

## When You Can't Meet Face-to-Face

For the 475 Canadian men diagnosed with prostate cancer each week, prostate cancer support groups across Canada provide an opportunity to come together to share their experiences, suggestions, and offer support. But what about those who have difficulty accessing this support due to where they live, their lifestyle, or privacy issues? A research project is looking at using innovative communication alternatives for these individuals.

Text messages, IMs, blogs, video conferences, discussion boards, and chat rooms are new systems we are using to reach out to and communicate with one another. We integrate these technologies into our lives to assist us with our work and personal lives.

Earlier this year, a teleconference support group was organized for eight prostate cancer survivors residing across Canada in British Columbia, New Brunswick, and Ontario. The group was co-facilitated by two experienced peer support group facilitators. Group members phoned in to a toll-free conference number over a six-week period through January and February, on the same day and at the same time each week. The study coordinator contacted participants and facilitators after each session by e-mail or phone for feedback. The participants evaluated their experience at the end of the six weeks during an in-depth telephone interview.

### **Overall, how do you believe the group went over the six weeks?**

For some, this was their first support group while others had attended face-to-face groups in the past. They were at various stages, including one with a high PSA rating and others in the watchful waiting stage or coping with difficult side effects of treatment. Overall, they were positive about their experience in the group.

- *“I’m convinced that it provided me with more information than I would have gotten elsewhere. The group is primarily the reason my cancer is reduced because I followed up with activities and changed my diet based on what I heard on the calls. It contributed significantly to my understanding and to feeling that there was something I could do to control my own fate, which helped me cope. It was nice to be able to talk to others who had done research, been through it, and had knowledge about it.”*
- *“The first few meetings after listening to all of the views, everyone seemed to have a different experience, which was an eye opener for me. They had to deal with things differently ... emotionally. Great to hear the different responses, the research they did, and how much knowledge they put out there. The information exchange was unbelievable. Prevention was a big thing for me ... food and exercise. I*

*wasn't taking good care of myself health wise ... sedentary lifestyle. I was looking forward to every Thursday."*

### **Did you get the support you wanted?**

Most felt that the teleconference support they received was what they wanted. However, some felt that they would have also liked to have had a professional speaker involved in some of the meetings.

- *"It was worthwhile, but I would have preferred some professional involvement."*
- *"Yes, this group was what I would have chosen earlier in my diagnosis. Had it been available at that time I would have jumped on it because it would have been easier. I was chasing down doctors and didn't have the time to chase down meetings."*
- *"It was really helpful and supportive, and it was worthwhile. Since I've been diagnosed it was the most important thing I ever did."*

### **Phone vs. Face-to-Face**

The prostate group did not have difficulty using teleconference technology. The convenience of accessing the group by phone from wherever they happened to be at that time was considered preferable to leaving home to attend a group. The phone also provided anonymity when talking about sensitive issues like erectile dysfunction and incontinence.

- *"Given the kind of workload that I have and my extra-curricular activities, it was easy for me to do it as opposed to doing it face-to-face. Doing it on the phone made it more accessible."*
- *"It's a time thing. Doing it on the phone was convenient. Face-to-face wouldn't have the same appeal because I would have to go out and I'm very busy."*
- *"Compared to the meetings I go to, this is a lot faster approach for people who don't have the time initially to seek out a group and go. The fact that it is weekly is better because you get the information quicker."*
- *"Gave me a good feeling about the fact that men can get together and talk about stuff like this. It's not easy for me to talk about erectile dysfunction and incontinence. Perhaps talking on the phone had something to do with that."*

## **National Reach**

This initiative aimed to include participants from across Canada. As the feedback shows, this was perceived as a further strength, particularly for the prostate cancer group.

- *“It was great that they were from different parts of Canada, because you can evaluate the availability of health care in different parts of the country. Toronto and Vancouver have better facilities. Many things are not available in smaller rural communities.”*
- *“I enjoyed talking to people across the country. It was a very Canadian experience.”*

## **Next Steps**

The Canadian Partnership Against Cancer has provided funding to continue this research. New groups will start this fall for survivors of prostate, breast, ovarian, lung, and colorectal cancers and for First Nations and Lesbian cancer survivors and for caregivers. Due to the high cost of traditional teleconferencing, alternative technologies are being investigated. Text-based chats and Voice Over Internet Protocol (VOIP) technology such as SKYPE will be used to bring people together using computers and land or cell phones. Professionals will be recruited to participate at meetings. A training manual will be developed for facilitators interested in providing online or teleconference support.

If you have questions about the project or would like participate in a support group, please contact Kathy Thompson toll-free at 1-888-837-9071 or by email at: [Kathy@cancersupportnetwork.ca](mailto:Kathy@cancersupportnetwork.ca)