



A guiding hand

Navigators see people through treatment, starting with the diagnosis

By Angela Mombourquette

Sandra Cook, project manager for patient navigation, Cancer Care Nova Scotia.

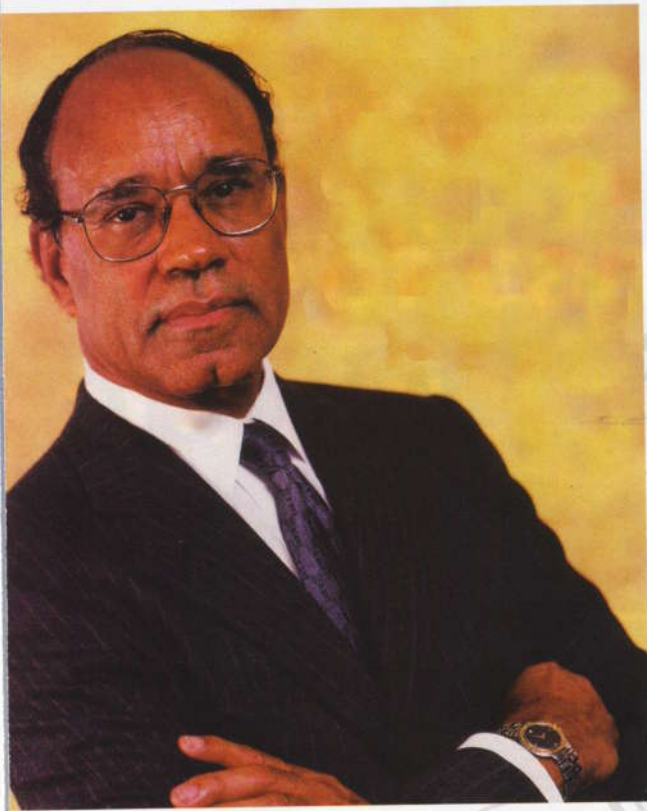
“From the minute I was diagnosed with breast cancer, I knew that this would be a mental journey for me,” says Chris Ross. The normally energetic 52-year-old tutor from St. Andrews, NB, had been monitoring a persistent lump, and a biopsy had confirmed her suspicion. “I knew I could withstand and get through the physical part, but I also knew that I’d have to keep my head on straight for the entire journey. And Wendy was a kick-start for that.”

“Wendy” is Wendy Cyr, nurse case manager for the breast health program at the Atlantic Health Sciences Corporation in Saint John, NB. She is one of a relatively new breed of health-care providers known as patient navigators. “A navigator is just what it sounds like,” says Cyr. “It’s to help people navigate through the complexities of health care.”

Cyr gets newly diagnosed breast cancer patients to the people who can help them. “These patients and families are going to see people from over 16 disciplines as they work their way through the diagnostic, treatment and recovery process,” she says. “It’s very confusing and overwhelming. I explain to them that the patient, the family, and myself are the hub of the wheel, and the spokes are all the different disciplines — and I’m going to help them get through all those spokes.”

It’s not an easy task. It’s a job that requires a deep well of empathy, a broad knowledge base, phenomenal coordination skills, and the ability to communicate well with both patients and doctors. Cyr takes advantage of many of these skills when patients arrive at her office, just a few days after their diagnosis, for their first anxious meeting.

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Dr. Harold Freeman, president of the American Cancer Society and a surgeon at the Harlem Hospital Centre in New York, created the first "patient navigation" program in the early 1990s.

determinants of health with the patients, which could be financial concerns, could be psychosocial issues. For example, the elderly lady who needs breast surgery and is the sole caregiver of her elderly husband. Or the single young mother who has no benefits. There are many, many issues surrounding a long-term treatment. But once they get a good understanding of all the information and how it fits together, they really leave with a different attitude."

Chris Ross remembers feeling as if she had "the weight of the world" on her shoulders before that first meeting. "But Wendy takes some of that weight off you. She has that ability to calm you down, to be caring — professional, but very caring. There's an intimate quality there that makes you feel, 'Yes, it's going to be okay. I'm going to get through this.'"

Navigators in PEI, Newfoundland and New Brunswick

Throughout Atlantic Canada, there is growing support for the idea of cancer patient navigation.

- Late in the summer of 2008, Prince Edward Island hired its first cancer patient navigator.
- In Newfoundland and Labrador, there are currently no specialized cancer navigators, but Sharon Smith, director of its provincial cancer care program, says that navigation still happens, "it's just not in an organized format. There are positions within the cancer care program — in particular, the nurses at the breast screening program — where people function as navigators as part of other job responsibilities."
- New Brunswick is set to roll out two new pediatric oncology patient navigator positions by the fall of this year. In addition, there are plans to have eight new adult cancer patient navigators in place throughout the province by the fall of 2009. That's on top of the three full-time and three half-time breast cancer navigators already in place in Saint John, Moncton, Bathurst and Campbellton. - AM

Navigators are also a source of information and support for other health care professionals. "There are 200 different types of cancer, and every single one of them is diagnosed differently," says Sandra Cook, project manager

for patient navigation for Cancer Care Nova Scotia. "The treatment protocols and surgical options are all different. So the big challenge for the generalist population working in communities — family doctors, general surgeons, the primary health care team — is that they don't have expertise in cancer. A navigator who is a certified oncology nurse can offer expert advice to the primary health care team, in addition to the patient."

It's a role that has evolved, primarily in cancer care, in response to that complexity. Even within cancer care, the term "navigator" can cover a broad spectrum of responsibilities. Some navigators are involved only in the screening process, some from screening through diagnosis, and some from diagnosis through treatment and recovery. Some work with only one kind of cancer and others with all types. Patients are generally referred to a cancer navigator by a clinician immediately after an abnormal test result, but patients and family members can contact navigators directly.

Patient navigation is a relatively young, and still-evolving, concept. In the early '90s, the Nova Scotia Breast Screening Program was the first in Atlantic Canada to provide a form of navigation designed to expedite the investigation of breast abnormalities. Typically, when a breast lesion is detected at a medical imaging centre, a written report is faxed or mailed to the referring physician. The patient is notified, and arrangements made for further investigations or treatments. Each step has an associated delay. In the Nova Scotia Breast Screening Program, a radiologist contacts the navigator when a suspect lesion is detected. The navigator then contacts the referring physician by telephone, and can immediately book the patient for the next diagnostic imaging session or biopsy appointment.

Dianna Schreuer is the program's navigator and a breast cancer survivor. In 2004, Schreuer co-authored a study of



Perry Jackson

Patient navigator Crystal Harris, chatting with patient Wanda Broone.

536 women who underwent biopsy at the QEII Health Sciences Centre during comparable six-month periods in 1999 and 2000. The study found that the breast screening navigation program had significantly improved timeliness in the diagnosis of breast abnormalities, reducing biopsy wait times from 20 to 14 days, thereby improving the quality of life for women with benign conditions and leading to earlier treatment for those with malignancy.

Because the program's emphasis is on screening and diagnostics, rather than treatment, Schreuer's role is not actually focused on providing emotional support to patients — although as a breast cancer survivor, she has a bond with patients and deals with their emotions every day. Like other navigators, Schreuer sometimes provides a critical information link. "I think it's crucial to heal the body, but you need to heal the mind too. People get back from the doctor's office and say 'I have no idea what they just told me.' So I'm able to access their stuff and explain it to them in words they can understand. It normalizes a lot of their feelings, and that really helps."

Nova Scotia has expanded on the breast screening program's model to develop another, broader kind of navigation that guides all kinds of cancer patients through care and treatment. Cancer Care Nova Scotia held province-wide focus groups, with patients, families and health care providers, who told CCNS that the system was like a maze, says Cook. Everyone said they needed someone to help coordinate patient care between family doctors, cancer centres and specialists, and general surgeons.

That led to the February 2002 creation of three "early adopter" cancer patient navigation sites in Nova Scotia: South West Health Authority, which covers Digby, Yarmouth and Shelburne counties; Pictou County Health Authority; and Guysborough Antigonish Strait Health Authority, which includes Guysborough, Antigonish, Richmond and

Inverness Counties. The CCNS pilot project was designed to provide cancer patients with support at two critical points: at diagnosis, and after treatment, when they return to their communities.

"Everybody's going to have a high level of distress upon being told they have cancer," says Cook, "but patients have told us that once they get to the cancer centres, they are fairly comfortable, because they are surrounded by experts. But when they finish their treatment and go back home, of course they're always living in fear of a reoccurrence. And they're always wondering, 'Who out here is going to recognize if I have a symptom? Who do I go to?' So that's why we deliberately placed navigators in communities outside of where the cancer centres are."

Darolyn Walker, who works in South West Health, was one of the first three navigators with the pilot project. Like all CCNS navigators, Walker is a registered nurse with specialized training in oncology. But in this job she's also part educator, part coordinator, and part counselor. "In some ways, I am their lifeline at a really vulnerable point. People may be going about their lives and be very in control of their world, and they get a cancer diagnosis and all of a sudden things change. Their ability to cope can be affected, no matter who they are. Once they get their feet under them, they do fine, but it's those initial days that are really tough."

After its first year of operation, over 800 referrals had been made to the navigation pilot project, and the results were remarkable. An evaluation confirmed that navigation had "significantly benefited cancer patients



The 2004 evaluation of Nova Scotia's navigation program showed significant benefits to cancer patients and their families.



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Patients can contact navigators directly by calling 1-866-524-1234 in Nova Scotia. The call will be directed to the patient navigator in your district or to the Cancer Care Centre in Halifax. Navigator contact information is also listed at www.cancercare.ns.ca. Patients in other provinces can contact their local hospital.

Navigators Colleen Cameron-Mosher, Kristina Andrews and Crystal Harris.

and their families in dealing with the emotional turmoil, informational needs and logistical challenges associated with having cancer." It also resulted in more efficient use of physicians' clinical time and more appropriate use of community health professionals. Navigation, overall, addressed problems related to integration, coordination and continuity of care. That same year, the program expanded to include two more navigators: one in the South Shore Health Region (covering Lunenburg and Queens counties) and one in the Annapolis Valley Health District (covering Kings and Annapolis counties).

"Navigation has made such a difference in people's lives. I could tell you stories that would make you cry. The patient will say, 'She saved my life.' I've seen navigators move mountains."

Dr. Shelagh Leahey recognizes the program's worth. She divides her time between her family and palliative care practices in Yarmouth, NS, and she says that the role Darolyn Walker performs is invaluable to her. "She is a person we can all check with: myself, the consultants, and the patients, to say, 'Where are we going? Can you connect us?' It takes the level of care I can provide up about three notches, because she gets me the information I need."

But it's the patients and their families who benefit most. Sharon Rhyno is a 52-year-old Yarmouth resident who has thyroid cancer. She's been through a complicated course of treatment, involving many different specialties

and a lot of travel to and from Halifax (17 trips and counting). She says Walker has been a lifeline for her and her family. When Rhyno experienced life-threatening complications after surgery in Halifax, her distraught daughters called Walker in Yarmouth. Walker hooked them up with a support person in Halifax, a nurse from the Nova Scotia Cancer Centre. "That family needed to have someone in the local area who was familiar with their mom who also had a connection with the cancer centre," says Walker. "She could reassure the patient, and that was reassuring to the family." As Rhyno says, "It was very helpful. [My daughters] had somebody to talk to, and that really helped calm them down a lot."

"Navigation has made such a difference in people's lives," says Cook. "We have case studies and testaments to that effect, and I could tell you stories that would make you cry. The patient will say, 'She saved my life.' I've seen [navigators] move mountains — setting up emergency daycare, emergency housing. The navigator is able to pull the whole team together, that's the important thing. Everybody has a piece in it, but the navigator has the whole journey."

Nova Scotia's 2004 Cancer Patient Navigation Evaluation Report strongly recommended the implementation of patient navigation in all of the province's remaining health districts. Theresa Marie Underhill, the chief operating officer of Cancer Care Nova Scotia, says they are working with the districts to make that happen.

Project manager Sandra Cook is optimistic about the future. "This is a simple concept which is really very inexpensive — the salary of an oncology nurse, which is \$85,000. And the level of patient satisfaction can skyrocket, and access to care can be more timely, and there is more informed consent, which lowers risks to everybody. So it's a concept that has a high, high impact, and it's low technology," says Cook. "And in this world where everything is expensive and high-tech, to me, this is the most cost-effective solution." 