

help and hope

for persons diagnosed with
alzheimer's disease and related disorders



alzheimer's  association™



This publication was edited by staff and volunteers of the Alzheimer's Association in Northern California and Northern Nevada including: Elizabeth Edgerly, Ph.D., Chief Program Officer; Judy Filippoff, MSW, Early Stage Program Coordinator; Kathryn Laudin, Policy Administrative Assistant; and Verlene Perry, volunteer.

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This handbook was written for...

It was written especially for persons with Alzheimer's disease or a related dementia. It is meant to provide you with some basic information about what you may be experiencing and offer suggestions that may make life easier.

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24/7 Helpline 800-272-3900

www.alz.org

Aura of Love...

By Patricia O'Neal Chudacoff

When your Hippocampus★ dances
And forgets the melody
Your early stage performance
Could be a catastrophe
But when your friends and family
Look on with love and pride
You will know it's more important
That at least they know you tried

★*The Hippocampus is the part of the brain where new learning is turned into memory.*



Patricia O'Neal Chudacoff

"A large dose of humor is a great antidote for the serious issues that come with battling Alzheimer's disease. I believe that the laughter we experience in our Early Onset group goes a long way in banishing denial and making our condition bearable".

Alzheimer's Disease or Dementia?

Confused about the difference between Alzheimer's disease or dementia? You are in good company! *Dementia* is a term used to describe the loss of memory and other mental abilities severe enough to interfere with daily life. *Alzheimer's disease* is the most common form of dementia, accounting for 50–70% of all cases. Other disorders classified as dementia include: Vascular Dementia, Lewy Body Dementia, Frontal Temporal Dementia and over 50 others.



What is happening to me?

You may have been asking yourself that question for some time now. You have probably been worried and anxious about the changes you have noticed. Certainly, knowing that you have Alzheimer's disease or a related disorder can be upsetting. Perhaps having information about the disease will help you cope more easily.

For reasons we are only beginning to understand, Alzheimer's disease and related disorders cause gradual irreversible changes in brain cells. The changes usually cause confusion, memory loss and difficulty making decisions, and caring for yourself. Communication may be a challenge, both in expressing your thoughts and with understanding what others say and mean.

Getting a Diagnosis

Because it takes time to make a diagnosis of Alzheimer's disease, you may have found visits to the doctor frustrating. However, a complete medical examination is necessary in order to make a diagnosis of Alzheimer's disease or a related disorder. This examination will normally include:

- A complete physical examination.
- A detailed medical history.
- Blood work and urine tests.
- Memory and skills tests.
- An assessment of your mood or emotional status.
- X-rays or brain scans (CT or MRI are optional).
- A visit to a specialist, such as a neurologist, psychiatrist or geriatrician, may also be required.

If you do not understand what these tests are for or what the results mean, ask your doctor to explain them to you. If you have not already had these tests, it may be a good idea to take a family member or friend with you when you are scheduled to review the test results with your doctor.

It is common to question the accuracy of your diagnosis and to feel uncertain about how to respond. We hope this handbook will be a useful guide to help you cope with this experience by offering some suggestions on where to go from here.

Learning to live with Dementia

Many people with Alzheimer's disease or related dementia experience similar problems and difficulties. Following are some comments and suggestions that we hope will be helpful to you.

First, it is important to know that:

- You are still the same person.
- The changes that you are experiencing are because of a disease that affects your brain.
- Each person is impacted differently and symptoms will vary.
- This illness was not acquired by any action or inaction on your part.
- You will have good and bad days.
- You are not alone. There are people who understand what you are going through and can help.
- Accept help when it is offered; ask for help when you need it.
- There are ways to help yourself – Call the Alzheimer's Association 24/7 Helpline (800-272-3900) for information about joining an Early Stage support group or to connect with peers through the internet. Challenge yourself, don't be afraid to try new things and continue to learn. There are many resources available to you for the positive support you need.
- Become an Alzheimer's Activist! You can help others by becoming an advocate. Increasingly, those with Alzheimer's are speaking for themselves and find they can have a powerful impact when they tell their story and demand elected officials take meaningful action. Learn more – and sign up – www.alz.org/norcal or www.alznornev.org.



Memory Loss

Alzheimer's disease is always changing you. Some days you may be able to do something, and the other days you may struggle with the same task. However, you can continue to live independently during the early stages of the disease by making simple adjustments, taking safety precautions and enlisting the support of others.

Younger people with dementia

Many people assume that Alzheimer's disease and other causes of dementia only affect older people. In fact, about 1 person in every 1,000 below the age of 65 develops dementia. While rare, it can affect people in their 40's and 50's. Any dementia beginning before age 65 is known as "younger onset" or "early onset" dementia. Each person's experience of dementia is unique. Although the symptoms of dementia are similar whatever a person's age, younger people with dementia have different needs. They may:

- Be working at the time of diagnosis;
- Have dependent children living at home;
- Have greater financial commitments;
- Be physically fit and behave in ways that other people find challenging;
- Be more aware of their disease in the early stages;
- Find it hard to accept and cope with losing skills at such a young age;
- Find it difficult to access information, support and services for younger people with dementia.

Source: Adapted from Alzheimer's Disease International – www.alz.co.uk

If you are a younger person living with dementia, you are not alone. Learn more about programs and resources just for you. Contact the Alzheimer's Association at www.alz.org and search for your local office, or call 1.800.272.3900.

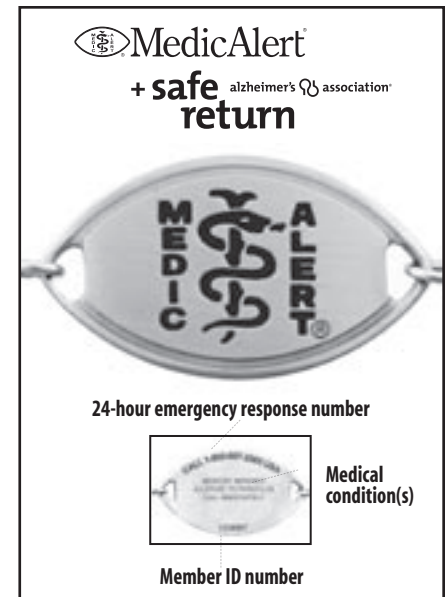
Finding your way

There may be days when places that are usually familiar to you look unusual or become unfamiliar. For example:

- You may get lost traveling a familiar route.
- A favorite park may look different to you and you may not recognize which way to turn.

If this should happen to you – don't panic. Just be prepared:

- Carry a cell phone.
- Don't be afraid to ask for help.
- Explain to people that you have a memory problem and need assistance.
- Take someone with you when you go out.
- When you think you are lost go to the nearest house or store for help. Don't keep trying to find your way.
- Register with MedicAlert + Safe Return® by calling 888- 572-8566. Be sure to wear the bracelet. An example is shown at right.

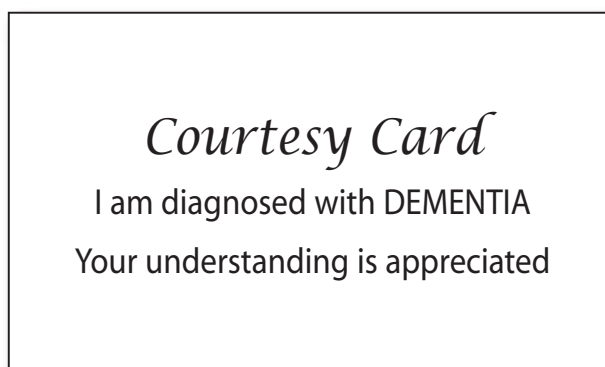


When a person with dementia wanders or becomes lost, one call immediately activates a community support network to help reunite the lost person with his or her caregiver. When a person is found, a citizen or law official calls the toll-free 24-hour emergency response number on the identification product and the individual's family or caregivers are contacted. The nearest Alzheimer's Association office provides support during search and rescue efforts. In addition, should medical attention be required, access to a personal health record is immediately available.

Talking To Others

Finding the right words to express your thoughts may become harder and understanding what people are saying may also be challenging at times. Some suggestions that may ease this experience are:

- Take the time you need to express yourself.
- If you did not understand a statement, ask that it be repeated, more than once if necessary.
- If too many people or too much noise bothers you, find a quiet place nearby.
- If you lose a thought, let it go! It is normal to temporarily forget things and very often the thoughts will come back to you.
- Talk openly to friends about your memory loss. Your friends may not know how "to be with you" after you disclose your diagnosis. Put them at ease and allow them to ask questions. You will likely get their support and understanding. Sometimes it helps to simply sit quietly with a companion and enjoy the experience of just being together.
- Some people find it helpful to give out a courtesy card, available at Alzheimer's Association offices (800-272-3900).



How can I take care of myself?

Get help with daily tasks.

Give yourself more time to accomplish tasks and reduce stress by using services to provide help with everyday activities. Some services you might use are:

- Shopping: Get meals or groceries delivered to your home. Also consider stocking your freezer with microwave meals.
- Hire a home cleaning service to help with vacuuming, dusting, mopping, laundry, etc.
- Hire a lawn or gardening service to do essential yard work.
- Most banks provide services to pay bills and keep track of your accounts. Your bills can be paid directly from your checking or savings account. Visit your bank and ask them to set up this service for you.
- Medications – Taking your Alzheimer meds, as prescribed, can help minimize symptoms. Consider using a pill box to help you organize medications. Ask the pharmacist or a family member to place pills in the pill box for you. Write down the times to take your medicine on a calendar.



Make a plan to get around.

If it is no longer safe for you to drive, there are other ways to get where you need to go. Ask family and friends for a ride. Take taxi cabs or other public transportation. Some communities offer Paratransit services for seniors and those with special needs.

Protect yourself from solicitors and potential fraud.

Do things that will limit solicitors calling you on the phone or sending you mail. Get your phone number registered on the “*National Do Not Call List*” (888-382-1222, make sure to call from your home phone number). Consider getting Caller ID so you know who is calling you. Stop unwanted junk mail by taking steps to get off mailing lists. If someone comes to your door that you do not recognize, ask for their name and telephone number instead of letting them in. Then you or your family member can call them back later.

Get support.

Get in touch with the Alzheimer’s Association for information and support. We can give you referrals to local programs and services that can help you keep your independence. You can also talk to others who know what you are going through, both on our message boards at the national Alzheimer’s Association site, www.alz.org, or in an Early Stage local support group.

Stay active.

Continue doing hobbies you enjoy. Whether it’s walking, gardening, dancing, drawing and painting, volunteering, playing sports or card games, you will benefit from the mental and social stimulation, and most people find it helps them keep a positive outlook.

Use memory aides.

Calendars, labels, lists, notebooks and sticky notes can help you cope with memory loss.

- Keep important numbers by the phone.
- Post reminders to lock doors or shut windows.
- Have step-by-step instructions on how to work appliances (such as the computer and the dishwasher) or complete routine tasks.
- Keep keys, glasses, wallet, etc. in the same place every time.
- Leave a set of keys with a trusted neighbor.
- Write your medications on a daily calendar. Include what medications you take, when you take it or them (how many times per day). Also note where the medicines are kept.

Why do I feel this way?



Alzheimer's disease and related disorders may cause you to have feelings of loneliness and depression, or irritation and anger. It is important to know that these are natural responses to the disease. Having such feelings is not bad. But it is important that you share them with others. Talk to someone with whom you are comfortable, explain how you feel. Your moods may vary and be inconsistent – the feelings you experience one day may change by the next.

You may feel angry, frustrated or upset about the changes in your life, as well as worried about the impact your disease will have upon your family. Talking about these feelings and concerns with trusted family members or friends may help. The Alzheimer's Association also has counselors and services tailored specifically to your needs. Your local chapter of the Alzheimer's Association can be reached at 800-272-3900.

Below are some quotes capturing the feelings people with Alzheimer's disease have told us they have experienced. These are only a sample and it does not mean you will experience any or all of them. There are also some suggestions that others with Alzheimer's have found helpful in dealing with these feelings.

It is important to talk to your family and friends about your worries. Some of the things you may be worried about are:

“What is going to happen to me?”

“How will I respond?”

Although there are no definite answers to these questions, talking about them with those you care about may reassure you and help you feel stronger and better able to handle the challenges you face.

- Keeping a sense of humor is very important. Laughter feels good and is good for you. Watching a funny movie or TV show may help you relax and put you in a better frame of mind.
- Joining a support group and meeting others who have Alzheimer's disease can be enlightening and reassuring.

“Sometimes I feel embarrassed”

- Changes in memory, communication and other abilities can be embarrassing. Explaining to people that these changes are due to Alzheimer's disease may help you ease those feelings.

“It's not all bad”

- Many people note that while living with the challenges related to their diagnosis, they still have very meaningful lives. Appreciating special moments with family, having time to learn new hobbies, meeting others with a similar diagnosis and forming new friendships are just some of the experiences they enjoy and that enhance their quality of life.
- Try to concentrate on the things you continue to enjoy and do well rather than the things you may be struggling with. Pat yourself on the back for taking the time to learn more about how to live and cope with Alzheimer's disease.

“I feel guilty asking for help”

- We all value our independence. Few of us like to rely on others for help. Over time you may find it necessary to ask for help more often. Asking for help and having to rely on others sometimes brings feelings of guilt. Try to remember: You like to help others; others are also pleased to help you. Talk about your feelings but also try to accept the help you need.

Emotional reactions such as those mentioned above are normal because you are facing many challenges and adjustments. Each of us has our own way of dealing with feelings. The important thing is to find ways of coping with these feelings that makes **YOU** feel better.

How else can I take care of myself?

People with Alzheimer's disease have told us some of the things they have done to make life a little easier. We share them with you as suggestions:

General Health

Researchers are finding that certain mental, social and physical activities influence our brain health. Adopting a “brain healthy lifestyle” may help you feel better physically, emotionally and for some, may even boost cognitive functioning. **There are four basic areas you should focus upon:**

- 1) **Challenge yourself mentally.** Find activities that you enjoy that engage your brain. Good examples are word games, puzzles or cards, attending workshops, playing a musical instrument and reading books. Find challenging fun activities that are suited to your individual tastes, abilities and needs. If the task is too frustrating or difficult, you won't want to do it.
- 2) **Exercise!** The single best thing you can do for your brain and cognitive functioning is to exercise. Scientists have found a link between heart health and brain health so watch out for high blood pressure, high cholesterol and try to exercise two or more days per week (doctor permitting).
- 3) **Eat a diet rich in:**
 - a. Dark green leafy vegetables such as spinach, kale, Swiss chard
 - b. Omega 3 fatty acids such as salmon, tuna and flax seed oil
 - c. Antioxidants – which are found in dark skinned fruits and vegetables
- 4) **Be socially active:** It is important for brain health to maintain and expand friendships and keep in touch with friends and family. You may also consider joining a group for persons with early stage dementia.



The best brain activities are those that are social, mental and physical all at the same time. Examples of this are dancing, group exercise classes, taking a nature walk with friends. If you can think of other activities that you enjoy, try to do them regularly.

Safety

The gradual loss of memory and the difficulties with decision-making and communication often raise concerns over safety. The following are a few suggestions to consider.

Staying Alone

Your family or care partner may worry about leaving you alone for a long period of time. While you may feel you will be fine alone, having a companion will help the time pass more pleasantly and decrease the worry for everyone.

Living alone

Many individuals manage on their own during the earliest stages of Alzheimer's disease, with support and assistance from others. If you live alone, you may need to arrange for someone to help with practical tasks, such as meals, paying bills and taking your medications. Some find it helpful to have a family member, friend or community service call or visit daily. Keeping a list of concerns that you want to discuss as questions arise can be helpful.

Driving

At some point it will no longer be safe for you to drive. This is because of your loss of memory, ability to make decisions and react quickly. Becoming confused while driving could become a problem. Giving up your license is not easy, but you can adapt to other ways of getting around – friends, family, public transportation and taxis.

Take personal safety measures.

Enroll in MedicAlert + Alzheimer's Association Safe Return[®] to help protect your safety in case you cannot find your way home or if you have a medical emergency.

Home Safety:

Make home safety improvements, such as installing grab bars in the bathroom to minimize falls.

Electrical Appliances – If there are items that you use frequently such as irons and toasters, make sure that they have an automatic shut-off feature.

Smoke Detectors and Carbon Dioxide Detectors – Every home should have a smoke and CO2 detector. Ensure that your home does. A smoke and CO2 detector could save your life in case of a fire or gas leak. These items should be available at a hardware or department store.

What about the future?

Unfortunately, Alzheimer's disease is a progressive illness. Over time, the symptoms you are experiencing will become worse and you will need more help. There is no way to predict how or when this will happen for you. It is a good idea for you to make and record decisions about your future as early as possible in the course of disease.

You may want to discuss and make plans for:

Work

- If you are still working, speak to your employer or business partner regarding your symptoms. You may be able to cut down your hours and transfer some of your responsibilities.
- If you own your own business, you will want to develop a plan for its future.



Money and Legal Matters

- Talk to your family about appointing someone as Durable Power of Attorney for Finance.
- It will be important to make sure money matters are in the hands of someone you trust like your spouse or partner, son or daughter.
- When you seek legal consultation consider taking someone with you to help explain and interpret the information you are given.
- You should also appoint or obtain a Durable Power of Attorney for Health Care to make decisions for you when you are unable to do so. This person may or may not be the one helping you with your finances. It is important that this person knows your wishes regarding your future healthcare.
- You should also consider whether you want Advanced Directives. These clarify your wishes regarding your future healthcare. Refer to your primary healthcare provider to receive these documents.

Living Arrangements

- Talk to your family and friends about future living arrangements.
- Explore options with a financial advisor to help determine what you can afford.

"To be aware can be a 'gift' of sorts because we in early stages can participate in planning for the future with our special loved ones."

–Thaddeus M. Raushi, Ph.D., A View From Within: Living With Early Onset Alzheimer's Disease

Early Stage Resources: A Brief and Partial List

Articles (Contact the Northern California/Northern Nevada Chapter for copies)

Brilliant Insights: Reflections from people living with dementia

Forgiving, Forgetting and Building a Circle of Friends, by Carole Mulliken

Learning to Live with Dementia, by Jan Phillips and the Orange County Chapter of the Alzheimer's Association

Thoughts from an early stage group, Alzheimer's patients talk about still enjoying life

Books

Dancing with Dementia: My Story of Living Positively with Dementia, by Christine Bryden (formerly Boden), Jessica Kingsley Publishers, 2005 (Philadelphia, Pennsylvania)

Living Your Best with Early Stage Alzheimer's – An Essential Guide, by Lisa Snyder, Sunrise River Press, 2010 (North Branch, MN).

A View From Within: Living with early onset Alzheimer's, by Thaddeus Raushi, Ph.D., Northeastern NY Chapter of the Alzheimer's Association, 2001. To order: 800-303-2218

The Japanese Therapists: Another Alzheimer's Autobiography, by Michael Livni, published by the author, 2010 (Johannesburg, South Africa).

Newsletters

Perspectives: A Newsletter for Individuals Diagnosed with Alzheimer's Disease. La Jolla, CA: Lisa Snyder. (858)-622-5800. lsnyder@ucsd.edu.

Alzheimer's Association Chapter Newsletter 800-272-3900, or
www.alz.org - search for your local chapter to subscribe

Web sites

www.alz.org (includes online messaging)

www.Dasninternational.org (includes link to online chat room)

www.clinicaltrials.gov

Contact your local Alzheimer's Association chapter office for a more detailed list of early stage resources, copies of articles and fact sheets, and access to a growing trove of resources.

Helpline: 800-272-3900

www.alz.org



An Alzheimer's Disease Bill of Rights

Every person diagnosed with Alzheimer's disease or a related disorder deserves:

- To be informed of one's diagnosis.
- To have appropriate, ongoing medical care.
- To be productive in work and play as long as possible.
- To be treated like an adult, not a child.
- To have expressed feelings taken seriously.
- To be free from psychotropic medications if at all possible.
- To live in a safe, structured and predictable environment.
- To enjoy meaningful activities to fill each day.
- To be out-of-doors on a regular basis.
- To have physical contact including hugging, caressing, and hand-holding
- To be with persons who know one's life story, including cultural and religious traditions.
- To be cared for by individuals well-trained in dementia care.

From: The Best Friends Approach to Alzheimer's Care, by Virginia Bell and David Troxel, Health Professions Press, 1997



Notes

brilliant insights

reflections from people living with dementia

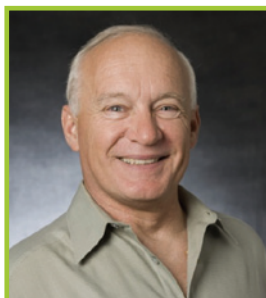


“I am committed to helping others deal with this disease and to help others who are touched by Alzheimer’s. I mentor new people entering our support group. It feels good to help and to be with people who have the disease.”

Sue Roby, 73

“There are challenges, but I’m still at a point where I can figure out a way of accomplishing what it is I want to accomplish. I might need more assistance, but I know where to find it. I’m not dependent on people for things yet. If I just sit down to think it through I can get whatever I want done, I can do it.”

Jestene McCord, 76



“You could just lie down and die, but I don’t think there’s any honor in that. I’d rather go out fighting and I can’t think of anything better right now than to fight against Alzheimer’s disease and to fight for research and funding.”

Alan Romatowski, 58

“My recommendation for those who have received an early stage diagnosis is get into a support group. It’s a wonderful place where you can go and talk freely and it stays in the room. You can laugh, you can cry, share your stories...You build relationships with people who truly understand what you’re going through. It’s very important. Very important.”

Pat Van Dyke, 57



“It’s been over a year and a half or so that I was diagnosed and I have yet to shed a tear because I am not going to lay down without a fight and I find it very comforting to myself knowing that I am doing all I can do to help myself and hopefully others down the road.”

Karen Zimmerman, 54

“I struggled with fear and sadness at first, feeling sorry for myself and asking ‘why me?’ Then I wrote myself a little poem — something I had never done before. Looking back, that’s probably the point when I began to concentrate on leaving self-pity behind and focusing on learning more about Alzheimer’s.”

John MacInnes, 82



“I think that in the African-American and Hispanic communities there needs to be a lot more outreach to talk about the signs of Alzheimer’s, especially early signs, because I think that people can actually be helped. What is termed “forgetfulness” or “a senior moment” doesn’t necessarily have to be a senior moment. It can be Alzheimer’s and just the word is scary for people.”

Joyce Simons, 57

“After leaving my job and volunteer fire fighting, I am still able to educate people about Alzheimer’s disease. I believe that education of the disease is very important for everyone, including doctors, nurses, and first responders. The voices of those with Alzheimer’s disease are important to be heard and I want to help the Alzheimer’s Association expand its outreach to people when they need support the most.”

John McClelland, 57



“Life’s too short to be angry. I have a great family. I no longer drive but still enjoying riding my bike. I still go to the gym to work out. My family and I want to continue lending our voices for the cause.”

Jay Jones, 53

“I embraced my diagnosis and made the decision to do something good with it. The good I saw was to try and be of value to others. Doing this has given me a real sense of purpose. There is so much that needs to be done. It is providing a sense of peace, serenity and fulfillment.”

Mike Donohue, 73



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