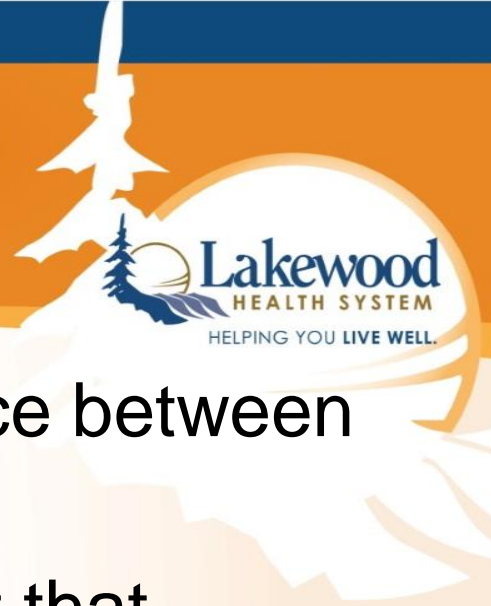




End of Life Care in Dementia

Julie Benson MD
March 9th, 2017

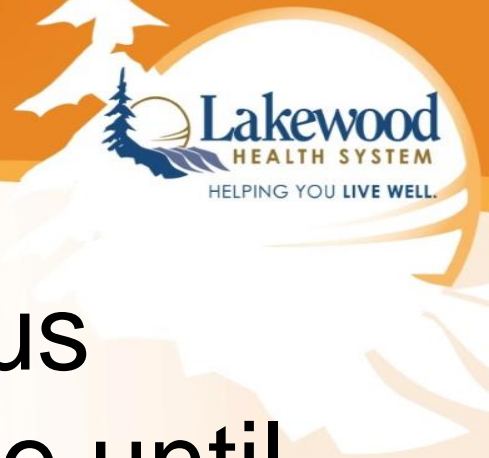
Objectives



- Identify and understand the difference between palliative care and hospice care
- Gain an understanding of the impact that utilizing these services can have on the dementia process
- Gain an understanding of the resources that are available to help the process of dying and how to utilize these resources
- Focus on living while dying



HOSPICE AND PALLIATIVE CARE



Caring for people with serious illnesses by helping them live until their death is how we have cared for people since the beginning of time until this last century.



**Palliative and hospice care are not
about dying.**

**This type of care is about *living*,
each day the best that it can be.**



hospes...

host a guest or stranger

palliare...

to cover or cloak



Palliative Care

Hospice

People often confuse palliative care with hospice.

They are not the same thing.

Hospice is a form of palliative care, but most of palliative care is NOT hospice.

Hospice Definition



Hospice provides medical services, emotional support, and spiritual resources for people who are in the last stages of a terminal illness.

Hospice Definition



It is a specific Medicare insurance benefit that was started by Congress in 1982 as a pilot project and made permanent in 1986.

Hospice Qualifications

(Medicare)



- Terminal illness and 2 physicians agree the prognosis is likely less than 6 months if the disease runs its usual course (hospice medical director & attending MD)
- You accept palliative care (for comfort) instead of care to cure your illness.
- Sign a statement choosing hospice care instead of other Medicare-covered treatments for the terminal illness and related conditions.

Venues of Hospice Care



- Home with family support
- Care Center
- Assisted Living
- Hospice House/Residential Hospice
- General inpatient at a hospital
- Respite care

Who Provides the Care



The Interdisciplinary Team (IDT):

Nurses

Physician

Social Worker

Chaplain

Pharmacist

Volunteers

Therapists – PT, OT, massage

Care Center staff

Services...



Supports families by:

- Medications, equipment
- Personal care and homemaking services
- 24 hour telephonic care & as needed RN care

Does not:

- Provide 24 hour care in the home
- Pay for room and board in care center or hospice house

Hospice Limitations



- Cannot opt for hospice insurance benefits while still receiving curative or life-prolonging treatments
- Cannot opt for services if life expectancy is greater than 6 months

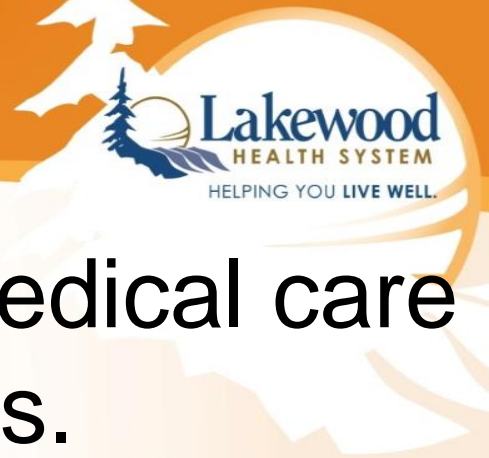


Many people still would benefit from expert medical, spiritual, psychological and social care during disease treatment or well before 6 month life expectancy



**This is where palliative care
comes in**

Definition



Palliative care is specialized medical care for people with serious illnesses.

It is focused on providing patients with relief from the symptoms, pain, and stress of a serious illness—whatever the diagnosis.

Definition



The goal is to improve quality of life for both the patient and the family.

Definition



Palliative care is provided by a team of doctors, nurses, and other specialists who work together with a patient's other doctors to provide an extra layer of support. It is appropriate at any age and at any stage in a serious illness and can be provided along with curative treatment.

Palliative Care is not...



- just for those at the end of life
- just for adults
- just for patients when nothing else can be done
- just for people with cancer
- Hospice

All hospice care is palliative care

But all palliative care is NOT hospice



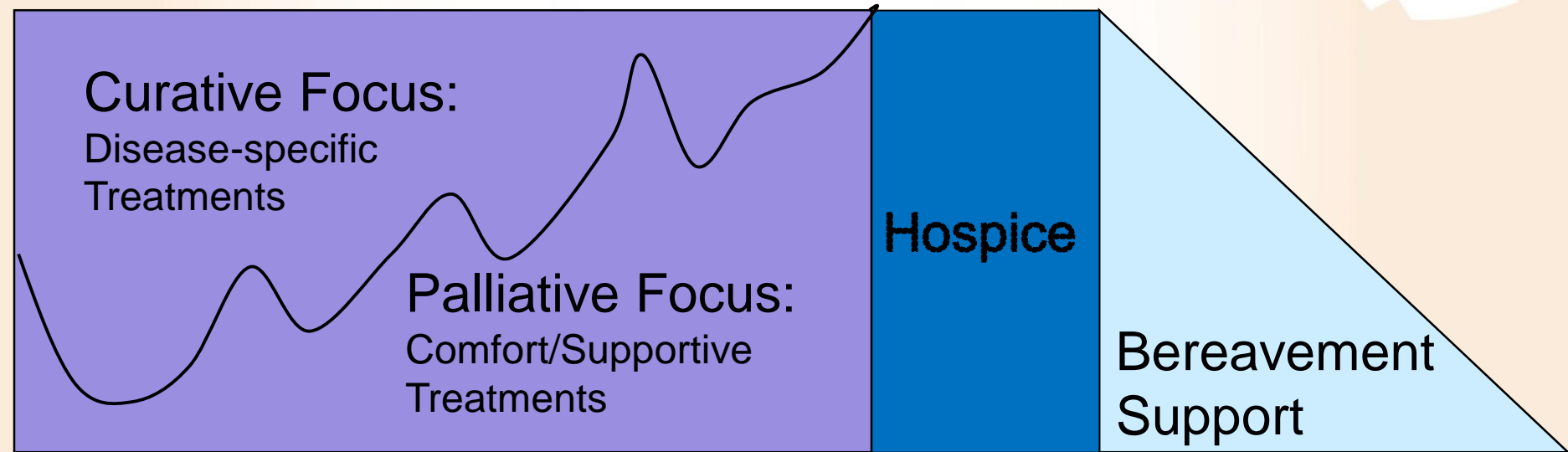
Palliative Care

Hospice

Palliative Care



Diagnosis



Curative Focus:
Disease-specific
Treatments

Palliative Focus:
Comfort/Supportive
Treatments

Hospice

**Bereavement
Support**

Death



Palliative Care

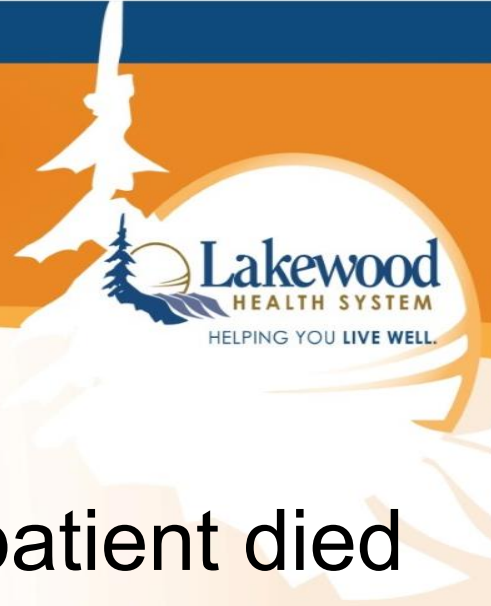


“Qualifications”

- Anyone with a serious illness or potentially life-threatening illness
- Cancer, stage 3 or 4
- Congestive heart failure
- Chronic lung disease
- Severe liver or kidney disease
- Lou Gehrig’s disease
- Dementia
- Stroke
- Pediatric congenital or genetic diseases



“Qualifications”



Surprise question

“Would you be surprised if this patient died in the next 2 years?”

Venues of Care

- Inpatient unit
- Outpatient clinic
- Assisted-living facility
- Group homes
- Long-term Care Centers
- Home through Homecare services



Who Provides the Care



The Interdisciplinary Team (IDT):

Nurses

Physicians

Social Workers

Chaplain

Pharmacist

Volunteers

Hospice/Home care staff

Care Center staff

Palliative Care



Disease often robs patients and families.

Palliative care seeks to restore:

- Control
- Choice
- Comfort
- Support
- Respect

Payment



- Not a specific insurance benefit at this time
- Paid for like other typical services
- Some non-reimbursed services are offered free or minimal charge depending on the venue of care

Examples of PC services



- Relieve symptoms so patients can live their lives more comfortably
- Family meetings
- Assist with documenting goals of care
- Assist with documenting Advance Directives
- Serve as medical interpreters
- Legacy building

Examples of PC services



- Disease education – what to expect
- De-prescribe medications to lessen pill burden
- Educate about hospice
- Assist transition to hospice when appropriate
- Bereavement care
- Grief support

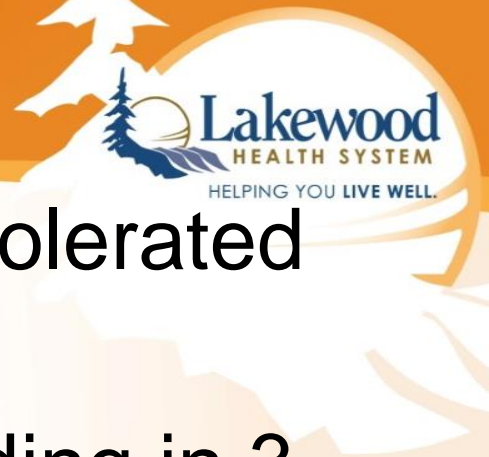
Gladys



57 year old woman with ovarian cancer

- admitted to PC when diagnosed with recurrence for symptom control (pain)
- Life expectancy was still > 6 months
- Began advance directives discussion which began with goals of care discussion
 - Stay out of hospital & continue chemo
 - Control pain and nausea
 - Finish the house her family was building

Gladys



When 3rd chemotherapy was not tolerated she reviewed goals of care again

- Priority: to make it to son's wedding in 3 months
 - Stopped chemo
 - Felt better, more energy
 - Willing to have less time if she could have quality time with her family

Gladys



Hospice elected

- Team worked to keep her out of hospital
- Moved wedding date up
- Danced at her son's wedding
- Died 1 month later
 - “no regrets”

Myths



There are many myths and misconceptions regarding **hospice** that have then translated to **palliative care**.

Myths



- Can't go to the ER or hospital for treatment
- Must be "DNR"
- Can't receive antibiotics
- A place where the ill go to die
- A patient can no longer see his or her regular physician
- Giving up hope or that there is nothing left to do

Myths



Not left to die...but free to live!!

Myths



What beliefs or myths have you heard?



Hospice is an opportunity to capture dignity in a challenging time for both the recipient and the family.

Hospice works to provide comfort and promotes an opportunity to bond emotionally and spiritually.



DEMENTIA



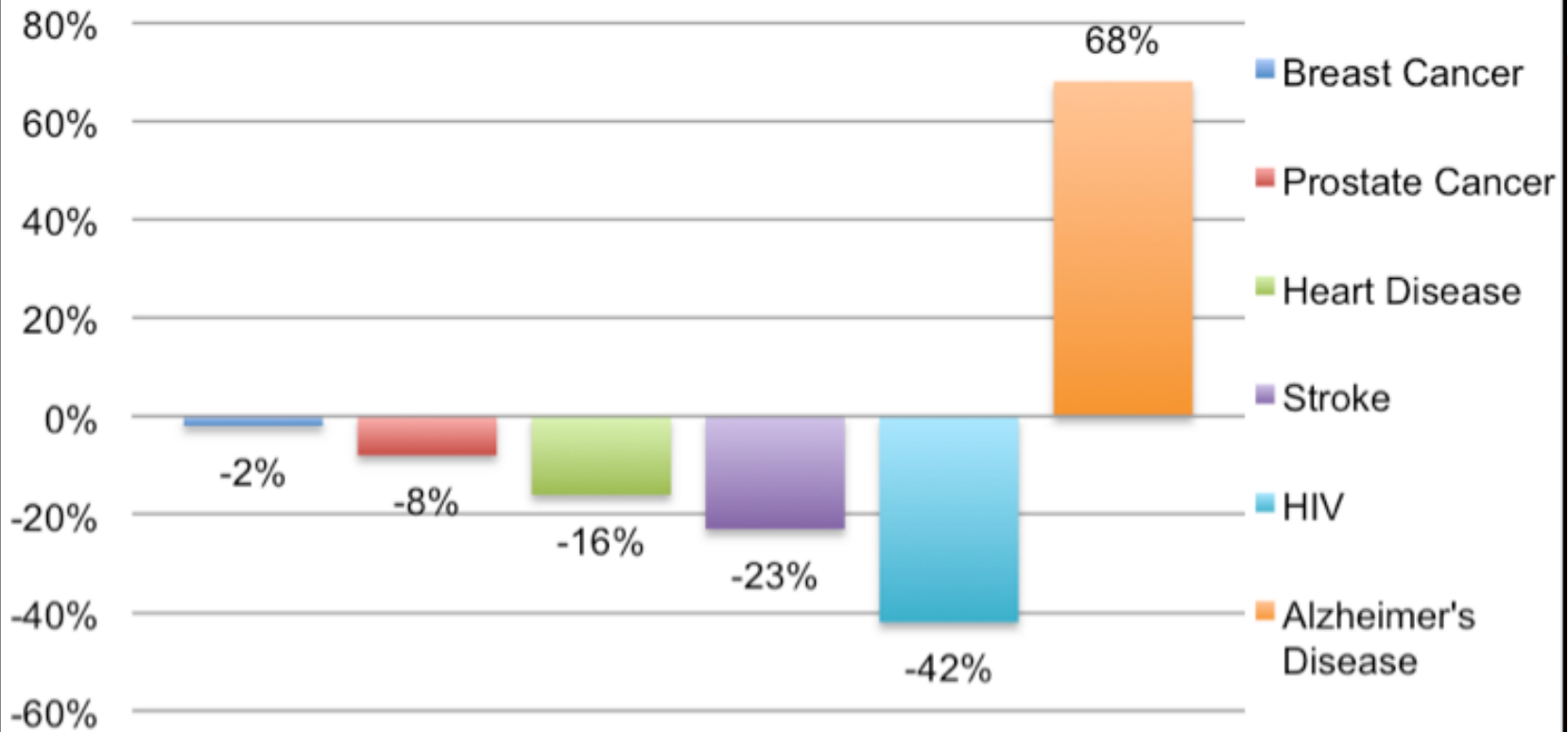
Humans have never lived
so long or in such good
health as we do currently

History of Dying

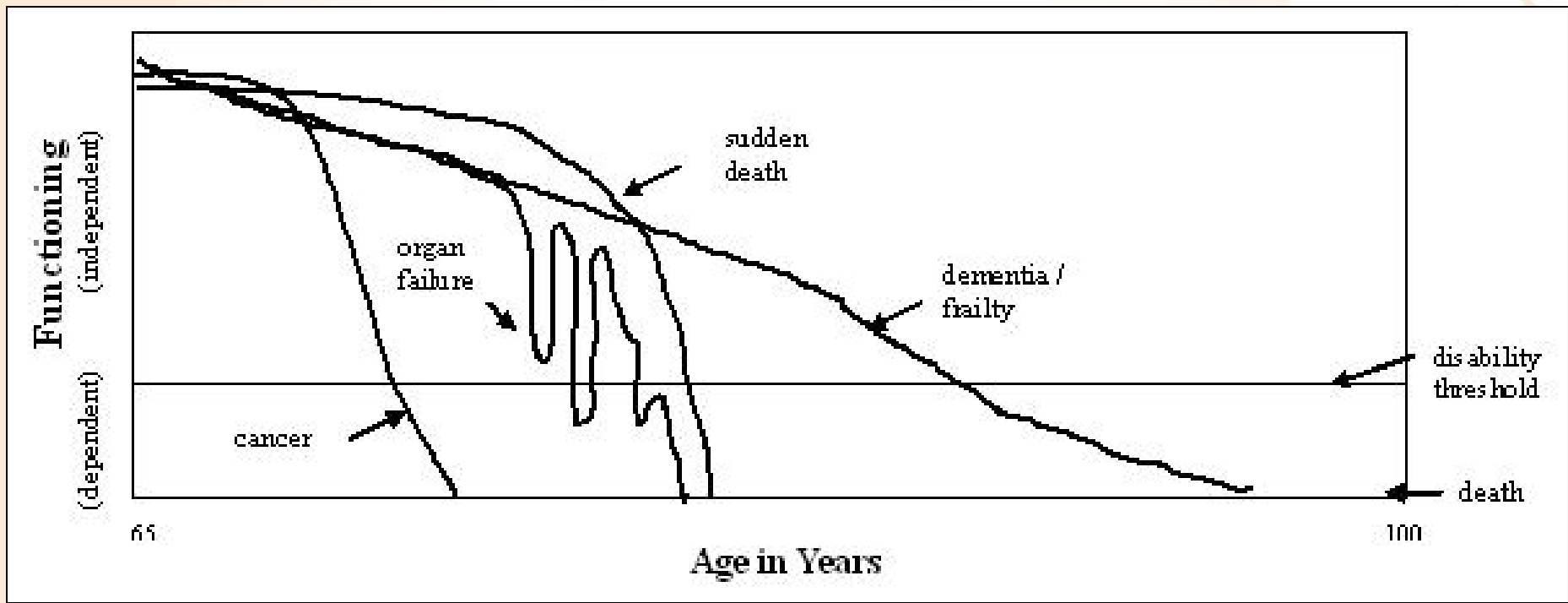


	1900s	2000s
Avg life expectancy	47 years	78 years
Causes of Death	Infections Accidents Childbirth	Cancer Organ failure Frailty
Disability before death	90% quickly 10% slow degenerative	10% quickly 90% slow degenerative

Change in the Number of Deaths between 2000-2010



Source: Alzheimer's Association



Alzheimer's Disease



- Difficulty remembering recent events, names, events and appointments
- Decline in mental ability severe enough to interfere with daily life.
- Gradual brain changes years before clinical symptoms
- Dementia is a neurodegenerative disease
- Dementia is fatal disease

Treatment



- “At this time, there is no treatment to cure, delay or stop the progression of Alzheimer's disease. FDA-approved drugs temporarily slow worsening of symptoms for about 6 to 12 months, on average, for about half of the individuals who take them.”
- Medications and behavioral options to manage symptoms

Prognosis



- Average life expectancy after onset of symptoms is 4-8 years
- Up to 20 years
- Depends on timing of diagnosis
- 3 stages of disease
 - Early: *can make decisions still*
 - Middle: *variable ability to make decisions*
 - Late: *no ability to make significant decisions*

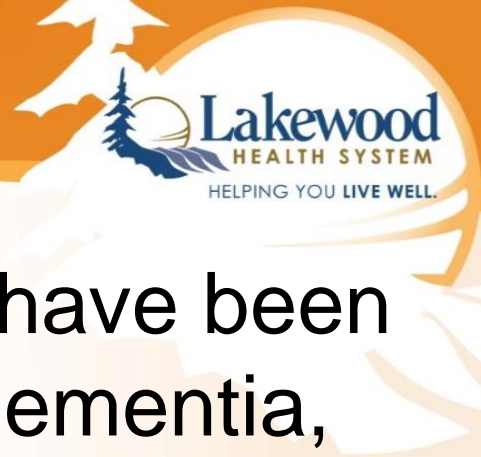


PALLIATIVE CARE & DEMENTIA

Why PC is needed for dementia



- 67% of dementia-related deaths occur in nursing homes.
- 71% of residents with advanced dementia died within 6 months of admission, yet only 11% were referred to hospice.
- ***Non-palliative care treatments are quite common in residents with dementia. This includes tube feeding, laboratory tests, restraints, and intravenous therapy.***



- Unless clear medical directions have been set up at the earliest stages of dementia, families and caregivers often must face heartbreaking decisions when a patient can no longer make decisions for themselves.
- Making difficult decisions early decreases stress and angst at stressful times; rather than focusing on celebrating life.



There is a significant difference between making decisions for:

Someone who is *unconscious*

&

Someone who is *conscious but unable to make complex medical decisions*

Actions to take early



- A. Advance Care Planning
- B. Understand your financial and legal resources and update as appropriate
- C. Discuss when to retire from driving
- D. Bucket list
- E. Legacy building

A. Advance Care Planning



What it is:

Advance Care Planning is a **process** focusing around **conversations** about healthcare choices for the future

Why it matters:

Any one of us could be in a situation at any time where we are unable to speak for ourselves or make choices about healthcare. Your doctors and loved ones can't follow your wishes if they don't know what they are.

How to begin:

Resources are available online, through many healthcare providers, faith centers, and Honoring Choices Minnesota

Advance Care Planning



- Select a decision maker
 - Power of Attorney for Healthcare
- Learn, discuss and document goals of care should you be unable to make a decision for yourself
- What does your decision-maker need to know about your beliefs
- Ongoing conversations

Advance Care Planning



- Documentation is the goal but the conversations are much more important
- The Advance Directive or Living Will is the product of your conversations and decisions
- Copy to family, important people, hospital/clinic – NOT safety deposit box

Advance Care Planning



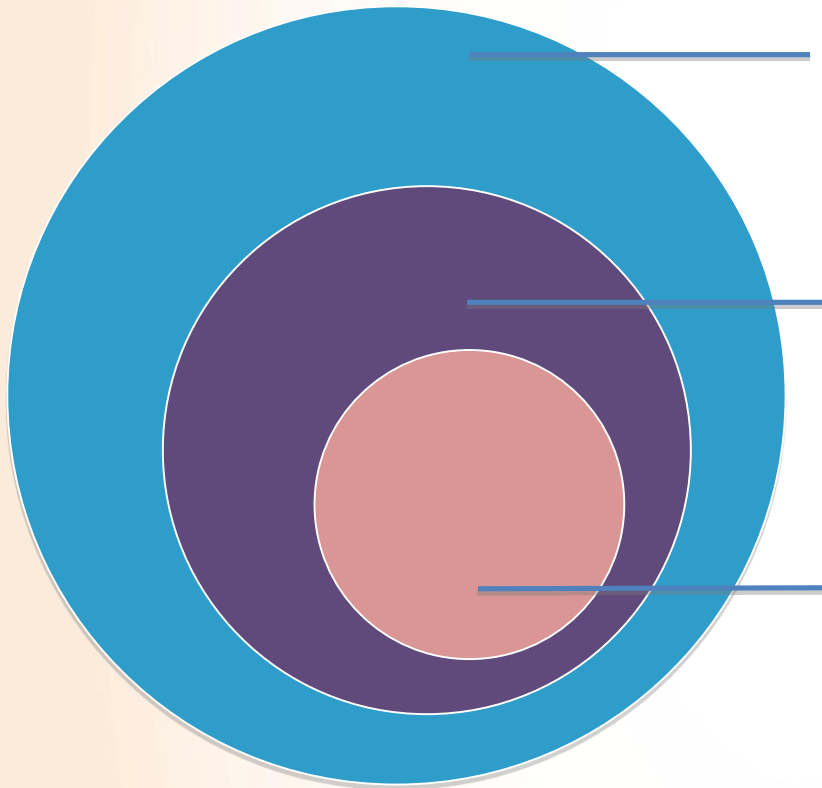
Special situation

POLST

Provider Orders for Life Sustaining Treatment

- 2 years or less to live
- Must be signed by provider
- Keep original in the home in obvious spot

Advance care planning: Components



Advance Care Planning:

A conversation process every adult should have.

Advance Health Care Directive:

A written document all adults age 18 and over should complete after contemplation and discussion.

POLST (Physician Orders for Life Sustaining Treatment):

A specific medical order written for seriously ill people meeting specific criteria.

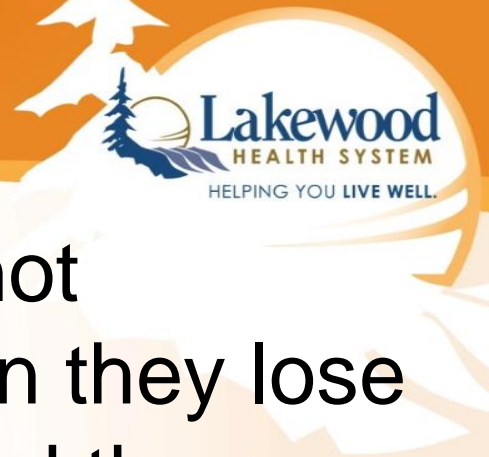
B. Common Decisions

- Nutrition
- Hydration
- Dialysis
- CPR or resuscitation
- Antibiotics
- Hospitalizations or ER visits

What are the goals of care?



Nutrition



- People with dementia begin to not recognize hunger and thirst, then they lose the ability to feed themselves and then even the ability to swallow.
- Artificial nutrition through a feeding tube (in the nose or stomach) or the vein has often been thought to be the next logical step in providing nutrition

However...



- Feeding tubes are not recommended in advanced dementia
- Increase risk for pneumonia, pressure sores and skin breakdown, bleeding, diarrhea, fevers, agitation, and trips to the hospital
- Does NOT prolong life, increase weight gain or improve strength and skills

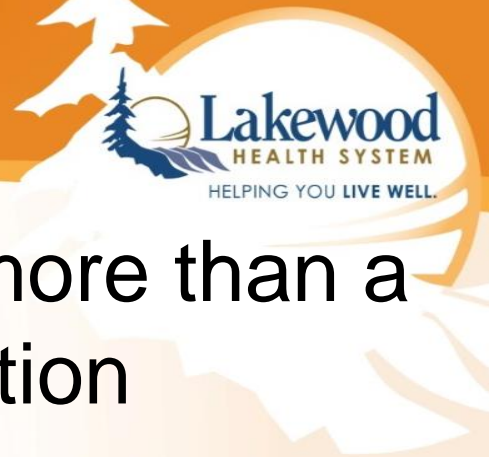
Nutrition



Careful hand feeding:

- safe
- increases *person to person contact*
- requires position changes
- provides pleasurable taste experience
- Patient can refuse to eat and feedings can be stopped when clinically indicated
- comforting

Hydration



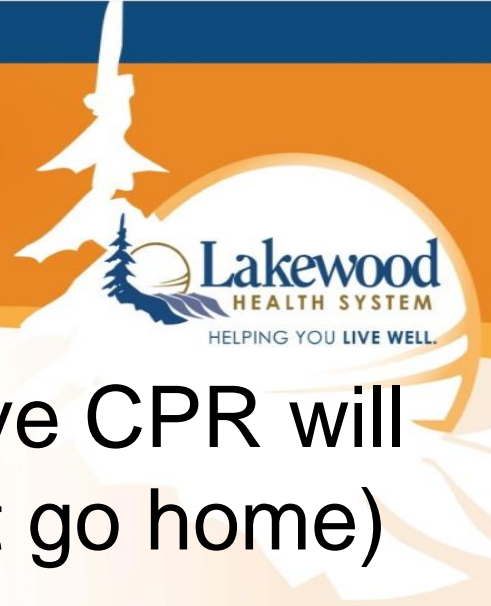
- IV fluids will not sustain life for more than a few days in the absence of nutrition
- Meant to treat dehydration in a setting of reversibility (ie acute diarrhea)
- May actually add to burden of symptoms
- Prolonging life or prolonging death?

Dialysis



- 3 days/week for 4-6 hours in a chair
- Increased confusion, weakness, fatigue, depression and anxiety
- “dialysis dementia”
- Increased need for medications to treat agitation, anxiety and restlessness
- Increased hospitalizations, infections, blood tests, procedures
- Prolonging life or prolonging death?

Resuscitation (CPR & Intubation)



- 17% of hospitalized pts who have CPR will leave the hospital (many will not go home)
- 3% of care center residents survive and most do not return to previous level of functioning
- Side effects
 - Rib fractures, ventilator dependence, artificial nutrition, brain damage

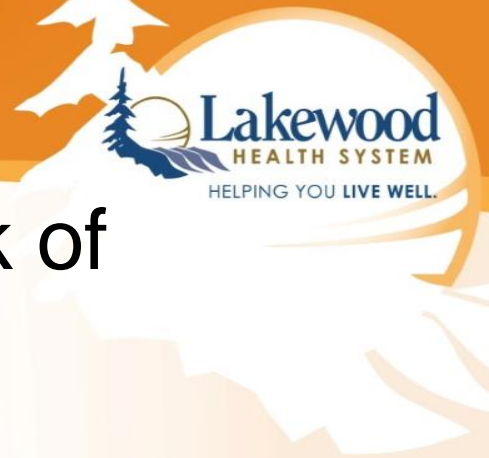
Resuscitation (CPR & Intubation)



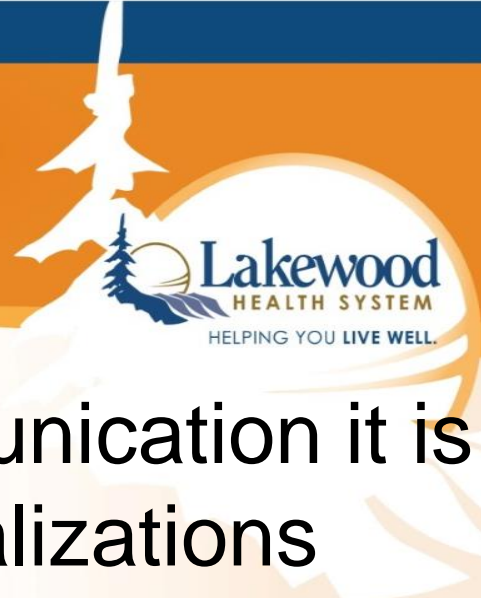
- **Choosing not to attempt resuscitation is not the same as ‘doing nothing’**
- When a patient is so sick that their heart or lungs are failing simply restarting a heart is not likely to be successful or likely to reverse the other medical issues that originally caused the failure

Antibiotics

- Recurrent infection is a hallmark of end-stage dementia
- May also relieve some symptoms temporarily
- Prolonging life or prolonging death?



Hospitalizations or ER



- With careful planning and communication it is possible to prevent many hospitalizations and ER visits for patients living with dementia at the end of life.
- Action plan in the home or care center
- Ability to access medications for symptom management
- Focus on comfort not ‘fixing’ the problem

Ethics



- Medical interventions are not required interventions
- May choose to not start an intervention
- May choose to stop any intervention (ie. pacemakers or dialysis or feeding tubes)
- Bioethicists agree that these choices are ethically equivocal

C. Financial Resources



- Estate planning
- Longterm care insurance
- Contact lawyer about asset management
- “no matter what I don’t want to go to the nursing home”
 - Consequences of these statements
 - Guilt of family members

D. Driving



- Retire from driving
- Preferred to revocation of license
 - Consequences
 - Family guilt
- Intermittent family ride-alongs
- “I’ll know when it is time”
 - Loss of insight as part of disease process makes this unlikely

E. Bucket lists

- Don't wait until the last minute
- Make new memories and record for future review
- Travel
- Family reunions

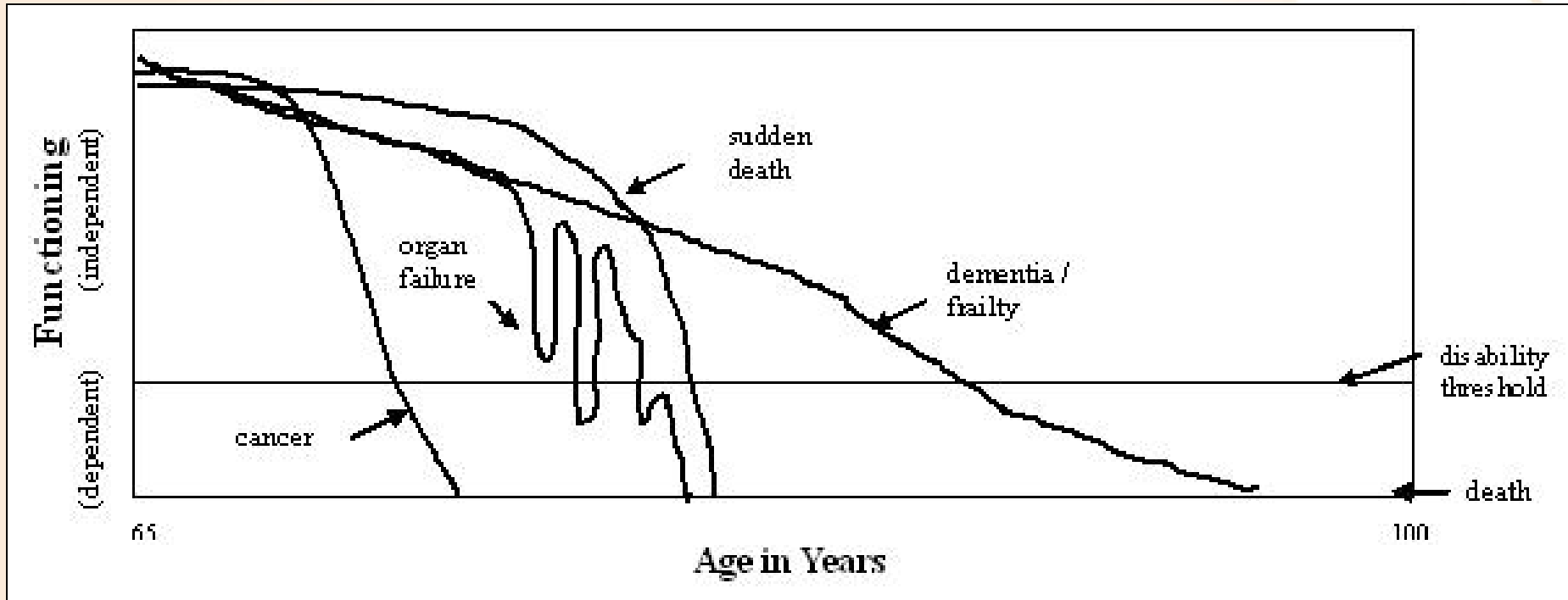


F. Legacy building

- Heirlooms & stories
- Photos
- Videos
- Oral stories
- Family history
- Letters for future events
- Structured programs to help guide families



When to refer?



When to refer in general?



- Depends on prognosis
 - Which the medical field is terrible at
 - Pretty good at < 2 weeks and > 2 years
- Extremely variable - so physicians don't
 - afraid they will “take away hope”
- Wait for patients to bring it up
 - The elephant in the middle of the room
 - Handouts to help lead discussion

When to refer? (Ideally)



- At time of diagnosis – basic palliative care (primary physicians, specialists, social workers)
- Advancing disease – interdisciplinary care assessments
- End-stage disease – hospice care

When to refer?



- To palliative care program
 - Surprise question
“Would you be surprised if this patient were to die in the next 2 years?”
- Most frequently at time of crisis
 - Frequent infections
 - Recurrent hospitalizations
 - Decision making capacity concerns

When to refer?



- To hospice
 - Weight loss of $> 10\%$ in 6 months
 - Dependence on activities of daily living
 - Recurrent infection (urinary or pneumonia)
 - Change in functional scores
 - Poor nutrition as noted by low albumin

Access



- Ongoing programmatic support for patients living with dementia do not exist uniformly in every community
- Resources are variable and limited
- Don't give up
- Advocate – advocate - advocate

Wayne



78 year old gentleman with end-stage kidney disease on dialysis living in care center for 2 years.

- Recent decline in cognition
- Increased delirium and depression
- Increased pain
- Very agitated at dialysis
 - Increased medications, wife had to come sit with him, often stopped his run early

Wayne



Palliative Care referral:

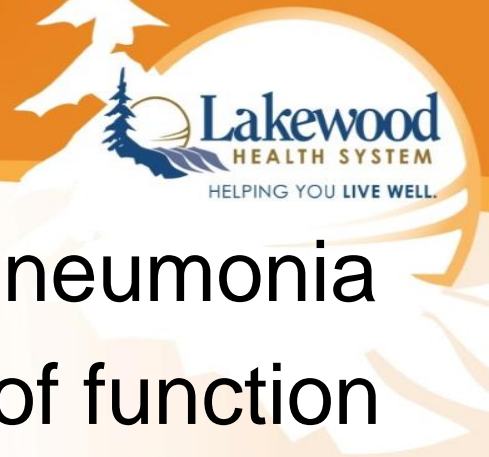
- Staff concerned dialysis was causing more distress
- Manage symptoms
- Discuss goals of care
- Review advance directives
- Facilitate family discussions
- Present hospice as an option in the future

Wayne



- Updated advance directives
- Medication changes to improve symptom control
- Supported wife in understanding his advancing dementia and help her understand progression of disease
- Facilitated blended family discussions

Wayne



Month later hospitalized for acute pneumonia

- Did not recover to previous level of function
- Reviewed goals of care
- Previously established trusting relationship allowed frank discussions about end of life
- Hospice referral
 - Blended family all in agreement

Living, not dying



Positives about dementia

- More time to prepare
 - Comfort in caring gently for someone you love
 - A chance to return the care
 - Time to share the care amongst many family members who may need more time coming to terms with the impending death

Living, not dying

- More time to create memories
 - Not just relive old ones
 - Legacy building
- Focus on what *can* be done, not what *can't* be done



Living, not dying



- More time to say the things that we need to say
 - Please forgive me
 - I forgive you
 - Thank you
 - I love you
- Ira Byock



***You matter because of who you are.
You matter to the last moment of your
life, and we will do all we can , not
only to help you die peacefully, but
also to live until you die".***

--Dame Cicely Saunders

Resources



- Minnesota Network of Hospice & Palliative Care
- GetPalliativeCare.org
- Honoring Choices Minnesota
- www.nhpco.org/resources-access-outreach/dementia-resources
- Hospice handout
www.medicare.gov/Pubs/pdf/02154.pdf

Thank You



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