

# Caring For A Loved One With Dementia

*a practical*  
**guide**  
*for family*  
**caregivers**  
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## Assembling a Team for your Journey

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## Introduction

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**Your loved one was just diagnosed with dementia and you are starting a new life as a caregiver.** You may feel scared, angry, shocked or sad –perhaps all of the above. There are a great number of resources available to support you and your loved one, and this book is designed to connect you with tools to guide this journey.

**No one can do it alone, nor should they.** The statistics are shocking: according to a Stanford study, 60% of dementia caregivers pass away before their loved one. Why? Because they neglect their own health, stop doing activities they enjoy that reduce stress and bring them joy, and sacrifice themselves while caring for another. While at times it may feel like this is the only way, the most successful, healthy, and balanced caregivers take time for themselves, ask for help, continue their lives with friends, activities, and events, and use the resources that are available to them. They don't feel guilty doing these things because they know that taking care of themselves allows them to better take care of others.

**Although it may seem like staying healthy when caring for someone with memory loss is impossible, the good news is, it's not. Put resources in place early, and make self-care a top priority.**

This book will lay out the different resources every dementia caregiver needs, following the “5 Pillars of Health”. These include social health, physical health, mental health, spiritual health, and legal/financial health.

## Assembling a Team



## 1. Social Health and Well-Being

Socialization is one of the most profound and important activities for patient with memory loss. The stimulation of interacting with others provides the brain “exercise” that helps slow the progression of disease, improves mood, and decreases loneliness and isolation.

Socialization is also critically important for caregivers. Being a caregiver is often both physically and mentally challenging. One of the ways that people cope with overwhelming challenges is to use their social networks to decompress, have a sounding board, and receive support from. Although you may feel like you are the only one going through these challenges, talking about it with others will help normalize your challenges and frustration, and it may simply feel good to have someone to talk to.

### Share your story.

Talk to others, and communicate with friends and family about what you are going through. Caregivers may feel that talking about their loved one’s diagnosis might be embarrassing, or humiliate them. While being protective of your loved one is natural, letting others in while give you both increased support, and allow others to help you. Often times friends and family want to help, but are unsure how, or want to respect your privacy.

Caregivers may feel that their friends have stopped calling, coming by, or inviting them out. Remember that people frequently avoid situations that are uncomfortable or that they don’t understand. The more you can talk, share and open up about what is going on, the better others can understand.

Tell them how they can help. Be specific. Ask them to come and spend two hours with your loved one while you go to the store. The more you engage your social network, the more connected and supportive others can be, enhancing the quality of your loved one's life and providing them more individuals to interact with.

Isolation is a recipe for trouble. You may not have the same amount of free time you previously enjoyed, but make it a priority to dedicate some time for social activities and interaction. Find a caregiver support group, continue to meet with your friends, and maintain activities you really enjoy. To accomplish this, identify sources of respite well before you feel like you need it. In addition to calling on friends and family for help, resources like the Family Caregiver Resource Center or the Alzheimer's Association<sup>1</sup> can connect you with respite options and in some cases funding to support you in continuing to be a social and healthy caregiver.

You may find support in your worship community, if you have one. Some of them offer respite care or may have members who will come to your home to provide you a break when needed. You will also find other caregivers who understand what you are experiencing. Talk, share, and connect.

Share what you are learning about Alzheimer's Disease with your family and friends. This will make it easier for them to help you plan for the next stages of the disease. It will also help them understand why you need planned time off for yourself and how they can support you.

## Utilize a Geriatric Care Manager.

Making health decisions for you and you loved one may seem complex and overwhelming. There may also be many family members involved in the decisions, which could be stressful and make it difficult to make efficient decisions. In some situations, there may be "too many cooks in the kitchen". To help manage, mediate, and find productive solutions and resources, considering utilizing a Geriatric Care Manager. This is a professional who is trained to assess, plan, coordinate, monitor and provide services for the elderly and their families. He or she has been educated in various fields of human services such as social work, psychology, nursing, and gerontology.

A Geriatric Care Manager can help solve complex family-related problems and advocate for your loved one. They will assess, plan, coordinate, monitor, and provide services for your loved one and your family, and put you in contact with other geriatric professionals as needed.

## Where to find a Geriatric Care Manager?

The National Care Planning Council's website<sup>3</sup> lists the places where to find a Geriatric Care Manager in your area. You can also ask your doctor, your local Senior Center, or your local Adult Day Care/Adult Day Health Care centers to send you a list of local Geriatric Care Managers.

## Why is it helpful?

*“My brothers and I were fighting all the time about how to manage our mother’s situation when she got dementia. We never agreed about anything. Eventually, we hired a care manager and she helped us tremendously in navigating the medical system and making the right decisions for Mom.”*

## 2. Physical Health and Well-Being

There are few things as important, or as valuable as your health, and you hold the responsibility to take care of it the best you can. While not all factors related to your health are within your control, taking steps to manage, treat and become informed about health conditions are. It is critical to be a strong advocate for yourself, ask questions, and seek out the right providers and resources to receive the most effective and comprehensive treatment available. This is true for Alzheimer’s Disease and other dementias. There is a common belief, and you may have heard that there is nothing that can be done to treat dementia, however, that is not entirely true. While there is no known cure to reverse Alzheimer’s Disease, there are medications and other lifestyle changes that may impact the progression of the disease in favorable ways. Early intervention is key.

### See a neurologist.

A neurologist is a medical doctor who specializes in treating diseases of the nervous system, which includes the brain and the spinal cord. Neurologists see patients with seizure disorders, stroke, multiple sclerosis, neuromuscular disorders, infections of the nervous system, spinal cord disorders, headaches and

migraines, and neurodegenerative disorders, such as Parkinson’s disease, Alzheimer’s disease, Lewy Body dementia, vascular dementia, Frontotemporal dementia, and other types of dementia.

A neurologist is a specialist. Your insurance may or may not require that your doctor makes a referral to a specialist. If a referral is not required, you can look for neurologists in your insurance networks and make an appointment. Do not delay as it is common for the wait to be a month or more. If your insurance requires a referral from your primary care, and a diagnosis is made, or is suspected, and a referral was not made, you can ASK to be referred to a neurologist. Neurologists may have resources to provide you with more information about a diagnosis, may use different tools or imaging to make a diagnosis, and may have different treatments available than your primary care doctor. Being a good advocate means that you seek out the best possible treatment options available.

If it feels uncomfortable to ask your doctor for another provider, remember that you are responsible for being an advocate for your health and well-being. Express your concerns and insist on a referral. Consider changing to a doctor you don’t feel comfortable asking for another opinion. Just as anyone would contact an oncologist should they be diagnosed with cancer, it is imperative that a person sees a neurologist as soon as they are diagnosed with any kind of memory loss.

### 3. Mental Health and Well-Being

#### Psychiatrists and psychologists

When you are assembling a team for your journey of ups and downs, don't forget to uphold the pillar of mental health. While mental health issues may be less obvious in some cases, and certainly more concealed than say, a broken leg, managing your mental health is an important key to quality of life. Issues such as depression, anxiety, and stress can rob you of joy and pleasure, and may affect your relationships, and your physical health and well-being.

Having a therapist on your team provides an outlet for you to process the changes that are occurring in life. These changes may be physical, mental, social, relationships may change, abilities may change. Processing these is often cathartic and alleviates stress. You may also benefit from talking about your concerns and worries with a professional outside of your family. This is a judgement-free zone, so you can talk about your feelings freely, without the burden of worry that you may upset or concern others. Many people find that things they worry about or felt guilty about are common for others as well.



A therapist can be an important team member for both caregivers and those living with a progressive illness. People who have received a diagnosis may be upset, feel that life is unfair, be concerned about others, or become depressed. Depression can have significant consequences – both for mental health and for memory. People who are depressed tend to isolate themselves, eat too little or too much, have sleep disturbance, and often times do not enjoy things they used to. In serious situations, they may feel hopeless and feel that life is no longer worth life. In addition, depression can make memory problems worse. People who are struggling with depression tend to have more trouble thinking, remembering, and learning, and may progress into dementia much faster than someone who has memory loss but is not depressed.

Mental health professionals include psychiatrists, psychologists, marriage and family therapists, clinical social workers, and others which may vary by state. Psychiatrists are trained medical doctors who may prescribe medications as a course of treatment. Psychiatrists may specialize in an area, such as geriatric psychiatry. Psychologists earn a doctoral degree such as a Ph.D. or PsyD, and they focus extensively on treating emotional and mental suffering in patients with behavioral interventions, and conduct testing and assessments, such as neuropsychological testing. Some psychologists specialize and may be called Neuropsychologists. They specialize in assessment, diagnosis, treatment, and rehabilitation of individuals with neurological disorders. Marriage and family therapists and clinical or medical social workers also provide therapy and behavioral interventions. Your therapist may refer you to a psychiatrist if medication is a treatment option, and the therapist and psychiatrist work together to treat patient symptoms with a combination of therapy and medication.

Chances are that high that your loved one may also be experiencing depression, anxiety, or other psychological conditions. This is, after all, a normal response to fear, loss, and unwanted change. Caregivers also experience these emotions, and are likely to benefit from an individual therapist and regularly attending a support group.

### **Where to find a Mental Health Professional?**

Many mental health services are covered by insurance, so checking with your insurance carrier is a good first step. You can also ask your primary care physician for a referral. Your local Senior Center may have referrals, or may even have providers available. You can choose a provider that you will feel comfortable with, and know that you are taking steps towards maintaining good health.

## **4. Legal & Financial Guidance**

End of life planning is not just about the legal paperwork. These conversations are about being able to direct your life with the care and support you want until the end. They are about letting your loved ones know how you wish to live it until the very end, or in the event that you are unable to make your own decisions. By doing so, you will be taking the burden off of your loved one's shoulders so that you can all enjoy each other's company until the very end, and provide a roadmap to fulfill your final wishes.

**Some paperwork is necessary. Having your affairs in order will make the end of life transition so much more relaxed and pleasant.**

Navigating legal and financial matters can be overwhelming and tedious, and may be more complicated when caring for someone with memory loss. Experts in Elder Law, Trusts and Wills, Durable Power of Attorneys, or Estate & Financial Planning have resources to help ease this process and complete it in a timely manner. They will help review your current designees, beneficiaries, and can assist with benefits, insurance, long term care, and other financial and health planning.

### **Get your documents in order.**

If you are caring for your loved one with dementia and they have the capacity to remember where everything is placed, work with them to organize every important document and papers.

- Collect all important documents: social security card, birth certificate, marriage certificate, divorce papers, insurance certificate, stock certificates, etc.
- Store all important legal and financial documents in a safe and accessible location
- The health care papers: Medicare<sup>+</sup> and/or Medicaid card, doctor's name and telephone number, list of current medicine
- Other papers: life and burial insurance, house insurance, car insurance, long-term care insurance, etc.

More importantly, let key people know where these documents are kept.

## Get a consultation.

Make it a priority to meet with a Trust, Estate Planning, or Elder Law attorney. Understand the documents that you wish to have in order, and begin a plan to make decisions that the attorney will be able to put in writing for you. You may consider the following:

- **Advance Directive or Living Will**

This legal paper lets you state your wishes for end-of-life medical care in case you become unable to communicate your decisions. The document has no power after death.

- **Durable Power of Attorney for Healthcare & Finance**

A Durable Power of Attorney (DPOA) is a written authorization to represent or act on another's behalf in private affairs, finances, medical care, business, or other legal matters when the person becomes mentally incapacitated and cannot give medical consent. With a valid DPOA, the trusted person you name will be legally permitted to take care of important matters for you, such as paying your bills, managing your investments, or directing your medical care, when you are unable to do so yourself. It is typical to nominate one party to be a power of attorney for healthcare, and a different party to be a power of attorney for finances. This helps protect both your health and your assets, and minimize conflicts of interest in making decisions.

- **HIPAA waiver for medical privacy**

The HIPAA waiver is a legal document that allows an individual's health information to be used or disclosed to a third party. The waiver is part of a series of patient-privacy measures set forth in the Health Insurance Portability and Accountability Act (HIPAA) of 1996.

- **Physician Orders for Life-Sustaining Treatment (POLST) form**

A POLST form is a medical order for the specific medical treatments you want during a medical emergency. It needs to be signed by your physician.



## Benefits and Insurance

- **Medicare**

Medicare is the federal health insurance program for people who are 65 or older, certain younger people with disabilities, and people with End-Stage Renal Disease.

Medicare helps cover specific services, such as hospital insurance (inpatient hospital stays, care in a skilled nursing facility, hospice care, and some home health care) or medical insurance (certain doctors' services, outpatient care, medical supplies, and preventive services). For more information and check what kind of coverage you or your loved one qualify for, visit [www.medicare.gov](http://www.medicare.gov) or call 1-800-633-4227.

- **Long-term care insurance**

Long-term care insurance generally covers home care, assisted living, adult daycare, respite care, hospice care, nursing home and Alzheimer's facilities. It will pay for a visiting or live-in caregiver, companion, housekeeper, therapist or private duty nurse up to seven days a week, 24 hours a day (up to the policy benefit maximum). Many experts suggest shopping by age 50 as part of an overall retirement plan to protect assets from the high costs and burdens of extended health care.



## Consider making burial and memorial plans to make sure that your loved one's wishes are honored.

For example, encouraging your loved one to communicate clearly whether they would like to be cremated or buried can save you and your family from having to make hard decisions when the person is deceased. Here are a few funeral options: donation to medical science, direct cremation or cremation after a formal funeral, ground burial.

## Schedule a consultation with an Elder Law Attorney, or Estate and Trust Attorney.

- **Elder Law**

Elder Law prepares an elderly person for financial freedom and autonomy through proper financial planning and long-term care options.

Estate planning is part of Elder Law. It is the process of anticipation and arranging for the management of a person's estate during their life and after death.

- **A Will or Living Trust**

These two terms can be confusing. What is the difference between the two?

A will is a document that sets forth your wishes about distributing property, assets, or caring for children.

Creating a will gives you the opportunity to decide how your assets will be distributed, including your belongings, such as cars or family heirlooms. If you do not have a will, your loved ones may not receive the assets you wish to leave them in the event of your death. A will becomes effective only after you die. It is public record.

A living trust, like a will, spells out your wishes about how to distribute your assets and possessions, however, unlike a will, a living trust designates a trustee, who can carry out your instructions before your death, in the event that you are unable to manage your financial, healthcare or legal affairs. The document covers only property that has been transferred to the trust. A trust can remain private.

Consult with an attorney about which type of will or trust is best for you. Wills and trusts may have different tax implications and rules with regard to how real estate is handled, so it is important to work with a legal professional to create official documents.

The court oversees the process of a will, while it doesn't oversee the process of a trust.

### **Look for legal resources available around you.**

It may seem overwhelming to think about planning for end of life, and the process of finding an attorney may seem difficult and expensive. Seek resources to help with legal and financial decisions that may be available where you live.

Ask your local Senior Center for referrals. You can also contact organizations like your local Council on Aging for guidance. The local Caregiver Resource Center may be able to assist in connecting you with resources to have these documents completed. Many attorneys will offer a free consultation to discuss your needs, and financial resources or scholarships may be available through caregiver services or the Legal Aid Society.

### **Time is of the essence.**

While gathering paperwork and planning your death may not be an enjoyable process, once it is complete you can relax knowing that your affairs ARE in order. Your wishes are specified to be carried out as you directed, and the arrangements you made for yourself and family members, property, possessions, and even pets are secure.

If you are a loved one have memory loss or have been diagnosed with Alzheimer's Disease, starting and completing this process needs to become a top priority. For individuals to create an advanced health care directive, will, or trust, they must have capacity. This means they must be able to make the decision on their own, and fully understand the consequences of their decisions. In the event that a power of attorney, will, or trust is not complete, and you or your loved one no longer has the ability to make decisions, your family may have to go to court to obtain permission to manage these areas of your life when you are no longer able to.

Further, it may place a burden on them to be forced to make difficult decisions about your care, or family members may disagree. Without a financial power of attorney, your family may not be able to take care of financial affairs, such as paying bills or cashing checks, and may have to petition the court to become a legal guardian to gain these powers.

## 5. Spiritual Guidance

Religious or not, spiritual or not, everyone wishes to live peacefully until the end. The more one prepares end of life decisions, the less of a burden it will be for one's entourage. Think of a legacy as "instructions" on how someone wishes to take their last breath. Talk to your loved one about what will make them feel more at peace when they are facing their own end of life.

Before it is too late, encourage your loved one to answer questions like:

- Do I want to die alone or surrounded by people?
- Who do I want to be surrounded with?
- Will I want to be held, touched, or not at all?
- Do I want to say goodbye to each of my loved ones before I go?
- Do I want my loved ones to gather together after I die?
- Is there something I need to tell my children? Will I tell them in a letter, or face to face?
- Do I prefer to be celebrated with a religious ceremony, spiritual ceremony, or a celebration of life?
- Do I have any loving requests for my end of life such as "Please tell me funny stories and sing happy songs"?

## Religion or spirituality?

A great number of people are religious or spiritual. Whether they would like to follow certain religious traditions, with the help of clergy and their religious community, or they would prefer to plan for their own kind of celebration, the most important thing is that all their wishes are communicated in advance. It will help the person transition from the body to the spirit.

Encourage your loved one to answer questions like:

- What kind of memorial ceremony do I want after I die?
- Do I want a religious ceremony with clergy? What would be the tone (ceremony, wake or celebration)? How do you want them to feel when remembering you? What kind of music would I like to be played?
- Do I want flowers, or do I prefer that my loved ones donate to my favorite cause?
- Do I prefer a "celebration of life", with no religion involved?
- Do I want to be buried or cremated?

If your loved one is not spiritual or religious, the practice of love is equally as important.

## Making peace with self and others.

When making peace with yourself or with others, please know they do not have to be there. You can write a sentence or two about them and end it in love. Remember when offering an apology try not to explain why.

Just say, I wish I would have behaved better or known better or remembered to love you more than what I was expressing at the time. Each person and situation is different so allow your heart to direct your words and know you have done your best. We could all do better and life is an experience not a perfection.

Encourage them to answer questions such as:

- Do I feel anything is being left undone or not expressed?
- Is there anyone I wish to have one more conversation with?
- Do I want to say “I am sorry, please forgive me”?

*“When my Mom was dying, I begged her to write down what she thought about me and my siblings. I never saw her do it and thought she did not honor my request. But my sisters found a letter underneath her bed when she passed and brought it to the funeral without telling anyone. They read it out loud to everyone: the letter contained the sweetest words to each one of her children and grandchildren. It has filled my heart with happiness ever since.”*

This may be a challenging journey, and for most, these are challenging topics and questions to ponder. A religious or spiritual member of your team may be able to support you in creating these plans, and provide guidance should you desire support.

A Chaplain is versed in many religions and multiple faiths. They serve the spiritual and emotional needs of others. They may provide counseling, offer prayer or deliver spiritual messages, or function as advocates, such as in hospital to help meet the needs of a patient. Chaplains can be found in many environments, such as hospitals, military settings, and other institutions.

You may also have a relationship with a religious leader, such as a Priest, Pastor, Rabbi or other clergy that can be requested to perform rituals, consult, or provide counseling and comfort.

## Resources

### <sup>1</sup>Family Caregiver Resource Center

Website: [www.caregiveroc.org](http://www.caregiveroc.org)

Phone: 800-543-8312

### <sup>2</sup>Alzheimer’s Association

Website: [www.alz.org](http://www.alz.org)

Phone: 800-272-3900

### <sup>3</sup>National Care Planning Council

Website: [www.longtermcarelink.net](http://www.longtermcarelink.net)

### <sup>4</sup>Medicare

Website: [www.medicare.gov](http://www.medicare.gov)

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