# Caregiver Handbook

An Informational Tool to Support Your Caregiving Journey



# **Acknowledgements** Handbook content curated, edited, reviewed, and written by: Caregiver Coalition of San Diego, www.CaregiverCoalitionSD.org. Funding provided by the National Family Caregiver Support Program through the County of San Diego Health and Human Services Agency, Aging & Independence Services

### Dear San Diego Caregivers:

The Caregiver Coalition of San Diego (Caregiver Coalition) is here to help you find answers to all your caregiving questions. Members include representatives from non-profits, businesses, and government agencies, as well as other professionals who are experts in caregiving, senior care, aging, and end of life issues. Our purpose is to make the job of caring for loved ones less stressful by helping you become a more knowledgeable caregiver.

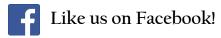
### The Caregiver Coalition offers:

- Free Conferences: Held at various locations throughout San Diego County. The conferences include presentations by highly-trained professionals on topics of interest to caregivers. Each conference includes a resource fair and free respite care.
- Webinars: Access free 30-minute educational webinars from your computer or mobile device.
- Speakers: Members of the Caregiver Coalition and associates are available to speak to various groups throughout San Diego County. Choose from a variety of topics of interest to older adults.
- Referrals: Our members can help you find the community resources that best meet your needs.
- Caregiver Handbook: Our members have gathered, compiled, and contributed their knowledge and resources to create this book.

We wish you success and a sense of fulfillment throughout your caregiving journey!

To learn more about the Caregiver Coalition of San Diego and connect with us:

Visit Our Website: <a href="www.CaregiverCoalitionSD.org">www.CaregiverCoalitionSD.org</a>
Send Us an Email: <a href="mailto:InfoSDCaregiverCoalition@gmail.com">InfoSDCaregiverCoalition@gmail.com</a>









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### Introduction

### Who is a Caregiver?

Many men and women are caregivers without realizing it. Do you take care of your spouse, take your elder family member to doctors' appointments, or help your parents with their finances? Do you take older relatives to the grocery store or regularly do shopping for a friend? If so, you are a caregiver. Caregiving can be a once-weekly activity, full-time physical care, or anything in between.

If you are taking care of a loved one, whether they are a relative, neighbor, or friend, this handbook can help. It is designed as a road map and source of resources for your journey. Each person has different needs and challenges. What help is needed now? What help may be needed in the future? Will your loved one be willing to accept help? There is no single answer for every situation.



### **You Are Not Alone**

Today, greater numbers of people are fortunate to live to an older age, but many are also facing chronic health problems that can develop in later years. Families are stepping up to help. According to AARP and the National Alliance for Caregiving, over 34 million Americans provided unpaid care to an adult age 50 or older in the last 12 months (as of 2015). Nearly 75% of caregivers are female, but a growing number of men are becoming involved

with caregiving. With an average age of 49.2, many American caregivers are "sandwiched" between taking care of children and older relatives. However, a sizeable number of caregivers are older adults themselves, with caregivers age 65 or older comprising one-third of the population of family caregivers.

Whether male or female, young, middle-aged, or older, unpaid caregivers devote significant amounts of time, energy, and their own resources caring for loved ones, and play an important role in strengthening the social fabric of our communities.

### **Get the Resources and Support You Need**

Providing assistance to your loved one may not always be easy. Some people are better able to provide help, such as financial resources, time, and emotional support, than others. Given the right tools and support, you can make caregiving work for your loved one and your family.

Whether your loved one has Alzheimer's disease or another form of dementia, a chronic illness like Parkinson's, heart disease, or lung disease, or any other kind of illness or disability that requires the assistance of a caregiver, the Caregiver Coalition of San Diego hopes this handbook will help you become a more confident, able, and balanced caregiver.



# **NOTES**

### SECTION #1: How to Find Help

### • What You'll Find In This Section:

- Getting Started
- General Information and Assistance Clearinghouses
- Caregiver Websites

### **Getting Started**

Taking care of others can be rewarding and an honor, but it can also be challenging and overwhelming. We often deal with vast, bureaucratic, health, legal, and government systems. It can be hard to know where to start, or even which questions to ask. Taking the time to be an educated consumer will allow you to make the best decisions possible.

At various points throughout the caregiving process, it will be helpful to stop and do what social workers do: an assessment. Define what your loved one can manage and not manage. What aspects of physical or mental functioning have changed? Is the change consistent or does it vary? What are the best and worst times of day? What does your loved one say about the situation? (Sometimes our loved ones can, and want to, manage more than we expect.) What is the elder's financial situation? Are there family members or friends who can help financially or otherwise? What about emotional, social, and spiritual supports?

As you gather information, you may wish to write down your observations and your loved one's needs in a caregiving plan. In addition, you will want to keep handy important information such as details on your loved one's medical history, financial resources, and the location of important documents. Refer to the Appendix for a chart that you can fill in with this information.

San Diego County is fortunate to have a wealth of programs and resources to assist older adults and caregivers. However, many people do not know about all that is available. A variety of local agencies, general resources, and public benefits programs are listed within this section. Specific resources pertaining to topics such as transportation or in-home help can be found within the *Common Needs* section of this handbook.





# General Information & Assistance Clearinghouses for Local Resources

Whether you know exactly the types of assistance that you need, or would like help identifying available programs, 2-1-1 and the Aging & Independence Services Call Center are two good places to start.

### 2-1-1 San Diego

### www.211sandiego.org

Dial 2-1-1 at any time of the day or night to be linked to the vast network of social service programs and non-profit organizations that meet the needs of San Diegans.

### **Aging & Independence Services Call Center**

(800) 339-4661

### www.aging.sandiegocounty.gov

The County of San Diego Health and Human Services Agency, Aging & Independence Services (AIS) is the Area Agency on Aging for San Diego County. AIS Call Center staff are trained social workers who are able to connect callers to both County and non-County services and programs, including: in-home help, case management, meals, and more. Refer to Page 12 for some of the programs offered by AIS.



### **Caregiver Websites**

### **San Diego Eldercare Directory**

### www.sandiegoeldercare.com

This free guide to independent living, long-term care, and resources for older adults and caregivers is published annually by the San Diego Union-Tribune. It includes non-profit resources, as well as for-profit businesses specializing in services for older adults. To obtain a printed copy, call (619) 293-1680.

### **San Diego Union-Tribune Caregiving Site**

### www.caregiversd.com

The San Diego Union-Tribune compiles caregiving-related articles, local resources, and advice on topics such as caregiving essentials, getting help, dementia care, staying healthy, and financial matters.

### **AARP® Caregiving Resource Center**

### www.aarp.org/caregiving

Here you will find many tips, tools, and resources for family caregivers including downloadable guides such as the *Prepare to Care Guide*. Caregiving Basics, Care at Home, Financial and Legal, and Caregiving Life Balance.

### **AARP® Caregiving Tool**

### www.aarp.org/caregivingtools

This site provides a variety of free, web-based tools that will help you find services, keep track of health records, access templates for legal documents, and more.

### **Caregiver Coalition of San Diego**

### www.caregivercoalitionsd.org

The Caregiver Coalition website provides family caregivers with information, resources, and upcoming local events for caregivers.

### Family Caregiver Alliance (FCA)

### www.caregiver.org

This national organization aims to improve the quality of life of caregivers and those they care for through information, services, and advocacy. Their website provides information on a wide variety of caregiving topics (assistive technology, diversity & cultural issues, long-distance caregiving) and health-related topics (dementia, Parkinson's Disease, traumatic brain injury).

### **Veterans Administration (VA) Caregiving Support**

https://www.sandiego.va.gov/services/caregiver/index.asp

The VA offers services and support to caregivers of veterans. Visit their website to learn about special programs, such as those for family caregivers who are caring for veterans who were injured post-9/11. There is also a special caregiver support line **(855)** 260-3274 to assist with linking caregivers and veterans to services.



NOTES

### SECTION #2: Resource Directory

### • What You'll Find In This Section:

- Aging & Independence Services
- Public Benefits
- Local Non-Profit Agencies
- Geriatric Care Management

### **Aging & Independence Services**

The County of San Diego Health and Human Services Agency, Aging & Independence Services (AIS) offers a variety of programs and services for older adults. For general information and referral assistance, as well as information about any of the programs listed below, call the AIS Call Center at (800) 339-4661. Social workers help connect callers to both County and non-County services, including: in-home help, case management, meals, and more.

### **In-Home Supportive Services (IHSS)**

IHSS provides personal care and homemaker assistance to low-income older adults (65+) and individuals with disabilities who would otherwise be unable to remain in their homes. IHSS services are provided by independent caregivers and are selected by the IHSS client. Many clients elect to have a trusted family member or friend assist them, or they can select a screened professional from the caregiver registry.

### **Adult Protective Services (APS)**

Adult Protective Services (APS) investigates reports of elder and dependent adult abuse, including cases of neglect, abandonment, physical, sexual, and financial abuse. The primary mission of APS is to provide protection; another important goal is to preserve the independence and dignity of older and disabled adults. In addition to investigation of abuse, APS conducts wellness checks and works with other agencies and community partners to enhance client safety and provide supportive resources.

### **Case Management Programs**

These programs involve comprehensive social and healthcare management, typically for low-income clients who have multiple health problems. A case worker assists the client and family with a variety of services, such as: assessment of needs, care planning with the client and the family, advocacy, coordination of care with other community agencies, arrangement of services, quarterly home visits, and monthly check-in. Currently, the following types of clients are served by AIS case management programs:

- Older adults age 65+ who are Medi-Cal eligible and at risk of placement in a skilled nursing or intermediate care facility.
- Frail and disabled adults age 60+ who are of low or moderate means (may or may not be Medi-Cal eligible) and are at risk of placement in a skilled nursing facility.
- Adults age 18+ with disabilities who are at risk of institutionalization.

### **Public Benefits**

Depending on age, income, disability status, or other requirements, you or your loved one may be eligible for the following programs or benefits.

### **CalFresh (SNAP in other states)**

CalFresh, formerly known as food stamps, helps people with limited resources buy food with an electronic benefits card that looks like a credit card. To apply, contact the County of San Diego Health and Human Services Agency Access Customer Service Call Center at (866) 262-9881.

### **Medi-Cal (Medicaid in other states)**

This federal and state health insurance program assists people with limited resources to receive medical care. For disabled older adults, it supplements their Medicare. Contact the County of San Diego Health and Human Services Agency Access Customer Service Call Center at (866) 262-9881.

### **Medicare**

Medicare is a national health insurance program that helps people age 65 and over, (and some younger people with disabilities), pay for their health care. Call Medicare at (800) 633-4227, or visit <a href="www.medicare.gov">www.medicare.gov</a>. The non-profit Elder Law & Advocacy is our local provider of the national Health Insurance Counseling & Advocacy Program (HICAP) which provides free and objective information and counseling about Medicare. For more information, call Elder Law & Advocacy at (858) 565-1392 or visit <a href="www.seniorlaw-sd.org">www.seniorlaw-sd.org</a>.

### **Social Security**

This national program provides monthly income to people starting at age 62 or those who become disabled and meet strict disability and work eligibility requirements. To receive retirement benefits you must have paid Social Security retirement taxes for at least 10 years or meet other requirements. To apply, visit your local Social Security Administration office, call (800) 772-1213, or go online: <a href="www.ssa.gov">www.ssa.gov</a>.

### **Supplemental Security Income (SSI)**

SSI pays monthly income benefits to people age 65 and over, as well as to the blind or disabled if they have limited resources. People may receive both Social Security and SSI payments if they meet the requirements. Visit the local Social Security office, call (800) 772-1213, or go online at <a href="https://www.ssa.gov">www.ssa.gov</a> to learn more or apply.

### **Veterans Benefits (VA)**

The Veterans Administration (VA) offers a variety of services for veterans and their caregivers. Visit your local Regional Benefits office, call (800) 827-1000, or visit <a href="www.benefits.va.gov/sandiego/">www.benefits.va.gov/sandiego/</a> to learn more. In addition, the County of San Diego's Office of Military & Veterans Affairs (OMVA) can assist with comprehensive benefits counseling, preparation and submission of claims, and more. For information, contact the OMVA at (858) 694-3222 or email <a href="mailto:sdevso.hhsa@sdcounty.ca.gov">sdcounty.ca.gov</a>.



### **Local Non-Profit Agencies**

The following local, non-profit agencies provide resources and support to older adults and/or caregivers. These are a few of the organizations that can be helpful.

### Alzheimer's Association, San Diego/Imperial Chapter

(800) 272-3900

www.alz.org/sandiego

The local chapter of the national Alzheimer's Association offers services such as: educational programs, a Helpline that operates 24 hours a day/7 days a week, resource information, a monthly telephone caregiver support group, and online community message boards.

### **Alzheimer's San Diego**

(858) 492-4400

www.alzsd.org

Alzheimer's San Diego offers a variety of innovative programs and services, including: classes and workshops for caregivers, support and discussion groups, resource information, guidance from professional dementia experts, social activities, and respite care.

### **Caregiver Coalition of San Diego**

www.caregivercoalitionsd.org

The Caregiver Coalition offers support, education, and advocacy to families who are caring for their loved ones. The Coalition is made up of a diverse group of agencies, both non-profit and for-profit, that serve families. Visit the website to access information, resources, and upcoming events for caregivers.

### **Elder Law & Advocacy**

(858) 565-1392

www.seniorlaw-sd.org

Elder Law & Advocacy provides free legal assistance to residents of San Diego who are over the age of 60 or care for someone who is over 60. In addition, their Health Insurance Counseling & Advocacy Program (HICAP) provides unbiased, impartial information and counseling regarding Medicare.

### **ElderHelp**

(619) 284-9281

www.elderhelpofsandiego.org

ElderHelp provides webinars and online courses for family caregivers, in addition to services for older adults such as care coordination, transportation, and a home sharing program.

### **Interfaith Community Services**

www.interfaithservices.org

(760) 489-6380

Interfaith Community Services provides services to keep older adults who live in Escondido, Oceanside, and surrounding communities in the North County living safely in their own homes for as long as possible.

### **Jewish Family Service of San Diego**

(858) 637-3018

www.jfssd.org

Call the JFS Older Adult HelpLine to get support and information on services for older adults. Jewish Family Service's Balboa Avenue Older Adult Center offers a safe haven for older adults living with Mild Cognitive Impairment, including early stage Alzheimer's disease and dementia, to enjoy a half-day of activities and socialization.

### **Sharp Senior Resource Centers**

(619) 740-4214

www.sharp.com/services/seniors/resource-centers.cfm

Older adults and caregivers can access information, resources, health screenings, and free health education and caregiver classes through the Sharp Senior Resource Centers. The Centers are free to the public.

### **Southern Caregiver Resource Center (SCRC)**

(800) 827-1008

www.caregivercenter.org

SCRC provides no-cost services to family caregivers, including: family consultation/case management services, short-term counseling, legal/financial consultations, education and training, support groups, and respite care.

### **Geriatric Care Management**

The logistics of caregiving can be extremely complicated and sometimes it can make sense to employ a professional geriatric care manager to help. A professional geriatric care manager (PGCM) is an expert such as a social worker, counselor, gerontologist, or nurse who specializes in assisting older adults and their families to attain the highest quality of life given their circumstances. Businesses and professionals in the legal, health, and financial arenas often utilize PGCMs to ensure their clients understand their options, have their needs met, and receive quality care. As a caregiver, you can work with a PGCM to identify what may work best for your loved one's situation.

PGCMs assist families and caregivers in numerous ways, such as:

- Conducting elder care-planning assessments to identify problems and provide solutions.
- Screening, arranging, and monitoring in-home care.
- Providing short- or long-term assistance for caregivers living near or far away.
- Reviewing financial, legal, or medical matters and offering referrals to geriatric specialists in these fields.
- Providing crisis intervention.
- Conducting regular visits to assess and monitor clients' well-being.
- Assisting with moving clients to or from different care settings.
- Providing client and family education and advocacy. Some PGCMs also provide family or individual therapy/counseling, finance management, conservatorship or guardianship assistance.

Most care managers focus on older adults, though many have the capability and knowledge to serve others with chronic conditions. Geriatric care managers may charge between \$50 and \$200 an hour. Most insurance plans don't cover these costs.

To locate a geriatric care manager near you, visit the Aging Life Care Association's website: <a href="https://www.aginglifecare.org">www.aginglifecare.org</a>. This industry organization, formerly the National Association of Geriatric Care Managers, provides information on services, how to select a professional with whom to work, standards of ethics, and a listing of local professionals.

Low-income older adults may qualify for no-cost care coordination assistance through one of case management programs offered by Aging & Independence Services. Call the AIS Call Center at (800) 339-4661 to learn more.

Some community agencies, such as Elderhelp (<u>www.elderhelpofsandiego.org</u>), may provide free care coordination assistance as well.

NOTES

### **SECTION #3:**

### **Common Needs**

### • What You'll Find In This Section:

- Transportation
- In-Home Care
- Housing Options
- Adult Day Care
- Respite Care
- Nutrition Programs
- Companionship and Emotional Needs
- Technology and Medical Equipment

### **Transportation**



When it comes to transportation, begin planning early and build a network of resources to meet your loved one's transportation needs. While your loved one may still be safe to drive now, their needs and abilities could change over time. Transportation options depend on where the person lives and the type of transportation needed.

### **Driver Safety**

Getting older does not necessarily mean a person can no longer drive safely. However, if you are concerned about your loved one's safety behind the wheel, it is important that you have a conversation with them. The National Highway Traffic Safety Administration (NHTSA) has a website with information on older driver safety and how to initiate a conversation about driver safety (<a href="www.nhtsa.gov/road-safety/older-drivers">www.nhtsa.gov/road-safety/older-drivers</a>). AARP® has a website that covers safe driving tips and links to online and classroom-based Smart Driver courses (<a href="www.aarp.org/auto/driver-safety">www.aarp.org/auto/driver-safety</a>).

If, after approaching your loved one, you still have concerns, you may contact the DMV and ask that the person be tested. Physicians can also notify the DMV if they feel their patient is no longer able to drive safely. Individuals can contact the Department of Motor Vehicles for more information on San Diego driver safety at (619) 220-5300.

### **FACT**

FACT is a non-profit agency that was created in 2005 to improve access to transportation for seniors, persons with disabilities, veterans, and others. There are numerous individuals in San Diego County that are unable to access public transportation due to their special needs, their distance from transit routes, or due to a lack of transportation services. FACT acts as a mobility manager for individuals who are looking for transportation by referring them to the most appropriate mode for them.

Referrals: Transportation referrals are provided in person, via telephone, and through the webbased trip planner, Find-A-Ride. FACT maintains a comprehensive database of transportation agencies, social service agencies, faith-based organizations, and specialized transportation services. Visit the FACT website at <a href="https://www.factsd.org">www.factsd.org</a> or call (888) 924-3228.

Low-Cost Rides: RideFACT is a low-cost transportation service that provides general purpose trips for seniors (60+) 7 days a week, 7a.m. – 8 p.m. RideFACT is for seniors who do not have any other transportation options and is available to those residing within all of the cities in San Diego County, as well as in the communities of Ramona and Spring Valley. Reservations may be requested by calling FACT at (888) 924-3228 from 9 a.m. – 4 p.m. Trips may be requested up to 7 days ahead. The cost for a ride starts at \$2.50 for one-way trips up to 5 miles. Rides of 5 miles or more cost between \$4.00 and \$10 depending on the distance. Personal care attendants may be accommodated upon request at the time of reservation at no extra charge. To learn more about FACT, visit www.factsd.org or call (888) 924-3228.

### **Volunteer Driver Programs**

Many local non-profit organizations provide transportation to medical appointments, as well as for business appointments, personal care, and shopping to individuals 60 and older who are no longer able to drive independently. The organizations require an application to determine eligibility and individual programs serve specific geographic areas by zip code. These programs use community volunteer drivers and private vehicles to provide rides to program participants. All volunteer drivers undergo a background check and training and must have current car insurance coverage. Most programs request a donation, and some have an application fee. In addition, some organizations offer taxi vouchers at a reduced cost and shopping shuttles. For more information, contact the San Diego County Volunteer Driver Coalition at www.sdevdc.org.

### **Public Transportation**

San Diego public transit agencies offer individuals 60 years of age or older discounted fares and monthly passes. To apply for a discounted monthly pass, an application is required along with

proof of eligibility. Visit North County Transit District (NCTD) at <a href="www.gonctd.com">www.gonctd.com</a> or San Diego Metropolitan Transit System (SDMTS) at <a href="www.sdmts.com">www.sdmts.com</a>.

In addition, transit systems offer Paratransit service in accordance with the Americans with Disabilities Act (ADA) for individuals unable to travel on the fixed route bus system. Individuals must be certified as eligible to use this service. For ADA certification for North County Transit District, visit <a href="www.adaride.com">www.adaride.com</a> or the San Diego Metropolitan Transit System at <a href="www.rideonmts.com">www.rideonmts.com</a>.

### **Veterans Transportation**

For Veterans Administration medical appointments, the Veterans Transportation Network program provides free, round-trip transportation for patients with a medical appointment to the VA Medical Center and the VA Mission Valley Clinic. For more information, call (858) 552-7470 or visit <a href="https://www.bit.ly/sdvarides.">www.bit.ly/sdvarides.</a>



### **In-Home Care**

Most professional in-home caregivers are considered non-medical in nature. While a non-medical caregiver can assist with much of a client's personal and physical care needs (bathing, dressing, toileting and transferring), there are certain tasks that a non-medical caregiver should not perform, such as nail-trimming, shaving, or medication management. Because most in-home care is categorized as non-medical, a person's medical health insurance does not cover the cost of care. However, there are other options for families to supplement or fully cover the cost of care, such as long-term care insurance and VA benefits (Aid & Attendance).

Local social service organizations, such as Southern

Caregiver Resource Center, Alzheimer's San Diego, Jewish Family Service, or ElderHelp, may be able to assist with some tasks in-home tasks.

In-Home Supportive Services (IHSS) is also available to qualified individuals.

## Did You Know?

The County of San Diego offers a program called In-Home Supportive Services (IHSS) which assists in providing home care assistance to eligible individuals who qualify for Medi-Cal and need help to remain independent at home. Call (800) 339-4661 for more details.



### **Home Care Companies**

California now regulates the home care industry and has required all home care companies to register with the state. This regulation ensures that every state-licensed Home Care Organization (HCO) hires workers who have passed a background check and complies with state-required annual training, among other regulations.

When choosing a home care company to provide care for your loved one, it is vitally important to ask the following questions for your protection:

- 1. Is the company a licensed HCO with the State of California, Department of Social Services? If so, ask for their HCO number. Visit <a href="https://www.cdss.ca.gov/inforesources/community-care/home-care-services/home-care-org-application-process">https://www.cdss.ca.gov/inforesources/community-care/home-care-services/home-care-org-application-process</a>
- 2. Does the company employ their caregivers (issuing W2 tax forms) or do they use independent contractors?
- 3. Does the company provide workers' compensation insurance (if the caregiver gets injured while working with you), or is that the responsibility of the client?
- 4. Do they have proof that each of their employees/caregivers has passed a background check?

Most care services are charged at an hourly rate. Families can expect to pay \$22 to \$33 per hour, based on the type of care they are receiving. Many home care companies charge a higher hourly rate if a short shift (less than 4 hours) is requested or if care is for more than one person.

The Caregiver Coalition of San Diego does not recommend that families hire independent caregivers. If you decide to hire someone privately, please educate yourself on the responsibilities that you assume as the employer. There is a burden of liability that the client/family assumes when hiring a private caregiver instead of using a state-licensed and qualified home care company.

There are dozens of home care agencies in San Diego County. Consult the San Diego Eldercare Directory for a list of companies to consider (<a href="www.sandiegoeldercare.com">www.sandiegoeldercare.com</a>). Companies that have been certified by the American Board of Home Care (<a href="www.americanboardofhomecare.org">www.americanboardofhomecare.org</a>) carry workers' compensation insurance and provide caregivers that are employees of the company rather than independent contractors.

### **Housing Options**

If you are no longer able to care for your loved one at home, finding the right facility is a key step in making the transition more comfortable for you and your loved one. It is important to understand the various levels of care available in senior housing.

### **Types of Residential Services**

- Independent Living: Senior apartments where residents manage their own needs. Some apartments provide meals, transportation, and activities.
- Assisted Living: A licensed residence with apartment-style units. Provides meals and offers assistance with activities of daily living such as bathing, dressing, medication management, meals, transportation and more.
- Board and Care: An informal term referring to smaller assisted living facilities that are licensed home-like settings offering assistance with activities of daily living and medication management.
- Memory Care: Licensed facilities that offer supervision, guidance, activities, and more. Facilities will have security measures to minimize wandering.
- Skilled Nursing Facilities: Nursing homes in California are licensed, regulated, and/or certified by a number of public and private agencies at the state and federal levels. They provide a full range of assistance, such as nursing care, aid with daily activities, and skilled help such as rehabilitation. Patients may stay for a short amount of time while recovering from an illness or procedure, or long-term. Medicare and Medicare Advantage Programs may pay for a skilled nursing facility for a prescribed time. Medi-Cal may cover some long-term costs.

### Choose Well: A Tool to Locate Quality Assisted Living

Choose Well is a free, innovative, web-based program sponsored by the County of San Diego that helps older adults and their families make informed decisions when selecting assisted living facilities. Visit

https://choosewellsandiego.org/home to discover specially evaluated Choose Well facilities that have voluntarily agreed to be scored on 11 measures of quality. Call (619) 795-2165 or email choosewellsandiego@gmail.com for more information.



### **Adult Day Care**

Adult day care and adult day health care centers provide a safe, secure place specially designed to provide activities, nutrition and a warm atmosphere. Adult day health centers may include medical services such as physical and occupational therapy. Services may be covered by Medi-Cal, long term care insurance, VA benefits, or may require you to pay out-of-pocket. To locate an adult day care or adult day health care center, call the AIS Call Center at (800) 339-4661.

### **Respite Care**

Respite is the opportunity to take a break, rest, and re-charge. Respite is important when it comes to maintaining your own health and, therefore, the health of your loved one. There are many ways to receive help, but you may need to ask. Too many caregivers tend to just "go along" and not consider other choices or even be aware of them. Talk to family and friends about assisting you with caregiving duties. This may sound easy, yet caregivers and those they support may often be reluctant to seek help from others. If someone asks if they can help, say "YES" and explain how and when you need help. If no one volunteers, ask for help. Be specific about what would be most helpful. Most importantly, schedule respite and then take that time away to do something for yourself. Leave your guilt at home.

You may decide to hire an aide to help in the home. There are numerous agencies and services from which to choose. If necessary, your loved one could also temporarily move to a facility. In addition to hiring someone, there are several free respite services that your loved one may qualify for that would allow you to get a break for a few hours from time to time. To find a respite care program, you can call the AIS Call Center at (800) 339-4661.



### **Nutrition Programs**

Nutrition programs can help simplify mealtimes and ensure that a loved one has a balanced diet. There are congregate (group) luncheons throughout the county where older adults share lunch together. Some of the sites also provide programs before or after lunch. The cost of lunch is a recommended donation, which varies depending on the site. If the older adult is not able to leave their home, there are several home-delivered meal programs available depending on the geographical location. Contact the AIS Call Center at (800) 339-4661 to get the name and number of a nearby meal program.

### **Companionship and Emotional Needs**

A basic need of most human beings is companionship. As we age, we are likely to lose friends and family members either through death or relocation. Consequently, some older people get lonely. In addition, retirement can leave an elderly person with excess time and little to do. Community agencies and senior centers offer the kinds of social support and companionship that older adults need. Call the AIS Call Center at (800) 339-4661 for a list of senior centers.

It is important to remember that many older adults and individuals requiring caregiving assistance, still have much to give. Encourage your loved one to share his or her time and talents with others—perhaps by volunteering at a school or hospital, or providing service to a church or synagogue. There are even possibilities for those who are homebound. For instance, some hospitals rely on volunteers to knit caps for newborns that are in the neonatal intensive care unit. Help your loved one think of meaningful ways that they can contribute. Older adults who are able to do volunteer work outside the home might consider learning about opportunities through the County of San Diego's Retired and Senior Volunteer Program (RSVP). To learn more about available opportunities, call the senior volunteer programs office at (858) 505-6399.

### **Technology and Medical Equipment**

Technology offers a variety of ways to assist in the safety and well-being of older adults and those requiring care. Products are available that provide reminders, surveillance, and assistance with communication. In addition, a variety of safety products are available for those with dementia or other memory impairments. They range from window and door alerts to automatic stove turn-offs and medication management tools.

A medical alert system is an emergency response device designed to help seniors in a moment of need and provide peace of mind to caregivers. They are an affordable way to provide a safety net for someone who is alone by providing a way to call for help in an emergency.

Here are some important things to consider when shopping for medical alert system:

- The button must be waterproof! Most accidents occur in the restroom or kitchen.
- Do not sign a contract, as it may be uncertain how long you will need the service.
- Watch out for companies that offer lower pricing if you prepay. You may not need the product for as long as you have paid for, or the company may not stay in business.
- With advances in technology, some medical alerts now can be used outside the home.
- When it comes to payment, medical alerts may be covered by your Medi-Cal or Medicare Part B. They are also generally covered under private long-term care insurance.



Medical equipment can be very helpful in maintaining the independence of the person needing care. A variety of wheelchairs, transport chairs, walkers, canes, and other devices can help prevent falls and increase safety. Assistive devices can also help people when they are using the restroom, bathing, dressing, cooking, eating, and transferring from one place to another.

Some equipment may be covered by insurance with a doctor's prescription. Medical supply stores can be helpful in identifying equipment that is best suited for the person needing care. Medicare Part B covers durable medical equipment prescribed by your doctor. Refer to the San Diego Eldercare Directory (www.sandiegoeldercare.com) for a list of companies offering home medical equipment.



### **Durable Medical Equipment Fraud: A Warning**

Durable medical equipment fraud is one of the leading ways criminals commit health care fraud. They do so by filing false insurance claims with Medicare or a private insurance company. These scammers bill for duplicate orders, ship medical equipment to patients that their doctor hasn't prescribed, and fail to give credits for items that have been returned. If you see



any charges for durable medical equipment that you or your loved one do not need or did not receive, report it as suspected fraud to Medicare and/or private insurance.

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# SECTION #4: Communication

- What You'll Find In This Section:
  - Having Crucial Conversations Early
  - How to Talk to Healthcare Providers

# **Having Crucial Conversations Early**

Topics related to caregiving are sometimes awkward or uncomfortable to talk about. Perhaps you are worried that your loved one is no longer able to drive safely. Or, maybe you have noticed some changes in cognitive functioning and believe it is time for you and your loved one to have a conversation about managing their own affairs. These topics are challenging because they may result in a loss of independence or significant lifestyle adjustments.

For some, discussions about care preferences and end-of-life choices are among the most difficult. It's easy to postpone upsetting tasks, but the delay often leads to much greater difficulty. It's best to share our thoughts and concerns with those we love and trust so that we're prepared in times of need and can honor the preferences of our loved one. Getting the conversation started about caregiving needs, health care preferences, and end-of-life concerns is essential.

A good place to look for tips to getting a conversation started and topics to cover is at The Conversation Project's website: <a href="https://theconversationproject.org/">https://theconversationproject.org/</a>. The Conversation Project is dedicated to helping people talk about their wishes for end-of-life care and is an initiative of the Institute for Healthcare Improvement. Some of their suggested discussion items and tips are below.

### Things you might discuss with your loved one:

- Do you have any particular concerns about your health?
- Would you prefer to be actively involved in decisions about your care? Or, would you rather have your doctors do what they think is best?
- Who do you want (or not want) to be involved with your care? Who would you like to make decisions on your behalf if you are not able to?
- Are there types of treatment you would want (or not want)?
- Are there any disagreements or family tensions that you're concerned about?
- What affairs do you need to get in order, or talk to your loved ones about?
- When would it be okay to shift from a focus on curative care to a focus on comfort care alone?
- When you think about the last phase of your life, what's most important to you? What do you envision this phase to be like?

### **How to Talk to Healthcare Providers**

Before the appointment, make sure you have a complete medical history and maintain a health record of current symptoms and medications. Decide which problems you are most concerned about and make sure to discuss these first. As a caregiver, it can be difficult to talk to the healthcare provider about your loved one. It is important to be informed about any healthcare issues and to be assertive and involved.

The following information should be discussed with your loved one's healthcare provider:

- Any new or recurring symptoms, including details of when symptoms occurred, how much increased discomfort they caused, and specific location of body parts affected.
- Personal information, including feelings of stress, depression or memory loss.
- Be honest regarding health habits, including smoking, alcohol and caffeine use, eating, exercising, sleeping, etc.
- Provide a list of all medications, including any over the counter medications, vitamins, herbs, supplements, and eye drops and any side effects experienced. List any medications no longer taken.
- Provide information on x-rays, lab work, tests results or medical updates received since your last visit.
- Talk to the doctor about any recent falls and their circumstances.



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# SECTION #5: Financial and Legal Issues

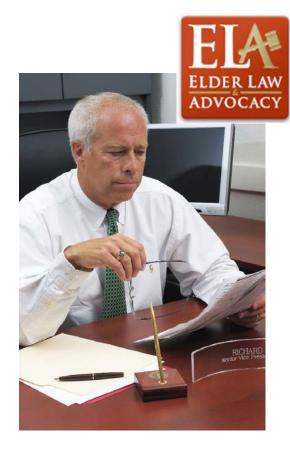
- What You'll Find In This Section:
  - Key Financial and Legal Documents
  - Resources to Assist

# **Key Financial and Legal Documents**

One of the most important steps you can take as a caregiver when assisting a loved one is understanding the legal rights and obligations provided by various legal documents:

- Advanced Healthcare Directive
- Power of Attorney (POA)
- Financial Power of Attorney (FPOA)
- The Physician Order for Life-Sustaining Treatment (POLST)
- Trust
- Will

Refer to the *Glossary of Documents/Terms to Know* section for more details on the purpose of each document and why they may be needed. These legal documents allow older adults to take control of their healthcare and financial decisions by establishing their preferences prior to an emergency and loss of capacity. Capacity is a term that describes whether or not a person has the mental ability to make effective decisions about his/her life, including the creation of legal documents. Once a person loses capacity, legal documents cannot be created or changed in most cases. Similarly, if the documents cannot be located, they effectively do not exist. Often in an emergency, essential documents cannot be located because they were put someplace "safe" and no one knows where that safe place is. Therefore, it is not only important to create these documents, but it is also crucial to make them accessible and easy for loved ones to find.



If your loved one does not have any of the essential documents, consult with an elder law attorney. The local non-profit organization Elder Law & Advocacy provides free legal services to adults 60 and older, including the preparation of some legal documents, such as advance healthcare directives and powers of attorney. You can contact Elder Law & Advocacy at (858) 565-1392 or visit their website at www.seniorlaw-sd.org/.

For those who may need more extensive legal assistance, the National Academy of Elder Law Attorneys (NAELA) website provides a list of elder law attorneys: www.naela.org.

For your convenience, forms are located in the back of this guide to help you keep track of which documents your loved one currently has and ones they may need. Please see the Appendix.

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# SECTION #6: Safety

### • What You'll Find In This Section:

- Disaster Preparedness
- Medication Management
- Fall Prevention

# **Disaster Preparedness**

There are measures that everyone can take to start preparing for emergencies before they happen. It is essential that caregivers have their own disaster preparedness plan. If you do not have your own plan in place, it will be difficult to assist your loved one with their needs during a disaster.

You can access a helpful guide to disaster preparedness for people who may need assistance and their caregivers on the Caregiver Coalition website at <a href="www.caregivercoalitionsd.org">www.caregivercoalitionsd.org</a>. Under the Resources section, scroll down to Office of Emergency Services: Disaster Preparedness Plan. This handbook outlines ways to prepare for different types of disaster, what to do during a disaster, and a customized personal disaster plan section designed for individuals receiving caregiving assistance. For additional disaster preparedness information and to sign up to receive emergency alerts, visit <a href="www.readysandiego.org">www.readysandiego.org</a>.

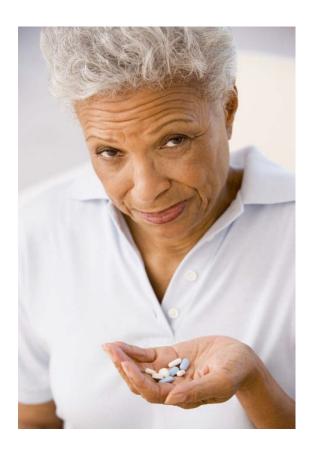


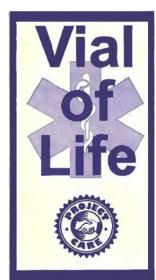
### **Medication Management**

Tracking prescriptions can be challenging. Not only are most of the names unfamiliar, but the varying instructions for dosages and times can easily get mixed up. It is good practice to list the name of the medication, the doctor who prescribed it, the strength of the medicine (for example, 150 mg.), what it was prescribed for, and how many times per day it's to be taken, on a piece of paper or an electronic device, such as your phone. Should you have any questions about your medications or any potential interactions between them, pharmacists can review your medication list for free.

You can complete a Vial of Life form to assist with keeping track of your medications (see Appendix for sample form). The Vial of Life is a tool that allows individuals to have their complete medical information ready in their home for emergency personnel to reference during an emergency. This tool is used to provide the patient's medical information when a patient is not able to speak or remember this information.

Print all the information into the chart so that anyone can read it easily. Any time a prescription changes, be sure to update the list. This tool will be very helpful to have with you each time you visit the doctor, so keep it handy and keep it current. Keep an updated list with you and a Vial of Life on your and your loved one's refrigerator. Take it when you travel and give a copy to the health care agent and other relatives who may be involved in care. To request a Vial of Life, call AIS at (800) 339-4661.









### **Fall Prevention**

Every 11 seconds, an older adult receives treatment in an emergency room for a fall. Falls pose a significant threat to the safety, independence, financial security, and physical activities of older adults. Additionally, several psychological implications can arise from a fall, such as anxiety, depression, and feelings of helplessness, which in turn can lead to activity avoidance, isolation, and social disconnectedness. While much of the conversation surrounding falls is focused on older adults, caregivers can also be adversely affected by the event. Caregivers may

### Did You Know?

One in four older adults falls every year. Falls are the leading cause of both fatal and non-fatal injuries for people age 65 and older.

experience excessive fear about the possibility of their care recipient falling or experiencing pain. Additionally, when caregivers witness a fall, it can be an equally traumatic event with significant mental health consequences.

Although falls are the leading cause of fatal injuries and nonfatal trauma-related hospital admissions among older adults, they are not an inevitable result of aging. In fact, through practical lifestyle adjustments, participation in community-based programs that improve balance and strength, and adoption of fall prevention practices, older adults can reduce their risk of falling. As a caregiver, it is important for you to be aware of the common risk factors for falls, appropriate steps you can take to prevent falls, and community resources to which you can refer for additional information.



### **Steps to Prevent a Fall**

- Physical activity: Identify opportunities to engage your care recipient in activities that boost their physical performance. Fitness programs that strengthen leg muscles and improve balance have been proven to reduce fall risk.
- Medication and chronic disease management: Many older adults are prescribed several different types of medication to help alleviate pain and other symptoms associated with chronic diseases such as arthritis, diabetes, and heart disease. A thorough medication review by your care recipient's physician or pharmacist may result in changes that can reduce fall risk.
- Home safety: Over half (55%) of fall-related injuries among older adults occur inside the home; therefore, it is important to inspect your care recipient's home for fall risks. Home modifications such as installing grab bars in the bathroom, using double-sided tape to keep rugs from slipping, and cleaning up clutter are simple methods of making a home safer and reducing the opportunity for trips and slips. Also, we need brighter lighting as we age, so check your light bulbs. For professional assistance, consult an occupational therapist.
- Vision check: Visual impairment is a leading contributor to falls among older adults; therefore, ensuring that your care recipient receives an annual vision exam is crucial. If your care recipient wears tint-changing lenses, it is recommended that they change glasses when going from bright sun into darkened buildings and homes or stop moving until the lenses adjust. Bifocals can be problematic when travelling up and down stairs, so proceed with caution. Those struggling with poor vision should consult with a low vision specialist to maximize safety. The San Diego Center for the Blind (<a href="www.sdcb.org">www.sdcb.org</a>; (619) 583-1542) and Braille Institute (<a href="www.brailleinstitute.org/sandiego">www.brailleinstitute.org/sandiego</a>; (858) 452-1111) are two organizations that can assist those with visual impairment.





### **Fall Prevention Action Plan**

Here are some simple steps you can take as a caregiver today to reduce your care recipient's fall risk, maintain his or her health and safety, and promote his or her independence.

Discuss current health conditions: Determine if your care recipient is having difficulty managing his or her own health. Warning signs could be forgetting to take medications or having difficulty with transfers to and from a chair. If you suspect your care recipient is experiencing changes in his or her health status, help him or her schedule an annual wellness visit with his or her healthcare provider. These visits are covered as a preventative benefit under Medicare.

Notice if your care recipient is holding onto walls, furniture, or someone else when walking, or experiencing difficulty rising from a chair: All of these actions indicate that your care recipient may need to consult with a physical therapist that is trained to improve balance, strength, and gait via exercise. Depending on the unique needs of your care recipient, a physical therapist may recommend the use of an assistive device such as a walker or cane and provide guidance on how to use these devices.

Find an appropriate community-based fall prevention program: There are several fall prevention programs in San Diego County that have been proven to help people reduce their risk and fear of falling. Below are two such programs that aim to reduce falls through physical activity:

- Feeling Fit Club: This is a free functional fitness program designed for older adults of all abilities. The goals of the Feeling Fit Club are to offer a safe, comfortable environment for older adults to engage in physical activity as well as to help older people develop and maintain their level of physical fitness. Feeling Fit classes also encourage social interaction, fun, and the building of self-esteem. All moves and exercises are designed to be adapted to various physical abilities and can be performed from a seated or standing position. The Feeling Fit Club is offered via four different delivery methods throughout San Diego County:
  - On-site classes two to three times a week with trained instructors at over 30 community sites
  - Telecast three times daily on the following channels: Cox channels 19 or 24,
     TimeWarner channel 83, and U-Verse channel 99
  - o Online at <a href="https://www.CountyNewsCenter.com">www.CountyNewsCenter.com</a>
  - Video/DVD program for home use (free copies may be requested by calling (858) 495-5500

• Tai Chi: Moving for Better Balance: This free program is modified and especially designed for older adults to reduce their fear and risk of falls. There are classes offered at several sites throughout San Diego County.







For additional information about these programs and other activities related to fall prevention, call (858) 495-5500, or visit the following websites:

- <u>www.SanDiegoFallPrevention.org</u> videos, local resources (exercise classes, local physical therapists, information on home modification, medical alerts), toolkit, and more!
- www.HealthierLivingSD.org includes schedules for programs and classes







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# SECTION #7: Self-Care and Support Services

- What You'll Find In This Section:
  - Self-Care Tips
  - Support Groups

# **Self-Care Tips**

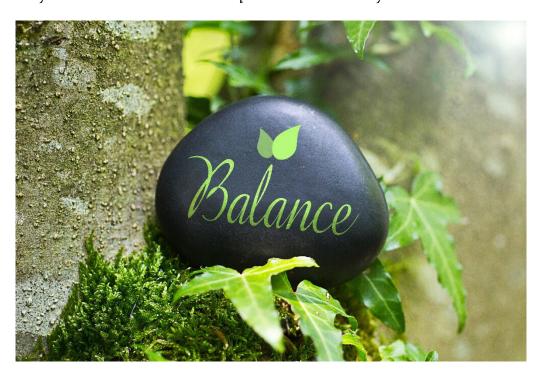
Caring for another person can have high physical, emotional, and financial costs. Being well-informed and building a support system is important.

Taking care of your own emotional health is one of the most significant things you can do for the person you are caring for. It is normal for a caregiver to occasionally feel discouraged, guilty, sad, lonely, frustrated, confused, or angry. All too often, caregivers find themselves in poor health, overwhelmed, and physically and emotionally exhausted. There's no better time than the present to start taking care of yourself.

Asking for help can be difficult, especially if you have always done everything on your own, are unsure what others can help with, or feel you are imposing. The Caregiver Coalition encourages you to seek help - your health depends on it!

### **Self-Care Tips**

- **Join a support or discussion group.** These groups offer a wealth of information, support, solutions, and new knowledge to help you on your caregiving journey.
- Find time for yourself. Take a break from time to time. Ask trusted family members or friends to help with caregiving tasks so you can focus on your own needs for a while. Respite programs are also available.
- Manage your level of stress. Stress can cause physical problems (blurred vision, stomach irritation, high blood pressure) and changes in behavior (irritability, lack of concentration, change in appetite). Note your symptoms and discuss with your doctor as needed. Try to find relaxation techniques that work for you.



- Spend time with friends. Connecting with others, stimulating your brain and having an outlet to revive yourself are all ways to reduce stress and maintain a healthy lifestyle.
- Schedule time for your hobbies and interests. Doing the things you love will increase your energy levels and help you maintain positivity and patience.
- Eat nutritious foods. It's tempting to eat comfort foods, but they can add to fatigue, poor health, and other medical problems. Staying energized and alert will help with cognitive functioning and a healthier heart. Diets such as the Mediterranean and Dietary Approaches to Stop Hypertension (DASH) have proven to be effective diets for maintaining a healthy brain and body.
- Get exercise as often as you can. If you aren't able to get out of the house each day, look for ways to stay active in the home. Consider using the Feeling Fit DVD or following along to a workout on the exercise channel on television.
- See your doctor on a regular basis. Regular check-ups are a good way to monitor your overall health and to alert you if early health intervention is needed.
- Learn about community resources. Adult day programs, in-home assistance, companion care, and meal delivery are just some of the services that can help you manage daily tasks. Explore this handbook and the websites on Page 10.
- Become an educated caregiver. If your loved one's condition declines, it may become necessary to adopt new caregiving skills. Look for free educational seminars offered by the Caregiver Coalition and other community organizations.
- Keep your health, legal, and financial information up-to-date. Having a plan in place in the event that anything happens to you will ensure the safety of the person you are caring for and can prevent unnecessary stress for the family.



### **Support Groups**

Joining a support group can be an important step in caring for yourself. Support groups can be a great opportunity for you to freely say what you are thinking and feeling to others who are in similar situations. The other members can offer suggestions, tell their own stories, and help you realize you are not the only one feeling overwhelmed or anxious. Whether groups are "disease-specific" or focus on general caregiving, they can be an excellent place to educate yourself or find a shoulder to lean on in a supportive environment.



If you hear someone say, "I tried a support group once and it wasn't for me..." consider that each group is as unique as the individuals involved. No one group is right for all people at all times. There will likely be a group that will suit you and your circumstances. If you are not able to attend an in-person group, there are groups and message boards available online.

If you have trouble asking for help, try these tips:

- Ask people to help out in specific ways like making a meal, picking up a prescription, visiting the person you are caring for, or taking the person out for a short time.
- Use the help of in-home care providers, respite programs, adult day care, and/or residential care services when you need them. To get started locating resources near you, contact 2-1-1 San Diego (<a href="www.21lsandiego.org">www.21lsandiego.org</a>), visit The San Diego Union Tribune's caregiver website (<a href="www.caregiverSD.com">www.caregiverSD.com</a>), or contact the Aging & Independence Services Call Center at (800) 339-4661.
- If you are a veteran or caring for one, several resources may be of help to you. The U.S. Department of Veterans Affairs (VA) has a VA Caregiver Support website at <a href="https://www.caregiver.va.gov">www.caregiver.va.gov</a> or contact the San Diego County Office of Military & Veterans Affairs at (858) 694-3222.



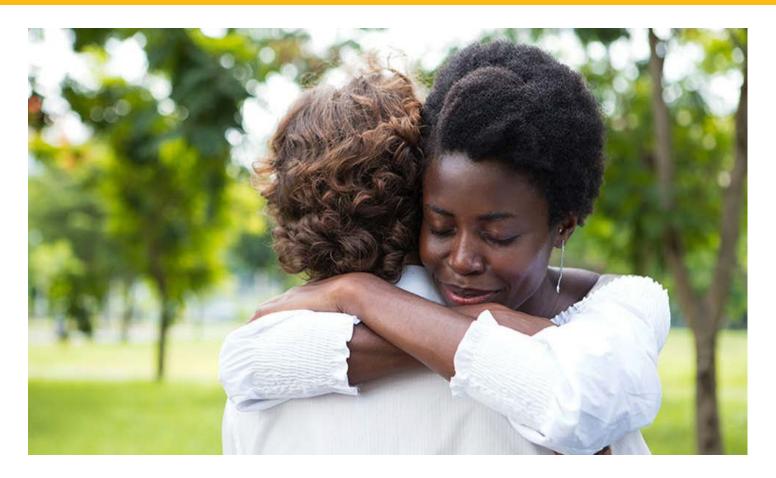




# SECTION #8: Understanding Alzheimer's Disease and Related Dementias

### What You'll Find In This Section:

- Diagnosis of Alzheimer's Disease and Related Dementias
- Stages of Alzheimer's Disease
- Common Behaviors and Triggers
- Tips for Communication and Behavioral Symptom Management
- Safety Considerations
- Tips for Addressing Common Behaviors During Stages of Dementia
- Take Me Home Program
- Tools for Better Communication
- Tips for Talking About Difficult Subjects
- Tips for Dealing with Stress
- Parkinson's Disease, Alzheimer's and dementia



Experts suggest that more than 5 million Americans may have some form of dementia. Dementia is an irreversible, progressive brain disorder that slowly impacts memory, thinking skills, and eventually, the ability to carry out the simplest tasks. Although symptoms can vary widely, the first problem many people notice is forgetfulness that's severe enough to interfere with daily life. As of 2015, over 84,000 San Diegans age 55 and older were estimated to be living with some form of the disease.

The most common type of dementia among older adults is Alzheimer's disease; other dementias include Lewy Body dementia, frontotemporal disorders,

### Did You Know?

Alzheimer's disease is currently ranked as the sixth leading cause of death in the United States and the third leading cause of death in California and San Diego County.

vascular dementia, and dementia from Parkinson's disease and similar disorders. Due to the nature of the disease, it can be particularly challenging and stressful for individuals providing care to a person with Alzheimer's disease or a related dementia diagnosis.

### **Diagnosis of Alzheimer's Disease and Related Dementias**

Physicians can conduct comprehensive evaluations to determine whether or not a person could possibly have Alzheimer's disease or a related dementia. These tests may be repeated to give doctors information about how the person's memory and cognitive function might change over time. Alzheimer's disease can only be definitively diagnosed after death, by linking clinical measures with an examination of brain tissue in an autopsy. Current clinical trials are looking at ways of diagnosing and detecting brain abnormalities before symptoms appear

People with cognitive impairment concerns should talk to their doctor to find out whether their symptoms are due to Alzheimer's or other causes such as stroke, tumor, Parkinson's disease, sleep disturbances, side effects of medication, infection, or vitamin deficiency or a non-Alzheimer's dementia. Some of these conditions may be treatable and possibly reversible.

If the diagnosis is Alzheimer's disease, seeking support early in the disease process may help preserve daily functioning for some time, even though the underlying disease process cannot be stopped or reversed. An early diagnosis also allows families to plan for the future. They can take care of financial and legal matters, address potential safety issues, learn about memory care, and develop support networks. In addition, an early diagnosis gives people greater opportunities to take part in clinical trials that test for possible new treatments for Alzheimer's disease.



### **Stages of Alzheimer's Disease**

While the first symptoms of Alzheimer's disease vary from person to person, and the disease advances at different rates, stages provide a general guideline for understanding the progression of Alzheimer's disease. It is important to remember the disease will affect everyone differently, the time spent in each stage varies, and not everyone experiences all Alzheimer's disease symptoms.

Early Stage: In the early stage, people can experience changes in their short-term memory, have difficulty remembering names of words, get lost more frequently, have trouble handling money and paying bills, repeat questions, take longer to complete normal daily tasks, and exhibit personality and behavior changes. The average length of this stage is 2-3 years.



The disease will affect everyone differently, the time spent in each stage varies, and not everyone experiences all Alzheimer's disease symptoms.

Middle Stage: In the middle stage, damage occurs in areas of the brain that control language, reasoning, sensory processing, and conscious thought. People may have more difficulty communicating or following the sequence of a conversation or storyline. They may be unable to learn new things, carry out multistep tasks such as getting dressed, or cope with new situations. In addition, people at this stage may experience delusional thinking, paranoia, and may behave impulsively. The average length of this stage is 6-8 years.

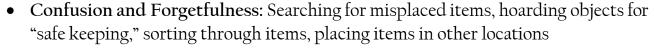
Late Stage: In the late stage, damage continues to spread throughout the brain causing further problems and brain atrophy (shrinkage). It becomes difficult for people to communicate and they will need full assistance with activities of daily living (bathing, dressing, toileting, eating, ambulation). The body begins to prepare for end of life. The average length of this stage is 2-23 years.

### **Common Behaviors and Triggers**

It is common for people living with dementia to show changes in behavior and their ability to communicate. A behavior is often a form of communication and may be an attempt to express discomfort. Looking for these causes or "triggers" can help you identify needs expressed by behaviors, therefore allowing you to address the behavior before it escalates. Although causes of behaviors may be difficult to sort out, it is important not to ignore the problem, but acknowledge the emotional needs of your loved one.

### Common behaviors may include:

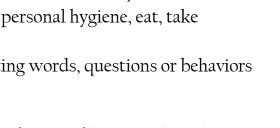
- Agitation: Pacing the room, fidgeting, easily upset, yelling
- Aggression: Verbal arguments, threatening others, physically harming oneself or others
- Hallucination: Seeing, hearing, smelling, tasting, or feeling something that isn't there
- Delusion: Believing something to be true when it is not
- Paranoia: Believing others are stealing or lying to them, claiming others are "out to get me"



- Sundowning: Late afternoon or early evening restlessness, irritability, or confusion
- Refusal to Complete a Task: Declining to perform personal hygiene, eat, take medications
- Repetition: Saying something over and over, repeating words, questions or behaviors

### Common triggers may include:

- Pain, depression, fear, or stress
- Unmet needs such as hunger, thirst, boredom, constipation
- Too little rest or sleep
- Soiled underwear or briefs
- Sudden change in a well-known place, routine, or person
- Interaction of medicines
- Urinary tract infection (UTI)



- A feeling of loss such as the person may miss the freedom to drive or the company of their deceased spouse
- Too much noise or confusion or too many people in the room
- Being forced by others to do something, such as bathe or to remember events or people
- Feeling lonely and not having enough contact with other people

### **Tips for Communication & Behavioral Symptom Management**

- Give short explanations and allow extra time for comprehension.
- Validate the feelings behind what your loved one is saying.
- Avoid using reason, logic, or confrontation.
- Use humor when you can. Be patient and reassuring.
- Help your loved one complete tasks, while still considering their independence and self-regard.
- Create a daily routine so your loved one knows when certain things will happen. Build quiet times into the day, along with activities.
- Keep familiar objects and photographs nearby to help your loved one feel more secure.

- Reassure your loved one that he or she is safe, and you are there to help.
- Reduce noise, clutter, or the number of people in a room.
- Learn where your loved one might hide things, or purchase duplicates.
- Turn on lights and close the curtains or blinds before dusk to minimize shadows.
- Ask the doctor if medicine is needed to reduce or prevent agitation or aggression.
- Do not argue.
- Meet individuals in their reality.
- It is not necessary to correct your loved one's perception of reality.
- Play soothing music, read a good book, or take a nice stroll.



### **Safety Considerations**

Individuals living with mild memory cognitive impairments can often live and be left alone safely; however, at some point it will become necessary to have someone with the person at all times in order to prevent injury or harm. Planning ahead and preventing injury can extend the person's independence. If you notice some of the changes listed below, consider planning for more supervision, support, or alternative housing options.

### It has become challenging to:

- Take medications successfully and safely
- Grocery shop, prepare meals, pay bills, maintain household cleanliness and home repairs
- Use the telephone, television, or other technology
- Remember the current phone number or home address
- Remember to extinguish cigarettes, turn off burners or oven, lock or secure the home
- Eat well-balanced meals and drink appropriate amounts of water
- Judge the appropriate temperature for getting dressing or using the thermostat

### Your loved one experiences:

- Feeling worried, anxious, isolated, and lonely
- Paranoid thoughts, hallucinations, delusions, aggression, or thoughts of suicide
- Being the victim of fraud, telemarketers, or a crime
- Becoming lost while walking and/or driving, or is often disoriented
- Weight loss or gains and/or their pets have weight loss or gains

### You, as their caregiver, are noticing:

- They call others constantly or the police are being called by the neighbors
- Items are missing around the home
- Your loved one has mysterious bruises, scratches, or unusual marks
- Your loved one gets locked out of the home frequently
- Personal care/hygiene is neglected; your loved one wears the same clothing all the time
- Their vehicle has new dents or scratches or they make frequent driving errors

# Tips for Addressing Common Behaviors During Stages of Dementia

### Behaviors you may encounter during early stages of dementia:

### **Short Term Memory Concerns**

- Try using photographs to help remind individuals of important relationships and places.
- If the person's memory is focused on a particular time in their life, talk to them and ask questions about that time.
- Use memory aids, such as notes, clocks, calendars, or photographs, if appropriate.

### Repetition

- It is important to be patient. Reassure the person with a calm voice and gentle touch. Keep in mind that the person may not recall they already asked the question before.
- It is generally not helpful to point out that the person is repeating themselves.

### Behaviors you may encounter during middle stages of dementia:

### Suspicion and Delusions

- Avoid arguing with the individual. Let them share their concerns and acknowledge their feelings.
- Provide simple explanations so you do not overwhelm the person.
- Try to shift the person's focus by asking for help with a chore or engaging them in an activity.

### Hallucinations

- Respond in a calm, supportive manner and acknowledge the feelings behind the hallucination. You might want to say, "It sounds as if you're worried" or "I know this is frightening for you."
- Modify the environment by listening for sounds that might be misinterpreted or lighting that casts shadows, reflections, or distortions on the surfaces of floors or walls.

### Behaviors you may encounter during later stages of dementia:

### Aggression and Anger

- Try to identify what may have triggered the person. Did something cause this reaction?
- Make sure the person is not in pain or experiencing discomfort.

### Sundowning (agitation in the later part of the day)

- Schedule activities such as trips and bathing in the morning or early afternoon hours when the person living with dementia is more alert.
- As much as possible, encourage a regular routine of waking up, meals, and going to bed.

For more suggestions, visit <a href="https://www.alz.org/">https://www.alz.org/</a>.

### **Take Me Home Program**

Getting lost is scary and can be dangerous; especially for someone living with dementia, autism, or other cognitive conditions. The Take Me Home program is a registry designed for individuals who may have difficulties communicating or finding their way home.

You can sign your loved one up for the Take Me Home program by contacting your local Crime Prevention Specialist at the following patrol stations:

- 4S Ranch
- Alpine
- Borrego Springs
- Boulevard
- Campo
- Dulzura
- Fallbrook

- Imperial Beach
- Julian
- Lakeside
- Lemon Grove
- North Coastal
- Pine Valley
- Poway

- Ramona
- Ranchita
- Rancho San Diego
- San Marcos
- Santee
- Valley Center
- Vista

To enroll someone in the registry, submit a photo, along with descriptive and contact information online at <a href="www.sdsheriff.net/tmh">www.sdsheriff.net/tmh</a>. Participating law enforcement organizations will have access to critical information about a registered person in case of an emergency.

# What should I do if my loved one goes missing?

Call 911 immediately and explain that your loved one has dementia or another disability. If they are enrolled in Take Me Home, be sure to let the dispatcher know that as well.

### How will this help?

Information about their physical appearance, the most likely places they would go, as well as triggers and de-escalation techniques will be sent to all law enforcement in the area to look for the missing person.



### **Tools for Better Communication**

Through kindness and understanding, we can improve the quality of life of our friends and neighbors living with dementia.

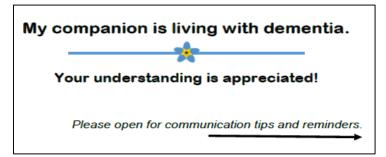


### The following tips and reminders can help:

- Dementia causes changes in thinking, memory, reasoning, and behavior; please be patient.
- When speaking with someone living with dementia, approach them slowly from the front, use simple sentences, and allow ample time for a response.
- If the person cannot find the right word, encourage visual communication such as gestures or pictures. Try guessing the right word.
- 4. When all else fails, a friendly smile goes a long way.

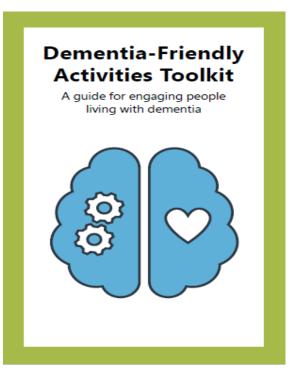
### **Tip Card**

Those living with dementia may have limited communication skills, making social interactions difficult. The Dementia Friendly Team developed communication tip cards to use when you are in the community with a companion with dementia. The card has tips and reminders on how to interact with a person who has dementia.



To download a copy of the tip card that you can print out, or to join the Dementia-Friendly Team, visit: <a href="https://www.LiveWellSD.org/DementiaFriendly">www.LiveWellSD.org/DementiaFriendly</a>

### **Dementia-Friendly Activities Toolkit**



- The Dementia-Friendly Activities Toolkit provides resources, guidance, and ideas for activities to help keep those living with dementia engaged.
- Some activities may be used on a one-to-one basis, others may be suitable for small groups.
- This Toolkit introduces "dementia-friendly practices," or ways of better communicating with and supporting those with dementia. By applying a dementia-friendly lens to activities and interactions, communication will improve, frustration may decrease, and time spent together will be more enjoyable.
- To access a downloadable pdf version of the Toolkit, visit: www.LiveWellSD.org/DementiaFriendly

These resources are brought to you by the Age Well San Diego Dementia-Friendly Team.

### **Become a Dementia Friend**

Learn more about what it is like to live with dementia and turn your understanding into action by attending a 60-minute virtual workshop! You can become a Dementia Friend by emailing AISAlzheimer.HHSA@sdcounty.ca.gov for more details.

### **Tips for Talking About Difficult Subjects**

Although talking with a loved one about dementia and its impact on their day-to-day life can be tough, it is important to have these conversations as soon as possible. Plan ahead on how you might guide the discussion to a positive outcome. Practice what you will say and try to be as relaxed as possible. (For more tips, see pages 34 and 35.) Below you can find some conversation suggestions.

### Going to the doctor:

- Tell your loved one: "I'm noticing that you're forgetting more things lately. Let's talk with the doctor about it to see what we can do."
- Suggest pairing a trip to the doctor with an enjoyable outing.
- Use comforting language. Reassure your loved one that you want to stay focused on what they can do, rather than what they can't.
- Advise your loved one to take advantage of Medicare's free Annual Wellness Visit and suggest going out to a meal afterward.

### Deciding when to stop driving:

- Express your concern about changes in driving skills you have noticed.
- Try this conversation prompt: "Would you want to know if I noticed any changes in your driving?"
- Tell your loved one: "I know that you wouldn't want an accident to happen or for you or someone else to get hurt."
- Offer other transportation options, see page 22.

### Making legal and financial plans:

- Explain that you are in this together and that making plans helps assure that your loved one is cared for in the ways they would want.
- Emphasize that medical directives and related documents should be completed by everyone as they get older.
- Tell your loved one: "By getting all this necessary paperwork done now, we can relax and focus on enjoying time together. It would be much more difficult to make plans in a crisis."
- Discuss these subjects over a series of conversations because they can be complicated and difficult.
- Involve experts and family members as needed.
- For more information, see page 37.

### **Tips for Dealing with Stress**

Caregiving can be overwhelming. It can take a big toll on your physical and mental health, along with family finances. See Pages 50 and 51 for details on the importance of self-care.

### Here are some additional suggestions:

- Keep a daily journal. Write or draw to express how you feel and what's on your mind.
- Download and try a meditation app like Headspace or Calm. There are many available for your cell phone. Some are free.
- Exercise. It doesn't have to be anything strict or formal. Do what feels right for you. For example, you can go for a walk or practice yoga.
- Take free Feeling Fit classes right from your own home. For more information, see page 46.
- Sit outside and soak up the sun and nature. Take a deep breath.

### For additional resources, see page 17 and 18.



### Alzheimer's Association – (800) 272-3900 or www.alz.org/sandiego

The local chapter of the national Alzheimer's Association offers services such as: educational programs, a Helpline that operates 24 hours a day/7 days a week, resource information, a monthly telephone caregiver support group, and online community message boards.

### Alzheimer's San Diego - (858) 492-4400 or www.alzsd.org

Alzheimer's San Diego offers a variety of innovative programs and services, including: classes and workshops for caregivers, support and discussion groups, resource information, guidance from professional dementia experts, social activities, and respite care.

### Southern Caregiver Resource Center - (800) 827-1008 or www.caregivercenter.org

SCRC provides no-cost services to family caregivers, including: family consultation/case management services, short-term counseling, legal/financial consultations, education and training, support groups, and respite care.



### **Parkinson's Disease**

Parkinson's is progressive nervous system disorder that affects movement. Symptoms often vary from one person to another and can include a combination of body tremors, rigid limps, balance problems, and slowness of movement. Other possible symptoms include small handwriting and reduced facial expressions.

The cause of the disease remains largely unknown, but researchers believe it may be a blend of environmental and lifestyle factors, along with genes. There is no known cure. Treatment typically includes a combination of medication, exercise, and physical and speech therapy. While Parkinson's itself is not fatal, complications from the disease can be serious.



- Parkinson's affects roughly 1 million to 1.5 million Americans, with 50,000 to 60,000 new cases reported annually.
- Most people diagnosed with Parkinson's are over 65 and about 60 percent are men.
- It is second to Alzheimer's as the most common neurodegenerative disease in the United States.

### Parkinson's, Alzheimer's, and dementia

Most people with Parkinson's eventually develop some cognitive impairment, but cognitive impairment does not usually appear until the later stages of the disease. These impairments are characterized by slowed thought, along with difficulty resisting impulses, and combining thoughts into a new idea or plan.

Slowing of thought can cause major problems for people with Parkinson's, making it difficult to take part in conversation. They can also appear to lose interest in their surroundings, creating the impression of lost thinking ability.





### **13 Tips for Caregivers**

- Soon after your loved one receives a diagnosis, talk with them about how to share the news with family and friends.
- Join a Parkinson's disease support group in your area.
- Talk with an experienced Parkinson's caregiver. They can provide perspective and reassurance.
- Be prepared for a lot of well-intended advice from friends and family who may promote "miracle cures" they saw online or elsewhere.
- Have an honest talk with your loved about when they truly want or need help. A caregiver sometimes takes on responsibilities that the person with Parkinson's can do.
- Educate yourself on the disease and its likely progression.
- Attend your loved one's medical appointments. Be prepared to ask questions and advocate for their needs.
- Adapt or modify the home so it's safe and accessible.
- Stay on top of any insurance and other health care coverage-related issues.

### Parkinson's, Alzheimer's, and dementia

### 13 Tips for Caregivers (cont.)

- Make sure medications are taken.
- Watch for changes in symptoms, abilities, and moods. All can be affected by shifts in medication or therapy.
- Take advantage of respite care services to help avoid burnout.
- Take care of your own physical and mental well-being.



### For additional resources:

- Parkinson's Association of San Diego (858) 999-5671 or www.parkinsonsassociation.org
- Parkinson's Foundation (800) 473-4636 or <u>www.parkinson.org</u> (866) 358-0285
- Davis Phinney Foundation for Parkinson's or davisphinneyfoundation.org
- American Parkinson Disease Association (800) 223-2732 or www.apdaparkinson.org

# **NOTES**

# SECTION #9: Caring for Someone Living with Mental Health Challenges

- What You'll Find In This Section:
  - Seeking Help Together
  - Support for Mental Health

Mental illnesses are medical conditions that can disrupt an individual's thinking, feeling, mood, ability to relate to others, and daily functioning. There are over 200 classified forms of mental illness and they include various anxiety disorders, mood disorders, eating disorders, and psychotic disorders among others. They affect persons of any age and often result in a diminished capacity for coping with the ordinary demands of life. It can be difficult to provide care to individuals with mental illness as every mental health condition brings with it unique challenges and symptoms specific to the disorder.

When a friend or family member develops a mental health condition, it is important to know that you are not alone as their caregiver. A misconception among many people is that mental disorders are rare when, in fact, they are quite common and widespread. An estimated 26% of Americans age 18 and older – about 1 in 4 adults – experiences a diagnosable mental disorder in a given year. Some individuals will suffer from more than one mental disorder at a given time.



### **Seeking Help Together**

Mental health challenges not only affect the individual, but often their social circles too – their neighbors, coworkers, friends, and others in the community. Despite the prevalence of mental illness, the stigma surrounding behavioral health issues can deter people from seeking help or telling their loved ones. Family members and caregivers play a large role in helping and supporting these individuals.

Mental illnesses are treatable. People diagnosed with a serious mental illness can experience relief from their symptoms by actively participating in a treatment plan. Caregivers can help establish this plan and work with their loved one to explore psychosocial treatments (as appropriate) such as cognitive behavioral therapy and interpersonal therapy, as well as get connected to local peer support groups and other community services to assist with recovery.

Individuals living with mental health challenges and their caregivers are encouraged to call the San Diego County Access and Crisis Line at (888) 724-7240 if they need someone to talk to and/or if they want to learn about programs and services available to them. Trained professionals operate the prevention/intervention hotline 24 hours a day/7 days a week and help residents to identify and navigate behavioral health resources specific to our region.

Tips for caregivers of individuals with mental illness:

- Find and attend educational classes to learn about the latest information and/or treatments regarding your loved one's specific mental health condition.
- Build a relationship with your loved one's treatment provider. It is important that you feel comfortable sharing information and discussing concerns together confidentially.
- Utilize any faith or spiritual connections.
  Research indicates individuals with mental
  health challenges often trust a member of the
  church or synagogue they belong to. Many faith
  and spiritual institutions have support groups
  or mental health ministries.
- Talk to others going through a similar caregiving journey. This could be via an inperson or online support group. Speaking with someone who understands what you are going through may relieve stress for both parties. Helping others evokes gratitude and research has found this naturally instills health and happiness within us.

# Did You Know?

In the event of an emergency connected to your loved one's diagnosis, you can call 9-1-1 and specifically request help from the Psychiatric **Emergency Response Team** (PERT). PERT pairs licensed mental health clinicians with law enforcement. Members of PERT are specifically trained to evaluate situations and assess an individual's mental health condition and needs.

### **Support for Mental Health**

### Local Resources:

- National Alliance on Mental Illness (NAMI) San Diego (800) 523-5933
- NAMI North Coastal **(760) 722-3754** (not a crisis line)
- Mental Health America of San Diego County (619) 543-0412
- Contact the San Diego Access & Crisis Line at (888) 724-7240 or visit www.livewellsd.org/checkyourmood for a more comprehensive list of regional resources

### National Lifelines:

- National Suicide Prevention Lifeline (800) 273-8255
- Substance Abuse and Mental Health Administration (SAMHSA)
   National Helpline (800) 662-4357
- Veterans Crisis Line (800) 273-8255, then press 1
- The Trevor Project: Trevor Lifeline (866) 488-7386

# **NOTES**

# **SECTION #10:** End of Life Care

### • What You'll Find In This Section:

- Palliative Care
- Hospice Care
- Making Final Arrangements
- Steps to Take at the Time of Death

### **Palliative Care**

Palliative Care is a special form of medical care that helps patients with a chronic or serious illness feel relief from pain, symptoms, and emotional stress. Palliative care is comfort care that can be administered any time during the course of an illness. The goal of palliative care is to improve the quality of life for both the patient and family. Palliative care is appropriate at any age and any stage of a serious illness. Talk with your physician if you think palliative care might help.



# **Hospice Care**

Hospice care is a special kind of palliative care used for patients who are no longer seeking curative treatment. Medicare, Medi-Cal and most private insurance companies provide for hospice care once a physician determines the patient has about six months or less to live. Through pain management, symptom control, and comfort measures, the treatment team provides support to the patient and family in their own home. Hospice care can also be provided in skilled nursing facilities, assisted living facilities, and hospital settings. Hospice can help ease the burden of caring for a loved one. Hospice focuses on dignity, comfort, and respect at the end of life. Bereavement support is offered after your loved one passes away, regardless of whether someone received care from a hospice agency. Families can choose their preferred hospice agency. For more information, ask your care provider or refer to the National Hospice and Palliative Care Organization website: <a href="https://www.nhpco.org">www.nhpco.org</a>.

# **Making Final Arrangements**

Items you may want to discuss include:

- Would the person want burial or cremation? Where would the burial take place? If cremation is chosen, would the cremains be returned to the family in an urn, buried at a cemetery, or scattered at sea?
- Choosing a casket, urn, burial site, and/or a mortuary in advance can help relieve the stress of making decisions while grieving a recent loss.
- What type of service is preferred? Would the person and family prefer flowers or a charitable donation?
- Has your loved one already made a plan or paid for any funeral services in advance?
- Is your loved one an organ donor? Do they wish to donate their body for medical research?

Consider budget and costs involved when making decisions. Costs may be pre-paid or identified in advance. If the person was a veteran or spouse of a veteran, some cemetery costs may be covered through the Veterans Administration.

Many families find it helpful to discuss specifics about a funeral service and burial or cremation options with a loved one before the death occurs. It can be an uncomfortable topic, but by having the conversation in advance, the family experiences less stress at the time of a death. It may be a comfort to the person to know they have discussed their wishes with their loved ones.



# Steps to Take at the Time of Death

A legal declaration of death needs to be made. This can be done by a doctor or a hospice nurse. If the person dies at home without hospice care, you will need to call 9-1-1. The paramedics will attempt cardiopulmonary resuscitation (CPR) unless you have "Do Not Resuscitate Orders" (DNR). After administering CPR, the paramedics will take your loved one to the emergency room for a doctor to make the legal declaration of death. The legal agent or next-of-kin will be the one in charge of the final arrangements.



### **Next Steps**

- Choose a mortuary once the medical examiner or hospice provider gives you authorization that your loved one can be released.
- Decide what kind of services you will have cremation, traditional burial, or possibly arrangements in another region.

# **Life After Caregiving**

In the days, weeks, and months after your loved one has died, you may experience a wide variety of emotions. There is likely to be grief over the loss of an important relationship. Remembering happy times, reaching out to others for support, or participating in a grief support group can be healing for many people. However, in addition to feelings of grief, you may also experience other emotions, some of which you might feel uneasy about. For instance, it is quite common for caregivers to feel a sense of relief that they no



longer are in the caregiving role. This is understandable given how stressful, time-consuming, and emotionally taxing caregiving can be. If you find yourself feeling guilty about this, it is important to remind yourself that you also feel relief because you no longer have to witness your loved one suffer and decline. Feelings of guilt about caregiving performance may also arise after your loved one has passed. It is common to worry that not enough was done for your loved one or recall the times when you may have been short on patience or lost your temper. If these feelings come up, it is important to reflect on the many times you did show up in a positive way and how, overall, you did a good job caring for your loved one.

It is also common for caregivers to feel emptiness in their lives after their loved one has died. For some, much of their lives was consumed with meeting their loved one's needs. Whether it was getting their ailing mother to all of her medical appointments or taking care of their spouse's personal care needs, caregivers often find that their social world shrinks. Out of necessity, your loved one became the center of your life and most activities were organized around meeting their needs.

Once a loved one has died and the flurry of activity that comes with planning a memorial and getting their affairs in order has passed, caregivers may also find that they suddenly have a lot of time that they don't know what to do with. You will need to start to get in touch with your own needs and wants again. Whether that is making your health a priority by improving diet and exercise habits, pursuing a new interest, or reconnecting with your friends, it is important that you turn the focus back on yourself and find new meaningful roles and activities.

Caregiving is a crucial role and a gift to those who are being cared for. When your caregiving journey comes to a close, be sure to give yourself credit for the positive difference you made in your loved one's life.

# **NOTES**

GLOSSARY		

## **Documents and Terms to Know**

### **Advance Healthcare Directive (AHCD)**

This document describes a variety of ways in which you specify and explain your health care wishes. In California, the advanced health care directive may take the place of both the health care power of attorney and the living will. This document should be frequently updated. Let your agents (your spokespersons) and loved ones know where the document is kept, and give copies of the AHCD to your agents, your physician, and your health care system. If you are ever unable to speak for yourself, an AHCD makes sure health care providers are talking to the right person about your care, and ensures they understand your health care wishes.

### Conservatorship

A conservatorship is the legal proceeding used to manage an adult's physical or financial affairs when he or she has lost the ability to do so for themselves and has not pre-designated someone else to take on this role. This pre-designation can be done by creating a durable power of attorney and an advance healthcare directive.

There are two types of conservatorships: physical and financial. Each requires a series of court hearings and could require a trial to determine whether the person is unable to manage their affairs and who should be in charge. This court process is overseen by the probate court and can be quite expensive and time consuming.

### **Power of Attorney**

A power of attorney (POA) is a legal document that enables the grantor (the person who is the subject of the document) to designate another person, called the agent or attorney-in-fact, to act on his/her behalf. The agent should be a trusted person of the grantor. All powers of attorney expire at death.

A POA can be "General" or "Durable."

- A General POA lapses when the grantor is incapacitated (i.e., when caregivers need it most!).
- A Durable POA will continue to be in effect after the onset of incapacity.

### **Financial Power of Attorney**

A financial power of attorney is a document that allows an agent to manage the grantor's financial resources and obligations. Resources include assets and income sources, and obligations include debts that are in the name of the grantor. A durable financial power of attorney will continue to work after the onset of incapacity.

# Health Insurance Portability and Accountability Act Waiver (HIPAA Waiver)

HIPAA was passed in 1996. Significantly, it provides that an individual's health care information is private and requires all health care providers to safeguard all medical information. This, in short, means that your medical records are confidential and are not to be reviewed by anyone without prior written consent. It also means that spouses do not have the right to any medical information on each other. Parents have no right to information about their children aged 18 or older. Adult children do not have the right to access a disabled parent's record or even discuss the parent's treatment plan with the physician. The problem can be fixed by creating a HIPPA Waiver. This document specifically authorizes a person or group of people the right in writing to access medical records. This right to access can be broad or narrow depending upon what the individual wants.

### Intestacy

This occurs when a person dies without a written estate plan. If this occurs, assets will be distributed according to a predetermined distribution pattern created by the California legislature. This process will be overseen by the probate court.

### **Joint Ownership**

Joint Ownership is often referred to as the poor man's probate by attorneys because it allows a person to transfer management and distribute assets without having to go through the probate process. Quite simply, this is putting someone else's name on your property. This is most often done with married couples (i.e. a joint bank account). Beyond that, it often creates more problems than it solves as these jointly-owned assets are now owned by multiple people. These problems include the loss of control, loss of creditor protections, and potential tax problems.

### The Physician Order for Life-Sustaining Treatment (POLST)

The POLST form is a physician order that helps give seriously ill patients, and people who have strong feelings about their healthcare treatment, more control over their care. Produced on a distinctive bright pink form and signed by both the doctor and patient, POLST specifies the types of medical treatment that a person wishes to receive toward the end of life. As a result, POLST can prevent unwanted or medically ineffective treatment and, in some clinics, may replace the Pre-Hospital Do Not Resuscitate form. For more information, visit <a href="https://www.capolst.org">www.capolst.org</a>.

### **Trust**

A trust is a document that works much like a financial power of attorney and a will. Trusts control both the management and distribution of assets while a person is alive, but incapacitated, and continues to work after death. Critically, trusts will only manage assets that are held in the name of the trust. All assets that are not specifically put into the name of the trust will not be considered held in trust and therefore will not be subject to the terms of the trust.

### Will

A will is a document that directs the disposition of a person's assets after death. All wills must be administered by the Probate Court and the proceedings are public.

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# **NOTES**

# **Personal and Family Information**

Legal Name:	Nickname(s):		
	Social Security Number:		
	Cell Phone Number:		
Location of Citizenship Papers	s: Passport No:		
Date of Birth:	Place of Birth:		
Location of Birth Certificate: _			
	Marital Status:		
	State of Jurisdiction:		
	Last Military Rank:		
	Serial (Service) No:		
Branch:	Country Served:		
Spouse's Name:	Nickname(s):		
Other Names (Maiden):	Social Security Number:		
Address:			
	Cell Phone Number:		
Date of Birth:	Place of Birth:		
Location of Birth Certificate:			
Date and Place of Marriage:	Marital Status:		
Location of Divorce Papers:	State of Jurisdiction:		
Location of Discharge Papers:	Last Military Rank:		
Military Service Dates:	Serial (Service) No:		
Branch:	Country Served:		
Father's Name:	Date of Birth:		
Place of Birth:	Date of Death:		
Place of Death:			
Mother's Name:	Date of Birth:		
Place of Birth:	Date of Death:		
Place of Death:			

Children's Names and Addre	esses:	
Sibling's Names and Address	Ses:	
Legal Residence		City <sup>.</sup>
State:	Zip Code:	City
	ame(s) of:	
	Date Acquired:	
	nts:	
	Mortgage Copy:	
Title Insurance Policy:	Title Abstr	act:
Surveys:	Closing Statement: _	
Tax Receipts:	Cost Figures:	
Leases:		
Landlord Name:	Phone Num	ber:
Address:		City:
State:	Zip Code:	_

Employment Hi		
Name of Last Employer	r:	
State:	Zip Code:	_
Pension or Benefits Off	ice Phone Number:	
Location of Retirement	Papers:	
Date of Hire:	Date of Termination:	
Starting Salary:	Salary at Termination:	
Name of Previous Emp	loyer:	
	,	
	Zip Code:	
	ice Phone Number:	
	Papers:	
	Date of Termination:	
Starting Salary:	Salary at Termination:	
	•	
Name of Previous Emp	loyer:	
	•	
	Zip Code:	
	ice Phone Number:	
	Papers:	
	Date of Termination:	
	Salary at Termination:	
Social Socueity	Popolito	
Social Security		
	Social Security Claim Number:	
	Monthly Pension Inc	come:
Location of Related Do	cuments:	

# 

- Antiques
- Art
- Cameras
- Collectibles
- Furniture
- Furs
- Jewelry
- Other Precious Metals

Accountant	
	Phone Number:
	City:
State:Zip	
Location of Recent Tax Filings:	
Bank Accounts	
Name:	Account Number:
Address:	
Location of Bank Statements:	
Other Signature:	
Name:	Account Number:
Address:	
Location of Bank Statements:	
Other Signature:	
	Account Number:
Address:	
Location of Bank Statements:	
Other Signature:	
Safe Deposit Box	
Location:	Box Number:
() 8	
Location of Keys:	

## **Investments**

Broker Name:	Phone Number:	
Address:		
	Phon	
	Account 1	
Other Signature:		
Account Type:	Account Number:_	
	Phone Number:	
Address:		
Date Account Opened:	Original Deposit Amou	ınt:
Interest Rate:	Maturity Date:	
Account Type:	Account Number:_	
Name of Institution:	Phone Number:	
Address:		
Date Account Opened:	Original Deposit Amou	int:
Interest Rate:	Maturity Date:	
Account Type:	Account Number:_	
Name of Institution:	Phone Number:	
Address:		
<del>-</del>	Original Deposit Amou	int:
Interest Rate:	Maturity Date:	

Shares Purchased	Date of Purchase	Purchase Price
	pl 27 1	
	oration Date:	
cution:	Phone Number:	
. •	pl v l	
	DITATION Date:	
cution:	Phone Number:	
ution:	Phone Number	
	Shares Purchased  Shares Purchased  Expectation:  Expectation:  Expectation:  Expectation:  Expectation:  Expectation:  Expectation:  Expectation:  Expectation:	tatements, Purchases and Sales:    Shares Purchased

## **Personal Loans**

Loan in the Name of:	Loan Type:
	Original Amount of Loan:
Interest Rate:	_ Due Date:
Term:	Lender:
Phone Number:	Fax Number:
Loan in the Name of:	Loan Type:
	Original Amount of Loan:
Interest Rate:	_ Due Date:
Term:	Lender:
Address:	
	Fax Number:
Loan in the Name of:	Loan Type:
	Original Amount of Loan:
Interest Rate:	_ Due Date:
Term:	Lender:
	Fax Number:
Loan in the Name of:	Loan Type:
	Original Amount of Loan:
Interest Rate:	_
	Lender:
	Fax Number:

# **Insurance Information**

Life Insurance	
Life Insurance Company:	Policy No:
Address:	
	Fax Number:
Name(s) of Insured:	
Beneficiary(ies) Names and	Addresses:
	Location of Policy:
	Phone Number:
	NO Assigned: YES NO
National Service L	_ife Insurance (GI)
Name(s) of Insured:	
Type of Policy:	Policy No:
Address:	
Phone Number:	Fax Number:
Beneficiary(ies) Names and	Addresses:
Location of Life Insurance I	Documents:

# **Insurance Information**

Home Insurance	
Insurance Company:	Policy No:
	Phone Number:
Auto Insurance	
Insurance Company:	Policy No:
	Phone Number:
_	
<b>Long-Term Care Ins</b>	urance
Insurance Type:	Insurance Agent:
Insurance Company:	Policy No:
Address:	
I am the beneficiary of the follo	owing policies:
	ong-Term Care Insurance Documents: ritical Care, or Disability Insurance
Insurance Company:	
	Insurance Agent:
	Fax Number:
Beneficiary(ies) Names and Ad	
	<del></del>
Location of Policy and Identific	cation Card(s):
•	• •

# **Legal and Estate Information**

Will	
Execution Date:	Will Drawn By:
Location of Codicil:	Execution Date:
	Phone Number:
Address:	
	Phone Number:
Address:	
Name(s) and Contact Informatio	
Living Will/Advance H	lealthcare Directive
Execution Date:	Drawn By:
Name of Individual with a Copy:	Phone Number:
	Phone Number:
	nate Organs to:
	Healthcare Directive:
Trust Funds	
Trust Name:	Date Established:
Trustee Name:	Phone Number:
Trustee Address:	
Name(s) and Contact Information	on of Beneficiary(ies):
Location of Trust Agreement:	

# **Legal and Estate Information**

Trust Name:	Date Established:	
Trustee Name:	Phone Number:	
Trustee Address:		
	ormation of Beneficiary(ies):	
	ent:	
C		
Power of Attorn	ey (POA) for Finances	
	POA Phone Number:	
POA Address:	City:	
State:	Zip Code:	
Location of POA:		
<b>Power of Attorn</b>	ey (POA) for Healthcare (Primary)	
POA Name:	POA Phone Number:	
	City:	
	Zip Code:	
Power of Attorn	ey (POA) for Healthcare (Secondary, if t	he
Primary POA is	ot available)	
POA Name:	POA Phone Number:	
	City:	
	Zip Code:	

# **Burial Instructions**

# **Cemetery and Funeral Director Information** Name of Cemetery: \_\_\_\_\_ Cemetery Plot Number: \_\_\_\_ Cemetery Address: Location of Deed: \_\_\_\_\_ Funeral Director Name: \_\_\_\_\_\_ Phone Number: \_\_\_\_\_ **Burial Instructions:**

# **Burial Instructions**

Name(s) and Contact Information of Organiza	tions to Notify in the Event of My Death:
Church or Synagogue Informat	tion
Name of Institution:	Phone Number:
Name of Clergy or Representative:	Phone Number:
Church or Synagogue Address:	
Other Information:	

Items to attach to this document:

- Copy of Living Will/Advance Healthcare Directive
- Copy of Medicare Card
- Copy of Social Security Card
- Copy of Health Insurance Card
- Recent Photograph of Individual
- Valuable Tangible Property Inventory

# **Medical Information - Vial of Life**

### VIAL OF LIFE: MEDICAL INFORMATION Information & Assistance/ Información y Ayuda 1-800-339-4661 | www.aging.sandiegocounty.gov







Updated On / versión actualizada: / /	•		
Name/Nombre_			
☐ Blind/ Ciego ☐ Deaf/ Sordo ☐ Alzheimer's Disease o	or Related Dementia/ Alzheimer u otra demenci		
Address/ Dirección City/Ciudad	Zip/Código Postal		
Phone/TeléfonoMale/Hombre Female/Mujer Date of	of Birth/ Fecha de Nacimiento		
Social Security # Last Four Digits/Número de Seguridad Social; Cuatro últim	os dígitos		
Medicare # (Last Four Digits)/Número de Medicare—Cuatro últimos número	s		
Other Insurance/Otra aseguranza médica Policy Number/ N	Numero de póliza		
Do you have an Advance Health Care Directive?/¿Tiene Usted un Formulario Di	rectivo Medico Anticipado? Yes/Si No No		
If yes, location / Si la respuesta es sí, ¿Dónde está? Agent/Quien Responsab	ole Tel#/Teléfono		
Do you have a Do Not Resuscitate order?/Tiene usted un formulario de no res	sucitar? Yes/Si No		
Registered with Sheriff's 'Take Me Home'?/ Está registrado con el programa	"Take Me Home"? Yes/Si No		
Emergency Contacts/Contacto de emergencia			
Name/Nombre Relationship/Relación	Tel# E-mail/Teléfono/Correo electrónico		
Name/Nombre Relationship/Relación	Tel# E-mail/Teléfono/Correo electrónico		
Caregiver/Cuidador	Tel#/Teléfono		
Clergy/Clérigo	Tel#/Teléfono		
Pet's Information/Información de la Mascota- Name & Type/ No	ombre e Tino		
Veterinarian/Veterinario	_Tel#/Teléfono		
Medical Information/Información de Médica Primary Doctor/Doctor Primario	Tel#/Teléfono		
Secondary Doctor/Doctor Secundario	Tel#/Teléfono		
Hospital/Hospital	Tel# /Teléfono		
Height/Estatura Weight/Peso	Blood Type/Tipo de Sangre		
Normal Blood Pressure/Presión Arterial Normal			
Allergies to drugs or foods/Alegarías a medicamentos o alimentos			
Please list any medical conditions that apply/Favor de marcar cada conditions (for example: cardiac, diabetes, hypertension, stroke / Por ejemplo: cardiaca,			
(Continued on other side / Continue on	al adva la da)		

# **Medical Information – Vial of Life**

Surgeries (type and date) / Cirugía (tipo	y clase)					
		7	2 2			·
Do You/ Usted						
Wear dentures?/¿Usa dentadura postiza?	Yes/Si 🗌	No 🗌	Wear g	lasses?/¿Usa lentes?	Yes/Si	No 🗌
Wear contacts?/¿Usa lentes de contacto?	Yes/Si	No 🔲	Use oxy	ygen?/¿usa oxigeno?	Yes/Si	No 🔲
Wear hearing aids?/¿Usa audífonos?	Yes/Si 🔲	No 🗌	o ☐ Wheelchair?/¿usa silla de rueda:		Yes/Si	No 🔲
Other Important Emergency Informati	on / Otra info	ormación i	m portan	te de emergencia		
Immunizations / Vacunas						
Where do vou keep vour medications?/	; Dónde guaro	da sus med	licament	os?		
Medications/Medicamentos (Prescription, Over-the-counter Drugs, Vitami: (Recetas médicas, Medicamentos Sin Receta, Name/Nombre		rbas Medicii	15.0	Purpose/¿Para Que Es	?	
Name/Nombre	Dose-Freq/Dosis-Frecuencia		Purpose/¿Para Que Es?			
Name/Nombre	Dose-Freq/Dosis-Frecuencia		Purpose/¿Para Que Es?			
Name/Nombre	Dose-Freq/Dosis-Frecuencia		Purpose/¿Para Que Es?			
Name/Nombre	Dose-Freq/Dosis-Frecuencia		Purpose/¿Para Que Es?			
Name/Nombre	Dose-Freq/Dosis-Frecuencia		Purpose/¿Para Que Es?			
Name/Nombre	Dose-Freq/Dosis-Frecuencia		Purpose/¿Para Que Es?			
Name/Nombre	Dose-Freq/Dosis-Frecuencia		Purpose/¿Para Que Es?			
Name/Nombre	Dose-Freq/Dosis-Frecuencia		Purpose/¿Para Que Es?			
	_,					

Please record all information in a manner easy to read by emergency medical personnel. Por favor de registrar toda la información de una manera fácil de leer por personal médico de emergencia.

# **Fall Risk Assessment**

Yes (2)         No (0)         I have fallen in the past year.         People who have fallen once are likely to fall again.           Yes (2)         No (0)         Unse or have been advised to use a cane or already be more likely to fall.         People who have been advised to use a cane or walker may already be more likely to fall.           Yes (1)         No (0)         I steady myself by holding onto furniture         This is also a sign of poor balance.         People who are worried about falling are more likely to fall.           Yes (1)         No (0)         I meed to push with my hands to stand up         This is also a sign of your balance.         People who are worried about falling are more likely to fall.           Yes (1)         No (0)         I meed to push with my hands to stand up         This is also a sign of weak leg muscles, a major reason for falling.           Yes (1)         No (0)         I have some trouble stepping up onto a curb.         This is also a sign of weak leg muscles, a major reases your chance of falling.           Yes (1)         No (0)         I have lost some feeling in my feet.         Numbness in your feet can cause stumbles and lead to falling.           Yes (1)         No (0)         I take medicine that sometimes makes me feel         Chance of falling.         Numbness in your feet can cause stumbles and lead to falling.           Yes (1)         No (0)         I take medicine to help me sleep or improve         Numbness in your feet can cause stumble and or feeling		Circle "Y	Circle "Yes" or "No" for each statement below	Why it matters
No (0)  I use or have been advised to use a cane or walker to get around safely.  No (0)  I steady myself by holding onto furniture when walking at home.  No (0)  I am worried about falling.  I need to push with my hands to stand up from a chair.  No (0)  I have some trouble stepping up onto a curb.  No (0)  I have lost some feeling in my feet.  No (0)  I take medicine that sometimes makes me feel light-headed or more tired than usual.  I take medicine to help me sleep or improve my mood.  I often feel sad or depressed.  Add up the number of points for each "yes" answer, If you Discuss this brochure with your doctor.	Yes (2)	No (0)	I have fallen in the past year.	People who have fallen once are likely to fall again.
No (0) Sometimes I feel unsteady when I am walking.  I steady myself by holding onto furniture when walking at home.  No (0) I am worried about falling.  I need to push with my hands to stand up from a chair.  No (0) I have some trouble stepping up onto a curb.  No (0) I have lost some feeling in my feet.  I take medicine that sometimes makes me feel light-headed or more tired than usual.  I take medicine to help me sleep or improve my mood.  I often feel sad or depressed.  Add up the number of points for each "yes" answer. If you Discuss this brochure with your doctor.	Yes (2)	No (0)	I use or have been advised to use a cane or walker to get around safely.	People who have been advised to use a cane or walker may already be more likely to fall.
No (0) I steady myself by holding onto furniture when walking at home.  No (0) I am worried about falling.  I need to push with my hands to stand up from a chair.  No (0) I have some trouble stepping up onto a curb.  No (0) I have lost some feeling in my feet.  No (0) I take medicine that sometimes makes me feel light-headed or more tired than usual.  I take medicine to help me sleep or improve my mood.  Add up the number of points for each "yes" answer. If you Discuss this brochure with your doctor.	Yes (1)	No (0)	Sometimes I feel unsteady when I am walking.	Unsteadiness or needing support while walking are signs of poor balance.
No (0) I need to push with my hands to stand up from a chair.  No (0) I have some trouble stepping up onto a curb.  No (0) I have lost some feeling in my feet.  I take medicine that sometimes makes me feel light-headed or more tired than usual.  I take medicine to help me sleep or improve my mood.  I often feel sad or depressed.  Add up the number of points for each "yes" answer. If you Discuss this brochure with your doctor.	Yes (1)	No (0)	I steady myself by holding onto furniture when walking at home.	This is also a sign of poor balance.
No (0) I need to push with my hands to stand up from a chair.  No (0) I have some trouble stepping up onto a curb.  No (0) I have lost some feeling in my feet.  I take medicine that sometimes makes me feel light-headed or more tired than usual.  I take medicine to help me sleep or improve my mood.  No (0) I often feel sad or depressed.  Add up the number of points for each "yes" answer. If you Discuss this brochure with your doctor.	Yes (1)	No (0)	I am worried about falling.	People who are worried about falling are more likely to fall.
No (0) I have some trouble stepping up onto a curb.  No (0) I often have to rush to the toilet.  I take medicine that sometimes makes me feel light-headed or more tired than usual.  I take medicine to help me sleep or improve my mood.  I often feel sad or depressed.  Add up the number of points for each "yes" answer. If you Discuss this brochure with your doctor.	Yes (1)	(0) oN	I need to push with my hands to stand up from a chair.	This is a sign of weak leg muscles, a major reason for falling.
No (0) I often have to rush to the toilet.  No (0) I have lost some feeling in my feet.  I take medicine that sometimes makes me feel light-headed or more tired than usual.  No (0) I take medicine to help me sleep or improve my mood.  No (0) I often feel sad or depressed.  Add up the number of points for each "yes" answer. If you Discuss this brochure with your doctor.	Yes (1)	No (0)	I have some trouble stepping up onto a curb.	This is also a sign of weak leg muscles.
No (0) I have lost some feeling in my feet.  I take medicine that sometimes makes me feel light-headed or more tired than usual.  I take medicine to help me sleep or improve my mood.  No (0) I often feel sad or depressed.  Add up the number of points for each "yes" answer. If you Discuss this brochure with your doctor.	Yes (1)	No (0)	I often have to rush to the toilet.	Rushing to the bathroom, especially at night, increases your chance of falling.
No (0) I take medicine that sometimes makes me feel light-headed or more tired than usual. I take medicine to help me sleep or improve my mood.  No (0) I often feel sad or depressed.  Add up the number of points for each "yes" answer. If you Discuss this brochure with your doctor.	Yes (1)	No (0)	I have lost some feeling in my feet.	Numbness in your feet can cause stumbles and lead to falls.
No (0)  No (0)  I take medicine to help me sleep or improve my mood.  No (0)  I often feel sad or depressed.  Add up the number of points for each "yes" answer. If you Discuss this brochure with your doctor.	Yes (1)	No (0)		Side effects from medicines can sometimes increase your chance of falling.
No (0) I often feel sad or depressed.  Add up the number of points for each "yes" answer. If you Discuss this brochure with your doctor.	Yes (1)	No (0)	I take medicine to help me sleep or improve my mood.	These medicines can sometimes increase your chance of falling.
	Yes (1)	No (0)	l often feel sad or depressed.	Symptoms of depression, such as not feeling well or feeling slowed down, are linked to falls.
	Total		Add up the number of points for each "yes" answer. If Discuss this brochure with your doctor.	ou scored 4 points or more, you may be at risk for falling.

This checklist was developed by the Greater Los Angeles VA Geriatric Research Education Clinical Center and affiliates and is a validated fall risk self-assessment tool (Rubenstein et al. J Safety Res; 2011: 42(6)493-499). Adapted with permission of the authors.

# **NOTES**

# **Home Safety Checklist**

## **Floors**

- · Clear pathways of furniture.
- Pick up objects that are on the floor.
- Remove low chairs that are difficult to sit in and get out of easily.
- Remove throw rugs or secure them with double-sided floor tape.
- Secure carpet edges.
- Gather cords and wires, and tape them to a wall.
- · Do not use floor wax.

## Stairs and Steps

- Remove all objects from the stairs.
- Fix broken or uneven steps, and secure loose carpet.
- Install handrails on both sides of stairs. Fix any loose handrails.
- Apply reflective tape to the top and bottom of stairs.
- Have an electrician install an overhead light at the top and bottom of the stairs.

# Clothing/Accessories

- Wear sturdy shoes with thin, non-slip soles.
- Hem pants so they don't touch the floor when walking bare foot.
- Wear non-slip socks with grips on the bottom.
- Consider wearing a medical alert device.

### **Outdoors**

- Repair cracks and gaps in sidewalks and driveways.
- · Trim shrubbery along the path to the door.

## **Kitchen**

- Keep frequently used items within reach on lower shelves (about waist level).
- Keep a current list of healthcare information on your refrigerator in case of an emergency.

### **Bathrooms**

- Use a non-slip rubber mat on the shower or tub floor.
- Install grab bars next to the tub and toilet.
- Install a raised toilet seat.
- Use a padded tub or shower seat.
- · Use a handheld shower head.
- · Have a low- or no-threshold shower.

# **Telephones**

- Make sure the phone can be reached from the bed and the floor.
- Consider keeping a cordless or cellular phone in your pocket.
- Keep a list of emergency numbers next to each phone.

# Lighting

- Install good lighting by doors and walkways.
- Install lights at the top and bottom of stairs.
- Replace burnt out light bulbs.

# **Bedrooms**

Adjust bed height to a comfortable position.

# **NOTES**

