

# Teen Toolkit

Navigating the teenage years with type 1 diabetes can be difficult. This guide can help parents and teens make the journey a much more pleasant—and even enjoyable—experience.



*Eloise, diagnosed at 18 months*

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# Introduction

For many parents, the teen years loom ahead like some giant shadow. Even the most confident, involved family worries about how they will maneuver the teen years.

JDRF understands, and hopes with this toolkit, parents will find a starting point and what to expect and how to deal with the many issues facing teens with type 1 diabetes. From driving to drinking to hormones to newer school issues, we try to help you think ahead, plan ahead and be ready.

But remember, this is a toolkit meant to be used with other programs. Reach out to your JDRF chapter and find out about meet ups for teens with diabetes and for parents of teens and for advocacy programs to make all of you feel like you are making a difference.

The teen years do pass, and with some special care and work, we make it through. That's why there is no Walk to Cure Adolescence. The cure is thoughtful action, some patience, and of course: time.



# Welcome to the Teen Years

*It's coming. Adolescence. And while there is no way for any child to avoid it, when type 1 diabetes (T1D) is involved, it can create a whole new level of confusion, challenge, and worry—for the parent and the child.*



It's coming. Adolescence. And while there is no way for any child to avoid it, when type 1 diabetes (T1D) is involved, it can create a whole new level of confusion, challenge, and worry—for the parent and the child.

Some parents have an older child without T1D whom they have ushered through the teen years. Those parents are able to discern what goes on in the adolescent body and mind and understand those times when hormones may be playing games. While it still can be an extremely challenging time, those experienced parents are able to think, “I’ve seen this. I’ve survived this.” But for parents whose oldest child has T1D, adolescence can be a time of even more confusion. They ask themselves, “Is it the disease or is it puberty?”

Unquestionably, T1D adds a new layer onto everything. The trick, and the challenge, is to understand what goes on in the adolescent body and then try to understand how T1D may, and may not, impact that. As for the adolescent mind, that's a whole new level of T1D understanding—and a source of confusion. The other trick, for the parent, is to know when to hover and when to back off. For the teen, finding a way to understand that your parents care about you is the challenge. For both teen and parents, these are no simple tasks.

## Signals of the changing times

Wouldn't it be nice if we had a signal to tell us when puberty begins? Puberty, like T1D, is different in every single child. But there are guidelines you can learn and expectations that you can be ready for.

Type 1 diabetes takes on a new life in the teen years. Whether you are dealing with a new diagnosis or continuing a long-running relationship with the disease, everything that makes teens the unique creatures they are complicates the disease structure. It takes patience, adaptation, and sometimes a bundle of help and support to get through those years.

If your child has had T1D for a number of years before adolescence and has been managing well with the disease, you may feel that she will not face a struggle as she gets older. Then again, if your child is new to T1D as the teen years approach, you may hope that a lifetime of healthy habits and cooperation ensure that T1D management will not present a challenge. But it's often the case that with teens attitudes change and so does T1D self-management.

## Teens with established type 1 diabetes

For children who have been managing T1D for a long time, the teen years can be particularly difficult. Part of the issue can be T1D “burnout.” This can happen at any age, but it can be prompted by your teen now wanting to be even more like her peers. All kids grow past the phase of always wanting to please you, and other important adults in their lives, to thinking they know more than any of us do. When your child brings that mindset to curfews or homework demands, it can be stressful enough. But when a teen at this stage has to manage a life-threatening disease, it's a whole new level of worry for parents.

Shifts in attitude and actions usually emerge around the age of 12 or 13—just about the time that children are truly becoming teens. The girl who once simply clipped her pump to her belt buckle and let it hang out there now painstakingly finds ways to hide it. The boy who whipped out his meter on the sidelines at Little League now wants to check his blood sugar in the car and not bring his meter with him to the playing field. Kids who once complied with your every order to do a bolus, check blood glucose, or eat a snack begin to question your requests, or, worse, ignore and avoid you.

A worrisome part about teens who have had T1D for a number of years is that they have learned the ins and outs of disease management. When it comes to T1D, it takes some time and experience to figure out how to outsmart your parents and even your diabetes equipment. Most newly diagnosed teens do not consider manipulating a meter to show a different number or to not check blood sugar at all. However, kids with long-established T1D have been known to do this.

For kids with longstanding T1D, they may suffer from the rest of the world being “over” their disease. If in their first years with the disease their friends donated to their JDRF Walk team or offered to help, that attention may have diminished. It can be the case that while our children never reach T1D “remission” and never get a break from their disease, the rest of the world tends to move on. If this is the case, try to find a new way to make your child feel that people care. A feeling of “getting over it” from the rest of the world could lead your teen to feeling like she should be “over it,” too, when in fact, T1D is a continuing marathon.

## Newly diagnosed teens

It's a question kids with T1D debate all the time—is it easier to be a teen who does not recall what it's like to live without diabetes, or easier to be older when you begin this new life? Some say that if you don't know anything different, it has to be easier to accept; others say not knowing anything different makes it harder to accept. Whichever you believe, everyone agrees that adapting to a new disease and new lifestyle smack in the middle of the teen years can be rough.

First, as a parent, your teen is not in your constant care. While a small child with T1D tends to be in the capable hands of a caring adult at all times, teens spend more time on their own. They're at sports practice, hanging out with friends, or just in their room with the door shut. They're beginning to create their own world, and the invasion of a parent nagging, “Are you low? Are you low?” can be a nuisance.

When teens, who want to feel independent, are diagnosed with T1D, they often find themselves in a place they dread—having to rely on their parents again. Some teens will be aggressive about taking on the responsibility right away. Here's a tip: even if your teen is mature, it's still important for you to learn all about T1D management, too. There will come a time when he needs your help, and knowing how to give injections, count carbohydrates, test blood sugar, and the multitude of T1D-related responsibilities will only help you.

As you explore this guide, keep in mind that although your teenager may protest, he or she needs you. Big time!

# The Physiology of the Teen Years

*Adolescence with T1D may be more stressful and may take more thought, but teens go through these years and emerge as positive young adults.*





These are the times of change. And that means in a physical way. Parents all wait—usually with some concern—for puberty to appear in their child’s life. When T1D is added, it can be particularly worrisome.

But parents should realize that millions of adults have lived through adolescence with T1D. It may be more stressful and may take more thought, but teens go through these years and emerge as positive young adults. As your child’s puberty begins, it helps to know what to expect.

## Navigating the signposts of puberty

For girls, medical professionals consider the beginning of puberty to occur between the ages of 9 and 13<sup>i</sup>, on average. Hormones, particularly estrogen, begin pumping through the young girl’s body and nudge changes to begin. First signs usually include the development of breast buds, an increase in hair on arms, legs, underarms, and genital areas, and a more rapid increase in height and weight. Another sign is body odor. The first time your child needs deodorant, you can pretty much know you’re into puberty now. As for menstruation, medical professionals regard the average age of commencement to occur between the ages of 12 and 13<sup>ii</sup>.

For many teenage girls and their parents (and/or caregivers), managing T1D routines during a menstrual cycle is a whole new scenario. Some girls experience changes that affect their T1D management during menstruation. They may need more or less insulin than usual. A smart thing that parents and teens can do is to check blood-glucose levels regularly during menstrual periods and, over time, compare the numbers to look for patterns. The more information you gather, the better off your teenage daughter will be during this time. She may not like to do this, but just explain to her that by gathering information, you can help her learn how to simplify her T1D management during her menstrual period. It’s also important to keep a food log during menstruation. This will help inform your teen’s medical team and identify any changes in basal or long-acting insulin that may be needed during a menstrual period.

For boys, the kickoff to puberty usually begins between the ages of 9 and 14, and the hormone that is a driving force at this time is testosterone. Growth in height and weight is a good first sign, as is a visible broadening of the shoulders. Increased testosterone production affects the larynx, which causes the voice to crack and then deepen. Boys will also develop more hair—on their chest, arms, legs, armpits, and genital areas.

Both boys and girls often experience an increase in appetite as puberty begins. This means, of course, an increase in insulin requirements for meals. It’s important to know that both the growth of a teen’s body and the hormones responsible for this growth can affect insulin needs at the same time. In most cases, the result is an increase in insulin needs. For example, parents who once managed their child’s eating with a ratio of one unit of insulin for about 30 grams of carbohydrates are surprised when suddenly the same child needs one unit of insulin for 10–15 grams of carbohydrates. Clearly, the challenge for parents is to keep up with which increases are due to more food and which are due to changes in the growing teen’s body. And it is indeed just that—a challenge.

So what exactly does puberty do to T1D overall? According to medical studies, teens have an average hemoglobin A1c level that is one percent higher than that of adults<sup>iii</sup>. As a result, they typically require more insulin. To complicate matters, the sex hormones (estrogen and testosterone) that are the hallmark of puberty work against insulin. While insulin lowers blood glucose, sex hormones raise it. Stress hormones, such as cortisol, also raise blood-glucose levels, and there can be a significant amount of stress experienced by a teen. In addition, during puberty, insulin action decreases by 30 to 50 percent, which also contributes to high blood-glucose levels<sup>iv</sup>.

Puberty is also a time when kids would much rather be with their friends than deal with T1D. This can make it difficult to figure out if it is the impact of puberty or the result of your child not doing what he needs to do to manage his blood sugar (or both) that is causing a high level. For the multitasking parent, this may be hard to accept, but teens also have a lot on their minds. Their preoccupations can lead to forgetting boluses/injections, blood-sugar checks, necessary supplies, and more. While trying to prepare children with T1D for independence, parents also have to make sure that they have everything that they need. In other words, your sometimes-surly child who thinks you know nothing actually needs you to make sure he is safe and has all the resources he needs to stay safe. It really can seem like you are walking on a tightrope.

One thing is for sure, children in puberty do need increased daily insulin. If you or your teen sees a sudden unexplained spike in numbers, it’s probably time to talk to your medical team about this and come up with a plan. This guide emphasizes that it is imperative to include your teen in every part of the process that impacts his T1D management. If you can engage him in decision-making early, he will have a



better understanding of what is going on. This understanding may help soothe him when he is upset or despondent about blood-sugar levels that seem out of his control. Explain to him (and yourself) that taking more insulin during puberty is expected, important, and all-around acceptable. He may worry about gaining weight from the additional insulin that is needed for good control. Explain to him that taking the amount of insulin his body needs to keep his blood glucose in a safe and healthy range does not lead to weight gain. As long as he is making healthy food choices and being physically active, his weight should stay in a healthy range. Encourage your teen to discuss this concern with his diabetes professional, such as an endocrinologist or certified diabetes educator (CDE). During high school and especially college, teens can find themselves eating a lot of junk food, taking even more insulin, and gaining a lot of weight. This can be a vicious cycle that is hard to break, which is why it's important to have an open and ongoing discussion with your teen's diabetes professional.

## Mood swings

Mood swings are something to expect in all teens. And when you add the possibility of wildly fluctuating blood-sugar levels, these swings can result in a flare in temper or other less-than-desirable behavior.

The challenge for parents is to know when a blood-sugar fluctuation is or is not the cause of your child's mood swing. It's important to not immediately "blame" a mood or outburst on T1D. The challenge for teens is to learn how to control these mood swings.

Some teens like to say they should not be held responsible for what they say during a high- or low-blood sugar-related mood swing. But here's the thing: you are raising your child to function in society. Someday, he'll be out in the world, at work, in college, or just at the local store, and may feel a "rage" coming on that is induced by high blood sugar. He needs to learn to recognize that a high—or a low—is affecting his behavior and then find a way to work around it. If you have taught him how to remove himself from a situation, fix what is wrong (take insulin or have food), and then wait to respond, you have done a great job.

## Daily type 1 diabetes management

Both parent and child are going to experience frustration during the teenage years. T1D is a marathon, not a sprint. Ask your medical team for some guidelines that are reasonable for a teen in puberty. Parents may need to back off a bit on the kind of diligent control they were able to have when their kids were little. And teens may need to find a way to give an extra bit here and there. Teens care about their friends, their sports, and their social life. Remind her that taking care of herself and feeling well directly impacts those interests. Even if she complains about feeling "different" at an age that most kids want to feel "the same," let her know that taking better care of her T1D actually makes it less of an issue.

Help your teen focus on what is important right now and explain that maintaining a safe, healthy blood-glucose level will help her to achieve immediate goals. If her blood glucose is too high or too low, she may not be able to do the things that she loves. If her blood glucose is well-managed, she will not have to feel "different" when she is with friends.

## Looking toward the end of puberty

There is no quick "off switch" for puberty, and some research has suggested that the effects of adolescence, from the workings of the mind to the growth of the body, can actually extend beyond the teenage years. Parents should expect that a child with T1D will need their support for a lifetime, especially until he is truly an adult. This time will come. It will seem like forever as you inch toward it, but one day the child with T1D will be the adult, and much of the angst of puberty will be in the past.

# Keeping Communications Open

*Teens may open up at the most random times, and parents need to be ready and available, no matter what.*



Families that are managing T1D often find that communications begin to break down as a child enters the teen years. As much as you may raise your child with the mantras of “you can tell me anything” and “honesty is always a better choice,” the teen mind switches that off. Conversations that once went smoothly seem full of uncomfortable traps. It’s not easy for any family in these teen years.

Remember that the goal of communicating about T1D is to keep the teen safe and healthy. Parents need to be open to the possibility that their access to information could shift a bit. Teens need to accept that, at the end of the day, they are still their parents’ children, even if they need a little outside help in the communications area.

Teens may open up at the most random times, and parents need to be ready and available, no matter what. If your teen suddenly asks you a question or starts talking about something—even if it doesn’t seem important to you at the time—drop everything and simply listen. Don’t ask questions or overreact. This is one of the most effective ways to show your teen that you can be trusted and that you care about what matters to him or her.

## At medical visits

You’ll notice that endocrinologists and diabetes educators often want to meet with your teen alone first, and then invite you into the room. The first time that this happens, it can be jarring. But really, the medical team is doing what needs to be done—giving your teen some space to communicate without worrying about what a parent thinks. In these situations, it’s important to realize that your teen, deep down, probably wants to protect you and not disappoint you. Often, teens fear that they will lose your love and support if they confess to something you might not like. As much as you tell a teen over and over that this could never happen, they have not matured enough to trust that. So if being able to talk something through with the medical team first helps, all the better. Plus, your teen is moving slowly toward being an adult who deals with his or her medical care alone. When that first independent appointment comes, embrace it. Most times, teens end up telling their parents what went on at the appointment. And if they don’t, rest assured that it is the medical team’s professional responsibility to keep your child safe and healthy. If there was something you needed to know, they would contact you.

Savvy parents may want to offer that their young teen attend the appointment alone, before the medical team makes the suggestion. Showing you’d be willing to trust your child with some private time with his or her healthcare provider might

win you some respect. And teens who are willing to share most of what went on in the private appointment might win extra trust, too. It works both ways.

You are still at a point where the results of your teen’s lab work (and in most cases a doctor’s written review of the appointment) will come to you. You can let the teen read the results first and then read them on your own, or read them well before you are going to see your child. This way, if there is something like an elevated HbA1c that surprises you, you’ll have time to prepare your response.

You can also call your teen’s medical team for a follow-up discussion. It’s a good idea to let your teen know if you plan to do this. Even if you don’t want to worry your child, he should know and will not see it as sneaking around behind his back.

Make sure that your teen has a healthcare provider whom she is able to relate to and communicate with comfortably. If the present provider is not a good fit, it may be time to find a different one. It is important for your teen to feel comfortable about being open with and taking guidance from her diabetes health professional. If your child really likes her general practitioner, you can always have that person stay in close contact with the endocrinologist, and have your teen meet with the general practitioner. Talk it over with your teen.

Of course, parents need to let teens know that at the end of the day, it is the teen’s relationship with the healthcare team that matters. Communicate openly with your teen that if he does not like a healthcare provider (even if you feel differently), you will find a new one. Hearing his concerns shows that you respect his feelings.

## In day-to-day life

Probably one of the biggest challenges that parents of kids with T1D face is how not to ask about their T1D first. As much as parents may think, “child first, diabetes second,” T1D is always on our minds. It’s understandable that you may forget to ask first about the math test or the field trip. Some teens have even said they can tell when their parents are “fake waiting,” in other words, asking three other questions and then asking, “how is your blood sugar?”

Sometimes, it’s better to ask without using words. Meters and pumps have all the answers you need on them. Set a rule that the meter must be placed, for example, on the kitchen counter each evening. Then find a time each day when you can look at it alone, and get your answers. But remember to react calmly to the numbers. Let’s say you look at the meter and see that your teen did not check at all that day. Instinct makes you want to

scream. The better solution is to calmly sit down with her and say, “Today must have been really busy at school. Can we figure out how you can check at least X times tomorrow?” As hard as it is, don’t show anger. Make sure your teen knows that you, too, blow things off some days, and that the next day is a new day.

When your teen is heading off to a sports event, a party, or just to hang out with friends, it’s also instinct to want to verbalize a T1D plan with him. It’s fair to ask, “You have your cell phone and meter, right?” and ask him to shake the test strip bottle since even you forget to replenish that from time to time. But as far as how to handle his T1D while he is out, you have to start to trust him. Give him the chance to succeed. If it is an unusual event, it’s fair to suggest you discuss a plan. But for regular day-to-day life, let him give it a try and see how he does. You can always look at the meter to see the results.

The teen years may be a time when the level of care the parent gives has to adapt to the life of a teen. There is usually an opportunity in a meeting with your teen’s medical team to discuss goals and priorities. Let the teen and the medical team work out a daily plan, as well as special plans for things like sports events or outings, that the teen feels she has helped to create and bought into. Even if it’s not exactly what you as a parent would want, if the teen agrees to it and the medical team says it’s perfectly fine, your teen might be less apt to blame you for forcing her into a T1D routine that she is not happy with.

## Dishonesty

Often, teens with T1D are dishonest about their numbers or their boluses. And they know how to manipulate their meters, too. They don’t do it to be bad. They do it to try to protect you. (See “Dangerous behavior” on page 29 for more.) How does a parent encourage a teen to be open and honest about T1D care? Why would she not be honest? Well, let’s say a teen decides she just does not want to check her blood sugar one morning. So she does not. But she writes in her log book, or manually enters into her pump, a number. Then she moves on, simply wishing the entire moment away. The same goes with boluses for teens who use pumps. A teen might forget to bolus, or choose not to, and then claim his site was bad or the insulin was at an unsafe temperature.

Here are some tips to watch for if you suspect that your teen is being dishonest:

1. **Lost meters.** Teens who may have skipped checking will simply hide a meter. Often this might happen just before an endocrinologist appointment.
2. **Frequent claims of needing an injection site change.** If you notice lots of blood-sugar highs being blamed on site changes, watch carefully.
3. **Control solution bottles out in plain sight or running out quickly.** Some teens will use control solution rather than blood for a check. Some parents keep the solution in a place that the teen doesn’t know about just to remove that chance.
4. **Numbers that appear too good to be true, too consistent, or numbers that don’t match up with the A1c.**

How do you respond if your teen is dishonest about his T1D care? Set aside your own hurt or shock, for the sake of your child, and work to find a solution. Let your teen know that you know things are not as he has told you. Tell him you are not angry with him, but you want him to get help to figure out why he did it. Some teens may not seem to understand the simple truth that the only people they hurt by lying are themselves. Make an appointment with the diabetes educator or endocrinologist, whomever your teen communicates with best, and let him go alone to speak to this person. He should come out with a plan or solution, and then put that to work and see if it helps. In the meantime, parents should be sure to visibly watch their teen draw blood, see a number, and then inject insulin at least one time every single day. If you see that happen, no matter what the number, you’ll know your teen has insulin in her body to ward off diabetic ketoacidosis (DKA).



## When you are not enough

What if your teen just simply cannot talk to you about diabetes or be honest with you? Then it's time to let someone else help out. There are a lot of places teens can find to vent and talk about their diabetes, and honestly, so long as they are talking to someone responsible and caring, it's better than not talking at all. Some ideas include:

- An older friend with T1D. Maybe it's someone with the disease who was his camp counselor, an older cousin, or someone you were introduced to, whom your child respects. Encourage this relationship. Having someone who “gets it” listen to him can be key to keeping healthy as a teen with T1D.
- Your JDRF chapter. Many JDRF chapters have mentors, support groups, and other outreach programs to support families that need a helping hand with T1D. JDRF also offers online resources that might be helpful. Our Online Diabetes Support Team (<http://jdrf.org/life-with-t1d/get-support/>) is a group of volunteers with a T1D connection that can provide firsthand advice to assist you through a difficult time. TypeOneNation ([typeonenation.org/](http://typeonenation.org/)) is an active online community with thousands of people who are touched by T1D.
- A counselor. If you can find a counselor your teen likes who is located in a place that does not interfere with her life too much, this can be a great asset. You should tell your teen and the counselor that you only need to know information that might put your child in danger. Other than that, it's your child's relationship to use for her benefit.
- Some communities have a partnership program for kids who just need extra support or friendship. Kids who have been through divorce, trauma, or other loss often benefit from these programs.

It's not easy, but the good news is that teens grow up. And when they do, they say things to their parents like, “You sure were right about that.” It just takes patience to get there.

# The Taste of Freedom

*A funny thing happens when hormones come to town. Teens—even preteens—begin to think they know more than their parents. T1D takes a backseat and, as hard as a parent can try to keep diabetes in the forefront, it can be a challenge for most.*



For families who have been managing T1D for a long time, things can seem to go along well for years. Smaller children like to please their parents and seldom question what they need to do. Parents have a tendency to think they've raised a child who lives relatively at peace with his T1D and who understands the implications of not doing the right thing, diabetes-wise.

It's a fair assumption. Because really, in almost every case, the parent has done the right thing and the child has embraced their guidance. But a funny thing happens when hormones come to town. Teens—even preteens—begin to think they know more than their parents. They shift to a place where they care more about the immediate, be it the game that day, the party that night, or what their friends are saying. T1D takes a backseat and, as hard as a parent can try to keep diabetes in the forefront, it can be a challenge for most. The tricky part is that while parents understand the absolute necessity to maintain diabetes control, many teens feel indestructible—so it's possible that your teen may not consider having T1D to be a big deal.

It can happen slowly. Your teen might skip one blood-glucose check and tell you she forgot her meter. Or she might say she checked and make up a number. Then, she eases into doing it more and more. It can get to a point where T1D management becomes a battle, a battle the parent loses more times than wins.

So what's a parent, and a teen for that matter, to do? For the parent, start with trying to understand what is going on in your teen's mind. In almost every case, this is not about him not wanting to be alive, or not wanting to do his best, or not wanting to please you. Put simply, the long-timer teen with T1D just wants to be free of it all. Call it burnout if you wish. But what it really is might just be a hunger to feel what it's like not to think about T1D all the time. Unfortunately, that could mean high blood-sugar levels and the risk of DKA.

Being ahead of the game can help. Some hints as your child eases into the teen years with T1D are:

**\*Don't ever say, "Not my child."** No matter how well you've raised her and how much she's cooperated all those years, there is the chance of your child struggling in the teen years. Embracing that is a first step toward keeping her safe through those years.

**\*Stay on top of things.** This is not easy with teens. With sports and jobs and social lives, they often leave the house early in the morning and don't get home until after the sun sets. But if you watch your child actually check his blood sugar and administer insulin at least one time a day, that should reduce the likelihood of him having a hospital DKA situation. (So long as some insulin is in the body, severe DKA should remain at bay.) Plan a time each day when you are both always in the same place, and work it out so a blood check and insulin dose is done at that time.

**\*Take the "dishonesty" out of the equation.** It's hurtful on many levels when a child with T1D lies to a parent. You've preached honesty all her life, and lying adds another layer to the entire diabetes situation. So how do you remove it? Ask the machine, not the teen. Instead of asking, "Did you check at lunch?" or "Did you bolus for that snack?" let your teen know that you will be checking her meter, pump, or both. Let her know you are not checking it to judge, but just to keep track, since it is your role as a parent. Once a day (or once every couple of days) take the meter and the pump (if your teen uses one) and review it. Your challenge as a parent is to not react in a negative way. Remember what they told you back when your child was diagnosed: a number is not good or bad. It's just information. Use it and don't judge it. In fact, any check is a success. So while you should steer away from negative judgment, do reward any activity you see. For instance, say, "That's great you found the time to check before field hockey practice. I know how rushed you are at that time of day."

**\*Work off of one meter.** A backup meter at the nurse's office is fine, but other than that, using one meter keeps things clean. Your teen cannot claim to have done the check on that other meter he left in his locker. If your teen needs a reason for using one meter, you can let him know it's easier for the endocrinologist's office to download information from just one meter. If your teen is on a continuous glucose monitor (CGM), you should stick with the one meter rule for backup checks and recalibrations. Of course, you won't have to worry about more than one CGM, since that one loads all its information to the same place automatically.

**\*Consider a new plan.** As much as we like to check our kids as often as possible, sometimes a good thing to do is have the teen sit down with her endocrinologist or diabetes educator and come up with a plan she feels is reasonable. By making it between her and the medical person she respects, it's more her choice and her idea (although at this age parents absolutely need to be aware of what the plan is and in on the final decisions). What if your teen told her doctor she would not mind checking five times a day, and also before games? If the doctor and your teen are in agreement, it might be a good step toward your teen feeling she has freedom to decide her plan and was not forced into it. As challenging as it may be, try to let your teen and the healthcare team steer this effort, with you as the willing and cooperative participant.

## Who does what?

Remember how proud you were the first time your child checked his own blood sugar, gave his own injection, or changed his own pump infusion site? Yes, it's an amazing thing to see your child take control. But it could very well be that this praising is not what is best for our children and that moving toward freedom is more nuanced. Because some kids—even teens—don't necessarily want total control, and, in fact, may be safer without it.

## Rules, regulations, and diabetes

It's not unfair for parents to set rules that take T1D into account. After all, it is your job to keep your child safe, and when it comes down to it, whether a teen likes it or not, T1D makes things just a little more difficult. That said, there are places you can bend and places you cannot bend. Showing your teen you are willing to accommodate her wishes within reason can help. Here are some situations and ideas on how to handle them. Because while it's nice to be able to say, "She has to do her homework, the same goes for her T1D care," diabetes care brings an entirely different feel to the situation.

**\*Sports, band, drama, and other out-of-school activities:** Being a part of a group, be it for sports, music, or anything else is a commitment to the entire team. It is your child's duty as a team member to be at his best and do all he can for the team to succeed. With T1D, this means trying to stay on top of what is going on T1D-wise. It's fair for you as a parent to set up guidelines with your child, such as you must do a check just after school or before the practice or event, or you must be sure to have the supplies and glucose you need with you. Compare it to what the coach demands of the players on a team. You must attend most practices (or have a good excuse why you could not). You must remember your uniform and equipment. These are rules to play. You, too, can set rules to play as well. Just make sure you are reasonable about them, and do allow for some not-so-perfect episodes. Diabetes is not easy, and you don't want your teen to resent it even more if he goes through a hard time. It's important to note here: kids forget. Kids mess up. Be willing to back him up if he is in a bind.

**\*Parties and sleepovers:** They are just so unavoidable. And the reality is that your teen will be out of your direct control and around all kinds of temptations for as long as 24 hours. You don't want to deprive your teen of a fun social invitation, but you need to keep him safe. For parties, be sure your teen checks his blood sugar after or late into the party. Grazing is tough for anyone, and you really cannot expect your child to count out chips into his own bowl at a party. Instead, try to show him how to come up with a plan, do his best, and learn to correct quickly afterward. Sleepovers are a different scenario. Some parents of teens with diabetes simply opt to offer to always host them in their own home. But if you do want to allow your teen to go to them, as much as your teen might not like it, someone there has to know that your teen has T1D. The parent in the home simply must know what is going on. Give your teen the option: he can tell the parent or you can. From there, set goals for your teen for the night and see how your teen does. It's hard to let go when you've been in charge of his diabetes care for so long, but your goal is to raise a confident, happy, independent person who happens to have diabetes.

It's helpful to think about giving a teen the freedom he wants by allotting it to him in small increments. This can be challenging for parents who have been in control of their child's T1D management since diagnosis. But in the end, if it helps him not to rebel, it is truly all for the best.



## Continuous glucose monitors

More and more parents are helping their teens use continuous glucose monitors (CGMs) to help manage their T1D. CGMs are excellent tools and can help track how hormonal swings, sports, and other factors might impact blood sugar. It is important to note some things with teens and CGMs:

1. CGMs are complicated tools, and teens need their parents to be copilots in using them. Make sure you, as a parent, are active in the training and daily use of the CGM. It's easy at this age to let the teen take over (particularly since teens are more tech-savvy than most adults), but don't let that happen. You need to understand the working of any tool that your teen with diabetes is using, and you need to be an active part of using it.
2. CGMs do not replace blood-glucose checks. Teens can tend to think they should. After all, there your blood sugar is, trending on a graph right in front of you. But CGM usage still requires finger-prick blood checks. Make sure your teen's endocrinologist or CDE makes that clear from the start. And a CGM reading does not ever replace a blood-glucose check before driving. Ever.
3. There is a lot of information on a CGM, and how you and your teen use it is key. Don't let too much information cause you to overreact to daily care. Instead, work with your endocrinologist or CDE to learn how and when to react, and how to use the trends over time to finetune your teen's diabetes care.

Overall, CGMs can be great tools for teens. They are new technology and that can sometimes be enough to motivate a teen. And it can help you find clues to make things better in his daily care.

# Diabetes and Teen Friendships

*Type 1 diabetes adds another layer to everything in the teen life. As if social situations and friendships weren't tricky enough in the adolescent years, T1D can make them all the more so.*



Type 1 diabetes adds another layer to everything in the teen life. As if social situations and friendships weren't tricky enough in the adolescent years, T1D can make them all the more so. For the newly diagnosed teen, there is the question of whom to tell and how. And even for teens who were diagnosed as young children and who educated all their young friends, what to talk about and when gets trickier as a teen. Most teens just want to be "normal." T1D complicates that in their eyes.

## Who should know that a teen has type 1 diabetes?

To make it simple, everyone should know. Like it or not, teens need to let the people around them know they have T1D. And the people around them need to know how to act about it as well. The reason, first and foremost, is safety—if everyone knows you have diabetes, should there ever be an emergency, whomever you are with will know it might be diabetes-related. The reasons are more intrinsic, too. If everyone around you knows you have diabetes, it actually becomes less of a big deal. But how does a parent get a teen to let others know? Here are some situations to consider.

### The newly diagnosed teen

It's unlikely that a parent will be able to come into her teen's school and give her class a lesson about T1D. And while it is the parents' role to let the school staff know about their child's disease (see "School and the Teen with Type 1 Diabetes" section on page 22), it really is up to the teen to let her friends know. In some cases, the teen may have been hospitalized, which can actually make a useful opening to let people know. But in many cases, teens with T1D can be diagnosed and start on their diabetes plans while only missing a day or two of school. The best thing for the newly diagnosed teen to do is to gather her closest friends and give them an overview of "T1D 101" in her own terms. Remember, many of her friends may have heard mistruths about both T1D and type 2 diabetes (since most people's experience is with type 2).

Perhaps there could be an opportunity to invite friends to your home and provide an explanation about what T1D is and what is involved in managing the disease. In sharing some of the basics about daily life with T1D, your teen can let her friends know that:

1. She is going to be fine. While T1D is complicated to treat, it is treatable.
2. T1D is not contagious, nor did the teen do anything (like eating poorly or having unhealthy lifestyle habits) to get it. It's important to stress that.

3. She will be injecting herself with insulin, checking her blood-sugar levels, and possibly using an insulin pump. The teen should ask her friends to try to think of it as no big deal, since that is what it needs to be.
4. The teen can still eat anything, as long as she works it into her diabetes management plan.
5. The teen can still do any sport, attend any event, and live life just like any other teen.
6. The best thing her friends can do for her is to learn about T1D and be supportive.

For teens who need help communicating about their T1D to their friends, JDRF can help. JDRF's online community, TypeOneNation, features an "Educating Others" resource center that's perfect for teens who want to talk to their friends about T1D: [typeonenation.org](http://typeonenation.org). The resources are presented in a fun, humorous, and nonthreatening way and include lots of illustrations, so teens should feel comfortable sharing them with their friends.

While parents need to let the teen do this communication on his own, it's a good idea for the parent to give a call to their teen's closest friends' parents and give them a briefing on the above as well. Encourage the parents to come to you with questions before making any judgments or having any major concerns.

### The teen with established type 1 diabetes and new friends

Our kids' social circles evolve as they grow. Particularly in the teen years, new friends come along frequently. A teen with T1D doesn't want to start a friendship by saying, "Oh, and I have this serious disease that I have to manage and take care of all the time." But at the same time, taking out a syringe and injecting insulin in front of an unknowing friend is not really fair to the friend. The best thing for the teen to remember is, again, once someone knows, it is less of a big deal. For a teen who is hanging out with a new friend, when it comes time for a blood-sugar check, insulin injection, or insulin pump check, it can help to simply explain that he has T1D, that it's not a big deal, and that he has to check blood-sugar levels and take insulin regularly. It's good to encourage friends to ask questions whenever they have them. Let them know it's not a taboo subject.

For the teen with T1D who moves to a new school and has to make an entirely new group of friends, circumstances can be more challenging. The details of letting the new school know about the teen's T1D (covered in the school section of this guide), along with sharing the information with new friends can be tough. It's difficult to be a new kid at a school, and adding T1D to the mix can make it more awkward at times. Teens should be encouraged to be open about their disease, as detailed above. Parents should be on the alert, too—a new school and new situation could be a time when a teen is tempted to skip a check at lunchtime or does not want to do a bolus in front of people. Encourage your teen to be open. But let her know if she doesn't want to do what she needs to do to manage her blood sugar in front of people, the nurse's office is always an option. That said, she should still let her new friends know why she is going to the nurse daily. The school nurse may also be able to introduce your teen to another student in the school with T1D.

## Dating and type 1 diabetes

Even for teens with years of T1D life under their belt, talking to a date about it or even managing it in front of the date can be awkward. Dating is an entirely new world for teens and often an important one for them. Some teens already secretly harbor the (silly) notion that someone might not want them because they have T1D and are “damaged” in some way by it. Parents of kids with T1D need to be sensitive to the fact that their teen might be feeling sensitive about the subject. It's fine to ask your teen if his date knows he has T1D. If the date does not know, remind your teen that at some point during the evening he is going to have to check his blood sugar or take insulin. While he does not have to let the date know ahead of time, he does owe the date a simple explanation just before he does what he needs to do.

If a teen gets more serious in a relationship, she should be willing to share more. It's not easy to convince a teen of this, but again it cannot be said enough—the more others know and understand about T1D, the less of a big deal it will be. One teen tells a story of her former boyfriend and prom date. He fully understood that she had to check her blood sugar frequently on prom night and probably was not going to want to. Knowing she would always check her cell phone for texts and knowing her meter was in her purse with that cell, he discreetly texted her, “how about a quick check?” The teen opened her purse, read the note, and saw her meter right there. “It was the most discreet, sensitive, and caring thing to do,” she says. Had her date not understood what was needed for her T1D management, he may not have had the opportunity to make it easier for her that night.

## When friends interfere

Sometimes a friend may try to “parent” the teen with T1D. Often, out of concern for their friend, the teen's friends will say something like “should you be eating that?” or “have you checked your blood?” Teens should try to remember that, like their parents, their friends care about them. Try to encourage your teen to not get too angry at these actions and to communicate his feelings with his friends. TypeOneNation's “Educating Others” resource center can help here as well ([typeonenation.org](http://typeonenation.org)).

## Enlisting the help of friends

In this day and age, many teens need community service and extra activities on their resumes. Enlisting friends in the JDRF Walk to Cure Diabetes or another T1D event is a great way to educate them and inspire them at the same time. Some teens initially feel embarrassed to ask. But since raising money for research helps millions of people living with T1D, your teen should feel comfortable suggesting that friends help with fundraising events. Walk days can be a fun party-like event for groups of teens.

Parents should encourage their teen to enlist her friends or acquaintances to join in a fundraising event. Offer to help find sponsorships, to have team shirts printed, and even to host a post-Walk party at your home. The entire event can not only help teens perform community service, but help them show solidarity for the teen with T1D. If a teen is shy about asking, offer to contact her coach or class advisor on her behalf. And set the fundraising goals at a reasonable amount. Even an average of \$50 raised per walker makes a good, strong Walk team. Teens love team spirit, and spirit for something that helps a friend really works in their world.

Learn more about the JDRF Walk to Cure Diabetes at [www.walk.jdrf.org](http://www.walk.jdrf.org).

## What about the teen who just doesn't want to talk?

Find out what your teen is feeling. Why doesn't he want anyone to know about his T1D? Perhaps it's something you can work through together. If not, your teen might benefit from talking with a counselor about it. It is possible that there are certain people that your teen does not want to know about his T1D. In some cases this is just fine—it is typically not the people he spends the most time with. As long as the key people in his life know and understand T1D, less involved people on the periphery can remain uninformed.



# Diabetes and Driving

*It's scary enough to think of any teen behind the wheel of a giant mass of steel, but adding T1D to the equation amplifies that fear. Parents should think of this time as a chance to get a foothold on some T1D rules, since most teens truly yearn to get a driver's license.*



It's one of the life events that parents of teens with T1D approach with the most trepidation: winning the privilege of driving a car.

It's scary enough to think of any teen behind the wheel of a giant mass of steel, but adding T1D to the equation amplifies that fear. It is important for parents and teens to realize that driving is not a right but a privilege that one earns. Even people without T1D have to prove themselves before driving and can be stripped of that privilege at any time. Parents should think of this time as a chance to get a foothold on some T1D rules, since most teens truly yearn to get a driver's license. The strong parent sets up rules of the road (in concert with the medical team and the teen) and then insists that they be kept.

## The law and driving with type 1 diabetes

Just as wearing a seatbelt and driving within the speed limit are the law, there are laws about driving with T1D.

Yes, you absolutely can get a driver's license if you have T1D. Keep in mind, though, that there are rules and restrictions in place that vary from state to state. For instance, in Texas and Minnesota, a physician must verify the applicant's ability to drive safely by filling out a medical evaluation form provided by the state. Massachusetts and Connecticut are both "self-reporting" states, in which a person with a medical condition that could potentially result in an unsafe driving situation (such as severe hypoglycemia) must report that condition and then submit an evaluation from a physician. In these and many other states, regular re-evaluations are required to renew a license, and episodes of hypo- or hyperglycemia while driving may necessitate even further steps. California has the strictest rules of all. In that state, any medical professional who treats a seizure (which can result from a severe low) must, by law, report that incident to the DMV, *even if the seizure did not occur while the person was driving*. (All the above laws are current as of August 2013.)

So your best bet is to get online and look up your state's driving laws when it comes to T1D. First and foremost, those laws must be met. It's a good idea to research them early and discuss them with your teen. Print them out, too—your teen may not believe them until she actually sees them.

The law comes into play after a teen with T1D gets his driver's license, too. If your teen should experience an episode of hypoglycemia and get into an accident as a result, he can be held accountable by the law for the incident. Like it or not, your teen needs to understand that driving while experiencing hypoglycemia is not that different from driving drunk. In this

dangerous scenario, a teen with T1D's instincts, motions and actions are impaired and, if he is behind the wheel of a car, that can spell danger. It is imperative that your teen understand that he simply must be extra-responsible about his blood-sugar levels when he drives.

## How to start

Yes, T1D complicates everything. And because of that, you may need to have your own "family driver's education" for your teen before she even begins to learn to drive. The first rule is simple: she must do a blood-sugar check just before getting behind the wheel. It is a good idea to set the blood-sugar target range a little higher than it usually is. For instance, if you and your medical team consider anything below 100 mg/dL to be a treatable low, you could make it 130 mg/dL when driving. Again, make this decision with your teen and her medical team. You will also need to set a time limit for when your teen needs to repeat a blood-sugar check if driving a long distance. Make this decision based on your teen's high- and low-blood-sugar patterns.

Stock the glove compartment of each car you own with a fast-acting glucose, such as glucose tablets or juice boxes. Make sure your teen knows where these supplies are stored in the vehicle. He should always remember that it is better to treat and be wrong than not treat and be wrong. If he is behind the wheel and feels low, he should pull over to a safe spot immediately, check, and treat.

Teens with T1D who drive also need to wear or carry medical identification. With so many teens using insulin pumps today, many think of the pump as their identification, but it is not. Make carrying a medical identification card or wearing an ID bracelet a "must do" for your driver.

## When to say no

That may sound simple, but with teens and T1D, saying and doing are often two separate things. But here, with driving, parents really do hold the ultimate control. Make sure your teen knows this is a "one strike and you're out" situation, and that if she drives the car without checking her blood-sugar level, she won't be driving for a while. Remember, your action is for the safety of not only your teen but also for the public. Your teen wears a seatbelt to avoid getting a ticket and to keep her body in one piece. Remind her that keeping her blood-glucose level in a safe driving range is like wearing a seatbelt.

Parents should see this as a chance to reach their teens. Teens are very in-the-moment. No articles about complications or

lectures about long-term results of poor control are going to get through to most of them. But the privilege of driving a car? Now that resonates. Use that power for good.

The hard part of sticking to that is if you take away the right to drive, you are back to being a parent-taxi again. But hopefully, one short time with his driving rights revoked will remind the teen to do what he should.

Acknowledge openly to your teen that it will not feel “cool” to pull over to check her blood sugar or to treat a low. Let your teen know that you understand her frustration with having to think about these extra things. Encourage your teen to be open with her friends about it, too, which will make it more likely that her friends will understand when the situation arises. Also, let her know that not pulling over because she doesn’t want to look bad in front of friends can lead to losing the privilege of driving. Which is worse?

### **It’s in the contract**

So how do you make all this happen? You create a driving contract. This toolkit provides you with a sample driving contract in the Appendix on page 38. Use it as a starting point to draft your own. As always, try to do it in cooperation with your teen and with the advice of his medical team. The more involved the teen is in the contract, the more he is going to embrace it. And if your teen balks at the idea, remind him that all drivers in America sign a “contract” to drive once they pass their driving tests. For the teen driver with T1D, his contract just has an addendum. Treat the contract seriously. Print up a real contract, have your teen sign it, sign it yourself, and keep it on file. Should situations come up, you can refer back to the contract and discuss the ramifications of any actions that are in violation.

Driving is a normal part of growing up. With some extra precautions and an airtight contract, you and your teen can survive it.

# School and the Teen with Type 1 Diabetes

*When children with T1D become teens, parents must balance the fast pace of high school classes, the long days, the desire of teens to have independence, and the ever-changing beat of each day. Sound impossible? It's certainly not easy, but it can be done.*





As your child with T1D gets older, he will spend more time in and around school. In fact, for teens involved in extracurricular activities and sports, school time can take up as much as 50 percent of their weekday. That means a comprehensive and smart plan for how to deal with T1D at school is a must-have tool.

When children with T1D are young, this can be a challenge as well, but when they become teens, parents must balance the fast pace of high school classes, the long days, the desire of teens to have independence, and the ever-changing beat of each day. Sound impossible? It's certainly not easy, but it can be done.

### The newly diagnosed teen

For the teen with newly diagnosed T1D, it's often the case that not many days of school are missed because of the diagnosis and initial treatment plan. It's also often the case that she may return to school before knowing all that's needed about daily care, including recognizing a low blood-sugar level, counting carbohydrates, and giving insulin injections. It's a good idea, at the start, to have the school nurse directly involved in the teen's care while in school. She might balk at having to take precious lunch (read: socializing) time to go to the nurse's office. Meet with your nurse and your teen to discuss scheduling. Find the least intrusive way for her to connect, check blood sugar, and do any injections before eating lunch. It also might be a good idea for a newly diagnosed teen to check blood sugar with the nurse at the end of the school day and before sports or activities.

Encourage your teen. Let him know that as he feels more and more comfortable with what the numbers mean and how to react to them, he can shift to carrying a meter and checking on his own. Another option for newly diagnosed teens is texting their caregivers when they check. You'll need to get permission from the principal for your teen to use his cell phone for this reason (please refer to the JDRF School Advisory Toolkit for tips on creating a "504 Plan" at [jdrf.org/life-with-t1d/starting-school/](http://jdrf.org/life-with-t1d/starting-school/)), since most schools do not allow phone use during class time. In this case, the teen would check blood sugar, text the caregiver, and then await instructions.

Another important note is that all teachers and coaches must know about the teen's new diagnosis. Sure, teens can hate being singled out, but the adults supervising them must know. Parents should draft a letter (see Appendix on page 39 for sample letter) explaining the diagnosis and what it means during school, activity, and sports times. Offer to meet or talk on the phone with any educators who might have concerns. And tell your teen the first trick to success with diabetes is just letting people know. The sooner people know, the sooner it is not as big a deal.

It's also important to note here that in the current economy, more and more schools are going without fulltime nurses and sometimes without nurses at all. This is a challenge to newly diagnosed teens and their families. If this is the case, you'll need to meet with your school's administration and come up with a plan. Ideas include using texts, cell calls, and emails to keep up to date with what is going on with your child through the day, as he will need your support and help. Ask if there is another teen with diabetes in the school and if the school can facilitate an introduction to the parents. (The laws governing certain schools may not allow your school to provide you with other families' information, but you can ask your school's administrators to provide those families with your information). Another parent may have good ideas about how to handle school and T1D without a nurse present.

### The teen with established type 1 diabetes

Students who have had T1D for many years often enter high school yearning for new freedom. If they have been comfortable with the same school nurse for years, they may dread the time it takes to adapt to a new one. High school is a reasonable time to begin a shift to self-care in school. The first step in this shift is having a discussion with your medical team, your teen, and you. With the school schedule in hand, allow the teen to have equal responsibility in coming up with a proposed plan for the school day. Are there certain times of day when the teen will be able to check his blood glucose relatively easily (and for his sake, privately)? Often, a good idea is to set a quiet alarm on the student's cell phone or insulin pump as a reminder. For instance, if lunch is at 12:10 pm and world history class goes until 12:05, you may want to have the teen reminded to check just before the class ends. Blood-glucose monitoring in class may have to be part of a 504 Plan.

Of course, the teen will need to count carbohydrates. If she is bringing lunch to school, parents should label each piece of food with a sticker and a carbohydrate count. If she buys her lunches at school, it's simpler if she chooses her foods ahead of time. However, with the variety of foods offered in high schools today, that may feel too constricting to the student. Encourage her to count and, if she uses a pump, to bolus. When you see highs or lows later in the day, ask her if she remembers anything different or unique that day. If the response is that a new food was offered in the café, help her figure out a carb count for it. Remember, highs happen. It might just be a high, so don't always attach highs to food choices. In an ideal world, the teen chooses some favorite meals, you help figure out the carbohydrate count, and all goes well. But it's important to allow for situations that are not ideal in the teen's world.

As for self-administration of insulin, with a pump it's a nonissue. But if a teen uses injections or an insulin pen, you'll need to discuss this with your school. Once again, you will have to work it into the teen's 504 Plan if you want him to be able to manage insulin injections. Leave it up to your teen. If he feels ready and his medical team agrees, work out a plan that allows for self-care at school. But remember that proper handling and disposal of sharps (syringes) is critical. If your child uses an insulin pen, request that he leave the needle attached to the pen until arriving back at home. If your teen uses insulin injections, you will have to work out a system of disposal (either disposing of syringes at the nurse's office or placing them in a tiny container in his backpack to be brought home for disposal). Again, this all must be included in your teen's 504 Plan.

## Sports and activities

Your teen may want to be involved in afterschool activities, but what happens when the school nurse goes home when the last bell rings? One way to keep a teen on track and safe is to educate her about how much blood-sugar control (or lack thereof) can impact performance. Be it on a stage or a sports field, in a pool or on a track, people with T1D perform better if blood-sugar levels are within a certain target range. Find examples of successful athletes and performers to share with your child, like Olympic swimmer Gary Hall, NFL quarterback Jay Cutler, or *American Idol* finalist Crystal Bowersox, all of whom have spoken publicly about balancing their high level of success with T1D management. Remind your teen that for the sake of the team or the cast of the play, she should try to know what's going on with her T1D at all times.

Each sport is unique and each athlete is unique. So, for the first weeks of any sport, you may need to ask (or beg) your teen to check a few more times than usual and experiment with things like Gatorade or similar sports drinks. Let your teen know that the goal is to find some patterns that he will be able to use as a good starting point for each practice and/or game. Acknowledge that it may be annoying, but in time, it will pay off when it helps your teen to perform the best he can at his activity. Of course, always make sure your child has glucose, a meter, and insulin at any event. You may want to ask to have the school athletic trainer (most schools have one on duty during afterschool sports) trained in administering glucagon, just in case. And while the fear in every parent tells them they probably should be at every practice and game, this might be a good time to let your teen begin to deal with such situations on his own. Particularly during practices, teens may not want you hovering about. Take some small steps toward letting your teen handle his activities independently. And remember, if a day goes slightly wrong (a high or a treatable low blood sugar), it is not a sign of failure. It goes with the T1D territory. When a situation is managed safely, your teen is moving toward independence.

## Blood-sugar lows, highs, and academic performance

Do fluctuating blood-sugar levels negatively impact academic performance? More and more studies are confirming what people with T1D have long claimed: a low, a high, or a big swing in blood sugar really does affect the ability to focus. So when you consider that T1D is difficult to "stabilize," how can you help your teen perform at her best in an educational setting? Again, details on a 504 Plan can be found in the JDRF School Advisory Toolkit. A teen's plan can include a section that allows her to delay a test if her blood-sugar level is too high or too low (as determined by the teen's medical team) or to stop a test if she becomes too high or too low. In a perfect world, this means the teen will check blood sugar before any test. But the problem for most teens is that the last thing they want to do is, "wave the 504 flag." Again, it comes down to feeling different. But if you can point out to your teen that doing well on school tests and placement tests will lead to achieving her long-term goals, you might have some luck getting her to check blood-sugar levels before tests.

It is important that each one of your child's teachers knows and understands the section of his 504 Plan on testing and the reasoning behind it. You don't want a teacher accusing your child of "using it," and you want the teacher to embrace the idea of how a low or high blood-sugar level can affect his mind.

As for big tests like statewide testing or national standardized exams, teens with T1D can qualify for untimed testing and other special options. Check with your school administration to find out what is available in your area. Before an exam, eating a breakfast with slow-digesting carbohydrates is a good idea for teens with T1D. Fewer fluctuations in blood-sugar levels can help give your teen the best chance possible for doing well on the test.

School is a challenge for teens with T1D as well as their parents. But remember, each step you take toward helping your teen develop independence in high school is another step toward sending him into the world on his own.

# Rebellion and Dangerous Behavior

*For teens with T1D, these years of beginning to feel the power of freedom can have an entirely different taste than they do for teens without diabetes.*





No one raises their child thinking, “Teens will be teens. They will rebel.” And no teen, as a younger child, thought, “When I’m a teen I want to be as difficult as I possibly can be.” And yet the teen years can be fraught with rebellion for many kids. (Maybe they’re just rebelling against *being teens*—it is a tough time, after all.) With T1D on board, teen rebellion takes on an entirely different spin. For parents, any kind of rebellion causes angst. And for teens with T1D, these years of beginning to feel the power of freedom can have an entirely different taste than they do for teens without diabetes.

When it comes to diabetes care, some teens (particularly those who have had T1D for a long time) begin to move away from being the “model patient.” Why does it happen? That’s a question that parents, doctors, and even the teens themselves often just can’t answer. Some say it’s burnout and that the mere act of caring for T1D over a long period of time wears on a kid (and her parents). Oftentimes, the trouble comes from the convergence of burnout from the teen and the parents. Others say it’s a question of the teen wanting to feel “free” from her T1D. And others say it’s the adolescent mind simply playing tricks on a teen—much the way it does for teens in general. The “why” is hard to pin down, but the “how” is more tangible.

So how does a parent sense T1D burnout and how might a teen deal with it?

## Signs of type 1 diabetes rebellion

Rebellion in a teen’s T1D care can sneak up on a parent, and it can sneak up on a teen. Usually, the first sign of burnout is skipping blood-glucose readings. That is often followed by skipping boluses or injections. Teens often realize that the trust they’ve won from their parents over the years may allow them to perhaps fudge with things a bit. In an era of downloadable meters and pumps replacing handwritten log books, this is not as immediately possible as it once was, but it can still be done. A teen looking to avoid checking or taking insulin often, ironically, goes through more trouble working around it than it takes to just do it. Teens can be creative in their rebellion. Some may use control solutions on a meter or use a friend’s blood, while others may push a bolus through a pump with the pump unattached.

While parents of younger kids think, “I’ll always supervise them,” the reality is, this is simply not possible if you want your teen to live a normal and active life. A teen has school, sports, other activities, a social life, and more. It could be that your teen is away from you more than he is home. So how is

a parent supposed to recognize if any rebellion is going on? Often, an elevated HbA1c level can be the first sign that makes parents wonder if their teen is starting to rebel. But an elevated HbA1c is not reason to immediately scream, “rebellion!” since hormones and growth can affect HbA1c levels. It is also important to realize that this could actually take the teen by surprise. While the teen may be doing some “sneaking,” he is probably thinking that it will not be that big of a deal and that he can turn things around any time. Remember, this is a challenge for the teen as much as it is for the parent. Here are some signs to watch for:

- **Missing meters.** Sometimes a teen will “lose” a meter to avoid the parent finding out about skipped or faked blood-sugar checks.
- **Empty control solution bottles.** It sounds mistrustful, but it’s often best to keep the control solution somewhere other than with the meters.
- **More frequent and unexplained high blood-sugar levels when you witness a reading.** Some may be from growth, but there is the possibility of a missed bolus earlier in the day.
- **Rapid weight loss** (more on that later in this section).

## How to react

The challenge for parents who notice and realize their teen is rebelling in her T1D care is reacting calmly and reasonably.

If you find proof, take a deep breath. Yelling at your teen or even punishing her for this behavior is not the solution. Somehow, somewhere, you as a parent have to find a combination of empathy and responsibility. It’s not easy. But start by knowing this: your teen is far from alone if she is rebelling with her T1D care.

The JDRF support system (<http://jdrf.org/life-with-t1d/get-support/>) is flooded with parents asking for help in this exact situation. Your teen is not bad or unusual; your teen is just trying to find his way through a difficult time with a chronic disease—and probably feels as upset and mixed up about all this as you do. Your teen does not need you to beat him up about it; your teen needs your support and help.

Come up with a plan before you even approach your teen about the situation. It’s okay to call your teen’s diabetes educator or endocrinologist ahead of time to discuss what

you suspect and how you should proceed. The medical team may suggest an appointment sooner than one that you have scheduled. If they do, take them up on it. Let them know that your plan is not to attack your teen, but instead provide support and help.

A great way to prompt teens to open up and talk about any subject—not just T1D—is to suggest that they read something on the topic. An honest article about teen struggles may open your teen up to discussing things with you (we’ve included some in our Appendix on page 40). If it does not, remember that part of what may compel your teen to be dishonest with you may be a need to not upset or disappoint you.

If you have proof of a false or skipped blood-sugar reading or insulin dose, approach it carefully. Instead of saying, “I know you did this. Why did you do it?” you can sit down with your teen and say, “I can only imagine how hard it is for you to do this constantly. I noticed that it’s been really difficult for you to get your blood checks in during school hours. Do you want to talk about figuring out a schedule that works better for you?” This kind of “positive suggesting” may help your teen admit something like “I just cannot test before lunch.” If your teen opens up to the idea of a different plan, suggest that she and her diabetes educator or endocrinologist come up with a new plan that works better.

Parents have to be prepared for a teen’s medical team to agree to a plan that involves less checking than they may be used to. But if the medical team and your teen are in accord with a plan, and it keeps your teen safe, healthy, and willing to engage in his care during some tough years, it’s a winner. These years are about slowly moving your teen toward independence. If a teen is willing to be responsive in this way, you are taking a great step toward that independence (as hard as it is for a parent to let go a bit, in the end, it is a smart thing to do).

It’s important to remember that teens experience something called the “personal fable.” This means that they literally do not have the ability to think about what their current actions can mean for their future. Saying, “If you run high blood-sugar levels now, you might be blind when you’re 40,” will not have any effect on them whatsoever. As teens, who cares about 40? “I want to live right now” is what they are thinking. Try to put everything in terms of the present. Relate your teen’s blood-glucose levels to how he feels, performs in school or sports, and what it does to his mood or energy level.

What about the teen who keeps on rebelling and whose HbA1c level keeps rising? More action may be needed, again, keeping the teen’s medical team in the loop. Some ideas:

Has she outgrown her medical team? It can be the case that even the most beloved medical team is no longer the perfect fit once the teen years come along. Ask your teen if she is happy with her team. If the answer is no, make a change and let your teen be an active participant in the choice. If you can find an endocrinologist who specializes in teens, that’s a bonus. But at the very least, by starting fresh you may allow your teen to feel that she is the “in-charge” person in the relationship as opposed to you, the parent.

Set boundaries, within reason. For instance, if a driving-age teen is not checking his blood-sugar levels, you cannot allow him to drive. Driving with unknown blood-sugar levels is not that different than driving without a gas gauge or a seatbelt. It’s dangerous not only to your child but also to everyone on the road. Teens usually care deeply about driving. Use it to your benefit and take away the privilege if he is not being responsible. This is not the same case as your teen going to a party or event without your permission. The idea of punishing or “grounding” a teen who rebels with diabetes is a hot topic. It might be a good idea to limit your restrictions to ones that simply make legal sense.

Reward her richly. If your teen comes up with a plan with her medical team and somewhat follows it, reward her with whatever you can. Let her know that you understand that this is not easy and it’s not a normal way for a teen to have to live her life. You get it and you respect it. So praise it. And don’t lure her with the reward—have the reward on hand and then randomly give it to your teen when she least expects it. Remind her you get it, you care, and you support her.

Find him support. Teens don’t like being forced to attend support groups, but there are ways to get them together with a group of peers who are going through the same thing. Diabetes camp is a big way to do this. Even if he’s never gone before, there are adventure camps and leadership programs that may resonate with him. Find one in your area (see Appendix on page 40) and encourage your teen to consider the idea. This may mean missing a few weeks of a summer job or some fun at home while he is away, but the camp experience usually pays off, with the teen returning home having found a new peer group who “gets” him. And that’s a good thing. If he adamantly insists he does not want to go to diabetes camp, it’s probably not a good idea to force him. Perhaps a weekend program where he can bring a friend or a situation where he can be a helper or even a staff member might be more effective. The point is to introduce him to other kids in his age group who are experiencing similar T1D and life challenges.

## Dangerous behavior

But what about when a teen's behavior is threatening her life? That's an entirely different level of concern and action. From drinking to sex to drugs to weight issues, teens with T1D need to understand the implications of their actions, and parents need to take strong action when danger presents itself.

## Alcohol and drugs

Teens everywhere get tempted by alcohol and drugs. Parents of teens with T1D are wise to have open discussions about alcohol and drugs early, because teens with T1D need to understand that the risks and the consequences for them can be quite different than for their friends. Open discussions from an early age may encourage honesty from your teen. You may want to consider a policy that communicates that you do not condone the illegal use of alcohol, but if your teen tries it, he can call you and you will help him without punishment. Think of it this way—would you rather your teen with T1D pass out and be in danger somewhere, or call you and have you guide him through it safely?

Alcohol is dangerous for kids with T1D because it can cause low blood-sugar levels—even severe ones—later on. Teens are not always aware of the added danger of drinking alcoholic beverages when they have T1D. Their friends most likely have no idea either. Because the liver is busy detoxifying the alcohol, it cannot help out in a low-blood-glucose situation by releasing glucose, as it normally would. This means that if someone with T1D is drinking alcoholic beverages and her blood-sugar level drops, not only does being drunk hinder her ability to detect and treat the low, but her body will not help her out. Most people think that because alcohol acts like a carbohydrate and has a tendency to raise the blood glucose—especially if the beverage has sugary or high-calorie mixers like juice, regular soda, or margarita mix—they may even take more insulin. It is very important to teach your kids that if they are going to drink alcohol, moderation is the best practice, along with always eating food while drinking.

If a teen begins using alcohol or drugs regularly, the same skills that parents of kids who don't have T1D employ should be used. Trust is an important tool, and your teen has the ability to use it wisely or abuse it and lose freedom. Regular use of alcohol or drugs in the teen years is grounds for restrictions and loss of freedom. Point out to him that if he is part of any kind of sport or school club, his fellow students who are caught drinking are often banned from or suspended from school events and programs. The same rules can apply at home, too.

You may gain some ground by pointing out this isn't just about T1D. You would be taking action even if your teen did not have T1D.

That said, it's fair to point out that drinking and drugs are different when someone has T1D. Make sure your teen understands what alcohol can do to the body with T1D and how drugs can wreak havoc as well. Then give your teen permission to discuss it all with her medical team. Some teams have an agreement that if a teen finds herself in a bad situation, she can call the endocrinologist or diabetes educator without it being reported to the parent. Consider this option. In the end, would you rather your teen deal with a situation safely without you knowing, or would you rather she be in danger just so that you can know? It's a choice for you, your teen, and the medical team to make.

If you find out that your teen is involved in dangerous behaviors after the fact, it's still important to intervene. You cannot turn back the clock, but you can help your teen going forward. Your teen may need to enroll in a program to get the help he needs. However it plays out, having your support and knowing that you will be consistent in how you interact with him will help your teen get through difficult times.

## Eating disorders

The subject of eating disorders is a prevalent one these days—and for many good reasons. Our culture often glamorizes excessive thinness and extreme diets. Mental health issues, family circumstances, and environmental factors can all have a role in promoting the risk of a child or teen developing an eating disorder.

Since your child's diagnosis with T1D, it's understandable that food has been a focal point of family concern. You have had to count every carbohydrate, study every plate of food, and listen to endless (and more often than not unsolicited) input from well-intentioned people about what they think your child should and should not be eating. If your teen was diagnosed back in the days of regular and NPH insulin, she probably lived through a period of time when food was considered like medicine and certain foods and certain eating times were completely off limits. All that weighs on a child's mind—and it can lead to unhealthy eating behavior.

Add to that the fact that a teen who wants to lose a few pounds quickly can just cut back on insulin, and there is potential temptation. Manipulating insulin doses to bring on weight loss now has a name. In the press and conversationally, it is called "diabulimia," but the formal clinical term for this disorder

is Eating Disorder–Diabetes Mellitus Type 1 (ED-DMT1). This name makes more sense, since medical experts believe “diabulimia” trivializes the very serious dual diagnosis of two separate diseases: T1D and bulimia. Any parent of a teen with T1D should watch closely to make sure the child is not manipulating his insulin to promote weight loss. Think of it this way: If you had the ability to lose a quick 5 to 10 pounds, would you be tempted? But the danger in doing this, which teens just may not comprehend, is serious.

If your teen seems to be losing weight without explanation, it's important to consider the possibility that she may be manipulating her insulin. Check meters and doses on pumps. And even if the numbers seem to be fine, if you see the combination of an elevated HbA1c and weight loss, contact your medical team about how to make sure your teen is safe and not struggling with eating issues. If this turns out to be the case, it is a situation that demands immediate and expert attention. Ask your medical team to help you find a local counselor to help your teen address this dangerous behavior. Keep in mind that your team can help you to find an inpatient facility that specializes in T1D and eating disorders, if needed.

Eating disorders can cause lifelong damage, both physical and emotional. The sooner you get your teen help, the better.

It's important for a parent to watch closely but not overreact. Jumping on a teen for the slightest food situation could lead to resentment and even more issues with food. Find a way to be calm and, when in doubt, discuss what you suspect with your medical team before approaching your teen. Make sure that you have the support you and your teen need to help identify and manage an eating disorder.

## Depression

In recent years, more and more research studies have found that a significant number of people with T1D suffer from clinical depression. Some studies claim that teens with T1D are far more prone to depression when compared to teens without the disease. The issue gets complicated since depression can lead to a lack of desire to administer T1D care, and a lack of administering diabetes care can lead to depression. Which came first, the depression or the poor adherence?

And since just about all teens can experience times when they are feeling low, how is a parent supposed to identify a true bout of depression? It is not always easy to distinguish signs of depression in adolescents, as mood fluctuations are quite natural in this developmental period. But doctors suggest that depression is distinct in that the symptoms tend to persist for at least two weeks.

The most common symptoms are:

- loss of pleasure in things previously found enjoyable
- withdrawal from social interaction
- feeling tired most of the time
- trouble falling asleep, waking during the night, or sleeping more than usual
- eating more or less than usual, resulting in weight gain or loss
- trouble with concentration
- feeling worse in the morning; questioning one's ability to make it through the day
- thoughts of self-harm

If a parent or caretaker identifies any of these behaviors, it can be a smart move to first approach the teen and try to discuss things with him. Of course, there is a good chance that your teen will not want to admit any of this to you, but you can tell him that feeling blue is actually not out of the norm for teens in general and teens with T1D specifically. Let your teen know that you are there to help him. Remember, your teen is in your legal care, so it is your responsibility to help him get the support needed to treat depression.



## Teens and sexual activity

All teens need their parents to openly discuss sex with them. Teens with T1D need this discussion even more. Some parents find that talking about the consequences is a great way to help their teen engage in discussing sexual activity. And while parents of all teens can try to drive home ideas like self-worth and respect, parents of teens with T1D can explain exactly why it is best for women with T1D to plan far in advance for pregnancy. (For details, you can refer to the JDRF Pregnancy Toolkit: <http://jdrf.org/life-with-t1d/pregnancy/>).

For adolescents with T1D, they need to understand that sexual activity can affect blood-sugar levels, too, at times causing low levels from exertion or high levels from stress; it differs with each person. Hopefully, your teen will realize that these additional factors simply mean he has to take sexual activity very seriously and consider waiting before engaging in sex.

You should expect your medical team to have a discussion about sexual activity with your teen as well, and if your teen is not comfortable with you being in the room for that, respect that decision. Once again, it's better if your teen is honest and open with someone who has his care at heart than to not be honest and open with anyone.

As hard as it is to accept, if your teen does become sexually active, it's better that you or someone who can help her knows, so that that she can use appropriate protection.

## Hope and faith

Of course, all of these discussions can make a parent's head spin and a teen want to cringe. But the more open and honest you can be with one another about these situations, the better things will likely be. Teens with T1D and their parents have a difficult road with lots of extra bumps, but if both parents and child can find a way to communicate calmly and respectfully, they will strengthen a wonderful lifetime relationship.

# Transitioning to Self-Care

*How—and when—to transition to self-care is an answer as unique as each person with T1D. The goal is to find a way to shift the diabetes care to the person with the disease in a slow and steady way.*



For the teen who has had T1D for a long time, adolescence can mean the slow transition from parental care to self-care. For the person diagnosed as a teen, self-care is often the goal from the start.

How—and when—to transition to self-care is an answer as unique as each person with T1D. The goal is to find a way to shift the diabetes care to the person with the disease in a slow and steady way without too much impact on the outcome of that care.

## When?

It would be nice if there were a cutoff age to guide people. For example to drive, you have to be 15 years old to have a permit and 16 years old to drive (although that varies from state to state). But with diabetes care, it's about the readiness of the child, the willingness of the parent, and above all the safety of the person with T1D.

When kids are younger, we tend to praise them for any tiny show of self-care. Pricking their own fingers the first time or doing their own injections—parents tend to feel these are both reasons for celebration and even bragging. But the simple truth is this: kids need their parents or guardians who care for them to help manage their T1D, often even past their teen years. While it's hard to be the parent of a child with T1D, he needs your support and care for a long time. Transferring responsibility—or giving high praise for him doing such things on his own and setting a subliminal bar for transfer in his mind—may not be what is best for a child. Again: kids need parents to help manage their T1D, especially in the teen years.

For parents, this can be exhausting. Particularly in the case of parents whose child was young when diagnosed with T1D, they are often ready for a break from constant care by the time their child is a teen. And parents can feel that the child moving quickly toward independence is something for which to be proud. But in many cases, teens move toward independence with a secret: they just are not ready for all the responsibility yet.

So how do you tell when? For children diagnosed with T1D long ago, most if not all are doing their own injections or pump-site changes and finger pricks at this point. But in many cases, parents are still filling out logbooks, making basal and bolus change decisions, and sitting in on all the child's medical appointments. In just about every case, parents are managing the medical supplies, prescriptions, and medical appointments.

The best way to figure out when it's time to begin to transition the teen's care to the teen himself is through an open and honest discussion with the teen, the parents, and the medical team. Parents will notice as kids become teens, the diabetes educators and endocrinologists may like to meet for part of the appointment alone with the teen. This is normal. Usually, the medical team leaves it up to the teen to decide how much of what is discussed at the appointment can be shared with the parent (if a child is in danger in any way, medical teams clearly speak to the parent no matter what the teen feels). This is a good first step. The teen can get a feel for advocating for himself in the doctor's office and can have a place to discuss things without parents taking over or listening in.

The medical team may suggest that the teen try keeping the logbook (or in these days, the meter memory, database, online recordkeeping tool, or phone app) and being in charge of sending it in to the medical office on his own. It is probably a good idea, at least the first year of this transition, to have the parent included in these responsibilities. As much as a teen may want to keep it all private, a parent should know what is going on. The challenge for the parent will be to let the teen try to deal with the information by speaking to the medical team. In many cases, teens just won't be ready for this. And that's okay. You can ask the medical team to come up with a system that they think will help the teen learn to manage things while the parent is still involved.

## Little things mean a lot

You may find that a teen is putting up a brave front and really is not ready to shoulder much of this responsibility. There are little things you can continue to do. Some parents always fill the pump reservoir for the teen. Some always make sure her school bag or backpack has glucose tablets in it. You can find tiny ways to remind your teen that you are still there for her.

And teens should not be afraid to admit they are not ready, if they are not. There is nothing wrong with needing assistance and support with T1D. Many adults with T1D do as well. It's true teens want to feel mature and independent. They can feel that way while still getting support, advice, and care from their parents. Teens should try to be vocal about what they need and want; it's only going to help.

It means a lot to parents for their teens with T1D to keep them informed, too. Having teens keep tabs on their T1D, for the first time, can be scary for parents. Teens who offer to make their meters or pumps available for review from time to time or copy their parents on emails and other communications to the medical team are going to be the ones who help their parents to transition to trusting them and letting go. It's a process for the parents as much as the teens, so there are little things that teens with T1D can do for their parents, too.

For the newly diagnosed teen with T1D, parents can feel very much in the dark. Most teens are ready to do their own shots from the start and learn about their disease in a much more meaningful way than small children can. This is good. But newly diagnosed teens should realize that having their parents in the know is only going to help them. While they may feel confident in it all—and they may remain that way—there is always a time when they need their parents to understand. Helping parents learn along with them will help for a lifetime. They are, after all, the teen's biggest champions. (Even if they are annoying sometimes!)

It's not unusual for teens to come home from college and want their parents to take over their T1D care for a few days. Perhaps they want their parents to give them their injections or calculate insulin doses for them. This is an indication that they need a break. Imagine the stress of managing T1D along with studying, making new friends, writing papers, and taking exams.

## Changing medical teams

Most pediatric endocrinology groups will allow a patient to stay in their practice at least through college. In most cases, teens and young adults with T1D choose to stay with the same practice through their college years, since they don't know where they may be living once they leave college.

But there are some things to consider. First, does your pediatric team have an endocrinologist or diabetes educator who specializes in teens and young adults with T1D? The challenges and experiences of teens and young adults with T1D are very different than those of smaller children. If a team has not had experience with older teens, you may want to discuss with the team—and your teen—how you will navigate this new time. The team should have a plan (find other practices to benchmark, etc.). And your teen should have a say, too. While you, as a parent, may love the medical practice that you have been going to for years, sometimes a teen just feels like he wants to move on to an adult practice.

The first step toward knowing is simple: ask your teen. If she is happy with her care and feels comfortable, there is no need for change. But if she feels like she needs something new, it could be a good time to transition to adult care (most adult endocrinologists want their patients to be 18 years old or nearly that age).

Some teens with T1D find that adult endocrinologists (and make sure it's an endocrinologist who specializes in T1D) have more experience in working with and treating the more adult issues they may be facing. It's scary, yes, but as your teen with T1D moves toward college age, subjects such as birth control, alcohol, and other adult situations need to be not just discussed but understood and managed in a mature way.

In the end, if your teen wants change, even if you don't, you probably should go with what the teen wants. The step toward an adult practice may be his first giant leap toward independence. If you need additional guidance in this area, the National Diabetes Education Program (NDEP) has a resource guide for transitioning from pediatric to adult healthcare: <http://ndep.nih.gov/transitions/index.aspx>.

## When to say no

So what if your teen with T1D wants almost total independence, and you see her take a turn for the worse? After all, as much as a teen may dream of no more nagging from Mom, Dad, or whoever is the adult in her life, the constant job of counting carbohydrates, calculating insulin requirements, and monitoring blood sugar can be an overwhelming one. And the teen, thirsty for independence and maturity, may not want to admit that.

It's important to be aware of warning signs. Large swings in HbA1c levels are one red flag. (By that we mean that your medical team feels the situation is cause for alarm and immediate action. Don't forget teens are going to have a harder time with HbA1c levels even with you in charge.) If your medical team sees your teen struggling, you will want to find a way to re-insert yourself into his daily care. Goodness knows, a parent cannot be around to count carbohydrates for a teen at every meal and every time he eats. However, a parent can find ways—with the help of the medical team—to make sure high blood-sugar levels are corrected in a reasonable amount of time and low ones are avoided as much as possible. Remember, this transition should be a slow one; sometimes it might involve taking a step backward for a while. The goal, of course, is to send a teen with T1D to college with healthy self-care practices.



As one adult with T1D has said about learning self-care as a teen:

*It was a slow process throughout high school. It wasn't like a one-time deal. It was kind of like getting your license. You go for short test drives with your parents, who are watching your every move. Eventually, you prove that you won't crash the car and you are given the keys. No good comes from dumping that kind of responsibility [T1D self-care] on a kid, and even then mistakes will be made. I only wish my internal organs came with a bumper.*

Have a conversation with your teen about her T1D supplies. She may think that diabetes supplies magically appear in the cabinet/closet/shelf every 30 to 90 days, but at some point she will have to know how to obtain them independently. Ask if your teen would like to take on the responsibility of ordering supplies during college (if the teen is not going to college, this may not be a negotiation). It is likely your teen will say no. Let him know the steps that are involved and that you will talk about it again at a future date. This is also a perfect time to discuss the importance of health insurance. Make sure your teen is aware that diabetes supplies are very expensive, so having a good job with health insurance will be crucial throughout his life. These are big topics for a teen, and it's important to discuss them early and often.

## Trust and independence

Of course, this is all about trust, but it is also about compromise. We all want to trust our teens to do the right thing, and, for the most part, teens want to earn that trust. But they, like us, are human. Think about the adult who tries to go on a diet and falls off. Falling off a bit on T1D care is really not that different. It's hard to stay on track all the time. Your best bet is to push honesty as much as you can. Promise your teen that she is safe in admitting challenges to you and that you are there to help her, not punish her. It might even be more important that she trust you than you trust her. The teen who can come to an adult and admit she is having trouble is the teen who will move toward independence more smoothly and with fewer bumps. But there are going to be bumps.

So what if your teen lies to you? Try to remember it's not personal. Teens still take part in "magical thinking," as discussed earlier. The best thing to do is to let him know you do know what the truth is and that you need him to just tell you that in the first place. Remind him of your promise to always help him when he needs it and not punish him instead. Tell him you know that you'd struggle too, if you had to do what he has to do. Create a place of trust for him, so that you in turn can trust him outside of that space. It's not easy to do, and it takes incredible reserve from parents. But if you can make it happen, you're doing something great for your teen as he moves on to be an adult with T1D.

There are cases where you have to take action though, such as any situation that puts your teen, or others, in immediate risk. Things like drinking too much alcohol with T1D (particularly when underage) or completely ignoring all their diabetes needs mean a parent has to step in. When a child's life is at stake, nothing else matters. But do remember that an occasional missed bolus or a slightly elevated HbA1c level is not an immediate crisis. Make sure you learn to weigh just how important a situation is and react based on that. When in doubt, call your teen's medical care team before talking to your teen and share the situation with these professionals. They should be able to help you know how to react and what to say. If they are an experienced team, they are likely to have seen and managed all this before.

In the end, your teen with T1D will most likely go off to college, trade school, or work, and eventually live on her own. It is, after all, the sign of a good parent when a child grows up and moves on to an independent and successful life. With T1D in their lives, your children are always going to need you and understanding how to help them without hindering them is a lifelong process.

# Looking to the Future

*Getting involved—be it with JDRF or any other group in the T1D community—will not only expose a teen to all the new and great things coming along for people with T1D, it will also bolster his life experience and resume for college.*



While it's one thing to tell a parent that puberty has a cure (it's called growing up), it's another to find a way to instill confidence in a bright future for our teens with T1D. And it is important that we do that, constantly. True, it may be that our teens don't really care about much past the homecoming dance on Friday or the party at a friend's on Saturday that everyone is going to, but it is important to keep the faith.

We live in a changing, modernized world. Remember, it was only a couple of decades ago that people with T1D had no meters for blood-glucose testing and few choices in the types of insulin to use. Now there are many insulins, fast meters, great pumps, and even continuous glucose monitors. Are they the be-all and end-all? Not yet. But they are proof that we are moving, step by step, to a better world for people living with T1D, and yes, toward a cure.

So how do you get a teen with T1D to “get” all that? One way is by weaving it into his immediate future. Today's teens face the most competitive college application process ever. Kids across the country are trying every way possible to stand out and to make a difference.

The teen with T1D has that opportunity right in front of her. Getting involved—be it with JDRF or any other group in the T1D community—will not only expose her to all the new and great things coming along for people with T1D, it will also bolster her life experience and resume for college.

Consider learning, along with your child, about advocacy. JDRF conducts a campaign called Promise to Remember Me that asks people with T1D to meet with their Congressional representatives. Often, teens who do this not only learn more about the federal government, how it functions, and why it is important to advocate for support for T1D research, they also form personal connections with their elected officials. It's educational while doing good, and it gives them a sense of having a hand in their own futures on many levels. Learn more on the Advocacy section of the JDRF website at <http://advocacy.jdrf.org>.

Walks to support T1D research are great too, be it a school walk or joining up with a larger regional walk. Teens with T1D should be encouraged to help actually run the team. Think of the goal, reach out to folks, get friends to join in, and most of all, learn the message and the goal of the organization that they are walking for. “Walk day” can be empowering, educational, and hope-instilling. Many teens with T1D who lead and participate in Walks for JDRF compare the day to a great big party for themselves. Learn more about the JDRF Walk at <http://walk.jdrf.org>.

You can also encourage your teen to be a mentor to younger kids with T1D. There is nothing that makes the teen think more about his own care than helping a little one get a grasp on things. Often, those friendships are as beneficial to the teens as they are to the kids. Contact your local JDRF chapter for mentoring opportunities: [www.jdrf.org/locations](http://www.jdrf.org/locations).

And what if your teen has had it? What if she says, “You told me I'd be cured. I'm not. I'm never going to be.” It is okay to admit to her that you, too, have times of doubt. But show her all the changes that have come about even in her lifetime. Show her the stats that show that the lifespan of people with T1D is now nearly the same as that of people without T1D, and the gap is getting smaller all the time<sup>vi</sup>. (Admittedly, it's not easy to have diabetes every day, but there was a time when a person with diabetes would not live as long.) Offer to take her to hear a researcher speak, or ask your endocrinologist's team if you can tour a lab.

Promise your teen with T1D you are there for him, and you are never going to stop working toward a cure, even when he is grown up.

There is so much on the horizon. The future is bright. And involving a teen with T1D directly with the JDRF mission to find a cure for T1D will show him that, build his character and experience, and maybe even bolster his college application.

Hope is a powerful medication. A dose or two of it can even calm a teen (though she might not admit it for a few years). Join up. Take action. And look toward the future together. There's a cure for adolescence. And we all can work as a team for a cure for T1D.

# Appendices

## Driving contract

I, \_\_\_\_\_, on this day do agree to the stipulations stated before rendering me the privilege of driving my parents' cars. If, at any time, I violate said agreement, the driving privilege will be forfeited to the extent and degree of the violation.

1. The use of cellular phones in cars are for your safety and to let us know of your whereabouts—not for conversation.  
I will make outgoing calls only for issues of safety or directions or letting parents know where I am.
  - a. All outgoing calls will be made while the car is parked—not ever while moving—for the first six months.
  - b. I will answer incoming calls from my parents only on the speaker phone (hands free).
2. We strongly discourage the use of the sound system in the car, at all, for the first six months of driving experience.
3. I promise not to have any passengers in the car, while I am driving, other than my siblings or parents until \_\_\_\_\_ (six months). I will never transport more passengers than there are seatbelts, and will not drive the car until all passengers have buckled up.
4. Should I get a traffic violation ticket, I agree to pay for the ticket (or, preferably, attend traffic school) as well as the difference in the insurance premium for as long as the premium is in effect. If the amount exceeds monies I have saved, I will work off the amount of money owed at minimum wage.
5. I agree to pay for damages that I incur not covered by insurance (deductible).
6. I will keep the car that I drive clean, inside and out, and be aware of its need for gas, oil, windshield washer fluid, etc.  
I will not bring the car home with the yellow “low gas” light lit.
7. Never let the gas tank go below half full.
8. I will use the car with the permission of my parents. If they have no knowledge of the fact that I am using it and to what purpose, I am in violation of this contract.
9. Should this car be given over to you for your exclusive use, this contract still applies and, in addition, you will be responsible for arranging and implementing (paying with your gas credit card) regular service for the car (check-ups, oil changes every 2000 miles, tires, wipers, etc.).
10. AT NO TIME will I ever drink alcohol or do drugs and then drive. Nor will there be any alcohol, drugs or cigarettes in the car at any time—even if it is friends who are doing it.
11. I will test my blood-glucose level before beginning to drive the car each and every time I start to drive after a lapse of 2 hours since last being in the driver's role.
12. I will double check that I have rapid acting glucose available in the car before I begin driving, each time I begin driving.
13. If I feel low or high, I will immediately pull off at the nearest safe spot and check, and call a parent while doing so.

I have read the above agreement and do sign this in accordance with the rules.

Signed,

Driver \_\_\_\_\_

Date \_\_\_\_\_

Parent \_\_\_\_\_

Parent \_\_\_\_\_



## Sample letter

Dear (School Name) T1D Care Team:

Our daughter (child's name) was diagnosed with insulin-dependent (type 1) diabetes just after her second birthday. Most people know someone with type 1 diabetes (T1D) but do not know much about the actual disease. It is our desire to share some information that will give you both comfort and confidence as you support (child's name) in caring for her T1D at school.

(Child's name) is very comfortable talking about her T1D. She doesn't like to consider herself to be "different" from other children, and we strive to make the mechanics of her care so routine that it seems invisible to those not looking for it. She is accustomed to the requirements at each snack and mealtime: checking her blood glucose beforehand, eating and finishing "counted" foods, and "pumping" insulin. Occasionally, she may need an extra snack or water. Otherwise, she can do all of the same things as anyone else.

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

Many thanks for your care and support,

Parent's name

---

### Our contact information is:

Home: \_\_\_\_\_

Dad's work: \_\_\_\_\_

Mom's work: \_\_\_\_\_

Dad's cell: \_\_\_\_\_

Mom's cell: \_\_\_\_\_

Physician: \_\_\_\_\_

Physician's address: \_\_\_\_\_

Physician's phone number: \_\_\_\_\_

## Links to articles

**Teens With Diabetes: Freedom Is Their Secret Drug**  
diabetesmine.com/2010/02/teens-with-diabete.html

**The Diabetes Rebellion—Who Is in Control?**  
healthcentral.com/diabetes/c/9993/130875/rebellion-control/

**Managing Diabetes as a Teenager**  
youthhealthtalk.org/Diabetes\_type\_1\_in\_young\_people/  
Topic/1521

**Help Your Teen Deal With the Ups and Downs of Diabetes**  
ndep.nih.gov/media/help\_your\_teen\_deal\_with\_the\_ups\_and\_downs\_of\_diabetes\_508.pdf

**Helping Your Child or Teen Live With Type 1 Diabetes**  
jdrf.org/life-with-t1d/type-1-diabetes-information/control-and-management/helping-your-child-or-teen-live-with-type-1-diabetes/

## Diabetes Education Camping Association

The mission of **Diabetes Education Camping Association (DECA)** is to promote communication, provide education, share resources and serve as a worldwide voice to advance diabetes education and camping associations that meet the diverse needs of individuals and families.

JDRF and DECA work together to promote diabetes awareness, diabetes camping programs and diabetes research worldwide. By educating and supporting children and families who live with diabetes, our organizations meet the common goals of promoting volunteerism, increasing cooperative diabetes education, reducing the devastating complications of diabetes, conducting essential research and fostering fellowship among diabetes-interested organizations worldwide. For more information on DECA visit their website at [www.diabetescamps.org](http://www.diabetescamps.org).

## Thank You

*On behalf of the JDRF Outreach staff and volunteers, we would like to thank Moira McCarthy for her dedication to this critical topic and this toolkit. We'd also like to recognize Moira for her efforts to bring in the expertise of Jane K. Dickinson, RN, PhD, CDE for this toolkit. We are truly grateful as an organization to have such wonderful supporters like Moira and Jane, as we work to provide much needed resources to the T1D community.*

## Footnotes

<sup>i</sup>The timing of normal puberty and the age limits of sexual precocity: Variations around the world, secular trends, and changes after migration. A.S. Parent et al. *Endocrine Reviews* 24, 668 (2003).

<sup>ii</sup>Menstruation in girls and adolescents: Using the menstrual cycle as a vital sign. American Academy of Pediatrics. *Pediatrics* 118, 2245–50 (2006).

<sup>iii</sup>Is poor metabolic control inevitable in adolescents with type 1 diabetes? D. Daneman et al. *Annals of Pediatrics* 54, 40–4 (2001).

<sup>iv</sup>The challenge of adolescence: Hormonal changes and sensitivity to insulin. H. Tfayli and S. Arslanian. *Diabetes Voice* 52, 28–30 (2007).

<sup>v</sup>Depressive symptoms in children and adolescents with type 1 diabetes: Association with diabetes-specific characteristics. K.K. Hood et al. *Diabetes Care* 29, 1389 (2006).

<sup>vi</sup>R.G. Miller. Presentation at American Diabetes Association 71st Scientific Sessions, June 24–28, 2011, San Diego, CA.

## \* DISCLAIMER

This manual is not intended to replace legal or medical advice. JDRF offers the information in this manual for general educational purposes only, and it is not to be used or relied on for any diagnostic or treatment purposes. The JDRF staff/volunteers responsible for compiling the resources presented in this manual are not healthcare professionals. Neither JDRF nor its staff/volunteers engage in rendering any medical professional services by making information available to you in this manual, and you should not use this manual to replace the advice of qualified medical professionals. You should not make any changes in the management of type 1 diabetes without first consulting your physician or other qualified medical professional. JDRF reserves the right, in its sole discretion, to correct any errors or omissions in any portion of this manual. JDRF may make any other changes to the manual at any time without notice. This manual, and the information and materials in this manual, are provided “as is” without any representation or warranty, expressed or implied, of any kind. Information in this manual may contain inaccuracies or errors. JDRF believes that the information contained in this manual is accurate, but reliance on any such opinion, statement, or information shall be at your sole risk. JDRF has no obligation to update this manual, and any information presented may be out of date. Under no circumstances will JDRF be liable for any direct, indirect, special, or other consequential damages arising out of any use of this manual.

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Printed in the United States of America  
JDRF

The ISBN is 978-0-615-87035-9

# 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.

As the largest charitable supporter of T1D research, JDRF is currently sponsoring \$530 million in scientific research in 17 countries. 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.

For more information, please visit [jdrf.org](http://jdrf.org).

