

## **“Medical Advocacy for Patients Facing Cancer and Other Complex Illnesses”**

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The way I describe my work to puzzled fellow physicians is that I am doing what they probably do for a personal family member or very close friend or an extra special patient just diagnosed with or dealing with a tough cancer. It's all the extra things: checking key records, making sure they've got good people working with them and if need be, communicating with the surgeon or pathologist or radiologist, and often then searching the medical literature with that person's case in mind, not just glancing at a few abstracts, but putting in the time to come up to speed and actually read full-text articles, then calling or emailing authors of on-point papers or those putting on clinical trials; maybe even scouring the country or world for pre-publication information from recent meetings; and, most importantly, spending time on an ongoing basis debriefing with the patient and family after key appointments or procedures, fielding the multitude of questions and worries that inevitably occur – all the while providing counsel and helping plot a course for the future. That's when fellow physicians realize what medical advocacy is.

I started this work in 1988, as a way of trying to help those trapped in medical situations where their doctors or an institution couldn't find a diagnosis or a treatment that worked, or where everything had gone wrong, or where they had completely given up on a patient, or worse, that the doctors or institution were utterly unwilling or actively obstructionistic to what the patient hoped to have done. For whatever reason, I've always been pretty good at resolving such dilemmas, and early on found that the answer was to not align myself with the medical profession per se, but rather with the patient.

Medical advocacy, then, is to be wholly patient-centered and to go one step further and be patient-directed. The patient (and/or, if so designated, their family) is my boss. I'm a physician in their corner, serving as their personal consultant and researcher, advocating to help them gain the information and access and authority they need to be in charge of their own case.

I'll consider taking on any patient, any age, any problem. All told about half my cases are cancer-related, often high-risk or unusual tumors, recurrent or metastatic disease, and when expected-to-work treatments just haven't been working.

70% of my patients are from outside the Bay Area – from all parts of the country and world – which has helped me see the profound geographical differences in the practice of medicine, and also to have a sense of what is going on where, leading to a unique network of colleagues and healers.

About 30% of my patients or their spouses are MD's, PhD's, or lawyers – in other words, people who recognize when “standard of care” isn't enough. I've always had more patients than I can accept, and so have tried to stay underground and, for instance, have never put up a website – just giving this talk is a stretch for me. Patients find their way to me by word of mouth, mainly from people I've worked with, and so they've usually heard that I like patients who aren't passive and are ready to work.

I don't assume their care, nor do I treat them, other than with information and ideas and hope. I charge as a lawyer would, just for my time, all out of pocket - but with a sliding scale, plus there's a slush fund from grateful past patients to help out.

I've always done this work by phone, with 2+ hour new patient appointments and 1+ hour follow up appointments. Most cases go on over several months, some for years. I don't give up; there are always new things to try.

I have had the privilege of working with many “exceptional patients” – in other words, those who become long-term survivors, including several high-grade ovarian cancers, who despite all odds – and often with use of innovative approaches like immunotherapies – are alive and free of disease 10, 20+ years out.

I only take on one new patient a week – anymore than that and I've found my case load gets too large and I become like most physicians, with too many balls in the air and not enough time. Time, really, is what is unique about my practice – complex medical problems require a lot of time, and very few physicians or clinics are set up to provide that time.

In fact I would say that has become the number one reason why patients find they need my help – their doctors keep schedules that don't allow them to spend nearly enough time. Even the most straight-forward seeming case of a localized breast cancer or newly diagnosed ovarian cancer generates an ever growing array of questions and issues that need to be worked through.

In fact, if I were to make a list of additional major reasons why patients with GYN or other cancers come to me, it's:

- (1) Feeling that their doctors are missing something but they are struggling with how to go about getting outside opinions without alienating their doctor
  - (2) They are struggling with treatment toxicities
  - (3) They want a plan to prevent recurrence
  - (4) They want an integrative plan, addressing nutrition, exercise, the psycho-spiritual, sleep, sexual functioning, use of unconventional therapies
  - (5) They are suffering from imposed hopelessness and a feeling of having been given up on –
- AND Covid restrictions haven't helped any of the above.

I've had several physicians who came to study with me who after a year or two started their own medical advocacy practices, and with them, from 2016-2018, we put on a community-based medical advocacy fellowship training program for 10 experienced practitioners from various fields of medicine, who on completing our very hands-on fellowship then either became full-time advocates or folded advocacy into their own practices. We've continued a monthly salon in which we present cases and problem-solve and mentor each together. It's been a godsend to have other advocates I can refer patients to who need help sooner than I can start with them.

Last thing to leave you with is that most advocacy is self-advocacy, so don't hold back – stick up for yourself, and if you're too ill or too beaten down, ask someone in your family or a close friend to be your advocate or help you find an advocate.