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ONLINE CONTINUING EDUCATION FOR THE LIFE OF YOUR CAREER

End-of-Life Care for the SLP Part 1: How and where we die

Amanda Stead, PhD, CCC-SLP

Moderated by:
Amy Natho, MS, CCC-SLP, CEU Administrator, SpeechPathology.com

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- Must pass 10-question multiple-choice exam with a score of **80%** or higher
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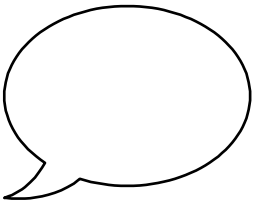
- Two opportunities to pass the exam

End-of-Life Care for the SLP Part 1: How and Where We Die

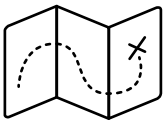


Hello!

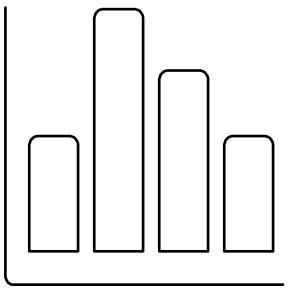
Amanda Stead, Ph.D., CCC-SLP,
Associate Professor CSD
Pacific University

Learner Outcomes

- Describe major physiological changes at the end of life.
- List similarities and differences between hospice and palliative care.
- Describe issues related to providing quality end-of-life care.
- Identify goals of care for the dying patient.
- Describe how and where people die in the US.



Dying in America



Average life expectancy 78.6 years
Up from 70 years in 1980 & 51 years a century ago

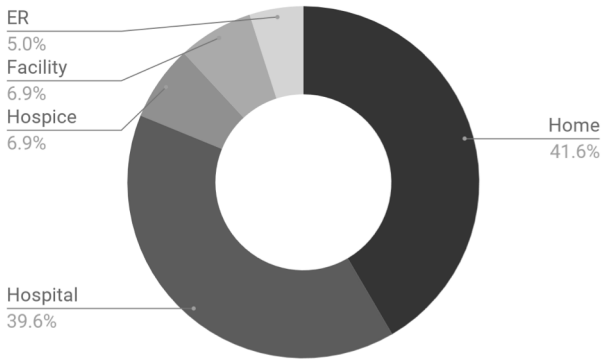
Leading Cause of Death is Heart Disease
Accounting for nearly 600,000 deaths in 2016

For the past 3 years life expectancy in the US has declined
A trend driven by Drug Overdoses and Suicide

National Center for Health Statistics. (2019, April 22). Retrieved April 24, 2019, from https://www.cdc.gov/nchs/

´“The medicalization of dying has shifted the experience of aging and dying, bringing therapeutic professionals in close contact with those that need support communicating their end of life wishes.” -Pollens

Where we Die



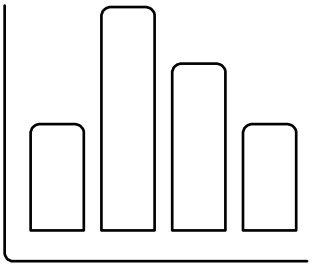
The Final Year: Visualizing End of Life. (2018, July 30). Retrieved April 21, 2019, from https://www.arcadia.io/final-year-visualizing-end-life/

Where we Die

- Many patients move from home to hospice to hospitals and back during the last 30 days of life.
- Some end up in the hospital because their pain or symptoms weren't adequately controlled at home.

The Final Year: Visualizing End of Life. (2018, July 30). Retrieved April 21, 2019, from https://www.arcadia.io/final-year-visualizing-end-life/

"Your chances of avoiding the nursing home are directly related to the number of children you have,"
— Atul Gawande, Being Mortal: Medicine and What Matters in the End



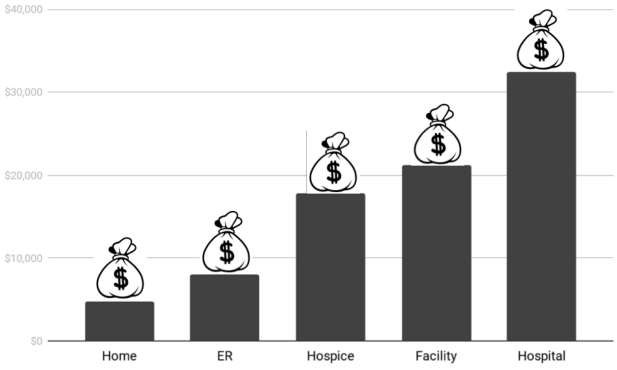
4 of 5 People Who Die in the United States are covered by Medicare
2.1 of 2.6 million deaths

14% of Total Medicare Expenditures are spent on EOLC in 2016
A decrease from 19%

$10.4 Billion spent on Medicare Hospice Benefit
An increase from $2.3 Billion

Source: Kaiser Family Foundation analysis. Original data and detailed source information are available at kff.org/JAMA_11-01-2016.
Please cite as: *JAMA*. 2016;316(17):1754. 10.1001/jama.2016.15577

Cost of Where We Die



The Final Year: Visualizing End of Life. (2018, July 30). Retrieved April 21, 2019, from https://www.arcadia.io/final-year-visualizing-end-life/

30%

The number of families impoverished in the dying process

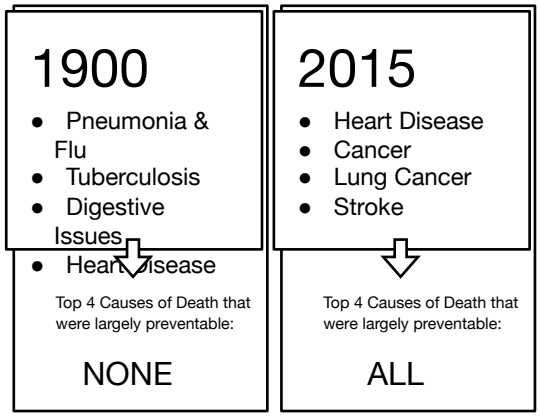
How we die

Number of deaths for leading causes of death (2017)

- Heart disease: 635,260
- Cancer: 598,038
- Accidents (unintentional injuries): 161,374
- Chronic lower respiratory diseases: 154,596
- Stroke (cerebrovascular diseases): 142,142
- Alzheimer's disease: 116,103

National Center for Health Statistics. (2019, April 22). Retrieved April 24, 2019, from https://www.cdc.gov/nchs/

Things Have Changed



Physiology of the Dying

What's Happening?

- The body is shutting down
- People begin to sleep more and more
- People need less nourishment
- People can because nauseous or have incontinence as their body is less able to process food and waste.

**The most common symptom of dying is fatigue

Pre-Active Dying

- Increased restlessness, confusion, agitation, inability to stay content in one position and insisting on changing positions frequently (exhausting family and caregivers)
- Withdrawal from active participation in social activities
- Increased periods of sleep, lethargy
- Decreased intake of food and liquids
- Beginning to show periods of pausing in the breathing (apnea) whether awake or sleeping

SIGNS AND SYMPTOMS OF APPROACHING DEATH. (n.d.). Retrieved April 21, 2019, from https://hospicepatients.org/hospic60.html

Pre-Active Dying

- Patient reports seeing persons who had already died
- Patient states that he or she is dying
- Patient requests family visit to settle "unfinished business" and tie up "loose ends"
- Inability to heal or recover from wounds or infections
- Increased swelling (edema) of either the extremities or the entire body

SIGNS AND SYMPTOMS OF APPROACHING DEATH. (n.d.). Retrieved April 21, 2019, from https://hospicepatients.org/hospic60.html

Active Dying

- Inability to arouse patient at all (coma) or, ability to only arouse patient with great effort but patient quickly returns to severely unresponsive state (semi-coma)
- Severe agitation in patient, hallucinations, acting "crazy" and not in patient's normal manner or personality
- Much longer periods of pausing in the breathing (apnea)
- Dramatic changes in the breathing pattern including apnea, but also including very rapid breathing or cyclic changes in the patterns of breathing
- Severely increased respiratory congestion or fluid buildup in lungs
- Inability to swallow any fluids at all (not taking any food by mouth voluntarily as well)
- Patient states that he or she is going to die

SIGNS AND SYMPTOMS OF APPROACHING DEATH. (n.d.). Retrieved April 21, 2019, from https://hospicepatients.org/hospic60.html

Active Dying

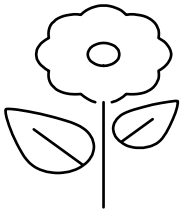
- Patient breathing through wide open mouth continuously and no longer can speak even if awake
- Urinary or bowel incontinence in a patient who was not incontinent before
- Marked decrease in urine output and darkening color of urine or very abnormal colors
- Blood pressure dropping dramatically from patient's normal
- Patient's extremities (such as hands, arms, feet and legs) feel very cold to touch
- Patient complains that his or her legs/feet are numb and cannot be felt at all
- Patient's body is held in rigid unchanging position

SIGNS AND SYMPTOMS OF APPROACHING DEATH. (n.d.). Retrieved April 21, 2019, from https://hospicepatients.org/hospic60.html

"A few conclusions become clear when we understand this: that our most cruel failure in how we treat the sick and the aged is the failure to recognize that they have priorities beyond merely being safe and living longer; that the chance to shape one's story is essential to sustaining meaning in life; that we have the opportunity to refashion our institutions, our culture, and our conversations in ways that transform the possibilities for the last chapters of everyone's lives." - Atul Gawande, Being Mortal: Medicine and What Matters in the End

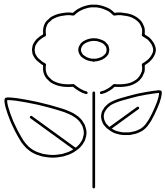
Goals of Patient Care at End-of-Life

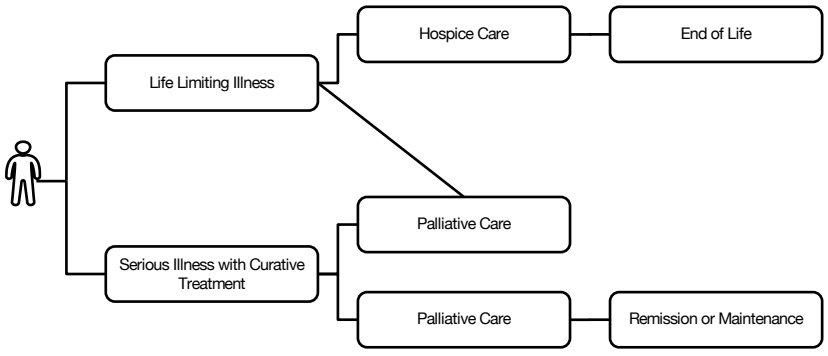
- Cure of disease
- Avoidance of premature death
- Maintenance or improvement of function
- Prolongation of life
- Relief of suffering
- Optimized quality of life
- Maintenance of control
- A good death
- Support for families and loved ones
- A Review of one's life



Hospice and Palliative Care

The hospice and palliative care movement has helped people come to terms with their terminal illness, impending death, and the importance of spiritual issues and needs.

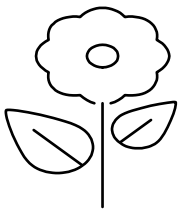




Palliative and Hospice Care Pathways

Palliative Care

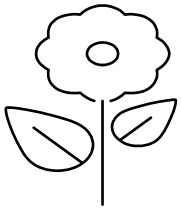
Palliative care is essentially adopting a plan of care that aims to control symptoms and provide physical, psychosocial, and spiritual support to patients as opposed to pursuing aggressive treatment that can often worsen symptoms and pain.



Focus on quality of life

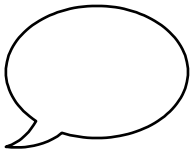
Palliative Care

- The GOAL of palliative whenever possible is to identify the underlying cause of the symptoms
- This care is frequently administered in Hospitals but conditions depending, can be prominent in outpatient settings



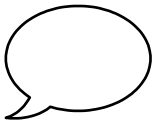
Language Matters: Bad Examples

- Do you want us to do everything possible?
- Will you agree to discontinue care?
- It's time we talk about pulling back.
- I think we should stop aggressive therapy.
- I'm going to make it so he won't suffer.



Language Matters: Good Examples

- I'm going to give the best care possible until the day you die.
- We will concentrate on improving the quality of your child's life.
- We want to help you live meaningfully in the time you have left.
- I'll do everything I can to help you maintain your independence.
- I want to ensure that your father receives the kind of treatment he wants.
- Your child's comfort and dignity will be my top priority.
- I will focus my efforts on treating your symptoms.
- Let's discuss what we can do to fulfill your wish to stay at home.



Case Study

Dolores' Story

Choosing hospice does not have to be a permanent decision. For example, Dolores was 82 when she learned that her kidneys were failing. She thought that she had lived a long, good life and didn't want to go through dialysis, so Dolores began hospice care. A week later, she learned that her granddaughter was pregnant. After talking with her husband, Dolores changed her mind about using hospice care and left to begin dialysis, hoping to one day hold her first great-grandchild. Shortly after the baby was born, the doctors said Dolores' blood pressure was too low. At that point, she decided to re-enroll in hospice.

What Are Palliative Care and Hospice Care? (n.d.). Retrieved April 24, 2019, from https://www.nia.nih.gov/health/what-are-palliative-care-and-hospice-care#palliative-vs-hospice

CONTINUED

Case Study

Tom's Story

Tom, who retired from the U.S. Air Force, was diagnosed with lung cancer at age 70. As his disease progressed and breathing became more difficult, he wanted to explore experimental treatments to slow the disease. Through the palliative care provided by the Veterans Health Administration, Tom got treatment for his disease and was able to receive the care and emotional support he needed to cope with his health problems. The palliative care program also helped arrange for assistance around the house and other support for Tom's wife, making it easier for her to care for him at home. When the experimental treatments were no longer helping, Tom enrolled in hospice. He died comfortably at home 3 months later.

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CONTINUED

"Modernization did not demote the elderly. It demoted the family. It gave people—the young and the old—a way of life with more liberty and control, including the liberty to be less beholden to other generations. The veneration of elders may be gone, but not because it has been replaced by veneration of youth. It's been replaced by veneration of the independent self. ***" -Atul Gawande, Being Mortal: Medicine and What Matters in the End

Hospice Care

Hospice care enables a person to retain his or her dignity and maintain quality of life during the end of life. Hospice care encompasses the support given to the patient and the family during the illness and through their bereavement.

Hospice Care

- Addressing the patient's emotional, physical, psychological, and spiritual needs
- Managing the patient's pain and symptoms
- Providing need drugs, medical supplies, and equipment
- Delivering special services like speech and physical therapy when needed
- Enabling a person to live the last weeks and months of life as fully and comfortably as possible, with dignity, at home, or in a homelike setting
- Making short-term inpatient care available when pain or symptoms become too difficult to manage at home, or the caregiver needs respite time
- Accepting death as a natural part of life, seeking neither to hasten nor prolong the dying process
- Providing bereavement care and counseling to surviving family and friends

Hospice Care

Medicare usually covers these hospice services and pays almost all of the costs

(Centers for Medicare & Medicaid)

- Physician services
- Nursing care
- Medical equipment (wheelchairs, walkers, hospital beds, etc)
- Medical supplies (bandages, catheters, ostomy supplies, etc.)
- Medications for symptom control and pain relief
- Social work services
- Short-term care in the hospital, including respite and inpatient care for pain and symptom management
- Home health aide and homemaker services
- Physical and occupational therapy
- Speech therapy
- Dietary counseling
- Grief support for the patient and family

Case Study

Annie and Maria's Story

Eighty-year-old Annie had advanced metastatic melanoma and asked for help through a hospice program so she could stay in the home she had lived in for more than 40 years. After Annie died, hospice continued to support her family, offering bereavement counseling for a year. Hospice services greatly reduced the stress of caregiving for Annie's family. This was especially true for Annie's wife, Maria, who weathered the sadness of her loss without her own health declining.

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End Game

A Netflix Documentary

YouTube Link:
https://www.youtube.com/watch?v=FgJD6ksdkWY

Goals of the Dying Patient

Dying Patients Bill of Rights

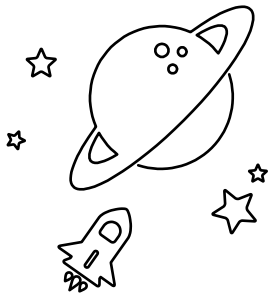
- I have the right to be treated as a living human being until I die.
- I have the right to maintain a sense of hopefulness however changing its focus may be.
- I have the right to be cared for by those who can maintain a sense of hopefulness however changing that may be.
- I have the right to express my feelings and emotions about my approaching death in my own way.
- I have the right to expect continuing medical and nursing attention even though 'cure' goals must be changed to 'comfort' goals.
- I have the right not to die alone.

Dying Patients Bill of Rights

- I have the right to be free from pain.
- I have the right to have my questions answered honestly.
- I have the right not to be deceived.
- I have the right to die in peace and dignity.
- I have the right to participate in decisions concerning my care.
- I have the right to have help from and for my family in accepting my death.

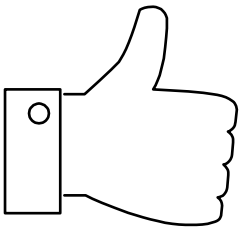
Dying Patients Bill of Rights

- I have the right to retain my individuality and not be judged for my decisions which may be contrary to the beliefs of others.
- I have the right to discuss and enlarge my religious and/or spiritual experience whatever these may mean to others.
- I have the right to expect that the sanctity of the human body will be respected after death.
- I have the right to be cared for by caring, sensitive, knowledgeable people who will attempt to understand my needs and will be able to gain some satisfaction in helping me face my death.



Your Own Personal Experience Matters

"Man is fallible, but maybe men are less so."
— Atul Gawande, The Checklist Manifesto: How to Get Things Right



Thanks!

Any questions?
You can find me at
amanda.stead@pacificu.edu

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ONLINE CONTINUING EDUCATION FOR THE LIFE OF YOUR CAREER

End-of-Life Care for the SLP Part 2: Roles, Responsibilities & Ethics

Amanda Stead, PhD, CCC-SLP

Moderated by:
Amy Hansen, MA, CCC-SLP, Managing Editor, SpeechPathology.com

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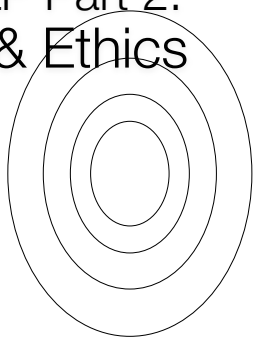
End-of-Life Care for the SLP Part 2: Roles, Responsibilities & Ethics



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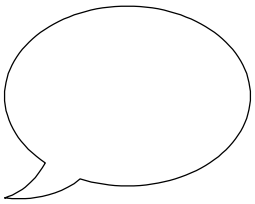


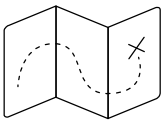
Hello!

Amanda Stead, Ph.D., CCC-SLP,
Associate Professor CSD
Pacific University

CONTINUED

Learner Outcomes

- Explain key concepts of ethical principles as they relate to dying patients.
- Identify key components and factors in care planning documentation.
- Describe the role of the SLP and other key professionals in end-of-life care.



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Ethics in EOLC

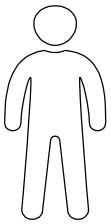
"With the availability of increasingly sophisticated health care technology, end-of-life care presents unprecedented ethical challenges for individuals, families, health care professionals, and policy makers. The role of health care professionals and the use of these technologies are changing how death, dying, and end-of-life care are viewed and managed."

CONTINUED

Autonomy 101

There are four basic elements of autonomy (Burkhardt & Nathaniel, 2013; Jech, 2000):

1. Autonomy implies respect for the individual.
2. Individuals must be capable of determining their personal goals.
3. Individuals have the capacity to decide up on a plan of action for care. They must be able to understand the meaning of their choice, must be able to select from alternatives, and must be able to understand the consequences of their choice.
4. Individuals have the freedom to act upon the choices they have made.



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Violations of Autonomy

Health care providers can mistakenly violate a patient's autonomy when they do any or all of the following (Burkhardt & Nathaniel, 2013):

- Mistakenly assume that the patient has the same values and goals as they do
- Fail to recognize that the patient's thought processes may be different from their thought processes
- Fail to understand the patient's level of knowledge about his or her disease or illness
- Fail to treat the patient as a person instead of a "job" that has to be completed before their shift ends

CONTINUED

Widely Accepted	Controversial	Legality Issues
• Accepting increasing sedation from opioids • Stopping life-sustaining therapy	• Voluntarily stopping eating and drinking • Terminal sedation	• Physician-assisted suicide • Voluntary active euthanasia

Last Resorts

What are the options when death is inevitable?

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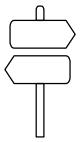
Ethics Dilemmas

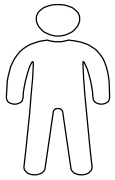
Neighbors (2011) presents many ethical dilemmas for health care providers, including the following:



- Who should be resuscitated?
- In what circumstances should life be prolonged?
- Who should make the decision to prolong life with extraordinary measures (such as feeding tubes or ventilators)?
- Who should make the decision to discontinue these extraordinary measures?
- How should healthcare professionals be involved in these decisions?
- Should decisions of such a personal and private nature be left to the courts? If not the courts, then by whom should the decisions be made?

Case Study

An elderly woman told her daughters that if she ever ended up with dementia she wouldn't want to live like that. Years later she developed senile dementia and her daughters had her move into a nursing home. Although she did not recognize family or friends, she enjoyed the company of others and the nursing home's cat. When she stopped eating, her daughters were asked whether she should receive a feeding tube



Futility

- What constitutes futile intervention remains a point of controversy in the medical literature and in clinical practice
- Use of life-sustaining or invasive interventions in patients in a persistent vegetative state or who are terminally ill may only prolong the dying process.
- These controversies arises when the patient or proxy and the physician have discrepant values or goals of care

Case Study - Futility

An elderly man who lives in a nursing home is admitted to the medical ward with pneumonia. He is awake but severely demented. He can only mumble, but interacts and acknowledges family members. The admitting resident says that treating his pneumonia with antibiotics would be "futile" and suggests approaching the family with this stance

Documentation

The Five Wishes

The Five Wishes includes documentation on the following

(Kuebler, Berry, & Heidrich, 2002):

1. The person chosen by the patient to make care decisions for the patient when he or she cannot
2. The kind of medical treatment the patient wants or doesn't want
3. How comfortable the patient wants to be
4. How the patient wants people to treat him or her
5. What the patient wants his or her loved ones to know

Why Facilitate This Conversation

- Giving the person a sense of control in the dying process.
  - Advance care planning ensures that the patients goals will be followed should the patient become incompetent.
- Reflecting clearly the patient's personal values and goals for terminal care.
- Enabling patients to anticipate and consider aspects of the dying process that they might not have considered previously.
  - This may help patients think about goals that they otherwise might not have considered (i.e., a last trip to visit family, writing a will, etc.).

Why Facilitate This Conversation

- Facilitating communication with significant others.
  - Making sure their family is taken care of.
  - Make it easier for surrogates to act in keeping with patients' goal should they need to make decisions for them.

- Allow the identification of the patient's preferred spokesperson (health care proxy)

"I have an advanced directive not because I have a serious illness, but because I have a family"

-Ira Byock MD

Advanced Directive

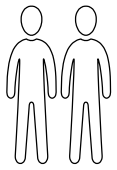
- Written legal documents that state your wishes if you can no longer speak for yourself.
- With these documents in place medical personnel and loved ones don't have to guess what you would prefer or make decisions you would not want for yourself.
- Since advance directives cannot predict every clinical scenario you may be part of in the future, choosing a health-care proxy in most situations is more helpful.

Advanced Directive

- Resuscitation
- Ventilation
- Non-oral feeding
- Artificial hydration
- Narcotic Pain Control
- Dialysis
- Special Circumstances

Health Care Proxy

- Names someone to make medical decisions for you when you are not able to make such decisions.
- This person should be someone you trust, who knows what treatments you would want or would reject, and who will respect these preferences.
- Your proxy does not have to receive specific instructions from you and can make decisions as if he were in your situation, but conscious and able to communicate.



DNR

- A do not resuscitate order instructs medical personnel not to bring you back to life if you stop breathing or your heart stops.
- CPR can often involve more than just chest compressions and mouth-to-mouth resuscitation.
- Although CPR can save lives, it frequently does not work. Even if a person is resuscitated, they may suffer painful injuries during CPR or may be left in a worse condition than before.
- People with terminal illnesses or other serious medical conditions might not want to have CPR performed on them, even if that means they might die as a result.

Case Study

Alice is a 81-year-old who resides in an assisted living facility. When her health condition was determined to be terminal, an slp is called in to consult and support Alice in her swallowing abilities. After extensive cancer treatment Alice's swallow was impaired and she was losing weight. The slp worked with Alice to modify her diet as was acceptable to her. During the discussions and evaluations of Alice's swallow the slp got to know her well and took the opportunity to discuss her end of life decisions. Because Alice wanted to eat food that was not necessarily safe for her, the slp documented her wishes in regards to her oral intake. The slp then inquired about her wishes in regards to IV hydration and non-oral food intake. This opened the door to a more general discussion about end-of-life care. The slp recorded the wishes of Alice and made copies for her chart, her home, her family, and her doctor. The management of Alice's swallow impairment provided an opportunity to discuss and document Alice's wishes in regards to not only the management of food and water intake, but also her wishes regarding other medical decisions and proxies.

Case Study

Amelia is a 67-year-old woman who has recently be diagnosed with early stage Alzheimer's disease. Upon her diagnosis she sought support for her memory and cognition from her primary care physician who referred her to a speech pathologist. Upon meeting with the slp a discussion took place as to her goals for therapy and her reason for referral. The slp then asked Amelia if she had an AD in place. Initially, Amelia was shocked and angry and did not wish to discuss it. Throughout the short course of her treatment addressing living independently, Amelia became concerned with how she could remain independent across the disease course. On the last day of treatment Amelia and the slp were discussing her future plans. The slp asked what her fears were and also what her goals were. She replied that as long as she was still able to meaningfully interact with her grandchildren she would feel content. The slp then asked about her worries, and Amelia stated she was concerned about being incontinent and living in "locked-unit." The slp then asked her if she wanted to document these fears and wishes. After Amelia realized that an AD is in place to help honor her wishes she became more open to the idea of filling on out. The slp helped Amelia document her basic wishes and passed a copy onto her doctor.

Roles & Responsibilities of SLPs

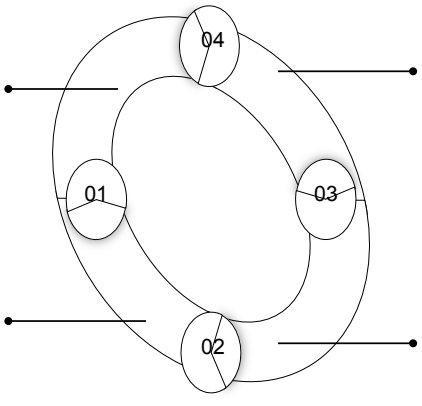
Role of the SLP

Consultation with family and team

How best to support or what the current level of function is related to communication, cognition and swallowing

Manage Swallowing

Support feeding for both nourishment and satisfaction



Develop Strategies

To maintain communication for both decision making and socialization for quality of life

Communicate with Hospice Team

Pollens (2004)

Supporting Communication

- Training Carepartners
- Supported Communication
- External Aids
- AAC
- Accessibility

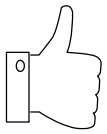
Feeding & Swallowing

- Caregivers and family connect food with comfort and care
- Dysphagia is a poor prognostic sign
- Adherence to recommendations for safe swallowing is problematic.
- Patients often choose not to alter their diet consistency, and
- serious illness may impact their vigilance and attention to treatment recommendations
- *We are a partner in decision making

Hawksley et al., 2017; Goldsmith & Cohen , 2018

Reimbursement

- Hospice benefits include speech-language pathology services:
  - "for purposes of symptom control or to enable the individual to maintain activities of daily living and basic functional skills" (Sec. 230.1.I of the Medicare Hospice Manual).



- In addition, Medicare has alerted claims reviewers that they cannot automatically deny a claim based on a diagnosis of dementia. This allows for the provision of reasonable and necessary skilled services to those patients with dementia who can benefit from them.

Other Professionals Roles

Primary Team

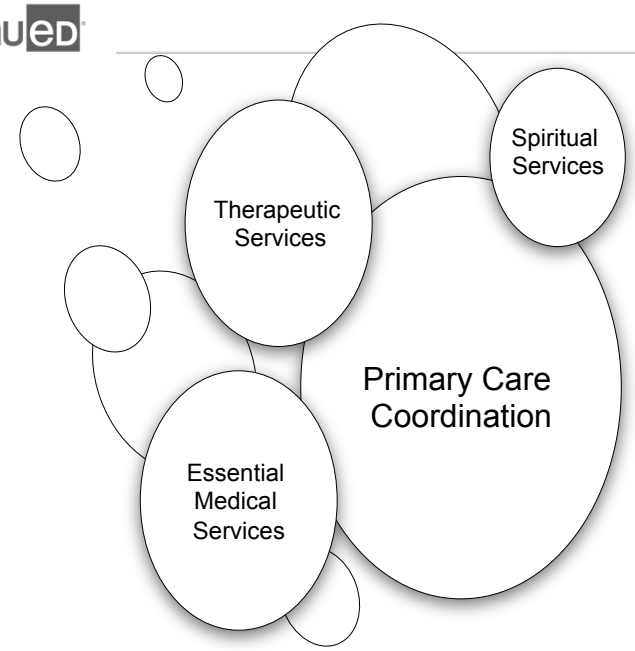
- Physician
- Nurse
- Care Coordinator
- Hospice/ Palliative team Volunteers
- Carepartners

Frequent team members

- Psychologist
- Physical Therapist
- Occupational Therapist
- Speech Therapist
- Chaplain

Frequent team members

- Nutritionist / Dietician
- Pharmacist
- Social Workers
- Alternative providers
- Counselors



Extremis:
A Netflix
Documentary

Thanks!

Any questions?
You can find me at
amanda.stead@pacificu.edu

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ONLINE CONTINUING EDUCATION FOR THE LIFE OF YOUR CAREER

End-of-Life Care for the SLP Part 3: Grief, Spirituality & the Good Death

Amanda Stead, PhD, CCC-SLP

Moderated by:
Amy Hansen, MA, CCC-SLP, Managing Editor, SpeechPathology.com

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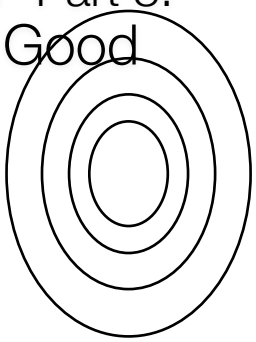
End -of-Life Care for the SLP Part 3: Grief, Spirituality & the Good Death



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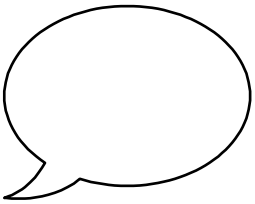

Hello!

Amanda Stead, Ph.D., CCC-SLP,
Associate Professor CSD
Pacific University

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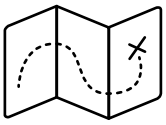
Learner Outcomes

After this course, participants will be able to:

- Explain key aspects of the "Good Death."
- Identify institutional changes that could support patient care at the end-of-life.
- Describe the spiritual, psychological, social, and physical aspects of the process of dying.



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“We shower so much love on babies and children," she said. "But as we grow up, it stops. No one showers love on grown-ups. But I think we need more love as we get older, not less. Life gets harder, not easier, but we stop loving each other so much, just when we need love most.”

— **Kerry Egan, On Living**

7

The Good Death

8

Fantasy Death

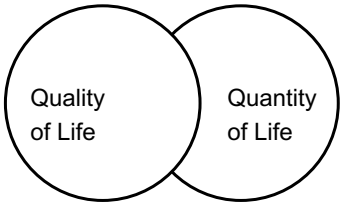
If you could decide when, where & how you die, what would it look like?

What does that tell you about your values?

9

Values: Start with Good Questions

- What matters to me at the end of life is…
- Are there particular concerns that you want to be sure are talked about?



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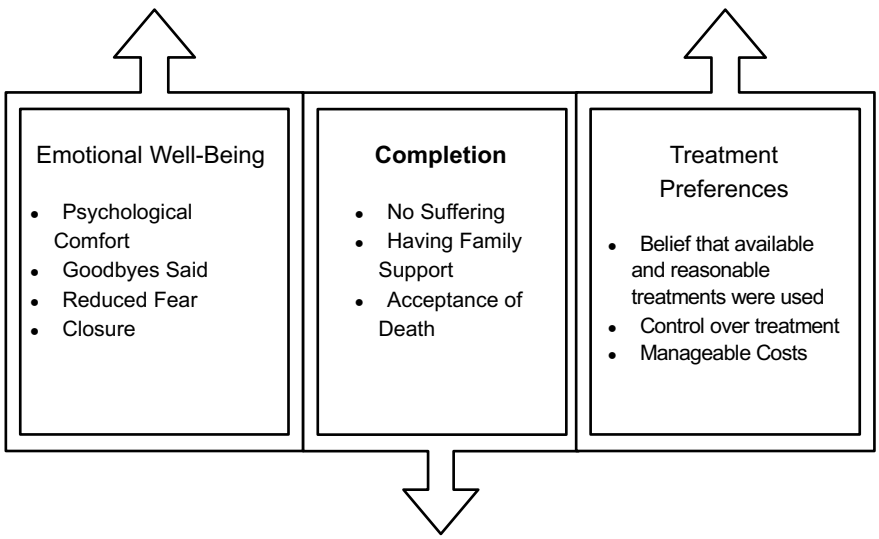
"You learn working in hospice

that a person can, in fact, live too

long."

— **Kerry Egan, On Living**

11



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Location Decisions

Why People Want to Be Home

- Better environment for maximizing the life that remains and for achieving personal closure.
- The stress of traveling to and from the hospital or hospice facility is eliminated
- Dying persons often are psychologically more comfortable in a familiar environment with continuous support of family, friends, and pets.
- The ability to prepare meals makes it easier to offer what the individual likes

13

Location Decisions

Why People **DO NOT** Want to Be Home

- There may be inadequate support for, or difficulty in coping with, care needs.
- There may be competing needs for care by small children, older adults, or other sick or disabled family members.
- The stress of caring for a dying person might be overwhelming.

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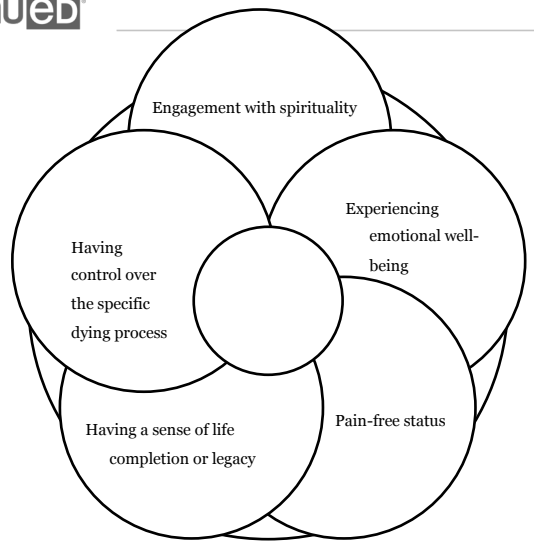

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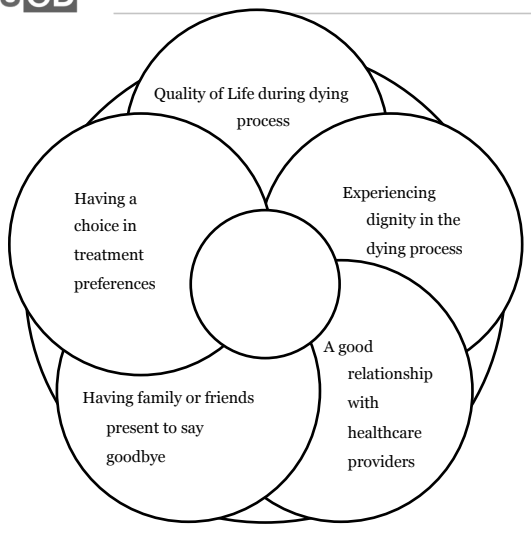

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16

"Death must be so beautiful. To lie in the soft brown earth, with the grasses waving above one's head, and listen to silence. To have no yesterday, and no to-morrow. To forget time, to forget life, to be at peace."
-Oscar Wilde, The Canterville Ghost

17

Grief & Spirituality

18

Spirituality

Spirituality in healthcare is a controversial but necessary subject.

It can present an opportunity to explore patient preferences, to communicate, and to try to understand what is important to patients.

19

Spirituality

Doka (2019) identified these three spiritual needs of the dying:

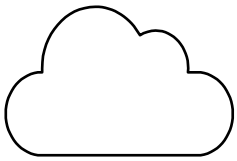
1. The need to search for the meaning of life
2. The need to die appropriately
3. The need to find hope that extends beyond the grave

20

What do you think is the role of the provider in dealing with patients' spiritual or religious needs in the dying process?

21

Spirituality



"Why did God do this to me?"

"What do you think will happen to me when I die?"

"Do you believe in God (or Jesus, heaven, etc.)?"

"It would feel like murder to _____"

"I know this is God's will. Only God knows when someone will die, so…" (either)

- "…keep my loved one on life support forever"
- "…I don't need therapy because I'm waiting for a miracle"

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Spirituality:
Why we are uncomfortable...

- Science versus religion
- Not my job (division of labor)
- Don't wish to impose my beliefs on others
- Don't want others to impose their beliefs on me

23

Spirituality: what do I do?

- Affirm
  - "This is very important for you."
  - "This is a real source of strength for you, isn't it?"
  - "It takes courage to grapple with these things."
- Share your beliefs as appropriate (do not impose)
- Facilitate environmental support for ritual
- Refer as appropriate

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Spirituality: what do I do?

- The health-care team may help provide for a patient's spiritual needs by the following (National Cancer Institute, 2013).
  - Suggest goals and options for care that honor the patient's spiritual and/or religious views.
  - Encourage the patient to speak with a religious or spiritual leader.
  - Provide information regarding other adjunct therapies that have been shown to increase spiritual well-being, such as mindfulness meditation, art and music therapy, and journaling.

25

Hospice Chaplain

- Chaplains are part of a larger hospice health care team.
  - Medicare requires hospice providers to offer the option of spiritual care from a trained hospice chaplain. (72% opt in for this)
- Hospice chaplains need to hold a master's degree and have completed Clinical Pastoral Education.
- Chaplains are required to be ordained ministers and usually need certification.
- Hospice chaplains work in hospitals, nursing homes, health care facilities and patients' homes.

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Hospice Chaplain

27

Emotional Coping

- The end-of-life process takes a spiritual and emotional toll on a patient's family, who may find themselves:
  - Confused;
  - Angered;
  - Anxious;
  - Guilt-ridden;
  - or questioning the meaning of life itself.

28

Grief is Normal

Preparatory or anticipatory grief

- Bereavement (after the patient dies; the experience of death)
- Grief of Loss (Response to a loss)

*Grief is subjective and can occur as a physical, emotional, and social response to loss.

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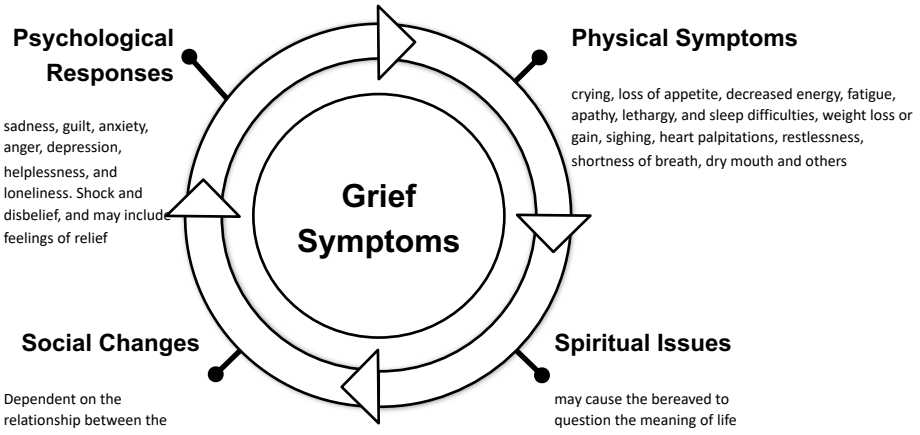

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Healing From Grief

- The healing of cells and tissues
- A shift from resentment to forgiveness, a release of old hurts, and new energy for growth and an expanded consciousness
- A feeling of being loved unconditionally and for all time so there is no separation between a feeling of oneness with a higher power and a oneness with all creation

31

Complicated Grief

Complicated Symptoms:

- Clinical Depression
- Psychosis
- Lack of progress over time

Risk factors:

- Traumatic, violent, unexpected deaths
- Death involving children
- Multiple losses
- Overt mental illness

**unable to address acceptance and adaptation to the loss

32

"No one ever told me grief

felt so much like fear"

-CS Lewis

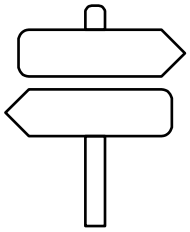
33

Institutional Change

34

Driving Questions

- If there were no obstacles or barriers, what is the best end-of-life care we could have here?
- What kinds of changes would you like to see happen in end-of-life care here?



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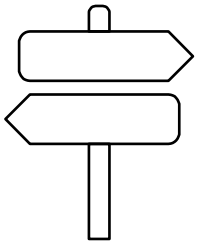
Obtaining Buy-in

- What do we need to know to institute these changes?
- What do we need to do to institute these changes?



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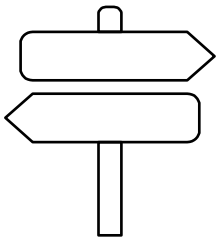
How Can You Make This Happen?

- Who are the allies?
- How can we build on strengths?
- What are the barriers?
- What Training is Necessary?



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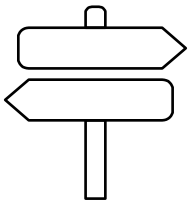
Mission Accomplished?

- How Will We Know the Goals Have Been Accomplished?
  - What Data are you taking
    - Participation
    - Outcomes
    - Pre-/Post-
    - Patient/Family Survey
  - What are you comparing it against?



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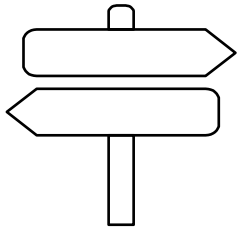
Sustaining the Work

- In-house newsletter announcement
- Special achievement awards
- Newspaper article
- Report research in a journal article



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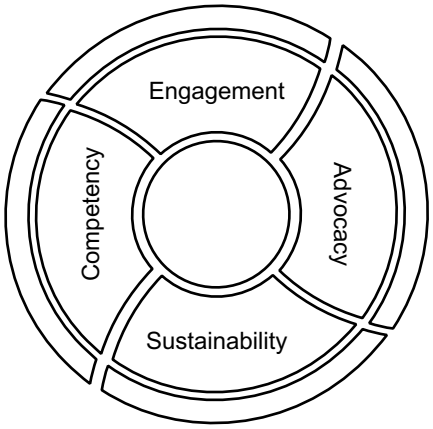
Moving the Needle



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"We listen to the stories that people believe have shaped their lives. We listen to the stories people choose to tell, and the meaning they make of those stories."

— **Kerry Egan, On Living**

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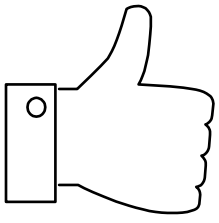

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