Conversation of Your Life is a program of the New Jersey Health Care Quality Institute's Mayors Wellness Campaign. The program aims to bring advance care planning conversations to New Jersey communities. Conversation of Your Life is generously funded by The Horizon Foundation for New Jersey. To learn more, visit http://www.njhcqi.org/COYL.

The Facts:

According to a recent "Health Matters" poll conducted by the New Jersey Health Care Quality Institute and Rutgers Eagleton Center for Public Interest Polling:

- 61% of New Jersey adult residents are comfortable with the idea of aging and have thought about their wishes for medical treatment near the end of their life.
- 6 out of 10 New Jersey adult residents have no written documents expressing their wishes for end-of-life care.
- 38% of New Jersey adult residents have not had conversations about advance care planning.
- Only 3 out of 10 New Jersey adult residents who are 65 years and older are aware about Five Wishes or POLST.

The public is comfortable with aging and discussing end-of-life, however very few are making plans and many are not aware of important end-of-life care options or advance care planning documents.

Our goal:

After successfully piloting Conversation of Your Life in Tenafly, Princeton, and Gloucester Township in 2015, the Mayors Wellness Campaign is expanding Conversation of Your Life. Conversation of Your Life's goal is to develop and promote a community conversation around advance care planning. Our hope is that more individuals in New Jersey will engage in fruitful dialogue—the Conversation of Your Life—to let their family, friends, or doctors understand and respect their end-of-life wishes through advance care planning. Ultimately, we hope that these wishes are documented in writing.

The Program:

New Jersey residents will have the chance to participate in community reads, film festivals, game nights, and seminars that will drive discussion about advance care planning. It may feel daunting, but as a community, we will delve into these conversations together. More than anything else, advance care planning is about giving the gift of clarity to the people you care about most.

Expert Steering Committee:

- Aline Holmes, New Jersey Hospital Association
- Dr. Dave Barile, New Jersey Goals of Care
- Deborah Levine, Mayors Wellness Campaign, New Jersey Health Care Quality Institute
- Don Pendley, NJ Hospice & Palliative Care Organization and NJ Bar Association
- Dr. Eric Shaban, VITAS
- Dr. Frank Urbano, AmeriHealth New Jersey
- Linda Schwimmer, New Jersey Health Care Quality Institute
- Loretta Kaes, Health Care Association of NJ
- Dr. Randy Krakauer, Former Medical Director at Aetna
- Ruth Charbonneau, Former Chief of Staff at New Jersey Department of Health
- Steven Wishart, VITAS
- Dr. Terry Shlimbaum, Summit Medical Group

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What is advance care planning? Why is it important?

Advance care planning consists of sharing your preferences for end-of-life care with loved ones and physicians and putting them in writing, so in the case that you are unable to speak for yourself, the healthcare 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. That's why we have created this ***checklist*** to simplify 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 physicians.

3. Create.

If you are uncomfortable with any of the italicized terms below, refer to our "End-of-Life Term Sheet."

- ☐ 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)
    - *5 Wishes* (requires two witness signatures)
    - *POLST* (requires signature of attending physician 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 care conversations every few years or whenever your health changes. Circumstances change and priorities shift, so it's important to keep your documents up to date.

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Advance Care Planning: Useful Terms

Advance Directive	An advance directive is a legal document that allow 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. An advance directive can give you a way to tell your wishes to family, friends, and health care professionals and to avoid confusion later on if you become unable to make decisions yourself. 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 physician. 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.
Physician order for life-sustaining treatment (POLST)	A POLST form is a medical order indicating your preferences for end-of-life care. In most states, this form is intended for use only during the final stages of life. In New Jersey, the POLST can be filled out at any time. It is filled out with your physician based on the contents of your directives, discussions with your doctor, and your treatment preferences. POLST forms are intended for people who have already been diagnosed with serious illness, so even if you have one before, it is important to speak with your physician regularly and update your POLST form as your preferences change as you age. The POLST serves as doctor-ordered instructions—not unlike a prescription—to ensure that, in case

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	of an emergency, you receive the treatment you prefer. A POLST travels with you, at whatever facility you are being cared for.
Artificial Nutrition and Hydration	Supplements or replaces ordinary eating and drinking by giving nutrients and fluids through a tube placed directly into the stomach, intestine, or a vein.
Intubation	The insertion of a tube through the mouth or nose into the trachea (windpipe) to create and maintain an open airway to assist breathing
Mechanical Ventilation	Used to support or replace the function of the lungs. A machine called a ventilator (or respirator) forces air into the lungs and is attached to a tube inserted in the nose or mouth and down into the windpipe (or trachea).
Hospice	Hospice offers medical care toward a different goal: maintaining or improving quality of life for someone whose illness, disease or condition is unlikely to be cured. Each patient's individualized care plan is updated as needed to address the physical, emotional and spiritual pain that often accompanies terminal illness. Hospice care also offers practical support for the caregiver(s) during the illness and grief support after the death. Hospice is something more that is available to the patient and the entire family when curative measures have been exhausted and life prognosis is six months or less.
Palliative Care	A comprehensive approach to treating serious illness that focuses on the physical, psychological and spiritual, and existential needs of the patient. Its goal is to achieve the best quality of life available to the patient by relieving suffering and controlling pain and symptoms. Palliative care may be given at any time during a patient's illness, from diagnosis on.

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Name of Resource	Description	Link
Death Over Dinner	An interactive website that allows for users to have a virtual "test dinner" to practice the process of discussing end of life planning	http://deathoverdinner.org/
Department of Health	Features information regarding end of life are, palliative Care, hospice, and advance directives	http://nj.gov/health/advancedirective/
National Institute on Aging	Provides information about what ACP is, why it is important, and how to set up your Advance Directive	https://www.nia.nih.gov/health/publication/advance-care-planning
New Jersey Hospital Association	Defines advance care planning and resources to help you talk to your doctor and understand the hospital's role.	http://www.njha.com/quality-patient-safety/advanced-care-planning/
Baylor Health Care System: Advance Care Planning	Features information on the importance of ACP, multiple parts of ACP, and cites general end of life scenarios where ACP is crucial.	https://www.baylorhealth.com/SiteCollectionDocuments/Documents_BHCS/BHCS_Patient%20Info_DocumentsForms/AdvanceCarePlanning_rev10.pdf
My Health Care Wishes App	Links to an app that gives individuals the ability to store and share important health care wishes electronically through their mobile device.	http://www.americanbar.org/groups/law_aging/MyHealthCareWishesApp.html
Advance Care Planning Decisions	Provides consumers with videos that explain the goals of palliative care as well as the kind of medical decisions involved in end of life care. The videos are meant to supplement provider-patient discussions.	https://www.acpdecisions.org/products/videos/
Family Caregiver Alliance	Information on how to begin end-of-life decision making, why to prepare a directive, and what type of decisions this process entails.	https://www.caregiver.org/end-life-decision-making
Conversation Starter Kit	A user-friendly toolkit on how to start end of life conversations.	http://theconversationproject.org/starter-kit/intro/
Consumer's Tool Kit for Health Care Advance Planning	A detailed 10-part toolkit for consumers on the process of advance care planning and the legal jargon behind advance care directives.	http://apps.americanbar.org/aging/publications/docs/consumer_tool_kit_bk.pdf
CSU Institute for Palliative Care Courses	Provides a variety of instructor-led and self-paced online courses for nurses, social workers, chaplains, and other healthcare professionals on palliative care.	https://csupalliativecare.org

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Good Books to Read	Being Mortal, Atul Gawande Can't We Talk About Something More Pleasant?, Roz Chast Final Exam, Pauline Chen The Conversation: A Revolutionary Plan for End-of-Life Care, Angelo Volandes The Best Care Possible, Ira Byock When Breath Becomes Air, Paul Kalanithi
Good Films to Watch	Amour Being Mortal: PBS Frontline Documentary Considering the Conversation Life As a House The Bucket List The Diving Bell and the Butterfly You're Not You

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