



Advance Care Planning Conversations During COVID-19

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NEW JERSEY
HEALTH CARE

**QUALITY
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About the Quality Institute

- We are a nonprofit, nonpartisan, multi-stakeholder advocate for health care safety, quality, and affordability for everyone.
- We are a membership organization, with over 105 member organizations across all of the sectors of the health system.
- We accomplish our mission through:
 - Policy changes
 - Community Health and Wellness programs
 - Education
 - Quality Improvement

Objectives

- Describe the importance of advance care planning, and the importance of *conversations*.
- Learn tips on how to talk to patients about advance care planning.
- Identify resources to help patients and their families consider and communicate their wishes.

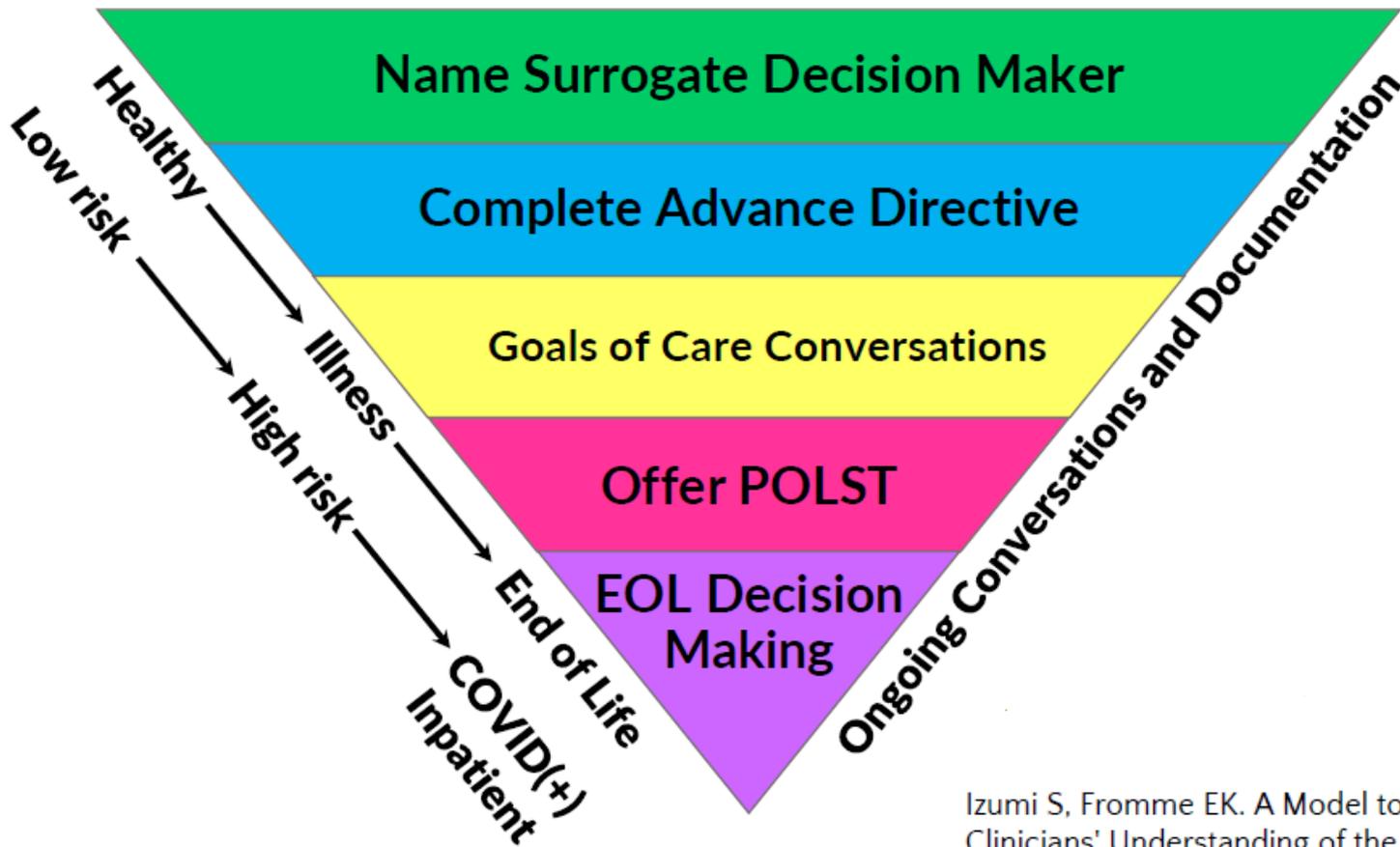
End-of-Life Care in New Jersey

- NJ patients at the end-of-life receive some of the most aggressive care in the country.
- 70% of residents have not documented their end-of-life wishes; only 24% have spoken to a health care provider about their wishes.
- Large racial and ethnic disparities exist when it comes to advance care planning.

Importance of Advance Care Planning Conversations

- Patient's Expectations
 - Patient's current understanding of their illness and COVID-19
 - What is most important to them? What are their goals, treatment preferences, worries?
- Reality of Patient's Illness
 - Assessment of patient's diagnosis and how it might be impacted by COVID-19
 - Devise a plan of care based on the patient's preferences and goals
- During COVID-19, we want to avoid unwanted care:
 - That does not align with the patient's wishes
 - To minimize risk for transmission
 - To reduce further impact on limited resources

Advance Care Planning Continuum



Izumi S, Fromme EK. A Model to Promote Clinicians' Understanding of the Continuum of Advance Care Planning. *Journal of Palliative Medicine*. 2017;20(3):220-221.

Resource: Conversation of Your Life (COYL)

- COYL, which launched in 2015, is a program of the Quality Institute's Mayors Wellness Campaign.
- Engages health care providers and community leaders to lead culturally competent, accessible conversations about advance care planning in community settings.
- COYL is operating in 15 counties; led by county-wide task forces that organize engaging programming.



Engaging Residents During COVID-19

- The pandemic is prompting many people to consider their life, goals, and end-of-life wishes.
- COYL continues to engage and reach health care providers and residents through:
 - COYL Brochure
 - Webinars
 - Podcasts
 - Animated videos
 - Digital resources

www.njhcqi.org/COYL



What is advance care planning and why is it important?

Advance care planning consists of sharing your preferences for end-of-life care with loved ones and doctors and putting them in writing, so in the case that you are unable to speak for yourself, the health care treatment you receive at the end of life is consistent with what you want. More than anything, advance care planning is a gift of clarity for both you and your family. Indicating your preferences for end-of-life care well ahead of time saves your loved ones from having to make emotionally taxing decisions on your behalf; instead, they can have clarity in their actions and focus on spending time with you.





We understand that advance care planning can be daunting – not only because it is difficult for many of us to think about aging and death, but also because there are a lot of terms and forms that can complicate the process. This *checklist* simplifies things for you, so you can start—and finish—your advance care planning journey.

- 1. Consider.**
 - Consider your own priorities for end-of-life care.
 - Consider what might happen if you don't discuss end-of-life care and become unable to make healthcare decisions for yourself.
- 2. Communicate.**
 - Communicate your end-of-life care wishes with your loved ones and doctors.
- 3. Create.**
 - Designate your health care agent (the person who can legally make decisions for you if you are incapable of making them on your own), and formalize this relationship by signing your *Proxy Directive*.
 - Put your end-of-life care wishes in writing. There are several options. You do not need to fill out all of these forms. Take a look at them and decide what is right for you.
 - New Jersey Instruction Directive* (requires two witness signatures or notarization)
 - 5 Wishes* (requires two witness signatures)
 - POLST* (requires signature of attending doctor or nurse practitioner)
 - Share your advance directives with loved ones and your healthcare providers.
 - Keep your advance directives in an accessible and secure location.
 - Revisit your advance directives and end-of-life conversations every few years.

Advance Care Planning: Useful Terms

Advance Directive:
An advance directive is a legal document that allows you to spell out your decisions about end-of-life care ahead of time. Each state's advance directive varies. In New Jersey, you do not need a lawyer to complete an advance directive. If you choose to get your advance directive notarized, you don't need additional witnesses; if you choose not to get your advance directive notarized, you must sign and date it in front of two adult witnesses who must also sign and date the document. The form can be updated and/or cancelled at any time. In New Jersey there are two parts to the Advance Directive—the Living Will (Instruction Directive) and the Power of Attorney (Proxy Directive).

Living Will (Instruction Directive):
A living will is a written, legal document that spells out medical treatments you would and would not want to be used to keep you alive, as well as other decisions such as pain management or organ donation. Have conversations with your primary care doctor, family, friends, and anyone you feel comfortable with to determine your personal wishes regarding these issues.

Durable Power of Attorney for Health Care (Proxy Directive):
The proxy directive is where you name a person to make decisions for you when you are unable to do so. This person can be anyone—family or friend—except for your personal doctor. The Proxy Directive will only go into effect if you are no longer able to speak for yourself.

Five Wishes:
The Five Wishes is an alternative form that is acceptable as an Advance Directive in the state of New Jersey. The Five Wishes form is written in everyday language and has become the most popular Advance Directive in America.

Useful Resources	Link
NJ DOH (Instruction Directive & Proxy Directive)	http://www.nj.gov/health/advancedirective/ad/forums-faq/
Aging with Dignity (5 Wishes)	https://www.agingwithdignity.org/five-wishes
Goals of Care (POLST)	http://www.goalsofcare.org/nj-polst/nj-polst-form/
Death Over Dinner	http://deathoverdinner.org/
National Institute on Aging	https://www.nia.nih.gov/health/publication/advance-care-planning/
New Jersey Hospital Association	http://bit.ly/2j9omKk
Advance Care Planning Decisions	https://cpdecisions.org/products/videos/
Family Caregiver Alliance	http://bit.ly/2k8Q7SR
Conversation Starter Kit	http://theconversationproject.org/starter-kit/intro/
Toolkit for Health Care Advance Planning	http://bit.ly/1sSihdi
CSU Institute for Palliative Care	https://csualliativecare.org

Advance Care Planning: Preparing for the Unexpected



COVID-19 has taken away our control over daily life. But we do not need to lose control over how we want to be treated at the end of our lives. The pandemic is prompting many people to consider the advance care directives they may have been putting off. The Quality Institute's [Conversation of Your Life \(COYL\) program](#) has advocated for everyone to talk openly with their loved ones about their end-of-life wishes—whether it's months, years, or even decades before a medical crisis. The truth is none of us know the future.

COYL guides families toward valuable and supportive conversations, and then helps people express their wishes in legally binding documents. Many of our COYL events are community gatherings. Physical distancing, however, does not have to prevent you from having these vital conversations with your family, especially if you are all hunkered down together. Great conversations can also take place through the phone or other means, such as video-chatting platforms such as Skype, Zoom, or FaceTime.

Many COYL participants tell us that they document their wishes as a gift to the people they love. We also find that in the most unsettling times being prepared can bring a measure of peace and comfort.

Safe Social Distancing Practices to Share Your End-Of-Life Care Wishes Virtually



Below we compiled trusted resources, all accessible from home, to help you start thinking about your wishes and to show you how to approach these important conversations with loved ones and document what's most important to you.

Consider Your Priorities



What Do I Value and Want? Play a round of [Go Wish](#) online. Go Wish is a game, which helps you find words to talk about what is most important to you and your end-of-life care planning. View instructions on gameplay [here](#).



Who Will Be My Health Care Proxy? The Conversation Project's YouTube Video, "[Who Will Speak For You](#)," is a great way to begin thinking about who you would ask to be your health care proxy (someone you designate to make health care decisions for you if you become unable to speak for yourself).



Listen to BBC Radio's Podcast, [My Dying Wishes](#). Joan Bakewell, and her panel, explore why it's so important to make your wishes known—and how to go about doing it.



Why is Advance Care Planning Important? Learn why by reading [Mrs. Lee's Story](#) (available in both Chinese and English) and [Finding Your Way](#) (available in Spanish), which was developed by the Coalition for Compassionate Care of California.

Resource: Ariadne Labs' Serious Illness Conversation Guide

COVID-19 Conversation Guide for Outpatient Care

SET UP	This is a difficult and scary time with the coronavirus. I'm hoping we can talk about what is important to you, so that we can provide you with the best care possible. Is that okay?
ASSESS	What do you understand about how the coronavirus could affect your health? What are you currently doing to protect yourself from getting the virus? May I share with you my understanding of how the coronavirus could affect your health?
SHARE	Most people who get the coronavirus get better on their own. However, people who are older or have other health problems like yours can get very sick and may not survive. The treatments that we use to try to help people live, like breathing machines, may not work. If they do work, recovery from the illness is uncertain. <i>[Pause, respond to emotion]</i> . We really hope that you don't get the virus, but it is important to prepare in case you do. Given your [medical condition]/age, I'd like to think together about what would be important to you if you became very sick and couldn't speak for yourself.
EXPLORE	What would be most important for your healthcare providers or loved ones to know if you became very sick and couldn't speak for yourself? With all that's going on, what are you most worried about? What abilities are so important to you that you can't imagine living without them? If we think they may not help or may cause suffering, some people make decisions to avoid treatments like breathing machines or CPR if they get very sick. If that happened to you, have you thought about medical treatments that you may or may not want?

Thank You

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References

- COYL www.njchqi.org/COYL
 - COVID-19 Resources <https://bit.ly/QICOVID19Resources>
- Ariadne Labs Serious Illness [COVID-19 Toolkit](#)
 - [In-patient Conversation Guide](#)
 - [Outpatient Conversation Guide](#)
- Coalition for Compassionate Care for California [COVID Conversations Toolbox](#)
- VITALtalk [COVID Ready Communication Playbook](#)