

## **Discussing Life-sustaining Treatments**

*(excerpted from The Risky Business Roadshow manual – prepared by Dr. Merrill Pauls – please do not distribute without permission or attribution)*

It is important that we engage in these discussions because we take care of sick people, many of whom do not want resuscitation and many for whom resuscitation was never designed or intended. If we don't write a DNR order someone will call a code. We also need to consider how we can make the best use of limited resources

However it is a difficult discussion to have because:

**Families are stressed** - they often feel guilty or fearful, have unrealistic beliefs about the effectiveness of CPR, and fear they are being abandoned, AND

**Physicians are stressed** - they want to avoid harming patients and prolonging death, are not sure if resource allocation should play a role, and are often unsure if they can draw and enforce what they see as reasonable limits

### **ASK – LISTEN – TALK**

The following is a five-step approach to discussing life-sustaining treatment. It is mostly based on expert opinion but there is also empirical work that has been done in the area.

#### **1) Clarify understanding**

Start by finding out where the patient and/or their family are at – do they understand the acute problem that has arisen? Do they understand the prognosis of any underlying medical conditions and the expected course in the short and longer term? This helps you know where to start your discussion and how to match your language and level of sophistication with the patient/family.

*“What have you been told so far?”*

*“Where do you see things heading in the next little while?”*

*“It's important that we talk about this now because...”*

#### **2) Ask about prior wishes**

The transition to the actual discussion about LST can be difficult. It may leave patients and families wondering why you are discussing this now and if things are worse than you are letting on. The following approach is intended to help patients/families feel more in control and take a more active part in the discussion. If the patient has an advance directive it must be located and interpreted in light of the clinical situation. If the patient has expressed their wishes verbally these need to be explored and a judgment made as to their

applicability to the current situation. If they have not expressed relevant wishes then the substitute decision-maker (SDM) is asked to make a substituted judgment – we should ask what they believe the patient would have wanted. (not what they want for the patient)

*“Many people have wishes about what they do or do not want done if they become ill. Can you tell me if John has ever expressed these kind of wishes? Did he ever write them down?”*

*“Tell me about “John”. If he were here with us now, what do you think he would want?”*

### **3) Focus on goals – what can be achieved**

The next important step is to steer the conversation away from specific treatments and towards goals. Examples of some possible goals include - cure, prolongation of life, avoidance of premature death, maintain or improve function, relieve suffering, improve quality of life, preserve control, achieve a good death, support for family/loved ones. These goals are not on a continuum and are not mutually exclusive. Many patients will have multiple goals and at times these goals will conflict with one another. Many patients will need help and encouragement to articulate their goals. As part of this process the physician should explain if certain goals can not be achieved, and work with the patient to prioritize those that can.

*“Anything we do at this point will not be able to treat/cure the underlying disease, but we can...”*

### **4) Match treatments with goals**

Try to match the possible treatment options with the goals that have been negotiated. Use this time to explore the meaning of different treatments for families and educate them as to the (in)effectiveness of many LST's. If a trial of therapy is being considered be sure to negotiate the time-frame and the outcome that will be used to determine success or failure.

*“ So based on what you are telling me, it doesn't sound like John would have wanted to be on a breathing machine if there was little hope for recovery.”*

*“ I realize that John said he would not want to be on a breathing machine if there was no hope, but in this case he may be able to recover if the pneumonia responds to our treatment”*

## 5) **Finish strong**

Clarify and summarize what has been decided and what the next steps will be. Always emphasize and reiterate that symptomatic care will be provided regardless of the decision that is made. In cases where treatments are being withheld or withdrawn it is important to reassure families they are not responsible for the outcome – they are not “killing Grandma” – rather they are trying to do what she would have wanted and are pursuing the goal of comfort care. In some cases families are too overwhelmed to make a decision, in which case the physician should be willing to make a recommendation based on the goals that were expressed.

Many doctors say they make recommendations based on what they would want done for themselves or for their own family. (“If that was my mother I wouldn’t want them to keep going.”) This is a questionable approach to take, as the patient may have completely different values and/or beliefs from you and your family. Your recommendation should be based on their values, not yours.

*“So we will put a Do Not Resuscitate order on the chart - which means that resuscitation will not be attempted if his heart stops. We will do everything else we can to prevent that from happening, and will make him as comfortable as possible.”*



### **Problems that arise in the “DNR discussion” ...and suggestions for addressing them**

#### 1) “What aren’t they telling me” syndrome

Problem - Patient and family blind-sided by the discussion and wonder “what aren’t they telling me” - Often due to an abrupt or awkward introduction of the topic and/or a focus solely on limiting resuscitation. Also may result from prior interactions the patient/family have had with the system

Suggestions – be sure to start the discussion by asking what they know so far - determine their understanding of the current situation and address any misconceptions

#### 2) The ER effect

Problem – Patient and family often have unrealistic expectations of the effectiveness of CPR and other LST’s (not to be confused with Reader’s Digest Syndrome)

Suggestions – need to educate patients and families as to the actual benefits that can be expected, the likelihood of them occurring, and the possible risks of LST’s

### 3) Resuscitation fixation

Problem – Patient or family demand a specific intervention regardless of appropriateness or relevance to the clinical situation

Suggestions – need to explore the significance of this treatment for the patient/family. Moving the conversation from treatments to goals can help address this problem

### 4) “Who is the patient?”

Problem - the family requests interventions that don't appear to be what the patient wants or are in the patient's best interests. Family members are often motivated by guilt or fear

Suggestions – ask for help from nursing and/or social work with the goal of gaining a better understanding of family motivations and addressing their fears (not just trying to get them to agree with what you want) Consider the benefits and risks of a trial of therapy or observation (in some cases may allow for acceptance and a negotiated withdrawal – in others may feed false hopes)

### 5) Reader's Digest Syndrome

Problem - Some patients/families insist on certain treatments because they have worked in the past or they know of someone who survived the same condition. (i.e. they read about the one survivor in Reader's Digest) If we fail to understand this anecdotal reasoning, and try to use prognostic data to convince these families of the hopelessness of the situation it rarely works and often makes the conflict more intractable.

Suggestions – We need to explore the motivation and rationale families have for wanting treatments. This alone may help them feel listened to and build some trust. Try to identify differences between the anecdote they are clinging to, and the actual patient

### 6) Deer in the headlight phenomena

Problem - Some patients/families may disagree with your prognosis and want to explore the use of certain LST's even if the odds of success are very small

Suggestions – we need to keep an open mind, remember that physicians are often overly pessimistic in their prognoses, should consider a second opinion or a transfer of care

### 7) “Come Hell or High Water”

Problem – Some families are so overwhelmed they can not make a decision. Some feel they are responsible for the patient's condition. Others believe they are “killing” the patient if they agree to stop or withhold treatment.

Suggestions – Still need to explore the patient's values and negotiate some goals, but should be more proactive in the decision phase and make specific recommendations based on their goals. Need to reassure families they are not responsible for the death, and emphasize that comfort care will be provided.

### 8) You may be wrong

Problem - Some patients/families will have deeply held moral and religious beliefs that will determine what they want (or demand) no matter the clinical situation or the discussion that occurs

Suggestions - In these cases a second opinion is crucial in order to confirm diagnosis and prognosis as well as to insure the standard of care has been met. Early involvement of administration (and even legal assistance) is also indicated. Involving religious leaders may help you understand the family but rarely changes their mind



*Remember that while this may be the first time you meet this patient/family they may have had previous interactions with the medical system and may start with a low level of trust or confidence in you. At the same time your biases and previous difficult interactions will influence the way you interact with them. Relationship building is just as important as conveying facts in these situations.*