

Does the doctor know best? What I learned through self-advocacy.

Lynn Nye, PhD



I began my career developing immunodiagnostic tests in London, England where I obtained a PhD in immunology. I am the owner and founder of Medical Minds, Inc, a medical communications agency that specializes in healthcare professional and patient education. Over the past 25 years I and my colleagues at Medical Minds have developed national and international educational initiatives in almost every disease category, including oncology diagnostics and therapeutics.

I am a cancer survivor.

In 2019, I moderated a panel discussion at EyeforPharma (now Reuters) entitled *Does the Doctor Know Best?* The focus was on patient-centric care, specifically the gaps between patient and physician opinions and perspectives, and how these gaps can affect patient management.

Fast forward to 2023, a year in which the question “Does the doctor know best?” turned, for me, from an academic one to one that has been deeply personal. The following story is a real-world example of self-advocacy, a topic I have talked and written about since the late 1990s. I am sharing it to:

- Inspire us all to learn about our options and advocate for ourselves before making decisions about care
- Help healthcare professionals understand the need for patients to be well informed and to encourage physicians to proactively encourage patients to participate in joint decision making

My story starts with a diagnosis of breast cancer. It was early stage, but the cancer was in several locations. So, after multiple tests, my doctor and I decided that a mastectomy was the best option. That was a good decision, and I am now cancer free. However, the next steps were not so straightforward.

At the time of my mastectomy, my oncology surgeon and breast reconstruction surgeon persuaded me to have a full implant as part of the surgery. I was a bit stressed at the time and trusted their judgment. But I should have followed my own advice and done some more research. After the fact, I learned that complications are more likely with this approach versus implanting a tissue expander as a first step at the time of surgery.

As it turns out, I was one of the unfortunate ones who experienced complications. I got an MRSA infection and had an allergic reaction to the infection. I was hospitalized for three days and received intravenous steroids and vancomycin. Despite subsequent oral antibiotics, the infection never went away, so the implant had to be removed.

A year later, having healed fully from two surgeries as well as the infection, I had to decide what to do next. This time, I did my research and reviewed the published literature to understand the options. I also took the time to talk with a number of different physicians to see how they would approach continued treatment. These included my oncologist and primary surgeon, as well as five different cosmetic, plastic, and reconstructive surgeons. The recommendations I received from these professionals were surprisingly conflicting:

- Remove some of the remaining tissue and insert a new breast implant
- Receive a latissimus dorsi (LD) flap, where skin, fat and muscle from the back are used to make a new breast
- Receive a transverse rectus abdominis muscle (TRAM) flap, where tissue from the abdomen is used to create a new breast
- Undergo a two-stage procedure where in the first stage, a tissue expander is inserted and slowly filled with saline during periodic visits and in the second stage, the expander is removed and replaced with an implant

After receiving these varied recommendations, I again checked the information available on some reputable advocacy websites and reviewed recent publications. The literature seemed to favor the two-stage procedure, and that also seemed to be the most common approach. But a friend of mine had had a TRAM flap and was very happy with it, and one surgeon thought this could be an option for me. However, two of the surgeons said the LD and TRAM flaps are major operations with several disadvantages, and they recommended the two-stage procedure.

In addition, there were insurance issues. Neither of the two surgeons who recommended the two-stage procedure—which I was leaning towards—took my insurance. One wanted to charge more than \$40,000 and the other, who was in the same hospital system, only \$15,000 for the same procedure! Both surgeons were highly recommended and seemed equally competent. So I was thinking about scheduling the \$15,000 surgery. But I also had an upcoming consultation with a final surgeon who had an excellent background and was highly recommended. We met and he had what felt to me to be the most logical approach, one that incorporated fat transfer to protect and strengthen the skin, followed three months later by a modified procedure with a tissue expander that further protects and strengthens the skin, followed by the final placement of the breast implant after another three months. He also took my insurance. He was the one I moved forward with.

Advocating for myself has been a very interesting learning experience that has reinforced my belief in self-advocacy. I am not a typical patient, since I have spent my entire working life in healthcare, but I believe that everyone can advocate for themselves. Everyone has access to information on the internet, and if in doubt we can always get a second opinion.

Healthcare professionals sometimes complain when patients “Ask Dr. Google,” but a well-informed patient can participate in treatment decisions and is most likely to have the best outcomes. So, it’s in a doctor’s best interest to recommend that the patient does their own research before making important and sometimes irreversible decisions.

The bottom line is that it’s important for patients to practice self-advocacy and to learn as much as possible about treatment options and participate in joint decision making. The doctor may know what’s best, but the best chance for the best possible outcomes comes from patients being involved in the decision making.

Want to learn more about self-advocacy? A colleague of mine, Kristen Allen, and I have collaborated on a workbook that may be of help. It’s called *Good Decisions Are the Best Medicine: How to Work With Your Doctor to Optimize Outcomes* and it’s available [here](#).