Advocating for Your Best Healthcare

Resources for Individuals and Families When Facing Challenging Healthcare Decisions

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Goals

- Provide resources and information to allow individuals and their family members to be able to advocate for their best healthcare, no matter where a person is in their healthcare journey:
  - Share information on different types of home health care options
  - Provide an overview and resources on the different types of advance directives to make certain your healthcare wishes and options are understood and followed
  - Share helpful tips on how to discuss your healthcare preferences with your providers to ensure your wishes are followed

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Healthcare in Your Home

It can be confusing when referring to the different types of healthcare that can be provided in your home. There are two primary types of care:

Non-Medical Care

Non-medical care includes assistance with activities of daily living—things like bathing, dressing, meal preparation, transportation to and from appointments, running errands, shopping and housekeeping. It's provided by home care aides and home makers. This is also known as Home Care or Private Duty Care.

Medical Care

This type of home health care—often called skilled care—is provided by licensed medical professional, such as a registered nurse or physical therapist. Services they could provide include nursing care, and physical, occupational and speech therapy. Other potential services include patient and caregiver education, injections and nutrition therapy. Medical home health care is prescribed by a doctor.

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Healthcare in Your Home

Non-medical home healthcare includes the following types of care:

- Home Care (Private Duty Care)—Home Care, also known as Private Duty Care, aims to help maintain a person's ability to stay in their home comfortably and offer a break to other caregivers. It is typically provided to individuals who require assistance with their day-to-day activities. Their staff assist with housekeeping, meal preparation, and offering companionship to those who need additional assistance to remain safe and comfortable in their own homes.

Home Care or Private Duty Care is not covered by Medicare and is typically paid for by the client. If a person has a long-term care insurance policy, it may be used to cover the cost of private duty care in the home, depending on the terms of the policy.

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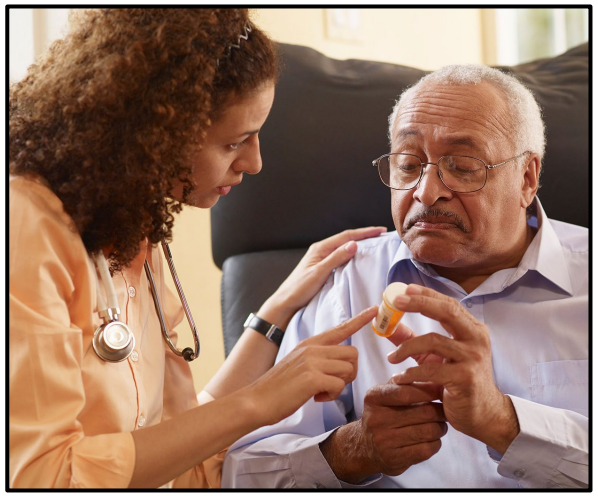
Healthcare in Your Home

Medical home healthcare include the following types of care:

Home Health Care—Home Health Care provides a wide range of skilled healthcare services in your home by licensed healthcare professionals for an illness or injury. Home health care is usually less expensive, more convenient, and just as effective as care you get in a hospital or skilled nursing facility.



These services may include, but are not limited to:

- Wound care for pressure sores or a surgical wound
- Patient and caregiver education
- Intravenous or nutrition therapy
- Injections
- Monitoring serious illness and unstable health status, including labs
- Physical, Occupational, Speech Therapy
- Medical Equipment, if needed

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Healthcare in Your Home

In general, the goal of home health care is to treat an illness or injury. Home Health Care helps you:

- Get better
- Regain your independence
- Become as self-sufficient as possible
- Maintain your current condition or level of function

To be eligible for Home Health Care services, you need to be considered “homebound”, which means you have trouble leaving your home without help because of an illness or injury or isn’t recommended because of your condition.

Home Health Care services does not cover 24-hour-a-day care at your home or homemaker services that aren’t related to your care plan.

Medicare, Medicare Advantage and most insurance plans will cover Home Health Care services. A doctor’s order is needed to begin care.

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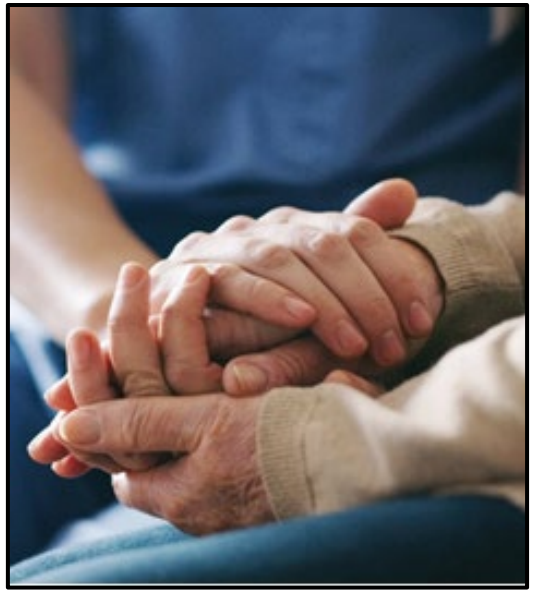
Healthcare in Your Home



Palliative Care—Palliative Care is specialized medical care for people living with a serious illness. Someone in palliative care may receive medical care for their symptoms, along with treatment intended to cure their serious illness. Palliative care is meant to enhance a person's current care by focusing on quality of life for them and their family.

Palliative care can be helpful at any stage of illness and is best provided soon after a person is diagnosed. In addition to improving quality of life and helping with symptoms, palliative care can help patients understand their choices for medical treatment. The organized services available through palliative care may be helpful to anyone having a lot of general discomfort and disability during their healthcare journey.

Insurance will usually cover Palliative Care as a physician expense or as a home health care expense, depending on the billing.

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Healthcare in Your Home

Hospice Care—Hospice care focuses on the care, comfort, and quality of life of a person with a serious illness who is approaching the end of their healthcare journey. At some point, it may not be possible to cure a serious illness, or a person may choose not to undergo certain treatments. Hospice is designed for this situation. Hospice provides comprehensive comfort care and support for the family but attempts to cure the person's illness are stopped.

Hospice is provided for a person with a terminal illness whose doctor believes he or she has six months or less to live if the illness runs its natural course. Hospice is an approach to care. It is not tied to a specific place. It can be offered in multiple of settings — at home or in a facility such as a nursing home, hospital, or hospice house.

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Healthcare in Your Home

It's important for a person to discuss hospice care options with their doctor. Sometimes, people don't begin hospice care soon enough to take full advantage of the help it offers. Perhaps they wait too long to begin hospice and they are too close to death. Starting hospice early may be able to provide months of meaningful care and quality time with loved ones.

Hospice care brings together a team of people with special skills — among them nurses, doctors, social workers, spiritual advisors, and trained volunteers. Everyone works together with the person who is dying, the caregiver, and/or the family to provide the medical, emotional, and spiritual support needed.

A member of the hospice team visits regularly, and someone is available by phone - 24 hours a day, seven days a week. Hospice is covered by Medicare and Medicaid at 100%, and other insurance companies often have hospice benefits included in coverage.

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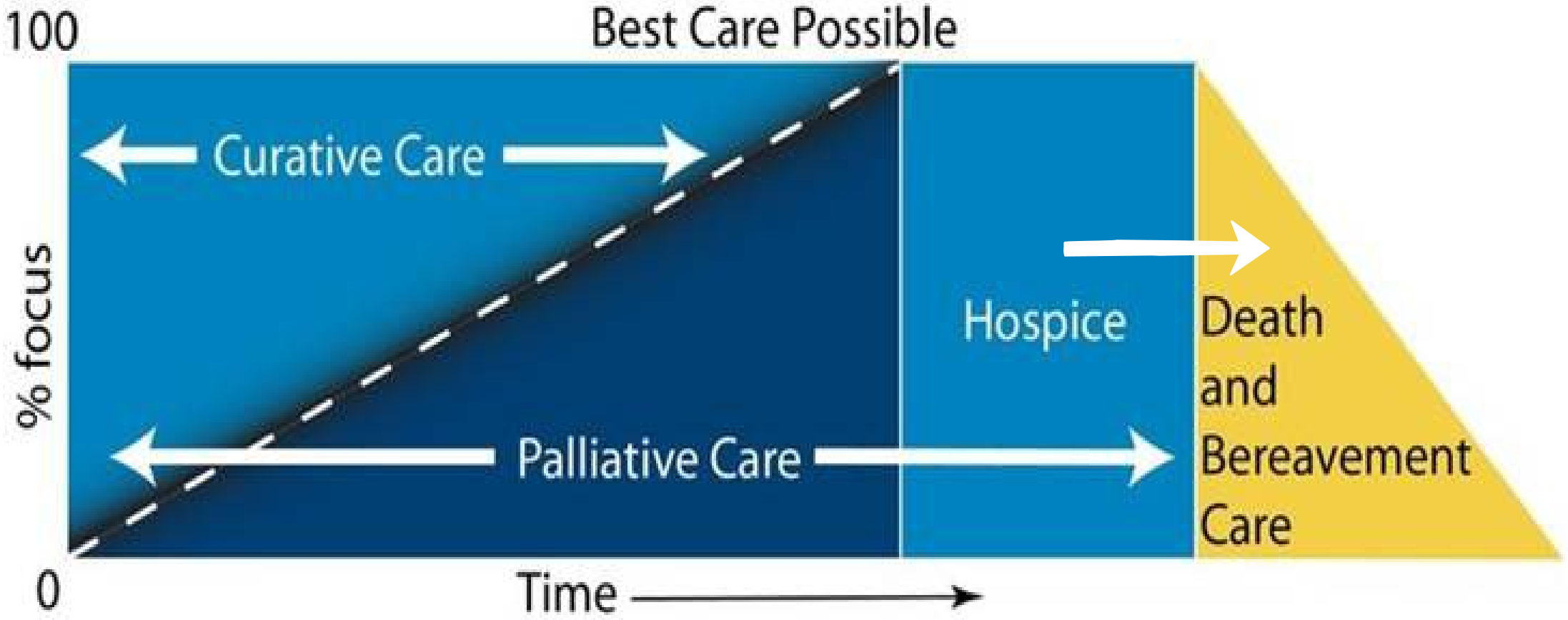
Hospice and Palliative Care

To clarify the relationship between Hospice Care and Palliative Care, the image below provides a good explanation:



Overview of In-Home Care

Services	Home Care (Private Duty)	Home Health	Palliative Care	Hospice
Eligibility Requirements	None	Prognosis not required	Prognosis varies by agency, usually life-defining illness	Prognosis required: 6 mo if the illness runs its usual course
	Skill need not required	Skill need not required	Skilled need not required	Skilled need required
Plan of Care	None required	Restorative care	Quality of life & defined goals	Quality of life & defined goals
Length of Care	Unlimited	Limited, with requirements	Variable	Unlimited
Homebound	Not required	Required, with exceptions	Not required	Not required
Disease- Specific Programs	Variable	Variable	Variable	Depends on the Agency
Medications Included	X	X	X	✓
Equipment Included	X	X	X	✓
After-Hours Staff Availability	Scheduled	X	X	✓
RT/PT/OT/Speech	X	✓	X	Depends on the Agency
Nurse Visit Frequency	Limited, if available	Limited, based on diagnosis	Variable	Unlimited, depends on agency
Levels of Care	1	1	1	4
Bereavement Support	X	X	X	✓

What is an Advance Directive?

- An advance directive is a patient's written legal instructions to a healthcare provider(s) that describes their wishes for medical care if they are no longer able to make decisions for themselves because of illness or incapacity.

- In completing your advance directive, it is important to have conversations with your medical provider(s) about your healthcare decisions. This conversation is often called a ***Goals of Care Conversation***, and you can schedule this with your provider to make sure that your future treatment decisions are aligned with your wishes, values and beliefs for your care now and in the future. They are also important to make sure that you get the support you need throughout your care, including access to palliative care when the time is right.

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Advance Directives Specifics

- You do not need an attorney to complete an advance directive as long as approved, state-specific documents are utilized.
- If you wish to consult a lawyer, an elder law attorney specializes in advance directives.
- State specific documents are available at www.CaringInfo.org
- Advance directives become legally valid as soon as a person signs them in front of the required witnesses. Some states additional require a notary.
    - Kansas requires two witnesses
    - Missouri requires a notary.
- Advance directives do not go into effect unless a person is unable to make his/her own decisions
- Advance directives can be revoked by a person at any time

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Types of Advance Directives

Living Will - Patient writes their wishes about the medical treatment they desire and do not desire in the future—specifically related to their end-of-life—if they are unable to make decisions on their own.

Medical Durable Power of Attorney (DPOA) - A document that enables a patient to appoint someone they trust to make decisions about their medical care if they are not able to do so.

Physician Orders or Life Sustaining Treatment (POLST)/Transportable Physician Orders for Patient Preferences (TPOPP) – POLST/TPOPP were developed to complement Advance Directives and Do Not Resuscitate Orders (DNR) in order to adhere to the patient's preferred interventions in an emergency, end-of-life situation. It is intended to serve patients with grave illnesses and a limited prognosis, for whom death may be expected in the next year. This medical order is required to be honored across state lines.

Do Not Resuscitation (DNR) - Resuscitation means an attempt by medical staff to re-start the patient's heart and breathing, such as by performing Cardio-Pulmonary Resuscitation (CPR).

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What Is A Medical Durable Power of Attorney?

- A Medical Durable Power of Attorney (DPOA) is someone that the person appoints to make their decisions about medical care if they are unable to make those decisions because of illness or incapacity
- There are two separate Power of Attorney designations, one for medical and one for financial.
- The person designated as POA for medical and/or financial does not need to be the same person, nor does it need to be a family member. It does need to be someone you trust.

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Considerations Regarding Medical Durable Power of Attorney

- The person named as the patient's proxy or agent should be someone the patient trusts to carry out his/her wishes
- The patient should name a back-up person in case the first choice becomes unable or unwilling to act on his/her behalf
- The patient's proxy can speak with all caregivers on their behalf & make decisions based on directions the patient gave earlier
- If the patient's wishes in a certain situation are unknown, the proxy will decide based on what he/she thinks the patient would want
- The law doesn't allow the agent to be a doctor or a nurse providing health care to the patient unless he/she is a close relative
- Some states do restrict the proxy's ability to carry out some requests.

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Do Not Resuscitate (DNR) Considerations

- If you are in the hospital, you can ask your doctor to add a DNR order to your medical record. This type of DNR order is only good while the patient is in the hospital.
- An Outside of the Hospital DNR order is needed, which is a separate order from your doctor, if you would like to keep your DNR status once you leave the hospital. This order and form is usually posted in a place that is easy for others to see (e.g. on the refrigerator) in case of an emergency, so your wishes are known.
- Healthcare personnel have an obligation to revive a patient unless this order is in place

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Common Misconceptions of Advance Directives

Let's review some of the misconceptions that people may have about Advance Directives:

- Many people think that a financial Power of Attorney (POA) allows them to make medical decisions. Financial and Medical POAs are defined in separate documents.
- Some people think that if they complete an Advance Directive, they won't get medical treatment. Having an Advance Directive does not mean "don't treat me". It means "treat me the way I want to be treated."
- People often think that talking about Advance Directives means that they may be sicker than they know. The best time to make important decision is when one feels well, before something serious happens.

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Common Misconceptions of Advance Directives

- People often fear that once they name a healthcare surrogate, they will lose control of their own healthcare. This is not the case. If you can make your own decisions, you retain control of your treatment choices.
- Some people believe that having an Advanced Directive will save their families from difficult decisions. The burden of surrogate decision making can be significant, causing anxiety and tension amongst family members.
  - Choose with care your Medical Durable Power of Attorney. It does not need to be a family member, but someone you trust to follow your wishes.
  - Have multiple conversations with your Medical DPOA and your loved ones about what you would want and not want, this will make their decisions easier if/when that time arrives.
  - If appropriate, give your Medical DPOA and your loved ones permission not to prolong the dying process.

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Next Steps After Completing Advance Directives

- Talk to your family members and other important people in your life about your Advance Directives and health care wishes.
- Review the Advance Directives with your doctor, Medical Durable Power of Attorney (DPOA), and alternates
- Give a copy of your Advanced Directives to each and keep a record
- Keep the originals in a safe but easily accessible place.
- Carry a wallet-sized card that indicates you have an advance directive on file and who to contact if needed
- Keep a copy of any advance directive with you while traveling

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Good Tips for Goals of Care Conversations with Your Doctor

- **Don't rush.** Take some time prior to your conversation with your physician to write down the questions you have about your future medical care at the end of life. Remember, often a goals of care conversation is more than one meeting.
- **Listen carefully.** Your physician may have a lot of information to share about your current medical state and information about end-of-life treatments and care. These may or may not align with your wishes or beliefs, and that's ok, you can continue to talk about it.
- **Do not hesitate to ask the tough questions.** It is hard to discuss end-of-life options and care, but this is a very important topic. It is ok to become emotional or upset when you discuss this with your physician but DO ask these tough questions!
- **If you don't understand, ask for clarification!** If your doctor is describing treatments that you don't understand the treatments they are describing, ask for them to clarify what they are saying until you do understand.

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Good Tips for Goals of Care Conversations with Your Doctor

- **Share your personal, underlying values and goals with your doctor**
  - Let him/her know what things are important to you in life
  - Share your beliefs about what quality of life you want at the end of life
- **Ask questions about your disease(s) and prognosis** – Ask about what are the chances that a medical treatment will work and share your feelings about the potential risks
  - If a treatment/surgery/intervention has a 20% or less chance of being successful, share how you feel about these odds? Is this acceptable or unacceptable to you?
- **If you don't understand the answers provided to your questions, ask clarifying questions until you receive answers you DO understand!**
  - Try rephrasing the statement - "What you are saying is that there are not any more treatments available for my disease, correct?"
  - OR "Would you explain what the next step is again, I don't understand how this will help control my symptoms."

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Good Tips for Goals of Care Conversations with Your Doctor

- **Share how you want your future healthcare to be and goals you'd like to accomplish:**
  - When my illness gets worse and I have a less than 12 months , I wish to be cared for in this way…
  - I have the following goals that I would like to accomplish in the time I have left…
- **Start your conversation with your doctor where you are *now* in your healthcare journey and move to where you want to or will be:** If you just came out of the hospital, you might focus on the hospitalization. For example:
  - "I know things went ok in the hospital, but I don't want to spend my time in the hospital if there isn't something that can be done to cure my disease. Can we talk about this now?"

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Advance Directives Resources

Caring Conversations

An excellent resource available to assist in advance care planning is *Caring Conversations*, developed by the Center for Bioethics. See below for an overview:

- Reflect—on your personal experiences, values, desires and preferences.
- Talk—to the person you are considering as your Agent.
- Appoint—the person who will speak for you when you cannot speak for yourself using the Durable Power of Attorney for Healthcare Decisions form.
- Act—by sharing your decisions about your healthcare preferences with family, friends, healthcare providers, clergy or attorneys if desired and reviewing your preferences on a regular basis.

Go to www.practicalbioethics.org to learn more about *Caring Conversations* and download forms.

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Questions?

Thank you for joining us today. We hope we were able to provide resources on how to advocate for you and your loved ones when facing challenging healthcare situations. Please feel free to reach out to today's speaker at

Shawn Mueller

Director of Market Development

VITAS Healthcare

Shawn.mueller@vitas.com or 913/563-8877

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www.kcrhca.org

Resources

For information on home care services in the Kansas City area:

- Kansas City Regional Home Care Association (KCRHCA) - www.kcrhca.org

For information on resources for completing advance directives:

- Caring Conversations - www.practicalbioethics.org for information and to download forms.
- Five Wishes - www.fivewishes.org for information to order forms for Five Wishes.
- Caring.org - www.caring.org for state specific advance directive information and sample forms.

For information on:

- Physician Orders or Life Sustaining Treatment (POLST)--www.POLST.org.
- Transportable Physician Orders for Patient Preferences (TPOPP)--www.KFMC.org for state-specific forms and procedures.

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References

Caring Conversations Workbook, Revised 2013. The Center for Practical Bioethics-Guidance at the Crossroads of Decision. Available at www.practicalbioethics.org/featured-resources/caring-conversations.

Kansas City Regional Home Care Association. Available at www.kcrhca.org

Medicare.gov. Your Medicare Coverage>Home Health Services. Available at www.medicare.gov/coverage/home-health-services

Medicare.gov. Your Medicare Coverage>Hospice Care. Available at www.medicare.gov/coverage/hospice-care

National Hospice and Palliative Care Organization. (2020). Facts & Figures: Hospice care in America. Available at: https://www.nhpco.org/hospice-care-overview/hospice-facts-figures/

NIA-National Institute on Aging. “Making Decisions for Someone at the End of Life.”, November 17, 2022. Available at www.nia.nih.gov/health/making-decisions-someone-end-life

NIA-National Institute on Aging. “What are Palliative Care and Hospice Care?”, May 14, 2021. Available at www.nia.nih.gov/health/what-are-palliative-care-and-hospice-care.

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