Tips for Managing TBI By author and brain injury survivor Louise Mathewson



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A note from the author

In February of 2003, I emerged from a coma following an automobile accident in which I suffered a traumatic brain injury (TBI). Serious head injuries can have an enormous impact on the injured person and his or her family, with far reaching implications. That was the case for me and my loved ones. Since the accident, I have faced some of the biggest challenges of my life as I have worked to recover physically, mentally and emotionally.

Here, I address a few of those challenges and share tips for coping with the *new normal* of living in the wake of TBI. I delight in sharing what has worked for me in my recovery with other TBI survivors. If you or a loved one is in a similar situation, I hope these tips prove useful. I invite you to visit my website, <u>www.louisemathewson.com</u>, for more information and resources to aid you in your recovery.



Credit: Keith Baumbaugh Tropical Photography

You may also contact me directly; I read with interest and respond to all messages. Just look for the "Contact" button, located to the left of the screen on every page of my website!

Blessings, Louise Mathewson

Connect with me at My Website, Facebook, Pinterest, Twitter, LinkedIn, and Goodreads,

or find me at Pearlsong Press and Amazon.



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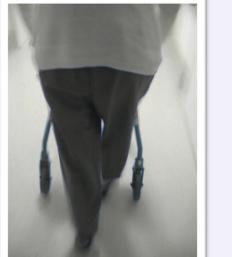
Balance and Motor

If you're physically able to, then walk, walk, and walk some more! Walking is good for health in so many ways. It gets oxygen to your brain, which is one of the best medicines. It also gets you out of the house with different scenery and can lift your mood. However, with TBI I've found that my formerly motivated self sometimes has a very difficult time getting out the door! On days when my energy is low, I use these tips to get me moving:

• Find safe but interesting places to walk. I walk along the beach or bay most days. There is nothing like the ocean or mountains for lifting one's mood. In addition, the repetitive nature of walking is both soothing and reenergizing. Where might you walk? Do you have nice sidewalks in your

neighborhood? Are you near a local park, lake or pond, or how about an indoor mall for walks on inclement days?

- Bring props! To motivate myself on low energy days, I bring along my phone camera and take photos of scenery or things that catch my eye. I also use an iPod or Pandora on my phone to play my favorite music. My preference is relaxing piano solos or sometimes Disney movie tunes. What's yours? What's your favorite instrument? Who is your favorite singer?
- Take a mental walk. When quietly sitting on a chair or sofa, I will visualize myself walking on a log in a brook. After I've mentally mastered that, I'll add an imaginary balancing pole as I cross the log. These mental practice sessions can help build confidence.
- Locate a Labyrinth. In the early months of recovery, making turns was very difficult. One day I walked the labyrinth in downtown
 Naperville, Illinois, where we lived at the time, and found I could hardly make the turns without risking a fall. I decided to walk it every day, which I did, very slowly. After about two weeks, I discovered my balance and ability to make turns were no longer a problem. I've heard that the labyrinth is also good for balancing the brain. You can search and see if there is a labyrinth near you at http://labyrinthlocator.com.





Organization

Since my own TBI, I have wrestled with getting organized mentally and physically. Getting and staying organized on a regular basis can be frustrating and challenging. I have found that the following actions help me to feel both more organized and in better control:

• Journal. The therapeutic benefits of writing are documented by research. Journaling can take any form you wish! Write several times a week or as often as you can; write about your feelings about anything in your day or life: activities, the weather or anything else; make it private and let your feelings out! If you need a witness to your pain, find a counselor, minister or someone you trust to "walk with you." I found that having a witness to



my journaling was very healing and helped me move forward, rather than be stuck in grief forever. On another note, at times when I couldn't get myself to clean off a counter, I wrote about a cluttered table and used personification for the items; for example: papers wanted a home, pencils were looking for a container to rest in, etc. For an interesting approach to organization, check out <u>ConfrontingClutter.com</u>, the helpful website of clutter specialist and journal instructor Carolyn Koehnline, LMHC.

- Make a mind map. A "mind map" is a visual way to organize information. I use a mind map when I can't figure out what to write. Do an internet search for "mind map" to see examples and find instructions to create your own. Mind maps are much more fun than working with lists. For example, you can make a map of things on a table that belong somewhere else, then draw lines out and name a room, closet, drawer or the trash where each might belong.
- **Create!** What might you like to create for yourself? If nobody were watching and you weren't concerned about being judged on the outcome, would you write a story or poem, bake a cake, sew, knit, do woodworking, decorate, sing or play an instrument? Think about creating something for your eyes only, just for the fun of it. Perhaps write a poem personifying items on your kitchen counter or bedroom dresser? If writing isn't for you, try using a tape recorder to tell a story.

My ideas for improving organizational skills and systems

Memory & Processing

TBI often has a dramatic impact on long and/or short term memory. Personally, I have found memory loss to be one of the most difficult after-effects of my injury.

To help me with recall and retention, I use the following:



- Read out loud. I often read instructions, short passages, poems, rhymes or numbers out loud. Reading aloud helps me better understand and remember because it engages both visual and auditory processes in my brain. In conversations with a lot of abstract words to understand, I mouth (move my lips) and that helps me understand and remember at least part of what is said because it accesses my auditory system. Using auditory to support visual cues helps with processing and memory.
- **Create lists.** It's hard for me to sit down to make lists, but I find it so helpful and love the feeling of checking off something I have accomplished. In addition, it gives me a clear picture at the end of the day that I have accomplished more than I thought, because I often forget that I've done anything. The biggest challenge with regard to lists is learning to keep the lists themselves organized. A list is no help at all if I can't find it! I keep a notebook or small pad of paper on the kitchen counter at all times to jot ideas down as they come to mind. Technology, too, has streamlined list taking and keeping. There are many computer apps expressly for this purpose. I use Evernote these days.
- Keep Post-It Notes Handy. In the early days, when my memory was very compromised, I put several Post-It notes around the house if I had an appointment. That way, I never missed an appointment. A visual reminder for things needing attention or tasks or appointments helped my memory improve, so now I only use my calendar. More convenient than a large pad of paper or virtual list on my computer, post-its can be used as things come to mind (because the problem for many people with TBI is that as quickly as something comes to mind, it might leave!).

My ideas for improving memory and processing

Vision

One's vision can be affected as a result of TBI.

When I got permission to start driving again after the accident, I found I couldn't see over my right shoulder. My mind, remembering that my head had been hit when I looked over that shoulder, blocked my vision so I couldn't see. To deal with this, I went to a neuro-optometrist who gave me some exercises to erase the mind-eye connection. Doing those exercises reprogrammed my brain so that it is now safe to look over my right shoulder in traffic.

Depth perception was also a part of my vision affected by TBI; stairs were particularly challenging. To meet the stair challenge:

- I always hold stair railings.
- I keep an eye on the stairs rather than surroundings, since my body will go where my eyes are focused, just like a horse will go where the rider looks. In my early days of recovery, if I looked at a picture on the wall, I started walking into the wall. When walking outdoors, I stop when I want to look up at the sky. I walk deliberately and slowly when I'm on challenging terrain of any kind.



My vision challenges

Managing Stimulation in Crowds

For anyone with a TBI or other brain injury, navigating crowds of people can be incredibly stressful. Colors, the energy of people, and sounds are big distractions and a lot of stimulation for a brain to process.



When in a crowded area or among a lot of people:

- At shopping malls, parties and church, I keep to the perimeter of the gathering if possible, as often as I can.
- At the theater and movies, I do my best to get an aisle seat or sit in the back.
- When in a department store or other crowded, highly stimulating environment, I pay special attention to what my body's telling me. Feeling anxious is a clear signal that it's time to go home, where the stress of overstimulation is relieved.

My ideas for managing stimulation in crowds

Dealing with Catastrophic Thinking

When plagued by thoughts of doom ("*what if XYZ happens?*"), it's important to try to disrupt that thought process. Because when is X, Y, or Z ever something good? It's less like human nature to wonder "what if everything goes great today?" than "what if everything goes wrong today?"



To calm and disengage from those "what if" thoughts, I pull one of these soothers from my tool box:

- Light a candle or fire in winter; sit down and read a book; look at peaceful pictures; do a crossword or Sudoku; or meditate. My favorite is to meditate with my CD playing with ocean waves.
- Make a list of things I am grateful for.
- Look around the room and try to focus on only what I see, and then write and describe it in great detail remaining open to a shift in my mind.
- **Begin thinking or writing** using the sentence stem, "I wonder...", or any other stem that strikes me. For instance: "I wonder who might call today, what I will find on my walk today, what will happen today that I did not plan," etc.

Ways I can redirect my thinking

Moods

For me, moods are can be a sign that feelings want my attention. While I know TBI has affected my mood stability, I also have found that there are actions that may positively impact moods:

- Pay attention to your mood. Get your journal and start describing it or make a list. For instance, I might say "depression is like mud in my gas tank;" then continue with other metaphors: "depression is like..." Often feelings are eased by writing using metaphors.
- **Redirection**. I redirect my thinking by saying out loud or writing, *"I wonder..."* (I use *"I wonder"* a lot!). This allows anticipation and imagination to step in, where endless possibilities live and breathe. Then wonder itself can send new roots into the ground of life. *"I wonder"* can chase dark clouds away from our minds.
- Meditation. There is a lot in the news these days about how good meditation is for a brain, especially an injured one. Meditation can calm an overactive brain. There are many ways to meditate. Meditation involves emptying your mind as much as you can. When thoughts intrude, which happens to all of us, some teachers suggest focusing on a sound, your breath, or an image. Another way is to use a word, like peace, calm, joy, love or another word that helps you regain a calm, empty-of-worry mind. If you are new to meditation, start with 1-3 minute sessions. Guided imagery programs, such as <u>A Guided Meditation for Traumatic Brain Injury</u> by Belleruth Naparstek, can also be helpful in developing a mediation practice.
- **Practice Loving Kindness Meditation**. Another type of meditation is Loving Kindness Meditation (LKM). Sit quietly, close your eyes or focus on a candle, breathe from your belly, and repeat to yourself: *May (person's name) be healthy and happy; May (name) be safe; May (name) be at ease with life*. Or you can create your own set of good wishes. You can also insert your own name and do it for yourself. I find when I am worried about someone, if I practice LKM, it often dramatically changes my worry pattern to positive thoughts about a person. I worry much less and that improves relationships because I am not sending out worry or negative energy. LKM can help with focusing, attention, anxiety, mood and other issues commonly affecting individuals with TBI.
- Create a calming visual aid. I took

 a 6x8 photo book and inserted
 ocean pictures from a small
 calendar from the past year. Water
 is very calming for most people.
 What do you find calming? Make
 your own book of animals, people,
 colors, sights, flowers, water,
 mountains or whatever calms you.

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- Nourish. There is a direct link between low blood sugar and mood. Consider consuming a protein drink, almonds or other nutritional snack if more than 2-3 hours since you last meal.
- Set the mood. Play music, light candles, add fragrance, and use pleasing colors in each room of your home or office. Color can positively influence mood. I play my favorite, calming music, with my favorite instrument. Music is a powerful influence on one's mood. Piano and harp are my favorite instruments to listen to (Lorie Line and George Winston are my favorites). When I am writing poetry, I listen to *Creative Mind* (CD), by Jeffrey Thompson. *Creative Mind* increases alpha waves in my brain which help me to relax and access my creativity.
- Mandala Coloring. Coloring geometric figures known as mandalas is a very relaxing exercise and can have a positive impact on mood. You don't need any artistic ability to benefit from the back and forth movement of hand and the simplicity of adding color within the shape's outlines. As I color, I often visualize the Caribbean on a sunny day. Google the word "mandala" to get more information. There are also instructional and coloring books at to be found online at <u>Amazon</u> and <u>Barnes & Noble</u>, and at chain and independent bookstores nationwide.





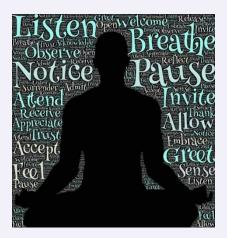


Ways I can positively impact my mood

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Fear and Anxiety

When I was discharged from the hospital, my speech therapist told me that my circle of comfort would shrink after the accident. She explained that was normal for someone with TBI, and that pulling back a little would reassure my nervous system that I was listening. She suggested I think of gently stretching a rubber band; when it stretches too far, it wants to come back in. She pointed out that the same was true of me and that was okay, but to be aware of stretching myself so I could improve and heal. (Note: If anxiety is too great, some people need to see a doctor. Medication can help.)



- **Breathe:** Breathe, breathe and breathe some more. I have found that the more I pay attention to myself, my body and my breath, the more recovery I am able to achieve.
 - Breathe from the diaphragm! When I start feeling anxious, becoming mindful of my breath and practicing diaphragmatic breathing has been very helpful. By holding my hand on my belly and taking in deep breaths to fully engage my diaphragm, I feel my belly rise and fall and avoid the shallow chest breathing that actually contributes to anxiety.
 - Sometimes I focus on my breath and count to 4 or 5 on an inhale, and then count to 6 or 7 on an exhale. I do that 5 times or so and it usually calms me down.
 - When I notice that I am jittery or anxious, I take as deep a breath as possible and shape my mouth like an 'O,' and blow out my cheeks like blowing out a candle slowly, as if to say "whooooo."
 - Taking a deep breath and letting out a sigh is also very relaxing.
- **Relax:** When I can, I lie down and do a body scan, starting with my head and saying "My head deserves to relax; my neck deserves to relax, my shoulders deserve to relax," and so forth all the way down. Repeating the phrase "deserves to relax" gives me permission to let go and allows my body and mind to respond.
- Plan: I have learned that making a written plan for each day has also eased my anxiety. I use a weekly, *At-A-Glance*, 8x11" planner which works very well for me.

Ways to calm myself when I am afraid or anxious

Recommended Resources

The following resources have been invaluable in my own physical and emotional recovery from traumatic brain injury.

Brain State Technologies' System for Brainwave Optimization is technology designed for relaxation, self-regulation and meditation to balance and optimize your brain. Brain State Technologies in Bloomington, MN is where I received excellent treatment. <u>www.brainstatetech.com</u>

Hyperbaric Oxygen Therapy uses a special pressure chamber to increase the amount of oxygen in the blood. This treatment is often available at centers for autistic children.

Interactive Metronome addresses neural timing deficits (your brain's internal clock) that can be caused by TBI, stroke, ADD and other conditions. <u>www.interactivemetronome.com</u>

Kay Adams is a best-selling author, speaker, and psychotherapist at the heart of The Center for Journal Therapy (<u>www.journaltherapy.com</u>), Journalverse (<u>www.journalverse.com</u>), and the Therapeutic Writing Institute (<u>www.twinstitute.net</u>).

Linda Leedy Schneider ACSW, LMSW, MSW is a psychotherapist in private practice, and professional poetry and writing mentor. <u>http://www.pw.org/content/linda_leedy_schneider</u>

Meditation for Traumatic Brain Injury (TBI). Naparstek, Belleruth. Health Journeys, Inc., 3 Sept. 2012. CD, MP3. <u>http://www.healthjourneys.com/Store/Products/Traumatic-Brain-Injury-TBI/643</u>

Somatic Experiencing Therapy - Lynn Bartoszek, Venice, FL, trained in Peter A. Levine's work, helped me get back feelings that had been trapped in my body from the beginning of the accident and from time spent in ICU, which I have no memory of. My body told the story and I was able to put words to the experience with the guidance of Levine's work (www.traumahealing.com). It erased almost all the flares of anger that used to come without any warning.

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Louise's Website, Facebook, Pinterest, Twitter, LinkedIn, and Goodreads, or find her at Pearlsong Press and Amazon.



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My Notes

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