People with HIV are treading a path that I have never had to walk. Their world has often been shattered to pieces - physically, socially and spiritually. In an instant their lives have gone from making some sense to making no sense at all. From all of this, with what is left, they have no choice but to begin to rebuild. This is something bigger than most of us have ever had to go through. But then again, it is something all of us are going through all the time – having our world shaken in some way that changes who we think we are, what our lives will be, and how we make sense of it all.

I recall vividly the early days of the AIDS epidemic. At the time, enrolled in undergraduate studies in a Canadian university, and just beginning to grapple with my own sexuality, the news of gay men dying of some unknown infectious agent, which then became known as AIDS, and then finally as the HIV virus, felt at once too far away and abstract to stare at and yet too big to ignore. It became difficult to talk about sex without talking about AIDS, and new words were quickly becoming entrenched in everyday language. For a young man seeking a sexual identity, sex and disease became inseparable, deeply personal and altogether confusing.

Later on, in my days of medical training, I did my best to avoid being involved with people with HIV. I did not understand this fact well enough to have been able to speak it, but I know now that subconsciously I wanted to be as far away from them as possible. It wasn’t exactly their disease I feared; I wasn’t scared of getting infected myself. No doubt I found the depth of their suffering, the weight of their need, left me feeling overwhelmed and incompetent. But this is not what I was running from. Rather, I was more afraid of what it might mean to be associated with this disease, with these people, and what others might think or assume about me. These were the early and uncertain days of AIDS.

My own attitude was reflected back to me when, after completing several clinical rotations as a medical student in which my performance was reviewed quite positively, I received a rather negative review from the doctor who was leading AIDS care in this organization. He pointed out that I seemed disinterested in HIV medicine, and that I had made little effort to learn about the disease or the patients to whom I had been assigned. This reflection was tough to disregard. From this training, I chose to work as a family doctor in an inner city clinic that served homeless people. I was a middle class boy who had never known the hard life. I needed to know what this other side of the world was all about and I needed to feel that I could do something to bridge the enormous gap. What I had not counted on were the people with HIV who came to see me and ask if I could provide their care since they had no interest in attending the HIV specialty clinic at the hospital. Presented with this challenge, I had to decide whether to rise to it or to run away. I chose to dive in, and finally began to face straight on the thing I had worked so hard to avoid. At about the same time, people in my personal life began to get sick, and this was even more impossible to ignore.

HIV quickly became my most important teacher, and I expect it will remain so for years to come. I learned that suffering has dimensions that go so much deeper than physical pain, that a society and a culture provide the rules for how people will be affected by a disease, and that healing can happen even if a person is dying, even if there is no hope of cure. I learned that the medical profession thinks about disease in ways that are often not helpful to the people who live with it, that our science easily washes out the most important colours and textures that need attending, and that my profession finds it difficult to face what needs facing in a suffering person when the science we work with is either inadequate or unwanted. HIV keeps teaching me what healing means, both for others and for myself, a lesson for which I will be forever indebted to this scourge. HIV has taken much from me, but as all of the great philosophers have noted, such loss also comes with many gains.

This epidemic has changed dramatically since its earliest days, and with change there are new lessons we need to learn about healing. Yes, we do need to keep striving for cures, for vaccines, for technological breakthroughs. It is our undeniable human “race.” But honestly, this is the mundane work of medicine. We have some idea that longer and less disease-
ridden lives are more worth living, but alas, this idea is difficult to substantiate. More than anything we have to be attentive to what helps us to heal, rather than cure, when we inevitably hit a hard turn we had not expected.

For people with HIV who live in Canada, today’s challenge is how to make life worth living when neither cure nor death is likely in the near future. Living year after year surrounded by stigma, with weakness, with uncertainty, without employment, or in pain is a hard road. Today’s challenge for people who work with HIV issues is to get beyond being angry. Anger is the energy that has, justifiably, driven the response to HIV for more than twenty years, and with great effect. But important work like eliminating stigma needs to continue and the culture of anger is turning from waking people up to alienating those we need working with us. It is also wearing down those working in the field. We need a new response. Finally, today’s challenge for our planet is to take care of the most disadvantaged in order to take care of ourselves. Entire countries are being wiped out by this epidemic, and the answer will be not in a vaccine, but in our ability to narrow the gap between who have and those who do not. The answer will be about justice and not about science.

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