

Alzheimer's Aid Society

OF NORTHERN CALIFORNIA

“THE BLUE BOOK”

2016 Edition



A PRACTICAL GUIDE FOR ALZHEIMER'S CAREGIVERS

Part 4: RESOURCES FOR PROVIDING CARE

Our Mission:

We exist to provide support, education and compassion to patients and caregivers throughout the journey of Alzheimer's Disease, to support medical research, and to promote public awareness.

*The Alzheimer's Aid Society of Northern California is a
Non-Profit, Tax-Deductible 501(c)(3) corporation*

Federal ID Number: 94-2721961

Alzheimer's Aid Society

OF NORTHERN CALIFORNIA



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Alzheimer's Disease

Alzheimer's Disease was first discovered in 1906 by a German doctor named Alois Alzheimer. It is a disorder of the brain, causing damage to brain tissue over a period of time. Alzheimer's accounts for more than half of all organically caused memory loss. Age is the greatest risk factor. Alzheimer's affects almost 50% of all persons over age 85. At present, the cause of Alzheimer's is not fully understood, and researchers strive to find a cure. The disease progresses for up to twenty-five years before death.

The disease develops very slowly with primary symptoms of short-term memory loss and mild disorientation. These symptoms worsen over time. As the disease progresses, additional cognitive problems appear and behavioral or personality changes are often present.

The Importance of Early Diagnosis

Alzheimer's is diagnosed by testing for, and excluding, other conditions that can cause similar symptoms. It is an essential process, since some of these conditions can be treated or cured. If the final diagnosis is indeed Alzheimer's, then there are important steps to be taken. Medications can give the patient valuable years of independence and improve quality of life.

Early Symptoms Of Alzheimer's Disease

Problems with Recent Memory

Forgetfulness that is interfering with day to day independence and the quality of life.

Disorientation of Time and Place

Losing sense of time passing, becoming confused in familiar settings, getting lost when driving.

Difficulty Performing Familiar Tasks

Problems in completing all the steps in a common task such as setting the table or any multi-step task. Difficulty balancing a check book or maintaining organization.

Problems With Language

Struggling to find common words, especially nouns. Losing train of thought in conversation.

Possible Changes in Mood, Personality, and Initiative

Withdrawing from social situations, inflexibility, frustration or anger, mood changes.

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RESOURCES FOR PROVIDING CARE

Cynda Rennie, Resource Specialist

As Alzheimer's progresses the caregiver's burden increases. No caregiver can do it alone; many try but the price they pay is often exhaustion resulting in health problems of their own. Family members and dear friends rarely are able to relieve the caregiver sufficiently. In most cases family and friends just don't have enough available time.

The options available include hiring a caregiver yourself, hiring an agency to provide a caregiver, utilizing a day-care program, or placement of your loved one in a long-term-care facility for respite or full-time care. Here and in the pages that follow, are a review of these options. Also, please be sure to see the pages in the **Legal Issues** section of this book to learn more about public and veteran benefits which may defer some of the costs of care.

Hiring A Caregiver

Advertising for, and hiring a caregiver for your loved one, without help from an agency, can save money but is not recommended for most people. There are cautionary tales as you can well imagine. It is an option for the individual who has expertise in checking backgrounds and references; interviewing and writing job descriptions. It is also important to check with a tax professional since you, or your loved-one, will be the employer.

Agencies for In-Home Care

Home Health Agencies

These agencies are licensed by the state to provide in-home care. They are a medical-model of care, meaning the primary care focus is health care. The Home Health Agency can provide a Home Health Aide to care for your loved one. Care is monitored by a registered nurse. Physical therapy, speech therapy and dietary consultation are also available. **Some care requires a physician's referral, and Medicare or private insurance** may pay for some services which are medically indicated. General care, including help with grooming, bathing, meal preparation and supervision are not covered by Medicare or private insurances. Some Long-Term-Care policies may cover care in all the categories mentioned on this page.

Home Care Agencies

These agencies hold a general business license, but have no specific licensure and are not regulated. They are a social-model of care, meaning the primary care focus is on the safety and well-being of the clients they serve. The staff is generally able to provide personal care and assistance, help with meals, errands, household chores and companionship. Some are able to provide incontinence care. Home Care Agencies are less expensive than Home Health Agencies.

While these agencies are not regulated by the state, there are many out there with good reputations for reliable care. Be sure to do your own homework: How long have they been in business? Is the agency bonded? Registered with the Better Business Bureau? How much caregiver training is offered? Is there training specifically for Alzheimer's Disease? How are the employees screened? Costs can vary from \$20 to \$26 per hour. There is usually a four-hour minimum.

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IN-HOME CARE AGENCIES

Kelly Rogers, Gerontologist

In-Home Assessment is the first step when you have tentatively selected an agency.

Each agency has their own policies and procedures, however it is reasonable to expect the agency to send a representative who is knowledgeable of the philosophy and operations of its company. You should be able to get answers to any and all questions you may have. Prepare your list of questions and concerns before your interview. A few questions to include are **Does your agency:**

- | | |
|--|---|
| ◆ Specialize in dementia and Alzheimer's care? If so, how? | ◆ Have Worker's Compensation and a Bond? |
| ◆ Have caregiver requirements? (i.e.: min years of exp, state or national background checks, specific training) | ◆ Follow up and reassess periodically? |
| ◆ Have any upfront costs or deposits? | ◆ Have any hourly or weekly rate and minimums? |
| | ◆ Have any testimonials and/or references? |

The agency should have experienced staff in Alzheimer's disease and memory loss.

The assessment should be approximately an hour long. It should generally consist of observing the person with Alzheimer's behaviors, mannerisms and ADL's (Activity of Daily Living). An assessment of the home is essential too. A proper assessment of the needs and personality is essential for a good plan of care.

Have the representative go over all of their written materials, policies and procedures with you at this time. Make sure you understand the entire working relationship prior to signing any agreements. Note: There should never be a "Contract" that forces you to use the agency for any period of time.

Go over the care needs, care plan, and consistent schedule with the set days and times to expect the caregiver's services. A set schedule will not only provide a helpful routine for the person's with Alzheimer's, but will also ensure the same caregiver providing services (A consistent caregiver and care plan routine is key).

The focus should always be on how the agency can maximize and personalize the quality of care. If the representative is focused on the "sale" and you feel any pressure, it would be wise to shop around until you find the perfect fit.

How to Maximize Your Caregiving Services

1st priority: Caring for all ADL's, while maintaining the person's dignity and safety at all times.

2nd priority (during up/awake time): Activities and hobbies that will trigger their long term memory (watering the lawn, gardening, music, crafts, etc...) This will increase their mental stimulation, neurotransmitter activity, circulation, and possibly the biggest reward of all.....self worth.

3rd priority (during down/nap time): Basic housekeeping (dishes, laundry, vacuum, dusting, bathrooms, sweeping, etc...). This is a great way to not only increase your quality time with loved ones by eliminating some of the household chores; it is also a great way to maximize the services you are paying for.

Remember...an In Home Caregiver becomes an extended family member to the person in need of assistance. Keep exploring until you find a good match.

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WHEN YOU HIRE AN AGENCY CAREGIVER

Kelly Rogers, Gerontologist

Introducing a caregiver for the first time requires teamwork and communication between the family and the agency. Working together is essential in making the first connection to a “Stranger”.

Here are some steps that will improve the initial contact:

Meet with the agency prior to the first day of care to go over the plan of care, life story, caregiver personality and skill level.

Make sure the agency and caregiver are fully informed about your loved one’s likes, dislikes, pet peeves, preferences, interests, behaviors, etc...

Stay positive and optimistic. Always communicate in a nonthreatening, relaxed tone and body language.

Allow time for the caregiver and your loved one to develop a bond together. Keep in mind; if you act comfortable with the caregiver in their home then they will often follow/mirror.

If they are resistant to the idea of a “Caregiver”:

The word “Caregiver” can create anxiety, fear and sometimes depression. We can avoid this by replacing it with: “Homemaker, Housekeeper, Attendant, Personal Assistant, or Friend.”

Having a long term family member present that they know, recognize and trust for the first introduction can be very helpful and reassuring.

Ask your loved one for their help. Even a person with Alzheimer’s likes to feel needed. Tell them that it’s “You” that needs the “Homemaker” or “Friend” to come help with day to day needs.

Reassure them: “We will just give it a try.” Take it one day at a time.

Although it might be challenging when introducing a new caregiver at first, over time it will get easier as the relationship and routine develop. The person with Alzheimer’s might not always remember the new caregiver’s name, but they will get familiar and respond to their touch, routine, voice, and personality which will develop their own trusting relationship with one another.

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ADULT DAY CARE PROGRAMS

Cynda Rennie, Resource Specialist

Adult Day Care

Adult Day Care facilities are licensed under the State Department of Social Services. Some are able to provide supervision and care for Alzheimer's and dementia patients who may wander or need special attention.

In an Adult Day Care, you can expect appropriate supervision, a noon meal, a diverse activity program, and opportunities for socialization. Most centers do not provide transportation.

Generally, individuals sign-up for the schedule that best suits the needs of the patient and family. That may be one half-day per week, five full-days per week, or anything in-between.

Adult Day Care is not covered by MediCal, Medicare or private insurance. Some long-term-care insurance policies may include day care. Private pay costs vary and are usually lower than in-home care.

Adult Day Health Care

Adult Day Health Care facilities are licensed by the State Department of Health. Some can provide supervision and care for Alzheimer's and dementia patients who may wander or who need special attention.

Adult Day Health Care will offer the same services as the Adult Day Care centers. A hot meal, socialization and activities are comparable to what is offered at the Adult Day Care program.

The only real difference is, because of the Health Care designation, there are added optional/MD ordered services or therapies. Physical therapy, speech therapy, diabetes care and consultation with a registered dietician are some of the additional services available at this type of day care. Transportation is provided, door to door, within a determined number of miles surrounding the center.

Medicare and private insurance may pay for MD ordered therapies but will not pay for care and supervision. MediCal will pay in some circumstances. Some long-term-care insurance policies may include Adult Day Health Care.

Socialization and activities for the patient and a bit of a break for the caregiver.

The individual with Alzheimer's or dementia may be resistant to going to a day care setting. Changes in routine are often met with negative feelings. As you can imagine, it is very difficult to be in new surroundings when you have memory problems.

Your loved one may never learn the names of people at the center. They may not remember what type of a place it is at all. But, amazingly, people with Alzheimer's and dementia DO develop familiarity and a sense of belonging if given time to do so.

If you decide to enroll your loved one in a day care program, there are steps you can take to ensure the transition from resistance to enjoyment is as smooth as possible.

Consider going together for the first few visits. **"We are signed-up at the Senior Center. We'll give it a try, if we don't like it, we'll quit."** On the second or third day, tell your loved one you have to help someone with an errand, **"I'll be back soon."** As soon as he/she feels fairly comfortable you will be able to leave at the start of the program.

Do not call it what it is! If your loved one would be angry, frightened or insulted by the thought they may need supervision, then just refer to it as the Senior Center or The Club or any name which may be less intimidating.

In the first weeks, your loved one may continue to be oppositional to going. Communicate well with the center's staff and give it several weeks at least. Most families find that, quite suddenly, the loved one begins to look forward to going. And, comes home with a smile.

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CHOOSING A FACILITY

Cynda Rennie, Resource Specialist

There are only two categories for care in a facility. Within those two categories, or licensures, there is a huge variance in the type of care, level of care, and quality of services and living arrangements.

Assisted Living, Residential Care or Board and Care.

These facilities can vary in size from four beds to over one hundred. Regardless of what they are called, they all have the same license. They are licensed by the state Department of Social Services as

“Residential Care Facility-Elderly (RCF-E)”

These facilities **must provide** housekeeping, laundry, medication management, all meals and snacks, activities, and at least minimal assistance with daily dressing, grooming and bathing. They must monitor the resident and notify family and the doctor of changes.

RCF-E’s **may also provide** a much higher level of care and supervision which may include incontinence care, supervision and safety for wandering, higher staff ratio and training for the behavior problems of Alzheimer’s, assistance with all hygiene, dressing and grooming, lifting and transferring for non-ambulatory, hands-on assist with walking, and help with feeding. Some **may provide, with a special waiver**, care for insulin dependent diabetics, catheter care, or hospice care. Generally a Home Health Care Agency or Hospice Agency works with the facility and family for these special health care needs.

When you visit each facility, observe the peer group, view the menu and inquire about activities. Look at the available room and see if you can envision this room and bath fitting the needs of your loved one. Is the room close to common rooms and activity areas? Observe the cleanliness of the home and the interactions between staff and residents. If you have used a referral agency, homes that are unclean or have had poor reviews by the state should not be on your list.

Be brutally honest in describing the caregiving challenges your loved one presents. A good care home will tell you if that behavior or condition can be managed in their home. Protecting your loved one by omitting issues or by minimizing the challenges can result in a placement that fails.

Costs will vary widely in residential facilities and are usually based on the level of care and supervision needed by the individual. The small facilities which are typical homes in a residential neighborhood are usually lower in cost. Some people do better in small homes; others thrive in the large facilities because of a greater variety of social activities and more room to walk about.

Continued on page 52...



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Thousands of these "BLUE BOOKS" are distributed annually, without charge, to new callers, support groups, health fairs, health agencies and Alzheimer's programs.

	A. Warren McClaskey Adult Center <i>Offering adult education to developmentally disabled adults</i>
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The printing of the "BLUE BOOK" is done by the
A. Warren McClaskey Adult Center,
which offers job training and employment to developmentally disabled workers in the Sacramento area.
Their reasonable rates and excellent service allow us to make maximum use of donated funds.

Can You Help?

Your tax-deductible donation of **just \$10.00** will cover the cost to print and distribute three "BLUE BOOKS" to caregivers right here in your community.

Your tax-deductible donation in **any amount** will assist in maintaining and expanding services in Northern California such as support groups, peer counseling, seminars, newsletters, respite care, and more.

Please use the donation envelope in the center section of this book or mail your donation to:

Alzheimer's Aid Society of Northern California
P.O. Box 60095
Sacramento, CA. 95860



Every donation, in any amount, provides help LOCALLY!
THANK YOU!