PIERRO, CONNOR
& STRAUSS, LLC
Trusted Counsel

2023 HEALTH CARE DECISION-MAKING GUIDE

www.pierrolaw.com
info@pierrolaw.com
Toll Free: **866-951-PLAN**

Albany | New York City | Ronkonkoma
Garden City | Hudson | Utica | Lake Placid
Fort Lee, NJ | Falmouth, MA | Clearwater, FL

TABLE OF CONTENTS

A Personal Guide for Making Health Care Decisions And How to Have Your Wishes Honored

INTRODUCTION

Making decisions about one's life and medical care is a basic right of an autonomous human being. In health care, as in many areas involving experts and professionals, individuals are only recently getting accustomed to making their own decisions and, perhaps more importantly, questioning the decisions of others, including their physicians, in areas that have a direct bearing on their lives.

This Guide is designed to provide you a path to keep control of your health, your body and your life to the maximum extent possible, even if you become ill and are unable to communicate your decisions and wishes for yourself. As Pierro, Connor & Strauss's founding partner, Lou Pierro says, "Life Happens," and we will work with you to be prepared and ensure it happens your way.

Each day medical science offers new technologies; new technologies offer new options; and new options create new dilemmas. With advanced technologies capable of keeping more and more people alive longer and longer, life-and-death decision-making issues have become both more complex, and more common.

At the same time, patients have fought for and won the right to make decisions about their own health care, which were formerly the exclusive province of medical practitioners. Compounding the difficulty for patients or their surrogates, they must make these decisions at times of crisis, often under extreme stress. Under optimal circumstances it would be hard to absorb all the information thrown at you—options, therapeutic benefits, risk factors, possible side effects—all in scientific terms guaranteed to alarm even the most stout-hearted. Medical crises are rarely optimal circumstances. The more life-threatening the situation the more difficult the decision; the more difficult the decision, the more stressful the situation. It is a vicious cycle.

While you're trying to determine what's best to do, others may be undermining your efforts, trying to take the choice away from you. When it comes to confronting life-and-death issues, there are no easy answers. But there are legal techniques that will empower you to assert your rights.

Our guide is designed to prepare you for critical future planning. We believe our clients must utilize the tools available today, so that each of you will be protected and your wishes about the kinds of medical treatment you want or don't want are carried out, especially at a time when you are not able to communicate your choices because of incapacity. Part One (pp. 3-16) will explain the legal documents available to you to accomplish this goal, what factors you should consider in choosing the persons who you wish to speak for you and how you communicate your wishes and values to them and your physicians.

Part Two (pp. 17-26) is designed to provide you with a history of the law and background about the relationship between patients and their rights with respect to health care providers regarding health care decisions, particularly decisions regarding treatment at the end of life. This Part will also discuss practical steps a patient can take when dealing with physicians and the health care system with respect to honoring their treatment decisions.

Finally, Part Three (pp. 27-30) will discuss the rights of persons who are terminally ill, and their options to hasten death to avoid prolonged suffering in the various states.

PART ONE
THE TOOLS: ADVANCE DIRECTIVES FOR HEALTH CARE

Unfortunately, medical decisions are not usually made at leisure. Nor are they always made when the patient is in a position to understand, make, and communicate decisions about his or her health. As noted, your right to have your wishes respected continues even if you are incapacitated. If you are no longer in a position to state them, others may assert them on your behalf as your surrogate. If a person's wishes are expressed when he or she has capacity, either through a written document such as a living will - which we prefer to call a Health Care Directive (HCD) - or orally to another person, those wishes must be respected. There are tools to make this happen: health care advance directives.

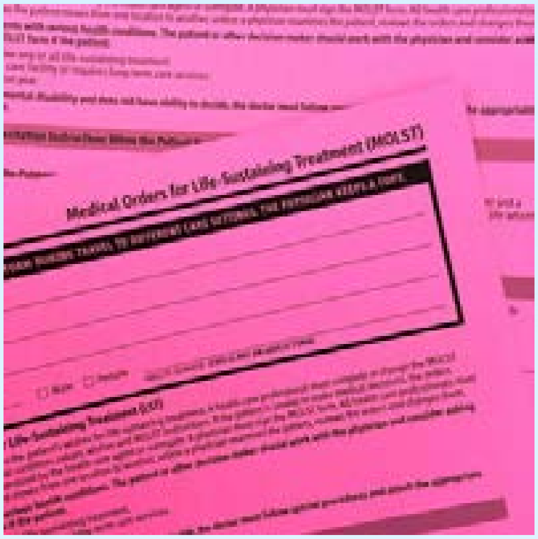
THE BASIC ADVANCE DIRECTIVES

Advance directives commonly used include:

- Health care proxy. Also called in some states a durable power of attorney for health care, the health care proxy (HCP) allows you to designate an agent in advance to make decisions on your behalf if you later become incapacitated. The proxy form designates someone else to ensure that the wishes you have expressed—in your health care declaration (HCD), often referred to as a "living will" or otherwise—are carried out, and to make health care determinations on your behalf, if you're not capable or don't have a HCD, or for things not anticipated in your HCD . The health care proxy is sometimes combined with a HCD , but it is our practice at Pierro, Connor & Strauss to combine the two tools in one “combined” instrument along with HIPAA release section.

- Health Care Declaration (“Living will”) The health care declaration states your desires concerning future medical care, specifying what procedures you want or don’t want. These are sometimes called health care directives, medical directives, or instructional directives. We use the expression health care directive because that’s a more descriptive term for what it is.

- MOLST. Medical Order about Life Sustaining Treatment. The MOLST is a form authorized by state law in several states prepared by a physician working with the patient, used in a hospital setting for a patient who is terminally ill. It is a detailed form – almost a chart – of the patient’s wishes about very specific treatments and procedures. Because it is a physician’s order and is in the patient’s chart, it is more likely to be followed in the hospital setting and may in some cases minimize the issue of compliance with patient’s wishes, a serious issue that we will discuss later.


Medical Orders for Life-Sustaining Treatment (MOLST)

The MOLST document, kept in the patient’s chart, does not replace the health care declaration or health care proxy but rather supplements them. It can also guide the health care agent’s decision if she or he is not sure of the maker’s wishes, just as the health care declaration does.

- DNR Order. A physician’s instruction stating do not resuscitate if the patient’s heart or breathing stops. It is a form signed by a patient who has capacity or can be signed by the health care agent when the patient lacks capacity to give informed consent. A DNR order need not be executed in advance and can be signed in the hospital at admission or during a procedure.

THE HEALTH CARE DECLARATION

The Health Care Declaration (“Living Will”) has become common since the U.S. Supreme Court decided the case of Nancy Cruzan in 1990 which established the legal authority recognizing patients’ wishes expressed through advance directives. The famous actress Helen Hayes had one. Her story is vividly told in a video prepared by the American Bar Association’s Commission on Law and Aging. The video has an epilogue by her son, James MacArthur, movingly demonstrating the important role the document had at the time of Ms. Hayes’ death. You can view the video at https://www.americanbar.org/groups/law_aging/resources/health_care_decision_making/

(Scroll to Videos). Pierro, Connor & Strauss Senior Partner Peter J. Strauss is one of the participants in the film (at 9 minutes. 49 seconds).

How does it work? If you're well enough and have capacity, you tell your doctors what you want and don't want. If you're not able, your Health Care Directive does it for you; it speaks for you when you can't. It ensures that your family, your health care agent and your doctor - and any other doctor or medical facility treating you - knows your wishes in the event you aren't able to make your own medical decisions.

What else do you need to know about a health care directive?

- When and under what conditions it becomes effective
- What medical care is authorized and what medical care is not authorized
- How the directive itself is sanctioned in your state, by what form and with what necessary signatures and witnesses

Health Care Directives are governed by state law. Most states and the District of Columbia have specific laws authorizing and regulating their use. The other states recognize them and rely on interpretation of court decisions. New York does not have an authorizing statute, but they are recognized by court decisions.

You should talk with those closest to you and your health care agent about your wishes ahead of time—that's why your written expression of your wishes is called an "advance directive." Take the time now to talk to family, physicians, and clergy. A health care directive is your protection when and if you become incapable of making or communicating decisions about your health care. While it may not seem like an appropriate discussion for the Thanksgiving table, if that is the only time the family gathers together, it should be done.

When does a health care directive become effective?

When you're incapable of making or communicating your own necessary health care decision. In other words, when you have lost the capacity to give informed consent. If you could speak for yourself, you wouldn't need that document.

What is the definition of capacity? For health care purposes, a person with capacity is able to understand the illness, the nature and benefits of the proposed treatment, and the risk in accepting or refusing it.

Several states impose restrictions on the use of living wills. In many states, the statutes say a living will may be used only if the patient has a "terminal condition;" in some states, death must be "imminent." The wording of these statutes can make the effectiveness of a health care declaration less meaningful. For example, a person with advanced Alzheimer's disease or totally incapacitated from a stroke might not be deemed "terminal" so that the health care declaration may not be deemed to be in effect. And the patient's death may not be deemed "imminent."

Statutory language such as this is unfortunate and probably not binding. Under the Cruzan decision, you have the right to refuse treatment through stating your wishes or through your health care directive, whether you are in a terminal condition and your death is "imminent" or not. Since New York does not have a living will law there is no such legal limitation. But many New York living wills are badly drawn and include such wording – Don't sign such a form! And because you may at some time move to a state that imposes such restrictions you should state in your living will that your wishes are to be binding "even if I am not in a terminal condition and even if my death is not imminent." And do not include wording that you don't want "heroic measures." Be precise in the language you use. Is a heart transplant "heroic" or routine medical procedure today?

A HCD becomes effective only when and if you are incapable of making or communicating decisions about your health care. If you are capable, you can speak up – after all, you may have changed your mind.

Must my wishes be honored? If not what do I do?

How serious is the problem of hospitals and physicians refusing to honor a patient's wishes?

Very serious (we discuss this issue here and again in Part Two of this Guide).

Patient wishes, even if there is a health care declaration, are not always honored. Having an agent acting under a HCP advocate for your stated wishes may make a difference, but there will be situations where you receive unwanted treatment. The courts have not been comfortable in punishing hospitals and physicians who provide unwanted treatment – "erring" on the side of life is usually not viewed as a wrong, notwithstanding Justice Cardoza's words.

You (or your family acting as your surrogate) may need a lawyer to enforce your rights. In Florida, Estelle Browning left specific written instructions not to give her tube feeding. Because she was in a vegetative condition, but death was not imminent, as she specified in her living will, her instructions were ignored and she was kept alive against her wishes. Subsequent legal action, unfortunately too late for Mrs. Browning, upheld her right to refuse the tube feeding.

This is a national problem, particularly in New York, where recent court decisions make it almost impossible to successfully sue health care providers when they fail to respect the expressed wishes of patients near the end of life and the patients suffer as a result.

In a 2009 New York case, Cronin v. Jamaica Hospital Medical Center, 60 AD.2nd, 803 (2009), a lawsuit for medical malpractice and negligence, the Appellate Division, Second Department, of the NYS Supreme Court, upheld a lower court decision dismissing the case of 72 year old man admitted to Jamaica Hospital Medical Center suffering from various illnesses who was resuscitated on two occasions, allegedly in violation of two do-not-resuscitate orders which had been issued by the hospital and executed by members of the decedent's family. On June 9, 2004, following the second resuscitation, two weeks after the decedent would have died if the DNR order had been respected initially, he was removed from life support systems and died. The case was dismissed because the court held that the plaintiff was asserting a claim for "wrongful living" and that no such claim could be made.

More recently, in Greenberg v. New Rochelle Montefiore Hospital, (decided February, 2021) a patient with advanced dementia was given life sustaining medications, contrary to provisions in his living will and Medical Order for Life Sustaining Treatment.. The suit charged that he survived for about a month in the unresponsive state that he had sought to avoid. "They made the end of his life horrible and painful and humiliating," his widow said. "What's the sense of having a living will if it's not honored?" This case was dismissed by a NY Supreme Court Justice, following the ruling in the Cronin decision.

And also in February of 2021, Lanzetta v. Montefiore Med. Center, another suit to recover damages for the pain and suffering experienced by a man who lived 20 days after being administered certain life-sustaining medical treatment, including multiple doses of antibiotics and intravenous fluids, in contravention of both the terms of his living will and the directives of his health care agent. The judge dismissed the complaint, holding that "Plaintiff's claim is, in effect, one for wrongful prolongation of life. Such a claim is neither cognizable under New York's common law nor recognized by statute."

While New York is very conservative about this problem, there is some new

thinking in other states about the right to sue because of "wrongful prolongation of life." In a 2017 New Jersey case, Koerner v. Bhatt, a trial court judge held that a woman could sue her deceased mother's (Suzanne Stica) health care providers for reviving her against her clearly stated instructions after she went into cardiac arrest. Stica lived for several month's in a "terrible state." The case was settled for an nondisclosed amount, so there was no subsequent appeals court decision.

These decisions clearly demonstrate the need to change New York law to permit such lawsuits. A bill has been introduced in the New York 2021 legislative session by Assemblyperson Richard Gottfried to correct this situation (2021 A.250).

What can be done to enforce my wishes?

At Pierro, Connor & Strauss, we have developed a new approach to deal with this issue by including some strong language in our health care proxy and health care declaration that states:

Enforcement of My Directives:

It is my intention that my wishes, as evidenced by this document and my agent's instructions, be honored by everyone, including my family, friends, courts, physicians and all others concerned with my care. I expect all such persons to be legally and morally bound to act in accord with my wishes, as expressed on my behalf by my agent. If any hospital or other institution or any physician, nurse or other health care personnel refuses to obey my wishes as set forth herein, I hereby direct my agent to take one or more of the following actions: (1) commence suit against such institution and/or personnel for all hospital costs, drugs, medical expenses and all other damages flowing from such refusal, including my pain and suffering, (2) not to pay bills for unwanted services from any such health care provider, (3) file objections with Medicare, Medicaid and any private insurance company for payment of such charges and (4) file complaints against such providers with appropriate state regulatory agencies and licensing and professional associations. Assault and battery charges should also be seriously considered. I request, but do not direct, my agent acting from time to time to consult with the persons I have nominated as successor agents to advise and support the acting agent in his or her responsibilities and decision making.

We also empower a client's agent appointed in a property Power of Attorney by including a provision that allows the agent to provide funds to the health care agent so that agent can hire an attorney to enforce compliance with the patient's wishes.
We believe that this language that we include in our Health Care Declaration and Power of Attorney will make compliance with client wishes more likely.

Specific treatment instructions:
People do not generally clearly express their feeling about illness and dying either in their advance directives or in conversations with family. They generally phrase their thoughts in vague expressions like "I don't want to be kept alive like that," which may refer to anything from being mentally incapacitated to receiving artificial feeding or respiration. Drafting and executing a living will forces you to confront these issues.

Should you be specific about the kinds of treatment you want or wish to forego? Some documents spell out categories, and that may be sufficient. But being too specific can be misunderstood to mean that treatments you would not want that were not specifically mentioned would be acceptable.

ARTIFICIAL NUTRITION AND HYDRATION

People have special feelings about eating and drinking. Although many people have no qualms about refusing medication or ending aggressive measures for themselves or family members who are very ill (such as kidney dialysis), they balk at ending basic support of nutrition and hydration, sometimes because of religious, moral or ethical reasons.

The Supreme Court decision in the 1990 case of Nancy Cruzan made clear that there was no legal distinction between artificial nutrition and hydration (nasal-gastro tubes or PEGs) and other forms of life-sustaining treatment (such as antibiotics, ventilators or kidney dialysis). In fact, studies indicate that even competent hospital patients eat and drink little at the end of their lives and do not experience additional discomfort by avoiding artificial nutrition and hydration. According to some medical experts, there is no evidence that individuals dependent on artificial nutrition and hydration would experience any discomfort if these treatments were foregone or removed if started; in fact, the imposition of artificial nutrition and hydration may actually contribute to an uncomfortable death. Modern medicine acknowledges that artificial feeding may sometimes be harmful for a patient and constitute inappropriate and harmful treatment.

Nevertheless, problems arise with artificial or tube feeding. In some states, you must expressly indicate in your living will that that you don't want nutrition and hydration. This is the case in New York. You must make it clear in your living will that artificial nutrition and hydration is not wanted. And, in New York, your health care agent cannot withhold or withdraw this unless he or she has specific knowledge of your wishes, so the health care proxy mist state that the health care agent is aware of your wishes regarding artificial feeding..

What is the difference between withdrawing and withholding life sustaining treatment?

None from a legal or moral point of view. As we noted, the Supreme Court has made it clear that there is no valid legal distinction between withholding a treatment (refusing to start it) and withdrawing it once it has begun. The New York courts have agreed. Yet withdrawing treatment is often resisted by health care providers who feel more deeply involved morally by actually turning off a machine than by just not turning it on in the first place. Drafting your living will to address both possibilities can help alleviate this problem.

An emerging new issue: the Supplemental Advance Directive for Oral Feeding of Dementia Patients

A person who is diagnosed with Alzheimer's disease or another incurable dementing disease may wish to have control over the circumstances and timing of his or her death. You probably have taken a major step to maintain such control by signing a Health Care Proxy and a Health Care Declaration ("Living Will"), and. working with your physician, you may also have executed a MOLST order (Medical Order on Life Sustaining Treatment). While Alzheimer's disease is considered a terminal disease, because the duration of the disease can be long and vary from patient to patient, the terminal stage of the disease may not occur for many years, and long after decision-making capacity and the ability to self-feed are lost. The average time from diagnosis to death is 7 years, but many individuals live considerably longer. So long as those with advanced dementia receive good physical care and are assisted with eating and drinking, it can be difficult to predict when death will finally occur.

In the final, "terminal" stage of all dementias, a person may become unable to swallow what is placed in his or her mouth, and lose the ability to ambulate, speak, recognize loved ones, and control bowel or bladder functioning. Many clients who have been diagnosed with Alzheimer's disease or other form of dementia want to know how they can avoid the prolongation of the final stages of such diseases by means of artificial feeding. It is for those clients, and others who fear being in a state of advanced dementia in the future, that the Supplemental Advance Directive about assisted oral feeding has been created. The form provided to our clients for consideration is a modified version of the supplemental directive developed by End of Life Choices of New York, developed under the direction under the direction of Judith Schwarz, R.N., its clinical director.

“DO NOT RESUSCITATE” ORDERS – “DNR”

“DNR” stands for do not resuscitate, a code for an order commonly used in a hospital or nursing home. DNR indicates that if the patient’s heart or breathing stops, he or she is not to be revived. Hospitals used to routinely enter a DNR on the charts of severely ill elderly patients, without asking. New York passed a DNR law to stop such abuse of patient rights many years ago.

Health Care Declarations can authorize DNR orders, certain family members and health care agents can sign them on behalf of patients. Many states have laws requiring hospitals and nursing homes to withhold emergency cardiopulmonary resuscitation from patients who note their refusal in advance.

Interestingly, New York, which has no living will statute, has a DNR law covering hospitals and nursing homes as well as nonhospital DNR situations. Extending DNR regulation to homes as well as hospitals was intended to benefit many people with advanced medical conditions who prefer to die at home or in hospices.

A DNR order outside the hospital or institutional setting is hard to enforce. Emergency workers generally have no knowledge of a patient’s wishes unless the patient is in a position to tell them, and often this is not possible, or a “non-hospital” DNR order is placed prominently in the home. Some patients wear bracelets with the order on it or carry a card in their wallet so that emergency service workers are more likely to see it. Laws generally grant immunity to health professionals who carry out a DNR order in good faith, as well as to those who attempt resuscitation unaware of the order. Does “do not resuscitate” mean “do not treat”?

DNR should not be confused with DNT (“do not treat”). In practice, some hospitals or health care providers may he casual about the difference, assuming that if you sign a DNR, meaning you don’t want resuscitation, you don’t want other treatment. But this is not necessarily so. You may very well want continued treatment, for infections or for life-threatening situations other than cardiac arrest, particularly if there is a chance of recovery. Not all ways to go are equally bad. Make sure the people who are treating you know the difference.

THE HEALTH CARE PROXY

The Heath Care Declaration is a statement of your wishes with regard to your medical treatment, but it does not cover all possibilities. What happens if you're incapacitated and you don't have a heath care declaration or if your living will doesn't cover the situation? Or if its language is too general to express what you would want in a given situation and needs interpretation? Or if the hospital seems unwilling to follow your expressed wishes?

You need a person - a health care agent – an advocate - to act on your behalf when you are unable to speak for yourself. You can appoint a relative or friend to act as your health care agent, in a written document called a health care proxy in New York (or power of attorney for health care or durable power of attorney for health care in some states. New York has a Health Care Proxy statute.

This is important: the health care agent tells your doctors what you would have decided if you were able to speak, based on what he or she knows are your wishes, as expressed in your HCD or in conversations with you. Only if it's not clear what you would have decided, may your agent may make decisions in accordance with your best interests. Your agent's primary duty is to advocate for your wishes – even if he or she doesn't agree or you might make a different decision.

As noted above, even if your wishes are clear, physicians may not always honor them. In those cases, your health care agent acts as your spokesperson, advocating to ensure that your wishes are carried out.

Each of the states recognizes some kind of health care power of attorney. The Supreme Court in the Nancy Cruzan case suggested that a chosen health care agent would have the same power to refuse treatment as the patient.

Can the agent appointed in a property power of attorney make health care decisions as well?

The answer, in most states, is no. Don't confuse a power of attorney for health care with the power of attorney used in financial affairs. (Alaska and Pennsylvania are exceptions in that they have a durable power of attorney statute that does extend to health care decision making).

When does a health care proxy become effective?

A health care proxy, like a HCD, only becomes effective when the declarant is incapable as determined by a physician of making and communicating decisions. If you are capable of making and communicating your own decisions, there is no need for your agent to be involved. Technically, if your agent is with you in your doctor's office your agent's authority has not yet become effective unless the doctor makes a determination that you, the patient, lack capacity to give informed consent.

Appointing a health care agent

Theoretically, designating a health care agent may be more useful than preparing a heath care declaration, because a person rather than a document will be advocating on your behalf. Remember, too, that when you make out your HCD you are unable to anticipate every situation that might develop. The health care agent can interpret and apply your wishes as the situation warrants and make "best interests" decisions if your wishes are not clear (except as to artificial nutrition and hydration).

Appointment of an agent for health care decisions is regulated by New York law. In certain circumstances, this may take on great importance. For example, the law forbids the appointment of an "operator, administrator or employee" of a health care facility to be a patient's agent. Nor can any person be agent for more than 10 persons.

Who should I appoint as my health care agent?

Someone you trust to carry out your wishes. That may not be "my daughter the doctor." She may have the medical knowledge and experience, but that may make her less likely to do what you want because she may feel she knows better. The agent also needs to be emotionally and psychologically capable of making end of life decisions. Many persons say "I could decide to end my own treatment, but I can't "do that" to my mother." You're not – you are carrying out mother's wishes, not imposing your own values and views. That is your agent's legal and ethical obligation.

And make sure you've asked the person you intend to name if she or he will accept the responsibility and how she or he feels about the obligation to advocate for your spoken choices. A person can't be compelled to act as your agent - she or he must voluntarily accept the responsibility. More to the point, only someone you've discussed your wishes with can know how to make decisions as your agent. If you don't have someone you trust for these kinds of intimate and painful decisions, don't appoint anyone, but at least sign a HCD.

And physical proximity may not be as important as in prior years. If anything the pandemic has taught us it is that technology allows us to pick the person most suited to be your advocate regardless of where that person lives, not the one who lives close by (so long as she or he has a computer and knows how to "Zoom").

Is it all right to designate more than one person as my agents?

No. New York does not allow that, for good reason. You are only asking for trouble if you leave your health care up to a committee. Your agent can consult with people, but don't go beyond that. And don't put a consultation requirement in the proxy document; that might require the physician to investigate whether there has in fact been "consultation" (whatever that means) and delay the ability of your agent to act in an emergency – to give necessary consent or not.

Pick one and only one as an alternate. Don't be misled by thinking it's "only fair" to designate your two children or your three sisters as co-agents. If they argue, you will suffer. But always appoint a successor agent.

Should I execute both a living will and a health care proxy?

Since it is our practice at Pierro, Connor & Strauss to have a combined HCD and HCP that's not an issue. But if you choose to have separate documents, then yes! Your agent and successor may both die, become disabled, or refuse to act. In that case, you don't have an advocate.   Further, your agent's decision may be challenged, either by someone on the medical team or in the family. In that case your HCD speaks for itself and supports compliance with your wishes.

Proxy formalities

State requirements regarding the validity of a document differ in substance and procedure. Usually they require two witnesses or notarization, or both. New York requires two witnesses, but need not be notarized. The New York Department of Health has a recommended form which should be used, but alternatives are allowed. It's a good idea to use the Department of Health form.

There may also be restrictions on who can be a witness. A number of states provide that the witness may not be a health care provider or employee of a facility, an heir or a person responsible for health care costs.

Remote document signing

Another change in law in many states resulting from the Covid-19 pandemic is allowing documents to be signed and notarized through video conferencing. This is being allowed by a state governor's "executive order" in some states (such as New York), or by statutes in others. We believe that the states will adopt laws allowing remote execution on a permanent basis in the near future. The existing rules are complicated and differ from state-to-state, but there will be no turning back. We have done many remote documents signings since the pandemic began and it has created new opportunities for older clients and those with disabilities to do necessary future planning.

Is the health care proxy valid if I move to another state?

Generally, yes. States are obliged to recognize a health care proxy from another state because of the U.S. Constitution's requirement that states give "full faith and credit" to the laws of other states. However, if you move to a new residence or buy a vacation home in another state, you should review the validity of your health care proxy and living will in your new state and possibly execute a new ones that are recognized in accordance with the requirements of that state, so that the doctors who may need to make decisions based on the instructions of your agent will be familiar with the local forms and not need to seek advice from hospital lawyers.

Where should I keep it?

Keep the original in an accessible place, and give copies to your primary doctor and close members of your family. Copies should also be given to other doctors and hospitals when you are admitted so it will be in your chart (copies are usable). Remember, federal law provides that you be asked whether you have one and that your health care proxy be made part of your hospital record when you enter the hospital.

How do I make sure my proxy is current?

In New York and in most states, a health care proxy will remain in effect indefinitely, unless you revoke it. Updating your health care proxy is not required, and no other action is required. You may wish to appoint a new agent if circumstances change. If you want to make sure everyone is assured of your intentions, you can re-initial your signed proxy and date it on a periodic basis.

Can my health care proxy be revoked?

Yes. To revoke your health care proxy, or to designate a new health care agent, you can destroy the old document and execute a new one, signifying repeal of all prior documents.

You don't actually have to rip up the old document. But you must signify your intent to revoke it, and you must notify both the agent and any other family members, lawyer, or doctor who have copies of the original document. Some states, including New York, provide that the signing of a new proxy revokes the old one automatically, and this seems to be the logical consequence of the new proxy.

SURROGATE AND FAMILY CONSENT

What happens when there is no living will, no health care proxy, and no clear evidence of the patient's wishes?

In some states, surrogate decision making has been allowed for some time. In some, laws set forth a hierarchy of relatives to make medical decisions for an incapacitated person, in the absence of instructions to the contrary. As noted above, New York moved into the mainstream in 2010 with the passage of the Family Health Care Decisions Act (FHCDA). Nevertheless, people should not rely on that law and its hierarchy of decision makers. The person on the top of the list may not be the one you would choose.

Capacity to execute advance directives

We are often asked whether a client who has had a stroke or been diagnosed with dementia - such as Alzheimer's disease - has the legal capacity to sign an advance directive. Is it too late? Does a family member need to do a guardianship proceeding and be appointed guardian of the person to make medical decisions for the relative? Traditionally the answer would have been that the mere diagnosis of a disabling illness meant it was too late. But that is not necessarily true today.

In an article in the Journal of the American Geriatrics Society Mathy Mezze wrote:

It is often difficult clinically to determine the extent of a person's incapacity. Traditionally, clinicians have tended to construe capacity as either present or absent. More recently, rather than regarding capacity as a general domain, clinicians have endorsed the construct of "decision-specific capacity," whereby the measure of capacity is a person's understanding of a specific decision or task. Individuals have gradations of capacity. Persons with mild and even moderate levels of Alzheimer's disease have been found to retain the ability to make some, but not all, treatment choices.

* * *

The decisional capacity needed to execute a health care proxy in which another person is designated to make treatment decisions has been described as low level of capacity. Thus, the informed consent process used to assure that a person understands the issues relating to executing a health care proxy can be simpler and less stringent than the process used to determine understanding of other tasks, such as a living will. Vol. 48, p. 79, Feb. 2000.

Bottom line: it may not be too late to sign an advance directive (and possibly even a

property power of attorney) based on a careful assessment of a person by a trained professional, depending on the particular document to be signed and its complexity.
Consequences of not executing advance directives

Probably a guardianship proceeding. If you don't pick your advocate – your health care agent – a judge hearing a guardianship proceeding because life and death decisions need to be made will appoint someone to decide for you – and that person may well be someone you would not have chosen. And, further, some health care decisions may require court approval. Your wishes not to treat or to end treatment may not be approved by a judge who does not share you values of wishes or by the person that judge appointed as your guardian. A decision not to execute necessary advance directives can have dire consequences for you.

PART TWO
THE EMERGENCE OF PATIENT RIGHTS

Part One of this Guide discussed the refusal of some doctors and hospitals to comply with the clearly expressed wishes of patients. Part Two will discuss the emergence of patient rights to decide, outline some of the additional problems a patient may face and why the recommendations we make in Part One are necessary. We will describe some of the history and background of your right to be heard in regard to your medical treatment. Laws and policies protecting patients, however well motivated, are not generally what lawyers call "self-executing." Nor are they types of laws for which you can scream "Call a cop!" and expect enforcement. Rather, these are laws that require the participation of the people they're designed to protect in order to ensure that they are followed. Patient's rights are protected by civil laws with remedies available through bureaucratic processes, agency hearings, administrative law and judicial intervention when necessary.

Let's first look at some practical things you can do to ensure your doctors provide clear advice, explanations and instructions and comply with your wishes. For starters, there are some basic principles that may sound simple, but you'd be surprised how often people neglect to do just these things that will deal with the problem.

- Assert your rights. You have them. Shyness is not appropriate here. We're talking about your health and your life; Talk to your doctor and nurses and the hospital administrators. Tell them your wishes. Ask questions, even if you think they are dumb. And if you don't understand the answer, get a clearer one. Make sure to ask this question: "Do you agree to respect and honor my wishes, even if you do not agree with my decision?" If you discover that your doctor does not share your views and evidences reluctance to comply, perhaps you need to consider an alternative.

- Make yourself heard. Studies show that doctors often ignore patient wishes, often administering unwanted aggressive treatment to terminally ill patients. Insist on the care you want and the care you don't want for you or your spouse or parent—and keep insisting on it. Repeat yourself until you are sure the message is getting through.

- Write it down. Make a record of both the treatment or care you're objecting to and the conversations you have about it—including who you're dealing with, when the conversation or action takes place, what people say to you, and what you say to them. And be prepared to put it in writing—to the doctor or the hospital. One of the things we do as lawyers is write letters for people. You'd be surprised how often that makes a difference.

- Get a lawyer. You may want to consult a lawyer to be sure of your grounds and to help you assert your rights against a recalcitrant bureaucracy. The mere presence of a lawyer may get you action.

- Plan ahead. We can't say this often enough. This Guide Waiting to deal with these matters until you are hospitalized, especially for critical care, is a mistake. As discussed in Part One There are a number of techniques, such as health care proxies and health care declarations ("living wills") that will help you avoid some of the problems discussed here.

- Don't wait to get outside help. Start with the patient advocate in the hospital, who can help you cut through any number of problems. If he or she is unable to help you, see if there is a hospital ethicist or ethics committee, and contact them.
Call the New York State Department of Health Consumer Protection Office, 800-804-5497, https://www.health.ny.gov/health_care/consumer_information/complaint.htm
Also keep in mind that you may also try to be transferred to another doctor or facility if you continue to have concerns. This is generally your right if a doctor or hospital will not comply with your wishes. Although it may feel you are fighting the entire medical establishment in trying to assert your legal rights, remember that the law is a powerful ally.

THE HISTORY OF PATIENT RIGHTS

Gaining patient rights is relatively recent. Not so long-ago patients could be subject to experimentation by doctors, without their knowledge or consent, or doctors could make decisions without obtaining patient approval. Although the role of the patient has changed, the concept of patient rights is not new. As far back as 1914, in a landmark decision, New York's highest court ruled:

Every human being of adult years and sound mind has a right to determine what shall be done with his own body; and a surgeon who performs an operation without his patient's consent commits an assault for which he is liable in damages.

The author of those words was Judge Benjamin Cardozo, renowned jurist of the New York State Court of Appeals, New York's highest court, who later served on the United States Supreme Court. In that one opinion, Judge Cardozo established your absolute right as a patient to determine your own treatment and the liability of those who fail to respect that right.

The need for patient consent to treatment: the doctrine of informed consent

When you go to a doctor, there are certain assumptions that are understood by both parties. You enter a relationship with expectations of each other:

- The doctor will examine you, either as part of a routine checkup or in response to specific complaints, or a combination of both.
- The doctor will evaluate your medical condition and, if appropriate, attempt to offer a diagnosis and possible treatment plan, or further tests to aid in diagnosis or treatment.
- The doctor will offer you treatment recommendations and options, fully explaining advantages and disadvantages, benefits and risks.
- You will decide whether to accept or reject the doctor's advice.
- You (or your insurance company, Medicare or in some cases Medicaid) will pay for the service.
- And that your conversations will be confidential because of the patient-physician privilege, except to the extent you authorize disclosure.

That's the extent of the relationship. If you don't want to have your blood drawn or X- ray taken, you can refuse. No one may force you. In a nutshell, that's informed consent:

- Informed: Doctors provide information to patients to help them understand their condition and proposed treatments
- Consent: Patients agree to a course of treatment before it starts, to protect doctors from liability for things that go wrong

Under the law you have a right to refuse. You have a right to make a foolish or bad decision even if your decisions may result in your death, unless you have been determined by a court to be incapacitated or by a physician (or perhaps two) that you lack the capacity to provide informed consent.

Before you undergo any medical treatment or procedure, you need to know what is planned for you and you need to agree to it. Informed consent requires full disclosure to you, the patient, of the risks and benefits of the proposed treatment, as well as any possible alternative treatments. Without this information, your assent is worthless, because you haven't been given the information that would make your consent "informed." Consent is not simply a blanket agreement to treatment.

The average encounter requiring your approval for a procedure may have more emphasis on the consent side of the equation than on the informed. This is due to the inherently unequal nature of the doctor-patient relationship. Don't put your faith blindly in experts and professionals. Hospitals have systems to prevent errors, but systems break down. Things go wrong. Doctors prescribe medicines and forget to ask about allergies or other medications. Medicine gets delivered to the wrong patient or the dosage may be wrong, or the wrong patient gets delivered to the operating room. From Grey's Anatomy to E.R., comedies and dramas depict incompetence, larceny, and medical malpractice on a regular basis. Unfortunately, such horror stories are not confined to television.

A published in the New England Journal of Medicine several years ago found that thousands of hospital patients have suffered medical malpractice. Several well-known institutions have received national publicity for performing the wrong surgery—wrong limb, wrong brain hemisphere, wrong patient—with tragic results. Medical errors are responsible for 44,000 to 98,000 deaths a year, according to a study by the Institute of Medicine. Often a big error is the result of a series of small mistakes, system flaws like inadequate recordkeeping, error in computer data entry or mislabeled medications. Don't assume that a procedure that you haven't heard of or approved is intended for you at all! Make sure anything that your primary doctor has not discussed with you beforehand is in fact intended for you. Listen carefully when the surgeon or the nurse in charge tells you what surgery is to be performed and ask for an explanation if it doesn't sound right.

My doctor is pressuring me to sign a consent form. What are my options?

If no medical emergency exists, get a second opinion. This is always your right. Your consent must be voluntary, without any coercion. Most insurance companies will back you up on this. Ask to talk with the hospital's patient advocate, who will explain your rights to you. Ask for time to think about it. And remember you can always alter the form, deleting or editing the words that make you feel uncomfortable.

The most important step to take with a consent form, as with any other paper you may be asked to sign, is: read it before you sign. And ask questions. Your signature signifies both your understanding and your agreement.

- Don’t sign what you don’t understand.
- Don’t sign what you don’t agree with.
- Always get a copy of what you sign.

Having a release form put in front of you as you are about to go into the operating room is bad practice, but done all the time. Ask your physician to see the release forms ahead of time; you are not in great shape in the admissions office or just outside of the OR to handle this issue with your usual way of handling things.

You are as important as the physician standing before you, and your wishes and requests for information must be respected and honored. That’s only fair—and it’s the law! And it’s not impolite.

Remember, signing does not keep you from changing your mind during your treatment or bringing a lawsuit afterward if you were not properly advised or if you received negligent treatment. And always get a second opinion before you agree to any high-risk treatment. Most insurance policies now require this, if for no other reason because it cuts down on unnecessary surgery.

Is informed consent required by law?

Yes. Treating you without your consent may constitute assault or battery. It may be grounds for a malpractice lawsuit. The right to informed consent is included in the American Hospital Association’s Patient’s Bill of Rights. Hospitals are required to give you a copy when you are admitted. That’s New York law.

Written consent is merely documentation of your agreement. In most cases other than experimental treatments, writing itself is not required by any statute or regulation. Nevertheless, you can wind up signing as many as three or more consent forms when you’re in the hospital. Whether any of these is legally valid depends on the circumstances. Read the forms carefully and ask what the provisions mean. For example, the release may say that you consent to your surgeon or his associates performing the operation – are you OK with that?

Although a signed form can be used as “evidence” of informed consent, it does not necessarily preclude you from bringing a suit after treatment if things go wrong and there is some fault.

Are there exceptions to the requirement that a patient give informed consent?

In an emergency situation, where there is no one available to authorize treatment, doctors may proceed without consent. This emergency authority is sometimes abused in institutional settings to give unwanted medication. Problems also arise in emergency situations when elderly people are given treatment by doctors and other personnel without knowledge of or in disregard of contrary prior instructions.

In cases where the patient is unable to give consent due to incapacity, doctors may proceed with consent from a designated health care agent acting under your health care proxy or family members pursuant to New York's Family Health Care Decisions Act enacted in 2010. Many adults with mental illness receive drug treatments with the consent of relatives or friends (see discussion later).

Doctors sometimes cite "therapeutic privilege" to withhold information. This may be done in limited circumstances when the doctor believes that disclosing it would have an adverse effect on the patient's condition, for example, on a depressed or critically ill patient. Sometimes doctors withhold bad news because they think patients can't handle it - "truth telling" is sometimes a serious issue.

REFUSING LIFE SUSTAINING TREATMENT

The corollary to informed consent is the right to refuse treatment. If you have the right to consent to treatment, it necessarily follows that you have the right to refuse it.

Traditionally, the right to refuse treatment has been based on your common-law right to bodily integrity, your constitutional right to privacy, and, under certain circumstances, your constitutional right to the free exercise of your religion. Theoretically at least, treatment performed against your wishes could be a form of negligence or assault.

According to the law - upheld in the Supreme Court's 1990 Cruzan decision - the decision to reject lifesaving treatment is protected by the guarantee of the right to liberty embodied in the 14th Amendment to the Constitution. The right to refuse treatment is included in the American Hospital Association's Patient's Bill of Rights, by New York law and is included in most individual hospitals' patient bill of rights. Hospitals are also required by federal law to notify patients of their right under state law to refuse medical treatment.

PATIENT RIGHTS AND PATIENT AUTONOMY

At the age of 25 Nancy Cruzan had a tragic automobile accident in Missouri. She fell into what doctors call a "persistent vegetative state" and was kept alive only by artificial feeding. When her parents sought to disconnect the feeding tube, citing their daughter's wishes in the matter, the hospital refused. The Cruzans went to court.

Cruzan provided the ultimate test between medical authority and patient rights. Eventually the Missouri case went to the United States Supreme Court, which in 1990 ruled that there was a constitutional right to refuse treatment, even treatment that that was sustaining life (such as artificial feeding, resuscitation or ventilators). The liberty interests of the individual under the 14th Amendment were held to be paramount. Nancy Cruzan had the constitutional right to determine her own care which was not lost because she was incapacitated (in this case through her parents as her surrogate). Cruzan built on the decision in the 1976 case of Karen Ann Quinlan, also a young woman in a persistent vegetative state, where the New Jersey Supreme Court ruled that Karen Ann did not lose her right to refuse treatment when she became incapacitated and that her father, as her representative ("surrogate") could decide for her, even if death would occur.

Not everyone is comfortable with patients' and their families' exercising their rights to make these important medical decisions. Changes to the traditional patient-doctor relationship are resisted both within and outside the medical community. As the decision-making role of the doctor has diminished, patients have been transformed from unquestioning supplicants to wary consumers in dealing with doctors, hospitals, Medicare, insurance companies and many conservative judges. There continues to be a large "care gap" between what patients want and what they get. That's why it's so important for patients to learn how best to exercise their rights - and the responsibilities that come with them. We discussed the tools to do so in Part One.

Is there any exception to my right to refuse all treatment?

Yes, but only a very limited one, to protect public health, when vaccinations required by an appropriate government authority or agency. Even this kind of requirement may be overridden in some cases by objections based on sincere religious belief. We only need to look at the current Covid 19 pandemic and the refusal of some persons to receive a vaccination to see situation where refusal can happen.

Is the right to refuse treatment lost when a person becomes incapacitated?

No. If a person's wishes were expressed when he or she was competent, either through a documents such as a health care proxy and a health care declaration or orally to another person, those wishes must be respected. A health care agent acting under a health care proxy can advocate for the wishes of the patient who becomes incapacitated as known to the agent, but if not, based on the patient's best interests. Decisions for incapacitated adults or children who have not expressed their wishes are usually made by relatives pursuant to family consent laws (such as New York's Family Health Care Decisions Act) or the doctrine of substituted judgment.

The Patient Self-Determination Act

The Patient Self-Determination Act (PSDA) was enacted by Congress in 1990 on the heels of the Supreme Court's Cruzan decision, in an effort to avoid repeats of Nancy Cruzan's situation by spelling out those rights to refuse medical treatment and encouraging patients to exercise those rights through advance directives. Under the law, all hospitals, nursing homes, home health agencies, hospices, and prepaid health care organizations receiving federal aid must notify patients of their right to receive or refuse medical treatment. The Patient Self-Determination Act mandates that health care facilities that participate in Medicare and Medicaid must

- Provide written information to all adult patients as to their rights under state law to make decisions about their medical care, including the right to accept or refuse care and their right to sign advance directives—living wills and health care proxies—for health care decisions
- Provide a written description of state law and their own internal policies governing patients' rights
- Inquire whether any advance directives have been signed, document the existence of any directives, and avoid discriminating in the kind of care provided based on whether the patient has executed advance directives
- Ensure compliance with state law on advance directives

The PSDA applies only when a patient is admitted to the hospital. Outpatient services are not covered. Under federal law, health care facilities that do not comply risk loss of funding. Hospitals and nursing homes are not required to provide forms for patient use, although materials for the public are prepared by the Department of Health and Human Services. In New York hospitals and nursing homes are required to provide information and health care proxy forms.

In many respects, the law has been a disappointment. Studies show little if any improvement in public understanding of advance directives or doctor-patient communication about these important end-of-life medical decisions. Legislation to strengthen the law has been stalled in Congress for several years.

In 2010 New York, however, acted to protect patients to some extent, passing the Palliative Care Information Act (PCIA) and the Palliative Care Access Act (PCAA). The PCIA requires that terminally ill patients have the right to receive information and counseling about palliative care and end of life options, including hospice. The PCAA requires hospitals, nursing homes, home care agencies and certain assisted living facilities to adopt policies to inform patients about palliative care and pain management. And there must be an appropriate discharge plan before any patient can be forced out. Under what circumstances can I leave a hospital?

If you want to leave the hospital, the hospital can't stop you. Some people prefer not to stay in the hospital, risking unwanted infections; others want to be far away from possible extraordinary lifesaving measures. Provided you're of sound mind, you can leave anytime. You can sign yourself out of hospital "AMA" (against medical advice).

Most hospitals will ask you to sign a form saying, "discharged against medical advice." You don't have to sign this or any other form to leave the hospital, even if you haven't paid the bill. Keeping you against your will would be false imprisonment.

Can the hospital kick me out for not following its advice?

No. The hospital cannot discharge you for other than medical reasons. Anti-dumping laws guarantee that the hospital will continue to provide medical care if you need it. You can be transferred to another hospital only if you're in stable condition.

END OF LIFE DECISIONS - THE "RIGHT TO DIE"

With the U.S. population living longer - older Americans constitute the fastest growing segment of the population - more and more seniors are facing awesome decisions at the end of life. By 2050 20% will be over 65 and 5% will be over 85. Half of those over 85 will not be functional and will suffer from long term chronic illness. Over 100,000 Americans are over the age of 100.

The phrase "right to die" means different things to different people. It is used and misused by advocates and opponents alike, as the Cheshire Cat explained to Alice, to mean what they want it to mean. What it means to patients who assert their rights when they are critically ill - and to lawyers who help them - is this: it is your right to determine what treatment you will get and what treatment you may refuse, even if it will result in death.

In simple terms, this is just an extension of the "informed consent" rights you've had all along to situations in which refusing treatment could result in your death. Consider this common scenario: People with chronic diseases live longer, sicker lives because of advances in technology. The terminally ill, once left at home to die among their loved ones, are now ensconced in hospitals and nursing homes, at the mercy of technology available to save them and strangers ready to administer it prolonging lives with minimal or no quality of life, often in violation of the patient's wishes. We can learn a great deal about this by reading Being Mortal by Atul Gewande, M.D.

Patients with capacity can speak for themselves. Patients who no longer have capacity must rely on their representatives - their health care agents or a surrogate acting under New York's 2010 Family Health Care Decisions Act (FHCDA), which passed after 17 years of debate. Prior to the enactment of the FHCDA New York had the most conservative law in the nation: with few exceptions, no substituted judgment was allowed; no surrogate decision making. Unless the patient's wishes were known by clear and convincing evidence all treatment had to be provided (Matter of Eichner – the Brother Fox Case). So, for example, in the case of John Storar, a 52 year old intellectually disabled man suffering from terminal leukemia, his treatment had to be continued over the wishws of his guardian/mother because he could never have met the clear and convincing test since – retarded since birth – his wishes could not be expressed at all. Does my right to determine my own treatment mean that I must cease treatment?

No. While that may be the most common outcome, your right to determine the medical interventions you will and will not allow may include determining that you want to continue treatment, even though doctors may not want to continue because they believe it has no medical value in your case. What's called the right to die can also be called the right to treatment as you choose. (End of Life Choices New York can provide you information about life-sustaining technology and how to enforce your wishes. For information, telephone (212) 726-2010 or go online at http://www.endoflifechoicesny.org).

MEDICAL "FUTILITY"

Do I have the right to all the treatment I want?

There is a point at which further treatment may be so medically ineffective that it should be ended, although where society will draw the line between appropriate and non-effective treatment is thus far unresolved. The media called this "medical futile" treatment, a term now widely used. While doctors are required to treat and stabilize patients in all emergency conditions, regardless of their medical belief that no treatment is warranted, under the federal antidumping law, that rule doesn't apply in most other situations. While a few courts have held that patients do not have a right to demand treatment that the physician deems medically inappropriate, most states have mixed policies about this.

In Texas, for example, a physician who feels treatment has no medical value can give notice to the patient or his or her representative that the treatment will be ended in 10 days unless a court order directing treatment is obtained or the patient is transferred to another hospital. In New York, the FHCDA Act states that wanted treatment must be provided to the patient even where the physician thinks it has no medical value unless the hospital gets a court to sustain its position or a transfer to a willing hospital can be arranged. And under the Health Care Proxy law the same rule applies; patient's demand or the agent's decision prevails. In most other states the rule is unclear.

What's the difference between the right to die and suicide?

Refusing treatment is not suicide. Withholding or withdrawing treatment is, legally, not the cause of death – the underlying illness is the cause. It is not suicide, nor is the decision of your surrogate assisted suicide. It is the right to determine what treatment you will get, and what treatment you may refuse, in accordance with your personal values and wishes

PART THREE
THE GREAT DEBATE: CAN A DYING PATIENT HASTEN DEATH

Throughout the nation, Americans are debating the rights of persons who are in the last stages of life because of an illness that will result in their death in the near future to hasten their death. Of course, these persons are entitled to palliative care and may be eligible for hospice care, but their suffering may be so great that they wish to accelerate their death. The debate centers on the question as to what steps such dying persons are legally available to them when death is near to end suffering.

Let's discuss the legal options that differ vastly from state-to-state:

Terminal Sedation: Terminal sedation is a practice – legal in all states – where physicians provide medication to sedate a dying patients so that she or he will be unconscious until death occurs. Consent to such practice may be given by a patient with capacity or by the patient's health care agent or other surrogate. This practice is usually performed in cases when withdrawal of medical treatment, discussed earlier in this Guide, has not resulted in the patient's death and she or he is suffering.

VSED – Voluntarily Stopping Eating and Drinking

Many older persons who wish to hasten death because of the present severity of their illness or who have decided that the progression of their illness will result in unwanted suffering or leave them in a state of advanced dementia, often from dementia caused by Alzheimer's disease. Cancer patients may wish to avoid the significant pain their disease may bring. Palliative care, hospice or terminal sedation may not be an acceptable option for them.

Surprisingly, there is great interest in VSED. In most cases persons who chose to end their lives via VSED do so at home, often with the support and care of spouses or other family members. There are, of course, serious ethical and medical concerns about VSED, including whether the decision is driven by depression that could be treated.

An excellent analysis and discussion about VSED is contained in a recent article by Judith Schwarz, R.N. PhD, available on the website of End of Life Choices New York, www.endoflifechoicesny.org. Go to Education/Resourses/VSED/Reading (Hastening Death by Voluntarily Stopping Eating & Drinking: Why Do Some Consider This Option? Why Should They? What Should They Know Before Proceeding?

Medical Aid in Dying (Physician Aid in Dying)

Many dying persons who reject terminal sedation or VSED to end their lives and who want another means to terminate their lives by want the right to ingest terminal medication. This practice is generally known today as Medical Aid in Dying “MAD”) or Physician Aid in Dying, and is legal now in ten states, and is a physician-supervised practice where a terminally ill adult with capacity and a prognosis of six months or less to live may request a prescription from her or his physician for medication they can self-administer causing a peaceful and dignified death, usually at home surrounded by their family.

As of April, 2021, ten states allow MAD by statute, often called “Death with Dignity” statutes, plus one by court decision:

California	**2018**
Colorado	**2016**
District of Columbia	**2016**
Hawaii	**2018**
Maine	**2019**
New Jersey	**2019**
New Mexico	**2020**
Oregon	**1994**
Vermont	**2013**
Washington	**2008**
Montana	**(By court decision)**

MAD statutes (and Montana’s court decision) allow adults who are residents of the state with cognitive capacity who have a terminal illness (a confirmed prognosis of six or fewer months to live and whose decision is determined not to be driven by depression) to voluntarily request and receive a prescription medication to hasten their certain, imminent death. The patient must be able to self-administer the medication. These laws give patients dignity, control, and peace of mind at the end of their lives with the support and involvement of family and loved ones.

All of these laws include provisions to ensure that patients remain in control during the discussions with their physicians and family so that the protections of the laws are followed. Two physicians must confirm the patient’s residency, diagnosis, prognosis, mental capacity, and voluntariness of the request. Two waiting periods, the first between the oral or written requests for terminal medication and another between receiving and filling the prescription, are required.

Most MAD laws are based on Oregon's 1994 Death with Dignity Act, widely viewed as successful and which independent studies have showed that the statutory safeguards to protect patients and prevent misuse have worked.

The death with dignity process is robust: Two physicians must confirm the patient's residency, diagnosis, prognosis, mental competence, and voluntariness of the request. Two waiting periods, the first between the oral requests, the second between receiving and filling the prescription, are required.

The Oregon Heath Authority issues comprehensive reports that demonstrate there is no "slippery slope" leading to "euthanasia" (where persons other than the patient can decide to terminate the patient's life, a practice allowed in Belgium, the Netherlands and Switzerland). The Oregon report for 2019 shows that 112 physicians wrote 290 prescriptions for terminal medication which 188 patients self-administered. Since 1994 a total of 2,216 prescriptions were written (through 2019) with 1,459 taken (65%). Oregon had a population of 4,218,000 in 2019.

Medical aid in dying is sometimes incorrectly referred to as "physician assisted suicide." MAD is not assisted suicide or suicide. These terms are misleading and factually incorrect. Physicians and psychiatrists generally agree that suicide is an act of a person who is not dying but who chooses to kill herself or himself. A person who seeks terminal medication from a physician wants to live but cannot. A person who commits suicide is generally driven by mental illness; that is not the case with a person who seeks terminal medication, because a prescription for terminal medication can not be written for such person.

Legislation to legalize Medical Aid in Dying has been introduced in New York each year for several years; the general view is that the legislature will not enact Medical Aid in Dying in 2021. In 2017 the New York Court of Appeals ruled against the plaintiffs who challenged the constitutionality of New York's law making "assisting a person to commit suicide" a crime in Myers v. Schneiderman. New York's highest appellate court did not find that the provisions of the New York "assisted suicide" law violated the New York State Constitution. In 1997 the U.S. Supreme Court held in Washington v. Glucksberg and Vacco v. Quill that such laws did not vilolate the Constitution of the United States. But it is worth reading the concurring opinion of Judge Jenny Rivera in Schneiderman, who, although she did not vote to strike down the New York statute, in effect made a strong argument for doing so with a concurring opinion that said, in part:

...the right of a patient to determine the course of medical treatment does not, in general, encompass an unrestricted right to assisted suicide, and the State's prohibition of this practice in the vast majority of situations is rationally related to its legitimate interests. Nevertheless, this conclusion does not support the State's position that its interests are always superior to and outweigh the rights of the terminally ill. In particular, when these patients are facing an impending painful death, their own interest may predominate. For the reasons I discuss, in those limited circumstances in which a patient seeks access to medical treatment options that end pain and hasten death, with the consent of a treating physician acting on best professional judgment, the State's interest is diminished and outweighed by the patient's liberty interest in personal autonomy...

The liberty interest protected by our State Constitution is broader than the right to decline medical treatment...

For the terminally ill patient who is experiencing intractable pain and suffering [*12]that cannot be adequately alleviated by palliative care, plaintiffs and amici affirm that the ability to control the end stage of the dying process and achieve a peaceful death may lead to a renewed sense of autonomy and freedom [FN7]. So while the State's interest in protecting life is paramount, the law requires that we balance that interest against those of an individual facing an imminent and unbearably painful death..., the government's interest in protecting life diminishes as death draws near, as that interest "does not have the same force for a terminally ill patient faced not with the choice of whether to live, only of how to die" (Glucksberg, 521 US at 746 [1997].

The legislators in the ten states that now have enacted laws that allow MAD because the legislators obviously held the same views as Judge Rivera; so did the Justices of the Supreme Court of Montana. Many more state legislatures are expected to to pass MAD laws in the next few years. Readers may be interested in watching the film The Brittany Maynard Story about Brittany's decision to end her life as allowed by the Oregon statute.

CONCLUSION

If nothing else, this Guide should be a wake-up call to protecting yourself from the consequences of failure to plan ahead. It is critical to execute advance directives: a health care proxy, health care declaration and if hospitalized, a MOLST. Doing so will maintain your independence and control over critical health care decisions to the maximum extent possible.

This Guide has not touched on other extremely important issues: establishing systems to manage your financial affairs if you become incapacitated - planning through trusts and wills and powers of attorney, and estate planning and estate and gift tax issues. Dealing with how to pay for the costs of long term care must be considered, including purchasing long term care insurance, using life insurance and home equity as funding sources and Medicaid, which in New York, unlike most states, has a generous home care program.

The attorneys at Pierro, Connor & Strauss, LLC, are available to assist our clients at any time with issues related to the subjects discussed in this Guide.

This Guide was based in part on The Complete Retirement Survival Guide: Everything You Need to Know to Safeguard Your Money, Your Health and Your Independence (Second Edition, 2003, revised and updated November 2016, by Peter J. Strauss and Nancy M. Lederman.

LOCATIONS

PIERRO, CONNOR
& STRAUSS, LLC
Trusted Counsel

CAPITAL REGION

43 British American Boulevard
Latham, NY 12110
Phone: 518-459-2100

NEW YORK CITY

260 Madison Avenue, 16th Fl.
New York, NY 10016
Phone: 212-661-2480

HUDSON, NY

LAKE PLACID, NY

AFFILIATE OFFICES

RONKONKOMA, NY
GARDEN CITY, NY
UTICA, NY

OF COUNSEL OFFICES

FORT LEE, NJ
FALMOUTH, MA
CLEARWATER, FL