

Adult Type 1 Toolkit

Newly diagnosed

Receiving a diagnosis of type 1 diabetes (T1D) is somewhat like starting a journey on a new and unfamiliar road. Consider this guide your road map as you go through the various life stages with T1D.



Betsy, diagnosed at age 11

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Introduction and Goal of this Guide

This tool is one that I wish I had when I was first diagnosed with type 1 diabetes (T1D). It not only discusses diagnosis and management of T1D, but also the psychological impact and feelings that come with the disease, perhaps the biggest long-term challenge you will face.

One of the toughest psychological challenges T1D presents is that it is always there, and taking a vacation from it is simply not an option. As I heard it put when I was first diagnosed, “T1D is a marathon, not a sprint.” It is about doing the best you can over the long haul. The disease requires constant and consistent vigilance, just as a marathon requires a strong steady pace from start to finish. If you are newly diagnosed with T1D, you need to be prepared mentally for this significant upheaval in your life. Getting this message early on definitely helped me a great deal, and I think that anyone new to the disease should hear this message, too.

Given that you will be dealing with T1D every day, you should be aware of the fickle nature of the disease. Patterns in control can change dramatically in a short period of time, and more often than not, you are not at fault for these fluctuations. I like to say that managing blood glucose is an art and a science, but not an exact science. Things will not always go as planned or may be unexplained from time to time—this is just a fact of living with T1D—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’ll also find great information on educating others about the disease, especially in case of an emergency. My endocrinologist recommends having a “fire drill” for my friends, significant other, etc., to see what they would do if I passed out from low blood glucose. Just knowing that someone has T1D is not necessarily enough to save them in an emergency. I had a few situations arise in college in which my friends were able to help me when I was having a severe low, thanks to my openness and willingness to educate them beforehand.

Early on, many people with T1D don’t know whom to tell about their disease, and they may feel uncomfortable talking about their condition. The visibility of the disease, one of the tougher things to cope with, is another topic you will find covered in the following pages. The disease requires so much constant attention that it is impossible to hide it for very long. I always encourage people to be upfront about it. Tell everyone. Never be ashamed or try to hide it, and show that you have a sense of humor about it. The more upfront you are, the more comfortable everyone else around you will be. Anyone who would judge another person based on their T1D is someone you would not need in your life anyway. I personally am not shy about it, and actually enjoy educating others about my T1D. I consider myself a T1D ambassador of sorts, and would encourage others to adopt the same mindset.

Anyone new to the disease should also be prepared to occasionally field some awkward and seemingly ignorant questions and remarks. Be prepared to hear things like, “You can’t eat that!” This toolkit will help you to be mentally prepared to deal with these issues, bearing in mind that the more practice you get in these situations, the easier it becomes to handle them. Personally, I think of it like the old Nike ads: if I have to test, give myself an injection, or bolus, no matter where I am or whom I’m with, I “just do it.”

T1D is a disease that requires you to take charge. Once you know, understand, and feel comfortable with your T1D, you will have less stress and be better able to manage your T1D over the long term. So enjoy reading the following pages, use this toolkit as a resource, but most importantly, know that there are people out there like you who have been in your shoes, who care for you and are fighting for a cure. Simply put, this is not a disease you have to go through alone. Finally, on behalf of everyone with T1D, we are sorry you have to be in our club, but welcome to it!

Darren Bolton

Adult living with T1D since age 19

Diagnosis

Most people will eventually complete the transition from “life before T1D” to accepting T1D as part of their new reality. The timing of this transition varies from person to person.



Brian, diagnosed at age 18

Dealing with the Diagnosis

Being diagnosed with T1D as an adult can be difficult. People often don't know much about T1D, and don't expect an adult to be diagnosed with the disease. As an adult, you already have responsibilities and tasks that you need to perform each day, and you may be feeling that T1D will get in the way of what you want to do. A diagnosis of T1D is somewhat like starting a journey on a new and unfamiliar road. It is not chosen and not wanted.

You may experience feelings such as:

Shock: “T1D? Are you kidding?”

Denial: “No—this isn't real! I want a second opinion!”

Fear: “How am I going to cope? This is going to destroy my life!”

Grief: “This is so unfair. I feel so unhappy.”

Loss: “I wish things were how they used to be.”

Hopelessness: “Life is never going to get better for me.”

Depression: It's normal to be “down in the dumps” or overwhelmed initially; if it persists, however, it is important to talk about your feelings with your health care provider.

Family and friends can also experience these feelings, often causing these relationships to change. After learning of their diagnosis, many people find it hard to accept that they now have T1D. Denial is a normal reaction and 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 allows you to accept the news little by little, as you are ready. As you do this, feelings of acceptance should slowly begin to replace denial. Long-term denial can prevent you from taking care of yourself. Denial may stay around for weeks, months, or even years for some people. 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 T1D care go. However, denial usually adds to our stress, because in the back of our minds we know the damage it could cause.

Telling people about it

Keeping your T1D secret can make it harder to move on and accept your diagnosis. Make sure people around you know about your T1D—it will make it a lot harder for denial to take hold in the longer term. Figure out who you want to tell and involve them as much or as little as you like, but make sure they are at least aware of your disease. While you may not want to tell anyone at first, it won't be long before family and friends figure it out—why else would you be administering insulin? It's okay to tell them you need space to process your thoughts, but they will be there to help you when you are ready. At times, talking to family and friends may not be enough. If this is the case, you should talk to your doctor or T1D team about finding a counselor or psychologist to share with, if you feel this would help.

Adjustment and acceptance

You will eventually complete the transition from what was familiar to you in life before T1D came along to accepting T1D as part of your new reality. The timing of this transition varies from person to person. Sometimes people go back and forth between being okay with T1D and not being okay. This is normal. During this journey, there are emotional ups and downs. Some people say it is like being on a roller coaster ride. At some point, though, you will start to have more ups and fewer downs, which also won't last as long. You start to incorporate T1D into life. You get back on track with your life, with just a new chapter added to it. Eventually, you will arrive at the point where T1D is a part of your life. But be aware that living with T1D 24/7 leads to some ongoing ups and downs. This is normal—we all have a bad day or moment with T1D!

T1D Explained

Why me?

If you have just been diagnosed with T1D you are probably wondering, “Why me?” It is important to know it is not your fault that you have T1D and there was nothing you could have done to prevent it. It is not associated with any dietary or lifestyle decisions you made.

What is T1D?

T1D is an autoimmune disease. For reasons we don't yet understand, your immune system, which is meant to protect you from foreign bodies, such as viruses and bacteria, 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 T1D?

There is an enormous amount of research into what causes T1D, but so far there are no clear answers. Here's what we know:

- **Failure of the 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 T1D, but are not the only factors 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.**

Wait a minute—I thought only kids got T1D?

While most people associate T1D with children, half of the people diagnosed with T1D are adults. You are not unique in developing T1D at your age.

Did you know?

- **About 85 percent of people living with T1D are adults.**
- **80 percent of people diagnosed with T1D have no family history of the disease.**

How long have I had T1D?

Just because you are older, that doesn't mean you have been walking around with T1D for many years. In type 2 diabetes, the most common form of diabetes, blood glucose levels tend to climb slowly and people develop very subtle symptoms over time. People may not notice these subtle symptoms, so they can have high blood glucose levels for many years before type 2 diabetes is diagnosed. However, in T1D, your immune system rapidly destroys your beta cells, so your blood glucose level is likely to rise much more quickly. This rapid rise produces obvious signs and symptoms, such as significant weight loss, fatigue, excessive thirst, and frequent urination. As a result, your T1D is unlikely to go undiagnosed for long.

Honeymoon period

If you have only had T1D for a few weeks or months, you may experience a honeymoon period, in which your T1D may appear to go away for a period of time, ranging from a few weeks to a year or so. During this time, you will find that the amount of insulin you need to inject decreases and you're able to keep your blood glucose levels within the normal or near normal range, taking little or no insulin. Sadly, this does not mean your T1D has gone away. By the time you developed symptoms of T1D, the majority of your insulin-producing cells had been destroyed by your immune system. Depending on your health situation at the time of diagnosis, you may have enough functioning beta cells left to provide you with insulin for a short period of time. While research is progressing into ways to protect these remaining cells, it is not currently possible to stop the autoimmune processes, and you will eventually lose those cells and your ability to produce your own insulin.

Why do I have it when no one else in my family does?

Although other family members may carry the same “at risk” genes, the overall risk of T1D for multiple family members is generally low. The long-term risk of a brother or sister developing T1D (assuming you are the only one in the family with T1D) is about three to six percent.

How is T1D 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 food down 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 T1D, 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. Poorly managed high blood glucose levels create a number of symptoms and health problems with time.

There are three major types of diabetes: T1D, type 2, and gestational T1D. All types of diabetes cause blood glucose levels to be higher than normal. However, they do this in different ways.

T1D (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 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. T1D affects only about 10 percent of adults with diabetes.

Latent Autoimmune Diabetes in Adults (LADA)

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 T1D.

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 diabetes is often referred to as a lifestyle disease, but this is not the entire explanation. It can usually be managed by diet, exercise, and oral medication, at least in the first few years following diagnosis. However, type 2 diabetes is a progressive disease, and most people will need to take tablets and/or inject insulin after living with it for five to 10 years. Type 2 diabetes is the most common type of diabetes, accounting for about 90 percent of all T1D. It usually develops after the age of 40; however, its incidence is increasing among younger people due to lifestyle. The symptoms of type 2 diabetes are not always obvious, and they can take a long time to develop. It is more common among people who are older, sedentary, overweight/obese, or who have a family history of the disease. It may reappear in women who had gestational diabetes, and it is more common among people of Native American, Asian, Pacific Islander, African-American, or Latin American ancestry. According to some experts, up to 10% of people who are diagnosed with type 2 diabetes actually have LADA.

Gestational Diabetes is a form of diabetes first detected during pregnancy that goes away after a woman gives birth. Pregnant women produce large amounts of hormones such as estrogen and progesterone, which can cause the body to become resistant to the effects of insulin. By the time a woman reaches the end of the third trimester, her insulin requirements have tripled. If the pancreas is unable to match this increased demand, blood glucose levels start to rise. Women diagnosed with this type of diabetes are at significantly higher risk of developing type 2 diabetes later in life.

A Helping Hand from Health Professionals

Living successfully with T1D requires you to be fully in control of your T1D 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 T1D team is essential for effective self-management. The foundation for success is T1D education. A thorough knowledge of T1D and how to best 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 a daily basis. This means 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 healthcare professionals who can help you manage your T1D. In the ideal situation, a patient with T1D would have a team of specialists whom they meet with on a regular basis. The team might include an endocrinologist, certified T1D educator and dietician. In addition to these care team members, you might also seek other specialists.

Endocrinologist

An endocrinologist is a doctor 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, T1D 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 T1D 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 doctor, including a link to search for endocrinologists by state, is available from the American Association of Clinical Endocrinologists (AACE) at: aace.com.

Diabetologist

This is a term for a physician with an interest in treating those with T1D. There is no specific training or certification for this designation. It is a self-appointed title.

T1D educator

T1D educators are a significant source of information about T1D 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 T1D educators, including a link to search for educators by state, is available from the American Association of Diabetes Educators (AADE) at: diabeteseducator.org

Internist or Family Practitioner (FP)

Your internist or family practitioner will focus on your overall health. They 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

A specialist T1D dietitian can provide you with information on 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 T1D, such as celiac disease.

Counselor

Learning how to manage life with T1D can be a difficult, and at times daunting experience. A counselor can provide you and your loved ones with support as you adjust.

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 T1D is manageable with early intervention, so make sure you have an annual dilated eye check-up to help keep damage at bay.

Podiatrist

Since T1D can affect circulation and sensation, feet are particularly vulnerable and need careful attention.

Finding the right doctor

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 T1D health care professionals.

It is important to find a doctor or team with whom you feel comfortable and can discuss your T1D 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 GP or friends who also have T1D to see who 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 doctor to manage your T1D at jdrf.org/T1Dinfo.

Impact of T1D

Your T1D 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: Available Resources

There is no doubt that living with T1D will impact your budget, but there are ways you can get assistance if you need it.

Medicine, supplies, and T1D equipment

Some drug companies offer pharmaceutical assistance programs. These programs are typically for people with T1D who have little or no insurance to help offset the cost of supplies or prescription medications. The Partnership for Prescription Assistance offers a point of access to hundreds of assistance programs that have joined together to provide savings to the uninsured. To learn more about these programs, visit pparx.org or call 1-888-477-2669.

Additionally, leading pharmaceutical companies have created the Together Rx Access Card to provide access to savings on prescription products. To learn more about the card, visit: togetherrxaccess.com or call 1-800-444-4106.

Healthcare services

The National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) has a publication called “Financial Help for Diabetes Care,” which offers information about resources that may help with medical expenses of a person with T1D. You can view this publication online at diabetes.niddk.nih.gov/dm/pubs/financialhelp/index.htm or order copies from the National Diabetes Information Clearinghouse at 1-800-860-8747.

You may also try contacting your county or town health department. It’s possible that there are local resources that don’t exist on a statewide or national level.

Assistance Programs

The Medicine Program is a patient-advocacy organization that assists individuals and families find, apply and qualify for the right patient assistance programs. This free service works with patients, their healthcare providers, and prescription drug manufacturers to help obtain needed medications free or almost free of charge. Visit themedicineprogram.com.

Rx Assist offers a comprehensive database of patient assistance programs run by pharmaceutical companies to provide free medications to people who cannot afford to buy their medicine. Visit rxassist.org.

Free Medicine is a patient-advocacy organization that links patients to privately sponsored free or very low-cost prescription plans available to eliminate or substantially reduce their prescription cost. Visit freemedicine.com.

NeedyMeds is a nonprofit information resource devoted to helping people in need find and apply for assistance programs to help them afford their medications and costs related to healthcare. Visit needymeds.org.

Connecting with Other People Who Have T1D

The value of talking to other people who have T1D cannot be overestimated. There is something comforting in knowing that you are not the only one living with the condition. While everyone is different, and your T1D 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 strategies.

There are various ways to get in contact with other people who have T1D. Once you tell people about your T1D, you may be surprised by how many people have connections to others who have the condition.

You can:

- **Join JDRF’s T1D social network, TypeOneNation (typeonenation.org), which offers a variety of groups and forums categorized by topic. You can even start your own group. It is a great place to make connections with people like you. More information on this site can be found in the resources section of this toolkit.**
- **Talk to your doctor and T1D educator about upcoming meetings or educational sessions where you could meet people in similar situations 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 jdrf.org/locations/.**
- **Visit the Taking Control of Your Diabetes website (TCOYD), tcoyd.org. JDRF has partnered with TCOYD to provide local programs to help you connect with other adults with T1D and to inform, motivate, and empower participants to take control of their T1D. TCOYD and JDRF are working together to fill a void in resources specific to T1D adults. TCOYD is a not-for-profit organization directed by Steven Edelman, M.D., an endocrinologist who has lived with T1D since he was 15. TCOYD provides live national conferences, local events, publications, online resources and an educational tv series to help people with all types of T1D become actively involved in their own health.**

Relating to Family and Friends

How to tell your partner or family

It is not easy being diagnosed with T1D. It is also not easy telling your loved ones. Family members, particularly parents, may be distressed and blame themselves for your diagnosis, and you may not feel up to dealing with their emotions on top of your own. However, it is often easier telling your loved ones sooner rather than later. It's okay to tell them you need space to process your thoughts, knowing they will be there to help you when you are ready.

You may find that your loved ones 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. While 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. Misunderstandings about T1D and how it is managed can also cause friction, so you may consider taking your family member with you when you next see your endocrinologist or T1D team.

Telling your friends and colleagues

If you choose to tell your friends and colleagues, you should be prepared for them to ask questions or make comments that you may think are inappropriate. They often don't understand what having T1D means. Talking about how you developed T1D and how you treat it can be helpful. Friends who know about your T1D can be a source of support. Having friends who are willing to listen to how you are feeling, even if they don't have T1D themselves, may help you better adjust to living with it.

Chances are, you didn't know a great deal about T1D before your diagnosis, and your friends, family, and colleagues are probably the same way. Being open with them about your experience will make it easier for them to understand what T1D 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 T1D 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 T1D 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 T1D. 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 T1D and that you need to inject insulin. You might consider letting them know about low blood sugar and what to do when this occurs.

One thing nobody warns you about with T1D is 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 reply. You can find tips on how to respond and educate others about T1D at TypeOneNation: typeonenation.org.

Do you have 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.

T1D in the Media

Now that you have a connection to T1D, 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 T1D educator, to find out the real story. JDRF often covers these issues relevant to the T1D community, so bookmark JDRF.org 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 T1D 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 big happens in T1D research. However, if you want insight from others living with T1D on this or other topics, be sure to check out JDRF's social network, typeonenation.org. Here you can connect with other adults who have T1D to ask these and other questions you might have.

Media and public (mis)understanding

T1D 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 T1D.

The most common misunderstandings are caused by confusion between T1D and type 2 diabetes. Journalists will 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 diabetes. Understandably, this can result in feelings of frustration or anger by members of the T1D 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 e-mail 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.

T1D is different from other chronic diseases. It requires continual self-management, as well as guidance from your healthcare team, so it's easy to feel overwhelmed at times. T1D 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 T1D.

Keeping Your Spirits Up

Having realistic goals and a good understanding of what T1D is all about will go a long way toward your mental and emotional well-being.



Alexandra, diagnosed at age 8

T1D and Your Mood

Many factors can affect your T1D, 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 T1D 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 T1D as an excuse, you are stating a fact.

Having realistic goals and a good understanding of what T1D is all about will go a long way toward your mental and emotional well-being. In addition, identifying other problems in your life that impact your T1D and dealing with them one by one is 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 T1D makes you more than twice as likely to experience depression than 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, 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, so if you suspect you are experiencing symptoms of depression, speak to a trusted health care professional.

Avoiding T1D burnout

Having T1D 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 T1D experience worries, fears, and negative feelings at some stage. This can lead to T1D 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 T1D most of the time. T1D burnout is seen as one of the major psychological complications of T1D.

You need realistic expectations and practical strategies for managing the emotional side of T1D. 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 blood glucose instead of good and bad can really help. 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 T1D care or making it harder?**
- **What problems outside of T1D could be addressed?**
- **What are my expectations for my T1D management—what do I want?**
- **Are my goals realistic right now? Perhaps they are too high or too low?**
- **What particular areas of T1D are causing me problems?**

When the going gets tough, the tough get support!

If things are not going so well with your T1D, it's important to work out why and see that you are not the problem. If your T1D 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 T1D, such as a need for a management change, or they might be problems unrelated to your T1D, 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 T1D

Now that you have T1D, 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 and maintain a hold on fluctuating blood glucose levels.



Bethany, diagnosed at age 21

Before you developed T1D, 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 T1D, 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 maintain a hold on fluctuating blood glucose levels.

“Must-Have” equipment

There are some key items you should not be without, and 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're out and decide to stay overnight at a friend's place, you'll be glad you took your overnight insulin with you. Carrying your meter with you will let you eat unfamiliar foods, confident 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 so you can quickly find what you're looking for, and protects items from being damaged. Bags specifically made for this purpose can be found by typing “T1D bag” into an internet search engine.

“Must-have” items to keep on hand:

- **Insulin, insulin pen, or insulin pump**
- **Syringes, pen needles, or infusion sets**
- **Blood glucose meter and testing strips**
- **Lancet devices**
- **Book to record blood glucose levels**
- **Blood or urine ketone strips**
- **Sharps container**
- **Snacks to treat low blood glucose**
- **Automobile hypoglycemia supplies**
- **Glucagon**
- **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 in case.

If you use intermediate or long-acting insulin, you should take it with you when you go out at night. If you end up sleeping over at someone's place, 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 glove box, 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, insulin pens, and insulin pumps all serve the same purpose: to deliver insulin to people with T1D, who do not produce insulin on their own. 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.

Blood glucose meter 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!

Lancets devices

Carrying spare lancets for your lancing device (or using one of the new lancet 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 lancets. You don't necessarily have to use the one that comes with the meter; it's ok 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 sized 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.

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 T1D who were strict in managing their T1D 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 T1D team, they will be able to help you manage your T1D 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 keytone testing device, will enable you to identify whether you are at risk of ketoacidosis. Ketone strips can be purchased in individual foil wrapped strips. (For more information on ketones, see the Day-to-Day Life with T1D: 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: epa.gov/osw/nonhaz/industrial/medical/med-home.pdf.

Snacks to treat low blood glucose

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 15g 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.

Your treatment for low blood glucose will often be in your bag (or pocket) for a while, so you need something with resilient packaging. Or, 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 you can treat yourself if you go low again or need more glucose.

Automobile hypoglycemia supplies

It's a good idea to have a source of glucose in your car (and your friends' 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 T1D and lists all of your medications.

Glucagon

People with T1D who experience severe low blood sugar emergencies (altered mental status, loss of consciousness or seizure) may require glucagon. Glucagon raises the blood sugar when a person with T1D 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 sugar 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, 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 healthcare provider for more explanation, if necessary.

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

Identification

You should always wear a medical alert bracelet that identifies you as a person with T1D. You should also carry a card in your wallet or purse that provides your doctor's contact details and a brief description of the medication you are taking. In the (hopefully unlikely) event you have a severe hypoglycemic emergency, the identification will enable health 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 unwell 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 T1D 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

Giving your first injection can be a daunting experience. However, over time, you will probably become more relaxed about administering your own shots. If the injections hurt, you may be administering the insulin just under the skin where you have an abundance of nerve endings. Talk to your T1D 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 T1D 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 T1D. Your endocrinologist or T1D team 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.

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 T1D 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 dietician will be invaluable to you as you learn to calculate carbs.

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 T1D 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 where 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 you will be exercising within the next 2 or 3 hours after a meal. In this case, your endocrinologist or T1D team 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 T1D. Intermediate or long-acting insulin is often given once or twice a day to mimic the basal insulin profile of people without T1D. Testing your blood glucose levels before meals will help you and your T1D 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 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 fill upside down—if you see any tiny particles, your insulin has probably gone bad. Check with your physician or pharmacist about replacing it.

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 turned 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 a cannula (a flexible plastic tube), which attaches to the body through a small needle inserted into the skin. The cannula is taped in place and the needle is removed. Common insertion sites on the body include the thighs, buttocks, upper arms, and other areas with fatty tissue.

When a person wearing a pump eats, 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 sugars)**
- **Ketosis and ketoacidosis (risk of very high blood sugar)**
- **Constant physical reminder of T1D**

People with T1D who use an insulin pump may need to test their blood sugar more frequently. Pumps have become increasingly more popular among people with T1D, and several brands and models are available. Speak with your endocrinologist about whether the pump is a good option for you.

Managing Blood Glucose Levels

Why treating T1D is important

In the time before you had T1D, 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 would help move blood glucose into your muscles and liver to be stored as glycogen. If your blood glucose level dropped during the day, this 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.

Without a properly functioning pancreas, your body cannot move glucose from the bloodstream into the cells of 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 cells or stored. High blood glucose levels also result in serious health complications. (For further information on health complications, see Looking to the Future: Future Health and 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 before you eat and less than 150 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 T1D (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 T1D. This allows you to identify the patterns of high or low blood glucose levels. This information will also help you and your doctor or T1D 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 T1D 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 doctor. 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 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, that 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 doctor or T1D educator if they have any free samples you could 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 just use one finger.**
- **Target the sides of your fingers instead of the soft center area where there are more nerve endings.**

Advancements in blood glucose control

JDRF has been working hard to help patients improve their T1D control and to make the management aspect of T1D easier. One of JDRF's initiatives working toward this goal is called the Artificial Pancreas Project. An artificial pancreas system will integrate two currently available technologies—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 T1D 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 jdrf.org/research/treat/artificial-pancreas-project/.

Continuous glucose monitor (CGM)

A continuous glucose monitor (CGM) is a device for people with T1D that provides continuous “real-time” readings and data about trends in glucose levels. This information allows people with T1D 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, several continuous glucose monitors have been approved by the FDA, and a major clinical trial funded by JDRF found that most people with T1D 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, a person 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 artificialpancreasproject.com/about/steps.html.

Be realistic

Living with T1D 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. One of these hormones is glucagon (same as what is in the emergency kit you were asked to obtain). 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 stressed 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 T1D, 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 T1D 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 T1D 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, and manage your T1D better.

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

- **T1D record books**

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

- **Blood glucose meters**

One 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.

- **Computer software**

Blood glucose monitors and insulin pumps often have 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 web site 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 T1D team.

- **Hemoglobin A1c test**

Your doctor or T1D 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 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.

T1D 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 T1D also requires a focus on blood pressure, renal function, and cholesterol levels. This is because the risk of T1D-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 doctor) 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 doctor or T1D 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 doctor's suggestions.**
- **Don't expect perfection! Just aim to get more of your readings within target.**
- **Ask for help from your doctor or T1D educator when you need it.**

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 in this toolkit, this is known as hypoglycemia, or low blood sugar.

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 confused, disoriented**
- **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 T1D team work out when you need less insulin and when 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 let your doctor or T1D team know if your blood glucose level is dropping low regularly (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 and/or give you an injection of glucagon. It is very important to always wear a bracelet, necklace or other identification stating that you have T1D.

Food

For many years, people with T1D 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 T1D no longer need to live with such a regimented diet. They 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 T1D 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 T1D 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 and therefore 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 T1D. It is important that you speak to your T1D team to identify whether this method is suitable for you. You can also learn more about the glycemic index at 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 working well. 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 fats 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 your blood glucose level being higher 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 & Carbohydrate Counter* book (2013) can help you assess the carbohydrate, fat, and energy content of foods that do not come with labels.

Counting carbs

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 doctor 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 carbs to ensure you eat the same amount of carbohydrates 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 T1D 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 sized 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 now that you have T1D, although you will need to think a bit more about the foods you eat.

Today, many fast food chain restaurants have nutrition information about their foods available on their web sites, posted in their restaurants or available if you ask. Using these web

sites, 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 a friend'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 T1D.

For people with T1D, 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 T1D 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 hung over 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 T1D, 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 T1D 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 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 T1D 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 T1D 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 T1D.

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 adrenalin 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 adrenalin 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 eight- 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 T1D 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—that is, insulin from a previous bolus that is still active in the body—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 T1D 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 get more experienced, 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 T1D 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 used stores for eight 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 T1D 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 T1D, 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 stomach bug. 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 stomach bug, 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 keep up your fluids. 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 T1D 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 T1D, provided you are properly prepared. The key is to be well-informed, take an active role in managing your T1D while in the hospital, and plan well before the event.

** 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 T1D and are in a committed relationship with someone, T1D is bound to come up at some point. The way you and your partner handle T1D can have a significant impact on your relationship and on your management. This section will cover how to approach someone new about T1D, 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 T1D. 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 T1D. 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 short of leaving. So you might test and dose, and if the question comes up, which it usually does, mention that you have T1D, 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 T1D. Managing T1D is sometimes a team effort requiring strong communication between you and your partner, especially when discussing how involved your partner should be in your T1D management. A solid sense of self, combined with an honest and supportive relationship, make all facets of T1D 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 T1D. Communication is key, so if you're feeling crabby or snappy, try to be aware of what 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 T1D management, as that can help him or her understand your state of mind. T1D brings mood swings into any relationship. Sometimes the best thing to do is be aware of that, and in heated discussions, try to step back and ask yourself if that is playing a role.

Remember that your T1D isn't something you should keep locked up and only grapple with in privacy. Healthy T1D management is an open and constant part your life, something that touches so much of your everyday activities. Pretending it's not a part of your partner's life, too, is foolish. Remember, you don't have to be alone in your T1D management if someone is willing to be there and help you along the way. It's your T1D 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 T1D reading this: Be supportive, but 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 T1D. This is a very personal condition, but at the same time, it's tough to live with alone. Make sure you are there to help and support, not to become the "T1D Police."

Parenting as An Adult With T1D

If you have children, it's important to discuss your T1D with them. When explaining T1D, 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 long biology lesson. One of the normal fears parents with T1D have is having a blood sugar low when they are alone with their children. Of course, you want to prevent hypoglycemia as much as you can, and most parents don't want to burden their kids with their T1D 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 T1D and might be having a low blood sugar. He or 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 T1D 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 ground 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 will often achieve your goals faster than if you rush through it 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 T1D, you really have to take a little extra time, plan for your T1D needs, and be purposeful about how you take care of yourself in order to successfully care for your family.

T1D and Work

To tell or not to tell

Your medical information is confidential unless you work in a position where your T1D 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 T1D, unless you wish to disclose it, or you need them to make some accommodation to your work situation to help you manage your T1D, such as ensuring meal breaks. Remember, it is important to have someone with whom you work who can respond to T1D emergencies. For more perspectives on the pros and cons of disclosing your T1D to your employer, visit jdrf.org/T1Dinfo.

Job interviews

Both disclosure and non-disclosure of your T1D during a job interview have their drawbacks and merits. While people with T1D successfully perform all types of jobs, some employers may be reluctant to employ someone with T1D in particular positions because of misconceptions about the disease. For example, they may wrongly assume that people with T1D can't hold a position that requires regular driving. If you choose to tell your potential employer about your T1D, 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 T1D, 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 T1D and how it is managed. Your employer may be concerned about loss of work time and productivity, and this may influence his or her 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 T1D. The laws within this act say that a person with T1D has the right to do everything else that adults without T1D do. It further states that the workplace and other covered organizations must make “reasonable accommodations” for your T1D. This Act was amended in 2008 (the ADA Amendments Act “ADAAA”) and expands the definition of who qualifies under the legislation. Specifically, the use of “mitigating measures”—medications and devices, which lessen the burden of the disease—cannot disqualify a person from protection under the ADA.

Despite all the advances in managing T1D, 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 neuropathy or a heart condition, you should not be performing tasks such as heavy lifting. Speak with your doctor or T1D 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 T1D, shift work can put a strain on health. No medical evidence indicates you shouldn't perform shift work; however, you should be aware that managing T1D may be more difficult, especially if you are working a rapidly changing shift pattern. Even if you manage your T1D 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 analogs 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 T1D 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 T1D. However, with some careful planning, you can successfully manage your T1D 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 T1D

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 T1D 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 T1D was part of the cause, you can have your license taken away, maybe permanently.

On the other hand, many people with T1D 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 T1D.

In case of an accident, you should always have something that identifies you as having T1D 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 T1D. You should find out what your state's requirements are, and consult your endocrinologist. (Also see: "Automobile hypoglycemia supplies," p. 17.)

Traveling with T1D

T1D 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 T1D. 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 T1D at jdrf.org/travel.

Tips for a successful trip

Visit your endocrinologist 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 doctor 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 T1D educator, and work out a plan for meals and medication, especially if you are traveling through different time zones.

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 doctor stating that you have T1D and are likely to have problems with unexpected low or high blood glucose levels. You must be able to access good quality healthcare if you need it. Make sure your travel insurance covers T1D, as not all policies do. Remember to take your insurance card with you. Take identification with you that explains that you have T1D, 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 head for 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 T1D 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. 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 T1D educator.

Flying with T1D supplies

All travelers, and particularly those who travel infrequently, are encouraged to visit the Transportation Security Administration's website on travel tips before their trip. Frequent flyers should review the information periodically for changes and updates. You can go directly to the information specific to travelers with T1D at [tsa.gov/traveler-information/passengers-diabetes](https://www.tsa.gov/traveler-information/passengers-diabetes).

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 Contact Center toll free at 1-866-289-9673.

Notify the screener that you have T1D and are carrying your supplies with you. The following T1D-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, needle, CGM sensors and transmitters); glucagon emergency kits; 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 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 T1D 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 T1D 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 re-screened.**
- **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 T1D 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 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 T1D 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.

T1D in Women

Men and women face different challenges managing T1D. Issues women may need to consider include:

- **Menstruation**
- **Contraception**
- **Sexuality**
- **Infections**
- **Reduced lubrication**
- **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 T1D find 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 T1D because there are greater risks for a woman with T1D and her baby when pregnancy is unplanned. The contraceptive options for women with T1D 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 T1D.

It used to be that women with T1D 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 diabetes who also smoke.) Blood glucose fluctuations are more likely with combination pills, and some doctors may suggest progestin-only ("mini") pills to avoid this issue.

In the past, there was concern that intrauterine devices (IUDs) might pose an increased risk of pelvic infection or trauma to the uterine wall, and that women with T1D 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 T1D. Speak with your doctor and T1D educator about suitable contraception options.

Sexuality

Living with T1D 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 doctor and/or T1D educator. 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.

Infections

Vaginal infections and urinary tract infections are more common in women with T1D, 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 doctor will prescribe an antibiotic and your pharmacist can provide over-the-counter remedies to reduce any associated pain.

Reduced lubrication

After having T1D 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 in improving dryness and sensitivity. For severe dryness, a vaginal suppository can be used.

Pregnancy

In the past, women with T1D 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 T1D can expect to have a healthy baby.

The key, as with all aspects of T1D management, is planning. Women with T1D 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**
- **T1D educator**

Preparing for pregnancy

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

- **Achieve an HbA1c below 7 percent (below 6.5 percent, if you can achieve this without increased episodes of hypoglycemia). The first eight 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 doctor and 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 doctor.**
- **Visit your dietitian: They can advise you on the most appropriate foods during your pregnancy.**
- **If you smoke or drink alcohol, stop!**

During pregnancy and birth

Pregnancy can present some particular challenges for women with T1D.

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 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 professionals.

You will need to visit your endocrinologist and obstetrician more regularly than women without T1D. Your doctor will provide you with a schedule of check-ups and tests. Certain complications are aggravated by pregnancy (e.g., nephropathy and retinopathy). Your doctor will closely monitor you during pregnancy.

The growth of your baby also needs to be closely monitored. Babies of women with T1D are at risk of developing a condition known as macrosomia, which means large body. 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 T1D carry their baby to full-term and go into labor on their own. Some women are advised to have their baby early for various reasons, including T1D control or the baby becoming too large. Most women with T1D have a vaginal delivery, although they have a slightly elevated chance of having a Caesarean section, compared to women without T1D. 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 T1D?

It is natural for people with T1D to worry about passing the disease on to their children. It is important to remember that 80 percent of people with T1D have no family history of the disease.

For more information, you can request JDRF's Pregnancy Toolkit, a guide filled with practical advice to help parents-to-be have the healthiest pregnancy and childbirth experience possible. To request a copy, visit jdrf.org/toolkits/.

Body image and weight management

Many factors affect our body image, and one of them is the presence of an illness. In T1D management, the constant focus on diet and weight management can also impact body image. Weight and T1D are intertwined.

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.

Some people find weight gain difficult to achieve, particularly when blood glucose is elevated. Other people find that administering insulin causes significant weight gain, and some people have dangerously disrupted their insulin regimen—skipping insulin doses or intentionally tampering with the insulin's effectiveness—for the purpose of losing weight. In fact, a growing number of people with T1D are also being diagnosed with an eating disorder. The dual diagnosis is called ED-DMT1 or, more commonly, diabulimia.

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 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 doctor or T1D health care team and ask them to recommend a therapist to help you resolve some of these issues.

Menopause

Women with T1D may experience menopause earlier than other women. Like 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 T1D. 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 T1D 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 T1D-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 doctor 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 T1D is the same as for women without T1D. Try to eat regular, well-balanced meals; stay as physically active as possible; have regular check-ups with your doctor; and ensure that you manage your T1D 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 T1D 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 doctor tests you for signs of osteoporosis.

T1D in Men

There are several aspects of living with T1D that are particularly relevant to men, including:

- **Self-esteem**
- **Body image**
- **Erectile dysfunction**
- **Thrush and balanitis**
- **Fertility and inheritance**
- **Seeing a doctor or specialist**

Self-esteem

Living with T1D may affect your self-esteem. It's easy to become too focused on taking charge of your T1D 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 dent your self-esteem.

To maintain a healthy self-esteem, you need to accept that you don't have total control over your T1D, or 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 T1D 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 T1D.

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 doctor or T1D health care team and ask them to recommend a counselor to help you resolve some of these issues.

Erectile dysfunction

Erectile dysfunction, or impotence, means 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 T1D. Many men experience short-term episodes of impotence, but, for about one in ten men, the problem may continue. Men with T1D can also experience problems with their libido.

Impotence can be caused by physical and psychological factors, such as:

- **Stress**
- **Performance anxiety**
- **Work and family pressures**
- **Problems in relationships**
- **Drinking too much alcohol**
- **High blood pressure**
- **Peripheral vascular disease (hardened arteries)**
- **Neuropathy (nerve damage)**
- **Some medications**
- **Some operations such as prostatectomy**
- **Low levels of testosterone**
- **Chronically high blood glucose levels**

The reasons why men with T1D are more prone to problems with impotence are not fully understood. Some people with T1D 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 our 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 or general practitioner (GP). There are many treatment alternatives for decreased libido and impotence, ranging from counseling to oral or injectable drugs to surgery. Your GP or endocrinologist can discuss these options with you.

Thrush and balanitis

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 balanitis. 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 re-infection. However, if the infection persists, you should see your GP for further advice.

Fertility and inheritance

While there are no specific fertility issues concerning men with T1D, it is natural to worry about passing the disease on to your children. It is important to note that 80 percent of people with T1D have no family history of the disease.

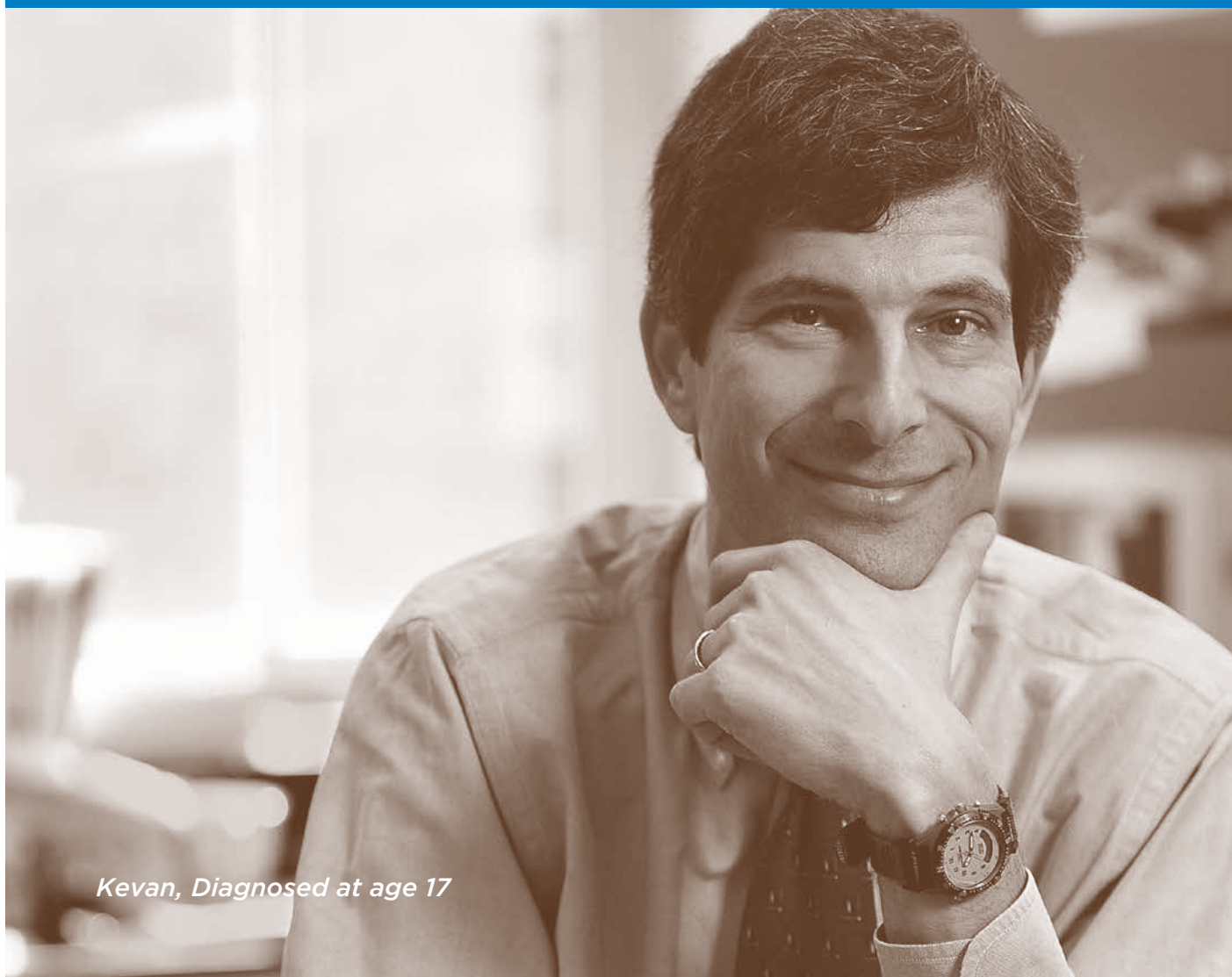
Seeing a doctor/specialist

Now that you have T1D, it is very important that you are under the ongoing care of a T1D specialist or T1D team—not receiving such care may affect your long-term health. Many complications of T1D, 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 T1D management, such as blood glucose testing and regular attendance at appointments, take a lower priority at times. Your T1D 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's okay 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 T1D 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

Future Health and Complications

Thyroid and celiac disease

T1D 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 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. T1D is associated with an increased risk of an autoimmune thyroid disease called Hashimoto's thyroiditis. It is (like T1D) associated with the presence of specific antibodies. It results in hypothyroidism. This is easily treated by thyroid hormone given 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 being 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 T1D, 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 like to think about: complications. The long-term health problems related to T1D—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 T1D complications. Other factors, like genes, also play a role.

Common complications

The parts of the body that can be most affected by T1D complications are the:

- **Heart and blood vessels**
- **Kidneys**
- **Eyes**
- **Nerves**
- **Gums**

Once you have lived with T1D 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 T1D don't show up until you've had T1D 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 T1D-related complications. For this reason, it is recommended that you are screened for T1D complications two to five years after being diagnosed with T1D 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.

Resources

JDRF has a number of resources that offer personalized support to adults living with T1D. Our goal is to provide information and resources to help families and individuals learn more about T1D, T1D 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 T1D connection, JDRF goes beyond funding research by providing social, emotional, and practical support to people who have been diagnosed with T1D and their families. JDRF has a number of resources that offer personalized support to adults living with T1D. Our goal is to provide information and resources to help families and individuals learn more about T1D, T1D 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 T1D can access these resources in a number of different ways. Much of JDRF's support is provided through our local chapters. To contact your local chapter, visit jdrf.org/locations/.

Other JDRF support services are accessible online through our web site, jdrf.org.

In creating JDRF's programs and resources, we've kept in mind the fact that people with T1D 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 T1D and their families. The descriptions include how you can access the resources.

JDRF chapters

In addition to holding events and raising funds to support JDRF's mission to cure T1D and its complications, our local chapters offer important support and resources for people with T1D 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 T1D 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.

To find your chapter, visit jdrf.org/location/, or you can call 1-800-533-CURE and JDRF will be glad to put you in touch with your local chapter.

Mentor programs

Your local JDRF chapter can connect people with T1D and their families to other individuals or families facing similar life circumstances.

For example, adults with T1D may be dealing with workplace issues, planning to have children, having financial or insurance concerns, and more. Our mentors are volunteers who can share their personal experiences, answer non-medical questions, and most importantly, lend valuable, specialized support when you need it most.

Support groups

A support group is a great way for people with T1D and their families to connect and share common experiences with others who are touched by T1D. Many JDRF chapters have a number of volunteer-led support groups, including groups for adults with T1D. 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

From time to time, JDRF chapters may host special events for adults with T1D. These events may include social events for adults or talks focused on T1D 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.

The Online T1D Support Team

The JDRF Online T1D Support Team comprises a nationwide group of volunteers working to provide one-on-one support, a sympathetic ear, and practical suggestions to individuals and families touched by T1D. All volunteers on the team have a personal T1D connection (either themselves, a relative, or a friend), and all requests to the team are assigned to team members based on their own relationship with T1D and life experiences in order to receive a prompt, personalized reply. (Note that the members of the Support Team are not medical professionals, and their practical advice about living with T1D is not meant to replace medical advice and treatment from a patient's healthcare team.) You can contact the support team at jdrf.org/get-support/online-T1D-support-team/.

TypeOneNation

TypeOneNation is a social network created by JDRF especially for people with T1D. You can access TypeOneNation by going to typeonenation.org.

When you register with TypeOneNation, you can create a profile, participate in online discussion groups, create and comment on blogs, upload videos, and more. TypeOneNation is the place for you to share thoughts, concerns, and tips about living with T1D, educate yourself about new gadgets and technologies, and just have fun meeting others like you who are living with the disease.

Since its launch, TypeOneNation has been a resounding success within the T1D community. Participants in the social network have reported that they have begun to better manage their T1D thanks to ongoing support from the online T1D community.

JDRF T1D Clinical Trials Connection

As both a service to patients with T1D and a move to quicken the pace of T1D research, JDRF has created Clinical Trials Connection. The service, located at 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 funded by JDRF.

Through this web site, you can provide certain criteria, like what type of trial you might be interested in, how long you've had T1D, 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 those 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 trial sponsors and talk with your healthcare provider to help you make decisions about whether you might want to participate in a clinical trial. All information collected as part of the Clinical Trials Connection is held in the strictest of confidence.

JDRF.org

JDRF.org is the place to go for up-to-the-minute news from JDRF research and advocacy, timely articles on the issues important to the T1D community, and practical advice on how to live well with T1D.

Helpful T1D websites

- **American Association of Diabetes Educators (AADE)**
diabeteseducator.org
Offers general T1D information and a search to find a T1D educator.
- **Insulindependence**
insulindependence.org
Insulindependence exists to enhance the quality of life for people with T1D through exercise and physical fitness.
- **Insulin Pumpers**
insulin-pumpers.org
Provides information and support for adults interested in insulin pump therapy.
- **National Institute for Diabetes and Digestive and Kidney Disease**
niddk.nih.gov
The NIDDK provides helpful information about T1D and the latest news in government-funded T1D research.

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.

About JDRF

JDRF is the world's leading funder of science to deliver treatments—and ultimately a cure—for people with T1D. Working toward this goal, JDRF has taken the lead in translating basic research breakthroughs into new therapies. The foundation creates multidisciplinary programs that bring together T1D researchers from both academic institutions and industry to find a cure for T1D and its complications.



Michele, diagnosed at age 11

About JDRF

JDRF is the leading global organization funding type 1 diabetes (T1D) research. JDRF's goal is to progressively remove the impact of T1D from people's lives until we achieve a world without T1D. JDRF collaborates with a wide spectrum of partners and is the only organization with the scientific resources, regulatory influence, and a working plan to better treat, prevent, and eventually cure T1D.

In 2012 alone, JDRF provided more than \$110 million to T1D research. More than 80 percent of JDRF's expenditures directly support research and research-related education. In 2012 *Forbes* magazine named JDRF one of its five All-Star charities, citing the organization's efficiency and effectiveness.

Building upon research successes

JDRF funding and leadership is associated with most major scientific breakthroughs in T1D research to date. In fact, JDRF funds a major portion of all T1D research worldwide, more than any other charity. Our research review process includes not only leading research scientists from around the world, but also lay reviewers who have either T1D or family members with T1D. This process ensures that JDRF funds research with the greatest impact throughout the world, leading to results as quickly as possible.

Moving research from bench to bedside

JDRF is driving science to deliver treatments that improve the lives of people with T1D in the near term. Working toward this goal, JDRF has taken the lead in translating basic research breakthroughs into new therapies. The foundation creates multidisciplinary programs that bring together T1D researchers from both academic institutions and industry to find a cure for T1D and its complications.

Efficiently organized for successful results

JDRF is structured on a business-world model that efficiently and effectively directs resources to research aimed at finding a cure as soon as possible. More than 80 percent of JDRF's expenditures directly support research and research-related education. Because of unwavering focus on its mission to find a cure, JDRF annually receives top rankings from independent sources that rate charitable giving. JDRF leverages its research impact by partnering with and stimulating increased research spending by public and private medical organizations and other entities throughout the world.

A backbone of dedicated and active volunteers

JDRF volunteers have a personal connection to T1D, which translates into an unrelenting commitment to finding a cure. These volunteers are the driving force behind more than 100 locations worldwide that raise money and advocate government spending for T1D research.

JDRF's research goals

JDRF has established a set of therapeutic areas to guide its research funding efforts. These research areas hold the greatest potential to lead to life-changing treatments and a cure for T1D and its complications:

Artificial pancreas: A series of increasingly sophisticated artificial pancreas systems that progressively eliminate blood-glucose testing and automate delivery of insulin and additional hormones.

Complications: Therapies that progressively treat and reverse debilitating complications resulting from the impact of T1D throughout the body.

Encapsulation: Implantable beta cell replacement therapies that restore insulin independence without the need for intensive immune suppression.

Smart insulin: Single dose of insulin that circulates in the bloodstream and turns on when it's needed and off when it's not.

Restoration: The body's beta cell function is restored and the autoimmune attack is halted—in short, the biologic cure for T1D.

Prevention: Slow or halt the progression of T1D before insulin dependence, and long-term, eliminate the risk of developing the disease.

How to Get Involved

While JDRF is committed to providing support and resources to people with T1D, our primary mission remains finding a cure for T1D and its complications through the support of research. Adults with T1D 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 T1D. 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 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 the research that will cure T1D, 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 at: ride.jdrf.org.

The JDRF Gala is a wonderful party for a great cause. The Gala raises money to find a cure for T1D with live and silent auctions and Fund A Cure. Fund A Cure is a part of the evening when everyone has the opportunity to make a direct contribution that goes 100% towards research. This is your opportunity to participate in the ultimate "party with a purpose" to help us find a cure! Find out more details from your local JDRF chapter.

Team JDRF is a way for anyone and everyone to make a difference in the fight against T1D. There are three ways to join Team JDRF. JDRF Challenge Events bring together your passion for endurance events and your drive to help others. JDRF Community Events harness the power of grassroots fundraising. And JDRF Personal Campaigns are a great way to turn a life celebration, such as a birthday, wedding, or graduation, into a charitable opportunity.

The JDRF Kids Walk to Cure Diabetes is an educational, in-school fundraising program with two goals: 1) to educate students about T1D and type 2 diabetes and the importance

of a healthy lifestyle, and 2) to provide them an opportunity to make a difference by raising money for T1D research.

JDRF chapters also hold many other exciting special events to raise funds in support of JDRF's mission to find 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 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 on supporting JDRF through workplace giving, contact your payroll manager or visit jdrf.org.

Planned giving

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 T1D 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 bift annuities**
- **Beneficiary designation (retirement accounts and life insurance policies)**
- **Charitable trusts**

Major gifts

Philanthropists all over the country have chosen to support the search for a cure for T1D 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 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 donor relations officer, please contact JDRF at 1-800-533-CURE.

Corporate partnership

The generous support of our corporate partners enables JDRF to fund research leading to life-changing therapies. Our partners give to JDRF in a variety of ways, including employee engagement, customer involvement, program sponsorship, local chapter and national event sponsorship, and cause-related marketing campaigns. To learn how your company can support JDRF, visit jdrf.org/get-involved/our-corporate-partners/.

Volunteer opportunities

JDRF's volunteers are the driving force behind our progress toward a cure, generously giving their time, money, and expertise in an ambitious plan of fundraising, outreach, and advocacy activities.

Local JDRF chapters use their volunteers to help organize fundraisers and support and outreach activities. JDRF volunteers also have opportunities to connect with people who are just becoming familiar with T1D or who may have questions about this disease. Volunteers address concerns about how T1D may change people's lives or the lives of their children.

JDRF volunteers include people who have T1D, have a friend or family member with T1D, and healthcare professionals who provide medical care for people with T1D. They have a vested interest, and are committed to finding a cure for T1D and its complications. More information about volunteering is available from your local JDRF chapter.

Many JDRF chapters have a Young Leadership Committee (YLC), comprising talented professionals who volunteer, fundraise, and network for JDRF. With YLC, you can get social for a great cause. To learn more, contact your local JDRF chapter.

Advocacy

JDRF Advocacy provides a unique opportunity to support JDRF and be an active part of the democratic process. When you sign up to be a JDRF advocate, you'll receive alerts and instructions on how to communicate with your elected representatives in Congress to show them your commitment to continued federal funding of T1D research. There are many ways to be an advocate. You can visit your Members of Congress in their offices, both in Washington, D.C., and in their home states; you can call their offices directly; and you can email them. JDRF advocacy staff will provide you with all the information you need to get started, and will help you every step of the way. It's easy! To learn more and sign up, visit advocacy.jdrf.org.

Closing Thoughts

Dear Reader:

Congratulations! Especially to those who finished reading this grand volume overnight (not suggested)! I hope that this will become a useful reference to assist you along with others who are applying themselves daily to manage the uniqueness of T1D. Remember that your primary source of specialized guidance is your willing T1D professional team.

I hope that you can use part of my life story to make T1D a positive experience. I have been living with T1D for 45+ happy and rewarding years. The confirmation of my T1D diagnosis came on the birth date of a very close elder family member. I have vivid memories of what it was like to be told I couldn't have the birthday cake or the ice cream! I still had a wonderful time, and that just shows the importance of relatives, good friends, and peers. I can also remember my first visit, as a pre-teen, to the "T1D specialist" (endocrinologist), with my anxious parents. I can recall, word for word, what he told me. He said "... if you can follow your insulin regimen and what I've told you to do, while keeping detailed records and keeping in contact with your care partners, then you'll be able to do whatever you want to do and live to at least 80." This continues to be a profound mandate, and I wish to pass it on to encourage you, as it has worked very well for me.

Learning to successfully manage my T1D has resulted in me becoming disciplined, patient, compassionate, attentive to detail, focused, and goal oriented, while having fun with the journey.

We wish to thank all the individuals who have devoted their efforts in making T1D increasingly more manageable. We support JDRF as it works diligently towards a cure.

Very Sincerely,

Horace

A passionate JDRF Online T1D Support Team member

On the journey for 45+ years

Special thanks to the following:

Portions adapted from Straight to the Point—A Guide for Adults Living with T1D, with the permission of JDRF Australia. Copyright ©2008 Juvenile T1D Research Foundation Australia.

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Appendix: T1D Dictionary

This dictionary has been compiled so that you can become familiar with words that are associated with T1D and used by doctors, nurses and other health care professionals.



Michael, diagnosed at age 15

The T1D Dictionary

This dictionary has been compiled so that you can become familiar with words that are associated with T1D and used by doctors, nurses and other healthcare professionals. We have also included certain terms that people with T1D 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**
- **JDRF**
- **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 and is called “acetone breath.”

Acidosis Too much acid in the body. For a person with T1D, this can lead to diabetic ketoacidosis.

Alternative Sweeteners Food additives that duplicate the taste of sugar but have fewer carbohydrates. Many people with T1D look for alternative sweeteners in packaged food and purchase them for use in the home. Common types include aspartame, cyclamate, mogrosides, saccharin, stevia, and sucralose.

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.

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. T1D 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. Also called labile and unstable diabetes.

Calorie Energy that comes from food. Some foods have more calories than others. Fats have many calories. Most vegetables have few. People with T1D 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, which 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 T1D. Also see: Fats; Protein.

Chronic Present over a long period of time. T1D is an example of a chronic disease.

Complications of T1D Harmful effects that may happen when a person has T1D. Some effects, such as hypoglycemia, can happen any time. Others develop when a person has had T1D 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 T1D can “control” the disease by staying on their diets, exercising, taking their medicine if it is needed, and monitoring their blood glucose. This care will help 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 blood stream 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 reversible coma caused by either: severe hyperglycemia and dehydration; severe hypoglycemia; or diabetic ketoacidosis. Also see: Hyperglycemia; Hypoglycemia; Diabetic Ketoacidosis.

Diabetic Ketoacidosis (DKA) 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 kinds and amounts of foods to eat. A registered dietitian (R.D.) has special qualifications. The healthcare team for T1D 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 T1D or other medical problems to alert others of their condition and identify in case of a medical emergency, such as coma.

Endocrinologist A doctor who treats people who have problems with their endocrine glands. T1D 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 T1D have to take special care of their feet because nerve damage and reduced blood flow sometimes mean 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 levels return to normal in about 95% 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 level.

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

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 T1D 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 T1D, hyperglycemia may lead to diabetic ketoacidosis.

Hypoglycemia Too low a level of glucose (sugar) in the blood. This occurs when a person with T1D 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.

Injection Putting liquid into the body with a needle and syringe. People with T1D inject insulin by putting the needle into the tissue under the skin (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 T1D 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 comes 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. 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 (T1D).

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 T1D.

Insulin Reaction Too low a level of glucose (sugar) in the blood; also called hypoglycemia. This occurs when a person with T1D 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 T1D. 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 T1D 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 number of calories, carbohydrates, proteins, and fats a person eats. People with T1D can use such plans as the Exchange Lists or the Point System to help them plan their meals so that they can keep their T1D 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% 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. 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% 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 somatostatin. 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 doctor 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 T1D.

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% or more) than they should.

Shock A severe condition that disturbs the body. A person with T1D 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 and 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 T1D.

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 T1D treatment approach in which medical care is provided by a physician, T1D nurse educator, dietitian, and/or 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" or "liable 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.

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About JDRF

JDRF is the leading global organization funding type 1 diabetes (T1D) research. JDRF's goal is to progressively remove the impact of T1D from people's lives until we achieve a world without T1D. JDRF collaborates with a wide spectrum of partners and is the only organization with the scientific resources, regulatory influence, and a working plan to better treat, prevent, and eventually cure T1D.

In 2012 alone, JDRF provided more than \$110 million to T1D research. More than 80 percent of JDRF's expenditures directly support research and research-related education. In 2012 *Forbes* magazine named JDRF one of its five All-Star charities, citing the organization's efficiency and effectiveness.

