

***DYRK1A Syndrome Conference
2022***

**Parenting and Loving Your
Challenging Child
While
Surviving and Thriving**

Nancy George-Nichols, MA
Child and Adolescent Behavioral Supports
nancy.george-nichols@cabsupports.com

**Understanding and Managing
Ongoing Persistent Trauma Grief Stress**

- An event or series of events or circumstances which are physically or emotionally harmful and has lasting adverse effects on a person’s functioning.
- Traumatic, fearful, stressful events that happen over and over.
- Grief, even anticipated grief, is a partner of trauma.

**Understanding and Managing
Ongoing Persistent Trauma Grief Stress**

- Personal trauma, grief, significant stress
- Communal trauma, grief, stress within a community of families who have a child with DYRK1A or another significant disabling condition.
- Collective trauma, grief, stress

**Understanding and Managing
Ongoing Persistent Trauma Grief Stress**

Collective Trauma, Grief, Stress

- Relentless pandemic
- Escalation of war
- Climate crisis
- Community safety
- Economic turmoil
- Division of country
- The spread word

Chronic exhaustion

**Understanding and Managing
Ongoing Persistent Trauma Grief Stress**

- Shared experiences with a community gives us a sense of belonging. It allows us to learn from each other.
- Shared experiences can also extend the grief, the fear and trauma when something happens to another family who is similar to ours.

**Understanding and Managing
Ongoing Persistent Trauma Grief Stress**

- As important as it is to share communal experiences, we can get trapped or ‘stuck’ in what has happened to others, good, bad, and terrifying.
- We often get ‘stuck’ on what has already happened in our own families, what could happen, what could have been or what you have to live with.
- This can lead to the many emotional states of stress, grief and trauma.

Surviving

- When trapped or stuck in an emotion, it is a problem that is hard to define, hard to understand, hard to manage.
- Getting unstuck, becoming flexible, helps to manage or even remove that stamp of depression and anxiety on our foreheads.
- It's not who we are. There is more to us than....

Surviving and Thriving

- To survive and thrive as a parent, to support your family, it takes training your *mind, heart and body* to work together.
- Understand where emotions come from.
- This is especially helpful for emotions related to persistent, ongoing grief, trauma, stress.

Mind Heart Body

- **Thoughts** come first. We **think** something.
- A **thought** tells us what to **feel**.
- That **feeling** tells us what to do, how to **respond**.
- We **react, respond, we behave**.

After our reaction, the next *thought, feeling and action* comes



Surviving and Thriving

- A thought reviewed, a second thought, gives us a chance to balance feelings and responses.
- Second thoughts, balanced feelings, and the resulting responses help us cope and respond to events in more productive ways.
- Feelings are valid, first and second. They need to be understood, to be heard.

Surviving and Thriving

- A cautionary tale... you are not your emotion, a feeling is not who you are, your identity
- Your emotion comes, goes, comes back, goes away again.
- Avoid identifying as a feeling: "I am scared" "I am angry" "I am frustrated".
- Instead Identify the transient nature of your feelings. I feel sad, I feel overwhelmed, I feel anxious.

Surviving and Thriving....

- Emotions are a state of being. States change, they come and go.
- Recognizing and labeling those states of stress, grief and trauma is a major step in understanding yourself, your needs and the self-care that follows.
- Naming it begins to tame it.
- Put your thoughts, feelings, hopes, fears, your needs into words.

Write it down and it holds still....

- Describing what you are feeling and why to yourself and/or others can be a major first step in your own self care.
 - ✓ I feel anxious because I am thinking.....
 - ✓ I did that because I thought of.....
 - ✓ I felt angry and then I
- Intensity, duration and frequency of thoughts, feelings and responses.

Use Your Mind to Name the State of Your Stress, Your Trauma, Your Grief

- **Anxiety, fear, bewilderment** – for my child, my life, my other children, ‘what if’
- **Anger** – at others, at myself
- **Guilt** – it’s my fault
- **Depression**, heartbreak, hopelessness, grief – a sense it will never change
- **Acceptance**, moving forward, learning from each state, each experience – the turning of a corner, a breath of air, HOPE (Hang On Pain Ends)

The Sixth Stage

- Finding meaning and value in what you experience, what you feel, and what you do
- Build your foundation to live, to give, to survive and thrive



River of Calm

- Looking at and accepting our feelings, thoughts, and actions allows us to develop and use skills to control what we can control and to accept what we can’t control.
- Skills – self care, working with and supporting your spouse and others who support you, continually developing skills to parent your child with significant needs and your other children.
- Can’t control when the next crisis or event comes, you can have a plan for what to do when that crisis or event happens.
- Develop responses based on experience (yours and others), learned skills, and flexibility of thought.

Remember....

Between a stimulus and a response there is a space. In that space is our power to choose our response. In our response lies our growth and our freedom.

Man’s Search for Meaning
Viktor Frankl

Caring for the Caretaker Mind Body Heart

- The most important relationship you will ever have is the one you have with yourself
- Finding support
 - ✓ Your friends here
 - ✓ Someone who will listen: Sharing experiences gives us a sense of belonging, allows us to learn from each other.
 - ✓ Professional providers who know your child with significant needs well and have ideas, suggestions
 - ✓ Mental health therapy and support

Caring for the Caretaker Mind Body Heart

- Focus on excellence and let go of perfection.
- Patterns can be very helpful as long as flexibility is always there when needed.
- Reduce your negative self-judgement.
- Set boundaries.
- Self-compassion is your most important gift to yourself.
- Make time for yourself and as a couple.
- Focus on the **NOW**. It's the only moment that's guaranteed.

Caring for the Caretaker Mind Body Heart

- Engage in physiological strategies to reset your nervous system and impact your bodily responses:
 - ✓ Deep, paced breathing
 - ✓ Fast and furious exercise (short/intense)
 - ✓ Stretching muscles
 - ✓ Temperature change
 - ✓ Paired breathing with increased muscle tension and relaxation
 - ✓ Butterfly hug

Caring for the Caretaker Mind Body Heart

- Gift of a crisis: With each crisis or mistake, troubling or even small event we build confidence and strength that we thought we could never have.
- Expect and accept that today is not like yesterday won't be like tomorrow.
- Let go of envy: Fair is about the weather.

Caring for the Caretaker Mind Body Heart

- **Remember:**
- It is not just your child who is unique. So are you. Who could teach or guide others more than a parent of a child with significant needs.
- Be grateful for every little stride your child makes in life.
- You are making a difference in your child's life and in the lives of all your family members.

Partners in Parenting

- Communication is key.
- Avoid assumptions about your spouse wants or needs.
- Give each other some freedom to be with other children, friends and family.
- Be vulnerable. Recognize a need for help.
- Acknowledging what your partner is doing.
- Acknowledge your own and your spouse's strengths and weaknesses in living with your situation.
- Recognize when there is a need for professional support together.

A Few Tips for Parenting Your Child with Significant Needs

- Children who need us the most ask for help in the most difficult ways.
- Patterns and schedules can be comforting and reassuring not only for your child but for your family (keep flexibility in mind when needed).
- Patience and flexibility can be our most effective skills.
- Continue to observe carefully to notice needs, changes, and growth in all areas of need.

A Few Tips for Parenting Your Child with Significant Needs

- Seek information, guidance, and coordination from skilled and experienced providers, yet remember, you may be the teacher they need.
- Measure goals by effort, determination and what is fair for your child.
- For every corrective you give your child, give hmmm...5 to 20 praises for behaviors.
- Have a safe plan in place and review it frequently with family.
- Prepare for IEP meetings.

A Few Tips for Parenting Your Other Children

- Establish availability for your children however you can.
- Shower your children with love, attention and reinforcement when possible.
- Have a safe plan for when your child acts out or displays behaviors that are concerning and could impact your child with special needs.

A Few Tips for Parenting Your Other Children

Explain why their sibling has significant needs and what that means.

- ✓ Our brains, hearts, bodies all work together.
- ✓ His/her brain doesn't have all the parts that are needed to learn and grow like you do.
- ✓ His/her heart doesn't always know how to share, be kind, or grateful the same way you do.
- ✓ Her/his body isn't build to do all the things you do.

A Few Tips for Parenting Your Other Children

- All the missing or weak pieces can lead to things such as medical or behavioral events.
- Share this is why mom, dad, and others have to spend so much time with their sibling.
- Let them know their sibling is not the only child with this special need and they are not the only children whose sibling has significant needs.

A Few Tips for Parenting Your Other Children

- Help them understand how they can use their 'superpowers' to help
- Yet, with all these missing pieces, thanks to all of us, he/she is learning.
- We can see that can't we? What have you seen him/her learn this week?
- Have you seen him/her do something differently lately?

A Few Tips for Parenting Your Other Children Who Might Need Help

- Some children are at more risk of grief, trauma or stress than others.
- Some can become hyper focused as what they saw, heard, experienced
- Watch for signs of trauma
 - ✓ Problems with sleeping, eating, anger and/or attention
 - ✓ Avoiding school
 - ✓ Withdrawal
 - ✓ And all those states we named earlier

A Few Resources for Kids

- Shadow Siblings: Discover Your Unknown Superpower by Nicole Leinback and Claire Reyhl
- I Am Just As Special: How To Be A Sibling Of A Special Needs Child by Lena
- The Invisible String by Patrice Karst

A Few Resources for Adults

- A Lifetime of Lessons from a Parent of a Special Needs Child: A Caretaker's Guide to Disability Management by Brian Wilk
- Trauma Stewardship: An Every Day Guide to Caring for Self While Caring for Others by Laura van Dernoot Lipsky and Connie Burk
- When Children Grieve: For Adults to Help Children Deal with Death, Divorce, Pet Loss, Moving and Other Losses by John W James and Russell Friedman
- The Whole Brain Child by Daniel Siegel and Tina Payne Bryson, Ph.D.
- Deep Survival: Who Lives, Who Dies and Why by Lawrence Gonzales
- The Power of Now by Eckhart Tolle

On Line Resources

Parenting Resources:

- Childmind.org
 - ✓ Healthy Minds, Thriving Kids Project at Childmind.org
 - ✓ Grief Resources at Childmind.org
 - ✓ Sibling Support at Childmind.org
 - ✓ Signs of Trauma at Childmind.org
- Barton Lab
- 7 C's of Resilience Podcast
- TheMighty.com
- Heartlight Center Inc
- Trauma Stewardship Institute.com