

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



CHANGES, CHALLENGES, AND CHEERS

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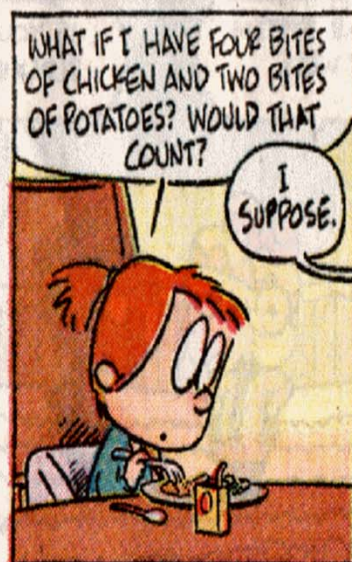
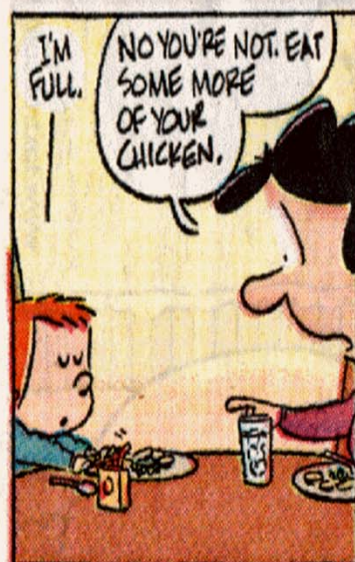
Diabetes is not a “Do It Yourself Disease”

- Need a team
- Need cheerleaders
- Need a helping hand
- Need support from loved ones
- Diabetes is cared for within a family

Developmental Issues for Preschoolers

- Learning and discovering
- Magical thinking and creativity
 - Magical Thinking and Type 1 Diabetes: A child may think their thoughts or actions caused them to get T1D
- Want to have control over their world
 - Difficulty in not having control over diabetes diagnosis and treatment
- “NO’S”
- Picky Eating, Unpredictable Behavior

BABY BLUES



KIRKMAN & SCOTT 200

Emotional Issues That May Arise for Preschoolers

- Emotions are not well-regulated
 - Difficulty distinguishing between out of range blood sugar and typical temper tantrums
- Communication skills are still developing
 - Difficulty communicating worries and fears about their diabetes
- May develop fears around blood sugar checks, insulin injections, and site changes

Parents and Preschoolers

- Offering choices when possible
- Using clear, simple language to talk about type 1 diabetes and tasks
- Use distraction during regimen tasks: bubbles and songs
- Get diabetes tasks done as quickly as possible in order to reduce the time leading up to the injection or finger poke
- Remaining calm: children observe their parents' emotions
- Not allowing diabetes-specific tasks to become the primary source of attention
- Balancing normative experiences and safety
 - Avoiding message that child is fragile or weak in any way

Developmental Issues for School-Age Children

- Time away from parent supervision
- Expanding “known world”
- Learning self-control
- Recognizing differences among peers
- Issues of fairness
 - Type 1 diabetes will feel extremely unfair, and it is!

Baby Blues By Rick Kirkman and Jerry Scott



Emotional Issues for School-Age Children

- Roots of self-esteem begin to grow
- Pitfalls of blame and shame
- Miscarried helping may begin
- Peer teasing may begin

Parents and School-Age Children

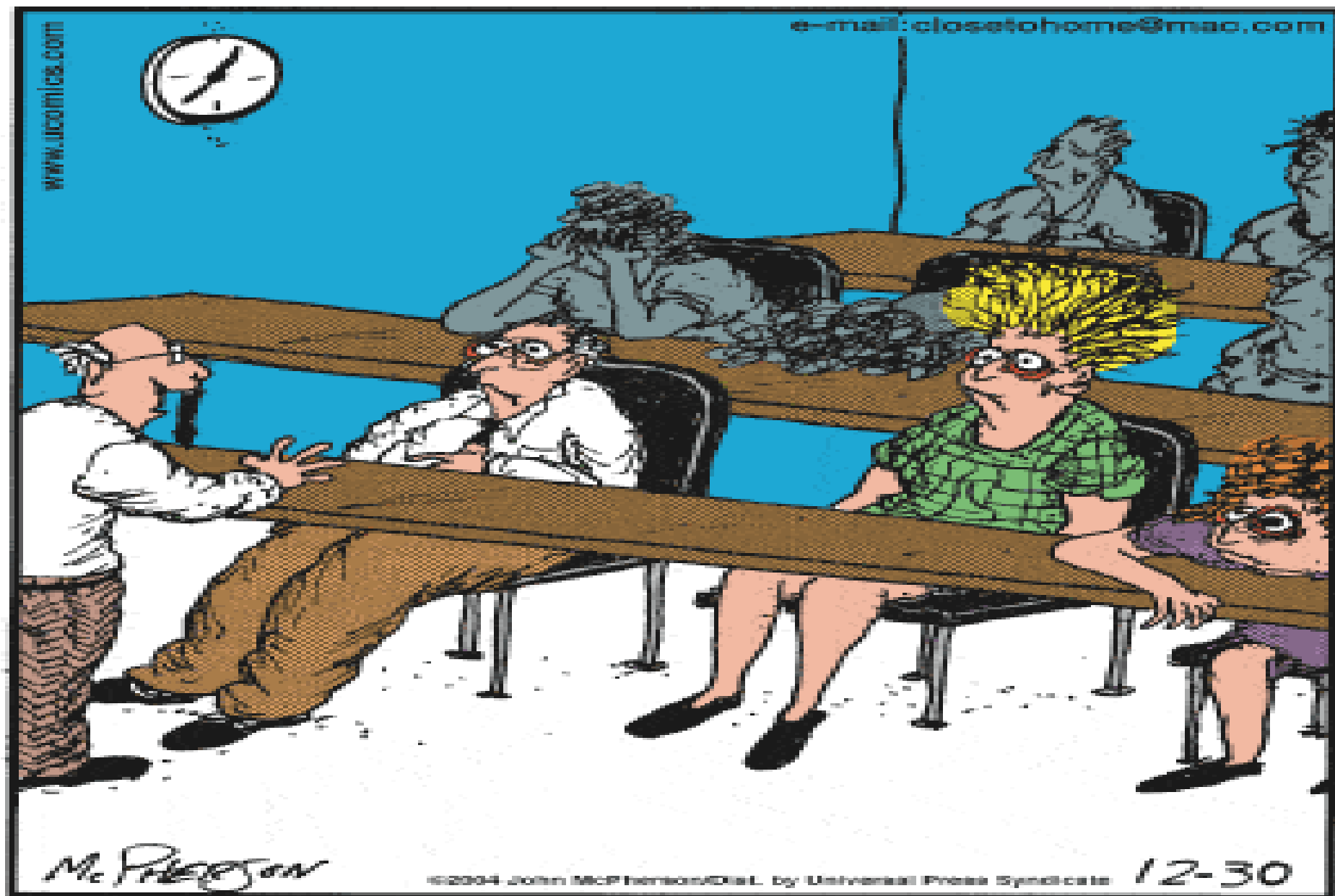
- Separating normative independence goals from the non-normative task of managing diabetes
- Providing routines and consistency is critical
- Important to include child in family discussions and problem solving..
“Think Aloud”

Developmental Issues for Early Adolescence (10-13 years of age)

- **PHYSICAL:** Puberty begins. Rapid growth begins.
- **COGNITIVE:** Tends to still be fairly concrete. Emergence of more sophisticated thinking.
- **EMOTIONAL:** Peer teasing/Bullying. Sense of belonging
- **SOCIAL:** Interested in forming intimate relationships with peers.
- **FAMILY:** Increased need for privacy, push for independence/beginning to detach from parents

Developmental Issues for Middle Adolescence (14-17 years of age)

- **PHYSICAL:** Puberty is ending. Girls are ending their growth spurt. Boys may be just starting.
- **COGNITIVE:** Emergence of more sophisticated thinking.
- **EMOTIONAL:** Identity development. Thinking about leaving home.
- **SOCIAL:** Peers, sexuality, dating.
- **FAMILY:** Interdependence?



"Good evening, and welcome to our seminar,
'Living With Teenagers.'"

Developmental Issues for Adolescents

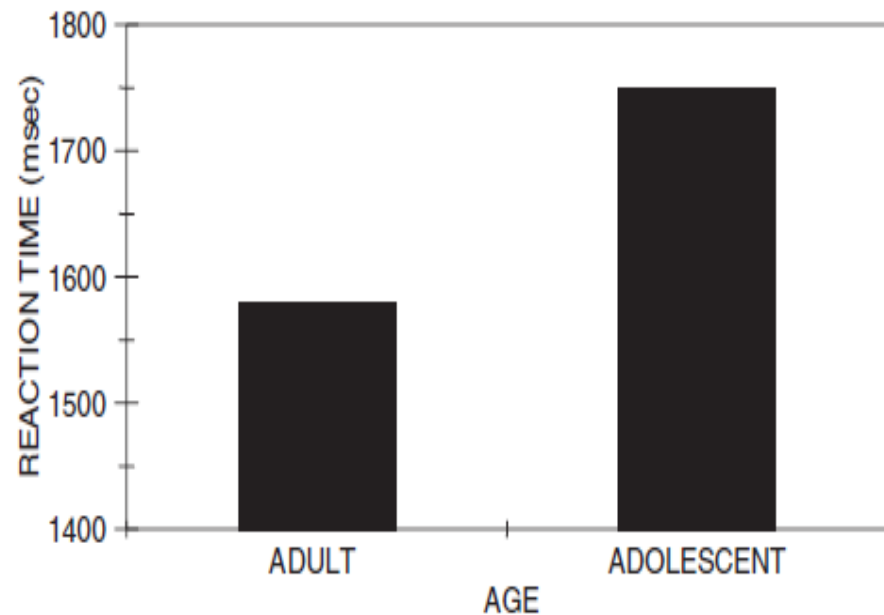
- Wanting to be the same as peers
- Increased problem-solving and abstract thinking skills
- Ability to understand goals of treatment regimen
- Frustration that adherence to diabetes regimen doesn't always lead to improved outcomes, and poor adherence doesn't always lead to worse outcomes.
- Desire for increased independence and responsibility

Developmental Issues for Adolescents

- Increasing independence often results in decreasing supervision
 - Sometimes leading to declines in adherence
- Schedules are more erratic
 - After school activities, sports, and more time with peers away from parents
- Puberty may play a role in diabetes outcomes
- Experimenting in sex, drugs, alcohol
- Sense of invulnerability in this age group
 - Can be difficult for teens to consider long term consequences

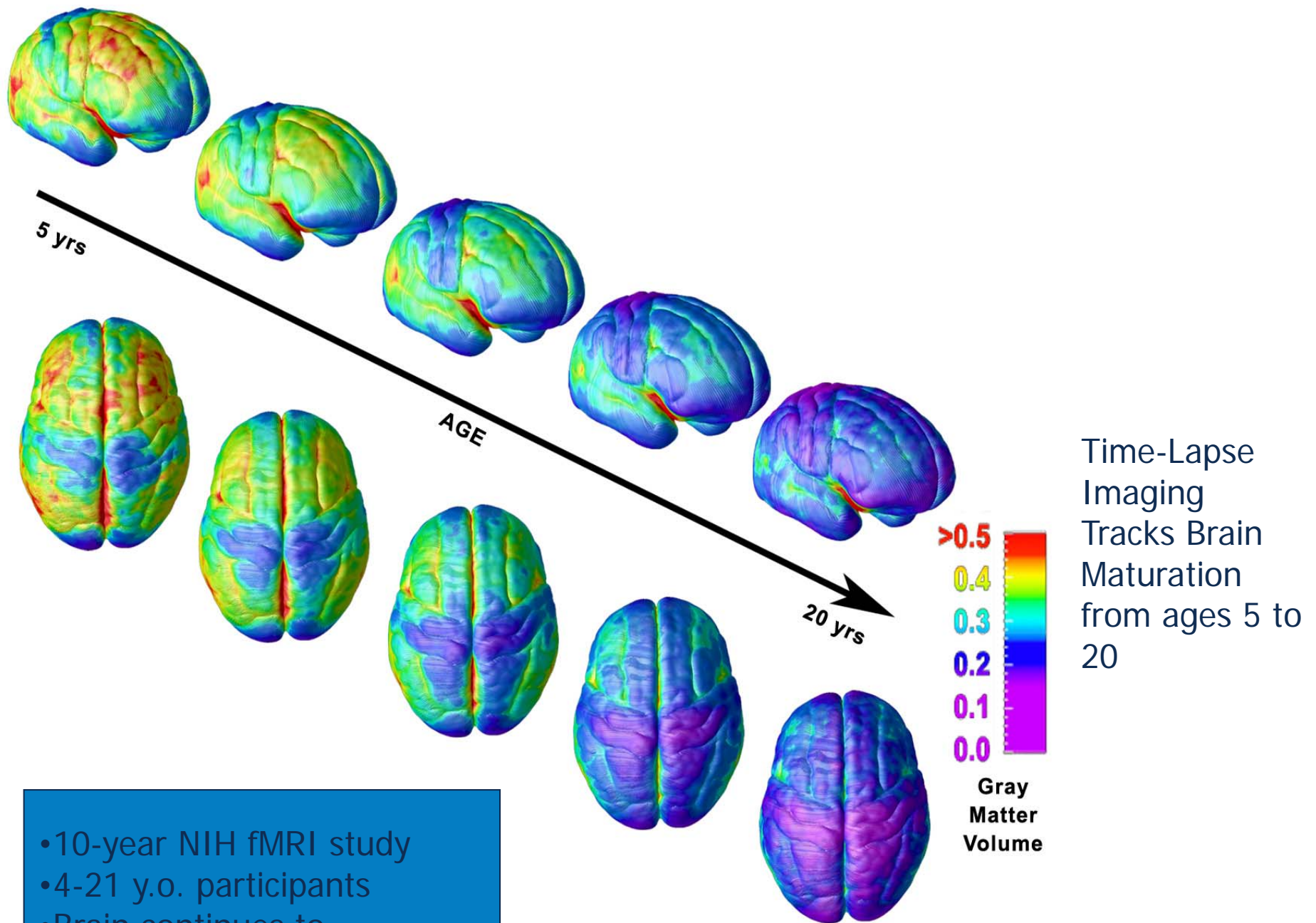
Developmental Issues for Adolescents

- Sense of invulnerability in this age group.
- Sometimes will not pay attention to the risks or consequences of what they do
- Is it wise to...
 - Swim with Sharks?
 - Drink Drano?
 - Set your hair on fire?



The Developing Brain

- fMRI data shows huge changes as individuals move from childhood through adulthood.
- Prefrontal Cortex:
 - Planning ahead
 - Controlling impulses
 - Decision making
 - Goal setting
 - Metacognition/Understanding one's own thought process
 - Emotion regulation
 - Evaluating risks and rewards

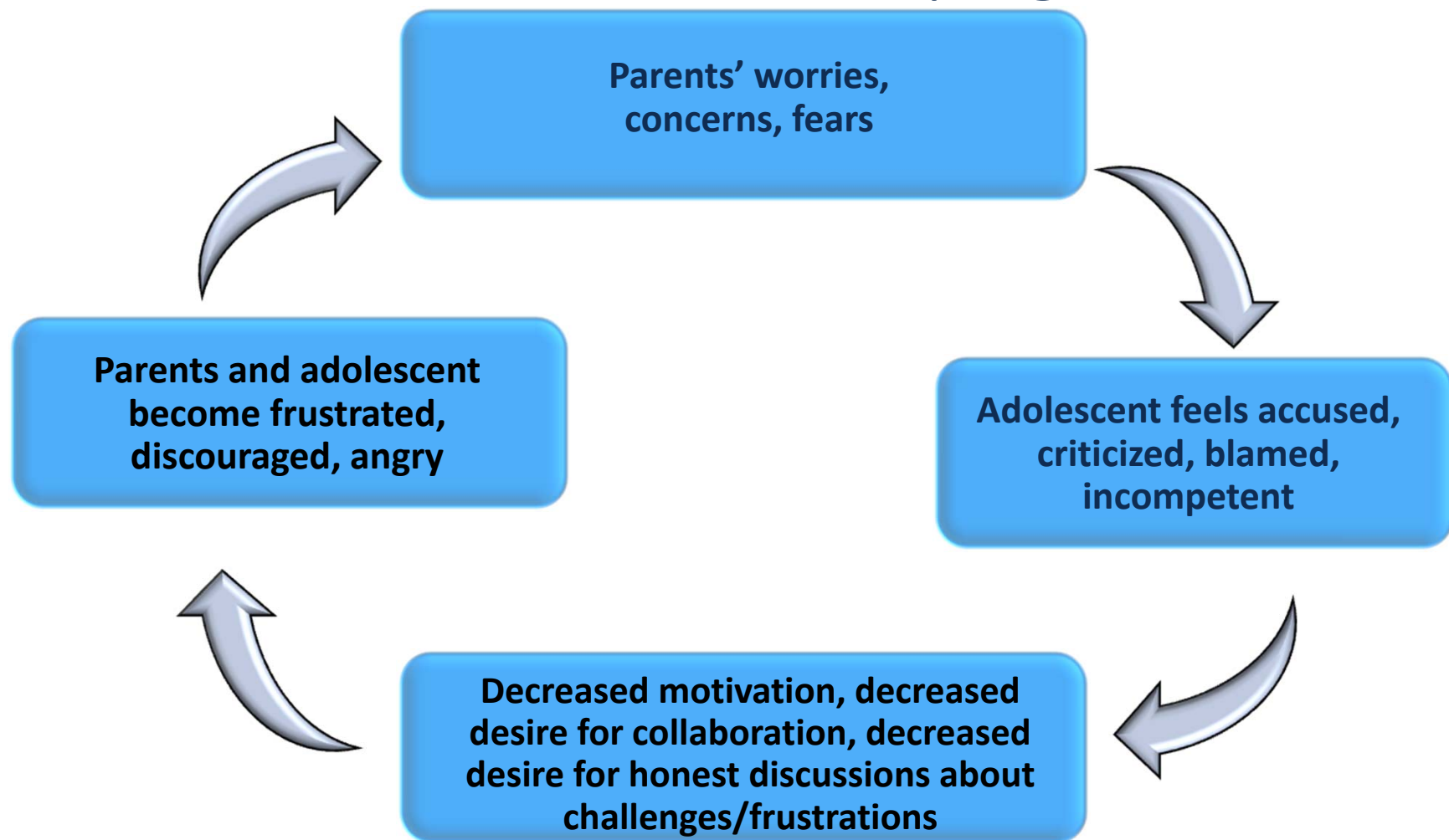


- 10-year NIH fMRI study
- 4-21 y.o. participants
- Brain continues to Change until mid 20s

Emotional Issues for Adolescents

- Pubertal changes
- Managing moods
- Increased risk for emotional distress and/or depression
- Miscarried helping may lead to increased conflict

The Vicious Cycle of Miscarried Helping



Anderson BJ, et al. *Diabetes Care*. 1999;22:713-721.

Parents and Teenagers

- Diabetes is a family disease
- Avoiding a blame/shame cycle
- Balancing nagging with monitoring
- Matching self-care responsibility with level of skill
- Promoting family discussions and family problem-solving
- Does your tone of voice change when talking about diabetes?

Why Nagging Does Not Work



Parents and Adolescents

- Separating normal responsibilities from diabetes-specific responsibilities
- Clarifying who is responsible for:
 - Monitoring supplies
 - Watching the clock
 - Carbohydrate counting
 - Insulin administration
 - Blood sugar checking

Interdependence is Key

- No one is truly independent.
- Isolation leads to poor psychosocial and medical outcomes
- The hallmark of being an adult is knowing when you need help, and asking for it.
- Normalize feelings of “burn-out” and plan for them. This is not a failure.
- Schedule times when responsibility is turned back to parents and then back to teen.

Survival Advice

- Sharing Responsibility
- Avoid excessive self-care autonomy
- If you notice that your child is struggling, step in early. Relieve the pressure of trying to “get it right” or to “be perfect.”
- Talk about normal, regular, every day things before you talk about diabetes
- Validate your child’s feelings. Everyone is allowed to have a “terrible, horrible, no good, very bad day”
- Separate knowledge from judgment and maturity
- Avoid vicious cycle of miscarried helping
- Take care of yourself

The hallmark of being an adult is knowing when you need help, and asking for it.

ADULTHOOD

Moving into Adulthood

- Many similar challenges carried over from childhood/adolescence
 - Managing care tasks
 - Making decisions regarding disclosure
 - Feeling overwhelmed by diabetes care
- New types of challenges
 - Managing diabetes away from home/in the workplace
 - Potentially decreased social support/more independence in care
 - Navigating new relationships/disclosure decisions
- Diabetes burnout (could be carried over)
- Depression
- Anxiety/Fear of hypoglycemia

Diabetes in higher education/the workplace

- Can feel overwhelming and scary to ask for accommodations
- “Reasonable accommodations” are required by law
 - Breaks for checking blood sugars, having snacks, taking insulin
 - Keeping diabetes supplies nearby
 - Areas to test blood sugars, administer medications
 - Leave for medical appointments

Changes in Social Support

- More independence for diabetes care
 - Decisions about telling others about diabetes
 - New partners, employers, roommates, co-workers, etc.
- Alternatively, feeling “policed” by others in regard to diabetes care
- Transition in support from parents and family members
 - May now include other sources of support
 - Partners/spouses
 - Children
 - Friends

Diabetes-specific distress/diabetes burnout

- Emotional distress related specifically to diabetes care and management
- Related to:
 - Disease management
 - Support
 - Emotional Burden
 - Access to Care
- Commonly seen in adolescents and adults
- Feeling “sick of” diabetes
- Feeling like you are failing in management

Esbitt, Tanenbaum, & Gonzalez, 2013
Fisher, Glasgow, Mullan, Skaff, & Polonsky, 2008

Sources of Distress

- 24/7 job of managing type 1 diabetes
- Frequently out of range, unexpected, and/or erratic blood sugars
- Feeling that diabetes is “off track”
- Constraints around food and eating
- Distress about weight
- Feeling unsupported or negative interactions by friends, family, or diabetes provider
- Feeling that family or friends don’t understand how difficult T1D is
- Feeling alone
- Misperceptions of type 1 diabetes and limited understanding of the disease
- Feeling that you are treated differently by some
- Transitioning diabetes management independence
- Transitioning to living independently

Diabetes-specific distress

- Feeling scared when you think about living with diabetes
- Feeling depressed when you think about living with diabetes
- Worrying about the future and the possibility of serious complications
- Feeling that diabetes is taking up too much of your mental and physical energy every day
- Managing coping with the complications of diabetes

“Checking out”/Ignoring diabetes

Depression

- Clinical depression is diagnosed when a person experiences depressed mood and a range of the symptoms below for 2 weeks
- Symptoms may include:
 - Reduced interest in pleasurable activities
 - Reduced energy and increased fatigue
 - Altered appetite and sleep
 - Diminished concentration
 - Feelings of worthlessness
 - Suicidal thoughts

Impact of Depression on Health

- Depression in T1D is serious and can lead to:
 - Reduced motivation to take care of oneself, including diabetes tasks
 - Poor sleep
 - Poor appetite
 - Low self esteem and loss of confidence in abilities
 - Isolation
 - Loss of joy in activities
 - Hopelessness
 - Higher A1c
 - More diabetes complications

Anxiety and Fear of Hypoglycemia

- Can relate to:
 - Fears/misunderstandings about new diagnosis
 - Trouble managing care tasks
 - Worry about complications
 - Worry about blood glucose levels
- Fear of Hypoglycemia
 - Intense anxiety related to anticipating hypoglycemia (low blood sugar) *and* behaviors to prevent episodes of hypoglycemia
 - Common in parents of children with type 1

Driscoll et al., 2016

Patton, Dolan, Henry, & Powers, 2007

What to do if you see red flags...

- Tell someone you trust
 - Supportive family member
 - Friend with type 1 or close friend who “gets it”
 - Diabetes provider or primary care provider
 - Ask yourself, “What would help me manage my diabetes?” “What can X person do to help me meet my goals?”

- Seek support from a mental health provider who is knowledgeable of type 1 diabetes
 - Can help to talk to someone outside of your bubble
 - Helps with the identification of coping strategies and with problem solving current obstacles

What to do: Coping

- Making small goals and small gains
 - Create short-term, attainable goals related to diabetes care and to other life tasks
 - Be clear with these goals
 - Rather than saying, “I will check my blood sugar when I am supposed to,” say “I will check my blood sugar before each meal” or “I will check my blood sugar 4 times per day”
 - Don’t expect or force large changes all at once
 - One small goal at a time vs. Becoming “perfect” in diabetes management
- Accept that no one manages diabetes perfectly
 - No one *can* manage diabetes perfectly

Diabetes is not a 'do it yourself' disease.