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**Diabetes Distress and Burnout: Helping Youth and Families Live Well with Diabetes**

- Assessing Diabetes Burnout
- Factors Contributing to Burnout
- Fostering Positive Change
- Setting Realistic Goals
- Resources for Support

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### Diabetes is Hard

There's a lot we ask of kids with diabetes (and caregivers)

- Besides the multiple daily injections and finger sticks, there's...
  - Many daily decisions
  - Impulse control
  - Initiating tasks (that aren't much fun and they may not want to do!)
  - Doing things differently than friends
  - Speaking up for yourself
  - Tolerating pain
  - Multitasking
  - Emotion awareness and regulation
  - And more!



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### Diabetes is Hard

- Behavior is the foundation of diabetes management, AND
- Diabetes is impacted by many factors besides behavior
- Many adjustments
  - "Year of firsts"
  - Development/transitions
  - The "daily grind"



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### Burnout is Real

- Recipe for burnout
1. Ask people to work really hard
  2. Don't notice their efforts
  3. Efforts don't always affect the outcome

- Signs of burnout
- Mood changes; task avoidance; strong emotional response to BG's; "tired of it"

- It's real for parents and providers too
- Worry, helplessness when patients are struggling - cycle of misdirected helping
  - Even when you are doing your best, people might still struggle

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Social Factors Contributing to Burnout

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**Social Factors**

- Diabetes care affordability
- Two parent households
- Multiple caregivers or few caregivers
- Diabetes technology not available to all
- School nurse availability
- School embarrassment/bullying
- Neglect

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**Questions You Can Ask to Assess Burnout**

- "There's a lot you have to do to take care of diabetes. What parts are hardest for you?"
- "Diabetes is hard, and sometimes people start to feel overwhelmed or burned out. When have you felt that way?"
- "Do you feel upset or like you're in trouble when your numbers are high?"
  - (often a precursor to burnout)

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## Fostering Positive Change

- Every patient/family is doing something to manage diabetes
  - (Almost) no one is "non-compliant"
  - Also be aware of terms like "non-adherent" and "poorly controlled"
  - Behavior intervention rules:
    - Provide three behavior praises for every one correction
    - Best way to increase a behavior is to pay attention to it
- Kids get lots of attention for the things they forget - let's help providers and parents also notice what kids did well

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### Blood Glucoses (and Hgb A1c) are Data to Help Us Make Decisions – They are NOT a Grade

- Dr. Barbara Anderson: "The only bad blood sugar is the one you don't know"
- Instead of BG testing → BG checking or monitoring
- Instead of "good" and "bad" numbers → high/low, in target range
- When numbers change, talk about behavior
  - If A1c goes down, avoid praising the number → instead, ask "what do you think you're doing that's helping it stay in range?"
  - Save "good job!" for the actions they are taking
  - If A1c goes up, find out if anything has changed, what part of their daily routine is hardest, and what the team can do to help
    - "You're not in trouble! Let's just make a plan together"

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### Diabetes Management is Behaviorally Based, But Many Factors Outside the Youth's/Family's Control Can Impact Blood Glucose

- Diabetes control → emphasis on biology
- Diabetes management → emphasis on behavior
- Be careful about only saying "control"
  - Implies diabetes is fully within someone's control
  - By extension, if BG is out of range, then it's someone's fault
- Focus on management - families have more control over behaviors
- Help families remember that a high number doesn't always mean the child ate/missed something



What affects my blood sugar?

EVERYTHING

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### Avoiding Diabetes as a Source of Conflict

- Validate both the patient and the caregiver(s) in their frustration
- Identify that diabetes has become a source of conflict and that it shouldn't be - we're all on the same team!
- Provide strategies to help prevent future conflicts



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### Assist in Setting Realistic Goals

- Focus on 1-2 behavior changes
- May not be ideal management, which can be difficult to recommend as a provider
- Allow the patient to choose
  - Something does not feel overwhelming
  - Something that will set him/her up to succeed
- Improvement and honesty leads to building confidence and success



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### The Importance of Being United

- Patients need to see consistency with the type of support they're receiving from providers
  - Maintenance of rapport is essential
  - Ensure ALL of care team are in agreement with the care plan
  - When following up with a patient – review the whole story to ensure forward progress

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**Resources For Support**

- Involve a social worker and psychologist as part of the care team
- If unavailable, you can consult your insurance provider or primary care physician for a counseling referral.

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