Adult Type 1 Toolkit

No matter where you are on your journey living with type 1, consider this toolkit your guide through the various stages of life with diabetes.

Kevan, diagnosed at age 17
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Over the past several decades, living with type 1 diabetes has gotten easier and easier. And yet, it remains a far distance away from being easy. At home we've gone from measuring glucose levels through urine tests that told you roughly where you might have been hours ago to home blood glucose tests that tell you in as little as five seconds exactly where you are right now. Insulin is no longer derived from pigs or cows, but is made in laboratories to resemble and act like human insulin as closely as possible. The days of carrying syringes and vials wherever you went have been replaced with implantable pumps or slim, barely noticeable, pre-packed and easy-to-set dosage pens that can make giving yourself an injection a private affair, even in the most public of arenas.

But because there is so much to know about living well with type 1 diabetes, this toolkit has been developed for people of all ages who have had type 1 for any length of time. I've personally had type 1 for more than 40 years, and still find that there is more to learn as science, product development, and research all move forward to achieve better treatments and a cure.

The Juvenile Diabetes Research Foundation (then known as the Juvenile Diabetes Foundation) was created in 1970 by dedicated parents seeking a cure for their children with type 1 diabetes. The organization was founded on grit, determination, intelligence, dedication, and perhaps most importantly, love. And while the cure remains the organization's unchanged ultimate goal, JDRF has taken on the critical responsibility of propelling research that helps those people with the disease live as well as possible until the moment the cure is delivered.

One of the toughest psychological challenges diabetes presents is that it is always there, and taking a vacation from it is simply not an option. The disease requires constant and consistent vigilance, just as a marathon requires a strong, steady pace from start to finish. It is about doing the best you can over and over and over again, for the moment and for the long haul.

At its core, controlling type 1 diabetes is about matching the sugar we take in with the insulin we inject to keep blood glucose levels as stable as possible. But if you have had the disease for more than a month, you've already learned it is so much more than that. It is about what we do, what the body does (sometimes without us knowing it), what the stomach does, and what the mind does. If an illness arises, what worked yesterday might not work today. A stressful day can throw control for a loop. As we change the location of an injection, we may be impacting the speed at which insulin works, just as how we inject can change the speed at which insulin is absorbed. The same food made by different people using different recipes might have very different impacts on our control.

As we live with type 1 diabetes, we learn that it touches every system, every organ, and every fiber of our being. It is a condition that raises not just physical issues, but emotional, psychological, financial, and legal ones as well.

If I have learned one thing in the past 40 years, it's that perfect control of type 1 diabetes is not achievable. Managing the disease is both an art and a science, and becoming both an artist and a scientist is the path to good control. Though perfect control is not yet achievable, with careful attention, you can create your path to the critical and realistic goal of ever-better control—in fact, it can even be a motivating process.

From time to time, things will not go as planned or may be unexplained—this is just a fact of living with type 1 diabetes—so it is important for everyone with the disease to get support.

That support will come from others who care about you, but they'll need information in order to understand. In this toolkit, you will find great information about educating others about the disease, especially in the case of an emergency.
Early on, many people with type 1 diabetes don't know whom to tell about their disease, and they may feel uncomfortable talking about their condition. Hopefully, in a short amount of time, that reticence is long gone. The more upfront you are, the more comfortable everyone else around you will be. Half the people who develop type 1 do so as children, the other half as adults. But over time, all of us deal with adult type 1 diabetes whether we come to it new or with years of experience. Regardless of when you’re diagnosed, the sooner you take ownership of your disease, the sooner you become its master. Type 1 diabetes is a disease that requires you to take charge. Once you know, understand, and feel comfortable with your diabetes, you will have less stress and be better able to manage your disease over the long term.

I was a 17-year-old college freshman when my diagnosis came in 1969. After a week in the hospital, given a choice between returning to school or moving back home so my parents could help me adjust to my disease, I chose to return to school. And though I made some foolish eating (and drinking) decisions over the years, having to figure out how to take control, and to make my peace with my type 1 diabetes, was the smartest decision I ever made. I’ve traveled the world, insulin and syringes always nearby, and built a successful career and family life. My complications so far have been few and minor (trigger finger four times, but no retinopathy, heart problems, or kidney disease). I never hid my diabetes from anyone and virtually everyone admired, rather than resented, my openness about the condition.

In 1969, at age 17, I was told that the remainder of my life expectancy would be only two-thirds of what it was before I got the disease—living to age 57 instead of age 72. But by the time I got to 57, my cardiologist said I had a least another good 20 to 25 years to go. He, I am sure, is underestimating me as well. I know that’s only an anecdotal example, but it’s mine and I live it proudly. This toolkit doesn’t have all the answers, but it has a lot of them, and it will help point you where to find some of the others. But equally important, it will put you in contact with others just like you. Others who bravely face and battle the day-to-day inconveniences, issues, and real health concerns that come with living with type 1 diabetes. Furthermore, it will put you in contact with those who know that research for better treatments, prevention, and, eventually, a cure are in the hands of some very good people.

Bob Seltzer
Adult living with type 1 since 1969
Diagnosis

Most people will eventually complete the transition from “life before type 1 diabetes” to accepting type 1 diabetes as part of their new reality. The timing of this transition varies from person to person.

Ryan, diagnosed at age 7
Dealing with the Adult Diagnosis

This is the second of two toolkits we have developed at JDRF. If you are newly diagnosed, please refer to our Newly Diagnosed Toolkit online at www.jdrf.org/adults. If you have been living with type 1 diabetes for more than a year, this version may be more relevant to you.

After learning of their diagnosis, many people find it hard to accept that they now have type 1 diabetes and try different ways of coping with the condition. Denial is a normal reaction. It is so common that it’s accepted as part of the process of dealing with the diagnosis. Initially, this response serves as a way of coping with bad news. It can keep you from getting overwhelmed and depressed and can allow you to accept the news little by little, as you are ready. But the shorter your denial, the better your ultimate care will be. Long-term denial can prevent you from taking care of yourself. Denial may stay around for weeks, months, or even years. It may also come and go depending on what else is happening in your life. Sometimes when we have too much on our plate, it can seem easy to let diabetes care go. However, denial usually adds to our stress, because in the back of our minds we know the damage it could cause.

Questions every person with type 1 diabetes faces are: How do I manage the disease without it managing me? How do I find the balance that lets me behave responsibly without allowing the disease to own my life? How do I make care a simple fact of life and not a burden? Now that complications are arising, what does that mean in terms of my ability to enjoy life?

Remember: Managing the personal and emotional aspects of type 1 diabetes is as important as managing the physical aspects. If you are human, you probably control some aspects of the condition better than others. That’s normal. But mastering every aspect of type 1 diabetes—the physical, the emotional, the social, the professional, and the moral—requires just two things: effort and information.

We’ll provide the information that we hope will help provide the spirit to make the effort to manage, and master, your type 1 diabetes.

Diabetes Explained

What is type 1 diabetes?

Type 1 diabetes is an autoimmune disease. For reasons we don’t yet understand, your immune system, which is meant to protect you from foreign molecules, such as those in viruses, bacteria, and/or toxic substances, mistakenly attacks and destroys the beta cells in your pancreas that produce insulin.

Insulin is crucial to life. Without it, glucose cannot move from your bloodstream into the cells of your body to provide them with energy to function. When your pancreas fails to produce insulin, glucose levels in your bloodstream start to rise and your body can’t function properly. Over time, this high level of glucose in the blood may damage nerves and blood vessels and the organs they supply.

What causes type 1?

There is an enormous amount of research into what causes type 1 diabetes, but so far there are no clear answers. Here’s what we know:

- Failure of the beta cells in your pancreas is due to damage inflicted by your immune system.
- Something triggered your immune system to attack your beta cells.
- Certain genes put people at a greater risk for developing type 1 diabetes, but this is not the only factor involved.
- While there are no proven environmental triggers, researchers are looking for possible culprits, such as viral infections and toxins within our environment, and foods.

Did you know?

- 50 percent of people with type 1 diabetes are diagnosed after the age of 18.
- 80 percent of people diagnosed with type 1 diabetes have no family history of the disease.

How is type 1 different from other types of diabetes?

Diabetes mellitus is the medical name given to a group of conditions in which people have too much glucose in their blood. Glucose comes from the food we eat, and is the major source of energy for the body. After we eat, our body breaks down food into glucose and other nutrients, which are then absorbed into the bloodstream from the gastrointestinal tract. The glucose level in the blood rises after a meal, which
triggers the pancreas to make insulin and release it into the bloodstream. Insulin works like a key that opens the door to cells and allows the glucose in. In people with diabetes, the pancreas is unable to produce sufficient amounts of insulin. Without insulin, glucose is unable to get into the cells, so it stays in the bloodstream. As a result, the level of blood glucose remains higher than normal. Over time, poorly managed high blood glucose levels can create a number of symptoms and health problems.

There are four major types of diabetes: type 1, LADA, type 2, and gestational diabetes. All types of diabetes cause blood glucose levels to be higher than normal. However, they do this in different ways.

**Type 1** (formerly called “insulin-dependent diabetes” or “juvenile diabetes”) occurs when the person’s immune system recognizes its own tissue as foreign. Evidence of this reaction is the presence of antibodies in the blood. The body attacks and destroys the beta cells in the pancreas that produce insulin. Insulin injections (or continuous infusion of insulin through a pump) are then needed to control blood glucose levels. The illness and symptoms typically develop quickly (over days or weeks). However, the destructive process has been going on for a much longer time. Of adults living with different types of diabetes, type 1 affects 10 percent.

**Latent autoimmune diabetes in adults (LADA)**
Type 1 diabetes diagnosed in adults over 30 may be latent autoimmune diabetes in adults (LADA), sometimes known as type 1.5 diabetes. LADA is often misdiagnosed as type 2 diabetes because of age; however, people with LADA do not have insulin resistance like those with type 2 do. LADA is characterized by age, a lack of family history of type 2 diabetes, a gradual increase in insulin requirements, positive antibodies, and decreasing ability to make insulin as indicated by a low C-peptide. In addition, medications used to treat type 2 diabetes by decreasing insulin resistance are not effective for those who have LADA. Treatment for LADA is the same as for type 1 diabetes.

**Type 2** (formerly called “non-insulin-dependent diabetes” or “adult-onset diabetes”) is different. There are two key issues—people with type 2 diabetes do not make enough insulin for their body’s needs, and the cells in their bodies do not properly use the insulin they produce. The cells in the body become resistant to insulin, making a greater amount of insulin necessary to keep the blood glucose level within a normal range. Eventually, the pancreas can wear out from producing extra insulin, and it may start making less and less. Type 2 generally strikes older people, but it is on the rise in children. Type 2 may usually be controlled with diet and exercise or oral medications; in some situations it is necessary to inject insulin.

**Gestational diabetes**
A type of diabetes mellitus that can occur when a woman is pregnant. In the second half of the pregnancy, the woman may have glucose (sugar) in the blood at a higher than normal level. However, when the pregnancy ends, the blood glucose levels return to normal in about 95 percent of all cases.

**A Helping Hand from Health Professionals**
Living successfully with type 1 diabetes requires you to be fully in control of your diabetes management. Self-management means having a daily management plan, setting goals, solving problems, and taking responsibility. But it certainly doesn’t mean that you are on your own. Clear and ongoing communication between you and your type 1 diabetes team is essential for effective self-management. The foundation for success is diabetes education. A thorough knowledge of type 1 diabetes and how best to manage it will give you the confidence and motivation to keep on top of your disease. Everyone is different, and decisions need to be made on an individual, daily basis. This means that your management plan must be tailored to suit your medical needs and goals, taking into account your resources and lifestyle. You can turn to a team of health care professionals who can help you manage your type 1 diabetes. In the ideal situation, a person with type 1 diabetes would have a team of specialists with whom they meet on a regular basis. The team might include an endocrinologist, certified diabetes educator, and dietitian. In addition to these care team members, you might also seek other specialists.

**Endocrinologist**
An endocrinologist is a physician who specializes in disorders of hormones. Training in endocrinology is called a fellowship, and takes place after completion of a pediatric or internal medicine residency. Because insulin is a hormone, diabetes is one of the diseases that endocrinologists are trained to take
care of. You should see an endocrinologist at regular intervals—every three months at first, then less frequently when your disease is under control. Since this will be a long-term relationship, it is a good idea to find an endocrinologist you like, who is conveniently located, and whom you can contact for help when you are sick. More information about this type of physician, including a link to search for endocrinologists by state, is available from the American Association of Clinical Endocrinologists (AACE) at: www.aace.com.

**Diabetologist**
This is a term for a physician with an interest in treating those with diabetes. There is no specific training or certification for this designation. It is a self-appointed title.

**Diabetes educator**
Diabetes educators are a significant source of information about diabetes and how to manage it in the real world. They can help you learn about taking insulin, monitoring blood glucose, foot care, physical activity, and more. More information about diabetes educators, including a link to search for educators by state, is available from the American Association of Diabetes Educators (AADE) at: www.diabeteseducator.org.

**Internist or family practitioner (FP)**
Your internist or family practitioner will focus on your overall health, and can also provide you with referrals to other specialists. (In the past, the FP had different training and was known as a general practitioner or GP.)

**Dietitian (RD)**
A specialist diabetes dietitian (registered dietitian or “RD”) can provide you with information about food choices, portion sizes, glycemic index (GI), and menu planning (taking into account your own preferences). Dietitians are a particularly useful resource if you also suffer from other conditions related to type 1 diabetes, such as celiac disease.

**Counselor**
Learning how to manage life with type 1 diabetes can be a difficult and at times daunting experience. A counselor can provide you and your loved ones with support as you adjust. Often, counselors are affiliated with physicians, and the best way to find one is to ask your physician or look online for a counselor who specializes in chronic illness. Be sure to interview several before deciding which counselor is the right one for you.

**Pharmacist**
Get to know your local pharmacist. He or she will keep a record of the medications you take and can inform you of any potential side effects or interactions.

**Ophthalmologist**
Eye damage from diabetes is manageable with early intervention, so make sure you have an annual dilated eye check-up.

**Podiatrist**
Since diabetes can affect circulation and sensation, feet are particularly vulnerable and need careful attention.

**Dentist**
People with diabetes have a higher risk of plaque and oral bacteria entering the bloodstream (which can damage the heart). It is important for adults with type 1 to floss daily and to have their teeth professionally cleaned regularly.

**Finding the right physician**
In all areas of your life, you will come across people you connect with and others you don’t. The same is likely to happen with diabetes health care professionals.

It is important to find a physician or health care team with whom you feel comfortable and can discuss your disease and concerns. You also need to like and trust them. If you don’t, you have the right to seek care elsewhere. Be proactive about this; otherwise you are likely to avoid scheduling regular appointments, which may affect your long-term health.

In addition to online searches to locate health care professionals in your area, you can talk to your internist or FP or friends who also have type 1 diabetes to see whom they recommend. Your next step would be to call around to inquire about what type of services the different practices provide, whether they have waiting lists, and what appointments cost. The final step is to try them out.

JDRF has additional information about working with your physician to manage your diabetes at www.jdrf.org/diabetesinfo.
Impact Of Diabetes

Your type 1 diabetes is unique to you. Hearing the experiences of other people and learning what has worked for them in different situations can help you to develop management strategies.

Patrick, diagnosed at age 6
The Financial Impact: Insurance

The passage of the Affordable Care Act in 2010 carried a number of favorable consequences for people with type 1 diabetes that made coverage for type 1 easier to obtain and to maintain. Some of these measures have already gone into effect, and others will be phased in between now and 2014. Of specific interest to people with type 1 are:

- Effective as of mid-2010, children with pre-existing conditions such as type 1 can no longer be denied coverage simply based on the existence of the condition.
- By 2014, no person with type 1 can be denied access to coverage as a result of type 1.
- The lifetime cap on coverage is eliminated. This is particularly important for people with type 1, who, until a cure is found, will have this chronic condition all their lives.

Finding the right health insurance for you and your family is still essential, and a person with type 1 diabetes seeking coverage needs to pay attention to many factors, including the right to see specialists, coverage of supplies (such as test strips, meters, etc.), and access to glucose-monitoring devices and insulin pumps. A careful review of options that factors in all aspects of your type 1 diabetes care is always suggested to find the right type of insurance for you.

Finding a health insurance plan

Even with new health care laws in place, finding the right health insurance plan may still be a challenge for a person with type 1 diabetes. Here are some resources that may help:

- **Healthcare.gov**: The federal government’s new site, [www.healthcare.gov](http://www.healthcare.gov), has information about health insurance options as well as an easy-to-use guide to help you find out which private insurance plans, public programs, and community services are available to you.

- **HealthInsuranceInfo.net**: The Health Policy Institute at Georgetown University has published consumer guides for getting and keeping health insurance for each of the 50 states, available at [www.healthinsuranceinfo.net](http://www.healthinsuranceinfo.net/).

- **State Regulatory Insurance Office**: Every state government in the nation has an office that regulates insurance within the state. In most states, this office can provide information to consumers seeking information about insurance options within the state. To find your state’s insurance regulatory offices, visit [www.healthinsurancefinders.com/cr_state_department_of_insurance.html](http://www.healthinsurancefinders.com/cr_state_department_of_insurance.html).

Health care Assistance

There is no doubt that living with type 1 diabetes will impact your budget. Unfortunately, many people with no health insurance or limited coverage may need additional resources to help them care properly for their type 1 diabetes. But there are ways you can get assistance if you need it. Below is a listing of resources and programs that may help.

- **Partnership for Prescription Assistance** — Offers a point of access to hundreds of assistance programs from drug manufacturers that have joined together to provide savings to the uninsured. To learn more about these programs, visit [www.pparx.org](http://www.pparx.org) or call 1-888-477-2669.

- **Together Rx Access Card** — Provides 25 to 40 percent off brand-name prescription medications at pharmacies nationwide. Income and residency requirements exist. To learn more about the card, visit [www.togetherrxaccess.com](http://www.togetherrxaccess.com) or call 1-800-444-4106.

- **NeedyMeds** — Nonprofit organization that provides a database of clinics that offer health care at no cost, for a small fee, or on a sliding scale. To learn more visit: [www.needymeds.org](http://www.needymeds.org).


- **National Drugstores and Pharmacy Chains** — Many have their own prescription programs to help customers save money on certain medications. Stores with these programs include Costco, CVS, K-mart, Rite Aid, Target, Walmart, and others. Speak with your local pharmacist to learn more.
• **State Programs** — Many states offer pharmaceutical assistance programs for people without insurance and others who need assistance. To learn if your state has a program, visit www.ncsl.org/IssuesResearch/Health/StatePharmaceuticalAssistanceProgramsNCSL200/tabid/14334/Default.aspx.

• **Medicare and Medicaid** — To learn whether you’re eligible for these federal programs, visit the Centers for Medicare and Medicaid Services at www.cms.gov/, go to www.medicare.gov, or call 1-800-MEDICARE.

Disclaimer: This information is not endorsed by JDRF or any other organization. It is provided only as a general resource and should be used only as a guide. Always consult your physician.

**Companies That Donate Supplies**

• **Medisense Meter** — donates free meters and strips. 800-527-3339

• **Lilly Care** — donates free insulin. A patient can apply for a three-month supply of insulin for free. A patient must submit a new application each time he/she is applying. The patient needs the physician’s involvement or letter stating the need for insulin. 800-545-6962

• **Medic Alert** — donates free sterling silver bracelets or necklaces. 800-432-5378

• **Aventis** — donates Lantus insulin. 800-221-4025

• **BD** — money-saving coupons for syringes. Patients just need to call and request coupons. The company also offers a one-time-only coupon for a free box of syringes.

• **Lifescan** — Contact for assistance with glucose monitor supplies. 800-227-8862 or send an email request with name and address to CustomerService@Lifescan.com

• **FreeMeds.com** — 888-722-7556. You cannot have an insurance prescription card and access this program, but you can have insurance and this program.

• **ipump.org** — provides insulin pumps and supplies assistance to qualifying persons with diabetes throughout the United States.

**Connecting with Other People Who Have Type 1 Diabetes**

The value of talking to other people who have type 1 diabetes cannot be overstated. There is something comforting in knowing that you are not the only one living with the condition. While everyone is different, and your type 1 diabetes is unique to you, hearing the experiences of other people and learning what has worked for them in different situations can help you develop management and coping strategies.

There are various ways to get in contact with other people who have type 1 diabetes. Once you tell people about your diabetes, you may be surprised by how many people have connections to others who have the condition.

**You can:**

• Join Juvenation, JDRF’s type 1 diabetes online community (www.Juvenation.org), which offers a variety of groups, forums, and resources categorized by topic. You can even start your own group. Juvenation has an active community of thousands of members touched by type 1 diabetes, and is a great place to make connections with people like you. More information about Juvenation can be found in the resources section of this toolkit.

• Talk to your physician and diabetes educator about upcoming meetings or educational sessions where you could meet people in situations similar to yours.

• You may also like to join JDRF and get involved in your local chapter and their activities. To find a chapter near you, visit www.jdrf.org/chapters/homepage.php. Chapters can also provide type 1 connections, support, and resources for help with day-to-day life with type 1 diabetes through local Outreach programs such as peer-to-peer mentoring, type 1 educational events, and social groups.

• Visit the Taking Control of Your Diabetes (TCOYD) website, www.tcoyd.org. JDRF has partnered with TCOYD to provide local programs to help you connect with other adults with type 1 and to inform, motivate, and
empower participants to take control of their diabetes. TCOYD and JDRF are working together to fill a void in resources specific to type 1 adults. TCOYD provides live national conferences, local events, publications, online resources, and an educational television series to help people with all types of diabetes become actively involved in their own health.

Transitioning from a Child to an Adult with Type 1

If you developed type 1 diabetes as a child, most likely your parents played an active role in helping you learn to manage your diabetes. Transitioning to adulthood brings a whole series of new responsibilities to you, and a whole series of new questions. In college life, meals are often skipped or eaten outside of traditional hours. Your first job raises questions of what to say about your condition and to whom, particularly to people who may choose not to hire or keep you out of their ignorance of the disease and the law. Relationships raise all kinds of questions.

The following section looks at issues that all of us face at some point, and that become particularly acute during key periods of transition.

Helping Friends, Institutions, and Coworkers Relate to Your Diabetes

You may have loved ones who show their concern for you in ways you find irritating. For example, they may constantly ask how you feel or whether you need to have something to eat, test your blood glucose, or take your insulin. Although they are likely to be doing this with the best of intentions, it can place pressure on your relationship. The best way to address this behavior is to explain how it makes you feel. Find a good time to talk about it calmly and openly.

Friends and colleagues

Other people, even those closest to us, often don’t understand what having type 1 diabetes means. Talking about how you discovered your diabetes and how you treat it can be helpful. Friends who know about your diabetes can be a source of support. Having friends who are willing to listen to how you are feeling, even if they don’t have diabetes themselves, may help you better adjust to living with it.

Being open with relatives about your experience will make it easier for them to understand what type 1 diabetes is all about. Friends and colleagues can also offer practical help when you have low blood sugar or in other situations.

Meeting new people

Once you have lived with type 1 diabetes for some time, you will have to decide the right time to tell new friends and colleagues. While it can seem embarrassing to bring your diabetes into the conversation, not doing so may be even more embarrassing later on. For example, new friends and colleagues may misinterpret signs of hypoglycemia if they don’t know you have type 1 diabetes. While you may not want to disclose your condition on your first meeting, it is often easier to do so sooner rather than later. Depending on how you feel, you might want to simply explain that you have type 1 diabetes and that you need to inject insulin. You might consider letting them know about low blood sugar and what to do when this occurs.

When you have type 1 diabetes, no one warns you about the things people will say or ask. Sometimes these comments may seem insensitive, ignorant, or unkind. It’s best to be prepared for what people will say and to think about what you should and should not say in response. You can find tips on how to respond and educate others about type 1 diabetes on Juvenile diabetes in the Media

If you have a connection to type 1 diabetes, you will find that you are faced with it almost every day in the media. Even if you don’t see the stories yourself, it is likely that some well-meaning person will point them out for you. Here are a few points that you need to keep in mind.

Is it OK to inject in public?

Most people won’t even notice that you’re injecting insulin if you’re using a pen and not a syringe. If you’re shy, you can even inject through a layer of clothing. If you are using a syringe, you may feel more comfortable in a more secluded area. But it is your comfort you should be worried about, not someone else’s. For example, don’t feel obligated to use a restaurant bathroom to inject if you are comfortable doing it discreetly at your table.

Diabetes in the Media

If you have a connection to type 1 diabetes, you will find that you are faced with it almost every day in the media. Even if you don’t see the stories yourself, it is likely that some well-meaning person will point them out for you. Here are a few points that you need to keep in mind.
Just because it is on television doesn’t mean it is true

If you see, hear, or read something that you think is interesting but you’re not entirely convinced about the accuracy, contact someone you trust, such as your endocrinologist or diabetes educator, to find out the real story. JDRF will often post a statement at www.jdrf.org if something is relevant to the type 1 diabetes community, so make that a bookmark and check it frequently.

Making sense of “breakthroughs”

You open the newspaper and there is yet another news story about a diabetes breakthrough. Is it a real cure this time, or just another bit of interesting science?

The truth is probably somewhere between the two. Researchers face the constant challenge of publicly explaining complicated research results in the simplest way possible. They are often pressured to emphasize the importance of their breakthrough, but also to explain their findings in 200 words or a 30-second sound-bite.

The reality of the research process is that the average “breakthrough” can take years to be translated from a laboratory bench to a therapeutic treatment. That’s not to say that a cure won’t suddenly be found, but it’s important to recognize that most research reported in the media is more likely to be an important step toward finding a cure, but not necessarily signaling the end of type 1 diabetes in our community. Keep an open mind, and if you have any questions about a research finding, contact JDRF for more information. As a JDRF member, you will always be among the first to know if something important happens in type 1 diabetes research. However, if you want insight from others living with type 1, be sure to check out JDRF’s online community, www.juvenation.org. Here you can connect with other adults who have type 1.

Media and public (mis)understanding

Diabetes is a condition that is featured heavily in the media. This has been driven by a number of factors—dramatic increases in incidence of type 2 diabetes, government focus on preventative health, and a spotlight on obesity, to name a few. While diabetes is always in the news, it’s not always portrayed accurately, which may affect the public’s understanding and awareness of type 1.

The most common misunderstandings are caused by confusion between type 1 and type 2 diabetes. Journalists often generically refer to “the risk of diabetes” when writing a story about obesity, or include images of overweight children when showing a television story about type 1 diabetes. Understandably, this can result in feelings of frustration or anger by members of the type 1 diabetes community.

JDRF places a strong focus on correcting these misconceptions, but there are actions you can take to make a difference too. If you see an incorrect story, write a letter or email to the editor or journalist that politely outlines the mistake they have made. Volunteer to become a JDRF advocate to help change the perceptions of those people who are in charge of setting the political agenda. Don’t get discouraged if your actions don’t get an immediate response.

Type 1 diabetes is different from other chronic diseases. It requires continual self-management, as well as guidance from your health care team, so it’s easy to feel overwhelmed at times. Type 1 diabetes is also tied up with many physical targets and tests, which can become stressful and hinder your enjoyment of day-to-day living. This next section will give you the tools you need to keep your spirits up despite the difficulties you face with type 1 diabetes.

Diabetes Information Resources

Knowing where to find information is critical. Following is a list of important websites and publications that you should use as a resource whenever you wish to research an issue or learn more about standard or new treatment options for type 1 diabetes or any of the complications related to the condition.

Juvenile Diabetes Research Foundation (JDRF)
www.jdrf.org
JDRF is the world’s leading charitable funder of type 1 diabetes research, and works to improve the lives of people with type 1 diabetes through research leading to better treatments, and ultimately, a cure. JDRF’s website has information and publications about research progress and breakthroughs, new treatments, and resources for people living with type 1 diabetes.

Juvenation www.juvenation.org
Juvenation is JDRF’s online community for people touched by type 1 diabetes. In addition to groups and forums, Juvenation plays host to many blogs that report on new research and treatments, as well as a resource center devoted to a number of important topics.
American Association of Diabetes Educators (AADE)
www.diabeteseducator.org
A professional medical organization for Certified Diabetes Educators. Find general diabetes information; search to find a diabetes educator.

American Association of Clinical Endocrinologists (AACE)
www.aace.com
A professional medical organization devoted to the enhancement of the practice of clinical endocrinology. Search to find an endocrinologist.

Diabetes Exercise and Sports Association (DESA)
www.diabetes-exercise.org
DESA exists to enhance the quality of life for people with diabetes through exercise and physical fitness.

Insulin Pumpers
www.insulin-pumpers.org
Provides information and support for adults with diabetes interested in insulin pump therapy.

National Diabetes Education Program (NDEP)
ndep.nih.gov/
Federally sponsored program to provide education and information about diabetes. Provides publications and resources about living with diabetes.

National Institute for Diabetes, Digestive, and Kidney Disease
www2.niddk.nih.gov
National Institutes of Health's (NIH) Diabetes and Digestive Kidney division. Site includes numerous facts and extensive information on type 1 diabetes.

Disclaimer: This information is not endorsed by JDRF or any other organization. It is provided only as a general resource and should be used only as a guide. Always consult your physician.
Keeping Your Spirits Up

Having realistic goals and a good understanding of what type 1 diabetes is all about will go a long way toward improving your mental and emotional well-being.

Alexandra, diagnosed at age 8
Type 1 Diabetes and Your Mood

Many factors can affect your type 1 diabetes, including: stress, activity and exercise, illness, excitement, travel, work and routine changes, hormones, age or stage of life, food and drink, insulin type or dose, and injection site. Pinpointing the actual factor can sometimes be difficult or impossible. This ambiguity can lead to lowered motivation and feelings of powerlessness. Staying on top of your diabetes management can be tough, especially when results are not as you would like them to be.

To make matters even more complicated, your mood and actions can be closely linked to your blood glucose levels. As you have probably already noticed, you may feel short-tempered and out of sorts when your blood glucose levels are high. Hypoglycemia also has its problems—you may find that a different side of your personality comes out when your blood glucose level is low. If you are usually loud and gregarious, you may become quiet and withdrawn. If you are naturally a serious person, you may find yourself laughing more.

If you are normally even-tempered, you may become argumentative. At times, this may cause you embarrassment, but it is okay to tell people that your blood glucose is low and that you will be your normal self once you have had something to eat. In doing so, you are not using your diabetes as an excuse, you are stating a fact.

Having realistic goals and a good understanding of what type 1 diabetes is all about will go a long way toward improving your mental and emotional well-being. In addition, identifying other problems in your life that impact your diabetes and dealing with them one by one is also important. Again, it is critical that you are comfortable telling your health care team about your needs and priorities in order to make life as enjoyable as possible over the long term.

Keeping an eye out for depression

Living with type 1 diabetes makes you more than twice as likely to experience depression as those without the disease. It is important to be aware of the signs and symptoms so that you know when to seek help.

Symptoms of depression can include extended periods (more than two weeks) of:

- Feeling sad or miserable most of the time
- Losing interest or pleasure in most of your usual activities
- Becoming withdrawn, not going out
- Stopping activities you used to enjoy
- Thoughts about being a failure, being worthless, thinking life is not worth living
- Feeling overwhelmed, tearful, guilty, irritable
- Having physical symptoms such as feeling tired all the time, having a churning gut, irregular sleep patterns, or changing appetite

Depression is treatable and most people recover with the right treatment. It is important to seek help sooner rather than later. If you suspect you’re experiencing symptoms of depression, speak to a trusted health care professional.

Avoiding diabetes burnout

Having type 1 diabetes is like a job, and the day-to-day effort to manage it can become too hard and frustrating, especially when the results are not what you would like. Studies have shown that a majority of people living with diabetes experience worries, fears, and negative feelings at some stage. This can lead to diabetes burnout.

Burnout is much more than feeling a little down. It includes overwhelming feelings of helplessness and hopelessness. Signs might include not checking blood glucose levels, stopping or reducing insulin injections, not caring about your eating habits or exercise, and ignoring or trying to forget your diabetes most of the time. Diabetes burnout is seen as one of the major psychological complications of diabetes.
You need realistic expectations and practical strategies for managing the emotional side of diabetes. One simple strategy that can help is to change the way you think about your blood glucose levels. Rather than getting angry or upset, look at your blood glucose results as information to help you decide what to do next. Don’t waste time punishing yourself over a high number. Use what you know to plan ahead and make positive adjustments. Using words like “high” and “low” when referring to your blood glucose instead of “good” and “bad” can really help create a positive attitude. Consider the possibilities one by one: Have you injected in a location that speeds up or slows down your absorption of insulin? Is the insulin vial or pen within its usage period? Do you have an illness or an infection? Stress? Too much or too little exercise? Although you’ll be able to find a suspect for most highs or lows, the truth is that sometimes you’ll have a glucose reading that doesn’t make sense and you’ll never know why. That’s okay if it’s isolated. The next reading will come soon.

If you think you are experiencing burnout or are at risk for experiencing it, ask yourself:

- What’s happening in my life that might be conflicting with my diabetes care or making it harder?
- What problems outside of my diabetes could be addressed?
- What are my expectations for my diabetes management—what do I want?
- Are my goals realistic right now? Perhaps they are too ambitious or not ambitious enough?
- What particular areas of my diabetes are causing me problems?

**When the going gets tough, the tough get support!**

If things are not going so well with your type 1 diabetes, it’s important to work out why and see that you are not the problem. If your diabetes management is off track, then there are likely other problems getting in the way. This does not diminish your responsibility in dealing with the problems, but opens up possibilities for change. These problems might be directly related to your type 1 diabetes, such as a need for a management change, or they might be problems unrelated to your disease, such as depression or issues at work.

Ultimately, you need to give yourself a break to identify and tackle the problems and get support. Talking to other people who understand is very important.
Day-to-Day Life with Type 1 Diabetes

Now that you have type 1 diabetes, you need to do the job of the pancreas yourself. This means administering the appropriate type and amount of insulin at the appropriate times, and managing your lifestyle to try to maintain a hold on fluctuating blood glucose levels.
Before you developed type 1 diabetes, your pancreas would release a low level of insulin throughout the day and also produce surges of insulin in response to food. Now that you have type 1 diabetes, you need to do the job of the pancreas yourself. This means administering the appropriate type and amount of insulin at the appropriate time and managing your lifestyle to try to control fluctuating blood glucose levels.

**“Must-Have” equipment**

There are some key items that you should not be without, and that you should replace when supplies run low. While you may feel that carrying some of these items around is tedious, they give you flexibility. If you get delayed away from home, you’ll be glad you took your overnight insulin with you. Carrying your meter with you will let you eat unfamiliar foods, because you will be confident that you can test your blood glucose level afterward to check whether you’ve taken the right amount of insulin.

It’s a good idea to have a bag that contains enough pockets to protect items from being damaged and so that you can quickly find what you’re looking for. Bags specifically made for this purpose can be found by typing “diabetes bag” into an online search engine.

**“Must-have” items to keep on hand:**

- **Insulin, insulin pen, or insulin pump**
- **Syringes, pen needles, or infusion sets**
- **Lancet devices**
- **Book to record blood glucose levels**
- **Blood or urine ketone strips**
- **Blood glucose monitor and testing strips**
- **Sharps container**
- **Snacks to treat low blood glucose**
- **Glucagon**
- **Medical identification**
- **Emergency contact numbers**

**Insulin, insulin pen, or insulin pump**

You should always carry insulin and the means of delivering it with you, even when you don’t expect to eat, since you never know when you might be out longer than you expect. Be careful to regularly check the amount of insulin left in your vial, cartridge, pen, or pump, since you don’t want to run out of insulin. Insulin pump users should also carry a spare infusion set and inserter as a back up, as well as spare syringes, just to be safe.

If you use intermediate or long-acting insulin, you should take it with you when you go out at night. By doing so, if you are unexpectedly delayed away from home, you won’t miss your evening or morning injection. It is also a good idea to keep a spare insulin pen and extra insulin in the refrigerator at work in case you accidentally leave your insulin at home. Remember to keep track of the expiration dates of your supplies at work.

Insulin can be damaged by low (freezing) or high temperatures, so don’t leave your insulin in your car’s glove compartment, in direct sunlight, or anywhere that gets extremely hot or cold. Insulin can be kept at room temperature for one month, after which it should be thrown out. Some types of insulin are more sensitive than others to high and low temperatures. See the insert in your insulin package or visit the manufacturer’s website for more specific storage instructions.

**Syringes, pen needles, or infusion sets**

Syringes, pen needles, and infusion sets all serve the same purpose: to deliver insulin to people with type 1 diabetes. 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 people also find the pen needles more comfortable than the syringes. When it comes to pumping insulin with an insulin pump through an infusion set, there are a variety of choices. Most pumps have multiple infusion sets that work with them; some are applied more manually while others are more automatic. Be sure to explore the options with your health care provider to find the best fit for you.

**Blood glucose monitor and testing strips**

It might be tempting to leave your meter at home; however, knowing what your blood glucose levels are doing will help you avoid hypoglycemia and reduce your risk of high blood glucose levels, which can leave you feeling tired and emotional. Of course, you can’t test without a lancing device so make sure you pack that, too!
**Lancet devices**

Carrying spare lancets for your lancing device (or using one of the new lancing devices that store multiple fresh lancets inside them) will reduce any blunt lancet testing pain while you are out. Additionally, you have a choice when it comes to lancing devices. You don't necessarily have to use the one that comes with the meter; it's fine to mix and match to find a lancing device that works best for you. If your meter is taking up too much space in your kit, have a look at the different-size meters available.

Keeping a spare meter and test strips at work or in a frequently used bag can help you avoid the stress of forgetting and then spending a day wondering if your blood glucose levels are going high or low. It's important to have clean fingers when you test your blood glucose levels, as the accuracy of your test can be impacted by the presence of food on your fingers. Usually you will be able to wash your hands, but for those times when you can't, you may want to carry some finger wipes with you. However, if you do clean your finger first, be sure to have it dry before testing.

Just like insulin, meters and strips can be affected by low (freezing) or high temperatures, so don't leave your blood glucose monitor in the glove compartment of your car, in direct sunlight, or anywhere that gets extremely hot or cold. Some types of meters are more sensitive than others to high and low temperatures. See the insert in your package or visit the manufacturer's website for more specific storage instructions.

**Book to record blood glucose levels**

It is important to note that “perfect” blood glucose levels are quite uncommon. A 2005 study of people with type 1 diabetes who were strict in managing their diabetes found that the participants’ blood glucose levels were only in the ideal range for 30 percent of the day. If you record your blood glucose levels and share your results, including the “bad” days, with your diabetes team, they will be able to help you manage your type 1 diabetes better. But if you don't record or share your results (or if you make them up), you won't be able to benefit from their feedback and suggestions. Companies that manufacture insulin or blood glucose meters often provide blood glucose record books free of charge.

**Blood or urine ketone strips**

Ketones are a product of fat. They accumulate in the blood as a result of inadequate insulin (often due to illness) or inadequate food or energy intake. Having some way to test for ketones, either using urine strips or blood test strips with a ketone-testing device, will enable you to identify whether you are at risk of ketoacidosis (see definition of diabetic ketoacidosis in the Appendix of the toolkit). Ketone strips can be purchased in individual foil-wrapped strips, which have a longer shelf life. (For more information on ketones, see the Day-to-Day Life with Type 1 Diabetes: Managing Sick Days section.)

**Sharps container**

A sharps container is essential for safely disposing of used pen needles, syringes, or lancets in your home. Medical sharps containers are available from pharmacies. In some states, a sturdy plastic bottle with a screw-on lid will be accepted for disposal. They are available in many sizes—even very small containers to use while traveling. The U.S. Environmental Protection Agency has information about safe options for needle disposal at: www.epa.gov/osw/nonhaz/industrial/medical/med-home.pdf.

**Snacks to treat low blood glucose levels**

Always carry at least one treatment for low blood glucose with you at all times. If your blood glucose level is low, you will need to consume food or drink that contains around 15 grams of carbohydrates to help bring your blood glucose level back into the normal range. It can be hard to walk around all day with your favorite candies in your pocket, so try to carry a glucose tablet instead of food to reduce the temptation to snack when you're bored or hungry.

Your treatment for low blood glucose will often be in your bag (or pocket) for a while, so you need something with resilient packaging. You can also get a small airtight plastic container to keep it safe from opening or getting squashed. It is also a good idea to carry an extra one so that you can treat yourself if you go low again or need more glucose.

• **Automobile hypoglycemia**

It’s a good idea to have a source of glucose in your car (and your friends’ or loved ones’ cars), such as glucose tablets or a couple of tubes of cake frosting in the glove compartment. If you feel that you are having a low glucose level while driving, do not try to treat your symptoms while behind the wheel. Pull over and have a snack. Wait until your glucose is in the normal range before continuing to drive. Then travel to a gas station to obtain an extra drink or snack, if needed. Think about what caused the low blood sugar. Did you: Skip a meal? Eat less than normal? Exercise more than usual? Forget to check your glucose level? If you can identify behavior(s) that caused your hypoglycemia, try to prevent it from happening.
again by following your treatment plan. Always wear a medical alert bracelet or necklace and carry a card in your wallet or purse that identifies that you have diabetes and lists all of your medications. If you experience hypoglycemia unawareness (which is defined in the Appendix of this toolkit), you might consider checking your blood glucose levels prior to operating a vehicle.

**Glucagon**

People with type 1 diabetes who experience severe low blood glucose emergencies (altered mental status, loss of consciousness, or seizure) may require glucagon. Glucagon raises the blood glucose 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. It can be injected into muscle or under the skin. It is a hormone that helps the liver release glucose in order to raise blood glucose levels.

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. If you need glucagon, most likely you will not be able to administer it yourself. Read the directions carefully, and train a trusted friend or companion how to administer it and when. Ask your health care 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.

It is important to note that glucagon may raise your blood glucose by 140 milligrams/deciliter (mg/dL), while glucose tablets only have four grams of carbohydrates. Glucose tablets do not substantially raise blood glucose as quickly as glucagon in severe low-glucose emergency situations.

**Medical Identification**

You should always wear a medical alert bracelet that identifies you as a person with type 1 diabetes. You should also carry a card in your wallet or purse that provides your physician's contact information and a brief description of the medication you are taking. In the (hopefully unlikely) event that you have a severe hypoglycemic emergency, the identification will enable health care professionals to quickly provide the care you need.

**Emergency contact numbers**

Emergencies can happen at any time, so make sure those around you know whom to contact in an emergency. Also, be sure you know whom to contact if you become ill overnight or on the weekend.

**Insulin Delivery Method: Insulin Injections**

There are five main types of insulin. Each type differs with respect to how quickly it begins to act and how long its effect persists. Most people with type 1 diabetes need to use more than one kind of insulin to mimic the role of the pancreas as closely as possible. While it is possible to estimate when different insulins peak and how long they remain active, there is still no guarantee that the pattern will remain consistent. The absorption of insulin can vary, so one type of insulin may peak at different times on different days.

**Getting used to injections**

If your injections hurt, you may be administering the insulin just under the skin, where you have an abundance of nerve endings. Talk to your diabetes team to see whether you should use a slightly longer needle, or whether you need to change the angle at which you inject. Using different insulin preparations or administering insulin straight from the refrigerator may also cause slightly more discomfort. You may also experience occasional bruising at the site of your injections. This usually occurs because you have pierced a tiny blood vessel while injecting. Although bruising can look unsightly, it will not affect the absorption of your insulin. You may also bruise if you withdraw the needle too quickly. Your diabetes educator can help you refine your injection technique.

**Calculating insulin**

As mentioned previously, you may need to use different types of insulin to best manage your type 1 diabetes. Your endocrinologist or another diabetes care team member can help you decide which combination of insulin is right for you. A common approach is to use one of the longer-acting insulin preparations once or twice a day to provide your body with background (basal) insulin. You may supplement this with rapid-acting or short-acting insulin given at meals to move the extra glucose entering your bloodstream after food. This is often referred to as bolus insulin.
Remember though, no matter when or where you take your insulin, make sure the syringe does not contain an air bubble. The best calculation of how much insulin you should take becomes ineffective if the syringe or pen has less than you think it does because of an air bubble.

To try to mimic the natural meal-time release of insulin by a healthy pancreas, you may be asked to count how many carbohydrates you eat and take a dose of bolus insulin to cover the total number of carbohydrate exchanges in each meal or snack. Your endocrinologist or diabetes team can help you decide how much insulin to give for each carbohydrate exchange (“insulin-to-carb ratio”).

It probably sounds daunting to be making these decisions yourself, but learning how to count carbohydrates and understanding your insulin-to-carb ratio will give you more freedom to decide how much you want to eat at each meal. A dietitian will be invaluable to you as you learn to calculate carbohydrates.

Correcting high or low blood glucose levels before a meal

If your blood glucose level is high before you eat, your blood glucose level will also be high after the meal if you only take enough insulin to cover the carbohydrates in your food. Taking some “extra” insulin with your meal will help get your levels closer to the normal range in about three to five hours, depending on the type of insulin you’re using. Just as your diabetes team will help you determine your insulin-to-carb ratio, they will also help you to determine your “sensitivity factor,” an estimate of how much a single unit of insulin will lower your blood glucose level. Your sensitivity factor is just an estimate, so there will be times when one unit of insulin will lower your blood glucose level more and others when it will lower it less. Testing your blood glucose levels will help you see if this sensitivity factor is right for you (most of the time), or if it needs modifying. The goal of the sensitivity factor is to help you estimate how much extra insulin you need to take to return your blood glucose levels to normal if they are high. You can also use the insulin sensitivity factor if your blood glucose level is too low before a meal. In this case, you would subtract an amount of insulin from your meal-time or bolus injection. Your health care team will help you with this.

You may also want to adjust your insulin dose if you anticipate that you will be exercising within two or three hours following a meal. In that case, your endocrinologist or another diabetes care team member may suggest a reduction in your usual pre-meal dose of bolus insulin.

*This publication is not intended to replace medical advice. Please discuss with your physician what would be considered the correct insulin regimen for you.

Getting your insulin levels right

The amount of insulin you need to inject each day is influenced by your age, your weight, and how long you have had type 1 diabetes. Intermediate or long-acting insulin is often given once or twice a day to mimic the basal insulin profile of people without diabetes. Testing your blood glucose levels before meals will help you and your diabetes team determine whether your basal insulin levels are right.

What if you make a mistake?

Like everything in life, taking your insulin regularly will become a habit over time, and if you’re not concentrating or if you’re in a hurry, you may make a mistake with your insulin dose. If the mistake is that you have taken too much rapid-acting or short-acting insulin, you will need to keep an eye on your blood glucose level for the next three to six hours and balance the extra insulin by eating carbohydrates every hour or so to prevent your blood glucose level from dropping too low.

If you haven’t taken enough insulin with your meal, you can compensate by taking extra rapid-acting or short-acting insulin if you realize your mistake within one hour of eating. Taking extra insulin more than one hour after eating may increase your risk of hypoglycemia before the next meal, so it may be safer to leave your high blood glucose level untreated.

Unexplained high blood glucose levels

If you have ongoing unexplained high blood glucose levels, you should check if your insulin is still okay to use. Check the expiration date and visually check that the insulin looks as it should. Turn your insulin vial or pen upside down—if you see any tiny particles, your insulin has probably gone bad. Check with your physician or pharmacist about replacing it. And always double-check at each injection to make sure you have not left air in the syringe.
It is also a good idea to check that your blood glucose monitor is correctly calibrated. Check that the number on the vial of your blood glucose strips matches the number displayed on the monitor.

Also, physical or emotional stress can unexpectedly raise your blood glucose level. Examples of physical stress may be a sore throat or infection, or a sprained ankle. Even good or bad stress such as a surprise birthday party or unfortunate family- or work-related news can raise your glucose level.

**Insulin Delivery Method: Insulin Pump**

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 rapid-acting insulin through two different styles of devices. The first is a cannula with a flexible plastic tube (taped in place). The device attaches to the body through a small needle inserted into the skin. The second device is a tubeless cannula that delivers insulin with no needles in sight. Common insertion sites on the body include the thighs, buttocks, upper arms, and other areas with fatty tissue. Pumps are continually improving, with new methods being made available.

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

For many, 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

For some, the disadvantages of the pump include:

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

People with type 1 diabetes who use an insulin pump may need to test their blood sugar more frequently. Pumps have become increasingly popular among people with type 1 diabetes, and several brands and models are available. Speak with your endocrinologist about whether an insulin pump is a good option for you.

**Managing Blood Glucose Levels**

**Why treating type 1 diabetes is important**

In the time before you had type 1 diabetes, your pancreas used to produce insulin in low levels all day to help move glucose from your bloodstream into the various cells of your body to provide them with energy. When you ate, your blood glucose would rise, and your pancreas would respond by producing a surge of insulin. This helped move blood glucose into your muscles and liver to be stored as glycogen. If your blood glucose level dropped during the day, glycogen would be broken down and released back into the bloodstream as glucose. By constantly sensing how much glucose was in the bloodstream, and adjusting how much insulin it secreted, your pancreas kept your blood glucose level between 80 and 120 mg/dl at all times. Note: mg/dl is a measure of concentration (mass per unit volume) using milligrams per deciliter.

Without a properly functioning pancreas, your body cannot move glucose from the bloodstream into the cells in your body, leaving them without the energy to function. If your body can’t use glucose for fuel, it starts to break down fat to use for energy instead. When fat is broken down, the body produces chemicals called ketones, which are released into the bloodstream. High levels of ketones cause the blood to become more acidic and can lead to a condition known as ketoacidosis. Symptoms of ketoacidosis include nausea, vomiting, abdominal pain, and rapid breathing. In severe cases, it is life-threatening.

In addition to your body burning fat, your bloodstream is accumulating the glucose that would normally be used by the cells or stored. High blood glucose levels also result in serious health complications. (For further information on health complications, see Looking to the Future: Complications.)

By replacing insulin through injections or the use of an insulin pump, your body can resume using glucose for energy and you will no longer be at risk of harm from ketoacidosis and high blood glucose in the short term.
The main aims of treatment are:

1. To allow you to live a long, fulfilling, and healthy life
2. To keep your blood glucose level as near to normal as possible (between 70 and 120 mg/dl before you eat and less than 150 mg/dl about two hours after you eat)
3. To reduce any other factors that may increase your risk of developing complications, such as lowering your blood pressure if it is high, and keeping your cholesterol low
4. To detect any health problems related to your type 1 diabetes (i.e., complications such as heart disease, kidney failure, blindness) as early as possible

*This publication is not intended to replace medical advice. Please discuss with your physician what would be considered a normal blood sugar range for you.

Aiming for a normal blood glucose level

To maintain normal blood glucose levels, you now need to do the job of your pancreas. This means:

- Administering insulin during the day
- Regularly testing blood glucose levels
- Making constant decisions about how much insulin is needed to balance your blood glucose

How do you know if your blood glucose is in good control?

Checking the level of glucose in your blood and keeping a record of the levels is an important part of managing your diabetes. This allows you to identify the patterns of high or low blood glucose levels. This information will also help you and your physician or diabetes team balance food, exercise, and insulin doses. Ideally, you should aim to do at least four blood glucose tests a day. To get the most out of testing, your diabetes team may advise you to test your blood glucose levels before eating, and then again two to three hours afterward. Testing at bedtime is especially important, because it allows you to determine if your blood sugar is lower than your goal—and if so, to know to eat a snack to avoid middle-of-the-night hypoglycemia. It is also a good idea to test before and after exercise. If your blood glucose level is high, such as at the time of diagnosis, or when you are ill, you should also test for ketones, based upon the advice of your physician. You can do this by testing your blood using a blood glucose meter that also tests for ketones, or by testing your urine. Ketones in the blood or urine can also indicate that your insulin levels are too low and that additional insulin needs to be taken as a matter of urgency so that your body can use glucose, rather than fat, for energy.

There is no avoiding the fact that pricking your finger can be painful. However, there are various finger-pricking devices on the market, and you may find one type more comfortable than another. Most devices allow you to adjust the depth of the needle if you are not getting a large enough drop of blood. The tips of your fingers are also more sensitive, so try pricking your finger off to one side. Also, be careful how vigorously you pump your finger for blood once your finger is pricked—this can squeeze blood into the surrounding tissue, causing bruising and discomfort. It might be encouraging to know that testing your blood glucose becomes less painful over time. There are glucose sensors, which will be described later, which may require less frequent finger pricking, and may give more glucose information.

Tips to make testing easier

- Instead of using alcohol wipes, just wash your hands (and then make sure hands are dry) prior to testing.
- Use a fresh lancet every time—they hurt more when they're blunt.
- Once you've pricked your finger, hang your hand down and let gravity do the work for you, or you could try gently massaging your finger prior to using the lancet.
- Look at different blood glucose monitors before choosing one—some need less blood than others or use blood from sites other than the fingertip.
- Try different lancets. Some are thicker than others—look for a shorter and finer variety (ask your physician or diabetes educator if they have any free samples you can try before you purchase).
- Try setting your lancet to a shorter puncture; the deeper the finger prick, the more tissue you damage.
- Alternate your sites—don’t use just one finger.
- Target the sides of your fingers instead of the soft center area in the middle where there are more nerve endings.
Advancements in blood glucose control

JDRF has been working hard to help patients improve their type 1 diabetes control and to make the management aspect of type 1 easier. One of JDRF’s initiatives working toward this goal is called the Artificial Pancreas Project. An artificial pancreas will integrate two technologies currently available—continuous glucose monitors and insulin pumps—in a “closed loop” system. The system will use an algorithm to calculate and automatically provide the right amount of insulin at the right time. It will enable people with diabetes to achieve tight blood glucose control, avoiding both highs and dangerous lows, and thereby significantly reducing the risk of developing complications. For the latest updates on research related to the Artificial Pancreas Project, visit www.jdrf.org/artificialpancreasproject.

Continuous glucose monitor (CGM)

A continuous glucose monitor (CGM) is a device for people with diabetes that provides continuous “real-time” readings and data about trends in glucose levels. This information allows people with diabetes to understand their glucose level, and whether it is rising or falling. They can then intervene by eating food or taking insulin to prevent it from going too low or too high. To date, continuous glucose monitors from three companies have been approved by the FDA, and a major clinical trial funded by JDRF (www.jdrf.org/cgmtrial) has found that most people with type 1 diabetes who use CGM experience significant improvements in blood sugar control.

As a result of the new evidence from the JDRF CGM trial, many health plans are increasing coverage for CGM. If a health plan doesn’t have a formal coverage policy for CGM yet, you may still be able to get coverage by applying for “case-by-case” coverage. For more information about obtaining insurance coverage for a CGM, visit www.jdrf.org/cgmcoverage.

Be realistic

Living with diabetes can sometimes be incredibly frustrating. Over the course of a couple of days, you can eat the same amount of food, take the same amount of insulin, and do the same amount of exercise, but your blood glucose levels from day to day can be completely different. While food and exercise help determine how much insulin your body needs each day, other factors that you may not understand or control play an important role as well.

You may also find that your blood glucose levels run high for many hours after an episode of hypoglycemia. These levels may be the result of overeating to correct the low blood glucose level. However, if your blood glucose has been low for some time, your body will make and release stress hormones to try to protect you from having a serious low blood glucose incident. One of these hormones is glucagon. Glucagon triggers the release of the stored glucose (glycogen) from your liver. The glycogen is converted to glucose, and this raises your blood glucose level. It takes hours to refill the glycogen “storage” in your liver. So if you become low and your body makes glucagon (or someone gives you a glucagon shot)—causing glycogen release—you may have no more glycogen to release if you become low again in a short period of time. Your body also produces stress hormones when you are anxious or unwell that can also affect your day-to-day blood glucose control.

Today’s insulin therapies are much better than previous ones, but they are still not perfect. So until there is a cure for type 1 diabetes, you need to know that there will be times when your blood glucose level is too high, and other times when it is too low. If your blood glucose is outside the normal range, try not to think of it as being “bad.” Rather, look for a pattern and talk to your diabetes team about developing strategies to improve your blood glucose level.

Keep a record of your blood glucose levels

Someone very wise once said, “Sometimes you can’t see the forest through the trees.” This is true of managing type 1 diabetes when, over time, little by little, your blood glucose control may change in ways you can’t determine by just looking at one or two days of test results. By keeping a record of your blood glucose levels over time, you can often see trends that will help you make changes to improve your blood glucose levels, reduce hypoglycemia and/or hyperglycemia (high blood glucose levels), and manage your type 1 diabetes better.

There are a few ways you can keep track of how your blood glucose levels are fluctuating.

• Diabetes record books
One of the most popular ways to keep track of blood glucose levels over time is to use a small book to record blood glucose levels, food intake, insulin, and activity levels.

• Blood glucose monitors
A benefit of some blood glucose monitors is that they automatically store your test results. A limitation is that viewing the historic data on the screen can make it difficult to see recurring patterns throughout the day, week, or month. Monitors generally don’t provide the means to track other
aspects of your management, such as exercise, food, stress, and insulin, although some have begun to do so.

• **Computer software**

Blood glucose monitors and insulin pumps often provide the ability to download their data to a computer so you can view your blood glucose and/or insulin history. The software is available from the pump or monitor manufacturer (do a quick search online for the manufacturer's website to see what it has available) and generally gives you the ability to see graphs and statistics that can help you spot trends and make adjustments to your management plan in consultation with your diabetes team.

• **Hemoglobin A1c test**

Your physician or diabetes team will arrange for you to have a special blood test, known as a hemoglobin A1c (HbA1c), every three to four months, in addition to you testing your blood glucose levels at home. When you test your blood glucose level, you are measuring how many molecules of glucose are in your bloodstream at the time of testing. However, your HbA1c result is measured as a percentage, and looks at your overall blood glucose control for the preceding two to three months. Glucose in your bloodstream will attach itself to the hemoglobin part of your red blood cells. If there is a lot of glucose in your bloodstream over time, this will result in a higher percentage of hemoglobin with glucose attached. The hemoglobin with attached glucose is referred to as HbA1c or glycated hemoglobin. Since your blood cells, and therefore your hemoglobin, live for around 120 days, the HbA1c test gives you an idea of how your blood glucose levels have been tracking over the same time period. Ideally, you should aim to keep your HbA1c under seven percent, as long as you can achieve this goal without significant episodes of hypoglycemia. Research has shown that keeping your HbA1c near seven percent can significantly reduce your risk of developing long-term complications.

**Diabetes management involves more than just blood glucose control**

You may be surprised that your endocrinologist does not focus exclusively on blood glucose levels. Optimum management of diabetes also requires a focus on blood pressure, renal function, and cholesterol levels. This is because the risk of diabetes-related complications is reduced when blood glucose levels, blood pressure, and blood fats are kept under control. Have your blood pressure checked regularly (at every visit to the physician) and treated if necessary.

**Tips to improve your blood glucose control**

• Keep a good record of your blood glucose levels.

• Review your blood glucose records regularly to look for patterns of highs/lows.

• Work with your physician or diabetes educator to make adjustments to your insulin intake, diet, and exercise until your control improves.

• Learn what causes highs and lows for you—the more you recognize what triggers them, the better you will be able to adjust your insulin, carbohydrate intake, or exercise to avoid problems.

• Manage hemoglobin A1c (HbA1c) based upon your physician's suggestions.

• Don't expect perfection! Just aim to get more of your readings within target.

• Ask for help from your physician or diabetes educator when you need it.

**Protective medications**

The fact that type 1 diabetes can lead to a wide array of complications is well known. But medications can be used to help stave off certain complications, such as high blood pressure or high cholesterol. Discuss with your physician the types of medications that may be considered preventively to keep blood pressure and cholesterol levels in check even if you do not yet have signs of elevated levels.
Everything to Know about Hypoglycemia

When you inject or pump insulin, there will be times when you have too much insulin in circulation. This may be because you accidentally gave yourself more than you needed, you have been more active than you anticipated, your meal is delayed, or your meal has fewer carbohydrates than you thought. It may also be because the insulin preparations you use aren’t perfect and don’t work exactly the same each day. No matter what the cause, there will be times when you have too much insulin and your blood glucose level drops. As discussed earlier, this is known as hypoglycemia, or low blood sugar.

Although an insulin reaction is an opportunity to have a high-sugar food you enjoy but might not otherwise get to eat often, the key goal should always be to avoid reactions whenever possible and to never use them as an excuse to cheat. Remember, it is a serious medical condition that should be avoided if possible, and one that requires the best possible treatment at the earliest possible moment.

Having hypoglycemia can be a frightening experience. Symptoms are different for different people, but they may include:

- Shaking
- Sweating
- Dizziness
- Hunger
- Blurred vision
- Difficulty concentrating
- Feeling anxious, irritable
- Changes in behavior

Examples of a quick hypoglycemia fix are:

- Two to four glucose tablets
- Two packets of sugar
- A glass of regular (not diet) soft drink or fruit juice

You should check your blood glucose 10 to 15 minutes after you have treated your low blood sugar. If your blood glucose level is still low, you should eat another 15 grams of carbohydrates and retest your blood glucose in another 10 to 15 minutes. Depending on the timing and cause of your low, you may also need to eat a snack to prevent another episode (for example, if it’s due to increased exercise or taking too much insulin).

You can’t always predict when your blood glucose is going to drop too low, so you need to carry a hypoglycemia fix with you at all times. Some useful places to keep a low blood sugar fix include:

- The glove compartment of your car
- Your handbag or backpack
- Beside your bed
- In your desk drawer
- In your back pocket

You may find that your blood glucose levels run high for many hours after a low. This may be related to overeating to try to correct the low blood glucose level or due to your body trying to help you raise your glucose levels by producing extra stress hormones. To stop the highs, you have to stop the lows. Doing some blood glucose tests throughout the day will help you and your endocrinologist or diabetes team work out where you need less insulin and where you might need more.

If you start having too many low blood glucose levels, you will find it harder to recognize signs and symptoms of hypoglycemia. The obvious signs of shaking and sweating may not occur, and you may just feel vaguely out of sorts. This condition is called hypoglycemia unawareness. To avoid this, you should advise your physician or diabetes team member that your blood glucose level is dropping regularly to low levels (more than three to four lows in a week, or less if you are newly diagnosed).

Getting help in an emergency

If you are not able to recognize signs and symptoms of low blood glucose levels or you ignore them, your blood glucose may drop so low that you are unable to treat it yourself. For this reason, you should teach your family, friends, and work colleagues how to recognize and treat a low if you cannot. They should only give you something to eat or drink if you can respond to their commands. If you can’t, they need to call an ambulance right away or give you an injection of glucagon. It is very important to always wear a bracelet, necklace, or other identification stating that you have type 1 diabetes.
If you ever THINK you are having a reaction when driving, pull over immediately and take an appropriate snack. In these instances always err on the side of too much sugar, not too little, and more caution rather than less. Make sure all symptoms have subsided before driving again.

**Food**

For many years, people with type 1 diabetes were told that they needed to eat three meals and three snacks a day to keep their blood glucose levels from swinging too high or too low. Thankfully, with the advent of modern insulin delivery and monitoring technology, most people with type 1 diabetes no longer need to live with such a regimented diet. People with the disease can eat a little or a lot depending on what they feel like doing. While at first it may seem like your former life of carefree and spontaneous eating and drinking is over, your diabetes care team can help you tailor your insulin treatment to your lifestyle.

To make sure you are getting the correct amount of insulin, you will need to consider what and how much you eat so you can match the glucose entering your bloodstream with the insulin dose you take. Your blood glucose level after you eat will depend most on the amount of carbohydrates contained in your meal or snack.

**Sugar**

It is a common myth that people with type 1 diabetes need to avoid all sugar. This is not true. As part of general healthy eating, you should cut down on foods containing sucrose (e.g., table sugar, candies, and regular soft drinks) because they have little nutritional value and won’t satisfy your appetite. This doesn’t mean they are banned from your diet. Small amounts are unlikely to do you any harm, especially if used in cooking or in tea or coffee, or eaten with other foods. Fruit and milk products contain naturally occurring sugars, but unlike sucrose, these foods do offer significant nutritional value and play an important role in a healthy diet.

**Glycemic index**

The glycemic index is something you will probably hear a lot about. We used to think that starches were broken down into glucose at a slower rate than sugars, but we now know this is not always true. You digest different types of carbohydrate foods at different rates, and they can have different effects on your blood glucose level. Some foods that are quickly digested—for example, carbohydrates with high sugar content—may result in a sharp rise in your blood glucose level soon after you eat. Other foods, such as pasta, can take longer to digest, in which case it takes longer for the glucose to enter the bloodstream.

The effect of different carbohydrate foods on blood glucose levels is the glycemic index (GI). Foods with a low GI cause less of a spike in post-meal blood glucose than those with a high GI. However, you still must consider how many carbohydrates are in what you are eating.

Some clinicians and researchers believe that the GI concept can be useful in managing the diets of people with type 1 diabetes. It is important that you speak to your diabetes team to identify whether this method is suitable for you. You can also learn more about the glycemic index, and determine the glucose index of the foods you eat at [www.glycemicindex.com](http://www.glycemicindex.com).

**Protein and fat**

Protein and fat are vital components of a healthy diet. Protein is important for growth and repair of cells. It also plays a role in producing antibodies that help fight infection and in creating hormones to keep your body healthy. The best sources of protein in the diet are meat, poultry, fish, eggs, dairy products, and legumes. Fat is a rich source of energy and is important for carrying fat-soluble vitamins A, D, E, and K, as well as antioxidants. Certain types of fat supply the essential fatty acids that play a role in regulating many body functions.

While carbohydrate foods have the largest and most direct effect on blood glucose levels, proteins and fats in the diet can influence blood glucose levels, too. Excess protein is ultimately converted to glucose by the liver. This means that consuming large amounts of protein can result in an increase in blood glucose levels several hours after eating. Fat can have variable effects on your blood glucose levels, the most significant of which is to slow down the rise in blood glucose after a meal. Fat delays the rate at which the stomach empties, which slows down the absorption of glucose from digestion. This might sound like a good thing, but a high-fat diet is not usually a healthy diet. In fact, eating too much fat (particularly saturated or animal fat) can be harmful and increase your risk of obesity and heart disease. A high-fat meal can also make it more difficult for your insulin to work well, resulting in a higher blood glucose level than expected.
**Determining what is in foods**

In the United States, all packaged foods have a nutrition information panel, and you can use this to ensure you know what you are eating. But not all food comes in a package. Using resources such as the CalorieKing Calorie, Fat, and Carbohydrate Counter (2011) can help you assess the calorie (energy), fat, and carbohydrate content of foods that do not come with "Nutrition Facts" labels.

**Counting carbohydrates**

To have good control of your blood glucose levels, you will need to learn how to count carbohydrates. This is because research has shown that it is the total amount of carbohydrates you eat that matters most to your blood glucose control. In other words, you may choose to eat a bowl of pasta for lunch or a chocolate bar and they may have the same insulin needs, if the two meals are fairly equal in total carbohydrates.

If your physician has instructed you to take set doses of rapid-acting or short-acting insulin with your meals, you will need to be able to count carbohydrates to ensure you eat the same amount at the same times each day to balance the insulin and keep your blood glucose levels in the target range.

However, if you would like more freedom with your diet, your endocrinologist or diabetes team will probably suggest you use the insulin-to-carb ratio, so that you can take a dose of rapid-acting or short-acting insulin to cover the expected rise in your blood glucose level.

Adding up how many carbohydrate exchanges you eat will help you decide how much insulin to take with each meal. For example, if your insulin-to-carb ratio is two units per carbohydrate exchange and you eat a sandwich and drink a glass of milk for lunch (containing approximately three exchanges), you would inject yourself with six units of rapid-acting insulin directly before eating. Monitoring and recording your blood glucose levels before and after each meal will tell you if your insulin-to-carb ratio and your calculations are correct.

It is a good idea to weigh and measure your food until you can visualize carbohydrate exchanges to help you accurately estimate how many carbohydrates you eat. You don’t need to keep weighing food for the rest of your life, but you might repeat these measures from time to time. For example, if you think you usually eat a cup of rice, which is approximately three exchanges of carbohydrates, use a cup measure when you serve the rice to confirm your estimate.

You might also want to measure the amount of food found in different-size plates, bowls, or takeout food containers to make it easier to estimate the carbohydrate amount when you are not at home. For example, measure how much rice is normally included in your Asian lunch take-out and this will help you keep on track at work.

All this probably sounds daunting, but measuring your food and learning to count carbohydrates will help give you freedom to decide how much you want to eat at each meal. Being confident in estimating carbohydrates will also make eating out a lot easier. A dietitian can help.

*This publication is not intended to replace medical advice. Please discuss with your physician what would be considered correct carbohydrate ratios for you.*

**Eating out**

Many people eat out at restaurants or buy take-out or delivery a number of times a week. You probably do this because it’s quick, it’s easy, and it’s a great way to catch up with colleagues and friends. The good news is that this routine doesn’t have to change if you have type 1 diabetes, although you need to think a bit more about the foods you eat.

Today, many fast food and chain restaurants have nutrition information about their foods available on their websites, posted in their restaurants, or available if you ask. Using these websites, you can look up your favorite menu items and record how many carbohydrate exchanges (and other nutrients) these items contain.

Nutrition information can be harder to come by when eating at someone’s house or at a restaurant. In this case, you need to make your best estimate, taking into account the size of the serving and the amount of carbohydrates you think are in the food. Checking your blood glucose before you eat and then several hours after will help to determine if your estimate was correct. In addition, when you eat out, your meal may be served later than usual. To avoid a low, you might want to wait until the meal has arrived to take your insulin. Obviously, when eating out, there are other nutritional goals that may come into play. For example, if you are trying to lose weight, cutting down on calories is important. For overall health, you should also consider how much fat and salt foods contain. But remember, the occasional splurge won’t hurt you.
**Alcohol**

Although alcohol is not a food, it does provide energy, and the amount you drink is also important to consider when you have type 1 diabetes.

In the United States, it is recommended that men drink no more than two alcoholic drinks per day, and women no more than one alcoholic drink per day, with one to two alcohol-free days each week. If you drink more, it may increase the risk of high blood pressure and heart disease, as well as a number of different cancers. In the short-term, alcohol can cause you to gain excess weight because of its high calorie content.

For people with type 1 diabetes, excess alcohol can also increase the risk of hypoglycemia. When you drink alcohol, the liver has to stop everything to break it down and remove it. While your liver is doing this, it can't do all the other jobs it normally would do, such as releasing stored glucose if your blood glucose level starts to fall. This effect can last for many hours after you have been drinking, and may continue overnight and into the next day.

To avoid hypoglycemia, it's best to avoid drinking large amounts of alcohol in one session, and to make sure you always have some carbohydrates to eat before or while you drink. You should also test your blood glucose level before you go to bed and eat a snack if your level is normal to low. It is also recommended that you don't include the carbohydrate content of alcoholic beverages in your carbohydrate counting calculations.

On occasion, you may find that your blood glucose level rises too high after drinking an alcoholic beverage that contains carbohydrates, such as hard alcohol mixed with regular soft drinks, sweetened liqueurs, or large amounts of beer. You may also find that you eat more when you drink alcohol. Where possible, choose a diet soft drink as a mixer and keep an eye on your food intake.

**Avoid hypoglycemia hangover**

While the risk of hypoglycemia is increased by alcohol, there are strategies to reduce this risk. For example, if you are going out drinking, make sure you eat some carbohydrates at the beginning of the night. A snack containing two to three exchanges of carbohydrates is probably ideal. You should also eat some carbohydrates every few hours while you are drinking and before you go to bed.

If you have previously experienced problems with low blood glucose levels overnight, it may be worthwhile to reduce your evening dose of insulin slightly, especially if you are planning a very active night, such as dancing, or if you have played a sport during the day. However, you should discuss this with your diabetes team first.

The morning after a night out can also be problematic. Delaying or missing your morning insulin can result in your blood glucose levels rising too high. To avoid this, set your alarm clock to wake you within an hour or so of your usual waking time. If you are hungover and don't feel like eating, take your normal or a slightly reduced dose of your intermediate or long-acting insulin and go back to bed. You should set your clock to wake you again in two hours so that you can check that your blood glucose level is not too low.

**Weight management**

Prior to being diagnosed with type 1 diabetes, you probably lost a considerable amount of weight over a very short period of time. Some of this weight loss was due to fat loss as your body burned fat for energy rather than burning glucose. However, around half this weight loss would have been due to dehydration. As your blood glucose levels rose, your kidneys started to work overtime to filter the excess glucose. It is normal to regain several pounds over the first week after commencing insulin therapy as your body becomes hydrated. During this time, the excess glucose is taken up by the cells of the body and your kidney function returns to normal.

Over the next few weeks or months, your body will also replace the fat stores lost leading up to the time of your diagnosis. Unfortunately, excess weight gain is a potential side effect of intensive diabetes control with insulin. This may occur if you have recurrent hypoglycemia and/or need to eat excessively to prevent hypoglycemia. High levels of insulin can also prompt your body to store excess carbohydrates as fat, meaning that you can still gain weight while eating only healthy foods. It's not just a matter of what you eat; it is also a matter of how much you eat. If you eat more calories than you burn, you will gain weight. If you eat fewer calories than you burn, you will lose weight. Your having type 1 diabetes hasn't changed this equation.

Ideally, you should eat when you're hungry. If you need to eat regularly to avoid your blood glucose level dropping too low, you probably need your insulin regimen adjusted. Talk to your endocrinologist or diabetes team for further advice.
As you get older, your metabolism slows down, causing you to put on weight more easily. If you are in your forties, you can no longer eat the same amount of food you did when you were in your twenties and expect to maintain your weight. How active you are during the day will also affect your energy requirements. If your blood glucose levels are normal or high, and you are gaining excess weight, the chances are you are eating too much. Surprisingly, the extra pounds from servings that are just a “little” too large can add up quite quickly. Certain foods and drinks, such as cakes and alcohol, are also very high in calories, so small amounts can throw your energy balance off. While you can still eat and drink these foods in moderation, they need to be balanced with the rest of your daily or weekly intake.

**Exercise**

There is no doubt that exercise is good for you. It slows the aging process, helps with weight management, and is good for your overall health. However, adjusting food and insulin around exercise can be tricky, since different types of exercise can have different effects on people with type 1.

In general, sustained moderate exercise such as walking will result in a slow drop in blood glucose levels. However, intense exercise that really gets your heart pumping may result in your blood glucose level rising in the short-term. This occurs because your body releases high levels of adrenaline that trigger your liver to break down stored glucose and release it into your bloodstream. This reaction will be exaggerated if your insulin levels are too low at the time of exercise. Once you stop exercising, and your adrenaline levels drop, your muscles and liver will start to take up extra glucose to replace their stores. This means you are at risk of your blood glucose level dropping too low in the 8-to 12-hour period following exercise. You will need to take this into account when estimating your insulin dose prior to, or immediately after, exercise.

Test your blood glucose before, and then every few hours after exercise, and record what exercise you do and what food you eat in your blood glucose record book. This will make it easier to see trends and will also assist you and your diabetes team in developing good management strategies.

**Exercise and insulin action**

The key things to consider when exercising are the type of exercise you plan to do, the action and timing of your insulin, and your carbohydrate requirements. The overall goal is to begin exercise with just the right amount of insulin in the blood. Having too much active insulin at the start of exercise reduces the amount of glucose the liver adds to blood, thereby increasing the risk of hypoglycemia. Conversely, exercising with too little insulin stimulates glucose production from the liver, which can cause hyperglycemia. Exercising in the late evening after dinner may increase the risk of hypoglycemia overnight, often around 2:00 a.m. to 3:00 a.m., but you can reduce this risk by lowering your evening insulin or eating a low glycemic index snack before bed. You should discuss this situation with your endocrinologist or diabetes team and develop a plan.

When the start time of a sporting event dictates the time of exercise, you may need to reduce your insulin prior to the event. The amount by which you reduce your insulin dose depends on the type and duration of your chosen activity. Generally, the main things to consider when adjusting insulin prior to exercise are the intensity and duration of exercise. Initially, small adjustments between 10 percent and 20 percent are recommended for moderate exercise. Larger adjustments (50 percent to 75 percent) may be needed for prolonged, intense exercise. As you gain more experience, you will be able to fine-tune your insulin dose to your individual responses. Adjusting your insulin dose is just like any other component of type 1 diabetes management. Getting it right requires practice!

Even when exercise is timed well with insulin action, you may need to eat extra carbohydrates to balance your blood glucose levels. Whether you need to eat them immediately prior to exercise will depend on your blood glucose level, the type of exercise you intend to do, its duration, and its intensity. Everyone's carbohydrate requirements for exercise are unique. Testing your blood glucose before, during, and after exercise will help you develop your own plan.

If you are exercising intensely and/or over an extended period of time, you are likely to need extra carbohydrates during exercise. How many carbohydrates you need will differ depending on the timing of the exercise relative to the action of the insulin you have injected. In general, you require fewer carbohydrates as the time since your last insulin injection extends.
To help maintain hydration during exercise, you can take your carbohydrate in the form of a carbohydrate-electrolyte beverage, such as a sports drink, which provides the best available fluid and carbohydrate absorption rates. Other more concentrated drinks such as juice or carbonated drinks have slower absorption rates and can cause an upset stomach.

After exercise
Your muscles and liver can take up extra glucose to replace their loss of stored glucose for 8 to 12 hours after exercise. This means that exercise places you at risk of hypoglycemia for many hours after you have finished exercising. This risk is even greater if you have drunk alcohol within the same period or in the hours following exercise.

If your blood glucose levels continue to fall after exercise, you may need to decrease your insulin doses before and after exercise. The amount by which you reduce your insulin will depend on your blood glucose trend. Your endocrinologist or diabetes team will be able to give you advice about insulin adjustment.

This publication is not intended to replace medical advice. Please discuss with your physician what would be considered a normal blood glucose treatment for you.

Managing Sick Days
Being stressed or unwell can affect your blood glucose levels. During times of mental or physical stress, especially if you have the flu or a serious bacterial infection, your body will make and release stress hormones. These hormones can trigger a release of stored glucose from your liver and interfere with the action of insulin. On these days, your body will need significantly more insulin.

Before you had type 1 diabetes, your pancreas automatically produced insulin for you. If you get sick now, however, you may not be taking the amount of insulin your body will need. Too little insulin and your body will start to burn fat as an alternative energy source, producing ketones that can build up and make you even sicker. In severe cases, this situation can be life-threatening.

You are less likely to produce stress hormones if you have a gastrointestinal infection. In this case, your blood glucose levels are more likely to be low because you’re not eating or not absorbing the food that you are eating. Other illnesses, such as chicken pox, seem to have little or no effect on your blood glucose. The impact of illness is very much dependent on the type of illness you have.

A relatively minor viral illness such as a cold should not have a major effect on your blood glucose level, though you should still keep an eye on it. If you have a gastrointestinal infection, you need to keep up your fluids by drinking one to two glasses of fluid every hour or so. The type of fluid will depend on your blood glucose levels. If you are normal to low, you should drink normal soft drinks or some other drink with sugar. If your blood glucose is high, all you need is the fluid, so water or a diet drink is a far better choice. You may also need to take less insulin.

If you’ve got a serious viral or bacterial infection, you will need to maintain your fluid intake. If your blood glucose levels are high or you have a fever, you are especially prone to becoming dehydrated. If you are feeling particularly ill, you should test your glucose levels more frequently. You should also test either your blood or your urine for ketones. If you have ketones, you will need to take quick or rapid-acting extra insulin so that your body can use the glucose in your blood for energy rather than having to burn fat. You will need to develop a plan with your diabetes team that covers how much extra insulin to take in case of illness.

A trip to the hospital
Having to go into the hospital, whether it’s planned or an emergency, can be a stressful and uncomfortable experience for anyone. It shouldn’t be more difficult for someone with type 1 diabetes, provided you are properly prepared. The key is to be well-informed, take an active role in managing your diabetes while in the hospital, and plan well before the event.

Often the team assigned to serve you when you are in the hospital knows a lot more about type 2 diabetes than type 1, and may not grasp the full dynamics of glucose control based on multiple injections. You have the right to ask for assistance from someone who is knowledgeable in the issues you face. Don’t hesitate to ask for a consult from an endocrinologist if your glucose levels are not in good control while you are in the hospital.

This publication is not intended to replace medical advice. Please discuss with your physician what would be considered proper sick day management for you.
Marriage and Relationships

When you have type 1 diabetes and are in a committed relationship with someone, diabetes is bound to come up at some point. The way you and your partner handle the disease can have a significant impact on your relationship and on your management. This section will cover how to approach someone new about your type 1 diabetes, how to handle its impact on intimate moments, and what kind of advice you can pass along to your significant other.

New romantic relationships

When starting a new romantic relationship with someone, you have to decide how to approach telling him or her about your life with type 1. It’s a personal choice whether to tell him or her on the first date or wait a few dates. There are plenty of people out there who are accepting, supportive, and caring when it comes to type 1 diabetes. But there are the few who aren’t, and to some, it’s important to know what kind of potential partner you are dealing with right from the start. In general, there’s a balance that can be found in sharing it, but also not making a point of dwelling on it, either. It’s best to show that while it’s something you have to deal with, it’s also not the core of your existence. For example, if you’re going out to dinner, there’s really no way to hide the need to dose insulin with a meal. So you might test and dose, and if the question comes up, which it usually does, mention that you have type 1 diabetes, which requires insulin to be dosed whenever you eat. Sometimes, that may lead to a deeper conversation on the subject; other times, it may finish that conversation.

Committed relationships

Committed relationships take teamwork, and it’s no different when you or your partner has type 1 diabetes. Managing the disease is sometimes a team effort requiring strong communication between you and your partner, especially when discussing how involved your partner should be in your diabetes management. A solid sense of self, combined with an honest and supportive relationship, make all facets of diabetes management easier. That being said, it is important to be able to talk about all the different bits and pieces that come with a committed, intimate relationship and type 1 diabetes. Communication is key, so if you’re feeling crabby or snappy, try to be aware of where your blood sugar is — that can affect your mood. It’s also a good idea to make your partner aware of any frustrations you’re dealing with related to your diabetes management, as that can help him or her understand your state of mind. Type 1 diabetes brings mood swings into any relationship. Sometimes the best thing to do is be aware of the possibility of mood swings, and in heated discussions try to step back and ask yourself if that is playing a role.

As in any relationship, compromise is key, and when one of the partners is a type 1, compromise becomes harder since the person with type 1 is often driven by medical need (e.g., what time to have dinner) rather than just by preference. But a person with type 1 diabetes whose blood glucose is under control can make remarkable adjustments on a case-by-case basis as necessary — if time is provided to develop a strategy about changes in meal time, exercise schedule, etc.

Remember that your type 1 diabetes isn’t something you should keep locked up and only grapple with in privacy. Healthy diabetes management is an open and constant part your life, something that touches so much of your everyday activities. It’s important to not pretend that it’s not part of your partner’s life, because it is. Remember, you don’t have to be alone in your diabetes management if someone is willing to be there and help you along the way. It’s your type 1 diabetes and your ultimate management and self-care, but you can work through it all together with your partner.

Note: To all you partners of those with type 1 reading this: Be supportive, and be patient. Keep the lines of communication open, and ask questions about things you don’t understand. Educate yourself, join online communities where others talk about and discuss type 1 diabetes. This is a very personal condition, but at the same time, it’s tough to live with it alone. Make sure you are there to help and support, not to become the “Diabetes Police.”

Parenting as an Adult with Type 1

If you have children, it’s important to discuss your type 1 diabetes with them. When explaining the disease, keep it simple and answer the questions they ask, but try to avoid elaborate lessons. They usually really only want to know what it is you are doing at the moment; they don’t need a biology lesson. One of the normal fears of parents with type 1 diabetes is having a low blood sugar incident when they are alone with their children. Of course, you want to prevent your low blood sugars as much as you can, and most parents don’t want to burden their kids with their diabetes care, but even young children can assist in an urgent situation. Keep a “low box” stocked with juice boxes, glucose tabs, or other quick-acting sugar in a child-accessible place. Teach them to go get that box if you ask for it — it’ll be much easier than having them attempt
to get and pour juice, or locate other treatment items. Very young children (age four or five) can be taught how to use the 911 system and you should practice it with them. A best practice for very young children is to give them a laminated card with emergency contact information on one side, and a simple statement on the other: “My parent has type 1 diabetes and might be experiencing low blood sugar. He/she needs juice or regular soda quickly.” You might consider teaching your young children to show the card to an adult if you or the parent with type 1 is not acting normally.

Also remember that all blood sugar extremes, not just lows, can really impact how you might interact with others. Whether it’s a cranky high or an incoherent low, this can definitely impact your kids, because parenting is all about patience and dependability! Often, it helps to stop during a particularly difficult parenting situation and think about whether or not you are high or low. Yes, sometimes the kids may have just pushed you too far, but if your blood sugar is causing you to be irrational or less patient, it’s a good idea to stop, test, and treat before you punish your kids for the rest of the year!

Consider the saying “go slow to go fast.” It means that if you stop and take the time to do something right, you may often achieve your goals faster than if you rush through and do a haphazard job. As a parent, you might be rushing around to do all the things you think you need to do to be a “good” parent. But as a person with type 1 diabetes, you really have to take a little extra time, plan for your diabetes needs, and be purposeful about how you take care of yourself in order to successfully care for your family.

Type 1 Diabetes and Work

To tell or not to tell
Your medical information is confidential, unless you work in a position where your type 1 diabetes may have safety implications for your colleagues or the general public (e.g., if you drive public transportation or are a police officer). Otherwise, you do not need to inform your employer about your type 1 diabetes, unless you wish to disclose it, or you need them to make some accommodation to your work situation to help you manage your disease, such as ensuring meal breaks. Remember, it is important to have someone with whom you work who can respond to type 1 emergencies.

Job interviews
Both disclosure and non-disclosure of your type 1 diabetes during a job interview have their drawbacks and merits. While people with type 1 diabetes successfully perform all types of jobs, some employers may be reluctant to employ someone with the disease in particular positions because of misconceptions. For example, they may wrongly assume that people with type 1 diabetes can’t hold a position that requires regular driving. If you choose to tell your potential employer about your type 1 diabetes, you need to be prepared to help dispel these myths.

Dealing with employer discrimination
Employer discrimination can occur in many forms. Based on your having type 1 diabetes, an employer might refuse to hire you, limit your job responsibilities or promotions, or fire you. They might also be unwilling to accommodate your need for regular meal or snack breaks, or to provide a private location where you can test your blood glucose or inject your insulin. Often, discrimination in the workplace occurs because employers and co-workers don’t understand type 1 diabetes and how it is managed. Your employer may be concerned about loss of work time and productivity, and this may influence their willingness to hire or support you within the workplace. However, workplace laws require employers to take reasonable steps to accommodate your needs. For instance, if you need to take a short break to have a snack or test your blood glucose level, your employer would be legally obliged, in the majority of cases, to allow it.

The Americans with Disabilities Act (ADA) of 1990 specifically prohibits all employers from discrimination against people with disabilities. Its definition of disability includes type 1 diabetes. The laws within this act say that a person with diabetes has the right to do everything else that adults without diabetes do. It further states that the workplace and other covered organizations must make “reasonable accommodations” for your diabetes. This Act was amended in 2008 (the ADA Amendments Act “ADAA”), expanding the definition of who qualifies under the legislation. It prohibits the consideration of mitigating measures when considering protection under ADA. Episodic disabilities can also be considered.
Despite all the advances in managing type 1 diabetes, there are certain jobs that may no longer suit you. If you have foot problems for instance, wearing steel-toed boots on a cold concrete floor for 12 hours a day may not be for you. Similarly, if you have retinopathy or a heart condition, you should not be performing tasks such as heavy lifting. Speak with your physician or diabetes educator if, in the future, you have concerns about the possible health risks associated with the demands of your job.

Managing shift work

Even if you don't have diabetes, shift work can put a strain on health. No medical evidence indicates that you shouldn't perform shift work; however, you should be aware that managing type 1 diabetes may be more difficult, especially if you are working a rapidly changing shift pattern. Even if you manage your diabetes well, shift work may increase your risk of high or low blood glucose levels due to changes in your body’s circadian rhythms, which regulate daily processes such as hunger and fatigue. When you start eating and sleeping at different times, you disrupt your body’s internal clock, which can affect blood glucose control. Different insulin regimens, such as taking long-acting insulin analogues at the same time once or twice a day, supplemented by rapid-acting or short-acting insulin when you eat, and regularly monitoring your blood glucose levels during and after shifts, can help reduce day-to-day fluctuations in blood glucose levels. For this reason, you should speak to your endocrinologist or diabetes team about your job so that they can assist you in developing a management plan that works for you.

During shift work, meals are often disrupted and occur at irregular times. You may not always be able to eat when you expect to. These issues can pose a challenge for controlling type 1 diabetes. However, with some careful planning, you can successfully manage your diabetes through healthy eating, no matter what hours you work.

Tips for healthy eating during shift work

1. Include regular meals and regular carbohydrate intake. No matter what working hours you have, try to eat three meals with some carbs, and spread your meals throughout the day (or night).
2. Always keep a supply of carbs nearby. If you are working unusual hours, be aware that shops and cafeterias may not be open, so you must have a supply of long-lasting (non-perishable) carbs on hand (e.g., in your desk or locker at work). Examples of long-lasting carbs include dried fruit, cereal bars, or peanut butter crackers.
3. Keep drinking your fluids. Many people don’t drink enough water. Even slight dehydration can contribute to tiredness, headaches, and possibly reduced alertness. Try to drink six to eight glasses of water a day.

Driving and Diabetes

Having good blood glucose control is important for safe driving. You should always check your blood glucose levels before getting behind the wheel, and carry extra snacks and supplies in your car. Many diabetes educators say that driving with a low blood glucose is the equivalent of driving drunk. In fact, if you get into an accident and your type 1 diabetes was part of the cause, you can have your license taken away, perhaps permanently.

On the other hand, many people with type 1 diabetes have learned to be very safe drivers. Regularly checking blood glucose levels, carrying extra snacks, and communicating with loved ones and others around you are all keys to driving safely with type 1 diabetes.

In case of an accident, you should always have something that identifies you as having type 1 diabetes, such as a bracelet or necklace. Other medical identification options available online include beads, leather bracelets, and keychains, or cards for carrying in your wallet or glove compartment.

All states have different regulations concerning drivers with type 1 diabetes. You should find out what your state’s requirements are, and consult your endocrinologist. (Also see: Automobile hypoglycemia.)

Traveling with Type 1 Diabetes

Type 1 diabetes shouldn’t stop you from doing the things you want to do, including traveling. For any traveler, planning ahead is the key to a successful trip. This is particularly true for people with type 1 diabetes. Preparing ahead of time will take you a long way in keeping you healthy once you’re there, as well as in helping you avoid unnecessary stress. In addition to the information below, you can learn more about traveling with type 1 diabetes at www.jdrf.org/travel.
Tips for a successful trip
Visit your endocrinologist, internist, or FP for a check-up several weeks before you leave for a trip. Make sure you ask them how to manage a potential illness, whether you should take glucagon with you, and how to adjust your insulin dose if required. Be sure to get any required vaccinations at least four weeks before you travel so you have time to deal with any possible side effects. You will need a letter from your physician that outlines your medical situation and lists all related prescription medications and delivery devices, including syringes. The letter must stress the importance of carrying your medications with you. Discuss your itinerary with your diabetes educator, and work out a plan for meals and medication, especially if you are traveling through different time zones. You may also consider asking your physician for the name and contact information of an endocrinologist in the local area where you will be traveling.

Ask your pharmacist for a list of your medications, including the generic names and doses. Make sure you carry a copy with you in your travel documents with a letter from your physician stating that you have type 1 diabetes and are likely to have problems with unexpected low or high blood glucose levels. You must be able to access good quality health care if you need it. Make sure your travel insurance covers type 1 diabetes, as not all policies do. Remember to take your insurance card with you. Take identification with you that explains that you have type 1 diabetes, in case you are unable to give instructions yourself. If you are flying, review your airline’s latest security information (usually available online) to check for any special policies or guidelines before you go to the airport.

Essential items to pack
Take extra testing supplies, medication, and snacks with you in case of theft, loss, or accidental destruction. If you use insulin pens, infusion sets, and/or glucose sensors, take extras to cover more than the length of time you will be away. Also, pack some syringes, since you can use them to withdraw insulin from an insulin cartridge in an emergency. If necessary, divide your medicines and diabetes supplies and pack them in more than one place, in case you lose one of your bags. Ideally, you should make sure that you have all the above items and most importantly your insulin, testing supplies, and treatment for low blood glucose in your carry-on luggage.

Extreme temperatures affect insulin, and it should never be stored in the baggage area of aircraft. The temperature in the hold is too low and the insulin will freeze and lose its effectiveness. There are a variety of ways to keep your insulin cool while you are away. Insulin must be stored properly, since it will spoil if left in temperatures that are too hot or too cold. Insulin retains its potency at room temperature for 30 days. However, some of the newer insulins are more sensitive to changed storage conditions.

If your trip is short, you may want to keep your needles and sharps and dispose of them on your return home. For longer trips, you can purchase small containers that store or disintegrate needles and syringes.

Consider taking an emergency kit for sick-day management. Discuss these arrangements with your endocrinologist or diabetes educator.

Flying with diabetes supplies
This information, along with other travel tips, is located on the Transportation Security Administration (TSA) website at www.tsa.gov/. All travelers, and particularly those who travel infrequently, are encouraged to visit the section on travel tips before their trip. Frequent flyers should review the information periodically for changes and updates. You can go directly to these tips at www.TSAtravelTips.us.

You should always notify your air carrier of your special screening needs before you arrive at the airport. This should include any assistance you will need with connecting flights. You might also want to take a copy of these tips with you when you travel. If you encounter problems with the screening process, ask to speak with the TSA security supervisor. You can report problems encountered while traveling by calling the TSA Consumer Response Center toll free at 1-866-289-9673.

Notify the screener that you have type 1 diabetes and are carrying your supplies with you. The following diabetes-related supplies and equipment are allowed through the checkpoint once they have been screened: insulin and insulin-loaded dispensing products; syringes; lancets; blood glucose meters; blood glucose meter test strips; alcohol swabs; meter-testing solutions; insulin pump and insulin pump supplies (cleaning agents, batteries, plastic tubing, infusion kit, catheter and needle, CGM sensors and transmitters); glucagon emergency kit; urine ketone test strips; unlimited number of used syringes when transported in sharps disposal container or other similar hard-surface container.
Insulin in any form or dispenser must be clearly identified. If you are concerned or uncomfortable about going through the walk-through metal detector or scanner with your insulin pump, notify the screener that you are wearing an insulin pump and would prefer a full-body pat-down and a visual inspection of your pump instead. Advise the screener that the insulin pump cannot be removed because it is inserted with a catheter (needle) under the skin. Insulin pumps and supplies must be accompanied by insulin. Advise screeners if you are experiencing low blood glucose and are in need of medical assistance.

Note on diabetes technology: Pumps usually do not set off security alarms, nor do security officials ask you to remove them. If you do set off an alarm, show your pump and explain what it is and that you cannot remove it. Also, a CGM does not need to be turned off during a flight—although CGMs do use some radio frequency, it is not the type that would interfere with a flight. You may leave it running during your entire flight.

**Before you go**
- Provide advance notice to your airline or travel agent if you require assistance at the airport.
- If you require a companion or assistant to accompany you through the security checkpoint to reach your gate, speak with your airline representative about obtaining a gate pass for your companion before entering the security checkpoint.
- The limit of one carry-on and one personal item (purse, briefcase, or computer case) does not apply to medical supplies, equipment, and mobility aids, and/or assistive devices carried by and/or used by a person with a disability.
- Make sure all your carry-on items—equipment, mobility aids, and devices—have identification tags attached.
- Disability-related items permitted through the security checkpoint include: wheelchairs, scooters, crutches, casts, canes, walkers, prosthetic devices, support braces, exterior medical devices, orthopedic shoes and appliances, augmentation devices, Braille note takers, and all diabetes-related equipment and supplies.

**Tips for the screening process**
- If a personal search is required, you may choose to remain in the public area or go to a private area for your screening. If you refuse either option, you will not be able to fly.
- You should be offered a private screening before the beginning of a pat-down inspection if the pat-down will require the lifting of clothing and/or display of a covered medical device.
- You should be offered a disposable paper drape for additional privacy before the beginning of a pat-down.
- You may request a private area for your personal search at any time during the screening process.
- Your companion, assistant, or family member may accompany you and assist you during a private or public screening. After providing this assistance, the companion, assistant, or family member will need to be rescreened.
- You may ask for a chair if you need to sit down during the screening process.

**Adjusting to time zones**
Long journeys often cross several time zones, so a regular 24-hour day can be extended or shortened, depending on the direction of travel. Either way, keeping your blood glucose close to target levels can be a challenge. If you are crossing more than two time zones, you will need to prepare a meal and insulin schedule with your endocrinologist or diabetes educator. A pump is an ideal way to deliver your insulin across time zones, since you can pump and dose for meals in the normal way, with no real change to your insulin dosage. Remember to reset your pump and blood glucose meter time and make the suggested delivery changes at the prescribed time on the outbound trip and on the return trip.

**At your destination**
Try to avoid situations that dramatically alter blood glucose levels, such as significantly more intense physical activity than usual. If you are extremely active, you may need to decrease your insulin, so be sure to discuss this with your diabetes educator or endocrinologist before you head off. Make sure you eat and drink enough to meet your needs, and be careful of contaminated foods and drinks. Carry extra food, water, medication, and sugar with you at all times. Try to avoid getting cuts, bruises, sunburns, blisters, or insect bites.
Diabetes in Women

Men and women face different challenges managing type 1 diabetes. Issues women may need to consider include:

- Menstruation
- Contraception
- Sexuality
- Infection
- Pregnancy
- Body image and weight management
- Menopause
- Osteoporosis

Menstruation

We all know how powerful hormones can be in controlling menstrual cycles, so it’s no surprise that they can also affect blood glucose levels. These changes are due to two hormones, estrogen and progesterone. When these hormones are at their highest level just before your period, they affect insulin, which may cause blood glucose levels to rise.

Some women with type 1 find that their blood glucose rises considerably, while others do not notice a difference. In others, blood glucose levels are lower before and during their periods. You need to discover your own pattern so you can adjust your insulin accordingly. Often it is the fasting blood glucose before breakfast that tends to fluctuate the most. Also, being physically active the week before your period can help control fluctuations in your blood glucose levels.

Contraception

Birth control is an important issue for women with type 1 diabetes because there are greater risks for a woman with diabetes and her baby when pregnancy is unplanned. The contraceptive options for women with diabetes are the same as for any woman, and are based on individual preferences. The effectiveness of various birth control options is the same for women with or without diabetes.

It used to be that women with diabetes were advised to avoid taking the birth control pill because of an effect on blood glucose and the risk for heart disease and stroke. However, changes to the level of hormones in the pill in the last few decades have greatly decreased the risk of these problems. (But the risk of heart disease and stroke remains higher for women with type 1 diabetes who also smoke). Blood glucose fluctuations are more likely with combination pills, and some physicians may suggest progestin-only (“mini”) pills to avoid this issue.

In the past, there was concern that IUDs might pose an increased risk of pelvic infection or trauma to the uterine wall, and that women with diabetes might be particularly vulnerable to these infections. The new generation of IUDs appears to be safe in this respect. Using a diaphragm does not affect blood glucose levels, but there may be an increased risk of yeast infections for women who have diabetes. Speak with your physician and/or diabetes educator about suitable contraception options.

Sexuality

Living with type 1 diabetes can influence your sexual experiences, both physically and emotionally. Your sexual health is important to your overall health, and it is important that you discuss any concerns with your physician and/or diabetes educator.

High blood glucose

Persistently high blood glucose levels can influence your energy level and cause significant fatigue. Unsurprisingly, this in turn may decrease your interest in sex. Achieving a good blood glucose level can improve mood and libido.

Reduced lubrication

After having type 1 diabetes for many years, some women experience a complication called neuropathy (nerve damage), which can reduce vaginal lubrication. This can make sex uncomfortable. A decrease in or lack of lubrication can occur for many other reasons such as menopause, the use of birth control pills, and stress. Water-based lubricants are effective at improving dryness and sensitivity. For severe dryness, a vaginal suppository can be used.

Infections

Vaginal infections and urinary tract infections are more common in women with diabetes, especially in those whose blood glucose is generally too high. Vaginal infections, such as yeast infections, can lead to itching, unusual discharge, and pain during intercourse, but they are easily treated. A urinary tract infection can lead to cloudy or bloody urine, a burning sensation, and/or a constant feeling that you need to urinate. This should be treated immediately to decrease the chance of subsequent kidney infection. Your physician will prescribe an antibiotic and your pharmacist can provide over-the-counter remedies to reduce any associated pain.
Pregnancy
In the past, women with type 1 diabetes were discouraged from becoming pregnant because they faced increased risk of complications, including miscarriage, stillbirth, and birth defects. Thankfully, this is no longer the case, and women with type 1 diabetes can expect to have a healthy baby.

The key, as with all aspects of diabetes management, is planning. Women with type 1 diabetes must plan their pregnancies and be prepared to put in a little extra work during pregnancy to ensure a healthy baby.

You will need support from a team of health professionals, who will help you plan a healthy pregnancy, including:

- A dietitian
- An endocrinologist
- A specialist obstetrician
- A diabetes educator

Preparing for pregnancy
You should start working on the following goals about three months before conception:

- Achieve an HbA1c below seven percent (below 6.5 percent, if you can achieve this without increased episodes of hypoglycemia). The first 8 to 12 weeks are when a baby’s major organs develop, so it is important to gain tight blood glucose control before you get pregnant. Persistently high blood glucose levels dramatically increase the risk of abnormal development of your baby. Work with your physician and diabetes educator to achieve the best blood glucose level you can. It might be time to consider an insulin pump and/or a continuous glucose monitor.
- Have a medical exam: You will need a medical examination by an endocrinologist prior to and during your pregnancy. They need to check blood pressure, immunity to rubella and chicken pox, and conduct a complications screen (particularly for your eyes and kidneys).
- Start taking a folic acid supplement and daily multivitamin: Discuss an appropriate dose with your physician.
- Visit your dietitian: They can advise you on the most appropriate foods to eat during your pregnancy.
- If you smoke or drink alcohol, stop!

During pregnancy and birth
Pregnancy can present some particular challenges for women with diabetes.

Achieving very tight blood glucose control throughout your pregnancy can be extremely stressful and demanding. Your insulin requirements will change as you battle morning sickness and your pregnancy progresses. You might find that your usual early warning signs for hypoglycemia change or disappear completely. Persevere though—it will be worth it! Seek the support and understanding of family, friends, and your health care professionals.

You will need to visit your endocrinologist and obstetrician more regularly than women without diabetes. Your physician will provide you with a schedule of check-ups and tests. Certain complications are aggravated by pregnancy (e.g., nephropathy and retinopathy). Your physician will closely monitor you during pregnancy.

The growth of your baby also needs to be closely monitored. Babies of women with diabetes are at risk of developing a condition known as macrosomia, which means that the fetus has an extra-large body for its gestational age. If your blood glucose level is high during pregnancy, extra glucose crosses the placenta. Your baby will produce its own insulin from around 15 weeks into gestation. The extra glucose stimulates your baby’s pancreas to make increased levels of insulin. This, in turn, makes the baby grow faster and store extra glucose as fat. The baby may also have problems with low blood glucose levels at birth as it continues to make extra insulin for a day or two. Keeping your blood glucose levels within target will significantly reduce the risk of these problems occurring.

There is no reason for you not to expect a normal birth. Many women with type 1 diabetes carry their babies to full-term and go into labor on their own. Some women are advised to have their baby early for various reasons, including diabetes control or the baby becoming too large. Most women with type 1 diabetes have a vaginal delivery, although they have a slightly elevated chance of having a Caesarean section, compared to women without diabetes. You will be able to discuss all options with your obstetrician and make a plan for your baby’s birth toward the end of your pregnancy. If you wish to breastfeed, there is no reason why you will not be able to do so. You will just have to watch for fluctuations in your blood glucose levels.
Will my baby have diabetes?
It is natural for people with type 1 diabetes to worry about passing the disease on to their children. Researchers are still trying to get a clear picture of how genes and environmental factors interact to determine a person’s risk of developing type 1 diabetes. It is important to remember that 80 percent of people with type 1 diabetes have no family history of the disease. For more information on pregnancy and type 1 diabetes, visit the JDRF website for more detailed and thorough information in the pregnancy and additional type 1 toolkits.

Body image and weight management
Many factors affect our body image, and one of them is the presence of an illness. In type 1 diabetes management, the constant focus on diet and weight management can also impact body image. Weight and type 1 diabetes are intertwined. Some women find that administering insulin causes significant weight gain, while others find weight gain difficult to achieve, particularly when blood glucose is elevated.

Sometimes our lifestyles are unhealthy because of the time demands we face in our daily lives. Sometimes we use food to relax, for comfort, or to help us cope with negative feelings such as anger, boredom, fear, loneliness, or a sense of inadequacy.

If you struggle with maintaining a healthy weight, it may be helpful to separate the issue of how much you weigh from the behaviors you want to adopt to stay healthy. It may help if you work with a dietitian to develop a plan of action that will help you stay healthy. Then try to focus on the plan, and not just your body size. Are you able to meet your goals for eating and activity? Let this be the measure of your success, not how your body looks.

You may feel that you need more help and support to deal with these concerns. It can be useful to have professional counseling to help you examine the barriers to your health, and how you can change your thinking and behaviors. If this is the case for you, talk to your physician or diabetes health care team and ask them to recommend a therapist to help you resolve some of these issues.

Menopause
Women with type 1 diabetes may experience menopause earlier than other women. Similar to menstruation, menopause will cause your hormone levels to change, and this can also cause blood glucose levels to fluctuate. In fact, hypoglycemia can be one of the first signs of menopause for a woman with type 1 diabetes. In the years leading up to menopause, surges and reductions in estrogen and progesterone can affect women in various ways, such as mood changes, increased PMS signs, menstrual periods that are more or less frequent, and heavier or lighter blood flow during menstruation. For some women, the hormonal changes are scarcely noticeable; however, for others, fluctuations in blood glucose levels can mean that they need to test more frequently and adjust their insulin intake.

One of the major difficulties is that some symptoms of diabetes and menopause can be very similar. Both menopause and low blood glucose can cause dizziness, elevated body temperatures, moodiness, and short-term memory loss. High blood glucose, like menopause, can cause fatigue. The only way to tell if your symptoms are diabetes-related or menopause-related is to test your blood glucose.

During menopause, it is important to maintain an active lifestyle. Some women stop exercising and begin to gain weight, which in turn affects their ability to absorb insulin and control their blood glucose. Sometimes, during menopause, women find they have negative side effects, such as vaginal dryness, an increase in yeast infections, and urinary tract infections. See your physician to discuss how you can manage these side effects with possible hormone replacement therapy or changes to your insulin regimen.

The key to staying healthy after menopause for women with type 1 diabetes is the same as for women without diabetes. Try to eat regular, well-balanced meals; stay as physically active as possible; have regular check-ups with your physician; and ensure that you manage your diabetes as well as you can. While there may be times when you ignore some (or all) of these recommendations, remember that it’s what you do most of the time that counts.

Osteoporosis
Osteoporosis is a condition in which bones become thinner and more porous, making fractures more likely. Although osteoporosis is common in women as they age because of the reduction of estrogen after menopause, women with type 1 diabetes have a higher incidence of osteoporosis if blood glucose levels have been high for a prolonged period. They
may also develop osteoporosis prior to menopause. As you approach your 50s, make sure your physician tests you for signs of osteoporosis.

Diabetes in Men

There are several aspects of living with type 1 diabetes that are particularly relevant to men, including:

- Self-esteem
- Body image
- Erectile dysfunction
- Thrush and banalities
- Fertility and inheritance
- Seeing a physician or specialist

Self-esteem

Living with type 1 diabetes may affect your self-esteem. It’s easy to become too focused on taking charge of your disease and keeping your blood glucose levels within the normal range at all times. When you are unable to achieve this, you can quickly become overly critical of yourself and lose self-confidence or become depressed. Fluctuations in your blood glucose levels can also make you vulnerable. For example, you may experience an episode of hypoglycemia during a sporting event or an important meeting, and perform at a level below your expected standard. Such episodes can negatively impact your self-esteem.

To maintain a healthy self-esteem, you need to accept that you don’t have total control over your diabetes, nor any other area of your life, while still accepting and valuing yourself unconditionally. This means being able to realistically acknowledge your strengths and limitations.

Body image

It is a misconception that poor body image is just a female issue. Weight loss prior to type 1 diabetes or subsequent weight gain once you begin insulin treatment may affect how you view your body. Bruises or marks left by injections, or wearing an insulin pump, can also have a negative impact on your body image by being physical reminders of your type 1 diabetes.

There may also be times when your lifestyle is unhealthy because of the time demands you face in your daily life. You may use food or alcohol to relax, or for comfort. You may also overindulge to keep up with your peers. Over time, this may lead to excessive weight gain. If you struggle to maintain a healthy weight, it may be helpful to separate the issue of how much you weigh from the behaviors you want to adopt to stay healthy. It may help if you work with a dietitian or personal trainer to develop a plan of action that will help you to stay healthy. Then try to focus on the plan and not just your body size. Are you able to meet your goals for eating and activity? Let this be the measure of your success, not how your body looks.

At times, you may need more help and support to deal with self-esteem or body image concerns. It can be useful to have professional counseling to improve your perceptions of self, or to identify ways to change your thinking and behaviors. If this is the case for you, talk to your physician or diabetes health care team and ask them to recommend a counselor to help you resolve some of these issues.

Erectile dysfunction

Erectile dysfunction (ED), or impotence, means that you cannot have an erection sufficient for having sexual intercourse. Impotence is a common problem for some men, but it is more common in men with diabetes. Many men experience short-term episodes of impotence, but for about one in 10 men, the problem may continue. Men with diabetes can also experience problems with their libido. It is estimated that more than 50 percent of men with diabetes will suffer from some degree of ED.

Impotence can be caused by any one, or a combination of, physical and psychological factors, such as:

- Stress
- Performance anxiety
- Pressures from work and/or family
- Problems in relationships
- Drinking too much alcohol
- High blood pressure
- Peripheral vascular disease (hardened arteries)
- Neuropathy (nerve damage)
- Some medications
- Some operations such as a prostatectomy
- Low levels of testosterone
- Chronically high blood glucose levels
The reasons why men with diabetes are more prone to problems with impotence are not fully understood. Some people with diabetes suffer from hardened arteries and this may contribute to impotence by restricting the flow of blood to the penis. Nerve damage may also play a role. Keeping your lipids (cholesterol) and blood glucose at goal levels can help reduce the chance of these problems occurring.

However, if you do experience problems with sexual function, you should speak with your endocrinologist, internist, or FP. There are many treatment alternatives for decreased libido and impotence, ranging from counseling, to oral or injectable drugs, to surgery. Your endocrinologist, internist, or FP can discuss these options with you.

**Thrush and banalities**

Thrush is a yeast infection caused by excessive growth of a fungus (known as *Candida albicans*) that lives on and in the body. Although thrush is usually associated with vaginal infections, men can also get thrush, both orally and on the penis. Symptoms of oral thrush include redness and white spots coating the surface of the tongue. Symptoms of penile thrush include inflammation of the head of the penis. This inflammation is often referred to as banalities. In this condition, the head of the penis becomes red and sore. Irritation and itching are also common. Small red spots may appear and penile discharge can occur.

High blood glucose levels can lead to outbreaks of thrush. Antibiotics and asthma inhalers can also increase the risk of infection. Your pharmacist can provide over-the-counter remedies to treat both oral and penile thrush. Your partner should also be treated to prevent reinfection. However, if the infection persists, you should see your physician for further advice.

**Fertility and inheritance**

While there are no specific fertility issues concerning men with type 1 diabetes, it is natural to worry about passing the disease on to your children. Researchers are still trying to get a clear picture of how genes and environmental factors interact to determine a person’s risk of developing type 1 diabetes. It is important to note that 80 percent of people with type 1 diabetes have no family history of the disease.

**Seeing a physician or specialist**

Now that you have type 1 diabetes, it is very important that you are under the ongoing care of a type 1 diabetes specialist or diabetes team—not receiving such care may affect your long-term health. Many complications of type 1 diabetes, such as retinopathy, can be prevented or reversed if they are caught early enough, so regular check-ups, even if you feel well, are vital.

It is also important that you are honest with your health care team. Other commitments, including family and work demands, may mean that areas of your diabetes management, such as blood glucose testing and regular attendance at appointments, take a lower priority at times. Your diabetes team will be better able to support you knowing these commitments. Also remember that if you don’t feel comfortable with your health care professional, it is fine to see someone else. Keep looking until you find someone you connect with and trust, as this will be a very important and long-term relationship.
Looking to the Future

The long-term health problems related to type 1 diabetes are linked to having higher blood glucose levels over a long period of time. Thankfully, leading researchers worldwide are working to develop treatments to prevent this damage.

Kevan, diagnosed at age 17
Complications

Thyroid and celiac disease
Type 1 diabetes is an autoimmune disease, which means that your own body’s immune system has mistaken the beta cells in your pancreas for a foreign body and has worked to destroy these cells. If your immune system has turned on you once, you are at increased risk of it doing so again. This means that you are at increased risk of other autoimmune diseases, such as thyroid and celiac disease.

The thyroid is a small gland located at the front of the neck. It manufactures thyroid hormone, which helps control metabolism and growth. If the thyroid is overactive, it releases too much thyroid hormone into the bloodstream, resulting in hyperthyroidism. Hyperthyroidism causes the body to use up energy more quickly than it should, and chemical activity (like metabolism) in the cells speeds up. An under-active thyroid produces too little thyroid hormone, resulting in hypothyroidism. When the amount of hormone released into the bloodstream is below normal, the body uses up energy more slowly, and chemical activity in the cells slows down. Type 1 diabetes is associated with an increased risk of an autoimmune thyroid disease called Hashimoto’s thyroiditis. It is (like type 1 diabetes) associated with the presence of specific antibodies. It results in hypothyroidism. This is easily treated by thyroid hormone taken in a pill form once a day. Because thyroid disease can have a negative impact on your blood glucose levels, if your blood glucose levels go out of control for no obvious reason to you, it may be worthwhile to be tested for thyroid disease.

Celiac disease is a digestive disease that damages the small intestine and interferes with the absorption of nutrients from food. People who have celiac disease cannot tolerate a protein called gluten, which is found in wheat, rye, and barley. For this reason, the disease is also known as “gluten-sensitive enteropathy.” Just like Hashimoto’s thyroiditis and type 1 diabetes, this disease is associated with a specific antibody. When people with celiac disease eat foods containing gluten, their immune system responds by damaging the small intestine. This affects the absorption of essential nutrients, such as glucose, as well as vitamins and minerals. This disease is treated by avoiding gluten in the diet. Screening for this disease is done with a simple blood test to detect the specific antibody.

While some people develop obvious symptoms of thyroid or celiac disease, others do not. For this reason, it is recommended that you are screened for these conditions every one-to-two years. You can be screened by simple blood tests.

Complications
Here comes the part none of us likes to think about: complications. The long-term health problems related to diabetes—otherwise known as complications—are linked to having higher blood glucose levels over a long period of time.

Certain cells do not require insulin for glucose to move into them. Such cells are found in the brain, nerves, eyes, kidneys, and blood vessels. If your blood glucose levels are high, the cells that do not require insulin will absorb large amounts of glucose. In the long run, this can be toxic to the cells, and these organs will be vulnerable to damage.

Research has shown some ways in which excess glucose is toxic. If there is too much glucose, the amount of sorbitol (a type of alcohol) in the cells increases, causing damage through swelling and chemical reactions. Too much glucose can also lead to increased production of advanced glycation end-products (AGEs). These accumulate in the blood vessel walls, making the walls thicker and less flexible. The blood vessels can also become more permeable. AGEs can accumulate in the cells, too, disturbing important cell functions. Additionally, too much glucose leads to excess levels of an enzyme called protein kinase C (PKC), which can damage the cells that line the blood vessels. While these complications are clearly linked to higher blood glucose levels, blood glucose control isn’t the only factor that determines whether a person will develop diabetes complications. Other factors, like genes, also play a role.

Common complications
The parts of the body that can be most affected by diabetes complications are the:

- Heart and blood vessels
- Kidneys
- Eyes
- Nerves
- Gums
Once you have lived with type 1 diabetes for a couple of years, you are at risk of developing some subtle changes to the organs containing non-insulin-requiring cells. Many of the complications of type 1 diabetes don’t show up until you’ve had the disease for many years, sometimes decades. Complications usually develop silently and gradually over time, which makes regular check-ups a must.

If changes to your organs are found early, there are strategies to stop or delay the progression of diabetes-related complications. For this reason, it is recommended that you are screened for diabetes complications two-to-five years after being diagnosed, and annually thereafter.

Now that we have an understanding of how glucose can be toxic to the cells, leading researchers around the world are working to develop treatments to prevent this damage.

Research into a Cure

A diabetes research history

Living with type 1 diabetes is such a day-to-day struggle that it’s easy to forget that this struggle, until recently, was not even possible. For thousands of years, people knew about diabetes and could do nothing about it. While easily recognized by symptoms of intense thirst, excessive urination, and wasting of the body, the disease—especially in young people—was previously regarded as a death sentence.

Before the discovery of insulin in 1921, there was no effective treatment for people with type 1. In order to keep blood glucose levels low, the best that physicians could do was place patients on diets that severely restricted the number of calories. In effect, the patients were slowly starving, and the eventual outcome was an early death. Injection of insulin had a dramatic effect, transforming emaciated, sickly patients into active, healthy individuals.

After this major breakthrough, other advances have helped greatly with diabetes management and—most important of all—provided essential information on the road to a cure. Since its founding in 1970, JDRF has played an integral role in these advances, supporting the best scientists and helping shape the research landscape to produce results with the most impact.

What follows is a list of the major diabetes breakthroughs since the late 19th century, when researchers first established the link between the pancreas and diabetes.
Selected Diabetes Highlights
Living with type 1 diabetes is such a day-to-day struggle that it’s easy to forget that this struggle, until recently, was not even possible. For thousands of years, people knew about diabetes and could do nothing about it. While easily recognized by symptoms of intense thirst, excessive urination, and wasting of the body, the disease—especially in young people—was previously regarded as a death sentence.

1889
Diabetes in Dogs
In Germany, Joseph von Mering and Oscar Minkowski produce diabetes in dogs by removing the pancreas.

1921
Discovery of Insulin
At the University of Toronto, Frederick Banting and Charles Best discover insulin.

1922
The Mass Production of Insulin
14-year-old Leonard Thompson becomes the first human to receive insulin extracts, which proved greatly successful. Eli Lilly and the University of Toronto enter a deal for the mass production of insulin in North America.

1944
Syringe
The standard insulin syringe is developed, making diabetes management more uniform.

1950
Measuring Insulin Levels
A test measuring insulin levels is perfected and becomes useful for research purposes.

1940s
Complications
Scientists discover a connection between diabetes and complications such as kidney and eye diseases.
1959

**Two Forms**
Scientists categorize diabetes into two forms—type 1 (insulin-dependent or “juvenile”) diabetes and type 2 (non-insulin-dependent) diabetes.

1960

**Amino Acid Sequence**
The amino acid sequence of insulin is established.

1965

**First Blood Glucose Strips**
Ames Company develops and introduces a product called Dextrostix®, paper strips used to test blood glucose, primarily in doctors’ offices.

1970

**First Blood Glucose Meter**
Anton H. Clemens of the Ames Company develops the first blood glucose meter. It is simply a light meter that reads reflected light.

1974

**Islet Cell Antibodies (ICAs)**
Researchers identify islet cell antibodies (ICAs), which indicate that one precursor of type 1 diabetes is that pancreatic islet cells are undergoing destruction.

1976

**Islet Transplantation**
Paul E. Lacy, a JDRF-funded researcher at Washington University School of Medicine, performs the first successful islet transplantation in diabetic animal models.

1978

**Measure for Hemoglobin A1c**
A test is developed to measure hemoglobin A1c (HbA1c) levels. Adding this test to the standard blood glucose test, scientists could determine the state of diabetic control over a period of months. This test made the DCCT possible (see 1993).

1979

**Insulin Pump**
The first experimental insulin pump is developed.

1980

**Nobel Prize**
The discovery of human leukocyte antigen (HLA) is awarded the Nobel Prize in Physiology or Medicine. The HLA proteins on the surface of cells are inherited from generation to generation, and confer susceptibility or resistance to diabetes.

1980

**Animal Model**
Researchers breed the non-obese diabetic (NOD) mouse as an animal model to study diabetes.

1982

**Human Insulin**
The Food & Drug Administration (FDA) approves the first man-made (bacterially produced) human insulin.

1993

**Diabetes Control and Complications Trial**
The Diabetes Control and Complications Trial (DCCT) establishes conclusively that tight blood glucose control can dramatically delay the development of diabetes-related complications such as retinopathy (eye disease), nephropathy (kidney disease), and neuropathy (nerve disease).

1994

**18 Genes**
Researchers identify a constellation of 18 genes that contribute to the onset of type 1 diabetes.

1998

**Human Islet Cell Isolation**
Researchers optimize the method for isolating human islet cells from other pancreatic cells, vastly improving the islets’ viability.

1998

**Embryonic Stem Cell**
Researchers create the first human embryonic stem cell lines that will open the door to exciting treatments for type 1 diabetes, including the establishment of a new, unlimited source of insulin-producing beta cells for transplantation.
1999

“Edmonton Protocol”
The “Edmonton Protocol” is used for the first time in islet transplantation.

1999–2004

Glucose Monitoring Devices
The FDA approves initial and updated versions of continuous glucose monitoring devices, the Continuous Glucose Monitoring System (CGMS) and the GlucoWatch Biographer.

2000

“Master Switch”
Researchers are able to show that many complications resulting from high blood glucose are triggered by one “master switch” that initiates different pathways.

2001

Type 1 Diabetes Genetics Consortium
Establishment of the Type 1 Diabetes Genetics Consortium (T1DGC), an ambitious undertaking to combine and share genetic information from diabetes studies around the world.

2002

Anti-CD3 Antibody Slows the Autoimmune Attack That Causes Diabetes
In JDRF-funded research, an anti-CD3 antibody slows the autoimmune attack that causes diabetes, and preserves insulin production in the remaining unharmed islets for up to a year.

2003

CTLA4 Gene Identified
Researchers identify a gene, CTLA4, that contributes to susceptibility to type 1 diabetes. The mechanism underlying this susceptibility operates not just in diabetes but also in other autoimmune diseases, such as Grave's disease and autoimmune hypothyroidism.

2004

17 New Human Embryonic Stem Cell Lines
JDRF-supported researchers at Harvard University announce that they have derived 17 new human embryonic stem cell lines.

2005

Clinical Trial of Anti-CD3
Scientists working collaboratively in four countries achieve remarkable success in a phase II clinical trial of anti-CD3. Injections of this antibody significantly lower the insulin requirements of most patients for at least a year after diagnosis.

2006

Artificial Pancreas
Using a working prototype of a complete closed-loop artificial pancreas, researchers at Yale University are able to maintain normal insulin levels.

2007

A Protein in Beta Cells
Researchers at the University of Massachusetts identify a protein in beta cells that regulates the production of insulin. This finding points to the possibility that a drug or therapy that increases the activity of that protein could enable people with type 1 diabetes to boost their own insulin production and better manage their diabetes.

2008

Pancreatic Progenitor
Researchers in Belgium discover a pancreatic progenitor cell that generates mature beta cells in mice—significantly advancing the potential of beta cell regeneration as a cure for type 1 diabetes.

2009

Conversion of Alpha Cells to Beta Cells
Researchers show that alpha cells in the pancreas, which normally do not make insulin, can be changed into insulin-producing beta cells—further boosting the prospects of using regeneration to treat type 1 diabetes.
Resources

JDRF has a number of resources that offer personalized support to adults living with type 1 diabetes. Our goal is to provide information and resources to help families and individuals learn more about type 1 diabetes, diabetes research, and how best to manage and cope with this disease during each new phase of life.

Michael, diagnosed at age 8
JDRF and Its Resources

As an organization whose volunteer leadership largely has a personal type 1 diabetes connection, JDRF goes beyond funding research by providing social, emotional, and practical support to adults and children who have been diagnosed with type 1 diabetes and their families. JDRF has a number of resources that offer personalized support to adults living with type 1 diabetes. Our goal is to provide information and resources to help families and individuals learn more about type 1 diabetes, diabetes research, and how best to manage and cope with this disease during each new phase of their lives.

Our resources and support services are varied, and adults with type 1 diabetes can access these resources in a number of different ways. Much of JDRF’s support is provided through our local chapters. Local chapters have programs that provide mentors, care packages, resources, and regular events that bring together groups of people with type 1 diabetes. A list of JDRF chapters with contact information is at the back of this booklet.

Other JDRF support services are accessible online through our website, www.jdrf.org. These services include our national Online Diabetes Support Team; our Clinical Trials Connection, which helps people with type 1 diabetes locate clinical trials; and an online community, Juvenation, which allows people with a type 1 connection to interact.

In creating JDRF’s programs and resources, we’ve kept in mind the fact that people with type 1 diabetes and their families have different needs, depending on where they are in their life stages. The following listing provides a detailed description of all the JDRF resources available for adults with type 1 diabetes and their families. The descriptions include how you can access the resources.

The Online Diabetes Support Team
The JDRF Online Diabetes Support Team comprises a nationwide group of volunteers working to provide one-on-one support, a sympathetic ear, and practical suggestions for individuals and families touched by type 1 diabetes. All volunteers on the team have a personal type 1 connection (through either themselves, a relative, or a friend), and all requests to the team are assigned to team members based on their own relationship with type 1 diabetes and life experiences in order to receive a prompt, personalized reply. (Note: The members of the support team are not medical professionals, and their practical advice about living with type 1 diabetes is not meant to replace medical advice and treatment from a patient’s health care team.) You can contact the support team at www.jdrf.org/diabetesupport.

Juvenation online community
Juvenation is an online community created by JDRF for people of all ages with type 1 diabetes. You can access Juvenation by going to juvenation.org.

When you register with Juvenation, you can create a profile, participate in online discussion groups, create and comment on blogs, upload videos, and more. Juvenation is the place for you to share thoughts, concerns, and tips about living with type 1 diabetes, educate yourself about new treatments and technologies, and just have fun meeting others like you who are living with the disease.

Since its launch, Juvenation has been a resounding success within the type 1 diabetes community. Participants in the social network have reported that they have begun to better manage their diabetes thanks to ongoing support from the online type 1 diabetes community.

JDRF’s Clinical Trials Connection
As both a service to patients with type 1 diabetes and a move to quicken the pace of type 1 diabetes research, JDRF has created Clinical Trials Connection. The service, located at www.trials.jdrf.org, is an online tool that provides information about and access to clinical trials listed by the National Institutes of Health, including those that are funded by JDRF.

Through Clinical Trials Connection, you can provide certain criteria, like what type of trial you might be interested in, how long you’ve had type 1 diabetes, and how far you’d be willing to travel to take part in a trial. The service will let you know about scientific programs that might match your criteria. Once registered, you can also request to be notified by email if new trials become available matching your criteria.

When you sign up for Clinical Trials Connection, you can get information directly from the trial sponsor and talk with your health care provider to help you make decisions about whether you might want to get involved in your own better treatments and/or cure by participating in a clinical trial. All information collected as part of the Clinical Trials Connection is held in the strictest of confidence.
Countdown magazine

*Countdown* tells the story of JDRF’s progress toward finding better treatments and a cure for type 1 diabetes. Launched as an online publication in December 2010, it is published a number of times a year.

*Countdown* features news and in-depth analysis about the cutting-edge research JDRF funds and the foundation’s efforts to improve the lives of people with type 1 diabetes. It also includes messages from JDRF’s leadership, stories about people managing the challenges of daily life with the disease, and news about how JDRF chapters and affiliates worldwide are working to fund more research through fundraising and advocacy.

Subscribing to *Countdown* is free and easy! See the current issue and sign up now at countdown.jdrf.org.

Life with Diabetes

JDRF’s *Life with Diabetes* stories and Q & A provide information and support for individuals and families dealing with a recent type 1 diagnosis, or ongoing issues related to living with type 1 diabetes.

*Life with Diabetes* offers practical advice and inspiration from experienced JDRF volunteers. Topics include managing sick days, supporting a partner with type 1 diabetes, and coping with depression. *Life with Diabetes* is specifically written to include practical advice that complements an individual’s medical care.

JDRF chapters

In addition to holding events and raising funds to support better treatments and a cure for type 1 diabetes and its complications, our local chapters offer important support and resources for people with type 1 diabetes and their families. JDRF chapters offer one-on-one connections, practical information, fundraising, and advocacy. Services range from support groups to the welcoming hand of a trained mentor, all linking people with JDRF volunteer families. Our passionate and dedicated volunteers are the backbone of all JDRF chapters. In addition to a small staff, all chapters are led by volunteer boards and committees comprising people with a type 1 diabetes connection.

How to find your local JDRF chapter

Every area of the country is covered by a local JDRF chapter. Even if your specific chapter office isn’t nearby, the chapter may still support a wide range of volunteer activity in your area.

You can find a list of JDRF chapters and their contact information at the back of this document. You can also find a similar list on JDRF’s website, www.jdrf.org, or you can call 1-800-533-CURE and JDRF will be glad to put you in touch with your local chapter.

Local chapter support

Even if you’ve been living with type 1 diabetes for a number of years, you may still have times when you feel alone or overwhelmed by questions. A health care team can provide many answers, but you may want to reach out to others who have gone through what you are experiencing. By connecting with the local JDRF chapter, people with type 1 diabetes gain access to an array of support services, including:

Mentor programs

Your local JDRF chapter can connect people with type 1 diabetes and their families to another individual or family facing similar life circumstances.

For example, adults with type 1 diabetes may be dealing with workplace issues, planning to have children, financial or insurance concerns, and more. Our mentors are volunteers who can share their personal experiences, answer non-medical questions, and most important, lend valuable, specialized support when you need it most. If you would like to be connected with a mentor, or are interested in serving as a mentor yourself, contact your local JDRF chapter.

Support groups

A support group is a great way for people with type 1 diabetes and their families to connect and share common experiences with others who are touched by the disease. Many JDRF chapters have a number of volunteer-led support groups, including groups for adults with type 1 diabetes. If the chapter itself doesn’t have a support group, they may be able to direct you to other groups in the local area.
**Outreach support and education events**
JDRF chapters host events for adults with type 1 diabetes. These events may include social events for adults or talks focused on diabetes research. These events represent another opportunity for you to connect with others and share experiences. The local JDRF chapter can provide you with a calendar of events.

**Other support websites**

**The National Diabetes Education Program:**
[www.ndep.nih.gov](http://www.ndep.nih.gov)

The National Diabetes Education Program is a federally sponsored initiative that involves public and private partners to improve treatment and outcomes for people with diabetes, to promote early diagnosis, and to prevent the onset of diabetes.

**The National Diabetes Information Clearinghouse:**

A service of the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK), the clearinghouse provides information about diabetes to people with the disease and to their families, health care professionals, and the public.

**CDC Diabetes Public Health Resource:**
[www.cdc.gov/diabetes](http://www.cdc.gov/diabetes)

The Centers for Disease Control and Prevention (CDC), an agency of the Department of Health and Human Services, provides information about diabetes and its impact.

**Taking Control of Your Diabetes (TCOYD):**
[tcoyd.org](http://tcoyd.org)

TCOYD provides live national conferences, local events, publications, online resources, and an educational television series to help people with all types of diabetes become actively involved in their own health.

**Children with Diabetes:**
[www.childrenwithdiabetes.com](http://www.childrenwithdiabetes.com)

Children with Diabetes is an online community originally created for parents of children with diabetes, and it also includes content for adults with type 1.

**dLife:**
[www.dlife.com](http://www.dlife.com)

dLife serves as a total diabetes hub, featuring the latest information and content about both type 1 and 2 from many of the top experts in the world.

**Diabetes Health:**
[www.diabeteshealth.com](http://www.diabeteshealth.com)

*Diabetes Health* is an online magazine dedicated to living a healthy life with diabetes.

**Adult Type 1 Blogs and Social Networks**

**A Sweet Life:** [asweetlife.org](http://asweetlife.org)

**Close Concerns:** [www.closeconcerns.com](http://www.closeconcerns.com)

**Diabetes Daily:** [www.diabetesdaily.com](http://www.diabetesdaily.com)

**Diabetes Mine:** [www.diabetesmine.com](http://www.diabetesmine.com)

**Diabetes Talkfest:** [diabetestalkfest.com/blog](http://diabetestalkfest.com/blog)

**Six Until Me:** [www.sixuntilme.com](http://www.sixuntilme.com)

**TuDiabetes:** [www.tudiabetes.org](http://www.tudiabetes.org)
About JDRF

JDRF is the world’s leading funder of science to deliver treatments—and ultimately a cure—for people with type 1 diabetes. Working toward this goal, JDRF has taken the lead in translating basic research breakthroughs into new therapies. JDRF creates multidisciplinary programs that bring together diabetes researchers from both academic institutions and industry to find better treatments and a cure for type 1 diabetes.

Michele, diagnosed at age 11
About JDRF

JDRF is the worldwide leader for research to cure type 1 diabetes. It sets the global agenda for diabetes research, and is the largest charitable funder and advocate of diabetes science worldwide.

The mission of JDRF is to find a cure for diabetes and its complications through the support of research. Type 1 diabetes is an autoimmune disease that strikes children and adults suddenly, and can be fatal. Until a cure is found, people with type 1 diabetes have to test their blood sugar and give themselves insulin injections multiple times or use a pump - each day, every day of their lives. And even with that intensive care, insulin is not a cure for diabetes, nor does it pre-vent its potential complications, which may include kidney failure, blindness, heart disease, stroke, and amputation.

Since its founding in 1970 by parents of children with type 1 diabetes, JDRF has awarded more than $1.5 billion to diabetes research, including $107 million last year. More than 80 percent of JDRF’s expenditures directly support research and research-related education. For more information, please visit www.jdrf.org.

A global leader in type 1 diabetes research

Many important developments in type 1 diabetes research have resulted from JDRF funding, as well as its many partnerships and public awareness efforts. JDRF funds more type 1 diabetes research worldwide than any other charity. To ensure that it supports science with the greatest potential to produce results as soon as possible, the people who decide where to focus JDRF’s research funding include leading scientists from around the world, JDRF’s team of scientists, as well as people who either have type 1 diabetes themselves or have family members with the disease.

Improving lives today and in the future

JDRF-funded research encompasses type 1 diabetes at every life-stage: stopping or slowing its progression in people who are newly diagnosed; reversing it in those who have lived with the disease for years; avoiding or reversing complications; improving the lives of people who have been living with the disease for years; and preventing the disease in people at risk and in future generations. Areas of focus include developing immune therapies, replacing and regenerating beta cells, achieving tight glucose control, and stopping or reversing complications.

JDRF funding and leadership go well beyond basic research. JDRF supports and exploits scientific discoveries and translates them into solutions, such as therapies and devices that can tangibly benefit people with type 1 diabetes today. JDRF has placed emphasis on funding human clinical trials, several of which are in the advanced stages of clinical testing needed before government approvals are required.

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 and developing new treatments as soon as possible. More than 80 percent of JDRF’s expenditures directly support research and research-related education. JDRF leverages its impact by partnering with academic institutions, governments, biotechnology and pharmaceutical companies, other disease organizations and foundations, and people with type 1 diabetes.

A backbone of dedicated and active volunteers

JDRF was founded in 1970 by parents of children with type 1 diabetes. Today, volunteers at JDRF’s more than 100 locations worldwide remain the driving force behind JDRF’s success in advancing research toward better treatments and a cure. Because of their personal connection to type 1 diabetes, JDRF’s volunteers have a passionate and unrelenting commitment to the JDRF mission.

JDRF’s research goals

JDRF is committed to improving the lives of people with type 1 diabetes today and in the future. To achieve these goals, JDRF focuses on research that seeks to:

• Stop type 1 diabetes or slow its progression in people who are newly diagnosed
• Reverse type 1 diabetes, and prevent or reverse its complications, in those who have lived with the disease for years
• Prevent type 1 diabetes in people at risk and in future generations
• Improve treatment of type 1 diabetes and provide better tools to achieve tight glucose control for people at all stages of the disease
How to Get Involved

While JDRF is committed to providing support and resources to people with type 1 diabetes, our primary mission remains to find a cure for diabetes and its complications through the support of research. Adults with type 1 diabetes and their families and friends who wish to support JDRF's mission can get involved in a number of ways.

Donation opportunities and fundraising activities

The Walk to Cure Diabetes is JDRF’s largest and most successful fundraising program. More than 500,000 people participate in the Walk at our 200 sites nationwide each year. The Walk draws people together in a healthy activity for the worthy cause of raising money to help find a cure for type 1 diabetes. Walk events are family-friendly, held at great locations, and feature plenty of entertainment, food, and fun. Find out more from your local JDRF chapter or at: walk.jdrf.org.

The JDRF Ride to Cure Diabetes is an adventure of a lifetime. Bicycle riders from around the world take on two challenges: raising the critical money needed to fund type 1 diabetes research and reaching a personal training goal that will prepare them for their destination cycling experience. Participants spend the weeks before the Ride working with a USA Cycling certified coach and a JDRF fundraising coach to help them reach their goals. Find out more about joining the team that moves us toward better treatments and a cure at: ride.jdrf.org.

Team JDRF is a way for anyone and everyone to make a difference in the fight against type 1 diabetes. Whether it’s a walk, a bowl-a-thon, a lemonade stand, or whatever you dream up, Team JDRF pairs our families’ passions for the cure with grassroots fundraising. The JDRF toolkits help inspire you and get started. Here you will find ideas, best practices, and printable materials—everything you need to be successful. We have also got a terrific online system, to make your fundraising even more effective, efficient, and fun! To learn more about getting involved, visit: www.jdrf.org/teamjdrf.

The JDRF Gala is a wonderful party for a great cause. The Gala raises money to find better treatments and a cure for type 1 diabetes through the support of research with Fund A Cure and live and silent auctions. Fund A Cure is a part of the evening when everyone has the opportunity to make a direct contribution that goes 100 percent toward research. This is your opportunity to participate in the ultimate “party with a purpose” to help us find better treatments and a cure! Find out more details from your local JDRF chapter.

JDRF chapters also hold many exciting special events to raise funds in support of JDRF’s goal of finding better treatments and a cure. These events typically include golf outings, food and drink gatherings, fun family excursions and others. Contact your local JDRF chapter for information about events near you.

Individuals wishing to support JDRF’s cutting-edge research efforts can do so by visiting us online at www.jdrf.org and clicking on the “Donate Now” tab. From this page, you have the choice of making a one-time donation, becoming a monthly donor, becoming a member of JDRF, or making a donation in memory or in honor of someone you love.

You can support JDRF through the mail by sending an individual gift of any type (one-time, monthly, memorial, or tribute) to JDRF National Headquarters, 26 Broadway, 14th floor, New York, NY 10004.

JDRF is also a participant in many workplace giving campaigns in which employees can donate through payroll deductions. There are many campaigns offered for state and federal employees, as well as many campaigns run by private companies. For more information about supporting JDRF through workplace giving, contact your payroll manager or visit www.jdrf.org.

JDRF offers a variety of planned-giving opportunities with important tax and financial benefits that can help you achieve your philanthropic goals. By including JDRF in your charitable/estate plans, you help ensure that type 1 diabetes research will continue until a cure is found. Anyone who includes JDRF in their charitable/estate plans is eligible to become a member of the BETA Society. BETA Society members receive special benefits and help us raise awareness of JDRF’s Planned Giving Program opportunities.

JDRF’s planned giving options include:

- Charitable bequests (in a will or trust)
- Charitable gift annuities
- Beneficiary designation (retirement accounts and life insurance policies)
- Charitable trusts

Philanthropists all over the country have chosen to support the search for better treatments and a cure for type 1 diabetes by making a direct investment in research through a major gift to JDRF. Recognizing JDRF’s worldwide leadership and expertise, they know that an investment in JDRF is the wisest
investment they can make in finding better treatments and a cure. Major gifts are the most efficient way to raise funds to accelerate progress toward the JDRF mission. A major gift is a non-event donation of $10,000 to JDRF, either paid outright or pledged, with payments spread over several months or years. Donations to the JDRF Major Donor Program can be made in the form of a general, unrestricted gift, or they can be designated to support a specific research area. If you have any questions or would like to speak with a Major Gifts officer, please contact JDRF by email at majorgifts@jdrf.org or via phone at 1-800-533-CURE.

Volunteer opportunities
JDRF’s volunteers are the driving force behind our progress toward better treatments and a cure, generously giving their time, money, and expertise in an ambitious plan of fundraising, outreach, and advocacy activities. The passion of our volunteers drives JDRF’s agenda.

Local JDRF chapters use their volunteers to help organize walks, fundraisers, and support and outreach activities. JDRF volunteers also have opportunities to connect with people who are just becoming familiar with type 1 diabetes or who may have questions about this disease. Volunteers address concerns about how type 1 diabetes may change people’s lives or the lives of their children.

JDRF volunteers include people who have type 1 diabetes, have a friend or family member with type 1 diabetes, and health care professionals who provide medical care for people with type 1 diabetes. They have a vested interest, and are committed to finding better treatments and a cure for type 1 diabetes. More information about volunteering is available from your local JDRF chapter.

Advocacy and government relations
JDRF has built a nationwide network of advocates who are dedicated to finding better treatments and a cure for type 1 diabetes. We are all working together to advance the search for a cure faster and more effectively.

JDRF advocates build relationships with their legislative leaders and tell them their personal stories about living with type 1 diabetes, and why we need a cure. These relationships strengthen the type 1 diabetes community, provide support for those who are living with type 1 diabetes, and deliver JDRF’s message—the need for a cure—faster and more effectively.

Information about becoming a JDRF advocate is available at: advocacy.jdrf.org.

Closing Thoughts

Dear reader:

Congratulations! Especially to those who finished reading this volume overnight (not suggested)! I hope that this will become a useful reference to assist you and others who are applying themselves daily to manage the uniqueness of type 1. Remember that your primary source of specialized guidance is your diabetes professional team.

When I first developed type 1 diabetes as a college freshman at the age of 17 in 1969, I knew virtually nothing about the disease. There were no relatives who had it and there were no public fundraising efforts for it, either. My parents did what many caring parents do: they panicked. They sought help, and miraculously within a year they found an organization of parents called the Juvenile Diabetes Foundation that was there to help them. My parents and I were, I believe, among the organization’s first 250 family members when it formally launched in 1970.

So now, more than 40 years later, living with the condition, I have some things to report:

1. When I developed type 1 diabetes at 17, I was led to believe my life expectancy would probably be to age 57. When I turned 57, my life expectancy was deemed to be 80.

2. My mother developed type 1 diabetes when she was 77 and as I write this, at 92, she monitors her blood, takes her shot three times a day, lives alone, is president of her building’s condominium board, drives during the daytime, sees friends, and plays a mean game of mahjongg.

3. Before retiring I traveled the world, ate airline and hotel food in abundance and at the oddest of times, and never once had to be hospitalized or treated for any diabetes-related problem.

4. I have tested my blood sugar and taken injections not only around the world but at dinner tables, in meetings, and at athletic activities. I make no apologies for my diabetes to anyone, but happily answer anyone’s questions about what I just did and why as it relates to injections and testing. I have led, and still lead, an active life in which my type 1 diabetes has always been present, but never in control over my life.

How do you do it? Because type 1 diabetes is a very personal condition, each person has a different experience in how the condition presents itself, how they manage it and its outcomes. Therefore, it is essential that you and your team find your
own best management structure to make sure you control the condition for your maximum benefit until the cure is found. Personally, I have found success in a three-step approach:

Step 1: Meticulously MONITOR the condition. Knowledge is power. Know where you are as much as possible. Understand your body and how it responds to food, exercise, illness, etc. A finely tuned personal antenna can help you get the best picture possible.

Step 2: RESPOND to what you learn. Take the steps necessary to solve a problem and learn about it for next time. If you are low, take something to eat. If you are high, adjust your insulin dosage. Have a good sense of what it takes for you to bring your blood sugar back to normal.

Step 3: RELAX. You will, on occasion, have a high reading that has no basis in fact that you can determine. For example, you could experience a high blood glucose measurement after a light meal with a regular dose of insulin matched with the meal that has been sufficient every other time you had it. Or, you could engage in exercise that results in an unexpectedly higher rather than lower blood glucose level. Measuring your blood sugar four, five, or six times a day can certainly seem like work. But when you accept it as your reality, and you just do it, it is much easier to move on. When I was a teenager and was told to move from one shot a day to two, I cried. Now an extra injection means no more than the 15 seconds or less it takes to administer it.

To me the message has always been: Take the information, act on it, and then move on. Another reading is right around the corner. One high reading can be insignificant as long as you don't allow yourself to have a string, a plethora, or even a trio of them in a row. The A1c will give you a good sense of total performance and a true picture of how you are doing.

It's your body and it's your life. Control your type 1 diabetes. Don't let it control you.

We wish to thank all the individuals who have devoted their efforts in making type 1 diabetes increasingly more manageable. We support the Juvenile Diabetes Research Foundation as it works diligently toward better treatments and a cure.

Very Sincerely,
Bob

A Passionate JDRF Online Diabetes Support Team Member
Appendix: Diabetes Dictionary

This dictionary has been compiled so that you can become familiar with words that are associated with diabetes and used by doctors, nurses, and other health care professionals.

Michael, diagnosed at age 15
The Diabetes Dictionary

This dictionary has been compiled so that you can become familiar with words that are associated with diabetes and used by physicians, nurses, and other health care professionals. We have also included certain terms that people with diabetes will also use when describing what is going on with them when they experience symptoms. This is just a selection of the most common terms used, and will hopefully be helpful as a guide.

The words are listed in alphabetical order. Resources for this listing include, but are not limited to:

- National Diabetes Information Clearinghouse; National Institute of Diabetes and Digestive and Kidney Diseases, National Institutes of Health
- The Juvenile Diabetes Research Foundation
- The American Diabetes Association

**Acetone** A chemical formed in the blood when the body uses fat instead of glucose (sugar) for energy. If acetone forms, it usually means that the cells do not have enough insulin, or cannot use the insulin that is in the blood, to use glucose for energy. Acetone passes through the body into the urine. Someone with a lot of acetone in the body can have breath that smells fruity—this is referred to as “acetone breath.”

**Acidosis** Too much acid in the body. For a person with diabetes, this can lead to diabetic ketoacidosis.

**Antiseptic** An agent that kills bacteria. Alcohol is a common antiseptic. Before injecting insulin, many people use alcohol to clean their skin to avoid infection.

**Aspartame** A man-made sweetener that many people use in place of sugar because it has very few calories. This is an especially great alternative for people living with diabetes.

**Autoimmune Disease** Disorder of the body’s immune system in which the immune system mistakenly attacks and destroys body tissue that it believes to be foreign. Type 1 diabetes is an autoimmune disease because the immune system attacks and destroys the insulin-producing beta cells of the pancreas.

**Beta Cell** A type of cell in the pancreas. Beta cells make and release insulin, a hormone that controls the level of glucose (sugar) in the blood.

**Blood Glucose** The main sugar that the body makes from the three elements of food—proteins, fats, and carbohydrates—but mostly from carbohydrates. Glucose is the major source of energy for living cells, and is carried to each cell through the bloodstream. However, the cells cannot use glucose without the help of insulin.

**Blood Glucose Meter** A machine that helps test how much glucose (sugar) is in the blood. A specially coated strip containing a fresh sample of blood is inserted into a machine, which then calculates the correct level of glucose in the blood sample and shows the result in a digital display. Some meters have a memory that can store results from multiple tests.

**Blood Glucose Monitoring** A way of testing how much glucose (sugar) is in the blood. A drop of blood, usually taken from the fingertip, is placed on the end of a specially coated strip, called a testing strip. The strip has a chemical on it that makes it change color according to how much glucose is in the blood. A person can tell if the level of glucose is low, high, or normal in one of two ways. The first is by comparing the color on the end of the strip to a color chart that is printed on the side of the test strip container. The second is by inserting the strip into a small machine, called a meter, that “reads” the strip and shows the level of blood glucose in a digital window display. Blood testing is more accurate than urine testing in monitoring blood glucose levels because it shows what the current level of glucose is, rather than what the level was an hour or so previously.

**Blood Sugar** See: Blood Glucose.

**Brittle Diabetes** An antiquated term; not a distinct form of diabetes. A term used when a person’s blood glucose (sugar) level often swings quickly from high to low and from low to high.

**Calorie** Energy that comes from food. Some foods have more calories than others. Fats have many calories. Most vegetables have few. People with diabetes are advised to follow meal plans with suggested amounts of calories for each meal and/or snack. Also see: Meal Plan; Exchange Lists.
**Carbohydrate** One of the three main classes of foods and a source of energy. Carbohydrates are mainly sugars and starches that the body breaks down into glucose (a simple sugar that the body can use to feed its cells). The body also uses carbohydrates to make a substance called glycogen that is stored in the liver and muscles for future use. If the body does not have enough insulin or cannot use the insulin it has, then the body will not be able to use carbohydrates for energy the way it should. This condition is called diabetes. Also see: Fats; Protein.

**Chronic** Present over a long period of time. Diabetes is an example of a chronic disease.

**Coma** A sleep-like state; not conscious. Can be due to a high or low level of glucose (sugar) in the blood. Also see: Diabetic Coma.

**Comatose** In a coma; not conscious.

**Complications of Diabetes** Harmful effects that may happen when a person has diabetes. Some effects, such as hypoglycemia, can happen any time. Others develop when a person has had diabetes for a long time. These include damage to the retina of the eye (retinopathy), the blood vessels (angiopathy), the nervous system (neuropathy), and the kidneys (nephropathy). Studies show that keeping blood glucose levels as close to the normal, non-diabetic range as possible may help prevent, slow, or delay harmful effects to the eyes, kidneys, and nerves.

**Controlled Disease** A disease that has less of an effect on the body because it has been properly managed. People with diabetes can “control” the disease by staying on their diets, exercising, taking their medicine if it is needed, and monitoring their blood glucose. This care helps keep the glucose (sugar) level in the blood from becoming either too high or too low.

**Dehydration** Great loss of body water. A very high level of glucose (sugar) in the bloodstream causes loss of a great deal of water and the person becomes very thirsty.

**Dextrose** A simple sugar found in the blood. Also called glucose. It is the body’s main source of energy. Also see: Blood Glucose.

**Diabetes Mellitus** A disease that occurs when the body is not able to use sugar as it should. The body needs sugar for growth and energy for daily activities. It gets sugar when it changes food into glucose (a form of sugar). A hormone called insulin is needed for the glucose to be taken up and used by the body. Diabetes occurs when the body cannot make use of the glucose in the blood for energy because either the pancreas is not able to make enough insulin or the insulin that is available is not effective. The beta cells in areas of the pancreas, called the islets of Langerhans, usually make insulin.

**Diabetic Coma** A severe emergency in which a person is not conscious because his or her blood glucose (sugar) is too low, he or she has hypoglycemia; if the level is too high, the person has hyperglycemia and may develop ketoacidosis. Also see: Hyperglycemia; Hypoglycemia; Diabetic Ketoacidosis.

**Diabetic Ketoacidosis** Severe high blood sugar that needs emergency treatment. DKA happens when blood sugar levels get too high. This may happen because of illness, taking too little insulin, or getting too little exercise. The body starts using stored fat for energy, and ketone bodies (acids) build up in the blood. Ketoacidosis starts slowly and builds up. The signs include nausea and vomiting, which can lead to loss of water from the body, stomach pain, and deep and rapid breathing. Other signs are a flushed face, dry skin and mouth, a fruity breath odor, a rapid and weak pulse, and low blood pressure. If the person is not given fluids and insulin right away, ketoacidosis can lead to coma and even death.

**Dietitian** An expert in nutrition who helps people with special health needs plan the kind and amounts of foods to eat. A registered dietitian (R.D.) has special qualifications. The health care team for diabetes should include a dietitian, preferably an R.D.

**DKA** An abbreviation of Diabetic Ketoacidosis.

**Emergency Medical Identification** Cards, bracelets, wallet cards, or necklaces with a written message used by people with diabetes or other medical problems to alert others of their condition and identify them in case of a medical emergency, such as coma.

**Endocrinologist** A physician who treats people who have problems with their endocrine glands. Diabetes is an endocrine disorder.
Exchange Lists  A grouping of foods by type to help people who are on special diets stay on the diet. Each group lists food in serving sizes. A person can exchange, trade, or substitute a food serving in one group for another food serving in the same group. The lists put foods in six groups: (1) starch/bread, (2) meat, (3) vegetables, (4) fruit, (5) milk, and (6) fats. Within a food group, each serving has about the same amount of carbohydrate, protein, fat, and calories.

Fats  One of the main classes of foods and a source of energy in the body. Fats help the body use certain vitamins and keep the skin healthy. They also serve as energy stores for the body. In food, there are two types of fats: saturated and unsaturated. Saturated fats are solid at room temperature and come chiefly from animal food products. Some examples are butter, lard, meat fat, solid shortening, palm oil, and coconut oil. These fats tend to raise the level of cholesterol, a fat-like substance in the blood. Unsaturated fats, which include monounsaturated fats and polyunsaturated fats, are liquid at room temperature and come from plant oils such as olive, peanut, corn, cottonseed, sunflower, safflower, and soybean. These fats tend to lower the level of cholesterol in the blood. See: Carbohydrate; Protein.

Food Exchange  See: Exchange Lists.

Foot Care  Taking special steps to avoid foot problems such as sores, cuts, bunions, and calluses. People with diabetes have to take special care of their feet because nerve damage and reduced blood flow sometimes mean that they will have less feeling in their feet than normal. They may not notice cuts and other problems as soon as they should. Good care includes daily examination of the feet, toes, and toenails, and choosing shoes and socks or stockings that fit well.

Fructose  A type of sugar found in many fruits and vegetables and in honey. Fructose is used to sweeten some diet foods. It is considered a nutritive sweetener because it has calories.

Gestational Diabetes Mellitus (GDM)  A type of diabetes mellitus that can occur when a woman is pregnant. In the second half of the pregnancy, the woman may have glucose (sugar) in the blood at a higher than normal level. However, when the pregnancy ends, the blood glucose level returns to normal in about 95 percent of all cases.

Glucagon  A hormone that raises the level of glucose (sugar) in the blood. The alpha cells of the pancreas (in areas called the islets of Langerhans) make glucagon when the body needs to put more sugar into the blood. An injectable form of glucagon, which can be bought in a drug store, is sometimes used to treat insulin shock. The glucagon is injected and quickly raises blood glucose levels.

Glucose  A simple sugar found in the blood. It is the body's main source of energy, also known as dextrose. See: Blood Glucose.

Home Blood Glucose Monitoring  A way a person can test how much glucose (sugar) is in the blood. Also called self-monitoring of blood glucose. See: Blood Glucose Monitoring.

Human Insulin  Man-made insulins that are similar to insulin produced by your own body. Human insulin has been available since October 1982.

Hyperglycemia  Too high a level of glucose (sugar) in the blood; a sign that diabetes is out of control. Many things can cause hyperglycemia. It occurs when the body does not have enough insulin or cannot use the insulin it does have to turn glucose into energy. Signs of hyperglycemia are great thirst, dry mouth, and a need to urinate often. For people with type 1 diabetes, hyperglycemia may lead to diabetic ketoacidosis.

Hypoglycemia  Too low a level of glucose (sugar) in the blood. This occurs when a person with diabetes has injected too much insulin, eaten too little food, or has exercised without extra food. A person with hypoglycemia may feel nervous, shaky, weak, or sweaty, and have a headache, blurred vision, and hunger. Taking small amounts of sugar, sweet juice, or food with sugar will usually help the person feel better within 10 to 15 minutes. See: Insulin Shock.

Hypoglycemia Unawareness  The phenomenon of hypoglycemia unawareness, known as hypoglycemia-associated autonomic failure, makes people with diabetes who have frequent blood sugar dips unaware of impending low blood sugar and unable to take proper steps (such as eating) to prevent further episodes.
**Injection** Putting liquid into the body with a needle and syringe. People with diabetes inject insulin by putting the needle into the tissue under the skin (called subcutaneous). Other ways of giving medicine or nourishment by injection are to put the needle into a vein (intravenous) or into a muscle (intramuscular).

**Insulin** A hormone that helps the body use glucose (sugar) for energy. The beta cells of the pancreas (in areas called the islets of Langerhans) make the insulin. When the body cannot make enough insulin on its own, a person with diabetes must inject insulin made from other sources, i.e., beef, pork, human insulin (recombinant DNA origin), or human insulin (pork-derived, semisynthetic).

**Insulin-Dependent Diabetes Mellitus (IDDM)** A chronic condition in which the pancreas makes little or no insulin because the beta cells have been destroyed. The body is then not able to use the glucose (blood sugar) for energy. IDDM usually occurs on abruptly, although the damage to the beta cells may begin much earlier. The signs of IDDM are great thirst, hunger, a need to urinate often, and a loss of weight. To treat and manage the disease, the person must inject insulin, follow a diet plan, exercise daily, and test blood glucose several times a day. IDDM usually occurs in children and adults who are under the age of 30. This type of diabetes used to be known as “juvenile diabetes,” “juvenile-onset diabetes” and “ketosis-prone diabetes”. It is also called type 1 diabetes mellitus.

**Insulin-Induced Atrophy** Small dents that form on the skin when a person keeps injecting a needle in the same spot. They are harmless.

**Insulin-Induced Hypertrophy** Small lumps that form under the skin when a person keeps injecting a needle in the same spot.

**Insulin Pen** An insulin injection device the size of a pen that includes a needle and holds a vial of insulin. It can be used instead of syringes for giving insulin injections.

**Insulin Pump** A device that delivers a continuous supply of insulin into the body. The insulin flows from the pump through a plastic tube that is connected to a needle inserted into the body and taped in place. Insulin is delivered at two rates: a low, steady rate (called the basal rate) for continuous, day-long coverage, and extra boosts of insulin (called bolus doses) to cover meals or other times when extra insulin is needed. The pump runs on batteries and can be worn clipped to a belt or carried in a pocket. It is used by people with type 1 diabetes.

**Insulin Reaction** Too low a level of glucose (sugar) in the blood; also called hypoglycemia. This occurs when a person with diabetes has injected too much insulin, eaten too little food, or exercised without extra food. The person may feel hungry, nauseated, weak, nervous, shaky, confused, and sweaty. Taking small amounts of sugar, sweet juice, or food with sugar in it will usually help the person feel better within 10 to 15 minutes. See: Hypoglycemia; Insulin Shock.

**Insulin Shock** A severe condition that occurs when the level of blood glucose (sugar) drops quickly. The signs are shaking, sweating, dizziness, double vision, convulsions, and collapsing. Insulin shock may occur when an insulin reaction is not treated quickly enough. See: Hypoglycemia; Insulin Reaction.

**Jet Injector** A device that uses high pressure to propel insulin through the skin and into the body.

**Juvenile Onset Diabetes** Former term for insulin-dependent or type I diabetes. See: Insulin-Dependent Diabetes Mellitus.

**Ketoacidosis** See: Diabetic Ketoacidosis.

**Ketone Bodies** Chemicals that the body makes when there is not enough insulin in the blood and it must break down fat for its energy. Ketone bodies can poison and even kill body cells. When the body does not have the help of insulin, the ketones build up in the blood and then “spill” over into the urine so that the body can get rid of them. The body can also rid itself of one type of ketone, called acetone, through the lungs. This gives the breath a fruity odor. Ketones that build up in the body for a long time can lead to serious illness and coma. See: Diabetic Ketoacidosis.

**Ketosis** A condition of having ketone bodies build up in body tissues and fluids. The signs of ketosis are nausea, vomiting, and stomach pain. Ketosis can lead to ketoacidosis.

**Kidney Disease** Any one of several chronic conditions that are caused by damage to the cells of the kidney. People who have had diabetes for a long time may have kidney damage. Also called nephropathy.
**Lancet** A fine, sharp-pointed blade or needle for pricking the skin to obtain a sample of blood in order to test for glucose (sugar). Also see: Blood Glucose Monitoring.

**Lente Insulin** A type of insulin that is intermediate-acting.

**Meal Plan** A guide for controlling the amounts of calories, carbohydrates, proteins, and fats a person eats. People with diabetes can use such plans as the Exchange Lists or the Point System to help them plan their meals so that they can keep their diabetes under control. See: Exchange Lists.

**Mixed Dose** Combining two kinds of insulin in one injection. A mixed dose commonly combines regular insulin, which is fast-acting, with a longer-acting insulin such as NPH. A mixed dose insulin schedule may be prescribed to provide both short-term and long-term coverage. Also see: NPH Insulin.

**Noninsulin-Dependent Diabetes Mellitus** (NIDDM) The most common form of diabetes mellitus. About 90 to 95 percent of people who have diabetes have NIDDM. Unlike the insulin-dependent type of diabetes, in which the pancreas makes no insulin, people with noninsulin-dependent diabetes produce some insulin, sometimes even large amounts. However, either their bodies do not produce enough insulin, or their body cells are resistant to the action of insulin. People with NIDDM can often control their condition by losing weight through diet and exercise. If not, they may need to combine insulin or a pill with diet and exercise. Generally, NIDDM occurs in people who are over age 40. Most of the people who have this type of diabetes are overweight. Noninsulin-dependent diabetes mellitus used to be called “adult-onset diabetes,” “maturity-onset diabetes,” “ketosis-resistant diabetes,” and “stable diabetes.” It is also called type 2 diabetes mellitus.

**NPH Insulin** A type of insulin that is intermediate-acting.

**Nutrition** The process by which the body draws nutrients from food and uses them to make or mend its cells.

**Nutritionist** See: Dietitian.

**Obesity** When people have 20 percent or more extra body fat for their age, height, sex, and bone structure. Fat works against the action of insulin. Extra body fat is thought to be a risk factor for type 2 diabetes.

**Overt Diabetes** Diabetes in a person who shows clear signs of the disease, such as great thirst and the need to urinate often.

**Pancreas** An organ behind the lower part of the stomach that is about the size of the hand. It makes insulin so that the body can use glucose (sugar) for energy. It also makes enzymes that help the body digest food. Spread all over the pancreas are areas called the islets of Langerhans. The cells in these areas each have a special purpose. The alpha cells make glucagon, which raises the level of glucose in the blood; the beta cells make insulin; and the delta cells make somatostain. There are also the PP cells and the D1 cells, about which little is known.

**Pharmacist** A person trained to prepare and distribute medicines and to give information about them.

**Podiatrist** A physician who treats and takes care of the feet.

**Rebound** A swing to a high level of glucose (sugar) in the blood after having a low level.

**Regular Insulin** A type of insulin that is fast-acting.

**Retinopathy** A disease of the small blood vessels in the retina of the eye. One of the potential complications of diabetes.

**Risk Factor** Anything that raises the chance that a person will get a disease. With noninsulin-dependent diabetes, people have a greater risk of getting the disease if they weigh a lot more (20 percent or more) than they should.

**Saccharin** A man-made sweetener that people use in place of sugar because it has no calories.

**Self-Monitoring of Blood Glucose** A way a person can test how much glucose (sugar) is in the blood. Also called home blood glucose monitoring. See: Blood Glucose Monitoring.

**Shock** A severe condition that disturbs the body. A person with diabetes can go into shock when the level of blood glucose (sugar) drops suddenly. See: Insulin Shock.

**Sliding Scale** Adjusting insulin on the basis of blood glucose tests, meals, and activity levels.

**Subcutaneous Injection** Putting a fluid into the tissue under the skin with a needle and syringe. See: Injection.
**Sucrose**  Table sugar; a form of sugar that the body must break down into a more simple form before the body can absorb it and take it to the cells.

**Sugar** A class of carbohydrates that taste sweet. Sugar is a quick, easy fuel for the body to use. Types of sugar are lactose, glucose, fructose, and sucrose.

**Symptom** A sign of disease. Having to urinate often is a symptom of diabetes.

**Syndrome** A set of signs, events, or conditions occurring together that make up a disease or health problem.

**Syringe** A device used to inject medications or other liquids into body tissues. The syringe for insulin has a hollow plastic or glass tube (barrel) with a plunger inside. The plunger forces the insulin through the needle into the body. Most insulin syringes now come with a needle attached. The side of the syringe has markings to show how much insulin is being injected.

**Team Management** Describes a diabetes treatment approach in which medical care is provided by a physician, diabetes nurse educator, dietitian, and behavioral scientist working together with the patient.

**Type 1 Diabetes Mellitus** See: Insulin-Dependent Diabetes Mellitus.

**Type 2 Diabetes Mellitus:** See Noninsulin-Dependent Diabetes Mellitus.

**Ultralente Insulin** A type of insulin that is long-acting.

**Unit of Insulin** The basic measure of insulin. U-100 insulin means 100 units of insulin per milliliter (mL) or cubic centimeter (cc) of solution. Most insulin made today in the United States is U-100.

**Unstable Diabetes** A type of diabetes in which a person's blood glucose (sugar) level often swings quickly from high to low and from low to high. Also called "brittle diabetes"

**Urine testing** Checking urine to see if it contains glucose (sugar) and ketones. Special strips of paper or tablets (called reagents) are put into a small amount of urine or urine plus water. Changes in the color of the strip show the amount of glucose or ketones in the urine. Urine testing is the only way to check for the presence of ketones, a sign of serious illness. However, urine testing is less desirable than blood testing for monitoring the level of glucose in the body. See: Blood Glucose Monitoring.

**Void** To empty the bladder in order to obtain a urine sample for testing.

**Compiled by:**

**Grenae D. Dudley, Ph.D.**

Mother of a Child with Diabetes

JDRF Metro Detroit Chapter, Board Member

**Kenneth E. White**

Step-Father of a Child with Diabetes

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Juvenile Diabetes Research Foundation

About The Juvenile Diabetes Research Foundation

JDRF is the worldwide leader for research to cure type 1 diabetes. It sets the global agenda for diabetes research, and is the largest charitable funder and advocate of diabetes science worldwide.

The mission of JDRF is to find a cure for diabetes and its complications through the support of research. Type 1 diabetes is an autoimmune disease that strikes children and adults suddenly, and can be fatal. Until a cure is found, people with type 1 diabetes have to test their blood sugar and give themselves insulin injections multiple times or use a pump - each day, every day of their lives. And even with that intensive care, insulin is not a cure for diabetes, nor does it prevent its potential complications, which may include kidney failure, blindness, heart disease, stroke, and amputation.

Since its founding in 1970 by parents of children with type 1 diabetes, JDRF has awarded more than $1.5 billion to diabetes research, including $107 million last year. More than 80 percent of JDRF’s expenditures directly support research and research-related education. For more information, please visit www.jdrf.org.