

# Seven Principles for Patient-Centered End-of-Life Care



## *Our Mission*

Compassion & Choices improves care and expands choice at the end of life.

We support, educate and advocate.

## *Support*

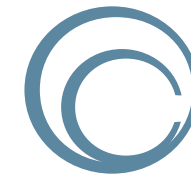
Using the power of choice and comfort to restore hope to individuals and their loved ones.

## *Educate*

Promoting informed decision making, educating the public and advising health care professionals.

## *Advocate*

Pursuing legal and legislative initiatives to secure comprehensive and compassionate options.



compassion & choices

Support. Educate. Advocate. Choice & Care at the End of Life.

## Seven Principles for Patient-Centered End-of-Life Care



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# Principles for Patient-Centered End-of-Life Care

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## 1. Focus. End-of-life care should focus on the patient's life and current experience.

Too often death is seen as a failure of treatment, not a natural event. This deprives patients of the opportunity to enter what Kubler-Ross calls "the final stage of growth."

Too often physicians either withdraw from patients in the terminal stage of illness, or encourage them to continue intensive therapies and not "give up."

## 2. Self-determination. Individuals vary in their tolerance for pain and suffering.

Only patients can determine whether they are suffering, or are suffering too much. They should receive state-of-the-art comfort care accordingly.

Providers should prescribe opioid analgesics generously for pain and breathlessness. Patients should control the dose and frequency of administration.

Symptoms such as hiccoughs, nausea, diarrhea, itching and fatigue can be oppressive and should not be disregarded.

## 3. Autonomy. Decisions about end-of-life care begin and end with the autonomous patient.

The answer to the question "who should decide?" is "the patient decides."

Even very ill patients usually retain decisional capacity. Loved ones and providers should avoid inadvertently usurping decisions when communication becomes difficult.

If patients are no longer capable of decision making, their known wishes still dictate decisions.

## 4. Personal Beliefs. Patients should feel empowered to make decisions based on their own deeply held values and beliefs, without fear of moral condemnation or political interference.

Law and policy should not put the provider's moral beliefs above the patient's, or protect providers who withhold vital information about treatment options.

Dying patients should not be subject to subtle or overt suggestions that their choices are wrong or immoral.

## 5. Informed Consent. Patients must have comprehensive, candid information in order to make valid decisions and give informed consent.

Patients should receive encouragement to exercise a "**BRAIN**" process assessing the:

**B**enefits,  
**R**isks,  
**A**lternatives, their own  
**I**nsight into what these mean to them,  
and consequences of doing  
**N**othing,

before giving consent to procedures and treatment.

Four crucial questions often go unasked or incompletely answered when a patient consents to disease-specific treatment:

*What is the chance it will prolong my life?*

*By how much?*

*What are the side effects?*

*What are the alternatives?*

Providers should never withhold information about legal alternatives. This deprives the patient of crucial information to give informed consent.

## 6. Balance. Patients should feel empowered to make decisions based on their own assessment of the balance between quantity and quality of life.

Patients may reject treatment because of unacceptable side effects.

Saying "no" to burdensome treatment may mean saying "yes" to the joyful experience of life for as long as possible.

## 7. Notice. Patients must have early, forthright and complete notice of institutional or personal policies or beliefs that could impact their treatment wishes at the end of life.

Dying patients often discover too late that the beliefs and values of their chosen health care provider limit end-of-life choices.

Consumers need clear, forthright, prominent notice of all such limitations in health plan marketing materials and enrollment documents. Restrictive policies of a religious or moral nature should be prominently displayed in entry areas of hospitals, clinics, pharmacies and other health care institutions.