How can I advocate for my loved one with Dementia, while they are in the hospital?

Objectives

- Understand documents and conversations needed for patient advocacy
- Learn how to interact with the care team and advocate for your loved one
- Understand Hospital Acquired Delirium
- Discuss Delirium prevention and treatment
- What to know before Discharge

Person-Centered Care

Empowering people to take charge of their own health rather than being passive recipients of services

World Health Organization

The Key to Hearing Your Voice

"May your ***choices*** reflect your ***hopes***, ***not*** your ***fears***."

- Nelson Mandela

2025 DOUBLING DOWN on Dementia NEGA DEMENTIA SYMPOSIUM

Speaking the Same ACP

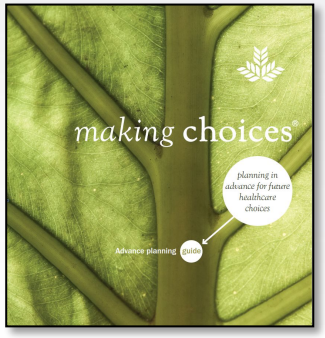
Advance Care Planning (ACP)	The CONVERSATION
Advance Directive for Healthcare	The LEGAL document
Used To Be Called	Durable Power of Attorney for Healthcare Living Will
Choices	Healthcare Agent Treatment Preferences
What It's NOT	Financial (Will) or Financial (POA) Behavioral Health Directive

2025 DOUBLING DOWN on Dementia NEGA DEMENTIA SYMPOSIUM

Initiate this Conversation

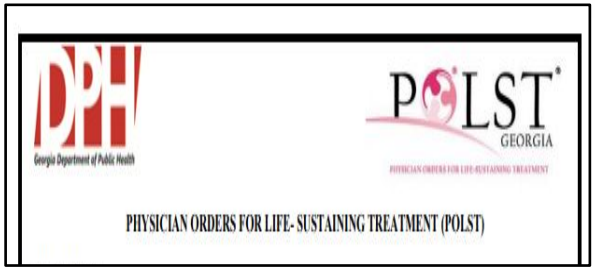
Advance Care Planning

Respecting Choices



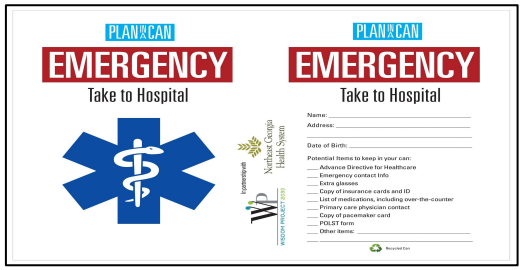
POLST Collaborative

Georgia POLST



Community Communication Tool

Plan in a Can



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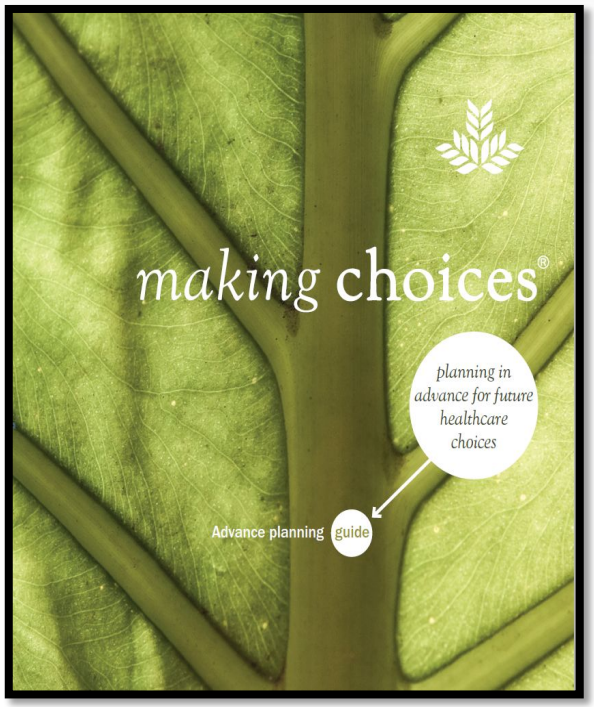
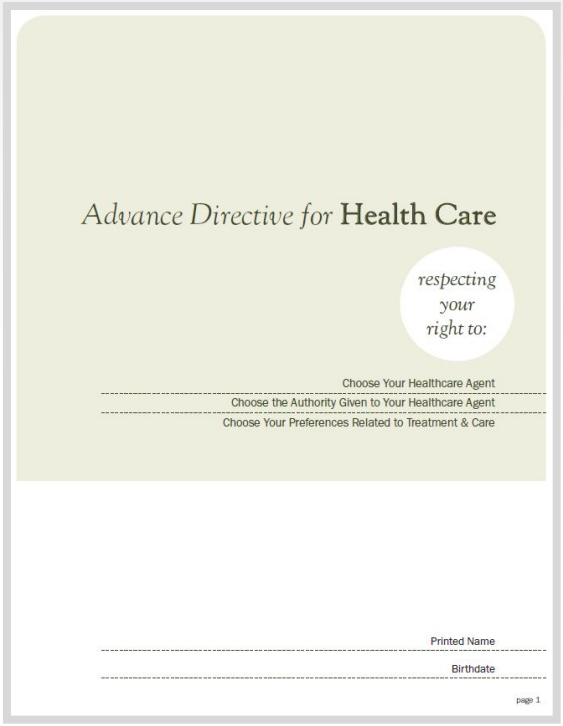
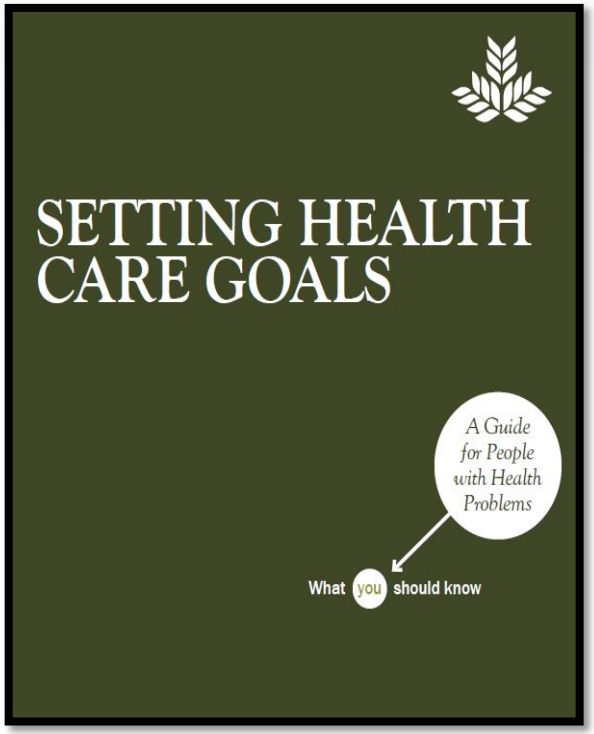
Making Your Choices







2025 DOUBLING DOWN on Dementia NEGA DEMENTIA SYMPOSIUM

POLST: Stepping Beyond the AD

- An **Advance Directive** documents your legal wishes
- A **POLST** makes those wishes a portable medical order

DPH Georgia Department of Public Health

POLST GEORGIA
PHYSICIAN ORDERS FOR LIFE-SUSTAINING TREATMENT

PHYSICIAN ORDERS FOR LIFE- SUSTAINING TREATMENT (POLST)

Patient's Name _____ _____ _____
(First) (Middle) (Last)

Date of Birth _____ **Gender:** Male ☐ Female ☐

A CODE STATUS Check One	**CARDIOPULMONARY RESUSCITATION (CPR): Patient has no pulse and is not breathing.** ☐ **Attempt Resuscitation (CPR).** ☐ **Allow Natural Death (AND) - Do Not Attempt Resuscitation.** ** *Signature of a concurring physician is needed for this section to be valid* ***if*** *this form is signed by an Authorized Person who is not the Health Care Agent. See additional guidance under III on back of form.* **When not in cardiopulmonary arrest, follow orders in B, C and D.**
B Check One	**MEDICAL INTERVENTIONS: Patient has pulse and /or is breathing.** ☐ **Comfort Measures**: 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. *Do not transfer to hospital for life-sustaining treatment.* ☐ **Limited Additional Interventions**: In addition to treatment and care described above, provide medical treatment, as indicated. DO NOT USE intubation or mechanical ventilation. *Transfer to hospital if indicated. Generally avoid intensive care unit.* ☐ **Full Treatment**: In addition to treatment and care described above, use intubation, mechanical ventilation, and cardioversion as indicated. *Transfer to hospital and/or intensive care unit if indicated.* Additional Orders (e.g. dialysis):
C Check One	**ANTIBIOTICS** ☐ No antibiotics: Use other measures to relieve symptoms. ☐ Determine use or limitation of antibiotics when infection occurs. ☐ Use antibiotics if life can be prolonged. Additional Orders:
D Check One In Each Column	**ARTIFICIALLY ADMINISTERED NUTRITION/FLUIDS** **Where indicated, always offer food or fluids by mouth if feasible** ☐ No artificial nutrition by tube. ☐ Trial period of artificial nutrition by tube. ☐ Long-term artificial nutrition by tube. Additional Orders: ☐ No IV fluids. ☐ Trial period of IV fluids. ☐ Long-term IV fluids. Additional Orders:

DISCUSSION AND SIGNATURES

The basis for these orders should be documented in the medical record. To the best of my knowledge these orders are consistent with the patient's current medical condition and preferences and comply with the requirements of applicable Georgia law.

Physician Name: License No.: State:	Physician Signature:	Date: Phone:

2025 DOUBLING DOWN on Dementia NEGA
DEMENTIA SYMPOSIUM

Being Prepared: Plan in a Can

PLAN IN A CAN

- Community Involvement
  - Wisdom Keepers
  - Recycled Tennis Cans
    - Benefit to EMS
  - Benefit in Transitions of Care

*Every person who **prepares** is one **less** person who **panics** in a crisis*

attributed to Mike Adamson, British Red Cross

Comfort is More Than Medicine

People…Music…Pets…
Foods…Places…
Memories…Events…

2025 DOUBLING DOWN on Dementia NEGA DEMENTIA SYMPOSIUM

Geriatrics

- Geriatrics refers to medical care for older adults, an age group that is not easy to define precisely.
- Gerontology is the study of aging, encompassing biological, sociological, and psychological changes.
- While there isn't a single, universally agreed-upon age, 65 is generally considered the threshold for becoming elderly in the United States, especially for programs like Medicare and Social Security

Background

- Adults aged 65 and older are the fastest growing population in the United States
- 93% of adults 65+ have at least one chronic health condition while nearly 79% have two or more
- Approximately 17% of adults age 65+ are hospitalized per year
- 1 in 10 adults age 65+ are estimated to have dementia and the percentage grows as we age

What makes Geriatrics Special

- Older adults require a different level of care than younger patients
- Prone to complications, functional decline, loss of independence and other untoward outcomes
- Optimal care requires a thorough assessment of the individual's health status

2025 DOUBLING DOWN on Dementia NEGA DEMENTIA SYMPOSIUM

Most common reasons for Hospitalization

- Falls and Fall Related Complications
- Medication Mismanagement and Adverse Drug Reactions
- Chronic Disease Complications
- Infections
- Cognitive Decline and Behavioral Crises

2025 DOUBLING DOWN on Dementia NEGA DEMENTIA SYMPOSIUM

Prepare to Meet the Healthcare Team

- Emergency Department staff
- Admitting Providers
  - Hospitalists, Surgeons, Specialists, APP, PA
- Nurses, Techs, Physical Medicine, Pharmacists, Dieticians, Chaplains, and many others

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Identify the Family Spokesperson, Be the Advocate

One voice for provider reference

Ask for a family meeting to establish Goals of Care

- Be the ADVOCATE

Keep notes for questions and concerns

Be available for hospital rounds if possible

2025 DOUBLING DOWN on Dementia NEGA DEMENTIA SYMPOSIUM

Dementia vs Delirium

- Slow or gradual loss of brain functions
- Memory
- Planning
- Language
- Activity

- Sudden change in thinking or mental state
- Difficulty paying attention
- Abnormal behavior
- Agitation or withdrawn

Delirium

- May last for hours to weeks
- Symptoms may come and go
- May be worse at night=Sundowners
- Can be treated

Who is at Risk for Delirium

History of dementia or previous episodes of Delirium

Infection, pain, dehydration, constipation

Surgical procedures

Use of multiple medications, Alcohol use

Poor eyesight or hearing

What are the Symptoms?

- Fast onset
- Trouble with thinking, acute confusion, agitation, mood swings
- Hallucinations
- Being withdrawn or increased sleepiness
- Insomnia

2025 DOUBLING DOWN on Dementia NEGA DEMENTIA SYMPOSIUM

What Will the Medical Team Do to Address Delirium?

01

Order tests to uncover Medical Problems

02

Review Medications

03

Provide Safe and Supportive Environment

2025 DOUBLING DOWN on Dementia NEGA DEMENTIA SYMPOSIUM

Role of Family and Caregivers

- Stay with your Loved One and Advocate
- Report any Sudden Changes in Mental or Physical Condition
- You Know the Patient Best

2025 DOUBLING DOWN on Dementia NEGA DEMENTIA SYMPOSIUM

Delirium Prevention

- Maintain a calm environment
- Glasses, hearing aids and dentures
- Familiar things from home, family presence
- Address pain, toileting, food and fluids
- Regular sleep wake cycle
- Encourage mobility

2025 DOUBLING DOWN on Dementia NEGA DEMENTIA SYMPOSIUM

What Else Should You Know

DELIRIUM MAY LAST A FEW DAYS TO WEEKS

INCREASES THE RISK OF COMPLICATIONS

INCREASES THE TIME IN THE HOSPITAL

STRESS ON CAREGIVERS AND STAFF

2025 DOUBLING DOWN on Dementia NEGA DEMENTIA SYMPOSIUM

What Happens After Discharge

- Short Term Rehab versus Home
- May not Return to Previous Level of Function
- Update Community Healthcare Providers

2025 DOUBLING DOWN on Dementia NEGA DEMENTIA SYMPOSIUM

Discharge Planning

- Should begin as soon as patient is admitted
- Family/caregiver involvement
  - May have input
    - final decision made by patient, if able
  - Case management / social work
  - Healthcare team rounds
- Depends on overall clinical picture
  - Certain clinical requirements may require a higher level of care

Options

Long Term Acute Care facility (LTAC)

- Designed for medically complex patients who require extended hospital-level care
- Certain medical conditions require LTAC
- Few in the state of GA

Inpatient Rehab & Sub Acute Rehab (SAR)

- Differences: Intensity of rehab, necessity per medical condition, setting, goals/duration
- **Inpatient** – shorter duration (~14d), higher intensity therapy, held in inpatient unit
- **SAR** – longer duration (~21 d), more gentle therapy, typically held in nursing home
- Discharge to home, SNF, ALF, etc from both

Options, continued

Skilled nursing facility (SNF)

- Nursing home, may be referred to as a “sniff”
- 24/7 care provided by nursing and aid staff
  - Meals, activities, therapies, socialization, hygiene, etc provided

Assisted Living facility (ALF)

- Residents live independently (apartments or townhomes)
  - Designed for older adults – convenience features
- No 24/7 care, staff checks in, usually emergency pull cord
- Different services provided per facility
- Generally not covered by insurance

Options, continued

Home, no resources

- Resumes care of themselves or family care
- May display loss of function compared to previous status

Home Healthcare (HHC)

- Patient resides in a residence (home, ALF, SNF, etc.)
  - live independently or with family/friends
- Healthcare professional(s) come to residence to provide services
  - Nursing, PT/OT/ST, aide visits

Home Hospice

- Eligible when a physician determines patients has ≤ 6 months to live
- Occurs wherever the patient resides
- More frequent visits by healthcare workers than HHC
- Goal is to live out natural life as patient wishes
  - Maintain dignity & control pain
  - Gives patient control

Next steps

- Update patient's private physician (PCP)
- Continue to advocate with for your loved one
  - Communicate with HC team
- Continue to utilize family spokesperson
  - Keeps everyone on the same page, including HC team at times
- Plan for the future **early**
  - Discharge planning continues, if in a facility
    - Utilize case manager and/or social worker
  - Where will your loved one be going next?
    - Back home, loved one's home, facility, resources, services?
  - Prepare for increased weakness and possible loss of function/independence

Common post acute complications

- Increased weakness and loss of function
  - Causes increased dependence on caregivers
  - Required equipment
  - Stressful for patient
  - Can be disastrous if not prepared
- Changes for caregivers
  - Different medication regimen
  - Increased number of appointments
  - Required therapies
  - New equipment/medical devices
  - Changes in loved ones

2025 DOUBLING DOWN on Dementia NEGA DEMENTIA SYMPOSIUM

Common post acute complications

- **FALLS!**
  - Historically the primary chief complaint at NGMC Gainesville trauma center
  - Currently, falls are the leading cause of nonfatal injuries in older adults
  - **In 2015, the American Journal of Lifestyle Medicine published an article showing that the estimated number of *fatal falls* in older adults are predicted to reach *at least 100,000 by the year 2030*.**
  - Same article reports the estimated cost of these falls is $100 billion
  - Prevention is key

Citation: Houry D, Florence C, Baldwin G, Stevens J, McClure R. The CDC Injury Center's response to the growing public health problem of falls among older adults. Am J Lifestyle Med. 2016 Jan-Feb;10(1):74–7. doi: 10.1177/1559827615600137. PMID: 26688674; PMCID: PMC4681302.

Common post acute complications

- **FALLS!**
  - Prevention is key
    - Evidence-based fall prevention classes available at NGMC Gainesville and Braselton
    - Legacy Link - Local area agency on aging
      - Serves Banks, Dawson, Forsyth, Franklin, Habersham, Hall, Hart, Lumpkin, Rabun, Stephens, Towns, Union and White counties
    - STEADI – CDC older adult fall prevention program
    - Aging Well - National Council on Aging (NCOA)
    - Web addresses on handout

Citation: Houry D, Florence C, Baldwin G, Stevens J, McClure R. The CDC Injury Center's response to the growing public health problem of falls among older adults. Am J Lifestyle Med. 2016 Jan-Feb;10(1):74–7. doi: 10.1177/1559827615600137. PMID: 26688674; PMCID: PMC4681302.

Thank You!
What questions do you have?

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