



Brain Injury
Alliance
of New Jersey

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Helpline: 1-800-669-4323
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No Brain Injury is
Too Mild to Ignore,
or Too Severe to
Lose Hope

Take Care of Yourself

By Garry Prowe

Studies show that caring for a person with a brain injury leaves you vulnerable to stress-related illnesses. So, how do you prepare yourself for this difficult job? Let's start with your physical health. It's okay to skimp on sleep, munch on fast food, and ignore your exercise routine for a week or two. However, when the adrenalin and the nervous energy that have been keeping you going well beyond your normal limits fade, your survivor may be emerging from her coma or just starting her rehabilitation. This is not the time to run out of gas. So, follow Mom's advice:

- Get enough sleep.
- Eat well.
- Exercise.
- Have some fun.

Maybe Mom didn't mention that last one, but it's as crucial as the first three. I can't overstate the importance of taking occasional vacations from the unrelenting responsibilities of caregiving. I waited too long to refresh myself. At times, I was merely a presence, rather than a participant, in Jessica's care, and she suffered because of this. Be kind to yourself. Take regular breaks from brain injury.

- Read a book about something other than brain injury.
- Go to a movie, a concert, a museum, or a sporting event.
- Take a walk. Go for a run.
- Knit a scarf. Play a round of golf. Sing a song.
- Find ways to relax. Meditate. Pray. Practice yoga.
- Stay in contact with family, friends, and colleagues.
- Talk about something other than brain injury.
- Laugh as often as you can.

Next, ask yourself what you know about brain injury. If you're like I was, the answer is probably "not much." So, resolve to learn as much as you can. If one family guide is not enough, here are two others that merit your attention:

- *Mindstorms: The Complete Guide for Families Living with Traumatic Brain Injury* by John W. Cassidy, M.D. with Karla Dougherty, Da Capo Press, 2009.
- *Head Injury: The Facts* by Audrey Daisley, Rachel Tams, and Udo Kischka, Oxford University Press, 2009.

Here are five other easy ways to learn more about brain injury:

1. Contact the Brain Injury Association of America (800-444-6443 & www.biausa.org) and / or your state brain injury organization. These organizations have an abundance of useful information, particularly on local resources.



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2. Join a support group, either locally—ask the people at your state association—or online. Support groups are a great way to learn from the folks who have been there. They can give you valuable advice and guide you through the endless waves of emotions you're struggling to control. You also may find a new friend who knows exactly what you're going through.
3. Keep an up-to-date list of questions for the doctors and don't hesitate to ask them every chance you get.

Now let's talk about how you're going to find the time to: Be a full-time caregiver to your survivor, meet your obligations to family, job, studies, and the other demands of your life, learn about brain injury, have some fun. Simply put, you're not. There aren't enough hours in the day.

If you haven't already been asking for help, start now. You shouldn't be spending 24 or even 12 hours a day at the hospital or rehabilitation facility.

An Exception: Three panel members asked me to make an exception to this advice for mothers. As one told me, "I needed to be there every minute. It was just that simple." Okay, I'll make an exception for moms, with one condition. Always remember that when your child comes home, even if she is an adult, she will be totally dependent on you, 24 hours a day, every day. If you compromise on your health now, you may be endangering her well-being later. At the first sign of declining health, please, take a break to refresh yourself.

Not only must you be physically fit to be an excellent caregiver, you also must be emotionally fit. You may not realize that emotions run amok can overwhelm and immobilize you. Caring for someone who has just acquired a brain injury leaves you vulnerable to at least ten emotions that can compromise your caregiving abilities.

1. Shock
2. Denial
3. Panic
4. Anger
5. Guilt
6. Grief
7. Helplessness
8. Loneliness
9. Fear
10. Depression

Just being aware of the potential havoc these emotions can wreak gives you a head start in handling them well.



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Shock: This is a common reaction to any terrible news.
This can't be happening. It doesn't feel real.

Denial: Shock often leads to denial.
*There must be a mistake. Jessica wouldn't drive like that.
Not my son. He'll be back to his old self in no time.*

Shock and denial are healthy. They give you time to accept the reality of a sudden tragic event. They become unhealthy when allowed to linger. For example, too many survivors and caregivers deny that a serious brain injury is forever. Denial then becomes an insurmountable obstacle to a successful recovery.

Panic: Panic usually accompanies shock and denial. Your thoughts are jumbled. Your body is shaking. Adrenaline is shooting through your veins, making you restless, if not hyperactive. Nothing makes sense. You don't understand and you cannot recall what the physicians are saying. You're in no condition to make vital decisions.

On day two of Jessica's recovery, I asked Dr. Zimmerman—the neurosurgeon consulting on Jessica's case—the same question five times, never absorbing his response. Fortunately, Barbara was with me and she took over the questioning when Dr. Zimmerman lost his patience.

Shock, denial, and panic usually are short-term emotions. When they are preventing you from facing your survivor's injury realistically and rationally, it's best to have someone at your side to help you cope with the situation.

When the adrenaline stops flowing and you've had time to digest the bad news, other emotions can distract you from your caregiving responsibilities.

Anger: Something immensely unfair has happened to your survivor, to your family, and to you. Your lives are about to be changed dramatically. The future suddenly has become cloudy. It's not unreasonable to be angry at:

- Your survivor, for putting herself at risk
- The person who caused the injury through recklessness
- Yourself, for somehow not preventing the injury

If you're really losing your cool, you may direct your anger at:

- The doctors for not being more definitive in their statements
- The nurses for not treating your patient better
- The custodian who mops the floor at an inconvenient time



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Here are three suggestions for harnessing your anger:

1. Try to forgive everyone responsible for the injury—including the survivor and yourself. Blaming others accomplishes nothing. If you can't forgive, set blame aside for a while.
2. Vent your anger. Letting it boil will make you even angrier until you explode.
3. But be careful how you vent. Directing your anger at the people caring for your loved one—doctors, nurses, therapists, and health insurance bureaucrats, for example—is never beneficial and can be harmful.

Twice, in the early days of Jessica's recovery, I let anger overwhelm me. The first time I punched the wall of an elevator. The second time I screamed at Jessica's Uncle Elliot. No harm done. My weak punch didn't send me to the emergency room and Elliot understood my need to vent. A punching bag, however, would have been a better choice in the first case.

Guilt: Guilt is another potentially harmful emotion. Spending hours wondering what you could or should have done to prevent the injury will not help your patient recover. Don't lose sleep over the "why" questions. *Why did I let her drive at night? She's too young.*
Why did I let him get a motorcycle? They're so dangerous.

There are no answers to these questions. Focus on the future, not the past. Accidents happen.

Guilt also can arise from how you have chosen to spread your time among your survivor, family, employer, and anyone else who depends on you. Remember, you can't satisfy everyone. You have made an informed decision regarding what's best for you, your patient, and others. Now, you mustn't allow guilt to weaken your resolve to stick to that decision.

Guilt can be unhealthy in two ways:

1. It can crowd out the positive emotions—joy, hope, and determination—essential to being an excellent caregiver.
2. It can cause you to try to absolve yourself by attempting to be a superhuman caregiver.

Grief: Grief is a natural and healthy response to a brain injury. You, too, are a victim. But, unlike death and a funeral, there's no social convention for publicly acknowledging your grief. Most people are ignorant of the life-altering consequences of a brain injury. You may not receive the support you need to work your way through the mourning process.

Coping with your grief is a crucial aspect of your recovery. Here are six suggestions for healthy grieving:



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1. Don't let yourself be rushed. Everyone grieves at his own pace.
2. The only way to get past your grief is to experience it.
3. Let it ebb slowly.
4. If you have the urge to cry, let the tears flow.
5. If you need to talk, find a good listener.
6. If grief is distracting you from your caregiving duties, see a professional counselor.

Helplessness: Helplessness is a hallmark of brain injury. Much of what will happen in your patient's recovery is beyond your control. You can't wake your survivor from her coma. You can't heal her brain. You can't accelerate her recovery; it is a slow, lifelong process. Worst of all, you can't foresee the future. No one knows how well your patient will recover. Helplessness can be maddening. More importantly, it can lead to lethargy.

This situation is so bad.

There's nothing I can do to help.

I guess I'll stop trying.

Here are five ways to combat helplessness:

1. Identify what you can control. The Checklists for Success are a great place to start.
2. Record your goals.
3. Plan how you will accomplish these goals.
4. Concentrate your energy on implementing these plans.
5. When helplessness resurfaces, refer to your list, your goals, and your plans, and put yourself back on track.

Loneliness: Only those who have experienced brain injury can truly appreciate the unique challenges you face. Your relatives and friends won't fully understand what you're going through. They may not know how to support you.

When loneliness is weakening your resolve, try these five suggestions:

1. Reach out to others. Ask for their support.
2. Explain that your survivor has been transformed forever and you have no idea what the future will bring.
3. Ask those closest to you to read this book.
4. Join a support group, either locally or online.
5. Don't go through this ordeal alone.

Fear: Fear is another potentially debilitating emotion. Brain injury can cause a multitude of fears, for example:

- Your patient may not recover as well as you hope.
- You may lose your job if you spend too much time at the hospital.
- The medical bills may bankrupt you.



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- Your family may fall apart.
- You may not be up to the role of caregiver.
- You are terrified by the unknown.

Unresolved fears will eat away at you and compromise your ability to care for your survivor. Fear is best countered with education and action. If the unknown is keeping you awake at night, follow these eight suggestions:

1. Identify and confront your fears.
2. Absorb the information contained in this book.
3. Review and follow the advice offered.
4. If you're worried about money, read the article "Paying the Bills". Then, review your finances and adjust your spending, if possible.
6. If your survivor is eligible for government benefits, apply now.
7. Be sure your employer fully grasps what you're going through.
8. If you're worried about your caregiving abilities, honestly assess your shortcomings and start asking for help.

Depression: Unless you always view the glass as half-full, expect to be hit by depression soon, if it hasn't hit already. This is natural. The loss you suffered is shattering. The task ahead appears insurmountable. Some depression is okay, but don't let your brain become habituated to depression. The actual mix of chemicals produced by your body when you are depressed can be tough to turn off if it flows for too long.

If depression is making it difficult for you to get out of bed in the morning, driving you to drink too much, or interfering with your caregiving, follow these four suggestions:

1. View your depression as the first step in adjusting to your loved one's brain injury.
2. Share your concerns and grief with somebody.
3. Seek professional counseling.
4. Tell your doctor about your depression and its causes. The temporary use of prescription medication can help lift the cloud of despair and re-energize you.

A major turning point for every caregiver is being able to conquer much of the anger, guilt, grief, helplessness, loneliness, fear, and depression that accompany this major, unanticipated life change. (These emotions will never go away completely.)

To be an excellent caregiver, you must trade your negative emotions for feelings that will focus your energy on supporting and advocating for your survivor. These are:



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Joy
Hope
Determination

Joy: I know it's not easy to imagine feeling joy in the face of the daunting challenges you and your loved one face. However, it's crucial that your patient—who may sense and mimic your state of mind—be surrounded by positive energy. Even today, Jessica is quick to recognize my moments of emotional turmoil and adopt my mood. Don't let your negative thinking thwart your survivor's progress.

Keep these four suggestions in mind:

1. Celebrate even the tiniest gains—the first opening of an eye, the first spoken word, the first hug, the first meal.
2. Don't dwell on what your survivor was able to do before her injury.
3. Focus on what she can do now and the huge advances she will make in rehabilitation.
4. Remind yourself frequently that countless survivors of serious brain injuries create new, rewarding, and happy lives after their recovery and rehabilitation.

Hope: Hope is essential to a successful recovery. Without hope there is helplessness. When you're dragged down by helplessness, the rigors of living with a brain injury soon will exhaust you. Without hope, you become one more obstacle for your survivor. With hope, you can motivate her to work hard at her recovery and rehabilitation. Some overly cautious doctors and nurses will try to stifle your hope by mistaking your realistic optimism for denial. Don't let them. But remember, there can be a fine line between hope and denial. A successful recovery is not a full recovery, but considerable headway is possible with perseverance and patience by the survivor and the unending support of her family and friends.

Determination: Your loved one is facing a monumental task. Her success depends on her determination to work hard and your determination to support her in every way possible.

To summarize the main points of this section, there are eight different ways you should be preparing yourself to be the caregiver your survivor deserves:

1. Focus on what you can control.
2. Take excellent care of yourself, both physically and emotionally.
3. Learn all you can about your survivor's brain injury.
4. Take regular vacations from caregiving duties, even if just for a day.



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5. Ask for help often.
6. Turn unhealthy emotions into an optimistic outlook.
7. Focus on the strength and resilience you share with your survivor.
8. Always remember, you can do this.

Faith

For many caregivers, the comfort and strength they derive from their faith gives them the joy, hope, and determination they need to excel at their new responsibilities. For certain believers, however, a brain injury is a formidable challenge to their faith. “Why me?” they ask. “What did I do to deserve this misfortune?” They struggle to make sense of their lives, suddenly filled with disheartening and undeserved new trials. These feelings of abandonment can undermine their value as a caregiver. If your survivor’s brain injury has you doubting your faith, consider the following twelve suggestions:

1. Be open to the renewal of your faith.
2. Think back to a time when you felt the loving presence of God.
3. Pray, even if you doubt its usefulness.
4. Ask others to pray for you.
5. Attend services.
6. Try to identify and confront the emotions that may be overpowering your faith.
7. Remember, it’s okay to be angry with God.
8. Talk to someone of faith whom you respect and trust; speak honestly about what has stolen your faith.
9. Talk to others who faced challenges and kept or regained their faith.
10. Stop asking “Why me?” There is no answer to this question.
11. Be mindful of the blessings you have been given.
12. Surround yourself with spiritual experiences: uplifting and inspirational music, books, poetry, and talks.

Asking for Help

Supporting a person with a brain injury through her grueling recovery and rehabilitation is more than a full-time job. Most of us can’t devote all our time and energy to our survivor. We have responsibilities to our children, to our employers, or both. In my case, poor health forced me to be a part-time helper. Even if you have no other responsibilities and are available full-time to support your survivor, spending every hour of every day at the hospital is a poor decision for nearly everyone. This is exhausting work. Fatigue inevitably leads to illness, and an ailing caregiver is a poor caregiver.



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Recognize that you need help. People will be willing, even eager, to help you and your survivor. They may even feel honored that you turned to them in a crisis. Give these folks the opportunity to help. Accept their assistance without embarrassment. Someday, you will be able to return the favor or aid someone else in need. I asked everyone we knew for help and I was gratified by the response. A few “close” friends disappeared, and it hurt. But, you should expect this. To make your requests for help easier and more productive, here are nine suggestions:

1. Identify and record your needs. My biggest need was for people to spend the afternoon with Jessica at the rehab facility. They encouraged her in her therapy, reminded her to rest between sessions, and cheered her when she became discouraged. You may need folks to

- Compile information on brain injury.
- Review your insurance policies.
- Help you select a rehab facility.
- Sit with your survivor.
- Provide transportation.
- Prepare meals.
- Baby-sit or check on folks and animals at home.
- Run errands.
- Clean the house.
- Mow the lawn.
- Shovel the driveway.
- What else do you need?

2. Broadcast your needs widely. People lead busy lives. They won't always be available when you need them. Here are five easy ways to reach everyone:

- Send emails.
- Record a message on your answering machine or voicemail.
- Form a telephone tree.
- Ask someone to organize a network of helpers and schedule their activities for you.
- Create a Web site to post the latest news. You can do this for free at www.CaringBridge.org and www.CarePages.com.

3. Be prepared with a list of needs. When people ask, “What can I do to help?” pull out your list and put them to work. People will stop asking if their initial offers are not accepted.

4. Give people permission to say no. In an email, I wrote, “I plan to ask for your support soon. This is difficult for me. You can make it easier by simply and directly saying ‘No’ when you’re not available, for any reason. I promise I won’t be hurt and I’ll keep asking.”

5. Find the right man or woman for the job. Jessica’s well-read Uncle Elliot was unable to spend a full afternoon at the rehab hospital. He was,



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however, the ideal person to find me a few books about brain injury rehabilitation.

6. Be creative. There are all kinds of ways people can help. Jessica's cousin, Lisa, was housebound with a complicated pregnancy. From her bed, she maintained the ever-growing list of folks receiving my emails. Lisa circulated the messages and compiled the responses. This saved me hours of aggravation.

7. Let others perform tasks that may upset you. On the day of Jessica's accident, the hospital social worker handed me a plastic bag containing Jessica's clothing. I discarded the bag because I couldn't bear to open it. Six months later, we realized that the bag I discarded probably contained a cherished necklace. It didn't occur to me at the time to set the bag aside and ask someone to check its contents.

8. Keep asking for help as long as you need it, even if others question you. About six weeks after Jessica's accident, my mother asked, "Don't these people have families of their own to care for?" I think she was embarrassed by my frequent appeals for help. I learned, however, that many people were happy to support and to continue supporting Jessica's recovery.

9. Periodically ask someone if you have overlooked something that will help your survivor. In my discombobulation, I didn't think to bring Jessica her favorite foods when she was in rehabilitation. I also learned too late—from Karen Brennan's moving memoir, *Being with Rachel: A Story of Memory and Survival*—how much Jessica might have benefited from my cuddling in bed with her. What are you overlooking?

Garry Prowe is well known in the brain injury community for his research and expertise in how survivors of a brain injury and their families overcome the considerable challenges they face every day. The author, who holds a master's degree in public policy from the University of Michigan, formed a panel of more than 300 survivors, family members, and healthcare professionals. The author's research also is informed by his role as caregiver to his wife, Jessica, who has a severe brain injury.

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