

A tropical beach scene with palm trees and a double rainbow over the ocean. The sky is a mix of blue and grey, suggesting a recent rain. The palm trees are dark silhouettes against the lighter sky. The rainbow is vibrant and spans across the middle of the image.

CARING CHOICES:

*A Guide to End-of-Life
Decisions and Care*

When people begin to address their needs for end-of-life care, they find they have many important decisions to make. These decisions are often hard ones. This guide is designed to help you to:

- **Think about what you want;**
- **Ask for what you need;**
- **Understand some of the steps to make sure you receive the care you desire.**

This guide is dedicated to the people in the Michigan communities of Muskegon, Detroit, and Sault Ste. Marie. We are indebted to those who generously shared their personal stories, thoughts, and feelings to help write this guide.

Produced by the Michigan Partnership for the Advancement of End-Of-Life Care, a collaborative effort by healthcare organizations dedicated to improving the quality of end-of-life care. The Partnership is managed by Penny Murphy, RN, MS, CRNH, of the Michigan Hospice & Palliative Care Organization and Karen Ogle, MD, of Michigan State University. Brad McKinney, MPH, MSW, serves as the Partnership's project director. This guide was developed by a project team led by Mary Raymer, MSW, ACSW.

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Caring Choices:

A Guide to End-of-Life Decisions and Care

As an illness progresses, a person's need for care increases. Although it might not always seem so, there are choices to be made about what that care should consist of. The kind of care you need and want is up to you.

One option is comfort care. Comfort care, also known as palliative care, offers people a way to control their pain and other symptoms even when it is no longer possible to cure the disease that causes those symptoms.

Comfort care *does not* mean giving up hope or doing without care you are entitled to. Even when an illness cannot be cured, you still have reason to hope for good things to come out of this time of your life. Comfort care helps you live your life as fully as you can while providing respectful care that follows your wishes.

People are different and each of us will choose to deal with a serious illness at the end of life in our own way. Some will want to talk about how they are feeling while others will not. Some will seek out treatments that others decide to do without. There are no right or wrong answers.

Care at the end of life is very personal and people's needs will differ. But there are some common questions and concerns that everyone faces. This guide is designed to help you think about these issues and the choices you can make.

Thinking about your Decisions

It can feel overwhelming to think about all the decisions that need to be made during a serious illness. In figuring out how you will make those choices, it may be helpful to answer the following questions first:

- **What is most important for me and my family now?**
- **What help do I need to reach my goals?**
- **Who are the best people to ask for support among my community?**
- **Who are the best people to answer my questions in my community?**

“You think you’re doing a good job taking care of your parents, but you’re not doing as good as you think. I needed qualified people to come in and help me and I didn’t know where to go. I guess the help is out there but where do you go to find out about it?”

Maria

No Matter Who You Are

All of us are different and will have our own wishes for care at the end of life. But we also have many common needs during this difficult time.

Regardless of where you come from, where you are living now, who is providing your care, or how much money you have, you have a right to expect care that is respectful of your wishes, needs and decisions:

- You have a right to care that respects you and your family’s traditions, beliefs, and rituals.
- You have a right to accept or refuse any medical treatment.
- You have a right to have questions answered by your healthcare providers.
- You have a right to be informed of all your options for care.
- You have a right to care that controls uncomfortable symptoms like pain or anxiety.

“Look, this is my life, sick or not, and I want to make the most of it in my own way. Basically, I don’t want anyone telling me what to do – they’ll get their own turn.”

Oscar

Getting the Support You Need

It is very hard to face the fact that a serious illness cannot be cured. For that reason, people often put off thinking about palliative or comfort care as an option. But people who choose comfort care usually find that they receive the help and support they need from those who care for them.

Family

Family and friends who are closest to you will probably be your first line of support. It is important for you to honestly tell them what your needs are. And just as important, you need to allow them to say how much help they feel able to offer. You can ask the people close to you to:

- Help you learn the best ways to find comfort and do the things most important to you at this time of your life.**
- Help you make decisions if you ask.**
- Honor your wishes even if they disagree with them.**
- Continue to honor your wishes if you can't speak for yourself.**
- Help you by taking care of their needs and concerns and avoid being overwhelmed.**

Healthcare Providers

Healthcare providers like doctors, nurses, healers, social workers, or spiritual counselors will work with you to relieve physical and emotional symptoms when you are seriously ill.

When you speak with these health professionals there are some important things for you to keep in mind:

- Think in advance about the concerns and questions you have for your healthcare team. Write them down so you can raise those issues if your provider doesn't bring them up. It can also help to bring a family member or friend who is prepared to raise your concerns.
- Your healthcare providers need to know what you're really feeling in order to help, so be as clear as you can about your symptoms. It's hard to get the help you need if you try to be a "good patient" by downplaying how you feel.
- Pain is a very common symptom and one that your health providers are trained to address. But they can't help with pain unless they hear about it from you. They will not see you as weak or complaining because you talk about your pain.

"When I go to the doctor I feel rushed - I forget the questions I wanted to ask. I can't hear him very well sometimes and I feel like I just shouldn't bother him."

Josephine

- **It's OK to be assertive with your providers. Ask questions or raise concerns until you get a complete answer. Doing so will help your providers care for you.**
- **Share what is important to you so your health providers can respect your decisions and beliefs.**

Some people are not sure what to ask their healthcare providers. Here are some questions you might think about asking:

- **What is likely to happen with my disease?
What changes can I expect over time?**
- **Rather than trying to cure my disease, is comfort care a good choice at this time?**
- **Can the pain and discomfort caused by my illness and by additional medical treatments be controlled?**
- **If my family has questions about my care, who can answer their questions?**
- **What help is available for my family?**

Finally, bear in mind that over time your needs may change. It's important to let your family and healthcare providers know about your changing needs.

Making Your Wishes Known

As you think about the type of care you want, it is important to share your wishes with your loved ones and healthcare providers.

When you share your concerns and wishes, you give your family and healthcare professionals the information they need to make decisions if you become unable to do so. The people who care for you will not have to guess what you would want done.

It is important that you share this information with your loved ones and healthcare providers in writing. Having a clear, written record of what you do and do not want helps ensure that those responsible for your care will act according to your wishes.

With all of this in mind, there are two important steps you can take to make sure your choices are followed:

- **Select a trusted relative or other person to make medical decisions for you if you become unable and sign a document that names that person your *patient advocate*.**

“When I was a kid my elders never said a word. I don’t want to burden my children – they’re so busy. But my transition time is coming and I want them to be prepared so they are comfortable with me when I go.”

Sam

- Create a written *medical directive* (sometimes called a *living will*), which contains your choices about what medical care you do and do not want.

It is a good idea to talk about these decisions before the need is urgent or you are under great stress. Remember that you can always change your decisions in a new written document if you feel the need to do so. Your patient advocate and medical directive will be used only when you are unable to speak for yourself.



Phrases You Might Hear

When talking with your healthcare team and family, you may hear some unfamiliar words or phrases:

Quality of Life – Rather than length or quantity of life, this term refers to *how* you want to live. It often refers to your ability to participate in the activities that are most important to you.

Palliative Care – Also known as comfort care, this is care that helps relieve pain and other symptoms and focuses on a patient's quality of life.

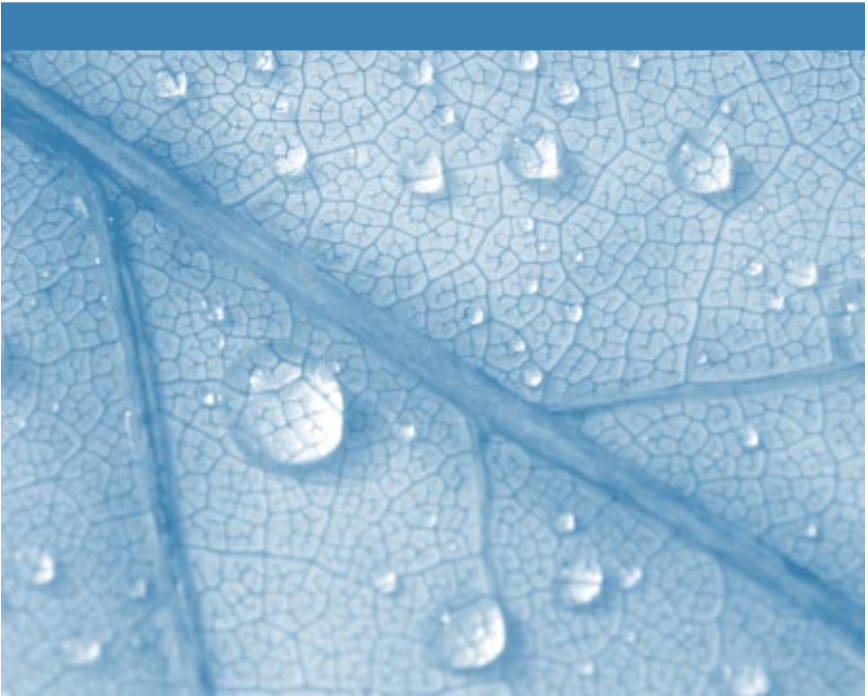
Hospice Care – A type of palliative care that offers a wide range of services to individuals and their families facing a life-limiting illness. Hospice services may be offered in the home, in nursing facilities, in hospitals, or in a hospice residence.

Living Will or Medical Directive – This is a document in which you state your choices about what medical care you do and do not want.

Durable Power of Attorney for Health Care - This document names a person you select to be your patient advocate and allows that person to make healthcare decisions for you if you become unable to.

Psychosocial Care - Care that addresses the emotional, social, and family relationship aspects of illness, loss, and dying. Social workers, psychologists, psychiatrists, or counselors may offer psychosocial care.

Spiritual Care - Care that addresses the spiritual and/or religious aspects of illness, loss, and dying. Traditional healers, pastors, priests, rabbis, imams, chaplains, or volunteers trained in spirituality and religion may offer spiritual care.



Where to Turn for Information

In addition to your family, friends, and healthcare providers, there are many resources to draw upon for help with end-of-life care and decision-making. Here is a sampling of people and organizations within your community and across the state and nation that are available to assist you:

Statewide and National Resources

- ◆ **Michigan Hospice & Palliative Care Organization** – Can answer questions about hospice and palliative care, and help you contact hospice programs in Michigan. Offers a free guide to hospice services. They can be reached at 517-886-6667 or 1-800-536-6300, or www.mihospice.org
- ◆ **National Hospice & Palliative Care Organization** – Can help you contact hospice programs in states outside Michigan. They can be reached at 1-800-658-8898 or www.nhpco.org
- ◆ **Last Acts** – Offers a wide variety of patient and family resources about end-of-life care, and connections to other statewide and national organizations. They can be reached at www.lastacts.org

- **Partnership for Caring** – Offers material and support to patients and families and operates a crisis and information hotline. They can be reached at 1-800-989-9455 or www.partnershipforcaring.org
- **American Pain Foundation** – Offers resources for patients and families regarding pain control. They can be reached at 1-800-492-3805 or www.painfoundation.org
- **American Association of Retired Persons (AARP)** – Offers information about long-term care, end-of-life care, and grief and loss. They can be reached at 1-800-424-3410 or www.aarp.org/lifeguide

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