

This is a resident case log of a patient encounter in which an “Aware Medicine topic” was central.

Terminal Illness Too Young

Caring for a young woman with cancer is difficult. Caring for a young woman with six children and metastatic cancer with no treatment options is devastating. However, working with the patient, understanding her goals and expectations, and just being a resource and friend can help improve the quality of each day. I first met NP at my continuity clinic. She was transferred to my care by a graduating resident. This patient was a challenge from the start. With anxiety and agoraphobia, it was difficult for NP to come to the clinic and wait in an exam room. Having put off diagnosis and treatment of her cancer for years due to fear and distrust of the medical system, NP now faced a grim prognosis. She continued to have hope for the future and did not want to consider palliative care as an option. Her concerns about palliative care were twofold. She felt like it was a sign of giving up, and she did not want the intrusion into her family life.

Getting NP involved with hospice was my primary goal. I felt that it would not only be a vital resource for the patient, but for her children as well. Each visit that I had with NP would include a discussion of hospice, and continuously, she refused. This continued for several months. During this time, I would fit NP into my schedule when she had pain needs or acute issues related to her cancer. I went on home visits and met members of her family. Despite my efforts, NP would have multiple ER visits that would result in extensive testing and procedures. I continued to think that she needed hospice. Hospice would satisfy all of her needs. I could not understand why she would not want to have extra help and extra resources. Visit after visit I explained the benefit and my reasoning for her involvement with hospice. One day, NP told me that she did not want hospice care because she did not want to face death. She did not want to deal with leaving her young children behind. Her goal each day was to get up and do something memorable with her children. Taking time to work with hospice would take time away from that. I presented hospice as a way for her children to start to cope with her death. NP stated that she wanted to do that in her own way. She was making tapes, writing in journals, and talking to her children about her illness.

One clinic visit, I asked if NP would bring her oldest daughter with her. She was a nurse and a main caregiver when NP needed help. During that visit, her daughter offered much insight and guidance. It was at that visit that NP agreed to speak with hospice. I made the referral, and now NP is getting hospice care, but on her terms. She has a nurse available if needed, but no one will come to her home unless she has a problem. Her daughter told me that the family is relieved to have extra help and someone to assist them, no matter the time.

Overall, I think that the outcome was positive. NP now has extra help as she deals with a terminal illness. I also think that our relationship has grown, and NP trusts me as her physician. I would probably change my level of persistence for hospice. I did not need to mention it at every visit. NP was thinking about her mortality and making arrangements and would likely have come to the same conclusion without my constant input. I also would have liked to involve her daughter sooner, as that visit provided significant insight into the patient’s life and way of thinking. I often felt frustrated during this process, like when NP would go to the ER multiple times. I kept thinking, hospice, hospice, hospice. I wanted NP to make the decision on my timeline, not hers. I learned to respect each patient’s individual time. I felt very supported by my clinic partners and NP’s family. Everyone wanted to see NP have the best quality of life.