Dementia: Where Do We Go From Here?
# TABLE OF CONTENTS

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Introduction</td>
<td>3</td>
</tr>
<tr>
<td>Facts About Dementia</td>
<td>3</td>
</tr>
<tr>
<td>Types of Dementia</td>
<td>5</td>
</tr>
<tr>
<td>Important Medical Steps</td>
<td>7</td>
</tr>
<tr>
<td>You Are Not Alone</td>
<td>8</td>
</tr>
<tr>
<td>Hope Continues</td>
<td>8</td>
</tr>
<tr>
<td>Progression of Dementia</td>
<td>8</td>
</tr>
<tr>
<td>Understanding Behavioral Problems</td>
<td>9</td>
</tr>
<tr>
<td>Medical and Psychological Causes of Behavioral Problems</td>
<td>10</td>
</tr>
<tr>
<td>Environmental Causes of Behavioral Problems</td>
<td>11</td>
</tr>
<tr>
<td>Task-Related Causes</td>
<td>11</td>
</tr>
<tr>
<td>Psychiatric Causes</td>
<td>12</td>
</tr>
<tr>
<td>Communication</td>
<td>12</td>
</tr>
<tr>
<td>Tips for Good Communication</td>
<td>13</td>
</tr>
<tr>
<td>Using a Script</td>
<td>14</td>
</tr>
<tr>
<td>Caregiver Stress</td>
<td>15</td>
</tr>
<tr>
<td>Legal/Financial Preparation</td>
<td>15</td>
</tr>
<tr>
<td>Plan for Your Estate</td>
<td>16</td>
</tr>
<tr>
<td>Financial Planning</td>
<td>16</td>
</tr>
<tr>
<td>Durable Powers of Attorney for Finances</td>
<td>16</td>
</tr>
<tr>
<td>Nomination of a Conservator</td>
<td>17</td>
</tr>
<tr>
<td>Durable Power of Attorney for Personal Care</td>
<td>17</td>
</tr>
<tr>
<td>Durable Power of Attorney for Health Care</td>
<td>17</td>
</tr>
<tr>
<td>Understanding the &quot;Care Continuum&quot;</td>
<td>18</td>
</tr>
<tr>
<td>In-Home Living Situations</td>
<td>18</td>
</tr>
<tr>
<td>Assisted Living Setting</td>
<td>19</td>
</tr>
<tr>
<td>Skilled Nursing Home Setting</td>
<td>19</td>
</tr>
<tr>
<td>Adult Driving</td>
<td>20</td>
</tr>
<tr>
<td>Conclusion</td>
<td>20</td>
</tr>
<tr>
<td>Community Resources</td>
<td>22</td>
</tr>
<tr>
<td>References</td>
<td>27</td>
</tr>
</tbody>
</table>
Dementia: Where Do We Go From Here?

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.

- **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
Dementia: Where Do We Go From Here?

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 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.

<table>
<thead>
<tr>
<th>Normal Aging</th>
<th>Early Signs of Alzheimer’s</th>
</tr>
</thead>
<tbody>
<tr>
<td>Forgetting the names of people you rarely see</td>
<td>Forgetting the names of people close to you</td>
</tr>
<tr>
<td>Briefly forgetting part of an experience</td>
<td>Forgetting a recent experience</td>
</tr>
<tr>
<td>Occasionally not being able to find something</td>
<td>Not being able to find important things</td>
</tr>
<tr>
<td>Mood changes because of an appropriate cause</td>
<td>Having unpredictable mood changes</td>
</tr>
<tr>
<td>Changes in your interests</td>
<td>Decreased interest in outside activities</td>
</tr>
<tr>
<td>Usually able to follow spoken and written directions</td>
<td>Gradually unable to follow spoken or written directions</td>
</tr>
</tbody>
</table>

(Alzheimer’s Association, 2008)

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 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.

Common Types of Dementia and Their Typical Characteristics
<table>
<thead>
<tr>
<th>TYPE OF DEMENTIA</th>
<th>CHARACTERISTICS</th>
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<tbody>
<tr>
<td>Alzheimer's Disease</td>
<td>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.</td>
</tr>
<tr>
<td>Vascular Dementia (also known as multi-infarct or post-stroke dementia or vascular cognitive impairment)</td>
<td>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.</td>
</tr>
<tr>
<td>Mixed Dementia</td>
<td>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.</td>
</tr>
<tr>
<td>Dementia with Lewy Bodies</td>
<td>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.</td>
</tr>
<tr>
<td>Frontotemporal Dementia</td>
<td>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.</td>
</tr>
</tbody>
</table>

(Alzheimer's Association, 2008)
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 future².

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.
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.

<table>
<thead>
<tr>
<th>Stage of Dementia</th>
<th>Problems with Thinking</th>
<th>Problems with Daily Functioning</th>
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<tbody>
<tr>
<td>Mild</td>
<td>Recall/learning</td>
<td>Work</td>
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<tr>
<td></td>
<td>Word finding</td>
<td>Money/shopping</td>
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<tr>
<td></td>
<td>Problem solving</td>
<td>Cooking</td>
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<tr>
<td></td>
<td>Judgment</td>
<td>Housekeeping</td>
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<tr>
<td></td>
<td>Calculation</td>
<td>Reading</td>
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<td></td>
<td></td>
<td>Writing</td>
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<td></td>
<td></td>
<td>Hobbies</td>
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<td></td>
<td></td>
<td>Medications</td>
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<tr>
<td>Moderate</td>
<td>Recent memory</td>
<td>Misplacing objects</td>
</tr>
<tr>
<td></td>
<td>Remote memory is</td>
<td>Getting lost</td>
</tr>
<tr>
<td></td>
<td>generally unaffected</td>
<td>Bathing</td>
</tr>
<tr>
<td></td>
<td>Language (names and</td>
<td>Grooming</td>
</tr>
<tr>
<td></td>
<td>paraphrases)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Insight</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Orientation</td>
<td></td>
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<tr>
<td></td>
<td>Visual/spatial ability</td>
<td></td>
</tr>
<tr>
<td>Severe</td>
<td>Attention</td>
<td>Eating</td>
</tr>
<tr>
<td></td>
<td>Difficulty performing</td>
<td>Continence</td>
</tr>
<tr>
<td></td>
<td>familiar activities</td>
<td>Walking</td>
</tr>
<tr>
<td></td>
<td>Language</td>
<td>Motor slowing</td>
</tr>
</tbody>
</table>

(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.

**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
Dementia:
Where Do We Go From Here?

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. 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.
Dementia: Where Do We Go From Here?

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.

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.

**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:

<table>
<thead>
<tr>
<th>Instead of saying...</th>
<th>Try saying...</th>
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<tbody>
<tr>
<td>“You can't call your Mom. She's been dead for years!”</td>
<td>“I'm sure she's not home right now. Let's call her later.”</td>
</tr>
<tr>
<td>“I just told you! Your appointment is at 2:00!”</td>
<td>“Don't worry. I'm going too, and I won't leave without you.”</td>
</tr>
<tr>
<td>“Do you want to take your bath now?”</td>
<td>“Your bath is ready. Here's your towel”</td>
</tr>
<tr>
<td>“Where do you think you're going this time of night? You can't leave by yourself!”</td>
<td>“Before you go, could you help me in the kitchen, I'm going to make some tea.”</td>
</tr>
</tbody>
</table>

**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.

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: ²

- Anger
- Social Withdrawal
- Anxiety
- Depression
- Exhaustion
- Sleeplessness/Insomnia
- Irritability
Dementia: Where Do We Go From Here?

- Lack of Concentration
- Health Problems

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 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.

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. If you would like a referral to an attorney who has an interest in elder law, please see page 24 of this booklet for 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, 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, 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, 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 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 “Durable Power of Attorney” or “Advance Directive”). A 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.

Another document you may soon encounter is the Physician Order for Life-Sustaining Treatment (POLST). This relatively new program is designed to improve the quality of care people receive at the end of life and is based on effective communication of patient wishes.

One final comment: if you are chosen to make medical decisions for a person with dementia, it is very important that you spend some time talking 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 know his/her wishes and properly carry them 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 Durable Power of Attorney for Health Care is valid until it is revoked and it can be changed as often as you want.

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 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 providers 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. Please see the Community Resources section of this booklet for information and listings of these agencies.

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 behavior 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.

For information on long term care options, call the social services department (415-833-3530) at Kaiser San Francisco. Ask for the "Lifestyles" booklet of San Francisco which is a guide senior housing and care.

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.

California Advocates for Nursing Home Reform (CANHR) has updated information on nursing homes in San Francisco and surrounding counties. 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. There are numerous transportation options available in the San Francisco area. Call the Kaiser San Francisco Social Services Department for more information.

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.

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 other 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, the social services department or any other member of the health care team.
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.

**KAISER RESOURCES**

**Information/ Support Group for Caregivers of Patients with Memory Loss/ Dementia - 2 Sessions**

Kaiser San Francisco offers an information/support group for caregivers and family members of patients with dementia. The group consists of two 2 hour sessions with a geriatric clinical nurse specialist and a social worker. The group is offered every other month on the second and third Wednesdays of the month at 4141 Geary Blvd - French campus – 3 – 5 PM. This group is designed to give caregivers comprehensive information regarding the disease process, behavior management strategies and the importance of caring for oneself. For information or to register for the sessions call Marilyn Williams at 415-833-4486.

**Advance Directive Workshop**

Advance Directive workshops are held on the first Friday of each month at 2238 Geary Blvd., 8th fl Topaz Room, from 11 a.m.– 12:30 p.m. Forms are available at this workshop. Copies can be obtained from a social worker, discharge planner, or case manager, or from the Health Education Department at 2241 Geary Blvd.

Call 415-833-2430 for more information.

**Alzheimer's Association**

Northern California and Northern Nevada Chapter
1060 La Avenida Street
Mountain View, CA 94043
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
- MedicAlert and Safe Return programs
- Respite services
- Legal assistance and advocacy
- Membership

Family Caregiver Alliance (FCA)
785 Market Street Suite 750
San Francisco, CA 94103
(415) 434-3388 or (800) 445-8106
http://www.caregiver.org
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

Adult Day Care/ Adult Day Health 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.

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 all of the cost. Many facilities also offer “sliding scale”, or adjustable fees for service based upon your income (frequently ranging from $35 to $60 per day). Therefore, if your funds are limited and yet your care needs are complicated, you may want to discuss payment options further with the facilities themselves.

Referral Phone Number for ADHC SF: 415-355-6700
Hospice

Hospice is a very individualized, special form of care for people who have been diagnosed with a terminal illness. It is usually provided in the home, and the focus is on comfort rather than on trying to cure an illness. Hospice provides physical, emotional, and spiritual comfort, but also gives support to caregivers and family.

Kaiser Permanente Hospice Programs
San Francisco and South San Francisco
(415) 833-3655

Legal/ Financial Assistance

California Advocates for Nursing Home Reform (CANHR)
650 Harrison Street, 2nd Floor
San Francisco, CA 94107
(415) 974-5171 or (800) 474-1116
http://www.canhr.org

State Bar of California
Lawyer Referral Services Program (LRS)
180 Howard Street
San Francisco, CA 94105
Phone: 415-538-2250 or 1-866-442-2529
http://www.calbar.ca.gov
e-mail: LRS@calbar.ca.gov

Lawyer Referral and Information Services (LRIS) and Volunteer Legal Services Program (VLSP) of the Bar Association of San Francisco
301 Battery Street, 3rd Floor
San Francisco, CA 94111
415-989-1616

Legal Assistance for the Elderly, Inc.
995 Market Street
San Francisco, CA 94103
415-538-3333

Meals

Meals On Wheels of San Francisco, Inc.
1375 Fairfax Avenue
San Francisco, CA 94124
Telephone: (415) 920-1111
Dementia: Where Do We Go From Here?

Meals-on-Wheels of San Mateo
36 37th Avenue
San Mateo, CA 94403
(650) 295-2173

Protective Services
Adult Protective Services
City and County of San Francisco
Human Services Agency
415-355-6700
1-800-814-0009

Aging and Adult Services
County of San Mateo
TIES Line (24-hour emergency response)
1-800-675-8437
http://www.smhealth.org

Ombudsman Program, California Department of Aging
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.

San Francisco Long-Term Care Ombudsman Program
6221 Geary Blvd., Second Floor
San Francisco, CA 94121
C/O Family Services Agency of San Francisco
(415) 751-9788

Ombudsman Services of San Mateo, Inc.
1-800-675-8437
http://www.aging.ca.gov/programs/ombudsman_contacts.asp

Respite
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 in outside 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.

**Alzheimer's Association**
1060 La Avenida Street
Mountain View, CA 94043
650-962-8111
1-800-272-3900
www.alz.org/norcal

**Family Caregiver Alliance (FCA)**
785 Market Street, Suite 750
San Francisco, CA 94103
(415) 434-3388 or (800) 445-8106
http://www.caregiver.org

**Telephone Help Line (24 hours)**

**Alzheimer's Association**: 1-800-272-3900 (for advice, support and referrals)
REFERENCES


WEBSITES

Family Caregiver Alliance: caregiver.org

Alzheimer's Association: alz.org/norcal

Alzheimer's Store: alzstore.com

FILM

Complaints of a Dutiful Daughter: DVD 1994; Filmmaker: Deborah Hoffman
# Dementia: Where Do We Go From Here?

## Caregiver Checklist

<table>
<thead>
<tr>
<th>TASK</th>
<th>DATE</th>
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<tbody>
<tr>
<td>A. Get the diagnosis</td>
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<td>B. Understand the diagnosis</td>
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<tr>
<td>C. Obtain Advance Directive Paperwork</td>
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<tr>
<td>D. Complete an Advance Directive:</td>
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<tr>
<td>a. Patient wishes</td>
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<td>b. Durable Power of Attorney for Health Care</td>
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<tr>
<td>E. Give to a health care provider to have scanned into Health Connect</td>
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<td>F. Complete a POLST</td>
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<tr>
<td>G. Get a Release of Information (ROI) signed by patient so that provider can give you health care related information</td>
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<tr>
<td>H. Consult with physician to find out patient’s medication list and work simplify when possible</td>
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<tr>
<td>I. Create an electronic copy of “Current Medications” so it can easily be updated</td>
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<td>J. Know support resources for getting more information</td>
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<tr>
<td>a. Informational/Support Groups for Caregivers of Persons with Dementia – See page</td>
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<tr>
<td>b. Kaiser classes and ongoing support groups – See page</td>
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<tr>
<td>c. Family Caregiver Alliance – See page</td>
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<tr>
<td>d. Alzheimer’s Association – See page</td>
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<tr>
<td>K. Connect with Social Worker or Case Manager associated with patient’s MD</td>
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<tr>
<td>L. Make list of whom you can ask for help</td>
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<tr>
<td>M. Become aware of finances of patient</td>
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<tr>
<td>a. Bank accounts: Savings and Checking</td>
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<td>b. Social Security income</td>
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<tr>
<td>c. Pension income</td>
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<tr>
<td>d. IRA’s, Annuities, Bond, Stock, Real estate</td>
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<tr>
<td>e. Insurance policies</td>
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<tr>
<td>f. Key for the safe deposit box</td>
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<tr>
<td>N. Know where important papers are kept:</td>
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<tr>
<td>a. Deed to house</td>
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<tr>
<td>b. Automobile title</td>
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<tr>
<td>c. Loans</td>
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<tr>
<td>d. Tax records</td>
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<td>O. Inventory of money owed:</td>
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<tr>
<td>a. Monthly bills</td>
<td></td>
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<tr>
<td>b. Mortgages including liens</td>
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<tr>
<td>c. Home loans</td>
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<tr>
<td>d. Auto loans</td>
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<tr>
<td>e. Credit card debt</td>
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<tr>
<td>P. Identify alternative family member who can handle any of the above pertinent information</td>
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<tr>
<td>Q. Obtain resource when home is no longer a safe place to live</td>
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</tbody>
</table>