



Making Choices

Planning in Advance for Future Health Care Choices

Information Booklet

BeRemarkable.

All patients will be asked about their choices.

A law, which took effect in December, 1991, requires health care facilities that accept Medicare or Medicaid funding to present patients with information about advance directives on admission to either a hospital or nursing home.

This means that if you have to go to the hospital, even for a simple procedure, someone on the staff will ask you if you have filled out an advance directive. They will also provide written information about your right to refuse medical care.

Life Choices

You make choices on a daily basis – choices about where you want to live, who'll you want to marry, your career, your home, your life.

Perhaps one of the most important choices facing you is your choice for future medical care.

Who decides when enough is enough?

You do. Or at least you should.

You should decide about the kind of care you want or don't want while you are capable of making your own decisions.

Technology has advanced to a point where individuals with little or no hope of recovery can be kept alive indefinitely. For that reason, it's more important than ever for people to express what matters most and what kind of care they would want if they would become unable to make their own decisions.

Think about the kind of treatment you want or don't want, and talk about it with your loved ones and your health care provider. Talking about these issues may not be easy; there may be resistance, even denial. Many people are uncomfortable talking about how they will live at the end of their life.

Yet putting loved ones in the position of having to make decisions for you can also be difficult. Discussing your choices now can help.

Talk about the kind of care you want and then put it in writing.

Imagine...

You are in a hospital's intensive care unit and without warning, you develop a life-threatening illness. Despite the best medical treatment, your physicians believe that it is unlikely you will leave the hospital alive. You are no longer able to interact with anyone. At this point, your heartbeat and respiration can be prolonged for some time through continued use of artificial life support. What would your goals be for medical treatment?

Gifts We Can Give Our Children

It occurred to me that my mother gave me a very loving and insightful gift in my life – namely, careful direction about what to do when she became irreversibly ill and unable to make her own decisions.

During the time in our lives when we were able to discuss this issue, it seemed so far off, but within a few years she was the victim of Alzheimer’s disease. The issue then became very difficult to discuss because of the impairment in her ability to make judgments and decisions, and understand the complexity of her situation. It was necessary, at this point, to become her advocate and rely on the direction she had given me.

The first experience in decision-making occurred when the doctor discussed the “no resuscitation” issue with me.

“We need to know what your mother’s choice would be if her heart should stop,” he stated. She had prepared me for this – the answer was clearly not to initiate resuscitation. There were not many other illnesses along the way that required much decision-making which was fortunate for us. But if there had been, I do think I would have known what she wanted and acted accordingly.

I lost my mom on April 30 – not to Alzheimer’s disease but heart failure.

Amidst the sadness, there was peace. Peace in knowing that many times she had said to me, “No medical intervention when there’s nothing that can be done for me.” I am grateful that I didn’t have to struggle with decisions during that time.

Linda Butterworth’s Story

Imagine...

You are living at a nursing home because your ability to make your own decisions is gone. You can feed yourself and interact, but the meaning of your interaction is minimal because you no longer know who you are, who your family members are or what happens from one moment to another. You will never regain your ability to know who you are or who you are with. What would your goals be for medical treatment?

Knowing the Language

Advance Care Planning

This is a process of coming to understand, reflect on, discuss and plan for a time when you cannot make your own medical decisions. Advance care planning conversations are the best way to make sure your views are respected by your loved ones and health care providers. These conversations will provide great comfort to those who may make health care decisions for you. Advance care planning conversations improve the quality of your advance directive.

Advance Directives

Advance directives are the plans you make for your future health care decisions in the event you cannot make these decisions for yourself.

An advance directive can be completed orally or in writing. Putting your plan in writing helps people accurately remember your plan, makes it easier to communicate to health care providers who do not know you, and provides the possibility for it to be a legal document.

In Michigan, an advance directive lets you appoint the person you want to speak for you and make decisions on your behalf when you're not able to do so. That person is called your Patient Advocate. An advance directive also allows you to write down information about your beliefs, values and treatment preferences, all of which can help your Patient Advocate and your health care providers make the decisions you would want made.

Commonly Asked Questions

Advance Care Planning

How can I talk about these issues with my family?

Plan for yourself first and let your family know what you want. Tell them you don't want them feeling the burden of making the decisions for you.

Who do I talk to?

Talk to those who are close to you and most likely to be involved in decision making if you are very ill. Just because you have a close relationship does not necessarily mean you know what your loved one thinks or wants for future medical care.

What would I talk about?

- 1) Who would make decisions for you and how they would make these decisions?
Make sure whoever you choose to represent you not only knows what you want but is able to make complex decisions in difficult situations.
- 2) Consider what your goals for medical treatment would be if you had a serious, permanent injury to your brain. How bad would such an injury be in order for you to say, "Don't use medical treatments to keep me alive in that state." Many people simply say, "Don't keep me alive if I am a vegetable." If you feel that way, can you describe what it would mean to you to "be a vegetable?"

Do I need to talk with my physician?

You may have questions for your physician that can help you with your decisions. When possible, it is important for you to talk with your physician to make sure your planning is clear, complete, and will be supported by your health care providers.

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Imagine...

You have suffered severe, permanent brain injury. You are totally unconscious of your environment, yourself and others. It is not expected that you will recover the ability to know who you are, or who you are with. With proper medical and nursing care, your heart and other vital organs can be maintained for an indefinite period of time – years or even decades. In this situation, what would your goals be for medical treatment?

About Advance Directives:

When is an advance directive used?

As long as you are capable of making your own decisions, you remain in control of your own medical care. If you're unable to make your decisions, your plans in the advance directive would guide decision making.

Can my advance directive be changed?

Advance directive documents can be changed at any time, as long as you are capable of making decisions. A copy can become part of your medical record. It is important to regularly review and update the plan you create.

What if I am injured or become ill when I am away from home?

The best way to ensure that you receive the type of care you want is to discuss your choices with the person who will represent you, and make sure they have a copy of your advance directive. A wallet card, indicating you have an advance directive, is also available.

What happens in an emergency?

In the event of an emergency, life-sustaining measures may be started, possibly before your medical record is available. Treatment can be stopped if it is discovered that it's not what you would have wanted.

Do I have to have a lawyer to complete an advance directive?

No. The law does not require you to have an attorney. The choice is yours.

If you were in one of the three imaginary situations on the previous pages, what would your goals be for treatment?

- To prolong your life with medical treatments offered by your physicians? These treatments may include an array of medications, surgery, tubes for nutritional support and hydration.
- To make sure you are kept comfortable and maintain the highest level of function possible? Your physician might recommend a wide range of medical approaches. In most instances, comfort can be maintained with medication to control pain.
- In thinking about life-sustaining medical care, you are not judging what other people might want in these situations but what you want.
- Reflect on what's important to you.

Lyle Greiner's Mother was Dying...

As a chaplain, he'd seen death many times, yet, with his own mother, somehow it was different. The family gathered at her bedside, told stories, prayed, sang hymns and grieved.

"It was a marvelous time of family leave-taking," says this gentle bearded giant of a man who looks as though he could have stepped from the pages of "Little House on the Prairie."

"Mother died on Easter morning, just as the sun was coming up," says Greiner. She'd had a massive brain stroke and all brain activity had ceased. She was 75 years old.

The decisions the Greiners had to make during the days between their mother's stroke and her death are the kinds of choices everyone faces eventually. How long should life support be continued when there is no hope for recovery? And if her heart would stop beating, should there be an attempt to revive her? What would she have wanted?

Greiner works in a hospital and is sensitive to those all-important questions. He hears families asking them all of the time. He had, in fact, been talking with his family about recording their advance directives for a year and a half – but they hadn't actually done it.

These are uncomfortable things for some people to talk about under the best of circumstances. Add the emotional stress of a critical health situation, and it's even more difficult.

People aren't speaking the same language in these critical times, says Greiner. Physicians often talk in clinical language, members of the clergy talk in spiritual language, and family members are too emotionally involved to understand.

Thankfully, Greiner's mother had expressed her wishes to her husband. Yet it still took a few days for the family to come to terms with those decisions.

Would an advance directive have helped? "You bet," says Greiner. "Talk about this with your family and then put it in writing."

What if you choose not to have an advance directive?

Without an advance directive, your family physician, hospital – and in some cases a judge – would need to make decisions regarding your future care, should you become unable to make them yourself.

Talk With Your Doctor...

I had a patient with a serious lung disease. His life consisted of moving from his bed to a nearby chair, and even that would leave him short of breath. We talked about what he would want us to do if his lungs failed. Since it was likely he would be totally dependent on a machine for the rest of his life, he refused to consider it as an option.

His wife understood his decision and was very supportive, and his decision was recorded in his medical record as an advance directive.

Six months later, he was brought to the hospital very short of breath; and, without mechanical support, he would clearly die. The physician on duty asked him what he wanted them to do. He, again, said he only wanted to be comfortable, he didn't want assistance from mechanical breathing machines. The physician did not know the patient or his family, so she was not sure if a lack of oxygen was affecting his judgment.

The written advance directive in his chart indicated that his decision was carefully considered by him and his family.

His choices were respected by the medical staff and he died according to his wishes. Discussing his medical care in advance, with both his family and physician, made his final hours less traumatic.

Talk about your concerns, your fears and your decisions with your own physician. It's critically important.

A Physician's Story

Glossary

Antibiotics

Medications used to fight infection (pneumonia, for example).

Cardiopulmonary Resuscitation

A medical procedure involving external chest compression, administration of medications and electrical shock used in an effort to restore the heartbeat.

Dialysis

A dialysis machine is used to cleanse the blood when the kidneys cannot function normally.

Intravenous (IV) Line

A tube placed in a vein that is used to administer fluids, blood or medication.

Nutritional Support and Hydration

Using IVs or tubes to supply food (nutrients) or water when a patient is unable to eat or drink.

Ventilator

A breathing machine attached to a tube that is placed into your windpipe, for persons unable to breathe on their own.

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