The Gray Zone:  
When Life Support No Longer Supports Life

When is Enough, Enough?

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Deborah Day Laxson, Author

The backstory

Making ‘the decision’

Living with ‘making the decision’

Call to action
The backstory

The Laxson Family Locations
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

\[
N (N-1) \div 2
\]

\[ N = \text{the number of people} \]

56 Total Loved Ones:

\[
56 (55) \div 2
\]

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
Treatments prolonging death

Life                           Death

Treatments are stopped
allowing a natural death

Being a health care agent changes

From intellectual exercise

To emotional event
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


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.
Honoring Bill’s choices

What did he want?

What did he NOT want?

The stories he told made it clear
I had what I needed

or

I didn’t

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

One ‘tree’ment at a time

...resulted in not seeing the forest called life support
Remembering to wear the ‘right’ hat

Started as ‘wife’…..

…..Became agent

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
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

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
Living with ‘making the decision’

I didn’t cause Bill’s death

but

I influenced the how / when
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)?

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
Hidden emotional guilt for some health care agents?

Call to action
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.

Let’s acknowledge some agents may experience a form of PTSD after making ‘the decision’.
Let’s make

November 16th

National Health Care Agent’s Day

Are you READY?