per every 523 youth (ages 0-19 y).
- Warning signs of type 1 diabetes include, but are not limited to: extreme thirst, frequent urination, drowsiness or lethargy, increased appetite, sudden weight loss for no reason, sudden vision changes, sugar in urine, fruity odor on breath, heavy or labored breathing, stupor or unconsciousness. These may occur suddenly.

## What is it like to have juvenile diabetes?

Ask people who have juvenile diabetes. It's difficult. It's upsetting. It's life threatening. It doesn't go away.

"Both children and adults like me who live with type 1 diabetes need to be mathematicians, physicians, personal trainers and dieticians all rolled into one. We need to be constantly factoring and adjusting, making frequent finger sticks to check blood sugars, and giving ourselves multiple daily insulin injections just to stay alive."

—Actress *Mary Tyler Moore*, *JDRF's International Chairman*

"Diabetes is always there. There's never a vacation. It's like a bad dream that lasts all day, all year, for my entire life."

—*Patrick Finan, 16, New York*

"Every day I have to endure up to six injections of insulin and more than ten finger pricks to keep me alive. When my blood sugar is high, my head hurts, I feel angry and sad, and it is hard to concentrate. When my blood sugar is low, I am dizzy, shaky, and in danger of becoming unconscious."

—*Emma Melton, 16, Massachusetts*

"I already have problems with my kidneys, and I take medicine every day so my kidneys won't fail. I worry about what will happen if a cure isn't found soon. I don't have time to wait."

—*LaNiece Evans-Scott, 11, Ohio*