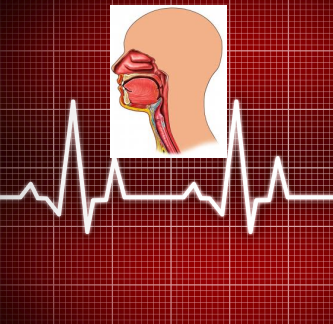


Dysphagia Management in Hospice: Continuum of Care by the SLP and Related Professionals

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Financial Disclosure

- To comply with professional boards/association standards:
- We declare that we do not have any financial relationship in any amount, occurring in the last 12 months with a commercial interest whose products or services are disclosed in this presentation.

Learner Outcomes


- Describe hospice and the classification for speech language services.
- Discuss how patients are eligible for hospice services.
- Discuss the role of the speech language pathologists in hospice.
- Describe an SLP hospice plan of care for service.
- Describe biopsychosocial assessment.

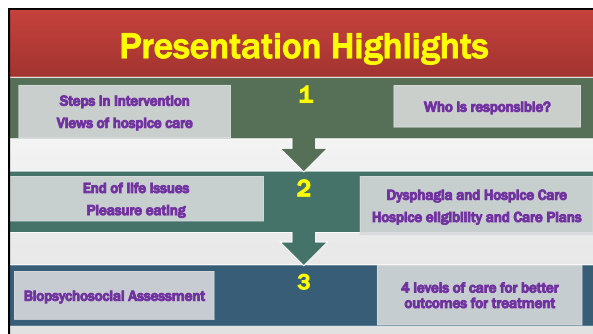
Quote

You matter because you are you, and you matter to the end of your life.

We believe human life is sacred... for every person, at every moment



-Dame Cioely Saunders, Founder of the Hospice Movement





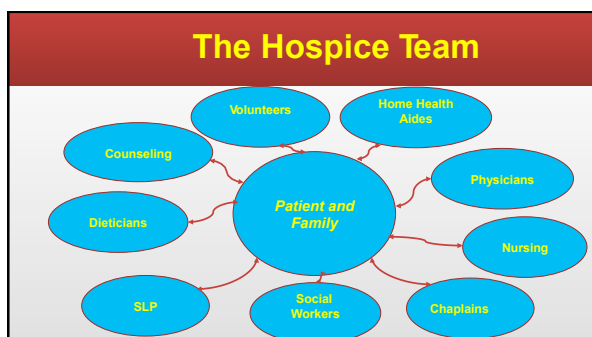
What is hospice?

A philosophy of care that provides comfort as life nears its end, rather than heroic lifesaving measures when they no longer offer any promising outcomes.

Hospice Care

- **Goal is comfort at the end of life for those with a terminal illness for whom there is little to no curative alternatives.**



The Facts

- Although a large majority of Americans say they would like to die at home...a majority of deaths still occur in hospitals.

Profession of Speech Language Pathology

- The SLP

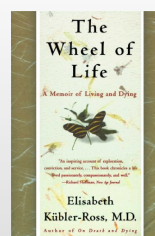
Quote

“People are like stained-glass windows. They sparkle and shine when the sun is out, but when the darkness sets in, their true beauty is revealed only if there is a light from within.”

-Dr. Elisabeth Kubler-Ross

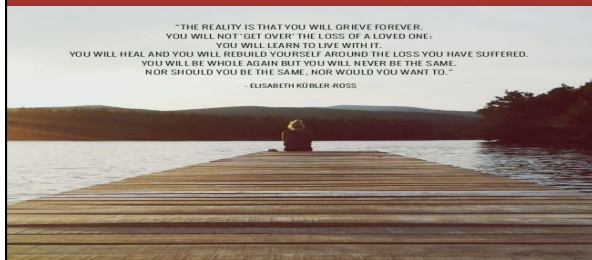
Dr. Elizabeth Kubler-Ross

- Dr. Ross Foundational Approach

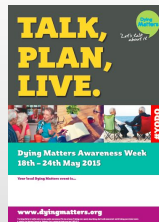


Quote

"THE REALITY IS THAT YOU WILL GRIEVE FOREVER.
 YOU WILL NOT GET OVER THE LOSS OF A LOVED ONE.
 YOU WILL LEARN TO LIVE WITH IT.
 YOU WILL HEAL AND YOU WILL REBUILD YOURSELF AROUND THE LOSS YOU HAVE SUFFERED.
 YOU WILL BE WHOLE AGAIN BUT YOU WILL NEVER BE THE SAME.
 NOR SHOULD YOU BE THE SAME, NOR WOULD YOU WANT TO."
 - ELISABETH KUBLER-ROSS



Dying Matters



Goals of Hospice

- Is to provide non-curative pain control and symptom management utilizing a patient-centered, community-based, multi-disciplinary approach which seeks to avoid inappropriate prolongation of the dying process

(Singer, Martin, & Kolner, 1999)

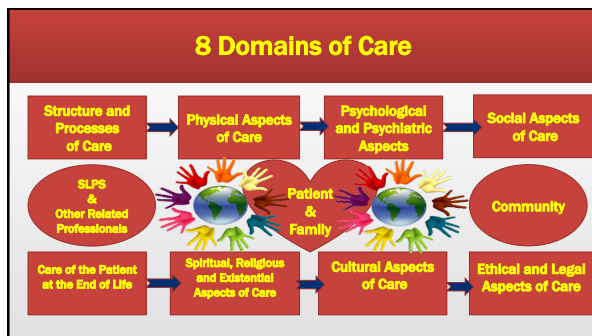
Palliative versus Curative Care

- Hospice care is appropriate when active treatment is no longer effective and supportive measures are needed to assist the terminally ill patient through the dying process.
- It offers the patient a supported and safe passage from life to death in a way that preserves dignity and important relationships.

National Hospice and Palliative Care Organization. (2014). Hospice and palliative care. Retrieved from <http://www.nhpc.org/-/about/-/hospice-care>
 World Health Organization. (2014). WHO definition of palliative care. Retrieved from <http://www.who.int/-/cancer/-/palliative/-/definition/-/en/>

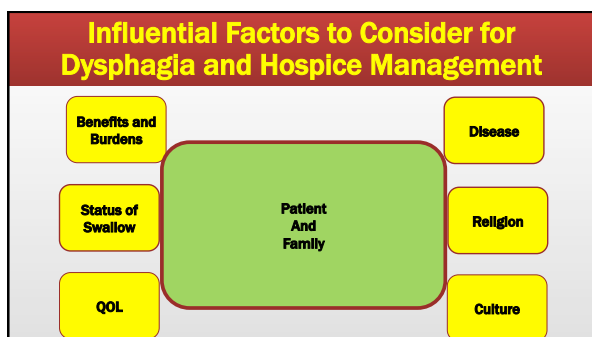
Hospice vs. Palliative Care

Hospice	Palliative Care
<ul style="list-style-type: none"> • You must generally be considered to be terminal or within six months of death to be eligible for most hospice programs or to receive hospice benefits from your insurance. • Focus on comfort care • Medicare hospice benefit 	<ul style="list-style-type: none"> • Any time during illness • May be combined with curative care • Independent of payer • Complimentary therapies



Hospice

Hospice philosophy



**Cultural Diversity and Dysphagia/
Hospice Care**

<p>European American</p> <ul style="list-style-type: none"> • European American Asian/Middle Eastern • Favor directives • Limit treatment at EOL • Primarily future oriented • Prefer direct eye contact • Prefer large amount of personal space • Value privacy • Low to moderate amount of touching 	<p>Asian/Middle Eastern</p> <ul style="list-style-type: none"> • Protect pt. from bad news • Family makes decisions • Primarily present oriented • Some groups past oriented • Not likely to make direct eye contact with those perceived to be in authoritative positions • Low volume • Small amount of personal space • Little touching in public
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**Cultural Diversity and Dysphagia/
Hospice Care**

<p>African Americans</p> <ul style="list-style-type: none"> • Object to limiting treatment • Prefer aggressive treatment • More likely dc'd to extended care • When death inevitable, 2X as likely as Caucasians to request life sustaining treatment 	<p>Older African Americans</p> <ul style="list-style-type: none"> • May distrust healthcare system based on hx of segregation/discrimination • Strong religious beliefs • "Fictive kin" – people considered family but not linked by blood ties • Primarily present oriented • Prefer direct eye contact • Moderate amount of touching • Comfortable with small personal space
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**Cultural Diversity and Dysphagia/
Hospice Care**

<p>Native Americans</p> <ul style="list-style-type: none"> • Reject directives • Tribal leader • Self fulfilling prophecy • Primarily present oriented • Not likely to make direct eye contact w those perceived to be authoritative • Small amount of personal space • Use touch lightly 	<p>Hispanics</p> <ul style="list-style-type: none"> • Less likely to institutionalize, value touching • More likely to use CPR, intubation, ANH than Caucasians • Dr. knows best – Mexican Americans • Religious – heavily influenced by Catholic beliefs • Family makes decisions to spare pt. unnecessary pain – detrimental to pts to know of seriousness of illness • Less likely to use hospice- denotes giving up • Not likely to make direct eye contact w those perceived to be authoritative • Small amount of personal space
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**Cultural Diversity and Dysphagia/
Hospice Care**

<p>Japanese</p> <ul style="list-style-type: none"> • May agree to ANH based on wishes of families/dr. • Preference for natural death & fighting cancer valued as important • 40% pts in survey prefer not being informed of bad news • 1 study – 30-50% general public said ANH is minimum standard of care • 30% believed ANH relieves symptoms • 32% allowing pt. to die under dehydrated conditions is ethically impermissible 	<p>Chinese</p> <ul style="list-style-type: none"> • Eating is as important as the emperor" • Worry pt. will starve to death and become a "starving soul" after death • Utilize TCM – traditional Chinese medicine • Herbal remedies • Eldest male child is primary decision maker • Decision inclined toward family's best interest, but perhaps not pt.'s. • Provision of food/drink is basic act of caring • Feeding has powerful symbolic & social significance • Many believe ANH prevents dehydration/starvation
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Living with Grief: Ethical Dilemmas at the End of Life

- **Hospice Foundation of America**
 - Asians/Latinos living in US want everything done
- 5 yr. study in N. California: ANH at death in Hispanic/Asian/Pacific Islanders 5.2 times that of non
 - **Hispanic Caucasian group**
- In North America, withholding diagnosis from pt. may be grounds for legal action
 - Chinese, East Indian, Filipino, Hmong, Iranian, Korean, Latino, Russian, Vietnamese prefer family spokesperson be informed first before pt. is told

Standards of Care

<p>SLPs question</p> <ul style="list-style-type: none"> • Lack of outcomes data for other options • Continued hand feeding • Time limited trial and withdrawal of PEG • Forgoing food and fluid • Uncertain outcomes w peg > certain death • Discomfort w letting pt. die • Uncertainty w role in suggesting palliation 	<p>Pt. Preferences</p> <ul style="list-style-type: none"> • If there is something to fix, fix it • Must consider • Culture • Religion • Individual differences in perception about feeding
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4 Levels of Care

Routine Care

Inpatient Care

Continuous Care

Respite Care

Utilization of Therapy Services, cont.

Hospice

- SLPs obtain orders and make arrangements for therapy services.
- Therapy services, goals, duration, and interventions will be included in the integrated plan of care and in the hospice progress notes.

Utilization of Therapy Services, cont.

SLP and Hospice Collaboration

- Scope and frequency of therapy services will be agreed upon and documented.
- Both will monitor the efficacy and communicate recommendations.

Arora AC et al. (2014). "Medical Orders for Life-Sustaining Treatment: Is It Time Yet." *Palliative and Supportive Care* 12(2):101-105.

Responsibilities at the Time of Death

Collaboration is critical during this time!

Determine in advance who is responsible for notifying the physician, pharmacy, mortuary, and coroner (per county procedure).

Biopsychosocial Assessment

- Review and discuss physical and psychological stages of the dying process
- Physical and psychological manifestations of pain
- Range of psychosocial interventions that can alleviate discomfort
- Biopsychosocial needs of clients and their family members

(Borrell-Carrío, Suchman, Epstein, 2004)


Biopsychosocial Assessment

Should address:

- Current symptoms including duration and severity
- Personal history of depression
- Family history of mental illness
- Quality of interpersonal relationships
- Living Conditions

Five Wishes

- www.agingwithdignity.org
- 888-594-7437
- In 26 languages
- 5 Wishes
- –10 states have special requirements (me)
- My Wishes
- –Children
- –Not legal document



Five Wishes Valid in:

- Alaska, Arizona, Arkansas, California, Colorado, Connecticut,
- Delaware, District of Columbia, Florida, Georgia, Hawaii, Idaho,
- Illinois, Iowa, Kentucky, Louisiana, Maine, Maryland, Massachusetts,
- Michigan, Minnesota, **Mississippi**, Missouri, Montana, Nebraska,
- Nevada, New Jersey, New Mexico, New York, North Carolina, North
- Dakota, Oklahoma, Pennsylvania, Rhode Island, South Carolina, South
- Dakota, Tennessee, Vermont, Virginia, Washington, West Virginia,
- Wisconsin, Wyoming
- **May attach it to other state's forms** - Alabama, Indiana, Kansas,
- New Hampshire, Ohio, Oregon, Texas, Utah

Let Me Decide – New Grange Press

- **Dr. William Molloy** Price per Book: €10
- [Let Me Decide Series – book, video](#)
- [Let me Pass Gently](#)
- Pt. lists what unacceptable level of functioning means to them
- Additional sections to identify treatments
- –If loss of functioning Not Acceptable and Not Reversible
- –If loss of functioning acceptable and/or IS reversible
- Section to address updating directive In 12 months with new signature and date

Resources

- www.cspc.org – Center to Advance Palliative Care
- www.experc.mcw.edu – End of Life Physician Education Resource Center
- geripal.com – geriatric and palliative care blog
- www.medscape.com – March 2012 Issue on oncology – special report on palliative care
- www.medscape.com – August 20, 2012 Special Report - Tough talks from Medscape Oncology
- How and why to talk to the dying patient
- How to have difficult conversations with patients, families
- Psychosocial needs matter most at the end of life
- 5 (Incorrect) reasons oncologists avoid bad news talks

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SLPs Remember.....

"We are all visitors to this time, this place. We are just passing through. Our purpose here is to observe, to learn, to grow, and to love....and then we return home."



Australian Aboriginal Proverb

Don't forget

What to say to someone who is dying...

Show your love through words and touch.	"Is there anything you want to talk about?"	"Is there anything you want me to take care of?"
Listen with patience and full attention.	Follow the lead of the patient in meaningful conversation.	Share pleasant instances of the past, especially the patient's good deeds.
Be calm and natural.	Bring spiritual comfort according to the patient's beliefs.	

- Paul TP Wong

