



Resources for the Rare Disease Community

Most rare diseases already come with risks greater than everyday life and COVID-19. The Rare Disease Community has experience with unexpected change, living with uncertainty, and isolation, and is a resilient group.

How to manage a complex medical condition when panic is in the air?

- Don't Panic. Stop, Think, and Plan.
- Listen and Obey Public Announcement about Social Separation, stay away from others, and self-quarantine.
- Make sure you have refills and a good stock of all medicines, formulas, etc.
- Check to see if your regular hospital has diverted non-COVID-19 patients elsewhere.
 - Find out who at this facility you might need and how to connect them to your regular care team.
- Make sure any treatment letters are up to date.
- Do not let fear drive you to the Emergency Room.
 - Be objective about symptoms and what they are
 - ERs will be crowded; if admission is necessary, then discuss direct admit with your team
- Do not let fear drive you from the Emergency Room.
 - If needed, get seen and treated
 - Rare disease may be the greater risk than the virus
- If you absolutely need to go to the hospital, plan ahead.
 - Visitation will be limited.
 - If the hospital is a frequent stop for you, have a kit ready to go.
 - Make sure you have phones/tablets/portables AND chargers
- Take a supply of medication with you.
 - If you are visiting a new facility, they may not have your medications, formulas, etc.
 - The distribution center may be slower to respond.
- Hospitals/Clinic may seem busier than usual, and may appear chaotic. Many people will be wearing mask. Do not be afraid. Ask if you think you need one too.

Adapted from the Webinar: A Rare Response: Addressing the COVID-19 Pandemic (3/31/20)

Sponsored by National Organization for Rare Diseases (NORD)

Speakers: Dr. Marshall Summar, Chief, Division of Genetics and Metabolism, and Director of the Rare Disease Institute at Children's National Hospital, Dr. Bernhard Wiederman, Infectious Disease Specialist at Children's National Hospital, and Dr.

Albert Freedman, Counseling Psychologist and rare parent.

How the Medical Model has changed during the Pandemic

- Telemedicine
- Cross-state licensure are easing during this crisis

What's Safe for Medical Care?

- Have a plan for office visits, emergency visits, and hospitalization.
- If you have not already, check with your child's provider by checking their website, emailing them or giving them a call.

Safe Shopping

- Delivery services, online shopping
- Shop during "off hours" if necessary
- Touch only what you intend to buy
 - Some businesses are offering special accommodations for high risk group
- Avoid touching your face

Getting Out of the House

- Walking around the neighborhood is fine
 - General rule to keep at least 6 feet distance from others
- Avoid public parks and playgrounds are they become crowded
- Do not go out if you are sick

How to Manage Stress

Focus on what is in our control

- Take care of ourselves
 - Get enough sleep
 - Eat a healthy diet
 - Sunlight and Fresh Air
 - Exercise as much as you can
- Stay connected with others
 - Use technology to connect with family and friends; get in contact with old friends
- Choose to use your time
 - Make lists of what you would like to do throughout the day
 - Limit Exposure to the News
- Plan and Prepare

Mental Health Resources:

[CDC: Managing Stress and Coping Resources](#)

[The Mighty: Online Community for Health Challenges](#)

[Massachusetts General Hospital Guide to Mental Health Resources](#)

Apps: Calm, Headspace, Sanvello