Practical Tools for Advance Care Planning

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Let's admit it,
we've totally screwed up
advance care planning.

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Traditional Tools Don't Work

- Traditional Living Wills
  - Don't get written, can't be found, don't make sense, don't apply…
  - Only operative when patient has in "incurable and irreversible condition"
  - All the important decisions happen before then
- Power of Attorney
  - Didn't get appointed
  - Didn't show up
  - Didn't know what the principle wanted
  - Disagree with what the principle wanted
  - Doesn't want to upset the rest of the family
  - Knows what the principle wanted but "just can't pull the plug on him/her"

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"Withholding or withdrawing"

- Those are two entirely different decisions
- Driven by different information
- We forced all-or-nothing thinking
- We can de better

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Death is Certain → 

→ **Death is Possible**

A few people who are close to death can plan appropriately for dying.
The rest of us die while we are still trying to live.
Healthy people planning for "a good death" leads to unrealistic expectations of control

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Helping Patients Deal With the Uncertainty of Serious Illness and Injury

- Helping them retain their voice and values
  - "In emergencies hospital dominates unless you have a plan."
  - "Their values might not be your values."
- Helping patients sort through their choices
  - Death may or may not be avoidable
  - Death may or may not be desired, or at least the least bad outcome.

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Plan for emergencies.
“What if you get hit by a bus?”

You need a plan incase you can’t speak for yourself.

If you can’t speak for yourself, your surrogate is going to really appreciate guidance.

Being hypothetical reducing defensiveness.

Just in case planning. (the bus)

90% who might have a really, really bad day.

Just in time planning. (the COPD)

5% in and out of the hospital,

5% who are getting old.

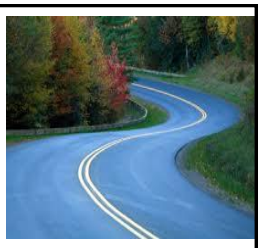
Don’t make the conversation harder than it is.

Most people are happy to place sensible limits on their treatment. Honest.

There are only a few actionable decisions to make

The planning conversation gives you reason and context to have the “reality check” conversation.

“Only plan for the foreseeable future”



Change the plan when the view changes

Only 2 meaningful questions

1: Is there any reason to consider limiting initial treatment?

“Based on what you know about yourself now, what are you willing to go through to get more time?”

How’s your quality of life? How’s your illness effecting it?

Initial scope of treatment

1) Passing lane- ICU with all the bells and whistles
2) Traveling lane- General hospital care, no intubation, avoid ICU and surgery
3) Exit lane- Comfort care, don't treat the emergent condition, allow natural death

Who is in which lane?

- Exit lane
  - People who have exhausted, or are exhausted by, treatment.
  - People who have really poor quality of life.
  - People who have a great quality of life and don't want to dwindle.
- Traveling lane
  - People who have advanced illness who want more time, but know they. wouldn't survive an ICU stay or would be too debilitated by it.
- Passing lane
  - Just about everybody else.

2: Are there reasons we should stop treatment if things aren't going well?

When is enough, enough *for you*?

Medical culture is designed to exhaust all treatment before thinking about stopping.
This can leave people in places they would rather avoid.

Stopping Treatment

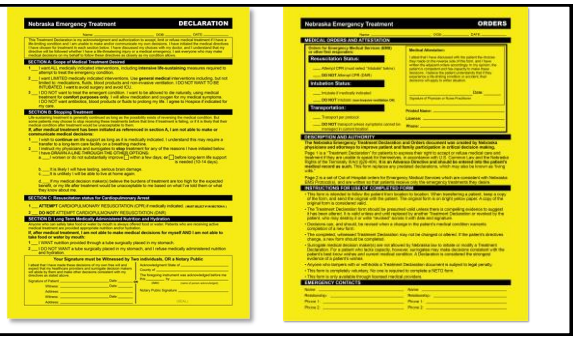
- Treatment usually stops when all medical interventions have been tried and failed,
- But that can leave a person alive yet peg'ed, trach'ed and dialyzed at a facility in Milwaukee.
- Common reasons for stopping treatment
  - Treatment isn't working (short trial vs longer trial).
  - Likely serious brain damage
  - Likely serious debility, requiring institutional care
  - Burdens exceed benefits according to family/surrogate

2 less important questions

Code Status
Tube Feeding
Yes, or No?

Now What?

Introducing NETO!
Nebraska Emergency Treatment Orders
Hybrid document: Standardized "declaration" and orders for EMS
Compatible with existing Nebraska laws and regulations



NETO is a Piece in a Puzzle

- It takes a Village
  - EMS and first responders MUST be on board
  - ED staff
  - Admitting doctors
  - Facilities

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Make Specific Recommendations

"Joe, based on what I know about you, here's what I think, <u>you tell me if you think I'm close:</u>

- "You want to go to the hospital for treatment, but you don't want to get carried away with it. You didn't like being on the ventilator last year, so I'd do everything up to that point."
- "Then, If you're getting better in a couple of days, great. But, if your still struggling after a few days, I'm afraid you wouldn't like how things would turn out if you survived. I know you're struggling to stay in you house now, and if you get worse you're looking at a nursing home. You might rather take the exit lane than end up there.
- "As for code status, that's for young, healthy people. For older, sicker folks the juice isn't usually worth the squeeze.
- "And I know you'd never want to be kept alive on a feeding tube if you weren't able to speak for your self."

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One Rebuttal

- I hear you, Joe. You aren't ready to die yet, and I get that.
  - **I WISH** I had a way to keep you around forever.
  - **I WORRY** that if we push your treatment too far, you are going to end up in exactly the place you are trying to avoid.
  - **I WONDER** if there is a way we can work at checking of some of your bucket list, so that when it is your time you are ready?

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Go with whatever they are comfortable with

Revisit it as things change

Anything on paper is better than guessing

Lays out a roadmap and mental framework for future decisions

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Office Flow

- Make it a priority! (At least for a while)
- Introduce the idea- posters, brochures, letters
- Provide information- patient education booklet, group visit, CHW, etc
- Make recommendations- Yes! You <u>can</u> make recommendations
- Initial decisions (encourage family participation)
- Sign (the patient and you)
- Witness/Notarize
- +/- scan
- Give Original to Patient

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Advance Care Planning is a Billable Service

- Anyone with serious illness (organ failure, malignancy, dementia)
- 99497 First 30 Minutes
- 99498 Each additional 30 minutes

- Face to face time with pt or surrogate 30min= 16-30min
- No Physical exam required
- Document the content of conversation

The habit of planning is more important than the plan.

Lots of supporting material

Provider Guide
Patient Guide
Poster
Brochure
"The Truth About… Life sustaining treatment, code status, feeding tubes."

https://www.nebraskahealthnetwork.com/nebraska-emergency-treatment-order-neto/