Talking to your Child about His/Her Diagnosis In a Developmentally Appropriate Way

Liz Harstad, MD, MPH, Developmental Behavioral Pediatrician
DeWayne Lazenby, MD, Developmental Behavioral Pediatric Fellow
Division of Developmental Medicine
Boston Children’s Hospital
Goals for this session:

- Discuss ways to share medical information with your child
- Understand children's thinking abilities at different developmental age
- Learn about importance of self-determination
- Discuss developmental conditions that commonly affect children with developmental issues
We all come in as experts
Background

- Our journey as parents to love/accept child relative to hopes/expectations
- Impact of medical/developmental issues on independence, family, work, companionship
- Child factors
  - Developmental level (separate slide)
  - Temperament
  - Showing signs he/she wants more information
- Parent factors
  - Grieving process (denial, anger, bargaining, depression, acceptance)
  - Level of acceptance of child’s medical/developmental issues
Thinking/reasoning abilities evolve over time

**Sensorimotor**
Exploring objects through touch, only think about things in the present

**Preoperational**
Think and talk about things beyond immediate experience

**Concrete operational**
Can now reason, but only about concrete, real life situations

**Formal operational**
Abstract thinking, critical analyses of different points of view

- **Birth - Toddler**
- **Toddler - 7 years old**
- **7-12 years old**
- **≥12 years old**
Sharing medical information with your child…

- When?
- Where?
- With whom?
- How?
- What?
Sharing medical information with your child...

- No exact “right” time
- Gradual unfolding better than one big explanation
- Follow child’s questions
- On the way to appointments - explain why
- Hidden information may be confusing and children may come to their own (often incorrect) conclusions
Sharing medical information with your child...

- Anywhere - spontaneous unfolding
- For planned discussions
  - Minimize distractions
  - Comfortable setting
- Avoid delaying while awaiting the “perfect” spot to discuss
Sharing medical information with your child...

- Identify your child’s strengths and areas that are challenging
- Discuss strengths and weaknesses of other family members
- Child’s developmental level
- Be sure to answer questions child has asked
- Write down key points ahead of time
- Decide key wording to use
- www.kidshealth.org

Sharing medical information with your child...

• Keep it positive
• Give opportunity for discussion
• Expect follow up questions, keep dialogue open
• Information can be conveyed in ways other than words
Sharing medical information with your child...

- Parents, guardians
- Discuss with siblings separately from first discussion with child
- Consider discussion with therapists, doctors, teachers, babysitters, neighbors, classmates, etc.
- Consider creative ways to communicate with strangers
Using a Strengths Based Approach

- Everyone has strengths and weaknesses
- What are things you are good at? What comes easily?
- What are your challenges or barriers? What is harder for you?
- Use child’s words or examples if appropriate
Now, let’s put this into action!
Self-Determination

• All individuals have a right to direct their own lives

• Key components:
  • **Autonomy** = Person acts according to his/her own preferences, interests, or abilities
  • **Self-regulated** = Person creates a plan of action and makes changes in this when necessary
  • **Psychologically empowered** = Person speaks up for him or herself
  • **Self-realized** = Person knows what supports are needed for success and knows how to evaluate outcomes
Research on Self-Determination

- Supports the benefits of self-determination

- Wehmeyer and Schwartz (1997)
  - Studied 80 students ages 17-22 years old with cognitive or learning impairments
  - Collected data about student’s self-determination prior to high school exit
  - Nearly one year later those with higher self-determination scores were more likely to be employed, earn more, have a checking and savings account, and have a desire to move out of the parents’ house
Promoting Self-Determination

- Real-world experience
- Taking risks, making mistakes, and reflecting on those mistakes
- Youths need to know themselves
  - Open and supportive discussion about child’s medical/developmental issues
  - Understand how these might affect learning, relationships, employment, and need for supports
- Caregivers must be open to new possibilities and take seriously youths’ dreams for the future
Promoting Self-Determination

- Adolescents can prepare for IEP meeting
  - Short list of strengths and what they want to work on
  - Goals for the upcoming year
  - Goals for after school ends
- Specific teaching of self-determination through curriculum
- Hold high expectations and expect some failures as part of the learning process
Common Concurrent Conditions
Increased risk in many developmental disorders, like autism...

- Worldwide population prevalence 1%
- >70% have concurrent conditions
- What you experience regularly may not seem to be a problem
Concurrent Conditions - Autism

- Intellectual disability 45%
- Language disorders (variable definitions)
- ADHD 28-44%
- Tic disorders 14-38% (6.5% Tourette’s)
- Motor abnormality 70%
- Epilepsy 8-30%
- Sleep disorders 50-80%
- Anxiety 42-56%
- Depression 12-70%
Concurrent Conditions - Autism

- Obsessive-compulsive disorder 7-24%
- Psychotic disorders 12-17%
- Substance abuse 16%
- Oppositional defiant disorder 16-28%
- Eating disorders 4-5%
- Aggression <68%; self injury <50%; pica 36%; suicide ideation/attempt 11-14%
What is Anxiety?

- Anxiety is a sense of uneasiness, worry, fear, or dread about what’s about to happen or what might happen.
- Natural human reaction that involves mind and body:
  - Live preserving at the appropriate level
  - Limiting when excessive
- Fight or flight response (parasympathetic and sympathetic nervous systems)
Schema Explaining How Parasympathetic and Sympathetic Nervous Systems Regulate Functioning Organs

Parasympathetic

- Eyes
  - Constrict Pupil
- Salivary Glands
  - Stimulates Salivation
- Heart
  - Slows Heartbeat
- Lungs
  - Constrict Bronchi
- Stomach
  - Stimulates Digestion
- Liver
  - Stimulates Bile Release
- Intestines
  - Stimulate Peristalsis and Secretion
- Bladder
  - Contracts Bladder

Sympathetic

- Eyes
  - Dilate Pupil
- Salivary Glands
  - Inhibit Salivation
- Heart
  - Accelerates Heartbeat
- Lungs
  - Dilate Bronchi
- Stomach
  - Inhibits Digestion
- Liver
  - Stimulates Glucose Release
- Kidneys
  - Stimulate Epinephrine and Norepinephrine Release
- Intestines
  - Inhibit Peristalsis and Secretion
- Bladder
  - Relaxes Bladder

Vagus Nerve

Medulla Oblongata

Chain of Sympathetic Ganglia

<table>
<thead>
<tr>
<th>Age Range</th>
<th>Fear</th>
</tr>
</thead>
<tbody>
<tr>
<td>Infant/Toddler</td>
<td>Loud noises, strangers, dark, large objects, separation</td>
</tr>
<tr>
<td>Preschool</td>
<td>Separation, dark, monsters and ghosts, animals, storms</td>
</tr>
<tr>
<td>School Age</td>
<td><strong>Bodily injury and death, school performance</strong>, natural disasters and storms</td>
</tr>
<tr>
<td>Adolescent</td>
<td><strong>Social situations, school performance</strong>, health, public speaking</td>
</tr>
</tbody>
</table>
When is Anxiety a Disorder?

- Fears, worries, or anxiety occur outside the range of normal developmental responses
- Responses are extreme
- Cause significant distress or impairment in functioning (school, home, or social settings)
- **Fear response is no longer adaptive**
How Common are Anxiety Disorders?

- Most common psychiatric disorders in children and adolescents
- 8-10%
- More common in females
- More common in people with medical illnesses, ADHD, learning problems
What Causes Anxiety Disorders?

Many Factors!

- Genetics
- Stressors
- Temperament
- Physiologic Factors
- Modeling
What do Anxiety Disorders Look Like in Children?

- May occur in specific situations or be generalized
- Stomachaches, nausea, headaches
- Avoidance
- Tantrums, aggression, irritability
- Crying, trembling
- Frequent seeking of reassurance
- Poor concentration, sleep, appetite
Different Types of Anxiety Disorders

- Generalized Anxiety Disorder
- Phobias
- Social Anxiety
- Separation Disorders
- Obsessive Compulsive Disorder
- Panic Attacks
- Posttraumatic Stress Disorder
Treatment

- Therapy/Behavioral Interventions
  - Cognitive-behavioral therapy
  - Accommodations in home and school

- Medications
  - SSRIs
  - Benzodiazepines
Cognitive Behavioral Therapy

- Specific # of treatment sessions with therapist
- Homework often given in between sessions
- Components of therapy:
  - Recognizing mind and body reactions to anxiety
  - Changing thoughts in anxiety producing situations
  - Developing a coping plan
  - Evaluating performance and administering self-reinforcement as appropriate
Accommodations for Anxiety

• Help child recall past instances of anxiety that she has successfully overcome

• Dispel myths about feared situation

• Provide accurate information to remove uncertainty and “unknowns”

• Coach in positive self-talk: “I’ve done it before. I can do it again.”
Accommodations for Anxiety

- Have an organized, predictable routine
- Foster tolerance and acceptance
- Normalize and model imperfection
- Teach child to estimate the realistic probabilities of bad outcomes
- Teach to examine worst consequences of making a mistake
Medications for Anxiety

- **Selective Serotonin Reuptake Inhibitors (SSRIs)**
  - Prozac, Celexa, Zoloft, Luvox, Lexapro, Paxil
  - Take several weeks to work
  - Black box warning for increased suicidal thoughts/activation
  - Can be very effective

- **Benzodiazepines**
  - Xanax, Klonopin, Ativan
  - Work quickly
  - Used for short term or specific events
Attention Deficit Hyperactivity Disorder (ADHD)

- More difficulty than expected for child’s developmental level
- Occurs in multiple settings & causes problems
ADHD = Brain-based disorder

- 8% of school aged kids
- Impacts family life, friendships, learning
Treatment of ADHD

- For school aged children, American Academy of Pediatrics recommends trial of stimulant medication + behavioral therapy

- Goal is to find medication that helps WITHOUT significant side effects

- Behavioral accommodations for home and school
Autism Spectrum Disorders (ASDs)

- Difficulty with social and communication skills with repetitive, restricted behaviors
- ASDs are diagnosed clinically
- Diagnostic and Statistical Manual of Mental Disorders (DSM)
Autism Spectrum Disorders

- Diagnostic criteria changed with release of new DSM-5
- Media coverage
- What do the changes mean?
The Changing Criteria

DSM-IV-TR

Social Interaction
Communication
Restricted, Repetitive Behaviors

DSM-5

Social Communication/Social Interaction
Restricted, Repetitive Behaviors
The Changing Criteria

DSM-IV-TR

Social Interaction

Communication

Restricted, Repetitive Behaviors

Autistic Disorder

Pervasive Developmental Disorder, not otherwise specified (PDD-NOS)

Asperger’s Disorder

Rett Syndrome

Childhood Disintegrative Disorder

DSM-5

Social Communication/
Social Interaction

Restricted, Repetitive Behaviors

Autism Spectrum Disorder
Implications of These Changes

- Fewer children may be diagnosed with autism spectrum disorders
- Children who previously would have had PDD-NOS and young children may be less likely to get diagnosis
- More research needed to see how this influences prevalence rates
Thanks for your participation today!