

Beginning the Conversation

ABOUT, DEATH, DYING AND END-OF-LIFE CARE IN CONNECTICUT

CTEOL Speaking Engagement

About this Booklet

Beginning the Conversation

Rights and Choices

Making Decisions

Pain Management

Palliative Care

Hospice Care

Talking with Health Care Professionals

Talking with the Dying Person

Physical Changes when Death is Near

Spirituality at the End of Life

Comforting the Dying

Comforting the Grieving

Talking with Children

Resources

About this Booklet

The Connecticut Coalition to Improve End-of-Life Care was founded in 1998 by health care providers, government agencies, community groups and individuals to develop a comprehensive approach to understanding and supporting the needs of dying persons and their families. The Coalition's mission was to facilitate the creation of programs to improve care of the dying and to ensure that every individual has information about and access to compassionate, quality end-of-life care.*

Grants from the Robert Wood Johnson Foundation, the Connecticut Health Foundation and the Hartford Foundation for Public Giving as well as donations funded the Coalition's early work.

The original edition of this "Beginning the Conversation" booklet evolved from the voices of participants in 20 focus groups that were convened to explore attitudes about end-of-life care. Meetings were held in many Connecticut communities with representatives of diverse religious, racial, ethnic and socio-economic groups. The groups represented elders and youth, as well as recently bereaved individuals and person with life-threatening illnesses. Transcripts of the focus group discussions were analyzed to identify those issues of most concern to participants. This booklet addresses ten key questions raised during the focus group discussions on end-of-life care. We extend our thanks to all who shared their thoughts and experiences so freely and honestly in these discussion groups. It is our hope that this information will serve as a helpful resource for all Connecticut residents.

This booklet was originally printed in 2003, updated and reprinted in 2009, & updated and formatted for posting on the Coalition's website in 2014. Whole or parts of the booklet may be linked, quoted and shared without prior permission provided appropriate credit is given to the Coalition.

*The mission was revised in 2014 to read: *"to promote compassionate care for all people touched by life-limiting conditions."*

CTEOL Speaking Engagement

Would you like to receive educational programming from one of our experts in palliative and end-of-life care? If your organization would benefit from education in advance care planning, MOLST, or a related palliative and/or end-of-life topic, we would be happy to assist you. For this service, we would suggest that the organization join CTEOL for an organizational membership fee of \$200. We understand that this fee may not be possible for some organizations, and hope that you will contact CTEOL with your requests so that we may assist you in a manner that would meet your needs.

Beginning the Conversation about death, dying & end-of-life care

Terminal illness, natural aging, accidents and other events that lead to loss are among the hardest issues to discuss and accept. Years ago, people died at home, usually after a short illness, and were attended by family members and the family physician. Now, the dying process is more complex, often preceded by long periods of chronic illness, hospitalization and aggressive treatment. Although we have been able to treat or cure many of the illnesses that were previously fatal, we ultimately cannot prevent death and always face the challenge of our mortality.

What we can do, however, is to take actions that address our fears of death and dying. We can develop health care systems and supports for dying individuals, their families and loved ones as death becomes imminent. We can work to educate providers, policy makers and ourselves on what is needed to provide the most compassionate, individualized and supportive end-of-life care.

This booklet is designed to provide basic information about some of the terms and services related to care at the end of life. As these issues have gained public attention, a whole new vocabulary has evolved that is often confusing and misunderstood. This guide answers ten of the most commonly asked questions about end-of-life care. It also offers basic information to help individuals make informed choices about end-of-life care for themselves and their loved ones.

Rights and Choices

People have certain rights regarding access to information related to their medical conditions and the ability to make their own medical decisions. Various choices are available to individuals to help guide the care they receive at the end of life.

Informed Consent

Patients' rights are protected under state laws ~~which~~ that guarantee that every patient has the right to be informed about his or her medical condition and prognosis, the risks and benefits associated with a procedure or course of treatment, and any treatment alternatives that exist.

Patient Self-Determination Act

Enacted into federal law in 1990, the Patient Self-Determination Act requires facilities that receive Medicare and/or Medicaid funding to provide patients with a statement of their rights concerning advance directives, to ask whether they have advance directives, and to place patients' advance directives in their medical charts.

Cruzan Case

In the Cruzan case, the Supreme Court found that a competent person has a constitutionally protected liberty interest in refusing unwanted medical treatment. The Court also found, however, that states can require clear and convincing evidence of individuals' health care wishes.

ADVANCE DIRECTIVES

Advance directives are:

- documents that provide instructions concerning an individual's health care preferences (instruction directives); and
- documents that appoint proxies to speak for individuals who are unable to speak for themselves (proxy directives).

Putting health care instructions into writing is considered by the medical community and the courts to be the most reliable evidence of an individual's wishes. Advance directives also help to avoid disputes among family members, protect the privacy of these very personal decisions, and give guidance in situations in which emergency medical treatment is required.

Each state has its own law concerning advance directives. Connecticut law recognizes a number of options through which individuals can express their wishes. These are described below.

Living Will

A living will is a document that expresses an individual's wishes concerning life support and any other medical treatment. In Connecticut, life support includes CPR, mechanical ventilation, and artificial means of providing nutrition and hydration. These are described in more detail later in this booklet. A living will only becomes operative if 1) an individual has a terminal condition or is permanently unconscious; and 2) a doctor finds that he or she is unable to understand and communicate an informed decision about treatment. A living will can be used to indicate that an individual wants to refuse certain treatments. It can also be used to indicate that an individual wishes to receive certain treatments.

Appointment of Health Care Representative

In situations in which an individual is unable to speak for him or herself, an appointment of health care representative authorizes another person to accept or refuse any treatment, service or procedure used to diagnose or treat a physical or mental condition, including withholding or withdrawing life support. This advance directive replaces the older appointment of health care agent and durable power of attorney for health care decisions forms. Please note, however, that if an individual completed one of those forms prior to October 1, 2006, it remains valid.

Advance Designation of Conservator

An advance designation of conservator is a document through which an individual can indicate whom he or she would wish to have serve as conservator if a probate court later determines that the individual is legally incapable of making decisions and the court finds it necessary to appoint a conservator.

Document of Anatomical Gift

A document of anatomical gift authorizes donation of all or part of an individual's body upon or after death.

Designation of Disposition of Remains

A designation of disposition of remains is a document through which an individual can indicate his or her wishes concerning custody of his or her body, as well as wishes concerning burial, cremation and/or interment.

Making Decisions about end-of-life care

There are different ways in which your condition might be described when you are unable to make your own health care decisions; there are also a number of life-sustaining treatments that you may or may not elect to choose. Listed below are definitions of these conditions and treatments to help you make your health care decisions.

Incapacitated

A person is considered to be incapacitated when, in the opinion of the attending physician, he or she is unable to understand the nature and consequences of health care decisions and is unable to communicate an informed decision.

Permanently Unconscious (Permanent Vegetative State)

A person is considered to be permanently unconscious when his or her condition is irreversible and he or she 1) is at no time aware of himself or herself or the environment; and 2) shows no behavioral response to the environment.

Other important provisions of Connecticut law concerning health care decision-making include the following:

- medical care cannot be conditioned on whether an individual has or does not have an advance directive
- medical providers cannot make any assumptions about an individual's wishes if he or she has chosen not to complete an advance directive
- even individuals who choose to forego medical care have the right to receive comfort care and to have their pain controlled
- if a medical provider is unable or unwilling to follow an advance directive, the provider must arrange to transfer the involved individual to a provider that can do so
- Connecticut now recognizes advance directives from other states and even foreign countries

Terminal Condition

A terminal condition means the final stage of an incurable or irreversible medical condition which, unless life support is administered, will result in death within a relatively short period of time.

LIFE-SAVING/LIFE-SUSTAINING INTERVENTIONS

Cardiopulmonary Resuscitation (CPR)

CPR is used when a person's heart and/or breathing stops. CPR may include applying force to the chest with the hands, electrical shock to the heart, injection of medications and the use of a mechanical respirator. Every person receives CPR when his or her heart stops upon admission to a medical facility, when emergency services are contacted through 911 or when medical attention is sought unless a Do Not Resuscitate (DNR) order is present. To resuscitate when an individual has a DNR order in place may represent a violation of a person's preferences or right to die with dignity. Refer to the next page for additional information about DNRs.

Mechanical Ventilation

Mechanical ventilation is used when a person can no longer breathe naturally. A breathing tube may be inserted and a ventilator utilized after an individual is resuscitated through CPR when mechanical ventilation is needed to maintain breathing. Individuals in this situation often become dependent on mechanical ventilation, never regaining the ability to breathe naturally and being at risk of developing complications such as pneumonia. Mechanical ventilation can also be used to support breathing during a short-term acute illness or after an accident until the individual has recovered. Mechanical ventilation cannot, however, provide a cure or restore breathing functions for persons who are terminally ill with conditions that affect their ability to breathe naturally or for those who are in a Persistent Vegetative State.

Artificial Hydration and Nutrition

When a person can no longer take food or fluid by mouth, these nutrients can be administered artificially through several different mechanisms; namely,

- *A Nasogastric Tube* that is inserted through the nose, down the esophagus and into the stomach.
- *A Gastrostomy Tube* that is inserted surgically through the skin of the abdomen into the stomach. Liquid nutrition, water and medication may be administered through a gastrostomy tube or a nasogastric tube.
- *An Intravenous (IV) Hydration* line that is inserted through a needle into a vein. Fluids and medications flow through tubing into the vein.

Whether to withhold or withdraw artificial nutrition and hydration is one of the most painful decisions of end-of-life care. The question becomes whether the absence of artificial nutrition and hydration causes suffering as a result of starvation and dehydration. As the end of life approaches, the body requires little or no food. Research has shown that prolonged use of intravenous fluids and/or artificial nutrition is usually not effective and can even complicate a person's care. Medical evidence regarding dehydration at the end stage of a terminal illness indicates that it is a very natural and compassionate way to die. In fact, it may help to make breathing easier and may reduce discomfort or suffering.

Do Not Resuscitate Order (DNR)

A separate type of advance directive is a Do Not Resuscitate Order (DNR), which directs medical personnel *not* to perform CPR or other life-saving procedures on an individual experiencing one or more body system failures. A DNR order requires a special signature from this person's physician and can only be signed with the consent of the person or of his or her authorized representative. Persons may have active DNR orders when they are in the hospital or in another health care facility, or when they are living at home and have a terminal illness. Having a DNR order does not prevent a person from receiving treatment for pain and other comfort measures. The order only applies to performing life-saving resuscitation measures like CPR.

Pain Management

Treatment for pain has evolved to the degree that it now is recognized as a specialized area of medicine. Throughout the country, hospitals and health care providers are committed to assessing and managing pain symptoms for both chronic and acute conditions. In fact, there is such a strong emphasis on treating pain that the Joint Commission, which certifies hospitals, now requires that pain assessment be considered a “vital sign” like a pulse or blood pressure measurement. Hospitals must now inform patients of their right to appropriate treatment for pain, must assess a patient’s pain and treat it until it is relieved, and must educate providers on proper pain management techniques. Fortunately, this new focus on pain management has been met with great success. Most pain can be controlled or significantly minimized.

People are often afraid to talk honestly about their pain or to take medication that will relieve their suffering because they are afraid of side effects. In fact, many of these worries are myths. The realities of good pain management lead to vastly improved quality of life for most people. Some common myths that are associated with pain management are listed on the next page.

COMMON MYTHS

Myth: A person could become addicted to pain medication, especially if narcotics are prescribed.

REALITY: STUDIES SHOW THAT THERE IS VERY LITTLE LIKELIHOOD OF BECOMING ADDICTED WHEN THERE IS NO PRIOR HISTORY OF DRUG ADDICTION.

Myth: There are some types of pain that can’t be relieved.

REALITY: INJURY, SURGICAL PROCEDURES AND CERTAIN DISEASES WILL CLEARLY PRODUCE PAIN; HOWEVER, WITH THOROUGH EVALUATION AND USE OF THE APPROPRIATE MEDICATIONS, PAIN CAN BE EFFECTIVELY MANAGED IN AT LEAST 90 PERCENT OF PEOPLE. MOREOVER, PROPER TREATMENT OF PAIN HELPS TO SPEED RECOVERY AFTER INJURY OR SURGERY. PERSONS WITH LESS PAIN ARE ABLE TO BREATHE MORE DEEPLY, WALK WITH GREATER EASE AND RECOVER FASTER WITH FEWER COMPLICATIONS. PROPER TREATMENT OF PAIN ALSO IMPROVES THE QUALITY OF LIFE FOR THOSE WITH TERMINAL CONDITIONS.

Myth: Treatment with pain medications produces side effects equally as unpleasant as the pain.

REALITY: THE VAST MAJORITY OF SIDE EFFECTS FROM PAIN MEDICATION CAN BE TREATED SUCCESSFULLY.

Myth: Taking pain medication will make a person sleep all of the time.

REALITY: DIFFERENT COMBINATIONS OF MEDICATIONS ARE AVAILABLE THAT MINIMIZE DROWSINESS FOR THOSE INDIVIDUALS WHO WISH TO REMAIN AWAKE. FOR SOME PEOPLE, SLEEP MAY BE A WELCOME RELIEF.

Myth: People have to be in the hospital to get their pain relieved.

REALITY: PAIN CAN BE MANAGED EFFECTIVELY AT HOME WITH ORAL MEDICATIONS AND OTHER THERAPIES. IF A PERSON BECOMES MORE DEPENDENT ON THESE, HOSPICE OR HOME CARE NURSES CAN HELP MANAGE A PERSON’S PAIN AND TEACH THE PERSON’S FAMILY MEMBERS TO HELP.

PALLIATIVE CARE

The goals of palliative care are to optimize quality of life by providing symptom management, pain control, and spiritual, emotional, and social support to patients and families facing the stresses of serious illness.

Palliative care differs from hospice as it is provided early and across the course of the illness. A person is not required to have a terminal illness to receive palliative care and it can be provided alongside aggressive life prolonging and curative treatment.

Palliative care is provided in many hospitals and in outpatient clinics. Recently, some home health agencies have begun to provide palliative services in the home.

Palliative care is not strictly regulated as is hospice. Services vary from one health care provider to another but, ideally, palliative care should be provided and coordinated by an interdisciplinary team.

What is the difference between hospice and palliative care?

All of hospice is palliative care, but not all of palliative care is hospice.

Hospice Care

Hospice care is a part of palliative care that was developed as a philosophy of caring for dying individuals. According to the National Hospice Association, the focus is on compassionate, quality care at the end-of-life. Hospice care involves a team-oriented approach that includes expert medical care, pain management, and emotional and spiritual support that is tailored especially to the dying person's needs and wishes. Support is also extended to the dying person's loved ones. Central to hospice care is the belief that every individual has the right to die pain-free and with dignity, and that our families will receive the necessary support to allow us to do so.

Hospice care concentrates on caring not curing and. In most cases, it is provided in the home of the terminally ill person, but it may also be provided in freestanding hospice facilities, hospitals, nursing homes, residential care facilities, and assisted living communities. Hospice services are available to persons of any age, religion, race, or illness.

Medicare, Medicaid and most private insurers cover hospice care if eligibility requirements are met. A patient is eligible if a physician determines that the patient has six months or less to live if the terminal illness runs its normal course. Patients must be re-assessed for eligibility at regular intervals, but there is no limit on the amount of time a patient can then spend under hospice care.

A person's physician, other health care professionals, family members, friends or clergy may recommend hospice care. Typically, a family member serves as the primary caregiver and, when appropriate, helps make decisions for the terminally ill person. Members of the hospice staff make regular visits to assess the ill person and to provide additional care or other services. Hospice staff is available 24 hours per day, seven days per week.

The hospice team develops a care plan that meets each terminally ill person's need for physical, psychosocial, and spiritual comfort and support. This plan outlines the medical and supportive services an individual requires such as nursing care, personal care (dressing, bathing, etc.) dietary and social services, physician visits, counseling and homemaker services. The plan is adjusted as a person's condition changes.

A Typical Hospice Team

- A personal physician
- A hospice physician or medical director
- Nurses
- Home health aides
- Social workers
- Clergy or other counselors
- Trained volunteers

- Speech, physical and occupational therapists, when needed.

Talking With Health Care Professionals

Communication with health care providers is one of the most important aspects of care at the end of life. Often these conversations are difficult for the terminally ill person, his or her provider and family members because it means sharing bad news that can be overwhelming and frightening. It is important to talk with the personal physician, but it might also be helpful to talk with other health care professionals. A person may want to learn as much as possible about his or her condition or only choose to know the general picture. It is always helpful to begin by asking the doctor to explain the clinical aspects of the disease. Understanding the typical progression of the condition will help a person to grasp what to anticipate in terms of what is happening, types of treatment, and the quality of life that can be expected. Try to bring a family member or friend along when you speak with the doctor. These people can help remember questions to ask and responses, which may be hard to recall when you are alone.

Questions to Consider When Discussing Treatment Options:

- What are the benefits of each treatment?
- What are the risks?
- How can one expect to feel during treatments?
- What kinds of services (e.g., hospice) may be available to help me and my family?
- What quality of life can be expected as I become more dependent?
- Will I be in pain?

Treatment plans can be developed to help manage a person's medical condition and to ensure comfort. The doctor should know the things that are important and give life meaning to you or to your loved one. This information is helpful in making decisions about the type of care that is provided. Express any fears and concerns that you may have, and let the doctor know if there is anything that you do not understand. Remember that a treatment plan can be changed at any time as a person's condition changes.

Talking with health care professionals is a process and it is recommended that you and your family develop a schedule of how frequently you have contact, with whom, and what to do when you have additional questions or concerns.

Talking With a Dying Person about Death

Friends and family members often have a difficult time interacting with a dying person because thinking of someone we love who is dying can make our own mortality seem very real. However, open and honest communication can help friends and family members connect with each other and prevent feelings of regret that arise when things are left unsaid.

Sometimes friends and family members worry that they will upset their dying family member by asking questions or by bringing up the topic of dying. Likewise, sometimes the dying person fears that family members will be upset if he or she begins a conversation about death.

Tips for Talking with the Dying

- Ask the dying person to share his or her thoughts and feelings.
- Just listen. If the person is in denial or does not wish to talk about it, respect that.
- Let the dying person know if you are feeling fearful or uncomfortable.
- Ask the dying person what he or she expects from you.
- Be honest about what you can offer.
- Be honest about what you feel comfortable talking about.
- Let the person know that you are available if he or she wants to talk.
- If you feel you are too upset to talk with the dying person, ask the dying person's provider for a referral to help you with your feelings.

Physical Changes when death is near

Sometimes it is important to know when death may be near, especially if you are the primary caregiver for a family member or loved one. There are experts to help you and your family and there are different physical signs that mean death is approaching. They are to be expected, and although they may be upsetting, symptoms can be very effectively managed through a variety of simple interventions or through the administration of medications. Hospice personnel are skilled at knowing how to respond to a person's needs as death nears and with keeping the family informed about what to expect.

Physical signs that may mean death is near

- Less interest in eating and drinking. For some, refusal of food is an indication that they are ready to die. Fluid intake may be limited to what keeps the mouth from feeling too dry.
- Urinary output may decrease in amount and frequency.
- As the body weakens, the person will sleep more and begin to detach from the environment. Attempts to make the person more comfortable may be refused as if he or she does not wish to be disturbed.
- Mental confusion may become apparent as less oxygen is available to supply the brain. The individual may also be disturbed by strange dreams.
- Vision and hearing may be impaired, and speech may be hard to understand.
- Secretions may collect in the back of the throat and rattle or gurgle as the person breathes through the mouth. He or she may try to cough up mucous, and the mouth may become dry and encrusted with secretions. Secretions may drain from the mouth if the individual is placed on his or her side.
- Breathing may become irregular with periods of no breathing or apnea lasting about 20 to 30 seconds. A person may seem to be working hard to breathe and may make a moaning sound with each breath. As death approaches, breathing may again become regular but shallower and more mechanical in nature.
- As the oxygen supply to the brain decreases, the person may become restless. It is not unusual at this point for individuals to pull at bed linens, to have visual hallucinations, or even to try to get out of bed.
- The person may feel hot one minute and cold the next as his or her body loses its ability to control temperature. As circulation slows, the arms and legs become cool and may be bluish in color. The underside of the body may darken and a pulse may be difficult or impossible to find.
- Loss of control of bladder and bowel functions may occur around the time of death.

Spirituality at the end of life

The period of time before a person's death can be one for growth and healing if supportive care is available to address the inevitable feelings of confusion, anger, sadness and fear. By addressing a dying person's spiritual needs, the friends and family members can facilitate feelings of emotional healing and peace.

Spirituality is sometimes equated with religion. They are not, however, the same. Spirituality is the compiled wisdom gained over a lifetime concerning existence and one's relationship with others and nature. Spirituality deals with the important events or experiences that bring a deep sense of belonging, trust and connectedness to a person's life.

Religion is one direct expression of spirituality. It is a specific organized belief system that has standards and beliefs that accompany a religious practice. Most often, religion is experienced through participation with others in set rituals. It is not uncommon for the dying to find comfort in the religion of their childhood even if they have not been religious or practicing a religion in the recent past. Therefore, friends and family members should support the dying person's desire to see a chaplain, religious leader, or pastoral counselor to discuss spiritual issues, provide guidance and offer comfort at the end of life.

Friends and family members may also be called upon to address the spiritual needs of a dying person. Questions regarding the meaning and purpose to life, presence of hope, peace, values and belief may become very important at this time, as the person seeks to understand what is happening and to gain support during the dying process. At the end of life, the expression of spirituality through organized religion may take on a greater meaning. Prayer, ritual, life review or conversations with others can heal relationships and comfort the dying person, as well as bring a sense of value and purpose to life.

Comforting the Dying

To provide comfort to someone who is dying, one should establish a bond of safety and trust. Listen with an open heart and without judgment or an agenda. Always treat a dying person with dignity and with respect for his or her beliefs. The dying often find value and meaning in remembering and reviewing the achievements, successes and disappointments in life, no matter how small or significant they may be. People want to believe that they made a difference in the world. They sometimes need to settle unresolved issues as a prelude to “letting go.” One can help bring peace of mind by simply being there to listen and offering empathetic support to the dying person in addressing these issues. One should express his or her interest, concern, and love. Just a gentle touch can be invaluable in conveying to a dying person that you care. Often, one of the most important gifts we can give others is our quiet presence.

Comforting the Family

Immediate family members may have their hands full of grief and may find it difficult to give support to one another. Their grief may be increased if they do not live nearby. Likewise, it may be difficult for you to provide support for others when you are actively grieving. If you are struggling with the loss of a loved one, during the dying person's life or after the death, a family member, friend, volunteers, social worker, or other counselor can help you. If you or a family member have seen a therapist or counselor in the past for some other life event, it may be helpful to renew that relationship. Their help and understanding can make a significant difference in the healing of grief.

Tips for Comforting the Grieving

- Say, "I'm sorry" or "I care."
- Listen. Let the bereaved tell you as much as they want when they are ready.
- Cry with them
- Reminisce
- Recognize that the bereaved may be angry.
- Be patient. Remember that mourning may take a long time.
- Be aware that grief may have physical symptoms such as lack of appetite, sleeplessness, headaches, and inability to concentrate. These affect the person's coping ability, energy and recovery.
- Encourage participation in bereavement support groups or grief counseling.
- Consider sending a note at the time of their loved one's birthday, anniversary, or death.

Providing comfort after the loss of a loved one can be particularly challenging when children are involved. However, providing them with support and allowing them to grieve can be very important in their healing process.

Talking with Children about someone who is dying

Open honest discussions that encourage children to ask questions are one of the most effective ways to communicate. When talking with children about death, it is important to use age-appropriate language. Always answer a child's questions. A child will often not need or want the same kind of information as an adult (for example, clinical details). No matter how children cope with death or express their feelings, they need empathetic and non-judgmental responses from adults. Careful listening and watching are important ways to learn how to react appropriately to a child's needs. Convey to the child that you want to hear his or her feelings and share your own emotions. If you repress your feelings, the child will be more apt to deny his or her own. Allowing a child to share his or her fears, anger and grief openly and without embarrassment can help both the child and adult to cope, accept and heal.

A child's concept of illness and death varies depending upon his or her age. Be sure that the child is aware of an impending death or lack of a "cure" so that he or she can feel included as part of the family dynamic. Do not avoid telling children about the "facts" so that they can understand the situation, interpret all that is happening around them and do their part to help out.

Tips for Talking with Children

- Maintain order and stability in the child's life
- Children cannot sustain emotional pain for long periods of time.
- Do not reject a child's emotions; do not tell him or her how either to feel or not to feel.
- Allow the child to comfort you.
- Be patient; children may need to ask the same questions over and over.
- Be sure to explain that death is not contagious.
- Avoid equating death with "going to sleep."
- Be sure to explain that death is not their fault.
- Children often need to idolize the dead; help them gently to regain balance and perspective.
- Encourage children to talk with a social worker, therapist, or school nurse if you feel they could benefit from hearing another perspective.

Resources

- American Bar Association Commission on Law and Aging
“Toolkit for Advance Health Planning”
<http://www.abanet.org/aging/toolkit/home.html>
- American Pain Society
An educational and scientific organization that is focused on advancing research education and treatment for people in pain.
www.ampainsoc.org
- Americans for Better Care of the Dying
A source for information and news about end-of-life issues, including legislative initiatives.
www.abcd-caring.org
- Caring Connections
Information on advance directives from other states
<http://www.caringinfo.org>
- Caregiver Action Network (formerly National Family Caregivers Association)
The Caregiver Action Network is the nation’s leading family caregiver organization working to improve the quality of life for the than 65 million Americans who care for loved ones with chronic conditions, disabilities, disease, or the frailties of old age.
<http://www.caregiveraction.org/>
- Center to Advance Palliative Care (CAPC): <http://www.capc.org>
- Choice in Dying, Inc.
A source that provides information on advance care planning and living will forms.
(800)-989-9455
- Connecticut Association for Health Care at Home
The Connecticut Association for Healthcare at Home is the industry champion for quality, cost-effective home health, hospice and community-based solutions.
<http://www.cthealthcareathome.org>
- Connecticut Coalition to Improve End-of-Life Care
An organization committed to developing a comprehensive approach to improving the care and support of dying patients and their families during end of life and bereavement.
<http://www.ctendoflifecare.org>
- Connecticut Department of Social Services: Aging Services Division
A state government site that provides Advanced Directives planning forms in both English and Spanish
<http://www.ct.gov/agingservices>

- The Dougy Center : The National Center for Grieving Children & Families
Provides support in a safe place where children, teens, young adults, and their families grieving a death can share their experiences.
<http://www.dougy.org>
- Infoline
A statewide health and human services information and referral service, which operates 24 hours per day, 365 days per year and provides assistance in English and Spanish.
Dial 2-1-1- in Connecticut,
<http://www.211ct.org/InformationLibrary/Documents/endoflifecare.asp>
- National Alliance for Grieving Children
Lists grief support service providers who serve children, teens and their families.
<http://nationalallianceforgrievingchildren.org>
- National Consensus Project for Quality Palliative Care
<http://www.nationalconsensusproject.org>
- National Hospice and Palliative Care Organization (NHPCO)
A comprehensive source for information about hospice and palliative care.
(703) 837-1500;
<http://www.nhpco.org>
- Office of the Attorney General – State of Connecticut
A source that provides information about and forms for advance care planning.
(860) 808-5318; <http://www.ct.gov/ag>