The New Language of Advance Care Planning

John Maycroft, MPP, Optum
Jennifer Drakellis, MBA | Justin Altum, BA, Leemor Nir, BA, Monica Nolasco | Jonathan Suber, MBA
UnitedHealth Care | maslansky + partners | AARP Services, Inc.

Objectives

- Share findings from the New Language of Advance Care Planning study
- Share ideas and seek feedback and advice for UHG’s involvement in advance care planning

Outline

- Study overview
- What works
  - Recognizing the barriers
  - Protecting and removing a burden from your loved ones
  - Future Care Preferences
  - Choosing an advocate
  - Striking the right tone
  - Easing into the conversation
  - Making it for everyone
  - Life Events
  - Validating and easing uncertainty
  - Flexibility and “a plan to build off of”
- UHG’s future in advance care planning

Our purpose

Create the language for advance care planning that will encourage and facilitate open, honest, and importantly, timely conversations between patients, families, doctors and other care givers

Motivate people to start having conversations about advance care planning, sooner.
Despite the fact people aren’t acting on this topic today, your audience sees themselves as proactive doers.

- 84% claim they are more likely to do tasks to get them done until they need to do it.
- 63% claim they are more likely to stick to New Year’s Resolutions and complete them than start it but not finish it.
- 65% claim they would rather have a tough conversation in a challenging situation than let it work itself out.

And there are many patient-friendly and specialized institutes focused on motivating your audience today.

- The messaging they use cover a range of reasons why people should be having these conversations now and acting upon them.

so...why is this still a challenge?

Methodology

- Communication and Research Audit to understand the insights and strategy to date
- Language Lab in Washington, D.C. with 15 key stakeholders to uncover new and existing ideas on communicating in this space.
- Fifteen Stakeholder Interviews: One-on-one interviews with internal and external (C-TAC speakers, partner organizations, subject and policy experts) stakeholders for a 360-degree view of the space today.
- Eight 2-hour Instant Response Dial Sessions in Nashville and Miami, N=160 to provide a targeted, clear direction for our audiences with quantitative data.
- National Online Survey, N=1000.
- 15 In-Depth Specialized Audience Interviews to begin understanding the best ways to engage experts and professionals who can widen the opportunity with our audience.
today's language is agreeable, not motivating.

barriers to the conversation
Q. What would you say is or would be most holding you back from completing a plan like this?

<table>
<thead>
<tr>
<th>The real barriers</th>
<th>Not the barrier</th>
</tr>
</thead>
<tbody>
<tr>
<td>I don't know where to start</td>
<td>It's not necessary to discuss</td>
</tr>
<tr>
<td>I don't want to talk about death</td>
<td></td>
</tr>
<tr>
<td>It doesn't apply to me yet</td>
<td>I'm not doing it</td>
</tr>
<tr>
<td>It's too expensive</td>
<td></td>
</tr>
<tr>
<td>I don't think my family wants to discuss it</td>
<td></td>
</tr>
<tr>
<td>It's not necessary to discuss</td>
<td></td>
</tr>
</tbody>
</table>

ambiguous + complicated + unpleasant + costly = I'm not doing it

making this a priority.

- Our audience knows this is a necessary conversation to have... at some point
- Once they know what this is about and what they need to do, the real challenge is moving this to the top of their long list of to-dos so that it's a priority to talk about now—not 10 or 20 years down the line

because they think it is... the language must be... so that they...

<table>
<thead>
<tr>
<th>Ambiguous</th>
<th>Direct</th>
<th>understand exactly what this is about and who this is for</th>
</tr>
</thead>
<tbody>
<tr>
<td>Complicated</td>
<td>Simple</td>
<td>know what this entails, rather than assuming it's too much to handle</td>
</tr>
<tr>
<td>Unpleasant</td>
<td>Approachable</td>
<td>have resources and reasons why to have this conversation now that best fits with their life</td>
</tr>
<tr>
<td>Costly</td>
<td>Accessible</td>
<td></td>
</tr>
</tbody>
</table>

necessary ➡️ priority
• While there is language in use today around taking the burden off family members, it’s often buried under language all about protecting your own values.

• But a top driver of how our audience prioritizes today is based on the instinct to protect their loved ones, which is more than just emotional—it’s primal.

**Peace of Mind**

The power in peace of mind is that it connects to all the main drivers to have this conversation today.

- You won’t leave a burden on your family.
- You have an advocate to be your voice.
- Your preferences will be there for your doctor.

**“Protection” and “Removing a Burden”**

• Both “protection” and “removing a burden” for loved ones are powerful motivators.

• While the former speaks to a primal instinct to shelter our family, the latter is a strong visual that subtly hints at the consequence of not having this conversation soon enough.

**“Advance Care Planning”**

It’s misunderstood!

- “Preferences” came out on top as the most motivating descriptor of what this is, for two main reasons—
  - there’s an inherent element of a “preference” that makes the conversation more approachable and personal.
  - it’s less final than “decisions” or “choices,” which can have the negative implications that a) they can’t change what their choices or b) that all the “what ifs” they’re planning for are inevitable.

**“Future Care Preferences” adds clarity**

- “Preferences” came out on top as the most motivating descriptor of what this is, for two main reasons—
  - there’s an inherent element of a “preference” that makes the conversation more approachable and personal.
  - it’s less final than “decisions” or “choices,” which can have the negative implications that a) they can’t change what their choices or b) that all the “what ifs” they’re planning for are inevitable.

- “Preferences are about YOU, and what you want at that time.”
  - Potential Caregiver, Miami

- “Choice makes it sound final, like you can’t revisit it.”
  - Potential Caregiver, Nashville
Healthcare "Agent" and "Proxy"

- Healthcare "proxy" and "agent" are both dominant terms in the space today—but they are both clinical and cold, detaching your audience from the importance of this role.

<table>
<thead>
<tr>
<th>you say</th>
<th>they hear</th>
</tr>
</thead>
</table>
| healthcare proxy | "My first question is, what's a proxy?"  
- Participant, Nashville |
| healthcare agent | "It sounds like a third party, not like somebody I love."  
- Participant, Nashville |

"Advocate"

- On the other hand, the term "advocate" suggests a degree of trust, respect, and understanding that many instantly recognize as critical.

<table>
<thead>
<tr>
<th>advocate</th>
<th>substitute decision maker</th>
</tr>
</thead>
<tbody>
<tr>
<td>20%</td>
<td>20%</td>
</tr>
<tr>
<td>healthcare agent</td>
<td>14%</td>
</tr>
</tbody>
</table>

- Participants commented on the value of the term "advocate".

| "I want someone totally on my side that will fight for me and what I want."  
- Participant, Miami |
| "It's all about my connection with my family... and it makes me feel in control."  
- Participant, Miami |
| "It's someone who knows you and will be your voice—we need that."  
- Participant, Miami |
| "I want someone totally on my side that will fight for me and what I want."  
- Participant, Miami |
| "It sounds like a third party, not like somebody I love."  
- Participant, Nashville |
| "My first question is, what's a proxy?"  
- Participant, Nashville |
| "It's someone who knows you and will be your voice—we need that."  
- Participant, Nashville |

 striking the right tone

- While much of the current language focused on death is too negative to motivate many, sugarcoating the conversation as a very positive one causes a similar reaction.

- A clear, direct, and encouraging tone ensures the message gets right to what your audience really wants to hear—what this is, and how to do it.

<table>
<thead>
<tr>
<th>negative</th>
<th>clear and direct</th>
<th>positive</th>
</tr>
</thead>
<tbody>
<tr>
<td>4%</td>
<td>62%</td>
<td>5%</td>
</tr>
<tr>
<td>8%</td>
<td>63%</td>
<td>10%</td>
</tr>
<tr>
<td>19%</td>
<td>16%</td>
<td>15%</td>
</tr>
<tr>
<td>20%</td>
<td>20%</td>
<td>20%</td>
</tr>
<tr>
<td>27%</td>
<td>6%</td>
<td>17%</td>
</tr>
<tr>
<td>17%</td>
<td>6%</td>
<td>5%</td>
</tr>
</tbody>
</table>

- Participants shared their preferences on tone.

| "I liked that because it was a clear message about what to do and how to prepare yourself—simple and straight to the point."  
- Miami, Potential Care Recipient |
| "While I know we’re talking about death, I don’t want to get hit over the head with my own mortality."  
- Miami, Potential Care Recipient |
| "I want someone totally on my side that will fight for me and what I want."  
- Participant, Miami |
| "It sounds like a third party, not like somebody I love."  
- Participant, Nashville |
| "My first question is, what’s a proxy?"  
- Participant, Nashville |
| "It’s someone who knows you and will be your voice—we need that."  
- Participant, Nashville |

 Ease them into the conversation

- Almost half our audience lists not knowing where to start as one of the biggest reasons they haven’t had this conversation today.

<table>
<thead>
<tr>
<th>you say</th>
<th>they hear</th>
</tr>
</thead>
</table>
| It can be an informal conversation, and doesn’t have to start with a form | 63% agreed  
This makes me feel that this is simpler than I thought  
— Care Recipient, Miami |
| It’s all about my connection with my family... and it makes me feel in control.  
— Participant, Miami |

- Participants shared their preferences on ease of conversation.

<table>
<thead>
<tr>
<th>Experts say it’s here</th>
<th>Your audience thinks it’s here</th>
</tr>
</thead>
<tbody>
<tr>
<td>15-29</td>
<td>3%</td>
</tr>
<tr>
<td>30-39</td>
<td>19%</td>
</tr>
<tr>
<td>40-49</td>
<td>20%</td>
</tr>
<tr>
<td>50-59</td>
<td>27%</td>
</tr>
<tr>
<td>60-69</td>
<td>17%</td>
</tr>
<tr>
<td>70+</td>
<td>6%</td>
</tr>
</tbody>
</table>

 when is the right time to start?

Q. In my opinion, the best age to begin planning for this is when someone is _____ years old.

- Experts have different opinions on the best age to begin planning.

- Participants shared their preferences on the best age to start planning.
**Who it’s for**
- The impression that this type of planning is only for older audiences is a barrier to having these conversations sooner.
- Make it clear this conversation may be applicable at any time—and that these situations can be temporary, and aren’t just for end-of-life situations, which makes the conversation more approachable and applicable.

<table>
<thead>
<tr>
<th>you say</th>
<th>they hear</th>
<th>instead say</th>
</tr>
</thead>
<tbody>
<tr>
<td>[prepare for] end of life care</td>
<td>this is for later</td>
<td>[prepare for] when an accident or illness may make it challenging for you to think clearly</td>
</tr>
</tbody>
</table>

54% agreed

Having this conversation is important because an accident or illness can happen at any time.

**Tying to life events**
- When it comes to the specific language of when to have these discussions, our audience connects most to “life event”—it’s the natural language they use to describe significant changes in their lives.

<table>
<thead>
<tr>
<th>life event</th>
<th>they hear</th>
<th>instead say</th>
</tr>
</thead>
<tbody>
<tr>
<td>life change</td>
<td>I think differently because of the different events in my life. And those different life events would prompt me to think about this.</td>
<td>“I’m more likely to discuss advance care planning when I experience a significant milestone.”</td>
</tr>
</tbody>
</table>

“Tying it to life events makes it more approachable”
- Care Recipient, Nashville

**Flexibility**
- Many hesitate to document their preferences now because they think it’s impossible to know what they’d want years in advance, and they’re afraid they can’t change it.
- Let them know their plan works with their changing life—and they can change it as their views change.
- “Flexibility” tests much better than “change” or “evolve.”

<table>
<thead>
<tr>
<th>you say</th>
<th>they hear</th>
<th>instead say</th>
</tr>
</thead>
<tbody>
<tr>
<td>It’s flexible and can be revised as your life changes</td>
<td>“It’s encouraging because you don’t have to cross every ‘t’ and dot every ‘i.’ It’s just getting the ball rolling, then changing it later.”</td>
<td>“It doesn’t have to be perfect right away—it’s a process and can be changed as our views change.”</td>
</tr>
</tbody>
</table>

“Those who have advance care planning discussions are three times more likely to have their wishes followed.”
- Potential Caregiver, Nashville

**directing conversations to happen sooner**
- Tying this conversation to an age feels arbitrary to many who point out that their beliefs are influenced by what’s happening in their lives—not by their age.
- Tying this conversation to life events—such as starting a job, getting married, or having kids—allows us to strategically:
  - Tie this conversation to events that happen earlier in life.
  - Reinforce that this conversation can and should be revisited.
  - Position this as a natural conversation to be had as you discuss other aspects of your life.

**The freedom of an imperfect conversation**
- When it comes to deciding on their preferences, many feel stuck—giving them permission to be unsure and provide a path for them to find out what they do want given where they are today.

Q. It’s okay to not know what you want right now—you may even start with what you don’t want.

On a scale of 0-10, this message…

<table>
<thead>
<tr>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>Strongly Disagree</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

I’m not in the medical field, so I don’t know all my options. But I know I can make a list of things I wouldn’t want.”
- Potential Caregiver, Miami

**summary language to use and lose**

<table>
<thead>
<tr>
<th>language to use</th>
<th>language to lose</th>
</tr>
</thead>
<tbody>
<tr>
<td>future care</td>
<td>end-of-life care</td>
</tr>
<tr>
<td>[future care] preferences</td>
<td>[future care] decisions</td>
</tr>
<tr>
<td>discuss with your loved ones</td>
<td>discuss with your family (only)</td>
</tr>
<tr>
<td>if it can be an informal conversation and it doesn’t have to start with a form</td>
<td>[lead with] complete an advance directive</td>
</tr>
<tr>
<td>it’s a simple process</td>
<td>it’s an essay process</td>
</tr>
<tr>
<td>the right time can be when experiencing a life event that you’re already preparing and planning for</td>
<td>the best time to start is at 18 years old, when you become independent from your parents</td>
</tr>
<tr>
<td>advocate voice</td>
<td>healthcare proxy</td>
</tr>
<tr>
<td>positive facts, like “Those who have advance care planning discussions are three times more likely to have their wishes followed.”</td>
<td>negative or fear-based facts, such as “More than one-third of patients are inaccurate in predicting their pain, preferences.”</td>
</tr>
</tbody>
</table>
**Honoring Choices Minnesota 2017 Conference**

**UHG and Advance Care Planning**

**Causes of lower ACP adoption and utilization across the clinical pipeline**

- Lack of awareness and understanding of what’s in it for them
- People not invited to participate
- Not prepared for discussion
- Physicians rely on patient to take action, no follow-up

- Physicians lack of time and training
- Encountering barriers in conversation with family that pause the discussion
- Literacy issues
- Ability to find witnesses
- Documents not all encompassing

- Not knowing where they are stored
- Difficulty in location
- Physicians difficulty with interpreting meaning
- EMS will follow physician’s orders so AD may not be contemplated

- Value is not clearly understood

**ADVANCE CARE PLANNING ECOSYSTEM**