

*Decisions
About the
End
of
Life...*

**Help for
Those Who
Must Decide**

Second Edition

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*One
Community's
Approach to
Health Care
Decisions
at the
End of Life*

The Pikes Peak Forum for Health Care Ethics (PPFHCE) was launched in Colorado Springs in 1996 in response to community conferences addressing “Community Values and Care of the Dying Patient.” Those conferences brought together local health care professionals (from both military and civilian settings) and representatives from the legal, religious and education professions. Joined by concerned members of the community and representatives of over 30 community agencies, PPFHCE’s scope of participants placed it in a unique position to engage the often complex and emotionally charged issues surrounding end-of-life care in our community. PPFHCE strongly believes that broadly based dialogue and careful consideration of these concerns are long overdue.

Early on, members of our community reached a clear conviction that these discussions and considerations had to be done in our own community with our own constituents and their unique concerns represented. Any community is made up of a variety of voices and views. PPFHCE provides a local forum for sharing and weighing different views and concerns relating to health care ethics and end-of-life care. The very success of the dialogue resulted in greater trust and mutual understanding. So, from 1996 to the present, the Pikes Peak Forum for Health Care has facilitated this process of dialogue and has represented our community’s concerns and priorities for end-of-life decisions.

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These guidelines are also available on the Pikes Peak Forum website and can be downloaded from <http://www.pikespeakforum.org>

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PPFHCE has benefited from the efforts of other organizations and groups; we used ideas and materials from other sources as a launch pad for our own discussions and resulting End of Life Guidelines and supporting materials. In particular, we benefited from dialogue and collaboration with a Denver based group (Colorado Collective for Medical Decisions) examining these same issues. Ultimately, we found a community that takes on the task of discussing medical decision-making at the end of life will inevitably find a voice and ownership of its own. After years of ongoing work, the Pikes Peak Forum for Health Care Ethics has succeeded in broad-based dialogue and the development of this publication. The materials from the PPFHCE depend upon one another and are intended to be distributed together and in their entirety. These materials include:

- Statement of Principles
- Discussion Guidelines for Decisions at the End of Life
- Considerations for Decision-Making Regarding Artificial Nutrition and Hydration
- Ten Frequently Asked Questions About Artificial Nutrition and Hydration
- Glossary of Terms

It is our hope these materials will be of assistance to members of the community facing health care decisions at the end of life and will serve to broaden the community discussion already under way. These guidelines and materials are meant to encourage ongoing conversation between health care professionals and patients, within families, between loved ones, and within community groups.

In 2004, in the interest of consolidating efforts, three active committees in the El Paso County health care community joined forces to create a single committee to be known as the Pikes Peak Forum for Health Care. The three committees were the Pikes Peak Forum for Health Care Ethics (previous publisher of this pamphlet), the El Paso County Medical Society's Thanatology Committee, and the Robert Wood Johnson Foundation's Rally Points Committee.

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Our community is seeking, and deserves, responsible guidelines, which will constructively and concretely assist patients, families and their health-care providers in making critical decisions with regard to medical treatment, especially at the end of life.

The following Guidelines have been developed through an intensive process of discernment conducted among a broadly representative, community-based assembly of health-care professionals, pastoral caregivers and civic organizations. We have developed the Guidelines within a framework of fundamental values and processes on which all those participating have agreed.

In developing the Guidelines, the participants have been scrupulously conscientious about the sensitive nature of our task. The ethical issues we have addressed are always complex, often highly controversial, and deserving of careful, respectful analysis.

These Guidelines are *never* to be construed as compulsory or as having the force of law. They are advisory and are not binding on any patient, proxy/surrogate decision-maker, family or health care provider. Nevertheless, the Guidelines are a significant ethical resource for persons facing critical decisions.

Our Guidelines are grounded in, and should always be interpreted in the light of, the following overarching principles:

*Statement of
Principles to
Accompany
Guidelines for
End-of-Life
Decisions*

STATEMENT OF PRINCIPLES

1. Health-care providers must do no harm to the patient.
2. Among the primary tasks of health-care providers is to continue to care even if they cannot cure.
3. Health-care providers should tell the truth.
4. The free and informed judgment made by a competent adult patient (or duly-appointed proxy/surrogate decision-maker) concerning the use or withdrawal of life-sustaining procedures should always be respected.
5. Ordinarily, the patient (or proxy/surrogate decision-maker) must give informed consent to the medical care given.
6. The religious faith and cultural heritage of the patient should be respected by all health-care providers.
7. Health-care providers must maintain confidentiality.
8. Health-care providers should offer persons in end-of-life situations whatever information is necessary and desired by them to help them understand their condition. Such patients should have the opportunity to discuss their condition and the information received with family members and health-care providers. This information can be helpful to patients not only in accepting their end-of-life situation but also in addressing what they perceive to be the morally legitimate choices available to them.

STATEMENT OF PRINCIPLES

9. Health-care providers should be aware that it is widely accepted in our community that a person has a personal moral obligation to use proportionate means of preserving his or her life. Proportionate means are those which are physiologically possible and which, in the judgment of the patient, will offer a reasonable hope of significant benefit (i.e., they will substantially prolong life or relieve useless pain) and which do not entail an excessive burden.

It is also widely accepted in our community that a person may choose not to utilize disproportionate means of preserving life. Disproportionate means are those that, in the patient's judgment, do not offer a reasonable hope of significant benefit (i.e., substantially prolonging life or relieving useless pain) or which entail an excessive burden.

10. Patients' pain and symptoms should be controlled so that they may die comfortably and with dignity, and in the place where they wish to die.
11. Health-care providers, and our community, should recognize that the field of Medical Ethics does have valid general principles. At the same time, it is flexible because these general principles must be applied to individual patients who have different needs, beliefs and value systems.

Discussion Guidelines for End-of-Life Decisions

Modern medicine has achieved many good and important goals, but new challenges continually arise. Our Colorado communities deserve responsible guidelines which will constructively assist treatment, especially at the end of life. Indeed, many hospitals and other agencies have published discussion guidelines and principles for their own organizations. The Pikes Peak Forum for Health Care Ethics Discussion Guidelines (or Guidelines) are an attempt to distill the best thoughts contained in these efforts and discussions in communities across our State with the goal of attaining a concise consensus.

These Guidelines have been developed through an intensive process involving broadly representative, community-based assemblies of healthcare professionals, ethicists, legal experts, pastoral care givers, civic organizations, advocacy groups and concerned citizens in both Denver and Colorado Springs. Having first developed draft guidelines in their own communities, the Colorado Collective for Medical Decisions (Denver) and the Pikes Peak Forum for Health Care Ethics (Colorado Springs) then collaborated in a process aimed at reaching a genuine and reasonable consensus. What follows is the product of many months of dedicated joint effort.

It is crucial to note that these Guidelines are *never* to be construed as compulsory. They are educational and advisory only; they are not law. They are offered to patients, families and care givers as a reliable ethical resource to use when approaching critical healthcare decisions. Our hope is that these Guidelines will offer greater clarity and better understanding about the complicated choices we face, and will assist everyone in reaching sound and sensitive decisions at the end of life.

GUIDELINE I: APPROPRIATE END-OF-LIFE CARE

Medical care for a person of any age who is approaching the end of life, who has an irreversible disease or whose condition is terminal, should emphasize palliative/comfort care, including control of pain and meeting other personal needs.

GUIDELINE II: PALLIATIVE/COMFORT CARE

In addition to other medically indicated treatment, health care professionals and the public should recognize the need for palliative/comfort care and encourage its timely use. Each hospital and extended care facility should provide, or provide access to, palliative/comfort care.

GUIDELINE III: DECISION-MAKING AND SHARED RESPONSIBILITY

Hospitals and extended care facilities should encourage nurses, social workers, physicians and chaplains to discuss medically appropriate end-of-life care with patients, families, proxy/surrogate decision-makers and other health care professionals. The patient or proxy/surrogate decision-maker has authority to accept or refuse medically indicated treatment, and to seek a second opinion, and to seek different care providers.

GUIDELINE IV: CARDIOPULMONARY RESUSCITATION

Cardiopulmonary Resuscitation (CPR) should not be performed when the patient or proxy/surrogate decision-maker has given an Advance Medical Directive that CPR is not desired, or when the patient or proxy/surrogate decision-maker has otherwise clearly indicated that CPR is not desired. CPR is not appropriate when survival is expected to be extremely unlikely. CPR is not medically appropriate for an individual with severe, progressive and irreversible brain disease.

GUIDELINE V: SEVERE, PROGRESSIVE, IRREVERSIBLE BRAIN DISEASE AND THE PERMANENT VEGETATIVE STATE

Treatment for persons of any age who are appropriately diagnosed in a permanent vegetative state, or are approaching the end of life with severe progressive, irreversible brain disease, should emphasize palliative/comfort care instead of life-sustaining intervention.

GUIDELINE VI: DIALYSIS

Short-term dialysis is not medically appropriate when significant benefit is expected to be extremely unlikely. Long-term dialysis should not be used for persons in a permanent vegetative state, or for persons with severe, progressive, irreversible brain disease.

GUIDELINE VII: ARTIFICIAL NUTRITION AND HYDRATION

Artificial Nutrition and Hydration (AN&H) may be utilized to sustain a patient when normal ingestion and digestion are not possible. AN&H may be used in both short-term and long-term situations. AN&H may not be medically appropriate in every medical circumstance. It may be withheld or withdrawn when, in the patient's or proxy/surrogate decision-maker's view, either there is no apparent significant benefit, or it would impose a disproportionate burden. Further discussion on AN&H follows on page 17.

GUIDELINE VIII: PATIENT AUTONOMY, PHYSICIAN AND INSTITUTIONAL INTEGRITY, AND MEDICAL FUTILITY

Respect for patient autonomy entails that patients or their proxy/surrogate decision-makers have the right to limit or refuse treatment, even when recommended by the responsible physician. On the other hand, “patient autonomy” is not a trump principle. Other moral considerations may be relevant when a patient or proxy/surrogate decision-maker requests treatment judged by the responsible physician to be medically inappropriate or futile (see medical futility). All parties are encouraged to work together toward a mutually acceptable resolution. When the physician’s or institution’s integrity are in conflict with the patient’s or proxy/surrogate decision-maker’s requests for medical interventions, the process included here is suggested as being fair and just for all.

- 1) The responsible physician should provide to the patient or proxy/surrogate decision-maker an explanation of the diagnosis, its prognosis, and the reasons why the requested intervention is medically inappropriate. Palliative/ comfort care should be offered along with institutional resources for physical, emotional and spiritual assistance.
- 2) Failing agreement, the responsible physician should obtain a second medical opinion. If disagreement persists, the case should be considered by an institutional interdisciplinary body, where the responsible physician and the patient or proxy/surrogate decision-maker should present their views.

- 3) If the reviewing body agrees with the physician’s determination, then the physician’s order to limit the medical intervention will be upheld, and a plan should be developed for providing palliative/comfort care. A patient or proxy/surrogate decision-maker who does not accept this decision is free to seek a transfer to another institution and another physician.
- 4) If the reviewing body disagrees with the physician’s determination, then the order to limit the medical intervention should be reversed.

GUIDELINE IX: ADVANCE DIRECTIVES, DURABLE MEDICAL POWER OF ATTORNEY, AND PHYSICIAN ORDERS FOR LIFE SUSTAINING TREATMENT (POLST)

Ways of exercising patient autonomy include executing an Advance Directive which can be done formally by completing a common state form of a Living Will which indicates levels of treatment the competent individual selects to guide caregivers and trusted loved ones in case the individual lacks capacity and is terminal. A Durable Medical Power of Attorney is another Advance Directive which designates a specific person to make medical decisions for the patient who becomes unable to do so. The third Advance Directive in the state of Colorado is the legal document, CPR Directive, which directs emergency personnel to provide comfort measures only when responding to a cardiac or respiratory

arrest. The Physician Orders for Life Sustaining Treatment (POLST) goes further as it translates the competent patient's wishes directly into medical orders. The POLST is a standardized form, currently used in several states, but as of this printing (February 2008) not yet adopted in Colorado. It is brightly colored and easily identifiable. It is designed for patients with serious illnesses and completed by competent patients or their proxies indicating treatment preferences regarding CPR and other medical interventions. It may include a summary of the patient's medical condition. It must be signed by a physician. The POLST form is designed to accompany the patient in all health care settings. Experience with the POLST form in other states has thus far shown it makes it more likely that Advance Directives (and thus patient's expressed wishes) will be followed because POLST is a medical order and immediately available and identifiable in the patient's records.

Note: The best way to use this document is to read and discuss it with a knowledgeable health-care professional and/or qualified pastoral care provider. These professionals can help you arrive at your decision, as well as assist you with terms used in the document which may not be familiar. This document should also be used in conjunction with its companion document, "Ten Frequently Asked Questions About Artificial Nutrition and Hydration." (See page 23.)

*Considerations
for Decision-
Making
Regarding
Artificial
Nutrition and
Hydration*

Artificial nutrition and hydration (AN&H), sometimes referred to as "tube feeding," is a medical intervention to supply nutrition and/or hydration by tube, catheter or needle to patients who cannot or will not eat or drink.

The following considerations are pertinent when making decisions regarding the beginning, withholding or withdrawing of AN&H. As you can see, these considerations fall into four categories: Medical, Ethical, Moral/Religious and Legal. They may be helpful in decision-making, or to revisit a previous decision, as appropriate. While these considerations were developed for patients at the end-of-life, they may be helpful in other medical situations as well.

ARTIFICIAL NUTRITION AND HYDRATION

The consideration of these categories may take place in one or more meetings that involve the patient, family members and other interested and/or knowing parties. (For a list of possible participants, see definition of “decision-making and shared responsibility” in the Glossary.) The number of meetings necessary to consider all the pertinent information will vary according to the patient and circumstances.

The order of the following questions (Medical, Ethical, etc.) is purposeful. In some cases, the Medical category may be sufficient, while other situations may require addressing the other categories. The questions are designed to provide guidance in all circumstances: whether the patient is competent or incompetent; with or without an Advance Medical Directive or oral directions.

Following each question, you will find columns listing the options of “yes,” “no” and “don’t know.” Your answers to these questions may assist you in assessing all the relevant information in making your decision. Again, the best way to use this document is with the assistance of professionals.

ARTIFICIAL NUTRITION AND HYDRATION

I: Medical Considerations	Yes	No	Don't Know
Do the health care providers agree that AN&H is physiologically possible and <u>medically appropriate</u> for the patient?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you understand the possible <u>risks</u> and <u>benefits</u> ?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you understand the <u>prognosis</u> with <u>intervention</u> ?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you understand the <u>prognosis</u> without <u>intervention</u> ?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Will AN&H avoid causing unnecessary pain or other suffering? Will it avoid significantly adding to the physical/medical <u>burdens</u> of the patient?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Would you like to consult with an additional physician?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

ARTIFICIAL NUTRITION AND HYDRATION

II: Ethical Considerations	Yes	No	Don't Know
Does the patient have the mental capacity to make the decision?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Is there an <u>Advance Medical Directive</u> concerning AN&H?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
If not, did the patient provide any oral or written guidance concerning AN&H?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Is a <u>proxy/surrogate decision-maker</u> part of this assessment?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Will AN&H avoid significantly adding to the other <u>burdens</u> of the patient, such as emotional or family concerns?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Are the ethical views of the physician influencing the medical recommendations?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Would you like to consult with a representative(s) of the hospital ethics committee?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

ARTIFICIAL NUTRITION AND HYDRATION

III: Moral/Religious Considerations	Yes	No	Don't Know
Are you aware of the patient's moral/religious values?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
If so, are the patient's moral/religious values influencing the medical recommendations?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do the moral/religious values of the family or the <u>proxy/surrogate decision-maker</u> differ from the patient's?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
If so, are the moral/religious values of the family or the <u>proxy/surrogate decision-maker</u> influencing the medical decisions?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Are you aware of the attending physician's moral/religious values?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
If so, are the moral/religious views of the attending physician influencing the medical recommendation?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Would you like to consult with a spiritual caregiver?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

ARTIFICIAL NUTRITION AND HYDRATION

IV: Legal Considerations (may involve legal counsel)	Yes	No	Don't Know
Is the patient mentally <u>competent</u> ?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
If not, has a decision-maker been properly identified (e.g., by a <u>Durable Medical Power of Attorney</u> , <u>Health Care Proxy</u> , appointment of Guardian)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Is a legal dispute likely?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Would you like to consult with an attorney to make sure the decision meets legal requirements?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

PIKES PEAK FORUM FOR HEALTH CARE

*Ten
Frequently
Asked
Questions
About
Artificial
Nutrition and
Hydration
(AN&H)*

The following are some frequently asked questions regarding the use of Artificial Nutrition and Hydration (AN&H). Discussion of these questions may be helpful to patients, families, proxy/surrogate decision-makers and healthcare professionals. This document should also be used in conjunction with its companion document, "Considerations for Decision- Making Regarding Artificial Nutrition and Hydration." (See page 17.)

1) What is Artificial Nutrition and Hydration (AN&H)?

AN&H, sometimes referred to as "tube feeding," is a medical intervention to supply nutrition and/or hydration either by intravenous (IV) means or tube (PEG tube) to patients who are unable or unwilling to eat or drink.

2) What are the most common ways AN&H is provided?

Intravenous (IV), Peripheral or Central - A needle or catheter is inserted into a vein and fluids are infused providing nourishment and/or hydration through the circulatory system. This method of AN&H is generally provided on a short-term basis.

Nasogastric (NG) tube - A soft, pliable tube is inserted through the nose to the stomach and a nutritional liquid formula is given through the tube to provide nourishment. This method of AN&H is generally provided on a short or intermediate-term basis.

Gastrostomy (PEG) tube - A tube is inserted into the stomach and a nutritional liquid formula is given through the tube to provide nourishment. This method of AN&H is generally provided on a long-term basis. Placement of the tube requires a surgical procedure, which can usually be done under local anesthetic at the bedside.

3) *What are the medical purposes of AN&H?*

AN&H is not a required nor medically appropriate intervention in every circumstance. AN&H may be used to sustain a patient in both short-term and long-term medical situations. The purposes may include:

- Sustaining the patient when he or she cannot eat or drink due to temporary trauma, accident, disease or surgery. In these cases, AN&H may serve as a bridge, allowing for stabilization and assessment of the patient's condition;
- Sustaining the patient when he or she is unable to ingest (swallow) or digest and there is little or no likelihood of change;
- Sustaining the patient who is terminally ill and whose disease prevents ingestion and/or digestion.

4) *What are some examples of the circumstances under which health-care professionals might recommend AN&H?*

- Following surgery, treatment or a traumatic event when the ability to ingest and/or digest are interrupted;

- Patient has severe brain damage resulting in an inability to ingest;
- Patient has a disease process that causes the inability to ingest and/or digest;
- Patient has dementia or another psychological disorder, which interferes with the ability to ingest.

5) *What are the physiological benefits and potential complications of AN&H?*

When weighing the decision about whether or not to begin, withhold or withdraw AN&H, it is important to consider the goal of the intervention. Differing circumstances may lead to different conclusions about whether AN&H will assist in achieving the goal. A patient who is unable or unwilling to eat or drink may benefit from AN&H on either a short-term or long-term basis.

Possible BENEFITS may include:

- a means to provide nutrition/hydration when normal ingestion and/or digestion are not possible
- stabilization of physical status following severe trauma
- enhanced healing or stabilization of diseases
- restful healing time for a diseased or damaged gastro-intestinal (GI) tract
- a means to provide nutrition/hydration during a restoration period following surgery
- reversal of malnutrition and dehydration

Possible BURDENS may include:

- pain, discomfort or infection
 - Nose and throat irritation when AN&H is provided through a nasogastric tube;
 - Skin irritation and/or infection when AN&H is provided through a gastrostomy tube;
 - Pain at the site of the needle when AN&H is provided intravenously
- infections, ulcerations or bleeding of the stomach wall and/or GI tract
- aspiration into lungs and potential pneumonia
- interruption or impairment of liver and kidney functions
- fluid overload causing shortness of breath, need for suctioning, edema of extremities, increased urinary output and/or incontinence
- need to restrain patient to prevent pulling tubes out

6) Who makes the decision about the use of AN&H?

The patient should make the decision. If the patient is unable, the decision should be made by his/her proxy/surrogate decision-maker. While the decision lies with the patient, health-care professionals have the responsibility to provide the patient and/or proxy/surrogate decision-maker with all information necessary to make an informed decision.

7) If I am a proxy/surrogate decision-maker, what do I need to know?

- Mentally competent adult patients have a right to refuse AN&H.
- Mentally incompetent adult patients may have previously refused AN&H through an Advance Directive they executed while mentally competent.
- The proxy/surrogate decision-maker must honor any Advance Directive.
- In the absence of an Advance Directive, the proxy/surrogate decision-maker should consider any and all indications of the patient's wishes, including input from relatives, friends and others who may know the patient's wishes.
- The proxy/surrogate decision-maker should consider the patient's physical condition and prognosis.
- The proxy/surrogate decision-maker should base the decision regarding AN&H on the needs of the patient. AN&H should not be provided merely for the convenience of the caregiver.
- A patient or proxy/surrogate decision-maker may decide to withhold or withdraw AN&H in order to allow the natural dying process to unfold. However, AN&H should not be withheld or withdrawn for the purpose of intentionally ending the patient's life.
- A patient who is able to ingest and digest food and water should receive this sustenance by mouth.
- The proxy/surrogate decision-maker is responsible for monitoring and assuring that the patient receives thorough, medically appropriate and dignified care

including feeding, personal hygiene and a clean environment.

- A primary consideration for the proxy/surrogate decision-maker is to honor the patient's views regarding the value of life, to the degree those views are known. The less known about the patient's values, the more the proxy/surrogate decision-maker may ultimately have to rely on his or her own reasonable judgment regarding the best interests of the patient.

8) ***When is it permissible to withhold AN&H or withdraw AN&H after starting it?***

It is permissible to withhold or withdraw AN&H when:

- the patient's death is imminent, expected within days, weeks or perhaps months
or
- the patient's physical condition is irreversibly deteriorating beyond a reasonable hope of recovery
and
- AN&H will be or is, in the view of the proxy/surrogate decision-maker, excessively burdensome to the patient.

It may be medically appropriate to begin AN&H at a given time; it may also be medically appropriate to discontinue it at a later time. In either case, the principles which guide the decisions are the same. However, it may feel more difficult to withdraw AN&H than to withhold it.

9) ***What happens physiologically to a person if they do not receive AN&H?***

- When an individual is in an advanced disease state: that condition causes human body systems to slow down and eventually stop. In the absence of food and water, mouth secretions diminish, urinary output lessens, swelling diminishes, consciousness decreases, and metabolic changes act as a natural anesthesia (pain killer) to the nervous system. The sensation of hunger subsides quickly. Thirst is managed by thorough mouth care and assistance with fluids as long as possible.
- When an individual is not in an advanced disease state: the absence of food and water causes human body systems to slow down and eventually stop.

10) ***Is a decision by a proxy/surrogate decision-maker to withhold AN&H, or to withdraw AN&H, equivalent to "starvation" of the patient?***

In approaching this question, a person must sensitively consider: With whose interests and values am I chiefly concerned? Is the provision of AN&H burdensome to the patient, to the family or to the proxy/surrogate decision-maker?

What is most important is the intention of the decision-maker. Certainly, one may make a proper, ethical decision to withhold or withdraw AN&H based upon the conviction that the treatment has become disproportionate or excessively burdensome. This would be a

decision to allow death to occur naturally, due to the underlying disease process

By contrast, many in our community - and many professional ethicists - would be gravely concerned about any decision by a caregiver or proxy/surrogate decision-maker to withhold or withdraw AN&H that was based upon an intention to directly bring about the person's death, before it occurs naturally. Similarly, there would be concern about a decision based solely upon the needs or convenience of the caregivers or the decision-maker.

This is an emotionally charged issue, especially because the proxy/surrogate decision-maker wishes to minimize any pain or discomfort for the patient. It will be helpful for the decision-maker to be mindful that, as discussed in #9 above, the actual physiological effects of withholding or withdrawing AN&H do not typically involve increased pain or discomfort. In the absence of AN&H, caregivers can ably manage thirst and other symptoms. The body's systems will slow down, diminishing the sensation of hunger, and providing a natural anesthesia.

Physicians, other health care professionals and a knowledgeable chaplain or spiritual caregiver should assist the decision-maker in reaching a better understanding of these complex issues. Remember: the decision-maker is entitled to good counseling in approaching this decision.

Definitions for underlined words in the text are found in the Glossary of Terms.

Glossary of Terms

A

ACUTE CARE – care for an illness or condition characterized by sudden onset, marked symptoms, and short course.

ADVANCE MEDICAL DIRECTIVE – a legal document prepared when an individual is competent and able to give informed consent. It provides guidance to the health care team if the person is no longer capable of making decisions. An advance directive may specify medical treatment to which the individual consents or refuses, designate a proxy/surrogate decision-maker, or both.

ARTIFICIAL NUTRITION AND HYDRATION (AN&H) – sometimes referred to as “tube feeding,” is a medical intervention to supply nutrition and/or hydration either by intravenous (IV) means or tube (PEG tube) to patients who are unable or unwilling to eat or drink. AN&H is most commonly administered through the following three methods: Intravenously through a catheter inserted into the vein, through a Nasogastric (NG) tube inserted through the nose to the stomach, and through Gastrostomy (PEG) tube inserted into the stomach.

ARTIFICIAL VENTILATION – the use of mechanical or manual means to replace normal respiration.

ASPIRATION – the inhaling of fluid or solids into the airways or lungs; most commonly causing aspiration pneumonia.

B

BENEFIT – any result of a medical treatment or procedure that sustains or improves a patient’s life and/or health.

BURDEN, BURDENSOME – any result of a medical treatment or procedure that has a negative impact on a patient’s life and/or health.

C

CARDIOPULMONARY RESUSCITATION (CPR) – a basic emergency procedure for life support, consisting of artificial respiration and manual external cardiac massage. A range of technologies used to restore and maintain blood circulation and breathing in a person who has experienced cardiac and/or respiration arrest.

CHRONIC CARE – care for an illness characterized by extended duration or frequent recurrence, and slow development.

COGNITIVE – having the mental ability to be aware of objects, thoughts and perceptions, including all aspects of perceiving, thinking, and remembering.

CPR – see Cardiopulmonary Resuscitation

CPR DIRECTIVE – a document in which a competent person expresses in advance his or her wish not to receive CPR in the event that he or she becomes incompetent in the future (see Cardiopulmonary Resuscitation)

COMPETENT – having the mental ability to understand the nature and effects of one’s decisions.

CONFIDENTIALITY – the holding in strict confidence information obtained about the person and his or her circumstances.

D

DECISION-MAKING AUTHORITY – the authority to make medical or other decisions regarding a person. This could be competent adults or their proxy/surrogate decision-maker appointed by means of a durable medical power of attorney, medical proxy, guardianship proceedings, or by other legally recognized means.

DECISION-MAKING AND SHARED RESPONSIBILITY – the patient or proxy/surrogate decision-maker has final decision-making authority. Hospitals and extended care facilities should encourage nurses, social workers, physicians and chaplains to discuss medically appropriate end-of-life care with patients, families, proxy/surrogate decision-makers and other health care professionals.

DEMENTIA – the loss of previously attained intellectual ability; a severe, progressive and irreversible brain disease.

DIALYSIS – process of artificially cleaning the body when the kidneys are unable to perform this function. Dialysis can be short term as in acute renal failure when the kidneys are expected to return to normal functioning, or long term as in permanent renal failure.

DIGEST, DIGESTION – to dissolve or break down food into simpler chemical compounds so the body can absorb nutrition.

DISPROPORTIONATE MEANS – medical treatments or procedures which would not be ethical because they would be physiologically impossible or their burdens outweigh their benefits.

DNR – see Do Not Resuscitate

DO NOT RESUSCITATE (DNR) – strictly speaking, this means that CPR will not be administered. This is a decision which should be made by the patient (or proxy/surrogate decision-maker) and the physician.

DURABLE MEDICAL POWER OF ATTORNEY – a legal instrument empowering a designated person to act on another's behalf. Unlike traditional power of attorney, the "Durable" power does not lapse if the person who executed it becomes incompetent. Originally intended to permit financial or property transactions, durable powers of attorney are also used to delegate medical decision making authority.

E

EDEMA – the abnormal and excess accumulation of fluids in body tissues.

END OF LIFE, END-OF-LIFE CARE – the care of a patient whose medical condition indicates the final stages of life; care that is medically appropriate to their needs and consistent with their wishes; care may be curative or palliative, involving a wide range of medical and supportive services.

ETHICS – the rules or principles which define, guide and lead to right conduct; relating to the moral action, conduct, motive or character.

ETHICIST – a person in the field of medical ethics who is learned in the application of ethical reasoning to issues raised by medical treatments, interventions, technologies and the life sciences.

EXTENDED CARE FACILITIES – a facility for the care of patients who do not need hospital care but still need medical care or assistance in daily living needs (ranges from assisted living facilities to skilled nursing care).

EXTRAORDINARY MEANS – an aggressive medical procedure in a dangerously ill patient which in itself may endanger the patient but which has a possibility of being successful.

F

FULL CODE – in the event of cardiopulmonary arrest, all available medical procedures are used to reestablish cardiopulmonary function.

G

GASTROINTESTINAL TRACT – oral structures, pharynx, esophagus, stomach, liver, pancreas, small and large intestines.

I

INCAPACITY, INCAPACITATED, INCAPABLE – a legal designation recognizing that someone no longer has the mental ability to make decisions.

INCOMPETENT – lacking the mental ability to understand the nature and effects of one's decisions.

INCONTINENCE – loss of urinary or anal control

INFORMED CONSENT – a person’s agreement to allow something to be done to him or her (such as surgery) that is based on a full disclosure of facts needed to make that decision and the competence to understand.

INGEST, INGESTION – to take in, to swallow for the purpose of digestion.

INTERVENTION – a medical procedure performed to alleviate a medical condition.

L

LIFE-SUSTAINING TREATMENT – a medical treatment that is intended to prolong life.

LIVING WILL – a document in which a competent person expresses in advance his or her wishes about certain life-sustaining treatments in the event that he or she becomes incompetent in the future.

M

MEDICALLY APPROPRIATE – medical procedures which are indicated for the treatment of specific conditions.

MEDICAL FUTILITY – when a medical treatment or procedure will not achieve its physiological objective, and so offers no physiological benefit to the patient.

METABOLIC – relating to the chemical and physical processing which occur within the body.

N

NO CODE – in the event of cardiopulmonary arrest, no medical procedures are started.

P

PALLIATIVE/COMFORT CARE – the active, total care of patients whose disease is not responsive to curative treatment; control of pain, of other symptoms, and of psychological, social and spiritual problems is paramount.

PERMANENT VEGETATIVE STATE – a continuing and unremitting clinical condition of complete unawareness of the self and the environment accompanied by sleep-wake cycles with either complete or partial preservation of hypothalamic and brainstem autonomic function. The diagnosis is established if the condition is present for one month after acute or nontraumatic brain injury or has lasted for one month in patients with degenerative or metabolic disorders or developmental malformations.

PIKES PEAK FORUM FOR HEALTH CARE ETHICS – formed in 1996 to assist patients, their families, physicians and other health care professionals in making reasonable and medically appropriate decisions in difficult situations. The group includes representatives from the medical, legal, faith, human services and cultural communities in the Pikes Peak region.

POLST Physicians Orders for Life Sustaining Treatment – Signed physician orders regarding patient wishes for resuscitation status, feeding tubes, and other treatments at end-of-life. these orders are portable and are to accompany the patient to each health care setting.

PROGNOSIS – the prospect of recovery from a disease or condition.

PROPORTIONATE MEANS – medical treatments or procedures which would be ethical because they are physiologically possible and their benefits outweigh their burdens.

PROXY – a person legally designated, not necessarily by the patient, to make medical decisions for the patient when he or she is unable to do so.

PROXY DECISION MAKING – an authorization given by one person for another (see Decision-Making Authority.)

R

RESUSCITATION – see Cardiopulmonary Resuscitation (CPR)

RISKS – the possibility of an adverse reaction or complication.

S

SECRETIONS – solid, liquid or gasses produced by cellular or glandular activity

SEVERE, PROGRESSIVE AND IRREVERSIBLE BRAIN DISEASE – examples include dementias such as Alzheimer's disease, Huntington's disease and Parkinson's disease, and non-dementia degenerative diseases such as amyotrophic lateral sclerosis (ALS), also known as Lou Gehrig's disease.

SUBACUTE CARE – care provided to a patient whose condition is of moderate duration or severity.

SURROGATE; SURROGATE DECISION-MAKER – an agent, one who functions for another. A person who is designated to make decisions on behalf of a person who is incapable of making decisions.

SUSTAIN – to nourish, support, maintain or continue.

T

TERMINAL – diagnosis of an illness that has a predictable fatal progression.

U

ULCERATION – a lesion on the surface of the skin or mucous membrane.

V

VENTILATOR – a mechanical device that helps the patient to breathe. Also known as a respirator.

W

WITHDRAW – to remove or discontinue use or administration.

WITHHOLD – to refrain from initial use or administration.

