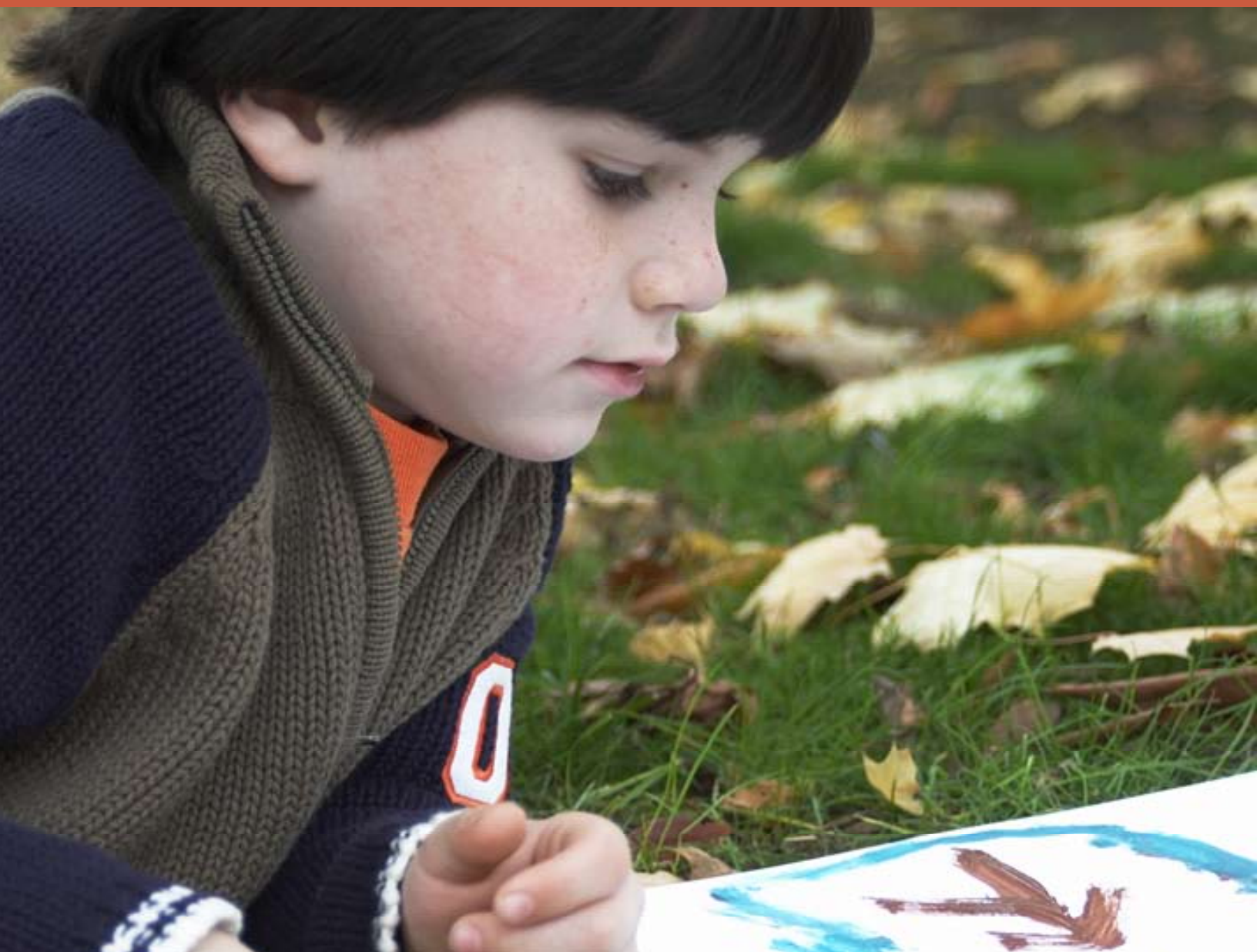
JDRF Juvenile Diabetes Research Foundation International

dedicated to finding a cure

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 and selecting the Locations tab near the top of the homepage.

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Communicating with Schools

- A message to school staff
- A message to parents
- Scenario No. 1 – The cooperative and respectful way
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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 the 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

Diabetes Control & Management

Treating Type 1 Diabetes

The main goals of treating children with type 1 diabetes are:

- Maintaining normal growth and development
- Keeping blood sugar levels within a target range (not too high, not too low)
- Promoting healthy emotional well-being

The key to good diabetes control is a careful balance between food, exercise, and insulin. It's a juggling act to keep blood glucose levels within the target range. Therefore, children with type 1 diabetes must stick to their scheduled blood check, insulin injection, and snack times. Even small changes from a child's diabetes care plan schedule can cause blood glucose levels to rise or fall.

Remember: Food raises blood glucose levels, while insulin and exercise lower them. A good type 1 diabetes treatment plan includes:

- Eating reasonably, consistently, and on schedule
- Testing blood sugar levels regularly
- Adjusting insulin based on blood sugar levels and activities
- Exercising regularly

High Blood Sugar – Definition, Symptoms

High blood sugar, or hyperglycemia, occurs when the body has too much food or glucose, or too little insulin. The following are all potential reasons that a person with type 1 diabetes might have high blood sugar:

- Not enough insulin taken
- Eating more than usual
- Eating earlier than usual
- Eating food with higher glucose content without injecting extra insulin
- Injecting insulin at a site on the body where the absorption rate is slower
- Missing or skipping an insulin dose
- A clog in insulin pump tubing
- Less exercise than normal
- Stress
- Illness or injury
- Other hormones
- Medications

High blood sugar generally does not immediately put the person with type 1 diabetes in danger. However, high blood sugar levels over long periods of time can lead to serious complications. The complications for diabetes primarily involve small blood vessels (microvascular) or large blood vessels (macrovascular). Microvasular disease includes eye disease, kidney disease, and nerve disease. Macrovascular disease includes heart disease and stroke. Disease leading to amputation usually involves both loss of sensation (nerve disease) and large vessel disease.

Very high blood sugar levels can lead to diabetic ketoacidosis (DKA), or a "diabetic coma." DKA occurs when the cells can't get the energy they need from glucose, and the body begins to burn fat and body tissue for energy. This causes the release of byproducts called ketones, which are dangerous when released at high levels. Ketones become like poison to the body and are passed in the urine as they build up in the blood.

A person with type 1 diabetes and high blood sugar may exhibit one or more of the following symptoms:

- Thirst (dehydration)
- Frequent urination
- Blurry vision
- Stomach pain
- Increased hunger
- Nausea
- Drowsiness, lethargy, exhaustion
- Confusion
- Sweating
- Fruity, sweet, or wine-like odor on breath
- Vomiting
- Inability to concentrate
- Weight loss (a longer term symptom) that eventually leads to coma

What to do About High Blood Sugar Levels

The following recommendations are general treatments for high blood sugar. Specific actions — such as giving additional insulin — should be determined by the caregiver responsible for type 1 diabetes management, in consultation with the health care provider prescribing the diabetes medicines.

1. If blood test results are slightly above normal*:

- Continue regular activity
- Drink water or sugar-free drinks
- Monitor blood sugar levels by checking regularly
- Chart blood glucose test results

2. If blood test results are moderately high:

- Don't engage in strenuous exercise
- Drink water or sugar-free drinks
- Inject additional insulin if instructed by physician or parents
- Monitor blood sugar levels by checking regularly
- Chart blood glucose test results

3. If blood test results are very high:

- Don't engage in strenuous exercise
- Drink water or sugar-free drinks
- Inject additional insulin if instructed by parents or physician
- Test ketone levels if advised by parents or physician. If high, contact parent or physician immediately
- Monitor blood sugar levels by checking regularly
- Chart blood glucose test results

* Please discuss with your physician what would be considered a normal blood sugar range for your child.

Low Blood Sugar – Definition, Symptoms

Low blood sugar (hypoglycemia) is the most common and most dangerous condition for many people with type 1 diabetes. Very low blood sugar may lead to insulin shock, which can be life threatening if not promptly treated. Low blood sugar occurs when the body has too little food/glucose or too much insulin. The following are all potential reasons that a person with diabetes might have low blood sugar:

- Too much insulin taken
- Eating less than usual
- Eating later than usual
- Insulin was injected at a site on the body where the absorption rate is faster than usual
- Injecting extra insulin after forgetting about a previous dose
- More exercise than normal
- Illness or injury
- Other hormones
- Medication interaction

The following is a list of general symptoms that indicate low blood sugar (the person with type 1 diabetes may exhibit one or more of these):

- Dizziness
- Nervousness
- Personality change/irrational behavior
- Blurry vision
- Shakiness
- Nausea
- Crying
- Sluggishness
- Sweating
- Poor coordination
- Hunger

- Lightheadedness
- Irritability
- Drowsiness
- Erratic response to questions
- Inability to concentrate

Severe Symptoms (symptoms as listed above, plus):

- Convulsions
- Unconsciousness

What to do About Low Blood Sugar Levels

A blood glucose meter reading below the target range specified by the physician indicates low blood sugar. The following are general treatments for low blood sugar. The physician and parents (for a child) should determine what course to follow. Please note that people with type 1 diabetes have symptoms of low blood sugar at various readings. Some people with type 1 diabetes feel perfectly fine at readings below 70. Others begin to show low blood sugar symptoms at readings somewhat above 70.

1. If blood sugar levels are slightly low and the person is alert and lucid, he or she should:

- Not exercise
- Eat. After eating, check blood sugar level again to make sure it is within the target range. The person may require another snack later in the day
- Continue to check blood sugar levels regularly

2. If blood sugar levels are low and individual is showing signs of low blood sugar but is still able to eat,

- He or she should immediately eat or drink a fast-acting source of glucose (i.e., juice, glucose gel, or tablets). He or she may need to eat more food after that (i.e., crackers or other complex carbohydrate)
- Continue to check blood sugar levels regularly

3. If blood sugar levels are low and individual is showing signs of low blood sugar and is unconscious, convulsing, and/or an unable to swallow:

- Remain calm
- DO NOT administer food or drink to someone who has an altered mental status or is unconscious, as it may obstruct the airway
- Call 911
- Administer emergency glucagon shot. It MAY take up to 10 minutes for the shot to cause the blood sugar to rise, and for the person to respond. The shot can cause some people to vomit, so make sure to keep the person positioned on his or side to prevent choking in case vomiting occurs
- Continue to check blood sugar levels regularly
- Give additional food (i.e., crackers or other complex carbohydrate) when able to eat, if needed, in order to keep blood sugar levels in target range

What is Glucagon?

People with type 1 diabetes who experience severe low blood sugar emergencies may require glucagon. Glucagon raises the blood sugar when a person with type 1 diabetes is unable to swallow liquid or food because of severe sleepiness, unconsciousness, or seizure activity. Glucagon, like insulin, must be injected with a syringe into the skin. It is a hormone that helps the liver to release stored glucose in order to raise blood sugar levels. If there is not stored glucose in the liver, glucagon will not work.

Glucagon Kits

Glucagon is packaged in a kit with a vial of powder containing the medicine and a syringe filled with liquid to mix with the medicine. Directions for mixing and injecting the medicine are in the package. Read the directions carefully and ask your healthcare provider for more explanation, if necessary.

Do not mix glucagon after the expiration date printed on the kit and on the vial. Check the date regularly and replace the medicine before it expires. After mixing glucagon, discard any unused portion, regardless of the expiration date.

Tip: Expired glucagon kits may be a good way to "practice" mixing the powder and liquid; after practicing dispose of the expired glucagon.

Checking Blood Sugar Levels

People with type 1 diabetes must check their blood sugar (glucose) levels throughout the day using a blood glucose meter. The meter tells them how much glucose is in their blood at that particular moment. Based upon the reading, they take insulin, eat, or modify activity to keep blood sugars within their target range. Regularly checking blood sugar levels is an essential part of type 1 diabetes care.

Methods for Checking Blood Sugar Levels

Checking, or testing, involves taking a drop of blood, usually from the fingertip, and placing it on a special test strip in a glucose meter. Blood glucose meters are easy to use, and even young children often learn quickly how to do their own blood glucose checks. In order to properly manage their diabetes, individuals with type 1 diabetes check their blood sugar levels several times per day. For example, they may test before eating lunch and before strenuous exercise.

Blood sugar levels are measured in milligrams per deciliter (mg/dL). A normal blood sugar level is between 70 and 120 mg/dL. Keeping blood sugar levels within this range may be difficult in children with diabetes. Therefore, an individual's doctor may adjust the target range (for example, 80-180 mg/dL).

However, people with diabetes can't always maintain blood sugar levels within the target range, no matter how hard they try. A person's varying schedules and eating habits, as well as the physical changes that occur as they grow, can send blood sugar levels out of range for no apparent reason. A person with type 1 diabetes should never be made to feel that it is their fault if their blood sugar levels are out of range.

The Latest Technology in Blood Glucose Checking

As of 2006, a new device called a continuous glucose monitoring (CGM) system is available to test blood sugar. It works much like an insulin pump and constantly displays an individual's blood glucose level on a screen. This system still requires a few finger pokes during the day but greatly reduces the number of meter tests. The CGM attaches to the body like an insulin pump, and the site must be changed at least every 3 to 5 days.

Insulin Delivery Methods

Syringes, insulin pens, and insulin pumps all serve the same purpose: to deliver insulin to a person with type 1 diabetes, who does not produce insulin on her own.

Insulin Injections

To stay alive, people with type 1 diabetes must inject insulin many times a day. The exact number of injections varies from person to person. Insulin injections typically occur at regularly scheduled times during the day. Syringes or insulin pens are both used for injections, but both essentially do the same thing. Some people find the pen to be more convenient when they only need a single kind of insulin. Some children also find the pen needles more comfortable than the syringe needles. The age at which children are able to administer their own injections varies. After working through the initial trauma of being diagnosed with type 1 diabetes, however, most children eventually inject their own insulin.

Insulin Pumps

An alternative to insulin injections is the insulin pump. The pump is a computerized device, about the size of a beeper or pager, often worn on a belt or in a pocket. The pump delivers a continuous low (basal) dose of insulin through a cannula (a flexible plastic tube), which attaches to the body through a small needle inserted into the skin. The cannula is taped in place and the needle is removed. Common insertion sites on the body include the thighs, buttocks, upper arms, and other areas with fatty tissue.

When a person wearing a pump eats, he/she pushes a button on the pump to deliver an extra amount of insulin called a bolus.

The advantages of the pump include:

- Greater flexibility with meals, exercise, and daily schedule
- Improved physical and psychological well-being
- Smoother control of blood glucose levels

The disadvantages of the pump include:

- Risk of infection
- More frequent hypoglycemia (low blood sugars)
- Ketosis and ketoacidosis (risk of very high blood sugars)
- Constant physical reminder of diabetes

A person with type 1 diabetes who uses an insulin pump may need to test her blood sugar more frequently.

Personal Choice

Choosing an insulin delivery method is a personal decision for a person with type 1 diabetes, made by the individual, family (if a child), and medical provider. The same method may not be the right choice for everyone.

Effects of Exercise, Illness, Stress, and Growth on Blood Sugar Levels

Exercise, illness, stress, and growth all affect blood sugar levels in a child with type 1 diabetes.

Exercise makes insulin work more effectively because it takes less insulin to balance the carbohydrates consumed. Therefore, children who begin to exercise more may find that taking their typical doses of insulin before eating a typical amount of food may result in lower blood sugar levels. (Note: Every child is unique and several factors affect blood sugar levels, so exercise will not always result in lower blood sugar levels.)

At school, this situation occurs in physical education classes, where activities and intensity levels vary daily. Sometimes students are learning how to play a game, and the physical intensity level is low. Other days, students spend more time playing games, running, or doing other strenuous activities. On days like this, children with diabetes should be more aware of how they are feeling and have extra snacks and insulin on hand. Physical education teachers should monitor the student more closely before and during the activity.

A child may also be more active during recess and field trips. Older children with diabetes who participate in a sport need to plan for this additional activity. They may reduce insulin intake or eat extra food before the activity begins.

Illness and stress, on the other hand, often cause blood sugar levels to rise. A child who doesn't feel well may have trouble performing in class. She may have difficulty concentrating, for example. In such cases, the teacher can help reduce some of the stress by providing extra time for students with type 1 diabetes to complete tests or other work. Teachers may also need to be more patient as the student works to grasp new ideas and concepts.

Sometimes a child will achieve (at least for a short time) the "perfect balance" of insulin and food intake. Life can be rewarding and even close to normal for several months or longer. Then something as simple as a growth spurt could suddenly throw everything off. Early adolescence is an especially difficult time: the body grows, and hormones turn boys and girls into men and women. Children may have more issues with blood sugar at this time and require more help emotionally and physically, both at home and at school.

Parent/School Partnership

- An adult and a backup
- Recommended parent responsibilities
- Recommended administrator responsibilities
- Recommended school nurse responsibilities
- Recommended student responsibilities
- Recommended teacher/staff member responsibilities
- Other Staff responsibilities (i.e. bus driver, PE teacher, food service coordinator)
- The most important rules

**See Disclaimer on Pages 2 and 3 of this Manual.*

Parent School Partnership

It is essential to establish a partnership with your child's school in order to create a supportive environment in which he can learn and thrive. The parents', students', and school's needs must be mutually communicated, heard, and understood.

From the first day your child returns to school post-diagnosis you should make every attempt to establish a positive partnership with the school. Be sure on the first day to explain the vast differences between type 1 and 2 diabetes to your child's teacher. While most people know of diabetes, much of their knowledge is usually about type 2. The Diabetes Basics section of this manual is designed to help with the education of teachers and even school nurses about type 1. The school nurse may or may not have had previous experience with other children with type 1 diabetes; regardless, it is important for the school nurse to understand that each person's experience with the disease is different.

In cases where there is no school nurse on site, another adult in the school - usually a teacher or administrator - should be designated as the "go to person" for your child. That adult needs to learn all he or she can about your child's diabetes management routine in order to support your child throughout the school day.

A key part of a positive parent/school partnership is a clear understanding of who will be responsible for each task. In this section you will see a suggested list of responsibilities for all parties involved. You should feel free to tailor this list to your personal situation.

Here are a few more ideas for nurturing the partnership with your child's school:

- Keep the lines of communication open and show that you appreciate the partnership
- E-mail care team members after first meetings thanking them for attending, offering them your complete contact information and any useful local information. Let them know they can contact you with any questions at any time
- When and if appropriate, inform them of the presence of JDRF in your community and the work they are doing to find a cure
- Check in with the teacher about your child's diabetes regimen regularly, and separately from academic conferences
- Check in regularly with the school nurse as she may be aware of other concerns
- Check in about replenishing supplies as necessary
- From time to time, eat lunch with your child at school to meet the lunchroom staff and monitors
- After each grading period teachers may change or unused information may be "compartmentalized"; consider holding another informational or training session with new staff
- Send a holiday greeting thanking administration and all care team members for their participation and constant care

An Adult & A Back-Up

Ideally, at least one adult and one "back-up" should be trained to check your child's blood sugar and recognize and treat low blood sugar (hypoglycemia) and high blood sugar (hyperglycemia) levels. These adults should also know when and how to check for ketones and what to do if the ketone level is abnormal. If the child is mature enough to treat himself/herself, he/she should be allowed to do so — but the student should remain under the supervision of an adult at all times during a hypoglycemic reaction and should not be allowed to walk alone to another part of the school to test blood glucose or get treatment.

If the parent or child requests it, the school should provide a location in which the child can check her blood glucose or take insulin privately (but still with adult supervision, if needed). The two adults should also be trained to give a glucagon injection in case of emergency. The responsibility for glucagon administration by school staff is similar to school staff being prepared to give a shot (epi-pen or similar) to a child in the school who is allergic to bees.

Further responsibilities of adult caregivers should include:

- Knowing the student's meal plan and working with the parent to accommodate special events/meals if possible.
- Allowing the student to see the school nurse or other school medical personnel whenever needed
- Allowing the student to eat a snack anywhere as needed, and to use the restroom and drink water at any time
- Allowing the student to miss school for doctor's appointments to monitor diabetes without incurring negative consequences
- Providing a safe and secure location for storage of insulin and glucagon, and allowing the student immediate access to diabetes supplies at any time
- Ensuring the student's full participation in all sports, extracurricular activities, and field trips, with any necessary supervision provided
- Providing aids to help the student academically, if needed. Examples of situations in which this might be necessary include making up for class time missed due to diabetes care or academic problems that can be traced to frequent hypo- or hyperglycemia

Recommended Parent Responsibilities

- Inform the school/administrator that your child has type 1 diabetes
- Provide the information needed for training of school staff (samples provided in Diabetes Basics and Educate the Educator sections of this guide)
- Work with the administrator and/or school nurse to provide this training
- Understand teacher and school personnel schedules and that all staff members involved with your child may not be able to attend the same training time, so training may have to be given more than once
- Work with the principal or building administrator to identify school staff (hopefully including main academic teacher) for more in-depth training
- Provide specific information about your child (include your child's picture on forms)
- Work with school staff to determine when and where blood testing is to take place
- Clearly communicate (verbally and in writing) your permission for school staff to call 911 whenever they deem it necessary and to administer glucagon – no questions asked
- Clearly communicate that the school has your permission to share the needed medical information about your child with everyone who needs to know
- Provide multiple emergency contact people and phone numbers including your physician
- Be sure to communicate with school staff any changes that occur concerning your child and his/her diabetes management
- Provide all the necessary equipment, supplies, snacks, and emergency items needed. You will also want to set up a system with teachers and other staff to alert you when supplies or snacks are getting low. A school kit might include:
  - ❍ Vials of your child's insulin – clearly labeled with child's name
  - ❍ Syringes
  - ❍ A second glucose meter to keep at school – including batteries and test strips
  - ❍ One or more glucagon kits (renew each year as they expire)
  - ❍ Glucose tablets, juice boxes, or another form of fast acting sugar
  - ❍ Cake Icing or glucose gel
  - ❍ Snacks containing protein, such as peanut butter crackers
  - ❍ A mini carb counting guide (found at most bookstores)
- Work with the principal to develop a process to cooperatively and amicably address disagreements or issues if and when they arise
- Encourage your child to wear a medical alert ID

- Make sure that your child understands that he/she is not to take unfair advantage of modifications or accommodations provided (e.g., trying to get out of physical education activities when she feels just fine)
- Accept the fact that it may be your child who is resistant to the assistance or procedure that school personnel are trying to provide. Don't blame, but work with school personnel to resolve these issues
- Provide an emergency/disaster kit for any situation which might require your child to stay at school for a longer than expected period of time
- Work with appropriate school personnel to develop a 504 plan. Remember that a 504 plan provides reasonable accommodations for your child. Also remember that the goal is to provide accommodations that your child really needs or would need in a special circumstance (e.g., standardized testing)
- Communicate with and train staff members new to your child during the school year (e.g., after-school club sponsor if your child joins a club after the school year begins)
- When appropriate, include your child in all discussions and decisions made about him/her
- Clearly state to your child who should be contacted at school if she feels ill
- Promote, encourage, and teach your child the skills to become more and more independent in her diabetes management and care. Discuss the level of independence of your child for blood testing and shot/insulin pump management (depends on age level/maturity of child) with school staff
- If the school and school personnel are making a good faith effort to do all that is possible for your child, help out as much as you can when the school requests your assistance. (e.g., legally, the school may be responsible for providing a nurse to provide for your child's needs. But if the school nurse is ill and school personnel are unsuccessful in arranging for a substitute, thank them for trying and then give up your day to go to school and provide services for your child.)
- Help out at some after-school or extra-curricular events when your child is participating. These are especially difficult times for schools to provide the appropriate trained staff members

Recommended Administrator Responsibilities

- Become knowledgeable about diabetes, especially the differences between type 1 and 2
- Meet with the parent/student at the beginning of the year or when the child is diagnosed to set up the year-long plan for management and care
- Identify and arrange for training of appropriate school staff. Besides the more obvious classroom teachers, don't forget the band teacher, coach, librarian, any special education teachers, bus driver, substitute bus driver, lunchroom supervisors, hall monitors, etc.
- Identify school staff (including main academic teacher) for more in-depth training. These staff members are then available to provide an extra level of care when the nurse is not available
- Work with parent and school staff to determine where blood testing is to take place
- Provide leadership to foster and support a positive learning environment for the student; act as an advocate for the student; clearly communicate to teachers and other staff members in contact with the student your expectations for them to cheerfully follow through on the modifications and accommodations set up for the student.
- Set up an "emergency" system that clearly communicates to the student what to do if an adult in the building refuses to allow the student to do what is needed. Make sure that the student understands that there will be no disciplinary action taken against the student for following through on the agreed upon actions (e.g., leaving class to come to the nurse's office even if a substitute teacher says that the student cannot leave class). Remind the student not to take advantage of these "special" rules
- Work with the parent to develop a process to cooperatively and amicably address disagreements or issues if and when they arise

- Work with the parent to address the emotional issues involving the student. Identify/introduce the child to school support staff (e.g., counselor, social worker, and administrator) to whom the child should go to for emotional help
- Ensure the student's confidentiality and right to privacy are maintained
- At quarter, trimester, semester times, ensure that teachers and staff members new to contact with the student are trained/reminded
- Ensure that the office secretary/aide who meets substitute teachers when they arrive reminds the substitute teacher to be sure to look in the substitute folder for the names and information about students with medical needs
- Ensure that every teacher has a substitute folder that includes the names, information, and pictures (if possible) of students with medical needs
- Understand and implement federal and state laws regarding students with diabetes
- Genuinely welcome the parent and student to your school
- Support the parent/child in working with "reluctant" teachers or other school staff
- Work with the parent and other appropriate personnel to develop a 504 plan
- Ensure that the student receives the needed modifications and accommodations

Recommended School Nurse Responsibilities

- Clarify roles and responsibilities with trained school personnel (roles for the other trained school personnel are listed in the rest of this section)
- Maintain or gain familiarity with current standards of care for children and teens with type 1 diabetes
- Work with an interdisciplinary team to implement the Health Care Plan and Section 504, IEP, or other education plan, and then monitor compliance
- Coordinate care at school and school-sponsored events for students with diabetes, and serve as a liaison between the school and the students' families or make sure there is a trained school staff member who is responsible for this coordination
- Train or coordinate training of school personnel in diabetes care
- Perform or assist with students' diabetes care in accordance with their Health Care Plan including blood glucose monitoring and insulin and glucagon administration
- Be available on site throughout the school day and when students with diabetes are involved in field trips, extracurricular activities, or school-sponsored events or make sure trained school personnel are available. Carry emergency diabetes supplies
- Serve as a resource for school personnel regarding up-to-date information about diabetes
- Advocate for the student with less accommodating school staff
- Respect the student's confidentiality and right to privacy
- Communicate regularly with the parents. Use them as a resource and partner with them to provide the best learning environment possible. Let parents know when snacks or other diabetes supplies are low and need replenishing

Recommended Student Responsibilities

- Participate and contribute to the best of your ability in the discussions of how the school will help you manage your diabetes
- Clearly communicate to school personnel how you are feeling
- Understand what you are to do if an adult at school doesn't give you permission for something you know you need to do (e.g., doesn't let you blood test or go to the nurse for food.)
- Learn what to say to students who make inappropriate or mean comments to you about your diabetes
- Know how you will handle the situation if food that isn't good for you is passed out during class or other times
- Do not take advantage of the accommodations and modifications that the school is providing
- Make sure you have your supplies (blood testing meter, etc.) with you when needed
- Talk to the school counselor, social worker, or other appropriate school staff member about problems you may be having. These can be long-term emotional problems or even simple problems, such as: you'd rather have your snack at 10:30 a.m. instead of 10:45 a.m.
- Work to become as independent as possible in your own diabetes care and management
- Do not let any other student use or have any of your diabetes supplies (e.g., syringes, glucose tablets)
- Don't be afraid to let good friends know about your diabetes and how they might help if you ever need assistance

Recommended Teacher/Staff Member Responsibilities

- If the student with diabetes states he/she doesn't feel well, NEVER, EVER, send the student to the nurse's office without another student or adult accompanying him/her!
- Genuinely welcome the student with diabetes into your classroom and create a supportive environment for him/her
- Assure the parent that you will do everything in your power to keep the child safe
- Willingly give time to be trained in understanding diabetes and the care of the student
- Advocate for the student with less accommodating school staff
- Create a "system" for a regular reminder to yourself to be vigilant and observant concerning the student with diabetes. Use the same system to remind yourself of low/high blood sugar symptoms and emergency responses
- Create a "system" to make sure that when field trips or other special/different kinds of activities are planned, that the child whose diabetes needs are remembered and addressed
- Provide agreed upon modifications and accommodations to the student. Don't make the student and parents jump through hoops if another modification/accommodation needs to be added to the agreed upon list. Find ways to help the student feel less "different"
- When you are out of the classroom, ensure that the substitute or other person covering your classroom knows what to look for, what to do, and what modifications or accommodations are necessary. Have a Substitute Teacher Folder in an obvious place and include the appropriate information on the student with diabetes. See Substitute Teacher Form in the *Educate the Educator* section
- Communicate regularly with the student's parents. Use them as a resource and partner with them to provide the best learning environment possible. Let parents know when snacks or other needed supplies need to be replaced
- Respect the student's confidentiality and right to privacy
- Work with the parent and child to determine how to address diabetes issues that may arise in the classroom

PE Teacher & Coach

- Work with an interdisciplinary team to implement written care plans, including Section 504, IEP, or other education plan and the Health Care Plan
- Provide instruction to students for information and assignments missed due to diabetes related care
- Develop and provide a written plan for substitute teachers and other classroom aides that details diabetes-related needs and emergency plans
- Inform students with diabetes and their families about changes in class schedules such as class parties, field trips, extracurricular activities and special events
- Maintain emergency diabetes supplies
- Allow student/athlete with diabetes to eat food or drink liquids in class or at practice/games as needed

School Counselor

- Learn about, support, and respond to – as appropriate – the emotional needs of students with diabetes
- Promote and encourage independence and self-care consistent with student's abilities

Food Service Staff

- Provide students with diabetes and their families with lunch menus in advance that include the nutritional content of menu selections (including calories and grams of carbohydrates, sugar, protein and fat)
- Ensure that students with diabetes have easy and timely access to food and enough time to finish their meal
- Allow student with diabetes to eat first if low blood sugar (hypoglycemia) symptoms are present

Bus Driver

- Know which students on your bus route have diabetes
- Have Emergency instructions regarding diabetes care on the bus
- Be aware of where students normally keep their supplies
- Permit students with diabetes to eat snacks on the bus, if necessary

The Most Important Rules

Rule # 1

The number one and most important rule is: When a student with diabetes says he/she doesn't feel well or thinks he/she is having a blood sugar problem, NEVER, EVER, send the student to the nurse's office without another student or adult accompanying her! This one is worth repeating. A student with diabetes who is beginning to have an insulin reaction (low blood sugar) may not be capable of getting to the office on her own. Remember that some of the symptoms of low blood sugar are erratic behavior, confusion, and inability to concentrate.

It is imperative that a student with diabetes has an adult or dependable student go with her to ensure that the student makes it to the office. Failure to follow through on this rule could result in a life-threatening emergency. It is also a good idea to use the intercom or classroom phone (or teacher cell phone) to call the nurse's office to let her know that the student is on the way.

(If possible a better practice would be to have the treatment/nurse come to the student versus the student going to the treatment/nurse.)

Rule # 2

The second rule is, when in doubt, if a student with diabetes is experiencing a blood sugar problem, and a blood testing meter is unavailable to determine whether the blood sugar level is high or low, treat for low blood sugar. In other words, when in doubt – have the student eat. Test as soon as possible to determine a further course of action.

Rule # 3

If a student with diabetes is beginning to shake, lose consciousness, or experience convulsions, lay the student on the floor on her side. This is to prevent further injury to the student and to prevent choking.

Educate the Educator: Staff Training

- Identification of staff for training
- School staff training tools/samples
- Potential academic and school rule modifications
- Emotional issues involving the student
- Extra-curricular/After hours school events
- Notification/training of substitute teachers
- Educational tools and templates

Educate the Educator

In caring for children with type 1 diabetes, educational professionals must understand the importance of their involvement in the child's diabetes management. Young children, including school-aged children, need assistance with their diabetes care, while middle and high school students can often manage their own diabetes more independently. Each student is different, thus, education and training on how to care for a child and adolescent with diabetes must be an ongoing group effort of the parents, school staff, and the student with diabetes.

When a student has been newly diagnosed, it is critical that the parent initiate a partnership with the school to care for his diabetes. Many teachers may only have had past experience with older relatives with type 2 diabetes. For this reason, it is important to start with the basics in your training. Included in this section are training tools that might assist with educating your child's teacher and training school staff in diabetes management.

Effective diabetes management at school has numerous positive outcomes. It can:

- Promote a healthy, productive learning environment for students with diabetes
- Reduce the number of absences of students with diabetes
- Reduce classroom disruptions and disturbances
- Help ensure an effective response in case of a diabetes-related emergency

Identification of Staff for Training

Following is a list of staff members who should be considered for diabetes training.

- Principal
- Assistant Principal
- Dean
- Nurse
- Health Aide
- Guidance Counselor
- Social Worker
- Psychologist
- Academic teacher(s)
- Physical Education Teacher
- "Specials" teachers (music, art, etc.)
- Librarian
- Classroom aides
- Cafeteria manager and lunchroom monitors
- Hall monitors
- Bus drivers/bus driver manager
- Coaches
- Sponsors of clubs which the student might attend
- Secretaries
- Band/orchestra teacher

Diabetes Care Team School Year Plan

(Your child's name) Diabetes Care Team
Plan 200_ - 200_ School Year

Step 1: Contact school to request care team meeting, teacher assignment, and schedule for the next school year
When: April/May

Step 2: Provide introduction to diabetes/diabetes care, emergency kits and instructions to:
Who: Nurse and Administration. Nurse should provide copies of care plan
When: Shortly after contacting school to set up meeting. Familiarity with these materials before the meeting will lead to more active and productive team meetings.

Step 3: Diabetes Care Team Meeting – Preliminary Session
Who: Classroom Teachers, Administration, Nurse, and Parents
When: Preferably before the end of the school year

- Inquiry: What is your familiarity with diabetes?
- Overview of materials: What is diabetes? What is involved with daily care?
- Tools: Glucose meter, pump, mini backpack, emergency kits (glucagon), instructions
- Overview of materials: Highs and lows, symptoms, emergencies, treatment, effects
- Influences: Schedule (timing, activity), meals/snacks, other hormones, illness

Additional Topics:

- Request that Taking Diabetes to School by Kim Gosselin be read to class, if age appropriate
- Determine how and where to perform classroom blood glucose checks
- Determine schedule strengths/weaknesses
- Discuss timing/strategies of snacks and meals
- Discuss situations requiring communication/coordination: celebrations, lessons with food, treats, birthdays, field trips, field day, delayed start, early dismissals, substitutes, nurse/specials substitutes, fire emergencies/drills, lockdown emergencies/drills

Step 4: Diabetes Care Team Meeting – Group Session
Who: Classroom & Specials Teachers, Nurse, Administration, Counselor, Parents, Child
When: Prior to the start of the new school year

- Inquiry: What is your familiarity with diabetes?
- Overview of materials: What is diabetes? What is involved with daily care?
- Tools: Glucose meter, pump, mini backpack, emergency kits (glucagon), instructions
- Overview of materials: Highs and lows, symptoms, emergencies, treatment, effects
- Glucagon demonstration and exercise
- Influences: Schedule (timing, activity), meals/snacks, other hormones, illness
- Question and Answer period

Step 5: Follow Up

- E-mail links to additional resources/more detailed information (following meeting)
  - E-mail Nurse for progress/issues report (1 wk, 2 wks, 1 mo, 3 mo)
  - E-mail reminder to send home perishables in emergency snack kits over the holidays
  - Replenish perishables in emergency snack kits upon student's return in January
  - E-mail reminder for kits and supplies to be sent home the last day of school
  - Check in frequently and offer thanks readily

Sample

Diabetes Care Team Meeting Talking Points

- Student has type 1 diabetes and requires insulin so his/her body can use the food he/she eats. Daily care requires a regimen of checking blood glucose levels throughout the day to monitor the effects of food intake, insulin, time, activity, other hormones and illness
- He/she uses a blood glucose (BG) monitor or "meter". The meter sends the level to his/her insulin pump using RF communication. We've programmed the pump with settings so that it can calculate a dosage of insulin based on that BG level, "active" insulin, and the grams of carbohydrates to be eaten. His/her supplies are kept in his/her backpack and back-up supplies are located in emergency kits throughout the school. Emergency glucagon injection kits with instructions (orange) are in his/her backpack, nurse's office, and PE pack
- "Normal" BG levels are 80-120. (Child's name) "target" level at school is 100-200. Low BG levels occur when there is too much insulin and/or too much activity and not enough sugar in the body. Immediate action (giving sugar) is necessary to prevent nerve/brain damage, loss of consciousness and/or seizure. It can take 10 minutes for sugar to get into the bloodstream, so a short break or rest is also helpful. Signs to look for include pallor, nausea, frustration and uncharacteristic or emotional behavior. he/she typically feels shaky. Prolonged periods of high BG levels (above 240) occur when there is not enough insulin and can cause acid levels to build up in the body, which can cause vomiting, dehydration or coma
- Therefore, we must commit to a daily regimen designed to prevent avoidable emergencies and we must prepare for influences which can put (Child's name) at risk such as changes to the schedule - timing, activity, meals and snacks - as well as illness, hormonal changes, and stress
- Glucagon demonstration and exercise

A Few Reminders…

- Checks can be done anywhere and at anytime. It's best to wash hands or use an alcohol wipe prior to checking. His/her trash capsule is emptied at home
- If child feels low, it's OK and preferable to drink a juice box before checking
- Treat lows immediately according to guidelines on daily sheet - do not call home first
- (Child's name) should have backpack with his/her always. No one else should carry it or open it
- His/her food is "counted", so she must finish all food that is packed. Call if there is a spill or problem
- If in doubt, ALWAYS call
- If his/her pump alarm goes off, it has a message…time to check BG, low insulin or low battery. He/she should respond with the appropriate action
- If he's/she's been ill or fighting off an infection or after a break, occasionally extra BG checks may be necessary. Otherwise, he/she will check before snack, lunch and administer a "bolus" of insulin. He/she will also check before getting on the school bus
- ALWAYS be on the lookout for things that threaten the regimen. Please e-mail me or call with changes to the schedule which affect the activity level and/or timing of snack or mealtime, so we can ensure my child's safe participation in activities such as assemblies, standardized testing, celebrations, lessons with food, treats, birthdays, field trips, field day, delayed starts, early dismissals, substitutes, nurse/specials substitutes, fire drills, and lock-down drills

Thank you for your care and support!

Sample

Letter for the Children's School Diabetes Care Team

Dear (School Name) Diabetes Care Team,

Our daughter (child's name) was diagnosed with insulin-dependent (type 1) diabetes just after her second birthday. Most people know someone with diabetes but do not know much about the actual disease. It is our desire to share some information that will give you both comfort and confidence as you support (child's name) in caring for her diabetes at school.

(Child's name) is very comfortable talking about her diabetes. She doesn't like to consider herself to be "different" from other children and we strive to make the mechanics of her care so routine that it seems invisible to those not looking for it. She is accustomed to the requirements at each snack and mealtime: checking her blood sugar beforehand, eating and finishing "counted" foods and "pumping" insulin. Occasionally, she may need an extra snack or water. Otherwise, she can do all of the same things as anyone else.

During the school year, there are special occasions, learning experiences and celebrations, which include food and treats. With minimal planning and coordination, we can easily develop a plan for any event, activity or change in schedule – but advanced notice isn't always possible. Since (child's name) inclusion hinges on our ability to coordinate her participation, please know that we are just a phone call away at any time for questions, concerns or feedback.

Many thanks for your care and support,

Parent's name

Our contact information is:

Home: _____

Dad's Work: _____

Mom's Work: _____

Dad Cell: _____

Mom Cell: _____

Physician: _____

Physician address: _____

_____

Physician phone number: _____

Continued Sample:

Letter for the Children's School Diabetes Care Team

What is Diabetes?

Diabetes is a chronic disease that impairs the body's ability to use food properly. Under normal circumstances, the hormone insulin, which is produced in the pancreas, moves sugar to the cells of the body to convert food into energy. In people with diabetes, either the pancreas doesn't make insulin or the body cannot use insulin properly. Without insulin, glucose - the body's main energy source - builds up in the blood and causes severe damage.

Children with diabetes usually have insulin-dependent (type 1) diabetes, in which the pancreas doesn't make insulin. They need daily insulin injections or wear an insulin pump to enable their bodies to use food properly. Two kinds of problems occur when the body doesn't make insulin.

Hyperglycemia occurs when blood glucose levels get too high - for example, when the body gets too little insulin or too much food. The body produces ketones, harmful acids that poison the body and its organs. Untreated, hyperglycemia may develop into ketoacidosis, a very serious condition that requires hospitalization. Treatment includes extra fluids and insulin.

Hypoglycemia is the exact opposite of hyperglycemia. It occurs when blood glucose levels get too low - for example, when the body gets too much insulin, too little food, or too much activity or stress. Hypoglycemia is the most common problem in children with diabetes. Usually it is mild and can be easily treated by giving the child a sweet food or drink.

Diabetes is not contagious. You cannot "catch" it from someone who has it. Diabetes can run in families. Researchers are still studying how and why diabetes occurs in certain children and families. Children cannot outgrow type 1 diabetes. Although there isn't a cure for diabetes, it can be controlled. Research has shown that maintaining good control of blood glucose levels can possibly prevent or at least postpone some of the long-term complications of diabetes.

Diabetes care is more flexible today than it used to be. With good medical care and support from other children and adults, children with diabetes can lead healthy, active, fulfilled lives.

Sample:

Letter for the Child's Classmates Families

Dear Fellow Parents of Mrs. Webster's Third Grade Class,

Our daughter (child's name) was diagnosed with insulin-dependent (type 1) diabetes just after her second birthday. Most people know someone with diabetes but do not know much about the disease. Since (child's name) is in your child's class, we wanted to provide some information for you to share with your child. Also, Mrs. Webster will read a book to the class, *Taking Diabetes to School by* Kim Gosselin, and have (child's name) talk about what she does to take care of her diabetes.

(Child's name) is very comfortable talking about her diabetes, wearing an insulin pump, and taking her backpack of supplies with her wherever she goes. She doesn't consider herself to be "different" from other children and we refrain from referring to her as a "diabetic". She is accustomed to a daily routine that helps to control her diabetes. At each snack and mealtime she must check her blood sugar, eat and finish "counted" foods, and calculate a dose of insulin to match her intake. To make the calculation, we must count up the total grams of carbohydrate that she will eat and her pump's computer determines the right amount of insulin.

When there is a class celebration or if you send in treats for the class, we can plan for (child's name) to take part if we know the "count" to use. She is not on a restricted or special diet. (Child's name) can eat anything sweetened with sugar, Splenda or Nutrasweet, but she avoids other artificial sweeteners and sugar alcohol since they cause severe digestive discomfort. Thank you for your cooperation in planning for an amazing year for all of our children!

We hope you will call us if you have any questions. Thank you!

Sincerely,

Parent's names

Phone number

Continued Sample:

Letter for the Child's Classmates Families

What is Diabetes?

Diabetes is not contagious. You cannot "catch" it from someone who has it. Diabetes can run in families. Researchers are still studying how and why diabetes occurs in certain children and families.

Diabetes is a chronic disease that impairs the body's ability to use food properly. The hormone insulin, which is produced in the pancreas, helps the body to convert food into energy. In people with diabetes, either the pancreas doesn't make insulin or the body cannot use insulin properly. Without insulin, glucose - the body's main energy source - builds up in the blood.

Children with diabetes usually have insulin-dependent (type 1) diabetes, in which the pancreas doesn't make insulin. They need daily insulin injections to enable their bodies to use food properly.

Two kinds of problems occur when the body doesn't make insulin. Hyperglycemia occurs when blood glucose levels get too high - for example, when the body gets too little insulin or too much food. The body produces ketones, harmful acids that poison the body and its organs. Untreated, hyperglycemia may develop into ketoacidosis, a very serious condition that requires hospitalization. Treatment includes extra fluids and insulin ([Child's name] drinks extra water and may have to skip a snack).

Hypoglycemia is the exact opposite of hyperglycemia. It occurs when blood glucose levels get too low - for example, when the body gets too much insulin, too little food, too much activity or stress. Hypoglycemia is the most common problem in children with diabetes. Usually it is mild and can be easily treated by giving the child a sweet food or drink ([Child's name] uses fruit snacks or a juice box).

Children cannot outgrow insulin-dependent diabetes. Although there is no cure for diabetes, it can be controlled. Research has shown that maintaining good control of blood glucose levels can prevent or postpone some of the long-term complications of diabetes.

Diabetes care is more flexible than it used to be. With good medical care and support from other children and adults, children with diabetes can lead healthy, active, fulfilled lives.

Sample
Diabetes Management Overview for Staff/Substitutes

Overview – Daily Care

Eight year-old (child's name) is a child with insulin-dependent diabetes attending the third grade at (school name). She wears an insulin pump that continuously gives her insulin. Her mini backpack contains the necessary items to perform the frequent blood sugar checks that help to control her diabetes, avoid low blood sugar emergencies, and prevent long-term complications. Both must be with her at all times.

(Child's name) is capable of checking her blood sugar level and programming her pump under supervision. At this age, she requires support evaluating numerical results to determine the action required. Every day, she must maintain a regimented schedule and prepare for any changes or adjustments to that schedule. Since her pump calculates insulin amounts based on the grams of carbohydrates eaten at each snack and meal, it is extremely important to make sure that she always finishes all of the food that is "counted".

All adults who come in contact with the child (classroom and specials teachers; substitutes and school administration) should be made aware of the child's medical condition, symptoms of low and high blood sugars and emergency care. On a daily basis, those familiar with (child's name) personality, demeanor and behavior should keep in mind recognizable symptoms of low blood sugar and act immediately when symptoms are exhibited, reminding his/her to consider how she feels, and having his/her perform a blood sugar check if in doubt. Ignoring symptoms or using a "wait and see" approach can quickly lead to an otherwise avoidable emergency situation such as discussed below.

(Child's name) target blood sugar range is _____ during school hours. Sudden drops in blood sugar levels lead to "insulin reaction", low blood sugar emergencies. Levels below 65 cause brain and/or nervous system damage; levels below 45 can cause seizure, coma or even death. Daily log sheets kept in his/her mini backpack display up-to-date blood sugar level guidelines/charts to consult whenever a check is performed; making it easy to prevent emergencies and administer treatment for "lows". High blood sugars are less worrisome over a short period of time and should be treated with extra fluids and/or corrected with insulin when discovered, unless accompanied by nausea.

In the case of a seizure, convulsions, or loss of consciousness, a glucagon injection must immediately be administered by the school staff. 911 should be called before administering the glucagon, but there should be NO delay in administering the glucagon while waiting for the ambulance to arrive.

Potential Academic and School Rule Modifications

Academic and school rule accommodations and modifications should be tailored to the unique needs of each student with diabetes. Factors such as age and maturity, illness, and stress can impact when accommodations and modifications might be necessary. Accommodations and modifications may include:

- Allow food to be stored/eaten in the classroom
- Allow insulin injection in classroom or nurse's office
- Allow the student to carry a minipack for diabetes supplies
- Allow food to be stored in student's locker
- Allow student to have/eat food on field trips or other outside school activities
- Allow student to have a water bottle or quick access to water
- Allow student to test blood sugar level in the classroom and/or other school areas and/or to leave the classroom to go to the nurse's office as often as needed
- Allow student access to bathroom as often as needed
- Allow student to be first in the lunch/cafeteria line

- Allow student to determine level of participation in strenuous physical activities without penalty
- Allow student to keep a cell phone on his/her person (Clearly define that the only appropriate use of the cell phone is for diabetic emergencies. At all other times, school rules for cell phone use should be followed!)
- Provide storage areas for food or equipment
- Provide additional time for academic tests (including standardized tests)
- Allow student to test blood sugar level/eat before tests (including standardized tests)
- Allow student extra time for homework completion
- Provide modified homework or tests
- Provide additional academic help (and assign no penalties) after illnesses/absences/missing instruction due to diabetes issues
- Assure that the nurse and other staff are appropriately trained in diabetes care and management and emergency treatment
- Assure student's full participation in all school activities with necessary assistance
- Provide counselor or social worker services
- Delay testing if blood glucose levels are too high or too low

The parent(s), student, principal, and/or guidance counselor should discuss the modifications/accommodations with the student and the need for the student to not take advantage of any changes in classroom and school rules.

Emotional Issues Involving the Student

When a student is diagnosed with type 1 diabetes his/her whole life changes in an instant. All of a sudden he/she can't eat and drink the things all of his/her friends are eating and drinking. After the baseball game, everyone runs to the ice chest to get a soda, but he/she has to find diet soda. He/she may be looking forward to a class or activity all day, but then his/her blood sugar acts up and he/she has to miss it. As if these challenges are not enough, he/she also has to deal with prejudice and teasing from other students, and sometimes even adults, who don't understand the disease.

Although some students are very open about their diabetes, most don't like to be considered "different." Once again, the age when diabetes onset occurs, and the age, maturity level, personality, and emotional state of the student all affect how he/she will adjust to life with diabetes. Diabetes is stressful at any age, but particularly during adolescence when a student is most craving his/her independence. Conflicts between the student and his/her parents and teachers are almost inevitable, but having an understanding support network to help him/her work through these issues can do wonders for his/her emotional well-being.

In order to create such a support network, discussions between the parent(s), student, nurse, administrator, guidance counselor, and teachers should always include consideration of emotional and social issues. The student's desire for privacy should be respected whenever possible. Some emotional/social issues to consider include the following:

- Where will testing of blood sugar levels take place?
- Where will snacks be eaten?
- Will the student simply state to the teacher that he/she needs to go see the nurse or does a "signal" need to be established between student and teacher for the student to communicate this need? (Either way, don't forget to send another student or adult with the student with diabetes!)
- Will classmates be told/educated about diabetes and the student with diabetes?
- Who will do the talking/educating, and how?
- How will parties/food be handled so that the student is not left out or put in an embarrassing situation?
- Will the student wear an insulin pump during physical education class (if not, where it will be stored?)
- Will the student wear a medical ID bracelet?
- How will the school and/or the parent deal with the student if he/she resists **care, does not take his/her insulin, refuses to check blood sugar** levels, reports false glucose levels, etc.?
- If the student with diabetes manipulates his/her insulin/food intake to gain or lose weight, how will that be handled?
- How will depression or anger issues be handled?

Extra-Curricular/After-Hours School Events

Students with diabetes, like other students, should be encouraged to participate in extra-curricular activities. Being in the play, working on the yearbook, playing a sport, participating in intramurals, joining a club, joining the band, attending the school dance/activity night – all of these activities contribute to the future success of any student and can support the student with diabetes both physically and emotionally.

It is important to have a staff member who is informed, trained, and capable of caring for the student with diabetes in the case of low or high blood sugar issues at any of these extra-curricular or after-hours school activities. For most of these activities, the sponsor or leader of the activity would be the ideal choice to support the student's diabetes management. In the case of a school dance/activity night or similar kind of event, it would certainly be reasonable to expect that parents might want to volunteer to attend.

Tips for Coaches

How to help a young athlete with diabetes

- Review the athlete's diabetes management plan
- Know how to check blood sugar levels
- Know how to recognize and learn to treat hypoglycemia (low blood sugar), including how to administer glucagon
- When the student experiences and treats low blood sugar; it is still critical to have him/her sit out for a period of time in order to recover and allow the body time to bring the blood sugar up within the target range
- Know how to recognize and learn to treat hyperglycemia (high blood sugar), including how to administer insulin
- Allow the athlete to eat whenever and wherever necessary
- Allow extra trips to the bathroom or water fountain if needed
- Allow the athlete to miss occasional practices for medical appointments
- Pump sites can be a sensitive topic with regards to athletics; be aware that the student must determine if/where to wear their pump during practice/competition

Notification/Training of Substitute Teachers

In the ideal school world, all substitute teachers for a school would receive the same diabetes training that regular teachers receive. Unfortunately, there is sometimes a good deal of turnover in available substitute teachers during a school year. "Regular" substitutes move and/or get full-time teaching positions. New people move into the area during the school year and apply to be a substitute teacher. It is most difficult to keep up with these changes and ensure that all substitute teachers in a building are fully aware and trained to deal with students with diabetes.

Due to these challenges, the school should do the following:

- Ensure that the secretary who meets substitutes as they arrive has set up a system for alerting subs when a student with diabetes will be in one or more of their classes. These substitute teachers should be told specifically to look for the diabetes information sheet in each teacher's substitute folder. The secretary should emphasize to the sub Rule #1: If the student with diabetes states he/she doesn't feel well, NEVER, EVER, send the student to the nurse's office without another student or adult accompanying the student!
- Ensure that every teacher with a student with diabetes in his/her classroom has a substitute teacher folder with emergency information about the student with diabetes.

Substitute Teacher: Emergency Medical Form

The following student has type 1 diabetes. Please read this information carefully as failure to react properly can result in a potentially life-threatening situation.

Name of student _____

Student is in my class during the following time period(s):

_____

Student should never ever be sent to the nurse or out of class without another adult or trusted student with him/her!

Picture of Student

Symptoms indicating a problem may be occurring
(Common symptoms for this child have been circled)

Dizziness	Nervousness	Personality change
Blurry vision	Shakiness	Nausea
Crying	Sluggishness	Pale coloring
Irrational behavior	Sweating	Poor Coordination
Hunger	Confusion	Headache
Light headed	Irritability	Drowsiness
Erratic response to questions	Unable to concentrate	Thirst
Frequent urination	Stomach pain	Lethargy
Exhaustion	Fruity odor on breath	Vomiting
Convulsions	**Unconsciousness**	_____
		Other *(provided by parent or physician)*

If one or more of the above symptoms are occurring, call for immediate assistance. Use the school intercom system, in-class telephone, or a cell phone – or immediately send another adult or trusted student to get help. If needed, obtain help from a nearby teacher. If the student with diabetes is unconscious or having convulsions, you should immediately:

1. Place the student on the floor, preferably on his/her side
2. Call for *immediate* school assistance.
3. Call 911

The following are special accommodations for this child (e.g. ok eat in class, go to restroom).

_____

_____

Field Trip Checklist

- Contact parent to discuss duration and location of field trip to determine the student's needs, the location and contact numbers of parents during the field trip, and to get an updated contact list with emergency phone numbers
- Ensure that at least one chaperone is trained in the student's diabetes regimen
- Ensure that the student has the right amount and types of food (lunch and snack) plus extra food and plenty of water
- Ensure that the student has fast acting (high sugar) liquids (e.g., orange juice, cola), glucose tablets, and glucagon in case of low blood sugars
- Ensure that the student has a blood glucose meter, testing strips, lancets, antiseptic wipes (staff should bring gloves if student will not test independently) and logbook
- Ensure that the student has enough insulin, the right types and syringes
- If the student wears an insulin pump, be sure he/she has the pump and related supplies

Other, as specified by parent or student's physician

_____

Notes:

High Blood Sugar Help Sheet

Symptoms:

Thirst (dehydration)
Blurry vision
Increased hunger
Lethargy, drowsiness, exhaustion
Sweating
Vomiting

Frequent urination
Stomach pain
Nausea
Confusion
Fruity, sweet, or wine-like odor on breath
Inability to concentrate

_____
_____
_____

_____
_____
_____

Response:

1. If blood tests results are very slightly high _____ (insert blood sugar level)

- Regular activity may continue
- Drink water or sugar free drinks
- Monitor by testing regularly to see if blood sugar continues upward
- Chart test results

2. If blood test results are moderately high _____ (insert blood sugar level)

- No strenuous exercise
- Drink water
- Possible additional insulin (by chart or by instructions from physician or parent)
- Monitor by testing regularly to see if blood sugar continues upward or comes down
- Chart test results

3. If blood test results are very high _____ (insert blood sugar level)

- No strenuous exercise
- Drink water
- Additional insulin (by chart or by instructions from physician or parent)
- Ketone test if advised by physician or parent
    - If student has ketones, contact parent immediately
- Monitor by testing regularly to see if blood sugar continues upward or comes down
- Chart test results

*Please have your child's doctor enter blood glucose ranges

Low Blood Sugar Help Sheet

Mild to Moderate Symptoms:

Dizziness	Nervousness	Personality change
Blurry vision	Shakiness	Nausea
Crying	Sluggishness	Pale coloring
Irrational behavior	Sweating	Poor coordination
Hunger	Confusion	Headache
Light headed	Irritability	Drowsiness
Erratic response to questions	Unable to concentrate	

Severe Symptoms:

Convulsions Unconsciousness _____

Response:

1. If blood test results are slightly low and student is alert and lucid

- No exercise
- If it's almost lunchtime – eat lunch (student should be accompanied to make sure he/she gets to lunchroom and is eating); after eating, student should test again to make sure blood sugars levels are back within target range; may need an additional snack somewhat later in day
- Any other time – eat a snack; after eating, student should test again to make sure blood sugars levels are back within target range; may need an additional snack somewhat later in the day
- Continue to monitor by testing regularly to see if blood sugar comes up

2. If blood tests results are low and student is showing signs of low blood sugar but is able to eat

- Immediate food intake (quick-acting source of glucose e.g. juice, glucose gel or tablets)
- Additional food intake may be necessary (e.g. crackers)
- Direct monitoring of student by nurse or trained personnel until blood sugar levels return back within target range

3. If blood test results are low and student is showing signs of low blood sugar and is UNABLE to eat (student may be unconscious and/or experiencing convulsions and/or unable to swallow)

- Position student on floor on side to prevent falling/injury or choking
- Call nurse or other knowledgeable staff member
- Call 911
- Administer emergency glucagon shot
- Call Parent/ask office to call parent
- Direct monitoring of student by nurse or trained personnel until blood sugar levels return back within target range
- Additional food when student is able (e.g. crackers) if needed to keep blood sugar levels in target range

Emergency Contact Numbers

Student's Full Name _____

Mother _____

Home Phone _____ Work Phone _____ Cell Phone _____

Father _____

Home Phone _____ Work Phone _____ Cell Phone _____

1st Emergency Contact _____

Home Phone _____ Work Phone _____ Cell Phone _____

2nd Emergency Contact _____

Home Phone _____ Work Phone _____ Cell Phone _____

Physician/Endocrinologist _____

Office Phone _____ Other Contact Phone _____

Hospital of Choice _____

Address _____

Phone _____

Insulin information/dosages _____

_____

Other medical issues or other medication taken _____

_____

The Rights of Your Child with Diabetes

- Your child's rights
- Section 504
- Legal rights of the child with diabetes
- References for those who desire more information

Your Child's Rights

An important part of building a good working relationship with your child's school is a discussion regarding the rights of your child. It is important that you are aware of these rights and the laws that protect your child relevant to her education. While most of you will never have a problem with your school, it is still a good idea to have a plan in place that protects your child and her educational services.

There are at least three federal laws that address a school's responsibility to provide care to students with diabetes:

1. Section 504 of the Rehabilitation Act of 1973 (also known simply as Section 504)
2. The Americans with Disabilities Act of 1990 (ADA)
3. The Individuals with Disabilities Education Act (IDEA)

This section will give a general overview of these laws and how they protect your child. Additionally this section will provide you with the knowledge of how to effectively advocate for your child and initiate the programs and plans that protect her while in the school setting.

DISCLAIMER

The JDRF staff/volunteers compiling this manual are not attorneys and do not purport to give legal advice. While the information provided in this manual is believed to be accurate and up to date, JDRF makes no representations as to the accuracy or completeness of the information contained in this manual.

Section 504

According to this law, parents of qualifying children have the right to develop a Section 504 plan with their child's school. Any school that receives federal funding must comply with Section 504 laws, or they may lose the federal funds. This Act further prohibits programs and activities that receive federal financial assistance from discriminating against anyone with a disability. You do not need to wait until discrimination occurs to seek the protections of this law. Rather, initiating a 504 plan is a very proactive step in advocating for your child's rights. This law requires schools to identify educational needs and – when necessary – develop a "504" plan. A 504 plan is a legal (written) document specifying what "reasonable" modifications and accommodations the school must provide for a student with a disability (generally put into place for a student with a medical disability such as diabetes). A child does not need to require special education to be protected; children with type 1 diabetes are protected under this law.

Note on Standardized Testing

Under this law high school students (and students in lower grades taking state tests) with diabetes can receive special accommodations when taking standardized tests (e.g., PSAT, SAT, and ACT). These accommodations usually include "stop the clock" breaks for blood glucose testing, bathroom visits, or taking emergency glucose to treat low blood sugars. Testing organizations (for PSAT, SAT, and ACT) generally require that students have a 504 plan on file before providing the accommodations.

Americans with Disabilities Act (ADA)

This law specifically prohibits all schools and day care centers – except those run by religious institutions – from discrimination against people with disabilities, including diabetes. Its definition of disability is the same as in Section 504 (includes diabetes).

The laws within this act say that your child with diabetes has the right to go to school, play a sport, join a club, and do everything else that kids without diabetes do. It further states that public schools and other covered organizations must make "reasonable accommodations" for your child's diabetes.

Individuals with Disabilities Education Act (IDEA)

Many students with diabetes do not qualify for IDEA protection, but it is important to know what it is in case you may qualify. This law covers children whose disability impairs their academic performance. It requires that such children be given a "free, appropriate public education." Qualification depends on how diabetes affects the student's ability to learn. If a student qualifies, he has the right to develop an Individualized Education Program (IEP) with his school. An IEP is similar to a Section 504 but includes specific measures to address your child's academic performance and needed special education and other related services.

Additional State Laws

Even though federal laws already provide protection for children with disabilities, some states provide greater protection to students with diabetes due to the passage of school diabetes care legislation. States with such legislation include:

- California
- Connecticut
- Hawaii
- Kentucky
- Massachusetts
- Montana
- Nevada
- North Carolina
- Oregon
- Oklahoma
- South Carolina
- Tennessee
- Texas
- Utah
- Virginia
- Washington
- West Virginia
- Wisconsin

Each state varies in its coverage. The most comprehensive laws are currently found in North Carolina, Virginia, and Washington.

The Parent/School Partnership Continues

504 plans are a way for you to hold the school accountable for meeting your child's needs while in the school's care. Remember, though, that this is a partnership you are building with your child's school and all parties have a role in the 504 process.

School's Role in the 504 Process

It is the responsibility of the school and its personnel to have an understanding of diabetes and be trained in its management and in the treatment of diabetes emergencies. Knowledgeable, trained school personnel are essential to a student's safety and physical well being when dealing with immediate health risks of high or low blood glucose levels.

Furthermore, an individualized Diabetes Medical Management Plan (the 504 plan) should be developed and signed by the school, the parent or guardian, and the child's diabetes management care team. The Diabetes Medical Management Plan (the 504 plan) should address the specific needs of the child and provide specific instructions related to the following:

- Times/places for blood sugar monitoring, including accommodations for testing and treating
- Ensuring that staff members are trained in checking blood sugar levels, recognizing and treating high and low blood sugar symptoms, and administering both insulin and glucagon
- Allowing the student to eat whenever and wherever necessary, including eating lunch at an appropriate time and allowing enough time to finish eating
- Allowing extra trips to the bathroom or water fountain
- Ensuring the student's full participation in all sports, extracurricular activities, and field trips, with the necessary care and/or supervision
- Permitting extra absences for medical appointments and sick days when necessary, without penalty

Parent's Role in the 504 Process

In addition to submitting a formal request for a 504 plan and a cover letter to the school, a parent or guardian is responsible for providing the school with the following:

- All materials and equipment necessary for diabetes care tasks, including blood sugar testing supplies and insulin administration (if needed). The parent is responsible for the maintenance of the equipment and must provide instructions to ensure the proper disposal of materials. A separate logbook should be kept at school for the staff or student to record blood glucose test results.
- Supplies to treat hypoglycemia, including a source of glucose and a glucagon emergency kit.
- Information about diabetes.
- Emergency phone numbers for the parent and the student's diabetes doctor (and staff) so that the school can contact these individuals with diabetes–related questions or during emergencies.
- Information about the student's meal and snack schedule. The parent should work with the school to coordinate this schedule with that of the rest of the class as much as possible. For young children, instructions should be given for when food is provided during school parties and other activities.

Legal Rights of the Child with Diabetes

If a school attempts to discriminate against your child with diabetes or is unable or unwilling to commit to some agreement with the parents and child about how the child will be provided equal opportunity to participate in academic, extracurricular, or other school activities, then schools can be compelled by the legal system to provide these services.

It is suggested that the following steps be followed in such cases:

1. If the parents, school, and student cannot come to a mutual agreement about a 504 Plan or the parents suspect that the school isn't abiding by the agreement, the parents must request in writing that a 504 meeting take place. Prior to the meeting, the parent should review sample 504 plans (see Educate the Educator section) and prepare a list of modifications and accommodations they feel are appropriate. The parent has the right to bring a friend, advocate, or lawyer to the 504 meeting to assist in the discussion.
2. On rare occasions, the student's academic performance may be so adversely affected by diabetes complications that he/she may need special education services. In such cases it is the parent's responsibility to formally request special education testing. Before this testing can take place, parents must give written permission to the school to administer these tests. The student must complete the testing and meet certain criteria to be eligible for special education services. If he/she is deemed eligible, an IEP (individualized education plan) is written and certified special education teachers become involved in the education of the child.

If your child is denied a 504 Plan or you feel he/she has been discriminated against, please contact your local chapter for resources related to being denied a 504 Plan and suggested next steps.

Common 504 Plan Questions

Is a child with Type 1 diabetes automatically eligible for a 504 Plan?

The law does not provide any automatic eligibility for a 504 Plan. 504 eligibility is made on an individual basis. A team of people knowledgeable about the student must convene and determine eligibility. That being said, it would be highly unlikely that a student with Type 1 diabetes would not qualify for a 504 Plan. Several life functions are certainly impacted which would provide the basis for eligibility (e.g. "caring for oneself" and "learning" come quickly to mind.) If a school has not suggested a 504 Plan, the parent should request, in writing, a 504 evaluation to take place. There are numerous sources (some included in this Manual) which can help a parent with writing this request as well as provide information on what is to be considered by the team to determine eligibility.

Must the parent of a child with Type 1 diabetes be a part of the 504 Team?

The law provides for the parent to be notified of the result of the 504 meeting/evaluation/discussion but does not specifically say a parent must be present at the meeting. However, the law does state that the 504 team is made up of persons knowledgeable about the student, which implies that if a parent is not allowed to attend, there may be cause for complaint and a hearing. It would be hard to argue that the parent is not a knowledgeable person about the child.

Must the 504 Plan be in writing?

The law says that the child must receive the accommodations agreed to but does not specifically state that the plan must be in writing. That being said, it certainly would be best practice (and common sense) to put the plan in writing. A written plan is the only way that a school can document that they are providing all of the accommodations agreed to. Not having the plan in writing could easily be cause for a complaint and violation of Section 504. As one of the representatives from the Department of Education Office of Civil Rights stated, "OCR would have no concept how a district/school would prove a 504 plan exists and the accommodations being made without the Plan being in writing."

Is there a requirement for an ANNUAL review of a 504 Plan?

The law does not require an annual review. It does require a "periodic" review. If the 504 Plan is well written and includes a requirement for any new teacher or staff member who will be in contact with the child to be informed and trained, and nothing has changed in terms of the needs of the child, an annual review wouldn't be necessary. This is one of those areas where parents can be sympathetic to school personnel time constraints. If the school is doing everything necessary and willingly trains the child's teachers every year, and the 504 Plan already covers everything it needs to, then why make the school have an unnecessary meeting.

The law does require a "periodic" review. IDEA requires a review every three years and that should also probably be the maximum time frame a 504 Plan should go without a formal review. There would also have to be a formal review at any time a change is needed in the 504 Plan to meet the needs of the child. It also may be necessary to have a review when the child goes to a new school in the same district (e.g. elementary to middle school building or middle school to high school building.)

Must the school provide a nurse or other trained person to provide services for my child (e.g. give insulin, test blood sugar, give glucagon in an emergency?

Yes. This should be written into the 504 Plan. Nurses get sick and are absent from school for that and other reasons, so it is very important to include in the 504 Plan that staff members in addition to the nurse be trained to provide these services.

Some states have laws that state that only licensed staff members can give medication and/or injections. California is one of those states. However, a recent California decision based on a lawsuit states that:

> When federal and state laws are reconciled, it is clear that it is unlawful for an LEA [local school district] to have a general practice or policy that asserts that it need not comply with the IDEA or Section 504 rights of a student to have insulin administered at school simply because a licensed professional is unavailable. In such situations, federal rights take precedence over strict adherence to state law so that the educational and health needs of the student protected by the Section 504 Plan or IEP are met.

Can the school say they will not qualify a child with Type 1 diabetes because the child is doing well academically and is socially responsible and personally independent?

Again, eligibility is not automatic for anyone and a team with knowledge about the child must evaluate and determine eligibility. However, Section 504 protects all persons with a disability who:

1. Have a physical or mental impairment which substantially limits one or more major life activities;
2. Have a record of such an impairment; or
3. Are regarded as having such an impairment.

In number one, above, major life activities are defined as functions such as caring for oneself, performing manual tasks, walking, seeing, hearing, speaking, breathing, learning or working. A strong argument could be made that students with Type 1 diabetes are substantially limited, especially when blood sugars are not normal, in caring for oneself, performing manual tasks, walking, seeing, hearing, speaking, and learning. How can a school argue that when a student is in insulin shock, that this student's abilities in these areas are not substantially limited. A student in insulin shock cannot walk, speak, learn, or care for themselves. Learning would be substantially limited if a student with Type 1 diabetes missed field trips, missed instruction due to high blood sugar, missed class due to being in the nurse's office testing blood, etc. A child with Type 1 diabetes would also be eligible for a 504 Plan in numbers 2 and 3 above. Certainly a child with Type 1 diabetes has a record of an impairment AND would be regarded as having an impairment.

There are certainly other arguments which can be made that a student with Type 1 diabetes, who is doing well, is still eligible for a 504 Plan. Things do change and learning may be substantially impacted by changes in blood sugar due to a growth spurt, early adolescence (hormones), etc. School or teacher rules may prevent snacks in the classroom, which would need a 504 Plan to provide for an exception to this rule. School rules may prevent blood testing to occur in the classroom and again, a 504 Plan would be needed to provide for an exception to this rule.

A school that will not provide a 504 plan because a student with Type 1 diabetes is "doing well" is setting itself up for great trouble. This is a lawsuit against the school district waiting to happen if a school has not set up a 504 plan with training for teachers, procedures for handling a child with Type 1 diabetes ongoing needs as well as procedures for emergencies, and a written plan demonstrating that the school is providing full access to school activities and learning opportunities.

Can the school prevent my child with Type 1 diabetes from wearing a diabetes ID bracelet?

Unless a school has a "no jewelry of any kind" rule (which VERY few schools have), a student should be able to wear an ID bracelet. If it's written into the 504 plan, the child should be able to wear it, no matter what the school rule. On occasion, there may be a legitimate safety reasons for a particular teacher or coach to ask the child to temporarily remove the ID bracelet (e.g. a shop class where power tools are being used and where a bracelet may be dangerous; a sport with a lot of physical contact where another child may be injured by the ID bracelet.)

What is the difference between IDEA and Section 504? What should I be requesting for my child with Type 1 diabetes?

IDEA is an education act (and sometimes known as Special Education) and Section 504 is a Civil Rights Act. In practical terms, the vast majority of students with Type 1 diabetes will fall under the Section 504 umbrella which is to prohibit discrimination on the basis of a disability. Most students with Type 1 diabetes will have no reason to be involved in the world of IDEA. There are only two reasons a diabetic student might be eligible for IDEA.

- The impact on diabetes is so great that the student's learning is severely impacted (which might qualify the diabetic child for special education services under the other health impaired category, or
- The diabetic child has an additional disability (most likely not related in any way with diabetes) which demands an individualized education plan (IEP) e.g. mental retardation, autism, emotional disturbance, learning disability, etc.

What should I do to make sure that my child with Type 1 diabetes has accommodations available for ACT/SAT tests and state standardized tests?

Accommodations for state standardized tests should be listed in a student's 504 plan For the ACT test, there is a form to complete which is available at **http://www.act.org/aap/disab/opt1.html.** Note that one of the requirements is to, "Enclose written documentation from your school describing in detail the accommodations you normally receive in school." Some high schools may require a 504 plan stating these accommodations before they would provide them to ACT. Note that another requirement is to provide, "The name and phone number of a school official familiar with your current testing accommodations." It would be a good idea to meet with the child's counselor a few months before the test will be given to make sure that the counselor (or another identified school staff member) is able to respond if contacted by ACT.

The SAT has similar requirements such as:

- have documentation on file at your school that supports the need for requested accommodations and meets the Guidelines for Documentation, and
- receive and use the requested accommodations, due to the disability, for school-based tests.

For further information on the SAT test, go to **http://www.collegeboard.com/ssd/student/index.html**

Where do I go when I believe that the school is discriminating against my child with Type 1 diabetes and not providing the appropriate services?

Step 1: Try one more time at the school level. Try to have a one-on-one heart-to-heart with the school principal. Acknowledge that school people are busy and working hard. Be nice, be respectful, be reasonable.

Step 2: In almost all school systems, there is a special education coordinator or someone who is charged with being in charge of Section 504 issues. Again, be nice, be respectful, be understanding of school limitations, and have your list of items that are on your non-negotiable list.

Step 3: Contact the school superintendent with the same attitude and issues as above.

Step 4: Obtain the services of an attorney and file for a due process hearing.

Step 5. Contact an appropriate person at the state department of education. Be prepared with any documentation you have (request for a 504 meeting, dates of any meetings, paperwork from these meetings) along with your non-negotiable list. Based on the advice of this agency, filing a formal complaint may be the next step.

Step 6: Contact the regional office of the Department of Education Office of Civil Rights for your state. Available at **http://www.ed.gov/about/offices/list/ocr/addresses.html.** Based on the advice of this agency, filing a formal complaint may be the next step.

Do private schools have to provide the same services as public schools?

1. If the private school does not receive federal funding, then the 504 Act does NOT apply. Therefore, the school would not have to consider or provide a 504 plan. If the private school DOES receive federal funding, then they would have to provide the same services as public schools.
2. The ADA (American Disabilities Act) applies to all schools EXCEPT those run by religious institutions. If this private school is run by a religious institution, then the parent is pretty much at the whim of what the school is willing to do and the parent/child have little recourse as far as I can see. If the private school is NOT run by a religious institution, then ADA applies and the school would be prohibited from discrimination against people with disabilities, including diabetes. "Reasonable accommodations" must be provided.

References for Those Who Desire More Information

A great deal of information about schools and students with diabetes is available, including sample 504 plans, checklists for school personnel, details on the Law and Schools, information for teachers and other school personnel, help for parents, help for the child with diabetes, etc. The following list is just a sampling of such resources:

- Helping the Student with Diabetes Succeed: A Guide for School Personnel: This guide was produced by the National Diabetes Education Program and is a joint program of the National Institutes of Health and the Centers for Disease Control and Prevention and more than 200 other partner organizations. It is available at **http://www.ndep.nih.gov/resources/school.htm**
- Juvenile Diabetes Research Foundation: **www.jdrf.org (Check the Diabetes in School link.)**
- Children With Diabetes: **www.childrenwithdiabetes.com**
- American Diabetes Association: **www.diabetes.org**

Diabetes in the Day Care Setting and in the College Years

- Diabetes in the Day Care Setting
- Diabetes in the College Years

Diabetes in the Day Care Setting

First and foremost, remember that the laws just discussed in the previous sections apply to the parent with a child in daycare as much as they do for a school aged child. Day care centers (with the exception of religious affiliations) cannot legally deny your child access to their services because of diabetes. Many day care centers receive federal funding through Head Start or other child development government programs. Under these laws, diabetes is considered a disability, and it is illegal for day care centers to discriminate against children with disabilities. In addition, any school that receives federal funding or any facility considered open to the public must reasonably accommodate the special needs of children with diabetes.

Remember, all of the information in the previous sections of this guide also applies to the parent with a child in day care.

The parent/guardian and the child's diabetes doctor should develop an individualized plan for the child's day care; the plan should address the specific needs of the child and provide specific instructions for each of the following:

1. Blood glucose monitoring, including the frequency and circumstances requiring blood glucose checks.
2. Insulin administration (if necessary), including doses/injection times prescribed for specific blood glucose values, and the storage of insulin.
3. Meals and snacks, including food content, amounts, and timing.
4. Symptoms and treatment of hypoglycemia (low blood glucose), including the administration of glucagon if recommended by the student's health care provider.
5. Symptoms and treatment of hyperglycemia (high blood glucose).
6. Checking for ketones and appropriate actions to take for abnormal ketone levels, if requested by the student's health care provider.

Do day care centers have to take my child with Type 1 diabetes?

Based on the American Disabilities Act (ADA) and Section 504 of the Rehabilitation Act of 1973, it is illegal for schools and/or day care centers to discriminate against children with disabilities. In addition, any school that receives federal funding or any facility considered open to the public must reasonably accommodate the special needs of children with disabilities. The exception is child care centers that are actually run by religious entities. So, almost all day care centers are covered.

- Children with disabilities must have an equal opportunity to participate in the child care center's programs and services. This means that if a day care center is full, a child with Type 1 diabetes must be put on the list for openings. It does not mean that the child with Type 1 diabetes must be taken ahead of other applicants
- Centers have to make reasonable modifications to their policies and practices to integrate children, parents, and guardians with disabilities into their programs unless doing so would constitute a fundamental alteration of the nature of the child care program. Children with diabetes can usually be integrated into a child care program without fundamentally altering it, so they should not be excluded from the program on the basis of their diabetes
- Centers must provide appropriate training to one or more employees and provide for the administration of insulin, glucagon, and blood testing and provide access to snacks and other appropriate food
- The child's parents are responsible for providing insulin, glucagon, blood testing equipment, training, and food necessary for the child's care

A special note: The Department of Justice has settlement agreements with KinderCare, La Petite Academy, and others which address the issue of admitting children with Type 1 diabetes to their child care centers

Diabetes in the College Years

It is important for parents to be aware that things change a bit at the college level. At the elementary and secondary levels, the school district is responsible for identifying, evaluating, and providing the appropriate services for students with diabetes. Colleges and universities, on the other hand, have no responsibility to identify diabetes or any other disabilities. It is the student's responsibility to make his or her disability known and to request special accommodations. Once the student or parents have done that, the college should be willing to fulfill the requirements of Section 504.

As parents, you may want to inquire about special accommodations while exploring colleges with your teen in order to help guide his decision based on his specific needs. Once your teen is accepted to the college and you begin the enrollment process, housing applications, etc., you can work with a disabilities coordinator to complete the necessary paperwork. If your teen is living on campus, it is suggested that you put in writing any desired accommodations and the need for nutritional data from food services.

Regarding confidentiality: Most colleges will request that parents indicate on a special signed form who needs to know about the student's disability. In most cases, the Dean of Students, the accommodations coordinator, food services, the RA, and professors need to know. That form does not give them consent to discuss your student's health issues with other parents, students, or outside personnel who have no need to know why certain accommodations are being made.

Alcohol and Diabetes

It is no secret that many students consume alcohol during their college years. It is very difficult to control blood sugar in the presence of alcohol, and the presence of alcohol can impair judgment needed to detect and treat hypoglycemia. Because of the possibility that some students will choose to drink while at school, we have included some important information about the effects of alcohol on the body.

Moderate alcohol usually causes the blood sugar to rise. If you choose to drink alcohol, it is best to do so only occasionally and when your diabetes and blood sugar levels are well-controlled. One drink of alcohol should be counted as two fat exchanges, and regular beer also counts as an extra 1 starch exchange.

While a moderate amount of alcohol can cause blood sugar to rise, excess alcohol can actually decrease your blood sugar level by preventing the liver from adding glucose to the bloodstream sometimes causing it to drop dangerous levels. Alcohol can also interfere with insulin efficiency, increase triglyceride levels, increase blood pressure, and cause flushing, nausea, increased heart rate, confusion, and slurred speech.

Following are a few ways for people with type 1 diabetes to drink more responsibly if they choose to drink:

- Do not drink more than two alcoholic drinks in a 24-hour period. (One alcoholic drink = 5 oz. glass of wine, 1 ½ oz. "shot" of liquor, or 12 oz. beer).
- Drink alcohol only with food.
- Drink slowly.
- Avoid "sugary" mixed drinks, sweet wines, or cordials.
- Mix liquor with water or alternate between glasses of water and alcoholic beverages.

Warning: Glucagon shots may be less effective in treating severe low blood sugars caused by drinking because of the effect of alcohol on the liver.

For the Student: Going Away From Home - JDRF.org Resources

Going away to college can be scary, especially if it's your first real foray into working with type 1 diabetes professionals on your own. Your medical care team is critical to your physical well-being as well as your success in college, so invest time up front in finding good medical professionals to work with. When you visit colleges, be sure to visit their health centers. Make an appointment to meet with representatives there regarding available type 1 diabetes care. Interview the doctors, nurses, and educators.

Your parents will most likely be very helpful to you in completing this process. Don't feel you have to rely on the school health center if better health care is available elsewhere in the area. You may want to ask your pediatrician for recommendations of endocrinologists in the area.

Discuss health insurance coverage with your parents before you leave home. You should know what your options are, how to handle emergency situations, and what your insurance requires.

More tips for college:

- Request a meeting with your parents and the Resident Assistant to go over emergency procedures. Offer to give the RA a glucagon kit to use in case you have severe low blood sugar
- Have a small refrigerator in your room for supplies and snacks. You may want to buy it yourself instead of sharing the expense with a roommate so you won't feel guilty taking up so much of the space. Let friends know that snacks in the refrigerator are necessary for you and ask them not to help themselves without asking first
- Whatever you take for insulin reactions, have your parents buy it in bulk. That way, you won't think twice about sticking a handful into whatever bag or coat you grab
- When you go to a party, make sure that someone you know will be there - someone who knows you have type 1 diabetes and what to do in case of a reaction
- If you don't have relatives or friends nearby, have your parents network through their friends to find someone who can act as a local emergency contact if needed
- Make the decision to ALWAYS wear a Medic Alert bracelet. There are many different styles available these days
- Photocopy insurance and prescription cards, in case your wallet is lost or stolen. Your parents should keep a copy Keep another in your dorm room
- Have two blood glucose meters, in case one malfunctions, and extra batteries
- Make sure you have a safe system for discarding needles and strips
- Keep a three-month inventory of supplies. Be sure to check periodically and call home before you start to run low. As a safeguard against running out of insulin, make sure your prescriptions are on file at a local pharmacy
- Thank your roommate ahead of time for providing support. An occasional card or small gift works wonders
- Give your roommate a "dear roommate" letter explaining type 1 diabetes and what your needs are

Letter to the Roommate – JDRF.org Resources

When you head off to school, you don't need to tell everyone you have type 1 diabetes, but some key people need to know: Health services, of course; also, your roommate, the resident assistant (RA), and a few close friends. Here is a sample letter to a new college roommate, provided by a JDRF volunteer whose daughter has type 1 diabetes; it can also be adapted for the RA.

Dear Roommate:
I am letting you and a few other people around me know that I have type 1 diabetes (juvenile diabetes). Please understand that I do not want or need to be treated differently because of my diabetes, but there are some things I'd like you to know about the condition.

Usually my type 1 diabetes is under control, but sometimes my blood sugar gets too low or too high, which can endanger my health. To keep that from happening, I have to do certain things, like test my blood sugar and (wear an insulin pump/give myself insulin shots). It may help you to understand if I first tell you a little about diabetes.

First of all, please know that type 1 diabetes is not contagious. When a person eats a meal, the food is broken down into different substances, is absorbed, and enters the bloodstream. One of these substances is glucose, a sugar. The body cannot function without glucose. In turn, the body cannot use glucose without insulin, which is produced by the pancreas. My pancreas, like that of other people with type 1 diabetes, doesn't produce insulin, so I have to take insulin shots every day. It's mainly insulin, exercise, food, and stress that cause my blood sugar to go up or down.

I do not expect you to have to take care of me, but I do sometimes have low blood sugars or insulin reactions, which might confuse or scare you if you don't understand what's happening. During a reaction, for no apparent reason, you may notice any of these symptoms coming on suddenly:

- confusion
- moodiness
- irritability
- incoherence
- shakiness
- glassy stare

I usually know when my sugar is getting low and can avoid a reaction, but not always. If the low blood sugar persists too long, I may seem sleepy and withdrawn. At these times, I need to drink a sugared drink or eat something from my "low blood sugar food stash" right away. I may not be able to get it myself, so I would appreciate your help, even if I resist. If you don't feel comfortable with that, please call the RA or health services to help me.

Once I have some sugar, I should seem much better within 10-15 minutes. If not, try giving me more food and call one of my contacts listed below. Low blood sugar can be life threatening to me, so my food stash is like my "medicine" and needs to be kept separate from the food we can share. Finally—and hopefully this will never happen—if you ever find me unconscious, anytime, including after partying, or if I am sleeping longer than usual and you cannot wake me, I am probably in serious danger. Please call 911.

If you feel uncomfortable about being around the shots and finger pricks, or keeping an eye open for emergencies, I'm happy to talk with you about it. My type 1 diabetes is totally familiar to me but I realize it may take a little time and experience for you to adjust. Believe it or not, in spite of all the challenges that come with diabetes, I am able to lead a pretty "normal" everyday life. Most people won't even know that I have diabetes unless I tell them. I'm sure you have lots of questions, so let's set a time to talk.

Thanks,

(Signature)

You may also want to include a list of emergency contacts for low blood sugars

About JDRF

- Research Funding Facts

About JDRF

Dedicated to Finding a Cure

The Juvenile Diabetes Research Foundation International is the world's largest charitable funder and advocate of type 1 diabetes research. The mission of JDRF is to find a cure for diabetes and its complications through the support of research. Type 1 diabetes is a disease, which strikes in childhood, adolescence, or adulthood, but lasts a lifetime. It requires multiple injections of insulin daily or a continuous infusion of insulin through a pump. Insulin, however, is not a cure for diabetes, nor does it prevent its eventual and devastating complications, which may include kidney failure, blindness, heart disease, stroke, and amputation.

Building Upon Research Successes

JDRF funding and leadership is associated with most major scientific breakthroughs in type 1 diabetes research to date. In fact, JDRF funds a major portion of all type 1 diabetes research worldwide, more than any other charity. JDRF provided more than $137 million to diabetes research in FY2007, and is responsible for more than $1.16 billion in direct funding since it was founded. Our research review process not only includes leading research scientists from around the world, but lay reviewers who either have type 1 diabetes or have family members with type 1 diabetes, ensuring that JDRF funds research with the greatest impact throughout the world, leading to results as soon as possible.

Moving Research from Bench to Bedside

JDRF is driven to be a leading catalyst for development science that delivers therapeutics to improve the lives of people with diabetes in the near term, ultimately leading to a cure. Working toward this goal, JDRF has taken the lead in translating basic research breakthroughs into cure therapies in such areas as restoring autoimmunity, preventing and reversing complications, islet replacement, beta cell regeneration, and achieving metabolic control. The Foundation creates multidisciplinary programs that bring together diabetes researchers from both academic institutions and industry to find a cure for diabetes and its complications.

Efficiently Organized for Successful Results

JDRF is structured on a business-world model that efficiently and effectively directs resources to research aimed at finding a cure as soon as possible. More than 85 percent of JDRF's expenditures directly support research and research-related education. Because of its unwavering focus on its mission to find a cure, JDRF annually receives top rankings from independent sources that rate charitable giving. JDRF leverages its research impact by partnering with and stimulating increased research spending on the part of public and private medical organizations and other entities throughout the world.

A Backbone of Dedicated and Active Volunteers

JDRF was founded in 1970 by the parents of children with type 1 diabetes. As a result, JDRF volunteers have a personal connection to type 1 diabetes, which translates into an unrelenting commitment to finding a cure. These volunteers are the driving force behind more than 100 locations worldwide that raise money and advocate for government spending for type 1 diabetes research.

Research Funding Facts

Since it's founding in 1970 by parents of children with type 1 diabetes, JDRF has awarded more than $1.16 billion to diabetes research, including more than $137 million in FY2007. More than 85 percent of JDRF's expenditures directly support research and research-related education. In FY2007, the Foundation funded more than 700 centers, grants, and fellowships in 20 countries.

Areas of Scientific Investigation:

- Artificial Pancreas
- Beta Cell Development
- Beta Cell Function
- Beta Cell Regeneration
- Clinical Trials
- Environmental Triggers
- Gene Therapy
- Genetics
- Hypoglycemia
- Immunology
- Islet Transplantation
- Nephropathy
- Neuropathy
- Retinopathy
- Stem Cells
- Technological Interventions
- Tolerance
- Wound Healing

JDRF's Research Goals

JDRF plays a unique role in setting the global direction of diabetes research resources, to ensure that they are used as effectively as possible as a "cure enterprise" to bring about a world without diabetes and its complications. To that end, the organization has identified a set of cure therapeutic goal areas on which it will focus its research funding efforts. JDRF believes some combination of these areas of research focus currently holds the best potential to lead to breakthrough cures and treatments for type 1 diabetes and its complications.

JDRF will continue to actively pursue research within the framework of the following goals while remaining flexible enough to quickly respond to new opportunities as they arise:

Autoimmunity: Stopping or reversing the immune system response that causes diabetes -- the attack on insulin-secreting cells in the pancreas.

Complications: Understanding how diabetes causes complications, and developing drugs, treatments, and therapies to stop that process, or reverse the impact of the different types of individual complications.

Replacement: Replacing cells killed off by diabetes with functioning ones from a donor -- similar to a heart or kidney transplant -- including increasing the supply of cells that can be transplanted.

Regeneration: Regenerating insulin-producing cells in people who have diabetes (as opposed to transplanting cells from organ donors or other sources).

Metabolic Control: Demonstrating that advanced monitoring tools might significantly improve the health of people with diabetes, and developing technologies that link insulin pumps and continuous glucose monitors.

FY2007 JDRF Research Funding

Autoimmunity: $38.5 million

Complications: $29.6 million

Metabolic Control: $7.6 million

Regeneration: $14.6 million

Replacement: $47.6 million

Resources/References

Below is a listing of published government materials and other information sources containing additional information about the topics covered in this guide.

Helping the Child Succeed: A Guide for School Personnel issued by the National Diabetes Education Program and endorsed by JDRF and many other organizations.
http://ndep.nih.gov/diabetes/pubs/Youth_NDEPSchoolGuide.pdf

Sample 504 Plan and Individualized Healthcare Plan issued by the Disability Rights Education & Defense Fund (in collaboration with the ADA). These are extremely thorough and comprehensive plans that can be tailored to meet a child's individual needs.
http://www.dredf.org/504/504-plan-2004.pdf

Protecting Students with Disabilities issued by the U.S. Dept of Education's Office for Civil Rights. Written in a frequently-asked-questions format.
*http://www.ed.gov/about/offices/list/ocr/504faq.*html

Legal Text of Section 504 of the Rehabilitation Act of 1973 posted on the OCR website.
http://www.ed.gov/policy/rights/reg/ocr/edlite-34cfr104.html

Legal Text of Americans with Disabilities Act of 1990 posted on the OCR website.
http://www.ed.gov/policy/rights/reg/ocr/edlite-28cfr35.html#S101 or this pamphlet version at http://www.ed.gov/about/offices/list/ocr/docs/hq9805.html

The Civil Rights of Students with Hidden Disabilities issued by the OCR and posted on its website. NOTE: This is the only official document I've ever found which specifically recognizes "diabetes" as a medical condition that meets the eligibility criteria of "disabled". As such, it becomes very useful when a school tells a family that diabetes isn't a condition eligible for Section 504.
*http://www.ed.gov/about/offices/list/ocr/docs/*hq5269.html

What is "Free, Appropriate Public Education"? issued by OCR
http://www.ed.gov/about/offices/list/ocr/docs/edlite-FAPE504.html

Listing of U.S. Department of Education's OCR Regional Offices
http://www.ed.gov/about/reports/annual/ocr/annrpt2004/report_pg22.html

OCR Listing of Parental Advocacy Resources
*http://www.ed.gov/parents/needs/rights/ocr/par*ents2.html

OCR Online Grievance of Non-Compliance / Discrimination Complaint Form
http://www.ed.gov/about/offices/list/ocr/complaintintro.html

Clarification on the Process of Delegating in the School Setting Position Statement issued by the National Association of School Nurses (NASN) adopted 9/15/05.
http://www.nasn.org/Portals/0/statements/consensusdelegation.pdf

School Nurse Role in Care and Management of the Child with Diabetes in the School Setting reissued and adopted by NASN in June 2006.
http://www.nasn.org/Default.aspx?tabid=216

Caring for Diabetic Children in the Classroom position statement issued by the American Federation of Teachers, as well as related printed materials.
http://www.aft.org/topics/diabetes/index.htm

Resolution: Recognition and Care of School-Aged Children with Diabetes adopted by the National PTA in June 2006.
http://www.pta.org/archive_article_details_1152136026718.html

Diabetes and the School Setting, American School Health Association
Health In Action: www.ashaweb.org

Diabetes Management in the School Setting: A Resource Guide for School Health Nurses, Missouri Association of School Nurses
Contact: MO Dept. of Health & Senior Services; Division of CDC and Health Promotion Box 750, Jefferson City, MO 65102 (573) 522-2861

The Diabetes Ready-Reference Guide for Healthcare Professionals, Pathophysiology of Diabetes & Sick Day Rules Ballard, AM American Diabetes Association

Type 1 Diabetes in School, Juvenile Diabetes Research Foundation
http://www.jdrf.org/index.cfm?page_id=103439

School Discrimination, American Diabetes Association
www.diabetes.org/advocacy-and-legalresources/discrimination/school.jsp

Sample Section 504 Plan, Disability Rights Education and Defense Fund
www.dredf.org/504/504-plan-2004.pdf

Resolution-Recognition and Care of School-Age Children with Diabetes, National Parent Teach Association
www.pta.org/archive_article_details_1152136026718.html

The Americans with Disabilities Act, US Department of Education, Office of Civil Rights
www.ed.gov/about/offices/list/ocr/docs/hq9805.html

How to file a discrimination complaint with the Office of Civil Rights, US Department of Education, Office of Civil Rights
www.ed.gov/about/offices/list/ocr/docs/howto.html

Legal Rights of Students with Diabetes, James Rapp, Arent Shereen, Brian Dimmick, Brystal Jackson
www.diabetes.org/advocacy-and-legalresources/attorneymaterials/legalrights.jsp

Position Statement: Diabetes Care in the School & Daycare Setting, Diabetes Care Journal
http://care.diabetesjournals.org/cgi/content/full/29/suppl_l/s49

Care of Children and Adolescents with Type 1 Diabetes, Diabetes Care Journal
http://care/diabetesjournals.org/cgi/content/full/28/1/186

Sample 504 Plan by Age and Insulin Therapy, Children with Diabetes
http://www.childrenwithdiabetes.com/504/

Type 1 Diabetes in College, Juvenile Diabetes Research Foundation
http://www.jdrf.org/index.cfm?page_id=103581

For Parents & Kids: For Schools, American Diabetes Association
http://www.diabetes.org/for-parents-and-kids/for-schools.jsp

For School: Tips for Teachers, American Diabetes Association
http://www.diabetes.org/uedocuments/TenTipsforTeachers.pdf

For Schools: Diabetes Management at School, American Diabetes Association
http://www.diabetes.org/for-parents-and-kids/for-schools/diabetes-management.jsp

For Schools: Roles & Responsibilities, American Diabetes Association
http://www.diabetes.org/for-parents-and-kids/for-schools/roles.jsp

Diabetes and the Law: Discrimination at School, American Diabetes Association
http://www.diabetes.org/for-parents-and-kids/diabetes-and-the-law/school-discrimination.jsp

Diabetes and the Law: Know Your Rights, American Diabetes Association
http://www.diabetes.org/for-parents-and-kids/diabetes-and-the-law/know-your-rights.jsp

Diabetes and the Law: La diabetes y la legislacion, American Diabetes Association
*http://www.diabetes.org/espanol/diabetes-y-la-legis*lacion.jsp

Diabetes at School, Children with Diabetes
*http://www.childrenwithdiabetes.com/d_0q_000.*htm

States with Special Laws: School Legislative Efforts, American Diabetes Association
www.diabetes.org/advocacy-and-legalresources/discrimination/school/legislation.jsp

Contact your local JDRF chapter for more resources:

Alabama Chapter
Birmingham, AL 35223
(205)871-0333

Austin Chapter
Austin, TX 78759
(512) 343-0663

Bakersfield Council
Bakersfield, CA 93301
(661)636-1305

Baton Rouge Branch
Baton Rouge, LA 70809
(225) 932-9511

Capitol Chapter
Washington, DC 20005
(202) 371-0044

Central Florida Chapter
Altamonte Springs, FL 32714
(407) 774-2166

Central Jersey Chapter
Shrewsbury, NJ 07702
(732) 219-6654

Central New York Chapter
Liverpool, NY 13088
(315)453-9327

Central Oklahoma Chapter
Oklahoma City, OK 73112
(405) 810-0070

Central PA Chapter
Harrisburg, PA 17112
(717) 901-6489

Central Virginia Chapter
Richmond, VA 23230
(804)254-8014

Charlotte Chapter
Charlotte, NC 28273
(704) 561-0828

Colorado Springs Branch
Colorado Springs, CO 80907
(719) 633-8110

Delaware Chapter
Wilmington, DE 19801
(302)888-1117

Desert Southwest Chapter
Phoenix, AZ 85018
(602)808-9548

East Central PA Branch
Wyomissing, PA 19610
(610)373-6488

East Tennessee Branch
Knoxville, TN 37919
(865) 544-0768

Eastern Iowa Branch
Cedar Rapids, IA 52403
(319) 393-3850

Eastern PA Chapter
Bala Cynwyd, PA 19004
(610)664-9255

Fairfield County Chapter
Norwalk, CT 06854
(203) 854-0658

Florida Suncoast Chapter
Sarasota, FL 34231
(941) 929-0621

Georgia Chapter
Atlanta, GA 30346
(404)420-5990

Gr. Adirondack Region Branch
Glens Falls, NY 12801
(518) 743-1700

Gr. Ft Worth Arlington Chapter
Ft. Worth, TX 76107
(817) 332-2601

Gr. Palm Beach Cty Chapter
West Palm Beach, FL 33401
(561)686-7701

Greater Arkansas Chapter
Little Rock, AR 72212
(501) 217-0321

Greater Bay Area Chapter
San Francisco, CA 94105
(415)977-0360

Greater Blue Ridge Chapter
Roanoke, VA 24018
(540) 772-1975

Greater Cincinnati Chapter
Cincinnati, OH 45236
(513)793-3223

Greater Dallas Chapter
Dallas, TX 75231
(214)373-9808

Greater Dayton Chapter
Dayton, OH 45458
(937)439-2873

Greater Iowa Chapter
Johnston, IA 50131
(515) 986-1512

Greater New Haven Chapter
Hamden, CT 06518
(203)248-1880

Hawaii Chapter
Honolulu, HI 96814
(808)988-1000

Houston Gulf Coast Chapter
Houston, TX 77057
(713)334-4400

Hudson Valley Branch
Wappingers Falls, NY 12590
(845) 297-8600

Illinois Chapter
Chicago, IL 60610
(312)670-0313

Indiana State Chapter
Indianapolis, IN 46240
(317) 202-0352

Inland Empire Chapter
Colton, CA 92324
909-424-0100

Inland Northwest Branch
Spokane, WA 99201
(509) 459-6307

Kansas City Chapter
Kansas City, MO 64105
(816) 472-7997

Kentuckiana Chapter
Louisville, KY 40243
(502)485-9397

Lincoln Chapter
Lincoln, NE 68506
(402) 484-8300

Long Island Chapter
Melville, NY 11747
(631) 414-1126

Los Angeles Chapter
Los Angeles, CA 90017
(626)403-1480

Maine Branch
Portland, ME 04101
(207) 761-0133

Maryland Chapter
Towson, MD 21286
(410)823-0073

Metro St. Louis/Gr. MO Chapter
St. Louis, MO 63105
(314)726-6778

Metro-Detroit/SE MI Chapter
Southfield, MI 48075
(248) 355-1133

Mid Jersey Chapter
East Brunswick, NJ 08816
(732)296-7171

Middle Tennessee Branch
Brentwood, TN 37027
(615)383-6781

Mid-Ohio Chapter
Columbus, OH 43215
(614) 464-2873

Minnesota Chapter
Bloomington, MN 55425
(952) 851-0770

Mississippi Chapter
1640 Lelia Drive Suite 130
(601)981-1184

Nevada Chapter
Las Vegas, NV 89148
(702)732-4795

New England/Bay State Branch
Wellesley, MA 02481
(781)431-0700

New Hampshire Branch
Nashua, NH 03064
(603)595-2595

New Mexico Branch
Albuquerque, NM 87110
(505) 255-4005

New York City Chapter
New York, NY 10016
(212)689-2860

North Central CT/W. MA Chp
West Hartford, CT 06107
(860)561-1153

North Florida Chapter
Jacksonville, FL 32256
(904) 739-2101

Northeast Ohio Chapter
Independence, OH 44131
(216)524-6000

Northeast Wisconsin Chapter
Menasha, WI 54952-1195
(920)997-0038

Northeastern NY/Capital Region Branch
East Greenbush, NY 12061
(518)477-2873

Northern CA Inland Chapter
Sacramento, CA 95825
(916)920-0790

Northern Indiana Branch
South Bend, IN 46635
(574) 273-1810

Northern Nevada Branch
Reno, NV 89511
(775) 786-1881

Northern NJ/Rockland Cty Chapter
Engelwood Cliffs, NJ 07632
(201)568-4838

Northwest Arkansas Branch
Fayetteville, AR 72701
(479) 443-9190

Northwest Ohio Chapter
Toledo, OH 43606
(419) 873-1377

Northwestern PA Chapter
Erie, PA 16501
(814)452-0635

Omaha Council Bluffs Chapter
Omaha, NE 68114
(402) 397-2873

Orange County Chapter
Irvine, CA 92614
(949)553-0363

Oregon/SW WA Chapter
Tigard, OR 97223
(503)643-1995

Palmetto Chapter
Columbia, SC 29204
(803)782-1477

Panhandle Branch
Amarillo, TX 79109
(806) 356-6042

Piedmont Triad Chapter
Winston-**Salem**, NC 27103
(336)768-1027

Rhode Island Branch
Warwick, RI 02886
(401) 738-9898

Rochester Chapter
Rochester, NY 14624
(585) 546-1390

Rocky Mountain Chapter
Greenwood Village, CO 80111
(303) 770-2873

San Diego Chapter
San Diego, CA 92121
(858) 597-0240

Seattle Guild
Seattle, WA 98101
(206) 398-1123

South Central Texas Chapter
San Antonio, TX 78209
(210)822-5336

South Florida Chapter
Ft. Lauderdale, FL 33309
(954) 565-4775

South Jersey Chapter
Cherry Hill, NJ 08034
(856) 429-1101

Southeastern Wisconsin Chapter
Wauwatosa, WI 53222
(414)453-4673

Southern Arizona Branch
Tucson, AZ 85711
(520) 327-9900

Tampa Bay Chapter
St. Petersburg, FL 33710
(727)344-2873

Tidewater Chapter
Norfolk, VA 23502
(757) 455-6676

Triangle/Eastern NC Chapter
Raleigh, NC 27604
(919) 431-8330

Tulsa Green Country Chapter
Tulsa, OK 74136
(918) 481-5807

Utah Chapter
Salt Lake City, UT 84111
(801)530-0660

West Michigan Chapter-
Grand Rapids, MI 49546
(616)957-1838

West Tennessee Branch
Collierville, TN 38017
(901)861-6550

Westchester County Chapter
White Plains, NY 10603
(914)686-7700

Western Carolinas Chapter
Greenville, SC 29615
(864) 770-0276

Western New York Chapter
Amherst, NY 14226
(716) 833-2873

Western Pennsylvania Chapter
Pittsburgh, PA 15222
(412)471-1414

Western Wisconsin Chapter
Madison, WI 53719
(608) 833-2873

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