

legal and financial planning

for alzheimer's disease



tips for putting plans in place

tip 1: understand the terms

When making legal and financial plans, you will come across a lot of terms and phrases that you may not normally use or that might not be familiar to you. Here are some definitions that you can use as a reference after the presentation.

If your presenter indicates that a different term or phrase is used in your state, write that in the space provided along with any additional notes.

- Advance directives:** legal documents that enable a person to document preferences regarding treatment and care, including end-of-life wishes

- Americans with Disabilities Act:** protects those with any disability, including dementia, from discrimination in hiring, firing, training, pay and benefits as well as harassment related to their disabilities

- Beneficiaries:** those named to receive a person's finances and/or property after the person dies

- Caregiver tax credit:** can alleviate expenses incurred as a result of in-home care of a chronically ill person

- Child and dependent care credit:** may apply if you paid someone to care for your dependent (a person of any age who is physically or mentally incapable of self-care) so you could work

- ❑ **Compassionate Allowance Initiative:** allows those with younger-onset (early-onset) Alzheimer’s disease to be fast-tracked through the Social Security Disability Insurance application process as long as they meet the other criteria
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- ❑ **Durable Power of Attorney for Health Care:** designates another person to make health care decisions about treatments, providers, clinical trial participation, medical record access, and life support when the person is no longer able
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- ❑ **Durable Power of Attorney for Finances/Property:** designates another person to make decisions regarding finances such as income, assets, and investments when the person is no longer able
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- ❑ **Executor:** the person named to manage an estate after the estate’s owner dies
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- ❑ **Guardianship** (sometimes called conservatorship): declared by the court when it finds that a person is no longer able to make decisions about his or her care or property, and needs a guardian to assume significant responsibility for the person
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- ❑ **Legal capacity:** the level of judgment and decision-making ability needed to sign official documents or to make legal or financial decisions
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- Living trust:** allows a person to pool financial resources in one place and provide instructions about how to handle these resources when he or she is no longer able

- Living will:** spells out what medical treatment a person does and does not want near the end of life

- Mediator:** a neutral third party who helps a care team reach true consensus on decisions regarding care

- Medicaid:** a government assistance program based on medical need, income and assets

- Medicare:** a federal health insurance program for people 65 and older, people under 65 with certain disabilities, and people with End-Stage Renal Disease

- Medicare Advantage Plans:** sometimes referred to as Medicare - Part C, these plans are offered by private insurance companies approved by Medicare

- Medicare—Part D:** created for the sole purpose of assisting Medicare recipients in covering or lowering the costs of outpatient prescription drugs

- ❑ **Medigap:** private insurance designed to supplement Medicare by helping to cover co-payments, co-insurance, deductibles, and other costs not covered by Medicare (fills the “gap”)
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- ❑ **Older Americans Act:** authorizes funds for supportive services, nutrition programs, family caregiver support, and disease prevention/health promotion programs for older adults
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- ❑ **Physician Orders for Life Sustaining Treatment (POLST):** an advance directive used in several states that allows a person to indicate wishes about life sustaining treatment if he or she becomes seriously ill
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- ❑ **Social Security Disability Insurance (SSDI):** benefits paid to people who have worked for a specified number of years and have a condition so severe that they are not able to work any longer
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- ❑ **Social Security Representative Payee:** appointed by the Social Security Administration to manage Social Security benefits when the person is no longer able (*Note: a Durable Power of Attorney for Finances/Property is recommended in addition*)
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- ❑ **State Health Insurance Counseling and Assistance Program (SHIP):** a national program offering one-on-one counseling and information about how to access benefits to Medicare recipients and their families
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- Supplemental Security Income (SSI):** a benefit paid monthly to individuals who are aged, blind, or disabled and have limited income and assets

- Trustee:** a person named to follow instructions for managing another person's estate after the person is no longer able

- Veterans Administration:** the federal organization that provides benefits to veterans and qualifying family members

- Will:** used after a person dies to determine how the estate will be distributed

Notes:

tip 2: make legal plans early

There are several reasons to make legal and financial plans early in the disease process. For instance, the legal and financial issues related to Alzheimer's are complex, so it takes time to become informed in order to make decisions appropriate to your unique situation. Also, planning early in the disease process means that the person with dementia can have a voice and make choices about important issues. Finally, if families wait too long to plan, there can be difficult consequences.

Here are the steps to putting legal plans in place. These documents are crucial for someone with an Alzheimer's diagnosis, but they should be completed by everyone. Check off each box after you have completed the step.

- Gather all existing legal documents**
- Determine which of the following need to be updated or created:**
 - Durable Power of Attorney for Health Care
 - Durable Power of Attorney for Finances/Property
 - Living Will
 - Physician Orders for Life Sustaining Treatment (POLST; if applicable)
 - Living Trust
 - Will
- List people you can talk with about updating or creating documents:**
 - Spouse/Partner
 - Adult child: _____
 - Other family member: _____
 - Friend: _____
- If you want to try to make plans without professional assistance, see if forms for your state are available through the following:**
 - Your state's government website
 - The American Bar Association (click on "Download State-Specific Advance Directive Forms"): http://www.americanbar.org/groups/law_aging.html
 - The MedicAlert® website (enrollment not required to access): http://www.medicalert.org/join/advance-directives.htm?selected=MedicAlert0Membership_Advance0Directive
 - Office supply stores

- If the situation is more complex, or if you would prefer to complete forms with professional assistance:**
 - Consult with your own attorney if you already have one and he or she is knowledgeable about elder issues
 - Call our 24/7, toll-free Helpline for referrals for elder law attorneys in your area (1-800-272-3900)
 - Search the National Academy of Elder Law Attorneys website (www.naela.org)
 - If you are concerned about cost, check www.lawhelp.org to find out about free or reduced-cost legal services in your state
- If there are disagreements among family members about legal or financial issues and you would like to explore professional mediation/ conflict resolution:**
 - Try searching through your local court system
 - Try searching online through the Association for Conflict Resolution (<http://www.acrnet.org>)
- If you are in a same-sex relationship or marriage:**
 - Have copies of legal documents easily accessible to both of you
 - Bring copies of legal documents when traveling to strengthen your case in the event of a medical emergency
 - Complete a hospital visitation authorization form, if necessary (check hospital visitation laws in your state at http://www.hrc.org/documents/hospital_visitation_laws.pdf)
 - Make your wishes and documents known to:
 - Your physician
 - Your family

Notes:

tip 3: create a long-term budget

Paying for care can be a significant concern after an Alzheimer's diagnosis, but creating a long-term budget can help you plan for the future. To create your budget, first list the personal resources you can draw upon. Then, check off the services and items you think you might need so you can research the potential costs associated with each service or item.

Personal Resources

- Monthly income**
 - Employment income**
 - You _____
 - Spouse/partner _____
 - Other _____
 - Retirement plans**
 - You _____
 - Spouse/partner _____
 - Other _____
 - Reverse mortgage income**
 - You _____
 - Spouse/partner _____
 - Other _____
 - Other income (rental property, etc.)**
 - You _____
 - Spouse/partner _____
 - Other _____
 - Long-term care insurance**
 - Monthly benefit _____
 - Maximum lifetime payment _____

Total estimated amount of monthly income: \$ _____

Assets

Savings

- You _____
- Spouse/partner _____
- Other _____

Stocks

- You _____
- Spouse/partner _____
- Other _____

Bonds

- You _____
- Spouse/partner _____
- Other _____

Property (value if sold)

- You _____
- Spouse/partner _____
- Other _____

Total estimated amount of additional assets that could be drawn upon: \$_____

Costs

The following services and items may be used at some point during the course of the disease. Use the websites and phone numbers provided to research costs for each service or item, and check each one as you enter the associated costs. Be sure to reexamine this list approximately every 6 months to be sure costs are current and to research any additional needed services.

- Personal care/safety items** (unless otherwise noted, research monthly costs by checking your local pharmacies and department stores, and/or searching for Alzheimer’s resources online):

- Grab bars—One-time cost: _____ *
- Medication dispenser—One-time cost: _____ *
- Incontinence products—Monthly cost: _____
- Other: _____

Prescription drugs (list monthly out-of-pocket cost, using the spaces to list each drug's cost if needed):

- Drug: _____ Cost: _____
- Drug: _____ Cost: _____
- Drug: _____ Cost: _____
- Drug: _____ Cost: _____
- Drug: _____ Cost: _____
- Drug: _____ Cost: _____

Total monthly out-of-pocket cost: _____

Adult day services (call our 24/7, toll-free Helpline at 1-800-272-3900 for a list of centers in your area):

- Average cost per day: _____
- Number of visits per month: _____
- Cost per day X visits per month: _____
- Services not included in daily rate (e.g., bathing):
 - _____ \$ _____
 - _____ \$ _____

In-home care (call our 24/7, toll-free Helpline at 1-800-272-3900 to find in-home care options near you):

- Average cost per day: _____
- Number of visits per month: _____
- Cost per day X visits per month: _____
- Additional services not included in daily rate:
 - _____ \$ _____
 - _____ \$ _____

Assisted living (use our Community Resource Finder tool at www.communityresourcefinder.org to find assisted living options):

- Estimated cost per month: _____
 - Additional services not included in monthly rate:
 - _____ \$ _____
 - _____ \$ _____
 - Nursing home care** (use our Community Resource Finder tool at www.communityresourcefinder.org to find nursing homes):
 - Estimated cost per month: _____
 - Additional services not included in monthly rate:
 - _____ \$ _____
 - _____ \$ _____
- Total estimated monthly costs:** \$ _____
Total estimated one-time* costs: \$ _____

Now that you have an idea of what resources you can already draw upon and how much Alzheimer’s care will cost, the rest of this booklet focuses on additional ways to pay for care and the steps to take to access the programs available to you.

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tip 4: take advantage of informal and formal resources

Sometimes, it can be hard to ask for help. Other times, when help is offered or available, you may not be sure what kind of help you need. Try keeping a running list of tasks or errands that others could assist you with so that you have ideas ready when help is offered.

There are several informal and formal resources that could provide free or reduced-cost Alzheimer's care. Below, check the boxes next to the resources that you want to pursue, learn more about, and/or apply for:

- Informal resources:** Use *Lotsa Helping Hands* to coordinate informal care providers: <http://alzheimers.lotsahelpinghands.com>
 - Family members:

 - Friends:

 - Neighbors:

 - Faith communities:

 - Volunteer groups (to find volunteers, call the Alzheimer's Association (1-800-272-3900), your local senior center, or your Area Agency on Aging (<http://www.eldercare.gov>):

- Older Americans Act Services:** Check off the services that interest you, then contact your Area Agency on Aging (find your local agency at www.eldercare.gov).
 - Adult day care
 - Transportation
 - Legal services
 - Senior center meals
 - Home-delivered meals
 - Respite care
 - Home modifications
- Medicare:** Information on the programs below is found in **Tip 5**.
 - Medicare (Parts A and B)
 - Medicare—Part D
 - Medicare Advantage Plans
 - Medigap
- Medicaid:** Information on Medicaid is found in **Tip 6**.
- Veterans Administration benefits:** Information about benefits available through the Veterans Administration is found in **Tip 7**.
- Benefits for those with Younger-Onset Alzheimer's:** Information about the following benefits is found in **Tip 9**:
 - Social Security Disability Insurance
 - Supplemental Security Income

Notes:

tip 5: make sure your medicare benefits meet your needs

As you plan how to pay for Alzheimer's care, it's important to consider what Medicare will and will not cover, and to know what kinds of choices you have regarding your Medicare coverage. Remember that Medicare is:

- A government health insurance program
- Age-based, except for people with certain disabilities
- Administered by the federal government
- Not a program that normally pays for long-term nursing home care

To learn about any of the Medicare programs listed below, go to the Medicare website at <http://www.medicare.gov> and download the free booklet, "Medicare & You," by clicking on the link that says, "Medicare & You 2011 Handbook." Below, check off which parts of Medicare you want to learn more about:

Medicare

Part A: Hospital Insurance

- Inpatient care in hospitals
- Skilled nursing care for short-term rehabilitation
- Home health care
- Hospice care

Part B: Medical Insurance

- Physician services
- Outpatient services (e.g., lab tests, MRIs)
- Durable medical equipment (e.g., walkers)
- Some preventive services

Part D— Prescription Drug Coverage

- You must already have Part A and/or B in order to sign up.
- If you are eligible to enroll but do not enroll, a penalty will be assessed unless you provide proof of alternate coverage.
- To explore and compare plans according to your needs and area, use the Medicare Drug Plan Finder at <https://www.medicare.gov/find-a-plan/questions/home.aspx>
- Find more information about Medicare—Part D on our website at http://www.alz.org/living_with_alzheimers_drug_coverage.asp

❑ Medicare Advantage Plans

- Managed care alternative to Medicare
- Combine Parts A, B, and usually D
- Monthly premiums vary
- Out-of-pocket costs vary

❑ Medigap

- Supplements Medicare
- Helps cover “gaps” in Medicare coverage
- Not used with Medicare Advantage Plans

If you have questions about Medicare, Medicare-Part D, Medicare Advantage Plans, or Medigap, or if you would like assistance utilizing the Medicare program, the **State Health Insurance Counseling and Assistance Program (SHIP)** can help. This national program offers one-on-one counseling and assistance to Medicare recipients and their families. Services are provided over the telephone and face-to-face, as well as through public education programs. To find a SHIP near you, or to find a public program to attend, go to <https://www.shiptalk.org>.

Notes:

tip 6: see whether medicaid can help you pay for long-term care

It's also important to think about whether Medicaid might be able to help you pay for long-term care, including nursing home care, especially since Medicare does not normally cover this.

Medicaid is:

- A government assistance program
- Need-based, which includes both medical and financial need
- Administered by states
- A program that can cover long-term care, including nursing home care

Here are some things to keep in mind about Medicaid:

- **Specific criteria and regulations vary** by state.
- **Medicaid payments are made directly to providers** instead of to the person receiving assistance.
- **In some states, Medicaid helps pay for assisted living and adult day** services as well.
- Many states have **home-based and community-based care options** for people who qualify for nursing home care but could live at home with more help (*please note that there may be waiting lists for these programs*).
- The **Children's Health Insurance Plan (CHIP)** may help those with younger-onset Alzheimer's who have children or those with Alzheimer's who have custody of grandchildren.
- Low income is only one test for **Medicaid eligibility**. Assets and resources must also be within a certain range, and applicants need to meet a number of criteria to be considered for Medicaid.
- Provisions are in place to prevent **"spousal impoverishment."**
- **"Spending down" assets** to qualify for Medicaid is complex, so it is helpful to look into specifics by consulting the state Medicaid office and/or an elder law attorney.

Check off the steps you need to take to explore Medicaid as an option:

- Find out whether you or the person you care for may qualify:**
 - <http://www.benefits.gov>
 - <http://www.benefitscheckup.org>

- Complete and submit application forms.** Depending on where you live, applications may be accepted at:
 - State Medicaid offices
 - Departments of Welfare
 - Departments of Health

If you are unsure where to submit application forms in your area, try contacting your Area Agency on Aging (www.eldercare.gov).

- If you decide to look for a nursing home, be sure to ask the director of admissions or social services:**
 - Whether Medicaid is accepted there
 - If the person might need to pay privately first, and for how long
 - What happens when the person's resources are depleted (e.g., Will a social worker onsite help you complete and submit the necessary paperwork?)

Notes:

tip 7: explore benefits for veterans

If you or the person you care for served in the military for any period of time, you may be eligible for a number of resources through the Veterans Administration. Families often assume that only career military personnel are eligible, but broader criteria are used to determine eligibility. Check off any of the following that may apply to your situation:

- Veteran
- Veteran's dependent
- Surviving spouse, child or parent of a deceased Veteran
- Present or former reservist or National Guard member

You will need to provide records proving veteran status for you or your family member in order to apply for benefits. If you cannot find these records and you are the veteran or next of kin, you can request records at this link:

- <https://vetrecs.archives.gov/VeteranRequest/home.asp>

If you are not the veteran or next of kin, you will need to complete a document called Standard Form 180 in order to request records, which can be found at this link (please note that a signature of the veteran or his/her legal guardian will be necessary to allow the release of information):

- <http://www.archives.gov/research/order/standard-form-180.pdf>

Check off the services you think you or the person you care for may need:

- Medical benefits package
- Health care insurance
- Service-connected disability income
- VA pension
- Aid and attendance benefit
- Housebound benefit
- Death pension
- Dependency and indemnity compensation
- Burial and final expenses

Now, refer to the services you checked off when you contact the Veterans Administration to find out what kinds of help you might be eligible to receive. Here are some ways to learn more about Veterans benefits and to access application forms:

- Veterans Administration website: <http://www.va.gov>
- Veterans Administration Benefits and Assistance: 800-827-1000
- VA Facility Locator:
<http://www2.va.gov/directory/guide/home.asp?isflash=1>
- Veterans Administration Benefits application forms:
<http://www.va.gov/vaforms>

Notes:

tip 8: consider your work situation

If you have dementia and are still working, there are some important things to consider and steps to take.

- Do a personal work assessment:**
 - What are the essential functions of your job?
 - _____
 - _____
 - _____
 - What job tasks are still easy to do?
 - _____
 - _____
 - _____
 - What job tasks are difficult to do now?
 - _____
 - _____
 - _____
 - What types of accommodations would help you be successful?
 - _____
 - _____
 - _____
- Explore your benefit plans *before* making any decisions:**
 - Short-term disability plan:

 - Long-term disability plan:

 - Long-term care coverage:

 - Conversion options for health and life insurance:

 - 401k loan options:

 - Family medical leave:

Personal leave :

Employee Assistance Program:

Communicate with your employer:

Maintain open communication with:

Your manager

Your Human Resources Department

Provide documentation from your physician about:

Your diagnosis

Your ability to do your job with accommodations

Provide specific examples of the types of accommodations needed

Meet regularly to review your performance

Plan your eventual transition

Notes:

tip 9: explore younger-onset benefits

If you or someone you care for has younger-onset Alzheimer’s disease, these government programs could provide valuable financial assistance. Check off the programs that interest you and then use the websites and phone numbers to find out more.

- Social Security Disability Insurance (SSDI):** Applying for SSDI involves completing an application for Social Security Benefits and a Disability Report. Medical documentation of your diagnosis is also necessary. You can complete forms online at www.socialsecurity.gov/disabilityreport. You can also print the forms, complete them in hard copy, and return them to your local Social Security office.
- Supplemental Security Income (SSI):** A large portion of your application can be completed online at www.ssa.gov. You can also call 1-800-772-1213 and make an appointment with a Social Security representative.

Notes:
