



Fact Sheet: Dementia, Caregiving and Controlling Frustration

The Stresses of Caregiving

Caring for an individual with Alzheimer's disease or a related dementia can be challenging and, at times, overwhelming. Frustration is a normal and valid emotional response to many of the difficulties of being a caregiver. While some irritation may be part of everyday life as a caregiver, feeling extreme frustration can have serious consequences for you or the person you care for. Frustration and stress may negatively impact your physical health or cause you to be physically or verbally aggressive towards your loved one. If your caregiving situation is causing you extreme frustration or anger, you may want to explore some new techniques for coping.

When you are frustrated, it is important to distinguish between *what is and what is not within your power to change*. Frustration often arises out of trying to change an uncontrollable circumstance. As a caregiver of someone with dementia, you face many uncontrollable situations. Normal daily activities—dressing, bathing and eating—may become sources of deep frustration for you. Behaviors often associated with dementia, like wandering or asking questions repeatedly, can be frustrating for caregivers but are uncontrollable behaviors for people with dementia. Unfortunately, you cannot simply change the behavior of a person suffering from dementia.

When dealing with an uncontrollable circumstance, you do control one thing: *how you respond to that circumstance*.

In order to respond without extreme frustration, you will need to:

- learn to recognize the warnings signs of frustration;
- intervene to calm yourself down physically;
- modify your thoughts in a way that reduces your stress;
- learn to communicate assertively;
- learn to ask for help.

Warning Signs of Frustration

If you can recognize the warning signs of frustration, you can intervene and adjust your mood before you lose control. Some of the common warning signs of frustration include:

- shortness of breath
- knot in the throat
- stomach cramps
- chest pains
- headache
- compulsive eating
- excessive alcohol consumption
- increased smoking

- lack of patience
- desire to strike out

Calming Down Physically

When you become aware of the warning signs of frustration, you can intervene with an immediate activity to help you calm down. This gives you time to look at the situation more objectively and to choose how to respond in a more controlled way.

When you feel yourself becoming frustrated, try counting from one to ten slowly and taking a few deep breaths. If you are able, take a brief walk or go to another room and collect your thoughts. It is better to leave the situation, even for a moment, than to lose control or react in a way you will regret. If you think someone may be offended when you leave the room, you can tell that person you need to go to the restroom. You can also try calling a friend, praying, meditating, singing, listening to music or taking a bath. Try experimenting with different responses to find out what works best for you and the person you care for.

The regular practice of relaxation techniques can also help prepare you for frustrating circumstances. If possible, try the following relaxation exercise for at least ten minutes each day:

Sit in a comfortable position in a quiet place. Take slow, deep breaths and relax the tension in your body. While you continue to take slow, deep breaths, you may want to imagine a safe and restful place and repeat a calming word or phrase.

Modifying Your Thoughts

As you take time out to collect your thoughts, try rethinking your situation in

ways that reduce frustration. How you think often affects how you feel. Of course, feelings of frustration arise from difficult circumstances. If, however, you analyze your response to a frustrating situation, you will usually find some form of *maladaptive*, or negative, thinking that has the effect of increasing your frustration, preventing you from looking at your situation objectively, or finding a better way to deal with it.

Below are six major types of unhelpful thought patterns common among caregivers. Following each unhelpful thought pattern is an example of an *adaptive*, or more helpful, thought that can be used as self-defense against frustration. Familiarizing yourself with the unhelpful thought patterns and the adaptive responses can help you control your frustration.

Over-generalization

You take one negative situation or characteristic and multiply it. For example, you're getting ready to take the person in your care to a doctor's appointment when you discover the car battery has died. You then conclude, "This always happens; something always goes wrong."

Adaptive response: "This does not happen all the time. Usually my car is working just fine. At times things don't happen the way I would like, but sometimes they do."

Discounting the positive:

You overlook the good things about your circumstances and yourself. For example, you might not allow yourself to feel good about caregiving by thinking, "I could do more" or "anyone could do what I do."

Adaptive response: "Caregiving is not easy. It takes courage, strength, and

compassion to do what I do. I am not always perfect, but I do a lot and I am trying to be helpful."

Jumping to conclusions

You reach a conclusion without having all the facts. You might do this in two ways:

1. **Mindreading:** We assume that others are thinking negative thoughts about us. For example, a friend doesn't return a phone call, and we assume that he or she is ignoring us or doesn't want to talk to us.
2. **Adaptive response:** "I don't know what my friend is thinking. For all I know, she didn't get the message. Maybe she is busy or just forgot. If I want to know what she is thinking, I will have to ask her."
3. **Fortune-telling:** You predict a negative outcome in the future. For example, you will not try adult day care because you assume the person in your care will not enjoy it. You think, "He will never do that. Not a chance!"
4. **Adaptive response:** "I cannot predict the future. I don't think he is going to like it, but I won't know for sure unless I try."

"Should" statements:

You try to motivate yourself using statements such as "I should call mother more often" or "I shouldn't go to a movie because Mom might need me." What you think you "should" do is in conflict with what you want to do. You end up feeling guilty, depressed or frustrated.

Adaptive response: "I would like to go to a movie. It's okay for me to take a break from caregiving and enjoy myself. I will ask a friend or neighbor to check in on Mom."

Labeling

You identify yourself or other people with one characteristic or action. For example, you put off doing the laundry and think, "I am lazy."

Adaptive response: "I am not lazy. Sometimes I don't do as much as I could, but that doesn't mean I am lazy. I often work hard and do the best that I can. Even I need a break sometimes."

Personalizing:

You take responsibility for a negative occurrence that is beyond your control. For example, you might blame yourself when the person in your care requires hospitalization or placement in a facility.

Adaptive response: "Mom's condition has gotten to the point where I can no longer take care of her myself. It is her condition and not my shortcomings that require her to be in a nursing home."

Using the "Triple-Column Technique"

Unhelpful thought patterns are usually ingrained reactions or habits. To modify your negative thoughts, you will have to learn to recognize them, know why they are false, and talk back to them.

One helpful way to practice using more adaptive thinking processes is to use the "triple-column technique." Draw two lines down the center of a piece of paper to divide the paper into thirds. When you are feeling frustrated, take a personal "time out" and write your negative thoughts in the first column.

In the second column, try to identify the type of unhelpful pattern from the six examples above. In the third column, talk back to your negative thoughts with a more

positive point of view. See below for examples:

Negative Thoughts	Thought Patterns	Adaptive Thoughts
(Caregiver burns dinner.) "I can't do anything right!"	Over-generalization	I'm not perfect, but nobody is perfect. Sometimes I make mistakes, and sometimes I do things well.
(Caregiver has coffee with a friend and spouse has accident at home.) "I'm selfish and rotten! If I had been home, he wouldn't have fallen."	Labeling; personalizing	I'm not selfish or rotten. I do a lot to take care of my husband, but I need to take care of myself as well. He might have fallen even if I had been home.
(Brother does not show up to take your Dad to the doctor.) "I knew I couldn't trust him. I should just do it myself next time."	Jumping to conclusions; should statements	I don't know why he didn't come, but I need his help, so we'll have to find ways for him to share the burden of Dad's care.

Communicating Assertively

Good communication can reduce frustration by allowing you to express yourself while helping others to understand your limits and needs. *Assertive* communication is different from passive or aggressive communication. When you communicate passively, you may be keeping your own needs and desires inside to avoid conflict with others. While this may seem easier on the surface, the long-term result may be that others feel they can push you around to get their way.

When you communicate aggressively, you may be forcing your needs and desires onto others. While this allows you to express your feelings, aggressive communication generally makes others more defensive and less cooperative.

When you communicate assertively, you express your own needs and desires while respecting the needs and desires of others. Assertive communication allows both parties to engage in a dignified discussion about the issue at hand.

Keys to assertive communication are:

- Respecting your own feelings, needs and desires.
- Standing up for your feelings without shaming, degrading or humiliating the other person.
- Using "I" statements rather than "you" statements. For example, say, "I need a break" or "I would like to talk to you and work this out" instead of "You are irresponsible" or "You never help out!"
- Not using "should" statements. For example, say, "It's important to me that promises be kept," instead of "You should keep your promise."

The Critical Step: Asking for Help

You cannot take on all the responsibilities of caregiving by yourself. It is essential that you ask for and accept help. Discuss your needs with family members and friends who might be willing to share caregiving responsibilities. People will not realize you

need help if you do not explain your situation and ask for assistance. Remember, you have the right to ask for help and express your needs.

When to say "Yes"

Don't be afraid to say "Yes" if someone offers to help. Say "Yes" at the moment a person offers to help, rather than saying "maybe" and waiting until you are in a fix. Have a list handy of errands or tasks you need help with. Keep in mind that people feel useful and gratified when they are able to help others.

When to say "No"

Often, caregivers are pulled in multiple directions. In addition to the demands of caregiving, you may feel compelled to meet the demands of your immediate and extended family, your friends and your employer. Learn how to say "No" to the demands of others when you are overwhelmed or need a break. It is your right to say "No" to extra demands on your time without feeling guilty.

Learning Effective Communication Techniques for Dementia Caregiving

Many families find it frustrating to communicate with a loved one who has dementia. The person with dementia may repeat questions over and over or mistake you for someone else. It is important to remember that the person with dementia cannot control behavior caused by their disease. They do not need to be corrected or grounded in "reality." You can distract them or just agree with them as a way to reduce your frustration.

It can be helpful, however, to learn more about dementia and effective communication techniques which will ease

your frustration. For example, use simple, direct statements, and place yourself close when speaking to a person with a cognitive disorder. Try not to argue about unimportant things such as what the date is. Allow extra time to accomplish tasks such as dressing. Remember, people with dementia often react more to our feelings than our words. Finding ways to be calm can help you to gain cooperation. See fact sheet: *Caregiver's Guide to Understanding Dementia Behaviors* for more helpful strategies.

Self-Care to Prevent Frustration

Caregiving can be tiring and stressful. When you're caring for others, it's easy to forget to care for yourself. While it may be difficult to find time to focus on yourself and your needs, it is very important that you do so to prevent frustration and burnout. See fact sheet: *Taking Care of YOU: Self-Care for Caregivers* for additional information.

Here are three steps to taking better care of YOU:

Make Time for Yourself

You may feel guilty about needing or wanting time out for rest, socialization and fun. However, everyone deserves regular and ongoing breaks from work, including caregivers. "Respite" providers can give you the opportunity to take the breaks you need. Respite breaks may be provided by in-home help, adult day care, "friendly visitor" programs, friends and neighbors, or other means. The important point is to allow yourself to take a break from caregiving. See "Resources" at the end of this fact sheet for organizations that might help you give yourself time off from caregiving.

Take Care of Yourself

Although caregiving may make it difficult to

find time for yourself, it is important to eat well, exercise, get a good night's sleep and attend to your own medical needs.

When you do not take care of yourself, you are prone to increased anxiety, depression, frustration and physical distress that will make it more difficult to continue providing care.

Seek Outside Support

Sharing your feelings with a counselor, pastor, a support group, or with another caregiver in a similar situation can be a great way to release stress and get helpful advice. You may want to contact the organizations under "Resources" at the end of this fact sheet or look in the community services section at the front of the *Yellow Pages*, under "Counseling" or "Senior Services" to find services to help you get some caregiver support.

Credits

Burns, David D., M.D., (1980, 1999). *Feeling Good: The New Mood Therapy*, Revised and Updated Edition, Avon Books, New York, NY.

Gallagher-Thompson, D., Rose, J., Florsheim, M., Gantz, F., Jacome, P., Del Maestro, S., Peters, L., Arguello, D., Johnson, C., Moorehead, R.S., Polich, T.M., Chesney, M., Thompson, L.W., (1992). *Controlling Your Frustration: A Class for Caregivers*. Palo Alto, CA: Department of Veterans Affairs Medical Center.

Parrish, Monique, L.C.S.W., Dr. PH., (2000). *"Stress: What is it? What can be done about it?" Stress Reduction Instruction Manual*, written for John Muir Mount Diablo Medical Center, Concord, CA.

Resources

Southern Caregiver Resource Center

3675 Ruffin Road, Suite 230
San Diego, CA 92123
(858) 268-4432; (800) 827-1008 (in CA)
scrc@caregivercenter.org
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

235 Montgomery Street, Suite 950
San Francisco, CA 94104
(415) 434-3388; (800) 445-8106
www.caregiver.org
info@caregiver.org

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

Alzheimer's Association

(800) 272-3900
www.alz.org

Eldercare Locator

(800) 677-1116
www.eldercare.gov

Call to find your local Area Agency on

Aging and services for the elderly and caregivers, including respite care providers.

National Volunteer Caregiving Network

(512) 582-2197

www.nvcnetwork.org

Visit website or call to find volunteer caregiving assistance.

ARCH National Respite Network and Resource Center

www.archrespite.org

Visit website to find local respite providers

Recommended Reading

Caregiver's Guide to Understanding Dementia Behaviors

Hiring-In-Home Help

Taking Care of YOU: Self-Care for Family Caregivers