





Brain Injury and COVID-19: Tips for Successful Navigation

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The introduction of COVID-19 to the human population around December 2019 has resulted in a pandemic that continues to affect the entire world. While research to date has focused on potential neurological impairment to COVID-19 patients, little attention has been placed on the effects of the fallout caused by COVID-19 on individuals who are living with brain injury. Specifically, the pandemic has resulted in job loss, social isolation, interruptions to routine, and a need to adjust previously successful compensatory strategies, all highlighting some of these unique challenges. The general population has experienced the same issues. However, individuals with brain injury were already experiencing these prior to the pandemic. Examples of this include:

-  More than 70% of individuals with brain injury experience a deterioration in their social lives following brain injury.
-  Approximately 50% of individuals with brain injury experience depression within the first year following brain injury; approximately two thirds are affected even seven years post-injury. ([Headway.org: The Debilitating Impact of Social Isolation](https://www.headway.org.uk/about-brain-injury/individuals/brain-injury-and-me/the-debilitating-impact-of-social-isolation); [headway.org.uk/about-brain-injury/individuals/brain-injury-and-me/the-debilitating-impact-of-social-isolation](https://www.headway.org.uk/about-brain-injury/individuals/brain-injury-and-me/the-debilitating-impact-of-social-isolation))

The pandemic has exacerbated these issues and has challenged the compensatory strategies that people have developed post-injury to cope with their impairments.

The Research

Researchers at the New York Traumatic Brain Injury Model System at Mount Sinai and the Northern New Jersey TBI Model System at Kessler Foundation are leading an effort to better understand the impact of the COVID-19 pandemic on those living with brain injury. These researchers are surveying individuals with brain injury and asking key questions about their experiences as they are navigating the COVID-19 world. Some of these questions include:

- How isolated or cut off from family and friends are you feeling due to COVID-19?
- How disruptive has the COVID-19 pandemic been to your everyday life?
- Since the start of COVID-19, how often have you felt that you were unable to control the important things in your life?
- Have you noticed any changes in your memory and thinking, depression, anxiety, or behavioral symptoms since the COVID-19 pandemic began?

The study—which is funded by the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR)—is ongoing; however, preliminary results suggest that the impact of the pandemic—including social isolation, disruption to daily life, and effect on cognition—is great for those who have lived experiences with brain injury. This proves true whether the person has had COVID-19 or not.



Most of the survey respondents to date indicate that they feel isolated from family and friends.

Additionally, 92% of the respondents indicated that the pandemic has been disruptive to their daily lives, and 55% stated that since the start of COVID-19 they have felt unable to control the important things in their lives ranging from “sometimes”, “fairly often”, to “very often.”

The Traumatic Brain Injury Technical Assistance and Resource Center (TBI TARC), funded by the Administration for Community Living, sought to better understand how people with brain injury have been affected by COVID-19. To that end, TBI TARC interviewed five members of the TBI Advisory and Leadership (TAL) group. The purpose of the TAL group is to guide the priorities of TBI TARC. TBI TARC asked the following questions of the five TAL group members:

1. How has COVID impacted you personally?
2. How has COVID impacted you professionally?
3. What would you want to share with others about your experience?
4. Are virtual supports helpful?

The goal was to understand the effects of COVID for these members and to gain insight related to how they were navigating these effects. What resulted is an understanding of the resiliency and ingenuity of these individuals. The following are highlights of the themes that emerged from these interviews.

Common Themes

Social isolation has been the biggest challenge.

This is already a common issue for individuals with TBI, and further separation from family, friends and coworkers has been extremely overwhelming. Those who appear to be coping well are either setting up new, or attending existing, networks and support groups to connect with other survivors. These networks have largely moved to a virtual format. However, at least one member talked about forming a pod with a few friends to help reduce the isolation. Talking about the stress of social isolation has been therapeutic.

The ability to handle change is a trademark challenge that accompanies brain injury. The abrupt and monumental amount of change caused by the pandemic has introduced or heightened existing feelings of anxiety.

Regardless of the length of time since injury, individuals who have sustained a TBI were surprised at how quickly change brought about a feeling like “experiencing a new TBI all over again.” For many, this element has required accessing old information learned through compensatory strategies and putting it into practice, potentially in new ways, to be able to effectively cope.





Individuals who are responsible for older adult dependents in their household experienced challenges managing healthcare needs for others as well as for themselves. Access to home health staff has been reduced, which has placed additional burdens on individuals with brain injury to manage their own healthcare needs or the needs of others in the household. COVID-19 has not only restricted access for the individual, but it also restricted access for those requiring outside care.

For survivors with children, managing home school measures has been equally challenging. The change of having children (or spouses) at home all day has caused issues, and individuals with brain injury feel poorly equipped to manage at-home academic approaches. The routine of their days has been thrown off, which for some, has made their existing/usual compensatory strategies less effective.

Fatigue has increased, at least initially; there was a greater need for more rest throughout the day in order to cope. Medication dosage has been increased for emotional or physical issues (depression, seizures, etc.). Interestingly, a decrease in driving has been helpful for some in terms of having energy to handle other things while at home.



Although COVID-19 has resulted in more depression and anxiety, it has also created a slower pace, and there is more time to be able to address these challenges; more time is available to manage daily tasks and to explore academic, employment and recreational pursuits.

Strong family and friend supports are critical, regardless of age or length of time post-injury. Support systems are also stressed which makes caregiving, at times, more challenging.

Business staff reductions and closures have created additional financial and emotional impact. Individuals with brain injury or partners/spouses have lost employment and have had changes in household income and even healthcare access. Individuals with TBI are disparately impacted economically; household income changes have caused additional stress and burden. Financial hardship has caused individuals to learn to be more creative (accessing food banks, selling clothes and other property).

There have been challenges with accessing support for medical needs, substance use or mental health counseling. Some have expressed that ultimately, access to therapeutic or medical interventions through telehealth has been very useful and hope that virtual health solutions will continue. Additionally, accessing community supports/programs can be helpful.



With the heavy reliance on technology to access supports virtually, individuals with TBI have had to become more comfortable with learning a variety of platforms and applications. They have also had to learn more about online etiquette and strategies for managing virtual meetings. For some, it is much easier to participate in virtual meetings when everyone can see and be seen rather than phone calls. Others have found it to be initially overwhelming and have had to incorporate a number of strategies to manage this.

Coping Tips

It is important to note that just as no two people are alike, there is not a single set of strategies that works for everyone. However, the strategies presented on the following pages can be beneficial for many individuals living with brain injury.



General Strategies

- Everybody has different strengths and abilities. Get to know your strengths and use them. If it is difficult for you to recognize your strengths, ask family or friends what they have observed.
- Everyone asks for help at some point. If you do not know the answers or need help, ask someone. It is ok to be unsure, to have needs, and to express them.
- Being involved is important and may make you feel better by improving social skills and increasing social reintegration. If you are struggling to learn how to get involved, reach out to your local brain injury alliance, association, or head injury foundation as they will often have support groups, programs, or suggestions for you.
- Creative writing, games, cooking classes, art classes, music all can be helpful to staying busy and expanding your experiences as well as for positive mental health. Do not be afraid to try something new. However, don't push yourself too hard if symptoms flare.
- Try to find what makes you laugh; comedy is a healthy tool and a mood lifter that last long after the laughter does.
- Finding things to be grateful for and focusing on others instead of self will help. Expressing this gratitude can be uplifting.







- Having a routine is important. A daily schedule can increase productivity, help manage stress, and enable progress towards short-term and long-term goals. Your routine might change during the COVID-19 pandemic; be open to the changes.
- Exercise is critical. It helps with physical and mental health, lifting a person’s mood, improving balance and fatigue issues, and increasing self-esteem. There are ways to stay active, no matter your state of recovery.
- Facebook Groups, Instagram, and other social media platforms can be incredibly helpful resources for TBI specific information and for uplifting/motivating you personally.
- Take time to self-reflect and try things previously not experienced.
- Feel thankful for the things that are going well rather than focus on issues or needs.
- Just talking about the challenges that COVID with another person is useful.
- Resist becoming isolated. If you feel the desire to self-isolate, tell someone.
- Remain patient and try to be more mindful. Suggestions for mindfulness can include intentional breathing exercises, practicing positive affirmations, practicing guided meditations, and connecting with nature.

- Change your perspective, for example see having a lack of memory as a bonus: when things are over, they can be forgotten.
- Be happy in any situation and decide how to be happy with yourself.
- Express gratitude for your support system; that helps everyone.
- Become a stronger advocate. Take advantage of opportunities in community advocacy skills building and leadership training to learn more.
- Do small things to make others smile; it will also help your own frame of mind.
- Smile yourself! Smiling elevates mood, relaxes the body, and reduces physical pain.



Technological Tips & Strategies

- Change phone, laptop, or platform background colors to blue and white or greyscale which can be easier to process and reduce eye strain.
- Manage texts and emails in small amounts rather than all at once throughout the day if possible.
- Increase the spacing or size of documents on the computer to make information easier to digest. Changing your computer screen size might also be useful.
- Apply the 20 minutes on, 20 minutes off, rule to technology; it can help reduce cognitive fatigue. For eye strain, consider looking away at something that is 20 feet from you for a total of 20 seconds, and do this every 20 minutes.
- Virtual meetings can cause difficulties integrating and prioritizing all the features at one time. It can be a good practice to physically cover the chat feature, or only focus on one aspect of a virtual meeting at a time. It is difficult at times to determine which is most important, the slides or the speaker.
- Be aware of your surroundings and tune into things that can create sensory distractions, such as fans and other background items.
- During virtual meetings, ask people to minimize their movement and backlighting (e.g., people walking by, moving a device that jiggles the camera).

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- Use natural light when possible, or if not, bring in incandescent lighting and turn off fluorescent lights.
 - Do not hesitate to ask for more details (notes, outlines, recordings, other materials) before and/or after a meeting.
 - Ask others to introduce themselves and to please refrain from using acronyms.
 - Practice with your devices before joining a meeting or call so you are fully comfortable with the settings that work for you.



Additional Resources Used by Participants

1. Accessible Technology, University of Colorado Boulder, Office of Integrity, Safety and Compliance, 25 Mar. 2020, [Zoom Accessibility Best Practices](https://colorado.edu/accessibility-technology/resources/zoom-accessibility-best-practices) (colorado.edu/accessibility-technology/resources/zoom-accessibility-best-practices)
2. Depression and Anxiety Resources from [Friendly Harbor Community Center](https://friendlyharborpueblo.org) (friendlyharborpueblo.org), a peer-run organization
3. Brain Injury Association of Virginia, [Going Virtual A Tip Sheet Series: Effective Video Conferencing Tips for Persons with Brain Injury](https://biav.net/wp-content/uploads/2020/08/2020.0630-Going-Virtual-Tip-Sheet-Series-Part-1-for-PWBI.pdf) (biav.net/wp-content/uploads/2020/08/2020.0630-Going-Virtual-Tip-Sheet-Series-Part-1-for-PWBI.pdf)
4. Brain Injury Association of Virginia, [Going Virtual A Tip Sheet Series: Hosting a Video Conference Tips for Support Group Leaders](https://biav.net/wp-content/uploads/2020/08/2020.0630-Going-Virtual-Tip-Sheet-Series-Part-2-for-SG-Leaders.pdf) (biav.net/wp-content/uploads/2020/08/2020.0630-Going-Virtual-Tip-Sheet-Series-Part-2-for-SG-Leaders.pdf)
5. Hammond, Flora, et al. [Getting the Most out of Your Telehealth Visits](https://archives-pmr.org/action/showPdf?pii=S0003-9993%2820%2931218-1) (archives-pmr.org/action/showPdf?pii=S0003-9993%2820%2931218-1). *Archives of Physical Medicine and Rehabilitation*, 102(2)
6. [How to Zoom: User-friendly instructions](https://frnohio.org/products-media/) (frnohio.org/products-media/). Prepared by Andrew Buck & Christine Brown (The Ohio State University Nisonger Center Rehabilitation Research and Training Center on Health and Function), Tracey Manz (Nisonger Center Family Resource Network of Ohio and Aspirations), Dana Charleton (Ohio Self-Determination Association)



- [Join a Zoom Meeting from an Email Message - Part 1 of 4](https://nisonger.osu.edu/wp-content/uploads/2020/04/1.-Join-a-Zoom-Meeting-from-an-Email-Message-Part-1-of-4-.pdf) (nisonger.osu.edu/wp-content/uploads/2020/04/1.-Join-a-Zoom-Meeting-from-an-Email-Message-Part-1-of-4-.pdf)
 - [Set up Sound and Video in a Zoom Meeting - Part 2 of 4](https://nisonger.osu.edu/wp-content/uploads/2020/04/2.-Set-Up-Sound-and-Video-in-a-Zoom-Meeting-Part-2-of-4.pdf) (nisonger.osu.edu/wp-content/uploads/2020/04/2.-Set-Up-Sound-and-Video-in-a-Zoom-Meeting-Part-2-of-4.pdf)
 - [Zoom Meeting Controls \(Buttons\) - Part 3 of 4](https://nisonger.osu.edu/wp-content/uploads/2020/04/3.-Zoom-Meeting-Controls-Buttons-Part-3-of-4.pdf) (nisonger.osu.edu/wp-content/uploads/2020/04/3.-Zoom-Meeting-Controls-Buttons-Part-3-of-4.pdf)
7. BrainSTEPS, [Online Learning for Students with Brain Injury – 2020](https://brainsteps.net/_corbs/about/BrainSTEPS.Adjustments.Online.Learning.pdf) (brainsteps.net/_corbs/about/BrainSTEPS.Adjustments.Online.Learning.pdf) Academic adjustments that can be used for students with brain injury who are participating in remote online learning during the COVID-19 pandemic
8. [Panel Presentation](https://youtube.com/watch?v=bABOSUTD9AU) (youtube.com/watch?v=bABOSUTD9AU) discussing telework for people with disabilities in celebration of Global Accessibility Awareness Day

ABOUT TBI TARC

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TBI TARC
Traumatic Brain Injury
Technical Assistance and
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TBI SPP
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State Partnership Program