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When Caregiving Ends

Caregiving can last for many years. Caregivers set their own lives aside to care for someone else. When that person dies, caregivers have to figure out what to do with their lives now. There is no preparation for this transition. Generally you are so busy caregiving, and life changed so long ago, that there has not been time nor energy or even the psychological will to think about what comes next. Here are some tips that might help you during this time:

Loss

Grief — It is normal to feel sad, angry, hopeless, bereft, devastated. Our society says you should get over it in a week or two. Actually, it often takes one to two years. Allow yourself these feelings. They are normal and appropriate. (See FCA Fact Sheet *Grief and Loss*).

Relief — Many caregivers feel relieved that their ordeal is over and that the care receiver is no longer suffering. This is not something to feel guilty about. It is one of many feelings that people have when caregiving ends. Grieving may have started many years before with a gradual letting go process, particularly with dementia.

Forgive Yourself — Caregivers often feel guilty about every time they were not the perfect caregiver. There is no such thing. Everyone was impatient, angry, frustrated, unkind at some point during their time as a caregiver. It's OK. Don't second guess yourself with "what ifs." You probably couldn't have done anything else, even though you are thinking you could have. Celebrate how well you did this job!

Sleep — Often, one of the first feelings caregivers have is exhaustion. Now is the time to sleep. You need to renew your energy. Sometimes you need to stay in bed for a day and cry or just pull the covers up and watch TV. You deserve to take a break. You might enjoy the quiet, the doing nothing.

Confusion — Caregivers have put their lives on hold in order to be a caregiver. Now you are out of the job that you held for the past several years and you might have to redefine your purpose. It's normal to feel adrift as you try to find your place in the world and figure out who you are now.

Re-Entering

Time — What to do with it? Time was structured for you while you were caregiving. Now you have to figure out what to do each day. You learned good time management skills while you were a caregiver. Use these skills now for you to achieve new goals. Celebrate having time to reflect and make new decisions. Thinking about the future can be scary. Take one day at a time.

Loneliness — There can be an emptiness/void that comes from not being needed in the same way anymore. Since caregiving is so all consuming, caregivers often end up isolated. When caregiving ends, you often have to re-build a social network. Make social engagements when you feel you want to but also allow others who invite you to do things back into your life by saying yes.

Activities — Take small steps in re-entering into life again. Identify activities or hobbies that you enjoy and energize you. Volunteer—many caregivers find their skills can be used to help others. Exercise. It may have been a long time since you were able to focus on your needs. Your body now needs attention. Your mind also needs exercise. Take a class, read a book or even the newspaper

Take care of YOU — Exercise, get enough sleep and eat right. The three things we all have to do. But now you can. You had to be strong for someone else, now you can be strong for you. But you can also now let down and express your vulnerability. You have the right to the full range of emotions, now you can feel them. Caregivers' financial situation often changes when caregiving ends. Make sure to pay attention to finances, whether your situation is better or worse than before. Get help if you need it. Seek counseling if you need support or to just talk through all that you have been through and continue to go through.

Embrace Life Now — Appreciate the skills you learned while caregiving and find a way to use them. You did things you never thought you could—appreciate your strength. Create a new focus for your life. Maybe find a new job or a new interest. It's OK to enjoy life again, to laugh and play. It's not being disloyal to your loved one. Realize that you have to invent a "new normal" from what you've been doing. Make your home your own again. Depending on your situation, you might want to start dating or looking for romantic relationships. Take it slow. It's ok to get guidance from friends and professionals to help you navigate this new world.

You are in a time of transition. Don't expect to know all the answers or every step.

This tip sheet was written by Donna Schempp, LCSW, © 2013 Family Caregiver Alliance. All rights reserved.

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