Are you READY?

The Overlooked Role of Agent

Preparing Agents for Their Role

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.
There is more information on how to "choose" an agent than "be" an agent.

Agenda

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

Identify *responsibilities* for each role

Explore potential *tools* for the agent

Call to *action*
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.

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
**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.

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**

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.
Let's Talk About Communication Channels

Let's Talk About Communication Channels

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

N = the number of people

Example: Team of 4 persons

\[
\frac{N \cdot (N-1)}{2} = \frac{4 \cdot 3}{2} = 6
\]

6 Potential communication channels

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!!
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.

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.
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

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
Tools for the agent

Patient Age / Health Continuum

Treatment Comparison

Patient Communication Tool

Where is the patient on the continuum?

<table>
<thead>
<tr>
<th>HEALTH</th>
<th>AGE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Healthy, Sudden Event</td>
<td></td>
</tr>
<tr>
<td>Healthy</td>
<td>18-29</td>
</tr>
<tr>
<td>Chronically Ill</td>
<td>20-29</td>
</tr>
<tr>
<td>Terminally Ill</td>
<td>30-39</td>
</tr>
<tr>
<td>Extreme Aging</td>
<td>40-49</td>
</tr>
<tr>
<td></td>
<td>50-59</td>
</tr>
<tr>
<td></td>
<td>60-69</td>
</tr>
<tr>
<td></td>
<td>70-79</td>
</tr>
<tr>
<td></td>
<td>80-89</td>
</tr>
<tr>
<td></td>
<td>90+</td>
</tr>
</tbody>
</table>

**Focus is planning for a sudden, unexpected medical event.**

**Focus is on ensuring quality-of-life decisions are made.**

**Focus is on preserving current quality-of-life.**

**Focus is on planning for end-of-life.**

**Focus is planning for end-of-life.**
Where is the patient on the continuum?
Care goals will be different

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*?
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?

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*?
Is the desired care plan

*Curative Care*

Or

*Comfort Care?*

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

- What do they like to do?
- What don't they want to live with?
- What triggers an emotional response for them?
- How do they mentally challenge themselves?
- What spiritual or religious practices or beliefs are important to them?
### 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

**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
### Treatment Comparison Decision Table

**Patient:** 94 year old mother with Alzheimer’s

<table>
<thead>
<tr>
<th><strong>MEDICAL SCENARIO</strong></th>
<th><strong>Treatment Option A</strong></th>
<th><strong>Treatment Option B</strong></th>
<th><strong>Do Nothing</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Car Crash resulting in mangled leg / medically induced coma for pain</td>
<td>Repair leg resulting in 50% range of motion</td>
<td>Amputate leg / Use Prosthetic Leg</td>
<td>Mom is unable to make decision, decision will need to be made</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>PHYSICAL</strong></th>
<th><strong>Treatment</strong></th>
<th><strong>EMOTIONAL</strong></th>
<th><strong>MENTAL</strong></th>
<th><strong>SPIRITUAL</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Unable to walk / confined to wheelchair</td>
<td>Would result in extensive recovery period as well as physical therapy</td>
<td>Does not recognize family</td>
<td>Does not communicate</td>
<td>No longer able to participate</td>
</tr>
</tbody>
</table>

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### Treatment Comparison Decision Table

**Patient:** 94 year old mother with Alzheimer’s

<table>
<thead>
<tr>
<th><strong>MEDICAL EVENT – Extreme aging / terminal illness – no longer able to feed herself – 7d by FAST scale</strong></th>
<th><strong>Treatment Option A</strong></th>
<th><strong>Treatment Option B</strong></th>
<th><strong>Do Nothing</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Hand feeding by staff / family</td>
<td>Feeding Tube</td>
<td>Not acceptable option – Mom’s care plan is comfort care only</td>
<td>When Mom no longer accepts food – allow a natural death</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>PHYSICAL</strong></th>
<th><strong>EMOTIONAL</strong></th>
<th><strong>MENTAL</strong></th>
<th><strong>SPIRITUAL</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Unable to care for herself</td>
<td>Does not recognize family</td>
<td>Does not communicate</td>
<td>No longer able to participate</td>
</tr>
</tbody>
</table>
## Interpreting Medical Data

Use Colors to represent status:

- **Green** - organ is functioning
- **Yellow** - organ is slowing
- **Red** - organ is failing

### From data to information

```
<table>
<thead>
<tr>
<th>Lab Results</th>
<th>Use Colors to represent status:</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Lab</strong></td>
<td><strong>Color</strong></td>
</tr>
<tr>
<td>Choice</td>
<td>Green</td>
</tr>
<tr>
<td>Option</td>
<td>Yellow</td>
</tr>
<tr>
<td>Selection</td>
<td>Red</td>
</tr>
</tbody>
</table>
```

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The Patient Communication Tool

The Assessment – 1st Consultation

Explaining the Colors

The Dashboard

Patient’s condition getting worse

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

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

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)*
‘Making the decision’

Living with ‘making the decision’

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

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.
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?