

# End-of-Life Decision Making

A Guide to Assist Patients and Families



 **St. Cloud Hospital**  

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**CENTRACARE** Health System

## 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 fear you will not receive the care you need.

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.

We suggest after reading this booklet, you discuss these matters with your family, doctor, clergy or other informed persons. These people should be aware of your wishes to assist you in decision making.

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

*Henry Ellis*



# Patient and Family Decision Making

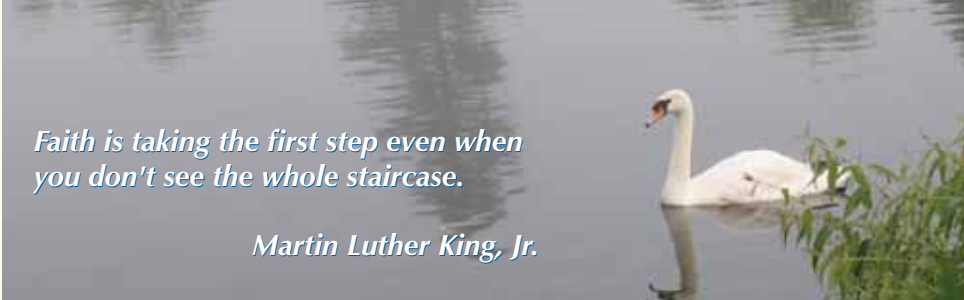
While you make many choices every day, end-of-life decisions can be some of the most difficult. Hospitals may seem intimidating with unfamiliar machines, treatments and technical terms. But the hospital is a place of people caring for people. Skilled, trained and compassionate professionals reach out 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 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 preferences 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 may also 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. Usually, the goal of medical care is to help people get better. We may use a treatment like a ventilator or dialysis temporarily until healing can occur.

## 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 medications and treatments, as well as their purposes
- 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 benefit you. They may cause excessive pain or 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 treatments 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 (or “palliative care”). It allows you and your loved ones to prepare for a peaceful death.

## Decisions to Make

When facing difficult medical decisions, it helps to complete a health care directive. A health care directive can guide your family in making decisions for you if you are unable to make the decision. If you would like to complete a health care directive, please ask your nurse. You may even complete the document today, if you wish.

The following may be things to consider:

**Cardiopulmonary Resuscitation (CPR):** CPR is performed when breathing or heart beating stops or slows severely. Our team will not begin CPR if your doctor orders otherwise based on your health care directive. If you do not want resuscitation, you must tell your doctor. We will always perform CPR during surgery if heart beating or breathing stops.

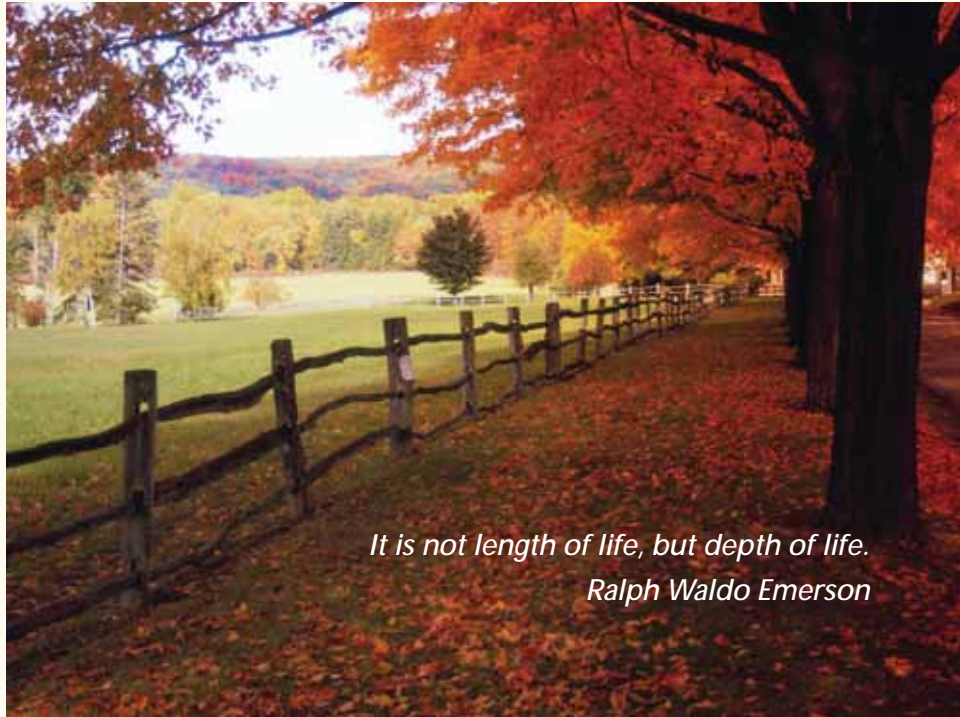
CPR involves applying force to the chest to compress the heart and breathing into the mouth. In addition to CPR, treatment may include:

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

Your survival after CPR depends on your age and health. According to statistics, few aged patients with multiple medical problems survive — even when CPR is done in a medical facility with lifesaving equipment and trained personnel.

**Dialysis:** When kidneys can no longer take care of a body's needs, dialysis treatment may 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. Home care and hospice services are available to assist you at home.



*It is not length of life, but depth of life.  
Ralph Waldo Emerson*

**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. Sometimes IV fluids can cause discomfort, but little benefit.

**Medications:** Medication may be used to control heart rate and blood pressure. If you stop these medications, it will not cause discomfort. You may want to continue antibiotics to relieve uncomfortable symptoms of fever. Medications also may reduce 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.

**Pacemakers:** A pacemaker can help a heart to beat. Once you decide to discontinue treatment, we may turn off implanted pacemakers and/or defibrillators to ensure comfort in the dying process.

**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).

These feedings can provide many benefits and are usually appropriate for most people. They can help you stay nourished and can speed the healing process after surgery. You may continue to need artificial feedings for a period of time at home.

Burdens and risks exist with these feedings. Feeding tubes can be uncomfortable. Pneumonia can develop if fluid enters the lungs. In some situations, feedings may be ineffective and/or cause excessive problems. 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. When the ventilator is removed, death may not occur immediately. Your health care team will treat pain or shortness of breath for your comfort. Removing the ventilator, when it is an extraordinary means of prolonging life, allows a natural death to occur. The cause of death is the disease that brought on respiratory failure. Death is not caused by turning off the machine. Death would have occurred earlier if not for the initial use of the ventilator.



# Symptom Management

Our ultimate goal is the comfort of you and your family. As a patient, 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 pain through other means. We will monitor your vital signs and behavior to see if pain is present. We can give you pain and sedation medicine as well as non-medicated treatments.

Other pain and anxiety-reducing measures include:

- family presence at the bedside
- noise and stimulation reduction
- repositioning for comfort
- promotion of the best sleep patterns
- minimization of bright lights
- elimination of lab tests and other unnecessary activity
- comfort through IV medication and fluids.

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

*David Sarnoff*



# Care and Communication

## Asking Questions

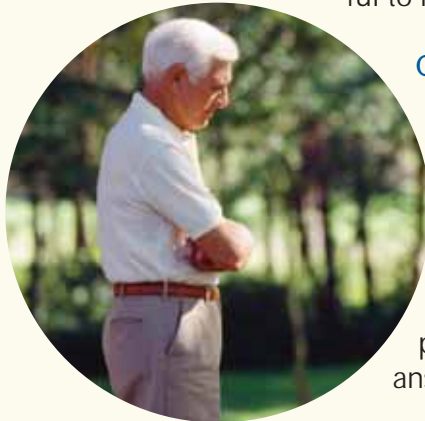
We encourage you and your loved ones to ask questions and express fears and uncertainties. You deserve clear, consistent and compassionate responses from the health care team. You should always be well-informed.

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 present information to you in 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, case managers 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 and Hospice

Palliative care and hospice support the belief that each of us has the right to die with comfort and dignity. They also give your family the support needed to help you through this time.

**Palliative care** aims to relieve the stress and symptoms related to a serious illness. The palliative care team helps you set and evaluate your care goals. They will support holistic care to help you maintain the highest quality of life possible.

**Hospice** uses the combined specialties of a team of health care professionals to assist you at home in the final stages of life.

### 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 discussions. Please ask your nurse for assistance.



# Emotional and Spiritual Support

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.

At some point, medical treatment may become burdensome or ineffective. 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.

## Support from St. Cloud Hospital

St. Cloud Hospital is rooted in Catholic Christian tradition. This tradition assures us of God's loving embrace in this life and the next. As a Catholic health care institution, we strive to be a community of respect, love and support for patients and families of all faith traditions. 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.

As a part of this journey, pastoral caregivers (chaplains) on our hospital staff are available to assist you. Our chaplains are trained to be a supportive presence to you. They will support you in a manner that has meaning to you, your faith tradition and view of life. 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.

## Ethics Committee

St. Cloud Hospital has an Ethics Committee to help with end-of-life decisions. The committee is made up of:

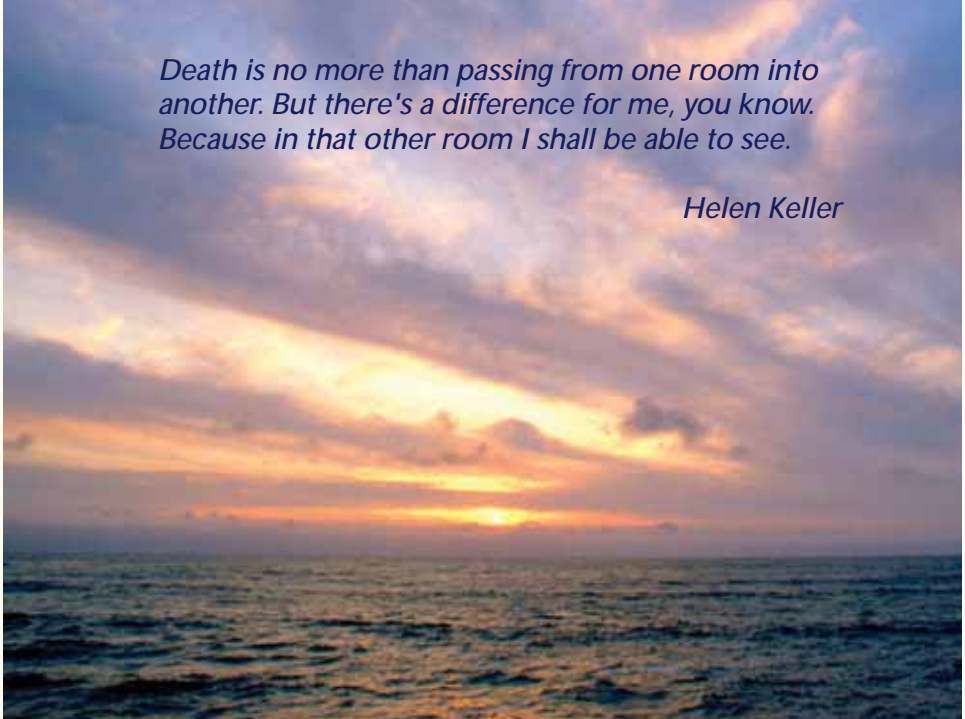
- doctors
- nurses
- social workers
- lawyers
- clergy
- patient representatives
- a bioethics consultant.

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 is still up to you, your family and your doctor. If you would like to consult the Ethics Committee, contact 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 losses 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.

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 soft, colorful clouds in shades of orange, yellow, and blue. The sun is low on the horizon, creating a bright glow. The ocean is visible in the foreground, with gentle waves.

*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

St. Cloud Hospital. (2006). St. Cloud Community Grief Services [Brochure].  
St. Cloud, MN: Author.

St. Cloud Hospital. (2000). Your Right to Decide Your Health Care [Brochure].  
St. Cloud, MN: Author.

St. Cloud Hospital Hospice - (320) 259-9375 or (800) 835-6610.

St. Cloud Hospital Palliative Care - Palliative care is available while in the hospital or at home. For hospital services, call (320) 251-2700, ext. 54810. For home care services, call (320) 259-9375.

[www.caringbridge.org](http://www.caringbridge.org) - A nonprofit, free online service connecting friends and family when a loved one is receiving care.

[www.cityofhope.org](http://www.cityofhope.org) - Offers a broad array of support and educational services to patients, their loved ones, the local community and health care professionals.

[www.dyingwell.org](http://www.dyingwell.org) - Resources for people facing life-limiting illness, their families and their professional caregivers.

[www.icu-usa.com](http://www.icu-usa.com) - Information about medical conditions, treatments, tests, equipment, drugs, medical terms and many other aspects of the intensive care unit.

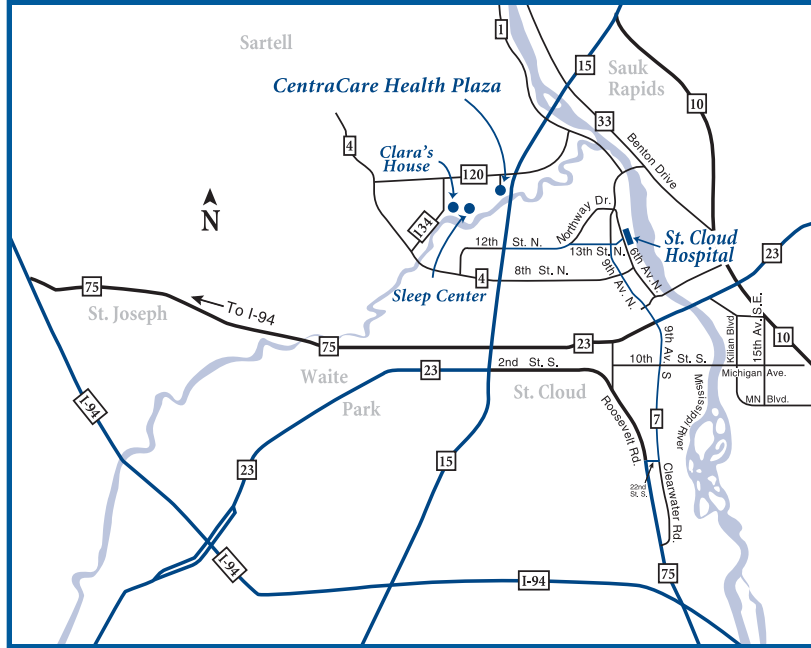
[www.partnershipforcaring.org](http://www.partnershipforcaring.org) - Caring Connections, a program of the National Hospice and Palliative Care Organization (NHPCO), is a national consumer engagement initiative to improve care at the end of life, supported by a grant from The Robert Wood Johnson Foundation.

[www.supportivecarecoalition.org](http://www.supportivecarecoalition.org) - A coalition of Catholic health care organizations working to improve care of the dying within our own facilities and in the nation at large.





## MAP OF ST. CLOUD



**St. Cloud Hospital**

**CENTRA CARE Health System**

care above all

1406 Sixth Avenue North | St. Cloud, MN 56303-1901  
(320) 251-2700 | [www.centracare.com](http://www.centracare.com)