



# How Family Dynamics Can Affect the Health of an Adolescent with Type 1 Diabetes

Quinn Nystrom, M.S.

## Helpful Diabetes Terms



- **Type 1 diabetes (T1D)**, the pancreas no longer makes insulin and therefore blood glucose cannot enter the cells to be used for energy.
- **Type 2 diabetes (T2D)**, either the pancreas does not make enough insulin, or the body is unable to use insulin correctly.
- **Blood Glucose**: the main sugar found in the blood and the body's main source of energy. Also called blood sugar.
- **Hemoglobin A1C (HbA1c)** is a test that measures a person's average blood glucose level over the past 2 to 3 months. Hemoglobin (HEE-mo-glo-bin) is the part of a red blood cell that carries oxygen to the cells and sometimes joins with the glucose in the bloodstream. Also called hemoglobin A1C or glycosylated (gly-KOH-sih-lay-ted) hemoglobin, the test shows the amount of glucose that sticks to the red blood cell, which is proportional to the amount of glucose in the blood.

## Helpful Diabetes Terms

- **Continuous Glucose Monitor (CGM):** Continuous glucose monitoring automatically tracks blood glucose levels, also called blood sugar, throughout the day and night. You can see your glucose level anytime at a glance. You can also review how your glucose changes over a few hours or days to see trends. Seeing glucose levels in real time can help you make more informed decisions throughout the day about how to balance your food, physical activity, and medicines.
- **Time in Range:** Time in range is the amount of time you spend in the target blood sugar (blood glucose) range—between 70 and 180 mg/dL for most people.
- **Ketones:** When the body starts to break down fat in order to get energy, ketones are a byproduct. When too many of those build up in the blood, it makes the blood acidic and can lead to diabetic ketoacidosis.
- **Diabetic Ketoacidosis (DKA):** an emergency condition in which extremely high blood glucose levels, along with a severe lack of insulin, result in the breakdown of body fat for energy and an accumulation of ketones in the blood and urine. Signs of DKA are nausea and vomiting, stomach pain, fruity breath odor and rapid breathing. Untreated DKA can lead to coma and death.



## Type 1 Diabetes

- About 1.25 million people in the U.S. have type 1 diabetes
- Nearly 18,000 new cases diagnosed annually in people under age 20
- The life expectancy of a type 1 diabetic is a decade shorter than those without the disease

American Diabetes Association. Type-1 Diabetes. [www.diabetes.org](http://www.diabetes.org). Retrieved on: August 18, 2021.



Family Dynamics



Illness Perception

## Illness Perception Definition

- Petrie, Jago, and Devcich define illness perception as, “the organized cognitive representations or beliefs that patients have about their illness”.
  - Several research findings on this topic show when you change a patient's illness perception, they will be “successful in reducing disability and speeding return to work”.
  - The internalized feelings that a patient has about their diagnosis plays an integral role in how they perceive what is going on in their day-to-day world.

Petrie, K., Jago, L., & Devcich, D. (2007). The role of illness perceptions in patients with medical conditions. *Current opinion in psychiatry*, 20(2), 163-167.

## Illness Perception

- Research has shown that the greatest impact to a patient being diagnosed with a chronic or acute illness is their perceived ability that they will get to still have a ‘normal’ life (Hale, Treharne, & Kitas, 2007).
- 5 components to illness representation:
  - 1. Identity: The label or name that is used to describe the illness.
  - 2. Cause: what does the patient perceive as the reason they got diagnosed?
  - 3. Time-line: how long does the person believe they will have this chronic illness?
  - 4. Consequences: what might happen medically to this patient over time if they don't adhere to the strict medical regimen that they've been given?
  - 5. Curability/controllability: the patient's belief about hope for a cure one day and keeping the disease in control, and how self-management can help them achieve either.

Hale, E., Treharne, G., & Kitas, G. (2007). The common-sense model of self-regulation of health and illness: How can we use it to understand and respond to our patients' needs? *Rheumatology (Oxford, England)*, 46(6), 904-906.

Hill, S., Dziedzic, K., Thomas, E., Baker, S., & Croft, P. (2007). The illness perceptions associated with health and behavioral outcomes in people with musculoskeletal hand problems: Findings from the north staffordshire osteoarthritis project (NorStOP). *Rheumatology (Oxford, England)*, 46(6), 944-951.

# Social Learning Theory

## Albert Bandura

- Perceived self-efficacy is conceptualized as perceived operative capability. It is concerned not with what one has but with belief in what one can do with whatever resources one can muster. The operative nature of perceived self-efficacy is an integral feature of the procedure used to access people's efficacy beliefs.
- "...of learning that incorporates both behavioral and cognitive learning components and emphasizes observational learning".
- People learn behaviors from their environment through observing it.
- "Need to shift the emphasis from trying to scare people into healthy behavior to empowering them with the tools and self-beliefs for exercising personal control over their health habits."

Bandura, A. (1977). Social learning theory. Englewood Cliffs, NJ: Prentice-Hall. Bandura, A. (2001). Social cognitive theory of mass communication. *Media Psychology*, 3(3), 265-299. Bandura, A. (2007). Much ado over a faulty conception of perceived self-efficacy grounded in faulty experimentation. *Journal of Social and Clinical Psychology*, 26(6), 641-658.

## What's at Stake

Only 1/3 of children with type 1 diabetes achieve their targeted Hemoglobin A1c

Hoey, H. (2009). Psychosocial factors are associated with metabolic control in adolescents: research from the Hvidoere Study Group on Childhood Diabetes. *Pediatric Diabetes*.

## Hemoglobin A1C

- 2020 Standards of Care (ADA) issued a new recommendation for children with T1D: "A1C goals must be individualized and reassessed over time. An A1C of <7% is appropriate for many children".
- A higher target of <7.5% may be more appropriate for youth who cannot articulate symptoms of hypoglycemia or have hypoglycemia unawareness, as well as those who do not have access to analog insulins, cannot monitor their blood glucose regularly, or do not have access to advanced diabetes technologies, including insulin pumps and CGM.
- A target of <8% is recommended for youth with a history of severe hypoglycemia, severe morbidities, or short life expectancy.

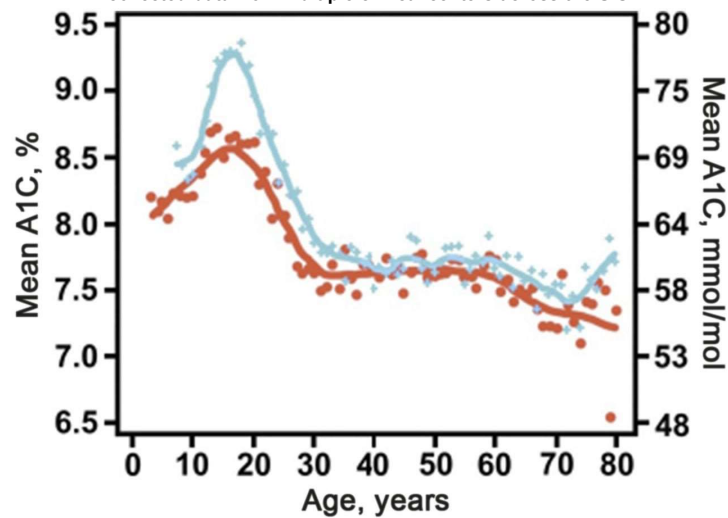
Redondo, M., et. al. (2021). The Evolution of Hemoglobin A<sub>1c</sub> Targets for Youth With Type 1 Diabetes: Rationale and Supporting Evidence. *Diabetes Care*.

## Effects of Hyperglycemia

- Since its 1993 landmark publication, the DCCT and many other studies have progressively provided overwhelming evidence that near-normal glucose control diminishes the risks of:
  - Retinopathy
  - Nephropathy
  - Neuropathy
  - Macrovascular complications

Redondo, M., et al. (2021). The Evolution of Hemoglobin A<sub>1c</sub> Targets for Youth With Type 1 Diabetes: Rationale and Supporting Evidence. *Diabetes Care*.

Higher A1C in the 2016–2018 period compared with 2010–2012 across all ages, with particular elevation in adolescents and young adults (56) in the T1D Exchange Clinical Registry, which collected data from multiple clinical centers across the U.S.



Maria J. Redondo et al. *Diabetes Care* 2021;44:301-312

## Family Dynamics

- Studies have shown that how a parent models coping with the stress of this diagnosis can often be a large indicator as to how the child handles the diagnosis.
- Depending on the family structure in the home, it can lead to higher rates of DKA, hypoglycemic reactions, and hospitalizations.
- The mother is predominantly placed in the position as the main communicator to the adolescent with type 1 diabetes.
  - Because of that role, she will take on the task of learning about the disease so that she can assist the type 1 adolescent with the self-management.
  - In doing so, it may isolate other members of the family from taking an active role in assisting with the child.

Seiffge-Krenke, I. (2001). Cambridge studies on child and adolescent health. Cambridge University Press.

C. Baechle, A. Stahl-Pehe, K. Castillo, V. Gontscharuk, R.W. Holl, J. Rosenbauer. (2020). Family and household structure are associated with acute type 1 diabetes complications: results of cross-sectional analyses. Diabetes Medicine.

## Parent/Child Relationship

- A lack of involvement between a mother and child coping with diabetes led to, "...greater depressive symptoms and that collaboration is associated with less depressive symptoms and more positive emotion, with support associated with less depressive symptoms for children"
- Helping the caregivers obtain age-appropriate independence while ensuring the child's safety.

Berg, C., Wiebe, D., Beveridge, R., Palmer, D., Korbel, C., Upchurch, R.,...Donaldson, D. L. (2007). Mother-child appraised involvement in coping with diabetes stressors and emotional adjustment. Journal of Pediatric Psychology, 32(8), 995-1005.

C. Baechle, A. Stahl-Pehe, K. Castillo, V. Gontscharuk, R.W. Holl, J. Rosenbauer. (2020). Family and household structure are associated with acute type 1 diabetes complications: results of cross-sectional analyses. Diabetes Medicine.



- Parents are placed into a tricky situation. While the adolescent with diabetes seeks a degree of autonomy in self-management, natural parental fear incites a form of helicopter parenting.
- The child may resent the overbearance, and, according to the research, is being stunted by it.
- At the same time, parents are invaluable resources to the child.
- A high level of nuance is required of parents who hope to strike the perfect balance between being a valued resource and allowing the child to take control of their own disease.
- Parents who collaborate with their adolescent with type 1 diabetes tend to get the best results.
  - This collaboration didn't stunt the child's autonomy but has shown to facilitate more information disclosure to their parents.
  - When a parent was viewed as intrusive and controlling, adolescents had adverse reactions.

## Parent/Child Relationship

Berg, C., Wiebe, D., Beveridge, R., Palmer, D., Korbel, C., Upchurch, R.,...Donaldson, D. L. (2007). Mother-child appraised involvement in coping with diabetes stressors and emotional adjustment. *Journal of Pediatric Psychology*, 32(8), 995-1005.

## Parent/Child Relationship

- This balancing act is made more precarious because it can affect the parent's own mental health.
- Parents giving their type 1 adolescent autonomy may see an increase of stress, research shows, and parents who are especially protective or controlling of their child display less warmth.
- Researchers recommend that medical providers view parents as an extension of the child getting diagnosed. Further, it suggests that parents may need to seek extra medical assistance in the form of therapy.

Wiebe, D., Berg, C., Korbel, C., Palmer, D., Beveridge, R., Upchurch, R., Donaldson, D. (2005). Children's appraisals of maternal involvement in coping with diabetes: Enhancing our understanding of adherence, metabolic control, and quality of life across adolescence. *Journal of Pediatric Psychology*, 30(2), 167-178.

Seiffge-Krenke, I. (2001). *Cambridge studies on child and adolescent health*. Cambridge University Press.

## Co-Occurring Illnesses

- 33-50% of people with diabetes will experience diabetes distress at some point
- Up to 45% of mental health conditions and cases of severe psychological distress go undetected among patients being treated for diabetes.
- Higher risk for other autoimmune conditions.

Fisher, L., Polonsky, W. H., Hessler, D. M., Masharani, U., Blumer, I., Peters, A. L., Bowyer, V. (2015). Understanding the sources of diabetes distress in adults with type 1 diabetes. *Journal of Diabetes and Its Complications*, 29(4), 572-577.  
 Li, C., Ford, E. S., Zhao, G., Balluz, L. S., Berry, J. T., & Mokdad, A. H. (2010). Undertreatment of mental health problems in adults with diagnosed diabetes and serious psychological distress: the behavioral risk factor surveillance system, 2007. *Diabetes care*, 33(5), 1061–1064.

## Mental Health

- People living with type 1 or type 2 diabetes are at increased risk for depression, anxiety and eating disorders.
- Rates of depression across the lifespan are 2 times greater for people with diabetes than in the general population.
- People with type 1 diabetes are twice as likely to live with disordered eating.
- In women with type 1 diabetes, bulimia is most common eating disorder while women with type 2 diabetes are more likely to deal with binge eating.
- It is estimated that only around 1/3 of people with diabetes and mental health conditions receive a diagnosis and proper treatment.

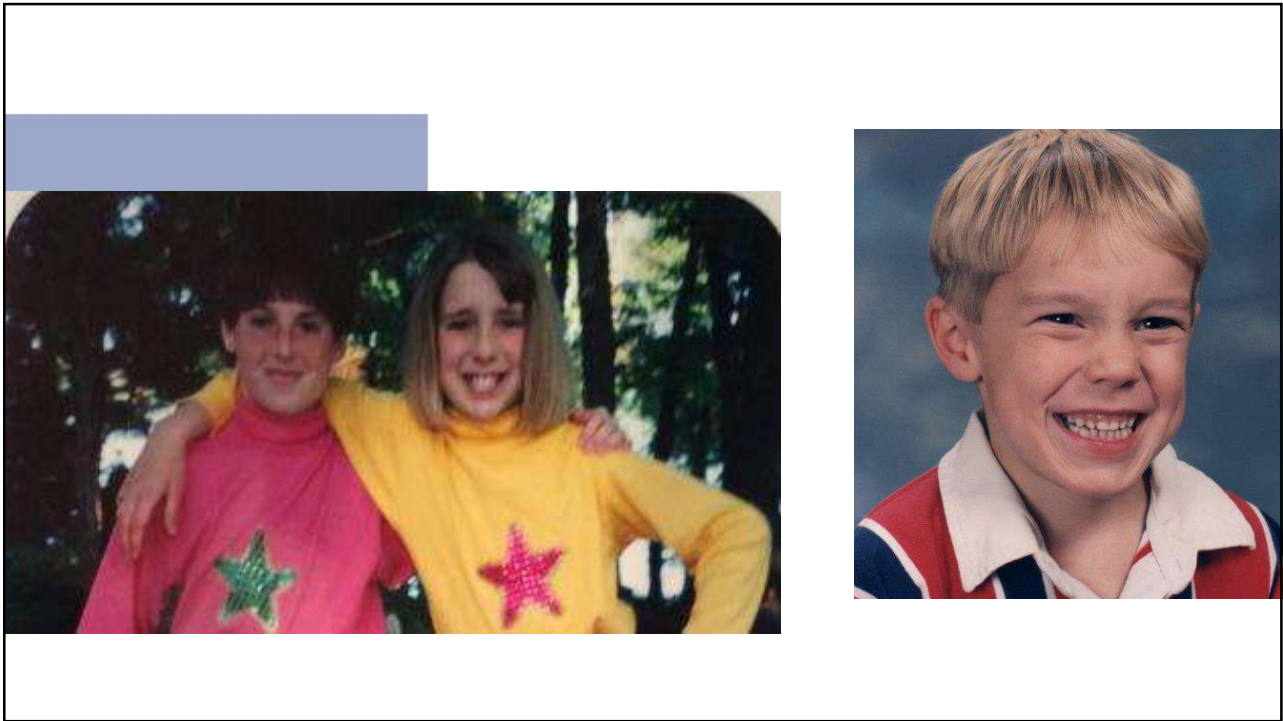
Ducat, L., Philipson, L. H., & Anderson, B. J. (2014). The mental health comorbidities of diabetes. *JAMA*, 312(7), 691–692. 2 Eating Disorders.

## Financial Distress

- Price of insulin has skyrocketed 1200% in the past 20 years
- 40% of American patients with diabetes report financial hardship
  - Including patients with health insurance
- 46% of people with diabetes have reported difficulty in affording food, cost-related medication underuse, housing instability and energy instability, and poor diabetes control.
- 1 in 2 people with diabetes can't afford or get access to insulin worldwide
- 15% of people with type 1 diabetes on CGM in the US. Only 3% of people globally can afford a Continuous Glucose Monitor (CGM)

Patel, M. (2016). Financial stress: a barrier to diabetes care. *Practical Patient Care*. Retrieved from <https://www.practical-patient-care.com/features/featurefinancial-stress-a-barrier-to-diabetes-care-5683743>.  
 Suthar, M. (2020). 40% of American Patients with Diabetes Report Financial Hardship. *Diabetes in Control*. Retrieved from [www.diabetescontrol.com/40-of-American-patients-with-diabetes-report-financial-hardship/](http://www.diabetescontrol.com/40-of-American-patients-with-diabetes-report-financial-hardship/).

## Personal Experiences



“The good news was,  
we knew how to live  
with diabetes. The bad  
news was, we knew  
how to live with  
diabetes.”





## Dani, T1D

- Diagnosed at 13 – 2015
- Older sister is 4 years older
- Parent describes being terrified at dx, “I was paralyzed with fear. Who is going to help me keep her alive?”
- Parent had gestational diabetes, and when she was diagnosed was sobbing. “I couldn’t imagine giving myself a shot or poking my finger. I was fine with practicing on the orange. When I had to start doing it myself, I just sobbed.”
- Financial stress: Do we sell our house? T1D child feels guilty for debt because of them.
- Husband almost lost his sight because of the stress we were under. He gets a \$2,500/month eye injection now. Without T1D, I don’t think he would’ve had that medical issue.
- The more they learned, they got more empowered.
  - But husband couldn’t make all the appts, or even the majority, so the more we learned, the more he felt inadequate in his knowledge. “I can see how the more I learned, the more he stepped back. So, I became more resentful of the position I was being put in.” I was the one with the panic and anxiety. He never experienced that intensity of worry. It took a lot of patience! I had an anxiety attack, between trying to manage two children.
- Other family doesn’t understand. “I post about tough stuff on FB, and then my family points out to when she goes on vacation and seems ‘normal’. It’s life or death for my child. People say she looks great so she must be fine.”

## Dani's Mom

- Ask until you find other families in your area or region that have a T1D loved one, and learn from them, their experience, knowledge and support will be priceless.
- Bring your child's friends and their families along with you as you become educated, share what you are learning with them.
  - This has been shown to be a powerful tool in helping our daughter become more independent through the teen years, both her and us as parents were much more at ease knowing her friends and their families knew and/or felt comfortable asking questions, learning, taking her with on sleepovers, trips, chaperoning events, mission trips etc. I gave Danika so many more people in her web of support than just Mom.
- **“Our daughter's life is more important than politics, greed, indifference. The only way to solve the problem is to keep advocating for accessible and affordable insulin and supplies, politely educating others and striving every day to make a difference. .**

## Susan, T1D Mother

- All 5 children have type 1 diabetes
- They were told (before T1D) that they had “great health insurance”.
- Each T1D child costs roughly \$1,700/year x 5 = \$8,500
- Terrified for when children turn 26 and are forced off parent's insurance
- Filed for bankruptcy
- They were involved in the community, and then one child got involved with drugs and they were ostracized.
  - “We couldn't just send our T1D child out on the streets. People just don't understand.”

## Kara, Sibling of T1D

- Younger brother, Jason was diagnosed with T1D in 1978 when he was four. This was a time without information at our fingertips. "My mom had to become dietician, nurse instantly. This had to be a very lonely time for her as she had four older kids."
- Doctors kept sending him home saying he had flu. When he was finally diagnosed, he was in a coma for two days. "My mom's whole life was devoted to making sure he was ok. Looking back, I can't imagine the stress she was under."
  - It really affected every single family member. "Everyone needs their mom growing up, but everything was focused on Jason. I felt I was ignored and neglected. Timing snacks, signs of low blood sugar....my mom was always busy."
  - "My dad felt (he was gone a lot) he was always in the back, because my mom needed the control to manage the diabetes. My mom never wanted to leave him alone if it was just going to be my dad at home. He never had that closeness with Jason because he was part of the managing of diabetes."
  - Mom wouldn't let him attend Camp Needlepoint b/c of control.
  - "Even after he went off to college, she kept worrying. Her stress has contributed to poor health outcomes. She never had a good night sleep."
- Brother passed away in 2003. Died unexpectedly. Didn't have a pump and was struggling with hypoglycemia unawareness.

## Chris, T1D & T1D Dad

- Diagnosed at age 8, over 50 years ago.
- The standards of care then were totally different.
- Parents had a mainstreaming methodology where I pretty much lived a normal life with the exceptions of diabetes care and issues.
- Son was diagnosed in 2004 and dealing with diabetes from the outside was an eyeopener.
- **"We are extremely fortunate that his T1D was in a situation where he had seen me living with it and he had a very good idea of what someone could do dealing with it. He did not let it have that great of an affect. He is far more open than I ever was about his condition. It is an interesting dynamic and relationship."**



## Raya, T1D

- Diagnosed at 10. Is an identical twin. Younger brother Emmett was 6 months old.
- Mother had a newborn, two twins, and a new job.
  - Extremely expensive first year.
  - Is a nurse but didn't have a lot of knowledge about T1D. Husband Eric was very involved in the care.
  - Was there an affect on the other twin? "We had to put so much attention on Raya, so it really became we had to keep her safe and healthy. For sports, what are we going to do to keep her safe in sports? So much attention on her. We had all these medical bills for her."
  - "Lyn really felt unseen, unnoticed, unheard. She felt she was in the backseat. I don't know if there is anything else we could've done. Lyn has always struggled with anxiety, and after R's dx, it really ramped up. The thought of is this going to happen to me as a twin? Her mental health took a hit. We sought counseling for her."

## Lyn, T1D

- Diagnosed with T1D three years after identical twin sister at age 13. Diagnosis sort of eased that anxiety, b/c she was in a constant state of waiting. They're genetically identical. It wasn't a sure thing though that she would get T1D.
- Dexcom has made life a bit easier. "I don't have to wake up to test blood sugars, but just last night I stayed on the couch with one daughter b/c she kept going low."
- Emmett asks all the time when does he get to test his BG, when is he going to get diabetes, and when is he going to get a phone. There is a certain bond that two siblings have with T1d.
- Burnout: that's very real and both twins go through it. **"I try to combat it, if they ever ask me to take the wheel, I will. If that's decision making, if that's me putting in the bolus or I'll do every sight change they ask. I'll never let them know how tired I am. This has been helpful so that they don't hit the teenage burnout as quickly. It's a partnership between us."**

Our philosophy is “kid first, diabetic second.”

## Personal Experiences

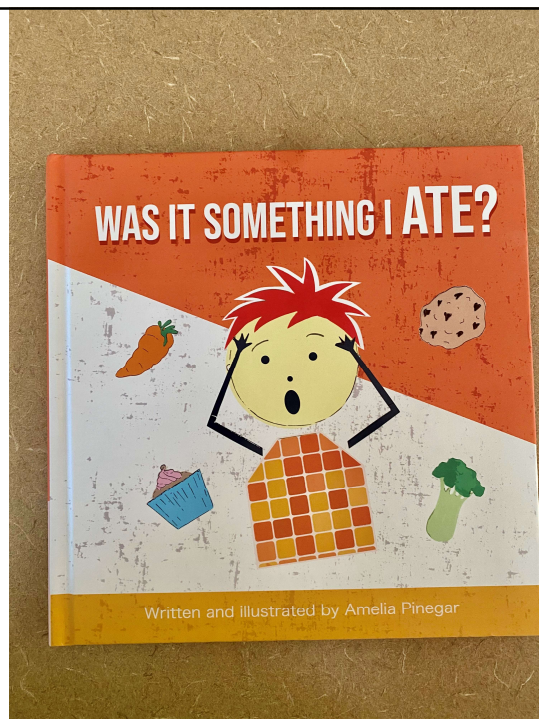
- Rosie: My husband and I are both T1 and my stepdaughter is T1. We notice that at our house with both of us having T1 that things are controlled better with her than at times with her mom. I know with both of us we help each other be held accountable.
- Hillary: One thing that's very hard for my other kids is that my T1 gets “more attention” in their eyes, doesn't matter that it's needed as he was two when diagnosed and has celiac. Sometimes they sing in chorus together and other times it's like a Picasso painting. Abstract, nonsensical, consuming/confusing.
- Deidre: I was diagnosed very late in life . No one in family cares or gets it
- Tina: My father has passed away now, but his T1 had significant impact on the time we ate meals. We had to have breakfast at 7am SHARP and dinner at 5pm SHARP or he could have an insulin reaction.
- Cara: My parents used to get up multiples times a night to check my blood glucose while I slept to keep me safe. Definitely had an impact on my relationship with my parents, especially in my teen years when I didn't want to take care of it. I used to get frustrated with them for trying to help me, and they were as tired as I was.

- Justine: My hubby has had T1D since 18 months old. Totally has affected our relationship and family dynamics, especially for our kids when he had some health issues. I hardly slept for years before he was able to get a CGM, which affected my health for some time. I used to play, "Let's touch the husband's skin multiple times in the middle of the night to judge if he's off." In perhaps a positive way it's forced us to plan better for future things that we may not have planned so well for if we weren't in the same situation.
- Abigail: I am the only person in the history of my family to have diabetes and it was a huge learning curve for my parents and myself growing up. Being that I've had diabetes my whole life it has impacted every milestone and relationship I've had or currently have. I'm one of the lucky ones who has a husband who gets it, but it has impacted my kids and husband some days just as much as it has impacted me. There is a level of trauma that family members go through right along with you.
- John: Spent every afternoon from Kindergarten through 12th grade racing home to make sure my mother wasn't in a diabetic shock or coma because she wouldn't take her insulin. Called 911 enough to know the names of all the cops and medics in town by the age of 6. Moved back to Minnesota during college (which I could never return to) to help my father take care of my mom and help manage her diabetes. I knew how to make sugar-loaded OJ and open my mother's clenched jaw while she was violently shaking with one hand and pour in the OJ by 1st grade. I could work a glucometer to measure her blood sugar in kindergarten. I recorded her numbers in her tracking book too. Not the funnest childhood, but I learned an awful lot about responsibility from an early age.
- Jeff: My mother paid more attention to me over my brother. My mom only did it because diabetes was tough on all of us. My brother at 38 years old is finally getting over it.
- Pam: We've had to cancel plans when sugars run high and headaches ensue. We are reluctant to make plans with others because of the unpredictability of the disease. For instance, a few days ago his newest pump injection site evidently had too much scar tissue because he wasn't responding to repeated bolus pushes. Hours later he was back on track after changing the site but it affected him for hours. We put off our lunch date, his team at work let him take a few hours to nurse the headache (he works from home for NASA), and our dinner plans were turned into a much later, smaller meal.

## Top 10 Tips - ADCES

1. Neither you nor your child did anything wrong.
2. You will adjust to your new normal.
3. Diabetes impacts the whole family.
4. Focus on the now.
5. Diabetes is unpredictable.
6. You are not alone.
7. You and your child will become diabetes experts.
8. Take care your mental health and your child's.
9. Support your child.
10. Empower your child.

Association of Diabetes Care & Education Specialists. (2021). Top 10 Tips for Parents of Newly Diagnosed with Type 1 Diabetes (T1D).



[www.QuinnNystrom.com](http://www.QuinnNystrom.com)

