

SHOULD I GET A SECOND OPINION?

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Whether an individual should get a second opinion for a medical condition is not a simple “yes” or “no” question. The answer is dependent upon the patient’s level of trust and their relationship with their physician, the level of confidence in the facilities of the associated medical center, plus the patient’s understanding of the condition and the therapeutic options available.

There are many very well-trained medical oncologists in practice who have received superb mentorship at large academic medical centers who are extremely bright and facile in the management of malignant disease. Unfortunately, in most practices, Waldenström’s macroglobulinemia constitutes no more than one-half of 1% of a general oncology practice. Therefore, in most practices, a physician can be expected to see a patient with newly diagnosed Waldenström’s every second or third year.

This raises unique issues for Waldenström’s patients, issues that are not shared by patients with breast, colon, lung, prostate, or stomach cancer.

In a disease with unique issues, there is no greater teacher than direct experience. I, myself, am extremely thankful to all the Waldenström’s macroglobulinemia patients whom I have had the privilege to see and serve over the years because they have taught me more about the disease than anything that can be printed or written in manuscripts or textbooks. A reasonable metaphor to consider is as follows. How would you feel if a plumber came to your house, a problem was reported, and his response was: “I have never seen this type of hydraulic problem before, but I brought my plumber’s manual with me to help me manage the situation.” How comfortable would you be in this situation?

A similar example would be if you brought your car to a repair shop and you were told, “I have never seen this type of automotive problem before in my career, but I will read the manual, which should get me up to speed with the types of problems your car has had.” Do you not owe it to yourself to treat yourself better than you would your car or your plumbing? Would you place your trust concerning a medical problem in an individual with no experience pertinent to the problem at hand?

Speaking personally, I would prefer to consult with someone who graduated in the middle of their medical school class but who had decades of experience with my problem than with someone who, while graduating first in their class, had no experience with the problem but committed themselves to learn as much as they possibly could about it. I would not choose this second option. I would not allow this to occur at my own expense. I think, in the situation where a practitioner has limited experience, it is reasonable to obtain a second opinion to help guide care.

There are other issues. In medical centers that have extensive experience with the disease, oftentimes research is actively ongoing. Being a patient at a medical center may allow the biobanking of specimens such as blood and bone marrow that could be used for a better understanding of the disease itself. The finding of the MYD88 mutation was certainly derived from patients who were willing to allow research on their blood and bone marrow, thus leading to a breakthrough discovery applicable to

all patients with Waldenström's macroglobulinemia. Therefore, it is relevant to ask whether the diagnostic testing that you are subjected to will benefit other patients or is simply being used as a diagnostic tool.

At medical centers where Waldenström's macroglobulinemia is infrequently seen, there may be no available treatment protocols designed by the best and brightest in the field to move outcomes to the next level. Being seen at a medical center that specializes in Waldenström's offers the potential for clinical trial participation that might in turn allow treatment with a brand new agent that is promising in Waldenström's or might allow treatment with new combinations of existing agents. Eitherway, the resulting outcomes are potentially better than at other medical centers that do not provide such options. These types of protocols are frequently unavailable at smaller medical centers because the cost of opening clinical trials where accrual numbers are expected to be small is an inefficient use of resources. It is, therefore, important to ask the oncologist whether they participate in a cooperative group and, if so, does this group offer the opportunity to participate in clinical trials or is the only available option the same therapy that has been used for decades.

There are other obvious considerations (the expense of travel, the difficulty of accessing a large medical center with expertise) that will influence the decision. IWMF- Talk, the Waldenström's talklist, contains many reports of patients who went for a second opinion and were disappointed. Alternatively, quite a number of reports are recorded by those who were reassured by the fact that the treatment they were receiving was first-tier, and appreciated the opportunity to have a large medical center with expertise to follow along their disease course in the background. These patients also appreciated the opportunity to establish a relationship with an expert in the disease that would allow access to new agents should the need arise.

Clearly, there is no "one size fits all," but, hopefully, this article helps with some of the pros and cons that an individual diagnosed with WM needs to address in making this important decision.

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