

Sometimes, despite the best treatment efforts, breast cancer grows and spreads. When this happens, many people begin treatments that may prolong and improve the quality of life. Sometimes, the side effects of treatment outweigh the benefits. Some people then choose to stop getting treatment. The process leading up to this difficult decision is different for each person. Anger, fear, sadness and loss are all common feelings. There are resources that can help you and your loved ones during this time.

Palliative care

Once a person decides to stop treatment that may prolong life, palliative care begins. Palliative care, also called comfort care, provides relief of a chronic illness through symptom and pain management. The main goal of palliative care is to provide comfort and a high quality of life for as long as life remains. A hospital social worker can tell you about the palliative care services in your area.

Hospice

Hospice is a special concept of care that includes and extends beyond palliative care. Hospice focuses on the total care and support of people near the end of life and their loved ones. Hospice services may include:

- Comfort care (like symptom control)
- Psychological, social and spiritual support
- Daily care support
- Grief counseling

Hospice care is given by teams of trained professionals, volunteers and family members. One common myth about hospice is that it is a place to go to die. Hospice is not a place. It is a type of care that is received at a place of your choice, such as in your home or in a hospital. A hospital social worker can also tell you about hospice services in your area.



Talking about death

Perhaps one of the hardest things to do is talk with your loved ones about dying. There is no “right” way to talk about death. Starting off by saying, “I know that I am dying,” can give others permission to talk openly with you. Family members and friends may seem uncomfortable at first. Often, they want to talk but are afraid of upsetting you or saying the wrong thing. The more open that you are with your feelings, the more comfortable they will become. Hospital social workers and hospice workers may also be able to help you open the lines of communication.

Your legal rights

One major concern people have is that the end of their lives be a time spent with dignity, and not a time spent fighting unwanted treatments. You have legal rights at this time. You have the choice of where and how you want your treatment to be handled should you not be able to express your wishes. But you must write a legal document, called an advance directive, if you want to protect your rights and make your choices known. Writing an advance directive can save your loved ones the stress of making some hard choices during this time.

There are two parts to an advance directive. Each state has its own legal requirements so you should get legal advice. You can change or cancel advance directives at any time.

Resources

Organizations

National Family Caregivers Association — support and information for caregivers.

1-800-896-3650

www.nfcacares.org

National Hospice and Palliative Care Organization — offers information and referrals for end-of-life care.

1-800-658-8898

www.nhpco.org

Caring Connections: America's Voices For The Dying — supplies end-of-life information and state specific legal resources.

1-800-658-8898

www.caringinfo.org

CancerCare® — provides online support, information, and referrals for people at all stages of cancer.

1-800-813-HOPE

www.cancercares.org

- **Living Will** — This lists which treatments should be given or withheld (such as life support) and under what circumstances. It can be very specific or general.
- **Durable Power of Attorney for Health Care (Medical Power of Attorney)** — This allows you to appoint a person to make health care decisions on your behalf should you no longer be able to do so yourself.

Copies of these should be given to your lawyer, doctor, hospital and family. It also helps to keep a copy with you.

Internet

Growth House — provides in-depth information on end-of-life care.

www.growthhouse.org

Hospice Foundation of America — gives information on hospice.

www.hospicefoundation.org

Related fact sheets in this series:

- Clinical Trials
- Complementary Therapies
- Getting the Support You Need
- Metastatic Breast Cancer