Dementia:
Where do we go from here?

As we continue to age, the likelihood we will develop dementia increases. Although typically associated with aging, dementia can occur in middle age and occasionally in the fairly young. Currently, approximately 5 million individuals in the United States are afflicted with Alzheimer's disease or another type of dementia.

Most individuals with dementia 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 that are available in our community. The important thing to remember is that you are not alone. There are numerous places to go for help, advice, and education.

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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, fronto-temporal, dementia with Lewy Bodies, and other less common ones. Dementia causes many problems for the afflicted individual, as well as for their 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 rates.[1]

- **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 and 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, and 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.

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 to 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. Not everyone experiences the same symptoms but there is a general idea of how abilities change during the course of the disease. The stages of Alzheimer’s dementia as described by Dr. Reisberg of NYU are described below:[1]

Mild or early-stage Alzheimer's disease: at this point, a careful medical interview should be able to detect clear-cut symptoms in several areas:

- Forgetfulness of recent events
- Impaired ability to perform challenging mental arithmetic — for example, counting backward from 100 by 7s
- Greater difficulty performing complex tasks, such as planning dinner for guests, paying bills or managing finances
- Forgetfulness about one's own personal history
- Becoming moody or withdrawn, especially in socially or mentally challenging situations

Moderate or mid-stage Alzheimer's disease: gaps in memory and thinking are noticeable, and individuals begin to need help with day-to-day activities. At this stage, those with Alzheimer's may:

- Be unable to recall their own address or telephone number or the high school or college from which they graduated
- Become confused about where they are or what day it is
- Have trouble with less challenging mental arithmetic; such as counting backward from 40 by subtracting 4s or from 20 by 2s
- Need help choosing proper clothing for the season or the occasion
- Still remember significant details about themselves and their family
- Still require no assistance with eating or using the toilet

Moderately severe or mid-stage Alzheimer's disease: memory continues to worsen, personality changes may take place and individuals need extensive help with daily activities. At this stage, individuals may:

- Lose awareness of recent experiences as well as of their surroundings
- Remember their own name but have difficulty with their personal history
- Distinguish familiar and unfamiliar faces but have trouble remembering the name of a spouse or caregiver
- Need help dressing properly and may, without supervision, make mistakes such as putting pajamas over daytime clothes or shoes on the wrong feet

- Experience major changes in sleep patterns — sleeping during the day and becoming restless at night
- Need help handling details of toileting (for example, flushing the toilet, wiping or disposing of tissue properly)
- Have increasingly frequent trouble controlling their bladder or bowels
- Experience major personality and behavioral changes, including suspiciousness and delusions (such as believing that their caregiver is an impostor) or compulsive, repetitive behavior like hand-wringing or tissue shredding
- Tend to wander or become lost

Severe or late-stage Alzheimer's disease: in the final stage of this disease, individuals lose the ability to respond to their environment, to carry on a conversation and, eventually, to control movement. They may still say words or phrases.

At this stage, individuals need help with much of their daily personal care, including eating or using the toilet. They may also lose the ability to smile, to sit without support and to hold their heads up. Reflexes become abnormal. Muscles grow rigid. Swallowing becomes impaired.

Terminal Stage and End of Life Care

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.

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 or 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.

It is always helpful to discuss the issue of interventions with the person with dementia at an early state in the illness. 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.

Hope Continues

While there is no cure for dementia, intensive research efforts are ongoing, and significant amounts of money continue to be committed to finding a cure in the future. As a result, new medications are constantly being developed, investigated, and tested. 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.

If you or your loved one would like to participate in clinical trial, let us know. We have partnered with a few organizations such as UCSF. There are also numerous other clinical trials, email trialmatch@alz.org or call 800-272-3900 for more information.

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 in making important preparations for the time when your loved one can no longer 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.

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 wealthy 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. 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 Power 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 become unable to continue caring for the person with dementia due to changes in your health or other unexpected problems of your own someday. 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 wish to entrust with these responsibilities. Should you have any 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 on your own.

As was noted earlier, in the state of California you do not have a 'legal next-of-kin' while you are living so the person you wish to be legally authorized to make medical choices and to speak on your behalf must be explicitly named within a document called a “Durable Power of Attorney for Health Care.” 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 an 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 or she would need to appoint that person as his or her decision-maker in a “Durable Power of Attorney for Heath Care” or “Health Care Directive.”

There is a copy of a Durable Power of Attorney for Health Care in this handbook (see plastic sleeve). A durable power of attorney for health care requires the signature of two witnesses or a notary. Thus, it does not cost you anything to obtain and complete this particular durable power of attorney form.

Finally, 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 or 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 will know his or her wishes and can 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.

Another document you may soon encounter is the Physician Order for Life-Sustaining Treatment (POLST). This form clearly states what medical treatments a patient would want at the end of their life. It is a signed medical order by a physician with directions regarding patient's specific wishes about certain types of medical treatment. It includes the patient's desire to have or refuse CPR, to be taken to a hospital, and whether to receive artificial nutrition. A POLST is printed on bright pink paper and is signed by both the patient and physician. A POLST allows patients to make their treatment wishes known to family, emergency personnel, and healthcare providers. It goes with you to your home, hospital, or care facility. In this scenario, it is best to have both an Advanced Healthcare Directive and a POLST.

Persons who desire, less than heroic, life support efforts in the face of a medical emergency should complete a POLST form. We have a physician and/ or a licensed clinical social worker who can help you through the process of completing a POLST. A copy of your completed POLST form will be put into your electronic medical record so you can feel confident that your wishes will be known and honored.

If you would like assistance completing any of the above documents, please call our Life Care Planning department at (707) 393-4482.

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 or 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 or her doctor must fill out. With this information, and possibly a driving or written test re-evaluation, the DMV will decide whether he or she may continue to drive. At times, this may mean that he or 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 for the person with dementia stop driving if the DMV says he or 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. It also opens the person with dementia up to enormous legal and financial liability. There are some transportation options available in the Sonoma County. Please look at the Senior Resource Guide for more information.

UNDERSTANDING BEHAVIORAL PROBLEMS

Because of damage to the brain associated with dementia, there can be a number of accompanying behavioral problems. 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 behavioral 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 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 the risk of falls.

Impaired vision or hearing

Both these problems can affect a person's ability to understand what is being said. If possible, it is important to see a doctor to correct any hearing or vision problems. If caregivers are aware of these deficits, they can often help the person compensate for them.

Acute illness

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.

Fatigue

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

Physical discomfort and pain

The patient may exhibit with 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.

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. Was there 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 if 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 items in 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

A new or unfamiliar environment 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 is 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

Behavioral problems can often 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.
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:

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 has been found to decrease mistrust, lessen anxiety, and foster calmness 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 dementia can be stressful. Too much stress can be damaging to both the caregiver and the person with dementia. If you feel overwhelmed and are neglecting your own physical, mental and emotional well-being, you may be putting your own health 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]

- **Denial** about the disease and its effect on the person who has been diagnosed.
  ”I know Mom is going to get better.”
- **Anger** at the person with Alzheimer's, anger that no cure exists or anger that people don't understand what's happening.
  ”If he asks me that one more time I'll scream!”
- **Social withdrawal** from friends and activities that once brought pleasure.
  ”I don't care about getting together with the neighbors anymore.”
- **Anxiety** about the future.
  “What happens when he needs more care than I can provide?
- **Depression** that begins to break your spirit and affects your ability to cope.
  “I don't care anymore.”
- **Exhaustion** that makes it nearly impossible to complete necessary daily tasks.
  “I'm too tired for this.”
- **Sleeplessness** caused by a never-ending list of concerns.
  “What if she wanders out of the house or falls and hurts herself?”
- **Irritability** that leads to moodiness and triggers negative responses and actions.
  “Leave me alone!”
- **Lack of concentration** that makes it difficult to perform familiar tasks.
  “I was so busy, I forgot we had an appointment.”
- **Health problems** that begin to take a mental and physical toll.
  “I can't remember the last time I felt good.”

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

There are many ways that patients and family members meet these very important needs. Many turn to extended family, friends, and religious groups for help, social involvement and support. Others become involved with various organizations in the community, such as the Alzheimer’s Association, Redwood Caregiver Resource Center, Catholic Charities, and Council on Aging.

Kaiser Permanente Dementia Care Program
We have various educational programs throughout the year that will provide you tips on how to provide better care for your loved ones. Please check with the staff regularly for specific programs and when they’ll be offered. Review the first few pages of this handbook for a description of our current program.

Caregivers Support Group

There are several caregiver support groups available in Sonoma County. Read the next pages for location/time.

We have included fact sheets from the the Redwood Caregiver Resource Center that most caregivers found helpful.

REDWOOD
caregiver resource center

Support Groups (as of 2/2019)

SONOMA COUNTY

+Share & Care
2nd & 4th Thursday
10 am – 12 noon
Catholic Charities
987 Airway Court
Santa Rosa, CA 95403
Facilitated by:
Connie Lorenz, LCSW

First Presbyterian
Faith-based Support Group
2nd Thursday
6:00 PM – 7:30 PM
Santa Rosa First Presbyterian Church
1550 Pacific Avenue
Santa Rosa, CA 95404
Facilitated by:
Alexis Glidewell, LCSW

+Caregiver Express
2nd & 4th Tuesday
1:30 PM – 3 PM
Petaluma People
Services Center
25 Howard Street
Petaluma, CA 94952
Facilitated by:
Petaluma People Services Center for Redwood CRC

+Russian River Support Group
1st Tuesday
1 pm – 3 pm
Russian River Sr. Resource Ctr / Marshall House
15010 Armstrong Woods Road
Guerneville, CA 95446
Facilitated By:
Maisie Hak, MSW

+Huntington's Disease Support Group

2nd Monday
6:30pm – 8:00 pm
Redwood Caregiver Resource Center
1140 Sonoma Ave., Ste 1 B
Santa Rosa, CA 95405
Facilitated by:
Lana Reuter, LMFT

These groups are funded in part by our partnership with
+Sonoma County Area Agency on Aging / Family Caregiver Support Program

LAKE & MENDOCINO COUNTIES:

***Clearlake Support Group**
2nd & 4th Wednesday
9:30 AM – 11 AM
St. John's Lutheran Church
14310 Memory Drive (off Olympic)
Clearlake, CA 95422
Respite provided, on-site
Call prior to meeting to arrange - 707-350-3030 - Jenny
Facilitated by: Jenny Johnson for Redwood CRC

***Lucerne Support Group**
3rd Thursday
1:00 PM – 2:30 PM
First Lutheran Church
3863 Country Club Lane
Lucerne, CA 95458
Respite provided, on-site
Call prior to meeting to arrange 707-263-9481 – ask for Caroline
Facilitated by: Jenny Johnson for Redwood CRC

NCO
NORTH COAST OPPORTUNITIES

***Ukiah Support Group**
2nd & 4th Monday
10:00 AM – 12 Noon
Community Care Management Corporation
301 South State Street
Ukiah, CA 95482
Facilitated by:
Connie Lorenz, LCSW

These groups are funded in part by our partnership with
**Lake and Mendocino Counties Area Agency on Aging / Family Caregiver Support Program*

NAPA COUNTY

Napa Support Group
1st Thursday
1 pm – 3 pm
Collabria Care
414 S. Jefferson Street
Napa, CA

This group is done in partnership with Collabria Care

SOLANO COUNTY

^Vallejo Support Group
2nd & 4th Tuesday
10:30 am – 12:30 pm
Florence Douglas Center
333 Amador St.
Vallejo, CA 94590-6320
Facilitated by: Nancy Powers-Stone, MA
Redwood CRC, Director

These groups are funded in part by our partnership with
^Solano County Area Agency on Aging / Family Caregiver Support Program

REDWOOD
caregiver resource center

Feelings Often Expressed by Caregivers and Care Receivers

CAREGIVER

ANGER

- For being trapped
- That others in the family don't carry their share
- At the impaired person's demands and behaviors
- At the health- care system and health professionals

DEPRESSION

- Because of an emotionally and physically draining experience
- Because of feeling overwhelmed

EMBARRASSMENT

- At the impaired person's behavior
- At the thoughtlessness of others

FEAR

- That they may be the next in line; particularly with inherited conditions
- Of not being able to handle the situation
- Of what other people are saying about how the situation is being handled

GRIEF

- For the way the care receiver used to be
- For the way things used to be
- For lost relationships – emptiness

GUILT

- For wanting "out" of the caregiver role
- For wishing the care receiver would die
- For not having done enough – and not being able to do more even when you do all you can

HELPLESSNESS

- The situation is too great & there is no way to control it

SHAME

- Of the loved one for their failings – for what they were or are now

WORRY

- That they may later feel they did not give enough
- That their best was not good enough

CARE RECEIVER

ANGER or FRUSTRATION

- For being treated like a child
- For being confined or limited

FEAR

- Of what is happening
- Of what the future may hold
- Of loss of control
    familiar role is gone
    power & influence are gone
    mental stability failing
    loss of independence

HELPLESSNESS

ISOLATION

CONFUSION

DEPRESSION

EMBARRASSMENT

- Because of need for personal care
- Because of disability

GUILT

- For spoiling the caregiver's life

SHAME

- For behaviors which he or she cannot control
- For being a burden

REDWOOD
caregiver resource center

FACT SHEET
Taking Care of YOU:
Self-Care for Family Caregivers

First, Care for Yourself

On an airplane, an oxygen mask descends in front of you. What do you do? As we all know, the first rule is to put on your own oxygen mask before you assist anyone else. Only when we first help ourselves can we effectively help others. Caring for yourself is one of the most important—and one of the most often forgotten—things you can do as a caregiver. When your needs are taken care of, the person you care for will benefit, too.

Effects of Caregiving on Health and Well Being

We hear this often:, "My husband is the person with Alzheimer's, but now I'm the one in the hospital!" Such a situation is all too common. Researchers know a lot about the effects of caregiving on health and well being. For example, if you are a caregiving spouse between the ages of 66 and 96 and are experiencing mental or emotional strain, you have a risk of dying that is 63 percent higher than that of people your age who are not caregivers.1 The combination of loss, prolonged stress, the physical demands of caregiving, and the biological vulnerabilities that come with age place you at risk for significant health problems as well as an earlier death.

Older caregivers are not the only ones who put their health and well being at risk. If you are a baby boomer who has assumed a caregiver role for your parents while simultaneously juggling work and raising adolescent children, you face an increased risk for depression, chronic illness and a possible decline in quality of life.

But despite these risks, family caregivers of any age are less likely than noncaregivers to practice preventive healthcare and self-care behavior. Regardless of age, sex, and race and ethnicity, caregivers report problems attending to their own health and well-being while managing caregiving responsibilities. They report:

- sleep deprivation
- poor eating habits
- failure to exercise
- failure to stay in bed when ill
- postponement of or failure to make medical appointments for themselves

Family caregivers are also at increased risk for depression and excessive use of alcohol, tobacco and other drugs. Caregiving can be an emotional roller coaster. On the one hand, caring for your family member demonstrates love and commitment and can be a very rewarding personal experience. On the other hand, exhaustion, worry, inadequate resources and continuous care demands are enormously stressful. Caregivers are more likely to have a chronic illness than are non-caregivers namely high cholesterol, high blood pressure and a tendency to be overweight. Studies show that an estimated 46 percent to 59 percent of caregivers are clinically depressed.

Taking Responsibility for Your Own Care

You cannot stop the impact of a chronic or progressive illness or a debilitating injury on someone for whom you care. But there is a great deal that you can do to take responsibility for your personal well being and to get your own needs met.

Identifying Personal Barriers

Many times, attitudes and beliefs form personal barriers that stand in the way of caring for yourself. Not taking care of yourself may be a lifelong pattern, with taking care of others an easier option. However, as a family caregiver you must ask yourself, "What good will I be to the person I care for if I become ill? If I die? Breaking old patterns and overcoming obstacles is not an easy proposition, but it can be done—regardless of your age or situation. The first task in removing personal barriers to self-care is to identify what is in your way. For example:

- Do you think you are being selfish if you put your needs first?
- Is it frightening to think of your own needs? What is the fear about?
- Do you have trouble asking for what you need? Do you feel inadequate if you ask for help?
- Do you feel you have to prove that you are worthy of the care recipient's affection? Do you do too much as a result?

Sometimes caregivers have misconceptions that increase their stress and get in the way of good self-care. Here are some of the most commonly expressed:

- I am responsible for my parent's health.
- If I don't do it, no one will.
- If I do it right, I will get the love, attention, and respect I deserve.
- Our family always takes care of their own
- I promised my father I would always take care of my mother

"I never do anything right," or "There's no way I could find the time to exercise" are examples of negative *self-talk*, another possible barrier that can cause unnecessary anxiety. Instead, try positive statements: "I'm good at giving John a bath." "I can exercise for 15 minutes a day." Remember, your mind believes what you tell it.

Because we base our behavior on our thoughts and beliefs, attitudes and misconceptions like those noted above can cause caregivers to continually attempt to do what cannot be done, to control what cannot be controlled. The result is feelings of continued failure and frustration and, often, an inclination to ignore your own needs. Ask yourself what might be getting in your way and keeping you from taking care of yourself.

Moving Forward

Once you've started to identify any personal barriers to good self-care, you can begin to change your behavior, moving forward one small step at a time. Following are some effective tools for self-care that can start you on your way.

Tool #1: Reducing Personal Stress

How we perceive and respond to an event is a significant factor in how we adjust and cope with it. The stress you feel is not only the result of your caregiving situation but also the result of your perception of it—whether you see the glass as half-full or half-empty. It is important to remember that you are not alone in your experiences.

Your level of stress is influenced by many factors, including the following:

- Whether your caregiving is voluntary. If you feel you had no choice in taking on the responsibilities, the chances are greater that you will experience strain, distress, and resentment.
- Your relationship with the care recipient. Sometimes people care for another with the hope of healing a relationship. If healing does not occur, you may feel regret and discouragement.
- Your coping abilities. How you coped with stress in the past predicts how you will cope now. Identify your current coping strengths so that you can build on them.
- Your caregiving situation. Some caregiving situations are more stressful than others. For example, caring for a person with dementia is often more stressful than caring for someone with a physical limitation.
- Whether or not support is available.

Steps to Managing Stress

1. Recognize warning signs early. These might include irritability, sleep problems, and forgetfulness. Know your own warning signs, and act to make changes. Don't wait until you are overwhelmed.
2. Identify sources of stress. Ask yourself, "What is causing stress for me?" Sources of stress might be that you have too much to do, family disagreements, feelings of inadequacy, or the inability to say no.

3. Identify what you can and cannot change. Remember, we can only change ourselves; we cannot change another person. When you try to change things over which you have no control, you will only increase your sense of frustration. Ask yourself, "What do I have some control over? What can I change?" Even a small change can make a big difference. The challenge we face as caregivers is well expressed in the following words modified from the original Serenity Prayer (attributed to American Theologian, Reinhold Niebuhr):

   "God grant me the serenity to accept the things I cannot change,
   Courage to change the things I can,
   and (the) wisdom to know the difference."

4. Take action. Taking some action to reduce stress gives us back a sense of control. Stress reducers can be simple activities like walking and other forms of exercise, gardening, meditation or having coffee with a friend. Identify some stress reducers that work for you.

Tool #2: Setting Goals

Setting goals or deciding what you would like to accomplish in the next three to six months is an important tool for taking care of yourself. Here are some sample goals you might set:

- Take a break from caregiving.
- Get help with caregiving tasks like bathing and preparing meals.
- Engage in activities that will make you feel more healthy.

Goals are generally too big to work on all at once. We are more likely to reach a goal if we break it down into smaller action steps. Once you've set a goal, ask yourself, "What steps do I take to reach my goal?" Make an action plan by deciding which step you will take first, and when. Then get started!

Example *(Goal and Action Steps):*
Goal: *Feel more healthy.*
Possible action steps:

1. *Make an appointment for a physical check-up.*
2. *Take a half-hour break once during the week.*
3. *Walk three times a week for 10 minutes.*

Tool #3: Seeking Solutions

Seeking solutions to difficult situations is, of course, one of the most important tools in caregiving. Once you've identified a problem, taking action to solve it can change the situation and also change your attitude to a more positive one, giving you more confidence in your abilities.

Steps for Seeking Solutions

1. Identify the problem. Look at the situation with an open mind. The real problem might not be what first comes to mind. For example, you think that the problem is simply that you are tired all the time, when the more basic difficulty is your belief that "no one can care for John like I can." The problem? Thinking that you have to do everything yourself.
2. List possible solutions. One idea is to try a different perspective: "Even though someone else provides help to John in a different way than I do, it can be just as good." Ask a friend to help. Call Family Caregiver Alliance or the Eldercare Locator (see Resources List) and ask about agencies in your area that could help provide care.
3. Select one solution from the list. Then try it!
4. Evaluate the results. Ask yourself how well your choice worked.
5. Try a second solution. If your first idea didn't work, select another. But don't give up on the first; sometimes an idea just needs fine tuning.
6. Use other resources. Ask friends, family members and professionals for suggestions.
7. If nothing seems to help, accept that the problem may not be solvable now. You can revisit it at another time.

Note: All too often, we jump from step one to step seven and then feel defeated and stuck. Concentrate on keeping an open mind while listing and experimenting with possible solutions.

Tool #4: Communicating Constructively

Being able to communicate constructively is one of a caregiver's most important tools. When you communicate in ways that are clear, assertive and constructive, you will be heard and get the help and support you need. The box below shows basic guidelines for good communication.

Communication Guidelines

- Use "I" messages rather than "you" messages. Saying "I feel angry" rather than "You made me angry" enables you to express your feelings without blaming others or causing them to become defensive.
- Respect the rights and feelings of others. Do not say something that will violate another person's rights or intentionally hurt the person's feelings. Recognize that the other person has the right to express feelings.

- Be clear and specific. Speak directly to the person. Don't hint or hope the person will guess what you need. Other people are not mind readers. When you speak directly about what you need or feel, you are taking the risk that the other person might disagree or say no to your request, but that action also shows respect for the other person's opinion. When both parties speak directly, the chances of reaching understanding are greater.
- Be a good listener. Listening is the most important aspect of communication.

Tool #5: Asking for and Accepting Help

When people have asked if they can be of help to you, how often have you replied, "Thank you, but I'm fine." Many caregivers don't know how to marshal the goodwill of others and are reluctant to ask for help. You may not wish to "burden" others or admit that you can't handle everything yourself.

Be prepared with a mental list of ways that others could help you. For example, someone could take the person you care for on a 15-minute walk a couple of times a week. Your neighbor could pick up a few things for you at the grocery store. A relative could fill out some insurance papers. When you break down the jobs into very simple tasks, it is easier for people to help. And they do want to help. It is up to you to tell them how.

Help can come from community resources, family, friends and professionals. Ask them. Don't wait until you are overwhelmed and exhausted or your health fails. Reaching out for help when you need it is a sign of personal strength.

Tips on How to Ask

- Consider the person's special abilities and interests. If you know a friend enjoys cooking but dislikes driving, your chances of getting help improve if you ask for help with meal preparation.
- Resist asking the same person repeatedly. Do you keep asking the same person because she has trouble saying no?
- Pick the best time to make a request. Timing is important. A person who is tired and stressed might not be available to help out. Wait for a better time.
- Prepare a list of things that need doing. The list might include errands, yard work, or a visit with your loved one. Let the "helper" choose what she would like to do.
- Be prepared for hesitance or refusal. It can be upsetting for the caregiver when a person is unable or unwilling to help. But in the long run, it would do more harm to the rela-tionship if the person helps only because he doesn't want to upset you. To the person who seems hesitant, simply say, "Why don't you think about it." Try not to take it personally when a request is turned down. The person is turning down the task, not you. Try not to let a refusal prevent you from asking for help again. The person who refused today may be happy to help at another time.

- Avoid weakening your request. "It's only a thought, but would you consider staying with Grandma while I went to church?" This request sounds like it's not very important to you. Use "I" statements to make specific requests: "I would like to go to church on Sunday. Would you stay with Grandma from 9 a.m. until noon?"

Tool #6: Talking to the Physician

In addition to taking on the household chores, shopping, transportation, and personal care, 37 percent of caregivers also administer medications, injections, and medical treatment to the person for whom they care. Some 77 percent of those caregivers report the need to ask for advice about the medications and medical treatments. The person they usually turn to is their physician.

But while caregivers will discuss their loved one's care with the physician, caregivers seldom talk about their own health, which is equally important. Building a partnership with a physician that addresses the health needs of the care recipient and the caregiver is crucial. The responsibility of this partnership ideally is shared between you, the caregiver, the physician, and other healthcare staff. However, it will often fall to you to be assertive, using good communication skills, to ensure that everyone's needs are met—including your own.

Tips on Communicating with Your Physician

- Prepare questions ahead of time. Make a list of your most important concerns and problems. Issues you might want to discuss with the physician are changes in symptoms, medications or general health of the care recipient, your own comfort in your caregiving situation, or specific help you need to provide care. The physician only sees a moment in time with the patient. Make sure you let him/her know what your concerns are in their daily care/health.
- Enlist the help of the nurse. Many caregiving questions relate more to nursing nurses than to medicine. In particular, the nurse can answer questions about various tests and examinations, preparing for surgical procedures, providing personal care, and managing medications at home.
- Make sure your appointment meets your needs. For example, the first appointment in the morning or after lunch and the last appointment in the day(no way!!) are the best times to reduce your waiting time or accommodate numerous questions. When you schedule your appointment, be sure you convey clearly the reasons for your visit so that enough time is allowed.
- Call ahead. Before the appointment, check to see if the doctor is on schedule. Remind the receptionist of special needs when you arrive at the office.
- Take someone with you. A companion can ask questions you feel uncomfortable asking and can help you remember what the physician and nurse said.
- Use assertive communication and "I" messages. Enlist the medical care team as partners in care. Present what you need, what your concerns are, and how the doctor and/or nurse can help. Use specific, clear "I" statements

like the following: "I need to know more about the diagnosis; I will feel better prepared for the future if I know what's in store for me." Or "I am feeling rundown. I'd like to make an appointment for myself and my husband next week." Or "I need a way for my mother to sleep at night as I am now exhausted being up every two hours at night with her."

Tool #7: Starting to Exercise

You may be reluctant to start exercising, even though you've heard it's one of the healthiest things you can do. Perhaps you think that physical exercise might harm you or that it is only for people who are young and able to do things like jogging. Fortunately, research suggests that you can maintain or at least partly restore endurance, balance, strength and flexibility through everyday physical activities like walking and gardening. Even household chores can improve your health. The key is to increase your physical activity by exercising and using your own muscle power.

Exercise promotes better sleep, reduces tension and depression, and increases energy and alertness. If finding time for exercise is a problem, incorporate it into your daily activity. Perhaps the care recipient can walk or do stretching exercise with you. If necessary, do frequent short exercises instead of those that require large blocks of time. Find activities you enjoy.

Walking, one of the best and easiest exercises is a great way to get started. Besides its physical benefits, walking helps to reduce psychological tension. Walking 20 minutes a day, three times a week, is very beneficial. If you can't get away for that long, try to walk for as long as you can on however many days you can. Work walking into your life. Walk around the mall, to the store or a nearby park. Walk around the block with a friend.

Tool #8: Learning from Our Emotions

It is a strength to recognize when your emotions are controlling you (instead of you controlling your emotions). Our emotions are messages to which we need to listen to. They exist for a reason. However negative or painful, our feelings are useful tools for understanding what is happening to us. Even feelings such as guilt, anger and resentment contain important messages. Learn from them, then take appropriate action.

For example, when you cannot enjoy activities you previously enjoyed, and your emotional pain over-shadows all pleasure, it is time to seek treatment for depression—especially if you are having thoughts of suicide. Speaking with your physician is the first step. (Please refer to the Fact Sheet on Caregiving and Depression, listed below.)

Caregiving often involves a range of emotions. Some feelings are more comfortable than others. When you find that your emotions are intense, they might mean the following:

- That you need to make a change in your caregiving situation.
- That you are grieving a loss.

- That you are experiencing increased stress.
- That you need to be assertive and ask for what you need.

Summing Up

Remember, it is not selfish to focus on your own needs and desires when you are a caregiver—it's an important part of the job. You are responsible for your own self-care. Focus on the following self-care practices:

- Learn and use stress-reduction techniques, e.g. meditation, prayer, yoga, Tai Chi.
- Attend to your own healthcare needs.
- Get proper rest and nutrition.
- Exercise regularly, if only for 10 minutes at a time.
- Take time off without feeling guilty.
- Participate in pleasant, nurturing activities, such as reading a good book, taking a warm bath.
- Seek and accept the support of others.
- Seek supportive counseling when you need it, or talk to a trusted counselor, friend, or pastor.
- Identify and acknowledge your feelings, you have a right to ALL of them.
- Change the negative ways you view situations.
- Set goals.

It's up to you!

Credits

[1] Shultz, Richard and Beach, Scott (1999). *Caregiving as A Risk for Mortality: The Caregiver Health Effects Study*. JAMA, December 15, 1999 - Vol. 282, No.23

A special thank you the Powerful Tools for Caregivers program for permission to use information from The Caregiver Helpbook and their Powerful Tools for Caregivers Class Leader Tips Manual. The Caregiver Helpbook, is highly recommended reading for caregivers.

RESOURCES

FCA Fact Sheet:

Caregiving and Depression

FCA Fact Sheet:
Dementia, Caregiving and Controlling Frustration

AARP

Administration on Aging
Washington, DC 20201,
Phone: (202) 619-0724
Eldercare Locator

Alzheimer's Association

Gambone, James, PhD, Rhonda Travland, MS, *Who Says Men Don't Care?* 2011, www.MaleGuideForCaregiving.com

How To Be a Resilient Caregiver

Schmall,V, Cleland,M, Sturdevant,M, *The Caregiver Helpbook: Powerful Tools for Caregivers*, Legacy Health Systems.(2000)

Sheehy, Gail, *Passages in Caregiving*, Harper Collins, 2010

Organizations

Family Caregiver Alliance
National Center on Caregiving
785 Market Street, Suite 750
San Francisco, CA 94103
(415) 434-3388
(800) 445-8106
Web Site: caregiver.org
E-mail: info@caregiver.org

Family Caregiver Alliance (FCA) seeks to improve the quality of life for caregivers through education, services, research and advocacy. Through its National Center on Caregiving, FCA offers information on current social, public policy and caregiving issues and provides assistance in the development of public and private programs for caregivers.

For residents of the greater San Francisco Bay Area, FCA provides direct support services for caregivers of those with Alzheimer's disease, stroke, traumatic brain injury, Parkinson's and other debilitating disorders that strike adults.

Area Agency on Aging

For caregiver support groups, respite providers, and other caregiving services.

Eldercare Locator:

(800) 677-1116

ARCH National Respite Network and Resource Center

Call to find local respite providers.

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Date:

Sunday, December 30, 2012