

**Stuart Laidlaw • Toronto Star • September 25, 2007**

Away from the office, away from clients, a businessman stirs his coffee and talks about a "silver bullet" cancer treatment he found too late to save his wife.

It may, however, offer him some hope as he also battles a tumour growing in his body.

"I did everything I possibly could to keep her going," he says, his own illness seemingly secondary to the missed opportunity for his wife.

The man – we'll call him John – does not want his name used. Cancer is a private thing, he says, and he fears that knowledge of his disease and his use of an alternative treatment might affect the way clients and associates see him.

John takes DCA, or dichloroacetic acid, to treat his cancer, putting himself at the centre of a growing controversy over patients' rights to experimental or unapproved medications.

"This thing could be the silver bullet, at least for some people," he says.

DCA is approved in Canada for lactic acidosis, a rare childhood disease, but not cancer. John gets his "off label" from a Toronto cancer clinic – meaning it's a legal drug, but is not being used the way it was intended.

"We're pretty comfortable saying the drug does work for some patients," says Akbar Khan, medical director of Medicor Cancer Centres in Toronto, and John's doctor.

Khan requires that all DCA patients (he has about 40) sign a four-page consent form he developed after talking to the Ontario College of Physicians and Surgeons.

The college says doctors can prescribe any approved drug, but have a responsibility to inform patients of its risks and limitations.

"The patient's best interest must always be a physician's top priority," says college spokesperson Kathryn Clarke.

Since it began offering DCA to patients last winter, about two weeks after John's wife died, Khan's clinic has had inquiries from across Canada and as far away as Australia. Some of Khan's DCA patients have experienced a reduction in tumour size.

"There's no such thing as money when you're trying to keep someone you love alive," says the husband of a patient from Philadelphia. The couple is spending about \$600 a month to treat his wife's breast cancer. They have not told her oncologist in the U.S. about the DCA, fearing the doctor would cut off other treatment if their secret got out.

The furor over DCA began with a paper published in the journal *Cancer Cell* in January about the potential of DCA to shrink tumours. The preliminary study sparked an online buying frenzy by desperate cancer patients who administered the unpatented drug themselves.

A website set up by a California man to sell DCA, [buydca.com](http://buydca.com), was shut down by the U.S. Federal Drug Agency in July, though the site [thedcasite.com](http://thedcasite.com) continues as a discussion forum.

John read about the January study and told Khan about DCA. The doctor looked into the issue, checked out [buydca.com](http://buydca.com) and decided it would be safer if the drug was administered by a physician.

"You have to be a medical person to understand the side effects and make the assessments" of how the drug is working, says Khan, who runs the clinic with his wife, Humaira, who is also a physician.

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Khan worries that self-medicating patients won't get the dosages right, and will ignore side effects such as numbness in the fingers, forgetfulness and even potential nerve damage. They may also be susceptible to a placebo effect, believing the drug is working when it isn't and cut back on other treatment.

Jonathan Kimmelman has other concerns, however. The McGill University bioethicist says off-label prescription of any drug hinders the potential for doing the research needed to confirm its effectiveness.

Typical clinical trials, he says, allow researchers to account for a possible placebo effect.

"Who is going to want to take part in a clinical drug trial if you might get a placebo, when you know you can get the drug off-label?" Kimmelman asks.

The University of Alberta researcher behind the January study, who did not respond to requests for comment, has called for an end to off-label prescriptions.

The university wants to do more study, but can't get the \$1.5 million needed because, as a generic compound, DCA can't be patented, meaning no drug company would recoup its research investment.

DCA is not unique. The Internet has given patients unprecedented access to information about new and alternative treatments.

"It used to be that all the information that patients got was through their caregivers," says Kimmelman, adding that cancer patients are particularly keen to try new treatments.

Last week, about 80 protesters demonstrated outside the FDA's offices in suburban Washington, demanding a faster approval process for cancer treatment Provenge. Advocacy group Abigail Alliance for Better Access to Developmental Drugs organized the protest.

Margaret Somerville, also an ethicist at McGill, says a doctor friend once had a patient come into her office with 200 pages of computer printouts and a list of questions.

Somerville, however, supports greater patient awareness of alternative treatments and easier access to experimental drugs for patients who have little, if any, hope of recovery through approved treatments.

"They die wondering if something else could be done," she says, adding controls would be needed to ensure patients are not victimized.