### What about assisted suicide?

With the legalization of physician-assisted suicide in some states, it is essential to choose physicians, health care providers, hospitals, nursing homes, assisted living facilities and hospices, that you can trust with your life—and the lives of your loved ones. Be sure to ask if your health care provider or institution intentionally hastens the deaths of patients or participates in assisted suicide. Giving vulnerable patients lethal drug overdoses instead of the support they need is not compassionate care.

### Decision-making and Advocacy

In all these health care decisions, it is essential to have a compassionate and informed advocate. Family members and friends should know that health care is changing. Those seeking health care are consumers, requiring them to be strong, clear, advocates for themselves or for the needs of loved ones in their care. One's personal physician used to be involved in treatment questions no matter where the patient was. Now, the treating physician may be unfamiliar with the patient who is under his or her care—which is why the patient will need a family member or friend who may need to make decisions if the patient is unable.

### In Conclusion

In this present climate, the dignity of human life has all too often been reduced to more pragmatic evaluations of costs, risks and benefits. Caregivers must become tireless advocates for the vulnerable. They must be unafraid to ask questions and, if necessary, to be aggressive in protecting the rights of those in their care. We must work together to protect frail loved ones from being left alone to face illness, aging, and death.

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# A Simple Guide for Medical Care and Decision-Making

***"Making good medical decisions can be quite a challenge. It can even be tough to figure out which questions to ask, much less what to do next. This brochure was invaluable in helping me care for my mother…"* Lydia**

*True Compassion Advocates* offers life-affirming resources and positive alternatives to assisted suicide. For more information: www.truecompassionadvocates.org

### Medical Decision-Making

Making medical decisions can be confusing, even overwhelming. When faced with an array of medical care options, many people wonder: *What should I do? Which is the right decision?* This brochure is designed to provide seriously ill persons and their caregivers with the basic information needed to decide the best course of medical care or treatment. What follows is a simple guide for asking good questions and navigating tough medical situations.

### Power of Attorney for Health Care

Prevention works. It's always best to prevent a decision-making crisis by having a "power of attorney for health care" document drawn up *before* a health-related emergency. This allows you to choose someone who will speak for you in case you are unable.

Be sure to pick someone who will respect your wishes and have the wisdom, with medical help, to determine your best care and treatment options. Check out your states requirements for DPOA-HC (Durable Power of Attorney for Health Care). These forms aren't hard to fill out but may need to be witnessed or notarized.

Generally speaking, the patient's representative, or someone with Durable Power of Attorney for Health Care, should know the patient's history and preferences, while assisting in decision-making for care and treatment. This "attorney in fact" has the legal right to speak for that individual silenced because of illness or disability.

In the case of serious or chronic illness, it's a good idea for the patient, family, and physician to complete and have a Durable Power of Attorney for Health Care and *Resuscitate* or *Do Not Resuscitate* order (POLST form) on hand.

### What To Do In An Emergency

A completed Durable Power of Attorney for Health Care form provides emergency medical personnel with clear instructions about medical decisions and about who will speak on your behalf if you or your loved one are incapacitated.

Without documentation, in an emergency, patients will likely be automatically resuscitated (in case of heart or respiratory failure), placed on a ventilator, IV, and medications—depending on the extent or seriousness of their illness or injury—to stabilize them until a further course of action is decided. A physician should then explain the long-range health outlook and treatment options.

**Some useful questions:**

- Is the patient's condition stable or not?
- How are his/her vital signs?
- Are major organs functioning well or not?
- Is the overall health outlook for the patient positive after treatment?
- If so, what steps need to be taken?
- Or, is death imminent, with little or no hope of improvement? What happens next?

If it appears that major organs are failing and the patient's life is ebbing away, with little or no hope of improvement, comfort care is usually the best course to follow. With input from patient, family, and medical staff, decisions will be made about medical treatment, home care, or hospice care.

Don't be rushed. Be sure to take the time you need to ask good questions and make informed decisions. Get a second opinion, if necessary. Remember, your job is to advocate for your loved one and help discern the best course of action.

## Topics of Discussion Concerning Care

Questions that may arise in caring for someone in failing health include:

- The use of IVs or feeding tubes for the delivery of food and fluids
- Pain management
- Resuscitation orders in case of heart or respiratory failure
- Using of ventilators (breathing machines) to assist breathing
- Surgery
- Chemotherapy in the case of cancer
- Discharge issues in moving a patient to a nursing facility, home care, or hospice.

**How to Judge the Best Course of Action**

First, try to determine whether the ill person will be helped, or not, by whatever choice is made. In many cases the medical care offered is essential for treatment, recovery, and comfort. If a situation, or outcome is unclear, treatment may be recommended on a trial basis in order to determine effectiveness and plan what to do next.

But there are some treatments and options which go beyond normal care, which involve risks, and which may in the end be more detrimental than helpful to the patient. When such treatments are harmful or unhelpful, then keeping the patient as comfortable as possible without use of risky surgery or drug regimens might be the best course of action.

This would include keeping the patient warm, clean, as pain-free as possible, and providing breathing assistance in the form of a nasal tube for oxygen. It would include food and fluids which are administered by mouth, feeding tube, or IV—if, and only if, they are tolerated by the patient without causing other complications.

Ethics would remind us that every person is worthy of our respect, no matter the stage, condition, or circumstances of that human being's life. The seriously ill, disabled, or dying person deserves treatment and care as long as it brings him or her comfort. Any treatment which causes additional pain and suffering, while providing no hope of improvement or relief, should be avoided.

## Do Not Resuscitate Orders

Resuscitation (CPR) is performed to revive someone who has experienced respiratory or cardiac failure. For many, it is a second chance for life and essential for further treatment and recovery. In an emergency, healthy people, along with people who aren't very seriously ill, should generally choose to be resuscitated, at least initially, until the medical situation can be clarified.

There are, however, some circumstances where resuscitation may not be advisable. If a person is very seriously ill, extremely medically fragile, has a terminal disease, or is already close to death, CPR may cause additional health complications, and not offer hope of recovery. The process of getting the heart and respiration started may cause additional problems for some patients. For instance, pumping the rib cage of a very ill elderly patient could cause rib fractures, lung punctures, or other complications. And if the brain has been without oxygen, additional difficulties may arise.

The question of resuscitation is usually brought up when a patient is first admitted to a hospital or nursing home. This decision can be adjusted as the patient's condition changes. If there is a question on the appropriateness of a "Full Code" or "Do Not Resuscitate" order, ask to speak to the attending physician.

## What Is Hospice Care?

For persons who have a terminal disease with a life-expectancy of six months or less, hospice may be suggested. Hospice provides expertise in comfort care, pain control, the alleviation of suffering, and support for the patient and family members. Hospice services are covered by Medicare, Medicaid, and most insurance, and can occur at home, in a hospital, nursing home, or assisted living facility.

## Managing Pain

This is another area that causes much confusion, as far as how much or how little pain medication should be administered. In hospitals and nursing homes, every patient's pain must be measured, just like other vital signs are measured, and proper pain relief must be provided. Pain, in most cases can be well-controlled, though difficult cases may require a specialist with experience in pain control.

Be sure to be persistent in asking that pain be responded to promptly and adequately. (Sometimes it's best to place pain medication on a schedule to prevent pain.) In fact, not giving adequate medications to control pain may not only hinder healing, but could even hasten death. Increasing the dosage gradually to meet increased pain shouldn't be a cause for concern. If a patient dies while under sedation, death may have been close already.

## Breathing Assistance

Use of oxygen by nasal tube or mask can assist patients who are having difficulty breathing, lessening the effort required to breathe. Ventilators are breathing machines used following surgery, or in order to stabilize patients following serious injury or health emergency. Ventilators can be removed if they are no longer needed or are no longer helpful to the patient.

## Food and Fluids

No one, no matter whether healthy or ill, can survive long without food and fluids. Nutrients and fluids are a part of normal human care and a natural way of preserving life. This remains true whether they are provided by feeding tube, IV, spoon, cup, or glass.

But sometimes, depending on the medical circumstances (for instance, in the event of a terminal disease), a person may be no longer able to assimilate solids or liquids. The key to discern from within the particular medical context of the patient whether nutrition and hydration are helpful or not.

Sometimes it is not immediately obvious whether putting a patient on a feeding tube or IV will be tolerated. As death nears, bodily functions begin to slow down, and the appetite wanes. In that case, adding food or fluids may cause great discomfort such as gas and bloating in the abdomen, regurgitation and vomiting, possible aspiration of food into the lungs, or diarrhea. If a person suffers from congestive heart problems or circulation difficulties, adding liquid to an already overburdened system can increase a build-up of fluids around the heart and lungs, leading to breathing difficulties and heart failure.

All of these issues must be taken into consideration. Be sure to ask the doctor about the overall prognosis of the patient, and whether food and fluids will benefit the person at this point, and be tolerated without worse complications. If the person can no longer assimilate food or fluids, then keeping the patient's mouth clean and moist, and providing comfort, may be the best care.