

# Optimizing Nursing Care during End of Life

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# Optimizing Nursing Care During End of Life



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# Conflict of Interest Statement

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The presenter of this lecture does not have any relationship with industry or any commercial interests that might affect the presentation, and therefore has nothing to disclose.



# Objectives

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- List pharmacologic and non-pharmacologic interventions that may reduce pain and distress during end of life care
- Discuss the importance of educating the family and the patient about the physiologic process of dying
- Identify the components of the CARES tool



# Introduction

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- Many of the dying do not fear death as much as they fear how they will die. (Byock, 2012)
- Average initiation of comfort care plans occurred 9 days prior to death.
- 1/3 of the dying continued to receive active life sustaining treatment until death.
- Average prognosis of dying was made 3.8 days prior to death.
- 50% of terminally ill individuals die in pain.
- 80% of the dying will experience sub-optimally treated dyspnea and terminal restlessness or delirium before they die. (LeGrand & Walsh, 2011; Ong, Yee, & Lee, 2012)

# Statistics

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- By 2050, 88.5 million adults in the United States will reach age 65+ years accounting for 20.2% of the population. (Thurston, Wilson, & Hewitt, 2011).
- 85% of all deaths in the United States occur within this 65+ age group. (American Medical Association, 2012; Whitbourne & Whitbourne, 2011)
- 60% of this group will die in a hospital, and **80% to 90%** of their deaths will be expected. (Thurston, Wilson, & Hewitt, 2011).
- The average amount of time expended on end-of-life care education in medical and nursing programs is 15 hours. (Dickenson, 2007)



# Establishing an Acute Event

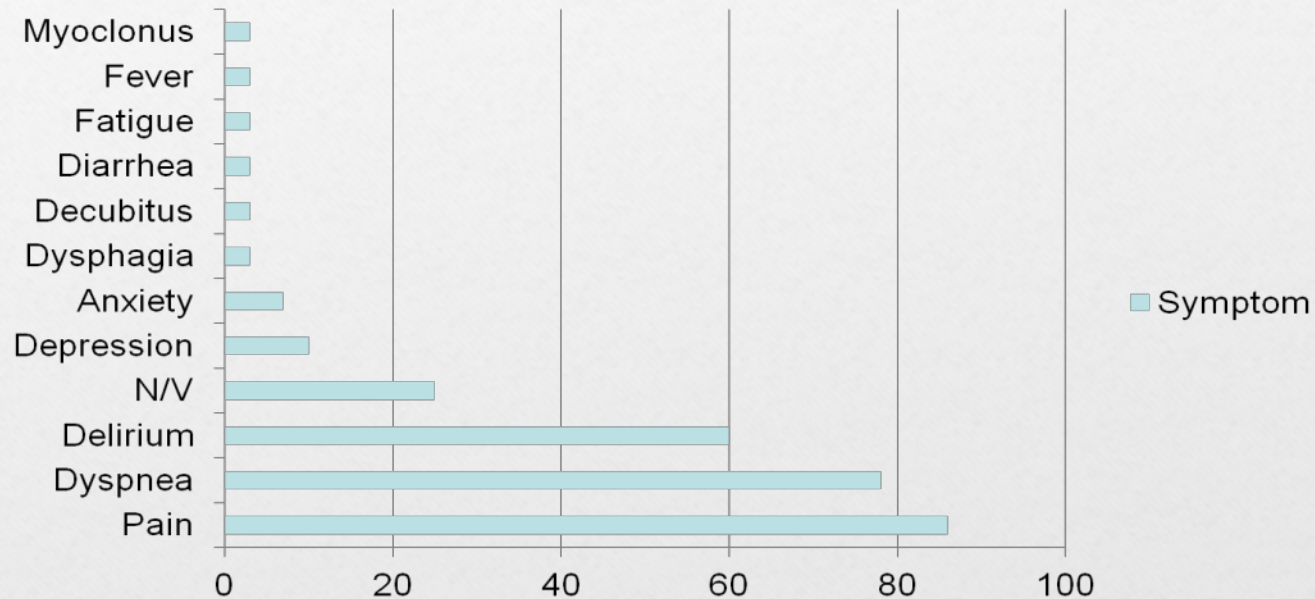
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- Care of the dying may not be high-tech, but it is definitely high-touch and deserving of treatment as an acute event. (Quill, 1998)
- The communication and high-touch skills required for quality end of life (EOL) care requires an emphasis in compassion, empathy, and acceptance of individual grieving processes and needs. (Ferrell & Coyle, 2010)



# Symptom Management Needs of the Dying (Freeman, 2013)

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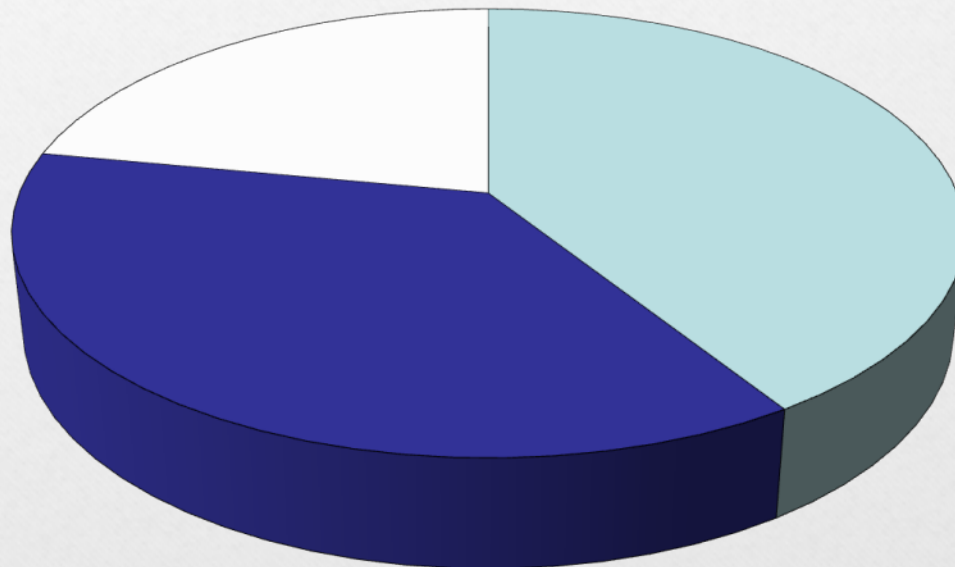




# Common Needs of the Dying

(Freeman, 2013)

Based on 68 Studies



- Symptoms 41%
- Spiritual 37%
- Self Care 22%

# The CARES Tool Organization and Considerations

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The CARES tool is an acronym organized educational tool that addresses the most common symptom management needs of the dying:

- **C**omfort
- **A**irway
- **R**estlessness and delirium
- **E**motional and spiritual support
- **S**elf-care.

Freeman, B. (2013). [CARES: An acronym organized tool for the care of the dying](http://www.medscape.com/viewarticle/803156).  
Journal of Hospice & Palliative Nursing, 15(3), 147-153.  
<http://www.medscape.com/viewarticle/803156>



# Comfort

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- Act as a patient advocate.
- 90% of patients die in pain (LeGrand & Walsh, 2011).
- If they were in pain before they became unresponsive, they are probably still in pain.
- There will always be a last dose.
- Intent.
- More likely to die of their disease than from the opioid.
- There is no maximum dose of opioids for pain control.



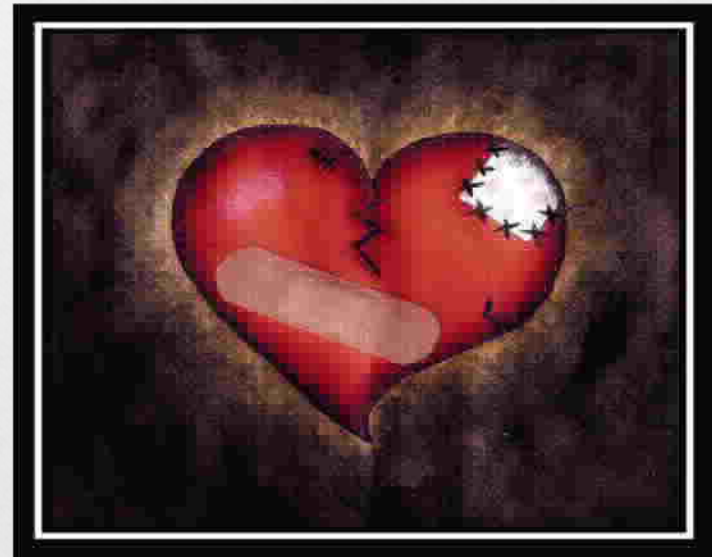
(Quill, 2006; Byock, 2012).

# The Focus of Care is Comfort

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Evaluate need for procedures, tests and activities.  
Provide as much time for the patient and family to be together as possible. (Ferrell & Coyle, 2010)

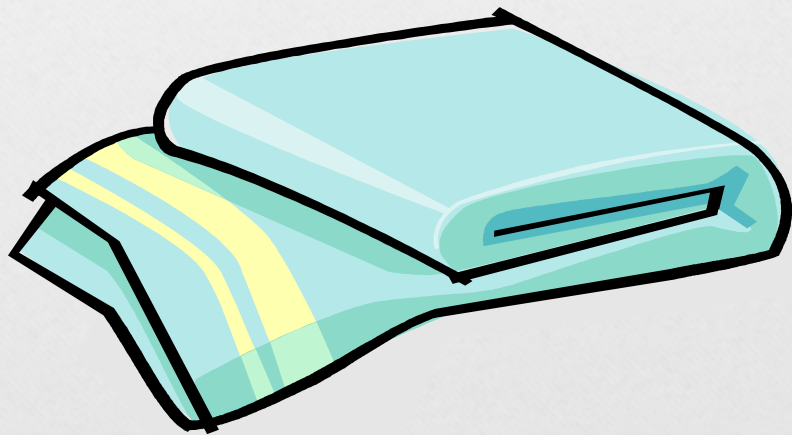
- Stop or modify vital signs.
- Stop nonessential medications.
- Clarify IV fluids.
- Stop or reduce tube feedings.
- Turn off monitors and alarms.
- Stop or decrease labs.
- Discontinue isolation.



# Comfort

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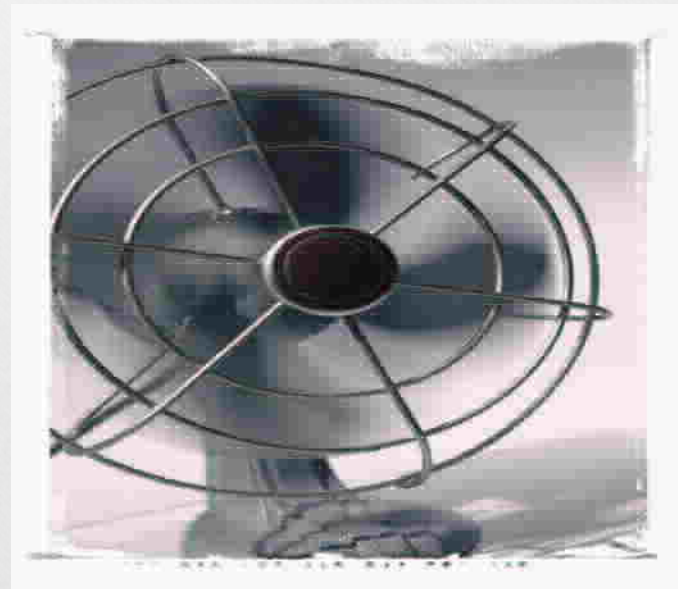
- **Never underestimate the power of a washcloth.**
  - Be a Patient and Family Advocate.
  - Explain the difference between a normal dying process and suffering.
- (Ferrell & Coyle, 2010)



# Airway

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- Shortness of breath can be reduced with use of a fan.
  - Explain agonal breathing vs. suffering.
  - Use of supplemental oxygen is more for the family.
  - Control death rattle.
  - Morphine is still the gold standard of care.
  - Emphasize use of touch and talking to patient.
- (Ferrell & Coyle, 2010)



# Restlessness and Delirium

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- Rule out treatable causes.
- Address possible unfinished business.
- Importance of saying good-bye and to give permission to stop fighting.
- Important family event or anniversary. (Ferrell & Coyle, 2010)

Educate the family:

- Patient lacks awareness of behavior.
- Possible to be peacefully confused.



# Restlessness and Delirium

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Let Grandma Stay in the Bahamas





# Emotional and Spiritual

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- **Caring for the soul.**
- Know your resources.
- Focus on retaining the patient's dignity and feelings of value.
- Every family is unique and grieves differently.

(Pulchalski & Ferrell, 2012)

**Good Communication is  
Essential.**



# The ELEPHANT in the Room

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# Emotional and Spiritual Support

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**Just be** with patient and family.

Work with family to provide favorite activities, smells, sounds, etc.

Support rituals.

**Your humanity is needed the most.**

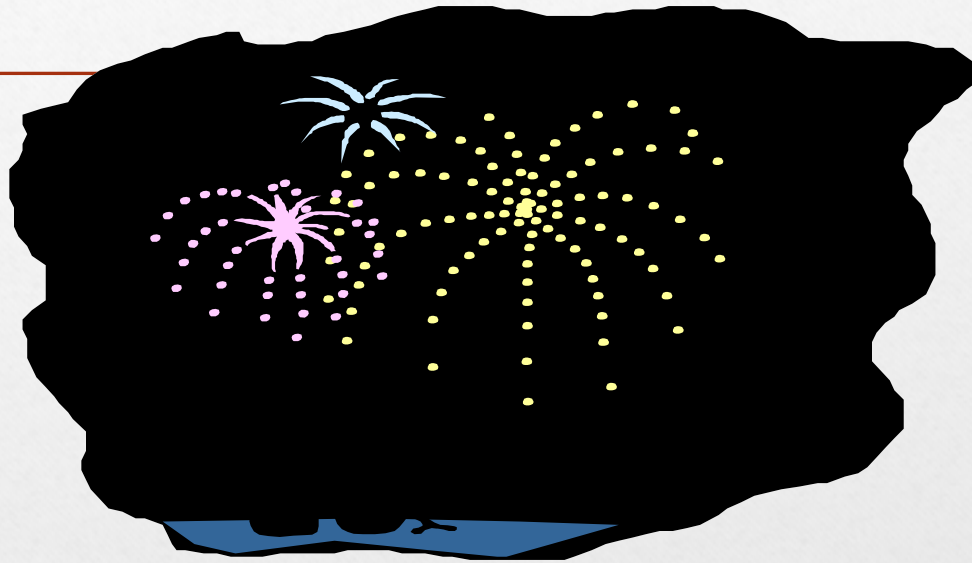
**Always be available.**

The **family** becomes your focus.

- Be sure families are getting rest and breaks.
- Provide coffee, water, etc.
- Continue to be available to answer questions.

(Ferrell & Coyle, 2010)

# Emotional and Spiritual

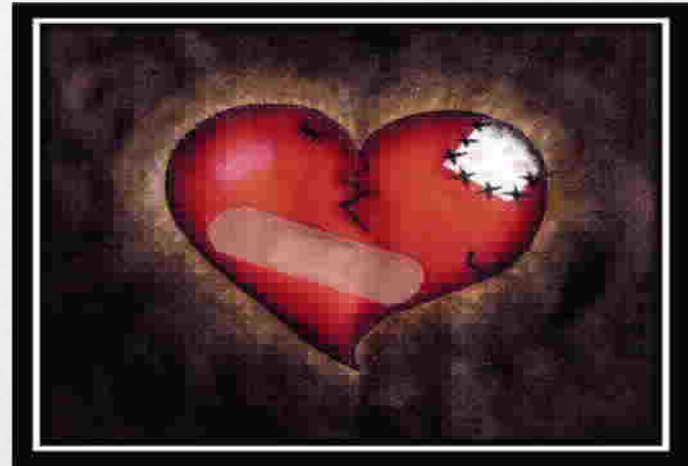


**Celebrate the Person.  
They are NOT their disease.**

# Self-Care

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- **Allow yourself to be human.**
- Professional grieving
  - Its okay to cry.
- Importance of debriefing
  - Tea for the Soul
  - Hope Rounds
- Challenges and privilege of assisting a fellow human being through the dying process. (Ferrell & Coyle, 2010)
- Acknowledging the spiritual impact of witnessing death.



# Self-Care Issues

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- Moral distress.
- Death anxiety.
- Exploring how your care made a difference.
- Reviewing effective communication techniques, available resources and support. (Lang, Thom, & Kline, 2008)

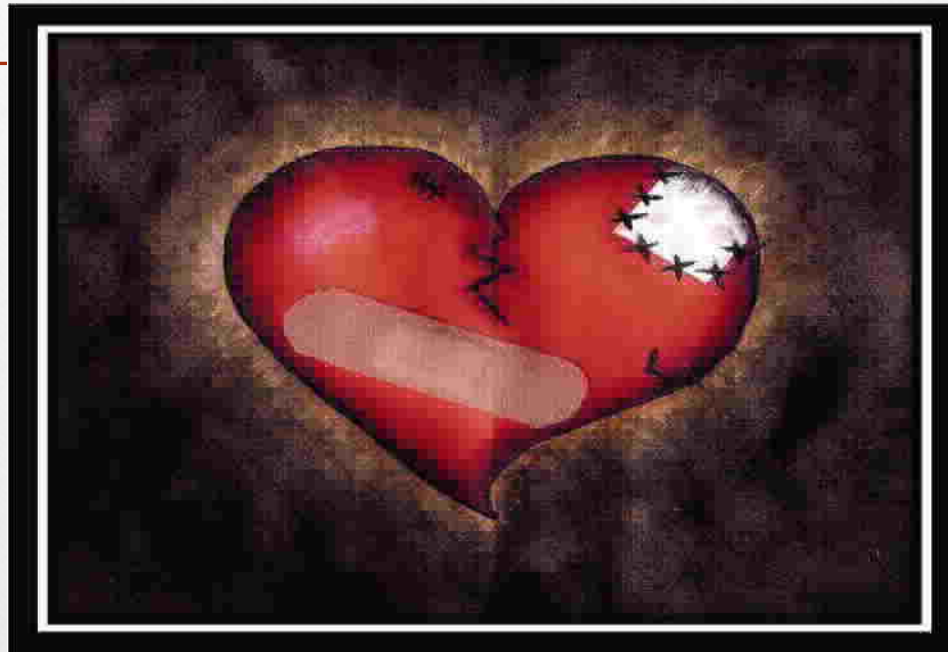


# Self-Care Pearls

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- Be realistic, don't believe the pedestal you were placed upon.
- You are not all-knowing or all-powerful.
- Acknowledge that a power greater than yourself will ultimately determine the fate of the individual.
- Find comfort in knowing you did your very best.
- Learn to celebrate the journey and the opportunity.
- Identify parallels or issues about death causing over-identification.
- Stay in the now and separate personal issues from what actually happened.
- Take the time to identify, explore, and work through personal issues that surfaced.
- Personal growth occurs best when the heart is most broken, identify it.

# Putting It Into Practice





# Audience Response Question

*Are you ready to  
answer?*



# The most common symptom management need of the dying is:

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- A. Delirium
- B. Pain
- C. Nausea
- D. Dyspnea



# Pain is:

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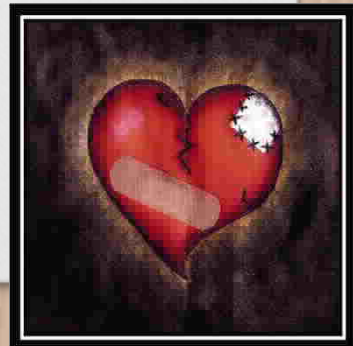
- A. Holistic
- B. Rarely just physical
- C. Influenced by culture, life experiences, emotions, and spiritual beliefs.
- D. All of the above



# The best example of a nurse acting as a patient advocate is when he or she:

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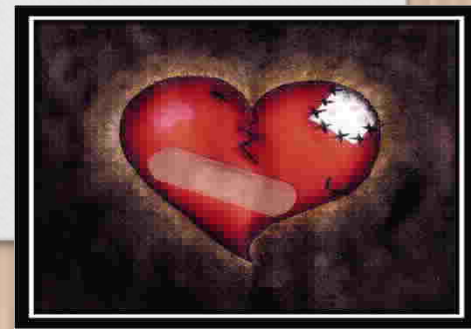
- A. Takes the lead in obtaining goals set by the patient and their family.
- B. Ensures care is patient- and family-focused.
- C. Promotes communication.
- D. Promotes and nurtures transcendence and hope.



# The best method to promote a peaceful death occurs when:

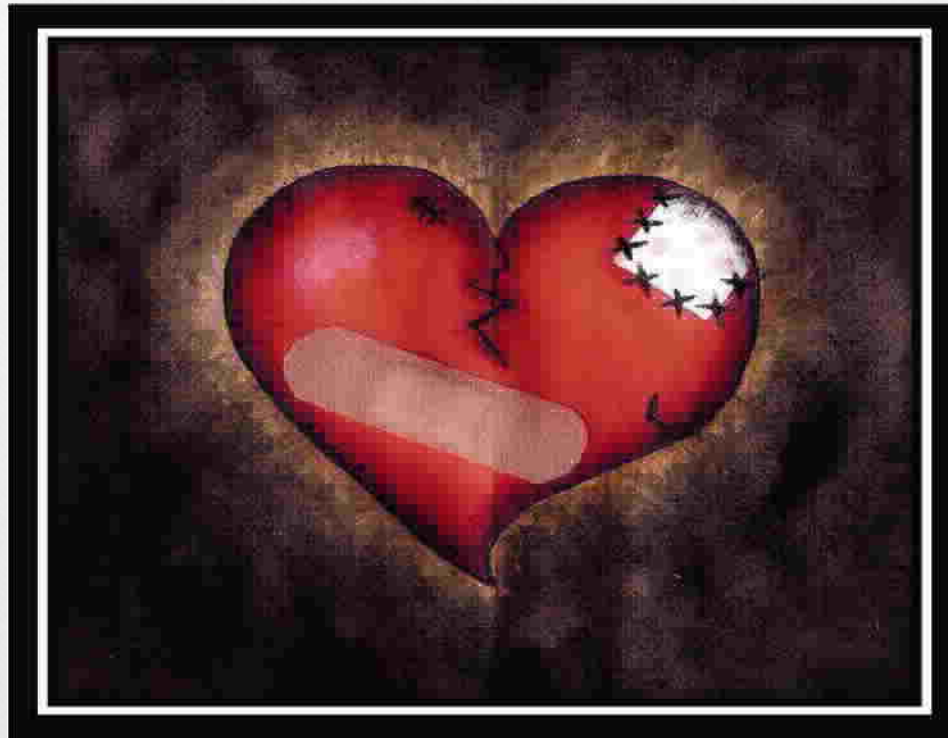
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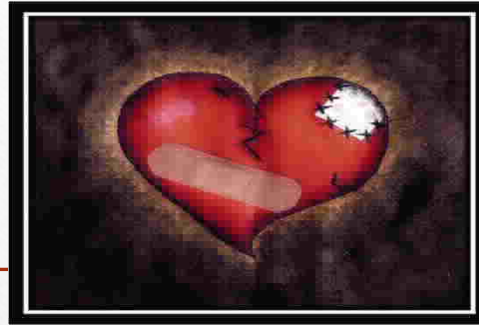
- A. Suffering is controlled and symptoms are managed.
- B. The family has closure and unfinished issues are resolved.
- C. Dignity is preserved and feelings of being loved and valued were addressed.
- D. A peaceful atmosphere achieved and a supportive presence is provided.



# Conclusions and Resources

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“It is the power of our own humanity that can make the difference in the lives of others. We must value this as highly as our own expertise”

(Puchalski & Ferrell, 2010).



“...there are worse things than having someone you love die. Most basic, it is having the person you love die badly, suffering as he or she dies. Worse still is realizing later on that much of his or her suffering was unnecessary.” (Ira Byock, 2012)



# Resources

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## **ELNEC:**

The End-of-Life Nursing Education Consortium (ELNEC) Project is a national end-of-life educational program administered by City of Hope (COH) and the American Association of Colleges of Nursing (AACN) designed to enhance palliative care in nursing. The ELNEC Project was originally funded by a grant from The Robert Wood Johnson Foundation with additional support from funding organizations (Aetna Foundation, Archstone Foundation, California HealthCare Foundation, Cambia Health Foundation, Milbank Foundation for Rehabilitation, National Cancer Institute, Oncology Nursing Foundation, Open Society Institute/Foundation, and the US Department of Veterans Affairs). Further information about the ELNEC Project can be found at: [www.aacn.nche.edu/ELNEC](http://www.aacn.nche.edu/ELNEC).

# Resources

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## **CITY OF HOPE PAIN & PALLIATIVE CARE RESOURCE CENTER (COHPPRC)**

The COHPPRC, a clearinghouse to disseminate information and resources that will enable other individuals and institutions to improve the quality of pain management and palliative care. The COHPPRC, established in 1995, is a central source for collecting a variety of materials including pain assessment tools, patient education materials, quality assurance materials, research instruments and other resources. Website: <http://prc.coh.org>

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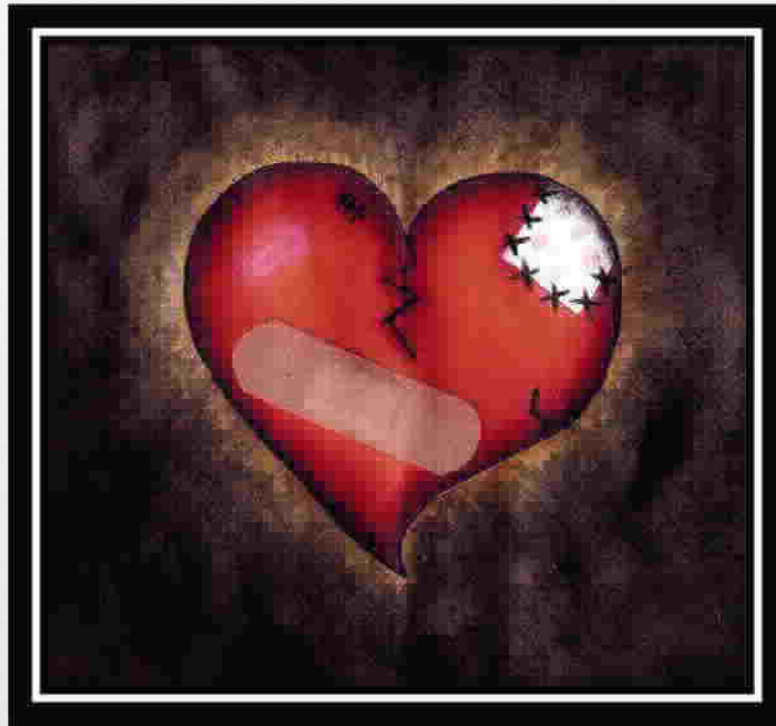
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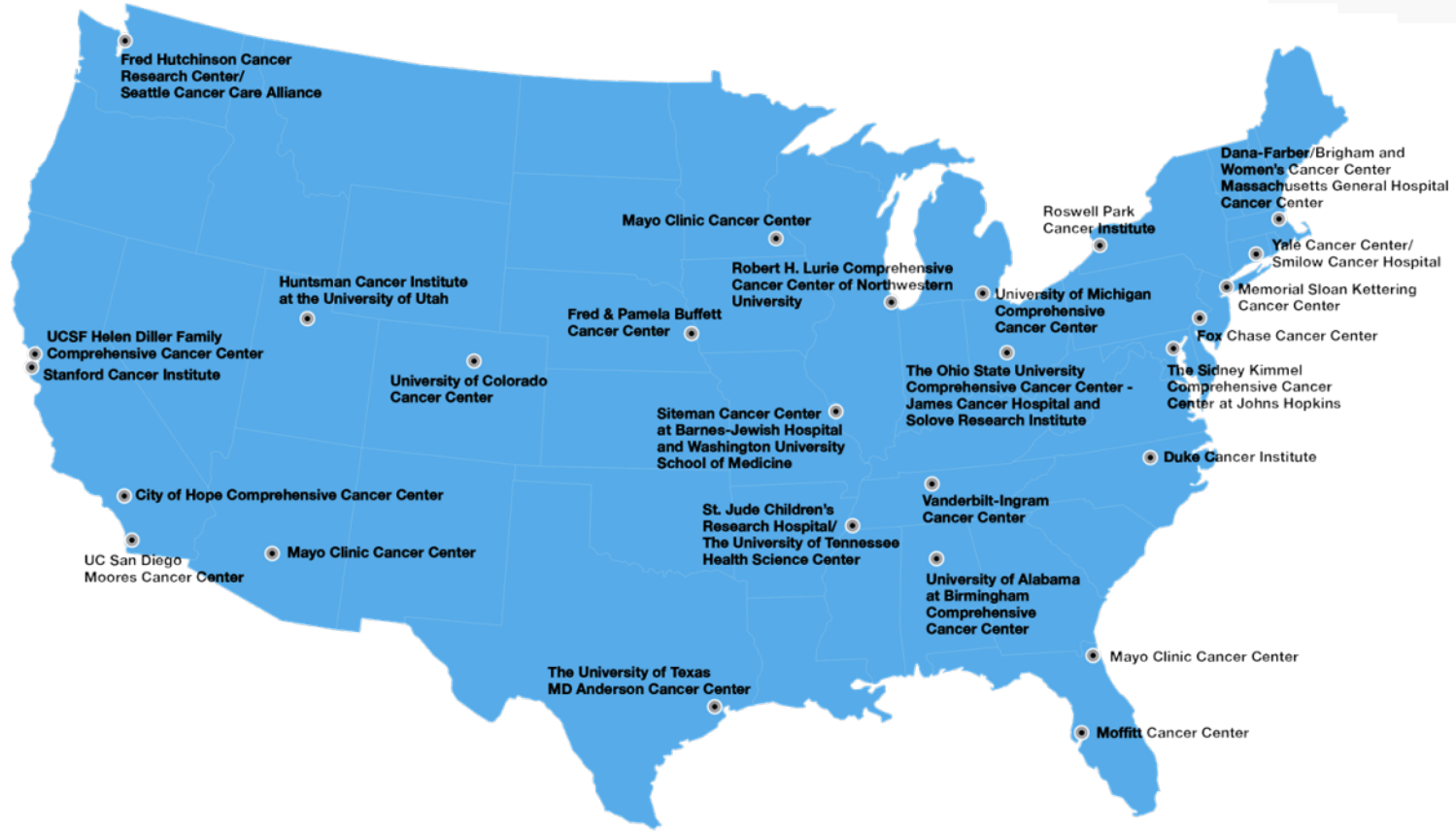
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# The Beginning

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