

# **CAREGIVER'S GUIDE**

**By: Dennis Pezzato, PhD**

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# **CAREGIVER'S GUIDE**

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## **CAREGIVING—A CHALLENGING JOURNEY**

**Being a caregiver to a loved one, family member or friend is likely to be one of the most important and challenging roles a person will ever have in life. The challenges are all at once physical, emotional, and even spiritual for most of us.**

**Care-giving is an age old tradition of love and kindness that will become increasingly more prevalent as we move forward, given that we are living longer. Because medical advances and lifestyle changes allow us to live longer, we have learned how to live with and manage serious illness that might have been fatal in the past. It is likely that most of us will either need a caregiver, or will become a caregiver.**

**Most of us were not trained to be caregivers, and may not have envisioned ourselves in such a role. Whatever the case, if we suddenly find ourselves in the position of needing to care for a loved one or friend, we may feel overwhelmed with this role.**

**The good news is that we can all learn some basic skills and coping strategies that will make care-giving easier, more satisfying, and less stressful.**

**A diagnosis of any serious or life-threatening illness such as but not limited to cancer, coronary disease, diabetes, stroke or a dementia, is usually a very traumatic experience for the patient and the loved ones. There are so many things to deal with, and so much information to sort through and understand. The days, weeks and months following diagnosis, event, and/ or procedure can be filled with overwhelming issues and emotions, It is extremely important to have some way of understanding what to expect and ways to cope with and manage the situation, not to mention the distress this situation may create.**

**Information, understanding, coping tools, emotional support, and self-care are keys to how each person and their care-givers will experience what lies ahead. This is a journey that requires patience with the process, the patient, and oneself. Remember that impatience and unrealistic expectations increases stress, while patience and realistic expectations decrease stress. A high level of stress or feelings of distress can interfere with the recovery process and the quality of life for the patient, as well as create an ever increasing risk of emotional and physical issues for the care-giver.**

**Whether you are new to care-giving or not, there are some important things to be aware of: Learn about the disease(s) or medical conditions in order to better understand what processes occur, and how to best plan for care. Have conversations about the patient's treatment wishes, recovery requirements and expectations, and end-of-life wishes. Discuss when and how to create a Durable Power of Attorney for healthcare and finances where appropriate. Gather, with the patient present, family and friends who are willing to participate in helping the primary caregiver. The primary caregiver needs to have a support system.**

**Some of the key ingredients to successful care-giving are: education, resource information, emotional support, self-care, behavior awareness, stress management, and a pragmatic approach to this role. Participating in a Care-givers Support Group can provide caregivers with all of those things. A support group offers a safe, confidential environment where caregivers can share experiences, skills, ideas, and emotional support for one another.**

## **CAREGIVER TOPICS**

**SELF CARE**

**FAMILY INVOLVEMENT**

**EMOTIONAL AND SOCIAL SUPPORT**

**FALL PREVENTION**

**RESPIRE CARE**

**GRIEVING FOR CURRENT & FUTURE LOSS**

**STRESS EDUCATION & MANAGEMENT**

**RESOURCE INFORMATION**

**DISEASE EDUCATION**

**PATIENT BEHAVIORS**

**BOUNDARIES**

**Note: At the conclusion of each Caregiver Topic in this booklet, you will find Bullet Points for each topic. The purpose of the Bullet Points is to serve as a reminder.**

## **SELF CARE**

**Too many caregivers get so consumed with their duties that they neglect some of their own basic needs. It is critical not only for quality of life but for survival that we take care of ourselves.**

**Self care means achieving and maintaining a reasonable level of wellness. Wellness constitutes overall good health, not just the absence of disease.**

**Understanding the mind-body connection is an important basis for achieving wellness. The mind and body are inextricably connected in ways we may not be aware of. Simply put, when the body is unwell in some way, it impacts our minds by affecting our emotions; Conversely, when our minds and emotions are unwell, overtaxed, stressed, or otherwise out-of-sorts there is a negative effect on our bodies.**

**When these conditions exist, we unknowingly compromise and suppress our immune systems. This can lead to illness and disease.**



**It is a widely held belief that the best form of medicine is Diet, Exercise and Rest. We must take care of ourselves if we want to provide the best care possible to our loved ones, and if we want to survive this care-giving experience.**

### **Bullet Points**

- **Don't neglect your own needs**
- **Achieve wellness**
- **Strive for a reasonable level of proper Diet, Exercise and Rest**

## **FAMILY INVOLVEMENT**

**To whatever extent possible, enlist the help of all family members who are willing to make any kind of commitment to provide help, assistance and support.**

**Try not to have expectations beyond what a family member feels he/ she is willing to do. If the desire or motivation exists, each member has something of value or capability to contribute.**

**Whether it is financial assistance, direct caregiving, running errands, doing gardening, grocery shopping, or giving the primary caregiver occasional respite, those who reside nearby can help in many ways that can ease the workload.**

**Family members who do not reside geographically close can also find ways to be supportive and helpful. Those members might help financially, might have frequent supportive phone/ video contact with loved ones, they might be in a position to keep track of legal and financial matters, or just provide a soft shoulder and be a good listener. One of the most important things to remember is that frequent and thorough communication and inclusion, increases the odds of achieving a supportive circle of family care. The primary caregiver must not be afraid to ASK for what they need; family members are not mind-readers.**

**Finally, it is very important that family members, especially the patient and the primary caregiver, do not “keep score” of the quantity of help given by individuals. Accept**

**that others will give what they want and/ or what they can. Anyone who tries to “keep score” will only create stress and hard feelings, which will be a destructive influence on the overall situation.**

### **Bullet Points**

- **Have realistic expectations of others**
- **Be grateful for any help**
- **Communicate regularly with others**
- **Don't keep score**

## **EMOTIONAL AND SOCIAL SUPPORT**

**In general, we all can benefit in life from having some sources of emotional and social support; as social beings, this is something we all need. Obviously, this need can vary with each individual.**

**When we become caregivers, that benefit not only increases but can be one of the things that enable us to find the strength to persevere and succeed.**

**None of us gets through life without help and support from others; at no time in our lives is this more important.**

**Nurture your close relationships. Participate in these reciprocal relationships throughout your life, so that in times of need you may be able to rely on the mutual benefits that exist. When others offer to help, they are giving you a gift of themselves. Do not deprive them of that opportunity by refusing help and support.**

### **Bullet Points**

- **There are many mutual benefits**
- **Nurture your relationships**
- **Accept help; remember it is a two-way gift**

## **FALL PREVENTION**

- **MEDICATIONS: Review them regularly with the physician, including vitamins,**

supplements. Beware of mixing alcohol with certain meds.

- **HEALTH CONDITIONS:** Monitor eyesight, inner ear, joint pain, numbness, shortness of breath.
- **ASSISTANCE DEVICES:** Use grab-bars, walkers, canes, wheelchairs, shower seats, toilet aids, etc.
- **LIGHT SUFFICIENTLY:** Lighting needs to be plentiful, especially where steps or obstacles occur.
- **HOME HAZARDS:** De-clutter, eliminate throw-rugs in areas of high traffic, keep pertinent items within easy reach.
- **SENSIBLE FOOTWEAR:** Use footwear that is supportive, stable, and that does not increase the risk of slipping.
- **KEEP MOVING:** Exercise is critical for strength, balance, flexibility, and coordination. Consult with the physician first.
- **HOME ASSESSMENT:** Have home assessed by a qualified professional

### **Bullet Points**

- Follow simple suggestions to prevent accidents that can create **MORE** challenging issues to deal with

## **RESPITE CARE**

**Respite care can be beneficial to both the caregiver(s) and the loved one. Respite care can provide much needed breaks for everyone involved.**

**One type of respite care commonly used is Adult Day Care. In this setting the loved one spends hours or an entire day at a community facility where a variety of activities are offered. Things like entertainment, exercise, crafts, games, music, etc. are offered by trained staff and volunteers. These programs are usually offered 5-6 days a week for 5-10 hours per day.**

**Another type of respite care is residential in nature. Your loved one would reside there for a few days or a few weeks, in the event the caregiver(s) needed to travel, address personal issues, or just have time away from caregiver duties.**

**Respite care is one of the tools a caregiver needs in order to provide Self Care. It can also be very beneficial for the loved ones because it gives them the opportunity to be social, have a change of pace with different surroundings instead of the “same old thing”. Can be a “win-win” situation.**

## **Bullet Points**

- **Take regular brakes and time away from your duties**
- **Respite care is also part of practicing self care**
- **Loved ones need a change of environment too**

## **GRIEVING FOR CURRENT & FUTURE LOSSES**

**Most of us think of grief as it relates to loss due to a death. In that situation the grief tends to taper off after the initial period of shock and/ or emotional trauma. However, grief associated with a chronic or terminal illness seems never ending for some. Our emotions may shift between hope, anger, sadness and hopelessness.**

**Watching long term suffering can be very traumatic and very exhausting at the same time. For many of us it is also a subconscious reminder of our own mortality; we may even “see ourselves” in the person who is being cared for.**

**This entire process can bring with it physical and emotional challenges that we may not understand at the time they occur. It is important to be aware of**

**the possibility that your grief may have a negative impact on your quality of life.**

### **Bullet Points**

- **This kind of grief can affect our quality of life without us understanding what is taking place within us**
- **This will increase stress levels**

## **STRESS EDUCATION & MANAGEMENT**

**Stress is a normal part of living, and is not necessarily a bad thing if experienced occasionally. However, when stress becomes chronic, it can be very destructive to our physical and psychological well-being.**

**Stress may mean different things to different people. When we experience frustration, fear, anger, resentment, sadness, worry, etc., we are in a stressful state of mind. That state of mind and those emotions can change the chemistry of our bodies, our physiology.**



**The effects of chronic stress can cause or make worse, diseases and illness. It can compromise and suppress our immune systems; it can diminish our cognitive function.**

**Life can be challenging in many ways for all of us but when we take on the role of caregiver, the challenges can become much more than we ever expected. So, it is extremely important that we pay attention to our emotions and feelings in an effort to find ways to cope with the stresses that may become part of our everyday lives.**

**Once we recognize that we have feelings of distress that are not normal, we need to determine what the causes of that distress might be. Then we need to find ways to eliminate, modify, or manage the stress in our lives. There are many ways to accomplish this.**

**Eliminating stressors may be difficult or impossible but establishing boundaries may be useful in that regard. Modifying stressors is more easily accomplished, usually by enlisting help from others or establishing new boundaries, or even practicing more self care.**

**Managing stress, in many ways can be easier, and should become a way of life that can have unexpected benefits. I'm referring to things like**

proper diet, regular exercise, adequate rest and leisure. Beyond those lifestyle issues are things like relaxation techniques: Deep Breathing Exercises, Meditation, Guided Imagery, Tai Chi, Qi Gong, Prayer, Music Therapy, Aroma Therapy and many more.

Stress levels can be reduced by implementing areas in all the topics we are discussing here.

### **Bullet Points**

- Stress is unavoidable
- Chronic stress can be a silent killer
- Learn ways to recognize and manage stress
- Find techniques that work for you

### **CAREGIVER RESOURCES**

In most communities there are more resources than most people are aware of. Those listed below would be a good place to start. There are times when you may have to dig a little deeper to find what you are looking for.

**Most communities have access to the following agencies or entities:**

### **AGENCY ON ELDERLY AFFAIRS**

- **Services for senior care**
- **Family support programs**
- **Financial Aid**
- **Legal Aid**
- **Meals on Wheels**

### **HOSPICE**

- **End of Life care, bereavement services**
- **Palliative Care**
- **Caregivers support groups**

### **ALZHEIMER'S ASSOCIATION**

- **Education**
- **Screening**
- **Referrals**
- **Support groups**

### **ADULT DAY CARE PROGRAMS**

- **Drop-off for partial or full day**
- **Supervised programs**
- **Caregiver respite**

**There are also many On-Line resources that provide a considerable amount of local and national information as well as chat-rooms:**

### **FAMILY CAREGIVER ALLIANCE**

- **Education and self-care**
- **“Handbook for Long Distance Caregivers”**

### **AGING CARE.COM**

- **Education and Chat-Room**

### **CAREGIVERS ACTION NETWORK**

- **Education**
- **Video series (“Life as a caregiver”)**

### **HOME INSTEAD SENIOR CARE**

- **Education**
- **Video series for caregivers**

### **IMPORTANT NOTE**

**Planning in advance of needs can make the journey much easier.**

## **DISEASE EDUCATION**

**One of the most important tools a caregiver can have is knowledge of the disease(s) or illness(s) a loved one is dealing with. A familiarity with the progressions and processes that are involved will make things easier and much less stressful. Knowing what to expect allows one to be more prepared and less caught off guard.**

**This applies to symptoms, medications, behaviors, and changes that are likely to occur over time. This is a classic example of saying that “Knowledge is Power”.**

**This is probably a good time to advise you to keep a journal or log of what your loved one is experiencing in regards to physical symptoms, behavioral changes, medication regimens, etc. Keeping good notes, which can be used during doctor visits, will be very helpful with all aspects of treatments.**

## **BULLET POINTS**

- Know the disease(s)
- Learn what to expect
- Keep a log, journal or notebook

## **HANDLING DIFFICULT PATIENT BEHAVIORS**

Let's take a look at a few examples of difficult behaviors:

### **RAGE, ANGER, YELLING**

- Try to identify the root cause of their anger. The aging process is not easy, and it can spark resentment in seniors who are living with chronic pain, losing friends, experiencing memory loss issues, and all the other undiagnosed things that come with getting older. Care patients often reserve their worst behavior for those they are closest to, like family members. In this case, it may be beneficial to hire in-home care or consider Adult Day Care. Their bad behavior might not surface in front of strangers, and you will get a much-needed break.

## **ABUSIVE BEHAVIOR**

- **Try explaining to your loved one how their behavior makes you feel. Unfortunately, many caregivers don't get very far by talking. If the abuse is verbal and/ or emotional, help them realize how much you do for them by stepping back for a while. Yes, that means withholding some care activities; this does not apply to health and safety issues. If your loved one requires supervision and assistance to ensure their safety, then bring in outside help to take over some of your duties.**
- **Removing yourself from the situation may drive home the point that abusive behavior is not acceptable and will not be tolerated. Your loved one may come away from the experience with renewed appreciation for what you do. In the meantime, you'll get some valuable respite time. If physical abuse is the issue, then seek professional help from a physician or mental health professional. You might even have to involve Adult Protective Services or the Police Dept.**

## **THOSE WHO REFUSE TO SHOWER OR BATHE**

- **The first step is to determine why the patient has stopped bathing. If depression is the cause, speak with their doctor. If modesty is a problem, perhaps a same sex loved one or professional caregiver can assist. If the patient is afraid of the water in some way, you can try a softer and more soothing approach such as a hand-held device or a tub already filled.**
- **If the patient is afraid of slipping or falling, there are many types of chairs and assistive devices available that may offer increased comfort and safety. Do your best to keep your loved one clean but keep your expectations realistic. Bathing two or three times a week is usually enough to avoid skin breakdowns and infections.**

## **EXCESSIVE SWEARING, OFFENSIVE LANGUAGE**

- **If this behavior seems out of character for your loved one, there may be medical issues that are the cause; things like urinary tract infections, dementia, drug interactions, or pain and discomfort. If there is no medical issue but this is more or less normal to a lesser degree, then you may want to discuss**



**boundaries of unacceptable behavior. When a tirade sets in, another technique is to use distraction. If the person becomes hostile, back off, disappear and wait for it to blow over.**

## **PARANOIA, DELUSIONS & HALLUCINATIONS**

- Any of these conditions can be serious warning signs of a physical or mental problem. Keep track of these instances and discuss them with the doctor as soon as possible. These symptoms can also be associated with dementia. Do not try to talk the person out of a delusion. Validation is a good coping technique because what they are seeing, hearing, or experiencing is very real to them. Better to just play along until it passes, unless they are putting themselves in harm's way somehow.**

**Note: This material was excerpted and paraphrased from AgingCare.com**

## **Bullet Points**

- Try reasoning when possible
- STAY CALM
- Detach or disengage when appropriate
- Adjust expectations
- Seek professional help

## **BOUNDARIES**

**Boundaries can serve as a means to communicate the things you find acceptable, tolerable, and useful while trying to accomplish your goals. Boundaries can apply to one-self where personal structure and discipline are desired or needed. In so doing, we impose limits on ourselves.**

**Boundaries can, and should apply to relationships of all kinds. But let's focus on boundaries that would be beneficial to a caregiver, where the loved one is concerned.**

**When you establish useful and realistic boundaries as a caregiver, you are basically communicating what you are willing to do and what you are not willing to do. You are also using the boundaries to "Teach people how to treat you". To use the**

**appropriate boundaries can also serve as a way to practice Self Care and not feel taken for granted.**

### **Bullet Points**

- **Boundaries can provide us with structure and discipline**
- **We teach people how to treat us**

## **DEMENTIA EDUCATION TOPICS**

**WHAT IS DEMENTIA?**

**WARNING SIGNS**

**BEHAVIORAL SYMPTOMS**

**DISEASE PROGRESSION & DEFINITIONS**

**RESOURCE INFORMATION**

**SPECIAL NOTE FOR CAREGIVERS**

### **WHAT IS DEMENTIA?**

**Dementia is not a specific disease. It is an overall term that describes a wide range of symptoms associated with a decline in memory or other thinking skills severe enough to reduce a person's ability to perform everyday activities.**

**Alzheimer's disease is the most common type of dementia and accounts for 60-80 percent of cases. Other types of dementia include Vascular, Frontotemporal, and Dementia with Lewy Bodies.**

**\*Source: Dementia Friendly Hawaii**

## **WARNING SIGNS**

**There are ten (10) warning signs as put forth by the Alzheimer's Association:**

- **Memory loss that disrupts daily life**
- **Challenges in planning or solving problems**
- **Difficulty completing familiar tasks at home, at work, or at leisure**
- **Confusion with time or place**
- **Trouble understanding visual images and spacial relationships**
- **New problems with words and speaking or writing**
- **Misplacing things and losing the ability to retrace steps**
- **Decreased poor judgment**
- **Withdrawal from work or social activities**
- **Change in mood and personality**

**\*Source: Alzheimer's Association**

## **BEHAVIORAL SYMPTOMS**

**A loved one can exhibit any one or any number of these behaviors at any time:**

- **Agitation**
- **Anxiety**
- **Catastrophic reactions**
- **Confusion (can wax or wane)**
- **Delusions**
- **Hallucinations**
- **Hoarding**
- **Paranoia**
- **Inappropriate sexual behavior**
- **Repetitive behaviors**
- **Withdrawal**
- **Sun-downing**
- **Wandering**

**\*Source: Dementia Friendly Hawaii**

**Note: One of the reasons for many of the above behaviors has to do with the fact that cognitively, the patient's world is continually shrinking. As their perception of their existence shrinks, there is a tendency to be fearful and unsure of so many things.**

## **DISEASE PROGRESSION**

### **Alzheimer's Disease**

- Live 8-10 years after symptoms begin

### **Vascular Dementia**

- Live 5 years after symptoms begin

### **Dementia with Lewy Bodies**

- Live 6-12 years after symptoms begin

### **Frontotemporal Dementia**

- Live 6-8 years after symptoms begin

### **Parkinson's Disease**

- Live 20 plus years after symptoms begin

**\*Source: Webmd**

**Note:** Following is a brief description of each type of dementia listed above. This information comes from different sources and may be paraphrased for simplicity.

## **DEFINITIONS OF DEMENTIA TYPES**

### **Alzheimer's Disease**

- Cognitive impairment and decline due to brain cell death which involves plaques , tangles, and a certain type of protein

### **Vascular Dementia**

- Lack of blood flow to the brain which can be related to hardening of the arteries and/ or stroke; also including TIA or mini-stroke

### **Dementia with Lewy Bodies**

- Typically, caused by protein deposits in the nerve cells which causes interruptions of chemical messages

### **Frontotemporal Dementia**

- Affects the front and side parts of the brain; affects language and behavior. This is also known as Pick's Disease

### **Parkinson's Disease**

- This is a progressive nervous system disease that effects movement. Dementia can become a component during the advanced stages



## **RESOURCE INFORMATION**

**There are many sources of information available for most types of dementia. The Alzheimer's Association is at the forefront of providing information and support for all types of dementia.**

**There are numerous books available to help caregivers with their roles in dealing with a loved one's journey with dementia. My personal favorite is entitled: "The 36 Hour Day" by Mace and Rabins.**

**There are many quality online resources as well as disease-specific local and/ or national associations who provide information.**

**Many medical doctors such as, but not limited to, neurologists, geriatricians, psychiatrists, and palliative care physicians are familiar with the most common forms of dementia.**

## **SPECIAL NOTE FOR CAREGIVERS**

**Although I speak to you as a mental health professional with expertise regarding the dementias and human behavior, I also speak to you as a former caregiver of a parent who suffered from vascular dementia for over five years.**

**I understand the challenges for everyone involved in this experience. I understand the importance of information and knowledge. I understand the importance of planning and being familiar with what to expect as things evolve and change.**

**My goals for you are simple: I want to equip you with as many tools as possible so that you have maximum quality of life for yourself and your loved ones.**

## **What is the Dementia Friends Program?**

**Dementia Friends is a global movement developed by the Alzheimer's Society in the United Kingdom, and now underway in the United States. The goal is to help everyone in a community understand five key messages about dementia, how it affects people, and how we each can make a difference in the lives of people living with the disease. People can help by becoming a Dementia Friend.**

**A Dementia Friend participates in a one-hour Dementia Friends Information Session offered by a Dementia Friends Champion or pair of Champions. In addition to the five key messages, you will learn a bit about what it's like to live with dementia.**

**An Information Session is a face-to-face session that lasts approximately one hour, and is not formal in nature. Those who attend are asked to commit to a dementia-friendly action and become a Dementia Friend. Perhaps your community has this program in place; check online for a program in your area.**

**Please see the Five Key Messages on the next page.**

## **DEMENTIA FRIENDS FIVE KEY MESSAGES**

- **Dementia is not a normal part of aging. Not everyone who grows old will develop dementia.**
- **Dementia is caused by diseases of the brain. The most common is Alzheimer's**
- **Dementia is not just about having memory problems. It can affect thinking, communication and doing everyday tasks.**
- **It is possible to have a good quality of life with dementia.**
- **There's more to the person than the dementia. People with dementia are a valuable part of the community.**

## **DR. DENNIS PEZZATO**

**Dr. Pezzato is a Behavioral Specialist who has written six self-help books geared toward helping others with their life skills. He has, for many years done cancer counseling for both patients and their caregivers, served on the Area Agency on Aging Advisory Board, is an RSVP Volunteer, conducts caregiver support groups, and been a volunteer and consultant with both the Alzheimer's Association and Kauai Hospice.**

**Dr. Pezzato feels strongly that being a caregiver is one of life's most difficult challenges. He was primary caregiver for a father with dementia for five years; experience created connection and passion for others' struggles. This passion was the reason for him to write this book.**