

# Advanced Directives: Spotlight on Health Care Agents

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# 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

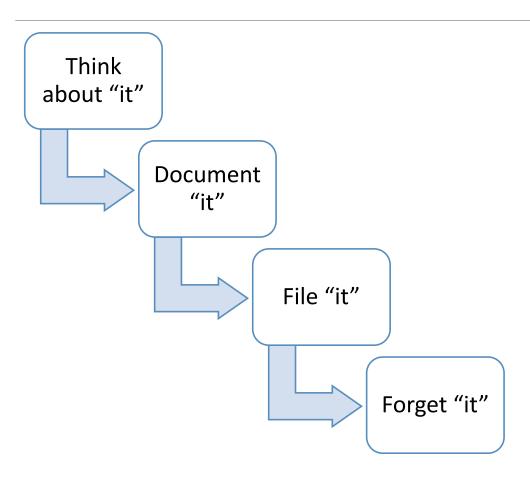
HCD = Health Care Directive

### HOW THE SLIDES ARE ORGANIZED

INTRODUCE CONCEPT
ON LEFT

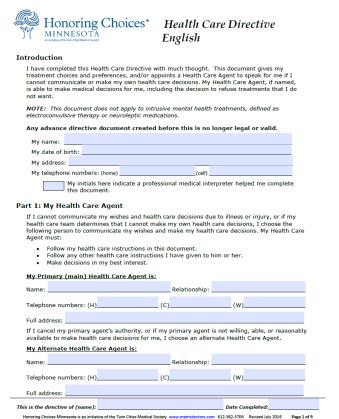
Give explanation on right

# THE PROCESS OF ADVANCE CARE PLANNING



- "It" = Advance Care Plan / Health Care Directive - our definition of Quality of Life.
- 2. Make "it" legal
- 3. Make "it" accessible
- 4. Done with "it"

# YOUR HEALTH CARE DIRECTIVE (HCD) DOES.....



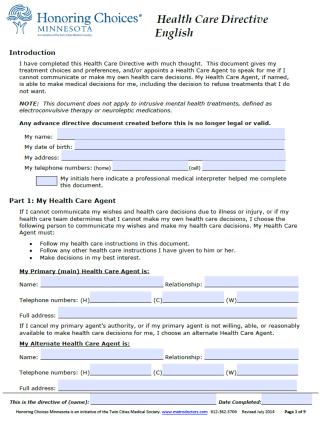
#### WHO.....

- Owner (current or future Patient)
- Primary Agent
- Alternate Agent

#### WHAT....

- Powers granted to Agent
- Decisions can be made by Agent

# YOUR HEALTH CARE DIRECTIVE DOESN'T ......



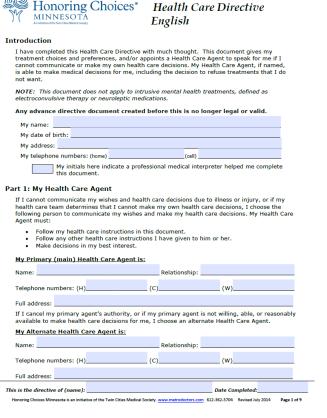
# **EXACTLY HOW to honor your choices** by .....

- 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

# DID YOU "TEACH" OR "MENTOR" YOUR AGENT?



Completing your Healthcare Directive is like writing a minitextbook.

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.

### DECISION MAKING - IS IT WORKING?

		Orir NESO Tuin-Chias Medica		oices*	Health Co English	are Directive		
Introduction								
treatr canno	ment cho ot comm e to mak	ices and unicate	f preference or make m	es, and/or app y own health o	points a Health Car care decisions. My	This document gives my e Agent to speak for me if Health Care Agent, if name o refuse treatments that I	ed,	
NOTE: This document does not apply to intrusive mental health treatments, defined as electroconvulsive therapy or neuroleptic medications.								
Any advance directive document created before this is no longer legal or valid.								
My date of birth:								
	address:							
My	telephon	e numb	ers: (home)		(cell)			
My initials here indicate a professional medical interpreter helped me complete this document.								
Part 1: My Health Care Agent								
If I cannot communicate my wishes and health care decisions due to illness or injury, or if my health care team determines that I cannot make my own health care decisions, I choose the following person to communicate my wishes and make my health care decisions. My Health Care Agent must:  • Follow my health care instructions in this document. • Follow any other health care instructions I have given to him or her. • Make decisions in my best interest.								
My Primary (main) Health Care Agent is:								
Name	9:			_	Relationship:			
Telen	hone nu	mbers: (	'H)		(C)	(W)		
					(-/	,		
Full address:  If I cancel my primary agent's authority, or if my primary agent is not willing, able, or reasonably available to make health care decisions for me, I choose an alternate Health Care Agent.								
My Alternate Health Care Agent is:								
Name	9:				Relationship:			
Telep	hone nu	mbers: (	(H)		(C)	(W)		
Full address:								
This is the	e directive	of (nam	e)·			Date Completed:		
	Honoring Choices Minnesota is an initiative of the Twin Cities Medical Society, www.metrodoctors.com 612-362-3704 Revised July 2014 Page 1 of 9							

#### 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

Devani, R. (2017). How surrogates decide: A secondary data analysis of decision-making principles used by the surrogates of hospitalized older adults. Journal of General Internal Medicine, Online August 24.

# 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

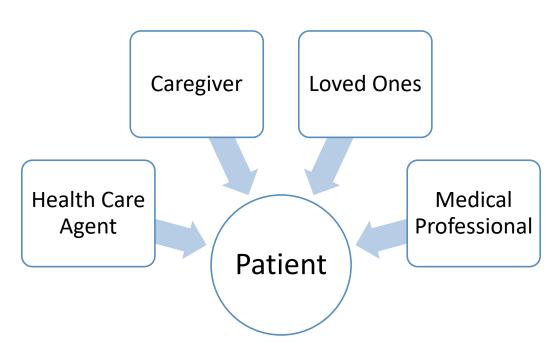
not understanding, accepting, or agreeing with

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
- Uncertainty about who is the substitute decision maker
- 17. Patient does not have advance directive
- 18. Advance directive lacks sufficient detail

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

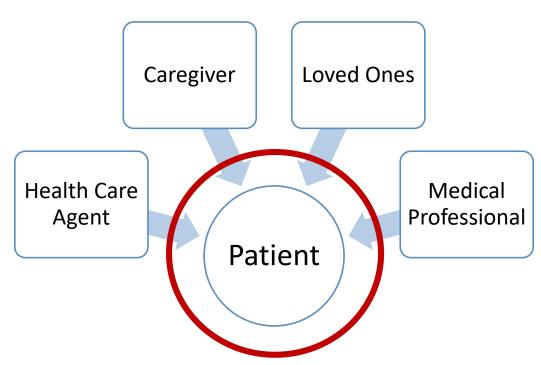
# ROLES & RESPONSIBILITIES



Everyone has an opinion.
The Patient's opinion is the only one that matters.

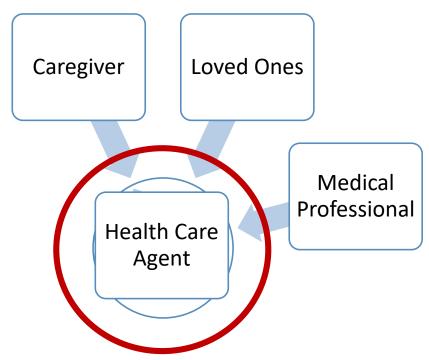
- 1. Patient person with medical event
- 2. <u>Health Care Agent</u> "on call" to make the Patient's decisions when patient cannot speak
- 3. <u>Caregiver</u> helps with personal care and needs if needed
- Loved Ones the Patient's family & friends.
- 5. <u>Medical Professional</u> includes but not limited to physicians, nurses, social workers, chaplains

# DECISIONS – WHEN THE PATIENT CAN SPEAK



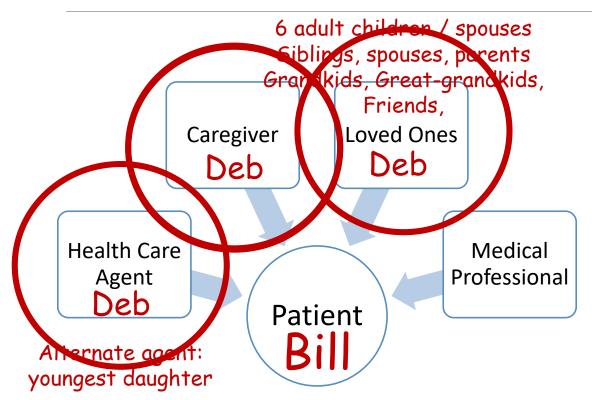
The patient makes the decision.

# DECISIONS – WHEN PATIENT CANNOT SPEAK



The Agent makes decisions per the guidance of the Patient in their health care directive and prior conversations.

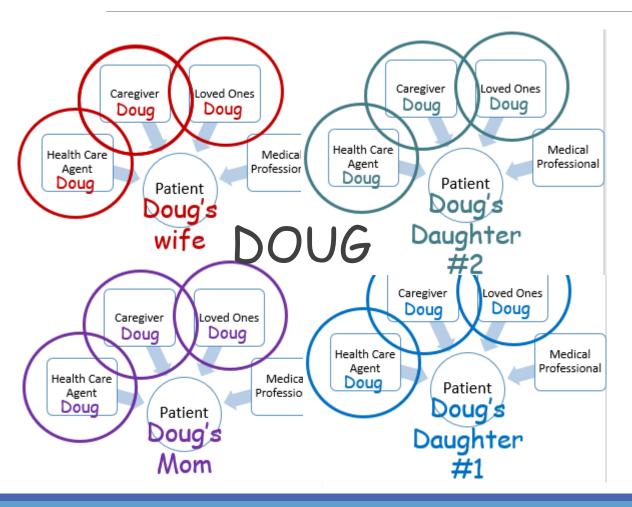
# ROLES & RESPONSIBILITIES – Example



#### WHAT IS MY PRIMARY ROLE?

- 1. Indigestion
- 2. Fever (mild)
- 3. Fever (severe, trip to ER)
- 4. Intensive Care Unit (ICU) (medically induced coma)

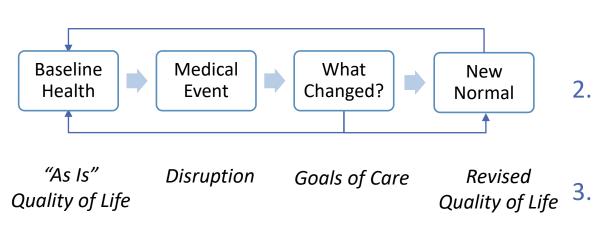
# ROLES & RESPONSIBILITIES – Example



# MAY BE MULTIPLE ROLES FOR MULTIPLE FAMILY MEMBERS

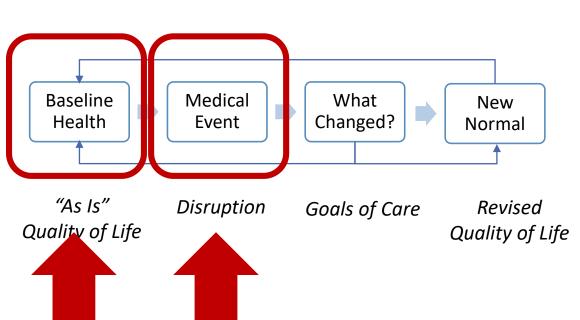
- 1. Wife
- 2. Mother
- 3. Daughter #1
- 4. Daughter #2
- 5. Patient (his choices)

# MEDICAL EVENTS — CONTEXT



- Baseline Health: Patient's health before current medical event (best time to CREATE / UPDATE HCD)
- Medical Event: Patient requires medical intervention (NOT the best time to create HCD)
- What Changed: Goals of Care conversation around can Patient return to Baseline Health or better, if not
- 4. New Normal: Unable to return to Baseline Health. New Normal becomes updated Baseline Health

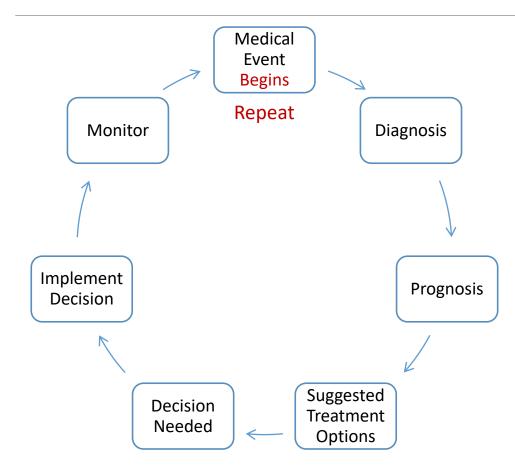
## MEDICAL EVENTS — WHERE TO START



#### STARTING WITH THE MEDICAL EVENT MEANS:

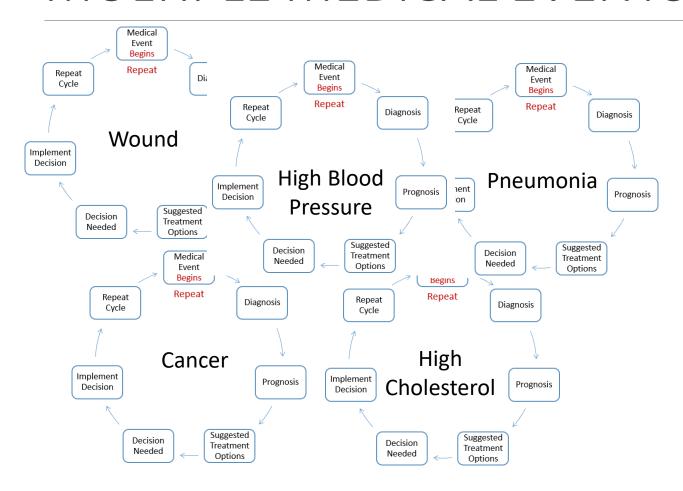
- Patient's preferences / choices out of context
- 2. Patient, Agents and Loved Ones may experience fear-based thinking, not critical thinking (Russell)
- 3. Hear with confirmation bias (Heshmat 2015)
- 4. Experience role confusion
- May not make informed decisions ensuring patient's choices are represented

### PROCESS OF A MEDICAL EVENT

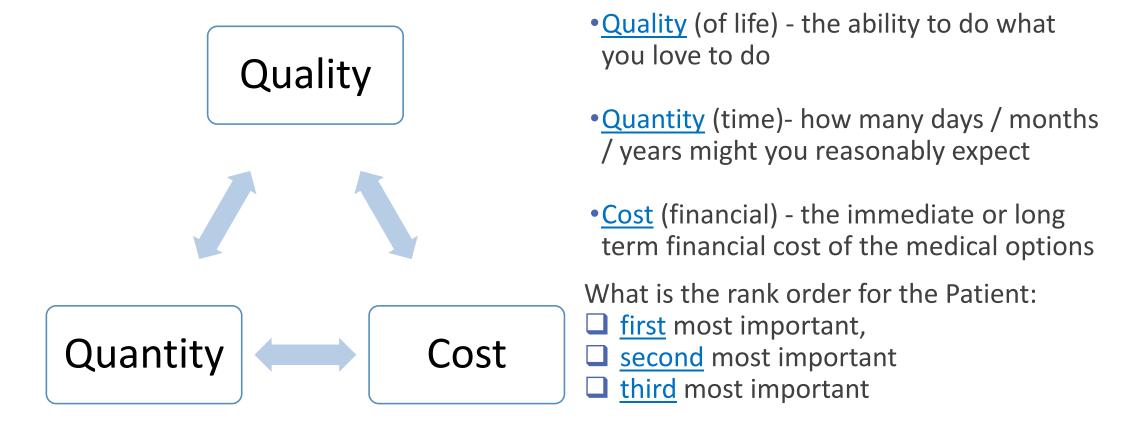


- Medical Event something happened or update from medical team
- 2. <u>Diagnosis</u> the <u>cause</u> of the symptoms
- 3. <u>Prognosis</u> the potential and timeline for recovery. This is a *prediction not a promise*.
- 4. <u>Suggested Treatment Options</u> procedures or medicines that may help with recovery. Multiple options usually exist. <u>"No treatment" or "wait and see"</u> are always an options.
- 5. <u>Decision</u> <u>choosing</u> an option.
- 6. <u>Implement Decision</u> taking the steps to <u>start, not start,</u> <u>continue, stop, OR WAIT,</u> medical treatment(s).
- 7. <u>Monitor</u> Is the Patient improving, staying the same, getting worse?
- 8. Repeat cycle with new information repeat process.

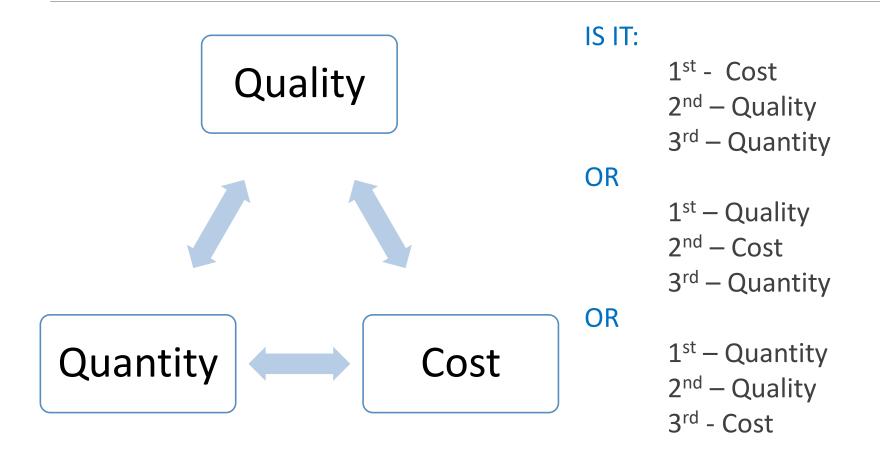
### MULTIPLE MEDICAL EVENTS



### DECISIONS — THE PATIENT'S PRIORITIES



## DECISIONS – THE PATIENT'S PRIORITIES



## DECISIONS — THE PATIENT'S PRIORITIES

Quality Quantity Cost

#### **COST CONSIDERATIONS**

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

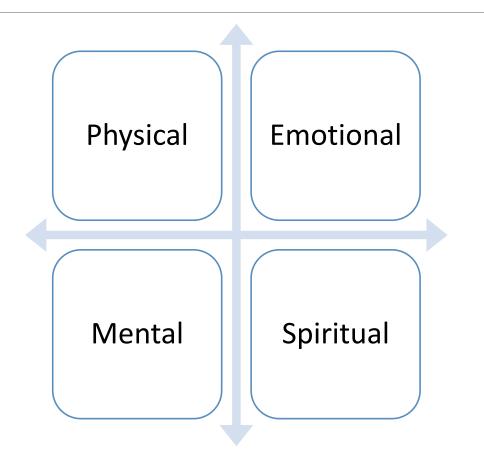
#### **QUALITY CONSIDERATIONS**

- 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**

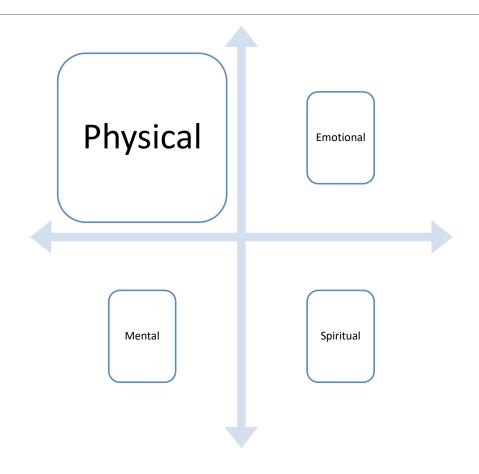
- Trial period of XX days
- Want to be able to attend event on XX date

# DECISIONS – QUALITY OF LIFE



- PHYSICAL the physical aspect of being able to do what one loves
- <u>EMOTIONAL</u> how one interacts with others and feels about one's life
- MENTAL where one hold their beliefs and ability to process information
- •<u>SPIRITUAL</u> where one experiences being connected a community

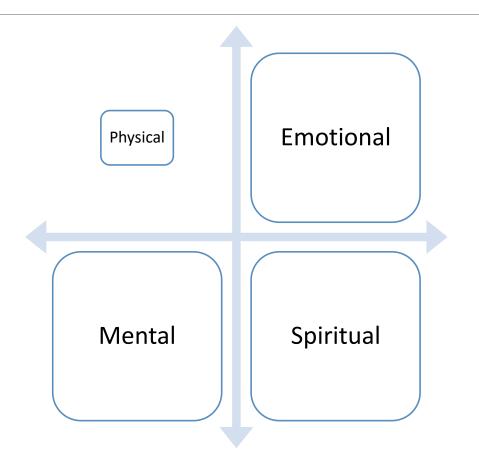
# DECISIONS – WHY THIS MATTERS/ ALZHEIMER'S



- 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?

# DECISIONS – WHY THIS MATTERS – S. HAWKING



 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?

## DECISIONS - WHAT ARE THE PRIORITIES



Does the 'recommended'

medical treatment option(s)

become the 'choice' by default?

# CONVERSATIONS

ARE YOU TRANSPARENT ABOUT YOUR HEALTH AND PRIORITIES

## INTER-GENERATIONAL DISCUSSIONS

**Parents Parents Parents** (our kids) (ours) (us) Kids (us) Kids (us) Kids (ours)

#### 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

# INTER-GENERATIONAL DISCUSSIONS

1 2 3

Parents (ours) (us) Parents (our kids) (our kids) (ids (ours)) Kids (ours)

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

1

2

3

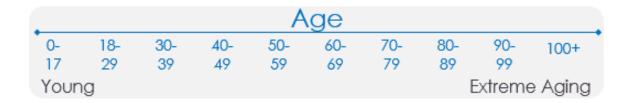
Parents (ours) Kids (us)

Parents (us) Kids (ours) Parents (our kids) Kids (us)

# INFORMAL CODE OF SHARING INFO:

- If "they" don't' ask, don't tell.
- Answer only the question asked.
- If "they" don't ask the right question, oh well.
- If "they" do ask the right question and you don't want to answer, deflect, deny / distort, or distract.
- Don't volunteer information.

# THE PATIENT'S BASICS - AGE



- 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 knowledge of the YOUR AGE and the ages of YOUR family align?

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

### THE PATIENT'S BASICS — ACTIVITY LEVEL

\*Active Moderately Inactive Active

#### HAVE YOU SHARED:

- What you do to keep active?
- What is important to you?
- What you want to be able to do for fun?

Inactive HAVE YOU ALIGNED EVERYONE?

Would everyone's perception of the YOUR ACIVITY LEVEL align with the medical data?

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

# THE PATIENT'S BASICS - HEALTH

# Health Conditions Healthy Underlying Conditions Conditions Health Conditions Terminally

#### HAVE YOU SHARED:

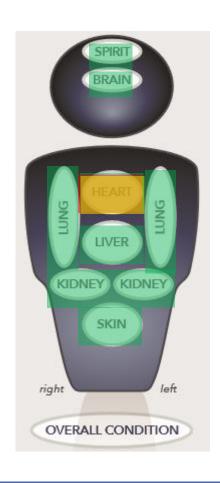
- What underlying conditions you have, e.g., overweight?
- What chronic conditions you have, e.g., chronic heart condition?
- What terminal conditions you have, e.g., cancer?

#### HAVE YOU ALIGNED EVERYONE?

Would everyone's knowledge of the YOUR HEALTH and the medical data align?

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

# HOW DOES YOUR HEATLH 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

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

#### **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

#### Number of Over the Counter Medications

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

- HAVE YOU SHARED:
- What over the counter medications you're taking, and for what condition?
- Vitamins?
- Herbs?

#### 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?

### THE PATIENT'S BASICS - PAIN SCALE

#### Pain Scale

No Pain Moderate Pain

Severe Pain

#### **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?

# THE PATIENT'S BASICS - ANXIETY / DISTRESS

#### **Anxiety Scale**

No Anxiety Moderate Anxiety

Severe Anxiety

- HAVE YOU SHARED:
- What keeps you up at night?
- What concerns you have?
- What are you most worried about?

HAVE YOU ALIGNED EVERYONE?

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

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

# PUTTING IT ALL TOGETHER

BEING TRANSPARENT WITH YOUR HEALTH AND PRIORITIES

## PUTTING IT ALL TOGETHER







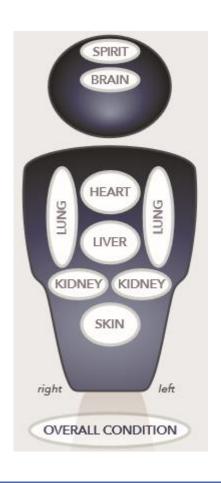


	Pain Scale	
No Pain	Moderate Pain	Severe Pain

Health Conditions			
Healthy	Underlying	Chronic	Terminally
,	Conditions	Conditions	

	Anxiety Scale	
No Anxiety	Moderate Anxiety	Severe Anxiety

### PUTTING IT ALL TOGETHER



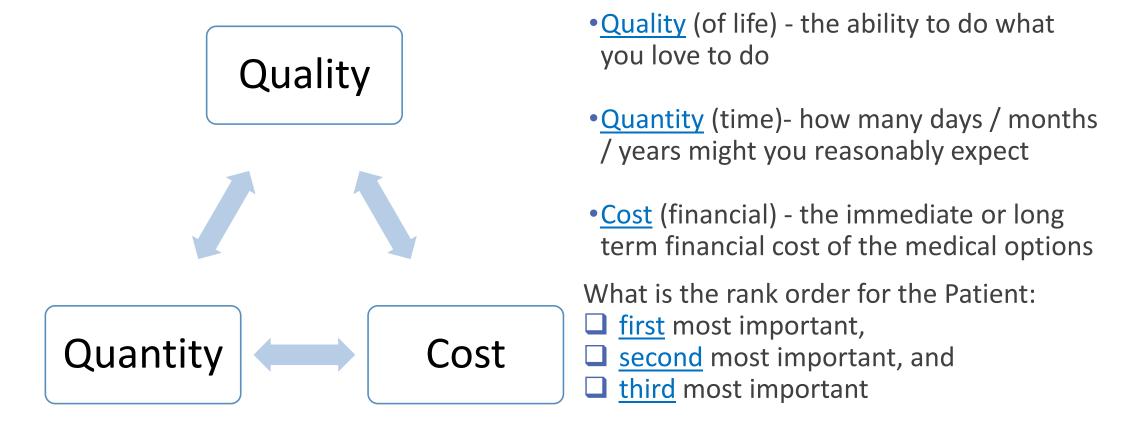
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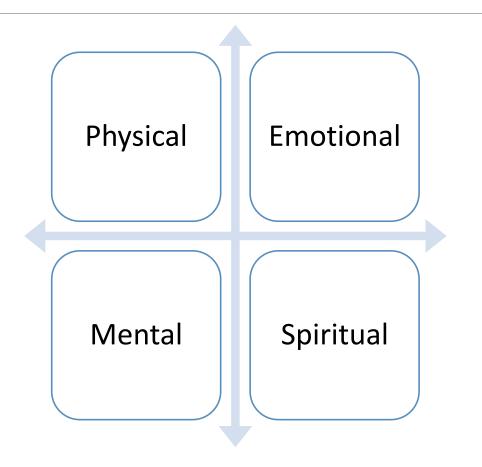
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YELLOW = Controlled with medications

#### DECISIONS — THE PATIENT'S PRIORITIES



# DECISIONS – QUALITY OF LIFE



- Physical the physical aspect of being able to do what one loves
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- Spiritual where one experiences being connected a community

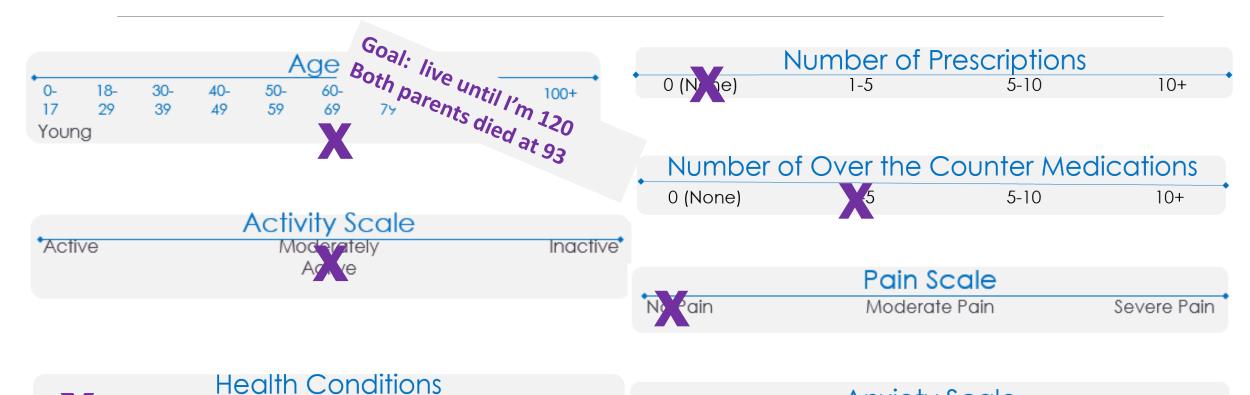
## DEB - 2019

Underlying

Conditions

Chronic

Conditions





He thy

Severe Anxiety

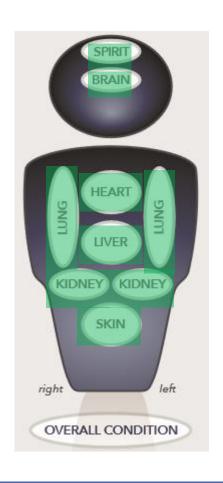
**Anxiety Scale** 

Moderate Anxiety

No nxiety

Terminally

# DEB - 2019



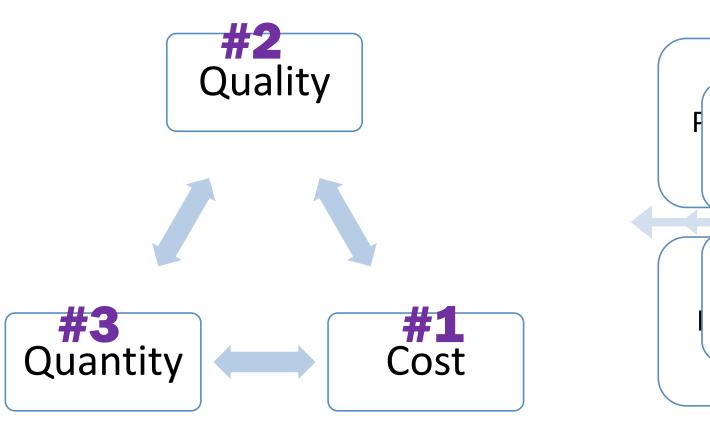
#### FOCUS ON THE MAJOR ORGANS

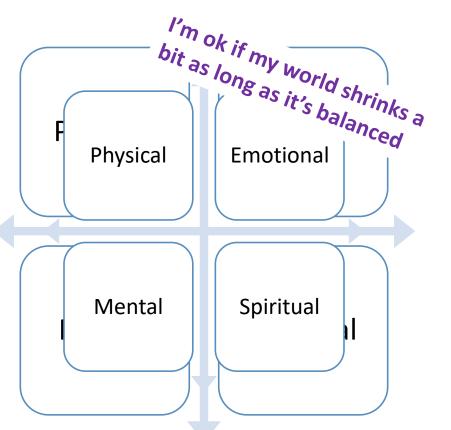
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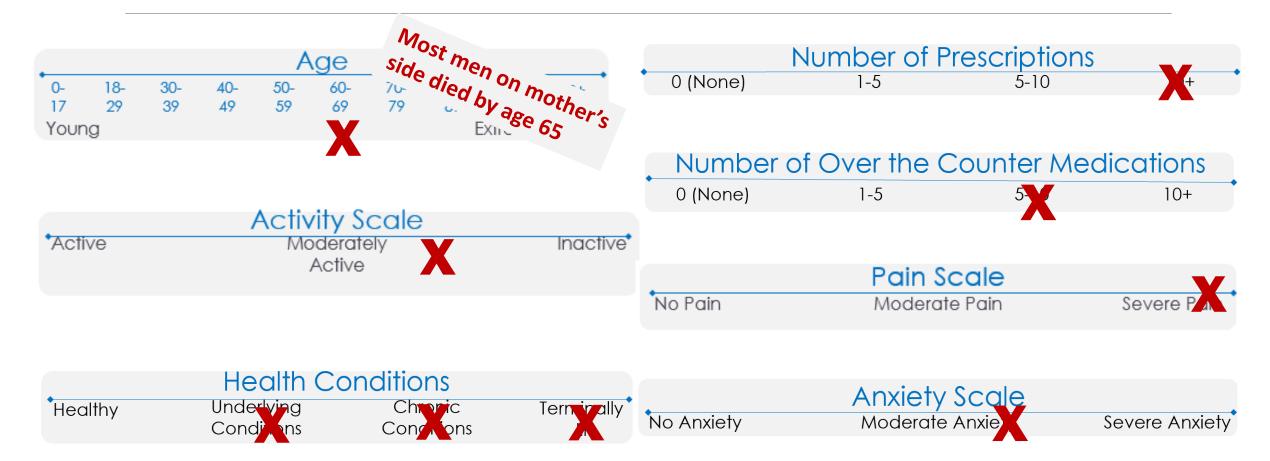
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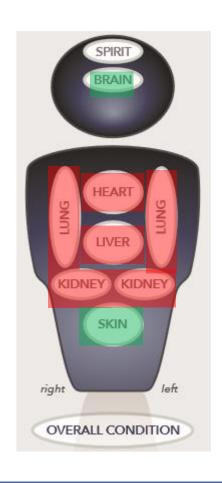




### BILL - 2011



## BILL - 2011



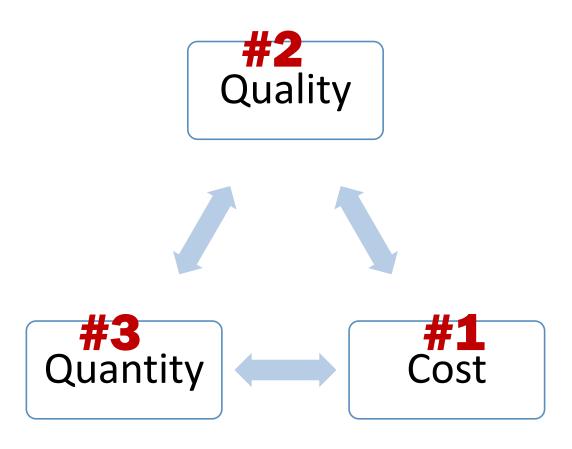
#### FOCUS ON THE MAJOR ORGANS

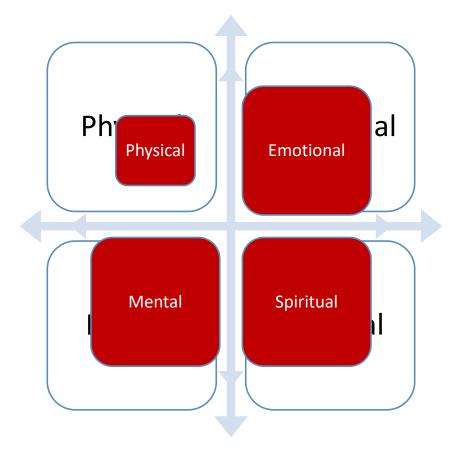
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# BILL - 2011





## **MARION - 2016**







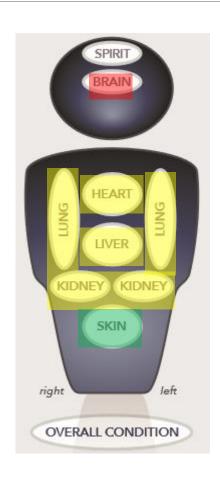


	Pain Scale	V	
No Pain	Moderate Pain	X	Severe Pain

Health Conditions			
Healthy	Underlying	Chronic	Tern in ally
	Condit ins	Concrons	

	Anxiety Scale	
No Anxiety	Moderate Anxie	Severe Anxiety

### MARION - 2016



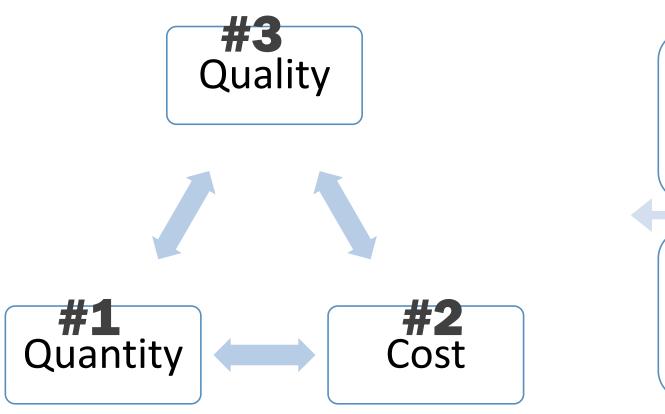
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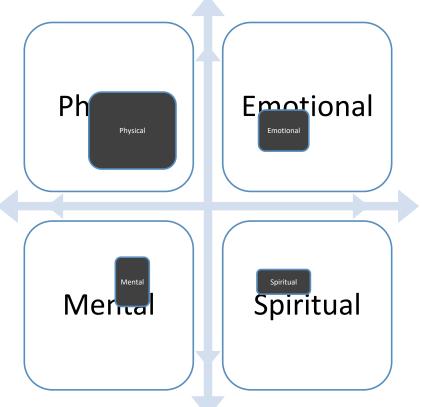
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# MARION - 2016





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

Deborah Day Laxson

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# THANK YOU!

#### SUMMARY REFERENCES:

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