

A Vast Injustice – Ombudsman's Remarks André Marin

Governments make difficult decisions every day, especially in health care. The costs are staggering and the stakes are literally life and death. There are enormous opportunities to help people through new technologies and medications, but these must always be weighed against the overall burden on the public purse.

The report I'm releasing today is about one of those difficult decisions – and how it was handled in the worst possible way. Ontario is one of seven provinces that now fund the drug Avastin for colon cancer patients. Avastin is considered part of the standard first-line chemotherapy for certain colon cancers, and after some years of study, Ontario announced last year that it would start funding it.

But what the government's press release didn't say was that the government would only pay for Avastin for so long. You could get 16 treatments – about eight months' worth – and then you'd be on your own, whether the drug was working for you or not. To be clear, Avastin is not a cure. But for patients whose cancer has already metastasized, it stops their tumours from growing and prolongs their lives, at least for a while. It is, without exaggeration, their lifeline.

Not all patients make it to 16 cycles of treatment. That's the tragedy of cancer – in fact, only about 14% of those who received funding for Avastin in Ontario in the summer of 2008 were still doing well enough to continue taking it past 16 cycles. These patients faced a hideous irony – thanks to the drugs that the government paid for, they were lucky enough to beat the odds and survive past 16 cycles with no cancer growth. Their government rewarded them by saying: "Sorry, we're cutting you off. If you want to keep taking this drug, it's up to you to figure out how to pay for it."

My report tells the story of the patients who were shocked when they came up against this cruel cutoff this past spring. Some have since paid thousands of dollars out of their own pockets to keep up treatment; some have battled with insurance companies – and some have had to give up on Avastin completely and await their fate.

This should never have happened. It's not that the government doesn't have the right to deny funding for drugs if it determines the cost is simply too high – such decisions are common, and they are understandable and necessary. But they also must be well-informed and reasonable.

From an ethical perspective, once a decision is made to fund a drug, any limit on the duration of funding should be firmly supported by medical evidence.

That did not happen with Avastin. My investigation has disclosed that there was no medical support for the 16-cycle treatment cutoff. The limit was essentially an artificial cost-containment measure, in diametric opposition to the generally accepted standard of patient care in Ontario.

In this report, I recommend that the funding cap be lifted and funding be extended on a case-by-case basis for patients who continue to do well on Avastin. I also called for compensation for those who've had to pay for their own treatments because of the arbitrary cutoff. The Ministry did not agree to these recommendations. Instead, it agreed to work with Cancer Care Ontario to develop a new compassionate review policy for cancer drugs and it invited the current patients to apply for extensions under the present compassionate review policy.

Many of these patients and their families are terrified and desperate. Their situation is urgent. Many found it bitterly ironic that the Ministry was so quick to justify cutting off Avastin funding, while at the same time its intemperate spending in connection with e-Health Ontario had been exposed and come under fire.

Instead of a workable solution, supported by sound medical practice, the Ministry's retention of the Avastin treatment cap continues to perpetuate a vast injustice.