

MAKING A DIFFERENCE

A Guide for Defending the Medically Vulnerable



Providing a voice for medically vulnerable people when healthcare providers fail to appreciate the inestimable worth and dignity of every human life.



Why HALO? Why Now?

The increasing number of reported cases of negligence, abuse, and even intentionally caused deaths in healthcare settings is truly alarming. Many more cases go unreported. These are not just “cases”; these are human beings in need of our genuine concern and protection NOW.

HALO’s founders recognized the urgent need to provide aid to patients and their families primarily through advocacy, education, and promotion of life-affirming healthcare alternatives for patients whose lives are in danger.

Many healthcare providers conscientiously strive to preserve the lives of their patients. However, some medical professionals do not recognize the value of every human life and cannot be trusted to safely treat you or your loved ones. MAKING A DIFFERENCE is designed to help YOU navigate the complicated and sometimes perilous healthcare system.

We advise everyone to interview their doctors. Here are two questions to ask them:

- Do you view nutrition and hydration as basic care to which every patient is entitled for as long as it will sustain life and/or is beneficial to the patient?
- Do you reject the intentional causing of the deaths of patients, even if they request assisted suicide or euthanasia, and believe that no class of human beings (e.g., the sick, disabled, elderly, poor, preborn) ought ever to be deprived of life for the benefit of other individuals or society?

We are all vulnerable when in need of medical treatment and/or dependent on others for basic care. HALO is here to help families, friends and volunteers be life-affirming advocates for the medically vulnerable. To that end, we offer MAKING A DIFFERENCE.

Each of us can help restore reverence for life within healthcare.

Together we can make a difference!

The Healthcare Advocacy and Leadership Organization

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DEFINITIONS

Life-affirming Healthcare: Medical care in which the paramount principle is the sanctity of life, which means that the life and safety of each person come first and each person receives medical care across their lifespan based on their need for care and never with an intention to hasten death, regardless of their abilities or perceived “quality of life.”

Health Care Advance Directive: The general term for any document in which you provide instructions about your health care wishes or appoint someone to make medical treatment decisions for you when you are unable to make them for yourself. Living wills and medical powers of attorney are both types of health care advance directives.

Euthanasia: An act (e.g., lethal injection, smothering) or an omission (e.g., withholding or withdrawal of lifesaving or life-sustaining medical treatment or basic care) which ends the life of a person for the purpose of eliminating suffering, rationing medical resources, etc.

Stealth Euthanasia: The intentional hastening of a patient’s death while pretending to provide appropriate palliative treatment. (See page 9, “The Earth-Shattering Shift in Medical Ethics.”)

Terminal Sedation: Administering large dosages of sedatives to render and keep a patient unconscious until death. Near the end of life, terminal sedation (TS), also known as “palliative sedation,” is properly used only to relieve extreme pain or agitation when all other comfort measures have proven ineffective. TS is frequently misused with the intention to cause death—the patient is heavily sedated and nutrition and hydration are withheld.

Physician-Assisted Suicide (PAS): A physician provides a patient with the means (e.g., a lethal dose of drugs and/or information needed to commit suicide). The last act is done by the patient. This is legal in a small number of states and Washington, D.C., as well as some other countries. (Physician-assisted suicide is a misnomer. There are always others involved—pharmacists, nurses, family and/or friends.)

VSED (voluntarily stopping eating and drinking): A person refuses to eat and drink in order to cause or hasten his/her death. This is suicide. If healthcare providers assist with “comfort measures” (e.g., drugs) while the patient starves and dehydrates to death, this is a form of assisted suicide.

Conscientious Objection: When exercised by healthcare practitioners, this is a refusal to do something which conflicts with the practitioner’s religious or ethical principles. Ominously, not only euthanasia activists, but also some prominent academics and lawmakers seek to exclude from the practice of medicine those who refuse to kill their patients.

“Conscience is the most sacred of all property.” – James Madison

Need Help Now?

Contact us: feedback@halovoice.org

Helpline: 1-888-221-4256 (HALO)



THE BEST ADVANCE DIRECTIVE

By Julie Grimstad, President of HALO

At first glance, health care advance directives (see p. 3, “Definitions”) don’t appear problematic, but consider their origin. In 1967, the Euthanasia Society of America (later renamed the Society for the Right to Die and a succession of other names) introduced the first advance directive, the Living Will, as a step toward social and legal acceptance of euthanasia. Today every state’s advance directive law permits euthanasia by omission: the withholding or withdrawal of life-sustaining procedures—including basic measures such as providing food and fluids by tube or intravenously—when their omission will be the direct cause of death.

Living Wills are fatally flawed

A Living Will (often called a Directive to Physicians) is a legal document that instructs physicians to use or not use certain treatments and/or tube-feeding in the event of an illness or injury. *It is impossible to foresee what you may want or need in a future situation when you are unable to speak for yourself.* A Living Will is based on mere guesswork. This is dangerous.

It is never wise to specify conditions under which you would rather be dead. Anything you write or say could lead to the premature and involuntary ending of your life.

If you refuse treatment, you risk tying the hands of a physician whose skills could restore you to health. Also, it is surprisingly difficult to state treatment wishes understandably. You may think you are clearly stating your preferences, but the terms used in advance directives often have legal and medical meanings that are quite different from what many people think they mean. When you are hospitalized, physicians may be strangers who do a poor job of interpreting your wishes, particularly if they do not share your values.

A LETHAL CHECK MARK

In 2005, a young soldier suffered a severe brain injury while serving in Iraq. Before being deployed, he had signed a Living Will, checking a box refusing tube-feeding in the event he became terminally ill or permanently unconscious. His wife insisted that nutrition and hydration be withdrawn, and a doctor mistakenly determined he was permanently unconscious. This young man was admitted to a hospice for “comfort care” while being starved and dehydrated to death. A family member called me, desperately asking what they could do to save her loved one’s life. She said that, while he was in a rehabilitation facility, he would squeeze a ball with his hand. When he dropped it, he would pick it up by himself and continue with therapy, showing a determination to get better. His best friend told a reporter that he was responding “yes” or “no” to questions and nodded “yes” when asked if he wanted to live. Nevertheless, because he had checked a box in his Living Will refusing tube-feeding, his fate was sealed.

The wiser choice: a Medical Power of Attorney

A much better option is a Medical Power of Attorney (MPA) in which you appoint a trusted family member or friend to be your “proxy” (called an “agent” in some MPA documents). Your proxy will make medical decisions for you in the moment of need if you are unable, either temporarily or permanently, to do so for yourself.

Your proxy will endeavor to honor your values and wishes while basing decisions on current medical information. You cannot know today the treatments that will be available tomorrow, let alone 5 or 10 years after signing a Living Will. This is just one reason why appointing a proxy (agent) to make your medical decisions in a future situation may save your life.



It is important that you discuss your wishes and principles with your proxy when you sign your MPA and periodically thereafter. Your perspective may change as your circumstances change. It is not unusual for healthy people to imagine that certain medical treatments would be intolerable, but then change their minds when faced with life-threatening conditions. On the other hand, when their health is declining, some people may wish to limit or forgo medical treatment that they previously said they would want.

A Medical Power of Attorney is a necessity for anyone who is 18 years old or older. Any person can suddenly be incapacitated due to an accident or illness. To be certain someone you trust will have access to your medical records and be permitted to participate in making medical decisions for you, you must name that person in a legal document.

The standard MPA, however, presents problems because it uses the same language as does a Living Will.

Safeguard your life

Should you become seriously ill or injured and unable to speak for yourself, your greatest advantage will be a tenacious proxy committed to protecting your best interests. Your next of kin may not be that person. Do your best to choose a proxy who will not be intimidated easily by healthcare providers or medical terminology. If you haven't spoken to someone you would trust with your life about being your MPA proxy in a time of crisis, consider having that conversation today.

Next, choose an MPA document that is carefully worded to ensure that no one, not even your proxy, has the authority to approve the direct and intentional ending of your life. HALO's **Life-Affirming Medical Proxy (LAMP)** fits this description. We recommend the LAMP document, (downloadable free at halovoice.org/pdf/LAMP.pdf).

The American Bar Association advises, "Even if your state requires a specific form, doctors have a legal obligation to respect your clearly communicated treatment wishes in any manner or form expressed, as long as the wishes are medically appropriate" ("Myths and Facts About Health Care Advance Directives." *American Bar Association*, Bifocal Vol. 37, 2015). Therefore, no matter where you live, a signed and witnessed LAMP document is a valid expression of your wishes.

The LAMP clearly states, "I direct that nutrition and hydration, administered either orally or by artificial means, be provided to me unless death is inevitable and imminent from a cause independent of nutrition and hydration so that the effort to sustain my life is futile or unless I am unable to assimilate food and fluids." And to preclude misinterpretation of your directions, the LAMP specifically says, "I have discussed the meaning of the words used in this document with my proxy and my proxy's interpretation of them is controlling."

The wording of a Medical Power of Attorney is critically important. Be wary of any advance directive given to you at a health care facility or doctor's office.

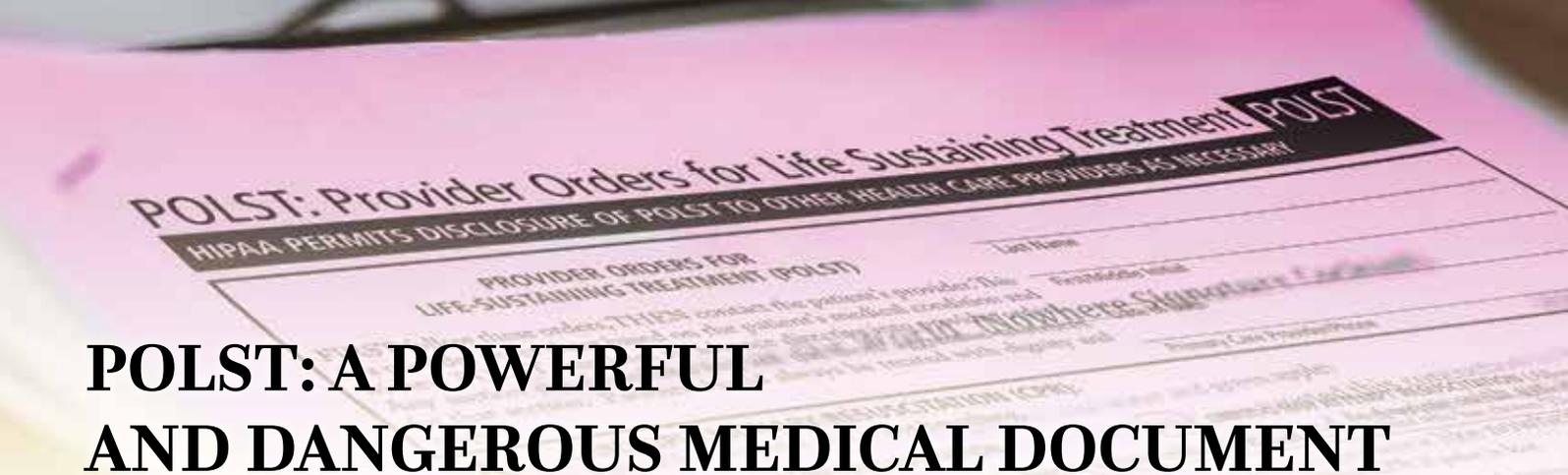
Be prepared

When admitted to a health care facility, you will be asked if you have an advance directive. If you answer "no," one will be offered then and there. This is often a stressful time and therefore not an ideal circumstance for filling out a legal document with life and death consequences. It is wise to have your completed LAMP document in hand when you arrive at the emergency room or admission desk.

For more information on advance directive options, see HALO's Advance Directives Comparison chart at: halovoice.org/comparison

What's right? What's wrong? How do I decide?

HALO's fact sheet called "Life-Affirming Principles for Medical Decision-Making" explains seven basic principles that will help you make life-affirming, medically appropriate, sensible, and informed health care decisions. This fact sheet is an easy to use tool designed to help you formulate and discuss your values and wishes with your proxy and health care providers. Check it out at: halovoice.org/pdf/HALO_Life-Affirming-Principles.pdf



POLST: A POWERFUL AND DANGEROUS MEDICAL DOCUMENT

By Julie Grimstad, President of HALO

Physician's Orders for Life-Sustaining Treatment (POLST) is a medical document used extensively throughout the U.S. POLST has numerous names and acronyms, such as Clinician Orders for Life-Sustaining Treatment (COLST), Transportable Physician Orders for Patient Preferences (TPOPP), etc.

Usually a neon pink, green or yellow form (highly visible in a patient's chart), the POLST reduces complicated medical decisions to a "check the box" format. A "facilitator" asks a patient questions and checks boxes indicating whether they do or do not want cardiopulmonary resuscitation (CPR), a ventilator, antibiotics, IV fluids, tube-feeding, etc. After filling out the POLST, the facilitator presents it to a doctor or nurse practitioner (NP) for a signature. Once signed, it becomes medical orders that can go into effect even when a patient is fully capable of making his or her own medical decisions and/or does not have a terminal condition. Furthermore, a POLST can override a patient's Medical Power of Attorney.

POLST orders travel with the patient from one healthcare setting to the next, and even home to be followed by EMTs in an emergency. Using medical orders that were written weeks, months or years earlier is not sound medical practice.

Tilted toward refusal of treatment

Facilitators follow a script presenting all treatment options as if they are morally neutral. The Respecting Choices program provides them with fact sheets to "educate" patients. The "Long-Term Tube Feeding Facts" sheet concludes, "Whatever you decide, plans can be made to follow your wishes." [1] It does not explain what those "plans" might include, so I will. When tube-feeding is withheld from patients who are not dying otherwise (hence the word "long-term"), they will be given "comfort care" which may include terminal sedation (see p. 3, "Definitions") to cover up the pains of thirst and hunger.

The way questions are phrased manipulates patient responses. For example, a facilitator may ask, "Do you want us to focus

on keeping you comfortable?" The patient responds, "Yes, of course," unaware that this answer may be interpreted, "Stop treating my illness and only provide comfort care." Also, patients probably don't know that, even if they could recover, it's likely treatments they refuse will not be provided. If an elderly person is in an accident, will he be given life-saving treatment? Or denied it because of check marks on his POLST?

A Cost-saving/Rationing Strategy

John M. Haas, president of the National Catholic Bioethics Center, in a letter to the Secretaries of Health and Human Services and the Veterans Administration regarding POLST, June 7, 2017, noted "Evidence suggests that such approaches have more to do with cost saving than the protection of informed consent. In fact, the very means by which costs will be saved is the premature death of a patient through the denial of basic care." [2]

Listening to POLST advocates leads to the conclusion that POLST is indeed a strategy to cut spending and ration medical care for elderly, chronically ill, and seriously ill patients, many of whom are not expected to die soon enough to please the cost-controllers. For example:

- Dr. Robert L. Fine, Director, Office of Clinical Ethics and Palliative Care, Baylor Health Care System (Texas), addressed "Why should we support POST?" One of several reasons he listed was "High costs in the last year of life with 28% of Medicare dollars spent in the last year and 14% spent in the last 2 months of life." [3]
- The Gunderson Health Systems, La Crosse, WI, has promoted a model for advance health care planning—Respecting Choices—since 1991. This program trains POLST facilitators. An article advertising it stated, "Partly due to Gunderson's Respecting Choices program, end-of-life medical costs in La Crosse are nearly half the national average." [4]

POLST is extremely dangerous

Every other type of advance directive requires witnesses, yet many POLST forms do not. For instance, the La Crosse Area POST does not require witnesses and, incredibly, permits a physician or NP to initial a box “to verify that the patient or surrogate consent [sic] to these orders but was unwilling or unable to sign.” If a person was unwilling to sign a document, it is doubtful they consented to it. Without witnesses, how can we prevent fraud and protect patients from being coerced to refuse treatment?

In January 2016, Medicare started paying for conversations about “advance care planning” as a routine part of a visit to the doctor. The goal is to get patients to fill out advance directives, most likely POLST forms. According to the

National POLST website, completing a POLST form is always voluntary. When approached with a POLST form, firmly state, **“I have a Medical Power of Attorney for Health Care which will go into effect if ever I need my proxy to make decisions for me. Until such time, I want to discuss my condition and treatment options with my attending physician as needed. Please respect my wishes.”**

[1] http://www.northtexasrespectingchoices.com/wp-content/uploads/MC760-E-TubeFeedFacts_v9-15.pdf

[2] <https://www.ncbcenter.org/files/4715/0896/0198/HaasPolst.pdf>

[3] “A POLST form for Texas: What is it and why is it important?” A presentation to GETAC Medical Directors, Robert L. Fine, MD, FACP, <https://www.dshs.texas.gov/emstraumasystems/POLST.pdf>

[4] Modern Healthcare, 6/11/2015, “‘Revolutionary’ change for life’s final choices would reduce unwanted care,” by Andis Robeznieks]

POLST’s Reach is Expanding

According to the National POLST Paradigm website (polst.org), “The POLST form is for seriously ill patients for whom their physicians would not be surprised if they died in the next year, not for all patients.” Despite this qualification, POLST’s reach is expanding.

Case: Jo Tolck, Vice President of HALO, received a call from a woman in Minnesota who had been given a POLST at her doctor’s office when she was there for a procedure necessary to have a prescription renewed. She reported being strongly encouraged to sign the POLST form. She knew this was not a good idea and was incensed at the pressure being put on her to sign it. The staff member finally asked her to take it home and think about it.

Case: An attorney in Wisconsin, who has “heard many stories like this,” reported: A woman in her forties came to the Emergency Department. She was in such respiratory distress that she could not talk. While waiting for a doctor, she was approached by the unit clerk who wanted to complete a POLST with her. The nurse, who had brought the woman to the hospital, intervened and stopped the POLST process. The ward clerk said it was their policy to do a POLST on anyone with respiratory problems. The woman’s problem was an allergic reaction to a new medication. An Epi-Pen injection completely restored her health.

The National POLST website also states, “It should always be your choice to have a POLST form —*you should never be forced to have a POLST form.*” Nevertheless, HALO has received reports from credible sources that some hospices and nursing homes are requiring every resident to sign a POLST before they will be admitted.



What About Ventilators and “Pulling the Plug”?

By Nancy Valko, RN

The medical definition of informed consent requires understanding “the purpose, benefits, and potential risks of a medical or surgical intervention.” Most people have only a vague understanding of the ventilator and very little information about this often life-saving medical intervention.

The ventilator’s many life-saving uses

Most people—especially the elderly—tend to automatically refuse ventilators when filling out medical advance directives without understanding that a sudden problem with breathing can come from treatable conditions that don’t require long-term use of a ventilator, such as asthma, drug overdose, pneumonia, and some brain injuries.

In some circumstances, the ventilator is necessary long-term to live. People like Christopher Reeve and Stephen Hawking used portable ventilators to continue with their lives. Some people with disabilities use small ventilators only at night.

It’s important to know that not all machines that assist breathing require the insertion of a tube into the windpipe. Non-invasive positive-pressure ventilation (like the BiPAP) allowed my elderly friend Melissa to use a face mask to assist her breathing until antibiotics cured her pneumonia.

Ventilators move air in and out of the lungs but do not cause respiration—the exchange of oxygen and carbon dioxide that occurs in lungs and body tissues. Respiration can occur only when the body’s respiratory and circulatory systems are intact. A ventilator cannot keep a corpse alive.

Weaning from a ventilator

As an ICU Nurse in the 1990s, I was shocked by the development of the “terminal wean” for some patients on ventilators. Often the families were told that there was no hope of a “meaningful” life. The terminal wean involved abruptly disconnecting the ventilator and “allowing” the patient to die. I brought up at least trying gradual weaning and oxygen as we did for other patients on ventilators, but I was ignored.

Many patients are easy to wean from a ventilator, but some are more difficult.

Years ago, I cared for an elderly woman with Alzheimer’s who needed a ventilator when she developed pneumonia. She had made her son and daughter her medical decision makers. When the woman improved, the doctors found it very difficult to wean her from the ventilator. They spoke to the family about removing the ventilator and letting her die. The daughter agreed but the son was adamantly against this.

I knew some great respiratory therapists in the past who were able to successfully wean difficult patients from ventilators. At my suggestion, this woman was transferred and a week later we were told that she was successfully weaned. About a year later, I encountered the woman again when she was recuperating after routine surgery. Although her Alzheimer’s disease was unchanged, she was doing well in an assisted living residence.

There are no guarantees

As a student nurse, I was initially intimidated by ventilators. As I learned how to use them and saw the constant improvements, not only in the technology but also in our care of patients on ventilators, I came to see ventilators as a great blessing when needed.

Most of my patients on ventilators recovered, but some could not be saved. We were surprised and humbled when patients with poor prognoses recovered while others who seemed to have a better chance died unexpectedly. There are no guarantees in life or death.

Nancy Valko, RN, ALNC, is a member of HALO Board of Advisors, a spokesperson for the National Association of Pro-Life Nurses, and a past president of Missouri Nurses for Life. This information about the ventilator was adapted with the author’s permission from a post on her blog: nancyvalko.com/2019/03/08/what-about-ventilators-and-pulling-the-plug/

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The Earth-Shattering Shift in Medical Ethics

The New Bioethics

Profound respect for the sanctity of life has always been the core ethical principle of medicine, but that is changing. Today, sadly, the truth that every human life has equal worth is rejected by utilitarian-minded bioethicists. The new bioethics divides human beings into two categories: the “wanted” and the “unwanted.” Like their brothers and sisters who are aborted at the beginning of their lives, the chronically or terminally ill, disabled, and elderly are in danger of being killed simply because it is inconvenient and/or costly to care for them.

Palliative medications designed to relieve suffering are being misapplied in the hospice care setting as a tool in this new bioethics to make “unwanted” people die.

When hospice and palliative care are provided by healthcare professionals who truly respect life, it is a blessing. However hospice and palliative care, in practice, often is not as advertised.

Stealth Euthanasia

Hospice care, whether provided in a patient’s home or a facility, is the “ideal” setting for the misuse of palliative medicines to secretly eliminate the “unwanted.”

“Stealth euthanasia” means the intentional hastening of a patient’s death while pretending to provide appropriate treatment.

A typical report that we receive from grieving family members is that their loved one, who had been alert and was not complaining of pain, was administered increasingly frequent and larger doses of pain medications and sedatives to the point where they were sleeping all the time and could not eat or drink. Some reported that patients were also denied their usual medications to control blood pressure, diabetes, etc.

In September of 2000, the World Federation of Right to Die Societies (an association of organizations which promote euthanasia) issued an ominous declaration, stating in part:

We wish to draw public attention to the practice of “terminal sedation” or “slow euthanasia” which is performed extensively today... A physician may lawfully administer increasing dosages of regular analgesic and sedating drugs that can hasten someone’s death as long as the declared intention is to ease pain and suffering... Compassionate physicians, without publicly declaring the true intention of their actions, often speed up the dying process in this way.

Stay alert!

Doctors (and nurses) who intentionally kill selected patients represent an earth-shattering shift in medical ethics. Thankfully, there are still many members of the medical profession who embrace the sanctity of life ethic. The difficulty lies in discerning who can be trusted never to kill. When a loved one is referred to hospice or palliative care, be wary and stay alert!



Questions to Ask a Hospice BEFORE Admission

It is imperative that you interview a hospice agency before entrusting yourself or a loved one to its care. All hospices are not the same. The services one hospice provides may be very different from those provided by another hospice. Also, the philosophy of a hospice agency is vitally important. A hospice that respects the sanctity of life, that truly abides by the founding principles of hospice—to maintain dignity, to increase quality of life, and to provide comfort and pain control—is a safe haven for patients in need of expert end-of-life care. **Unfortunately, the aim of many hospices has shifted from helping patients who are dying to helping patients die more quickly.** Because hospice marketers will tell you what you want to hear, you must do your homework.

Ask questions and get a copy of the answers in writing (especially for question #9).

1. Is the hospice life-affirming? If yes, is this evidenced on the website, in the brochures, in the mission, etc.?
2. Is the hospice non-profit or for profit? [1]
3. Is the hospice licensed by the state?
4. Is the hospice Medicare certified?
5. Has the hospice ever committed insurance fraud? (Google the name of the hospice and Medicare fraud.)
6. How many counties does the hospice serve? [2]
7. How are services provided after hours? How long may it take for an on-call nurse to respond to my call? How long may it take for an on-call nurse to get to my home?
8. Can I meet with the hospice administrator and the staff members prior to hospice admission?
9. In detail, what types of services are provided? How often will each of these services be provided?
10. Will services be provided by the same individuals throughout the course of my care?
11. What kinds of support are available to my family/caregivers?
12. What do hospice volunteers do? Am I eligible for volunteer services?
13. Can the hospice provide care in a nursing home or personal care home/assisted living?
14. Must someone (a family member, friend, or caregiver) be with me at all times?
15. Must I commit to a DNR (Do Not Resuscitate) status?
16. Does the hospice require that every patient sign a POLST-type form? [3]
17. Can I receive intravenous fluids and tube feedings?
18. Will my usual medications (e.g., blood pressure medication, insulin, etc.) be continued?
19. Does the hospice administer medications to relieve pain and anxiety only on an as-needed basis, or are patients routinely started on these types of medications on admission? [4]
20. What is the hospice's position regarding Terminal Sedation (also called Palliative Sedation)? [5]
21. Will I receive a bill for expenses not covered by insurance?
22. What should I do first if I am having a problem with the care my hospice is providing?
23. What should I do if I feel the hospice hasn't addressed my concerns adequately?



Important Notes

- [1] Most of the hospices caught for insurance fraud are for-profits. Additionally, many for-profits are governed by shareholders concerned about returns on their investments. As a result, monies are often allocated away from the bedside and into their pockets. However, many non-profits also follow a business model resulting in the same problems. Therefore, asking about a hospice agency's business status is as important as asking about profit status. If the hospice employs marketers, this is often an indication that they are more interested in putting money in the bank than in providing services to patients. Any hospice that keeps saying "We don't provide that" is not enhancing life and is most likely cutting costs at the bedside in order to enrich investors and pay executives' salaries.
- [2] Hospice agencies often serve many counties from a single office. The on-call nurse may have difficulty reaching you quickly in an emergency as he/she may be several hours away.
- [3] Physician Orders for Life-Sustaining Treatment (POLST) is an advance directive form used extensively throughout the United States. POLST has many different names and acronyms, such as Medical Orders for Scope of Treatment (MOST), Clinician Orders for Life-Sustaining Treatment (COLST), and Transportable Physician Orders for Patient Preferences (TPOPP). These forms differ, and some are worse than others, but all of them can be used to encourage refusal of life-saving and life-preserving treatment and care, resulting in avoidable deaths. HALO recommends that people refuse to sign any POLST-type form.
- [4] Medications used to manage pain and other symptoms—opiates, sedatives and barbiturates—can be misused to cause death. The intention to kill a patient, not just to treat pain and other symptoms, is becoming more common in end-of-life care settings. See "Drugs Commonly Used in Hospice and Palliative Care" on pp. 12-13.

[5] Sedation has a legitimate place in end-of-life care but must be used only when absolutely necessary. When sedation is misused to cause death, the patient is placed in a medically induced coma and nutrition and hydration is withheld.

Know Your Rights

1. While the role of the physician is to recommend hospice care, it is the patient's right to decide when or if hospice care is appropriate. However, the physician must certify that the patient has been diagnosed with a terminal illness and the patient must meet the Medicare or insurance criteria for their end stage disease to be eligible for hospice care.
2. The role of physicians and hospital/nursing home social service professionals is to recommend hospice care and provide names of local hospices. The patient/family has the right to interview hospice programs before making a decision. It is the patient's right to choose their hospice provider.
3. Medicare guidelines stipulate that hospice services may be provided to a terminally ill individual with a life expectancy of six months or less. If the patient lives beyond six months, their attending physician and the hospice medical director may recertify the patient to continue to receive hospice care. However, when patients are on hospice 2, 3, 4, even 5 years, Medicare fraud should be considered.
4. A patient/family has the right to change to another hospice provider once during each benefit period. The Medicare hospice benefit consists of two 90-day benefit periods and an unlimited number of 60-day benefit periods.
5. At any time, the patient/family has the right to reinstate the patient's former medical treatment plan.
6. Under federal law hospice agencies may not force the signing of a DNR order prior to or during the care of any individual.

A DNR (do not resuscitate) order means that cardiopulmonary resuscitation (CPR) will not be used in the event of cardiac arrest (the moment a person's heart stops and breathing becomes impaired). Be wary. A DNR order may be misinterpreted. There is a tendency to reduce other kinds of treatment and care when a patient has a DNR order. It is imperative that you/your proxy state clearly to the physician that refusal of CPR does not limit or eliminate any other form of therapy or the attentiveness of the medical team caring for you.

For more information: www.all.org/learn/organ-donation/life-life-support-and-death/



Drugs Commonly Used in Hospice and Palliative Care

This is a general guide to help patients and families discuss with their physicians and caregivers the drugs used to treat pain and other symptoms. These drugs may have side effects not listed here. Also, combinations of drugs may contribute to adverse effects.

When correct doses are utilized, many of these medications very effectively alleviate symptoms commonly experienced near the end of life and are a great blessing. Also, the reported side effects can be confused with true end-stage symptoms. Stopping medications that are mitigating end-stage symptoms may make symptoms worse.

Ethical healthcare providers administer only the doses necessary to alleviate pain and other symptoms, and never intend to shorten life.

Be vigilant. Not all healthcare providers are ethical. Numerous reports from families of hospice and palliative care patients indicate that a one-size-fits-all pattern of administering a combination of opioids and anti-anxiety drugs has emerged. **Whether or not patients have pain and/or agitation, they may begin to receive these drugs upon admission.** Be wary of combinations of drugs such as morphine, Ativan, and Haldol, as well as the administration of opioids when they are not necessary for pain relief or the amount and/or frequency seems excessive. Be suspicious of any medication, especially an opioid or benzodiazepine (primarily used to treat anxiety), given every hour or two.

Pain Management: Opioids

Side effects: nausea, vomiting, slowed and shallow breathing, itchiness, rashes, constipation, confusion, coma, and in rare cases, increased pain. Some side effects are common; others are rare. The likelihood of some increases as the dosage increases; others can occur even in very low doses.

Morphine

- Short-acting (MSIR, Roxanol, suppositories)
- Long-acting (MS Contin, Oramorph SR, Kadain, Avinza)

Oxycodone

- Short-acting (Roxicodone, Oxyfast, Oxydose)
- Long-acting (OxyContin)

Hydromorphone (Dilaudid)

Codeine

Oxymorphone

Fentanyl

- Short-acting (Actiq Lozenges)
- Long-acting (Duragesic patches)
- Also available in nasal sprays and injections.

WARNING: Fentanyl is about 100 times more potent than an equal amount of morphine. The difference between a therapeutic and a deadly dose is small.

Pain Management: Combination Drugs

Hydrocodone/Tylenol-acetaminophen (Anexsia, Lorcet, Lortab, Norco, Vicodin, Zydone)

Codeine/Aspirin (Empirin with codeine)

Oxycodone/Tylenol-acetaminophen

(Percocet, Roxicet)

Oxycodone/aspirin (Percodan)

Codeine/Tylenol-acetaminophen

Hydrocodone/Ibuprofen (Vicoprofen)

WARNING: In 2016, the U.S. Food and Drug Administration (FDA) ordered that its “strongest warnings” be added to labels on opioid pain medications and benzodiazepines after finding that the growing use of opioid medicines combined with benzodiazepines or other drugs that depress the central nervous system has resulted in serious side effects, including slowed or difficult breathing, and deaths.

www.fda.gov/Drugs/DrugSafety/ucm518473.htm

Opioid Agonist

Naloxone (Narcan) – This drug can reverse the effects/side effects of opioids; SAVES LIVES IN CASES OF LETHAL OVERDOSING.

Drugs Used to Treat Anxiety and Delirium: Antipsychotics

These may cause neurological symptoms (e.g., Parkinson's-like movements), flushing, dry skin, altered mental state, tremors, muscle jerking, insomnia, difficulty speaking or swallowing, fast heartbeat, constipation and even death.

Haloperidol (Haldol)*

Risperidone (Risperdal)**

Olanzapine (Zyprexa)

Quetiapine (Seroquel)

Aripiprazole (Abilify)

Benzodiazepines (Valium, Librium, Klonopin, Ativan) – **should not be used in delirium**

- Short-acting (Opana)
- Long-acting (Opana ER)

***Haldol** is not commonly used to treat nausea and vomiting (N/V). However, it can be tried when several other N/V medications have been used without result. Be cautious if the provider suggests Haldol as a first attempt to alleviate N/V or prescribes it to be given every 1-2 hours.

** **Risperdal**, in particular, is not approved for the treatment of patients with dementia due to increased risk of death.

Pain Management: Non-opioids

These can cause agitation, anxiety, confusion, vision problems, headache, constipation, insomnia and dizziness, as well as other side effects listed.

Tramadol HCL (Ultram)
– similar to opioids

Tricyclic antidepressants
(amitriptyline, a.k.a. Elavil;
desipramine, a.k.a. Norpramin;
imipramine, a.k.a. Tofranil;
nortriptyline, a.k.a. Pamelor) –

tremors, tingling, numbness,
hallucinations, urinary retention

Steroids (such as dexamethasone,
a.k.a. Decadron, DexPak) – tiredness,
mood swings, elevated blood sugar,
high blood pressure, infection,
sweats, digestive upset, edema

SNRIs (venlafaxine, a.k.a. Effexor;
Effexor XR; amitriptyline, a.k.a.,
Cymbalta)

Anti-inflammatory drugs (Motrin-
ibuprofen, Advil)

Anti-epileptic drugs (carbamazepine,
a.k.a. Tegretol; gabapentin, a.k.a.
Neurontin; pregabalin, a.k.a. Lyrica;
phenytoin, a.k.a. Dilantin; valproic
acid, a.k.a. Depakene; clonazepam,
a.k.a. Klonopin) – **sedation, drunk-
like walk.**

INFORMATION ABOUT PAIN CONTROL

Nonpharmacological pain control methods (e.g., ice, heat, elevation, immobilization, rest, relaxation techniques, or meditation) should be utilized as part of any pain management plan.

Treating pain requires current knowledge about drugs and their proper use. The realistic goal should not be zero pain, but rather a tolerable level of pain that allows for optimal physical and emotional functioning. The patient's alertness and ability to interact with others should be preserved as much as possible.

Not all acute pain requires treatment with opioids. Opioids should be prescribed only when necessary, in the lowest effective dose, and for the shortest duration necessary. Due to their slower metabolism, most elderly

patients need much less opioid medication for treatment of acute pain. Because of the significant risks of central nervous system depression and other side effects, as well as potential interactions with routine medications, the initial opioid doses prescribed for elderly or frail patients should be reduced.

Opioids should not be prescribed for sleep, to relieve anxiety, or for any purpose other than pain control.

Ongoing discussion between patients and their care providers is crucial for proper symptom management. Providers should never simply (or forcibly) medicate without discussion.

Cristen M. Krebs, DNP, ANP-BC



Death by Starvation and Dehydration

Assisted Nutrition and Hydration (ANH), when needed long-term, commonly means delivering food and fluids directly into the stomach via a tube that has been surgically implanted. Implantation of the feeding tube takes medical expertise, but it is an ordinary life-preserving procedure for a person who has a working digestive system but is unable to eat by mouth. Whether a person is fed with a spoon or through a tube, this is basic care, not medical treatment. Feeding a person who cannot feed himself is the natural and caring thing to do.

At the 1984 World Federation of Right to Die Societies meeting, Australian bioethicist Helga Kuhse explained their strategy:

*If we can get people to accept the removal of all treatment and care, especially the removal of food and fluids, they will see **what a painful way this is to die**, and then, in the patient's best interest, they will accept the lethal injection." (Emphasis added.)*

This has transpired exactly as planned, both here and abroad. Euthanasia by starvation and dehydration is now an everyday way of eliminating incapacitated people.

Case: Vincent Lambert was a 42-year old French patient purportedly in a "vegetative state"—a frequently inaccurate diagnosis which may result in unjust depreciation of a person's value. His parents wanted to take him home and care for him, but they were not allowed to do so. In July 2019, Vincent died just over one week after doctors withdrew ANH. The lengthy court battle for his life finally ended when, despite pleas from his mother and the Catholic Church, a judge ruled he could be killed in this horrendous manner.

Several countries, including Canada, have already legalized euthanasia by lethal injection. Clearly, France has been infected by the "right to die" movement's deadly agenda, as have many other countries, including the U.S. Which country will be next to "accept the lethal injection"? Pray for this madness to end.

BEWARE: A "Medical Futility" Policy May Be Lurking In Your Hospital

"Medical futility" policies and laws permit hospitals/ doctors to stop patients' life-sustaining treatment based on often biased "quality of life" evaluations, regardless of the wishes of the patients, their authorized agents or families. A prime example is the Texas "10-Day" law. A Texas hospital may render a medical futility decision, then notify the family that they have 10 days to find another facility (one willing and able to provide appropriate treatment) and transfer the patient. If this proves impossible, the hospital cuts off treatment after the tenth day. Such medical futility decisions assault human dignity, freedom, and life itself.

Case: In 2012, twelve-year-old Zachary suffered a gunshot wound to the head. Within 48 hours of arriving at Cook's Children's Medical Center in Fort Worth, the medical staff's conversation focused on the quality of his life instead of the medical care that would foster healing and recovery. Even though Zachary was seriously injured,

his brain stem was not harmed. A week after his injury, the hospital ethics committee began the medical futility process. Zachary's parents pleaded for the hospital to give him more time to recover. But, on the very day Zachary began to breathe on his own, the attending physician withdrew his food and water. Fortunately, the ten-day countdown was stopped when a patient advocate (called in by Zachary's mother) pointed out to the hospital's attorney that they had not followed the law and therefore would not be immune from liability. After being transferred to Children's Medical Center in Dallas, where he received treatment and reconstructive surgery, and then to a rehabilitation facility, Zachary regained his ability to speak, see, and walk, and his full cognitive abilities.

If not for the patient advocate, Zachary would be dead.



Caring For A Loved One In The Final Phase Of Life

“A NATURAL DEATH IN GOD’S TIME: A Caregiver’s Life-affirming Guide,” a booklet authored by Dr. Cristen Krebs, DNP, ANP-BC, helps caregivers understand and recognize common signs and symptoms of approaching death, as well as meet the ever-changing needs—physical, emotional, and spiritual—of loved ones as they approach the end of life. Dr. Krebs was the director of a pro-life hospice for 23 years and is a member of HALO’s Board of Advisors.

Well-informed family members, friends, and other caregivers are able to confidently surround a loved one with comfort and peace, enabling their loved one to experience a natural death in God’s time—a beautiful gift and privilege.

To order “A Natural Death,” email feedback@halovoice.org. Your generous donation will help us print and mail this valuable resource to you as well as to caregivers who are unable to donate. See **donation information at the bottom of the back cover**.

ARE ORGAN DONORS TRULY DEAD BEFORE THEIR ORGANS ARE TAKEN?

Surprisingly, this is not a settled issue. Find out:

- why “brain death” is a controversial diagnosis;
- what organ donation after “circulatory death” means and how it is done;
- how changes to the Anatomical Gift Act might adversely affect you or a loved one; and
- what you need to know before you consider signing up to be an organ donor.

“ARE ORGAN DONORS TRULY DEAD ...?” is a straight-talking fact sheet available at halovoice.org/pdf/HALO_Brain-Death-and-Organ-Donation.pdf.

FOR HISTORY BUFFS

Discover the history of the “right to die” movement. Read “**Origins and History of the Deadly Living Will and Its Sequel, Assisted Suicide**” – a timeline extending from 1938 to 2019 which highlights and briefly describes many of the organizations, individuals and events that have little by little infused a culture of death into our laws, our attitudes and our healthcare system. It is available at halovoice.org/pdf/Timeline-Living-Will.pdf.

Almost every group that promotes the “right to die” sprang from the Euthanasia Society of America and the Hemlock Society—deadly accurate names. Don’t be deceived by the kinder, gentler names and language they’ve adopted over the years. Words like compassion, rights, choice, and dignity are employed to appeal to emotions and mask the truth. Regardless of how it is dressed up, deliberately ending any person’s life for any reason and by any method is killing. Once a society permits certain people to be killed, where will that dark path lead?

Children's Lives Need Protection Too.

From left to right: Israel, Faith Victoria, and Clifton all fought to stay alive when hospitals gave up on them.



A WORD OF GRATITUDE

The Healthcare Advocacy and Leadership Organization (HALO) would like to extend a huge thank you to **American Life League** for spreading the word about HALO and the life-affirming work we do! Whether they are running articles in their print and/or online publications, referring people to HALO or helping promote this power-packed publication, American Life League has been a valuable partner in ensuring that HALO continues to be a voice for the medically vulnerable. For more information on American Life League, visit www.all.org.

RESOURCE ORGANIZATIONS

American Life League
all.org

Choice Is An Illusion
choiceillusion.org

Culture of Life
Studies Program
cultureoflifestudies.com

Euthanasia Prevention Coalition
epcc.ca
alexschadenberg.blogspot.com

Gospel of Life Disciples +
Dwellings
gospeloflifedisciples.org

Homes of Life Across America
homesoflife.net

Human Life Matters
www.humanlifematters.org

Life Legal Defense Foundation
lifelegaldefensefoundation.org

National Association of
Pro-Life Nurses
nursesforlife.org

Options for Women of
Chisago County
optionsforwomenhelp.org

Pro-life Wisconsin
ProLifeWi.org

Prenatal Partners for Life
prenatalpartnersforlife.org

Scholl Institute of Bioethics
schollbioethics.org

Simon's Law
SimonsLaw.org

The Simplicity Project
Wellness Initiative
TheSimplicityProject.org

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