



FORUM/ESSAY & COMMENT

# Wanted: a professional patient's advocate

By LORI WALD FRIEDBERG

**HELP WANTED:** Dynamic individual sought, adept at problem-solving, with excellent communications skills. Requires a B.A. in a medical field along with hospital experience.

In November 1989, my 34-year-old, healthy husband was diagnosed with lymphoma, and I began my new (and unwanted) career of patient advocate. Anyone burdened by this career understands the paradox. The occupation is thrust upon the recipient at the beginning of a major medical and life crisis. The crisis saps all available energy, and nothing is left for the important task at hand.

My new job entailed researching medical facilities; communicating with oncologists, radiologists, nutritionists, therapists and assorted other medical personnel; tracking down hospital records, reports, X-rays and

slides and making sure they arrived at the right medical facility at the right time, and ensuring that our medical insurance paid as many bills as possible.

I began as an uneducated health-care consumer and have unwillingly graduated to patient advocate.

My fantasy is to have a medical professional at the helm who is entirely objective and unaffiliated with any medical institution. In this way, the advocate consistently has the patient's best interest at heart.

Blind faith in a family physician can result in referrals to institutions that the physician has an allegiance to and not necessarily the best institution for the patient's treatment. When referring a patient to a medical facility, the advocate has no pecuniary or other connection to the medical facility recommended, so any conflict of interest is eliminated. The advocate also has access to information regarding medical and research facilities in a large geographic area.

A patient advocate could advise patients regarding traditionally non-medical issues and medical support information. It would be wonderful to be able to have information and the best way to deal with ornery insurance companies.

Beyond that, conferences with highly acclaimed and highly specialized physicians are often painful and unproductive. Physicians' egos frequently get in the way of good communication. Disorganized hospital systems contribute to non-productive meetings. Often necessary hospital documents or records do not arrive on time. Meetings with doctors are unproductive because the right records have not reached the right destination at the right time.

Further, the patient advocate could inform the patient and take the time needed to help patient prepare. In preparing for the delivery of our three children, my husband and I attended Lamaze preparation for childbirth

classes, my daughter attended a sibling preparation class, we were entertained on a hospital tour of the labor and delivery room and shown a lot of cute babies in the nursery.

By contrast, when my husband was admitted for his bone marrow transplant we were hustled down a long scary corridor filled with patients wearing sterile masks and attached to IV poles. We were subsequently informed he was lucky not to need the routine tooth removal and here comes your first spinal tap. There was in essence no preparation for a month-long ordeal that we affectionately refer to as the mother of all hospital procedures. A patient advocate could alleviate some of the anxiety and the unknowns.

Unfortunately, the least qualified person to be a patient's advocate is one who has an intensely personal and unprofessional relationship with the patient. As the spouse of a cancer patient, I freely admit that I am totally subjective when it comes to medical care for

my husband. I simply want the best medical treatment available.

Other considerations are irrelevant. That attitude often puts me at odds with all kinds of hospital personnel and pencil-pushers intent on accomplishing their assigned task in the least energy-expanding way. An objective advocate, focused on his client's best interest, could much more easily keep things in a proper perspective since the advocate's emotions are not a prominent part of the decision-making process.

The fantasy help-wanted ad simply does not exist in the classified ad section of this newspaper. And the existence of the ad would not do much to solve this country's health-care crisis. But the existence of a patient advocate would earn eternal gratitude from those who continue their very personal struggle to get the best medical care available for someone they love.

Friedberg lives in Lyndhurst.