# Managing care at home

This section includes ideas about how to plan the work of caregiving, and tips for keeping track of health information.

## Plan the work of caregiving

Make a list of routine and patient care tasks you need to do. Talk with your loved one so they can stay involved.

### Routine tasks

**Meals**

- ☐ Plan, cook and serve meals
- ☐ Buy food
- ☐ Clean up

**Transportation**

- ☐ Travel to/from appointments
- ☐ Run errands
- ☐ Get disabled parking permit from DMV

**Housework**

- ☐ Do laundry
- ☐ Take out trash
- ☐ Do house and yardwork

**Bills and scheduling**

- ☐ Apply for programs or services
- ☐ Manage insurance
- ☐ Schedule appointments
- ☐ Manage financial and legal matters

**Other tasks**

- ☐ Care for children or other family members
- ☐ Care for pets
- ☐ Handle tasks your loved one used to manage
- ☐ Manage helpers (paid or volunteer)

### Patient care tasks

**Personal care**

- ☐ Bathe and groom
- ☐ Brush teeth
- ☐ Care for skin

**Medical care**

- ☐ Pick up medicines
- ☐ Manage medicines
- ☐ Help move to/from bed or chair

**Emotional care**

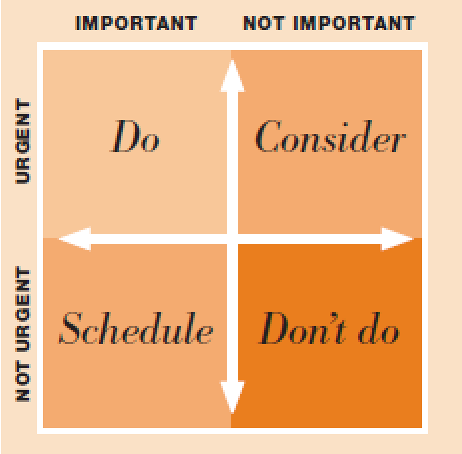
- ☐ Keep your loved one company
- ☐ Provide a safe, comfortable home
- ☐ Plan breaks and outings with family

# Decide how you will complete tasks

Options can include 1) caring for your loved one yourself, 2) building a team of volunteer caregivers to help you, or 3) hiring outside help. You can combine these methods and change your approach over time.

## 1 Caring for your loved one yourself

- **Decide what tasks must get done**. Use the graphic at right to help you decide. If a task is:
  Urgent and important = Do it.
  Urgent and not important = Consider it.
  Not urgent and important = Schedule it.
  Not urgent and not important = Don't do it.
- **Find out what benefits your employer offers**. Talk with your human resources department. If your loved one's income is low, they may be able to receive financial help with care.
- **Learn caregiving skills**. Look online, ask a social worker, or contact your local social service agency for resources.



Adapted from First Things First, (1994) Covey, Merrill & Merrill

## 2 Building a team of volunteers to help you

- **Request help from family and friends**. Even though help can be hard to accept, you simply cannot and should not do it all yourself.
- **Most family members and friends want the chance to be helpful**. Ask your loved one which people they want to involve. As people help, check in to make sure they are not wearing out.
- **Create a care team that will support you and your loved one**.

## Tips for getting and managing caregiving help

### Build your team

With input from your loved one, find people well suited to help.

☐ Think about people’s skills, strengths and weaknesses.

☐ Contact people from your loved one’s contact list or from their social, religious or work groups. Ask them who else they suggest.

☐ Find professional home-care agencies. A social worker can help, or you can look online or in your local newspapers.

### Manage helpers

Once you have a team of helpers, manage their efforts so that they can be effective.

☐ You or a family member can call to invite the person to help.

☐ Hold a 1-hour meeting for all helpers to talk about:
  - Your loved one’s illness and current needs.
  - Roles or tasks each helper can take.
  - Helpers’ schedules.

☐ Make a list of helpers’ contact details.

☐ Choose a “leader” to make phone calls during emergencies, when there is a change in plans, or if schedules need to change.

☐ Manage helpers’ schedules on a master calendar. This can be a paper schedule kept in the home, or an online schedule all have access to.

☐ Post or share a list of important details, such as:
  - Pharmacy and grocery store locations.
  - Provider’s contact information.

**Resources: Free online schedules and message boards to help you organize and manage your team of helpers.**

- CaringBridge caringbridge.org
- Lotsa Helping Hands lotsahelpinghands.com

## 3 Hiring outside help

You may want to hire someone to help with house work or patient care tasks. There are many agencies that offer certified nurses, companions, or house cleaners. You can choose to advertise, interview, and hire help on your own, or you can go through an agency.

### Tips for hiring paid help

**Hiring on your own**

If you choose to hire caregiving help on your own, you can usually negotiate the price. The state Employment Development Department (EDD) will help you set up the paperwork you need.

Keep in mind these risks:

- There are no substitutes if the helper is sick or does not show up.
- You must take the time to do interviews and do background checks.

**Using an agency**

If you use an agency, you may pay more per hour, but the agency will handle employment details. It will provide substitutes and make sure helpers are qualified and bonded.

To find an agency:

- Ask your provider or social worker for a referral.
- Search online or in the phone book for local agencies.
- Ask people you know for suggestions.

**Resource: National Hospice and Palliative Care Organization**
nhpco.org

## Stay organized

When it comes to caregiving, the more organized you are, the better. It will help you make decisions and prevent errors.

### Manage medicines

Living with a serious illness usually means taking many medicines. The best way to prevent errors is to keep track of your loved one’s medicine schedule.

### Track treatments and side effects

It is common for some treatments to cause new symptoms or side effects. Keep a log of:

- What treatments were given.
- What symptoms or side effects were.
- What time they happened.

Refer to your log when you report issues to the care team. Some may be resolved by speaking with a nurse over the phone, others may need a visit with the provider.

### Resource: Pain scale

If your loved one is having pain, ask them to rate their pain level using the 0-10 pain scale where 0 is no pain, and 10 is the worst pain possible.

### Prevent medicine errors

☐ **Make sure prescription bottles include**: your loved one’s name, the correct pills, and the right dosage.

☐ **Make sure you can read the drug name and dosage clearly**. If not, ask the provider or pharmacy to print it out clearly.

☐ **Learn about each medicine**. Know what it is for, what it does, and what to do if there are side effects.

☐ **Keep a log of all prescription and non-prescription medicines your loved one is taking**. Include supplements and herbal products. Share the list with your loved one’s provider.

### Questions?

Ask a member of your palliative care team.

# Caregiving in the hospital and clinic

This section explains what happens in the hospital and clinic, and provides helpful tips for giving care in those settings.

## What to expect during a hospital stay

The team taking care of your loved one in the hospital can include:

- **Attending physician** – the main doctor in charge of your loved one's care. This doctor may be a "hospitalist," who leads the medical team in the hospital.
- **Specialists or consulting physicians** – doctors who have expertise in certain diseases or part of the body (for example, experts in problems with the lungs, kidneys, or infectious diseases). Specialists may work with the main doctor taking care of your loved one in the hospital.
- **Nurses** – the care team members who often interact most with your loved one in the hospital. Nurses give medicines, assess symptoms, and communicate with the doctor(s).
- **Social Workers, Care or Case Managers** – people who help plan for when your loved one leaves the hospital.

Providers see patients each day on a schedule.

- Nursing schedules vary. Most nurses work 8- or 12-hour shifts.
- Doctors see patients (or "round") throughout the day. Ask your loved one's doctor a day in advance when they expect to round. Allow a window of 1 – 2 hours around that time so you are there when they visit.

# What to expect during clinic visits

A doctor’s office and a clinic are alike in many ways. Both offer many of the same services. A clinic is a larger health system’s version of a doctor’s office. The office or clinic you visit may depend on where your doctor is, or what your health plan offers.

## Topics to discuss with your loved one’s provider

**About the illness**

- What it is called
- What causes it

**Treatments**

- Options
- Timing
- Outcomes

**Tests and procedures**

- Options
- Timing

**Quality of life**

- Impact on life
- Impact on work

**Care team contact information**

- Name
- Phone and email
- Clinic hours

**What to do in case of emergency**

- Whom to call
- Where to go

## Communication tips for the hospital and clinic

- **Make a list of your questions**. Leave room to write down answers.
- **Know that all of your questions are important**. No one should dismiss your questions or concerns.
- **Ask providers to explain using plain language**. Most people find medical terms hard to understand.
- **Ask yourself, “How much information do I want?”** Share the answer with the care team. Patients and family members often have different needs.
- **Select a family member to be the main contact for the care team**. That person can collect everyone’s questions and share any answers they get.
- **Bring up issues even if they are hard to talk about**. Some doctors raise serious issues on their own, while others may wait until you bring them up.
- **Ask how you can learn more.** If you run out of time and still have questions, ask the provider to suggest helpful websites or articles, or ask for another time to meet.
- **Save your time with the provider for talking about health issues**. Bring questions about insurance claims or billing to the clinic’s front desk or billing staff, or to the hospital’s social worker.
- **Share contact information of other care team members with clinic staff**. This includes contacts for local treating or referring doctors.

# Special considerations in your loved one’s care

## Questions to ask before surgery

Ask questions before surgery so you will know what to expect. The answers will help you prepare and can help reduce stress.

- How long will the surgery last?
- What do I need to know about what will happen after surgery?
  - Will my loved one be in the Intensive Care Unit (ICU)?
  - How long will they need to stay in the hospital?
- Will I receive a report about the results (pathology report)? If so, how long will it take until I receive it?
- How do I schedule a meeting with a social worker or case manager to learn about resources?
- How will my loved one feel when they return home?
  - Pain level?
  - Able to eat and drink?
  - Able to move around?
- What symptoms or issues should we be aware of once we return home?
- Which health care provider do I contact if there are issues after my loved one is home?

## Questions to ask your loved one to help with decision-making

When treating serious illness, some things remain unknown. Your loved one's answers to these questions might help when making decisions.

- What makes life worth living?
- What do you hope or expect will be the result of treatments?
- If your health were to worsen, what would be most important to you?
- What are the abilities that you cannot imagine living without?

### Questions?

Ask a member of your palliative care team.

# Talking with children about serious illness

This section includes tips on what to share, and ways to talk with children that match their age and level of understanding.

## Topics to share with children

Sharing how serious an illness is lets children know it is okay to ask questions. Children become aware of death at a young age. They may see insects, animals or pets die. Death is often shown in books, on TV, and in movies. Topics to bring up with children include:

**The illness is hard on the family.**
Illness is hard to understand, and not every illness has a cure. Sharing this helps explain why other family members may be upset or crying.

**The illness is not their fault.**
Young children may think they (or someone else) might have done something to cause the illness. If this idea comes up, stress that no one caused the illness. If your children do not raise the idea, then avoid talking about fault. It could lead children to wonder if they did have a role.

**The illness is not contagious.**
Explain that, for example, you will not get cancer from your loved one. Young children think all illnesses are caught like colds. Assure them that no one in the family will get sick from spending time with the love one who is ill.

**The illness and treatments may change how their loved one looks.**
Prepare children that treatments can have side effects, such as hair and weight loss. These changes can frighten children. Explain that treatments are helpful even if they change how someone looks.

### Use simple terms to talk about illness

Example: “Grandpa has a disease called cancer. The disease is taking away his energy to do things. It’s making him weaker and weaker. One day he won't be able to get out of bed anymore. At some point his heart will stop working and he will die.”

# How children and youth think about illness

The chart below can help you decide how to share based on your child's age or development stage.

| | Level of skill | Level of understanding | Tips for talking about illness |
|---|---|---|---|
| **Ages 2 – 3** | • Has limited language skills.<br>• May sense that something is wrong. | • No concept of death. | • Use simple words.<br>• Use picture books. |
| **Ages 4 – 6** | • Is more self-secure.<br>• Plays well with others.<br>• Tests the rules. | • Believes death is temporary (like sleeping) and can be reversed.<br>• Believes death can be caused by thoughts. | • Pick books with stories that show families like yours to help your child relate.<br>• Engage in symbolic play with your child. |
| **Ages 7 – 12** | • Has concrete thinking skills. | • Develops adult concepts of death.<br>• Understands that death can be personal.<br>• Curious about the details of death. | • Read books and create stories with your child.<br>• Watch movies with stories that reflect your family's experience.<br>• Allow children to take part in making decisions. |
| **Ages 13 – 18** | • Has a better understanding of logic and cause/effect.<br>• Is less centered on self and able to understand others' feelings. Can empathize.<br>• Is focused on being accepted by peers. During puberty, body image and self-esteem are most important. | • Explores non-physical reasons for death.<br>• Has adult concept of death. | • Talk with your children, not at them.<br>• Listen closely to your child's thoughts and input.<br>• Be honest with your child.<br>• Give facts about what is likely to happen. Talk about the diagnosis, treatments, and likely outcomes.<br>• Check in often, and offer time to talk about concerns.<br>• Encourage them to connect with peers. |

# Resources to support talking with children and youth

A social worker from your loved one's palliative care or other medical team can suggest books and other resources to help you or your loved one talk with children. Also, ask if the hospital or clinic where your loved one gets care has a child life specialist. This helpful service is designed to support children.

The table below includes some resources for talking with children of different ages.

| | **Resources** |
|---|---|
| **Ages 2 – 6** | *Someone I Love is Sick: Helping Very Young Children Cope with Cancer in the Family*, by Kathleen McCue<br>*How to Care for a Very Sick Bear*, by Vanessa Bayer<br>*The Invisible String*, by Patrice Karst<br>*When Pete's Dad Got Sick: A Book about Chronic Illness*, by Kathleen Bostrom |
| **Ages 7 – 12** | *When Someone Has a Very Serious Illness*, by Marge Heegaard<br>Little Parachutes has picture books for children related to some illnesses such as dementia, cancer, etc. littleparachutes.com |
| **Ages 13 – 18** | The Dougy Center has helpful online resources for talking about serious illness with children of all ages, including many for teenagers. dougy.org |

**Questions?**

Ask a member of your palliative care team.

# Paying for healthcare and other basic needs

This section includes tips for dealing with insurance companies and resources for managing health care costs.

## Health insurance

The health system and health insurance can be confusing. Knowing what is and is not covered in advance can prevent surprises and stress later on.

### Know what your plan covers

Ask about:

- **Referrals** to other doctors and providers.
- **Types of services covered**, such as follow-up appointments, MRIs, clinical trials, home care, or reimbursement for alternative medicine treatments.

### Know what you must pay

Ask about:

- **Co-payments or “copays”** – A fixed amount (for example, $15) you pay for a covered health care service, usually when you receive the service. The amount can vary by the type of covered health care service.
- **Co-insurance** – Your share of the costs of a covered health care service, calculated as a percentage (for example, 20%). You pay co-insurance plus any deductibles you owe.
- **Deductibles** – An amount you could owe during a coverage period (usually one year) for covered health care services before your plan begins to pay.
- **Out-of-pocket limit** – The most you could pay during a coverage period (usually one year) for your share of the costs of covered services. After you meet this limit the plan will usually pay 100% of the allowed amount.
- **Pre-authorization** – Your health insurance or plan may require you get pre-authorization, or prior approval, for certain services before you receive them.

Plain language insurance glossary: healthcare.gov/sbc-glossary

You may hear the term "**medically necessary**" which means health care services or supplies that are part of standard medical care and are needed to diagnose or treat an illness or its symptoms. Examples of medically necessary services the doctor may order:

**Therapies**

- Speech therapy
- Occupational therapy
- Physical therapy

**Treatments**

- Radiation
- Chemotherapy
- Medicines

**Imaging**

- CT scan
- Ultrasound
- MRI

**Care in a facility**

- Rehabilitation hospital
- Skilled nursing facility (SNF)

**Home care services**

- Skilled nursing
- Social work
- Nutritional care
- Physical therapy
- Occupational therapy
- Speech therapy

Each of these services need to meet certain criteria in order for insurance to pay. Ask your care team for help with finding out whether insurance will cover your loved one's recommended services.

## Tips for dealing with insurance companies

- Ask questions of the insurance company and your loved one's care team.
- Keep a paper trail! For every phone call note:
    - The date and name of the person you spoke with.
    - What was said.
- Ask if pre-authorization is needed before you make an appointment.
- Fill out every form completely and keep a copy for your records.
- Do not wait long for a call back. Call often. Be polite and persistent.
- Read the materials that explain your coverage and your rights.

# Helpful resources

If you must leave your job to care for your loved one, and you lose heath care benefits, you may be able to receive benefits through federal, state, local or other programs. **A case manager or social worker at the hospital or clinic can help you find and apply for services.**

### Government resources

- Department of Social Services:
  - Social Security Disability Insurance (SSDI)
  - Supplemental Security Income (SSI)
  - Medicaid (Medi-Cal)
  - In-Home Support Services (IHSS)
- Department of Aging – Department of Housing and Community Development
- State Pharmaceutical Assistance Programs

### Community and other resources

- Clinics or health care providers with sliding fee scales
- Discounted prescription drug programs
- Utility company subsidies – based on doctor's support or financial status
- Food banks
- Meals on Wheels
- Salvation Army
- Local religious groups
- Call "2-1-1" or visit 211.org

## Tips for keeping financial information organized

It can be helpful to create a folder that contains all of your loved one's important financial and insurance information. Include copies of their insurance card and policy, claim forms, and medical bill statements.

### Questions?

Ask a member of your palliative care team.

# Planning ahead

This section explains some of the ways you and your loved one can plan ahead for medical care and financial decisions.

## Getting affairs in order

While it may be hard to look ahead, it is very important that you and your loved one talk in advance about their beliefs, values, and wishes for medical care. If you wait until their health worsens, it may be harder to have these conversations. Make sure your loved one has enough time to share their requests, make decisions, and sign important documents.

### Advance directives

Advance directives are legal forms that help guide the medical care your loved one receives if they, or you, are not able to make decisions at the time. An advanced directive will ensure your loved one's wishes are honored.

**Advance directives include:**

- Advance Healthcare Directive
- Living will
- Durable power of attorney for healthcare

**General instructions:**

- Fill out forms completely.
- Make sure to have your loved one sign and date them. Once forms are signed, they become legal forms.
- Keep a copy at home and also give a copy to the provider. It should be added to the medical record.

### Where do I get an advanced directive?

Advance directive forms can vary by the state your loved one lives in. You can get their state's version from their:

- Doctor
- Lawyer
- Local Area Agency on Aging

**Resources**

Information to help prepare an advance healthcare directive:

**The Conversation Project** theconversationproject.org

**Prepare for Your Care** prepareforyourcare.org

For simple estate planning and writing a will: **AARP online tool** aarp.org

## Financial matters

Most people have finances that will need to be managed by someone they trust. Naming someone to take charge of financial matters is very important. Doing this before your loved one is too ill can prevent years of legal battles and financial burdens.

### Durable power of attorney for finances

- Use a durable power of attorney for finances to name who will manage financial matters.
- This is a separate form from the advance directive.
- Your loved one can choose the same person named in their advance directive, or someone else. It does not need to be the same for both.

**Resource: Family Caregiver Alliance fact sheets on legal and financial matters**
caregiver.org

### Planning tip

Some financial institutions may only give access to the person(s) named on an account. Adding a name on accounts is easier when done well in advance of when the additional person might need access. This is also true for other assets and legal documents, like:

- Investments
- Properties
- Car titles

## Estate Planning

Many people have things that they want to give their loved ones to remember them by. Property, financial gifts, heirlooms, objects of sentimental value, or even personal memoirs can be part of a legacy. Helping your loved one prepare a will is an act of caregiving.

### Important points to keep in mind

- The best way to learn about wills and estate planning is to talk with an estate attorney. You can also ask a social worker for resources.
- The Internet has many resources on this topic. Be sure to check that the information is recent and from a trusted source.
- Each state has its own rules for estate planning. Please check with a social worker or an attorney about the rules in the state where your loved one lives.

## Questions?

Ask a member of your palliative care team.

# End-of-life care

This section includes information about care to keep your loved one comfortable, and tips to help you both cope.

## The difference between palliative and hospice care

### Palliative care

The goal of palliative care is to reduce your loved one’s suffering.

- Palliative care is appropriate at any stage of illness and can start as soon as there is a diagnosis.
- Palliative care is medical treatment used to relieve pain and manage symptoms.
- Palliative care can take place while your loved one gets treatment to cure their illness.

### Hospice care

The goal of hospice is to focus on comfort as your loved one nears the end of life.

- Hospice is offered to people who may have less than 6 months to live.
- Hospice is for people who have stopped getting treatment to cure their illness.
- Hospice care can occur at home or in a hospice facility.
- Hospice care focuses on treatments and supports to help provide the best quality of life at the end of life.

## Choosing the best care

Your loved one will make the final choice about starting hospice care, but you can play a key role in the process. Speak with your loved one and consult with their care team. They can help you learn what type of care would be best and support you through the process.

**Resource: National Hospice and Palliative Care Organization**
nhpco.org

# Bringing hospice into the home

Your loved one can choose to receive hospice care at home. In this case, family caregivers provide care under the guidance and support of trained hospice staff. This can include:

- Doctors who visit the home
- Nurses
- Social workers
- Chaplains
- Health aides

Hospice care includes physical, mental, and spiritual care for your loved one and their family. Hospice care also includes:

- Needed medical equipment and supplies.
- Medicines to treat symptoms.
- Spiritual, nutrition, and other counseling.
- Trained volunteers to offer support.
- Grief services for the family.

## Tips for getting your home ready for hospice

Ask about any equipment that may be needed at home:

- Walker or wheelchair
- Portable toilet (commode)
- Hospital bed

Make a plan for who will care for your loved one at home with the guidance of the hospice team.

## Tips for choosing a hospice agency

- What types of services are offered? What supports are offered for children?
- How long has it been in business?
- Does it accept your insurance? Can it help you find financial help if you need it?
- How does it train and manage its staff? Does a supervisor come to the home? Are hospice workers licensed?
- What happens in case of an emergency? Will the hospice agency still be able to provide services?

# What to expect near the end of life

With guidance to help keep your loved one comfortable, and support for emotional and spiritual needs, the end of life can be a sacred time. This section includes some things you can do, and advice about when to contact the palliative care or hospice care team.

### Managing symptoms

Managing symptoms may get easier as your loved one's care begins to focus more on comfort rather than treatment. Contact the care team if your loved one has these symptoms so they can help address them:

- Trouble breathing
- Pain
- Anxiety
- Confusion or trouble thinking clearly

### Eating and drinking

Food and feeding can be a way to express love. But at the end of life, your loved one may not be able to eat, or eating may make them feel worse. The care team can help you through this process by:

- Sharing how you can help your loved one enjoy food and drink safely.
- Helping you find other ways to express love when your loved one is no longer able to eat or drink, such as holding their hand or playing music.

### Spiritual and emotional needs

Death is a natural phase of life. Your loved one may have hopes for other things, such as:

- Relief from pain
- Moments of pleasure or discovery
- Gaining closure of important relationships
- A sense of peace

Your loved one may struggle with emotional and spiritual pain at the end of life. If they show signs of depression, such as deep sadness, hopelessness or guilt, contact the care team. These symptoms can be treated.

Take time to talk with your loved one about their hopes and fears. Share your feelings and try to make sure your loved one feels supported.

If your loved one would like to speak to someone else about how they feel, offer to connect them. It can be with a friend or a member of their care team, such as a chaplain.

## Having hard conversations

If you are having trouble knowing what to say or how to begin a hard conversation with your loved one, try starting with:

- Forgive me.
- I forgive you.
- Thank you.
- I love you.
- Goodbye.
- I'll be okay without you.

## Taking care of yourself

At the end of life, caregivers often face their own grief and sadness. Despite the amazing work that most caregivers provide, many worry that they did not do enough. These feelings are common. As a caregiver you helped your loved one through this most important time. Be sure to care for yourself after this experience.

After your loved one passes, you may feel intense sadness for days, weeks, or months. People who are grieving often talk about having "bad days" mixed with "good days." Each day may bring a different emotion. Pay attention to your needs, and be sure to seek help from friends, family, or a support group. The hospice care team will offer support and guidance through this time and can be a great resource.

Over time, you will find ways to absorb the loss of your loved one into your life. While you will never forget them, you will make new relationships and find new ways to celebrate them.

**Questions?**

Ask a member of your palliative care team.

# Taking care of yourself

This section includes ways that you can take care of yourself while being a caregiver for your loved one.

## Focus on what is most important

Making a list of what is most important can strengthen your sense of purpose and guide your choices.  For some people, love matters most. For others, it is about being a “good person,” or taking care of tasks having to do with money, insurance, or getting time off. As the caregiver, you get to decide what matters most. It is not a competition and there many ways to support your loved one as they face illness.

Figure out what values are most important to you, and why.

- Build your list around these values.
- Use your list to remind and center yourself – especially during hard times.

## Set and work on personal goals

Caring for someone with a serious illness can change your plans and bring a sense of loss.  To succeed at caregiving, you must stop and take time for yourself.  No one is perfect. We know caregivers cannot fully care for others when they are exhausted themselves. Make goals and discuss them with your loved one so you can maintain your well-being.

It is **not selfish** to make personal goals.

Examples of personal goals include:

- I want to eat nutritious meals.
- I want to get enough sleep.
- I want to have time to myself.
- I want to see my friends and family or talk with them by phone.
- I want to exercise.

## Manage stress

Research on stress shows that many people find something good can come out of a stressful experience. Some caregivers build self-confidence. Others feel pride at learning a new task or growing a deeper connection from having open-hearted talks with loved ones. Taking time to reflect on the gains, not just the losses, can improve caregiver well-being. When something positive happens – no matter how small – dwell on it. Take note of why it makes you feel good. Regular events can uplift your mood if you take time to "smell the roses."

Try to look for a positive moment each day.

It might be:

- Waking up to nice weather.
- Hearing a happy song.
- Picking out a food you love at the store.

## Seek out humor

Humor, even during times of crisis, can be a powerful coping method. Even something small like a comic strip, a playful picture, or a TV show can have great short term physical and mental health benefits. While it can be very hard to find humor during a hard time, let yourself expect to have positive moments and feelings while caregiving. Humor can lighten your load and provide a fresh view.

## Seek help when you need it

Sometimes it can be helpful to discuss what you are going through and how you feel. Taking care of your mental health needs is essential for your own well-being. It can also influence the care you provide for your loved one. A social worker on your loved one's care team can refer you to counseling resources. For some people, joining a support group can also be useful, and a chance to talk with others who are going through something similar.

**Taking care of yourself** will help you to better care for your loved one.

**Questions?**

Ask a member of your palliative care team.

# Resources

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

## Caregiver resources

| | |
|---|---|
| **Today's Caregiver Magazine**<br>caregiver.com | A magazine, newsletter, general information, and resources for all types of caregivers. |
| **Caregiver Action Network**<br>caregiveraction.org | Peer support, education and online resources. |
| **Family Caregiver Alliance**<br>caregiver.org | Support, education and online resources in many languages, including fact sheets on legal and financial matters. |
| **AARP**<br>aarp.org | Resources to support caregivers. |
| **CaringBridge**<br>caringbridge.org | A centralized, private place to share health updates with friends and families, and an easy way to request help. |
| **Lotsa Helping Hands**<br>lotsahelpinghands.com | A central place to coordinate meals and help for friends and families. |
| **National Hospice and Palliative Care Organization**<br>nhpco.org | Resources for planning for the future, advanced directives, and information about hospice and palliative care. |
| **Medicare**<br>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**<br>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

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

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| **Pancreatic Cancer** | Pancreatic Cancer Action Network (PanCan)<br>pancan.org<br>Hirschberg Foundation for Pancreatic Cancer Research<br>pancreatic.org |
| **Prostate Cancer** | Prostate Cancer Foundation<br>pcf.org |

## Resources for other conditions

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| **Heart Failure** | American Heart Association<br>heart.org |
| **COPD** | COPD Step by Step<br>copd.com |
| **Pulmonary Hypertension** | Pulmonary Hypertension Association<br>phassociation.org |
| **End Stage Liver Disease (ESLD)** | American Liver Foundation<br>liverfoundation.org |
| **End Stage Renal (Kidney) Disease (ESRD)** | National Kidney Foundation<br>kidney.org |
| **ALS** | The ALS Association<br>als.org<br>The ALS Foundation for Life<br>alsfoundation.org |
| **Interstitial Lung Disease** | Pulmonary Fibrosis Foundation<br>pulmonaryfibrosis.org |

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| **HIV** | A Positive Life<br>apositivelife.com |
| **Dementia and Alzheimer’s Disease** | Alzheimer’s Association<br>alz.org<br>Alzheimer’s Foundation of America<br>alzfdn.org<br>Alzheimer’s Family Center<br>afscenter.org |
| **Stroke** | American Stroke Association<br>stroke.org<br>American Stroke Foundation<br>americanstroke.org |

## Resources for advance care planning

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|---|---|
| **The Conversation Project** | theconversationproject.org |
| **Prepare for Your Care** | prepareforyourcare.org |
| **The Coalition for Compassionate Care of California** | coalitionccc.org |
| **AARP online tool**<br>For simple estate planning and writing a will | aarp.org |

**Want more information on a topic?**

Ask a member of your palliative care team.

# Medication Log

Patient First Name: ________________________ Middle Initial ___ Last Name:______________________

Patients’ Primary Caregiver:____________________________ Phone # ___________________________

Patients’ Primary Care Provider:_________________________ Phone # ____________________________

| Name of Medication | Dose | Time Taken | PRN | What is medication used for? | Was the medication effective? | Side Effects |
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# 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: _______________________________________________

Address: _______________________________________ City: __________________________ State: _______ Zip:__________ Specialty: _______________

Provider:______________________________ Phone # __________________________________ Email: _______________________________________________

Address: _______________________________________ City: __________________________ State: _______ Zip:__________ Specialty: _______________