

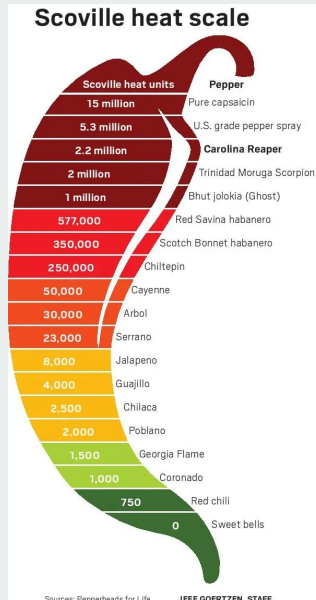
# Don't Fear the Reaper!

Discussing End-of-Life Wishes with Loved Ones

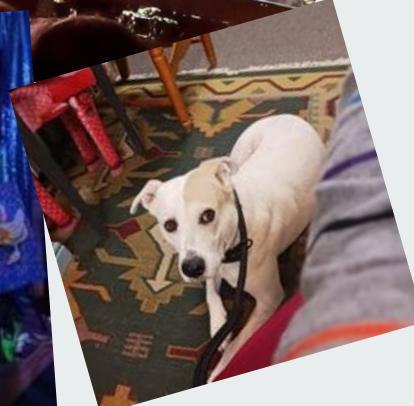


**NOT AN  
ATTORNEY!  
CANNOT GIVE  
LEGAL  
ADVICE!**

Presented by:  
Carrie Forbes, MLS  
Liaison Librarian for Nursing  
East Carolina University, Laupus  
Library  
EOL/Death Doula, NEDA  
Proficient  
[forbesc@ecu.edu](mailto:forbesc@ecu.edu)  
Text (252) 689-8734



# A little about me...

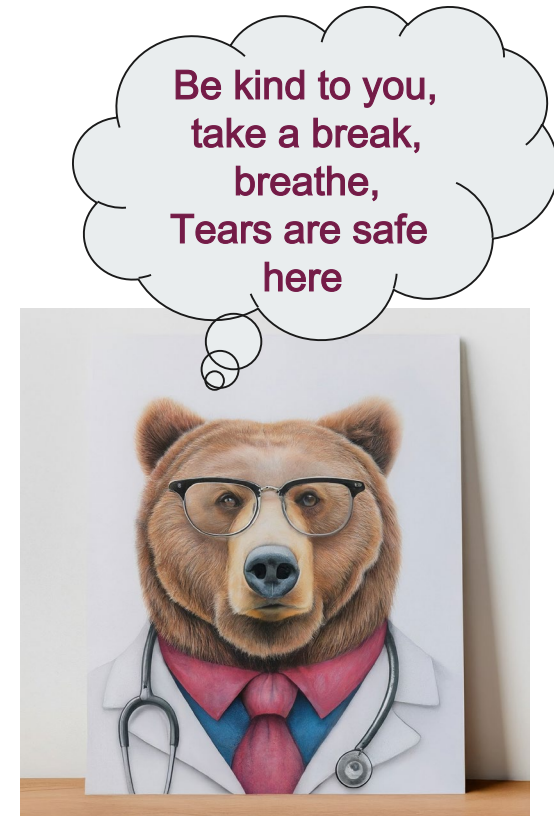


Presented by:  
**Carrie Forbes, MLS**  
Liaison Librarian for Nursing  
East Carolina University,  
Laupus Library  
EOL/Death Doula, NEDA  
Proficient  
[forbesc@ecu.edu](mailto:forbesc@ecu.edu)  
Text (252) 689-8734

# What we'll cover today:



- Why this conversation matters
- What are Advance Directives anyway?
- Death over dinner... and other ways to talk about the end-of-life
- Q&A



# Why this discussion matters

## We are ALL going to die

- Fear of loved ones being seriously ill (#5)
  - Fear of our loved ones dying (#6)
- (Chapman University, <https://tinyurl.com/58j8pnfa>)

## Death is inevitable and a natural part of life

- Leading causes of death in 2021: Heart disease, cancer & COVID-19 (USAFACTS, <https://tinyurl.com/ya6db4d5>)

Only 45% of Americans have a living will according to a 2020 Gallup poll. (AARP, <https://tinyurl.com/4ss2bkm6>)



Image from:  
<https://www.pinterest.com/pin/459226493258871944/>



# Why this discussion matters

## Our older population is getting older and living longer

- The **average lifespan** of Americans in 2023 is 76
- There are currently 56+ million adults **over 65**
- You **will most likely become** a caregiver
  - **Caregiver Crisis**

## By 2038, US could have more deaths than births

- In 2018 there were over 92.2 million adults over 55
- Of those, 15.2 million do not have children  
(Elliot, <https://tinyurl.com/2swy9mk5>)



**“The last thing I remember, I was sitting in a staff meeting. Apparently, I died of boredom.”**

Image from: <https://www.glasbergen.com/about-death/>

# Why this discussion matters

**Title:**  
Barbie The Movie |  
**Thinking About  
Dying**

**By:**  
Barbie The Movie

**Date:** October 16,  
2023

Barbie The Movie. (2023, Oct.,  
16). *Barbie the movie: Thinking  
about dying* [Video]. YouTube.  
<https://tinyurl.com/mudskkn6>



# Advance Directives & Other End of Life Decisions

**Title:** Doc Vader Talks “End-of-Life”

**Author:** @ZDoggMD

**Date:** September 26, 2023

@ZDoggMD. (2023, September 26).  
*Doc Vader talks “end-of-life”* [Video short]. YouTube.  
<https://tinyurl.com/3ee8vkc8>



<https://www.youtube.com/shorts/DQadYOQ2LnA>

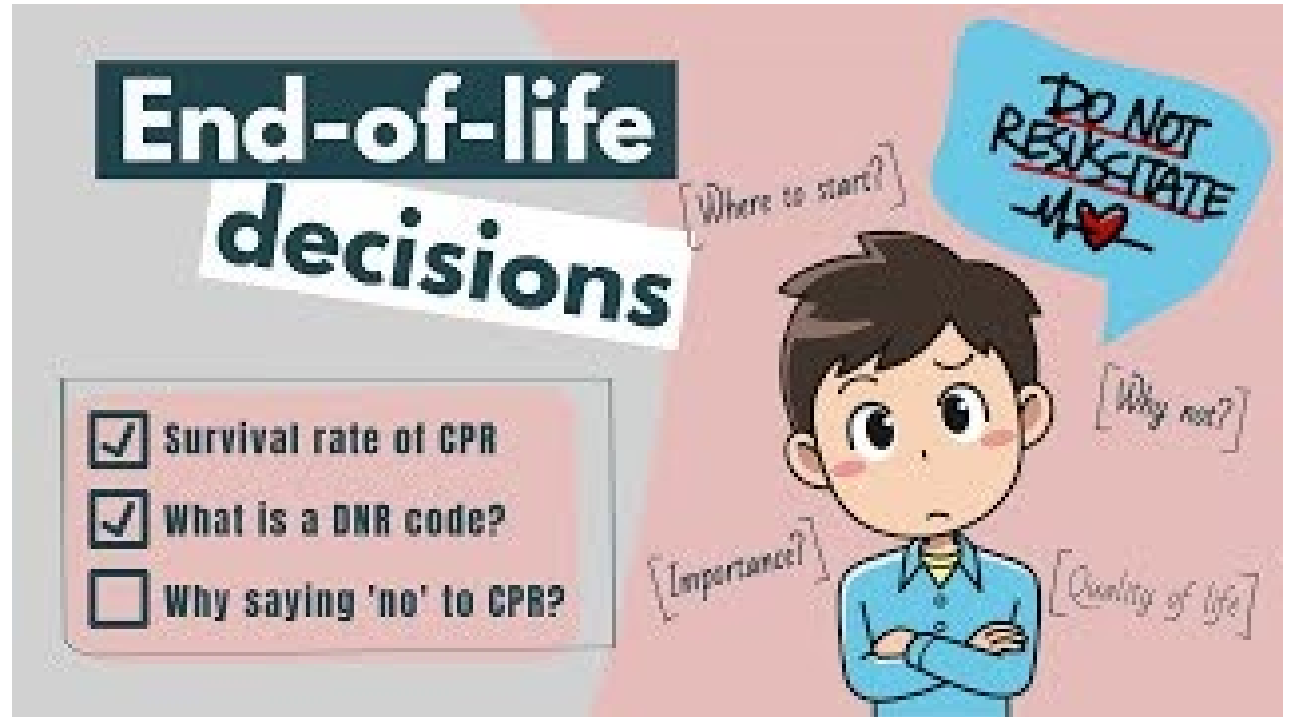
# Advance Directives & Other End of Life Decisions

**Title:** End-of-Life Planning - Do you want to be resuscitated?

**Author:** Dr. Paulien Moyaert

**Date:** 2022

Moyaert, P. (2022, March 25). *End-of-life planning: Do you want to be resuscitated?* YouTube. <https://tinyurl.com/2jzumfw9>





# Advance Directives & Other End of Life Decisions

## End-of-Life Document Terminology (*Can be very confusing!*)

<b>Advance care planning</b>	Involves <b>learning &amp; thinking about</b> your preferences for future healthcare needs
<b>Advance Directive/s</b>	A general term for a set of documents that designate your <i>chosen health care decision maker</i> (in the event you are incapable) and outlines your personal goals and values for future health care.
<b>DNR</b>	Do Not Resuscitate order
<b>POLST</b> <a href="https://polst.org/">https://polst.org/</a>	A portable order for life sustaining treatment ( <b>a doctor's order</b> ) goes under several different titles, similar to Advance Directives



Image from <https://tinyurl.com/4rnpzwex>

# Advance Directives & Other End of Life Decisions

## A closer look at Advance Directives:

<p><b>Advance Directive/s</b></p> <p><i>Also known as:</i></p> <ul style="list-style-type: none"><li>• Advance Healthcare Directive/s</li></ul> <p><i>**Sometimes incorrectly referred to just as a <b>Living Will</b></i></p>	<p>A general term for a <b>set of documents</b> that designate your <i>chosen health care decision maker</i>(in the event you are capable of making decisions) and outlines your personal goals and values for future healthcare care.</p> <p><b>Can be comprised of:</b></p> <ul style="list-style-type: none"><li>• <b>A Living Will</b></li><li>• <b>A Healthcare Power of Attorney</b></li><li>• <b>A DNR (Do Not Resuscitate) Order</b></li><li>• <b>Donor Registry Enrollment Form</b> (<i>sometimes</i>) <a href="https://www.donatelifenc.org/">https://www.donatelifenc.org/</a></li></ul>
<p><b>Living Will</b></p>	<p>Instructions for your personal wishes for the type of care that you want in the event you are unable to speak for yourself - <b>ONLY</b> applies to health care</p> <ul style="list-style-type: none"><li>• <b>Free options available online</b></li></ul>

# Advance Directives & Other End of Life Decisions

## A closer look at Advance Directives:

<b>Health Care Power of Attorney</b>	<p><b>Thing 1: A PERSON</b> chosen to make health care decisions for you in the event you are unable to.</p> <p>Also known as: HCPOA, health care <b>proxy</b>, health care <b>agent</b>, health care <b>surrogate</b>, medical power of attorney, etc...</p>
<b>Health Care Power of Attorney</b>	<p><b>Thing 2: A LEGAL DOCUMENT</b> appoints and authorizes a person of your choosing to speak for you in the event you are medically unable, <b>MUST</b> be at least 18, mentally competent, and <b>MUST</b> be signed with 2 witness and a Notary Public.</p> <p>Also known as: <i>Durable</i> Power of Attorney for Health Care</p>



Image from: <https://tinyurl.com/2zubmfh6>

# Additional Terms to Know



<p><b>Will</b></p> <p>Also known as:</p> <ul style="list-style-type: none"><li>• <i>Last Will and Testament</i></li></ul>	<p>Legal document that describes how a person's estate (property, money, financial assets) will be distributed and managed when they die.</p> <ul style="list-style-type: none"><li>• An executor is the person appointed to administer the last will and testament.</li></ul>
<p><b>Durable (Financial) Power of Attorney</b></p> <p>Also known as:</p> <ul style="list-style-type: none"><li>• <i>DPA</i></li><li>• <i>Legal agent</i></li><li>• <i>Legal proxy</i></li><li>• <i>General POA</i></li><li>• <i>Special POA</i></li></ul>	<p>A legal document that gives a trusted person of your choosing the authority to make legal and financial decisions for you in the case that you cannot make those decisions for yourself.</p> <p>Also refers to the actual person</p> <p><b>To learn more about the two types of POA's:</b> <a href="https://tinyurl.com/mrf8msfh">https://tinyurl.com/mrf8msfh</a></p>



# Free Resources for Advance Care PLANNING

- NIH: National Institute on Aging
  - Advance Care Planning FREE Guide
    - <https://tinyurl.com/mr2bhubm>
- ECUHealth Advance Care Planning
  - Advance Care Planning FREE Guide
    - <https://tinyurl.com/3xsxh4b4>
- Hospice Foundation of America
  - What Are Advance Directives FREE Guide
    - <https://tinyurl.com/3x7tysxs>



# Free Resources for Advance DIRECTIVE FORMS



## **NORTH CAROLINA Advance Directive Planning for Important Healthcare Decisions**

Courtesy of CaringInfo  
[www.caringinfo.org](http://www.caringinfo.org)  
800-658-8898

CaringInfo, a program of the National Hospice and Palliative Care Organization (NHPCO), is a national consumer engagement initiative to improve care and the experience of caregiving during serious illness and at the end of life. As part of that effort, CaringInfo provides detailed guidance for completing advance directive forms in all 50 states, the District of Columbia, and Puerto Rico.

This package includes:

- Instructions for preparing your advance directive. Please read all the instructions.
- Your state-specific advance directive forms, which are the pages with the gray instruction bar on the left side.

**BEFORE YOU BEGIN**

- **NC SECRETARY OF STATE**
  - <https://tinyurl.com/mtnt6e3e>
  - Affordable online cloud storage registry
- **Five Wishes**
  - <https://www.fivewishes.org/>
  - Plain language
  - Small charge for digital or print copy
- **AARP Advance Directives**
  - Available for every state
  - <https://tinyurl.com/2ef849uf>
- **Check your Employee Assistance Programs**
  - May not be free. ECU - ComPsych

- **DON'T FORGET... YOUR DIGITAL ACCOUNTS**
  - <https://tinyurl.com/4ua97sed>



# Ideas: The Dreaded Conversation

## EVENTS

Free conversation guide:

- **Death over Dinner (I wasn't kidding!)**
  - <https://deathoverdinner.org/>
- 1. Invites people to have an **open conversation** about death/dying
- 2. **Share a meal** while engaging in conversation
- 3. Helps to **break the taboo** of death/dying
- 4. **Topics can range** from personal experiences with loss, cultural attitudes, funeral preferences, etc...
- 5. Meaningful **connection**



Image from:  
<https://www.orderofthegooddeath.com/article/dremains/>

# Ideas: The Dreaded Conversation



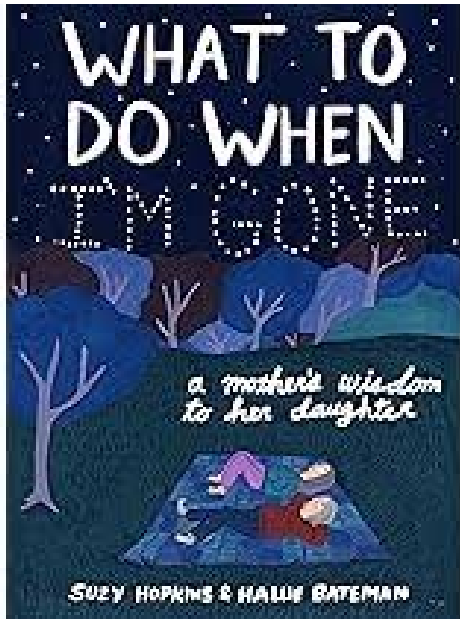
Official logo of "Death Cafe" from  
<https://deathcafe.com/418/>

## EVENTS:

A group of people (often strangers) who get together over a hot beverage and dessert, to have the opportunity to informally talk about death.

- **Bernard Crettaz, Swiss sociologist** - "Cafe Mortals" in 2004
- **Jon Underwood** - Quit his job to bring bring the idea of "Death Cafes" to London in 2011
- [Underwood passed away in 2017](#) from acute promyelocytic leukemia at the age of 44, stated it was "the most meaningful work of his life"
- By 2019, 6000+ death cafe events

# Ideas: The Dreaded Conversation



BOOK: What To Do When I'm Gone: A Mother's Wisdom To Her Daughter

By: Suzy Hopkins & Hallie Bateman

- Practical day by day guide to surviving after the loss of a parent
- Thoughtful insights, recipes, parental guidance on marriage, sex, relationships, emotional health, decision making
- Share with a parent or a friend & discuss
- This was a huge help to me after my Dad died

# Ideas: The Dreaded Conversation

## BOOK: Can't We Talk About Something More Pleasant



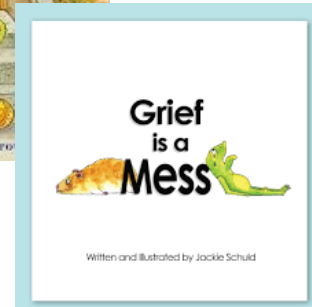
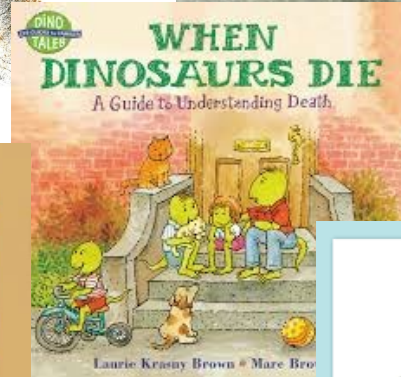
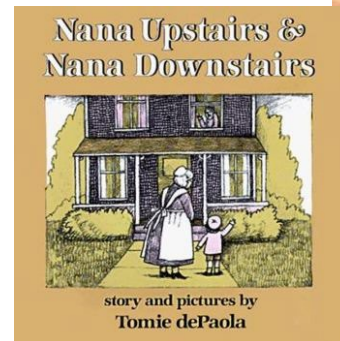
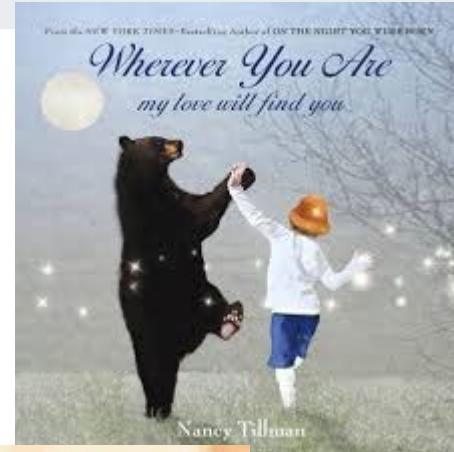
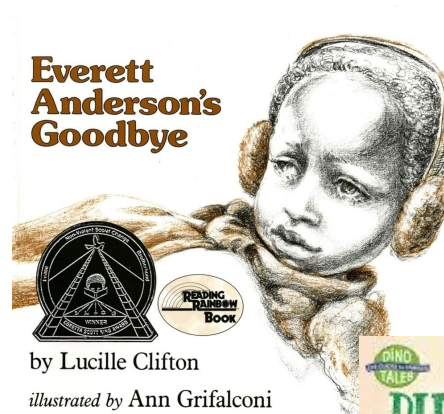
An Interview with author/artist Roz Chast on her book:  
"Can't We Talk About Something More Pleasant?"  
<https://www.npr.org/transcripts/310725572>

- By Roz Chast, an illustrator for The New Yorker, 2014
- Award winning graphic novel
- Themes:
  - Sandwich gen caregiving
  - Mental & emotional toll
  - Time, energy, expense, and STUFF
  - Talking about difficult subjects with parents

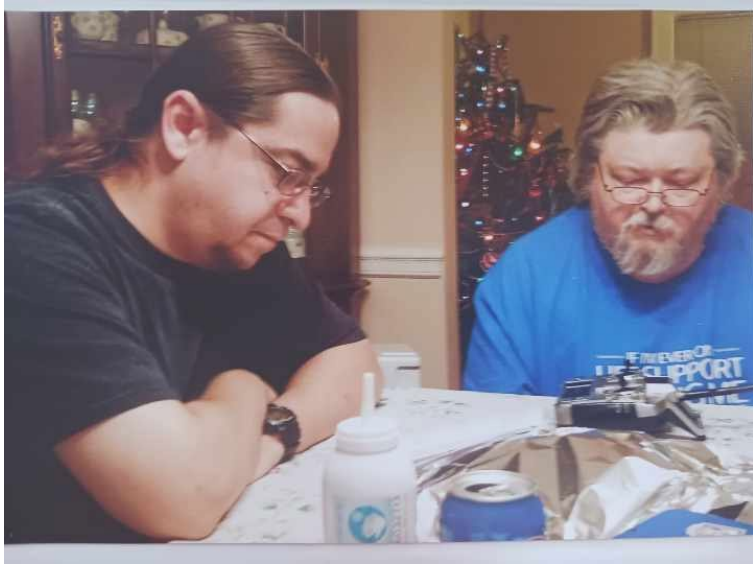
# Ideas: The Dreaded Conversation

## Children's Illustrated Books

- **Everett Anderson's Goodbye** by Lucille Clifton, Illustrated by Ann Grifalconi
- **Grief is a Mess** by Jackie Schuld
- **Nana Upstairs & Nana Downstairs** by Tomie dePaola
- **When Dinosaurs Die** by Laurie Brown, Illustrated by Marc Brown
- **Wherever You Are My Love Will Find You** by Nancy Tillman



# Ideas: The Dreaded Conversation



- **Talking is easier over shared projects or crafts –**
  - Start a scrapbook using pictures of deceased loved ones & ask about what it was like to lose that person
  - Personal book of memories or stories, you type/write & listen, while they share
- **Ask for help** in preparing for your own future –
  - What would you do if you were me? What should I think about? Prepare for?
  - How did your parents or family handle death?
- **Offer to visit the cemetery** where a deceased loved one is buried.



# Ideas: The Dreaded Conversation

<https://bkbooks.com>

## Barbara Karnes Booklet & Book Resources

- Renowned Hospice nurse & pioneer, end-of-life educator
- Been at the bedside of hundreds of dying people throughout her career
- Teaching is profound, but uses simple, plain language
- Easy to discuss, share during all aspects of end-of-life
- By Your Side - Fully explains advance directives, how to work with funeral home, make plans, etc...



# Ideas: The Dreaded Conversation



## Card Games & Board Games

- Elephant in the Room
  - <https://tinyurl.com/5cz39tjt>
- The Grief Deck
  - <https://griefdeck.com/>
- Heart to Heart
  - <https://tinyurl.com/mtvzyw9k>
- Hello Game
  - <https://tinyurl.com/ykc4xwmj>
- ANY Card Game!

# End-of-Life Doula & Grief Resources:

---

ALL of the information shared today can be found on this corresponding libguide:

<https://tinyurl.com/SupportingEOL>



# Additional References:



<https://trustandwill.com/learn/advance-directive-vs-living-will>

<https://thelastjourney.info/advance-care-planning/step-5-create-your-advance-directive/>

<https://www.cancer.gov/publications/dictionaries/cancer-terms/def/durable-power-of-attorney>

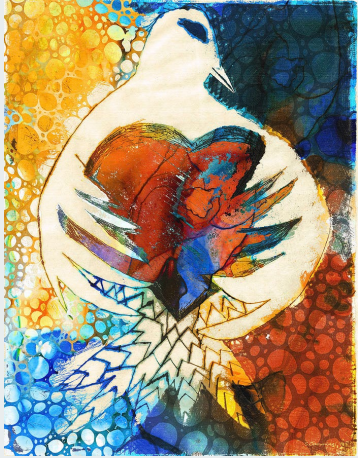
<https://vtethicsnetwork.org/medical-decision-making/how-to-begin/faqs-about-advance-directives>

<https://www.winstonmedical.org/visitors-patients/advanced-directive/>

<https://tinyurl.com/4v35e82a>

# Don't Fear the Reaper:

*Discussing End-of-Life Wishes with Loved Ones*



*Comfort* by Sharon Cummings  
January 2021  
Mixed Media:  
<https://tinyurl.com/vp6mc78d>

## Questions?

**Instruction Survey:**

<https://tinyurl.com/2t5sefkt>



Presented by:  
**Carrie Forbes, MLS**  
Liaison Librarian for Nursing  
East Carolina University  
EOL/Death Doula, NEDA Proficient  
[forbesc@ecu.edu](mailto:forbesc@ecu.edu)  
Text (252) 689-8734