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STEPHEN SCHNEIDER ISN'T ANTI-DOCTOR. But he's convinced his persistence is a huge factor in his being alive.

## Are you absolutely sure about that, doctor? A cancer survivor advises patients not to be passive about their care

**BY JULIA MCKINNEL** • To say that Stephen Schneider is smart and well connected is an understatement. Schneider has a doctorate in plasma physics and is a professor of biological science at Stanford University in Palo Alto, Calif. When Schneider found a lump the size of a BB on his upper right arm, he knew immediately who to call: his friend and internist Dr. Michael Jacobs at Stanford University Medical Center. After a biopsy, the diagnosis came back as a type of rare and aggressive non-Hodgkin's B-cell lymphoma known as mantle cell. Jacobs made a call and within a week arranged for Schneider to see another Stanford associate, Dr. Sandra Horning, an oncologist considered to be the leading expert in mantle cell lymphoma. The average Joe should be so lucky. As of this month, Schneider's cancer is in its fourth year of remission. He is teaching and writing again. In fact, he's just published a book, *The Patient from Hell*, an emotional account of the pain and fear he felt while he was ill, and the life-saving treatment he says he often had to fight for and sometimes deceive his doctors to get.

Schneider is not "anti-doctor," he says. Yet he's convinced that his persistence is a huge factor in his being alive. "Most physicians—and patients—act as if the patient's role is simply to take orders and be co-operative."

When he started asking questions, "it was at first difficult to be taken seriously." Early on, wondering why he didn't need further blood tests he was told, "It's just how it's done. Don't worry." Sneaking behind the doctor's back, he tricked a nurse by saying, "Excuse me, I was told to get a blood test on August 17." "Of course," she said, and entered it into the computer. Another time, he was sent to a surgeon for a biopsy. Wait a minute, he thought, and asked the doctor: "Why do I need surgery? Can't we just stick a needle into my lump and do the biopsy that way?" "I'm a surgeon. I

don't do that kind of thing," said the doctor. "But I agree with your point." The surgery was cancelled. "I wondered why I even had to ask," Schneider writes.

Research is essential. If Schneider had listened to his oncologist who told him, "Don't read the Web; it'll depress you," he wouldn't have unearthed key information he used to demand changes. His doctor wanted to protect him from the huge amount of online data that can be discouragingly out of date. Schneider writes, "The good news is... your prognosis may be better than the Web would lead you to believe." On the other hand, "even if

**'Don't read the Web,' he was told. 'It'll depress you.' But Schneider found key information there.**

your doctor is diligent, there is so much new... information being released... it is possible—even likely—that your doctor just hasn't gotten word of a specific study. Therefore, if you come across something interesting on the Web, gather as much information as you can and bring it to your next appointment."

He suggests drawing up a list of questions, and attending appointments with a friend or family member. Also, patients should not be afraid to voice concerns. In Schneider's case, because of a pre-existing heart condition, he asked whether he should receive Coumadin, an anticoagulant to reduce stroke risk. The

intern disagreed, saying that the probability of stroke is less than five per cent. "If there were a five per cent chance that there was salmonella in your chicken tonight, would you eat it?" he asked. "Well, of course not," was the reply. Schneider got the Coumadin.

The good news for the little guy, in Canada anyway, is that most major hospitals have a full-time patient representative who will listen to concerns. Sharon Rogers is the director of patient relations for Princess Margaret Hospital, Toronto General, and Toronto Western Hospital. Rogers says that if "communication is not as good as it should be," it's "entirely appropriate" for the patient to ask questions, particularly if "they don't understand why X is not possible." She admits, however, it's more difficult when a patient says, "I read it on the Internet" and the "cure" in question is "shark cartilage or high colonics." In Canada, doctors will individualize treatment only where there is "a body of knowledge, clinical trials, and [it is] proven by scientific evidence," says Rogers. Likely, the patient will hear, "That's not something we have confidence in." Schneider ran into the same problem of "lack of scientific evidence" for a procedure he wanted, but managed to persuade his doctor to let him be "the experiment."

"Don't take a fatalistic approach when dealing with your diagnosis" is the ultimate message of Schneider's book. "Becoming a 'patient from hell' may well delay your trip to the next world." M

MACLEAN'S JAN. 9 '06



### MOST IMPROVED...ALEX KOVALEV

Just another temperamental Russian before the NHL lockout, Montreal Canadiens forward Alex Kovalev is becoming the soul of the franchise. In a triumphant return from knee surgery on Dec. 20, he scored the tying goal, the shootout winner and assisted both of Montreal's other markers in a 4-3 win over the Ottawa Senators. Not long ago booed by New York fans for lacklustre performance as a Ranger, now he blows kisses to the Bell Centre faithful.

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