

UNDERSTANDING LONG-TERM CARE OPTIONS

Prepared by Rowena Rye

**Western and Central Washington State Chapter
12721 30th Avenue NE – Suite 101
Seattle, Washington 98125
206-363-5500 or 800-848-7097
www.alzwa.org**

Understanding Long-Term Care Options

CONTENTS

Getting Organized.....	PP. 1-3
Financial Support Programs.....	PP. 3-5
Medical Expense Programs.....	PP. 5-8
Other Programs.....	P. 8
Protecting Patients' Rights and Obtaining Needed Benefits....	P. 9
Legal Planning.....	PP. 9-12
What Are the Care Options?.....	PP. 13-14
How to Choose a New Home for Someone With Alzheimer's or a Related Disorder.....	PP.15-16
Websites.....	PP.16-18

UNDERSTANDING LONG-TERM CARE OPTIONS

Long-term care planning can feel overwhelming. With the many options for both home-based and residential care, how do we begin to consider the options and to develop a plan that is right for us?

GETTING ORGANIZED: THE KEY TO LONG-TERM CARE PLANNING

Paperwork is an inevitable element of caregiving. You will need to locate legal, financial and insurance documents. Locating, reviewing and organizing these documents can be time consuming and tedious but will pay off in the long run.

You may not know where certain information is located. If you are assisting a loved one with memory loss, these documents may not be filed where you would expect them to be. If this is the case, you may find yourself sorting through piles of paper located in unpredictable places both inside and outside of the house. Here are a few common places to look for records:

- Filing cabinets
- Dressers, desk drawers, closets
- Attic, garage, basement
- Under the bed
- Scrapbooks
- Safe deposit box or safe
- Attorney's or accountant's office
- Another relative's home
- Home of the executor of the will

To help you to organize your search, develop a long-term care planning log that itemizes the location and status of various documents. The following planning log is one example of the type of information you may need to collect.

Adapted from "Organization: A Key To Caregiving",
Alzheimer's Association of St. Louis, September 1998

LONG-TERM CARE PLANNING LOG

LA – located/available

UD – needs to be updated

C – make copy

LN – located/not available

GD – get document

L – lost/request duplicate

DOCUMENT	STATUS	COMMENTS
<p>LEGAL DOCUMENTS</p> <ol style="list-style-type: none"> 1. Birth certificate 2. Social Security card 3. Marriage licenses(s) 4. Divorce decree(s) 5. Military records 6. Will 7. Durable Power of Attorney 8. Health Care Power of Attorney 9. Health Care Directives (Living will) 10. Legal agreements 	<ol style="list-style-type: none"> 1. ____ 2. ____ 3. ____ 4. ____ 5. ____ 6. ____ 7. ____ 8. ____ 9. ____ 10. ____ 	
<p>FINANCIAL DOCUMENTS</p> <ol style="list-style-type: none"> 1. Checking account 2. Savings account 3. Retirement account 4. Stock certificates 5. Savings bonds 6. Real estate deed(s)/title(s) 7. Automobile title(s) 8. Investment income 9. Other income 10. Mortgage statement 11. Property tax statement 12. Lease agreement 13. Utility & phone statements 14. Doctors/hospital bills 15. Credit cards 	<ol style="list-style-type: none"> 1. ____ 2. ____ 3. ____ 4. ____ 5. ____ 6. ____ 7. ____ 8. ____ 9. ____ 10. ____ 11. ____ 12. ____ 13. ____ 14. ____ 15. ____ 	
<p>INSURANCE DOCUMENTS</p> <ol style="list-style-type: none"> 1. Auto 2. Homeowner's 3. Life insurance 4. Medicare 5. Medigap 6. Long-term care 7. Disability <p>Other _____</p> <p>Other _____</p>	<ol style="list-style-type: none"> 1. ____ 2. ____ 3. ____ 4. ____ 5. ____ 6. ____ 7. ____ 	

BEGIN BY ASSESSING AVAILABLE FINANCIAL RESOURCES

A well thought out long-term care plan begins with an assessment of finances. Attorneys, accountants and financial planners can help you to assess your finances and evaluate what will be available to pay the expenses for long-term care.

IS LONG-TERM CARE INSURANCE FOR YOU?

Is purchasing long-term care insurance realistic? There are many factors that influence whether or not this is an option. If one has already been diagnosed with a long-term disability, chances are this is no longer an option. The best time to purchase a long-term care policy is in middle age when premiums are less expensive. If you have not yet assessed the affordability of long-term care insurance, and wish to do so, the Washington State Office of the Insurance Commissioner has the **SHIBA** (Statewide Health Insurance Benefits Advisors) Program available to help you to get started. SHIBA has information about all long-term care policies approved for sale in Washington, what services they cover, under what conditions the plans pay, and expected costs given an individual's age and health history. You can locate the local contact in your area and schedule an appointment with a trained volunteer for objective, reliable information by calling **1-800-397-4422**. In Seattle/King County assistance is also available through the Senior Services' **Senior Rights Assistance Program** at **206-448-5720** or **1-800-972-9990**.

WHAT IF I CAN'T AFFORD LONG-TERM CARE INSURANCE?

If purchasing long-term care insurance is not a viable option, do you know how far your assets will take you? Once your assets are exhausted, what public programs will you qualify for that will cover the costs of care? Your local Senior Information and Assistance Program can help you to identify both long-term care facilities and programs that may help to fund the costs of care. To find out how to contact your local Senior Information Program, call the **Eldercare Locator** at **1-800-677-1116**.

There may be financial assistance and health care benefits available through various government resources. There are 2 types of entitlement programs that persons with Alzheimer's may apply for: **Financial Support Programs** and **Medical Expense Programs**.

FINANCIAL SUPPORT PROGRAMS

- ***Social Security Disability*** is a program to assist wage earners under age **65** who can no longer work because they are disabled. The applicant must have worked a minimum of **5** of the past **10** years, although the years do not have to have been consecutive. A diagnosis of Alzheimer's

disease does not, in itself, establish Social Security Disability status. *It must be proven that the person is unable to work.* Alzheimer's progresses differently in every individual, so "disability" must be established in each situation. Physician's statements and other documentation must be submitted to the local Social Security office to prove that the individual is unable to be gainfully employed. *Although many applicants are initially rejected, there is an appeal process, and many persons who are initially denied eventually do receive benefits.* Monthly payments are based on the person's past earnings and may be greater than those provided through other government financial assistance programs. To apply for Social Security Disability, contact your local Social Security Office.

- ***Supplemental Security Income (SSI)*** is a program that guarantees a minimum monthly income to persons who are age 65 or over, or disabled or blind, and have a limited number of assets. It provides an income "safety net" for those who qualify. For persons under age 65, to qualify as a disabled person, it must be proven that the Alzheimer patient is unemployable. Persons 65 or over who meet the income and assets standard for eligibility are categorically eligible. A person may have some financial or property assets, including a small amount of cash, a home and modest income, and still qualify for SSI, as well as Medicaid and other social services and disability benefits provided by the state or county. *It is important to apply for SSI as soon as possible after a diagnosis of probable Alzheimer's disease because payments ordinarily begin with the date of the application or date of eligibility, whichever comes later.* Contact your local Social Security Office.

For more information about Social Security programs, or information about the location of your local Social Security office, contact the Social Security Administration at **1-800-772-1213** or visit the website at **www.ssa.gov**

- ***General Public Assistance*** helps persons who cannot qualify for Social Security Disability, SSI or other public assistance programs. It can provide financial benefits while you wait for confirmation of Social Security or SSI eligibility, or for receipt of your first payment. To find out if you may qualify, contact your local Community Service Office of the Department of Social & Health Services. Call **1-800-422-3263** for the location of the office nearest you where you can apply.

MEDICAL EXPENSE PROGRAMS

Two entitlement programs that provide assistance with medical costs are **Medicare** and **Medicaid**.

- **Medicare is a federal health insurance program generally for people age 65 or older who are receiving Social Security benefits.** Individuals who opt for reduced Social Security benefits at age 62 will not receive Medicare coverage until they reach age 65. Individuals with Alzheimer's who are younger than 65 must receive Social Security Disability benefits for 24 months before establishing Medicare eligibility.

Medicare coverage provides hospital insurance, which helps to pay for inpatient hospital care and limited nursing care during recovery from an illness. Medicare's medical insurance covers a portion of doctors' fees and other medical items.

Medicare covers some, but not all, of the services a person with Alzheimer's needs. It does *not* pay the ongoing cost of nursing home care. It may cover less than 50% of the cost of other medical expenses unless the physician or other provider accepts Medicare "assignment". Medicare assignment means that the doctor or medical services provider will accept the Medicare rate for the services provided and bill the patient nothing more. Many state and local Offices on Aging maintain lists of providers who accept assignment with Medicare.

Applications for Medicare may be sent to a local Social Security office. A formal appeal process exists in the event that coverage is denied.

For more information about Social Security programs, or information about the location of your local Social Security office, contact the Social Security Administration at **1-800-772-1213** or visit the website at **www.ssa.gov**

- **Medicaid is a federal program administered by each state. Eligibility and types of benefits vary from state to state.** In Washington State, the Department of Social & Health Services administers Medicaid. There are several kinds of Medicaid assistance available. It is important to know about Medicaid programs that can cover long-term care expenses.
- **Medicaid for Nursing Homes** can cover all or a portion of nursing home costs for those who qualify. A person's home and other selected assets are "exempt" and are not considered in determining eligibility. If you are a spouse of the person needing Medicaid assistance, you may keep either *all of the income in your name, regardless of the amount, or all of the income paid in your name plus as much of your spouse's income as necessary to bring your income up to \$1,604 per month.* If your housing costs (rent or mortgage, taxes, insurance and utilities) exceed \$481/month, the \$1,604 level can be increased up to \$2,378 by the amount of this excess. (In calculating housing costs, actual costs for rent, mortgage or taxes and insurance are used. (For utilities, a *standard figure* of \$304/mo is used.) The spouse at home can keep all "exempt" resources, which can include the home, household goods, a car and personal effects. (See **"Questions and Answers on Medicaid for Nursing Home Residents", provided by Columbia Legal Services** for a complete list.)

- The **COPES Program** (Community Options Program Entry System) is a Medicaid program available in Washington State. To be eligible for COPES in 2005, a single person must have less than \$1737/mo. in income (with some fairly rare exclusions-See Washington Administrative Code (WAC) 388-513-1340.). If a married person is applying for COPES, DSHS first looks at all the income paid in that applicant's name. If the income of the married person applying for COPES is not more than \$1,737/mo., he or she may be eligible regardless of how much income his or her spouse receives. If the married individual applying for COPES receives more than \$1,737/mo., he or she may still be eligible *if their income when combined with the spouse's income is less than \$3,474/mo.*

COPES is designed to be an alternative to help people who without COPES would be in nursing homes. Care options may provide personal care and housekeeping services in the home or care in a group facility or home. Financial eligibility rules are very similar to Medicaid for Nursing Homes.

*When living at home and on the COPES program, however, the spouse covered by COPES can keep an additional \$579 of his or her income. The spouse not on COPES can keep the greater of all the income paid in his or her name, or his or her income **plus** as much of the spousal income to bring it up to \$1,604/mo. If housing costs exceed \$481/mo, the \$1,604/mo can be increased up to \$2,378 by the amount of the excess. A single person living at home can keep \$798/mo. If both spouses are living at home and on the COPES Program, they can each keep \$798/mo, or a total together of \$1596/mo.*

*When living in adult residential care facility, an assisted living facility or an adult family home the person on COPES can keep \$58.84/mo. for personal expenses (or \$38.84/mo. for certain residents on General Assistance). See **Columbia Legal Services publication "Questions and Answers on the COPES Program"** for complete information. This publication (and the previously mentioned attorneys' list) are also available through many local Senior Information Program or through this chapter of the Alzheimer's Association.*

- The **Medically Needy Residential Waiver** program is available under a new rule effective March 17, 2003. Under this program, "residential" services similar to those available under COPES for care in Adult Family Homes, Assisted Living, and enhanced residential care facilities are covered for some individuals whose income exceeds the COPES standard of \$1,737/mo. Unlike the COPES program, it will not cover in-home care, and the special protections for income and resources for spouses who are not on Medicaid will not apply.
- The **Medicaid Personal Care Program** is available to persons receiving SSI who qualify based on care needs. In some cases, if the services you need *are not* available through this program, and *are* available through COPES, you may be able to get services through the COPES Program.

Income and assets limits for Medicaid programs may vary from state to state and Medicaid rules can change. The above referenced information on the COPES and

Medicaid for Nursing Homes Programs is **current as of April 2005**. There have been many changes to these two programs recently, notably rule changes in the amount of assets a spouse of a person on one of these programs can keep in his or her name. The Community Spouse Resource Allowance, or CSRA is at least \$40,000, and may be more. In addition, the spouse applying for one of these two programs is allowed to keep \$2,000 in assets. Sometimes the Community Spouse Resources Allowance can be more than \$40,000. For more information about the CSRA see **Columbia Legal Services** publications ***Questions and Answers on Medicaid for Nursing Homes*** and ***Questions and Answers on the COPES Program***

More changes to these Medicaid programs' rules are anticipated. It is important to get the latest information if you want to determine whether Medicaid funding may be an option.

Contact the Alzheimer's Association or your local Senior Information & Assistance Program for current information on these programs, and for copies of the Columbia Legal Services publications, ***Questions and Answers on Medicaid for Nursing Homes and Questions*** and ***Answers on the COPES Program***.

A list of attorneys familiar with Medicaid rules is also available. It is highly recommended that you get individualized legal advice before taking steps you don't fully understand. Medicaid eligibility rules are complicated and the rules change frequently. Always make certain you have the most current information and the assistance you need before you apply!

To apply for Medicaid, contact your local Home & Community Services Office (a division of the Department of Social & Health Services). Call 1-800-422-3263 for the location of the office nearest you where you can apply.

OTHER PROGRAMS

There are many programs that provide assistance to persons with Alzheimer's that are available through senior centers and local Area Agencies on Aging. Such programs may include Senior Information & Assistance, Meals on Wheels, home repair, respite, in-home care, and visiting nurses, While some services are specifically geared toward meeting the needs of lower income persons, **Older Americans Act** programs are available to all persons age 60 and over. Contact us for further information about these programs, or contact your local Senior Information program for specific information on local resources.

Veteran's Administration benefits may be available for veterans who need hospitalization, respite care or nursing home care. For more information, contact the Veteran's Administration at **1-800-827-1000**.

PROTECTING PATIENT RIGHTS AND OBTAINING NEEDED BENEFITS

Financial and medical benefits can play a vital role in your future. *It is highly recommended that you investigate them right away. You should apply for Social Security and Medicare benefits as soon as you qualify.* If you are under 65 you will have to satisfy disability criteria to receive these benefits. You may opt to accept reduced Social Security benefits at age 62, *but unless you have established that you meet the disability criteria, you will have to wait until age 65 to receive your Medicare benefits.*

As you are obtaining information about both Medicare and Medicaid benefits, make the following questions a part of your inquiry:

- What are the requirements for eligibility?
- What benefits are available?
- How soon will payments be made?
- If my application is denied, how can I appeal?

If you do not understand an answer, ask for a clearer explanation. Continue to ask questions until you are satisfied that you understand all that you need to know.

Once you begin the application process, be sure to:

- Document everything.
- Make copies of each form you complete and every letter you write.
- Ask for the name of any person you talk to on the phone
- Make notes of the conversation and *date* the notes.

Having copies of everything will make it easier to appeal if your application is denied. In addition, keep all receipts and tax records. Make sure you have current copies of insurance policies and employee benefits.

Finally, don't get discouraged if your applications are denied the first time. **Many applications that are rejected initially are approved upon appeal.**

Adapted from "Financial and Health Care Benefits You May Need", Alzheimer's Association, 1991; Questions and Answers on the COPES program, Columbia Legal Services, 10/2002; Questions and Answers on Medicaid for Nursing Home Residents, Columbia Legal Services, 10/2002

LEGAL PLANNING

Legal planning should begin soon after a diagnosis is made. You will want to put in place documents that:

- **Authorize another person to make health care and financial decisions**
- **Include financial plans for long term care coverage**

If the person with Alzheimer's has legal capacity (the level of mental functioning necessary to sign official documents) he should actively participate in the legal planning process.

Determining Legal Capacity

In general, if the individual with Alzheimer's has sufficient cognitive ability to understand the meaning and significance of a legal document, he probably has the legal capacity to execute it.

An attorney can help to determine the level of legal capacity required to execute a particular legal document since the level of legal capacity required may vary from document to document.

It is important to determine whether or not the person with Alzheimer's is able to understand explanations of legal documents and the implications of signing them. In order to do this:

- **Talk with the person.** Find out if the person with Alzheimer's understands what is being explained and asked of him.
- **Ask for medical advice, if needed.** Consult a medical professional if there is a question about whether or not the person with Alzheimer's has legal capacity.
- **Take inventory of existing legal documents.** Check to see if living wills, trusts and powers of attorney were executed prior to the diagnosis of Alzheimer's disease.

Understanding Legal Documents

Commonly used legal documents in planning for individuals with Alzheimer's disease include:

Durable Power of Attorney

A durable power of attorney gives a person with Alzheimer's (the **principal**) an opportunity to authorize an **agent** (usually a trusted family member or friend) to legally make decisions for him or her when he or she needs assistance. Durable powers of attorney remain in place after the principal becomes disabled and is no longer able to make decisions for himself. A durable power of attorney can, in many cases, help a family to avoid the need to file a guardianship. Durable powers of attorney may be either *effective immediately* or *upon disability*.

It is important to note that a power of attorney does not give the agent the authority to override the decision-making of the principal. For example, the principal can still sign contracts. In some cases, a guardianship may be required to, for example, prevent an individual from harming herself financially by giving away all of her belongings, or exhausting her resources that are needed for her care.

The agent is authorized to manage and make decisions regarding the income and assets of the principal. He is responsible for acting according to the instructions, and in the best interests of the person with Alzheimer's disease. A durable power of attorney may also include health care decision-making authority.

Power of Attorney for Health Care

The power of attorney for health care appoints an agent to make all decisions for health care, including choices regarding health care providers, medical treatment and facilities. For persons in the later stages of Alzheimer's, the health care agent will choose care services and make end of life decisions, such as whether or not the person with Alzheimer's is given artificial nutrition or "do not resuscitate" orders.

Advance Directives to Physicians or "Living Wills"

In advance directives to physicians, a person with Alzheimer's can express her wishes on the use of artificial life support systems. It is useful only in situations where a doctor has determined that the person is irreversibly ill or near death.

Living Trusts

Trusts created by a person with legal capacity during his lifetime are known as "living" trusts. A living trust is another way to ensure the management of property. The person with Alzheimer's (the **grantor** also known as the **trustor**) creates the trust and appoints himself or someone else as trustee. **Trustees**, usually an individual or a bank, have the responsibility to carefully invest and manage trust assets. The living trust provides that once the grantor (who is also acting as the trustee) is no longer able to manage finances because of cognitive impairment, another person is appointed as trustee.

In order for the trust to accomplish its goal, all assets must be transferred to the trust. An advantage of a living trust is that it may avoid the necessity of probate – the legal process by which the court distributes the deceased's assets. However, it is important to note that there are not necessarily tax advantages for creating a living trust.

Wills

A will is a document created by an individual that names an **executor** (the person who will manage the estate) and the **beneficiaries** (the person or persons who will receive the estate) at the time of death. Wills are effective only when the person who has created and executed the will dies. An executor named in a will has no authority to act during the lifetime of the individual making the will. A will cannot be used to communicate health care preferences. However, it can give an individual peace of mind that his wishes will be fulfilled after death. All persons, including those with Alzheimer's disease, can benefit from having a will.

Guardianship

A caregiver of an individual who no longer has legal capacity to execute powers of attorney or trusts may have to become that person's guardian.

Guardianship is a legal proceeding where, based upon medical evidence, a court finds that a person is incapacitated (in the case of Alzheimer's disease because of cognitive impairment) and unable to make decisions related to her care or the management of her assets. Once an individual is determined to be incapacitated, the court appoints a guardian. A **guardian** has the legal authority to make decisions regarding the care of the person with Alzheimer's. (In some states guardianship is called a conservatorship and the guardian, the conservator.)

Before a decision is made about whether a guardian is needed, four steps must be taken:

1. Notice of the guardianship petition must be given to the person identified in the petition.
2. The court must appoint a "*guardian ad litem*" to make an investigation and report to the court.
3. The guardian ad litem must obtain a statement from a physician or psychologist
4. A hearing must be held.

Some local Bar Associations may offer a referral service that will connect you with an Elder Law Attorney. If your local Bar does not have such a service, check with your local Senior Information and Assistance Program.

Adapted from "Steps to Understanding Legal Issues: Planning For The Future", Alzheimer's Association, 1997

WHAT ARE THE CARE OPTIONS?

You may wish to think in terms of both in-home care options and support, and residential care options should you or a loved one is no longer able to be cared for at home.

SERVICES WHEN LIVING AT HOME

When you or a loved one begins to need assistance, there are many options and community supports you may wish to consider. **Homecare** services through a licensed, bonded homecare agency is a relatively fast way to hire someone to come to your home and assist you. Hiring an independent caregiver is another option. In general, finding an independent caregiver unaffiliated with an agency is more time intensive, requires you to do more of a search for a suitable caregiver, do a thorough background check, but is usually a less expensive option. If you or your family member qualifies, the COPES Medicaid program may cover the costs of homecare.

Adult Day Centers are another alternative to consider. Many adult day centers offer not only activities, a meal and snacks, but are licensed to provide health care services as well. An adult day program may provide a safe, secure environment and an opportunity to socialize for the person attending, and a respite for the family member or caregiver. Most will provide or help to arrange transportation to and from the center.

Other services that can help are **Home Repair Programs**, **Meals-on-Wheels**, and **Case Management** or **Care Coordination Services** (public or private).

Caregivers can also benefit from **Caregiver Support Groups** that provide a supportive environment and an opportunity for caregivers to talk about their experiences, share caregiving tips and receive ongoing information and education about caring for a loved one with dementia. **Respite Care Programs** that provide an occasional break for an unpaid caregiver (usually a family member or loved one) and use a sliding fee scale to determine the cost of care based on the caregiver's income.

Respite Care, to relieve caregivers who need a break from time to time, can be provided in several ways. **In-Home Respite** may be provided by another family member who can stay with your loved one a few hours a week so that you can shop, have your hair done, attend a support group meeting, visit friends, get a massage, go for a leisurely walk or to an exercise class – all of the things that some caregivers too readily give up that may keep them healthy and enhance their own quality of life! Caregivers who have learned to take care of themselves tend to be healthier, happier and more energized, and these traits pay off not only for the caregiver, but also for the loved one receiving his or her care. If there is no family member or friend available to give you a much-needed break, you may want to hire someone to come in or contact your local Caregiver Respite Care Program. **Adult Day Care**, even a day or two each week can make a big difference, and benefit you both. **Residential Respite** can also

be considered when a caregiver needs a more prolonged break of several days or a few weeks due to fatigue, illness, need for a vacation, or to attend important out-of-town events such as a wedding, graduation or funeral. Some nursing homes and Assisted Living Facilities will provide residential respite care. Many facilities have a minimum stay requirement, some do not.

RESIDENTIAL CARE

When living at home or with family is no longer an option, there are several options you may wish to consider. Currently there are no standards for dementia-specific care, and the ability to meet the needs of residents with dementia beyond the early stage of Alzheimer's varies greatly.

Assisted Living Retirement Homes (licensed in Washington State as Boarding Homes) provide services to older and disabled adults who require assistance with their activities of daily living. Needs addressed include help with bathing, dressing, and medications monitoring. Meals are provided, although some facilities may also provide refrigerators and microwaves in residents' rooms. Emergency response systems are generally provided in residents' rooms, and most provide an activities program, either part-time or full-time.

In general, facilities accept Alzheimer's residents on a case-by-case basis and will do a dementia assessment. Most have clear limitations on accepting prospective residents who are wanderers or are combative.

Adult Family Homes are state-licensed private residences. They provide a smaller, homelike setting and can care for no more than 6 people at a time. They vary in the levels of care they can provide.

Nursing Homes provide an intermediate or skilled nursing care setting for those with heavy care needs.

Continuing Care Facilities can provide independent retirement living, assisted living and skilled nursing care. Some also have specialized dementia care areas. Continuing Care Facilities tend to have a one time "buy-in" fee that varies with the age of the person seeking care. Generally the buy-in fee increases with the age of the person seeking care. There is also a monthly fee for care that varies depending on the level of care that is provided.

HOW DO I CHOOSE A NEW HOME FOR A LOVED ONE WITH ALZHEIMER'S OR A RELATED DEMENTIA?

Moving a person with Alzheimer's to a new home requires some planning. Be prepared for a period of adjustment. This new experience can be very disorienting at first. The Western and Central Washington State Chapter of the Alzheimer's Association has information that will help you to know when it is time to find a new home, lists of Assisted Living Facilities and Nursing Homes that help to clarify services that are provided, and information to help you to determine if it's time to move, help with planning and preparing for the move and making as smooth a transition as possible to the new home.

In seeking care for a loved one with Alzheimer's or a related disorder, consider the following questions:

Does the facility provide dementia specific care? Is there a special area, unit or wing that provides specialized care?

What criteria are used for admission?

What are the diagnoses and functional capacities of the other residents? How does this fit with your family member's needs?

Is the environment clean, calm and pleasant? Do residents appear to be well cared for, happy and engaged in conversation or activities? Does the staff appear to be communicating and connecting with residents?

How are new residents supported during admission and during the adjustment to their new surroundings? Are families encouraged to visit often?

Has the staff been trained to provide dementia-specific care? Is this training provided regularly?

Is there a special activities program for residents with Alzheimer's to mitigate anxiety and agitation? Is it full-time or part-time? If there is not a dementia-specific activities program, do activities meet the special needs of residents with dementia?

How are resident needs identified and goals addressed in an individualized plan of care? Is care planning done by a staff team from various departments with cooperative professional expertise? Is the family involved in or informed about the care plan meeting?

If issues develop with challenging behaviors that are characteristic to middle stage Alzheimer's (agitation, restlessness, sundowning) how are they addressed? Does the facility develop a care plan that includes strategic approaches to limiting or modifying the difficult behavior?

Are there security measures in place to discourage and prevent wandering? Are there areas where residents can wander safely without feeling confined?

***Is there a safe accessible outdoor area with shade and comfortable seating?
Are there outdoor activities available and interesting things to see?***

***Is there adequate staffing throughout the day? What is staffing like at night
and on weekends?***

What are the policies related to discharge or transfer of a resident?

What happens if a resident is considered inappropriate for the program?

What are the policies related to transferring a patient to a hospital?

***What happens if resources are exhausted? Can a person who has been
private pay transition to the Medicaid program and remain in the facility?***

Our nationally produced publication "Residential Care: A Guide For Choosing A New Home" will help you to identify other important considerations in choosing a home for your loved one.

"Family Guide to Alzheimer's Care in Residential Settings", Alzheimer's Association, 1992.

WEBSITES TO VISIT

Alzheimer's Association,

Western and Central Washington State Chapter

Information about services of this local chapter. Several articles available on-line. List of support groups. Events information. [**www.alzwa.org**](http://www.alzwa.org)

National Office of the Alzheimer's Association

Information about Alzheimer's Disease and related disorders. Updates on research and treatments. List of local Alzheimer's chapters throughout the United States.

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

Benjamin B. Greenfield Library

Alzheimer's Association's Library and Resource Center

[**www.greenfld.alz.org**](http://www.greenfld.alz.org)

Alzheimer's Disease Education and Referral (ADEAR)

Sponsored by the **National Institute on Aging (NIA)**. Provides press releases about current Alzheimer's Disease Publications, about Alzheimer's Disease and Related Disorders. Largely research oriented; information on clinical trials; large bibliographic database. Links to sites of other federal agencies with information about Alzheimer's Disease. www.alzheimer's.org/adear

Alzheimer's Disease International

International umbrella association of 50 Alzheimer's organizations worldwide. Has printed information about Alzheimer's disease and caregiving in several languages. www.alz.co.uk

National Organization for Rare Disorders (NORD)

Federation of voluntary health organizations helping people with rare "orphan" diseases. Includes information about medical equipment, products and services and medication assistance programs. www.rarediseases.org

Health Care Financing Administration

Website for Medicare information. Includes a Nursing Home Compare list with information about staffing, resident characteristics, history of complaints and more. www.medicare.gov

Aging and Adult Services Administration

Provides directory of boarding homes (retirement residences and assisted living communities) adult family homes (smaller care settings with no more than 6 residents) and a link to Nursing Home Compare. www.aasa.dshs.wa.gov

Senior Services of Seattle and King County

Information about local Seattle/King County resources for seniors and their family members. www.seniorservices.org

Social Security Administration

Information about your benefits or to locate the social Security Office nearest you. www.ssa.gov

CAREGIVER WEBSITES

National Office of the Alzheimer's Association

Connects caregivers with a caregiver's guide, answers to frequently asked questions, an opportunity to share experiences and more. www.alz.org; click on *Family Caregivers and Friends*

Family Caregiver Alliance

Informational site; includes an on-line support group. www.caregiver.org

National Family Caregivers Association

Education and information support and validation. Helps caregivers with care of family member as well as with self-care. www.nfcacares.org

American Association of Retired Persons (AARP)

General caregiving information. www.aarp.org/caregive

Other key booklets are available with information you may need:

- **Facts About Alzheimer's Disease**
- **Especially For Caregivers: Early Stage Care**
- **Especially For Caregivers: Middle Stage Care**
- **Especially For Caregivers: Late Stage Care**
- **Understanding Long Term Care Options**
- **Alzheimer's: No Cure Yet, But Reasons For Hope**
- **Activities: Ideas For Sharing Your Time Together!**
- **Assisted Living Retirement Homes**

In addition, we have extensive topical files with articles on a wide variety of concerns related to providing dementia care.

***If you need additional information, contact our
24/7 HELPLINE 206-363-5500 or 800-848-7097***