



A Guide for Living with Dementia

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Introduction

This brief guide is designed for you to consider some steps you may take after you or a loved one is diagnosed with Alzheimer's disease, or another type of dementia. It is written for those who have been diagnosed very early on, or for those who may wish to make certain preparations for their future. It also contains helpful suggestions for family members and other caregivers.

Alzheimer's disease is the most common type of dementia, so most statistics and other specific information given in this booklet will use the term Alzheimer's disease. Most of the suggestions and steps outlined here, however, will be valuable for anyone diagnosed with a dementia or mild cognitive impairment.

This introductory booklet is not intended to be comprehensive. There have been many books and brochures written about Alzheimer's disease, its causes, treatment, and continuing hopes for a cure. To become well informed, you will probably need to consult these resources. However, it is our hope that this booklet will be a valuable "first step" in helping you and those you love to understand where to start in coping with this new and challenging situation in your life.

Disclaimer: Information and fees for private businesses, government programs, and non-profit agencies mentioned and listed in this guide are subject to change. Kaiser Permanente Health Plan, Inc. coverage does not include payment for services in this guide, which is not inclusive of all local resources. Kaiser Permanente does not endorse or make any representations regarding the quality of such services, nor the financial integrity of these entities. Kaiser Permanente expressly disclaims any liability for the services provided by these entities.

Facts About Dementia

Dementia is a general term for loss of memory and other mental abilities severe enough to interfere with daily life. It is a disease that attacks the brain, causing changes in brain function. While some people believe that Alzheimer's disease and dementia are two diseases, Alzheimer's is in fact the most common type of dementia.

Dementia causes many problems for the person who has it and for the person's family and caregivers. Many of the problems are caused by memory loss. The most common symptom of dementia is loss of short-term memory; long term memory is preserved for a while. Some common signs and symptoms of dementia are listed below. Not everyone who has dementia will have all these signs and people may lose abilities or notice changes at different rates¹.

- **Recent memory loss.** All of us forget things for a while and then remember them later. People with dementia often forget things, but they never remember them. They might ask the same question over and over, each time forgetting that they have been given the answer. They won't even remember that they already asked the question.
- **Difficulty performing familiar tasks.** People who have dementia might cook a meal but forget to serve it. They might even forget that they cooked it.
- **Problems with language.** People who have dementia may forget simple words or use the wrong words. This makes it hard to understand what they want.
- **Time and place disorientation.** People who have dementia may get lost on their own street. They may forget how they got to a certain place and how to get back home.
- **Poor judgment.** Even a person who doesn't have dementia might get distracted. But people who have dementia can forget simple things, like forgetting to put on a coat before going out in cold weather.
- **Problems with abstract thinking.** Anybody might have trouble balancing a checkbook, but people who have dementia may forget what the numbers are and what must be done with them.
- **Misplacing things.** People who have dementia may put things in the wrong places. They might put an iron in the freezer or a wristwatch in the sugar bowl. Then they can't find these things later.
- **Changes in mood.** Everyone is moody at times, but people with dementia may have fast mood swings, going from calm to tears to anger in a few minutes.
- **Personality changes.** People who have dementia may have drastic changes in personality. They might become irritable, suspicious or fearful.
- **Loss of initiative.** People who have dementia may become passive. They might not want to go places or see other people.

As stated above, the most common symptom of a dementia is the loss of short-term memory. In the early to middle stages of the disease, the short-term memory loss is often not consistent; sometimes the person is able to remember incidents, at other times, not at all. It is helpful to think of the brain during early stages as being like a broken circuit board - sometimes the circuits connect, and sometimes they don't. The important thing to remember is that there is brain damage. It is not true that the person with dementia "could remember if he really tried." During the middle to late stages of the disease, the short-term memory loss becomes consistent.

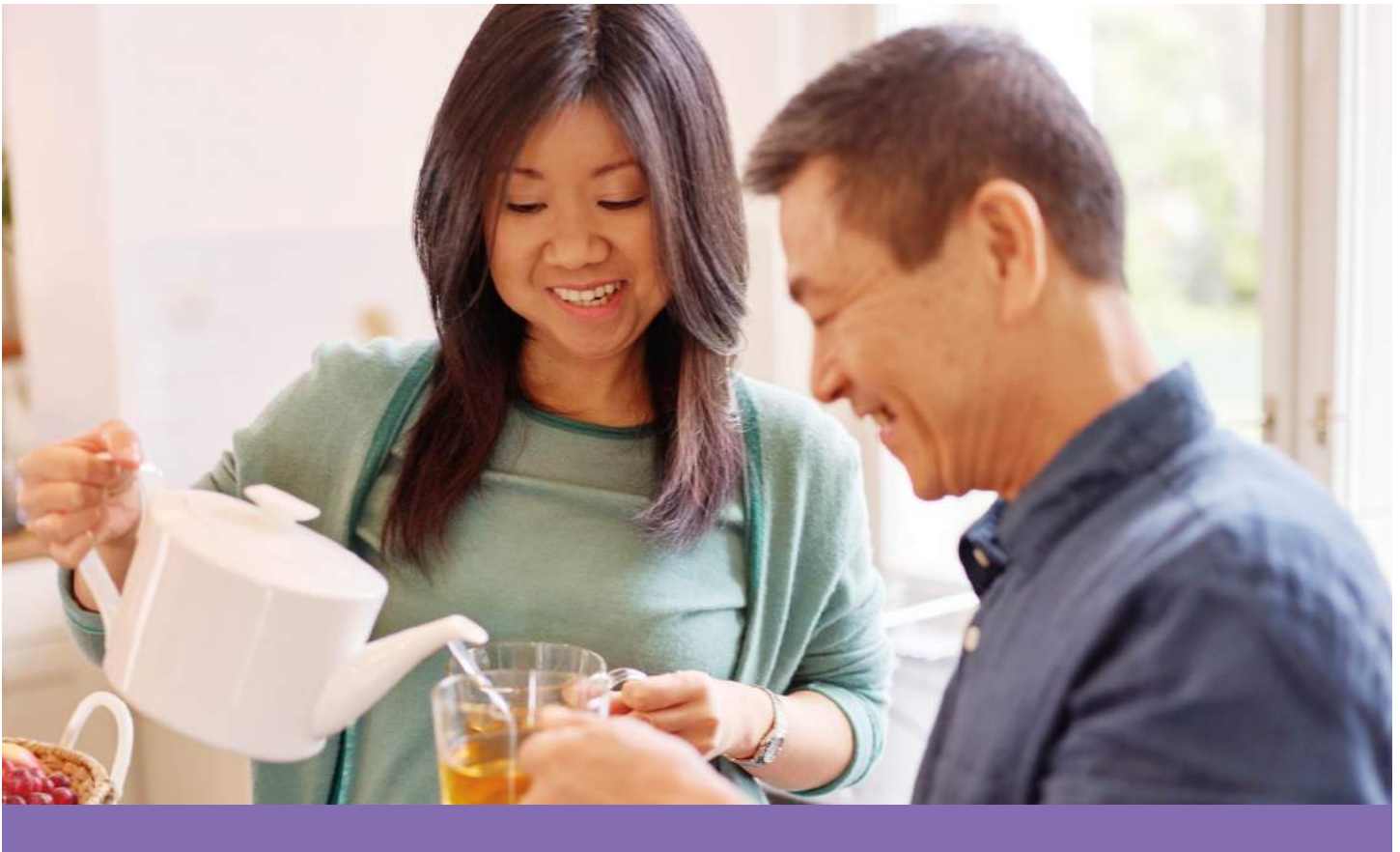
Dementia is caused by many conditions. Some conditions that cause dementia can be reversed, and others cannot. Reversible conditions with symptoms of dementia can be caused by a high fever, dehydration, vitamin deficiency and poor nutrition, bad reactions to medicines, problems with the thyroid gland, or a minor head injury. Medical conditions like these can be serious and should be treated by a doctor as soon as possible.

Sometimes older people may experience emotional problems that can be mistaken for dementia. Feeling sad, lonely, worried, or bored may be more common for older people facing retirement or coping with the death of a spouse, relative, or friend. Adapting to these changes can leave some people feeling confused or forgetful. Emotional problems can be eased by supportive friends and family, or by professional help from a doctor or counselor.

Some people do become more forgetful as they get older, such as misplacing car keys or not remembering a familiar name. That is a normal part of aging. Alzheimer's disease is not. The changes in normal aging can sometimes show up as difficulties with short term memory and/or mood changes. People often worry when these changes occur that they might be showing the early signs of Alzheimer's disease. Make an appointment with your doctor or health professional just to make sure, but more than likely they are normal changes. The table below compares common signs of normal aging versus early Alzheimer's disease.

Normal Aging	Early Signs of Alzheimer's
Sometimes forgetting names, but remembering them later.	Forgetting recently learned information or the names of people close to you.
Briefly forgetting part of an experience.	Forgetting a recent experience.
Misplacing things from time to time and retracing steps to find them.	Placing things in unusual places. May lose things and be unable to trace steps to find them.
Developing very specific ways of doing things and becoming irritable when routine is disrupted.	May experience mood and personality changes and become confused, suspicious, fearful or anxious.
Changes in your interests.	Decreased interest in outside activities.
Sometimes having trouble finding the right word.	Gradually unable to follow or join conversations.

(Alzheimer's Association, 2019)



Types of Dementia

Dementia is generally classified according to its cause, i.e., what changes in the brain have caused the symptoms to develop. Dementia is a general term that describes the loss of memory and other intellectual abilities that are serious enough to interfere with a person's daily life². If a doctor is unable to determine the cause, he or she may use the general diagnosis of dementia.

Alzheimer's disease is the most common form of dementia. It accounts for 60 to 80 percent of Dementia cases. This type of dementia was first described by the German physician, Dr. Alois Alzheimer in 1906. The brain of a person with Alzheimer's is characterized by formations of microscopic structures called plaques and tangles. As these plaques and tangles are forming, brain cells begin to die. The parts of the brain that control memory, language and reasoning are affected first. Other areas of the brain are usually affected much later in the disease. The cause of the disease is not fully understood and there is currently no cure, although research is ongoing.

Some other types of dementia include vascular dementia, mixed dementia, and dementia with Lewy bodies. There are also other types of dementia that are much less common, such as frontotemporal and alcoholic (Wernicke - Korsakoff) dementia. However, all types of dementia cause memory loss, impaired thinking and behavioral problems. The table on the next page summarizes the common characteristics of each type of dementia mentioned.

Common Types of Dementia and Their Typical Characteristics

Type of Dementia	Characteristics
Alzheimer's Disease	Most common type of dementia; accounts for 60 to 80 percent of cases. Difficulty remembering names and recent events is often an early clinical symptom; later symptoms include impaired judgment, disorientation, confusion, behavior changes and trouble speaking, swallowing and walking.
Vascular Dementia (also known as multi-infarct or post-stroke dementia or vascular cognitive impairment)	The second-most-common type of dementia. Impairment is caused by decreased blood flow to parts of the brain, often due to a series of small strokes that block arteries. Symptoms often overlap with those of Alzheimer's, although memory may not be as seriously affected.
Mixed Dementia	Characterized by the presence of the hallmark abnormalities of Alzheimer's and another type of dementia, most commonly vascular dementia, but also other types, such as dementia with Lewy bodies, frontotemporal dementia and normal pressure hydrocephalus.
Lewy Body Dementia (LBD) and Parkinson's Disease (PDD)	These conditions are like other dementias and share features such as problems with memory, judgment, and behavior changes. However, the microscopic brain changes are very different and show protein deposits called Lewy Bodies that are seen in Parkinson's Disease whereas beta-amyloid protein deposits are seen in Alzheimer's. LBD is suspected when alertness and severity of cognitive symptoms fluctuate daily along with visual hallucinations or features of Parkinson's Disease such as muscle rigidity and tremor. Many people who have Parkinson's disease develop dementia in the later stages of the disease.
Frontotemporal Dementia	An umbrella term for a diverse group of disorders that primarily affect the frontal and temporal lobes of the brain. Signs and symptoms depend on the area affected and can include being socially inappropriate, impulsive, or being emotionally indifferent. Symptoms also may include the loss of ability to use and understand language.
Additional Types of Dementia	In addition, there are less common types of dementia including: <ul style="list-style-type: none"> • Creutzfeldt-Jakob • Huntington's Disease • Normal Pressure Hydrocephalus • Posterior Cortical Atrophy • Parkinson's Disease Dementia • Korsakoff Syndrome For more information, visit www.alz.org/alzheimers-dementia/what-is-dementia/types-of-dementia

Risk Factors

The three risk factors that increase the likelihood of developing Alzheimer's disease are age, family history and genetics. Age is the greatest known risk factor for developing Alzheimer's. It tends to affect those over 65 but has been seen in those as young as 40. For every five years after 65, the likelihood of developing Alzheimer's disease doubles. The risk increases to nearly 50 percent after 85².

Family history is also a significant risk factor for Alzheimer's. Those with a parent, brother or sister with the disease are two to three times more likely to develop Alzheimer's, and the risk can increase if more than one family member has the disease. However, there have been cases where no other family members have been affected.

Scientists have identified a specific gene that is a marker for at risk individuals, and other rare genes that, when present, guarantee an individual will develop the disease. These special findings account for only five percent of cases, therefore, experts believe it is more likely that Alzheimer's disease is caused by a combination of genetic and non-genetic factors.

There are other factors that have been linked to the development of dementia. Sustaining a serious head injury can cause brain damage and therefore make you susceptible to the disease. Also, individuals with high rates of vascular disease, particularly Latinos and African Americans, are especially at risk for vascular dementia.³

Important Medical Steps

If your doctor or health professional suggests that you or a family member may have dementia, it is important to first rule out other conditions. A brain scan is done to rule out conditions that include brain tumor, stroke, hydrocephalus, or blood clot. Blood tests are done to rule out low thyroid, altered blood chemistry, or B12 deficiencies that can look like dementia. Sometimes severe depression might appear like dementia but is treated very differently. Only after these conditions are ruled out that a diagnosis of dementia is considered.

For most patients, the diagnosis of dementia is straightforward. Often, dementia and Alzheimer's disease are used interchangeably because Alzheimer's accounts for 60-80% of all dementias. However, one can only know the precise diagnosis when the brain is examined under the microscope, which is mostly done for research purposes. Your primary physician may begin treatment after ruling out other causes for dementia or refer to a specialist when there is suspicion for less common forms of dementia. Further specialty evaluation may include additional mental status/psychiatric/cognitive tests, further lab tests, and neurological examination to assess thinking, behavior, and physical function. In addition, the physician may ask a family member or friend about overall health, use of prescription and over-the-counter medicines, diet, past medical problems, ability to carry out daily activities, and changes in behavior and personality. For list of possible changes in behavior and personality, please see link

www.nia.nih.gov/health/managing-personality-and-behavior-changes-alzheimers

Making an early diagnosis of dementia is very important for several reasons: (1) it allows individuals and families to make choices on how to maximize their quality of life, (2) reduces anxiety about unknown problems, (3) allows a person to possibly benefit from treatment, (4) gives individuals more time to plan for the future², and (5) allows the individual, family and friends to access education, support, and connection to community resources earlier on.

You Are Not Alone

As people age, it becomes more likely that they will develop a dementia, most likely Alzheimer's disease. Although it is associated with aging, Alzheimer's disease can occur in middle age as well as, rarely, in the fairly young. Currently, approximately 5.5 million individuals in the US are afflicted with Alzheimer's disease or related dementias.

Most individuals with Alzheimer's disease live at home and are cared for by family members. The individuals and their families and caregivers have a wide variety of needs. To assist this large group of individuals and families, many organizations and support services have been established. We will discuss some of the local resources and services in this booklet. The important thing to remember is that you are not alone. There are numerous places to go for help, advice, and understanding.

Hope Continues

While there is no cure for Alzheimer's disease and related dementias, intensive research efforts are ongoing around the world committed to finding a cure in the future. Currently available medications have modest temporary benefits but do not slow, stop, or reverse the brain degeneration that causes dementia. Nevertheless, there is steady stream in the news about novel treatments in development although not yet to be proven safe and effective.

For more information about current medications available for those with dementia, contact your doctor or health care professional.

The Alzheimer's Association annually hosts the world's largest event, Walk to End Alzheimer's, to raise awareness and funds for Alzheimer's care, support and research. The inspiring event calls on participants of all ages and abilities to join the fight against the disease!



Progression of Dementia

It is difficult to predict the course of Dementia because there are many different causes of dementia. Generally, it is believed that the average life span from diagnosis to death is 4 to 8 years. However, it has been known to progress much more rapidly in some patients, but last as long as 25 years in others.

During this time, as the thinking processes become more impaired, there is difficulty in performing activities of daily living. Below is a chart which roughly graphs the progression of the disease.

Stage of Dementia	Problems With Thinking	Problems With Daily Functioning	
Mild	Recall/Learning Word Finding Problem Solving Judgment Calculation	Work Cooking Reading Hobbies	Money/Shopping Housekeeping Writing Medications
Moderate	Recent Memory Remote memory is unaffected Language (names and paraphrases) Insight Orientation Visual/Spatial Ability	Misplacing Objects Getting Lost Bathing Grooming	
Severe	Attention Difficulty performing familiar activities Language	Loss of interest in eating Incontinence Difficulty Walking Motor Slowing Difficulty Swallowing	

Later Stages

As dementia worsens, people are able to do less and less for themselves. During the end stage there is difficulty in eating resulting in weight loss. The person loses the ability to walk and becomes bed-bound. There is a gradual loss of speech though they may repeat some words or cry out from time to time. The person no longer has control over bladder and bowel and needs to be cleaned, bathed, and turned.

Several medical problems develop as dementia progresses, including infections and problems with eating, drinking and swallowing.

Infections and Fevers: Almost half of people who have dementia will get pneumonia at least once. Repeated infections are also common. These infections are not always preventable and may not improve with antibiotics.

Eating and Drinking Difficulties: As dementia reaches the end stage, eating and drinking difficulties occur in almost all people. They will forget or refuse to eat or drink.

Swallowing Problems: Some people hold food in their mouth or let the food spill out, even when they are assisted by a caregiver. A person may appear to be swallowing but it is possible that the food, liquid or saliva may go down the wrong way and enter into the lungs. This can cause a lung infection called aspiration pneumonia.

Heart or Breathing stops: Unlike what we see on TV, very few people with end stage illnesses survive by others restarting their hearts or lungs (resuscitation).

Families of the person with dementia may eventually face very difficult decisions regarding the patient's medical treatment. One of the most common decisions is whether to use a feeding tube when the person can no longer chew and swallow food. Some families wish to have the patients fed this way. Others feel that this is a quality of life issue and that their loved one would not want to live this way. At that time, care can be focused on comfort measures and hospice services may help in allowing the person to die naturally.

Often persons in the early stages of the illness can communicate wishes about which interventions they may want at the end of life or whether they would prefer to let nature take its course, as long as they are protected from undue pain or distress. Because deciding for someone else is stressful, it is always helpful to discuss the issue of interventions with the person with dementia at an early state in the illness.

(Adapted with permission from Laguna Honda Hospital and Rehabilitation Center)

At later stages of dementia, one may be eligible for hospice, which is a very individualized, special form of care for people who have been diagnosed with a terminal illness and life expectancy of 6 months or less. It is usually provided in their residence or where they now reside, including nursing homes or other care facilities, and the focus is on comfort rather than on trying to cure an illness. Hospice provides physical, emotional, and spiritual comfort, and also gives support to caregivers and family. At later stages, the treating physician may discuss a palliative care consultation or hospice referral. The goals of a palliative care consultation are improving quality of life, helping with distressing or disabling symptoms, and helping patients and family members understand their choices for medical treatment. Hospice has similar goals, but it is for those who have been diagnosed with a terminal illness and have a life expectancy of 6 months or less. Please contact the treating physician if you are interested in learning more about these options.



Understanding Behavioral Problems

Because of damage to the brain causing impaired thinking, there can be a number of behavioral problems which accompany dementia. These behaviors may include resistance to bathing or grooming, wandering, aggressive outbursts and agitation. The presence or absence of these behaviors can vary greatly from one person to another throughout the course of the disease. Often finding the cause of the behavioral problem can go a long way in helping to resolve it. The cause of the behavioral problem can be related to illness (medical cause), the environment, the task itself, or a psychiatric sign of the disease.⁴

Medical Causes of Behavioral Problems

People with dementing illnesses suffer progressive brain damage that can affect their behavior. This is an important factor to consider when planning interventions for behavior problems. People with dementia can also have other medical problems that greatly affect behavior. Listed below are some of the more common physical problems that caregivers should be aware of.

Effect of medications. People with dementia are very vulnerable to over-medication, to reactions from combinations of drugs, and to their side effects. Drugs can cause confusion as well as sudden changes in a person's level of functioning. Falling, drowsiness, a sudden increase in agitation, or strange hand or mouth movements (tardive dyskinesia) may be side effects of medication and should be reported to the doctor immediately. Tranquilizers and sedatives are sometimes given to facilitate sleep or calm behavior, but these medications can also affect bladder functioning and can cause incontinence problems. They can also increase fall risk.

Impaired vision or hearing. Both these problems can affect a person's ability to understand what is being said. It is important to see a doctor to correct any hearing or vision problems if possible. If

caregivers are aware of these deficits, they can often help the person compensate for them.

Acute illness such as a urinary tract infection, pneumonia, gastrointestinal infection or fever may lead to increased confusion. It is not always easy to recognize acute illness in people with dementia, since they may not be able to verbalize symptoms. Any sudden changes in behavior should be reported to the doctor.

Dehydration. Many people suffering from dementia do not get enough fluid, because they no longer recognize they're thirsty or they forget to drink. Symptoms of dehydration may include dizziness, confusion, refusal to drink, skin that appears dry, flushing and fever, and rapid pulse.

Constipation. This can be very uncomfortable and eventually can lead to bowel impaction. In some people with dementia, fecal impaction can contribute to delusional behavior.

Depression. Many of the symptoms of depression, such as impaired concentration, memory loss, apathy, and sleep disturbances resemble those of dementia. It is often very difficult to tell which are caused by depression, by the dementia, or a combination of both of these problems. It is important to bring to the doctor's attention any suspicion you may have depression. The doctor should be aware of your family member's symptoms and do a thorough evaluation for depression.

Fatigue. If confusion or agitation increases late in the day, suspect fatigue to be a factor.

Physical discomfort because the person's immediate needs aren't being met. For example, the person may be hungry, the person may need to use the bathroom, or the temperature of the room may be too warm or too cold.

Environmental Causes of Behavioral Problems

Excessive stimulation. Some people with dementia may respond with anger or frustration when there is too much going on in the environment, such as music during a conversation or there are too many people around. They may have reached a point when they may no longer be able to cope with stress. It is important for caregivers to think about what was going on right before the outburst. Too much noise? Was the size of the group too big?

Excessive demand. There is a tendency to want to exercise the brain of the person with dementia. This means asking questions, testing the person, trying to retrain for lost skills, and pushing them to try harder. This implies that the problem is laziness rather than actual disability from brain damage. Caregivers and families must try to accept that the person is often trying as hard as possible, provide positive support, and assist when the person is unable to perform a task.

Unstructured environment. People with dementing illnesses need a certain amount of routine and daily structure on which they can depend. This consistency is important in helping to minimize the amount of stress the person with memory loss may be experiencing. For example, don't rearrange furniture in the house or move the person's bedroom. At the same time, there needs to be flexibility in the daily routine to accommodate the changing moods of the person. For example, a rigid bath schedule can cause problems for both the impaired person and the caregiver.

Unfamiliar environment. An environment which is new or unfamiliar is more likely to be confusing to the person with dementia. Try to focus on familiar situations that the person is used to when planning activities or changing the physical environment to accommodate the special needs of a person with memory impairment. For some people, going to a restaurant or going on a trip may be terribly upsetting but for others, it may be a wonderful outing.

Task-Related Causes

Task too complicated. Sometimes we ask people with dementia to do tasks that are too overwhelming and difficult for them, although they may seem simple to us. Getting dressed or brushing our teeth are examples of tasks that are very complex because of the many steps involved. Breaking a task down into small, concrete steps is one effective technique which enables a person with dementia to continue to do tasks successfully.

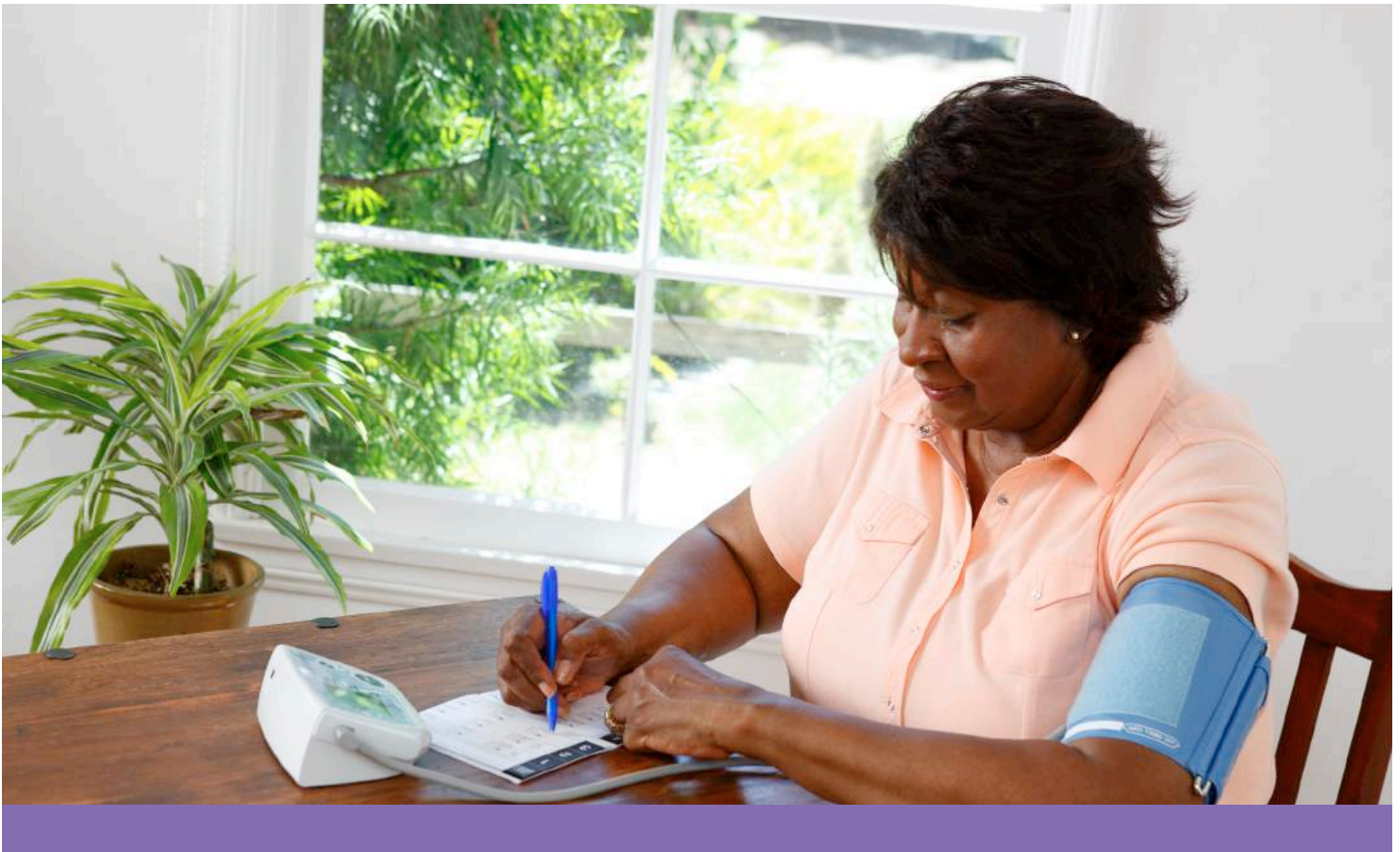
Too many steps combined. Make sure the person is doing one small step at a time. Sometimes caregivers combine several steps together not realizing the impaired person may no longer be able to do two or three steps at a time.

Task not modified for increasing impairments. As the person's functioning declines, the caregiver may have to do the first few steps of the task to get the person started. Eventually the caregiver may have to do most of the steps him/herself; even then it is important to try to keep the person involved, doing one or two simple steps.

Task unfamiliar. People with dementia gradually lose their ability to learn new tasks or skills. Try to focus on familiar tasks the person may have done before the onset of the illness, such as washing and drying dishes, making beds, folding laundry, gardening, etc.

Behavioral Symptoms

Often behavioral problems can be treated by modifying the environment or changing activities in the person's life. At other times, a medical evaluation will indicate that the person has an acute illness such as urinary tract infection, pain, pneumonia, dehydration, etc. Often after treatment, the behavioral problem goes away. However, there are times when neither of these approaches works and the behavior becomes more problematic and interferes with the ability to provide care. At these times, your doctor may want to try to manage the behavior with medications. It will be up to the caregiver or family member to clearly define the behavior and how often it occurs. If medication is given, the caregiver will need to monitor the effect on the person with dementia as well as watch out for any side effects which the doctor, pharmacist, or nurse describes.



Tips for People with Mild Memory Problems

- Use memory aids and tools such as brightly colored Post-it notes (virtual on computer, or paper) posted in a noticeable place (i.e., bathroom mirror, or on door you leave out of) for reminders. Discard or delete the Post-it notes when reminders are no longer needed to avoid confusion.
- Erasable whiteboards can be used for communicating with others in the home and reminding appointments and tasks.
- Timers and alarms are helpful for cooking safety, laundry, and appointment reminders.
- Put an emergency contact list on the fridge in case paramedics are called.
- Use calendars on cell phones, computers, along with paper calendars for appointment reminders.
- Medication Reminders: leave bottles in plain view as a visual reminder to take them (i.e., near coffee maker for a.m. medications). Use a mediset box with compartments for day of the week and time of day - this can help you and others track if medications are being taken at the right time and dose. Use a calendar to mark and track if you have taken and when taking medications. Set an alarm on your cell phone for medication reminders OR have a friend/family member(s) call for reminders.
- Day to Day Memory Strategies if you are having trouble remembering: use visual clues to remember tasks (i.e., hang a bag on door as a reminder to bring it when you leave; put laundry basket in living room as reminder to do laundry). Keep a notebook or journal with you to note who you spoke to, phone numbers, to-do list for later, and conversations that you need to remember (i.e., instructions from doctor). Cross out items on to-do list that have been completed to avoid confusion. Keep belongings in one place to save time looking for them and reduce confusion. Have duplicates of items you use often in case you

misplace them. Flag emails that need follow-up and delete emails if you do not need them. Ask friends/family for scheduled reminders.
(Alzheimer Society of Canada)

Recommendations to maximize cognitive function, independence & safety

Studies show that physical and mental/cognitive stimulation are beneficial to people with Alzheimer's dementia. No single type of cognitive stimulation (learning new things, crossword puzzles, etc.) was identified in studies as being more effective than another. (From the Alzheimer's Association's 2019 Alzheimer's Disease Facts and Figures.) In addition to exercise, social stimulation, getting enough sleep, eating a heart healthy diet, limiting cigarette smoking, limiting alcohol intake, and taking medications as directed are recommended for brain health.

Request that your doctor refer you to a Social Worker for individualized information on community resources related to above recommendations. Call Kaiser Permanente Social Services Department, Family Caregiver Alliance, or the Alzheimer's Association for individualized information on formal social stimulation options such as senior centers, day programs, and psycho-educational support groups for people living with dementia and their caregivers. See Contact info in the list of Kaiser Permanente and Community Resources starting on page 30.

Communication Tips for Persons with Dementia

How to communicate diagnosis to others and ask for support

Allow yourself time to process the diagnosis. Plan to bring a family member/friend with you to appointments from this point on.

Decide if you would like to tell friends/family members or if you prefer a family member/friend communicate on your behalf.

What to tell others:

- Be direct and clear: I have been diagnosed with dementia.
- Let others know that they may notice that you repeat yourself at times and/or forget things that they may have told you in the past. Ask them to please be patient and kind.
- Ask others to write down important information so you may refer back to it.
- Remind them to please continue to include you in activities and social events, not only are they an important part of your life, they also keep you as healthy as possible.
- Let them know that they should ask permission on any given day to ask questions about your condition. And you can say no if you don't want to talk about it.

Let them know there are resources available online if they have more questions. Alzheimer's Association's website, www.alz.org, provides the tips below.

Be open and direct

Engage others in discussions about Alzheimer's disease and the need for prevention, better treatment and an eventual cure. Engage with others on dementia-focused social media message boards.

Communicate the facts

Sharing accurate information is key to dispelling misconceptions about the disease. Whether a pamphlet or link to online content, offer information to help people better understand Alzheimer's disease. Learn the facts about Alzheimer's and find an education program near you.

www.alzconnected.org/?_ga=2.102829056.1407238120.1610653217-1011347020.1610653217

Seek support and stay connected

It is important to stay engaged in meaningful relationships and activities, whether it includes family, friends or a support group. A network is critical. Find an early-stage support group near you here:

www.alz.org/events/event_search?etid=2&cid=0

Don't be discouraged

Denial of the disease by others is not a reflection of you. If people think that Alzheimer's disease is normal aging, see it as an education opportunity. Here is a link to some tips for helping family and friends adjust to your diagnosis.

www.alz.org/help-support/i-have-alz/live-well/helping-family-friends

Be a part of the solution

As an individual living with the disease, yours is the most powerful voice to help raise awareness, end stigma, and advocate for more Alzheimer's support and research. Learn how you can make a difference in the fight against Alzheimer's.

www.alz.org/help-support/i-have-alz/make-a-difference

Tips for Caregivers

Good Communication with people with Dementia

Communication between the caregiver and the person with dementia is an extremely important, and often difficult, part of the caregiving process. Many times, people with dementia become angry or agitated because they do not understand what is expected of them. Or they may be frustrated with their inability to make themselves understood. This could lead to a decline in their ability to interact with others over time.

- **Use short simple sentences when communicating.** People with dementia may not be able to remember more than a few words at a time. Pause between sentences and allow plenty of time to be understood.
- **Use very concrete terms and familiar words.** As people become more impaired, they lose the ability to understand abstract concepts.
- **Look directly at the person and make sure that you have his or her full attention before speaking.** Gently touch an arm or hand or call the person by name. Speak slowly, keep eye contact and say individual words clearly.
- **Talk in a warm, easy-going, pleasant manner.** People with dementia are often extremely aware of non-verbal signals such as facial expressions, body tension and mood. If you are angry or tense, they may become annoyed, angry or tense too.
- **Use a non-demanding approach and try and use humor, cajoling or cheerfulness.** Humor can help caregivers through difficult moments. Convincing someone to get out of bed or to use the bathroom is often easier if you can make a game or joke of it. Ordering or demanding is often met with resistance and anger, making the task even more difficult.
- **Turn down the volume of televisions and radios.** Noise from television, radio or other conversations can make it difficult for the person with dementia to understand what you are saying. People with dementia often have very little ability to screen out distractions.

- **Give choices, whenever possible.** This allows the person with dementia some measure of control over his or her life. The choices should be limited such as between two blouses or bathing before or after breakfast. Offering too many options can result in confusion and agitation.
- **Avoid reasoning.** The person with dementia often has a poor understanding of their decision-making abilities. They may strongly believe that they can still drive; manage their medications; or handle their finances. Be creative in addressing their need for support. Avoid telling them what they can't do or pushing your point of view. They know what they know, and you won't be able to convince them otherwise.
- **Have a script ready to answer repetitive questioning.** The person with dementia has short term memory loss. He or she cannot remember what you answered when the question was asked just minutes before. Using a script allows the caregiver to respond to the person's demands without the frustration of constantly trying to come up with a new response. Once a response "works," it is used over and over. The following are examples of what to say:

Instead of Saying...	Try Saying...
"You can't call your mom. She's been dead for years!"	"I'm sure she's not home right now. Let's call her later."
"I just told you! Your appointment is at 2:00!"	"Don't worry. I'm going too, and I won't leave without you."
"Do you want to take your bath now?" "Where do you think you're going this time of night? You can't leave by yourself!"	"Your bath is ready. Here's your towel!" "Before you go, could you help me in the kitchen, I'm going to make some tea."
"No, I'm not coming to get you tonight! You can't go home. You don't live there anymore. We moved you there because you can't take care of yourself."	"It's so late. Let's go to bed. I'll call you in the morning."
"No one is stealing the jam from your refrigerator!"	"Are you almost out of jam? I'll pick some up for you in the morning and stop by."

Tips for Addressing Caregiver Stress

Taking care of an individual with Alzheimer's disease can be extremely stressful. Too much stress can be damaging to both a caregiver and the person with Alzheimer's. If you feel overwhelmed and are neglecting your own physical, mental and emotional well-being, you may be putting your health and yourself at risk.

If you are experiencing some of these signs of stress on a regular basis, consult your doctor. Ignoring them can cause your physical and mental health to decline.

Some symptoms of caregiver stress are:

- Anger
- Anxiety
- Depression
- Exhaustion
- Health Problems

- Irritability
- Lack of Concentration
- Sleeplessness
- Social Withdrawal

To learn more about caregiver stress or tips for managing caregiver stress, contact the Family Caregiver Alliance at 1-800-445-8106 or visit www.caregiver.org and view:

- A Guide to Taking Care of Yourself
- Caregiver Depression: A Silent Crisis
- Caregiver Self-Care - Caring For You
- Saying "Yes" to Offers of Help

You can also contact The Alzheimer's Association at 1-800-272-3900 or www.alz.org and view:

- Be A Healthy Caregiver
- Caregiver Stress Check
- Learn 10 Symptoms of Caregiver Stress and Tips to Avoid Burnout
- Reducing Stress

Respite

Respite is an important part of managing caregiver stress. The term "respite" is often used in the field of chronic illness to refer to the need of both patients and families to have away-from-home activities. Alzheimer's patients, for example, often benefit greatly from involvement with social groups and activities. Not only are these groups and activities enjoyable, but they also help Alzheimer's and other memory loss patients to maintain their social skills and develop important friendships.

Family members also benefit greatly from having their loved one involved in such activities. The stresses and frustrations of coping with Alzheimer's more easily develop when persons and caregivers are confined together on a constant basis. As housekeeping, grocery shopping, and other important tasks often get backed-up with the demands of caregiving, caregiver stress or 'burn-out' can be high unless regular uninterrupted time can be found to keep up with such home and life demands.

There are many ways that patients and family members meet these very important needs. Many turn to extended family, friends, and religious groups for help, social involvement and support. Others reach out to various organizations in the community. (See Community Resource Page 30 under Alzheimer's Association and Family Caregiver Alliance.)

Legal/Financial Preparation

Alzheimer's disease and other types of dementia usually develop very slowly. However, illness, injury, or other events can sometimes hasten its progression. You should not delay making important preparations for the time when the person with dementia can no longer his or her own affairs. Life is unpredictable. Something could happen that could impair your ability to manage your own affairs or those of your loved one.

An attorney specializing in "elder law" may be able to provide many other suggestions and guide you in making choices most appropriate for you. However, an elder law attorney may be unavailable because it is a relatively new law specialty. Another option is to use an attorney who is knowledgeable in estate planning, wills, probate and Medi-Cal issues. If you would like a referral to an attorney who has an interest in elder law, please see page 34 for list of resources.

The following is a short list of legal issues you may need to consider.

Plan for Your Estate

Many of us feel that if we are not "millionaires" we do not have an "estate" that needs legal planning. However, if you own your own home or are buying one, if you have stocks, bonds, negotiable securities, a life insurance policy, or even a modest savings account, you may need to make advance preparations for the time when disability may overtake you or your family member. Consultation with a qualified attorney can help you better protect your assets for yourself and the person with dementia. It is important that you consult with your attorney as soon as possible.

Financial Planning

Regardless of the size or amount of your resources, you may want to consult with a certified financial planner. He or she can discuss important options with you to ensure that your future needs are properly met. Options may help you and the person with dementia to live more comfortably, safely, and happily should gradual changes in your health become especially burdensome. Consult with the Alzheimer's Association or the Professional Fiduciary Association of California.

Durable Powers of Attorney for Finance

A Power of Attorney (POA) for finance gives a person the legal authority to act on your behalf in the financial matters of your choice. A Power of Attorney may be limited to a single purpose such as the sale of a home or may be expanded to include additional matters. Most Power of Attorney forms can be found online and printed out, but they must be notarized to become effective. Another option is to have your attorney complete the documents for you.

It is also very important to keep careful records. A POA's performance as money manager is open to question from any other family member and the courts. Careful records of expenses (best if limited to only essential bills) can save them a great deal of embarrassment, cost, and even legal action if someone later wants an account of how the money has been spent. In fact, it is a good idea for the POA to enter all expenses into a financial ledger - complete with explanatory notes for any unusual expenses - to make sure that complete records and notes are always available to anyone who has questions.

Nomination of a Conservator

A conservator is someone who is given the authority to make financial and or health care decisions, under court supervision, when a person lacks the capacity to manage them on their own. A conservator might also be necessary if, as a caregiver, you someday become unable to continue caring for the person with dementia due to changes in your health or other unexpected problems of your own. It may be helpful for you to have previously designated a backup Power of Attorney for Health Care and a backup Power of Attorney for Finance who are willing, trusted, and able to assume the care of the person with dementia in your place, in order to avoid conservatorship. Conservatorship is often the last resort and may be required when patients need to be placed in care facilities against their will, if patients need to be medicated against their will, if patients do not have decision making capacity, or if there is family conflict.

Many people are unaware that in the state of California there is no 'legal-next-of-kin' - a person presumed and preferred over your other relatives to make your important medical decisions. Only if you are named as the Power of Attorney for Health and/or the Power of Attorney for Finance can you then legally act on behalf of the person with dementia. This becomes particularly important if there are family members you do not trust. If you currently have such concerns, you should discuss them thoroughly with your attorney and a financial planner to ensure your future interests and wishes are protected and honored.

The Public Guardian's Office is the county version of a conservator. Kaiser Permanente will refer patients to the Public Guardian's Office when there is nobody to act as a health care and financial decision maker for the patient. Involving the Public Guardian's office is the last resort.

Durable Power of Attorney for Health Care (Advance Healthcare Directive)

The person you wish to make medical choices for you can be legally authorized to speak for you, if you name him or her within a document called a "Durable Power of Attorney for Health Care." You can obtain a copy of a Durable Power of Attorney for Health Care (aka Advance Healthcare Directive) from your local Kaiser Permanente hospital, through the Member Services, Health Education, or Social Services Departments. The form is also available online at kp.org/lifecareplan.

A durable power of attorney for health care requires the signature of two witnesses or a notary. Thus, it does not cost you much to obtain and complete this particular form. The Durable Power of Attorney for Health Care is valid until it is revoked, and it can be changed as often as you want. Kaiser Permanente has a free program called Life Care Planning that will assist you in filling out this document and scanning it into the medical record. Contact **510-752-2349** to learn more about this program and to schedule a free consultation.

Another document you may soon encounter is the Physician Order for Life-Sustaining Treatment (POLST). The POLST document is designed to improve the quality of care people receive at the end of life and is based on effective communication of patient wishes. It is a standardized, portable, brightly colored pink single page form which documents a conversation between a doctor and a seriously ill patient or their surrogate decision-maker. The POLST document is a medical order and is always signed by the doctor, nurse practitioner, or a physician's assistant. It also must be signed by the patient or the patient's decision maker (who is not necessarily the Durable Power of Healthcare.) This form states the patient's preference for end-of-life care, including decisions regarding cardiopulmonary resuscitation, full treatment, selective interventions, or comfort focused care, and the use of artificial nutrition. This form is meant to travel

with the patient as he/she moves from one setting to another, conveying the patient's wishes to doctors, first responders, emergency rooms, hospitals, and nursing homes. The Kaiser Permanente Life Care Planning Department can help you complete a POLST form at no cost.

If you are chosen to make medical decisions for a person with dementia, it is very important that you spend some time talking with that person about his/her health care wishes. In this way, should there come a time when you are asked to make choices for the person with dementia, you can ensure his/her wishes are properly carried out. This discussion should include the kinds of medical treatment that he/she does want, as well as a discussion of what he/she does not want (for example, would the person with dementia want to be permanently fed by a tube if he or she becomes so mentally or physically incapacitated that he or she can no longer eat?). In this way you will be carrying out his/her wishes exactly as desired. The Kaiser Permanente Life Care Planning Department provides free assistance helping people with dementia and their caregivers explore and talk about their values and preferences for future health care.

Kaiser Permanente East Bay Life Care Planning Department

The Kaiser Permanente Life Care Planning Department offers free assistance from a nurse or social worker who will help you and your decision maker think about what type of medical support best honors the values and health care preferences of people living with dementia and other serious illnesses. The nurse or social worker will help create Durable Power of Attorney/Advance Healthcare Directive and POLST documents, if appropriate, and document these preferences for future health care in the medical record where they can be read by your care team.

Contact **510-752-2349** to learn more about this program and to schedule a free consultation.



Understanding the “Care Continuum”

In the health professions, we often speak of a “continuum of care.” This refers to those care systems that meet patient and family needs as one’s health condition changes over time, becoming either better or worse. Kaiser Permanente does not cover the cost of this care. For persons with Alzheimer’s disease, the continuum of care includes the following options:

In-Home Living Situations

Many people with Alzheimer’s can remain living in their own home for extended periods following diagnosis. If the person with dementia has available family members, particularly a spouse, or other extended family or community support, he/she may be able to receive most if not all of the needed care while continuing to live in his/her own home.

The first level of service needed is usually respite care for you and your family members, provided by extended family, private organizations, churches, or other programs found in the community as described in this booklet.

You may also need to hire in-home services for short periods each week, though you would still provide for most of the care. These support services can be obtained via bonded and licensed agencies that will contract with your family to provide both basic home and personal care services, as well as limited health care services. In this way, you and your family can receive the help you need, while the person with dementia remains at home. Please contact your Kaiser Permanente Social Work Department for a list of home care agencies.

Assisted Living /Residential Care Facility (Board and Care)

Sometimes the care of a person with Alzheimer's disease can become extremely difficult or even impossible to manage in the home. This is most likely to involve changes in sleep and activity patterns. People with Alzheimer's sometimes sleep very little, or only at odd moments, leaving those they love unable to obtain their own rest. They may also unexpectedly wander away from their homes quite easily - often while others are sleeping - and forget to tell others when and where they are going. They may then also forget how to return home.

In situations such as this, for the safety of the person with dementia and the well-being of loved ones, it may become necessary to live outside the home. Supervised living settings will provide care (activities of daily living) and have staff available around-the-clock to meet any changes in sleep and behavior needs of the person with dementia. Families can remain highly involved in the patient's life; taking the person with dementia home on weekends, out to dinner with family, and continuing to enjoy regular involvement with them. It is just a safer and less stressful living situation for the person with dementia and their loved ones. We encourage families to explore such living situations earlier rather than later, so that they can become familiar with all resources available well before any need arises.

Assisted living facilities are for people needing assistance with Activities of Daily Living (ADLs) but who wish to live as independently as possible for as long as possible. Assisted living facilities offer help with ADLs such as eating, bathing, dressing, laundry, housekeeping, and assistance with medications. Assisted living exists to bridge the gap between independent living and nursing homes. Residents in assisted living centers are not able to live by themselves but do not require constant care either. Assisted living is not an alternative to a nursing home, but an intermediate level of long-term care appropriate for many seniors. These facilities are licensed to care for more than six residents and are usually retirement complexes or specialty facilities.

The term residential care refers to a system of non-medical custodial care which can be provided in a single family residence, a retirement residence or in any appropriate care facility including a nursing home. More than 90% of the residential care homes are licensed for six or fewer residents housed in a private residential home setting; these homes are also called board and care homes.

For information, call the Kaiser Permanente Social Work Department at **510-752-6305**. Ask for the "New Lifestyles" booklet of Alameda County and Contra Costa County.

Nursing Home Settings

In the late stages of Alzheimer's disease, persons often come to require more extensive and expert health and medical care. Feeding, bathing, and other activities such as transportation to doctor's appointments may become overwhelming in the home, or even in an assisted living setting. Ongoing health changes may also require that a medical professional be regularly available to assess and meet the health and care requirements throughout the day. At this time, it is often essential that persons with Alzheimer's disease live in a skilled care setting - frequently in a specialty setting such as a dedicated "Alzheimer's or Memory Care Unit." There are several such settings in the greater Alameda and Contra Costa County area where these needs can be met.

California Advocates for Nursing Home Reform (CANHR) has updated information on nursing homes in Alameda and Contra Costa County, and their surrounding counties. They also have information on other topics related to nursing home placement. www.canhr.org

The California State Long-Term Care Ombudsman Program is authorized by the Federal Older Americans Act and its State companion, the Older Californians Act. The primary responsibility of the program is to investigate and endeavor to resolve complaints made by, or on behalf of, individual residents in long-term care facilities. These facilities include nursing homes, residential care facilities for the elderly, and assisted living facilities. The Long-Term Care Ombudsman Program investigates elder abuse complaints in long-term care facilities and in residential care facilities for the elderly. See page 36 under Community Resources.

Safety

Driving

Once someone has been diagnosed as having Alzheimer's disease or any other form of memory loss, California State Law requires that his/her physician notify the Department of Health. They in turn notify the Department of Motor Vehicles (DMV), and the person with dementia will be sent a medical questionnaire that his/her doctor must fill out. With this information, and possibly a driving or written test re-evaluation, the DMV will decide whether he/she may continue to drive. At times, this may mean that he/she can no longer drive.

Losing one's driving privilege can be a great hardship, but it is important to recognize that it is imperative that the person with dementia stop driving if the DMV says he/she must. If a person with dementia forgets or refuses to stop driving, here are some methods to prevent access to the car include: hiding the car keys, removing the car battery, selling the car, or moving it out of sight.

As Alzheimer's or any other form of dementia progresses, there will be visual-spatial changes, disorientation, changes in motor coordination and decreased judgment and concentration. It will become increasingly difficult for the person to remember to drive the correct speed, to use turn signals and mirrors, and to stop or go as the lights change. In emergencies that require a quick response (such as someone stopping too quickly), it is usually impossible to react in time. Failure to stop driving can cost his/her life and possibly the lives of others. It also opens the person with dementia up to enormous legal and financial liability. [See the Hartford "Safe Driving for a Lifetime, At the Crossroads" booklet, www.s0.hfdstatic.com/sites/the_hartford/files/cmme-crossroads.pdf]

There are numerous transportation options available in the Alameda and Contra Costa County areas. Call the Kaiser Permanente Social Work Department for a list of options and website references on page 28 of this book.

Home Hazards

People with Dementia can more safely live in their homes if certain measures are in place. As dementia progresses, a person's abilities change. With some creativity, problem solving, and a focus on prevention, you can adapt the home environment.

To reduce falls*:

- Ensure adequate lighting
- Provide visual cues
- Clear walking paths and remove throw rugs
- Avoid clutter
- Keep important things by the bed to reduce need to look for them in the dark
- Supply safe footwear
- Tack extension cords to the baseboards of a room to avoid tripping

*A fall prevention class is available, contact Health Education (see reference page)

To address wandering: (*Reference: Alzheimer's Association*)

- Plan activities/exercise that help reduce anxiety, agitation and restlessness
- Identify the most likely times of day that wandering may occur
- Reassure the person if she/he feels lost, abandoned or disoriented
- Ensure all basic needs are met
- Avoid busy places that are confusing and can cause disorientation
- Place locks out of the line of sight
- Use devices that signal when a door or window is opened
- Provide supervision
- Keep car keys out of sight
- Obtain the Alzheimer's Association Safe Return ID jewelry
[See www.alz.org/documents/national/brochure_masr_enrollment.pdf]

To reduce risk of fire: (*Reference: Alzheimers.org*)

- Ensure smoke alarms are in working order
- Purchase electric stove, rather than gas stove, or unplug stove
- Monitor cooking or remove knobs from stove if necessary
- Never allow the person to smoke in bed or unattended
- Buy fire retardant bedding and furniture
- Replace candles with flashlights, or purchase electric candles
- Remove portable space heaters

To reduce other risks:

- Remove guns and sharp kitchen utensils
- Remove or secure medications
- Secure ladders and step stools
- Set water to a comfortable temperature to reduce burn
- Consider disconnecting the garbage disposal
- Keep commonly used items within reach



Conclusion

After reading this short overview of Alzheimer’s disease and dementia, we hope that you and your family will better understand how to meet the many important needs that may arise over the course of this illness.

If the information in this booklet does not answer your questions or concerns about available community resources, medical care, how to manage in the home, or when to consider seeking outside help or living settings, please do not hesitate to call your doctor or Social Services Department.

*This booklet was originally funded by a grant from the Kaiser Permanente Interregional Committee on Aging and created in 2009 for South San Francisco area. It was edited by the Kaiser Permanente East Bay Dementia Workgroup in 2020 to include resources in the Alameda and Contra Costa County areas and current data.

Dementia Checklist

Items in BLUE* should be considered high priority and completed as soon as possible.

Diagnosis & Education

- Get the diagnosis
- Learn about dementia and what to expect as the disease progresses (see page 8)
- Learn about behavioral problems and how to navigate them (see page 10)
- Make sure to schedule follow-up primary care appointments every 3 to 6 months
 - Primary care doctor's name and contact info: _____

Planning for the Future

- *Ensure involved caregivers have permission to assess health care information
 - Get a Release of Information (ROI) signed so that providers can give you health care related information
 - Enable proxy access on kp.org for caregivers that need ability to communicate with providers and schedule appointments easier
- *Ensure you are informed and able to help honor wishes for future healthcare
 - Find and review any existing legal documents including Advance Directive or Durable Power of Attorney
 - Call Kaiser Permanente East Bay Life Care Planning Department at **510-752-2349** for help documenting future health care wishes (including assistance completing an Advance Directive or POLST)
 - Ensure Kaiser Permanente has scanned these documents into the medical record (provide instructions)
- *Ensure you have a trusted caregiver who can take care of your finances and assign a Durable Power of Attorney for Finance
 - Consult with an attorney to complete all the relevant legal documents for this to happen
- Begin planning for a time when home may no longer be a safe place to live
 - Call Kaiser Permanente East Bay Department of Social Work at **510-752-6305** (Oakland) or **510-307-2962** (Pinole/Richmond) when you are ready for help arranging in-home support and placement
- Schedule a driving test and make alternate transportation plans well in advance of when driving is no longer an option
 - Call Kaiser Permanente East Bay Department of Social Work at **510-752-6305** (Oakland) or **510-307-2962** (Pinole/Richmond) when you are ready for help securing alternate transportation
- Know where important papers are kept:
 - Deed to house
 - Automobile title
 - Loans
 - Tax records
 - Will/Trust
 - Attorney information
 - Insurance documents (all types - home, long term care, medical, etc.)

Dementia Checklist Continued

Safety

- *Assess home environment for safety hazards (see page 23)

Support & Resources

- Know the support and resources available to you (see pages 28 to 37)
 - Kaiser Permanente East Bay dementia support groups
 - Kaiser Permanente East Bay Health Education classes
 - Alzheimer's Association
 - Family & Caregiver Alliance
- Connect with a Kaiser Permanente East Bay social worker and learn what type of support and assistance they provide
 - Call Kaiser Permanente East Bay Department of Social Work at **510-752-6305** (Oakland) or **510-307-2962** (Pinole/Richmond)
- Make a list of people you can ask for help if you are a caregiver
 - Identify who could step in and help if you were ever unable to respond to an urgent caregiver issue
- Set aside time to take care of yourself—being a caregiver is hard work and you must stay physically and emotionally healthy to do this well

Financial Considerations

- Contact Social Worker on eligibility to public benefits
- Take inventory of money owed and when payments are due:
 - Monthly bills
 - Mortgages and liens
 - Auto loans
 - Credit card debt

Kaiser Permanente East Bay Resources

Family members also benefit greatly from having their loved one involved in such activities. The stresses and frustrations of coping with Alzheimer's more easily develop when persons and caregivers are cooped-up together on a constant basis. And, as housekeeping, grocery shopping, and other important tasks often get backed-up with the demands of caregiving, caregiver stress or 'burn-out' can be high unless regular uninterrupted time can be found to keep up with such home and life demands.

There are many ways that patients and family members meet these very important needs. Many turn to extended family, friends, and religious groups for help, social involvement and support. Others become involved with various organizations in the community.

Medical Social Work Services

Kaiser Permanente Oakland

510-752-6305

Kaiser Permanente Richmond & Pinole

510-307-2962

Our Kaiser Permanente Outpatient Social Workers offers counseling, information, resources and support to all our patients and their families who would benefit from guidance around the Dementia diagnosis and planning for your current and future needs. We are here to help you better understand your options on topics such as:

- Adult Day Care
- Advance Directives
- Applying for Medi-Cal
- Board & Care, Assisted Living and Skilled Nursing Facility Placement
- Conservatorship
- Home Safety Evaluation Resources
- In-Home Care
- Respite
- Support Group
- Transportation
- Utilities (PGE, water, phone services)

Nutritional Services

If you are worried about maintaining a healthy diet, our dietitian team may be able to help. Ask your doctor if a nutrition consultation is right for you and they can send a referral.

Health Education

Our Health Education Department offers a variety of classes to assist you with maintaining good health and managing health conditions. We also offer 1:1 health coaching with a skilled health educator to assist you improve your sleep, reduce stress, increase physical activity, quit smoking or eat better.

Contact your local Health Education Department to find out more about the classes and services which are right for you.

Health Education Centers-East Bay:

Oakland: 510-752-6150

Richmond: 510-307-2210

Pinole: 510-243-4020

Behavioral Medicine

Behavioral Medicine Clinic (BMC) offers people support around stress, anxiety, depression, grief, etc. We offer solution focused support and our sessions are 25 to 30 minutes long. On average we meet with people 1 to 6 times. If someone is needing more support than that, a referral to psychiatry is best.

What kind of health concerns are seen?

The BMC helps the patient reduce symptoms associated with various chronic medical conditions, and cope better with these conditions. A few of these are: headaches, insomnia, high blood pressure, asthma, diabetes, pain, and irritable bowel syndrome.

The BMC works with the primary care physician and the patient to develop behavioral change plans for lifestyle modifications. The BMC also helps develop skills to effectively manage emotional or behavioral difficulties such as anxiety, bereavement, depression, and stress.

Community Resources

AARP Prepare to Care: A Caregiving Planning Guide for Families

www.aarp.org/caregiving/prepare-to-care-planning-guide/ (printable resource)

1-877-333-5885 (request by mail)

Prepare to Care Resource Guides are designed to help develop and implement a caregiving plan for a loved one or friend. The guides include:

- Information on how to have vital conversations
- Ways to assess your loved one's needs
- Tips for organizing important documents
- A roundup of federal and national resources
- Information on caring for yourself
- Checklists, medication charts and contact lists

Languages: English, Spanish, Chinese

Area Agency on Aging provides senior information and resource referrals

Alameda: 1-800-510-2020

510-577-3530

Contra Costa: 925-229-8434

Alzheimer's Association

Northern California and Northern Nevada Chapter

3675 Mt. Diablo Blvd, Suite 250, Lafayette 94549

925-284-7942 or 1-800-272-3900

www.alz.org/norcal

The Alzheimer's Association is the leading voluntary health organization in Alzheimer care, support and research. Their mission is to eliminate Alzheimer's disease through the advancement of research, to provide and enhance care and support for all affected, and to reduce the risk of dementia through the promotion of brain health. The following services are provided:

- Education
- Support groups
- Referral service
- 24/7 Telephone Helpline at 1-800-272-3900
- MedicAlert and Safe Return programs
- Respite services
- Legal assistance and advocacy
- Membership

Family Caregiver Alliance (FCA)

180 Montgomery St, Suite 1100, San Francisco, CA 94104

415-434-3388 or 1-800-445-8106

www.caregiver.org

www.caregiver.org/family-care-navigator (state by state resource guide)

Family Caregiver Alliance was the first community-based nonprofit organization in the country to address the needs of families and friends providing long-term care at home. FCA now offers programs at national, state and local levels to support and sustain caregivers. Services provided include:

- Support groups
- Referrals for legal and financial services
- Respite care
- Social worker services
- Education and support
- Family consultation
- Referrals to therapists who specialize in working with dementia caregivers
- One time free legal consultation with qualified elder law attorney

Ethnic Elders Care Network

www.ethnicelderscare.net

A resource for caregivers of ethnic elders with Alzheimer's and related disorders that aims to improve access to care that is culturally appropriate. The Ethnic Elders Care Network provides articles and research, tips and advice, and links to additional resources.

Institute on Aging

415-750-4111

www.ioaging.org/services

For those with memory loss looking for compassionate advice and support to deal with their stressors, the Institute on Aging has a 24-hour toll-free Friendship line at 1-800-971-0016. This is an accredited crisis line in the country for people aged 60 and older. This allows for a daily ten-minute call where you can get compassionate advice and support to deal with your stressors. The Institute on Aging also has additional resources for home care, support services, social day programs, psychology and counselling services, community and living services, and more!

Adult Day Care/Adult Day Health Care Centers

These centers are designed to not only provide social and recreational services, but nursing care as well (especially for seriously incapacitated Alzheimer's persons who have special care needs), and various forms of therapy and restorative or maintenance treatments, where needed. It also allows for caregivers to receive a much-needed break from caregiving responsibilities.

They may be staffed with nurses, physical therapists, speech and occupational therapists and/or social workers, and often have activity directors and other staff to assist them. Consequently, they can be expensive. However, they can also provide important assistance when necessary. Under certain conditions, Medi-Cal may cover part or the total cost of adult day health care centers only. Many facilities also offer "sliding scale," or adjustable fees for service based upon your income. Therefore, if your funds are limited, you may want to discuss payment options further with the facilities themselves. The cost of adult day care, as of June 2020, \$50 per day, \$55 with transportation, \$66 with transportation and after care. The cost for adult day health care is \$120 per day, which includes breakfast, lunch, snacks and transportation.

Bay Area Community Services Adult Day Care Program

5714 Martin Luther King, Oakland 94609; 510-601-1074

10963 Grimmer Blvd, Fremont 94538

510-656-7742

www.Bayareacs.net/adult-day-programs

Alzheimer's Services of the East Bay Adult Day Health Care Program

2320 Channing Way, Berkeley 94704

510-644-8292

1105 Walpert St, Hayward 94541

510-888-1411

43326 Mission Circle, Fremont 94539

510-656-1329

www.aseb.org

Daybreak Adult Care Centers (formerly the Adult Day Services Network of Alameda County)

12 locations throughout Alameda County

Languages: Chinese, English, Spanish

510-834-8314

www.daybreakcenters.org

Family Bridges Hong Fook (2 locations)

14th St. Center, Oakland

275 14th St, Oakland 94612

510-839-9673

Harrison St. Center, Oakland

1388 Harrison St, Oakland 94612

510-302-0460

www.familybridges.org/hong-fook-cbas-centers/

Guardian Adult Day Health Care

3905 San Pablo Dam Rd., El Sobrante 94803;

510-669-1005

www.cei.elders.org/guardian-adult-day-health-center/

Diagnosis/ Assessment

Contact your primary care physician - he or she may set up a routine appointment or refer you to someone who specializes in diagnosis, assessment and treatment of individuals with dementia. If you are interested in clinical trials, visit:

www.clinicaltrials.gov/

www.alz.org/alzheimers-dementia/research_progress/clinical-trials

Dental Assistance

Referral Sources for dental care.

Alameda County Dental Society (resource for finding low-cost dental options)

510-547-7188

www.alamedacds.org

Berkeley Dental Society (referrals in Albany and Berkeley)

510-644-9800

www.berkeleyds.org

Blende Dental Group

Private pay for service dental care for patients who have special needs and also offers home dental care.

415-563-4261

www.blendedentalgroup.com

Life Long Medical Care

Provides health, dental and social services to low-income persons regardless of ability to pay.

510-981-4100

www.lifelongmedical.org

Emergency Response Services

Medical Alert Monitoring

In the event of a fall or an emergency, help is available at the push of a button. Medical Alert Monitoring Systems connects you to a trained associate who can send help quickly; 24 hours a day, seven days a week.

LifeStation

1-877-744-2389

www.lifestation.com

Vital Link

1-800-752-5522

www.vital-link.com

Medic Alert + Safe Return ID Bracelet

Alzheimer's Association

3675 Mt. Diablo Blvd, Suite 250, Lafayette 94549

925-284-7942

www.alz.org/help-support/caregiving/safety/medicalert-with-24-7-wandering-support

Friendly Visitors/Telephone Reassurance Programs

Provides non-emergency support calls for socially isolated seniors.

Alameda Friendly Visitors

510-748-0342

www.alamedamealsonwheels.org/about-afv.html

Covia, Well Connected or Social Call (formerly Senior Center Without Walls)

1-877-797-7299 (group activities & friendly conversation)

www.covia.org/services/well-connected/

Family Bridges (for socially-isolated Cantonese or Mandarin speaking seniors)

510-763-9017

www.familybridges.org/

J-Sei Friendly Visitors & Callers

510-654-4000, extension 13

www.j-sei.org/seniorservices/services/

Lavender Seniors of the East Bay (support for LGBTQ seniors)

510-736-5428

www.lavenderseniors.org/programs-services/

Senior Companion Program (Oakland seniors)

510-238-2987

In-Home Care

In Home Supportive Services (IHSS) Programs (for those who have Medi-Cal)

Alameda County: 510-577-1800

Contra Costa County: 510-231-8296

www.cdss.ca.gov/in-home-supportive-services

Private Duty Caregivers

Call the Kaiser Permanente Oakland Social Services Department at 510-752-6305 or Kaiser Richmond Social Services Department at 510-307-2962.

Ask for the "Home Care Resource Directory."

Legal Assistance

Alameda County Bar Association

510-302-2222

www.acbanet.org/

Bay Area Legal Aid

Eligibility: Low income Californians

Oakland: 510-250-5270;

Walnut Creek: 925-219-3325;

Toll-free: 800-551-5554

1-www.baylegal.org/

California Advocates for Nursing Home Reform (CANHR)

Referral service for legal services specializing in elder law issues, fact sheets and resources on elder abuse (including financial abuse).

415-974-5171

1-800-474-1116

www.canhr.org

East Bay Community Law Center

510-548-4040

www.ebclc.org/

Housing and Economic Rights Advocates (HERA)

Housing advocacy, financial and debt, consumer scams, estate planning, medical debt for low-moderate income Californians.

Languages: English, Chinese (Cantonese & Mandarin), Filipino, Korean, Russian, Spanish, Vietnamese

510-271-8443

www.heraca.org

Legal Assistance for Seniors

510-832-3040

www.lashicap.org/

Meals

Meals-on-Wheels Programs

Alameda residents: 510-865-6131

Albany residents: 510-524-9124

Berkeley residents: 510-981-5250

Contra Costa residents:

West County 510-412-0166

Central & East County 925-937-8607

Far East County 925-625-4545

Emeryville residents: 510-596-3730

Oakland residents: 510-460-5855

Project Open Hand

510-622-0221

www.openhand.org/get-meals/how-apply

Meals (Private Home Delivery Meal)

Mom's Meals Nourish Care Program

1-888-860-9424

Home on the Range Meals

510-452-1787

www.homeontherangemeals.com/

Ombudsman Program, California Department of Aging

Alameda County: 510-638-6878

Contra Costa County: 925-685-2070

[www.aging.ca.gov/Programs and Services/Long-Term Care Ombudsman/](http://www.aging.ca.gov/Programs_and_Services/Long-Term_Care_Ombudsman/)

Placement

If you or your loved one are seeking board and care, residential care, assisted living, or nursing home placement, contact the Kaiser Permanente Medical Social Work Department:

Oakland: 510-752-6305

Richmond: 510-307-2960

Protective Services

If you or your loved one has concern about elder abuse or neglect or self-neglect, contact the social worker or one of the services below.

Adult Protective Services

Alameda County: 510-577-1900

Contra Costa County: 1-877-839-4347

www.cdss.ca.gov/adult-protective-services

Aging and Adult Services

Alameda & Contra Costa County: 1-800-510-2020

www.aging.ca.gov/

Safety and Fall Prevention

Center for Independent Living

Berkeley: 510-841-4776

Oakland: 510-635-4920

Re-Cares

Provides redistributed wheelchairs, walkers, and other medical equipment for free.

510-251-2273 (Oakland)

www.recares.net

Mount Diablo Falls Prevention Program

Provides home safety evaluation and minor home safety repair if you meet criteria.

925-937-8311

Hartford "Safe Driving for a Lifetime, At the Crossroads" booklet

www.s0.hfdstatic.com/sites/the_hartford/files/cmme-crossroads.pdf

Support Groups

Oakland Kaiser Permanente

3801 Howe Street, Ground Floor, Room G-26, Oakland 94611

LoWanda Moore, MSW

510-752-7682

Open to members and non-members. Free.

Oakland Center for Spiritual Living Caregiver Support Group

Emotional and spiritual support group for those in a caregiving relationship with a loved one.
5000 Clarewood Drive, Oakland, CA 94618
510-986-1133
Language: English

West County Adult Day Care

1015 Nevin Ave, Ste 108, Richmond 94804 (across from Kaiser Permanente Richmond)
510-235-6276

Alternatively, call the Alzheimer's Association at 1-800-272-3900 or www.alz.org for support groups with locations or times more convenient for you.

Transportation

Paratransit

For persons with disabilities who cannot independently use regular AC Transit bus service some or all of the time. An application is required, and trips must be prearranged. Paratransit is a curb-to-curb service. Caregivers are able to ride as well.

East Bay Paratransit: 510-287-5040

Richmond Paratransit: 510-307-8027

*Talk to a Social Worker for alternate transportation options.

Veterans Services

Alameda County Veteran's Service Office: 510-577-1926

Contra Costa County Veterans' Service Office: 925-313-1481

Books and Videos

Books

1. Alzheimer's/Dementia Interactive Activity Books for Patients and Caregivers
2. Caregiver's Path to Compassionate Decision Making: Making Choices for Those Who Can't
3. Coping with Behavior Changes in Dementia: A Family's Caregiver Guide
4. The Mindful Caregiver
5. The 36-Hour Day

Videos

1. Alzheimer's Disease: a guide for Patient's families.
www.youtube.com/watch?v=olMjP2t5Xn4
2. Alzheimer's, the 36 hour day: the Complete Journey
Check your local library for a copy of this video in DVD.
3. Complaints of a Dutiful Daughter. DVD 1994; Film maker: Deborah Hoffman
4. Positive approach to care DVD's
Find at www.teepasnow.com

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