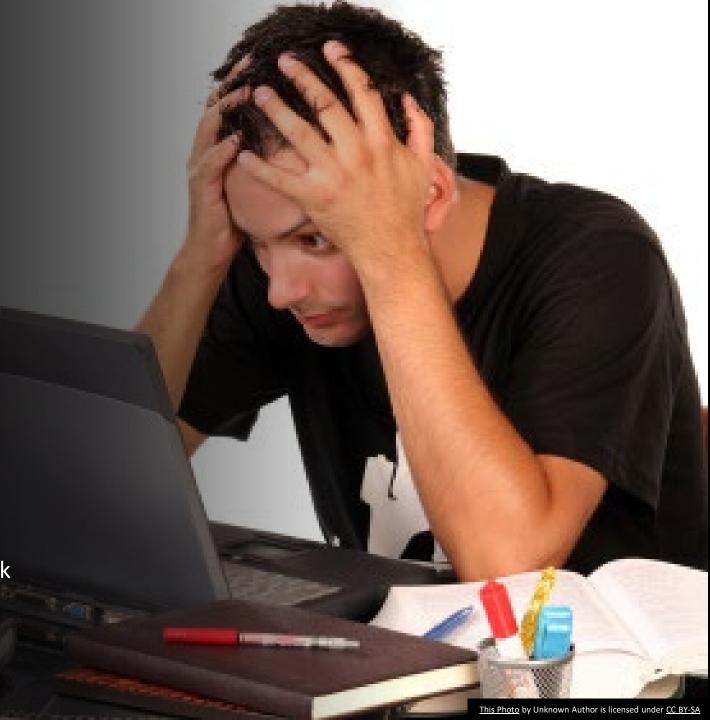
Relieve *Stress* in Times of Crisis

Martha Johanson, MS, MRC

Presented to: Special Parents Information Network

December 5, 2020



Agenda

- Impact of Stress in Parents of Children with ASD & Other Developmental Disabilities
- Stress Magnified by COVID-19
- Practical Ideas to Relieve Stress
- How to Help Our Children During the Pandemic

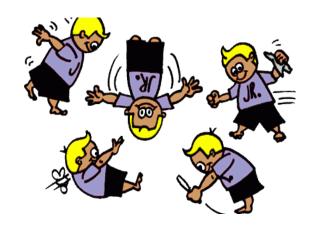
VERY HIGH STRESS!



- The stress level of parents with children with ASD is greater than that of:
 - Parents with typically developing children (Kiami and Goodgold, 2017).
 - Parents of children with other neurodevelopmental disorders such as intellectual disabilities,
 Down Syndrome or Attention Deficit Disorder (Barroso et al., 2018).

CHILD'S CHARACTERISTICS THAT MAY ACT AS STRESSORS:

- Cognitive or development level
- Symptom severity
- Frequency and severity of behavioral difficulties:
 - √ Hyperactivity
 - ✓ Demandingness
 - ✓ Disturbed mood



INDIVIDUALS WITH ASD ARE SOMETIMES DESCRIBED AS (Atwood 2008, Grandin 2011):

- Literal
- Direct, honest
- Persistent and loyal
- Uncomfortable with eye contact
- Preferring certain types of food or clothing



MOST PEOPLE WITH ASD ARE DISTRESSED BY:

- Unanticipated schedule changes
- Unexpected events



They thrive on "routines"→

When overwhelmed by anxiety they may exhibit repetitive "stimming" behavior:

- Pacing
- Flapping
- Repeating certain words or phrases



MOTHER'S WELLBEING SEEMS TO BE RELATED TO THE CHILD'S SYMPTOMS:

- More severe symptoms (Benson, 2010) make the mother more tired.
- Child's behavior contributes to maternal fatigue:
 - ✓ Unpredictable demands
 - ✓ Changes in behavior create constant concern in the mothers
 - ✓ ...producing physical and mental fatigue that increases stress and the frequent application of ineffective strategies to deal with it



SEVERITY OF AUTISM...

- ✓ Self-isolating ritualistic behaviors
- ✓ Repetitive Behaviors
- ... IS RELATED TO PARENTAL STRESS, POORER PARENT OUTCOMES, ANXIETY, DEPRESSION (Bitiska and Sharpley, 2017).



PARENTING STRESS DEPENDS ON A SET OF RISK FACTORS:

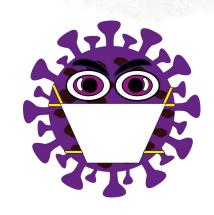
- ✓ Personal characteristics of the individual with ASD
- ✓ Social support
- ✓ Family copying strategies



Stress Magnified During COVID 19

COVID 19:

- Has altered our lives
- Disrupts routines, situations and environments
- Social distance and shelter-in-place:
 - ✓ closing workplaces, churches, schools, community centers, therapies
 - ✓ many services no longer available



Source: Institute of Mental Health, Joshua Gordon on April 14, 2020

Stress Magnified During COVID 19

CHANGES IN ROUTINE MAY LEAD TO:

- Increased anxiety
- Disruptive behavior
- Aggressive behavior
- Trouble coping with stress

post trained to the state of th

Caused by....

- Uncertainty about current situation
- Disruption of comforting routines
- Sadness at loss of social connectivity
- Grief with the passing of friends and loved ones.

Source: Institute of Mental Health, Joshua Gordon on April 14, 2020

Stress Magnified During COVID 19

FAMILIES MAY FIND IT CHALLENGING TO MANAGE ADDITIONAL STRESS BROUGHT BY:

- Changes in the family routine (due to pandemic)
- Lifestyle changes (Hackensack Meridian Health, Sarah Edenbaum, April 27, 2020):
- Social distancing
- Remote learning
- Self quarantine

Families & caregivers may need extra support – may need to REACH OUT IF SO!

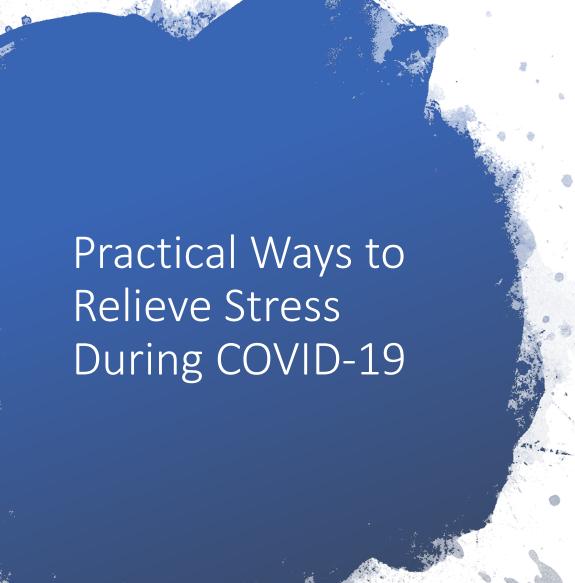
Source: National Institute of Mental Health, Joshua Gordon on April 14, 2020

Stress Magnified During COVID-19

STRESS IS EXACEREBATED DURING THE PANDEMIC FOR PARENTS OF CHILDREN WITH DEVELOPMENTAL DISABILITIES:

- On top of jobs/daily duties, parents have been asked to become 'around the clock'...
 - ✓ Babysitters
 - ✓ Teachers (e-learning)
 - √ Therapists
 - ✓ Need to be constantly supervising children

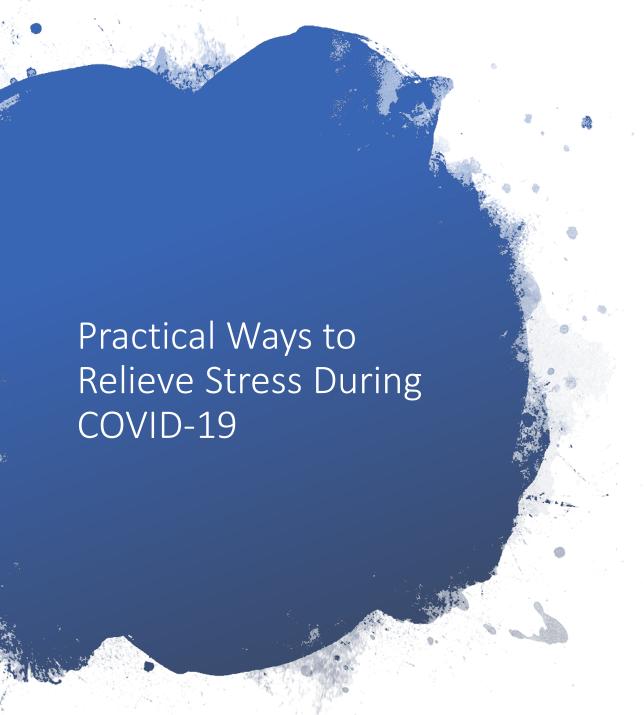
Source: Research Square, The Experience of Parents of Children with Autism Spectrum Disorder During COVID-19 Pandemic: A Qualitative Analysis, China Parenteau UCSF



- Set a routine (schedule for the day)
- Create a child-friendly visual routine
- Continue **therapy services** at home
 - ✓ Preparing meals
 - ✓ Dressing
 - ✓ Cleaning
 - ✓ Communication (give your child your undivided attention)

- Set **boundaries** (work-space and playroom)
- Don't forget about yourself
- Routine is everything-- make it your own
- Be patient
- Use visual cues to evoke happy memories
- Tap into resources (family or friends), support groups).
- Don't be judgmental of yourself

Source: Hackensack Meridian Health, Sarah Edenbaum, April 27, 2020



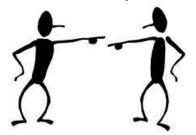
Five coping responses that can heighten a parent's mood (Pottle and Ingram 2008):

- 1. Social support
- 2. Positive reframing
- 3. Problem focused
- 4. Emotional regulation
- 5. Compromising

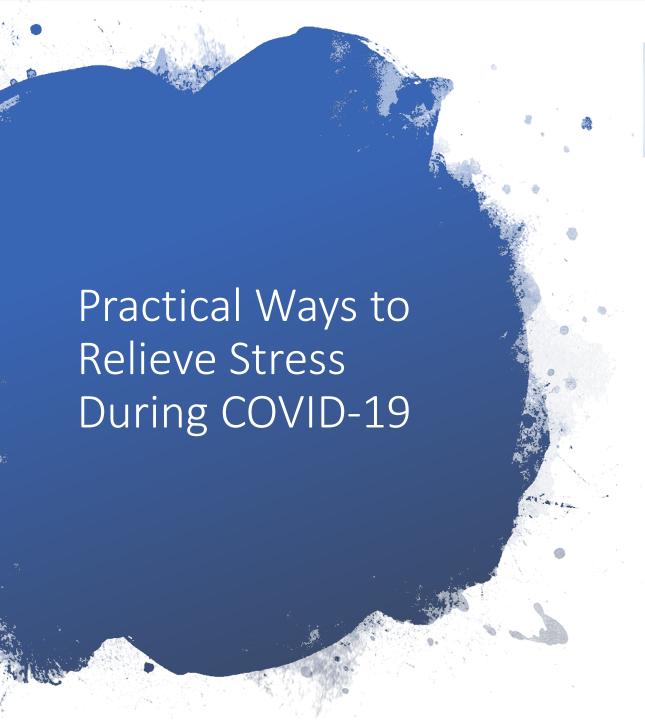


Four coping responses that decrease positive mood:

- 1. Escaping
- 2. Blaming
- 3. Withdrawal
- 4. Helplessness



Source: Research Square, The Experience of Parents of Children with Autism Spectrum Disorder During COVID-19 Pandemic: A Qualitative Analysis, China Parenteau UCSF)







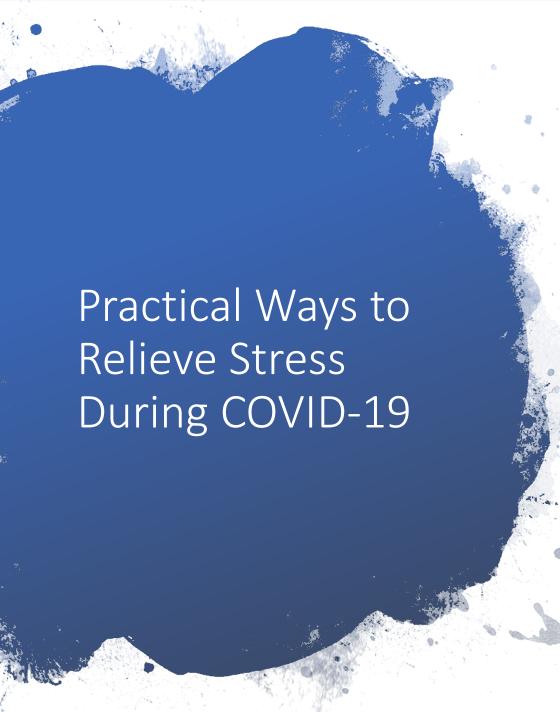
Effective Stress Relief =

- Sleep
- Healthy eating
- Exercise— nearly any kind (yoga, aerobics, etc.)— for additional stress relief and mood boosting benefits take your workout outdoors

All are essential to mental well being.



Source: Secrets of the Most Productive People, Bored or Overloaded? This is the amount of stress you need to get things done, 09/23/2020.



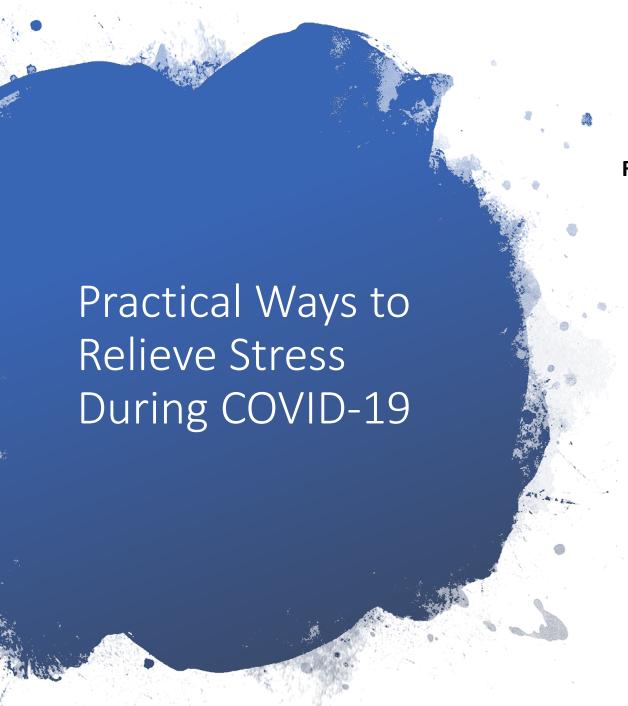


- Exercising (walking, biking, yoga)
- Meditation
- Praying
- Reading
- Create outlets (art, baking, cooking)
- Attending virtual groups
- Self care (taking a bath, doing nails, online shopping,

- Having a glass of wine
- Creating a private time (with or without the spouse) away from the children to relax
- Talking to families, friends, coworkers, counselors or therapists
- Get rest breaks
- ...beneficial for both parents and child !!!!



Souce: Research Square, The Experience of Parents of Children with Autism Spectrum Disorder During COVID-19 Pandemic: A Qualitative Analysis, China Parenteau UCSF

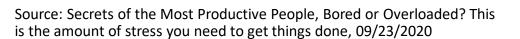






- Deep abdominal breathing
- Visualizing a favorite relaxing place
- Repeating a soothing word.
- Connecting with loved ones.
- Sorting through emotions (with journaling)
- Differentiate between what you can and cannot control (create a two- column list)





Empirical evidence indicates that Mindfulness training:

- Reduces stress
- Improves psychological well being (Cachia, Anderson, & Moore, 2016)
- Can change the brain in areas that influence:
 - ✓ Attention
 - ✓ Emotional regulation
 - ✓ Mood
 - ✓ Psychological well being
 - ✓ Behavior (Cachia, Anderson & Moore, 2016)



Souce: Autism Parenting Magazine, Using Mindfulness to Conquer Parental Stress Now

Recent studies support the effectiveness of Mindfulness in parents of children with developmental disabilities. Shown to reduce:

- Stress
- Anxiety
- Depressive symptoms
- Challenging behaviors in children

...and

Enhance mother child interaction (Dykens, et. al., 2014)



Source: Autism Parenting Magazine, Using Mindfulness to Conquer Parental Stress Now)

Mindfulness Attitudes:

- An open heart (avoid judgment)
- An open mind (as if it were the first time)
- Patience (with yourself and others)
- Loving kindness (unconditional love and kindness to yourself and others).
- Try to be rather than do (present instead of anticipating)
- Try to let things be (accept it for what it is)



Source: Autism Parenting Magazine, Using Mindfulness to Conquer Parental Stress Now

Mindfulness Practice:

- Find time for yourself (if you care for yourself you can better care for your family)
- Breath Awareness (inhaling –exhaling)
- Body Awareness (notice the sensation of your body)
- Bringing Awareness to thoughts and feelings

Source: Autism Parenting Magazine, Using Mindfulness to Conquer Parental Stress Now



Mindful daily activities:

- Draw attention to what is happening in the moment (while you are brushing your teeth, preparing food or while you are eating)
- Gratitude (focus on positive events in your life)
- Meditation:
 - Body scanning (noticing sensation in each part of your body)
 - Seated meditation (observing different aspects of yourself and the environment)



Source: Autism Parenting Magazine, Using Mindfulness to Conquer Parental Stress Now

Mindfulness Exercise



RAIN (practicing mindfulness and compassion)



Recognize what is going on (thoughts, feelings, beliefs, behaviors)



Allow the experience to be there, just as it is (don't try to fix or avoid anything)



Investigate with interest and care (How I am experiencing this in my body, non-judgmental)



Nurture with self compassion (recognize we are suffering, I am sorry, It is not your fault)



The fruit of rain is to acknowledge your own presence and rest

Mindfulness Exercise: Loving Kindness Meditation

Sylvia Boortein's version:

May I feel happy.

May I feel safe.

May I feel strong.

May I live with ease.

John Teasdale's version:

May I be safe and protected.

May I be peaceful.

May I live with ease and kindness.

Christopher Germer's:

May I be safe.

May I be peaceful.

May I be kind to myself.

May I love myself as I am.

Another version:

May I be happy.

May I accept myself as I am.

May I love myself for who I am.

Bogels' version:

May I be happy.

May I accept myself as I

am.

May I love myself for who I am.

For your child:

May [name of child] be happy.

May I accept [name of child] as he/she is.
May I love [name of

child] as he/she is.

Source: Bogels, Susan and Restifo, Kathleen. Mindful Parenting: A Guide for Mental Health Practitioners. Springer, 2014.

How to Help Our Children During Pandemic

- Parents worry about the long-term impact of the COVID-19 crisis on their children.
- Parents have "more influence on the resilience, confidence and assuredness of our children's psychological wellness during this time than any other variable."
- "If a parent's thoughts are generally negative or scarcity-based, our children will feel and develop similar negative, scarcity-based thinking pattern....if we struggle with staying positive in the face of challenges, then your children also struggle."
- "When you find healthier ways to process emotions, you also ended up modeling that for your kids."

Source: Jessica DuLong, CNN, 09/28/2020

How to Help Our Children During Pandemic

- "If caregivers are feeling stressed out about something big, like the pandemic, then odds are our children are experiencing some stress about it too."
- Be honest with them about the situation
- Acknowledge to them that you ae stressed out
- Show them what you do to help yourself feel calmer and better.
- This makes you a role model of emotional resilience for your children
- This allows you to work together with your child to come up with methods to help them feel better too."

Source: Parents may transmit suppressed stress to children, Joe Gramigna, MA, April 24, 2020.

Questions for Parental Self-reflection (1 of 2)

- 1. Who was in your family growing up and where did you grow up? What was your childhood like growing up?
- 2. How did you **get along** with your parents early in your childhood? How did the relationship evolve throughout your youth and up until the present time?
- 3. What was your **relationship like with your mother**? Are there ways in which you try to be like, or try not to be like, your mother?
- 4. What was your **relationship like with your father?** Are there ways in which you try to be like, or try not to be like, each of your father?
- 5. How did your parents **discipline** you as a child? What impact did that have on your childhood, and how do you feel it affect your role as a parent now?

Questions for Parental Self-reflection (2 of 2)

- 6. What are the ways that your **parents treated you** that you'd like to **continue and would not want to continue?**
- 7. What are things your parents did that you'd like to continue for your children and what are things your parents did that you would not like to do for your children?
- 8. How did your **parents communicate with you** when you were **happy and excited**? Did they join with you in your enthusiasm? When you **were distressed or unhappy** as a child, what would happen? Did your father and mother respond differently to you during these emotional states? How?
- 9. What **impact** do you think your childhood has had on your adult life in general, including the ways in which you think of yourself and the ways you relate to your children? **What would you like to change** about the way you understand yourself and relate to others?

Source: Modified from Siegel, Daniel and Hartzell, Mary. Parenting from the Inside Out. Penguin Random House, 2004.

If You Need to Get Help...



- Call 911
- Disaster Distress Helpline:
 - √ 1-800-985-5990 (2 para espanol)
 - ✓ Text TalkWithUs (English) OR Hablanos (espanol) to 66746
- National Suicide Prevention Lifeline:
 - ✓ 1-800-273-8255 (English); 1-888-628-9454 (espanol)
- National Domestic Violence Hotline 1-800-656-4673



What If Instead Of Being Behind These Kids Are Ahead?

What if, instead of falling behind, our kids are advanced?

What if they have more empathy, they enjoy family connection, they can be more creative and entertain themselves, they love to read and express themselves in writing?

What if they enjoy the simple things, like their own backyards and balconies, sitting near a window in the quiet?

What if they notice the birds and the dates and different flowers emerge and the calming renewal of a gentle rain shower?

What if our kids are the ones to learn to cook, organise their space, do their laundry and help keep a well run home?

What if they learn to stretch a dollar and live with less?

What if they learn to plan shopping trips and make meals at home?

What if they learn the difference between want and need?

What if they learn the value of eating together as a family and finding the good in sharing the small delights of every day?

What if they are the ones who place great value on our teachers and educational professionals, librarians, public servants and the previously invisible essential workers like truck drivers, grocers, cashiers, healthcare workers... just to name a few who are taking care of us right now while we are sheltered in place?

What if among these children a great leader emerges who had the benefit of life to truly learn what really matters in life?

What if they are ahead?

By Jaime Ragsdale

It is not what we have that matters; what matters is what we give away with love.

Debasish Mridha

Never let hard lessons harden your heart; the hard lessons of life are meant to make you better, not bitter.

Roy T. Bennett, The Light in the Heart



