

Setting goals at the end of life

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Who makes decisions for this patient?

- Custodial parent
- Legal guardian
- Patient
- Health care team

Some things that can go wrong

- What if they are unable to make decisions?
- What if they are unwilling to make decisions?
- What if they want to do something that we don't think they should do?
 - The "if this were my child" discussion
- Why do we force them to make decisions?

Minor problems

- It is good for minor patients to be involved in decision making
- It is hard to watch kids die
- It is sometimes even harder to watch them live
- "The State" has a role in keeping people alive until they can make their own decisions
- It is really hard to figure out when that occurs

American Academy of Pediatrics

- Children should participate in decision-making commensurate with their development.
- They should assent to care whenever reasonable.
- Parents and physicians should not exclude adolescents from decision-making without persuasive reasons.

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But practically speaking

- Nobody likes to talk about death
- It is easy to avoid having "the talk" in the inpatient setting
- Parents often try to "protect" their children from end of life discussions
- The doctor who knows you best may not be around when you are dying

So...

- Its good to involve minors in medical decision making
- But
- It is really hard to find the time, place, and the right words for these discussions (especially when we come in late in the game)

Assent: a worthwhile goal

- What is wrong with me?
- What are you going to do to me?
- What will it feel like?
- What if I ask you to stop?

Gaining a voice in decisions

- Emancipated minor
 - Self-supporting and/or not living at home
 - Married
 - Pregnant or a parent
 - In the military
 - Declared to be emancipated by a court

Gaining a voice in decisions

- Mature minor
 - Understands disease and treatment according to adult standards
 - Understands meaning of death
 - Meets some developmental standard
 - Typically seen for decisions about STD, pregnancy, substance abuse

Legal Considerations

- Cognitive development considerations
- Parental agreement
- Impact of decision
- Burden of treatment vs. efficacy (long and short term)

Assessing development

- A whole lot happens between 10 and 18
- Chronic/serious illness changes things
- Hormones, peer groups, and other toxins
- Structural as well as functional changes
- Lost of theories, no reliable tools

Setting goals

- In a setting of difficult communication/decision making, we are not doing the patient or family any favors by asking them to make decisions about each individual treatment/procedure

How do you want to spend your remaining time?

- Several possible ethically appropriate goals:
 - Fighting until the last breath
 - Living as long as possible as long as I'm not suffering
 - Being as comfortable as possible for the time I have left