



# Life after cancer Life

Unique followup clinics created by Bloomberg Faculty of Nursing alumni are helping to make the transition to 'life after cancer' a little bit easier for survivors

By Lucianna Ciccocioppo

## The 'transitional' clinic

At the Hospital for Sick Children in Toronto, the clinics for children suffering from acute lymphoblastic leukemia are extremely busy. About 100 children suffering from ALL, the most common childhood cancer, make the trek to these clinic appointments every week. But children who had completed their treatment were also seen in these clinics for their followup care. They were waiting three, sometimes four hours to be seen by a pediatric oncologist, pediatrician or nurse practitioner, only to be told in a five-minute meeting that "the blood counts are good, you're fine and you can go now," without much time for questions and answers.

Nurse practitioner Sue Zupanec, RN, MN (ACNP) cT4 thought there must be a better way to serve patients off therapy, and their families, during this stressful time. After five years off therapy, these children are seen in the late effects clinic for follow up. But Zupanec found out from colleagues that these patients had missed significant followup diagnostic tests in the meantime. "They hadn't had their echocardiograms done, nor bone mineral density tests," she says. The followup schedule, as outlined by the Children's Oncology Group, was in reality off-schedule. "I saw an opportunity to start the transition to an off-therapy clinic sooner."

She proposed an NP-led transitional clinic and the hospital gave her the green light. In late in 2006, a nurse-led leukemia follow up clinic was started, focusing not only on possible relapse, but also on health and well-being, health education, and monitoring of treatment late effects. Heather Jones RN, BScN 9To, MN (ACNP) cT2, another nurse practitioner who runs the clinic with Zupanec, says the focus is also on "normalization."

"The other goal is to get the families in and out quickly. The children are off treatment and moving on with their lives; we should let them do that." Patients are now seen within 12 minutes of their appointment time, and sessions have been bumped up to 45 minutes. Now there's time to "keep on top of the evaluations that need to be done," says Jones.

The nurses screen for issues such as weight gain and obesity, cardiomyopathy (thickening of the heart muscles), and neurocognitive effects that could affect learning in school.

To fine-tune their assessment skills, Jones and Zupanec developed a screening tool, together with neuropsychologist Dr. Brenda Spiegler, with specific questions to determine possible neurocognitive changes because of the medication, methotrexate. "We know the right questions to ask, and as a result, we've picked up a lot more subtle neurocognitive changes," says Zupanec. These children are referred to neuropsychological screening, where any learning deficits can be identified, their schools

notified, and appropriate assistance or program changes offered. Says Jones: "We're looking for it because we now have the time, and the situation is not deteriorating so that the child is disinterested in school, or worse, failing."

Another effect they look out for is decreased bone mineral density caused by dexamethasone, a steroid used in treatment. There are tests recommended two years off therapy to see if bone mineral density has re-absorbed on its own, says Jones. "We've found a couple of cases with significantly low bone mineral densities, so that allowed us to put the children on calcium and vitamin D supplements. Is this going to decrease the potential for osteoporosis and fractures later on? We don't know, but we can refer them to the osteoporosis clinic early for further monitoring."

Health promotion is a big part of the transitional clinic as well. "If there's a pattern in the child's life for weight gain, we can start to make changes sooner, and track their height and weight statistics," says Zupanec. After five years off therapy, it can be tough to ask an overweight child to start eating healthily and get into an exercise routine.

Their counseling skills extend to parents as well, says Zupanec. "We address anxiety issues. Parental anxiety once the children are off therapy is quite significant." Adds Jones: "It's actually the most stressful time for parents because there's a sense of comfort when children are on chemotherapy every day. But as soon as you stop treatment, parents worry: is it going to come back?" These advanced practice nurses address the issues, particularly if the impact on daily life for parents is great. "We refer parents to counseling, to adjust to life after treatment, and the fear of relapse," says Zupanec.

Zupanec and Jones continue to work in the active clinics as well, and their expertise and new knowledge in areas such as weight maintenance, calcium intake and school issues are shared with their colleagues. "We're promoting preventative interventions through our knowledge transfer to colleagues in our group," says Zupanec.

The success of this unique APN-led transitional clinic has elicited much attention at scientific meetings, while physicians and service providers appreciate the decreasing pressure off their active clinics, and can now focus exclusively on children currently in treatment, says Jones. "They also appreciate our focus on the psychosocial aspects of care...which, in the middle of a busy crazy clinic, is not the first thing you worry about."

But more importantly, says Jones, "They know that we know what we're doing. We know leukemia."



Transitional clinic nurse leaders, Sue Zupanec and Heather Jones: “We know leukemia.”

## The new ‘normal’

Every pain, every ache can prompt an anxious question: is it back? For survivors, the cancer journey is only 50 per cent over when the treatment stops. Trying to get back to “normal” takes up the remainder, says Pamlyn Preston, a breast and kidney cancer survivor from Milton, Ont.

“Your family and friends try to be positive, but nobody really knows if you’re okay,” says Preston, who’s been cancer-free for about seven years. “I still get really nervous when I feel a new pain. But sometimes their optimism is hard to take—they don’t really understand what you’re going through,” she says.

Emotional distress and fear of recurrence are some of the challenges survivors have to face once their therapy is completed because they now have time to think about things, says nurse practitioner Jennifer Wiernikowski, RN, MN (ACNP) oT3, CON (C). Other challenges include combating fatigue, changes in diet and exercise, and cognitive changes. For breast cancer survivors, treatment effects such as hot flashes and menopause symptoms, lymphedema (swelling of the arm where lymph nodes were removed) and painful sex can be disruptive to their lives.

Wiernikowski heard these stories at the Hamilton Health Sciences Juravinski Cancer Centre, and six years ago, proposed a nurse-led followup clinic to help those struggling with the after effects of cancer

therapy. She offered thorough assessments with 20-minute appointments. “These patients are well, but are having complications getting ‘the rubber back on the road.’ So we have a little more time for them. I can still do breast cancer surveillance, and get their mammograms ordered. But I also become the content expert on issues such as lymphedema, fatigue, and cognitive changes. And I can help with their care plans to make the plans a little bit more supportive in nature.”

Wiernikowski went a step further and created specialized symptom-management clinics focusing on menopause after breast cancer and lymphedema. “There’s significant health teaching in the lymphedema clinic, so the patient learns how to manage it, and hopefully it doesn’t worsen.” There’s also substantial support for women “whose sex lives get really derailed,” says Wiernikowski. “Surgery can be disfiguring. These women are dealing with loss of hair, perhaps weight gain and loss of libido. We counsel them. There are some fairly non-invasive medical and non-medical interventions one can try. I also have a number of local specialists to whom I can refer patients when nursing interventions are not effective. We have a sexual medicine clinic and a local physiotherapist who has a great deal of expertise working with cancer patients, so they are a great resource.”

She’s currently the chief of nursing practice at the JCC, but still manages to dedicate one half-day a week to attend to breast cancer



Jennifer Wiernikowski and Margaret Forbes: nursing's answer to the growing number of breast cancer survivors transitioning to their new 'normal.'

patients in the clinics. She's pleased to see the clinic grow "more robust" with Margaret Forbes, RN, CON (C) who took over the initiative, and is currently an online master's student (ACNP) at the Bloomberg Faculty of Nursing. Forbes has partnered with a general practitioner in oncology (a family physician with specialized oncology training) for the well followup clinic, and continues to lead the managing menopause and lymphedema clinics. Some of the stories she hears are more poignant.

"A lot a younger women are concerned about what the future holds for their family, and their children. They worry if they have a genetic predisposition to breast cancer," says Forbes.

And with the increasing number of cancer survivors, Forbes says the importance of these followup clinics cannot be stressed enough. "The patients declare them to be a vital part of their survivorship," she says. Not only do these APN-led clinics alleviate overbooking at the oncologists' visits, but they also give a sense of empowerment to survivors. "People tell me 'I now have the information to do x, y or z and get on with my life.'"

The oncology nurse has 19 years of clinical knowledge and expertise behind her to examine and assess patients for possible recurrence, and assess them in a broader psychosocial context as well. "Unfortunately, a routine followup appointment with an oncologist doesn't allow

enough time to delve into the complexities of survivorship issues. What Jennifer Wiernikowski and I have managed to do is carve out the role to be the content experts in the field. So we can give the latest information on managing lymphedema or menopause effects not only to our patients, but also to our team," says Forbes.

Their health educator roles extend outside the cancer centre. Forbes is collaborating with the local YWCA on "Encore," a rehabilitation program which combines land and water exercises for breast cancer survivors, and is also an informal support group. Wiernikowski was a founding organizer in 2001 of an annual Life After Breast Cancer conference for survivors to hear the latest in managing their treatment effects, physical and psychosocial.

It's nursing's answer to the questions arising from the growing number of survivors making the transition to their "new normal." It's a streamlining of services to address the ballooning followup practices oncologists are struggling to maintain on limited time.

"It means breast cancer survivors who are having trouble managing long term side effects will be more successful in managing their own health—coping, living and moving beyond their breast cancer therapy, to engage in their normal activities. It definitely takes an interdisciplinary team to make all this happen, but I do believe nursing contributes a great deal to that," says Wiernikowski. ♣♣