



NF1 FAMILY DAY

Behavior, Anxiety and COVID-19

Laura Kurzius, Ph.D.
Psychology Postdoctoral Fellow
Children's National Hospital

Anxiety in Neurofibromatosis Type 1



- What is anxiety?
- COVID-19 worries in NF1: the importance of executive functioning
- How parents can support children with worry and practical strategies

FEAR

- Fear is a normal, natural part of development
 - Humans are hardwired to feel fear for survival
 - **FIGHT, FLIGHT OR FREEZE**



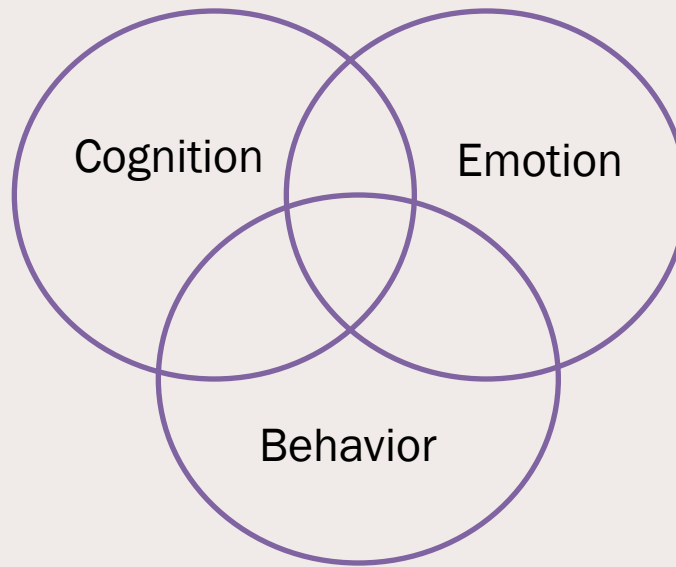
What is Anxiety?

- Anxiety arises when the normal fear response becomes excessive or occurs too frequently in the absence of an *actual* threat
- Children with anxiety perceive situations as more dangerous than they actually are and this interferes with how they function at home and at school



What Does Anxiety Look Like??

- Worrying way too much about bad things happening
- Thinking that danger is everywhere
- “what ifs”



- Heart pounding
- Sweating
- Muscle tension
- Headaches
- Stomachaches
- Trouble concentrating
- Shortness of breath
- Dizzy, faint or lightheaded
- Trembling and shaking

- Avoiding situations, people or things
- Clinging to safe people or refusing to leave them
- Meltdowns and irritability when faced with separation or feared situations
- Reassurance seeking
- Trouble falling or staying asleep

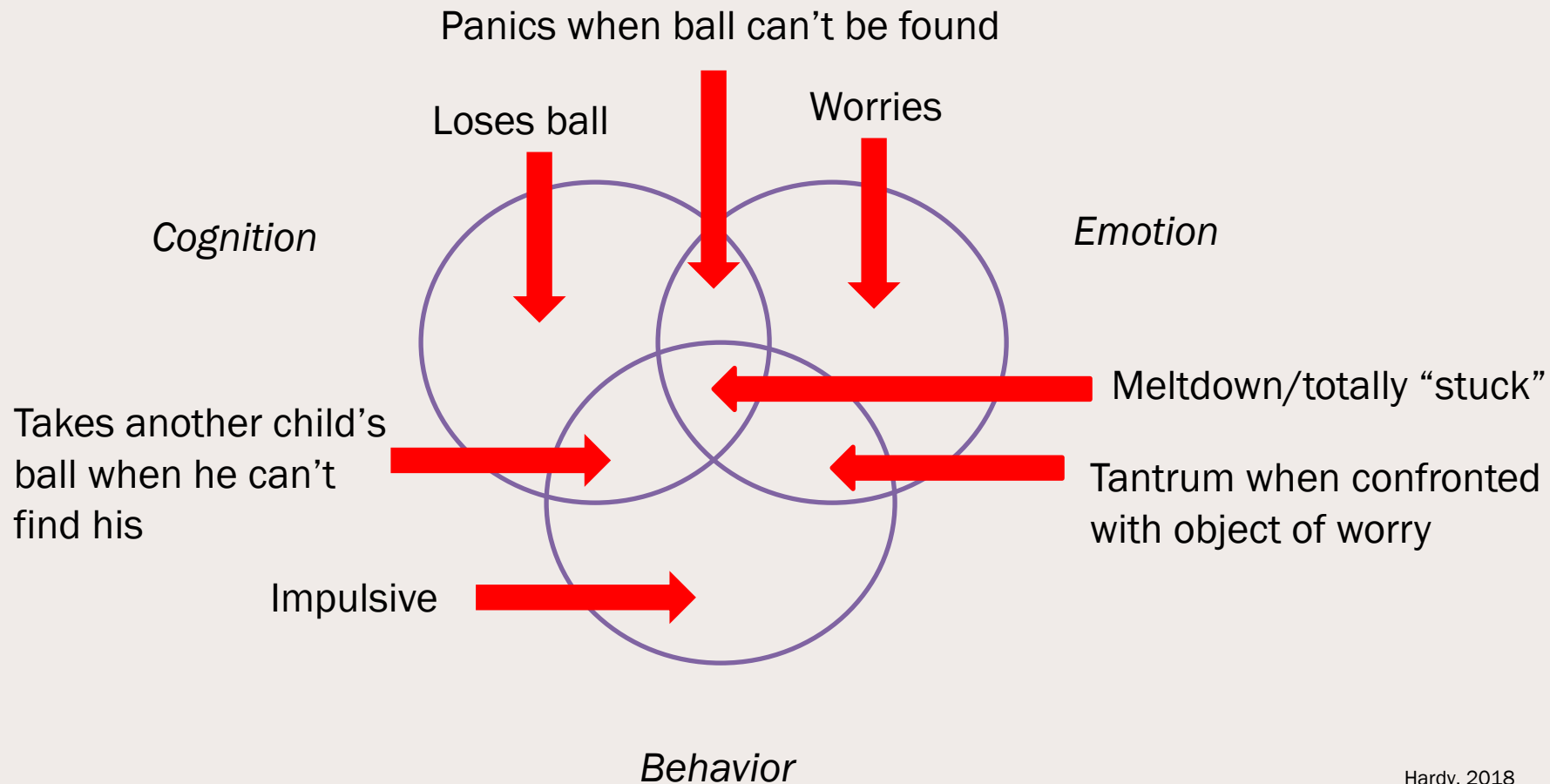
Executive Function Deficits and Neurofibromatosis

Executive Functioning is a complex set of skills we need to:

- navigate unpredictable events
- make plans, adjust and compromise
- negotiate
- exhibit flexibility of thought and action
- regulate worries and remain calm

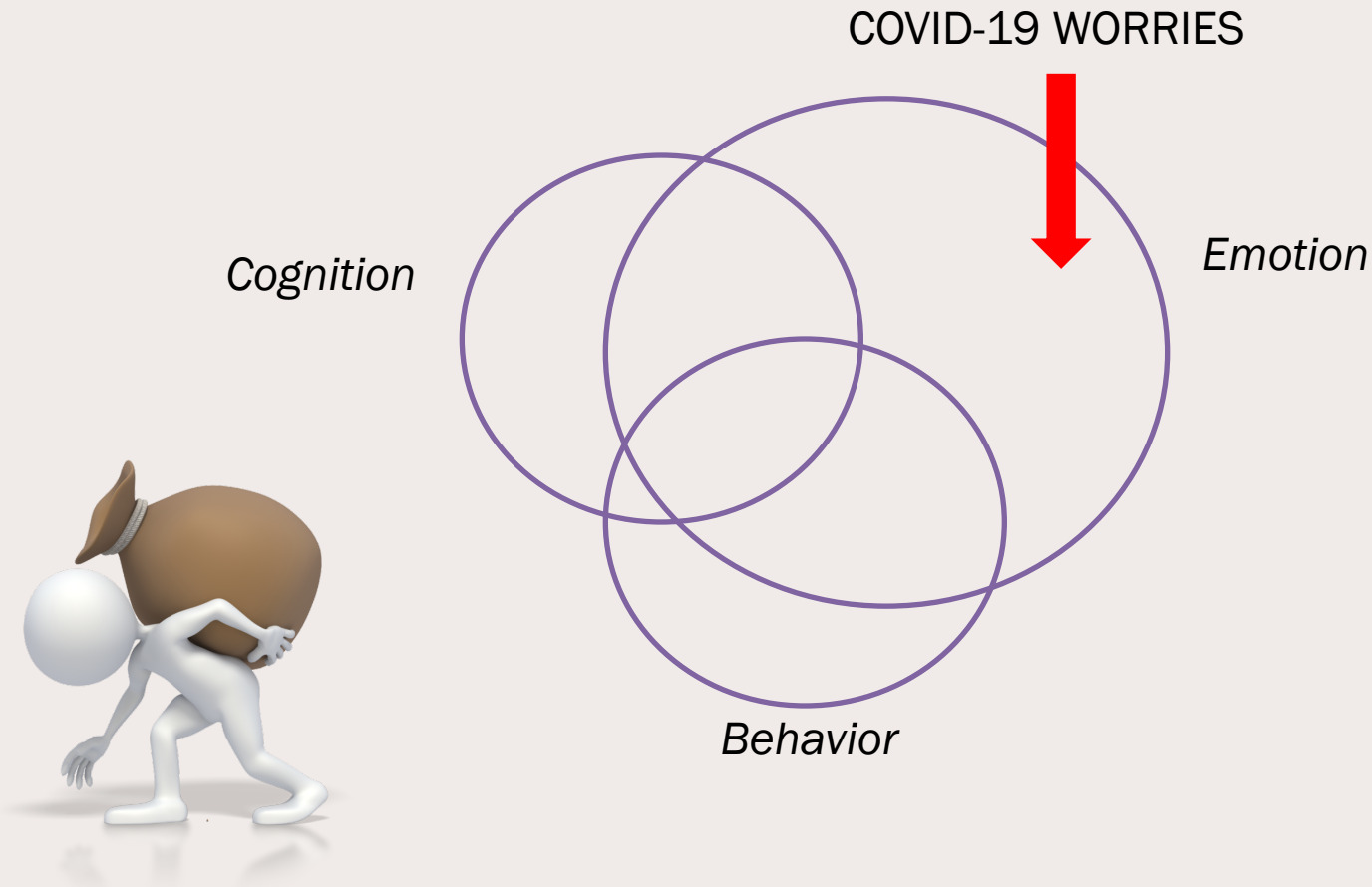


Executive Functioning Explains Everything!



Hardy, 2018

EF System is OVERBURDENED during COVID



Hardy, 2018

- Worries about COVID-19 are increasing the *load* on this system and trying to think, organize, plan and regulate when **overwhelmed** is really hard!!



HOW TO MANAGE WORRY

Role of parental beliefs on worry response

Parent Belief:

“I must keep her safe”

Parent may say:

“She can’t handle things well”

”I should protect her”

Child hears:

“This situation is too scary for me and I should avoid it”

“I cannot deal with this on my own”

Parent Belief:

“My child must figure this out on his own”

Parent may say:

“There is nothing to worry about, so just go have fun and play”

Child hears:

“My parents don’t understand me”

“Oh no, it’s bad I am worrying. Is there something wrong with me?”

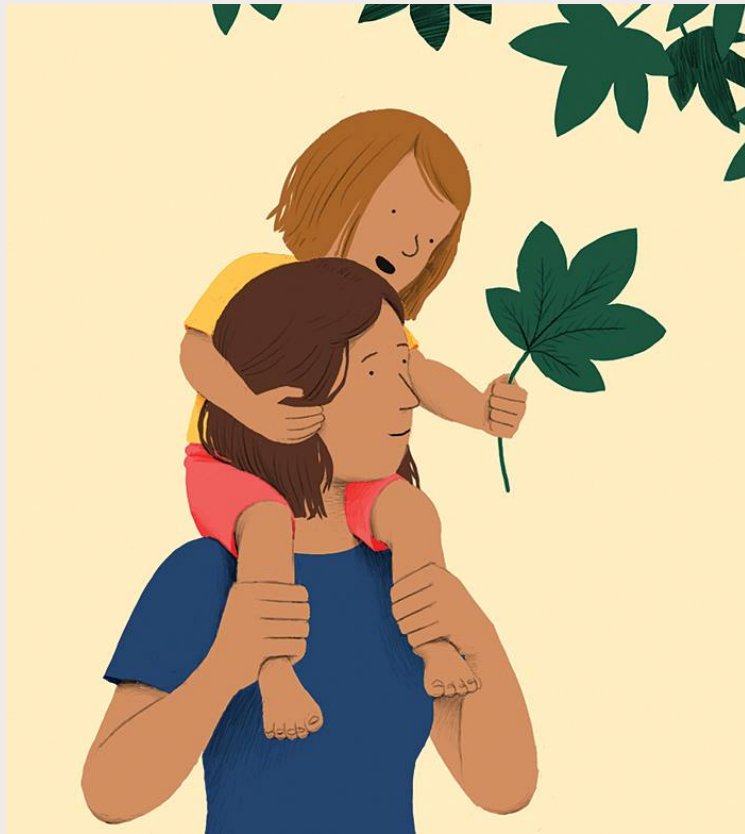
Penela, 2020

“Anything that’s human is mentionable, and anything that is mentionable can be more manageable when we can talk about our feelings. They become less overwhelming, less upsetting and less scary.”

– Mister Rogers



HOW TO MANAGE WORRY



How to respond when kids come to us with worries

- Listen closely and reflect
“Tell me more about that”
- Notice, label and accept emotions
“You sound really worried, and it’s okay to feel this way”

HOW TO MANAGE WORRY

Respond to worry with a *supportive statement*

Demonstrate **acceptance** by *validating* the emotion

“I can see how hard this is for you”

“I know you’re really worried”

Show you’re **confident** in your child’s ability to cope

“You can tackle this”

“I know you’ll get through it”

“I can see how difficult this is for you, but I know you can do it”



Lebowitz, 2019

HOW TO MANAGE WORRY

A few more tips on how to respond

Fight the instinct to:

- Provide reassurance
- Encourage avoidance

Work to “solve the worry” together:

- Ask open ended questions with the goal of gathering facts to “talk back” to the worry
- Discuss past experiences and use this information to **show** your child how they can navigate tricky situations



Penela, 2020

HOW TO MANAGE WORRY

Resilience Building: Model Accepting Uncertainty

Worry: “I don’t want to go for a socially distanced bike ride! What if I catch COVID-19!”

False Reassurance

“Don’t worry, you won’t catch it”

Avoidance

“I understand, you can stay home”

Instead

“It’s okay to feel scared about coronavirus, we do not have all the answers”

Spend time researching safety guidelines together

“I see. We have been going for a ride almost every day for the last month. How has that been? Have you gotten sick? I wonder what’s different about today?”

Penela, 2020



HOW TO MANAGE WORRY

Additional Strategies: The Mind-Body Connection



- Relaxation and Mindfulness
 - Slow Breath
 - Color Breathing
 - Squeeze and Release
 - Five Senses Activity
 - Imaginary Vacation
 - Mindful Eating
 - Peace Out Podcast (bedtime.fm/peaceout)
- Worry Time
 - 10 minutes a day
 - Postponing worry is a helpful skill
 - Avoid bedtime

HOW TO MANAGE WORRY

Additional Strategies: The Mind-Body Connection



- Establish a daily routine, and find the right balance of structure and flexibility
 - Regular sleep and wake times
 - Be active, get moving, go outside
 - Limit overall screen time, and join if watching news to have a discussion together
- Pay attention to **joy** and practice **gratitude**
 - Dinner : highs/lows or roses/thorns
 - Bedtime: list 3 things you enjoyed today
- Invest in social connectedness
 - Schedule regular calls with friends and grandparents
 - Write letters
 - Socially-distanced activities

Resources

TRAILS TO WELLNESS materials: worksheets, handouts, videos, and more!

<https://trailstowellness.org/materials/resources>

Kids Health: Relaxation Techniques

<https://kidshealth.org/en/parents/relaxation.html>

American Psychological Association: tips for building resilience

<https://www.apa.org/helpcenter/resilience>

Go Zen 50 Calm Down Ideas

<https://gozen.com/50-calm-down-ideas-to-try-with-kids-of-all-ages/>

SMARTPHONE APPS

- Calm
- Headspace
- Mindshift CBT
- Smiling Mind
- Stop, Breathe and Think
- Take a Chill



www.abct.org

www.adaa.org

www.anxietycanada.com

www.sleepfoundation.org

www.youtube.com/thepsychshow

STAY Safe

