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Guidance for Parents

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Outline

Psychosocial Barriers

- Diabetes and the Family
- Common challenges in diabetes
- Barriers to management in children
- Encouraging change without adding burden



Diabetes Can Be Tough!

Psychosocial Barriers

- Treatment takes both physical and mental energy
- Time-consuming
- Can disrupt daily life and activities
- No breaks
- No end



Diabetes and Family

Psychosocial Barriers

- Diabetes affects the whole family!
- Adjusting to diabetes as part of daily life:
 - Can happen at different rates for different family members
 - May not be stable over time, as life situations change over time



Growing Up With Diabetes

Psychosocial Barriers

- Childhood and adolescence have different challenges for families.
- Parents take primary responsibility when children are young.
- But pre-teens and teens may want more independence.
- More independence does not always translate to more independent self-care behaviors!



Physical Challenges in Childhood

Psychosocial Barriers

- Pain associated with fingersticks or insulin administration
- Growth affecting BGs
- Food choices and adult supervision in new situations
- Carrying supplies for low/high BGs



Social Challenges in Childhood

Psychosocial Barriers

- Pressure on parents to teach other adults about diabetes
- Parents must manage diabetes during new schedules and activities
- Family conflict
 - Parent and child
 - Child and sibling(s)
 - Parent and siblings
 - Parent and spouse/significant other



Childhood Challenges

For those of you with school-aged children, what are the challenges your child faces with diabetes care?

What are the challenges you face?

Preteen's Diabetes Management Checklist

	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
Morning Blood Sugar Check							
Morning Insulin							
Pack Diabetes Bag							
Lunch Check Blood Sugar							
Lunch Insulin							
Exercise							
Dinner Check Blood Sugar							
Dinner Insulin							
Night Snack Check Blood Sugar							
Night Snack Insulin							

Physical Challenges in Adolescence

Psychosocial Barriers

- Changing weight and body shapes
- Puberty
- Clothing style vs insulin regimen/technology
- Food choices and availability of food in new situations
- Carrying supplies for low/high BGs



Social Challenges in Adolescence

Psychosocial Barriers

- Managing transitions: middle school, high school, college
- New friendships
- Fitting in with peers
- Romantic relationships
- Less parent involvement
- Managing new schedules and activities
- Feeling like life is disrupted by diabetes



Adolescence Challenges

For those of you with pre-teens or teens, what are the challenges your teen faces with diabetes care?

What are the challenges you face?

Family Responsibilities

Psychosocial Barriers

- For children, parents take on the majority of responsibility for diabetes care.
- As the child ages, there is a transition to more shared responsibility, and then a transfer of certain diabetes-related responsibilities
- Pre-teens/teens desire more independence
 - Diabetes management, schoolwork, socially, etc.



The Transfer of Responsibility

Psychosocial Barriers

- Some parents may struggle to transfer some responsibilities to their child
- The transition to more independent self-care is a key shift in the parent-child relationship
- Some parents may expect a lot of their child while others may worry that their child will not be able to handle independence



Older Teen's Diabetes Management Checklist

	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
Wake up for Breakfast/BS check/Insulin							
Eat dinner/BS check/Insulin							
Exercise							
Meds							

> 85% completed => Privilege to take driver's license test

Transferring Responsibility

What did you expect to happen once you give your child more responsibility over his/her diabetes?

Did your child behave as you expected?

The Million Dollar Question

What advice did your diabetes care team offer as guidance?

What worked? What didn't work?

Encouraging Behavior Change

Psychosocial Barriers

- Learn how to discuss diabetes within your family
- Share responsibility and value your child's opinion
- Help create habits
- Be flexible with goals
- Offer and utilize support
- Eliminate blame and shame
- Model a positive attitude
- Give credit and validate emotions
- Empowerment



Discussing Diabetes

Psychosocial Barriers

- No one wants to be around the “diabetes police” all the time!
 - Eliminate key phrases (e.g., “Did you check?”) if they bother your child.
 - Find new ways to elicit info (e.g., “Dinner in 5 min, time to check!”)
- Avoid scare tactics
 - Praise good self-care behaviors and offer help on behaviors that need more work.



Share Responsibility

Psychosocial Barriers

- If you just ask, your child may tell you exactly what he/she wants and needs from you!
- Split up diabetes-related tasks to ease the burden on everyone.
 - E.g., At dinnertime: Mom reminds child to check, Dad counts carbs, Child takes bolus/injection
 - Don't be afraid to involve siblings or school nurses



Making Diabetes a Habit

Psychosocial Barriers

- It can be hard to fit tasks that are not routine or enjoyable into your daily life.
 - e.g., checking BGs, taking insulin, counting carbs, exercise, etc.
- Small steps are key!
 - Keep goals small and doable.
- No goal is too small
 - Don't set yourself up for failure (e.g., don't aim for 5 checks/day if they're only doing 1-2).
 - Everything can be “manageable”, but choose a goal that you're CONFIDENT you can accomplish.



Be Flexible

Psychosocial Barriers

- Be open to different treatment options
 - Different pumps, different insulins, CGM, etc.
 - Consider what works best for your child rather than the most advanced or best sounding regimen.
 - Don't be afraid to try new treatments!
- Engage your child's diabetes care team to help find the most effective treatment for your child
 - And remember: mental and emotional health are important and substantial parts of physical health and diabetes care



Offering the Right Support

Psychosocial Barriers

- Everyone needs support
 - Encourage your child to share their diabetes-related struggles, and ask how you can help
 - Coach others in your life on how to best support you
- Diabetes is too big to handle alone! Support is important for EVERYONE in the family.
- Practice diabetes etiquette
 - Avoid anger over high numbers
 - No lectures about complications



Eliminate Blame and Shame

Psychosocial Barriers

- How do you feel when you discover your child has not checked all day, and his/her blood sugar is high?
 - You might feel: angry, upset, sad, overwhelmed, overworked, tired, irritated, etc.
 - All your emotions are valid!
- How do you think your child feels?
 - Probably all that, and more!



Model a Positive Attitude

Psychosocial Barriers

- Your children watch everything you do
 - How you discuss and react to diabetes will affect the way your child discusses and reacts to diabetes
- Try finding benefits and positive aspects of diabetes (e.g., strength, maturity, etc.) to help your child accept diabetes and who he/she is as a person with diabetes.
- Negative attitudes can be hurtful



Go Easy on Your Child and Yourself

Psychosocial Barriers

- Emotions around numbers/tasks can make diabetes feel harder
 - Numbers can feel like grades rather than data points
- There is NO failure in diabetes
 - Nothing is perfect every day
 - Treat each day like a new chance to engage



The Power of Empowerment

Psychosocial Barriers

- Incorporate hope into your view of diabetes
- Give credit where it's due, to yourself and your child
 - Think about everything your family has accomplished while living with diabetes
 - Reframe diabetes as a task, not a barrier
 - You choose your barriers!



Remember...

Psychosocial Barriers

- Small goals build up to long-term habits
- Be flexible and find what works for your family
- Eliminate blame and shame
- Model a positive attitude and reframe diabetes
- Give yourself credit and eliminate blame
- Find the right support for yourself and your child



A Special Note

Psychosocial Barriers

- Parents take on a significant amount of responsibility for diabetes: you are a team member AND a role model for your child.
- Parents also need support in adjusting to the diagnosis and navigating life with diabetes for your family.
- Reach out to your diabetes care team for assistance and guidance to help relieve some burden.



Resources

Resources



JDRF T1D Connections

- Newly diagnosed individuals and families are matched with others who have lived with T1D for years.
- JDRF mentors provide resources, advice and support to help get you through this difficult time.

Get Connected!

JDRF offers a variety of meet up and support groups throughout the New Jersey Metro and Rockland County Chapter. It's a great way to connect with other's living with T1D (for both the parents and the children). Stop by the JDRF table for more information.

Outreach Manger- Shannon Dutton

sdutton@jdrf.org

Outreach Coordinator- Gretchen Van Mater

gvanmater@jdrf.org

The Chronic Illness Management Program

Children's Specialized Hospital
200 Somerset St, New Brunswick, NJ

Setting : 4-week stay at an Inpatient Rehabilitation Hospital

Medical Oversight by Physician and Advanced Practicing Nurse

Illness-specific education (Pharmacist and nursing)

Nutritional counseling (Dietician)

Psychological counseling (Psychologist)

Occupational therapy and Physical therapy

Recreational and Child Life therapy (including aquatherapy, Community Skills Integration)

Nursing (24 hours/day)

Patient care coordination/Social work to coordinate care with outpatient providers



THANK YOU

Questions?

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