What Do You Mean by Do Everything? Reframing Discussions of Advance Directives

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Tell us what you want to learn today…

Learning Objectives

- Identify when and how to start discussions about advance care planning
- Define DNR/AND and various other terms used in advance care planning
- Discuss the role of the hospitalist in initiating, documenting, and communicating these discussions
- Review legal and ethical aspects of advance directives as related to pediatrics

Outline for the Day

- Introduction cases (Poll Everywhere)
- Didactic
- Video cases with discussion

Case 1

- You are admitting a 1 year old with spinal muscular atrophy who is having an acute respiratory illness requiring additional support. You ask the parents what they would want if the child's breathing worsens. They reply "please do everything." You reply

a. Of course we will do everything.

b. Do you know your child has a terminal condition?

c. What do you mean by "do everything?"

d. Let me tell you what a code looks like.

Case 2

- You are caring for a 15 year old male with CF whose lung function has been declining for the last few months. He is now in the hospital for a CF exacerbation and has been having worsening respiratory status. You are concerned he may need transfer to the PICU and intubation at some point. Parents state that they do not want the pt involved in these discussions. What do you do next?

a. The parents have the legal right to make that decision so no need to involve the pt

b. Ask the parents why they don't want the pt involved

c. Tell the parents that the pt has a right to be involved

d. Get an Ethics consult

Case 3

- You are called by one of the floor nurses about a 7 year old with cerebral palsy who was transferred from the ICU to the floor today. The patient is in for an aspiration pneumonia and has a DNR in the chart. The nurse wants to know if it is ok to suction or put the patient on oxygen. You tell the nurse
  a. No, a DNR is in place so those things shouldn't be done
  b. Yes, those would be considered comfort measures
  c. You're not sure, you need to talk with the parents
  d. You're not sure, you need to talk with the ICU

Background

- Families feel quality of care is higher when advance care planning occurs earlier rather than later
- Families and physicians often feel planning happens too late
- Physicians report little to no training in how to have Advance Care planning discussions
- ICU and oncology clinicians may report being “prepared” to have these discussions, but still may not have them
    - (Sanderson et al, 2016)

Defining Advance Directives

Advance Directives

For Adults

- Living Will
- Medical Power of Attorney

For Pediatrics

- The parent or legal guardian makes all decisions related to end of life care
- No standard format for documentation
- State to state out of hospital DNR
- POLST may be an option

What can be included in an Advance Directive?

- Code Status
- Intubation
- ICU care
- Artificial Nutrition/Hydration
- Hospitalization
- Antibiotics
- Organ donation
- Comfort care

Terms Used for Code Status

- DNR/DNAR = Do Not Resuscitate/Do Not Attempt Resuscitation
- DNI = Do Not Intubate
- AND = Allow Natural Death

Should I talk about it now or later?

Hospitalist Role

Acute

- Code
- Imminent Respiratory Failure
- CAT
- ICU transfer

Chronic

- Life Limiting Condition
- Decisions about life prolonging interventions (trach/vent)
- Recurrent admissions
- Decline or new baseline

Acute

- Discussion dictated by acuity of the situation
- Very difficult to initiate a new discussion in crisis mode
- “Has anything like this ever happened to your child before?”
- “Has anyone ever discussed this type of situation with you before and what you would want for your child should it happen?”
- “Has your family ever discussed what you would want if your child were requiring increased interventions/breathing support/resuscitation?”
- “Has anyone ever discussed resuscitation with you?”

Chronic

- NOT in crisis mode
- Families and medical team feel better prepared when discussions happen earlier
- Should be a discussion that is initiated for all children with life limiting conditions
- Ideally a routine discussion on or shortly after admission and is ongoing as the child’s condition evolves
- We will address further with approaches to communication

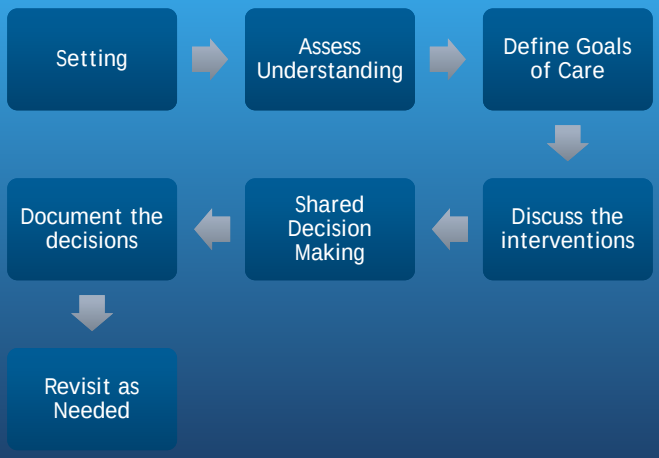
Where Do You Start??

Communication, Communication, Communication

Approach to Communication

- When possible, discussions about advance care planning and code status should always take place **within a broader discussion about goals of care**
- Think of it as a conversation and discussion
- Check your agenda at the door
- Discussions may occur over time and decisions may change as the child's condition changes

Overview



Assess Understanding

- Establish what the patient/parent understands both about this acute illness and the underlying chronic medical issues
- "Tell me what you understand about your child's condition"
- "Has anyone ever discussed with you what to expect for your child's future? Has anyone ever told you they thought your child's life might be shortened by their condition?"

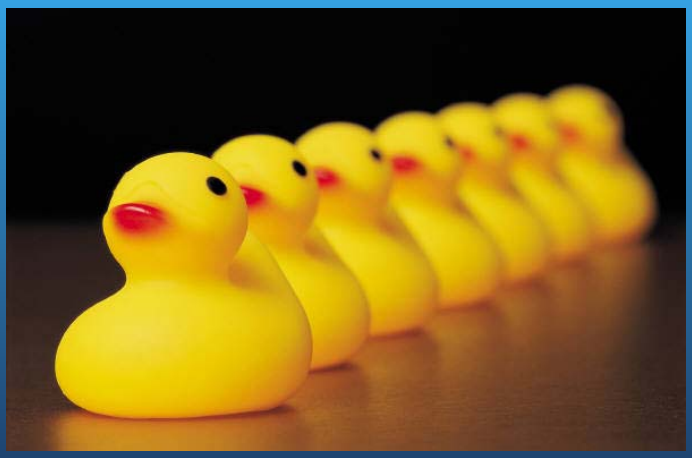
Define Goals of Care

- Need to ensure family has good understanding prior to moving forward with goals
- Usually consistent with either disease directed therapies, comfort measures, or somewhere in between
- Cure or getting better is often the first goal, but key is to address other goals if this isn't possible

Define Goals of Care

- "Given what we know about your child's condition, tell me what you think is important for your child."
- "What do you envision for your child's future? What do you hope for them?"
- "What do you think this treatment/therapy/medication will do for your child?"
- "If time was short, what would you want for your child/what would you want that time to look like?"

And then it's time to dive in…



What can be included in the discussion?

- Code Status
- Intubation
- ICU care
- Artificial Nutrition/Hydration
- Artificial airways and vent support (prolonged)
- Hospitalization
- Antibiotics
- Organ donation
- Comfort care

Discuss the Interventions

- Not every intervention applies to every situation
- Try to individualize the discussion to that patient's situation
- Need to describe the intervention - both burdens and benefits

About a DNR...

- DNR ONLY refers to cardiopulmonary arrest
- DNR does NOT refer to any other aspect of the pt's care
- If possible know the outcomes and be realistic with the patient/family
- Have the discussion in the context of the overall goals
- Use language about resuscitation that the patient/family can understand, avoid medical jargon

About a DNR...

- http://thecarenet.ca/docs/CPR%20Decision%20Aid%20revised%20to%20PDF%20brochure%20Nov%203%202009.pdf

CPR Outcomes

- 25% of children survive to discharge for in hospital cardiac arrest
- 5-10% of children survive to discharge for an out of hospital cardiac arrest
- Neurologic outcomes variable

- Topjian et al, Pediatrics 2008
- Nadkarni et al, JAMA 2006

Some helpful phrases

- "Have you ever thought about what you would want for your child if her time was short?"
- "Has your child ever been on a breathing machine/ventilator? If yes, how did you feel about that?"
- "Has your family ever discussed how you feel about artificial life support? Resuscitation?"

Decision Making

- Paternalism - Prior to 1980s most prevalent approach to decision making
- Assumptions
  - Single best treatment option existed
  - Physicians would apply this info to their patients
  - Physician expertise placed them in best position to make decisions
  - Professional code of ethics, bound physicians to act in best interest of their patients

Decision Making

- During 1980s – credibility of paternalism questioned
- For many illnesses, not one best treatment option
- Treatment options led to risk/benefit tradeoffs
- Patient will have to live with the consequences
- Research into quality of medical care - led to awareness of variation in treatment patterns
- Combination of rising health care costs and quality concerns – physicians more accountable to patients

Shared Decision Making

- "Increasingly advocated as an ideal model of treatment decision-making in the medical encounter."
- Linked with positive patient outcomes (satisfaction and improvements in functional status)
- More than just informed consent – minimum of shared decision making

Shared Decision Making

- Four Necessary Characteristics
  - At a minimum, physician and patient involved
  - Both physician and patient share information
  - Both physician and patient take steps to participate in decision-making process by expressing treatment preferences
  - A treatment decision is made and both the physician and patient agree on the treatment to implement

How do you document?

In Hospital DNR/AND

- Refer to your hospital's policy
- Physician order with documentation of discussion vs. signed consent by parent/patient
- Avoid partial/menu option DNR

Out of the Hospital DNR/AND

- Each state has a recognized form
- Patient/Legal guardian signature required
- In addition, licensed provider and witness signature
- Variable recognition among EMS
- Sometimes not recognized by school or home health agencies

POLST

- Another way to document
- Considered a medical order

POLST vs. Advance Directive

POLST

- For persons with serious illness — at any age
- Provides medical orders for **current treatment**
- **Guides actions by Emergency Medical Personnel when made available**
- **Guides inpatient treatment decisions when made available**

Advance Directive

- For anyone 18 and older
- Provides instructions for **future treatment**
- **Appoints a Health Care Representative**
- **Does not guide Emergency Medical Personnel**
- **Guides inpatient treatment decisions when made available**

www.polst.org

POLST

- http://www.polst.org
- http://capolst.org/wp-content/uploads/2015/12/2016_CA_POLST_English.pdf

Difficult Issues

Legal Issues

- Parent or legal guardian is decision maker for matters regarding advance care planning and code status
- Who makes decisions can be more complicated if Child Protective Services are involved

Ethical Issues

- Withdrawing interventions is the same as withholding
- Best interest decision making
- Surrogate decision makers
- Involving the child in the decision
- Futility
- Unilateral DNR

Involvement of the Patient

- Age of involvement depends on developmental level more than age
- In general if the child can verbalize understanding and consequences of decisions they should be involved
- Even if not involved, child should be given developmentally appropriate information

Video Case Discussions

Changes You May Wish to Make to Your Practice

- Initiate discussions about goals of care for all children with life limiting conditions
- Use these discussions as a context for advance care planning
- Involve children in discussions about goals and advance care planning when developmentally appropriate
- Document these discussions with recognized tools when available

Resources

- www.polst.com POLST
- http://www2.aap.org/sections/palliative/ Section of Hospice and Palliative Medicine AAP
- www.aahpm.org American Academy of Hospice and Palliative Medicine

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