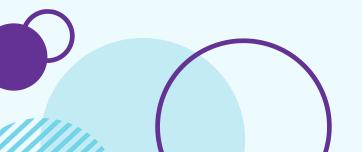


NAVIGATING T1D & ADOLESCENCE RESOURCES FOR CAREGIVERS





What's Inside

Resources for T1D Caregivers is a collection of resources, worksheets, and references collected during the development of DHF's <u>PEP Talks</u> (Parents Empowering Parents) Caregiver Program. The resources are organized into four sections, each containing information and tools designed to help you and your family navigate adolescence with T1D. To access a specific section, click the title below.

Mindset Matters: Managing Expectations

Learn how a developing a growth mindset can lead to more successful diabetes management.

Talking with your Teen: Navigating the Highs & Lows

Explore communication tools to best support your adolescent as they manage diabetes during the transition years.

Sharing Responsibility: How to Foster Interdependence

Discover the important distinction between *in*dependence and *inter*dependence, learning how to shift T1D management responsibilities collaboratively and mindfully.

Building Your Village: Collaboration & Self-Care

Recognize that the weight of T1D will have a significant impact on you and your family, and examine ways to cope with this stress as a team.

Using This Document

<u>Underlined</u> Indicates

Indicates a live link you can use to get more information from external resources.



Text

Link to downloadable forms and resources related to the topic. All downloads are also available at www.diabeteshopefoundation.com.



Click the back arrow to return to the What's Inside page.

DISCLAIMER

The information in Resources for T1D Caregivers is intended as guidance only and is not intended to be used for medical advice or planning. Please talk with your health care team about your child's personal diabetes management plan before making any changes to their health care. Information in the Guide is not exhaustive - your care team and the linked referenced materials should be used to enhance your knowledge.

Welcome to Resources for T1D Caregivers!

DHF is excited to offer you a collection of resources, reading materials, and practical tips to support you and your family as you navigate the challenges of life with type 1 diabetes. These resources were designed to provide you with important information that will help foster mindfulness, communication, interdependence, and self-care during the adolescent and early adult years.

Along with Resources for T1D Caregivers, be sure to explore DHF's youth programs and resources, including:

- The <u>HOPE Connects Program</u> matches students in grade 12 or first- and second-year college/university with a peer mentor, allowing them to talk to someone who knows first-hand what it's like to manage T1D while at post-secondary school.
- The <u>Guide to Adult Care</u> is a downloadable resource which provides detailed insight into every step of the transition between pediatric diabetes care and adult diabetes care!
- The <u>Student Transition Planner</u> is a comprehensive resource that contains all the information students need to successfully navigate post-secondary school with T1D.

All of DHF's programs are created in collaboration with youth and families impacted by T1D to help navigate the transition years.

We wish you all the best in your diabetes journey, and welcome to the DHF Community!



Message from the PEP Talks Team



Barbara Pasternak, DHF Founder

As a mom with two boys living with T1D, I always wished there were more resources for parents like me. At Diabetes Hope Foundation, we recognize that diabetes impacts parents and caregivers too. In 2021, at the height of COVID, we launched the 'Let's Talk About It' webinar series for caregivers to come together and talk about shared challenges around T1D.

With generous funding from Ontario Trillium Foundation in 2023, we expanded this program to include webinars and online resources specific to navigating adolescence with T1D. As with all of our programs, PEP Talks has organically grown from a need in the community, and we are proud to have consulted and collaborated with community members and health partners in the development of this program and the accompanying resources.



Heather Miller, MSW, DHF Executive Director

As a mom of three I am reminded everyday that parenting requires constant adaptation as we help our children navigate each new developmental stage. With a teenager of my own, I know firsthand how challenging it can be to find the balance between giving our children the space to become young adults while still acting in a guiding role.

Adding T1D into that process introduces challenges that are hard to explain to those outside the community. I have truly enjoyed being able to bridge my experiences as a parent of an adolescent with my experience as someone living with T1D to develop resources that respect both of these perspectives, providing thoughtful tools and tips that we hope will make your own journey into parenting an adult a little easier to navigate.



Nathaniel Kinghan, PEP Talks Facilitator

I've lived with diabetes since 2005 and my teen years were by far the most challenging. Diabetes made a difficult time of transition even harder. I wish my family had resources like this to help. I hope these pages give you context and comfort for the journey ahead, and that you feel equipped to give yourselves the grace to grow closer because of diabetes.

It took into my mid-20s for my parents and I to share just how stressful T1D was for us at the time. Now diabetes is a positive part of our relationships. I still fall back on asking carb counts for dinner when I visit, and my parents are the first people I call if I have questions about my health. We talk openly about diabetes (my mum was even a guest speaker for PEP Talks!), and we didn't get here easily. I hope the lessons we learned together will help you as you need them.

MINDSET MATTERS: MANAGING EXPECTATIONS

Acknowledging that T1D management is an ongoing challenge for youth and their families, developing a growth mindset can have a positive impact on both your child's health and your relationship with them.

Included in this section:

What is a Growth Mindset?

Growth Mindset Strategies

Growth Mindset In Action: Worksheet



What Is A Growth Mindset?

It Starts With Expectations...

Expectations are the hopes and goals we (and others) have for a given activity, experience or potential outcome. Our own expectations are be shaped by past experiences, current circumstances and/or external influences (family, clinical team, society, etc.). It's common to feel the weight of expectations when it comes to diabetes management including being able to keep blood sugars in range, expecting ourselves or our children to adhere to strict routines, or expecting to become the "perfect diabetic". These expectations and where they come from play an important role in our mindset, which then in turns plays an important role in how our health is managed.

In a recent <u>study</u>, having a growth mindset was linked to better glycemic outcomes in young adults after transitioning to adult care, suggesting that a growth mindset can be a powerful tool for efforts to improve health in youth with T1D.

Fixed Mindset vs. Growth Mindset

A **fixed mindset** focuses on the present, where skill levels, habits, and accomplishments are seen as permanent and unchanging. In a fixed mindset, people often compare themselves to others and find difficulty adapting to new challenges. (e.g. my A1c will never be as good as....).

A **growth mindset** embraces challenges and sees failures or setbacks as a chance to develop oneself further to strengthen our abilities and overcome new challenges.

Fixed Mindset

Avoids challenges

Sees **no way** to improve

Ignores feedback & criticism

Threatened by the success of others

Gives up easily

Growth Mindset

Embraces challenges

Believes things can improve

Open to feedback & criticism

Inspired by the success of others

Persists through setbacks

Source: Health Mindset and Health Outcomes for Adolescents with Type 1 Diabetes

Growth Mindset Strategies

It is natural to fluctate between a fixed and a growth mindsets, and it can take time and effort to learn how to embrace a growth mindset. It's a constant process of awareness, reflection, and subtle changes to the way we think and speak about challenges using specifid strategies.

A. Notice, Then Shift

The key to changing your mindset is to notice when you or your child is operating with a fixed mindset and then actively work to shift your thinking. This two-stage practice becomes a habit through repetition.

STEP 1: NOTICE

- How are you FEELING? Anxious, dejected, frustrated, angry, etc.
- What are you THINKING? "I'm not good at this, I can't, I'll never..."

STEP 2: SHIFT

- Focus on Progress
 - Instead of focusing on "Where am I now?", embrace a broader perspective to ask "Where was I....where am I....where do I want to be?"
- Change your language
 - Focus on using action words such as will, improve, become, develop to focus on growth and moving forward.

Fixed Thought	Strategy	Growth Thought
I want to have healthy habits.	Shifting from passive language ('have') to active language ('develop') helps to shift to a growth mindset.	I will develop healthy habits.
I should be better at this .	Words like 'should' compare us to others/external expectations, and are generally unhelpful.	I will improve my diabetes management.
	Being specific when defining goals (e.g. 'diabetes management' rather than 'this') helps us plan how to achieve them	

Continued...

Growth Mindset Strategies

(...continued)

B. 'Yet'

A helpful word to add to statements that to shift from a fixed mindset to a growth mindset. Using 'yet' encourages us to reframe obstacles as not only temporary but also as opportunities, openning us up to areas of potential growth.

Fixed Thoughts

We are not able to able to achieve my child's target A1c.

My child never carb counts when they are out with friends.

Strategy

Adding 'yet' to a fixed idea shifts focus from the present to the future and frames an obstacle as an opportunity.

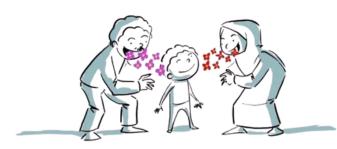
Growth Thoughts

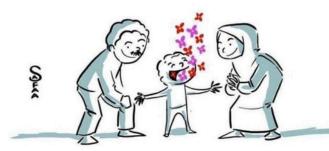
We are not not able to achieve my child's target A1c **yet**.

My child hasn't started carb counting independently when they are out with friends **yet**.

C. Modelling

As critical role models, it's important for caregivers to let their children hear and see how they use a growth mindset. Be honest about something that is difficult for you. Share when you're discouraged and be open to discussing solutions together, framed with a growth mindset language. By demonstrating what a growth mindset looks like and how it impacts you, your child will learn how to work through challenges more effectively as they encounter them.





Art by: Safaa Odah

Sources: <u>TED Talk - The Power of Believing That You Can Improve</u>

<u>A Growth Mindset: Changing Your Diabetes Management</u>

<u>How to Help Students Develop a Growth Mindset</u>

Growth Mindset Worksheet

Steps

- Identify a fixed thought you/your child has about diabetes management.
- · Record that thought in the left-hand column.
- Use the right-hand column to reframe the original thought using a growth mindset.
- Repeat this exercise often to form a habit of growth-minded thinking

My Mindset

Fixed Thought	Growth Thought
E.g. I should trust my child to manage their T1D when they're out of the house.	E.g. I will develop trust in my child to manage their T1D when they're out of the house.

My Child's Mindset

Fixed Thought	Growth Thought
E.g. I'm not able to perform site changes myself.	E.g. I'm not able to perform site changes myself yet .

HELPFUL TIP

If you notice you or your child feeling frustrated or upset during a conversation, pause and reflect on the language being used and, if needed, shift to a growth mindset. Be sure to give yourself grace as you incorporate a growth mindset into your life!

TALKING WITH YOUR TEEN: NAVIGATING THE HIGHS & LOWS

Conversations about T1D can often be difficult as your child matures and embraces their independence through setting new boundaries and taking on more responsibility. In this section we explore new tools and approaches to help navigate this transition, including:

Communicating with Adolescents

The Impact of Language

Communication Tools

Prioritizing Conversations

Prioritizing Conversations: Worksheet

Talking About T1D Responsibilities

Communication Agreement: Worksheet



Communicating with Adolescents

Understanding The Adolescent Brain

The prefrontal cortex - or, the 'rational' part of the brain - is responsible for exercising good judgment and considering long-term consequences and does not fully develop until the age of 25. To compensate, the adolescent brain processes information with the amygdala - or, the 'emotional' part of the brain - which develops much earlier. As a result, adolescents will often make decisions based on impulse and emotions - decisions which often "don't make sense" to those with a fully developed prefrontal corte.g.

This staggered brain development accounts for behavioural challenges and frustrations when communicating with and understanding adolescent thinking. It's important for adults to consider the physical differences between their brain and the brain of their child, and how the differing brain structures can both clash and complement each other.



Avoiding "Why?"

Conversations about T1D that start with why questions (e.g. "Why was your blood sugar high all day?", "Why did you sneak food in the middle of the night without giving insulin?", etc.) are more likely to spark conflict because of the different way adolescents make decisions. "Why...?" is a question about logic and reason - which belong to parts of their brain which are still in development - and this can cause frustration and derail the conversation.

Instead, asking your child to recount their actions that led up to the moment you're curious about will reframe the *why* conversation into something that the adolescent brain more easily understands. Also, *why* questions imply that there's a simple answer to a question about diabetes, which is rarely ever the case. They might not be able to tell you *why* their blood sugar did this or that, but working backwards can help you to problem solve together.

HELPFUL TIP

As useful as this information can be for a parent to know, **be mindful of how you communicate this science to your child**. Allow them to feel empowered by the elasticity and potential of their adolescent brain without feeling put down or lessened by being told their brain isn't "developed enough" to make good decisions.

Sources: <u>Understanding the Teenage Brain</u>

<u>Perks of the Teenage Brain</u>

<u>Communication and the Teenage Brain [VIDEO]</u>

The Impact of Language

Your choice of language can influence how a conversation goes, as well as impact both you and your child's relationship to T1D. Check out <u>DHF's webinar with Dr. Michael Vallis</u> on the ways that language impacts the T1D experience. Through being mindful of the language you use, you are more likely to find ways of talking about diabetes that open up conversations rather than shutting them down. Try language that:

Is Strengths-Based and Imparts Hope

Be sure to include what is working, rather than only what is wrong. Empowering a child's strengths encourages them to engage with new challenges.

Is Collaborative

Though it may not always feel like it, you and your child are on the same team. Replace phrases like "you need to..." or "you should..." with thoughts like "how can I support you?" and "let's work together to...".

Is Neutral, Nonjudgmental, and Based on Facts

Rather than saying, "your blood sugar is good/bad", refer to the numbers themselves. You can provide further, nonjudgmental context such as "that's higher than the target we talked about of x mmol/L".

Makes Space for the Emotional Impact of T1D

Whether intentional or unintentional, words carry weight for people living with T1D. Work with your child to identify words or phrases they find stigmatic, and brainstorm alternatives to use instead. The burden of T1D feels different every day. Try asking "how heavy is your T1D backpack today?" to gauge the level of diabetes distress. Some days may feel like they're carrying a laptop, and some feel like a bag full of bricks.

Focuses on Actions, Not Personality

Help your child know that they are greater than their highs and lows. Remember, you want your child to feel like they are the hero of their story with you as their sidekick.

HELPFUL TIPS

- Diabetes is a marathon not a sprint, and you and your child are not defined by today's blood sugars.
- T1D management is a partnership, with your child as the hero of their journey.
- The way you and your child discuss diabetes will shift over time, and it's normal and healthy to revisit conversations and management strategies throughout the many phases of adolescence.

Communication Tools

Offering feedback and direction is a necessary part of parenting, but it can also open the door for misunderstandings and conflict. When approaching important conversations about diabetes management, encorporarting communication tools will help to ensure both sides are heard in an open and constructive way.



The Feedback Sandwich

Begin and end each conversation with positive feedback, and sandwich constructive criticism in between.



Check In first

Before starting the conversation, ask if now is a good time for your child. If not, set another time to talk.



Encourage Ownership

Give your child space to take the lead on making their own decisions, and be there if/when they need help.



Strengths-Based Language

Focus on what your child does well, rather than where they're failing.



Stay Solution Focused

Avoid blaming, and work to come together to solve the problem.



Ask Open-Ended Questions

Avoid 'yes' and 'no' questions in order to allow your child to explore their experience.



Practice Active Listening

Listen without interrupting and focus on what is said rather than how you will respond.



Pause Before Feedback

Ask yourself: What's my goal with this feedback, and is it helpful?. This helps to focus the discussion.



Model Desired Behaviour

Your child is learning from you in every interaction. Approach challenges with a <u>Growth Mindset</u>.

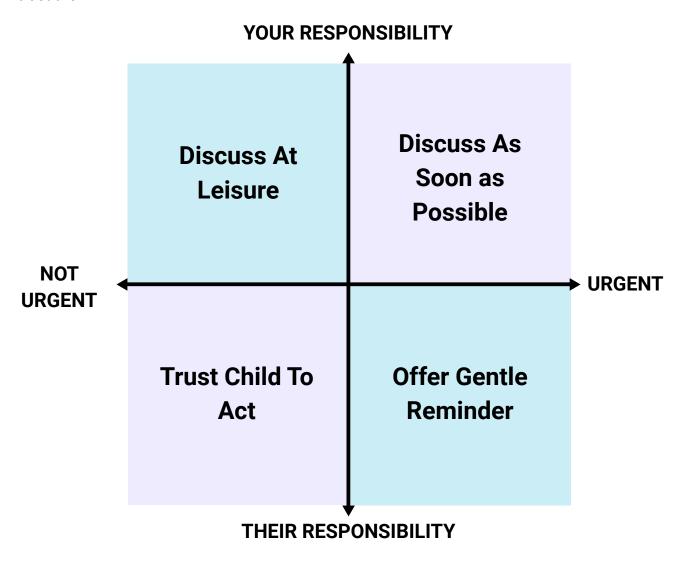
Prioritizing Conversations

Being a T1D caregiver can feel like you're constantly on high alert, and every discussion can feel loaded with importance and urgency. Being asked about diabetes as soon as they walk in the door after school can feel overwhelming and burdensome to your child.

To reduce stress on your child and on your relationship, you can prioritize conversations related to T1D by asking yourself two questions to determine when to raise concerns you have:

- 1. Whose responsibility is this?
- 2. Is this urgent? (e.g. will postponing this conversation cause immediate harm?)

Challenge yourself to save some of the less urgent conversations for quieter moments, and re-evaluate when/if the conversation needs to happen. Work to let go of conversations that concern parts of T1D that are your child's responsibility and are not putting them in harms way. This will help your child take on more responsibility over time and let them know you trust them.



Prioritizing Conversations Worksheet

It's helpful to pause before important conversations and determine when you should start the discussion. Use this worksheet to log any T1D-related questions/topics you frequently bring up with your child, and mark down which column(s) you feel best represents the topic.

Every topic may feel like it belongs in the *now* column. Challenging this impulse can help to alleviate stress in your relationship.

Discussion Topics	Information I Need to Know Now	Information I Can Know Later
e.g. Did you remember to bolus for dinner?		

HELPFUL TIP

Sometimes the weight of living with diabetes can cause conflict in even the most benign conversations. If you find that your child is reactive to any T1D-related comment or question, **consider having a conversation** *about* **T1D conversations**. Collaborate to find the timing, language, and frequency that works for you and your child.

Talking About T1D Responsibilities

You may feel a big shift in your family dynamic as your child assumes more responsibility for their T1D management. It's important to talk with them to clarify what supports they want and need from you as they gain more autonomy. Try to have these conversations when there is a shift in routine and establish clear boundaries to help make the transition easier for everyone. Consider inviting your child to help draft a <u>T1D communication agreement</u> for your family to articulate and specify everyone's communication needs and boundaries.

Remember that as your child matures, they will need to develop into a responsible person capable of taking ownership of their T1D management. Let them know you are always there to support them, but encourage them to take the lead on what that support looks like.

Setting Boundaries



Boundaries are about what you are going to do, not about telling others what to do.



Setting boundaries may feel uncomfortable but it helps clarify roles & expectations.



Stating your feelings & intentions early prevents resentment and confusion later.



Remember to use
I-statements
when sharing
feelings and
focus on moving
forward together.

When discussing boundaries, make sure that everyone is clear on who is responsible for what. Boundaries are fluid and can change over time, so expect to revisit these conversations as these new boundaries develop.

Questions to Consider Asking

- Do they want reminders about doctor's appointments?
- Who will be in charge of ordering supplies?
- If a **low alarm** goes off, at what point should you get involved and what steps should you take?
- How often does your child want you ask about T1D and what is the best way to ask?

HELPFUL TIP

CGM technology that allows others to 'follow' blood sugar readings from afar may be an important tool in your family's current T1D management plan. As your child matures, it's natural for them to seek some independence by wanting to keep their data private or to set limits on when you can follow them. Be sure to talk about what works best for your family based on individual boundaries and **ensure that your child feels in control** of this decision.

Communication Agreement Worksheet (Example)

Scenario

Sam is a student living with T1D who is getting ready to move away for school. Sam's mom and dad are concerned about nagging Sam too much after the move, but they still want to be able to support Sam with T1D management. Sam is excited to embrace the independence of living away from home, but also feels nervous to handle T1D management alone for the first time. Together, they use the following agreement to establish clear boundaries about T1D communication that takes into account all of their needs.

Goals:

- 1. Sam will be able to experience the freedom and autonomy of living away from home by managing T1D independently.
- 2. Mom and Dad will be kept in the loop regarding T1D and other aspects of Sam's life.
- 3. Sam will know that they always have support available from Mom and Dad.

Student Strategies:

- Sam will handle day-to-day T1D management, including bolusing and correcting.
- Sam will:
 - Update Mom and Dad on major health changes.
 - Provide general T1D updates at some point during the weekly family phone call
 - Sundays at 7pm.
 - Sam has control over when in the conversation to bring up T1D and how much information to disclose.
 - Allow Mom and Dad to follow CGM activity when going out with friends.
- Sam is encouraged to phone home or text if they ever have a T1D-related question.

Caregiver Strategies:

- Mom and Dad will defer to Sam to initiate conversations about T1D.
- Mom and Dad are allowed to contact Sam's roommate if:
 - a. Sam doesn't respond to emergency texts within 30 minutes when CGM following is turned on, OR
 - b. The weekly family phone call is missed without explanation by Monday morning.
- Mom and Dad will continue to manage supplies and prescriptions, restocking Sam on holidays and visits.

Communication Agreement Worksheet

Use this agreement to:

- Promote collaborative conversations about your individual needs and boundaries.
- Outline your family's collective goals for communication and transition.
- Highlight individual strategies to achieve these goals.
- Hold each other accountable for your commitment to these goals and strategies.

Goals:		
Student Strategies:		
Caregiver Strategies		

SHARING RESPONSIBILITY: HOW TO FOSTER INTERDEPENDENCE

Learn how *inter*dependence is different from *in*dependence, and how you and your child can collaborate to gradually shift T1D responsibilities as they approach adulthood.

<u>Defining Interdependence</u>

<u>Visualizing Interdependence</u>

Growth Zones & New Boundaries

Scaffolding

Scaffolding in Action

SMART Goals: Worksheet



Defining Interdependence

The transition from adolescence to adulthood is often talked about in terms of dependence and independence. *Inter*dependence is a third way of thinking that this transition that strengthens confidence through collaboration and support.

Dependence - When someone depends on others to fulfill their needs. **Independence** - When someone does things on their own without relying on others. **Interdependence** - When someone is capable, confident, and seeks collaborative support when needed.

You may find that you and your child have different thresholds of dependence for different aspects of T1D management (the physical, emotional, or intellectual).

	Physical	Emotional	Intellectual	
Dependence	Needs physical assistance for diabetes management (i.e. site changes, administering insulin, etc.)	Bases identity and self-worth on other people's opinions and behaviors (caregivers, health care team, etc.)	Relies on others to make decisions for them (food choices, carb counting, deciding insulin doses, speaking at clinic visits)	
Independence Takes care of their own physical needs around diabetes management.		Derives sense of worth from within, independent of others' opinions.	Makes decisions and forms opinions without others' input.	
Interdependence	Can manage the physical aspects of diabetes by themselves, but asks for help when needed (i.e. when sick).	Has an strong internal sense of self-worth, but also takes other's opinions and feedback into consideration.	Thinks independently, while also considering information and perspectives from others, especially when facing challenges or new situations.	

Source: 7 Habits: Dependence, Independence, Interdependence

Shifting Interdependence in T1D

Dependence is often how a child begins their journey with T1D. As families learn to manage diabetes, caregivers often assume the responsibility for some or all of the tasks. How much a child depends on their caregivers for their diabetes care depends on the age at diagnosis, the capacity of the child, and what works best for each individual family.

Independence is a critical developmental milestone during the adolescent years as your child matures and works towards self-sufficiency. This may include a rejection of support and/or feedback as they test the boundaries of their <u>learning zone</u>. Stay available to support your child while trying to respect their push towards independence.

Interdependence is built on collaboration. You trust your child to handle the responsibilities of T1D management, and they trust that your support is available when they need it. Interdependence will likely last through adolescence and long into adulthood - many adults living with T1D still reach out for parental support as needed.

How Thoughts Can Shift

Dependent Thoughts

I can't make a decision on my own.



Interdependent Thoughts

I can decide on my own but I value your opinion.

I cannot trust myself and I need you.



I trust myself, and I know that you are there if I need you.

I cannot handle doing things on my own.



I can do things alone most of the time and be okay.

I'm not sure I know what to do without you telling me.



I know what to do on my own, and know if I forget I can ask you.

Growth Zones And Interdependence

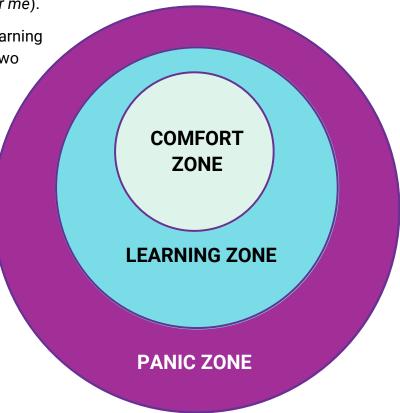
The Learning Zone Model

Learning how to navigate between zones of comfort, learning, and panic can help your child approach new challenges and responsibilities with confidence and excitement. Moving between the different zones is a fluid process. Let you and your child return to the comfort zone when needed, especially during times of stress. Use familiar skills from your comfort zone to anchor you as you explore the learning zone, and make sure to check in with your child about how they are feeling throughout the process.

The Comfort Zone: Staying in the comfort zone, you continue doing what you know you are good at and don't push yourself to learn and achieve more. (e.g. *I feel comfortable when someone else changes my T1D tech for me*).

The Learning Zone: Moving into the learning zone, you are striving to move one or two steps forward. This takes confidence in yourself and trust in those around you. (e.g. I trust in my ability to change my tech with a parent watching).

The Panic Zone: Moving into this zone may be a sign that you are overconfident. You may be jumping ahead of what you are ready for. Make sure you fully evaluate what you and your child are ready for. (e.g. I feel panicked if I need to change my tech alone at a friend's house).



HELPFUL TIPS

- Challenge yourself to identify what your *own* current learning zone might be around transferring responsibility for T1D management, and recognize that it might be different from that of your child. Invite your child to share their own learning zone with you, and be prepared to push them if needed.
- Allow you and your child to step back into the comfort zone if the need arises, and give
 yourselves the grace to stay there until the learning zone feels accessible again (this
 may be for a day, a week, or even a year depending on the situation).

Source: The Learning Zone Model

Scaffolding

One tool to help your child move into the learning zone is scaffolding, designed to help develop new skills and responsibilities. Much like scaffolding around a construction site, support systems are built around your child and gradually and mindfully pared back as they develop the skills needed to manage new responsibilities. Remember that scaffolding can be re-introduced if it is removed too soon! Make sure your child knows that you're there to offer support at every step and that you are there to help them when they stumble (or fall!).

Procedural Scaffolding

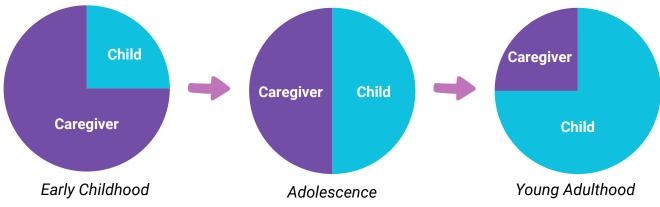
Precedural scaffolding focuses on giving your child hands on experience with the task with you there to guide them. Their confidence will grow through support and exposure, and you will strenghten your relationship by reassruing them you are there to support them through every challenge. Try using some of the <u>communication tools</u> from earlier in this resource to help make the following steps feel more collaborative.

- 1. Direct Modeling (The I DO Phase) Demonstrate the task in real time.
- 2. **Guided Learning (The WE DO Phase)** Approach tasks collaboratively, offering guidance and support as necessary. When something is challenging or goes wrong, problem solve *together*.
- 3. **Independent Practice (The** *YOU DO* **Phase)** Promote the expectation that tasks can be completed without supervision, and **remain available to support as needed**.

The Impact of Scaffolding

You'll notice that your role scales back as you promote more interdependence through scaffolding. The figure below shows the gradual impact that scaffolding will have over time, with your child assuming more responsibility for T1D management as they become ready, and you supporting them throughout their T1D journey. Remember that every family's journey is different, and there are no set deadlines for your child to take on more than they are ready for.

Shifts in Responsibility for T1D Management



Sources: What Is Scaffolding? [VIDEO]
A Gradual Release of Responsibility

Scaffolding in Action

Let's examine the process of scaffolding in the context of a T1D task many adolescents work to take on before moving out: **ordering prescriptions**.

Check In First

Have a conversation about ordering prescriptions with a focus on your child's expectations and confidence. Let them take the lead communicating what they're ready to take on, and be prepared to gently push them out of their comfort zone.

Step 1 - Direct Modeling

Start by directly modeling the process of ordering prescriptions - place the phone call or fill out the form with your child present to see how it works. Bring them with you to pick up the order if they're unfamiliar with the process, and share your system for tracking when prescriptions need to be refilled by a doctor.

Step 2 - Guided Learning

Once they understand the process of ordering prescriptions, have your child place the next order with you nearby to guide them as needed. Go with them to pick up the order, and let them take the lead throughout the process.

Step 3 - Independent Practice

Once your child feels comfortable, transfer full responsibility of the task. Let them track and order their presceriptions on their own. Make sure that they know you are available to assist as needed, but give them space to make mistakes, learn, and grow.

HELPFUL TIPS

- If you or your child prefers a more structured approach, use the following SMART Goals worksheet for reach new skill that they will be developing.
- Take time to reflect on each step and the outcomes before moving on. If needed, you can always return to earlier steps to ensure everyone is ready for moving forward.
- Work together to build a list of T1D responsibilities that need to be transferred before transitioning into adulthood. Consult DHF's <u>Guide to Adult Care</u>, for a comprehensive transition readiness checklist.
- Remember to allow both yourself and your child the grace to make mistakes and learn from them. This encourages them to come to you when something goes wrong, and keeps you engaged in their growth.

Source: <u>Diabetes and Teens: Three Keys for Parents [VIDEO]</u>

SMART Goal Worksheet

Initial Goal - what is it that you want to accomplish related to T1D management?

Using the chart below, ask questions and add SMART details to your goal.

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Narrow down your goal to something more specific. Who is involved? Why do you want to accomplish it? Wat resources will you

Measureable

How will you know when you have accomplished your goal?

necessary to achieve this

Do you have the skills

goal? What barriers may

exist that you need

to take into account? Is it

something you have

control over?

Relevant

Achievable

Is this the right time for this? Does it fit with your families current needs and capacity?

Time Bound

When will your goal be accomplished? Is this a realistic deadline?

SMART Goal - rewrite your goal to include the information above.



Source: What are SMART Goals?

BUILDING YOUR VILLAGE: COLLABORATION & SELF-CARE

Diabetes will have a significant impact on your entire family, yourself included. This section includes strategies to support everyone that is impacted both directly and indirectly by T1D, including:

Family Care

Family Care Wheel

Building Your Village

Building Your Village: Worksheet

Self-Care

Nurturing vs. Depleting: Worksheet

Simple Self-Care Practice



Family Care

It's Not All About Diabetes!

Having T1D in the family is a big deal, and it can be easy to let it take over conversations and relationships. As serious as T1D is, avoid family burnout by remembering to:

- Emphasize the importance of everyone developing their own interests (including you!).
- Help your family recognize each other's experiences, and emphasize that it's not a competition. One person's challenges with T1D may be another's ADHD, asthma, etc.
- Let your non-T1D children know that you appreciate their help but try to not overload them with responsibility by putting them in a position of caregiving.
- Find opportunities for independence. This extends to the home environment where siblings need their own space and privacy.
- Avoid letting T1D completely stop an activity from happening (unless it is an emergency situation).
- Avoid letting your child with T1D out of everyday responsibilities.

Talking with Siblings about T1D

Being the sibling of someone growing up with T1D can be a complicated emotional experience. Be mindful of the signs of stress that may arise and be sure to help other children in your family navigate their feelings.

Listen. Make time for siblings to talk openly about T1D, and let them know you understand that having T1D in the family can be difficult for everyone. Allow them to express feelings of frustration, guilt, jealousy, etc., and let them know their experiences are important.

Talk About Feelings. Give siblings a safe space to explore their feelings – both good and not so good. Let them know all their feelings are okay and that they are understandable. Help them reframe statements that are harmful (i.e. "no one cares about me"), and be sure to aovid language like "you're lucky you don't have diabetes!" when they are struggling with their own challenges.

HELPFUL TIP

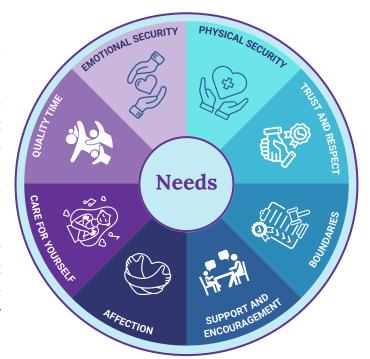
- Approach your child with age-appropriate language and don't expect them to use adult logic or reasoning in processing their experiences and emotions. To learn more about each stage, resouces like <u>An Age-By-Age Guide to Helping Kids Manage</u> <u>Emotions</u> can be helpful.
- Make sure to reach out to professionals if anyone in your family seems like they may need help talking about how T1D is impacting them, including <u>The Mental Health + Diabetes Directory</u>.

Family Care Wheel

Every member in a family has a spectrum of needs and to feel nurtured and safe, each one must be acknowledged and met.

Remember that each member of the family has strengths and weaknesses that need to be supported. T1D is one of those things, but it's not the only thing and it's important to not let it take over the entire family.

For each member of your immediate family (including yourself!), think about what their unique needs are. Consider the specturm of needs for everyone in your household using the Family Care Wheel.



Emotional Security

- · Talk and act in a manner that everyone feels safe and comfortable
- Be dependable, consistent and gentle.
- Listen without judgement and value emotions.

Physical Security

- Ensure there is food, shelter, clothing and medication.
- Teach proper hygiene & health care, monitoring safety and attending to wounds and medical needs.

Trust and Respect

- Acknowledge a child's right to their own feelings, opinions, interests and friends.
- Believe in your children's ability to to succeed.

Boundaries

- Clearly articulate expecations and rules that are age appropriate.
- Be consistent and clear about expectaiotns and limits.

Support and Encourage

- Encourage individual interests and opinions.
- Allow room for disagreements, mistakes and growth and be affirming.

Give Affection

- Express verbal and physical affection.
- Comfort when children are physically or emotionally hurt.

Care for Yourself

- Give yourself time to prioritize your own health and interests.
- Accept love and help.

Give TIme

- · Participate in things that are part of your children's world.
- Include your family in your activities so your children get to know who you are.

Source: 8 Ways to Love and Care for Your Children

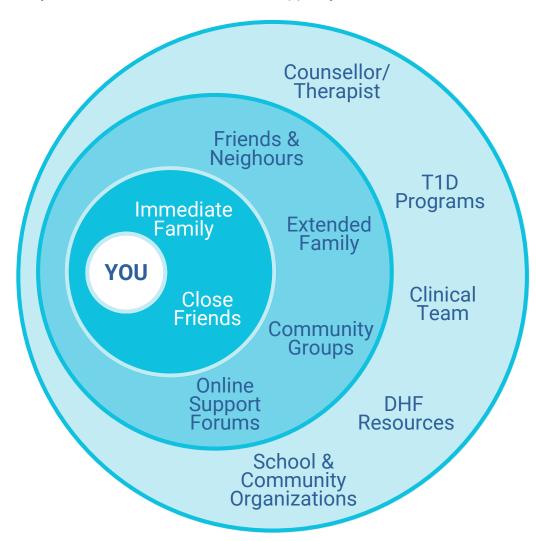
Building Your Village

Living with type 1 diabetes in the family can often feel like an isolating experience, and the responsibilities of acting as a caregiver can weigh heavily over time. It can be a difficult moment to acknowledge that you don't have to handle these responsibilities alone. You might experience feelings of guilt, sadness, or anxiety at the thought of asking others for help. Be sure to give yourself the grace to build your village so that you and your family can feel supported.

Finding Support

Finding support and community can allow you the time and space to practice self-care, and regular self-care can make you a better helper and supporter for others.

You can find help and support as a T1D caregiver in different circles. Everyday help may be available in the members of your household or among close friends, and you may be able to develop trust with extended family or neighbours to access external help. Professional help exists in many different forms based on what support you need.



Continued...

Building Your Village

(...continued)

How to Ask for Help

Use	Assertive Communication Skill	s. Be h	onest and o	open,	stating	the request	directly	and
with	respect. Try phrases such as: "I	ve beer	n struggling	with		. Would you	be willin	g to
	?", "Could you help me out by		_?", etc.					

Be Specific. Try to make your request simple and direct. Include specifics such as timelines and individual tasks, and offer to provide education and resources to help build trust with your support network. If you're not exactly sure what kind of help you need, ask if you can talk it over together.

Be Prepared To Educate. Not everyone who wants to help knows as much about T1D as you do. You can build trust by patiently educating those who are receptive to learn. Providing clear instructions and resources (like this <u>Blood Sugar Response Chart</u>) will build confidence in your supporters. Investing effort into educating your support system will pay off once they are fully prepared to help.

Accepting Help

Acknowledge Any Discomfort. Accepting help may trigger you to feel pushed out of your comfort zone. Recognize feelings of guilt, shame, or feeling like a burden. These are thoughts, not facts. Ask yourself: "Would I offer this help to a friend?"

Say 'Thank You'. Give an honest response that accepts the help, rather than "I don't know what to say" or "you shouldn't have". Verbal gratitude communicates to the helper that you appreciate their support and effort.

Pay It Forward, Not Back. Help shouldn't feel transactional - this can create a feedback loop of discomfort. Try reframing help as something that's passed along, rather than something that's owed or collected.

HELPFUL TIPS

- Ask your clinic for tips on how to educate friends and family members by providing educational resources and support.
- When building support systems with close family and friends, remember that everyone
 has their own strengths and weaknesses. Work together to identify who is best suited
 to take on each role based on their capacity and capabilities.
- Accepting external help requires trust, and trust can take time to build. Build this trust
 with others through communicating, educating, and collaborating.

Sources: <u>How Would You Treat a Friend?</u> How to Ask for Help

Building Your Village: Worksheet

Consider the strengths of your support network. Different people can help to support you with different needs. It's important to continue building your village and your needs and those of your family change. Consider looking into online groups and communities to hear new perspectives about parenting with T1D.

What Do You Need? (be specific - e.g. someone to vent to, someone to help plan meals, etc.)	Who to Contact (include contact information for quick reference)	Back-up Support (who to contact if your primary contact is unavailable?)

Self-Care

How Self-Care Helps

Self-care is often presented as something extravagant - candles and bubble baths and spa days and expensive treats. It can feel like an extra chore and people tend to think thoughts such as "I don't have time for self-care", or "self-care is selfish". But self-care isn't selfish, and there are plenty of opportunities to find nourishment and rejuvenation in your current day-to-day schedule. You can't take care of others without first taking care of yourself.

Self-care can help replenish your energy, focus, and positivity by reducing stress and decreasing your chance of burn out. It helps us to set boundaries for ourselves, and boundary setting helps us to have more energy for ourselves, our children and our other relationships. As a role model, practicing self-care demonstrates to your kids the importance of self-worth.

Nurturing Activities vs. Depleting Activities

Consider the existing activities that make up your daily routine. Are they nurturing, depleting, or a bit of both?

Nurturing Activities. These are opportunities for self-care. These activities cheer us up, give us energy, improve our well-being, and help us to better manage stress. They lift our mood, fill our cups, and help us to feel calm and centered.

Depleting Activities. These activities sap our energy, increase our stress levels, and take away from our happiness. They lower our mood, drain us, and leave us feeling physically and/or emotionally exhausted.

Activities can shift from one category to another based on when, how, and with whom you do the activity. If your list of depleting activities feels overwhelming, look to your support system for help. Is there an activity that someone else in your family has the capacity to take on? Are there activities they find depleting which you enjoy? Work together to find a balance and maximize your support system's capacity for self-care!

HELPFUL TIP

Nurturing activities aren't limited to spa dates and yoga class (although these are great when we can find the time and resources for them!). The key to practical self-care is to identify what moments in your day-to-day life are **already** nurturing you. Some examples may include family meals, walking the dog, picking kids up from school or reading on the way to work.

Nurturing vs. Depleting: Worksheet

Write down your daily activities, from the first thing you do in the morning to the last thing before going to bed. Then, mark whether each activity leaves you feeling nurtured, depleted, or both (depending on the day!).

Nurturing	Depleting	Both
	Nurturing	Nurturing Depleting

NEXT STEPS

- Observe your ratio of nurturing to depleting activities (likely, you'll notice quite a few more depleting activities).
- Try to reframe depleting activities by changing when/how/with whom you do them.
- For activities that are harder to reframe, consider people in your life who can help manage the activity sometimes to help lessen your load.
- Think about how you can work in more nurturing activities to try to find more balance.

Taking in the Good

Finding time and space in already busy schedules can often get in the way of practicing self-care. It's important to remember that nurturing activities can also be found in smaller moments as you move through your day. The following practice is adapted from <u>Dr. Rick Hanson</u>'s exercise of *Taking in the Good*, and invites you to develop the habit of noticing and appreciate good moments as they happen.

By consciously and deliberately noticing positive moments over time, we are able to train our brains to learn to acknowledge nurturing experiences **automatically**. The following three-step practice takes less than one minute to complete, and can happen anytime, anywhere.

- 1. **Notice the Little Things.** As you're going through your day, keep an eye out for moments that make you feel good (e.g. the weather is nice, this coffee tastes good, etc.).
- 2. Pause and Enjoy the Good Experience. Spend 10-20 seconds with the good moments, letting it become a good experience.
- 3. **Notice How You Feel.** Make a mental note of how you feel physically and emotionally after sustaining a good experience.

Modeling as a Caregiver

Taking in the Good doesn't need to be an exclusively internal practice. You may wish to share moments of noticing out loud with your child. Modeling this practice can teach an appreciation for good and nurturing moments, a practice that can stay with your child long past the transition to adulthood.

Remember to also pause and notice moments spent with your child, appreciating the good in who they are.

HELPFUL TIP

Along with moments that make you feel happy and joyous, make sure to also acknowledge times that you feel:

- Safe and secure
- Included
- Grateful
- Understood

Strong

Worthy

Loved

Valued

Source: <u>Dr. Rick Hanson - Taking in the Good</u>
Taking in the Good [VIDEO]

PEP Talks Reference List

Growth Mindset

TED Talk - The Power of Believing That You Can Improve

A Growth Mindset: Changing Your Diabetes Management

How to Help Students Develop a Growth Mindset

Health Mindset and Health Outcomes for Adolescents with Type 1 Diabetes

Communication

Understanding the Teenage Brain

Perks of the Teenage Brain

Communication and the Teenage Brain [VIDEO]

<u>Tips for Talking to Your Teenager with Diabetes</u>

Let's Talk T1D Management with Dr. Michael Vallis [VIDEO]

Words Have Power - A Study on Language and Diabetes

Interdependence

What Is Scaffolding? [VIDEO]

A Gradual Release of Responsibility

Diabetes and Teens: Three Keys for Parents [VIDEO]

7 Habits: Dependence, Independence, Interdependence

The Learning Zone Model

Words Have Power - A Study on Language and Diabetes

What are SMART Goals?

Self-Care

<u>American Diabetes Association's Tools for Caregivers</u>

8 Ways to Love and Care for Your Children

Ways to Support Siblings

How Would You Treat a Friend?

How to Ask for Help

Nourishing vs. Depleting Activities

Why Self-Care is Important for Parents

The Ripple Effect of Self-Care

Dr. Rick Hanson - Taking in the Good

Taking in the Good [VIDEO]

45 Simple Self-Care Practices





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