

How to Have a 'Good Death'

Explore What's Beyond Wills, Trusts & DNRs...

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We're all just walking each other home. - Ram Dass

Getting It Right: What Planning Is Essential for a 'Good Death'?

- 1. Your estate & finances. Will, durable power of attorney for finances, living trust.
- 2. Your health care. A Living Will; durable power of attorney for health which names your health care proxy—a person who will make decisions for you if you can't.
- **3.** Advanced care planning ACP is included FREE as part of your Medicare Annual Wellness Visit and some insurance plans. This includes your medical wishes related to...
 - <u>CPR</u> (DNRs-Do Not Resuscitate), in and out of the hospital (at home, elsewhere).
 - Ventilators (DNI's-Do Not Intubate)
 - <u>Artificial nutrition & hydration</u> (intravenous)
 - Palliative Care & Hospice Care
 - Organ & tissue donations.

NIH (National Institute on Aging in the NIH) has a very helpful FREE publication called **Advance Care Planning: A Conversation Guide.** Includes includes tips on how to BE a Health Care Proxy yourself. (See Resources).

Most of us know, we need to:

- Put your preferences in writing.
- Put your important papers & copies of legal documents in one place, and tell your family or proxy where these are.
- Discuss your wishes with your family, so there are no surprises.

Define What a 'Good Death' Would FEEL & Look Like to YOU

How you <u>define</u> a 'Good Death' will be informed by what <u>you've experienced</u> in your life's journey, including your <u>religion or spiritual preferences</u>. **Things to consider:**

- What **experience** do you want to have? **And**...what experience do you want your family and others to have (including the people who read your obituary or pass by your gravestone)?
- Where do you want to be when you're dying? Home? Hospital? Assisted Living facility? The beach? Elsewhere?
- How will you enjoy the time you have left? Go on an adventure? Visit with loved ones? What really makes you happy? Do more of that now! Don't wait to live your Bucket List.
- Do you want to be alert...or do whatever is needed to be pain free? Let your caretakers know!
- Surrounded & supported by friends and family ... who can come and go as they want?
- What **music** do you want to hear during the dying process (if any)? What books read, if any?
- How do you want people to talk to you and touch you? Lots of talking & sharing? Or more quiet?
- Do you want a "LIVING FUNERAL" where people come when you're dying and talk about their favorite memories of you... BEFORE you die (not just at your funeral)?
- Do you want lots of prayer & spiritual encouragement for your departing soul? Or just dancing? Or both?
- What pictures do you want around you?

- How do you want to **say Goodbye** to your loved ones? Will you write love letters to them? Speak with them one-on-one? What do you want to tell them?
- What do you need to have **peace & dignity** at this time? Certain **rituals**, **traditions** or **guided imagery**?
- What people or animals do you want/don't want present for your last hours?
- What do you want to happen right after you pass? How do you want your body & soul tended to?

Knowing the answers to such questions is essential to planning for a Good Death.

A Good Death is Most Likely to Follow a Life that Is Lived-Well

The way we live is the way we die.

- If you're <u>agitated</u>, <u>angry</u> and <u>impatient</u> now... then you'll likely be agitated, angry and impatient on your death bed.
- Stressed out and worry a lot? Then the less likely you'll be peaceful and at ease in the end.
- If you judge & complain a lot *if things need to be a certain way for you to be happy* then happiness will elude you then.
- If you live consciously, caringly, with gratitude and compassion present and joy-full now you'll likely take that with you.

As mindfulness meditation teacher & author Jon Kabat-Zinn says: "Wherever you go, there you are." If you don't like who you are, change NOW!

Live Your Values. We have to know what's MOST important to us...and let that guide what we do each & every day. What truly matters in YOUR life? What makes a fulfilling life ...for YOU? Fulfilled now? Then, satisfied in your final days. Live your values and then ... on your death bed:

- You'll be less likely to focus on or be bothered by the "little stuff."
- You'll have fewer regrets to mull over and apologize for!!

The 3 Most Important Things to People on Their Death Beds

1. Our relationships. We need to have them in order. Regrets, bad relationships, unfinished business, forgiveness to do, lack of faith.... Will be on your deathbed with you. So will joy and love.

Remember, what we don't speak in our lifetimes can hurt us and those we love. Remember to speak the "essential sentiments" of: "Thank you." "I forgive you." "I love you." And, "I forgive you." Let your loved one know you care. Decide today if you want to bring misery or joy to people! Judge and complain? Or approval and love.

Having a strong <u>relationship with God</u> (or whatever you call creator or something bigger than yourself) is also beneficial.

- **2. We don't want to be forgotten.** What do you want your loved ones and the world to remember <u>about you?</u> How much you loved or laughed? How good you made them feel about themselves? Other? Some people go extra steps to be remembered like letter writing, Legacy Journaling, establishing a Scholarship Fund, getting something named after you!
- **3.** We want to have made a difference in this world. This can be something BIG like saving lives or building a hospital... or just sharing your philosophy of life with your loved ones... who might some day say, "Because of her, I became a teacher."

"We all die. The goal isn't to live forever, the goal is to create something that will." - Chuck Palahniuk

<u>Great Talking Points</u>. These three important things can also <u>guide you if you're comforting someone</u> with a terminal diagnosis: You can:

- 1. Hone your relationships. Tell and show them you love them.
- **2.** Tell them you'll never forget them and why.
- 3. Remind them of all the things they did that have made a difference in your life, your community and beyond.

Other Things that Make for a Good Life until Your Last Breath

Talk, Talk, Talk about What You Want - to Your Loved Ones, Doctors & Other Caretakers

Be less fearful...

"The patients and families who are willing to say and listen to these uncomfortable things,—talk about it out in the open—are ahead of the curve. They tend to have a more peaceful life and a more peaceful death.... There is something about speaking your truth that really lessens the grip of fear." — -Hospice Nurse Julie McFadden

Be more connected...

Avoiding or ignoring feelings, fears and conversations about death and dying, sadly, also leads to avoiding or ignoring important connections, so needed at the end of life.

- Patty Burgess, Doing Death Differently - Doula Trainer

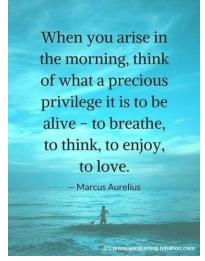
See Your Guide for Talking with a Health Care Team in Resources

Know this About Talking to Doctors:

- Western doctors are **programmed to fix us** and do all they can—even when they know 99% that the Western treatments aren't going to help.
- They **don't frequently offer end-of-life care** as a treatment option. In a state of panic, people end up doing surgery, chemo or a lot of other things that can hurt more than they help. You or your loved one can suffer more than needed and be robbed of a better end-of-life.

"I firmly believe that being given the treatment option of "end-of-life care" or "hospice care" is a gift, a priceless gift of time. Time that allows us to be present with our loved one in the final stages of their life story.

Time for any last words, thoughts, or wishes exchanged." – Katie Duncan, The Dying Process



Consider Getting a 'Death Doula.' (See details below.)

Mind Your Mind. Know how to focus and direct it when it's making you unhappy. Meditate, sleep well to keep it healthy.

Know That You Can Change Your Mind. A good death involves letting go...and sometimes what you thought you wanted for your care, where you want to be, if you want to be resuscitated, etc., can be different as you get closer to the end-of-life.

Practice Gratitude to reduce stress, redirect a negative mind, change your mood, and uplift your spirit. We also know that gratitude will improve help your health ... And make you WISER!

Keep Your Sense of Humor. "When I die, I want to go peacefully like my grandfather did – in his sleep. Not yelling and screaming like the passengers in his car." - Unknown

Plan to Give Up Your Plans. – Death is "messy." Have fun making plans. Take the "right action." Then give up the results. Go with the FLOW. You're still doing a "good job" of dying, even if it doesn't go according to you plan. The "Universe" might have better plans for us!

Do It Your Way! It's YOUR special time!!



"Try not to resist the changes that come your way. Instead let life live through you. And do not worry that your life is turning upside down. How do you know that the side you are used to is better than the one to come?"

Rumi

What Is a 'Death Doula?' (AKA End-of-Life Doulas, Coaches or Transition Guides)

Are holistic in their approach. They provide emotional, physical, spiritual and informational support to a patient and family before you face any end-of-life challenges; while you're facing a health crisis; and before, during and after death.

You can think about Death Doulas like you might Birth Doulas. "Birth Doulas" are family-centered—they help women and their families bring in new life. Death Doulas do the same kind of thing – educating, handholding, advocating for -- but at the end of life. The Doula's end goal is to help you have a "Good Life" until your last breath.

> "Just as Birth Doulas or midwives usher in new life and support mom and baby, End-of-Life Doulas lovingly offer holistic, practical, emotional and spiritual support of the dying and their loved ones."

Doing Death Differently / Teaching Transitions

End-of-Life Doulas can:

- Guide early or proactive planning for end-of-life wishes.
- Discuss care options, including assisted living, hospice or palliative care.
- Encourage planning for financial, legal and medical needs (trust funds, wills, executor, power of attorney, DNRs, health-care directives).
- Provide companionship, a comforting presence, dignity and guidance to those on their final journey and their loved ones ... with the ultimate goal of facilitating an easier, more meaningful end-of-life.
- Share resources and referrals to appropriate community resources and care providers including Massage, Handson-Healing (Reiki), and other healing services.
- Advocate for your needs with medical staff and attendants, your nursing home or assisted living home, and Hospice Team.
- Provide "Respite" for caregivers who are exhausted or need time to take care of other obligations.
- Help create a supportive environment for the patient how it looks, feels and sounds.
- Guide Therapeutic Yoga & Yoga Nidra/Sleep Meditations.
- Support the spiritual practices of all involved.
- Help the dying person in leaving a lasting legacy assisting in making sure the individual's memories or wishes are preserved for posterity by helping to write letters, transcribe memories into a journal, create a scrapbook, articulate heartfelt messages. Think: What do you want your loved ones and the world to remember about you?

- Help incorporate traditions or create new rituals to mark special moments.
- Assist with end-of-life <u>logistics</u> locating important documents, gathering passwords and pictures, closing accounts, stopping mail.
- Help write letters to loved ones, remembrances, obituaries, other.
- Provide insight into the dying process.
- Facilitate bedside Vigil & Visualizations at the end-of-life.
- Assist with Funeral/Ceremonial planning.
- Guide people through the early <u>stages of grieving</u>.
- Offer other support to family <u>after death</u>.

FEES for Death Doula/Guide Services: The fees for a Doula will depend on the Doula and services selected. Doulas usually charge by the hour or the day. Some may charge a flat fee to assist a person in their dying process. The hourly rate can range from \$20 to over \$100 an hour, sometimes depending on the client's ability to pay. Usually fees are lower when more extended assistance is needed. At this time, insurance does not pay for Doula services.

The Differences between Palliative & Hospice Care

Hospice and Palliative Care have a lot in common. They are both medical specialties aimed at supporting people of all ages with serious, long-term illnesses. Regardless of the illness, they both have the ultimate goal to:

- Improve quality of life
- Increase the level of comfort staff are *very* skilled with pain and symptom management.
- Provide emotional, spiritual and financial support, and education about your medical treatment, for you & family.

The main differences are:

Palliative Care: Anyone with a terminal or chronic illness can enter at any time to help manage/stabilize your symptoms. You don't have to stop curative or life-prolonging treatments and might even recover while on this care. Depending on where you live, home care is sometimes available, but care is mostly offered through a hospital or outpatient clinic. A person may receive PC for many years before entering Hospice Care. PC treatments are sometimes covered by Medicare or private insurance.

Hospice Care: Hospice, established 35+ years, focuses on team-based, end-of-life care with an understanding that you will stop all curative or life-prolonging treatments. To enter, a doctor must determine your illness will likely give you 6 months or less to live. (*Note:* If you are still living in 6 months, you can re-qualify to stay in Hospice.) Medicare covers.

The care is mostly in your home, nursing home or assisted living facility—a more comfortable place for you and your family. Hospice brings their staffing, hospital bed/medical equipment, medications, oxygen, etc. to you. Care can also be in a hospice facility or hospital.

The **Hospice Team** usually consists of:

- Doctor & a Nurse who comes in weekly to assess the patient. Staff is on call 24-7.
- Health Aides who come in several times a week to check on, bathe, groom and feed the patient. Often 3x/week.
- A Social Worker to help you manage paperwork and the details of planning for end-of-life.
- Chaplain (interdisciplinary)
- Volunteer. Volunteers bring flowers, offer patient care & companionship, pet & music therapy, reiki, respite, more.

Know that, with Hospice, you can **use as little or as many of the services as you want.** Ask your doctor what they recommend and why. Research has shown that both Palliative and Hospice care can be more effective when started early.

"If we can contemplate death and plan for it, we can live more consciously and creatively."

- Amy Cunningham, Licensed Funeral Director in the State of New York

Comforting the Dying

"There is a way to BE with the dying that is transformative. Living and dying can co-exist beautifully in any present moment." — Patty Burgess, Doing Death Differently -Doula Trainer

Some things to say and do/not do for a person who is actively dying (from weeks to hours before death):

Do:

- Listen more than you talk. Consider recording what your loved ones says. It's perfectly okay to sit in silence, or talk about what you normally talk about.
- Educate yourself about the dying process.
- Check to see if they are clean, safe and comfortable. If so, just sit with them and watch TV. Hold hands. Stroke their head/hair. Kiss them. Talk to them, even if they aren't responding. Tell them how important they are to you Bring up memories and things that are funny.
- Redefine "Hope." Instead of hoping for something in the future, ask them: "What do you hope for today?" (Answers might be someone's visit, to have less pain, to do something they enjoy, eat chocolate, etc.)
- Redirect their mind if all they do is complain. Ask them, "What has made you happy today?" "What are you grateful for?"
- If they say they are afraid, hear them out. Affirm their reality. Tell them that being afraid is normal, even for people with a strong faith. Not knowing...can be scary.
- Respond honestly. If you're afraid, say do. If you don't know the answer to a question, simply say that you don't know.
- Speak the "essential sentiments" of "I love you." "Please forgive me." "Thank you." And, if warranted, "I forgive you."
- Give them **permission to go.** Tell them that you will miss them; but you don't want them to suffer. "We will miss you so much! but we will be okay." "Your work is done here." "You did good." "You will always be in my heart."
- You can **suggest** that they, "Imagine taking the hand of (a special someone who has gone before them).... Let them guide you on your journey."
- Wish them ease, peace and grace; safe and fearless travels.
- Trust the process. The body knows how to die, just as it knows how to be born.

Don't:

- Speak –or make decisions—for your loved one if they can do so for themselves. Don't disempower them.
- Encourage the dying person to eat or drink if they are not asking for same. Food and drink (including IVs) at the end of life when the body no longer can swallow or digest/process well —can cause aspiration pneumonia, asphyxiation, coughing, choking and other problems.
- Talk about the person as if they are not there with you in the room. Hearing is believed to be the last sense to go. Assume they can hear you, even if they don't respond.
- **Deny them morphine or other needed pain medications**. "Getting addicted" is not a concern. Their comfort should be your main concern.
- **Assume that they are hallucinating** when they tell you that so-and-so is in the room. They just might be seeing someone you can't see!
- **Don't take it personally** if your loved one waits for you to leave the room to die. This is how THEY wanted it. Perhaps they wanted to spare you.

"There is love in holding and there is love in letting go." - Elizabeth Berg

Resources on Life, Death & Dying Well

Katy Butler, The Art of Dying Well: A Practical Guide to a Good End of Life (2019).

Margaret Rice, A Good Death: A Compassionate and Practical Guide to Prepare for the End of Life (2019).

Stan Goldberg, Lessons for the Living: Stories of Forgiveness, Gratitude, and Courage at the End of Life (2009).

Judith Johnson. *Making Peace with Death and Dying: A Practical Guide to Liberating Ourselves from the Death Taboo* (2022). Learn to live with greater purpose and passion, be more peaceful in the presence of death, and to approach death on one's own terms with wisdom and competency.

The Good Life Project (2024). Offers podcasts, tools, programs and experiences aimed at helping you live a more vital, meaningful life. See **Bucket Quiz** to help you discover where to focus to live best life now. https://www.goodlifeproject.com

Caitlin Doughty, *From Here to Eternity: Traveling the World to Find the Good Death*. Illustrated. 2017. A New York Times and Los Angeles Times Bestseller. Read to expand your sense of what it means to treat the dead with "dignity."

Advance Care Planning: A Conversation Guide (2023). A helpful FREE publication from the National Institute on Aging (NIH). Includes legal and healthcare needs; long-term care options; worksheets; choosing a health care proxy; and how to be a Health Care Proxy for another. https://order.nia.nih.gov/publication/advance-care-planning-a-conversation-guide

Your Guide for Talking with a Health Care Team in Handouts: How to talk about the care that is right for you or someone you care for (2021). The Conversation Project / Institute for Healthcare Improvement.

Hospice Nurse Julie McFadden, R.N., B.S.N. Educates and advocates for open discussions about how we die/how it's a natural process. Follow her posts social media posts.

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Hospice Nurse Hadley Viahos, R.N. Death-Positive Educator & New York times bestselling author of *The In-Between: Unforgettable Encounters During Life's Final Moments* (2023). https://nursehadley.com/; https://nursehadley.com/; https://nursehadley.com/; https://nursehadley.com/; https://nursehadley.com/;

Katie Duncan. *The Dying Process: Your Essential Guide to Understanding Signs, Symptoms & Changes at The End of Life* (2021). A Nurse Practitioner, educator and Death Coach explains the dying process from three to one 1 month... to hours/minutes before death...and what you can do to help.

The Art of Dying Well Podcast (2024). The Centre for the Art of Dying Well at St. Mary's University. Focus is on Dying Well, Talking About Death, Facing Death Personally, Bereavement and Caring for the Dying. https://www.artofdyingwell.org/

CAKE (2024). Resources and directory for end-of-life planning. https://www.joincake.com/welcome.

National Hospice and Palliative Care Organization (NHPCO, 2024). Includes information for patients and caregivers; plus directory of hospice, palliative care and bereavement service providers. https://www.nhpco.org.

Final Wish (APP). One of the mantras of every funeral pre-planning arrangement is to make your wishes clear to your loved ones. Final Wish is a tool that makes this easy to do. Photo galleries, questionnaires, social media.

iFuneral (APP). Pick your music, casket, outline your burial/cremation plans. This Apple app allows you to make clear all those things you would like done at your funeral so that your family has a physical resource to turn to.

Once I've Gone (APP). Helps you organize both your death & your life. You can store important documents, messages, final wishes. There's a Bucket List option to check off desired experiences. Designated people can access after you're gone.

WeCroak (APP). Bhutanese folk saying that to be truly happy, a person must contemplate death five times a day. To this end, WeCroak sends a reminder five times a day that you will someday die...so you will appreciate the moment.

Barbara Karnes, R.N. **By Your Side: A Guide for Caring for the Dying at Home** (2022) workbook; plus a series of nuts-and-bolts booklets to guide and support anyone who is addressing end-of-life situations, including Living with a Life-Threatening Disease, End-of-Life Pain, The Dying Experience, Losing a Pet, and Grieving. www.bkbooks.com

Linda Bryce, The Courage to Care: Being Fully Present with the Dying (2021).

"90+ Death Quotes that will Comfort & Inspire You." (2024). Sympathy Message Ideas. https://www.sympathymessageideas.com/death-quotes

The Inspired Funeral Website (2024). Wisdom for all phases of the end of life. Living memorials, end-of-life readings, obituary platform, funeral/ritual/burial ideas/templates to download. https://theinspiredfuneral.com/.

Kirsten DeLeo, Present to the End: A Caring Companion's Guide for Accompanying the Dying (2019).

Walk with me to the water, when it comes my time.
What we say will not matter, Just keep your hand in mine.
I'll cross the water by myself, I know that's what I must do.
But the chilling sting won't be felt, Because I've walked with you.

- Nellie Keller

Notes: