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HEAL Project
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A Case in Point:

Jason was 16 years old when he died from Cystic Fibrosis (CF). He lived his life fully, setting important goals like striving for good grades in school, with the hope there would be a cure for CF. However, as he sensed the end of his life was near, he spent his last 4 months wrestling with the reality that a cure would not come in time for him .

Jason was the oldest son of Mary and John and he had two sisters, ages 9 and 15. Because Jason didn't talk much about his prognosis, the health care team believed he was in denial. Jason was a private person and the truth was that he and his mother often talked about his dying, even the planning of his memorial service.

Jason did not communicate these things to his father. Why? The answer is "*mutual pretense*". His mother often discussed these topics aloud and gave the impression that she could handle Jason's hard questions. Jason's father, on the other hand, always denied the reality of his disease process. His father never stopped talking to his son about the future. Why did Jason go along with this pretense? He went along because he was protecting his father from additional suffering.

What about his sisters? They said Jason knew he was going to die but never wanted to talk about it with them and they didn't have much luck talking about it with their parents either. As is often the case, this situation reflects the fact that the parents' attention is generally focused upon the seriously ill child.

For the most part, the needs of all family members were more or less met. While the ideal is "*open awareness*" for all, the reality is that this perfect scenario is beyond the ability of many families. At the time, everyone did the best they could.

Case study provided by:
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Caring for a Child Approaching the End of Life & Keeping the Family Together:

A Child's Perceptions of Illness & Death

There are two perspectives one might take in discussing a child's perceptions of illness and death. One would be based upon age-related childhood development and the corresponding cognitive ability to understand concepts of illness severity and death. Another would be a child's ability to perceive and understand the nature and severity of their illness at various stages of its progression in ways you may not have thought of. This issue focuses more on the latter.

Choosing a Family Communication Strategy - when parents choose to bring a child into the world, that choice generally brings with it certain societal responsibilities and expectations with regard to the child's upbringing. Additionally, it is the instinctual nature of parents to love and protect their offspring until they can survive on their own. These factors have a significant influence on our choice of family communication strategies if our child has a life-limiting illness. The first inclination is often to 'protect' the sick child and the siblings by either limiting the flow of information to them or practicing protective deception. Such strategies for communicating the ongoing status and severity of a child's life-limiting illness rarely succeed in their intent.

Illness-Derived Perceptions – children who experience life through the filter of a chronic and life-threatening illness will often do so with a keen awareness. A child has no less desire than an adult to try and minimize the fear of the unknown by collecting as much information as possible, especially when it involves their very existence. The assumption that is frequently made is that children do not have the ability to understand the complexity of their situation and by telling them too much we may instill fear. The hope is that the less they know, the safer they will feel.

Researchers found that children who spent extended periods of time in hospitals as their disease progressed, developed an astute knowledge of their disease and its treatments that was equivalent to that of an adult, despite the parents' best efforts to keep the information from them. This begs the question, "If the child knows this information, why do they often not disclose it to their parents?"

Protection by Mutual Pretense – psychologists answer this question by describing the parent-child relationship as being ruled by '*mutual pretense*'. Webster defines *pretense* as "a claim made or implied, one not supported by fact". Under the concept of *mutual pretense* the parents' intentions are to protect the ill child while at the same time the child is attempting to protect the parents. Such intentions apply equally well to communications with the child and the health care team. The intentional withholding of information, the bending of facts or simply ignoring questions posed by either side are methods used to create mutual pretense.

The series of events required to set up a mutual pretense condition are rather complex and beyond the scope of this issue. However, it is sufficient to note here that the conditions gradually appear to a greater degree with time as the implied rules of the limits of communication about the illness become clearer to both sides (i.e. child vs. parents or child vs. health care team). As the child's illness progresses and he or she is able to assimilate more and more information by experience, the conditions for maintaining the mutual pretense become a delicately balanced drama that can eventually break down.

Open Communications – a child with a chronic and life-limiting illness will perceive more than they will likely disclose to adults. The degree of openness with adults will depend upon the child's assessment of their honesty and the extent to which they can trust them. It is important that the child be given the opportunity to have open communications around their dying if that is their wish.

> "The way we are permitted to die, and the way that we permit others to die, is to enable the living to continue the process of their lives."
> *from The Private Worlds of Dying Children by Myra Bluebond-Langner*

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