



How to Talk to Your Patients about End-of-Life Care

A Conversation Ready Toolkit for Clinicians

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ACKNOWLEDGMENTS

We acknowledge and appreciate the time and talent of our editors: Jane Roessner, PhD, Val Weber, and Cayla Saret, MPH. We are grateful for the keen and compassionate eyes of our internal reviewers: Niñon Lewis, MS, and Rosemary Lloyd, BSN, MDiv; and the wise and experienced input of our external reviewers: Cara L. Coleman, JD, MPH, of Family Voices and IPFCC, Jane Coppola, RN, MHA, of Kaiser Permanente, Danielle J. Doberman, MD, MPH, HMDC, of Johns Hopkins University, Shiyun (Cici) Guan of Boston Senior Home Care, and Gloria E. White-Hammond, MD, MDiv, of the Bethel AME Church.

This toolkit is funded by the **Gordon and Betty Moore Foundation**. We are deeply grateful for their commitment to the development and dissemination of this work. The Moore Foundation fosters path-breaking scientific discovery, environmental conservation, patient care improvements, and preservation of the special character of the San Francisco Bay Area. Visit Moore.org or follow @MooreFound

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INTRODUCTION

Becoming “Conversation Ready”

The ultimate goal of a Conversation Ready health care organization is respectful end-of-life care that is concordant with patients’ stated goals, values, and preferences.

In 2012, in partnership with the Institute for Healthcare Improvement (IHI), The Conversation Project launched a public engagement initiative designed to help people have conversations with their families and other loved ones about their wishes for end-of-life care.

In parallel with this work, IHI launched the “Conversation Ready” initiative to support a broad range of health care organizations — including community settings that serve diverse patient populations — to put processes in place to document patients’ end-of-life care wishes and then respect patients by providing care aligned with those wishes. The vision of a Conversation Ready health care organization is one that is ready to reliably guide all patients and families through the advance care planning process and, in the context of serious illness, to ensure that their wishes are always respected.

Through this work, IHI has learned many key lessons about taking a systems approach to improving the care of patients by ensuring that what matters most to them is expressed and respected at the end of their lives. The history of and lessons from this work can be found in a 2019 IHI White Paper, [*“Conversation Ready”: A Framework for Improving End-of-Life Care*](#).

This approach includes clinicians proactively engaging in discussions with patients and their families to understand patients’ end-of-life care wishes; reliably documenting and stewarding this information; examining their own biases around end-of-life care; and learning how to connect with patients in a culturally humble way. The ultimate goal of a Conversation Ready health care organization is respectful end-of-life care that is concordant with patients’ stated goals, values, and preferences.

While it is vital to ensure that processes are in place at a systems level to support this work, we have also heard from clinicians across the continuum of care that the actual process of starting end-of-life care conversations with patients can be a significant barrier. We developed this toolkit for clinicians specifically to address this need.

About This Toolkit

***How to Talk to Your Patients about End-of-Life Care: A Conversation Ready Toolkit for Clinicians* uses a case-based approach with four patients drawn from actual stories — each with a different disease course, different family composition, different cultural background, and different answer to the question, “What matters most to you at the end of life?”**

No story can ever reflect the multiplicity of these variables. These cases are intended to demonstrate only some of the many considerations clinicians balance when caring for patients. This toolkit aims to be useful to a wide variety of clinicians who are working in diverse care settings and are at different career stages. The toolkit authors acknowledge the influence of our own backgrounds and biases in developing these cases. We hope that each case offers useful guidance about how to effectively engage with patients and their families throughout the context of serious illness and end-of-life care.

This toolkit presumes that your professional experience as a clinician provides a foundation in good communication skills such as empathic and reflective listening, allowing space and time in the conversation for emotion, recognizing significant issues that might need additional attention, and engaging other professionals in end-of-life care discussions with patients. It also presumes that you are aware of your organization’s policies for determining patient capacity around decision making.

While this toolkit can be used to build upon your professional training, it is not meant to be a substitute for examining the overall systemic issues in your setting. Rather, this toolkit is intended to help you address some of the challenges of engaging fully with patients and families in conversations about end-of-life care over time. Thank you for seeking to improve your own practice. We welcome your feedback at conversationproject@ihi.org.

How to Use This Toolkit

The four cases in this toolkit present patients with diverse backgrounds and experiences at different points of illness, as well as diverse clinicians and care settings. Each case describes the progression of the patient’s illness to illustrate the Conversation Ready principles at each phase and outlines key considerations for clinicians to engage the patient and family (as defined by the patient) in discussions about what matters most to the patient at the end of life.

Please note that the phases within each case represent excerpts of conversations between clinicians, patients, and their families, rather than entire visits. As such, they are short on clinical details and more focused on the Engage principle (more to follow in the Conversation Ready principles section).

In each case, you will find opportunities to think about issues at the individual patient level as well as at the system level, which refers to the workflow, policies, procedures, and documentation systems that might need improvement.

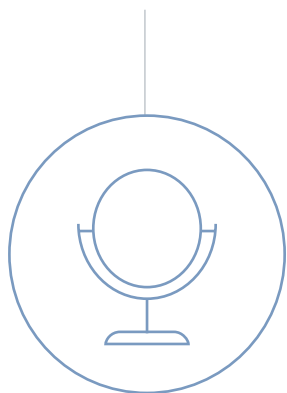
This toolkit is intended for use in a variety of care settings by clinicians representing different disciplines. It can be used individually or by a team. Each case provides an opportunity for discussion among clinicians in your care setting, for example, during a “Brown Bag Lunch” or “Lunch and Learn.” This toolkit might also be used in a classroom setting while coaching clinicians about how to start conversations about end-of-life care. We aim to highlight direct, specific ways to talk with patients and their families without leaning on jargon.

In using this toolkit, we hope that you will give attention to what it illuminates about your own practice and what it highlights about your organization’s current systems for talking with patients about what matters most to them at the end of life — as well as how reliable those systems are in stewarding that information and respecting those wishes.

Throughout this toolkit we reference and link to free Starter Kits from The Conversation Project website that can be used as companion tools to this resource.

The Conversation Ready Principles

IHI's recommended approach to becoming Conversation Ready is based on four core principles, all leading to the fifth and most important principle: **Respect for what matters most to each individual at the end of life.** The principles are referred to throughout this toolkit and are used to help guide conversations.

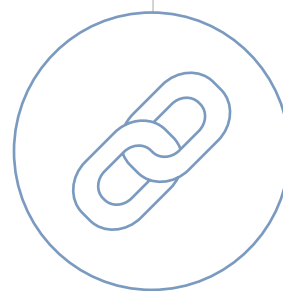


Exemplify this work in clinicians' own lives to more fully understand the benefits and challenges.

Health care professionals who practice and model the behaviors they are encouraging their patients and families to undertake — such as having conversations about what matters most to them at the end of life with their own selected surrogate medical decision maker — are more likely to appreciate the importance of and difficulty inherent in those activities. They may thereby more effectively encourage patients and their families to do the same.

Connect with patients and families in a culturally and individually respectful manner.

Appreciating the context of patients' lives (and that of their loved ones) — recognizing that socioeconomic status, racial identity, religion, ethnic heritage, educational history, primary language, cultural background, sexual orientation, gender identity, and many other factors shape perspectives and interactions — and attending to one's own biases are critical prerequisites to building trust. Without this foundation, it is difficult or impossible to understand and support patient and family decisions or behaviors. Health care professionals who have exemplified the work may be better able to develop awareness of their own biases. *Exemplify and Connect have an important interconnection, as our experiences with patients across areas of cultural difference call us to explore and mitigate our own biases.*





Engage with patients and families to understand what matters most to them at the end of life.

Just as health care professionals are not passive about addressing the topics of smoking cessation, obesity, substance abuse, and safety in their patients' homes, so too are they called on to be proactive about knowing what matters most to their patients at the end of life. *Engage* is closely interwoven with *Steward* (see below) because together these two principles create the back-and-forth process by which critical information about end-of-life care wishes is obtained, stored, accessed, and reviewed with patients and families throughout the care continuum.

Steward reliably patients' end-of-life care information.

It is critical to the overall reliability and integrity of the advance care planning process to consistently capture, store, and maintain information about patients' expressed end-of-life care wishes, and then to retrieve that information in order to provide care in accordance with those wishes when the time comes. *The presence and quality of information that can be Stewarded depends on the effectiveness and reliability of the way in which patients and families are Engaged. This connection and feedback repeat throughout the duration of a clinician-and-patient relationship.*



Respect people's wishes for care at the end of life by partnering to develop a patient-centered plan of care.

The four previous principles all lead to the fifth and most important: *Respect* for what matters most to each individual at the end of life. Respectful end-of-life care is concordant with patients' stated goals, values, and preferences for what matters most to them at the end of life.

Four Patient Cases



CASE 1

Mr. Lynch

- Diagnosis of dementia
- Declining decision-making capacity
- Tension between family members

[LEARN MORE](#)


CASE 2

Mrs. Jones

- Diagnosis of ovarian cancer
- Strong religious faith
- Frustrations with navigating the health care system

[LEARN MORE](#)


CASE 3

Mr. Mendez

- Diagnosis of COPD
- Limited social supports
- Strong religious faith

[LEARN MORE](#)


CASE 4

Mrs. Nguyen

- Sudden cardiac event
- Unable to speak for herself and end-of-life care wishes unknown
- Need for language interpretation

[LEARN MORE](#)



CASE 1

Mr. Lynch

MEDICAL DIAGNOSIS/HISTORY

- Diagnosis of dementia
- Declining decision-making capacity
- Tension between family members

BACKGROUND

Mr. Lynch is an 85-year-old man with a medical history of mild hypertension, well-controlled hypothyroidism, and Alzheimer's disease diagnosed two years ago.

He has a daughter and a son. He married his wife of 60 years when they were both 18 years old. She died seven years ago from heart failure. In her final years of life, he served as her caregiver at home, managing her appointments and care.

He lived alone after her death until two years ago, when he was diagnosed with Alzheimer's disease and moved in with his daughter. His daughter had noticed that he was having increasing difficulty balancing his checkbook and remembering details about household management. She alerted the nurse that he was the cause of a recent minor car accident, but thankfully was willing to surrender his keys.

Phase One

Mr. Lynch is now living with his daughter, Susan. He comes to you, his primary care physician (PCP), for a routine visit. Based on your prior interactions with him, you anticipate he will be able to participate in the conversation but will get confused when talking about his medications and recent events. You want to start a conversation with him and his daughter about advance care planning.

Key Considerations

- Be clear with yourself about why you, as Mr. Lynch's PCP, want to talk about advance care planning with him and his daughter at this stage. First and foremost, your intent is to identify who will speak for Mr. Lynch when he loses the capacity to make medical decisions for himself (an anticipated outcome of progressive dementia).
- Take a look at the [*Conversation Starter Kit for Families and Loved Ones of People with Alzheimer's Disease or Other Forms of Dementia*](#). How might you introduce the topic and the Starter Kit during your conversation with Mr. Lynch and his daughter?



EXEMPLIFY/CONNECT

Reflection Questions for Clinicians

- Has a family member or someone close to you had Alzheimer's disease or another form of dementia? What was most challenging about that, both emotionally and from a communication standpoint, for you? For your family?
- How might your own experiences affect how you interact with this patient?
- What do you worry about most when connecting with someone with cognitive decline?
- How might Mr. Lynch's past experiences, both with his own health care and as a caregiver to his wife, affect his experience of care now?



ENGAGE

Conversation Starters

Primary Care Physician

Please tell me about the people who give you support, Mr. Lynch.

Mr. Lynch

My daughter is a big help to me. She helps me get things done. I have two adorable grandchildren. They light up my life. I have a son, too. He has a very important job and lives far away. Thank goodness for my Susie.

Primary Care Physician

How would you describe your quality of life?

Mr. Lynch

Um. Quality of life?

Primary Care Physician

Oh, I'm sorry. I mean how are things going for you at home these days?

Mr. Lynch

It's okay. Not as good as it used to be. My wife and I used to travel and go out to eat and go dancing. Can't do that anymore. But things change. You can't do all the things you did. I get a little confused sometimes.

Primary Care Physician

What worries you most about when you get confused?



STEWARD

Considerations for Clinicians

- Mr. Lynch stated some important preferences about his end-of-life care based on his past life experience and his glimpses of his disease process. He trusts and relies on his daughter, hopes not to suffer at the end of his life, and draws comfort from the close presence of family.
- Although the conversation was quite brief, it is important to reliably document these preferences in a way that allows them to be accessed at future points of care. Locations and systems vary greatly in the physical and virtual documentation realms across health care organizations. How can you start to work with colleagues on how best to do this in your setting?

Mr. Lynch

I do my best not to worry. I know that Susie will take care of things. She is a good girl. When my love died, Susie took care of everything. I hope things can be easy, because when it's your time, it's your time. Not much you can do about it. My wife suffered and that does not need to happen.

Primary Care Physician

Thank you for sharing that with me, Mr. Lynch. It is helpful for me to know what worries you and what is important to you. One thing that worries me is that there might be times when your confusion makes it hard for you to make medical decisions, and I want to make sure that we are able to talk with the people you would want us to.

Mr. Lynch

I know Susie will take care of things. She's my girl.

Additional Considerations

- This is a great opportunity to share The Conversation Project's [Conversation Starter Kit](#) or [Conversation Starter Kit for Families and Loved Ones of People with Alzheimer's Disease or Other Forms of Dementia](#) with Mr. Lynch and his daughter.
- Mr. Lynch leans heavily on his daughter, and this might make Susan a natural surrogate medical decision maker. Have they already had this conversation and agreed that Susan will serve as his proxy? Have they filled out health care proxy forms?
- If so, are there other members of the family who need to be involved or made aware that Mr. Lynch's daughter will be his proxy?
- While Mr. Lynch has not expressly stated his wishes regarding specific medical decisions, such as resuscitation, he has stated a few preferences that can help inform such conversations in the months and years ahead. It will be important for you to continue to learn about what matters most to him so that you have as complete a picture as possible by the time it becomes necessary to make care decisions.

CASE 1**Mr. Lynch****Phase Two**

At his last medical visit, Mr. Lynch expressed interest that his daughter, Susan, be his surrogate medical decision maker. As he and his daughter spoke, it became clear that Mr. Lynch would not want aggressive medical treatment when his health begins to decline. He filled out a form naming his daughter as his health care proxy. His daughter noted that her brother travels a lot for work, lives abroad, and prefers to leave all these tasks to her.

Mr. Lynch lives with his daughter for another four years, but his Alzheimer's disease has progressed, and his daughter needs to act as his surrogate decision maker. He becomes incontinent and is primarily chair- or bed-bound. He only speaks a few words and has lost approximately 20 pounds in the past year.

One day, Susan notices that he is starting to have difficulty swallowing his food; the following week, he spikes a fever and has difficulty breathing. She brings Mr. Lynch to the hospital, where he is diagnosed with aspiration pneumonia. His son, Jason, an executive businessperson who lives abroad and has not visited his father for two years, arrives and is shocked by his father's appearance. Jason pulls you, Mr. Lynch's PCP, aside and says he is worried that his sister has been neglecting their father and not feeding him enough. The son demands that his father have a feeding tube.

Key Considerations

- How can you use your knowledge of Mr. Lynch's preferences to inform your sense of what kind of care he would want at this point?
- How can you help manage the conflict in this family about Mr. Lynch's care?
- What is Mr. Lynch's prognosis?
- Is there anyone else on the care team who could be helpful in navigating these issues?



EXEMPLIFY/CONNECT

Reflection Questions for Clinicians

- Issues related to feeding and hydration can affect us as clinicians very deeply, based on our perspectives and experiences. How might your own experiences and relationships with loved ones affect how you interact with Mr. Lynch and his family?
- How are you affected by the family's perspectives? Do you feel yourself taking sides with either Susan or Jason, Mr. Lynch's adult children? If so, how does that affect how you care for Mr. Lynch?
- Have you identified your own health care proxy, or helped to identify one for a family member? If you have, has doing so helped you empathize with Mr. Lynch and his family?



ENGAGE

Conversation Starters

Primary Care Physician

Perhaps we could start by talking about how your father is doing. What is your understanding of your father's medical situation?

Susan

Dad has had Alzheimer's for a while now and I can see him failing. He is sleeping more, eating less, and overall doing poorly. He rarely knows who I am.

Jason

We don't want him to starve to death. Fine, he has Alzheimer's, but he still needs to eat. Can't we just get him over this bump in the road, treat the pneumonia, and try to build up his strength? I was reading about feeding tubes on the plane on the way here.

Susan

You just have no idea what it is like day to day, Jason.

Jason

You're right! I don't! But you can tell me.

Susan

I try, but I'm not sure you really understand how hard it is.

Primary Care Physician

I am grateful that you are both here to be able to have this conversation. What is your understanding about what your father would want in this situation?

Susan

When our mother was sick, Dad was her decision maker. He made choices to help make sure she was comfortable. He used to say that sometimes we can live too long. Now he has just been sitting and staring for a long time. He doesn't even smile at my kids anymore.



Other Conversation Starter Options

- "I'm concerned about your father. Even if he makes it through this pneumonia, his dementia will keep getting worse, and I think it may just be a matter of time before the next pneumonia."
- "Can you please share what you are taking away from what we've discussed? What questions do you have?"
- "How are you feeling about what I just said?"
- "I'm worried that your father may be getting closer to the end of his life."
- "When your father was healthier, he mentioned wanting to focus on comfort when he is at the end of his life. I think we are approaching the end of his life now."



STEWARD

Considerations for Clinicians

- As Mr. Lynch's condition continues to deteriorate, it will be important to easily access documents such as his health care proxy and previously documented conversations about his end-of-life care goals. Does your organization have processes in place for you to be able to access these documents when needed?
- Depending on the outcome of this conversation with Susan and Jason about how best to care for Mr. Lynch, he might transition from the hospital back home, or to a nursing home, or to a hospice facility. Are processes in place to ensure that Mr. Lynch's documented care preferences are proactively communicated to clinicians in the next care setting?

Jason

I didn't know. We never talked about this.

Susan

Right. Because you weren't here.

Jason

I am here now.

Susan

And right now, Dad needs us to pay attention to what is going on.

Jason

Right, Susie. And we are not going to starve Dad.

Primary Care Physician

I imagine it feels terrible to think that your father is starving. What we are seeing is the natural, expected progression of this devastating illness. As people approach the end of their lives, it is common for them to not feel hunger and not want food. I think that is what we're seeing with your father.

Whenever your father and I talked, he spoke about valuing being active and interacting with family. Sadly, in the face of this progressive disease, we are not going to be able to bring him back to that point. Based on my prior conversations with your dad about his preferences, and what he wrote down, I believe that in this situation, he would want us to focus on his comfort.

Unfortunately, a feeding tube would not help with his comfort, and research has shown that feeding tubes don't even extend life for people with advanced dementia. For now, I recommend we follow your father's lead. If he wants food, I would recommend we carefully give him small amounts of food by mouth, but if he doesn't want it that's okay, too.

Epilogue

Mr. Lynch did not have a feeding tube placed. He had a brief stay in a subacute rehabilitation unit and then transferred to his daughter's home on hospice services with some private caregivers paid for by his son. Mr. Lynch's son, Jason, continued to feel challenged by concerns that they were starving his father, and Jason received a lot of support from the hospice social worker during this time. Jason returned to his home abroad, came back two days before Mr. Lynch died, and stayed through the funeral. Jason and Susan are trying to mend their relationship while dealing with their father's estate issues.

- It might have been helpful to be aware of the son's perspectives earlier on, so that his concerns might have been better addressed. Consider whether your organization has processes in place to evaluate family systems and document the dynamics as they relate to medical decision making.
- Does this case recall similar experiences you have had with other patients and families? How do you manage situations like this in your care setting?
- How can we as clinicians be sure to lift our eyes up from the daily management of symptoms, lab work, and procedures to see when a patient is dying and help them and their family to see the transition?



CASE 2

Mrs. Jones

MEDICAL DIAGNOSIS/HISTORY

- Diagnosis of ovarian cancer
- Strong religious faith
- Frustrations with navigating the health care system

BACKGROUND

Mrs. Jones is a 64-year-old woman. For years, she has had regular appointments with her primary care physician (PCP), with whom she has a very good relationship. Many of her friends and family members have not been as fortunate with their health care experiences and have told her disturbing stories about the implicit and explicit racism they have experienced, especially when visiting the nearby large tertiary care hospital.

Mrs. Jones develops abdominal bloating and swelling in her legs. She undergoes an ultrasound, which shows large masses on both ovaries — a possible indication of ovarian cancer. Her PCP refers her for evaluation to a gynecologic oncologist at the tertiary care hospital.

Phase One

When Mrs. Jones arrives at the hospital with her husband, she is seen initially by a medical assistant. She is then seen by a nurse, who takes her history and vitals and asks her to fill out some paperwork. You are her new oncologist, and you are seeking to gather more information and talk with Mrs. Jones about treatment options. As you enter the exam room, she appears tearful and frustrated. She is upset that she has had to repeat the same story two times already and suspects she will need to do so yet again with you. She says she feels overwhelmed.

Key Considerations

- How might you begin to build trust with Mrs. Jones?
How can you build on that trust in future interactions?
- How might the ways you approach your interactions with this patient need to be different from your approach with other patients?



EXEMPLIFY/CONNECT

Reflection Questions for Clinicians

- How might Mrs. Jones' friends' and family's past experiences with health care affect her experience of care now?
- How might your own experiences affect how you interact with this patient? If you, like Mrs. Jones, have friends and loved ones who have experienced racism and/or other forms of discrimination in health care, how might this affect your understanding of her experience of care? If you do not, how might that impact your empathy with her experience of care?
- How can you keep the need to build trust top of mind in your interactions with Mrs. Jones?



ENGAGE

Conversation Starters

Oncologist

Mrs. Jones, I know you've had to describe what's been going on a few times already and that's really frustrating. I'm sorry. I know you've already seen your own doctor. What do you understand about what she shared with you about your condition?

Mrs. Jones

My doctor told me I might have cancer, and I'm here to figure out from you what we do about it. As I already told the other people, I noticed swelling in my belly. I went to an urgent care down the street that is run by this hospital, and they told me it was just gas. They didn't even do any tests. Then I went to my PCP when it didn't get better and she ordered an ultrasound. She told me there were growths on my ovaries and that it was likely cancer. That is what I am here to figure out.

Oncologist

I'm so sorry to hear you had that experience. I can understand how that might make it hard for you to trust what health care professionals tell you.

Mrs. Jones

It is important to me that my doctors listen to me. Many times, they just don't listen. Now I'm dealing with this and wondering if it is cancer.

Oncologist

I want to help answer your questions. From this point on in your journey, I am going to be here with you every step of the way. Can I ask, what worries you most right now?



STEWARD

Considerations for Clinicians

- Mrs. Jones is clear that she wants her husband to be her surrogate medical decision maker. This might be a good time for her to fill out a health care proxy form if she hasn't already. If you are concerned that you might need to build more trust before suggesting she fill out the form, flag this issue for the next visit. What processes does your hospital have in place to ensure this happens reliably? Do you have a way of accessing proxy forms that she may have already filled out?
- Mrs. Jones is worried about fragmented care and is frustrated that she has had to repeat her story so many times. Does your organization have processes in place to ensure the conversations you have today are documented and carried over into the next visit in a readily accessible way? Does your organization have processes to ensure that the next care team reviews such notes before they see her?

Mrs. Jones

I am worried it might be cancer, and worried about what's coming next. I know what cancer means — it means radiation, chemotherapy, losing your hair. All of that scares me. And I certainly do not want to die.

Oncologist

I really appreciate that you are letting me know what is on your mind. We can talk today about what we know so far and what we need to do moving forward. I am worried this could be cancer, but we will need to do more tests to be sure. This can all be really frightening, and it can be important to have support. Can you please tell me more about who you have in your life for support?

Mrs. Jones

Well, my husband Michael is my main support. He has always been right here at my side. We have three children. Two of them live just a couple blocks from me and I see them quite a bit. One is out of state on a military base. They are worried about all of this, as you might imagine.

I also have a lot of church friends who have always been very supportive. We lean on each other when we need it. They're already bringing over food, even though I tell them I'm perfectly fine and able to cook, and they have me in some prayer circles.

Oncologist

It sounds like you have a lot of support in your life. Mrs. Jones, right now you are able to communicate your wishes and make your own decisions about your care. But if there ever comes a time in the future when you are unable to speak for yourself, who would you want making decisions about your care on your behalf?

Mrs. Jones

My husband Michael. He knows everything that is going on with me and he would be the best one to ask.

Additional Considerations

Mrs. Jones is frustrated with having to repeat her story over and over. Use the technique of naming what is happening in the situation: “You’ve had to describe what’s been going on a few times already and that’s really frustrating. I’m sorry.” Observe the emotion; provide silence, space, and time for the emotion to come out; and then respond to it.

CASE 2

Mrs. Jones



Phase Two

Mrs. Jones underwent surgery for the ovarian masses, and pathology from that surgery was diagnostic for ovarian cancer. She undergoes treatment for her cancer and does well with no evidence of disease on her CT scans for two years. Two years after her treatment is completed, she develops severe abdominal pain and imaging reveals recurrence of her cancer, now with liver involvement. As her oncologist, you want to discuss the incurability of the cancer and, in this context, you want to understand her goals and values for end-of-life care and how those inform her treatment options.

Key Considerations

- How can you affirm Mrs. Jones’ selection of her husband as her health care proxy?
- How can you raise the topic of referring Mrs. Jones to palliative care, especially as she might be afraid at this point?
- How can you discuss Mrs. Jones’ prognosis in a kind and honest way?



EXEMPLIFY/CONNECT

Reflection Questions for Clinicians

- How might Mrs. Jones' past experiences with health care affect her experience of care now?
- The first time you met Mrs. Jones, she indicated she has a strong connection to her church. Are there ways to explore how her religion might relate to her decision making moving forward?
- How does your own spirituality affect how you respond to Mrs. Jones' statements?



ENGAGE

Conversation Starters

Oncologist

Mrs. Jones, I am hoping we can talk about where things stand with your cancer. Unfortunately, when cancer comes back like it did with you, it is, sadly, no longer curable. However, it is still treatable.

Mrs. Jones

I had hoped I would have more time. When you first told me that I had cancer, you said there was a decent chance it would come back, but I was hopeful I would have more time. My youngest granddaughter is only three. I want to be around as long as possible for her.

Oncologist

I also want you to be around as long as possible. Even though we can't cure your cancer, we can talk about options to shrink your cancer, with the goal of helping you live longer and feeling the best that you can. I know you have significant pain, and I want to do everything I can to help with that. I would like to refer you to palliative care; they are experts in pain and symptom management. Have you heard of palliative care?

Mrs. Jones

Isn't that like hospice? I know the cancer is back, but is it really that bad? I want whatever treatment you have to buy me as much time as possible.

Oncologist

Actually, palliative care is different from hospice. Palliative care focuses on treating symptoms for people with a serious illness, like your cancer. These symptoms might include pain and nausea. Palliative care is not just for people at the end of life. We know that when people feel better, they do better. Helping your pain will help you feel well enough to be able to do more with your grandchildren.



STEWARD

Considerations for Clinicians

- Mrs. Jones is stating she would want to be at the hospital at the end of her life. Do you have ways to document and share this information? Does your organization have processes in place to be able to access these documents when needed?
- Mrs. Jones is clearly articulating the power of her faith in her life. How can you document this and incorporate it into her care if she wishes?

Mrs. Jones

Well, okay then. I would like to have my pain better managed.

Oncologist

Mrs. Jones, at a previous visit, you told me that your husband would be your health care proxy if you weren't able to make decisions for yourself at any point. You signed a form indicating him as your proxy and we have that on file with your medical record. Are there any changes you would like to make to your proxy at this time?

Mrs. Jones

No, there are no changes to my proxy. I still want my husband Michael to make decisions for me if I'm not able to do that for myself.

Oncologist

Have you ever spoken with your husband about the type of care that you would want if you got really sick?

Mrs. Jones

It's not something I like to think about. I want to be here for Michael, the kids, and the grandkids. I have a strong faith and will continue to pray on this. Life is precious, and it would be a sin to throw it away. I want to fight and get all treatment as long as I can to live every day that is given to me. It is important to me to be at the hospital if things are bad so that every option is available.

Additional Considerations

It isn't clear if Mrs. Jones has spoken with her husband about what matters most to her, and as a result, she may benefit from some deeper exploration about what her wishes would be at the end of her life in different areas of care — the amount of information she would like her doctors to share, the people she would like to be included in these conversations, how much intervention she wants, etc. Having such conversations can also help her husband if he needs to get involved in making decisions on her behalf. This is an opportunity to introduce The Conversation Project's [Conversation Starter Kit](#).

CASE 2

Mrs. Jones



Phase Three

Mrs. Jones undergoes treatment with two lines of chemotherapy with some benefit; however, her disease continues to progress. She comes in to see you and reports that she has minimal appetite and has lost 30 pounds over the past six months. She has constant nausea due to the cancer and treatment, and she is requiring increasing doses of pain medications. She has had numerous admissions to the hospital due to pain and nausea. As her oncologist, you feel that further chemotherapy would be harmful and not beneficial to her.

Key Considerations

- How will you discuss Mrs. Jones' understanding of her illness at this point?
- How will you assess whether Mrs. Jones' goals, values, or preferences for care at the end of life may have shifted given her challenging experiences with chemotherapy?
- If what matters most to Mrs. Jones has shifted, how will you approach the idea of a referral to hospice?
- If what matters most to Mrs. Jones has stayed the same, how will you approach her choice to continue to be cared for in the hospital?
- Mrs. Jones might feel that hospice means either that her oncologist is giving up on her or she is giving up on herself. What are some ways to manage these perceptions?
- How will you make clear to Mrs. Jones how important it is to you to maintain the relationship between the two of you throughout the full trajectory of her disease?



EXEMPLIFY/CONNECT

Reflection Questions for Clinicians

- If Mrs. Jones states that she wants “aggressive” disease-modifying care as she approaches the end of her life, how will you feel about this?
- How do your feelings affect how you care for her?
- Some of us have strong beliefs about what we consider a “good death.” Some people think it is important to “fight to the end,” while others would prefer to be at home with a focus on quality over quantity. How do your own beliefs influence how you see Mrs. Jones and the choices she faces?



ENGAGE

Conversation Starters

Oncologist

I know you have been in and out of the hospital quite a bit lately. How do you feel you are doing?

Mrs. Jones

I am not doing well. I am sick a lot of the time and in bed too much. I have no appetite. I know Michael wants me to eat, but food just makes me sick.

Oncologist

What is your understanding of where things are with your cancer at this point?

Mrs. Jones

Well, I know you can't cure it. I know I will always have the cancer. I think that if I could just eat and get my strength up, I would be doing better. It scares me, feeling this poorly. I am scared about what this all means. My friends pray with me and that gives me tremendous comfort. We pray for a miracle so that I can see my grandchildren grow up.

Oncologist

I'm glad to know that you feel comforted by your friends and your faith. As you pray for that miracle, I want to make sure that I am here with you to address your symptoms. I am worried that giving you more chemotherapy will cause more harm than good and make you feel weaker instead of stronger.

Mrs. Jones

I agree that I can't start another chemo now. I am too weak — that last one you gave me really knocked me out. I would like to take some time to try and get stronger. I am hopeful that if I take a break from chemo, I could get stronger and maybe get more treatment down the line.



STEWARD

Considerations for Clinicians

- Do you have a process in place to document Mrs. Jones' wishes for end-of-life care now, and update them if they change in the future?
- In this conversation, you laid the groundwork for future conversations about Mrs. Jones' goals, knowing that her clinical condition can change. Ensuring that your medical record has a way to track these ongoing conversations is important.

Oncologist

Okay, I'd like to suggest that we focus for now on treating your pain and nausea, helping you feel as comfortable as possible, making the most of every day. What do you think about that?

Mrs. Jones

That sounds okay for now, but I definitely want to continue treatment. I am not ready to give up. I want to get whatever treatment is available. I am a fighter and I will not let this cancer beat me. We can take a break from chemo for now, but I want to keep fighting. I want my kids and grandkids to know that I did everything in my power to spend as much time with them as possible.

Oncologist

I am hoping you will be getting stronger, but I worry that you may not be able to get strong enough for more treatment. What is in our power right now is to focus on the pain and nausea to help improve your time with your family. We can see how you do, but the best option might be to focus on treating your symptoms and on what matters most to you like having time with your grandchildren. No matter what happens, I will be there to support you every step of the way.

Epilogue

Mrs. Jones clearly stated her wishes to continue treatment if at all possible. Mrs. Jones died two weeks later during a hospitalization.

Although there were many conversations among Mr. and Mrs. Jones and her care team about transferring her home on hospice, her husband continued to advocate for her wish to remain in the hospital and continue treatment when she was not able to speak for herself. He and their family received support from the chaplaincy and palliative care team throughout her stay and had many visitors from their church.



CASE 3

Mr. Mendez

MEDICAL DIAGNOSIS/HISTORY

- Diagnosis of COPD
- Limited social supports
- Strong religious faith

BACKGROUND

Mr. Mendez is a 79-year-old man with hypertension, hyperlipidemia, mild anxiety, a history of smoking, and recently diagnosed chronic obstructive pulmonary disease (COPD).

He lives alone in an apartment and is close with his neighbor, Lucy, and friends from his nearby Catholic church, where he attends Mass a few times each week. He lives independently and never married. He does not have children and is a retired postal carrier. He was very close to his brother, who died of cancer three years ago.

Phase One

Mr. Mendez comes to your primary care office for his routine check-up for hypertension. He recently stopped smoking after he was diagnosed with emphysema and COPD. As the nurse care manager in his PCP's office, you want to start a conversation with him about his end-of-life care goals and preferences.

Key Considerations

- How do you start conversations about end-of-life care with patients who do not have a serious illness?
- What processes does your primary care office have in place to document these conversations?
- How can you use tools such as the [Conversation Starter Kit](#) in this situation?



EXEMPLIFY/CONNECT

Reflection Questions for Clinicians

- How might having limited social supports affect Mr. Mendez? How might your approach to talking with this patient about his end-of-life care preferences need to be different from your approach with other patients?
- How might Mr. Mendez's past experiences with health care, including his brother's death, affect his experience of care now?
- How might you explore how this patient's faith might intersect with his medical decision making?
- How might your own experiences affect how you interact with this patient?



ENGAGE

Conversation Starters

Nurse Care Manager

Can you tell me about the people who give you support in your life, Mr. Mendez?

Mr. Mendez

My friend Lucy is good to me. She lives next door and we have been friends for 20 years. I live alone and I don't have family anymore. I have nice friends from my church. If I ever needed a meal or someone to help me with things around the house, I know that they would be there.

Nurse Care Manager

If you were too sick to make medical decisions for yourself, who would you want to speak for you?

Mr. Mendez

I don't know. My brother Bob died three years ago, and he was my last relative. Lucy is very helpful, but I think that would be too much to ask. I know that God will help me know what to do if that time comes.

Nurse Care Manager

Can you please tell me more about the kind of care you'd want if you got really sick someday?



STEWARD

Considerations for Clinicians

- It is important that if Mr. Mendez eventually fills out the health care proxy form, the person he chooses to be his proxy is aware of his choice, as well as any key medical providers. Ideally, your office is able to scan the proxy form into the electronic health record and update it as needed so that it is accessible and up to date for all relevant providers to access.
- In addition to encouraging Mr. Mendez to fill out the health care proxy form, note that he has shared key information about his hopes and fears at the end of life. It is important for you to document his reflections on his brother's death and how that influenced his own wishes, along with the importance of his religious beliefs. Does your organization have a process in place to document such information and make sure it is accessible?

Mr. Mendez

My brother died of cancer. He lived here in town. I'd never had to care for someone who was sick before because my mother took care of my father and my mother died suddenly. Caring for Bob was difficult at times, although of course I was blessed to have that time with him.

He was in the hospital at the end and having trouble swallowing. He kept asking me for a drink of soda, but I didn't give it to him because I was so afraid he might get pneumonia. But he got pneumonia anyway and needed a breathing machine. When the doctors recommended we take him off the machine, it felt like we were killing him. When it is my time to go, I trust that God will guide the doctors.

Nurse Care Manager

It seems like you have thought about this quite a bit. It might be helpful to think about who could speak for you if you couldn't speak for yourself. May I offer you some tools to start thinking about this, so we can talk about it again at a future appointment?

Additional Considerations

- Mr. Mendez seems hesitant to ask his friend and neighbor, Lucy, to be his health care proxy and is concerned about burdening her. With Mr. Mendez's new diagnoses, you might be concerned that a health crisis could leave him without a surrogate medical decision maker.

At a future office visit you might say, "Mr. Mendez, it sounds like your friendship with Lucy is very important to you and that you are both very good to each other. I am concerned that if you had a health crisis and could not speak for yourself, Lucy would not be in a position to help us understand what matters most to you, even though she might be the one who would know best. May I share with you a helpful brochure so that we can talk about this more at your next appointment?"

- The Conversation Project's Proxy Kit — [*How to Choose a Health Care Proxy and How to Be a Health Care Proxy*](#) — could be helpful in having that conversation.
- Mr. Mendez's faith is clearly very important to him. It is important to discuss this with him and to further understand the ways his faith intersects with his decision making around end-of-life care. If you have access to spiritual care colleagues, they could be helpful here.

CASE 3**Mr. Mendez****Phase Two**

After that routine check-up visit, Mr. Mendez did well for a few years. Then at age 84, he developed a COPD exacerbation, which turned into a pneumonia with significant shortness of breath. He was admitted to the hospital and required an intensive care unit (ICU) stay. He became delirious and unable to communicate with the health care team.

His friend and neighbor, Lucy, arrived at the bedside but could not be given updates about Mr. Mendez's condition (because he had not named her as his health care proxy) even though she clearly wanted to be helpful. Lucy expressed that she was willing to be helpful in whatever way would be useful as her friend's health worsened. Lucy mentioned that Mr. Mendez's strong religious beliefs influenced his decisions about his care, and noted they were different from her own beliefs. She also knew that feeling short of breath was frightening to him. Mr. Mendez did not require intubation and ultimately recovered and returned home.

As the nurse care manager in his PCP's office, you are aware of his recent hospitalization and want to talk to him about it, with the goal of understanding more about how his experience might influence what matters to him at the end of life.

Key Considerations

- How do you start conversations about end-of-life care goals after a medical emergency has resolved?
- How do you know who the surrogate medical decision maker is for patients who are unable to make decisions for themselves?
- How do you build upon the last conversation you had and clarify who the surrogate decision maker should be?
- Now that Mr. Mendez has a new sense of what can happen with his illness, what are his wishes regarding a health care proxy and care at the end of life?



EXEMPLIFY/CONNECT

Reflection Questions for Clinicians

- How might this patient's past experiences with health care — including the care of his brother — affect his experience of care now?
- Do your own experiences with death in your family or with other loved ones affect how you feel about his decisions?
- Mr. Mendez referred to his faith in God during your prior discussion. How do you navigate these conversations if a patient's spirituality or religion is different from your own? How can you learn more about how spiritual traditions influence patients' preferences at the end of life? What are the advantages and risks if his beliefs or traditions are similar to yours?



ENGAGE

Conversation Starters

Nurse Care Manager

Can you tell me your understanding of what happened in the hospital?

Mr. Mendez

I don't remember a whole lot of it, but I know that in the days leading up to going into the hospital, I was getting more and more short of breath. When I got there, they told me it was pneumonia, and of course my lungs are not as good as they should be. I don't remember the details, but I know they had some kind of oxygen mask on me, and the doctors were worried.

Of course, I was thinking that this is what happened to my brother in his last days and I wondered if I was going to recover. There were times that I felt like I couldn't breathe, which was terrifying. It felt like things were happening all around me that I wasn't really aware of and I couldn't control.

Nurse Care Manager

How are you doing now?

Mr. Mendez

I'm not back to myself yet. My breathing is still rough. Honestly, I feel a bit weak and scared. Not being able to breathe is a terrible feeling.

Nurse Care Manager

I am so sorry you went through that. You are right, not being able to breathe can be a really horrible feeling. I am worried that you might get sick like this again. If that were to happen, the medical team might consider putting you on the breathing machine. How would you feel about that?



Other Conversation Starter Options

- "We're all hoping things go well, but, as you've experienced, that doesn't always happen. At your next medical appointment, would it be okay to talk about a plan in case things don't go the way we'd like?"
- "Is there anyone else that you would like to include in this conversation? If so, could we have them join us during that appointment, or include them on speakerphone or using video chat?"
- "You have told me how important your church community is to you. Have you thought about sharing your experience with your parish priest or pastoral associate?"

Mr. Mendez

You know, I have been thinking about this quite a bit. The doctors said that my lungs were getting pretty far along with the COPD, and one of them mentioned in the hospital that if they put me on a breathing machine, they might not ever be able to get me off.

Of course, I want to get better, and if going on a machine would help, great. But if I were dying, I wouldn't want those machines. I went through that with my brother and it was really hard. I hope that God just takes me when it is time.

Nurse Care Manager

I am grateful to you for letting me know what it was like to see your brother struggle. If you get sick again, it's important to me that we are certain we're respecting your wishes. It sounds like you do not want to be stuck on a machine, but that you also worry about what it feels like to be short of breath.

There are medications, such as morphine, that we can use to help with feeling short of breath if you were at the end of your life. By using these medications, we could keep you comfortable without putting you through something like what your brother went through.

Can we also please talk again about appointing a health care proxy? That is the form we talked about that makes it possible for you to choose a person who would speak for you to make medical decisions if you could not speak for yourself.

I know you were a little hesitant to ask Lucy, but the hospital doctor said that she is willing to help in this way. It is my sense that Lucy would be a strong advocate for you if you could not speak for yourself.



STEWARD

Considerations for Clinicians

- It is important to go beyond the documents and ensure that Mr. Mendez's friend Lucy has heard him say what his wishes are. Sometimes a discussion with a member of the health care team present can help those conversations go more smoothly.
- What if Mr. Mendez gets sick and comes into the office next week to see another member of the primary care team? It is important to document this conversation so that other care team members can be aware of his wishes and pick up where you left off, as needed. Does your organization have a process in place to document and store information about end-of-life care wishes for all patients? Do you have colleagues interested in working with you to make sure reliable systems are in place? Do you and your colleagues have a system for reviewing such information prior to speaking with patients?
- What if Mr. Mendez presents to another setting in a medical crisis? How would those clinicians know about these conversations?

Mr. Mendez

I remember that we talked about that. I still worry that it is too much to ask of Lucy. But I would do it for her, and she looked at the brochure you gave me. She said we could do it together and name each other. Lucy is a widow. She has an older sister, but her sister has dementia, so Lucy doesn't think her sister could be of help to her. We lean on each other.

Nurse Care Manager

It sounds like Lucy really wants to be of help to you. Can we talk more about how to finish the health care proxy process and how to make sure Lucy has the gift of understanding what matters to you?

Mr. Mendez

Yes, I understand that you all need to know who you can call, so Lucy and I will sign the forms for each other. She knows that I want to pray about what is the right thing to do, but I know I won't live forever. I don't want to struggle to breathe like Bob did. I will talk with her when I get home.

Additional Considerations

- Given what Mr. Mendez shared during your discussion, it sounds like he might prefer to undergo resuscitation if he were to become sicker, but not continue those measures over the long term if he doesn't start to improve or if his health declines further.
- It is important to reconfirm with Mr. Mendez your understanding of his wishes and then clearly document this information. Often such a care preference is called a "limited trial of life-sustaining treatment," which means that as long as there is a reasonable hope for a meaningful recovery, treatments continue to see if things will get better. But when there isn't a reasonable hope, or the treatments don't work after a reasonable trial period, then the life-sustaining treatments are limited or stopped.

CASE 3**Mr. Mendez****Phase Three**

Mr. Mendez did well for a few years after your last conversation. During that time, he had a couple of hospitalizations for less severe COPD exacerbations. At age 88, he was placed on home oxygen, and then about two months ago his illness seemed to worsen. He is no longer able to walk around the block, and now can only go to and from the bathroom before getting so short of breath that he must stop and rest. Mr. Mendez's friend Lucy is with him at today's office visit. As the nurse care manager, you are doing a joint visit with his PCP to discuss Mr. Mendez's care goals moving forward.

Key Considerations

- When "another hospitalization" becomes the norm, how do you ensure that the patient's goals are kept front and center?
- What treatment options do you believe align best with Mr. Mendez's goals and wishes for the end of life?
- How do you start a conversation about end-of-life care and decision making with Mr. Mendez at this stage of his illness?
- How do you introduce the option of hospice?



EXEMPLIFY/CONNECT

Reflection Questions for Clinicians

- How might Mr. Mendez's experiences around end-of-life care affect his thoughts about hospice?
- How do your experiences with end-of-life care affect your thoughts about hospice?
- Some of us have strong thoughts about interventions as we near the end of life. Some people think it is important to continue treatment for as long as possible, while others want to avoid prolonged use of "machines" if they may be unlikely to improve quality of life. How do your own thoughts and preferences about this influence how you see Mr. Mendez and his choices?



ENGAGE

Conversation Starters

Nurse Care Manager

You have been in and out of the hospital quite a bit. How has that been for you?

Mr. Mendez

It's exhausting. I feel like every time I'm getting a bit stronger and things might be getting a bit better, something else happens. It's like that old saying: one step forward and two steps back.

Lucy

He was in a bad way. I wasn't sure he was going to come back home.

Nurse Care Manager

That must have been so hard to see. Given everything that has happened, what are you hoping for now, Mr. Mendez?

Mr. Mendez

I see myself getting sicker and weaker, and I know I'm not going to live forever. There are some nice young families at my church expecting babies, but I don't know if I will meet them all. I would love to be able to stay out of the hospital for a few weeks and be able to be at home. I would say that I am definitely not going back into the hospital, but I don't want to suffocate. Not being able to breathe is the worst feeling. It scares me. I am trying to trust that God knows what is best for me, but I get pretty panicked when I feel short of breath.

Primary Care Physician

I am so sorry that you had that experience of feeling like you couldn't breathe. I think that there are some things we can do to help with how that feels, but unfortunately we don't have any additional treatments to make your lungs better.



STEWARD

Considerations for Clinicians

- It is important to document conversations about end-of-life care wishes so that members of the hospice team, other members of the primary care team, and any other health care providers that Mr. Mendez interacts with are clearly aware of his desires.
- It is ideal to have a way to store documents such as the health care proxy, a living will, and Physician Orders for Life-Sustaining Treatment (POLST) or Medical Orders for Life-Sustaining Treatment (MOLST) forms as part of Mr. Mendez's medical record. These documents provide key information about his wishes at the end of life, and those involved in his care should be aware of and have access to this information.
- If Mr. Mendez goes to the emergency department tonight, is there a process in place to ensure that his end-of-life care preferences are communicated to care providers and respected when the time comes?

Mr. Mendez

I know. They told me in the hospital that time is short. There isn't a lot more they can do for me.

Primary Care Physician

If you got sick again, one option would be for you to stay at home. We wouldn't be able to put you on a ventilator, but we could give you some oxygen and medication to treat your shortness of breath, as well as any other symptoms like pain. How would you feel about that?

Mr. Mendez

I would like to be able to stay at home, but I don't want to suffer, and I don't want to be gasping for breath. I know that there is not much more they can do for me in a hospital, and putting me on machines seems like it would just be prolonging the inevitable.

Nurse Care Manager

Given all that you just told us, hospice might make sense. Have you ever heard of hospice?

Mr. Mendez

I have. When my brother was dying from his cancer, they put him on hospice after they took out the breathing tube. They gave him lots of morphine and kept him comfortable and he passed on the next day. I know I am not doing well, but I'm not quite ready for that, am I?

Lucy

Do you remember how they tried to get my Aunt Jean on hospice, but it was too late?

Mr. Mendez

Oh, I forgot about that.

Primary Care Physician

I don't think you are dying in the next few days. Hospice is a program for people who are approaching the end of their lives, typically with a prognosis of around six months or less. Given everything that has happened recently, I think hospice might be a good option for you.

Hospice focuses all their care on making you comfortable and keeping you at home if that is your goal. If you had trouble breathing, they would give you oxygen and medication to help with the sensation of shortness of breath. It would not make your lungs get better, but it would make you feel better.

It would be a way to keep you at home, and the hospice team would support your friends and church community in caring for you. What are your thoughts about this?

Epilogue

Mr. Mendez died at home after four months of hospice care. He had some complex symptom management related to his breathing, but it was navigated at home and Lucy reported that he seemed comfortable at the time of his death. Mr. Mendez did get to meet some of the new babies in his church and he was frequently visited by his parish priests.



CASE 4

Mrs. Nguyen

MEDICAL DIAGNOSIS/HISTORY

- Sudden cardiac event
- Unable to speak for herself and end-of-life care wishes unknown
- Need for language interpretation

BACKGROUND

Mrs. Nguyen is a 42-year-old woman who recently suffered an out-of-hospital cardiac arrest and is now in the intensive care unit (ICU) on a mechanical ventilator. Mrs. Nguyen lives with her husband and has two sons, ages 12 and 14. She immigrated to the United States from Vietnam two years ago and speaks limited English.

Yesterday, she presented to the emergency department (ED) due to a funny feeling in her chest. Her husband was working, so she went to the ED with her 14-year-old son, who has been learning English at school. The medical team attempted to use the interpreter telephone line to understand what was going on; however, they could not get the connection to work. Since Mrs. Nguyen's son spoke some English, they asked him to help interpret. He explained that

his mother had a burning feeling in her chest that had been getting worse over the last couple of days. The ED medical team felt that the burning sensation was related to some spicy food that Mrs. Nguyen had eaten and sent her home with medication for heartburn.

While Mrs. Nguyen was in the bathroom getting ready the next morning, her husband heard a loud crash. He rushed in to find her unresponsive on the bathroom floor. He immediately called 911 and the ambulance arrived 8 minutes later. They found Mrs. Nguyen pulseless and performed CPR. After 10 minutes of advanced cardiac life support protocol, they were able to get her back in normal sinus rhythm. She was intubated in the field, then brought to the ED and admitted to the ICU.

CASE 4**Mrs. Nguyen****Phase One**

Workup revealed that Mrs. Nguyen had a serious heart attack, with evidence of anoxic brain injury. She remains intubated in the ICU for 10 days, fed through a nasogastric feeding tube. When examined, she withdraws from pain and opens her eyes but does not respond in any other way to her family or medical caregivers. Her husband, children, and other friends and family are frequently at her side. Over the 10 days, Mrs. Nguyen shows minimal improvement. As the social worker on the ICU team, you and the ICU physician want to talk about what has happened and Mrs. Nguyen's goals moving forward. You arrange for an in-person interpreter and a meeting with her husband. A previous social work assessment has already established that Mrs. Nguyen does not have an advance directive.

Key Considerations

- Remember to orient yourself to look at and speak with Mr. Nguyen during your conversations, rather than looking at or speaking with the interpreter.
- How do you help the family make decisions when Mrs. Nguyen's wishes are unknown?
- How do you align care with Mrs. Nguyen's goals when those goals are unknown?



EXEMPLIFY/CONNECT

Reflection Questions for Clinicians

- During her first ED visit, Mrs. Nguyen may have encountered bias that contributed to her misdiagnosis — in other words, the way health care professionals perceived her gender, ethnicity, and the language barrier may have influenced the quantity and quality of information solicited from her, and how they interpreted it. Have you experienced situations, personally or professionally, where you encountered racial, gender, language, or other forms of bias? How did those situations make you feel?
- When Mrs. Nguyen went to the ED, they could not get an interpreter and asked her son to translate. How do you think this affected her care? How do you think this affected her son?
- What did you think of Mrs. Nguyen's initial presentation and the decision to send her home with medication for heartburn? Do you think an English-speaking man with the same symptoms might have been diagnosed with heart disease earlier? How might the words her son used to describe her symptoms (doing his best with a language that was new to him) have affected the ED providers' understanding of her symptoms?



ENGAGE

Conversation Starters

ICU Social Worker

I know a lot has happened very quickly, Mr. Nguyen. How are you and your boys doing?

Mr. Nguyen (via interpreter)

I am still in shock. She was fine! She was very healthy, she ate healthy foods, and she took good care of herself. She had some difficulty adjusting to this country. Things are different here and she was not able to be as close to her family. I know that was hard. Our boys are very sad and scared.

ICU Social Worker

I am so sorry that you are all going through this. Could you please tell me your understanding of your wife's medical situation?

Mr. Nguyen

They tell me that her heart stopped. I don't understand it; she came into the hospital the day before, and they told her she was fine. They just told her that she needed some pills for her stomach. Now she is there with all these tubes coming out of her. I just don't know how this could happen.

ICU Physician

I understand you feel shocked and upset, Mr. Nguyen. Please tell me more about your wife. Before this happened, what was she like? What kinds of things did she like to do?

Mr. Nguyen

She is always moving around doing things. She spends a lot of time with our kids, making sure they go to school and study when they get home. She played the flute as a child and she makes sure the kids practice their music. She was taking English classes and spends time with her friends. She has always been full of energy. She makes everything work.



STEWARD

Considerations for Clinicians

- Mr. Nguyen is clearly describing the importance of family to his wife, and stating his wife's wishes to be at home and not in a long-term care facility. It is important to document this in the medical record.

ICU Physician

She sounds like an amazing woman. I wish I had the opportunity to meet her before all of this. I was hoping to speak with you a bit about what is going on with her medically. Is that okay?

Mr. Nguyen

Yes, I want to know what is happening.

ICU Physician

We are worried that there has been a lot of damage to her heart and brain. We are worried that this might affect her to the point that she might not wake up and might not be able to recognize you.

Mr. Nguyen

I see.

ICU Social Worker

This is a lot of information to try to take in, and I am so sorry this is happening. Your wife may end up needing a lot of care, including help with eating, bathing, and using the bathroom. I'm concerned that it might be difficult to provide this level of care at home. In such situations, we often recommend that patients be moved to a nursing home. How do you think she would feel about that?

Mr. Nguyen

No, she won't go to a nursing home. She will come home, and we will care for her there. I am there, our kids are there, and we have friends and family who could help. I would never send her to one of those places.

ICU Social Worker

Has she ever experienced the death of a loved one? How did she feel about their experience at end of life?

Mr. Nguyen

She has seen a lot of death in her life; we both have. But this is not death. She is still alive. Her parents died before we moved here, and she helped care for them every day.

Additional Considerations

- Mrs. Nguyen does not have an advance directive. In the absence of a health care proxy and other advance directives, how do you know who to talk to? Many states have regulations about who makes decisions for a patient if they are unable to do so themselves. What are the regulations in your state? How might understanding this process better help you talk with your patients about appointing a health care proxy when they are well?
- In-person interpreters can make a huge difference in conversations about medical decision making. Take advantage of using interpreters if you have the opportunity. It is suboptimal to use family members as interpreters, especially children, both because of the ways it may influence or impede communication and because of the emotional burden it can place on the family.

CASE 4

Mrs. Nguyen



Phase Two

Mrs. Nguyen undergoes a tracheostomy and feeding tube placement. Her family states that what is most important to her is having her family around. She becomes more alert over the next two weeks, to the point where she can track family members with her eyes and squeeze people's hands. She doesn't speak and is unable to eat; she can breathe for short periods of time off the ventilator. She is at a point where she is stable for a transition out of the hospital.

Key Considerations

- What would Mrs. Nguyen consider a good quality of life?
- What medical emergencies can you anticipate for Mrs. Nguyen, and how can you understand what would matter most to her in those situations?



EXEMPLIFY/CONNECT

Reflection Questions for Clinicians

- What is it like for you as a clinician when you cannot directly hear your patient's voice?
- You anticipate that Mr. Nguyen may still want to take Mrs. Nguyen home. Is your own perspective on what you would want for yourself in this same situation different from what Mr. Nguyen is sharing? How does that impact your interactions?
- Could there be cultural considerations affecting how you are communicating with Mr. Nguyen? Do you have resources to help you communicate more effectively?



STEWARD

Considerations for Clinicians

- Mr. Nguyen continues to want all possible measures taken to treat his wife. Do you have good ways to document this in the medical record? Does your organization have processes in place to update the conversations about end-of-life care goals over time? If Mrs. Nguyen needs to transition to another care setting, like long-term care, is there a process in place to ensure that her end-of-life care preferences are communicated to care providers in that setting?



ENGAGE

Conversation Starters

ICU Social Worker

Mr. Nguyen, how do you feel your wife is doing at this point?

Mr. Nguyen (via interpreter)

We see her getting better. Enough to give us hope. I am hopeful that she will continue to get better and wake up and talk with me and the children, but of course I will love her and care for her no matter what. What matters to her is being part of the family and being a mother. It will be important that we remain around her and she is able to be with our children.

ICU Social Worker

The doctors think she might need to spend years, if not the rest of her life, in a long-term care facility. How would she feel about that?

Mr. Nguyen

She is getting better here. We can see that. She squeezed my hand the other day. As long as they can help her get better, she should stay here in the hospital. If she is not getting better here, she should come home. We will care for her there.

ICU Physician

It might be helpful to take a moment to talk about what we would do if your wife got sicker. Would that be okay? For instance, if her heart were to suddenly stop, or if she developed a very serious infection?

Mr. Nguyen

What do you mean? We would give her medicine for an infection. And if she had heart problems, of course you should do everything you can to fix them. Part of the reason she is so sick is because it took the ambulance so long to come. I see her getting better and I know she would want you to do everything to help her get better. We want her with us as long as she is able to be.

Epilogue

Mrs. Nguyen was transitioned to a long-term acute care facility for two months. She improved enough to not require a ventilator, but was not able to walk or speak with her family. After two months, her family transitioned her home, where they provide care for her with the help of family and neighbors. Her husband continues to express that she would want all possible medical treatments.

What's Next?

We hope that this toolkit has given you opportunities for reflection, some practical guidance about how to start talking with patients about what matters most to them at the end of life, and some ideas about how to begin implementing these actions in your daily practice.

If you're considering making some changes, it's also important to consider how the five Conversation Ready principles (Exemplify, Connect, Engage, Steward, and Respect) might be integrated into the larger system in which you are working. We welcome your feedback about this toolkit at conversationproject@ihi.org.

The vision of a Conversation Ready health care organization is one that is ready to reliably guide all patients and their families through the advance care planning process and, in the context of serious illness, to ensure that their end-of-life care wishes are always respected.

More specific guidance for health care organizations seeking to integrate the Conversation Ready principles is presented in an IHI White Paper, which describes in detail the principles and specific ideas for implementing them, based on learning from more than six years of study and experience: [*"Conversation Ready": A Framework for Improving End-of-Life Care*](#).

Resources

The Conversation Project

theconversationproject.org

Website with free downloads of many of the tools mentioned in these cases, including:

- [*Conversation Starter Kit*](#)
 - [*How to Choose a Health Care Proxy and How to Be a Health Care Proxy*](#)
 - [*Conversation Starter Kit for Families and Loved Ones of People with Alzheimer's Disease or Other Forms of Dementia*](#)
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Institute for Healthcare Improvement

ihi.org

Free IHI White Paper that presents the "Conversation Ready" approach to help health care organizations and clinicians provide respectful end-of-life care that is concordant with patients' stated goals, values, and preferences

[*"Conversation Ready": A Framework for Improving End-of-Life Care*](#)

Ariadne Labs

ariadnelabs.org/areas-of-work/
serious-illness-care/

Free guide for structured conversations around goals of care and community of practice to engage with others about using the Serious Illness Conversation guide

Vital Talk

vitaltalk.org

Website with links to extensive in-person and online communication training

**Center to Advance
Palliative Care (CAPC)**
capc.org

Membership-based organization focused on spreading best practices, teaching, and training around palliative care

**Stanford School
of Medicine
Ethnogeriatrics**
geriatrics.stanford.edu/
ethnomed.html

Comprehensive website detailing ethnic-specific modules on the health and health care of multicultural older adults

**Select Journal Articles
with Information Specific
to Cases**

- Silva MD, Genoff M, Zaballa A, Jewell S, Stabler S, Gany FM, Diamond LC. [Interpreting at the end of life: A systematic review of the impact of interpreters on the delivery of palliative care services to cancer patients with limited English proficiency](#). *Journal of Pain Symptom Management*. 2016 Mar;51(3):569–580.
- deLima Thomas J, Sanchez-Reilly S, Bernacki R, et al. [Advance care planning in cognitively impaired older adults](#). *Journal of the American Geriatrics Society*. 2018 Aug;66(8):1469–1474.
- Shinall MC Jr, Stahl D, Bibler TM. [Addressing a patient's hope for a miracle](#). *Journal of Pain and Symptom Management*. 2018 Feb;55(2):535–539.