

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.



7-11 1/17/83

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

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)

ALLERGY DIABETIC

Medicine	Daily Prescription	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	1				
Metoprolol Succ ER beta blocker+	2.5 ^(12 1/2 mg) 50 mg (one 25 mg. tab 2X/day)		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			
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 (Dorzolomide-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
Ipratropium 0.3%	2 sniffs each nostril 2X/da					
Ketoconazole 2% shampoo	1 X/week (scalp)					
Desonide .05% cream	as needed					
Fluocinidide .05%	as needed for scalp					

Allergies, sensitivities

Penicillin (swelling), Codeine (breaking out), Viox (Rofecoxib) (breaking out); Persantine (Dipyridamole) (shaking); Vesicare (Solifenacin) (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....”

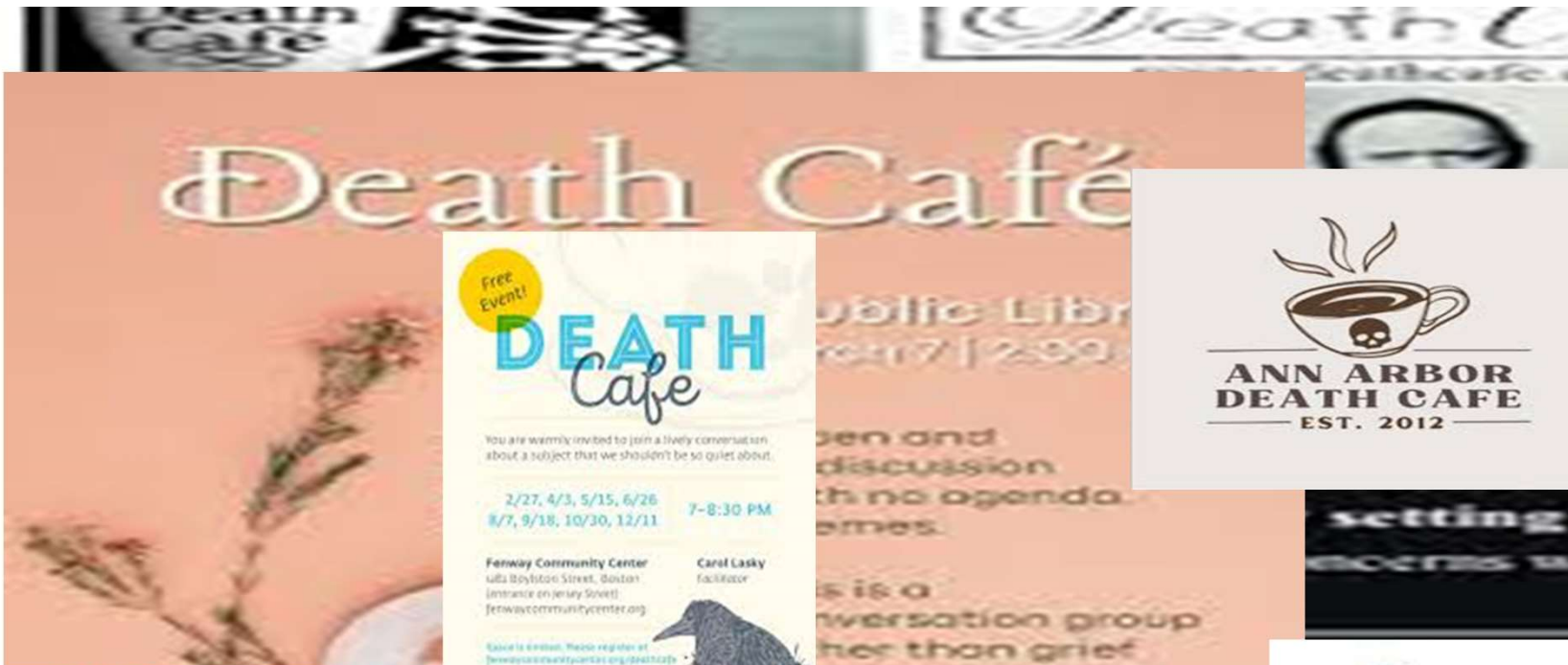
“Even though I feel fine today, I want you to do this if I am ever unable to speak for myself....”

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

Ways to Practice the Conversation

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





Free Event!

DEATH Cafe

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
8/7, 9/18, 10/30, 12/11 7-8:30 PM

Fenway Community Center
1414 Plymouth Street, Boston
(entrance on Jersey Street)
fenwaycommunitycenter.org

Carol Lasky
Facilitator

Space is limited. Please register at fenwaycommunitycenter.org/deathcafe

Free event!

*Refreshments are welcome in the community room.

Fenway Community Center

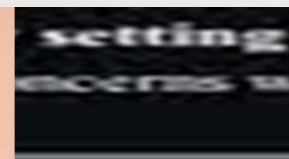




Death Cafe

JOIN US!

SATURDAY, 2:00 PM




Life & Death Cafe

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

Rx

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.

REFILL Zero TIMES

✓

DO NOT SUBSTITUTE

M.D.

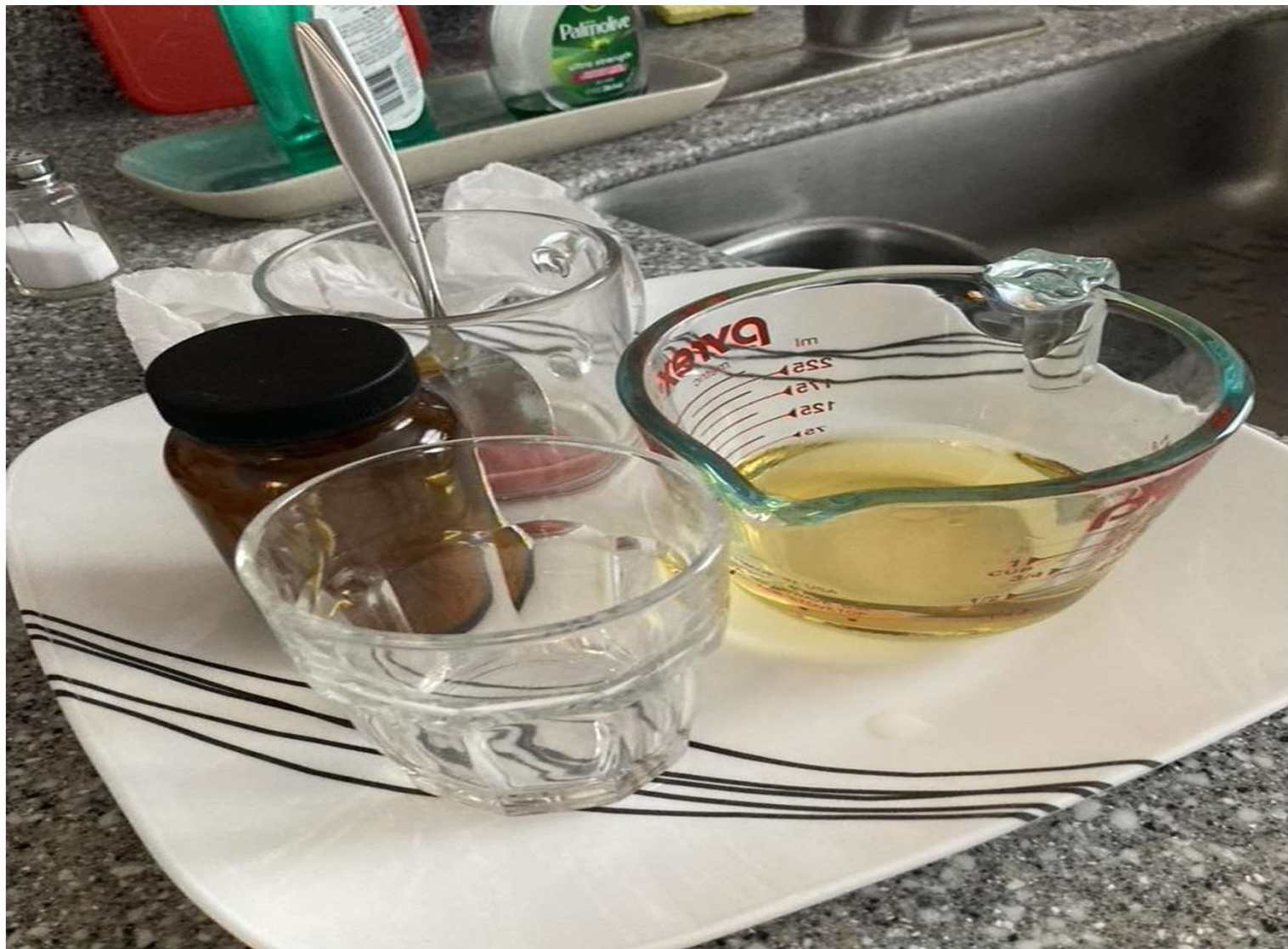
Aid-in-Dying Clinician

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

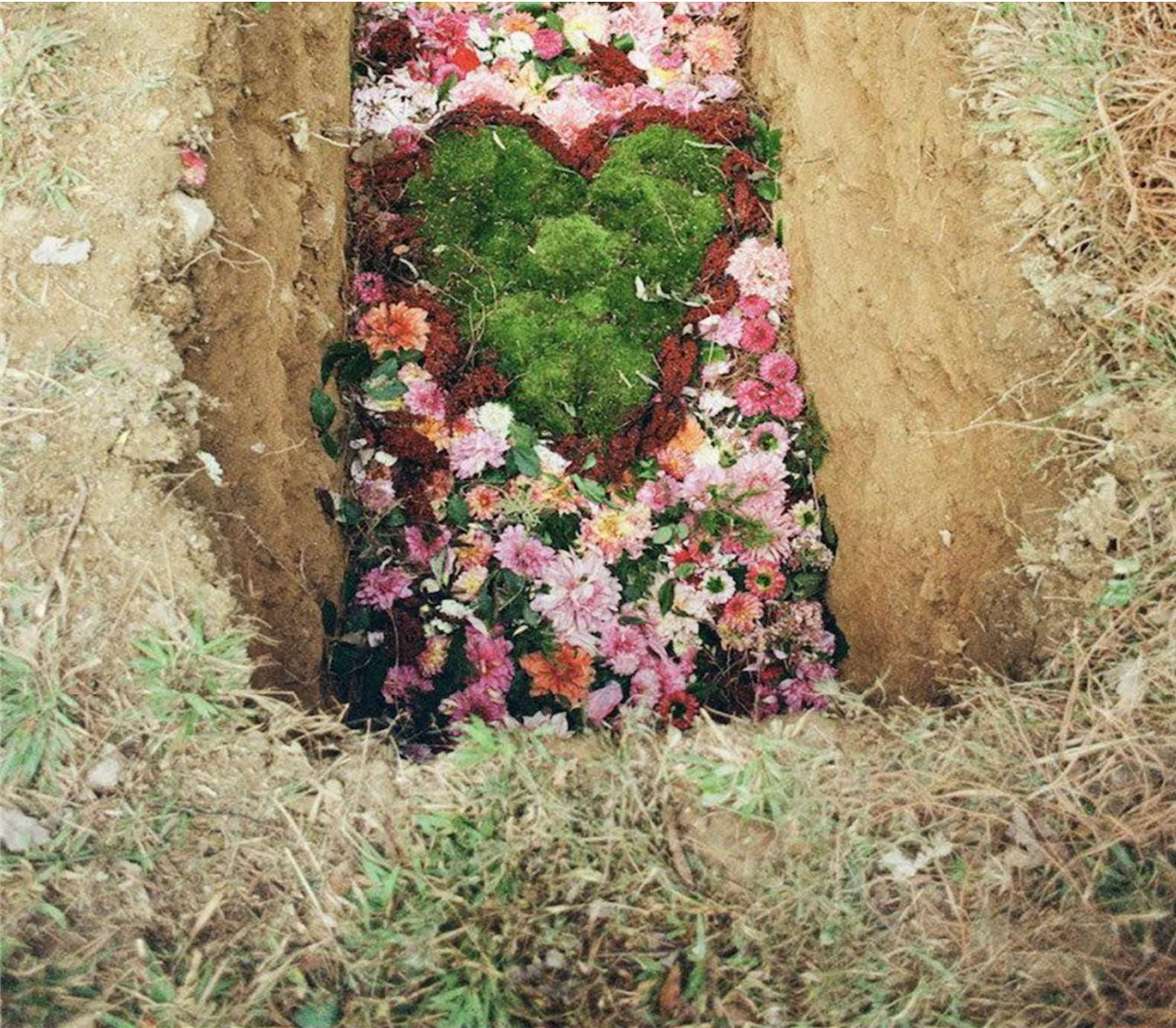
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HOOVER
DICKERSON N. HOOVER
1856 — 1921
ANNIE M. HIS WIFE
1860 — 1938
SADIE MARGUERITE
1890 — 1893
JOHN EDGAR HOOVER
1895 — 1972

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

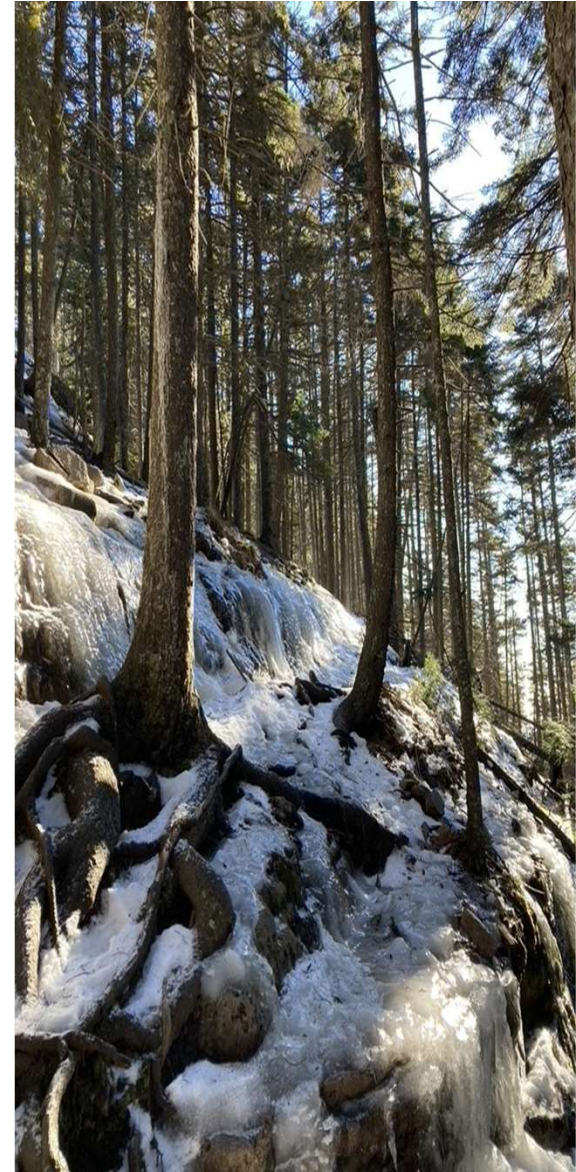
FIVE WISHES agingwithdignity.org/fivewishes

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: _____
 Date of Birth: _____ Religion: _____

Check All Medical Conditions That Exist

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

ALLERGIES

- | | | |
|---|--|---------------------------------------|
| <input type="checkbox"/> No Known Allergies | <input type="checkbox"/> Environmental | <input type="checkbox"/> Penicillin |
| <input type="checkbox"/> Aspirin | <input type="checkbox"/> Horse Serum | <input type="checkbox"/> Sulfas |
| <input type="checkbox"/> Barbiturates | <input type="checkbox"/> Insect Stings | <input type="checkbox"/> Tetracycline |
| <input type="checkbox"/> Codeine | <input type="checkbox"/> Latex | <input type="checkbox"/> X-Ray Dyes |
| <input type="checkbox"/> Demerol | <input type="checkbox"/> Lidocaine | <input type="checkbox"/> Morphine |
| <input type="checkbox"/> Novocaine | | |
| <input type="checkbox"/> 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

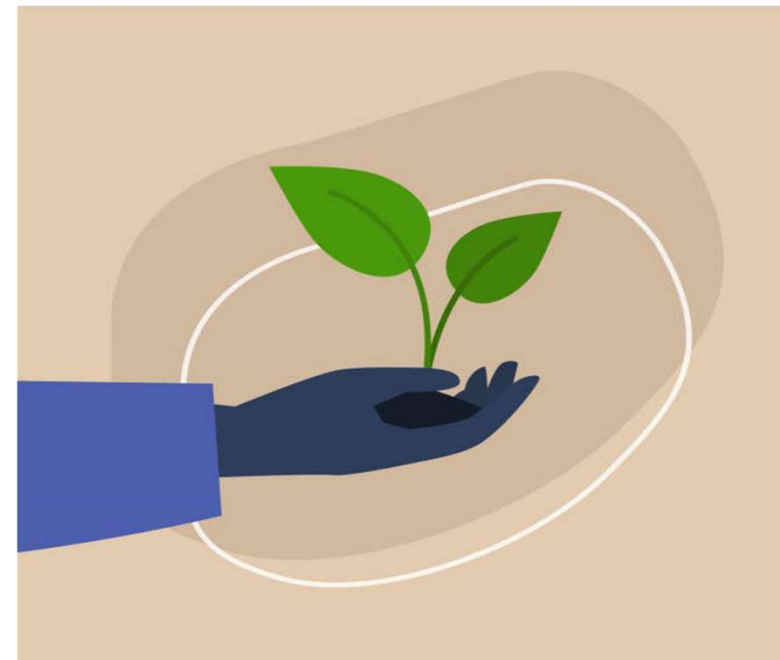
MY END OF LIFE DECISION:

An Advanced Planning Guide and Toolkit

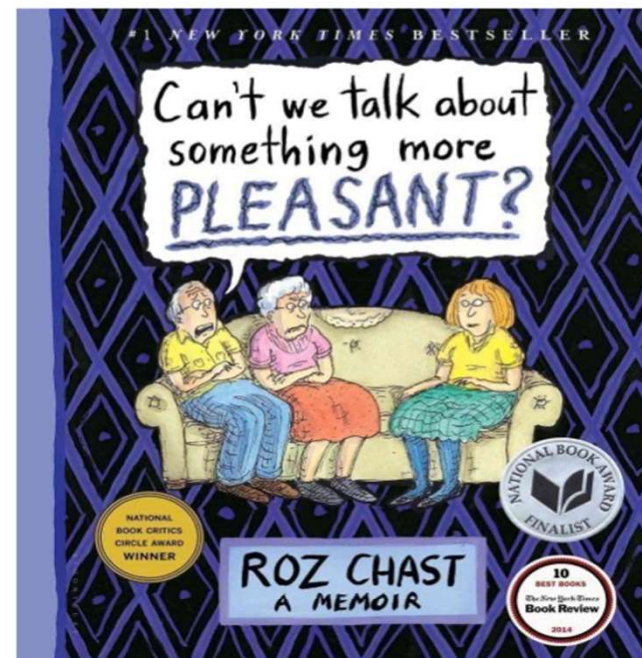
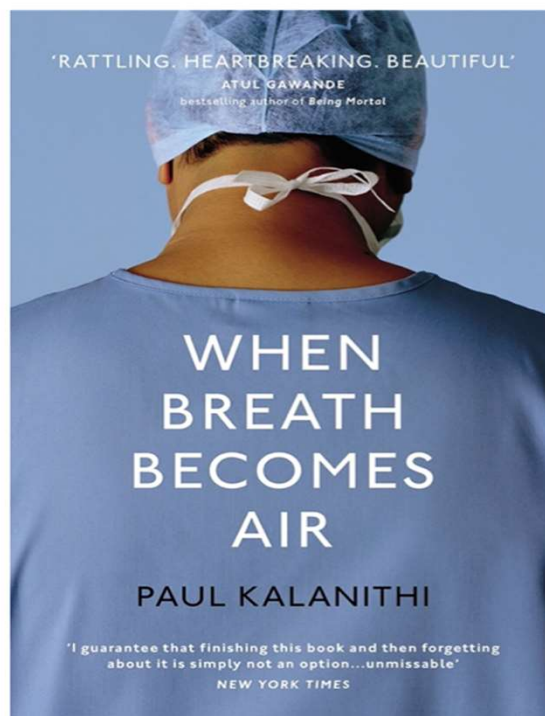
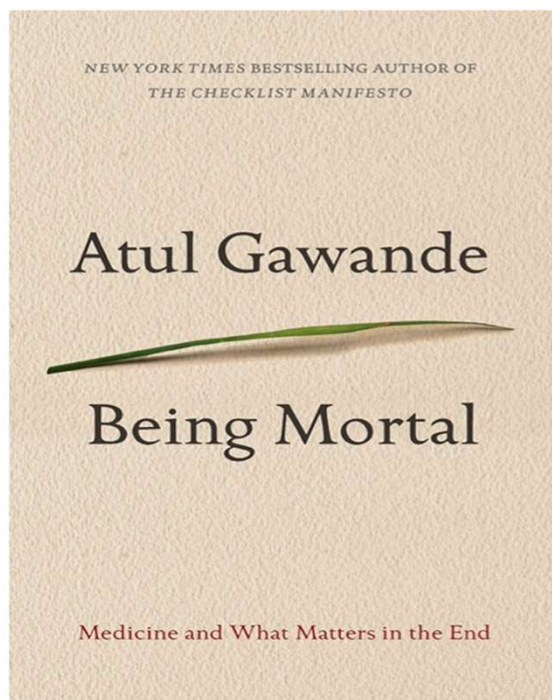
Order FREE copy

Wendy Minor

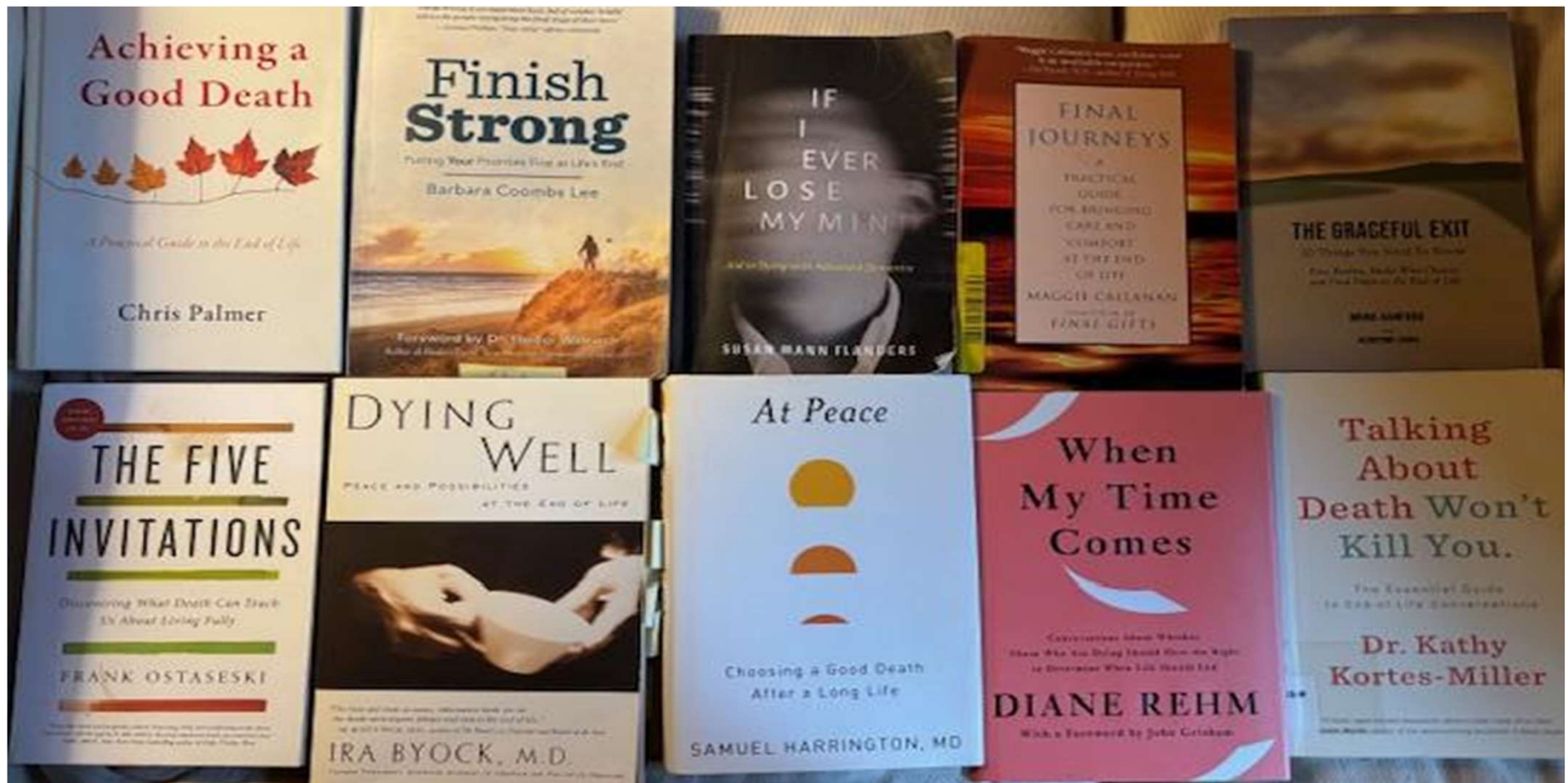
wminor@compassionandchoices.org



Signs of Cultural Change



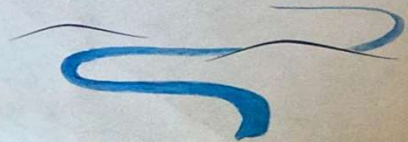
- The Institute of Medicine releases its report "Dying in America"
- CMS reimburses for End-of-Life Care Conversations



—BJ MILLER, MD

EXTREME MEASURES

FINDING A BETTER PATH
to the END of LIFE



JESSICA NUTIK ZITTER, MD

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."
—andra Martin, author of the award-winning bestseller *A Good Death*

"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*

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 Gisham

"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



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

