

Informed

A guide for critical medical decisions



About “Informed”

This magazine was designed primarily as an introductory tool to help patients, families and surrogates more fully participate in the interaction with doctors and other healthcare professionals.

Medical situations are often complex and require both medical information from healthcare professionals and a moral framework for good decisions. The essential moral principle that guides us is clear:

“[L]ife is something before which we stand (or should stand) with reverence, awe, and grave respect — because it is beyond us and unfathomable...to regard life as sacred means that it should not be violated, opposed or destroyed, and, positively, that it should be protected, defended and preserved.”

(Leon Kass, M.D., “Death With Dignity and the Sanctity of Human Life,” *Commentary*, March 1990)

Historically, governments, health care providers, and societies in general shared the presumption in favor of life. Regrettably, we can no longer consistently rely on this to be the case. Therefore, we strive to renew reverence for life—that is, to create an environment in which every person’s life is respected and protected by healthcare providers, by law, and by society.

We all have a responsibility to do good for ourselves and others.

We must prepare people to fully participate in decisions about their own healthcare. You can perform an essential role in this regard. First educate yourself. Then reach out to educate others.

It is our hope that you will find this magazine to be a positive, informative guide and that you will share it with your family, friends and neighbors.



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Pro-life Healthcare Alliance

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An Advance Directive That May Save Your Life

Medical treatment decisions must be made based on current facts, including your current condition and any applicable procedures, medications or surgeries that are available. Without knowing a diagnosis and whether or not a specific treatment can help you, it is impossible to know if you want to use a treatment or refuse it. Given the great number of possible illnesses and injuries, and constant medical research producing new treatments that reverse serious conditions, you cannot know today what treatments you would accept or refuse next week, next year or ten years from now. Also, numerous studies show that patients' treatment choices frequently change as their circumstances change.¹ Therefore, when filling out an Advance Directive for Health Care, you should not select or reject specific treatments.

Advance Directives for Health Care

There are two types of advance directives: Directive to Physicians (a.k.a., Living Will) and Durable Power of Attorney for Health Care (DPAHC). Both are legal documents by which competent adults express their wishes regarding future medical treatments if they become incapable of making their own decisions.

A Living Will can be dangerous. In a Living Will, you request or refuse life-sustaining treatment for some future illness or injury based on pure guesswork. Also, when hospitalized, your attending physician may be a stranger who does a poor job of interpreting your wishes, particularly if they do not share your values. Worse yet, a physician can be disciplined for failing to comply with your Living Will's refusal of treatment unless the

physician attempts to transfer you to a physician who will comply. Therefore, a Living Will may tie the hands of a physician who values your life and whose skills could restore you to health.



A much better choice is a Durable Power of Attorney for Health Care in which you appoint a trusted family member or friend ("agent") to make decisions for you if you are unable, either temporarily or permanently, to do so for yourself. Your agent will endeavor to honor your values while basing decisions on current information (your condition, treatment options, likely outcomes, etc.) provided by medical professionals.

Who should you appoint as your agent?

It is wise to choose someone who (1) genuinely respects human life and is capable of making morally sound medical decisions for you, (2) will ask questions in order to base

decisions on the best medical information and advice available, (3) will not be easily intimidated by medical professionals or terminology, and (4) will obtain a second opinion or legal advice if necessary. Discuss your wishes and moral principles with your agent when you sign your DPAHC and periodically thereafter, as your circumstances and perspective may change over time.

A DPAHC is essential for anyone who is 18 years or older. To be certain that a person you trust will make medical decisions for you if you become incapacitated, you must specifically name that person in a legal document.

Not just any DPAHC will do.

The wording of your DPAHC is critically important and it must comply with the laws of your state. For these reasons, the Pro-life Healthcare Alliance (PHA) recommends the Protective Medical Decisions Document (PMDD)* formulated by the Patients Rights Council. The PMDD gives your agent the authority to act on your behalf and take legal action, if necessary, to ensure your rights are protected. It also clearly states that your agent does not have the authority to approve the direct and intentional ending of your life. (This limitation not only protects you, it protects your agent from being pressured to authorize such actions.)

Filling out a PMDD takes only a few minutes—a few minutes that may mean the difference between life and death.

1. "Why do patients often deviate from their advance directives?" Jerome Groopman, MD and Pamela Hartzband, MD, Physician, 9/24/2012.

Information:

*To obtain a PMDD packet specific to your state, contact:
Patients Rights Council, P.O. Box 760, Steubenville, OH 43952
Phone: 740-282-3810 or toll-free 1-800-958-5678.

There are other excellent DPAHCs. For example:

-Pro-Life Wisconsin offers the *Wisconsin Protective Power of Attorney for Health Care*, which can be downloaded free by going to PLW's website, www.prolifewisconsin.org. To obtain a hard copy and a set of *End of Life Brochures*, call toll-free 1-877-463-7945.

-In Canada, order the *Life-Protecting Power of Attorney for Personal Care* by calling the Euthanasia Prevention Coalition: 1-877-439-3348.

Understanding POLST

"The POLST is a living will on steroids... The real danger is that people who sign a POLST often don't understand how powerful this instrument can be."—E. Christian Brugger, PhD¹

POLST stands for "Physician Orders for Life-Sustaining Treatment."²

Trained "facilitators"—usually not physicians—ask patients questions about their treatment wishes and check the boxes on POLST forms that correspond to patient responses. POLST protocols or laws require a healthcare professional's signature, but the patient's signature and witnesses often are not required or sought,³ which is quite the opposite of Living Will requirements. Without the patient's signature or impartial witnesses, how can anyone be certain that the POLST expresses the actual wishes of the patient and that he or she was not coerced or manipulated, or was even competent to make medical decisions when the form was filled out?

After filling out a patient's POLST form, the facilitator presents it to be signed by a physician or other designated healthcare profes-

sional—someone who may never have seen or talked with the patient. **Once signed, the brightly colored POLST form becomes the very visible first page of medical orders in the patient's chart.** It dictates whether to withhold or administer cardiopulmonary resuscitation (CPR), antibiotics, and/or assisted nutrition and hydration, and also whether the patient should receive "comfort measures only," "limited additional interventions," or "full treatment."⁴ POLST restrictions apply the instant the order is signed, whether or not the treatment is associated with an end of life condition.⁵

POLST medical orders travel with a patient from one healthcare setting to the next and even home to be followed by EMTs in an emergency. The first order in many POLST forms is "FIRST follow these orders, THEN contact Physician." It is always best to make medical decisions "in the moment," that is, based on the patient's current situation. Using medical orders that were written weeks, months or years earlier is not sound medical practice.



Some possible dangers include:

POLST programs promote refusal of treatment, not informed consent.

POLST is tilted toward non-treatment and can encourage premature withdrawal of treatment from patients who, but for the denial of treatment, would not die. Facilitators present options to accept or reject treatment and care as if these decisions are morally neutral, even though certain decisions may lead to euthanasia by omission.

POLST programs are biased in favor of refusing life-sustaining treatment and care. POLST forms, many times, are accompanied by handouts clearly biased against life-sustaining treatment.⁶ This does not foster informed consent which requires that the patient also be told the possible benefits of treatment, such as recovery.

Protect yourself and your loved ones.

Filling out a POLST form may render the agent you appointed in your Durable Power of Attorney for Health Care (DPAHC) powerless to protect your rights. If a POLST form and an advance directive conflict, the latest (usually POLST) often prevails, even if you (or your agent) did not sign the POLST.

POLST is not about ensuring that your medical treatment preferences are known and honored. That can be accomplished by using a pro-life DPAHC to appoint an agent to make medical decisions for you in the event you become incapable of voicing your own wishes.

POLST is not needed for treatment to be provided. A typical POLST form states, "Any section not completed implies full treatment for that section." Therefore, filling out a POLST form if you want full treatment is unnecessary.

POLST can be used to manipulate you, when you are sick and vulnerable, to refuse treatment which you may need now or in the future.

For all these reasons and more, the PHA advises you to refuse to answer POLST questions and to warn your loved ones, as well. No matter how many times you are approached by POLST facilitators, firmly state, "I have a Durable Power of Attorney for Health Care which will go into effect if ever I need my agent to make decisions for me. Until such time, I want to discuss my current and future medical conditions and applicable treatment and care options with my attending physician and no one else. Please respect my wishes."

1. "Physician's Orders for Life-Sustaining Treatment: Helpful or a New Threat?" Charlotte Hays, *National Catholic Register*, 8/20/2012
2. POLST is known by different acronyms in various states—MOLST, MOST, POST, COLST, etc.
3. Some states do require witnesses and/or patient signatures.
4. Wording from Colorado Medical Orders for Scope of Treatment (MOST) document.
5. "POLST and Catholic Health Care," E. Christian Brugger, PhD, Stephen Pavela, MD, William Toffler, MD, and Franklin Smith, MD, *Ethics & Medics*, Vol. 37, No. 1, 1/2012
6. A SPECIAL REPORT, California Advocates For Nursing Home Reform (CANHR), *Physician Orders for Life-Sustaining Treatment ("POLST") Problems and Recommendations*, 2010.

Case in Point

Change of Heart

Dr. Silvie Menard, head of the Experimental Oncology Department at the Institute of Cancer in Milan, was a supporter of euthanasia for many years. When she herself was diagnosed with bone cancer, "I changed my position radically," she told the Spanish magazine *Huellas*. "When you get sick, death ceases to be something virtual and becomes something that is with you every day," she said. "So you say to yourself: 'I am going to do everything possible to live as long as possible.'"

Source: "Renowned oncologist changes position on euthanasia after contracting cancer," *Catholic News Agency*, 4/11/08.

“Medical Futility”

The term “futile care” would seem to be synonymous with useless medical interventions—treatment and care that would provide no benefit to a patient. However, a bioethical concept called “Futile Care Theory” is sweeping through our healthcare system. This theory proposes that physicians and hospitals should have the right to withhold or withdraw life-sustaining treatment when a patient or family wants treatment. Based on judgments about the value or quality of patients’ lives rather than on the efficacy of specific treatments or therapies, “medical futility” decisions ride roughshod over the rights of patients to make their own healthcare decisions.

The essence of “Futile Care Theory” is involuntary euthanasia by omission.

Many hospitals have adopted policies granting themselves the right to decide when it is time to stop all treatment and “allow” a patient to die, even against the wishes of the patient or family. Worse yet, some states have added “medical futility” provisions to their Advance Directives for Health Care laws. These policies and laws have been crafted to shield physicians and hospitals from legal liability for hastening patients’ deaths. They do nothing to protect patients’ rights.

Consider the outrageous Texas “medical futility” law. When a patient’s life is deemed valueless, but the patient, family or agent¹ wishes to continue treatment regardless of the illness or prognosis, the dispute is referred to the hospital-appointed ethics committee for resolution. The hospital is only required to give the patient, surrogate or family 48 hours’ notice before this quasi court meets to decide the patient’s fate. If the committee agrees with the doctor (the usual outcome), the family must search for another facility willing to care for the patient. If another facility cannot be found or the transfer cannot be completed within 10 days, the law says “the physician and health care facility are not obligated to provide life-sustaining treatment.” That’s a death sentence issued by an unelected panel.

One Texas family who fought a “futile care” decision stated, “The battle for life is a difficult one in the best of situations, but when a family is put through what we had to go through at such a time,

it is especially agonizing...We wish so much that we could have spent more time at our sister’s side when she was living and fighting for her life, rather than having to visit our attorney’s office, give interviews to radio and television stations to let the public know of the atrocity about to befall Andrea, and literally stand outside the hospital and protest...”² Families must also prepare for the ethics committee meeting and search for another facility, efforts that take much time, thus depriving them of precious moments with their loved one who may be near death, and stealing their peace.

People need to understand this clear and present danger.

Most people will not become aware of their state’s “medical futility” law or the “futile care” policy of their hospital until they receive unwelcome information about the ethics committee hearing or until the patient is too ill to be transferred. All citizens must understand these things before illness or injury befalls them and they are consequently hospitalized.

Advice: Before you or a loved one are admitted to any hospital, ask for a copy of the hospital’s “medical futility policy.” Even if you have no alternative but to be admitted to a hospital with such a policy, at least you will not be caught unaware and unprepared.



CASE IN POINT

“Medical Futility” Judgment Proved Wrong

In 2012, 12-year-old Zachary suffered a gunshot wound to the head. Within 48 hours of arriving at Cook’s Children’s Hospital in Dallas, Texas, the conversation from the medical staff focused on the quality of his life if he did recover instead of the potential treatments and surgeries that would foster his healing and recovery. Even though Zach was seriously injured, his brain stem was not harmed and he was breathing on his own. A week after his injury, the hospital ethics committee decided to withdraw treatment. At the beginning of the ten-day countdown, the family discovered a DNR (Do-Not-Resuscitate) order in his medical records. The family brought the unwanted DNR order to the attention of the facility and it was revoked.

After being moved to another facility and receiving necessary treatment and surgeries, Zach recovered his ability to speak, see and walk, and his full cognitive abilities.

(Condensed from case reported by Texas Right to Life.)



1 “Agent” is synonymous with “surrogate”—both mean a person the patient legally appointed to make future healthcare decisions for him/her in the event he/she became unable to make healthcare decisions.

2 “Andrea Clark has Died: Family Issues Statement,” Wesley Smith’s blog, 5/08/06

Know Your Facts About Ventilators And CPR

Each patient's illness and treatment options are different. The physician's duty is to discuss with the patient and/or their healthcare agent any medical means under consideration to improve the patient's condition and/or preserve their life. This professional obligation includes a discussion of the benefits, risks and costs of a treatment. It is only through an adequate understanding of the benefits and burdens of a particular treatment that the patient or agent is able to make a judicious decision about whether its use is morally obligatory or optional. The patient may forgo a treatment that is minimally effective, too burdensome or excessively costly (i.e., it will impoverish the patient's family) so long as he does not intend to hasten his own death.

Physicians and other healthcare workers have no right to an opinion about the quality or value of a patient's life. Furthermore, the decision to accept or forgo a treatment belongs only to the patient or agent, and not to the physician or healthcare team.

When in doubt, a medical intervention can be tried with the option of stopping it if it proves ineffective or excessively burdensome for the patient.

This approach to medical decision-making applies when assessing most treatments, e.g., dialysis, chemotherapy, radiation therapy, etc.¹ Ventilators and cardio-pulmonary resuscitation (CPR) are two treatments about which many people have questions.

The Ventilator

A ventilator is a machine often used to provide breathing assistance and allow a patient's lungs to rest until he is able to breathe on his own again. In most cases, a ventilator is short-term help, as is the case with severe pneumonia. For patients with lung cancer, ventilator use often reduces the need for morphine and/or sedation in their final hours. In less common circumstances (e.g., spinal cord injuries or Lou Gehrig's disease), a ventilator is used for longer periods of time. If a ventilator is needed long-term to sustain life, there are portable ones. Many people live at home and go to work with ventilators to assist their breathing.

Not all machines that assist breathing require intubation (insertion of a tube into the windpipe). Non-invasive positive-pressure ventilation (NPPV)—a face mask with pressure pushing oxygen into the lungs—is now frequently used. Patients with chronic or acute respiratory failure have shown improved lung function and sleep quality with NPPV.

CPR and DNR

CPR may save a person's life when his heart stops beating and/or his breathing stops. However, the sicker a patient is, the less likely it is that CPR will significantly benefit him. Therefore, it is fair for a patient or agent to ask a physician about the effectiveness of CPR for patients in their condition.

A Do Not Resuscitate (DNR) order means that, in the event of a cardiac arrest (the moment the patient's heart stops and their breathing becomes impaired), the patient will not have chest compressions, electrical shock to the heart, resuscitative drugs, intubation or mechanical ventilation. Be wary. A DNR order may be misinterpreted. There is a tendency to reduce other kinds of treatment when a patient has a DNR. **Therefore, it is important for the patient (or agent) to state clearly to the physician that his refusal of CPR does not limit or eliminate any other form of therapy.**

Recommended reading: *Life, Life Support, and Death: Principles, Guidelines, Policies and Procedures for Making Decisions to Protect and Preserve Life*, Paul A. Byrne, MD, FAAP; William F. Colliton, Jr., MD, FACOG; Joseph C. Evers, MD, FAAP; Timothy R. Fangman, MD, FACC; Ralph J. Kramper, MD, FAAP; Jerome L'Ecuyer, MD, FAAR; Rev. George M. Rincowski; Frank G. Simon, MD; Richard G. Nilges, MD, FACS; Jerome T.Y. Shen, MD, FAAP; Walt F. Weaver, MS, MD, FACC; with Mary Sadick, JD

(Available from American Life League, P.O. Box 1350, Stafford, VA 22555, phone 540-659-4171)

1. This approach to medical decision-making does not apply to artificially-provided nutrition and hydration, which is ordinary care and, therefore, not optional. See "DEATH BY DEHYDRATION IS DEATH WITHOUT DIGNITY: The Matter of Nutrition and Hydration," pg. 11)

Signs And Symptoms Of Approaching Death

When a loved one is living the last stages of a terminal illness, family and friends often ask when death will occur. The time of death is difficult to pre-determine, even for doctors and nurses who specialize in care of the dying. While certain symptoms are usually associated with the natural dying process, these symptoms may vary depending on the unique end stage illness a person is experiencing. Most patients demonstrate a combination of these common symptoms in their final days or hours, but some display none of these symptoms. Being informed of these signs and symptoms assists the patient and loved ones with the difficult task of reaching acceptance of impending death.

This list was excerpted from an article called “Embracing the Journey,” which details essential information about how to appropriately and compassionately respond to and/or relieve these signs and symptoms. “Embracing the Journey,” by Cristen Krebs, DNP-ANP, may be downloaded at www.catholichospicepgh.org.

Dr. Krebs is the founder and director of the pro-life *Catholic Hospice of Pittsburgh*.



Withdrawal from Family and Friends

As patients begin the process of accepting their own mortality and approaching death, they often begin to withdraw from their immediate surroundings, family and friends closest to them, and even previously pleasurable activities. Separating from their earthly life, while contemplating their past, is a necessary part of the dying process for many patients.

Loss of Appetite and Weight Loss

As the body begins a natural decline, energy needs also decline. Patients often experience loss of appetite, refuse full meals and large amount of liquids, and prefer smaller quantities of food that are soft and bland. Caregivers may be troubled by this loss of appetite and subsequent weight loss, but the body naturally requires less food and drink as it declines.

Declining Metabolism, Excessive Weakness, Fatigue and Sleep

As food/fluid intake and metabolism decline, blood pressure slowly lowers and the pulse becomes irregular, either slowing down or speeding up; increased weakness results from less oxygen being available to the muscles; and discouragement or depression may be displayed. Patients often begin to sleep 12-20 hours a day and may be difficult to awaken.

Mental Confusion or Disorientation

As terminal illness progresses, vital organs, including the brain, slow down. A decrease of oxygen to the brain can result in confusion, inability to recognize familiar people or places, or know the current day or year. Patients may no longer answer questions or their responses may be slow and difficult to comprehend. They may see visions or hear voices and converse with people who can't be seen by others in the room.

Restlessness

The patient may become restless or agitated and make repetitive motions, such as picking at the air, bed sheets or clothing. These can be a sign of decreased oxygen to the brain or of physical stress such as pain, nausea, distended bladder or constipation. Restlessness can also indicate emotional stressors such as anxiety or spiritual distress. In some cases, a patient may experience “terminal delirium.” i.e., heightened restless activity and intense confusion, often accompanied by hallucinations and aggressive behavior, or attempts to climb out of bed or leave the room.

Difficulty Swallowing

As the body declines, the patient's swallowing reflex becomes weaker resulting in difficulty swallowing and even fear when taking food or fluids by mouth.

Elimination

As weakness increases, and circulation of blood and oxygen diminish, the muscles that control the bowel and bladder often begin to relax, causing “incontinence” (involuntary loss of urine or feces).

As oral intake diminishes, the amount of urine produced decreases and smaller less frequent bowel movements can be expected. As the kidneys shut down, urine becomes dark in color and fluid often accumulates in feet, ankles, face, hands, or the torso. As the skin begins to work to eliminate toxins from the body, the patient may complain of itching over different parts of the body and experience increased sweating.

Cooling Body Temperature and Skin Color Changes

In the days and hours before death, blood circulation draws back from arms and legs as vital organs work hard to retain circulation. Mechanisms that control body temperature start failing. The hands, feet, fingers, and toes become cool to the touch, and lips and nail beds may look paler or bluish. Some patients complain of feeling cold. One of the later signs of approaching death (resulting from reduction in circulation) is mottling, i.e., the skin develops a blotchy pale purplish/reddish/bluish coloring, often first detected on the soles of the feet, toes and knees and which may slowly work its way up the legs, torso, and arms.



Labored Breathing

As a patient approaches death, breathing often becomes irregular, shallow and labored. The exhalation (out-breath) is longer than the inhalation (in-breath). A distinctive pattern of breathing, known as Cheyne-Stokes respirations, often occurs. Cheyne-Stokes respirations consist of loud, deep, and rapid respirations (up to 30-50 per minute) that involve the whole rib cage, followed by a pause in breathing (apnea) for a period of approximately five seconds to as long as a full minute. Following this period of apnea, the loud, deep breathing resumes. The patient is not aware of this altered breathing pattern. Cheyne-Stokes respirations may continue for a few days, several hours or minutes, until death occurs.

Sometimes congestion and excessive secretions create coughing or loud, gurgling sounds during inhalation and exhalation. This “death rattle,” as it is sometimes called, is caused by the accumulation of saliva in the back of the throat when the patient can no longer swallow. This does not seem bothersome to the patient.

Unexpected Alertness and Increased Energy

Surprisingly, in the last days or hours, patients often experience an unexpected period of clarity, lucidity and energy lasting anywhere from less than an hour up to 24 hours. The patient can often eat, talk and spend quality time with loved ones. This is a very special time for final spiritual practices and mental preparations, which can be shared with loved ones. As quickly as it occurs, the period of attentiveness grows faint, and the patient returns to an unresponsive state.

Saying Good-bye

When it becomes evident that the patient’s death is near, family members and close friends should be notified and given the option to visit the patient one last time. This also allows family and friends the opportunity to support one another as they grieve their loss.

Case in Point

December 2013

My doctor predicted I had “only a month to live”—33 months ago! On Valentine’s Day, 2011, my wife and I received the stunning news that I had stage four pancreatic cancer. We fought it with every form of chemo known to medicine. After a CAT scan showed that I wasn’t getting any worse, my nice young doctor pulled his chair close, looked me in the eye and told me I had been given a gift. He had no idea why I was still alive.

Now, there is no more chemo to try. In June, the prediction was that I have three to six months left. But, who knows?

Don’t give up! No doctor can accurately pinpoint how long a person has to live. I’ve lived a full and happy life, and it’s not over yet.

*Larry Larson
Lake Nebagamon, WI*

Prenatal Partners For Life:

Replacing Fear with Love

New prenatal testing and modern technology have made it possible for parents to know more about their babies than ever before. When the results of these tests indicate a problem, parents are faced with fear, uncertainty, and often pressure to abort their child. The shock, sadness, and worry about what the future holds can be intense.

Abortion is frequently offered as the only solution or option to families. Many parents say they feel pressured and are not informed of the option to continue the pregnancy and embrace the life of their child. A false sense of compassion is often presented to families who are told that ending the life of their child is the most loving choice to make.

Even if families can resist the pressure to abort their child, the danger does not end. After the birth of their baby with special needs, they may have to fight for treatment and the risk of stealth euthanasia (passive or active euthanasia done in secret) is an ever-present concern. Conversations about the child's quality of life, projected life expectancy, futile care or resources may occur. Parents may be pressured to "wrap your baby up in a blanket and let him go."

The way they are treated with their baby who has special needs is a shock to many families. The negative and sometimes hostile attitude toward families who choose to keep their babies and help them reach their full potential is very disconcerting. This eugenic and utilitarian mentality is becoming more common and is a threat to all of us.

Thankfully, many support groups have been formed so families need not feel alone. **Prenatal Partners for Life** offers life-affirming support, information and encouragement to help families carry to term their baby with an adverse diagnosis, and support for raising their child with special needs after birth. With a wide variety of resources and by connecting families together, **Prenatal Partners for Life** has supported families in every state and 34 countries.

In addition to advocating for both parents and their baby experiencing health issues, **Prenatal Partners for Life** strives to educate and inform the world on the unique blessings and gifts children and persons with disabilities bring to their families and society. To soften hearts and replace fear with love is what **Prenatal Partners for Life** strives to do. Please contact them at 763-772-3868 or visit their website at www.prenatalpartnersforlife.org.



Death By Dehydration Is Death Without Dignity

The Matter of Nutrition and Hydration

Artificially-provided nutrition and hydration (ANH) is ordinary care which enables a person to receive adequate food and water when he or she is unable to take these by mouth. People are told it's a matter of "choice" whether they accept or refuse ANH. But this is a matter of life and death.

Inserting a feeding tube into the stomach or intestines is a life-saving procedure for a person who has a working digestive system but is unable to eat by mouth. Tube-feeding is not burdensome, costly, or difficult to manage. People insert feeding tubes at home every day and many people who depend on ANH go to work or school, play sports, and live normal lives.

Food and water taken by mouth or through a feeding tube is routine *ordinary care* that every person needs to stay alive. Doctors have a moral obligation to provide their patients with ordinary care.

Just Plain Common Sense vs. Just Plain Evil

There are situations in which providing nutrition and hydration is no longer morally obligatory. For instance, when the body is no longer able to absorb nutrients and fluids or when their provision will physically harm a patient, it is medically appropriate to stop administering nutrition and hydration while continuing to provide whatever care is necessary for the patient's comfort. In such circumstances, the cause of death will be the patient's disease or injury, not starvation and dehydration.

With these exceptions noted, ANH accomplishes the exact purpose for which it is given—it sustains life. Stopping it, then, is nothing more than intending to cause the patient's death.

Also, death by starvation and dehydration is often totally non-voluntary. At other times, it is supposedly voluntary because patients have checked a box refusing "life-sustaining procedures" in their Advance Directive or a facilitator has checked "no artificially administered nutrition and hydration" on a POLST form. (See "An Advance Directive..." page 3; and "POLST," page 4.) In recent years, death caused by withdrawal of food and fluids while medically sedated has become a "choice" available to patients who want to die. This is called voluntary stopping of eating and drinking (VSED) and is, in essence, medically-facilitated suicide.

The Brutality of Death by Dehydration¹

"Death with Dignity" is the bumper sticker slogan of the "right to die" movement. There is no way to dignify death by dehydration, which takes from 1-3 weeks and is a brutal experience for both the patient and those keeping watch. The patient's mouth dries out and lips and tongue crack and bleed; the lining of the nose dries out and bleeds; skin becomes dry and scaly; urine becomes highly concentrated, burning the bladder; the stomach lining dries out, causing dry heaves and vomiting; brain cells dry out, causing convulsions; thick secretions plug the lungs as the respiratory tract dries out; and heart muscle is consumed as the body searches for protein and finds it in muscle tissue. Finally, the patient dies.

Healthcare Professionals Who Refuse to Kill are Heroes

Dedication, compassion and high moral standards are sometimes tested when a doctor or nurse refuses to dehydrate a patient to death. Conscientious physicians and other healthcare professionals need support and protection for their conscience rights.

Dr. Allen Jay, a California cardiologist, refused to withdraw the feeding tube from a patient with dementia, 91-year-old Anna Hirth, at her daughter's suggestion that he let her "die with dignity." Dr. Jay thought that "removing her feeding tube would lead to an excruciating death." The daughter went to court. A Superior Court judge ordered Dr. Jay to remove Anna's feeding tube or find a doctor who would. Dr. Jay felt that to obey "would be to betray the trust" placed in him by his patients, so he defied the order. He was supported by the staff of Anna's nursing home and his fellow physicians. The judge next amended his order, allowing the daughter to move her mother. She took Anna from the nursing home to an undisclosed location. Nine days later, Anna was dead.²

Men and women like Dr. Jay will continue to make the practice of medicine a noble profession. They are heroes.

1. A person who is denied both nutrition and hydration will succumb to dehydration, not starvation. However, the process of starvation is equally miserable and enhances organ (especially kidney) failure, which in turn speeds up dehydration.

2. "The Judge Ordered Me to Kill My Patient," Julie Grimstad, *CRTI Report*, 09/1987.

Interviewing A Hospice Agency:

What Questions Should I Ask?

A hospice which respects the sanctity of life and truly abides by the founding principles of hospice—maintain dignity, increase quality of life, and provide comfort and pain control—can be trusted as a safe haven for patients in need of expert end-of-life care. In order to ensure full understanding, patients and families must do their homework by asking questions and getting a copy of the answers in writing (as any marketing or sales expert will tell a family what they want to hear).

Hospice programs are independent from one another and the services provided are not the same. It is essential you *interview* a hospice *prior* to signing on for care and allowing them into your home. When seeking hospice care, keep in mind your values should come first and must never be compromised.

1. What is the “mission” or “business statement” of the hospice?
2. Is the hospice non-profit or for profit?¹
3. Is the hospice pro-life? If yes, is this evidenced on the website, in brochures, mission, etc.
4. Is the hospice licensed by the state?
5. Is the hospice Medicare certified?
6. Has the hospice ever committed insurance fraud? *Google the name of the hospice and Medicare fraud.*
7. How many counties does the hospice serve?²
8. Can I meet or speak by phone with the hospice administrator *prior* to hospice admission?
9. Can I meet the staff who will be providing care *prior* to admission?
10. What types of services are provided? How often will each of these services be provided to me (or my loved one)? *Get these important details in writing.*
11. Will services be provided by the same individuals throughout the course of my care?
12. What kinds of support are available to my family/caregivers?
13. 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?
14. What do hospice volunteers do? Am I eligible for volunteer services?
15. Can the hospice provide care in a nursing home or personal care home/assisted living?
16. Must someone be with me at all times?
17. Must I commit to a DNR (Do Not Resuscitate) status?
18. Can I receive IV fluids and tube feedings?
19. What is the hospice’s position regarding Terminal Sedation (also called Palliative Sedation)?
20. Will I receive a bill for expenses not covered by insurance?
21. What should I do first if I am having a problem with the care my hospice is providing?
22. What should I do if I feel the hospice hasn’t addressed my concerns adequately?

1. Most 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 keeping 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.

Stealth Euthanasia Warning:

WATCH OUT FOR MISUSE OF OPIOIDS AND SEDATIVES

Every day terminally ill patients die naturally from their illnesses. These patients oftentimes are sedated and given opioids or other pain relieving drugs as needed to keep them comfortable and as pain-free as possible while they are approaching death. This is not euthanasia.

Euthanasia is an action or omission which, of itself or by intention, causes death in order to eliminate suffering. Hastening death, by neglect or intention, while pretending to provide appropriate end-of-life care is called “stealth euthanasia.”

When clinically unnecessary doses of opioids or extreme increases in dosage are administered with the intent to hasten death, it is stealth euthanasia. *The adverse effects of a clinical overdose conveniently—for the perpetrator—mimic some of the signs and symptoms of the end-stage of a terminal illness, making a cover-up easy.*

Deep continuous sedation (otherwise known as “terminal sedation,” “total sedation,” “palliative sedation,” etc.), while withholding food and fluids in order to cause death by dehydration, is also stealth euthanasia. Sometimes deep sedation is done to increase the level of patient acuity¹ as a means to bill for a higher level of care or make a patient appear to be in need of hospice services. This is Medicare fraud and, when the patient dies as a result, it is stealth euthanasia as well.

Doctors who do not recognize the sanctity and inviolability of every human life cannot be trusted to safely treat you or your loved ones.

The difficulty facing patients, families and healthcare agents is that they do not know how to discern which healthcare providers can be trusted to care and never to kill. It is crucially important, therefore, that they question the advice, orders, and actions of health care providers whenever they feel that something is not right. If you are unsure what to do, please call the PHA. We have physicians and nurses willing and ready to provide reliable pro-life healthcare advice.

(Also read “Interviewing a Hospice Agency,” pg. 12 and “Pain Management,” pg. 14.)

1. “Patient acuity” is a measure of the intensity of care required by a patient, ranging from minimal care to intensive care. Patient acuity determines how much the hospice is reimbursed for providing care.

Your Doctor's Ethics

It is incumbent upon patients to explore the ethical principles of their doctors. Do they uphold the sanctity of life from conception to natural death? Do they understand that treatments can be deemed burdensome, but human life is never burdensome? Do they view nutrition and hydration as ordinary care as long as a patient can derive a benefit from it? Do they reject all justifications for intentionally causing the death of their patients?

If your physician does not answer unequivocally “yes” to each of these questions, can you really trust him with your life?

Case in Point

December 2013

A Minnesota woman, now in her late 50s, was diagnosed with Multiple Sclerosis at age 28. Recently admitted to a hospital suffering from pneumonia, one of her lungs collapsed when a physician attempted to drain fluid from it. After a week, she still was not responding to antibiotics. The physician suggested that her husband might want to let her die. Shocked that a doctor would suggest such a thing, her husband said no. She began recovering the next day and is now home.

Comment: Medical advice for patients who are chronically ill or disabled is frequently based on a biased “quality of life” standard. This is both unjust and unethical. Physicians have a profound obligation to regard every patient as worthy of their best efforts to protect and preserve the patient’s life and never to extinguish hope, for there is no greater medicine than hope.

Pain Management: A Primary Purpose Of Medicine

Pain management in the care of patients, especially in the care of patients approaching death, is both one of the greatest challenges of medicine and one of the primary purposes of medicine.

Treating pain requires doctors to possess current knowledge about drugs and their proper uses. Doses exceeding what is minimally necessary to significantly lessen or eliminate the patient's pain should be avoided. In other words, by intending to treat pain and pain alone, the ethical provider administers only the doses that are necessary to achieve this goal. The ethical healthcare provider avoids unnecessary sedation and never intends to shorten life.

It is a physician's profound obligation to treat pain so patients may live out their final days in a dignified manner. There is also a professional duty to afford patients as much awareness as possible. The treatment of pain should not render the patient completely unable to communicate and should preserve, as much as possible, the patient's ability to interact with others.

The physician has another important duty—to provide patients who are in the throes of serious illness the opportunity to properly order and make right their relationships with God, family and friends. At times there may be circumstances where it is not possible to treat pain or other symptoms (e.g., agitation, anxiety, fear) effectively without sacrificing the patient's awareness and ability to communicate. However, good physicians treat with the objective of maintaining the patient's ability to communicate. This approach, which is both proper and just, has been a standard goal of pain and symptom management for many years.

The author, Ralph A. Capone, MD, FACP, is board-certified in Hospice and Palliative Medicine and Internal Medicine

For more information about appropriate pain management, contact the Pro-life Healthcare Alliance.

Case in Point

On January 11, 1996, Steven Fletcher hit a moose while driving in Manitoba, Canada. His neck snapped forward, leaving him paralyzed from the neck down. In 2004, Mr. Fletcher became Canada's first quadriplegic MP. "I was told if I were to live, I'd be institutionalized, but I don't think anybody thought the institution would be the Parliament of Canada," he quipped.

He stated, "It seems contradictory to say that my life is brutal and it's not a tea party and then say I like my work and find moments of joy in each day. But I don't think it is. ... We have to live with what we're handed, like it or not, and do the best we can."

Read: *What Do You Do If You Don't Die: The Steven Fletcher Story*, by Linda McIntosh

Source: Bea Vongdouangchanh, *The Hill Times: Canada's Politics and Government Newsweekly*, 12-1-08.

Pain Control

Q & A

Why is pain control important?

Pain and the fear of unbearable pain are common for many patients burdened by chronic illness. These are even more acute when the end of life seems near. Fear of uncontrollable pain is a reason some people favor euthanasia and physician-assisted suicide. Physicians have a duty to reassure patients that their pain can and will be treated. Furthermore, when pain is left untreated, it can lead to adverse effects on appetite, sleeping patterns, energy levels, mood, ability to work and relationships with loved ones, friends and God.

What if my doctor cannot control my pain?

Pain treatment is a specialized field of medicine. All physicians may not have the skills or competence to use analgesic drugs to their maximal benefits while minimizing their side effects. If your doctor does not treat your pain effectively, find a physician or healthcare facility that focuses on diagnosis and management of pain.

What is the “best way” to control pain?

There is no single “best way” to control pain. Whatever works for you is the best way to control *your* pain. Tell your doctor about your pain—how it feels and where it is. Most pain can be relieved safely and rapidly by drugs administered by mouth or through other routes (e.g., the skin) or more invasive means, including nerve blocks. Chemotherapy and radiation therapy directed at specific tumors to reduce their size often result in pain relief.

Will I become addicted to/develop a tolerance to pain medication?

The goal of pain management is to control pain on a continuing basis as a disease (e.g., cancer) progresses. When opioids (such as morphine) are given to relieve physical suffering, fear of addiction should not be an obstacle to their use. Addiction is a psychological condition of drug dependency and is not likely to occur in situations genuinely requiring pain control.

The ability of a given dose of pain medication to relieve the same degree of pain decreases over time. This “tolerance” occurs as the pain receptors “get used to” a specific dose. To treat a patient effectively, it is often necessary to gradually increase the dosage. Pain control needs may also increase as the underlying tumor enlarges, inflaming more tissue and nerves. A physician competent in pain management should be able to recognize all these factors and treat the patient in the most effective way.

Will pain medications cause me to sleep a lot?

Pain may cause you to be unable to sleep. Effective pain control will allow you to catch up on lost sleep. However, with continuing doses, you should soon be able to carry on normal activities. Prolonged sleepiness/sedation is most likely caused by other medications, such as tranquilizers and anti-anxiety drugs.

For questions related to medication,
contact a pharmacist directly.



Patient Advocate

Would you like to learn about being a patient advocate?
Are you willing and able to cheerfully and patiently help protect
a vulnerable person? Then you are compassionate in the real
sense of the word and patient advocacy may be your calling.
Contact the PHA for more information.

www.prolifehealthcare.org
651-484-1040