Honoring health care choices:

Your guide to advance care planning.

Making health care choices and choosing my patient advocate.
Make your voice heard.

None of us like to think about it, but a time may come when we can’t make important health care decisions for ourselves. What if you suffer a serious brain injury? What if a disease like Alzheimer’s makes it impossible for you to understand your medical options? Who will speak for you? Who will know what you would have wanted? Who will carry out your wishes?

An **Advance Directive for Health Care** is a legal document that allows you to choose a “Patient Advocate.” Your Patient Advocate should be a person you trust. It should be someone you would want to speak for you and make medical decisions for you if you become permanently or temporarily unable to make your own decisions.

This legal document also serves another important purpose. *It helps you clearly express your views so that your Patient Advocate and your physicians know what medical treatments you would — and would not — like to have.*

It’s important to understand that an Advance Directive for Health Care can only be used in situations when you are not able to make your own decisions. No one can make decisions for you if you are still able to make those decisions and speak for yourself.

**A GIFT FOR YOUR LOVED ONES**

If you don’t choose a Patient Advocate and complete an Advance Directive for Health Care form, it can be very difficult for your loved ones to try to guess what you would want. Think of an Advance Directive as a gift to your loved ones as well as a way of making sure you always have a say in your own medical care.

Everyone 18 and older should complete an Advance Directive for Health Care document. A serious illness or injury can happen at any time. It’s best to be prepared. You can always change your Advance Directive and name a new Patient Advocate at a later date by completing another document.
Start By Having Conversations

As you read through this booklet, think about the types of medical care you’d like to receive in different situations. Talk about it with your family, friends and physician(s).

• What if you were only able to be kept alive with artificial life support?
• What if you were very ill with little hope of survival. Would you want physicians to use CPR and other methods to try to keep you alive?
• What if you were in an irreversible coma or persistent vegetative state — unconscious and/or unaware of your surroundings and likely to stay that way for the rest of your life. What would your medical goals be?

Deciding what’s best for you: What do you value? What do you believe?

This is the first step toward deciding what medical care you would want in a life-threatening situation or medical crisis. Once you know what makes you happy to be alive, ask yourself if there are limitations or conditions that would make your life no longer meaningful. Answering the following questions can help you clarify your feelings.

But don’t forget that your feelings may change with age, changes in your health and other life events. So take time to think about these things periodically.

Your beliefs:

• What roles do pain and suffering have in life?
• Do you believe medical treatment should prolong life?
• When do you believe life stops?

Your quality of life:

• What do you fear most about being ill or seriously injured?
• How important is it for you to be physically, mentally or financially independent?
• How would you feel if you could no longer do the activities you most enjoy?
• How would you feel about being moved from your present home?
• How would you feel about being cared for in a hospital or nursing home at the end of your life?

REFLECT on your values and beliefs
SELECT your Patient Advocate
EXPLORE your goals of treatment
EXPRESS your wishes
SHARE your plan
UNDERSTANDING WHAT YOU VALUE

Check the box that best expresses how important you think it is to be able to do the following. Then ask yourself if you are able to see what your priorities might be in a medical crisis or illness.

<table>
<thead>
<tr>
<th>Importance</th>
<th>Very</th>
<th>Somewhat</th>
<th>Not Very</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Care for myself without being a burden to others</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Get out of bed every day</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Go out on my own</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. Recognize my family and friends</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. Talk to and understand others</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. Make decisions for myself</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. Remain in my home as long as I live</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8. Live without constant or severe pain</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9. Live without being dependent on medical treatment or machines to keep me alive</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10. Be financially independent</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>11. Leave money to my family or a cause I believe in</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>12. Be faithful to my beliefs</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>13. Live as long as possible</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>14. Receive all medical treatments possible</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>15. Die naturally, without lingering</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Having conversations about these important topics will be very helpful as you complete the Advance Directive form. And these conversations will help your loved ones know in advance what sort of health care you would want in different situations.

Here are a few of the topics you may want to discuss with your family, friends and Patient Advocate(s):

• **Pain Management and Comfort** — Serious illness or injury often includes pain that can be frightening or disabling. You should never be afraid or embarrassed to ask your caregivers for help managing pain or any other symptom or concern that is causing you discomfort. You have a right to have your pain managed so that you are comfortable.

• **Nutrition/Hydration** — Medically supplied nutrition and hydration (also known as tube feeding and IV fluids) are sometimes needed in order to help a person recover from an illness. For some patients, medically supplied nutrition can be a big help. But there may be times when a person’s illness cannot be cured and medically supplied nutrition/hydration simply prolongs suffering. Talk to your family, physician and Patient Advocate about whether you would want medically supplied nutrition/hydration if you were in a persistent vegetative state (PVS) or other medical situation with little hope of recovery.

• **Organ and Tissue Donation** — You may already have indicated on your driver’s license or on the Michigan Organ Donor Registry that you want to be an organ donor. These wishes should also be written in your Advance Directive and conveyed to your Patient Advocate(s) and loved ones. Michigan law requires that health care providers ask about organ donation at the time of death. Your physician and family members should be aware of your wishes. Making this decision now can relieve your family and loved ones of the burden of having to make this decision in emotionally difficult times.

**Cardiopulmonary Resuscitation (CPR)**

Making the choice of trying cardiopulmonary resuscitation (CPR) is not easy. This sheet provides answers to some questions about what CPR involves and what else is important to think about when making a decision about CPR.

**What is CPR?**

CPR is used to try to restart the heart and breathing after these have stopped. CPR actions are:

• Pushing on the chest to try to restart the heart, and
• Blowing in the mouth or putting a tube in the mouth and down the airway to provide air.

Shocking the heart or giving drugs through an intravenous line (IV) may also be needed. The person is then taken to the hospital emergency department. Those who survive are transferred to the intensive care unit (ICU) and attached to a ventilator (breathing machine) and a heart monitor.
When is Attempting CPR Most Successful?

On TV shows, CPR is shown as an easy life-saving action that is successful 67% of the time. A healthy person whose heart stops suddenly due to an accident or heart attack has the best chance to return to good health after having CPR. CPR is also more successful if the person is already in the hospital, where health care workers can give care quickly. In general, studies show about 18% of adults who receive CPR survive to leave the hospital. (Nakami et al JAMA 2006)

Having a chronic illness decreases the survival rate of CPR. An elderly person with a chronic illness has an average survival rate of less than 5%. For those with advanced illness, such as Alzheimer’s, Parkinson’s or end-stage heart, lung or kidney disease, survival rates are less than 1%. Those with advanced dementia have a survival rate that is three times lower than those without.

What is the Downside of Attempting CPR?

Because a lot of force is needed to move the heart, CPR causes pain. Ribs are broken in up to 97% of CPR attempts. CPR attempts can also hurt the liver, bruise the chest and cause burns from the electric shocks.

The brain loses air when the heart stops beating and the person is not breathing. Permanent brain damage may occur from lack of air in up to 50% of those who have CPR attempted. The heart also loses its ability to beat normally. The person may be on a ventilator for days, weeks, months or longer. The person will likely need placement in a long-term care facility that can meet his/her needs.

For a person who is very ill or dying, CPR is not likely to help since the heart and breathing stop because of the illness. CPR may put the sick person in pain and distress for the last days of his or her life.

Choosing Do Not Resuscitate (DNR)

After careful consideration of benefits and risks, persons can decide that they do not want CPR attempted. Choosing to not attempt CPR is called “do not resuscitate,” or DNR. DNR is also referred to as “allow natural death.” Persons who choose DNR still receive medical care and treatment. DNR only applies to the CPR process and not to overall care.

Whatever the decision, it’s important to talk to your health care provider about putting your wishes in writing or having a physician order, before a crisis occurs.

Treatments You Can Choose to Refuse

Medical treatments at the end of your life generally fall into three main categories: life-supporting, life-sustaining and life-enhancing. You usually can choose or refuse these treatments at any time. In most cases, you can also try a treatment and then stop it if you do not regain the quality of life you want.

Life-supporting

Life support uses CPR and machines to keep your heart and lungs going when they can no longer work on their own. CPR restarts your heart and lungs after your heart stops beating.
After successful CPR, you are usually transferred to a hospital’s intensive care unit (ICU), where you may be put on a mechanical ventilator. A mechanical ventilator pumps oxygen into your lungs through a tube inserted in your windpipe. In some cases, normal breathing can never be restored.

**Life-sustaining**

Life-sustaining care involves treatment and machines to prolong your life when your condition cannot be reversed or cured.

Tube feeding provides food and fluids through a tube or IV if you cannot chew or swallow. Tube feeding can help keep you alive indefinitely; without it your body will eventually shut down.

Kidney dialysis cleans your blood by machine when your kidneys no longer work. Dialysis can prolong your life, but cannot restore kidney function.

**Life-enhancing**

Life-enhancing care keeps you comfortable until death occurs naturally. Nothing is done artificially to prolong your life.

Comfort measures only and hospice care focus on keeping you comfortable as your condition progresses. Palliative care experts can help you remain comfortable and keep you from retuning to the hospital if this is your desire.

Pain medications, such as morphine and others can be given to keep you comfortable. Anti-anxiety medications and practical interventions such as fans, fresh air and warm blankets can also be parts of comfort measures only.

---

**Choosing A Patient Advocate**

Your Patient Advocate should be someone who knows you, your values and your beliefs. He or she may have to make important health care and/or mental health decisions for you if you are not able to make them for yourself.

- Your Patient Advocate needs to be at least 18 years of age.
- He/she can be a family member, but does not need to be. It should be someone you trust to honor your wishes no matter how difficult the situation may be.
- Your Patient Advocate cannot be your physician, your medical or mental health professional, or any other professionals providing care to you.
- It is important to discuss your medical preferences with your Patient Advocate and your physician(s) so that they will know what you want.
- Your Patient Advocate cannot delegate his or her responsibility to someone else. But you can choose a Successor Patient Advocate in case your first Patient Advocate is not able to fulfill his or her responsibilities.
- Your Patient Advocate and your Successor Patient Advocate must be willing to accept the responsibility that comes with this role. The Patient Advocate Acceptance Form in this booklet needs to be signed by your Patient Advocate and the Successor Patient Advocate.
Selecting Your Durable Power of Attorney for Health Care or Patient Advocate

When you decide to pick someone to speak for you in a medical crisis, in case you are not able to speak for yourself, there are several things to think about. The chart below is a tool to help you decide who the best person is. Usually it is best to name one person or agent to serve at a time, with at least one alternate, or back-up person, in case the first person is not available when needed.

<table>
<thead>
<tr>
<th>DURABLE POWER OF ATTORNEY</th>
<th>Name 1</th>
<th>Name 2</th>
<th>Name 3</th>
</tr>
</thead>
<tbody>
<tr>
<td>Meets the legal criteria in your state for acting as an advocate or representative</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Would be willing to speak on your behalf</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Would be able to act on your wishes and separate his or her own feelings from yours</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lives close by or could travel to be at your side if needed</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Knows you well and understands what’s important to you</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Could handle the responsibility</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Will talk with you now about sensitive issues and will listen to your wishes</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Will likely be available long into the future</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Would be able to handle conflicting opinions among family members, friends and medical personnel</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Can be a strong advocate in the face of an unresponsive doctor or institution</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Communicating With Your Physicians

As you think about these important health care decisions and prepare to fill out the Advance Directive forms, you will want to discuss your thoughts and feelings with your physicians. Be open and honest with your physicians and mental health professionals. They may be able to provide valuable insights that will help you make informed decisions.

You might also want to discuss your decisions with other health care professionals like social workers and spiritual care providers.

What Should I Do With My Advance Directive?

You should make several copies of your completed Advance Directive forms and keep them in many places.

- Give one to your Patient Advocate.
- Give one to your Alternate Patient Advocate(s).
- Keep one in your home where you and your family members can easily find it if you need to go to the hospital or call 911.
- Give one to each of your physicians and/or mental health professionals.
- Keep one in your car.

Review your Advance Directive every time you have an annual physical or whenever one of the Five Ds occurs:

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

Once you’ve completed your Advance Directive, be sure to give a copy to your physicians as well your Patient Advocate.
What If I Change My Mind?

If you ever change your mind about any part of your Advance Directive — including who you name as a Patient Advocate or Successor Patient Advocate — you can change it at any time. Here’s what you should do:

• Complete a new Advance Directive document.

• Write down, sign and date a statement that confirms you are cancelling your previous Advance Directive. In the presence of two witnesses, announce that you are cancelling your Advance Directive and notify your health care provider that it has been revoked.

• Destroy your previous documents and copies.

DON’T GET CONFUSED

Based on a Michigan law passed in 1990, the “Designation of a Patient Advocate” is legally binding and is sometimes called a “Durable Power of Attorney for Health Care.”

Don’t confuse the term “Durable Power of Attorney for Health Care” with the term “Durable Power of Attorney,” which relates to decisions about your financial matters.

Your Patient Advocate named in your Advance Directive for Health Care cannot make any decisions about your finances, unless you choose that same person to make financial decisions on your behalf in a separate legal document.
IMPORTANT TERMS

Allow Natural Death (AND)

This is a choice you can make about how you’d like to spend your final days and hours. If you choose to Allow Natural Death, physicians and health care providers will attend to your spiritual, social and physical needs by providing quality comfort care (excluding aggressive and invasive measures that do not provide comfort) and by encouraging the presence of family, friends and loved ones.

Brain Death

The patient is pronounced dead when the doctor determines that all brain functions that maintain vital life organs have stopped.

Cardiopulmonary Resuscitation (CPR)

An emergency procedure used to attempt to restore heartbeat when the heart and/or breathing has stopped. While this is important in an emergency, there are some situations that could make it ineffective or even undesirable. It is important that you discuss this with your doctor.

Code

An emergency response by a medical team to attempt to revive a patient whose heart or breathing has stopped.

Comfort Care

This is a means of minimizing pain and other symptoms. It includes support of family and loved ones as well as attention to your spiritual, social, emotional and physical well-being. It usually excludes the aggressive and invasive measures that can cause a person more suffering without any real benefit.
**Do Not Resuscitate (DNR) Order**

If you are a patient in a hospital or nursing facility and do not want CPR if your heart should stop, you should talk to your doctor about a DNR order. This order will prevent staff from performing CPR on you if your heart and breathing stop while you are a patient in a facility, but it will not remain active once you leave the hospital or nursing facility. If you wish to have a DNR in place once you are discharged, you must acquire a Michigan Do Not Resuscitate order. (Usually people don’t make this decision until they are ill or frail enough that it would not be a surprise if they were to die in the next 12 months.) It is important to know that a DNR does not mean that you will receive no treatment. You may receive aggressive comfort measures, or other appropriate treatments, when you have a DNR order, if that is your wish.

If you felt that this is the right choice for you because of your medical circumstance, speak to your physician about obtaining a Michigan Do Not Resuscitate Order. Once you have this order, you will be given a paper and possibly a bracelet to wear that will instruct others to not perform CPR on you if your heart and breathing should stop. If your heart and breathing stop and someone calls 911, emergency responders are obligated to treat you unless they see evidence of a Michigan DNR order.

Please speak with your physician regarding this important decision. Also, make sure that your loved ones understand this and do not call 911, but rather, help you have comfort measures in place if your condition should worsen. (It may be helpful for you to have hospice care in place if you are electing this option.) You may also discuss these issues with an advance care planning facilitator or social worker in your local medical center or hospital, or by contacting a local hospice provider.

**Hospice Care**

Care that addresses the physical, emotional, educational, social and spiritual needs of terminally ill patients, their caregivers and families. It provides a compassionate approach to health care when curative measures are no longer an option. Hospice services can be provided by a team of professionals and volunteers in a private home, a nursing home or a hospital.
**Palliative Care**

Specialized medical care for people with a serious illness. Palliative care is focused on providing people with relief from the symptoms, pain and stress of an illness with equal attention to emotional and spiritual well-being. Palliative care is delivered by a team of doctors, nurses and other specialists who work with a person’s primary doctor to provide an extra layer of support. This type of care can be provided at the same time as treatment that is meant to cure a person.

**Persistent Vegetative State (PVS)**

A rare, incurable condition in which the person is unable to speak, think or move purposefully, but breathing and heartbeat continue with periods of apparent wakefulness and sleep.

**Terminal Condition**

A condition caused by an incurable illness or injury in which death may be expected within days or months. Life-sustaining procedures may sometimes be considered as only prolonging the dying process.
We, Mercy Health and Trinity Health, serve together in the spirit of the Gospel as a compassionate and transforming healing presence within our communities.

As a faith-based organization, we believe that human life is a sacred gift from God. All persons, regardless of their medical condition, possess dignity and are worthy of respect, protection and excellent care.

Respect for human dignity and human life demands that we take reasonable care of our lives. Such respect, however, does not mean that we must do everything possible to extend physical life, especially when death is inevitable or when treatments would be too burdensome for the patient. A patient’s values and wishes regarding medical decisions will be honored as long as the request is not contrary to our Catholic church teaching (e.g., assisted suicide).

If there are ever concerns about the patients’ medical decisions, we always value the opportunity to have respectful and compassionate conversations with the patient and/or family to reach a mutually agreed resolution.

For questions or more information, visit MercyHealth.com/ACP