

"Expert Driver"

An Interview with Richard Rockefeller under the name of Gabe Lewis

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Gabe Lewis, MD: "God Bless My CML Support Group"

A friend I've known for many years-I'll call him Dr. Gabe Lewis here, to protect his privacy-recently called to tell me that he'd just been diagnosed with chronic myelogenous leukemia (CML). Gabe is a Harvard-trained physician in his early 50s. Two months earlier, he and I had been at a medical meeting together and he'd heard me speak about the value of online support communities for patients with life-threatening illnesses. So in the course of our conversation, I urged him to visit, and to consider joining, an online support community for his disease. Two months later, he sent me the following e-mail.

Hi Tom-As you suggested, I've joined an online support group for CML. And I can now confirm that everything you said about these groups is true. They offer their members a remarkable level of emotional and informational support. I now have 24/7 access to what I can only describe as a decentralized, caring, meta-human "brain." If you'd like to hear more about about my experiences in the group, please give me a call.

I decided to take him up on his offer. Here is the result. -TF

Tom Ferguson: Tell me about your online community and how it works.

Gabe Lewis: We have a lot of very smart people on the list who come at the problems of CML from very different points of view. Certain members routinely read the key medical journals. Others scour the Web for new research and new treatments. Among the many group members who do this regularly, somebody covers just about everything on CML published in the medical literature.

We have some members, like me, who specialize in interpreting these studies. Others answer technical questions about specific treatments, while still others specialize in providing practical advice on dealing with the day-by-day problems of living with this disease. And some have a special knack for asking those brilliantly simple questions that really cut to the heart of the matter.

TF: And you were saying that there's a whole other group that deals primarily with providing emotional support?

GL: Yes. When someone logs on in and they're clearly in pain and really suffering, there are certain members, mostly female, who can always be counted on to provide emotional support and understanding-the kind of warm personal support and caring I've come to think of as the chicken soup of the Internet. Some of our most remarkable members are those who provide a steady source of emotional support for all who need it-in spite of their own very difficult physical and personal situations.

TF: How many members are on the list? And about how many messages from the list do you receive each day?

GL: We have more than 600 members, and the list receives about 100 new postings per day.

TF: What have been the most helpful things you've received from the group?

GL: Number one has been the emotional support and encouragement. This was especially important in those early days, when I was still in shock from receiving the diagnosis, and even now when I'm really having a bad day. It's immensely comforting to know that there's somebody who cares and is out there rooting for you.

Number two is the superb information-reviews of wonderfully useful websites, the great explanations about the intricacies of this disease, and the latest up-to-date reports of new CML trials and treatments.

Number three is the encouragement to play an active role-both for myself and for others. For instance, I've learned how to attend and access the abstracts from the latest American Society for Hematology (ASH) meetings-the definitive source of up-to-date information for this disease, and how to make direct connections with many of the leading CML clinicians and researchers in the country.

TF: In reading the postings of the group these last few days, it's clear that you take a very active role in answering other group members' questions.

GL: That's true. Although I didn't remember much about CML-and most of what I knew was way out of date-my medical training helped me to get up to speed pretty quickly. And right from the start, I found that it actually made me feel healthier to be able to be of help to others. I think we all have this natural altruistic urge to come to the aid of those who are in the same boat. Helping out in this way mobilizes one's energy and elevates one's focus from your own day-to-day concerns and worries to the greater needs of the whole group.

TF: Of all the things you've learned from being on the list, what has been the biggest surprise?

GL: As a physician myself, I've been shocked and embarrassed to see how frequently other physicians give CML patients mistaken or outdated information-or bully them or patronize them or simply ignore their questions or their concerns. I see this so much, that I am often forced to say, when responding to a list member's question: "It sounds as though your doctor may not be up to date here. Unless they specialize in the leukemias, even hematologist-oncologists can't stay current with the fine points of knowledge that's changing as fast as it is in CML. Unfortunately our medical training discourages us docs from admitting what we don't know, encourages us to think we know more than we really do, and encourages us to make snap decisions. That may be what's going on here."

TF: Can you give some examples of the kind of thing you mean?

GL: Here's a very common one: Docs who are not CML specialists will often say, "The only known cure for CML is a bone marrow transplant." And they'll invoke this outdated nostrum as if they were quoting from the Bible. But that's just not true any more. We don't even do bone marrow transplants today. We do stem cell transplants. And with the development of Gleevec (STI-571) and other new anti-CML drugs, even stem cell transplants are no longer the uncontested gold standard of CML treatment.

TF: Any other examples?

GL: Several hematologists (who clearly didn't understand the standard treatment protocol for CML) have left their patients on hydroxyurea for long periods of time, telling them that this drug was keeping their disease under control. But hydroxyurea only controls the level of white cells in the blood, not in the bone marrow. So it does nothing to halt the progression of the underlying disease.

And here's another mistaken bit of advice docs are always giving CML patients: "Don't go out in the sun if you're taking Interferon." Now some types of chemotherapy for CML do make you sun-sensitive, but interferon does not. These doctors have mistaken the effects of one drug for those of another. And so dozens of patients on our list have needlessly been discouraged from being able to relax in their garden or go out for a walk or to enjoy a few minutes out on the beach.

TF: How do list members respond when someone recounts a story of receiving inappropriate medical treatment?

GL: Sometimes there's outrage, but people on the list are usually quite tactful. They might say, "Well, um... why did your doctor leave you on only hydroxyurea?" And they wait for the patient to answer, "Well I don't know, I didn't ask." And then they say, "Well, uh... did your doctor mention that this drug doesn't really treat the underlying condition but just masks the symptoms?" And they'll give them the URL of a National Cancer Institute Web site where they can read all about it. And once they're convinced they're receiving bad treatment, the group will coach them on what they need to do to put things right. This may involve anything from discussing it with their doctor to switching to a new physician immediately, depending on how flagrant the error or how glaringly insensitive the interpersonal interaction might have been.

TF: Can you give us another case example of a situation in which a list member was receiving bad treatment and how the list was able to help?

GL: A group member I'll call Annie signed up for a clinical trial at her local research hospital. And right from day one, the nurse who was running the trial began treating her horribly. She wouldn't give this poor lady the time of day. She repeatedly gave her false information. She wouldn't follow the proper protocol. And when Annie would come in for treatment, she would make her undress out in the hallway and would examine her spleen with other patients standing around watching!

When Annie reported this outrageous behavior on the list, we said, "No, that's not what they're supposed to be doing at all." And we coached her through a whole action plan-how to document the bad treatment and how to go back to the research director and lodge a formal complaint.

After a good bit of coaching, Annie went back and did exactly as we suggested. And the hospital caved right in and apologized and gave her everything she asked for. The nurse was disciplined and the whole hospital staff began treating Annie as if she was the Queen of England every time she came in.

TF: So you're suggesting that online support groups can be a positive force for monitoring and quality assurance of professional care?

GL: Yes. By providing this kind of online second opinion and consumer health activist coaching, these groups can do a great deal to help raise the bar for the acceptable level of professional care.

TF: Does it come as a shock to some new group members to realize how the group operates and the ways it can be of help? Is there a learning curve in the beginning?

GL: Oh, sure. At first a new member might say, "So... uh... how come you guys are giving me different advice than my doctor?" And somebody from the list will say, "You know what? A lot of doctors are not up to date on how to treat this disease." And the patient will go back and report this to their family members. And quite frequently some family member will say, "What! Are you kidding? You're going to take the word of this bunch of unqualified quacks and Bozos over that of your doctor? You've got to be crazy."

And the people on the list are so careful, so gentle. They'll say, "Yes, we know. We understand. Our families said the same thing at first. And it's really hard when you're feeling sick and scared to even consider the possibility that maybe your doctor doesn't know everything they should about your condition. But what we've learned, from all our combined years of experience on this list, is that unless you're seeing one of the very top CML specialists, your doctor is probably not going to be completely up to date." And then we go on to explain how a self-help list like this operates, and how it can possibly be that those of us on the list could possibly know as much as we do."

This initial learning curve is usually about a two-week process. They'll take some of the best posts from the list and share them with their friends and family members. They'll keep reading the list and they'll begin to realize, "My God, they're right. There's much better information here than we got from our own doctor. And many of the things our doctor told us really are out of date." And the family members will start reading the list too, and pretty soon they'll say, "OK, well, here's a physician with this disease. And here's a scientific researcher. And there's a technical researcher and writer."

And a little later, they'll say, "OK, I get it now. These are not just a bunch of cranks. These are serious people whose very lives depend on the choices they make. They are spending hundreds of hours scouring the Internet and are attending meetings and reading journals and going to incredible lengths to bring back the latest state-of-the art information on this disease to share

with this whole online community. This is amazing! This is really something!" And so most of the time the friends and family do eventually come around. And some will even join the list themselves.

TF: What do physicians and other health care professionals need to know about online support groups?

GL: They need to accept the fact that when their patients are diagnosed with a serious disease, more and more of them will be turning to these online communities. They need to realize that this is a good thing on the whole, and to begin to appreciate the good things these groups can provide for their members.

TF: Some doctors have told me that they see these communities as a challenge to the doctor's authority. Would you agree?

GL: A challenge to authoritarianism, yes, but not to any doctor's honest-to-God authority. The really good docs and centers are praised and acknowledged and recommended. I can assure you that there's not a single member of our group who would not love to be working with a doctor who is caring and considerate and knows a lot more than we do about CML.

While they certainly do not replace or compete with a doctor's care, online communities can provide a great deal of disease-specific information-and in addition, can help patients make sure that they are receiving very best and most up-to-date professional care. The combination of a good doctor and a good online support group can offer cancer patients-and those with other serious illnesses-the best of all possible worlds.

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