

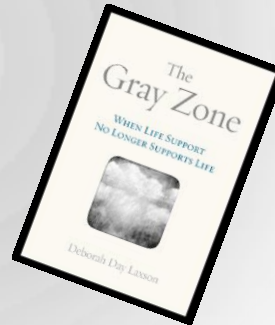
The Gray Zone:

When Life Support No Longer Supports Life

When is Enough, Enough?

July 21, 2016

Deborah Day Laxson, Author



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The backstory

Making 'the decision'

Living with 'making the decision'

Call to action

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The backstory

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The Laxson Family Locations



The image shows a map of the United States with several heart-shaped markers placed across different states. One marker in the upper Midwest is red, while all other markers are blue. A blue arrow points from a portrait of a man with glasses, located in the bottom-left corner of the map area, to the red heart marker. The portrait shows a middle-aged man with short hair and glasses, wearing a dark suit jacket and a light-colored shirt.

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The Loved Ones

12 - 6 adult children with spouses

14 - grandchildren

26 - 13 siblings with spouses

3 - living parents

1 - Me

56 interested / concerned loved ones

Communication Channels by the Numbers

$$\frac{N(N-1)}{2}$$

2

N = the number of people

56 Total Loved Ones:

$$\frac{56(55)}{2}$$

2

1,540 Communication Channels

Communication Channels Limited

$$\frac{N(N-1)}{2}$$

$N = \text{the number of people}$

23 Adult Children + Siblings + Living Parents + Me

$$\frac{23(22)}{2}$$

253 Communication Channels

From normal everyday life....

... to terminal diagnosis in the ER

From the new normal.....

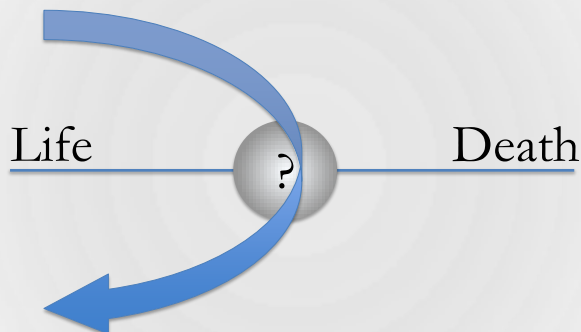
.... to 'the gray zone' in the ICU

What is 'the gray zone'?

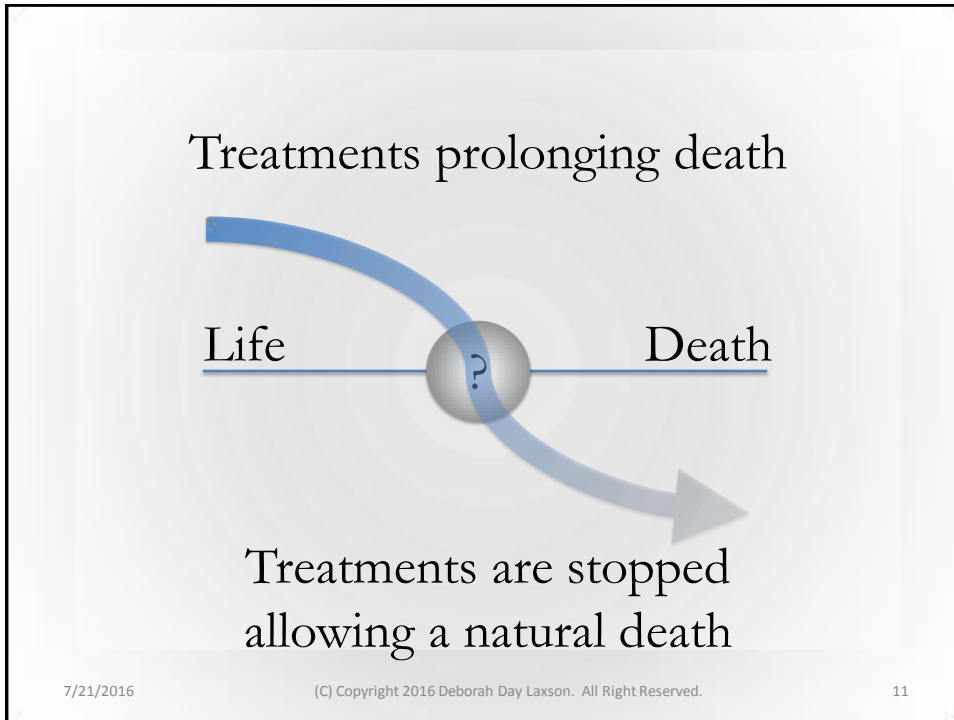


Are treatments prolonging life, or
prolonging death?

Treatments prolonging life



Patient recovers and is released to
continue their self-healing



From fighting to keep Bill alive....

*... to suddenly recognizing we
were in 'the gray zone'*

From the slow realization treatments
were prolonging Bill's death.....

.... to allowing Bill to die a natural death

Making 'the decision'

When is enough, enough?

What do you need to know?

How do you know?

Bill's Health Care Directive

4. Powers of Agent.

My agent must act consistently with my wishes as stated in this Health Care Directive or as I have otherwise made known to my agent. My agent may exercise the authority to make all health decisions for me when, in the judgment of my attending physician, I lack decision-making capacity. This authority includes the following powers:

- (a) Power to give consent, to refuse consent, or to withdraw consent to any care, treatment, service or procedure to maintain, diagnose or otherwise affect my physical or mental condition, including giving me food or water by artificial means.
- (b) Power, where consistent with the Minnesota law, to make a health care decision to withhold or stop health care necessary to keep me alive.
- (c) Power to choose where I live when I need health care and what personal security measures are needed to keep me safe.
- (d) My agent may choose my health care providers.

Bill's Health Care Directive — *con't*

6. Statement of Wishes.

I want appropriate measures to be provided to sustain my life, including medications and medical procedures that my agent believes will maintain my good health or improve my condition, but I want to be allowed to die naturally and I do not want my life prolonged by life-sustaining measures in the following circumstances:

- (a) I have been diagnosed with multiple myeloma, which is incurable and irreversible terminal condition; accordingly, the provisions of this section 6 are immediately applicable. If I am diagnosed with any other incurable and irreversible terminal condition (other than multiple myeloma), the provisions of this section 6 will be applicable with respect to that condition.
- (b) If I am diagnosed as being permanently unconscious or in a persistent vegetative state; or
- (c) If I am diagnosed as having an incurable and irreversible condition that is not terminal but which causes me to experience extreme or hopelessly severe and progressive physical or mental deterioration and loss of capacities I value, so that the burdens of continued life (with treatment) are greater than the benefits I experience.

In the circumstances I have described,

I do not want any medical treatment that will not improve my condition or help me recover, but only postpone the moment of my death. I want whatever care is appropriate to keep me as comfortable and as free of pain as is reasonably possible, including the administration of pain-relieving drugs and surgical or medical procedures calculated to relieve my pain, even if it exceeds accepted protocol or may hasten my death.

My agent may decide that (i) artificially provided fluids and nutrition, such as by feeding tube and intravenous infusion, should be withheld or withdrawn, (ii) that cardiopulmonary resuscitation should not be provided if I suffer a cardiac or respiratory arrest, and (iii) any other medications or medical procedures that may be available to prolong my life should not be used.

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Honoring Bill's choices

What did he want?

What did he NOT want?

The stories he told made it clear

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I had what I needed

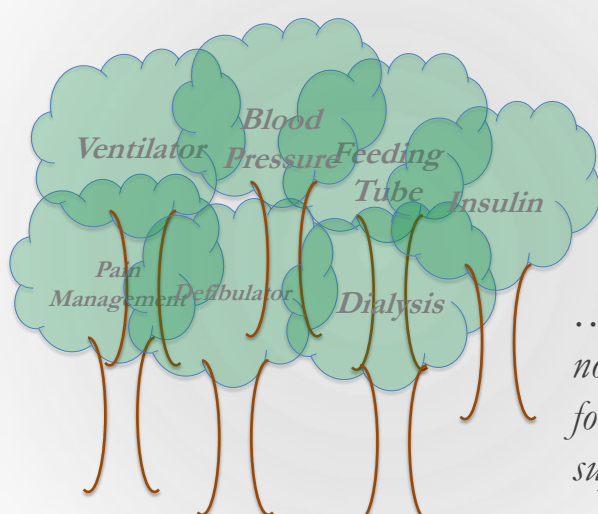
or

I didn't

By the time Bill was in a coma it was too late to ask him

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One 'tree'ment at a time



...resulted in not seeing the forest called life support

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Remembering to wear the 'right' hat



Started as 'wife'.....

.....Became agent



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Loved one's opinions, while important,
were also frequently biased

It was honoring Bill's wishes,
Bill's choices

Loved ones were *informed* about
what was happening but *not*
asked about what to do

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Remembering it's about Bill, not me

Recalling Bill's stories

Recalling Bill's concerns

Remembering Bill's readiness to die

I was the expert on Bill's care choices

The medical team was the expert on
treatments / expected outcomes

We compared Bill's choices / wishes
against treatments / expected outcomes

We discussed the options

*.... and yet,
they looked to me to
make 'the decision'*

I made 'the decision'

Summary

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What worked in my story:

- ✓ *Documenting his healthcare directive*
- ✓ *Sharing stories to clarify his choices*
- ✓ *Wearing the 'right' hat at the right time*
- ✓ *Creating the best, objective team to advise*
- ✓ *Informing loved ones, not asking*
- ✓ *Finding my mental fortitude*
- ✓ *Honoring his choices*

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Living with ‘making the decision’

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I didn't cause Bill's death

but

I influenced the how / when

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Silent about my actions

I evaded answering

You don't ask

I won't tell

Guilt

Doubt

Judgement

Isolation

Isn't that a form of Post Traumatic Stress Disorder (PTSD)?

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Definition of PTSD

Traumatic event occurred....and individual experiences:

Two or more of the following:

- *inability to remember an important aspect of the traumatic events (not due to head injury, alcohol, or drugs)*
- *persistent and exaggerated negative beliefs or expectations about oneself, others, or the world (e.g., "I am bad," "No one can be trusted," "The world is completely dangerous").*
- *persistent, distorted blame of self or others about the cause or consequences of the traumatic events*
- *persistent fear, horror, anger, guilt, or shame*
- *markedly diminished interest or participation in significant activities*
- *feelings of detachment or estrangement from others*
- *persistent inability to experience positive emotions*

Source: Anxiety Disorders Association of America

<http://www.adaa.org/understanding-anxiety/posttraumatic-stress-disorder-ptsd/symptoms>

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Hidden emotional guilt for some health care agents?

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Call to action

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Let's focus on getting patients, agents,
and loved one's ready for their
roles and responsibilities
during a medical event
BEFORE the medical event occurs

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Let's acknowledge some agents
may experience a form of
PTSD after making 'the decision'

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Let's make
November 16th
National Health Care Agent's Day

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Are you **READY?**

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