



WHEN IT'S A MATTER
OF LIFE AND DEATH...

THE QUESTIONS YOU SHOULD ASK

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WHAT QUESTIONS SHOULD YOU ASK YOUR DOCTOR IN LIFE-OR-DEATH SITUATIONS?

Your mother has a stroke and is rushed to the hospital. You receive a call from the hospital emergency room that your daughter has been critically injured in an accident. Your infant son is born with a life-threatening condition. Your husband suddenly collapses from a heart attack.

These are critical life or death situations which, unfortunately, ask you to make decisions for which you are ill-prepared. To complicate matters, medical terms which are unfamiliar, coming from “specialists” you’ve never met, suddenly need to be understood. At a time when you are in shock, worried, frightened, and vulnerable, you are asked to make decisions which may determine whether a loved one will live or die.

It is extremely important that if faced with critical health care decisions for a loved one, you have the information necessary to know whether a treatment recommendation is one which takes into account your concerns. This is especially true today when some believe that death should be an option if a patient is perceived as not having a good “quality of life.” This guide will not answer all of your questions, but is intended to help you ask the right questions, should you find yourself in such a situation.



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QUESTIONS TO ASK IN CRITICAL CARE SITUATIONS

Q. Is the patient terminally ill?

A. Is your loved one considered to be terminally ill? Is death expected within hours or a few days, within weeks or months, or within a few years?

It is important to know the answer because decisions will be different depending on whether an illness or condition is terminal and how long the patient is expected to live. If death is truly expected within hours or a few days and will happen whether or not treatment is given, it is generally accepted that life-preserving treatment and simple feeding tubes can be removed or not given. It is most important at this time to keep the patient as comfortable and pain-free as possible.

If death is not expected right away, feeding and routine care should be provided, at minimum.

Q. Is the patient competent or incompetent?

A. Does your loved one have the ability to understand the illness or condition and the treatment options?

If competent, it is critical that your loved one be given full information and allowed to make his or her own decisions. Family members may be consulted at the patient's request. However, it is the competent patient's right to make treatment decisions.

If incompetent or incapacitated, any documents signed by your loved one regarding health care preferences must be honored. If there is no document, or the patient's wishes are unknown, it is best to make decisions based on whether a treatment will actually help the patient, rather than someone's idea of the patient's "quality of life."

A good way to avoid being placed in a situation where you have to make a decision for someone who is incompetent is to talk about treatment concerns while your loved one is competent and encourage him or her to sign a document leaving instructions on desired treatments. It is a good idea for you to also do this for yourself to ease the burden on family members to try to decide what to do should you become incompetent.

If death is not expected right away, feeding and routine care should be provided, at minimum.

Q. Is the patient really “brain dead?”

A. Sometimes “brain death” is confused with “brain damaged.” These are two very separate things.

BRAIN DEATH

- If your loved one is truly brain dead, he or she has died, and treatment would be useless.
- True brain death occurs when there is a flat EEG (electroencephalogram), a lack of spontaneous response to outside stimulus, a lack of oxygen flow to the brain, and no functioning of the brain stem. The brain stem controls heart rate, breathing, and other spontaneous functions. It is possible for a patient who is brain dead to “appear” alive if the patient is on a respirator which is “breathing” for the patient. But if all of the above factors are present, the patient has died.

BRAIN DAMAGED

- If your loved one is brain damaged, he or she is very much alive. In this case, you want to assess treatment options very carefully, based on whether a treatment will help the patient. Also, you would not want to allow organs to be removed for transplant from a patient who is brain damaged since the patient has not died.
- With brain damage, there is brain wave activity, response to outside stimulus, and the brain stem continues functioning to control heart rate, breathing, and other spontaneous functions. These functions could be assisted by mechanical devices but the patient has not died if there is any circulatory, respiratory, brain, or brain stem activity.

If your loved one is brain damaged, he or she is very much alive.

Q. Should the patient be resuscitated?

A. Sometimes a patient or a patient's family will be asked to sign a "do not resuscitate" order. If such a document is signed, it means that no efforts will be made to restart a patient's heart should it stop beating or beat erratically.

"Do not resuscitate" orders are usually appropriate when a patient's condition is so serious that he or she is not expected to live more than a few hours or days, or the patient's health is so poor that resuscitation attempts will hurt the patient or have little chance of success. Restarting the heart at this time does not restore life for any length of time because the patient is expected to die from his or her disease.

Patients and their families should resist being rushed into signing such an agreement until it is certain the patient has an illness or condition severe enough to warrant such a decision. If the patient is competent, time should be taken to discuss a "do not resuscitate" order with him or her to be certain that the patient has given proper informed consent.

Q. Should the patient have a feeding tube?

A. Since we know that every patient dies if they are not given food and fluids, this is a very serious issue. Sometimes it is impossible to provide food and fluids because the patient has collapsed veins, with no ability to feed directly into the digestive system. Sometimes the patient would be harmed by food and fluids, for example, if there is already too much fluid in the lungs or the patient has advanced stomach cancer. If the patient's death is expected within hours or a few days, or the patient would be harmed, it is generally accepted that food and fluids can be removed or not given, with the patient kept as comfortable and pain-free as possible.

In other situations, if the patient is brain damaged, is expected to live longer than a few hours or days, or is unconscious, then removing or not giving food and fluids will cause the patient to die of starvation and dehydration, which can take from five to thirty days.

If the patient is competent, time should be taken to discuss a "do not resuscitate" order with him or her to be certain that the patient has given proper informed consent.

Q. What if the patient has expressed a desire not to be kept alive on “tubes” or “machines?”

A. If your loved one is competent, great care should be taken to know exactly what he or she means. Sometimes, “machines” are needed for a short period of time to relieve a life-threatening condition. Simple “tubes” are used for feeding or to provide medication to relieve pain. If your loved one makes a general statement regarding “tubes” or “machines,” more questions should be asked to learn the exact wishes about specific treatments he or she may want or not want.

If the patient is brain damaged, then removing or not giving food and fluids will cause the patient to die of starvation and dehydration.

CONCLUSION

This guide was not designed to answer all of your questions since it would be impossible to list every critical health care situation you might face. It is meant to guide you on questions you should ask so that you understand the consequences of decisions you are asked to make, especially at a time when you feel overwhelmed and helpless. Many times treatment decisions come down to what is good common sense, and if you’ve asked the right questions, you will find some degree of comfort in the decisions you have made.

Don’t let anyone pressure you into a quick decision. Seek a second, and even a third, opinion if you are not satisfied. If you decide to remove or not give life-preserving treatment and your loved one dies, there is no way to reverse that decision. If you wait and your loved one’s condition doesn’t improve, you can still make a decision at a later date -- a safer course of action.

It is hoped that this guide will assist you in making decisions that you and your loved one can live with.

If you decide to remove or not give life-preserving treatment and your loved one dies, there is no way to reverse that decision.

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