



Managing Behavior in Teenagers with Spina Bifida

Cortney Wolfe-Christensen, PhD

Pediatric Psychologist

Cook Children's STRONG Clinic

Justin Institute for MIND Health



How it started....



CookChildren's.



How it's going...





Objectives

- To understand the typical behavioral issues for teenagers
- To identify how Spina Bifida can contribute to these difficulties or protect against them
- To learn some techniques for management of behavioral difficulties



Welcome to being a parent of a teenager. Prepare for a large amount of eye rolling, emotional outbursts, and thoughts of running away. And that's just the parents.



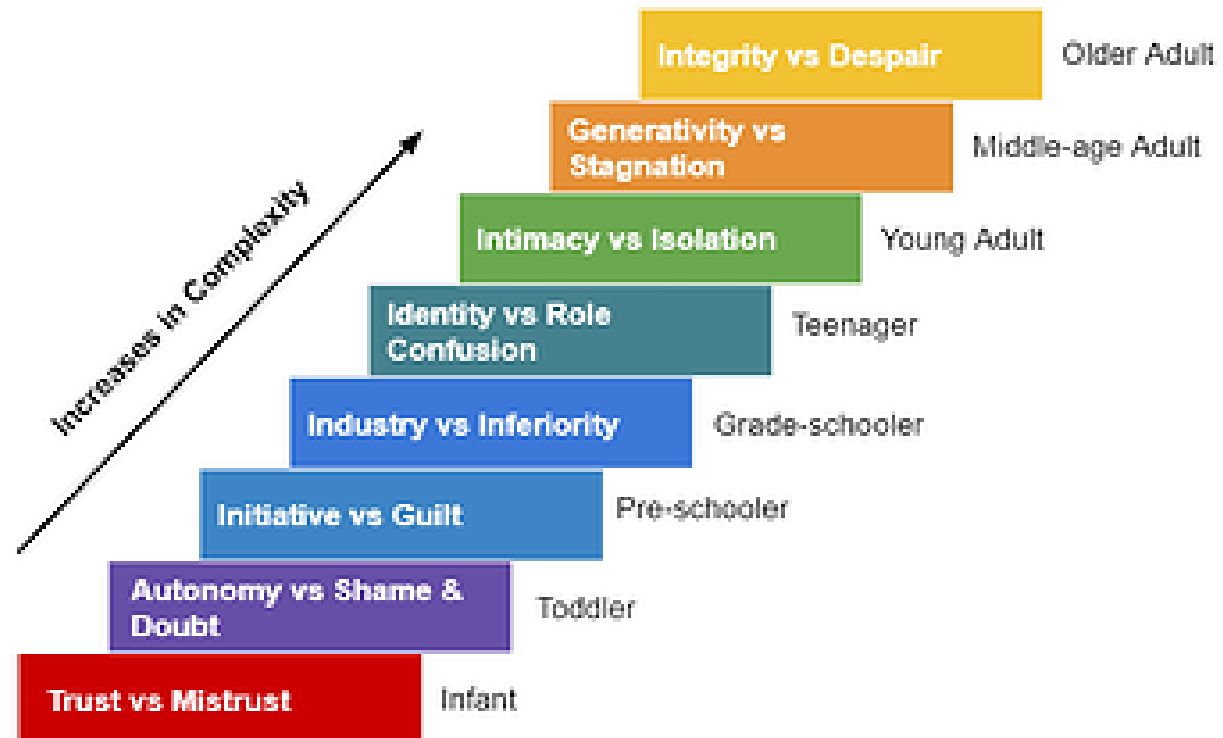
[FACEBOOK.COM/MOTHERHOOD.ORG](https://facebook.com/motherhood.org)

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Erickson's Stages of Psychosocial Development

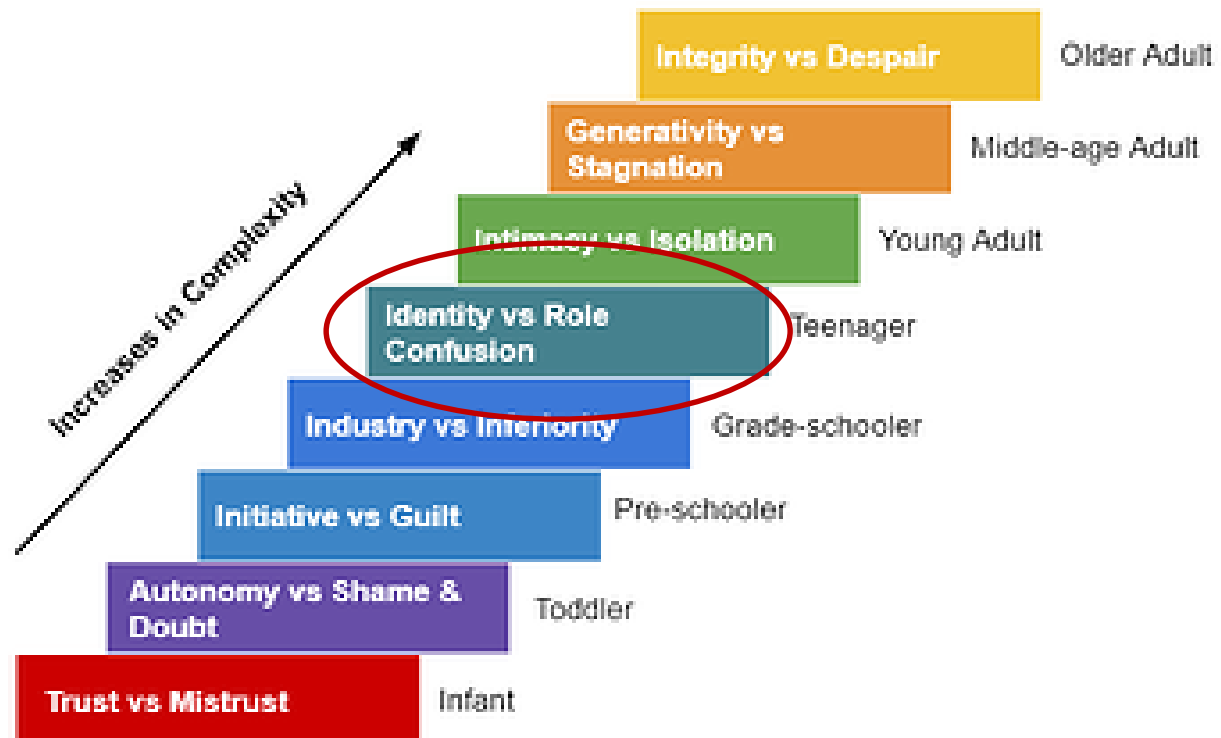
Stages of Psychosocial Development





Erickson's Stages of Psychosocial Development

Stages of Psychosocial Development





Identity vs. Role Confusion

Identity

- Experiences, Relationships, Beliefs, Values, and Memories that make up a person's "sense of self"
- Creates a continuous self-image that remains constant

Role Confusion

- Being unsure where you fit
- Drifting from one relationship to another
- Feeling disappointed and confused about your place in life



Benefits of Identity

- Commitment to a particular identity
 - Career path, social group, personal style
- Self-Confidence
 - Trust in their abilities, qualities and judgements
- Sense of Independence
 - Strong sense of self and feeling of independence and control
- Fidelity
 - Ability to relate to others and to form genuine relationships



Bottom Line

- TEENS JUST WANT TO FIT IN!
- THEY DON'T WANT TO BE DIFFERENT!





Teenagers and Chronic Medical Conditions

- Medical needs “make them different” from peers
 - School absences
 - Medication regimens
 - Privacy around diagnosis
 - Long-term effects of treatment



Teenagers and Chronic Medical Conditions

- Transfer of illness management from parent to child
 - Based on developmental level, not necessarily age
 - Gradual transition
 - Importance of supervision
 - 2 steps forward & 1 step backwards
 - Balance of trust





Teenagers and Chronic Medical Conditions

- Decreased compliance with treatment recommendations
 - Medical risks
 - Increased discord
 - Emotional distress



Prepare your child for adolescence

- Educate child on their medical diagnosis in a developmentally appropriate manner
- Difference between secrecy and privacy
- Utilize correct anatomical terms for body parts
- Encourage trust between your child and medical providers



Prepare your child for adolescence

- Allow your child independence in medical appointments
 - Get into the habit of “stepping out of the room”
- Importance of mental health in addition to physical health
 - Destigmatizing mental health
 - Family history





Spina Bifida Specific Information

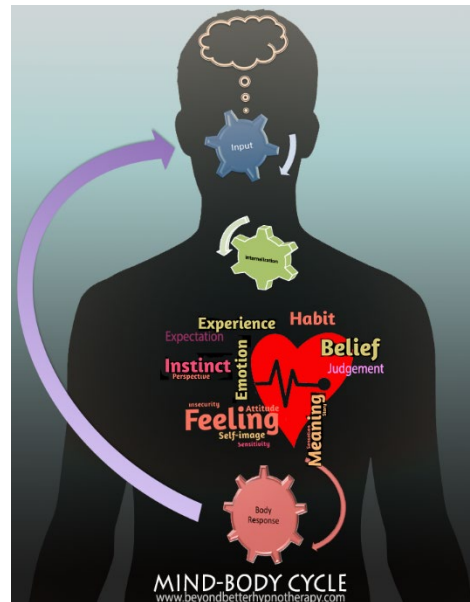
- Name of diagnosis
- Name of medications
- Reason(s) for each medication
- Catheterization Schedule
- Signs of UTI or Shunt Malfunction





Behavior & Emotions

- Difficult Behaviors are often manifestations of emotional distress
- Mind-Body Connection
 - Physical Symptoms





Mental Health in Patients with Spina Bifida

- Emotional, psychological, and social well-being
- Positive mental health → pursue goals and realize potential
- Poor mental health → interfere with achievement of life goals



Mental Health Risks

- Social difficulties
 - Fewer friends, fewer romantic relationships
- More dependence on parents
 - 43 – 77% of adults with SB live with parents
- Less involvement in physical activities and ADLs
 - Weight management, independence



Our local celebrity!



Search accounts and videos

 For You

 Following

 LIVE

Suggested accounts

 **madsbaileybabe** ✓
Maddie L Bailey

 **jennifercoolidge** ✓
Jennifer Coolidge



chase_cashman

Chase Harris

[Messages](#)



175 Following **255.4K** Followers **6M** Likes

Father/ Son Duo 🤝

For 📺

1540 Keller pkwy ste 108 #411 keller, TX 76248

linktr.ee/Chaseharrisfit



Depression Statistics

- 57% of females and 29% of males reported experiencing persistent feelings of sadness or hopelessness
- 30% of females and 14% of males have seriously considered attempting suicide during the past year



Depression

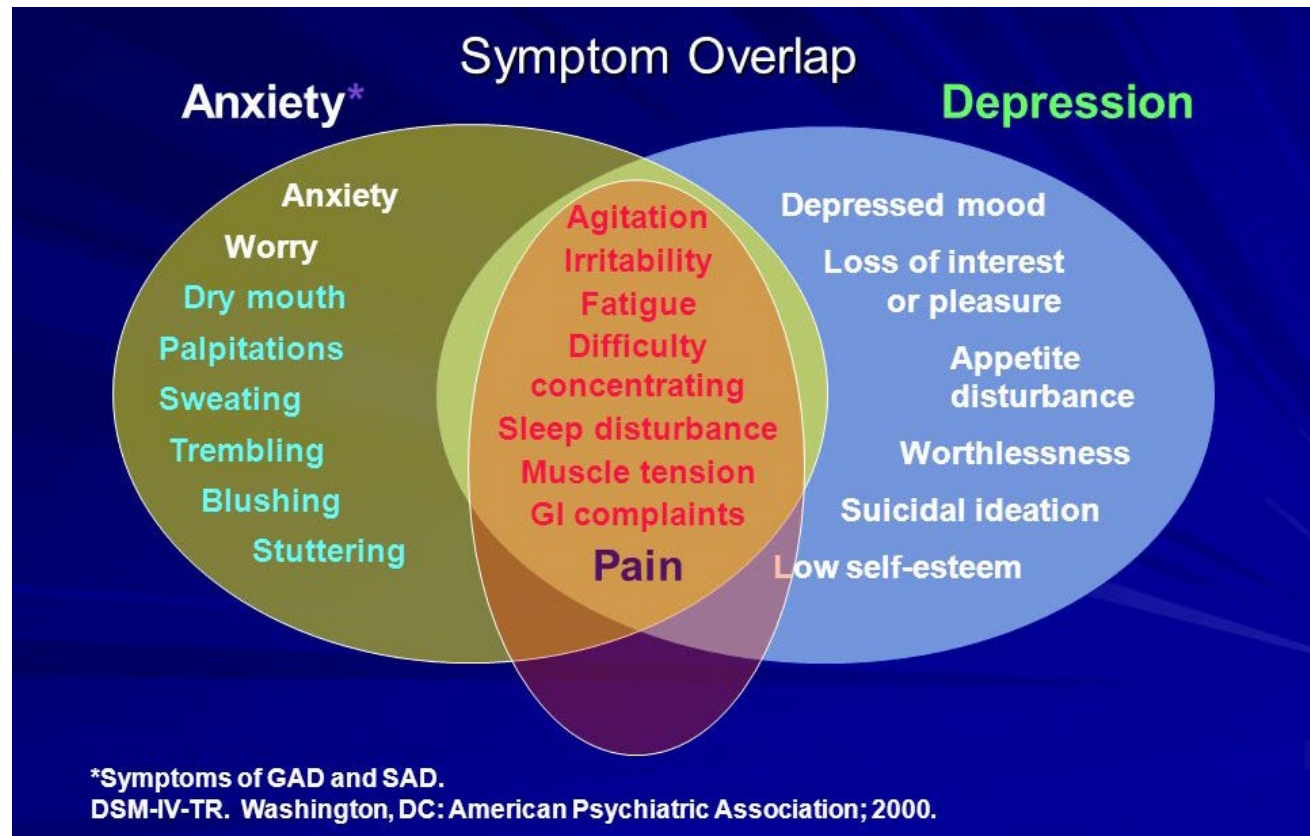
- No single cause for depression
- Genetics and environment both play a role in development of depression
- Triggering events for depression in children and teenagers
 - Stressful situations
- **Irritability, NOT sadness, is the hallmark symptom of depression in children and teenagers**



Symptoms of Depression

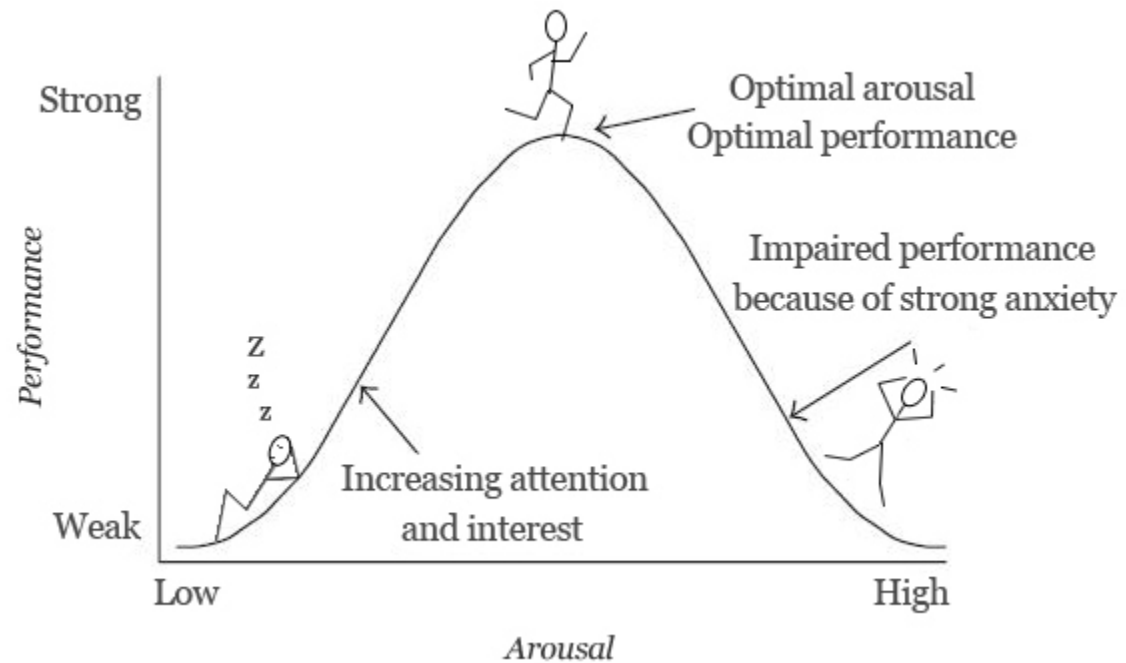
- Feeling or appearing sad, tearful, or irritable
- Decreased interest in activities (anhedonia)
- Change in appetite
- Change in sleep patterns
- Difficulty concentrating or thinking
- Appearing to be physically sped up or slowed down
- Increase in tiredness and fatigue or decreased energy
- Feeling worthless or guilty
- Thoughts of suicide or self destructive behavior

Relationship Between Depression and Anxiety





Optimal amount of anxiety





Anxiety Statistics

- 9.4 % of children and adolescents ages 3- 17 had ever been diagnosed with anxiety
- Prevalence of ever having anxiety:
 - 2.0 % (ages 3-5) → 8.6% (ages 6-11) → 13.7% (ages 12-17)



Anxiety Symptoms

- Restlessness, feeling “keyed up” or on edge
- Being easily fatigued
- Difficulty concentrating or mind going blank
- Irritability
- Muscle tension
- Sleep disturbance



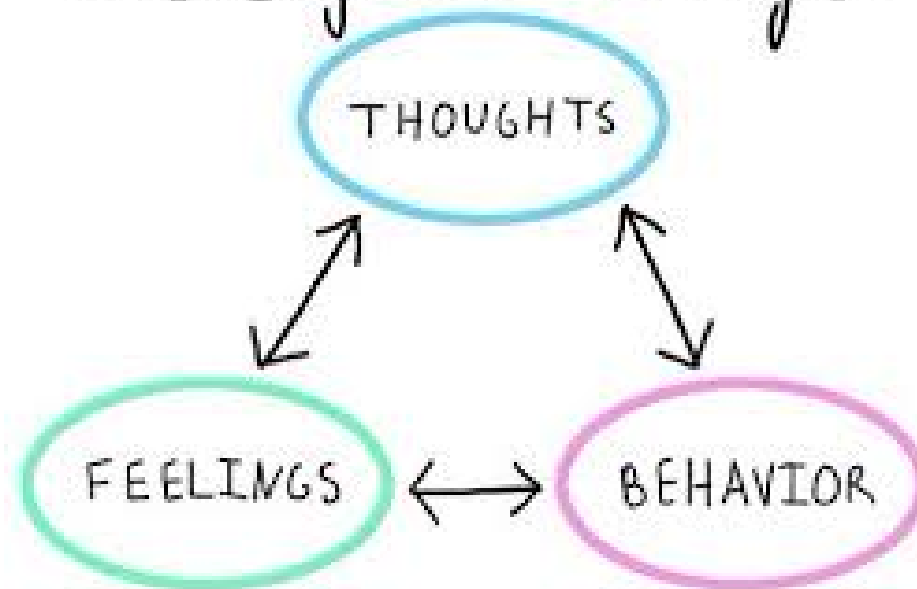


Treatment for Anxiety and Depression

- Medication
 - Increase or decrease amount of neurotransmitters in the brain
 - Serotonin, Norepinephrine, and Dopamine
- Cognitive Behavioral Therapy (CBT)
 - Individual therapy
 - Family therapy
 - Group therapy
- Combination of Medication and CBT



The Cognitive Triangle





Automatic Thoughts

- The thoughts that “pop up” in your head in response to an action or event.
- When people are depressed or anxious, their automatic thoughts tend to be negative (ANTs)
- ANTs need to be actively “challenged” because we fall into “thinking traps”



EXAMPLES OF COMMON NEGATIVE THOUGHTS

Check All that Apply

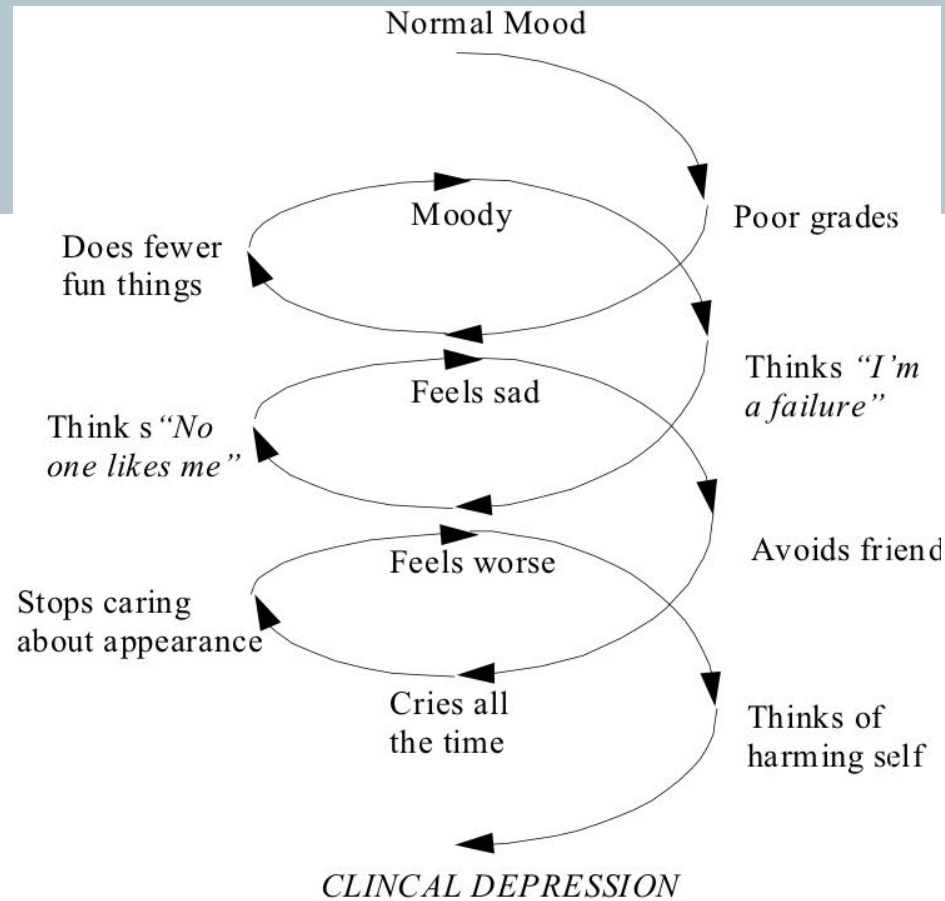
- ☐ I'm confused.
- ☐ I am wasting my life.
- ☐ I'm scared.
- ☐ Nobody loves me.
- ☐ I'll end up living all alone.
- ☐ I don't have enough willpower.
- ☐ I'll never be successful.
- ☐ I don't have any patience.
- ☐ There's no use trying, I never get it right.
- ☐ That was a dumb thing for me to do (or say).
- ☐ Life sucks.
- ☐ I'm ugly.
- ☐ I can't express my feelings.
- ☐ I'll never find what I really want.
- ☐ I can't get close to people.
- ☐ I am worthless.
- ☐ It's all my fault.
- ☐ Bad things always happen to me.
- ☐ I can't think of anything that would be fun.
- ☐ I'll never get over this depression.
- ☐ People don't consider friendship important anymore.
- ☐ Things are so messed up that doing anything about them is useless.
- ☐ Anybody who thinks I'm nice doesn't know the real me.
- ☐ I shouldn't even bother getting up in the morning.
- ☐ I'm afraid to imagine what my life will be like in ten years.
- ☐ Life is unfair.
- ☐ I wish I were dead.
- ☐ I wonder if they are talking about me.
- ☐ Things are just going to get worse and worse.
- ☐ I have a bad temper.
- ☐ No matter how hard I try, people aren't satisfied.
- ☐ I'll never make *any* good friends.
- ☐ I'm crazy.
- ☐ There is something wrong with me.
- ☐ I am selfish.
- ☐ My memory is lousy.
- ☐ I am not as good as _____ (*another person*).
- ☐ I get my feelings hurt easily.



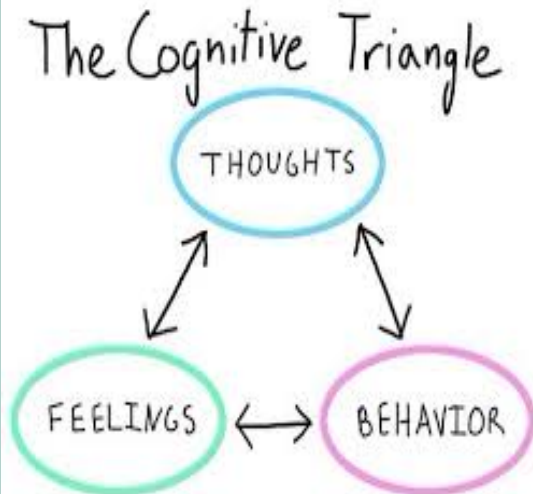
THINKING TRAPS

Thinking Traps	Examples
Fortune-telling: This is when we predict that things will turn out badly. But, in reality, we cannot predict the future because we don't have a crystal ball!	<i>"I know I'll mess up."</i> <i>"I will never be able to manage my anxiety."</i>
Black-and-white thinking: This is when we only look at situations in terms of extremes. For example, things are either good or bad, a success or a failure. But, in reality, most events call for a more "moderate" explanation. For example, cheating once on your diet does not mean you have failed completely. You had a small setback, and all you need to do is to get back on your diet tomorrow.	<i>"Anything less than perfect is a failure."</i> <i>"I planned to eat only healthy foods, but I had a piece of chocolate cake. Now my diet is completely ruined!"</i>
Mind-reading: This trap happens when we believe that we know what others are thinking and we assume that they are thinking the worst of us. The problem is that no one can read minds, so we don't really know what others are thinking!	<i>"Others think I'm stupid."</i> <i>"She doesn't like me."</i>
Over-generalization: This is when we use words like "always" or "never" to describe situations or events. This type of thinking is not helpful because it does not take all situations or events into account. For example, sometimes we make mistakes, but we don't always make mistakes.	<i>"I always make mistakes."</i> <i>"I am never good at public speaking."</i>
Labeling: Sometimes we talk to ourselves in mean ways and use a single negative word to describe ourselves. This kind of thinking is unhelpful and unfair. We are too complex to be summed up in a single word!	<i>"I'm stupid."</i> <i>"I'm a loser."</i>

Over-estimating danger: This is when we believe that something that is unlikely to happen is actually right around the corner. It's not hard to see how this type of thinking can maintain your anxiety. For example, how can you not feel scared if you think that you could have a heart attack any time?	<i>"I will faint."</i> <i>"I'll go crazy."</i> <i>"I'm dying."</i>
Filtering: This happens when we only pay attention to the bad things that happen, but ignore all the good things. This prevents us from looking at all aspects of a situation and drawing a more balanced conclusion.	<i>Believing that you did a poor job on a presentation because some people looked bored, even though a number of people looked interested and you received several compliments on how well you did.</i>
Catastrophizing: This is when we imagine that the worst possible thing is about to happen, and predict that we won't be able to cope with the outcome. But, the imagined worst-case scenario usually never happens and even if it did, we are most likely able to cope with it.	<i>"I'll freak out and no one will help."</i> <i>"I'm going to make such a fool of myself, everyone will laugh at me, and I won't be able to survive the embarrassment."</i>
Should statements: This is when you tell yourself how you "should", "must", or "ought" to feel and behave. However, this is NOT how you actually feel or behave. The result is that you are constantly anxious and disappointed with yourself and/or with others around you.	<i>"I should never feel anxious."</i> <i>"I must control my feelings."</i> <i>"I should never make mistakes."</i>



Downward Spiral





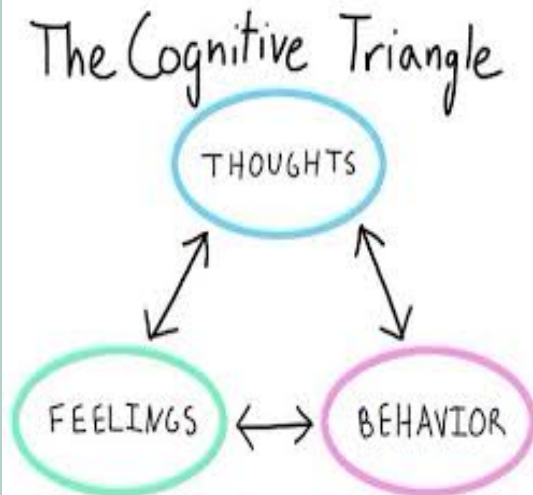
EXAMPLES OF POSITIVE THOUGHTS

Check All that Apply

- | | |
|--|--|
| <input type="checkbox"/> Life is interesting. | <input type="checkbox"/> My family cares about me. |
| <input type="checkbox"/> I really feel great. | <input type="checkbox"/> I'm attractive. |
| <input type="checkbox"/> I'm having fun. | <input type="checkbox"/> People can count on me because I'm reliable. |
| <input type="checkbox"/> I have great hopes for the future. | <input type="checkbox"/> I'm a good friend. |
| <input type="checkbox"/> I think I can do a good job at this. | <input type="checkbox"/> I think my life will turn out O.K. |
| <input type="checkbox"/> I have good self-control. | <input type="checkbox"/> I'm a generous person. |
| <input type="checkbox"/> I like people. | <input type="checkbox"/> I make friends easily. |
| <input type="checkbox"/> People like me. | <input type="checkbox"/> I care about people and the world. |
| <input type="checkbox"/> I have a good sense of humor. | <input type="checkbox"/> I have a good memory. |
| <input type="checkbox"/> There are some things that I'm very good at. | <input type="checkbox"/> I'm pretty lucky. |
| <input type="checkbox"/> I deserve to have good things happen. | <input type="checkbox"/> I have some very good friends. |
| <input type="checkbox"/> I can learn new skills to gain control of my mood. | <input type="checkbox"/> I know how to make my friends laugh. |
| <input type="checkbox"/> Other people think that I'm fun to be with. | <input type="checkbox"/> People value my opinion. |
| <input type="checkbox"/> I'm a good listener. | <input type="checkbox"/> I'm as good as _____ (<i>another person</i>). |
| <input type="checkbox"/> I'm OK the way I am. | <input type="checkbox"/> Good things can happen, if you work at them. |
| <input type="checkbox"/> I'm doing all right. | <input type="checkbox"/> Even if it's a rainy day, I can keep myself busy. |
| <input type="checkbox"/> I know how to deal with problems. | |
| <input type="checkbox"/> I'm optimistic about overcoming depression. | |
| <input type="checkbox"/> I'm a nice person. | |
| <input type="checkbox"/> My friends care about me. | |
| <input type="checkbox"/> I have enough time to accomplish the things I want to do in life. | |
| <input type="checkbox"/> I can learn to have control over my thoughts and actions. | |
| <input type="checkbox"/> I can find a solution to most of the problems that come up. | |
| <input type="checkbox"/> Even if things don't always go my way, I'll live through it. | |
| <input type="checkbox"/> I have some skills (sports, reading, art, etc.) that I'm good at. | |
| <input type="checkbox"/> Even if things are bad, I know how to take care of myself. | |
| <input type="checkbox"/> I often receive compliments for doing something well. | |



Positive Spiral





Coping

■ What do people want?

- To feel loved and to belong (security/relatedness)
- To feel good about who they are (self-esteem)
- To feel they are good at something (confidence/competence)
- To feel a sense of independence (autonomy, with some boundaries/limits)





Coping Strategies

- Open the lines of communication
- “Are you coming to me for advice or support?”
 - How do you know if someone is listening to you?
 - Empathic active listening
 - How does it feel to know you’ve been heard?





Communication

- Find a consistent way to ask your child about their day
 - Before bed or In the car
 - “What good thing happened today?”
 - “Did anything bad happen today?”
 - Tell your child something good that happened to you today.
 - Parental problems ≠ child problems
- Gives your child confidence that you will “open the door” for them to talk to you
- These conversations can be really difficult for kids to initiate
- Your response will determine if your kids tell you things in the future





Improving Communication

- Empathic active listening
 - Rephrase what you heard
 - Validate
 - Normalize
- Ex: “I know I was supposed to catheterize, but I didn’t because I just didn’t want to do it.”
 - Rephrase: “It sounds like you’re really tired of having to cath every three hours everyday.”
 - Validate: “I can understand why you would be frustrated. It would be really annoying to have to do something every 3 hours every day of your life.”
 - Normalize: “I don’t blame you for wanting to skip cathing. I think I would feel the same way.”



Suicide Assessment – Role of Adults

- If a child confides in you, your immediate reaction will set the stage for future disclosures
 - Don't Panic!
 - Ask for details
 - How long have they thought about this?
 - When was the last time they thought about this?
 - Do they have a plan for how they would hurt themselves?
 - Could they carry out the plan?
 - Have them evaluated in an Emergency Room



Discussion Points

- Talk about this difficult subject at home
- Open the lines of communication
- Come up with a “code word” for your
 - If a child just comes up and tells you the code word, you know they are needing help
 - Post this in the house
- #1 Protective Factor Against Suicide in Youth
 - Trusted Adult (parent, teacher, coach, etc)
- Suicide & Lifeline Hotline: 988
- National Suicide Text Line: Text “GO” to 741741



Resources

■ The Internet

- Teachers pay teachers
www.teacherspayteachers.com
- MentalHealthTX.org
- NIMH Children and Mental Health
www.nimh.nih.gov

■ App Store

- Breathing, relaxation apps
- Virtual Hope Box
- Coping apps



Resources

- County Health Departments
- Suicide & Lifeline Hotline
 - Call 988
 - www.988lifeline.org
- www.psychologytoday.com
 - Search by location, insurance, age, type of therapy



In memory of Blake W. Palmer, MD

- Each year in the US, 300 – 400 physicians die by suicide





Questions?

