



KAISER PERMANENTE®

Where Do We Go From Here?

Dementia Information Booklet

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INTRODUCTION

This brief guide has been designed to help you consider some steps you may wish to take after first receiving the news that you or a loved one has Alzheimer's disease, or another similar diagnosis of dementia. It is written to include those who have been diagnosed very early on and who may wish to make certain preparations for their future. It also contains helpful suggestions for family members and others in your care.

As Alzheimer's disease is the most common type of dementia, 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 of value for anyone diagnosed with a dementia or memory-loss related diagnosis.

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 understand where to start in coping with this new and challenging situation in your life.

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 progressive, degenerative disease that attacks the brain, causing changes in brain function. While some people believe that Alzheimer's disease and dementia are two separate diseases, Alzheimer's is in fact the most common type of dementia. Other types of dementia include vascular, frontal temporal, and dementia with Lewy Bodies.

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 actually preserved for a while). Some common signs and symptoms of dementia are listed below. Not everyone who has dementia will have all of 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 you the same question over and over, each time forgetting that you've already given them 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.

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- **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 has to 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. Apathy is also a very common problem found with this disease, interfering not only with the person's motivation but also affecting concern for feelings of others.
- **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, however, 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 “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 like symptoms 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. These medical conditions should be treated as soon as possible.

Sometimes older people may be experiencing 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 associated with normal aging can sometimes present as difficulties with short term memory and/or mood changes. People often worry when

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these changes occur that they might be exhibiting the early signs of Alzheimer's disease. You should 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
Forgetting the names of people you rarely see	Forgetting the names of people close to you
Briefly forgetting part of an experience	Forgetting a recent experience
Occasionally not being able to find something	Not being able to find important things
Mood changes because of an appropriate cause	Having unpredictable mood changes
Changes in your interests	Decreased interest in outside activities
Usually able to follow spoken and written directions	Gradually unable to follow spoken or written directions

(Alzheimer's Association, 2008)

Types of Dementia

Dementia is generally classified according to its cause, in other words 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 life. 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, accounting for 50 to 70 percent of 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. At the same time 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.

Other types of dementia include vascular dementia, mixed dementia (a combination of Alzheimer's disease plus another dementia, typically vascular), and dementia with Lewy bodies. There are other types of dementia that are much less common than the above, such as frontotemporal and alcoholic or Wernicke – Korsakoff) syndrome. All types, however, cause memory loss, impaired thinking and behavioral problems. The table below summarizes the common characteristics of each type.

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Common Types of Dementia and Their Typical Characteristics

TYPE OF DEMENTIA	CHARACTERISTICS
Alzheimer's Disease	Most common type of dementia; accounts for 50-70 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)	Considered 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.
Dementia with Lewy Bodies	Pattern of decline may be similar to Alzheimer's, including problems with memory, judgment and behavior changes. Alertness and severity of cognitive symptoms may fluctuate daily. Visual hallucinations, muscle rigidity and tremors are common. Hallmarks include Lewy bodies that form inside nerve cells in the brain. 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.

(Alzheimer's Association, 2008)

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Important Medical Steps

If your doctor or health professional suggests that you or a family member may have Alzheimer's disease or another form of dementia, it is important for the diagnosis to be formally confirmed. He or she may begin treatment or refer the person to a neurologist or geriatric psychiatrist who specializes in diagnosing and treating different types of dementia, including Alzheimer's disease. Diagnosis of Alzheimer's disease is most often made in the moderate stage. To diagnose Alzheimer's disease, doctors use a series of mental status tests, lab tests and careful physical examination to evaluate thinking, behavior and physical function. Research has shown that a diagnosis of Alzheimer's disease can usually be made with 90% accuracy by these methods. Aside from a brain biopsy or autopsy, however, there is no single scale or definitive test that is 100% accurate.

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, and
- (4) gives individuals more time to plan for the future.

Another reason why diagnosis of dementia-like symptoms is important is because some of them can be reversed. Conditions such as depression, thyroid problems, drug side effects and interactions, alcohol use or abuse or certain vitamin deficiencies can affect memory and/or mood but can be treated.

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 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 education.

Hope Continues

While there is no cure for Alzheimer's disease, intensive research efforts are ongoing, and much money continues to be committed to finding a cure in the future. As a result, new medications are constantly being developed, investigated, and tested. For more information about current medications available for those with dementia, contact your doctor or healthcare professional.

Although no one can know for sure when a cure - or at least a way of slowing or stopping the progression of the disease - may be found, all who are affected by the illness can take comfort from the fact that these investigative efforts actively continue.

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PROGRESSION OF DEMENTIA

Because there are many different causes of dementia, it is difficult to predict its course. Generally, it is believed that the average life span from diagnosis to death is 8-10 years. It has been known to progress much more rapidly in some patients and last as long as 25 years in others.

During this time, as the thinking processes become more impaired, there is also 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	Short term memory loss Some word finding Loss of reasoning Judgment Calculation Overestimate skills May have awareness	Work Money/shopping Cooking Housekeeping Reading Writing Hobbies Medications
Moderate	Poor recent memory Remote memory is generally unaffected Language (names and paraphrases) Still social but confusion Orientation Visual/spatial ability	Needs help but often refuses Misplacing objects Getting lost Needs help in bathing/dressing and grooming Overwhelmed in large social situations Increase in apathy
Severe	Attention Difficulty performing familiar activities Poor language	Needs to be fed Incontinent of bowel/bladder Unable to walk Motor slowing

(Alzheimer's Association, 2008)

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, agitation and apathy. 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 manifestation of the disease.

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Medical and Psychological 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 overmedication, 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, if possible, any hearing or vision problems. 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 the sensation of thirst 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 for you to bring to the doctor's attention any suspicion you may have of a possible 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 and pain 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.

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Environmental Causes of Behavioral Problems

Excessive stimulation. When there is too much going on in the environment, such as music during a conversation or there are too many people around, some people with dementia may respond with anger or frustration. They may have reached a saturation point and may no longer have the ability 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 one of 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 change the furniture arrangements 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. When planning activities or modifying the physical environment to accommodate the special needs of a person with memory impairment, try to focus on familiar situations that the person is used to. For some people going to a restaurant or going on a trip may be terribly upsetting. For others, though, 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 that 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 by 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

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onset of the illness, such as washing and drying dishes, making beds, folding laundry, gardening, etc.

Psychiatric Causes

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 is ill. Often after treatment, the behavioral problem goes away. There are times, however, 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.

If medication management is indicated, 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.

COMMUNICATION

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.

Tips for Good Communication

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 to 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.

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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.

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. Find the answer that works the best and use it 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?"	"Your bath is ready. Here's your towel"
"Where do you think you're going this time of night? You can't leave by yourself!"	"Before you go, could you help me in the kitchen, I'm going to make some tea."

USING A SCRIPT

A script is a set of words that can be used when a situation repeats itself. It is an explanation, a phrase, a way of dealing with a problem. It has been found to decrease mistrust, lessen anxiety, and foster calm in both the patient and caregiver. It is called a script because the same words, phrases or sentences are repeated whenever the situation arises. It is repeated because "it works". Some examples of ways in which a script is used are:

1) **"What Am I Doing Here?"**

Mother was moved to a board and care home because she could no longer care for herself at home. She spends each Sunday with her daughter but as she leaves she says, "I'm going home tomorrow. Make my plane reservation". When her daughter would explain that she did not do well at home, her mother would get angry, saying "I'm fine. What are you talking about?"

The script: It's too late tonight. I'll call in the morning. I love you.

2) **"You Stole My Jam"**

Every time Tom would visit his mother she would accuse him of stealing her jam. He would respond, "No one is stealing your jam. Why would anyone want to steal your jam?" These statements only made the situation escalate, turning a pleasant visit into an argument.

The script: Are you almost out of jam? I'll pick some up for you in the morning and stop by.

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3) "I Want To Go Home"

Mr. Taylor would wake up in his own home in the middle of the night, pace in the living room, saying, "I want to go home. I need to go home." His wife would respond that this was their home and that they had lived there thirty years. This did not calm him and would often increase his agitation so that neither could sleep, leaving both exhausted.

The script: It's so late at night. Let's go to bed. We'll go home in the morning.

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.

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. Symptoms of caregiver stress are:

- Anger
- Social Withdrawal
- Anxiety
- Depression
- Exhaustion
- Sleeplessness/Insomnia
- Irritability
- Lack of Concentration
- Health Problems

LEGAL and 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 your loved one cannot manage his or her own affairs. Moreover, life is unpredictable. Something could happen that could impair your ability to manage your own affairs or those of your loved one.

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An attorney specializing in “elder law” may be able to provide many other suggestions and guide you in making choices most appropriate for you. 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 MediCal issues

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, even a life insurance policy, or just 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 such as a 'reverse mortgage', which can free up equity in your home to pay for future in-home support services, and early release of a life insurance policy's benefits (under certain conditions) may help you and the person with dementia to live more comfortably, safely, and happily should gradual changes in your health become especially burdensome.

Durable Powers of Attorney for Finance

A Power of Attorney 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. Your 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 you 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 decisions and handle financial affairs, 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,

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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 someone who is willing, trusted, and able to assume the care of the person with dementia in your absence.

Furthermore, should the person you are caring for become seriously mentally disabled in the future, it may become necessary for the courts to appoint someone to manage his or her legal and financial matters. If you have been nominated (or chosen) in advance, you can ensure that you will be appointed as conservator.

Many people are unaware that in the state of California you have no 'legal-next-of-kin' – a person presumed and preferred over your other relatives to make your important medical decisions. Only if you are legally nominated in advance is there a preferred – or designated – person to act on behalf of the person with dementia. This becomes particularly important if there are family members whom you do not trust. Should you now 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.

Durable Power of Attorney for Personal Care

Personal care decisions are decisions about your health care and medical treatment, nutrition, shelter, clothing, hygiene and safety. A power of attorney for personal care is a legal document in which you name a person to make decisions about your personal care when you become unable to make those decisions yourself. This is an option you may wish to discuss further with your attorney.

Durable Power of Attorney for Health Care

In 1990, the United States Congress passed the *Patient Self-Determination Act*. Put before the legislature by the public, this Act, among other things, requires your health care provider (Kaiser Permanente, for example) to inform you that you have the right to legally choose someone to speak for you in making your medical decisions, should you ever become unable to make medical choices yourself.

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”. As was noted earlier, in the state of California you do not have a 'legal-next-of-kin' while you are living. This means that your spouse or adult child, for example, could request or refuse certain kinds of medical treatment he or she felt was in your best interest. But if another relative – even a distant one – disagreed with your spouse or child, that other relative must be recognized by your doctor and the courts as having equal interest in trying to make these medical decisions for you. Therefore, if the person with dementia wants to have someone he or she trusts making these decisions – he/she would need to appoint that person as his/her decision-maker in a “Durable Power of Attorney for Health Care” or “[Health Care Directive](#).”

You can obtain a copy of a Durable Power of Attorney for Health Care from your local Kaiser Permanente hospital, through the Member Services, Health Education, or Social Services departments. The form is also available online at www.kp.org (choose Northern California for region, and the use search terms “Advance Directive”). A

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durable power of attorney for health care requires the signature of two witnesses or a notary. Thus, it can cost you nothing to obtain and complete this particular durable power of attorney 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.

POLST (Physician Order for Life-Sustaining Treatment)

The POLST is an approach to improving end-of-life care. The POLST document 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. It is a medical order and is always signed by the doctor. This form states the patient's preference for end-of-life care, including decisions regarding cardiopulmonary resuscitation, limited or full treatment, and the use of artificial nutrition and hydration.

This form is meant to travel with the patient as he/she moves from one setting to another, conveying the patient's wishes through the continuum. It is meant to be respected by doctors, first responders, emergency rooms, hospitals, and nursing homes.

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. Respite means getting a break and it can be provided by extended family, private organizations, churches. It can also be provided by home care agencies, Adult Day Healthcare Centers, assisted living facilities or nursing homes.

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.

Dementia Information Booklet

Assisted Living Facilities, Board & Care Homes & Residential Care Facilities

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 move the person with dementia to an assisted living facility or Board & Care. Supervised living settings will provide care (activities of daily living) and have staff available around-the-clock to meet any changes in the behavioral needs of the person with dementia, including changes in sleep. 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 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 facilities offer help with ADLs such as eating, bathing, dressing, laundry, housekeeping, and assistance with medications. 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 long term 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.

Skilled Nursing Home Settings

In the late stages of Alzheimer's disease, persons often 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. The person's care needs may become more than an assisted living facility or the family can provide and at this time, nursing home care is needed. Long term nursing home care can be private pay or a Medi-Cal benefit, depending on the person's finances.

Dementia Information Booklet

California Advocates for Nursing Home Reform (CANHR) has updated information on nursing homes in the East Bay. They also have information on other topics related to nursing home placement including Medi-Cal.

ADULT 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 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, 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.

AND FINALLY

Terminal Stage and End of Life Care

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 bedbound. 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 one time. Repeated infections are also common. These infections are not always preventable and may not get better with antibiotics.

Dementia Information Booklet

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 medical treatment for the person in their care. One of the most common decisions is whether to use a feeding tube when the person can no longer chew and swallow food. There is no good evidence to demonstrate that feeding tubes prolong life nor improve quality of life in the person with end-stage dementia. Some families, however, wish to have the patients fed by this means. 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 be of assistance 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, providing 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)

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, please do not hesitate to call your doctor or any other member of the health care team.