

Too Much to Bear

By Dr. Giulio J. Barbero, (1923-1997)



A little boy of 6 years died last night as the result of having not one but two overwhelming diseases, cystic fibrosis and acute leukemia. The last two weeks have been horrible, with all the technology trying to handle the cascade of problems from both these diseases in the same person. I watched his devoted parents sitting by the bedside amongst myriad tubes and paraphernalia that characterize modern intensive care.

Two years ago the 12-year-old sister of this little boy died of cystic fibrosis. This was a girl with a beautiful smile—a source of inspiration to all about her. The grief of her parents and her little brother was profound. The boy had frequent talks with me about his sister. He couldn't wait (at 4 years of age) to come in, climb on the desk, and say "Let's talk about _____!" He would then tell me how he saw her in heaven with other angels all dressed in white, still looking as radiant as she had in times past, with her golden curls spilling down her shoulders. He glowed as he talked about her; and eventually he helped his sad parents go to the cemetery where he stood talking to his sister at her grave. In a few months, he seemed finally to have finished grieving, and he no longer felt the compulsion to discuss his sister as the main reason for our visits. Although his cystic fibrosis had flared up, he plateaued and remained stable for two years until he came down with the leukemia.

His short life was snuffed out by just too much disease. I had many questions, the most striking of which was whether there was a relationship between his sister's death and his leukemia? Some might say yes.

At the same time, it struck me how some people are confronted with a great burden of adversity and suffering, while others seem to be spared such large doses. It seems an incomprehensible fate that some, such as these two parents, have so much to bear. I have witnessed how important faith has been for people faced with disaster. The mother of the little boy said she told him that he was pretty sick. He agreed. She said God might need another angel to join his sister in heaven. He seemed to consider this picture with some deep thought and agreed that, yes, "God might need another angel in heaven."

Seeing suffering is a common experience in the life of a physician. Strangely, I've noted more similarities across people than difference—most show remarkable strength in handling major events. With support from family and medical staff, they somehow maneuver through the complex flow of therapy and suffering. At times they rage against the unfairness of their lives, and, then, they settle back into the unnatural current once more.

For our part as physicians, the process of care needs to include an ability to listen to the pain without the encumbrances of false assurance. Quiet reflection, untrammelled by the noise and rapid pace of life, allows the evolution of perspective. It is a shared sadness—loss and pain in the patient as well as a sense of failure and caring in the physician. It becomes almost a bond of strength forged between us so that, even in the midst of tragedy, the experience somehow also takes on rich and positive overtones.

How much can one bear? The question may seem to belabor the obvious. Yet it is important to incorporate it in our sensitivity so that we quietly listen to the pain and, thereby, relieve it in small measure. When human beings share in such struggles, tolerance and resilience tend to grow stronger. Isn't this by itself an important part of our role as healers.

About the author and the painting:

Barbero was part of the research team that described cystic fibrosis 50 years ago. The late professor emeritus pioneered special diets that helped improve the life expectancy of cystic fibrosis patients from just a few years to nearly 31 years today.

First a famous symbol of physicians' dedication, "The Doctor" was painted in 1891 by Sir Luke Fildes. The painting also was employed to stir popular sentiment in the American Medical Association's fight against socialized medicine in 1949-52.