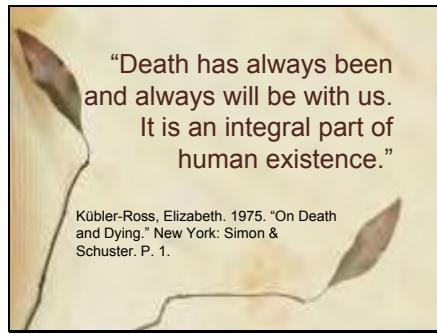


Slide 1



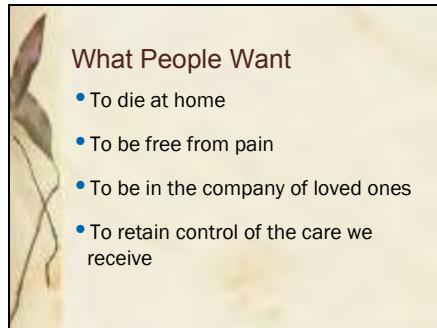
Meeting started at 12:30pm. A member introduced Sue Erlewine. Sue offered this powerpoint to anyone who wants it.

Slide 2



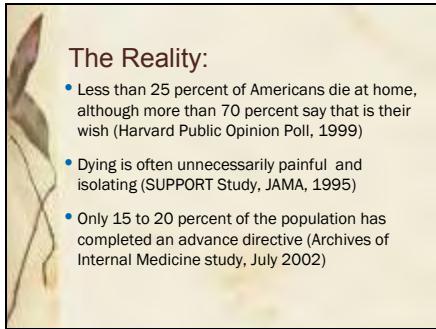
This is an important quote to Sue, who is a trained & experienced palliative & hospice care nurse. She has helped write books, training courses, and legislation for palliative & hospice care.

Slide 3



A member noted that many institutions fear litigation, so faculty & staff try as many tests as possible to rule in or out certain treatments. Hence the large hospital bills afterwards. Advance directives help but these are not infallible.

Slide 4

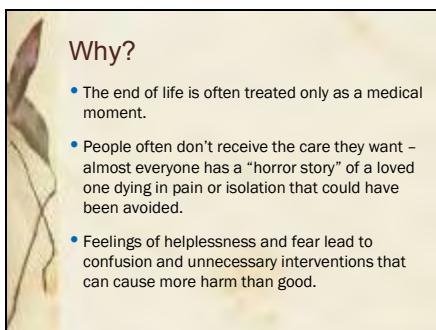


The Reality:

- Less than 25 percent of Americans die at home, although more than 70 percent say that is their wish (Harvard Public Opinion Poll, 1999)
- Dying is often unnecessarily painful and isolating (SUPPORT Study, JAMA, 1995)
- Only 15 to 20 percent of the population has completed an advance directive (Archives of Internal Medicine study, July 2002)

Sue Erlewine noted that advance directives (which include living wills and financial & healthcare powers of attorney) are useful but not always equally legal in every state. She believes that the most important point is that the family of the patient agrees on what to do, and when to do it. Having a family which is united in its support for the wishes of the dying patient is most useful for hospital & hospice staff. Q: Can advance directives be altered? SE: Yes, if spoken orally & witnessed. Usually such changes are for more care, not less. *See addendum at the end of these notes.*

Slide 5

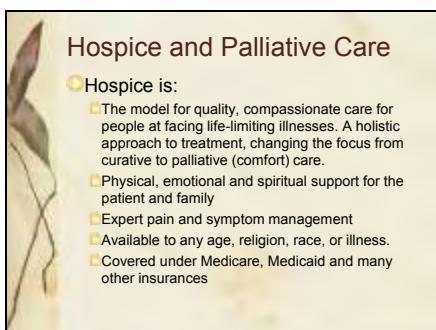


Why?

- The end of life is often treated only as a medical moment.
- People often don't receive the care they want – almost everyone has a "horror story" of a loved one dying in pain or isolation that could have been avoided.
- Feelings of helplessness and fear lead to confusion and unnecessary interventions that can cause more harm than good.

An advance directive should be in the possession of the patient, of the patient's family, of the hospital/hospice, and any other stakeholders. An advance directive is not the same as a will. (addressed later)

Slide 6



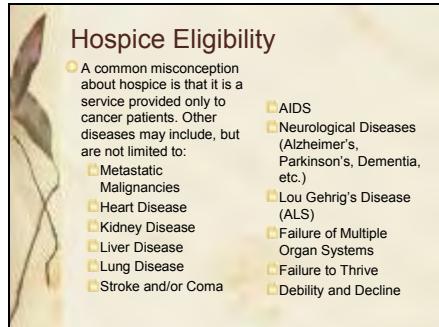
Hospice and Palliative Care

○ **Hospice is:**

- The model for quality, compassionate care for people facing life-limiting illnesses. A holistic approach to treatment, changing the focus from curative to palliative (comfort) care.
- Physical, emotional and spiritual support for the patient and family
- Expert pain and symptom management
- Available to any age, religion, race, or illness.
- Covered under Medicare, Medicaid and many other insurances

Interdisciplinary care; family as defined by patient.; medical treatment but not curing or prolonging life; wishes of family in POC; supportive services to help someone stay home with some inpatient coverage; volunteers.

Slide 7



Hospice Eligibility

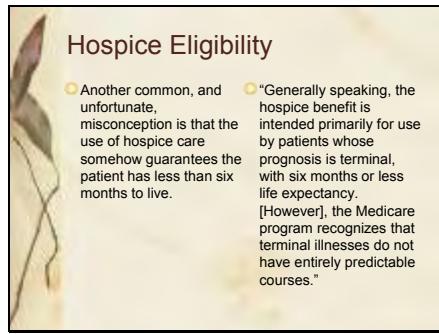
- ◉ A common misconception about hospice is that it is a service provided only to cancer patients. Other diseases may include, but are not limited to:
 - ◉ Metastatic Malignancies
 - ◉ Heart Disease
 - ◉ Kidney Disease
 - ◉ Liver Disease
 - ◉ Lung Disease
 - ◉ Stroke and/or Coma
- ◉ AIDS
- ◉ Neurological Diseases (Alzheimer's, Parkinson's, Dementia, etc.)
- ◉ Lou Gehrig's Disease (ALS)
- ◉ Failure of Multiple Organ Systems
- ◉ Failure to Thrive
- ◉ Debility and Decline

Conversations abt end-of-life are good to have now, around the kitchen table—before illness clouds judgments.

Medicare and medicaid can be used to pay for hospice, depending on state. Ohio medicaid/medicare supports hospice.

Hospice requires volunteers to be part of the system in patient care.

Slide 8

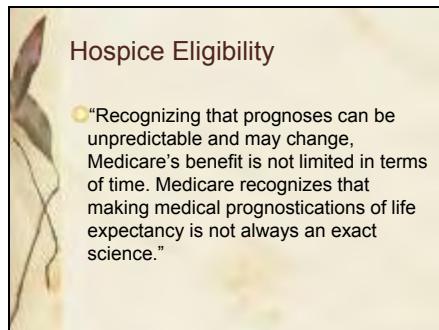


Hospice Eligibility

- ◉ Another common, and unfortunate, misconception is that the use of hospice care somehow guarantees the patient has less than six months to live.
- ◉ "Generally speaking, the hospice benefit is intended primarily for use by patients whose prognosis is terminal, with six months or less life expectancy. [However], the Medicare program recognizes that terminal illnesses do not have entirely predictable courses."

Under this philosophy, Medicare has specified a procedure for certification and periodic recertification of the patient's eligibility for care under the Medicare Hospice Benefit. This procedure provides two 90-day eligibility certification periods followed by an UNLIMITED number of 60-day eligibility certification periods.

Slide 9

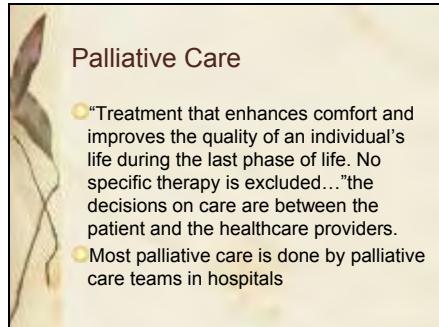


Hospice Eligibility

- ◉ "Recognizing that prognoses can be unpredictable and may change, Medicare's benefit is not limited in terms of time. Medicare recognizes that making medical prognostications of life expectancy is not always an exact science."

As long as the patient continues to meet the hospice end of life criteria during each certification period, the patient can continue to receive care under the Medicare Hospice Benefit. After 3 certification periods, the primary physician and hospice Medical Director must re-certify the patient meets end of life criteria.

Slide 10



Palliative Care

- "Treatment that enhances comfort and improves the quality of an individual's life during the last phase of life. No specific therapy is excluded..." the decisions on care are between the patient and the healthcare providers.
- Most palliative care is done by palliative care teams in hospitals

Palliative care might be able to be used for chronically-ill patients, to provide respite for caregivers. Check with dr, insurance co. Palliative care includes curative treatment and life- prolonging treatment as well as treatments to maintain quality of life for patient

Slide 11

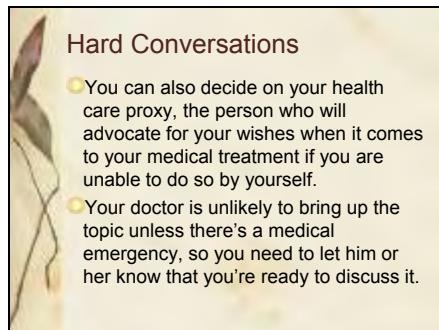


Hard Conversations

- There is no perfect time to start talking about your wishes but having this conversation with family earlier can help improve the quality of your care.
- As much as possible, these conversations should start around the kitchen table
- Let your family members know what kind of care you would like and what matters most to you.
- You should also get a better idea of what your loved ones hope for you.

"I think one mistake we often make is only having these difficult conversations when something's going wrong," says Dr. Jennifer Temel, clinical director of thoracic oncology at Massachusetts General Hospital.

Slide 12



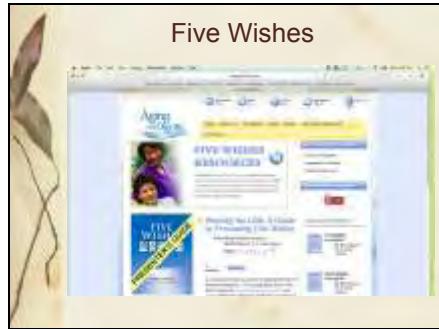
Hard Conversations

- You can also decide on your health care proxy, the person who will advocate for your wishes when it comes to your medical treatment if you are unable to do so by yourself.
- Your doctor is unlikely to bring up the topic unless there's a medical emergency, so you need to let him or her know that you're ready to discuss it.

"When someone's feeling terrible, and their family is very stressed that the patient is so sick, that's really not a time to have a calm and thoughtful conversation about prognosis and end-of-life care goals."

You can let the doctor's office know that you would like to talk about your end-of-life wishes when you call to make an appointment. That allows both you and your doctor time to prepare. You don't have to fit everything into your first talk with your doctor. "The conversation" is actually more a series of conversations, and it becomes easier once you start.

Slide 13



This is not a legal document in Ohio, but other states have accepted this document as legal. In Ohio, this document can guide the advance directive (AD). AD must be notarized and signed with witnesses. Often lawyers need to be involved.

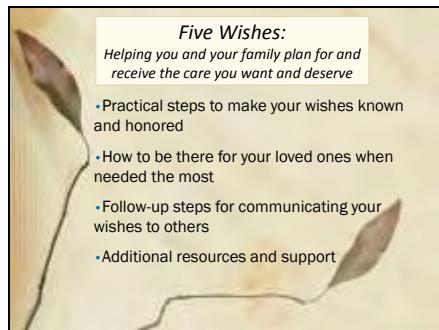
Slide 14



Additional links: Living wills & Advance Directives:

Www.americanbar.org/groups/real_property_trust_estate/resources/estate_planning/living_wills_health_care_proxies_advance_care_directives.html

Slide 15



Additional links: Feeding tubes:

www.comfortcarechoices.com/index

Search on “feeding tubes”

Slide 16



Additional links: Do Not Resuscitate (DNR) in Ohio (this is an article and a .pdf form)

www.ohiocathconf.org/homes_fears/dnrfrm.pdf

Slide 17



Additional links: Do Not Resuscitate (DNR) in Ohio (this is a .pdf form to print & fill out):

www.odh.ohio.gov/pdf/forms/dnrfm.pdf

Slide 18



People who travel should take their documents with them. The Five Wishes may or may not be legal in every state. Adv Directives/living wills/Healthcare & Legal Powers of Attys are probably legal in every situation. People who are part-time residents elsewhere (e.g. snowbirds) should have docs on file at the local hospital(s).

Slide 19



Q: How does mental competence figure into this? SE: That's a tough question. Until a person is deemed mentally incompetent, they can make their own decisions. Q: Do you know of a procedure to declare competence? SE: Yes, I believe there is. It requires lawyers and witnesses.

Slide 20



Q: There is a chart of procedures on how to save a life. I read a statistic that 80% of drs don't want to follow this chart. CPR rarely leaves a person healthy. There was a RadioLab/NPR segment on this (<http://www.radiolab.org/story/bitter-end/>; aired on 9 Feb 2015). Reported CPR aftereffects are not encouraging.

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Another RadioLab bcast was about end-of-life care (<http://www.radiolab.org/story/end-life-care/>, aired on 10 Feb 2015).

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Ohio has two types of DNR: 1. Comfort Care-Arrest Order DNR: meds are used for pain & breathing AND CPR or breathing/feeding tubes until heart or breathing stops; 2. Comfort Care Order does not include CPR or tubes.

[<https://www.ohiobar.org/ForPublic/Resources/LawFactsPamphlets/Pages/LawFactsPamphlet-24.aspx>]. MUST be written & signed by physician.

Slide 23



Tammy McGuire in Athens County is O'Bleness' chief hospice nurse. Hospice carers have special certification. Hospice requires volunteers (at least 5% of personnel). Q: Some hospices are for-profit, many other are non-profit. Comments?

15 Jan 2015 Diane Rehm show [http://thedianerehmshow.org/shows/2015-01-15/the_rise_of_the_for_profit_hospice_industry]

[had speakers for profit and NP hospices, and WashPost article link.]

Slide 24



Athens area hospices are all non-profit at the moment. There was a recent scandal in Michigan; a for-profit hospice took Medicare payments up front, then closed.

Slide 25



Assisted living facilities are NOT regulated, in Ohio or anywhere else. They *need not* provide nursing staff, oxygen, medical facilities. Ask before entering. Assisted living facilities are all for profit.

Slide 26

REFERENCES

- Aging with Dignity Five Wishes Powerpoint retrieved from: www.agingwithdignity.org/ppt/FW.ppt
- Facing Mortality: How to Talk to Your Doctor retrieved from: <http://www.pbs.org/wgbh/pages/frontline/health-science-technology/being-mortal/facing-mortality-how-to-talk-to-your-doctor/>
- Core Curriculum for the Hospice and Palliative Registered Nurse

Member comment: There are online memorials, e.g. DigitalBeyond.com, on which people can plan things after their deaths. Emails to grandchildren, disposal of documents.

Member comment: There is also a Willed Body Program, at OU and other medical colleges. Let's have a program on this & other funeral arrangements.

Discussion ended around 1:45pm.

Addenda on Advance Directives:

There tend to be at least three parts to an advance directive: the living will; the financial power of attorney which allows another person to make financial decisions for the patient; and the healthcare power of attorney which states the sort of care the patient wants. Care can include Do Not Resuscitate (DNR) and how strong any treatment drugs can be.

Q: Can I change my mind about what's written in my advance directive? Yes. Once you make an advance directive, you may change or revoke it (take it back) at any time while you are competent to do so. It's recommended that you review your advance directive **at least every 10 years** and update it if needed. Be sure to do this if:

- You have a major health change or are diagnosed with a serious illness
- You go through a divorce
- You experience the death of a loved one
- You have a decline in an existing health condition, especially if it makes it harder for you to live on your own

If possible, changes should be signed, dated, and witnessed. You should tell your proxy or agent, family, loved ones, and doctor if you change or cancel your advance directive. You should also destroy all copies of the old advance directive so there's no confusion on the part of your proxy or your family. Some states require that you notify your doctor in writing when you make changes to your advance directive.

There are some times that a health care provider **may reject a medical decision** made by you or your proxy based on your advance directive. For instance:

- When the decision goes against the individual health care provider's conscience
- When the decision is against the health care institution's policy
- if the decision violates accepted health care standards

In such cases, the health care provider or facility must tell you right away. You may be transferred to another facility that will honor your decision.

Next brownbag will be Thurs 26 March 2015, location TBA. A Kimes representative has been asked to come speak about nursing homes & assisted living.