

Do-it-yourself Chemotherapy Access

Internet chatrooms offer patients a forum to discuss new therapies and exchange tips on how to get access to experimental drugs – sometimes from sources that have neither responsibility for nor interest in their welfare. **Linda Geddes** received an ESO Best Cancer Reporter Award for looking at the case of DCA, in her article *When All Else Fails*, which is republished below.

Lawrence Burgh has a sober outlook on life. A 48-year-old physician whose career has centred on treating seriously ill patients, Burgh was diagnosed with cancer in December 2006. Yet despite his clinical experience, he has taken an extraordinary step to try to rid himself of his illness, a step many would consider to be a medical heresy.

Burgh is one of a growing number of patients who have been dosing themselves with a simple laboratory chemical that has never before been used to treat cancer in people. Most are doing so without the help of doctors, and none is enrolled in any systematic clinical trial of the substance. Instead, they are buying it over the Internet, and sharing their experiences of it in online chatrooms. For them, the unlicensed, untested drug represents their last best chance of survival.

That's not the way cancer specialists see it. For them, the activities of Burgh and those like him are indicative of what could become a dangerous new

trend, in which groups of seriously ill people get together online to discuss, source and try untested drugs whose safety and efficacy is uncertain.

The drug in this case, known as DCA, is a widely available chemical that cannot be patented. In basic laboratory tests and experiments in rats it has shown promise as an anti-cancer agent, but in people it may yet show side-effects that could further damage the lives of people who take it. Scientists investigating the potential of DCA as a cancer treatment fear that any deaths or injury caused by its premature, unregulated use could damage their work – and the welfare of patients far into the future.

Burgh's quest to cure himself began last month, shortly after he was told the cancer in his thigh had spread to his lungs. "My prognosis is very poor," he says. "Standard chemotherapy would give me only a slim chance of survival at five years." So he turned to DCA, after reading about the promising lab



Linda Geddes, winner of the Best Cancer Reporter Award

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experiments in *New Scientist* (20 January, p 13). DCA, or dichloroacetic acid, is an analogue of acetic acid in which chlorine atoms replace two of the three hydrogen atoms on the methyl group. Because it is a corrosive acid, it must be 'buffered' to damp down the acidity, and it is usually administered as sodium dichloroacetate.

In January, a study by Evangelos Michelakis and his colleagues at the department of medicine at the University of Alberta in Edmonton, Canada, suggested that DCA could shrink several types of tumour in rats, by exploiting a previously ignored metabolic pathway in the cell. "I was intrigued by the proposed mechanism," says Burgh (not his real name; this article uses a pseudonym to protect his privacy). "The biochemistry made sense to me. I

subsequently read dozens of articles and abstracts on DCA before I decided I wanted to try it."

On 27 February, he self-administered his first dose, and for the next month took DCA twice a day, monitoring his blood and urine for signs of any problems, and visiting his oncologist, who was aware of what he was doing, once a week.

Because DCA is not an approved drug in the US, the UK or anywhere else, Burgh had to find his own supply. Using his contacts he obtained raw DCA, then asked a chemist friend to buffer it and check its purity.

Burgh is not alone in his attempts to procure the drug. Already, within weeks of Michelakis's paper being published, a substantial online community has grown up, largely centred on the website

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AN ONLINE COMMUNITY IS BORN

Within weeks of the results from animal trials of DCA being published, two websites were promoting its benefits and facilitating online discussion about its use.

The first, www.thedcasite.com, claims to act as a gateway for information on DCA, while the second, www.buydca.com, offers to sell it for the treatment of cancer in animals. Both sites were founded by Jim Tassano, who operates a pest-control company in Sonora, California. While both sites state that DCA has not been approved for human use, [thedcasite.com](http://www.thedcasite.com) has been enthusiastic about cancer patients giving it a go. "Is DCA worth trying? We absolutely think so," the main site read when created in early February this year. "The risks of a DCA-based therapy are trivial compared to those of accepted cancer therapy."

The site also suggested that people donate money to the University of Alberta, where Evangelos Michelakis and his team continue to test DCA as a drug, and encouraged people to write to the US Congress and to doctors, urging them to kick-start clinical trials in cancer patients as soon as possible.

Michelakis says that since he published his study, and the appearance of the websites, he has received more than 15,000 emails from people enquiring about DCA. Around 3,000 of them ask about it as a veterinary drug, with the implication that they are trying to source it for themselves

or another person. He sees a clear link between the pet site and the questions he is being asked. "At first [people enquiring] were quite honest," he says. "But we're now getting emails from people asking for dosage information for, say, a 150-pound [68 kg] golden retriever."

Ron Marcinkoski, a pharmacist in Edmonton, Alberta, has also been contacted by people who he believes have bought DCA from the pet site. "People are asking me if I can test its purity, if I can encapsulate it," he says. "I think it is a major source."

Tassano maintains that the primary goal of the pet site is to sell DCA for animal use, although he is aware that people are buying it for themselves. On 5 March, he posted updates on the health of two people he claims to have sold DCA to, saying both were doing well. This post has since been removed. "I can understand why they do it," he told *New Scientist*. "The information is there so they can go to their doctor with it. Whether they buy their DCA from me is their choice."

Because DCA has not been approved for human use, it would be illegal for a website to sell it for human consumption in the US, says special agent Phil Walsky of the Food and Drug Administration's Office of Criminal Investigations. His office is investigating the links between the two sites. Marketing DCA for animal use is also an offence, as it has never been approved for veterinary use, an FDA spokeswoman says.

Tassano says he is now aware of the FDA's rules, and has amended his postings over the past few weeks to reflect this. For example, earlier postings which stated that he had managed to acquire large quantities of DCA have since been removed, and on 23 February a disclaimer appeared stating "We do not advocate the use of DCA for human cancer at this stage and time."

Tassano maintains he has not made any profit from the sites, and that they are playing an important role in helping to raise the profile of DCA. "We are only doing what we think is right."



“The Internet has changed the world for people who are looking for miracles.”

www.thedcasite.com, which declares itself to be a gateway for information on DCA. At least eight of the individuals who have posted contributions on the site's chatroom, including Burgh, claimed to be taking DCA or giving it to a close relative. By 21 March, the chatroom had 135 active members – most of them from the US, Canada, the UK and Australia – plus posts from numerous unregistered users, many swapping tips on how to get hold of DCA, how to prepare the chemical for human consumption, and what supplements they should be taking to minimise side effects.

“This is pretty much a new phenomenon,” says Kate Law, director of clinical trials at research charity Cancer Research UK. “There has always been an industry for vulnerable people, but the magnitude of it has multiplied exponentially. The Internet has changed the world for people who are looking for miracles.”

Michelakis himself warns that people taking DCA could do themselves serious harm. The chemical is known to increase the risk of nerve damage in people who have been given it in clinical trials for other reasons. It may also cause liver damage and interact with existing anti-cancer drugs in unexpected ways. “Since many anti-cancer drugs are neurotoxic, these interactions could be fatal,” Michelakis says. Worst of all, he says, if patients are taking DCA outside clinical trials, such damaging side-effects may go unrecorded.

DESPERATE MEASURES

Yet there are many desperate patients prepared to take this risk. Michelakis says his department gets thousands of emails from people saying they have nothing to lose, but that's not how he sees it. “Of course you've got something to lose,” he says. “There are many cases of people being

told ‘you've only got a month to live’, and a month later they're still alive. If you take DCA, it may not work, you could still have the cancer, and you'll be paralysed.”

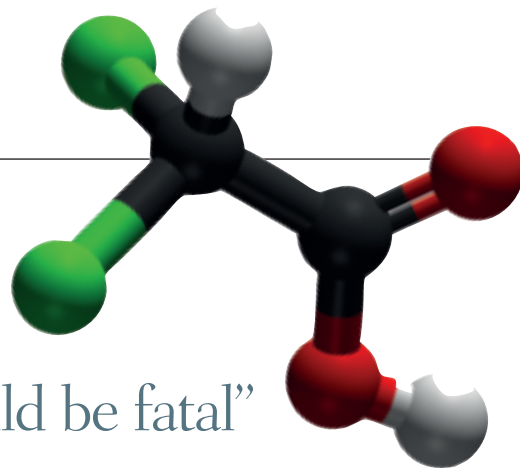
Despite such warnings, people are continuing to hunt down details of potential suppliers of DCA. “I have been getting three to four calls a day,” says Steve Grossman, manager of JE Pierce Apothecary in Brookline, Massachusetts. “I've had calls from pretty much the whole of the northern hemisphere now, plus Africa, the Middle East and south-east Asia. Mostly it is people with end-stage cancer, who have already gone through everything medicine had for them.” Grossman says he will not dispense DCA to anyone unless he sees a prescription from a doctor – and no one has yet provided one.

Because DCA has never been approved as a drug for human use, the sale of pharmaceutical-grade DCA, which has been sterilised, purified and had its pH adjusted, is tightly controlled. In the US, a doctor can only prescribe it if they have already applied for an Investigational New Drug (IND) number from the Food and Drug Administration for its compassionate use in a seriously ill patient, or in a clinical trial. Doctors in Canada must gain permission from their provincial college of physicians and surgeons, while companies who supply it to doctors in the UK must inform a national regulatory agency.

As word gets around that people are buying DCA to use as a drug, suppliers of the chemical are clamping down for fear of breaking the law. However, despite these restrictions, people are still acquiring it.



DCA can cause nerve damage and has no proven effect against cancer in humans. Yet buydca.com still advertise their product to cancer patients, citing its ‘amazing ability to shrink tumors’



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Thecdasite.com shows at least 34 people have got hold of DCA – either through doctors, or by obtaining raw laboratory-grade DCA from chemical supply companies, for example – and are either taking it, or plan to start taking it soon. At least another 50 are actively searching for a supply. One person claims to have got theirs from chemical giant Sigma-Aldrich based in St Louis, Missouri. Michael Hogan, the company’s chief administrative officer, says it will not dispatch any chemical to individuals or residential addresses, and after being alerted to the problem he says Sigma will now tighten up surveillance on DCA orders. He points out, however, that if a legitimate company places an order, Sigma has no control over who that company sells it on to.

In a further twist, thecdasite.com has a sister site that sells DCA as a treatment for cancer in animals, offering a further way for people to get hold of the drug (see *An online community is born*, p40). The FDA says it is investigating the websites, after being alerted to their existence by *New Scientist*. Yet ultimately there may be very little it can do, as DCA is already a widely used laboratory chemical that can be ordered from thousands of companies worldwide.

Hogan is clear that his company considers taking DCA to be unsafe. “We would no more encourage someone to self-medicate with DCA than to drink poison,” he says. As well as the inherent health risks, there is the possibility of contamination in laboratory-grade DCA, and not buffering it correctly could result in severe burns.

Burgh has yet to see DCA make any impact on his cancer. Medical scans on 19 March showed that the primary tumour in his thigh has shrunk, and is less active, but this may be due to the delayed

effects of radiotherapy and chemotherapy Burgh had in January. The number of metastatic tumours in his lungs has not changed since last month [February], and they are larger and more active. “These results are very preliminary,” Burgh stresses, “but I was really hoping for better results.” On 21 March, he stopped taking the drug after noticing symptoms which, by 24 March, included a numbness in his hands, which he believes to be a sign of neuropathy, and a hypoglycaemic attack. He advises other people with cancer not to self-medicate with DCA except under medical supervision. “I am concerned others may try this drug on their own in desperation,” he says. “DCA is chemotherapy, a serious drug with potentially serious side-effects.”

Michelakis opposes any self-medication with DCA, and the websites that facilitate it. Though he says he can understand why people with cancer are motivated to take DCA, he points out that not only are they placing themselves in danger, they may also be jeopardising the chances of finding out whether DCA actually works in treating cancer and of it becoming approved as a therapy. If people become sicker or die while taking DCA unsupervised, he says, funding and willingness to test it may disappear. “We are trying to do this the right way, by putting it into clinical trials, and these websites could destroy all of this.”

In July, Jim Tassano was banned from selling DCA after the FDA was alerted to the situation by Linda Geddes, the author of this article. In September, Evangelos Michelakis received the go-ahead to start clinical trials on DCA for cancer patients. The trials will study DCA used alone or in combination for a variety of cancers

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