Taking the Caregiver into Account

By Teri E. Layzell, MSW, LCSW

If you hired a financial advisor who recommended that you empty your bank account, live paycheck to paycheck and not bother to save for retirement, chances are you would fire that advisor on the spot. Practices like this are clearly detrimental to your financial health. But this is how many caregivers regard their emotional and physical health. They often feel physically depleted, live moment to moment and don’t bother to take time to restore their energy. Just as being financially bankrupt is unhealthy, it’s injurious for caregivers to ignore their own health and well-being when caring for someone with a long-term illness like chronic fatigue syndrome (CFS).

Caregiving is a difficult job, especially when added to the other duties of providing income, parenting and managing a household. It’s also a very admirable role, because it’s usually driven by love and compassion.

The downside to caregiving is exhaustion, resentment and anger. To avoid these pitfalls, it’s imperative that you remain mindful of your own needs, limitations and resources. Here are some pointers to help you do just that.

Invest in your physical well-being

CFS often demands many trips to the physician, numerous procedures and medication adjustments. With all the time this requires, it can be easy to let your own medical maintenance lapse. My advice to you is: don’t. Your physical health is just as important as that of the person you caretake. Routine screenings and annual exams are necessary to keep you in top shape so you can better manage life, work and the needs of your family. Remember, taking time out to care for yourself is not selfish; it’s an investment.
Nutrition and fitness are also important to good physical health. Households coping with chronic illness are often financially challenged as well. Money is tight, so memberships to the gym and high-end health foods may not be an option. But keep in mind that junk foods, convenience foods, sodas, alcohol and cigarettes are also expensive. Money spent on those items can often be transferred to fresh produce and wholesome foods. With more nutritional benefits, you actually get more for your money.

As for fitness, walking is free. Though someone with CFS must be careful about the effects of overexertion, a caregiver can greatly benefit from modest aerobic exercise. Just 20-30 minutes a few times per week will aid in the prevention of heart disease, depression, diabetes and many other chronic illnesses. The stamina you build will serve you well in taking care of yourself and your loved one with CFS.

And then there is sleep. Though many people with CFS experience sleep dysfunction, sleep can be elusive for caregivers as well. Worries about health, finances and time management often make it difficult to fall asleep or stay asleep. Recent studies indicate that a lack of sleep may lead to obesity, cancer, heart disease and diabetes. Although the jury is out on whether lack of sleep is a direct cause of these illnesses, we do know that good sleep is important for emotional and physical health. If you’re having trouble sleeping, basic sleep hygiene practices—like maintaining a consistent sleep schedule, avoiding physical stimulation before bed and making dietary and nutritional adjustments—can often help. (See the Online Bonus for more on sleep hygiene and other health resources.)

Your goal is to keep physical, emotional and spiritual reserves at their fullest. That way, as needs arise you can draw from your “Bank of Energy” account without draining your own health and well-being.

Take stock of your emotional well-being

It is not possible to separate your physical and emotional self. Deficits in one area will affect the other. In fact, studies show that the ongoing stresses associated with caregiving can impede the body’s ability to heal.

This is because our bodies are naturally equipped to go into battle to defend us. Perhaps you’ve experienced this during a medical emergency or other danger when your body goes into high alert—adrenaline pumps, pupils dilate, focus becomes keen. When the crisis passes, you may be exhausted while your body resets back to “normal.”

When we experience continued stress, our bodies stop resetting back to normal. Instead, they perceive us as living in a constant battle. This becomes the “new normal” and our bodies remain in a state of high alert. Each additional stress produces even more strain on a system operating beyond its means. Eventually, we can deplete our system, resulting in a multitude of physical illnesses, anxiety, or depression.

As a caregiver for someone with CFS, you are or will be faced with many stresses—some small, some big. Emotionally, you may feel angry, resentful, helpless, frustrated and/or guilty. Those feelings are normal. Remember, there is no such thing as a “bad” feeling. Some are more uncomfortable than others, but they’re all part of the human experience. While you might not have control over your loved one’s CFS or the associated emotions, you do have a choice about how you manage those feelings.

Communication is one of the greatest tools in managing stress and maintaining healthy relationships. Ignoring your feelings won’t make them go away. Pushing them down simply increases the likelihood that they’ll emerge via other means, such as angry remarks, emotional distance and passive-aggressive behaviors. Try sharing your feelings about caregiving with your loved one with CFS—ideally when things are going well and you’re less apt to make comments in the heat of moment. While these talks may be difficult, you’ll reap the benefits numerous times down the road. Be sure to share feelings of compassion, love and appreciation with your loved one as you experience them as well.

If you can’t share your thoughts with the person for whom you’re caring, a counselor, clergyperson or understanding friend may be able to provide a good sounding board for expressing your feelings.

Whether you’re caring for a child, partner or adult parent, it’s also imperative to your emotional health that you take time to pursue your own interests and relationships. Creating
a good support system that includes friends, family, clergy and/or professional mental health providers will provide an outlet to manage stress and learn new coping skills. While it may seem that you’re taking time away from your loved one with CFS, pursuing other interests and hobbies will help you stay energized and refreshed. It keeps you in the frame of mind to give care out of love rather than obligation.

**Don’t shortchange your spiritual well-being**

Just as your physical and emotional states are related, your spiritual health is interconnected as well. Whether at a place of worship, in your home or a quiet place outdoors, it’s important for you to find time for meditation, prayer or thoughtful repose. Whatever means you choose, find time to connect with inner peace and stillness. It will reduce stress, boost your physical health and help you manage your life from a perspective of gratitude and compassion.

Recent studies also demonstrate that intercessory prayer is beneficial in the recovery of illness and healing postsurgery. So, in addition to helping you keep yourself well and balanced, meditation or prayer may also benefit the healing of those around you.

**The bottom line**

Though none of the issues discussed here are new, it’s always beneficial to revisit the basics of sound body, mind and spirit—especially when someone else’s care relies partly on your well-being. Some of you longtime caregivers may say, “Yeah, yeah, I know all this. I’ve heard it before.” But, remember, this is a process, not something you do once and move on. Just as CFS ebbs and flows, so do the many ways that caretaking can impact your health. You must regularly reevaluate yourself and your relationship with the person in your life who is living with CFS. Your goal is to keep physical, emotional and spiritual reserves at their fullest. That way, when needs arise, you can draw from your personal “Bank of Energy” account without draining your own health and wellness.

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**TIPS FOR THE CAREGIVER**

**TAKE CARE OF YOURSELF**

Maintain good nutrition, fitness and sleep patterns. Pay as much attention to your own health as you do to the person whose care you provide.

**CREATE QUIET TIME**

Feed your spirit through prayer, meditation or thoughtful reflection. It can help restore balance and perspective.

**MAKE TIME FOR YOURSELF**

Pursue your own interests and create your own support system. It will help to recharge and refresh you.

**REFLECT ON THE GOOD**

Take time to consider and share your blessings and gratitude. Negativity is toxic to yourself and others.

**COMMUNICATE THOUGHTS AND FEELINGS**

Share what’s on your mind, even if it’s difficult. Repressing your feelings can have emotional and physical consequences.

**TREAT YOUR LOVED ONE WITH RESPECT**

Even when you are frustrated or tired, treat yourself and loved one with dignity and respect. People rarely look back and are sorry they showed respect under pressure.

**SEEK PROFESSIONAL HELP**

If you are having trouble coping, find someone to help you. Caretaking can be a difficult task. Seeking help when you need it is a conscientious response.

**Online Bonus:** A list of websites and resources, including advice on sleep, nutrition and mental health.

www.cfids.org/bonus/caregiver.asp