

H474: Case Application 1

Carlos is a 16-year-old boy who has recently been diagnosed with a rare form of cancer. His parents immigrated to the US illegally when he was 3 years old, so he doesn't have access to health insurance. Because he doesn't have access to health insurance, he does not see a doctor regularly, and his cancer was not discovered until late stages. Doctors have indicated he likely has less than a year to live.

Carlos' doctors want to enroll him in an experimental treatment that will likely decrease his quality of life, and it hasn't yet shown promising results as a cure. They feel, however, that it's their last option with any hope. Carlos' parents want him to try the treatment if there is any chance at all of a cure. They were given a paper that described the treatment, detailed the chances of success, and described the likely side effects, but they don't speak English very well, and don't fully understand the complicated medical language. All they know is that the doctors said it *could* help. Carlos really only understands that he will likely be in pain and confined to a bed, and he would rather live out the remainder of his life as fully as possible. He doesn't want to do the treatment.

Carlos' doctors are anxious to enroll patients in the study, because they feel the research could save lots of lives in the future, even if it can't help Carlos now.

One evening, Carlos is admitted to the ER in extreme pain, and scans show that the cancer has spread to his bones. It is important to make a treatment decision as soon as possible. While Carlos is resting in his room, he overhears nurses at the nurse's station complaining about how much care he needs, even though his family "doesn't belong here" and "taxpayers are footing the bill" for his care. Hearing the comments makes Carlos feel bad, and he decides to enroll in the study as a way to pay the medical community back for his treatment, even though he originally didn't want to do it.