

GETTING THE MOST FROM MY PROVIDER VISIT

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Introduction

The treatment of Waldenström macroglobulinemia is indicated only for those patients who have symptoms. If you are an asymptomatic patient placed on a “watch-and-wait” strategy, it is important for your provider to be able to identify whether any relevant symptoms exist. In other words, you as a patient need to be aware of what your provider is looking for so that your appointment time is optimized and leaves an ample period for questions to be satisfactorily addressed. Today, all providers are very busy and their time available to manage a face-to-face visit is a limited. As a consequence, having a checklist becomes important in expediting your evaluation.

First Visit to a General Oncologist

When patients are referred to a medical oncologist in this setting, typically they have already been identified as having a monoclonal IgM protein or they are being sent for evaluation of lymph gland enlargement or anemia. Reporting symptoms is of critical importance to the provider so that he or she understands what drove the evaluation initially. To say, “I have anemia” or “I have peripheral neuropathy” is *not* to state symptoms. Such statements represent diagnoses, and diagnosis is the responsibility of the provider. The responsibility of the patient is to report the symptoms that led to medical evaluation, whether stating, “I have no symptoms; my doctor found a low blood count or a protein abnormality on my annual physical examination,” or “I was feeling run down and tired, was unable to climb stairs, so I went to the doctor,” or “I have numbness and burning in my feet that began eight months ago,” or “I found a lump in my neck or a lump under my arm, which I believe to be a lymph gland.” Such symptomatic reports will allow your provider to immediately focus the evaluation to ensure that you have the greatest satisfaction from this first visit.

On seeing a general oncologist for the first time, you may have outside records from your primary care provider. To bring 200 pages that have been photocopied and are in random order is not particularly beneficial. Most of the office visit will be spent sorting records with very little time spent in face-to-face dialogue about your concerns. In the case of Waldenström, what the doctor will need to see on the first visit will include any protein levels done at any time over the past few years, as well as complete blood counts, since anemia is such a conspicuous problem with this disorder. If you have had regular checkups over a long time, tracking changes in the blood count levels can be extremely useful in trying to reconstruct the tempo of this disease. Therefore, if it is possible for you to sort through and get the specific laboratory tests that relate to protein levels and complete blood counts, the results of any imaging studies such as X-rays or CT scans, and year-over-year records that outline changes in these parameters, you will be helping your oncologist understand how long the disorder has been present.

By sharing this information, you will be able to give your provider answers to key questions, including: How long has this likely to have been present? How serious is the impact on my body? If treatment is indicated, how urgent is it? To understand some of the relevant testing that your doctor will be looking for in the records is to know the five key parameters for staging of Waldenström macroglobulinemia. These parameters are age, hemoglobin, platelet count, IgM level, and β_2 microglobulin. These tests will not only help your physician, but they will also help you since you will know what your disease stage is, should you require therapy.

Subsequent Visits to the Oncologist – “Watch-and-Wait”

In the situation where observation (“watch-and-wait” as it is often called) has been selected, the primary parameters will be monitoring for increases in the IgM level or declines in the hemoglobin level. The physical exam is adjunctive because it allows the physician to determine if there is lymph gland enlargement or liver/spleen enlargement. The key questions for patients include the following. Has there been increased fatigue? Have you noticed any lumps or bumps anywhere (lymph nodes)? Have there been any infections since I last saw you? If so, how were they treated, and how long did they last? Follow-up office visits for “watch-and-wait” patients generally can be efficiently accomplished in 15 minutes or less by recounting interim symptoms. Always point out if you have had nose bleeding or gum bleeding, or numbness or tingling in your hands or feet. Always bring to your visit a list of all medications that you are currently taking so that this can be reconciled with what the physician has on record. This is particularly important if there has been a change in medication since the last visit; if so, this should be identified clearly in the written list.

Subsequent Visits to the Oncologist – While on Therapy

For patients on therapy, the two key issues with each visit include understanding treatment efficacy as well as treatment toxicity and side effects. A change in clinical level of fatigue, whether better or worse, becomes important. Whether there were any interim infections related to therapy, reporting of fever or chills related to treatment, the need for any transfusional support since last seen, hospitalizations, numbness or tingling in the hands and feet – all are relevant for your provider to know because a key part of the subsequent visit of a patient on treatment is to determine if adjustment or modification of dosage is appropriate to help manage toxicity. Not all side effects can be measured by your provider using blood tests. Insomnia, mood swings, and agitation are common side effects of certain medications but cannot be measured on any diagnostic tests. The same is true for the development of numbness or tingling in your hands or feet, which can be a toxic and irreversible side effect that must explicitly be mentioned to allow dosing adjustment that prevents permanent effects of therapy.

Seeing a Waldenström Specialist for the First Time

When to Get the Second Opinion

In the majority of individuals, Waldenström macroglobulinemia does not require emergency treatment, so there is time to contemplate the next steps. Because there are so many different options available for patients and because patients may be potentially eligible for innovative and less toxic therapies, the ideal time for first contact would be *before therapy has begun*. Once therapy has been initiated, the ability to benefit from new and innovative therapies available at specialty centers is severely limited since many of them are reserved for previously untreated patients. Therefore, it is more preferable by far to get a second opinion *before* treatment rather than after two cycles.

It is important before seeking a second opinion to discuss it frankly with your local oncologist. This conversation will provide a significant degree of insight into the relationship as it goes forward. Given that Waldenström macroglobulinemia is an extremely rare disease and most local providers see it only occasionally, one would expect a warm response to the question of a second opinion. Confrontation or threats should suggest this relationship is not one that will be an ideal in the long-term. A new practitioner might be considered. Likewise, it is the responsibility of the Waldenström specialist to communicate respectfully with referring physicians, to respect their choices when they are reasonable, and not to try to set up a situation of conflict with the patient in the middle.

One of the advantages of early contact with a Waldenström specialist is that it allows development of a long-term relationship, so that if there is a status change, it becomes possible to return for ongoing care and advice with an already-established record.

Identifying a Waldenström Specialist

There are a number of ways to identify specialists in Waldenström. Most university medical centers have a list of experts who see large numbers of patients with Waldenström. Search engines such as Google Scholar will allow you to identify specialists who have extensively written about Waldenström macroglobulinemia. If you have a name in mind, a Google search of the physician will certainly identify whether he or she has specific expertise in Waldenström macroglobulinemia.

The International Waldenström's Macroglobulinemia Foundation (IWWMF) website is a tremendous asset in identifying a specialist. The IWWMF support groups will allow you to connect with individuals who have sought second opinions and identify specialists with expertise. Checking the agenda for the annual patient Educational Forum sponsored by the IWWMF will introduce you to WM experts among the speakers invited by the IWWMF to discuss aspects of Waldenström, usually based on expertise that has been identified by the Foundation. On its website, the IWWMF has a section called "Finding a Doctor," which includes an international directory of doctors and their locations. This list is by no means exhaustive, and there are many outstanding individuals who have not been mentioned, but it is a wonderful starting place.

What Do I Bring to the Second Opinion

Ideally, you should bring a short summary from your home physician outlining the indications for the referral and the pertinent laboratory studies. If a bone marrow or lymph node biopsy has been performed, carrying by hand or having the slides sent in advance for review is helpful. For pathologic tissue samples, a review of an outside photocopied report is insufficient. My best patients have gone to the trouble of providing a pertinent summary of prior therapy regimens and dates, protein levels, and complete blood counts over time. Even better, they will usually do this in Excel format and hand-carry it for me so that, at a glance, it is possible to see each treatment, the impact on the IgM level, the impact on the blood counts, both good and bad, and some discussion of side effects – this is the ideal situation. When patients are proactive, they get the most out of their second opinion since they can spend their time asking questions relevant to them and receive the most from an expert's advice, rather than spend the time in record review. In Figure 1, my patient shows, over a period of two years, serialized changes in the IgM level as well as the dates of rituximab therapy.

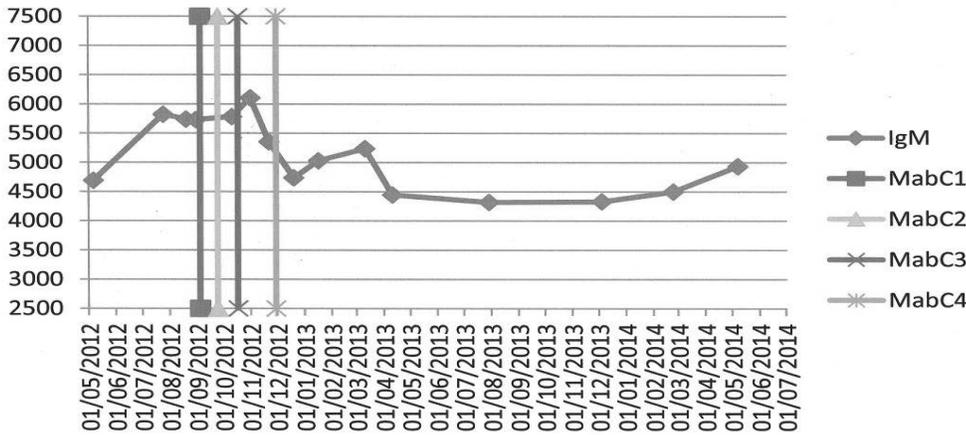


Figure 1

It is very easy, at a glance, to see that this patient had a very nice response to rituximab (Mab in the figure) therapy. The chart can be updated every three months to monitor ongoing response. In Figure 2, the patient has charted his hemoglobin level and demonstrated how the hemoglobin was in decline, fell further

with treatment, subsequently recovered and, after a period of two years, is showing modest reductions once again.

Even if a patient lacks the technical ability to produce such sophisticated charts, a simple lined table, showing the changes in IgM and blood counts over time, with treatments in the right

margin, can be invaluable. In this way, a long-term relationship can be established and updated periodically.

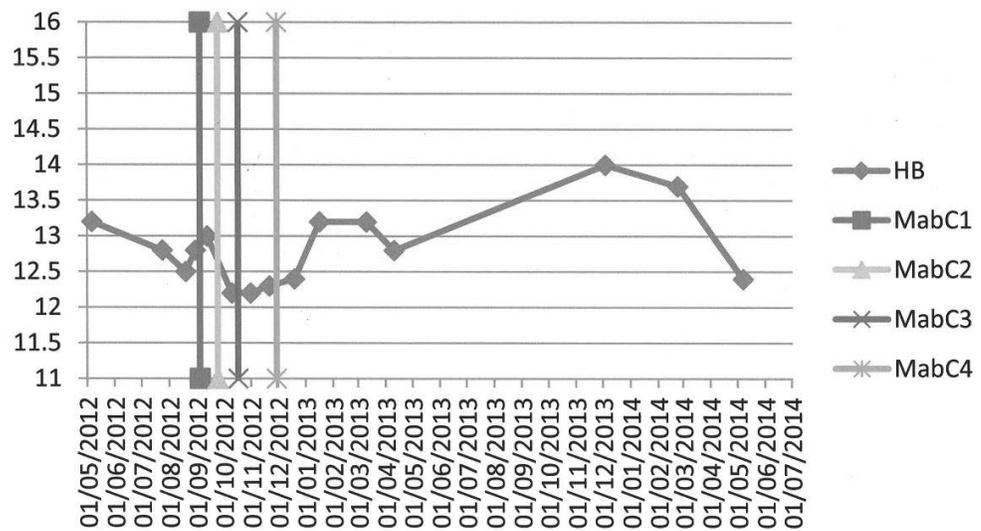


Figure 2

The doctor who provides the second opinion will want to know the same information as the doctor who first saw you, which includes the following: What were the symptoms? Have you had bleeding, lymph gland enlargement, infections, hospitalizations, numbness or tingling in your hands or feet? It is completely appropriate to ask an expert whether he or she agrees with the therapy that has been initiated.

Whether a second opinion includes additional testing will depend on how complete the outside information is. In some instances, an evaluation has been so thorough that no additional tests are required. In others, there may be some gaps that require filling to render an appropriate opinion. When research is involved, patients will often be asked to provide specimens, not for their own direct clinical benefit, but to further research in the field.

If the specialist disagrees with the local provider's opinion, a specific letter should be issued with the recommendation so that the patient does not find himself as a mediator between conflicting opinions. Typically, the local doctor will send subsequent follow-up visit information to the expert to be filed in the record for future visits. It may be necessary to return and see the expert if there is a status change or a need for additional therapy. Most academic centers have the ability to electronically file outside reports from a local doctor so that they can maintain current information during therapy. This, however, is not a substitute for the charts outlined in Figures 1 and 2.

Conclusion

When it comes to getting the most from your provider visits, keep in mind that if you become your own best advocate you will optimize your visits to both your local oncologist and your WM specialist. Your effort to organize records and to understand the key information set forth in the documents will pay you dividends. You will ensure an optimal consultation with your provider, and some initiative on your part will enable you to better understand your illness and to participate in the decision making process regarding your care.

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