Stress Management for Caregivers of Individuals with Traumatic Brain Injury

September 2021

www.msktc.org/tbi/factsheets

TBI Factsheet

This fact sheet explains strategies caregivers can use to manage stress.

Introduction

A traumatic brain injury (TBI) can change a person in many ways. As a caregiver of a person with a TBI, you may feel stressed or overwhelmed in this role. You are not alone; these feelings are normal. Using strategies to manage stress may help you take care of yourself.

Symptoms of Stress

Caregiver stress can take many forms. Some common symptoms of stress are shown below.



Physical Health

Cognitive Health

Emotional Health

- · Neck and shoulder tiahtness
- · Muscle tension
- Stomach upset; nausea
- Constant aches or pains. headaches, and cramps
- · Weight changes (overeating, undereating)
- Sleep issues/fatigue

- Forgetfulness
- · Difficulty with concentration
- Confusion
- Trouble making decisions
- Feelings of hopelessness
- Feelings of isolation
- Feelings of guilt, worthlessness
- Constant sadness, feeling blue
- Fear, worry, anxiety
- Crying spells
- · Viewing problems as overwhelming
- · Loss of interest in activities, hobbies, sex

Coping Strategies

A little stress is part of life. But having a lot of stress that lasts for a long time can have a negative effect on the mind and body. 1 Below are strategies to help you cope with

stress. There are many holistic strategies to help cope with stress. Some include yoga, meditation, and deep breathing exercises. You may want to try

For instant relief from stress, do deep breathing.

Take a breath, hold it for a few seconds, and let it out. Keep breathing until you feel yourself calm down.

the deep breathing exercise in this box.

These strategies can help you in the moment to instantly feel less stress. They can also help you manage stress over time. Resources are available to track your mood, help you relax, and practice these strategies. Check out some of these on the following website. https://www.medicalnewstoday.com/articles/mood-trackerapp#mood-tracker-apps Don't give up if something does not work right away. It may take time and practice to learn which stress management strategies work for you.

Injury Model Systems program is sponsored by the National Institute on Disability, Independent Living, and Rehabilitation Research. Administration for Community Living. U.S. Department of Health and Human Services. (See http://www.msktc.org/tbi/ model-system-centers for more information).

The Traumatic Brain





Mindfulness

Mindfulness is a mental state in which you focus your awareness on the present moment. This includes what you are thinking or feeling and what's happening around you. It helps you live in the present and not get caught up in worries about the past or future. You can practice mindfulness in your daily life. Try the 1-minute mindfulness exercise below.

STOP: 1-minute Mindfulness²

Stand up and breathe. Feel your connection to the earth.

Tune in to your body. Lower your gaze. Scan your body and notice physical sensations or emotions. Discharge any unpleasant sensations, emotions or feelings on the out breath. Notice any pleasant ones and let them fill you up on the in breath.

Observe. Lift your eyes and take in your surroundings. Observe something in your environment that is pleasant and be grateful for it and its beauty.

Possibility. Ask yourself what is possible or what is new or what is a forward step.

Reprinted with permission from Leoni Stewart-Weeks. (2020). 1-minute mindfulness exercises. PsychCentral®. Retrieved from https://psychcentral.com/blog/1-minute-mindfulness-exercises/

Accepting Thoughts and Feelings

Sometimes stress comes from us believing that we should think or feel differently than we do. There is no right way to think or feel. Whatever you are thinking or feeling is OK. If you learn to be OK with your thoughts and feelings, instead of struggling with them or trying to change them, you may find that you feel less stressed. Try to notice what you are thinking or feeling at different times each day. Don't judge your thoughts or feelings as good or bad. <u>All</u> your thoughts and feelings are legitimate. If you are having thoughts or feelings that could possibly lead to dangerous or harmful behaviors to yourself or others, reach out for help immediately.

Maintain Personal Activities and Reward Yourself

You're no good to anyone else if you're not good to yourself. This means that it's important to do things that you valued and enjoyed before your loved one's TBI.

Based on your answers to these questions, make a plan. Schedule time for the activities that you identified <u>IN PEN!</u> Especially at first, don't set the

To identify your interests, ask yourself:

- 1. What activities did I like doing before TBI became a part of my life?
- 2. Which one(s) do I miss doing the most?
- 3. How can I make it possible for me to do these again?
- 4. How will doing these things help me and my loved one?

bar too high. For example, to start, set aside 15 minutes a day to read a book, listen to music, or write in a journal in a quiet spot where you won't be distracted or interrupted. Over time, you could increase those 15 minutes to 30. If 15 minutes is all that's possible, that's fine, too, but <u>PROTECT THAT TIME!</u>





Reward yourself after getting through stressful activities and interactions.

Rewards may cost money (e.g., a massage) or they may be free (e.g., a walk). Depending on how much time you have, they can last for 5 minutes (e.g., step outside for a breath of fresh air) or longer (e.g., watch a 30-minute comedy).

To identify rewards, ask yourself:

- 1. What is rewarding to me?
- 2. What rewards can I realistically give myself?
- 3. When and why should I let myself have rewards?
- 4. How does letting myself have rewards help me and my loved one?

Creative Thinking and Problem-Solving

When you feel overwhelmed, even small problems can feel hard to solve. Here are some tips that may help.

- Don't try to solve problems when you are feeling high stress. Wait until you feel calmer and can think more clearly. Try a mindfulness exercise or a relaxation exercise to calm yourself.
- **Define your goal.** Where do you want to be? What do you want to happen? Work backward from that goal to figure out what steps you need to take to reach it.
- Brainstorm ideas. Do not worry about how possible each one is. The best ideas often seem crazy at first! Write down all ideas; then list pros and cons for each one. Pick the one with the most pros and the least cons and try it.
- **Start small.** Break bigger problems into smaller ones. Then brainstorm solutions to each one. Solving small problems can give you confidence to solve bigger problems.
- Don't give up! No one makes perfect decisions every time. If your first solution doesn't work, try to figure out why and try another solution.

Seek Support

Support from Family and Friends—As hard as it may be, share how and what you are feeling with your family or a close friend. If you feel overwhelmed, ask not only for a listening ear or a shoulder to cry on, but for help. Family and friends often truly want to help, but won't always know how to help, or may be uncomfortable offering. Try to think of and express specific ways they might be able to help you.

Example of Specific Request for Help:

If you could use some help during a doctor's appointment. ask a family member or friend to come with you.

Support from Other Caregivers—Consider forming your own informal support group in person or on social

media. Reach out to other caregivers you see in the waiting room or family room at a care facility or rehabilitation (rehab) center or online.

Introduce yourself!

- Ask how they are doing.
- Ask if they would like to get a cup of coffee.
- Share something about how your day is going





Support through Professional Counseling—Seeking needed professional counseling is a positive thing to do for yourself! Ask your care providers about the various types of counseling available for caregiver and family needs. The rehab facility counselor may offer counseling services or recommend counselors in your area who understand TBI and are a good match for you and your needs.

Family sessions focus on helping with communication, defining roles, or coordinating care.

Individual sessions allow you to freely say what you feel without the worry that may be felt when talking with other family members present.

Group Counseling or Organized Support Groups provide an opportunity to meet with a trained counselor in a group setting with other caregivers. A counselor's guidance and insight are combined with information sharing and support among families going through similar experiences. Topics covered may include stress management, coping skills, available resources, coordination of health care services and navigating insurance benefits. Program coordinators keep caregivers informed and emphasize the importance of "taking care of the caregiver."

Conclusion

Many strategies are available to help you manage stress when caring for someone with a TBI. It is important to be open to new ways to coping with stress. Consider these strategies and find out what works best for you, instantly and over time. Whether the person you are caring for makes a full recovery or not, these coping strategies can help you improve your stress levels and overall health. If you can help the person with injury compensate for cognitive difficulties in a way that helps them be more independent, that can also reduce your stress. At https://msktc.org/tbi there are some related factsheets you may want to review, such as: Changes in Memory; Cognitive Problems; Emotional Problems; Irritability, Anger, and Aggression; and Relationships after Traumatic Brain Injury.

For Caregivers of Service Members and Veterans

The Fisher House is a home for family members of injured and hospitalized service members and veterans. Many of our TBI Model Systems families have stayed here. Some caregivers who meet at the Fisher House form a strong connection and keep in touch after returning to their caregiver roles at home. Learn more about Fisher House at: Home-Fisher House Foundation

Impact of Military Culture: Research on caregivers of veterans and service members with TBI shows that these caregivers may have special difficulties because they may not feel comfortable showing sadness, worry, or stress. They may be used to putting on a brave face for others and may feel that they have to do this after TBI as well. But hiding feelings can lead to emotional issues. As a caregiver of a spouse with TBI, it's OK to feel stressed and to admit you need help. You are not alone. Finding safe ways to express what you're thinking and feeling is important.

Posttraumatic stress disorder (PTSD) is a health problem that some veterans and service members with TBI experience. It may increase your stress. To lower your stress, find a support group for caregivers of persons with PTSD or talk to a specialist to learn how to manage PTSD symptoms.





Recommended Readings and Resources

- ¹ Sander, A.M. (2011). Picking up the pieces: A guide for family members.
- ² Stewart-Weeks, L. 1-minute mindfulness exercises. Psych Central website, updated 30 March 2020; accessed 15 May 2020.

Authorship

Stress Management Strategies for Caregivers was developed by Bridget A. Cotner, PhD; Angelle M. Sander, PhD; Margaret Wells, BS; Therese M. O'Neil-Pirozzi, ScD, CCC-SLP; Jill Coulter, BS; and Bridget Miller, BA, in collaboration with the Model Systems Knowledge Translation Center.

Source: The content in this factsheet is based on research and/or professional consensus. This content has been reviewed and approved by experts from the Traumatic Brain Injury Model Systems (TBIMS), funded by the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR), as well as experts from the Polytrauma Rehabilitation Centers (PRCs), with funding from the U.S. Department of Veterans Affairs.

Disclaimer: This information is not meant to replace the advice of a medical professional. You should consult your health care provider regarding specific medical concerns or treatment. The contents of this factsheet were developed under grants from the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR grant number 90DP0082; 90DPTB0016, 90DPTB0011). NIDILRR is a Center within the Administration for Community Living (ACL), Department of Health and Human Services (HHS). The development of this factsheet was also supported by the Veterans Health Administration Central Office VA TBI Model Systems Program of Research and subcontract from General Dynamics Information Technology (W91YTZ-13-C-0015. HT0014-19-C-0004) from the Defense and Veterans Brain Injury Center (DVBIC); the United States Department of Veterans Affairs (VA; grant number W81XWH-13-2-0095); and the United States Department of Defense (DOD) Congressionally Directed Medical Research Programs. The contents of this factsheet do not necessarily represent the view or policy of NIDILRR, ACL, HHS, DVBIC, VA, or DOD, and you should not assume endorsement by the U.S. government.

Copyright © 2021 Model Systems Knowledge Translation Center (MSKTC). May be reproduced and distributed freely with appropriate attribution. Prior permission must be obtained for inclusion in fee-based materials.



