

The Emotional Burden of Diabetes

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Disclosures to Participants

Notice of Requirements for Successful Completion:

Learners must participate in the full activity and complete the evaluation in order to claim continuing education credit/hours.

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Anna Sabino, MSW, CDCES-none

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Learning Objectives/Program Overview

- increase understanding of the psychosocial impact of diabetes.
- increase understanding of roles and boundaries in clinical care
- discuss tools and strategies for support and importance of referrals

- *my goal is for your goal to feel like you can become the best "non-therapist" therapist for your patients!*

A bit about Anna

- T1D of 35 years
- Boston-based, mom, wife, rescue dog lover
- Social worker and diabetes educator
- Private practice for T1D families- virtually
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What we know:

- A diabetes diagnosis is a *life-changing* event.
- It is a TRAUMATIC event. It can be triggering.
- It doesn't just alter one aspect of life; it changes the **whole thing**.
- It takes at least a year (or more) to fully adjust to those changes.
- There are significant emotional components to a diagnosis.

"I wish we had more Real life education. They make it sound like you count carbs and dose. It's nothing like that! Variables are presented like no biggies and that's just not practical."

Parent of a child with T1D.

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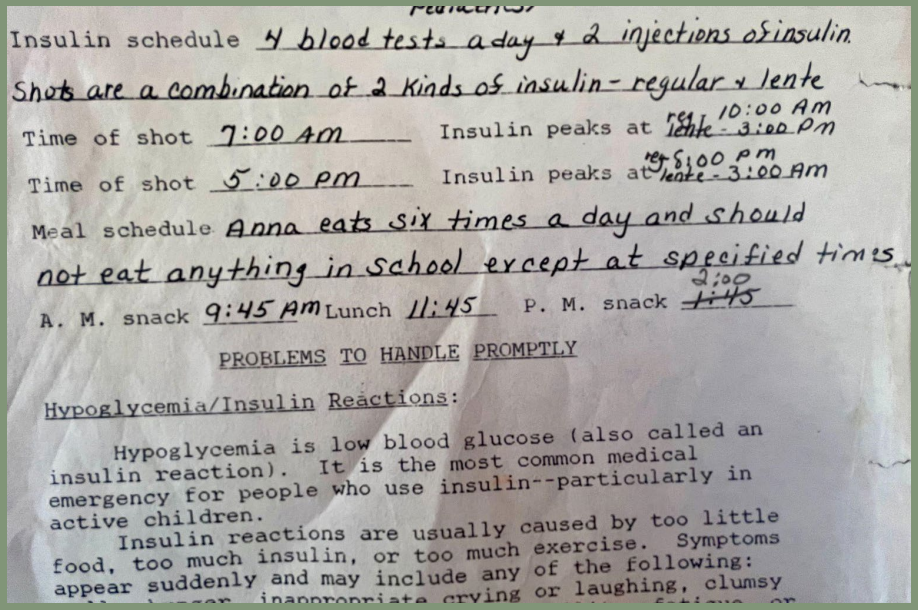
The first year...

- sanity
- safety
- survival



Insulin schedule 4 blood tests a day & 2 injections of insulin

Shots are a combination of 2 kinds of insulin - regular & lente

Time of shot 7:00 AM Insulin peaks at reg 10:00 AM lente - 3:00 PM

Time of shot 5:00 PM Insulin peaks at reg 5:00 PM lente - 3:00 AM

Meal schedule Anna eats six times a day and should not eat anything in school except at specified times.

A. M. snack 9:45 AM Lunch 11:45 P. M. snack ~~11:45~~ 2:00

PROBLEMS TO HANDLE PROMPTLY

Hypoglycemia/Insulin Reactions:

Hypoglycemia is low blood glucose (also called an insulin reaction). It is the most common medical emergency for people who use insulin--particularly in active children.

Insulin reactions are usually caused by too little food, too much insulin, or too much exercise. Symptoms appear suddenly and may include any of the following:

"We attended a couple programs at Joslin, and I had a friend who's daughter was diagnosed but it was just about trial and error, I was a wreck that first year."

Regardless of age or diabetes type…

A diagnosis will impact:

- Your body
- Your emotions
- Your relationships and social circle
- Your daily activities and schedule
- Your thinking about food and/or exercise
- Your view of yourself
- Your view of the future



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Common Emotions After Diagnosis

Denial: “this isn’t happening,” not believing its serious, not doing required self-care

Anger: “this isn’t fair,” resentment of body “failing”

Sorrow: hopelessness, sadness

Guilt: “why me/them?” “could I have done something?”

Fear: needles/injections, insulin initiation, hypoglycemia late complications, and obsessive behavior or overdosing

Jena, B. N., Kalra, S., & Yeravdekar, R. (2018). Emotional and psychological needs of people with diabetes. *Indian Journal of Endocrinology and Metabolism*, *22*(5), 696. https://doi.org/10.4103/ijem.ijem_579_17

Impact of Diagnosis on Parental Mental Health

The diagnosis of a child with chronic illness, such as type 1 diabetes, leads to family disturbance and stress. If parents cannot effectively cope with their stress, they often have difficulty managing their child's illness, leading to poorer outcomes for the child.

The Scientific Journal of Al-Azhar Medical Faculty, Girls 4(1):p 66-70, Jan–Mar 2020. | *DOI:* 10.4103/sjamf.sjamf_4_Arafa, Shaimaa M; Alwakeel, Mervat

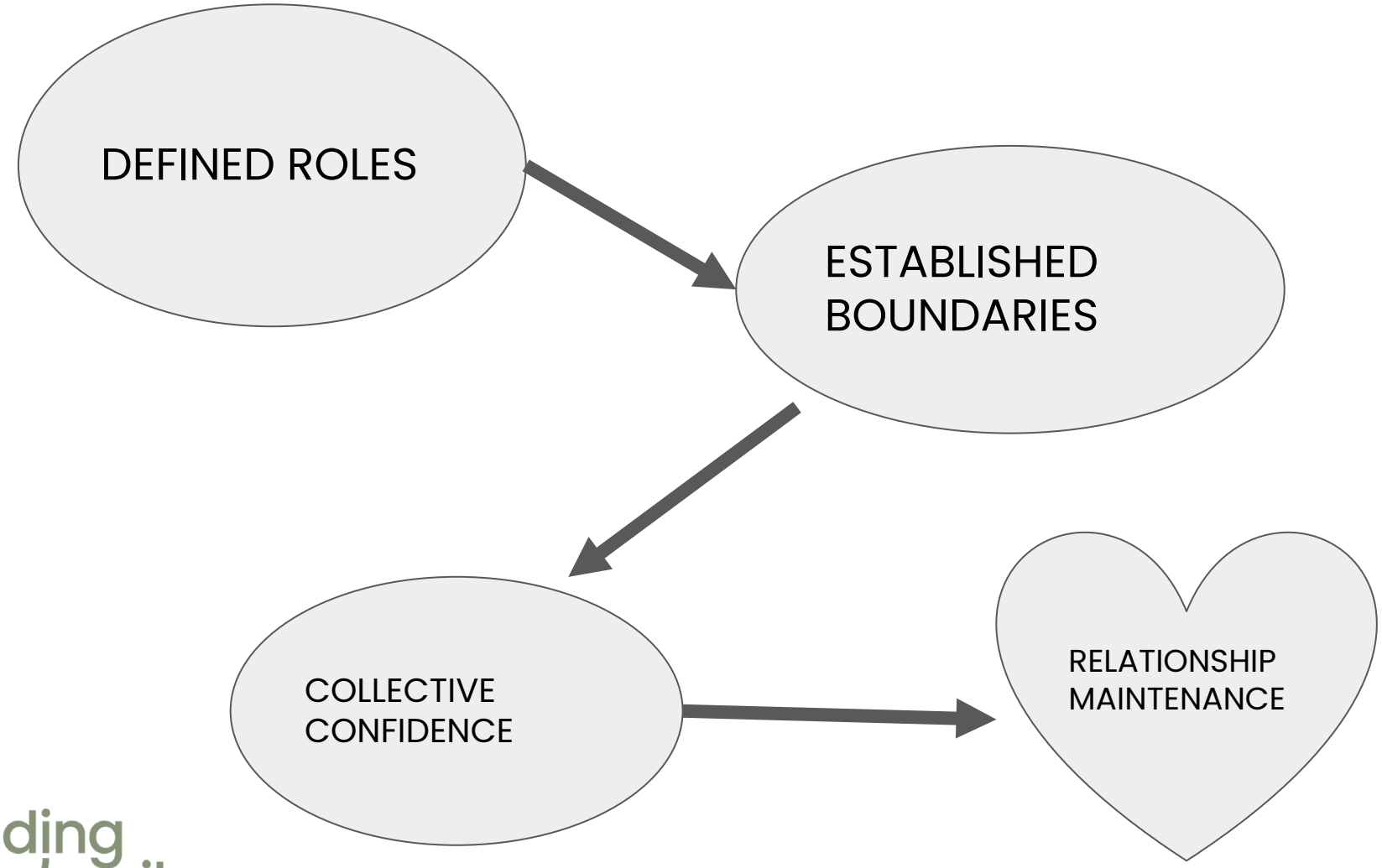
Impact on Work and Relationships

For parents of CWDs, research suggestions four main areas of impact:

1. cessation/reduction, employment flexibility, significant career impact, financial pressure
2. School/daycare competency and support around diabetes are a factor
3. For adults with diabetes, research indicates issues affecting work performance include hypoglycemia, social stigma, and discrimination
   Dawn2 study: 1/3 of PWD reported that diabetes had a negative impact on their work or studies, and less than a third reported that they experienced people at work or school as supportive.
1. In relationships, coping can involve distancing or withdrawing, fear of acceptance, isolation.

76, https://link.springer.com/article/10.1007/s11892-019-1234-2,
https://www.sciencedirect.com/science/article/abs/pii/S0168822718315961

Managing Diabetes Across the childhood experience



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Tween and teen

“Your a1c was over 11 at one point, you avoided pricking your finger, and I think we both know that sending you to camp that year was the best thing we could do for you, and us. We also did the walk each year, but really, it was camp.”





T1D in Adolescents and Young Adults

- brain still not all there
- safety vs preference is important!
- shared decision making and goal setting. Involve but don't dictate boundaries.
- digging up trust is key….
  - -sometimes this means letting go of a high blood sugar
- what's a priority vs "what can wait"
- repairing is key to relationship maintenance.

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Challenges of Diabetes in Adolescents and YA

- Adolescence and young adulthood are already known for their **multiple, frequent changes and transitions**.
- The burden of managing diabetes can conflict with the typical path of development:
  - Competing priorities
  - Fitting in with peers
  - Establishing independence
  - Identity exploration
- **Competing demands** often affect young people's ability and motivation to engage in diabetes care.

(Chase 2006; Commissariat, Wentzell, & Tanenbaum, 2022)

Diabetes Related Stress/Triggers:

For Kids/Teens	For Parents/Caregivers
● Will I go low during an exam and have to retake it. ● leave class early/miss school/work. ● How and where do I put my device during my game/show? ● My parents will yell at me if they knew I ate a bagel AND I don't want the beeping to disrupt. *"I don't want to be the reason this gets interrupted"*	● Did she take the lantus at the sleepover? ● Will the school nurse look at G6? ● Maybe I should text the roommate? ● Access to non-stop data. ● Alerts and alarms ● Insurance and prescription management. "I *wish he would tell more people about his diabetes, and talk about it."*

College Life and then some

- alcohol
- no schedule
- the pump

“We watched you have fun, and you still had your camp friends. I had to just trust that you knew what you were doing. And that was really it. I had a mental breakdown the weekend you left for college, but you did great.”





Who are you before diagnosis? Vs. who are you now?

Your Schedule of Acceptance



Others Schedule of Acceptance.

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Expectations for Diabetes Communication

- it comes with a cost to teens and YA
- it’s already a burden and a disruption and isn’t their priority.
- agendaless presence
- the growth mindset matters
- life goals matter more
- they are the team captain “how can I help?”
- power of the word “lets”

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For the first time in forever...

- I cared about my future with diabetes
- had a schedule
- set diabetes related goals
- gave back to research
- felt more connected and committed than ever.















Incorporation and Adaptation

- Incorporation does NOT mean loving diabetes!
- Incorporation means accepting, adapting, and fitting diabetes into your life (instead of the other way around).
- Everyone's experience with diabetes is unique, and the challenges are different for everyone.

Think about…

- What makes it hard to feel like diabetes is a natural, neutral part of your life?
- What would have to change to help you feel more accepting of diabetes as part of your life?

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Tools for your clinical mental toolbox.

Hint: the goal is for you to maintain your own role, and perfect your confidence in becoming a “non-therapist therapist”

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2 Important questions!

“How many people do you know that are also living with diabetes?”

“When was the last time you spoke with someone who also lives with diabetes?”

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Recognize your own role and THEIR strengths

- we can’t do it all-referring is ok!
- motivational conversations are key!
- Knowing your role and maintaining OUR boundaries!

What’s Going well? AND

What do you need help with? (hint-we should be asking parents this ? also)!

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HOW we refer matters…

- would you be open to doing xxxx…..
- It sounds like you could really benefit from….
- I am recommending this because….
- how would you feel about seeing someone to talk about processing all of your feelings around diabetes?
- Several of my patients speak very highly of xxxx and have found it helpful…

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Reframe reframe reframe!

“This patient would never see a social worker; he barely comes to my appointments even. “

REFRAME: Yes, he has a history of no shows, and seems very resistant, AND I know he could really use someone to talk to, AND even though I’m not hopeful he would actually call her, I have to trust that my role is to support him and this is what is best for him at this time. I know she is a well respected and liked social worker.

Approaches and Considerations to Communication

- I statements
- Ask
- Acknowledge
- Active Listening
- Teach-back method
- What's your goal?
- Books and crafts
- Am I being age appropriate?

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Acknowledge:

1. Thank you for telling me.
2. That is SO important.
3. I believe you.
4. Interesting, tell me more about that.
5. Help me understand….



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SUPPORT IS OUT THERE!

- Mental health directory ADA
- JDRF-Bag of Hope, walks, tours, rides
- TCOYD
- Friends for Life, Connected in Motion, Riding on Insulin, The Diabetes Link, TypeOne Together
- Podcasts-Diabetes Connections, JuiceBox, 108, Sugarmammas
- Social media with CAUTION!
- Finding Smiles Coaching- 1:1, groups, blogs
- Camp SureFire, Camp Jack, Barton Center



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Thank you and questions?

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