Sholom Glouberman, 70, is philosopher-in-residence at Toronto’s Baycrest Centre for Geriatric Care and a noted health care policy analyst. Six years ago, as a hospital insider, he thought—wrongly—that he was prepared for his own major surgery, a colectomy. His experiences before, during and after going under the knife, detailed in his new book, My Operation, led him to start the Patients’ Association of Canada.

Q: Why do we need a patients’ association?

A: I think the big problem in the health care system is that most of the conditions that people face now are chronic conditions, not acute, and we have a health care system that’s really bound to the acute. That’s what I’m on about now. For acute care you don’t really have to be present as a patient, but for chronic care you have to be there. If you have an acute problem, medical professionals are very good at it because they can go by protocol. You don’t have to be involved, you just stay out of the way and let them do what they do, and they’re really good at it.

Q: So not only are hospitals not patient-centred, patients are a problem for them?

A: Yeah, this system was designed in the 1880s when people like Koch and Pasteur discovered the cause and cure of acute infectious diseases. And when you get pneumonia, or you have a serious flu, what you do and think is irrelevant: what the doctors do is going to either save you or not. The whole system was structured around that kind of view, that diseases are understandable, they have clear causes, they have clear cures, we just have to discover them and then it’s “give us your body and we’ll fix you.” And they did save my life when I had the post-op septicemia, and I’m very grateful for that.

Q: Does this mean that the more patients become involved, the more they assert themselves, the more it gums up the works?

A: That’s right. But if you have a chronic disease, then the way in which you deal with it is very often very individual, there aren’t any rules. It can’t be so structured and it can’t be so protocol-driven. So the entire system is still based on a series of diseases that are not the majority of killers now. Managing the new killers needs more patient input.

Q: But you didn’t realize this when you went for your colectomy?

A: I had worked in the system for many, many years, I knew people in the hospital, I checked out everything. I really am somebody that understands—supposedly—how the system works. But when you get into it and you’re treated by it you give up—the system is too powerful for an individual. I suffered quite a severe shock to my system, I was surprised, and frightened, and the emotional upheaval lasted until quite recently.

Q: The main problem portrayed in your book is slipping into automatic deference, even when you suspected the doctors were wrong?

A: That’s right. That, I think, is a very big piece of patient dissatisfaction. And if it were one-sided it would be one thing, but in fact you’re encouraged to slip into that state—if you push a little bit, the pushback is much harder, you know? Moments when I tried to complain, or tried to say something, very quickly I’d be put back in my place.
Q: One specialist asked you to do something you thought (correctly) was unnecessary, and missed your high blood pressure, and claimed not to know the source of your infection although it was written on the chart on your bed. But you still did just what he told you to do?
A: Yeah, yeah. I ended up doing it anyway. I really want to emphasize the fact that passivity is something that’s trained into us and that the system expects. You don’t have to be that way, but it requires quite a lot of effort.
Q: It was almost funny the number of times you had to write on your reproduced records, “signature illegible.”
A: That’s a trick that nurses use. I wanted to find out why they were illegible, and I was told that a lot of nurses don’t want to be identified directly. The fear is that they’re going to be called to account. Nurses can be sued as much as doctors can, and that’s started to happen. There is a list of the nurses assigned to you, but it would be quite hard to track down, just like it was very hard for me to get my medical records.
Q: Would that be even harder for regular people?
A: Very hard, almost impossible. The way you get a record is by having a lawyer. I mean, when you’re ready to sue and you want to get the entire record for the suit then the hospital is bound to cough it up, and the person who gets it for you is the complaints officer. The complaints officer gave me a break and found it for me. The complaints officers in the hospitals call themselves patient representatives, but in truth they’re just employ-

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ees of the hospital and their job is to defend the hospital, in the end. So I was very lucky.
Q: Are the nurses’ fears justified?
A: I think it’s a false fear, but it’s one that they have. By and large, I think that, in the Canadian health care system, there isn’t a high degree of accountability. For doctors in particular, their protective association is so powerful that it’s very hard to sue doctors and win. Even if you do win, it’s never a substantial amount of money, so you can’t really teach doctors a lesson by going after them, here.
Q: The key moment in your surgery was when your doctor, inexperienced in laparoscopy, told you just before the procedure that the experienced man he had lined up to assist was unavailable but he had found another. Do you think, given your post-op complications, it was a mistake to go ahead?
A: I think it was a mistake in retrospect, I think that I should have let the surgeon do what he really knew how to do [a standard incision], but that’s what I chose at the time. I was in the same kind of position as the patient facing a sleep-deprived surgeon, I was shaved, I was enema’d, I had been preparing for six weeks. . .
Q: Now you believe that patients in your position should consider saying no?
A: I think that the whole way these things are structured should be changed, that there’s so much more that has to be told to the patient when the patient is comatos, and that the prep time for the surgeon has to be much longer than it is. Because this, after all, is not an emergency procedure, so it’s much more like a chronic condition than it is like an acute condition, but the way in which it’s treated is peremptorily, right? You’re given a peremptory discussion and they say, “Don’t worry about this, it’ll all be fine. I’m a great surgeon, I’ll take care of you.” So you back off. And all of that, it’s deep in the medical education, very, very deeply systemic.
Q: In your book you write that communication, or rather its lack, is a key source of patient frustration, but that health care professionals have a strong disinclination toward it. What did you mean by “pixie dust”?
A: The anxiety that the patient feels is not something that the practitioner or the provider is immune from. Cutting into somebody isn’t easy, you know, and the idea that you could cause infection and all kinds of pain and possibly death is something that you have to inure yourself against. So the pixie dust is the cloud of anxiety that affects everybody in the hospital in different ways, that I think the providers try to make themselves immune to. They Harden themselves against it. And it’s a disincentive to communication, creating an aversion to dealing with the emotion of patients and families.
Q: You note that CT technicians did tell you about the infinitesimal chance you might die during the scan, but not about the much higher possibility you would . . .
A: S--t my pants?
Q: That must have been a horrible low point.
A: Yeah, but it’s not atypical, and it goes together with the pixie dust stuff—it’s what they see and what they ignore.
Q: How did all of this lead to the Patients’ Association of Canada?
A: What I did was get myself onto a hospital patient-centred committee. I got a bunch of other people who had had patient experiences to sit with me, and that was the beginning.
Q: What, realistically, can be changed?
A: There are three different levels where the system has to change. At the individual level, patients have to be made more capable of dealing with the system as individuals with their practitioners. I think that’s really hard to do. I think that what requires changes in the education of practitioners, as well as helping people take on more responsibility for themselves. That’s tough, really tough. The middle level is designing services, and I think that patients can be more involved. There are examples of this in cancer care where families of kids who’ve had cancer are paid to come into the hospital and help families with new kids who have cancer, to give them a sense of what the system is like. The third level is at the policy-making level. Patient perspective is not part of the policy chain. Patients should be part of it.
Q: Do you see signs of that?
A: It’s beginning to happen. There are patients on boards of hospitals and health care organizations now. But the patients have to be trained up so that they’re not taken over by the system, and they have to have support. That’s why we need a patients’ organization that stands behind them and is a place where they can come to for resources and for help.