

Supporting Clinicians Through the COVID-19 Pandemic

Tip Sheet: Doctors who have Children (Kids and Adults) with Special Needs



This tip sheet offers suggestions for physicians and their families of children/adults with special needs during the COVID-19 pandemic. Children with special needs are valued and loved so much; it may be stressful to meet a child's needs even at baseline, and now with the pandemic, it may prove especially challenging.

We recognize that during this time of change and uncertainty, physician parents of children and adult kids with special needs may have additional stressors and fears. The concerns are not just because of the immediate disruption of special needs services that were once provided in person, but also due to the health risks of this group of children (young and old). Children with special needs have a variety of physiological and psychological differences that may place them in a higher-risk category should they acquire COVID-19. Nevertheless, there are steps that physician parents can take to help themselves and their children through this challenging time.

First – Know that you are not alone.

- Many other families are going through the exact same thing. Find out who they are and connect with them. Many national organizations related to your child's condition have local support groups and you can get to know other local parents in similar situations. Some of these groups are now meeting virtually! If you are unable to get with a support group, here are other groups that are available, as well as a physician support hotline:

1. Facebook group:

- Physicians of Children with Special Needs (closed group, admin invite)
- Chromosome Deletions-Support for Parents and Family of Children with CD
- Middle TN Disability Resources & Support (public)



2. [TN Disability Coalition](#) for resources

3. [Confidential Physician Support Hotline](#)

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What are the anxieties and fears of a physician parent of a child or children with special needs?

These are the questions that you may be asking yourself:

- Will I bring COVID-19 to my home/children and put my special needs child at risk of getting sick or having to go to the hospital?
- Will there be enough ventilators for individuals with special needs (young or old)?
- Will I get infected and put additional burden on the household if I am quarantined or hospitalized?
- If I die, who will take care of my special needs (and neurotypical) children?
- If I don't go to work, how will we pay for the enormous out-of-pocket costs of having a child with special needs? (Medical bills, uncovered therapies, uncovered medical and therapy devices and DME, home health and respite care)
- How do I ask my colleagues to cover for me while I am caring for my child with special needs?
- What if my child will not participate in teletherapies and regresses in their skills or abilities?
- What if I am too anxious or stressed to participate with my child?



Check in Time: How are things going?

- First – take inventory:
 - How are YOU doing?
 - How are your children doing? What behaviors or verbal complaints or joys are they sharing with you?
 - What adjustments has your family, your child's therapist, and clinics adjusted? What do you still need to know?
- Some children with special needs may benefit from being home more and being socially isolated with family members. For example:
 - Does the adult with Down Syndrome enjoy having family at home?
 - Does the child with Autism thrive when her parents are home more?
- Others, however, may have too many disruptions with the schedule resulting in unrest or anxiety.
 - Does the child with ADHD have more anxiety with a lack in scheduled activities?
 - Does a child regress due to reduced therapy sessions?
- How do you feel as a parent if you hear other children are thriving and your child is not? How does that and this whole pandemic play on your own psychological well-being? Remember, as a parent, you are the most critical person in the room. Check yourself first, because then you are better suited to check on others.
 - Is your work pace increased or reduced or about the same?

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- If there is more time at home, (example: you have an administrative day, are not in the clinic, and don't have the commute time), how can you optimize your own self-care (see our Tips Sheet on Well-being and Tip Sheet on Resilience)? How can you include down times? How can you include family times that are special for every family member?
- If your workload is increased, how can you reduce it or manage it so you are fully present when not at work? Are there things you can delay or postpone?
- How do you separate the work times when working at home? Do you need a mindfulness-based stress reduction activity or a brisk walk before engaging with the family?
- If going into work, what do you need to do to assure you are safe when coming home? (See our tip Sheet on Protecting the Physicians)

Where to start?

- Take notice of the behaviors and responses your child or adult child with special needs demonstrates and the comments he/she makes.
- Find those that are supportive. Reinforce these and build in activities resulting in positive changes.
- Recognize anything that reduces your child's stability or threatens their progress.
- Once you have recognized anything that reduces their stability or results in regression or negative behaviors, work to improve, enhance, or support those first.
- Remember to remain flexible. As things evolve with the pandemic, what worked two months ago may not work today. Build in flexibility in the routines when needed and adjust as time goes by.

How to care for you and your family during this historic and disruptive time when things aren't going so well.

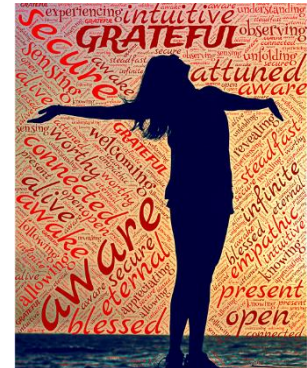
- Due to the unprecedented times, social isolation, disruption in daily routines, increased stress, and fear may cause adults and neurotypical children to have lower tolerance and more tantrums. If the child or adult with special needs has trouble keeping it together or is experiencing more tantrums, how is this affecting the parent (you), other siblings, or other household members? Regression may be occurring amongst these children and everyone in the family may be affected. Here are some tips to keep in mind:
 1. You've always been an advocate for your child and your child's health and well-being. It's time to be an advocate for your own self-care. (Remember, place the oxygen mask on yourself first, then you are better able to help others.)
 2. Identify and eliminate variables that might add stress and make every effort to assure your own selfcare first. (See our Tip Sheet on Stress.)



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3. Be sure you and your spouse or other caregivers are on the same page with parenting and behavior training. Parent/caregiver conflicts at this time can be confusing and have a negative impact on your child. Choose your battles wisely. Learn to let go of things that are less significant and won't have negative impacts on you, the child and the entire family.
4. Keeping a routine is critical. It may be a new/adapted routine, but all children (neurotypical or special needs) will benefit from what to expect next. Use story boards or time charts to help.
5. Redefine what it means to achieve progress for your child. There may have been IEP goals or medical/therapy goals that you had outlined pre-COVID. Not reaching those goals is okay. Redefine both short and long-term goals. As we get better at what we're doing with social distancing and virtual therapy, those original goals will not be lost. Your child will continue to make progress towards original goals, just in a modified version of those goals.
6. Schedule 30 minutes of gratitude in your calendar every week. Use this time to write what you're thankful for, the blessings you have experienced, and even the baby steps your child has accomplished in the last week. List names of people, list events, list progress.
 - a. Expressions of gratitude are spoken, written, or prayed.
 - b. Deeper dives into experiences that provide gratitude and can result in improved resilience. (See your Tip Sheet on gratitude.)
7. If financially feasible and practical, consider these tips:
 - a. Schedule telehealth therapy sessions (which are covered by most insurers during this pandemic)
 - b. Sign up for online communication with providers (if this is available communication may be easier)
 - c. When needed, purchase your own therapy tool sets so you can continue working with your child at home without risk of sharing equipment or supplies with other children at clinics
8. Hire assistants: virtual or in-person. One example is <https://getmagic.com/>. This program allows the doctor parent to off load some tasks that can be done virtually. There are other websites available that you can outsource work/chores.



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9. Offload shopping tasks or get groceries delivered: Consider having relatives or friends/neighbors bring groceries or pick up groceries for you. Consider using on-line shopping and delivery services for groceries and meals as these reduce the burden of family chores, parental out of house time, and potential family exposure to COVID (target SHIPT, Kroger or Wal Mart deliveries or pick up, Uber Eats, Grub Hub, Amazon, etc.)



10. Recalibrate your own personal trajectory at work. Most of the world is at a much slower pace right now. Review your work activities and determine what can slow down, what can be delayed until a later time, and what must be done now. Prioritize your work/career goals to allow focus on family.

11. Stay connected virtually to your usual support groups and schedule time with extended family, religious groups, social/civic connections, friends, etc. This is critical for all members of the family.



Unique situations:

- If your child becomes increasingly dysregulated during this time, maintain consistent contact with your provider as your child may require adjustments in his/her medication regimens or trials with new medicines. (Remember to maintain appropriate professional boundaries. You are the parent, not the child's provider. Always check with your care provider before adjusting medications.)
- If your child will not participate in teletherapies or they are not offered during this time due to social distancing, determine, with your child's therapist, what you need to do. Here are some websites to help:
 - [Interdisciplinary Council on Development and Learning:](#)
Home of [DIR®](#) and [DIRfloortime®](#):
 - This site offers free 45-minute parent orientations
 - Parent support meetings
 - Schedule learning sessions, free videos and more
 - [Help is in your Hands](#)
 - This site provides information and resources for parents with children on the Autism Spectrum
 - The site also hosts free videos for parents (requires a log in)
 - And other materials related to COVID-19 and children with Autism
 - [Autism Speaks](#) – provides information for children and adults with Autism and how to manage COVID-19

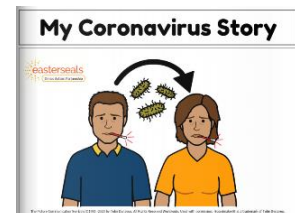


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Healthy Coping for All

- Be a self-reflector. How are you coping? Check in with your partner/spouse/significant other or a close friend or family member at least weekly and more often if you are already stressed or at burnout.
- Assess your child's level of wellness. Recognize stress reactions and act early to reduce stress situations and sources of stress for yourself and your family.
- Help your child/children understand the COVID-19 pandemic using social stories. Examples are:
https://www.flipsnack.com/KeshetChicago/coronavirus-social-story.html?fbclid=IwAR094-EV-mBLiJ_yN4OCpAnK7AHffnkm6_GaAlj2jhh02Sg4RPR_9GdsxxU
- Use healthy coping activities. Self-care is essential for everyone. (See our Tip Sheet on wellbeing.) Engage with your family on activities that promote self-care – healthy eating, sleeping, exercising, fun, etc.
- Maintain social relationships. Consider a phone call, FaceTime, ZOOM, socially distanced walks or writing letters. Have the family involved – use fingerprints and foot prints to sign for children who cannot write yet, include pictures of children reaching benchmarks, add video clips of children doing activities they are proud of, and tell stories of successes for the whole family, and share developmental timelines. Most importantly, stay connected.
- Beware of unhealthy coping mechanisms as they emerge. Increased use of alcohol, tobacco, sleeping pills, other drug/substances, etc., will not help you as much as you think they will. Avoid the slippery slope of misuse and seek assistance from your doctor, psychiatrist, therapist, coach, employee assistant program, etc. as needed. (See our Tip Sheet on recognizing substance use disorders in doctor spouses.)
- Other unhealthy behaviors due to stress and burnout may include avoiding going home, taking on more work to avoid home responsibilities, or procrastinating on home responsibilities. Be on the lookout for these more passive or the passive-aggressive behaviors of stress reactions – including yelling and avoiding personal relationships at home.



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- Remain vulnerable and resilient – that means asking for help. Practice asking for help and ask for help when needed. Many of your friends would be willing to help if they know you need it and HOW they can help. They cannot read your mind! Let them know. They will say no if they cannot, or may ask for another time if busy, or may just simply say yes!
- If you do think you can ask, give them this Tip Sheet and ask if they will read this to get a better understanding of what you are going through. Or ask them to volunteer for an activity listed below.



What Friends and Colleagues can do to Help the Doctor Parent of a Special Needs Child?

- Do you know a physician parent of a child who has special needs? You can help.
- Sometimes it just the simple things that can help your colleagues who is a parent of a child with special needs.
- Consider calling them (Zoom, Skype, or regular phone) and just ask how they are doing. Then listen patiently.
- Simple acts of kindness increase resilience and support gratitude. Consider a simple act of kindness that adheres to the appropriate social/physical distancing guidelines:
 - Offer to baby sit (But you cannot expose a child to risk – so you must have been appropriately isolated and COVID negative and without symptoms)
 - Send meal
 - Do chores for the family (use facemask, gloves, and leave your shoes outside) while the family is on a family drive
 - Drop off supplies
 - Drive by parades are fun for the children
 - Set up a socially distanced outdoor play activity in the yard
- Ask the doctor parent how you can help. Allow them to outline an activity that helps them, their child/children, or their family.
- Consider setting up a sunshine club. This is a rotation for volunteers who want to help. Groups of colleagues or staff within your department or office practices can sign up to provide simple acts of kindness.

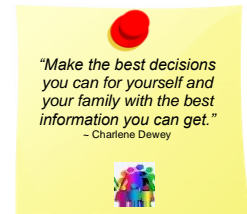
Thinking ahead – What will we do when school starts?

- This is a challenge for every parent!!

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- What happens if schools open? There are more fears and concerns such as these:
 - My child is too young or cannot assume the level of responsibility to keep socially distant or wear a mask.
 - What if my child gets COVID-19 and brings it home to us parents?
 - What if they open some schools but programs for children with special needs aren't open? How do we schedule for that?
 - What if my caregiver or family member who helps me with my kids gets COVID-19?
 - What if my child does not learn best using asynchronous or distanced learning? How do I advocate for him/her? How do I support him/her in advocating for themselves?
 - What if I home school? What do I need to get that approved and set up? Who will do it? Me? My spouse? A Family member or caregiver? How do they get trained? If we homeschool, what programs and website do we choose? What's best?
 - What if I am so scared, I cannot work?
- Where to start:
 - No one can predict what will happen. Do your best to feel empowered to ask the questions that inform your decisions.
 - Then remember to manage your own expectations. Get help if you need it.
 - Contact your child's current school and ask for information. Many are still in the decision-making process. Sign-up for email notifications.
 - Ask schoolteachers about teaching methods that work best for your child/children and have them provide some options.
 - Contact your local school board, school, and board of education via web or phone for information such as how they will support social distancing and safety, how the buildings are cleaned, setting up homeschools, on-line platforms, etc.
 - Many colleges are doing compact semesters without breaks. If your child is starting college, keep abreast of the methods they are using. If your child is able, also empower your child to seek out that information so you don't have too.
 - Contact your therapist's office and your provider's office for suggestions based on what they know about your child and they learn, and what needs they have and how to meet them.
 - Remember, caregivers burnout too. Look for information on relieving caregivers/spouses so they do not burnout. [Caregiver Support](#)
 - Lastly, you are only human. Make the best decisions you can for yourself and your family with the best information you can get. Hold no guilt for making an informed decision, but allow for flexibility. Remember as times change, decisions can change.



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Resources for Parents or Caregivers of Children and Adults with Special Needs:

- Interdisciplinary Council on Development and Learning:  Home of DIRFloortime® (Floortime)
<https://www.icdl.com/?gclid=EAlaIQobChMI9KqsjtKB6gIV3YVaBR3hIQbHEAAYASAAEgKr- D BwE>
- Help is in Your Hands:
 - (home page) <https://health.ucdavis.edu/health-news/mindinstitute/help-is-in-your-hands--a-great-resource-for-families-with-young-kids-on-the-autism-spectrum/2020/03> 
 - (Log in page) <https://helpisinyourhands.org/course?fbclid=IwAR26IGCF-ZkjmieRxhsGrLpaLceEcYI-YpE5IKNwTPdC-7r5OwkTL6gMGcA> 
- National Down Syndrome Society: <https://www.ndss.org/> 
- Autism Speaks: <https://www.autismspeaks.org/> 
 - Information related to COVID-19: <https://www.autismspeaks.org/covid-19-information-and-resources>
- National Institute of Mental Health:
 - Down Syndrome - <https://www.nichd.nih.gov/health/topics/downsyndrome> 
 - Autism Spectrum - <https://www.nimh.nih.gov/health/topics/autism-spectrum-disorders-asd/index.shtml> 
- Caregiver Support at USA.gov: <https://www.usa.gov/disability-caregiver> 

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General Physician Resources: MH specialists, coaches, psychiatry, primary doctor, etc. Each picture is hyperlinked to the actual webpage. Simply click on the picture or copy and paste the link into your browser.

- American Psychological Association: click on *psychological help center*, then *find a psychologist*. <https://www.apa.org/>

Resources

- [Find a Psychologist](#)
- [Order Free Brochures](#)
- [Request a Speaker](#)

- International Coaching Federation: <https://coachfederation.org/> - click on *find a coach*.

Find a Coach

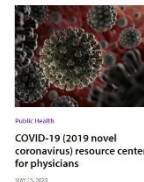
- American Psychiatric Association: <https://www.psychiatry.org/> - click on *Patient/Families* then click *find a psychiatrist*.

PATIENTS & FAMILIES

- The American College of Physicians – COVID-19 Resources for physicians. <https://www.acponline.org/>



- The American Medical Association – resources for Physicians. <https://www.ama-assn.org/>



- The National Academy of Medicine – Well-being resources. <https://nam.edu/initiatives/clinician-resilience-and-well-being/clinician-well-being-resources-during-covid-19/>



- Tennessee Medical Association - resources for COVID-19. <https://www.tnmed.org/>

