



Dr. Kelly Metcalfe counsels women at high risk of developing breast and ovarian cancer. She talks to them about preventative options. She helps them make the

## Ultimate decision

By Lucianna Ciccocioppo

Imagine being told you have an 80 per cent chance of developing breast cancer probably by the time you reach 50. What would you do? How many questions and fears are now running through your mind in this hypothetical scenario?

For some women, it's not a hypothetical but a very real situation. It's a conversation they have with nursing professor Dr. Kelly Metcalfe, RN, PhD '02, at her clinic at Women's College Hospital in Toronto. She meets with women who have undergone genetic testing for mutations in the BRCA1 or 2 genes, which indicate an 80 per cent risk of developing breast cancer and 50 per cent risk for ovarian cancer. By comparison, the average woman has a 10 per cent risk of developing breast cancer, and one per cent risk of getting ovarian cancer.

Metcalfe's goal is to prevent women at high risk from ever developing the disease. The associate professor at the Bloomberg Faculty of Nursing and adjunct scientist at Women's College Research Institute is an internationally renowned scholar on the prevention of breast cancer. Metcalfe counsels women about their options. Many struggle with the weight of their ensuing emotions, she says.

"In my research, I found that women had a really hard time making a decision. We're asking young women generally in their thirties and forties to think about removing their breasts and think about removing their ovaries as a preventative option. For some it's an easy decision, but for some women it isn't." The important thing, says Metcalfe, is that the women decide to do something.

That's why she developed an innovative "decision aid," a brochure-like information chart of cancer preventative options that walks a woman through the myriad treatments and side effects she needs to consider before deciding what is best for her. In addition to surgery, options include medications and an increase in MRI screening, now available in clinical practice. The decision aid helps women cut through the dizzying facts and figures and decide what is most important for them: reducing the cancer risk or maintaining the same body image?

"We have been able to reduce the decisional conflict significantly," says Metcalfe, "so women feel much more confident in the decision they're making about cancer prevention. And that's what we really want to impact. We don't want them to change their decision necessarily, but feel confident in their decision." She hopes to one day see the decision aid as part of standard genetic counseling everywhere.

A pilot test of the aid enabled funding by the Canadian Breast Cancer Research Alliance for a large randomized control trial which looked at its impact compared to standard genetic counseling. Initial pilot test results were positive and suggested women were making decisions about cancer prevention options, when previously they were not. It means fewer women will develop cancer and/or die of breast cancer, says Metcalfe.

"There's no right or wrong answer," she says. Still, Metcalfe is curious about the great variances in uptake of the various options, across Canada and in other countries, as her studies have shown. "In Quebec, nobody does anything [after counseling], whereas in BC, more than half of the women have prophylactic mastectomies. In France, nobody removes anything, but in the Netherlands, everybody has everything removed. We don't understand why." Her next project, funded by CIHR, is to investigate the decisions Canadian women make and why.

Metcalfe brings a unique perspective to the issue, given her clinical nursing skills combined with research expertise in genetics. "It's not just about presenting them with the pros and cons. Medically, I'm very aware of the psychosocial implications of all the preventative

# The average person doesn't understand what it's like to grow up surrounded by breast cancer

procedures which, for the majority of women, is what they struggle with the most. It's not about 'How am I going to feel physically after this treatment?' but 'How am I going to feel psychologically?'"

The average person doesn't understand what it's like to grow up surrounded by breast cancer and all the angst and fears that accompany the disease, says Metcalfe. For women who have tested positive for the gene, the median age of onset is the mid-40s, and typically the cancer is aggressive. They may have young children and careers to consider. "They're going to do whatever it takes to reduce their risk of breast cancer, and the only answer to that is prophylactic mastectomy; the risk is almost zero."

She thinks it's more accepted as a preventative measure nowadays, a far cry from the crank phone calls she used to get about "how barbaric and crazy" elective removal of the breasts was, when genetic testing first began in clinics in 1996 and Metcalfe wanted to hear from women who had the surgery for her research. About 25 per cent of Canadian women will opt for the prophylactic mastectomy, and almost 70 per cent will remove their ovaries as well.

As someone who watched her mother succumb to breast cancer, Metcalfe wants to ensure other women don't die from the disease "when they don't have to. We've identified these high-risk women and we need to do something about it." Her work attracts letters of gratitude and support from around the world, such as this one:

*"I recently received your article via a breast cancer e-bulletin list in Australia. I am a BRCA2 carrier and physician. I discovered my status 18 months ago and have since undergone both oophorectomy [removal of the ovaries] and bilateral mastectomy. I have never had cancer, but almost every other woman in my family has died of breast cancer and my younger sister has been treated.*

*In Australia I do not have access to regular breast MRI and [anti-cancer drug] Tamoxifen was not available for use prophylactically in high risk women when I was diagnosed. It seemed obvious to me, though horribly difficult to do, that these surgeries were the only sensible choice in my situation. I have seen enough cancer to know what I am up against.*

*However, though my genetic service mentioned these options to me, the information provided was little more than a paragraph outlining the benefits and the fact that most people who undertook these options were content with their decisions. Beyond that, the research and planning of my surgery options was all up to me... I was angry about the lack of support provided... If women are not supported to understand their options and make these decisions and to live with the consequences then of course the uptake rates will be low. These*

## Decisions for our daughters

It's called the "common flu" of sexually transmitted diseases, and 75 percent of people will get it at least once in their lifetime. Human papillomavirus causes genital warts and cervical dysplasia, the earliest form of pre-cancerous lesions recognizable in a Pap smear. But persistent high risk HPV infection can lead to much worse: cervical cancer, the second-leading cause of cancer in women worldwide.

Ontario funds HPV vaccination programs in schools for girls in Grade 8. But only about 50 per cent of schoolgirls opted to receive the vaccine in 2007 when it began. It was a hot topic in the media, given the age of its recipients, and parental fears it would promote promiscuity. The vaccination rate in Atlantic Canada, however, was higher: 80 per cent.

This raised questions for PhD student Catriona Buick Roberts, MN OT8. She wants to find out why the uptake rate in Ontario is so much lower. Her doctoral research, under the supervision of Dr. Kelly Metcalfe, will investigate attitudes and decision-making about HPV and its vaccine. "Are we getting the right information out to the right people?" asks Roberts. "What are their attitudes and beliefs about HPV and the vaccine? We'd like to give people information so they can make informed choices. Families need to make decisions that are right for them," she says.

The vaccine will have a large effect on pre-cancerous lesions on the cervix and genital area reducing not only the burden of cancer but also HPV and HPV-related symptoms. Hopefully, fewer procedures like colposcopy (diagnostic follow-up for abnormal Pap smears) will be required, says Roberts, saving resources and reducing anxieties for people. While we won't see the impact of the vaccine until these girls reach their forties, Roberts says her research results will help focus where better resources are required to get the word out about the preventative vaccine. "It's a unique way for a nurse to get involved in preventing cancer right from the start."

And yes, if Roberts had a daughter, she would have her vaccinated. ♣♣

*are very hard decisions to make and the support required is significant and is not routinely provided here... This is such an interesting and difficult arena. Thanks for your work."*

—Name withheld

It's not simply about preventing someone from going down the long, tortuous and costly road of cancer treatment, typically one year of radiation and chemotherapies. It's about thinking ahead to the next generation carrying the mutated BRCA1 and 2 genes and what their best options will be in 30 years' time.

It's about pushing through with breakthrough research, such as Metcalfe's, to fuel the growing global knowledge on genetic predisposition to disease, so maybe one day, there will be one less difficult decision for someone to make. ♣♣