

FAMILY CAREGIVER HEALTH BULLETIN



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THIS MONTH'S TOPIC END OF LIFE CARE



nd-of-life care describes the support and medical care during the days, weeks, or even months before a death. The National Institute on Aging recommends addressing four areas of care to support a peaceful death: physical care, mental or emotional needs, spiritual needs, and practical tasks.

Physical care

Health-care providers and hospice teams provide care and comfortwhen a person is dying. Family caregivers also play significant roles in managing physical care. For example:

• **Pain.** Watch for clues such as trouble sleeping, increased agitation, whimpering, or crying. When pain is detected, provide pain medicine as prescribed by a physician or consult with a health-care provider to reevaluate pain management.

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- **Breathing.** If breathing becomes labore, consider repositioning your loved one's head or body. If noisy breathing is upsetting, keep in mind it typically does not upset the person who is dying.
- Skin irritation. Keep the skin clean and moisturized. Moisten lips with a damp cloth or lip balm. Watch or discolored or dark spots on the skin that might indicate a bed sore and turn a person in bed every few hours to prevent sores and stiffness.
- Eating/Digestion. Nausea, vomiting, constipation, and loss of appetite are common at the end of life. Some people may have trouble with swallowing. Accept a person's decision to give up food. If a person wants to eat, offer small amounts of food throughout the day. Help a loved one eat if they have interest but feel too tired or weak.
- **Temperature sensitivity.** Watch for signs of being too hot (sweating, removing blankets) or too cold (shivering, pulling up covers). Adjust the temperature as needed or add or take away blankets.
- **Fatigue.** Help conserve energy by prioritizing and spreading out activities, providing sponge baths in bed or adding a commode next to the bed.

Mental or emotional care

At different points during end-of-life care, a person may feel depressed, anxious, helpless, isolated, scared, or concerned. The National Institute of Aging suggests asking the person who is dying what they need. Counselors or clergy can offer support. Medical providers can treat with prescriptions. As a caregiver consider:

- Providing physical comfort (hand-holding, massage),
- Setting a comfortable mood (quiet room, few people, soft lighting, relaxing music), and
- **Being present** (visit with the person, talk or read to them, listen).

Spiritual needs

When faced with death, a person may look to finding meaning in life, make peace with life's circumstances, find forgiveness, resolve unresolved issues, or say their goodbyes. Visits from social workers, clergy, or counselors may be helpful. Family caregivers can:

- Tell a dying person how much they mean,
- Share fond memories,
- Listen to the person if they feel like talking, and/or
- Accept sitting in silence.

Keep in mind that visits can be tiring and stressful for both the person who is dying and the caregiver. Take turns visiting. Trust that it is OK to leave the dying person alone.

Practical tasks

A person who is dying might fret over who will take care of things when they are gone. As a caregiver, you can provide reassurance that affairs are in order or that certain concerns will be taken care of.

Because providing care for someone who is dying can be a daunting task, ask for help and support. Accept offers for help and take time to manage your own stress and emotions, including taking breaks.

Hospice

Hospice care is a service for people with terminal illness who choose not to seek curative services. It focuses on care, comfort, and quality of life. In addition to spiritual support, hospice care can provide medications, supplies, and equipment. It can be offered in your home, hospital, or longterm care. It is covered by Medicare, Medicaid, and most insurance companies. Talk to your health-care provider to find a hospice program near you.

RESOURCES:

Brittany Thomas, Provider Liaison, Bluegrass Care Navigators. Tel: 855-492-0812; Email: bthompson@bgcarenav.org

REFERENCES:

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Written by: Amy F. Kostelic, Associate Extension Professor, Adult Development and Aging Edited by: Alyssa Simms Designed by: Rusty Manseau Stock images: Adobe Stock