



# Essential Tips for Caregiving

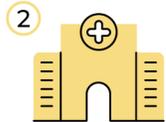


# TOOLKIT TOPICS

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1 Managing care at home



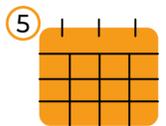
2 Caregiving in the hospital and clinic



3 Talking with children about serious illness



4 Paying for health care



5 Planning ahead



6 End-of-life care



7 Taking care of yourself

# What to expect as a caregiver

## The importance of caregiving

As a caregiver, you are essential. Caring for a loved one who is ill is the most important work you can do. It can also be a complex experience. **It is normal to have a mix of feelings that range in intensity.** Caregiving often creates a deepened sense of closeness between you and your loved one. You may feel fulfilled and have a sense of pride about the work. You may also find that you have to juggle your needs with theirs. You may feel stressed, guilty, sad, anxious, or overwhelmed. Your relationships may feel strained at times. Please know that your palliative care team is here to support you, as well as your loved one, throughout the course of their illness.

## Toolkit for caregivers

As a caregiver, you are also part of your loved one's health care team. The Caregiver Toolkit is designed to **give you a better sense of control** and to **prepare you for what to expect.**

The toolkit includes 7 sections and a list of helpful resources. Topics address some of the most common issues that arise while caregiving.

Look for the lightbulb icon. 

It is where you will find **tips** about:

- When to call a provider.
- What you can do at home to help your loved one.

### Toolkit Topics

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- 1 Managing care at home
  - 2 Caregiving in the hospital and clinic
  - 3 Talking with children about serious illness
  - 4 Paying for health care and other basic needs
  - 5 Planning ahead
  - 6 End-of-life care
  - 7 Taking care of yourself
- Resources

**To get started, click on a toolkit topic above.**



# 1. Managing care at home

## Keeping track of care and information

It can be a challenge to balance work, family, and your own needs – all while caring for someone else. This section offers a guide on how to tackle care tasks, while keeping track of health information, treatments, and medicines.

Start by thinking about the tasks that need to be done. Talk with your loved one about them so they can stay involved.

Routine tasks often include:

- Shopping and cooking meals
- Transportation
- Housework

Patient care tasks may include:

- Bathing
- Giving medicines
- Keeping your loved one company

There are many ways to complete caregiving tasks, and your approach may change over time. You can:

- Do the job yourself
- Get help from friends and family
- Hire a paid caregiver
- Combine these methods as needed

### Want more information on this topic?



See Managing care at home or ask a member of your palliative care team.



## Use a binder to keep health information organized

Having a system to keep health information organized gives some caregivers a sense of control and focus. Your binder can include sections for what you need to track. Be sure to review all logs with your loved one.

### Binder Sections

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#### **Health history log**

Create a brief health history, noting any allergies and current conditions.

#### **Notes and questions**

Write down notes and questions that come up in between health care visits.

#### **Medicine log (included in this booklet)**

Keep a list of all prescription and non-prescription medicines your loved one is taking. For all new medicines:

- Review the name and dosage
- Know what it is for and what side effects to expect.

#### **Treatment and symptom logs**

Log any treatments, tests, and procedures, and keep track of symptoms and side effects.

- Write down the dates of new treatments or procedures.
- Note any test results (blood sugar, blood pressure, etc.).
- Log any side effects or symptoms you or your loved one have noticed:
  - Pain (on a scale from 0-10)
  - Nausea or vomiting
  - Fatigue
  - Confusion or anxiety
  - Changes in appetite

## 2. Caregiving in the hospital and clinic

**As a caregiver, you are essential no matter where your loved one is.** Whether they are seeing the doctor in clinic, or getting care in the hospital, you can provide important information, advocate, and offer support.

### Caregiving in the hospital

Patients are often seen by a team of providers during a hospital stay.

Providers see patients each day on a schedule.

- This process of scheduled visits is called “**rounding.**”
- Ask about the rounding schedule(s) so that you can be present when providers visit your loved one. It is a good time to ask questions.

Planning for when your loved one will leave the hospital (“**discharge planning**”) often begins early in their stay.

- The health care team will likely discuss discharge plans with you.
- Discharge plans include the services and treatments your loved one will need once they leave the hospital.

### Caregiving in the clinic

Clinic visits usually last 30-45 minutes. Taking some time to prepare for clinic visits in advance can be helpful.

- **Bring your health care binder.** Review your questions, and the treatment and medication logs with the provider.
- **Show the provider your list of questions at the start of the visit.** You and the provider can decide which issues to address during the visit, and make plans to address the others at a later time.

Clinic visits are a good time to:

- **Ask questions.** Nurses can answer questions about the daily issues you face at home. Get to know these key members of your loved one's care team.
- **Ask for support.** If you need extra support, tell your provider or nurse. They can refer you to a social worker or nurse navigator.



## Decision-making

Open communication with the health care team can help you and your loved one get the information you need to make the best choices.

### Questions to ask your loved one's care team to help with decision-making

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- What is your loved one's current medical condition?
- What is the most likely outcome ("prognosis")?
- What does the best case look like? Worst case?
- What treatment does the care team suggest?
- What result does the care team hope for or expect from the treatment?

#### **Want more information on this topic?**



See Caregiving in the hospital or clinic or ask a member of your palliative care team.

# 3. Talking with children about serious illness

## Children have a need to understand what's happening

The thought of explaining a serious illness to a child or youth can feel overwhelming. Family members may want to avoid sharing to protect children.

Children of almost any age can sense when something is wrong. Sharing information about what is happening may help children feel less alone.

### Sharing information can help children

Sharing helps children trust what they are being told. It also gives them a chance to process their feelings with family members.



## Ways to share information

### **Describe the illness and treatment.**

It is okay to use the words “death” and “dying” to help avoid confusion. Picture books can be helpful for younger children. The palliative care team can help you pick the right language and suggest resources for the child’s age.

### **Practice what you will say.**

Your talks will be most effective if you know what you are going to say ahead of time. It will help if you are calm and able to focus on the child’s questions.

### **Listen closely and pay attention to the child's reaction.**

As children grow and go through different stages, what they understand will change. Meet each child where they are at. If you notice a child getting upset through their words or actions, it can help to have a loving adult gently take them out of the situation.

**Let children respond in their own way.**

Children may surprise you with their insight. They may have their own ideas about what is happening. Try to avoid correcting them too much. Give them the chance to offer their own take.

**Be honest and realistic.**

It is best to offer realistic but hopeful information. This approach can help children avoid feeling scared or confused if things do not happen the way you suggest.

**Let children help.**

Allow kids to be involved in small caregiving tasks. It can make them feel helpful. Try to match the tasks to the child's age so they do not feel stressed.

**Use helpful resources.**

There are many helpful books and websites that can prepare you for talking with children about illness and death. These resources offer age-appropriate language and tools for talking with children of all ages and levels of development.

**Want more information on this topic?**

See Talking with children about serious illness or ask a member of your palliative care team.

# 4. Paying for health care and other basic needs

## Getting started

There are many different insurance plans, and benefits vary among plans. A social worker or a member of your palliative care team can help you find out which benefits are covered by your loved one's insurance plan.

- Ask questions early so you can make informed choices.
- Get to know your loved one's insurance plan.
- Check into long term care coverage.
- Look for government programs and local resources.
- Talk with a hospital case manager or social worker.

## Insurance plans

Check with your loved one's plan to see what services it covers. Medicare and Medicaid (Medi-Cal in California) are two government insurance plans.

**Medicare** is a federal insurance program for people who are:

- Age 65 and older.
- Younger than age 65 and disabled.

Medicare covers:

- Some specific in-home health care services such as nursing, physical therapy, or occupational therapy.
- Some medical equipment and supplies.

**Medicaid (Medi-Cal)** is a federal and state insurance plan. **Coverage varies by county.**

Medicaid offers:

- Free or low-cost health care for adults and children. Your loved one may qualify based on family size and income.
- Benefits for In-Home Support Services (IHSS) that can be used to receive caregiving help at home.
- Contact your loved one's county to learn more about what is covered.

## Helpful resources

National Family Caregivers Association

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

1-800-896-3650

U.S. Department of Health and Human Services

[www.hhs.gov](http://www.hhs.gov)

1-800-575-9355



## Support with caregiving needs and costs

**If your loved one's insurance denies a claim**, they can pay out-of-pocket or file an appeal with the insurance company. Ask their care team about meeting with a health advocate or social worker who can offer guidance.

**If caring for your loved one affects your work**, contact your human resources department right away.

- Many companies have policies for sick leave and paid time off.
- You could try working flexible hours.
- You may qualify for the federal Family Medical Leave Act (FMLA). FMLA allows time off for caregiving and protects your job.

**If you or your loved one need support meeting expenses**, there may be programs in your area that offer financial assistance.

- Programs exist at many levels: federal, state, county and city.
- Community organizations and religious groups offer services.
- A case manager or social worker at the hospital or clinic can help you or your loved one apply for services, if needed.

### Want more information on this topic?



See Paying for health care and other basic needs or ask a member of your palliative care team.

# 5. Planning ahead

## Learning about your loved one's wishes

Most people do not want to think about the end of life, or talk about what might happen if they are very sick. It may help to think of these conversations as a gift your loved one can give to those they love. Sharing their wishes now can save others from trying to guess what they want. It can also give your loved one a way to stay in control.

Your loved one can decide:

- What kind of medical care they do, and do not want if they are very ill.
- What will happen to their assets and things they value.

### **Advanced care planning**

Advance care planning involves:

- Learning about treatments that can be used throughout their illness.
- Choosing what treatments your loved one would and would not want.
- Talking with your loved one about their personal and spiritual feelings around dying.
- Choosing whom your loved one would want to make care decisions if they cannot.
- Writing these decisions down in an “advanced directive.”
- Sharing the advance directive with your loved one's care team.

### Who can complete an advanced directive?

Any competent adult who is at least 18 years old can complete an advance directive.



## Tips for completing an advanced directive

Use an advance directive to share your loved one's wishes for care if they (or you) cannot make those decisions at the time.

- **Start early.** Try to work on financial and legal documents when your loved one is well enough to be part of the process.
- **Get the right forms.** There are separate forms your loved one can use to name someone to take charge of their financial affairs.
- **Get advice.** An attorney, social worker or other member of the palliative care team can help your loved one prepare a will or other plan for sharing gifts or objects of personal value.

### Why is an advance directive important?

An advance directive helps start a conversation about your loved one's wishes. The process gives your loved one a chance to think about and share their preferences for care. People in your loved one's life can also use advance directive forms to communicate with the care team.

### Want more information on this topic?



See Planning ahead or ask a member of your palliative care team.

# 6. End-of-life care

## Focusing on comfort

Even with excellent medical care, many people with serious illnesses reach the point when treatment is no longer helping to cure, or even control their illness. In these cases, your loved one can choose to focus on staying comfortable, rather than spending energy on getting treatments that may not provide much benefit.

There are two types of care that help your loved one focus on time with family, friends, and doing the things they find meaningful: palliative care and hospice care. Many insurance plans cover both care types.

### **Palliative Care**

Palliative care keeps your loved one comfortable while they are still getting treatment to cure their illness. Palliative care can help relieve pain and manage the symptoms of serious illness, such as:

- Nausea
- Fatigue
- Loss of appetite

Your loved one can start receiving palliative care at any time – even while they are still getting treatment to cure their illness.

### **Hospice Care**

Hospice care is designed to provide comfort, not treatment to cure an illness. As your loved one nears the end of their life, they can choose to receive hospice care in a setting they prefer. The hospice care team can visit your loved one:

- At home.
- In a hospital.
- In a skilled nursing or care home setting.

Hospice care can start when your loved one is no longer getting treatment to cure their illness, and their provider feels they likely have less than six months to live.



## Caregiving near the end of life

As a loved one is nearing the end of their life, caregivers play a very important role. Your loved one's needs may increase as they near the end of life.

### What to expect

- **Many people become weaker.** Your loved one may be less able to assist in their own care. They may begin to spend more time in bed or sleep more throughout the day.
- **Many people may eat less than they used to and may also lose weight.** Follow their lead and try to provide food they enjoy when they are hungry. Your palliative care team can help you find other ways besides cooking meals to express your love and care.
- **People often feel a range of emotions as they near the end of life.** Sometimes they may feel gratitude or peace. At other times they may feel deeply sad. If you notice your loved one feeling hopeless or depressed, let their provider know. These symptoms can often be treated.

### The gift of caring

Remember that death is a natural part of life. By caring for your loved one, you have given the gift of helping them cope during this important time.

### Want more information on this topic?



See End-of-life care or ask a member of your palliative care team.

# 7. Taking care of yourself

## Care for the caregiver

Caring for a loved one who is ill can be a complex experience. **It is normal to have a mix of feelings.** Many caregivers feel joy and purpose taking care of their loved one. At times they may also feel worried, sad, or frustrated. These feelings can impact sleep, diet, thoughts, and mood.

In order to care for someone else, you must first care for yourself. Learning to cope and accept help early on can make it easier for you down the road.

Taking good care of yourself is essential.

It maintains your wellbeing and helps you care for your loved one.



### Tips for taking care of yourself

- **Make a list of what is most important when it comes to caregiving.** Listing what is most important for your wellbeing, and that of your loved one, can help guide you and build a sense of purpose.
- **Set and work on personal goals.** Personal goals can be simple, such as a goal to get enough sleep or go for a walk each day.
- **Manage stress.** Make time to reflect on things that are hard. Also try to notice and enjoy the simple pleasures and positive moments throughout the day.
- **Seek out humor.** Humor can be found in television, books, magazines, or other forms. Laughing can be a great distraction. It can also improve your mental health.
- **Seek out support.** You are not alone. You are welcome to reach out to members of your care team for guidance and companionship throughout the journey. If you are able, join an in-person or online caregiver support group.

### Want more information on this topic?



See Taking care of yourself or ask a member of your palliative care team.

What's most important when it comes to caregiving


Personal goals




# Resources

Use these resources to find support and information about caregiving and specific illnesses.

## Caregiver resources

**Today's Caregiver Magazine**  
[caregiver.com](http://caregiver.com)

A magazine, newsletter, general information, and resources for all types of caregivers.

**Caregiver Action Network**  
[caregiveraction.org](http://caregiveraction.org)

Peer support, education and online resources.

**Family Caregiver Alliance**  
[caregiver.org](http://caregiver.org)

Support, education and online resources in many languages, including fact sheets on legal and financial matters.

**AARP**  
[aarp.org](http://aarp.org)

Resources to support caregivers.

**CaringBridge**  
[caringbridge.org](http://caringbridge.org)

A centralized, private place to share health updates with friends and families, and an easy way to request help.

**Lotsa Helping Hands**  
[lotsahelpinghands.com](http://lotsahelpinghands.com)

A central place to coordinate meals and help for friends and families.

**National Hospice and Palliative Care Organization**  
[nhpco.org](http://nhpco.org)

Resources for planning for the future, advanced directives, and information about hospice and palliative care.

**Medicare**  
[medicare.gov](http://medicare.gov)

Describes the basics about home health services covered by Medicare. Note: these services may be covered differently by other insurance plans.

**Eldercare Locator**  
[eldercare.acl.gov](http://eldercare.acl.gov)

A service of the U.S. Administration on Aging, offering links to local resources, like your Area Agency on Aging.

## Cancer resources

<b>American Cancer Society</b>	<a href="https://www.cancer.org">cancer.org</a> Support groups, resources, counseling and education for all types of cancer.
<b>Brain Tumors</b>	National Brain Tumor Society <a href="https://www.braintumor.org">braintumor.org</a>
<b>Leukemia/Lymphoma</b>	Leukemia and Lymphoma Society <a href="https://www.lls.org">lls.org</a>
<b>Multiple Myeloma</b>	International Myeloma Foundation <a href="https://www.myeloma.org">myeloma.org</a>
<b>Lung Cancer</b>	Team Draft <a href="https://www.teamdraft.org">teamdraft.org</a>  GO2 Foundation <a href="https://www.go2foundation.org">go2foundation.org</a>
<b>Oral, Head and Neck Cancer</b>	Support for People with Oral, Head and Neck Cancer <a href="https://www.spohnc.org">spohnc.org</a>
<b>Colon Cancer</b>	Colorectal Cancer Alliance <a href="https://www.ccalliance.org">ccalliance.org</a>
<b>Ovarian Cancer</b>	Ovarian Cancer Research Alliance (OCRA) <a href="https://www.ocrahope.org">ocrahope.org</a>
<b>Breast Cancer</b>	Tigerlily Foundation <a href="https://www.tigerlilyfoundation.org">tigerlilyfoundation.org</a>  Triple Negative Breast Cancer Foundation <a href="https://www.tnbcfoundation.org">tnbcfoundation.org</a>

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<b>Pancreatic Cancer</b>	Pancreatic Cancer Action Network (PanCan) <a href="http://pancan.org">pancan.org</a>  Hirschberg Foundation for Pancreatic Cancer Research <a href="http://pancreatic.org">pancreatic.org</a>
<b>Prostate Cancer</b>	Prostate Cancer Foundation <a href="http://pcf.org">pcf.org</a>

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## Resources for other conditions

<b>Heart Failure</b>	American Heart Association <a href="http://heart.org">heart.org</a>
<b>COPD</b>	COPD Step by Step <a href="http://copd.com">copd.com</a>
<b>Pulmonary Hypertension</b>	Pulmonary Hypertension Association <a href="http://phassociation.org">phassociation.org</a>
<b>End Stage Liver Disease (ESLD)</b>	American Liver Foundation <a href="http://liverfoundation.org">liverfoundation.org</a>
<b>End Stage Renal (Kidney) Disease (ESRD)</b>	National Kidney Foundation <a href="http://kidney.org">kidney.org</a>
<b>ALS</b>	The ALS Association <a href="http://als.org">als.org</a>  The ALS Foundation for Life <a href="http://alsfoundation.org">alsfoundation.org</a>
<b>Interstitial Lung Disease</b>	Pulmonary Fibrosis Foundation <a href="http://pulmonaryfibrosis.org">pulmonaryfibrosis.org</a>

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**HIV**

A Positive Life  
[apositivelife.com](http://apositivelife.com)

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**Dementia and Alzheimer's Disease**

Alzheimer's Association  
[alz.org](http://alz.org)

Alzheimer's Foundation of America  
[alzfdn.org](http://alzfdn.org)

Alzheimer's Family Center  
[afscenter.org](http://afscenter.org)

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**Stroke**

American Stroke Association  
[stroke.org](http://stroke.org)

American Stroke Foundation  
[americanstroke.org](http://americanstroke.org)

## Resources for advance care planning

**The Conversation Project**

[theconversationproject.org](http://theconversationproject.org)

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**Prepare for Your Care**

[prepareforyourcare.org](http://prepareforyourcare.org)

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**The Coalition for  
Compassionate Care of  
California**

[coalitionccc.org](http://coalitionccc.org)

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**AARP online tool**

For simple estate planning  
and writing a will

[aarp.org](http://aarp.org)

**Want more information on a topic?**

 Ask a member of your palliative care team.



# Physician Contact List

Provider: \_\_\_\_\_ Phone # \_\_\_\_\_ Email: \_\_\_\_\_

Address: \_\_\_\_\_ City: \_\_\_\_\_ State: \_\_\_\_\_ Zip: \_\_\_\_\_ Specialty: \_\_\_\_\_

Provider: \_\_\_\_\_ Phone # \_\_\_\_\_ Email: \_\_\_\_\_

Address: \_\_\_\_\_ City: \_\_\_\_\_ State: \_\_\_\_\_ Zip: \_\_\_\_\_ Specialty: \_\_\_\_\_

Provider: \_\_\_\_\_ Phone # \_\_\_\_\_ Email: \_\_\_\_\_

Address: \_\_\_\_\_ City: \_\_\_\_\_ State: \_\_\_\_\_ Zip: \_\_\_\_\_ Specialty: \_\_\_\_\_

Provider: \_\_\_\_\_ Phone # \_\_\_\_\_ Email: \_\_\_\_\_

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Provider: \_\_\_\_\_ Phone # \_\_\_\_\_ Email: \_\_\_\_\_

Address: \_\_\_\_\_ City: \_\_\_\_\_ State: \_\_\_\_\_ Zip: \_\_\_\_\_ Specialty: \_\_\_\_\_