



Southern Caregiver Resource Center

Caring for those who care for others

Fact Sheet: **The Emotional Side of Caregiving**

Whether you become a caregiver gradually or all of sudden due to a crisis, or whether you are a caregiver willingly or by default, many emotions surface when you take on the job of caregiving. Some of these feelings happen right away and some don't surface until you have been caregiving for awhile. Whatever your situation, it is important to remember that you, too, are important. All of your emotions, good and bad, about caregiving are not only allowed, but valid and important.

Many feelings come up when you are caring for someone day in and day out. Many caregivers set out saying, "This won't happen to me. I love my mother, father, husband, wife, sister, brother, friend, etc." But after awhile, the "negative" emotions that we tend to want to bury or pretend we aren't feeling come up. Caregivers are often reluctant to express these negative feelings for fear they will be judged by others (or judge themselves) or don't want to burden others with their problems.

If you don't deal with ALL of your emotions, they can be like a two-year-old who wants your attention: they will keep tugging at you until you stop and acknowledge them. Not paying attention to your feelings can lead to poor sleep, illness, trouble coping, stress eating, substance abuse, etc. When you admit to

your feelings, you can then find productive ways to express them and deal with them, so that you and the care receiver can cope better in the future.

This fact sheet will identify some of the common, often hard to admit, feelings that caregivers experience. Once identified, suggestions for how you might better cope with these feelings are offered.

If only we were perfect, we would not feel:

Ambivalence

This is the feeling of both wanting to be doing what you are doing and the feeling of not wanting to be doing it. On bad days, one often has the feeling of wishing you didn't have to be there, that this ordeal will be over soon. On good days, caring for someone can be a gift to both you and the care receiver.

Coping: Allow yourself to feel both sets of feelings. Everyone has these feelings sometimes. Neither the bad feelings nor the good ones will last forever.

Anger

How often have you "lost it" while providing care? Or felt like you were on your last nerve? Anger and frustration are a normal part of being around someone who needs help on an ongoing basis and

who might not be accepting of help. Caring for someone with dementia, in particular, can be even harder, as the care receiver can be irrational and combative. It's not always possible to be in perfect control of your emotions. Anger "just comes out" sometimes.

Coping: Forgive yourself. Find constructive ways to express yourself, learn to walk away and give yourself a "time out." Identify supportive people you can talk to who will listen as you vent about the things that happened that day.

Anxiety

Feeling like things are out of control and not knowing how to bring them back into control often produces feelings of anxiousness. Anxiety can emerge as a short fuse, the impulse to run away, not sleeping, heart palpitations or the urge to cry.

Coping: Pay attention to your anxiety—it is our body's early warning system that something isn't right. When you feel anxious: Stop. Breathe. Keep breathing. Pray. Meditate. Make some tea. Anything that will give you a break from what is happening in the moment.

Boredom

It is easy to become bored when you are stuck at home taking care of someone else and not doing things that fulfill your own wants and needs. And by the end of the day, you are often too tired to pursue something of interest to you.

Coping: Respite can help. Getting a break from caregiving and having some time for yourself will not only increase your patience and resilience but will give you a chance to do something that is meaningful to you, whether it is

socializing, going for a walk or reading a good book.

Crankiness, Irritability

When tired and stressed, it is harder to stay in control of the things we say and feel. Feelings can go up and down very rapidly. We can lash out at the littlest thing because we have no reserve.

Coping: If you find yourself feeling cranky and irritable, you probably need a break. You also may need to get some rest, as we are in less control when tired. Often, we will turn to alcohol or our favorite junk food to reward ourselves when feeling this way. It's more beneficial to keep a journal or talk with a friend or professional to let off steam.

Depression/Sadness

As a caregiver, you are at risk for depression. Sometimes this is feeling hopeless or helpless, the inability to sleep or trouble getting up and facing the day. And sometimes it makes you want to cry (See fact sheet, *Depression and Caregiving*.)

Coping: Depression is treatable and should be taken seriously. Professional help is available. Talk to your physician if you think you might be depressed, join a caregiver support group, find a counselor who understands caregiving and ask for help from friends and family. Exercise. Moving your body is a proven way to relieve some of the symptoms of depression.

Disgust

Having to help toilet someone can be too intimate an experience for many caregivers. If the care receiver is incontinent of stool as well as urine, then changing an adult diaper can be

nauseating and repulsive. Having to clean the private parts of someone, like a parent, can be unnerving and uncomfortable. Watching someone eat sloppily, not care for personal appearance, or having to clean up vomit can also cause feelings of disgust.

Coping: The hardest thing about accepting our revulsion to these things is that the care receiver is not in control of these behaviors. But sometimes we think they are doing it on purpose just to get us. Or we feel guilty because we think we should be accepting but we are not. Finding ways to minimize your need to do personal care is vital to weathering your caregiver journey, which could stretch on for years. Hire an attendant to do routine care or have someone from the family do these things who might cope better. Also, learn tricks to make tasks easier (e.g. during meal times consider using a spoon that is designed to be spill resistant.)

An occupational therapist can help you find this tool and other tools to make meal time easier and more enjoyable for both of you. It's important to know that when it comes to incontinence, you are not alone. Incontinence is one of the main reasons given for placing someone in a facility. There are resources to aid you in dealing with bathroom problems, like a Webinar entitled *Moving Beyond the Leakages: Practical Strategies to Manage Incontinence* or a segment from FCA's Caregiver College Video Series on their Video Channel. (Both of these resources are in the Caregiver Education section on their website.)

Embarrassment

Does your care receiver make impolite comments when you are out in public? Does he or she need to use the restroom right away and make a scene as you try

to find one? Does he or she refuse to bathe and now have body odor? It is easy for us to feel responsible for the behavior of someone else and feel like it is our fault when these things happen.

Coping: Some people create cards (similar to business cards) which read, "My loved one has dementia and can no longer control their behavior" which they hand out to those around them when they are having trouble, especially in restaurants. Some people just stop leaving the house because this is such a difficult problem to manage, it's easier to stay home. Others have friends, family members or an attendant accompany them when they go out to offer assistance, when needed.

Fear

What if something happens? Will I be able to cope? Will I feel guilty? Am I responsible for things that go wrong? Caregivers take on a huge amount of responsibility, not only for the day to day care of the care receiver, but also for all the other things that "might" happen while being a caregiver. Scaring ourselves about the "what ifs" can be paralyzing and keep us from enjoying the "what is."

Coping: It is important to have contingency plans. So, it might make sense to have a back up caregiver in mind in case something should happen to you, or to think about how you would handle predictable medical emergencies based on what disabilities your care receiver has. When you get scared, it is often helpful to talk to someone who knows your situation and can give you perspective and calm your fears.

Frustration

Frustration is part of many other feelings, such as ambivalence, anger and

impatience. Sometimes, as a caregiver, you feel that you can't do anything right or that things just don't go as planned no matter what you do or how hard you try. And if you are tired, you are more likely to get frustrated. Frustration may lead to stress eating, substance abuse, and a higher likelihood of losing your temper.

Coping: Acknowledge how frustrating caregiving can be. Join a support group to learn the tricks other caregivers have learned to make coping easier. Get breaks from caregiving so you have time for YOU and a chance to refresh your energy. Exercise. Sleep.

Grief

Watching the care receiver decline, not being able to do things that used to be easy and natural is sad. We also grieve for the care receiver, the person who used to be and our relationship with that person. We often need to grieve the loss we are experiencing on a daily basis or it will come out as something else.

Coping: Sometimes creating a ritual can be helpful. One caregiver would write on a piece of paper the things her husband could no longer do, then go to the ocean and throw the pieces in the water as a way of letting go. We tend to want to avoid the sadness that comes with grief, but allowing ourselves to feel (it) promotes healing (See fact sheet, *Grief and Loss*.)

Guilt

Guilt is the feeling we have when we do something wrong. Guilt in caring for care receivers comes in many forms. There is guilt over not having done enough to have prevented them from getting sick in the first place. There is guilt over feeling like you want this to end. Or guilt over having

been impatient with your care receiver too much. There is guilt over not loving or even liking the care receiver at times. There is guilt over not doing enough for the care receiver or not doing a good enough job as a caregiver. And if the care receiver falls or something else happens, there is guilt about it being your fault that it happened. And sometimes caregivers feel guilty about thinking of their own needs and see themselves as selfish, especially if they should do something like go to a movie or out to lunch with a friend.

Coping: You need permission to forgive yourself. You can't be perfect 24/7. It's impossible to be in perfect control of how you feel at all times. We all carry around a lot of "shoulds," such as "No one will do as good of a job as I do, so I have to be here all the time." Or "If I leave and something happens, I will never forgive myself." Consider changing guilt into regret, "I'm in a difficult situation and I have to make difficult decisions sometimes." "I regret that I am human and get impatient sometimes." "I am doing the best I can even though things go wrong from time to time and I regret that I am not perfect."

Impatience

How difficult is it to get your care receiver up in the morning? How about up, dressed, given breakfast and to their doctor's appointment all before 10am? And you have other things to accomplish that day. All this and the care receiver is acting unhelpful and moving slowly. Perhaps the care receiver refuses to use his walker even though he has fallen many times and the doctor and physical therapist emphasized he always needs to use it. It is understandable that you would get impatient at times.

Coping: Forgive yourself. When tired, frustrated and trying to keep things under control, it's natural to want to speed up and have compliance from the care receiver to keep them safe and healthy. So, first, slow down. Leave a lot of time to accomplish tasks. Leave a LOT of time. Control the environment as much as you can but know you can't always prevent your father from taking off without his walker. Create a list of the things you are in control of and are not. Understand what you can and cannot control.

Jealousy

Do you sometimes feel jealous of your friends who are able to go out and do things that you can no longer do, because of your caregiving responsibilities? Are you jealous of your siblings who are not doing their share to help? Do you feel jealous of a friend whose parent died quickly and easily while you take care of a parent who has had dementia for many years? Are we jealous of someone who got a big inheritance since we are struggling to pay bills and to be a good caregiver? We often don't admit to this feeling, because we have always been told not to be jealous. But that doesn't mean that we don't, in fact, feel jealous from time to time, of those who have it easier or better than us.

Coping: It's okay to admit to being jealous. Because things are not fair, we often have flashes of resentment and envy at other people's good fortune compared to our own. Jealousy is a problem when we wallow in it and prevent ourselves from enjoying the things we DO have. Focus on what you do have, whatever they may be and find a place in your heart for gratitude.

Lack of Appreciation

Most of us do not want to be dependent on someone else. Learning to accept help is hard. So, the care receiver is often pushing away our attempts to be helpful and caring. If someone has dementia, this problem is often much worse. And we get our feelings hurt because the care receiver does not thank us or even see how much we are giving up in order to care for them.

Coping: Sometimes we have to give ourselves our own pat on the back. Writing in a journal about the things you do each day might help you to appreciate how much you give and how much you do. Having a support group or a group of friends/family to cheer you on is important, and both comforting and necessary to remain resilient through your caregiving journey.

Loneliness

The longer you are a caregiver, the more isolated you become. With no one to talk to day in and day out except the care receiver, it is easy to lose a sense of yourself. Friends stop calling since we are no longer available, and we hesitate to call them because we know "they don't want to hear about it any more" or "I have nothing to talk about because my life is all about caregiving."

Coping: Find ways to get out of the house and involved in something other than caregiving. Learn about resources from your local Area Agency on Aging about respite programs or day care programs that will allow you to get a much needed and well-deserved break. No one can do this job alone. Look at your wider circle of support—faith community, neighbors, friends, distant relatives, etc.

to see where you might get some nurturing for you.

Loss

Caregivers experience many losses, some of which have already been mentioned: loss of control, loss of independence, loss of income, loss of your best friend, loss of the future, loss of a sense of yourself. Loss leads to grief and depression.

Coping: Identifying your losses can help you to cope with them. For each of us, the losses will be different. When you know what you are feeling, you will be able to look at the loss and think about what might work for you to help you deal with it, see fact sheet, *Caregiving and Ambiguous Loss*.

Resentment

When put in a situation not of our choosing, it's not uncommon to feel negative and resentful. Perhaps, you have siblings who are not helping provide care or maybe you are an only child, became the caregiver by default, and feel you have very little desire or support to offer care. Little things easily become big things when we feel unappreciated and unacknowledged. And feeling like you have to do it all, and do it all by yourself, is a guaranteed way to feel resentment.

Coping: Family situations and dynamics can be a real challenge. Having help from family may make your situation easier, but sometimes family tensions make it even harder to get help (See fact sheet, *Caregiving with Your Siblings*) the more help and support you accept, the easier it will be to let go of feeling burdened and resentful of those who are not doing their share. If family tensions are getting in the way, it could also help you to refer to the

fact sheet, *Holding a Family Meeting*. If you can't get help from the people you think should be offering it, then you need to broaden your circle of people to include those who can and will help. It is easy to forget about the good things that have happened or are happening when we only focus on the negative.

Tiredness

As a caregiver, how often do you get the full eight hours of sleep they always say you need? Sleep is often postponed while you grab a few minutes of alone time after the care receiver goes to bed. Sleep is often disturbed because the care receiver gets up at night and needs help going to the bathroom or being re-directed back to bed. Sleep is often disturbed because you can't fall asleep or stay asleep because you are worrying about all the stressors that come with being a caregiver.

Coping: Sleep has to be put on the priority list. Lack of sleep leads to obesity, illness, crankiness, impatience, inefficiency in accomplishing tasks, and a state of mental foggy among other issues. If you are having trouble falling asleep or staying asleep not related to direct caregiving, talk to your physician. If you are having trouble sleeping due to caregiving problems, talk to the care receiver's physician. There are ways to help both of you to get the rest you need. As a caregiver, you do amazing work caring for others in need. But as a caregiver, you also need to think about yourself. (See fact sheet, *Taking Care of YOU: Self Care for Family Caregivers*, and also the fact sheet, *Caregiver Health*. Just pushing through each day will eventually wear you out and cause you to burn out. Emotional issues can weigh you down and impact not only your ability to cope and provide care, but they can also

harm your health and well being. It is important to learn to ask for help and prioritize getting breaks from caregiving, so that you can be the caregiver you want to be.

Resources

Southern Caregiver Resource Center

3675 Ruffin Road, Suite 230
San Diego CA 92123
(858) 268-4432 | (800) 827-1008
Fax: (858) 268-7816
E-mail: scrc@caregivercenter.org
Website: www.caregivercenter.org

The Southern Caregiver Resource Center offers services to family caregivers of adults with chronic and disabling health conditions and is for residents of San Diego and Imperial counties. Services include information and referral, counseling, family consultation and case management, legal and financial consultation, respite care, education and training, and support groups.

Family Caregiver Alliance National Center on Caregiving

(415) 434-3388; (800) 445-8106
Website: www.caregiver.org
E-mail: info@caregiver.org

Family Caregiver Alliance (FCA) seeks to improve the quality of life for caregivers through education, services, research and advocacy. FCA's National Center on Caregiving offers information on current social, public policy and caregiving issues and provides assistance in the development of public and private programs for caregivers, as well as a toll-

free call center for family caregivers and professionals nationwide.

Eldercare Locator

www.eldercare.gov

National Association of Area Agencies on Aging

www.n4a.org

Alzheimer's Association

www.alz.org

Lotsa Helping Hands

www.lotsahelpinghands.com

Recommended Reading

The Caregiver Helpbook

www.powerfultoolsforcaregivers.org

The Emotional Survival Guide for Caregivers: Looking After Yourself and Your Family While Helping an Aging Parent, Barry Jacobs, 2006.

Passages in Caregiving: Turning Chaos into Confidence, Gail Sheehy, 2011.

Fact Sheets

Caregiving and Ambiguous Loss

Caregiving with Your Siblings

Caregiver Health

Depression and Caregiving

Grief and Loss

Holding a Family Meeting

Taking Care of YOU: Self Care for Family Caregivers

This FCA Fact Sheet was written by Donna Schempp, LCSW, and reviewed by Family Caregiver Alliance. Funding provided by private donor. © 2014 Family Caregiver Alliance. All Rights Reserved.

Rev. 12//2018