



Grief and Loss: A Beautiful Goodbye, Supporting Caregivers with a Loved One in Hospice Handout

Thinking about death, both when and how it will come, is at the heart of what drives our most basic human fears. This may stir up thoughts about what may lie beyond death as well, an uncertainty many may grapple with. It is human nature to struggle with these thoughts and feelings about death. It is important to try to not push aside this fear we all have or will face at some point in our lives. There are ways to feel more prepared and improve the quality of life for those facing death.

What steps can you take to prepare for this life transition?

Complete an Advance Directive and Health Care Proxy

Discuss pros and cons of life saving interventions with your medical providers. Clarify what circumstances you would want them delivered and provide them with a copy of your Advance Directive.

Identify a person you want as a health care proxy. Inform them and confirm they will be willing to carry out your wishes even if others disagree.

Talk with VA providers to assist with completing Advance Directive and Health Care Proxy forms and for non-VA care find forms on-line for your specific state at www.caringinfo.org

Utilize Palliative and Hospice Teams to improve the quantity and quality of life.

4 Questions Palliative Care Physician Dr. Susan Block asks to guide goals

- Do you know your prognosis and understand what it means or what to expect?
- What fears might you have about what is to come?
- What goals do you have, as your time gets short? How do you want to spend that time?
- What are you willing to trade off or sacrifice? How much suffering are you willing to go through for the sake of having more time?

Physical considerations for end of life care

- Inform treatment providers of changes in symptoms or pain. Follow rules for pain medications and tell providers if there are high pain levels. It is more difficult to reduce pain when it has increased than to keep relief stable.



- Pain reduction can be improved with soothing touch or massage, moving position, a cool or warm cloth, meditation, music, or other diversions.
- Doctors may provide oxygen for shortness of breath. Raising the head of the bed, opening a window, or turning on a fan may provide relief. Near death breathing may become noisy with gurgling in the throat, turning the patient on their side or use of medication can dry some of this fluid.
- Skin care-Dry lips and mouth provide lip balm, ice chips or damp cloth. Break down of skin can result in bed sores. Keep skin clean, dry, and moisturized on heels, hips, low back and back of the head. Near death, limbs may become cold, and skin tone may become dark or blue as circulation slows.
- Nausea, vomiting, constipation, and loss of appetite- discuss changes with medical team, try small amounts of favorite foods. Don't force someone to eat and drink as the body may not be able to process food, causing discomfort.
- Fatigue-your loved one may sleep for long periods and have a hard time getting to bathroom. Have a commode near the bedside. As the person nears death loss of bowel or bladder function may occur. A catheter may be placed, and adult briefs may be utilized.
- Agitation, restless and confusion- Medications may be provided for agitation. If no longer speaking remember that hearing is the last sense to go. It is important to talk as if they could hear what you are saying. Speak quietly or provide soothing music. Keep lights low and provide a calm environment. Spiritual rituals, prayer, or gentle touch provides comfort.

Caregiver Needs

- Utilize the Hospice Team-Doctor, nurses, home health aides, social worker, minister, psychologists to provide understanding the illness. This team may help plan for and manage the care needs of your loved one and support the family and caregiver in this journey.
- Follow pain medication schedule to control pain and seek help from doctor and nurse if pain or symptoms are controlled.
- Reach out to family, friends, neighbors, spiritual community to provide rest from your duties or to assist you in managing daily tasks.
- Take time to rest, reflect, reminisce, and communicate with your loved one as your time together in this transition will be memorable.
- Contact the Caregiver Support Line Mon-Fri 8am-8pm ET to speak with a licensed social worker who can provide you information and emotional support.