

## **Death/End-of-Life Doula Resources**

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### **Martin Prechtel**

<https://www.youtube.com/watch?v=UUwewfPPSbE>

An audio version of an inspiring presentation Martin Prechtel gave on the relationship between grief and praise. He is an author, educator, and shaman whose mixed Mayan & Swiss lineage gives him a unique perspective on how intact (mostly indigenous) cultures experience collective grief.

### **End-of-Life University, with Dr. Karen Wyatt**

<https://eolupodcast.com/>

Karen Wyatt is a former hospice/palliative care physician who has put together huge amounts of resources on all things emerging and innovative in the end-of-life world. See the variety of podcasts she has on this link, but check out her other generous resources on the rest of the website.

### **National End-of-Life Doula Alliance (NEDA)**

<http://www.nedalliance.org/>

This organization serves as one of the places doulas from different training backgrounds come together. You might be most interested in the sections on *Find a Training*, *Scope of Practice*, *Code of Ethics*, and *Learn More About Doulas*.

### **International End-of-Life Doula Association (INELDA)**

<https://www.inelda.org/>

The tabs that might be most interesting to you are: *Education*, *Articles & Blogs*, and *Resources*.

### **National Hospice & Palliative Care Organization (NHPCO) – End-of-Life Doula Council**

<https://www.nhpc.org/about-nhpc/committees-and-councils/end-of-life-doula-council/>

This is the national organization that represents most hospices and palliative care organizations in the US. They formed an End-of-Life Doula Council in partnership with leading doula program educators to co-create education about the end-of-life doula role as it relates to hospice care.

Good documents here that can be shared with hospices as you're building relationships with them in your community.

## End-of-Life Decision-Making Resources

How we make decisions about treating serious illness has changed dramatically over the past 70 years. When medical advances became available to prolong life and fight disease, this was seen as a very good thing. Infections could be treated, stopped hearts re-started, failing kidneys sustained, cancers imaged by machines, and insulin supplemented with a simple injection. The place we find ourselves now is a very different landscape. Most people are doing the best they can to navigate the *unintended consequences* of these many medical-technological advances.

Life-extending treatments also create situations where people may be kept alive despite poor quality of life. The cases of Karen Anne Quinlan (1976), Nancy Cruzan (1990), and Terry Schiavo (2005) – all of whom lived in a “persistent vegetative state” without clear end-of-life wishes – brought national attention to these issues.

**Advance directives were developed as an essential legal document that assures the right of an individual to refuse medical treatment and to have those wishes respected even if the dying person is unable to communicate.** They include a first part, called “Durable Power of Attorney (or Health Care Proxy),” which names who would speak for you if you were unable to speak for yourself. The second part is often called the “Living Will,” which states your wishes about medical care in the event that you develop a terminal condition or are in a persistent vegetative state.

Today, the default in our medical system is aggressive care unless there is a clearly written advance directive that has been communicated clearly to the health care team. However, only about one-third of adults have completed an advance directive. Contributing factors include lack of awareness or denial of the need for an advance directive and its importance, confusion and ambivalence about end-of-life decisions, and cultural differences in navigating end-of-life care.

End-of-life doulas and coaches have an opportunity to open conversations with people about what kind of care they would want if they were seriously ill or had a ‘catastrophic event’ (sudden stroke or heart attack, serious car accident, etc.) that left them incapacitated. Having an advance directive in place ensures that a person remains in control of their medical treatment regardless of circumstances, foreseen or not. It also lessens the burden on a person’s loved ones -- as they will know what to do for that person’s treatment, and not worry that they’re going against their wishes.

This is a gift that we might give each other – clear guidelines through difficult territory. What makes these decisions even more clear is to have *conversations* about the advance directives. Ideally, these conversations occur over time, and give a better understanding of the values and beliefs underlying the legality of the advance directives. Also, a person can revise their advance directive, as needed, if their circumstances or thinking have changed.

Remember to start with yourself and your loved ones – make sure you have these conversations and complete your own advance directives, regardless of your age or your circumstances. This is an important part of your own self-development as an end-of-life care advocate.

**Listed below are some resources you might draw from** – decision-making tools as well as conversation-starters. These are a few of many good resources that are available to people.

### **Advance Directives by State**

<https://www.nhpco.org/patients-and-caregivers/advance-care-planning/>

Caring Connections is an arm of the National Hospice and Palliative Care Organization, and has a list of state-by-state forms for advance directives available. Each state's form is preceded by Caring Connection's general suggestions about completing an advance directive. These forms must be signed and witnessed. Although other forms can be legal if signed and witnessed, doctors are more likely to pay attention to the state-approved forms.

### **Five Wishes Document**

<https://fivewishes.org/five-wishes/individuals-families/individuals-and-families>

A popular form of advance directive is the *Five Wishes* document. This document, written with the help of the American Bar Association's Commission on Law and Aging, gives you the opportunity to convey your personal, emotional, and spiritual needs as well as your medical wishes. Many people have found it a good conversation starter, especially in talking about the kind of care someone would like to have when they're seriously ill.

In 42 states and the District of Columbia, it substantially meets the legal requirements for an advance directive. Check the website to see if your state is included. Even if it isn't, you can complete the Five Wishes to accompany your state's approved advance directive.

The five categories of wishes are: The person I want to make care decisions for me when I can't, The kind of medical treatment I want or don't want, How comfortable I want to be, How I want people to treat me, and What I want my loved ones to know.

Each of the sections contains an extensive list of things to consider. For example, the document describes four situations — close to death, in a coma and not expected to wake up and recover, permanent and severe brain damage and not expected to recover, and in another condition in which I do not wish to be kept alive — and lists the choices that may apply.

Included on the website are a sample *Five Wishes* document, free guides for how to talk with loved ones about their health care choices, and even a document for young people called *Voicing My Choices*.

### **POLST/MOLST Forms**

<https://polst.org/programs-in-your-state/>

*Physician (or Medical) Orders for Life-Sustaining Treatments* are completed by a physician, summarize a person's end-of-life wishes, and give medical orders for emergency health care professionals to follow. It

goes into the person's medical record and is portable, so your wishes can be accessed wherever you are in a health care system. (Not all states have these forms available.)

### **The Conversation Project**

<https://theconversationproject.org/>

This organization provides conversation "starter kits" for people wishing to talk more openly about their preferences for end-of-life care. Included on the site are a conversation starter kit, guidelines for choosing a health care proxy (or medical power of attorney) and communicating with your health care team, as well as two specific conversation starter kits for dementia/Alzheimer's and pediatrics.

### **Advance Directives for Dementia**

<https://dementia-directive.org/>

This is new territory for advance directives, and they are not widely accepted at this point. This directive was developed by Barak Gaster, MD with help from experts in the fields of geriatrics, neurology, and palliative care. This site references interviews with NPR, the New York Times, and an article in the New England Journal of Medicine. You will benefit from educating yourself about this, as it's likely to become a hotter topic. Here's one article from JAMA to start:

<https://jamanetwork.com/journals/jama/fullarticle/2662678?guestAccessKey=62c6fc8c-aad3-4f4f-8196-3f3f2c37de4a>.

### **Let's Have Dinner and Talk About Death**

<https://deathverdinner.org/>

This website provides user-friendly materials to organize a dinner party for friends, family, or strangers with the express purpose of talking about death and dying in a social setting. Included are e-mail invitation, conversation prompts, and tips for a successful experience.

### **Hello (Card game)**

<https://www.takethis.org/2017/09/hello-is-a-card-game-that-makes-the-most-difficult-conversations-easier/>

This is one of several card games that spark conversations about what matters most to people in aging, illness, and end of life. The website states that their research has shown that around 75% of players go on to complete Advance Care Planning behaviors like making preparations with legal or financial professionals, or talking with healthcare providers.

### **GYST (Get Your Shit Together)**

<https://getyourshittogether.org/>

Chanel Reynolds created this website after her young husband died unexpectedly and she was completely unprepared. Easy-to-use resources cover legal and financial forms and planning, insurance, and end-of-life wishes.

## COVID-Related Resources

One opportunity we have from this unusual global pandemic is to clarify again what we would want for care if we became very ill with something like the COVID-19 virus.

**Here are a few resources that are specific to the reality of COVID-19, and apply to any circumstances where we need to determine our treatment choices, where we want to die, and who we want to be with us.**

### Ariadne Labs

Ariadne Labs' Serious Illness Care Program developed a COVID-19 Response Toolkit to support health systems and clinicians in addressing the communication needs of patients in the community and those in the hospital. The toolkit also includes resources for patients to begin having these conversations with people they trust within their support networks."

<https://www.ariadnelabs.org/coronavirus/clinical-resources/covid-conversations/?fbclid=IwAR2QqpEltX7MPmB4lxFxVT0o0nidnXdB0MwoD1zrt0sJjGymRZrKZaqtZQA>

### The Conversation Project

This is a helpful 2-page document called "Being Prepared in the Time of COVID-19: 3 Things You Can Do Now."

"This is a challenging time. There are many things that are out of our control. But there are some things we can do to help us be prepared — both for ourselves and the people we care about. Here are three important things each of us can do, right now, to be prepared."

<https://theconversationproject.org/wp-content/uploads/2020/04/tcpcovid19guide.pdf?fbclid=IwAR0-UdMFzKm9gly5ApNP48-sLmvUOEBrKV4CiWkBUgUNmncjISqqpsAKI>

### Karen Wyatt & End-of-Life University

Here's an excellent, free resource about Advance Directives and step-by-step end-of-life planning. Created and shared generously by Karen Wyatt, MD, founder of End-of-Life University.

[https://www.eoluniversity.com/roadmapcourse?mc\\_cid=10c71c966b&mc\\_eid=dc1c161f2c&fbclid=IwAR2RGBMFT5CSS4BRm9RhKwpy6pK3y7sOXHuJ4\\_Tmkk6bQj8yra21vMUVMho](https://www.eoluniversity.com/roadmapcourse?mc_cid=10c71c966b&mc_eid=dc1c161f2c&fbclid=IwAR2RGBMFT5CSS4BRm9RhKwpy6pK3y7sOXHuJ4_Tmkk6bQj8yra21vMUVMho)

### Respecting Choices

"Individuals and their families who are at highest risk for complications and death from this infection are feeling especially vulnerable. No one can eliminate the uncertainty about whether they will get sick, or how sick they will become. But there is a way to limit the uncertainty, through proactively asking about the type of care they want, should they become severely ill. Knowing this information also limits the uncertainty for their loved ones and for the clinical teams who can confidently create a plan that aligns with what matters most to each individual."

[https://respectingchoices.org/covid-19-resources/?fbclid=IwAR2IQGyRZKtp6fd49z\\_JxcJtyKMxcuvh4ooPkwZxvIU-4v43dyQA8jnWdkg#decision-aids](https://respectingchoices.org/covid-19-resources/?fbclid=IwAR2IQGyRZKtp6fd49z_JxcJtyKMxcuvh4ooPkwZxvIU-4v43dyQA8jnWdkg#decision-aids)