

End-of-Life Decision Making

A Guide to Assist Patients and Families



CENTRACARE Health

Beginning the Discussion ...

Advances in medical technology today extend life and cure many diseases. Yet the potential benefits also may bring difficult choices for patients and families. You may feel confused about your options for certain medical treatments. At the end of life, you may fear you will have to endure painful and expensive treatments. Or you may worry the care you need or want may not be given.

As your health declines, medical decisions often become more difficult. We hope this booklet will help make end-of-life decisions easier. You will need to consider how medical care will affect your life, comfort and death. It is important to outline your decisions prior to a health care crisis.

We suggest after reading this booklet, you talk about these matters with your family, doctor, clergy or other informed persons. These people should be aware of your wishes in order to help you make decisions about your care.

All the art of living lies in a fine mingling of letting go and holding on.

- Henry Ellis



Patient and Family Decision Making


While you make many choices every day, end-of-life decisions can be some of the most difficult. Hospitals may seem intimidating with unfamiliar machines, treatments and technical terms. But the hospital is a place where people care for people. Skilled, trained, and compassionate professionals reach out to others in need. Sometimes our best efforts cannot achieve a cure. Yet in all cases, we strive to provide care and comfort, even when a cure is not possible.

It is challenging to face serious illness. This human experience affects our bodies, emotions, relationships and spiritual beliefs. Serious illness presents many choices about medical care. You may want to know:

- What can be expected as the illness progresses?
- How can your wishes as a patient be made known and respected?
- Should resuscitation be attempted if the heart or breathing stops?
- What are the benefits and burdens of different treatment options?
- Can you ever decide not to use some treatments like ventilators, feeding tubes, antibiotics, dialysis and chemotherapy?
- How should you control pain, anxiety and other symptoms?
- Does expense ever count in making decisions?
- Should you donate organs and tissue after death has occurred?

Besides these specific questions, you also may wonder:

- Who should make these decisions?
- Who will help you understand your options?
- How will you know you are making the “right” decisions?



Faith is taking the first step even when you don't see the whole staircase.

- Martin Luther King, Jr.

Medical Decision Making

The health care team makes treatment decisions based on your condition, and most importantly, on your request for treatment.

Information Gathering

The first step in this decision-making process is to gather current information about:

- your diagnosis and overall condition
- realistic and appropriate goals of care
- your comfort level
- your medication and treatment, as well as their purpose
- your preferences (either current wishes, or if you are unable to speak, any previously expressed wishes)
- additional treatment options (including the benefits or burdens of each)

Decision to End Treatment

Sometimes a cure is not possible. Medications or treatments may no longer help. They may cause excessive pain or unnecessary expense. When the burdens outweigh the benefits of the treatment, they become “extraordinary means” of prolonging life. At this point, you have the option to stop treatment.

A decision to end life-sustaining treatment does not imply a lack of care. If you decide to remove extraordinary means of prolonging life, you allow a natural death to occur. The goals of treatment change from a cure to comfort. It allows you and your loved ones to prepare for a peaceful death.

Advance Directives

Advance directive documents allow a person to give directions about future health care or to designate another person(s) to make health care decisions if the individual no longer is able. Advance directives may include living wills, durable powers of attorney, do-not-resuscitate (DNR) orders, physician orders for life-sustaining treatment (POLST), or similar documents that express the person's wishes.

HealthCare Directive

A health care directive is a plan intended to guide treatment decisions in the event that you no longer can make health care decisions for yourself. There are many different health care directive forms available that meet the legal requirements in Minnesota. To be legal in Minnesota, a health care directive must:

- be in writing
- bear the name and signature (or mark) of the person to whom it applies
- be dated
- name a health care agent (decision-maker) and/or state wishes/preferences about care
- be carried out by a person with the capacity to understand and make decisions
- be verified by two adult witnesses or a notary public



Physician Orders for Life-Sustaining Treatment (POLST)

A POLST is a signed medical order form that communicates the person's end-of-life health care wishes to other health care providers during an emergency. Use of the form is most appropriate for persons who have advanced chronic progressive illness, those who might die in the next year, or those wishing to further define their preferences of care.

Power of Attorney for Health Care

This directive provides a legal form for designation of an agent to make health care decisions when the person is temporarily or permanently unable to do so. These forms (documented prior to Aug. 1, 1998, meeting legal requirements) are activated when a person is judged by the medical provider to be incapable (for whatever reason, temporary or permanently) of making his or her own decisions.

Living Will

A living will is a legal form for the person to indicate health care decision preferences as well as designate a proxy decision maker. These forms (documented prior to Aug. 1, 1998, meeting legal requirements) are activated when a person is both judged by the medical provider to be terminal and incapable (for whatever reason, temporary or permanently) of making his or her own decisions.

What can you put in an advance directive?

You may have many choices as to what you may want to include in your advance directive. For example,

- in the event your heart stops beating or breathing stops, what amount of resuscitation you would want
- the person you list as your health care agent to make health care decisions for you
- your goals, values, and preferences about health care and end-of-life care
- the type of medical treatment you would want or not want to receive
- arrangements for the care of your body after death and funeral
- donation of organs, tissue and eyes

What should you do after signing your advance directive?

You should inform family members, your health care agent(s) and your doctor that you have completed an advance directive. Give copies to these people. Also give a copy to your health care facility to keep with your medical record. Keep the original document in a safe place.

When will your advance directive go into effect?

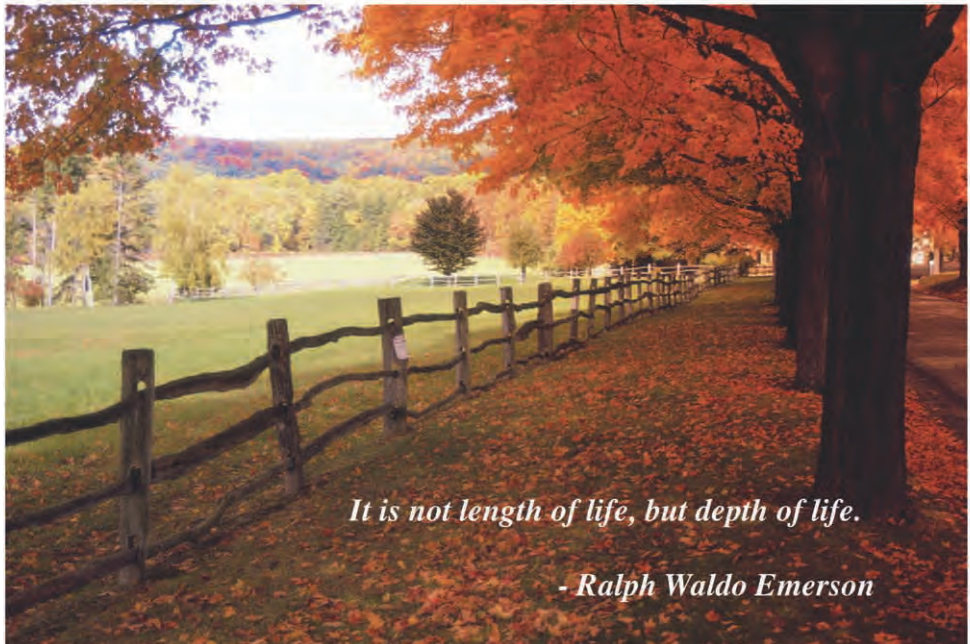
Your advance directive becomes legally valid as soon as it is signed. However, it will not go into effect unless you are unable to make your own informed decisions about your health care.

How long does an advance directive last? Can you change it?

An advance directive will last until you change or cancel it. You can revise your advance directive at any time unless your capacity to make informed medical decisions is impaired. A good practice is to review your advance directive after life events such as:

- Decade:** the start of each new decade of life
- Death:** whenever you experience the death of a loved one
- Divorce:** if you experience a divorce or other major family change
- Diagnosis:** if you are diagnosed with a serious condition
- Decline:** if you experience a significant decline or deterioration of an existing health condition, especially if you are unable to live on your own

An advance directive helps all people involved in your health care know your wishes. If you would like to complete an advance directive, please ask your nurse. You may even complete the document today, if you wish.



It is not length of life, but depth of life.

- Ralph Waldo Emerson

Decisions to Make

At some point, medical treatment may not work or become a burden. You and your family may decide to limit or end treatment. The focus then becomes providing a dignified and peaceful death. This decision is among the most difficult decisions one may have to make in life.

The following are things to consider in your care:

Cardiopulmonary Resuscitation (CPR): CPR is performed when breathing or heart beating stops or slows significantly. CPR involves applying force to the chest to compress the heart and breathing into the mouth. In addition to CPR, treatment may include:

- electric shock to the heart
- medications
- a tube inserted into the lungs to assist breathing

Our team will not begin CPR if your medical provider orders otherwise based on your request, which may come from your advance directive. If you do not want resuscitation, you must tell your medical provider.

Your survival after CPR depends on your age and health. According to statistics, few older patients with multiple medical problems survive — even when CPR is done in a medical facility with lifesaving equipment and trained staff. It is possible to survive after CPR; however, a person's quality of life may not be the same.

Dialysis: When kidneys no longer can take care of a body's needs, dialysis treatment may temporarily help. Kidneys remove waste products, salt and extra fluid from the body. If they are damaged or fail, dialysis replaces a small portion of kidney function. Dialysis can improve or at least maintain your current quality of life. However, when dialysis no longer achieves these goals, you may choose to stop it.

Hospitalization: Once you decide to stop treatments, you no longer need to stay at the hospital. Typically Medicare and other insurance providers will not pay for hospital stays without treatment. You may want to go home to be in familiar surroundings, and for some people this may be possible. If going home is an option, resources are available to assist with necessary care and supplies through home care and hospice services. Sometimes people decide not to return to the hospital for additional treatment.

Intravenous (IV) Fluids: IV fluids provide hydration when you are unable to drink adequate amounts. In addition to hydration, you may receive medications through an IV line. At the end of life, IV fluids can cause discomfort, but little benefit. In such cases, it may be best to stop or limit IV fluids to offer the most comfort.

Medications: Medication may be used to control heart rate and blood pressure. If you stop these medications, it will not cause discomfort. Some medications may be continued to relieve uncomfortable symptoms such as fever, pain and anxiety.

Organ and Tissue Donation: In some instances, you may want to consider organ and tissue donation. If you are a candidate, the health care team will ask you about donation. Please let your wishes be known to your family.

Defibrillators: Once you decide to stop treatment, we may turn off implanted defibrillators to ensure comfort in the dying process.

Pacemakers: A pacemaker can help a heart to beat. Once you decide to discontinue treatment, you may request to turn off your pacemaker. Leaving the pacemaker on will not prolong death and is not necessary to be turned off.

Artificial Nutrition (tube feedings): If you no longer can take food or fluid by mouth, today's medical technology allows us to nourish you. You can receive liquid feedings, water and medications through tubes into your stomach. Your health care team also can place food and medication directly into the bloodstream. This process is called total parenteral nutrition (TPN).

Although tube feedings may be appropriate in certain health conditions, at the end of life the body cannot absorb these feedings and the side effects outweigh the benefits. In these cases, you and your family have the option to discontinue the feedings or not start them in the first place.

Ventilator or Respirator: Ventilators breathe for people. Removing the ventilator, when it is an extraordinary means of prolonging life, allows a natural death to occur. Death is not caused by turning off the machine. The cause of death is the disease that brought on respiratory failure. Death would have occurred earlier if not for the initial use of the ventilator. When the ventilator is removed, death may not occur immediately. Your health care team will treat pain or shortness of breath for your comfort.

Care and Communication

Asking Questions

We encourage you and your loved ones to ask questions and express fears and uncertainties. You deserve clear, consistent and compassionate responses from the health care team. You should always be well-informed.

Ask doctors, nurses and other members of the health care team about your condition. You should know about your:

- diagnosis
- prognosis
- risks and benefits of treatments

When you receive an answer, make sure you understand it. Doctors and nurses must give information to you in a way you understand.

Life-threatening illness may cause fears and anxieties, which interfere with what you hear. You may need to ask the same questions a few times to understand. It may be helpful to write down your questions and the answers to review later. Many people find it helpful to keep a journal.



Care Conferences

If you feel confused by different caregivers and their comments, ask to have a care conference. Doctors, nurses, chaplains, care coordinators and social workers may participate in care conferences to discuss condition and treatment goals. These discussions provide consistent information and answers to assist you in decision making.

Patient- and Family-Centered Care

St. Cloud Hospital holds a patient- and family-centered care philosophy. We encourage your family to:

- be at your bedside as much as they choose
- talk to you and touch you as they feel comfortable
- reflect on your life events, experiences, hobbies and activities
- provide some care, if interested, such as back or foot rubs

Continuity of Care

During a long illness you will see many different doctors and nurses. The hospital strives to provide you with consistent caregivers.

Palliative Care

Palliative Care is specialized medical care for people with serious illnesses. It focuses on providing patients with relief from the symptoms, pain and stress of a serious illness — whatever the diagnosis. The goal is to improve quality of life for both the patient and the family. Ask your doctor to see a palliative care specialist if you feel it would be helpful.

Hospice

Hospice manages the care needs of a person at the end of life and supports families through the final months and weeks of life. It may be provided at home, in the hospital or in a nursing home. Hospice care also addresses the needs of family and friends following a person's death.



Both Palliative Care and Hospice are provided by a team made up of doctors, nurses, social workers, chaplains, bereavement specialists and other disciplines as needed.

Other Resources

Some people find it difficult to talk about death and whether to prolong life or not. We have many resources to help you in these decisions. Please ask your nurse about them.



Symptom Management

Our ultimate goal is comfort for you and your family. You can expect to be free of pain, anxiety and shortness of breath. We will provide personal care and comforting touch.

If you are unable to tell us about discomfort verbally, we will evaluate your symptoms through other means. We will monitor your vital signs and behavior to see if discomfort is present. We can give you pain, sedation medications, or other medications as well as non-medicated treatments to help you be more comfortable.

Other comfort care measures include:

- family presence at the bedside
- noise and stimulation reduction
- repositioning for comfort
- promotion of the best sleep patterns
- minimization of bright lights
- presence of Spiritual Care
- healing touch
- meditation
- oral care
- elimination of lab tests and other unnecessary activity
- comfort through medication

***We cannot banish dangers,
but we can banish fears.
We must not demean
life by standing in awe
of death.***

- David Sarnoff



Emotional and Spiritual Support

Our staff strives to create a community of respect, genuine care and support for patients and families. We support and cherish life, but accept death as a part of life. As we provide care through the dying process, our goal is to offer a supportive, compassionate presence to you and your family.

It is never easy to make decisions about end-of-life treatment. At times family members may disagree. End-of-life decisions often have little to do with medical, legal or ethical aspects of the decision-making process. The real struggles are emotional and spiritual.

Family members come to terms with these decisions in different ways and in varying timelines. As a part of this journey, pastoral caregivers (chaplains) are available to assist you. Chaplains are trained to be a supportive presence to you. They will support you in a manner that has meaning for you, your faith tradition and view of life, assisting you with any spiritual, emotional, moral or ethical challenges you may be feeling. If you would like to speak to a chaplain, ask your nurse. You also may call upon your own spiritual care providers to come to the hospital, if desired.

Once you and your family decide to limit or end treatment, the focus then becomes providing a dignified and peaceful death. This decision is among the most difficult decisions one may have to make in life.

Ethics Committee

St. Cloud Hospital and other CentraCare Health hospitals have an Ethics Committee to help with end-of-life decisions. The committee is made up of:

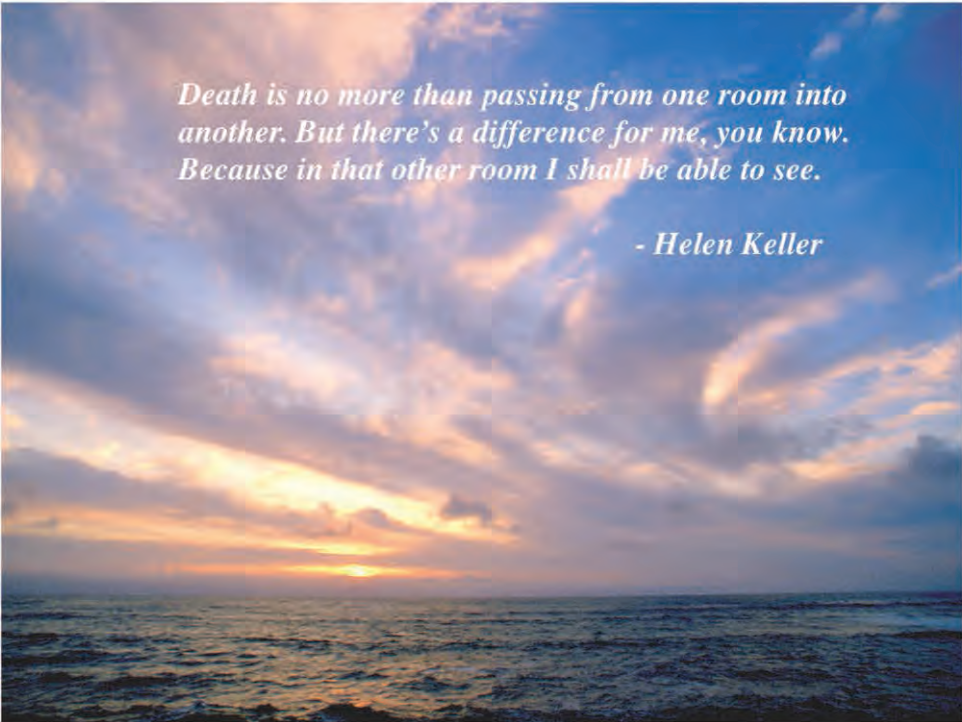
- doctors
- nurses
- social workers
- lawyers
- clergy
- patient representatives
- a bioethics consultant

This group discusses with you and your family situations needing clarification or conflict resolution. The Ethics Committee will provide counsel and make recommendations. The final decision still is up to you, your family and your doctor. If you would like to consult the Ethics Committee, talk to your nurse.

Advice to Families

The body, mind and spirit are all touched by the loss of a loved one. We all grieve and face loss differently. Therefore, others around you may have little understanding of your grief. It may help to share your feelings with others. If you are interested, we can provide you with a list of area support groups and other grief resources.

Be patient with yourself. You are providing your loved one with support, comfort, and most importantly, love during his or her final journey. You are giving him or her a tremendous gift.

A photograph of a sunset over the ocean. The sky is filled with dramatic, colorful clouds in shades of orange, yellow, and blue. The sun is low on the horizon, creating a bright glow. The ocean waves are visible in the foreground.

Death is no more than passing from one room into another. But there's a difference for me, you know. Because in that other room I shall be able to see.

- Helen Keller

Resources

CentraCare Hospice is a special way of caring for people in the final stages of life. Hospice provides comfort and dignity for patients who have a six month or less life expectancy and are accepting of comfort care. 320-259-9375 or 800-835-6610.

Life After Death: Grief Support brochure.

St. Cloud Hospital Palliative Care is available while in the hospital, as an outpatient or at home. Call 320-656-7117 for hospital and outpatient services; 320-259-9375 for in-home services.

St. Cloud Hospital Spiritual Care provides resources for multiple faiths. For more information call 320-251-2700, ext. 54621, toll free at 800-835-6652, ext. 54621 or visit www.centracare.com/services/spiritual-care/

St. Cloud Hospital Bereavement Line. Call 320-255-5725 at any time to leave a message, and you will be contacted by a member of our Spiritual Care staff. This line is not for an emergency. If you feel your grief is overwhelming, call your doctor or seek help through the St. Cloud Hospital emergency room 320-255-5656.

Websites:

CaringBridge allows people in a time of need to create their own web page to share health updates, photos and videos with friends and family. www.caringbridge.org

CentraCare Health – Multiple resources dedicated to grief and bereavement are available at www.centracare.com/services/grief-and-bereavement-services/

The Institute for Human Caring provides multiple resources for people facing life-limiting illness, their families and their professional caregivers. www.dyingwell.org

ICU-USA provides explanations about ICU-related medical conditions, drugs, procedures, equipment and supplies — virtually all aspects of the ICU environment. www.icu-usa.com

Caring Connections provides people with information and support who are planning ahead for their end-of-life wishes, caring for a loved one, living with an illness or grieving a loss. <http://www.caringinfo.org/i4a/pages/index.cfm?pageid=1>

Light The Legacy is a community-based organization dedicated to working collaboratively with the community to improve end-of-life care for the people of Central Minnesota. <http://lightthelegacy.org/>

Supportive Care Coalition is a partnership of Catholic health ministries, informed by our faith and values, advancing excellence in palliative care. www.supportivecarecoalition.org

Catholic End-of-Life Resources provides health care directive and end-of-life resources specific to the Catholic faith. <http://www.mncc.org/resources/mn-catholic-healthcare-directive-2/>

Minnesota POLST gives information about developing a standardized Provider Orders for Life-Sustaining Treatment (POLST) form that can be used for patients diagnosed with serious illnesses throughout Minnesota. <http://www.polstm.org/>

The Minnesota Department of Health provides legal information about advance directives. <http://www.health.state.mn.us/divs/fpc/profinfo/advdir.htm>



*Those we love don't go away, they walk beside us every day,
unseen, unheard ... but always near, still loved, still missed
and very dear.*

- Anonymous

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