SLIDE 1 INTRODUCTION

Making decisions about life-sustaining medical treatments are one of the greatest challenges that patients, their families and healthcare teams make. The guiding principle for most decisions regarding the initiation or the withdrawal of life-sustaining treatment is autonomy. The foundational idea is that medical interventions should be in line with the goals, preferences and values of the person receiving these interventions. It is the individual patients who are in the best position to make these decisions.

Of course the perspective of family and friends can help a patient clarify the situation and the special knowledge and experience of the doctors and the rest of the healthcare team are crucial for rational decision making but in the end, it is the patient that will have to endure the treatment and will have to bear the consequences for his or her decision.

SLIDE 2: THE RIGHT TO DECIDE FOR ONE’S SELF

There is no doubt that most of us know far less about certain technical fields than medical professionals know. This is especially true when we are confronted with making serious decisions about medical treatment. Medicine is highly technical and its practitioners are highly trained and experienced. There is a real sense that they know better when it comes to treatment options.

Most rational adults will eagerly seek direction from medical professionals. Often, they will consent to follow the recommendations of their physicians. This is not by itself a threat to autonomy. Autonomy is threatened when the healthcare professionals attempt to override the decisions of the patient by appealing to the goals of beneficence and non-maleficence. This is called paternalism.

The principle of autonomy recognizes that individuals have the right to request or refuse medical treatment, even when the healthcare team does not believe that the decision is in the patient’s best interest. Ideally every medical intervention begins with the patient’s consent.

SLIDE 3: 2 REQUIREMENTS FOR PATIENT CONSENT

Consent is the primary way in which patients exercise autonomy. Still, consent is more than merely saying yes. In order for a patient’s consent to be valid, it must meet two requirements.

First the patient must be capable of making decisions. This means that they must have the ability to understand the consequences of their consent and they must be free from coercion and undue influence. Infants and young children are not able to understand what is happening and therefore are not considered to have the capacity to make medical decisions. The same can be said for adults with dementia. In addition, medications or traumatic injuries may impair the ability of the patient to reason. In this case, they may lose the capacity to make their own decisions, at least temporarily.

The second requirement is a recognition that in order to choose, a person needs enough information to make to make a rational decision. This is the standard of informed consent. The principle
of informed consent is not only an attempt to preserve autonomy, it also is a way of encouraging rational decision making by the patient.

Informed consent means that the patient must receive enough information to make a rational decision. It is not necessary for all of the technical medical details to be presented to the patient. In fact, too much complicated information may confuse the patient. Risks and benefits as well as treatment options must be presented. Consent is informed only when it is understood. Signing a waiver without understanding does not constitute consent.

SLIDE 4: PROXIES, SURROGATES, HEALTHCARE AGENTS

A person retains autonomy even when he or she has lost capacity. When a patient has lost capacity through illness or injury and is unable to make their own healthcare decisions, a healthcare agent may be appointed as a means of preserving that person’s autonomy. Whether called a proxy, surrogate or agent, this person’s first duty is to represent the patient, making the same decisions that the patient would most likely make for his or her self.

SLIDE 5: SUBSTITUTED JUDGEMENT

The patient’s clearly articulated preference is the gold standard for medical decisions. This preference can be oral or in writing. If the patient has not directly expressed her wishes, then the agent’s duty is to try and determine what decision the patient would have made based on her values and knowledge of her as a person.

This is called substituted judgement. A surrogate or a healthcare agent makes a decision by drawing an inference from the patient’s values, beliefs and life-long patterns of behavior. For example, a surrogate might look at patient who has throughout his adult life avoided doctors, refused to visit friends in the hospital, and expressed a general distrust of the healthcare system and infer that the patient would not want treatment that would result in long term or permanent nursing care.

SLIDE 6: BEST INTEREST

Sometimes little or nothing is known about a patient. There are no friends or family present and no designated agent. Substituted judgement is based on knowledge of the individual. Best interest comes into play only when the patient's autonomous choices cannot be known. Making decisions for others can easily become paternalistic and to guard against this the best interest standard is the standard of last resort.

SLIDE 7: BEST INTEREST

While a primary goal in medical decision making is to preserve the patient’s autonomy, in cases where autonomous decisions cannot be known, decisions are primarily made using the principles on beneficence and non-maleficence. Best interest requires a risk/benefit analysis and decisions are primarily made on the basis of quality of life.

SLIDE 8: ADVANCE DIRECTIVES

Advance directives are documents that a person creates when they have decisional capacity with the purpose of preserving their autonomy whenever they are no longer able to make their preferences
known directly. Advance Directives are sometimes called living wills and may or may not include the designation of a healthcare agent through a durable power of attorney.

SLIDE 9: ADVANCE HEALTHCARE DIRECTIVES

Karen Ann Quinlan was 21 years old when in 1975 she lapsed into a persistent vegetative state after mixing alcohol and prescription drugs. When it became clear that Karen was not going to improve, her parents requested that she be removed from the ventilator so that she could die naturally. The Quinlins argued that their daughter would not desire to continue living in such a state and that her wishes should be honored.

At that time Karen’s doctors believed that they would be charged with murder if they removed the ventilator and ended life-sustaining treatment. Karen was appointed a guardian by the state and the parents’ request was refused.

The parents went to court and lost the first round, but in 1975 the New Jersey Supreme Court ruled in the parents’ favor. Karen’s ventilator was removed. Surprisingly, she continued to live for another nine years, dying in 1985.

The ruling that allowed for Karen’s ventilator to be removed was based on the right to privacy, which the court extended to the right for Karen to have control over her body, even to the point of being allowed to die. Since Karen could no longer speak for herself, her parents, because they knew Karen better than anyone else were allowed to make the final decisions concerning her treatment. Based on their knowledge of her faith, her values, and her desires, the decision was made to remove the artificial respirator and allow her to die.

SLIDE 10: ADVANCE HEALTHCARE DIRECTIVES

Karen Ann Quinlin’s story is a sad one but in one small way she was fortunate. Karen had parents who were able to put aside their grief and choose, to determine to the best of their ability what Karen herself would have wanted. Karen was able to exercise autonomy through her parents.

Advance Healthcare Directives were not common in 1975. Since then they have become an important tool for preserving a patient’s autonomy.

In an advance directive any person with the capacity to make decisions, regardless of age, is able to communicate her or his wishes concerning medical treatment even when they can no longer communicate directly.

SLIDE 11: ADVANCE HEALTHCARE DIRECTIVES

Advance directives provide a means of protecting a person’s autonomy in two ways. First the directive provides written documentation of the person’s wishes and gives direction to those who will speak for the person when she is no longer able to speak for herself due to injury or illness.
While some Advance Directives give only the most basic instructions such as “Do everything” or “Do not intubate,” the contemporary trend is to paint a picture of the person by including material about faith, values, fears, hopes and other factors that will help the decision maker in choosing a treatment plan that will reflect and honor the patient’s desires.

The second way in which advance directives protect a person’s autonomy is by providing the opportunity to name a proxy or healthcare agent. The first duty of this agent or proxy decision maker is to become a surrogate for the patient. It is therefore important that the agent is someone who will represent the wishes of the patient’s even if the agent disagrees with the patient’s choices.

Often people assume that their closest relative is the best choice their healthcare agent. It is true that the best agents have a deep knowledge of the patient’s values. But knowledge of the patient isn’t enough. The best agents also understand that they only represent the patient and are willing to take a stand on his or her behalf.

For example sometimes families are divide over decisions to treat or not treat. The agent might be tempted to try to be the peacemaker by making compromises or by going with the majority. An advanced directive provides the opportunity to choose the best person to represent you even if that person is not your spouse, parent, or other close relative.

SLIDE 12  **IF NOT NOW, WHEN?**

The best way for an individual to preserve autonomy when capacity is lost is by choosing a healthcare agent who understands the person and who understands the importance of honoring that person’s wishes. It is never too early to begin end of life planning. No one wants to have their first conversation about end of life decisions in the emergency room, a hospital critical care unit, or at the deathbed. Conversations with those who are most likely to make decisions on your behalf need to begin early in life, and should be revisited regularly.

Completing an advance directive provides the opportunity to begin these conversations.