"If you're okay, they're okay"

A wellbeing guide for parents and carers of children and teens living with type 1 diabetes

By Simone Collins
and Elissa Jacobs

Acknowledgements

This mental health resource has been developed with the knowledge, support and expertise of diabetes healthcare clinicians.

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

This book would not have been possible without the funding and support of Apex Foundation Charitable Trust and JDRF Australia.

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This guide was launched at Parliament House, Canberra, on September 12, 2023

"Research has clearly shown the impact of chronic conditions on emotional wellbeing and mental health. When the person with the chronic condition is a child, the burden falls both on the child and the parents. I welcome this resource from JDRF Australia, and congratulate them and the authors on its publication."

The Hon Emma McBride MP,
Assistant Minister for Mental Health and Suicide Prevention

"As the Shadow Minister for Mental Health, and as the mother of a son living with type 1 diabetes, I am very aware of the importance of professionally produced resources to promote mental wellness in parents who support children and adolescents living with the condition. I congratulate JDRF Australia and the authors on their leadership in this space."

Melissa McIntosh MP,
Shadow Assistant Minister for Mental Health and Suicide Prevention

Left to right: The Hon Emma McBride MP, authors Elissa Jacobs and Simone Collins, and Melissa McIntosh MP

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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.

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

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

Simply put, diabetes 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 book, it makes complete sense that we feel that 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 diabetes is a destabilising event. It challenges your ability to set and enforce limits, and can make you second guess boundaries and consequences that have always been in place.

This book will help support you to better understand the power and protection of the relationship you have with your child. It's been written to help you:

- regain your parenting confidence
- stop giving diabetes more power than it deserves
- learn how you can effectively self-care

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 to build resilience in your child — and your whole family too, because your family 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, which can sometimes cloud our judgement.

Of course, diabetes is an individual journey, so what challenges and affects you 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! As a result, we've aimed to cover the most common issues and offer practical, helpful insights.

As always, please see your healthcare team for advice specific to your child or seek extra support for you when needed (you'll find a list of resources to help on page 62).

We hope you enjoy reading this resource as much as we have enjoyed writing it.

Simone Collins: Senior Diabetes Social Worker, Canberra Hospital, Canberra Health Services

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We acknowledge that all families are different. You may not be a biological parent – you may be a step-parent, guardian or close relative – but either way, you are a carer. For the purpose of this resource, we'll use the word 'parent' because we're talking about the act of parenting and the relationship you have.

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

Section 1: Chronic illness, wellbeing and mental health

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

Parental wellbeing 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 diabetes 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.

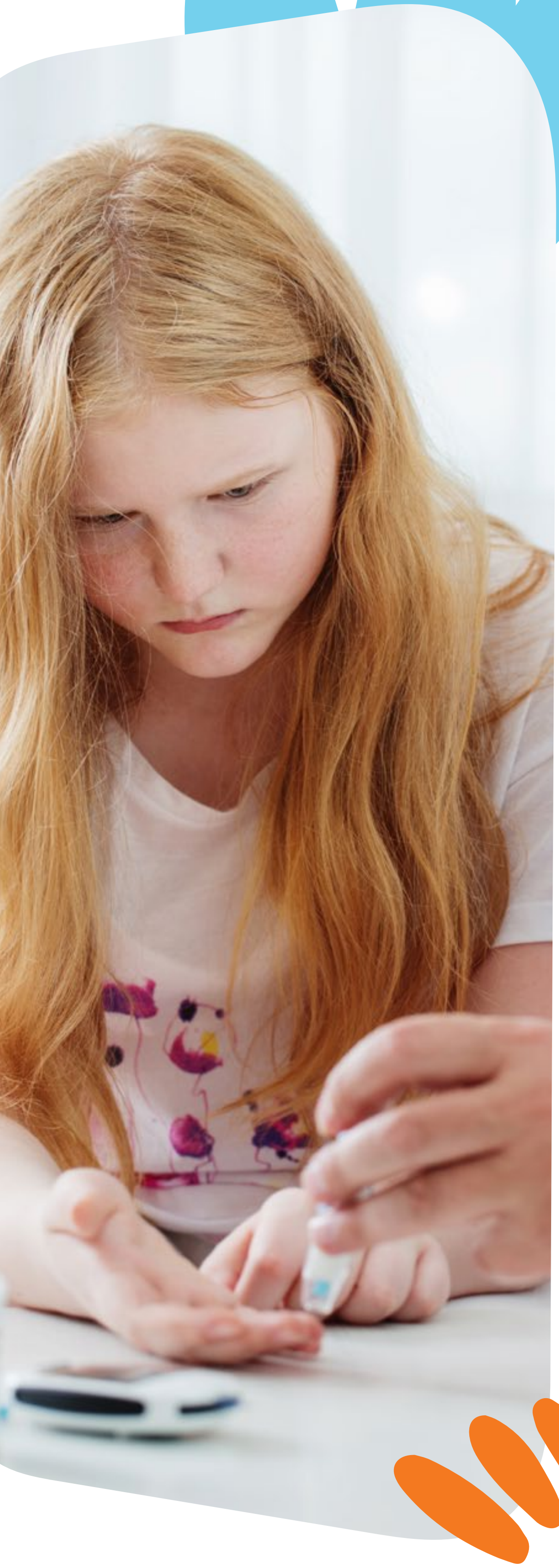
To add insult to injury, you can feel as if you're following all the steps you've been asked to follow, engaging with diabetes to the best of your ability, and the 'diabetes beast' still isn't happy.

It's also one of the only chronic illnesses where your adherence to your child's treatment can be so closely monitored by your treating team, which can seem hugely unfair! While it allows your team to make recommendations and adjustments remotely, it can leave you feeling judged, rather than supported (of course this may never be the intention, but it can feel that way). And ultimately, all this close monitoring can sometimes leave you feeling more anxious, rather than reducing your worries.

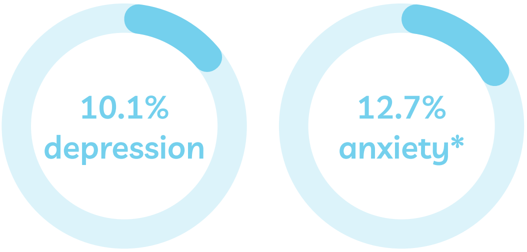
The impact on the person who lives with T1D

For those diagnosed as kids or teens, 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 impact on your emotional wellbeing at the best of times.

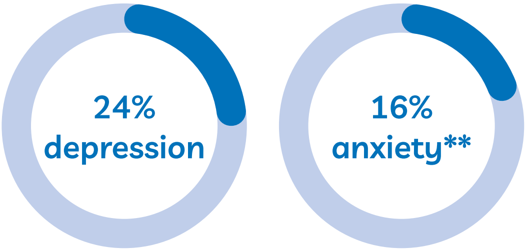
There's been a lot of research done on how chronic illness impacts emotional wellbeing and mental health. We know that chronic illness is a risk factor in the development of mental illnesses, such as depression and anxiety. When we look at studies focusing specifically on T1D, there's evidence of high levels of depressive and anxiety symptoms in young people who live with T1D. Symptoms of anxiety were reported in 32% of patients, while depressive symptoms ranged from 17.2% up to 63%.[1] This is greater than the symptoms experienced by the overall Australian population.



General Australian population



People living with T1D



* Australian Bureau of Statistics, 2020-2021
** 2016 Diabetes MILES Study[2] (moderate to severe symptoms)

We haven't included these statistics to scare you. It's important that, as parents, we understand that it's much harder for our children to manage diabetes while experiencing these symptoms. We need to balance the demands of managing a chronic illness with quality of life, as there will be certain times during their childhood when their diabetes control will suffer, particularly in adolescence.[3]

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.[4] That's where you come in!

So we know that positive parenting behaviours are associated with better psychological health outcomes for your child, but what are they?

As a parent:

- you work together with your child, including them in decision making
- you have insight into your own emotions, as well as 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.

T1D's impact on parents

Whether we like it or not, once T1D enters our lives it becomes a family illness, mainly due to the all-encompassing aspects of T1D care. Parents are an essential part of the team because sometimes they're driving all T1D tasks, or they're modelling and teaching steps to independent self-care, or they're chasing and motivating their child.

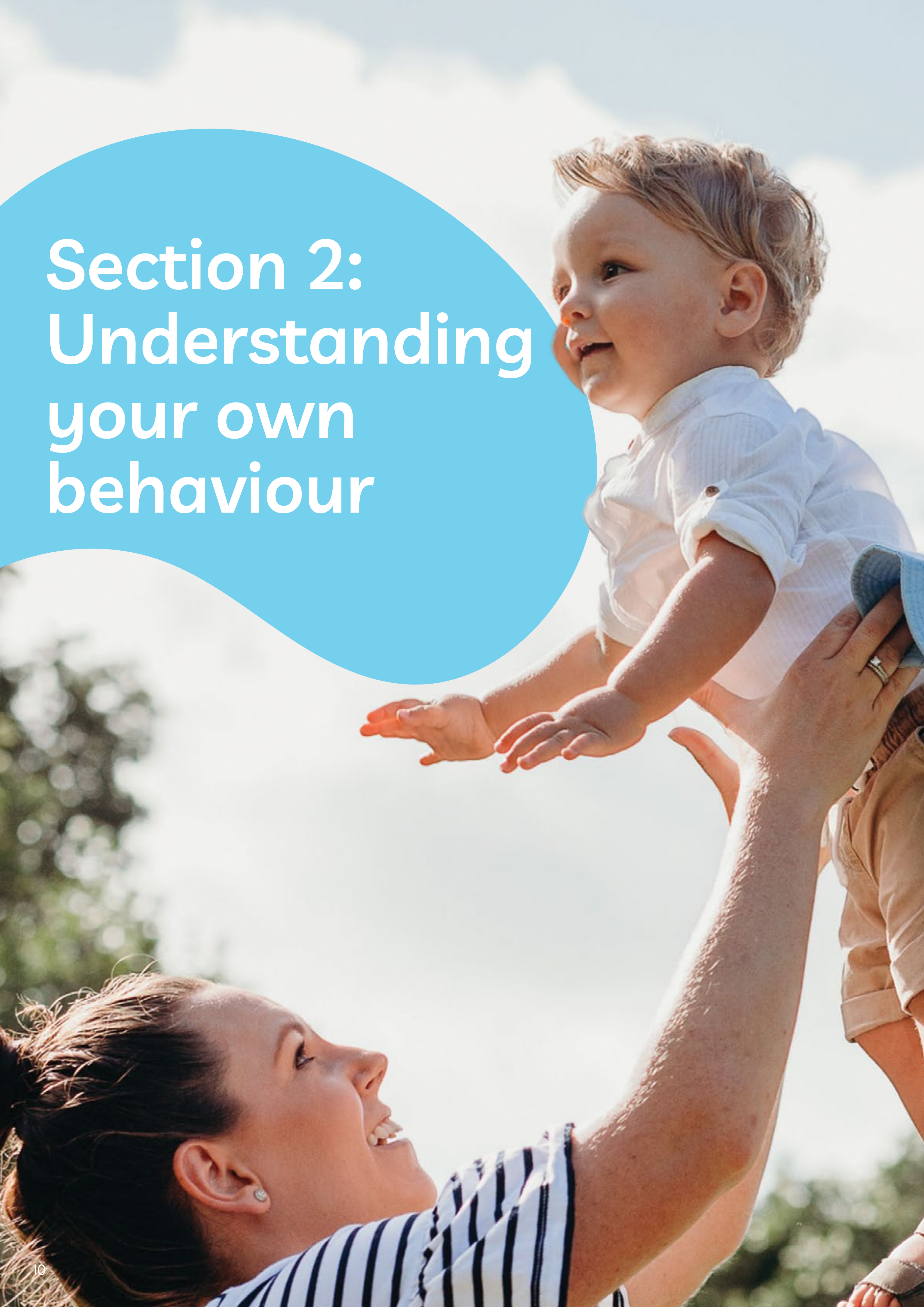
It's important to understand and be aware that there are very real potential consequences to the stress you're experiencing, particularly because of the demanding nature of being a carer, as well as the parental concerns linked to it all. This increases the psychological distress parents can experience.[5,6] For example, studies have found clinically elevated levels of depressive symptoms two to three times higher in mums of young people with T1D than in the general population.[7]

(As a side note, a lot of the research 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 as they play a larger role in their children's lives.)

Why are we telling you all this about parental distress? It's common for parents to prioritise their children's needs above their own, and this 'selfless' nature of being a parent is reinforced by our 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 fit your own oxygen mask before fitting 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 we know that's not the way you want to live!

Section 2: Understanding your own behaviour



A diagnosis of type 1 diabetes (T1D) has the potential to turn your world upside down. Not only is T1D a chronic, lifelong condition, but most of the time its arrival is quite shocking and out of the blue.

Depending on how T1D entered your world, you may also be feeling quite traumatised by it all — and of course the thought of living with T1D, day in and day out, can be very confronting. Because 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, realised 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 suddenly there.

We know it's a lot to take in. But understanding your own reactions and behaviours can help you deal with the situation better.

What to expect after the diagnosis

You're going to experience complex emotions at the time of diagnosis. This is expected, necessary and completely normal. After all, you've just found yourself 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 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
- shell shocked
- confused
- sad.

The reality is that you might not recognise yourself in those early days or weeks. You might start *reacting* instead of *responding* to situations in ways that can really 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 expected!

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

Boosting your own 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.

The families we work with are amazingly resilient. They do adapt to the challenges of living with a chronic illness (often with lots of humour and love). But we 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 take a moment to recognise the good stuff you're doing, too.

Here are a few things to keep in mind.

Remember this...	For example...
It's important to not be too critical of yourself. Treat yourself with love and patience.	"I have never forgotten my best friend's birthday until now!"
Be careful to not 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, we may find ourselves slipping into fear, overwhelm and negativity without even realising it.	Lots of things have changed with diabetes, but more things stay the same. "I enjoyed coffee with my friends and realised 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 BGLs!"
Practice self-care.	See page 54 (section 10) for self-care ideas.

Interpreting your child's behaviour

Let's shift gears now and talk about normal, 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.

On the other hand, your child may want you less. They might seem angry, irritable and frustrated. They could even act as if this is all your fault, like you're in cahoots with T1D 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 and get on with it! Remember that every child is different.

What we're describing is 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 diabetes diagnosis is a hugely destabilising 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.

Rest assured that when we're working with you as clinicians, we're pretty confident that you and your family will adjust. We see it time and time again. Have faith that it will happen.

Section 3: How stress protects us

So far, we've talked about the normal responses to a stressful event, such as your child being diagnosed with a chronic illness. 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, 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 gets in on the act, and 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

Why are we talking about our natural response to stress? It all 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 type 1 diabetes (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 may feel overwhelming and dangerous.

This is how your body may react

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.

↓

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

↓

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

↓

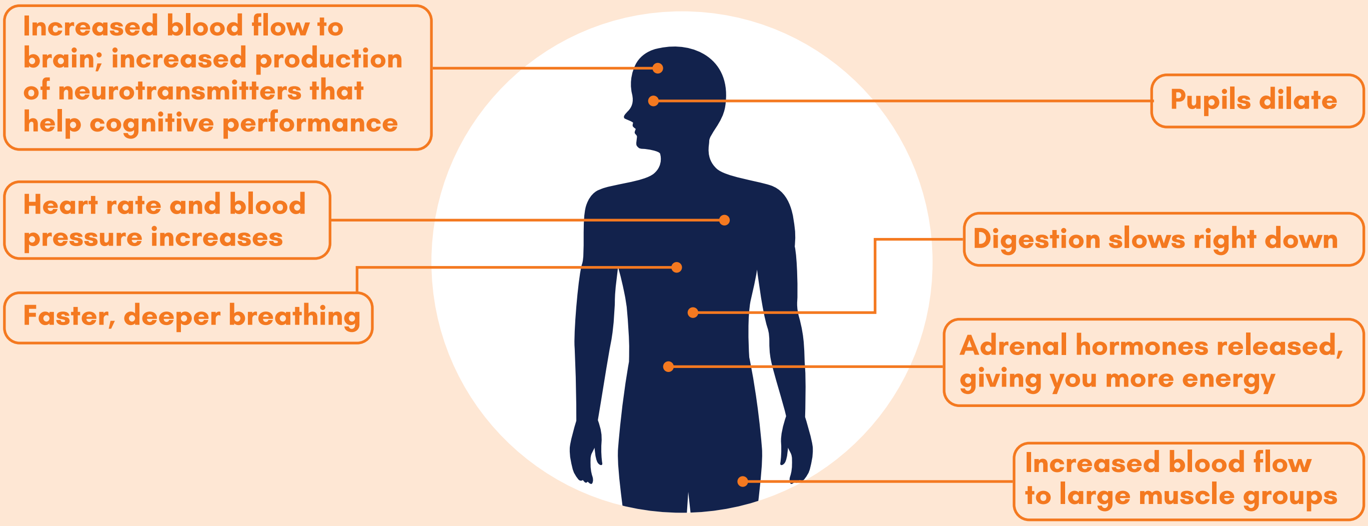
Your breathing rate will increase, with the airways in your lungs opening wider to get more oxygen in. This extra oxygen goes to your brain, making you more alert and focused.

↓

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

Turn to page 58 for a more detailed look at what happens to your body when you respond to stressful situations.

Fight or flight: acute stress response



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'

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 Betty'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 just aren't designed to stay revved up in 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.[8]

One of the most important factors in counteracting this kind of stress is how you perceive the situation.[9] As you move through the diabetes education process, you'll start to gain an understanding and build confidence in yourself. 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 kids diagnosed with a chronic illness, the stress response does settle on its own, particularly once you've returned home and are able to settle back into elements of 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.

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

Strategies to help

If you're continuing to feel revved up or feel like your stress 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 becoming a chronic issue.

Here are some ideas that will help your body stay in balance. Turn to page 62 to find links and resources to describe the activities below.

Relaxation

Breathing techniques,
like deep breathing,
box breathing, etc

Progressive muscle relaxation

Guided imagery

Mindfulness

Mediation

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.[10]

Regulating your own emotions and showing that you believe you can manage their illness (even when you're feeling overwhelmed!) goes a long way when building confidence in your child.

Section 4: Coping with feelings of grief and loss

When we talk about manageable chronic conditions like type 1 diabetes (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 does settle, there's also a misconception that it will disappear completely once our child's T1D management becomes second nature. In this section we want to help you to understand the different ways that grief can show up down the track, so it doesn't surprise you.

We usually associate grief and loss with death, so what do we call this distinct feeling of sadness when there's no actual physical death? We're talking about the concept of non-finite loss.[11]

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 illness is a prime example of non-finite loss. There will be a sense of grieving for life before the illness, and for what might have been.

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

1

For you, non-finite loss may represent a loss of the hopes and dreams you had for your child.

2

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

3

For teenagers, it could be a 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 stages of grief, a model coined by psychiatrist Elizabeth Kubler-Ross. It's become quite ingrained in our Western understanding of grief, and it provides a good description of some of the emotions we might experience during the normal grieving process.

Aspect of grief	Description
Denial	At the time of diagnosis, we can experience shock or disbelief that manifests as denial. 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 our 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 lots of different ways. You might be angry at the illness, angry there's no cure, angry at the challenges it 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.
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. 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 illness. It's important to recognise 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 the illness, and finding ways to integrate it into your life without it taking over, come under the acceptance stage. 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[12]

Unfortunately, these five stages are a 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' to move through the stages.

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

T1D and ambiguous loss

The loss experienced with chronic illness is even more complicated, as it's a form of 'ambiguous loss'.[13] This is where the loss relates to a profound change in your child or loved one, but as they're still physically present it's not recognised as a loss by others.

T1D is particularly invisible as a condition, and your sense of loss as a parent isn't likely to be understood by those around you. Chances are it won't be recognised as grief, as most people will see your child as being 'okay'. This can leave you feeling disconnected from others, with no sense of 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 can 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 the ones below.

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

"Eventually you'll be managing on autopilot"

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

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

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

- discharge from hospital or any supported environment
- readmissions to hospital
- returning to school
- developmental milestones
- life events (it can be as simple as when your child has a sleepover or goes on a school 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 illness, is often described as 'chronic sorrow'.[14,15]

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'. We can then help ourselves find the ways and words to understand our 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.[16,17]

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 we need to make sure that we move between them, not getting stuck in our emotions or being too goal focused.

We have to give ourselves space to feel grief, but we also need a break from our overwhelming emotions. It's a balance between facing your loss and avoiding reminders.

Coping with grief

The loss/restoration-oriented model focuses on normalising the grieving process. It recognises that grief isn't a problem to be solved, but that we can use coping strategies that help us 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 normal 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 own responses to it.
- Seek out others who understand. While they'll be travelling their own journeys, peer support in challenging situations can be invaluable. Online support groups can also help.

Restoration-oriented

- Connect with others through peer support. Seeing how other families cope helps reduce isolation, supports normalisation and validates how you're feeling.
- Denial and distraction can help, so try to focus on other tasks.
- Get back to 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 of you (knowing that denial might show up!).
- Work together as a family to start creating an alternative story of your life, building on your resilience as individuals and as a family.

Boosting your resilience

By understanding the impact of grief, we can show some much-needed self-compassion, particularly in the early stages of adjusting to life with diabetes, when it's really important that we're kind to ourselves and each other.

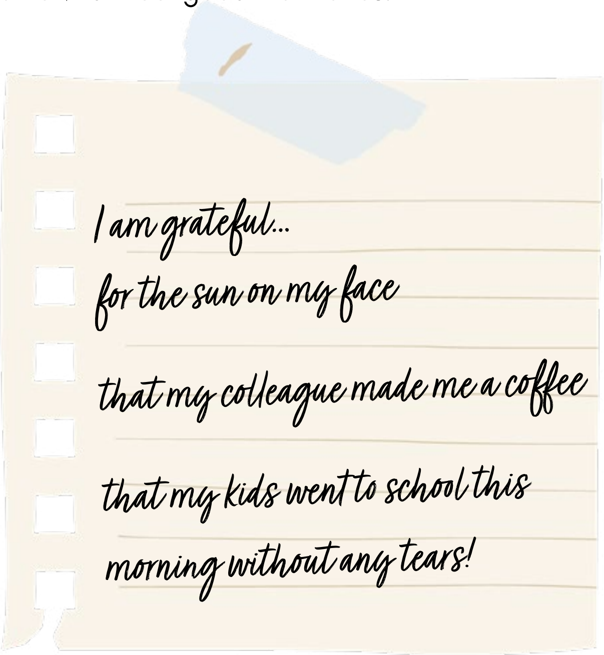
Introducing the practice of gratitude is another way to boost your resilience. This lets us recognise that even in the toughest of times, we're still able to find joy and pleasure in the simple and small things in life.

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

- set a time daily (it could be at a meal time, 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 bad day.

It's also important to recognise 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.



I am grateful...
for the sun on my face
that my colleague made me a coffee
that my kids went to school this
morning without any tears!

"When this first happened I didn't think we would ever get through this. But some really kind people reminded me that we've already been through many challenges. We can do this!"

Section 5: Understanding how trauma can affect you and your family

We'll be honest — a type 1 diabetes (T1D) diagnosis can leave the family feeling pretty traumatised. It's completely common for children and their families to experience traumatic stress reactions following serious illness, injury or hospitalisation, particularly if there was associated medical trauma (like your child becoming seriously unwell and ending up in ICU when they were first diagnosed).

There's a chance the 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/illness, 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."[18]

Sound familiar? In the world of type 1 diabetes (T1D), medical trauma might look like:

- your child being acutely unwell at diagnosis, with serious fears for their survival
- a severe event of hypoglycaemia, 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.[19]

Avoidance
You might avoid any reminders of the trauma, trying to minimise 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.

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.

Remember: some of these behaviours are a normal 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:

- **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.

It's easy for us to say 'get enough sleep', but we know that for some people it can be difficult. It may be worthwhile looking at resources online, such as information on sleep hygiene (turn to page 62 for details).

If a lack of sleep is starting to really compromise your physical and mental health, reach out to your GP for support.

Finding support

How to support yourself

Think about the aircraft oxygen mask analogy: you have to look after yourself before you can care well 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 all!

Here are a few ideas on how you can support yourself at this time.

Get enough sleep

When looking after your child in hospital — and even beyond that, when you come home — 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. This will help you be able to function, and means you won't be using up all your valuable reserves.

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 meals in the freezer can be useful.

Don't be afraid to ask for help

Ask your treating team, family and friends to lend a hand. Be specific and let them know what practical supports will be helpful ("Can you pop over 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 to help your child.

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 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 help.

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 normal.

Rely on routine

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

Remain calm

Try to stay calm, 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

Assist your child to talk about their feelings and what's going on.

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 the most powerful support system children have, and having access to caring and safe relationships reduces the impact of traumatic stress.[20] These relationships and connections can act as a buffer, supporting your child to adjust 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 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. It can be as simple as taking a deep breath when you're feeling frustrated.
- 'Tune in' to your child and help them recognise and cope with their emotions.[20]

When to seek further help

While most children and their families are amazingly resilient and their stress reactions resolve within a few weeks, it's important to recognise that these symptoms can continue, and will need to be acted on if they keep up.

A study in 2007 investigated the psychological distress mums experience following their child's diagnosis of T1D.[21] They found that 40% of mums 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 chronic illness diagnosis, such as T1D. The parents themselves may have experienced trauma in the past, or could be living with their own mental health issues. They may lack 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[22]
- 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 psychiatrist, psychologist, social worker or counsellor. The longer these symptoms go on unrecognised and untreated, the greater the risk of developing mental health illnesses such as PTSD, depression or anxiety.

It's important to speak about what you're experiencing. As a parent, you can talk to your child's healthcare team and accept their guidance and/or a referral to a mental health professional. You can also just start a chat with your GP.

If your child is the family member who might need more help, you can take them to their GP or speak to their healthcare team for support and referrals.

Turn to page 62 for national support services.

"Seeking help and support was so important in managing our child's diagnosis and then her journey through her teens living with T1D. It was a critical step on an unfamiliar road to seek the help we needed, and it has had a lasting positive impact on our lives. Having a social worker and psychologist didn't mean we'd failed – it simply meant we weren't alone, and it was the helping hand we needed."

Section 6: Comfort zones and your coping strategies

We often talk about how type 1 diabetes (T1D) needs to fit into your life, not the other way around, because T1D can — and will — be a real bully. It's easy to feel consumed by it: it's a dynamic, ever-changing condition that demands your attention. It requires engagement and a relationship, which is easier said than done.

T1D would love nothing more than to dominate every thought, feeling and conversation you have. But this is exhausting and not sustainable. You need to 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? (Your values matter!)

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 into your decision making. But what happens if we make decisions based on the fear and worry that's generated by a chronic condition? How do we stay true to ourselves, our parenting style, and uphold our family values when we'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 important to consider because they haven't been changed by the arrival of diabetes!

What do I value as an individual and as a parent?

What do we value as a family?

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 your child learn the difference between right and wrong.

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, we often forget our strengths and resilience amongst the stress and turmoil.

Adversity, no matter how big or small, will go a long way in building resilience – our own as an individual, and our 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 cubby houses 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 will 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're a teenager and they only want to do what feels good, what their friends are doing, and, well ... whatever they want to do.

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

Coping strategies and how T1D fits in to 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.

Your comfort zone is a lovely psychological state that makes you feel like you're in control. These are things that are familiar, where anxiety is relatively low. So basically, in this state, we're feeling comfortable, unchallenged and secure. An example is when we always park in the same place at the shopping centre — we know what we're doing, how to get there, and what to expect.

But with a diagnosis of T1D, you and your family have now been expected to learn a whole heap of new information, gain specific knowledge, and then apply it in real life. With these newfound skills and knowledge comes 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. Following on from our last example, this could look like when you have to park somewhere else, away from your usual spot ... and then can't find your car.

While it's great to acknowledge the boundaries of your comfort zone, it's even more important to understand how you respond when pushed well outside of it. It can be a good idea to consider your coping styles and what they may look like, because the strategies we use to cope can either help or hinder us.[23]

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

Solution-focused
(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 super organised, 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 will cringe at the thought of handing over T1D care to a teen, who is in the most chaotic and disorganised phase of life.

Emotional support and acceptance-based
(think of a nurturing type of person)

Advantages

- Managing your own emotional response, seeking emotional support.
- Taking a more accepting stance, 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 diabetes management in a more predictable way.

Dysfunctional
(strategies that become problematic over time)

Advantages

- Denial and avoidance are helpful at the start, when we're overwhelmed and need a break (but this isn't helpful in the long term).

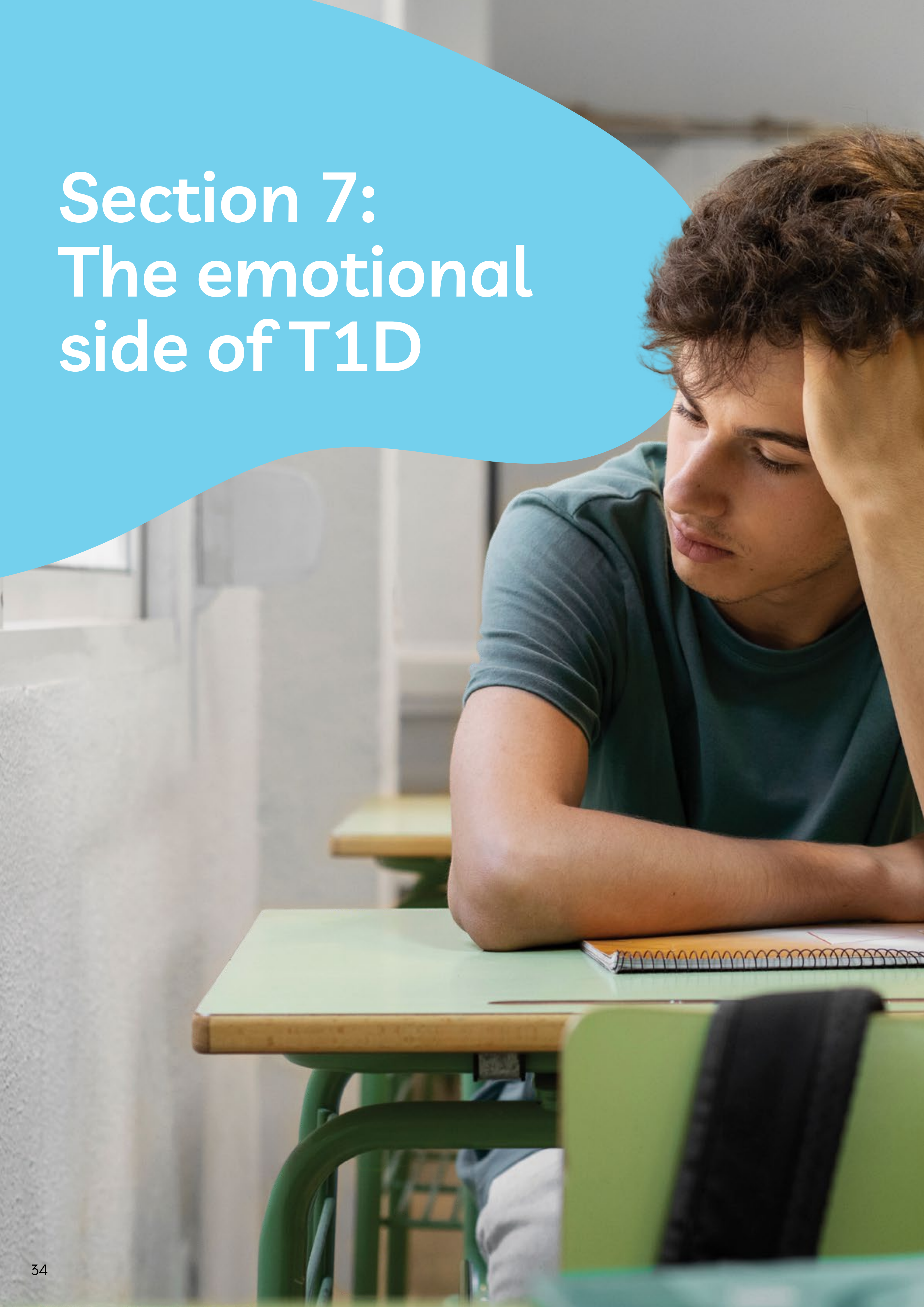
Disadvantages

- Avoiding people, places and decisions that trigger feelings of discomfort.
- Reducing connectedness with others.
- May experience denial and wishful thinking, only giving the illusion of remaining in control.
- Engaging in vices such as alcohol or drugs as a way of managing.

Recognising that there's more than one way of coping — not only individually, but also as a family — is important. We 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 of dysfunctional coping strategies as a long-term solution, as it's not sustainable. Increasing your use of emotion-focused coping strategies will help you adjust and reduce your risk of developing anxiety and/or depression, in response to stressful and traumatic situations.[24]



Section 7: The emotional side of T1D

It's time to focus on understanding some 'emotional aspects' of type 1 diabetes (T1D) management from the perspective of your child.

Yes, this is a parent wellbeing resource. But as most parents know, the more you know about your child's emotional capacity, challenges and triggers, the better off you'll be.

Pausing to listen

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

While we're busy solving problems for our child, trying to repair damage or make the hurt go away, we can't see that we're inadvertently being dismissive of their intense, complex emotions. But our children want to be heard (even if the way they're delivering their message is confronting and, at times, triggering!). It's vital that we pause our 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 will remain the same: the sense of fear and dread 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 rationalise their pain away.

As a parent, you're so valuable and integral in your child's life. As clinicians, we often see 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 our children are engaging in distressing, risk-taking behaviours or doing the exact opposite of what we want from them, we often develop a type of amnesia. Basically, you can easily forget everything you've spent years teaching your child.

Think about all the things that go unsaid: how you instil your values in them, treat them with respect and kindness, have faith in them, and support them in their endeavours (no matter how foolish they may seem at the time!). 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'll also be the emotional punching bag, the one who deals with the storm before the calm returns. You may be blamed — quite unfairly! — for everything that's gone wrong and continues to go wrong.

The power of validation verses 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. After all, diabetes does suck!

In this case, you have two options.

Option 1

Rationally tell them that if you could, you would take 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 rationalise it or find a silver lining. This situation does suck for your child, so let them feel it.

As a parent, option one 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 minimise 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 our 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 minimise 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 do we solve an unsolvable problem? In the eyes of your child, T1D is a problem that can't be solved, so we're better off learning how to tolerate uncomfortable and complex emotions, rather than avoiding them. Then we can focus on what they 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. Our kids – especially our adolescents – are actually pretty good at dropping these clues all over the place. We just tend 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 whinging 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 can be downright rude and irritable. This can backfire and work as a deterrent, making you feel rejected and hurt.

But this is when our ability to contain our own emotions is so valuable. Often, our child's behaviour is a real trigger, and our emotional response will cloud our ability to persevere. But we need to be aware of what they need, what clues they're giving, and the best way to reach out to them.

Section 8: The practical side of T1D

A lot of this resource covers the emotional aspects of life with type 1 diabetes (T1D), but it's equally important to consider the practical care aspects that can create resistance and 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 a 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 resistance, 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 diabetes 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 our children want to regain some of that control back, often in creative and challenging ways. Manipulating food 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 know what we mean.

Another classic example is the headstrong teenager who won't manage diabetes 'like Mum and Dad do'. Even though you'll have a tried and tested method of managing their care, they'll be compelled to forge ahead in their own haphazard trial-and-error way.

Have a think: What are your non-negotiables? In terms of T1D, as well as every day life?

Practical examples from life with T1D

The following situations are all normal 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 diabetes 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 all.

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 inbuilt warning system. Their apprehension and resistance is normal, 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 normal 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 in control of all injections and finger pricks, so your own anxiety may be triggered. Along with your biological 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 is very real, and waiting around while someone else calms their own nerves only makes you more nervous.

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 will only increase their anxiety.
- **Don't set yourself up to fail:** Address your own needs first – you're going to need to 'loan' 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 nature is calling and you really need the loo! 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 lounge room at 4pm). 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. (Kids have an amazing ability to drag things out, especially in the evenings!)
- **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 and saying things like, "It might sting for a second" or "Should we practice on your Rufus teddy first?"
- **Focus on the task:** The more you talk about it, trying to get your child's agreement or apologising to them, the more time you're giving your child's anxiety to rev up and take over. Minimise the discussion, get the job done, then make sure you have a cuddle when it's all said and done.
- **Don't try to rationalise with the irrational:** We say this because 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, have to be addressed. There's a huge difference between feeling anxious about something and living with a diagnosed anxiety disorder.

Fear of hypoglycaemia

Fear of hypoglycaemia 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 hypoglycaemia 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 hypoglycaemia is maintaining glucose levels above target overnight, as this period is often a time where 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 hypoglycaemia is very real, but we need to remember that fear as an emotion isn't particularly helpful. Think of the phrases 'paralysed 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 that are designed to be assistive? How confident are you with your problem-solving skills?
- **Reach out:** Never be afraid to link in with your diabetes 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), predictive low glucose suspend and hybrid closed loop systems provide real-time monitoring of blood glucose levels and adjusting insulin infusion doses. These are designed to reduce the incidence of nocturnal hypoglycaemia and address some of the difficulties in managing children's T1D during sleep.[25]
- **Work on your own anxiety:** Anxiety can be catching, 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 team. The last thing you want to do is give in to your anxiety and give the perception that fear is a normal part of managing diabetes, especially overnight. No one can address your own anxiety, except you.

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.

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 carer 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.
- Our ever-present friend, 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 in managing anxiety levels.
- Your child might not be as enthusiastic about technology as you are (or vice versa). They might 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.

What you can do about it

- **Knowledge is power:** Research the technology you're interested in. Talk with your care team if you have any specific questions or concerns.
- **Pace yourself:** Don't feel like you need to be an expert in the technology straightaway. 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 care team to get support to adjust the technology to make sure it's working for you.
- **Alarm fatigue is very real:** We do have the power to turn things off and decide which alerts are assisting us to manage diabetes 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 specialist doctor, a diabetes educator, dietitian or social worker about your concerns or issues. They're there to support you and help you gain confidence in using technology, safely and effectively.

In the face of anxiety, talk less. You may be able to rationalise that you're 100% acting in your child's best interest, but you won't get their agreement.

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

It's normal to want the very best for your child, and to want to protect their wellbeing 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 our children spend more time at school than at home, and having T1D managed away from home can be anxiety-driving for parents.
- It's essential to balance good mental health with physical health. By focusing all our efforts on optimal control, at the expense of balance, mental wellness and connection, we can burn out and create greater T1D conflict and distress.
- Most teachers and carers 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 easily 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 too, but school provides a structured environment that's both nurturing and challenging. It's vital they get these opportunities.
- **Keep up to date:** Ensure that all school management plans are current, reflect what's happening in terms of T1D care, and have all the relevant details. With the support of your care team, adjust any management plans that are outdated.
- **Be involved**: Know what's in the care plan so it matches your expectations, as well as those of your diabetes teams.
- **Be prepared:** Make sure the school 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 tricky balance – you don't want to freak the teacher out 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. 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 communication books: 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 — we can be kind but firm!

A shout out to all the single parents/carers! 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.

Section 9: Age-appropriate expectations

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 type 1 diabetes (T1D), and to help you manage your own expectations. This will give you context around normal 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 is not 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 their sport, friends and gaming. This won't be consistent with your own expectations.

But while T1D doesn't accelerate development, we often ask our children to develop behaviours they may simply not have the ability to do. It's important to consider what you want or need your child to be doing versus what they're actually capable of.

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 over time. Again, this is a journey, and we can't rush it (no matter how much we 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.

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 illnesses to manage, or live with a physical or mental disability. This will add greater complexity.

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 illness, pre-diagnosis. The difference now is that diabetes is constant, needs regular participation, and has delivered you 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 we may want our child to do more than we would normally expect of them.

This is not an unheard-of parent struggle. Most of us fantasise 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 these types of fantasies are harmless. We might get frustrated if we need to step in and help, but we tend to not overthink it.

Then in comes T1D and suddenly the stakes are higher, and we forget that our children won't prioritise 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 see resistance, 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 of others.

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 sugar 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 their behaviours.

What happens when we add T1D into the mix? Parents of children diagnosed in this age group have to use a unique set of parenting skills — which seems to include mind reading, as your child will lack the thinking and language skills to identify when their blood sugar 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 thinking and language skills also means kids this age struggle to communicate their emotional state. Their uncertainty, distress and fear will come across in their behaviour, and this can look like tantrums, aggression and refusal to comply with T1D tasks.

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

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.
- 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 of the dramatic variations 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 improve, and they'll be better able to articulate their needs and wants.
- Children will start to be more independent in 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 calm 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 verbalise 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 normalise T1D for your child in a way they'll understand, while also trying to reduce their distress and improve compliance … 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 great at problem solving yet, 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 we need to be very careful that we're not expecting them to be more responsible than they have the capacity to be because of our own fears or concerns.
- It's important that we, as parents, manage our own expectations. We can come across as hypercritical and judgemental because we've already mastered these tasks and skills, and often forget that our 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. If we can be warm and understanding in our approach, 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 adhere to their treatment. 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 actually 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 development stage can be unpredictable in their actions and ability to follow through.
- Talk about why your child needs to do their diabetes 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 we want their T1D management to be the smallest inconvenience and interruption 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 rejection, as they feel the need to be as different from their parents as possible.
- At this age, your influence will recede 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 their T1D as they enter high school.

Unfortunately, your teen doesn't quite have the skills to successfully pull it all off. 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 mates decide to play basketball after school. Josh knows he doesn't have his T1D kit on him, but that's okay because he'll be home for dinner. His mates 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 improve this behaviour, 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.

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, judgement 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, 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 that aren't 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 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 speed while driving and take dangerous risks!

JDRF offers resources especially for teenagers living with T1D, as well as their parents. Download our book filled with practical advice for parents at jdrf.org.au/teen-toolkit, or download our wellbeing guide, written for teens, at jdrf.org.au/testing-times.


JDRF

TESTING TIMES

A WELLBEING GUIDE FOR TEENAGERS LIVING WITH TYPE 1 DIABETES

TEEN TOOLKIT

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

JDRF

The importance of the parent-child relationship

As clinicians, we support parents to build confidence in their own parenting skills and instincts — and a chronic illness diagnosis often means parents need to upskill in certain areas. Parenting programs can help with that.

Many parenting programs focus on attachment. This is the process we use to protect our 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 our children having a secure figure they can trust, who'll be responsive to their needs when they're distressed. Doing this supports our 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 compliance 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!)
- being consistent in your behaviour, expectations and consequences.

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

"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 negatively impact all your children, not just the one who has been diagnosed with it.

We know that:

- siblings can — and do — worry about the wellbeing of their brother or sister[28]
- siblings can worry that T1D is contagious[28]
- siblings can feel they need to help with daily T1D management, increasing their general responsibilities[29]
- 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]
- 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 not have any increased behavioural or emotional difficulties.[30]

Overall, we 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 maybe some age-appropriate additional 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.

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

Tips to help every child

The strategies you use to support your child living 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 their 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.

A note on parental guilt

We know that parents often feel guilty about prioritising T1D over the needs and desires of their other children.[29] But try to 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 beat yourself up for not functioning as you did pre-diagnosis!

Try to not 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 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 put your hand up.

You might want to look into the parenting programs listed on page 62 – these recommended programs have an attachment focus, as well as a component that aims to improve parent-child relationships using behaviour management strategies.

Section 10: Self-care (your oxygen mask)

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

You may be tempted to skip this section because on the surface it's about you, not your child. But stick with us, 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, filling your cup and restoring your energy. When we do it, we're also role modelling prioritising our health and wellbeing.

But how do you know what you're doing is self-care? Well, for starters… it feels good! It energises 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 the 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. Here are some ideas to get you started.

Emotional wellbeing

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

Physical wellbeing

- 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 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
  - men's sheds
  - 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

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.

From a type 1 diabetes (T1D) perspective, it's about being careful with your expectations. While we strive to have good control and may want to do everything perfectly, this really isn't possible, and only sets us up to fail.

It's not just our own expectations: 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 we're practicing self-compassion we're being kind to ourselves, and not judging our thoughts, emotions or actions. It's about recognising that we're only human, and that managing T1D is extraordinarily difficult (as is parenting in general)! We're not defined by the difficulties we experience.

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.

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 we 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.

Getting support when you need it

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

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

Never be afraid to ask for help. It's important that at these times you link in with the formal supports around you, such as your diabetes care team, your GP 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.

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

A final word from our authors...

This is a perfect opportunity for us to acknowledge how much we learn from the families we work with. We see so much individual and family resilience in our diabetes community, and we witness fantastic parenting every day.

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!

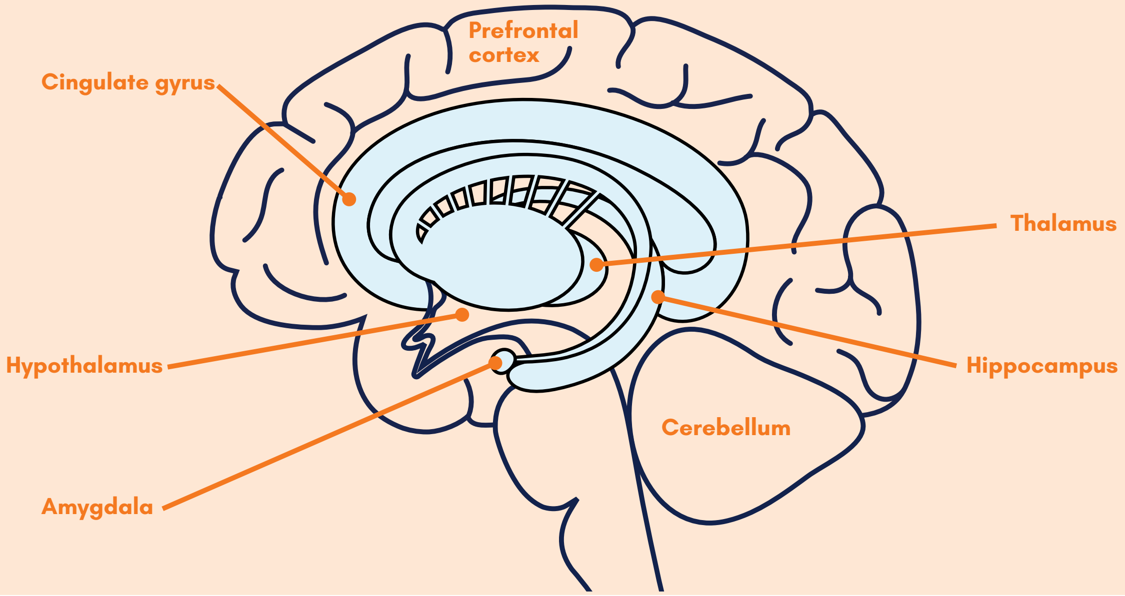
Section 11: Appendix (more information on the stress response)

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

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 emotions 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 an in-built 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 have heard this described 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 diabetes, while seeing your child crying and distressed, will feel overwhelming and dangerous.

Your amygdala will send a distress signal to the hypothalamus, which functions as the control centre of the brain. The hypothalamus then sends out the alarm to the rest of your body through your autonomic nervous system.

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.

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.

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 type 1 diabetes (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.

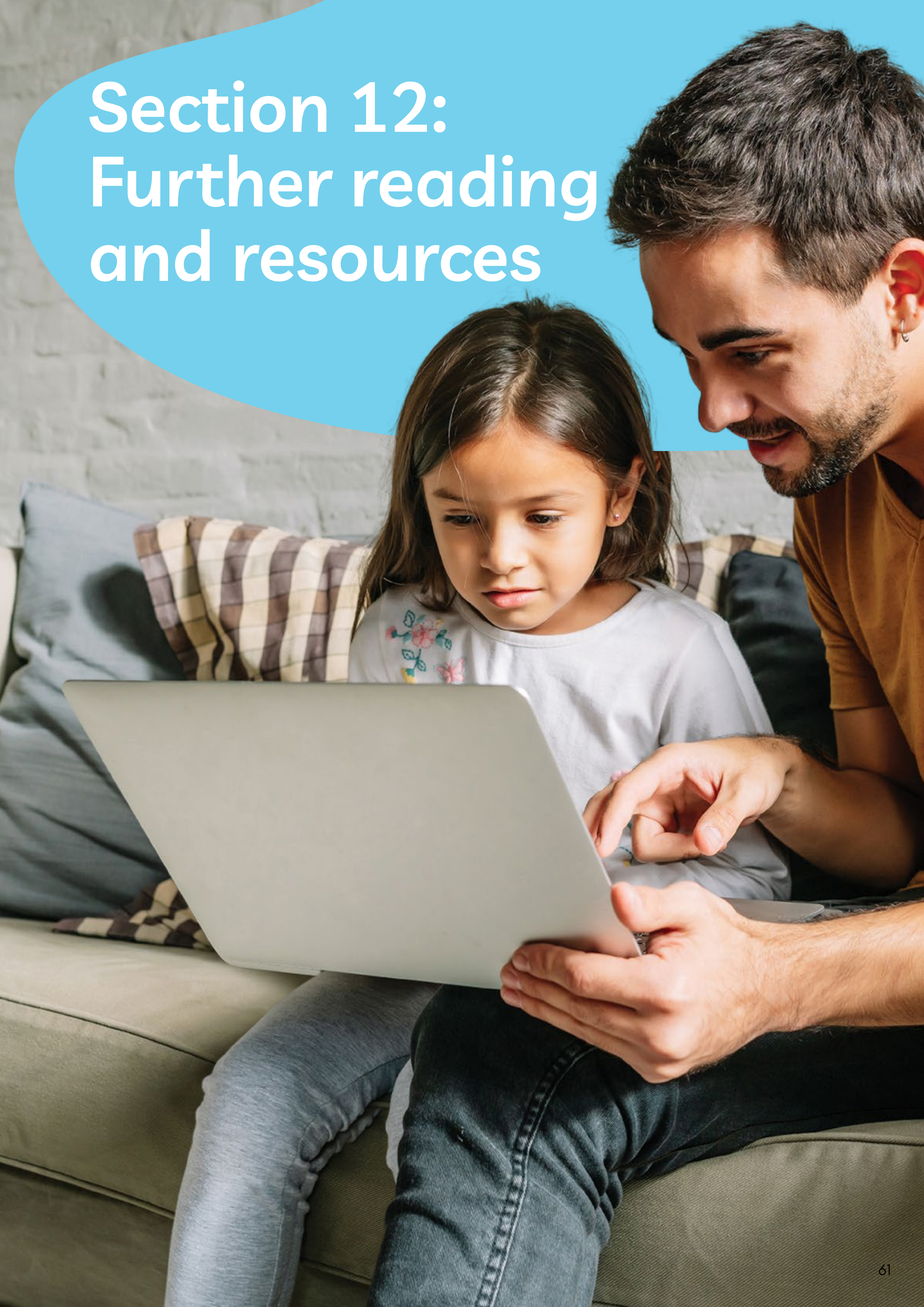
If this system stays on high alert it can lead to chronic stress, which can have long-term implications for overall physical and mental health. Our bodies just aren't designed to stay revved up in the long term — in fact, the hypothalamus works hard to keep us in balance.

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.[8] 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 important to put some strategies in place to prevent this becoming a chronic issue.

Section 12: Further reading and resources



National support services

Beyond Blue: call 1300 22 4636 or visit beyondblue.org.au

Carer and Community Support: visit carersupport.org.au

Lifeline: call 13 11 14 or chat online at lifeline.org.au/crisis-chat

MensLine Australia: call 1300 789 978 or visit mensline.org.au for a chat online or via video

Emergency services: call 000

National Carers Counselling Program: call 1800 242 636

Suicide Call Back Service: call 1300 659 467 or chat online at suicidecallbackservice.org.au

Call the public mental health crisis number in your state or territory

Section 3

- **Calm app:** calm.com
- **Headspace app (guided meditation and mindfulness):** headspace.com/headspace-meditation-app
- **Smiling Mind app:** smilingmind.com.au/smiling-mind-app

The Centre for Clinical Intervention (Western Australia Health) has excellent resources. Visit jdrf.org.au/parent-resources for links to learn more about:

- breathing retraining
- changing your thinking
- coping with stress
- distress intolerance
- mindfulness
- progressive muscle relaxation.

Section 5

- **Healthcare toolbox (helping children and families cope with illness and injury):** healthcaretoolbox.org
- **Phoenix Australia (trauma and recovery):** phoenixaustralia.org/your-recovery
- **Visit jdrf.org.au/parent-resources for fact sheets on:**
    - » sleep hygiene (Centre for Clinical Interventions)
    - » supporting your child after trauma (Australian National University)
    - » what is child trauma/trauma types (The National Child Traumatic Stress Network)

Section 8

- **Diabetes in Schools:** diabetesinschools.com.au

Section 9

Search these courses in your state or territory:

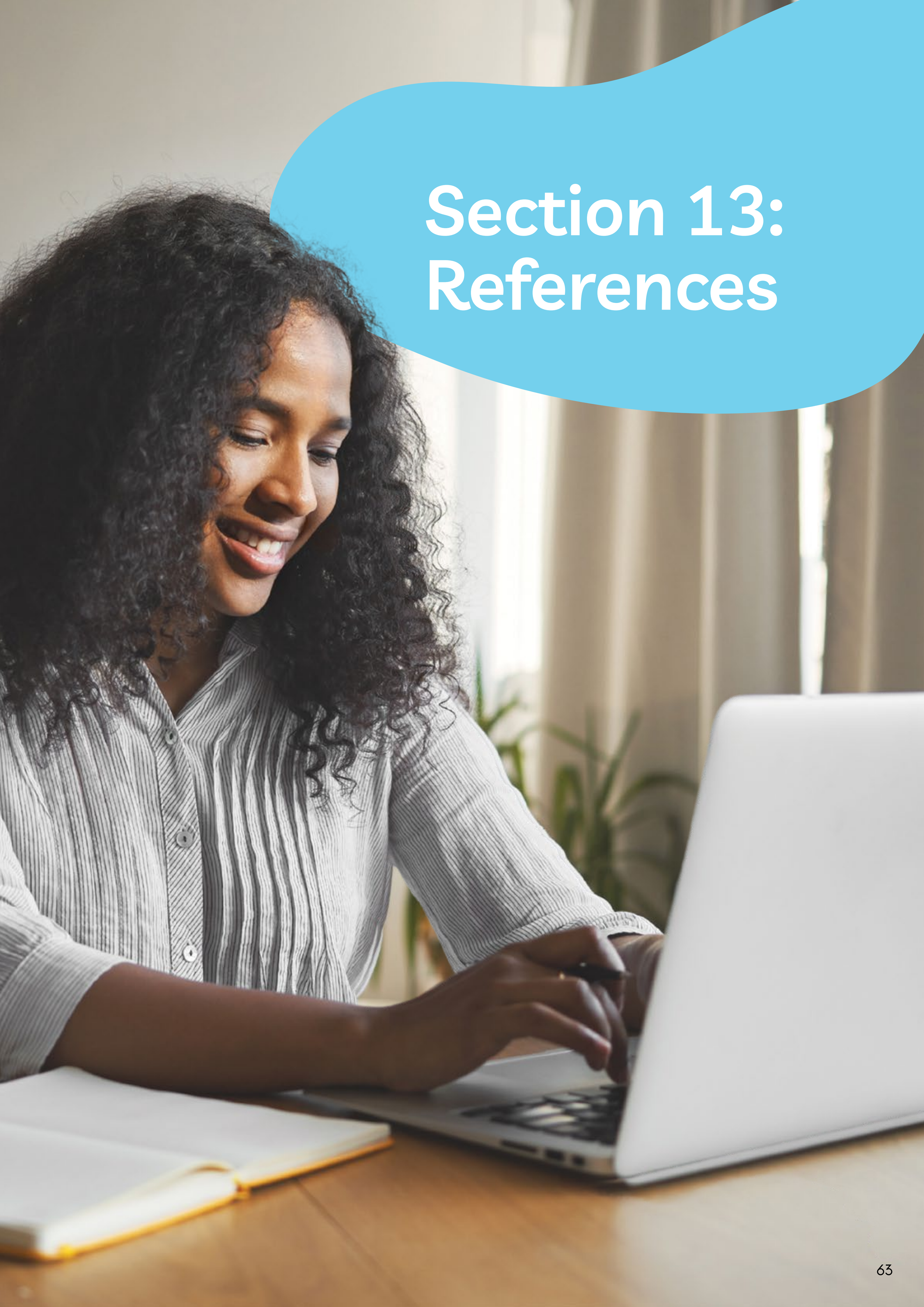
- **Circle of Security**
- **PACE**
- **Positive Parenting**
- **Triple P**
- **Tuning in to Kids/Tuning in to Teens**

Section 10

- **Raising Children Network (looking after yourself):** raisingchildren.net.au/grown-ups/looking-after-yourself

Scan the QR code or find all these links at jdrf.org.au/parent-resources

Section 13: References



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