

Unwanted Medical Care and Treatment—Things You Can Do to Get Only the Care and Treatment You Want and to Which You Are Entitled

By David C. Leven

Too many people die suffering unnecessarily in this country and in New York State. Some patients receive unwanted, often aggressive care which contributes to or causes this suffering until they die. This care may be provided because wishes regarding care and treatment were never expressed. For others, it is provided contrary to clearly expressed wishes.

This article will focus on the issue of unwanted care and treatment (these words are used interchangeably) and what you can do (for yourselves, loved ones, and possibly clients) including enforcing rights under laws designed to help you get care and treatment in accordance with your wishes, to improve your quality of life and to allow you to have a death in accordance with your values and goals. What is discussed in this article applies to you but also to loved ones and clients, if you are still providing representation.

Dying Today

A very brief summary about how we die today is provided here because it is important to know that when considering what your goals of care are, what matters to you, and what suffering you might endure relevant to quality of life, as decisions are made by you or by others for you. Understand that while people are living longer they are not necessarily dying better. Increasingly, medical technology can keep us alive longer. That is good for some of us who may have a good quality of life and relatively good deaths, but it is not good for others who may have a prolonged dying process and who die badly. Now, some 70% of people die each year from chronic diseases, with more than half of those dying from heart disease, cancer or stroke. Many people die with poorly controlled symptoms and pain; psychiatric disorders and psychosocial and spiritual distress; concrete needs in the home; and challenges in care coordination, communication, decision making, and goal-setting.

A 2015 report, *Dying in America*, by the Institute of Medicine, confirms that many drastic improvements are needed in the treatment of the dying. It states that "...improved care for people near the end of life is a goal within the nation's reach," meaning, of course, that much change is needed. It notes too, "As much as people may want and expect to be in control of decisions about their own care throughout their lives, numerous factors can work against realizing that desire." The report documents many areas where changes are needed and makes numerous good recommendations.

Unwanted Health Care Treatment (and Wanted Treatment)

The wishes of patients need to be honored far more than they are now. This will require changes in the way that medicine is practiced and how doctors and patients interact. It will certainly require that patients take essential steps to ensure that they do not get unwanted treatment but do get treatment that they wish. Just two years ago, a national survey conducted by Purple Strategies revealed that about one in four Americans say that they or a family member experienced excessive or unwanted medical treatment. That is about 25 million people. This is unacceptable.

The survey also revealed that older Americans strongly support holding doctors accountable when they fail to honor patients' end-of-life health care wishes and that older Americans want both incentives and sanctions to ensure physicians respect patients' preferences. Six out of 10 (61%) of those polled support reimbursing doctors for end-of-life consultations; nearly two-thirds (65%) support withholding payment to health care providers who fail to honor their end-of-life medical wishes.

Large majorities of the survey respondents would discuss (93%) or write down (90%) their advance directive, or change (91%) or speak (84%) to their own doctors. Two-thirds (66%) say they would "take political action to protect patients' rights to their own choice in end-of-life care." Four out of 10 said they would "take legal action" (41%) or "not pay for the treatment" (40%) in response to unwanted medical treatment. Not surprisingly, 95% said it is important for health care providers to respect their end-of-life medical wishes. Almost eight out of 10 (79%) would be angry if their health care providers did not honor those wishes.

According to a recent study, most patients with metastatic cancers receive aggressive care at the end of life that does not appear to be of value. Aaron Falchook, MD, a co-author of a study on this topic says, "Overuse of aggressive care at the very end of life for a cancer patient can translate to increased burden on patients and their families. In essence what we're doing is we're giving patients side effects without giving them the benefits of the treatment, and that's really the fundamental problem with aggressive care at the end of life." Many if not most of the patients in the study should probably have been transitioned earlier from disease-directed treatment to palliative care or hospice. The quality of their lives would

have been better. As Ronald C. Chen, MD, a lead study author said, "Additional efforts are critically needed to improve end-of-life care for patients with terminal disease to ensure that the care provided meets the goals and preferences of patients and their families."

This study on aggressive cancer care was presented at a recent meeting of the American Society of Clinical Oncology. It found that three-quarters of patients with metastatic cancers (lung, colorectal, breast, pancreatic or prostate) received aggressive invasive procedures or were admitted to tertiary care facilities within the last 30 days of life. The study examined some 28,000 patients from 14 states, all 65 years or younger.

An important lesson here is that you, as a patient with a terminal illness, must be informed of the risks and benefits of any disease directed treatment and all alternative treatments including palliative care and hospice, so that you can make informed decisions about your treatment. But, unfortunately, you may have to initiate the discussion about treatment options with your health care providers as they may not provide you with essential information, even though they are ethically and legally obligated to do so.

For a detailed article on the topic of unwanted or overtreatment, see "Avoiding Overtreatment at the End of Life: Physician-Patient Communication and Truly Informed Consent," *Pace Law Review*, Vol. 36, p. 737, 2016. Also for a review of cases of unwanted or futile care, characterized as the Medical Futility Blog, see feedblitz@mail.feedblitz.com. The blog is by law school professor Thaddeus Pope.

Health Care Proxies

To meet the goal of having health care wishes respected there are certain steps which should be taken to increase the likelihood of that happening. Most importantly, all adults, 18 and over, including your clients, as well as your children and you, should complete a health care proxy. Some 70% of people, when terminally ill, will at some point no longer have decision-making capacity and will not be able to make decisions about health care options. If you or your clients have not appointed a health care agent to make decisions and no one knows what your goals of care are and what treatments would or would not be wanted, decisions may easily be made that are contrary to what would have been wanted.

Too many times we hear stories about people no longer able to make health care decisions, who suffered terribly at the end of their lives, and were kept alive on machines because no one knew their health care wishes. Many people will have in fact considered their end-of-life treatment preferences and, of course, expect and want them to be honored. Still, only about 30% of them have communicated these preferences to loved ones or doctors and have appointed a health care agent to make health

care decisions for them when decision-making capacity is lost. The time to appoint a trusted person to make these decisions and to have conversations with loved ones and doctors about goals of care and treatment preferences is now, while people are relatively healthy and have decision making capacity. This is a gift to loved ones and yourselves.

There are many reasons why people do not take the time to discuss their treatment options with loved ones and their doctors such as "I don't have time," or "It's too overwhelming," or "I don't like talking about these things." None of these reasons is good enough, particularly when considering the significant benefits to people and those close to them when conversations occur and a health care proxy is completed. When people know our wishes, and understand the reasons behind them, they may be more likely to be honored; communication between loved ones and doctors may be facilitated when the time comes for health care decisions to be made, relieving the burdens on all involved; and serious and sometimes never-ending conflicts, which often arise between family members, may be avoided. Those who have these discussions may feel good about having had them, and their stress level about end of life may be reduced.

Values, religious and otherwise, about what makes life worthwhile, what gives life meaning, what matters to us should be discussed. One consideration is whether it is more important to have a better quality of life or an extended life. Decisions concerning life-sustaining treatment are the most difficult for people to make. So, you might discuss with loved ones different scenarios which might confront you to help with the decision-making process. A few short examples of situations that might arise and that might be considered for discussion are:

- You have advanced dementia, are 90 years old, have been bedridden for years and no longer recognize your loved ones. You now cannot eat or even be hand fed. Would you want a feeding tube?
- If you were terminally ill and in great, intolerable pain, would you want to be sedated to unconsciousness if it were necessary to control the pain (this is known as "palliative sedation")?
- If you were permanently unconscious, would you want a feeding tube?

Completing the simple two-page health care proxy form itself is simple. Two witnesses are needed, neither of whom can be the agent (who is appointed). The person appointed as the agent (an alternate agent should also be appointed if possible) should be: willing to speak on your behalf, able to act on your wishes even if different from theirs, a strong advocate who is trusted, someone who knows you well and understands what is important to you, and who would be able to handle conflict if it arises. After discussions have been had with loved ones and

doctors and the health care proxy form is completed, copies should be made for all, including your lawyer if one is involved. Keep a wallet-size copy with you and/or take a photo of your health care proxy and put it on your cell phone and ask your health care agent and alternate to do the same.

Discussions should continue about end-of-life preferences through the years as your thinking may change, and you should communicate changes so that your health care agent (and alternate) and other loved ones continue to understand current preferences and values. By having conversations about health care and end-of-life decisions and appointing a health care agent, a significant gift will be given to those who most matter as well as yourself.

and antibiotics. For each category of treatment at least two options are offered.

As an example, for intubation and mechanical ventilation (to help with breathing), there are three choices: do not intubate, a trial period, and intubation and long-term mechanical ventilation, if needed. Other instructions can also be indicated.

As an example as to how the MOLST form can be completed, assume a patient retains medical decision-making capacity and wants to die naturally in a residential setting, not in the intensive-care unit of a hospital on a ventilator with a feeding tube. Using MOLST, after discussion with the patient and with his or her informed consent, the patient's doctor could issue medical orders

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Medical Orders for Life Sustaining Treatment (MOLST)

Completing a MOLST form might be a good option for some elderly patients and especially for those people who may not have anyone to appoint as a health care agent. Medical Orders for Life Sustaining Treatment (MOLST) can help ensure patients receive desired health care treatment and interventions and that unwanted treatment and interventions are not provided. As important as MOLST is, most people, including many health care professionals, are unaware of it nine years after it was initiated statewide in New York.

MOLST is on a bright pink form. It is signed by a doctor and patient, or by a health care agent or surrogate for patients who do not have decision-making capacity. It tells others the patient's wishes regarding life-sustaining treatment. It is appropriate for patients who have serious health conditions who live in a long-term care facility or require long-term care services, or who might die within a year, or who want to avoid or receive any or all life sustaining treatments. As medical orders, MOLST is transferable between health care settings.

The first page of the document mainly concerns cardio-pulmonary resuscitation. For those who do not want to be resuscitated it is a substitute for the traditional Do Not Resuscitate Order (DNR). The second page has treatment guidelines with several options, where the patient can choose comfort measures only or limited medical interventions or no limitations on medical interventions, all of which are explained, as well as instructions for intubation and mechanical ventilation, future hospitalization transfers and artificially administered fluids and nutrition

regarding life-sustaining treatment, including any or all of the following medical orders: provide comfort measures (palliative care) only; do not attempt resuscitation (allow natural death); do not intubate; do not hospitalize; no feeding tube; no IV fluids; do not use antibiotics; no dialysis; no transfusions. If the patient wants aggressive treatments or some treatments on a trial basis, then those decisions would be indicated on the MOLST form.

The orders should be honored by all health care providers in any setting, including emergency responders who are summoned by a 9-1-1 telephone call after the patient loses medical decision-making capacity. Although it is critically important to appoint a trusted person to be a health care agent and to complete the health care proxy form, MOLST, which should be compatible with what the health care agent has been told about goals of care, gives people added assurance that their goals of care and specific health wishes will be adhered to. And, because MOLST are written orders of a physician, they may carry more weight with health care professionals in an emergency or other situation when decisions about life sustaining treatment must be made. When the MOLST form is prepared, it is probably wise to have the health care agent present too, if possible, so that everything stated in the MOLST is in fact consistent with what has been told to the health care agent. The health care agent should be given a copy of the MOLST form, as should other loved ones and doctors who may be involved with care.

People for whom it is appropriate should be encouraged to complete a MOLST form primarily to avoid life sustaining treatment interventions in situations where they would not want them and would prefer palliative care to provide a better quality of life rather than an ex-

tended life. As explained earlier, too many people are now kept alive contrary to their goals of care because they did not previously express their desire to forgo certain or all life sustaining treatments and now cannot do so (most of us will no longer have the ability to make health care decisions when decisions about life sustaining treatment must be made). The consequence is that too many patients suffer as they are provided life-prolonging treatments which may diminish quality but not extend life by any appreciable amount of time. For others who have not in the past stated their wishes, life sustaining treatments may have been withheld or stopped, contrary to their wishes, which were never expressed.

Many doctors are reluctant to have discussions with their patients about goals of care and end-of-life care and avoid doing so even though Medicare will now reimburse doctors for having such discussions. MOLST is an excel-

The lack of timely physician-patient communication—or any physician-patient communication—is evident regarding hospice. Hospices provide high-quality end-of-life care with well-trained interdisciplinary teams, like palliative care teams. Since hospices provide significant benefits to patients and their families, discussions should take place about hospice and how it can be helpful, and referrals for most patients should be made soon after or even at the time of a terminal diagnosis. However, hospice referrals have usually been made close to death or not at all, even though patients are eligible when a doctor determines that, with a reasonable degree of medical certainty, the patient will die within six months. In New York State about two-thirds of patients are enrolled for less than a month and one-third for a week or less before they die. New York State also has had a poor record regarding hospice utilization. The state has

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lent tool to promote more and better physician-patient communications. Studies show that having these conversations, particularly near or at the end of life, results in patients better accepting their terminal illness, significantly increasing those who have DNRs, reducing aggressive treatment, and increasing the number of people referred to and enrolled in outpatient hospice. Studies on the actual use of MOLST are quite positive and indicate good outcomes with the wishes of patients, particularly regarding resuscitation, more likely to be followed than where there is not a MOLST. Since many health care professionals are still unaware of MOLST or are not yet using it, you may have to bring it to the attention of your doctor.

Palliative Care Laws in New York

There was an urgent need in New York for laws to ensure that health-care practitioners provide, and patients receive, the information and counseling needed to make informed decisions about their treatment and care to reduce the number of patients dying badly. Many physicians have historically been unwilling or unable to have discussions with their dying patients about their diagnosis, prognosis, and treatment options, and the risks and benefits of alternative options, or those discussions have been inadequate and/or untimely, to the detriment of their patients. Since patients have an absolute right to accept or reject any treatment that is offered, doctors have an ethical responsibility to provide information about treatment options so patients can make informed decisions.

one of the lowest rates in the country of patients dying in hospice: about 30% compared to the national average of close to 50%.

There are significant benefits for patients when end-of-life discussions between physicians and their dying patients occur. Quality of life is improved, decisions are made to pursue less aggressive interventions, patients are more likely to receive end-of-life care consistent with their wishes, and hospice referrals occur earlier. End-of-life discussions often produce dramatic positive results. It is the responsibility of health-care practitioners to initiate these discussions, as they are now required to do in New York and as both a best practice and standard of care dictate. It should also, it seems, be the responsibility of lawyers to inform their clients of their rights regarding palliative care and hospice and to be advocates for them, when appropriate.

New York Laws on Palliative Care

New York State has wisely enacted laws, unique to this state, to begin to address the problems of inadequate pain and other symptom control, the lack of information provided to patients about palliative care, hospice and other end-of-life options, and the failure to provide timely palliative care, and hospice care, if at all.

The Palliative Care Information Act and Palliative Care Access Act, both effective in 2011, are critically important patient rights laws.

Palliative Care Information Act (PCIA)

The Palliative Care Information Act (PCIA), Public Health Law, Section 2997-c, is a patients' rights law that is a model for the nation. Terminally ill patients now have a clearly defined right to receive information and counseling about their palliative care and end-of-life options, including hospice, which will enable them to make informed treatment decisions during the final months of their lives. The law states, in part:

If a patient is diagnosed with a terminal illness or condition, the patient's attending health care practitioner shall offer to provide the patient with information and counseling regarding palliative care and end-of-life options appropriate to the patient, including but not limited to: the range of options appropriate to the patient; the prognosis, risks and benefits of the various options; and the patient's legal rights to comprehensive pain and symptom management at the end of life; and information regarding other appropriate treatment options should the patient wish to initiate or continue treatment.

Definitions

"Palliative Care": Health Care treatment, including interdisciplinary end-of-life care, and consultation with patients and family members, to prevent or relieve pain and suffering and to enhance the patient's quality of life, including hospice care.

"Terminal Illness or Condition": Reasonably expected to cause death within 6 months.

"Appropriate": Consistent with applicable legal, health and professional standards, the patient's clinical and other circumstances; and the patient's reasonably known wishes and beliefs.

"Attending health care practitioner": A physician or nurse practitioner who has primary responsibility for the care and treatment of the patient. Where more than one physician or nurse practitioner share that responsibility, each of them has responsibility [to offer information and counseling], unless they agree to assign that responsibility to one of them.

Compliance with PCIA

Offer to provide information and counseling:

Patient accepts:

- Provide information and counseling directly, orally or in writing.
- Arrange for another physician, NP or professionally qualified person to provide the information and counseling.

- If unwilling to or does not feel qualified to provide information and counseling, either arrange for another physician or NP or refer to another physician or NP.

Patient declines:

- Patient is not provided with information.
- Information and counseling shall be provided to a person with authority to make health care decisions for the patient if the patient lacks decision making capacity.

If you believe that you may have a terminal illness and you have not yet been offered information and counseling, then you may want to ask your attending health care practitioner to provide you with information and counseling so that you will be able to make informed treatment decisions for yourself. You should also inform seriously ill family members and clients of their rights under the PCIA and recommend that they too raise the issue of being provided the required information and counseling if they want it.

Studies have demonstrated the need for the PCIA:

- Dying patients are not informed or sufficiently informed of diagnosis, prognosis and treatment options.
- The vast majority of dying patients in fact want to know their diagnosis and prognosis.
- The lack of physician-patient end-of-life discussions results in hospice referrals only very near death or not at all.
- End-of-life discussion with patients results in a better quality of life, and they have better deaths and may even live longer.
- Costs are reduced.

Palliative Care Access Act (PCAA)

The PCAA: Expands on the PCIA, Public Health Law, Section 2997-d

- Applies to hospitals, nursing homes, home care agencies and enhanced and special needs assisted living residences.
- Applies to patients with advanced, life limiting conditions and illnesses who might benefit from palliative care (defined as in the PCIA).
- Requires providers to establish policies and procedures to provide these patients with services with access to information and counseling concerning palliative care and pain management appropriate to the patient.

- Facilitates access to appropriate palliative care and pain management consultations and services.
- Provides the information and counseling to those lawfully authorized to make decisions for patients who lack capacity to make medical decisions.

According to the NYS Department of Health,

Like the PCIA, the PCAA is intended to ensure that patients are fully informed of the options available to them when they are faced with a serious illness or condition, so that they are empowered to make choices consistent with their goals of care, and wishes and beliefs, and to optimize their quality of life. The law is not intended...to discourage conversations about palliative care with patients who have distressing symptoms and serious conditions, but do not technically fall within the law's requirements. Palliative care and disease-modifying therapies are not mutually exclusive. Patients may opt to pursue palliative care while also pursuing aggressive treatment. Palliative care may be provided together with life-prolonging or curative care or as the main focus of care.

As with the PCIA, the PCAA may seem to apply but you still may not be provided the required information and counseling and services may not have been facilitated by the health care facility. You may need to be an advocate for yourself to ensure that you receive the treatment and care to which you are entitled and which will benefit you.

Resource for PCIA and PCAA :

- New York State Department of Health website, questions and answers and guidance for practitioners, http://www.health.ny.gov/professionals/patients/patient_rights/palliative_care/.

Legislation on Unwanted Medical Care

The chair of the Assembly Health Committee, Richard Gottfried, has introduced a bill. (A.2140-A; it will have a new number in 2017 after the new legislative session begins.) If enacted, it will hopefully reduce unwanted medical care and will provide potential remedies when such care is provided. It specifically provides, in part, that:

2. In a judicial or administrative action or proceeding relating to a health care provider's failure or refusal to adhere to or accommodate a patient's patient health care decision:

(a) The action or proceeding shall not be barred because the health care provider's

failure or refusal to adhere to or accommodate a patient's health care decision (i) did not cause physical, mental, emotional, or economic injury to the patient or (ii) improved the physical, mental, or emotional condition of the patient. However, the presence or absence of such injury or improvement may be considered in the measure of damages, penalty or other relief.

(b) A court may award damages for each day the health care provider's failure or refusal to adhere to or accommodate a patient's health care decision in the amount of two thousand dollars for each day or such other amount as the court may deem just.

(c) A waiver by or on behalf of a patient of the right to bring an action or proceeding under this subdivision shall be against public policy and shall be void.

(d) Laws and rules relating to civil actions or proceedings shall apply, except as explicitly provided otherwise in this section.

3. This section shall not change the authority of a health care provider to provide a health care service or treatment in the absence of or contrary to a patient's consent, where authorized by law.

4. No health care provider shall seek or accept payment or reimbursement from or on behalf of the patient or a third-party payer for a health care service or treatment that is provided in the absence of or contrary to the patient's consent, unless it was authorized by law to be provided in the absence of or contrary to the patient's consent.

Regarding this latter provision, the Family Health Care Decisions Act, PHL, Article 29-cc, has a provision which generally prohibits reimbursement for unwanted care, with certain exceptions.

As stated in the sponsor's memo to A.2140-A:

New York and other states provide a safe harbor for physicians and health care providers who adhere in good faith to valid advance directives and patient decisions. However, many states, including New York, do not provide corresponding punishment provisions or specifically allow for the recovery of damages, when appropriate, for disregard of such valid directives. This is unfair to patients and family members who suffer because of

having unwanted treatment provided, or not having wanted treatment provided. This bill will ensure that there may be remedies in appropriate cases. Additionally, providers should not be able to seek or recover payment for clearly expressed unwanted treatment. This bill will prohibit providers from seeking and obtaining payment for such unwanted treatment.

Final Thoughts

All of us have the right to accept or refuse any medical treatment that is offered to us at any time. Near the end of life, many of us will choose, and have the absolute right to choose, if we have decision making capacity, to either forgo certain treatments, or to have them stopped, at any time. These include feeding tubes, respirators, cardiac devices, dialysis, antibiotics or other life sustaining drugs, etc. And, if our symptoms become unbearable and cannot be controlled, particularly pain (which most often can be managed well, but not always), the option of palliative sedation, near the end of life, should be available. Life sustaining treatments, if any, are stopped as are food and fluids; the patient is sedated to unconsciousness, often until death arrives, although the patient may want to regain consciousness during the process to see if the symptoms are being controlled. Death occurs within days and up to about two weeks. For some, voluntarily stopping eating and drinking may be a reasonable end of life option, particularly in the absence of aid in dying, a process which generally takes 10 to 14 days for death to arrive. It is quite difficult for many because of thirst issues and requires a great deal of discipline. In this situ-

ation the cause of death is dehydration, not starvation as some believe.

We should be in charge of our own deaths as we have been our own lives.

Conclusion

Unwanted medical care or treatment is provided too often to patients, particularly the dying. You as a patient and your clients need to understand that this happens and why it happens. You and they also should know that there are things that can be done which will hopefully ensure that only that care and treatment that is wanted, will in fact be provided.

David C. Leven, JD, is the Executive Director Emeritus and Senior Consultant, End of Life Choices New York,* where he served as Executive Director for 14 years. The organization works to improve care and expand choices for the terminally ill. Leven is an advocate for patients and an expert on advance care planning, patient rights, palliative care and end-of-life issues, including aid in dying. He has played a leadership role in having legislation enacted in New York to improve pain, palliative and end-of-life care. He initiated the Palliative Care Education and Training Act, the Palliative Care Information Act and several laws to encourage the completion of health care proxies.

*** The organization provides free counseling services to the terminally ill and their families and to those planning for the end of their lives. Contact Judith Schwarz, PhD, Clinical Coordinator, Judy@endoflifechoicesny.org, 212 252 2015, who is available to speak with people about any of the issues discussed in this article.**

2019 Author Updates:

- On pages 17-18, under Medical Orders for Life Sustaining Treatment (MOLST), as of 2019 nurse practitioners also have the authority to sign the MOLST form.
- On page 20, under Legislation on Unwanted Medical Care, the current bill number is A.1150.

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