

**A Good Death:  
It Takes A Village**

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Nursing Grand Rounds  
September 13, 2017



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**Learner Outcomes**

- Recognize the importance of “presence” as a bedside provider supporting families of a dying child.
- Identify strategies and tasks that occur simultaneously while a child is actively dying.



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**A Good Death:**  
A Nurses Perspective

Presented by:  
Annamarie Borich, RN



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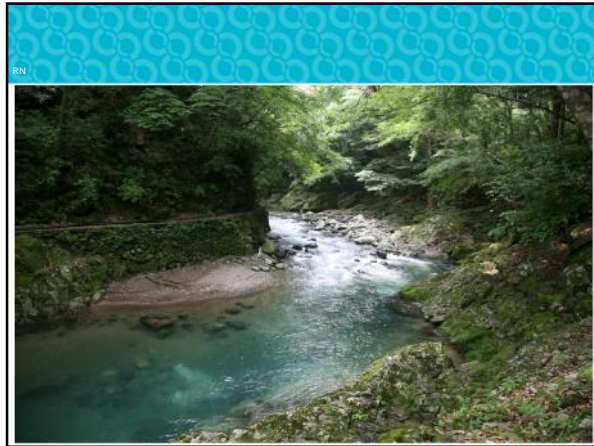
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RN

### Mindfulness in Death and Dying

- Once patients and their families enter the medical world , (...) their actions are guided by the values and pervasive practices of that world. Kaufman (2000)
- Dying may be an important part of living. Framing it as an unnecessary part of life may have damaging consequences for individuals, for families and for society. Cottrell & Duggleby (2016)
- Denying dying may preclude families from creating significant moments and from forming important memories to carry into subsequent generations. Cottrell & Duggleby (2016)



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RN

### Four Key Elements Influence Quality of Death Experience

- Dignity
- Preparedness
- Physical suffering
- Community



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RN

### Clinically Relevant Factors

- Communication
- Pain and symptom management
- Clinical expertise
- Palliative care service
- Patient goals match prescribed treatments



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RN

### MAKING A DIFFERENCE

- Stay informed on current best practices
- Communication on end of life matters
- Bedside compassion
- Manage pain
- Attend to non-medical needs, coping and social support
- Tailor treatment to patient wishes
- Timely referrals to Hospice and Starshine



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RN



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RN

Denying dying may destroy individuals' opportunities to grow, to find meaning, hope, and joy, and to live fully until they die.

Cottrell & Duggleby (2016)



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Physician

# A Good Death:

A Physician's Perspective

Presented by:  
Krista Nee, MD



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Physician



Guilt is perhaps the most painful companion of death.

Coco Chanel

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Physician

### What are the components of a good death?

- Clear communication
  - Patients and families know death is coming
  - Time to process and ask questions
  - Opportunities to express hopes and fears



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Physician

### What are the components of a good death?

- Symptom management
  - Pain
  - Dyspnea
  - Delirium/agitation
  - Anxiety
  - Depression



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Physician

## Pain

- Opioids do not have a "ceiling effect"
- The correct dose is that which provides adequate analgesia with acceptable side effects

**Non-Opioids**  
- Acetaminophen  
- NSAIDs

**Opioids**  
- "Personal Level"  
- "Nursing (Agency)"

**WHO-Principles**  
- "No ceiling"  
- "No ceiling"  
- "No ceiling"  
- "No ceiling"

**Integrative Therapies**  
- Massage  
- Heat/Cold  
- Acupuncture  
- Yoga  
- Tai Chi

**Adjuvants**  
- Antidepressants  
- Anticonvulsants  
- Muscle Relaxants  
- Corticosteroids  
- Medication  
- Non-pharmacological  
- Mindfulness

**Invasive Approaches**  
- Regional Anesthesia  
- Epidural  
- Spinal Cord Stimulation  
- Intrathecal  
- Intravenous  
- Intracranial

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Physician

## Dyspnea

- Treat the underlying disease
- Opioids are the mainstay of management
- Oxygen has not been shown to be beneficial
- Non-pharmacological therapies

**Physical**  
E.g. COPD, Emphysema, Lung cancer

**Psychological**  
E.g. Anxiety, Coping strategies, Catastrophizing

**Social**  
E.g. Spouse, Culture, Financial

**Spiritual**  
E.g. Meaning, Beliefs, Values

**TOTAL DYSPNOEA**

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Physician

## Delirium/agitation

- Antipsychotics (i.e., haloperidol, olanzapine)
- Benzodiazepines

**NORMAL**

**THE USUAL ROAD**  
Dyspnea → Confusion → Lethargy → Comatose → DEATH

**THE DIFFICULT ROAD**  
Restless → Confused → Hallucinations → Paralytic sedation → Intubation → Sutures → Comatose → DEATH

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Physician

## What are the components of a good death?

- Education and managing expectations around normal dying process

**A**

Component	Days from death
Diagnosis of illness	14
Decreased level of consciousness	12
Palliative performance scale <math>\leq 200</math>	10
Peripheral cyanosis	8
Cheyne-Stokes breathing	6
Urine output over last 24 hours <math>< 100</math> ml	4
Apnoe periods	4
Respiration with irregular movements	4
Death rattle	4
Pulslessness of radial artery	2

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Physician

## What are the components of a good death?

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Social Worker

## A Good Death:

A Social Workers Perspective

Presented By:  
Wanda Meriwether, SW

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Social Worker

- Being involved with a social worker may be new to some families. Sometimes having social work involved can have a negative connotation. i.e. (there must be a problem)
- Patients and family's can have social work involvement throughout their medical journey. Relationship may start due to a emergent need



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Social Worker

### Social Work Support

- Maintaining a relationship with patient and family becomes key during discussions regarding treatment, progression/relapse, and end of life concerns.
- Patient and family start to feel comfortable to share with social worker concerns and fears regarding end of life decisions.
- Discussions start early on with young adults and adolescents regarding decision-making and advance directives (over the age of 18 years old).



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Social Worker

### Multidisciplinary Team Approach

- Providing support to the patient and family at end of life becomes a multidisciplinary team approach.
- Social Workers work closely with the primary oncologist/ medical team, palliative care, child life, chaplains, behavioral medicine, nursing, music and holistic therapy.



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Social Worker

### Key Elements to a Multidisciplinary Model

- Honor the wishes of patient/family
- Provide comfort care and coping support
- Address issues of anxiety/depression
- Assist in memory making
- Address spiritual needs.
- Provide clarity regarding end of life issues.



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Social Worker

### Addressing Difficult Decisions

- Social Worker often acts as a sounding board for families as they process end of life concerns that have been discussed with the medical team. Often the family feels that the team has given up hope when addressing end of life concerns.
- Families can experience judgment for extend family members/community regarding decisions. Viewed as giving up on love one.
- Being able to provide supportive listening allows families to not feel judged by their decision, and be able to come to terms with impending death.



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Social Worker

### Preparing for Death

- As end of life approaches- social worker's assist patient and family in making decisions regarding being at home with the support of hospice or in the hospital.
- Discussions can also include making special memories (visits or outings), how much information to share with family/friends, and funeral expenses.



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Social Worker

### During the Death

- Peaceful death includes the family coming together for the patient.
- Having time after the death to be alone as a family.
- Allowing parents, caregivers, spouses, and extended family to participate in cleaning the body.




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Social Worker

### After the Death

- Social Work role continues after death with family.
- Along with Bereavement Coordinator, social worker maintains contact with family after death by making a phone call two to three weeks after death.
- Phone call is provided to let know family know that they are not forgotten.
- Social Worker will often schedule a meeting with primary medical team and nursing staff that provided care to patient when family is ready to visit.




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Chaplain

## A Good Death:

### THE ROLE SPIRITUAL CARE

Presented By:  
Judy McBride, MDiv, MA, LPC, BCC, CPLC




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## Religion vs Spirituality



**religion**

- : the belief in a god or in a group of gods
- : an organized system of beliefs, ceremonies, and rules used to worship a god or a group of gods
- : an interest, a belief, or an activity that is very important to a person or group




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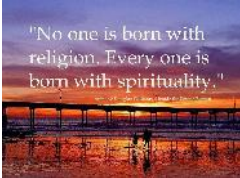
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## Religion vs Spirituality



In this question, spirituality is a noun that means concern with matters of the soul. Spirituality has to do with the spirit, not as in ghosts, but as in the essence of being human — your soul or your inner life.

spirituality - Dictionary Definition :  
Vocabulary.com  
[www.vocabulary.com/dictionary/spirituality](http://www.vocabulary.com/dictionary/spirituality)




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## Why Spiritual Care at End of Life?

Spiritual care is an essential aspect of the delivery of palliative care. The diagnosis of a life-threatening illness often results in the person reflecting on the meaning of life with concomitant spiritual, religious and existential questions. In fact, spiritual and religious needs and concerns may be equally, and sometimes more, important than those physical in nature.

The National Agenda for Quality Palliative Care: The Essential Elements of Spirituality in End-Of-Life Care. Katrina Scott, Mary Martha Thiel BCC, Constance M. Dahlin, Chaplaincy Today, Volume 24 Number 2, Autumn/Winter 2008.  
[http://www.professionalchaplains.org/files/publications/chaplaincy\\_today\\_online/volume\\_24/number\\_2/24\\_2scott.pdf](http://www.professionalchaplains.org/files/publications/chaplaincy_today_online/volume_24/number_2/24_2scott.pdf)




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## A GOOD (SUPPORTED) DEATH: SPIRITUAL CARE

- Assessment
- Empathetic Presence
- Normalization of Patient/Family Experience
- Exploration of Sources of Hope & Meaning
- Affirmation of Sources of Strength & Comfort
- Reframing
- Diversional & Life-Affirming Activities
- Prayer, Rituals & Observance of Religious Practices

EndLink: An Internet-based End of Life Care Education Program  
<http://endlink.lurie.northwestern.edu>  
 PART IV: BASIC SKILLS AND TECHNIQUES IN PROVIDING SPIRITUAL CARE  
[http://endlink.lurie.northwestern.edu/religion\\_spirituality/part\\_four.pdf](http://endlink.lurie.northwestern.edu/religion_spirituality/part_four.pdf)




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## RELIGIOUS BELIEFS AND TRADITIONS AT END OF LIFE

**Keep in mind...**

- Everyone is unique, so be sure to ask and verify
- Usually different expectations of or exceptions for children
- Sensitivity and respect matter more than expertise




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## Islam – Beliefs & Rituals

- God's plan – "Life and death is in God's hands."
- Reciting verses from the Koran and praying for peaceful departure of the soul very important.
- May want to position the body in direction of Mecca.
- Gathering memories, such as handprints or footprints as well as photographs of the baby, may cause distress to a Muslim family. This may be considered a desecration of the body.
- Muslim practice is to bury rather than cremate the dead.
- Postmortems are not agreed to unless required by law.
- Preparation for burial involves ritual washing of the body by next of kin (and same gender as deceased) then wrapped in white cotton.

<http://www.endoflifechoices.org/religious-cultural-affairs/child-care-and-conscience-of-pediatric-palliative-care.pdf>




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## Hindu – Beliefs & Rituals

- Things happen because they are predestined, actions in the present life are the result of sins in a past life. Death is viewed as rebirth, the transition to another phase of the life cycle
- After a death, readings from the Bhagavad Gita (holy scriptures) are conducted by Brahmin priests or elders from the upper caste community.
- A relative then bathes and anoints the body, males washing males and females washing females.
- After a tulasi (basil) leaf is placed in the mouth, the body is dressed in white cloth and is faced north with the feet facing south in preparation for rebirth.
- These preparations are vital to ensure purity surrounding rebirth and the final transmigration of the soul.

<http://www.cincinnatichildrens.org/healthcare/faithandspirituality/hinduism>




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## Jewish – Beliefs & Rituals

- When a Jewish patient dies, nurses should always try to contact the patient's rabbi or the Jewish chaplain designated to the hospital. If they are not available, staff are permitted to carry out basic procedures immediately. These include closing the eyes and mouth, with strapping if necessary. Any external catheters and medical equipment attached to the body may be removed and all incisions should be dressed.
- It is essential that the body is laid flat, with hands open, arms parallel and close to the body, and the legs stretched out straight. There is no need to remove identification bracelets or wash the body as the Jewish Burial Society will prepare it for burial.
- It is traditional for relatives or friends to keep vigil by the body and recite prayers. If possible, their wishes should be accommodated. Although the recital of prayers is encouraged, there is no concept in Judaism of last rites.
- A Jewish burial should take place as soon as possible after death and arrangements for the release of the body should be made without delay. Even if the patient had not been a particularly observant Jew, he or she would want to hasten the burial. But if death occurs on the Sabbath or a festival, there is little that the Jewish community can do to prepare for a funeral.

<http://www.cincinnatichildrens.org/healthcare/faithandspirituality/judaism>




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Chaplain

## Christian – Beliefs & Rituals

- Usually no preference for same-gender care
- May want their own clergy/faith representative present
- May request baptism or blessing or prayers
- Roman Catholic Catechism recognizes "In case of necessity, anyone, even a non-baptized person, with the required intention, can baptize, by using the Trinitarian baptismal formula."
- Roman Catholic "last rites" encompass several sacraments, including penance (confession of sins), viaticum (holy Communion given as food for the journey to eternal life) and the anointing of the sick.
- Autopsy and cremation or burial are personal choices




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Child Life

# A Good Death:

A Child Life Perspective

Presented By:  
Rachel Franklin, MS, CCLS



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Child Life



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Child Life



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## Overarching Goals

- Psychosocial care: whole family system
- Individualized: reflect beliefs, preferences, communication styles, defined as meaningful
- Ongoing collaboration with psychosocial and medical team
- Grief support: education, play, emotional support
- Legacy-building and memory-making



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Child Life

## Preparation for the Child or Adolescent

- Education, preparation and emotional support tailored to cognitive and emotional level
- Anticipation of developmentally-appropriate questions, concerns, misconceptions
- Involvement or presence of trusted adults/caregivers
- Information about physiologic and physical happenings
- Promoting control, choice, and comfort



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Child Life

## Medical Play



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Child Life

## Support for Siblings

- Follow guidelines for talking with and supporting patient
- Impact of situational factors
- Teach positive coping behaviors
- Double loss created, social isolation, own health concerns
- Cognitive, emotional, behavioral changes or difficulties



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## Guidelines for Interventions with the Child and Siblings

- Provide creative outlets for difficult emotions
- Create open communication but do not force it
- Allow children and adolescents time to say good-byes
- Allow them to decide when and with whom they want to share feelings of grief
- Promote routine, normalcy, and play or age-appropriate activities



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Child Life

## Therapeutic & Expressive Activities



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Child Life

## Therapeutic & Expressive Activities



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Child Life

## Keepsake Boxes



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Child Life

## Support for Caregivers

- Encourage self care
- Provide support and education focused on assessing and promoting patient and sibling coping
- Assist in facilitating family conversations
- Support caregiver in having opportunities for continued, familiar caregiving or parenting roles



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Child Life

## Involvement in Decision-Making

- Help the child live their available days
- Allow patient to engage in age-appropriate decision-making surrounding details related to death event (partnership with team, caregivers)
- Helping a child know what to expect with treatments and body changes
- Expressing wishes, giving items, post-bereavement planning
- Preparation for funeral or memorial events



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Child Life

## Building Legacy and Memories

- Beads of Courage
- Photographs
- Storytelling, special routines, and comfort items
- Ink Prints
- Lock of hair
- Canvas printing
- Plaster hand molds



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Child Life

## Beads of Courage



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Child Life

# Photographs



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Stronging the future together

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Child Life

# Photographs



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Stronging the future together

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Child Life

# Storytelling, Special Routines, and Comfort Items



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Child Life

### Ink Prints



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Child Life

### Ink Prints



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Child Life

### Lock of Hair



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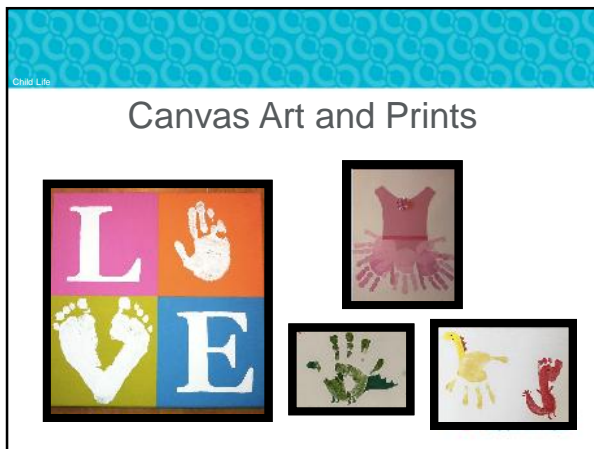
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Child Life



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Music Therapy

# A Good Death:

A Music Therapists Perspective

Presented By:  
Alexa Economos, MMT, MT-BC

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Music Therapy

is the clinical and evidence-based use of music within a therapeutic relationship to address physical, emotional, cognitive, and social needs of individuals.



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Music Therapy

In the best case scenario, there has been a music therapy relationship established prior to the days and hours before dying.

- Relationship with the patient
- Relationship with the family
- Assessment of goals and wishes for music therapy process

(Economos, 2015)



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Music Therapy

### Legacy Music

- Songwriting or original compositions
- Heartbeat Recordings (Schreck, 2015)
- Song dedications
- Musical autobiography

(O'Callaghan, 2013)



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Music Therapy

### Songwriting Piece



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Music Therapy

## What does music therapy look like during the dying process?

- Complementary pain and anxiety management (Bradt & Dileo, 2010)
- Shifting focus to family's needs (Krout, 2003)
- Facilitating meaningful shared experience
- Music as a catalyst for difficult conversations (Hogan, 2003)


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Music Therapy

## In defense of beauty

- Transforming the experience and the environment
- Creating something beautiful from something painful
- Facilitating final moments of connection
- Connecting with spirituality through music (Potvin & Argue, 2014)

(Economos, 2015)





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Music Therapy

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