

Supporting Families Touched by Neurodevelopmental Disabilities During Self-Quarantine

Jennifer Carlson, PhD

Ann & Robert H. Lurie Children's Hospital of Chicago

Division of Developmental and Behavioral Pediatrics

16 March, 2020



We're all in this together.



What can we share with caregivers?

- Changes in routine are imminent with quarantine and school closure
- Challenging or unsafe behaviors may be more likely to occur
- Consider the following strategies to alleviate additional stressors and behavioral challenges

Local Resources- Meals

Chicago Public Schools

- Your local school is offering meal pickups
 - 9:00AM-1:00PM, Mondays through Fridays
 - You do not need to be registered with the school in order to obtain meals
 - “Each child in the household will receive a food bag which will contain three days of breakfast and lunch meals. Families will also be able to pickup enrichment packets at CPS facilities.”
 - <https://www.nbcchicago.com/news/local/all-chicago-public-schools-to-offer-free-meal-pickup-during-coronavirus-closure/2237714/>
 - Your school is likely planning for your child’s ongoing learning needs and will be trying to communicate with you.
- CPS Command Center at 773-553-KIDS (5437) or email familyservices@cps.edu

The Greater Chicago Food Depository and Chicago’s network of food providers: locations is available at www.chicagosfoodbank.org/find-food/

Catholic Charities at 721 N. LaSalle St will be giving out packaged meals on **Wednesdays** to be taken home to eat only during this time.

Local Resources- Medications

ALL Walgreen's are providing FREE home delivery on medications. Patients must follow the below steps in order to be eligible PRIOR to the next medication refill.

1. Download the Walgreen's app on a smart phone
2. Verify identity on the app & register for text alerts
3. When rx is ready they will receive a text with a link
4. Click on the link in the text message to arrange shipment
5. Pay any co-pay online prior to shipping
6. Shipping is typically \$4.99 but is currently FREE during COVID-19 restrictions
7. Shipping takes 1-2 days Monday-Friday

Honesty and Openness is best

- Don't be afraid to talk to your children about Coronavirus
 - Chances are they have seen the news, heard rumors, or are noticing adults seem stressed
 1. Model calm behaviors
 - Limit viewing/listening to news outlets that may be upsetting for your child(ren)
 2. Listen to your child's questions
 3. Do your best to answer their questions
 4. Talk about how to keep safe
 - washing hands to a favorite song,
 - playing and learning at home this week,
 - coughing/sneezing into tissue, throwing away tissues and trash
 5. It's ok if you don't have all the answers. Be honest. Tell your child adults are working hard to keep them safe
 6. Children may be concerned about their other family members. Encourage them to call/video their loved ones to check in and ask how they are keeping safe.
 - <https://childmind.org/article/talking-to-kids-about-the-coronavirus/>

Talking to Your Child

- Find resources to help your child obtain age appropriate information
 - Your child will feel more reassured if they feel informed
 - Without help, they will likely find mis-information online/on the news themselves
- Resources for talking about COVID-19
 - [NPR's Comic Strip for Kids / Spanish Version](#)
 - [Autism Educator Social Story](#)
 - [English Social Story / Spanish Social Story](#)
 - [Social Story](#)
 - [PBS Parent's How-To](#) – Lots of links for videos to teach healthy habits
 - [Daniel Tiger App Practicing Doctor Visits](#)
 - [Daniel Tiger Gets a Cold Full Episode](#)
 - [School Closure Activities, Including Germ and Hand Sanitizer Learning Curricula](#)

Take home points for children

Courtesy of National Association of School Psychologists (NASP)

- Adults at home and school are taking care of your health and safety. If you have concerns, please talk to an adult you trust.
- Not everyone will get the coronavirus (COVID-19) disease. School and health officials are being especially careful to make sure as few people as possible get sick.
- It is important that all students treat each other with respect and not jump to conclusions about who may or may not have COVID-19.
- There are things you can do to stay health and avoid spreading the disease:
 - Avoid close contact with people who are sick.
 - Stay home when you are sick.
 - Cover your cough or sneeze into your elbow or a tissue, then throw the tissue in the trash.
 - Avoid touching your eyes, nose, and mouth.
 - Wash hands often with soap and water (20 seconds).
 - If you don't have soap, use hand sanitizer (60–95% alcohol based).
 - Clean and disinfect frequently touched objects and surfaces using a regular household cleaning spray or wipe.

[https://www.nasponline.org/resources-and-publications/resources-and-podcasts/school-climate-safety-and-crisis/health-crisis-resources/talking-to-children-about-covid-19-\(coronavirus\)-a-parent-resource](https://www.nasponline.org/resources-and-publications/resources-and-podcasts/school-climate-safety-and-crisis/health-crisis-resources/talking-to-children-about-covid-19-(coronavirus)-a-parent-resource)

Self-Care for Caregivers

Encourage caregivers to obtain credible updated information

- [Centers for Disease Control and Prevention](#)
- [World Health Organization](#)

[Coping with Stress during Infectious Disease Outbreaks](#)

[CDC Handwashing Factsheet for Adults](#)

[Interactive Anxiety Resource](#) - discusses practical information on meditations, managing anxiety, xenophobia, isolation, financial fears

Helpful Resources

Substance Abuse and Mental Health Services Administration
(SAMHSA)

5600 Fishers Lane

Rockville, MD 20857

Toll-Free: 1-877-SAMHSA-7 (1-877-726-4727)

Email: info@samhsa.hhs.gov

SAMHSA Store: <https://store.samhsa.gov>

SAMHSA Hotlines

SAMHSA's Disaster Distress Helpline

Toll-Free: 1-800-985-5990 (English and español)

SMS: Text TalkWithUs to 66746

SMS (español): "Hablanos" al 66746

TTY: 1-800-846-8517

Website in English: [https://](https://www.disasterdistress.samhsa.gov)

www.disasterdistress.samhsa.gov

Website in Spanish: [https://www.samhsa.gov/find-help/
disaster-distress-helpline/espanol](https://www.samhsa.gov/find-help/disaster-distress-helpline/espanol)

SAMHSA's National Helpline

Toll-Free: 1-800-662-HELP (24/7/365 Treatment Referral
Information Service in English and español)

Website: [https://www.samhsa.gov/find-help/national-
helpline](https://www.samhsa.gov/find-help/national-helpline)

National Suicide Prevention Lifeline

Toll-Free: 1-800-273-TALK (1-800-273-8255)

Toll-Free (español): 1-888-628-9454

TTY: 1-800-799-4TTY (1-800-799-4889)

Website in English: [https://](https://www.suicidepreventionlifeline.org)

www.suicidepreventionlifeline.org

Website in Spanish: [https://](https://www.suicidepreventionlifeline.org/help-yourself/en-espanol)

[suicidepreventionlifeline.org/help-yourself/en-espanol](https://www.suicidepreventionlifeline.org/help-yourself/en-espanol)

Treatment Locator

Behavioral Health Treatment Services Locator

Website: <https://findtreatment.samhsa.gov/locator/home>

SAMHSA Disaster Technical Assistance Center

Toll-Free: 1-800-308-3515

Email: DTAC@samhsa.hhs.gov

Website: <https://www.samhsa.gov/dtac>

**Note: Inclusion of a resource in this fact sheet does not imply endorsement by the Center for Mental Health Services, the Substance Abuse and Mental Health Services Administration, or the U.S. Department of Health and Human Services.*

Self-Care for Caregivers

Perinatal depression hotline:

24-Hour Crisis Hotline

Call 866.364.MOMS (6667)

Self-Care for Caregivers

Consider Asking Yourself:

- What reality-based problems do I need to solve today?
 - What can wait?
- What information do I need today?
- When is the best time of day for me to read the news to update myself?
- What's the difference between thoughtfully and anxiously focusing on this problem?
- How can I hold onto my best thinking when others are panicking?
- How can I be a resource to others without becoming over-responsible for them?
- What does it look like to be responsible for my health during this time?

Prevention Strategies

Schedule a time to have a regular family meeting

- Once per day is a good idea
- This meeting can be as short as 15 minutes
- Purpose:
 - Establish caregivers as reliable safe source of information
 - Reduce overthinking about fears

What to do:

- Use this time to update your child(ren) on work that adults are doing to help
- Remind what they can do to help at home
- Answer their new or same questions
- Discuss what the family's routine will look like tomorrow-
 - changes or additions
- Play a game or do an activity together! (e.g. board game, coloring, etc.)
- Pick the activity together for the next family meeting.

Prevention Strategies

Establish a household routine

- Don't worry about filling up the day!
 - Avoid stressing about the pinterest worthy, full activity schedules circulating around online
 - Do what works best for your family
- Try to keep the routine consistent each day to promote coping with this new normal
- Consider posting the schedule visually.
 - [Illinois Easter Seals Visual Templates](#)
 - Includes pictures of common:
 - leisure activities, chores, academic time
 - choice boards, first/then, token system, activity schedules
 - [Additional Online Academic and Leisure Activities](#)

Prevention Strategies

- Create separate work or play spaces for each child in the home
- Identify a highly preferred item of your child and consider reserving that item for times when you need your child to be calm and occupied
 - (for example, when you need to cook, talk on the phone, complete a household task, complete a work-related task)
- Catch your child in the act of doing something good and praise often!
 - While praising takes your effort and energy, you may otherwise find you're stuck reacting and putting out fires just as often.

Managing challenging behaviors

Reduce Demands

- These are extraordinary times! Everyone is affected, including our child with a developmental disability
- Don't feel guilty about allowing relaxing time with favorite items/activities during this time
- When ready to introduce academic times into the daily routine, consider starting with small amounts of work followed by break times to promote success

Managing Challenging Behaviors

Give in quickly on challenging days

- Pay close attention to warning signs that your child's unsafe behavior is more likely to occur

- What do you wish your child was doing instead?
 - Ask yourself, is my child trying a nice way of asking before escalating their behavior?
 - Encourage and provide reminders of an appropriate behavior to get what they want!

- Give in to the warning sign.
 - This way your child does not have opportunity to learn to escalate their unsafe behavior

Additional Resources

- 30 day free access to make your own online visuals database
 - <https://smartysymbols.com/>
 - Promo Code: HOMEVISUALS
- [CoughDrop Communication Board \(free\)- with COVID-19 friendly vocabulary](#)
- [Newsy video on Social Distancing for older youth](#)