



*The Women's Bar Association
of the State of New York*

presents

*Convention 2023
Continuing Legal Education Series*

Long Term Care Planning in New York

June 3, 2023
8:30 am - 10:00 am

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LONG TERM CARE PLANNING

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LEARNING OBJECTIVES

1. Understand the need for long-term care planning
2. Be familiar with the options for covering the cost of long-term care
3. Understand the basic eligibility requirements & planning techniques for Medicaid



NOT Means-Tested

- Medicare: Parts A, B, C and D

Eligibility is based on quarters worked & payments made into Social Security.

Means-Tested, i.e., eligibility is based on resources & income

- Medicaid, 42 U.S.C. § 1396 for Disabled, Aged and Blind (“DAB”)

MEDICARE V.
MEDICAID

Long Term Care Options

- Privately pay cost of long-term care
- Private long-term care insurance
- NYS Partnership for Long-Term Care hybrid policy: not currently available, may become re-available
- Medicaid

ADVANCE DIRECTIVES FOR LTC

- Health care proxy
- Living Will
- Power of attorney with gifting
- Advance Directive for Dementia
- MOLST



HEALTH CARE PROXY

- NY law allows you to appoint a person you trust to make health care decisions for you, i.e., your health care agent.
- For nursing homes, hospitals, hospice, even if you don't have a health care proxy, there's a default law that has a list of who can make health care decisions for you: guardian, then spouse, etc. : Family Health Care Decisions Act

LIVING WILL

- Legal document stating your wishes regarding life prolonging medical treatments:

- ☐ CPR
- ☐ Artificial nutrition/hydration
- ☐ DNI (Do Not Intubate)
- ☐ Mechanical Respiration
- ☐ Antibiotics

- Your agent under your Health Care Proxy should know your desires as set forth in your Living Will.

POWER OF ATTORNEY

- Agent under power of attorney can decide your domicile, approve costs for your care and apply for benefits for you
- Power of attorney needs to specify if you are allowing gifting. Without appropriate gifting powers, your agent may not be able to do effective Medicaid planning.
- In that scenario, a guardianship may be necessary to get court authority to engage in Medicaid planning on your behalf.



MEDICARE

- Federal health insurance program authorized by the Social Security Act that provides medical coverage.
- Must qualify for Social Security or Railroad Retirement benefits &
 - Be elderly (aged 65 and over) OR
 - If under 65, disabled and received Social Security Disability Insurance for 2 years.
- Individuals 65 and older who do not qualify for Social Security can obtain Part A coverage by paying a premium and enrolling in Medicare Part B.
- Penalties for late enrollment.



MEDICAID PROGRAM

- Joint program between federal & state governments to provide medical services to DISABLED, BLIND, OR AGED (DAB) individuals who meet certain income and resource levels.
- Each state's Medicaid program is different and eligibility is based upon the recipient's state of residence. Rules discussed here are for NY Medicaid. If client resides in different state, eligibility rules may be different.
- Covers hospital services, physician services, skilled nursing home costs, rehabilitation services, therapies, prescribed drugs, nursing services, home and community care for persons with disabilities, community support, personal care, case management services and medical transportation.

LONG-TERM CARE

- Generally, Medicare does not cover costs of long-term care.
- Long-term care insurance may cover all or part of the cost of long-term care.
- Private LTC insurance n NYS partnership policy.
- Medicaid covers costs of long-term care at home, assisted living facility or nursing home.
- Community Medicaid v. Nursing Home Medicaid: different rules for income, look-back and how home is treated.



MEDICAID ELIGIBILITY GENERALLY

- Income limits: \$1,677/month for individual; \$2,268/month for married couple where both are applying. (This is net of health care insurance premiums).
- “Pooled income trust” or “spend-down” are available as planning tools for excess income above the allowed amounts.
- Resource limits: \$30,180 for individual; For married couples, Medicaid considers income and assets of both spouses. Planning strategies available for assets.

Eligibility of married applicant & spousal refusal

- For married applicant, Medicaid looks at **both** spouses' resources & income.
- If a spouse executes a “spousal refusal,” in certain circumstances, the spouse's income and resources are **NOT** considered available
- “Spousal impoverishment”: “**well**”/**community spouse** allowed to keep certain amount of couple's joint income/assets
 - higher of \$74,820 or $\frac{1}{2}$ of total value of joint assets, up to \$148,620 (Community Spouse Resource Allowance)
 - joint income of up to \$3,715.50/month (Minimum Monthly Maintenance Needs Award)

EXEMPT ASSETS FOR MEDICAID

- \$30,182 for individual; \$40,820 for couples applying together.
- Primary residence, BUT equity limited to \$1,033,000.
- One vehicle.
- Retirement accounts in appropriate payout status.
- Burial fund or life insurance up to \$1,500.
- Irrevocable pre-paid funeral arrangements in any amounts.
- Household goods and effects.

MEDICAID LOOK-BACK

- Community Medicaid (home care) v. Nursing Home Medicaid: Community Medicaid only has 1-month look-back period. No penalty period for uncompensated transfers.
- Nursing Home Medicaid has 5-year look-back period for asset transfers and transfer penalty, i.e.
- Medicaid goes back 5 years from date of application to see whether applicant made any uncompensated transfers for purposes of qualifying for Medicaid, and, if so, penalizes applicant based on a formula.
- Transfers to trusts and gifts to third-parties are uncompensated, so subject to penalty period if within the look-back period.

COMMUNITY MEDICAID LOOKBACK/PENALTY

- Legislation passed for **lookback & penalty period** for Medicaid community based long term care services
- Lookback for home care is 30 months v. 60 months for nursing home
- Implementation of lookback period delayed until at least March 2024. This means that the lookback will apply to new applications or applications for increases in coverage filed on or after **March 2024**.
- The lookback and penalties for community home care will not apply to transfers made **on or before October 1, 2020**.

2023 Regional Rates for Calculating Transfer Penalties

CENTRAL: \$11,726

Broome, Cayuga, Chenango, Cortland, Herkimer, Jefferson, Lewis, Madison, Oneida, Onondaga, Oswego, St. Lawrence, Tioga and Tompkins.

NORTHEASTERN: \$12,744

Albany, Clinton, Columbia, Delaware, Essex, Franklin, Fulton, Greene, Hamilton, Montgomery, Otsego, Rensselaer, Saratoga, Schenectady, Schoharie, Warren, and Washington.

WESTERN: \$12,130

Allegany, Cattaraugus, Chautauqua, Erie, Genesee, Niagara, Orleans, and Wyoming.

NORTH METROPOLITAN: \$13,906

Dutchess, Orange, Putnam, Rockland, Sullivan, Ulster, and Westchester.

NEW YORK CITY: \$14,142

Bronx, Kings (Brooklyn), New York (Manhattan), Queens and Richmond (Staten Island).

LONG ISLAND: \$14,136

Nassau and Suffolk.

ROCHESTER: \$13,421

Chemung, Livingston, Monroe, Ontario, Schuyler, Seneca, Steuben, Wayne, and Yates.

EXEMPT TRANSFERS

- Spouse
- Disabled child
- Blind child
- Trust for sole benefit of disabled or blind child
- Supplemental needs trust for applicant if under 65

EXEMPT TRANSFERS SOLELY FOR HOME

- Spouse
- Minor child under 21
- Child who is certified blind
- Child who is certified disabled
- Sibling with equity interest (1 year residency requirement)
- Caretaker child (2 years requirement)

SPECIAL RULES FOR THE HOME

- Subject to equity limits, primary residence is exempt for community Medicaid purposes, currently.
- Question of how transfer of primary residence will be treated if home care look back implemented.
- Special rules apply for primary residence of Medicaid applicant in nursing home. Remains exempt so long as applicant has subjective “intent to return home.”

MEDICAID ASSET PROTECTION TRUSTS

- A planning tool to allow individuals with countable assets over the Medicaid limit to qualify for Medicaid long-term care coverage.
- Can provide for the protection of the family home, savings and other assets for family members, without the trust assets being counted as a resource for purposes of determining eligibility for Medicaid.
- Permits individuals to be eligible for Medicaid long-term care coverage without exhausting their savings or selling their home.
- Step-up in basis for property in MAPT if properly drafted.

LIFE ESTATE

- Life estate interest is not counted as an asset of an applicant for purposes of eligibility for Medicaid.
- Grantor has lifetime right of occupancy and right to income and obligation to pay carrying expenses.
- On death, property passes to remainderman/men (usually family members) with step up in basis and avoiding probate.
- Cons: loss of control, need consent of remaindermen to sell during lifetime, upon sale only receive proceeds attributable to life interest.
- If property is sold while applicant is on Medicaid, can cause eligibility issue.

SUPPLEMENTAL NEEDS TRUST

- Planning tool that allows maximization of monies available to disabled person without being counted as resource for purposes of eligibility for Medicaid eligibility so long as:
 - SNT meets legal requirements.
 - Funds are not distributed by the Trustee directly to the beneficiary.
-
- Properly drafted SNT provides that trust funds must be used to supplement, not supplant, government benefits.

BENEFITS OF AN SNT

- Assets held in an SNT are NOT deemed to be available resources to the Beneficiary for purposes of means-tested benefits. POMS SI 00120.200 & 01120.203.
- Supplemental needs that can be paid from an SNT can include any need of the disabled beneficiary, including health care, that is not taken care of by the government benefit, such as a home, care givers, computers, transportation, vocational training, insurance coverage, specially equipped vehicles, vacations, and luxuries.

PROMISSORY NOTE & GIFTING

- Gift/loan is advanced Medicaid planning strategy used in crisis situations where Medicaid applicant needs immediate nursing home care.
- Appr. $\frac{1}{2}$ of excess assets are gifted; the other $\frac{1}{2}$ are loaned to third-party secured by a promissory note.
- Payments on loan are used to privately pay for nursing home care during period of Medicaid ineligibility that is imposed b/c of gifting during lookback
- Rules are complex and intricate BUT the monthly payback from the loan must bring applicant under the nursing home private pay rate
- SSL §366 subd. 5 (e)(3)(i) & (iii)]

APPLICABLE LAW

- Omnibus Budget Reconciliation Act of 1993/New York Chapter 70 of the Laws of 1994
- 42 USC Section 1396p: Liens, adjustments and recoveries, and transfer of assets
- 18 NYCRR Section 360-4.5: Availability of assets held in trust
- Social Security Administration's Program Operations Manual (POMS)
- EPTL §§ 7-1.6, 7-1.9, 7-1.17, 7-1.18, & 10-6.6.
- 12 U.S. Code §1701j-3-(d)(8)
- State Medicaid Manual
- Fair Hearing decisions at Office of Temporary & Disability Assistance
- Caselaw

DISCLAIMER

The information contained in this presentation is provided for general information purposes only and is NOT legal advice.

Legal advice is dependent upon the specific circumstances of each situation.

Instructions for Completing Your New York Living Will

A Living Will **only becomes effective** if you are determined to have a terminal illness or are at the end-of-life and when you are no longer able to communicate your wishes. In New York State, the Living Will was authorized by the courts (not by legislation) so there are no requirements guiding its use. But, a Living Will can serve an important role to provide clear evidence of your wishes.

You can add personal instructions in Item 3 on the form if there are specific treatments that you wish to refuse but are not listed on the document.

You can also add a statement referring to your health care agent such as, “Any questions about how to apply my Living Will are to be decided by my health care agent.”

Item 1: Print your name

Item 2: Cross out any of the statements that **do not** reflect your wishes

Item 3: Write in any personal instructions

Item 4: Date and sign the document and include your address

Item 5: Two witnesses must sign the document and print their addresses.

Note: This form does not need to be notarized.

New York State Living Will

This Living Will has been prepared to conform to the law in the State of New York, as set forth in the case In re Westchester County Medical Center, 72 N.Y. 2d 517 (1988). In that case the Court established the need for “clear and convincing” evidence of a patient’s wishes and stated that the “ideal situation is one in which the patient’s wishes were expressed in some form of writing, perhaps a ‘Living Will’.”

I, [1]_____, being of sound mind, make this statement as a directive to be followed if I become permanently unable to participate in decisions regarding my medical care. These instructions reflect my firm and settled commitment to decline medical treatment under the circumstances indicated below:

I direct my attending physician to withhold or withdraw treatment that merely prolongs my dying, if I should be in an incurable or irreversible mental or physical condition with no reasonable expectation of recovery, including but not limited to: (a) a terminal condition; (b) a permanently unconscious condition; or (c) a minimally conscious condition in which I am permanently unable to make decisions or express my wishes.

I direct that my treatment be limited to measures to keep me comfortable and to relieve pain, including any pain that might occur by withholding or withdrawing treatment. While I understand that I am not legally required to be specific about future treatments **if I am in the condition(s) described above I feel especially strongly about the following forms of treatment:**

[2]

I do not want cardiac resuscitation.

I do not want mechanical respiration.

I do not want artificial nutrition and hydration.

I do not want antibiotics.

However, I **do want** maximum pain relief, even if it may hasten my death.

[3] Other directions:

These directions express my legal right to refuse treatment, under the law of New York. I intend my instructions to be carried out, unless I have rescinded them in a new writing or by clearly indicating that I have changed my mind.

[4]

Signed _____ Date _____

Address _____

I declare that the person who signed this document appeared to execute the Living Will willingly and free from duress. He or she signed (or asked another to sign for him or her) this document in my presence.

[5]

Name of Witness 1 (please print, sign and date)

Signed _____ Date _____

Address _____

Name of Witness 2

Signed _____ Date _____

Address _____

HEALTH CARE PROXY

Appointing Your Health Care Agent in New York State

The New York Health Care Proxy Law allows you to appoint someone you trust — for example, a family member or close friend — to make health care decisions for you if you lose the ability to make decisions yourself. By appointing a health care agent, you can make sure that health care providers follow your wishes. Your agent can also decide how your wishes apply as your medical condition changes. Hospitals, doctors and other health care providers must follow your agent's decisions as if they were your own. You may give the person you select as your health care agent as little or as much authority as you want. You may allow your agent to make all health care decisions or only certain ones. You may also give your agent instructions that he or she has to follow. This form can also be used to document your wishes or instructions with regard to organ, eye and/or tissue donation.

About the Health Care Proxy Form

This is an important legal document. Before signing, you should understand the following facts:

1. This form gives the person you choose as your agent the authority to make all health care decisions for you, including the decision to remove or provide life-sustaining treatment, unless you say otherwise in this form. "Health care" means any treatment, service or procedure to diagnose or treat your physical or mental condition.
2. Unless your agent reasonably knows your wishes about artificial nutrition and hydration (nourishment and water provided by a feeding tube or intravenous line), he or she will not be allowed to refuse or consent to those measures for you.
3. Your agent will start making decisions for you when your doctor determines that you are not able to make health care decisions for yourself.
4. You may write on this form examples of the types of treatments that you would not desire and/or those treatments that you want to make sure you receive. The instructions may be used to limit the decision-making power of the agent. Your agent must follow your instructions when making decisions for you.
5. You do not need a lawyer to fill out this form.
6. You may choose any adult (18 years of age or older), including a family member or close friend, to be your agent. If you select a doctor as your agent, he or she will have to choose between acting as your agent or as your attending doctor because a doctor cannot do both at the same time. Also, if you are a patient or resident of a hospital, nursing home or mental hygiene facility, there are special restrictions about naming someone who works for that facility as your agent. Ask staff at the facility to explain those restrictions.
7. Before appointing someone as your health care agent, discuss it with him or her to make sure that he or she is willing to act as your agent. Tell the person you choose that he or she will be your health care agent. Discuss your health care wishes and this form with your agent. Be sure to give him or her a signed copy. Your agent cannot be sued for health care decisions made in good faith.
8. If you have named your spouse as your health care agent and you later become divorced or legally separated, your former spouse can no longer be your agent by law, unless you state otherwise. If you would like your former spouse to remain your agent, you may note this on your current form and date it or complete a new form naming your former spouse.
9. Even though you have signed this form, you have the right to make health care decisions for yourself as long as you are able to do so, and treatment cannot be given to you or stopped if you object, nor will your agent have any power to object.
10. You may cancel the authority given to your agent by telling him or her or your health care provider orally or in writing.
11. Appointing a health care agent is voluntary. No one can require you to appoint one.
12. You may express your wishes or instructions regarding organ, eye and/or tissue donation on this form.

Frequently Asked Questions

Why should I choose a health care agent?

If you become unable, even temporarily, to make health care decisions, someone else must decide for you. Health care providers often look to family members for guidance. Family members may express what they think your wishes are related to a particular treatment. Appointing an agent lets you control your medical treatment by:

- allowing your agent to make health care decisions on your behalf as you would want them decided;
- choosing one person to make health care decisions because you think that person would make the best decisions;
- choosing one person to avoid conflict or confusion among family members and/or significant others.

You may also appoint an alternate agent to take over if your first choice cannot make decisions for you.

Who can be a health care agent?

Anyone 18 years of age or older can be a health care agent. The person you are appointing as your agent or your alternate agent cannot sign as a witness on your Health Care Proxy form.

How do I appoint a health care agent?

All competent adults, 18 years of age or older, can appoint a health care agent by signing a form called a Health Care Proxy. You don't need a lawyer or a notary, just two adult witnesses. Your agent cannot sign as a witness. You can use the form printed here, but you don't have to use this form.

When would my health care agent begin to make health care decisions for me?

Your health care agent would begin to make health care decisions after your doctor decides that you are not able to make your own health care decisions. As long as you are able to make health care decisions for yourself, you will have the right to do so.

What decisions can my health care agent make?

Unless you limit your health care agent's authority, your agent will be able to make any health care decision that you could have made if you were able to decide for yourself. Your agent can agree that you should receive treatment, choose among different treatments and decide that treatments should not be provided, in accordance with your wishes and interests. However, your agent can only make decisions about artificial nutrition and hydration (nourishment and water provided by feeding tube or intravenous line) if he or she knows your wishes from what you have said or what you have written. The Health Care Proxy form does not give your agent the power to make non-health care decisions for you, such as financial decisions.

Why do I need to appoint a health care agent if I'm young and healthy?

Appointing a health care agent is a good idea even though you are not elderly or terminally ill. A health care agent can act on your behalf if you become even temporarily unable to make your own health care decisions (such as might occur if you are under general anesthesia or have become comatose because of an accident). When you again become able to make your own health care decisions, your health care agent will no longer be authorized to act.

How will my health care agent make decisions?

Your agent must follow your wishes, as well as your moral and religious beliefs. You may write instructions on your Health Care Proxy form or simply discuss them with your agent.

Frequently Asked Questions, *continued*

How will my health care agent know my wishes?

Having an open and frank discussion about your wishes with your health care agent will put him or her in a better position to serve your interests. If your agent does not know your wishes or beliefs, your agent is legally required to act in your best interest. Because this is a major responsibility for the person you appoint as your health care agent, you should have a discussion with the person about what types of treatments you would or would not want under different types of circumstances, such as:

- whether you would want life support initiated/continued/removed if you are in a permanent coma;
- whether you would want treatments initiated/continued/removed if you have a terminal illness;
- whether you would want artificial nutrition and hydration initiated/withheld or continued or withdrawn and under what types of circumstances.

Can my health care agent overrule my wishes or prior treatment instructions?

No. Your agent is obligated to make decisions based on your wishes. If you clearly expressed particular wishes, or gave particular treatment instructions, your agent has a duty to follow those wishes or instructions unless he or she has a good faith basis for believing that your wishes changed or do not apply to the circumstances.

Who will pay attention to my agent?

All hospitals, nursing homes, doctors and other health care providers are legally required to provide your health care agent with the same information that would be provided to you and to honor the decisions by your agent as if they were made by you. If a hospital or nursing home objects to some treatment options (such as removing certain treatment) they must tell you or your agent BEFORE or upon admission, if reasonably possible.

What if my health care agent is not available when decisions must be made?

You may appoint an alternate agent to decide for you if your health care agent is unavailable, unable or unwilling to act when decisions must be made. Otherwise, health care providers will make health care decisions for you that follow instructions you gave while you were still able to do so. Any instructions that you write on your Health Care Proxy form will guide health care providers under these circumstances.

What if I change my mind?

It is easy to cancel your Health Care Proxy, to change the person you have chosen as your health care agent or to change any instructions or limitations you have included on the form. Simply fill out a new form. In addition, you may indicate that your Health Care Proxy expires on a specified date or if certain events occur. Otherwise, the Health Care Proxy will be valid indefinitely. If you choose your spouse as your health care agent or as your alternate, and you get divorced or legally separated, the appointment is automatically cancelled. However, if you would like your former spouse to remain your agent, you may note this on your current form and date it or complete a new form naming your former spouse.

Can my health care agent be legally liable for decisions made on my behalf?

No. Your health care agent will not be liable for health care decisions made in good faith on your behalf. Also, he or she cannot be held liable for costs of your care, just because he or she is your agent.

Frequently Asked Questions, *continued*

Is a Health Care Proxy the same as a living will?

No. A living will is a document that provides specific instructions about health care decisions. You may put such instructions on your Health Care Proxy form. The Health Care Proxy allows you to choose someone you trust to make health care decisions on your behalf. Unlike a living will, a Health Care Proxy does not require that you decide in advance decisions that may arise. Instead, your health care agent can interpret your wishes as medical circumstances change and can make decisions you could not have known would have to be made.

Where should I keep my Health Care Proxy form after it is signed?

Give a copy to your agent, your doctor, your attorney and any other family members or close friends you want. Keep a copy in your wallet or purse or with other important papers, but not in a location where no one can access it, like a safe deposit box. Bring a copy if you are admitted to the hospital, even for minor surgery, or if you undergo outpatient surgery.

May I use the Health Care Proxy form to express my wishes about organ, eye and/or tissue donation?

Yes. Use the optional organ, eye and/or tissue donation section on the Health Care Proxy form and be sure to have the section witnessed by two people. You may specify that your organs, eyes and/or tissues be used for transplantation, research or educational purposes. Any limitation(s) associated with your wishes should be noted in this section of the proxy. **Failure to include your wishes and instructions on your Health Care Proxy form will not be taken to mean that you do not want to be an organ, eye and/or tissue donor.**

Can my health care agent make decisions for me about organ, eye and/or tissue donation?

Yes. As of August 26, 2009, your health care agent is authorized to make decisions after your death, but only those regarding organ, eye and/or tissue donation. Your health care agent must make such decisions as noted on your Health Care Proxy form.

Who can consent to a donation if I choose not to state my wishes at this time?

It is important to note your wishes about organ, eye and/or tissue donation to your health care agent, or “health care proxy,” family members, and the person responsible for disposition of your remains. If you have not already made your wishes to become, or not to become, an organ and/or tissue donor known, New York Law provides a list of individuals who are authorized to consent to organ, eye and/or tissue donation on your behalf. They are listed as follows, in order of priority: your health care agent/proxy; your spouse, if you are not legally separated, or your domestic partner; a son or daughter 18 years of age or older; either of your parents; a brother or sister 18 years of age or older; an adult grandchild; a grandparent; a guardian appointed for you by a court prior to your death; or any other person authorized to dispose of your body.

HEALTH CARE PROXY FORM INSTRUCTIONS

Item (1)

Write the name, home address and telephone number of the person you are selecting as your agent.

Item (2)

If you want to appoint an alternate agent, write the name, home address and telephone number of the person you are selecting as your alternate agent.

Item (3)

Your Health Care Proxy will remain valid indefinitely unless you set an expiration date or condition for its expiration. This section is optional and should be filled in only if you want your Health Care Proxy to expire.

Item (4)

If you have special instructions for your agent, write them here. Also, if you wish to limit your agent's authority in any way, you may say so here or discuss them with your health care agent. If you do not state any limitations, your agent will be allowed to make all health care decisions that you could have made, including the decision to consent to or refuse life-sustaining treatment.

If you want to give your agent broad authority, you may do so right on the form. Simply write: I have discussed my wishes with my health care agent and alternate and they know my wishes including those about artificial nutrition and hydration.

If you wish to make more specific instructions, you could say:

If I become terminally ill, I do/don't want to receive the following types of treatments....

If I am in a coma or have little conscious understanding, with no hope of recovery, then I do/don't want the following types of treatments:....

If I have brain damage or a brain disease that makes me unable to recognize people or speak and there is no hope that my condition will improve, I do/don't want the following types of treatments:....

I have discussed with my agent my wishes about _____ and I want my agent to make all decisions about these measures.

Examples of medical treatments about which you may wish to give your agent special instructions are listed below. This is not a complete list:

- artificial respiration
- artificial nutrition and hydration (nourishment and water provided by feeding tube)
- cardiopulmonary resuscitation (CPR)
- antipsychotic medication
- electric shock therapy
- antibiotics
- surgical procedures
- dialysis
- transplantation
- blood transfusions
- abortion
- sterilization

Item (5)

You must date and sign this Health Care Proxy form. If you are unable to sign yourself, you may direct someone else to sign in your presence. Be sure to include your address.

Item (6)

You may state wishes or instructions about organ, eye and /or tissue donation on this form. New York law does provide for certain individuals in order of priority to consent to an organ, eye and/or tissue donation on your behalf: your designated health care agent/proxy; your designated agent to control the disposition of your remains; your spouse, if you are not legally separated, or your domestic partner; a son or daughter 18 years of age or older; either of your parents; a brother or sister 18 years of age or older; an adult grandchild; a grandparent; a guardian appointed by a court prior to your death; or any other person authorized to dispose of your body.

Item (7)

Two witnesses 18 years of age or older must sign this Health Care Proxy form. The person who is appointed your agent or alternate agent cannot sign as a witness.

HEALTH CARE PROXY

(1) I, _____
hereby appoint _____
(name, home address and telephone number)

as my health care agent to make any and all health care decisions for me, except to the extent that I state otherwise. This proxy shall take effect only when and if I become unable to make my own health care decisions.

(2) Optional: Alternate Agent

If the person I appoint is unable, unwilling or unavailable to act as my health care agent, I hereby appoint _____
(name, home address and telephone number)

as my health care agent to make any and all health care decisions for me, except to the extent that I state otherwise.

(3) Unless I revoke it or state an expiration date or circumstances under which it will expire, this proxy shall remain in effect indefinitely. (Optional: If you want this proxy to expire, state the date or conditions here.) This proxy shall expire (specify date or conditions):

(4) **Optional:** I direct my health care agent to make health care decisions according to my wishes and limitations, as he or she knows or as stated below. (If you want to limit your agent's authority to make health care decisions for you or to give specific instructions, you may state your wishes or limitations here.) I direct my health care agent to make health care decisions in accordance with the following limitations and/or instructions (attach additional pages as necessary):

In order for your agent to make health care decisions for you about artificial nutrition and hydration (nourishment and water provided by feeding tube and intravenous line), your agent must reasonably know your wishes. You can either tell your agent what your wishes are or include them in this section. See instructions for sample language that you could use if you choose to include your wishes on this form, including your wishes about artificial nutrition and hydration.

(5) Your Identification *(please print)*

Your Name _____

Your Signature _____ Date _____

Your Address _____

(6) Optional: Organ, Eye and/or Tissue Donation

I hereby make an anatomical gift, to be effective upon my death, of:
(check any that apply)

☐ Any needed organs, eyes and/or tissues

☐ The following organs, eyes and/or tissues _____

☐ Limitations _____

If you do not state your wishes or instructions about organ, eye and/or tissue donation on this form, it will not be taken to mean that you do not wish to make a donation or prevent a person, who is otherwise authorized by law, to consent to a donation on your behalf.

Your Signature _____ Date _____

(7) Statement by Witnesses *(Witnesses must be 18 years of age or older and cannot be the health care agent or alternate.)*

I declare that the person who signed this document is personally known to me and appears to be of sound mind and acting of his or her own free will. He or she signed (or asked another to sign for him or her) this document in my presence.

Witness 1

Date _____

Name *(print)* _____

Signature _____

Address _____

Witness 2

Date _____

Name *(print)* _____

Signature _____

Address _____



**Department
of Health**

What If I Had Dementia?

Planning for the future

Alzheimer's disease is one of the most common problems people face in their 70's and 80's. One of the most important things you can do is tell people who would be taking care of you what medical care you think you would want if you were to develop worsening dementia.

What is dementia? Over many years, people with Alzheimer's (and other forms of dementia) lose the ability to understand what is going on around them. In later stages, people with dementia no longer recognize people they know. They need help from others with their own basic body functions. At times they might still enjoy some experiences. At other times they can become angry and confused.

There is no cure for dementia. Gradually people lose the ability to speak, eat, and walk. Eventually people die from dementia, often from dementia-related pneumonia. This process can take anywhere from 5 years to 20 years.

One of the most important questions to consider is: what kind of medical care do you think you would want if you were to develop worsening dementia?

Why it is important to express your wishes. People with advancing dementia lose the ability to make decisions for themselves. Their families need to make medical decisions for them. Giving family members guidance about what type of care you would want can help ease the burden of their decision making and help you feel more secure that you will receive the care that you would want.

Some people may not want to give this type of guidance, but would rather trust their families to make decisions. For those people, this Directive may not be helpful. However, many people do want to provide some guidance for their family, even if it is hard to know exactly what your future situation might be.

What kinds of guidance can you give? You can say, ahead of time, what you would want the focus of your medical care to be. At what point would you still want everything done to keep you alive longer? At what point might you want only hospice-type care focused mainly on treating your symptoms and keeping you comfortable?

INSTRUCTIONS

1. On the following pages are descriptions of the stages of dementia. Read the description of each stage. Then mark one box under each stage that most closely fits what you would want the goals of your care to be if you had that stage of dementia.

2. Once you have filled out the Directive, the most important thing you can do is discuss these wishes with your closest family members. This is the most important thing you can do. In the future, if you have dementia, your closest family members will be the ones making medical decisions for you. Let them know what your wishes are, so if needed they will be able to honor them.

3. Make sure you give each of your closest family members a copy of your Dementia Directive. That way they will have it to refer back to, if needed, to help them better honor your wishes.

4. Finally, mail a copy of your Dementia Directive to your health care provider, so that it can be a part of your medical record.

Fill in the address of your health provider, to mail them a copy:

Name of Health Provider

← Address

Stage 1 -- Mild dementia

With mild dementia, people may often lose the ability to remember what just happened to them. Routine tasks become difficult, such as cooking. Some tasks can become more dangerous, such as driving.

If you were to be at this stage of dementia what medical care would you want?

Select **one** of the 3 main goals of care listed below to express your wishes. Choose the goal of care that best describes what you would want if you had Mild Dementia.

If I have **mild** dementia then I would want the main goal for my care to be:

- ☐ **To live for as long as I can.** I would want full efforts to prolong my life, including efforts to restart my heart if it stops beating.
- ☐ **To receive treatments to prolong my life, but** if my heart stops beating or I can't breathe on my own, then I would **not** want my heart shocked to restart it and I would **not** want to be put on a breathing machine. **(DNR and Do Not Intubate)** Instead, if my heart stops or I can't breathe on my own, allow me to die peacefully.

Why you might choose this goal: If your mind were already not working well due to dementia, and something suddenly happened which stopped your heart or made you unable to breathe on your own, the chances are high that even if you survived the ICU, your brain would be more damaged. So some might say, "If I would likely be worse off if I survived, then I would prefer to die peacefully."

- ☐ **To receive comfort-focused care only.** (Including DNR and Do Not Intubate) I would only want medical care to relieve symptoms such as pain, anxiety, or breathlessness. I would not want care to keep me alive longer. It would be important to me to avoid sending me to a hospital or ER, unless that was the only way to keep me more comfortable, because trips to the hospital when someone has dementia can be quite traumatic.

Stage 2 -- Moderate dementia

In moderate dementia, communication becomes very limited. People lose the ability to understand what is going on around them. People require daily full-time assistance with dressing and often toileting. They can sometimes become quite confused and agitated and paranoid. Some people appear to be content much of the time.

If you were at this stage of dementia what level of medical care would you want?

Select one of the 3 main goals of care listed below to express your wishes. Choose the goal of care that best describes what you would want if you had Moderate Dementia.

If I have moderate dementia then I would want the main goal for my care to be:

- ☐ **To live for as long as I can.** I would want full efforts to prolong my life, including efforts to restart my heart if it stops beating.
- ☐ **To receive treatments to prolong my life, but** if my heart stops beating or I can't breathe on my own, then I would not want my heart shocked to restart it and I would not want to be put on a breathing machine. **(DNR and Do Not Intubate)** Instead, if my heart stops or I can't breathe on my own, allow me to die peacefully.

Why you might choose this goal: If your mind were already not working well due to dementia, and something suddenly happened which stopped your heart or made you unable to breathe on your own, the chances are high that even if you survived the ICU, your brain would be more damaged. So some might say, "If I would likely be worse off if I survived, then I would prefer to die peacefully."

- ☐ **To receive comfort-focused care only.** (Including DNR and Do Not Intubate) I would only want medical care to relieve symptoms such as pain, anxiety, or breathlessness. I would not want care to keep me alive longer. It would be important to me to avoid sending me to a hospital or ER, unless that was the only way to keep me more comfortable, because trips to the hospital when someone has dementia can be quite traumatic.

Stage 3 -- Severe dementia

In severe dementia, people are no longer able to recognize loved ones and family members. Some people with severe dementia may be calm and serene much of the time, but many go through periods of agitation. They can be awake through the night. They can be angry, disruptive, and yelling. People need 24-hour help with all daily activities, including bathing and assistance with all basic body functions.

Select one of the 3 main goals of care below you'd want if you had Severe Dementia.

If I have severe dementia then I would want the main goal for my care to be:

- ☐ **To live for as long as I can.** I would want full efforts to prolong my life, including efforts to restart my heart if it stops beating.
- ☐ **To receive treatments to prolong my life, but** if my heart stops beating or I can't breathe on my own, then I would not want my heart shocked to restart it and I would not want to be put on a breathing machine. **(DNR and Do Not Intubate)** Instead, if my heart stops or I can't breathe on my own, allow me to die peacefully.

Why you might choose this goal: If your mind were already not working well due to dementia, and something suddenly happened which stopped your heart or made you unable to breathe on your own, the chances are high that even if you survived the ICU, your brain would be more damaged. So some might say, "If I would likely be worse off if I survived, then I would prefer to die peacefully."

- ☐ **To receive comfort-focused care only.** (Including DNR and Do Not Intubate) I would only want medical care to relieve symptoms such as pain, anxiety, or breathlessness. I would not want care to keep me alive longer. It would be important to me to avoid sending me to a hospital or ER, unless that was the only way to keep me more comfortable, because trips to the hospital when someone has dementia can be quite traumatic.

Signature

Date

Print Name + Date of Birth

Dementia Directive -- Frequently Asked Questions

Why consider a Dementia Directive?

Many people have clear ideas about the medical care they would want if they were to develop dementia. But standard advance directives (also known as living wills) do not cover dementia. Dementia is the most common reason people lose the ability to guide their own care, so expressing and documenting these wishes is very important.

A Dementia Directive is a simple way to communicate your wishes if you were to develop dementia. It is a way to be more sure that if you develop dementia that you'll get the type of medical care you would want.

Families often face difficult medical decisions if their loved one has dementia. Having a Dementia Directive to refer to can help them feel clearer that the decisions they make reflect what their loved one would have wanted.

When is the best time to fill out a Dementia Directive?

Ideally, everyone should be given the chance to fill out a Dementia Directive before they develop dementia. It is especially recommended after age 65. It can be difficult for someone to complete a Dementia Directive once they are already experiencing signs of cognitive impairment.

How does a Dementia Directive relate to other advance directives?

A Dementia Directive can be used as a stand-alone document to communicate one's wishes. It can also be included as a supplement, attached to a standard advance directive form.

Is a Dementia Directive legally binding?

The Dementia Directive is a form of written communication to help guide those who might need to make medical decisions on your behalf in the future. As such, it is a way to record your wishes. The guidance it provides is not legally binding, however. If someone has lost the ability to make medical decisions, family members will still need to address clinical situations as they arise and decide how a dementia directive might provide guidance in a given situation. That is why it is important to talk to those closest to you (who might later help make decisions about your care) about your wishes, so that they understand as clearly as possible what your wishes would be.

Should I get the Dementia Directive notarized or witnessed?

If you are worried someone might challenge your dementia directive in the future, then it is reasonable to sign it in front of a notary or in front of witnesses. These signatures can be added as an additional page if desired. But having it witnessed is not required.

Viewpoint

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Advance Directives for Dementia Meeting a Unique Challenge

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In the coming years, an increasing number of people will experience dementia. Worldwide, the number of people living with dementia is projected to increase from 47 million in 2015 to 132 million by 2050.¹ Family members and clinicians are often unsure whether the care they provide for such patients is the care that patients would have chosen. Across the care spectrum, including skilled nursing facilities, hospital wards, intensive care units, and outpatient clinics, family members and clinicians commonly encounter this dilemma.

National campaigns have increased awareness of advance care planning to guide care for patients who can no longer make decisions for themselves. The Conversation Project, for example, has developed partnerships with more than 400 community organizations across the United States to provide tools to promote end-of-life conversations.² Advance directives, when incorporated into comprehensive goals-of-care discussions, are an important part of this planning and help reduce family anxiety about surrogate decision-making.³

Standard advance directives are often not helpful for patients who develop dementia. Dementia is a unique disease from the standpoint of advance directives. It usually progresses slowly over many years and leaves people with a long time frame of diminishing cognitive function and loss of ability to guide their own care. Advance directives typically address scenarios such as an imminently terminal condition or a permanent coma, but they generally do not address the more common scenario of gradually progressive dementia.

choosing from a specific set of options at each stage. A possible example of such goal-oriented options is presented in the **Box**.

Box. Possible Example of Goal-Directed Options for a Dementia-Specific Advance Directive

If I had (mild, moderate, or severe) dementia, then I would want the goal for my care to be:

- To live for as long as I could. I would want full efforts to prolong my life including efforts to restart my heart if it stops beating.
- To receive treatments to prolong my life, but if my heart stops beating or I can't breathe on my own, then I would not want my heart shocked and I would not want to be placed on a breathing machine. Instead, allow me to die peacefully. I choose this option, at this stage, because if I took such a sudden turn for the worse, my dementia likely would be worse if I survived, and I would not want the trauma of cardiopulmonary resuscitation or a breathing machine.
- To receive care only in the place where I am living. I would not want to go to the hospital even if I were very ill. If a treatment, such as antibiotics, might keep me alive longer and could be given in the place where I was living, then I would want such care. But if I continued to get worse, I would not want to go to a hospital. Instead, I would want to be allowed to die peacefully. I choose this option, at this stage, because I would not want the possible risks and trauma that can come from being in the hospital.
- To receive comfort-oriented care only, focused only on relieving my suffering such as pain, anxiety, or breathlessness. I would not want any care that would keep me alive longer.

The best time for patients to complete a dementia-specific advance directive would be before they develop signs of dementia. This is because even with early cognitive impairment, patients may lose the ability to complete complex planning about future medical decisions. As such, a directive like this ideally should be offered to patients before dementia occurs, as a supplement to a standard advance directive form.

One particular issue that causes difficulty for some families is whether to use feeding tubes in late-stage dementia. This raises the question of whether the use of feeding tubes should be included as an option in a dementia-specific advance directive. Their use in advanced dementia has been carefully studied, however, with wide consensus that they pose significant harm without measurable benefit.⁸ For this reason, there is little rationale for offering artificial nutrition as an option in a dementia-specific health directive.

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