

Avoiding Healthcare Dilemmas

SIMPLE SOLUTIONS

Video 1 of a 3 part series

Donna Westmoreland
MSN, FNP-BC, ACHPN

Nurse Practitioner - Palliative Medicine

1: Decision maker defaults

2: 'Do everything' dilemma

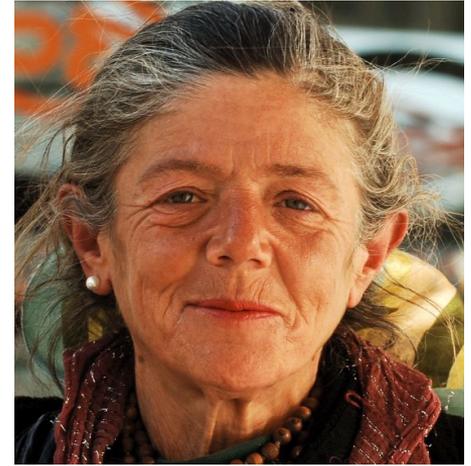
3: Life support challenges

Disclaimer: this is not medical advice

— I practice in Michigan, some
details may differ in your state —

Marlene

Dilemma: Decision Maker Default



CASE STUDY: Marlene is a 59 y.o. woman in the ICU for both bacterial and viral pneumonia, with advanced COPD. She was placed on the ventilator this morning, is lethargic and may not be decisional. She called 911 herself for shortness of breath, and her ICE in case of emergency phone contact listed a friend, Sue.

Sue says Marlene and her husband have no children, he moved out two years ago - she is unclear if they are legally divorced. Sue states Marlene has six siblings but only speaks to one of them. She shares brother Mark's number.

True or False?

Your spouse is automatically your medical decision maker if you become unable.

What if you are

- **Separated?**
- **Living in another state?**
- **Common law?**
- **In the middle of a divorce?**



Answer: TRUE

Your spouse is **automatically** your medical decision maker if you become unable to decide for yourself.

Even if you are

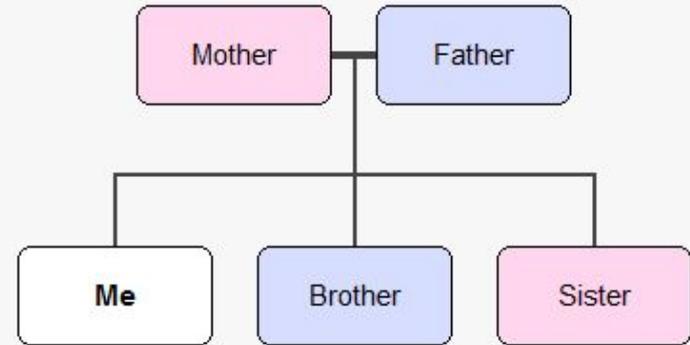
- Separated
- Living in different states
- In the middle of a divorce



Yvonne's brother Mark states they were common law.
Common law is **not** a default decision maker in MI.

True or False?

**When there is no spouse,
adult child or parent,
your oldest sibling is your
default decision maker.**



Answer: FALSE

When there is no spouse, adult child or parent, then **ALL siblings as a group** are the default decision makers - majority rules.

Let's see how this affects Marlene...



Marlene becomes alert - an opportunity for choice

Three days later, Marlene becomes alert on the ventilator and can write. She confirms she is not legally married and is in touch with her older brother Mark. She writes "Isn't my oldest brother Mark in charge?"

She has failed three prior attempts to get off the ventilator and likely will not be decisional in the near future due to the nature of her illness.

I explain that because she is not married, has no adult children, and her parents are no longer living, ALL of her siblings as a group are her default decision makers.

Her eyes widen and she writes in large letters "No - not all of them!"

Marlene becomes alert - an opportunity for choice



- I explain COPD is making it hard for her to stay off the ventilator
- It is likely she will become sleepy again from CO₂ retention
- We need to understand her wishes and goals for future goals care

She needs a DPOAHC/Durable Power of Attorney for Healthcare at minimum, a full Advance Directive will provide the most control

Durable Power of Attorney for Healthcare - DPOAHC

- Form needs to be done while she is alert and decisional
- It does not require an attorney, just two witnesses
- It is only for medical decisions (not financial)
- It only takes effect *if she is not able to decide for herself*



Marlene becomes alert - an opportunity for choice

Marlene wants Mark to sign the form to be her DPOAHC.

Mark says he can't be DPOAHC if she wants comfort care, especially because several other siblings favor long term, aggressive care.

I explore with Marlene who she can trust to uphold her wishes without pressure from other family members. She asks her friend Sue, who agrees and signs the DPOAHC form.

Marlene also documents her wishes for withdrawal of the ventilator after a **time limited trial** x 1 week if she is not interactive. Also, if she can get off the ventilator this time, she never wants to be intubated again.

What if no choice is documented?

Without a DPOAHC, people you may not want involved can be in charge of your healthcare decisions - in Michigan the order is:

1. Spouse
2. Adult Children (majority)
3. Parents
4. Siblings (majority)
5. Nieces and Nephews (majority)



If no one can be found, the court is petitioned for guardianship.

Simple Solutions for choosing your decision maker

Clarify your wishes and goals- TheConversationProject.org starter kit can help you think about who could be a good substitute decision maker.

Choose a decision maker and a backup - You need someone who is strong enough to advocate for your wishes, whether family or not.

Ask them to be your advocate - Make sure your choice is able to serve.

Share your wishes with your DPOAHC, your health care providers and your entire family so everyone can understand and respect YOUR choices.

Simple Solutions for choosing your decision maker

NEXT STEPS

Take a copy of the State of Michigan - Advance Directive form today

Other states: search Free Advance Directive forms by state from AARP

Make multiple copies for your DPOAHC/family - keep handy

If you choose no CPR or DNAR - post it on fridge for EMS to find!

Thank You

Advance Care Planning side effects:

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Beverly Dilemma: “Do Everything”

CASE STUDY: Beverly is 98 and has Alzheimer’s Dementia. She completed her DPOAHC 15 years ago naming her son James. When her husband died of a heart attack five years ago, she told James she wanted him to “do everything” for her if her heart stopped like her husband’s did.

Beverly is now hospitalized with pneumonia and weight loss. She speaks a few words a day and needs help with all bathing and toileting activities.

Where is the dilemma here?

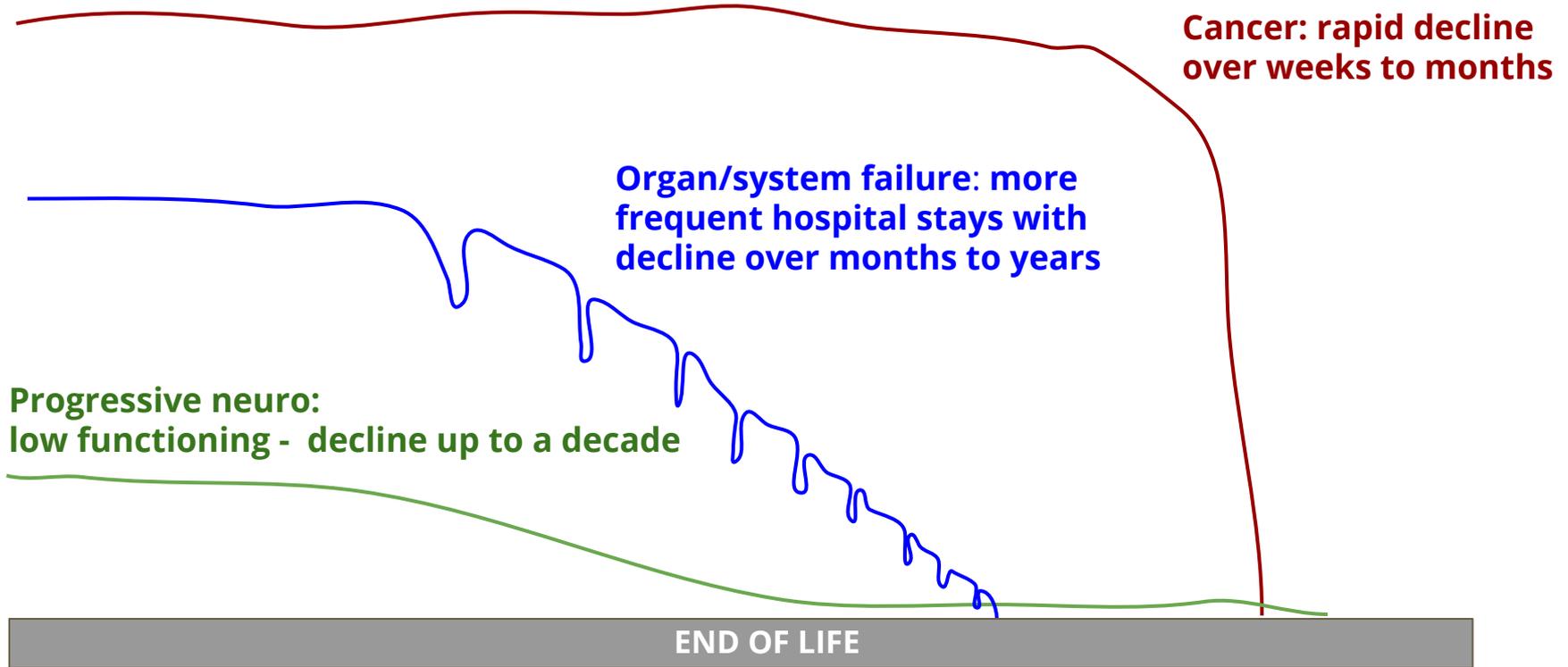
Positives: DPOAHC is documented and they have had a discussion about her wishes.

Dilemma: Heart disease and Alzheimer's dementia are very different - disease progression is not 'apples to apples.'

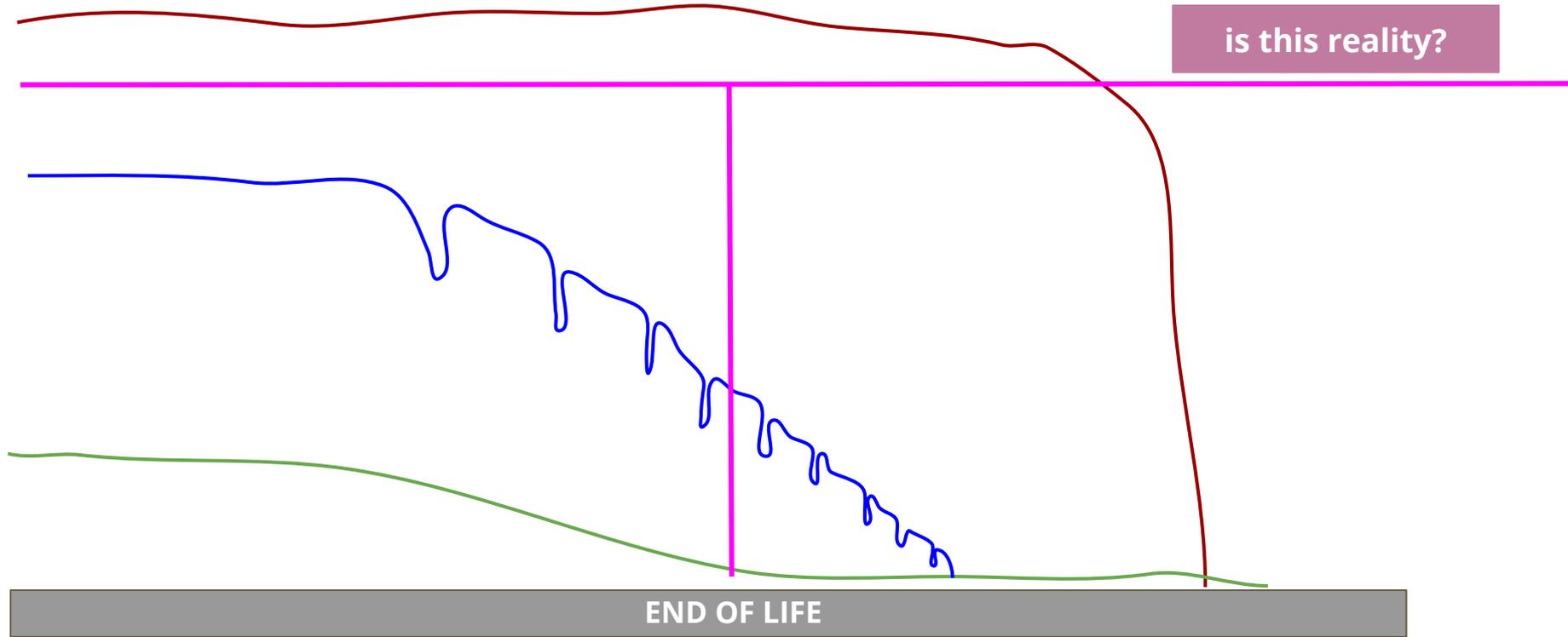
Beverly likely did not have a detailed understanding of what 'doing everything' could mean for her dementia.

Without exploring options, 'doing everything' could bring unintended burdens and consequences.

The illness trajectory concept



How TV and movies can alter our concept



Words and wishes matter

DNR vs **DNAR** - do not attempt resuscitation

"if it's my time, it's my time"

What do *you* consider quality of life?

- Aware vs likely unaware on life support
- Quality vs quantity of time
- Fixable vs permanent problems
- Substitute judgment - what would they say if sitting right here?



Back to Beverly

Palliative care consultation ordered

Hospitalist asks Palliative team to discuss:

- **Clinical trajectory**
- **Goals of care**
- **Code status**
- **Wishes regarding artificial nutrition and hydration**



What is James thinking and worried about?

Palliative care meets with son James to assess:

- What is his understanding of her health and current issues?
- What kind of conversations and/or documents about wishes have happened?
- What matters most right now and for the future?

Palliative care meets people where they are to help them make informed decisions and plans



James shares:

- **More forgetful over past 8 years but 'doing ok' overall**
- **She last said 'do everything' and made him decision maker, no other conversations or documents**
- **He sees she is getting more frail but doesn't know what that is from, maybe the pneumonia?**
- **He wants to honor her wishes and avoid suffering**

Where are we now?

- Alz Dementia = predictable mental and physical changes
- Beverly is at FAST stage 7a
- Everyone moves forward at a different speed - months, years
- Beverly is eligible for hospice
- James worries that would be giving up, not 'doing everything'
- Wants pneumonia treated

| Functional Assessment Scale (FAST) | |
|---|--|
| 1 | No difficulty either subjectively or objectively. |
| 2 | Complains of forgetting location of objects. Subjective work difficulties. |
| 3 | Decreased job functioning evident to co-workers. Difficulty in traveling to new locations. Decreased organizational capacity. * |
| 4 | Decreased ability to perform complex task, (e.g., planning dinner for guests, handling personal finances, such as forgetting to pay bills, etc.) |
| 5 | Requires assistance in choosing proper clothing to wear for the day, season or occasion, (e.g. pt may wear the same clothing repeatedly, unless supervised.* |
| 6 | Occasionally or more frequently over the past weeks. * for the following A) Improperly putting on clothes without assistance or cueing . B) Unable to bathe properly (not able to choose proper water temp) C) Inability to handle mechanics of toileting (e.g., forget to flush the toilet, does not wipe properly or properly dispose of toilet tissue) D) Urinary incontinence E) Fecal incontinence |
| 7 | A) Ability to speak limited to approximately ≤ 6 intelligible different words in the course of an average day or in the course of an intensive interview. B) Speech ability is limited to the use of a single intelligible word in an average day or in the course of an intensive interview C) Ambulatory ability is lost (cannot walk without personal assistance.) D) Cannot sit up without assistance (e.g., the individual will fall over if there are not lateral rests [arms] on the chair.) E) Loss of ability to smile. F) Loss of ability to hold up head independently. |
| *Scored primarily on information obtained from a knowledgeable informant. Psychopharmacology Bulletin, 1988 24:653-659. | |

Code status - only if no pulse or breathing

What are Beverly's specific risks?

GO-FAR calculator (gofarcalc.com) shows 1.9% chance of meaningful recovery after attempted resuscitation. High risk of death/PVS.

I help James evaluate the four separate elements of CPR or Code status

- **Chest compressions**
- **Defibrillation - shock**
- **Intubation & ventilation/breathing machine**
- **Vasopressors - IV medicines for blood pressure and pulse support**



Code status can be personalized and adapted

James chooses a custom code status

- Chest compressions will break ribs when done correctly - NO
- Defibrillation / shock could restart a pulse - YES
- Very unlikely she would be able to wean off a ventilator - NO
- IV meds are not painful, may help maintain pulse if regained - YES

Code status changed to: No chest compressions, no intubation

James feels confident this option honors Beverly's wishes and also reduces her risk of suffering, both short and long term.

She still receives full treatment for her pneumonia in the hospital.

**reframing a
common wish**

**DO
EVERYTHING**

**DO EVERYTHING
HELPFUL**

Planning ahead - anticipatory guidance

Palliative care helps people plan ahead with anticipatory guidance - what is around the corner?

With progression, dementia always causes problems with eating

- Uncoordinated swallow and loss of cough / gag reflex
- Food and fluids enter the lungs and cause aspiration pneumonia
- Swallow study shows dysphagia
- Diet on hold - NPO



Planning ahead - anticipatory guidance

Advanced dementia and artificial nutrition/hydration

Dilemma: Beverly is found to have pneumonia because her swallow study shows she is aspirating food and fluids

She is ordered NPO - nothing by mouth and scheduled for an evaluation for a PEG (feeding tube)

- **What are the important things to consider?**
- **Isn't a feeding tube the only ethical thing to do?**

Choosing Wisely

Feeding tubes work best as a short term bridge for problems like head and neck cancer

Tubes can do more harm than good in advanced dementia

- **Families want to provide nutrition**
- **Tubes are more convenient for healthcare staff**
- **Careful hand feeding is best**
- **Consider - why is this person not eating and drinking? Often it is because they are in late stages of dementia**

Facts about feeding tubes and advanced dementia

Source: ChoosingWisely.org/feedingtubes

Feeding tube risks:

- Bleeding, infection, blockage, leaking
- Fluid overload which makes breathing tougher
- Higher incidence of pneumonia
- Higher incidence of pressure ulcers
- Often need restraints to avoid pulling tube out



Extends life expectancy by days to weeks on average

Comfort care for advanced dementia

Inability to protect the airway and aspiration of food/fluids is a sign of the last stage of dementia

- **Comfort care focuses on pleasure foods and connection**
- **On demand feeding - body knows what it can handle**
- **Hospice can provide support, comfort and guidance**

Old adage: “they are not dying because they are not eating or drinking - they are not eating or drinking because they are dying”

James' plan forward for his mother

I ask James how he is handling this information. He is tearful for a minute, then says he is glad to know exactly where things stand. He says that the last stages of dementia are not the kind of time Beverly would want to prolong.

We talk with her physician and develop a plan:

- Beverly will finish the two remaining days of IV antibiotics
- James meets with hospice at the hospital to explore options
- She will return to her assisted living with hospice

James' plan forward for his mother

How does hospice fit in with dementia care at assisted living/memory care?

- **Most hospice is provided wherever people call home**
- **Hospice provides specialized physician management, hospice nurse visits, personal care, spiritual care & social work guidance for the entire family, all comfort medications, supplies/equipment and 24/7 support**
- **Beverly can have small amounts of foods/fluids for pleasure, with her body language being the cue to stop**

Simple Solutions for 'doing everything helpful'

NEXT STEPS

- Talk with your primary care provider about your illness trajectory
- Explore www.GetPalliativeCare.org search disease types
- Talk with your DPOAHC/family about your wishes and what you consider quality of life
- Complete your advance directive including code status and your thoughts about feeding tubes

Thank You

Advance Care Planning side effects:

May reduce pain, suffering and unwanted interventions. Most people report an increase in comfort, confidence and sense of control over their future. Report any changes in goals to your healthcare provider immediately.

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Dilemma: Long Term Life Support Jonathan



CASE STUDY: Jonathan is 81 and on the ventilator in the ICU. His son Joe found him at home lying on the floor. EMS did CPR and regained a pulse. When Joe saw his father's house, it was clear he had been living in a small area surrounding his recliner chair, TV and main floor bathroom. Jonathan was stubborn and would not let Joe visit inside his house for over 1 year.

Workup revealed urosepsis, end stage heart failure, and hypoxic brain injury.

Family meeting

The palliative social worker and I meet with Joe and his wife Sue who is a nurse.

Sue has been offering help to her father-in-law for years and he always declined. Joe offered to have him move into their home, which he also declined.

Joe shares his father is divorced and has two daughters he has not seen in over fifty years. Joe is in touch with one of them.

Jonathan had not completed an Advance Directive or discussed his healthcare wishes.

Family meeting

We ask Joe to imagine what his father would want in this situation.

Sue says he told her he never wanted to be on machines if “I am not myself.”

Because he is not waking up on the ventilator, the plan is set to see if finishing the 3 remaining days of antibiotics will improve his mental status.

Joe is calling his sister to reach out to the rest of the family to come see him.

Clinical picture in the ICU



Each specialist describes a picture of worsening illness:

- **Cardiac - end stage heart failure (15% EF) and on levophed pressor support**
- **Neuro - not responsive to commands/stimuli, EEG likely hypoxic brain injury**
- **GI - low albumin (blood protein) and not tolerating NG tube feedings/ascites**
- **Resp - intubated day 5, not overbreathing the vent/ tolerating weaning trials**
- **Renal - BUN/Creatinine show rising toxins, not making normal amounts of urine even with IV diuretics, finishing antibiotics for urinary tract infection**
- **Liver - widespread bruising due to impaired clotting, rising liver enzymes**
- **Skin - pressure ulcers at bony sites (due to low blood protein)**

Joe asks questions about what these reports mean and our team helps him sort out the jargon. Joe is struggling since his father rarely went to the doctor or shared anything about his health status.

Second meeting and decision deadline

At the second meeting on day 7, only Joe and Sue attend.

His sister Elizabeth told us she defers to Joe's decisions, but has not yet visited. Joe is torn because he knows his father is suffering but hopes his family can reconcile.

Jonathan is still not having any type of neurological activity after all antibiotics are finished and repeat tests show no infections remain.

His ventilator is set at 14/minute and he is not breathing over that rate. Labs show worsening of all major organ systems ongoing.

Second meeting and decision deadline

We revisit code status and Joe chooses Do Not Attempt Resuscitation.

Joe wants the IV medications keeping his blood pressure in the 90s to continue.

Because the temporary will eventually fail, the ICU physician needs a decision tomorrow AM for either tracheostomy, PEG tube and Long Term Acute Care vs comfort care with compassionate extubation and hospice.

Our calls to Elizabeth have gone unanswered.

Not deciding defaults to the most aggressive care

CPR > now intubated, how alert?

Trach and PEG decision

Long Term Acute Care

- For the few who survive CPR, many need a breathing tube/ventilator
- **If alert**, how much brain function is left? Dependent on how much down time. Can patient write?
- **If not alert**, can only be intubated up to 14 days - without any decision, the next step defaults to tracheostomy and PEG

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Trach and PEG decision

- Emergency breathing tubes press against the walls of the windpipe to make a seal for air to be forced into the lungs by the ventilator
- Walls eventually soften and the seal will be lost - decision by day 14
- Option for comfort extubation vs default of permanent airway - tracheostomy or 'trach' and 'PEG' or feeding tube in the stomach for liquid nutrition.

Long Term Acute Care

Not deciding defaults to the most aggressive care

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Long Term Acute Care

- After trach & PEG, ICU level care is usually no longer required
- People in persistent vegetative state transfer out to either
 1. LTAC beds - often in hospitals, or
 2. Nursing homes certified to accept ventilator patients (five in Metro Detroit currently)
- Insurance coverage varies widely, can persist for years

Surrogate decision making

We help Joe and Sue explore Jonathan's goals:

- **Jonathan was always very private**
- **He did not like medical care or going to the doctor**
- **He is currently 'not himself' and he said that was his cutoff point**
- **All physicians are recommending comfort care**



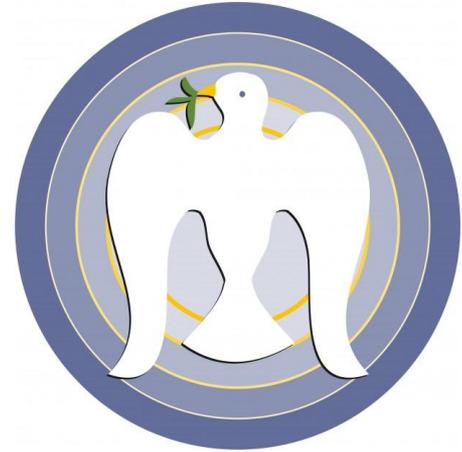
Surrogate decision making

We help Joe and Sue explore their thoughts and concerns:

- **Joe admits he was originally in denial about the severity of illness**
- **While Joe hoped his sisters would come see their father, he is sad they have had a full week and not chosen to visit or respond**
- **Sue supports Joe in any decision, but as a nurse she feels LTAC would be 'torture' based on how Jonathan chose to live his life**
- **Sue feels high intensity medical care indefinitely is not what he would have chosen**

Plan of care for Jonathan

- Joe chooses comfort care with hospice
- Our chaplains stay with Joe at bedside
- The hospice team comes to the ICU
- Joe asks them to wait until 5pm for one last chance for sisters to come
- Hospice nurse provides comfort meds via IV at 6:20pm
- The breathing tube and ventilator are removed at 6:30pm
- Jonathan dies peacefully at 6:48pm



Support for Jonathan's entire family



- Joe and Sue are sad but confident in their decision
- Hospice provides bereavement support to family for 13 months afterward, including the two daughters if they choose
- All are at risk for complicated grief due to strained relationships
- Hospice can help everyone cope

Simple Solutions for long term life support options

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- Explore www.GetPalliativeCare.org search disease types
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