Breakthrough T1D™
Formerly JDRF

Well-being for caregivers of children with type 1 diabetes (T1D)

A guide to support self-care and mental health for parents and guardians of children and teens with T1D

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You should not make any changes to type 1 diabetes management without first consulting your healthcare provider or qualified medical professional.

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Introduction

This resource is broken into sections so you can choose to read it from cover to cover, or you can jump to the section or topic that's most relevant to you at the time.

We acknowledge that all families are different. You may not be a biological parent – you may be a stepparent, guardian, or close relative – in any of these scenarios, you are a caregiver. In this resource, we use the word 'parent' because we're talking about the act of parenting and the relationship you have with your loved one with T1D.

The role of 'parent' is complex. It's full of contradictions, compromises, and sacrifices — with a world of love, laughter, patience, and fun thrown in.

Of course, if you're reading this resource, you also parent with type 1 diabetes (T1D), adding more to the mix.

Simply put, T1D is part of your family. It's in your life. As a result, it influences your decision-making, your confidence, and your perception of what parenting means for you.

As healthcare professionals and the authors of this guide, it makes sense that we believe the role of 'parent' is crucial in everything.

In fact, no one knows your child as well as you do. When it comes to your child, you're the expert in the room.

This resource is designed to support you to parent alongside T1D with confidence. The reality is that in any family, a diagnosis of T1D is often a destabilizing event. It challenges your ability to set and enforce limits and can make you second guess boundaries and limits that have always been in place.

This guide is intended to support your understanding of the connection and strength of the relationship you have with your child. It's been written to help you:

- regain and/or retain your parenting confidence
- learn how to keep T1D in perspective so it doesn't have more power than it deserves
- learn how you can effectively self-care, for both your and your child's benefit

Over the coming chapters, we'll also explain the expectations and skills that are age appropriate and consistent with your child's stage of development. It will support you building resilience in your child — and your whole family too, because your family (however you define it) is your team, and everyone has a vital role to play.

It's equally valuable to identify and understand when your thoughts, feelings and actions are being driven by fear and worry, or frustration and sadness, which can sometimes cloud our judgement.

Of course, parenting a child with T1D is an individual journey, so what challenges and effects you experience may be very different for another parent. You may not experience some of the emotions or struggles we mention, but that doesn't mean you're 'not doing it right' — every person, and every family, is unique! We've tried to cover the most common issues and offer practical, helpful insights to benefit you and your family.

As always, please see your healthcare team for advice specific to your child, or seek extra support when you need it (you'll find a list of resources to help on pages 66 and 67).

When we say 'child' we mean children, adolescents, and young adults. They will always be your child, no matter how old they are!

Section 1:

Chronic condition, well-being and mental health

> “Our sons both were diagnosed with T1D when they were very young... What first looked impossible soon became routine as we gained confidence. Thirty years later, they are confident adults with excellent control.”
>
> **Monica**
> Children diagnosed ages 18 months and 11 months

This resource has been developed to help support mental wellness in parents with children living with type 1 diabetes (T1D).

Parental well-being influences everyone’s adjustment to life with diabetes, as well as the ongoing demands of diabetes management.

Your role as a parent is crucial in this process.

As a family, you’ll already be making — or will have made — significant adjustments in your life to successfully accommodate diabetes. As you well know, there’s a constant demand and unrelenting nature to managing this chronic condition. While we can work very hard to incorporate T1D into our lives, there’s no ignoring the fact that the list of non-negotiable thoughts and tasks can be overwhelming. It’s all-encompassing and can be constantly on our minds.

You may also feel as if you’re following all the steps you’ve been asked to follow, to the best of your ability, and still experience many ups and downs.

It’s also one of the only chronic conditions where your T1D management decisions for your child are closely monitored by their healthcare providers, which can sometimes make you feel ashamed and overwhelmed as well! While it allows your team to make recommendations and adjustments to T1D care, it can leave you feeling judged, rather than supported (of course this may never be the intention, but it can feel that way). As well, this close monitoring can sometimes leave you feeling more anxious, instead of reducing your worries that you’re doing a good job as a parent of a child with T1D.

The impact on the person who lives with T1D

For those diagnosed as a child, T1D adds a layer of complexity as they grow up. It’s there as they navigate relationships, school and work — all the life stressors that can have an impact on emotional well-being at the best of times.

There’s been a lot of research done on how chronic conditions impact emotional well-being and mental health. We know that chronic conditions are a risk factor in the development of mental health conditions, such as depression and anxiety. When we look at studies focusing specifically on T1D, there’s evidence of high levels of depressive and anxiety symptoms in young people who live with T1D. For example, an international study reported anxiety disorders to occur in around 22% of children with T1D, while depression ranged from 19.7% (for boys) up to 29.7% (for girls).[1] This is greater than the symptoms experienced by the overall Canadian population of youth.

We haven't included these statistics to scare you. We've included them to highlight how important it is that, as parents, you understand that it's much harder for our children to manage diabetes while experiencing these mental health symptoms. We need to balance the demands of managing a chronic condition with quality of life, particularly in adolescence and young adulthood, when diabetes management can be less stable.[2] The good news is that research has also identified a key factor in supporting young people's emotional functioning and physical health — and that is positive parenting behaviours.[3] That's where you come in!

We know that positive parenting behaviours are associated with better psychological health outcomes for your child, but what are those behaviours?

As a parent:

- you work together as a team with your child, including them in decision-making
- you have insight into and can regulate your own emotions, as well as understand the impact they have on your child and your relationship, helping reduce the risk of you being overly controlling or critical
- you ensure there are low levels of family conflict regarding diabetes management and high levels of engagement

T1D's impact on parents

Once T1D enters our lives it becomes a family condition, due to the all-encompassing aspects of T1D care. Parents are an essential part of the team because sometimes they're responsible for all facets of T1D management, or they're modelling and teaching steps to independent self-care, or they're encouraging their child.

It's important to understand and be aware that there are very real potential consequences to the stress you're experiencing, particularly because of the demanding nature of being a caregiver, as well as the parental concerns that come with having a child with T1D. This can increase the psychological distress parents can experience.[4,5] For example, studies have found that clinically elevated levels of depressive symptoms were two to three times higher in mothers of young people with T1D than in the general population.[6]

(As a side note, a lot of the research that has been done focuses on mothers because they traditionally tended to be the primary caregivers. But we know that society is changing, and fathers are coming more into focus.)

Why is it important to know about parental distress? It's common for parents to prioritize their children's needs above their own, and the 'selfless' nature of being a parent is often reinforced by society. But constantly balancing competing needs and being pulled in multiple directions means that we do need to look after ourselves, every step of the way.

Nothing describes this better than the oxygen mask analogy: in case of an airplane emergency, it's recommended that you put on your own oxygen mask before your child's. This is because you're not able to look after your child if you're not looking after yourself first. You'll have nothing left to give. And that is no good for you, or your child.

Section 2:

Understanding your own behaviour

When your child is diagnosed with T1D, it has the potential to turn your world upside down. Not only is T1D a chronic, lifelong condition, but most of the time, diagnosis is shocking and out of the blue.

T1D doesn't discriminate. It can happen to anyone at any time, and it doesn't care what else is happening in your life. You might have just lost your job, had a baby, realized your relationship is over, or planned an amazing holiday. T1D doesn't care! Irrespective of whether you have the physical, mental and emotional resources to face it or not, T1D is there.

We know it's a lot to take in. But understanding your own reactions and behaviours can help you adjust more easily.

What to expect after the diagnosis

As the parent, you're going to experience many complex emotions at the time of diagnosis. This is expected, necessary and completely normal. You're in a situation where one of the people you love most in the world is facing a life-changing event.

And we all know that with or without T1D, parents often worry about their kids. Except now your worry has a specific — and, at times, laser-focus.

You're also about to begin an intense period of learning, where you'll see many new faces, meet countless people, and hear words and use terminology that you never expected you'd need to know or understand. Not to mention, you may also be trying to support and manage the emotions of those around you, which can create added stress.

Again, it's a lot to take in, and it's normal to feel a huge range of emotions as you go through it all. At times, you may feel:

- angry
- resentful
- irritated
- overwhelmed
- confused
- sad

The reality is that you might not recognize yourself in those early days or weeks. You might start reacting instead of responding to situations in ways that can surprise and unsettle you.

There's no right or wrong way to express and manage your grief, shock and sadness. The way you do it will be the right way for you at that time.

Why do I feel this way?

Think of it this way: your brain is working hard to protect you. You're experiencing a high-pressure, high-stress situation, with added shock and an incredible amount of uncertainty thrown in. It can help to keep the following points in mind.

1. Your ability to take everything in, process new information, sort through what's important and relevant, and then remember it, is going to be affected.
2. Your brain's protection mechanism is deliberately narrowing your scope of focus. This means you can be laser-focused on the essential things you need to know at this time.
3. You're learning skills and gaining very specific knowledge that's going to keep you all safe.

Remember that all this amazing new knowledge you're taking in is being learnt in a highly stressed state, so forgetting things is to be expected.

> "In the hardest moments, what helped me most was realizing I didn't have to do this alone… asking for support is not a weakness, but a vital part of this journey."
>
> **Miriam**
> Child diagnosed age 13

Resilience isn't about sailing through life without experiencing fear, distress or anger. It's about being able to adapt to life's challenges and continuing to function.

Boosting your family's resilience

So, what can you do to feel more on an even keel in the weeks and months ahead? Working on your resilience and how you respond to situations can help.

T1D families are amazingly resilient. They adapt to the challenges of living with a chronic condition (often with lots of humour and love). But know that parents are often striving so hard to do better and look after their child, that they can miss all the things they're doing well. It's important to recognize the good as well.

Here are a few things to keep in mind.

Remember this...	For example...
It's important not to be too critical of yourself. Treat yourself with love and patience.	"I have never forgotten my best friend's birthday until now!"
Be careful not to compare yourself to others, as everyone learns at their own pace.	Beware the "perfect" diabetes day posts you may see on social media. Comparisons can make us feel so much worse.
Hold on to hope and positivity. Otherwise, you may find yourself slipping into fear, feeling overwhelmed and negative without even realizing it.	Lots of things have changed with T1D in your life, but some things stay the same. "I enjoyed coffee with my friends and realized that we didn't talk about diabetes once — which means I didn't think about it for a change!"
Find and hold onto your humour.	"I've learned to laugh when I find test strips in weird places, like in my hair... at least it means my kid is checking their blood glucose levels!"
Practice self-care.	See pages 59-62 (section 10) for self-care ideas.

Interpreting your child's behaviour

Let's shift gears now and talk about typical, understandable and expected behaviours in our children after a T1D diagnosis.

(And remember that not all this information is going to apply to you, because every family is unique and very individual.)

You might find that your child simply wants you more: more cuddles, more reassurance, more attention.

In some cases, your child may want you less. They might seem angry, irritable and frustrated. They could even act as if this is all your fault and are now making them do things they really don't want to do.

Or they might just seem to take it in their stride! Remember that every child is different, and how they respond in the early stages after diagnosis may be different than in the future.

All of these reactions are your child responding normally to an abnormal event — their T1D diagnosis.

But while these behaviours are developmentally appropriate and expected, it doesn't mean that at this intensity, they're not frustrating, overwhelming and, at times, frightening or concerning for you. It's important to keep in mind that a T1D diagnosis is a hugely destabilizing event, and that your child is reacting accordingly.

Families and children are quite resilient, but in the early days, you might just find yourself needing to look a little bit harder to find that strength. You will get there.

Section 3:

How stress "protects" us

So far, we've talked about the typical responses to a stressful event, in this case your child being diagnosed with T1D. It's expected that you may be anxious and emotional, feeling fearful, angry or even guilty, and you might be having a hard time sleeping. This distress generally settles down over the next few weeks or months following a diagnosis, particularly as you get back into your normal activities and can access your usual coping skills and social supports.

The stress response

We often think of our strong negative emotions as 'the problem' — that these feelings are so uncomfortable they need to be pushed away and avoided.

But these emotions have always been essential to our survival. When we experience acute stress, our whole body and brain get in on the act, as we have an in-built stress response that's designed to protect us if we encounter a threat. You may have heard this described as the fight/flight response.

The fight or flight response:

- happens automatically
- happens very quickly
- feels out of your control
- can make you feel like you've developed tunnel vision, as you can only focus on your immediate concern: in this case, your child

Fight or flight: What you might notice

Understanding the natural response to stress helps you understand what's happening to your body, allowing you to practice self-compassion.

You might experience the fight or flight response at the time of your child's diagnosis. You could be listening to the healthcare team talk about the impact of T1D, while seeing your child crying and distressed at the news that they'll need to administer insulin multiple times a day for the rest of their life. Naturally, this can feel overwhelming and dangerous.

While this stress can be very uncomfortable, it does serve a purpose: to help you focus on what's important. So please don't beat yourself up for forgetting your aunt's birthday or leaving your keys at the hospital — your brain was just doing its best to deal with this situation.

What you might keep noticing

If your body stays on high alert it can lead to chronic stress, which can have long-term implications for your overall physical and mental health. We aren't designed to stay revved up over the long term — in fact, our bodies naturally want to remain in balance. So, once we perceive that the threat has passed, our body's systems start to slow down and reduce the stress response.[7]

One of the most important factors in counteracting this kind of stress is how you perceive the situation.[8] As you move through the diabetes education process, you'll start to gain an understanding and build confidence.

This builds on that sense of 'we've got this', making the situation feel like less of a threat. In time, you'll naturally feel like you have more capacity to deal with it all.

For most parents of children diagnosed with a chronic condition, the stress response does settle on its own, particularly once you've returned home and are able to settle back into your family routine. There's nothing like sleeping in your own bed or preparing a meal in your own kitchen to help you regulate this natural stress response.

This is how your body may react

1

Your brain can interpret the situation as a threat and will send an alarm signal out to your body to start the fight or flight response by releasing stress hormones.

2

This gets you ready to fight or run away, and keeps your body revved up.

3

Your heart will be pumping faster, getting blood to your muscles and organs quicker, increasing your blood pressure.

4

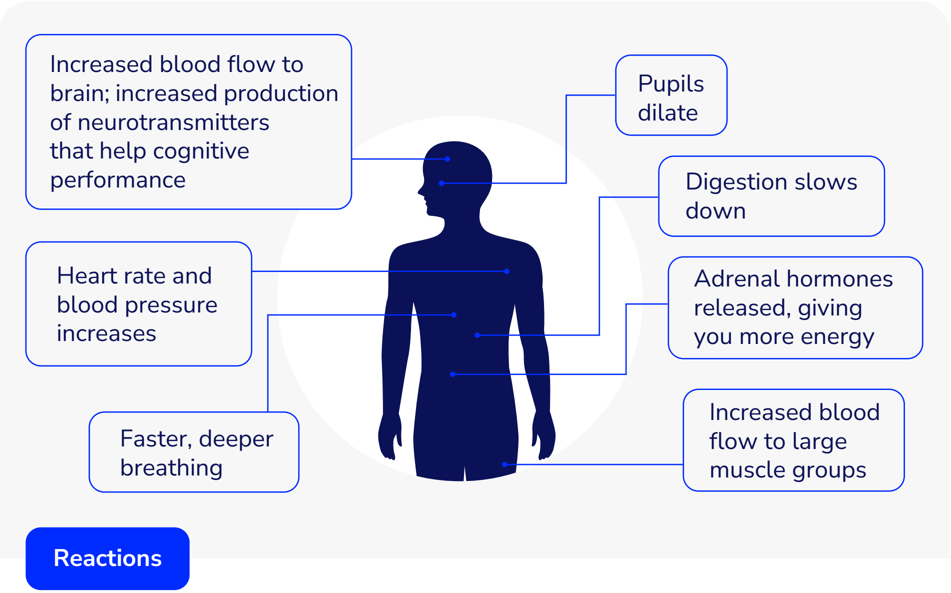
Your breathing rate will increase, with the airways in your lungs opening wider to get more oxygen in. This extra oxygen goes to your brain, making you more alert and focused.

5

At the same time, your body will release stored glucose and fats into the bloodstream, supplying a boost of energy to all parts of the body.

Turn to page 64 for a more detailed look at what happens to your body when you respond to stressful situations.

Fight or flight: acute stress response (diagram)



Reactions

- Body and mind are hyper alert
- A burst of increased physical strength

- More ability to focus
- Heightened sense of smell

- The body tries to cool itself down by sweating
- Muscle tension increases to prepare for 'fight or flight'

We know the 'You've got this' message can feel pretty awful when you feel you're not coping. Resilience is also about recognizing when you're not coping, and doing something about it by seeking additional help.

Strategies to help

If you're continuing to feel revved up or feel like your stress response (fight-and-flight response) is ongoing, and it's interfering with your day-to-day life, it's important to put some strategies in place to prevent this from becoming a chronic issue.

Here are some ideas that will help your body stay in balance.

Relaxation

Breathing techniques, like deep breathing, box breathing, etc

Progressive muscle relaxation

Guided imagery

Mindfulness

Meditation

Mindful breathing

Physical exercise

30 minutes of vigorous exercise per day

Yoga

Tai chi

Sport

Social connectedness

Spending time with friends and family

Peer support

Engaging in community activities

Looking after your physical wellbeing

Getting enough sleep

Eating nutritious food

Your child is relying on you to feel safe. They'll be looking to you for cues on whether this situation is a threat and if they'll be able to cope.[9]

Regulating your own emotions and showing that you believe you can manage their condition (even when you're feeling overwhelmed!) goes a long way to building confidence in your child. This is called "co-regulation" and our ability to help them mirror our calm is essential.

Section 4:

Coping with feelings of grief and loss

When we talk about manageable chronic conditions like T1D we often don't spend enough time considering and discussing grief and loss.

For the most part, there's an understanding that grief and loss will be part of this journey. While the intense aspect of grief will ease, there's also a misconception that it will disappear completely once your child's T1D management becomes second nature.

This section will help you to understand the different ways that grief can show up down the road, so it doesn't surprise you.

We usually associate grief and loss with death, so what is this distinct feeling of sadness called when there's no actual physical death? This is the concept of non-finite loss.[10]

What is non-finite loss?

Non-finite loss occurs when you experience grief due to a significant change or loss in your life, rather than grief through death.

Being diagnosed with a chronic condition like T1D is a prime example of non-finite loss. There will be a sense of grieving for life before the condition, and for what might have been.

Non-finite loss is characterized by uncertainty. A chronic condition is lifelong — and as there is (currently) no cure for T1D, it can leave you with a sense of powerlessness and hopelessness.

> "I felt overwhelmed by the complexity of managing the disease, along with a deep sadness for the carefree childhood I feared had been lost."
>
> **Mina**
> Child diagnosed age 10

1

For you, non-finite loss may represent a shift in the expectations you had for your child to be able to live without having to manage T1D.

2

For your child, it might be a sudden uncertainty about the future. ("Will I be able to be a pilot? Or continue playing my favourite sport? How will I cope with having needles every day?")

3

For teenagers, it could be a sense of loss of independence, a loss of freedom and bodily integrity, and a disruption of identity.

The traditional view of grief and loss

You've likely heard of the five aspects of grief, a model coined by psychiatrist Elizabeth Kubler-Ross. It's become ingrained in the Western understanding of grief, and it provides a good description of some of the emotions you might experience at various times in the typical grieving process.

Aspect of grief	Description
Denial	At the time of diagnosis, we can experience shock or disbelief that manifests as "denial" (not accepting that this is really happening). It can be useful at the start, as it helps us cope with overwhelming pain and emotion. But it's not a place where parents can stay very long, as your child's needs take over. Gradually you'll be able to take on your new reality and tasks, making room for more emotions to surface.
Anger	Anger can show up in many different ways. You might be angry at T1D, angry there's currently no cure, angry at the challenges T1D brings, irrationally angry at yourself for not (somehow) preventing this from happening. Anger can be an uncomfortable emotion for some people, as we're often brought up to believe it's a 'bad' feeling that shouldn't be expressed, so it can come out in awkward ways, such as getting angry at your doctor or having an outburst at a friend. We know that underlying anger is often intense fear and pain.
Bargaining	This can look like bargaining with a higher power or trying an all-vegetable juice diet as a 'cure'. In this stage, people are just looking for ways to make it all go away and keep life as it was before diagnosis. We can get a bit stuck in the 'what ifs', asking what we could have done to prevent this. This can lead to self-blame and guilt.
Depression	The depression stage can include feelings of intense sadness, isolation, hopelessness and emptiness. This is a normal reaction to an abnormal situation and doesn't necessarily indicate a mental health condition, if it's not impairing your daily functioning. It's important to recognize depression as a normal part of healthy grief. These feelings can frighten us (and others), and there can be pressure to fix it — or, even worse, to 'snap out of it'.
Acceptance	Coming to terms with T1D now being your reality, and finding ways to integrate it into your life without it taking over, represents the acceptance stage of grief. This means accepting that something has happened that you don't have the power to change, but knowing that you'll adjust to it over time, and that your child and family can adapt and continue to grow, thrive and find joy in life.

Adapted from **Why Has Nobody Told Me This Before?** by Dr. Julie Smith[11]

Unfortunately, these five stages are a somewhat simplistic view of grief. There's a tendency to feel that you're not 'grieving right' if you're not doing the work to 'confront your loss' and move through these aspects of grief.

But we don't move through the five aspects to end up in acceptance. It's a much more dynamic process. You might find yourself jumping around the aspects, skipping some, or going back again at different times.

T1D and ambiguous loss

The loss experienced with chronic conditions is even more complicated, as it's a form of 'ambiguous loss'.[12] This is where the loss relates to a profound change in your child or loved one's life, but as they're still physically present it's not often recognized as a loss by others.

T1D is particularly invisible, and your sense of loss as a parent isn't likely to be understood by those around you. Chances are it won't be recognized as grief, as some people will see your child as being 'okay'. This can leave you feeling disconnected from others, with little to no permission to grieve, and no access to the support we can expect when our grief is related to the death of a loved one.

Your experiences might be unintentionally invalidated by those around you, even by those closest to you. You might find people encouraging you to just get on with it, using well-intentioned but ultimately unhelpful statements like:

"It could be worse, at least it's not cancer"

"Eventually you'll be managing on autopilot"

"I don't you how you do it. I wouldn't be able to!"

The loss associated with a diagnosis like T1D can also be constantly evolving. On the surface you may look like you're coping well, with your child's diabetes well managed, but you might actually have an ongoing sense of loss.

Grief can also be triggered by certain events, such as:

- discharge from the hospital or any supported environment
- re-admissions to the hospital
- returning to school
- developmental milestones (e.g., going through puberty, wanting more independence)
- life events (it can be as simple as when your child has a sleepover or goes to a school or summer camp)
- your child transitioning to adult T1D services

There's often little to no validation for ongoing loss. This unique grief response, experienced by parents and families of a child diagnosed with a chronic condition, is often described as 'chronic sorrow'.[12,13]

It's important to make the distinction between the kind of grief that's seen as a process, with steps and an end point, and the more complex 'ambiguous loss' or 'chronic sorrow'. Understanding the difference allows you to help find the ways and words to understand your own grief experience.

An updated understanding of loss

People deal with their grief in many ways. In 1999, two researchers (Margaret Stroebe and Henk Schut) suggested that these ways of coping fall into two categories: loss-oriented and restoration-oriented.[14,15]

Loss-oriented

↓

Focusing on the pain and emotions surrounding your loss

Restoration-oriented

↓

Distracting yourself from overwhelming emotions to focus on daily tasks

Both forms of coping are valid and beneficial, but you need to make sure that you move between them, not getting stuck in your emotions or being too goal focused.

It's important to give yourself space to feel grief, but you also need a break from overwhelming emotions. It's a balance between facing your loss and avoiding reminders.

Coping with grief

The loss/restoration-oriented model focuses on normalizing the grieving process. It recognizes that grief isn't a problem to be solved, but that there are coping strategies that help to adapt.

Here are some common methods to help you cope with grief and loss.

Loss-oriented

- Be kind to yourself, and remind yourself this is all a typical response.
- Express your emotions, and don't be afraid to show how you're feeling (including crying or being angry).
- Grief work: confront your loss and let go.
- Understand grief and your personal responses to it.
- Seek out others who understand. While they'll be travelling their own journeys, high quality peer support in challenging situations can be invaluable. Online support groups can also help.

Restoration-oriented

- Connect with others through high quality peer support. Seeing how other families cope helps reduce isolation, supports normalization and validates how you're feeling.
- Distancing and distraction can help, so try to focus on other tasks as well.
- Get back to a typical routine, such as work and school.
- Building your skills can increase your confidence in your parenting and advocacy abilities.
- Work on understanding the realities of the diagnosis and the tasks ahead (knowing that denial might still show up).
- Work together as a family to start creating an alternative and strength-based story of your life, building on your resilience as individuals and as a family.

Boosting your resilience

By understanding the impact of grief, you can give yourself much-needed self-compassion, particularly in the early phases of adjusting to life with diabetes, when it's really important that you're kind to yourself and others impacted by the diagnosis.

Introducing the practice of gratitude is another way to boost your resilience. This lets us recognize that even in the toughest of times, we're still able to find joy and pleasure in the simple and small things in life.

Here are some ideas of how to practice gratitude as a family:

- set a time daily (it could be at a mealtime, school pick up or drop off) and each share one thing you're grateful for
- take a moment for yourself (maybe when you're in the shower or heading to bed) and remember three things you're grateful for
- start a habit where you and your family write what you're grateful for on small pieces of paper and keep them all in a jar. You can read them to pick yourself up on a difficult day

It's also important to recognize your own skills and your ability to get through this crisis. This can be seen as hope or optimism.

Lastly, you're going to need your sense of humour. You've got to be able to laugh at yourself. This can be an unconscious way of releasing pent-up stress while releasing some vital 'feel good' hormones.

Section 5:

Understanding how trauma can affect you and your family

> "Success is not guaranteed... no matter how hard you work with managing T1D. Just when you think all is well, it's not! This is a recurring stress that has a traumatic effect on the whole family. Embrace the wins when they come as they are earned!"
>
> **Jim**
> Child diagnosed age 7

A T1D diagnosis can leave the family feeling pretty traumatized. It's completely common for children and their families to experience traumatic stress, particularly if there was associated medical trauma (like your child being very unwell and in the ICU when they were first diagnosed).

There's a chance this psychological distress can continue, eventually interfering with you or your child returning to normal functioning. But there are ways to treat and manage it to help you all get through it.

What is 'medical trauma'?

The technical description of medical trauma is "exposure to a single or series of medical events related to injury/condition, painful or invasive medical intervention, and/or other hospital experiences that may be perceived by the child and/or caregivers as threatening, overwhelming or frightening."[16]

Sound familiar? In the world of T1D, medical trauma might look like:

- your child being acutely unwell at diagnosis, for example with diabetic ketoacidosis (DKA), with serious fears for their survival
- a severe event of hypoglycemia, maybe requiring medical intervention or the administration of glucagon. This experience is filled with fear and uncertainty, with worries about it happening again
- parents feeling distressed at the thought of causing their child pain or suffering when giving insulin injections

Acute traumatic stress: symptoms to look out for

Sometimes the traumatic stress can linger, causing longer-term problems for the person experiencing it (and their family). Here are some signs to look for in yourself or others.[17]

Avoidance

You might try to get rid of the feelings associated with trauma by avoiding reminders of the trauma, trying to minimize the risk of experiencing distressing thoughts, memories or feelings related to the event. For example, you might not want to go back to the same hospital for appointments after spending time there when your child was diagnosed.

Dissociative symptoms

You might have trouble remembering aspects of the traumatic event, with an altered sense of reality with yourself or your surroundings. For example, you may feel disconnected from what happened or feel like it happened to someone else.

Hyper-arousal

This starts as a normal fight or flight response but then continues, interfering with sleep as you become hyper-vigilant and always on the lookout for danger. In this state, you might be more jumpy, irritable, aggressive, and less tolerant.

Intrusive symptoms

This might occur as thoughts and memories about the traumatic event, including repeated nightmares or 'flashbacks', leaving you feeling like you're right back there experiencing the event again. While this is normal, it can be uncomfortable and distressing.

Negative mood

You might notice a persistent inability to experience positive emotions and primarily experience more 'negative' emotions (anger, sadness) or even empty or numb feelings.

Remember: some of these behaviours are a typical response to trauma. But if you find that they're lingering and impacting your day-to-day functioning, it's time to get help.

In children, symptoms are more likely to appear as changes in their behaviour. Keep an eye out for these signs:[18]

- **being clingy,** or regressing to behaviours they'd grown out of
- **being irritable** and uncooperative, easily upset or quick to anger
- **being jumpy** or more easily startled
- **repetitive play** featuring themes or aspects related to the event; it can even involve re-enactment of events

Older children may describe feeling anxious, worried or upset. On the other hand, they might describe the opposite, saying they feel empty or numb.

Finding support

How to support yourself

Think about the airplane oxygen mask analogy: you have to look after yourself before you can care for your family. Or you may have heard another similar saying: "you can't pour from an empty cup." If you're running on empty (emotionally, mentally and physically) you'll have nothing left to help support others around you. So how you're coping is just as important as how others in your family are dealing with it too.

Here are a few ideas on how you can better support yourself when needed.

Get enough sleep

When looking after your child in hospital — and even beyond that, when you come home and have to deal with the nightly demands of T1D — sleep can be hard to find. Try to tag team the night shift with your partner or extended family so you can get some rest.

Of course, not all of us have a significant other or family living close by who are able to lend a hand. In that case, think about the people in your life who might be able to support you so you can get the rest you need.

It's easy for us to say 'get enough sleep', but we know that for some people it can be difficult. It may be worth looking at resources online, such as information on sleep hygiene.

If a lack of sleep is starting to really compromise your physical and mental health, reach out to your primary care provider, if you have one, for support.

Rest and recharge

Speaking of rest: taking some extra moments to yourself can help. Set aside some time to do some deep breathing, add an extra couple of minutes in the shower, or take 10 minutes to sit with a cup of tea. Resist the urge to clean up as soon as the kids are asleep, and do something restful for yourself.

Make sure you eat enough

Being depleted and low on energy isn't going to help anyone! It can be hard to accept help, but frozen prepared meals in the freezer can be useful.

Don't be afraid to ask for help

Ask your diabetes care team, family and friends to lend a hand. Be specific and let them know what practical supports will be helpful ("Can you come by and feed the dog?").

Take breaks when needed

This is a marathon, not a sprint. You need to replenish your energy levels to be present for your child.

> "During the toughest moments after Rafael's diagnosis, connecting with other families living with T1D was truly life-saving. Hearing real experiences from people who understood helped me feel less alone and more capable."
>
> **Claudia**
> Child diagnosed age 4

Notice your emotions

Be aware of your own feelings and take time to process how you're feeling. Communicate those feelings with your partner, friends and/or family members.

How to support your child

If you're worried about how your child is processing everything that's happened, you can always reach out to your healthcare team for advice. In the meantime, here are some tips that may also be helpful.

Continue to be present

Your presence and reassurance will help your child feel safe. Physical contact is a great way to reassure your child — even just touching your child's shoulder when walking past each other, or having a cuddle while watching your favourite show can make a difference.

Explain it all

Help your child understand what's happening, using language they can understand. Let them know their reactions are valid.

Rely on routine

Use the comfort and safety of returning to your child's typical routines and activities. Support your child to get back into their usual social activities, to return to school, and do some activities on their own so they can build their confidence.

Remain calm

Try to regulate your own emotional responses, even in the face of challenging behaviours.

Set boundaries

While it's important to understand what underlies challenging behaviours, you also need to maintain your boundaries — for example, "You may be upset and angry, but it's still not okay to hit your brother!" Remind yourself how you would have dealt with this situation prior to diagnosis and support the 'safe' expression of emotions.

Talk it out

Help your child to feel empowered to talk about their feelings and what's going on with them emotionally.

You're the expert

Remember that you're the expert on your child — trust in your skills as a parent!

Your family and the protective nature of social connection

Family is one of the most powerful support systems children have and having access to caring and safe relationships reduces the impact of traumatic stress.[19] These relationships and connections can act as a buffer, supporting your child as they adjust to their new life with T1D, while feeling held and supported.

Here are some ways to reinforce those connections.

- A family who supports each other, with strong connections between family members, can cope better with what life throws at them. Check in with each other and make time to talk things through.
- Build trusted social supports in wider connections with extended family, friends, school and the T1D community.
- Say yes to opportunities to maintain social activities and routines that help support connections and relationships.
- Model positive coping strategies and manage your own emotional responses.[19] It can be as simple as taking a deep breath when you're feeling frustrated.
- 'Tune in' to your child to help them recognize and cope with their emotions.

When to seek further help

While children and their families can be amazingly resilient and their stress reactions resolve within a few weeks, it's important to recognize that these symptoms can continue, and will need to be addressed if they persist.

A study in 2007 investigated the psychological distress mothers experience following their child's diagnosis of T1D.[20] They found that 40% of mothers reported moderate to severe anxiety symptoms up to five years after diagnosis, with 17% reporting moderate to severe depressive symptoms. One in 10 met the criteria for post-traumatic stress disorder (PTSD).

Sometimes families are — or were already — experiencing difficulties and pressures before the added stress of a T1D diagnosis. The parents themselves may have experienced trauma in the past or could be living with their own mental health issues. They may lack high quality family and social support. All these things can increase the risk of having ongoing emotional difficulties following a traumatic event.

If you notice any of these symptoms, you (or your family member) may need to get some help:

- the initial high intensity stress reactions don't settle within a month [21]
- there's significant distress, and/or the symptoms are getting worse
- the symptoms are continuing to have a big impact on the ability to go to and engage with school or work, or to spend time with friends
- the family is under significant stress, and you're not able to manage your own (or your child's) reactions

It's when these reactions continue well beyond the point of being manageable that you may require the support of a mental healthcare professional, such as a social worker, counsellor, psychiatrist or psychologist. The longer these symptoms continue unrecognized and untreated, the greater the risk of developing mental health conditions such as depression or anxiety.

It's important to speak about what you're experiencing. As a parent, you can talk to your child's diabetes healthcare team and accept their guidance to follow-up with any referral to a mental health professional. You can also just start a discussion with your primary healthcare provider, if you have one.

If your child is the family member who might need more help, you can take them to their primary care provider, if they have one, or speak to their diabetes healthcare team for support and referrals.

Turn to pages 66 and 67 for national support services.

> "The T1D community became an extraordinary source of support on our journey. Connecting with other families, social workers, and accessing the resources available through Breakthrough T1D made an enormous difference for our family. Today, my son is doing wonderfully—happy, healthy, and thriving while managing type 1 diabetes—and we remain deeply grateful for the community that helped us get here."
>
> **Mina**
> Child diagnosed age 10

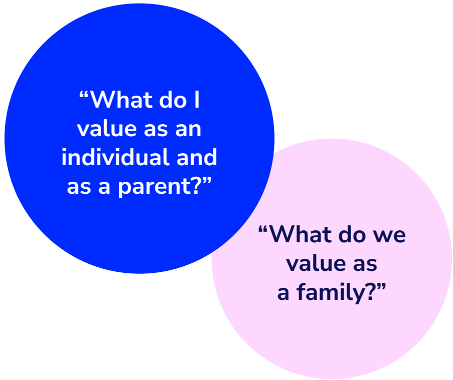
Section 6:

Comfort zones and your coping strategies

We often talk about how T1D needs to fit into your life, not the other way around, because T1D can — and will — likely be a real disruptor. It's easy to feel consumed by it: it's a dynamic, ever-changing condition that demands your attention. T1D could potentially dominate every thought, feeling and conversation you have. But this is exhausting and not sustainable. You need to also keep in touch with your family values, your individual beliefs, and your own coping strategies when managing life with this condition.

Is T1D making decisions for you? This is an interesting question, and one that's difficult to answer.

Of course, once T1D enters your life you'll be influenced by it, consciously or not. It will naturally factor in your decision-making. But what happens if you start make decisions based on the fear and worry that's generated by T1D? How do you stay true to yourself, your parenting style, and uphold your family values when you're feeling strong and complex emotions like guilt, fear and worry?



While many things have changed, so many more have not. Do you remember how you parented before T1D, and what was important to you? These things are vital to consider because they haven't necessarily been changed by a T1D diagnosis.

What you value as an individual will heavily influence what you value as a family. These beliefs will be the foundation of what you come to know as important and good for your family and will help guide your child in navigating T1D.

Here are a few common family values:

- educational values
- ethics (character of an individual)
- family time together, including family entertainment
- family traditions
- financial values
- fitness and health values
- morals (principles of right and wrong)
- religious or spiritual values
- social behaviour
- strong work ethic

Why are we talking about family values? Because when a life-changing event happens, it is important to lean into your values, strengths and resilience as guiding principles.

Adversity, no matter how big or small, will go a long way in building resilience — your own as an individual, and your collective resilience as a family.

Your child comes first, T1D second

It's important to parent as your authentic self. You need to maintain the boundaries and limits that were there before diabetes, relying on your own values and beliefs. Sometimes we second guess ourselves post-diagnosis, and this gives T1D more power than we intend it to have.

It might take a bit of getting used to, but in terms of parenting, your child comes first, with T1D a close second. Going to parties, sleepovers, school camps and visiting with family, to name a few, are essential and incredibly enjoyable aspects of growing up and feeling included. T1D doesn't determine whether your child can do these activities — you do. And your decision needs to be based on what you believe is important and what you value.

If you've always valued strong family connections, resilience-building through teamwork and participation, or the bonds that only best friends, secret chats, and sports teams can bring, it's understandable that you'll still want your child to take part in these experiences.

It's also completely understandable to feel scared or worried and lack the confidence to freely send your child away to camp or a sleepover. Whether you like it or not, your child's priority may not be T1D, especially in these situations. Sometimes they'll be too distracted, excited and overwhelmed with the situation to factor in their diabetes, or it could be because they are striving to be like their peers without T1D, or other competing developmental priorities.

Most people use a combination of coping strategies, dependent on the situation and how supported and confident they're feeling at the time.

But to break it down, the goal of a school or summer camp, sleepover or party is to have fun, hang out with friends and socialize — which is why avoiding these activities can cause more harm than good.

Coping strategies and how T1D fits into your life

T1D is workable around any life experience. There's always something you can do to manage it — it might just take a couple of extra steps. But your decisions will always be grounded in your parenting style and your level of comfort taking these steps.

Being in your comfort zone can make you feel like you're in control, but it also can get in the way of growth and learning new skills. These are things that are familiar, where anxiety is relatively low. So basically, in this state, we're feeling comfortable, unchallenged and secure.

But with a diagnosis of T1D, you and your family are now expected to learn a lot of new information, gain specific knowledge, and then apply it in real life. These newfound skills and knowledge can change into a significant and natural level of anxiety. We'd expect you to feel a little bit out of control, uncertain and very challenged — and definitely out of your comfort zone.

While it's great to recognize that you are outside comfort zone, it's even more important to understand how you typically respond when pushed well outside of it. It can be a good idea to consider your coping styles and what they may look like in these situations, because the strategies we use to cope can either help or hinder us.[22]

Behavioural support
(think of the ‘doer’, the person who just gets things done)

Advantages

- Taking active steps to reduce stress.
- Problem-solving the situation.
- Well-suited to organized, scheduled task-orientated, process-driven people.

Disadvantages

- May favour logic over emotion.
- May present as rigid, making it difficult to delegate tasks and accept help.
- Scheduled, process-driven people may have difficulty handing over T1D care to a teen who may not be highly organized.

Emotional and cognitive supports
(think of a nurturing and thoughtful type of person)

Advantages

- Managing your own emotional response, seeking emotional support.
- Taking an alternative perspective to reframe the situation, looking for a positive within the negative (searching for a silver lining).
- Well-suited to relationship-focused people who want to check in on how everyone else is managing.
- Also suited to less routine-driven people who are flexible and open to new and novel experiences without much warning.

Disadvantages

- May favour emotion over logic, so solving problems can be challenging.
- Flexible, spontaneous people can feel the pinch when asked to develop a routine that will support T1D management in a more predictable way.

Acceptance-based supports
(think of a person who tries to have a balanced approach over time)

Advantages

- Distancing from a distressing topic, when we’re overwhelmed and need a break.
- Taking a more accepting stance that there are ups and downs, and that they can ride the wave over time without dwelling or avoiding.
- Using mindfulness strategies to stay in the present moment (not focus on the past or the future) and practice self-compassion for struggles.

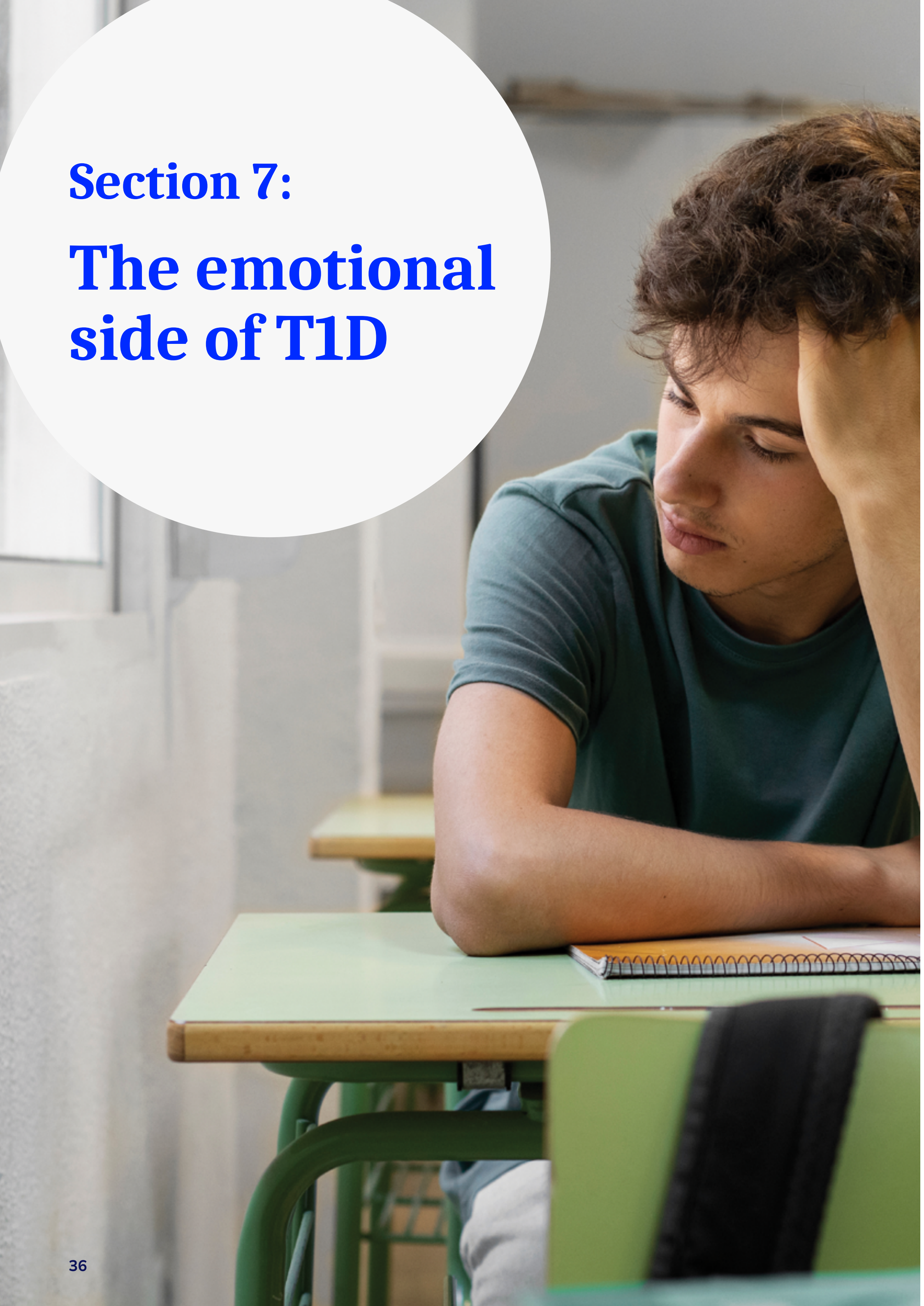
Disadvantages

- Avoiding or denying a distressing topic for long periods of time, without re-engaging after a brief break may not be helpful in the long term.
- May lead to experiential avoidance of people, places and decisions that trigger feelings of discomfort.
- May reduce connection with others who can be supportive.

Recognizing that there’s more than one way of coping — not only individually, but also within a family — is important. You might become good at seeing that everyone uses different coping strategies, but the challenging part can be building a tolerance to doing things differently.

What are your coping strategies? It can help to notice them and how well they work for you.

It’s definitely healthier and more helpful to reduce the use or overuse of any coping strategy that doesn’t result in any sustainable changes. Increasing your use of effective coping strategies will help you adjust and reduce your risk of developing anxiety and/or depression, in response to stressful and traumatic situations.[23]



Section 7:

The emotional side of T1D

It's time to focus on understanding some 'emotional aspects' of T1D management from the perspective of your child.

Yes, this is a well-being resource for caregivers. But as most parents know, the more you know about your child's emotional capacity, challenges and triggers, the better you'll be at supporting them and yourself.

Pausing to listen

Letting kids feel what they feel without rushing into problem-solving mode is often easier said than done, but it's a valuable skill to have in your parenting toolkit.

If you're busy solving problems for your child, trying to repair damage or make the hurt go away, you can't see that you're inadvertently being dismissive of their intense, potentially complex emotions. But children want to be heard and validated (even if the way they're delivering their message is confronting and, at times, triggering!). It's vital to pause the desire to 'fix it' and just listen.

You might have heard variations of these statements at different times since your child's diagnosis:

- "I hate diabetes"
- "Why me?"
- "I just want to be normal"
- "I don't want anyone to know I have diabetes!"

No matter how many times they say it, one thing may remain the same: the sense of fear and dread that may appear in the pit of your stomach. But there are methods to help them cope with these feelings while making them feel validated and heard, too.

'Emotionally tricky' aspects of T1D management require us to walk alongside our children, not to try to rationalize their pain away.

As a parent, you're so valuable and integral in your child's life. Many healthcare providers will note parents who are very concerned about the amount of distress their child is in, no matter how much comfort they give them. But the child will often say that the most helpful thing for them was being able to tell their parents how they were feeling, knowing they'd be comforted.

All your hard work counts

In times of stress, when children might be engaging in distressing, risk-taking behaviours or doing the exact opposite of what you want from them, one can resort to unhelpful ways of parenting (e.g., shaming, blaming, threatening, yelling). Basically, you can easily forget everything you've spent years teaching your child.

Think about all the things that go unsaid: how you instill your values in them, treat them with respect and kindness, have faith in them, and support them in their endeavours. All this unspoken connection and support, and your presence in your child's life, is what creates an amazing protective factor when they're experiencing distress, complex emotions, or are simply in trouble.

The downside of this, of course, is that you may be on the receiving end of their emotions, the one who deals with the storm before the calm returns. You may be blamed — unfairly — for everything that's gone wrong and continues to go wrong. They feel safe enough to share those big emotions with you and secure enough to know that you'll help them navigate these stormy waters.

The power of validating instead of problem-solving

It's common for kids living with T1D to tell their parents how much they hate diabetes, how unfair it is, and how they wish they never had it. It's all completely understandable, and a very reasonable request. Living with T1D can be very hard.

In this case, you have two options.

Option 1

Rationally tell them that if you could, you would take their T1D away. If you're being extra rational, you might even say, "Well, you do have T1D, and we can't take it away, so we're going to have to find a way of dealing with it." (Even more extreme, you could try and convince them that it's not that bad, and that it could be worse.)

OR

Option 2

Pause, then let your child know that you can only imagine how upset they must feel. Also acknowledge that you don't actually know how they're feeling. Validate how unfair this is without trying to rationalize it or find a silver lining. This situation is unfortunate for your child, so let them feel it.

As a parent, the first option makes us feel helpful and very competent. We've been clear and demonstrated our love and willingness to take the burden away and share the load. But we've also slipped into problem-solving mode as a way of trying to minimize distress. Unfortunately, this won't actually help your child build resilience and develop the skills they need to manage the difficult things in life, including T1D management.

On the other hand, the second option helps your child sit with uncomfortable feelings and build their tolerance for emotions such as fear, worry, frustration and disappointment. It's so valuable to use every opportunity to teach your child how to manage these difficult times, as opposed to trying to avoid or minimize them. It's these moments that will support your child to build emotional resilience for the uncertainty and frustration that comes with managing a chronic condition like T1D.

How to solve an unsolvable problem? In the eyes of your child, T1D is a problem that can't be solved, so it's better to learn how to tolerate uncomfortable and complex emotions, rather than avoid them. Then you can focus on what you and your child can actually control.

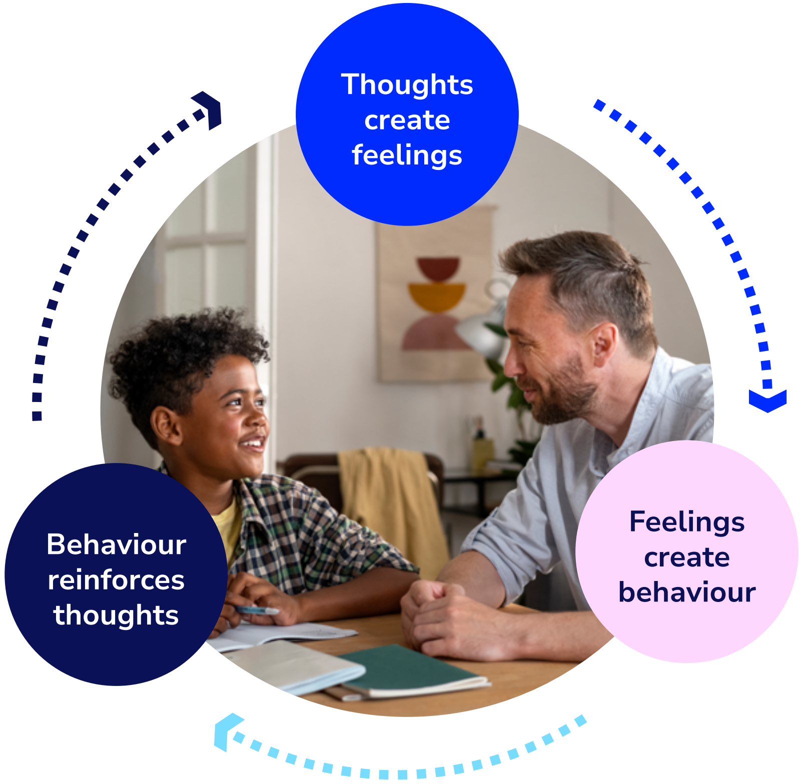
Thoughts, feelings and behaviours: the difference between them all

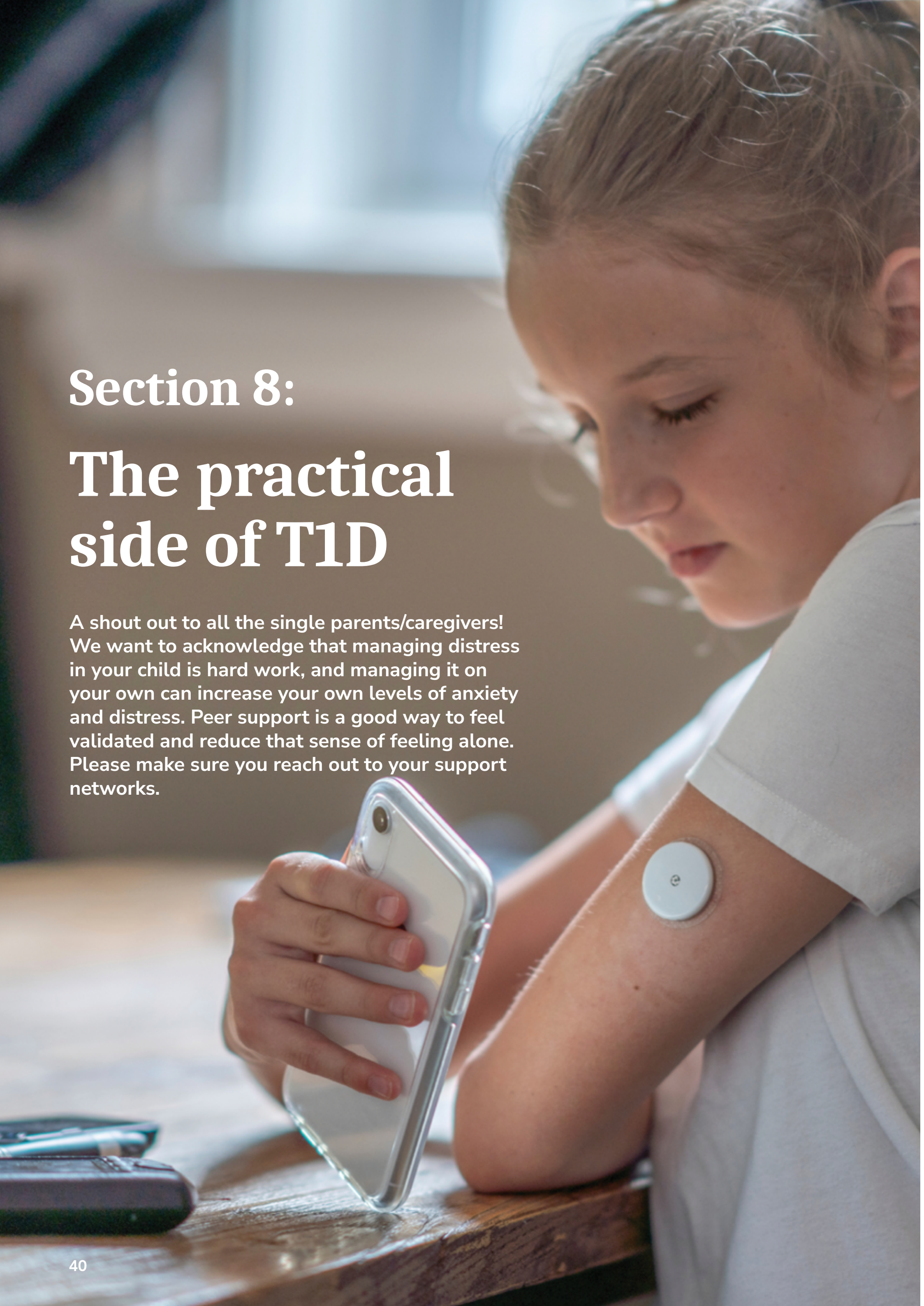
Before a behaviour presents itself, there was a thought and a set of emotions to accompany it. That's why we suggest you treat behaviour like a clue. Kids — especially adolescents — are actually pretty good at dropping these clues all over the place. It's just easy to miss them, because they often don't make sense!

As an example, younger children will smother you to let you know that they need something, completely invading your personal space and whining relentlessly until you stop, look and listen. But by the time you're ready and willing to listen, you're probably feeling frustrated and irritated.

In contrast, your teenager can let you know that they want connection with you by pushing you away. They can sometimes seem to have little to no tolerance for the fact that you're just not getting it and be downright rude and irritable. This can backfire and work as a deterrent, making you feel rejected and hurt.

But this is when your ability to manage your own emotions in response to this backlash from a child is so valuable. Often, a child's behaviour can be a real trigger, and the negative emotional response can cloud a parent's ability to respond effectively. But by paying attention to what they actually need, and what clues they're giving, you can learn the best way to reach out to them, regardless of how much they might be triggering you.





Section 8:

The practical side of T1D

A shout out to all the single parents/caregivers! We want to acknowledge that managing distress in your child is hard work, and managing it on your own can increase your own levels of anxiety and distress. Peer support is a good way to feel validated and reduce that sense of feeling alone. Please make sure you reach out to your support networks.

A lot of the content in this guide covers the emotional aspects of life with T1D, but it's equally important to consider the practical care aspects that can create conflict. These are the non-negotiables: the unwelcome but necessary aspects of T1D management.

The non-negotiables

There are many non-negotiable aspects of T1D care that can add to the frustration and burden of living with this chronic condition. Your child's age and their stage of development will influence how well they're able to understand it all, and how they express their feelings about it. Frustration, disbelief, grief and sometimes anger are all part of the process, but these complex emotions are often expressed as reluctance, bargaining, disengagement and avoidance.

The concept of 'doing something I don't want to do but know I have to' is a difficult one to master. And just because your child needs to know the practical aspects of T1D management — and then treat these tasks as non-negotiable — doesn't mean they'll be able to effectively do it every time without resistance. (If your child is also living with a neurodevelopmental disorder like autism or ADHD, their way of processing, retaining and recalling information will also be affected.)

When something is non-negotiable it can make us feel powerless, vulnerable and out of control. It can make children want to regain some of that control back, often in creative and challenging ways. Not eating certain foods is a classic way of trying to do that — if you've ever tried to get a toddler to eat what you want when you need them to, you'll understand this well.

Another classic example is a teenager who wants to manage their T1D in their own way and not 'like mom and dad do'. Even though you'll have had years of trial-and-error behind you, which has led you to think it's the best way to manage their care, they may want to have the autonomy to discover what works best for themselves.

Practical examples from life with T1D

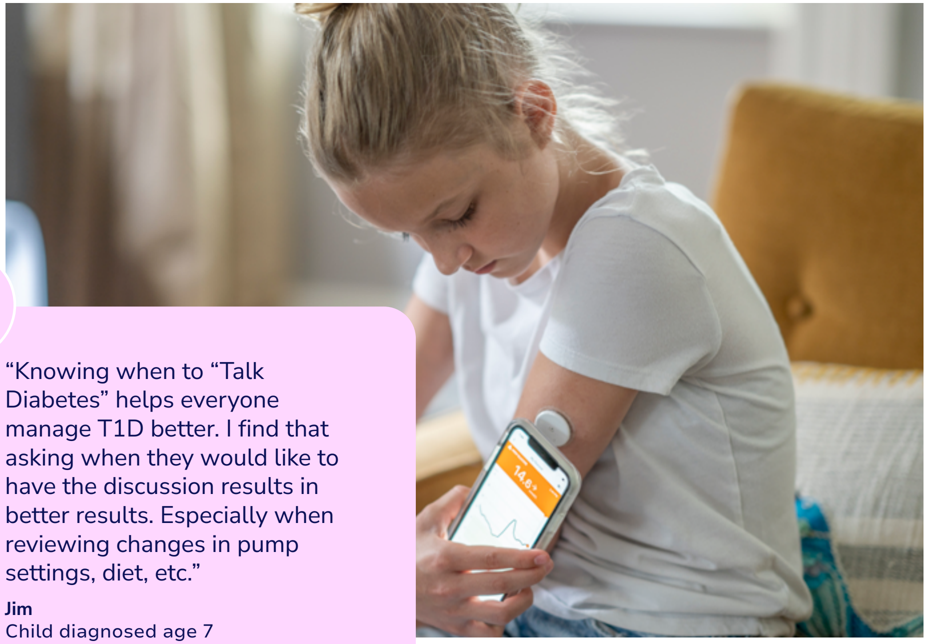
The following situations are all typical parts of managing T1D. This is by no means an exhaustive list, but it will give you some food for thought when it comes to understanding the difference between the emotional and practical sides of T1D care, and some ideas on how to deal with these issues.

Anxiety around injections and site changes

Injections and site changes are vital parts of T1D management, but it's a rare family who has never had any drama around these non-negotiables. Here's some insight into it.

Understand what you're seeing and feeling

- Children have a natural level of fear surrounding things that are unfamiliar and/or perceived as painful and scary. This is their protective factor and an intrinsic warning system. Their apprehension and resistance are to be expected, especially in the beginning.
- Everyone is learning a new skill, which will be coupled with a natural level of anxiety. This is unavoidable. Likewise, fear is typical and is not an emotion to be avoided. It's also not a reason to avoid a task.
- Depending on your child's age, you may be responsible for all injections and finger pricks, so your own anxiety may be triggered. Along with your desire to protect your child, you may find yourself having thoughts like "I don't want to hurt my child."
- If you had someone else giving you an injection or inserting a sensor or pump site, you'd feel scared and apprehensive, too! Anticipatory anxiety about something that is about to happen is very real and waiting while someone else calms their own emotions can make you more nervous.



> "Knowing when to "Talk Diabetes" helps everyone manage T1D better. I find that asking when they would like to have the discussion results in better results. Especially when reviewing changes in pump settings, diet, etc."
>
> **Jim**
> Child diagnosed age 7

What you can do about it

- **Be patient:** Adjustment takes time, and you and your child are both learning several new skills, all at the same time.
- **Be prepared:** When doing a site/sensor change or insulin injection, set it all up so everything you need is easily accessible, and then call in your child. Watching you gather what you need and waiting around may only increase their anxiety.
- **Don't set yourself up to fail:** Address your own needs first – you're going to need to 'mirror' your own calm to your child, then help them contain their emotions. The last thing you want is both of you crying because you're hungry, had a fight with the boss or simply because you need to go to the bathroom! You don't want to feel impatient, and rushing an anxious child or this kind of situation will never end well.
- **Be clear about what's happening:** Set your boundaries and clearly agree on the time and location where this task will take place (for example, the living room at 4 p.m.). Prepare everything you need beforehand and agree that you'll be the one to do the task (or agree on how your child will assist/participate). Communicate the amount of time you're willing to spend on this task and stick to it.
- **Practice really does make perfect:** Avoidance gives you short-term gains but long-term pain.
- **Be honest:** It can be tempting to say things to try to make your child feel better, like, "It won't hurt" or "You won't even feel it." But we know that injections or finger pricks do hurt, even if it's just a tiny quick sting. You want to be the safe and protective space for your child, and you can do that by being supportive by distracting the child or keeping a positive facial expression and upbeat tone of voice while saying things like, "You're almost done" or "Look at our Rufus teddy bear."[24]
- **Focus on the task:** The more you talk about it, trying to get your child's agreement or apologizing to them, the more time you're giving your child's anxiety to rev up and take over. Minimize the discussion, get the job done, then make sure you cuddle when it's done.
- **Don't try to rationalize with the irrational:** Anxiety is based in irrational thought. While the fear is real, the situation is often not an actual threat.
- **Get help if you need it:** It's normal to feel anxious about new and frightening experiences, but repeated, intense bouts of anxiety that affect functioning, or stop you from doing the things you want or need to do, must be addressed. There's a huge difference between feeling anxious about something and living with a diagnosed anxiety disorder.

To consider: What are your non-negotiables? In terms of T1D, as well as everyday life?

Fear of hypoglycemia

Fear of hypoglycemia can be difficult to talk about. You're essentially talking about anxiety, and this type of anxiety can quite literally keep you up at night. Fear of hypoglycemia is described as severe anxiety related to the management of blood glucose levels, and is often accompanied by avoidant behaviours.

Understand what you're seeing and feeling

A good example of fear of hypoglycemia is maintaining glucose levels above target overnight, as this period is often a time when parents worry the most.

Thought

"What if my child has a hypo while I'm asleep and I don't wake up?"

↓

Feeling

"If I don't wake up, I'm scared that something serious will happen"

↓

Behaviour

"I'll run them a little higher overnight" or "We can have a top-up snack before bed"

- When we're scared, we feel compelled to make decisions with our emotional brain, not our logical brain. This means we meet the short-term need of containing the fear (emotion), but we aren't able to consider the longer-term consequences (logic).
- Fear of hypoglycemia is very real, but remember that fear as an emotion isn't particularly helpful. Think of the phrases 'paralyzed with fear' or 'frozen on the spot': if you really needed to act, would fear be the best emotion to drive you?
- If we fear something we tend to avoid it — we're biologically driven to run in the opposite direction of threats. Fear cues us to perceive the situation as dangerous and either freeze, run or fight.

What you can do about it

- **What's in your toolkit**? What technology (if any) are you using? Do you understand and trust the features designed to be assistive? How confident are you with your problem-solving skills?
- **Reach out:** Never be afraid to link in with your diabetes care team and get the support and strategies you need. This will help you feel you have the knowledge and confidence to manage diabetes overnight.
- **Talk to your healthcare team:** Discuss devices that may be suitable for your child. Advances in diabetes technology such as continuous glucose monitors (CGMs) and hybrid closed loop systems provide real-time monitoring of blood glucose levels and help you better adjust insulin doses. These are designed to reduce the incidence of nocturnal hypoglycemia and address some of the difficulties in managing children's T1D during sleep.[25]
- **Work on your own anxiety:** anxiety can be contagious, so you need to check in with yourself and get professional help if you feel your own worries getting in the way of you trusting advice from your diabetes care team. The last thing you want to do is give in to your anxiety and that fear is a required part of managing T1D, especially overnight.
- **Tap into your community:** connect with peer support groups, in person or online. Talking with other parents who have gone through (or are going through) a similar experience to you can be helpful and remind you that you are not alone in the way that you are feeling.
- **In the face of anxiety, talk less.** You may be able to rationalize that you're 100% acting in your child's best interest, but you won't get their agreement.

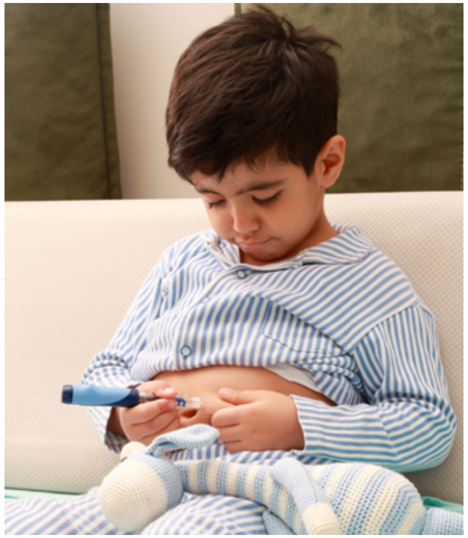
Use of technology

Advances in T1D technology have been outstanding, greatly improving the quality of life of children and young people living with T1D. These advances also support family functioning and reduce parent burnout. But they can also bring conflicting emotions.

Understand what you're seeing and feeling

- Be honest and patient with yourself — don't feel ashamed to admit that sometimes technology can be intimidating.
- You're developing a trusting relationship with your technology, and this takes time.
- Anxiety has a role to play in how we engage with technology. We're learning new skills, and a natural level of anxiety comes with that.
- We may find ourselves checking data at all hours (even when natural rises in glucose levels are expected, like after a meal). Knowing when to check data and understanding what you're seeing are vital to manage anxiety levels.
- Your child might not be as enthusiastic about technology as you are (or vice versa). They may not want to wear a sensor or insulin pump as they're worried about unwanted attention, or you could feel concerned about learning a new system or trying new technology.

If you find yourself saying or thinking "We need to keep you alive tonight" or "Your CGM keeps you alive", you might want to consider the language you're using and how helpful it is for you and your family.



What you can do about it

- **Knowledge is power:** Research the technology you're interested in. Talk with your diabetes care team if you have any specific questions or concerns. Connect with other families who are already well-acquainted with diabetes technology.
- **Pace yourself:** Don't feel like you need to be an expert in the technology immediately. This is a learning experience, and mastery takes time.
- **Work with the alarms:** If alarms are being disruptive, or your child is frustrated with alerts at school, check which alerts are activated and why they're in place. Talk to your diabetes care team to get support with adjusting the technology to make sure it's working for you.
- **Alarm fatigue is very real:** You do have the power to turn things off and decide which alerts are helping you manage T1D in a supportive way, without increasing anxiety. Never be afraid to question this.
- **Talk it out:** Always talk to a trusted member of your care team, whether it be your endocrinologist, a diabetes educator, dietitian or mental health provider about your concerns or issues. They're there to support you and help you gain confidence in using technology safely and effectively.

School (AKA "No one will manage my child's T1D the way I do")

It's natural to want the very best for your child, and to want to protect their well-being and longer-term health. After all, it's our job as parents to protect our children and keep them safe. But this also includes supporting and preserving their quality of life — which includes being away from you as they attend school. This all takes balance and practice!

Understand what you're seeing and feeling

- It can feel as if children spend more time at school than at home, and having T1D managed away from home can be a real source of anxiety for parents.
- It's essential to balance good mental health with physical health. By focusing all your efforts on glycemic goals, at the expense of balance, mental wellness and connection, you can burn out and create greater T1D conflict and distress.
- Most teachers and school staff won't be anywhere near as confident and knowledgeable as you are when it comes to T1D and its management. This can add to your concerns.
- Think about your expectations of how T1D is managed at school. Parents can feel frustrated by how structured or rigid they find processes and timetables, as the flexibility isn't there to troubleshoot or problem-solve situations.

What you can do about it

- **Remember why they're there:** Keep in mind why your child is at school — to learn, engage with friends and peers, and develop essential skills in building and sustaining healthy relationships. We foster these skills at home, but school provides an environment that's both nurturing and challenging. They need these opportunities.
- **Keep up-to-date:** Ensure that all school management plans are current, reflect what's happening in T1D care, and have all the relevant details. With the support of your diabetes care team, adjust any management plans that are outdated.
- **Be involved:** Know what's in the school care plan so it matches your expectations, as well as those of your diabetes teams.
- **Be prepared:** Make sure the school or your child has the necessary supplies stocked and easily accessible (including insulin that's in date, hypo kits and hypo food).
- **Communication is important:** Whether it's through a communication book or regular chats/texts with the teacher, keep the lines of communication open. Keep in mind that it's a difficult balance — you don't want to overwhelm the teacher with worst case scenarios that don't happen on a daily basis (or haven't even happened at all in your family), but you want them to understand the importance of not delaying tasks related to any potential T1D issues. Try to talk about how to follow the plan and be open and available (where possible) to answer questions. Remember how you felt trying to learn everything? We need to lend some of that compassion to the teachers. You're now the T1D expert and they're being educated on it all. (Note that personal opinions have no place in school agendas: if the teacher isn't policing every child's lunchbox or commenting on every child's behaviour, there's no reason for it to be happening to your child. T1D doesn't give anyone a reason to put your child under the microscope.)
- **Set boundaries:** Sometimes good intentions can turn into confronting conversations and increased conflict. Ask almost anyone and they'll think they know something about diabetes, which can lead to unsolicited advice. Don't be afraid to have boundaries — you can be kind but firm!

Section 9:

Age-appropriate expectations

In this section we're describing typical development to highlight the broad challenges during these stages. We'd like to acknowledge that many children have additional needs; they may be neurologically diverse, have additional chronic conditions to manage, or live with a physical or mental disability. This adds greater complexity.

We make countless decisions without consulting our children every day, mainly because they're not mature enough or developmentally ready to participate in the process. We don't question this, and we know that as time goes on, they'll mature and contribute to discussions across several areas, including their own health.

This section is designed to give you an overview of different developmental stages, providing some understanding of how they interact with T1D and to help you manage your own expectations. This will give you context around typical development that would happen with or without diabetes.

What is your child capable of?

There can be a tendency to think that T1D accelerates development — particularly when (in your eyes) your child isn't taking the diagnosis or their health seriously. Some children just want to return to business as usual, to the things that are meaningful to them, such as sports, friends or gaming. This won't necessarily be consistent with your own expectations.

But while T1D doesn't accelerate development, it can require our children to develop behaviours they may simply not yet be able to do. It's important to consider what you want or need your child to be doing versus what they're actually capable of doing.

Think of it this way: if your child didn't have T1D and felt sick, what would you expect them to do? They would come to you and ask for help. This is developmentally appropriate, as good health behaviours and asking for help is a skill we develop. Again, this is a journey, and it can't be rushed (no matter how much you may want to).

A diagnosis of T1D doesn't accelerate development in any way. Your child is still your child, and they're entitled to the carefree aspects that childhood brings.

Why do we feel like we want to rush development?

It's scary and stressful to think that your child isn't willing or able to look after themselves when they're away from you. You've probably experienced this when you tackled a bout of typical childhood condition, pre-diagnosis. The difference now is that T1D is constant, needs regular participation, and has delivered a decent dose of legitimate fear.

When you have a young child living with T1D everything is your responsibility, which has a big impact on family life. So, it makes sense that you may want your child to do more than would normally be expected of them.

This is not an unheard-of parent struggle. Most of us fantasize about the day our child will dress themselves or make their own school lunch — or, better yet, get themselves to school on time. This is normal and harmless. We might get frustrated if we need to step in and help, but we tend to not overthink it.

Then comes T1D and suddenly the stakes are much higher, and we forget that our children won't prioritize and value T1D and its management as much as we do — because developmentally, they can't!

Birth to 5 years

You'll see the largest changes in the growth and development of your child in their earliest years. (Think of the difference between the baby you bring home and the child you send to school!)

- With an increase in motor skills (fine and gross), your child's activity will become far more varied and difficult to predict.
- While there's rapid growth in the brain within areas of language, memory and learning, your child still lacks the cognitive ability to identify and alert you to their physical needs.
- As your child becomes a toddler, this rapid growth will slow down. Their appetite will reduce as a result, and they'll be more likely to display picky eating behaviours.
- When they start to develop more reasoning skills, you'll be more likely to experience some attempts to become their own person, as your child is more able to express their wants (including the discovery of the word "no"!).
- They'll develop more of an ability to share and take turns, having more of an awareness and empathy of others.

What happens when T1D is added into the mix? Parents of children diagnosed in this age group have to use a unique set of parenting skills — which can feel like it includes mind-reading, as your child will lack the thinking and language skills to identify when their blood glucose levels are either too high or too low. Parents will also have sole responsibility of T1D management tasks, as their child won't have the maturity or skills to take them on.

The lack of fully formed thinking and language skills also means kids this age struggle to communicate their emotional state. Their uncertainty, fear and distress will come across in their behaviour, and this can look like tantrums, aggression and refusal to comply with tasks.

To add more difficulty, it can be very tricky to tell the difference between developmentally appropriate behaviour (such as temper tantrums) and behavioural cues that signal high or low blood glucose levels.[26]

Try not to jump to T1D being the cause for all behaviours, as sometimes it is just normal development. But don't dismiss it either. A tantrum can be 'just a tantrum' or it can be a child whose blood glucose levels are high, and they can't explain how they're feeling so they lash out instead. Try to rule out T1D first, and then address the behaviours.

You may feel like you're intuitively managing their T1D in this developmental period, because you're constantly looking for clues. You'll also be challenged by rapid growth and changes in your child, and what this means in terms of their insulin needs.

This period of development makes T1D management unpredictable and far more challenging than one would expect. Please remember that when you're being hard on yourself.

How to manage this developmental period

Parents must access every skill in their toolkit.

- Be consistent with clear expectations. Set boundaries and limits.
- Explain things in a way your child will understand. If it sounds completely rational and logical to you, as an adult, you've probably over-explained.
- Help your child develop emotional awareness and language to support them to express their emotions appropriately. For example, try reading books specifically designed to talk about emotions.
- Validate and help your child manage their own emotions by using your co-regulation strategies.
- Manage your own anger and distress at your child's behaviour.
- There will be T1D non-negotiable tasks, and you'll need to be consistent in carrying these out. But watch your own expectations — just because you've explained why non-negotiable tasks exist (which is important for your child), it doesn't mean that they'll be accepting of them, or that they'll be able to manage the frustrations associated with them.
- Your child might want to feel in control or be involved and helpful — and you can make this happen. For example, your toddler might want to choose what to wear for the day, so you can help by giving them the option of two or three outfits, and then they can pick. You might do something similar with some T1D non-negotiable tasks: try to find ways in which they can take part or make choices that work for both of you, such as letting them choose which finger to prick, or give them options for where to put their sensor.

It's important to understand that you can't completely remove your child's distress surrounding their T1D diagnosis and the associated tasks. It's enough that you're providing validation and support.

Ages 6 to 12 years

Children grow at a more stable rate during this stage of development, with less variations seen in younger and older age groups.

- Their fine and gross motor skills will continue to develop, reaching a stage of mastery towards the end of this period.
- Their thinking and language skills will continue to grow, and they'll be better able to articulate their needs and wants.
- Children will start to be more independent during this stage (but keep their temperament and environment in mind, too).
- Kids in this age group will compare themselves to their peers and will be more conscious of rules and expectations.

While this can feel like a more stable period of development, there are still things that need to be taken into consideration from a T1D perspective.

At this stage, children can start to verbalize their distress about T1D, as well as their worries about being different from other kids. This can be pretty challenging as a parent, as you'll be trying to normalize T1D for your child in a way they'll understand, while also trying to reduce their distress and improve self-management… all while managing your own distress as your child struggles with being different from their friends.[27] It can be tough!

Your child's ability to understand their diabetes and communicate their needs means they can have a bit more autonomy. They might start to be more involved in their T1D care as they show a bit more interest. But while they may have the fine motor skills to do a finger prick, they'll still need your help and supervision to interpret any data. Children still have quite concrete thinking at this stage —they're typically not yet fully able to problem-solve, so you'll need to stay highly involved in supervising and participating in T1D care.

How to manage this developmental period

- All children are entitled to experience childhood, so it's important to be very careful that you're not expecting them to be more responsible than they have the capacity to be because of your own fears or concerns.
- It's important that parents manage their own expectations. It can come across as hypercritical and judgmental because as an adult you've already mastered these tasks and skills, and often forget that kids are still in their learning phase. (For example, think about how long it can take your six-year-old to do up a button or tie their laces!) Resist the urge to take over when they want to do tasks themselves. Try to be warm and understanding in your approach, and they're more likely to listen and learn.
- Don't be afraid to use rewards, incentives and other external motivators to support your child to engage in their treatment, especially for a new behaviour you're trying to kick start. You'll be using their currency and engaging in a way they understand. We all need motivators to keep us on track — even as adults we can think of times when we don't complete a full course of antibiotics, or don't do our 30 minutes of recommended exercise a day. Just because it's important doesn't mean it's easier to do or maintain, and it's genuinely hard to stick to any health behaviour consistently and indefinitely.
- It's important to reach a balance between autonomy and parental supervision. This is when your child can start to build their confidence in understanding the practical components of managing T1D. You'll still need to be clear around tasks and expectations, as children in this developmental stage can be unpredictable in their actions and ability to follow through.
- Talk about why your child needs to do their T1D tasks, but don't forget that kids also learn through the behaviour you model. They're learning from your attitude, the routine you set up, and how you incorporate T1D into family life.
- Remember that your child goes to school to learn and develop social and emotional skills, not to focus on T1D management. In saying this, your child may start to show more distress around the intrusive nature of T1D and the disruption it causes throughout their day. It's essential to engage with your child's school and actively facilitate support, as you want their T1D management to be as simple and with as little interruption as possible.
- Continue to validate and support your child when they share their distress about how T1D impacts their life.

Ages 13 to 18 years

Adolescence is another period of significant developmental change. It can also be quite a tumultuous period for parents!

- The rapid physical growth that's associated with puberty results in an influx of hormonal changes, which will invariably affect diabetes management.
- Your teen may have a preoccupation with their body image.
- This is a period where adolescents are forming their identities. This often looks like distancing from their parent, as they feel the need to be as different from their parents as possible.
- At this age, your influence will be less prominent (but still equally important to maintain!) while their peer influence grows.
- Your child will be more independent, spending less time with their parents.
- This developmental period sees teens taking more risks and displaying more impulsive behaviours.

This is a particularly challenging time for the management of glucose levels, as the body has a period of insulin resistance due to puberty and physical growth. It's also compounded by teens needing to take on more responsibility for their T1D care, as they'll be spending more time with their friends and less time with their parents. There may also be less supervision and support around T1D as they enter high school.

Unfortunately, your teen may still not yet have all the skills to manage everything they're faced with. Their brain is still maturing so their planning skills aren't fully developed; they're also more impulsive, and more governed by their emotions over logic. As a result, this very appropriate developmental need to separate from parents can create conflict, particularly around T1D care.

A real-life example

Josh and his friends decide to play basketball after school. Josh knows he doesn't have his T1D supplies on him, but that's okay because he'll be home for dinner. His friends then head to Matty's house for pizza and a movie afterwards. Josh doesn't want to miss out, so he goes along and decides he'll correct his blood glucose levels later.

Is Josh being completely irresponsible? Well... no, he's being a typical adolescent. You can bet that if he was switched on enough to call or text his parents, there's every chance he'd give the impression that he had his insulin with him and "everything's all good!"

Josh's parents may desperately want him to make different decisions, but the only solution is to accept that he'll make these mistakes. They'll need to be prepared to check in, remind him, and support him to plan. And yes, that may look like the dropping off of his insulin occasionally at a friend's house after basketball practice, instead of insisting he comes home.

If your child thinks to call you and let you know their plans have changed, yelling might be your first instinct, but try to fight that — it's not particularly helpful.

How to manage this developmental period

- You may need to put more effort into your own emotional regulation during this time, as parenting an adolescent can be incredibly triggering. Increase your behaviours that are supportive and understanding, like quietly listening to them tell a story about the wild party they went to, and try to reduce criticism, judgment and the urge to solve their problems. It's worth the effort, as these positive interactions can improve your relationship with your teen. Ultimately, you want to be their safe space when they need it.
- It's important to keep the lines of communication open, reassuring them that what they're going through is normal.
- Remember that your teenager's need to push boundaries is essential for their development, so try not to make T1D management your main area of conflict. Avoid making it the first question you ask when you see them.
- Engage your teen in joint decision-making around their T1D care, as they'll now be learning skills that will support them into adulthood. Negotiate the non-negotiables around T1D and how this might look — ask how, not if, they'll be completing the task.
- It can help your relationship if you let your child develop independence in other areas outside of T1D, especially within their social and peer relationships.
- There is such a thing as natural consequences to behaviour, and sometimes we can forget this. As parents, our job is to support our teens to develop self-care skills, but to also be there as a safety net when they need guidance. For example, think about how you parent behaviours not related to T1D. Do you feel guilty for giving a consequence when your child doesn't do their chores, or if they stay out after curfew? What about if they drove their car while their blood glucose levels were below five? Try not to let the emotion of T1D get in the way of your effective parenting behaviours.
- Finding their motivator or currency can be helpful in supporting your teen. We all need motivators to carry out tasks that we have to do, rather than want to do. T1D tasks are no different.
- Don't be tempted to scare your child with the risk of T1D complications. We know this doesn't stop kids taking risks — they think they're invincible and that the 'bad things' won't happen to them. That's why teens and young adults are more likely to speed while driving and take more risks than most adults!

The importance of the parent-child relationship

It's important to build confidence in your own parenting skills and instincts — and a chronic condition diagnosis often means parents need to upskill in certain areas. Parenting programs can help.

Many parenting programs focus on attachment. This is the process used to protect your child from harm, making them feel safe and secure, which gives them a sense of emotional security and a secure base for exploration. Rather than using rewards and discipline alone, attachment is based on children having a secure figure they can trust, who'll be responsive to their needs when they're distressed. Doing this supports your child's ability to develop their emotional regulation skills.

Ultimately, the goal is for parents to be able to tune in to their child, and to be predictable and safe. We can scare our kids if we're emotionally dysregulated and appear erratic in our behaviour, as then they don't know what to expect (for example, if your child broke your favourite mug and you then lost your temper, appearing out of control, yelling and throwing things).

Another thing to consider is that a positive attachment with your child supports their behaviour and engagement with T1D treatment — that's a win/win! So keep on:

- supporting, nurturing and connecting with your child
- actively talking about how your child is thinking and feeling
- creating shared experiences and family memories, such as special occasions and family traditions
- giving physical contact (hugs are healing at every age, but make sure you get permission first!)
- being consistent in your behaviour, expectations and consequences

"What about me?" The impact on siblings

This is the perfect time to talk about siblings, because what we've just discussed relates to all your children.

T1D affects all members of the family, but how this shows up in each child will be different depending on their temperament, age, other stressors and life experiences. It's understandable to think that the disruption that T1D creates will impact all your children, not just the one who has been diagnosed with it.

We know that:

- siblings can often worry about the well-being of their brother or sister
- siblings can worry that T1D is contagious[28]
- the parental focus on T1D management can increase sibling rivalry (in little kids, this might look like clinging to you and demanding your attention, while teens may focus on the 'injustices' and demand equality and fairness)[28]
- siblings can feel they need to help with daily T1D management, increasing their general responsibilities[29]
- there are developmental differences in responses (a five-year-old may worry about whether they did something to cause their sibling's T1D, while an older child may fixate on whether they'll develop T1D too)
- in some cases, siblings can also display resilience and increased empathy and not have any increased behavioural or emotional difficulties[30]

Overall, you would usually expect to see some reactions to the changes that are taking place in your family after a diagnosis. There's a natural period of adjustment that needs to take place, and some challenging behaviours could arise.

But with support, understanding, and some age-appropriate information, children should be able to regulate as they adjust. This is very different to behavioural and emotional difficulties that are prolonged and that don't resolve with adjustment.

Always talk to your diabetes care team if you have any worries about your child's challenging behaviours.

Tips to help every child

The strategies you use to support your child with T1D can also be used when raising your other children. Try to keep these in mind:

- stick to a routine and support your child to return to normal activities, where possible
- take the time to tune in to your child and listen to their worries and fears. This may mean quality time with each child (even a few quiet minutes together counts, you don't have to go to Disneyland!)
- you may have to explain T1D to them a few times, adjusting your language to suit their level of understanding
- be consistent in your parenting so you're predictable
- check yourself in terms of your emotional regulation

Remember that you can't expect siblings to suddenly become more accepting, mature or considerate just because the family stress has increased.

A note on parental guilt

We know parents often feel guilty about prioritizing the needs of their child with T1D over the needs and desires of their other children.[29] But remember that learning new skills takes time and focus, and that it's a necessary part of your new life. It's not an opportunity to be hard on yourself up for not functioning as you did pre-diagnosis!

Try not to let guilt undermine your confidence in your parenting and how you meet your children's needs. Sometimes we can find ourselves overcompensating due to guilt, becoming more tolerant of behaviours in our children we wouldn't have accepted before diagnosis. In contrast, our tolerance can also decrease, and guilt makes it difficult to remain consistent in our own behaviour.

We all need help sometimes, so don't be afraid to reach out when you do.

Section 10:

Parent well-being and self-care

We know this resource covers a lot of heavy topics. They're essential but also challenging, and may cause you some anxiety. And now we want you to recognize the importance of looking after your emotional well-being.

You may be tempted to skip this section because on the surface it's about you, not your child. But stick with it, as it's absolutely essential that you engage in self-care — not just for your own wellbeing, but for your family as well.

Principles of self-care

Self-care means taking the time to nurture and care for yourself, and restoring your energy. When we do it, we're also role modelling prioritizing our health and well-being. But how do you know what you're doing is self-care? Well, for starters... it feels good! It energizes you, helps with mental clarity, regulates your body in terms of sleep and appetite, and makes you feel positive and motivated.

One of the principles of self-care is regularly making time to engage in something we enjoy. The catch is to do it without guilt. Give yourself permission for some downtime!

Another principle is finding what fills your cup or what works for you. This can be different for everybody. Turn to page 61 for some ideas to get you started.

For some people, fear and worry can be a real barrier to accessing mental health support. While T1D is hard, suffering shouldn't be part of it. It's important to seek treatment – it really does help.

Don't forget self-compassion

It's a concept that's easier said than done, but self-compassion is all about directing the kindness and care that you'd extend to friends and family to yourself. We can all be our own worst critic. If you wouldn't say your comment aloud to a friend, then don't say it to yourself. Use the same kindness inward that you use outward.

From a T1D perspective, it's about being careful with your expectations. You will strive to have stability and time-in-range as much as possible, and may want to do everything "perfectly" but that really isn't possible, and only sets you up to fail.

It's not just your own expectations that can wear you down: what do we do with other people's expectations? All that well-meaning but unsolicited advice can wear you down. And all the times you say you're okay when you're really not can make self-care harder to engage in.

Show yourself compassion. You're doing the best you can. If you're practicing self-compassion you're being kind to yourself and not judging your thoughts, emotions or actions. It's about recognizing that you're only human, and that managing T1D is extraordinarily difficult (as is parenting in general)! Nobody is defined solely by the difficulties they experience.

> "Leaning on my family and giving myself permission to take small moments for self-care helped me stay steady. Processing my own emotions allowed me to show up fully for my child during this life-changing transition."
>
> **Claudia**
> Child diagnosed age 4

Emotional well-being

- Engaging in a hobby or interest
- Getting creative with:
    - music
    - arts and crafts
    - a building/DIY project
- Meditating
- Practicing mindfulness
- Touching or hugging someone you love
- Seeking emotional support from a mental health professional
- Practicing self-compassion
- Spending time with pets
- Talking through fears and worries with your support network
- Taking time to nurture yourself and having time undisturbed while you:
    - enjoy your favourite meal
    - have a long bath
    - watch your favourite movie

Physical well-being

- Eating well by:
    - eating nutritious foods
    - eating regularly
    - not using food for comfort
- Exercising so you can:
    - enjoy the social aspect of team sports
    - strengthen the mind/body connection (with yoga, pilates or tai chi)
    - use up anxious energy with vigorous activity
- Relaxing through:
    - deep breathing
    - guided imagery
    - progressive muscle relaxation
- Sleeping well, when possible, by:
    - developing a sleep routine
    - practicing good sleep habits/ good sleep hygiene
    - getting enough quality sleep (seven to eight hours a night)

Social connection

- Taking part in activities that have purpose or are meaningful to you
- Connecting with your community through:
    - community gardens
    - mentoring
    - volunteering
- Joining a peer support program (being with people who have similar experiences)
- Pursuing spiritual needs (this may be attending a worship service, practicing gratitude, or finding meaning and purpose)
- Spending time with people who are important to you and who provide high-quality social support

Empathy for your child

Remember to bring compassion to your child, too. They're also doing the best they can.

Pause for a moment if you find yourself thinking or saying, "We've had T1D for 10 years, why are we still having the same argument?" Sometimes it can be easy to forget that the difficult tasks don't really get easier over time, and that developing and maturing is a really long process. Sometimes self-care is about managing expectations and thinking about diabetes within each new developmental stage.

Getting support when you need it

We bring our previous experiences and own mental health difficulties with us wherever we go. This impacts how we cope and how much we'll be affected by the stressors of having a chronic condition in the family.

Remember that T1D joining your family impacts you too, not just your child. You may not know what it's like to have T1D yourself, but your child doesn't know what it's like to parent and support someone with T1D.

There might be times when you notice your self-care activities aren't enough — that you're not feeling replenished, and are starting to experience symptoms that are really affecting your mood and emotional well-being.

Never be afraid to ask for help. It's important that at these times you link to the formal supports around you, such as your diabetes care team, your primary healthcare provider, if you have one, and specific mental health services.

You might not have a psychologist or social worker as part of your diabetes care team, but you can talk to your endocrinologist and diabetes educator for advice and referrals to community support options.

You can also connect with a mental health provider trained in understanding diabetes at directory.breakthrought1d.ca.

A final word ...

We hope this resource can reinforce the amazing connection you have with your child and remind you to be confident in your parenting skills.

We believe in you!

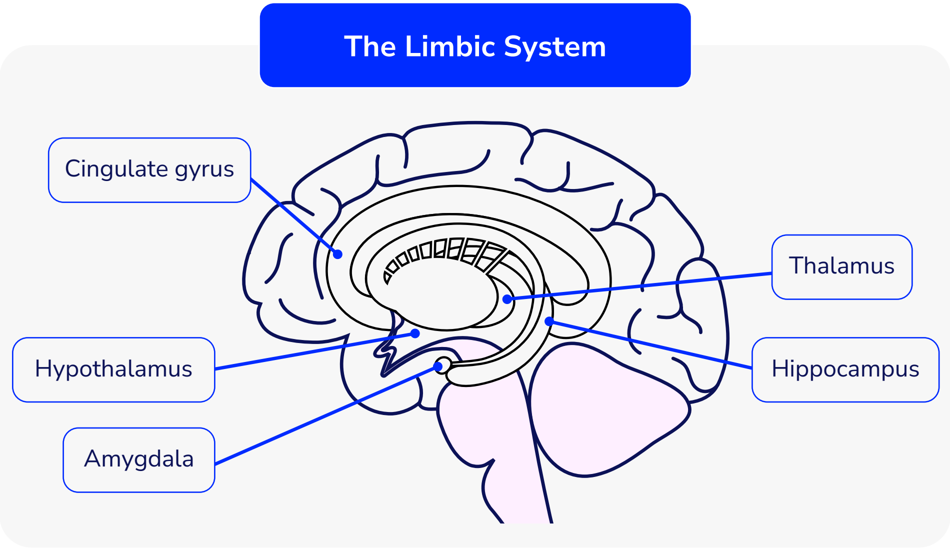
Section 11:

Appendix (more information on the stress response)

In section 3 we looked at responses to a stressful event, such as your child being diagnosed with a chronic condition.

At these times, it's normal to be anxious and emotional, to have difficulty sleeping, and feel fearful, angry or even guilty. This distress generally settles down, particularly as you return to your normal activities and are able to access those coping skills and social supports.

Here are more details on why your body reacts this way to stressful situations, and some strategies to get your body back into balance.



The Limbic System

Our stress response

As we said earlier, we often think of our strong negative emotions as a problem that they're so uncomfortable they need to be pushed away and avoided. But these have always been essential to our survival.

The limbic system, the part of the brain responsible for our emotional responses, is also responsible for regulating our survival responses. We have a built in stress response that's designed to protect us if we encounter a threat, and our whole body and brain get in on the act. You may know this as the fight or flight response.

On diagnosis, when you're filtering all this new information, your amygdala — the brain structure responsible for processing fear and anxiety — may start to freak out and interpret this situation as a threat. Listening to the team talk about the impact of T1D, while seeing your child crying and distressed, will feel overwhelming and dangerous.

Your amygdala will send a distress signal to the hypothalamus, which works as the brain's control centre. The hypothalamus then sends out the alarm to the rest of your body through its autonomic nervous system.[31]

The autonomic nervous system is responsible for the involuntary functions in the body like breathing, heart rate, blood pressure and digestion. It has two parts: the sympathetic nervous system and the parasympathetic nervous system.

The fight or flight response is where the sympathetic nervous system really shines. It's what revs you up, ready to fight or run away.

Meanwhile, the parasympathetic nervous system acts as the calming influence once the threat has passed. It promotes a 'rest and digest' response.[31]

Once the hypothalamus receives the distress signal, it sends out the alarm by activating the adrenal glands to release stress hormones, such as adrenalin. This starts our heart pumping faster, getting blood to our muscles and organs quicker, and increases our blood pressure. Our breathing rate increases, with our airways opening wider to get more oxygen. This extra oxygen goes to our brain, making us more alert and focused, and our senses are much sharper.[31]

At the same time, the body releases stored blood sugar and fats into the blood stream, supplying an energy boost to all parts of the body.

Time can feel like it's slowing down and you may notice that you develop a form of tunnel vision, only focusing on the immediate concern: your child.

This fight or flight response helps protect us and lets us deal with any threats we might encounter. This all happens very quickly, and initially you may not even be aware of these changes.

Your post-diagnosis stress levels

After the initial shock of diagnosis starts to settle, you might still perceive the situation as dangerous, particularly as you learn about the ongoing demands of T1D and how it will impact family life. The hypothalamus can then continue to maintain the level of cortisol (the stress hormone) to keep your sympathetic nervous system revved up.

If this system stays on high alert it can lead to chronic stress, which can have long-term implications for overall physical and mental health. Our bodies just aren't designed to stay revved up in the long term — in fact, the hypothalamus works hard to keep us in balance.

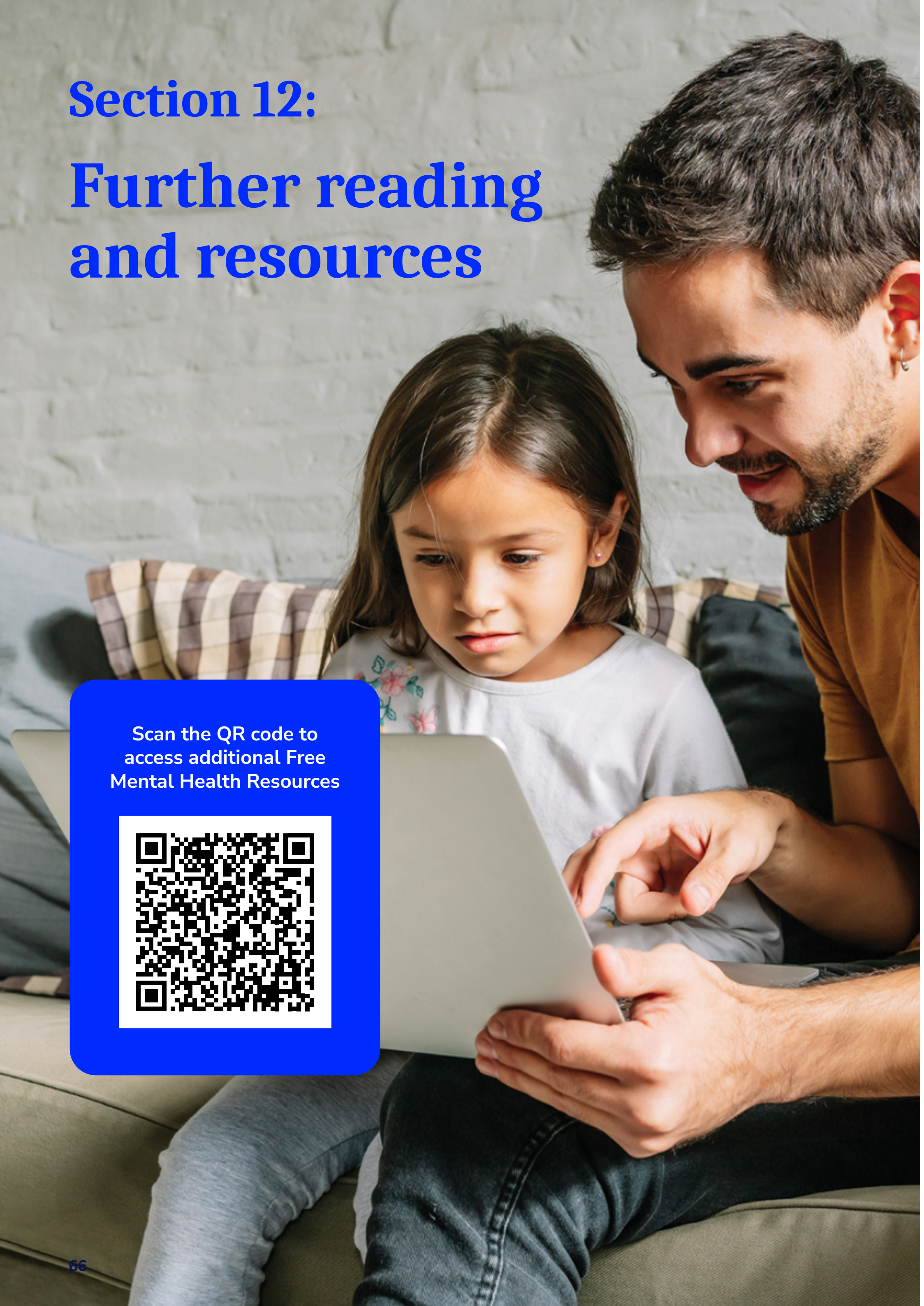
Our cortisol levels start to fall once we perceive that the threat has passed, and the parasympathetic nervous system then has an opportunity to act and reduce the stress response. It works to slow our body down so it can move into the 'rest and digest' response.

The stress response settles on its own for most people, particularly once you've returned home and have settled back into your old schedule. You'll begin to incorporate new aspects into your routine as you adjust to diabetes and the practical demands associated with its management.

It's important to keep an eye on how you're functioning emotionally and mentally. If you feel like your stress is lasting too long and you continue to feel revved up, it's best to put some strategies in place to prevent this becoming a chronic issue.

Section 12:

Further reading and resources



Scan the QR code to access additional Free Mental Health Resources

National Support Services

Mental Health + Diabetes Directory:
visit directory.BreakthroughT1D.ca

Breakthrough T1D Canada's Talk T1D Program – Peer Support for Adults Living with T1D and Parents:
visit breakthrought1d.ca/community-support/talk-t1d/

Breakthrough T1D Canada's Connection Series:
visit breakthrought1d.ca/community-support/

Breakthrough T1D Canada Type 1 Diabetes Support Group:
visit facebook.com/groups/jdrft1dsupport

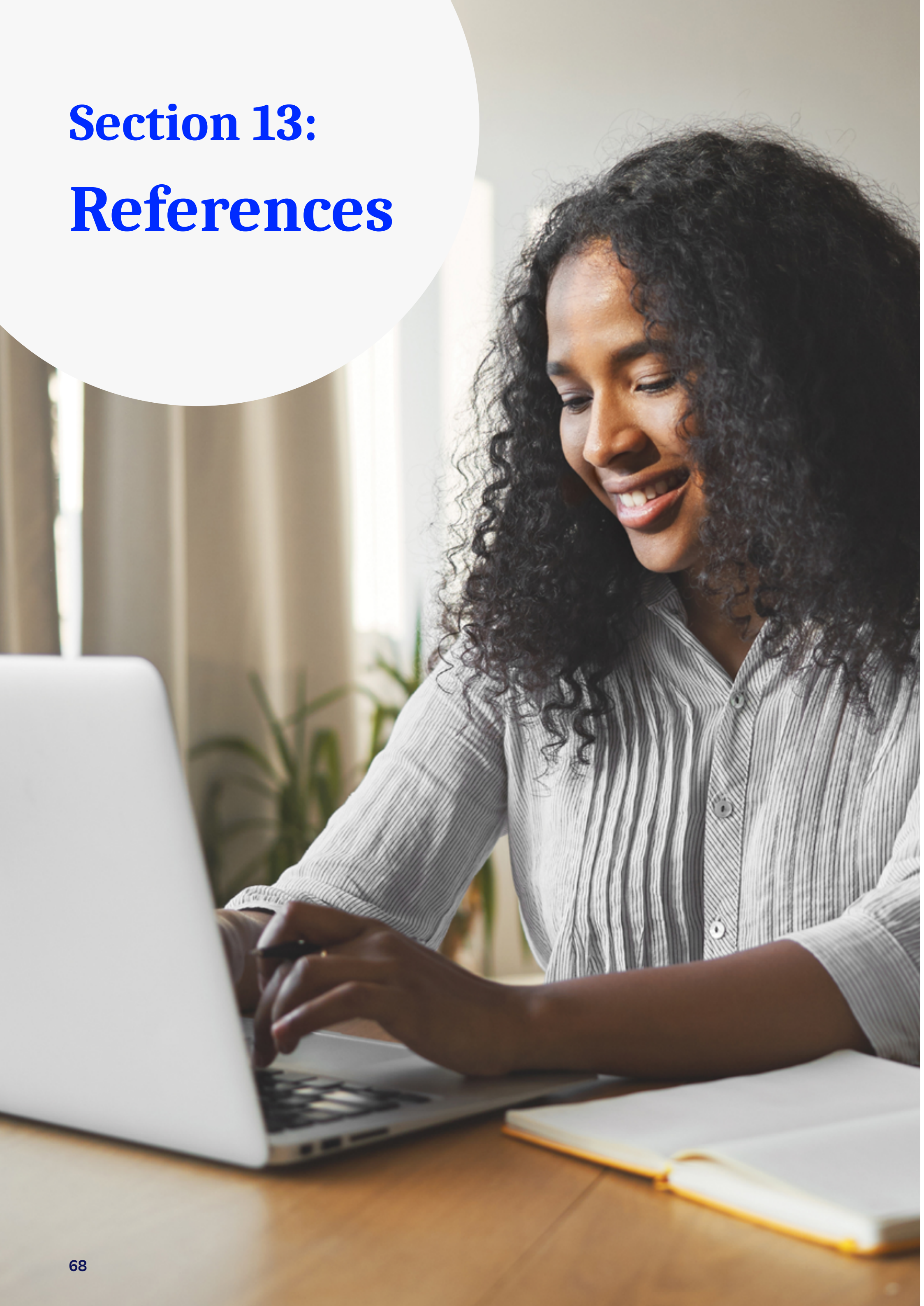
Canadian Centre for Caregiver Excellence:
visit canadiancaregiving.org

Mental Health Commission of Canada:
visit mentalhealthcommission.ca/caregiver-resources/

Emergency services: call 911

Canada's Suicide Prevention Service
If you are in distress, you can call or text 988 at any time, or visit 988.ca.
If you are in immediate danger, please call 911 or go to your local emergency department.

Section 13:
References



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