The Gray Zone: When Life Support No Longer Supports Life

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Disclosure / Credentials

- Founder and owner, Health Care Agent Literacy Project
- Author, The Gray Zone: When Life Support No Longer Supports Life

- PMP – Project Management Professional
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Survivorship – Lessons Learned

- Role confusion frequently exists between loved ones, caregivers and health care agents in medical events.
- How does a non-medically trained individual determine when enough is enough?
- There may be hidden impacts to health care agents responsible for making end of life decisions for their loved one.
Survivorship – My Story

- 2008 – Unexpected - Bill diagnosed with multiple myeloma in emergency room – normal to terminal in four hours
- 2009 – Treatment underway - chemotherapy, stem cell transplant
- 2010 – Recovering – Bill is holding his own
- 2011 – Unexpected – Bill contracts pneumonia, 10 day stay in Intensive Care Unit – on life support – in The Gray Zone
The People – The Roles

- Caregiver
- Health Care Agent
- Loved Ones
- Medical Team

Patient
The Roles – Their Purpose

Caregiver

“Do”

Health Care Agent

“Decide” (when patient unable)

Loved Ones

“Companion”

Medical Team

“Treat”

Patient
The People – Our Roles

12 adult children & spouses
14 grandchildren
26 siblings & spouses
3 living parents & friends & community

Caregiver
Deb

Health Care Agent
1st – Deb

Loved Ones
Deb

Medical Team
Oncology

2nd – Daughter back up to Deb
The Roles – They’re Situational

- **Patient**: Bill
- **Loved Ones**: Deb
- **Caregiver**: Deb
- **Health Care Agent**: 1st – Deb
- **Medical Team**: Oncology

- **ON CALL**: Patient (Bill)
- **ON CALL if Deb Unable**: 2nd – Daughter back up to Deb

- **ON CALL for CAREGIVER role**: 12 adult children & spouses, 14 grandchildren, 26 siblings & spouses, 3 living parents & friends & community
The Roles – They’re **VERY** Situational

Bill – 67 terminal ill patient

9am: Bill has indigestion – he goes to get antacid

11am: Bill is in bed – asks for aspirin

1pm: Bill has 102 degree fever, he calls doctor

2pm: Bill is advised to go to ER, cannot drive

3pm: Bill is admitted to hospital

2 days later: Bill in medical coma, ICU

Deb’s role is:

Loved One

Caregiver

Loved One

Caregiver

Loved One

Health Care Agent
Communication – It’s Complicated

Patient Bill

Caregiver Deb

Health Care Agent 1st - Deb

Loved Ones Deb

Medical Team Oncology

2nd - Daughter back up to Deb

6 adult children & spouses
14 grandchildren
13 siblings & spouses
3 living parents & friends & community
56 family members
43 adults in family

2 primary contacts
Communication – How Many Channels?

Loved Ones [1]  Health Care Agent [1]

4 – right?
6 – potential channels
The formula:
[“N” equals total number of people]

\[
\frac{N(N-1)}{2} = \frac{4(3)}{2}
\]
Communication – It’s *REALLY* Complicated!

Loved Ones

Health Care Agent

Patient

Medical

43 adult family members

43 (42)

2

903 Communication Channels

*(not including the medical team)*
The Roles – The Internal Conflict

Heart

Emotional

Deb as Loved One
Deb as Caregiver

Rational

Head

Patient Bill

Deb as Health Care Agent
The Roles – The External Conflict

Heart

12 adult children & spouses
14 grandchildren
26 siblings & spouses
3 living parents
& friends
& community

Head

2nd – Daughter back up to Deb

The medical team

Patient

Bill

In the ICU

Medical coma

Deb as Health Care Agent
The Conflict – Hanging On or Letting Go

“I’m not ready to let you go”

Heart

Patient Bill

Head

“I need to honor your choices and let you go”

Loved Ones Caregivers

Deb as Health Care Agent
Life Support – The Gray Zone
When Enough is Enough?

Able to recover? 
Allow a natural death
Life Support – Are You Really Hearing What’s Being Said?

Key functions – Heart, Liver, Kidneys, Lungs, Brain, Skin, Will to Live

Color code – Think Stoplight
Organ color is:
- Green – GO
- Yellow – SLOW
- Red – STOP

What I heard............
Life Support – The Gray Zone
When Enough is Enough?

What the Medical Team was saying
Life Support – The Gray Zone
When Enough is Enough?

Allow a natural death
Survivorship – Hidden Impacts

Potential of PTSD exists when an individual experiences two or more of the following after a traumatic event:

- 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
Survivorship – Lessons Learned

- Role confusion
- Challenges in navigating The Gray Zone
- Hidden impacts to health care agents