



# Caregiver's HANDBOOK

*An Organizer to Help Simplify Your Life*



**Institute for Palliative Care**

AT CALIFORNIA STATE UNIVERSITY SAN MARCOS

[www.csupalliativecare.org](http://www.csupalliativecare.org)



[www.caregivercoalitionsd.org](http://www.caregivercoalitionsd.org)



Aging & Independence Services

800-510-2020



## INTRODUCTION

If you are taking care of a loved one—or someone is caring for you—this Handbook will help. It is designed both as a road map and document file for your journey. There is no single prescription for every situation. You are unique and no one can predict exactly how you should proceed. You are gradually becoming your own “expert.”

Taking care of family is not new. People have always done so. The difference is that we now take care of each other in an enormous modern world. We have fewer family members and are spread thinner across the map. Gone are the village-like neighborhoods where we could always count on extended family for help.

And we no longer relate to long-standing professionals like the family doctor or attorney. Instead, we often deal with vast bureaucratic health, legal, and government systems. At each step, the path is guarded by a patchwork of gatekeepers whose purpose, too often, seems at odds with our efforts. Creating an effective plan is very porous. As a caregiver, it's like trying to hold water in a spaghetti strainer.

In this environment, the family obligation is not less; but the ability to fulfill that obligation is tested. With greater numbers of people living to old age and bringing along all of the health problems that develop in later years...it's the great modern dilemma. You are not alone.

Providing help is not easy, yet it is essential. It is the right thing for families to do and also very beneficial for a community. This is not a duty that can be discarded. Someone has to do it. The best situation is a willing-and-able family member providing care. Given tools and support, you can make caregiving work for your family.

If your loved one has Alzheimer's disease or other form of irreversible dementia, you are facing one of the more difficult caregiving tasks. However, any condition—chronic or acute, physical or mental—means that you will be gathering an encyclopedia's worth of knowledge.

Please enjoy using your new Handbook as a handy beginning for your personal care plan.



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***Give a Handbook to someone who needs it!***





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## **Palliative Care – What Everyone Needs to Know** *Are you or someone you love suffering from a serious or chronic illness? Palliative care can help.*

Once informed, **92%** of people are highly likely to consider palliative care for themselves or their families.

### **What is palliative care?**

Palliative (pronounced PAL-lee-uh-tiv) care is health care that focuses on improving quality of life and comfort for patients with serious or chronic illness. It focuses on relieving the pain and physical symptoms as well as the emotional stress, fear, frustration and spiritual concerns that major health problems can create for those with serious illness(es) and their families. Palliative care is provided by team of professionals, typically including doctors, nurses, social workers and spiritual counselors.

Palliative care can be received at the same time as other treatment and has been proven to help those with serious illness live longer, have a more rewarding life and to ease the stress on those who care for them. It is available for patients of all ages who are at any stage in their illness.

### **How do I know if I have a serious or chronic condition and need this care?**

In California, 14 million people live with at least one chronic condition, and more than half have multiple chronic conditions. Examples of serious or chronic conditions include:

- Hypertension
- Arthritis
- Heart disease
- Multiple sclerosis (MS)
- Respiratory disease or infection
- Diabetes
- Cancer
- Parkinson's disease

Whether or not you have any of these diseases, it is very important to talk with your loved ones about your wishes for medical care, and theirs, before anyone becomes seriously ill. Talking and planning for future medical needs can be difficult, but it is the best way to make sure that your wishes will be respected. Many people write their wishes down for their family and their doctor in a document known as an Advance Directive.

While **82%** of Californians say it is important to have health care wishes in writing, only **23%** say they have done so.

### **I have a serious illness. How can palliative care help me?**

Are your symptoms well managed and allowing you to experience the things in life that give you joy? If so, then simply know that should you need help, palliative care is another resource available to you.

However, if you are experiencing any of the following:

- Pain, nausea, or other physical symptoms?
- Anxiety, depression, or emotional distress?
- Loss of meaning, purpose or sense of worth?
- Difficulty communicating with your family or friends about what is happening to you and what is important?

Palliative care professionals have the skills to work hand-in-hand with your physician to make you more comfortable and improve your quality of life.

**60%** say making sure their family is not burdened by tough decisions about their care is “extremely important.” However, **56%** of Californians have not communicated their health care wishes to the loved one that they would want making decisions on their behalf.

## **I am caring for someone with a serious illness. What should I know about palliative care?**

Caring for a friend or family member with a serious or chronic illness can be very stressful and exhausting. Palliative care can help keep your loved one comfortable, and connect you with the resources and support you need to protect your own health and well-being. It can also help to give you the skills you need to be more comfortable providing care.

Do you know your loved one's choices for medical treatment? Do you feel comfortable having conversations about care planning and the future with your loved one as well other family members and friends? Do you know how to be an effective advocate for your loved one with the health care system? If your answer to any of these questions is “NO,” then palliative care can help.

## **Who provides palliative care?**

Currently palliative care is largely available only to patients in hospitals but the number of outpatient palliative care services is growing. More community agencies are offering palliative care-related services and having their staff trained in the essential palliative care skills. To learn more about where to access palliative care services in San Diego, southern Riverside and southern Orange Counties, go to [www.csupalliativecare.org/resources](http://www.csupalliativecare.org/resources).

## **Isn't palliative care the same as hospice?**

No. Hospice is very intensive palliative care suitable for the last 6 months of life. Palliative care is for anyone with a serious or chronic illness regardless of how long they have to live, and can be received right along with curative care.

## **What is the CSU Institute for Palliative Care at CSUSM, and how can it help?**

The CSU Institute for Palliative Care at CSUSM educates and trains the people who can deliver palliative care here in our community, around the state and across the country. The Institute opened at Cal State San Marcos in 2012 with three goals: to teach today's patients about palliative care so that they can ask for it when they need it, to teach today's professionals how they can better provide it, and to help today's nursing, social work and other students learn about palliative care so that they can help deliver it when they graduate. Visit our website at [www.csupalliativecare.org](http://www.csupalliativecare.org) for helpful online resources and to learn about the latest palliative care news and research as well as palliative care in our community.

## **Have more questions about palliative care?**

Talk to your doctor, nurse and/or caregiver about palliative care and how it can help you and your loved ones. We also encourage you to talk to your family about the type of care that's right for you. If you need help finding palliative care resources in your community, contact us at [www.csupalliativecare.org/contact](http://www.csupalliativecare.org/contact).

Initial funding for the CSU Institute for Palliative Care has been generously provided by the California HealthCare Foundation, the Archstone Foundation and philanthropist, Darlene Marcos Shiley.



Connect with us on Facebook,  
subscribe to our newsletter or  
find helpful resources at  
[www.csupalliativecare.org](http://www.csupalliativecare.org)



# ABOUT CAREGIVING

## Who is a Caregiver?

If you are reading these words, it is likely you are a caregiver. There are no strict definitions or standards of caregiving that apply to all situations. There is no registration or official designation and the title comes with few perks or bonuses. Whether legally recognized or not, “Family Caregiver” implies that responsibility is assumed without pay and there is a sense of duty to provide care for an adult with some impairment, often age-related. The “intensity” of caregiving can vary depending on the needs of the person needing care and the ability of the provider to meet those needs.

## The “Care Receiver”

If someone is providing care for you, remain as active in the decision-making as you are able. Some conditions (a broken bone, for example) require a lot of help but you are fully aware and able to direct your own care—and you expect to recover. Other conditions may be progressive or affect your ability to make good judgments. Even then you should not avoid ALL decisions. You can still give your input.

## Who Else is in the Same Boat?

- The vast majority of adults (78%) in the U.S. who receive long-term care at home get all their care from unpaid family and friends, mostly wives and adult daughters. Another 14% receive some combination of family care and paid help.
- 34 million adults provide care to adults 50+ years.
- 8.9 million caregivers (20% of adult caregivers) care for someone 50+ years who has dementia.
- An estimated 59% to 75% of caregivers are female.
- The numbers of male caregivers may be increasing and will continue to do so due to a variety of social demographic factors.
- While caregivers can be found across the age span, the majority of caregivers are middle-aged (35-64 years old).

## SECTION 1

- Of caregivers who live with their care recipients, spouses account for about 62% of primary caregivers while adult children comprise 26%. Secondary caregivers are more likely to be adult children (46%) than spouses (16%).
- Working caregivers often suffer many work-related difficulties due to their dual caregiving roles. Among working caregivers caring for a family or friend aged 65+, two-thirds report having to rearrange their work schedule, decrease their hours or take an unpaid leave in order to meet their caregiving responsibilities. Difficulties due to work and caregiving are even higher among those caring for someone with dementia.
- Older caregivers often spend the most hours providing care. Twenty-eight percent of caregivers who provide more than 40 hours of care per week are 65+ years.
- Studies have found that caregivers may have increased blood pressure and insulin levels, may have impaired immune systems and may be at increased risk for cardiovascular disease among other adverse health outcomes.
- Many caregivers are themselves in poor health; studies show that approximately one-third of caregivers provide intensive care although they are themselves in “fair to poor” physical health.
- Depression appears to be the most common psychological disorder, with 20% to 50% of caregivers reporting depressive disorders or symptoms. The higher levels of depression are mostly attributed to people caring for individuals with dementia.
- Spousal caregivers who are at risk of clinical depression and are caring for a spouse with significant cognitive impairment and/or physical care needs are more likely to engage in harmful behavior towards their loved one.
- While caregiving can be a very stressful situation for many caregivers, studies also show that there are beneficial effects, including feeling positive about being able to help a disabled spouse, feeling appreciated by the care recipient, and feeling that their relationship with the care recipient had improved.
- Caregiver interventions benefit both the caregiver and the care recipient. Use of caregiver support services has been shown to have clinically significant outcomes in improving caregiver depression, anxiety and anger.

## The Next Chart is Important

Please be certain to complete the information in the chart on the next two pages. This is information that you will need again and again, and having it clearly listed will save you time and effort.



## PERSONAL INFORMATION

NAME	Social Security #
------	-------------------

PERSONAL INFORMATION	WHO KNOWS WHERE IT IS LOCATED IF YOU NEED IT?
<input type="checkbox"/> BIRTH CERTIFICATE	
<input type="checkbox"/> MARRIAGE CERTIFICATE	
<input type="checkbox"/> DEATH CERTIFICATE (FOR DECEASED SPOUSE)	
<input type="checkbox"/> DIVORCE PAPERS	
<input type="checkbox"/> MILITARY RECORDS <ul style="list-style-type: none"> <li><input type="checkbox"/> BRANCH OF SERVICE:</li> <li><input type="checkbox"/> VA ID#:</li> <li><input type="checkbox"/> VETERANS MIL. SERVICE RECORD (DD-214)</li> <li><input type="checkbox"/> DATES OF SERVICE:</li> </ul>	
<input type="checkbox"/> DRIVERS LICENSE / ORGAN DONOR CARD	
<input type="checkbox"/> PASSPORT / CITIZENSHIP PAPERS	
<input type="checkbox"/> WILL	
<input type="checkbox"/> TRUSTS	
<input type="checkbox"/> LIFE INSURANCE POLICY(S)	
<input type="checkbox"/> DISABILITY INSURANCE (LONG- AND SHORT-TERM)	
<input type="checkbox"/> LONG TERM CARE INSURANCE	
<input type="checkbox"/> SAFETY DEPOSIT BOX 1 NUMBER: # OF KEYS: WHO HAS KEYS:	
<input type="checkbox"/> SAFETY DEPOSIT BOX 2 NUMBER: # OF KEYS: WHO HAS KEYS:	

PERSONAL INFORMATION	WHO KNOWS WHERE IT IS LOCATED IF YOU NEED IT?
<input type="checkbox"/> ADDRESS BOOKS	
<input type="checkbox"/> CHURCH	
<input type="checkbox"/> COMMUNITY ORG. MEMBERSHIP 1	
<input type="checkbox"/> COMMUNITY ORG. MEMBERSHIP 2	
<input type="checkbox"/> WAITING LISTS OR CONTRACTS WITH RETIREMENT COMMUNITIES OR NURSING HOMES	
<input type="checkbox"/> CEMETERY PLOTS & FUNERAL/BURIAL INSTRUCTIONS	
<input type="checkbox"/> PLAN FOR CARE OF FAMILY PETS	
<input type="checkbox"/> INTERNET PASSWORDS AND USERNAMES	
<input type="checkbox"/> BANK / FINANCIAL INSTITUTION LOG-INS, PASSWORDS AND USERNAMES	
<input type="checkbox"/> EMAIL ACCOUNTS, PASSWORDS AND USERNAMES	
<input type="checkbox"/> OTHER	



# CAREGIVING SERVICES TO HELP YOU

## Top Five Caregiving Tips

- 1 Be creative and flexible; no one knows exactly what works in every situation
- 2 Patience: you probably cannot “solve” the situation with one phone call
- 3 It is a team effort including you, your loved one, and community professionals
- 4 Something that doesn’t work today may work tomorrow; success is circumstantial and circumstances change
- 5 See “Self Care” tips under Health

**T**his section describes caregiving services and the possible ways these services might meet your needs. Use this information to unlock the doors to improve your circumstances.

A day in the life of a caregiver is full, to say the least. For most caregivers, there never seems to be enough hours in the day to get everything done. Care giving can be difficult and may cause health problems for the caregiver. Assisting with your loved one’s personal needs such as dressing, eating, bathing and going to the bathroom are essential parts of daily activities. Caregivers often overlook their own personal needs in the areas of socialization and health care as they help care for their loved ones. In-home care is a solution for caregivers who:

1. need respite,
2. need assistance when their loved one’s needs have increased,
3. need short-term assistance because they or their loved one is discharging from a hospital or rehab facility,
4. need for their loved one to be safe and cared for at home as they explore options for placement.

In-home care services can be employed beginning at two hours per day all the way up to 24 hour care.

## SECTION 2

# Respite

Respite is the opportunity to take a break, rest, and re-charge. Like the frog in the pot of water, we don't always realize the water is starting to boil. There are many ways to get help, but you have to ask. You must take action. Too many caregivers are content to know the choices but never engage.

## **1. Have family or friends come into your home.**

This one seems so easy, yet too many caregivers miss it. If someone asks, say "Yes" and explain when you need the help. If no one volunteers, you ask. Most important, schedule respite and then take the time away. Leave. Enjoy yourself or complete important errands. Leave your guilt at home.

If your loved one has physical impairment, he or she will enjoy the company. If your loved one has dementia, he or she will still be able to enjoy the familiarity of trusted company, unless in the very late stages.

## **2. Hire an aide.**

There are numerous individuals and agencies to choose from. Make sure you choose well. Remember you can hire someone to come TO your home, or your loved one can temporarily move to a facility. Otherwise the rules are the same. Schedule it, take time away, and make sure you plan rejuvenating activities for yourself.

## **3. Go to an Adult Day Health Center.**

This is not a senior center, but a gathering place specially designed to provide activities, nutrition, and a warm atmosphere. There is a cost for services, but insurance may pay and scholarships are sometimes available.

## **4. Seek voluntary respite services.**

There are limited, free services available for respite, both in and out of the home. You usually have to plan ahead so make sure you call BEFORE you need the service.

How do you accomplish this? Glad you asked. Next subject...

# Support Groups

You will find no shortage of professionals claiming the mantle of expert. The only real expert in caregiving is someone who has been or is going through it. Support groups are gatherings of such people. Whether "disease specific" or geared to caregiving in general, there is no better place to educate yourself or find a shoulder to lean on.

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 for all people at all times. There is a group that will suit you and your circumstances.

# Case Management

What happens if you cannot always be there? Or what if family members have different opinions about what to do? Geriatric Care Managers are professionals who function as “adjunct family” and assist with planning, executing a plan of care, and mediating among family members. Often trained as social workers, nurses, or counselors, case managers can be hired privately or provided through government programs for qualifying families. Some insurance policies now include case management as a benefit. Case managers act as consultants and can help guide you through other services on these pages.

## In-Home Care

In addition to hiring an in-home aide for temporary respite, in-home care is also an option for longer-term solutions. Most in-home care is considered “non-medical” and is not covered by health insurance. On the other hand, Long-Term Care Insurance often DOES cover this type of care. For qualified individuals, there are government programs available to help pay for some in-home services. See Section 3 beginning on page 14 for more information about how to research insurance coverage and financial considerations.

When employing a home care company it is important to ask a number of questions for your protection. The following are the most important questions to ask:

1. Does the company employ their caregivers?
2. Do they provide 1099's or W2's to their caregivers
3. Do they provide Worker's Compensation on all of their caregivers?
4. Do they take care of the payroll taxes?
5. Do they run criminal background checks on each caregiver?

It may seem as if this is a lot to ask, however companies who employ their caregivers are expecting to hear these questions. It is not advisable to hire a caregiver privately, and if you find yourself in this situation it is important to follow the above five steps.

Caregivers can expect to pay in the range of \$18 - \$25 per hour for in-home care. For those who qualify for in-home care through In Home Supportive Services (IHSS), the number to call is 1-800-510-2020. There are three organizations that are committed to providing caregiver's with a list of companies who employ their caregivers and who complete steps 1-5 in the previous paragraph. They are

- American Board of Home Care
- CAHSAH
- Private Duty Association

## Placement

Like in-home care, placement in an outside facility can function as respite, but it is also



an important long-term option when circumstances dictate. Similar hiring guides as in-home care apply here. Medical insurance pays ONLY for limited nursing home care. Types of placement include:

- **Nursing Home Care:** A nursing facility that provides a full range of assistance, such as nursing care, aid with daily activities, and skilled help such as rehabilitation
- **Assisted Living:** A residence with apartment-style units that provides meals and meets individual needs
- **Adult Day Services:** A program outside the home for adults who need some help during the day with health, social, and other support services in a supervised setting

## Assessment and Consultation

Less involved than Case Management, Assessment and Consultation is a process that takes a snapshot of a situation and starts creating a care plan. Essentially, a care consultant helps you fill out many of the blanks in this Handbook. You may hire a consultant, but there are also many no-cost services available to help fill this role.

## Protection Through Technology

Technology offers a variety of ways to assist in the safety and well-being of you and those for whom are in your care. Dependant upon the individual risks and how they present themselves you will be steered towards products that can be helpful. There are a variety of safety products available for those suffering with dementia or other memory impairment. They range from window and door alerts to automatic stove turn-off's.

Medical Alert systems are an affordable way to provide a safety net for someone who is alone during certain periods of the day/night or is living alone. Ask a friend, or search online for a company near you, check references and be aware of any contractual obligations on the monitoring of these systems. Many offer monthly contracts, while others may be significantly longer. The Better Business Bureau is a good place to check as well. You will also find resources on our website at [www.caregivercoalitionsd.org](http://www.caregivercoalitionsd.org).

## Where to Find These Services

[www.caregivercoalitionsd.org](http://www.caregivercoalitionsd.org)

## GENERAL NEEDS ASSESSMENT

NAME	Social Security #
AGENT	PHONE
OTHER CONTACT	PHONE

AREA OF NEED	TYPES OF TASKS	POINT PERSON (S)
HOME MAINTENANCE AND LIVING SITUATION	<input type="checkbox"/> PAY RENT/ MORTGAGE <input type="checkbox"/> HOME REPAIRS <input type="checkbox"/> ONGOING MAINTENANCE <input type="checkbox"/> SAFETY CONCERNS <input type="checkbox"/> ACCESSIBILITY FOR DISABILITIES <input type="checkbox"/> GROCERY SHOPPING & MEAL PREPARATION <input type="checkbox"/> LAWN CARE <input type="checkbox"/> PET CARE <input type="checkbox"/> HOUSEKEEPING <input type="checkbox"/> OTHER:	NAME _____ PHONE _____  NAME _____ PHONE _____  NAME _____ PHONE _____
FINANCIAL AFFAIRS	<input type="checkbox"/> PAYING BILLS <input type="checkbox"/> KEEPING TRACK OF FINANCIAL RECORDS <input type="checkbox"/> SUPERVISING PUBLIC BENEFITS PROGRAMS	NAME _____ PHONE _____
TRANSPORTATION NEEDS	<input type="checkbox"/> DRIVING DECISIONS <input type="checkbox"/> COORDINATING RIDES	NAME _____ PHONE _____
PERSONAL CARE	<input type="checkbox"/> ORGANIZATION OF FAMILY AND PROFESSIONAL CARE PROVIDERS <input type="checkbox"/> RIDES TO HAIR STYLIST/BARBER <input type="checkbox"/> HELP WITH BATHING	NAME _____ PHONE _____
MEDICAL CARE	<input type="checkbox"/> MAKE, ACCOMPANY, DRIVE OR ARRANGE FOR MEDICAL APPOINTMENTS <input type="checkbox"/> SUBMIT MEDICAL INSURANCE & BILLS <input type="checkbox"/> EXPLAIN MEDICAL DECISIONS	NAME _____ PHONE _____
COMMUNICATION	<input type="checkbox"/> KEEPING FAMILY CAREGIVING TEAM INFORMED <input type="checkbox"/> COORDINATING VISITS	NAME _____ PHONE _____
ADAPTIVE DEVICES	<input type="checkbox"/> ORDERING, MAINTAINING AND PAYING FOR DEVICES SUCH AS WHEEL CHAIR, WALKER, ETC.	NAME _____ PHONE _____

## HOME MAINTENANCE CHECKLIST

NAME	
AGENT	PHONE
OTHER CONTACT	PHONE

HOME ITEM	CONTACT	WHERE IS IT KEPT?
<input type="checkbox"/> MORTGAGE OR RENTAL REAL ESTATE AGENT: DOCUMENTS & BILLS		
<input type="checkbox"/> POWER COMPANY BILLS		
<input type="checkbox"/> GAS COMPANY BILLS		
<input type="checkbox"/> CABLE / INTERNET BILLS		
<input type="checkbox"/> LOW INCOME HOME ENERGY ASSISTANCE		
<input type="checkbox"/> TELEPHONE BILLS		
<input type="checkbox"/> HOMEOWNERS INSURANCE	INS. AGENT:	
<input type="checkbox"/> POLICY HOMEOWNERS INSURANCE	PREMIUM:	
<input type="checkbox"/> BILLS PERSONAL PROPERTY INSURANCE		
<input type="checkbox"/> RECEIPTS FROM PROPERTY TAXES	STATE PROPERTY TAX RELIEF? <b>Y N</b>	
<input type="checkbox"/> GARBAGE SERVICE	PICK-UP DAY IS: <b>M T W TH F</b>	
<input type="checkbox"/> PEST CONTROL		
<input type="checkbox"/> GARDENER		
<input type="checkbox"/> OTHER		
<input type="checkbox"/> OTHER		

## TRANSPORTATION CHECKLIST

NAME	
AGENT	PHONE
OTHER CONTACT	PHONE

ITEM	CONTACT / NOTES	WHERE IS IT KEPT?
<input type="checkbox"/> AUTO	MAKE/MODEL: BLUE BOOK VALUE:	
<input type="checkbox"/> AUTO	MAKE/MODEL: BLUE BOOK VALUE:	
<input type="checkbox"/> AUTO LOAN INFORMATION		
<input type="checkbox"/> AUTO TITLES		
<input type="checkbox"/> AUTO INSURANCE	INS. COMPANY/AGENT: PREMIUM:	
<input type="checkbox"/> PARKING		
<input type="checkbox"/> PUBLIC TRANSPORTATION OPTIONS	TRANSPORTATION ASSISTANCE FOR OLDER RESIDENTS? <b>Y N</b>	
<input type="checkbox"/> OTHER		
<input type="checkbox"/> OTHER		

NOTES





# LEGAL & FINANCIAL CONCERNS



## Legal Issues

(Adapted from [www.AARP.org](http://www.AARP.org))

It is important for you to help your loved ones take the proper legal precautions. Through a variety of legal documents, older people can take control of their health care and financial decisions and establish their preferences now for their peace of mind and that of their adult children. It's also much easier to speak about these issues before there is a crisis.

### **Important Legal Documents**

While each family's situation is unique, here are some of the legal steps and products family members to consider:

- **Advance Health Care Directives (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 Trustees and loved ones know where the document is kept, and give copies of the AHCD to people listed for emergencies.
- You can obtain blank templates through attorneys, physicians and online resources.
- **Will** This document instructs how people want their property to pass on after they die. Consult an elder law attorney for current information.
- **Revocable Living Trust** Like a will, this written document lets parents direct how their property will transfer after their death. It also lets them choose a person to transfer the assets. Unlike a will, however, trust property goes immediately to the beneficiaries without probate. Trusts also differ from wills in that they take effect during the parent's lifetime, when he or she transfers ownership of property to the trust.
- **Bank Account Access** Parents may make an adult child a joint owner of their bank and other accounts so that he or she will act for them in an emergency. They can also appoint someone as joint renter, deputy, or agent for their safe deposit box.
- 

## SECTION 3

- **Durable Power of Attorney for Finances (DPA)** This document allows you to give another person the authority to make financial decisions on your behalf. Without a DPA, the court must appoint a spouse, close relative, or companion to manage your financial affairs. Typically, a DPA goes into effect as soon as you sign it or, if you specify, when a doctor certifies that you have become unable to make decisions.
- **Health Care Power of Attorney (HCPA)** This special kind of durable power of attorney lets you give another person the power to be your advocate and make decisions regarding your medical treatment. It becomes effective only if you are temporarily or permanently unable to make your own decisions.
- **Living Will** More limited than the health care power of attorney, this document directs the doctor to withhold or withdraw life-sustaining treatment should a patient be diagnosed with a terminal condition and unable to state his or her preferences.

## Take Action

Here's how to get started. Discuss with your loved ones the legal protections described above. Find out if they have or want these documents. If they're unfamiliar with the products, you may want to gather more information to help decide what you and your loved ones need. Know where to find personal and financial documents in an emergency. Switch to direct deposit for Social Security and other benefit checks.

Work through sensitive issues, such as who your loved one wants to make financial or medical decisions on his or her behalf. What does your loved one want done with his or her property after death? Are there any life-sustaining treatments he or she would or would not want if a terminal condition was diagnosed?

Increase the likelihood that your loved one's advance directives will be followed. Talk with the doctor before and after you and your loved one create an AHCD to ensure he or she feels comfortable carrying out the terms. Make sure everyone who needs to know about the documents is aware of them. Make copies of the documents for all doctors and agents.

## Public Benefits

- **Social Security**, a 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 specific requirements. To apply, visit your parents' local Social Security office, call 800-772-1213, or go online at [www.ssa.gov](http://www.ssa.gov).
- **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. It has several parts: Part A helps pay for hospital care, limited nursing home and home health care, and hospice care; Part B helps pay for doctors' services,

outpatient hospital care, and some other medical services not covered under Part A; Part C (Medicare Advantage) generally covers both Medicare health coverage and prescription drugs through one plan (like an HMO), and Part D helps pay for prescription drugs. For more information, call Medicare at 800-633-4227, or go online at [www.medicare.gov](http://www.medicare.gov).

- **Medi-Cal** (Medicaid), a federal and state health insurance program, assists people with limited resources. Some who may be eligible for Medi-Cal include disabled or older individuals, and, in some cases, grandparents taking care of grandchildren. Certain people with higher incomes and high medical bills may also qualify, including long-term nursing home care. Contact the Centers for Medicare and Medicaid Services toll-free at 800-638-6833. Or go online at [www.cms.hhs.gov/MedicaidEligibility/](http://www.cms.hhs.gov/MedicaidEligibility/).
- **Veterans Benefits** The Veterans Administration offers a number of services for veterans and their caregivers, whether needing some help at home or someone to listen, services are available. If you are the Family Caregiver of a veteran who was injured post-9/11, you may be eligible for additional services through VA, including a stipend, comprehensive training and medical coverage through VA if you are not already covered by a plan. In addition to the VA, the County Veterans Service Office, re-established in 1987, assists veterans and their dependents and survivors obtaining benefits from the federal, state and local agencies administering programs for veterans, and provides advocacy to the veterans community regarding entitlement rights to federal, state and local benefits programs. An accredited Veterans Service Representative will assist you or direct you to the appropriate resource.
- **Food Stamps** help people with limited resources buy food. They are free and come in the form of coupons or an electronic benefit card that looks like a credit card. How much someone receives depends on his or her assets, expenses, and how many people live in the household. Residences with a person age 60 and older must adhere to specific rules. To apply, call your parents' local Department of Social or Human Services, or go online at [www.fns.usda.gov/fsp/outreach/map.htm](http://www.fns.usda.gov/fsp/outreach/map.htm).
- **Supplemental Security Income** (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 your parents' local Social Security office, call 1-800-772- 1213, or go online at [www.ssa.gov](http://www.ssa.gov) to learn more or apply.

## Long Term Care Insurance

Each year, about 7 million Americans receive some type of long-term care, which encompasses many kinds of help that people with chronic illnesses and disabilities need to function day-to-day. Most people need help only with basic daily activities like bathing, dressing, and preparing meals. Others need skilled nursing attention. Long-term care includes a wide range of services offered in personal residences, the community, or in group settings such as nursing homes.

## Why Buy Long-Term Care Insurance?

- To save resources for heirs.
- To spare family members from providing your care.
- To live longer—and independently—at home.
- To make it easier to get into the nursing home or assisted living residence of your choice.

## When to Buy

- Take into account your health, family medical history, needs, finances, lifestyle, and other factors.
- The older you are, the higher your premiums will be.
- Some companies might offer you a discount if you buy a policy when you are healthy.
- If you already have a serious condition or need help with daily activities, some companies may deny you coverage; if you have a condition you think may keep you from getting coverage, obtain an informal opinion before you apply.

## Top Five Legal/Financial Tips

- 1 Remember a care receiver's money and resources are there to help him or her; not for inheritance or other purposes.
- 2 If you feel anyone is taking advantage of you or your loved one in any way, report it to Adult Protective Services, 800 510-2020 in San Diego.
- 3 Talk to a professional – attorney, banker, financial counselor.
- 4 If you cannot afford one, services are available. Check for workshops by reputable agencies.
- 5 Keep documents organized. The checklists throughout this Handbook will help. Let loved ones know where important documents are kept.

## FINANCIAL CHECKLIST

NAME	Social Security #
AGENT	PHONE
OTHER CONTACT PHONE	

ITEM	NOTES	WHERE IS IT KEPT?
<input type="checkbox"/> BANK RECORDS (CHECKING / SAVINGS)		
<input type="checkbox"/> BUSINESS CONTRACTS OR RENTAL AGREEMENTS		
<input type="checkbox"/> COMPLETE LIST OF ASSETS & DEBTS		
<input type="checkbox"/> LIST OF ROUTINE HOUSEHOLD BILLS		
<input type="checkbox"/> FEDERAL & STATE TAX RETURNS (3-5 YRS)		
<input type="checkbox"/> RECORDS OF PERSONAL LOANS MADE TO OTHERS		
<input type="checkbox"/> BANK CONTACT		PHONE
<input type="checkbox"/> FINANCIAL PLANNER		PHONE
<input type="checkbox"/> ACCOUNTANT/ TAX PREPARER		PHONE
<input type="checkbox"/> ATTORNEY		PHONE
<input type="checkbox"/> OTHER		
<input type="checkbox"/> OTHER		
<input type="checkbox"/> OTHER		
<input type="checkbox"/> OTHER		
<input type="checkbox"/> OTHER		







# HEALTH CARE ISSUES

## Tips for Talking to Your Doctor

*Adapted from [www.familydoctor.org](http://www.familydoctor.org)*

It is difficult managing our own health care. The same applies when helping someone else. We have to be informed, assertive, and involved. Doctors and nurses are there to help. We have to let them know how. Taking an active role in your health care can help you get the best care possible from your doctor. One way to do this is to improve your relationship with your doctor. Be sure to tell your doctor about any current and past health care issues or concerns. It's important to share any information you can, even if you're embarrassed.

Give your doctor the following information during the exam:

- Any symptoms you are having.
- Your health history. You can create a "health journal" for yourself on paper or in a notebook, and bring it to your appointments.
- Personal information, including whether you are stressed or if your life is changing.
- Any medicines you are currently taking (see below)
- Any side effects you have from your medicine(s), especially if it makes you feel sick or if you think you may be allergic to it.
- Any vitamins or supplements you take.
- Any x-rays, tests results or medical records you have can be brought with you to the appointment.
- Any recent falls and their circumstances.

## Medication Management

**Tracking** Prescriptions are challenging to keep up with. Not only are most of the names unpronounceable, but the varying instructions for dosages and times can easily get mixed up. One way to track everything is to list all your medications in a chart, preferably on the computer using a spreadsheet or word processing software. List the name of the medication, the doctor who prescribed it, the strength of the medicine (for example, 150 mg.), how many times per day it's to be taken and when, and the cost.

### SECTION 4

If you don't have a computer or don't know someone who can set it up for you, do it manually. Use the form provided on page 24, or get a notebook of accounting pages or graph paper and draw your table using the grids. Carefully print all the information into the chart so that anyone can read it easily.

Any time a prescription changes, be sure to update your chart. 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 in your wallet and Vial of Life.

**Dispensing** Have your medication prescriptions filled at the same pharmacy. This offers many benefits for organization and tracking.

## Fall Prevention

When a senior falls, related injuries can have devastating and long lasting consequences. Statistics show that 4 out of 10 people over 65 fall annually. For some, the resulting injury may be so severe that they can not safely live alone and may require assistance in order to perform activities of daily living, like bathing, dressing or cooking.

An individual's risk of falling can be the result of how a chronic disease affects their eyesight, hearing, balance, muscles, and general physiology. The consumption of multiple medications also poses a risk of falling as medications often cause fatigue and balance issues. Therefore, decreasing ones risk of falling takes an individualized approach. However, one risk that all of us have is our environment. Something as simple as installing a grab bar, may save a life.

The following home safety checklist will help you create a more safe environment for you and/or your loved one.

## FALL PREVENTION CHECKLIST

The following items should be reviewed for the safety and security of the senior. If any item is not up to standard, discuss options with a repair service or remodeling company.

YES NO N/A

### FOUR POINT SAFETY:

- WORKING SMOKE/CARBON DETECTOR IN ONE OR MORE AREAS OF THE HOME
- GRAB BARS IN SHOWER OR BATH AND/OR NEAR THE TOILET
- PEEPHOLE IN AN EXTERIOR DOOR
- DOOR-BELL LOUD ENOUGH TO BE HEARD FROM ALL LIVING AREAS

YES NO N/A

### UNIVERSAL:

- ARE THE EXTERIOR STEPS AND WALKWAYS LEADING TO THE HOME IN GOOD REPAIR?
- ARE STAIRS AND WALKWAYS KEPT FREE OF DEBRIS?
- ARE THERE NON-SKID THROW RUGS AND SCATTER MATS?
- ARE THE TRAFFIC AREAS CLEAR OF TELEPHONE AND ELECTRICAL CORDS?
- ARE THE INTERIOR STAIRS IN GOOD CONDITION, WITH A NON-SKID SURFACE?
- ARE THERE SOLID HANDRAILS ON AT LEAST ONE SIDE OF THE STAIRWAYS?
- ARE STAIRS FREE OF CLUTTER?
- IS THERE A PHONE NEAR THE BED?
- ARE THERE NIGHTLIGHTS IN THE BEDROOM AND BATHROOM?

YES NO N/A

### BATHROOM:

- IS THERE A NON-SKID BATH MAT OR A NON-SLIP SURFACE IN BATHTUB OR SHOWER TO MAKE IT LESS SLIPPERY?
- DIFFICULTY GETTING ON AND OFF THE TOILET? NEED A RAISED TOILET SEAT AND/OR GRAB BAR?
- TROUBLE GETTING IN/OUT OF TUB/SHOWER? NEED GRAB BARS IN THOSE AREAS?

YES NO N/A

### KITCHEN:

- IS THERE A STABLE STEPSTOOL (WITH SAFETY RAIL) FOR REACHING HIGH PLACES?
- HOME SAFETY CHECKLIST FOR PEOPLE WITH ALZHEIMER'S DISEASE
- ARE THERE CABINET/REFRIGERATOR LATCHES TO PREVENT RUMMAGING THROUGH CABINETS AND REFRIGERATOR?
- ARE THERE CONFOUNDING DOOR LOCKS TO AVOID UNWANTED WANDERING?
- ARE THERE DOOR ALARMS TO ALERT RESIDENT(S) TO OPEN DOORS?
- HAVE RESIDENT(S) THOUGHT OF USING DOOR CAMOUFLAGE TO HIDE AN EXIT?
- ARE THERE DOOR KNOB COVERS TO PREVENT ROAMING?
- HAVE GATES BEEN INSTALLED TO PRECLUDE WANDERING?
- ARE ROOM MONITORS USED WHEN RESIDENT(S) ARE IN ANOTHER PART OF THE HOME? ARE WANDERING ALERTS KITS THAT "BEEP" WHEN THE SENIOR STRAYS AWAY BEING USED?

PERSONAL HEALTH INFORMATION		
NAME		
AGENT	PHONE	
OTHER CONTACT PHONE		
PHARMACY 1	PHONE	
ADDRESS		
PHARMACY 2	PHONE	
ADDRESS		
DOCTOR 1	PHONE	
ADDRESS		
DOCTOR 2	PHONE	
ADDRESS		
DOCTOR 3	PHONE	
ADDRESS		
OTHER	PHONE	
ITEM	NOTES	WHERE IS IT KEPT?
<input type="checkbox"/> WILL		
<input type="checkbox"/> POWER OF ATTORNEY		
<input type="checkbox"/> LIVING TRUST		
<input type="checkbox"/> ADVANCE HEALTH CARE DIRECTIVE		

ITEM	NOTES	WHERE IS IT KEPT?
<input type="checkbox"/> POLST (Phy. Instructions)		
<input type="checkbox"/> DNR (Do Not Resuscitate)		
<input type="checkbox"/> MEDICARE # and ID Card		
<input type="checkbox"/> MEDICAID # and ID Card		
<input type="checkbox"/> MEDICARE DRUG COVERAGE		
<input type="checkbox"/> HEALTH INSURANCE 1		
<input type="checkbox"/> HEALTH INSURANCE 2		
<input type="checkbox"/> VET. ADMIN. ID		
<input type="checkbox"/> OTHER		

PRESCRIPTION	STRENGTH	DOSAGE	DOCTOR	COST

# NOTES

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# SELF CARE

If you are a caregiver, be sure to take care of your own health and well-being so you can continue to provide care to others. Take time away to rest and rejuvenate.

- Visit a park and enjoy the outdoors if nature is where you find serenity.
- Listen to music.
- Window shop.
- Go to a movie or concert.
- Write a conversational letter to someone you haven't spoken to in awhile.
- Practice yoga or another form of gentle exercise like walking or bicycling.
- Meditate once daily if you can.
- At least once a day do something enjoyable for yourself, guilt free.

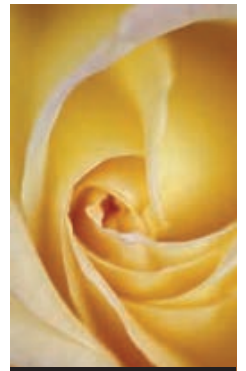
## Top Five Self-Care Tips

- 1 No secret—eat smart and exercise more. You already know how.
- 2 Be skeptical of miracle cures.
- 3 Remember that mental well-being is as important as physical.
- 4 Laughter is still the best medicine.
- 5 Stay connected with family and friends. Ask for and accept help when needed.

## SECTION 5



# END OF LIFE



## SECTION 6

**H**ospice is a philosophy of care, not a place, which seeks to enhance the quality of life for a person nearing the end of their life journey. Through pain management, comfort care and symptom control, the goal is to enable each individual to live with dignity surrounded by loved ones.

Hospice care becomes a choice when you and your doctor determine that future efforts to cure an illness are no longer realistic or desirable. The focus of treatment then moves from curing to caring using an interdisciplinary team approach addressing the medical, spiritual and emotional needs of both individuals and their families.

### FAQs

#### Are All Hospices the Same?

No, there are individual hospice organizations who provide the same philosophy of care to people at the end of life.

#### When Is It Time to Call Hospice?

- When a person or family decides that comfort care and quality of life matter more than a cure
- Changing goals of care
- Change in prognosis
- Decline in medical condition
- To gather information

#### Who Pays for Hospice Care?

- Medicare
- MediCal
- Private Medical Insurance
- Long-term Care Insurance
- Veterans Health Administration
- Patient and family

Choosing among the different options for care at the end of life can be difficult. Hospice can help ease that burden and retain the focus on dignity, comfort and respect.

National Hospice and Palliative Care Organization: [www.caringinfo.org](http://www.caringinfo.org)



## DON'T FORGET YOUR VIAL OF LIFE!

A **Vial of Life** is a magnetized envelope that sticks to your refrigerator. It includes blank forms that you fill in with your vital emergency information. Paramedics and other emergency responders are instructed to look for the **Vial**. Obtain your free **Vial of Life** by calling the number below.

For local resources, call 1-800-510-2020 or see [www.caregivercoalition.org](http://www.caregivercoalition.org)



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