OSF Care Decisions®

Advance Care Planning Information Booklet

alltogetherbetter

OSF Supportive Care

OSF Supportive Care Vision Statement

OSF will serve all persons facing chronic and/or terminal illness with the greatest dignity and respect by providing supportive care services in a coordinated, timely and compassionate manner in a community of caregivers committed to quality, safety and the value of life based on our Catholic tradition and ethics.

Our Goals

1. You will never be overwhelmed with symptoms.
2. Your care will be continuous, comprehensive and coordinated.
3. You will be provided with whatever information necessary to help you understand your condition and have the opportunity to discuss your condition with your family members and care providers.
4. Your decisions are important and will be sought out, respected and whenever possible, followed.

Our History

Providing care in the home is how OSF's pioneer Sisters began serving communities in Illinois in the 1870's. Initially, without a hospital or office to see patients, they went into the homes in the communities where care was needed. There they provided necessary care as possible, often sitting vigil hour upon hour for many of Peoria's sickest, most contagious residents, who otherwise would have no one to comfort them in time of need. Regardless of the social, economic or religious status of those they served, they provided comfort care for each person until their health returned or until they were called to their Creator.

This was OSF's calling. It was where our Sisters established a reputation of honesty, integrity, rugged determination, compassion and civility, and where surrounding communities embraced their Christian spirit of love and respect as a God-sent blessing.

Serving patients in their homes, our Sisters believed, was serving on sacred ground. Today, some 135 years later, this same belief lives on in our hospitals, physician offices, extended care facilities and in the homes of those we serve, "with the greatest care and love." We provide the very best and most appropriate care, especially at the end of life, with deep respect for our storied history.

What is OSF Care Decisions© and why did I receive this booklet?

OSF Care Decisions© is a program that was developed by the OSF Healthcare System to help patients think about health care decisions that they may need to make in the future. This program supports the belief that all persons should be given the information that they need to make future decisions based on their moral values and spiritual and religious beliefs.

What is advance care planning and how is it different than just completing advance directives?

Advance care planning is much more than just completing advance directives. It means talking with your doctor and family about your current health condition and the care decisions you may need to face in the future. The best time to talk about this is before an illness becomes worse.

What should I talk to my doctor about to help me plan for my care in the future?

You should talk to your doctor about your current health condition and what care decisions your doctor thinks you may need to make as your condition changes over time. Then, when future treatment questions come up, your doctor should tell you about the benefits and burdens of treatment or no treatment in words you understand.

Should I bring my spouse or adult family member to the discussion with my doctor or OSF Care Decisions© facilitator?

Yes. The most important part of advance care planning is the talk that you have with your family and doctor. This will help provide them with the knowledge and confidence they need to make care decisions for you in the future if you are not able to make them yourself. If you already have a Power of Attorney for Health Care Agent (Illinois) or Durable Power of Attorney for Patient Advocate (Michigan) named, this would be the best person to bring with you.

How will advance care planning help me and my family?

Modern technology and new medications have been good for the treatment and cure of disease but sometimes they can cause extra burden for little or no benefit when the disease is advanced and there is no cure. Advance care planning can help you and your family think about how you would want medical technology and medications used during these times based on your personal, religious and spiritual values.

What should I do with my advance directives once they are completed?

In addition to keeping a copy for yourself, give a copy to your Power of Attorney for Health Care Agent (Illinois) or Durable Power of Attorney for Patient Advocate (Michigan), your family members, pastor and doctor. The more you make your family and friends aware that these documents exist, the greater likelihood they will be used when needed.

What are some real life examples that may help me to understand the importance of advance care planning?

John's Story

Five years had passed since John Wilson was diagnosed with a chronic progressive disease. Initially he managed his condition fairly well. He had six children between the ages of 50 and 60 years old. Three lived nearby and three were out of state. His doctor encouraged Mr. Wilson to consider advance care planning but he refused, saying his children could speak for him if the need should arise. During his last year he experienced several hospitalizations and spent many days in the intensive care unit. One day he was brought into the emergency room unconscious with severe problems. Three days later he remained unresponsive and unable to make decisions for his care. His children all arrived at the hospital, but could not agree on the care decisions their dad would have made. One month later he died while still in the intensive care unit. The family remained at odds during this entire time, and even at his funeral would not sit together or speak to each other. Mr. Wilson would have been distressed if he had known the effect on his family of not having an advance care plan.

Jill's Story

Jill Jackson was diagnosed with an aggressive form of cancer. She had no children and was widowed. On one of her visits to her oncologist, she took her brother and sister-in-law. Together they discussed her prognosis and treatment options with the oncologist, and began a discussion about what her care wishes were for the future. Over the next month she continued these discussions with her family and physician. She completed her Power of Attorney for Health Care form and named her brother as her Health Care Agent. She was admitted to the hospice program and the hospice team worked closely with her physician to manage her care. She continued to decline over the next few months and was admitted to the hospital a few days before she died. Her family was at her bedside and pastoral care provided them with spiritual support. Although Jill was unresponsive the last 48 hours of her life, her care decisions were followed. The family was a peace knowing the care Jill received was exactly what she would have wanted.

"The family was at peace knowing the care Jill received was exactly what she would have wanted."

Jackie's Story

Jackie Stone was a healthy 41-year-old woman on her way to work one day when a car attempting to pass from the other direction hit her vehicle head on. She arrived in the emergency room in critical condition. Her husband and two daughters arrived at the hospital to find her in intensive care and unconscious with severe injuries. Over the next two weeks they were faced with many difficult care decisions. Jackie did not have any advance directives and had not talked to her family about decisions she would want in a condition such as this. Consequently, the family struggled with each care decision they had to make for her. At the family's request, a hospital ethics committee consult was provided to help the family make these difficult decisions. Not only did the family have to deal with the stress of Jackie's critical condition but also with the stress of whether or not they made the health care decisions she would have wanted.

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Can I change my mind about who I want as my Power of Attorney for Health Care Agent or Durable Power of Attorney for Patient Advocate?

Yes. You may change your mind at any time and sign new documents. If you do this, you should remember to have old copies destroyed and new copies distributed.

If I have a Power of Attorney for Health Care form filled out, will it stop me from being resuscitated if my breathing or heart stops when I am in the hospital?

No. A Power of Attorney for Health Care form is not the same as a Do Not Resuscitate (DNR) doctor's order.

Do health care providers have to follow my advance directives?

Yes, if they meet state law requirements and are not against the provider's ethical and religious standards for care. For example, a Catholic hospital will not agree to a directive like physician-assisted suicide.

What do the terms mean that are used when describing advance care planning and care options at the end of life?

See the glossary in this document for the definitions of commonly used terms. If you still have questions, please ask your doctor or call an OSF Care Decisions© facilitator in your area as listed at the end of this document.

Glossary

These definitions are meant to help you understand these terms. They are not legal or medical definitions, but general descriptions.

OSF Care Decisions: An advance care planning program to help patients plan for health care decisions they may need to make in the future. It includes using facilitators to help you identify what is important in your life and what your spiritual and religious beliefs and moral values are before making these decisions.

Advance Care Planning: A process of discussion that allows a person to think about their health care in the future. It considers the person's current health, along with their beliefs and values, and how their health may change in the future.

Advance Directives: These are the legal documents that can be prepared to help guide care in certain circumstances. Directives may be developed by a person, and can be stored and retrieved by those who need to know about them.

Power of Attorney for Health Care (Illinois) or Durable Power of Attorney for Health Care (Michigan): This is a legal document that allows you to appoint a person you know and trust as your Health Care Agent (Illinois) or Patient Advocate (Michigan) to make medical decisions for you if you become temporarily or permanently unable to make these decisions yourself.

Living Will: This is a type of advance directive that only applies if you are terminally ill or permanently unconscious. It is very limited and typically only tells the doctor what you do not want. It is not the same as a DNR order.

DNR: Do Not Resuscitate. This is a signed doctor's order to not perform CPR. For some patients with certain medical conditions, it is known in advance that CPR will not be successful or it may leave them worse off.

Palliative Care: Specialized medical care for people with serious illnesses. This type of care is focused on providing patients with relief from the symptoms, pain, and stress of serious illness – whatever the diagnosis or treatment.

Surrogate Agent: In Illinois, this is someone who is named to make decisions for another who has not completed a Power of Attorney for Health Care and cannot make decisions for themselves. This agent is usually a next-of-kin family member but can be a state-appointed person called a guardian. This practice is similar in Michigan although the term surrogate agent is not used, and if a family cannot agree on a decision, the health care provider may ask the court to appoint a guardian.

Hospice: Specialized health care for persons of all ages who have a life-limiting illness, a doctor's prognosis of six months or less to live, and a goal of symptom management without life-prolonging or curative disease treatment.

Hydration: Giving fluids. This could be drinking by mouth or giving fluids by IV or other means such as feeding tubes.

Proportionate (Ordinary): A distinction that helps guide treatment decisions. Catholic moral teaching says that all persons should use ordinary and proportionate means to preserve life when medical treatment offers a reasonable hope of benefit that outweighs the risks or burdens of the treatment. (For example, being on a ventilator or machine for 2-3 days to help you breathe so you can recover from pneumonia would be described as proportionate or ordinary treatment.)

Disproportionate (Extraordinary): A term used to describe medical treatment that does not offer a reasonable hope of benefit or has risks or burdens that exceed any possible benefit. (For example, continued chemotherapy for a patient in the end-stages of cancer that may not offer further benefit yet causes excessive fatigue and nausea could be described as disproportionate or extraordinary.)

Where do I get further advance care directive information and forms?

Illinois

You can get the State of Illinois advance directive information forms by going to:

www.idph.state.il.us/public/books/advin.htm

Michigan

You can get the State of Michigan advance directive information and forms by going to:

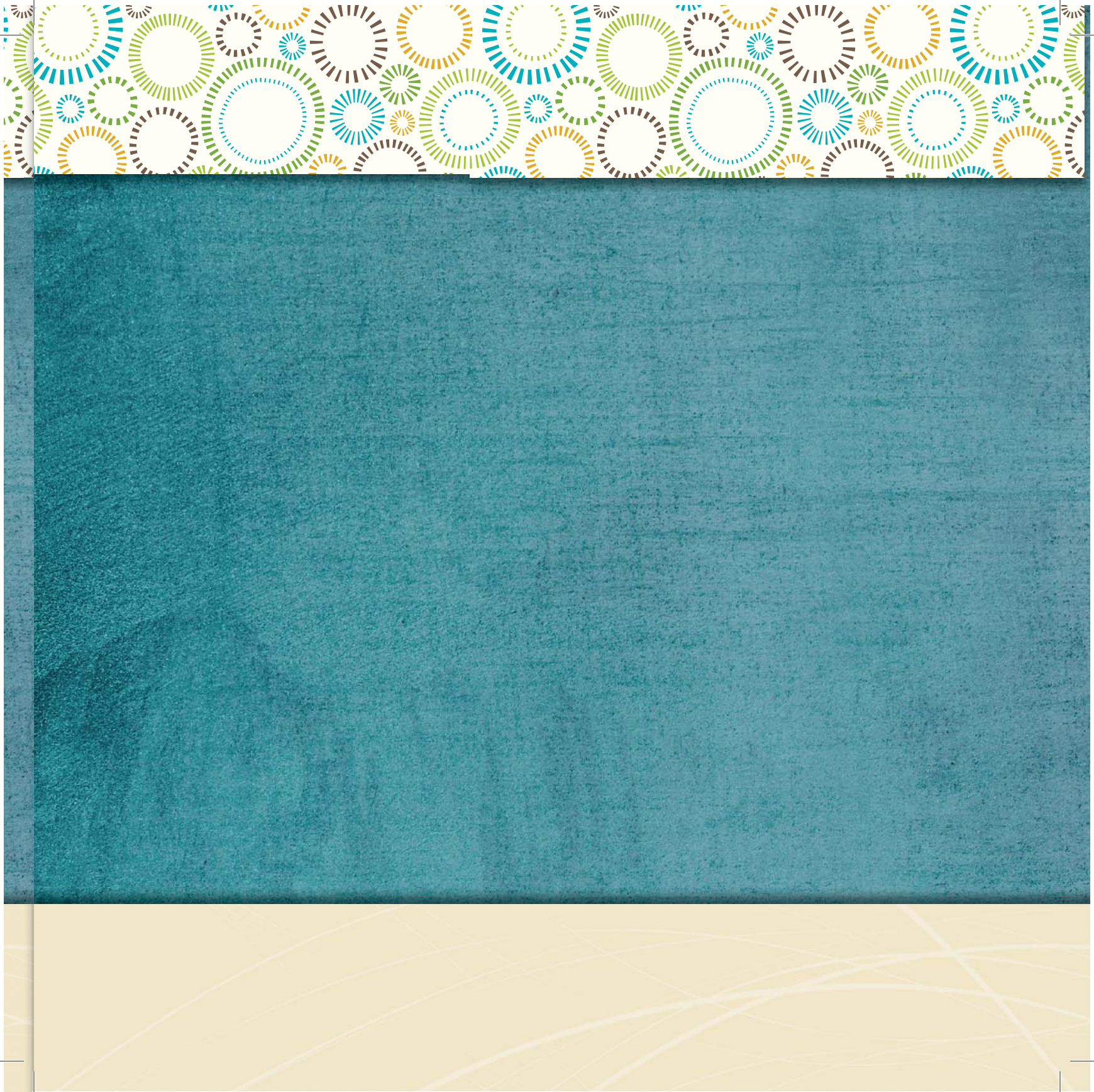
http://www.michigan.gov/miseniors

Other web sites with information about Advance Care Planning:
http://www.osfhealthcare.org/supportive-care/
http://www.supportivecarecoalition.org/
www.chausa.org/advancedirective

Prayer of St. Francis of Assisi

Lord, make me an instrument of Thy peace; where there is hatred, let me sow love; where there is injury, pardon; where there is doubt, faith; where there is despair, hope; where there is darkness, light; and where there is sadness, joy.

O Divine Master, grant that I may not so much seek to be consoled as to console; to be understood as to understand; to be loved, as to love; for it is in giving that we receive, it is in pardoning that we are pardoned, and it is in dying that we are born to eternal life.



Who do I contact if I would like more information about getting assistance with advance care planning locally?

You can get information about how to get assistance with advance care planning in your local area by calling the number below and asking to talk to an OSF Care Decisions© Facilitator.

Local Contact Information: