

# Getting Support for Yourself IS Supporting Your Family

The Unique Needs of Parents of Children with Autism and Developmental Disabilities

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Together, all the way.®



## Before We Begin



Disclaimer

This information is for educational purposes only. It's not medical advice. Always ask your doctor for appropriate examinations, treatment, testing and care recommendations.

# MENTAL HEALTH AND PARENTS OF CHILDREN WITH AUTISM



# Mental Health Needs

## Mothers of children with Autism Spectrum Disorders (ASD) often report:<sup>1,2</sup>

- Higher Parental Stress
- Increased Psychological Distress
- Social Isolation
- Increased Instances of Depression

<sup>1</sup>Catalano, D., Holloway, L., & Mpofu, E. (2018). Mental Health Intervention for Parent Carers of Children with Autistic Spectrum Disorder: Practice Guidelines From A Clinical Interpretive Synthesis (CIS) Systematic Review. *Journal of Environmental Research and Public Health*, 15, 341. <https://doi.org/10.3390/ijerph15020341>

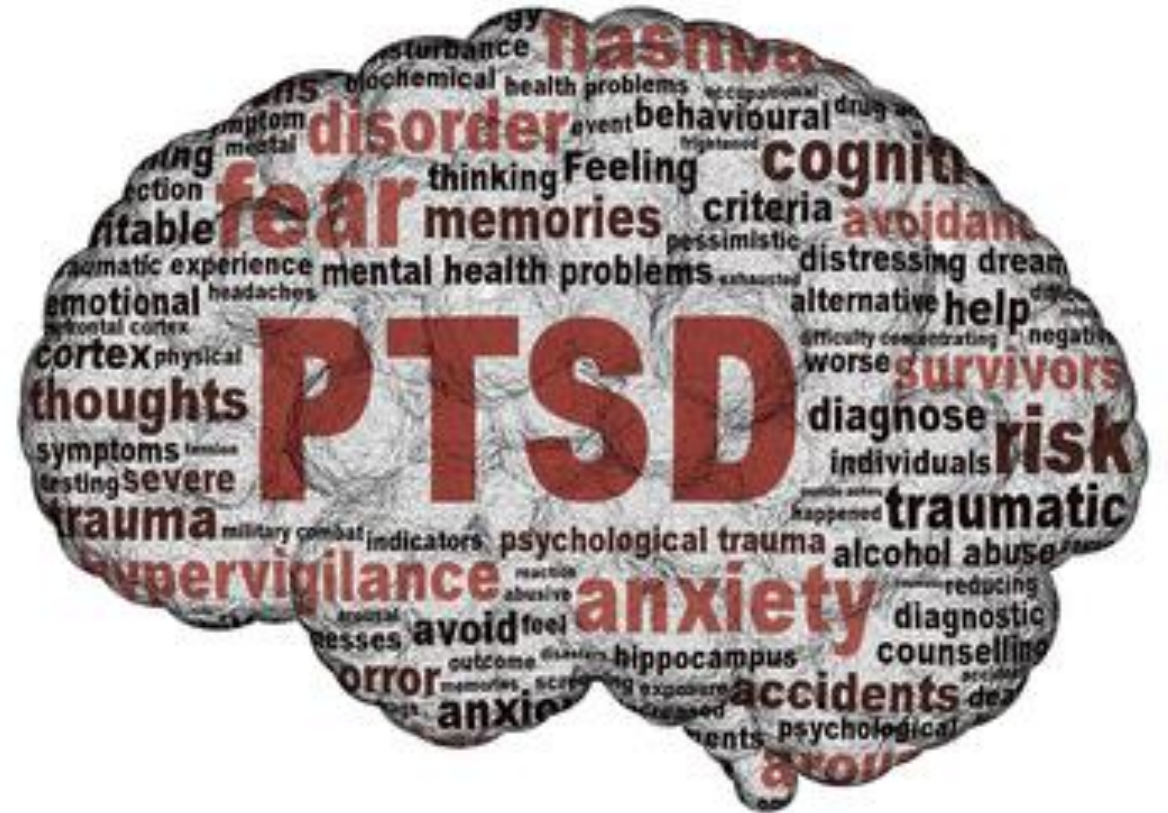
<sup>2</sup>Feinberg, E., Augustyn, M., Fitzgerald, E., Sandler, J., Ferreira-Cesar Suarez, Z., Chen, N., Cabral, H., Beardslee, W., & Silverstein, M. (2014). Improving maternal mental health after a child's diagnosis of autism spectrum disorder: Results from a randomized clinical trial. *JAMA Pediatrics*, 168, 40-46.



# Physiological Changes

**Mothers of children with ASD demonstrate a physiological profile similar to individuals experiencing chronic stress<sup>1,2</sup>**

- Combat Soldiers
- Holocaust Survivors
- Individuals with Post-Traumatic Stress Disorder (PTSD)



1. Seltzer, M. M., Greenberg, J. S., Hong, J., Smith, L. E., Almeida, D. M., Coe, C., & Stawski, R. S. (2010). Maternal Cortisol Levels And Behavior Problems In Adolescents And Adults With ASD. *Journal of Autism Developmental Disorders*, 40, 457–469.

2. Pattini, E., Carnevali, L., Troisi, A., Matrella, G., Rollow, D., Fornari, M., & Sgoifo, A. (2019). Psychological Characteristics And Physiological Reactivity To Acute Stress In Mothers Of Children With Autism Spectrum Disorder. *Stress and Health*, 35, 421-431. <https://doi.org/10.1002/smi.2870>



# Challenges Contributing to Mental Health Needs

- Most intervention programs are highly demanding of parents, requiring:
  - Large time commitment
  - 10-40 Hours per week within the home
  - Increased expectation of participation
  - Staff access throughout the home
  - Management of personnel
  - Disruption of family routine
  - Sizeable financial obligation

# Impact of Parental Stress and Child Progress

- Increased parental stress has been found to be associated with poorer outcomes in treatment programs for children with disabilities<sup>1</sup>
- Contributing factors associated with depressive symptoms may include:
  - Decreased energy
  - Poorer concentration
  - Lack of motivation
  - Decreased capacity to manage behavior challenges

1. Crowell, J. A., Keluskar, J., & Gorecki, A. (2019). Parenting behavior and the development of children with autism spectrum disorder. *Comprehensive Psychiatry*, 90, 21-29. <https://doi.org/10.1016/j.comppsy.2018.11.007>

# COVID-19 Considerations

- Overall parental stress and emotional well-being were significantly impacted by COVID-19.<sup>1</sup>
  - Lack of available support systems
  - Limitations in typical treatment delivery options
  - Disruption in routines/predictability
  - Social distancing measures
  - Lock down / Stay-at-home orders
  - Working from home
- Increased parental stressors may relate to additional challenges for children's progress<sup>2</sup>

1. Alhuzimi, T. (2021). Stress and emotional wellbeing of parents due to change in routine for children with autism spectrum disorder (ASD) at home during COVID-19 pandemic in Saudi Arabia. *Research in Developmental Disabilities*, 108. <https://doi.org/10.1016/j.ridd.2020.103822>

2. Lugo-Marin, et al., 2021. COVID-19 pandemic effects in people with Autism Spectrum Disorder and their caregivers: Evaluation of social distancing and lockdown impact on mental health and general status. <https://dx.doi.org/10.1016%2Fj.rasd.2021.101757>



# The Cycle of Distress

## Parents of children with ASD often:

- Limit their participation in pleasurable activities
- Withdraw from social opportunities
- Experience increased strain in personal relationships

**May be both the result of, and contribute to, mental health concerns<sup>1</sup>**

1. Miranda, A., Mira, A., Berenguer, C., Rosello, B., & Baixauli, I. (2019). Parenting stress in mothers of children with autism without intellectual disability. Medication of behavioral problems and coping strategies. *Frontier Psychology*, 8. <https://doi.org/10.3389/fpsyg.2019.00464>



## Warning Signs

- Lack of pleasure
- Feedback from friends and family
- Feedback from work
- More relationship problems
- Recurrent troubling feelings
- Difficulty concentrating
- Trouble sleeping
- Weight/Appetite changes
- Increased substance use



# Lack of Pleasure

- **What this looks like:**
  - No longer find pleasure in things once enjoyable
  - Limited motivation to participate in activities
- **Why you might miss this:**
  - Not able to participate in activities
- **Why it's still important:**
  - Concern for family's safety and well-being in new environments may lead to avoidance
  - Can lead to lack of motivation, depression, limited access to helpful coping strategies

# Feedback from Friends and Family

- **What this looks like:**
  - Friends and family constantly raise concerns about your well-being
- **Why you might miss this:**
  - May have distanced yourself from others
  - Worry about how others will perceive own feelings or challenges of the family
- **Why it's still important:**
  - Your experiences are your own, but you are not alone
  - Making connections can be exceptionally important in reducing stress

# Feedback from Work

- **What this looks like:**
  - Consistent negative or critical appraisal of your work performance
  - Difficulty maintaining adequate work attendance and participation
- **Why you might miss this:**
  - Competing responsibilities of being a parent of a child with special needs
- **Why it's still important:**
  - Difficulties at work can be impacted by negative mood and increased stress
  - Easy to mistakenly attribute all work challenges to parental responsibilities

# Relationship Problems

- **What this looks like:**
  - Decrease in communication between parents
  - Increase in combative interactions
- **Why you might miss this:**
  - Attribute relationship difficulties to having a child with special needs
- **Why it's still important:**
  - Conventional relationship struggles are often exacerbated
  - Dismiss relationship challenges
  - Devalue parental relationship to focus on needs of the child



# Recurrent Troubling Feelings

- **What this looks like:**
  - Feelings of anger, sadness, worry or fear
- **Why you might miss this:**
  - Very natural feelings to have
- **Why it's still important:**
  - While stress is understandable, seeking help in managing these feelings is possible

# Physical Changes & Concentration Problems

- **What this looks like:**

- Difficulty concentrating
- Trouble sleeping
- Drastic weight changes
- Unexplained health problems

- **Why you might miss this:**

- The often hectic schedule of being a parent of a child with autism can result in concentration and physical challenges

- **Why it's still important:**

- Attribute changes to managing responsibilities of being a parent without acknowledging well-being

# Substance Use

- **What this looks like:**
  - Using a substance to cope with, manage or suppress uncomfortable or painful feelings
- **Why it's still important:**
  - Regardless of the situation at home, relying on unhealthy or unsafe strategies may be a sign that you are not able to cope on your own

## Available Therapeutic Support

- Most interventions and therapeutic approaches aimed at families impacted by ASD focus on the direct needs and skills of the individual diagnosed
- Family support is often provided through behavioral parent training techniques aimed at assisting parents in facilitating their child's treatment
- Though this may help to decrease overall parental stress, it may not specifically address the mental health needs of caretakers

## Benefits of Therapy

- Adaptive coping strategies are associated with lower reported stress in parents of children with autism<sup>1,2</sup>
- Studies have repeatedly demonstrated the utility of parent-focused therapeutic support in reducing stress and depressive symptoms for parents of children with special needs<sup>3</sup>

1. Dykens, E. M., Fisher, M. H., Taylor, J. L., Lambert, W., & Miodrag, N. (2014). Reducing distress in mothers of children with autism and other disabilities: A randomized trial. *Pediatrics*, 134, 454-63

2. Feinberg, E., Augustyn, M., Fitzgerald, E., Sandler, J., Ferreira-Cesar Suarez, Z., Chen, N., Cabral, H., Beardslee, W., & Silverstein, M. (2014). Improving maternal mental health after a child's diagnosis of autism spectrum disorder: Results from a randomized clinical trial. *JAMA Pediatrics*, 168, 40-46.

3. Goedeke, S., Shepherd, D., Landon, J., & Taylor, S. (2019). How perceived support relates to child autism symptoms and care-related stress in parents caring for a child with autism. *Research in Autism Spectrum Disorders*, 60, 36-47. <https://doi.org/10.1016/j.rasd.2019.01.005>



## Based on the Research We Know:

- Parents of children with autism are:
  - At higher risk for mental health challenges
  - Psychological distress is often clinically significant
- When therapeutic support is accessed there is:
  - Overall benefit for parental well-being
  - Often positive carry-over effect for the child with autism and family
- Despite this, **parents of children with autism often do not access therapeutic support**



# TIPS FOR PARENTS OF CHILDREN WITH ASD



## Remember to Breathe

As a parent of a child with autism, it is understandable to sometimes feel heartbroken, frustrated or stressed. That does not make you a terrible person, or a bad parent.

It makes you human.

When you encounter a moment more stressful than normal, do your best to take a minute, breathe, and recognize that it will pass. Each moment can be a learning experience.

Even if you do not gain any new information, at least you learn that you survived the moment to breathe again.



## Celebrate Victories

Focus on the spectacular successes and achievements of your child and your family, no matter how tiny they may seem.

If your child waved, “hello” for the first time, gave a hug to a new friend or successfully asked for a break, each of these moments are steps toward the health and independence of your child, and should be celebrated.





## Keep a Journal

Whether it be a leather-bound portfolio, video blog or just a bunch of sticky-notes in an old shoe box, keeping a journal will help you save a record of the amazing triumphs of your child and free your mind of all the things that are running through your head at a mile-a-minute.



## Education is Power

You will never learn everything, but you can learn something.

Navigating the world of autism can be extremely daunting. There will always be more to learn, and the information will always change and progress.

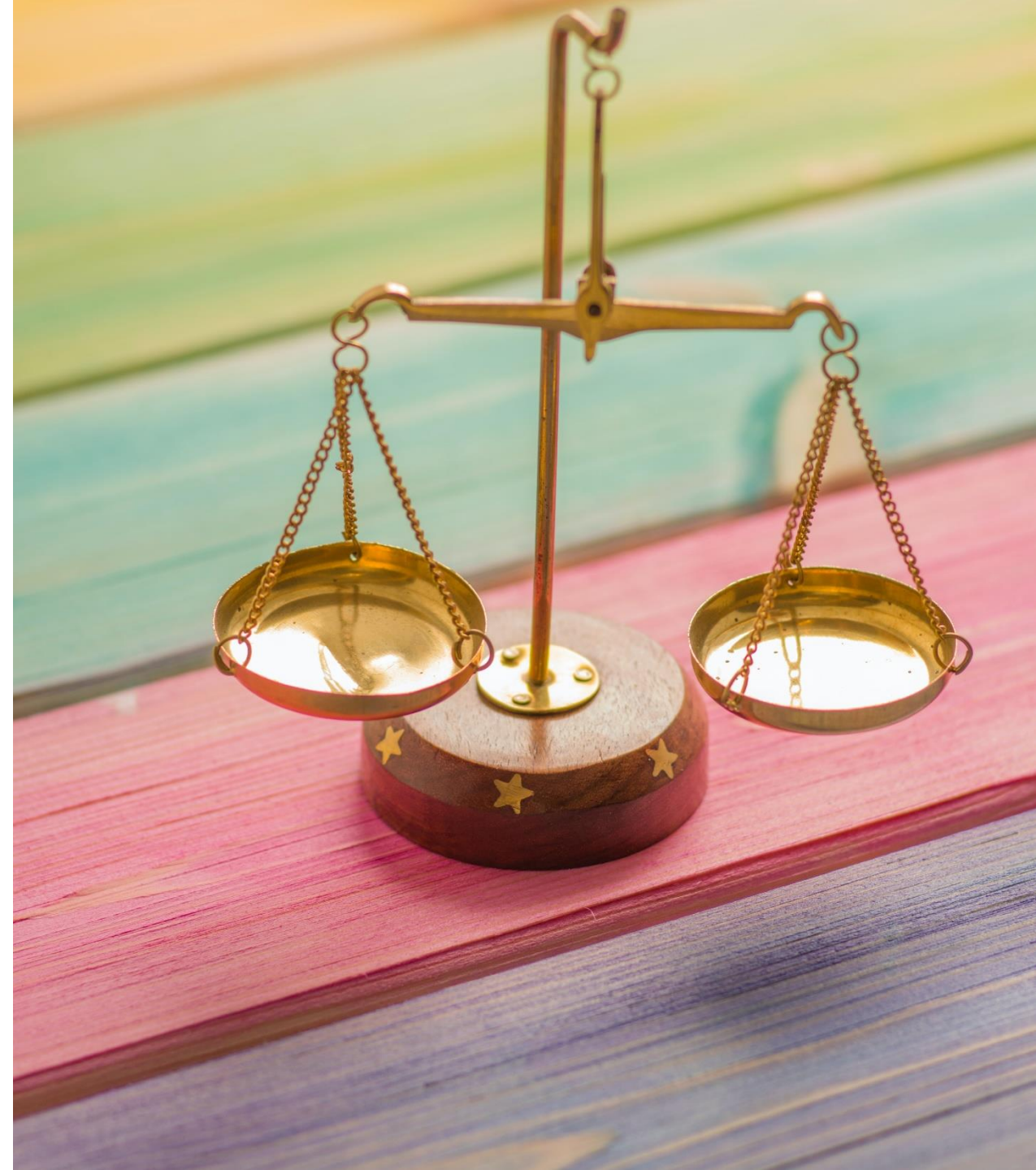
Yet, with each bit of information you gain, you will be more prepared and gain confidence and comfort.



## Everything Over Time

Taking one thing at a time may be impossible, but you still do not have to take on everything at the same time.

Differentiate what you can and cannot control and take action on what you can, when you can.





## Make the Old New

Remember the things that you once loved to do and make them new.

You may not be able to participate in all the activities that you once enjoyed, but that does not mean they are lost.

Re-invent and re-imagine.

You can share these experiences with your family. It may not be the same, but can still be great.



## Find Support

Often, parents of children with autism distance themselves from others.

They may worry about how their struggles will be interpreted or perceived, or may be concerned about the safety of their family outside of the home environment.

It is important to remember that your experiences are your own, but you are not alone.

Making a connection where you can freely share your thoughts and feelings can be exceptionally important in reducing stress.





## Don't be Afraid of Therapy

There is not necessarily a right or wrong way to get the help you need.

There are several different forms of psychotherapy, and the best process for you may be different than for someone else.

If possible, look for a therapist or support group that is knowledgeable about autism to save time having to educate them about the surrounding challenges.



# Questions?



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