

Helping Patients and Families Make End-of-Life Decisions

2.0 Contact Hours

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Helping Patients and Families Make End-of-Life Decisions

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Objectives:

At the conclusion of this course, the learner will be able to . . .

1. Discuss common end-of-life goals and wishes
2. Identify and discuss common barriers to end-of-life wishes being carried out
3. List and define the basic types of end-of-life documents
4. Compare and contrast in-home and hospice care
5. Identify and explain important coping tips for families
6. Define “overcaring” and discuss how it can be prevented

The American Cancer Society (2006) has observed, “It is usually not the act of dying, but the quality of dying that is the overwhelming issue at the end of life.” This is the key to end-of-life decisions: quality dying. While this may seem oxymoronic and incompatible with society’s negative view of death, quality dying is possible with proper end-of-life planning.

As a caregiver, the responsibility of helping patients and their families prepare for the end of life often falls to you. In their article “End of Life Decisions,” the Evangelical Lutheran Church in America (1992) points out, “While the achievements of modern medicine have been used to prolong and enhance life for many, they have also helped create an often dreaded context for dying.” The caregiver’s job is to alleviate that sense of dread and demystify the necessary decisions that must be made at the end of life.

Obviously, some deaths – particularly accidental deaths – are highly unpredictable and impossible to plan for. Many deaths, however, are the end result of prolonged illness or natural aging. These are the instances in which patients and their families must make a slew of decisions that will affect the quality and course of the dying process. In the face of grief and loss, many families look to healthcare providers to guide them through what can often seem a bewildering and overwhelming process.

In the throes of the depression and denial associated with grief, many patients and families put off difficult end-of-life decisions. While this may seem normal and natural, it can lead to significant problems down the road, especially for the family. It is important that the end-of-life wishes of a dying loved one are both known and observed. This helps prevent disagreement and discord among family members.

Disagreement among family members is one of the primary barriers faced when making end-of-life decisions. Each family member has his or her own view of what the end of life should look like. These individual views are often injected – consciously or subconsciously – into any discussion on end-of-life decisions. Broad disparities in these views can lead to simple disagreements, wounded feelings and pride, or even all-out physical confrontations.

Another common barrier to making end-of-life decisions is related to the grief cycle itself. As the patient and family members experience grief individually – and in different and unique ways – they find themselves at various different stages of the grief cycle at any given time. Therefore, one family member may be in the acceptance stage, while another is experiencing depression, and still others are still struggling with anger or denial. The different perspectives experienced throughout the grief cycle can easily become a barrier to effective end-of-life decision making.

By definition, “grief” is “the reaction to loss” (Corr, 2000). We often mistakenly believe that real grief only occurs after death, but anticipatory grief – mourning an impending loss – can also have a major impact on decisions. As a patient experiences the losses that naturally accompany the progression of a lengthy or terminal illness, those close to the patient experience a similar series of losses. The physical, psychological, social, and spiritual implications of these losses impact end-of-life decisions for both the patient and his or her family.

As a caregiver, you can help families through grief by reminding them that when doctors say, “There’s nothing more we can do,” they are only referring to healing. Encourage the family and the patient to make good end-of-life decisions that will result in tender, loving, compassionate care. Once the patient makes decisions – with or without consultation with the family – the conclusions should be clearly and calmly discussed with the entire participating family and care team.

Problems often arise in end-of-life care when decisions have been made but the details are unclear, impractical, or undocumented. Unfortunately, it is not enough for a patient to verbally express his or her end-of-life wishes to family and care professionals. Most states require a legal document – or at the very least, a written statement – affirming the wishes of a patient and/or family in order for those wishes to be carried out.

Legal documents designed to outline end-of-life wishes are broadly termed advance directives. Advance directives only take effect when a patient is no longer able to competently make care decisions for him or herself. These documents are designed to ensure that a patient's last wishes are respected and carried out without undue alteration. An official advance directive is legally binding and remains in effect until a patient passes away, cancels it, or updates it in some way.

Although advance directives are legal documents, many states allow them to be completed without the assistance of a lawyer. Approved forms are available through state offices – generally health departments or the Department of Health and Human Services. Some states do require that the forms be notarized and/or witnessed. This standard holds true for both major types of advance directives: living wills and medical powers of attorney.

A living will is an advance directive that guides the family and/or medical professionals about a patient's preferred medical care when the patient is no longer able to communicate his or her wishes. Living wills give specific instructions for the very end of life. They address such medical care issues as “heroic measures,” and the use of feeding tubes and ventilators.

Living wills are very helpful, as they alleviate the family of the responsibility of making decisions. On the other hand, it can be very difficult for a patient to have a realistic view of the end of life and to adequately anticipate all necessary decisions, especially if mitigating factors come into play. If a patient decides that a living will is the best option, the contents of the living will should be discussed in detail with both the family and the care team while the patient is still mentally competent.

An alternative to writing specific instructions for medical care is to establish a medical power of attorney, the other type of advance directive. A medical power of attorney – also called durable power of attorney, health care or medical proxy, or health

care agent – appoints a specific person to make health care decisions for a patient who can no longer make those decisions for him or herself. The medical power of attorney documents can specify certain medical procedures that are allowed or disallowed, but they generally just leave all decisions up to the appointed agent.

Designating a medical power of attorney is especially important if a patient wants a non-relative or a distant relative to be his or her decision maker. If there is no living will and no designated medical power of attorney, hospitals and/or courts will name the nearest living relative as the decision maker. It is also important for patients to name a secondary agent, whenever possible, in case the primary designee is unable to carry out his or her decision-making duties. All people named as agents should be highly trusted by the patient and should be comfortable making complex medical decisions.

If a patient is not interested in taking legal steps to ensure his or her end-of-life wishes are carried out, a letter of instruction is a practical option. The letter of instruction is not legally binding, but it can help a family and/or care team manage a patient's affairs after his or her death. It has no formal structure – every letter of instruction is different – and it can contain a wide variety of information.

Letters of instruction can include temporary guardian information for children and pets, as well as details on the location of important information and documents. These letters can also include the names and phone numbers of individuals that should be contacted upon the patient's death. In addition, organ/tissue/body donation preferences and funeral/burial/memorial wishes are often incorporated into a letter of instruction.

All documents related to end-of-life wishes – legally binding or not – should be kept in a safe place. Copies should be distributed to all interested parties, including family members, medical professionals, and, if applicable, legal professionals. The patient's wishes should be discussed calmly and in detail with both family and medical professionals to ensure that everyone is on the same page and to resolve any misunderstandings or lack of clarity. It is also important at this point to briefly consider arrangements for the survivors, where relevant, including elements of financial stability, living situations, etc.

One of the most vital decisions to make as the end of life nears relates to the dying environment. It is important that patients and their families make the decision, when it is possible and practical, about where death should take place: in a controlled medical environment or at home. If a patient desires a home death – and doctors agree that it is medically feasible – the environment can best be managed through either in-home care or hospice care.

In-home care is focused solely on providing medical care in the home, including doctor visits, medication administration, and even minor medical procedures. Because end-of-life care can be complex – and because it is not focused on recovery – in-home care is not always a viable option. In-home care must be prescribed by a doctor and should be thoroughly discussed before being considered. It is important that families, in particular, realize what in-home care does and does not provide; it does not generally alleviate the overall caregiving burdens on family and other caregivers.

An alternative to in-home care is hospice care, a service designed specifically for the end of life. Hospice does not require a prescription and focuses on adding dignity and quality to the end of life while neither lengthening nor shortening the dying process. Hospice focuses on the comfort of the patient and family – including both medical and non-medical needs – providing 24-hour-a-day care that allows the patient and family to deal with grief and cherish their remaining time together. While not right for everyone, especially those who are extremely private, hospice focuses on pain and symptom care, respite care, family conferences, and bereavement care.

Decisions about care – regardless of their nature – can be highly emotional and difficult for both patients and families. There are a number of resources available to help with these decisions. Several national and international organizations are dedicated to helping patients and families make end-of-life decisions. Some of these organizations include:

- **Choice in Dying/Partnership for Caring, Inc.** – Provides advance directive assistance, counseling, training, and advocacy.

- **Last Acts** – Works to advocate for patients and families and to improve care and caring at the end of life.
- **Patient Advanced Educational Resource (PAER)** – Publishes an educational guide on advance directives for patients and families.
- **Caring Connections** – Offers education, support, and information on all types of end-of-life care.
- **National Hospice and Palliative Care Organization** – Gives information, support, and education on all aspects of hospice care.
- **National Association for Home Care and Hospice** – Provides support, education, assistance, and information on both in-home care and hospice care.

One specific resource that bears further mention is Five Wishes, an educational system designed to help patients consider and clearly express end-of-life wishes. Created by experienced caregiver Jim Towey, the Five Wishes system addresses five key questions to be answered in end-of-life planning. Completing the questions on a Five Wishes document creates an advance directive that is legally binding in 37 states and the District of Columbia.

The questions of the Five Wishes system include:

- **Wish 1** – Whom do I want to make my health care decisions for me when I am no longer able to do so for myself?
- **Wish 2** – What specific types of medical care and/or treatments do I want? What do I want to avoid?
- **Wish 3** – How comfortable do I want to be at the end of life?

- **Wish 4** – How do I want people to treat me at the end of life?
- **Wish 5** – What personal and/or medical information do I want my loved ones to know when I am at the end of life?

In contrast to broad-based, universal, organizational support, many patients and families find the greatest support comes from those they know and love. Strong networks of friends often provide invaluable resources of personal strength. Communities of faith and/or spiritual mentors can also help patients and families prepare for death, often including the creation of legal documents and the planning of memorial services.

These personal resources can be the key to helping both patients and families cope with the impending end of life. Families and patients can also, however, help each other cope. Family members often do all they can to aid and assist dying loved ones. This “coping assistance” applies to each of the four basic aspects of life:

- **Physical Coping** – Families can help satisfy both basic and complex physical needs of a dying loved one.
- **Psychological Coping** – Families can provide emotional stability and security and help their loved one be involved with care decisions and day-to-day tasks.
- **Social Coping** – Families can assist their loved one in loosening unnecessary emotional bonds, creating advance directives, making funeral arrangements, etc.
- **Spiritual Coping** – Families can affirm or reaffirm the personal religious or moral beliefs of their loved one, providing a sense of comfort and peace.

Helping a dying loved one cope in these essential ways can be valuable in allowing both patients and family members to work through feelings of grief and helplessness. As such, hands-on care participation by willing family members should be strongly encouraged.

As much as possible, all immediate family members and members of the “inner circle” of friends should help with both caregiving and making end-of-life decisions.

As friends and family become involved in caregiving, however, they must not be overburdened, even if that is their desire. A professional caregiver should work with friends and family members to identify appropriate care roles for each person. Remind friends and family members who are participating in care that they still need to care for their own needs – physical, psychological, social, and spiritual.

Friends and family of a dying person will often throw themselves eagerly into caregiving roles as a way to deny, avoid, or mask their grief. As a professional caregiver, you should gently – but insistently – encourage family members and close friends to express their feelings rather than suppressing them. Grief doesn’t simply go away; it must be worked through from beginning to end. Writing or drawing in a private journal is a non-threatening way to express the often overwhelming emotions of the grief process. It is also important that loved ones find a way to say a proper goodbye.

Loved ones are not the only ones who grieve when a patient dies, however. Caregivers and other medical professionals can also experience profound grief and loss, especially when the person who dies is a long-term and/or “favorite” patient. It is often difficult – and sometimes virtually impossible – to determine where the line should be drawn between compassionate caregiving and a deep emotional bond. Becoming deeply emotionally bonded to your patients is easy to do, but it can lead to an unhealthy phenomenon known as “overcaring.”

Overcaring is the detrimental practice of over-committing and overextending oneself in caregiving duties. It occurs when a professional caregiver’s sole focus is his or her patients, often at the extent of other personal relationships. Overcaring caregivers constantly check on patients unnecessarily, trying to fix problems and helping with tasks and decisions that the patient and/or family can handle on their own. Overcaring caregivers need their patients even more than the patients need them.

While it is important for caregivers to connect with patients and invest themselves compassionately in their patients' lives, overcaring should be avoided for the good of both the patient and the caregiver. Some tips for avoiding overcaring include:

- As a caregiver, take care of yourself and your needs first and foremost.
- Be aware of the dangers of overcaring and try to encourage and support families and patients in caring for themselves instead.
- Forgive and nurture yourself when you do become too emotionally involved or bonded.
- Find other routes to personal happiness, such as hobbies, clubs, or healthy relationships.

As a caregiver, you can also help yourself stay strong and physically and emotionally healthy by practicing good time management skills, setting goals, refusing to multitask or over-commit, and using appropriate delegation techniques. You should also build a strong network of support, acceptance, and mentoring. Above all, you must take time to renew your spirit and take emotional breaks when necessary. The only way to effectively assist those in your care is to care for yourself first.

Experiencing the grief cycle and making end-of-life decisions are challenging for everyone involved: the patient, the family and friends, and care professionals. Being informed about end-of-life options better equips you to help patients and families through this difficult time. Compassionate, end-of-life care can only be achieved when end-of-life decisions are made with confidence and certainty in an atmosphere of knowledge, care, and calm.

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