

Hospice & End-of-Life Care Information Guide

The purpose of this guide is to help you find information and support on hospice and end-of-life care. This guide provides links and references to reliable and current information sources for patients, families, and caregivers.

Many of these materials are available to purchase through online resources, or to borrow at your public library.

Brochures and Fact Sheets

- Aging with Dignity. Five Wishes and Next Steps Guide.
 May be ordered for a fee online at: http://agingwithdignity.org/5wishes.html
- American Society of Clinical Oncology (ASCO). Advance Cancer Care
 Planning. Also available online at:
 http://cancer.net/sites/cancer.net/files/advanced_cancer_care_planning.pdf
- Hospice Foundation of America. Caring for Someone Who is Dying.
- Hospice Foundation of America. Choosing Hospice: A Consumer's Guide.
- Michigan Department of Community Health. An Information Resource Guide to End of Life Care. Printable version available at: http://michigan.gov/documents/End_of_Life_Resource_Guide_51281_7.pdf
- National Cancer Institute. Coping with Advanced Cancer. Printable version available at:
 https://www.cancer.gov/publications/patient-education/advancedcancer.pdf
- National Cancer Institute. When Someone You Love Has Advanced Cancer.
 A printable version is available at:
 https://www.cancer.gov/publications/patient-education/When-Someone-You-Love-Has-Advanced-Cancer.pdf

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- National Institute on Aging. End of Life: Helping with Comfort and Care.
 http://www.nia.nih.gov/health/what-end-life-care
- Next Step in Care. Family Caregiver's Guide to Hospice and Palliative Care.
 Available online at:
 http://nextstepincare.org/uploads/File/Guides/Hospice/hospice.pdf
- University of Michigan Health Systems. Living Wills and Durable Powers of Attorney for Health Care.
 https://www.uofmhealth.org/patient-visitor-guide/advance-directives

Books

- Bell, Karen Whitley. Living at the End of Life: A Hospice Nurse Addresses the Most Common Questions. New York, NY: Sterling Publishing Co., 2010.
- Berkley, Benjamin. My Wishes: Your Plan for Communicating and Organizing the Essential Information Your Family Needs. Naperville, Ill.: Sphinx Pub., 2006.
- Brody, Jane E. **Jane Brody's Guide to the Great Beyond: Prepare Now for a Smooth Ride to the End of Life.** New York, NY: Random House, 2009.
- Callanan, Magige and Kelley, Patricia. **Final Gifts: Understanding the Special Awareness, Needs, and Communications of the Dying.** New York, NY: Simon and Shuster, 2012.
- Dolan, Susan and Vizzard, Audrey. The End of Life Advisor: Personal, Legal, and Medical Considerations for a Peaceful, Dignified Death. Outskirts Press, Inc., 2013.
- Emmert, S. D. **The Consumer's Practical Guide to Funerals, Burials & Cremation** (Five star special ed.). Baltimore, Md: American Literary Press, 2005.
- Gawande, Atul. **Being Mortal, Medicine and What Matters in the End.** New York, NY: Metropolitan Books, 2017.

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- Halifax, Joan. Being with Dying: Cultivating Compassion and Fearlessness in the Presence of Death. Boston, MA: Shambhala Publications, 2008.
- Keeley, Maureen, P.: Yingling, Julie. **Final Conversations: Helping the Living and the Dying Talk to Each Other.** Acton, MA: VanderWyk & Burnham, 2007.
- Kessler, David. The Needs of the Dying: A Guide for Bringing Hope,
 Comfort, and Love to Life's Final Chapter. 10th Anniversary Ed. New York,
 NY: Harper, 2007.
- Smith, Fran. Changing the Way We Die: Compassionate End of Life Care and the Hospice Movement. Berkeley, CA: Viva Editions, 2013.
- Smith, Scott Taylor. When Someone Dies: The Practical Guide to the Logistics of Death. New York, NY: Scribner, 2013.
- Volandes, Angelo E. **The Conversation: A Revolutionary Plan for End-Of-Life Care.** New York, NY: Bloomsbury, 2015.

Audiovisual Resources

• Aging with Dignity. **Five Wishes.** Tallahassee, FL: Aging with Dignity, 2000. 25—minute DVD.

Web Resources

 Cancer.net. End-of-Life Care http://cancer.net

Select **Coping with Cancer**. This section provides detailed information on Palliative Care, preparing for the end-of-life, advanced directives, understanding CPR and DNR, and care during the final days.

CaringInfo

http://caringinfo.org

This site, a program of the National Hospice and Palliative Care Organization, provides a variety of free resources on topics such including advance care planning, caregiving, pain, financial issues, hospice, palliative care, and grief and loss. Printable versions of state-specific advanced directives, documents, and instructions are available for free on the site.

Center for Practical Bioethics

https://practicalbioethics.org

Includes resources to guide you, your family, and your friends through the process of advance care planning.

• Conversation Project

http://theconversationproject.org

The Conversation Project is dedicated to helping people talk about their wishes for end-of-life care. This helps people to share the way they want to live at the end of their lives.

HospiceDirectory.org

http://hospicedirectory.org

This site, sponsored by the Hospice Foundation of America, lets you search for nearby hospice care. Some information about hospice is also included.

Hospice Foundation of America

http://hospicefoundation.org

This site offers extensive information for people and caregivers facing death, including signs of approaching death, pain, patient comfort, paperwork, and logistics after a death in the family. Users may also locate local hospice providers and support organizations on the site.

Michigan Hospice & Palliative Care Organization (MHPCO) http://mihospice.org

This site offers extensive information relevant to people with a life limiting illness and their families. An interactive map helps users to locate hospice providers in their area. Each listing includes the name, address, phone number, and a description of the services provided by each hospice program.

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National Hospice and Palliative Care Organization http://nhpco.org

This site provides information, education, and resources about Hospice.

PREPARE

https://prepareforyourcare.org

PREPARE is a program to help with Advance Care Planning. PREPARE can help you:

- o Make medical decisions for yourself and others
- o Talk with your doctors
- o Get the medical care that is right for you

Disclaimer: This document contains information and/or instructional materials developed by Michigan Medicine for the typical patient with your condition. It may include links to online content that was not created by Michigan Medicine and for which Michigan Medicine does not assume responsibility. It does not replace medical advice from your health care provider because your experience may differ from that of the typical patient. Talk to your health care provider if you have any questions about this document, your condition or your treatment plan.

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