PLAIN LANGUAGE DOCUMENT

Impacts of COVID-19 on Caregivers for People with TBI

What is the purpose of this plain language document? To share what is known from academic research about the impact of the COVID-19 pandemic on friends and family who provide care to people with a traumatic brain injury (TBI).

Who is this plain language document designed for? Friends and family who provide care to people with TBI.

What does academic research tell us about the impact of the COVID-19 pandemic on caregivers for people with TBI? Academic research gives us some insights into the impact of COVID-19 on caregivers. These include:

1. **Providing different care than before.** One study of spousal caregivers highlighted three main changes in care practices: more reliance on food and supply deliveries, more cleaning, and more effort focused on maintaining social connections online.[i]

2. **Providing more care than before.** Spousal caregivers described taking on additional responsibilities due to the loss of home health supports and outpatient services.[ii] Caregivers' primary focus during periods of quarantine was on their partner and they felt at least somewhat responsible for filling the gap left when in-person services closed.[iii]

3. **Experiencing isolation and stress.** Caregivers experienced isolation during quarantine. Caregivers also experienced stress and anxiety from being the only caregiver during these periods.[iv] Caregivers worried that gains their partner had previously made would be lost because of not being able to access services.[v] Now, after COVID-19, some caregivers may be experiencing significant increases in stress because of their loved one's impulsive actions.[vi]

4. **Appreciating the slower pace of life during the COVID-19 pandemic.** In one study, caregivers described how the slower pace of life gave them and their partner with TBI time to reflect and process the events that resulted in the brain injury. Caregivers felt that this and other aspects of the time together strengthened their relationship.[vii]

Every person's experience with the COVID-19 pandemic is unique. As a caregiver, you may have experienced none of these situations, some of these situations, or all of them.

If you have experienced any of these situations, you are not alone. You can:

- **Check out the Brain Injury Alliance of Nebraska website for virtual and in-person support groups for caregivers.**
  - Website: https://biane.org/about/support-groups.html
- **Connect to the Brain Injury Alliance of Nebraska for help finding other caregiver support groups and resources for caregivers of people with TBI.**
  - Website: https://biane.org/
  - Telephone: 844-423-2463
  - Email: info@biane.org
- **Talk to a respite coordinator.**
  - Website: https://respite.ne.gov/
  - Telephone: 866-737-7483

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[i] Mauldin, L., & Defelice, C. (2024). The invisible frontline: Experiences of spousal caregivers during COVID-19. *Journal of Applied Gerontology*, *43*(2),160–169. https://doi.org/10.1177/07334648231205414. Note: This study includes but is not limited to spouses of people with TBI.

[ii] Same as above.

[iii] Beal, E. M., Pelser, C., & Coates, P. (2023). Lockdown life-experiences of partners of individuals with an acquired brain injury during the COVID-19 pandemic: A qualitative study. *Brain Impairment, 24(2), 260–273. doi:10.1017/BrImp.2023.7.* Note: This study focuses on caregivers of people with ABI, which includes but is not limited to TBI.

[iv] Mauldin, L., & Defelice, C. (2024). The invisible frontline: Experiences of spousal caregivers during COVID-19. *Journal of Applied Gerontology*, *43*(2),160–169. https://doi.org/10.1177/07334648231205414. Note: This study includes but is not limited to spouses of people with TBI.

[v] Beal, Erin M., Cara Pelser, and Peter Coates. "Lockdown Life - Experiences of Partners of Individuals with an Acquired Brain Injury during the COVID-19 Pandemic: A Qualitative Study." Brain Impairment 24.2 (2023): 260–273. Web. Note: This study focuses on caregivers of people with ABI, which includes but is not limited to TBI.

[vi] Garcia-Rudolph, A., Sauri, J., Garcia-Molina, A., Cegarra, B., Opisso, E., Tormos, J. M., Frey, D., Madai, V. I., & Bernabeu, M. (2022). The impact of coronavirus disease 2019 on emotional and behavioral stress of informal family caregivers of individuals with stroke or traumatic brain injury at chronic phase living in a Mediterranean setting. *Brain and Behavior, 12*(1), e2440. https://doi.org/10.1002/brb3.2440

[vii] Beal, E. M., Pelser, C., & Coates, P. (2023). Lockdown life-experiences of partners of individuals with an acquired brain injury during the COVID-19 pandemic: A qualitative study. *Brain Impairment, 24(2), 260–273. doi:10.1017/BrImp.2023.7.* Note: This study focuses on caregivers of people with ABI, which includes but is not limited to TBI.

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