

Take control, patients urged

A high-profile surgeon argues it's time for put-upon patients to fight for their rights.

Health editor Adam Cresswell reports

DON'T expect Mohamed Khadra's new book to be comforting reading if you're about to go into hospital. The author of the acclaimed *Making the Cut* and a professor of surgery at the University of Sydney, he is about to publish a follow-up that makes crystal clear the fact that unappealing food is the smallest of the many hazards facing patients admitted onto public wards.

The new book, called *The Patient*, is being published next week. It tells the story of a fictional male professional, Jonathan Brewster, who discovers mid-career that he has a bladder cancer. The book follows him through the various stages of his treatment, noting in pitiless detail along the way the impersonality of the health system, the strains it places on the legions of dedicated yet sleep-deprived staff, and also the unprofessional attitudes of some doctors and nurses.

It also documents the cavalcade of cock-ups, major and minor, that go on behind the scenes. But while the story is fictionalised — like Brewster, the Victoria Hospital in which it is set does not exist — *The Patient* is not fiction. Khadra, the book's sole real character, says most of the things that happen to the unfortunate Brewster and to others within the hospital are drawn from real-life experience.

The book confronts head-on the "corruption" of the health system: the fact that patients handed a cancer diagnosis who need an urgent specialist's appointment can effectively jump the queue, simply by having the right social connections — while other patients without strings to pull have to wait weeks or months.

It spells out the extreme patient-unfriendliness of a system that can bandy about terms such as "triage" that barely a handful of people understand. It scores in painful detail the rudeness of some doctors, nurses and other staff; the clock-watching, officious culture of the newer breed of nurses, and the madness of a health bureaucracy that alienates its own permanent nursing and medical staff by paying double rates to last-minute agency fill-ins.

Perhaps most tellingly, the book exposes the extraordinary lack of compassion that can be found in every corner of the system — from the receptionist who keeps a pain-wracked patient on his feet while she slowly fills in a form, to the haughty consultant whose aloof



Inside story: Mohamed Khadra believes it's time for patients to stand up and reject offhand treatment

Picture: Amos Aikman

arrogance scarcely conceals his disdain for public patients, who he believes contribute less to his income and prestige than those paying privately.

Khadra — who received a huge response to the criticisms of the health system in his previous book — says a prime motivation for writing *The Patient* was to help patients understand better what a spell in hospital involves.

"Day in, day out, I sit across the desk from people who are planning their next holiday, they've just been married, they've just bought a house, they've just started a new job — and I look down at a piece of paper that has words on it or numbers on it that are radically going to change their life for the worse over the next couple of years, or even curtail their life," Khadra says.

"And I find people just aren't prepared. They have this sense that the health system is a benevolent creation of the government that will look after them; they aren't prepared spiritually, they aren't prepared physically and financially."

But it's also a call to arms. Khadra himself has been a patient, after being diagnosed 10 years ago — just as he and his wife had bought a new house, were raising two boys, and as their careers were taking off — with a thyroid cancer that had already spread to his chest and neck.

"I had an extensive period of treatment," he recalls. "And what I saw of the health system then, and what continues — if anything — to get worse over the ensuing 10 years, is a health system that ... doesn't deliver compassionate health care to people most in need."

"And my basic feeling is that what has occurred in the 20-year period since the 1980s, when I trained, is a cancerous growth in the bureaucracy of health."

"The basic aim of the bureaucracy is to avoid making mistakes. And what that creates is a paralysis of decision-making throughout the system that now has kneecapped every single hospital general manager, health leader, and nursing leader."

Such a critique could not come at a more

poignant time: NSW Health and its minister, John Della Bosca, have been deeply embarrassed this week by further revelations of chronic late payment of debts — to the extent that some tradesmen and suppliers of drugs, food and other consumables are refusing to deal with hospitals in the west of the state.

It chimes with Khadra's own experience. He tells of a general manager of one hospital he worked at who was unable to spend just \$55 on a medical textbook without getting clearance from the central health department.

At the ward level, Khadra says the solution is to take the power away from the bureaucrats and give it instead to the clinicians and managers within each hospital who would then once again have the power, and incentive, to ensure their own units ran efficiently.

In a different way, power should be claimed by the patients themselves.

"There wasn't a ward I could walk into 20 years ago, in any hospital, where I couldn't go to the nursing unit manager and say 'How's Mr Jones', and that nurse would be able to tell

me that his cousin visited yesterday, that his toenails have been clipped today, and that he's been moved six times overnight to help with his pressure sores," Khadra says, echoing a criticism that earned him widespread public support following the publication of his previous book.

"Now, even from the nurse looking after the patient, I'd struggle to get any sense of what's going on with the patient."

"What has happened? What has happened is that local single-point accountability has been taken away from the hospital, so there isn't that opportunity for someone to say this needs to be changed."

"If the ward is unclean, who do I go to? The boss of that cleaner is somewhere in town, because it's all outsourced. If the food that I'm putting in front of the patient is unappetising, who do you go to? It's all outsourced somewhere, and there are policies upon policies that obstruct any sort of feedback on that."

Khadra — who says he received overwhelming backing from his peers after the publication of *Making the Cut* in 2007 — urges patients to ditch the passive role they suffered 50 years ago and claim a greater responsibility for their own care.

He accepts he might receive a "cold shoulder" from one or two doctors who take umbrage at the portrayal of their profession in the character of David Johnson, an arrogant, glib and dismissive consultant urologist who regards patients as stupid and their questions as irritants to be discouraged.

But he stresses the book also portrays "a number of heroic doctors ... who really are compassionate, who really are competent".

"The point that I make in *The Patient* — if you are dealing with a doctor who isn't communicative, who isn't able to sit down and really go through the benefits and risks of a particular procedure, who isn't transparent about why they are doing it and involves you in a shared decision-making capacity — perhaps you are going to the wrong doctor," he says.

"I welcome it when my patients are questioning about every step of the way. Why am I having a PSA test? Why am I having a prostatectomy? What are the alternatives? What are the risks of this, what are the benefits?"

"Gee, I love those questions, truly — it shows an involved, informed patient. And we know now there's some evidence to suggest that the outcomes for that type of patient are actually much better, because they are involved in their healthcare, they feel empowered in their own health care."

"Are there doctors out there who avoid that glare of light on their own practice? The answer is yes. But I can tell you the vast majority of competent doctors would welcome that type of questioning."

The Patient by Mohamed Khadra is published on February 2 by Random House, \$34.95