A close relative of mine has been diagnosed with breast cancer, and, once again, I find myself pondering how a patient manages to navigate through the healthcare system without being related to a nurse or physician. How can a layperson access information from the best literature, sift through the evidence, and decide what is the most appropriate treatment without professional guidance? I am sure that your first thought is to ask the nurse. But what if the nurse is not familiar with the evidence?

That is exactly what happened to my relative. She was initially seen in a neighboring community of New York City and was told by the nurses in a breast center that she needed a port. On what basis was this recommendation made to a healthy young woman, prior to even a venipuncture? I wonder if this is a reflection on the extravasation incidence at this center. She also was told that she should never lift anything heavier than 10 pounds or have blood drawn from the affected arm. Why are mastectomy precautions being given to a woman who had a sentinel lymph node (SLN) biopsy? There is a remarkable lack of substantive evidence that these precautions are effective in someone who actually had a mastectomy, and yet they are being extended to SLN biopsy patients? The oncologist recommended a treatment regimen that is not the current standard but did not discuss that fact, nor did he delineate the various treatment options available to her. The nurses and physician left her with the strong impression that she should hurry to start treatment, and she actually worried about taking time to seek a second opinion.

Fortunately, she sought a second opinion from the center that I recommended and is receiving a dramatically different treatment regimen than the one discussed originally. The evidence behind the treatment options were explained to her, and it was clear why one regimen was recommended for her specific case. I accompanied her to her first treatment and was delighted to hear the nurse at the Evelyn Lauder Breast Center at Memorial Sloan-Kettering Cancer Center teach my relative about side effects and self-care based on the literature.

What is troubling about these events is that most patients do not have a relative to send them articles to read, correct the misinformation given by some professionals, push them to get a second opinion, or tell them where they should go for that opinion and treatment. The average patient is dependent on the information given at his or her doctor’s office or treatment site. And, obviously, some cancer treatment sites are less equal than others. Some of the best care that my relative received was given by the hairdresser from whom she bought a wig. Edward, at “Barry Hendrickson’s Bitz-n-Pieces” in New York City, gave good information in a quiet, compassionate manner. He was able to talk about the most dreaded side effect in a way that left her optimistic. Quite a feat.

It is absolutely our professional obligation to be knowledgeable about the science upon which our care is based. It is our professional obligation to keep up with the evidence. It is our professional obligation to teach the evidence. We need to be writing about how we take care of patients with a specific diagnosis, including all of the treatment options available to them. How wonderful it would be to give a patient a CJON article that teaches him or her about the disease and care options! So, let us all get busy and write these articles. Then we can give them to those oncologists and nurses who are not informed about the current evidence. All patients with cancer will benefit directly, and isn’t that what we are all about?