

Meet me in the Middle: Caring for AYA's with Cancer

**POGO Multidisciplinary
Symposium on Childhood Cancer
November 7, 8 2025**

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Disclosure:

Disclosure	No	Yes, Details
Member of Advisory board	x	
Stipend from Commercial Organization	x	
Pharmaceutical Company Investments	x	
I intend to discuss therapies that have not received regulatory approval (i.e. “off-label” use of medication).	x	

Learning Objectives:

By the end of this workshop, participants will be able to:

- *Understand the unique medical and psychosocial needs of AYAs.*
- *Explore strategies to improve communication, support, and continuity of care.*
- *Learn foundational steps for developing an AYA oncology program.*

Let's get to know each other





8,000

AYA aged 15-39 newly
diagnosed/year in Canada

Cancer is the 2nd most
common cause of death

Public Health Agency of Canada. Cancer in Young People. Ottawa, 2024.

StatsCan 2023. <https://www150.statcan.gc.ca/n1/daily-quotidien/241204/dq241204a-eng.htm>

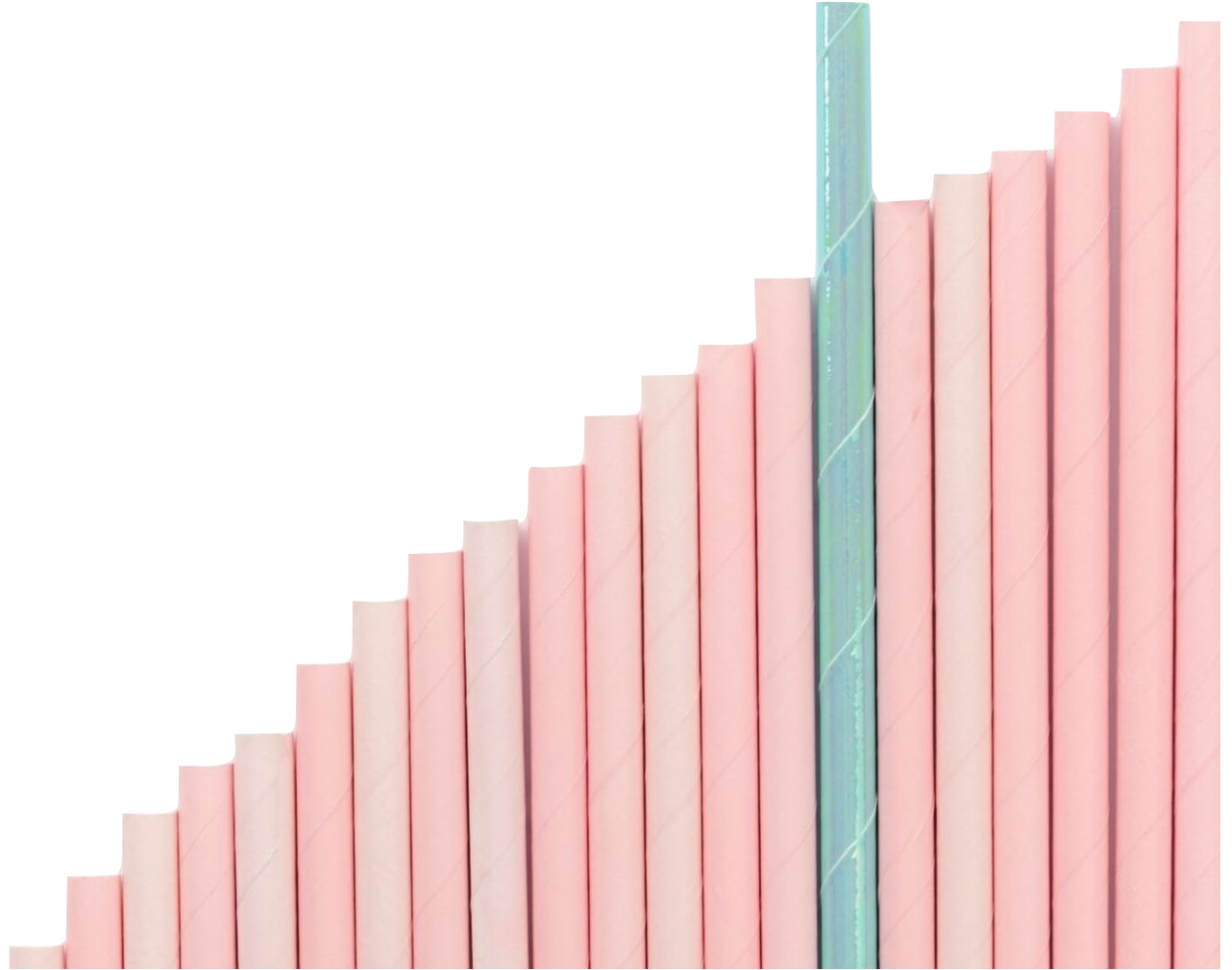


~ 1.2 million

AYA diagnosed/year
worldwide (6.8% of all
cancers)

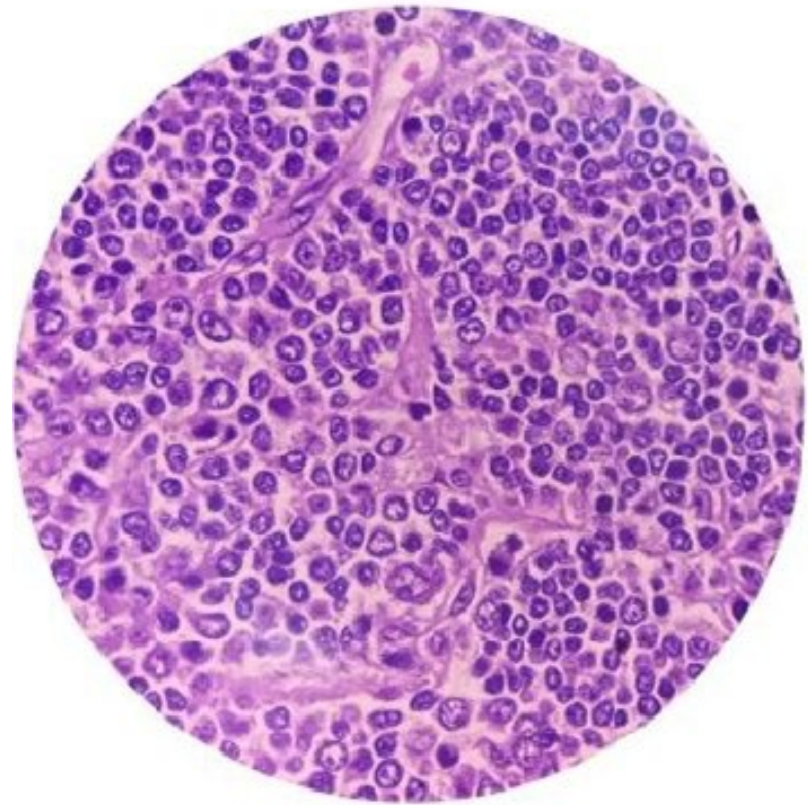
Ferrari, A., Stark, D., Peccatori, F. A., Fern, L., et al. (2021). Adolescents and young adults (AYA) with cancer: a position paper from the AYA Working Group of the European Society for Medical Oncology (ESMO) and the European Society for Paediatric Oncology (SIOPE). *ESMO open*, 6(2), 100096.

What makes AYAs unique



Different biologically

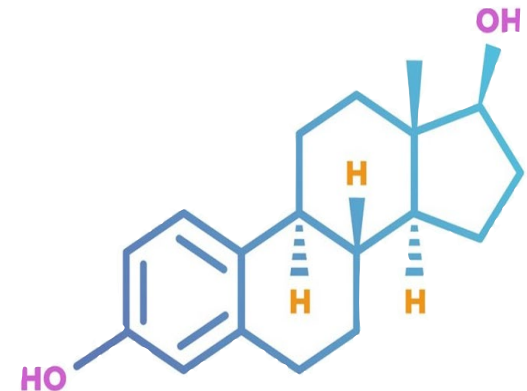
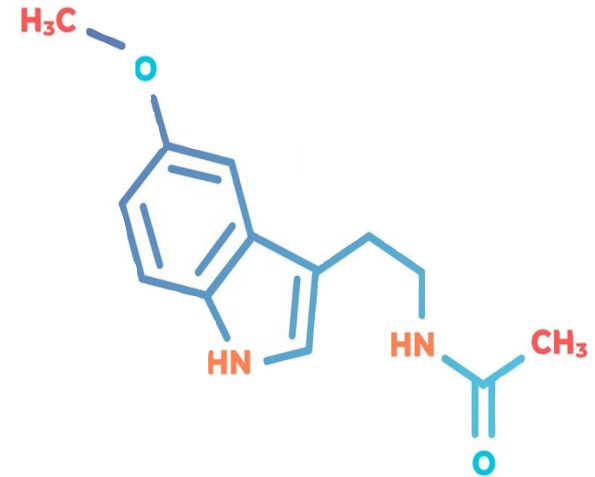
- Predominant types: Lymphoma, thyroid, sarcoma, germ cell tumors
- More aggressive tumour biology
- Longer delays between symptom onset, diagnosis



Weiss AR et al. Inclusion of adolescents and young adults in cancer clinical trials. Seminars in Oncology Nursing 2015;31(97)-205.

Different physiologically

- Rapid growth affects drug metabolizing enzymes → ↓ dosing or ↑ toxicity
 - Increasing fat/muscle mass
 - Increasing & pulsatile growth hormone levels
 - Maturation of sex steroid pathway
 - Substance use, disordered eating



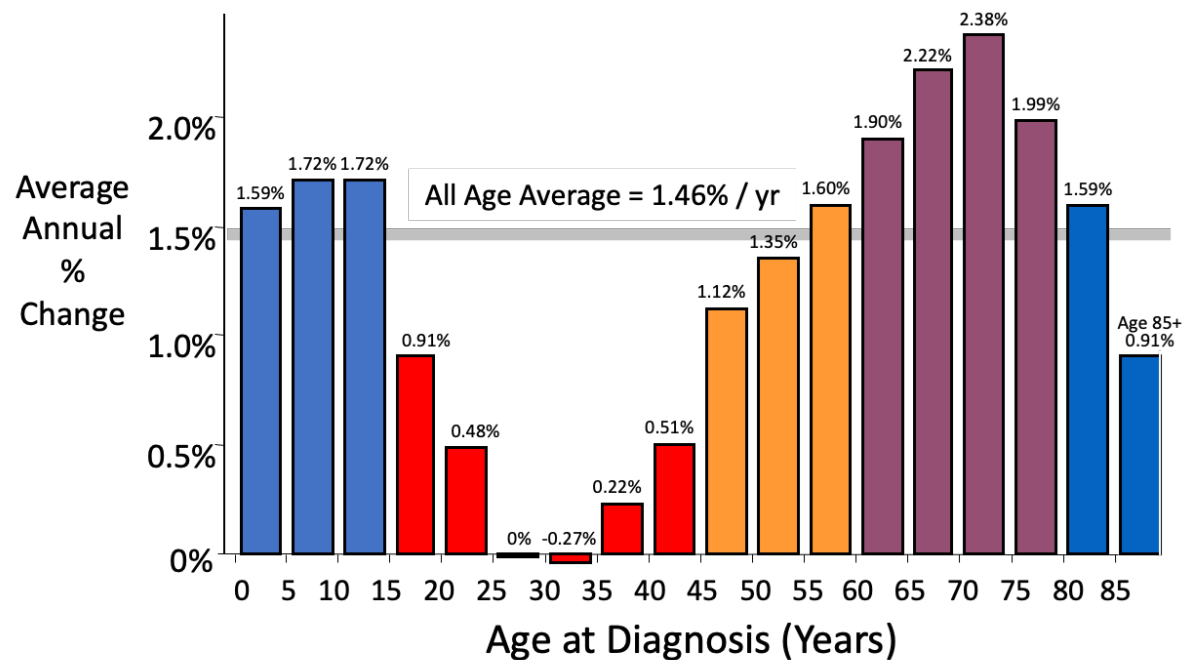
Veal GJ and Stewart CF. J Clin Oncol 2010;28(32):4790

McCance-Katz EF et al. Am J Addict 2010;19(1):4-16

Hukkanen J et al. Br J Clin Pharmacol 2011;72(5):836

Guengerich FP and Avadhani NG. Adv Exp Med Biol 2018;1032:1-35, 5. Carr RR and Ensom MHH. J Pediatr Pharmacol Ther

Different prognostically



Improvement in
5-Year Survival,
1975 to 1997,
USA

A. Bleyer 2005 Curr Probl Pediatr Adolesc Health Care 35; 182-17

AYAs and Fertility



ASCO Guidelines, March 2025

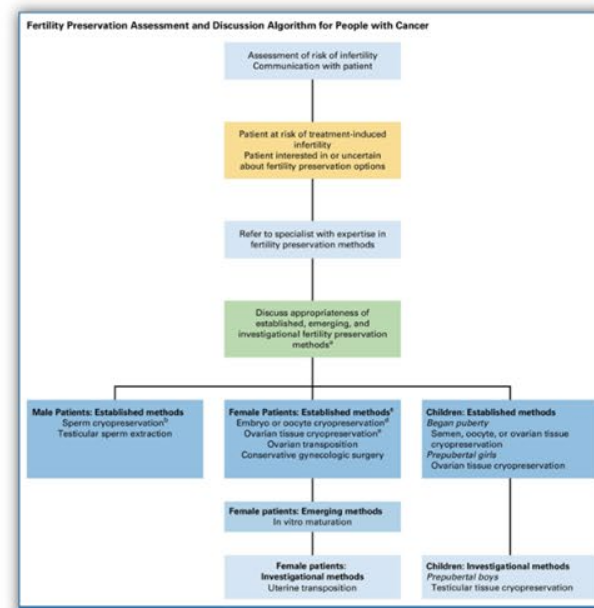
FREE ACCESS | ASCO SPECIAL ARTICLES | March 19, 2025



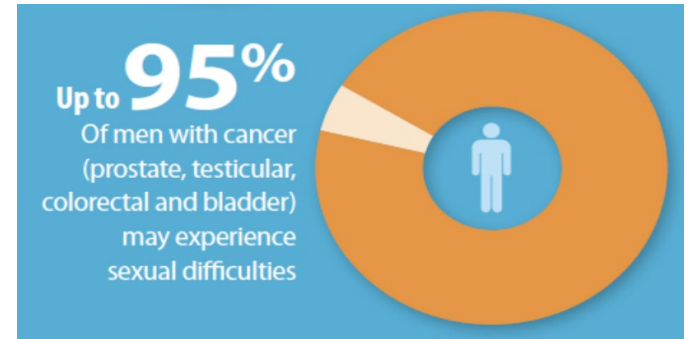
Fertility Preservation in People With Cancer: ASCO Guideline Update

Authors: [H. Irene Su, MD](#), [Christina Lacchetti, MHSc](#), [Joseph Letourneau, MD](#), [Ann H. Partridge, MD](#), [Rubina Qamar, MD](#), [Gwendolyn P. Quinn, PhD](#), [Joyce Reinecke, JD](#), [James F. Smith, MD](#), [Megan Tesch, MD](#), [W. Hamish Wallace, MD, FRCPC](#), [Erica T. Wang, MD](#), and [Alison W. Loren, MD](#) | [AUTHORS INFO & AFFILIATIONS](#)

Publication: Journal of Clinical Oncology • Volume 43, Number 12 • <https://doi.org/10.1200/JCO>



Common Sexual Health Concerns Among AYAs



Cancer Care Ontario

AYAs are at peak time for learning about their sexuality

Some common concerns that AYAs experience on cancer treatments include:

- Loss of Libido, troubles reaching orgasms
- Vaginal dryness, pain with penetration
- Erectile dysfunction, dry ejaculation, and painful orgasms
- Menopausal symptoms including hot flashes, insomnia and irritability

These symptoms can be distressing but there are ways that their oncology team can support!

Psychosocial Needs of AYA

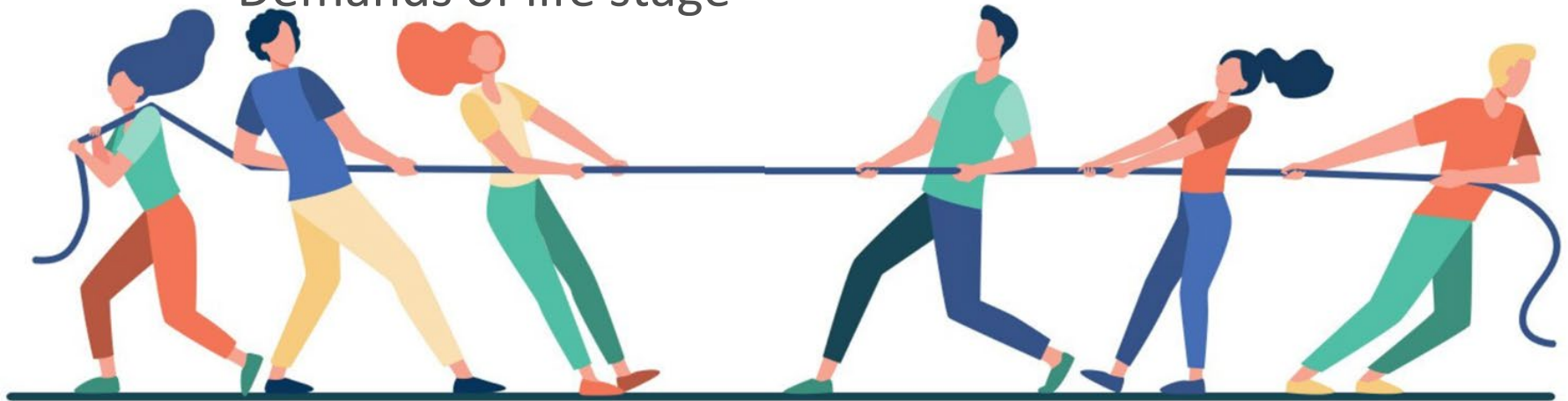
Imagine facing cancer while also navigating these developmental tasks

1. Achieving **independence**
2. Adopting **peer codes** and lifestyles
3. Accepting one's **body**
4. Establishing **identities** (social, romantic, professional, etc.)



Competing demands

Demands of cancer
Demands of life stage

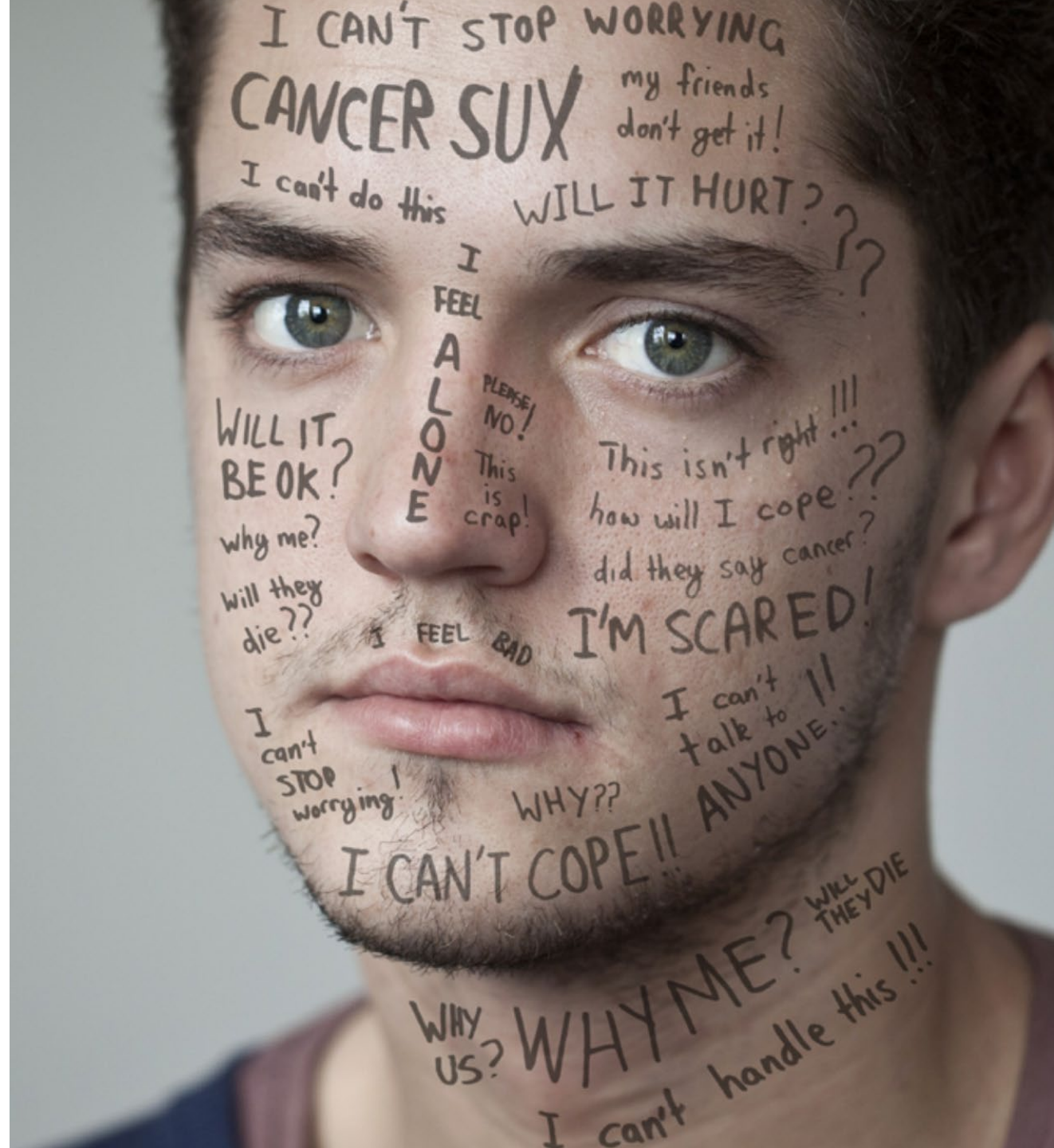


Isolation
Vulnerability
Dependence
Uncertainty

Intimacy
Invulnerability
Independence
Control



Cancer
disrupts
every
domain





Strengths



School



Home



Activities



Drugs/substance use



Emotions/eating



Sexuality/safety

Tips to **M.O.V.E.** the Conversation



PASS THE MIC

Listen attentively, with curiosity

- Avoid providing advice, solutions or trying to 'fix' the problem
- Use encouraging language like “uh-huh”, “I see” and “go on” to indicate attention and interest for the person to continue speaking
- Allow for silence



OPEN-ENDED QUESTIONS

Open-Ended Questions cannot be answered with one word and can elicit more detail

- Try: “Can you tell me more?”, “What happened next?”, “What was that like for you?”
- Summarize what you’ve heard to ensure accuracy. “What I’m hearing is...”, “Is that right/Is that fair?”
- If incorrect, offer an apology and ask for clarification



VALIDATION

Validation is the ability to acknowledge another person's feelings, thoughts or wants, without judgement

- Validation communicates acceptance and reduces emotional responses
 1. Listen for the person's underlying feelings, thoughts, wants
 2. Reflect it back to them: "It makes sense that you're feeling _____", "Most people would think that", "I could see why you'd want..."



EMPATHY

Empathy is the ability to see the world from another person's perspective

- Empathy offers comfort, builds trust and is key to creating a therapeutic relationship
- Cultivate empathy by adopting a non-judgmental stance, passing the MIC (listening), using open-ended questions and validation

The foundation of AYA rapport

Trust, Privacy & Autonomy

Acknowledge the AYAs right to privacy and outline strategies to support them in navigating the transitional dynamics between autonomy and dependence

Who has access to your chart?

Is it okay if we speak alone and then have your parents join?

Language

Normalize developmentally appropriate concerns, questions, and explorations characteristic of this stage

I am so sorry you have been feeling like sh*t.

How did your G2 test go?



Let's Practice What We've Learned: Meet Sara



Case Study: Sara (they/them)

18 year old who identifies as a woman with relapsed B ALL, previously treated in pediatric oncology at age of 15, they will likely require bone marrow transplant. Sara is currently admitted to the Oncology ward. No prior fertility preservation completed.

SS	Sara is really creative and good at drawing, Sara was doing highschool online
H	Sara lives with their aunt, but parents are involved in care (mom has a hx of anxiety and depression), they have a best friend and friends who game online
A	Sara enjoys arts and crafts, playing with their dog and drawing, they do not like to exercise, but like to take their dog for walks
D	Sara does not use alcohol, recreational drugs, nicotine products (cigarettes, vaping or zyn)
E	Sara is having anxiety related to the future and feelings of grief/loss They follow a regular diet, have decreased appetite, but are drinking well
S	Sara is not sexually active and describes sexual orientation as asexual, reports no concerns with body image at this time, has hx of regular periods, no vaginal dryness or hot flashes

SS - Sara is really creative and good at drawing, Sara was doing highschool online	Providing links to online support groups with AYAs who also enjoy arts and crafts, online support groups while in hospital, peer support groups, working with POGO interlink nurses to plan for return to school, work with child life to support transitions
H - Sara lives with their aunt, but parents are involved in care (mom has a hx of anxiety and depression), they have a best friend and friends who game online	Communication and collaboration with parents and aunt to support transitions and provide options for caregiver support groups
A - Sara enjoys arts and crafts, playing with their dog and drawing - doesn't like to exercise, but likes to take their dog for walks	Encouraging pt to draw and do crafts, working with family to see dog, provides education on exercise while going through tx, discusses the effects of CA tx on fertility , offer fertility referral
D - Sara does not use alcohol, recreational drugs, nicotine products (cigarettes, vaping or zyn)	Providing education on safe use
E - Sara is experiencing anxiety related to the future and feelings of grief/loss - follows a regular diet, has decreased appetite, but is drinking well	Providing non-judgemental space to talk about feelings, normalize and reframe. Provides education on diet/ nutrition on treatment
S - Sara is not sexually active and describes sexual orientation as asexual, has hx of regular periods, no vaginal dryness or hot flashes	Providing education/ educational materials on sexual health , discuss body image and strategies to support, common concerns

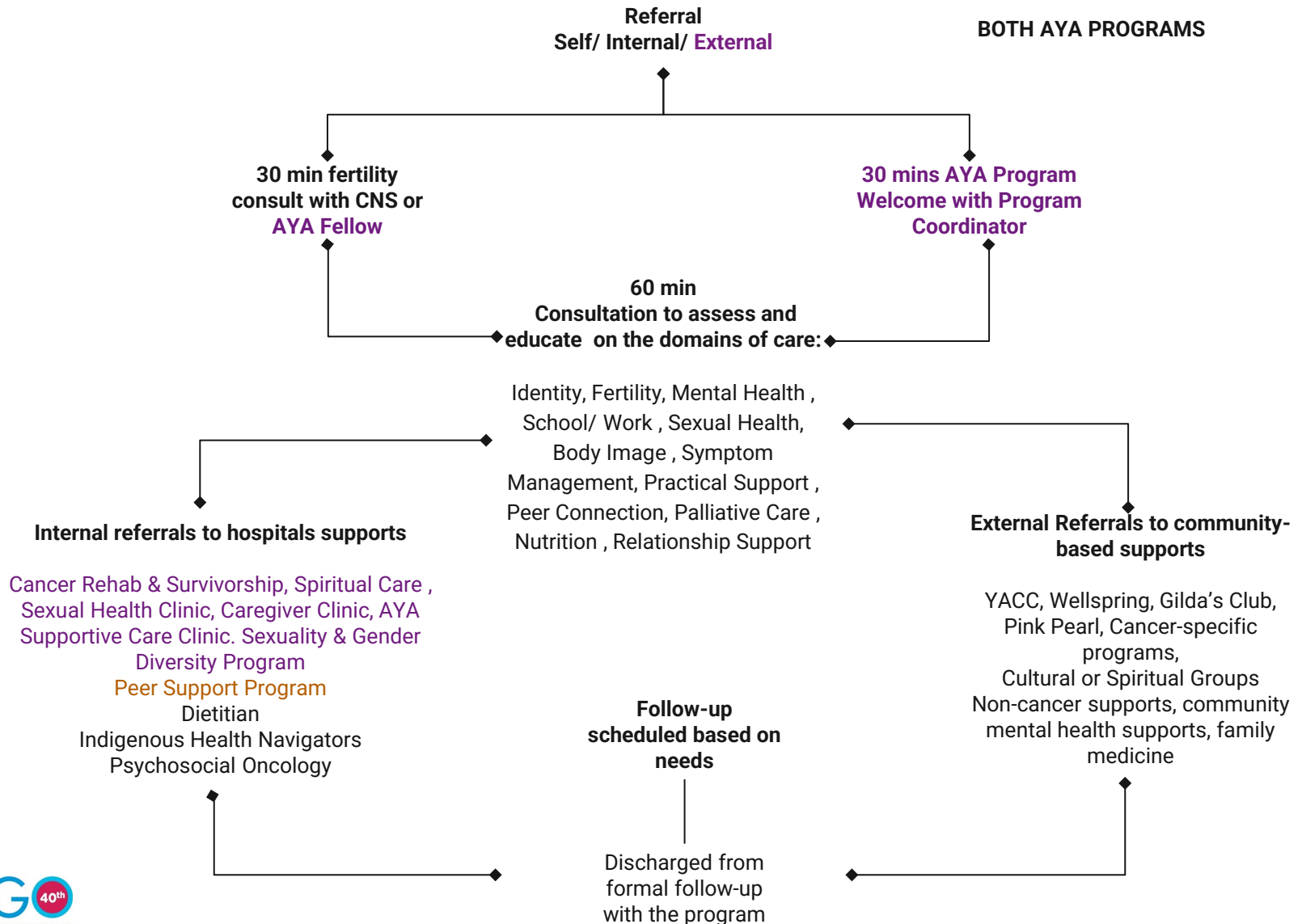


AYA Pathway to Care

PMH PROGRAM

LHSC PROGRAM

BOTH AYA PROGRAMS



Foundational Steps to Building an AYA Program

Needs assessment identifying needs of AYAs

- What does existing AYA care look like (programming, staff competency, etc.)
- Understand the current landscape in AYA care

Stakeholder engagement staff, physicians, leadership

- Who are the “AYA Champions” (micro, meso, macro levels)
- Who are also passionate about this population

Environmental Scan/ Asset Mapping the existing programs and resources that can meet the needs of the AYA population

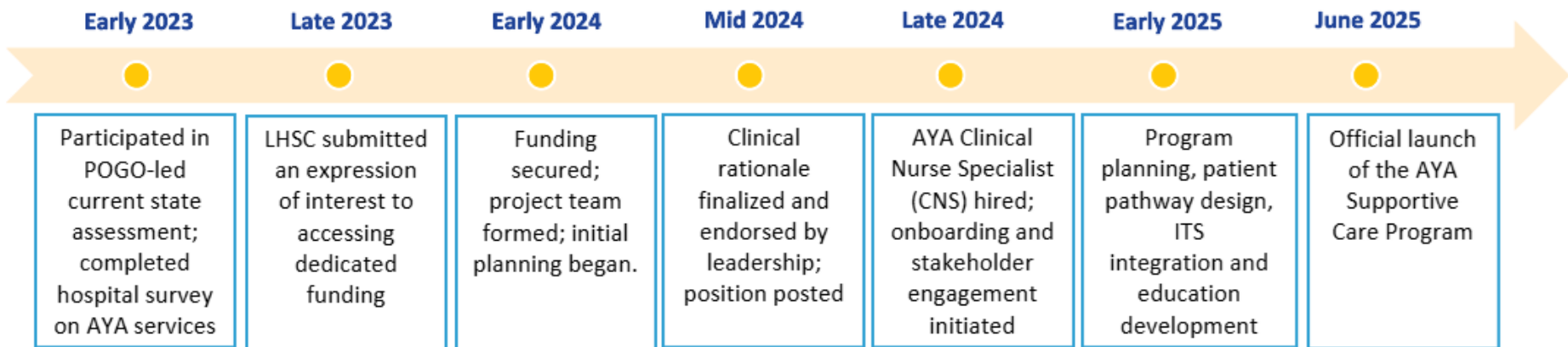
- Develop a resource sheet

Interprofessional collaboration

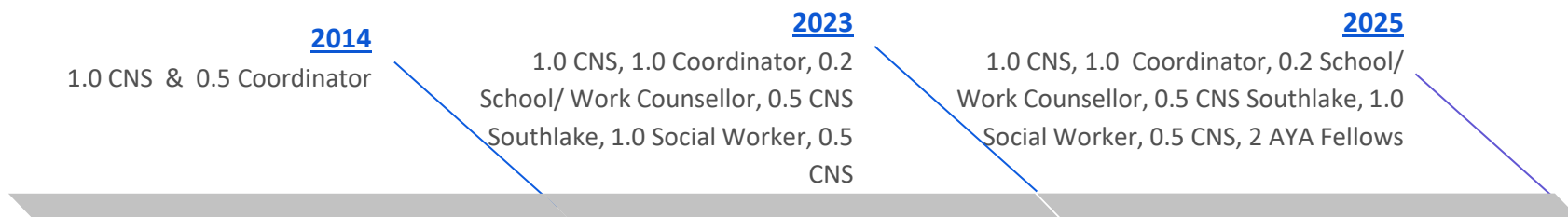
- Within the hospital and community to develop clinical pathway design
- With existing AYA programs to identify resources available and adapt to meet local patient needs

Establishing a Clinical Nurse Specialist-AYA Oncology Role at LHSC

- **Clinical and Patient-Driven Need:** Literature and internal assessments highlighted the need for age-appropriate support in areas of fertility, sexual health, and psychosocial care.
- **System-Level Prioritization:** The Ontario AYA Cancer Care Steering Committee, Pediatric Oncology Group of Ontario (POGO), and Ontario Health Cancer Care Ontario (OH-CCO) emphasized improving AYA experiences and outcomes through targeted programs and services.
- **Opportunity for Dedicated Funding:** With support from provincial partners, funding became available to establish a focused role to address these unmet needs.



The PMH AYA Program Timeline

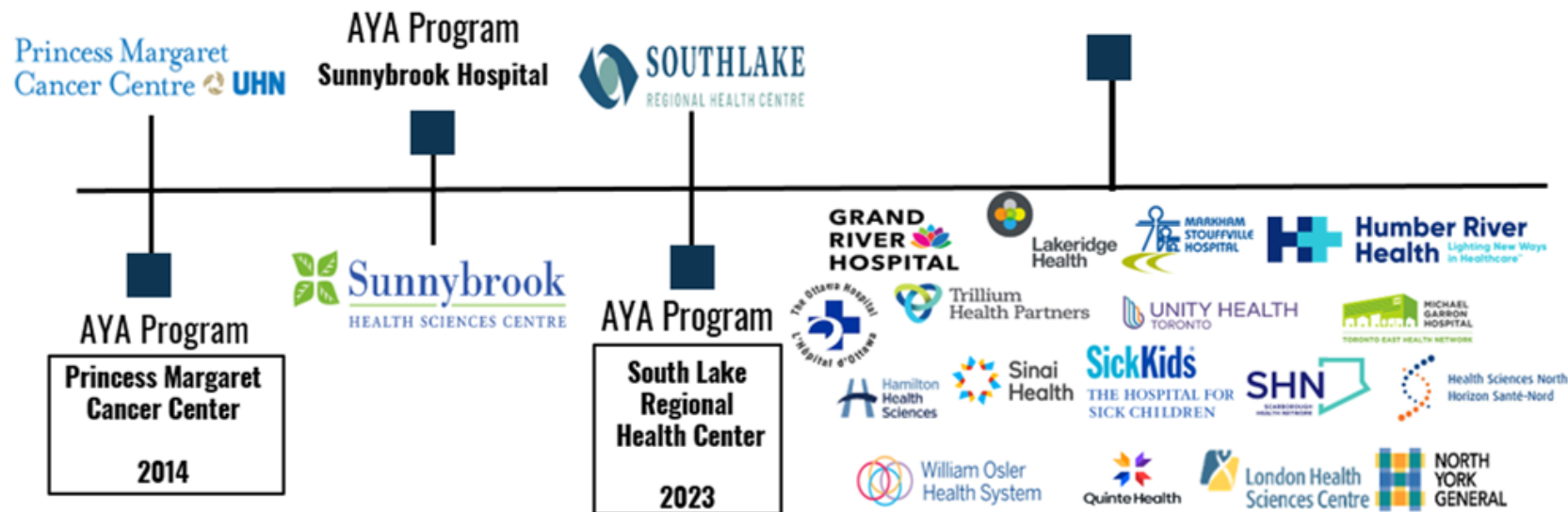


focus on fertility, expand pathways and resources in all domains

deliver healthcare provider education, expansion outside of UHN

expansion to education through conferences

**AYA Program
2023-2025**



How to support AYAs without a dedicated program

What are the needs of your local AYA patients?

- peer connection- groups & one-on-one
- educational resources - websites & handouts
- dedicated spaces- virtual & in-person

What local resources do you have?

- fertility clinics / pathways
- mental health, rehab, sexual health supports
- family medicine practices

Who are your partners/collaborators?

- AYA Champions
- community organizations
- leveraging existing AYA programs

Take Home Points

- AYAs with cancer have **unique medical and psychosocial needs** that differ from younger children and older adults
- Building an AYA program takes **time and resources** (and patience and champions)
- Even without a program, you can still take a “**teen-tailored,**” developmental approach to support AYA through their cancer experience
- You are not alone – We’re here to help!

Resources



AYA Workshop - Practical tips and resource list

Take home points

1. AYA with cancer have distinct needs
Their medical and psychosocial challenges differ significantly from those of younger children and older adults.
2. Adopt a developmentally informed, teen-tailored approach
Align care with their stage of growth and independence to better address these unique needs.

Practical tips

1. **Prioritize Confidential, Inclusive Care**
Whenever possible, dedicate part of the visit to seeing teens alone. If space or time is limited, get creative—integrate it naturally into the visit flow so it feels routine and normalized.
2. **Use Structured Tools for a Comprehensive Assessment**
Leverage templates that cover key AYA domains, such as SSHADES, to ensure you address social, sexual, home, activities, drugs, emotions, and safety.
3. **Validate Their Experiences**
Show empathy and understanding using frameworks like MOVE to acknowledge feelings and build trust.
4. **Manage Within Your Scope—Seek Support When Needed**
You don't need all the answers! Do your best and reach out to colleagues or specialists for advice when necessary.
5. **Advocate for Better AYA Care**
Don't give up—encourage your center to strengthen its resources and commitment to adolescent health.

Tips to M.O.V.E. the Conversation

PASS THE MIC
 Control conversations with courtesy

OPEN-ENDED QUESTIONS
 Open-ended questions cannot be answered with one word and can elicit more detail

VALIDATION
 Validation is the ability to acknowledge another person's feelings, thoughts or words without judgement

EMPATHY
 Empathy is the ability to see the world from another person's perspective

- Avoid providing advice, solutions or trying to "fix" the problem
- Use encouraging language like "uh-huh", "I see" and "go on" to indicate attention and interest for the person to continue speaking
- Allow for silence

- Try "Can you tell me more?", "What happened next?", "What was that like for you?"
- Summarize what you've heard to ensure accuracy: "What I'm hearing is..."
- "Is that right or that too?"
- If necessary, offer an opening and ask for clarification

- 1. Listen for the person's underlying feelings, thoughts, wants
- 2. Reflect it back to them: "It makes sense that you're feeling..."
- "Most people would think that", "I could see why you'd want..."

- Empathy offers comfort, builds trust and is key to creating a therapeutic relationship
- Cultivate empathy by adopting a non-judgmental stance, joining the AYA's experience, using open-ended questions and validation

- Strengths
- School
- Home
- Activities
- Drugs/substance use
- Emotions/eating
- Sexuality/safety

HEPACROSS 3.0, The psychosocial interview for adolescents updated for a new century. [Full text](#), David A. Klein MD MSc, John M. Goldstein MD MSc, J.D., William P. Adelman MD, Contemporary Pediatrics, January 01, 2014

Provincially accessible resources

1. [About Kids Health cancer information for teens](#)
2. [Princess Margaret AYA Program](#)
3. [Campfire Circle](#)
4. [Look Good Feel Better](#)
5. [Young Adult Cancer Canada](#)
6. [Gilda's Club](#)
7. [Bounce Back Ontario](#)

Suggested training courses

Fertility and sexual health

1. [ASCO fertility preservation series](#)
2. [De Souza Sexual Health and Cancer](#)
3. [Cancer in Pregnancy | de Souza Institute](#)
4. [Echo Training - The Oncofertility Consortium](#)

Psychosocial care

1. [Canteen AYA Psychosocial Training Program](#)
2. [Princess Margaret Cancer Campus: Return to Work](#)
3. [Princess Margaret Cancer Campus: Brain Fog](#)

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QUESTIONS?

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