

# **DUKE DEMENTIA FAMILY SUPPORT PROGRAM**

## **Caregiver Connections**

**An Educational Webinar Series With The Experts**

**The presentation will begin shortly.  
Thank you for your patience!**

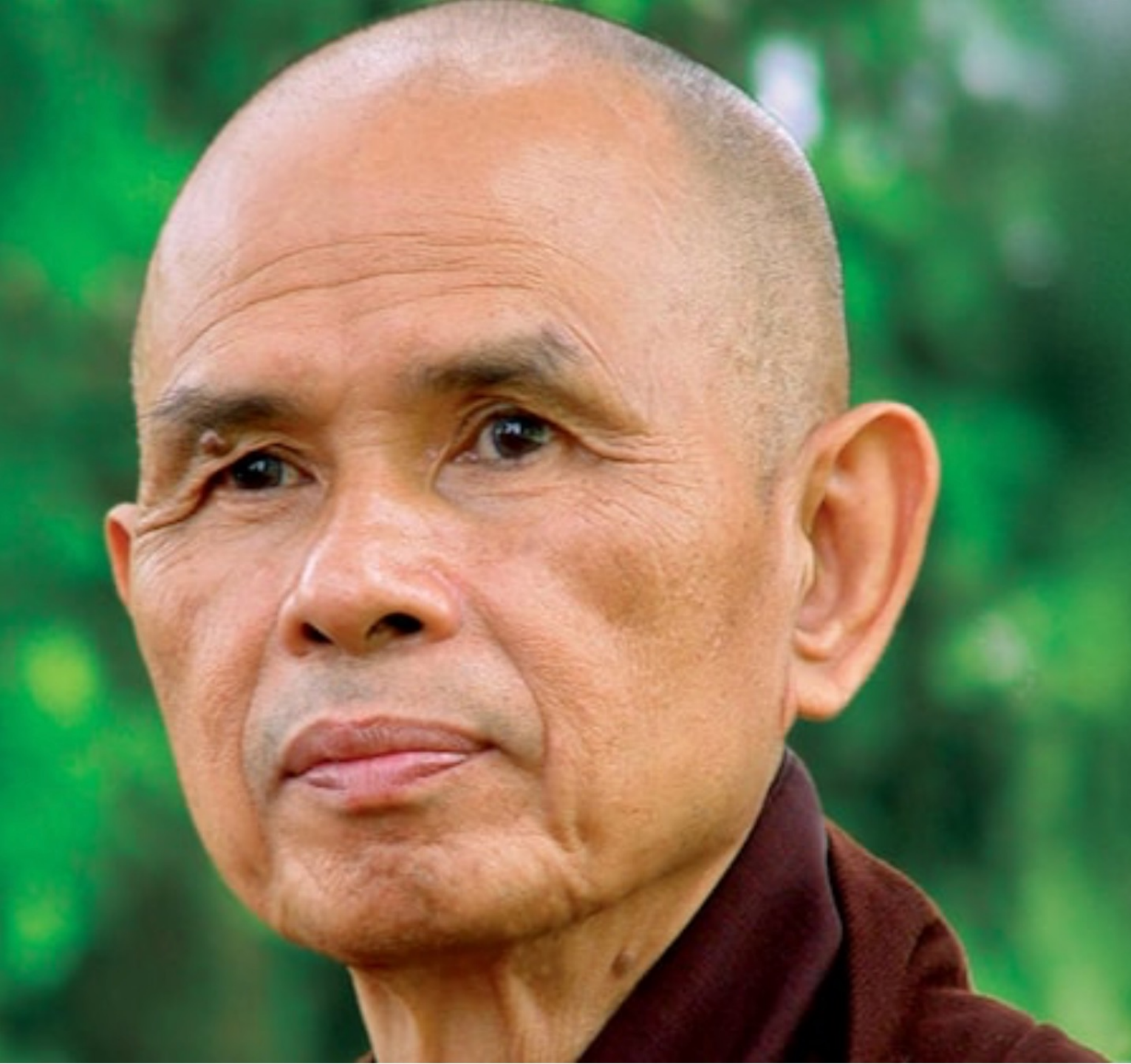
**[dukefamilysupport.org](http://dukefamilysupport.org)  
919-660-7510**

# Crossing the Drake Passage

Navigating the  
Dementia Journey

Liisa Ogburn  
Aging Advisors NC





“If even one person on the boat stayed calm, it was enough. It showed the way for everyone to survive.”

Zen master Thich Nhat Hanh said about escaping Vietnam in the crowded refugee boats.

# About Me

## Lessons in Living While Dying, From Pop

BY LIISA OGBURN NOVEMBER 16, 2014 8:19 AM 17



### Aging Well



LIISA OGBURN  
**Beginnings and Endings: 10 Lessons Before I Step Down**

As Kate Bowler says, "Life is beautiful. Life is hard." Here are some lessons I've learned over the last three years about savoring the beauty and weathering the hard.

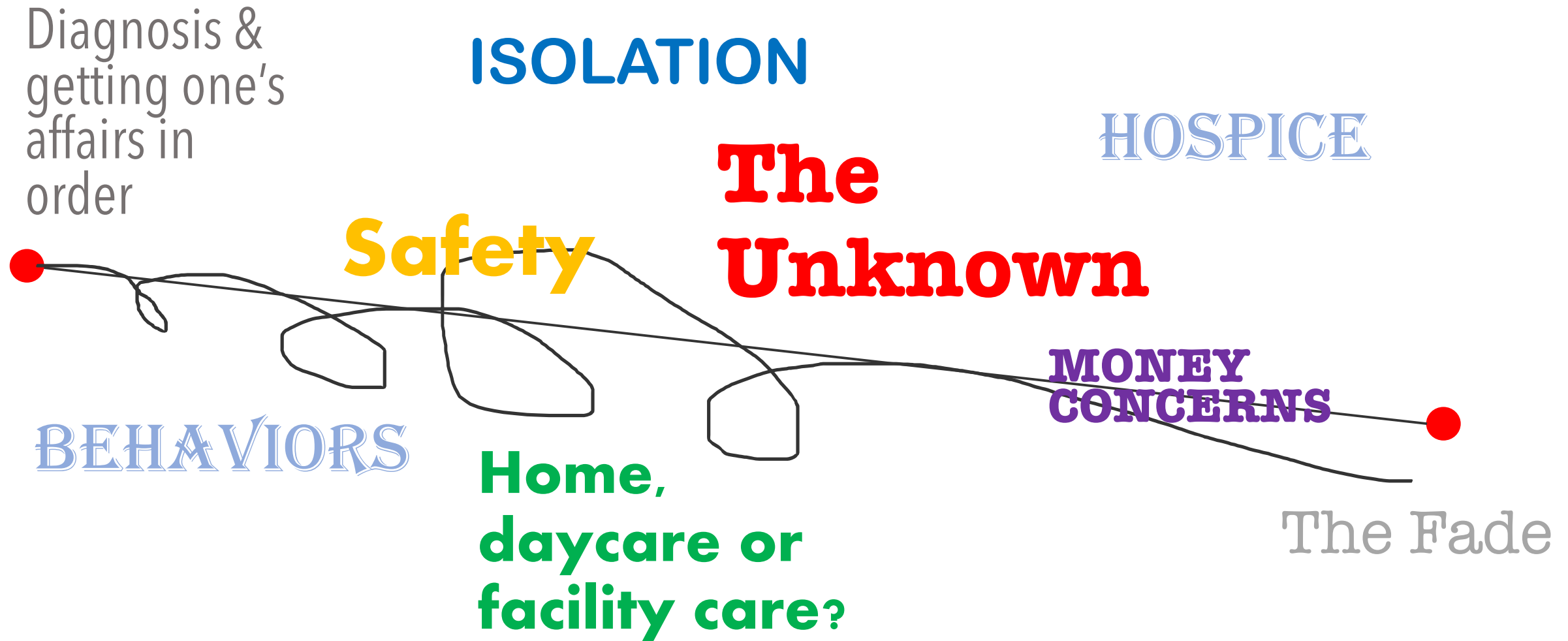
Tags: Aging Well, emergency, death, coronavirus, CDC, aging, Alzheimer's  
Posted January 3



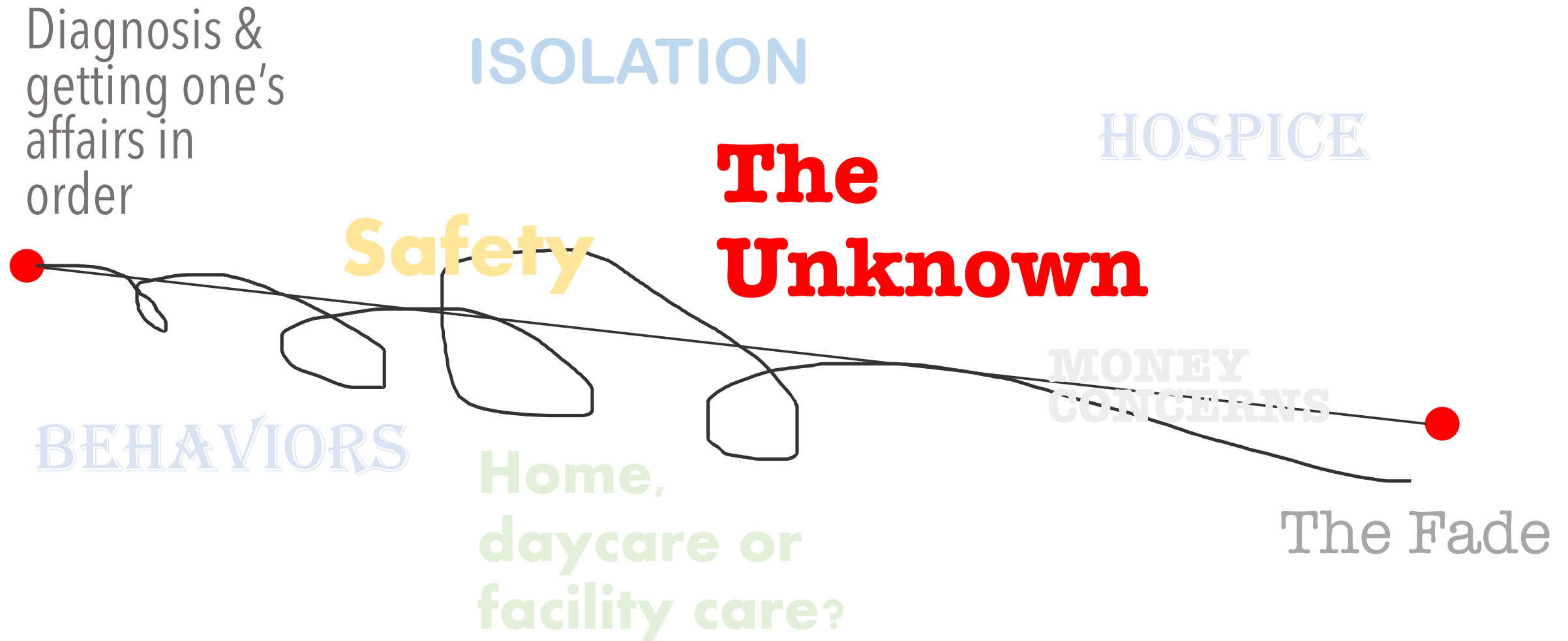
LIISA OGBURN, WRAL CONTRIBUTOR  
**Let grief and joy coexist this holiday season**  
If the last 21 months of the pandemic have taught us anything, it is that life, family and friends are precious, and that there can be joy and gratitude even in the midst of sorrow.



# Dementia Flashpoints



# Dementia Flashpoints



My mind is like a dangerous neighborhood. I don't like to go there alone at night.

- Anne Lamott

In the storm



Above the fray

# What Are Your Wishes?



*To my wife, my children, and any physicians, surgeons, attorneys or court officers who may become involved in my medical care in the future,*

*I would like to express my clear desire, should I be incapacitated by some illness, accident or unforeseen event at some time in the future to the extent that I am not able to communicate my thoughts or desires, not to have my life prolonged by what I consider artificial means, such as pulmonary ventilation, tube, parenteral or hand feedings, etc. if there is no reasonable hope that I will be able to recover and again lead a reasonably active and enjoyable life in the future...*

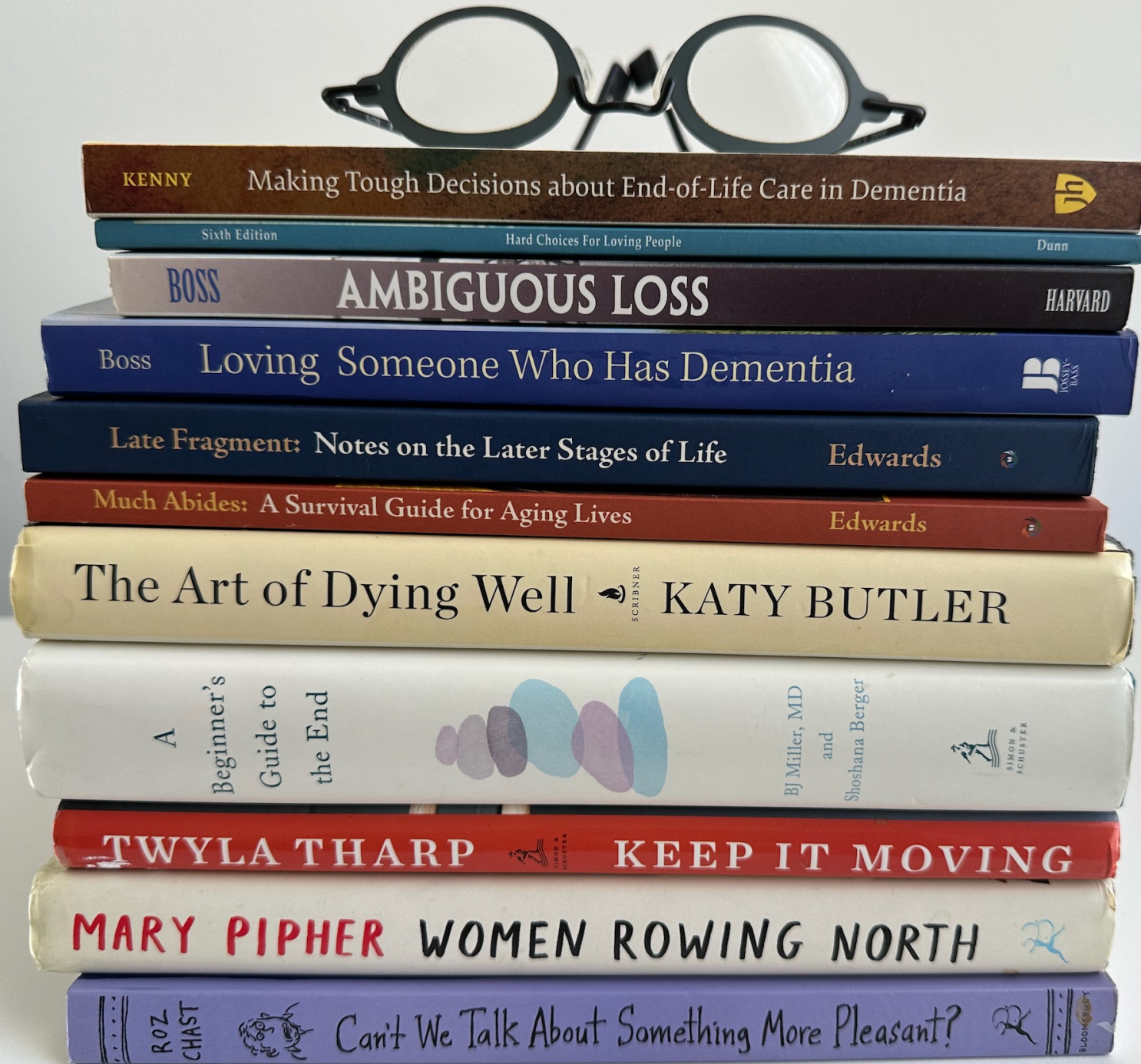
*(<https://www.wral.com/letter-to-my-children-and-physician-about-my-end-of-life-wishes/18622181/>)*



# Collecting New Maps



- Physician, Neurologist, Geriatric Psychiatrist
- Books
- Duke Dementia Family Support Program or Dementia Alliance
- Individual counseling
- Church support services
- Families you meet at Memory Cafés
- Adult Day Programs
- Geriatric Care Managers or elder consultants



# What is the need? Is there a solution?



Here is the world. Beautiful  
and terrible things will  
happen. Don't be afraid.

- Frederick Buechner

# Maintaining Safety & Dignity



- Car keys
- Alcohol
- Safe medication use
- Credit cards
- Vulnerability to scammers online or by phone
- Knives and guns
- Stove
- Appropriate dress
- Wandering

# Introducing Day Program or Home Care



**Total Life Centers**

**Adult Day Services of Resources for Seniors, Inc.**

- Adult Day Programs (\$55 to \$95/day)
- 100+ agencies CNAs with RN oversight; Minimum of 4-6 hour shifts; pay \$12-16/hr; charge you \$30-\$38/hour
- Private pay individuals:
  - NC Registry:  
<https://www.caregivernc.com/>
  - <https://www.careyaya.com/>
  - <https://acornhcs.com/>
  - <https://www.care.com/>

# Assisted Living, Memory Care or Family Care Home?

- ASSISTED LIVING  
1 to 20 care ratio; \$6,500-\$12,000+/month
- MEMORY CARE  
1 to 8 care ratio; \$8,500 - \$12,000+/month
- FAMILY CARE HOMES  
1 to 3 care ratio; \$8,000 - \$12,000/month

**WHEN?**

**HOW TO  
FIND?**

**WHAT TO  
SAY TO  
LOVED  
ONE?**

**HOW TO DO**

**PREPARATION**

**ASSOCIATED  
FEELINGS**

# Medical Documents

**STOP  
DO NOT  
Resuscitate**

Effective Date: \_\_\_\_\_  
Expiration Date, if any \_\_\_\_\_  
☐ Check box if no expiration

**DO NOT RESUSCITATE ORDER**

Patient's full name \_\_\_\_\_

In the event of cardiac and/or pulmonary arrest of the patient, efforts at cardiopulmonary resuscitation of the patient **SHOULD NOT** be initiated. This order does not affect other medically indicated and comfort care.

I have documented the basis for this order and the consent required by the NC General Statute 90-21.17(b) in the patient's records.

Signature of Attending Physician \_\_\_\_\_  
Printed Name of \_\_\_\_\_  
Address \_\_\_\_\_  
City, State \_\_\_\_\_  
Telephone Number (office) \_\_\_\_\_  
Telephone Number (emergency) \_\_\_\_\_  
**Do Not Copy**

**HIPAA PERMITS DISCLOSURE OF MOST TO OTHER HEALTH CARE PROFESSIONALS AS NECESSARY**

**Medical Orders for Scope of Treatment (MOST)**  
This is a Physician Order Sheet based on the person's medical condition and wishes. Any section not completed indicates full treatment for that section. When the need occurs, first follow these orders, then contact physician.

Section A Check One Box Only	<b>CARDIOPULMONARY RESUSCITATION (CPR):</b> Person has no pulse and is not breathing. <input type="checkbox"/> Attempt Resuscitation (CPR) <input type="checkbox"/> Do Not Attempt Resuscitation (DNR/no CPR) When not in cardiopulmonary arrest, follow orders in B, C, and D.
Section B Check One Box Only	<b>MEDICAL INTERVENTIONS:</b> Person has pulse and/or is breathing. <input type="checkbox"/> Full Scope of Treatment: Use intubation, advanced airway interventions, mechanical ventilation, cardioversion as indicated, medical treatment, IV fluids, etc.; also provide comfort measures. <b>Transfer to hospital if indicated.</b> <input type="checkbox"/> Limited Additional Interventions: Use medical treatment, IV fluids and cardiac monitoring as indicated. Do not use intubation or mechanical ventilation; also provide comfort measures. <b>Transfer to hospital if indicated. Avoid intensive care.</b> <input type="checkbox"/> Comfort Measures: Keep clean, warm and dry. Use medication by any route, positioning, wound care and other measures to relieve pain and suffering. Use oxygen, suction and manual treatment of airway obstruction as needed for comfort. <b>Do not transfer to hospital unless comfort needs cannot be met in current location.</b> Other Instructions _____
Section C Check One Box Only	<b>ANTIBIOTICS</b> <input type="checkbox"/> Antibiotics if life can be prolonged. Determine use or limitation of antibiotics when infection occurs. <input type="checkbox"/> No Antibiotics (use other measures to relieve symptoms). Other Instructions _____
Section D Check One Box Only in Each Column	<b>MEDICALLY ADMINISTERED FLUIDS AND NUTRITION:</b> Offer oral fluids and nutrition if physically feasible. <input type="checkbox"/> IV fluids long-term if indicated <input type="checkbox"/> Feeding tube long-term if indicated <input type="checkbox"/> IV fluids for a defined trial period <input type="checkbox"/> Feeding tube for a defined trial period <input type="checkbox"/> No IV fluids (provide other measures to ensure comfort) <input type="checkbox"/> No feeding tube Other Instructions _____
Section E Check The Appropriate Box	<b>DISCUSSED WITH AND AGREED TO BY:</b> Basis for order must be documented in medical record. <input type="checkbox"/> Patient <input type="checkbox"/> Patient or guardian if patient is a minor <input type="checkbox"/> Majority of patient's reasonably available parents and adult children <input type="checkbox"/> Health care agent <input type="checkbox"/> Majority of patient's reasonably available adult siblings <input type="checkbox"/> Legal guardian of the person <input type="checkbox"/> An individual with an established relationship with the patient who is acting in good faith and can reliably convey the wishes of the patient <input type="checkbox"/> Spouse
MD/DO, PA, or NP Name (Print) _____ MD/DO, PA, or NP Signature (Required) _____ Phone #: _____	
<b>Signature of Person, Parent of Minor, Guardian, Health Care Agent, Spouse, or Other Personal Representative</b> (Signature is required and must either be on this form or on file) I agree that adequate information has been provided and significant thought has been given to life-prolonging measures. Treatment preferences have been expressed to the physician (MD/DO), physician assistant, or nurse practitioner. This document reflects those treatment preferences and indicates informed consent. <i>If signed by a patient representative, preferences expressed must reflect patient's wishes as best understood by that representative. Contact information for personal representative should be provided on the back of this form.</i> <b>You are not required to sign this form to receive treatment.</b>	
Patient or Representative Name (print) _____ Patient or Representative Signature _____ Relationship (write "self" if patient)	
<b>SEND FORM WITH PATIENT/RESIDENT WHEN TRANSFERRED OR DISCHARGED</b>	

## For EMS

**Preferred Hospital:** Duke University

**Name:** John Smith

**Birthdate:** 9/1/1942

**Profession (retired):** Chemistry Professor/Department Chair (Duke)

**Emergency contact:** Carol Smith (wife): 919-111-1111

**Healthcare Power of Attorney:** Jenny Smith (daughter, local): 919-999-9999

**Primary Care Physician:**

**Other specialists:**

**Most Relevant Medical Conditions:**

**Allergies:**

**Medications:**

**DNR in place?**

# Navigating the Hospital



- What to expect if you call 911
- ER Waittimes
- Admission versus admission for observation
- How to get updates efficiently
- Hospital-based delirium
- Psych issues
- Questions about discharge home versus to rehab
- Choosing a rehab Rehabs are rated by Medicare on [Medicare.gov/Compare](https://www.medicare.gov/compare)

# Navigating Rehab

- 1 to 20 patient to caregiver ratio
- 90 minutes of rehab/day
- With a medical order from the hospital, then rehab is covered 100% by traditional Medicare for first 20 days; 80% for next 80 days
- Average rehab: 2-4 weeks
- Must show progress towards goals to continue Medicare coverage
- Therapy often follows patient home 3x/week for on average 2 weeks



# Navigating Hospice

- Understanding the difference between palliative & hospice
- Avoiding the ER
- Gaining more agency
- Gaining more support
- Hospice team
- Hospice at home versus Family Care Home versus Skilled Nursing



The only constant in life is  
change.

- Heraclitus

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**Thank you for joining us today!**

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