



TEEN TOOLKIT

Navigating the teenage years with type 1 diabetes (T1D) can be difficult. This guide aims to help parents make the journey a much more manageable experience.

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CHAPTER 1: INTRODUCTION

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

JDRF understands. We hope this toolkit will help parents get a grasp on what to expect and how to deal with the many issues facing teens with type 1 diabetes (T1D). From driving to drinking and hormones to school issues, we try to help you think ahead, plan ahead and be ready.

We've tried to include the more important tools you will need but we aren't able to include everything. For this reason, we've also provided you with a list of additional ["Resources and information" that you might find helpful](#). If you still have questions, you might like to contact your nearest JDRF office for some support.

Remember, the teen years will pass. With some planning, patience and of course time, you and your teen will make it through.



CHAPTER 2:

WELCOME TO THE TEEN YEARS

It's coming. Adolescence. While there is no way for any child to avoid it, when T1D is involved, it can create a whole new level of confusion, challenge and worry both for the parent and the child.

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Some parents have an older child without T1D who 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.” For parents whose oldest child has T1D, however, 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 or may not, impact. As for the adolescent mind, that’s a whole new level of T1D understanding and a source of confusion. For the parent, the other trick 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.

Signals of the changing times

Wouldn’t it be nice to have 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 for which you can be ready.

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 T1D, everything that makes the teen years unique may complicate the disease structure. It takes patience, adaptation and sometimes a lot 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 it well, you may feel that they will not face a struggle as they reach their teen years. 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. It’s often the case, however, if your teen’s attitude to life changes, so will their 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 their 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 we 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 waistline and let it hang out there now painstakingly finds ways to hide it. The boy who whipped out his blood glucose monitor on the sidelines at football now wants to check his blood sugar in the car and not bring his monitor with them to the playing field. Kids who once complied with your every order to do a bolus, check blood glucose or eat a snack may begin to question your requests or worse, ignore and avoid you.

A worrisome part about teens that have had T1D for a number of years is 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 blood glucose monitor 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 living with T1D their friends donated to their JDRF Walk team or offered to help, that attention may have diminished. While our children never reach T1D ‘remission’ and never get a break from T1D, 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 they 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 then 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 a new lifestyle smack in the middle of the teen years can be rough.

A particular challenge for parents is that your newly diagnosed 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 training, 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 newly independent teens 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 they need 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, **they still really need you. Big time!**



CHAPTER 3:

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 – both physical and mental. Parents often wait with some trepidation for puberty to appear in their child’s life. When T1D is added, it can be particularly worrisome.

Parents should realise, however, that millions of adults have lived through adolescence with T1D. It may be more stressful and it 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 13¹ on average. Hormones, particularly oestrogen, begin pumping through their body and trigger 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 odour. 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 13¹.

For many teenage girls and their 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 each menstrual period, comparing numbers over time 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 diabetes team and identify any changes in basal or long-acting insulin that may be needed during a menstrual period.

For boys, the kick-off 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 a higher carbohydrate ratio when matching their child's food to insulin, now may be suddenly surprised that their child now needs a smaller carbohydrate ratio in the teen years. 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. It is indeed just that—a challenge.

What exactly does puberty do to T1D overall?

According to medical studies, teens have an average haemoglobin A1c level that is one percent higher than adultsⁱⁱⁱ. As a result, they typically require more insulin. To complicate matters, the sex hormones (oestrogen 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 will 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^{iv}.

Puberty is also a time when kids would much rather be out with their friends than deal with T1D. This can make it difficult to figure out if it is puberty or your child not doing what they need to do to manage their blood sugar (or both). This can be frustrating for a parent that has focussed on tight management but teens do 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 they are safe and they have all the resources they need 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 diabetes team about this and come up with a plan. This guide emphasises that it is imperative to include your teen in every part of the process that impacts their T1D management. Engaging them in decision-making early will give them a better understanding of what is going on. This understanding may help soothe them when upset or despondent about blood sugar levels that seem out of their control.

Some dietary habits associated with adolescence, like eating more junk food, can contribute to higher insulin requirements and weight gain. Explain to your teen that taking more insulin during puberty is expected and that taking the amount of insulin their body needs to keep blood glucose in a safe and healthy range is essential. As long as they are making healthy food choices and being physically active, weight should stay in a healthy range. Encourage your teen to discuss this concern with a diabetes professional, such as their Endocrinologist, Diabetes Educator or Dietitian.

Mood swings

Mood swings are something to expect in all teens. 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 behaviour. The challenge for parents is to know when a blood sugar fluctuation is 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, they'll be out in the world, at work, in university or just at the local shop and may feel a 'rage' coming on that is induced by high blood sugar.

They need to learn to recognise that their blood sugar levels may affect their behaviour and find a way to work around it. If you have taught them how to remove themselves from a situation, fix what is wrong (take insulin or have food) and then wait to respond, you have done a great job.

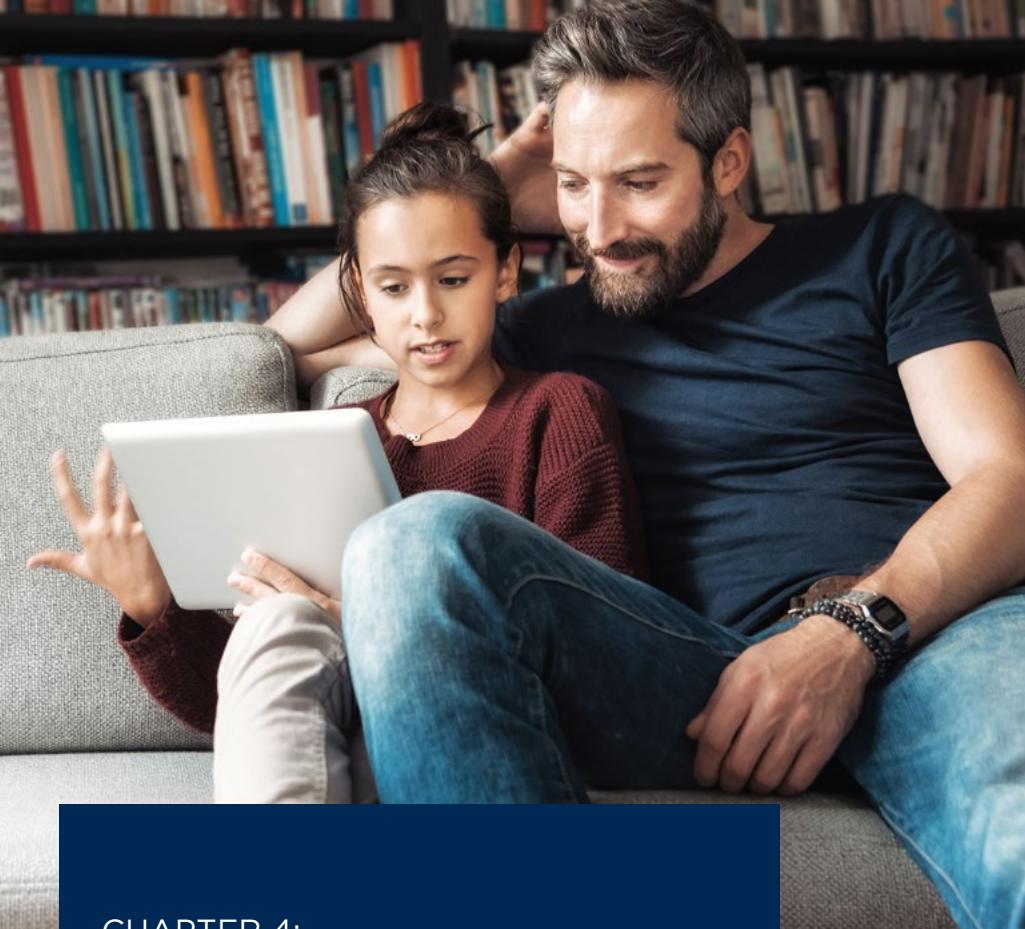
Daily type 1 diabetes management

Both parent and child are going to experience frustration during the teenage years. T1D is a marathon, not a sprint. Ask your diabetes 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. Teens may need to find a way to give an extra bit here and there too. Teens care about their friends, their sports and their social life. Remind them that taking care of themselves and feeling well directly impacts those interests. Even if they complain about feeling different at an age that most kids want to feel the same, let them know that taking better care of their 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 to achieve immediate goals. If blood glucose is too high or too low, they may not be able to do the things that they love. If blood glucose is well-managed, they will not have to feel different when they're with friends.

Looking toward the end of puberty

There is no quick 'off switch' for puberty and some research suggest 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 they are 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.



CHAPTER 4:

KEEPING COMMUNICATION 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 communication begins 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 them.

Transitioning to medical independence

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 diabetes 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 realise that deep down, your teen 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 being able to talk something through with the diabetes team may help.

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. If they don’t, rest assured that it is the professional responsibility of the diabetes team to keep your child safe and healthy. They will contact you if there is something you need to know.

Savvy parents may want to offer an opportunity for their young teen to attend the appointment alone. 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.

Up until your child transitions to adult services (usually from 16 years of age) you will receive the results of your teen's pathology results (and in some cases a clinical review of the appointment). You might like to let the teen read the results first and then read them on your own. This way, if there is something like an elevated HbA1c that surprises you, you'll have time to prepare your response.

Once transition to adult diabetes services is underway, you will not have automatic access to clinical results or files. In fact, the diabetes care team are not allowed to share any information with you without the explicit approval of your teen. The exception to this rule is if the clinicians have serious concerns that your child may be at risk of harming themselves or others.

You will need to have a frank discussion with them about how they would like to manage their health moving forward. Do they want the responsibility of dealing with their diabetes team one-on-one? Discuss ways you can still support them without being solely in control of the situation. Things like scheduling medical appointments can be helpful for your teen and comforting for you.

Make sure that you have a conversation with your teen about their connection with their current health professional and if they express that they don't connect then you should consider finding another healthcare provider. It is important for your teen to feel comfortable about being open with and taking guidance from their primary diabetes health professional, whether that is a GP, Paediatrician, Endocrinologist or Diabetes Educator. Keep in mind it is important to have a stable and ongoing relationship with that health professional. A GP is often a good place to start as they tend to be more quickly accessible and able to provide referrals to other specialists as required.

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. Hearing their concerns and acting on them if required, shows that you respect their feelings and experience.

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 maths test or the excursion.

Sometimes, it's better to ask without using words. Blood glucose monitors and pumps have all the answers you need on them. Set a rule that the monitor 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. Remember, however, to react calmly to the numbers. Let's say you look at the monitor 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 them 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 everyone slacks off sometimes and that tomorrow 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 make a T1D plan for them. It's fair to check that they have their monitor and ask them to shake the test strip bottle to check it is full. With the exception of unusual events, it is important to trust them when it comes to handling their T1D when away from you but for regular day-to-day life, let them give it a try. You can always look at the monitor or pump to see the results when they return.

The teen years are often a time for compromise and adaptation. There is usually an opportunity in a meeting with your teen's diabetes team to discuss goals and priorities. Let them work out a daily plan as well as special plans for things like sports events or outings. Even if it's not exactly what you as a parent would want, it's worth going along with the consensus of your teen and their diabetes team.

Dishonesty

Often, teens with T1D are dishonest about their numbers or their boluses and they know how to manipulate their blood glucose monitors too. They don't do it to be bad. They do it to try to protect you ([See "Rebellious and Dangerous Behaviour"](#)). Why would they not be honest with you? Well, let's say they decide they don't want to check their blood sugar one morning. Instead of leaving a blank, they make up a number for their log book or manually enter one into their pump. The same goes with boluses for teens who use pumps. A teen might forget to bolus or choose not to and then claim the 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 glucose monitors** Teens who may have skipped checking will simply hide a monitor. Often this might happen just before a medical 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. 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 their T1D care?

For the sake of your child, set aside your own hurt or shock and work to find a solution. Let your teen know that you know things are not as they have told you. Tell them you are not angry but you want to help understand why they did it. Some teens may not be able to see that the only people they hurt by lying are themselves. Make an appointment with their preferred diabetes health professional and let them go alone to speak to this person. In the meantime, parents should be sure to visibly watch their teen test their blood, see a number and then inject insulin at least one time every single day. If you see that happen you'll know your teen has enough available insulin 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? It's then time to let someone else help out. There are a lot of places teens can find to vent and talk about their diabetes and as long as they are talking to someone responsible and caring, it's better than not talking at all. Some ideas include:

- **Chatting with an older friend or relative with T1D** Encourage relationships with people who have been through it all before. Having someone who 'gets it' can be key to keeping healthy and staying positive.
- **Making contact with a local diabetes service** JDRF coordinates a national network of peer support for both young people and parents. They also have developed a book called Straight to the Point that contains lots of information for teens aged 16 years and older. Both of these can be accessed by contacting your local JDRF office. Some Diabetes Australia offices run camps for teens with T1D which can be a safe and fun way to meet others.
- **Seeing a counsellor** Having a relationship with someone who listens without judgement can be very helpful for both you and your child. If your teen doesn't want a face-to-face visit or it is difficult to access mental health care, there are online services available. Check out the Useful Links page on the NDSS website for details. If your teen is on social media, they might like to join the JDRF T1D Connect 14-24 closed Facebook group. Only accessible to teens and young adults 14 - 24 years of age living with T1D, this closed group is tightly moderated by JDRF Peer Support mentors and staff to ensure that shared information and discussion is safe.



CHAPTER 5:

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 management can take a backseat leading to some challenging times for everyone.

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 their 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. A funny thing happens, however, 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. Management of T1D can take a backseat. Whilst parents still focus on the importance of 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 they forgot their monitor. Alternatively, they might say they checked and make up a number. They ease into doing it more and more. It can get to a point where T1D management can become an ongoing battle between parent and child.

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 them not wanting to be alive, not wanting to do their 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 might be is just 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 them and how much they have cooperated all those years, there is the chance of your child struggling in the teen years. Embracing that is a first step toward keeping them safe through those years.
- **Stay on top of things** This is not easy with teens. With sports, jobs and social lives, they often leave the house early in the morning and don't get home until after the sun sets. If you watch your child actually check their blood sugar and administer insulin at least one time a day, however, that should reduce the likelihood of them having a hospital DKA situation. 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** 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 their monitor, pump or both. Let them 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 judgement, do reward any activity you see. For instance, say, "That's great you found the time to check before netball practice. I know how rushed you are at that time of day."
- **Work off of one blood glucose monitor** Using one monitor keeps things clean and your teen cannot claim to have done the check on that other monitor they left at school. If your teen needs a reason for using more than one monitor, you can let them know it's easier for the diabetes clinic to download information from just one monitor. If your teen is on a continuous glucose monitor (CGM), you should stick with the one monitor rule for backup checks and recalibrations.

- **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 their diabetes team and come up with a plan they both deem to be safe and reasonable. What if your teen told their doctor they would not mind checking five times a day and also before exercise? If the clinician and your teen are in agreement, it might be a good step toward your teen feeling they have freedom to decide their own plans. As challenging as it may be, try to let your teen and the healthcare team steer this effort, with you as a willing and supportive participant.

Who does what?

Remember how proud you were the first time your child checked their own blood sugar, gave their own injection or changed their own pump infusion site? Yes, it's an amazing thing to see your child take control but giving too much control might be detrimental.

Some teens might feel overwhelmed with being handed control over different aspects of their T1D.

Discuss this with your teen and their diabetes team to come up with a plan of attack that encourages independence but ensures safety. Remember, things change pretty fast in adolescence so you might find yourself having to regularly adjust your T1D management tactics.

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 whether they like it or not, T1D makes things a bit more difficult. That said, there are places you can bend and places you cannot bend. Show your teen you are willing to accommodate wishes within reason.

Here are some situations and ideas on how to handle them:

- **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 do their best. 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 you must be sure to have the supplies and glucose you need with you before the event. Like any good coach, you can set your expectations and expect them to be met. Just make sure you are reasonable about them and do allow for some not-so-perfect episodes. It's important to note here: kids forget. Kids make mistakes. Be willing to provide back up if they need it.
- **Parties and sleepovers** They are just unavoidable. 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 them safe. For parties, be sure your teen checks their 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 their own bowl at a party. Instead, try to show them how to come up with a plan, do their best and learn to correct quickly afterward.

Sleepovers are a different scenario. Some parents of teens with diabetes simply opt to always host them in their own home. If you do want to allow your teen to go to them, as much as your teen might not like it, someone there must know they have T1D. The parent in the home simply must know what is going on. In younger teens, it is best to contact that parent directly to ensure they are aware and educated. As teens get older you might like to give them the option to tell the parent in their own words. Work with your teen to set goals for the night and see how it goes. It's hard to let go when you've been in charge of their overnight care for so long but remember that the ultimate aim is to end up with a confident, happy, independent person.

It's helpful to think about giving a teen the freedom they want by allotting it to them 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 them 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 can be excellent tools to help track how hormonal swings, sports and other factors might impact blood sugar. The technology aspect may also help to provide motivation.

The [Australian NDSS](#) has committed to providing subsidised CGM and consumables to young people with T1D. Some private health funds will also provide a rebate. Do your own research to find out the best way to go about accessing CGM should it be a good fit for you and your teen.

It is important to note some things with teens and CGMs:

- CGMs can seem like complicated tools at first and it is important that both you and your child become confident with the technology. Your diabetes care team will provide comprehensive training once you start using the system. It's likely that your tech-savvy teen will grasp the concepts much faster than you so let them be your teacher.
- CGMs do not replace blood glucose checks. Sometimes, teens tend to think they should. After all your blood sugar is right there, trending on a graph in front of you but CGM usage still requires finger-prick blood checks. Make sure your teen's diabetes clinician makes that clear from the start.
- A CGM reading does not ever replace a blood glucose check before driving- Ever.
- A lot of information is generated by 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 clinicians to learn how and when to react and how to use the trends over time to fine tune your teen's diabetes care.



CHAPTER 6: **DIABETES AND FRIENDSHIPS**

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

Type 1 diabetes adds another layer of complexity to everything in the teen life. Who to tell and when to tell them can be stressful as most teens just want to be ‘normal’ and 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. The people around them need to know how to act about it as well. The reason, first and foremost, is safety. If everyone knows your teen has diabetes, there is a good chance someone will know what to do in a diabetes-related emergency. The reasons are more intrinsic too. If everyone around your teen knows they have T1D, it actually becomes less of a big deal. The dilemma is 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 a teen's school and give the class a lesson about T1D. While it is the parents' role to let the school staff know about their child's condition ([see “School and the Teen with Type 1 Diabetes”](#)), it really is up to the teen to let their friends know. In some cases, the teen may have been hospitalised which can actually make a useful opening to let people know. In many cases, however, 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 their closest friends and give them a 'T1D for Beginners' overview in their own words. Remember, it is likely that people may not understand the causes and impacts of T1D.

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 it. In sharing some of the basics about daily life with T1D, your teen can let friends know that:

- They are going to be fine. While T1D is complicated to treat, it is treatable.
- 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.

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

If your teen needs some help telling friends about their T1D, point them in the direction of JDRF's closed Facebook group, [T1D Connect](#), which has been set-up specifically for teens and young adults 14 – 24 years of age.

While parents need to let the teen do this communication on their own, you might like to contact the parents of their closest friends to give them a quick briefing 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 and new friends can come and go 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." At the same time, it's not really fair to simply start testing bloods or injecting insulin in front of them. Once again, it is good to remember that the more people know, the less of a big deal it is. When it comes time for your teen to manage their diabetes, suggest they let their friends know what they are doing and encourage their friends to ask questions. It doesn't have to be 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. Teens should be encouraged to be open about their T1D, 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 not want to do a bolus in front of people. Encourage your teen to be open but also let them know that a private space could be organised with the school if needed.

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 harbour 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 acknowledge the fact that their teen might be feeling sensitive about the subject. It's fine to ask your teen if their date knows they have T1D. Remind them that at some point during the evening they are going to have to check blood sugar or take insulin. While they don't need to let the date know ahead of time, they should provide a simple explanation at the time.

If a teen gets more serious in a relationship they should be willing to share more. It's not easy to convince a teen of this but 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 formal date. He fully understood that she had to check her blood sugar frequently on the night and probably was not going to want to. Knowing she would always check her mobile phone for texts and knowing her blood glucose monitor was in her purse with that mobile, he discreetly texted her, "how about a quick blood glucose check?" The teen opened her purse, read the note and saw her monitor right there. "It was the most discreet, sensitive and caring thing to do," she said. 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 their friends care about them. Try to encourage your teen to not get too angry at these actions and to communicate their feelings with their friends.

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 One Walk](#) or another T1D event is a great way to educate, involve and inspire them. 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 inviting their friends to join them on events like [One Walk](#).

You might like to involve the school to be part of these events and help raise awareness of type one diabetes within the school community. Offer to help find sponsorships, to have team shirts printed and even to host a post-event party at your home. Offer to get the ball rolling on your teen’s behalf if they feel shy about it. Learn more about how to get involved on the [JDRF website](#).

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

Try to find out why they don’t want anyone to know about their T1D? Perhaps it’s something you can work through together. If not, your teen might benefit from talking with a counsellor or psychologist about it. It is possible that there are certain people that your teen does not want to know. In some cases this is just fine—it is typically not the people with whom they spend the most time.

The exception to this is if your teen has a job. Having a staff member with T1D can be an occupational health and safety issue and employers do need to be informed. It would also be of benefit to give them some basic information about T1D. This will not only help them understand the situation, it will provide a safeguard for your teen should they become unwell or need urgent assistance whilst at work.



CHAPTER 7: TYPE 1 DIABETES AND DRIVING

It's scary enough to think of any teen behind the wheel of a car but adding T1D to the equation may amplify 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 licence.

It's one of the life events that parents of teens with T1D approach with the most apprehension: letting them drive a car.

It's scary enough to think of any teen behind the wheel of a car but adding T1D to the equation may amplify that fear. It is important for parents and teens to realise 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 licence. The strong parent sets up rules of the road (in partnership with the diabetes 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 licence if you have T1D. Keep in mind though, there are rules and restrictions in place and these rules need to be adhered. With T1D, there is a risk that concentration and action could be impaired. If this happens when someone with T1D is behind the wheel of a car, the outcomes could be devastating. It is imperative that your teen understand they simply must be extra-responsible about blood sugar levels when they drive.

How to start

To get a Learner Driver Licence in Australia, your teen will need a medical report to show that they are fit to drive. This involves a doctor checking HbA1c, blood glucose monitoring, eyes, frequency of hypos and awareness of hypo onset. You need to tell the licencing authority in your State that your teen has T1D and also obtain a medical certificate every two years to confirm that they are fit to drive. You should also need to let your car insurance company know that a person driving the car has T1D.

When your teen has obtained their Learner Driver Licence, you will need to have your own 'family driver's education' session. The first rule is simple: they must do a blood sugar check just before getting behind the wheel. The law dictates that their blood glucose reading must be above 5mmol/L before driving and this needs to be rechecked every two hours when they are on the road or driving intermittently.

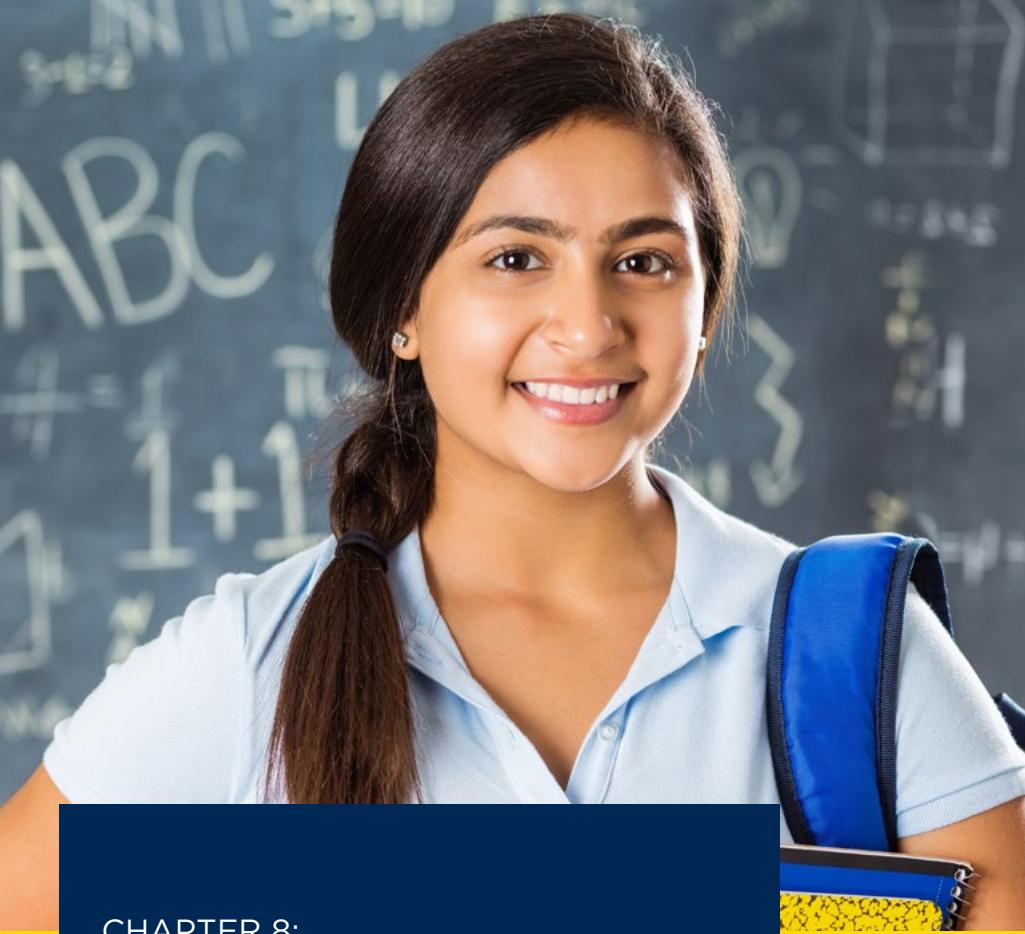
Stock the glove compartment of each car you own with a fast acting glucose, such as glucose tablets or lollies. Make sure your teen knows where these supplies are stored in the vehicle. It is always better to treat and be wrong than not treat and be wrong. If they detect the slightest hint of a hypo they should pull over to a safe spot immediately to check and treat. They then need to wait for at least thirty minutes to ensure their blood glucose rises and remains above 5mmol/l.

When to say no

With driving, parents really do need to hold the ultimate control for the first few years. Make sure your teen knows it is a ‘one strike and you’re out’ situation and that if they drive the car without checking their blood sugar level, they won’t be driving for a while. Remember, your action is for the safety of not only your teen but also for the public. Remind your teen that keeping blood glucose levels in a safe driving range is like wearing a seatbelt.

Parents could 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. Hopefully, just one short time without driving rights will remind the teen to do what they should.

Acknowledge openly to your teen that it will not feel ‘cool’ to pull over to check blood sugar or to treat a low. Let your teen know that you understand their frustration with having to think about these extra things. Encourage your teen to be open with their friends about it thus making it more likely that friends will understand when a situation arises. Teens need to understand that not pulling over because they don’t want to look bad in front of friends could lead to something far more serious should they have an accident.



CHAPTER 8:

SCHOOL AND THE TEEN WITH TYPE 1 DIABETES

When children with T1D become teens, **parents must balance the fast pace of high school with new social activities and the desire of teens to have independence.** Sound impossible? It's certainly not easy but it can be done.

As your child with T1D gets older, they 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 fifty 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 become teens, parents must balance the fast pace of high school with new social activities and the desire of teens to have independence. Sound impossible? It's certainly not easy but it can be done.

Engaging with the school

It is essential to involve the school when your teen has T1D. Australian schools have a responsibility to provide a safe environment and adequate supervision for your child and most schools will work closely with the family to ensure that your teen adheres to a treatment plan. This may include staff training, insulin, test strip and hypo kit storage, sharps disposal and provision of a private space for injections and testing. Regulations for how schools manage students with T1D are different in each Australian state so you will need to check with your local Department of Education.

As a parent, you are responsible for informing the school administration of their diagnosis and providing the school with your diabetes management plan. It may help to connect the school with your treating diabetes team to ensure a smooth process. Work with the school to identify appropriate staff contacts should your teen need assistance. If your teen is sporty, you might like to make a special visit to the school sports department to ensure they are aware of the situation.

Mobile phones can be important tools for managing diabetes, especially if using CGM devices. It is likely you will need to negotiate mobile phone access for your teen at school as many have a “no mobile” policy. Make sure you have this discussion with school administration and ensure that information is passed on to teachers. Ensure that emergency contacts are up-to-date and include contact details for your diabetes clinicians. Offer to present a short education session on T1D at a school staff meeting, speak with your teen’s

teachers directly or provide copies of the NDSS Mastering Diabetes at School booklet ([see Information and Resources section for link](#)). More resources including sample letters, management outlines and teacher training seminars can be found at <https://as1diabetes.com.au/schools/diabetes-resources-for-teachers-and-schools/>.

Schools are NOT obligated to assist with the delivery of diabetes medications. Unfortunately, you may also find that some schools are not particularly proactive about supporting diabetes management for your teen. In this case, you may need to take an active role yourself or look around for a school that is more in line with your needs.

The newly diagnosed teen

Many teens who are newly diagnosed with T1D will not need a long period off school. Whilst time is needed to get the hang of new treatment plans, they will often want to return to ‘normal’ life quite quickly. This can pose some challenges as both teens and parents get used to the routine of T1D management.

You may find that your formerly academic teen starts to let their homework slip following diagnosis. Your socially active teen may become a little isolated. This is normal in the first stages of T1D but should be addressed if it continues for a long period of time.

Adding in new routines to already complex timetables can be tricky. Encourage your teen to use aids like mobile phone alarms to remind them to test, bolus or inject. As your teen get used to counting carbohydrates, you might like to provide their lunch and recess for them and include small stickers that highlight the carb counts on each item. If they buy food from the school canteen, it’s simpler to choose foods ahead of time so they can plan their bolus accordingly.

From a social point of view, your teen may be reluctant to share their new diagnosis with their friends and peer group. As emphasised previously, they need to understand that the more people know, the less of a big deal it is. Every Australian high school has access to a school counsellor, you may like to consider this service should your teen continue to struggle socially.

If your teen is in their final years of study, you may want to investigate the possibility of special consideration for exams and assessments. Each State has different regulations in this regard so contact your local Department of Education for more information.

The teen with established type 1 diabetes

From a school perspective, management of teens with long term T1D should be the same as managing those who are newly diagnosed. All the same information is required, but you may find your teen is able to be more responsible for their own T1D care.

Starting high school is a good time to re-evaluate your diabetes management plan to incorporate the different requirements of high school. You may need to change things like blood glucose testing times to fit in with new class timetables. Work with your teen, the school and your diabetes team to come up with a new plan that ensures the best possible management with minimal interruptions to the school day.

In addition to the normal fluctuations seen during adolescence, these timetable changes may have some effects on HbA1C measurements. Encourage your teen to keep a daily diary for a few weeks so you can compare activities and food intake with blood glucose measurements.

Of course, students who have had T1D for many years may enter high school yearning for new freedom. You need to emphasise how important daily diabetes management is to their long term health whilst being understanding when things go a little awry. See the section on [“Rebellion and Dangerous Behaviour”](#).

Sports and activities

After-school activities, where the relevant school staff members have gone home, can pose a particular challenge to your teen. One way to keep a teen on track and safe is to reinforce 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 American singer Nick Jonas, Sydney Swans player Brandon Jack, American Olympic swimmer, Gary Hall Jr, ex-Wallaby player Rod Kafer and Australian Women's National League basketball player Lara McSpadden. Remind your teen that for the sake of the team or the cast of the play, they should try to know what's going on with their T1D at all times.

Each sport is unique and each athlete is unique. 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 bananas, lollies or juice. Let your teen know that the goal is to find some patterns that they will be able to use as a good starting point for each training session and/or game. Acknowledge that it may be annoying but will pay off when they are able to perform at their best. Of course, always make sure your child has glucose, a monitor and insulin at any event.

The fear in every parent tells them they probably should be at every training and game, however, this might be a good time to let your teen begin to deal with such situations on their own. Give them responsibility to manage their T1D at training sessions then gently check their readings afterwards. 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. Knowing this, how can you help your teen perform at their best in an educational setting?

As with diabetes management, regulations on the provision of special consideration for teens with T1D are different in each State. Assistance like being able to take food and drink into classrooms, being given more time to complete exams and the ability to leave exam rooms as required are often considered. You will need to check with your local Department of Education for the level of consideration given at each stage of your teen's schooling.

From your perspective, it is important to encourage your teen to check their blood glucose regularly during periods of academic stress. 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. 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 them into the world on their own.



CHAPTER 9:

REBELLION AND DANGEROUS BEHAVIOUR

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.

Adolescence can be fraught for many kids but with T1D on board, teen rebellion takes on an entirely different spin. For parents, any kind of rebellion causes angst. 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 their parents). Often 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 T1D or it's the adolescent mind simply playing tricks on a teen—much the way it does for teens in general.

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 often sneak up on a teen. Usually, the first sign of burnout is skipping blood glucose readings. This is often followed by skipping boluses or injections. Teens often realise 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 blood glucose monitors and pumps replacing handwritten log books, this is not as immediately possible as it once was but it can still be done. Ironically, a teen looking to avoid checking or taking insulin may go to more trouble working around it than just doing it. Teens can be creative in their rebellion. Some may use a friend's blood, while others may push a bolus through a pump with the pump unattached.

While parents of younger kids think they'll always be on hand to supervise, 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 they are at home.

How is a parent supposed to recognise 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. An elevated HbA1c, however, is not reason to immediately think ‘rebellion!’ since hormones and growth can affect levels. It is also important to realise that this could actually take the teen by surprise. While the teen may be making sneaky changes, they are probably thinking that it’s not a big deal and that they 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 blood glucose monitors** Sometimes a teen will ‘lose’ a monitor to avoid the parent finding out about skipped or faked blood sugar checks.
- **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, skipping meals or increased negativity about body image** (more on that later in this section).

How to react

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

If you find proof, take a deep breath. Yelling at your teen or even punishing them for this behaviour is not the solution. Somehow you have to find a combination of empathy and responsibility. It's not easy but start by knowing this: your teen is far from alone in rebelling against their T1D.

JDRF is flooded with parents asking for help in this exact situation. Your teen is not bad or unusual; they're just trying to find a way through a difficult time with a chronic disease. Your teen does not need you to get angry or frustrated at them; they need 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 scheduled. If they do, take them up on it. Let them know that your plan is to 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.

If you have proof of a false or skipped blood sugar reading or insulin dose, approach it carefully. Instead of accusing them of being dishonest, sit down with your teen and say something like “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 they meet with their diabetes health professional and 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 diabetes team and your teen come up with a plan that keeps them safe, healthy and willing to engage in 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.

Psychological theory tells us that all adolescents find it difficult 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,” may 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 they feel, perform in school or sports and what it does to their 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 diabetes team in the loop. Some ideas for this include:

- **Have they outgrown their diabetes team?** It can be the case that even the most beloved team is no longer the perfect fit once the teen years come along. Ask if they are happy with the team. If the answer is no, investigate the possibility of making a change and let your teen be an active participant in the choice. This may be difficult if you attend a public clinic but it is worth asking. Young people aged over 16yrs can transition into the adult system if that helps you find a more suitable diabetes health professional.
- **Set boundaries, within reason** For instance, if a driving-age teen is not checking their blood sugar levels, you cannot allow them to drive. Driving with unknown blood sugar levels is not that different from driving without a fuel 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 they are 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 richly** If your teen and diabetes team comes up with a plan and then somewhat follows it, reward them with whatever you can. Let them know that you understand that living with T1D is not easy for them. Providing frequent rewards will remind them that you recognise this and that you will always support them.
- **Find their 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. Type 1 Diabetes camps are a safe and effective way of doing this. Find one in your area ([see More Information section](#)) and encourage your teen to consider the idea. Don't push it if they are adamant that they don't want to go. Perhaps attending a T1D social gathering or fundraising event is an option. Alternatively you might like to investigate online communities and forums. The point is to introduce them to other kids in their age group who are experiencing similar T1D and life challenges and triumphs.

Dangerous behaviour

What about when a teen's behaviour is threatening their 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 from those of 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, they can call you and you will help them 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 them 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. The liver is busy detoxifying the alcohol so 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 their blood sugar level drops, not only does being drunk hinder their ability to detect and treat the low but their body will not help 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 or soft drink—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 strategies used by parents of kids who don't live with T1D should be used. Trust is an important tool and your teen has the ability to use it wisely or abuse it and lose freedom.

You may gain some benefit 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 encourage your teen to discuss it all with their diabetes team. Some teams have an agreement that if a teen finds themselves in a bad situation, they can call someone in their team without it being reported to the parent. Alternatively, you may wish to bring in a responsible family member or friend to act as an emergency contact. In the end, would you rather your teen deal with a situation safely without you knowing or would you rather they be in danger just so that you can know? It's a choice for you and your teen to make.

If you find out that your teen is involved in dangerous behaviours 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 enrol in a program to get the help they need and a list of help providers is included in the [Resources and Information section](#). However it plays out, having your support and knowing that you will be consistent in how you interact with them, will help your teen get through difficult times.

Eating disorders

Sadly, the subject of eating disorders is a prevalent one these days—and for many good reasons. Our culture often glamorises 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 simple, short-acting insulin, they 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 behaviour.

Add to that the fact that a teen who wants to lose a few kilograms 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' trivialises 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 their insulin to promote weight loss. Think of it this way: if you had the ability to lose a quick 2-3 kilograms, would you be tempted? The danger in doing this, however, is serious and something which teens just may not comprehend.

If your teen seems to be losing weight without explanation, it's important to consider the possibility that they may be manipulating their insulin. Regularly check blood glucose monitors and doses on pumps. Even if the numbers are fine, the combination of an elevated HbA1c and weight loss should be discussed with their medical team. If this turns out to be the case, it is a situation that demands immediate and expert attention. Ask your diabetes team to help you find a Clinical Psychologist who specialises in diabetes and/or body image disorders, to help your teen address this dangerous behaviour. Your GP can provide a primary care plan that can facilitate access to appropriate psychological services.

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 T1D care can lead to depression. Which comes first, the depression or the poor adherence? 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 as 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 behaviours, it can be a smart move to first approach the teen and try to discuss things with them. Of course, there is a good chance that your teen will not want to admit any of this to you but you can tell them 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 them.

If you are finding it difficult to talk to your teen or you have ongoing concerns, it is best to raise the matter with their diabetes team. Using a standardised Diabetes Distress Scale, they can assess whether your child needs to receive more comprehensive mental health treatment. [Check out the Resources and Information section for online tools and contacts.](#)

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. While parents of all teens can try to drive home ideas like self-worth and respect, parents of teens with T1D need to also explain the specific issues related to them.

Sexual activity can affect blood sugar levels, potentially causing low levels from exertion or high levels from stress. If you suspect your teen may be considering having sex or they are already having it, you might like to encourage them to carry extra glucose provisions and make sure their partner is aware of their T1D.

As with all teens, contraception is important to protect against sexually transmitted disease but also to prevent unwanted pregnancy. It is important to discuss methods of contraception with your teen’s diabetes team as some forms of the contraceptive pill could interfere with diabetes management. Pregnancy can be a challenging time for people with T1D, with increased risk to both mother and baby. You can find out more about these risks at [NDSS’ Diabetes and Pregnancy website.](#)

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

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 their relationship.



CHAPTER 10:
**TRANSITIONING
TO SELF-CARE**

How, and when, to transition to self-care is a question as unique as each person with T1D. The goal is to find a way to shift responsibility for type 1 diabetes care to your teen 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 a question as unique as each person with T1D. The goal is to find a way to shift the diabetes care to your teen in a slow and steady way without too much impact on the outcome of that care.

When?

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 can provide a reason for celebration and even bragging. The simple truth, however, is that kids need their parents or guardians who care for them to help manage their T1D, often past their teen years.

While it's hard to be the parent of a child with T1D, they need your support and care for a long time. This can be exhausting for parents and particularly so for parents who have been living with T1D for a long time. Many parents feel that moving quickly toward independence is something for teens to be proud but in many cases, teens are just not ready for all the responsibility yet.

In Australia, young people usually transition from paediatric to adult clinical services between the ages of 16 and 18 years depending on their needs, where they live and how they receive their diabetes care. Typically, the precise time of transition is based on the readiness of the child, the willingness of the parent and above all, the safety of the person with T1D.

How do you tell when? For children diagnosed with T1D long ago, most are doing their own injections, pump-site changes and finger pricks but parents are still filling out logbooks, making basal and bolus change decisions. In just about every case, parents are still managing the medical supplies, prescriptions and medical appointments.

The best way to figure out when it's time to begin to transition their care to themselves is through an open and honest discussion with the teen, the parents and the diabetes team. Parents will notice as kids become teens, their diabetes health professional may like to meet for part of the appointment alone with the teen. This is normal. Usually, the diabetes 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 themselves in the doctor's office and can have a place to discuss things without parents taking over or listening in.

The diabetes team may suggest that the teen try keeping the logbook (or in these days, the blood glucose monitor memory, database, online recordkeeping tool or phone app) and being in charge of sending it in to the medical office on their 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 diabetes team. In many cases, teens just won't be ready for this and that's okay. You can ask the 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 their school bag or backpack contains a hypo kit. You can find tiny ways to remind your teen that you are still there for them.

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 is important to acknowledge that transitioning into self-care can be a scary process for parents too and there are little things that teens with T1D can do to help.

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. Whilst this is a good thing, newly diagnosed teens should realise 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.

It's not unusual for teens to 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, playing sport or doing exams.

Changing medical teams

Many private paediatric endocrinologists will allow a patient to stay in their practice until they have finished studying but those attending public paediatric clinics will need to transition to adult care when they turn eighteen.

There are some things to consider when gauging the best age for transition. Firstly, does your diabetes health professional cater for teens and young adults with T1D? The challenges and experiences of teens and young adults with T1D are very different from those of smaller children. Secondly, will you still have the required degree of access and care in an adult clinic? If your teen is newly diagnosed or diabetes management is challenging, you may wish to stay longer with the team involved with your diagnosis.

The first step toward knowing is simple: ask your child when they hit 16 years. If they are happy with their care, there is no need for change but if they feel they need extra or different care, it could be a good time to start thinking about transition. Some teens with T1D find that adult Endocrinologists and Diabetes Educators 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 adulthood, subjects such as contraception, alcohol and other adult situations need to be addressed.

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 their first giant leap toward independence. If you need additional guidance in this area, check out the links in the Information and Resources section.

Changing health management

Have a conversation with your teen about their T1D supplies and administration of their healthcare appointments. They may think that supplies magically appear every 30 to 90 days. At some point, however, they will have to know how to obtain them independently. Let them know the steps that are involved and that you will talk about it again at a future date.

This is also a good time to discuss the importance of health care. Changing over the administration of health management is an important step towards independence for older teens as Medicare cards, NDSS registration and private health insurance are essential to those living with T1D.

While independence should be encouraged, it is important to realise that once administration has been transferred, your teen will be able make and attend their own health care appointments and purchase their own equipment. Conversely, they can also cancel their appointments and not order their equipment so any changes should be made carefully and in accordance with the needs of your teen.

Teens can obtain their own Medicare card from the age of 15 years but can also remain on their family Medicare card indefinitely.

NDSS registration is made under an individual name so that number will not change as your teen transitions to adulthood. As a parent of a child with T1D, you will be the primary contact until you actively change those details on the NDSS database. Full NDSS concession on diabetes equipment and consumables is provided until your teen turns 18 years of age. Concession rates continue if your child is a full time student or is eligible for a concession card. If they commence full time work then prices on some products do increase.

Eligibility for family private health insurance does differ from company to company so you will need to check what is covered with your provider. Most classify teens up to the age of 18 years as being dependants with some extending that up to the age of 24 years if they are still full time students (or in exchange for higher premiums if they are not studying).

When to say no to independence

What if your teen with T1D wants almost total independence and you see them take a turn for the worse? After all, as much as a teen may dream of no more parental nagging, the constant job of managing T1D can be an overwhelming one. Your 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. If your diabetes team sees your teen struggling, you will want to find a way to re-insert yourself into their daily care. Whilst you cannot be around to count carbohydrates for a teen at every meal and every time they eat, you can plan to be around for at least one meal per day and shadow them through some of their management regime. Remember, this transition should be a slow one; sometimes it might involve taking a step backward for a while.

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 licence. 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."

Of course, this is all about trust and compromise. We all want to trust our teens to do the right thing and, for the most part, teens want to earn that trust. They are, however, human like us. 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 they are safe in admitting challenges to you and that you are there to help, not punish them.

The teen who can come to an adult and admit they are having trouble is the teen who will move toward independence more smoothly and with fewer bumps.

What if your teen lies to you?

Try to remember it's not personal. The best thing to do is to let them know you do know what the truth is and that you need them to just tell you that in the first place. Remind them of your promise to always help them when they need it and not punish them instead. Tell them you know that you'd struggle too, if you had to do what they have to do. Create a place of trust for them so that you in turn can trust them outside of that space. It's not easy to do and it takes incredible reserve from parents. If you can make it happen, however, you're doing something great for your teen as they move 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 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.

Do remember, though, that an occasional missed bolus or a slightly elevated HbA1c level is not an immediate crisis. Make sure you learn to weigh up just how important a situation is and react accordingly. When in doubt, call your teen's diabetes 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 university, trade school or work and eventually live on their 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.



CHAPTER 11: 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 their life experience and confidence.

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 instil confidence in a bright future for our teens with T1D. True, it may be that our teens don't really care about much past the Year 10 Formal on Friday or the party at a friend's on Saturday that everyone is going to, however, it is important to keep your eyes on the prize.

We live in a changing, modernised world. Remember, it was only a couple of decades ago that people with T1D had no monitors for blood glucose testing and few choices in the types of insulin to use. Now there are many insulins, monitors, 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, towards a cure.

How do you get a teen with T1D to 'get' all that? One way is by weaving it into his immediate future. 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 them. Getting involved—be it with JDRF or any other group in the T1D community—will not only expose them to all the new and great things coming along for people with T1D, it will also bolster life experience as well as their CV.

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 government 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 whilst doing good and it gives them a sense of having a hand in their own future on many levels. Learn more on the [Advocacy section](#) of the [JDRF website](#).

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 organisation for whom they are walking. ‘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.

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 their 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 office to see if there are mentoring opportunities in your area.

What if your teen is over it? What if they say, “You told me I’d be cured. I’m not. I’m never going to be.” It is okay to admit to them that you also have times of doubt but show them all the changes that have come about even in their lifetime. Show them the statistics that indicate 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. Offer to take them to hear a researcher speak or ask to tour a lab. Promise your teen with T1D you are there for them and you are never going to stop working toward a cure, even when they are grown up. There is so much on the horizon. The future is bright and involving a teen with the JDRF mission to find a cure for T1D will show them that. Hope is a powerful medication and a dose of it can really help. Join up. Take action. Look toward the future together. We can all work as a team for a cure for T1D.

RESOURCES AND INFORMATION

General information on Puberty

[Raising Children – Puberty](#)

[Raising Children – The teenage brain](#)

Interesting reading on puberty and T1D

[How does puberty affect diabetes](#)

[The Diabetes Rebellion—Who Is in Control?](#)

[Teens With Diabetes: Freedom Is Their Secret Drug](#)

[Managing Diabetes as a Teenager](#)

Guides to T1D and the teenage years

[JDRF Service Directory](#)

[As1Diabetes Guide to life](#)

[JDRF Straight to the Point](#)

[NDSS Moving on Up](#)

Support groups for parents and teens

[JDRF Service Directory](#)

[JDRF Closed Facebook group for young adults:
T1D Connect 14-24 \(JDRF Australia\)](#)

Diabetes camps and social events

[NSW/ACT](#) / [VIC](#) / [QLD/NT](#) / [SA](#) / [TAS](#) / [WA](#)

Clinical management of T1D during transition

[NDSS Transition information](#)

[Children's Hospital Network Transition Trapeze](#)

[NDSS "Your health care team"](#)

[IDF International guidelines for management of diabetes in childhood and adolescence.](#)

Getting involved in fundraising or advocacy

<https://www.jdrf.org.au/get-involved>

Information on driving and diabetes

www.ndss.com.au/driving

Health management and administration

[Medicare](#)

[National Diabetes Services Scheme \(NDSS\)](#)

Access to Continuous Glucose Monitoring (CGM)

<https://www.ndss.com.au/cgm>

Federal Government Insulin Pump Program

<https://www.jdrf.org.au/type-1-diabetes/insulin-pump-program>

Online communities and forums

[JDRF Closed Facebook group for young adults:
T1D Connect 14-24 \(JDRF Australia\)](#)

[JDRF TypeOneNation](#)

[Type 1 Diabetes Network](#)

[Beyond Type 1](#)

Mental health and information tools for teens

[Reach Out](#)

[Kids Helpline 1800 55 1800](#)

[eHeadspace online counselling](#)

[Black Dog Institute](#)

[Beyond Blue BRAVE](#)

Drug and Alcohol information and tools

[Australian Drug and Alcohol Foundation](#)

[Counselling Online](#)

[NDSS drug and alcohol in young people with T1D](#)

<https://beyondtype1.org/your-type-1-guide-to-music-festivals/>

Disordered eating and body image

[The Butterfly Foundation](#)

Diabetes in the workplace

<https://www.diabetesaustralia.com.au/work>

T1D and school information and resources

[NDSS Mastering Diabetes in Preschools and Schools](#)

[As1Diabetes School resources](#)

Sexual health and pregnancy

[Pregnancy and Diabetes](#)

[Family Planning Alliance](#)

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Footnotes

- i 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).
- ii Menstruation in girls and adolescents: Using the menstrual cycle as a vital sign. American Academy of Pediatrics. Pediatrics 118, 2245-50 (2006).
- iii Is poor metabolic control inevitable in adolescents with type 1 diabetes? D. Daneman et al. Annals of Pediatrics 54, 40-4 (2001).
- iv The challenge of adolescence: Hormonal changes and sensitivity to insulin. H. Tfayli and S. Arslanian. Diabetes Voice 52, 28-30 (2007).
- v Life expectancy of type 1 diabetic patients during 1997-2010: a national Australian registry-based cohort study. Huo, L et al. Diabetologia. 2016 Jun;59(6):1177-85.

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JDRF
Level 4, 80-84 Chandos Street
St Leonards NSW 2065

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