Points to remember

- Understand your prognosis and your wishes. Communicate them clearly.
- Appoint a patient advocate with a Durable Power of Attorney for Health Care form which clearly spells out your wishes.
- You have a right to refuse unwanted or burdensome medical treatments.
- Pain control can be done effectively in practically every situation.
- Pain medications should be used incrementally to treat your symptoms—as much as needed—but not purposefully to hasten your death.
- The key to good pain control is communicating with your doctor.
- Food and fluids are necessities of life, not medical care. They should not be taken away for the purpose of causing death by starvation or dehydration.

Food and fluids should be considered a given for acute conditions—unless there is a short-term special situation, e.g. fasting before surgery. Even in special cases, providing intravenous fluids should be standard. Once the acute situation is resolved, an assessment can be made to see if longer-term assisted feeding is required.

At the very end of a terminal illness it is not unusual for some patients to reach the point of having no appetite or their body begins shutting down, leaving them unable to process food or fluids. Food or fluids might put more strain on body systems and would serve no benefit in those cases. The crucial question to ask is whether the underlying illness will cause death, or will withholding of food and fluids intentionally cause death by dehydration or starvation.

A chronically-ill patient with a long-term need for assisted feeding is the most vulnerable to pressures to remove food and fluids to intentionally cause their death. Again, the distinction between being in a chronic state rather than an end-stage terminal condition is crucial. Continuing to provide nutrition, when a feeding tube is working effectively, cannot be deemed "futile" on the basis that it doesn't cure the underlying condition. If a patient is not within days of dying, nor suffering other medical complications, a decision to withhold food and fluids is intended to cause their death.

ADVOCATES FOR BETTER CARE

P.O. Box 901 | Grand Rapids, MI 49509-0901
(616) 532-2300 | RTL.org

END-OF-LIFE CARE & DECISIONS

Positive Care or Euthanasia Pitfall?

HOSPICE

PAIN MANAGEMENT

MEDICALLY-ASSISTED FEEDING

Sometimes making medical decisions is not easy

While modern medical technology offers many opportunities for extending life or even curing once-fatal illnesses, it can sometimes make decisions complicated. A treatment can be ideal for one patient and inadvisable for another based on unique circumstances. It can leave us with difficult questions like, "How do I know when to accept or refuse a treatment?" or, "It is time to enter hospice care?"

In this era of medical cost concerns we must also guard against pressures and decisions that can lead to euthanasia. Two medical issues that most commonly present a challenge are the use of powerful pain control medications and medically-assisted feeding.

If I face a difficult medical decision, where do I start?

First ask: "Is it an acute, chronic or terminal condition?" An acute situation is serious but usually offers a chance to return to your previous state of health. Chronic conditions are long-term that may or may not get worse over time. A terminal condition is one which is likely progressing toward death regardless of available treatments. These differing levels of illness provide some parameters for good decision-making.

Second, determine if the available treatment options can produce a desired result without placing an unacceptable burden on you. You are not obligated to accept unwanted medical treatment which may have side effects you view as worse than your condition.

Is hospice care right for me?

Hospice care is a holistic approach to caring for a terminally-ill patient. It is a great blessing when done correctly. The core principle of hospice is to neither hasten nor prolong the dying process once curative treatment has ended. Hospice is there to meet your physical, emotional, relational and spiritual needs, allowing you to "live with dignity until death." A hospice team of doctors, nurses, a social worker and a spiritual advisor work with you and your family to set the course of your care. Hospice teams know dying is more of a process rather than an event.

Can I count on pain medications to really provide a peaceful death?

Once you enter a terminal stage of illness, pain management can become more aggressive with the goal of making you as comfortable as possible. Controlling pain and other symptoms without trying to cure the underlying condition is often called "palliative care."

Because the body can become tolerant of pain medications, it is not unusual to increase dosages over time. When done properly, incremental use of pain medications can control pain in most cases without leaving you addicted, in "a fog," or completely sedated.

You should never be in unrelenting pain. Even in a worst-case scenario for a patient near death, providing pain relief to the point of sedation can be legitimate and necessary. Do not hesitate to request whatever is needed.

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We must be vigilant, however, that narcotics are not used until needed. Pain management should be directed by your need for relief. Unfortunately, there is a growing trend of overusing narcotics in terminal patients with little or no regard for whether it prematurely causes a patient's death.

Can I manage long-term chronic pain without addiction?

Pain management techniques are continuously improving. If you are experiencing intolerable pain, you need to do some research and then request every option be explored until an effective treatment is found. Pain control is not just about drugs; there are different kinds of pain, generated in different ways, so different types of treatments may be needed and tailored to you. Health providers are increasingly sensitive to the problem of addiction when treating pain. Ongoing communication with your doctor about your body's response to pain treatment is the key.

What about tube feeding? What if I am terminally ill or in a coma?

Providing food and fluids—particularly via tubes for those in a coma or "vegetative state"—is a complex and emotionally intense area of medical decision-making.

It's important to remember that food and fluids are not a "medical treatment"; they are basic necessities of life and should be considered an automatic part of your care. Even helping someone eat is becoming controversial. Some medical ethicists are now suggesting that spoon feeding by mouth is the "artificial administration of nutrition and hydration."

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