Advanced Directives: Spotlight on Health Care Agents

DEBORAH DAY LAXSON, PMP, CHTP
AUTHOR, THE GRAY ZONE: WHEN LIFE SUPPORT NO LONGER SUPPORTS LIFE
FOUNDER, HEALTH CARE AGENT LITERACY PROJECT, LLC
TODAY’S PRESENTATION / DISCLAIMER

WHAT TODAY IS ABOUT

• Introduce to processes around medical events
• Provide suggestions to help jump start your conversations
• Based on my experiences
• Based on my observations

WHAT IT IS NOT

• It is not medical advice
• It is not legal advice
• It is not financial advice
• It is not telling you WHAT your decision should be during a medical event
TERMINOLOGY / ABBREVIATIONS

Health Care Agent, Agent, Surrogate will be used interchangeably

ACP = Advance Care Plan

HCD = Health Care Directive
INTRODUCE CONCEPT
ON LEFT

Give explanation
on right
2. Make “it” legal
3. Make “it” accessible
4. Done with “it”
YOUR HEALTH CARE DIRECTIVE (HCD) DOES.....

**WHO......**
- Owner (current or future Patient)
- Primary Agent
- Alternate Agent

**WHAT....**
- Powers granted to Agent
- Decisions can be made by Agent
EXACTLY HOW to honor your choices by ......

• Analyzing medical data
• Prioritizing treatment options
• Comparing treatments options against your goals of care
• Making decisions

EXACTLY WHEN to......

• Start, NOT START, continue, stop, or WAIT AND SEE regarding treatments
Completing your Healthcare Directive is like writing a mini textbook.

If you never “teach” or “mentor” your agent, the material in your directive, the concepts may not be learned and will probably be lost in the chaos of a medical event.
SURROGATES MAKE DECISIONS FOR:

- nearly 50% of hospitalized older adults
- up to 95% of patients in the intensive care unit (ICU)

HOWEVER........

- 78% of surrogates make decisions based on Patient’s Well-Being
- Only 22% of surrogates make decisions based on Patient’s Preferences

DECISION MAKING – WHY ISN’T IT WORKING?

Out of 21 identified barriers to Goals of Care Discussions in the Hospital, the **top 6 barriers** are the result of the: patient, health care agent, and family members not understanding, accepting, or agreeing with the patient’s medical status.

1. Family members’ difficulty accepting loved one’s poor prognosis
2. Family member’s difficulty understanding limitations / complication of life-sustaining therapies
3. Lack of agreement amongst family members about goals of care
4. Patients’ difficulty understanding limitations / complication of life-sustaining therapies
5. Patient lacks capacity to make goals of care decisions
6. Patient difficulty accepting poor prognosis
7. Language barriers
8. Lack of availability of substitute decision maker(s)
9. Cultural differences
10. Uncertainty about who is the substitute decision maker
17. Patient does not have advance directive
18. Advance directive lacks sufficient detail

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**Source:** You, John J., MD, MSc. (2015). Barriers to Goals of Care Discussion with Seriously Ill Hospitalized Patients and Their Families. *JAMA – Internal Medicine*. 175(4), 549-556.
ROLES & RESPONSIBILITIES

1. **Patient** – person with medical event
2. **Health Care Agent** – “on call” to make the Patient’s decisions when patient cannot speak
3. **Caregiver** – helps with personal care and needs if needed
4. **Loved Ones** – the Patient’s family & friends.
5. **Medical Professional** – includes but not limited to physicians, nurses, social workers, chaplains

*Everyone has an opinion. The Patient’s opinion is the only one that matters.*
DECISIONS – WHEN THE PATIENT CAN SPEAK

The patient makes the decision.
The Agent makes decisions per the guidance of the Patient in their health care directive and prior conversations.
ROLES & RESPONSIBILITIES – Example

WHAT IS MY PRIMARY ROLE?

1. Indigestion
2. Fever (mild)
3. Fever (severe, trip to ER)
4. Intensive Care Unit (ICU) (medically induced coma)
ROLES & RESPONSIBILITIES – Example

MAY BE MULTIPLE ROLES FOR MULTIPLE FAMILY MEMBERS

1. Wife
2. Mother
3. Daughter #1
4. Daughter #2
5. Patient (his choices)
1. Baseline Health: Patient’s health before current medical event (best time to CREATE / UPDATE HCD)

2. Medical Event: Patient requires medical intervention (NOT the best time to create HCD)

3. What Changed: Goals of Care conversation around can Patient return to Baseline Health or better, if not

STARTING WITH THE MEDICAL EVENT MEANS:

1. Patient’s preferences / choices out of context
2. Patient, Agents and Loved Ones may experience fear-based thinking, not critical thinking (Russell)
3. Hear with confirmation bias (Heshmat 2015)
4. Experience role confusion
5. May not make informed decisions ensuring patient’s choices are represented
1. **Medical Event** – something happened or update from medical team
2. **Diagnosis** – the *cause* of the symptoms
3. **Prognosis** – the potential and timeline for recovery. This is a *prediction not a promise*.
4. **Suggested Treatment Options** – procedures or medicines that may help with recovery. Multiple options usually exist. “No treatment” or “wait and see” are always an options.
5. **Decision** – *choosing* an option.
6. **Implement Decision** – taking the steps to **start, not start, continue, stop, OR WAIT**, medical treatment(s).
7. **Monitor** – Is the Patient improving, staying the same, getting worse?
8. **Repeat cycle** – with new information repeat process.
MULTIPLE MEDICAL EVENTS

- High Cholesterol
- Cancer
- High Blood Pressure
- Pneumonia
- Wound
DECISIONS – THE PATIENT’S PRIORITIES

- **Quality** (of life) - the ability to do what you love to do
- **Quantity** (time) - how many days / months / years might you reasonably expect
- **Cost** (financial) - the immediate or long term financial cost of the medical options

What is the rank order for the Patient:
- **first** most important,
- **second** most important,
- **third** most important
DECISIONS – THE PATIENT’S PRIORITIES

IS IT:
1\textsuperscript{st} - Cost
2\textsuperscript{nd} – Quality
3\textsuperscript{rd} – Quantity

OR

1\textsuperscript{st} – Quantity
2\textsuperscript{nd} – Cost
3\textsuperscript{rd} – Quality

OR

1\textsuperscript{st} – Quantity
2\textsuperscript{nd} – Quality
3\textsuperscript{rd} - Cost
DECISIONS – THE PATIENT’S PRIORITIES

COST CONSIDERATIONS
• Insurance: Covered, Not Covered
• Insurance: In Network, Out of Network
• Maximum Out of Pocket
• Now, next year, the following year, etc

QUALITY CONSIDERATIONS
• Must be able to <fill in activity / activities>
• Want to <fill in activity / activities>
• Ok if not able to <fill in activity / activities>

QUANTITY CONSIDERATIONS
• Trial period of XX days
• Want to be able to attend event on XX date
DECISIONS – QUALITY OF LIFE

- **PHYSICAL** – the physical aspect of being able to do what one loves
- **EMOTIONAL** – how one interacts with others and feels about one’s life
- **MENTAL** – where one hold their beliefs and ability to process information
- **SPIRITUAL** – where one experiences being connected a community
Alzheimer’s results in diminished capacity for Emotional, Mental and Spiritual processing.

The Physical declines slower and depends upon the quality of care one receives.

Does your Health Care Agent know your wishes?
Stephen Hawking had a brilliant mind, confined to a wheel chair, and totally dependent upon others taking care of him.

Does your Health Care Agent know your wishes?
Does the ‘recommended’ medical treatment option(s) become the ‘choice’ by default?
CONVERSATIONS

ARE YOU TRANSPARENT ABOUT YOUR HEALTH AND PRIORITIES
INTER-GENERATIONAL DISCUSSIONS

THE “KID” EFFECT OVER TIME

1. Young Kid: Our parents / We’re the kids
2. Adult: We become parents / We have kids
3. Elder kid: Our kids become our parents (or at least think they need to be) / We regress into kids again
INTERGENERATIONAL DISCUSSIONS

THE “KID” EFFECT OVER TIME

1. Hit tree when I was 16. (Don’t tell Mom and Dad – they’ll take the keys away.

2. Hit tree in January. (Don’t tell the kids – they’ll take the keys away.

3. Cut finger – “Do I have to be your Dad and tell you that was a stupid thing to do?”

Over time our kids become our parents.
THE “KID” EFFECT OVER TIME

INFORMAL CODE OF SHARING INFO:

1. If “they” don’t ask, don’t tell.
2. Answer only the question asked.
3. If “they” don’t ask the right question, oh well.
4. If “they” do ask the right question and you don’t want to answer, deflect, deny / distort, or distract.
5. Don’t volunteer information.
HAVE YOU ALIGNED EVERYONE?
Would everyone’s knowledge of the YOUR AGE and the ages of YOUR family align?

- Agent?
- Caregiver?
- Loved Ones?
- Medical Professionals?

HAVE YOU SHARED:

- Your age.
- Your parent’s age if living. If deceased, their age at the time of their death?
- Your siblings age if living. If deceased, their age at the time of their death?
- Do you have a sense of how long you’d like to live?
HAVE YOU ALIGNED EVERYONE?
Would everyone’s perception of the YOUR ACIVITY LEVEL align with the medical data?

- Agent?
- Caregiver?
- Loved Ones?
- Medical Professionals?

HAVE YOU SHARED:
- What you do to keep active?
- What is important to you?
- What you want to be able to do for fun?
HAVE YOU ALIGNED EVERYONE?
Would everyone’s knowledge of the YOUR HEALTH and the medical data align?

- Agent?
- Caregiver?
- Loved Ones?
- Medical Professionals?

HAVE YOU SHARED:

- What underlying conditions you have, e.g., overweight?
- What chronic conditions you have, e.g., chronic heart condition?
- What terminal conditions you have, e.g., cancer?
HOW DOES YOUR HEALTH LOOK?

FOCUS ON THE MAJOR ORGANS

Color code the status:

GREEN = Not taking any medications

YELLOW = Controlled with medications

RED = Medications not working
THE PATIENT’S BASICS – PRESCRIPTIONS

HAVE YOU SHARED:

• What medications you’re taking, and for what condition?

• Where those medications are filled?
  • Mail
  • Pharmacy, or pharmacies?

HAVE YOU ALIGNED EVERYONE?

Would everyone’s perception of the YOUR PRESCRIPTIONS align with the medical data?

• Agent?
• Caregiver?
• Loved Ones?
• Medical Professionals?
THE PATIENT’S BASICS – OVER THE COUNTER

HAVE YOU ALIGNED EVERYONE?

Would everyone’s perception of the YOUR OVER THE COUNTER MEDICATIONS align with the known data?

- Agent?
- Caregiver?
- Loved Ones?
- Medical Professionals?

HAVE YOU SHARED:

- What over the counter medications you’re taking, and for what condition?
- Vitamins?
- Herbs?

<table>
<thead>
<tr>
<th>Number of Over the Counter Medications</th>
<th>0 (None)</th>
<th>1-5</th>
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</thead>
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THE PATIENT’S BASICS – PAIN SCALE

HAVE YOU SHARED:

- What it feels like to live in your body?
- Whether the pain is temporary or constant?
- Do you experience breakthrough pain?

HAVE YOU ALIGNED EVERYONE?

Would everyone’s perception of the YOUR PAIN SCALE align with the medical data?

- Agent?
- Caregiver?
- Loved Ones?
- Medical Professionals?
HAVE YOU ALIGNED EVERYONE?

Would everyone’s perception of the YOUR ANXIETY align with the known data?

- Agent?
- Caregiver?
- Loved Ones?
- Medical Professionals?

HAVE YOU SHARED:

- What keeps you up at night?
- What concerns you have?
- What are you most worried about?
PUTTING IT ALL TOGETHER

BEING TRANSPARENT WITH YOUR HEALTH AND PRIORITIES
PUTTING IT ALL TOGETHER

**Age**

- Young: 0-17
- 18-29
- 30-39
- 40-49
- 50-59
- 60-69
- 70-79
- 80-89
- 90-99
- Extreme Aging: 100+

**Number of Prescriptions**

- 0 (None)
- 1-5
- 5-10
- 10+

**Number of Over the Counter Medications**

- 0 (None)
- 1-5
- 5-10
- 10+

**Activity Scale**

- Active
- Moderately Active
- Inactive

**Pain Scale**

- No Pain
- Moderate Pain
- Severe Pain

**Health Conditions**

- Healthy
- Underlying Conditions
- Chronic Conditions
- Terminally Ill

**Anxiety Scale**

- No Anxiety
- Moderate Anxiety
- Severe Anxiety
PUTTING IT ALL TOGETHER

FOCUS ON THE MAJOR ORGANS

Color code the status:

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DECISIONS – THE PATIENT’S PRIORITIES

• **Quality** (of life) - the ability to do what you love to do

• **Quantity** (time) - how many days / months / years might you reasonably expect

• **Cost** (financial) - the immediate or long term financial cost of the medical options

What is the rank order for the Patient:
- first most important,
- second most important, and
- third most important
DECISIONS – QUALITY OF LIFE

- **Physical** – the physical aspect of being able to do what one loves
- **Emotional** – how one interacts with others and feels about one’s life
- **Mental** – where one hold their beliefs and ability to process information
- **Spiritual** – where one experiences being connected a community
DEB – 2019

Age

- 0-17
- 18-29
- 30-39
- 40-49
- 50-59
- 60-69
- 70+
- 100+

- Young
- X

Goal: Live until I'm 120
Both parents died at 93

Activity Scale

- Active
- Moderately Active
- Inactive

- Active
- X

Number of Prescriptions

- 0 (None)
- 1-5
- 5-10
- 10+

- X

Number of Over the Counter Medications

- 0 (None)
- 1-5
- 5-10
- 10+

- X

Pain Scale

- No Pain
- Moderate Pain
- Severe Pain

- X

Health Conditions

- Healthy
- Underlying Conditions
- Chronic Conditions
- Terminally Ill

- Healthy
- X

Anxiety Scale

- No Anxiety
- Moderate Anxiety
- Severe Anxiety

- No Anxiety
- X
FOCUS ON THE MAJOR ORGANS

Color code the status:

- **GREEN** = Not taking any medications
- **YELLOW** = Controlled with medications
- **RED** = Medications not working
DEB - 2019

#2 Quality

#3 Quantity

#1 Cost

I'm ok if my world shrinks a bit as long as it's balanced
### Age

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**Most men on mother's side died by age 65**

### Activity Scale

- **Active**
- Moderately Active
- **Inactive**

### Number of Prescriptions

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### Pain Scale

- **No Pain**
- **Moderate Pain**
- **Severe Pain**

### Health Conditions

- **Healthy**
- **Underlying Conditions**
- **Chronic Conditions**
- **Terminal Illness**

### Anxiety Scale

- **No Anxiety**
- **Moderate Anxiety**
- **Severe Anxiety**
FOCUS ON THE MAJOR ORGANS

Color code the status:

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BILL - 2011

#2 Quality

#3 Quantity

#1 Cost

Physical

Emotional

Mental

Spiritual
### MARION - 2016

#### Age
- Young: 0-17
- 18-29
- 30-39
- 40-49
- 50-59
- 60-69
- 70-79
- 80-89
- 90
- 100+

#### Number of Prescriptions
- 0 (None)
- 1-5
- 5+ ✗
- 10+

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- 0 (None) ✗
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- Healthy
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- No Anxiety
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FOCUS ON THE MAJOR ORGANS

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MARION - 2016

#1 Quantity
#2 Cost
#3 Quality

Physical
Mental
Emotional
Spiritual
Just because modern medicine can, doesn’t mean modern medicine should.

Your first reaction may be fear-based.
Get to your second reaction. Do the work.

Please remember this is not about you.
This is about me (the patient). My choices.

Do the best you can.
Surround yourself with a trusted team.

TO YOUR HEALTH CARE AGENT
Saying “you’ll know” is not helpful to me. Don’t make me guess what you want. Talk to me. Really talk to me.

Making your decisions will not come naturally to me. (Mickey 2017) Give me examples of what you do want / don’t want.

Talk to the rest of the family so they know what you want. I don’t want to be judged for doing too little or too much.

Help me understand what you want. Even knowing, it will still be hard.

FROM YOUR HEALTH CARE AGENT
THANK YOU!

Deborah Day Laxson
deb@DeborahDayLaxson.com
dlaxson@HealthCareAgentLiteracy.com
SUMMARY REFERENCES:


