“No,” Ryan said, glaring at me through his sunken eyes. “I have had enough. I am through with Bi-PAP and the ventilators, the IV antibiotics, and the constant blood draws. I’m tired of experimental treatments that always let me down because in the end I always end up here, in the ICU. All of these interventions are just buying time against my inevitable death. But what kind of a life do I get in the meantime? This is no way to live. I have been in the hospital for more days than I have been in my own home.”

“No,” his eyes softened now, pleading and brimming with tears, “just let me go.”

Though I had only just met Ryan a week before when I started my rotation in the Pediatric ICU, I knew his entire medical history from a chart that was so extensive that it needed three volumes to contain all 16 years of Ryan’s short life.

Ryan suffered from a particularly severe case of cystic fibrosis. He was born with meconium ileus that required major surgery just days later. He suffered from constant diarrhea because he could not absorb fat and other fat-soluble vitamins in spite of the addition of pancreatic enzymes to his meals. Ryan was also unable to produce the insulin needed to allow his cells to access the glucose that he was able to absorb. After years of insulin injections, Ryan finally opted for an insulin pump. Even with these interventions, it seemed that Ryan was still malnourished. He weighed just 95 lbs and was much shorter than other boys his age.

Ryan also suffered from recurrent pulmonary infections that landed him in the hospital at ever decreasing intervals. At first, the pathogens were just the common community-acquired pneumonias and were easily treated with the conventional antibiotics. However, with multiple exposures to nosocomial pathogens during his time in the ICU and also at summer camps for other children with CF, Ryan now had pneumonia from *Pseudomonas aeruginosa*, difficult to treat due to the biofilm in his lungs that formed an impenetrable barrier to antibiotics.

As a result of the multiple lung infections and extensive bronchiectasis, Ryan’s pulmonary function had deteriorated to the point where lung transplantation was needed. It was this procedure that Ryan was objecting to now.

Ryan’s mother, who had been quietly observing in the corner while this exchange took place, gave me a meaningful look and stepped outside. I excused myself and followed her. “I know that Ryan has never had it easy, but lately he’s been even
more withdrawn. He doesn’t call any of his friends from school or camp anymore and refuses to get out of bed or eat.”

“I was worried that Ryan was giving up,” she continued, “but today was the first time he has said it aloud. I want you to know that though Ryan is giving on himself, I am not giving up on him. I want you to proceed with any treatment necessary to keep him with me. He is my life and I can not bear to let him go without a fight.”

By law, a minor is an individual who has not yet reached the age of 18, the age at which one is assumed to have reached maturity. The law considers a minor to be incapable of making medical decisions, so those decisions must fall to the designated caretaker, usually a parent or another close relative. The majority of the time, the parents make decisions in the best interest of the patient. However, situations do arise when the wishes of the patient are at odds with those of their parents.

At what age does a patient truly gain the maturity to make his or her own medical decisions? Physicians do not question maturity as a factor in the decision-making ability of patients who are 18 or older, however minors are held to a much higher standard.

The “mature” minor exception to the need for parental consent for medical treatment is a determination based on the criteria established in the West Virginia Supreme court Case, Belcher vs. CAMC in 1992. According to the court’s decision, factors to be considered when determining the maturity of the minor include age (15 or older), experience, education, degree of judgment exhibited, conduct and demeanor, and the minor’s capacity to appreciate the nature, risks and consequences of having or refusing a procedure.

Additional criteria to consider include whether the patient is capable of making an informed decision, if treatment must be in the patient’s best interest and that the treatment does not involve serious risks.

At the age of 16, Ryan meets the court’s age criterion for consideration as a mature minor. He probably has acquired enough education and experience with the treatments and consequences of his disease through a lifetime of hospitalizations, medical interventions and support groups such as his summer camp for other children with the same affliction. Ryan also demonstrates that he is able to appreciate the gravity of the situation if he does not receive the lung transplant. Indeed, he seems ready to die as a result of this decision.
Though Ryan seems to meet enough criteria to be considered mature enough to determine his own fate, we must question his ability to make an informed decision. Factors that may affect any patient’s decision-making ability include pain, depression, and coercion. With his pain controlled and when coercion has been ruled out, the physician must turn his attention to the possibility of depression. Ryan’s mother mentioned symptoms that may point to a depressive disorder. His loss of interest in activities and friends, his lethargy and loss of appetite are all common symptoms of depression. Perhaps his wish to refuse treatment is a manifestation of suicidal ideation. Regardless of his age, Ryan must be worked up and treated for his depression as a part of his medical plan.

Another factor to be considered is the nature of the treatment itself. While necessary to prolong Ryan’s life, lung transplantation is an extremely risky procedure that may have serious consequences, including rejection and death. Even if it were successful, Ryan would require lifelong immune suppression that would make him even more susceptible to future infections. On the other hand, survival rates following lung transplantation are 80% at 1 year and 60% at 4 years following transplantation. Candidates for lung transplant, like Ryan, are given only a 1-2 year survival rate without the treatment, so Ryan does stand a reasonable chance to extend his life.

In general, it is difficult for a physician to determine treatment based on the “mature minor” rule. Though the courts have provided some guidelines in determining the ability of a minor to make medical decisions for themselves, it remains difficult for psychologists to define maturity in a patient like Ryan.

While it is not clear at this time if Ryan should be considered a “mature minor,” it is certain that Ryan has mental health issues that must be addressed before he can even be assessed for mature minor status. Ryan’s wish to refuse medical treatment would not only result in death, but may be clouded by undiagnosed depression. It would be my recommendation that following mental assessment and treatment for depression, that the physician revisits his treatment options in an open dialogue with both Ryan and his mother. If they still are in disagreement, the physician should side with the mother because lung transplantation is a reasonable option that will probably result in the prolongation and improved quality of Ryan’s life.

In conclusion, it is my opinion that physicians should err on the side of liberty when dealing with an adult who makes a medical decision that adversely affects his health and conversely, physicians should err on the side of protection for children who wish to make those decisions for themselves.

Sources:
2. www.hsc.wvu.edu/chel/wvi/AdvanceDirectives/Minors.pdf