

# **A Checklist for Dementia Caregivers**

**Developed by a Dementia Support Group  
Under the Auspices of the Alzheimer's Association  
Albuquerque, New Mexico  
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# A Checklist for Dementia Caregivers

## Introduction

Being a caregiver to someone with dementia is a long and difficult journey. This checklist was developed by people who have traveled that road.

The checklist is intended for dementia caregivers who are close family members or legal guardians of the persons with the disease (PWD). The expectation is that you are very familiar with the individual who has the disease and are able to take over important, personal activities related to the topics below, or have already done so. If you are a family member, the assumption is that the person with the disease is your spouse, parent, sibling, adult child, aunt, uncle, grandparent, etc.

Not every item on this checklist will pertain to the person with the disease, in which case you can simply skip over what is not applicable. There may be additional activities that need to be done that are NOT covered in this checklist. Use blank lines at the end of the list to add any other items.

## Structure of the Checklist

The checklist is divided into seven sections, not necessarily in the order of importance. However, the authors of this checklist believe that the top three sets of activities (legal, medical and financial) should be your top priorities. The sections, in sequence are:

- *Legal-Related Activities*
- *Medical-Related Activities*
- *Financial-Related Activities*
- *Activities Related to Military Service (Retired or otherwise)*
- *Additional Activities for Your Peace of Mind*
- *Insurance Benefits Not Listed Elsewhere*
- *Activities Immediately Following Death*

## Be Organized, Consult Resources, Get Expert Advice

The average length of an Alzheimer type dementia is 8-12 years. However, depending on age of onset and the person's overall health, deterioration can happen leading to death within 4-5 years. Some individuals may progress very slowly and live 15-25 years. For some things, you would want the PWD to have an awareness of legal, financial, or personal consequences and obtain their agreement on key decisions early on. In short, *it is never too early to start putting things in place*. The checklist indicates which activities are best done after diagnosis. MANY activities can be done before the person dies, while several can only be done after death.

Please note that the developers of this checklist are not medical, financial, or any other type of professional experts. They urge you to contact the most knowledgeable specialists in the areas identified to answer your questions and give you the most up-to-date information and advice.

One further note. This checklist is designed for personal and family use. Any business-related concerns such as maintenance, sale, operation of, or liquidation of a business should be brought to an attorney who specializes in such matters.

There are several other resources in this document that you may find helpful, including phone numbers, terms/acronyms, websites, and publications. Please consult them, use them freely, and pass this document on to others in need of help.

## Helpful Hints:

- While you are doing this for the PWD, remember to consider doing many of these items for yourself. Booklets for recording data about important information in the event of your death are available from Amazon and elsewhere.
- Consider getting a 3-ring binder, subject dividers, and plastic sleeves to compile and store this checklist and any information gathered.

## How to Use This Checklist

*Print the checklist for ease of use. We suggest using a notebook in order to keep the checklist and other documentation in order. It is not possible, at this time, to type, online, in the spaces provided.*

1. **Peruse the structure and content of the checklist in its entirety. Any task that you are just starting, input the date in the column marked “start date.”** Add a few comments as you proceed within the checklist, on the back of the page if blank, or on the page titled *Progress Notes*. For example, after visiting the bank where your joint checking account is, make a few notes about bank procedures for reporting your loved one’s death.
2. **Definitely indicate, in the Completion Date column, the approximate date a task is finished.** Jot down a few notes within the checklist or on the back of the page. For example, once you’ve picked a funeral home, write down which one and a few words as to why you chose it.
3. **The X’s in the columns marked “After Diagnosis” and “After Death” are suggested time frames in which to tackle items.**
4. **Those items for which “Periodic Review” is checked means that an *appraisal (perhaps annually, or as needed as changes occur)* is prudent for what you, or you and your spouse, or the person for whom you are caring may want to change or confirm.**
5. **Page 13 is a blank sheet for you to add items that the authors of the checklist may have overlooked or are specific to your situation.**
6. **Resource information begins on page 15 and may help clarify some of the checklist items.**

*Remember that not every item will apply to the person for whom you are caring or to yourself. Tackle a few of the items every week so you are not overwhelmed at the end.*

### After Dementia Diagnosis/After Death Checklist

Item	After diagnosis	After death	Start Date	Completion Date	Periodic review advised?	Comments
<b>Legal-Related Activities</b>						
<b>Contact or hire an attorney</b> specializing in wills, trusts, and Powers of Attorney (POA) in your state. Search for someone knowledgeable about elder/dementia issues.	X					<i>An essential step if you haven't already done so. It is too late after the person has died. Also, seek an attorney, ASAP who is knowledgeable about Medicaid, if you think you may need financial assistance.</i>
<b>Select Medical POA</b> and a backup for the person with the disease (PWD) and yourself.	X				X	
<b>Select Financial POA</b> and a backup for the PWD and yourself.	X				X	
<b>Select appropriate legal instrument</b> (trust or will) for beneficiary designation, etc.	X				X	
<b>Designate or review/change trustee(s) or executor(s)</b> per legal instrument(s) selected.	X				X	
<b>Determine/have available any instructions created by the PWD</b> in the event of his/her death.	X				X	

Item	After diagnosis	After death	Start Date	Completion Date	Is periodic review advised?	Comments
<b>Items to assemble for possible use after PWD dies.</b>						<i>It is prudent to organize as many things as possible before the PWD dies.</i>
<i>Most recent copy of trust or will</i>	X				X	
<i>Birth Certificate</i>	X					
<i>Marriage Certificate(s)</i>	X					
<i>Divorce Certificate(s)</i>	X					
<i>Titles to motor and recreational vehicles (e.g., car, truck, boat, motorcycle, ATV)</i>	X				X	
<i>Lease agreement(s)</i>	X				X	
<i>Deeds, deeds of trust, mortgages, titles</i>	X				X	<i>Don't forget vacation homes, time shares, property, etc.</i>
<i>Buy/sell agreement(s)</i>	X				X	<i>Become familiar with the terms of such agreements that include family members or friends.</i>
<i>Safe Deposit Box Location /information</i>	X					

Item	After diagnosis	After death	Start Date	Completion Date	Is periodic review advised?	Comments
<b>Medical-Related Activities</b>						
<b>Have a Do Not Resuscitate (DNR) or Do Not Intubate (DNI)</b> prepared, or prepare it yourself, or locate if completed.	X				X	<i>Post it in a prominent place in case of emergency.</i>
<b>Research in-home care options</b> with trained dementia caregivers.						<i>Support group members are a knowledgeable source.</i>
<b>Have person declared incompetent</b> , if or when appropriate.	X				X	<i>This needs to be done if guardianship of the PWD is required.</i>
<b>Research long term care facility options.</b>	X				X	<i>E.g., Assisted living, memory care, nursing home</i>
<b>Research hospice organizations.</b>	X				X	
<b>Contact selected hospice to evaluate PWD, and contract when PWD becomes eligible.</b>	X					<i>This is usually done in late stage and is based on pre-established criteria by Medicare/Medicaid. PWD's physician can provide guidance.</i>
<b>Financial-Related Activities</b>						
<b>Contact or hire a Financial Advisor.</b>	X					<i>Can be connected to a big investment company like Fidelity or Schwab or a private individual.</i>
<b>Contact or hire an accountant.</b>	X					<i>Medical deductions can be substantial so getting advice is prudent.</i>

Item	After diagnosis	After death	Start Date	Completion Date	Is periodic review advised?	Comments
Know your banks' policies re: death of one of the account holders.						<i>Find out process of each for reporting a death and outcomes of doing so.</i>
Close bank accounts with PWD's name on them AFTER all known checks to him/her have cleared.		X				<i>Reporting time frame of death is usually up to the individual bank.</i>
Call PWD's retirement organization(s).	X	X				<i>Find out process of reporting death and what survivor benefits to expect.</i>
Find out where to get low cost legal or financial assistance, if applicable.	X					<i>Your support group, state's bar association, or state's web site may be good places to start.</i>
Research Medicaid information and apply, if and when appropriate.	X					<i>The sooner the better.</i>
Set up a checking account in your own name and transfer funds into it while leaving joint account in place for direct deposits to the PWD.	X					
Report PWD's death to credit reporting agencies.		X				<i>There are only three: Equifax.com Experian.com TransUnion.com</i>

Item	After diagnosis	After death	Start Date	Completion Date	Is periodic review advised?	Comments
<b>Items to assemble for possible use after PWD dies</b>						
<i>Pension/Retirement Documents</i>	X					
<i>Recent tax return and gift tax return</i>	X				X	
<i>Stock and bond certificates</i>	X				X	
<i>Brokerage or investment company statements</i>	X				X	
<i>Bankruptcy filings</i>	X				X	
<i>Unpaid bills/debts/liens</i>	X	X			X	
<i>Records of money owed to you or PWD</i>	X	X			X	<i>Items like rent, car sale, etc.</i>
<i>Bills on autopay</i>	X				X	
<i>Bank account info</i>	X				X	<i>Name of bank, types of accounts, names on accounts, etc.</i>
<i>Credit/debit cards in PWD's name and your own</i>	X				X	
<i>Certificates of Deposit (CD)</i>	X	X			X	
<i>Location of any storage lockers</i>	X				X	



Item	After diagnosis	After death	Start Date	Completion Date	Is periodic review advised?	Comments
<b>Activities Related to Military Service (Retired or otherwise)</b>						
Determine what benefits and entitlements you or the PWD, as former military, is eligible for. Then call to enroll.	X	X				Call the Veterans Affairs assistance number: 800-827-1000.  Call 505-265-1711 X 3059 (NM only),
Locate the PWD's DD214 (military records and discharge papers).	X					Call National Archives for replacement copy: 314=801-0800.
<b>Additional Activities for Your Peace of Mind</b>						
Find a support group.	X					Local or national offices of the Alzheimer's Association maintain lists.
Locate adult day care facilities in your area.	X				X	These can fulfill current and future respite needs.
Select a funeral home ahead of time from several in your area.	X	X				Only if you haven't pre-purchased a funeral package. Funeral costs can vary widely.
Determine PWD's preference for any service, celebration, burial, scattering, etc.	X	X				
Notify credit card companies related to any card in the name of the PWD.	X	X				Make changes as required. Make note of autopay withdrawals via credit card that might be affected.
Contact your local senior affairs office to see what services are available.	X				X	You may have one in your city or county.

Item	After diagnosis	After death	Start Date	Completion Date	Is periodic review advised?	Comments
Register PWD with Silver Alert in your community.	X					<i>Generally, consider an ID or tracking mechanism for the PWD if your loved one "wanders."</i>
Terminate PWD's personal cell phone account.	X	X				<i>A cell phone is a liability once the PWD does not know how to use it.</i>
Delete any of PWD'S social media accounts.	X	X				<i>E.g., Facebook, Instagram, Twitter</i>
Close email accounts in PWD's name.	X	X				
Cancel any other services no longer needed OR put them into your name, particularly things to which a credit card is attached.	X	X			X	<i>Utilities, cable, internet, streaming or shopping services (e.g., Netflix, Amazon, etc.)</i>
Know or collect passwords used by PWD.	X				X	
Review PWD's computer and any other electronic devices.	X	X				<i>Retain important/relevant files and delete others; wipe devices clean (electronically) and repurpose, as desired, or per PWD's wishes.</i>
Prepare contingency plans.	X				X	<i>In case you become ill; in case you die (Prep list of contact names/phone #s and make sure whereabouts of the list is known to several people.)</i>

Item	After diagnosis	After death	Start Date	Completion Date	Is periodic review advised?	Comments
Make decisions for rehomeing of pets, if necessary.	X				X	
Consider options for a funeral or memorial.						<i>Confer with family, if appropriate, on this item.</i>
<b>Insurance Benefits</b>						
Determine what, if any, life insurance the PWD has and beneficiary entitlements.	X	X				
Determine what, if any, health insurance benefits will be available and to whom.	X	X			X	
Determine what, if any, dental/vision insurance benefits will be available and to whom.	X	X			X	
Contact home owners , vehicle, etc. insurers to remove PWD from the policies.	X	X				
<b>Activities Immediately Following Death</b>						
Contact selected funeral home.		X				<i>May be done for you if using hospice at the time of death.</i>
Call VA to report death and find out burial options if PWD is a veteran.		X				<i>May be done for you by the funeral home at the time of death. Phone number is 800-827-1000.</i>
Determine or verify disposition of remains.		X				<i>In conjunction with the funeral home.</i>

Item	After diagnosis	After death	Start Date	Completion Date	Is periodic review advised?	Comments
Assign someone to write an obituary and decide where to place it .	X	X				<i>E.g., newspapers, funeral home website, neighborhood newsletter, etc.</i>
Order 10-20 death certificates through funeral home.		X				<i>These may be required as proof of death. (It may be cheaper to order through funeral home than via the state.)Check with requester if photocopy or scan is acceptable.</i>
Notify Social Security (SSA).		X				<i>Funeral home reports death to the state. SSA may be notified by the funeral home, but there are other survivor benefits that require you to call: 800-772-1213.</i>
Contact and inform your attorney.		X				
Contact and inform your financial advisor.		X				
Contact any financial institutions such as banks, where death must be reported immediately.		X				<i>You may delay notification until all direct deposits cease or are put into beneficiary's name at some banks.</i>
Contact insurers to report death.		X				<i>Particularly with regard to funds due to beneficiaries.</i>
Contact PWD's retirement organization(s) to report death.		X				

**Add Other Items As Needed**

Item	After diagnosis	After death	Start Date	Completion Date	Is periodic review advised?	Comments

### **Progress Notes**

Use this page to document related information.

Reference page and item. Make copies of this page to accommodate additional notes.

# RESOURCES

## Terms/Acronyms

**AutoPay:** A convenient option in which bills will be paid automatically each billing cycle on their due dates using your default credit card or bank account.

**Contingency Plan:** A course of action designed to help an organization respond effectively to a significant future event or situation that may or may not happen.

**Credit Reporting Agency:** A business that maintains historical credit information on individuals and businesses.

**Disposition of Remains:** What you want done with your body following death. The most common dispositions are burial and cremation.

**DNI:** Do Not Intubate

**DNR:** Do Not Resuscitate

**Executor:** The person appointed to administer the estate of a person who has died leaving a will which nominates that person.

**Hospice:** Hospice care focuses on the care, comfort, and quality of life of a person with a serious illness who is approaching the end of life.

**Medicaid:** Medicaid provides health coverage to millions of Americans, including eligible low-income adults, children, pregnant women, elderly adults and people with disabilities. Medicaid is administered by states, according to federal requirements.

**POA:** Power of Attorney (medical, sometimes referred to as the “health proxy,” and financial, sometimes referred to as “general power of attorney”)

**PWD:** Person with the Disease (In this case, the person with some form of dementia.)

**Silver Alert:** A public notification system in the United States to broadcast information about missing persons – especially senior citizens with Alzheimer's disease, dementia, or other mental disabilities – in order to aid in locating them.

**SS:** The United States Social Security Administration

**Trust:** a right in property (real or personal) which is held in a fiduciary relationship by one party for the benefit of another.

**Trustee:** a person or entity who holds the assets of a trustee for the benefit of the beneficiaries and manages the trust and its assets under the terms of the trust

**VA:** Veterans Affairs

**Will:** a written document which leaves the estate of the person who signed the will to named persons or entities including portions or percentages of the estate, specific gifts, and creation of trusts.



## Information about the Alzheimer's Association and Its Web Site

**Web site: *alz.org*** This Web address goes to the national association's home page. To get to resources in the chapter closest to your home, click on **Your Chapter** in the purple bar, and search by state or zip code.

In the topmost bar, click on **Events** for news about an assortment of Association initiatives.

Click on **Alzheimer's and Dementia** in the purple bar and find a variety of topics, a wealth of information and links for caregivers and others trying to understand what to expect of their loved one.

A **Search** function, accessible from the purple bar, allows you to type in ideas, phrases, words and more to try to find information about the disease and how it affects individuals. Here are just a few of the topics for which information and advice are available: Aggression and anger, Suspicions and Delusions, Long-term care settings, Stages of Alzheimer's, The 10 Warning Signs of dementia, How Alzheimer's is diagnosed—and so much more.

**24/7 Helpline:** 800-272-3900. There is always someone to talk to at the other end. You are not alone.

**Access to Support Groups:** Support groups sponsored by the Alzheimer's Association are available throughout the country. Group members have a collective knowledge, because they are all on the same journey. Some members may continue on in the group after their PWD dies, as they care deeply. Within a few clicks, you should be able to start on a search to find the right group for you, whether it meets in person or online.

**Access to Community Resources:** Search by zip code for such important resources as: **medical services** (e.g., geriatric psychiatrists, neurologists, and home health care); **at-home care** (e.g., adult day care centers, hospice organizations, geriatric case managers); **community services** (e.g., relocation advisors, elder law attorneys, Area Agency on Aging); **housing options** (e.g., assisted living, Continuous Care Retirement Communities, independent living). <https://www.communityresourcefinder.org/>

**Alz Connected:** An online way to connect with others including caregivers, people with the disease, family members, friends, and individuals who have lost someone to Alzheimer's or other dementias.

<https://www.alzconnected.org/>

## Other Websites

**Checklists of what to do when a loved one dies** (If you are viewing this document online, simply click on the link provided. If you have printed it out, see parenthetical instructions for getting to the lists more quickly without having to retype the URL.)

- AARP--<https://www.aarp.org/home-family/friends-family/info-2020/when-loved-one-dies-checklist.html> (Go to Google or your search bar. Type in **Checklist for What to do when Someone Dies – AARP**. Then click on the first hit. )
- Bereavement Advice Centre--<https://www.bereavementadvice.org/topics/what-to-do-when-someone-dies/step-by-step-checklist/> (Go to Google or your search bar. Type in **Bereavement Advice Step by Step Checklist**. It may be the first or second hit. Click on it to go to the list.)
- USAA--[https://content.usaa.com/mcontent/static\\_assets/Media/If\\_survivors\\_checklist.pdf](https://content.usaa.com/mcontent/static_assets/Media/If_survivors_checklist.pdf) (Go to Google or your search bar. Type in **USAA Survivor Checklist**. It may be the first hit. Click on it to go to the list.)
- Dennett, Craig, and Pate (law firm)--[http://www.dcpate.com/Survivors\\_Checklist.pdf](http://www.dcpate.com/Survivors_Checklist.pdf) (Go to Google or your search bar. Type in **dcpate Survivor's Checklist**. It may be the first hit. Click on it to go to the list.)
- The Legacy Lawyers (law firm)--<https://www.thelegacylawyers.com/free-guides/after-death-checklist/> (Go to Google or your search bar. Type in **Legacy Lawyer's after death checklist**. It may be the first hit. Click on it to go to the list.)
- Trust and Will--<https://trustandwill.com/learn/what-to-do-when-someone-dies> , particularly, What if Someone Dies without a Will section. (Go to Google or your search bar. Type in **Trust and Will What to do When Someone Dies**. It may be the first hit. Click on it to go to the list.)
- Atticus--<https://www.weareatticus.com/articles/what-to-do-when-loved-one-dies> (Go to Google or your search bar. Type in **Atticus, what to do when loved one dies**. It may be the first hit. Click on it to go to the list)
- Good Rx Health--<https://www.goodrx.com/insurance/health-insurance/after-death-checklist-what-to-do-when-a-loved-one-dies> (Go to Google or your search bar. Type in **Goodrx After Death Checklist**. It may be the first hit. Click on it to go to the list.)
- Legal Voice (Women's Rights)--<https://www.legalvoice.org/after-death-occurs-checklist> (Google **Legal voice after death occurs checklist**. It may be the first hit. Click on it to go to the list.)

## Information on Medicaid and Medicare

- Medicaid.gov
- CMS.gov (Centers for Medicare & Medicaid Services)

## Publications

### Books

- The Funeral is Just the Beginning: Everything You Need to Do When a Loved One Dies by Amy Levine; Copyright 2013  
This book has some topics that you might not find elsewhere, or at least wouldn't find in one place. For example, Transporting a Body by Plane, Donating a Body to Science, Writing the Obituary, and Your Rights at a Funeral Home. Available in paperback from Amazon.
- Remembering You; Celebrate the life of a loved one A Grieve in Peace Journal; Copyright 2019 Grief Journal for writing fond memories; provides help with the healing and grieving process Available in paperback from Amazon.
- A Good Goodbye: Funeral Planning for Those Who Don't Plan to Die by Gail Rubin; Copyright 2010  
provides the information, inspiration and tools to plan and implement creative, meaningful and memorable end-of-life rituals for people and pets. Available from Amazon.
- The Alzheimer's Journey, A Practical Perspective for Caregivers (Kindle version)  
by Barbara Michels and Chris McCaffery | Copyright 2013 Available from Amazon.

### Planners (Just a couple of examples. There are MANY of these out there.)

- Making Things Easy for My Family: What You Need to Know About My Belongings, Business Affairs and Desires  
Copyright 2002
- Everything You Need To Know When I'm Gone: End Of Life Planner Organizer Copyright 2021

Errors and feedback can be sent to [nmsupportgroups@alz.org](mailto:nmsupportgroups@alz.org)