Case: Mrs. White (not her real name) was a 55-year-old woman with metastatic lung cancer who received home hospice services for approximately nine months. Mrs. White lived alone after her husband died of cancer ten years earlier. They had no children. Her mother was her only close contact.

Mrs. White spent the last four months of her life in constant pain and short of breath. She had massive leg swelling and a large pleural effusion (fluid around the lung) that made it very difficult for her to breathe and move about. She spent almost 24 hours a day sitting in a chair with her head bowed on the table. Mrs. White was fully alert and oriented until the last week of her illness.

The hospice team saw Mrs. White at home at least twice a week during her illness. Multiple attempts were made by the team—nurses, aides, social work, clergy, and physician—to convince her that her pain, shortness of breath, and swelling could be controlled relatively easily with medicines. We also thought she was depressed. Despite our best efforts, Mrs. White refused to take medicines and she died in pain.

Discussion: Medications are not a panacea for all suffering. As expressed in a Paul Simon song, to believe medicines hold all the answers is to risk invalidating a patient’s experience.

Well there is no need to complain.  
We’ll eliminate your pain.  
We can neutralize your brain.  
You’ll feel just fine.  
Paul Simon—The Big Green Pleasure Machine

There are many reasons why patients may not take medicines, e.g., fears of addiction, fears of tolerance (“if I take the medicine too much it will stop working”), and concerns about side effects. I suspect these were not major reasons why Mrs. White refused to take medicine. Maybe she thought that medications were a reminder of her imminent death. Maybe she did not want to relinquish control. Whatever her reasons, we were never privy to them.

Taking care of patients such as Mrs. White can be very humbling. As clinicians we often think we can fix anything “if patients will just do as we say.” Some patients just can’t be “fixed.” For patients like Mrs. White, maybe the most important thing to do is the most difficult—being present and available, despite how hard it may be for us to watch. I believe Ms. White wanted us involved. After all, she never asked us to leave.

We will never know why Mrs. White preferred to suffer rather than take medications. She lived 54 years prior to our involvement. The sum of her experiences made her the person she was. It would therefore be arrogant of us to believe that in our limited time with her, she was obligated to share with us her innermost thoughts.

For more information about Forbes Hospice or Forbes Hospice home care services, please contact: Randy Hebert, MD, MPH, Medical Director, Forbes Hospice, at 412-302-8875 or at rhebert@wpahs.org.  
Cases of the month can be found at: http://www.wpahs.org/hospice/index.html