

From Curiosity to Courage : Values and Choices

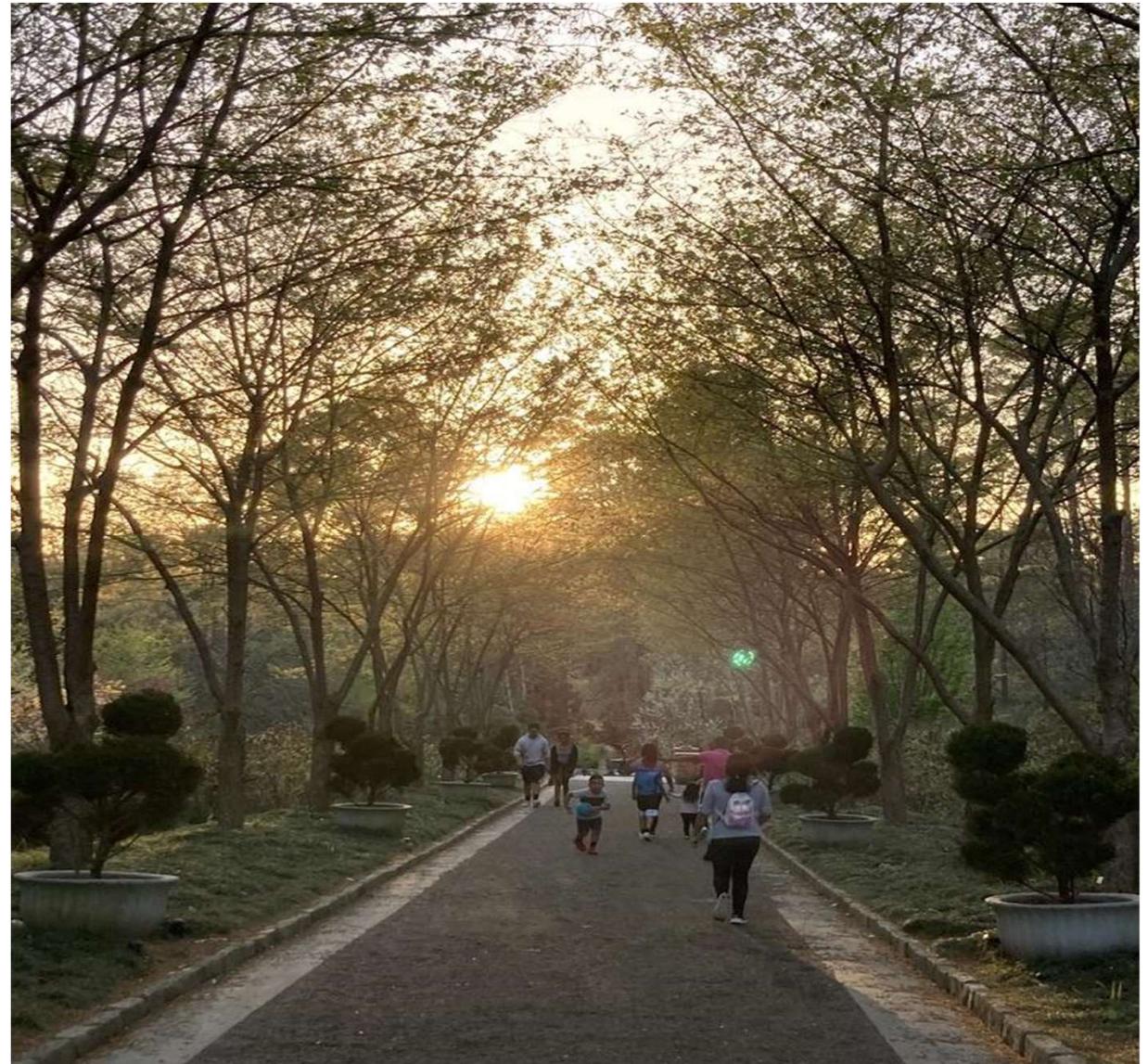


Dixcy Bosley RN, MSN, FNP

*AIDS/ Oncology/ Hospice Nurse, Hospital Chaplain, Care Manager,
Daughter, End of Life Advocate/ Activist*



PLANNING:
Temporary
measures we
take until
whatever
happens
happens



Steps along the path....



Understanding Your Health
Honest Talk with your Clinician
What Matters Most
Prolonging Life
Communicating / Documenting

**why don't we talk more
about goals of care?**



Death Denial

A death-denying culture
is one that is reluctant
to acknowledge
the reality of death and
tends to avoid
discussing it.



AREN'T YOU GUYS
A LITTLE OLD TO BE
LISTENING TO A ROCK
AND ROLL BAND?

7-11 11/18
THE ARENA
-TONIGHT-
**'60'S ROCK 'N'
ROLL BAND**

WE ARE
THE BAND.



Health Status of the Older Adult

Major health concerns:

Parkinsons, Afib (pacemaker), heart failure, earlier CABG 4, diabetes type 2, glaucoma. Weakness, balance.

Memory concerns: increasing. Can recite poetry in 4 languages and describe historical events and issues. Can also be confused about day, plans, what's happening

Primary Care Physician: Internist: Bradley Watkins 240-235-9100 (Johns Hopkins)

Specialists: (List all recent health providers)

Cardiologist: Edward Bodurian (Johns Hopkins) 202-960-1500

Endocrinologist: Shabina Ahmed 240-235-9120; ENT: Jessica Shen 301-652-8847

Gastroenterologist: Angelica Nocerino 202-295-0570; Urologist: Armine Smith 202-537-4498

Electrophysiologist: Alan Schneider (JH) 301-681-9095; Pulmonologist: Michael Solomon 301-656-7374

Ophthalmologist: Howard Weiss 301-654-5114; Retinologist: Reginald Sanders 301-656-8100;

Parkinsons Neurologist: Ishita Gambhir 202-295-0540 (Georgetown Neurology)

last medical visit: (June 29, 2023/ assistant to Primary)

last ER / hospitalization: (June 25, 2022/Sibley Hospital ER/Non responsive, unable to urinate)

Hearing loss: yes. Wears hearing aids

Vision loss: loss of vision left eye (retinal occlusion)

Medicine	Daily Prescription	FAMILY PHARMACY				
		Early 5	White 10	Blue 3	Red 5	Green 11
Eliquis (blood thinner)	5.0 mg (2.5 mg/2X a day)		1			1
Lipitor (Atorvastatin) cholesterol	40 mg.					1
Metformin; diabetes	2000 mg. (1000mg 2X/day)		1		1	
Protonix (Pantoprazole) reflux	20 mg.		1			
Lasix (Furosemide) diuretic	40 mg 2.5 (12 1/2 mg) 50 mg (one 25 mg. tab 2X/day)		1			
Metoprolol Succ ER beta blocker+			1			1
Flomax (Tamsulosin)	0.8 mg (two 0.4 mg. capsule)					2
Memantine HC (Namenda) memory	20 mg (one 10 mg. tab 2X/da)		1			1
Sinemet (Carbidopa/ Levodopa) Parkinson's	25/100 mg. (2.5 tabs 4X/day)	2.5		2.5	2.5	2.5
Myrbetriq ER (bladder)	25 mg.		1			
Bactrim 400/80 mg	1 tab/day					1
Nitroglycerin patch	0.1 mg (on AM, off PM)					
Claritin	1 tab					1
PreserVision	(1 tab 2X a day)			1		1
Acidophilus (digestion)	1 capsule			1		1
Centrum Silver (vitamins)	1 tab			1		
Glucosamin Condroitin Sulfate (arthritis)	2 tabs			2		
Latanaprost; glaucoma)	2 drops (1 drop each eye)		1 each eye			
Cosopt; glaucoma (Dorzolamide-HCL)	4 drops (1 drop each eye 2X/da)		1 each eye			1 ea
Brimonidine Tartrate	4 drops (1 drop each eye 2X/day)		1 ea eye			1 ea
Ipatropium 0.3%	2 sniffs each nostril 2X/da					
Ketoconazole 2%shampoo	1 X/week (scalp)	Ketoconazole 2% cream	as needed			
Desonide .05% cream	as needed					
Fluocinidine .05%	as needed for scalp					

Allergies, sensitivities

Penicillin (swelling), Codeine (breaking out), Viox (Rofecoxib) (breaking out); Persantine (Dipyridamole (shaking); Vesicare (Solisenacin) (dry mouth)
 Cortisone: Long-lasting high sugar after 4 injections in 6 mo. period

97 year old patient.... .

What are we doing wrong here????



Classic Signs of Denial:

1. Lack of open discussions
2. Over emphasis on youth and beauty
3. Medicalization of death / dying as a medical problem to be cured
4. Fear of aging - reminder of mortality
5. Obsession with immortality / technology
6. Lack of rituals / ceremonies around death
7. Discomfort with grief / mourning



How do you view your current health?

Young and healthy

Old and healthy

Chronically ill

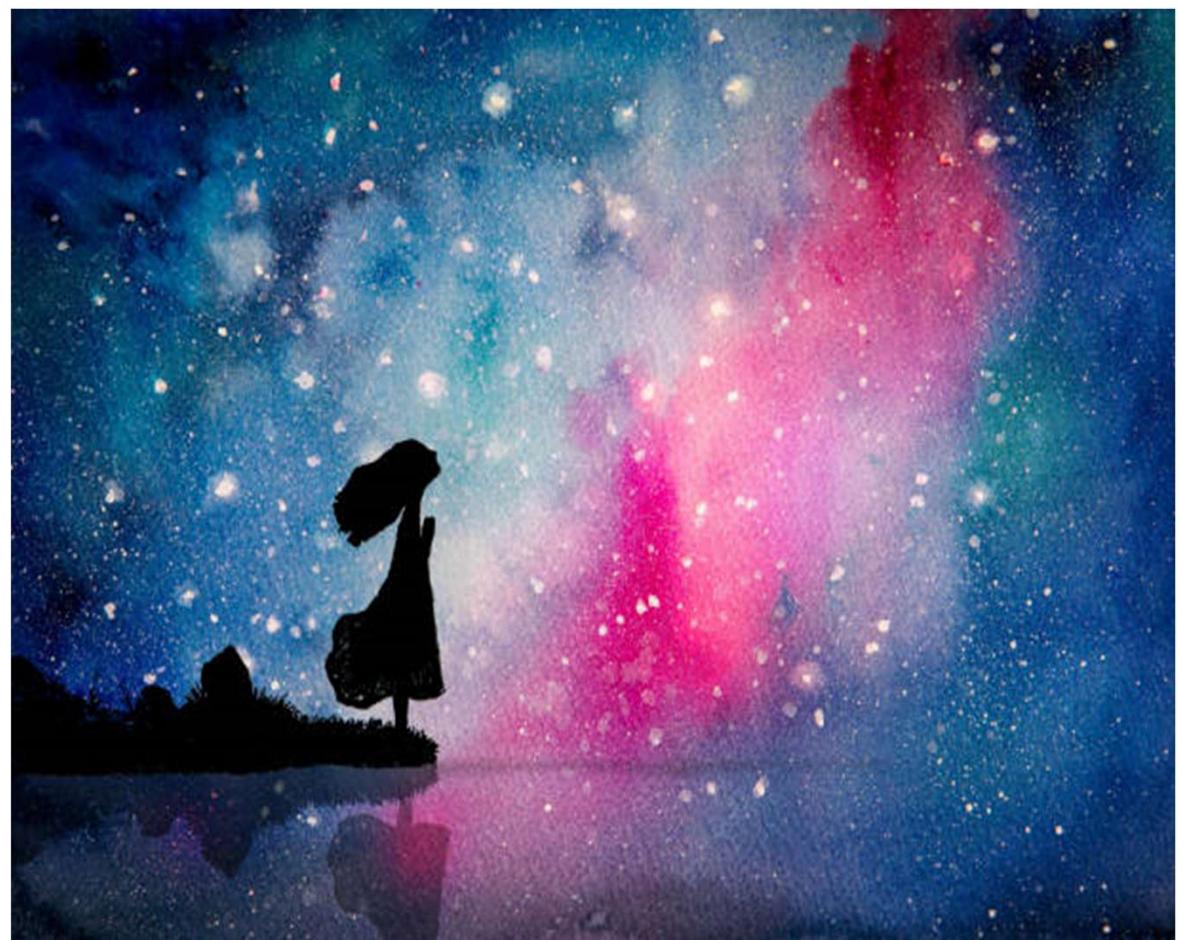
Seriously ill

Nearing death



How we die

Sudden death
Terminal illness
Organ Failure/
Chronic illness
Frailty



Step 1

Do I feel ready to have a conversation about death with :

myself?

someone who I love?

my clinician?

Step 2

How long do you want to receive medical care?

QUANTITY vs QUALITY OF LIFE

What are your concerns about medical care?

TOO MUCH vs TOO LITTLE

Step 3

Conversation starters :

“I need help with something that is important to me....”

“Remember when Aunt Mildred died....”

“Even though I feel fine today, I want you to do this if I am ever unable to speak for myself....”

“What does a good death look like to you?”

Ways to Practice the Conversation

- **Death Cafes**
- **Death over Dinner**
- **Death Positivity**
- **Death Podcasts**



Death Café



You are warmly invited to join a lively conversation about a subject that we shouldn't be so quiet about.

2/27, 4/3, 5/15, 6/26
3/7, 9/18, 10/30, 12/11
7-8:30 PM

Fenway Community Center
101 Boylston Street, Boston
(entrance on Jersey Street)
fenwaycommunitycenter.org

Carol Lasky
Facilitator



This is a conversation group other than grief support or counseling. Sweet treats will be provided.

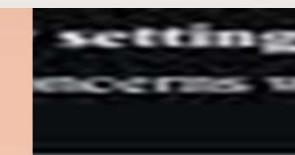
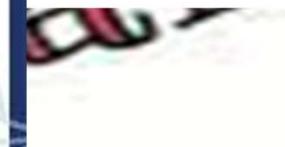


Death



Death Café

JOIN US!
SATURDAY, APRIL 3, 2021



DEATH CAFE

Last Tuesday of Every Month
7 - 9 PM

The Green House

(505 E. Washington in Iowa City)

Please join us for a lively, informal, and open-ended conversation about the end of life and what we make of it.

We have several hostesses and will move space for the group but the conversation is shaped by those who attend. Please support our host, The Green House, by purchasing a beverage. Free cake will be provided!

This is not a grief support group.

Visit deathcafe.com to learn more.



Life & Death Café

Zoom Meeting last Tuesday
of each month



Aging solo is
not
for sissies

Emmy Lu and Fritz





FINDING YOUR HEALTH ADVOCATE

Who will protect me and my wishes?

Qualities : Trustworthy, integrity, assertive, Knowledgeable, confident, objective, and ****understands and honors your goals and values

Who: Friends, family, constructed relationships, professionals

Risks: Court appointed guardian, financial vulnerability, no control.



No FAKE NEWS:

Get the facts from your clinician

- Understand the patterns of medical trajectories
- What treatment might offer optimal health?
- What treatments have potential benefits and burdens?
- If living longer, how much more life to expect?
- What potential symptoms will I encounter?
- Goal is TRUTH.

Bring a friend so the provider has a witness to help gather and retain information. Avoid going alone.



**Doctor: "Don't confuse
your Google search
with my 6 years of
medical school".**

©Addiction Actually

**Patient: "Don't confuse
the one-hour lecture
you had on my
condition with my 20
years of living with it".**



**Story
of Julie and Dominique
Early Hospice=
Prolonged life**





Bad news is hard to give and take

Studies show that providers tend to
OVER- estimate prognosis

30 % accurate prognosis

63 % over optimistic

17% under optimistic

WHY?



“How we seek to spend our time may depend on how much time we perceive ourselves to have”

Dr Atul Gawande



What makes life worth living?



What MATTERS MOST to YOU



What MATTERS MOST to YOU

What is your conception of a life worth living?

- **Every second counts, no matter my condition**
- **Free from pain**
- **Able to engage in relationships**
- **Retaining autonomy**
- **Retaining mentation over comfort**
- **Engaging in work, tasks meaningful to me.**
- **Being able to live in my own home**
- **Not being a burden to my family and friends**
(financially, emotionally, practically, physically)





Here are things to ask.....

Could you tell me like it is? I need to know so I can plan.

You see a lot of patients with this disease. What is the pathway my disease is likely to take?

Would you be surprised if I were alive in five years? One year? Six months?

What are the benefits and burdens of the treatments you are suggesting? What are the alternatives ? What happens if we don't pursue them?

What would you choose to do if this were you, your partner, your parent?



From Curiosity to COURAGE

Choosing the
untraveled path
requires self
awareness, informed
prognosis, family
support and true
courage to face death

What makes YOUR life worth living?
What is YOUR ideal quality of life?

Allow for natural death ----- or



Keep me alive at all costs

PROLONGING YOUR LIFE

How we keep folks alive despite poor prognosis

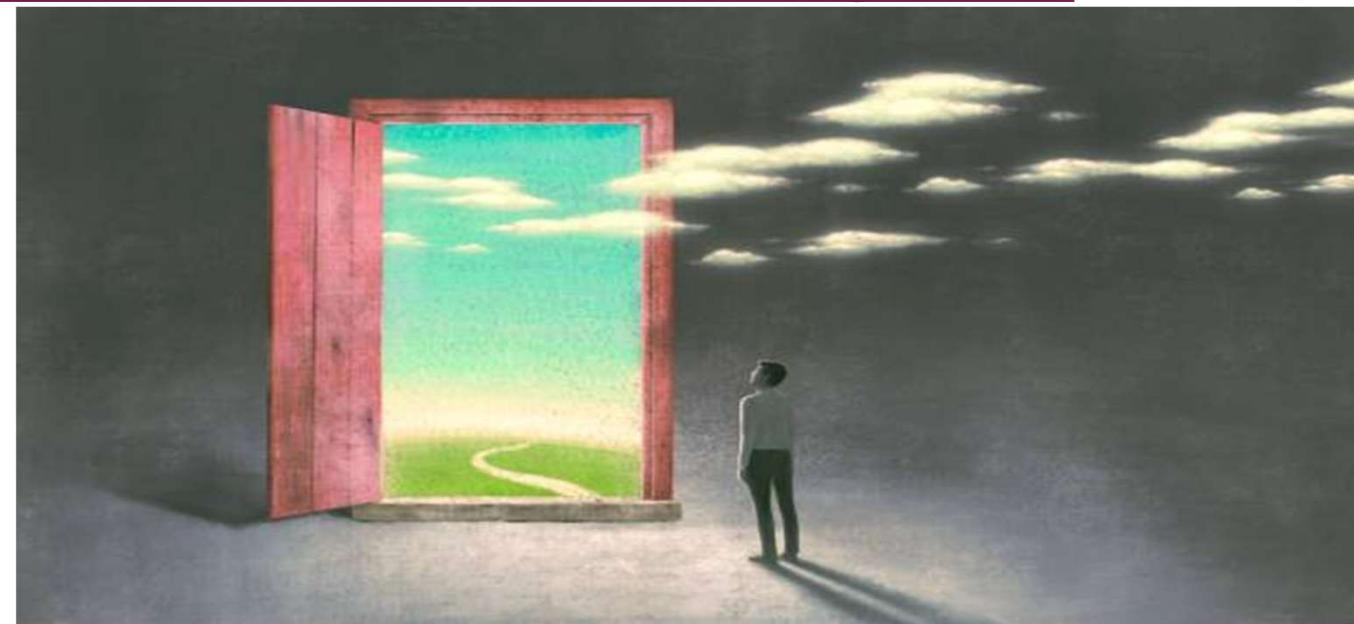
Breathing machines

Feeding tubes

Dialysis

Transfusions

Antibiotics



Surveys show that most people including clinicians do NOT want heroic measures and YET.....



**“Dying doesn’t cause suffering.
Resistance to dying does.”**

Dr. Ira Byock

How to Advance END OF LIFE

Palliative compassionate extubation

Palliative sedation

Palliative (not curative) radiation or chemotherapy

Stopping Implantable Cardioverter Defibrillators ICDs

Voluntary Stopping Eating / Drinking (VSED)

Stopping dialysis

Stopping Extracorporeal Membrane Oxygenation ECMO

Medical aid in dying

MAID Provider Components: How do you access the law?

Prescribing physician :

Assess and evaluate patient eligibility, document

Follow compliance process, provide written request form

Prescribe medication

Consulting physician:

Assess and evaluate patient eligibility, document, complete forms

Psychiatrists/ psychologists- optional in most states

Pharmacist : Fill the medication order

FOR Aid-in-Dying Patient
ADDRESS Final Resting Place DATE Death Day

R

Digitalis 100mg; Diazepam 1gm; Morphine 15gm;
Amitriptyline 8gm; Phenobarbital 5gm.

Dispense as powder.

Sig: Mix to 2 ounces with apple juice or water. Take
the liquid suspension by mouth, using no more
than 2 minutes to swallow it all. If burning occurs,
use spoonfuls of sorbet to calm it down.

II

REFILL Zero TIMES

✓

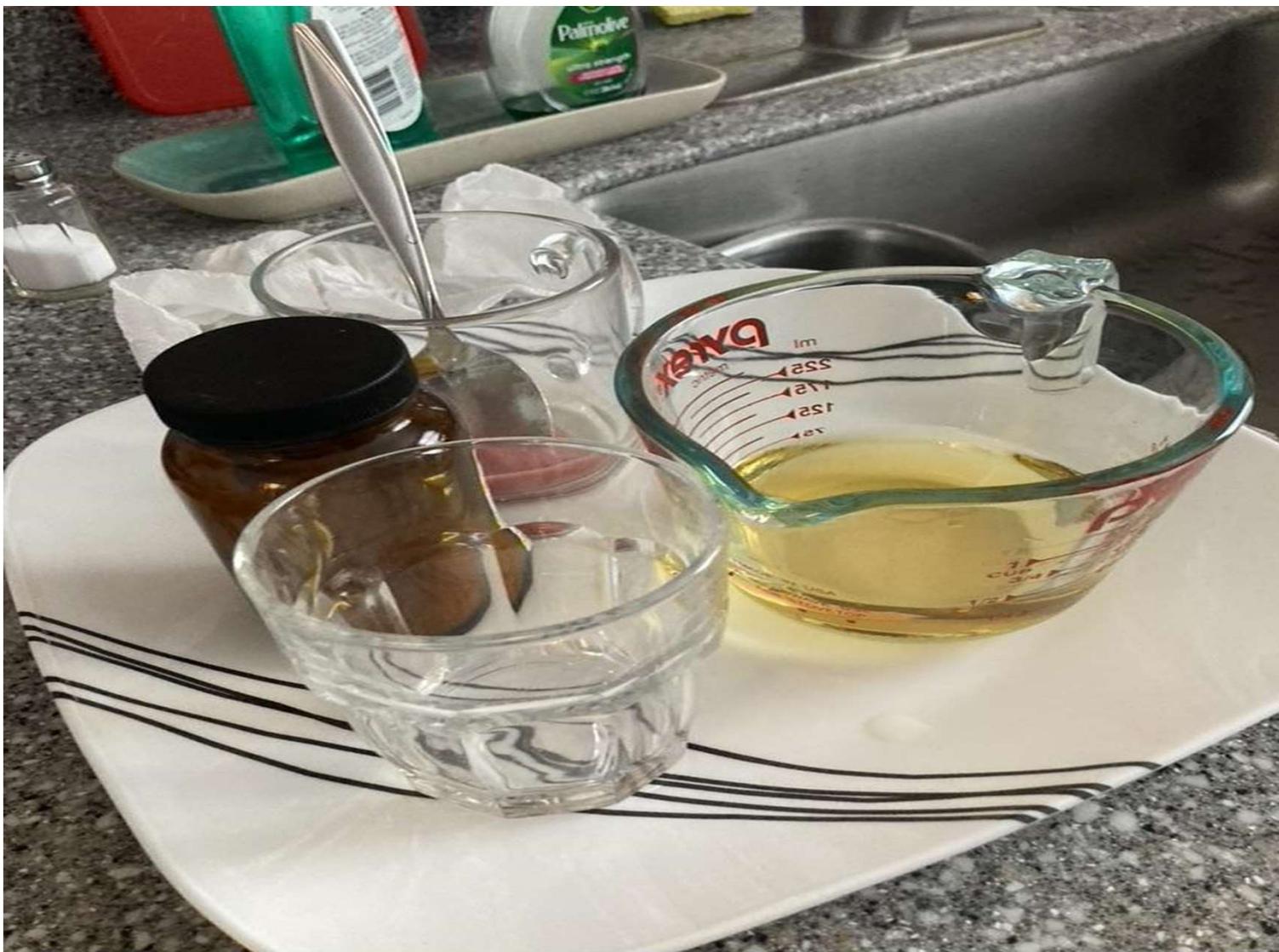
DO NOT SUBSTITUTE

M.D.

Aid-in-Dying clinician M.D.
SUBSTITUTION PERMISSIBLE

DEA NO. _____

ADDRESS



Maryland End of Life Option Act



After Brittany Maynard was diagnosed with glioblastoma multiforme, an aggressive form of brain cancer, she and her husband Dan Diaz moved from California to Oregon so she could have the option to utilize Oregon's Death with Dignity Act. California did not legalize medical aid in dying until the year following Maynard's death.

Dan Diaz said the End-of-Life Option Act will have no negative impact on vulnerable populations, like the elderly and disabled. To qualify for medical aid in dying, a patient must be terminally ill, mentally competent and able to self-administer the medication.

“This does not result in more people dying. This simply results in fewer people suffering,” Diaz said.

The End-of-Life Option Act will have hearings in 2026 Introduced four times...Don't give up on human rights.

LOSING OUR RIGHTS !!!!

What about DC's Medical Aid in Dying Law ????

**Appropriations Bill 7/25 “Enforces Constitutional
Oversight of DC”....thereby “repealing DC’s assisted
suicide legislation law”**

Welcoming community support / End of Life Options DC

Contact : www.CompassionandChoices.org

Communicate and Document

< 50 % family < 40 % provider 27 % Adv. Dir.

You may have the best plans but unless communicated and documented, chaos and suffering can result.

Care is impacted by not communicating.

Default is always treatment.

Early planning =

decreased excess treatment



A love letter to family about me

If you have to make a quick medical decision about me

Choose comfort

Choose home

Choose less intervention

Choose to be together with me,

holding my hand, me me singing, laughing, getting along,
resolving differences, telling stories. Don't make a fuss
and know I am proud of each of you.



Dear Family

If you have to make a fast decision...I fell or some event happens, it's ok.
I'll try to let you know what I would want but if you come to something
we not have anticipated, it's ok

And if you make a decision that ends my life, that's ok too

You don't need to worry that you caused my death because you haven't
The disease, and my age and body failing are why I died.

Please do not feel responsible

If you feel bad and guilty about any medical outcomes,

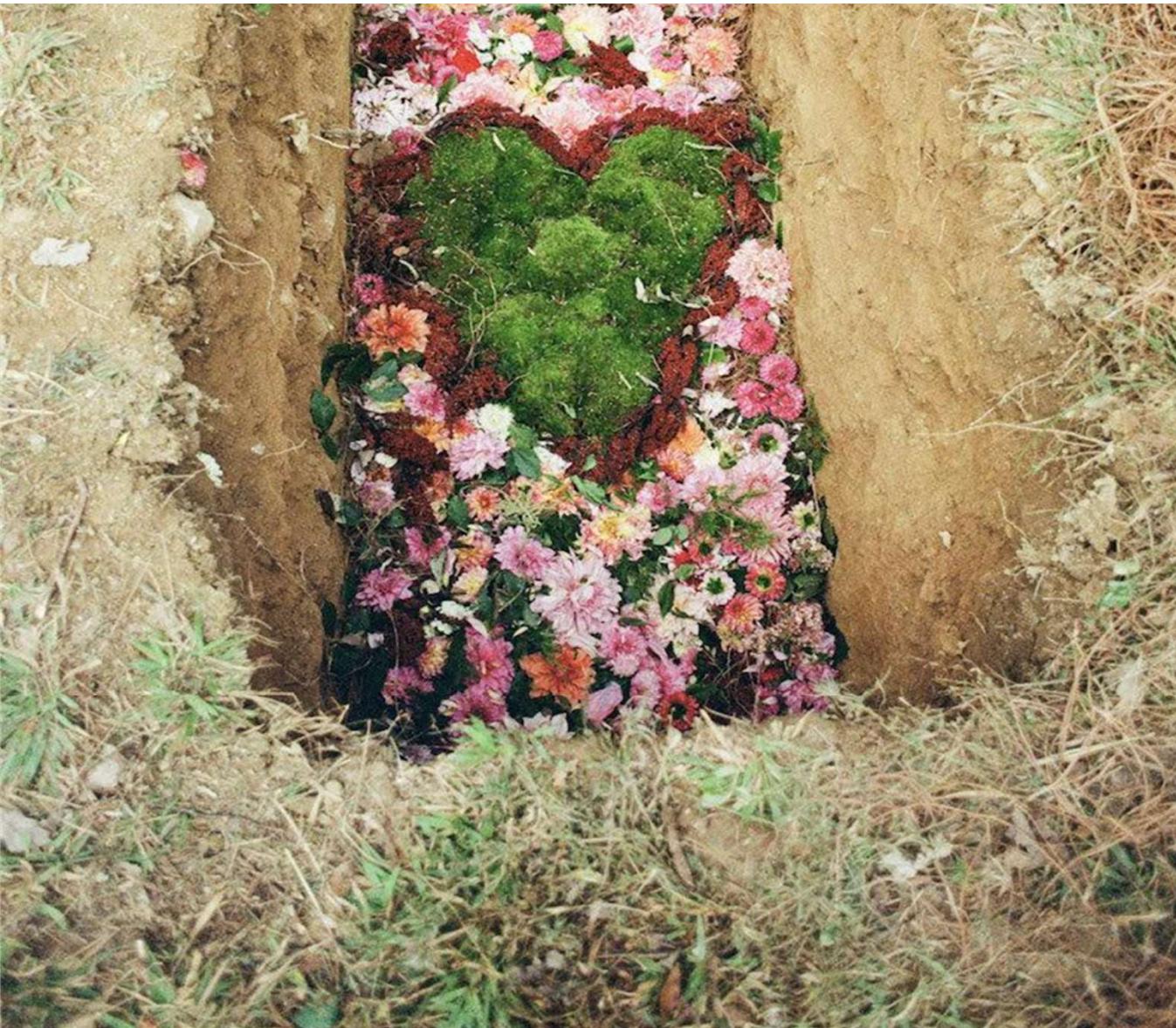
Please know I love you and forgive you and please love and forgive each
other

m



Larkspur Conservation: Preserve for natural burial TN

Upon my death I wish my body to be buried naturally without the use of chemical embalming, concrete, plastics and metals. I request that my body be buried at a conservation burial ground operated by Larkspur Conservation or other suitable conservation burial cemetery. It is my request that my family, power of attorney, or other person/agency tasked with the responsibility of my final disposition follows the request made herein.



land
*No chemicals,
concrete or
metals*
*Protects
wildlife,
reduces harm
and promotes
healing*









Tools to communicate

Advanced Directives

MOLST /POLST

Hospital DNR

Medical Alert bracelet

Letters/videos



Personal preferences : Tools to use

PREPARE prepareforyourcare.org

THE CONVERSATION PROJECT theconversationproject.org

GO WISH CARD GAME gowish.org

DEATH CAFE deathcafe.org

DEATH OVER DINNER deathoverdinner.org

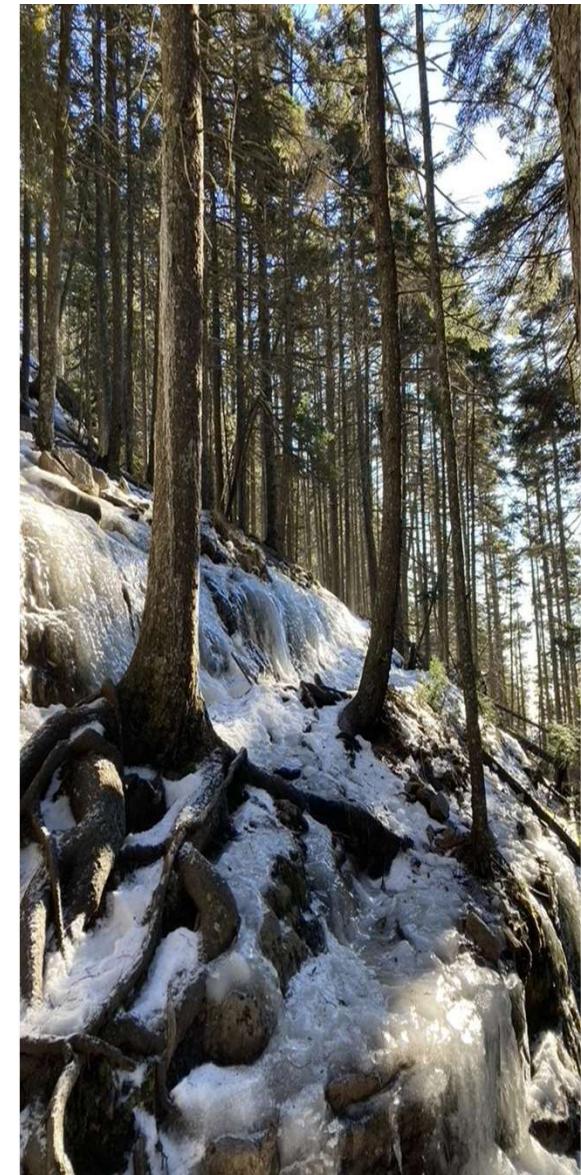
FIVE WISHES agingwithdignity.org/fivewishes

ADVANCED DIRECTIVES caringinfo.org

MY DIRECTIVES mydirectives.com

VITAL TALK vitaltalk.org

GET PALLIATIVE CARE getpalliativecare.org



Iona Senior Services
www.iona.org
Helpline: (202) 895-9448

Name: _____
Address: _____
Doctor: _____
Phone: _____
Language Spoken: _____ Sex: M F
Blood Type: _____ Religion: _____

Check All Medical Conditions That Exist

- No Known medical conditions Eye Surgery
- Abnormal EKG Glaucoma
- Adrenal Insufficiency Hard of Hearing
- AIDS Heart Valve Prosthesis
- Alcohol Addiction Hemodialysis
- Alzheimer's Hypertension
- Angina Internal Defibrillator
- Anxiety Irregular Heart Rhythm
- Asthma Kidney Failure
- Behavior Laryngectomy
- Snoring Disorder Leukemia
- Blind Lung Disease/Emphysema
- Cancer Lymphomas
- Cardiac Dysrhythmia Malignant Hypothermia
- Cataracts Memory Impaired
- Congestive Heart Failure Mental Illness
- Clotting Disorder Mental Retardation
- COPD Myasthenia Gravis
- Coronary Bypass Graft Pacemaker
- Deaf Previous Heart Attack
- Dementia Seizure Disorder
- Depression Sickle Cell Anemia
- Diabetes/Insulin Dependent Stroke
- Diabetes/Non-Insulin Tobacco Use
- Drug Addiction Vision Impaired
- Epilepsy/Seizures
- Other: _____

ALLERGIES

- No Known Allergies Environmental Penicillin
- Aspirin Horse Serum Soils
- Barbiturates Insect Stings Tetracycline
- Codeine Latex X-Ray Dyes
- Demerol Lidocaine Morphine
- Novocaine
- Other: _____

Date of last flu shot _____
Date of last pneumonia shot _____

EMERGENCY CONTACTS

NAME: _____
Address: _____
Relationship: _____ Phone: _____

NAME: _____
Address: _____
Relationship: _____ Phone: _____

HEALTH INSURANCE INFORMATION

Health Insurance Co. Name: _____
Policy Number: _____

Other Insurance Co. Name: _____
Policy Number: _____

Medicare Number: _____
Medicaid Number: _____

HEALTHCARE DECISIONS

Do Not Resuscitate Order on file? YES NO
If YES, Location: _____

Advance Directive on file? YES NO
If YES, Location: _____

To access File of Life, go to
www.MontgomeryCountyMD.gov
and search for "File of Life."

File for Life

Keep accurate
information on your
fridge and in your
wallet at all times.

The more your record
the more you will be
protected.

Compassion and Choices

MY END OF LIFE DECISION:

An Advanced Planning Guide and Toolkit

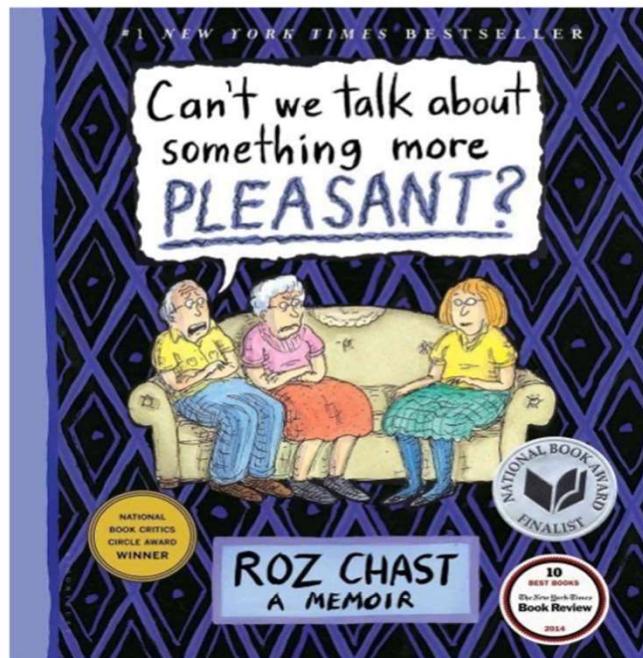
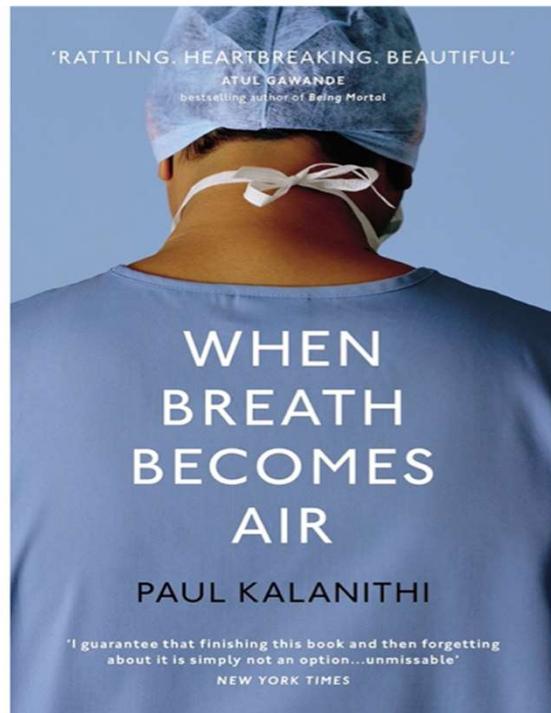
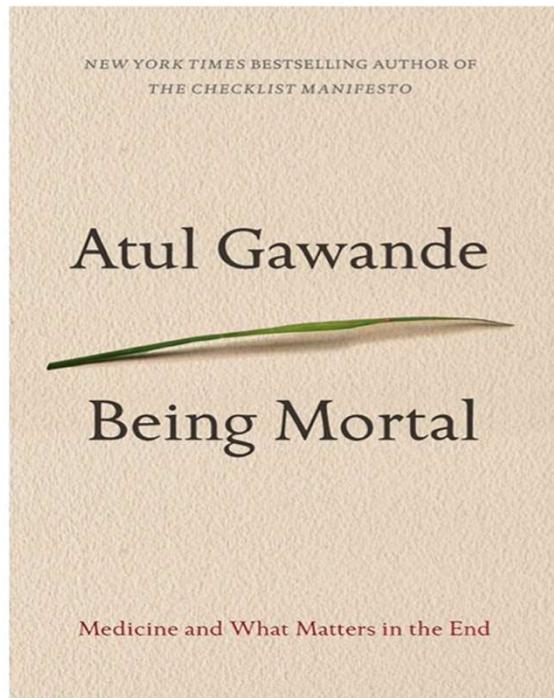
Order FREE copy

Wendy Minor

wminor@compassionandchoices.org

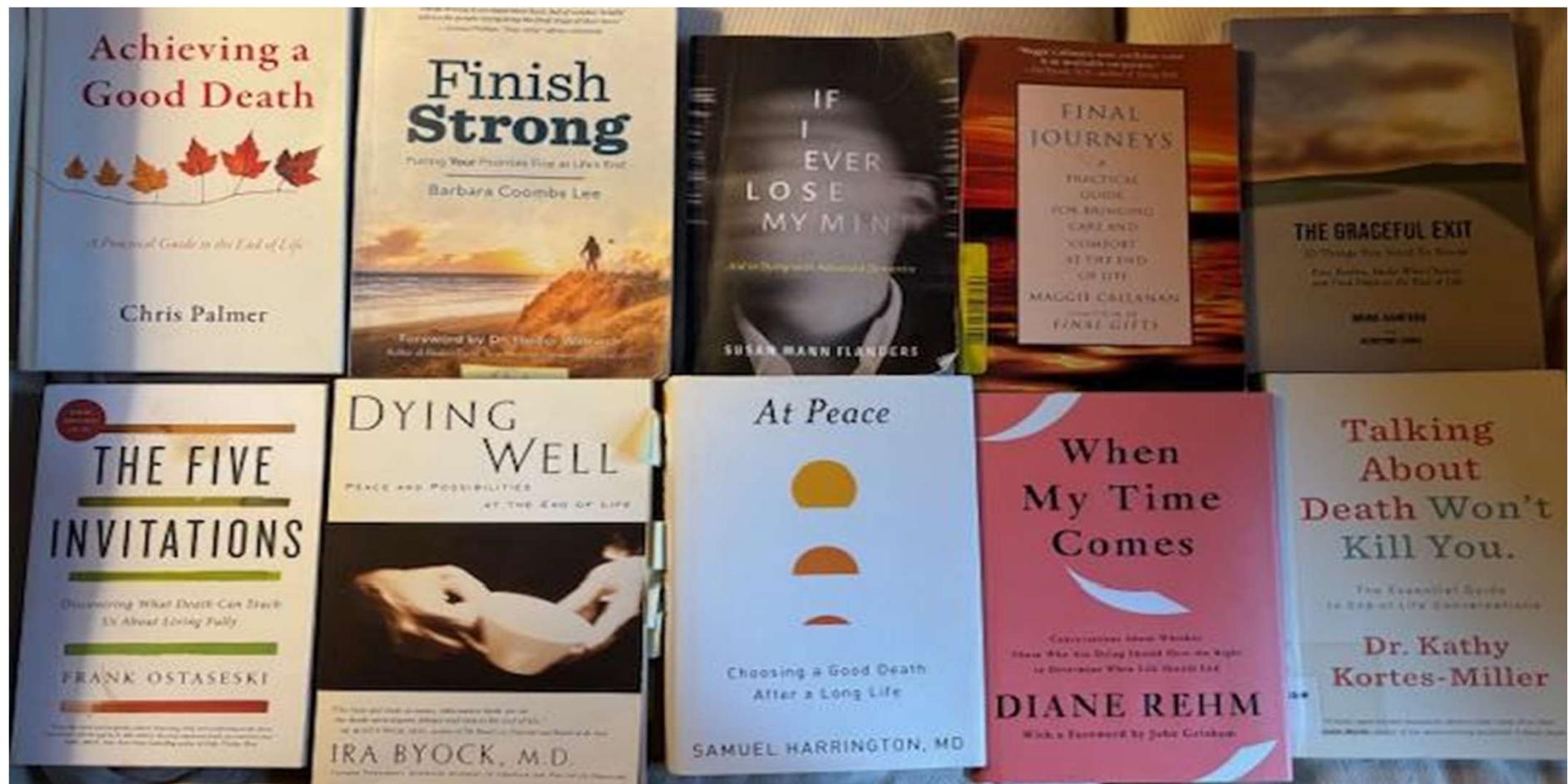


Signs of Cultural Change



- The Institute of Medicine releases its report "Dying in America"
- CMS reimburses for End-of-Life Care Conversations

IONA
Age Well. Live Well.



—BJ MILLER, MD

EXTREME MEASURES

FINDING A BETTER PATH
to the END of LIFE



JESSICA NUTIK ZITTER, MD

When My Time Comes

Conversations About Whether
Those Who Are Dying Should Have the Right
to Determine When Life Should End

DIANE REHM

With a Foreword by John Grisham

Talking About Death Won't Kill You.

The Essential Guide
to End-of-Life Conversations

Dr. Kathy
Kortes-Miller

"A frank, open-minded discussion about a topic many of us fear."
—Andrea Martin, author of the award-winning bestseller *A Good Death*

"Finish Strong is an important book, full of candid, helpful
advice for people navigating the final stage of their lives."
—Jeanne Phillips, "Dear Abby" advice columnist

Finish Strong

Putting Your Priorities First at Life's End

Barbara Coombs Lee



"This remarkable book ... illustrates how the medical community and society can
make the best of what is often the very worst time of life." An absorbing read.
—The Wall Street Journal

A PHYSICIAN'S QUEST
TO TRANSFORM CARE
THROUGH THE END OF LIFE

The Best Care Possible

IRA BYOCK, MD
author of *Dying Well*

THE NEW YORK TIMES BESTSELLER

ANOTHER COUNTRY

NAVIGATING THE EMOTIONAL
TERRAIN OF OUR ELDERS



MARY PIPHER, Ph.D.
Author of *Reviving Ophelia*

You are not alone. There are resources and people who can help you explore **YOUR** values and choices

