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Empowering Choices: Value-Driven Advance Healthcare Planning

Pam Edgar, MA, LCAT, RDT
Director of Education

Our Speakers

- Director of Education at CaringKind
- Licensed Creative Arts Therapist with MA in Drama Therapy from New York University
- Over 15 years experience with older adults and families impacted by dementia
- Expertise in Advance Care Planning and End Of Life Care

Pam Edgar, MA, LCAT, RDT

Director of Education, CaringKind

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Our Speakers

Brian Goldberg, MD, EMT-P

Emergency Medicine Resident

Former EMT & Paramedic

- Currently an Emergency Medicine Resident
- Over 15 years experience in Emergency Medical Services
- Served as an EMT, paramedic, educator and departmental manager across New York City, Nassau County and Chicago

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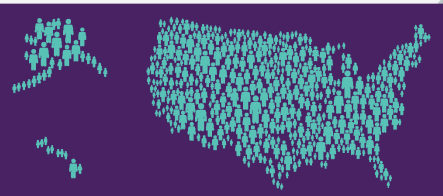
Empowering Choices Overview

- Why is advance planning important for families impacted by dementia?
- Benefits of Planning Ahead
- Start with Conversations
- Healthcare Planning Documentation –
  - Advance Directives
  - Health Care Proxies
  - Living Wills
  - Medical Orders
- Planning from a Paramedic's Perspective
- References and Resources

2025 ALZHEIMER'S DISEASE FACTS AND FIGURES



Over
7 MILLION
Americans are living with Alzheimer's

1 IN 3
older adults dies with Alzheimer's or another dementia

IT KILLS MORE THAN
breast cancer + prostate cancer
COMBINED

Between 2000 and 2022 deaths from heart disease have decreased **2.1%**

while deaths from Alzheimer's disease have increased **142%**

In 2025, Alzheimer's and other dementias will cost the nation **$384 BILLION**

By 2050, these costs could rise to nearly **$1 TRILLION**

The lifetime risk for Alzheimer's at age 45 is

1 IN 5 for women

1 IN 10 for men

NEARLY 12 MILLION
Americans provide unpaid care for people with Alzheimer's or other dementias

These caregivers provided more than 19 billion hours valued at nearly **$413 BILLION**

UP TO 4 IN 5
Americans feel optimistic about new Alzheimer's treatments in the next decade

92%
of Americans would want a medication to slow the progression of Alzheimer's following a diagnosis

For more information, visit alz.org/facts

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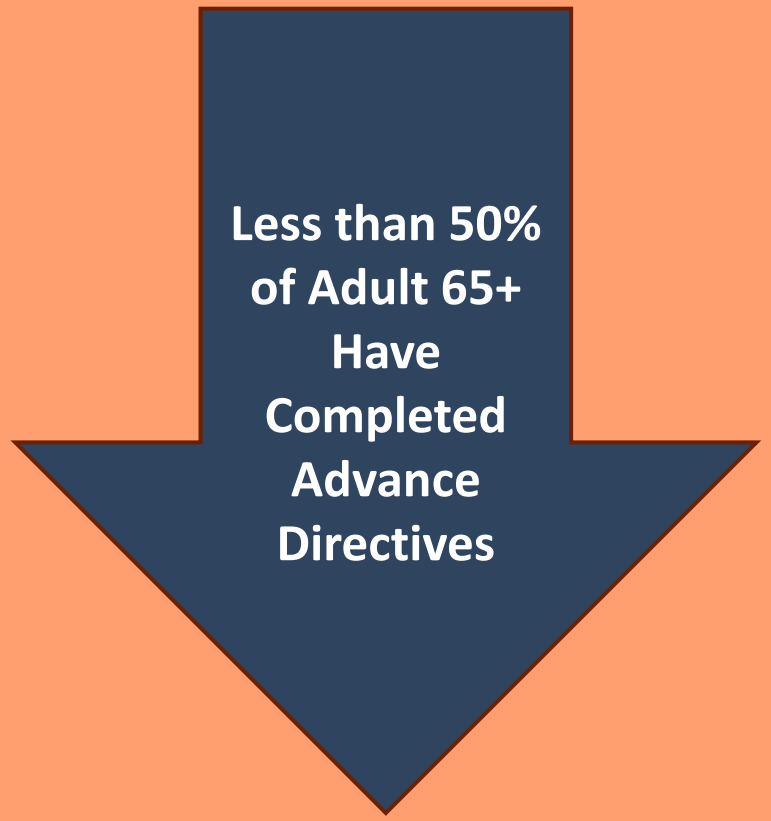
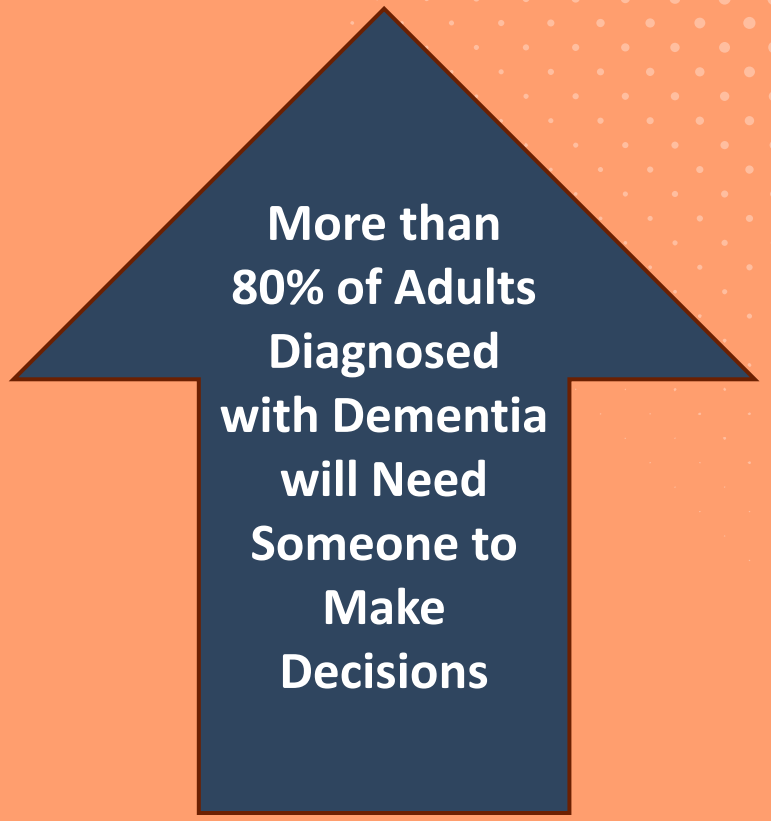
ALZHEIMER'S ASSOCIATION®





Alzheimer's Association 2025 Alzheimer's Disease Facts and Figures

Two out of Three U.S. Adults Have Not Completed an Advance Directive - Penn Medicine

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Approximately 70% of Americans Prefer to Die at Home

Approximately 31% die at home

Over 60% die in a facility

Facts & Figures | Facing Death | FRONTLINE | PBS

QuickStats: Percentage of Deaths, by Place of Death — National Vital Statistics System, United States, 2000–2018 | MMWR

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Benefits of Planning Ahead

- Learn about health conditions and progression
- Discuss values, preferences and wishes
- Allows for greater control
- Reduces stress, family conflict and uncertainty
- Minimizes complex grief
- Reduces unwanted hospitalizations and treatments
- Improves end of life care

Start with Conversations

Why Start with Conversations?

- Discuss conditions with doctors
- Define values and preferences
- Share your “why”?
- Discuss roles
- Hear different perspectives
- Ensure understanding
- Get on the same page!

Conversation starters

The most important things in my life

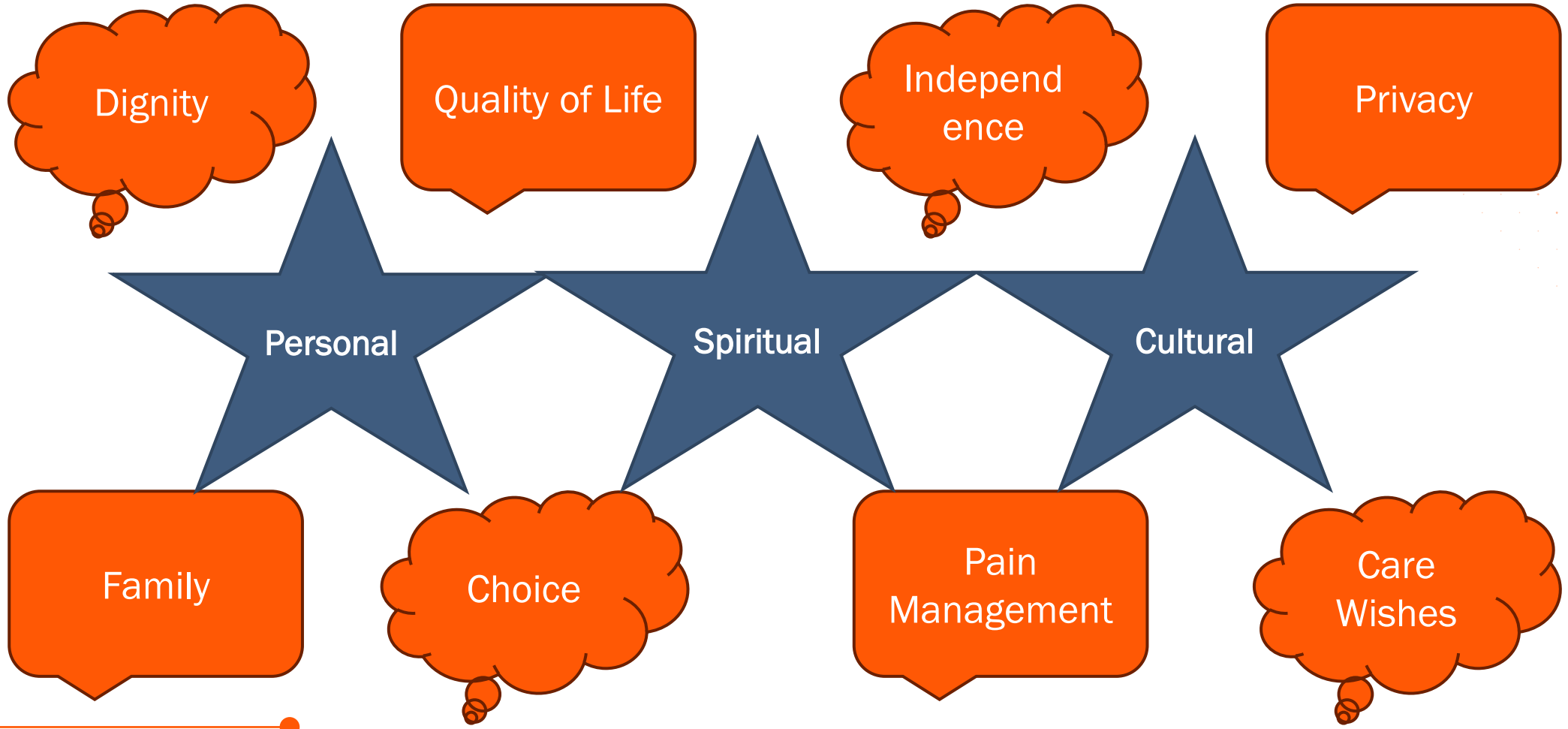
Advance Care Planning Australia

BE OPEN | BE READY | BE HEARD

About me	Being able to ..... is the most important thing to me because	I was thinking about what happened to ..... and it made me realise	As part of my culture, values and beliefs ..... is important to me because .....
About life	A good day for me is one where I ..... because	What I value and enjoy most in my life is ..... because	The most important things on my bucket list are .....
About health care	I would prefer to receive my health care at ..... because	When ..... happens I get worried about my health care because	I would want these people ..... included in discussions about my health.
About choices	An unacceptable health outcome for me would be ..... because	I would not want ..... treatments if there was little chance of recovery because	If I was choosing between quantity and quality of life, I would choose ..... because .....

https://thephn.com.au/what-we-do/care-for-older-people/advance-care-planning

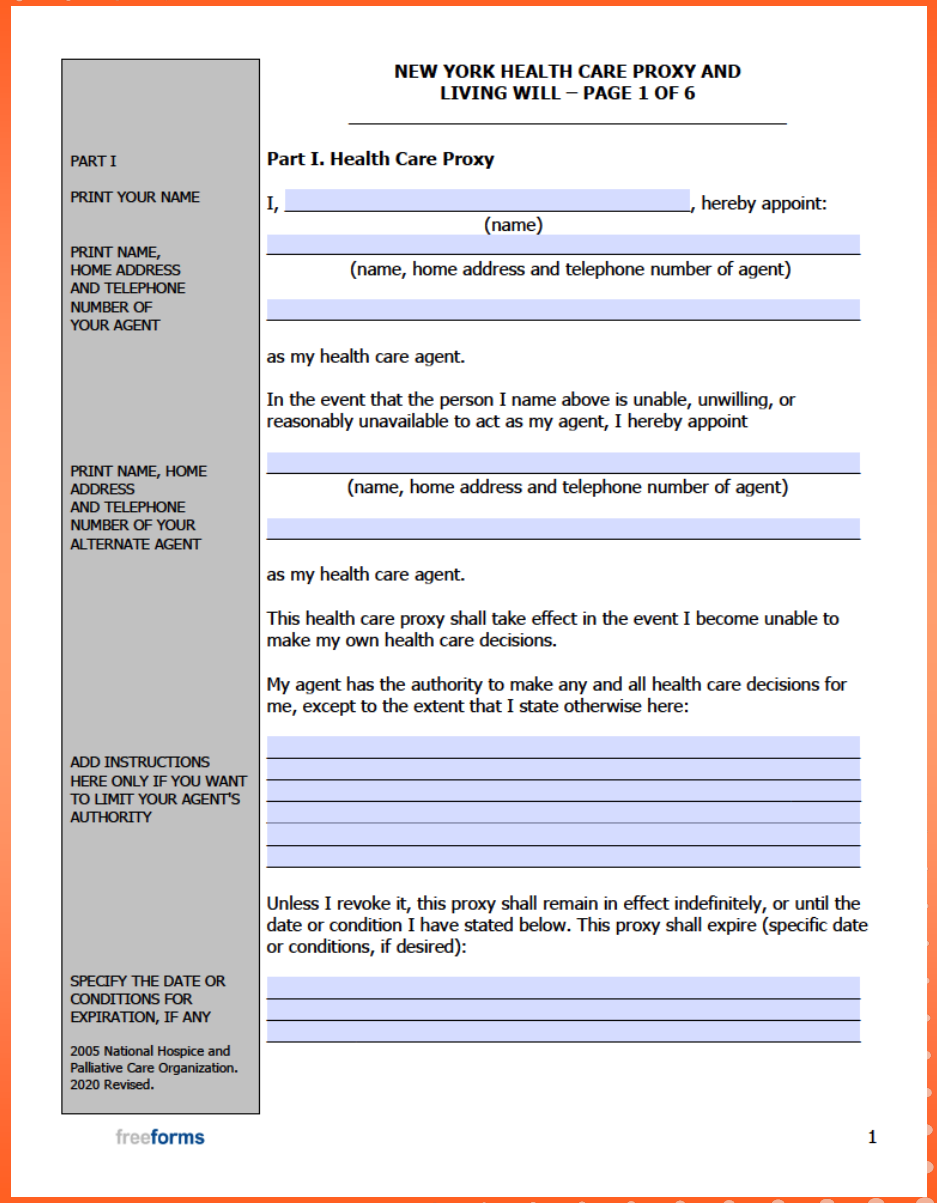
Define Your Values



Documentation – Advance Directives

Advance Directives

- Legal documents to convey decisions about health care
- Choose a trusted healthcare agent
- Determine healthcare decisions based on values and personal preferences
- End-of-life decisions – what interventions are acceptable or unacceptable



NEW YORK HEALTH CARE PROXY AND LIVING WILL – PAGE 1 OF 6

PART I

PRINT YOUR NAME

PRINT NAME, HOME ADDRESS AND TELEPHONE NUMBER OF YOUR AGENT

PRINT NAME, HOME ADDRESS AND TELEPHONE NUMBER OF YOUR ALTERNATE AGENT

ADD INSTRUCTIONS HERE ONLY IF YOU WANT TO LIMIT YOUR AGENT'S AUTHORITY

SPECIFY THE DATE OR CONDITIONS FOR EXPIRATION, IF ANY

2005 National Hospice and Palliative Care Organization. 2020 Revised.

Part I. Health Care Proxy

I, _____, hereby appoint:
(name)

_____
(name, home address and telephone number of agent)

_____

as my health care agent.

In the event that the person I name above is unable, unwilling, or reasonably unavailable to act as my agent, I hereby appoint

_____
(name, home address and telephone number of agent)

_____

as my health care agent.

This health care proxy shall take effect in the event I become unable to make my own health care decisions.

My agent has the authority to make any and all health care decisions for me, except to the extent that I state otherwise here:

_____
_____
_____
_____
_____
_____

Unless I revoke it, this proxy shall remain in effect indefinitely, or until the date or condition I have stated below. This proxy shall expire (specific date or conditions, if desired):

_____
_____
_____

freeforms

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Types of Advance Directives

Health Care Proxy	Living Will
Appoint a Health Care Agent to make medical decisions	Document written instructions or statement of healthcare wishes

Documentation –Health Care Proxies

What is a Health Care Agent?

- A person appointed to make medical decisions when someone is not able to make decisions for themselves
- Acts **only** when someone no longer has the capacity to make medical decisions
- Attorney not needed
- NY state form https://ag.ny.gov/health-care-proxy

How to choose your health care proxy

Select someone who:

- You'd trust with your life
- Is available for years to come
- Lives nearby or can get to you quickly when needed
- Is of legal age in your state
- Can be your advocate and ask important questions
- Is willing to manage conflicts that might arise between family, friends, and health care professionals
- Is able to separate their views from your wishes

Don't pick:

- Someone who is your health care provider or the owner of the health care facility where you're being treated*
- An employee of your health care provider*
- Your court-appointed guardian or conservator
- Anyone with a conflict of interest

Spouse or close relative excepted.

Source: American Bar Association Commission on Law and Aging

© Encyclopædia Britannica, Inc.

https://www.britannica.com/money/what-is-a-health-care-proxy

What Decisions Can The HCA Make?

Decisions that CAN be made

- Most medical decisions
  - For example: to authorize the MD to operate on you if you are too sick to talk and need an operation
  - Decisions to decline or stop most treatments

Decisions that CAN NOT be made

- Nutrition and hydration (in NY)
  - Even when there is no hope for recovery the HCP must have **specific written instructions** for nutrition and hydration to be stopped

NY – Family Health Care Decisions Act

- Enacted in NY in 2010
- Used when no health care proxy is appointed and person becomes incapacitated
- Provides hierarchy of decision makers
  1. Court-appointed guardian
  2. Spouse or domestic partner
  3. Adult child, in birth order
  4. Parent
  5. Adult sibling
  6. Close friend

Documentation – Living Wills

Living Wills

- instructions documenting wishes about medical care
- Used when someone becomes incapacitated, unable to communicate or make decisions
- Focuses on life sustaining treatment and interventions

Living Wills…Treatments To Consider

- Life support
- Cardiopulmonary resuscitation (CPR)
- Mechanical ventilation
- Artificial nutrition and hydration (tube feeding)
- Kidney dialysis
- Surgical procedures
- Diagnostic studies
- Intravenous lines
- Antibiotics
- Blood transfusions
- Chemotherapy & radiation therapy
- Organ or tissue donation

Living Wills - Example Language

BOX 45-2 ■ Sample Living Will Language

If I am in a terminal condition, irreversible coma, or in a persistent vegetative state, my wishes are as follows:

I ☐ **do** ☐ **do not** want to be in or taken to a hospital.

I ☐ **do** ☐ **do not** want pain medications to keep me comfortable.

I ☐ **do** ☐ **do not** want cardiac resuscitation, including drugs and electrical shock.

I ☐ **do** ☐ **do not** want mechanical respiration/artificial respiration.

I ☐ **do** ☐ **do not** want tube feeding or any other artificial or invasive form of nutrition (food).

I ☐ **do** ☐ **do not** want hydration (water), via tube or intravenously.

I ☐ **do** ☐ **do not** want blood or blood products.

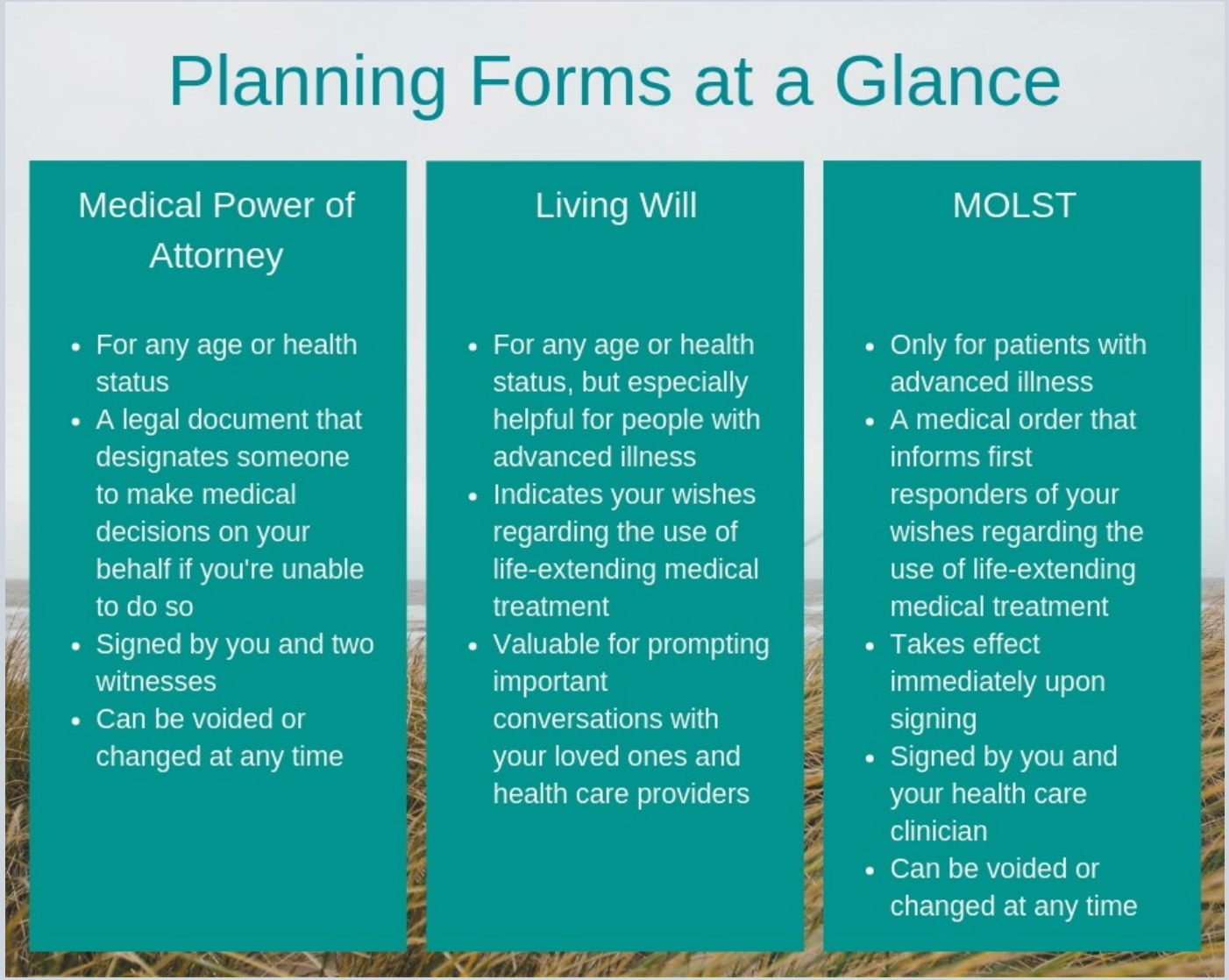
I ☐ **do** ☐ **do not** want any form of surgery or invasive diagnostic tests.

I ☐ **do** ☐ **do not** want renal dialysis.

I ☐ **do** ☐ **do not** want antibiotics.

Living Wills - Limitations

- Living Wills go into effect when the individual is unable to make decisions
- They do not guide immediate medical care
- If EMTs are called during an emergency, they will do everything to sustain life, including resuscitation, intubation, etc.
- The Health Care Proxy can not stop this with only a Living Will
- Once in the hospital, then the Health Care Proxy can make decisions if the individual is unable to do so



What are Medical Orders?

- Instructions given by a healthcare provider regarding the care and treatment of a patient
- Can be created and signed by Doctor or Nurse Practitioner
- MOs can cover different treatments and interventions
- Direct current care and treatment, unlike Living Wills

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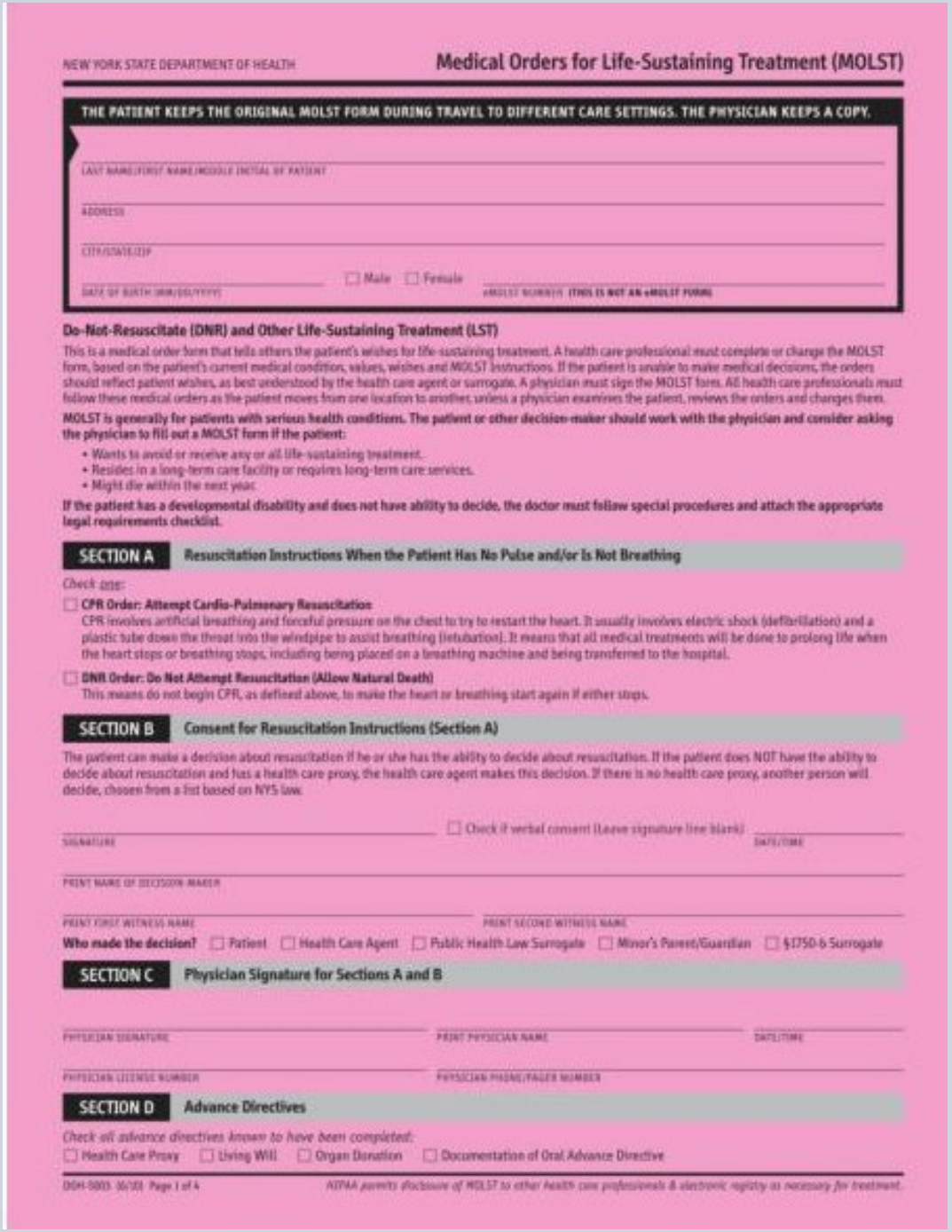
Medical Orders

- Do Not Resuscitate (DNR) – order specifying if heart stops, no Cardiopulmonary Resuscitation (CPR)
- Do Not Intubate (DNI) – order specifying no breathing tubes
- Can be specific to a hospitalization
- Out of Hospital DNR or DNI for home use
- Display on refrigerator for EMTs to find easily

Medical Orders for Life Sustaining Treatment

- **POLST / MOLST** – Dr. Orders for Life Sustaining Treatment
- Includes “Goals of Care”
- Enables decisions about CPR, respiratory support, feeding tubes, antibiotics, dialysis
- More binding than Living Will, can protect people from medical interventions at home (which Living Will can’t)
- Display on refrigerator



NEW YORK STATE DEPARTMENT OF HEALTH

Medical Orders for Life-Sustaining Treatment (MOLST)

THE PATIENT KEEPS THE ORIGINAL MOLST FORM DURING TRAVEL TO DIFFERENT CARE SETTINGS. THE PHYSICIAN KEEPS A COPY.

LAST NAME/FIRST NAME/MIDDLE INITIAL OF PATIENT

ADDRESS

CITY/STATE/ZIP

DATE OF BIRTH (MM/DD/YYYY) ☐ Male ☐ Female

eMOLST NUMBER (THIS IS NOT AN eMOLST FORM)

Do-Not-Resuscitate (DNR) and Other Life-Sustaining Treatment (LST)

This is a medical order form that tells others the patient's wishes for life-sustaining treatment. A health care professional must complete or change the MOLST form, based on the patient's current medical condition, values, wishes and MOLST instructions. If the patient is unable to make medical decisions, the orders should reflect patient wishes, as best understood by the health care agent or surrogate. A physician must sign the MOLST form. All health care professionals must follow these medical orders as the patient moves from one location to another, unless a physician examines the patient, reviews the orders and changes them.

MOLST is generally for patients with serious health conditions. The patient or other decision-maker should work with the physician and consider asking the physician to fill out a MOLST form if the patient:

- Wants to avoid or receive any or all life-sustaining treatment.
- Resides in a long-term care facility or requires long-term care services.
- Might die within the next year.

If the patient has a developmental disability and does not have ability to decide, the doctor must follow special procedures and attach the appropriate legal requirements checklist.

SECTION A **Resuscitation Instructions When the Patient Has No Pulse and/or Is Not Breathing**

Check one:

☐ **CPR Order: Attempt Cardio-Pulmonary Resuscitation**
CPR involves artificial breathing and forceful pressure on the chest to try to restart the heart. It usually involves electric shock (defibrillation) and a plastic tube down the throat into the windpipe to assist breathing (intubation). It means that all medical treatments will be done to prolong life when the heart stops or breathing stops, including being placed on a breathing machine and being transferred to the hospital.

☐ **DNR Order: Do Not Attempt Resuscitation (Allow Natural Death)**
This means do not begin CPR, as defined above, to make the heart or breathing start again if either stops.

SECTION B **Consent for Resuscitation Instructions (Section A)**

The patient can make a decision about resuscitation if he or she has the ability to decide about resuscitation. If the patient does NOT have the ability to decide about resuscitation and has a health care proxy, the health care agent makes this decision. If there is no health care proxy, another person will decide, chosen from a list based on NYS law.

SIGNATURE ☐ Check if verbal consent (Leave signature line blank) DATE/TIME

PRINT NAME OF DECISION MAKER

PRINT FIRST WITNESS NAME PRINT SECOND WITNESS NAME

Who made the decision? ☐ Patient ☐ Health Care Agent ☐ Public Health Law Surrogate ☐ Minor's Parent/Guardian ☐ §1750-b Surrogate

SECTION C **Physician Signature for Sections A and B**

PHYSICIAN SIGNATURE PRINT PHYSICIAN NAME DATE/TIME

PHYSICIAN LICENSE NUMBER PHYSICIAN PHONE/PAGER NUMBER

SECTION D **Advance Directives**

Check all advance directives known to have been completed:

☐ Health Care Proxy ☐ Living Will ☐ Organ Donation ☐ Documentation of Oral Advance Directive

DOH-5003 (6/10) Page 1 of 4 *HIPAA permits disclosure of MOLST to other health care professionals & electronic registry as necessary for treatment.*

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Other Considerations

- Start the conversation
- Ensure documents are signed and witnessed
- Give copies to healthcare agents, family members, doctors
- May keep copy in purse or wallet
- Guarantee ease of access in emergency

When to Change Your **Advance Directive** and **Living Will**

- **Life Circumstances/Health Status Changes**
- **Changes in Marital Status**
- **Every 10 Years**
- **Moving to a New State**
- **Experiencing the Death of a Loved One**

FINANCE STRATEGISTS

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Paramedic Perspective

EMS in a Nutshell

- EMS began in the 1970s to reduce deaths from cardiac arrest and trauma.
- Responds to medical emergencies, accidents, overdoses, and more.
- You may get responders from ambulance, fire, and police.
- Expect 2–8 people, using lights and sirens.

EMT vs Paramedic — What's the Difference?

Who's Treating You?

EMTs (Basic Life Support):

- Oxygen, CPR, bleeding control, oral meds

Paramedics (Advanced Life Support):

- IVs, EKGs, advanced meds, airway management

All follow standing medical protocols and live physician guidance

Call type determines who comes

What Happens When EMS Arrives

What to Expect

- One provider gets medical history, the other will start the physical exam or start treatments
- Questions include:
  - Why 911 was called, events leading up to injury or illness, medications, allergies, last meal or dose, pertinent medical history
- Physical Exam may include:
  - EKG, auscultation of heart or lungs, abdominal exam, neurological exam
- Hospital Destination
  - Often the closest hospital, but dependent on the situation

How You Can Prepare

How to Help

- Clear a path for responders and equipment
- Meet us at the door, if safe to do so
  - Alert doorman if possible
- Secure pets before EMS arrives
- Have updated list of medications, allergies, and conditions
- Have copies of DNR or MOLST easily accessible
  - EMS can only honor Out of Hospital DNR and MOLST/eMOLST forms
- Insurance card
- Set up Medical ID on cell phone


Think
What matters most to you?
Who could make health and personal care decisions for you if you cannot?
Talk
Discuss your thoughts with:
• the people you trust; and
• your health-care providers.
Review
Plan
Record your wishes.
Share your plan with:
• the people you trust; and
• your health-care providers

References & Resources

- National Institute on Health: https://www.nia.nih.gov/health/advance-care-planning/five-myths-about-advance-care-planning
- New York State Department of Health: https://www.health.ny.gov/community/advance_care_planning/
- NY State Advance Directives: https://ag.ny.gov/publications/advance-directives
  - Information and links to Advance Directive Documents and Medical Orders
- Five Wishes: https://www.fivewishes.org/
  - Type of Advance Directive, in plain language, allows for personalization
  - Valid in 46 states including NY
- The Conversation Project: https://theconversationproject.org/
  - Free guides for starting health care planning conversations

Questions

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