

Cancer is affecting more young people than ever before: How health care can learn to meet their needs

June 18 2024, by Cheryl Heykoop



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The Princess of Wales's [cancer diagnosis](#) at the relatively young age of 42 brought attention to the realities of being diagnosed with cancer as a

younger person. By definition, adolescents and young adults (AYAs) are people diagnosed with cancer between the ages of 15 and 39. In Canada, there are more cancer diagnoses in this age group than ever before: [nearly 8,300 diagnoses each year](#), or one AYA diagnosed every 65 minutes.

However, there is limited understanding and support for the distinct medical and psychosocial complexities adolescents and young adults face, and cancer care systems [rarely support the unique needs of patients in these age groups](#).

What is known is that cancer is different for adolescents and young adults than it is for children or [older adults](#). However, [only 0.4%](#) of all cancer research funding focuses on young adult cancer. Cancer diagnoses in young people often occur at a later stage with poorer outcomes and lower survival [rates compared to older age groups](#). Further, a [recent report in the journal of Nature](#) questions whether early onset cancer is a global epidemic.

Distinct challenges for younger patients

"It's a strange experience facing mortality at an age where the world assumes we're vivacious. Having cancer as a young person changes you in profound ways," says a young adult navigating cancer.

"Not only are patients in this age group navigating the challenges of facing a life-altering [cancer diagnosis](#), they are also often navigating other challenges distinct to their life stage. They may be mid-way through post-secondary education, building a career, establishing a relationship and/or a family, and becoming independent—all of which can be impacted significantly by cancer.

"Adolescents and young adults struggle with distinct fears, too, ranging

from early death, to infertility, to financial instability and cancer recurrence—each of which must be managed for however long life continues. For AYAs with diverse intersectionalities (for example, race, gender, sex, class, age, disability, geography, health status), the challenges are [further amplified and there is limited focus on understanding their distinct needs](#). There is an urgent need for AYA-specific care and support."

"At the time, I was just so floored that I had this sickness and that I had to stop nursing school. I had to stop everything that I had planned for myself," says another young adult navigating cancer.

The provision of [AYA-specific care](#) is standard in the United Kingdom and Australia, and the United States' National Cancer Institute and the American Society of Clinical Oncology Care recommend specialized training and oncologic and supportive care programs [focused on adolescents and young adults](#).

In Canada, although young people represent four percent of patients diagnosed each year, there are few oncologic and supportive programs specific to this age group. [Princess Margaret Cancer Centre](#) has a dedicated AYA Oncology Program; [CancerCare Manitoba](#) has an AYA support program as part of its patient and family support services; and [Alberta Health Services](#) provides AYA navigators as part of its development of an AYA support program. In British Columbia, despite a concentrated, [representative effort from 2016-18](#), there is currently no provincial AYA-specific program.

Inspiring change in B.C.

Yet, momentum and partnerships are growing to reshape young adult cancer care in B.C. The Anew Research Collaborative, based at Royal Roads University in Victoria, is led by Cheryl Heykoop, Michael Smith

Health Research B.C. Scholar and one of the authors of this story, who herself experienced cancer as an AYA. Anew is working with adolescents and young adults, BC Cancer, [BC Children's Hospital](#), related care providers and partners to create change for AYAs.

Anew works with [young people](#) navigating cancer, those who offer treatment and support, and those who make health system decisions to co-generate knowledge, relationships and strategies to improve cancer care for young adults, with a specific emphasis on those with diverse intersectionalities.

Our approach draws on the principles of [participatory action research](#), [patient-oriented research](#) and [creative action research](#) using a range of creative methods to support engagement, build capacity, share knowledge and facilitate tangible improvements in young adult cancer care. This approach acknowledges that adolescents and young adults are experts of their own cancer experiences, who--in engaging creatively with cancer care providers--inspire meaningful change.

The impact of such collaboration was evidenced at the BC Cancer Summit (BC Cancer's annual conference) in both 2022 and 2023. Anew co-facilitated sessions with BC Cancer both years, bringing adolescents and young adults together with cancer care professionals to begin improving care. The first year focused on identifying and prioritizing the key issues to address—a road map to guide efforts going forward, and the second year saw patients in this age group and care providers collaborate to explore the top three issues in depth:

- timely access to fertility services and effective information;
- provision of counseling services customized to meet the needs of adolescents and young adults experiencing cancer; and
- development of resources and supports to continue with life thereafter.

Participants also co-designed [tangible solutions to address each of these key issues](#).

Dedicated care for young patients

Since then, there's been a flurry of initiatives based on these priorities, including AYAs working together with Anew and care providers to establish:

- a [dedicated section of the BC Cancer website](#) providing links to AYA resources both within BC Cancer and externally;
- a pilot counseling program for AYAs newly diagnosed with breast cancer;
- improved fertility care for AYAs, including co-design of effective resources to enable timely decision-making, enhancement of BC Cancer's pregnancy policy to include fertility care; and educational opportunities for clinicians and care providers to increase understanding of fertility preservation and the barriers to be addressed.

This collaborative effort to streamline fertility care is impressive, with BC Cancer, BC Children's Hospital, Vancouver General Hospital and Yukon hospitals working together with B.C./Yukon AYAs, Anew and related care providers.

Further, Anew and BC Cancer will partner again at this year's Summit ([Nov. 21-23](#)) co-facilitating a session on improving fertility care for [young adults](#) and debuting an AYA Immersive Experience, designed by AYAs to provide a multi-sensory, living library-like perspective of what it's like to navigate cancer as an AYA and explore opportunities to improve cancer care and support. Together, we continue to take steps forward and create change. Amidst the devastating realities of being diagnosed with [cancer](#) as an adolescent or young adult in B.C., there are

promising times ahead.

Patients, families, health-care providers and researchers can learn more and register for updates at [Anew's website](#).

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