Patient Information:

RQ, 32-year-old, male.

Medical Indications

1. **Presenting Problem:**

   The patient has end-stage multiple sclerosis (MS). During the beginning of his current hospitalization, his condition became critical because he was in respiratory distress.

2. **Salient History:**

   RQ tried an experimental drug therapy from Germany for his worsening condition hoping that it would cure him. He lived independently up until 5 years ago when his condition progressed and ~~he now~~ then lived with his parents and ~~is~~ was cared for by in-home nurses. He has also had a few hospitalizations. before the current, lengthy hospitalization

3. **Diagnosis:**

   1° End-stage Multiple Sclerosis (MS) 2° respiratory failure d/t neuromuscular effects of MS

4. **Prognosis:**

   RQ's condition is worsening. It is likely that he will spend the rest of his life in and out of the hospital being treated for his MS. It is unlikely that he will be able to take care himself and will need to continue to be cared for by his parents and in-home staff. RQ will most likely experience respiratory distress more often and will have more frequent hospitalizations. May remain vent dependent

5. **Patient's Condition:**

   RQ's condition is chronic and progressive. As his condition worsens he will most likely need more help breathing and possible intubation. Advanced disease/ would die w/out LSTs.

6. **Care Goals:** Missing a reasonable care goal for apt w/ advanced disease
Keep RQ comfortable as he continues to deteriorate and his need for intubation may increase. RQ has expressed that he wants to live independently but his condition makes it unsafe for him to do so. It is important that he is educated on the seriousness of his ~~condition~~ and understands why he must be dependent on his parents and in-home staff for his care. Assistance w/ peaceful dying/ support near death?

7. **Summary:** What interventions are consistent w/ appropriate goals?
RQ has end-stage multiple sclerosis (MS). He has had more frequent visits to the hospital and during his most current stay he experienced respiratory distress and had to be intubated. RQ's condition is progressive and chronic. Ignores choice

Do parents need education about son's condition at this stage?

Patient Preferences

1. **Competency:**
When he first came to the hospital on this visit, he was fully competent and capable of making his own decisions.

2. **Decisional Capacity:**
As his condition worsened, the attending physician did not think he had ~~was not competent~~ capacity enough to make decisions regarding his own care. The other physicians did not know RQ well enough to argue with their attending about his judgement. Reference criteria?

3. **Stated Preferences:**
When he was intubated during his current visit he made it known to the staff that he wanted the tube out. b/c?
Towards the end of this case RQ stabilized and made it known that he was ready to die, he didn't want to be put back on the ventilator, and he wanted to be discharged so he could go home. Were his choices respected in a timely manner? Why or why not?

4. **Advance Directives:**
No advance directive was previously put in place or mentioned by the hospital.

5. **Surrogate:**
If he were to require a surrogate when he is no longer able to make his own decisions, his parents can speak on his behalf. Would they respect his wishes & make a substituted judgment or would they interject their own wishes in lieu of his?

6. **Summary:**

He was considered competent when he first came to the hospital, the attending physician started to question his judgement and whether or not he should be allowed to make his own health care decisions. RQ made it known when he was first intubated that he did not want to have the tube in. Towards the end, he made it known that he does not want to be intubated again, is ready to die, and wants to go home. There is not an advance directive in place.

Contextual Features

1. **Family Issues:**

RQ had been living independently until 5 years ago when his condition required him to move back home and be taken care of by his parents and in-home care staff. The case states that his family had been dysfunctional before he became terminal. His parents are extremely involved and controlling, they don't allow RQ to have much of a say in his health care decisions. They make decisions for RQ even though he is capable of doing so himself, they insisted that he should be a full code and that all measures be taken to sustain him. This decision was against what RQ previously stated that his wishes were. Towards the end of his hospital stay RQ was still in the ICU, his father became even more controlling and wouldn't allow RQ or his mother to have any say in the decisions or speak to anyone that had a part in RQ's care.

2. **Provider Issues:**

RQ's parents are making the decisions for their son even though he is still competent. The decisions that they are making are against those of the patient's. The physicians and parents are making the decisions, this was frustrating for the hospital ~~for the~~ staff because the decisions that they made went against the wishes of RQ.

3. In RQ's case, there was no mention of financial, cultural, allocation, research, legal issues or clinical teaching and public health or safety. Were there legal issues w/ unconsented treatment? Possibly battery case?

4. **Summary**

RQ's family is dysfunctional and seems like a protective family dynamic. Both parents tend to override RQ's decisions and towards the end of the case his father makes all the decisions without allowing RQ or his mother to be involved.

Quality of Life (Could locate before CF)

1. **Characterization:**

   RQ's quality of life is restricted. He is deteriorating and is requiring help breathing with a ventilator more frequently. Can still communicate so not severely diminished, though in poor general health & dependent.

2. **Normal Life:**

   ~~It is unlikely that~~ RQ will ~~be~~ not be able to return to normal life with or without treatment. His condition is worsening and he is in the end stages of his condition. If he were to get treatment his condition would still worsen and he would most likely suffer and not get any better. If he were to go without treatment, he would continue to deteriorate and will die a natural death ~~most likely need to go on the ventilator full time~~. Since RQ is in the end stages of his condition choosing treatment or no treatment would most likely not allow him to return to his ~~normal life.~~ prior baseline

3. **Likely Deficits:**

   Physical Deficits: RQ will most likely experience some physical losses such as, not being able to walk around and move that much since he is becoming more dependent on the vent and is also getting weaker. During this hospital visit RQ also experienced many infections and a few cases of MRSA, it is likely these infections could become more frequent as well.

   Social Deficits: If RQ were to be placed on a ventilator he would lose the ability to speak with the tube in (unless he was given a talking tracheostomy). If he were to become agitated again and need to be sedated, he would also not be able to speak since he would be asleep.

4. **Undesirable Quality of Life:**

   When RQ condition stabilized after he had conversations with the hospital staff and let them know that he did not want to be put back on the vent, he wanted to go home, and he was ready to die. RQ does not want to continue to his stay in the hospital but wants to go home and finish out his life there. He does not want to continue treatment or be placed on a ventilator.

5. **Plans to Forgo Life-Sustaining Interventions:**

   During the end of his current hospital stay, RQ made it known that he did not want to be intubated again and that he was ready to be discharged. b/c?

Discontinuation of ventilation since pt found it burdensome, rather than a comfort

6. **Comfort Care Plans**

No comfort care plans were in place out the end of the case but if he were to be discharged he would most likely need comfort care for his pain and breathing distress.

Problem Solving

1. **Problem:**

The main issue in this case is the patient's parents trying to overrule RQ's medical decisions. RQ has made it known that he doesn't want to be intubated, wants to be discharged, and was ready to die. His parents insisted that he be a full code and all measures be taken to sustain his life. Before RQ stabilized the physician questioned whether or not he was capable of making his own decisions.

2. **Alternatives:** Are there other alternatives? Try to avoid either/or.

- The hospital staff could start listening to their patient's wishes since he is fully competent and mentally sound. If they honored his wishes, RQ would be discharged and sent home to be cared for by his parents and in-home staff until he passed away.
- The hospital staff could ignore his wishes and listen to the parents. RQ would remain in the hospital, he most likely would be placed back on the ventilator and he were to code he would be resuscitated.

Evaluation of alternatives missing

3. **Recommendation:**

Even though the physician started to question RQ's competency, it is clear now that RQ is still capable of making ~~chooses~~ choices regarding his health care treatment. It would be best if the hospital staff disregarded his parents' wishes and allowed RQ to stay off the vent, be discharged, and go home to be care for until he passes away.

	Exemplary	Competent	Developing
• **Medical Indications (20 pts)**	○ Presenting problem ○ Salient history ✓ ○ Diagnosis ✓	○ Prognosis ✓ ○ Characterization ✓✓ ○ Care goals X2 N ○ TX alternatives ✓ ?	○ TX benefits/burdens ? ○ Contingency plan ○ Summary
• **Patient Preferences (20 pts)**	○ Competency ○ Decisional capacity ✓✓ ○ Maturity of judgment ○ Stated preferences ✓✓✓ ○ Advance Directive ○ Known values ○ Informed	○ Comprehending Voluntary/Cooperative ○ Surrogate needed ○ Surrogate identified ✓ ○ Surrogacy standards ○ Pure autonomy	○ Substituted judgment ○ Best Interests ○ Violation of right to choose/be informed – ? ○ Legal hold/involuntary committal ○ Medical neglect ○ Summary
• **Quality of Life (20 points)**	○ Characterization ✓ ○ Likely return to normal life ○ Tx ✓ ○ No tx ✓ ○ Likely deficits ○ Physical ✓	○ Mental ○ Social ✓ ○ (Un)desirable QL ○ Self-evaluation Implied ○ Observer assess. ○ QL Biases	○ "Double effect" issues ○ Plan to forgo life-sustaining intervention due to QL ? ○ Comfort care plans ○ Rational suicide
• **Contextual Features (20 points)**	○ Family issues ✓ ○ Provider issues ✓✓ ○ Financial issues	○ Cultural issues ○ Allocation issues ○ Legal issues ?	○ Research issues ○ Clinical teaching ○ Conflicts of interest ○ Public health or safety
Problem solving (20 pts)			
	Uses an orderly problem-solving strategy effectively, for example, • Defines problem ✓ • Identifies alternatives • Evaluates alternatives – ? • Selects best alternative ✓	Minor problem-solving problems, for example, • Considers only two alternatives • Evaluation of options not chosen is weak	Unorganized problem solving. Omits key problem –solving steps, e.g., does not identify alternatives or evaluate pros and cons.

18 1/2 / 20

19 1/2 / 20

Were choices respected in a timely manner?

19 1/2 / 20

K1 / 20

18 1/2 / 20

Rationale