

Reflections on Everyday Coping During a Pandemic When a Family Member has IDD:

LESSONS LEARNED FROM COVID-19

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Objectives for Today's Session

- ▶ Consider the psychological and social “footprints” of the current pandemic
- ▶ Identify ways to address the unique challenges for families with a relative with IDD
- ▶ Identify strategies to help all family members cope with their anxieties and the everyday stressors and hassles which accompany this pandemic

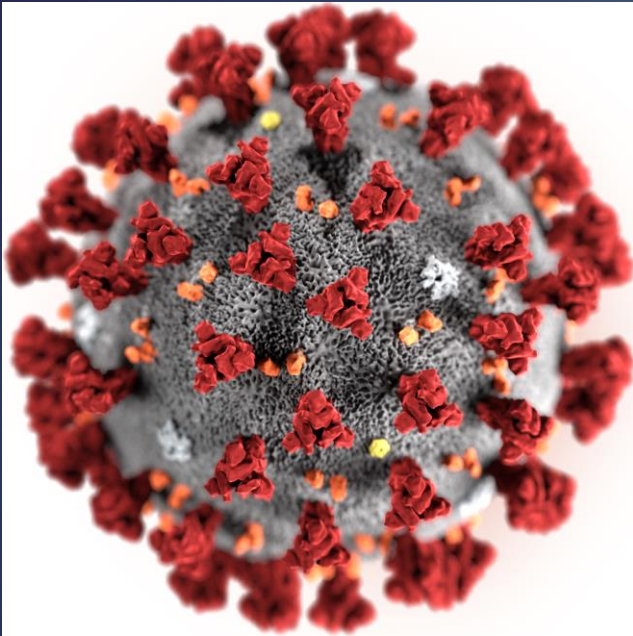


Help all members of the family feel safe

We are battling two enemies at once:

- ❖ Covid-19
- ❖ the anxiety about Covid-19
- ▶ Individuals with IDD may be more vulnerable to catching this new virus because of underlying medical conditions, and more susceptible to the anxiety surrounding the pandemic
- ▶ Watch your words , tone and what you communicate with **your** response to the pandemic
- ▶ Stay calm (address your own anxiety!)
- ▶ The situation is evolving: we have moved from a crisis mode to a marathon in terms of our response to COVID as a pandemic
- ▶ Reassure your family members that there are things that everyone can do to help reduce risks to safety and health

Try to Answer Your Family Members' Questions about COVID



Most people benefit from simple, straightforward answers to their questions:

You might say: “The coronavirus is a type of germ. These germs are small and when they get inside your body, they can make you sick. The germs get in your body through your nose, mouth or eyes. When someone coughs or sneezes and you are near them or they cough or sneeze and touch something that you then touch, like a doorknob and then you touch your face, those germs might get into your body. It’s helpful to wear a face covering, wash our hands and try to stay away from big crowds.”

A rule of thumb is to offer some information but not too much information, which can add to your family member’s worries

Support Understanding of COVID

- ▶ Right now, there is a virus that is making people sick. Because it spreads so quickly, many schools and workplaces are closed. It is important to keep myself and others healthy right now, so I need to change some of my routines. Staying home and staying away from other people will help keep me and others healthy. I also need to wear a face covering when I am in public and wash my hands often and keep my hands to myself.
- ▶ Doctors and leaders are doing their best to take care of sick people. If I am worried about the virus, I can talk to my family. I will do my best to stay healthy.

**STAY
HOME
SAVE
LIVES**

Do these Five Things to Stop the Spread of Coronavirus:



- ▶ **FACE** Cover with mask, bandana or face shield
- ▶ **FEET** Stay at least 6 feet apart from others (2 arms' lengths)
- ▶ **HANDS** Wash them often
- ▶ **FEEL** sick? Stay home
- ▶ **Flu shot**-discuss preparing for upcoming flu season with your health care provider

Unique challenges for individuals with disabilities

- ▶ Most of us have similar needs during the pandemic whether or not we have disabilities
- ▶ there may be unique challenges for persons with disabilities because of their neurodevelopmental status:
 - ❖ cognitive inflexibility or limited understanding with which to adapt to changing conditions
 - ❖ social communication problems
 - ❖ any tendency towards behavioral or emotional dysregulation
 - ❖ higher incidence of mental health challenges

Challenges for Family Members with IDD during COVID

- ▶ **Being out of routine** including being out of work, spending 24/7 at home with the same people and not participating in usual day program, work and/or leisure activities
- ▶ Having limited understanding of the current public health crisis
- ▶ Limited access to relatives, coworkers or friends resulting in increased risk of social isolation
- ▶ Being stuck at home with roommates, family members or staff who are not preferred individuals or with whom they may have strained relationships
- ▶ Limited access to usual sources of gratification, recreation and support



Keep the person's strengths, challenges and temperament in mind...



Individuals with who seek sensory, especially tactile input , won't suddenly start keeping "hands to self" just because the stakes are higher

The individual with poor memory or sequencing skills won't suddenly memorize the steps to correct hand-washing just because you've told her how to do it

Some individuals will require more reassurance or more time to transition than others. The situation is unique, and so is your relative; what works for one family member, may not work for another person in the same household

Strategies to Support Individuals through Uncertain Times

- ▶ Support understanding of COVID
- ▶ Offer opportunities for expression
- ▶ Prioritize coping and calming skills
- ▶ Maintain routines; build new positive routines, as necessary
- ▶ Foster safe social connections
- ▶ Be alert to changing mood, thinking and behaviors that may signal the need for professional assistance

Let your family member know what to expect

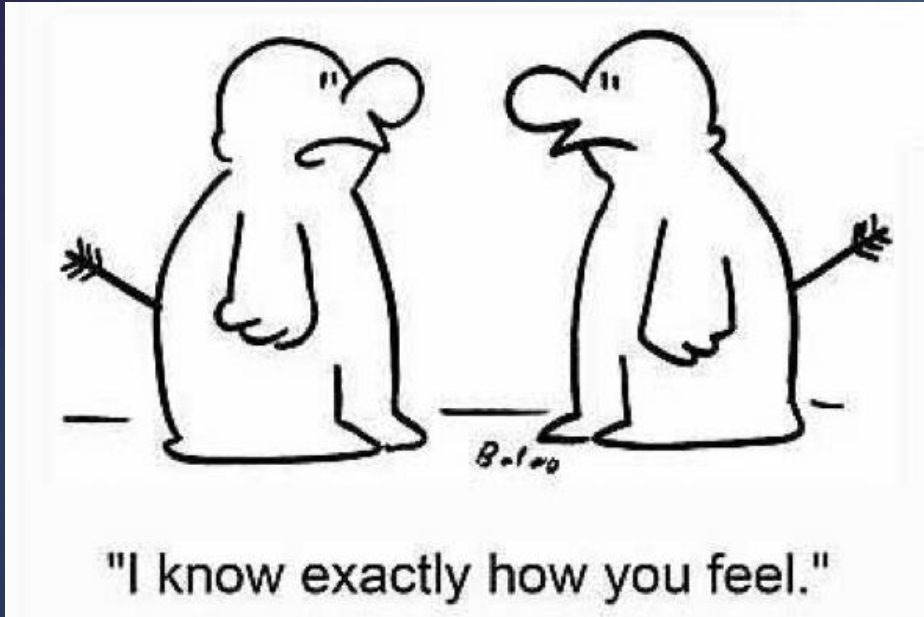
- ▶ The rough part for all of us is that we don't know exactly what to expect in the weeks and months ahead
- ▶ **However, we do know some things:**
- We know we're going to be seeing a lot less of the people in our lives who are not living with us (e.g. friends, neighbors, relatives not in our households, staff)
- We need to find creative ways to pass the time at home
- We know that we aren't going to have access to all the foods we like
- Covid-19 can resemble a typical cold. While there is a potential to get very sick and even die, people have also reported milder symptoms — fever, runny nose and cough.
- Covid can be spread by people who do not know they are carriers- they are “asymptomatic”

Greetings- A Social Story

- ▶ When I meet new people, I like to shake their hand. When I see people that I know, I like to hug them. Some people do not like to touch when they greet others. Now it is important to find other ways to greet people because we do not want to spread germs.
- ▶ When I meet people, I should ask how they want to be greeted. I can wave and just say “hi”. Asking before greeting can help everyone feel safe.



Empathy



You don't have to agree with what your relative says, but it does help to acknowledge their thoughts and feelings without judging or minimizing them.

We can help our family by encouraging them to express the full range of their emotions, to listen to those feelings with empathy, without judgement or doing anything about what they say. Just listen...

If someone's worries or fears are minimized or dismissed, these feelings will show up in other ways — fighting with family, staff or housemates, throwing tantrums or being generally uncooperative

For strong emotional responses, you say, "It sounds to me as though you are worried about getting sick. I wonder if you are frightened about all the things that are suddenly changing?"

In response to social isolation, you could say, "It's so frustrating to not be able to be with your friends and do the things you like to do!"

Offer Opportunities for Self Expression

- ▶ Frequent check ins
- ❖ Be mindful that individuals may be very concrete in their language skills, have limited language or may be non-verbal
- ❖ Your relative may not initiate conversation with you about Covid; they may not let you know they are worried, sad or need assistance
- ▶ Keep journal
- ▶ Draw/Color
- ▶ Dance
- ▶ Sing
- ▶ Create a music playlist

Prioritize Coping and Calming Skills

- ▶ Everyone reacts differently to stressful situations
- ▶ How you respond to the pandemic depends upon your background, the things that make you different from other people, and the community you live in
- ▶ **Practice desensitizing uncertainty for individuals with disabilities.**
- ▶ Uncertainty triggers fear for many individuals with disabilities who may depend upon others to get their needs met. At a time when everything is up in the air, it's important to help your family member deal with his/her worries about the unknown.
- ▶ You can try using games of chance or improvisation to practice reacting to outcomes that aren't predictable. You can also create a **Social Story** to explain parts of the day that may be unstructured. Introducing this thought process can help people manage anxiety and reduce stress responses when unexpected circumstances occur.

I CANNOT CONTROL

(So, I can LET GO of these things.)

IF OTHERS FOLLOW THE RULES OF SOCIAL DISTANCING

THE AMOUNT OF TOILET PAPER AT THE STORE

I CAN CONTROL

(So, I will focus on these things.)

THE ACTIONS OF OTHERS

MY POSITIVE ATTITUDE

TURNING OFF THE NEWS

FINDING FUN THINGS TO DO AT HOME

HOW LONG THIS WILL LAST

HOW I FOLLOW CDC RECOMMENDATIONS

LIMITING MY SOCIAL MEDIA

PREDICTING WHAT WILL HAPPEN

MY OWN SOCIAL DISTANCING

MY KINDNESS & GRACE

HOW OTHERS REACT

OTHER PEOPLE'S MOTIVES



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TheCounselingTeacher.com

Positive Coping

- ▶ Ways to cope with stress
- ▶ **Take breaks from watching, reading, or listening to news stories**, including social media. Hearing about the pandemic repeatedly can be upsetting.
- ▶ **Take care of your body.**
 - ▶ Take deep breaths, stretch, or meditate external icon.
 - ▶ Try to eat healthy, well-balanced meals.
 - ▶ Exercise regularly, get plenty of sleep.
 - ▶ Avoid alcohol and drugs external icon.
- ▶ **Make time to unwind.** Try to do some other activities you enjoy.
- ▶ **Connect with others.** Talk with people you trust about your concerns and how you feel

Stay Active at Home

- ▶ If you sit for long periods of time, take a 3-5-minute break every 20-30 minutes
- ▶ Make time in your daily schedule to be physically active. Setting a routine will help you stay active every day
- ▶ Record your activity on a weekly chart so you can see your progress
- ▶ Look for online classes for yoga, aerobics, dancing, and other activities you can do at home.
- ▶ **Adapted from the World Health Organization:**
<https://www.who.int/news-room/q-a-detail/be-active-during-covid-19>





Working on daily living skills

- ▶ This can be an opportunity to work on improving diets by increasing fruits and vegetables and lowering the use of starches, and excessive consumption of animal proteins
- ▶ This can also be a time to work with your relative on such life skills as budgeting, shopping for groceries (online or off hours) and meal preparation
- ▶ This could be the time to work on organizing possessions and learning to clear clutter in the household
- ▶ This could be the time to work on learning how to do laundry

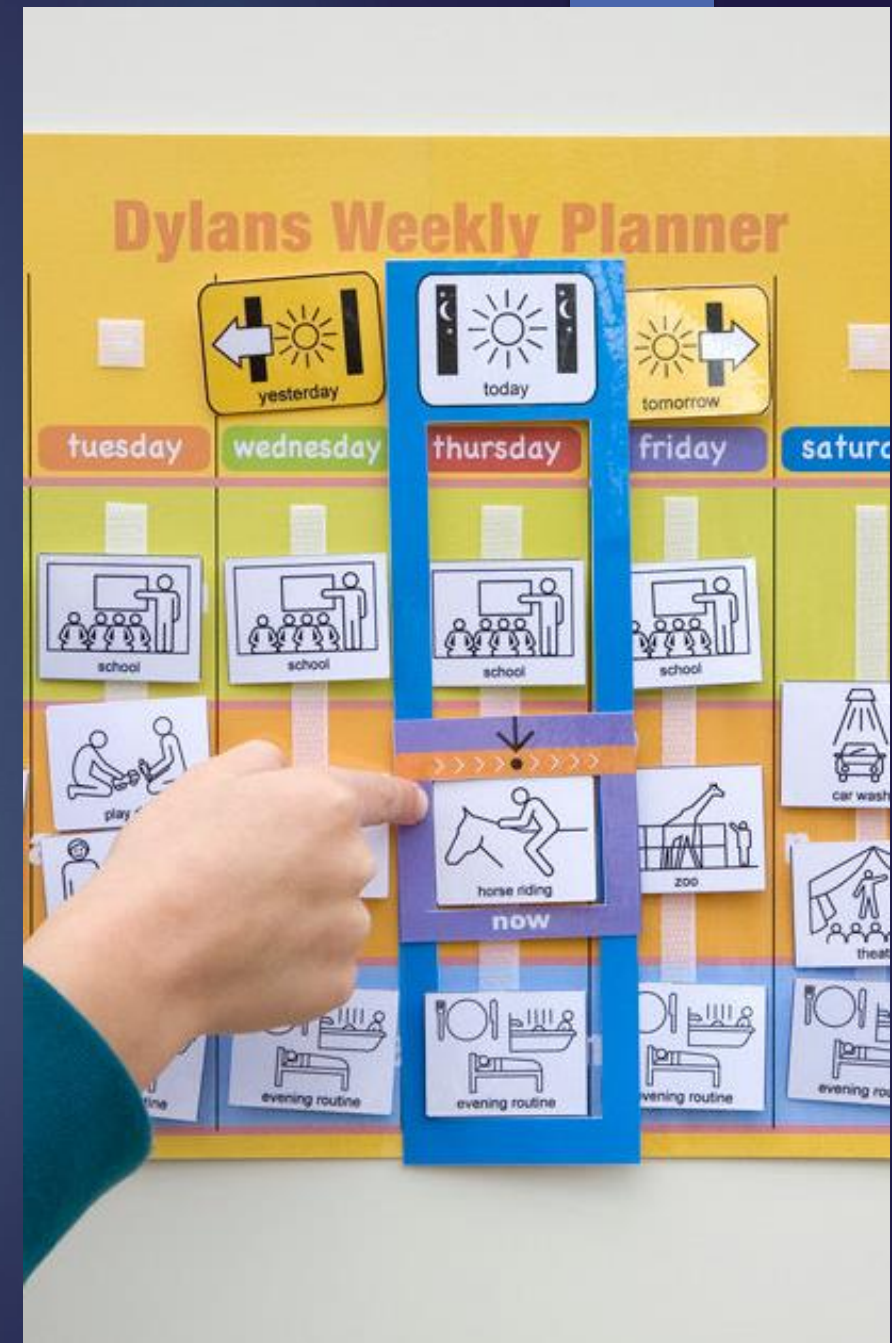
Stress Management

- Slow Down
- Meditation, deep breathing, mindfulness exercises and gentle activity can help you relax
- Hypnotherapy podcasts: HelloMind
- Yoga videos available on YouTube
- Self-massage
- www.calm.com
- <https://www.pocketmindfulness.com/6-mindfulness-exercises-you-can-try-today>
- www.Headspace.com



Try to Maintain a Normal Routine

- It's not easy to “stick to routine” when workplaces, programs and usual activities are closed.
- Try to establish a new routine, as best you can. Some individuals are frightened and overwhelmed by big changes in their environments.
- Allow your family member time to adapt to a new routine or new system.
- A picture calendar may help your relative learn a new household-bound routine



Build New Routines

- ▶ *It may take a week or two to discover a schedule that works for everyone in the household*

Schedules should include:

- ▶ *wake-up and bedtime*
- ▶ *getting dressed,*
- ▶ *Meals: breakfast, lunch and dinner*
- ▶ *Routines for food shopping, cleaning, and laundry*
- ▶ *Scheduled snack breaks and physical movement breaks,*
- ▶ *Use photographs, preferably of the person, in creating a visual schedule for the week/daily schedule*
- ▶ *Establish house rules and review during weekly family/house meetings*
- ▶ *New routines should reflect the current use of space within the household with everyone home (i.e. use of TV, computers, areas for quiet time)*



PROCOLS FOR ENTERING YOUR HOME

ACTIONS AGAINST COVID-19



1



When you come home, try not to touch anything.

2



Take off your shoes.

3



Disinfect your pet's paws if you were walking it.

4



Take off your outer clothing and put it in a laundry bag.

With bleach, recommend at more than 140f.

5



Leave bag, purse, keys, etc. in a box at the entrance.

6



Shower or, if you are not able, wash all exposed areas well

Hands, wrists, face, neck, etc.

7



Clean your phone and glasses with soap and water, or alcohol.

Prepare a mixture of bleach 20 ml per liter of water. 5 tbsp (1/3 cup) of bleach in one gallon of water or 4 tsp of bleach in one quart of water.

8



Clean the surfaces of what you have brought outside with bleach before storing.

Don't forget to wear gloves.

9



Remove your gloves carefully, throw them away and wash your hands

10



Remember that it is not possible to do a total disinfection, the objective is to reduce the risk

New Routines for entering/exiting the residence

Give individuals power and responsibility

We all feel less anxious and do better when we have some power/control in a situation:

- ▶ We all do better when we believe what we do makes a difference. We can help our neighbors and loved ones stay safe and healthy if we wear masks when in public and we frequently wash our hands with soap and water for 20 seconds, or as long as it takes to sing “Happy Birthday” or “Row, row, row your boat,” twice
- ▶ Everyone needs to remember to wipe down their devices often, as well, and to cough or sneeze into their elbows or a tissue
- ▶ You might want to reinforce that hand-washing is an important protective action to take against coronavirus, and hand-sanitizer is a perfectly good stand-in when soap and water are not available



**Did
you wash
them?**



**Hand washing stops
the spread of germs.**

Be Alert to Behaviors that compromise safety or QOL

- ▶ Individuals with disabilities may display behaviors of concern prior to the pandemic, and may experience heightened states of agitation or distress that lead to increased frequency of behavior problems
- ▶ Living in close quarters with people 24/7 may lead to heightened conflict with members of the household or with staff
- ▶ Having limited or no access to family, friends, work, recreation and usual sources of support and gratification may increase behaviors of concern
- ▶ Behaviors such as aggression, self-injury, elopement, etc., may increase in frequency or intensity during this period of heightened stress for all of us
- ▶ You may notice changes in your own behavior!



What are the opportunities?

- ▶ This may be the time to for all of us to learn new skills:
 - ❖ self-calming
 - ❖ cooperation
 - ❖ following instructions
 - ❖ Being more independent (less reliant on family or staff)
 - ❖ Having a good relationship with others in the household
 - ❖ Problem Solving
 - ❖ Conflict Resolution



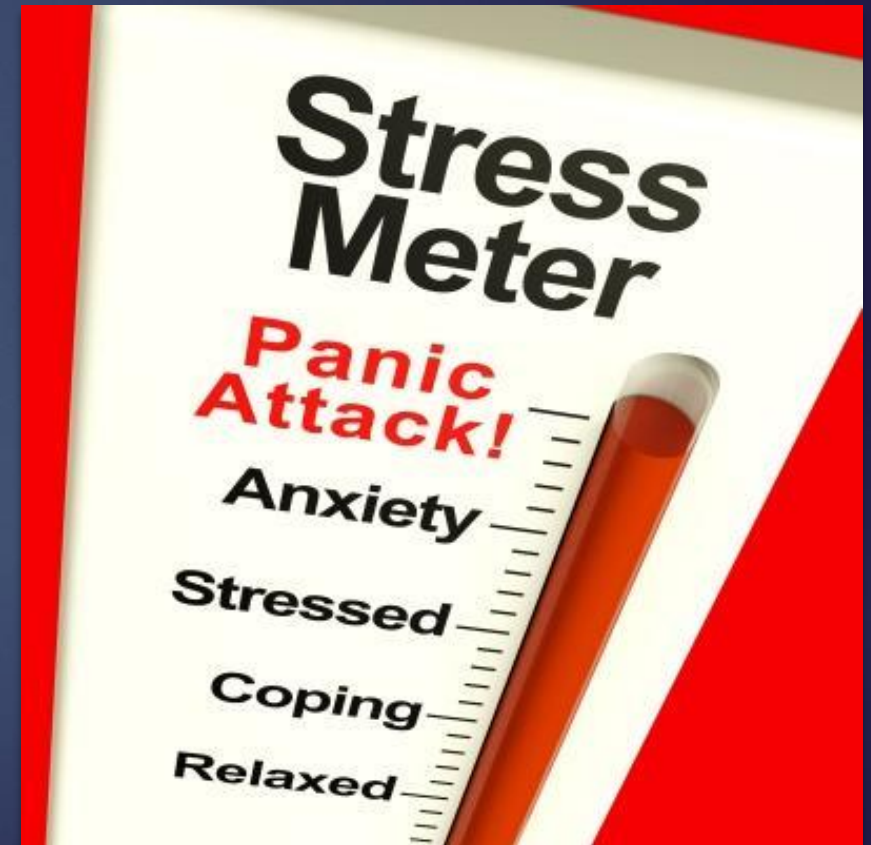
Extreme Stressors

- ▶ Infectious diseases, like any extreme life stressor, can challenge the way we cope. Whether we learn about a threatening situation on television or experience the pandemic personally, we can feel upset, fearful and anxious for our own personal safety and the safety of family and friends
- ▶ Stressful events can also bring up feelings and memories of previous traumatic events thereby compounding the distress that we feel.




Signs of Extreme Stress

- Avoiding others, even within the confines of social distancing
- ▶ Experiencing headaches, stomach problems, neck or back pain
- ▶ Crying
- ▶ Talking less
- ▶ Feeling anxious, depressed or having panic attacks
- ▶ Feeling angry, guilty, helpless, numb, or confused
- ▶ Thinking about or watching too much television about COVID-19 or pandemics
- ▶ Not wanting to get out of bed
- ▶ Having difficulties concentrating
- ▶ Excessive eating
- ▶ Drinking more alcohol or taking more prescription drugs



Recognize the need for referral for mental health services

- ▶ **Help keep your family member connected with family and loved ones** to help lower distress and feelings of social isolation.
- ▶ **It is common for people to feel distressed during a pandemic.** Remind them that asking for and accepting help is a sign of strength.
- ▶ **Most people will experience stress within manageable limits and not require professional attention**
- ▶ **Identify who you will contact** if your relative shows severe distress or expresses a desire to hurt him- or herself or someone else.
- ▶ **See [SAMHSA Coronavirus \(COVID-19\) Resources and Information](#)** 

For Family Caregivers...

Responding to COVID-19 can take an emotional toll on you

- ❑ Acknowledge that we are all affected by this current public health crisis which has disrupted our daily routines and heightened our anxiety of the unknown
- ❑ Learn the symptoms including physical (fatigue, illness) and mental (fear, withdrawal, guilt)
- ❑ Take a break from media coverage of COVID-19
- ❑ Look to local public health authorities for guidance about safety precautions—do not obtain your information from social media
- ❑ Be compassionate towards yourself and family members as you all learn new ways of dealing with the pandemic
- ❑ Create a menu of personal self-care activities that you enjoy, such as spending time with friends and family, exercising, or reading a book.
- ❑ Ask for help if you feel overwhelmed or concerned that COVID-19 is affecting your ability to care for your family and others as you did before the outbreak.

Some Considerations...

- ▶ **Setting a schedule for work and life**
- ▶ The COVID-19 pandemic will likely require you, your partners, and your children, to share “workspaces” for a longer period than is typical for you
- ▶ Although most people can imagine working around each other’s schedules for a day or two, managing a balance between multiple people’s schedules in the same space may be challenging
- ▶ People are driven by routines, and disruptions to those routines can be stressful
- ▶ The separation of your home and work schedules is typically easier when those locations are physically separate.:
- ▶ **Maintain a consistent routine when possible:** this includes sleep-wake times, exercise, and work/school schedules.
- ▶ Establishing and maintaining these routines will help everyone maintain a sense of normalcy

Maintain good communication and boundaries

- ▶ **Good boundaries and good communication** means laying out clear expectations and ground rules between yourself and your family, and yourself and your colleagues.
- ▶ For family members with the help of a schedule, it will be important to ensure that your work time is protected as best as it can be:
 - ✓ This can be as simple as trading off family care duties with your partner (if possible), or
 - ✓ establishing a “do not disturb” signal for your family
 - ✓ With colleagues, it is important to emphasize that you will “logoff” outside work hours, meaning that you can set and enforce the expectation that you will not be checking work emails/messages outside the hours you have set as your “work” hours.



Model Behavior that you want to see

- ▶ Your family member will be looking to you for guidance and support, especially during trying times
- ▶ Model a positive outlook about a safety practices that may be challenging for your relative; for instance, model personal hygiene and model behaviors related to handling social distance/sheltering-in-place and wearing masks
- ▶ You can't expect a 6-year-old to wash her hands, 10-year-old to isolate from his friends or a 40-year-old to wear face coverings in public if you or the others in the household aren't willing to do the same.

Take Care of Yourself!



These are anxiety-producing times. be sure to take care of yourself.

- ▶ Turn off the news; too much discouraging news is bad for everyone's health
- ▶ Obtain your information from reliable sources such as local public health agencies
- ▶ Run a bath; light candles; take a walk or a long afternoon nap; meditate. Look for sensory experiences — pet the dog or cat, flip through a family vacation album, put on some music or bake cookies.
- ▶ Do whatever you can to calm your own nerves so that you have the reserve to assist your family or the individuals whom you support

Practice your faith or practice something MEANINGFUL to you and do it everyday!

Journaling



Religion



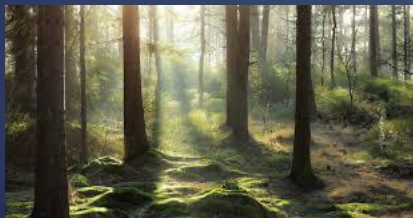
Yoga



Baths



Nature



Music



Meditation



Consider Adjusting Screen Time Limits

- ▶ You may need to temporarily adjust screen-time limits for your relative
- ▶ Remember: if you loosen all the limits around addictive games or programs, those things will be much harder to manage when we return to work, school and programming
- ▶ Be specific about how much time is allowed and with whom they can communicate online and via social media
- ▶ Without school recess, or regularly scheduled physical activity you may want to implement “yard time” to get your family moving, or schedule after dinner walks.
- ▶ Encourage the use of Skype or Facetime, through which your family members can interact with others. Social connection is important, especially at a time of social distancing.



For Family not in the same household as your relative...

- ▶ Establish regular phone or video contact with your relative
- ▶ Establish a regular phone or video check-in with staff
- ▶ Write down your questions and refer to them during your regularly scheduled check-ins with staff
- ▶ Keep your relative in phone or video contact with other members of the family
- ▶ Find ways to Zoom-connect for important events like birthdays and anniversaries for which you would normally gather to celebrate
- ▶ Mail care packages to your relative with favorite games, gift cards with which they can purchase items on-line

Foster Social Connection with your relative who is not with you...

- ▶ Video or phone calls (FaceTime, Skype, Google Groups)
- ▶ Play virtual games (apps like House Party, Uno! Online, virtual jigsaw puzzles)
- ▶ Write a letter or email
- ▶ Zoom meet ups
- ▶ on-line social groups



Take Home Messages

- ❖ **Reduce COVID's psychological footprint**
 - ✓ Identify what will maintain motivation to engage in risk mitigation and safety practices
 - ✓ Positive coping
 - ✓ Positive routine
 - ✓ Self-care
 - ✓ Identify when professional assistance may be warranted
- ❖ **Reduce COVID's social footprint**
 - ✓ Find ways to promote connection with valued others
 - ✓ Find ways to celebrate family events
 - ✓ Promote a sense of belonging





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