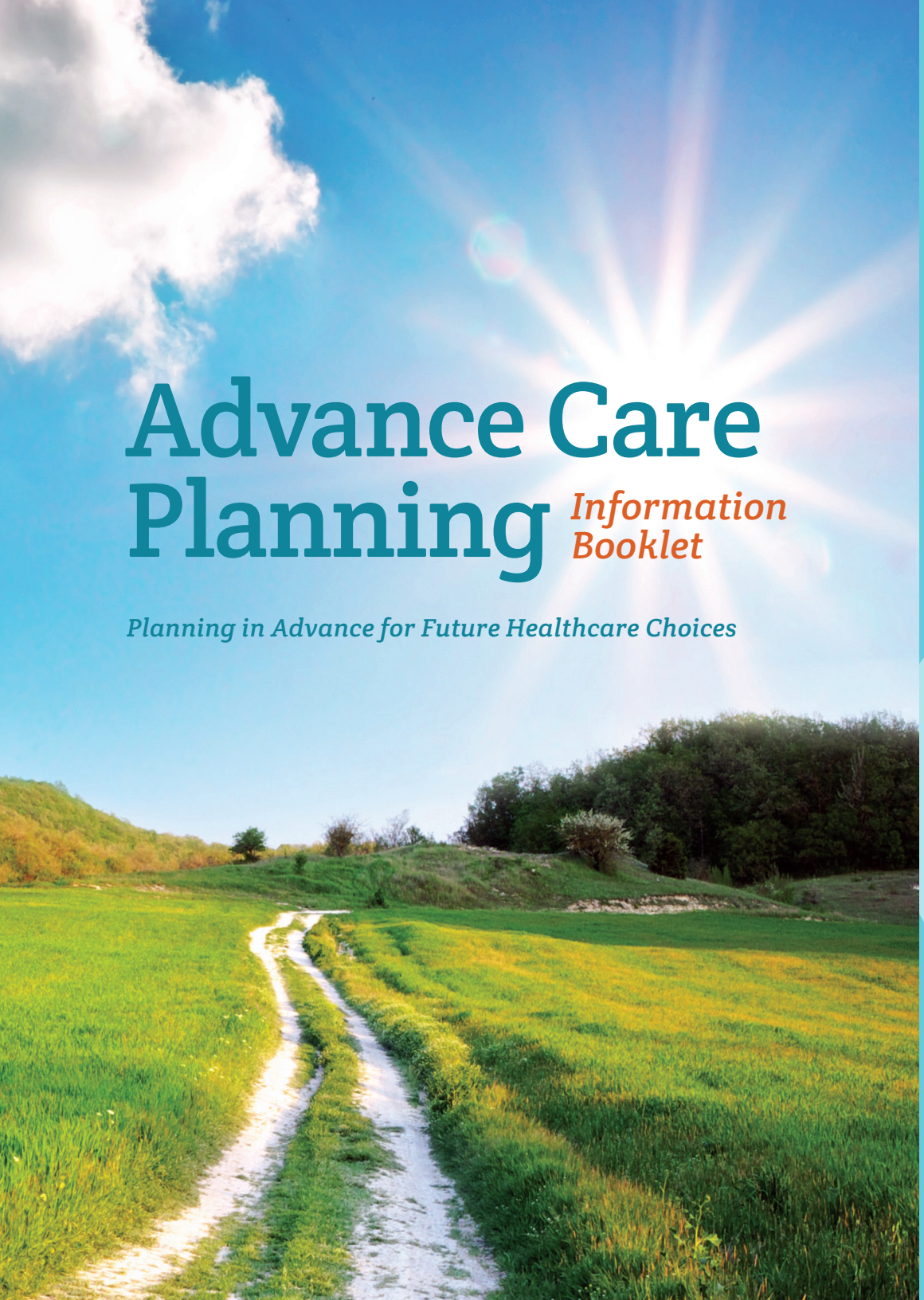
Advance Care Planning *Information Booklet*

Planning in Advance for Future Healthcare Choices



Your Health
Your Choice

Life Choices

Imagine...

You are in an intensive care unit of a hospital. Without warning, you have 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?

You make choices on a daily basis — choices about where you want to live, whom 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.

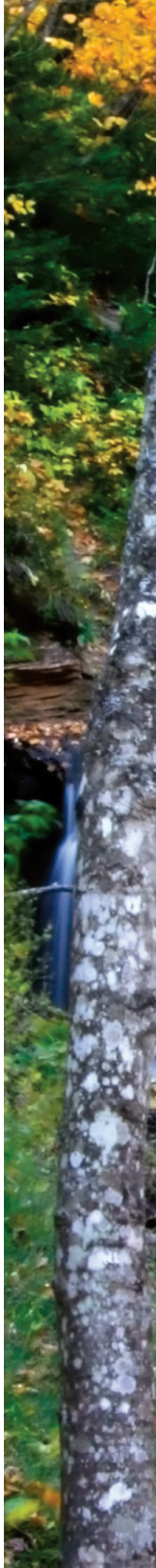
You should decide about the kind of care you want while you are capable of making your own decisions.

Technology today has advanced to a point where patients 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 how they feel 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 would want and talk about it with your loved ones and your healthcare provider. Talking about these issues may not be easy, there may be resistance, even denial. Many people are uncomfortable talking about living at the end of life.

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

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



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 regain any consciousness. 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. (Such a condition is called a persistent vegetative state which may be caused by trauma to the head or lack of blood flow to the brain.)

What would your goals be for medical treatment?

Gifts we can give our children

Imagine...

You are living at a nursing home because you no longer have the ability to make your own decisions. 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 interact and will likely get worse over time. (Such a condition is likely to occur because of a disease like Alzheimer's.)

What would your goals be for medical treatment?

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 are 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, 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 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

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 and are unlikely to recover from your injury or illness. Effective planning is the best way to make sure your views are respected by your loved ones and health providers. This process also will provide great comfort to those who may make end-of-life decisions for you. Good advance care planning improves the quality of your advance directive.

Advance Directives

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

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

When completing a written advance directive, two major choices exist. The first is to appoint someone else to make your healthcare decisions if you are incapable. In many places this type of document is called a power of attorney for healthcare. Typically such a document also allows you to provide written instructions. The second type of document simply provides a narrow set of instructions about care at the end of life. This document is a living will, but is known by many names in different places.

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 physician? 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.

Answers to Commonly

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. Then ask them to tell you what they want.

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 the person 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 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?
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 healthcare providers.

Asked Questions

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 directives can be changed at any time, as long as you are capable of making decisions. If you do fill one out, a copy can become part of your medical file.

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.

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?

All patients will be asked about their choices.

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

That means 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.

Greiner works in a hospital and is sensitive to those all-important questions. He hears families asking them all 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...

Glossary

Antibiotics Drugs used to fight infection (pneumonia, for example).

Cardiopulmonary Resuscitation A medical procedure involving external chest compression, administration of drugs, 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 the windpipe of persons unable to breathe on their own.

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, 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 this 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

For additional information on advance care planning, or to schedule an appointment with a certified advance care planning facilitator to assist you in reviewing and completing your advance directive document, please contact any one of the organizations below.

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Your Health
Your Choice

Your Health Your Choice is provided as a service to the residents of Genesee County. It is a joint effort of the members and partners of the Greater Flint Health Coalition.

GREATER FLINT HEALTH COALITION

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