Dementia: Information for caregivers during the later stages

You have a family member or friend who is in the later stages of dementia. This disease has affected many aspects of how this person functions. As a caregiver, you might feel overwhelmed or anxious about these changes. These feelings are natural. There are things you can be aware of and prepare for to help you as this condition changes over time.

**Change in symptoms**

Your loved one’s behavior may be drastically different from what you’ve known in the past. They may not recognize you or call you by different names, lash out unexpectedly, or be nervous or suspicious of things you do. It is important to remember that the person is not acting this way on purpose. Try not to take anything personal. The behaviors are not intentional and could be caused by a variety of feelings and emotions, such as frustration in not remembering things or physical pain from other illnesses.

As this disease progresses, the following symptoms may get worse:

- Memory loss
- Inability to do daily tasks, such as dress and bath
- Lack of recognition of familiar people, places, and objects
- Trouble with speech and writing
- Agitation, anxiousness
- Motor skills, such as driving a car
- Depression

**Know that you are doing a good job**

During this time, it may be difficult to know what to do or how to do it. Remember that you are doing what’s best for your family member or friend. If this is a parent, a role reversal may have occurred, placing you in the role of parent. You may feel fully responsible for the health and well-being of your parent. Be assured that you are doing a good job.

Try not to take it all by yourself. If possible, look for support from those around you. This may be a family member, friend, or neighbor. Say yes when people offer to help, and know that these people want to support you and your loved one.

**Make decisions now**

One thing you can do to feel more secure is to complete legal paperwork as needed, including documents for financial and health care issues. This could include a Durable Power of Attorney for Health Care, Living Will, or other form of advance directive. Having these documents completed and ready if you need them can make situations easier as they come up.
Take care of yourself
As a caregiver, it may be easy to forget about taking care of yourself while you’re caring for someone else. Take time for yourself and get help from others to keep from burning out. There are organizations and services available to help you take care of your loved one and yourself.

Resources to help you as a caregiver
The following resources can offer you the help and guidance you may need during this difficult and challenging time:

Alzheimer’s Association
www.alz.org
1-800-272-3900
Local chapters can provide core services to families and professionals, including information and referral, support groups, care consultation, education and safety services. Offers print material on various topics including caregiver stress, common behaviors and how to manage them, and a guide for respite care.

Kaiser Permanente Resource Line
1-800-992-2279
Call or email for information about resources and support available to help you as a caregiver. The Resource Line can provide printed material, as well as community services to help you with daily activities, such as housecleaning and transportation.

Kaiser Permanente Social Work Services
A social worker is available at all Kaiser Permanente medical offices to help patients and families cope with changes in health status and new medical needs. Talk with a member of the person’s health care team about connecting with a social worker.