

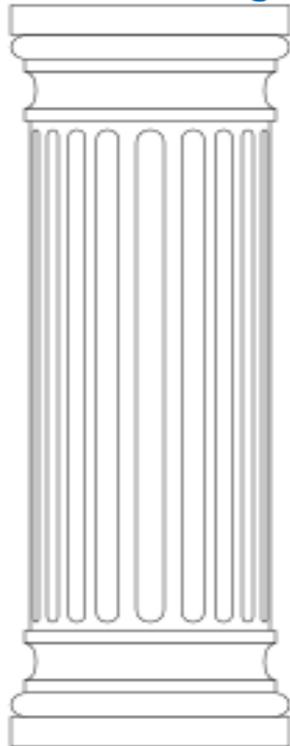
JDRF
typeone
nationsummit
IMPROVING LIVES. CURING TYPE 1 DIABETES. **T1D**



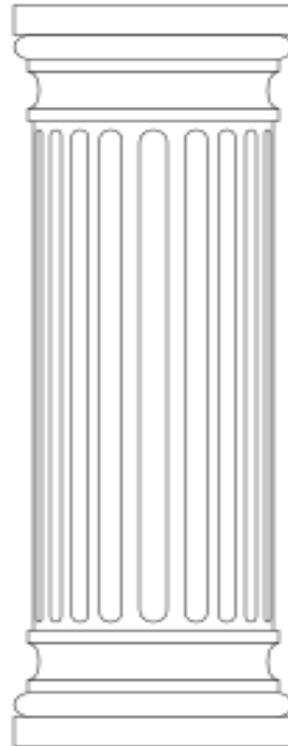
Parents: Tweens, Teens, and Everything in Between: Bridging the Gap Between Your T1D & You

3 Pillars to Diabetes Care

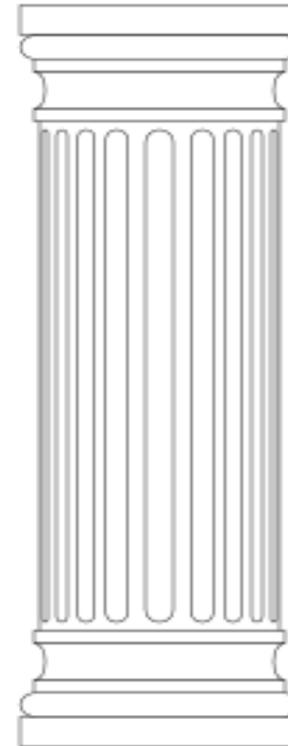
Test Blood Sugar



Count Carbs



Give Insulin



First things you learn after diagnosis

Everybody is Different

- Age of Diagnosis
 - 14 year old boy diagnosed at age 5 (never received formal education) **is different** than a 14 year old boy diagnosed 1 year ago (involved with education)
- Gender
 - Boys don't have periods!
- Pubertal Status
 - 12 year old girl who has regular periods **is different** than a 12 year girl with no periods
- Honeymoon

Everybody is Different

- Activities
 - Track, softball, soccer, reading, drawing, riding a bike, video games etc.
- Food Preference
 - Prepackaged foods vs. homemade foods
 - Dietary restrictions
- Family members with T1D
 - Easy to lump together
- Schedule
- Family Dynamics

Personalities

Open

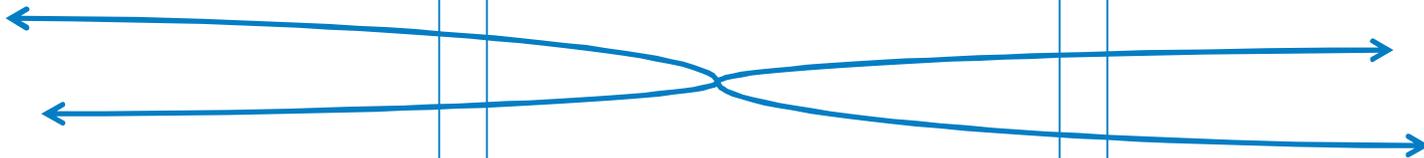
- Tests openly
- Does not mind technology
 - Pumps, CGM
- Alarms for lows

Indifferent

- More discrete with testing
- Ok with technology but doesn't want to stand out
- Silences alarms

Secretive

- May test but hides refuses to do in front of people
- May refuse technology because perceived as "different"
- Will not allow alarms



Different Views

Patient's Thoughts

- Diabetes can be frustrating
- Having diabetes can seem unfair
- "Wish I didn't have diabetes"
- "I'm starving"
- People think I can't eat carbs because they think I have T2D
- I don't want to stop to check blood sugar
- Annoyed by parents
- Happy I have not been hospitalized
- Proud of my accomplishments

Parent's Thoughts

- Scared of lows
- Afraid to let go
- Can't sleep because worried
- Exhausted
- Frustrated
- Supportive
- Proud



T1D effects the whole family

What Does this Mean?

- Multiple studies have shown positive family interactions (warmth/ parents sharing in tasks) associated with optimal T1D management
 - Prevent deteriorating adherence
- Families' with diabetes-related conflict
 - Tend to have poor adherence and worse health outcome
- Higher rate of depression among T1D youth
 - Linked to worse outcomes
 - Psychology is an important aspect in some individuals care

Williams, L. B., Laffel, L. M. B. and Hood, K. K. (2009), Diabetes-specific family conflict and psychological distress in paediatric Type 1 diabetes. *Diabetic Medicine*, 26: 908–914. doi:10.1111/j.1464-5491.2009.02794.x

We All Go Through Puberty

- Teenage years can be difficult without diabetes
 - Diabetes adds extra stress at times
- Numbers fluctuate even if doing everything perfectly
- Goal total independence prior to graduating high school
 - Use the support structure from home as you gain independence
- Shift of responsibility
 - Gradual transition of responsibilities to teen
 - Med refills
 - Setting alarms to remind to test
 - Dose adjustment suggestions?

Judgement Free

- Facilitate open discussion about blood sugar numbers
 - If son/daughter gets scolded with high numbers then they will just lie
 - Instead discuss why numbers may be higher and suggest things to work on
 - “Missed dose”
 - “Snack”
 - “Poor carb counting”
 - Set up reward system for compliance rather than punishment for “bad” numbers
- Clinic visits
 - Often feel “judged”

Trust

- This has to be earned
 - It can also be lost
- Parents have best interest at heart
- Weekly review of numbers
 - Discuss numbers and suggest changes
- Ultimate goal
 - Total independence



Training wheels aren't always touching the ground but are there just in case. Same goes with parents of T1D

My Perspective on Diabetes

TEEN

- **Annoyed** when asked if I tested
- **Upset** I had to go to the office at lunch and run late
- **Angry** I had to bring supplies and carry supplies everywhere
- **Frustrated** when I had to stop activities to test/treat low
- **Confused** why I had such different numbers without changing anything?
- **Accepting**
- **Supported** by family and medical team

ADULT

- Same feelings as a teen at times
- **Proud**

PROVIDER

- **Impressed**
- **Frustrated**
- **Proud**
- **Excited**
- **Honored**

Questions and Discussion

