

Adolescent and Young Adult Cancer program aims at expansion

Sarah Gallie was just 35 when she was diagnosed with hormone-positive breast cancer.

A nurse by vocation, her treatment started at Toronto's Humber River Hospital, where her family doctor is affiliated.

Navigating multiple healthcare providers and multiple treatment options to address the disease sometimes brought out the feeling of overwhelm, but when Sarah decided to bring her care closer to home, the Newmarket resident found a holistic approach at Southlake Health that went well beyond 'the big C.'

Sarah was one of the first patients at Southlake's Adolescent and Young Adult (AYA) Cancer Program, a partnership with Toronto's Princess Margaret Cancer Centre.

The unique local program, which is tailored to the specific needs of young adults between the ages of 18 and 43, helping them navigate challenges beyond medical treatment, is now marking its first year as a community success story.

To mark both the program's anniversary and this week's Adolescent and Youth Cancer Awareness Week, Sarah and members of the Southlake team came together her very personal journey.

'The young adult life is one of enormous transition and personal growth,' says Southlake. 'It often includes major milestones such as finishing school, pursuing a career, building relationships, and starting a family. Cancer is highly disruptive; it interrupts education, delays career starts and milestones, upends social networks and undercuts independence.'

'Adolescents and young adults make up five to ten per cent of the adult cancer population and [that] continues to increase. However, due to this being a lower population, patients tend to be treated in many cancer centres as adults. Few healthcare organizations have the expertise, comfort or infrastructure to provide skilful and customized care to young adult cancer patients.'

Says Sarah: 'This is happening to young people and we need to support them in a different way; not just the medical things, because whether you're having breast cancer at 35 or 60 it's probably the same chemo, the same radiation, the same options for surgery, but it is all those other pieces that really make a difference in how you come out at the other end of it.'

'The thing about going through this diagnosis when you're at a point in your life where you're managing a mortgage, figuring out kids-or-no-kids, what that pathway is going to look like, trying to figure out the next steps of my career? It's not to say it's any better to get cancer at a point in your life, but when you get cancer, you're 60, 70, 80 years old and you've probably done all those things,' she continues.

In addition to facilitating the conventional treatments, the AYA program offers a holistic approach tailored to the needs of the patient.

Clinical Nurse Specialist Sam Scime offers individual consultations and follow-ups for patients and such supports offered through the program include fertility preservation, school and work transitions, sexual health, body image counselling, and much more.

'Sarah and I [connected] at the beginning of my being in this role so it has evolved over the last year-and-a-bit,' says Scime. 'What happens now is we have an automatic referral process so everyone who is between the ages of 18 and 43 at Southlake automatically, as soon as they enter the cancer system, they are referred to me. My role within the Cancer Centre is to support a person and how they are impacted by a cancer experience in the ways of their life that are specific to being young.'

'We know there are so many milestones that are being reached in that period of 18 to 43. In Sarah's case, it was, where is my career going? Sarah is kind of a hot-shot nurse at SickKids and was thinking about what is going to happen next. The first time to talk to

you is going to be a long conversation because I want to get to know you as a whole human, how your cancer is impacting you, figure out where the gaps are, and how I can provide support.?

This approach was particularly welcomed by Sarah, who says she learned early on in her journey that a cancer plan is never a 'one-size-fits-all' approach.

Having that one-on-one approach was 'all the more meaningful' because it helped them both hone in on exactly what she needed and when.

Some elements of the tailor-made plan included virtual meet-ups with others, taking part in a book club 'reading is a good distraction, especially when you're in the chemo chair,' says Sarah 'and, down at Princess Margaret, a hair salon for people going through chemo called Hair Gone Rogue, and even a pottery class to which Sarah was able to bring her husband.

'I was able to stay working for the most part, only took time off for surgery, and sick days here and there for chemo; I'm a bit of a workhorse and I had the flexibility to work from home as my job allowed, which others don't have. Sam was able to connect me with Sharon [a counsellor] who was able to figure out if I needed any accommodations for work.'

Being able to walk on nice days from her Newmarket home to Southlake was an added bonus for Sarah. Now, she is herself part of the Southlake team, taking an 'informal' nursing role in their paediatric department.

As the AYA continues in partnership between Southlake and Princess Margaret Hospital, the local program is looking to expand.

They have had a successful year, says Dr. Alisha Kassam, Medical Director of the AYA Cancer Program and a leading force behind its creation locally, and they are looking forward to fostering further outreach.

'Now that we have been around for a year, we're able to engage with patients who have been through the program to be able to provide feedback and really looking to them to help us figure out next directions,' says Dr. Kassam, noting that some emerging themes so far include physical rehabilitation and wellbeing, and fostering Southlake and its Cancer Centre as a hub for smaller 'satellite' cancer programs in the area.

'Princess Margaret was the only place in Ontario who saw the need and developed a specialized program. Because they paved the way for the initial idea, which is having a clinical nurse-specialist-led program, that allowed us to adapt it to a Regional Cancer Centre in a community approach and make a few tweaks 'to have more local, community-based resources. I feel that partnership was very critical.'

Adds Sam: 'Replicating Princess Margaret's program is not realistic 'in the smaller regional cancer centres, but replicating what we have done at Southlake is. It's kind of this mutual, amazing synergy that is happening. There is a lot of uptake and awareness in the needs of AYAs and we're seeing programs popping up all over the Province' I think Southlake is a model and being connected to Princess Margaret, we're all working together as a group to try and replicate what we're doing here.'

By Brock Weir