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GROUNDED CONVERSATIONS

WHAT REMAINS

**Where To Start &
Definitions**

A Quick Guide: Palliative Care, Hospice & End-of-Life Doulas

Palliative Care: *Comfort Alongside Treatment*

What it is: Specialized medical care that relieves the symptoms and reduces the stress of a serious illness, and improves quality of life for patients and families.

When it is used: At any stage of illness, often beginning at diagnosis, and **alongside treatments intended to cure, control, or prolong life.**

Key point: Palliative care is **not limited to people who are dying.**

Hospice: *Comfort Near the End of Life*

What it is: Care focused on comfort, dignity, and quality of life when an illness is terminal.

When it is used: Generally when a physician determines that a person has a life expectancy of **six months or less** if the illness follows its expected course.

Treatment focus: Under the Medicare hospice benefit, the person chooses comfort-focused care rather than curative treatment for the **terminal illness and related conditions**. This does **not** mean that all medical treatment stops.

Key point: Hospice may continue beyond six months as long as the person remains eligible and is recertified as terminally ill.

End-of-Life Doula: *Presence, Not Procedure*

What it is: A non-medical professional or volunteer who provides emotional, spiritual, practical, and informational support to a dying person and their loved ones.

A doula may help with:

- Facilitating difficult conversations about fears and questions
- Helping explore and plan for a personally meaningful “good death”
- Creating legacy projects, such as letters, recordings, or life reviews
- Planning vigils and providing bedside presence
- Creating a calm and meaningful environment
- Providing caregiver respite and family support
- Helping families understand and navigate the care system
- Offering grief support before and after death
- Assisting with practical planning and post-death resources

Key point: Doulas **complement — not replace — medical or hospice care.**

EOL Planning Documents

<https://endoflifechoicesny.org/all-advance-directive-forms/>

Advance Directive: Allows you to appoint someone you trust to make health care decisions for you if you are unable to communicate or lose the ability to make your own medical decisions. The person appointed as the agent should be willing to speak on your behalf.

DNR Order: Do Not Resuscitate Order

A DNR is appropriate for people with advanced illness or frailty who do not want to be revived if they stop breathing or if their heart stops beating. If you are at home rather than in a nursing home or hospital, you must have an official “Out of Hospital” DNR form, and it must be signed by a doctor.

Living Will: A living will lists the types of health care treatments you would or would not want under various circumstances. There is no official New York State form for a living will; the one provided here is just an example that can be changed to be consistent with your wishes.

MOLST: Medical Orders for Life Sustaining Treatment

Unlike a living will, a MOLST is a physician’s medical order that communicates your treatment preferences about certain health care treatments, including CPR, intubation, artificial nutrition and hydration, mechanical ventilation and antibiotics. It must be signed by a physician and may be more likely to be honored.

VSED Directive: Voluntary Stopping of Eating and Drinking

A VSED Directive expresses your end-of-life wishes if dementia or other progressive illnesses cause you to lose the ability to make your own health care decisions. This VSED Directive can be used anywhere in the United States.

MAID: Medical Aid in Dying (NY)

Medical aid in dying is an end-of-life health care option in which a mentally capable, terminally ill adult may request a prescription from their health care provider for a medication that they may choose to self-administer to die peacefully.

<https://compassionandchoices.org/in-your-state/new-york/new-york-amendment-explainer/>

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