

ISSUES IN END-OF-LIFE CARE

FORGING PARTNERSHIPS FOR A CURE



WHAT IS END-OF-LIFE CARE?

- ☐ The goal of end-of-life care is to provide comfort through the dying process.
- ☐ Experts suggest that open patient-doctor communication and decisions about care should occur early in the illness. This helps to prepare the individual for the illness' progression and treatment. It also helps the patient to form realistic thoughts about the entire process!
- ☐ End-of-life care may include hospice care.

WHAT IS HOSPICE CARE?

Hospice focuses on support for individuals who are no longer receiving curative care and who have less than 6 months to live. Hospice care is supportive and seeks to ease the individual's pain and shortness of breath. It provides comfort and basic needs to improve the quality of life among people who are dying, and includes meeting an individual's definition of comfort, dignity and quality of life. It should also be acceptable within the individual's context of religious beliefs and cultural traditions. Hospice also provides support to families.



WHAT IS PALLIATIVE CARE?

The World Health Organization (WHO) defines palliative care as the active total care of patients whose disease is not responsive to curative treatment. Control of pain, other physical symptoms and psychological, social and spiritual problems is paramount. The goal of palliative care is the best possible quality of life for patients and their families. Palliative care can be offered at any time from diagnosis through the course of the condition.



WHAT SERVICES ARE PROVIDED IN PALLIATIVE CARE?

- ☐ Intensive treatment of pain, shortness of breath and other symptoms
- ☐ Guidance and counsel about treatment options
- ☐ Coordinated care across many settings
- ☐ Emotional support for individual and family
- ☐ Psychosocial and spiritual care (given by a counselor and/or clergy member to address sadness, grief, anxiety or depression due to the illness/condition)

WHAT ISSUES ARE INVOLVED IN END-OF-LIFE CARE?

There are many issues involved in end-of-life care that a person and family need to consider. In planning your care, you may want to ask yourself the following questions:³

WHAT KINDS OF MEDICAL CARE DO I OR DON'T I WANT?

Think about where you want to receive care (at home vs. a hospital, hospice or nursing home). What are your options? Who do you want to provide your care? Also think about whether you want any complementary care, such as aromatherapy, music therapy, massage, acupuncture or meditation. Speak to your doctor if you want to add any of these complementary therapies to your care plan.

HOW COMFORTABLE DO I WANT TO BE? DO I WANT TO KNOW ALL TREATMENT OPTIONS EVEN IF SOME MAY BE UNCOMFORTABLE?

By being open and honest with your doctor, he or she should be able to work with you to decrease your pain or discomfort. You should talk to your doctor about your desired level of comfort. Also ask about the level of pain or shortness of breath that you may be experiencing at any given time.

DO I WANT TO KNOW ABOUT TREATMENT OPTIONS IF THERE IS NO CLEAR EVIDENCE ABOUT WHETHER OR NOT THEY WORK?

You should discuss with your doctor whether or not you want to try new or experimental treatments.

WHEN ARE THE BENEFITS OF TREATMENT WORTH THE SIDE EFFECTS?

It is important to create goals for your care and treatment with your doctor and family. You should be open with them and discuss your progress toward these goals.

WHO DO I WANT TO MAKE CARE DECISIONS FOR ME WHEN I'M NOT ABLE TO?

You should name a family member or a close friend who knows how you feel about end-of-life issues as your representative, called a healthcare surrogate or proxy, to make decisions about your care if you are not able to make them yourself. To do this, you must sign a Durable Power of Attorney for Healthcare Surrogate or Proxy. It is very important that you discuss the types of medical services that you wish to receive with your healthcare surrogate. You may also want to write an Advance Directive to direct your care team, family and friends on how to provide, withhold or withdraw life-prolonging treatment if you are not able to make your own decisions.⁴ A good time to choose a surrogate and create an Advance Directive is shortly after diagnosis. This is a time when you are able to think clearly about your options and are able to make informed decisions.

IF I STOP BREATHING OR MY HEART STOPS BEATING, DO I WANT TO BE REVIVED?

It is important to discuss conditions and consequences related to heart and breathing cessation with your doctor. You should also discuss your wishes with your family to make sure that they are aware of them.

HOW DO I WANT PEOPLE TO TREAT ME?

Be open and honest with your family, friends and healthcare team about how you want to be treated. They want to help you through your end-of-life process, and may not know how you want them to do so.

WHAT KIND OF FINAL ARRANGEMENTS DO I WANT?

Think about what you want and tell your family and friends about your wishes for a funeral, memorial service, burial, cremation and/or organ donation. By doing so, you will help them during their time of grief and loss.

WHO PROVIDES END-OF-LIFE CARE?

- ⊖ A collaborative approach is often used to provide end-of-life care. This is done through a team, which may include doctors, nurses, social workers, chaplains, counselors or mental health workers, care managers and pharmacists. The team is patient-led and supported by physicians.
- ⊖ Care may be given at home, a hospital, nursing home, assisted living facility or in a hospice facility.



HOW DO I PAY FOR END-OF-LIFE CARE?

- ⊖ Medicare or Medicaid can pay for palliative or hospice care for those who are eligible.
- ⊖ If you have private health insurance, you should check to see if it covers palliative and/or hospice care and what the specifics are about the coverage.
- ⊖ If your insurance does not cover hospice care, many organizations offer payment options and a sliding fee scale that is based on your income or resources.



HOW CAN I LEARN MORE ABOUT END-OF-LIFE CARE?

- ☺ Talk to your doctor.
- ☺ National Hospice and Palliative Care Organization
www.nhpco.org
- ☺ Growth House, Inc.
www.growthhouse.org
- ☺ Hospice Foundation of America
www.hospicefoundation.org
- ☺ Well Spouse Association
www.wellspouse.org
- ☺ National Family Caregivers Association
www.nfcacares.org
- ☺ National Health Information Center
www.healthfinder.gov
- ☺ Children of Aging Parents
www.caps4caregivers.org
- ☺ Eldercare Locator
www.eldercare.gov
- ☺ Department of Pain Medicine & Palliative Care, Beth Israel Medical Center
www.stoppain.org

1 Center to Advance Palliative Care (2003). www.capcmssm.org

2 Cancer Pain Relief and Palliative Care: Report of a WHO Expert Committee. Geneva, World Health Organization, 1990 (WHO Technical Report Series, No. 804).

3 Back AL & Curtis JR. (2001). When does primary care turn into palliative care? The Western Journal of Medicine, 175 (i3) pp. 150-1.

4 Kuebler KK, Berry PH & Heidrich DE (2002). End-of-Life Care: Clinical Practice Guidelines. (pp.29-30). Philadelphia: W.B. Saunders Co.

About the cover illustration: This original artwork depicts the passing of knowledge from mother to child. The scene represents the importance of informing others about Alpha-1.



ALPHAONE.ORG

877•2•CURE•A1 | 877•228•7321

2937 S.W. 27TH AVENUE • SUITE 302 • MIAMI • FL 33133

Unrestricted educational grants provided by:
CENTRIC HEALTH RESOURCES, INC.
TALECRIS BIOTHERAPEUTICS
ALPHANET

ABOUT THE ALPHA-1 FOUNDATION

The Alpha-1 Foundation is a not-for-profit organization dedicated to providing the leadership and resources that will result in increased research, improved health, worldwide detection and a cure for Alpha-1 Antitrypsin Deficiency (Alpha-1). The Foundation provides the infrastructure to promote research and the development of new therapies for improving the quality of life of those diagnosed with Alpha-1. It is committed to close collaborations with medical experts, government agencies, international regulatory authorities, the pharmaceutical industry and other organizations to jointly resolve critical issues in the field of Alpha-1 research and treatment. Additionally, a Grant Award Program supports a wide range of meritorious scientific research in Alpha-1.

ABOUT THE ALPHA-1 ASSOCIATION

The Alpha-1 Association is a member-based not-for-profit organization founded in 1991 to identify those affected by Alpha-1 Antitrypsin Deficiency and to improve the quality of their lives through support, education and advocacy. The Association has a network of over 60 volunteer-led support groups throughout the United States.

© 2006 Alpha-1 Foundation, Version 1 (1/06)

FORGING PARTNERSHIPS FOR A CURE