

*As Dementia Progresses:
when can a caregiver say 'enough'*

Hospice of the Shoals Caring for Caregivers

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Silence is golden

- Please place pagers and cell phones on mute or vibrate.
- Ask questions anytime.

Dementia - Outline

1. Dementia's poor prognosis
2. What are the goals of care
 - What's the goal of medicine?
3. When to say 'enough' ?
 - TLC & "M&M's"
 - Who gets to decide?
4. Importance of Advance Care Planning:
 - Avoiding non-beneficial treatments
 - End of Life Care myths
 - Advance Directives
 - When is Hospice appropriate

1. Prognosis for Dementia

- Older you are, greater risk of Alzheimer's
 - Age 65-75 = 8%
 - Age 76-85 = 25%
 - >85 = ~50%
- Younger live longer – up to 10+ yrs
- Older live shorter - <4 yrs

...Prognosis for Dementia

NH study* of 323 residents x 18mo.

- Mortality: 54%
- Pneumonia: 41%
- Eating problem: 85%
- Dyspnea: 46% [>5days/mo]
- Pain: 39%
- Pressure Ulcers [stg.2+]: 39%
- Agitation: 53%

* Mitchell S, et al. The clinical course of advanced dementia. NEJM 2009

...Prognosis for Dementia

Last 3 mo life:

- 40% had 1+ burdensome intervention (hospital, PEG, ER, IV)
- **Symptoms similar to terminal cancers**
 - Dyspnea – 33%
 - Pain - 25%
 - Aspiration - 37%
 - Pressure Ulcer – 29%

Therefore: To prevent suffering in a terminal diagnosis, focus on goals & preferences !

2. Goals of Care in Dementia

- What are ‘goals’?
 - A result or end we want to reach
 - Are based on prognosis
- Why set goals of the medical care?
 - Care goals shape expectations & priorities
- What’s the goal of medicine?
 - To prevent and relieve suffering !
 - *Primum non nocere* - First, Do No Harm !

Goals - a spectrum of choices

From:

“DO EVERYTHING”

- CPR
- Dialysis/transplants
- Tx all conditions
 - Even if pain worsens

To:

COMFORT ONLY

- A.N.D. / DNAR
- Control symptoms
- TLC + M&M's
- Tx any discomforting symptom aggressively

Case Example – Mrs. A.A.

- 81 yof, Alzheimer's x 4 years
- HTN, PVD, OAB, OA, OP, GERD
- TIA's, CAD w/ stents, CHF
- Taking many prescriptions
- Widow, in ALF, 3 kids
- Walks with a cane

Goals - Mrs. A.A.

What does she (and her family!) want at this point in her life?

– **What's most important to her ?**

– “Do Everything” vs “Comfort only”

vs “In between (stabilize function)” ?

What information will help them?

Information to help their decision

She has two Life-Limiting Diseases [i.e. no cure]

– CHF

– **Alzheimer's**

- Only treatment is symptoms for comfort!
- What's the life expectancy for each ?
- What might make her memory and QOL worse?
- How do we rationalize the different choices for treating all her problems? ...Goals

How to Choose Healthcare Goals

- 1) Clarify status & prognosis of disease/condition & treatment options
[be informed via doctor & “internet”]
- 2) Identify patient/family goals !!
 - comfort, longevity, or mixture of both?
- 3) Accept that goals may change w/ more info!
 - e.g. if surgery might impair memory, patient could choose to not have it.

What Do Patients & Families with Serious Illnesses Want?

- Pain and symptom control
- *Avoid prolongation of the dying process [once it begins]*
- A sense of control & honor wishes
- *Included in decisions & to be listened to*
- ***Honest information***

Singer et al. JAMA 1999;281(2):163-168.

Tolle et al. Oregon report card.1999 www.ohsu.edu/ethics

Ms. A.'s dilemma

- How do we rationalize the different choices for treating all her problems?
 - **GOALS, GOALS, GOALS**
 - **“how will she be after a particular treatment?”**
- What has she told family in past ?!
[never keep me alive on a machine]

How do we help her and her family--especially if she is no longer competent ??!

3. When to say 'ENOUGH' ?

- The goal of medicine and defining *The Good Death*
- How do TLC & “M&M’s help?
 - Can *M&M’s* help reach our goal/purpose?
- Who gets to decide?
 - If patient hasn’t made wishes known, then what?

Goal of Medicine

- To prevent/relieve suffering.
 - Is that also a major *purpose of life*? [Buddhist]
- What is suffering?
 - Distress which has no purpose or end in sight
- Do dementia patients & their caregivers suffer?
 - Can memory loss ever be beneficial?

Any benefits to memory loss?

* THE *SENILITY* PRAYER

God grant me the senility to forget the people I never liked anyway, the good fortune to run into the ones I do, and the eyesight to tell the difference.

- Irish folk story

* Lots of 'new' friends !! [need humor, or go crazy]

Defining a Good Death

The 4 qualities of a peaceful death*:

- Having a peaceful mind
- Not to suffer
- Not dying alone
- Family acceptance of dying
 - Caregivers role and relationship

**Masel et al. Life is Uncertain. Death is Certain. Buddhism and Palliative Care. J pain & sympt mgmt. 2012*

...Goal of Medicine

- Dementia is a terminal illness and death is certain – only choice is “how” we die [photo]
- Since no ‘cure’, are these appropriate goals:
 - relieve/prevent suffering?
 - provide a peaceful & dignified death?
- How can you [patient or caregiver] be certain you’ll receive the best care to achieve that goal?

How do you want to live/die?



How do you want to live/die?



Treatment/Management Options to Achieve the Goal [prevent suffering]

A. Try to slow down the disease

B. Control the symptoms

C. Accept what can't be controlled and make choices to avoid suffering?

Making choices: who gets to decide?

- Choosing *M&M's* – caregiver's story
- “*My father's broken heart: how putting in a pacemaker wrecked my family's life*”
– Katy Butler. NYT magazine, June 20/10
- “*Waging Peace in the War on Cancer*”
[in *Treatment Options & Dilemmas* -
comfortcarechoices.com]
- **The importance of an Advance Care Plan**
- *For patient and caregiver*

4. Advance Care Plan Choices

- 1) If Futile Care causes suffering, how do we avoid it?
 - What's best and what's "comfort care" ?
- 2) Myths of End-of-Life Care
- 3) Advance Directives
 - Common sense care & decisions
 - the caregiver's role
- 4) Hospice Criteria for dementia

1) How to avoid futile care: What's best???

FOR BETTER OR FOR WORSE

IT'S ANOTHER STROKE, ELLY. EVEN WITH ALL THE MEDICATION HE'S ON—IT'S ANOTHER ONE.



THEY SAY IT WILL TAKE A FEW DAYS BEFORE WE KNOW WHERE HE IS... MENTALLY AND PHYSICALLY.



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WHAT IF HE NEVER WAKES UP? WHAT IF...

DON'T THINK THAT WAY, IRIS. WE HAVE TO HOPE FOR THE BEST!



IN THIS SITUATION...WHAT IS THE BEST?

10-4 www.fborfw.com

LYNN

Defining “Comfort Care” as a Goal

- What is comfort for one, may still be uncomfortable for another
- Pain (comfort) includes: physical, emotional, social, spiritual
- Each person must decide what’s tolerable and best for their own circumstances
- “Comfort” may change with situation

Mrs. A.A. – 1 year later

- Now requires walker and 1 assist all ADL's
- Admitted to hospital w/ fx hip + Delirium
- Surgeon says, “we need to fix her hip to control her pain and help walk again”
- What now: how does family make an informed decision?
 - They say, “do everything necessary”
 - What does that really mean ??

What Affects Decisions * ?

- Unrealistic expectations / false hopes (lack of information)?
- “selfishness” of family?
- GUILT ?? - ‘seagull children’ [story]
- ‘Rescue’ mentality?
- “Learned helplessness” – family’s [W.Berry] ?
- No plan of care in place?

* Read Hank Dunn’s “Hard Choices for Loving People”

Purpose of Informed Decisions: *Avoid Futile Care & Suffering*

- Since, only 10% people die suddenly
- 90% need some form of terminal care
- Providers must face decisions of “how many and what kind of interventions are needed”
 - Once dementia progressing, the more we do to these folks, the more suffering we may cause: **we can be primary cause of suffering or, we can be primary cause of its relief !**

Defining Futile Care

- “clinical care that has a $< 1-5\%$ chance of survival”, or
- “when desired goals not met or desired results cannot be achieved”
- **When treatment causes harm without benefit**

Futile Care is **NOT** Quality Care

- Having more care and more expensive care doesn't = quality care necessarily
- **Quality means the care:**
 - **Must be effective for the condition in light of patient's values and goals**
 - **Must maximize benefits, minimize risks**
 - **Must be cost-efficient**

Medical 'dependency' & 'abandonment'?

- Has society become 'addicted' or dependent on pills/doctors and the 'quick fix', and can't care for family members any more?
- Does dependency and 'learned helplessness':
 - lead to frequent futile care ?
 - result in our 'abandoning' loved ones to medical care ?

What's 'Abandonment'?

“... they saw finally that in their attempt to help they had not helped but only complicated his disease beyond their power to help. ... Loving him, wanting to help him, they had given him over to “the best of modern medical care”—which meant, as they now saw, that they had abandoned him.”

– Wendell Berry, *Fidelity*, 1992

...More Reasons for Futile Care

- **Poorly defined**
 - **Decision processes faulty**
 - **Goals are not made known**
 - **Patients/families have insufficient info**
 - **Choices may not be clear**
 - **Leads to incongruity between patient goals and physician's offered choices**
 - **Results in mutual misunderstanding**
- e.g. Mrs. A.A.

The Futile “Do Everything”

- **Doctor’s assumption:** provide all surgery & drugs & tests to keep alive
- **Patient’s assumption:** doctor will only do those things known to be effective in reaching their goals
- “Do Everything” really means “Do everything that will help reach goals”

Summary: How to Make Informed Decisions & Avoid Futile Care

- 1) Discuss status of conditions and prognosis
- 2) Clarify goals
- 3) Understand all the options (read available material)
- 4) Ideally, physician recommends one option based on Goals – “we should aggressively do everything necessary for comfort”

...How to Make Informed Decisions & Avoid Futile Care

- 5) Formulate a plan, including response to crises; make an ACP & tell all family!
- 6) Confirm: can you live with the decision?
- 7) Ideally, patient has ACP written – if not, surrogate/proxy caregiver must decide what's in *best interests* of patient – and can say “enough” !

Benefits of Info & Discussions

- Cancer pts who discuss EOLC wishes w/ MD have
 - Less aggressive care/admissions to hospital
 - Improved QOL w/ more peaceful death

** Zhang B. Health care costs in the last week of life. Arch Intern Med. 2009*
- Pts who choose hospice live ~29 days longer than those not in hospice

** Connor S. Comparing hospice & non-hospice patient survival among patients who die within a three-yr window. J Pain Symptom Manage 2007*

2) Information affects Decisions: **EOLC Myths**

1. Dehydration is painful
2. We cannot allow someone to starve to death
3. Feeding tubes prevent aspiration
4. CPR will resurrect most patients

...EOLC Realities

1. Dehydration improves comfort
2. People do not “starve to death”
We ‘step aside’ and allow them to die naturally from the disease !
3. Feeding tubes increase aspiration risk x 4
4. CPR only 5 % successful in those w/ LLD

McCann. Comfort care for terminally ill patients. JAMA. 1994
Christakis. BMJ 2000;320][Benkendorf. Prehosp EmCare 1997

...Myths of CPR

- What is the success rate of CPR on TV?
 - 67% !!
- What is it in real life?
 - 0-17% ! (for those >70 years of age)
- Is CPR a dignified procedure for elders?
 - It is a futile & unethical procedure for seniors
- **Need order for “Allow Natural Death”**
[“DNR” or “no CPR”]

3) Why have Advance Care Planning?

- Trust building – knowing wishes will be followed
[physician friend e.g.]
- Uncertainty reduced
- Helps to avoid confusion and conflict
 - In family & caregivers
 - With providers
- Permits peace of mind for patient and family
- Prevents unnecessary suffering

...Why have Advance Care Planning?

If have Dementia,

Who wants to:

- end up in a Nursing Home?
- be bed-bound and dependent?
- live not knowing family?

Or, would you prefer to:

- die “cutting the lawn”?
- live rather than be ‘kept alive’?
- die at home rather than in hospital/NH?

Making Choices

- If goal is to avoid ‘dependency’, indignity, etc, then can choose Comfort Care Only – at any time:
 - no surgery, no CPR, no ventilator, no PEG
 - TLC with M&M’s
 - Nothing “artificial” to interfere in life’s journey or to prolong dying:
 - Antibiotics
 - Drugs for BP, diabetes, etc

Living Will / Advance Directive

Definition:

A form to make your wishes known about medical treatment or other care you may or may not want if you became too sick to speak for yourself

Should help avoid those undesirable situations, such as a Nursing Home, or a PEG, or being 'kept alive'.

Advance Directives



Help avoid futile care !

- Select a healthcare proxy and discuss with them
- Write “A.N.D.” & “No CPR” in the “Other Directions” section [AL State form]
- Tell doctor to write order on every admission
- Avoid miscommunication or judging others !
 - Be clear in making wishes known !

A.N.D.= “Allow Natural Death”



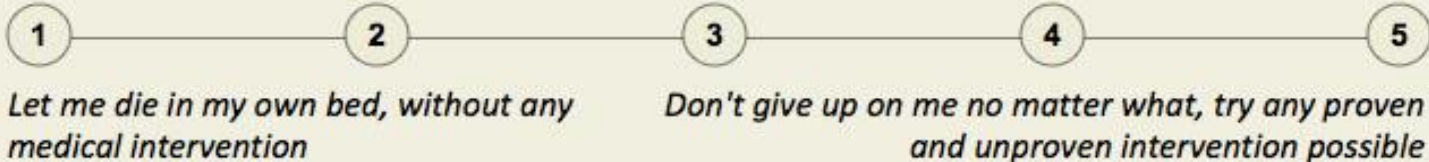
How you can avoid futile care:

- Be informed
 - Read available material
 - Engagewithgrace.org [**One Slide Project**]
 - **It's Ok to Die** [Dr. Monica Williams-Murphy]
 - **Comfortcarechoices.com**
- Tell your family and physicians what you want

One Slide Project

Can You and Your Loved Ones Answer These Questions?

1. On a scale of 1 to 5, where do you fall on this continuum?



2. If there were a choice, would you prefer to die at home, or in a hospital?
3. Could a loved one correctly describe how you'd like to be treated in the case of a terminal illness?
4. Is there someone you trust whom you've appointed to advocate on your behalf when the time is near?
5. Have you completed any of the following: written a living will, appointed a healthcare power of attorney, or completed an advance directive?



Values History “Example” of an Advance Directive

- I, **MAXINE**, being of sound mind and body, do not wish to be kept alive indefinitely by artificial means. Under no circumstances should my fate be put in the hands of pinhead politicians who couldn't pass ninth-grade biology if their lives depended on it, or lawyers/doctors interested in simply running up the bills.
- If a reasonable amount of time passes and **I fail to ask for at least one of the following:**

Example cont'd...

- glass of wine, chocolate, a Margarita, chocolate, a martini, a cold beer, chocolate, chicken fried steak w. cream gravy, chocolate, Mexican food, chocolate, French fries, chocolate, Pizza, chocolate, ice cream, cup of tea, chocolate, sex, chocolate;
- **Then, it should be presumed that I won't ever get better.** When such a determination is reached, I hereby instruct my appointed person and attending physicians to pull the plug, reel in the tubes and call it a day.

4) Hospice

- **Definition:** Medicare benefit for those with a terminal disease and less than 6 mo. to live under usual circumstances
- **Criteria for Dementia admission:**
 - FAST Stage 7c [if reached in sequence, expect avg. 3 mo. to live.]
 - Plus other illnesses usually

...Dementia criteria for Hospice

At least one of the following serious events w/ EOL impact has occurred in the past six months:

- __COPD
- __CHF
- __Fever recurrent after antibiotics
- __Recurrent aspiration pneumonia
- __Sepsis/Septicemia
- __Upper UTI (e.g. Pyelonephritis)
- __Progressive weight loss >10% in past 6 months
- __Serum Albumin <2.5 gm/dl
- __Decubitus ulcers (multiple- stage 3-4)

So, when should caregiver say *'enough'*?

Reminder: *is the goal "to live" rather than "be kept alive"?*

Ask: is she suffering, not enjoying life, & 'ready to go'?

Then,

- Choose comfort [i.e. *'enough is enough'*]:
 - Stop all non-comfort meds/tests & doctor visits
 - Do whatever's necessary for comfort [patient's and caregivers !]
 - May need nursing home ???!
 - Wait patiently...and leave rest to higher power!

Finally,

*As you slide down the banister of life, may
all the splinters point down!*

- Maxine

THANK YOU !