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Supporting Individuals with Autism through Uncertain Times

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All children and young adults require support from caregivers during times of stress and uncertainty, such as those we are facing now with the spread of the coronavirus (COVID-19). Coping with the unknown and navigating school closures, abrupt changes in routines, loss of connections with teachers and friends, and fear around contracting the virus- are burdens for all, and caregivers play an important role in helping children and young adults understand the changes and process their related feelings. Individuals with autism may need additional support to process the news and adapt to the many changes. This population may face additional challenges related to comprehension, communication, difficulty understanding

7 Strategies to Support Individuals with ASD through Uncertain Times



Support understanding



Offer opportunities for expression



Prioritize coping and calming skills



Maintain routines



Build new routines



Foster connections (from a distance)



Be aware of changing behaviors

abstract language, an insistence on sameness, and a greater likelihood of anxiety and depression—all of which may be exacerbated during this stressful period.

The following **7 support strategies** are designed to meet the unique needs of individuals with autism during this period of uncertainty. In addition, examples and ready-made resources are included to help caregivers implement these strategies quickly and easily. These materials purposely represent a variety of styles/designs/complexity to model the range of what may be most meaningful across ages and skills, and to demonstrate what can be generated with few materials by busy caregivers. Specific adaptations and additions may be necessary to best meet the varied needs of individual children and young adults.

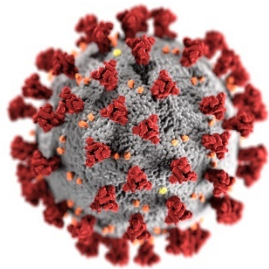
These strategies are intended to be a menu or toolkit of ideas that may be helpful-- caregivers may take one idea at a time and find a way to make it work for their child(ren) with autism and their family. Caregivers may want to start with a strategy they have used in the past, or perhaps find a tool to address the issue that is creating the most immediate stress. Consider involving the individual with autism in the decision-making process about what tools would be most helpful.



Support Understanding

Individuals with autism may have varied levels of understanding about the COVID-19 virus, how it spreads, and how to reduce risk of exposure. Below are several strategies to use to provide additional meaning to this complex scenario.

Describe the virus and current situation (e.g. closures, social distancing) in concrete language and terms and avoid flowery or abstract phrasing. The understanding of abstract phrases and metaphors such as “she is under the

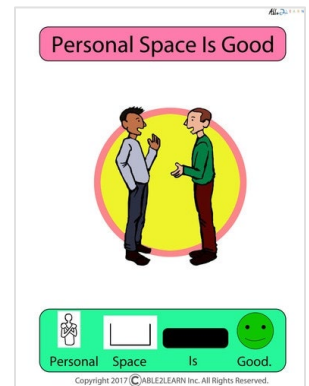


weather”, “she caught the virus”, and “he is scared stiff about this” can be difficult for individuals with autism and can create confusion (Lipsky,

2013). Using direct and clear language is recommended. Though stark-sounding, phrases like “The coronavirus is a type of germ. These germs are very tiny, and when they get inside your body, they can make you sick” may be easier for individuals with autism to understand. For more information, (<https://www.pbs.org/newshour/health/10-tips-for-talking-about-covid-19-with-your-kids>).

Use a **social narrative**, a story that clarifies a situation and possible responses through modified text, photos, or the use of technology (Wong et al., 2014). Individuals on the autism spectrum benefit from

receiving information in multiple formats, as they often have receptive language deficits (Mody et al., 2013). Several example social narratives have been developed to give individuals more information about COVID-19, help them understand how to reduce risk, provide insight into how they may be feeling, and offer assurance that those feelings are normal. Reading the narratives to/with the individual with autism regularly across several days is helpful. Revisit and adjust as needed as circumstances shift.



Provide **visual supports** to offer guidance on coronavirus specific actions and behaviors. The “rules” around how we greet people (e.g. no more handshakes), how we interact with



people, even family members (e.g. social distancing), and how often/when we wash our hands (e.g. every time we come inside) are changing. Using

visual cues to break down the steps of these new expectations may be helpful, as individuals with autism may respond best to a more explicit and concrete explanation. Several examples are provided.

Offering **visual cues to clarify the passage of time** may be helpful. Individuals with autism may have trouble perceiving the passage of time, an invisible concept, and the use of a monthly, weekly, and/or daily

calendar may aid in tracking time out of school/in a quarantine situation. While we do not know an “end” date to today’s uncertainty, marking the passage of time as well as including favorite activities, such as shows, online meetups, or game night on the calendar can be a helpful coping strategy.



Resources include:

[Social Narrative: COVID-19](#)

[Social Narrative: Coronavirus](#)

[Social Narrative: Greeting People](#)

[Social Narrative: Giving People Space \(Social Distancing\)](#)

[Social Narrative: Giving People Space When Talking](#)

[Visual Support: Hand Washing \(Clipart\)](#)

[Visual Support: Hand Washing \(Photos\)](#)

[Task Analysis: Hand Washing](#)

[Creating Visual Supports and Social Narrative Apps](#)

[Visual Support: Calendar Template](#)

[Visual Support: Countdown Example](#)

[Visual Support: Timer \(Using Stickers\)](#)

[Timer Apps](#)



Offer Opportunities for Expression

Children and young adults will likely have difficulty articulately expressing how they feel about the many unexpected changes. Fear, frustration, and worry may be expressed through challenging behavior like tantrums, refusing to take part in family activities, or withdrawal. For individuals with autism, these communication difficulties may be coupled with expressive communication delays, limited verbal or nonverbal skills, difficulty perspective taking, and/or social communication deficits.

Consider providing multiple opportunities for family members to express their feelings as they are able—through family and individual discussions, writing activities, movie making, or play. Feelings and needs may be communicated through alternate forms of expression such as the use of augmentative and alternative communication (e.g. iPad, pictures), listening or playing music, dance, yoga, and various visual art forms. In addition, recognize that an increase in challenging behaviors may be

an expression of anxiety or fear, and consider if support strategies in place are adequate (see strategy 3 for further discussion of coping and calming strategies). Several examples are provided that can support expressive communication.



Resources include:

[Communication Tools](#)

[Expression Activities](#)



Prioritize Coping and Calming Skills

Supporting individuals with autism to learn coping, self-management, and self-care skills is a priority during this time of uncertainty.

Ideally, individuals with autism have some **coping and calming strategies** in their repertoire of skills to access with support during their most anxious times. These may include rocking in a rocking chair, listening to music on headphones, deep breathing,



watching a preferred video clip, brief periods of vigorous exercise, or accessing a

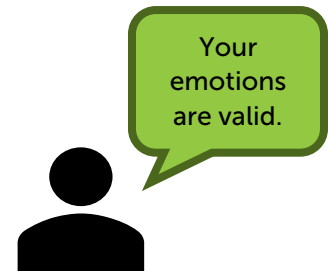
favorite activity or material. If coping or calming strategies are not yet part of the routine, caregivers can prioritize the teaching of these skills during this time of uncertainty.

- Strategically choose times of the day when the individual with autism is calm to initiate the instruction.
- Create a concrete and visual routine to support the use of these strategies.
 - Many free apps are available for calming strategies and guided meditations such as Calm, Headspace, Breathe2Relax,



Pacifica, and RainRain. Several examples of calming routines and self-management systems are provided.

- Ensure that the individual with autism has ample access to these calming activities.
- Coping/calming activities may be scheduled regularly across the day in the initial weeks of changes, then, if appropriate, caregivers may introduce and teach a **self-management plan** that helps individuals track their anxious or worried responses and identify when the calming strategies are required.



Exercise/physical activity is a proven strategy to reduce anxiety symptoms with the broader population, as well as with individuals with autism. Consider establishing or adding basic exercise routines for the family such



as wearing a FitBit and counting daily steps, a nightly walk, or an online/app-based workout. Many sites are offering free access

during this time, such as the Down Dog yoga app, Nike Run Club, and Facebook Live streams from Planet Fitness.

Resources include:

[Self-Management: Calming Routine](#)

[Self-Management: FACE COVID](#)

[Self-Management: Reinforcement](#)

[Inside and Outside Exercise Activities Choice Board](#)

[Exercise Activities](#)

[Mindfulness Apps](#)



Maintain Routines

While it is important to create time and space for all family members to process uncertainty, **individuals with autism may cope best when daily routines are only minimally interrupted.** Routines can provide increased comfort for individuals with autism (Faherty, 2008) and may allow them to better express their feelings related to the changes. For example, instead of skipping a Friday night movie tradition because of increased screen time at other times during the week, choose a movie that can facilitate a conversation about the changes, loss, and/or associated feelings (e.g. *Inside Out*, *Finding Dory*). Combining the stress of the COVID-19 related changes with the addition of changed routines--especially if the new activities are nebulous or unstructured--could potentially exasperate or extend the adjustment process (Lipsky, 2013). Important routines to maintain include:

Sleep/wake routines: Maintaining physical health is key for all family members and ensuring proper sleep is an important contributor. Sleep disturbances are more common in individuals with autism, thus extra attention may be required to support good sleep hygiene and maintain bedtime and waking routines (see more <https://www.autismspeaks.org/sleep>).



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required to support good sleep hygiene and maintain bedtime and waking routines (see more <https://www.autismspeaks.org/sleep>).

Household chores/daily living skills: Taking part in structured household chores and routines is a recommended strategy to support children and young adults coping with stress



related to COVID-19. Individuals with autism may need additional supports, such as a **task analysis**, to be able to take part in and/or complete these activities.

Several examples are provided for common chores along with a template that can be used for a variety of daily living activities. For more information related to COVID-19, see https://www.nctsn.org/sites/default/files/resources/fact-sheet/outbreak_factsheet_1.pdf.



Expanding the use of a **visual schedule**, and using one more regularly throughout the day, may help facilitate participation in activities at home and reduce anxiety. Many

caregivers use elements of a visual schedule already (e.g. a calendar on the refrigerator, a list of errand locations, a photo of which therapist is coming to visit) and these can be

extended for use across the day. The format and length of the schedule may vary based on the individual's needs, and several examples are included.

Resources include:

[Tips for Creating Task Analyses](#)

[Task Analysis: Unload the Dishwasher](#)

[Task Analysis: Make a Snack](#)

[Task Analysis Template](#)



Build New Routines

It may also be necessary to create **new routines** during this time, as there are many new demands of caregivers—possibly homeschooling for the first time, continuing to work in/out of the home, and/or caring for multiple children or other family members. Several new routines that may be helpful are described below:

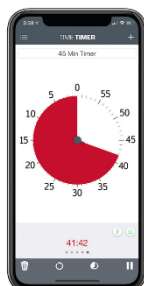
Transitioning off screens: For many reasons, including those listed above, children and



young adults may access screens more often and for longer periods of the day during this time.

Transitioning away from a device, especially after a period of extended use, may be difficult for many children and young adults; however, the behavioral rigidity and inflexibility often characteristic in individuals with autism may make these transitions problematic. Establishing a clear, consistent, and concrete routine for this transition can better prepare the individual for the coming transition and offer support throughout.

- **Use a visual timer.** It may be helpful for individuals with autism to “see” how much time remains of screen time before they will be expected to transition to off the device. Concepts related to time are fairly abstract (e.g. “You have a few minutes”), often cannot



be interpreted literally (e.g. “Just a second” or “We need to get off in a minute”), and may be confusing, especially if time-telling is not a mastered skill. Presenting information related to time visually can assist in making the concepts more meaningful. One example is the Time Timer™ app (<https://www.timetimer.com/collection/s/applications>), which displays a section of red that disappears when the time runs out.

- Another visual transition strategy to use is a **visual countdown system**. Like the visual timer, a visual countdown allows an individual to “see” how much time is remaining in an activity. The countdown differs, however, because there is no specific time increment used. This tool is beneficial if the timing of the transition needs to be flexible (e.g. caregiver would like the child to stay engaged on the device during a work

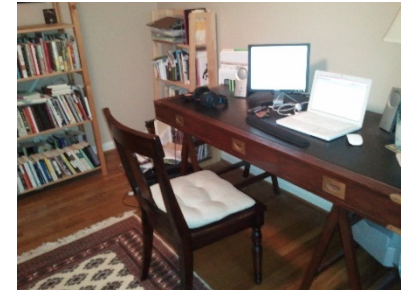


call but does not know when it will end). A countdown system can be made with numbered or colored squares or sticky notes, or any shape or style that is meaningful to the individual. As the transition nears, the caregiver can pull off or cross off the top item (e.g. the number 5) so the individual is able to see that only 4 items remain. The caregiver decides how quickly or slowly to remove the remaining items depending on when the transition will occur. Two minutes may elapse between the removal of number 3 and number 2, while a longer amount of time may elapse before the final number is removed. Once the final item is removed, the individual is taught that it is time to transition. Several examples are provided, and these can be used to support any transition.



the nightly walk, meal options, order of activities for the day, and/or preferences for activities. Several examples are provided for use across the day and age range.

Create a workspace with a to-do list. For the first time, many children and young adults will be expected to complete schoolwork in the home setting. Individuals with autism may have difficulty generalizing the strategies and skills they used in the school environment to the home environment (e.g. organizing materials, attending to work activities, submitting assignments online). Thus, it will be helpful to set up a designated workspace to help clarify expectations and reduce distractions. This may be a spot at the dining room table designated by a colored placemat and facing away from the television or window. If multiple children are working in one space, consider adding a small visual divider (e.g. an open folder) between them. Caregivers can create a visual “to-do” list in several different ways—a) placing the individual worksheets to be completed on the child’s left and a small basket on the child’s right to put them in when they are finished, or b) writing a short list on a sticky note of the tasks to accomplish during the work session (e.g. 1 science story and 15 minutes of ABC Mouse). These can be crossed off when they are



Offer choices. In a time of crisis, when most people feel like so much is out of their control, providing choices can increase a sense of autonomy and motivation. Creating regular opportunities across the day where family members have a voice about what happens and when it happens can serve as an effective anxiety reducing strategy and a communication tool. These choices might include the route for



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finished. Older children and young adults can likely generate their own to-do lists but

may need some initial support to set up a workspace and launch these routines.

Resources include:

[Visual Support: Example of a Daily Schedule](#)

[Visual Support: Daily Schedule Template](#)

[Visual Support: Example of a Daily Schedule \(Using Stickie Notes\)](#)

[Visual Support: Daily Schedule Template \(Using Stickie Notes\)](#)

[Visual Support: Weekly Schedule Template](#)

[Visual Support: Choice Board of Inside and Outside Activities](#)

[Visual Support: Weekly Choices and Goals Template](#)

[Educational Resources for Kids](#)

[Movement Resources for Kids](#)

[Educational and Movement Resources for Teenagers](#)

[Additional Activity Resources](#)

[How to Transition Off Screens](#)



Foster Connections (From a Distance)

Individuals with autism are more susceptible to social isolation and loneliness, and this may be worsened by quarantine conditions. Positive social support is important for everyone during this period, and individuals with autism may need more explicit facilitation to ensure that social connections continue. Caregivers may need to check in to **ensure social contact** is continuing via text or direct messaging, and/or build in opportunities for daily social contact with family, friends, neighbors, teachers, or others via FaceTime, What's App, Google Hangout, Marco Polo, or other apps. Scheduling time to connect with others via online platforms to attend religious services, play chess, participate in socially engaged gaming, complete online schoolwork, or virtually volunteer are ways to safely promote social interaction and stave off isolation. Several examples provide support around using apps that can foster connectedness.

Resources include:

[Task Analysis: Calling with FaceTime](#)

[Task Analysis: Marco Polo for Video Chats](#)

[Video Chat Apps](#)



Be Aware of Changing Behaviors

As described in **Foster Connections**, individuals with autism may not be able to verbally express their fear, frustration, and anxiety about the many changes and/or their health, so these expressions may be demonstrated through other means. Caregivers should be aware of the behavior of individuals with autism during these uncertain times and **be alert for signs of anxiety and depression**. These may include a change in sleeping or eating patterns, increases in repetitive behaviors, excessive worry or rumination, increased agitation, or irritability, or decreases in self-care (Hedges, White, & Smith, 2014, 2015). If these behavior changes are observed, additional support from mental health and/or medical providers such as a family doctor, therapist, psychologist, or psychiatrist may be warranted. The individual may require more support or different types of support (e.g., regular therapy, regular exercise, medication). Most mental health providers and non-urgent care medical providers are offering services via telehealth, and emergency legislation has expanded insurance coverage (including Medicaid) for these options.

Resources include:

[Crisis Supports](#)

Supporting Individuals with Autism through Uncertain Times



Plotting a course through the COVID-19 pandemic is a trying experience for all. Caregivers supporting individuals with autism during this time face extra challenges. These 7 strategies and the associated resources and examples will allow individuals with autism to better understand COVID-19, cope with the many changes associated with COVID-19, and practice communication, social, and adaptive skills that may reduce some of the trials during this very uncertain time.

As a caregiver, it is easy to be focused on how this time of uncertainty is impacting the child(ren) in the home, especially those with additional needs, but this pandemic has considerable impact on all family members. We encourage caregivers to prioritize their own self-care in whatever form that takes – meditation, connecting with other parents who understand the situation, watching a favorite show, enjoying a snack alone, exercise, or taking an extra-long shower. Caregivers, alongside the individual with autism, are navigating unprecedented territory without a clear end point which requires ongoing acts of self-kindness and self-preservation.

To learn more about autism, the strategies in this article, and other evidence-based practices, please visit our free, interactive online modules: <https://afirm.fpg.unc.edu/afirm-modules>

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