

We All Need An Advocate When Navigating Health Care Settings

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Who Can Advocate For Us In A Health Care Setting?

- Health Care Agent
- Surrogate Decision Maker
- Guardian of the Person

Health Care Proxy*

***information taken from health.ny.gov/publications/1430**

What is a Health Care Proxy?

- 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 and/or tissue donation.

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.

How do I **appoint** a health care agent?

- All competent adults, 18 years of age or older, can appoint a healthcare 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.

When would my health care agent **begin to make healthcare 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.

Is a Healthcare 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 know in advance all the 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.

The **MOLST (Medical Orders for Life-Sustaining Treatment) serves as a single document that contains a patient's goals and preferences, based upon conversations between the patient and his/her doctor, regarding:**

- Resuscitation instructions when the patient has no pulse and/or is not breathing
- Instructions for intubation and mechanical ventilation when the patient has a pulse and the patient is breathing
- Treatment guidelines
- Future hospitalization and transfer
- Artificially administered fluids and nutrition
- Antibiotics
- Other instructions about treatments not listed

What if a person is no longer able to sign a Health Care Proxy?

New York's Family Health Care Decisions Act:

- Establishes the authority of a patient's family member or close friend to make health care decisions for the patient in cases where the patient no longer has decision making capacity and did not appoint a health care agent.
- This "Surrogate" decision maker would also be empowered to direct the withdrawal or withholding of life-sustaining treatment when standards set forth in the statute are satisfied.
- Applies to patients in hospitals and nursing homes.

The key provisions of the FHCDA became effective on June 1, 2010.

Guardianship*

***information taken from guardianship.org**

Guardianship Overview:

- **Guardianship**, also referred to as Conservatorship, is a legal process utilized when a person can no longer make or communicate safe or sound decisions about his/her person and/or property or has become susceptible to fraud or undue influence.
- Because establishing a guardianship may remove considerable rights from an individual, it should only be considered after alternatives to guardianship have proven ineffective or are unavailable

Alternatives to Guardianship:

- Trusts
- Durable Powers of Attorney for property
- Health Care Proxy
- Living Wills
- Joint checking accounts
- Family Health Care Decisions Act

Guardianship of the **Person**:

- When the court appoints a guardian of the person, the guardian may have the following responsibilities:
 - Determine and monitor residence
 - Consent to and monitor medical treatment
 - Consent and monitor non-medical services such as education and counseling
 - Consent and release of confidential information
 - Make end-of-life decisions
 - Act as representative payee
 - Maximize independence in least restrictive manner
 - Report to the court about the guardianship status at least annually

Guardianship **Due Process:**

- Because establishing guardianship is a legal process that involves the removal of the individual's rights, considerable due process protection often exists when the guardianship is established.
- These include:
 - Notice to the individual of all proceedings
 - Representation of the individual by counsel
 - Attendance of the individual at all hearings/court proceedings
 - Ability of the individual to compel, confront and cross examine all witnesses
 - Allowance of the individual to present evidence

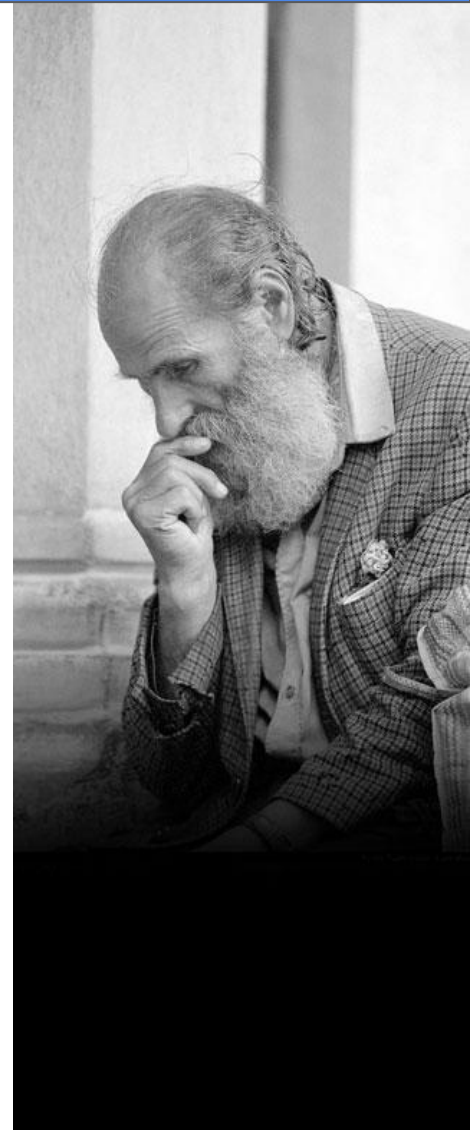
HIPAA: Acronym that stands for the **Health Insurance Portability and Accountability Act**, a US law designed to provide **privacy standards** to protect patients' medical records and other health information provided to health plans, doctors, hospitals and other health care providers.

These new standards provide patients with access to their medical records and more control over how their personal health information is used and disclosed.

HIPAA took effect on April 14, 2003.

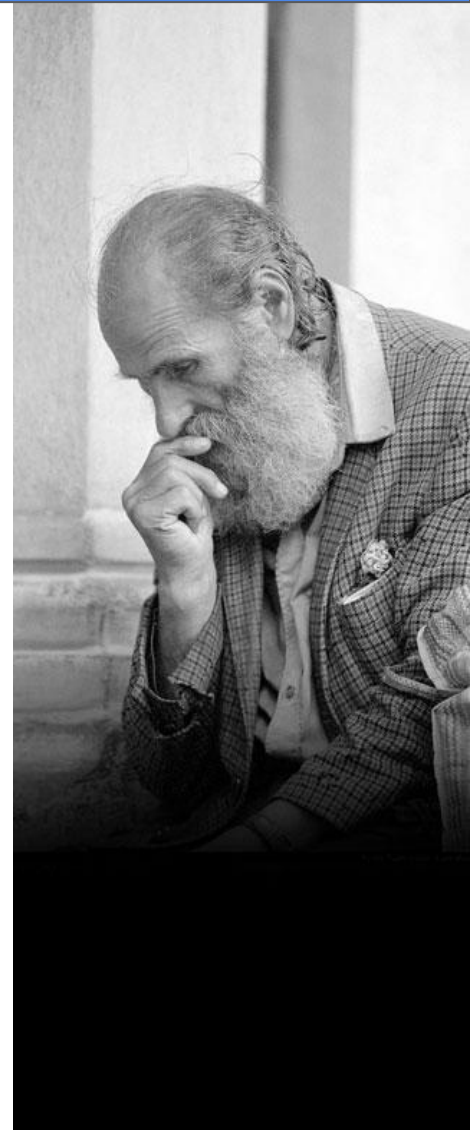
Ways to **Prevent** Neglect and/or Abuse:

- Before patient is admitted to a hospital, review <https://profiles.health.ny.gov/hospital> for quality/performance indicators.
- Before resident is admitted to a nursing home/short term rehabilitation, review www.Medicare.gov/care-compare and www.nursinghome411.org for the history of a nursing home's complaints/inspections and staffing indicators.
- **Visit** potential nursing homes or assisted living facilities unannounced. Request to see the actual floor/unit where resident's room will be.
- Be **involved** in the patient/resident's care; ask questions.
- For nursing home residents, attend care plan meetings; join family council.



Ways to **Prevent** Neglect and/or Abuse Cont.:

- **Don't leave the room** when the patient/resident is being changed/given care.
- Find out about the patient/resident's **diet, activities, and medications**. Ask to see the **MARS** (Medication Administration Records).
- In nursing homes, ask for meetings with the **Director of Nursing** or **Administrator** if you don't feel the resident is being properly cared for. Contact **Ombudsman**.
- **Visit** patient/resident as often as possible and at different times of day.



Ways to **Identify** Neglect and/or Abuse:

Look -

- Is patient/resident well cared for?
- Has patient/resident lost weight?
- Does patient/resident have bruises or bed sores?

Listen –

- What is the patient/resident saying? Complaints?
- Do you hear staff engaging in verbal abuse?
- Is the patient/resident no longer interested in pursuing activities he/she used to participate in?

Smell -

- Is there a urine odor in the patient/resident's unit or when you step off the elevator?
- Are there foul smells in the patient/resident's room?



Statutes and Regulations Protecting Residents/Patients:

- Federal Law – **The 1987 Nursing Home Reform Act** – (42 USC§1395i-3, 1396 r) – The basic objective is to ensure that residents of nursing homes receive quality care that will result in their achieving or maintaining their “highest practicable” physical, mental and psychosocial well-being. Established a survey/certification process with enforcement. (Updated 2016)
- Federal Regulations – Department of Health and Human Services – **42 CFR Part 482** (Hospitals) and **42 CFR Part 483** (Nursing Homes) – Established specific standards and regulations governing care.
- New York State Statutes – **Public Health Law Article 28** (PHL§2801-d) – Private right of action for violation of nursing home resident’s rights.
- New York State Regulations:
 - **10 NYCRR Part 415** – Nursing Homes
 - **10 NYCRR Part 405** - Hospitals
 - **18 NYCRR Parts 487 – 490** – Adult Homes
 - **10 NYCRR Part 100** – Assisted Living Residences
 - **10 NYCRR Parts 763 & 766** - Home (Health) Care

Public Health Law §2801-d(1):

- Any residential health care facility that **deprives any patient of said facility of any right or benefit, ..., shall be liable** to said patient **for injuries suffered** as a result of said deprivation, except as hereinafter provided.
- For purposes of this section a “right or benefit” of a patient of a residential health care facility shall mean any right or benefit created or established for the well-being of the patient by the terms of any contract, by any *state* statute, code, *rule or regulation* or by any applicable federal statute, code, rule or regulation.

THE INSTITUTION IS LIABLE FOR ALL INJURIES SUFFERED WHERE THERE IS A VIOLATION OF A NEW YORK STATE RULE or REGULATION or VIOLATION OF FEDERAL REGULATIONS.

Analysis:

- The standards of **good and accepted hospital, nursing home, assisted living and home health care**, under the Federal and New York State regulations, involves a repetitive analysis:
 - Did the facility/provider fulfill its duty to properly **assess** the patient/resident and the patient/resident's risks for certain injuries?
 - After assessment, was a proper **plan of care** (or **care plan**) designed?
 - Did the "care plan" call for **appropriate interventions** to avoid or lessen the specific risk of injury?
 - Was the "care plan" **actually implemented**?
 - Was the "care plan" appropriately **updated** and **kept current**?
 - After a passage of time; or
 - Due to intervening changes of condition; or
 - Due to incidents of injuries to the patient/resident.

Pressure Ulcers: What do we often hear?

- “We just found out that mom developed these terrible bed sores at the nursing home or hospital.”
- “We never saw the bed sores even though we visited often.”
- “The nurse at the hospital just told us about them.”
- Common misconception: “Pressure ulcers will develop because patients/residents are in bed or sitting for long periods”.
- Facilities often claim: “Pressure ulcers are unavoidable and develop due to co-morbidities”, without addressing the care that was or wasn’t provided to the patient/resident.

Possible Pressure Ulcer Interventions*:

- *Pressure reducing/relieving devices such as special mattresses, chair cushions, heel booties, and elbow pads;*
- *Proper incontinence care;*
- *Proper nutrition and hydration;*
- *Turning and positioning every two (2) hours in bed and every one (1) hour in chair;*
- *Limiting time out of bed if patient/resident has pressure ulcer(s);*
- *Avoid positioning on existing pressure ulcers;*
- *Proper treatments to heal wounds.*

**Each patient/resident's particular condition/needs will determine which interventions are appropriate.*

Falls: What do we often hear?

- “Dad got up to go to the bathroom overnight and fell fracturing his hip.”
- “They called us three times in the past month about dad getting up and they kept reminding him to use the call bell.”
- “Dad had unexplained bruises on his legs or face.”
- Common misconception: “Patients/residents will fall because they are frail and have unsteady gait and nothing can be done to prevent falls”.



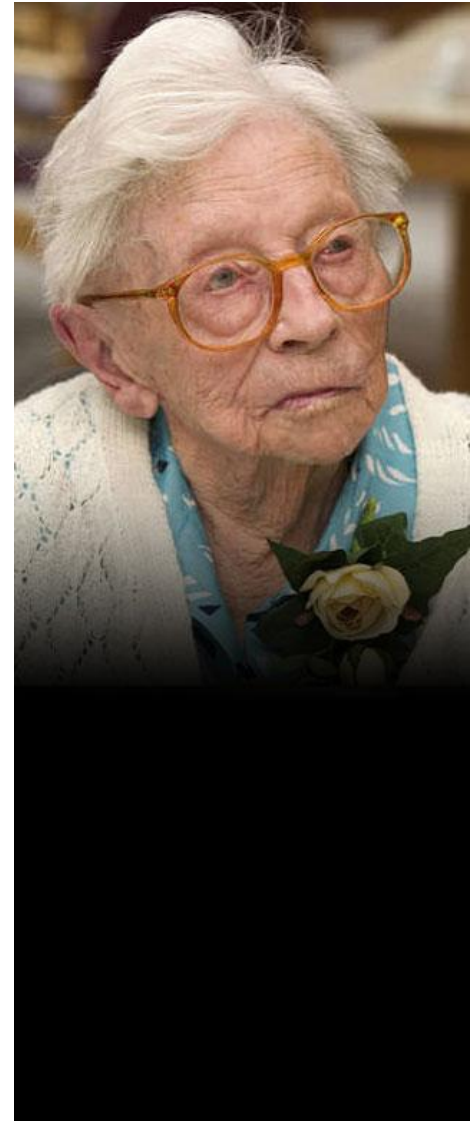
Possible Fall Interventions*:

- *Low Bed;*
- *Mats on the floor if patient/resident non-ambulatory;*
- *Bed alarm/Chair alarm;*
- *Toileting schedule;*
- *Not leaving awake patient/resident with cognitive issues in bed unattended;*
- *Non-skid socks;*
- *Moving patient/resident's room closer to nurse's station.*

**Each patient/resident's particular condition/needs will determine which interventions are appropriate.*

Malnutrition/Dehydration: What do we hear?

- “My aunt lost 20 pounds and her weight loss is not being investigated.”
- “When I visit, I see my parent’s food tray out of their reach and untouched.”
- “Staff is removing food tray and only half of the food has been eaten.”



Possible Nutritional Interventions*:

- *Speech/Swallow Evaluation if patient/resident not eating sufficient amount;*
- *Providing patients/residents with foods based upon their preferences (likes/dislikes);*
- *Taking appropriate amount of time to feed patient/resident if he/she needs assistance;*
- *Performing three (3) day calorie count to determine patient/resident's actual caloric and protein intake;*
- *Supplements if patient/resident not receiving enough calories or protein;*
- *Psychological evaluation to determine if depression is cause;*
- *Artificial nutrition or hydration.*

**Each patient/resident's particular condition/needs will determine which interventions are appropriate.*

Nursing Home Admission Agreements

General Advocacy Tips: *

Review admission agreement and addendums carefully.

- o Entering a nursing home, whether for short-term rehabilitation or long-term care is very stressful to the resident and representative. Review the agreement and addendums carefully. The resident or representative has the right to cross out provisions he/she does not agree with or are otherwise improper, i.e. mandatory arbitration and venue selection clauses.
- o If resident or representative has questions about anything, ask! The nursing home is required to explain the terms of its agreement and addendums.

* Center for Elder Law & Justice

How to **improve the quality of care** in hospitals, nursing homes, assisted living facilities and home care settings?

- Patients/residents and their families need to be **empowered** and to **know the rights** and **services** available to them;
 - i.e. Federal and state regulations, Ombudsman Program (nursing homes, adult homes and assisted living facilities), Family Councils, Filing Complaints with the DOH and MFCU (NYS Attorney General's Office), and pursuing legal claims.
- The more the rights and services available to families are utilized, the greater the likelihood that facilities will improve their quality of care.

For further information:

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We welcome patients, residents and their families to contact us if they have questions or concerns regarding rights, care or injuries, and to view our website: www.yournyadvocate.com where we have answers to many frequently asked questions regarding Neglect and Abuse and other topics.

Thank you for your time and attention!