

THE BRAIN HEALTH MAGAZINE

**AVOIDING Caregiver
Stress & Burnout**

Caring *for the*
Caregiver

**IT TAKES
A FAMILY:**
A Story of Mother & Sons

Living Your Best Life After Brain Injury | Nov/Dec 2021

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FROM THE EDITOR

As we are rounding out the year, I felt this is the appropriate time to celebrate caregivers who often go unrecognized for their daily efforts. This issue is packed full of information with the caregiver in mind.

As survivors, we often neglect to understand what our experiences have been like for the caregiver or loved ones in our lives. We tend to get wrapped up in our own feelings of anger, grief, sadness, and so on, with little regard to how this massive change impacts those around us.

While it may seem as if the caregivers in our lives don't understand what we are dealing with (Because how could they? Unless you've experienced a brain injury yourself, you can never fully understand.), they are doing the best they can with what they know.

The fact that doctors don't even fully comprehend the far-reaching effects of brain injury should make it apparent the lay-person also wouldn't be able to ... without doing a lot of research and educating on their own — which many of them do.

Most caregivers want the best for us; they want to help us get the best treatment available so that we are able to return to somewhat of a sense of normalcy in our lives. But in the process, they often become burnt out, overwhelmed, and left with lingering questions of how to help us (or in some cases, how to deal with us).

As most of you know, I am currently a caregiver for my mom, who is going through terminal cancer treatment. I know how exhausting caregiving can be, how unappreciated I can feel, and how overwhelmed I can be with treatment options and/or doctor visits. It's not an easy job, no matter how "able bodied" the person may seem to be.

"Most caregivers want the best for us; they want to help us get the best treatment available so that we are able to return to somewhat of a sense of normalcy in our lives. But in the process, they often become burnt out, overwhelmed, and left with lingering questions of how to help us (or in some cases, how to deal with us)."

So, the next time you get frustrated your caregiver just "doesn't get it," take a moment to remember how much they have to go through, as well. Their life is also turned upside-down and up-ended. They are likely trying to manage work, children, and caregiver duties all at



once, while also trying to spend copious amounts of time searching the internet for treatments and/or resources for you.

If you haven't done so lately, please tell your caregiver how much they mean to you, and how much you appreciate them. If you're the caregiver, have a candid conversation with your loved one about how much you try to understand their perspective, and how much you do to understand.

We all need each other. In a world where you can choose anything — choose to be KIND. ♡

AMY ZELLMER, EDITOR-IN-CHIEF

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AVOIDING CAREGIVER STRESS & BURNOUT



BY MACKENZIE LE

"There are only four kinds of people in the world: those who have been caregivers, those who are currently caregivers, those who will be caregivers, and those who will need caregivers."

– Former first lady Rosalynn Carter

A caregiver, often a family member or loved one, assists a person in need with daily activities including, but not limited to, bathing, dressing, grooming, meal preparation, and medical needs. While this can be a rewarding journey, many challenges inherently come with being a caregiver. Many caregivers find themselves overexerting themselves physically, mentally, or financially. Without proper assistance, these challenges have the potential to exacerbate and cause great levels of distress.

Accepting role challenges and changes

- Caregiving can be gratifying through making a difference in someone's life, improved relationships with the care recipient, and personal growth as a caregiver.
- Many caregivers find themselves in the common position of being a caregiver to their spouse. Caring for a spouse can be rewarding, but this shift in the relationship can be challenging too.

Supporting loved ones after an injury or diagnosis

Check for environment/home safety:

- Research adaptive equipment and home modification needs. Seek assistance from an occupational therapist (OT), physical therapist (PT), or speech & language pathologist (SLP) to guide you into making more informed decisions and receiving the necessary recommendations based upon your loved one's needs.
- Learn about the assistive and adaptive equipment that may be needed at every stage of a disease, or as one ages, to ease your anxiety and improve your loved one's safety and quality of life.

Get organized:

- Make a list of all the names of your loved one's rehab/medical team, their respective specialty, and contact information. An OT would be a great resource to assist with creating this portable health profile.
- Make a list of your loved one's medications (dose, frequency, purpose, instructions). An OT can assist with creating a medication pictograph or tracking sheet.
- Make a list of other emergency contacts in case you cannot be reached.
- Keep all of this important information in a notebook or binder so that someone filling in for you knows where to find all



necessary health information pertaining to your loved one. An OT or SLP can assist with getting this set up and ensuring no important information is missed.

- To coordinate care, try using a shared calendar with family members and friends who may assist with caregiving and provide respite.

Complete advanced care planning:

- Advanced directives enable people to put their preferences for health-related needs and decisions in writing.
- A living will, healthcare power of attorney, financial power of attorney, and a plan for funeral arrangements can ensure peace of mind for everyone.

Common factors associated with caregiver stress and burnout

- **Role confusion or change in the family dynamic:** Separating the caregiver role from that of a spouse, child, friend, etc. can often be challenging.
- **Unrealistic expectations/demands:** Expecting involvement as a caregiver to positively affect the health and happiness of a loved one with a progressive diagnosis is not always reasonable. This can also become burdensome for the caregivers themselves.
- **Perceived control:** Lack of experience, financial resources, and skills can be

overwhelming for caregivers. Fortunately, rehabilitation providers (I.e., OT, PT, SLP, PSY, and Social Work) can assist with this.

- **The unfamiliarity of caregiving effects:** Caregiving can be detrimental to one's own health (physically or emotionally).

Signs and symptoms of caregiver stress and burnout

Signs and symptoms of caregiver stress:

- Anxiety
- Depression
- Irritability or overreacting to minor nuisances
- Difficulty sleeping
- New or worsening health problems
- Feeling tired and/or run down
- Trouble concentrating
- Feeling increasingly resentful
- Drinking, smoking, and/or eating more than usual
- Neglecting responsibilities
- Cutting back on leisure activities

Signs and symptoms of caregiver burnout:

- Low energy, feeling constantly exhausted even after rest
- Neglecting one's own needs

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- Having trouble relaxing even when help is available
- Feeling increasingly impatient and irritable with the person being cared for
- Feeling helpless and hopeless
- Withdrawal from friends, family, and other loved ones
- Loss of interest in activities previously enjoyed
- Changes in appetite, weight, or both
- Changes in sleep patterns
- Emotional or physical exhaustion

Remember: Once burnout occurs, caregiving is no longer a healthy option for the caregiver, or the person being cared for. It is essential to watch for the warning signs of caregiver burnout and act right away when you recognize the problem.

Coping with, and prevention of, caregiver stress and burnout


- Educate yourself about your loved one's diagnosis/diagnoses to better understand the condition, current treatments, and what to expect moving forward.
- Participate in a support network; consult with professionals to explore burnout concerns or attend an online/community-based support group.
- Ask for help, look for respite care, or enlist friends and family to rotate to help with errands and care.
- Practice acceptance: focus on what you can control, find the silver lining, and share your feelings (good and bad).
- Take time to focus on yourself and your health:
 - Exercise daily
 - Maintain a healthy diet
 - Get a massage
 - Participate in activities that promote joy
 - Take breaks
 - Wake up a few minutes earlier than the care recipient to have time to meditate, drink coffee, or enjoy alone time

Remember: when caregiver stress and burnout put a person's own health at risk, it affects his/her/their ability to provide care.

Respite care

- Respite care is the term used to refer to the act of leaving an ill or disabled loved one in the temporary care of another party while ensuring the continuation of care in a safe environment.
- Respite care can be for an hour, a day, a weekend, or an extended period.
- Respite care can be provided at home—by other family members, friends, or paid caregiving services—or in a care facility setting, such as adult daycare, residential facility, or hospice care center.
- Consider using students/volunteers to allow for time away.

Community Resources

- Caregiver Support groups: Caregiver Action online support groups (caregiveraction.org)
- Eldercare Locator: Connects care partners to local services for adults and their families
- Grief share: Enter a zip code to find in-person grief support groups in your area
- General caregiver support: Family Caregiver Alliance (caregiver.org)
- Respite locator: ARCH National Respite Network & Resource Center (archrespite.org)
- Homecare & Hospice: National Agency Location Service (NAHC.org) 

Mackenzie Le is an Occupational Therapist and Certified Brain Injury Specialist at Origami Rehabilitation. Origami Rehabilitation is a 501(c)(3) nonprofit organization. Origami provides comprehensive rehabilitation for children, adolescents, and adults with neurological, developmental, mental health, and orthopedic conditions through their residential and outpatient programs. With their compassionate and innovative services, Origami creates opportunities and transforms lives.





CAREGIVER SUCCESS TIPS



BY DR. EMILY REILLY,
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FOUNDER/CEO OF
PURPOSEFULLY HOME

Family members, primarily spouses, often adjust their roles and routines to take on caregiver responsibilities. The onset and progression of cognitive decline among loved ones brings unexpected dynamics within a relationship to maintain typical patterns. Small modifications may go unnoticed, but over time the caregivers' increased responsibilities and concern for safety and uncertainty ultimately produce stress and burden. When families are not adequately educated on what to expect with regard to the symptoms associated with their loved one's condition, the quality of life of both the individual and the primary caregiver suffers.

"When families are not adequately educated on what to expect with regard to the symptoms associated with their loved one's condition, the quality of life of both the individual and the primary caregiver suffers."

Occupational therapists play a crucial role in prolonging the function of a person in order to maintain autonomy and dignity of individuals along with their caregivers. Collaborating with family members and caregivers in treatment sessions will support meaningful activities and promote carryover within their home and community environment. In addition, by providing education and role training, caregivers may better understand how to engage with their loved ones in a new context while maintaining an appreciation for their distinct capabilities. Preparing family members for disease progression may improve success at home and allow individuals to remain "aging in place" for a longer duration than if they had not involved occupational therapy in their care.

"Occupational therapists can work with individuals and their care partners to create a plan that eases the burden of care and maximizes quality of life no matter what stage in the disease process they may be."

Often as clinicians, we hear caregivers report struggles of feeling helpless, overwhelmed, and isolated. They no longer partake in social activities because they feel embarrassed and are concerned their loved one may be a burden due to mobility issues, dietary restrictions, or incontinence. Isolation can have detrimental effects on health and wellness including difficulty sleeping, depression, and increased stress. Occupational therapists can work with individuals and their care partners to create a plan that eases the burden of care and maximizes quality of life no matter what stage in the disease process they may be.

Occupational therapists see people with unrealistic expectations. Ways to identify what an individual may be capable of to enhance success are available. Communication, grooming/hygiene, self-feeding, and engagement in leisure activities are the most common concerns, and we occupational therapists can help set you up for success!

The top five tips for caregiver training and support:

1. Communication

Speak **WITH** your loved one and avoid correcting them if they make comments that are not true. Ask questions and

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join their reality. Help them feel as if they still have some control in their life by letting them make decisions and offering them choices.

2. Minimize Stress

Our sensory system can become overloaded, and to prevent burnout or behavior responses from our loved ones, limit causes of stress or “triggers.” Light sensitivity, noise, smells, and visual stimulation may affect our mood and behavior, which indirectly causes stress responses.

3. Maintain Consistency

Routines are helpful for scheduling and tracking things such as medications and appointments. The finer details such as likes, dislikes, and typical patterns of doing things are important. A primary caregiver may not consider this until someone steps in to help, and things may not turn out as planned. We recommend keeping a calendar, journal, or “manual” of sorts to keep everyone on the same page.

4. Be Social

Caregivers and their loved ones stopping engagement in meaningful activities is a leading cause of isolation and depression. Some hobbies may seem impossible, but with some adjustments and modifications, getting out of the house regularly is possible.

5. Set-up for Success

Caregivers want to be helpful and make things easier for their loved ones. Often, we see how the caregivers inadvertently do too much, which leaves their loved ones feeling helpless. Simplify the environment and ask for help. Provide choices in activities that may take too long for a person to do on their own, such as getting dressed. Find “assembly” type recipes such as crockpot meals, salads, tacos, sandwiches, and foods that don’t require cooking. If you as the caregiver have to manage incontinence episodes, be sure to set up the space with all the supplies to avoid having to go from room to room “in the moment.”

Many helpful tools and tips to promote happy, healthy care-partner relationships are available. Occupational therapists train specifically in managing the person, their environment, and meaningful activities. We at Purposefully Home realize a “one size fits all approach” doesn’t work, and we are eager to spend time with you to create solutions that work for you.

As always, “Live your Life with Purpose!” 

Dr. Reilly is the Founder/CEO of Purposefully Home. With a background in occupational therapy, home modifications, and the person/environment relationship, Dr. Reilly works with individuals and their care teams to optimize the functionality of the home environment. www.purposefullyhome.com



“There are only four kinds of people in the world: those who have been caregivers, those who are currently caregivers, those who will be caregivers, and those who will need caregivers.”

— Rosalynn Carter, 2012

This quote is, for better or for worse, incredibly accurate. Oftentimes, a caregiver doesn’t even self-identify as a caregiver — they feel as if they are just doing what you do for people you love. A wife caring for her husband with Alzheimer’s, a mother caring for her son

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with special needs, or an adult child caring for one or both parents with failing health issues are roles that people step into out of love and compassion, but it does come at a price for the caregiver, and often the care recipient.

When a caregiver doesn't take the time for self-care, the result is compassion fatigue and burnout. Perhaps for some people on the outside, that just sounds like fluffy language, but the fallout of compassion fatigue and burnout is real. Caregivers are more likely to suffer from depression, isolation, anxiety, migraines, cardiovascular issues, obesity, and other mental and physical illnesses. Self-care for caregivers is not a luxury, but a necessity. When a caregiver isn't taking time for self-care, the care recipient feels the effects of the stress the caregiver is under.

"When a caregiver doesn't take the time for self-care, the result is compassion fatigue and burnout."

I understand full well the necessity of self-care and, unfortunately, I also understand full well the implications of not making it a priority. My husband and I have two children, and our son has a rare neuro-genetic disability, called SYT1 mutation, also called SYT1 associated neurodevelopmental disorder or Baker-Gordon Syndrome. He is 100% dependent on us for every single thing, and he will be for the rest of his life. He is also the sweetest, happiest kid. We are never fully "off the clock," even when he is at school with trained special education staff and nurses, we are always on-call, and are always at the ready to drop what we are doing to deal with his medical needs.

Additionally, we are constantly trying to balance his needs that are literally life and death, with those of our daughter. She is bright, very active in soccer, school, and church, and will soon be headed to college, so we want to soak in every moment we can with her and as a family. My husband and I both work in caregiving professions, so we are busy like most families, but the challenge of taking time to take care of our relationship as well as ourselves often feels impossible.

"[T]he challenge of taking time to take care of our relationship as well as ourselves often feels impossible."

I have fallen victim to the mentality that I don't have time to take care of myself, or maybe tomorrow I can eat healthier, sleep better, and exercise, but tomorrow turns

into next week, which becomes next month and then before you know a year or two or five have gone by. As the time is just ticking by, my anxiety, depression, and own physical health continue to slide into a dark place. By the time I realize how far down this deep hole I'm in, I'm discouraged to figure out how to get myself out of that dark space. Mitigating something before it even happens, as opposed to playing catch up years later, is so much easier.

Self-care looks different for everyone, and often people have several things they enjoy doing for self-care. At times, the best I can do for self-care that day is spend a few minutes outside, alone, to take some deep breaths. Other days, I go to the gym or for a walk, get myself coffee from my favorite coffee shop, or spend time with my family. Of course, we have the very rare occasions when my husband and I get away for a weekend and not have to worry about anyone's medical needs (but our phones are always on, waiting for the call).

The ideas for self-care are endless, but here are a few suggestions broken into categories:

- **Time in nature:** *walk, run, fish, hike, swim, kayak, or garden*
- **Literature:** *read, journal, listen to a podcast*
- **Arts and crafts:** *paint, take a pottery class, color, or work on photography*
- **Other ideas:** *take a drive with your favorite music, spend time with other children and/or your spouse, cook your favorite meal, exercise, do a deep cleaning (this can be quite therapeutic), enjoy the sunshine, make a snow man, or take an uninterrupted nap.*

Self-care needs to be a daily habit, and people will be more successful when it's on their calendars. The care time doesn't have to be perfect or an entire day (although that is nice), just small consistent pieces each day. Perhaps the best analogy is the flight attendant telling passengers that, in the event of an emergency, to put on their own oxygen mask first, and then help to put on the oxygen mask of someone traveling with them who may need more assistance.

If you do not take care of yourself first, you will not be able to care for others effectively. ♿

Kristin Steadman has a Bachelor of Science degree and is a certified nursing assistant, as well as running a non-profit for families of children with special needs. She lives in Littleton, Colorado, with her husband and two children. In her free time, Kristin enjoys spending time with her family and appreciating all the beauty Colorado has to offer.



UNDERSTANDING

Stages of Grief

BY KELLY HARRIGAN



I was reading an article that referenced Elizabeth Kubler Ross's theory of the five stages of grief with respect to the loss of a loved one. I thought how apt these stages are for those experiencing chronic conditions, particularly with the addition of two stages specifically for long term illness. I'd like to share this information with you and your caregiver.

Traumatic brain injuries are life-changing events creating not only physical changes, but emotional challenges.

That's certainly nothing new to anyone reading this magazine. When medical professionals and caregivers discuss TBI and emotional transformations, they state this liability is a direct physical result of TBI, without delving into deeper psychological discussions to see if the sadness, anger, and feelings of loss experienced by caregivers and patients stem from stages of grief.

1. DENIAL

Accepting a diagnosis of traumatic brain injury for your loved one is difficult. You question the alterations occurring in your life and theirs, and how you will all cope. "I can push through this" or "It will pass and go away" are phrases you might utter or hear your loved one say. This stage of denial may worsen your loved one's health as they might avoid therapeutic treatments thinking their brain injury will go away.

2. PLEADING and BARGAINING

At this point in the cycle, you and your loved one feel frantic to make your lives "go back to normal," an occurrence with which many during the pandemic can identify. Perhaps you both fixate on any treatment suggested to you in the hope it will quickly heal the brain, permitting you to return to your former lives.

Your loved one afflicted with a TBI may feel guilty because they perceive themselves as a burden. You both think that if either of you had changed your actions, this injury would never have happened. You fret about what

each of you could have done differently. You both try to bargain with the brain injury, starting sentences with "I will" and ending with "if you just let things go back to normal."

3. ANGER

Each of you plead with the traumatic brain injury to disappear, to go away, to allow you to return to your normal status quo. You both try to push through it, ignore it, bargain with it. When these stratagems fail, anger arrives.

Anger has no limits or boundaries, extending toward yourself, your medical professionals, and even your loved ones. You may express yourself through statements like "This is so unfair," "I (we) didn't deserve this," and "I can't do anything that I used to."

Simply recognize that anger is an important part of your healing path.

4. ANXIETY and DEPRESSION

It's necessary for you to remember anxiety and even depression are typical responses to sudden transformations in your lives.

Anxiety becomes commonplace. You experience anxiety over other's expectations, the future, finances, jobs, therapies and treatments, or daily activities. Each of you may feel deep-seated grief, a feeling that you are imprisoned in a dark cloud of sadness and emptiness in your life.

While you should consult with a mental health professional, it's also important to remind yourself this is not a sign of mental illness, nor is it something you can snap your fingers to make it disappear. Indeed, recognize these are normal feelings when experiencing a loss: a loss of self.

5. LOSS OF SELF and CONFUSION

Make no mistake: you both grieve the loss of yourselves, the you that you once had. During this cycle, you can't reconcile or recognize the current you with pre-TBI you. You might even look in the mirror, and while you physically

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look the same, you still can't accept that the image in the mirror is you. This confusion and loss of self phase is tremendously hard on both the caregiver and the individual with TBI.

We realize TBI often leads to calamitous life changes including career loss, financial pressures, physical changes and restrictions, perhaps even a loss of your support network as loved ones are not capable of adjusting or accepting these new circumstances. These losses and dramatic adjustments are very difficult as we often associate our identity with certain roles, familial and societal, and also with our careers. What happens if you feel you can't fulfill these roles? Sudden transitions naturally contribute to confusion and loss of self.

6. REEVALUATION OF LIFE and GOALS

With the loss of self, you ponder and reevaluate your future, your personal goals, what you might be able to do for work, how you will now be as a parent, child, sibling, or friend. You sort priorities and decide what activities need to be done and which ones you desire for your self care and positive mental state.


The old adage "you can do it all," particularly in our American 24/7 culture, is no longer a phrase you should push to achieve. Your reconsideration of your activities, goals, needs, and roles is an instrumental part of entering the final stage: acceptance.

7. ACCEPTANCE

This final stage is not, I repeat not, about either you as the caregiver or you as the patient saying it's all OK. Rather it is coming to terms with the new realities you face, the changes, and how to adapt to your new, dare I use the loathsome word, "normal." As I said, you may not feel OK with what has happened, nor should you. Finding a new path forward, meaningful moments, and searching out those moments of joy are desired outcomes of this cycle.

8. IT'S NOT A STRAIGHT PATH

These stages you and your loved one go through aren't necessarily experienced in a linear manner. In all likelihood, you will bounce back and forth among them as you deal with not only physical alterations, but the emotional ones described above.

TBI impacts quality of life, leading to a loss of self and identity and a withdrawal from familiar activities. Both those afflicted and their caregivers, offering each other encouragement, patience, and compassion is important as you progress through the stages of grief on your healing journey. 

Kelly Harrigan is a single mum, veteran, TBI survivor with a girl child and a Frenchie, oolong tea in hand and humor on hand, who lives in Annapolis, Maryland.

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by Amy Zellmer

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IT TAKES A FAMILY

a Story of Mother and Sons



BY IAN HEBEISEN



PHOTO BY AMY ZELLMER

“Now, don’t worry too much ... ”

During my junior year of high school, my dad picked me up after I finished play rehearsal. These car rides home became commonplace, except for one day in particular. I hopped into my dad’s van, and he started our usual car-ride conversation with the phrase, “Now, don’t worry too much”

Obviously, this worried me. My dad explained that mom was in a car accident that afternoon. It didn’t seem that bad — she was rear-ended by a young man who was texting and driving. Mom stopped at a red light, and, when the left turn arrow changed to green, the driver behind her — still focused on his phone — saw the cars next to him moving and drove forward. When mom saw the car behind her wasn’t slowing down, she instinctively locked her arms and braced for impact.

The accident seemed minor at the time. Both parties walked away believing they were fine. “I don’t really remember much of the aftermath,” mom said. She came home from the site of collision feeling lost in a fog. “It wasn’t until after we took care of the post-accident formalities I felt something was wrong.”

In the following days, mom started experiencing strange headaches located at the base of her skull. “Usually, my headaches were at the front of my head or from my sinuses. It took a long time to even figure out I was having headaches,” mom said.

Three weeks after the initial impact, we started seeing other symptoms unfold. Mom became rather ornery, and my dad commented on how easily she started to cry. Her emotions were heightened at the beginning, possibly from being in pain without fully realizing it or understanding why. She experienced lingering nerve pain in her arms and back. Tremors, spasms, and other movement disorders developed during this time, and debilitated her everyday life.

Her job grew more difficult for her as well — she worked as an early-childhood educator, and the fluorescent lights became overwhelming. When working with young children, vocal outbursts arose without warning. Too much noise triggered migraine-like headaches and increased tremoring. The job she used to love doing became an unbearable burden, and she struggled to pull through even a four-hour shift.

“Despite some obvious changes in our mother’s behavior and abilities, we thought they would be temporary, and we’d have our mom back to normal in no time.”

My two brothers and I thought the accident resulted only in a damaged bumper and repeated lectures on the dangers of texting while driving. Despite some obvious

changes in our mother’s behavior and abilities, we thought they would be temporary, and we’d have our mom back to normal in no time.

Eventually, mom went in for a cervical MRI. This scan revealed a couple herniated discs in her spine. Upon discovering this diagnosis, she began treatment targeting these herniated discs. We all breathed a sigh of relief — we wanted an explanation for the changes we were noticing, and we finally had one. We figured once the discs realigned and healed, her problems would disappear.

However, as time went on, the damage showed little sign of letting up. She continued feeling pain and wincing at bright lights and sporadic sounds. It looked like this would become the new normal for us, until our family chiropractor noticed mom struggled to differentiate her left and right. The chiropractor, Dr. Andrew Luing of Dynamic Family Chiropractic, had recently undergone training for identifying concussions, and recognized some of the warning signs in mom.

Dr. Luing referred mom to another doctor at Hennepin Health Care, where she learned she suffered a traumatic brain injury from the accident. By locking her arms to brace herself, she ended up not only herniating the discs in her spine, but rattling her brain in her skull.

She underwent another MRI at Hennepin Health Care (HHC) which revealed no physical damage to the brain. Her doctors were not surprised. “They told me any shearing of the brain for traumatic brain injuries can be so fine, it doesn’t register on the MRI,” mom said.

“‘[The doctors] told me any shearing of the brain for traumatic brain injuries can be so fine, it doesn’t register on the MRI,’ mom said.”

This news came as a shock. Nobody in our family had any prior experience with TBIs. Some of my friends sustained concussions in the past, but they never seemed to have a catastrophic effect — they would be out of commission for about a week, but then they’d be back in action. Seeing first-hand how serious the effects of a concussion could be caused quite a paradigm shift.

Mom started new treatments following the confirmation of a concussion. HHC wanted to put her on various medications, but she declined due to a history of allergic reactions to medicines. Chiropractic care proved beneficial at relieving headaches and reducing pain. In addition, Dr. Luing started other treatments including deep tissue laser therapy and decompression.

The TBI clinic instructed mom that she needed to quit working to focus on treatment for her condition. She began occupational therapy with a focus on speech and vision therapies to help retrain her memory, processing, and cognition, as well as ease her sudden stuttering. The family’s

Continued ...

involvement intensified at this point. We assisted with her visual exercises and physical therapy at home, whether that involved holding up a sheet of paper with various numbers and letters or helping with stretches.

Unable to work, mom found herself a bit stir-crazy at home. She attempted to do chores, but with such a fresh injury, it didn't take long for her to become overwhelmed and in need of a rest. We all adapted the way we approached chores to keep mom functioning as much as possible. For example, mom could load the dishwasher, but emptying proved difficult. "When loading, everything goes into one area, while with emptying, there's a lot of cognitive processing to determine where dishes need to be put away," mom said.

In time, they sent mom to a neuro-optometrist. In addition to her light sensitivity, she received five other diagnoses, including double vision and midline shift, a condition where pressure and swelling build up enough to push the brain off center.

The neuro-optometrist prescribed mom her first pair of glasses, and our family faced another side-effect of mom's condition: wounded pride. The glasses contained prisms to correct the double vision, as well as blue tinted lenses to remedy the light sensitivity. At first, mom felt embarrassed by the glasses – to her, the colored glass accentuated her vision problems and hinderances. "It was bad enough I was moving and contracting, and now I had these blue glasses to draw unwanted attention from others," said mom.

My dad gets the credit for selling mom on the new glasses. To boost her confidence, he printed a collage of celebrities who wore blue tinted glasses – Elton John, Robert Downey Jr., and so on – with the phrase "Now you're one of the cool people!" and taped the pictures to mom's closet. The role of caretaker involves so much more than opening doors and helping with chores. Finding ways to encourage mom and make her smile in times of trial proved beneficial to her journey.

"The role of caretaker involves so much more than opening doors and helping with chores. Finding ways to encourage mom and make her smile in times of trial proved beneficial to her journey."

We continued to gradually adapt to the changes in mom's condition. Her symptoms fluctuated, and we altered the way we helped her in those moments. For example, mom always had minor allergies to preservatives like sodium benzoate, but after the accident, she developed additional food allergies — another side effect of her TBI that blindsided us. We began to read food labels more

diligently, and modified our family meals to accommodate these changes in her diet.

When going on family trips, I usually try to linger at the end of the group in case mom's movement disorder flares up and she requires an arm for support. My brothers tend to monitor the media mom takes in — if a song contains too much dissonance or a certain pitch that'll send mom into contractions, they'll take note and skip over it. With movies and TV, we alert mom if an upcoming sequence will overstimulate her with lots of flashing colors or fast-paced visuals.

We chauffeur her around town. Driving requires a lot of focus on multiple moving parts and can drain mom quickly. If she needs to visit a store or run errands, we drive her to help reduce her fatigue and relieve some of the chaos. When on longer road trips, we need to plan for days of rest accordingly to help mom regain composure and remedy some of her exhaustion.

"When on longer road trips, we need to plan for days of rest accordingly to help mom regain composure and remedy some of her exhaustion."

One such trip involved a drive down to the Mind-Eye Institute in Northbrook, Illinois. Mom learned about the institute from the book *The Ghost in My Brain* by Dr. Clark Elliot, and reached out for help. At the institute, she went through a plethora of tests designed to analyze the way her eyes took in light, and how her brain reacted to visual stimuli. The Mind-Eye Institute prescribed a new set of eyeglasses, which they refer to as Brainwear™. These glasses, no longer tinted, were designed to emphasize peripheral awareness, not just improve central eyesight.

In fact, my mother's glasses actually don't give her 20/20 eyesight at all. After her first appointment at the Mind-Eye Institute, mom explained their current paradigm. Basically, when mom's systems get overwhelmed, her muscles contract because the central nervous system is trying to process too much information and attempts to pawn off some of the stress to the nerves in her arms. "The optometrists said I don't need to see at 20/20," said mom. "By decreasing my central eyesight, I'm subconsciously shifting to use peripheral eyesight, my brain doesn't get overloaded so easily, and my muscles don't stiffen as much."

The Brainwear™ glasses help to rebuild neural pathways, reducing sporadic movements and contractions. The improvement is gradual, but we've noticed fewer spasms and less stuttering. All of these symptoms still remain as obstacles that mom continues to battle, but the individualized glasses do help. Every few months, she needs

an update to her prescription as she adapts to the changes. “I used to have tinnitus, but that unexpectedly went away with the peripheral eyesight glasses™,” said mom.

We continue to monitor mom’s reactions to incoming sensory stimuli. We’ll recommend she take breaks as we work on projects at home, and adjust tasks like chopping vegetables if it proves to be too taxing on her mind and body. All of our aid doesn’t entirely solve her issues by any means, but it makes her injuries more manageable. “It makes life livable,” said mom.

Despite all mom’s improvement, she still struggles with her condition, especially when doing something out of her regular routine. “My world has become very small and comfortable, and if I step outside that comfort zone, that’s when my symptoms flare up. I’m managing because I keep my activities very small, but if I push beyond that it flares up.”

For example, mom went out on a friend’s boat this past summer, and ended up feeling miserable. The light reflecting off of the shifting water overstimulated her brain, causing spasms and offsetting her balance. “I don’t realize how much I’m managing until something triggers it and the brain injury rears its ugly head. Or something overstimulates me and I start stuttering.” When she returned home, she went straight to bed in an attempt to recuperate, even though it was still early in the day.

As much as mom has improved, she has a long way to go. During one conversation, she explained that a doctor declared that “he couldn’t cure me, but he could help me manage my symptoms”. It’s a frustrating process to partake in, but without our assistance, mom’s struggles would grow exponentially and become more taxing. Challenging as it may be, we’ve got to stick together as a family.

Some things to keep in mind as you assist your loved one with a TBI: chances are pretty good that some of their symptoms will linger for a long time. Stop trying to get them back to the person they were, start loving the person they are, and support them on their journey towards the person they can be with their treatments.

Little things can go a long way, and keeping an eye out for small acts of service to ease their symptoms can make their day much more livable. Remember to exercise patience – healing is a long and arduous process, and progress can recede as time goes on. Keep pushing forward, and things will start looking up. The ways you help your loved one mean more than you can realize. 🧡

Ian Hebeisen graduated from Saint Mary’s University in May 2020, earning a degree in Literature with a Writing Emphasis. Now living in the Twin Cities, Ian writes comics, graphic novels, and poetry. In his spare time, he enjoys playing board games with his family.



BY DEBORAH ZELINSKY, O.D.
EXECUTIVE RESEARCH DIRECTOR
THE MIND-EYE INSTITUTE

Ian’s mother is going through stages of acceptance after an injury, just as many patients do. When Louise Mathewson, another car accident survivor, went through the same emotional shifts of realizing she wouldn’t be back to exactly who she was, she embraced who she had become. Mrs. Mathewson’s website states that rather than viewing TBI as Traumatic Brain Injury, it can be viewed as “Transformed By Injury”!

As Ian beautifully wrote, balance among the entire family is disrupted, and everyone, including the survivor, needs to readapt. At the Mind-Eye Institute, we often relieve some visual stressors, such as imbalances between central and peripheral eyesight, processing between right and left sides, and spatial perception of sights as compared to sounds. Ian’s mom is on a road to recuperate while developing new visual skills and rerouting old habits; caregivers are instrumental in making that road stay straight without too many detours.

“[R]ather than viewing TBI as Traumatic Brain Injury, it can be viewed as ‘Transformed By Injury!’” 🧡

Deborah Zelinsky, O.D., is a Chicago optometrist who founded the Mind-Eye Connection, now known as the Mind-Eye Institute. She is a clinician and brain researcher with a mission of building better brains by changing the concept of eye examinations into brain evaluations. For the past three decades, her research has been dedicated to interactions between the eyes and ears, bringing 21st-century research into optometry, thus bridging the gap between neuroscience and eye care.
www.mindeye.com/tbiquiz

CAREGIVERS & SPOUSES:

The Key to Winning Your Personal Injury Case

BY JEFFREY M. HELLER, ESQ.



Who knows you best? Your spouse? Your children? Your co-workers? Your friends? When you file a lawsuit against a person or company that hurt you, whoever knows you best will be your star witness and crucial to your outcome. Here's why:

Personal injury litigation can be grueling. In your average metropolitan area, personal injury lawsuits take anywhere between 10 and 16 months to complete. Add in the usual delays, especially with your trial date, and you can easily add six months to both sides of that range. If you cannot prove you have a worthy cause, your lawsuit will be a major uphill climb and will likely end in a way that, even if you “win,” does not satisfy you.

As all traumatic brain injury lawyers know, the biggest dispute in your case will be whether you have objective evidence of injury. Except in the most serious cases, brain imaging (CT, MRI) will not show objective evidence of brain injury; therefore, your lawyer will have to prove the extent of your injuries through the impact they have on your life. One of the best ways to do this is by asking whoever knows you best to participate in your case. If you have someone who saw you frequently before the accident as well as after, or if you have someone who had to care for you, or continues to care for you, they would be a great witness to help your case.

If you have someone like this in your life, you should absolutely tell your lawyer about them and then ask them to participate personally in your case. All this means is they would need to make themselves available to give a deposition. A deposition is simply a statement under oath. It is like an interview, or a question-and-answer session. The deposition is taken by a lawyer for an insurance company, but your lawyer will be there as well and, if you want, you can be there too. The lawyer will ask a series of background questions about the witness – their name, address, birth date, occupation – and then will transition to asking questions about their relationship with you. Your


witness should be prepared to discuss how you appeared, acted, etc., before the accident versus after. Assuming you have “changed,” your witness should use this opportunity to explain that to the insurance lawyer. The deposition is a good opportunity for the insurance lawyer to hear what day-to-day life is like for you from an outsider's perspective.

One of the biggest mistakes lawyers and their clients make is not producing a witness like this or producing a witness like this too late. Some rules may prevent witnesses from participating in lawsuits unless they have been identified or disclosed in enough time for the insurance lawyer to take their deposition. Often, especially in tough cases, the lawsuit does not settle and is being prepared for trial. At that point, you will sit down with your lawyer and go through the strengths and weaknesses in your case. If your lawyer suggests to you the insurance company is questioning the impact your injuries have on you day-to-day, it will be too late to introduce other witnesses at that point. Therefore, it is crucial to discuss this with your lawyer up front. If your lawyer is prepared, they will bring this up during your first meeting.

A witness who can explain your “before and after” is critical. While you can obviously explain from your perspective how your injuries have affected you, having

a third-party who has no investment in your case or the outcome, can be a game-changer when it comes to describing the impact the accident and injuries have had on you. Everyone sees things through their own eyes, so having a witness who sees what you are going through and can explain it in their own words can really help your case.

Every personal injury lawsuit is tough. But with adequate preparation and help from your friends and family,

you can successfully achieve what you deserve and obtain a favorable result. 



Jeffrey M. Heller is a trial attorney with Nurenberg, Paris, Heller & McCarthy Co., L.P.A., in Cleveland, Ohio. Mr. Heller focuses his practice solely on personal injury and medical malpractice. He frequently represents traumatic brain injury (TBI) survivors in a wide range of cases, including motorcycle crashes. Mr. Heller firmly believes in the right to trial by jury and has tried more than 25 cases to a jury verdict. His past five jury verdicts have resulted in more than \$3 million in damages for his clients. Mr. Heller has been included on Ohio's Rising Star list, which is selected by the research team at Super Lawyers. He has also been selected to America's Top 100 Personal Injury Attorneys and the National Trial Lawyers Top 40 Under 40. He can be reached at 216.621.2300.

Caregiver's **THREE A'S**

for Observing a Brain-Injured Patient

Attention to detail is one of the most important duties that a caregiver can undertake in assisting recovery of a patient who has suffered a traumatic brain injury (TBI). The caregiver must be able to recognize variations – slight as they may be – that occur in a patient's physical, mental, and emotional status, and behavior following the injury.

The reason is simple. Brain trauma interferes with visual processing, and abnormal visual processing can affect a patient's decision-making, awareness, posture, and movement in diverse — and sometimes not entirely obvious — ways during both the short and long term. The slightest alteration in a way a person walks, tilts and moves the head, rotates, or positions an item (in relation to where he or she is standing or sitting) may signal a notable change in brain function. Such changes are what the caregiver needs to note in order to aid the patient's health care professional in determining the next best steps in recovery.

"Brain trauma interferes with visual processing, and abnormal visual processing can affect a patient's decision-making, awareness, posture, and movement in diverse — and sometimes not entirely obvious — ways during both the short and long term."

Indeed, researchers writing in a June 2021 edition of the Journal of Clinical Medicine conclude that "anyone involved in the patient's support [including the caregiver] should be viewed as [a] stakeholder in the recovery process. An in-depth and broad understanding of the medical and social ramifications of TBI should encourage caregivers to actualize the value of their interactions and lead the way toward the best outcomes."

As I have indicated previously in this magazine, visual processing is the simultaneous ability of the brain to take in external sensory signals (from eyesight, hearing, smell, taste, and touch) at all levels (unconscious, subconscious, conscious) meld them with internal sensory signals, and process the information. The processing of internal and external signals results in several types of movements that a caretaker can observe. Some movements are reflexes, others are habitual, and still others are purposeful.



**BY DEBORAH ZELINSKY, O.D.
EXECUTIVE RESEARCH DIRECTOR
THE MIND-EYE INSTITUTE**

An astute caretaker also can observe the patient exhibiting anticipatory movements. For instance, you walk in with a meal on a tray, and you observe the patient starting to reposition himself or herself in bed to sit up and eat. The visual input of the meal triggers the anticipation of needing to sit up. Intact visual processing requires central and peripheral eyesight to function in synchronization with listening and all other sensory inputs. When visual processing becomes dysfunctional due to concussion, TBI, stroke, or other neurological disorder, so does one's understanding of — and responses to — the surrounding environment. Having the big picture of understanding is necessary for organizing, planning, and making decisions.

With that in mind, what specifically should the caregiver be looking for? I call it the three A's — patient awareness, attention, and adaptability. Here are questions that caregivers of TBI patients should be considering and for which they should be closely observing and noting when any sudden or gradual changes occur:

Awareness

Which section(s) of surrounding space is the patient aware of in any given environment? Where does he or she tend to sit — or does the patient prefer to stand? If sitting, does the patient grasp both arms of a chair in a tense

Continued ...



... continued from previous page.

manner or place hands folded in the lap. Are the patient's shoulders hunched or do they appear relaxed? Does the patient normally sit near or against a wall or more so in the middle of the room? Is the patient more at ease in a larger space or smaller space? Does movement in the area bother the patient? Will the patient become stressed if someone walks behind him or her? What if someone is walking past the patient. Do the patient's eyes follow movement to the right? To the left? What about room clutter? Does clutter overwhelm the patient's senses? Is the patient at all aware of your (caregiver's) presence in the immediate area? What makes the patient nervous?

Now watch the patient's posture when sitting or standing. Does the patient tilt his or her head? If so, in which direction – right or left? If sitting at a computer, does the patient keep the screen directly in front of the face or move it to the side? Is the monitor tilted toward the patient or away? If reading, does the patient keep the book or magazine flat down in front, tilted upwards, or to the right or left? In other words, YOU can pay attention to where the patient places mental attention and observe what sensory cues elicit reactions and responses.

Attention

Does the patient still enjoy the same interests and hobbies that he or she had prior to the head injury, such as reading, sewing, cooking? How long does the patient remain engaged in any activity – a couple minutes or a much lengthier stretch of time? How much attention does the patient give to items within his or her immediate area, such as a painting or knick-knack recently hung on a wall? Is the patient even aware of the painting or knick-knack? How much time does a patient spend in any given space – an hour or just 10 minutes and then the patient is out of there? Does the patient watch television briefly, flip through the channels, or actually sit through an entire program? Do movies interest the patient? Does he or she watch a movie or get quickly bored with it and move on to something else? When paying attention to something, is the patient looking at details or just staring at a shape. When the patient's attention is engrossed in a task or object, does he or she lose awareness of surroundings?

Adaptability

In determining patient adaptability to change, the caregiver must take a more active part. Certainly, the ability of the patient to tolerate space that has just been repainted, reorganized, de-cluttered, or equipped with new furniture – that old familiar couch is gone – should be duly noted. However, the caregiver also should challenge the patient by purposely positioning familiar items in different ways within a known space, creating movement around the patient, or simply changing the patient's entire environment – from the home kitchen to an outdoor restaurant dining


location, for example. Simply making the patient sit in different locations when watching television forces the brain to readapt. Sometimes the television will be on the patient's right and, at other times, on the left. The visual processing pathways are routed differently when items are placed in different locations relative to the patient. As a caregiver, you might find that the patient is better able to adapt when people stand, or movement occurs, on a particular side.

Caregiving Challenging, Yet Gratifying

The brain has enormous capability to repair, reconstruct, and replace pathways. At the Mind-Eye Institute, we have enjoyed considerable clinical success in restoring comfort and relief to patients by applying new discoveries in neuroscience to assess patients' visual processing capabilities on every level. With highly individualized eyeglasses designed for balancing eyesight with comfort, we vary the amount, intensity, and angle of light dispersed on the retina. Prescriptions of this kind are often able to resynchronize a TBI patient's sensory inputs, particularly eyesight and hearing, as well as help the patient's brain build new informational pathways through change and rehearsal.

Authors of an article in a 2010 issue of the Journal of Neurotrauma described TBI as simply the "beginning of an ongoing, perhaps lifelong process," one that may call for "a long period of observation, supervision, and care." It is in doing such – observing, supervising, and, of course, challenging the patient – where caregivers play their most critical roles.

Being a caregiver is a difficult, sometimes thankless, yet often gratifying position, involving commitment and energy. It is a career that is so important and worthwhile. I hope the information presented here will be helpful to people working to provide a better life for those in need.

Remember: Your observations and work play a major role in patients' futures. Recall what the airlines teach us prior to most flights: Put on your own oxygen mask before placing one on your child or loved one. The concept for the caregiver is the same. Make sure YOU are not running yourself ragged to help the patient. Take time for yourself to de-stress on occasion and know that no one is ever the same after a head injury. The acronym TBI is typically defined as "Traumatic Brain Injury," but Louise Mathewson, a brain injury survivor and wonderful poet, renamed it "Transformed By Injury!" 

Deborah Zelinsky, O.D., is a Chicago optometrist who founded the Mind-Eye Connection, now known as the Mind-Eye Institute. She is a clinician and brain researcher with a mission of building better brains by changing the concept of eye examinations into brain evaluations. For the past three decades, her research has been dedicated to interactions between the eyes and ears, bringing 21st-century research into optometry, thus bridging the gap between neuroscience and eye care.
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BrainWear™ Glasses Are Playing A Critical Role in TBI Recovery



Kevin Pearce Professional Snowboarder
Recovers From Brain Injury
with Mind Eye Institute



“Ghost In My Brain” Author
Clark Elliott Recovers
Thanks To “Brain Glasses”



BrainWear Glasses
Play Critical Role
in TBI Recovery



Brain' Glasses Help
Shooting Victim Read,
Write Again

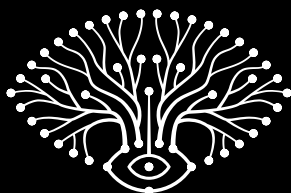


Mind-Eye Helps
Head-Injured Marine
'Return to Person I Was'



Utah Patient 'Blown Away'
by What Eyeglasses Do
for His Injured Brain

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is different,” please take our
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TBI *and* Caregivers

BY JAMES HEUER



A traumatic brain injury affects not only the person suffering from it, but their entire family and friends. Typically, a caregiver can be a spouse, child, relative, or close friend. Stressing the importance of seeking support services for the caregiver themselves is vital. Caring for someone with a traumatic brain injury can interfere with the caregiver's own personal responsibilities such as work and family, and can affect their health and finances negatively. Caregivers can end up losing work time, social activities, and family obligations. Studies have found and recognize those caregivers can experience feelings of distress, anxiety, anger and depression.

When a caregiver commits to taking care of a loved one, reaching out to the Brain Injury Association of America for information and educational materials is highly recommended. This is to help the caregiver understand the consequences of a TBI injury and their role in the course of recovery. Every brain is unique as every injury is unique. Understanding the steps of the journey of what your loved one with a TBI will go through is cardinal in a caregiver's role and duties.


Initially after an accident, a caregiver will be taking their loved one to scans, examinations, and physical therapies. Post-concussion symptoms will be apparent, and sometimes after many doctor visits, the incredible challenge may make you ask, "Will it ever get better?"

Once a patient realizes they cannot resume their daily activities, they can be upset and behavioral problems can arise. A caregiver should be sure to look for possible issues such as sensitivity to light and sound, pacing, and hallucinations. Mood and social problems can arise such as anxiety, depression, mood swings, and agitation. As a caregiver, limiting certain interactions with others while this is happening is essential.



Typically, a caregiver can experience burnout as a state of physical, emotional, and mental exhaustion. This can stem from overextending themselves physically and financially. Burnout can cause high blood pressure and coronary artery disease. The stress may alter and reduce a caregiver's ability to provide proper and quality caregiving. Oftentimes, therapy can offer both social support and coping mechanisms. Seeking help through a home health aide or a personal care assistant for services of care to provide breaks for the caregiver is recommended.

Mayo Clinic suggests caregivers should not try to do everything themselves. Taking a break and asking a friend or family member for help when it's needed is essential for a caregiver's mental health. Something such as running errands or taking a shower is a needed break in the caregiver routine. Caregivers should be aware of their limits and not overextend themselves. Overextending leads to exhaustion, which is harmful to the caregiver, making it even harder on the loved one with the traumatic brain injury.

Instead of dwelling on the consequences of the injury, caregivers should try their best to focus on daily successes and steer away from the loss and perceived failures. Set reasonable goals daily. With severe traumatic brain injuries for example, a caretaker may need to walk their loved one to a coffee shop, practicing the words needed to order a drink. The long-term goal would be to eventually walk alone to the coffee shop and order themselves a drink. In the rehabilitation stage, every task or activity they once loved may seem intimidating. Within this phase, a caretaker has the loved one work on language therapy, strength, coordination and motor skills. As a caretaker, you should be motivating and be specific with the goals you set with your loved one. To find a balance in meeting your own needs and their needs is the best way to create a successful journey in regaining a normal life. 

James A. Heuer, PA, is a personal injury attorney helping individuals with TBI after suffering one himself. He is located in Minneapolis, Minnesota.

Are you living with a TBI
caused by someone else's
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James A. Heuer
Attorney

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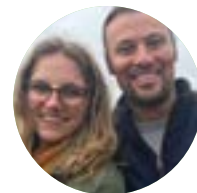
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BY TYLER BOUWENS

Taking Care of a **LOVED ONE** After a Traumatic Brain Injury

I hadn't ever conceived being a caregiver would be part of my story until a reckless and likely intoxicated driver hit my wife, Sophia in March of 2015. She spent a month in the hospital recuperating from a diffuse axonal traumatic brain injury, a broken shin bone, broken jaw, and a broken occipital condyle. I can never quite remember if it was her left or right, but she only had one broken. One of those strange details that remains fuzzy, I guess.

I was with her every day. The time was like a job. I would drop our two young kids off at their preschool, drive to the hospital, work as her caregiver, go pick up the kids, do dinner and bedtimes, and start over the next day. At the same time, I needed care myself. We had immense help from friends and family with food, chores, errands, financial support, household goods, anything.

Many reading this are likely familiar with all the "tasks" of caregiving, but perhaps the unforeseen impacts caregiving can have on a marriage is more unfamiliar. When life circumstances force one partner to care for the other, the natural reciprocity of caregiving within a healthy partnership is interrupted.

For a whole month, and then another year or more, that balance of mutual caregiving between Sophia and me was way off. I made medical decisions for my spouse that now cause me feelings of regret years later. But I also made decisions I am proud of years later. Now, whenever Sophia feels pain in her leg, I question whether or not I made the right decision having them insert the rod into her tibia. Maybe we should have just casted it? My empathy and ability to address her needs as a caregiver in the present is hijacked by these post-traumatic thoughts of doubt. I'm not able to meet her where she needs me now as well.

This "caregiving effect" impacts our marriage in other ways now as well. For instance, for a year or more after the accident, I saw Sophia strive towards working full time again. She pushed herself and was so driven to return to her work which she loves so much. And while I was supportive, seeing her come home so exhausted was hard. Often, she immediately needed to nap, or simply laid down for an hour or more. With time and distance from March 2015, she no longer needs those post-work naps,

but she can still get tired. We all get tired if we overwork ourselves, regardless of whether we have a brain injury. Now, when Sophia is working a lot or potentially taking on more responsibilities, I express concern she may be working too hard. It is difficult for us to navigate those conversations without retriggering feelings of inadequacy or stimulating fears of disability. We still clunk through these conversations, both having a commitment to make it to the other side loving each other.

Moving forward after brain injury and moving forward from that role of caregiver has been difficult in ways I keep secret from the world around me. For example, when we were recently camping, Sophia's hair was a bit disheveled, which is completely predictable when you are tent camping with three children. Nonetheless, it reminded me of how her hair needed brushing in the hospital. Seeing her hair while camping reminded me of how I washed, dried, and brushed her hair while she laid in a hospital bed unconscious or barely aware. Those lower brain feelings of fear kicked right back into gear, and I just wanted her hair to be brushed.

I harbor these feelings and thoughts so that no one else, especially Sophia, can see them, for fear she may be upset or retriggered to that traumatic time. Harboring these memories or ignoring how this "post caregiving effect" impacts our current relationships does not serve a partnership well. Sophia and I have found it helpful to talk about these things, write, see a therapist, and find new ways to care for one another in a more equitable and reciprocal way. We have also found healing through focusing our energies collaboratively to care for our children, home, and garden. We can be caregivers together too.

Thanks for spending your time to read part of my story. I hope it can help illuminate how your caregiving role may be impacting your current relationships. 🧡

Tyler Bouwens lives on the east side of St. Paul with his wife, Sophia, and their three children. He works with a local social service agency supporting American Indian families. In his free time, Tyler enjoys gardening, hunting, fishing, gathering wild plants and mushrooms, biking, canoeing, hiking, and camping with his family.

YOGA

Wide-Legged Forward Fold

BY AMY ZELLMER,
EDITOR-IN-CHIEF



Yoga is a powerful tool for recovery after brain injury. Contrary to some beliefs, everyone can do yoga — you don't need to be super flexible, be able to balance, or even be able to stand up. The beauty of yoga is that every pose can be modified to accommodate anyone.

An important aspect of yoga is breathing. Connecting your breath to your body and flow, and getting oxygen flowing to your brain, makes yoga powerful for recovery. Yoga is also a time to quiet the mind and let anxiety and distracting thoughts drift away.

"Connecting your breath to your body and flow, and getting oxygen flowing to your brain, makes yoga powerful for recovery."

The wide-legged forward fold (Prasarita Padottanasana I) helps strengthen and stretch your inner thighs, the backs of your legs, and your spine. The pose helps calm your brain and relieves mild backaches. This forward fold can help boost confidence and reduce depression.

Instructions:

1. Stand with your legs anywhere from three-to-four feet apart (taller people may need to step wider), making sure your inner feet are parallel to each other. Engage the thigh muscles and inhale, lifting your chest. Rest your hands on your hips.
2. Exhale as you lean forward from the hip joints. As your torso becomes parallel to the floor, press your fingertips onto the floor below your shoulders. Bring your head up, keeping your neck long and your gaze forward.
3. Take a few breaths here as you keep your thighs engaged.
4. While you inhale, rest your hands on your hips, pull your tailbone toward the floor, and bring your torso up. Bring your feet back together.

Modifications: You can bring your hands to a block or chair if you can't handle the inversion. 🧘

Join me for monthly yoga classes via zoom for only \$10 a month: www.patreon.com/amyzellmer



**Want to learn more about Amy's journey?
Purchase her books on Amazon!**



"Amy is a prime example of how powerful and life-changing combining personal experience, passion, and advocacy can be."

— Ben Utecht, 2006 Super Bowl Champion and Author

Three Ways **MOSS AGATE** Soothes Your Soul

HEALTHY LIVING



BY KRISTEN BROWN



Three ways Moss Agate can soothe your caregiving soul:

- 1. Connecting to Nature:** *Being a caregiver is often all-consuming and you don't have much time for outdoor hobbies or activities. Moss agate is a power crystal that can connect you to nature even when you can't be outside as often as you would like. Keep a moss agate in full view while in your caregiving space to remind you of your place in nature.*
- 2. Healing Heartache:** *A loved one who is feeling sick or in pain is demanding on your own heart. Seeing someone struggling isn't easy, and witnessing often uncontrollable circumstances can be heartbreaking. Moss agate is a powerful stone for soothing your heart. Keep one in your pocket, especially when you're actively caregiving.*
- 3. Emotional Balance:** *Caregiving is a rollercoaster of feelings and experiences. When you feel scattered or triggered, hold a moss agate in your hands and breathe deeply to slow your mind and body and let your emotions re-balance.*

When you are a caregiver, maintaining a connection to yourself is important to keep your energy high and your heart, soul, and mind in a positive place. Moss agate is the perfect power stone to bring this connection back into focus to keep you from losing yourself amid the stress of caregiving. 🌿

Kristen Brown is a bestselling author, keynote speaker, and energy medicine practitioner who charges up her clients by syncing their body/mind/spirit for work and life growth. KristenBrownPresents.com

During times of stress and overwhelming situations, you can easily become drained in many of your energy centers. One of the most stressful situations many people find themselves in at some point in their lives is caregiving. Whether caring for an aging parent, an ill child, or an injured or sick spouse, the task can take a huge toll on your mind, body, and spirit. Many tools, self-care tips, and resources are available for caregivers. Adding crystals to this list is one of my favorite ways to amplify the energy you are able to give back to yourself while you're giving so much as a caregiver.

Essential Oils: **Tangerine** and **Tangerine Vitality™**

BY AMY ZELLMER, EDITOR-IN-CHIEF

HEALTHY LIVING

Essential oils are a complementary tool that can help you achieve a healthy lifestyle. They are easy to use, smell great, and versatile.

All oils are not created equal. Young Living is the only brand I personally trust because I know they have complete control over their product from seed to seal. Oils sold at health food stores can be misleading. They are

not regulated by the FDA, so you must look closely at the labels. The labels may say they are 100% therapeutic-grade oils when they are not. If the ingredients list anything other than the plants, or if the label has statements like "For external use only," "For aromatic use only," and/or "Dilute properly," the oil inside that bottle may have been cut with other oils, synthetics, or chemicals.

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Tangerine

Children and adults alike love tangerine essential oil with its delightful sweet aroma that can create a happy, contented mindset when diffused. Tangerine Vitality™ essential oil offers a fresh, sweet, citrus flavor that can be used to elevate your favorite sauces, marinades, and desserts. The oil may also provide digestive, lymphatic, and immune support when taken as a dietary supplement.* Tangerine and Tangerine Vitality are the same essential oil.


Topical: Dilute one drop tangerine oil with one drop V-6™ or olive oil and apply to desired area as needed.
Aromatic: Diffuse up to one hour, three times daily.

Tangerine Vitality™

Tangerine essential is cold pressed from the rind of *Citrus reticulata*, a small citrus tree thought to be native to Southeast Asia. Tangerine fruits are considered symbols of abundance and good fortune during Chinese New Year. A winter fruit, the mandarin is traditionally given and consumed during the Christmas holiday in the United States, Canada, Russia, and the United Kingdom. Tangerine Vitality offers a fresh, sweet citrus flavor that can be used

to elevate your favorite sauces, marinades, and desserts. The oil may also provide digestive, lymphatic, and immune support when taken as a dietary supplement.*

Topical: Dilute one drop tangerine oil with one drop V-6™ or olive oil and apply to desired area as needed.
Aromatic: Diffuse up to one hour, three times daily.
Internal: Put two drops in a capsule. Take three times daily.

*These statements have not been evaluated by the Food and Drug Administration. Young Living products are not intended to diagnose, treat, cure, or prevent any disease. 



WALDORF CHICKEN SALAD

BY AMY ZELLMER, EDITOR-IN-CHIEF

HEALTHY LIVING

WHAT YOU NEED:

- 3.5 oz (100g) chicken, cooked, shredded or chopped
- 3 celery stalks, chopped
- 1 apple, peeled, deseeded, chopped
- ¼ cup (40g) raisins
- ¼ cup (30g) walnuts, chopped
- 1 tbsp. mayonnaise
- 1 tbsp. natural low fat yogurt
- 1 tbsp. lemon juice
- 3 oz. (90g) mixed salad leaves

Serves: 2

Prep: 10 mins

Cook: 0 mins

Nutrition per serving:

354 kcal

16g Fats

33g Carbs

20g Protein

DIRECTIONS:

1. Place the chicken, chopped celery and apple, raisins, and walnuts in a bowl. Add in the mayonnaise, yogurt and lemon juice, season with salt and pepper and mix well.
2. Divide the salad leaves between bowls and top with the filling. Serve with freshly ground black pepper.

VEGGIE OPTION: Instead of chicken add tofu. 



Taking a Step Outside the Head

BY IAN HEBEISEN



While working on her Master's degree, Dr. Mallory Fox studied traumatic brain injuries, sports-related injuries, and concussions. She wrote a paper on CTE, or chronic traumatic encephalopathy, in that time. Yet, despite all of her studies, Fox still struggled finding the steps to recover from her own TBI.

Fox received a few undiagnosed concussions as a child. One incident occurred during her time as a competitive swimmer when she struck

the bottom of a pool. None of these compare to what Fox calls her "Big TBI": a motor vehicle accident. "I was able to walk away from the scene, but within six hours I got a headache that lasted for over ten months," said Fox.

The accident not only left her with a persistent headache, but vision problems as well. "I had found out from seeing a specialist that my eye had moved in the accident, and my brain had shut off my other eye to give me, essentially, movement survival," said Fox. This made her legally blind in her left eye, and resulted in lifestyle changes, which included restricted driving.

Fox began all sorts of treatments and therapies. She underwent vision therapy, physical therapy, occupational therapy, and treatment for EMDR. "I truly tried everything," said Fox. "If someone said craniosacral therapy could help, I tried it. Acupuncture, massage, every medication that my doctor recommended, every type of therapy, every type of test."

But the recovery took longer than anticipated. "My doctors have said 'Here's the normal progression, all brain injuries are different but within this timeframe,'" said Fox. "And then when my recovery didn't meet that expectation, I didn't know what to do."

About four months after the accident, Fox hit her lowest point. She realized she created a life where people depended on her for different things, and expected her to deliver at full performance right away. And if she could not fully understand her condition, how could she expect other people to know what she was going through?

Fox concluded her life changed in a manner that made it impossible to return to her pre-accident self. That didn't mean she had reached the end of the road. "I made a promise to myself ... that I would do whatever I had to do to embrace the person I was becoming."

While on vacation in San Diego, her husband got sick, and the two of them ended up doing nothing for a few days. During that time, Fox noticed her headache

disappeared. Taking the time to actively rest – not just sleep – relieved her symptoms drastically.

From this active rest came a period of self-discovery. Fox started to identify indicators of an oncoming headache or jaw tremor. "My brain was getting exhausted from stimuli. And if I could notice that first sign that the overwhelm was coming on ... then I could potentially avoid the giant headache or aphasia."


In order to calm her system down, Fox turned to mindfulness. "I needed something that I could do anytime and anywhere ... I first started with meditation, mindfulness work, and breath work." When she felt an overload coming on, Fox would excuse herself and focus on her breath, her feet, or the world around her to bring herself out of her head and into the present.

Fox found mindfulness to be so valuable, she started a text message service to help others on their journey. "I wanted to make mindfulness really accessible to people. And I thought pretty much everyone has a phone." The text messages range from a simple "hello" and a deep breath, to more complicated exercises like "What are four things touching your body right now?" Each message is designed to remind the recipient to slow down and take a moment to enjoy the present.

According to Fox, mindfulness does not need to be a 20-minute meditation or an hour-long yoga session. It can only take a minute to come back to the present and reset yourself.

Continuing to forge ahead, Fox encourages others living with a TBI to connect with their communities and to keep persisting. "You are doing a great job with a really challenging circumstance. Don't give up; we need you."

To find Dr. Fox online, visit www.befoxyfit.com. To sign up for her text service, text "mindful" to 480-531-9810.

To listen to the entire conversation, the Faces of TBI podcast is on Apple Podcasts, or wherever you get your podcasts. 

Ian Hebeisen graduated from Saint Mary's University in May 2020, earning a degree in Literature with a Writing Emphasis. Now living in the Twin Cities, Ian writes comics, graphic novels, and poetry. In his spare time, he enjoys playing board games with his family.

You can listen to this episode of Faces of TBI on iTunes or wherever you listen to podcasts.



LIFE LESSONS LEARNED from a **TBI**



BY AMY ZELLMER
EDITOR-IN-CHIEF

The approaching holidays can be a season of overwhelming activities, exhaustion, and burn-out for many of us. Whether it's shopping for gifts, planning dinners with family, or traveling to loved-ones' homes for get-togethers, the experiences can all be too much at times.

Here are a few simple tips to help you navigate this challenging, yet joyous time of year:

- 1. Keep hydrated:** *The brain functions best when it is fully hydrated. When you are out shopping, you may become dehydrated rather quickly. You can combat this by always having a water bottle with you and refilling it often. As tempting as it is, drinking alcohol and caffeine will also cause you to get dehydrated, so it is best to avoid those types of drinks when you know you are going to be faced with overstimulation.*
- 2. Keep additional stimulation to a minimum:** *Decrease the amount of stimulation in places where you have control. If you know you're headed to the mall or crowded restaurant, don't watch television before heading out or listen to the radio on the way. Take your sunglasses and earplugs along, and use them if necessary.*
- 3. Get additional rest:** *While this one seems obvious, the hustle and bustle of the holiday season sometimes makes finding time to rest difficult. Rest is critical to help our brain recover from overstimulation. Take a nap before or after your big outings, and do your best to get a good night's sleep each night.*
- 4. Take shorter trips:** *If you have a lot to get done, you may want to consider breaking your errands into smaller trips. I find it easier to do one errand each day, rather than trying to cram five things into one outing. Your necessary tasks may take longer to do, but your brain will thank you.*
- 5. Make lists:** *I am the queen of sticky notes and shopping lists. Why add additional stress to the situation by going shopping without a clear list of where you need to go and what you need to get? Even with a list, you may still feel overwhelmed and out-of-sorts.*
- 6. Ask for help:** *This tip can be hard to do, but sometimes you need to ask for help—whether it's asking for someone to drive you somewhere, carry your bags for you, or even run an errand for you. Know when you've reached your limits (or, preferably BEFORE you've reached your limits), and ask for help.*

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