

# **First, Do No Harm Study Guide**

**First, Do No Harm by Lisa Belkin**

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# Contents

<a href="#">First, Do No Harm Study Guide.....</a>	<a href="#">1</a>
<a href="#">Contents.....</a>	<a href="#">2</a>
<a href="#">Plot Summary.....</a>	<a href="#">3</a>
<a href="#">May, Chapter 1: The Committee.....</a>	<a href="#">4</a>
<a href="#">June, Chapter 2: Taylor and Jake.....</a>	<a href="#">5</a>
<a href="#">June, Chapter 3: Patrick.....</a>	<a href="#">6</a>
<a href="#">July, Chapter 4: Armando.....</a>	<a href="#">7</a>
<a href="#">July, Chapter 5: The Committee.....</a>	<a href="#">8</a>
<a href="#">July, Chapter 6: Taylor.....</a>	<a href="#">9</a>
<a href="#">July, Chapter 7: Patrick.....</a>	<a href="#">10</a>
<a href="#">July, Chapter 8: The Hospital.....</a>	<a href="#">11</a>
<a href="#">July, Chapter 9: Armando, Chapter 10: The Committee.....</a>	<a href="#">12</a>
<a href="#">July, Chapter 11: The Cost of Care.....</a>	<a href="#">13</a>
<a href="#">August, Chapter 12: Patrick, Chapter 13: Taylor, Chapter 14: The Committee, Chapter 15: Armando, Chapter 16: The Cost of Care.....</a>	<a href="#">14</a>
<a href="#">September, Chapter 17: Patrick, Chapter 18: Armando, Chapter 19: The Committee.....</a>	<a href="#">16</a>
<a href="#">October, Chapters 20 - 29.....</a>	<a href="#">18</a>
<a href="#">Epilogue and Acknowledgements.....</a>	<a href="#">22</a>
<a href="#">Characters.....</a>	<a href="#">24</a>
<a href="#">Objects/Places.....</a>	<a href="#">33</a>
<a href="#">Themes.....</a>	<a href="#">35</a>
<a href="#">Style.....</a>	<a href="#">37</a>
<a href="#">Quotes.....</a>	<a href="#">39</a>
<a href="#">Topics for Discussion.....</a>	<a href="#">42</a>

## Plot Summary

First, Do No Harm is a real-life dramatization of the routine ethical dilemmas that healthcare professionals, patients and their relatives face on a day-to-day basis. The book reads like a novel, but author and New York Times writer Lisa Belkin maintains that every event in the book is true. This makes the experience of reading the book all the more gripping. Many of us familiar with medical ethics understand that there are difficult questions but we are rarely confronted with the real life situations where the question is relevant and the real life people who must answer it. Lisa Belkin's task is not to give us the answers, but to pose the questions in a powerful fashion. She aims to show us how real people struggled with these questions and how they came to live with their answers.

The book concerns a large cast of characters, a host of doctors, nurses, aides, parents, relatives, children, babies, and hospital administrators. It has no central main character, save perhaps Patrick Dismuke. It is structured chronologically over a six month period, May through October, 1988. The book has six parts with distinct characters and their unique dilemmas introduced each month. Some characters are recurring and their struggles continue throughout the entire book.

The setting of the book is Hermann Hospital in Houston, Texas and the main characters are either employees of Hermann, Hermann affiliates, Hermann patients or their relatives. One particular focal point of the book is Hermann hospital's ethics committee, composed of a large range of characters, from doctors to a mother with a handicapped child. The committee makes recommendations for how to resolve certain critical ethical questions concerning a patient's care. And it is with the committee our story begins.



# May, Chapter 1: The Committee

## May, Chapter 1: The Committee Summary and Analysis

The chapter opens with Patrick Dismuke, a fifteen year old boy who is constantly in and out of the hospital with significant health problems. He has been a patient at Hermann on and off for his entire life, spending more time in the hospital than out of it. He has Hirschsprung's disease, which affects the digestive tract, leaving Patrick unable to digest food. He is fed through a nutritive drip - a tube which feeds him the nutrients he needs to live. But the line can get infected and the infection can overwhelm his body. Thus his life is a constant struggle fighting both against starvation and against infection, and winning the battle against one weakens his chances against the other.

The chair of the committee is introduced in this chapter: Lin Weeks, a new employee of Hermann, is the chair of the committee. The committee, known as the Institutional Ethics Committee focuses primarily on the withdrawal of life support. The committee also faces the crushing question of financing patients who are unable to finance themselves. It sees itself as having a duty "to risk above any talk of dollars and cents" and instead focuses on "what is ethical and just" (17). Currently the committee faces the question of deciding whether or not to continue Patrick's nutrient drip. The system he is currently on is not meant to last for more than a short period of time. Javier raises the question of whether to continue Patrick's drip because the antibiotic they are using to keep the infection down causes Patrick enormous suffering. To continue the drip they must install a new line; installing the line requires surgery that is very dangerous to Patrick. The committee must decide whether Patrick will be left as DNR or "Do not resuscitate" in the case of surgical complications.

The ethical debate within the committee focuses on whether letting Patrick starve to death without the drip is "giving up" or whether it is simply letting Patrick's life take its natural course. The hospital decides to proceed with the surgery, but places Patrick on Supportive Protocol II, which permits doctors to stop treatment or keep them alive under certain circumstances, requiring that patients merely be kept "comfortable".



# June, Chapter 2: Taylor and Jake

## June, Chapter 2: Taylor and Jake Summary and Analysis

"Taylor and Jake" introduces us to the Poarch family. Fran and Carey Poarch are pregnant with fraternal twins, Taylor and Jake. But they face complications during birth. Fran and Carey's pregnancy precedes normally until the last day of May when Fran goes in for her monthly check-up. Dr. Jane Reed discovers that Fran's cervix has thinned which might induce premature labor. Reed prescribes drugs and sends Fran home. However, a few days later it becomes clear that the drugs haven't work. Fran is rushed to Hermann via helicopter and is propped up, head below her feet, to keep premature labor from birthing her babies too soon.

Fran and Carey meet Dr. Sharon Crandell once they arrive at the hospital, who they find cold and businesslike. She explains to Fran her condition: she must lay inclined to avoid premature birth because the lungs of her children are underdeveloped. The labor, however, will not stop. Fran must give birth. Carey and Fran beg the doctors to do whatever is possible to save the babies. Fran is taken to the emergency room where she gives birth to twins: first, Lee Taylor Poarch, 1 lb, 8 oz. and then Jacob Carey Poarch, 1 lb, 15 oz. Both babies are born alive. Both babies must be placed on ventilators. Jake's condition is worse than Taylor's. Fran and Carey have Jake baptized and he dies, and Fran and Carey begin the long process of traveling to and from home to the hospital to see Taylor live.



# June, Chapter 3: Patrick

## June, Chapter 3: Patrick Summary and Analysis

In Chapter 3, we return to Patrick. The chapter begins with a small informal meeting amongst five people that know Patrick best. First, Richard Weir, Patrick's play therapist is introduced. Then Sally Olsen, Javier's assistant arrives, and Kay Tittle follows. Javier is supposed to show up, but does not, and Patrick's mother, Oria Dismuke is unable to make it. Belkin details the long history that each of these people have with Patrick and the way that the boy has worked his way into their hearts over time. Patrick does not focus on the severity of his condition but instead merely wishes to live the life of an ordinary boy, a feature that endears him to hospital staff. Richard and Kay are both attached to Patrick, but this burdens Javier because he is responsible for all the children at Hermann. Javier has dealt with this burden by creating an independent clinic within the hospital known as CHOSEN - Chronic Health Oriented Services for Niños. Sally Olsen is his secretary, but to support him she must operate as a nurse, social worker, counselor, secretary and office manager. Sally claims to anticipate the deaths of CHOSEN patients, which cause hospital regulars to regard her either as "an oddball or a saint" (38). Yet when it comes to Patrick, Javier and Sally are outsiders. Richard, Kay and a few other medical staff members are Patrick's closest caregivers.

The debate over whether Patrick should be made DNR continues. Eventually, Patrick's mother, Oria Dismuke, appears. She is fairly disconnected from Patrick's life, as she works three jobs to support his medical bills. She is painted as a fairly exhausted woman, depressed about her son and constantly drained by her heavy workload. She is uncomfortable at these meetings as the medical personnel know her son better than she does. She has decided in her heart that the doctors and nurses will be better parents to Patrick, so she merely supports his care. The committee meets to convince Oria to tell Patrick more about his condition to get him to consider the DNR order. But Oria refuses to let them tell Patrick how bad his condition is because she doesn't want them to tell him to give up. At the end of the chapter, Oria asks Patrick: "Pat, do you want to talk about dyin'?" (46) but Patrick refuses and Oria never raised the subject again.

# July, Chapter 4: Armando

## July, Chapter 4: Armando Summary and Analysis

A Latino male, twenty-four, had been shot a few hours earlier. One bullet had entered his neck right below his brain and penetrated the spinal cord. Armando Dimas was paralyzed from the chin down. The doctors were certain he wouldn't make it. Armando appears to have little brain damage. Armando is thought to have no chance of recovery. Keeping Armando alive and giving him occupational therapy will cost Hermann an enormous amount of money and with no prospect of recovery it is not clear that the cost of Armando's care can be justified. Due to a language barrier, Armando's family is unable to understand little of Armando's condition. The mother, Victoria Dimas, is said to have always been afraid that Armando would get hurt or killed due to his "weakness for bad things" (54).

Armando and his family came from Matamoros, Mexico, an extremely impoverished community. His entire family came illegally. Armando grew up poor in the United States, knowing little English. At seventeen, he left his family for Ft. Worth doing various odd jobs. He met Carolyn Alvarez within a month, a single mother with two children. They lived together for five years and had a son Armando, Jr. One night Armando was laid off from his construction job, went to a bar, drank, and got into a fight. He ended up fleeing two men who were after him and decided to leave town, heading for Madisonville. One night in Madisonville, Armando went to his niece's birthday party and the beer ran out around midnight. Armando gave a drunken guest some water instead of Whiskey and the man became enraged and started a fight with Armando. Armando then hears two gunshots and took his family and left. Fifteen minutes after leaving, the man came out of a bush, and fired a gun twice at Armando, hitting him both times. The man was never found. After that Armando was rushed to the hospital. The chapter ends with David attempting to explain to the Dimas family that Armando would never walk again, but they simply could not understand what he was telling them.



# July, Chapter 5: The Committee

## July, Chapter 5: The Committee Summary and Analysis

Chapter 5 opens in the office of Lin Weeks where Weeks and Weeks's secretary Ellen Nuñez are viewing a note. The author of the note is a twenty-seven year old engineer named Teresa Knepper, who had never worked in medicine but wanted to be on the ethics committee. The committee has twenty-three members and includes doctors from different areas of expertise. It includes Sharon Crandell, Patrick's doctor Javier Aceves, a full-time ethicist, the head of Patient relations, the head of Patient relations and the hospital lawyer. The members of the committee are rarely present at the same time and so never become comfortable with one another. The committee meets sporadically, typically when an end-of-life issue arises; they address either patients or patient's relatives. They only officially consult and give advice which the parties can reject, but advice is usually followed.

The story returns to Teresa, who in 1981 at 19 years of age gave birth to two twins, Mark and Matthew. Mark died after two days but Matthew survived. Teresa and her husband David had enormous trouble caring for Matthew because he appeared to be in constant pain; it turns out the Matthew had cerebral palsy and as a result he did not learn even the basic baby and childhood abilities. When Matthew was two, Teresa joined the ethics committee at a hospital in Gainesville, Florida, learning more about medicine and medical ethics as time went on. Teresa maintains that keeping her son was a great good because Matthew regards his life as worth living: "He's happy because he doesn't know any other way," she often claims. In 1987, Teresa met with Javier's nurse Sally and Sally suggested that she become the first non-medical, non-clerical member of the Hermann ethics committee, which she ultimately did.





# July, Chapter 6: Taylor

## July, Chapter 6: Taylor Summary and Analysis

Fran and Carey Poarch have just buried Taylor's twin Jake. Taylor's appearance is fairly shocking, as she is still very small and covered in tubes, including a plastic ventilator tube stuck in her mouth, and a chest covered with two electrodes. Every extra moment is spent with Taylor. The chapter introduces one of Taylor's nurses, Virginia Lennox, who often grew attached to babies in Turner and describes her attachment to Taylor. Taylor's biggest health problem is that she was not ready to be born and had underdeveloped lungs. The ventilator helps this problem but it damages the lungs and makes permanent ventilation quite difficult. The damage increases over the weeks, and Taylor develops scarring of the lung tissue. She also develops stretching of the lungs' tiny air sacs until they become useless.

As time progresses, Fran and Carey begin to worry about how long they should keep Taylor on treatment. They attempt to discuss this question with Taylor's doctor, Sharon Crandell, but Sharon resists discussing the matter. Fran and Carey do not like Sharon in part because of her cold demeanor, yet she thinks that she's treating patients with respect by being honest with them. Fran and Carey are pleased when Sharon is rotated out later in the month for her supervisor Dr. Eugene Adcock who they connect with. Taylor has a complete kidney (renal) failure. Fran and Carey must decide whether to keep Taylor alive or let her die. Hermann will allow them to issue a DNR order if Taylor goes into cardiac arrest. That is what Fran and Carey want. In the morning, though, Taylor's kidneys begin to work again. For a time, Taylor is doing well, but a few days later her kidneys fail again. They must now reconsider whether to reinstate the DNR order.

# July, Chapter 7: Patrick

## July, Chapter 7: Patrick Summary and Analysis

Belkin begins by describing the origins of Patrick's medical chart and how it tracks his life by medical event. She notes that waste stays in Patrick's intestines for this reason and begins to kill his intestinal tissue. Patrick's nutrition therefore has to be fed to him through an IV, a measure that was at the start considered temporary. Belkin describes Patrick's two worlds - the hospital and his grandmother's small, dark home in one of the poorest spots in Houston. Patrick is emotionally addicted to Hermann and is dependent on powerful medications. He clearly prefers the time he spends at the hospital and prefers the company of hospital staff to his own family. Patrick eventually admits that he pollutes his nutrition line with 'feces and dirt' so he can return to Hermann. Patrick's line is becoming increasingly infected and needs to be replaced. However, the replacement surgery is dangerous and will only lead to a new infection in a new line. Richard, Kay, Javier and other members of the ethics committee debate Patrick's case and ultimately decide to make him DNR and Patrick's mother appears to agree. They do not bother Patrick with the matter so as not to upset him.

# July, Chapter 8: The Hospital

## July, Chapter 8: The Hospital Summary and Analysis

Chapter 8 concerns the history of Hermann hospital. It begins with a tale of the founder, George Henry Hermann. Hermann got rich with oil investments and left his fortune to build a hospital in Houston, insisting that a large portion of the hospital be used for charity care. Unfortunately, nothing was done for the first five years and the money was used in a variety of scandals. A board of trustees that were supposed to oversee the building of the hospital were constantly embroiled in controversy. Hermann hospital did not open until 1925 as a result. Hermann continued to grow and was incorporated with other medical facilities. Hermann continued to be caught up in scandals due to embezzlement and corruption on its board of trustees, continuing into the 1980s. Overtime the courts revised Hermann's will to allow for different financial arrangements; charity care shrunk as Hermann became increasingly unable to afford it. The hospital stands in 1988 as large, prestigious, but in debt and publicly humiliated by its board of trustees.



# July, Chapter 9: Armando, Chapter 10: The Committee

## July, Chapter 9: Armando, Chapter 10: The Committee Summary and Analysis

The chapter begins by considering Armando's mental state. He faces isolation and panic at night. He can watch television during the day but this is still difficult. His doctor, David MacDougall, did not tell him that his condition was probably permanent and is increasingly frustrated with Armando's family, who cannot grasp his condition. Norma McNair and the other nurses were responsible for all of his hygiene. The chapter discusses Mary Coffey's (Armando's occupational therapist) confusion with her assignment to Armando. Belkin discusses Armando's therapy routines and then introduces Cindy Walker, Armando's social worker, a rough woman who is the kind of social worker who is short on emotional comfort but extremely competent. Cindy has great trouble ascertaining Armando's family situation. Armando and his girlfriend Carolyn are not married, although they have a child. Cindy must quickly find a place for Armando to stay, but there are few options. Chapter 9 ends with Cindy making a call to Lin Weeks.

### Chapter 10

Lin calls Randy Gleason, the hospital lawyer, and Chapter 10 begins with a meeting between the three of them. They discuss whether to tell Armando about his condition. They also discuss how Armando's care will be financed. Ultimately they decide to inform Armando. Norma McNair tells Armando that his condition is permanent and that he would likely face severe health problems. She asks him if he wants to be DNR. He strongly declines. Armando wishes to live no matter his condition. It is clear that Armando is going to survive and it is not clear what the Hermann staff is going to do about it.



# July, Chapter 11: The Cost of Care

## July, Chapter 11: The Cost of Care Summary and Analysis

Hazel Mitchell is Hermann's financial administrator. She decides who gets which resources. This chapter is not merely about the tough decisions she faces but about the simple fact that healthcare is not free. Morality does not want to let us consider costs when it comes to those in extreme need, but in the end we must. Considering the cost is Hazel's unpopular job. Hazel has tabulated Armando's bill to date - \$57,020.86, a sum that he cannot hope to repay. Belkin goes on to describe the two other major hospital facilities in Houston. There is a poorer hospital that deals with uninsured patients, Ben Taub, and there is a richer hospital, Methodist Hospital, which is the largest private hospital on the planet. Hermann stands somewhere in-between. Hermann is not publicly funded like Ben Taub, but it must devote a large portion of its profits to charity, unlike Methodist. Hermann is currently \$4 million in debt and the situation is expected to worsen. Belkin tells us that the Hermann ethics committee must eventually face the fact that they cannot afford to give everyone all the care they need. She recounts briefly the story of Dexter Advani and his parents who expected Hermann to finance all of this expenses. The medical committee ultimately had to cut off their care and send them to another hospital. Belkin ends the month of July by returning to Armando and Hazel, with Hazel wanting to avoid yet another financial situation like the Advanis.



## **August, Chapter 12: Patrick, Chapter 13: Taylor, Chapter 14: The Committee, Chapter 15: Armando, Chapter 16: The Cost of Care**

### **August, Chapter 12: Patrick, Chapter 13: Taylor, Chapter 14: The Committee, Chapter 15: Armando, Chapter 16: The Cost of Care Summary and Analysis**

Patrick had enjoyed July but August is terrible for him. Patrick suffers more and more from the side effects of his Ampho treatment drugs and his nutrient line is becoming increasingly clogged and infected. Patrick's doctors have to try to clear his central line but the chemicals they use do not work well. They decide to also reduce his Ampho drugs, leaving the Ampho to eat away at his kidneys. Javier thinks this the least terrible of the options. As a result of weaker kidneys, however, Patrick is able to absorb fewer calories, which makes him even more vulnerable to the side effects of his Ampho treatment. Javier is faced with giving Patrick surgery to unclog his central line. The surgery is dangerous, but Javier opts for it. Patrick once again goes in for surgery, but he eventually recovers.

Chapter 13 brings us back to Fran, Carey and Taylor Poarch. Taylor's kidneys continue to weaken. Her body is swollen and her skin is stretching and splitting. She rarely moves. Fran is frustrated by the ventilator and how uncomfortable it seems to make Taylor; she wants to remove it. Fran and Carey have a conversation with Virginia, who does not think Taylor will survive. Carey springs the question of whether to remove Taylor's ventilator on some of the new doctors. They go to Dr. Adcock with their dilemma. After this conversation, they discuss the matter with Sharon, who is resistant; she suggests they convene the ethics committee.

In Chapter 14, the committee convenes to discuss whether to remove life support from Taylor. The committee argues for some time about the over whether the quality of quantity of life matters more. Ultimately the committee decides that Taylor is terminal and that the treatment is merely prolonging death. The committee issues a statement that it is appropriate to withdraw medical support. The decision was unanimous. Dr. Adcock informs Fran and Carey of the decision and they all make preparations to withdraw the ventilator, taking care of the remaining medical and legal obstacles to withdrawing life support. Fran and the day nurse Debbie Burns dress Taylor and made her presentable. Debbie then attempts to withdraw life support but cannot bring herself to do it. Sharon Crandell injects Taylor with morphine and withdraws the ventilator. Fran holds Taylor as she dies.



Chapter 15 returns to Armando. Armando's condition gradually improves - he can mouth words with his breathing tube. Over time, Dahlia, a speech therapist, helps Armando learn to eat. Health difficulties still accompany Armando, including running fevers and getting lung infections. He loses muscle tone and that reduces support to his veins and arteries, making them less effective. He also cannot cough or clear his throat on his own. Armando drives his nurses crazy. He gets his nurses' attention by making a high-pitched chirping sound with his mouth. And he makes constant demands of the nurses, even to perform menial tasks for him like shifting his pillow. He calls them names and sometimes spits at them. Mary helps him work towards sitting up in a chair; eventually he is able to do this. Belkin describes Mary's growing attachment to Armando. Mary had many potential career paths, but she chose occupational therapy. Working with Armando convinced her that she chose the right career.

Chapter 16 opens in a staff meeting where Hazel Mitchell and others discuss hospital finances. Lee Zacharias, director of social work, is introduced and so is Willene Guttenberger, director of Patient Financial Services. The financial committee faces a problem of forty uninsured and under insured patients who have cost over 2.3 million dollars to date. The chapter communicates primarily that dealing with the costs of helping the sick is a somber and demoralizing process. The hospital tries to ignore costs and then gets in over its head financially; the financial committee must then control the damage. The chapter ends with the committee's discussion of Armando, who is costing entirely too much. Cindy maintains that Armando will live and that he is a long-term liability to the hospital.



# September, Chapter 17: Patrick, Chapter 18: Armando, Chapter 19: The Committee

## September, Chapter 17: Patrick, Chapter 18: Armando, Chapter 19: The Committee Summary and Analysis

Patrick's central line is now totally blocked. Javier and his department chairman, Jan Van Eys, must now debate whether to put Patrick through another surgery. The chapter focuses in part on the stress that Javier deals with at his job. Cases like Patrick demoralize him and worry his wife Roseanne. The matter of Patrick's surgery cannot be decided by Javier alone, however. He must deal with Dr. Richard Andrassy, Hermann's chief pediatric surgeon. But they do not get along. Dr. Andrassy and Javier decide to continue to find new IV lines in Patrick's already overused veins, a temporary fix. But it is better, they think, than another surgery.

Chapter 18 notes that Armando is finally able to eat and he can talk with his breathing tube and an additional device, a "talking trach." Armando can sit as well, for around two hours. However, Armando's wheelchair is still too big and he cannot not control his head's position. Mary continues to try to get Armando a better wheelchair. After some difficulty, she decides to write directly to Hazel Mitchell with her request for a wheelchair. Hazel brings it up to the committee, and they consider sending him to "Bart's." "Bart," whose real name is Hermina Bartkowski, runs the Total Life Care Center in central Houston. She keeps high-cost patients in a nursing-home like facility, and that allows her to control costs. Bart treats patients with respect and refuses to condescend to them. The core idea behind the care center is to put groups of patients together in a house and rotate out nurses to care for them, reducing the number of nurses needed for constant care and holding down costs as a result. Willene decides to send Armando to Bart. Bart quickly clamps down on Armando's unacceptably rude behavior. She tells Armando to behave and demands that he keep his self-respect. Armando apologizes to his nurses and stops his bad behavior.

The Committee is the focus of Chapter 19. Belkin begins by discussing how Lin Weeks deals with death on a daily basis. She has made it a "policy question," but Lin's emotional detachment was not easy to acquire. She began her career caring too much and fighting the medical system's rules as a result. Over time, however, her energy is drained. Belkin then begins a discussion of end-of-life controversies, covering the debate from the early 1970s. Care for the elderly is an enormous burden on the medical system and some have controversially suggested that care be rationed to the elderly. However, the Hermann Ethics Committee desperately avoids economic considerations. They instead debate over how much care is too much care and whether a patient's condition counts as a genuine life. Belkin suggests that the debates in medical ethics





boil down to what the purpose of medical care is. Lin thinks that it is to give people healthy, pleasurable lives and argues with doctors who think that the purpose of medical care is to save mere life. The chapter ends with Lin visiting a woman who had her ventilator removed at the family's request, but she continued to breathe and her death was taking longer than doctors expected. The woman's doctor worries about "playing God" by not putting her back on the ventilator; they decide not to put the ventilator back in and the family thanks the doctor afterwards.

# October, Chapters 20 - 29

## October, Chapters 20 - 29 Summary and Analysis

October begins with Patrick as well. Javier faces Patrick with the fact of his clogged line. Patrick must choose between surgery and more IVs. Patrick opts for the IVs. Patrick is afraid of further surgery; while he dislikes the IVs, he thinks surgery is worse. The process of finding veins though takes hours and is emotional torture for Patrick's caregivers. They often test his line to see if it is clearing, but it is not.

We meet Claire Sparks in Chapter 21, setting up her unborn child's nursery. Claire's husband Kenny and she are preparing their trailer for their baby's arrival. In October, Claire is six months pregnant after years of fertility treatment. One October Sunday Claire begins to bleed from her womb and Kenny rushes her to the hospital. When Claire and Kenny reach San Jacinto Methodist hospital, Claire goes into immediate emergency Caesarian section surgery. When Claire's baby is finally born, he is rushed to Hermann hospital. His name is Landon. Landon has a large red mass on his back; while Claire is unconscious, Kenny is able to view Landon and does not know what is wrong.

In Chapter 22, Patrick's IV treatment continues, but Javier and Dr. Andrassy must revisit the surgery question again. They agree that the surgery is finally necessary. Javier searches for Patrick's mother Oria, but Oria is with her new boyfriend. Some of the hospital staff are resentful; they feel like she's being a bad mother. From Oria's perspective, however, she's simply trying to enjoy life, and wants to avoid Sally and Javier because she knows they only bring bad news. She tries more and more to avoid interacting with them, in part because she doesn't want to cry. Since Oria is not around, Javier tells Patrick about his need for surgery. Patrick summons Kay, and discusses his fears. Kay tells Patrick how serious the surgery is. Patrick understands the risks and decides to go ahead and have the surgery.

In Chapter 23, Kenny finds himself in the neonatal nursery where Fran and Carey Poarch once spent all of their extra time. Claire is still at San Jacinto, so Kenny must travel back and forth between the two hospitals. When he does, he brings Claire Polaroid photos of Landon. Landon has spina bifida - where the spine is split in two. Bone, muscle and skin do not form around the spine and leaves a mass on Landon's back - a meningomyelocele. Claire blames herself for Landon's affliction, for forcing the fertility treatment. They must now decide on Landon's surgery. The surgery cannot fix Landon's inevitable nerve problems and all the bodily problems the resulting nerve problems will create, but it can keep him alive. Dr. Jose Garcia, the attending physician, explains all of this to Kenny. Kenny next meets Dr. Hatem Megahed, the neurosurgeon. Drs. Garcia and Megahed explain Landon's condition to Kenny, who is overwhelmed. The only good news is that Landon does not have hydrocephalus — water on the brain. Kenny is worried mostly about Landon's future quality of life; he is referred to neurologist Ian Butler for those questions. Landon will probably never walk, sit, speak or



hear. He may have several mental handicaps. Dr. Butler informs Kenny that they might "let nature take its course." The next day Dr. Garcia brings the consent forms for the surgery to Kenny, but Kenny refuses to sign them on Dr. Butler's advice. Dr. Garcia is furious and has an argument with Dr. Butler. But their disagreement resolves nothing. Dr. Garcia is still convinced that Landon must live despite his parents' wishes. When he asks Kenny what he wishes to do, and they tell him that they do not want the surgery, he informs them that he may have to go over their heads for legal reasons. This makes Kenny furious. He has one more day to decide but continues to be indecisive. Claire wants Landon to die because he will not have a good life. Kenny continues to insist to Jose that Landon be allowed to die, and Jose is upset by this.

In Chapter 24, Patrick calls Kay in to his room to talk before surgery. Before the surgery, Richard had told Kay that he wouldn't want the surgery himself, but wasn't willing to let Patrick starve to death. Richard and Kay take Patrick to the operating room. Dr. Andrassy is prepping for surgery, thinking to himself that the others aren't willing to watch Patrick die should something go wrong. Dr. Andrassy begins the operation, opening Patrick's chest and replacing the tub. The surgery proceeds normally and without complication. Some of the staff wish that Patrick will die on the operating table, but only out of their sense of mercy. Nonetheless, when Patrick emerges from surgery, everyone is relieved.

In Chapter 25, the committee must meet about Landon Sparks. Those attending the committee include Lin, Sharon, Teresa, Dr. Stanley Reiser, Randy, Dr. Butler, Dr. David Oelberg, Jan Van Eys, Jose, and now Dr. Margo Cox, a neonatologist at Hermann. Cox and Sharon often clash because they had opposing views on end-of-life issues. Jose explains Landon's case to the committee. Jose wants to block Kenny and Claire Sparks' request to let Landon die. The committee debates the matter. All the standard considerations arise. Teresa notes that Landon's life could still have value, most of the committee emphasizes how painful and difficult his life will be, and few are willing to simply say that the committee should let Landon die. Some, like Sharon, argue that those on the committee are only willing to let Landon die because of "what his life will be like" and she argues that isn't a genuine reason. The committee cannot make judgments about who lives and who dies based on quality of life.

Randy reminds the committee that they can only withhold care when a patient is (a) permanently unconscious, (b) terminally ill, or (c) stricken with an incurable and incapacitating illness that more treatment can't fix. The committee brings in Claire and Kenny. They're confused why they're at the meeting at all. Claire had just seen Landon from the first time after being released from the hospital. Kenny and Claire briefly discuss what they'd say to the committee. They know that they want to be able to make the decision for themselves, but Kenny has no idea what the decision should be. "Hell if I know what's best," he exclaims. This brings out the theme of moral dilemmas in the book, where it isn't clear how to balance all of the relevant moral considerations to come to a reasonable and moral decision. Instead, in these cases, people make terrible, conflicted choices. The committee asks Claire and Kenny how they feel. Kenny says that they want Landon to have a normal life, but Claire worries to herself that God put the bump on Landon's back. Kenny claims that there is no right decision, that their



decision is just something they have to live with. Kenny's words before the committee move all of its members, with each member thinking of the particular person in their lives who has had a health problem. Claire and Kenny feel that the doctors don't understand their perspective. But then Teresa speaks, and tells them that she is the mother of a handicapped boy. Claire feels like Teresa understands them, and Kenny begins to speak directly to Teresa. As the committee asks them questions, Claire finally speaks up and wants to leave the committee. After they leave, both Dr. Van Eys and Lin claim there's no correct decision. Ultimately the reasons they cite in favor of letting Landon die or giving him the surgery have nothing to do with ethics. The committee decides to put Landon through the surgery, and all sign but Dr. Margo Cox.

Chapter 26 begins. Patrick is recovering from surgery, and fades in and out of consciousness. He's hooked up to a ventilator and his nutrition line is restored and clean; but after a few hours, Patrick begins to bleed and after the bleeding stops, his blood pressure plummets. The ICU staff believe he is bleeding into the sac around his heart. If they don't operate, Patrick will die. They call Dr. Andrassy, and while Patrick is DNR and Dr. Andrassy takes note of this, they decide to operate anyway. Dr. Andrassy opens Patrick back up and drains the sac of blood. When Patrick wakes up he discovers that he is largely paralyzed on his left side but neither Patrick nor the rest of the hospital staff think its more than temporary.

At the beginning of Chapter 27, Jose Garcia takes himself off of Landon's case; he feels he is too emotionally involved. Dr. Oelberg takes over for him, along with Dr. Megahed. They explain to Kenny and Claire that they can either do the surgery or not and they explain all the many things Landon will never do. Dr. Oelberg recommends that Landon have the surgery. Dr. Megahed argues that Landon has a chance. Kenny and Claire acquiesce, asking simply "When?" The next day Landon goes in for surgery.

In Chapter 28, Patrick is returned to his pediatric room. His line has slipped too far into his heart, but they leave things as they are due to risk. It becomes clear over time that Patrick is largely paralyzed on his left side and that things aren't getting better. Javier speculates that a blood clot from the surgery broke loose and got into Patrick's brain. Mary Coffey, the occupational therapist, does what she can for Patrick, helping him use the bathroom. Patrick demands to try on his own, but he cannot do it. He is humiliated. When Patrick sees Kay, he is angry, saying that she never said he'd be paralyzed. Kay is hurt and claims she didn't know. Over the next few days, Patrick asks when he'll be better, and when he can go back to school. Javier avoids explaining Patrick's condition to him again. What's more, another problem has arisen - Patrick's central line is interfering with the electrical signaling in his heart, giving him palpitations. During these times, he can't breathe. Javier decides tearfully that Patrick will not have any more surgeries. They will not resuscitate him, only give him Morphine. They aim to send him home to die. Patrick's last wish is to see the Blue Angels flying stunt show.

Chapter 29 begins with Patrick unable to make the Blue Angels show, but the Make-A-Wish foundation sends the pilots to meet him. Patrick barely smiles. He tells Kay that he wants to die because of his pain. Javier suggests that they stop the Ampho, which is making him miserable. Patrick thanks the hospital staff for their help, one by one. Oria

takes him home, noting how sweet he is that day. Nurse Christine Gladden, one of Patrick's nurses for five years, lets the staff know that Patrick meant to tell that hospital staff that he loves them all. By early morning, Patrick cannot breathe and is slowly dying. At 4:45 am, October 7th, 1988 Patrick dies. Sally's grandfather clock stops that the same time.



# Epilogue and Acknowledgements

## Epilogue and Acknowledgements Summary and Analysis

Belkin notes: "This book is about making choices - and living with them." (262). She wrote the book four years after the events took place. The epilogue updates us on her characters' conditions after October. Armando is fairly happy at Bart's, and while his new wheelchair ultimately doesn't suit him, he finds peace in the care facility. Armando continues to maintain that he wants to live. He says his life has value, that he sees his family and spends time outside. And he's happy to be alive because he knows that if he hadn't gotten shot he would have died some other time. But over time, his cost of care increases beyond Hermann's ability to pay, even at Bart's. Hermann gives Bart's one month to train Armando's family how to take care of him. Armando goes home, where his family cares for him. Fran and Carey Poarch can live with their decision about Taylor. They have two more children, Carey Poarch, Jr. and Lucy. They're both healthy. Fran and Carey ask themselves whether they did the wrong thing, but they still do not know. The ethics committee, the Poarches later discover, agreed with them, and this gives them some solace. Claire and Kenny take Landon home. He does well, and can see, hear and talk, but still has numerous health problems. At one point, he develops bronchitis and this pushes him into a fever-induced seizure which leads the Sparks's to return Landon to Hermann.

He has to be put on a ventilator. They have the ventilator turned off, but Landon keeps breathing. Landon now lives at home, in the same trailer. He has a younger brother, Jared, born six months after the seizure. Claire struggles not to resent Jared for being healthy. Kenny feels guilty for not taking Landon to Hermann when his fever rose. The Sparks's spend most of their money on Landon's medical bills, and few baby-sitters will deal with Landon. Landon has bedsores which make it hard for him to leave the house. Claire rarely goes anywhere that isn't necessary. But Claire and Kenny "wouldn't trade him for anything" despite their exhaustion. Teresa often runs into Clair, Kenny, Landon and Jared at the mall. She no longer sits on the ethical committee, and her son Matthew is doing well at school. When she sees the Sparks's, she often feels guilty because she worries that she encouraged them to make the wrong decision. Lin Weeks no longer chairs the Ethics Committee. She ran out of enthusiasm and time. She's now vice-president of operations at Hermann. She has her PhD and a larger office. Hermann is in a better financial condition; they made cutbacks. Through good marketing, they are able to fill their beds, and in fact have trouble finding empty ones.

A new scandal erupts, continuing to demoralize the staff, but they make the best of it. Oria, Patrick's mother, quit her job as a cafeteria worker at Hermann. She started coming late and was tired. She tells Belkin later that she just couldn't stand to go in the hospital after Patrick's death. She has met a man, and fallen in love. He was a worker at Hermann and was kind to her after Patrick died. They intend to get married. Oria



maintains she wasn't a bad mother, just exhausted from how much she worked. Javier quit Hermann and Sally did too. She now runs a pediatric clinic at a small hospital in San Antonio. Javier heads up a pediatric service at a small hospital in Albuquerque which helps handicapped children. Patrick's death affected Javier deeply, and he considered leaving the medical profession; but the job in Albuquerque helps him start over. Paco, his son, has been in remission for five years, so Javier's family is able to move away from Houston. Javier no longer has trouble caring for sick children and sees his time at Hermann as one of "growing pains." Javier wonders if he could have done more for Patrick, but he doesn't "hurt" because of it; he's learned to protect himself emotionally. In the Acknowledgements, Belkin claims that the book is entirely non-fiction. Only a few names were changed. She thanks everyone who helped her.



# Characters

## Patrick Dismuke

A 15-year old boy, African-American boy with Ricschsprung's disease, a disorder where one is born without the intestinal cells that help to digest food. As such, Patrick cannot eat on his own and must be fed with a nutrition drip. The drip leads to his enormous health problems. Patrick has been a patient at Hermann hospital on and off for all of his fifteen years. He is much beloved by the hospital staff, and is a fairly normal fifteen year old save his tiny size. He likes sports, Nintendo games and so on but cannot play sports and rarely has time for Nintendo or school due to his condition.

Patrick routinely faces life-threatening infections and illnesses, but resists thinking about his own death. For this reason, the hospital staff often avoid discussing his condition with him. He loves the hospital more than his own home, which is dark and impoverished. The hospital staff have largely raised him, as his mother Oria must work three jobs to pay for his medical bills. Sometimes he is so desperate to return to the hospital that he deliberately pollutes his central nutritive line. He is particularly bad about this around holidays. Patrick has a surprisingly high toleration for pain and hospital tests, given that they have formed the backdrop of his life. Patrick's condition is terminal, and is slowly dying as the book progresses.

## Javier Aceves

Javier Aceves is Patrick's pediatrician. Javier once considered become a Jesuit priest before becoming a doctor. He did not take up the priesthood because he wanted to have his own family and entered medical school in Mexico City. Weeks before his residency, one of Javier's twins, a two year old named Francisco (known as Paco), developed cancer, causing Javier and his family to move back to Mexico. Paco's doctors offered his residency at Anderson hospital in their pediatrics program. Javier was able to see his son, who survived, but he was burdened by the others who didn't make it. He had to become accustomed to giving parents bad news because of his position; as Belkin notes: "Javier's patients will never get better, and that emotional drain is more than many pediatricians are prepared to accept" (37). Javier has dealt with this pain by creating an independent clinic within the hospital known as CHOSEN - Chronic Health Oriented Services for Niños.

Javier is often deeply affected by his sick patients and struggles throughout the book to detach from the suffering he sees. Hermann's pediatric ward sees patients that are chronically ill to a degree that far exceeds the normal pediatrician's life of delivering good news to parents. This wears on Javier enormously. He constantly worries about Patrick's condition and represses the painful emotions that accompany his job. He has a wife Roseanne who rarely sees him and who he rarely talks to about work any longer.





## **Ellen Nunez (enye over the middle n)**

Ellen Nunez is Lin Weeks' secretary.

## **Kay Tittle**

Kay Tittle is Patrick's main nurse. Kay is perhaps closer to Patrick than anyone and is often his confidant. He eventually discusses whether he wants to continue living with her. She is his constant defender to the ethics committee and does everything she can to make his life comfortable.

## **Richard Weir**

Richard Weir is Patrick's play therapist. He, like Kay, is one of Patrick's closest friends and advocates.

## **Carey Poarch**

Carey Poarch is one of the two parents of Jake and Taylor Poarch, twins that are born prematurely. A young father and husband, he does not immediately know how to cope with their health problems. Carey and his wife Fran must make terrible decisions about whether to keep Jake and Taylor alive. They are young and hopeful, however, absorbing all the information about their children's health that they can. While Taylor and Jake are alive, they spend all of their free time at Hermann, concerned for their children.

## **Fran Poarch**

Fran Poarch is Carey Poarch's wife and the mother of their twins Jake and Taylor. She was once a pregnant young wife with few concerns other than preparing for her twins' arrival. Her premature birth takes its toll on her, but like her husband, she does what she can to adjust. Fran and Carey go through a great deal of suffering over deciding whether to keep Taylor alive, but ultimately decide to go through with it and are happy with their decision.

## **Jake Poarch**

Jake (Jacob Carey) Poarch is the second of two twins, the children of Carey and Fran Poarch. Jake is born too prematurely to survive and dies shortly after his birth.



## Taylor Poarch

Taylor is the first of Fran and Carey's twins to be born. She survives for week on a ventilator. Because her lungs are underdeveloped, she cannot breathe on her own. The ventilator damages her lungs further, however, making it more difficult for her to recover. Her parents keep her alive for weeks, holding out hope, but eventually they, and the Hermann Ethics Committee, decide to remove her ventilator and she dies.

## Sally Olsen

Sally Olsen is Javier's secretary but often plays the role of nurse, social worker, counselor, and office manager.

## Oria Dismuke

Oria Dismuke is Patrick's mother. She works three jobs to pay his medical bills and is constantly exhausted. The hospital staff often think she is a poor mother because she does not always come to meetings about his health. In reality, she feels guilty that she cannot spend more time with Patrick and realizes that the hospital staff know better how to raise and care for him. She struggles to understand Patrick's medical condition and leaves decisions about Patrick's care to Javier. She cares most that Patrick be able to be happy with whatever life he has, and resists letting the hospital staff inform Patrick of his condition.

## Paco

Paco is Javier's son, who developed cancer at an early age, but ultimately survives.

## Dr. David MacDougal

Armando Dimas's neurologist, who finds dealing with the Dimas family frustrating, due to their unwillingness to face the fact that Armando will never walk again.

## Armando Dimas

Armando is one of the main patients at Hermann. He is a young immigrant from Mexico who is shot in the neck after a bar fight. His partner is Carolyn Alvarez and they have a son Armando, Jr. Armando, in his mother's words, has a "weakness for bad things" and gets into trouble before his injury. He has trouble holding down a job. After his injury, Armando refuses to give up on his condition and consistently maintains that he wishes to live. He is, however, bitter about his condition and incredibly cruel to his nurses as a result. When he moves into Bart's, he finally calms down and comes to enjoy the life he has.



## **Victoria Dimas and family**

Poor illegal immigrants from Mexico who are Armando's parents, brothers, sisters, and cousins. They have a poor grasp of English and so do not understand the full extent of Armando's spinal damage. Even when they finally come to understand his condition, they have trouble accepting it.

## **Lin Weeks**

Lin Weeks is the chair of the Hermann Ethics Committee and a student of hospital structure generally. She also worries about end-of-life issues to a great degree. She has been associated with the committee since its inception in 1983. She often defends respecting patient's decisions concerning their own condition against what doctor's consider their better judgment.

## **Teresa Knepper**

Teresa Knepper is a chemical engineer employed by Exxon. In 1982 at the age of 19 she gave birth to twins, Mark and Matthew. Mark died after two days, but Matthew survived. Teresa and her husband David had enormous trouble caring for Matthew because he appeared to be in constant pain; it turns out the Matthew had cerebral palsy and as a result he did not learn even the basic baby and childhood abilities. When Matthew was two, Teresa joined the ethics committee at a hospital in Gainesville, Florida, learning more about medicine and medical ethics as time went on. Teresa maintains that keeping her son was a great good because Matthew regards his life as worth living: "He's happy because he doesn't know any other way," she often claims. She understands, however, what it is like to be in the position of parents who do not know whether keeping their children alive is a benefit or harm to them. In 1987, Teresa moved to Houston, starting a job with Exxon and her pediatrician sent her to Javier. She met with Javier's nurse Sally and Sally suggested that she become the first non-medical, non-clerical member of the Hermann ethics committee, which she ultimately did.

Teresa is often in the position of offering members of the ethics committee her real-world experience as the parent of a handicapped child. This has a large effect on Kenny and Claire Sparks' decision to have an operation for their son Landon, who has spina bifida.

## **Dr. Sharon Crandell**

Taylor's first doctor, Sharon Crandell is often seen as having a cool and emotionally detached demeanor. In fact, Sharon is attempting to avoid emotional attachment to her patients. Sharon is always on the 'life' side of the ethics debates, refusing in many



cases to allow children to die even when they're terminally ill. Her demeanor and ethical views cause her to clash with others in the hospital.

## **Virigina Lennox**

One of Taylor's nurses, Virgina has a hard time not getting emotionally attached to the children in the premature baby ward.

## **Dr. Eugene Adcock**

Dr. Eugene Adcock is Dr. Crandell's supervisor; He rotates attending physicians duty with Sharon and other doctors. The Poarches like Dr. Adcock much more than Dr. Crandell. He is older and has a warm, kind, fatherly demeanor. This leads him to constantly update Carey and Fran on Taylor's condition, making their experience with Taylor more of an emotional roller coaster than it was with Dr. Crandell.

## **George Henry Hermann**

George Henry Hermann was a 19th century oil man and the son of Swiss immigrants. He made a fortune with oil and when he became sick with stomach cancer in his sixties, he left a large portion of his money to found a hospital. It later became known as Hermann hospital, in honor of him.

## **Norma McNair**

Armando's nurse and manager of the neurology service.

## **Mary Coffey**

Mary Coffey is Armando's occupational therapist. Initially she is confused as to why she has been assigned to Armando; she is typically assigned to patients that have hope of recovery. She nonetheless puts a great deal of energy into Armando's treatment and ultimately fights for Armando to receive a new wheelchair.

## **Cindy Walker**

Cindy Walker is Armando's social worker. A rough woman who gets things done, she informs Armando of his condition, and is surprised that he wishes to live. She attempts to care for Patrick's financial and housing needs during Armando's stay at Hermann and Bart's.



## **Dr. Susan Conley**

Dr. Susan Conley is Dexter Advani's doctor.

## **Hazel Mitchell**

Hermann's financial administrator. A kind woman, Hazel faces the daunting task of deciding whose care Hermann will pay for and whose they will not. Once a nurse, she laments that early on after the Great Society's programs came into effect, little attention was paid to cost.

## **The Advanis, Dexter, Mohamad and Reena**

The Advanis are immigrants from India. Mohamad and Reena Advani have a child, Dexter who has pseudohypoaldosteronism, meaning that Dexter's kidneys do not have the receptors to respond to the crucial hormone aldosterone. This requires a special diet, high in salt, which makes Dexter Sick. The Advani parents are quite aggressive with hospital staff and are not well-liked. They guard Dexter closely so that he does not get used to his nurses. Dexter often screams at them as a result, making it hard for the nurses to not dislike taking care of him. Eventually, the financial administration at Hermann forces Mohamad and Reena to leave due to unpaid bills. They take Dexter home to India for treatment.

## **Dawn Semner**

A physical therapist and friend of Mary Coffey, who helps with Armando's treatment.

## **Lee Zacharias**

The director of Social Work at Hermann.

## **Willene Guttenburger**

The director of Patient Financial Services at Hermann.

## **Randy Gleason**

Hermann Hospital's lawyer.



## Dr. Richard Andrassy

Dr. Richard Andrassy is Hermann's chief pediatric surgeon. He rarely attends meetings about Patrick, frustrating many of Patrick's caregivers. He finds meetings frustrating generally because he thinks they do little good. He finds that most of the ethics committee is ambivalent, so he simply avoids the meetings and do as they recommend. Dr. Andrassy thinks that Patrick should be allowed to die, but does whatever surgery on Patrick that he is asked to do.

## Hermina Bartkowski

"Bart," whose real name is Hermina Bartkowski, runs the Total Life Care Center in central Houston. She keeps high-cost patients in a nursing-home like facility, and that allows her to control costs. Bart is Polish and stern, but with a great deal of optimism. She treats patients with respect and refuses to condescend to them. Bart immigrated from Poland and had been a nurse for along time; once in the United States, she slowly formulated her plan to open her care center. The core idea behind the care center is to put groups of patients together in a house and rotate out nurses to care for them, reducing the number of nurses needed for constant care and holding down costs as a result. Hospitals would help with the bills but her facility helps them control costs as well. Bart's program is successful but she becomes overloaded with patients. She must open a second house.

## Kenny Sparks

Kenny and Claire Sparks have been infertile for some time; they seek fertility treatment and become pregnant with Landon. Landon is born prematurely and has spina bifida. Since Claire is hurt during childbirth, Kenny is left to supervise Landon's care and must make the awful decision of whether to give Landon the surgery that will save his life or let him die. Kenny wrestles alone with his decision, and concludes, in an extremely genuine and human way, that there is no right answer.

## Claire Sparks

Claire Sparks is Kenny Sparks's wife. They give birth to Landon prematurely, who has spina bifida. Claire has some internal bleeding due to Landon's early birth and must stay in another hospital, leaving Kenny to supervise Landon's care. When Claire recovers and learns about Landon's situation, she and Kenny decide that they want to let Landon die. However, they are ultimately convinced by Teresa Knepper and some of the other doctors to give Landon the surgery. They end up raising him along with his younger brother Jared, but Landon's care impoverishes and exhausts them.



## **Landon Sparks**

Landon is the child of Kenny and Claire Sparks. He has a severe case of spina bifida, a condition where the spinal cord splits in two during development. The body does not cover the spine, leaving it exposed. This leads to numerous health problems. After a torturous period of debate, Claire and Kenny give Landon the surgery that will cover his exposed spine, and raise him. He cannot do much of what other children can do, but he can sit up, talk and eat.

## **Dr. Jose Garcia**

Landon's doctor who strongly opposes not giving Landon the surgery he needs. At one point, he tries to prevent Kenny and Claire from letting Landon die and ultimately steps down from taking care of Landon because he believes he is too emotionally involved.

## **Dr. Hatem Megahed**

Landon's neurosurgeon.

## **Dr. Ian Butler**

Another neurosurgeon who advises Kenny and Claire on Landon's future expected quality of life.

## **Eunice Fence**

A ninety-seven year old woman who ends up at Hermann after a severe stroke. Hermann's doctors use all their resources to save her life, frustrating Lin Weeks.

## **Dr. David Oelberg**

Dr. Oelberg takes over for Jose Garcia as Landon's doctor when Garcia steps down.

## **Dr. Jan Van Eys**

Javier's supervisor who often struggles with the same ethical dilemmas that Javier does.

## **Dr. Margo Cox**

A doctor on Hermann's ethics committee who clashes with Dr. Sharon Crandell. She often holds that patients with poor quality of life prospects should be allowed to die.



## **Christine Gladden**

One of Patrick's long-time nurses who informs the hospital staff of Patrick's love.

## **Dahlia Harper**

Armando's speech therapist.





# Objects/Places

## Hermann Hospital

Hermann hospital is located in Houston, Texas and is the location of nearly all of the story's main events. Hermann was created with the money of its founder, George Henry Hermann in 1925. It was created in part to serve charity cases, so a portion of its income is devoted to helping those who cannot help themselves. It is neither the richest nor the poorest hospital in Houston, and often finds itself in financial trouble and scandal, due to the constant, generations-long bad behavior of its board of trustees. Hermann is a fairly large hospital, housing numerous special care facilities, including a pediatric ward where much of the book takes place.

## Committee Meeting Rooms

The Hermann ethics committee often meets in various open hospital rooms.

## Ben Taub Hospital

Ben Taub is the public hospital in Houston which is responsible for the healthcare of those who cannot afford the cost of their care. Things are hectic there and often patients do not get enough attention.

## Methodist Hospital

Methodist Hospital in Houston is the largest private hospital in the world and incredibly wealthy. They are able to give their patients much better care than Hermann could hope to give them.

## Patrick's Home

Patrick spends much of his home time at his grandmother's house, but the house is small, dark and depressing, leaving Patrick longing for the hospital.

## The Total Life Care Center

Bart's Facility where Armando ends up. The Total Life Care Center has a more efficient allocation of healthcare staff than Hermann, allowing it to treat patients for less money. Bart keeps the Total Life Care Center clean, bright and happy. Armando comes to enjoy his life there until Hermann can no longer afford to pay his bills.



## **The Isla Carroll Sterling Turner Neonatal Intensive Care Uni**

Turner is the part of the hospital complex where premature babies are kept. This includes Taylor Poarch and is where her parents, Fran and Carey spend most of their free time until Taylor's death.

## **Patient Financial Services**

Patient Financial Services is where Hermann's finances are managed. They employ in particular Hazel Mitchell, who oversees the allocation of healthcare resources.

## **Patrick's Room**

Patrick more or less lives in his room in the pediatric ward, and much of Patrick's story takes place in that room.

## **Armando's Home**

Armando ends up living with his family at home. His family has been trained by Bart's staff to take care of him, and he finds value in his life.



# Themes

## Live or Let Die

A central theme of *First, Do No Harm*, is the question of whether severely and terminally ill patients should be allowed to die. An initial human motivation in the face of great sickness and need is to do everything possible to keep an individual alive. However, sometimes the patient's quantity of life conflicts with its quality. Should a child be kept alive if her life is going to be miserable and full of pain? Or suppose that she is comatose or severely mentally handicapped? Many argue that a life does not have value if enjoyment of that life is not at least part of it. In *First, Do No Harm*, the live or let die theme is represented by the constant struggle of families to decide whether to give their sick family member surgery to help them live or to allow them to die. Often they cannot determine which course of action is more humane. And sometimes the families worry that they are choosing either option for selfish reasons.

Fran and Carey Poarch face this decision over whether to keep their daughter Taylor alive. Taylor's young life appears to be miserable and her life prospects are exceedingly dim. Eventually Fran and Carey decide to let Taylor die. They believe in the end that they did the right thing, although this does not prevent them from doubting. In contrast, Teresa Knepper and the Sparks's elected to keep their children alive. Initially their lives are full of struggle to care for their handicapped children. Yet in the end they love their children, flaws and all, and are glad they kept them. Perhaps the largest 'live and let die' issue in the book is that of Patrick Dismuke. The hospital staff don't know whether they're 'keeping him alive' or forcing him to 'die in slow motion'. Such matters are hard to sort through for the Hermann staff. In the end, they do everything they can to keep Patrick alive although they realize that they are only prolonging his death.

## Moral Dilemmas and Living With Them

The idea of a moral dilemma plays a crucial role in *First, Do No Harm*. The major moral dilemma in the book comes between two of the doctor's traditional duties: doing good and doing no harm. For most of medical history, these two duties went together, but with the advent of modern medical technology, they are often at odds. In some cases, doing good might mean allowing a patient's suffering to end; but allowing a patient to die is sometimes thought to be a harm, and some think it is nearly always a harm. In this case, what is the right decision? Does one choose to do good? Or to do no harm? What is the duty of a doctor in this case? A nurse? A parent? And if you are in this situation, what is your duty to yourself? The problem with moral dilemmas like these is that there is no obvious answer. And many in the book conclude that the moral dilemmas they face have no right answer at all! Some think that moral dilemmas by their nature have no right answer, otherwise they wouldn't be dilemmas in the first place.



Belkin notes that "This book is about making choices - and living with them" (261). So not only are moral dilemmas problematic, but once a decision is made one must face the choice she has made. The Poarch's must live with the fact that they allowed Taylor to die. Yet the Sparks's must face the toil that is Landon's day-to-day care. While they do not wonder if they made the right choice in the end, from the outside they appear exhausted. It is not clear whether they've rationalized their choice. Kenny Sparks in the end cannot decide what the right thing to do is. Any option to him seems wrong and to have important costs. His exhaustion with his dilemma is a central feature of the book, as he seems to genuinely believe that there is no fact of the matter about what is right in Landon's case.

## The Cost of Care

A recurring theme in the book is the cost of care. For much of history, there was little if any medical technology. This kept healthcare costs fairly low. But as technology has advanced, healthcare costs have exploded. Our initial moral intuition in the face of sickness is to avoid thinking about the cost of care. What is humane is to do everything one can for a patient, no matter the cost, or so we often think. Yet in modern economies, this moral norm proves unsustainable. The care is so expensive sometimes and there is no such thing as a free lunch. Someone must pay the costs. Hazel Mitchell faces this problem daily and hates to deny patient's care; but if she doesn't, Hermann will go bankrupt, and there will be much less healthcare provided to its patients in general. This is in fact the problem: care must be denied in the short-run to keep it going in the long-run. Yet denying a person care goes against our fundamental moral ideal of care. The Hermann Ethics Committee attempts to not think about costs, but they are sometimes forced to by their circumstances. If they do not consider costs, then they threatened the hospital's financial viability. For the most part, when a patient is uninsured or underinsured, Hermann attempts to foot the bill. In many cases, however, Hermann's generosity must stop. This happens in particular with Armando's care and Dexter Advani's.

In the end, some decisions must be made with regard to cost, but it is not clear how to do so humanely. Is Hermann obligated to go into debt and risk financial ruin on behalf of just a few severely ill patients? Yet can they really justify throwing these patients out in the cold or sending them to inferior facilities?

# Style

## Perspective

Lisa Belkin's perspective is that of a background observer. Lisa's job is being a reporter for the New York Times. She was a national correspondent for the New York Times in Texas, Louisiana, Oklahoma, and Arkansas when she wrote the book. The book came out of her three years at the Ethics Committee of Hermann Hospital in Houston, Texas. She started in May, 1988. She sat in on the committee's meetings and observed life and death decisions by patients and staff. She attempts to the best of her ability to record the truth. To the best of her knowledge, she claims, the entire book is correct. When she was not present for an event, she had testimony from someone that was. To get the right wording, she asked her characters to read a manuscript of the book before it was published. All the names are real, save four.

Lisa Belkin attempts to be open, human and impartial. She goes to great lengths to present both sides of each issue, attempting not to judge. The point of the book is to familiarize her reader with the real-life struggles of life and death decisions in American healthcare; as such, she does not take sides. Her writing is lucid, forceful and non-judgmental.

## Tone

Belkin is a professional journalist for the New York Times. As such, her writing is clear, in the style of a late 20th century American editorial writer. Sentences are crisp and to the point. While she engages in descriptions of personalities, locales and patient conditions from time to time she largely avoids jargon. Instead her descriptions attempt to stay close to the personality of her characters. The tone is forceful at times, trying to communicate to the reader the seriousness of the situation at hand. Yet she remains non-judgmental, trying to give her reader both sides of the issues without showing her own view. The author is present at many of these events, but she is entirely invisible in the book, attempting to show her reader only what she saw and nothing about herself. The tone therefore is able to transition a bit between characters, reflecting not Belkin's mood but the mood of the character she is describing.

## Structure

The book is written chronologically, between the months of May and October, 1988. She follows the lives of nearly fifty characters throughout those months. Each month is divided into separate stories, usually surrounding a particular patient. Chapters are not numbered but instead are named after patients, like "Patrick," "Armando," "Taylor," and "Landon." She intersperses chapters on the cost of care, committee deliberations and even a short chapter on the history of the hospital. Towards the end of the book, the chapters are shorter and seem to speed up, particularly as Patrick nears death. The



book does not follow any one story without interruption. Belkin prefers for her reader to get a feel for the debates as they occur, which adds a dimension of stress and gravity to the story. A single story at a time allows one to lose track of what is going on elsewhere, but Belkin's structure makes it easy to see how busy and complicated Hermann Hospital life is.



## Quotes

"The physician must be able to tell the antecedents, know the present, and foretell the future — must mediate these things, and have two special objects in view with regard to diseases, mainly, to do good or to do no harm." (quote from Hippocrates after the table of contents)

"It was standing room only in Room 3485 the day the committee voted to let Patrick die." (13)

"There's no right answer to this one."  
"Is there ever?" (20)

"What the notes don't say and the nurses don't know is that Oria has decided that the doctors and nurses really are better parents to Patrick than she can ever be. They are more educated, more sophisticated, wealthier, and, most important, they can ease his pain and make him well when she cannot." (44)

"Pat, do you want to talk about dyin'?" she said to the tiny boy who was playing with Nintendo, refusing to meet her gaze.  
He shook his head and scribbled "leave me alone" in crayon on his note pad.  
Oria never raised the subject again. (46)

"Doctors have a tendency — and it's not just limited to doctors — to believe that a person's choice is somehow wrong if it is not the choice that the doctor would make," she (Lin) said. (62)

Virginia rarely becomes attached to those babies. Sometimes she even finds herself wondering why she is working so hard to save them. If they live, they will have to return home. "I think that may be more cruel than letting them die," she says. (77)

"Patrick has admitted that he contaminated his line with feces and dirt prior to admission," says one doctor's note. "Says he did not wish to die, just wanted to come back to the hospital." (95)

As they left the room Cindy whispered, "This guy is gonna survive. Now what do we do?" (126)

"We didn't think about money," said Hazel in a wistful tone she might use to describe a time when she still believed in the tooth fairy. "You thought about curing the problems of the world. Nurses certainly didn't think about money. Maybe if we'd all paid more attention then, we wouldn't all be paying so much attention now." (129)

When auto makers design a new car, their flights of imagination are constantly grounded by the question of what the consumer will be willing to pay. But when a surgeon finds a way to simultaneously transplant a heart, a lung, and a kidney, he does not spend time worrying about the bottom line. (129)



Such involvement contradicts the universally held truth that medical care is not based on the ability to pay. (137)

"But we're not supposed to be deciding based on the quality of life," Sharon said. "In this case that's part of the equation." (157)

"Are the parents basing this decision on the fact that their baby may die, or on the way they think her life will be if she lives?" she said.

"I've never taken a baby off a ventilator while she's looking at me," she said in a voice as uncertain as her hands. "I can't do it."

"I just feel there's a need, and I'm the one to fill it," he [Javier] told her. "But I'm less sure than I used to be that I can do this for the rest of my life." (183)

Faced, finally, with the choice he had been inching toward for years, Javier could not simply let Patrick die. ... By dinnertime, he decided to do what no one had done for fifteen years. He decided to ask Patrick. (185)

"We know you lost everything," she said to the veiled figure in the bed. "The one thing you have is your self-respect and you have to keep that. But you don't keep that by acting like an animal. You keep that by acting like a person." (196)

"This is playing God," he told Lin. "I don't feel comfortable with that, the magnitude of that. You make the policies, but I'm the one who actually has to do it. You can't possibly understand how that feels." (206)

... he felt Claire and Kenny had a right to reject the planned surgery if they felt letting Landon die would be more humane than helping him to live. (225)

"If he lives, that's the way it should be," she said. "But if he dies, I can live with that." (229)

"Hell if I know what's best," said Kenny, and they drove the rest of the way in grief-filled silence. (240)

"This is an ethical question that has no solution." (245)

"Ethical questions by their very definition have no solution." (245)

"I want to see the Blue Angels," Patrick said, naming a stunt flying show that was in town for several days. That week, Patrick had decided he wanted to be a pilot when he grew up. (257)

Patrick Dismuke was pronounced dead at 4:45 am on October 7, 1988. Sally Olsen's grandfather clock stopped at exactly that time. (260)

This book is about making choices - and living with them. (261)



"I still wonder whether I looked at all the possibilities to help him," he [Javier] said, "but I don't live hurting. Maybe I've finally learned how to protect myself." (267)



## Topics for Discussion

What is the difference between killing someone and letting her die? Is there a difference at all?

In the end, medical care has costs; but our natural inclination is to ignore those costs. How would you balance morality with the cold, hard economic facts about the cost of medical care?

Did Patrick's hospital caregivers do the right thing by keeping him alive for so long? Or did every extra moment of Patrick's life have value?

Are we obligated to do everything in our power to prolong life?

What matters more, the quantity of life or its quality? Can we cut life short intentionally to choose quality over quantity when they conflict?

Can we do good by harming? In other words, do the duties of doing no harm and doing good ever conflict? When they do conflict, which duty wins?

Did the Poarch's make the right decision by letting Taylor die? Did the Sparks's make the right decision by keeping Landon alive? Could they both have been right at the same time. If so, how?

Are there ethical questions with no right answers? Do any ethical dilemmas have answers?