INTEGRIS
Jim Thorpe Clinical Development

Caregiving: Taking Care of Yourself

Caring for a loved one can be a strain on even the most resilient individual. Caregiving is a job, with tasks, responsibilities, and the potential for stresses and rewards.

What is caregiving? The National Family Caregivers Association has developed this “Caregiving Is” list to give you an idea of just how varied and complex caregiving can be.

CAREGIVING:

- Is a multi-dimensional puzzle. For some it means providing 24-hour care for someone who can’t dress, feed, go to the bathroom, or think for himself or herself. For others caregiving is an emotional roller coaster because a diagnosed condition is sometimes more manageable than others.
- Can go on for a few months, years or for a lifetime. It means re-evaluating finances, re-evaluating job opportunities and making compromises.
- Is learning how to work with doctors and other healthcare professionals so they treat you as an important member of your loved one’s healthcare team.
- Is worrying about what’s wrong with your loved one. Why is he/she not remembering things anymore? Why is he/she acting so strangely? And then when you hear the diagnosis, your immediate reaction is wishing you had never asked.
- Includes learning about wheelchairs, adaptive equipment and other gadgets that help you button a shirt.
- Is wondering why no one ever asks how you are.
- Is dreaming about being alone in your own house.
- Involves learning about Medicare, Medicaid, social security and other public programs.
- Is the joy you feel when your loved one learns a new skill.
- Is hard work. Caregiving is pain. Caregiving is loving and giving and sharing. Caregiving is accepting and learning new things and going on, and

on and on. Caregiving is lots of questions and very few answers. Caregiving is being out of the mainstream.

- Is all of these things and a whole lot more.

An important part of being a good caregiver is taking care of ones' self. At one time you may have wondered if your loved one was even going to survive. The fact that they have come to Jim Thorpe Rehabilitation, an in-patient rehabilitation facility, is a good thing. They are now more medically stable and able to tolerate therapy. They are one step closer to getting home. In rehab you should be able to find trust in the care being provided to your survivor and also realize that you have needs of your own.

Although many caregivers have described themselves as feeling both physically and emotionally better as a result of successfully managing caregiving challenges, many also feel overwhelmed. Feelings of emotional distress or physical symptoms should be viewed as signals that caregivers need to take better care of their self. This will benefit the caregiver and survivor alike.

Although positive aspects of caregiving can exist, direct negative effects of caregiving are the stresses resulting from providing physical assistance to your loved one. For instance, dressing, bathing, or toileting may be physically difficult and the amount of time needed to complete them may be exhausting or time consuming. The closer your loved one gets to discharging, the more family training will be performed with therapy and nursing staff instructing you how to do things with your loved one. This increases your survivor's independence and decreases the amount of care that you will need to provide to accomplish a task. Furthermore, care can also be emotionally draining, particularly when the survivor is emotionally upset or agitated.

Ripple effects are the consequences of caregiving on other parts of the caregiver's life. Caregivers may feel torn between responsibilities to the survivor and to other family members; they may have to relinquish work, friendships or other personal interests or activities. For many caregivers, these ripple effects are more difficult and stressful than their actual care activities.

Support and encouragement from other people can buffer the caregiver from stress. Receiving emotional support from family and friends provides an important buffer against the stress and burden of caregiving. It is the social contact, more than any tangible care they may provide that is important.

When your survivor is in the rehabilitation hospital, it is a safe place. Even though you may feel like you need to be with them all the time, this is the place where you have help to care for your survivor. We don't expect to have your full trust when you walk in the door, however hopefully soon after admission you will discover the passion this staff has to increase your survivor's independence and decrease the burden of care for you. It is during your survivor's stay that you have the opportunity to step back and try to care for yourself as well. This is only a chapter of the journey for you and your family. There will be many more. You must take care of yourself!!

Because caregiving can be so overwhelming, it is important that you take steps to refresh yourself. This will help ensure that your loved one will get the best you have to offer on any particular day.

1. **Schedule some time for yourself.** Whether you feel like you need a break or not, schedule some time for yourself. Carefully guard this time and try to have it be close to the same time every day. It may mean going to a quiet place in the hospital to get on your computer. It may mean getting out of the building for a coke. It may mean taking a nap or a walk. Learn to say no when someone asks to come visit during that time or other activities try to fill up that time as well.

2. **Share your feelings.** Talking about your worries/concerns regarding caregiving is not complaining. Sometimes family and friends assume that you are doing fine because they simply don't know any better. Surround yourself with a strong support system if possible. A sympathetic and caring ear can do wonders for your piece of mind. Feel free to ask staff any question as to why we are doing what we are doing and what we are hoping to accomplish by doing it. You may consider keeping a journal. If the days haven't started running together yet, they will. By keeping a journal of your loved ones progress and your feelings, you may be better able to acknowledge minimal gains that you might otherwise overlook.

3. **Ask for help.** There is no reason to isolate yourself when you don't have to. Make an honest assessment of your strengths and weaknesses. You may be able to be a great "cheerleader" for your loved one but may not to be able to do the "physical" things demanded from you to perform various caregiver tasks. You may be able to do all the "physical" things but unable to keep optimistic regarding your loved one's outcomes. It has been said that it takes a village to raise a child. The same can be said when dealing with head injury survivors. Figure out tasks you need assistance with both while your loved one is in the hospital and as you plan for discharge. When enlisting help from others, be as specific as possible. When planning, don't ask someone to come to the hospital or to your home "anytime" to "lend a hand." Set a time and have specific task for them to do. Try not to ask someone for help only to make them a spectator. You may need someone to spend the night with your survivor so you can go home to sleep in your own bed. You may need someone to spend an afternoon keeping an eye on them as they wander the unit so you can rest. Put friends and family at ease by explaining exactly what it is that you need from them. Staff is available as well to help with instruction as needed.

4. **Give yourself grace.** You will not be able to do it all. You will make mistakes. Deal with yourself gently. You can only do what you can do. Don't beat yourself up.

5. **Eat smart and exercise.** You've heard this before but proper nutrition will make you a stronger person, and a stronger person makes for a stronger, happier, more effective caregiver. Structure a 20 minute walk throughout the day. Drink less caffeine which may cause anxiety, insomnia and nervousness. Drink more water. Try to get at least 7 hours of sleep a night. Touch/hug someone. (Staff is very good at giving hugs.)

6. **Keep the faith.** Your faith will become very important to you if it hasn't already been a major part of your life. Try to remain positive yet realistic. Realize your loved one, you, and the rest of your family may have a "new

normal”. Try to remain positive in focusing not on the things you have lost but the relationships you have the opportunity to improve.

7. **Get plugged into a brain injury support group.** Whether you realize it at the time of discharge or not, you will need to be plugged into a support group for both you and your loved one. In your journey, you will always find “someone better off than you”, and you will always find “someone worse off than you”. Jim Thorpe holds a brain injury support group the fourth Thursday of every month. We try to get you this information and allow you to attend the group prior to your loved one’s discharge from our facility. This group will become very important to you as you glean wisdom from them. It is very beneficial for both the survivor and their families.