

ADathOME

IMPROVES QUALITY OF LIFE

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HANDBOOK for Care for Caregivers

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1. INTRODUCTION

Informal caregivers provide regular care or assistance to a friend or family member who has a health problem or disability.

Caregiving means providing aid for another person's social or health needs and it is a very important public health issue that affects the quality of life for millions of individuals all around the world. Caregiving may include help with one or more activities important for daily living such as bathing and dressing, paying bills, shopping and providing transportation, but it also may involve emotional support and help with managing a chronic disease or disability. Caregiving responsibilities can increase or change in parallel with the recipient's needs.

Caregiving may be delivered by family members unpaid or friends, who are not paid or paid caregivers may be hired. Unpaid caregiving, which is also called Informal Caregiving is the pillar of long-term care provided in people's homes. In particular, the recipient may be a child or a parent or a spouse, disabled and/or aged person who cannot perform her/his care independently.

Caregiving also brings great satisfaction to the person herself/himself and even strengthen relationships between the caregiver and the cared one. This way it seems as if caregiving enhances the caregivers' quality of life, but regrettably it can affect the caregiver's life undesirably in many ways, including her/his ability to work, engage in social interactions and relationships, and even maintain good physical and mental health.

It is fundamental to understand the physical and mental health burden the caregivers experience, the range of tasks they are expected to perform, and the social and economic impacts of long-term chronic diseases or disability.

Caring a parent, a spouse, a disabled child, or even a dear friend requires a special sort of person, but unfortunately people do not often have a choice, they just find themselves in this position. Although being a caregiver can be extremely rewarding, it can also be overwhelming. Especially caring for a person with Alzheimer's or a related dementia takes time and effort. Caregiver can feel lonely and frustrating, even. angry, which could be a sign the carer is trying to take on too much. The most important insight for anyone in this position is this:

You cannot adequately care for a loved one if you do not take good care of yourself.

A caregiver of an aging relative with dementia, should be aware of the physical and emotional burdens she or he faces and should always monitor her/his own health in addition to the loved one's.

Caring for someone with dementia differs from non-dementia caregiving, here are some of the common health consequences of family caregiving, and resources to help safeguard their well-being.

2. CONCEPT

Significant research on the demographic points to specific challenges, including level of intensity and length of care reveal that:

- Dementia caregivers are more likely to provide “high-intensity care,” according to the level of care index, a measure medical provider use to rate how much care a recipient needs. This means people who care for loved ones with dementia offer assistance with more **activities of daily living (ADLs)** and spend more time each day on caregiving than non-dementia caregivers.
- Dementia caregivers also report higher amounts of strain, mental and physical health problems, and caregiver burnout.
- More than half of dementia caregivers provide care for four years or more, significantly longer than family caregivers for people with other age-related diseases.
- People with elderly dementia typically require more supervision, are less likely to express gratitude for the help they receive (due to inability), and are more likely to be depressed.

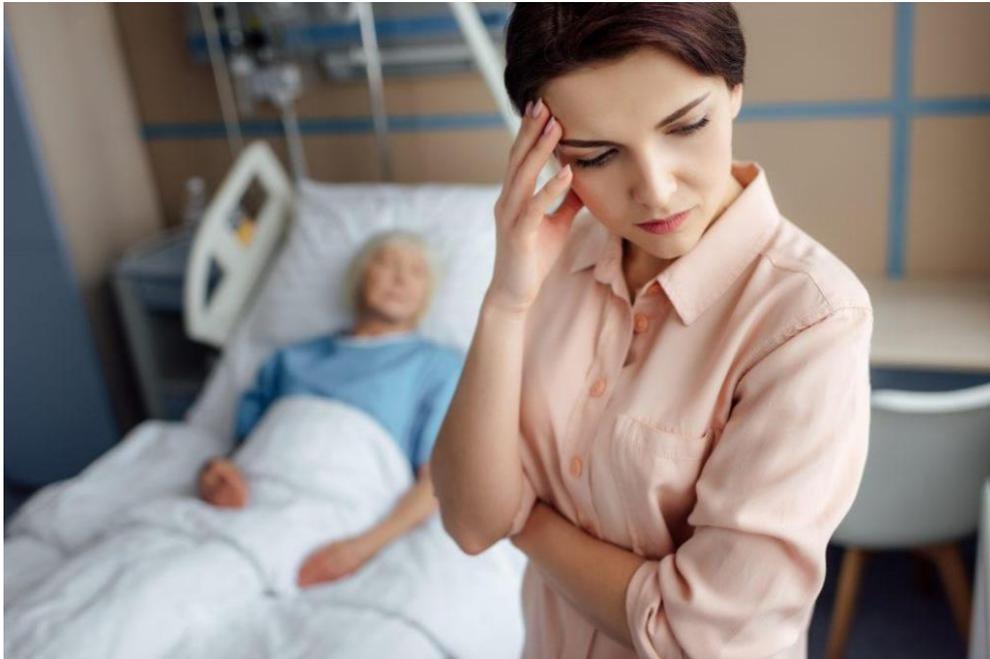


Dementia caregivers report higher levels of stress, more depression and anxiety symptoms, and lower levels of subjective well-being than non-caregivers, caregivers who feel unprepared or trapped in their role experience more significant mental health effects than those who chose or expected to provide care.

2.1 Caregiver stress and anxiety

Poor health and behavioral problems in elderly loved ones directly correlate to heightened caregiver stress levels. As an aging relative progresses through the stages of dementia, caregiving may become more emotionally difficult due to changes in personality and demeanor.

Dementia behaviors like wandering, aggression, inappropriate actions, and **sundown syndrome** can make family members feel like they're caring for a stranger. Emotional manipulation and verbal abuse from loved ones — potential late-stage signs of dementia —



can be crushing to family caregivers.

2.2 Depression

Unpaid family caregiving for 20 hours or more a week results in increased depression and psychological distress, impaired self-care, and worse self-reported health. Caregiver depression increases as the elderly relative's level of function declines. Because of this, dementia caregivers have higher instances of depression than non-dementia caregivers. The National Alliance of Caregiving estimates 30% to 40% of dementia caregivers suffer from depression and emotional distress.

2.3 Loneliness

Full-time caregiving can be an isolating experience. Especially for dementia caregivers who work from home or don't have a traditional career, peer interaction may be limited to occasional visits and phone calls. Dementia caregivers may avoid taking their aging loved ones on errands or to social events to reduce the likelihood of wandering or inappropriate behavior in public. Over time, this isolated lifestyle can increase the likelihood of depression and other health concerns.

There are fewer studies examining physical health risks in those caring for a loved one with dementia. However, in general, nearly one in four caregivers feel that their responsibilities have made their physical health worse. That number surges for caregivers who report loneliness — nearly half of lonely caregivers feel their health has been negatively affected.

Chronic conditions, persistent caregiver stress, and disregard for personal health all contribute to the physical impact of dementia caregiving.

2.4 Lack of self-care

Caregivers often become so focused on helping elderly loved ones with dementia that they neglect preventive health behaviors for themselves. Poor diet and exercise due to lack of time and energy can lead to long-term health consequences. The financial burden of caregiving can force family members to make choices between their aging relatives and themselves, and nearly three quarters of caregivers report making it to the doctor less often than they should. Since dementia caregiving often spans longer periods of time than other types of caregiving, these family members may go years without prioritizing their health, leading to complications later on.

1. 2.5 Increased morbidity

Chronic conditions and comorbidities coupled with caregiver stress can be especially dangerous for older caregivers, like spouses. According to the American Psychological Association, seniors with their own history of chronic illness who have caregiving-related stress have a 63% higher mortality rate than their non-caregiving peers.

Dementia caregiving increases mortality risks for healthy caregivers as well. Despite a significantly lower risk of mortality, research reveals that 18% of healthy spouse caregivers die before their partner with dementia.



2.6 Chronic stress

Chronic stress is a persistent version of the body's flight or fight response, during which a person feels constantly alert and in danger. It leads to physical and psychological strain over

long periods of time without predictability or control, like a loved one's gradual cognitive decline.

The chronic stress from caregiving often bleeds into other aspects of life, like family relationships and work, according to research chronic stress causes an endocrine system response in which corticosteroids, or stress hormones, are released. Long-term exposure to these hormones can disturb the immune, digestive, cardiovascular, sleep, and reproductive systems.

2.7 Compassion Fatigue

Compassion fatigue is an unfavourable consequence of caring for individuals in need and the caregiver may experience the symptoms of anger, depression, and apathy. Family caregivers, particularly those caring for older adults with dementia, display many of the characteristics of compassion fatigue, such as depression, anxiety, and stress and also feelings of resentment, helplessness, and hopelessness, in addition to feeling that they have little free time. Caregivers who have these feelings and experiences on top of the emotionally overloaded familial caregiving relationship may be suffering from compassion fatigue.

Informal caregivers for family members with dementia who develop compassion fatigue may terminate the caregiving relationship through premature nursing home admission or relinquishing care to another family member, and there may also be increased risk for abuse or neglect. Supporting these caregivers may improve outcomes for people with dementia because individuals who are cared for at home have lower morbidity and mortality than those in institutional settings, and caring for family members at home provides a significant decrease in cost to society.

Compassion fatigue is dependent on a caring relationship between the caregiver and a care recipient, who is suffering or traumatized and it is a form of burnout that has an acute onset and has negative emotional responses for the caregiver such as helplessness, hopelessness, isolation, and apathy or an inability to be empathic.

As shown in Figure below compassion fatigue is a process, where the caregiver has concern and an empathic ability or feel motivated to respond the care recipient's suffering while this empathic response, coupled with an unwillingness or inability to detach from the caregiving situation and the absence of feelings of satisfaction, develops compassion stress, resulting in compassion fatigue if the caregiver has prolonged exposure to these demands.

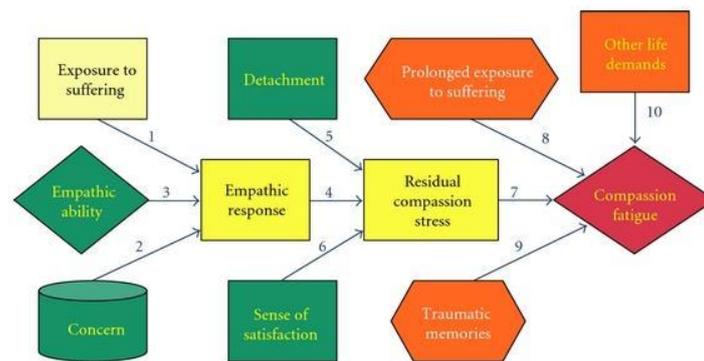


Figure 1. Compassion Fatigue Process

Informal caregivers for family members with dementia may be at an even greater risk for compassion fatigue than formal care providers given the emotional attachment to the care recipient. In the compassion fatigue process, detachment is the ability of the provider to distance themselves from the suffering. The strong emotional attachment between parent and child may prohibit the family caregiver from detaching and therefore removes an essential coping mechanism utilized by formal care providers.

Feelings of accomplishment and contentment from caring for a family member with dementia may protect family caregivers from compassion fatigue. Dementia caregivers are capable of experiencing satisfaction, but their satisfaction results from the family member with dementia's well-being, as well as from receiving appreciation for the care they are providing, both of which are compromised by the dementing condition.

The time caregivers spend on caregiving removes them from other relationships. Informal caregivers for family members with dementia often find themselves alone during the day with their family member, and, while this relationship is valuable, it does not replace peer relationships. Caregivers become isolated and often feel there is no one they can talk to about their feelings and that friends cannot relate to them, they feel resentful, helpless, and hopeless and that they have little free time. When a caregiver has little free time, they are unable to participate in activities focusing on themselves and fostering other relationships.

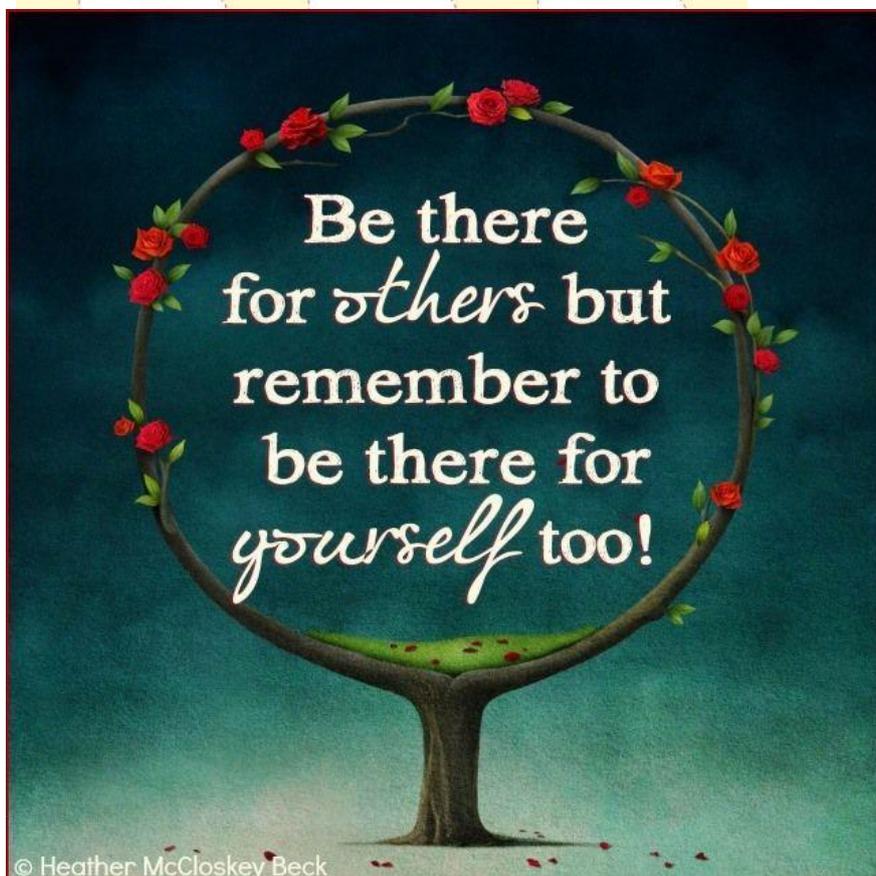
Indicators of Compassion Fatigue can be reiterated as:

- Hopelessness
- Helplessness
- Apathy
- Emotional Disengagement or Isolation

While the consequences of compassion fatigue can be summarized as:

- Depression
- Burden
- Caregiver Strain
- Decreased Relationship Quality
- Termination of Caregiving, Abuse, and Neglect

CAREGIVER'S BURNOUT



2.8 THE FIRST RULE OF CARING FOR A LOVED ONE: Prioritize Self

2.9 Care

Family caregiving can start gradually or as part of a crisis and it is not usually predictable. Taking on the role of a caregiver often happens when life is already full and is squeezed into a busy life without letting anything else go. Caregiving can be one of the most rewarding gifts you can give to another person, while also being emotionally and physical demanding.

Caregivers support the health needs of a family member or someone significant in their lives. This may be something they took on willingly or it may be a responsibility that landed on them. Either way, to provide good care to someone else, one needs to care for herself/himself.

Caregiving doesn't happen in a vacuum, the carer has other commitments, such as work, children or grandchildren, and maybe she/he have her/his own health or relationship issues to manage. It's hard to find the time and the energy to look after everything and everyone. As

a person's condition worsens, their world shrinks. It gets harder for them to do anything outside the home, such as attending a day program, religious services, or community events. Family gatherings can be overwhelming for them. As a result, caregiver also may get out less, especially if additional help is not available.

People may stop visiting when the person supported doesn't remember them or has trouble communicating. The carer may be so busy giving help that she/he doesn't realize that she/he feels mentally and physically exhausted. Getting worn down can create or worsen her/his own health problems.

The person receiving care may need assistance for a long time. Their symptoms may become more challenging. As they can do less for themselves, they will need more help from the caregiver. This makes it extra important for the caregiver, to check in and to take care of her/his own needs.

To be able to care for a loved one, the caregiver must first take care of herself/himself. It's like the advice we're given on airplanes: "put on your own oxygen mask before trying to help someone else with theirs." Taking care of oneself is a valid goal on its own, and it helps the caregivers support the people they love.

Caregivers who pay attention to their own physical and emotional health are better able to handle the challenges of supporting someone with mental illness. They adapt to changes, build strong relationships and recover from setbacks. The ups and downs in one's family member's illness can have a huge impact on the carer. Improving one's relationship with himself by maintaining her/his physical and mental health makes the person more resilient, helping her/him weather hard times and enjoy good ones.

2.10 Estrategies

Here are some suggestions for personalizing one's self-care strategy.

2.10.1 Understand How Stress Affects You

Stress affects your entire body, physically as well as mentally. Some common physical signs of stress include:

- 3 Headaches
- 4 Low energy
- 5 Upset stomach, including diarrhea, constipation and nausea
- 6 Aches, pains, and tense muscles
- 7 Insomnia

Begin by identifying how stress feels to you and identifying what events or situations cause you to feel that way.

2.10.2 Protect Your Physical Health

Improving your physical wellbeing is one of the most comprehensive ways you can support your mental health. You'll have an easier time maintaining good mental habits when your body is a strong, resilient foundation.

- 8 Exercise daily
- 9 Eat well
- 10 Get enough sleep
- 11 Avoid alcohol and drugs
- 12 Practice relaxation exercises.



Recharge Yourself

Any amount of time you take for yourself is important. Being out of “caregiver mode” for as little as five minutes in the middle of a day packed with obligations can be a meaningful reminder of who you are in a larger sense. It can help keep you from becoming consumed by your responsibilities. Start small: think about activities you enjoyed before becoming a caregiver and try to work them back into your life. If you used to enjoy days out with friends, try to schedule a standing monthly lunch with them. It becomes part of your routine and no one has to work extra to make it happen each month.

Try practicing meditation. Research suggests that practicing meditation may reduce blood pressure, anxiety and depression, and insomnia.



Before you assumed the caregiver role, you probably shared a relationship that involved activities you both enjoyed. To the extent possible, you want to maintain and even extend those relaxing elements.

For example, if you like watching movies together, never has there been a time when films were more accessible via streaming services.

The point is not what you do or how often you do it, but that you do take the time to care for yourself. It's impossible to take good care of anyone else if you're not taking care of yourself first. One of the real pleasures for homebound people is socializing. As restrictive as your circumstances may be, video conferencing helps re-establish ties. Consider welcoming new pets either to stay or just to visit.

Practice Good Mental Habits

- 3 Avoid Guilt
- 4 Notice The Positive
- 5 Gather Strength From Others



2.11 Lighten Your Load

A frequent mistake made by new caregivers is trying to do everything themselves. Engaging professional help with household chores gives more time for the important items one does not want to trust to others.

Those outside a caregiving relationship often do not recognize the benefits enjoyed both by the receiver and the giver of in-home nurture. Physical restrictions do not limit the ability of the mind and spirit to soar. Thus, the compassion and companionship of this experience can be a wonderful time of growth for both individuals, provided self-care is prioritized along with the care given.

1.

2. General Tips to lighten your load:

- Take breaks each and every day!
- Curb perfectionism. Not everything needs to be done to a high standard;
- Establish and stick to priorities, don't waste time or energy on unimportant things;
- Accept offers of help and ask other family members to share the load. Be specific about what you need;
- Pay for help if you can afford it – for example, a dog walker, housecleaning service or accountant;
- Get a portable phone so you can multi-task while conversing, and an answering machine to screen calls;

- Get organized or hire a professional organizer if paperwork or your whole home is in chaos.
- Get a computer, Internet access can help you stay connected to loved ones, keep up with local and world news, and gather information about medical conditions and community resources, among other things. You can also connect with other caregivers through Internet message boards and chat rooms.
- **ASK FOR HELP WHEN YOU NEED IT.**

3. 2.12 Checklist for self-care



Constantly check yourself for signs of caregiver burnout

Make personal time a priority

Have a set schedule

Take to someone, even if it's a therapist

Break goals and to-dos down into manageable pieces

Divide up responsibilities with others

Look into professional services



Improve the bond you have with your care recipient

Add some level of physical fitness into your day

Get enough sleep

Practice gratitude daily

Eat well

Implement stress relief techniques

See a doctor regularly

Try to get sunlight every day

Enjoy and view caregiving as a journey

Celebrate every victory

Create traditions with your care recipient

Add a flow of laughter into your day

Regularly do things that bring you happiness

Pamper yourself

Focus on what you can control

Be proactive instead of reactive

Be aware of the struggles associated with caregiving

Schedule out vacations

Take regular breaks throughout your day

Join caregiver support groups



10 TIPS FOR FAMILY CAREGIVERS

1



Ask support from other caregivers. Learning that others have had similar experiences can be an enormous relief.

2

The good you can do for your loved one is dependent on how well you take care of your own health.



3



Take some respite time, caregiving is hard work.

4

If someone offers help, take it. Accepting it is not a sign of weakness.



Ask for help if you have signs of depression.

5



6

Seek for training and get help from new technologies.



7

Organize medical information.



8

Learn how to



Plan early for the present and future needs

9

Give yourself credit for doing the best you can in



10



3. CONCLUSION

Caring for a person with dementia can have a big impact on your mental and physical health and your overall wellbeing. That's why it's important that you look after yourself – both for your own sake and so you can continue to care for the person with dementia. Carers often feel a wide range of emotions. Try to understand why you feel the way you do and to accept your emotions as a normal reaction to what may be a very difficult situation.

Don't be afraid to ask for help and support if you need it. Sometimes people don't offer help because they don't know what they can do. Try suggesting specific ways that other people can help. If you've previously said you can manage without someone's help, they may not think to offer again, even when your situation changes. Let people know how valuable their support is and how much it helps you. Try to make time to do something you enjoy every day.

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