Transforming Nursing Care for Adolescents and Young Adults with Cancer- Engagement and Communication skills!

Alison Baker, Tarnya Hotchkin, Fiona Maguire and Cath O Dwyer
Youth Cancer Service Clinical Nurse Consultants

YOUTH CANCER SERVICE | canteen

Acknowledgment of Country

We acknowledge Aboriginal and Torres Strait Islander peoples as the Traditional Custodians of this land. We pay respect to Elders past, present and future. We are committed to providing inclusive and appropriate support for Aboriginal and Torres Strait Islander young people, their kin and community.

menti

- https://www.mentimeter.com/app/presentation/aluv7i7usm5t96od8ecufpx9yw3c89fx/present?question=xhr7kq3bs1ha

- Join ww.menti.com
- use code. 8931 1211

Youth Cancer Services

Youth Cancer Services (YCS) are specialist, multidisciplinary services that provide age-appropriate treatment, care and support for adolescents and young adults, typically, aged 15–25 years with cancer and their families. (canteen.org.au; ycsnetwork.org;)

YOUTH CANCER SERVICE

Evolution of Youth Cancer Services (Australia)
Youth Cancer Services: From Gap → National Model

Pre-2007 | The gap
AYA patients (15–25) **fell between paediatric & adult systems**
Poorer outcomes + unmet psychosocial needs
Strong consumer advocacy (Canteen)
2007 | National program established
Federal Government + Canteen partnership
Investment in **national YCS network**
Focus: coordinated, equitable, age-appropriate care
2010–2015 | Implementation
5 lead YCS established (Sydney, Melbourne, Brisbane, Perth, Adelaide)
Introduction of:
- Cancer Care Coordinators
- Multidisciplinary AYA teams

Expansion to **national hospital network**
Key message ➡️ Shift from fragmented care → **structured national AYA model**

YOUTH CANCER SERVICE | canteen

Development of the YCS Model

2011 onwards | Consolidation – Phase 5 of Federal Funding

Delivery of **developmentally appropriate, multidisciplinary care**

National coordination + activity monitoring systems

Clinical priorities emerge

Clinical trials

Fertility care

Psychosocial screening

Survivorship pathways

2017 | Australian Youth Cancer Framework

National standard for AYA care

Defines:

- Person-centred care
- Coordinated pathways
- Data-driven improvement
- **Current state**

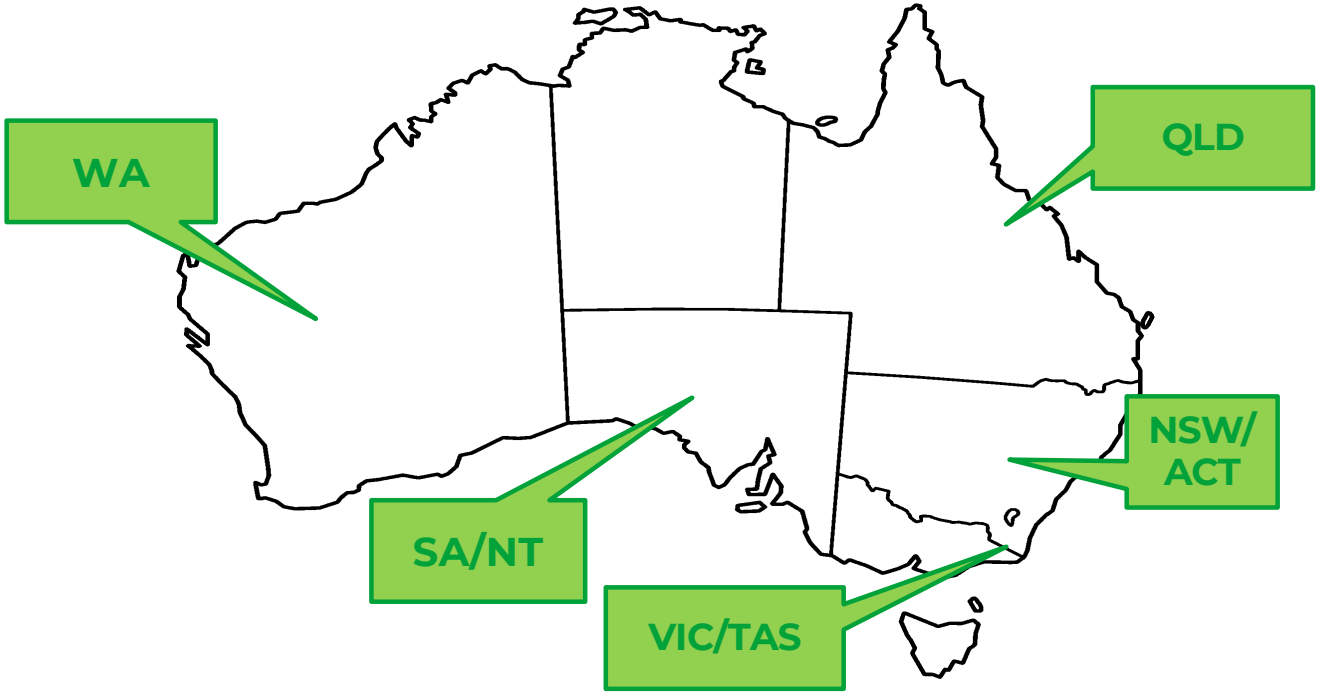
~75% of AYAs supported through YCS

Strong integration across states + local services

Ongoing focus: equity, survivorship, outcomes

Key message ➡️ Shift from service establishment → **quality, consistency & reach**

YCS Across Australia



YOUTH CANCER SERVICE | canteen

YCS Services Across Australia

New South Wales / ACT
Sydney YCS Prince of Wales Hospital & Sydney Children's Hospital, Randwick
Western Sydney YCS - Westmead Adults/Kids Hospital
Hunter & Northern NSW YCS Newcastle – JHH & The Calvary Hospital
RPA/Lifehouse YCS Camperdown RPA / Chris O'Brien Lifehouse
ACT YCS - ACT Canberra Hospital

Victoria
Victorian Adolescent & Young Adult Cancer Service, including major centres such as: Royal Melbourne, Peter MacCallum Cancer Centre (Melbourne)

Queensland
Royal Brisbane & Women's Hospital (with statewide outreach via partnerships)

Western Australia
WA Youth Cancer Service Based at **Sir Charles Gairdner Hospital (Perth)**

South Australia/NT
Adelaide (within the SA cancer system—linked to statewide services)

YOUTH CANCER SERVICE | canteen

Youth Cancer Service

It is an expert multi-disciplinary team that provides medical management & psychosocial support for young people with cancer, aged between 15-25 years

Designated Care Navigator – a nurse consultant – to be the key contact and help navigate the health system.

Medical consultant, Social workers, Clinical psychologist, Exercise Physiologist etc Closely work with many other teams to provide holistic care including Shared
and Transitional care

Education and vocation support, fertility and long-term follow-up, information about financial options and other support available

Cancer-related education for family, friends, schools & workplaces.
Ongoing Survivorship support

YOUTH CANCER SERVICE | canteen

Shared / Transition AYA Care

Shared care is a structured system for achieving integration of care across multiple autonomous providers and services, including GPs and specialist services

Shared care involves systems to create linkages between services or organisations

Common goals, objectives and guidelines, information and communication systems

Education and quality assurance

Care planning.

Implications for Your Practice as AYA CHAMPIONS
Access is not location-dependent — it is referral-dependent

Many young people are treated in **hospitals without embedded YCS teams**
Equity of access depends on **clinician awareness and engagement**
Role of local clinicians - "champions"
Identify AYA patients early
Initiate referral to YCS
Facilitate access to:
- Care coordination
- Psychosocial support
- Fertility services
- Clinical trials

Bridge local care with YCS expertise
Risk without champions
Delayed or absent access to age-appropriate care
Missed opportunities for supportive care and trials
Key message ➡️ Every service needs a **YCS advocate to ensure equitable access**

YOUTH CANCER SERVICE | canteen

Referrals

Referral pathways for treatment vary largely by cancer type.

Some referrals can be made through an **emergency department**, and others can be via a **GP**.

There is also clinical evidence showing pathways can vary according to whom the primary clinician refers a patient.

If the cancer is diagnosed by a paediatrician, it is likely the patient will be referred to a paediatric hospital with specialist paediatric oncologists.

However, if the cancer is diagnosed by a GP or hospital intern, patients over 16 years of age will be referred to local adult hospitals.

SNAPSHOT OF AYA CANCER in AUSTRALIA

The Problem

Young people with cancer don't fit neatly into a system built for children or adults.

Aged 15 to 25, they're too old for children's and too young for adult cancer services, leaving them without the specialist support that evidence shows improves survival rates and long-term wellbeing.

Youth Cancer Services exist to fill that gap

A Growing Need

- AYA cancer is under researched, and under recognised – and the consequences are real
- **Diagnoses have risen 50% since the 1980's**
- Yet awareness of AYA cancer as a distinct medical and social challenge remains low
- We are seeing an alarming and undeniable rise in aggressive cancers in AYA in Australia
- The system that should catch these AYA has gaps in it

YOUTH CANCER SERVICE | canteen

Key Diagnosis & Statistics

- **Incidence:** About 1,200 to 1,300 young Australians aged 15 to 25 are diagnosed with cancer annually, which makes up roughly 1.5% to 2% of all cancer diagnoses in the country
- **Survival Rates:** The 5-year survival rate for AYA cancer patients is high, sitting at roughly 89%
- **Second Primary Cancers:** Survivors of AYA cancers have roughly double the risk of developing a second cancer later in life compared to the general population

50%

Rise in youth cancer since the '80s.

Up to 270%

Rise in bowel cancer in young Australians.

40 years

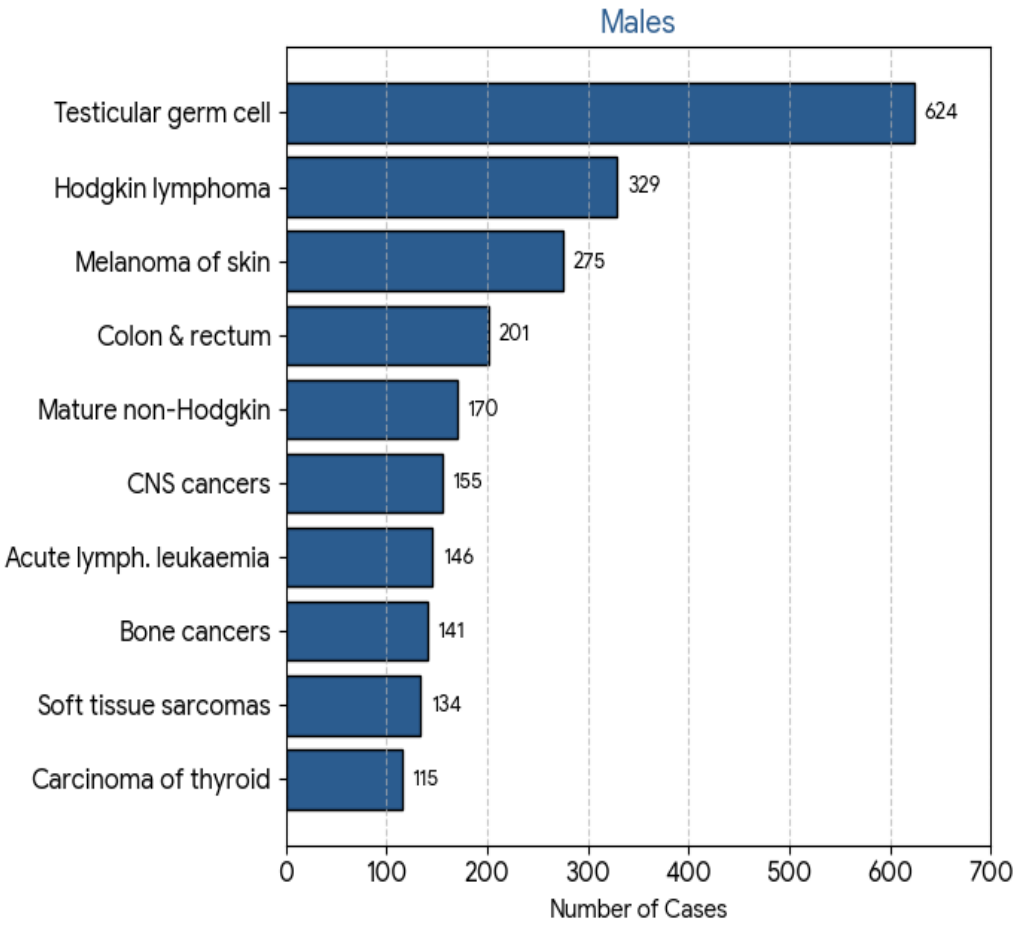
No improvement in sarcoma survival rate.

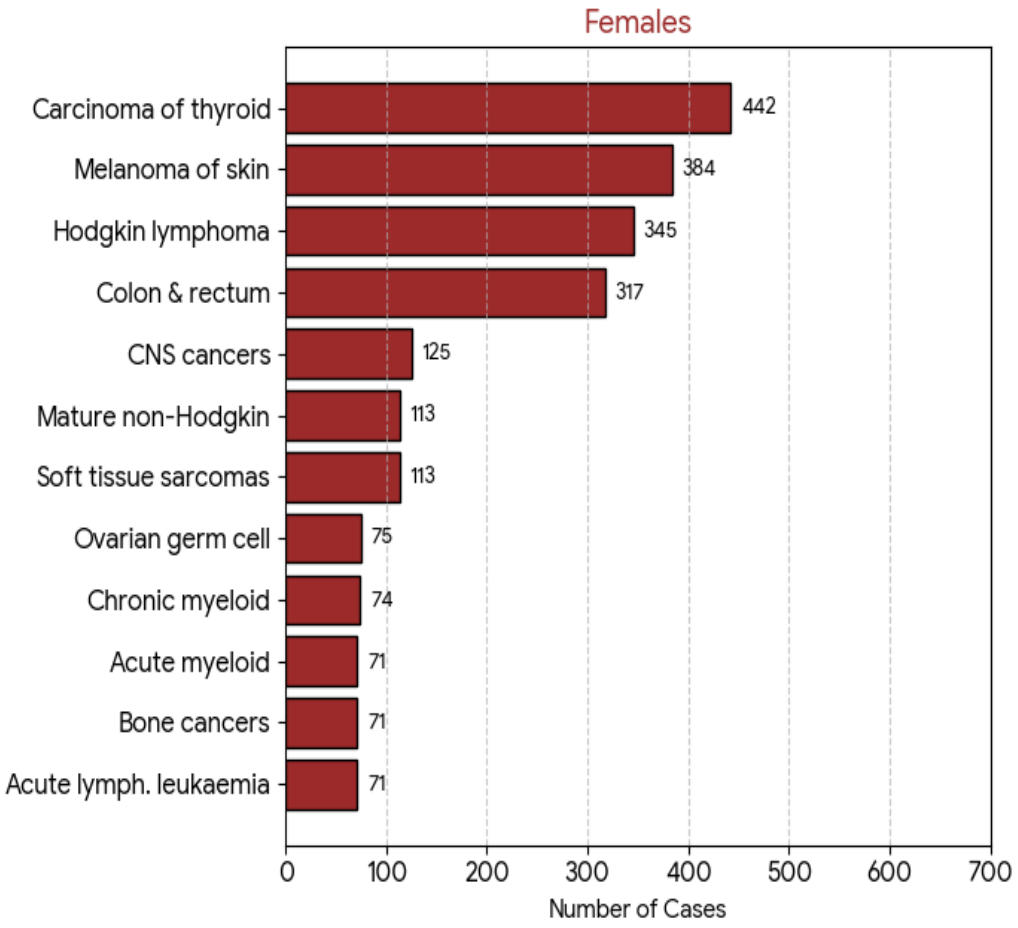
$1.3 million

Lifetime cost of a youth cancer diagnosis.

YOUTH CANCER SERVICE | canteen

Top Diagnosed Cancers (Ages 15–24), Cases 2014–2018





YOUTH CANCER SERVICE | canteen

Why are AYA Cancers different?

Unique Impact on Young People

- Cancer affects more than physical health in adolescents and young adults.

Educational and social impacts

- Interrupted schooling and university
- Reduced participation in work and social activities
- Isolation from peers
- Delayed independence and life milestones

Emotional impacts

- Anxiety and depression
- Fear of recurrence
- Body image concerns
- Loss of control and uncertainty about the future

Communication and Engagement with AYA

So what does all this translate into practice

- Lets hear from the expert.....

Case Study: Ryan (17 years)

Medical Background

Diagnosed with Stage IV Hodgkin Lymphoma
Undergoing chemotherapy (Cycle 3 of 4)
Admitted with infection, pain, fever, dehydration, and significant weight loss

Psychosocial Background

Year 12 student living with parents and siblings
Has a girlfriend, part-time job, and strong social network
Increasing fatigue impacting daily life

Presenting Concerns

Frustrated with ongoing hospital admission and treatment
Feels overprotected by his mother and wants more independence
Struggles to communicate his need for space without upsetting her
Feels guilty about the impact of his illness on his family
Anxious about upcoming scans and treatment outcomes

What are your first thoughts after reading the case study?

EFFECTIVE COMMUNICATION KEY ASPECTS

Tailoring information to AYA's preferences	What do they want to know, how much do they want to know, when do they want to know it
Empowering self-management	Using their unique strengths, resources and capabilities
Supporting advocacy	Actively involving AYAs in care conversations, encouraging questions, asking about preferences
Building trust	Communicating in a consistent, empathetic, non-judgemental and transparent way
Having a patient-centered approach	Recognising their unique needs and preferences
Respecting privacy and confidentiality	This creates a safe space and is essential at this developmental stage
Acknowledging uncertainty and distress	Helps them to feel heard and validated

Advice from AYAs on communication

Srinivas et al. 2023 - interviews with 80 parents, 37 AYAs (aged 13-24yo)

Theme	Advice from AYAs
Demonstrate empathy and caring	Recognise, acknowledge and respond to patient and family emotional state/s (read the room)
Show commitment	Help AYA to feel not alone, show that the team is available to them
Empower the patient and family	Make AYA important part of decisions and communication, encourage questions
Maintain hopefulness/optimism	Be honest and transparent, but portray information in hopeful manner
Building/Maintaining connections	Build relationship with AYA, ask about interests
Maintain a calm demeanour	Help AYA and family to feel that things are under control
Support understanding	Use simple terms, pace the amount of information to not overwhelm AYA and family
Prepare for the future	Help AYA to understand what to expect next, what to look out for etc.
Provide resources	Provide individualised resources to support self-management and emotional needs
Be competent	Demonstrate knowledge and skills

Communication

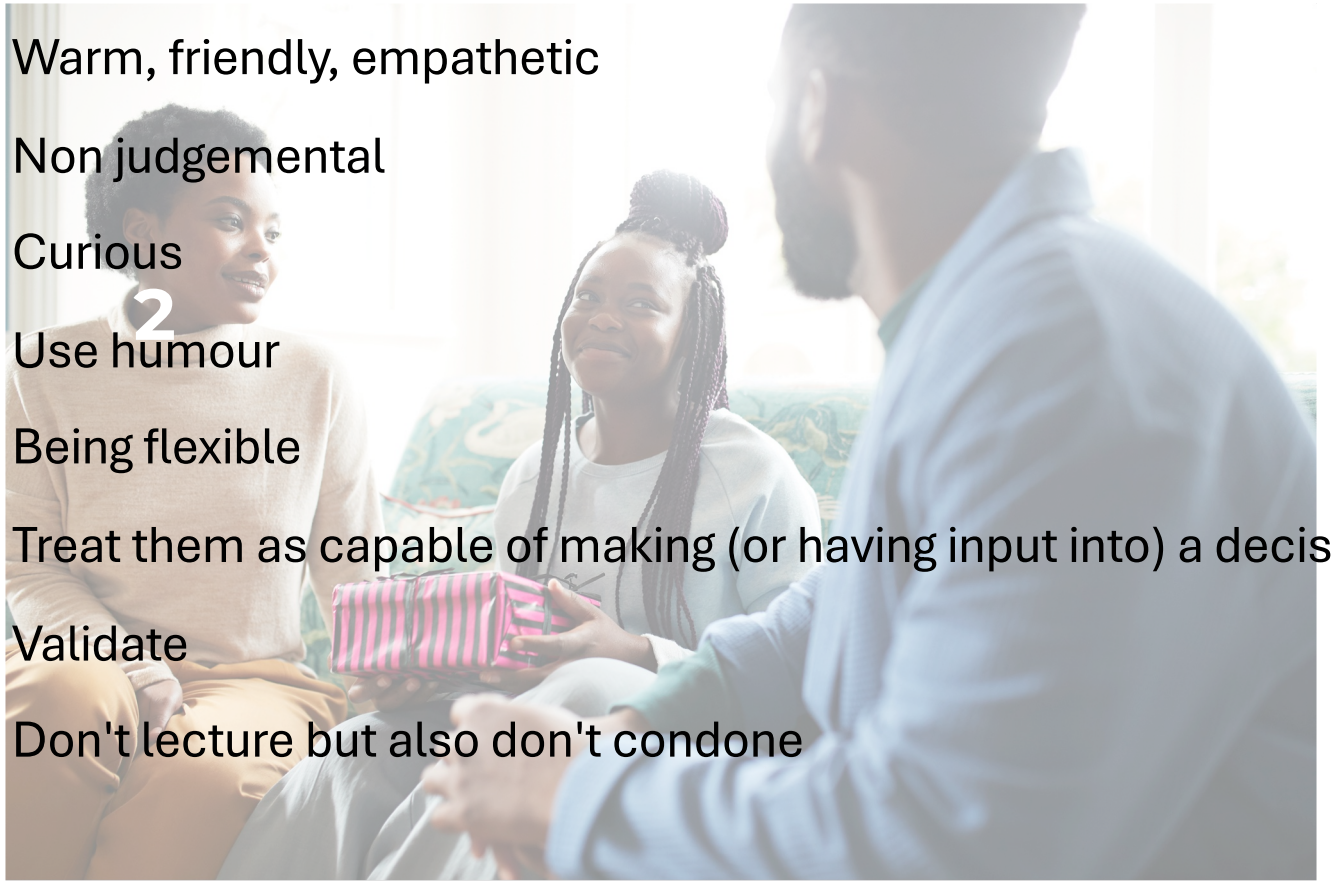
- ***What aspects of communication help engage young people?***
- Introductions- every time you see them
  - Something about them (remember this)
  - "tell me 3 things about you that have nothing to do with your cancer"
- Time alone
- Confidentiality

Tips on questioning

- Asking permission
- Sign posting (acknowledge that you have heard them)
- Generalising questions
  - e.g. "some people your age try"

YOUTH CANCER SERVICE | canteen

Approach



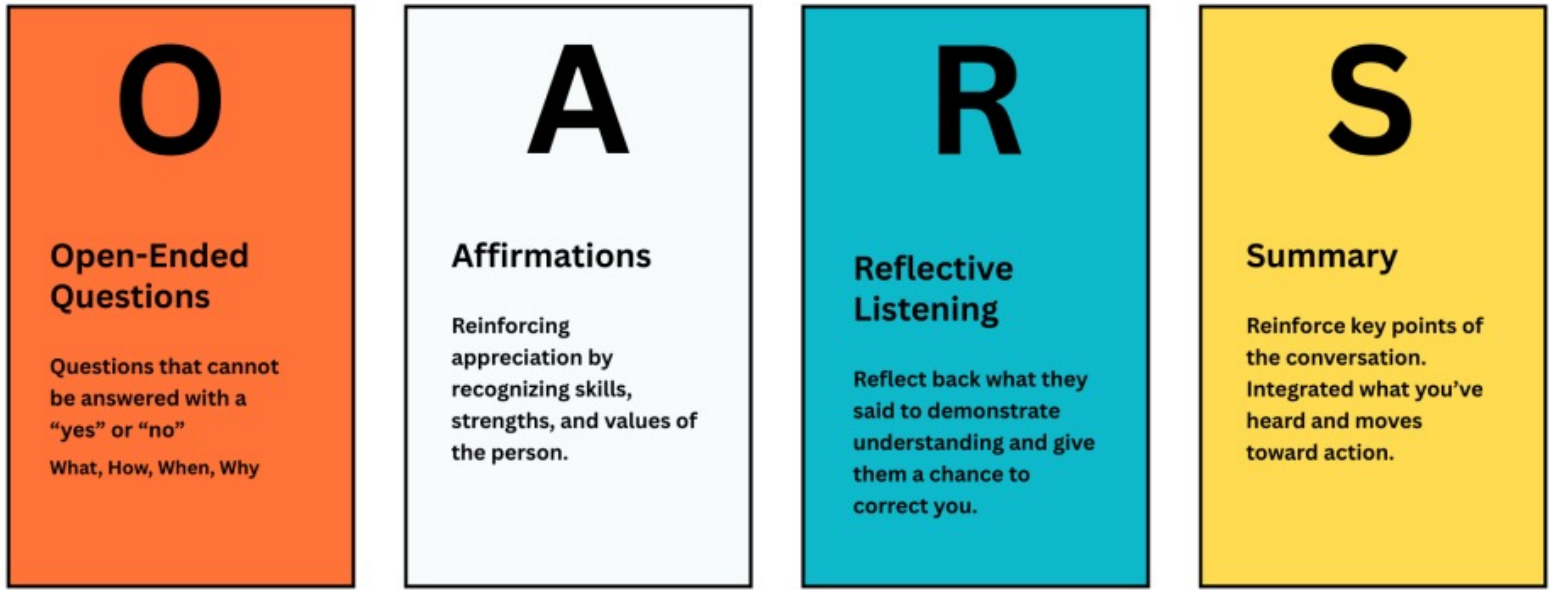
- Warm, friendly, empathetic
- Non judgemental
- Curious
- Use humour
- Being flexible
- Treat them as capable of making (or having input into) a decision
- Validate
- Don't lecture but also don't condone

Threats to engagement

- Stigma
- Ambivalence
- Denial/avoidance
- Hopelessness
- Coercion
- Dismissive

Toolkit: OARS

@sonyalooney
www.growthegoodinstitute.com



Goal: Presence. Intention. Response.

CANCER SERVICE | canteen

Resources

- Canteen Australia - Canteen Australia | Charity Support For Young People Facing Cancer
- Youth Cancer Services - Youth Cancer Services | Support for Young Cancer Patients | Canteen
- Cancer Council - Early Detection of Cancer in Adolescents and Young Adults | Cancer Council Australia
- Rare Cancer Australia - Home - Rare Cancers Australia
- Cancer Institute - Adolescents and young adults with cancer: Model of care for NSW/ACT | Cancer Institute NSW

Tumor specific cancer i.e.

- Lymphoma Australia https://www.lymphoma.org.au
- Leukemia Foundation Leukaemia Foundation
- Sarcoma Association Australia and New Zealand Sarcoma Association
- Look Good Feel Better Look Good Feel Better - Facing Cancer with Confidence
- Cancer Chicks Home | Cancer Chicks
- Discover YCS - Preview - Discover YCS

YOUTH CANCER SERVICE | canteen

Contact Details

- Cath O'Dwyer YCS CNC – Prince of Wales/Sydney Childrens Hospital, Randwick, NSW
  - Cath.odwyer@health.nsw.gov.au
- Fiona Maguire YCS CNC-Prince of Wales/Sydney Children's Hospital Randwick, NSW
  - Fiona.maguire@health.nsw.gov.au
- Alison Baker YCS CNC –The Children's Hospital Westmead, NSW
  - Alison.baker@health.nsw.gov.au
- Tarnya Hotchkin AYA CNC – Royal Children's Hospital, Melbourne,VIC
  - aya.cnc@rch.org.au

Interested in AYA oncology

YOUTH CANCER SERVICE | canteen