

The Caregiver Toolbox

Preventing Burnout Series: Challenging Care Situations

What Behaviors Do YOU Find Difficult? Issues to Consider:

1. **Sometimes “difficult behavior”** is not doing things the way we want them to be done.
2. **What one person may find difficult**, another may not.
3. **Most of us develop coping techniques** earlier in our lives, and these coping techniques go with us as we age. Some people, therefore, have what may be termed “difficult” behavior their entire lives. Chronic illness makes these behaviors more pronounced.
4. **Perceptions change over time**: what may be termed “inspiring” at one point of life may be called “difficult” at another point. Behaviors which may have served people well at another point in life may not serve them as well in a period of chronic illness.
5. **Chronic illness often involves new and unfamiliar challenges** for both caregivers and those receiving care. Even the best relationships are sometimes stressed under such circumstances.

When Difficult Behavior Becomes Abusive Behavior:

There is a **fine line** between these two but abusive behavior tends to **destroy** the underlying relationship. The relationship can get to a point that it is beyond repair.

Examples of potentially abusive behavior by the person receiving care are:

- Finding fault with errors made in good faith.
- Faking symptoms to get extra attention.
- Waking caregivers thoughtlessly during the night.
- Giving away resources promised to family members.
- Demanding help beyond the caregiver’s capacity.

Caregivers have the right not to be subject to abusive behavior regardless of the situation.



Specific Challenging Behaviors & Suggestions



The Desert of Time:

- **Time is opportunity** for those without illness and **time can become a burden** for those with illness who are not able to do what they used to do.
- Ill family members may give **great importance to events** that in earlier times would have not raised an eyebrow.
- Ill family members may spend a huge amount of time **preparing and waiting for a ten minute visit**. They may get angry at family members for being late or not staying long enough.
- **Families often** do not fully recognize or understand these issues.

What Is Helpful?

- **Suggest/facilitate** useful and interesting activities to fill the time more effectively.
- **Make an effort** to be on time and find ways to make visits truly enjoyable.
- **Suggest to** friends and other relatives ways that they can help the ill person fill the time (i.e. bring pictures, mementos, activities of shared interests).

Need for Balance Between Giving and Receiving:

- There is a powerful need for **balance** in our culture. It is difficult for most people to receive without giving in return. We spend most of our lives maintaining this balance in our families, among our friends, and in our organizations.
- **Asking for assistance** without a means of repaying it is not something most of us are comfortable doing; however, chronically ill people find themselves accepting assistance very often with no obvious opportunities to reciprocate.
- There can become this **lack of balance** in relationships which can be very uncomfortable and lead people to **conceal their true needs** from family and friends. It can lead them to react with **anger or resentment** toward people who are there to “help.”

What Is Helpful?

- Try as much as possible to **build balance** into any caregiving arrangement.
- Ill people should be **allowed and expected to contribute**.
- **Reciprocation can take many forms**, not just financial. Families often must get very creative to build this balance.



Circle of Influence Decreases:

- For many ill people the issues about which they formally **had influence decrease**. For example, people often no longer have jobs or major family responsibilities. They may not be able to keep responsibilities at clubs or at church.
- As a result, they may seem **hyper-concerned** with their own health, with food, with the organization of their belongings in the house etc. They may seem to have become very **self centered**.
- Family members do not always understand these changes though they are **quite common**.

What Is Helpful?

- Let ill people who find themselves in this situation retain as much **decision making and control** over their own lives as possible.
- Family members can also be sources for **new interests**, hobbies, and responsibilities.
- **Two very helpful sources** of activity are pets and music especially for those who have enjoyed these in the past.
- Sometimes people also need **touch, exercise**, and other **sensory stimulation** to remind them that there is a wider world of which they are a part.

Feelings of Regret:

- When faced with chronic or life threatening illness, many people **review their lives**. They look back on decisions they made, the families they came from, the tragedies and the joys.
- Many people want to **discuss these issues** with someone who will listen. Often it is an affirming and enriching experience for both parties. In some cases, however, the ill person is filled with regrets about “what could have been,” for decisions made long ago, for events that happened long ago.
- This overwhelming **sense of regret** can cause clinical depression, it can cause illness to get worse, and it is certainly painful to watch.

What Is Helpful?:

Sometimes family members can be of great assistance by:

- Allowing people to **talk** about these issues without offering platitudes or advice.
- **Listening** without judgment
- Bringing people together for **reconciliation**.
- **Reconnecting** the person with his or her religious tradition.
- **Professional counseling** can assist some persons to come to a sense of healing.

The “Fear” Factor:

Fear is a **natural product** of chronic and disabling illnesses. Most people are not comfortable admitting they are afraid. Fear often manifests itself as either **anger or anxiety**.

ANGER

- People who have **anger** as a result of fear can lash out at those who try to assist them. Often they are angry at medical providers as well. They often have **limited safe outlets** for anger so caregivers receive the brunt of their anger.

What Is Helpful for Anger?:

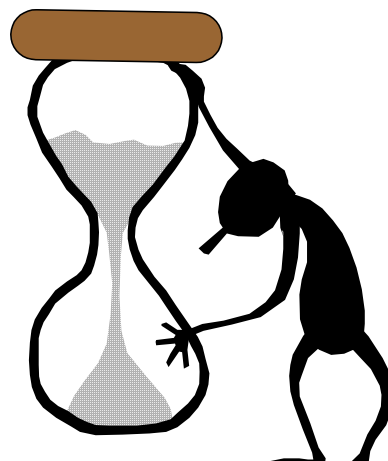
- **Looking** for the source of the anger/fear
- **Counting** to 20 before answering
- **Leaving** the room
- **Developing** defusing statements
- **Using** humor appropriately

ANXIETY

- People can also **worry excessively** as a result of fears. This anxiety can become disabling.

What Is Helpful for Anxiety?:

- **Often caregivers can alleviate** some worries by seeking and offering realistic information. Information is **very empowering**, but ill people may not be in a position to gather information about the illness, living options, care options and other issues.
- **Counseling and medication** can assist the person to feel less anxious.



Techniques to Improve the Caregiving Relationship

Communicate More Effectively:

- Effective communication can be **difficult** in any situation. It can be even more so in a family involved in caregiving. People do not express feelings for fear of hurting another; people do not want to ask for help for fear of being a burden; people respond in anger or frustration to difficult behavior and so on.
- **Communication** is a two way street. It involves **both listening carefully** and **expressing yourself clearly**.
- Sometimes we have to unlearn old habits.

Steps To Communicate More Effectively

- **Use “I” messages** (Start statements with “I feel..”, “I need..”, “I am frustrated...” etc. instead of “You.” This tends to keep both sides from getting defensive.
- **Respect** the rights and feelings of other people by what you say or do.
- **Be clear** and specific.
- **Speak directly** to the person(s) involved.
- **Listen** as you want others to listen to you.

Examine Your Own Feelings About Caregiving

- **Caregivers sometimes need to examine** their own feelings as they consider the behaviors of the person for whom they are caring. Feelings of guilt, fear, resentment, and anxiety **are very common**.
- **These may be influencing** your responses to difficult behavior. They may be even making the ill person’s behavior worse.
- **If you realize that you are feeling** resentful or experiencing more anxiety than usual, you may need to get some assistance to relieve your own stress in order to respond in a more effective way.

Enlist Support & Assistance:

Caregivers need to educate themselves and seek the information, support and assistance which is right for their situation.



This information is provided by: The National Family Caregiver Support Program



This is a nationally funded program operated in Central Ohio by the Central Ohio Area Agency on Aging (COAAA). It offers caregiver workshops and funds services designed to assist caregivers on a short term basis. The services include: information and assistance, counseling, respite, and other supplemental services.

Request a copy or download our other guides:

- Central Ohio Older Adults Resource Guide
- The Caregiver Toolbox
- Central Ohio Long Term Care & Hospice Guide
- Central Ohio Housing & Home Repair Guide
- Central Ohio Private Homecare Guide
- Central Ohio Utility Guide
- Central Ohio Prescription Guide
- Central Ohio Transportation Guide
- Central Ohio Support Group Guide
- Central Ohio Respite Guide
- Central Ohio Moving & Transitions Guide
- Books, Videos, and Websites for Family Caregivers.
- Central Ohio Kinship Care Guide
- Central Ohio Hiring Guide for In Home Caregivers
- Central Ohio Pet Care Guide

The COAAA also provides monthly Caregiver Support Groups & Information Sessions. For more information, call 1-800-589-7277 or visit www.coaaa.org.

Or in your county, call one of these agencies:

- **Delaware**-SourcePoint 740-363-6677
- **Fairfield**-Meals on Wheels Older Adult Alternatives 740-681-5050
- **Fayette**-Community Action Commission of Fayette Co. 740-335-7282
- **Franklin**-Franklin Co. Office on Aging 614-525-6200
- **Licking**-Licking Co. Aging Program 740-345-0821 or 1-800-452-0097
- **Madison**-Madison Co. Senior Center 740-852-3001
- **Pickaway**-Pickaway County Senior Center 740-474-8831
- **Union**-Union County Senior Services 937-644-1010