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New hope for patients who want kids after cancer

Medical advances in fertility preservation, knowledge sharing and even political support are helping survivors realize their dreams.

Melissa Beilhartz with daughter Ellery and husband Sean. The couple dreamed of having a larger family but treatment for cervical cancer left Beilhartz infertile. She wishes she could have properly explored her options to preserve her fertility prior to treatment.

By: **Isabel Teotonio** Living reporter, Published on Fri May 02 2014

When Melissa Beilhartz gave birth to her daughter Ellery in 2006, it was supposed to be a joyous occasion. But during delivery a nurse spotted something unusual with the first-time mother's cervix. At the six-week postpartum checkup, the 30-year-old was diagnosed cervical cancer.

"(Ellery) saved my life," says the St. Thomas, Ont. woman. "I would never have known something was wrong."

Beilhartz was thankful the cancer had been caught, thankful to have her daughter. But she was also petrified she might not live to see her baby grow up. And, if she did survive, she feared cancer would crush her long-held dream.

"I worried we may not be able to have other children."

Life-saving cancer treatments, such as surgery, radiation therapy and chemotherapy, can damage a patient's fertility and/or bring on early menopause. The extent to which fertility is affected depends on factors such as cancer type, the specific course of treatment and a patient's age.

Beilhartz was slated to undergo a hysterectomy — the removal of the uterus and cervix — followed by five weeks of radiation therapy. So she asked her cancer care team about her options to preserve fertility. But they initially didn't know what to tell her or where to refer her.

“There didn’t appear to be a clearly defined path, from my perspective,” recalls Beilhartz. “We weren’t sure what options were available but wanted to ensure we explored every possibility.”

Prior to treatment some patients can preserve their fertility for later use. For men, the process is pretty simple: they ejaculate into a container and bank their frozen sperm. Women can undergo a more complicated medical procedure called in vitro fertilization (IVF) that involves stimulating the ovaries and extracting their eggs, which are then frozen as eggs or embryos (eggs fertilized with sperm).

To better bridge the fields of oncology and assisted reproductive technology the Cancer Knowledge Network (CKN), which is an education resource for patients, doctors and caregivers, this year launched the first Canadian online referral system. Found on the CKN website, the Oncofertility Referral Network allows physicians to make timely referrals for patients to get pre-treatment consultations at local fertility clinics. And because many patients need to start treatment quickly, fertility clinics expedite these requests.

“Cancer patients are entitled to get information about the options they have,” says Dr. Hananel Holzer, medical director of the Reproductive Centre at McGill University Health Centre, who helped build the network.

“Unfortunately, not many are referred for a consultation, and that’s the challenge.”

According to Statistics Canada, each year some 11,000 Canadians, aged 20 to 44, are diagnosed with cancer — about half of them in Ontario. Thanks to earlier detection and better treatment, the five-year relative survival rate in Ontario, which compares cancer patients’ survival rates with those of peers in the general population, is about 80 per cent, according to Cancer Care Ontario. For some survivors being able to have children after cancer is vital to their quality of life.

Telling patients at the time of diagnosis about choices in preserving fertility is important, says Dr. Ellen Warner, a medical oncologist at Sunnybrook Health Sciences Centre who works with breast cancer patients under 40.

“The message you’re giving her is so powerful, it’s: ‘I believe you’re going to be well enough to be able to have a baby in the future and raise it to adulthood.’

“You can’t give more hope than that.”

When it comes to fertility preservation, attitudes and practices vary. Although there are no Canadian guidelines, many oncologists follow those of the American Society of Clinical Oncology (ASCO). In 2006, the ASCO recommended doctors tell cancer patients of child-bearing age about treatment-related infertility as early as possible after the diagnosis and refer them for consultation with a fertility specialist.

But the low referral rates to fertility clinics suggest “there is a disconnect between what we should be doing and what is actually happening,” says Dr. Ellen Greenblatt, medical director of Mount Sinai Hospital’s Centre for Fertility and Reproductive Health.

“Your health care team might be focusing on the obvious problem, which is the recent cancer diagnosis and it might not come to their mind (to discuss fertility.) . . . It’s important for people to be their own advocate.”

There are various reasons why oncologists may not broach the issue. Their primary goal is to save the

patient's life so they may not think to discuss fertility when there are so many other issues that need to be addressed. Plus, it can be tough to predict the risk of cancer therapy. And, some worry fertility preservation will add further stress on a patient who's grappling with a new diagnosis, delay treatment and be cost-prohibitive for some patients.

Also revealing was a 2009 survey led by Samantha Yee, a social worker at the Mount Sinai centre who is studying oncofertility practices in Canada as part of a PhD at the University of Toronto's Faculty of Social Work. She found a significant number of Ontario oncologists had limited knowledge of fertility preservation options or where to refer patients in a timely manner.

Even in cases where preservation isn't possible — either because the patient is too sick or needs to start treatment immediately — it's still important to tell them about fertility risks, says Dr. Abha Gupta, a medical oncologist at Princess Margaret Cancer Centre.

"We want to avoid people saying, 'Nobody told us,'" says Gupta, adding studies repeatedly show patients want the information.

Princess Margaret recently launched an initiative to help oncologists start the discussion. A clinical nurse specialist with the Adolescent and Young Adult Oncology Program provides materials and educates cancer care teams on how to have the conversation.

At St. Michael's Hospital, Dr. Nancy Baxter, a general surgeon who operates mainly on cancer patients, is developing an oncofertility decision-making aid to help women and their health care teams.

"Fertility is a huge issue for women," says Baxter, whose project is funded by the Canadian Cancer Society. "Being a surgeon I'm in the group of people who knows relatively little about (fertility) issues and wishes I had something better to help my patients with."

Lara McLachlan was only 32 when she was diagnosed with breast cancer in December 2011. Looking for hope from her Toronto oncologist, she initiated the discussion about motherhood.

"I love children and I feel it is a natural and important part of life to have them," explains McLachlan. "If there is a choice, I don't want to have a compromised life because I got cancer at a young age."

McLachlan had spent weeks looking for advice from other young cancer patients and in online discussion boards. But many said they were too overwhelmed fighting cancer to think about making babies. Feeling alone and scared, McLachlan yearned for advice.

But her doctor — and two of his colleagues — discouraged her. They didn't want McLachlan to delay chemotherapy for fertility preservation, which usually takes a few weeks because it's synchronized with a woman's menstrual cycle. And because they were dealing with an estrogen-sensitive tumour, they were concerned the hormone drugs used in IVF could stimulate its growth. Plus, they told her, the procedures are costly and there's no guarantee of success.

"They had a point but I wanted to explore my options," says McLachlan. "I was super-shattered. They were basically like, 'You're not going to have kids. There's no way.'"

But she was determined. She found Dr. Warner at Sunnybrook, who assured McLachlan fertility preservation was safe — even with her type of tumour.

At Mount Sinai's fertility clinic, McLachlan opted to freeze embryos created with donor sperm because they withstand the freezing and thawing process better than individual eggs, giving her a better shot, eventually, at a successful pregnancy. After three weeks of cycle monitoring, followed by a painful extraction procedure that involved inserting a needle into her ovaries, clinicians were able to fertilize her eggs in a petri dish and create two viable embryos.

With that glimmer of hope, McLachlan steadied herself for what lay ahead: chemotherapy, double mastectomy, breast reconstruction and hormone therapy.

Now 35, McLachlan is worried her window for motherhood is closing. She's decided to cut short her course of the hormone therapy drug tamoxifen because it can cause fetal malformations. Warner would have preferred McLachlan stay on the drug longer, but she supports her patient's choice to try intrauterine insemination (IUI), a procedure that involves inserting washed sperm into her uterus during ovulation. If IUI doesn't work McLachlan will consider using her embryos.

"My chances for fertility success are low, but that just makes me try hard and not give up easily," she says. "It is incredible to think that I might not lose all of what cancer threatened to take."

But the interventions do come with a high price tag. In general, the standard IVF procedure costs between $6,000 and $8,000 and drugs are between $2,000 and 4,000. Plus, there are annual storage fees, which amount to a few hundred dollars.

Many clinics reduce fees for cancer patients and work with pharmaceutical companies to cut drug prices on compassionate grounds. And for cancer patients who qualify, the national non-profit organization Fertile Future provides a reimbursement of up to $1,000 for females and up to $350 for males.

Advocates have long called for full funding of IVF for cancer patients, saying it's medically necessary since they are at risk of losing their fertility because of a disease. In April, Ontario announced it would pitch in $50 million a year, beginning in 2015, to help pay for one cycle of IVF for all forms of infertility, including cancer patients. The funds will cover only clinical costs and not fertility drugs. By comparison, Quebec pays for three rounds of IVF, including drugs.

For Ryerson University student Betty Chow, a 22-year-old with endometrial cancer, the thought of making a decision about future motherhood seemed a bit surreal. Plus, the cost of IVF seemed out of reach for the full-time student with a part-time gig as a cashier.

"I kept saying 'This is so expensive,'" recalls Chow. "But my mom said, 'Just go for it, maybe you can use (the eggs) later. Money's not a problem.'"

She opted to freeze her eggs, but not without reservations. Her uterus, ovaries and Fallopian tubes would all be removed, so she knew she would never be able to carry a baby, give birth or breastfeed. Even if doctors successfully harvested her eggs, Chow would have to rely on a surrogate and would miss out on what she felt were important aspects of the mother-child bond.

In an unusual turn of events, her body didn't respond to the IVF drugs and she didn't grow any eggs. But Dr. Karen Glass of Create Fertility Centre, director of the oncofertility program, remained determined to help Chow.

After surgery, Glass and her team were able to retrieve 24 eggs from Chow's ovarian tissue. In the lab, they

used a process called in vitro maturation (IVM) to mature 13 eggs, which are now sitting in a freezer.

“It gives me hope,” said Chow. “At least I have something for the future.”

That IVM procedure can also be used for women who have little time to delay treatment. At the McGill centre — the first and one of only a few clinics to offer this service in Canada — a baby was born in 2011 to a breast cancer survivor via IVM.

Even with the options available, some women choose not to proceed with fertility preservation because they’re too stressed about any delay in treatment, says Glass.

Sunnybrook’s Warner has also seen this fear firsthand in her own patients.

“The biggest problem is women can’t think ahead. They’re focused on ‘I have cancer, I’m going to die.’ So, thinking about a baby seems crazy. But five years later things are very different,” says Warner.

“Part of getting back to a normal life after cancer is being able to do all the things your peers are doing and if your peers are having babies and raising them, why shouldn’t you?”

Still, Glass always tells her patients: “Cancer first and fertility second. The number one thing is you have to be cured of your cancer so that you’re healthy enough to have a baby.”

But even patients who don’t pursue fertility preservation are glad they were able to make an informed decision, she says.

“The worst situation is when you see patients who had no idea what was going to happen to them and they have so much regret all these years later. And I do see many patients like that.”

Melissa Beilhartz’s cancer care team eventually found a fertility doctor to refer her to, but she called the consultation “disappointing.” The physician couldn’t answer her questions because they stemmed from an oncology angle, and was skeptical about the success of the costly preservation techniques. He also advised against delaying surgery to treat her cancer.

“I didn’t feel that as a patient, I was involved or engaged in the process, It was just ‘Listen to your doctors and don’t worry about (fertility) right now.’ Well, you have to worry because you can’t do anything about fertility once it’s gone.”

She and her husband, Sean Beilhartz, were crestfallen. Following the fertility expert’s advice, they did nothing. Weeks later she had a hysterectomy.

Melissa Beilhartz is now seven years cancer-free. While the couple feels very fortunate to have Ellery, they feel like the decision to not pursue fertility preservation was made for them.

“Young women need to feel as though they are making an informed choice about their future,” says Melissa Beilhartz. “If nothing else, a patient needs to feel like they are a part of their journey and not like they are being instructed. Because it’s our life, not the health care provider’s.”