



Area Agency on Aging, PSA 2

Caregiving Series

END-OF-LIFE CARE

Those last few months, she just seemed to be "fading away." Her appetite was gone; she didn't care about watching her "soaps," and she even looked smaller from day to day. I began to accept that we wouldn't have her much longer.

We each respond to death and dying in our own way. Although we can't control when life ends, we can develop strategies to deal with loss and grief. Caregivers and patients will find comfort in expressing their grief and sharing their emotions.

LOSS AND GRIEF

The diagnosis of serious or terminal illness sets in motion a range of feelings that include shock, sorrow, disbelief, anger, guilt, anxiety, resignation, shame, and relief by the patient and family, whether or not the diagnosis had been expected.

There are intangible losses such as hopes and dreams that will not be realized, or the loss of a significant role as spouse or parent. The patient and family may question their beliefs and wonder "why me." If the illness includes memory impairment, the family and the patient grieve the loss of connection to each other and to the outer world.

There are tangible losses such as loss of a spouse's income and resultant lifestyle changes. The caregiver may need to quit a job to care for the patient, adding financial problems to the other stresses of caregiving.

COPING WITH END-OF-LIFE ISSUES

To cope with these issues, share your feelings with the patient, use your support system, and accept help from family, friends, and community services such as respite. As the goal shifts from cure or control of the illness, make the most of the remaining time.

Most people with a serious or terminal illness live several weeks to several months. Use this time to express your love, share memories, apologize or accept an apology, talk about your grief, and spend time saying goodbye. Help your loved one take care of unfinished business and get his affairs in order. Ask how he wants to spend his last days and give him the opportunity to express his spiritual concerns and to meet with clergy. Respect his wishes even if you disagree.

GATHER INFORMATION

Get all the information you can about the patient's condition and what to expect. The patient needs to state how much information he wants about his illness, whether he wants to explore all available treatments or focus on comfort care, and under what circumstances he would want treatment withdrawn or withheld.

Help your loved one gather important information and documents. Items stored in a safe-deposit box in his name are not available upon death. You will need the following.

- Name, address and phone number of medical team, attorney, accountant
- Health care and long-term care plan information and membership cards
- Social Security, Medicare, and Medicaid numbers and identification cards
- Savings, checking, investment, and credit card account numbers
- Retirement accounts (IRA, 401K etc.), pension plans, veteran's benefits
- Deeds, titles, business agreements
- Records of credit card debt, mortgages, outstanding bills
- List of routine household bills, amounts, and due dates
- Insurance policies including life, homeowner's, liability, accident, auto
- Will and advance directives such as Durable Power of Attorney for Health Care, Living Will, and Do-Not-Resuscitate Orders
- Burial or funeral arrangements

TAKE TIME TO GRIEVE

Even after a long illness, no one can ever completely prepare for death. You may feel relief followed by guilt when the burden of caregiving has lifted. Give yourself time to grieve and give yourself credit for all you have done.

FOR MORE INFORMATION

Ohio Hospice & Palliative Care Organization

"Choices: Living Well at the End of Life" (includes Advance Directives Packet)

1-800-776-9513, info@ohpco.org.

Hospice Foundation of America

2001 S Street, NW, Suite 300, Washington, DC 20009

202-638-5419, www.hospicefoundation.org

American Cancer Society

1599 Clifton Road, NE, Atlanta, GA 30229-4251

800-227-2345, www.cancer.org English and Spanish

American Heart Association

7272 Greenville Avenue, Dallas, TX 75231

800-242-8721, www.americanheart.org

National Stroke Association

96 Inverness Dr. East, Suite 1, Englewood, CO 80112-5112

303-649-9299, www.stroke.org

For more information or a list of titles in this series,

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