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Who's Next? The realities of succession planning in prostate cancer support groups

By John Hoffman

One issue that all prostate cancer support groups face sooner or later is, who's going to be the next fearless leader? Conventional wisdom suggests that there's a best way to handle succession in support groups and other volunteer-driven organizations. Don't depend too much on one person. Have a succession process in place. Limit the terms of chairs so nobody gets burned out or starts to think he owns the place.



But, as is the case with many aspects of voluntary organizations, support group leadership, including succession planning, is the art of the possible, based on the abilities, interests, and capacities of the people involved. Emmett Mulvaney, who has chaired the Fredericton PC Support Group for three years, quips that his group used the army method---"We need a volunteer, and you're it." "When we were looking for a new chair, one member of the executive spoke up and said, 'I think Emmett would make a really good chair,' " says the retired supervisor with Natural Resources Canada.

Hint, hint.

Emmett, who had been involved in leadership and committee work through his church, stepped up to the plate, although not exactly eagerly. "It was completely contrary to my nature to be a chair," he says. "I'm not a good public speaker. But I could see that if I didn't do it, nobody would, and the group might fold. You know, when the boat's leaking you jump in the boat and try to plug up the hole. It was that sort of thing."

This is one of the realities in volunteer-driven organizations. If they had their druthers, many people would just like to be attendees. They might be willing to pitch in with a specific task, but who really aspires to be in charge? On the other hand, some fellows who find themselves in charge discover that they like it, and hang around for quite some time.

Bob Shiell, chair of Calgary's Prostaaid, has led his group for seven years. Bob also serves as president of CPCN's board of directors, is a director of the Canadian Prostate Cancer Research Initiative, and, in the past 16 months, has travelled to Washington and Barcelona to participate in the newly formed World Wide Prostate Cancer Coalition. Oh yes, and he's composed every one of the group's newsletters that have come out since he took over. Sounds like a recipe for burnout---or at least a one-man show that may not be sustainable. But that's not really true, he says. First of all, his group is flourishing. "We average 100 people per meeting, and we've had as many as 200," he says. Second, he really enjoys the work. "I really believe in giving back to the community, and I think having something to focus on helps

keep me young." Prostate cancer work also allows Bob to keep up some of the contacts and employ the skills he used during his career in sales with the CBC. And it's not quite the one-man show it appears to be. "We have an active executive of nine people, and we've recently brought in some new people with lots of skills and experience. A number of them could step in and take over if need be. I know I won't be here forever."

In fact, executive members have stepped in for Bob on several occasions. He explains. "About a year ago I was getting tired, juggling a number of responsibilities. I made it known to the group that I needed help, and they quite willingly took on more of the work." Having one person at the helm for a long time is just one model Shiell says. And it can work, as long as the leader shares responsibility in place and has some people who can step in if necessary.

On the other side of the country, the Avalon Prostate Cancer Support Group, based in St. John's, made a recent decision to rotate the chairship regularly---every two years at least. Ray Andrews started as chair this past September after serving on the executive for five years. "I started out on a social subcommittee and that helped me get a general sense of what the group was about," he says. Subsequently, Ray joined the executive and so was ready to accept the top job when the fickle finger of fate pointed at him. He hasn't found the responsibility onerous. "One of the strengths of our group is that we have three past chairs serving on the executive. That's very helpful to the new chair," Ray says. "And we are always on the lookout for people who show a real interest in the group. When we find somebody, we try to bring them on the executive with minimal duties at first. Sometimes we just say, 'Why don't you come on the executive for six months?' " Often they stay for longer. The Avalon group also tries to balance working people and retirees. "People who are still working can reach out to a different group of the public," he says. "Retirees, of course, have more spare time, so we need them too."

The Newmarket Prostate Cancer Support group takes a similar approach to maintaining a pool of potential future chairs, or at least people who are prepared to be actively involved in planning and operations. Ron Stephenson has been the group's chair for two years now. At 61, Ron is still in the work force, so he leans heavily on his seven fellow executive members and also his group's secret weapon, Mr. Derek Lawrence. "Derek is somewhat of a legend around here," says Ron. "He's been with the group for a long time. He chaired for a while. We have had a number of chairs since I've been here, but Derek has been a constant. He is very, very knowledgeable and well connected, and he does a lot of the work. I felt comfortable as chair very quickly."

Although these groups don't all operate in exactly the same way, they do share some strategies. Always be on the lookout for new people who show an interest and find ways to get involved. Make sure there's an active and committed group behind the chair, helping out with practical work, planning, and ready to step in when necessary. But whether you operate on one- or two-year terms or by the "chair as long as you want it" model, good meetings that balance information and education with a little fun will keep groups alive and well. Bob Shiell builds his meetings around good informative speakers, but he always starts and finishes with a humorous video, usually one he finds on the Internet. "I think you have to entertain as well as educate," he says. Another factor that keeps movers and shakers in the picture is the people factor. Ron Stephenson says his executive enjoys getting together each month. "There's always a lot of joking around at our executive meetings. People say things like, 'Well, I guess you're going to want me to do that job. You're going to have to double my "salary," you know.' "

Salaries may be in short supply in prostate cancer support groups, but most chairs and executive members would tell you that they like their work, especially the social aspect and camaraderie of coming

together with people of similar interests. Says Stephenson, "I'm sure I wouldn't have done this for so long if I didn't enjoy the people."

Personal health records: Survival tools

If you were to have a medical emergency, would your loved ones be able to provide the vital medical information necessary for your care? Does your wife know the proper names of all the drugs you are taking and the dates of your surgeries or other medical procedures? How about more detailed information, such as PSA test results, known allergies, immunization records, or the make and model number of assistive devices? If you are like most people, the answer to at least some of these questions is no. And that could be a problem.



Kevin J. Leonard, a University of Toronto professor, knows that collecting and communicating his own personal health information saved his life. "Over the years, I have insisted on having access to my records (i.e., lab and test results, radiology reports). I know that active management of my health care has led me to where I am today, and I would not be here otherwise."

Quick and easy access to personal health records is especially important for people with serious medical conditions or for those getting older. And---let's face it---prostate cancer is not only serious but also prevalent among men in that "getting older" category.

CPCN suggests a practical and simple approach to getting your personal health information to those who need to know: 1) create a portable medical emergency record and 2) keep an organized and up-to-date personal medical history.

Medical Emergency Record

You may not be able to give medical information when an emergency arises, so make sure that your spouse or adult child or trusted friend knows where you have recorded this information. A medical emergency record should have at least the following:

Your full name, date of birth, and health card number

Often, your doctor's office or local hospital will organize records according to this information, so having it handy can save time in an emergency.

Emergency contact name and telephone number

This information is particularly important if you live alone. Include also how this person is connected to you.

Doctors' names and telephone numbers

With this information, emergency staff can usually get important medical records fairly quickly, as well as details about your health history.

List of current medications and allergies

This information is important too, as some drugs may affect the kinds of treatments that are safe or best for you. List all the medicines you take, how much you take, and how frequently you take each. Also list your allergies, especially if you are allergic to any medicine, such as penicillin, or to any substance that might be used in medical equipment, such as plastics, latex, or the adhesive used on surgical tape.

Medical conditions and prior surgeries

Of course, you should include prostate cancer here, but do not neglect to mention other medical problems such as diabetes, asthma, arthritis, or heart disease, if these apply. Also list past medical procedures (e.g., radical prostatectomy or cardiac bypass surgery) and when these occurred.

Lifestyle information

Do you smoke or use alcohol? Knowing this information is helpful because tobacco use can lead to pulmonary and cardiovascular complications after surgery and alcohol can interact with other drugs.

Assistive devices

Do you have an artificial urinary sphincter or perhaps a pacemaker? It is useful to list the make and model number of any of these sorts of devices, as well as when they were inserted and last tested.

Advance directives (e.g., a "living will") and religious or personal beliefs

Some people decide to outline their decisions about health care in legal documents. In Canada, these documents are often referred to unofficially as "living wills," and they usually contain information about when to resuscitate or use life-support machines. A living will also names a person or a group to help interpret your health care decisions and make your wishes known to medical staff. (See how living wills are handled by Canadian provinces and territories in this excellent CBC article, "[Living Wills: FAQs](#)") Usually, a medical emergency record will list only the location of your "living will" and the name and contact information of the person responsible for seeing that your wishes are carried out. But if you have beliefs that prohibit the use of blood transfusions or other medical procedures, these should be outlined briefly.

Health insurance

If you have additional health coverage (e.g., the federal government's public service health care plan or a private policy), it is useful to list your insurer and your member number.

Date of the document

Indicate when your medical emergency record was completed or updated.

It is very important to review your medical emergency record regularly and keep it current. Remember to revise your "living will" too, as today's extraordinary measures quickly become tomorrow's common practices when it comes to extending life.

Keeping your record handy is just as important as keeping it up to date. Some men carry an abbreviated version in their wallets, some post it on the refrigerator door, and others create a grab-and-go file somewhere in the house. Also, make sure your emergency contact has a copy. Modern technology offers other options, such as a portable personal health record that fits on a key chain and plugs into any

computer's USB port or a machine-readable medical record card. "I keep my own medical records, and, like everyone else here, I carry a card containing a chip," writes Tom Kilcourse from Europe. "If I am taken ill anywhere in France, that card will be fed into a doctor's computer to reveal details of my medication and health history." Whatever you decide, keep your medical emergency record current and handy.

Medical History

Keeping track of your personal medical history is one of the most significant things that you can do to help others care for your health effectively. And this means recording your family's medical history as well. This family history provides information about the health of blood relations, as well as their causes of death (if these are known). Especially important are the diseases or chronic conditions found in your family.

In general, your medical history file should contain all of the information that is in your medical emergency record. But it usually provides more details. For example, your medical history file, like your medical emergency record, would list the dates and names of surgical procedures, but it might also contain operative reports, such as copies of biopsies performed, and give brief descriptions of your personal experience of these surgeries and your recovery.

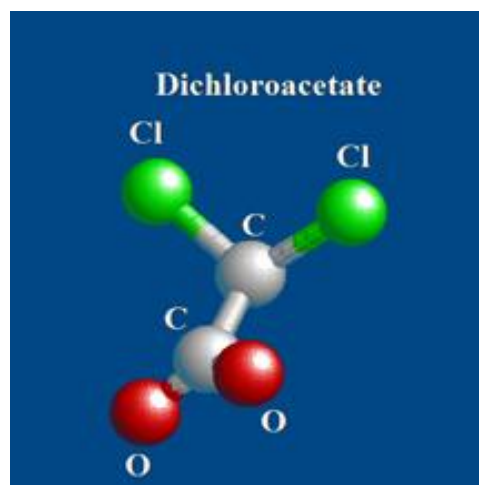
A very useful tool for men diagnosed with prostate cancer is the "Prostate Passport," which CPCN makes available as an insert in its publication *Prostate Cancer: A Booklet for Patients*. The "passport" enables you to record information about treatments, health care appointments, test results, and medications. You can also write down questions and your doctors' answers or comments. It even includes a PSA tracking graph. And, believe it or not, recording information about your health is necessary because even memories that seem stamped indelibly on your brain can fade: "Even though it has been just six months now since my prostate surgery, ... it seems like a distant memory," writes Mike Stuckey. But with a written record of your fight against prostate cancer, you can pass on essential information about your specific responses to treatments---even ten or twenty years after you were first diagnosed ----and play an active and informed role in your own health care.

DCA (dichloroacetate): Promising cancer treatment?

By Valerie Lapp

A tiny molecule that's been used for decades to treat other diseases is now looming large as a possibly highly effective treatment for cancer.

DCA, or dichloroacetate, has recently been approved by Health Canada for human trials in the treatment of an advanced form of aggressive brain cancer, and it is currently being prescribed as an "off label" treatment at Medicor Cancer Centre in Toronto for many different forms of cancers, including prostate cancer.



The excitement over DCA began in January 2007, when Dr. Evangelos Michelakis and his colleagues at the University of Alberta published a report in [Cancer Cell](#), showing that DCA caused regression in several cancers, including lung, breast, and brain tumours. Michelakis tested DCA on human cells cultured outside the body and found that only cancer cells were killed, but not the healthy cells. Tumours in rats caused by human cancers also shrank drastically when the rats were fed DCA-laced water for several weeks.

DCA is an odourless, colourless molecule, which has been used for many years to treat metabolic disorders. It has also been tested extensively for toxicity levels in humans, since it is a common by-product of chlorinated water.

For this reason, DCA is considered relatively low in toxicity, so Health Canada approved human trials in September. These will begin immediately with phase II testing on select brain cancer patients. Dr. Michelakis explains that a phase I trial, in which dosages are slowly escalated, would be futile for these patients because of the aggressive nature of their disease.

Even before that testing is fully under way, Medicor Cancer Centre, a private clinic in Toronto, is experimenting with DCA, both alone and in conjunction with other chemotherapies. (The cost of DCA treatment at Medicor is about \$160 to \$190 per week.) In December 2007, Medicor released a report evaluating the results of DCA treatment on 53 patients, including four with prostate cancer. Sixty-eight percent showed positive results after DCA treatment, including reduction in tumour markers (PSA levels) for at least one prostate cancer patient. Results for other cancers also included reduction in tumour size, improvement in blood tests, symptomatic improvement, and disease stabilization.

Medicor cautions: "We have ... observed positive responses [from DCA treatment] in brain, ovary, prostate and breast cancers; however the numbers are too small to report at this time.... The cancer-specific response rates are not meaningful because of the small number of patients treated so far."

The [Medicor report](#) also warns that its data is not from a clinical trial, cannot be generalized, and "should be interpreted with caution." Indeed, the Canadian Cancer Society reminds us that DCA, as a cancer treatment, has not been clinically tested on humans:

DCA must be tested for safety and effectiveness in patients with cancer through an appropriately conducted clinical trial on humans before it should be used by patients. Until these trials take place, the Canadian Cancer Society cannot advise its use by cancer patients.

Medicor has noted some serious side effects of the DCA treatment, including nerve injury in the hands and feet ("peripheral neuropathy"), as well as sedation, confusion, hallucinations, memory problems, and hand tremors. Patients being treated with DCA might also suffer digestion problems and pain at the site of their tumours.

Medicor comments that all side effects at this time appear to be reversible or treatable with supplements.

Certainly DCA does not seem to have the dramatic side effects of standard chemotherapies. It is also a very small molecule, so it is easily absorbed, and, after being ingested orally, it can reach areas in the body that other drugs cannot.

DCA functions by "waking up" the mitochondria in cancer cells. Mitochondria occur in all cells, but, in cancer cells, their action is suppressed, and, until now, most researchers believed that they were

irreparably damaged. Dr. Michelakis questioned that assumption and found that DCA was actually able to reactive the mitochondria in cancer cells.

This is an important reversal because of the mitochondria's crucial function in all cells: they recognize when the cell has an abnormality and activate apoptosis, the process by which cells commit suicide. With suppressed mitochondria, cancer cells do not commit suicide and thus achieve a kind of immortality. Once their mitochondria had been re-awakened by DCA, however, cancer cells, because of their abnormality, received the order to commit suicide.

"I think DCA can be selective for cancer because it attacks a fundamental process in cancer development that is unique to cancer cells," Michelakis said.

It is not clear at this time when DCA will be generally available to cancer patients, including those with prostate cancer. DCA is not patentable, so finding research funding can be difficult. Dr. Michelakis's research is currently funded by the CIHR, the Canada Foundation for Innovation, the Canada Research Chairs program, and the Alberta Heritage Foundation for Medical Research, as well as through local and international fund-raising initiatives, and he is constantly looking for new funding to continue his research.

However, as Dr. Philip Branton, Scientific Director of the CIHR Institute of Cancer Research, says, "Preliminary research [on DCA] is encouraging and offers hope to thousands of Canadians and all others around the world who are afflicted by cancer, as it accelerates our understanding of and action around targeted cancer treatments."

Other links

The Official University of Alberta DCA website: <http://www.depmed.ualberta.ca/dca/>

The DCA Site (articles and forum): <http://www.thedcasite.com/>

Medicor Cancer Centre DCA Therapy: <http://www.medicorcancer.com/DCAtherapy.html>

Prostate cancer survivors invited to World Cancer Congress

Representatives of the newly formed World Wide Prostate Cancer Coalition (WWPCC) have been invited to speak at the prestigious UICC World Cancer Congress to be held in Geneva this summer. This will be the twentieth conference sponsored by the International Union Against Cancer (UICC) since its foundation in 1933, but the planned presentation from the WWPCC marks a first. "We think it's the first time that people representing a coalition of prostate cancer survivors and interest groups from around the world have been invited to participate at this level," remarks CPCN Executive Director Wally Seeley. "It's a remarkable opportunity."

The World Wide Prostate Cancer Coalition was formed after the leaders of various national prostate cancer survivor organizations from Australia, Canada, Europe, Israel, Japan, New Zealand,



South Africa, and the United States met at the World Cancer Congress in Washington in the summer of 2006. A further meeting in Barcelona this fall fleshed out the details.

The WWPCC is dedicated to sharing "information, ideas, visions, and dreams to minimize the impact of prostate diseases, especially prostate cancer, in the global community." It will do this, in part, by providing an environment and repository where interested organizations can access and share relevant information.

The group plans to

- foster information to educate men based on relevant patient-centred care,
- collaborate with professional organizations to support optimal medical treatments,
- encourage organizations around to world to pursue quality of life issues based on solidarity and mutual respect, and
- promote the establishment of patient groups.

CPCN President Bob Shiell has been involved in this initiative from the start, and he and Wally Seeley are currently serving on the WWPCC executive (pro tem). Both plan to participate in the 2008 UICC World Cancer Conference. Watch the CPCN website for more World Wide Prostate Cancer Coalition news.