



## THE PATIENT NAVIGATOR

**SOME CALL HER A PN; OTHERS CALL HER AN ADVOCATE. BREAST CANCER PATIENTS LUCKY ENOUGH TO HAVE ONE CALL HER INDISPENSABLE**

*By* CYNTHIA BROUSE

Two weeks after Wanda Jamieson of Bridgewater, N.S., had her left breast removed, she travelled to Halifax to receive her pathology results. With her in the doctor's office were her husband, mother and sister. "It was devastating when he told me they didn't get it all," says Jamieson, a 44-year-old food services worker and mother of two who has Stage 4 cancer. "And it seemed to go on and on — we were in

his office for two hours. We came out, and it was like, 'Oh, my God.... Did you guys take it like this when he said this, or is this what he said?' It was just too overwhelming."

Cancer-care literature often refers to the experience of having cancer, somewhat poetically, as a journey. But people who've been through it prefer words like "maze," "labyrinth" or "obstacle course." At best the process is complex, tir-

ing and stressful; at worst it can lead to dangerous delays or inappropriate treatment, and impede recovery. “Just the paperwork that goes along with cancer and cancer treatment is almost a half-time job,” says Pam Petten, a 51-year-old HR specialist with two children, who this year had chemotherapy in her hometown of Yellowknife, as well as in Edmonton, followed by six weeks of radiation.

As it happens, the past few years have seen the appearance of a new player in the healthcare system, a sort of tour guide to lead cancer patients through this decidedly foreign territory. Most often they’re known as “patient navigators,” and they’re springing up in a patchwork across Canada.

Jamieson and Petten are fortunate to live in two of those patches. Right after she was diagnosed with breast cancer, Petten was paired with breast health patient navigator (PN) Nancy Cymbalisky in Yellowknife, who walked her through her travel grant application, dropped by on chemo days with books on the disease, and prepared her for what to expect in Edmonton. Cymbalisky also phoned Petten regularly to see how she was doing and solicited her opinions on how to improve the system. “If Nancy doesn’t know the answer to a question, she finds out,” says Petten.

The first North American PN program began in 1990 at Harlem Hospital Center in New York City. It suc-

ceeded in dramatically improving the breast cancer survival rates of African-American women, who are less prone to the disease but had been dying of it at a much higher rate than other women because — uninsured or defeated by the healthcare bureaucracy — they weren’t screened in time or didn’t complete treatment.

“To date, cancer care has focused on the care of the tumour,” says Sandra Cook, project manager of the PN program at Cancer Care Nova Scotia (run by the province’s health department). “Now the whole strategy is to move into person-centred care.” In five of the nine health regions in Nova Scotia, a leader among the provinces in this area, cancer

patients are assigned to one of six PNs there, usually a certified oncology nurse, who will act as a single point of contact throughout their illness.

Right after her mastectomy, Jamieson met navigator Crystal Harris, a nurse of 14 years who became a PN in Bridgewater last year. Harris notes that cancer patients meet with an average of 13 doctors over the course of their illness (that’s not counting the many nurses, technologists, social workers, pharmacists and dietitians they’re likely to see), each dealing with just one piece of the puzzle. In this fragmented environment, the most important service Harris provides is coordination. “The patient is worried about whether everybody

knows what's going on," she says. "I'm kind of in the centre of it all."

Education is another big part of Harris's job, on everything from the difference between hormone receptors and HER2-neu proteins to recognizing that "*positive lymph nodes*" and "*cancer progress*" are, counterintuitively, not good signs. There are more practical considerations too. Patients who continue to work during chemotherapy run the risk of getting tired and contracting infections, and a low white blood cell count may lead to postponing treatments. Anything the PN can do to sort out transportation, childcare, disability benefits and drug coverage might make it more likely that the patient

can take time off work during her care. She can also help expedite tests, appointments and treatments — before benefits run out.

"Family doctors, nurses and social workers have tried to do all of these things, but they don't have enough time," admits Sue Bates, director of the PN program at CancerCare Manitoba. Even if they do, like Jamieson, after the word "cancer" falls from your doctor's lips, you hear the rest of what's said as though you've just had a blow to the head — once you get home, you've forgotten many of the details, and turning to the Internet confuses you more.

Jamieson was able to call Harris right away to sort out what she'd missed during that terrifying doc-



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tor visit. Navigators know, says Cook, the importance of "breaking down the information you need into digestible pieces and repeating it over and over."

And anyone who's tried recognizes how difficult it can be to get a doctor on the phone to ask supplementary questions, or report unexpected or severe treatment side effects. A PN has access her patient doesn't have to both her chart and her physicians, and may get responses faster.

Emotional support is just as crucial; patients who are depressed sometimes fail

to complete their treatments. Harris's patients are thrilled to find that she spends an average of an hour per visit with each one. "Sometimes all I do is listen," says Harris. Perhaps a navigator's most important advice involves the patient's right to a second opinion. "We educate them to be advocates for themselves," she explains.

That self-advocacy role is key, says Richard Doll, director of cancer rehabilitation and sociobehavioural research at the BC Cancer Agency, which has implemented a cancer PN program in Prince George.

Doll is involved in the creation of a national PN strategy through the Canadian Partnership Against Cancer, and says there are many models for this service worldwide, bearing a variety of names and coming at the problem from different angles. Some PNs are more like case managers, who do things for the patient; others simply point the patient in the right direction. In Doll's view, PNs should empower patients — and their families and friends — to navigate the system themselves in the long term.

Many cancer PN programs focus on underserved populations that are far from treatment centres, acting as a bridge between the two communities. In Alberta, demonstration

projects in Lloydminster, Drumheller and Grande Prairie use PNs for all cancers, but Edmonton, Lethbridge, Red Deer and Calgary each have a couple of navigators devoted only to breast cancer, and other areas of the province are using a similar model for gynecological, bariatric, cardiac and stroke patients. A pilot project in Saskatchewan uses "nurse navigators" to guide women through breast cancer screening and diagnosis, but not treatment. Quebec has more than 150 cancer nurse navigators based in hospitals, but Ontario has no provincially led strategy yet — only a few isolated programs. That province is working on establishing a patient navigator project to assist

patients at the beginning of their cancer "journey."

Critics of patient navigation worry that it simply builds another professional layer on top of a broken system, which is why some jurisdictions would rather fix the process first. Others use navigators as a means of locating the gaps.

Private options also exist, although they're hard to find: If you're lucky, the company you work for may offer, as part of its benefits package, the consulting services of a company like CAREpath or Rupert Case Management, both based in Toronto; Rupert also sells the service directly to individuals, including those with serious illnesses, not just cancer.

So far, there's not much

research to suggest PNs themselves help improve health or prolong life, but there's plenty of evidence that education, timely treatment and attending to a patient's social needs all lead to better outcomes. Jamieson's journey has been made more bearable because of the little things: Harris connected her to a maker of mastectomy bras and prostheses, and to the Look Good Feel Better program in Halifax. When Jamieson wanted to go out with friends during chemo, she called Harris to ask if it was okay to have a beer. (It was, Harris advised, but only after checking to see what drugs her patient was taking.) Jamieson laughs: "You just don't call a doctor up and ask him that!" **M**

