




Some Realities of Supporting

Loved Ones Living With Dementia

CPI EXCLUSIVE DOWNLOAD



> You are not a bad person because at times you may feel angry, guilty, frustrated, and exhausted.

About DCS and CPI

Dementia Care Specialists (DCS) provides state-of-the-art dementia care training, resources, and consulting services that help transform staff capabilities and quality of care. As a result, people living with dementia experience a higher quality of life, caregivers find more satisfaction, and providers improve their caregiving and business results. We believe that every person living with dementia has many remaining abilities that, when recognized and nurtured, can lead to a life of quality at each stage of the disease.

CPI is the standard in behavior intervention training that equips employees to have an immediate, tangible, and lasting positive impact on the people and organizations they serve.

Part of a series, this guide describes how family members, friends, or volunteers can use DCS principles and strategies to support those living with dementia.

You will learn:

- About the array of emotions that can often occur when caring for a person living with dementia.
- You are not a bad person because at times you may feel angry, guilty, frustrated, and exhausted.
- Ways to maintain your own emotional and physical health while providing care.
- How family members may all be at different points of understanding about dementia.
- About the importance of seeking help and resources that are available.

Self-Assessment

The following questions are intended to help you assess how you are doing in your journey of caring for a loved one or friend who has dementia. Think about someone you know living with dementia, and answer the questions as they apply to you.

1. **True or False** When I am with my loved one or friend who is living with dementia, sometimes I do not know what to say or do.

2. **True or False** I really wish other members of my family would help me more with caregiving for my loved one.

3. **True or False** Sometimes I even worry about if I will have dementia too.

4. For the following question, please check descriptions of feelings you have about caring for your loved one or friend who is living with dementia. Select all that apply.
 - Frustrated and exhausted.
 - Enriched and rewarded.
 - Bitter and even angry at times.
 - Guilty about how I feel.
 - Fulfilled, blessed, and thankful.
 - Obligated to spend time with them.
 - Other _____.

5. On a scale of 1–5, how effective are you when caring for a loved one living with dementia? (1 = Not very effective; 3 = OK; 5 = Very effective)

1 2 3 4 5

Self-Assessment Answers

1. This is intended to be a subjective question to help you think about your personal feelings. Both answers are correct here. Your feelings are *your feelings*, and they are real.
2. This is also intended to be a subjective question to help you think about your personal feelings. Both answers are correct here. How families or individual family members cope with a person living with dementia may vary greatly.
3. Again, this is intended to be a subjective question to help you think about your personal feelings. Both answers are correct here. Answers will vary.
4. Answers will vary greatly among caregivers and within a group. There are no answers here that are either always correct or incorrect.
5. Answers will vary. Regardless of how effective you are now when caring for a loved one living with dementia, this information may help you be more effective in the future. Understanding more about some of the realities many face when caring for someone living with dementia will help improve the life of the person you care for.

Caregiver Stress and Emotions

Stress and Stressors

As a person living with dementia progresses through the stages, a loved one must cope with the functional decline in the person. Roles and relationships change, which can take an enormous emotional toll on you. During your journey with understanding dementia, you may experience an array of difficult emotions, including anxiety, anger, guilt, and grief.

Emotional Responses

There are common reasons why you may experience these emotions. For example:

- **Anxiety:** *You may fear for the future and worry about how you will handle the additional responsibilities.*
- **Anger:** *You may be angry at the person you are caring for, even though you know the change in abilities is not their fault. You may be angry at others who do not share in the caregiving responsibilities.*
- **Guilt:** *You may feel you are not doing enough, not having enough patience, or not handling the situation with enough composure.*
- **Grief:** *You may experience a sense of several losses, from the progressive and eventual terminal illness of a loved one to feeling that the person you love is different than before the onset of dementia, to the goals, dreams, and aspects of your own life you may have to put aside as you provide care.*

It is essential for you to recognize that you are not a bad person for experiencing these emotions. It is important to acknowledge and accept these feelings. These feelings do not mean you do not love the person; they simply mean you are human. These feelings are normal. In order to work through these feelings, it's important to talk about them.

Taking Care of You, Too

Your Physical Health

Your role as a caregiver becomes more difficult when you are fatigued, sick, or hurting. As always, you need balance in your personal life, work life, and family life. For example:

- **Exercise regularly. Walk. Ride a bike.** *Exercise helps to relieve stress and boost your energy.*
- **Eat right.** *Well-nourished, healthy bodies are better prepared to cope with stress.*
- **Get enough sleep.** *Aim for an average of eight hours every night.*
- **Keep up with your own healthcare.** *See your doctors and follow their advice.*

Your Emotional Health

Your role as a caregiver becomes more difficult when your loved one becomes irritable, angry, resists assistance, or even forgets who you are. You may feel discouraged and frustrated, causing additional stress. In these situations, remind yourself:

- **I am doing the best I can; I am human.**
- **I cannot control all things that happen.**
- **This journey would be difficult for anyone.**
- **My efforts do make a difference for my loved one.**

To maintain your emotional health, you must attend to your own needs. Some recommendations to consider:

- **Take time to relax; do something you enjoy every day.**
- **Share your feelings with a trusted friend.**
- **Stay social and connected to your circle of friends. Ask for help when you need it.**

Remain part of the community through a social club, religious group, civic organization, or support group. And remember:

- **Your loved one maintains a sense of love for you. Your loved one is doing the best they can. Your loved one has changed, yet this new person is someone who can still love and be loved.**
- **You are making quality of life possible for your loved one.**

You Are Not Alone; Seek Help

Caregivers like you often feel that asking for help shows weakness or a lack of caring. Plain and simply, **that is not true**. Asking for help shows your strength. It means you know your own limits and when to seek support.

Community Resources

Community resources can also help you gain assistance. Support groups may provide an opportunity for you to openly express your feelings and learn that other caregivers feel the same emotions. Educational materials can help you understand the disease. Organizations can also provide you with information that can support you in caregiving, such as adult day care, meal services, and respite services.

Here is a list of additional resources that may help:

- **Alzheimer's Association**

Website: alz.org

Phone: 800.272.3900

The Alzheimer's Association can assist with educational materials and locating a support group in your community.

- **Alzheimer's Disease Education and Referral Center**

Email: adear@nia.nih.gov

Phone: 800.438.4380

This referral center, which is a service of the National Institute on Aging, provides educational material and referrals to local support services.

- **Eldercare Locator**

Website: eldercare.alc.gov

Phone: 800.677.1116

Eldercare Locator, a public service of the US Administration on Aging, connects you to services for older adults and their families.

Family Support

In addition, friends and family often have a desire to help but are not sure what to do. Provide them with simple, specific suggestions. These could include:

- **Providing a meal.**
- **Spending a regularly scheduled hour or two with your loved one.**
- **Assisting with transportation for appointments or activities.**
- **Offering to listen, without judgment or criticism.**

It is important to note that each family member experiences feelings of grief and guilt in different ways and at different times. Often family members may be experiencing denial, a stage of grieving. Denial helps us to pace our feelings of grief. It is nature's way of letting in only as much as we can handle.

Not surprisingly, this can cause conflicts among the family members and may produce overwhelming emotions for the primary caregiver. If this persistently occurs, professional help may even be beneficial to assist in working through these issues.

Some Realities of Supporting Loved Ones Who Have Dementia

Post-Test

1. **True or False** Caring for a person who has dementia can cause caregivers to feel a wide range of emotions.
2. **True or False** There is nothing that can be done to help someone living with dementia, or you as a caregiver, once the disease is diagnosed.
3. **True or False** My friends and other family members may be able to help if I ask them.
4. **True or False** I will have to continue to learn, change, or adjust to the care needs of my loved one as they progress through the stages of dementia.
5. From the following list, mark which “realities” and suggestions may help you be at your best when caring for a loved one who has dementia. Select all that apply.
 - Anxiety, anger, guilt, and grief are real feelings for caregivers.
 - Accept that the feelings I have are real and normal.
 - Maintain my own physical health.
 - Accept that dementia is a hopeless condition for the person who has it and caregivers.
 - Work on sustaining my own emotional well-being.
 - Seek assistance from community resources.
 - Make time for “me” every day.
6. List two or three realistic, practical changes you can make within the next few weeks or months to help you better support your friend or loved one living with dementia.

Post-Test Answers

1. **True** Caring for a person who has dementia can cause caregivers to feel a wide range of emotions.
2. **False** There is nothing that can be done to help someone living with dementia, or you as a caregiver, once the disease is diagnosed.
*Although **False** is the preferred answer, some caregivers may feel this level of hopelessness and answer **True**.*
3. **True** My friends and other family members may be able to help if I ask them.
4. **True** I will have to continue to learn, change, or adjust to the care needs of my loved one as they progress through the stages of dementia.
5. From the following list, mark which “realities” and suggestions may help you be at your best when caring for a loved one who has dementia. Select all that apply.
 - ✓ Anxiety, anger, guilt, and grief are real feelings for caregivers.
 - ✓ Accept that the feelings I have are real and normal.
 - ✓ Maintain my own physical health.
 - Accept that dementia is a hopeless condition for the person who has it and caregivers. *(Note: Realistically, some caregivers may feel this way.)*
 - ✓ Work on sustaining my own emotional well-being.
 - ✓ Seek assistance from community resources.
 - ✓ Make time for “me” every day.
6. List two or three realistic, practical changes you can make. Answers to this question will vary depending on the caregiver’s unique experiences and situations.

Thank you! We hope you found this information helpful.

Please feel free to share this resource with a friend or colleague.

Have questions? We're here for you!

Give us a call at **800.558.8976** or email

info@crisisprevention.com

About Dementia Care Specialists (DCS)

DCS provides state-of-the-art dementia care training, resources and consulting services that help transform staff capabilities and quality of care. We educate, empower, and enrich the lives of these professionals and those in their care living with dementia.

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