

Advance Care Planning

Making decisions for your future

How to legally provide direction for your future medical care, if you become unable to make decisions or speak for yourself



Acknowledgement

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We are all human.

Natural disasters strike, medical emergencies happen and accidents occur. We cannot always prevent emergencies, but we can prepare for them. Advance care planning can provide peace of mind.

Begin advance care planning by thinking about and gathering information for future medical care. This process will help you to set your priorities and

formulate your preferences about the care you receive if you become incapacitated, are unable to make decisions or are approaching the end of your life. Share your preferences for medical care with your family and caregivers. If the people close to you understand what you want and your reasoning, they will be better able to support your choices.

Introduction

When a person becomes a legal adult, they can begin advance care planning and complete an advance directive. An advance directive consists of legal documents that outline your preferences for medical care and end-of-life wishes and appoints a person to make medical decisions on your behalf in case you are unable to speak for yourself.

All adults can participate in advance care planning.

Important aspects of advance care planning include

- Reflecting on what is important to you regarding your values, beliefs and preferences (for example, your quality of life)
- Learning about end-of-life considerations and the risks versus benefits of medical interventions (see *Medical Interventions* on page 8)
- Discussing your end-of-life wishes with your family, other people that matter to you and members of your healthcare team
- Preparing your advance directive, which includes
 - A living will and
 - A medical power of attorney.

Ideally, your advance directive will be in place before you are confronted by a serious illness or a medical emergency. Forms and guidance for preparing your advance directive are available from members of your healthcare team and on the Internet (see *Preparing Your Advance Directive* on page 11). These documents do not have to be created by lawyers.

Reflections, Information Gathering and Conversations

Thinking about your own potential future need for medical care and discussing end-of-life preferences with family members, close friends and caregivers may be difficult or uncomfortable. However, advance care planning is about taking steps to live as well as possible every day. Think about your priorities and goals for a good quality of life. You may want to ask yourself questions such as

- What do you feel would make you more comfortable as you approach the end of your life?
- How important to you is maintaining your independence and being self-sufficient?
- What are your priorities when making decisions about your future medical care (for example, symptom management, length of life, quality of life)?
- What are the most important activities of daily living that will contribute to your quality of life (for example, being able to complete daily tasks, speak with family and friends and enjoy food)?
- How important is it to be in a homelike environment as your condition worsens?
- What religious or spiritual considerations matter to you (for example, rituals)?

Take time to reflect and discuss preferences regarding end of life with your family and loved ones so that you can determine your priorities and set goals that guide your medical care.

The answers to these questions can help you to set your goals for care. They can help to structure conversations with your family members and caregivers. Be sure to share your goals, wishes and preferences with your healthcare team.

To make informed decisions and to receive the medical care that is right for you, it is important for you to be comfortable with thinking and talking about death and dying. Thinking about advance care planning early allows you to do the mental and emotional work of setting goals for end-of-life care before it is needed.

While you are still well, it is important to discuss your wishes and the reasons for the choices you have made with those close to you. Remember that your loved ones should respect your choices for end-of-life care, even if they disagree. Your choices are valid, and your preferences are the most important.

There are many tools available to help you make decisions and to facilitate conversations about end-of-life care.

- The “Go Wish Game™” (www.gowish.org) is a card game that helps you to prioritize what will matter most to you during end-of-life care and then share those feelings with your family. You can purchase physical cards to play the game, or you can play for free online.
- The following worksheets and educational materials can also help guide discussions:
 - The Conversation Project’s “Conversation Starter Kit” is free and can be downloaded at <https://theconversationproject.org/starter-kits/>
 - “Five Wishes®” is a legal document (available for purchase at <https://fivewishes.org/>) that guides you through advance care planning before you are faced with a health crisis. This Web site provides a free guide on how to talk about healthcare choices and a conversation guide for individuals or families.
 - “Voicing My Choices” is a discussion guide (available for purchase at <https://fivewishes.org/shop/order/product/voicing-my-choices>) that empowers young people who are struggling with a serious illness to communicate with family members, friends and caregivers about the type of care that they want now and in the future.

Defining Advance Directives for Medical Care

Advance directives are instructions about your future medical care in the event that you are no longer able to speak for yourself. You want to prepare an advance directive before you become ill or experience an emergency.

An advance directive is made up of the following two legal documents:

- **Living will**—this document outlines your wishes and details the medical treatment(s) that you have chosen to be available to you. It only becomes active when you are incapacitated and unable to speak for yourself.
- **Medical power of attorney**—this document names a person who is authorized to make medical decisions on your behalf if you are unable to do so yourself. This person is sometimes called a “healthcare agent.” (See *Medical Power of Attorney* on page 10.)

These documents should be

- Filled out and then signed (after careful consideration and conversations with loved ones)
- Kept in an accessible and safe place (you keep the original and provide copies to your healthcare agent and your healthcare team)
- Reviewed regularly and updated, as needed.

Estate Planning

When creating an advance directive, many people also consider estate planning. Estate planning deals with the financial and practical matters that come up at the end of life. It addresses questions such as

- What will happen to your property?
- Who will care for your minor children or dependents?
- What will your funeral be like?

Visit Triage Cancer at <https://tragecancer.org/estateplanning> to learn more about estate planning.

Why Should I Prepare an Advance Directive? An advance directive will

- Specify your medical wishes if you are no longer able to speak for yourself
- Lessen the burden of decision making in a crisis for family members and loved ones. If you do not have an advance directive in place, family members may have to make difficult medical decisions on your behalf. If they do not know what medical care you would want, they are faced with making hard choices that can lead to guilt, regret and tension between family members and caregivers.

Living Will. A living will is also referred to as a “directive to physicians” or a “declaration.” It outlines how you would like to be medically cared for if you are unable to communicate after a medical emergency, experience either extended or permanent unconsciousness, become incapacitated or are at the end of life. Your healthcare agent (see *Medical Power of Attorney* on page 10) and members of your healthcare team will use this document to guide decision making about your care. Your living will does not become active until you are unable to make decisions.

Medical Interventions. Medical interventions that your living will may address include

- Life support
 - The use of equipment such as dialysis machines, ventilators and respirators is called life support.
 - You can choose to opt out of this intervention in your living will.
- Cardiopulmonary resuscitation (CPR)
 - Cardiopulmonary resuscitation is an emergency procedure that is used when the heart stops beating or breathing stops. It attempts to restart the heart or breathing. Cardiopulmonary resuscitation combines chest compressions and artificial ventilation and may include electric shock and medications.
 - A “do not resuscitate (DNR)” order or an “allow natural death (AND)” order instruct healthcare professionals that CPR is not to be attempted. If this choice reflects your end-of-life care planning, your doctor can write the DNR (or AND) order and place it in your medical chart.

- Intubation
 - Intubation is the placement of a tube that is inserted either through your nose or through your mouth to help with breathing. You will most likely be sedated.
 - A “do not intubate (DNI)” order instructs healthcare personnel that you are not to be intubated. A DNI order can be written and placed in your medical chart by your doctor.
- Artificial nutrition and hydration
 - If you are unable to eat or drink, you can be given nutrition and/or fluids through an intravenous line or a feeding tube. At the end of life you may choose to forgo artificial nutrition and hydration if treatment will not offer improvement. However, you will never be denied food and fluids if you want (and are able) to eat or drink.

You may also include instructions for organ and/or tissue donation.

Risks and Benefits of Medical Interventions.

The medical interventions outlined above are used in many different situations. When you are confronted with a health crisis or an emergency, these interventions may stabilize your condition so that if you are being treated for a disease or illness, you can continue your treatment regimen. A successful treatment regimen may lead to a meaningful recovery along with a good quality of life.

If no treatment is available for the underlying disease, illness or injury, these medical interventions may prolong your life, but they may not lead to a meaningful recovery. Medical interventions also carry risks that can decrease your quality of life. For example, CPR compressions can fracture ribs. The balance of risks versus benefits changes depending on your overall health, diagnosis and prognosis. Discuss medical interventions with members of your healthcare team.

TIPS

- You can always change your mind and update the terms of your living will.
- You always have the right to refuse (or discontinue) treatment, regardless of the provisions specified in your living will.
- Even if you have a living will in place, you can voice new or updated preferences to members of your healthcare team and your healthcare agent. However, it is important to update your living will as soon as possible.
- At the end of life, pain management and comfort care will always be provided.

Medical Power of Attorney. This document names a person to make medical decisions on your behalf if you are unable to make decisions about your medical care yourself. You can appoint someone to be assigned your medical power of attorney. (Note that a medical power of attorney is not the same as the power of attorney assigned to someone who will deal with your legal and financial matters.)

The person assigned your medical power of attorney is often referred to as a “healthcare agent,” “healthcare proxy,” “a person who has durable power of attorney for healthcare” or a “healthcare representative.”

The person assigned your medical power of attorney (your healthcare agent) will use the terms of your living will when making decisions on your behalf. In some states, your healthcare agent does not have to follow your wishes as laid out in your living will; that is why it is important to feel confident that the person you have chosen as your healthcare agent understands and respects your decisions.

Assigning Your Medical Power of Attorney. When deciding on the person that you assign your medical power of attorney, keep in mind that this person (your healthcare agent) must be

- Able to advocate and make decisions on your behalf if others disagree with your wishes
- Comfortable discussing medical care and end-of-life issues with you
- Comfortable discussing medical care and end-of-life issues with members of your healthcare team and your loved ones.

Your healthcare agent

- Does not have to be your spouse or closest relative
- Cannot be a member of your healthcare team.

You can also list an alternate person who can act on your behalf if, for some reason, your healthcare agent cannot fulfill this responsibility. If you have not assigned your medical power of attorney to a named individual, someone will be named as your healthcare agent and be authorized to make medical decisions on your behalf (as specified by the laws in your state).

Preparing Your Advance Directive

Ask members of your healthcare team for information about advance directives and request the relevant documents for your state. The requirements for implementing advance directives differ from state to state. Visit the following resources for information about advance directives:

- The National Hospice and Palliative Care Organization has information on its Web site about advance care planning, along with information about planning and storing your advance directive. Visit www.caringinfo.org for more information. There is also a tool that allows you to download your state's advance directive paperwork (www.caringinfo.org/planning/advance-directives/by-state/).
- PREPARE™ For Your Care is a step-by-step program with videos that offers information about advance directives and easy-to-read advance directive forms for all states. Visit <https://prepareforyourcare.org/> for more information.

What Do I Do With My Advance Directive? Keep your original advance directive documents in a safe and accessible place. Give copies to your healthcare team to keep in your medical record and to the person who has your medical power of attorney (your healthcare agent). If your advance directive changes, provide your healthcare team and your healthcare agent with an updated copy.

TIP

Emergency personnel/ first responders (people who would assist you in an emergency) are charged with providing immediate life-saving care. Even if you have a living will, emergency personnel will use medical interventions to stabilize you in the event of a medical emergency or accident. Once you are stabilized, if you are unable to communicate, members of your healthcare team and your healthcare agent will use the terms set out in your living will to guide the decision making involved in your continued care.

Can My Advance Directive Ever Be Changed?

Advance directives can be changed or updated at any time. In fact, it is good practice to review your advance directive periodically, especially after major life events, such as a birth or a death in the family, marriage or divorce, or after a new medical diagnosis. It is also important to ensure that contact information is still accurate. You may want to update your priorities and wishes so that they reflect your changing situation or perspective, and/or you may want to choose a different person to be assigned your medical power of attorney.

Information About End-of-Life Care

The Physician Orders for Life-Sustaining Treatment (POLST) Paradigm.

“Physician order(s) for life-sustaining treatment (POLST)” are medical orders for a person who has a progressive serious illness or who is nearing the end of life. These orders are sometimes referred to as “medical orders for life-sustaining treatment (MOLST)” or by other names, depending on the state you live in. The POLST form is completed by your doctor with you or your healthcare agent’s input. It specifies treatments you want to receive during a medical emergency. Pain management and comfort care will always be a priority. Based on your preferences and priorities for end-of-life care, you may choose to decline other medical interventions. POLST forms differ by state, and not all states have a standardized form yet. Visit <https://polst.org/programs-in-your-state/> to find out more information.

Ideally, all people will have advance directives in place, but a completed, signed POLST form is only created for individuals who have a progressive, serious illness (for example, Alzheimer’s disease) or are nearing the end of life.

Differences Between a POLST Form and a Living Will

Physician Orders for Life-Sustaining Treatment (POLST) Form	Living Will
Completed by doctor (a medical order)	Completed by patient (a legal document)
Followed by emergency personnel and first responders	Not available to emergency personnel and first responders
For patients with a progressive and terminal illness	For all adults regardless of health status

A POLST form may address decisions about

- Attempting cardiopulmonary resuscitation (CPR) (see page 8)
- Intubation and mechanical ventilation (see page 9)
- Artificial nutrition and hydration (see page 9)
- Use of antibiotics
- Pain management
- Transfer to an emergency room or hospital.

Your doctor will fill out your POLST form based on your treatment preferences. Orders on a POLST form can always be cancelled, or an order can be updated.

For more information, visit <https://polst.org>.

Tips for Discussing Care Near the End of Life With Members of Your Healthcare Team

- Ask members of your healthcare team for information about your medical condition and what to expect as your disease progresses.
- Use your goals for treatment and your values and priorities to guide your decisions. If you have a signed POLST form, ask members of your healthcare team to explain how each of the treatments ordered complements your goals and priorities for care.
- Learn more about palliative care (supportive care) and hospice options that are available to you.
 - Palliative care is specialized care that focuses on providing relief from the pain, symptoms, side effects and emotional/spiritual stress of a serious illness. Palliative care can be implemented along with ongoing treatments to improve a patient's quality of life. It is an appropriate choice for anyone who has a serious illness, regardless of age, stage or prognosis. **Visit www.LLS.org/booklets to view the free LLS publication *Palliative Care*.**
 - Hospice care is initiated only after treatment for disease is discontinued. Hospice offers comfort care and support for the patient and family members. It addresses the specific physical, emotional and spiritual needs of patients who are approaching the end of life.

Visit the Hospice Foundation of America at <https://hospicefoundation.org> and the National Hospice and Palliative Care Organization at www.nhpco.org for more information about hospice.

Resources and Information

LLS offers free information and services to patients, caregivers and families affected by blood cancers. This section of the book lists various resources that can be helpful to you. Use this information to learn more, to ask questions and to make the most of your healthcare team members' knowledge and skills.

For Help and Information

Consult With an Information Specialist. Information Specialists are highly trained oncology social workers, nurses and health educators. They offer up-to-date disease and treatment information. Language services are available. For more information, please

- Call: (800) 955-4572 (Monday through Friday, 9 am to 9 pm ET)
- Email or live chat: www.LLS.org/InformationSpecialists

Clinical Trials Support Center (CTSC). Research is ongoing to develop new treatment options for patients. LLS offers help for patients and caregivers in understanding, identifying and accessing clinical trials. Patients and caregivers can work with Clinical Trial Nurse Navigators who will help find clinical trials and personally assist them throughout the entire clinical-trial process. Please visit www.LLS.org/CTSC for more information.

One-on-One Nutrition Consultations. Access free one-on-one nutrition consultations provided by a registered dietitian who has experience in oncology nutrition. Dietitians assist callers with information about healthy eating strategies, side effect management, and survivorship nutrition. They also provide additional nutrition resources. Visit www.LLS.org/nutrition for more information and to schedule a consult.

Free Information Booklets. LLS offers free education and support booklets that can either be read online or ordered. Please visit www.LLS.org/booklets for more information.

Financial Assistance. LLS offers financial support including insurance premium and medication co-pay assistance as well as travel and other needs to eligible individuals with blood cancer. For more information, please

- Call: (877) 557-2672
- Visit: www.LLS.org/finances

Telephone/Web Education Programs. LLS offers free telephone/web and video education programs for patients, caregivers and healthcare professionals. Visit www.LLS.org/programs for more information.

Podcast. *The Bloodline with LLS* is here to remind you that after a diagnosis comes hope. Listen in as patients, caregivers, advocates, doctors and other healthcare professionals discuss diagnosis, treatment options, quality-of-life concerns, treatment side effects, doctor-patient communication and other important survivorship topics. Visit www.LLS.org/TheBloodline for more information and to subscribe.

Free Mobile Apps.

- LLS Coloring For Kids™ - Allows children (and adults) to express their creativity and offers activities to help them learn about blood cancer and its treatment. Visit www.LLS.org/ColoringApp to download for free.
- LLS Health Manager™ - Helps you track side effects, medication, food and hydration, questions for your doctor, and more. Visit www.LLS.org/HealthManager to download for free.

Suggested Reading. LLS provides a list of selected books recommended for patients, caregivers, children and teens. Please visit www.LLS.org/SuggestedReading to view the titles.

Community Resources and Networking

LLS Community. This is the one-stop virtual meeting place for talking with other patients and receiving the latest blood cancer resources and information. Share your experiences with other patients and caregivers and get personalized support from trained LLS staff. Please visit www.LLS.org/community to join.

Weekly Online Chats. Moderated online chats can provide support and help cancer patients to reach out and share information. Please visit www.LLS.org/chat for more information.

LLS Chapters. LLS offers support and services in the United States and Canada, including the *Patti Robinson Kaufmann First Connection Program* (a peer-to-peer support program), local support groups, local education programs and other great resources. For more information about these programs or to contact the nearest chapter, please

- Call: (800) 955-4572
- Visit: www.LLS.org/ChapterFind

Advocacy. The LLS Office of Public Policy (OPP) engages volunteers in advocating for policies and laws that encourage the development of new treatments and improve access to quality medical care. For more information

- Call: (800) 955-4572
- Visit: www.LLS.org/advocacy

Other Helpful Organizations. LLS offers an extensive list of resources for patients and families. There are resources that provide help with financial assistance, counseling, transportation, patient care and other needs. Please visit www.LLS.org/ResourceDirectory for more information.

Additional Help for Specific Populations

Language Services. Let members of your healthcare team know if you need translation or interpreting services because English is not your native language, or if you need other assistance, such as the service of a sign language interpreter. Often these services are free.

Information for Veterans. Veterans who were exposed to Agent Orange while serving in Vietnam may be able to get help from the United States Department of Veterans Affairs. Please visit www.publichealth.va.gov/exposures/agentorange or call the Department of Veterans Affairs at (877) 222-8387 for more information.

Information for Firefighters. Firefighters are at an increased risk of developing cancer. There are steps that firefighters can take to reduce the risk. Please visit www.LLS.org/FireFighters for resources and information.

World Trade Center (WTC) Survivors. People involved in the aftermath of the 9/11 attacks and subsequently diagnosed with a blood cancer may be eligible for help from the World Trade Center (WTC) Health Program. People eligible for help include

- Responders
- Workers and volunteers who helped with rescue, recovery and cleanup at the WTC-related sites in New York City (NYC)
- Survivors who were in the NYC disaster area, lived, worked or were in school in the area
- Responders to the Pentagon and the Shanksville, PA, crashes

For more information, please

- Call: WTC Health Program at (888) 982-4748
- Visit: www.cdc.gov/wtc/faq.html

People Suffering from Depression. Treating depression has benefits for cancer patients. Contact your doctor if your mood does not improve over time—for example, if you feel depressed every day for a 2-week period.

Feedback. Visit www.LLS.org/PublicationFeedback to give suggestions about this booklet.



Get support.
Reach out to our

INFORMATION SPECIALISTS

The Leukemia & Lymphoma Society team consists of highly trained oncology social workers, nurses and health educators who are available by phone Monday through Friday, 9 a.m. to 9 p.m. (ET).

- Get one-on-one personalized support and information about blood cancers
- Know the questions to ask your doctor
- Discuss financial resources
- Receive individualized clinical-trial searches

Contact us at
800-955-4572 or
www.LLS.org/
InformationSpecialists

(Language interpreters can be requested)





For more information, please contact our Information Specialists
800.955.4572 (Language interpreters available upon request).

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The mission of The Leukemia & Lymphoma Society (LLS) is to cure leukemia, lymphoma, Hodgkin's disease and myeloma, and improve the quality of life of patients and their families.
Find out more at www.LLS.org.