



Stanford Caregiver Manual

Handbook for Family Caregivers
of Patients with Serious Illness

A Caregiver's Bill of Rights:

I have the right:

- To take care of myself. This is not an act of selfishness. It will give me the capability of taking better care of my loved one.
- To seek help from others even though my loved ones may object. I recognize the limits of my own endurance and strength.
- To maintain facets of my own life that do not include the person I care for, just as I would if they were healthy. I know that I do everything that I reasonably can for this person, and I have the right to do some things just for myself.
- To get angry, be depressed, and express other difficult feelings occasionally.
- To reject any attempts by my loved one (either conscious or unconscious) to manipulate me through guilt, and/or depression.
- To receive consideration, affection, forgiveness, and acceptance for what I do, from my loved ones, for as long as I offer these qualities in return.
- To take pride in what I am accomplishing and to applaud the courage it has sometimes taken to meet the needs of my loved one.
- To protect my individuality and my right to make a life for myself that will sustain me in the time when my loved one no longer needs my full-time help.
- To expect and demand that as new strides are made in finding resources to aid physically and mentally impaired persons in our country, similar strides will be made towards aiding and supporting caregivers.

Contents

• A Caregiver’s Bill of Rights.....	2
• Who is a Caregiver:.....	4
• Self-Care:	
○ Ten Tips for Family Caregivers.....	5
○ The Caregiver Experience.....	6
○ Taking Care of You: Self-Care.....	7-9
○ How Others Can Help.....	9-10
• Medical Tips and Resources:	
○ Understanding Your Loved Ones Wishes.....	10-11
○ Medication Management.....	11-13
○ Doctor Visits.....	14
○ How to Communicate Your Loved One’s Symptoms.....	15-16
○ How to Communicate with Insurance Company Personnel.....	16-17
• Advance Care Planning:	
○ Advanced Directives.....	17-19
○ Living Wills, Medical Power of Attorney.....	19-20
○ Personal Business.....	20-21
○ Estate Planning.....	20-21
• Caregiving Financials	
○ The Cost of Caregiving.....	21
○ Budget Worksheet.....	22-23
• Resources:	
○ Caregiver Support Groups.....	24-25
○ Online Resources for Caregivers.....	26-27
○ Recommended Caregiver Books.....	28
○ Recommended Articles on Caregiving.....	28-29

Who Is a Caregiver?

If you are helping someone you love, you are a “caregiver.” You may not think of yourself as a caregiver. You may look at what you’re doing as something natural—taking care of someone you love.

There are different types of caregivers. Some are family members. Others are friends. Every situation is different. So there are different ways to give care. There isn’t one way that works best.

Caregiving can mean helping with day-to-day activities such as doctor visits or preparing food. But it can also happen long-distance, when you are coordinating care and services by phone or email. Caregiving can also mean giving emotional and spiritual support. You may be helping your loved one cope and work through the many feelings that come up at this time. Talking, listening, and just being there are some of the most important things you can do.

During this time, the natural response of most caregivers is to put their own feelings and needs aside. They try to focus on the person with the patient and the many tasks of caregiving. This may be fine for a little while. But it can be hard to keep up for a long time. And it’s not good for your health. If you don’t take care of yourself, you won’t be able to take care of others. It’s important for everyone that you take care of *you*.

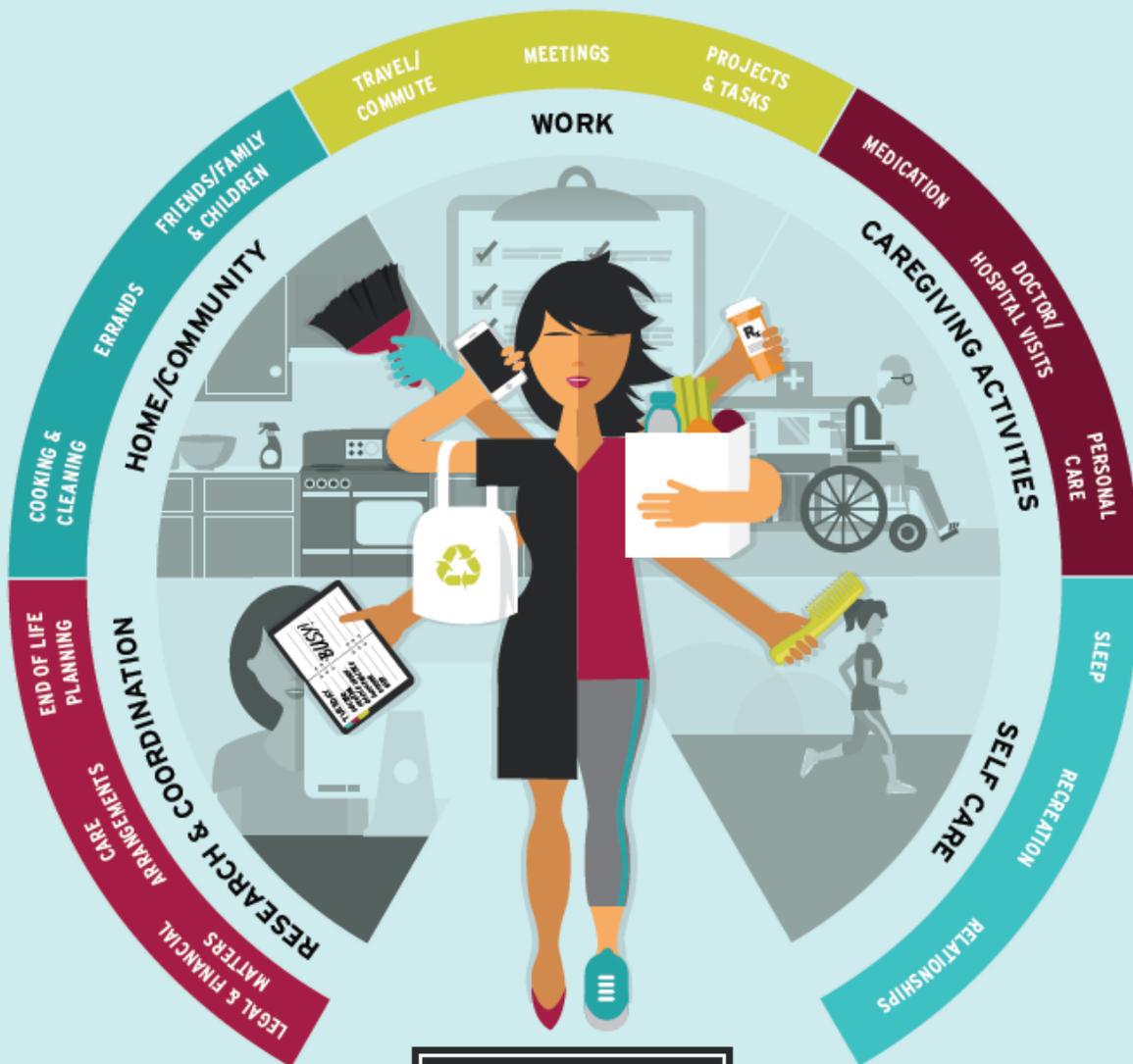
Ten Tips for Family Caregivers:

1. **Seek support** from other caregivers. You are not alone!
2. **Take care** of your own health so that you can be strong enough to take care of your loved one.
3. **Accept offers of help** and suggest specific things people can do to help you.
4. Learn how to **communicate effectively** with doctors.
5. Caregiving is hard work so **take respite breaks** often.
6. **Watch out** for signs of depression and don't delay in getting professional help when you need it.
7. **Be open** to new technologies that can help you care for your loved one.
8. **Organize** medical information so it's up to date and easy to find.
9. **Make sure** legal documents are in order.
10. **Give yourself credit** for doing the best you can in one of the toughest jobs there is!

THE CAREGIVER EXPERIENCE:

A SNAPSHOT OF THE CAREGIVER JOURNEY

OF THE 44 MILLION UNPAID ELDER CAREGIVERS IN THE U.S.,
75% ARE EMPLOYED.



Elder caregivers:

SOURCES: Gallup/Pfizer Study on Working American Caregivers (2011) | ReACT and NAC Best Practices in Eldercare Report (2012)
Caring.com/Pretell Market Research, Family Caregiver Survey (2014)

Taking Care of YOU: Self-Care for Family Caregivers

First, Care for Yourself

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

Effects of Caregiving on Health and Well Being

We hear this often: "My husband is the person with Alzheimer's, but now I'm the one in the hospital!" Such a situation is all too common. Researchers know a lot about the effects of caregiving on health and wellbeing. Those who assume a caregiver role while simultaneously juggling work and raising children, face an increased risk for depression, chronic illness and a possible decline in quality of life.

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

- Sleep deprivation
- Poor eating habits
- Failure to exercise
- Failure to stay in bed when ill
- Postponement of or failure to make medical appointments for themselves

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

Taking Responsibility for Your Own Care

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

Identifying Personal Barriers

Many times, attitudes and beliefs form personal barriers that stand in the way of caring for yourself. Not taking care of yourself may be a lifelong pattern, with taking care of others an easier option. However, as a family caregiver you must ask yourself, "What good will I be to the person I care for if I become ill? If I die? The first task in removing personal barriers to self-care is to identify what is in your way. For example:

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

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

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

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

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

How Can Others Help You?

Many people want to help, but they don't know what you need or how to offer help. It's okay for you to take the first step. Ask for what you need and for the things that would help you most. For instance, you may want someone to:

- Help with household chores, including cooking, cleaning, shopping, yard work, and childcare or eldercare.
- Listen to you share your feelings.
- Drive your loved one to appointments.
- Pick up a child from school or activities.

- Pick up a prescription.
- Look up information you need.
- Be the contact person and help keep others updated on your loved one.

Who Can Help?

Think about people who can help you with tasks. Besides friends and family, think of all the people and groups you and your loved one know. Some examples are neighbors, coworkers, and members of your faith community. The hospital or cancer center may also be able to tell you about services they offer or give you a list of agencies to call. Social workers can also put you in touch with support services.

Understanding Your Loved One's Wishes

For many families, it's important that your loved one be in charge of making decisions. But in some families and cultures, it's common for the caregiver to make many of the decisions. And they may make them with or without the patient knowing. Or sometimes the patient wants the caregiver to make all the decisions. This may be hard, for many reasons:

- Your own stress may make it hard to decide.
- Your ideas about how to move forward may differ from the ideas of other family members or friends.
- The patient may have different beliefs about care than you or other loved ones.
- The opinions of your health care team may differ from your loved one's or yours.

There may also come a time when you have to make decisions for your loved one because he can't anymore. It's important to get a sense of how they feel about this before it happens. How would they like to deal with it? This may mean letting go of some opinions that you have about treatment. (For example, you may want to keep your loved one alive, whatever it takes. But they may wish to stop receiving life-sustaining measures at a certain point.) Try to keep things in perspective by looking at the facts.

<http://www.cancer.gov/publications/patient-education/When-Someone-You-Love-Has-Advanced-Cancer.pdf>

Medication Management

Medication List

An up-to-date medication list is an important tool for the family caregiver and your care recipient's doctor(s). People with chronic diseases or disabilities take more medications than any other group of patients. With the number of medications some patients take, the issue of medication management and can easily become overwhelming. Good health outcomes are three times less likely for patients who do not take medications correctly as compared to those that do.¹ Improper use of medications causes 18 million emergency room visits per year.²

1. Maintain an up-to-date medication list

- Keep an up-to-date list of all the medications doctors have prescribed for your care recipient. Also, list over-the-counter medications and supplements. Be sure to list the name, dosage, and frequency of the medication, the reason for taking it, any dosing directions, the start date, and when appropriate, the end date.

- For prescription drugs, add the name and phone number of the prescribing doctor as well as the pharmacy that filled the prescription.
- Be sure to include your loved one's name and your emergency contact information. Note any allergies, or other significant medical information.
- Make multiple copies: one for you to carry; one for your care recipient's patient file; one on the refrigerator for paramedics to find in an emergency; and one for the primary doctor.
- A simple computer-based document is one of the easiest ways to keep the record current.

2. "Translate" hand-written prescriptions

- Don't be shy about asking all doctors to "translate" their handwriting, so you can have a record of what they prescribed and why.

3. Write the condition treated on each medicine bottle

- You might find that your care recipient is taking three different pills for the same condition, each prescribed by a different physician. That may be exactly what is needed, but it is definitely a red flag to alert you to ask questions.

4. Use the same pharmacy when possible

- If you do, there will be an official record of all prescription medications over an extended period. This can be a vital timesaver during an emergency.
- Develop a strong rapport with your pharmacist and let them know you value their advice. The pharmacist is a great resource. Ask your pharmacist's advice about over the counter medications and if they may react with prescription medications.

5. Understand potential side effects and interactions and monitor interactions

- Ask the doctor and pharmacist about potential side effects and interactions with others drugs, vitamins, or foods.
- Learn what to do if a dose is accidentally skipped.

6. Come up with an easy way for managing medications on a daily basis

- Use pill boxes or other technology to monitor and manage doses.
- Use auto-refill programs – when available.

What should be on the Medication List?

- Name of drug – generic and brand names
- Dose
- Start and stop dates
- What the pill/capsule/liquid looks like
- A record of any side effects experienced
- What the drug is treating
- Instructions – How and when to take the medication
- What not to do when taking the medication
- Over the Counter medications and supplements with their doses
- Drug and other allergies
- Drugs to which the patient experienced a negative reaction (couldn't tolerate it)
- Recently completed prescriptions
- Name/contact info of prescribers (physician/physician assistant/nurse practitioner, etc.)
- Name/contact info for pharmacy that filled the prescription(s)

Dispose of Unused Medications Properly

- Step 1: Crush or dilute medication
- Step 2: Put medication in plastic bag
- Step 3: Add kitty litter, sawdust, or coffee grounds to plastic bag
- Step 4: Seal plastic bag and place in trash.

NOTE: *Most medications should not be flushed*, but there are a small number that should be. Check with the pharmacist to find out if medications should or should not be flushed.

Going to the Doctor

You may want to accompany your care recipient to doctor's appointments. This way, the two of you can work together as members of the health care team to ensure that you both understand the recommended medical course of action. This is especially important if your care recipient is cognitively impaired. Here is a checklist to help you make the most of your doctor's visit:

Before the Visit

- Write down all questions or any concerns you might have so you don't forget them. This will help you state them clearly. Regardless of how insignificant you feel the doctor may think it is— ASK!
- Identify current symptoms. Use the following handy symptom-reporting guide.
- Update the patient file and medication list. Be sure to include all medications, over the counter drugs and supplements.
- Call to confirm appointment.

During the Visit

- Bring the updated medication list.
- Clearly report all of your loved one's symptoms; don't try to diagnose the problem.
- Ask your questions and record the answers.
- Record doctor's instructions.
- Discuss recommendations.
- Verify follow-up.

After the Visit

- Review your notes.
- Check prescriptions.
- Discuss the visit.
- Update your calendar.
- Call for test results.

How to Communicate Your Loved One's Symptoms Regarding Overall Wellbeing, Pain and More

Overall Wellbeing:

- Is the patient eating well? Any sudden changes in diet or fussiness about eating? Any sudden cravings?
- Are they weight stable? If not, what is happening?
- Are they sleeping well? Unable to fall asleep? Wakes up and is unable to go back to sleep? Has nightmares? Sleeps restlessly?
- Are they getting exercise? Suddenly doing less than typical?
- Is there any sign of abuse or neglect that you have seen? If so, what is it?

General Condition:

- Does the patient seem “slowed down” noticeably since the last visit? If so, how?
- Do they have any unusual bleeding? Where? How much?
- Do they seem to be breathing easily? If not, what is the quality of the breathing? Rapid, shallow, gasping, rattling, other?
- Do they cough when eating or drinking?
- Is their digestive system working well? If not, what seems to be the matter? Excessive gas, heartburn, diarrhea, constipation, other?
- Are their limbs moving as they usually do? Are they struggling to handle things?
- Have any rashes or welts appeared recently? Where? What do they look like?
- Has a mole changed shape or become dark? Has a new one appeared somewhere?
- In general, does the treatment plan seem to be working? If not, what seems to be wrong?
- Is a particular problem the reason for this office visit? If so, what are the major symptoms or concerns?

Pain:

- Is the patient complaining about pain? What do they say it feels like? Sharp, stabbing, dull, pounding, achy, tingling, other?
- Where is it located? All over, head, abdomen, limbs, other?
- On a scale of 1-10, with 1 being no pain and 10 being pain unimaginable, how does the patient rate the pain?
- How long has the pain lasted?
- Does it move around or stay in one place?
- Does it come and go or it there all the time?
- Does the pain seem to occur in relation to something else? (e.g., eating)
- Is there anything that makes the pain better/worse?
- Does pain medication help? If so, how much?

Medication:

- Is the patient taking their medication on time? At the prescribed dose? If not, why?
- Is the patient complaining about or suffering from any side effects? If so, what are they (drowsiness, hyperactivity, etc.)?

How to Communicate with Insurance Company Personnel

Before you pick up the phone to speak to a claims representative, you need to gather some information. When you start the conversation, ask for the name and telephone number of the individual who is handling your call. If you need to call again, you will want to try to speak with the same person. Be prepared to give the person you talk with:

- Your name and relationship to the care recipient
- Your care recipient birth date and insurance policy number
- The name and address of the organization that sent the bill and bill amount
- Diagnosis code on the bill
- The Explanation of Benefits

Communication Tips:

Here are some tips for effectively communicating with the people who work in the health care insurance system:

- **Be Prepared:** Write down a list of questions before you call so you can handle everything in one call.
- **Take Good Notes:** Take notes about phone conversation including date, the name of the representative you spoke with and information given.
- **Be Clear and Concise:** State your question or concern, what you need and what you expect.
- **Be Patient:** Health insurance issues can be frustrating and time consuming. Accept that you will be spending some time navigating the phone process.
- **Follow Through:** If the insurance company asks you to do something, do it right away. Also, be persistent and keep in touch until the issue is resolved.

Advance Care Planning

Part of helping someone live well with a serious illness involves accommodating their needs as the illness progresses. Although you may be dealing with adjustments to daily living, it is important that you and your loved one talk in advance about their beliefs, values and wishes for end-of-life care. If you wait until your loved one is badly debilitated before getting these affairs in order, it may be too late for them to express requests, make rational decisions, and sign important documents.

Advance Care Planning Includes:

- Learning what life-sustaining treatments are available (artificial nutrition, extended mechanical ventilators, resuscitation, etc.)
- Deciding what medical treatments your loved ones would want if their illness becomes life threatening.
- Communicating with your loved one about their personal values and spiritual beliefs about death and dying. Deciding who your loved one would want to speak for them and make decisions about their care if unable to do so for themselves.
- Preparing legal documents of your loved one's end-of-life preferences (advance directives) and giving copies to health care providers.

Advance Directives:

Advance directives are a set of documents that allow your loved one to identify his or her wishes for care at the end stages of life, in case they are not able to do so at the necessary time. Once the advance directive is completely filled out, they should be signed and dated, and copies should be kept at home and also included in the patient's medical records. Once they are signed, they become legal, official forms. These documents may vary by the state you live in, but you can obtain your state's version from your doctor, legal offices or state departments.

Living Wills:

A living will is the part of the advance directive that documents the patient's wishes about the medical care that they want at end of life. These written instructions are used if the patient is physically or medically unable to communicate wishes at the time. This document is extremely important because it protects a patient's rights to accept/refuse care and it removes the burden of life-or-death decisions from family or the medical team. It is important to know that someone can decide to refuse "aggressive medical treatment to attempt to cure a disease" but not to refuse all medical care. In other words, the patient can specify not to be kept alive artificially, but to be provided comfort care (pain medication.)

Typical Information in a Living Will:

- DNR (do not resuscitate) orders- instructions to refuse CPR if breathing/heartbeat stops
- Choices about artificial hydration and nutrition
- Choices about life-sustaining equipment (ventilators, respirators)
- Choices about comfort care (pain medication)
- Instructions about being an organ/tissue donor

Medical Power of Attorney:

The medical power of attorney is the part of the advance directive that names the patient's health care proxy- whom the patient designates to make decisions regarding end-of-life care if the patient is unable to do so. Typically this is someone whom the patient knows well and trusts will make decisions that represent the patient's wishes in case they are not well stated. The health care proxy is often a spouse or family member of the patient. The patient should make sure to ask this person if they agree to be the health care proxy and, if so, the person must sign the designated form.

Personal Business

In addition to the difficult decisions involving physical, emotional and spiritual care at end of life, most people have personal business that will require management by someone who can be trusted. Adjusting the information on important documents before the patient becomes too ill may prevent years of legal battles and financial burdens. The following is a list of important topics to become familiar with:

- **Bank Accounts:** Pay-on-death beneficiary designation; do you need to add co-signers?
- **Safe Deposit Boxes:** Where are the keys? Who are the co-signers?
- **Life Insurance Policies:** Who are the beneficiaries? Do they need amending?
- **Health Insurance Policies:** Where are membership cards? What are the ID numbers?
- **Durable Power of Attorney for Health Care:** Has this been signed? Where is the original? Do health care providers have copies?
- **Durable Power of Attorney for Finances:** Who has been designated? What is their contact information?
- **Will and/or Living Trust:** Where are they? What attorney drafted them?
- **Deeds/Property Titles:** Who has ownership of property? Does "tenancy" need to be designated?
- **Stock/Bonds:** Who are the beneficiaries? Do they need to be amended?
- **Birth Certificate:** Know where your loved one was born in case you need to order one.
- **Military Papers:** If applicable, where are the discharge papers?
- **Social Security Papers:** Where are these documents?
- **Benefits Forms:** Have copies of all forms (SSI, SSDI, GA, MediCal, Food Stamps, etc.)
- **Loan Papers:** Keep payments contracts and credit card statements organized.
- **Vehicle Registration:** Who is listed as the owners and where is the certificate?
- **Funeral Instructions:** Is there a contract with a funeral home? Are wishes written down?
- **Income Tax Returns:** Keep returns for last 5 years and the accountant's contract information.

Estate Planning

Many people have things that they want to leave to their loved ones to remember them by- some form of a legacy- usually identified in a will. These inheritances can be in the form of financial gifts, family heirlooms, objects of sentimental importance or even personal memoirs. Helping prepare a legacy with a loved one is a way to bring you closer by providing support they may not know to ask for.

If your loved one does not specify who is to inherit his/her belongings, each state has a formula that will disperse out the estate to next of kin after a lengthy and costly process. If a person dies *intestate* (without a formal will) the state takes control of the property, determines the legal nearest blood relatives and disperses the estate to them. Many times property is sold, all expenses are paid, and what is left goes to the heirs.

There are many issues involved in estate planning that you should be aware of. The best way to become educated on these topics is to seek legal advice or refer to a social worker in the hospital for resources.

The Costs of Caregiving

Caregiving often results in financial consequences for the caregiver. Some of the consequences are obvious –

- A decision to work part-time
- To decline a promotion requiring longer hours or
- To pass up a training opportunity requiring travel

But there are more subtle consequences as well. These include:

- Lost opportunities for compounded returns on 401(k) matching contributions
- A reduction in savings and investments, or
- An inability to finance home improvements that could increase the resale value of a residence.

One study found that, on average, caregivers lose \$659,130 over a lifetime in reduced salary and retirement benefits.

Take Control of Your Finances Today!

- Create a **household budget** and make realistic plans for how you will deal with your caregiving responsibilities and possible reduced pay and benefits. Focus on reducing your expenses and eliminating your debt. If you are a caregiver to another adult, you might find yourself paying small expenses out of pocket without even realizing how quickly these expenses add up. Establish a budget for the person you provide care for as well.
- Talk to your siblings and other family members about the various costs involved in your providing care to a family member.

Budget Worksheet

HOUSEHOLD EXPENSES	MONTHLY	ANNUALLY
Rent or Mortgage Payment		
Real Estate Taxes		
Home Owners Insurance Premiums or Renters Insurance		
Telephone		
Other utilities (gas, electric, water, sewage, garbage, etc.)		
Home Maintenance		
Other Household Expenses		
TOTAL		

FOOD/CLOTHING/TRANSPORTATION EXPENSES	MONTHLY	ANNUALLY
Food		
Clothing		
Laundry/Dry Cleaning		
Auto Loan Payments		
Auto Maintenance (gas, oil, filters, etc.)		
Auto Insurance Premiums		
Other Transportation		
TOTAL		

PREMIUMS/PAYMENTS/SAVINGS	MONTHLY	ANNUALLY
Adult/Child Education (tuition, books, etc.)		
IRA, 401(K), 403(B)		
Medical/Dental/Eye Care/Prescriptions		
Dependent/Child Day Care		
Loan Payments		
Credit Card Payments		
Life Insurance Premiums		
Medical Insurance Premiums		
Disability Income Insurance Premiums		
Other Savings		
TOTAL		

MISCELLANEOUS EXPENSES	MONTHLY	ANNUALLY
Personal Care (Haircuts, etc.)		
Pets/Pet Care		
Entertainment (Include Vacations)		
Gifts (Birthday, Holidays, etc.)		
Membership Fees (Health Club, Magazines)		
Other Expenses		
TOTAL		

GRAND TOTAL		
--------------------	--	--

Caregiver Support Groups

Online and Phone Support Groups:

- **Family Caregiver Alliance:** Offers online support groups for caregivers and their loved ones: <https://www.caregiver.org/support-groups>
- **WellSpouse:** Find support, sharing and a social community: <https://wellspouse.org/our-support/caregiver-support/>
- **Cancer Care:** Online and telephone support groups for cancer patients and loved ones, led by oncology social workers. http://www.cancercare.org/support_groups

Local Support Groups:

- **Cancer CAREpoint**
<https://www.cancercarepoint.org/>
(408) 402-6611
2505 Samaritan Dr #402, San Jose, CA 95124
Offers a wide range of free services and programs for cancer patients and their caregivers, including nutrition consults, guided imagery, massage therapy, yoga, collage art, wig consults, speaker series, counseling services and support groups.
- **Catholic Charities of Santa Clara County: Daybreak Adult Day Care Centers**
<https://www.catholiccharitiesscc.org/daybreak-cares-enterprise?locale=en>
Phone: (408) 270-4900
Address: 5111 San Felipe Rd San Jose, CA 95135
408-282-1134 Chinese
Address: 535 Old San Francisco Road Sunnyvale, CA 94087
A community-based program that provides non-medical care to meet the needs of functionally impaired Chinese and Vietnamese older adults while enhancing the quality of life.
- **Day Break II Asian Respite and Caregiver Support Services**
Offers center based respite, in-home respite, and escorted transportation designed for dependent Asian seniors with Alzheimer's or dementia. Other services include: caregiver support groups, community education, and case management.
- **Family Caregiver Alliance**
<https://www.caregiver.org/>
Phone: (415) 434-3388
Address: 180 Montgomery, Suite 1100 San Francisco, CA 94104
Offers support services, information and education for families throughout the Bay Area providing care to those with chronic health conditions.
- **Live Oak Adult Day Care Services**
<http://liveoakadultdaycare.org/>
Phone: (408) 973-0905, Address: 20920 McClellan Road, Cupertino, CA 95014
Phone: (408) 847-5491, Address: 651 West 6th Street, Gilroy, CA 95020
Phone: (408) 354-4782, Address: 111 Church Street, Los Gatos, CA 95030
Phone: (408) 971-9363, Address: 1147 Minnesota Avenue, San Jose, CA 95125
Provides a day care program of recreational and social activities for frail, disabled seniors and respite for their caregivers. Offers caregivers support groups, community resources, and case management.
- **Stanford Support Groups**
<https://stanfordhealthcare.org/for-patients-visitors/cancer-supportive-care-program.html>
Find a variety of support groups for various medical conditions, treatments, and caregiving.

Caregiver Resources:

- **American Cancer Society:** Excellent resource for all aspects of caregiving <http://www.cancer.org/treatment/caregivers/index>
- **CancerCare Caregiver Stories:** Inspiring personal accounts from caregivers affected by cancer and the ways they've found to cope <http://www.cancercare.org/stories#caregiver>
- **CancerCare Connect Education Work Shops:** Listen in by telephone or online as leading experts in oncology provide up-to-date information about cancer-related issues in one-hour workshops. Podcasts are also available. http://www.cancercare.org/connect_workshops
- **Cancer Legal Resource Center:** Provides information and education about cancer-related legal issues to the public through its national telephone assistance line (866) THE-CLRC <http://www.disabilityrightslegalcenter.org/cancer-legal-resource-center>

- **Caregiver Action Network:** Forum that serves a broad spectrum of family caregivers <http://www.caregiveraction.org/forum>
- **Caregiving.com:** An online community of supportive individuals caring for a family member or friend. <http://www.caregiving.com>
- **CaringBridge:** Provides a free personal website and all the tools to keep family and friends updated during a health crisis. Allows patients and caregivers to activate their community, coordinate help and receive emotional support. <https://www.caringbridge.org/>
- **Eldercare Locator:** Find local agencies in every U.S. community that can help older persons and their families access home and community-based services. (800) 677-1116; <https://eldercare.acl.gov/Public/Index.aspx>
- **Family Caregiver Alliance:** A public voice for caregivers including programs on services, education, research and advocacy. (415) 434-3388; www.caregiver.org
- **Helpguide.org:** Information and suggestions for reducing caregiver stress and burnout <http://www.helpguide.org/articles/stress/caregiving-stress-and-burnout.htm>
- **Imerman Angels:** Offers 1:1 peer support for both cancer fighters and their caregivers. The organization strives to match people with others who are uniquely familiar with their experience. <http://www.imermanangels.org>
- **Lotsa Helping Hands:** Free caregiving coordination web service that provides a private, group calendar where tasks for which a caregiver needs assistance can be posted. Family and friends may visit the site and sign up online for a task. The site tracks each task and notification and reminder emails are sent to the appropriate parties. www.lotsahelpinghands.com
- **MedLine Plus- Caregivers:** Resources on all aspects of caregiving, including financial. <http://www.nlm.nih.gov/medlineplus/caregivers.html>
- **National Hospice and Palliative Care:** Advancing care at the end of life. Provides free resources to help people make decisions about end of life care and services before a crisis. (703) 837-1500 www.nhpco.org
- **NeedyMeds:** An online organization that provides information on patient-assistance programs to help with the cost of medication. www.needymeds.com
- **Patient Advocate Foundation:** Provides no-fee professional case management to individuals facing barriers to health access. www.patientadvocate.org
- **The Art of Dying Well:** Practical and spiritual support for caregivers faced with caring for the dying. <https://www.artofdyingwell.org/>
- **Today's Caregiver:** Caregiving resources and current news about caregivers. (954) 893-0550; www.caregiver.com

Caregiver Books:

Chicken Soup for the Caregiver's Soul by Jack Canfield, Mark Victor Hanson and LeAnn Theimann

A Family Caregiver Speaks Up "It Doesn't Have to be This Hard" by Suzanne Mintz

The Caregiver Meditations – Reflections on Loving Presence by Erie Chapman

Caring for the Patient with Cancer at Home: A Guide for Patients and Families Available for free through the American Cancer Society (800-227-2345)

Daily Comforts for Caregivers by Pat Samples

The Human Side of Cancer: Living with Hope, Coping with Uncertainty by Jimmie C Holland, MD of Memorial Sloan-Kettering Cancer Center

A Husband, A Wife, and an Illness: Living Life Beyond Chronic Illness by Dr. William July

Mainstay: For the Well Spouse of the Chronically Ill by Maggie Strong

Passages in Caregiving: Turning Chaos into Confidence by Gail Sheehy

The Selfish Pig's Guide to Caring by Hugh Marriot

The Tough and Tender Caregiver: A Handbook for the Well Spouse by David and Rhonda Travland

Caregiver Articles:

- "What Can I Say to a Newly Diagnosed Loved One?" <http://www.cancer.org/publications/104-what-can-i-say-to-a-newly-diagnosed-loved-one>
- "Building a Community of Support" <http://www.cancer.org/publications/186-building-a-community-of-support>
- "Caregiving During Holidays and Special Occasions" <http://www.cancer.org/publications/145-caregiving-during-holidays-and-special-occasions>
- Caregiving for Your Loved One With Cancer <http://www.cancer.org/publications/1-caregiving-for-your-loved-one-with-cancer>
- Caring Advice for Caregivers: How Can You Help Yourself? <http://www.cancer.org/publications/47caring-advice-for-caregivers-how-can-you-help-yourself>
- Coping with the Stress of Caregiving <http://www.cancer.org/publications/142-coping-with-the-stress-of-caregiving>
- For Caregivers: Coping With Holidays and Special Occasions <http://www.cancer.org/publications/2-for-caregivers-coping-with-holidays-and-special-occasions>
- Managing the Practical Concerns of Your Loved One's Diagnosis <http://www.cancer.org/publications/144-managing-the-practical-concerns-of-your-loved-ones-diagnosis>
- Young Adults as Caregivers <http://www.cancer.org/publications/141-young-adults-as-caregivers>

Sources

Caregiving: Helping an Aging Loved One, Jo Horne

<http://www.cancer.gov/publications/patient-education/When-Someone-You-Love-Has-Advanced-Cancer.pdf>

<http://www.caregiveraction.org/resources/toolbox>

¹ DiMatteo, MR, Lepper, HS, Croghan TW...*Patient Adherence and Medical Treatment Outcomes: A Meta-Analysis*; Medical Care vol. 40 # 9, 2002, pp 794-811

² Zed, Peter J. PharmD, Abu-Laban, Riyad, MD, Balen Robert, M. PharmD, et al: *Incidence, severity and preventability of medication-related visits to the emergency department: a prospective study*, Canadian Medication Association Journal, June 3, 2008; 178 (12). doi:10.1503/cmaj.071594.