# UNDERSTANDING THE "CARE CONTINUUM"

In the health profession, we often speak of a "continuum of care". This refers to the 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 dementia, the continuum of care includes the following options:

# **In-Home Living Situations**

Many people with dementia 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 or she may be able to receive most, if not all, of the needed care while continuing to live at home.

The first level of service needed is usually respite care, services provided by various organizations intended to provide short-term temporary relief for the primary caregivers. Respite care is typically provided by extended family, private organizations, or churches, but it can also be provided by home care agencies, Adult Day Healthcare Centers, assisted living facilities and 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.

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

Sometimes the care of a person with dementia 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 dementia 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 like this, for the safety of the person with dementia and the wellbeing 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, or ADLs for short) and have staff available around-the-clock to meet any changes in the 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 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 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.

# **Nursing Home Settings**

In the late stages of dementia, people 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.

#### **CONCLUSION**

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

If the information in this booklet does not answer your questions or concerns about available community resources, medical care, how to manage in the home, or when to consider seeking outside help or living settings, please do not hesitate to ask us. We will provide you guidance throughout this journey.

# **COMMUNITY RESOURCES**

#### **Kaiser Permanente Resources**

#### Advance Directive Workshop

Advance Directive workshops are held throughout the year. Please call Health Education for dates and times they are offered and register at 707-393-4167 or 707-566-5277.

#### Fall Prevention Class

Most falls are preventable. Participants will learn about common causes of falls in and around the home and make a plan for one or more specific changes they can make to improve their safety and reduce their risk of falling. Call 707-566-5844 for class schedule.

#### Dementia Care Program Caregiver Classes

We have partnered with community organizations to provide you educational programs throughout the year. Please check with our staff regularly at 707-393-3340.

#### **Alzheimer's Association**

Northern California and Northern Nevada Chapter 1450 Neotomas Avenue, Suite 140 Santa Rosa, CA 95405 www.alz.org/norcal

24-hour helpline: 800-272-3900

Office: 707-573-1210

The Alzheimer's Association is the leading, global voluntary health organization in Alzheimer's 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 and training programs, family care planning, support groups, early stage program, referral service, 24/7 telephone helpline, and MedicAlert and Safe Return programs.

# **Redwood Caregiver Resource Center**

1140 Sonoma Ave., Ste. 1B Santa Rosa, CA 95409 Office: 707-542-0282

The mission of Redwood CRC is to help families and communities master the challenges of caring for adults with brain disorders through programs and services that address the emotional, physical, and financial needs of family caregivers. They provide information and assistance to families and caregivers of adults with brain impairments due to injury or disease, as well as to the caregivers of the frail elderly.

# **Adult Day Care Center**

These centers, also known as social clubs, are designed to not only provide social and recreational services, but nursing care as well (especially for seriously incapacitated persons with dementia 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. Ask our social worker for adult day care center in our community. Call 707-393-3340.

### **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. Our Kaiser Home Health Department handles the hospice referrals. The intake line is 707-566-5485. It is agency policy that the patient and/or family select the Hospice of their choice.

#### **Protective Services**

Adult Protective Services (APS)

707-565-5940

Each county has an APS agency to help dependent adults, when these adults are unable to meet their own needs, or are victims of abuse, neglect or exploitation. County APS staff evaluates abuse cases and arranges for services such as advocacy, counseling, money management, out-of-home placement, or conservatorship.

Ombudsman Program, California Department of Aging 707-526-4108

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.

# 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. Patients with dementia, 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 patients with Alzheimer's and other memory disorder to maintain their social skills and develop important friendships. Ask our social worker for places that provide respite services in our community. Call 707-393-3340.

Catholic Charities

987 Airway Court Santa Rosa, CA 95402

Phone: 707-528-8712

Primrose

2080 Guerneville Road Santa Rosa, CA 95403-4117

Phone: 707-578-8360

Council On Aging

30 Kawana Springs Rd. Santa Rosa, CA 95404 Phone: 707-525-0143

#### **REFERENCES**

- 1. American Academy of Family Physicians (AAFP). Dementia: What are the Common Signs? 2003. http://www.aafp.org/afp/2003/0301/p1051.html
- 2. Alzheimer's Associatin (2012). http://www.alz.org/care/alzheimers-dementia-caregiver-stress-burnout.asp
- 3. Kaiser Permanente. (1997). Alzheimer's/Dementia Program Handbook Tools for Clinicians. Kaiser Foundation.
- 4. Robinson, A., Spencer, B., & White, L. (1996). Understanding Difficult Behaviors: Some Practical Suggestions for Coping with Alzheimer's Disease and Related Illnesses. Geriatric Education Center of Michigan.
- 5. The Alzheimer's Disease and Related Disorders Association, Inc. (1987). Alzheimer's Disease: An Overview.

#### **WEBSITES**

Alzheimer's Store. www.alzstore.com

#### NATIONAL RESOURCES

AGS Foundation for Health in Aging. www.healthinaging.org/
Administration on Aging. www.aoa.gov/AoARoot/Elders\_Families/index.aspx
Fall Prevention Center of Excellence. www.stopfalls.org/
Geriatric Mental Health Foundation. www.gmhfonline.org/gmhf/consumer/index.html
National Institute on Aging. www.nihseniorhealth.gov/category/memoryandmentalhealth.html

#### CAREGIVING

National Alliance for Caregiving. www.caregiving.org Family Caregiver Alliance. www.caregiver.org

#### **ELDER RIGHTS**

California Adult Protective Services. www.cdss.ca.gov/agedblinddisabled/PG1298.htm California Advocates for Nursing Home Reform (Elder Law Attorney Referrals). www.canhr.org/LRS/index.html

National Center on Elder Abuse. www.ncea.aoa.gov/ncearoot/Main Site/index.aspx

#### PRESCRIPTION ASSISTANCE

Prescription Medication Discount Card/Program. www.needymeds.org/drugcard/index.htm

#### Alzheimer's Association

1450 Neotomas Avenue, Suite 140 Santa Rosa, CA 95405

www.alznorcal.org 707-573-1210 800-272-3900

alzheimer's Sociation

# Sonoma County Human Services Department Adult and Aging Division

2250 Northpoint Parkway Santa Rosa, CA 95407 www.socoaaa.org

707-565-5900

"Empower, Support, Protect"
Human Services Department

# SONOMA COUNTY ALZHEIMER'S DISEASE AND DEMENTIA RESOURCES

The following list of resources is intended as a guide for persons in need of community resources. For additional referrals, contact the Alzheimer's Association at 707-573-1210

ADVOCACY	
ADVOCACY  Alzheimer's Association  Ombudsman Program, Senior Advocacy Services (SAS)  Redwood Caregiver Resource Center	707-526-4108
ALZHEIMER'S RESIDENTIAL CARE  For information on residential care homes including assisted living ar  contact the Alzheimer's Association or the Sonoma County Ombudsn	
ADULT DAY CARE  Council on Aging	707-528-8712 415-897-6884 707-765-8490
Alzheimer's Association	707-525-0143 707-571-8533 415-897-6884 707-765-8490
CARE MANAGEMENT  Alzheimer's Association	707-525-0143 707-571-8533 707-765-8490 707-542-0282
DIAGNOSIS/ASSESSMENT  The Brain Health Center at California Pacific Medical Center  Kaiser Permanente Geriatric Medicine Clinic  UC Davis/VA @ Martinez Alzheimer's Center  UCSF Memory & Aging Center  VA @Stanford Alzheimer's Center	707-393-3340 925-372-2485 415-476-6880

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LifeLine	
Medic Alert	
Medic Alert + Safe Return (Alzheimer's Association)	888-572-856
SPICE	
Hospice of Petaluma	. 707-778-624
Hospice By The Bay	707-935-750
Memorial Hospice	707-568-109
Sutter Care at Home	. 707-535-570
FORMATION AND ASSISTANCE	
Alzheimer's Association	707-573-121
Council on Aging	. 707-525-014
HICAP – Senior Advocacy Services (Medicare insurance advocate)	
Petaluma People Services Center	
Redwood Caregiver Resource Center	
Sonoma County Adult & Aging Division	
West County Community Services (Sebastopol & River area)	
HOME CARE	
Provides in-home assistance for persons who are income-eligible:	
In Home Support Services (IHSS)	707-565-590
In Home Support Services (IHSS) – Public Authority	
GAL/FINANCIAL ASSISTANCE & INFORMATION	
Council on Aging Senior Legal Services	707-525-014
Medicare	
Legal Services of No. California/Senior Legal Hotline	
Medi-Cal, Department of Social Services	
Public Guardian	
Redwood Caregiver Resource Center	
Social Security Administration	
Veterans Service Office – Santa Rosa	
ALS	
Council on Aging – Meals on Wheels	707-525-014
Petaluma People Services Center	
OTECTIVE SERVICES	
Adult Protective Services (APS) in the community	. 800-667-040
	or 707-565-594
Ombudsman Program (SAS) in facilities	
SPITE	
Linkages	707-565-590
Marin Adult Day Health Center (Petaluma area)	
Redwood Caregiver Resource Center	
•	
ANSPORTATION	
Volunteer Wheels	