MY LIFE, MY DIABETES, MY WAY

CARING FOR SOMEONE WITH TYPE 1 DIABETES

From Childhood to Young Adulthood (and Taking Care of Yourself, Too!)

PLEASE CONSULT YOUR CHILD’S HEALTH CARE PROFESSIONAL IF YOU HAVE ANY QUESTIONS ABOUT HIS OR HER HEALTH OR TREATMENT.

Developed in partnership with JDRF
MESSAGE FROM NOVO NORDISK

Novo Nordisk is proud to be able to offer you this booklet as part of the “My Life, My Diabetes, My Way” series that we have developed in partnership with JDRF – the leading global organization funding T1D research. These booklets were developed as a resource for people who have been touched by type 1 diabetes. Maybe you just got your diagnosis. Or, perhaps you or a family member has been managing it for years. Wherever you are on your diabetes journey, Novo Nordisk is here to help. This is why we have partnered with JDRF to create a unique booklet series tailored to various ages and stages of life from children to young adults with type 1 diabetes – and the people who care for them. Because we know that every age brings new and unique challenges, we have designed these booklets to grow with you on your diabetes journey.

Who are we? Novo Nordisk is a global health care company with more than 90 years of innovation and leadership in diabetes care. In 1923, one of our three Danish founders, August Krogh, touched by his wife Marie’s struggle with diabetes, began a journey to change diabetes. We will continue to build on the legacy left by the founders of Novo Nordisk and do whatever it takes to support people with diabetes. It is this commitment which has led us to develop this booklet series.

We hope that these booklets will be helpful to you in your diabetes journey. Additional support is available online at type1.cornerstones4care.com.

Jesper Høiland
President,
Novo Nordisk
USA

MESSAGE FROM JDRF

Type 1 diabetes (T1D) is a challenging disease. It demands nearly constant attention and never takes a day off. People of all ages, from newly-diagnosed children to adults who have lived with T1D for decades deserve the tools and resources to help them live with T1D. Together with Novo Nordisk, we’ve created these booklets to be such a resource for anyone who needs it.

Since 1970, JDRF has been working tirelessly to realize our vision of a world without T1D, and we have been fighting for countless families and individuals affected by the disease. As the leading charitable funder of T1D research, we won’t stop until we achieve our mission of accelerating life-changing breakthroughs to cure, prevent and treat T1D and its complications.

For many years, Novo Nordisk has been a trusted ally and partner in the fight against T1D. JDRF is very grateful that Novo Nordisk shares our commitment to support everyone with T1D, and we are looking forward to seeing the positive impact these booklets have for anyone affected by T1D until we find a cure.

Derek Rapp
President & CEO,
JDRF
## Contents

**A MESSAGE FROM NOVO NORDISK AND JDRF** .................................................. 2  
**GETTING THE TYPE 1 DIABETES DIAGNOSIS** ........................................... 6  
Starting the Type 1 Diabetes Journey .................................................. 8  
Making Type 1 Diabetes a Part of the Family ........................................ 10  
Talking About Diabetes ........................................................................ 12  
**THE CORNERSTONES OF CARE** ................................................................. 14  
Healthy Eating ....................................................................................... 15  
Being Active .......................................................................................... 18  
Medicine .................................................................................................. 20  
Checking and Tracking Blood Sugar .................................................... 22  
**BLOOD SUGAR HIGHS AND LOWS** .............................................................. 24  
High Blood Sugar .................................................................................. 24  
Low Blood Sugar ................................................................................... 26  
Nighttime Low Blood Sugar ................................................................. 27  
Understanding A1C and Blood Sugar Goals ........................................ 28  
**COPING WITH YOUR CHILD’S TYPE 1 DIABETES DIAGNOSIS** ............. 30  
Helping Your Child (and Family) Cope With Type 1 Diabetes ............ 31  
Recognizing and Dealing With Caregiver Burnout ........................... 32  
**CARING FOR SMALL CHILDREN** ................................................................. 34  
Teaching Kids How to Take Insulin ....................................................... 34  
Making Blood Sugar Checks Easier for Young Children .................... 35  
Starting School or Day Care With Type 1 Diabetes ............................ 36  
What to Do on Sick Days ...................................................................... 38  
Is Your Child’s Emergency Kit Packed? ............................................. 39  
Guiding Temporary Caregivers ............................................................. 40  
Bullying and Children With Type 1 Diabetes ..................................... 42  
**CARING FOR PRE-TEENS AND TEENS** ...................................................... 43  
Should a Counselor Join Your Teen’s Care Team? ............................ 44  
Help Your Teen Eat Healthy, Even on the Go! .................................... 46  
Teen Type 1 Diabetes Troubleshooting ............................................. 48  
**CARING FOR YOUNG ADULTS** ................................................................. 50  
Helping Your Young Adult Prepare for New Type 1 Diabetes Challenges ........................................ 51  
Helping Your Young Adult Transition to Adult Care ....................... 52  
Helping Them Manage Their Own Diabetes .................................... 54  
Diabetes and College ........................................................................... 56  
Managing Diabetes in the Workplace .............................................. 57  
Helping Your Young Adult Avoid Alcohol ....................................... 58  
Insurance Before and After Age 26 ............................................... 59  
**CONCLUSION: FINDING THE SUPPORT YOU NEED** .......................... 60
GETTING THE TYPE 1 DIABETES DIAGNOSIS

There’s probably never a good time for your loved one to be diagnosed with type 1 diabetes. But whether you are a parent, aunt, uncle, older sibling, stepparent, foster parent, or other caregiver involved in the life of a child with diabetes, know that you and the child you care for are not alone. In fact, approximately 1.25 million American children and adults have type 1 diabetes.

Getting a type 1 diabetes diagnosis can be a shock. If you are feeling overwhelmed, angry, or even guilty (though there is nothing you could have done to cause or stop your child’s diabetes), having these strong feelings is natural. Many parents and caregivers of children with diabetes go through this. You may worry about what the future holds for your child. You can take comfort in knowing that the technology for managing type 1 diabetes has greatly improved over the past several years, providing more options for diabetes care than ever before. We’ve gone from relying on animal-derived insulin just a few generations ago to using specially engineered insulin analogs today that work faster and last longer than earlier insulins. The technology has gotten better and more personalized too—from smaller meters for checking blood sugar on the go to water-resistant insulin pumps for swimming. People with diabetes can now increasingly fit their diabetes treatment into their lifestyle. And, yes, with proper diabetes management, many people are able to live a full life with type 1 diabetes.

It may seem overwhelming at first, but you can do this! Remember to take good care of yourself and rely on your family, friends, the diabetes care team, and other resources for needed support. Ask for advice. Seek out new information. Because you’re reading this booklet, you’re already off to a great start!
Starting the Type 1 Diabetes Journey

What is type 1 diabetes? How did my loved one get it? What now?

Type 1 diabetes is an autoimmune disease.
What this means is that in type 1 diabetes, the body's own immune system attacks and destroys the insulin-producing cells in the pancreas (called beta cells) as if they were foreign cells. This is known as an autoimmune response. As a result of this beta cell destruction, the pancreas makes little or no insulin.

Why is insulin so important?
The insulin that the body makes naturally is a hormone that helps the body process sugar. It's kind of like a gatekeeper. Without insulin, the fuel (sugar) that the cells need for energy can't enter them. Without energy, the cells can't work the way they should. Since there's little to no natural insulin in the body of someone with type 1 diabetes, it has to be replaced multiple times every day, usually by injection (with insulin pens or vials and syringes) or with an insulin pump.

How did this happen?
It is not known exactly what causes the body to attack its own beta cells. It is believed that family history (genetics) may be involved, and there may be some environmental factors as well. There is a lot of research being done to try and determine the risk factors for type 1 diabetes and the potential causes, but at this point in time there is no way to prevent type 1 diabetes. The good news is, there are many things you can do to help your child or teen manage it.

Insulin therapy can help you and your loved one manage his or her diabetes. It may take some work to get started and figure out how to balance your child's meals with their insulin injections or pump use and physical activity, but just like anything else, the more you do it, the more it can fit into a routine. And the more positive and matter-of-fact you are about it, the more likely it is that your child will take it all in stride. Remember, one way your child learns is by watching what you do and how you react.
Making Type 1 Diabetes a Part of the Family

When someone you care for is diagnosed with type 1 diabetes, it can feel like your entire household has diabetes. Diabetes can touch almost every part of a person’s life—what they eat, their activity level, even their moods—and that can affect the whole family.

There is a lot that caregivers and other family members can do to help a child cope with managing his or her type 1 diabetes. When caring for someone with type 1 diabetes, it’s important to stay positive and supportive. And it may be both healthy and interesting to take on some diabetes-friendly habits. Family and friends can help show support by joining their loved one in:

► Choosing to eat healthier
► Enjoying the same foods as your child
► Joining in your child’s activities
► Checking, or helping to check, your child’s blood sugar, especially if they cannot or don’t like to self-check

Just make sure that good-natured concern doesn’t go too far—no one likes the “diabetes police!”
Talking About Diabetes

Here are some tips on how to talk to your child about their type 1 diabetes.

➤ **Speak their language.** Young children and teens respond to different levels of detail. Use language that best fits his or her age. Talk openly and honestly; encourage questions.

➤ **Let them know that it’s not their fault.** Explain to young children that they didn’t get diabetes because they are “bad” or did something wrong.

➤ **Explain diabetes.** Talk to your child in simple terms and explain that diabetes will not go away, like the flu or a cold does.

➤ **Be positive and straightforward.** Try to smile and be calm and friendly as you explain diabetes. If you’re upset, your child might get upset, too. Make sure that your child knows that he or she can do the same things as other kids and teens without diabetes—it just takes planning.

Help Your Child Talk About Diabetes, Too!

Telling friends about diabetes can be difficult. Work with your child’s diabetes care team to find simple ways to talk about diabetes, so your child can explain it to friends and school staff. You can also look up other children’s stories about type 1 diabetes online and watch videos together. Hearing about other children with diabetes may help them feel they’re not alone. A few helpful places to go for this include:

➤ **jdrf.org**—Find lots of great type 1 diabetes tips and tools, from personal support to chat groups and mentoring programs (that connect you directly with another person who’s been there, too) to advocacy and conference opportunities, as well as event information.

➤ **childrenwithdiabetes.com**—Read stories about kids with diabetes worldwide, learn about conferences and events, and explore type 1 diabetes books and research news.

➤ **type1.cornerstones4care.com**—Watch videos of kids talking about their diabetes and find diabetes care tips, information, and inspiration.

Another way to explain diabetes is for your child to show their friends or school staff their blood sugar monitor and insulin pen or pump. It’s also a good idea to explain to your child’s friends and their parents how your child may feel when having high or low blood sugar, so they can recognize the symptoms.

Diabetes is a special part of your child’s life and a part of who they are. There is no need to feel embarrassed. If your child is straightforward and doesn’t make a big deal of his or her diabetes or treat it like a secret, their friends will probably be cool with it, too.
THE CORNERSTONES OF CARE

The following 4 cornerstones of care are really important to pay attention to when raising a child with diabetes:

1. **Healthy Eating.** Making smart food choices and building a diabetes-friendly meal plan (with a variety of foods) will help make sure they get the right amounts of protein, fats, and carbohydrates.

2. **Being Physically Active.** Playing and staying active are important for every child, whether they play sports or just run around with friends.

3. **Taking Medicine.** Your diabetes care team will tell you which insulin is right for your child. It is also important that you make sure they take all of their other medicine(s) as directed.

4. **Tracking.** Checking and recording your child’s blood sugar can help you see patterns. These patterns can tell you how his or her diabetes care plan is working and what (if anything) needs to change.

Healthy Eating

Food can have a big effect on blood sugar. It's important for everyone to make good food choices. But it's even more important to pay attention when type 1 diabetes is involved.

Understanding what's in the food you cook and eat is really important. You and your child or teen with type 1 diabetes will have to learn how to count:

- Calories
- Fat grams
- Carbohydrate grams
- Salt (sodium) milligrams

It all comes down to balance. All people with type 1 diabetes need to make sure that the calories and carbohydrates (carbs) that they eat are balanced and accounted for with the insulin they take and the physical activity they do. So the more someone with diabetes understands about what’s in their food, the easier it becomes to stay balanced.
Meal Planning

With the help of a dietitian, you can create a meal plan that helps your child with type 1 diabetes meet their nutritional goals with different foods—without it being boring. To be able to create a plan that works for your child, the dietitian needs to know about lifestyle considerations, including:

➤ Busy school and activity schedules and caretaker work schedules

➤ Cooking ability, frequency of eating out, and/or familiarity with different foods

➤ Level of physical activity

A realistic meal plan will include some familiar favorite foods and may help your child reach his or her individual blood sugar goals, achieve and keep a healthy weight, and prevent health problems related to eating habits. It will take teamwork and practice, but soon you’ll be able to plan meals that work not only for your child with type 1 diabetes, but for your whole family, too!

What Is “Gluten-free” All About?

Gluten is a protein found in certain grains (wheat, rye, barley). For most people it is not a problem. But there is a condition called celiac disease, where the body cannot properly digest gluten and a gluten-free diet is often necessary. Because it is also an autoimmune disease, celiac disease may happen in people who have type 1 diabetes. Note that while most people with type 1 diabetes will not develop celiac disease, some might, so it is worth knowing about. If you have any concerns about your child’s diet and digestive health, talk to their health care provider.

Carbs and Blood Sugar

Sugars and starchy foods are examples of carbohydrates. Carbs can raise blood sugar levels more than other nutrients. That’s why it’s important to be aware of the amount of carbohydrates your child eats.

Foods containing large amounts of carbohydrates include:

➤ Starches—bread, cereal, crackers, rice, and pasta

➤ Starchy vegetables—potatoes, corn, peas, and beans

➤ Fruits and fruit juices

➤ Milk and yogurt

➤ Sugary foods—candy, regular soda, and jelly

➤ Sweets—cakes, cookies, pies, and ice cream

Because carbs can raise blood sugar faster than other nutrients, it may seem to make sense to cut them completely out of your child’s diet. But carbs provide the body with energy, along with many vitamins and minerals, so everybody needs some. Just make sure your child’s food is covered by the right amount of insulin.
Being Active

As a part of a type 1 diabetes care plan, staying active can help your child or teen manage their diabetes and improve their general health. Physical activity helps lower blood sugar levels and has many other health benefits. However, your child may need to either use less insulin or eat more on days when they are more active. Of course, you should talk to their diabetes care team before adjusting your child’s insulin doses.

Find activities that your child enjoys and work them into a routine. Do they enjoy sports? Help them join a sports team if they are interested. Just make sure they are prepared for low blood sugar (see next page). According to the American Diabetes Association (ADA), children with type 1 diabetes should participate in at least 30 to 60 minutes of moderate physical activity each day. Try not to be too harsh with any kind of strict exercise schedule—let your kid be a kid and just play! Always ask their health care provider about what kinds of exercise would be best for your child.

Here are a few things to keep in mind:

- **Play it safe.** Be sure to check with their diabetes care team before beginning or changing your child’s or teen’s physical activity plan.

- **Check blood sugar before, during, and after exercise.** If blood sugar is less than 100 mg/dL, according to the American Diabetes Association (ADA) your child or teen should have an extra snack with carbs, such as a piece of fruit or a few crackers. Then test 15 to 30 minutes after eating. Don’t start the activity until blood sugar is above 100 mg/dL.

- **Check later, too.** Blood sugar levels can drop as long as 16 to 24 hours after being active because the body uses blood sugar to replace the sugar that has been used by the muscles.

- **Prepare for low blood sugar.** Being active may increase the chance of low blood sugar (hypoglycemia). Watch for symptoms and respond quickly. For more information about high and low blood sugar, turn to the high and low blood sugar section, starting on page 24. Keep a sugary snack or glucose tablets nearby in case blood sugar levels drop quickly.

- **Help them keep a physical activity log.** Before and after starting any physical activity, write down their latest blood sugar readings or, if he or she is old enough, have your child do it. By reviewing written records, you’ll learn what works (or doesn’t) for your child.

Does your child with type 1 diabetes want to take it up a notch and play competitive sports? As a protective parent or caregiver, the idea of this can naturally seem a little bit scary, but playing competitive sports with diabetes is okay. If he or she does join a team, let the coach know that your child or teen has type 1 diabetes and what to do if they experience low blood sugar. And make sure to check with the diabetes care team and come up with a sports care plan.
People with type 1 diabetes need to replace the insulin their bodies are no longer making. They can take insulin by:

- Injecting it with an insulin pen
- Injecting it with a syringe that is drawn from a vial
- Infusing it with an insulin pump

Many people with diabetes use insulin pens. Young children will usually need their parents or caregivers to help give them injections. However, it is important to show your child how to do it and get them involved because it will eventually be their responsibility.

Some children and their caregivers prefer using a pump rather than having to inject several times a day. When children get older, start school, and spend more time away from home, delivering insulin via a pump may be a convenient option. An insulin pump is a small device—some are even smaller than most iPods. It provides a steady flow of insulin continuously throughout the day and night, matched to the child’s or teen’s basal rate. It is also used to give bolus insulin doses both at mealtimes and as adjustments if their blood sugar rises too high. Pumps provide a high degree of accuracy and can be set to pump out as little as one-tenth of a unit (0.1 unit) of insulin per hour.

There are several situations where an insulin pump may be helpful to a child with type 1 diabetes and his or her parents or caregivers, including if he or she:

- Often has serious episodes of severe low blood sugar
- Has wide changes in their blood sugar numbers
- Has an A1C higher than their recommended target
- Has good control over their diabetes but multiple daily injections get in the way of his or her lifestyle

And sometimes kids with type 1 diabetes will ask for pumps! Many children find out about insulin pumps through other kids with type 1 diabetes that they may meet at school, diabetes camps, or conferences—and they want to try them, too. This request should be taken seriously and discussed with your child’s diabetes care team. If your child’s health care provider decides that a pump is the right choice, you will get full training on how to help your child use it. Talk to the diabetes care team about which device is best for your child.
Checking and Tracking Blood Sugar

Checking blood sugar on a regular basis is very important in managing type 1 diabetes. Keeping a good record of blood sugar readings over time (tracking) gives clues to how well meal and activity plans are working together with insulin. It also allows the health care provider to see how well your child’s diabetes care plan is working or if it needs to change. Remember to:

- Check your child’s blood sugar levels as often as the diabetes care team suggests.
- Most people with type 1 diabetes should do several blood sugar checks every day.
- Ask the diabetes care team to help you pick a meter—and show you how to use it.
- Use reminders. Phone alarms, text reminders, or even simple notes.
- Remind your child/teen that it’s a reading, not an exam.

Sometimes getting an out-of-range blood sugar number feels like getting a bad grade. That’s why many people call monitoring doing “blood sugar checks” rather than “blood sugar tests”

Tools for Blood Sugar Checks

You will need to check your child’s blood sugar several times a day according to their health care provider’s instructions. Most people use meters that take a small drop of blood from a finger prick that is placed by the side of a test strip. The test strip draws the blood in by capillary action and then the meter produces an electronic blood sugar reading.

Another tool for checking blood sugar is called a “continuous glucose monitor” or CGM. The CGM has a small sensor probe that is inserted beneath the skin (like a pump infusion set), which measures the fluid between cells (“interstitial fluid”) to calculate blood sugar. The sensor communicates through a transmitter, which sits on top of the skin. It communicates wirelessly with a handheld device (known as a “receiver”) that displays real-time blood sugar readings at 1- and 5-minute intervals. You can also set alarms to alert you to high or low blood sugar levels.

CGM provides much more information than finger-prick readings alone. The detailed information CGM gives you about blood sugar changes may help you figure out your child’s blood sugar patterns, so you and your child’s care team can fine-tune food choices and insulin doses. Your child’s health care provider and diabetes care team will help you figure out when, how often, and with what tools your child’s blood sugar should be checked.
BLOOD SUGAR HIGHS AND LOWS

High Blood Sugar

High blood sugar, also called hyperglycemia, happens when the body either has too little insulin or can’t use insulin properly. Many things can cause people with type 1 diabetes to have high blood sugar, including:

- Not taking enough insulin for the food eaten
- Eating more than planned (especially carbs)
- Being less active than planned
- Physical stress from illnesses, such as a cold or the flu
- Emotional stress or excitement

Talk to the diabetes care team about what they think is a safe target for your child's blood sugar before and after meals.

Watch for these signs and symptoms of high blood sugar:

- High blood sugar readings when testing
- High levels of sugar in the urine
- Frequent urination
- Increased thirst

What do I do about high blood sugar?

Talk to your child’s health care team right away and discuss how best to handle it. In many cases, your child may need to take additional insulin, but their health care provider may have other recommendations and advice.

Why is high blood sugar a problem?

High blood sugar can be serious if left untreated. In the long term, it may increase the risk for diabetes-related problems.

What’s DKA?

DKA stands for diabetic ketoacidosis. It develops when the body doesn’t have enough insulin. Without insulin, sugar can’t get into the body’s cells to be used for fuel, so the body breaks down fats instead. But when the body breaks down fats, it produces waste products called ketones. When too many ketones build up in the blood, they can make it too acidic. Ketoacidosis is very dangerous and needs immediate treatment. Signs of DKA include nausea and vomiting, stomach pain, fruity breath odor, and difficulty breathing. Talk to your child’s health care provider about his or her risk for DKA and have an emergency plan for treating it.

DKA is an emergency.

Untreated DKA can lead to coma and loss of life, so watch for signs and call your child’s health care provider immediately if you think that he or she may have DKA.
Low Blood Sugar

Low blood sugar, or hypoglycemia, usually happens when blood sugar is lower than normal and can be a side effect of diabetes medications. Check your child’s blood sugar right away if you or your child notices any of these symptoms! Talk to your child’s health care provider to get guidance on what is considered low blood sugar for your child.

- Lack of control over simple movements, clumsiness
- Dizziness or light-headedness
- Rapid heartbeat
- Headache
- Hunger
- Nausea
- Seizure (fits)
- Shakiness
- Sleepiness
- Sweating
- A tingling feeling around the mouth
- Weakness

Checking blood sugar is the best way to find out if someone has low blood sugar. If it’s not possible to check blood sugar right away, but you notice (or your child experiences) some of the symptoms listed above, the ADA recommends that you play it safe and treat for low blood sugar with a quick carb snack or glucose tablet. If left untreated, low blood sugar can get worse and your child can pass out (become unconscious) or have seizures.

The quickest way to raise blood sugar and treat hypoglycemia is with some form of sugar. Many people with diabetes carry glucose tablets. You can purchase them at most drugstores. Other foods with sugar or fast-acting carbohydrates also work well to treat low blood sugar. Some examples are fruit juice or nondiet soda (about 4 ounces), hard candies (5 to 7 pieces). The American Diabetes Association recommends that you feed your child at least 15 grams of sugars or carbohydrates as soon as symptoms of low blood sugar show up. After drinking or eating, wait 15 minutes and check again. If it is still low or symptoms haven’t gone away, try another 15 grams of carbohydrates.

Sometimes low blood sugar can be severe enough that it can cause your child to pass out. When this happens, it is serious, but it is also treatable. In cases where they can’t swallow, low blood sugar can be treated with an emergency injection of glucagon. Glucagon does the opposite of what insulin does. It’s injected to raise blood sugar instead of lowering it.

You should have glucagon emergency medicine around at all times. Most likely, the doctor has already written a prescription for it. If not, talk to your child’s doctor as soon as possible about whether glucagon emergency medicine is appropriate for him or her. If it is, the diabetes care team can give you instructions on how to use it. Obviously, if your child passes out from low blood sugar, he or she won’t be able to inject glucagon. So you need to teach family and friends who are around your child the most how to inject it for your child. Go over the steps with them so they’ll know what to do if the time comes. If your child experienced a severe low blood sugar event that had to be treated with a glucagon injection, be sure to let the diabetes care team know immediately.

Nighttime Low Blood Sugar

Did you know that low blood sugar events sometimes happen in the middle of the night? There are many ways to figure out if your child may be experiencing nighttime low blood sugar. They may sweat so much that they wake up with damp pajamas or sheets. Your child may also wake up with a headache and feel tired, irritable, or confused. It can also cause them to cry out during sleep or have nightmares. A fast heartbeat and anxiety before bed are also signs. However, the best way to see if their blood sugar is heading too low is to check it before bedtime.

What causes nighttime low blood sugar? Sometimes being active too close to bedtime can cause low blood sugar. Having a late dinner and going to sleep a couple of hours later can also cause nighttime low blood sugar because the insulin your child took at dinner may still be working to lower blood sugar for several hours afterwards. This does not mean that your child cannot be active before bedtime or never have a late dinner. Talk to your child’s health care provider about their recommendations for your child.

If you think that your child has experienced nighttime low blood sugar, talk to their health care provider immediately about how to help prevent and treat it. Sometimes late night blood sugar checks are needed. And some continuous glucose monitor (CGM) systems even have a low blood sugar alarm that can wake your child up if their blood sugar falls too low during the night, so these may be an option. Nighttime low blood sugar can be scary, but it is also manageable.
Understanding A1C and Blood Sugar Goals

When it comes to taking care of their type 1 diabetes, you may hear a lot about your child's A1C numbers. This may be especially true if his or her numbers are not at goal, meaning that they are higher than the diabetes care team has decided they should be. So what do their A1C numbers really mean?

An A1C test measures the average blood sugar level over the past 2 to 3 months, and the results are shown as a percentage. But what does A1C actually measure? There is a protein inside red blood cells called hemoglobin that carries oxygen from the lungs to all the cells of the body. Blood sugar (or glucose) enters red blood cells and links up (or glycates) with hemoglobin to form glycated hemoglobin. This is also called hemoglobin A1C or just A1C. When more glucose is in the blood, more of it can attach to hemoglobin. When too much glucose is attached to hemoglobin, it’s a sign there's too much sugar in their blood. Red blood cells live for about 3 months. So an A1C test shows the level of glucose in the blood during that time. It's like a snapshot of blood sugar levels for the past 2 to 3 months.

While both A1C testing and regular blood sugar checks show how well diabetes is being managed, A1C provides a bigger picture of blood sugar control. So your child's health care provider should measure his or her A1C levels at least twice a year if their blood sugar goals are being reached. When their treatment plan has changed or their goals are not being reached, their A1C may be tested as much as 4 times a year.

While everyone’s goals are going to be slightly different, the ADA does have recommendations for A1C goals and for what blood sugar numbers should be when they are checked throughout the day.

However, your child’s blood sugar goals may be higher or lower than these recommended goals. Ask his or her diabetes care team what goals are right for your child.

**SUMMARY OF BLOOD SUGAR GOALS FOR CHILDREN AND NONPREGNANT ADULTS WITH DIABETES**

<table>
<thead>
<tr>
<th>Blood Sugar Goals for Children and Teens (ages 0-18)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Before meals (FPG)</td>
</tr>
<tr>
<td>Bedtime/overnight</td>
</tr>
<tr>
<td>A1C</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Blood Sugar Goals for Nonpregnant Adults (ages 19+)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Before meals (FPG)</td>
</tr>
<tr>
<td>After meals (PPG)</td>
</tr>
<tr>
<td>A1C</td>
</tr>
</tbody>
</table>

FPG=Fasting plasma glucose, or before meal blood sugar
PPG=Post prandial glucose, or after meal blood sugar

Talk to your health care provider about your child's personal blood sugar goals.

The Blood Sugar Tracker

You don’t need to use a complicated system to keep track of your child’s blood sugar numbers. In fact, you can use a simple notebook and pencil to write down the numbers and testing times. You should also make sure to read the instructions that came with your child’s blood sugar meter. Some meters automatically log (digitally record) your child’s blood sugar readings, which can then be downloaded to your computer and/or the computer at your health care provider’s office.
C OPING WITH YOUR CHILD’S TYPE 1 DIABETES DIAGNOSIS

When you first find out that your child has diabetes, you may be overwhelmed with feelings of shock, disbelief, sadness, anger, or even guilt. It can seem so unfair. It can be overwhelming, especially at first.

As you learn more about diabetes, you will also learn how to help your child incorporate diabetes management into his or her daily life. It may take some work as you figure out how to balance meals with insulin and activities. You may find that your child takes it all in stride and that the hardest part may be coming to terms with your own feelings. Your child looks to you for guidance. Your attitude will have a direct impact on how your child sees himself or herself and how he or she handles this new lifestyle. If you take your child’s diabetes in stride, it may be easier for your child to accept it. If you react with anxiety and fear, your child may also react that way.

How you manage diabetes in your home depends on your child’s specific goals and needs. No two people with diabetes are exactly alike. However, there are a few things that everyone who cares for someone with diabetes should consider:

1. Help them keep a healthy lifestyle and keep track of their blood sugar levels, food, and physical activity
2. Do your best to prevent short-term problems, such as high or low blood sugar
3. Managing their diabetes well over time may help avoid long-term health problems

Talk to your child’s health care provider about the best ways to accomplish these goals.

Helping Your Child (and Family) Cope With Type 1 Diabetes

Let your child know that it’s okay if they need to talk or vent or if they need help with their diabetes. There are many ways for them to build healthy coping skills. Three of the most important are:

1. Having enough information to make good decisions. Keep up with the type 1 diabetes research online by going to reputable sources, like jdrf.org, and speak with your child’s diabetes care team often. Knowledge is power!
2. Finding ways to feel in control of the situation. Let your child have some control, like choosing injection sites or what meals to eat. Active control may help them feel more empowered
3. Having the support of others. There are online groups, videos, and forums that your child can use to see other kids with diabetes living happy lives. Consider enrolling your child in a diabetes camp or local support group where he or she can meet other kids with diabetes

“Welcoming” type 1 diabetes into the family isn’t easy. The best way to deal with diabetes is to treat it openly and matter-of-factly. Explain what is happening to family members and ask them to be patient while you work things out as a family. Even young children can understand simple information. Once your child and his or her siblings come to accept diabetes care, the feelings of anger, jealousy, and fear that can sometimes happen usually begin to subside. However, if you continue to experience family turmoil, you may want to consider family counseling. If you think you or your child need this, ask your child’s diabetes care team for help finding a family counselor.
Recognizing and Dealing With Caregiver Burnout

Being a parent or caregiver of any child can be a wonderful experience, but also comes with its share of challenges. However, when you are taking care of a child with a chronic condition like type 1 diabetes, it can be even more stressful. And, over time, that additional stress can lead to burnout. In fact, in a clinical study that compared mothers and fathers of children with type 1 diabetes with mothers and fathers of children who did not have any chronic illnesses, over 44% of mothers and over 28% of fathers whose children had type 1 diabetes reported feeling burnout symptoms as compared with around 20% of mothers and fathers whose children did not have any chronic illnesses.

What does burnout really mean anyway? Burnout is what happens when long-term stress leaves you feeling physically and emotionally exhausted, negative, disconnected, and like nothing you are doing is really working as well as you want it to. You may have even heard of the term diabetes burnout. It’s what happens when you feel overwhelmed by diabetes and by the frustrating burden of diabetes self-care. People who have burned out realize that good diabetes care is important for their health, but they just don’t have the motivation to do it. They may feel that they are at war with their diabetes...and that they are losing. You might have even seen the signs of diabetes burnout happening in your own child from time to time.

But what is caregiver burnout? Caregiver burnout is not technically a medical term, but it has been defined as “…the physical, mental, and emotional exhaustion that comes with caring for a loved one dealing with any variety of health issues or aging.” As a caregiver who is busy taking care of a child with type 1 diabetes, you may be so busy meeting his or her needs that you don’t realize your own needs are not fully being met. And sometimes friends or family members may alert you to the fact that you are experiencing burnout before you yourself are aware of it.

What can you do about it? There are ways to try to prevent and deal with caregiver burnout. Some things that are recommended include:

- Consulting with health professionals to discuss burnout issues
- Attending support group meetings to get feedback and learn coping strategies
- Rotating caregiving responsibilities with family and friends (if possible) so it doesn’t feel like you are doing the same thing all the time
- Exercising daily and eating a healthy diet
- Establishing “quiet time” for meditation or other relaxation
- Staying involved in hobbies

If you have any questions or concerns about managing the stress that can come from caring for a child with type 1 diabetes, please do not hesitate to turn to your child’s health care provider or diabetes care team for support.
CARING FOR SMALL CHILDREN

Teaching Kids How to Take Insulin

Taking insulin (usually either by multiple daily injections or by using a pump) is necessary to manage type 1 diabetes. You will need to help your child take their insulin when they are young or first getting started with their diabetes care. But by the time they are in their pre-teen years, they are old enough that they should start taking steps towards giving themselves insulin and checking their own blood sugar.

If using a pump, you may want to involve an older child in changing the pump reservoir and injection site if you think that they are capable of doing so. The idea is to engage them in their own care and get them used to doing the things they will eventually be doing independently. When he or she is old enough, you can also teach them to program the pump and give themselves doses of short-acting insulin when they eat (called a bolus dose). If you need help, talk to the members of the diabetes care team and ask them to teach you how to change the reservoir and injection site and how you should teach your child to do the same.

Remember to always read the Instructions For Use of any insulin product before using it. Always give your child their insulin exactly as their doctor recommends.

Making Blood Sugar Checks Easier for Young Children

Finger pricks aren’t always easy. But there are ways to make young children feel more comfortable and at ease with the process.

- **Be prepared.** Set things up in advance (e.g., charging the meter, putting a new lancet in the device) out of sight of the child. Involving him or her only when everything is ready helps shorten the time in which your child may be anxious or upset.

- **Always use a new lancet.**

- **Don’t go too deep!** Using the shallowest poke possible to draw blood hurts less and causes less scarring, too. Prick on the side of the finger, not the center.

- **Try distraction.** If the child is upset by the finger pricks, it may help to get him or her interested in something else—like a favorite stuffed animal or toy, or watching a DVD—during the finger stick.

- **Avoid getting angry.** Dealing with a child who is refusing or resisting finger pricks is not exactly fun for you either! But taking a deep breath, controlling your feelings, and providing reassurance can help keep the process more positive.

- **Get it done quickly!** Try not to make it last longer than it has to and don’t forget to give your child a big hug once it’s done. Then move on with your day.
Starting School or Day Care With Type 1 Diabetes

Sending your young child off to day care or school for the first time can be a stressful and emotional experience for both of you! It may give you some reassurance if you meet with the school personnel beforehand to discuss your child’s diabetes care.

Reach out to your child’s diabetes care team and school or day care staff to create a school diabetes care plan that everyone can understand. This way, everyone will know what to expect and how to help. Two of the commonly used plans are listed below:

**Section 504 Plans** clearly outline the responsibilities of everyone involved: the student, the parents/guardians, and school staff. They help make sure that the child’s educational needs do not suffer because of their physical needs.

**Individualized Education Programs (IEP)** help make sure your child gets any special education services they may need.

---

Some more school situations to consider:

- **Show and tell.** Talk to your child and their teacher about whether it would be helpful for you to come into the classroom and do a presentation on type 1 diabetes. Letting their classmates know what to expect may help prevent a lot of awkward questions.

- **Does your child have a school emergency plan?** Make sure a specific staff member is designated to help the child in the event of an emergency.

- **School trips.** When they go on school field trips, make sure your child has a backpack with all necessary diabetes supplies. Talk to the people in charge of the trip to let them know your child has type 1 diabetes and answer any questions that they may have.

---

**Need More Help?**

JDRF.org has a “School Advisory Toolkit.” You can download it or request your very own printed copy for guidance on the steps to take to train and inform school staff about type 1 diabetes.
What to Do on Sick Days

If your child has an illness, such as the flu or a stomach bug, it can cause blood sugar to rise, even if the child is eating less. An injury, a surgery, and even certain dental procedures (like having a tooth pulled) can also cause blood sugar to go up. Here are some sick-day tips:

- Treat the underlying illness. Talk to your child’s health care provider about what medicines are safe for them to take.
- Keep taking diabetes medication as directed, unless the health care provider says not to.
- Check blood sugar often. If blood sugar is 250 mg/dL or higher, call the health care provider and check for ketones.
- Check with the diabetes care team about how to adjust insulin doses if blood sugar climbs too high and/or your child vomits.
- Try to follow the meal plan as best as you can. If your child is too sick to eat, make sure he or she drinks plenty of fluids (6-8 ounces every hour). Talk to your child’s health care provider about what food or drink choices they recommend during your child’s illness.
- Have them rest and keep them warm. No exercise.

Is Your Child’s Emergency Kit Packed?

Power outages, fires, floods, blizzards, and hurricanes can turn everyday life upside down. While being prepared for an emergency is important for everyone, it is even more important to be prepared when type 1 diabetes is involved.

Pack an emergency kit. The ADA recommends packing a clearly labeled emergency kit with at least 3 days’ worth of supplies and storing it in a place where it’s easy to find in a hurry.

Check off this list of supplies as you gather them:

- Your child’s medications. This includes insulin (which if unopened, should be kept refrigerated), insulin delivery supplies, and any oral medications. Routinely check all medicines and supplies for expiration dates.
- An extra blood sugar meter or pump.
- Lancets, test strips, and any other testing supplies needed.
- Extra batteries for meters and/or pumps.
- Quick-acting carbs to raise blood sugar if it goes too low.
- Glucagon emergency medicine in case of severe low blood sugar. Make sure someone with your child knows how to correctly use the glucagon injection.
- A written emergency contact list (remember, cell phone signals may jam or cell phones may run out of power just when a number is needed).
Guiding Temporary Caregivers

Worried about letting your child go off to their grandparents’ house, a friend’s house, or to a birthday party where they will be dropped off? That’s absolutely normal! Letting go for the first time is a big step. Your child may feel ready for it long before you are. And you are not alone—many parents before you have felt exactly the same way, including parents whose kids do not have diabetes.

You know that whenever you put your child in someone else’s care, you should give the temporary caregiver a rundown of your child’s likes and dislikes, eating habits, and allergies. It’s no different for children with type 1 diabetes; there are just a few more things to cover. Your child will require careful monitoring to maintain his or her blood sugar control. There is no reason why your child can’t go on school trips or stay at a friend’s house as long as they are prepared and the people who are looking after them are confident managing your child’s diabetes. Here are a few tips for making trips and sleepovers go more smoothly:

→ Make sure the person in charge of your child knows his or her diabetes needs and how to manage them. You may want to arrange a meeting ahead of time for training
→ If children will be staying away overnight, make sure both your child and the adult in charge are aware of the signs of nighttime low blood sugar and how to manage it if it happens
→ Find out what activities are planned and what meals will be served. You may want to pack your child a lunch if it is a day trip
→ See that they have enough insulin and supplies with them for all the prescribed doses during the trip and that their supplies are accessible to them
→ Pack enough fast-acting carbohydrates, such as glucose tablets, sugary candies, or cartons of fruit juice, to help manage low blood sugar should it occur

Depending on his or her age and level of ability, your child may be able to check his or her own blood sugar, or at least help in the process. Older children may be completely in control of their diabetes management. In that case, the caregiver may only need to observe the child and remind him or her when it’s time to check, eat, or take insulin.

More supervision and direct care are needed with younger children or those who are unable to manage their diabetes well. You should let temporary caregivers know:

→ What your child’s blood sugar goals are
→ When your child should take insulin
→ When their blood sugar should be checked
→ What numbers are too high or too low
→ When to check for ketones (that is, if blood sugar is very high or before strenuous exercise)

You should always provide the temporary caregiver with phone numbers to contact you and your child’s health care providers in case of an emergency or serious illness.
Bullying and Children With Type 1 Diabetes

Children with type 1 diabetes can become targets for bullying simply because their diabetes seems to make them “different” from their peers. Diabetes-related bullying can be a series of little things repeated over time that add up and chip away at a child’s self-esteem. Bullying includes teasing/taunting and arguing not just once, but many times.

**What can you do?**

- Explain to your child that being bullied is not his or her fault, that they do not deserve it, and that they should seek help from adults.
- Encourage your child to keep diabetes-related bullying from affecting his or her diabetes self-care. Whether the bullying is sparked by a classmate seeing a child taking medicine, doing regular blood sugar checks, or eating a healthy snack or lunch, children shouldn’t have to stop healthy habits because of teasing by their peers.
- If you suspect that your child is being bullied, take it seriously and talk to their teachers and other school administrators immediately. Make sure they are aware and see what steps can be taken to stop the problem immediately. It may help to put all concerns in writing in case you need to prove that this is an ongoing problem.

CARING FOR PRE-TEENS AND TEENS

As your child grows and develops, his or her needs will change and they will become more independent. It is likely that your pre-teen or teen will want to take a more active role in handling his or her diabetes, which is great! Encourage your child to keep a healthy lifestyle to help achieve better blood sugar control. It is important for school-age children to build self-management skills and a sense of responsibility for their own diabetes care, especially when they are not at home. And though your pre-teen or teen may want to become completely independent in their diabetes care, it is better to maintain some parental guidance. Research has shown positive results when parents continue to be involved in monitoring during the adolescent years.

During the pre-teen and teen years, it is important that you become aware of new social challenges as well as medical considerations. Your child’s diabetes care now needs to be flexible enough for him or her to participate in normal, age-appropriate activities, like sports, overnights, and parties independently of you.

Changing hormones during puberty will most likely bring an increased need for insulin and may make managing blood sugar more difficult. Your pre-teen or teen will probably now be able to handle many of the details of his or her own diabetes care. However, their changing roles and responsibilities (and new-found need for independence) can cause conflicts or risky behavior, so your continued involvement is important.
Should a Counselor Join Your Teen’s Care Team?

You may wonder, “What does diabetes have to do with mental health?” Diabetes may not directly affect your child’s mental health, but managing diabetes can be stressful and that can lead to depression and other mental health issues. Studies have shown that teens with type 1 diabetes are more likely to suffer from depression (feeling sad or “blue” for a long period of time) than teenagers who do not have type 1 diabetes. Everyone has a down day now and then, so it’s hard to know if your teen is depressed or just going through a rough patch. But if you think your teen may be depressed, consider counseling. Contact a health care provider right away if you notice that your teen has any of the following signs or symptoms:

- Loss of pleasure in activities he or she used to enjoy
- Trouble sleeping
- Lower energy levels
- Change in appetite and/or loss of enjoyment of certain foods
- Weight gain or loss
- Trouble focusing or making decisions
- Feelings of guilt or low self-worth
- Thoughts of suicide or self-harm

Remember, this short list does not take the place of talking to a health care provider. If you have any questions about your teen’s emotional health, ask someone on your child’s diabetes care team for help. If your teen is depressed, he or she may have trouble taking care of their diabetes and controlling their blood sugar. That’s why the ADA recommends screening for depression and other emotional problems.

Dealing with “teenage rebellion” in your teen with type 1 diabetes?

Most teens go through this to some extent, whether they have diabetes or not. However, this can seriously impact their diabetes self-care. Unfortunately, blood sugar control can often get worse in teens with type 1 diabetes, which makes it really important to stay involved and be supportive during this time. Here are some things to think about (or even expect):

- Your teenager may try to rebel by neglecting diabetes care
- He or she may try to deny their diabetes in an attempt to “fit in”

When talking to your teen, acknowledge that, yes, it can be inconvenient and awkward to take insulin, count carbs, and check blood sugar at school, or when he or she is hanging out with friends. However, emphasize that all of these self-care tasks are necessary and nonnegotiable. Advise your teenager that the best way to keep diabetes from interfering with their life is by keeping blood sugar on target.
Help Your Teen Eat Healthy, Even on the Go!

Your teen with type 1 diabetes can enjoy eating out with friends. But we know that it can cause some anxiety over unknowns, like: When is the meal going to be served? How many carbs are really on the plate? Going out is a special occasion. They should be able to relax and enjoy themselves, so long as they don’t go overboard. Here are some ordering tips to share with your teen:

- Don’t be afraid to ask your server about ingredients or serving sizes or for substitutions, such as a baked potato or vegetables instead of French fries.
- Try to eat the same portion size as you would at home. Some restaurants have huge dinner portions, but the portion size can be reduced by ordering a “lunch size” meal, sharing an order, taking some home, or simply leaving food on the plate.
- Find out how it’s prepared. Ask for less or no butter to be used in cooking your meal. Ask that sauces, gravy, salad dressings, and butter be eliminated, or at least served on the side.
- Avoid fried foods. To cut down on extra fats and oils, encourage them to choose broiled, baked, poached, or grilled meats and fish rather than fried.
Teen Type 1 Diabetes Troubleshooting

What about when the blood sugar numbers just don’t add up?
The goal of watching blood sugar numbers isn’t to “test” performance; it’s to get the information your teen needs for the daily management of his or her diabetes. And to watch for trends that can help make sure that the current treatment plan is working. The truth is, there is no way to always achieve perfect blood sugar numbers. So encourage your teen to try their best, but also reassure him or her that their body won’t always respond as planned. Unexpected blood sugar numbers can sometimes surprise even people who have lived with diabetes for decades. Tell your teen to be on the lookout, but not to freak out!

Help your teen stay at a healthy weight in a healthy way.
The best way to keep a healthy weight comes from a combination of physical activity and healthy eating. But no one plan works for everyone. Some people find it easier to take in fewer calories. Others find it easier to work out more. Whatever the approach, make a plan that works for your teen and stick with it. One dangerous and unhealthy way for teens to lose weight is by taking less insulin than they are supposed to, or skipping insulin doses. This is often referred to as diabulimia. Unfortunately diabulimia is very dangerous. It can also put your teen at high risk for DKA (see page 25) and other life-threatening high blood sugar emergencies as well as long-term diabetes-related problems (complications). If you suspect your child or teen is doing this, contact his or her diabetes care team immediately.

Is it time for them to have their own appointments?
You might suggest that your older teen visit with his or her diabetes educator or other diabetes care team members alone for at least part of their appointment. This gives him or her a chance to ask questions and establish a relationship that can be helpful in the future. When your child is treated like an adult, he or she may act more like an adult. It is critical that your child understands that it is eventually up to him or her to take charge of their own care.

Is your teen going through diabetes burnout?
People can get overwhelmed and tired of taking care of their type 1 diabetes at any age, but kids at this age who have had diabetes for a while are particularly vulnerable to it. This is a time when teens want to be more like their friends and may try to avoid things that make them feel different, like their diabetes care. Some of the signs of diabetes burnout include:

- Feeling "burned" or let down by diabetes care
- Feeling angry or having negative thoughts
- Feeling that diabetes controls their life
- Not following their diabetes care plan

If you notice that your teen seems to be neglecting his or her diabetes care, you need to talk to them about it in a constructive way and help him or her re-engage. Addressing diabetes burnout in your child is important because it can lead to low energy and less interest in taking care of themselves. Your teen may need help from a counselor to deal with his or her diabetes burnout. Reach out to his or her diabetes care team for help and referrals.
CARING FOR YOUNG ADULTS (AGES 17-24)

Young adults want independence, but at the same time they may be scared of it, too. Freedom from supervision and rules brings responsibilities that can be overwhelming. How do you choose a college or vocational training program? How do you find and keep a place to live? Pay your bills? Pick a career? And have a relationship? Young adults are trying to balance all of these new freedoms and responsibilities with less help from you and less structure in their daily routine. During these transitions, even some of the most “on-top-of-it” young adults may have trouble making their diabetes a high priority. It may be helpful to remind them that this is usually a “normal” transitional phase and not a sign of personal failure. All you can do is be there to support them when they want your help.

Getting first diagnosed as a young adult may bring on a lot of emotions that come with being told this news. The most important thing is for them to be patient with themselves. It takes time to learn how to manage type 1 diabetes. You and your young adult can do some research on type 1 diabetes and find the support of a good diabetes care team. Yes, there are many things to do when you have type 1 diabetes. But they will get the hang of it. An important thing to know is that type 1 diabetes doesn't have to keep your young adult from doing and accomplishing the things in life that they want to!

Helping Your Young Adult Prepare for New Type 1 Diabetes Challenges

There’s a lot to remember when it comes to caring for diabetes. Here are some questions you may want to ask your young adult to see if they’re prepared for these situations as they transition into being a truly independent adult.

- Do you know how to fill your own prescription(s)?
- Can you order your supplies before you run out?
- Do you have supplies to manage a low blood sugar reaction?
- Do you remember to check blood sugar levels and take your insulin on your own or do you need reminders?
- Do you know how to adjust your insulin based on your blood sugar readings and the amount of carbohydrates you eat?
- Can you adjust your food and/or insulin based on your physical activity?
- Do you know when to call to make a diabetes clinic appointment?
- Do you know whom to call if you have an urgent diabetes question?
- Are you comfortable telling your diabetes team how you’re feeling and asking them questions or expressing concerns about your diabetes?
Helping Your Young Adult Transition to Adult Care

There are a lot of reasons why your young adult may be ready to switch to an adult diabetes care provider. Maybe he or she is moving to a new city for college or work and it makes sense to have a local provider. Some pediatric endocrinology offices will require the young adult to transition to an adult endocrinologist when they turn 18 or 21. Whatever the reason, you will want to do all you can to ensure a smooth transition. Why is this so important? Because young adults with type 1 diabetes have been shown to be at high risk for poor blood sugar control. This could be a result of competing life experiences as they transition from being a teen to a young adult, or due to decreased parental control when they go to college or otherwise move away from home. So helping them get an actively involved diabetes care team is really important.

What can you do? If your young adult will accept your assistance, you can help him or her to find a new adult diabetes care team.

- Whether your child will be staying local or moving away, ask your child’s current care team if they have any recommendations for referrals or where your child may be able to find them.

- When he or she does find a new endocrinologist, offer to help them transfer their medical records. This is an important step that often does not happen. In a recent study of adult endocrinologists, only one-third of the adult endocrinologists reported having access to the medical records of young adults entering their practice from the pediatric endocrinologist.
Helping Them Manage Their Own Diabetes

You’ve taught your child how to think when he or she makes decisions, how to plan ahead for potential struggles, and how to become a great problem solver. As children grow up and move away, parents and caregivers have to let them handle their own problems and challenges.

**But how can you do that without worrying?**

You will most likely always worry. But the best approach is to help your child develop other resources for support and problem-solving. If he or she is in college, perhaps he or she can find other students on campus who are living with diabetes (the college health center may be a good resource for this). These more experienced students with diabetes may be able to help guide them through the experience. There will probably be support groups near his or her new home or workplace. If your young adult is really struggling, they could always reach out to their old pediatric diabetes care team and ask them for help in finding a new one. Also, remind them to have their records transferred from their pediatric endocrinologist to their new care provider. This is a small but important detail.

**Encourage your young adult to be realistic in their diabetes care goals.**

Having realistic goals is important for living well with diabetes and to living well in all aspects of life. Remind them that blood sugar checks are not a test. Blood sugar numbers are important information that give them direction. They help answer questions, like: How much insulin do I need? Is it safe to drive? Do I still need to continue snacking to treat my low?

**Help them keep things in perspective.**

Rather than scold them over the phone about their blood sugar numbers, remind them to keep in mind that even people who have lived with diabetes for decades will often be surprised by unexpected blood sugar changes. Nobody’s perfect, but that also doesn’t mean to stop trying. So encourage your child to find a balance that works for them.
Diabetes and College

Before he or she heads off to college, help your young adult pack all their necessary diabetes supplies, which may include:

- A blood sugar monitor and strips
- Insulin pens or vials
- Syringes/pump supplies (reservoirs/insertion sets) if used
- A sharps container
- Emergency sources of sugar to treat hypoglycemia, such as glucose tablets
- Glucagon emergency medicine in case of severe low blood sugar
- Medic Alert identification
- Important contact numbers (make a list to share with the health care center)
- Prescriptions for diabetes supplies (e.g., glucagon emergency medicine, needles, test strips)

As he or she settles into college, there are a few things they need to do:

- Decide who and what to tell about their diabetes, such as their resident assistant (RA), professors, peers, and health center
- Visit student health services and find out how to access night, weekend, and emergency services
- Find the cafeteria and try to get nutrition information. They may also want to stock their dorm room with food they know is on-plan

Prepare a dorm room sick-day kit. Talk to your child’s health care team about what should be in his or her sick-day kit, but some of the items that are generally included are sick-day guidelines for adjusting insulin, ketone strips, a thermometer, and a supply of nonperishable items for sick days consisting of bland foods and clear, sugar-free liquids.

One great online resource to point them toward is collegediabetesnetwork.org.

Managing Diabetes in the Workplace

If the person with diabetes that you’ve been caring for is just starting their career, they may be wondering how to manage work life and diabetes at the same time. It can be done. In fact, many people already do it every day. However, it may be necessary for them to talk to their employer and ask that some adjustments, usually called “accommodations,” be made to allow them to take care of their diabetes while at work.

Some of the common accommodations for people with diabetes include:

- Breaks to check blood sugar levels, eat a snack, take medicine, or use the bathroom
- A place to rest until blood sugar levels become normal
- The ability to keep diabetes supplies and food nearby
- The ability to test blood sugar and inject insulin while at work
- If requested, a private area to test blood sugar or take insulin
- Permission to work a modified work schedule or work a standard shift instead of a swing shift

Find a more complete list on diabetes.org. There might be other accommodations needed. Suggest to your young adult that he or she may want to meet with their employer privately to discuss the situation.
Helping Your Young Adult Avoid Alcohol

Alcohol can make it very difficult to manage blood sugar and that can be dangerous. And the patient instructions for most insulins specifically say that alcohol use is not recommended while taking insulin. Also, the things that make alcohol dangerous for people who do not have diabetes—like blackouts, drunk driving, and using poor judgment—are only the tip-of-the-iceberg for someone with type 1 diabetes. The impairment that comes from even slight alcohol intoxication can cause someone with diabetes to make the wrong decisions about their treatment.

Please remind your young adult that:

1. Drinking too much can impair their ability to recognize and manage hypoglycemia
2. Alcohol can mask the symptoms of hypoglycemia, so people may let him or her "just sleep it off" rather than treating their low blood sugar
3. Drinking can also impair judgment, so your young adult may forget to take their insulin or forget to eat before going to bed
4. Drinking alcohol can increase the risk of low blood sugar (hypoglycemia), particularly later at night after drinking, but also for up to 24 hours after drinking

Insurance Before and After Age 26

Health insurance coverage is confusing enough for just about everybody, but the ins and outs of coverage for young adults seem even more so. Some of the issues for young adults include:

- Some managed care plans may not cover nonemergency expenses that are out of the plan’s geographic coverage area. If they are thinking of attending an out-of-state school or living far from home, it’s important to check their coverage

- Some college-sponsored health plans may not cover preexisting conditions (such as diabetes) or the cost of outpatient prescription drugs (including blood sugar monitoring supplies). So before enrolling them in such a program, it’s important to check for these limitations

- Under the Affordable Care Act, if your health care insurance covers your children, they can stay on your policy until their 26th birthday. After that, they qualify for a special enrollment period

For more information about insurance coverage and the Affordable Care Act, go to hhs.gov.
CONCLUSION: FINDING THE SUPPORT YOU NEED

Caring for someone with diabetes is easier with the support of others. There are several places to turn to in order to learn more about diabetes and get the help you need. Joining a diabetes support group can be a good idea. Many diabetes support groups meet in different local settings, such as hospitals, community centers, and churches.

Diabetes magazines and websites are good resources for blogs, videos, and helpful food and lifestyle tips. Check the local library for magazines that can be read for free. If you haven’t yet, visit type1.cornerstones4care.com and jdrf.org for a ton of helpful information!

The health care professionals who care for your child, also known as the diabetes care team, can also be an important source of support. They can help you find out about a number of things, including:

- Follow-up care
- When and how to get emergency care
- How to get help (if you need it) paying for diabetes supplies and services

And don’t forget about yourself! Taking care of someone else takes time and energy. If you’re not taking care of yourself, you can’t take good care of anyone else, so make sure you get the support you need.
Here Are Even More Resources for Your Child’s Type 1 Diabetes Journey From Novo Nordisk and JDRF

This booklet is part of the "My Life, My Diabetes, My Way" educational series for people with type 1 diabetes. There are other booklets in this series, brought to you by Novo Nordisk and JDRF, that may be of interest to you, your family, and friends.

➤ Meet Dot: Your New Friend
Recommended for young children, ages 2 to 6

➤ Conquering the Elementary School Years
Recommended for school-age children, ages 7 to 11

➤ Type 1 Diabetes 101: Getting Started, Staying on Track
Recommended for those ages 13 and up newly diagnosed with type 1 diabetes and their family and friends

Ask your child’s doctor for your FREE copy of these and other type 1 diabetes booklets today! They are also available online as free PDF downloads at t1support.cornerstones4care.com.

Additional type 1 diabetes resources can be found online at:
jdrf.org diabetes.org
typeonenation.org type1.cornerstones4care.com
childrenwithdiabetes.com

Remember, these booklets and resources are for educational purposes only. If you have any questions about your child’s diabetes care, be sure to ask his or her diabetes care team.