

In Remission

A patient's experience of continued care after chronic lymphocytic leukemia

Andrew Schorr, MS, and Esther Schorr, MBA

Being a patient with chronic lymphocytic leukemia (CLL) now in the midst of infusion treatment after a 17-year remission, I cannot praise oncology nurses enough—Marie, Alex, Meghan, and Maria just in the past week here in San Diego, California, and my clinic nurses during many years of watchful waiting, Sheila, Sharon, and Laura. I am overwhelmed by their professionalism and warmth, and I am delighted to share my perspective as a patient.

Treatment Experience

Today's therapies are complex. I follow drug development carefully as a patient and cofounder of Patient Power (www.patientpower.info), an educational channel for patients that reaches about 100,000 patients with cancer each month. My current treatment is with the monoclonal antibody obinutuzumab (Gazyva®), a high-dose steroid, and immunoglobulin infused with each cycle. This regimen requires taking oral and IV premedication, flushing my IV, testing blood, testing insulin, and taking vitals every 15 minutes or so—a lot of work! Nurse after nurse does it with confidence and grace. I am grateful.

In 2001, I finished my earlier infusion therapy as part of a phase 2 trial. Although it was a trial with oversight by MD Anderson Cancer Center in Houston, Texas, much of the care was done in my hometown of Seattle, Washington. At that time, nausea was a real problem for me and it got worse with each successive cycle. During the last few cycles, simply entering the clinic could bring it on.

However, the nurses were there to comfort me and be my advocate for the best side effect management strategies. I never

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will forget how, at the end of cycle 6, they gathered around and sang to me to wish me well. I was touched.

Fortunately, my remission with CLL has been a long one and breakthrough medicines are available that may give me another 17 years. I sure hope so. However, no matter what, I clearly understand that today's healthcare team depends as much on the nurses as it does the physicians, pharmacists, and allied professionals. It gives me confidence that the members of the nursing profession will be there for me when needed.

As mentioned previously, I inform and correspond with many other patients with cancer. We have started producing Facebook Live broadcasts from infusion centers while undergoing treatment. A video my wife and I broadcast on my second day of treatment was seen more than 7,000 times in just a day or two. The "black box" of what goes on within an infusion center is being opened by patients who blog, tweet, and broadcast live. We patients think this is a good thing, and I hope you do, too. It enables us to get great, real-time support. While we are chatting to the camera, our nurses glide in and out, helping us get our treatment safely and efficiently.

As you well know, a cancer diagnosis is a family affair. Many of us come to cancer centers with a spouse, friend, son,

or daughter who sits by our side for many hours. In my case, it is my wife of 32 years, Esther.

A Care Partner's Perspective

As Andrew's life and care partner for many years, all the praise he has given to the cadre of oncology nurses we have encountered is well deserved. Although a patient with cancer must be the absolute center of attentive care, all the nursing staff I have interacted with have been incredibly sensitive to my needs as well. Care partners not only worry about their loved one endlessly, but also are on the same emotional rollercoaster as their loved one. Will a treatment be available that will work? Will my loved one suffer during treatment? How incapacitated will he or she be? How will we cope with activities of our daily life during treatment? We also wonder how to provide the best support possible.

Oncology nurses always have spent as much time with us as we both needed to get all our questions answered and have finer points clarified; when either or both of us missed details in discussions with the oncologist, the nurses always got us the answers. Their calls in between clinic appointments and infusions to

check in always have been comforting and supportive. If Andrew needs prescriptions filled or is concerned about a possible side effect, it feels like we have a team rooting for us—they have our back always.

Thank you from us both—individually and to the Oncology Nursing Society—for high standards and care with warmth and compassion.

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