WHY IS THIS SITUATION SO STRESSFUL?
When there are abrupt changes or our sense of safety is threatened it can trigger uncomfortable feelings. It is normal to experience a range of strong emotions during a crisis. Know that the rare disease community is uniquely prepared in this scenario because we have experience with unexpected change, living with uncertainty and dealing with isolation. The anxiety we feel is real. Many things do not feel in our control now, but we can choose to focus on what is in our control.

WHAT IS IN OUR CONTROL?

How we take care of ourselves
> Maintain a routine to structure your day.
> Get enough sleep and aim for consistent times for going to bed and waking up in the morning.
> Try to maintain healthy eating patterns and good nutrition.
> Social distancing does not need to mean isolation.
    • Practice physical distancing with social connectedness!

Staying connected with others
> Use technology such as videoconferencing, phone, email, and texts.

Choosing to spend your time wisely
> Use fear distancing strategies.
    • Limit your media consumption to the information you need to know to keep yourself and others as safe as possible.
    • Focus on things other than the virus. Read, watch movies and tv, play board games with family, video games, anything for you that’s entertaining and fun.
    • Do things you don’t usually have time to do.
How we set up our homes and living space
> Allow sunlight and fresh air into your living space, and spend time outside if you can do so safely.

Planning and preparation
> Make a health plan you feel good about.
  • Know how to contact your primary care doctor.
  • Follow the protocols you normally follow given your medical situation.
  • Have an up-to-date list of medications or equipment you require.
  • Avoid any activities that add an element of risk to reduce likelihood of needing medical care.
> If you require caregivers, consider putting protocol in place to reduce risks to you and your caregivers.

Fear is contagious, but so is a positive attitude, resilience, hope, and gratitude.
> We are experts at facing challenges and adversity.

WE ARE ADAPTIVE. WE ARE RESOURCEFUL. WE ARE RESILIENT. WE ARE HOPEFUL.

ADDITIONAL RESOURCES
CDC: Managing Stress and Coping Resources

The Mighty: Online Community for Health Challenges
themighty.com

Massachusetts General Hospital Guide to Mental Health Resources
massgeneral.org/psychiatry/guide-to-mental-health-resources/

Apps: Calm, Headspace, Sanvello

View the full webinar: youtube.com/watch?v=bmBShTojAYA&t=28s

COVID-19 EDUCATION SUPPORT
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