

This profile appeared in *Australian Doctor* in 1999. This is the unedited copy; minor changes may have been made to the published version.

Arthur Frank The Profile

CV

Arthur Frank, 53

1995: Published "The Wounded Storyteller: Body, Illness, and Ethics"

1992: Appointed Professor of Sociology, Calgary University, Canada

1991: Published "At the Will of the Body: Reflections on Illness"

THE WOUNDED STORYTELLER AND HEALER

Arthur Frank describes himself as a "fly on the medical wall". Actually, he is a professional storyteller, whose tales of illness and medicine are constructed from the perspectives of a sociologist and former patient.

Increasingly, his stories also reflect on the difficult experiences of many doctors working within managed care and other systems driven by the profit motive in North America.

During a recent hectic schedule of talks to Australian doctors, medical students and patients, Frank, professor of sociology at Canada's University of Calgary, gave many examples of the dilemmas facing medicine, now and into the future.

One involved a Canadian specialist who observed that a drug in clinical trial was causing pronounced adverse effects. When she announced her intention to inform other researchers of the problem, the manufacturer threatened legal action.

Her hospital and university declined to provide support. When her findings were published in a leading medical journal, she lost her position as director of a hospital clinic. An academic group which took up her case pointed out that her university was negotiating with that particular manufacturer for funds for a new university building.

Eventually, after much publicity, the doctor was reinstated to her hospital position.

Frank has many other stories which also illustrate the “loss of trust that pervades the medical scene today”.

“There was a time when to talk about medicine was to talk about the activity of physicians and activities which physicians had control over,” he says. “Medicine is now more complex than physicians.”

Frank’s own crisis began 14 years ago when jogging, as he loves to do. After falling to the ground in a faint, he staggered up and went home. Weeks later, after many tests and investigations, he learnt that he had suffered a virally induced heart attack.

He was then 39. A few months after his last cardiology appointment, he began to notice pains between his shoulder blades when running. Eventually, after months of misdiagnoses, these were eventually identified as secondaries from testicular cancer.

After surgery and months of chemotherapy, he was again propelled back into the world of hospitals when his mother-in-law came out of remission from breast cancer for the last time. At the same time, his wife, a social worker, was working on a research project involving interviews with the families of children who had died.

“I tended to see life in terms of terrible things happening to people,” says Frank. “I still do. I think of life in terms of illness and death - somehow both seem quite normal to me and I’m always vaguely distressed by periods of health... when you’re ill, at least you know what you’re dealing with.”

This is not to imply that Frank coped easily with illness or his experiences of health care. He found it traumatic, perhaps at least partly because it is both his nature and his professional discipline to be a critical observer, as much of self as of society.

Personally, it was a period of tremendous growth. “On TV the other day, an interviewer asked if cancer had transformed my life,” he says. “It’s more complicated than that. Illness created conditions wherein it was possible for me to change my life. The first important thing was realising what absolutely trivial nonsense most of the rest of the world is engaged

in most of the time...this sense that a lot of ill people talk about of seeing the healthy world wasting their valuable time.”

Frank, who had always been interested in the sociological study of medicine, helped his process of healing and of remaking himself by writing about his experiences. This led to his 1991 book, *At the Will of the Body: Reflections on Illness*, followed in 1995 by “*The Wounded Storyteller: Body, Illness, and Ethics*”. (They are a complex blend of personal and patient narratives and sociological/philosophical discourse.)

Frank is reluctant to prescribe storytelling for others, to say that people “should” tell their stories. But it has clearly helped him make sense of his encounters with mortality and medicine, and he has also seen others benefit. Hospitals sometimes call upon his services to help elicit patients’ stories.

“There’s a lot about illness and medical treatment that really takes away your sense of having a voice and being someone who people listen to,” he says. “It’s accepted that you have questions about treatment, but you’re not regarded as having anything to say.”

Frank believes doctors could play a far greater role in patients’ healing by hearing or at least acknowledging their stories and suffering - not to be confused with taking a medical history - and recognising that “this is a person who has a life outside their symptoms and disease”.

“For many people, having someone take their story seriously is an enormously empowering step,” he says. “I see that every time I go to a support group meeting. You can see people change physically when the audience takes their story seriously.”

Paying attention to patients’ stories is not only good for the patients; it can also provide useful insights for medical practice.

“Narrative ethics begins with the idea that lives are stories,” he says. “There is always another way of seeing and telling and interpreting the same events. It also reminds us that there is an enormous issue of who gets to tell the story. Every time you see a patient, however casually, you are a character in that person’s story and that’s a responsibility.”

Frank says one of the most powerful lessons of his illness came from a technician who came to draw blood. “She said to me that you’ve got to remember that everyone who touches you affects your healing. She acknowledged that it’s not just a process of treating the disease; it’s also a process of healing, and that anyone I came in contact with was literally or metaphorically touching me and that had an effect.”

Professor Miles Little, director of the Centre for Values, Ethics, and the Law in Medicine at the University of Sydney, which arranged Frank’s visit, says most doctors would find *The Wounded Storyteller* enlarging rather than intimidating.

“(It) is probably the best explanation of what is valuable about patients’ stories for doctors,” he says.

Paul McNeill, an associate professor in the University of NSW’s School of Community Medicine, says Frank made a huge impression when he addressed medical students there.

“I had students coming up to me and saying that’s the best thing that’s happened to me in three years of medicine,” he says.

Frank initially directed his writings and talks at patients and their difficulties. But he is becoming more and more interested in the problems of medicine and doctors - partly because he is so often asked to address medical meetings and has seen that many doctors are burnt out or disillusioned.

Just as he believes illness can provide the crisis which propels individuals to discover themselves as “moral beings”, so it seems that he is urging medicine to consider how it should develop in response to current crises.

Frank argues that medicine is facing crises on several fronts: a crisis of access in which there are “more and more treatments that fewer and fewer people can afford”; a crisis of enhancement in which medicine has moved beyond fixing broken parts to enhancing functioning; a crisis of professional self determination in which physicians are losing control over how they can treat patients; a crisis of profit-driven health care; and a crisis of technology in which machinery replaces hands on care.

How should doctors respond? Frank's advice: "What we need is people who dare to be utopian, to say we don't have to just accept...that this is the best we can do." He adds: "To be a good utopian nowadays you have to be a little bit cynical."

Frank is certainly cynical about the push for evidence-based medicine. While he acknowledges that its ideals may be sound, he warns that it is being harnessed in North America by a cost cutting agenda.

One of Frank's Sydney lectures was titled "A Letter to a Medical Student." In it, he asked: "Can you remember that institutions have the capacity for evil? It is so easy in a bureaucratic age to stand behind institutional regulations and not take personal responsibility."

However, he acknowledges that doctors have to balance increasingly complex roles. They must be both responsible to the community, as gatekeepers of resources, and advocate for their patient who wants the best possible treatment. They must be scientist and fellow sufferer. They must balance the scientific need to think in categories with the human need to see patients as individuals.

If Frank won lottery, and established his own medical school, the students would chant - after exercises each morning - "everyone must die and that's all right". He challenges medicine to learn to resist death while being able to welcome it when appropriate.

"I would like for physicians entering medicine to think of it as a dangerous opportunity," he says. "The danger is that it becomes a commodity enhancing the lives of the rich, versus the opportunities of connecting with people and of being the midwife to their new selves."

Meeting Art Frank, after having heard much of his work, is somewhat of a surprise. He looks far younger than might be expected at 53. He clearly puts some effort into self-preservation, but also credits his genetics, describing parents who "look fabulous pushing 80."

Frank is an eloquent speaker. But, given the powerful and often personal nature of his subject matter, his delivery can seem rather clinical and controlled.

Perhaps it is the mark of an analytical sociologist, who describes himself as someone who likes playing with philosophical and theoretical ideas. Or perhaps it is just that he has told these stories so many times, to so many different audiences.

We are most of the way through a lengthy interview and the pot of ginger tea is long since dry when the first hint of passion stirs in his voice. Somehow the discussion has swung from medicine to junk food, junk culture and cars, all of which he hates.

“We live in an increasingly McDonaldsised, Disneyfied culture,” he says quite angrily. “This is what we should be talking about. What you can do is still try to live your life in a responsible way, which means finding in your life roads of resistance.”

It is a philosophy which Frank recommends, not just to doctors fighting ten minute medicine, but to parents deciding whether to use television as babysitter.

Frank says the most important thing he and his wife, Catherine Foote, have done with their six-year old, Kate, is to bring her up in an environment in which she does not want to watch TV or videos.

“That involves a very particular kind of parental commitment to enhancing and being part of her rich imaginative life,” he says. “We spend a lot of time reading with her, telling stories and a lot of time doing imaginative play with her so that she can do herself what other kids get out of the box.”

Free time is scarce, but is likely to be spent walking in the beautiful mountains around Calgary. Frank goes into some detail about the gruesome injuries which bears can inflict on unwary hikers.

“When trails are closed because of bears, you take that very seriously,” he says. “Every time you’re out there, it’s a subtext. You’re attentive in various ways. You make noise and you do what you can.” A fitting analogy, perhaps, for Frank’s approach to life and work.