Are you READY?

The Overlooked Role of Agent

Preparing Agents for Their Role

Health Care Agent Literacy Project, LLC

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The role of the agent is *contextual* and *unique*.

We cannot presume to tell the agent *what* to decide.

We can provide a *repeatable framework that may help* agents organize their thoughts.

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There is more information

on how to

"choose" an agent

than *"be"* an agent.

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Agenda

Identify the *roles* or "hats"
during a medical event

Identify *responsibilities* for each role

Explore potential *tools* for the agent

Call to *action*

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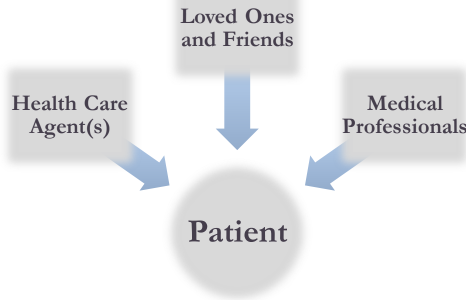
Meet the Medical Event team



The only criteria for success is whether or not the patient's choices are respectfully followed during the medical event.

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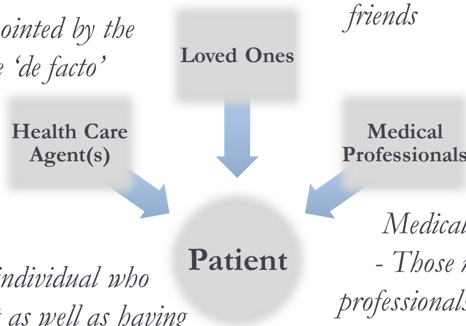
Role Definition

Agent(s) –individual(s) representing the patient when the patient cannot speak. May be appointed by the patient or may be 'de facto'

Loved Ones – includes the many relatives and friends



Patient – the individual who appoints the agent as well as having the medical appointment or medical treatment(s)

Medical Professional(s) - Those medically trained professionals providing service / treatments. May be more than one medical professional for the patient

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Key Responsibilities

Agent(s) –accept the role of agent only if you can represent the patient. Ask the patient clarifying questions about their intentions for care.

Loved Ones – recognize the role of the agent and that you may not be consulted during a medical event. Contact the medical ethics team if you believe the agent is not representing the patient accurately.

Loved Ones

Health Care Agent(s)

Medical Professionals

Patient

Patient – ask someone to be your agent. Be as clear as possible regarding your intent for medical care. Tell stories to help make it clear.

Medical Professional(s)
- Respect the patient's choices. Recognize the agent's role. Recognize the agent may not be the loudest voice in the room.

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What the health care agent does

PATIENT (unable to speak)

The agent: PATIENT'S VOICE

Loved Ones

Medical Professionals

The agent protects the patient from everyone else's best intentions.

The health care agent is the PATIENT's VOICE and represents the PATIENT's CHOICES when the patient is unable to speak.

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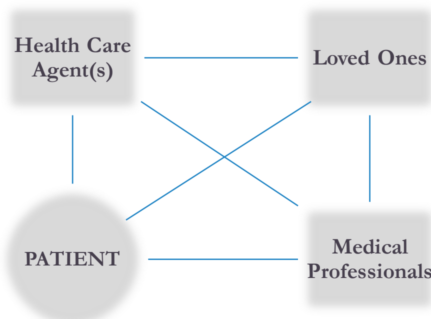
Let's Talk About Communication Channels



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

N = the number of people

Example: Team of 4 persons

$$\frac{4\,(3)}{2}$$

6 Potential communication channels

The more people involved the more likely the patient's desired choices get lost.

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No health care directive? There's still an agent

The 'de facto' agent guidelines in Minnesota:

- Spouse
- Adult children in birth order
- Parents
- Siblings in birth order

This sometimes feels like the game "duck, duck, goose!" Either that or SURPRISE!!

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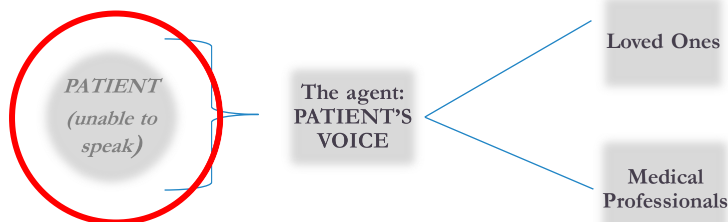
What the agent needs



From the patient BEFORE a medical event:

- Complete a health care directive and file with all appropriate medical clinics and hospitals. Give a copy to your agent. Keep a copy readily available to you and your agent.
- Be clear about YOUR (patient's) wishes.
- Tell stories to make your intent for care and your definition of quality-of-life as clear as possible.

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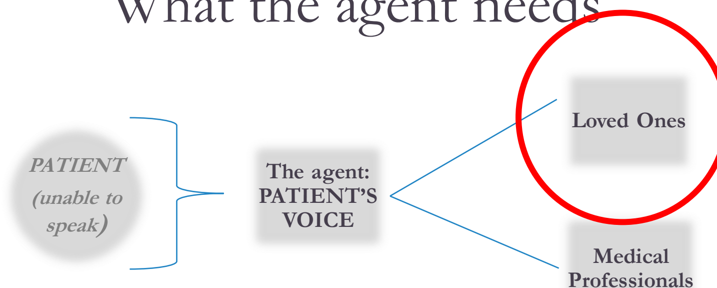
What the agent needs



From the Loved Ones during a medical event:

- Know who the health care agent is and support the agent during a medical event.
- Defer decisions back to the patient or their health care agent
- Acknowledge the goals of the patient's care plan may not be the same as the loved one's wishes for the patient
- Understand what the patient's choices mean regarding treatments to receive or not receive during a medical event, e.g., patient has a Don Not Resuscitate (DNR) or Do Not Intubate (DNI) order or is on comfort care only
- Contact the medical ethics team if the loved one feels the agent is not honoring the patient's choices

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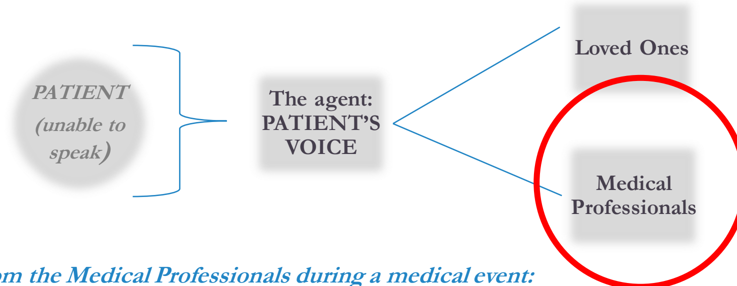
What the agent needs



From the Medical Professionals during a medical event:

- Know who the health care agent is and understand they may not be the loudest voice in the room
- Look to the agent to answer if the patient is unable to speak
- Transform medical data about the patient's medical status into consumable information that is more easily understood by the agent
- Understand the goals of the patient's care plan and their choices regarding treatments to receive, stop, or not start

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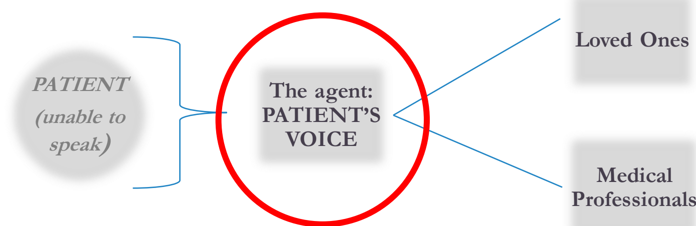
What the agent needs to remember



From the themselves during a medical event:

- Remember it's about the patient's choices / goals of the patient's care plan
- Re-read the health care directive with the current medical event in mind
- Assemble a team to help you sift through the medical data in order to make the best possible decision that aligns with the goals of the patient's care plan / the patient's definition for quality-of-life goals
- Ask questions until you feel you understand the patient's medical status, treatment options, and probable outcomes
- Ask for help from your team as appropriate / necessary

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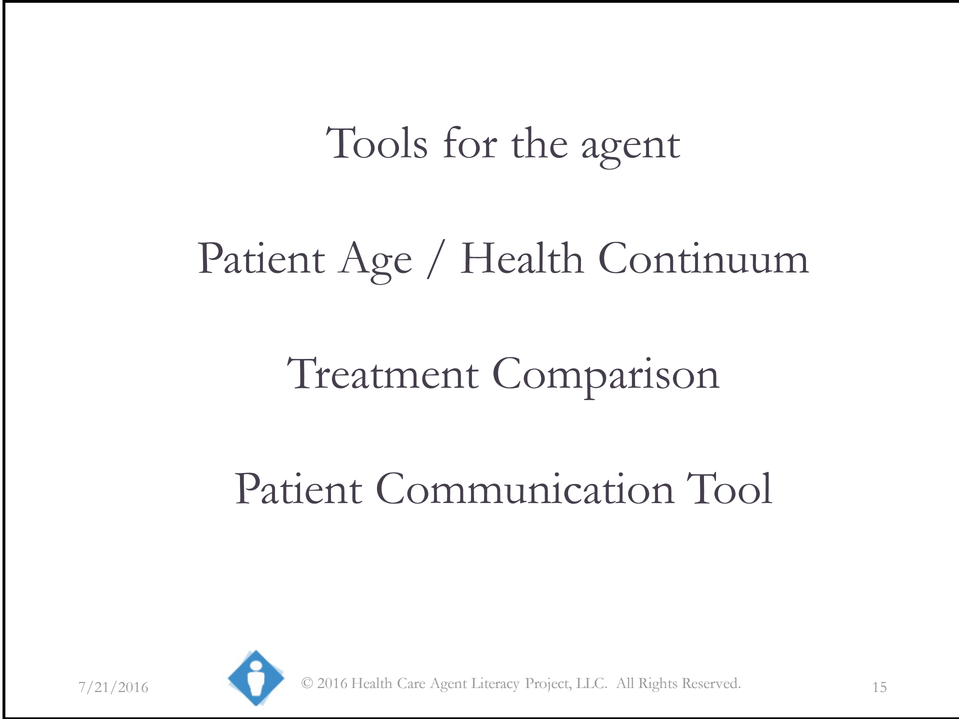
Tools for the agent
Patient Age / Health Continuum
Treatment Comparison
Patient Communication Tool
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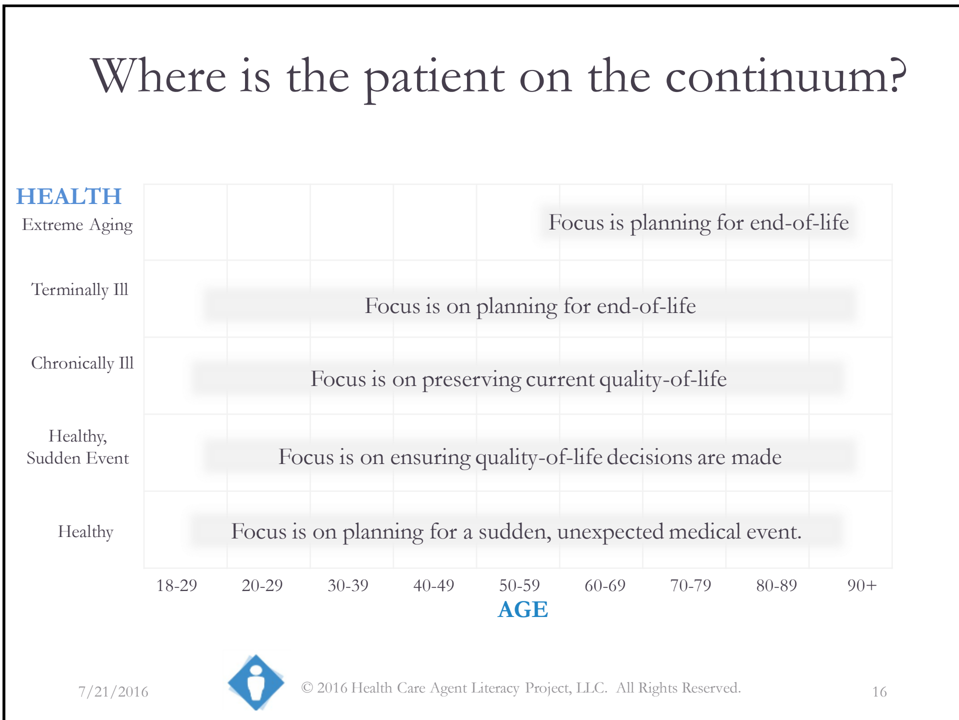
15


Where is the patient on the continuum?
HEALTH
Extreme Aging
Focus is planning for end-of-life
Terminally Ill
Focus is on planning for end-of-life
Chronically Ill
Focus is on preserving current quality-of-life
Healthy, Sudden Event
Focus is on ensuring quality-of-life decisions are made
Healthy
Focus is on planning for a sudden, unexpected medical event.
18-29
20-29
30-39
40-49
50-59
60-69
70-79
80-89
90+
AGE
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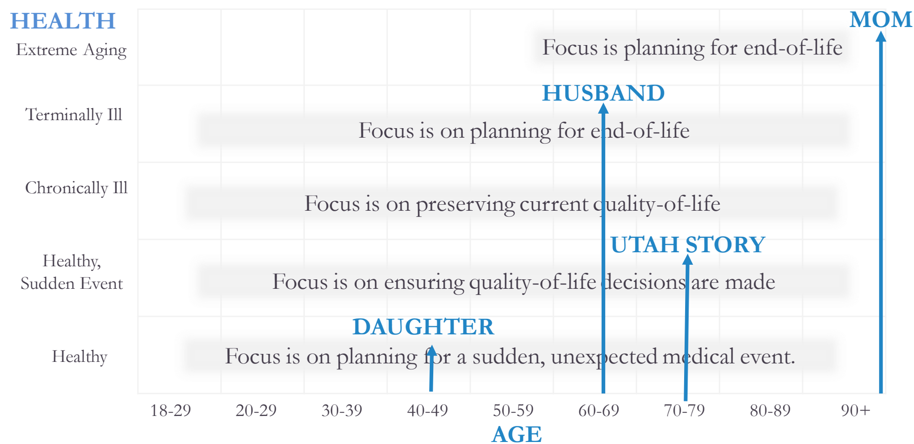
16

Where is the patient on the continuum? Care goals will be different



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Questions for the agent to consider:

Is the health care directive *current?*

What is the patient's *diagnosis?*

What is the patient's *prognosis?*

Are there *underlying conditions?*

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Additional considerations for the agent:

What is the medical event *today*?

Is this a *routine* appointment?

Is this a *procedure*?

Is this a *trauma* or *critical care* event?

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What does your patient *want*?

What does your patient *not want*?

What do they *like to do*?

Are you *clear* on their words?

Are you clear on their *intent*?

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Is the desired care plan

Curative Care

Or

Comfort Care?

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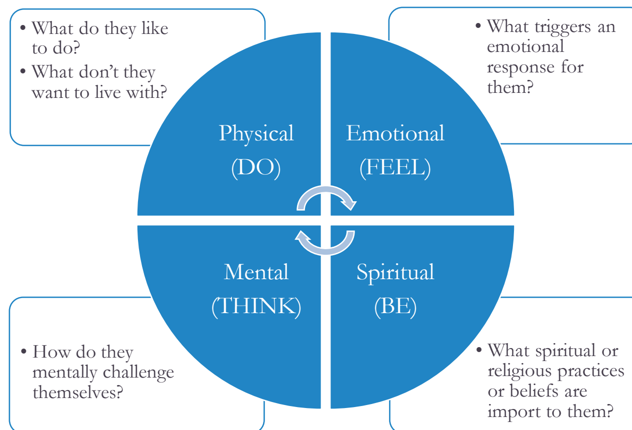
Can you recall stories that illustrate the patient's intent?



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Treatment Comparison Decision Table

MEDICAL EVENT (describe)	Treatment Option A	Treatment Option B	Treatment Option C	Do Nothing
PHYSICAL -				
EMOTIONAL -				
MENTAL -				
SPIRITUAL -				

GREEN = Patient's quality-of-life goals can be met with little to no modifications
YELLOW = Patient's quality-of-life goals can be met with modifications
RED = Patient's quality-of-life goals cannot be met

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Treatment Comparison Decision Table
Patient: 39 year old daughter

MEDICAL SCENARIO **Car Crash resulting in mangled leg / medically induced coma for pain**	**Treatment Option A** **- Repair leg resulting in 50% range of motion**	**Treatment Option B** **- Amputate leg / Use Prosthetic Leg**	**Do Nothing (buy time for daughter to make decision)**
PHYSICAL Running Biking Hiking	**Won't be able to run / bike / hike normally; will have limited mobility**	Will be able to run / bike BUT will have to use artificial leg	Stabilize leg but do not make major irreversible decisions right now.
EMOTIONAL Connect with family / friends	Can still connect – **DEPRESSION**	Can still connect – **DEPRESSION**?	Less depressions since daughter made decision
MENTAL Teaching / Problem Solving	Should not impact	Should not impact	Should not impact
SPIRITUAL Strong faith community	Should not impact	Should not impact	Should not impact

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Treatment Comparison Decision Table
Patient: 94 year old mother with Alzheimer's

MEDICAL SCENARIO Car Crash resulting in mangled leg / medically induced coma for pain	Treatment Option A - Repair leg resulting in 50% range of motion	Treatment Option B - Amputate leg / Use Prosthetic Leg	Do Nothing
PHYSICAL Unable to walk / confined to wheel chair	Would result in extensive recovery period as well as physical therapy	Since mom is not walking consider amputation without prosthetic leg	~~*Mom is unable to make decision, decision will need to be made*~~
EMOTIONAL Does not recognize family			
MENTAL Does not communicate			
SPIRITUAL No longer able to participate			

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Treatment Comparison Decision Table
Patient: 94 year old mother with Alzheimer's

MEDICAL EVENT – Extreme aging / terminal illness – no longer able to feed herself – 7d by FAST scale	Treatment Option A - Hand feeding by staff / family	Treatment Option B - Feeding Tube	Do Nothing
PHYSICAL Unable to care for herself	Feed as long as Mom accepts food – do not force feed	**Not acceptable option – Mom's care plan is comfort care only**	When Mom no longer accepts food – allow a natural death
EMOTIONAL Does not recognize family			
MENTAL Does not communicate			
SPIRITUAL No longer able to participate			

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Interpreting Medical Data

Lab Results

Lab Results

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---- CBC PROFILE ----

---- CHEMISTRY PROFILE ----

Page 1

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Page 3

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Making data visual

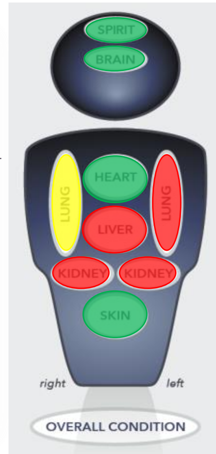
Lab Results

Use Colors to represent status:

Green – *organ is functioning*

Yellow – *organ is slowing*

Red – *organ is failing*



From data → *To information*

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The Patient Communication Tool

The Assessment – 1st Consultation

Explaining the Colors

The Dashboard

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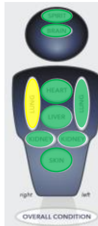
Patient's condition getting worse

Day 1



Day 2

Day 3

Day 4

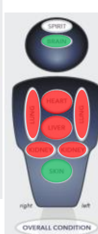
Day 5

Day 6

Day 7

Day 8

Day 9



Visually aiding the medical professional's conversation about the patient's medical status

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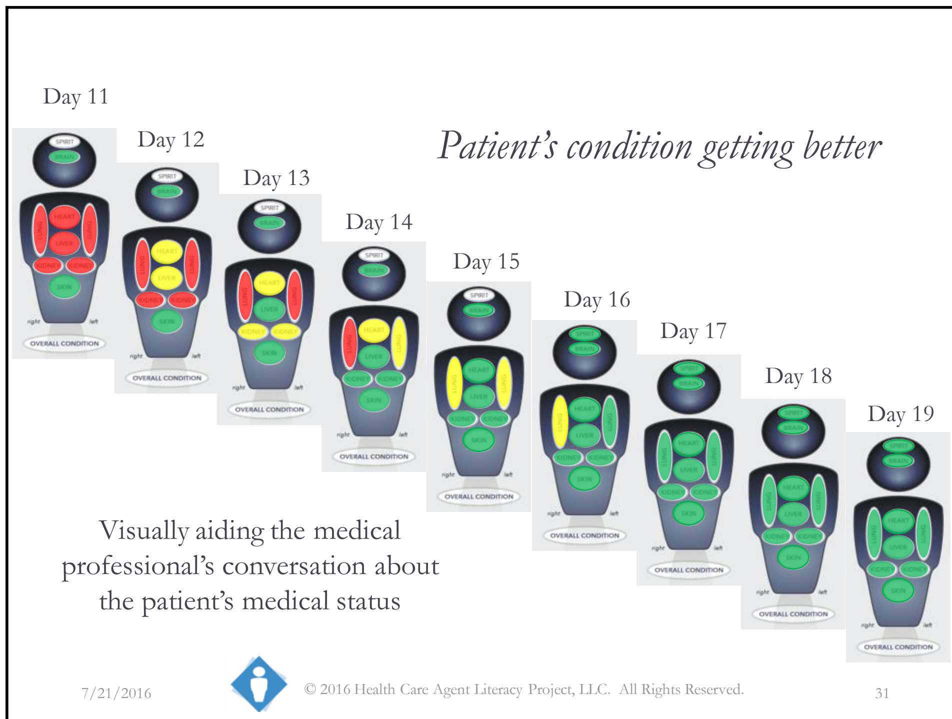

Remember words matter, OKAY?

- I agree with you *(agreement)*
- I heard you *(acknowledgement)*
- I accept what you're saying *(acceptance)*
- I consent to what you are proposing *(consent)*
- I hear what you're saying but I really don't know what it means *(need clarification)*
- Please continue *(continuation)*
- I'm scared and/or angry *(WHATEVER)*
- It really doesn't matter what I say or want *(passive resignation, whatever)*

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‘Making the decision’

Living with ‘making the decision’

Note: Will be explored in “The Gray Zone” presentation

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Remember that slide?

It’s equally important that agent and loved ones understand what comfort care means conceptually. And just as important, what comfort care might look like in a medical setting. For example, a Do No Resuscitate order means that if the patient’s heart stops, the staff will not perform Cardiopulmonary Resuscitation (CPR).
Or, a feeding tube will not be inserted when 94 year old mom is no longer able to feed herself and refuses food from staff.

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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 <u>roles and responsibilities</u> during a medical event *<u>BEFORE</u>* 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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