# ADOLESCENT AND YOUNG ADULT (AYAO) CARE IN LYMPHOMA - A SINGAPORE AND ASIAN PERSPECTIVE

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AYA
ADOLESCENT AND YOUNG ADULT CANCER

National Cancer Centre Singapore
SingHealth

# MEET OUR AYAOS

- 400-500 AYAs walk through NCCS doors annually
- >6000 young lives we have played a part in between 2018 - 2021
- Students, daughters, sons, fathers, mothers, artists, aged between 16-45 years old
- >80% will conquer their cancer, and change the world
  - **NCCN : 15 – 39 years old**
  - **NCI SEER database : 15 - 29 years old**
  - **US : 15 – 39 years old**
  - **UK : 15 – 24 years old**
  - **Australia/New Zealand and Canada : 15 – 29 years old**
  - **Shanghai Cancer Institute : 15 – 49 years old**

**For Us ,we have adopted 16-45 years old patients who are current/newly diagnosed.**


Ms Azhany Mohamed (fourth from left) when she was warded at the Singapore General Hospital in 2017.

BY **EVELINE GAN**

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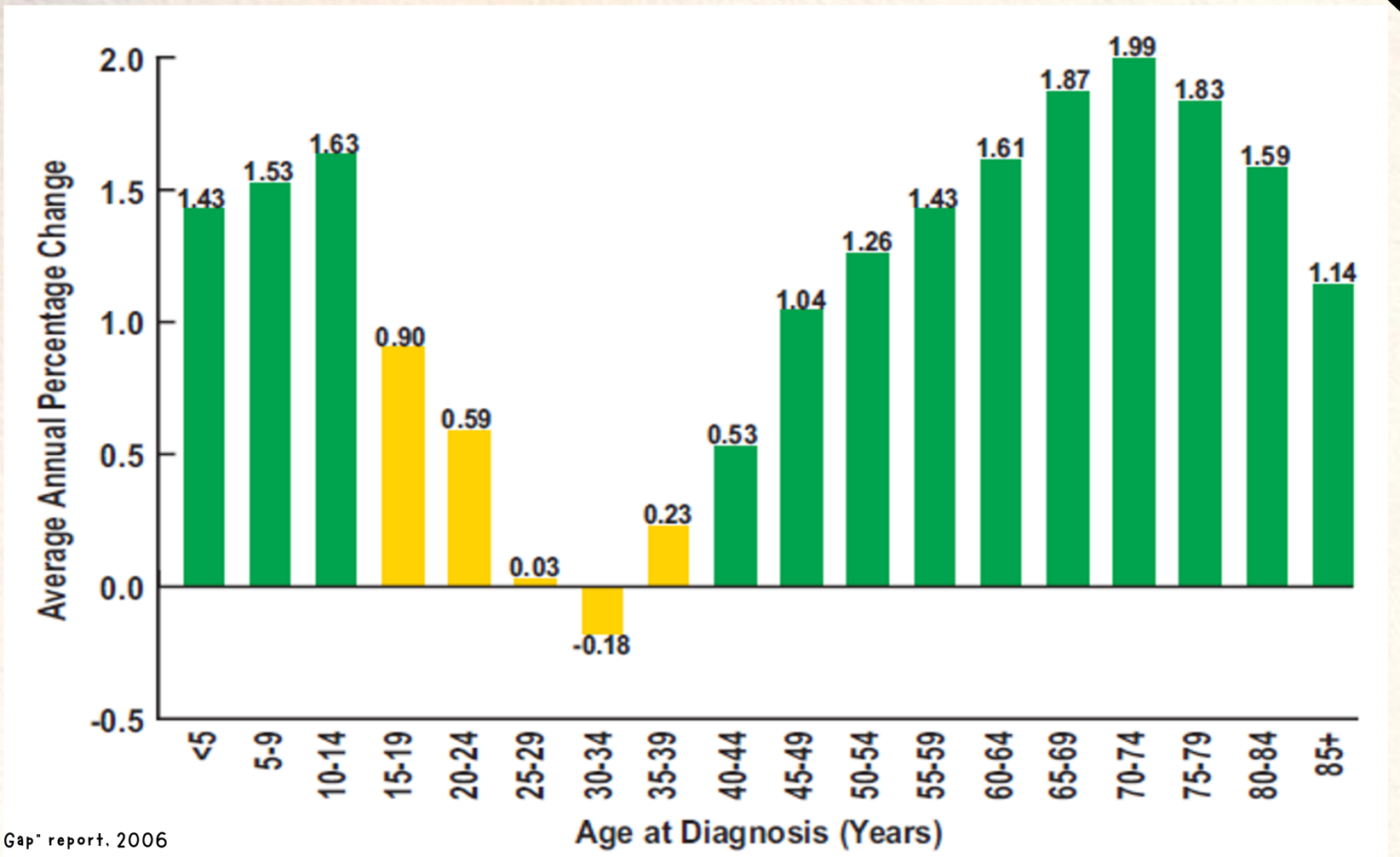
# WHAT ARE THE STATS?




NCI AYA Progress Review Group "Closing The Gap" report, 2006

# EVERY YOUNG LIFE SAVED TODAY SHAPES OUR FUTURE

But what does it mean to save a young life? Is it enough to be just simply alive?

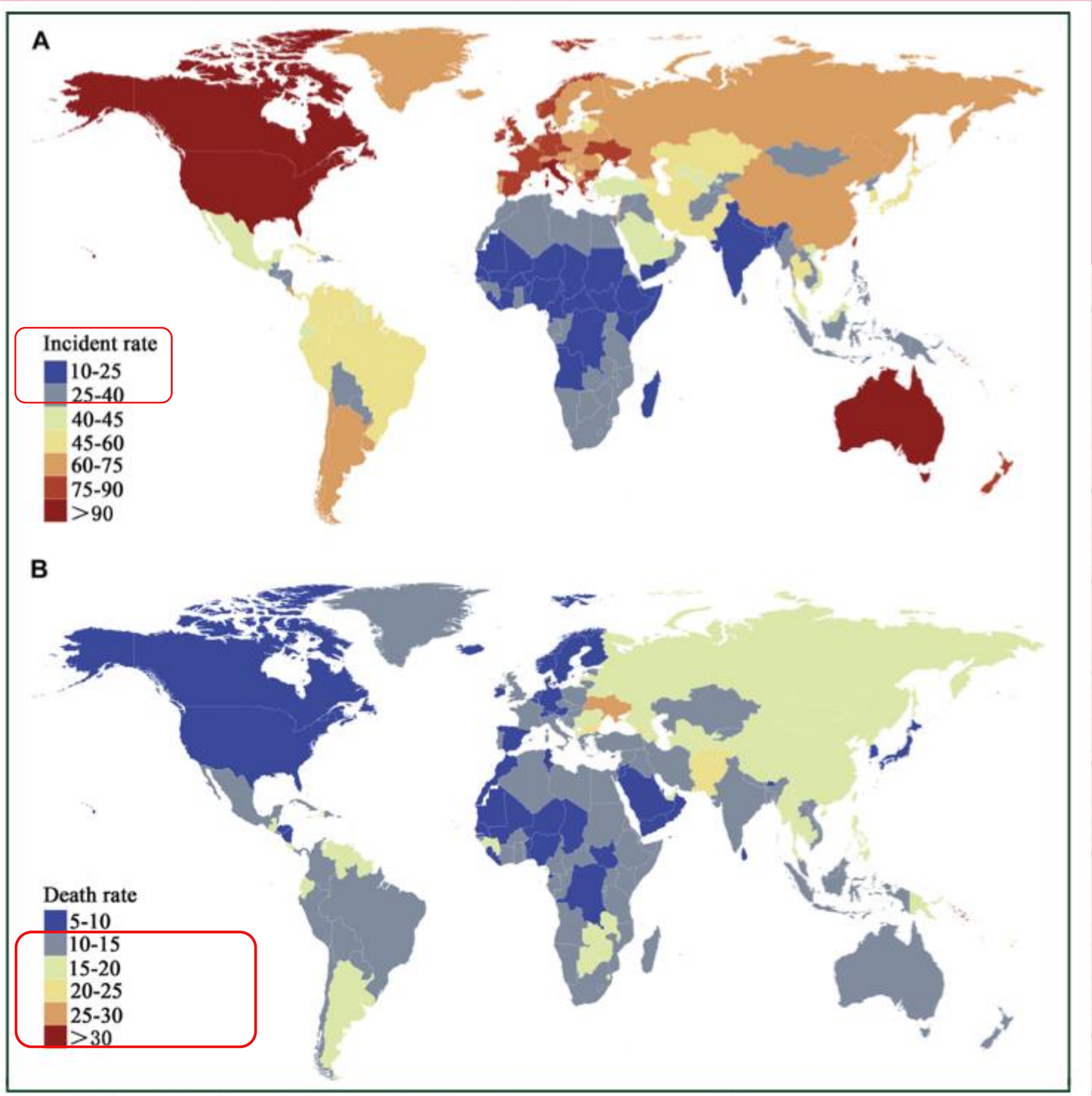



Figure 5. Global map of (A) incidence and (B) death rate for total cancers by country among 15-39-year olds in 2019.

ESMO Open 2021 L You et al

THEY ARE NOT JUST ANOTHER PATIENT - THEY ARE SINGAPORE'S/ OUR NATION'S NEXT GENERATION OF INNOVATORS, LEADERS AND CHANGEMAKERS

# WHY IS AYAO LYMPHOMA CARE IMPORTANT?

- AYA Lymphoma spectrum is remarkably distinct
  - Hodgkin Lymphoma has a striking age-related incidence pattern, with its first peak in AYA years
    - 70% present with mediastinal involvement, compared to 45% in older adults
    - Nodular sclerosis subtype comprises 75% of AYAs vs 50% in older adults
    - AYAs more frequently present with bulky disease and B symptoms, but paradoxically have better outcomes when treated appropriately

- AYA distribution in NHL is equally distinctive
  - PMBL affects largely AYAs, median age at diagnosis 35 years old
    - harbor unique molecular features (JAK2 amplifications, PDL1/PDL2 alterations, C11TA rearrangements
  - ALCL has a predilection for AYAs
    - ALK+ disease occurs largely in this this group, ALK+ determines treatment and outcomes
  - T-lymphoblastic lymphoma disproportionately affects AYA males
    - presents with anterior mediastinal masses that often present as oncological emergencies
  - AYA Burkitts often involve bone marrow and CNS at diagnosis, compared to endemic pediatric form

- All these are examples of how tumor biology in a unique age group can affect their disease status, treatment outcomes and long-term toxicities.

# A LYMPHOMA REVOLUTION

We are witnessing history:

- Global lymphoma incidence has surged 168% since 1975
- Hodgkin Lymphoma numbers are surging across Asia-Pacific

- Singapore leading the change, with 7-13% annual increase in teens
- Following socio-economic development, from a rare disease to what is now an epidemic
- NHL incidence doubled over past decades in Singapore
- 1225 new lymphoma patients in Singapore alone in 2022

- Classical Hodgkin Lymphoma is the most common AYA lymphoma with >15 000 patients, 3.44 per 100 000 incidence
- DLBCL is the 2nd most common
- AYAs represent 9% of all lymphoma diagnoses globally

- Mean age at diagnosis is 28

algrim, H., Seow, A., Rostgaard, K, & Friborg, J. (2008). Changing patterns of Hodgkin Lymphoma incidence in Singapore. Internal Journal of cancer 123(3), 716719
tps://www.cpr.cuhk.edu.hk/en/press/cuhk-finds-the-largest-rise-in-incidence-of-hodgkin-lymphoma-in-asia/
tps://gco.iarc.who.int/media/globocan/factsheets/populations/702-singapore-fact-sheet.pdf
tps://medicine.nus.edu.sg/wp-content/uploads/2024/05/Press-Release_SG-Ramps-Up-Cancer-Fight-with-S50-million-in-National-Grant-Funding-for-Precision-Oncology_24-May-2024.pdf

# ASIAN LYMPHOMAS ARE DIFFERENT

We are witnessing history:

- Environmental factors shape our disease patterns
- NK/T cell Lymphomas are more common in our populations
  - 15-20% in Asia vs 5-10% in West
- ENKTL dominance with 28.6% of all PTCLs across 6 Asian countries
  - Only 20-30% survive beyond 5 years
- EBV-associated lymphomas:
  - Unique Asian strains with distinct genomic signatures

What are the AYAO stats?

- Presence of unique genetic signatures in Chinese ALCL patients
- B-cell distribution shows lower FL and CLL/SLL , but higher MALT lymphomas
- Follicular lymphoma is becoming a rarity, and shows different distribution patterns
- Chinese females: 1.8-4.5 per 100 000 (1968-1992)
- Malay females: 32% higher risk than Chinese counterparts
- In Singapore: 5-year survival improvements: Indians 37%--> 61%, Malays 31%-->49%, Chinese 36%--> 51%

ps://www.nccs.com.sg/research-innovation/our-researchers/dmo-researchers/dmo-research-signature-programmes
n, R.B., Loy, E.Y, Lim, G.H, Zheng, H, Chow, K.Y., & Lim, S.T. (2015). Gender and ethnic differences in incidence and survival of lymphoid neoplasm subtypes in an Asian population: Secular trends of a population-based cancer gistry from 1998 to 2012. International Journal of Cancer, 137(11), 2674-2687
F, Syn NL, Lu Y, Chong QY, Lai J, Tan WJ, Goh BC, MacAry PA, Wang L & Loh KS (2021) Characterization and Establishment of a Novel EBV Strain Simultaneously Associated with Nasopharyngeal Carcinoma and B Cell mphoma. Front. Oncol 11:626659
nakanthan, S., & Bukelo, M.M. (2021). Molecular Genetics in Epstein-Barr Virus-Associated Malignancies. Life (Basel, Switzerland), 11(7), 593
rienne A.Phillips et al. Health Disparities and the Global Landscape of Lymphoma Care Today. Am Soc Clin Oncol Educ Book 37, 526-534 (2017)

# ASIA LEADS GLOBAL T-CELL LYMPHOMA BURDEN

- EKNTL geographic concentration
  - 48% of PTCLs in China, 29% in South Korea
- Pan-Asian PTCL registry
  - 486 patients across 6 countries
- Median Survival
  - 21.1 months PFS and 83.6months OS
- Age demographics
  - 57% presented with stage III/IV disease

What are the AYAO stats?

Yoon, S.E et al. (2021) Comprehensive analysis of peripheral T Cell and natural killer/T-cell lymphoma in Asian patients: A multinational multicenter, prospective registry study in Asia. The Lancet regional health. Western Pacific, 10, 100126
https://novotech-cro.com/sites/default/files/2021-08/T-Cell%20Lymphoma%20report.pdf

# LYMPHOMA OUTCOMES IN ASIA

- Asian-specific data serving as benchmark for Asia-pacific region
- Hodgkin Lymphoma: 89% 5-year OS in HK Chinese cohorts
- Korean cohort for Hodgkin: 98.7% low-risk and 97.7% intermediate-risk survival
- DLBCL outcomes: early stage 86.4% vs advanced 14.3%
- EKNTL improvements: combined modality therapy showing superior outcomes
- Registry improvements showing dramatic survival gains across all Asian ethnicities

This also translates into a growing Asian Survivor Population that we need to factor in our care.

What are the AYAO stats?

Law, M.F et al (2014). Clinical features and treatment outcomes of Hodgkin's lymphoma in Hong Kong Chinese. Archives of medical science: AMS, 10(3), 498-504
Istiadi, H et al. (2021). Role of cell-origin profiling using immunohistochemistry to predict the survival of patients with Diffuse Large B Cell Lymphoma in Indonesia. Yonago acta medica, 64(2), 200-206
Yoon, S.E et al. (2021) Comprehensive analysis of peripheral T Cell and natural killer/T-cell lymphoma in Asian patients: A multinational multicenter, prospective registry study in Asia. The Lancet regional health. Western Pacific, 10, 100126
Lim, R.B et al. Gender and ethnic differences in incidence and survival of lymphoid neoplasm subtypes in an Asian population: Secular trends of a population-based cancer registry from 1998-2012. International Journal of Cancer, 137(11), 2674-2687

# NCCS - A LYMPHOMA POWERHOUSE

- Singapore Lymphoma Study (2005), is now the largest Asian cohort
- 20 years of Asian-specific data, that is unmatched globally
  - 121 patients, 45% OS at 4 years
  - Real-world outcomes: 38% PFS and 24% non-relapse mortality

- Early-stage NKTL: 78.5% 5y survival for Stage I and 65.6% for Stage II
- DLBCL outcomes reaching 92% for 5y OS

What are the AYAO stats?

https://www.nccs.com.sg/research-innovation/our-researchers/dmo-researchers/dmo-research-signature-programmes
WS Joshua Loke et al, Long-term survival and clinical implications of allogenic stem cell transplantation in relapse/refractory lymphoma: A 20-year Singapore experience. Ann Acad Med Singap 2025; 54:5-16

# NCCS-ILLUMINA PARTNERSHIP (2024) - ASIA'S MOONSHOT

- $50million National Investment in Asian Lymphoma Precision Medicine
- First-ever Asian multiethnic lymphoma classification
- NovaSeqTM 6000 technology - cutting edge sequencing
- PD-L1 mutation breakthrough: 100% complete response in targeted patients
- Regulatory T-cell biomarkers with new therapeutic targets identified

- >1000 Asian patients annually accessing genomic-guided therapy
- Personalized medicine tailored for Asian Genetics

- 260 ENKTL patients sequenced across Singapore, China, Belgium, Taiwan
- 13-gene prognostic model: Machine learning predicting Asian lymphoma outcomes
- Novel combination therapy: 65% OS rate and 51% CR rate
- 21-month median response duration in relapsed patients

https://sapac.illumina.com/company/news-center/amea-news/new-research-collaboration-agreement-to-accelerate-genomics.html
https://healthcareasiamagazine.com/healthcare/news/nccs-and-illumina-collaborate-genomics-research-rare-cancers
https://sbr.com.sg/healthcare/news/nccs-and-illumina-collaborate-genomics-research-rare-cancers
https://www.nccs.com.sg/news/research/genomic-analysis-provides-insight-into-underpinnings-of-new-treatment-combination-for-deadly-asian-prevalent-lymphoma
https://ecancer.org/en/news/26336-genomic-analysis-provides-insight-into-underpinnings-of-new-treatment-combination-for-deadly-asian-prevalent-lymphoma

# LYMPHOMA OUTCOMES IN ASIA

We need to consider:

- Which protocol (Pediatric vs adult?)
- Optimizing the treatment to maximise effects, while minimizing toxicities (including long-term)
- Individualization of treatment to each patient

# ADDITIONAL CONSIDERATIONS IN VIEW OF LONGER RUNWAY TO MORTALITY

We need to consider:

- These are patients diagnosed when they are young, likely to be able to tolerate treatment and chemo doses better
- However, longer runway for them to develop side-effects that can affect quality of life
- We cannot just cure the lymphoma, but leave the patient debilitated and not able to function

- Eg. Using Brentuximab instead of Bleomycin in Hodgkin
- Eg. Using REPOCH instead of RCHOP+RT in PMBL

# NCCS AYAO EMPOWER- COMPREHENSIVE EVIDENCE-BASED CARE

- AYA Support group was established in 2017
- Symphony 2.0 $25M National research program for Asian Lymphomas
- Multidisciplinary teams: Proven to improve outcomes through coordinated  care
- Total health approach ensures we approach in a holistic manner, by addressing social determinants of health

# WHAT IS THE EMPOWER PROGRAMME?

EMPowering Our young ones to live WELl through cancER

- Providing age-appropriate holistic individualized care to young adults with cancer, in an Asian setting
- Run concurrently with the primary oncologist's care
- Not meant to replace, but to run in tandem
- Rapport-building, to ensure the same familiar team sees a patient through a cancer diagnosis to survivorship

# VISION

- All young adults with a history of cancer are able to receive age-appropriate, individualized holistic care

# MISSION

- **Provide age-appropriate, individualized holistic care**
- **Provide age-appropriate info-education**
- **Empower our young adults and healthcare workers with relevant AYAO knowledge**
- **Patient advocacy for AYAOs**
- **Become Asia’s leading centre for AYAO care**

# Our Path and History

# THE ROAD AHEAD


No One Fights Alone

## 2024

- Finalizing care plans and pathways
- Cementing AYAO service
- Patient advocacy
- Age-appropriate Info-education

## 2025

- Building ties and collaborations internationally in the Asian space
- Building community links
- Start work on transition care

## 2026

- Bringing EMPOWER into the community successfully
- Bringing EMPOWER to Singapore and to Asia

# Career, Interrupted: Facing Cancer in Your Twenties

By Tiffany Williams

Once I had the first round of chemotherapy, and learned how to manage and plan for the side effects, I felt more in control. I accepted the treatment plan and had faith that it would work. I kept my new job, told my mom I was fine, and still managed to make friends during treatment. By all accounts, on the outside I was the stereotypically "inspirational" patient. Of course on the inside, I was churning with anxiety.

The hardest part during that time was explaining my increasingly visible illness to my social work clients and colleagues. As my hair, eyebrows, and eyelashes started to fall out, it was nearly impossible for me to hide my cancer, which impacted my ability to inspire confidence. I looked sick. Even with a wig on.

The Huffington Post

HEALTH

# Too Young for This: Facing Cancer Under 40

By AMANDA SCHAFFER JAN. 30, 2007

"When I was diagnosed with cancer, all I really wanted was to connect to other people my age," said the group's founder, Matthew Zachary, 32, of Brooklyn, who learned at 21 that he had pediatric brain cancer.

Lauren Terrazzano, who writes a weekly column for Newsday called "Life, With Cancer," said that for a younger person, "cancer can be the ultimate form of identity theft, if you let it."

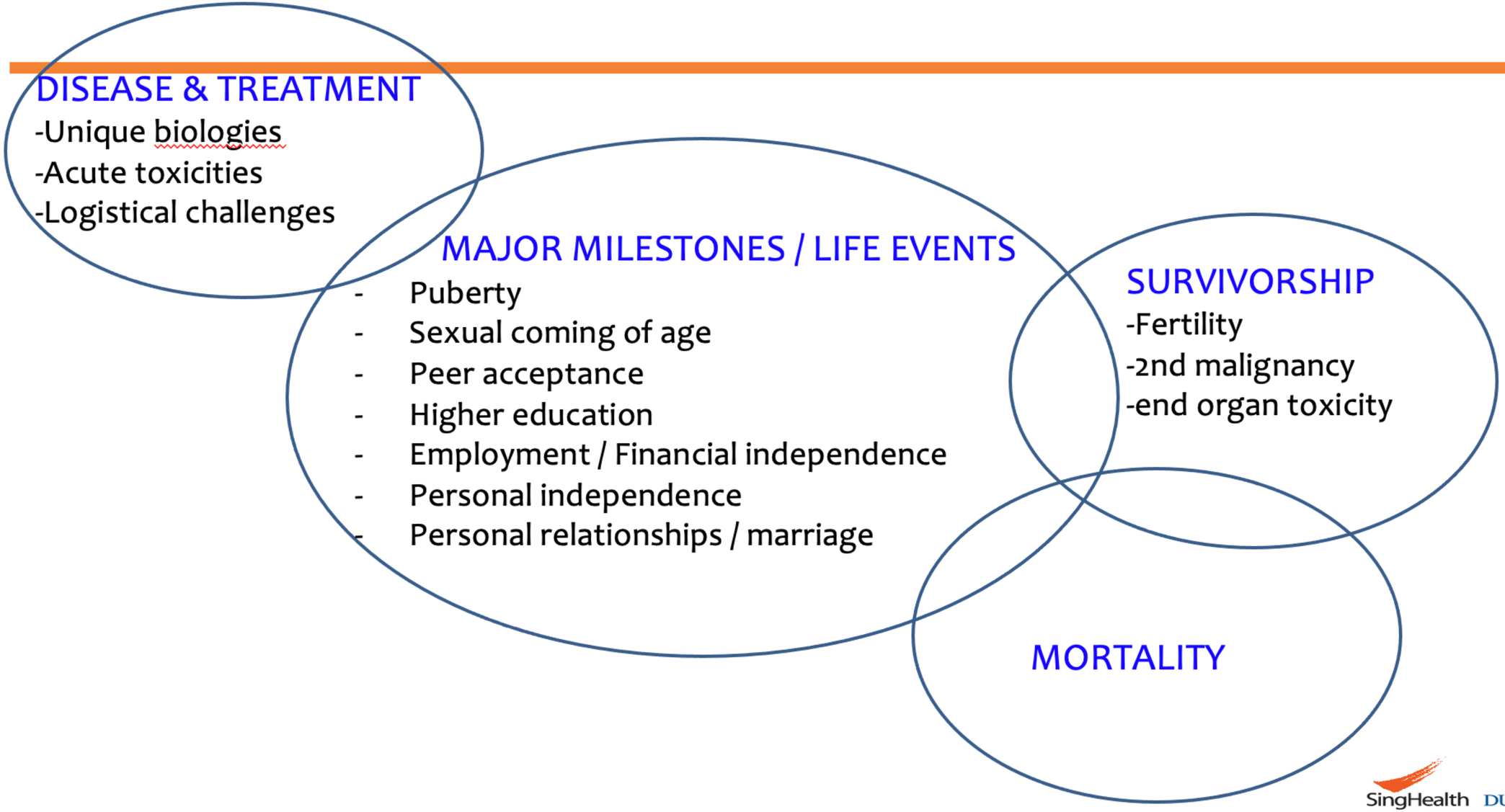
Ms. Terrazzano was told she had advanced lung cancer in 2004 and has since undergone three operations, including an extrapleural pneumonectomy, in which her right lung and part of the lining of her heart were removed. She has also undergone extensive chemotherapy and radiation.

"One day you're a healthy 36-year-old with long hair, black mascara and low-rider jeans," she said. "You're going through the rhythms of life, going to work, going to dinner, hanging out with friends. And the next minute you're Cancer Girl.

"It's a hard thing to reconcile."

Williams T. Career, Interrupted: Facing Cancer in Your Twenties. 2013
Schaffer A. Too Young for This: Facing Cancer Under 40. 2007

# Why AYA – Challenges of Young Adulthood




SingHealth DUKE NUS ACADEMIC MEDICAL CENTRE

# COMMON AYAO CHALLENGES

Clinical Distress up to 60% in any AYAO group.

5x more likely to report PTSD

AYAO survivors are 2x more likely to have clinical levels of distress

Lymphoma survivors are 2x more anxious and 2x more likely to have somatization

AYAO survivors are 80% more likely to report clinically relevant impairments in mental health

AYAO survivors have 5x more impairment in HRQoL

Ursula M. Sansom-Daly et al. Transl Pediatr 2013; 2(4): 167-197. Distress and adjustment among adolescents and young adults with cancer: an empirical and conceptual review

# Why is it distressing in particular for this group of patients?

## Skill Sets That AYAs are Expected to have developed

- Intellectual Maturity
- Social Maturity
- Emotional Maturity
- Sexuality Maturity

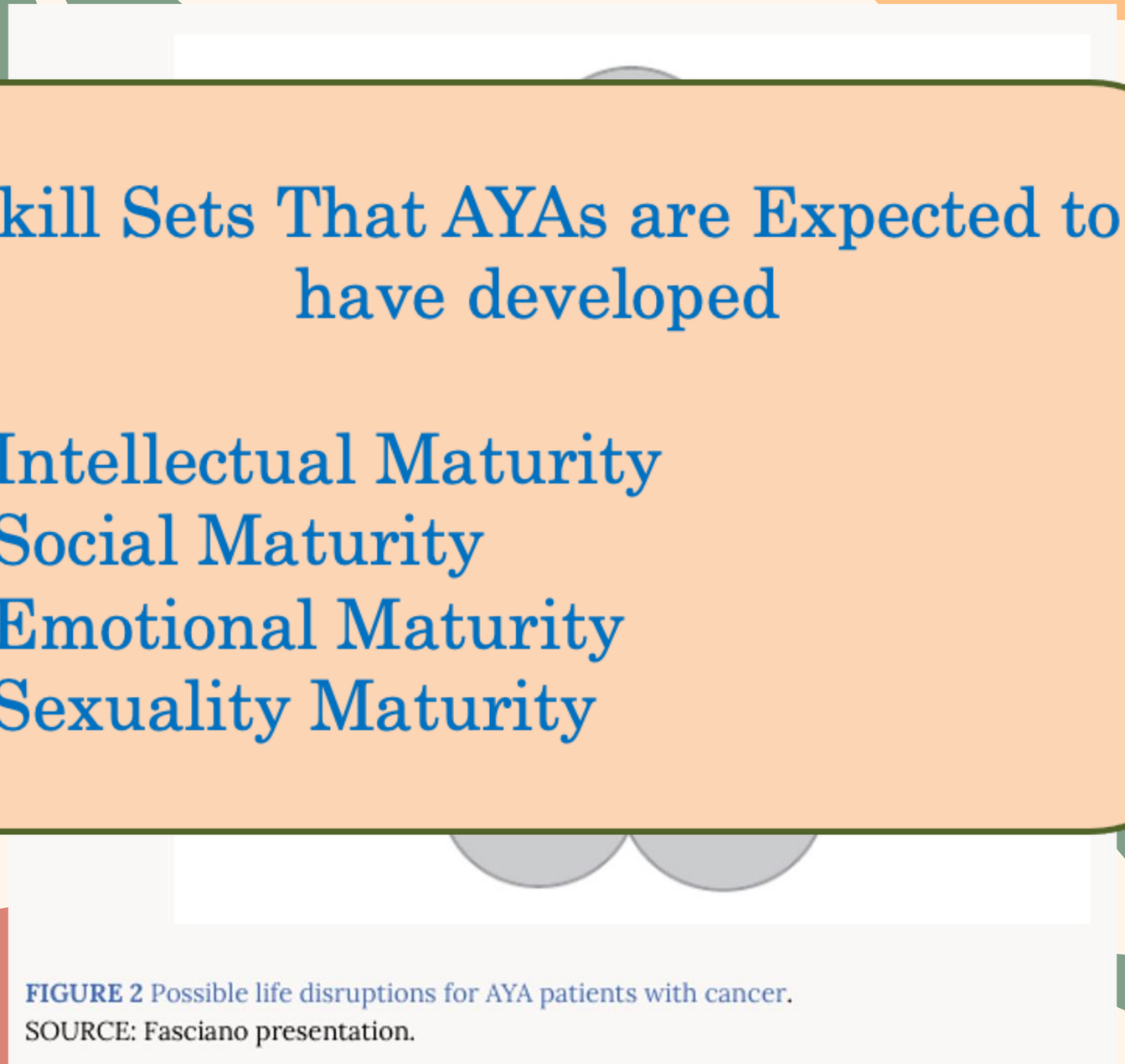
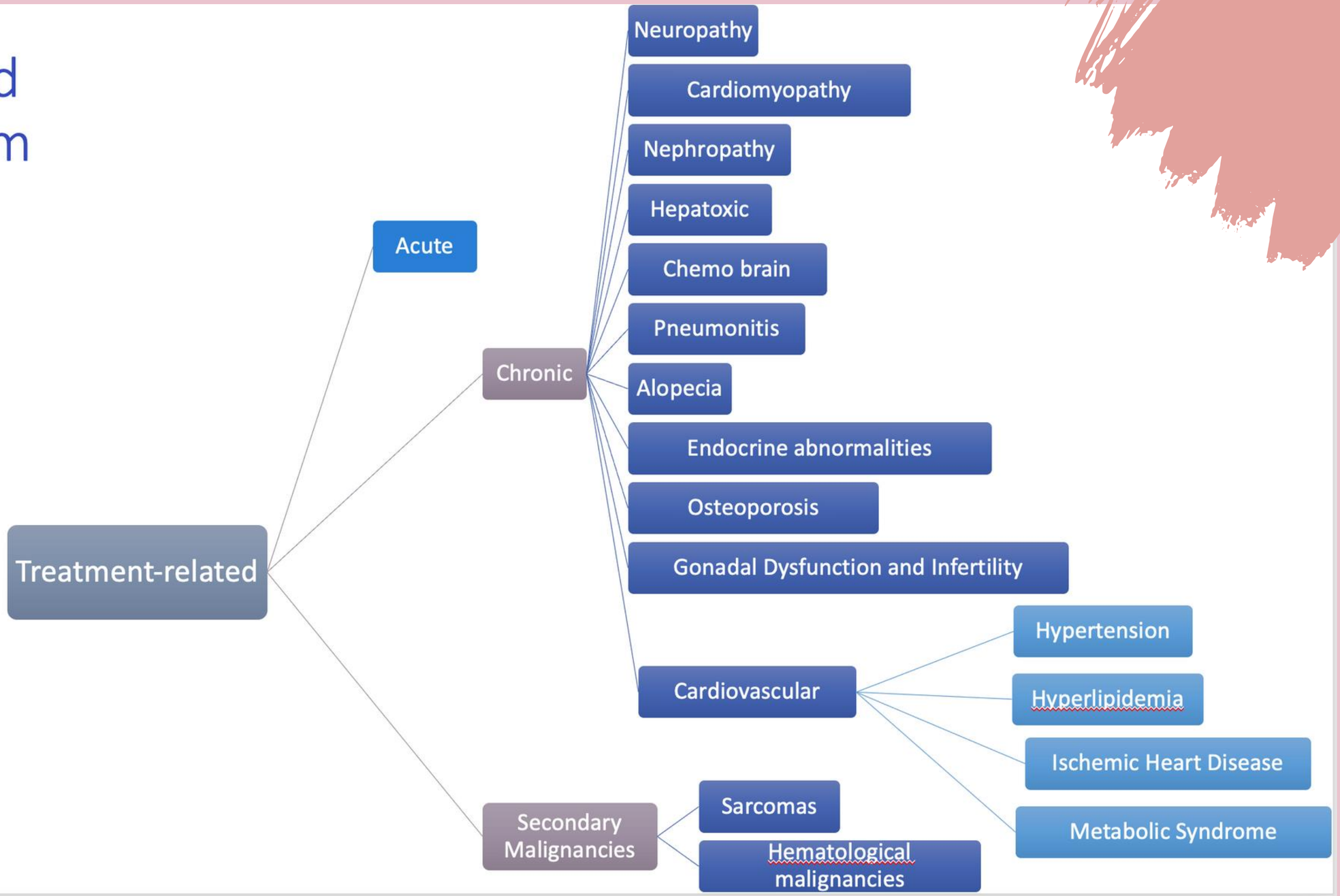


**FIGURE 2** Possible life disruptions for AYA patients with cancer.
SOURCE: Fasciano presentation.

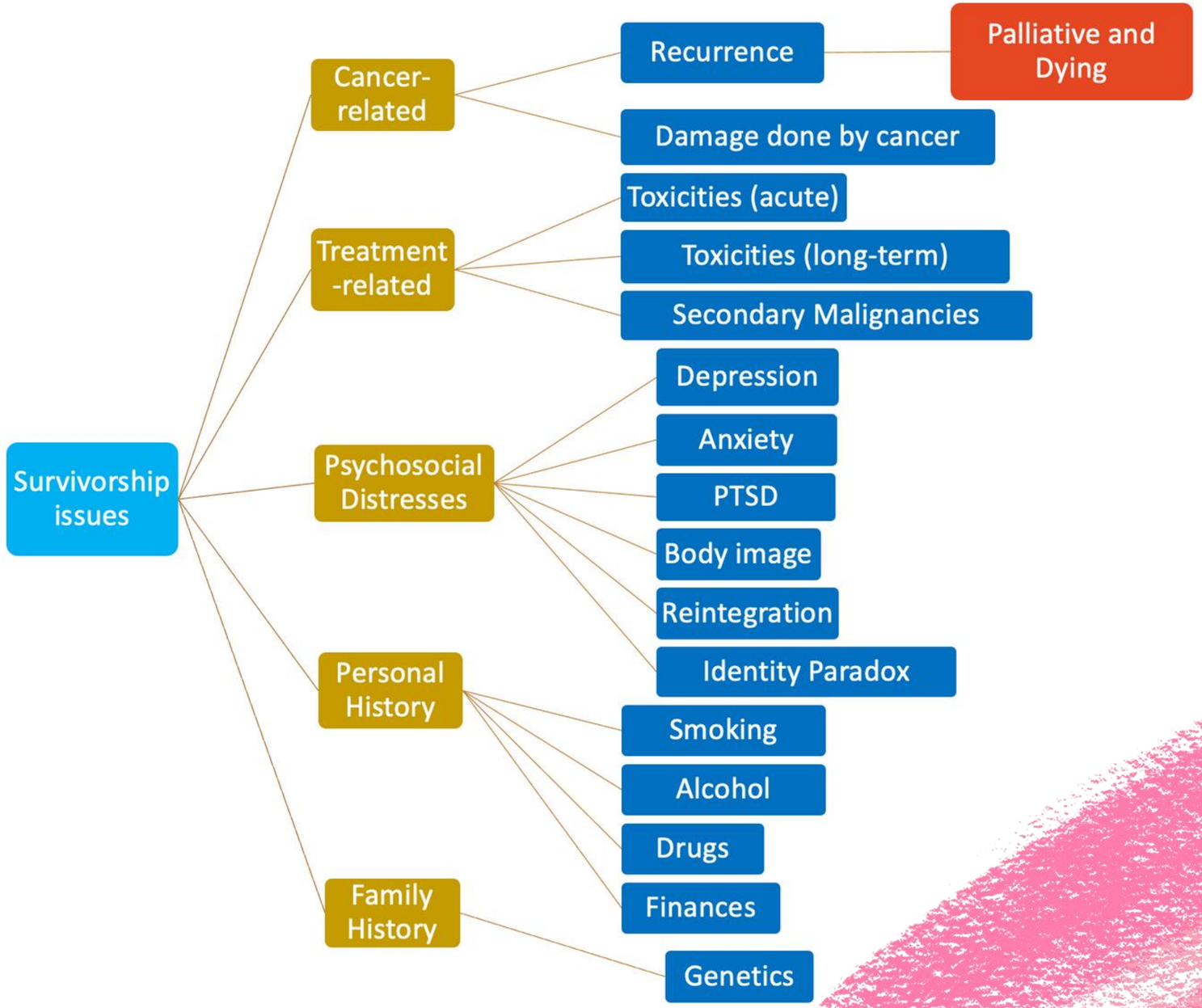
# What are the issues surrounding AYAOs?

1. Lack of age-appropriate info-education materials
2. Late Diagnosis
3. Decreased Compliance
4. FinancialToxicity
5. Sexuality, Fertility Health & Intimacy
6. Survivorship-issues
7. Lack of trained personnel
8. No Clear Guidelines
9. Palliation and Death
10. Mental Health

# Acute and Long-Term Toxicities



# What are the more common AYAO survivorship issues?



# LONG-TERM HEALTH IN AYA LYMPHOMA SURVIVORS

- Chronic condition risk: 4.2-fold higher than healthy siblings
- Second cancers, need for surveillance
- Risk of recurrence
- Cardiovascular monitoring is important due to heart disease risk elevation
- 1 in 3 experience distress, 1 in 4 depression
- Fertility worries are universal
- School/Work disruptions
- Relationship impacts
- Cultural considerations

# The problem of Recurrence

- Going into remission does not signify the end of cancer
- They go into a period necessitating frequent surveillance to ensure a relapse is not missed
- If the cancer relapses, the chance of surviving it inadvertently goes down
- How should we surveil the patient is also unknown
- A balance of risks associated with surveillance vs benefits of surveillance
- How long do we surveil them for is also a question
- What do we surveil them for is another a question

# Employment Pathways in a Large Cohort of Adult Cancer Survivors

Pamela FS et al. Cancer 2005

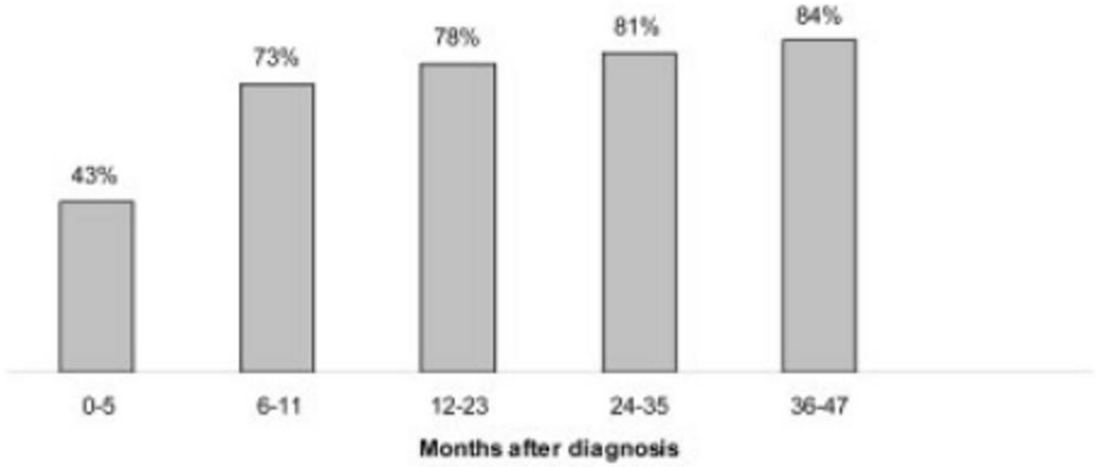



**FIGURE 1.** This chart illustrates the cumulative percentage of survivors who returned to work based on life-table projections of data collected in different years of survivorship.

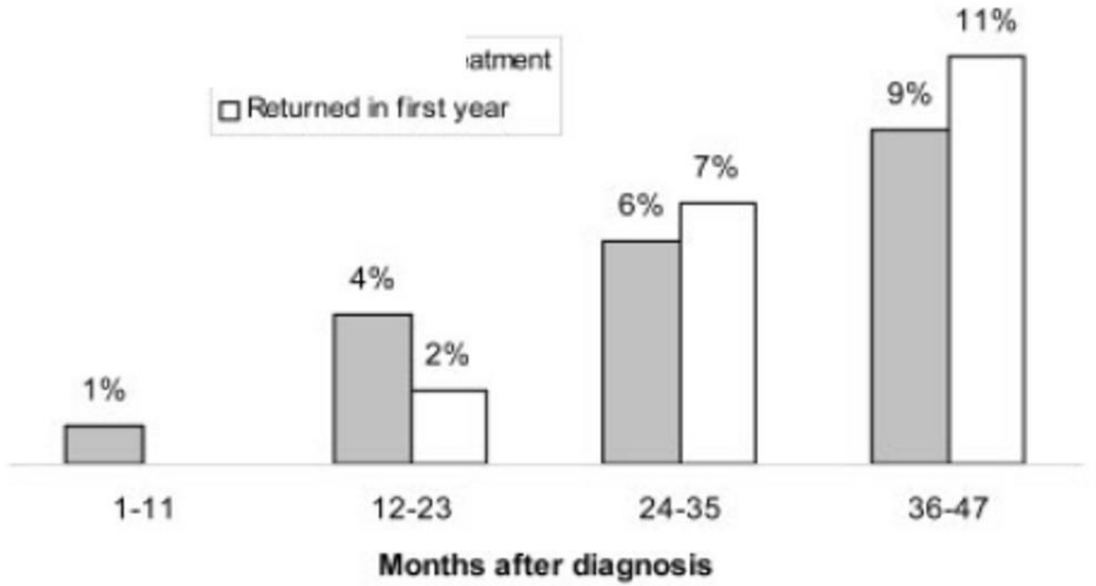



**FIGURE 2.** This chart illustrates the cumulative percentage of survivors who quit working for reasons related to cancer based on life-table projections of data collected in different years of survivorship.

- 1433 cancer survivors interviewed by phone from 1 year to ~5 years after diagnosis
- Retrospectively asked re: employment and work-related disability
- 1 in 5 survivors reported cancer-related disabilities
  - 50% of those with disabilities were working
- 13% of all survivors had quit due to cancer-related reasons within 4 years of diagnosis
- >50% of survivors quit working after the first year

**Table 2.** Physical symptoms prevalent and ease of accessing help in AYA sample.

| Physical Symptoms | Number of Respondents Who Answered the Question | Number of Respondents Indicating a Concern about a Physical Symptom (Mild, Moderate, or Big) | Number of Respondents Experiencing a Physical Symptom Whose Concern was 'Big' | Number of Respondents Experiencing a Physical Symptom Whose Concern was 'Moderate' | Number of those Experiencing a Physical Symptom Who Sought Help * | Number of those who Sought Help for their Concern that Experience Some Level of Difficulty (Hard or very Hard to Find Help/no Help Obtained) * |
|---|---|---|---|---|---|---|
| Fatigue or tiredness | 566 | 444 (78%) | 192 (43%) | 141 (32%) | 207 (47%)<br>*N* = 441 | 73 (35%)<br>*N* = 207 |
| Hormonal, menopause, or fertility | 561 | 280 (50%) | 141 (50%) | 74 (26%) | 184 (66%)<br>*N* = 279 | 55 (30%)<br>*N* = 184 |
| Changes to concentration, memory | 560 | 274 (49%) | 98 (36%) | 89 (32%) | 112 (41%)<br>*N* = 274 | 52 (47%)<br>*N* = 111 |
| Nerve problems (numbness or tingling) | 562 | 244 (43%) | 55 (23%) | 80 (33%) | 146 (60%)<br>*N* = 243 | 44 (30%)<br>*N* = 146 |
| Changes in sexual activity or function | 561 | 229 (41%) | 80 (35%) | 68 (30%) | 86 (38%)<br>*N* = 229 | 34 (40%)<br>*N* = 86 |
| Chronic pain or long-term pain | 561 | 209 (37%) | 52 (25%) | 75 (36%) | 137 (66%)<br>*N* = 209 | 51 (38%)<br>*N* = 136 |
| Gastrointestinal problems (i.e., digestion and/or bowl issues) | 559 | 180 (32%) | 55 (31%) | 57 (32%) | 115 (64%)<br>*N* = 180 | 25 (22%)<br>*N* = 115 |
| Swelling of arms or legs | 560 | 106 (19%) | 28 (26%) | 29 (27%) | 61 (58%)<br>*N* = 105 | 17 (28%)<br>*N* = 61 |
| Bladder and/or urinary problems (e.g., incontinence) | 560 | 58 (10%) | 15 (26%) | 19 (33%) | 37 (64%)<br>*N* = 58 | 13 (35%)<br>*N* = 37 |

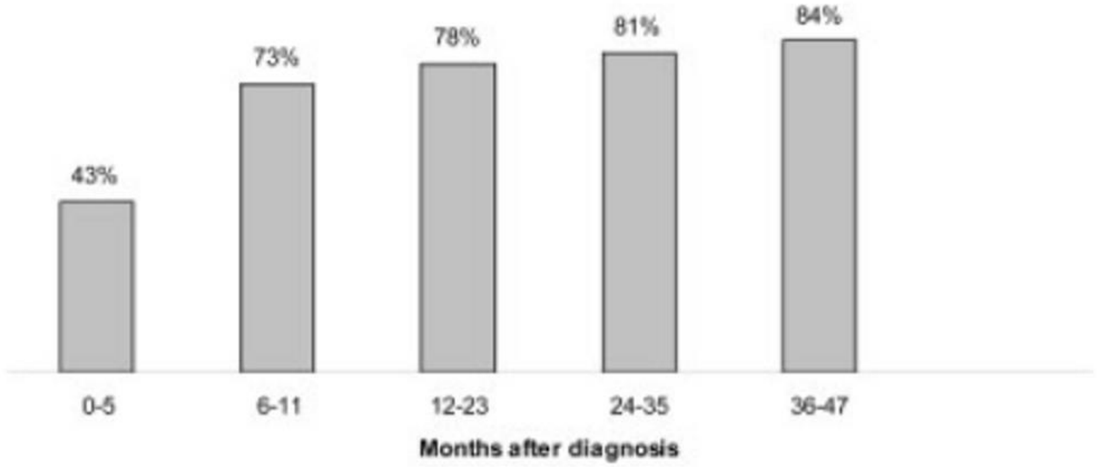
* Note: Those who did not answer relevant questions were excluded from the data set. *N* refers to the denominator used for a concern.

**Common reasons for not seeking help include not wanting to ask, being told it was normal, or embarrassment.**

**Of those who sought help, 37% encountered difficulty obtaining assistance**

# Employment Pathways in a Large Cohort of Adult Cancer Survivors

Pamela FS et al. Cancer 2005

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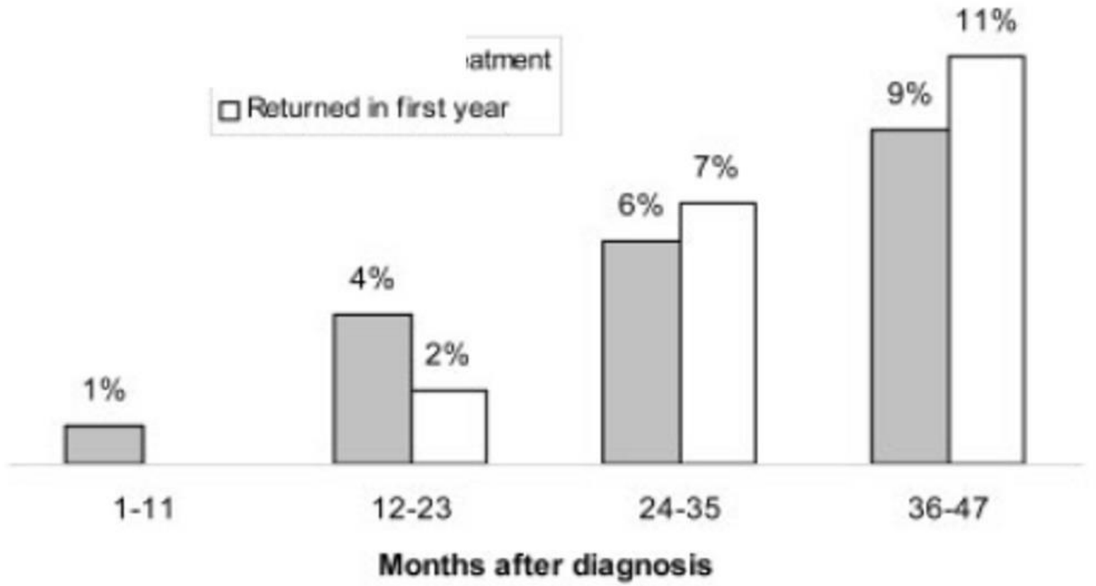


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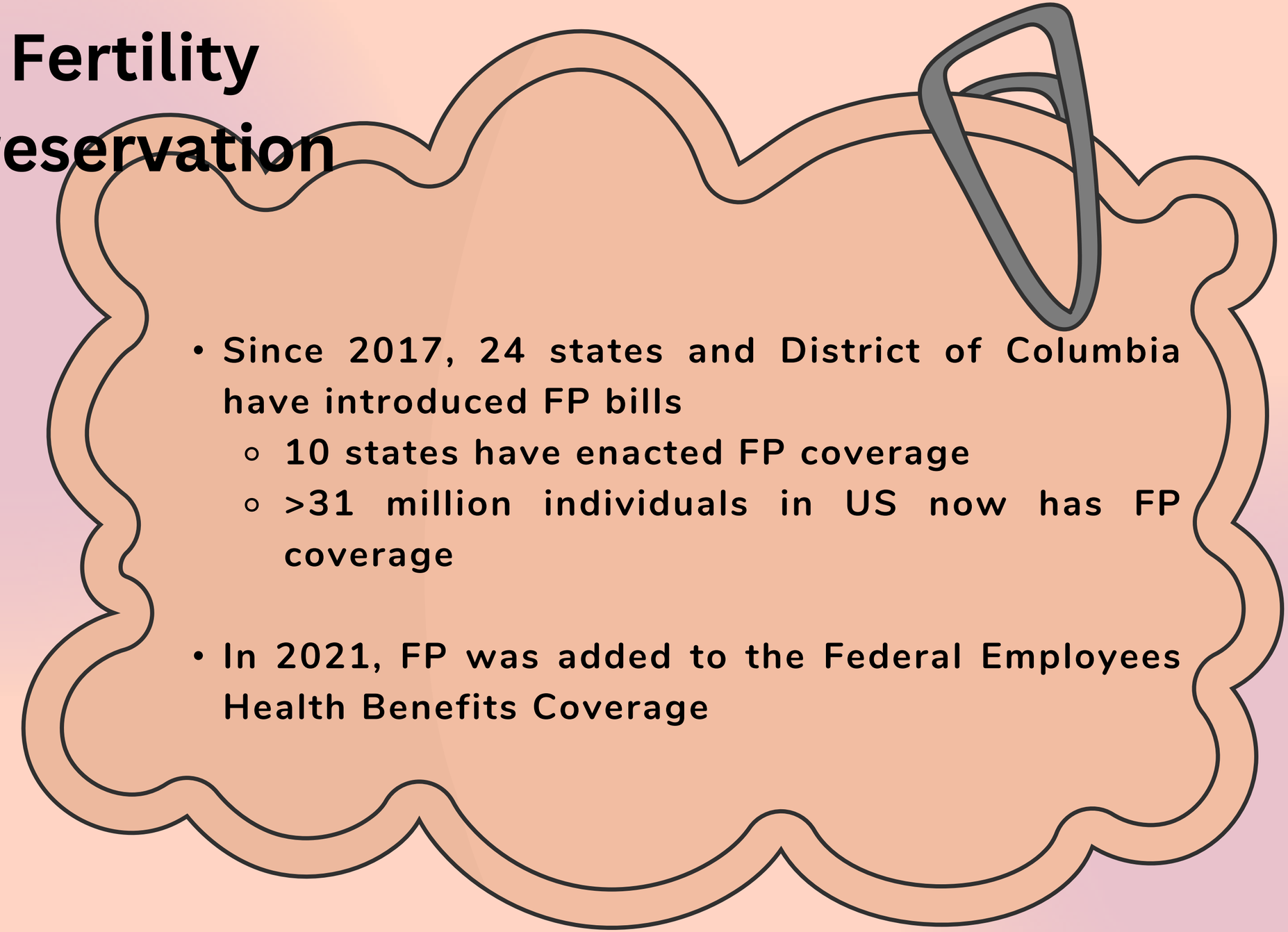
# Fertility Preservation



- Since 2017, 24 states and District of Columbia have introduced FP bills
  - 10 states have enacted FP coverage
  - >31 million individuals in US now has FP coverage

- In 2021, FP was added to the Federal Employees Health Benefits Coverage

# Fertility Preservation

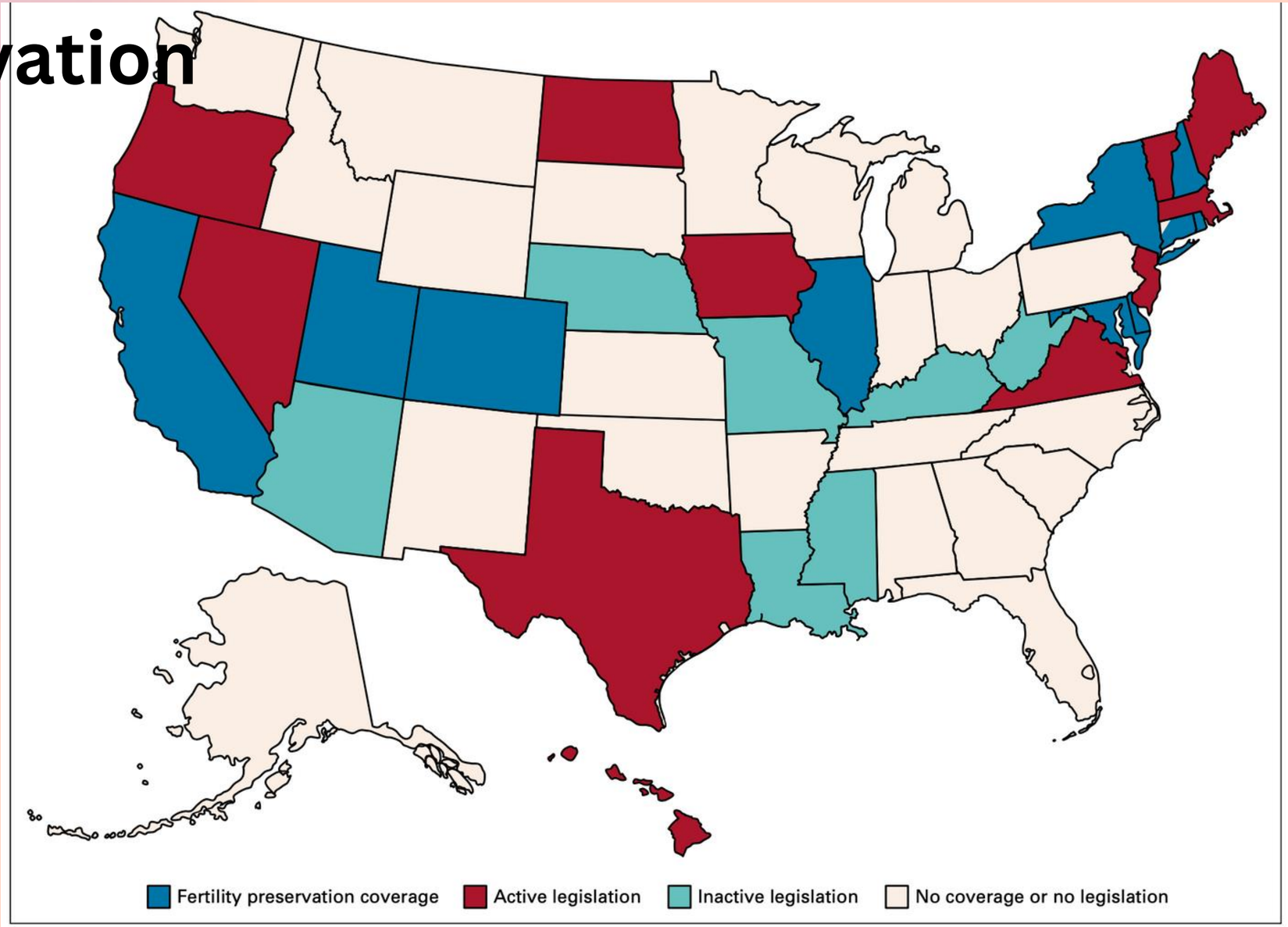



**FIG 1.** 2017-2021 fertility preservation legislative summary. Updated March 21, 2021.

JCO Kettler 2021

# HOW DO WE WANT TO SEE OUR AYAS EMERGE FROM THEIR CANCER JOURNEY?

# HOW DOES A WELL-ADAPATED FUNCTIONAL AYAO SURVIVOR LOOKS LIKE?

- Minimally scarred from cancer experience
- Minimal PTSD
- Able to work/return to school as close to 100% of their potential
- Able to share their cancer experience positively to benefit others and themselves
- Sexuality & Fertility not compromised
- Able to form meaningful and healthy relationships
- Not financially burdened
- Maintain good general health
- Minimal risk of cancer-related toxicities
- Minimal risk of secondary cancers
- Can be successfully right-sited into the community

# Our vision


PROVIDE

Holistic, individualized age-appropriate care

Provide

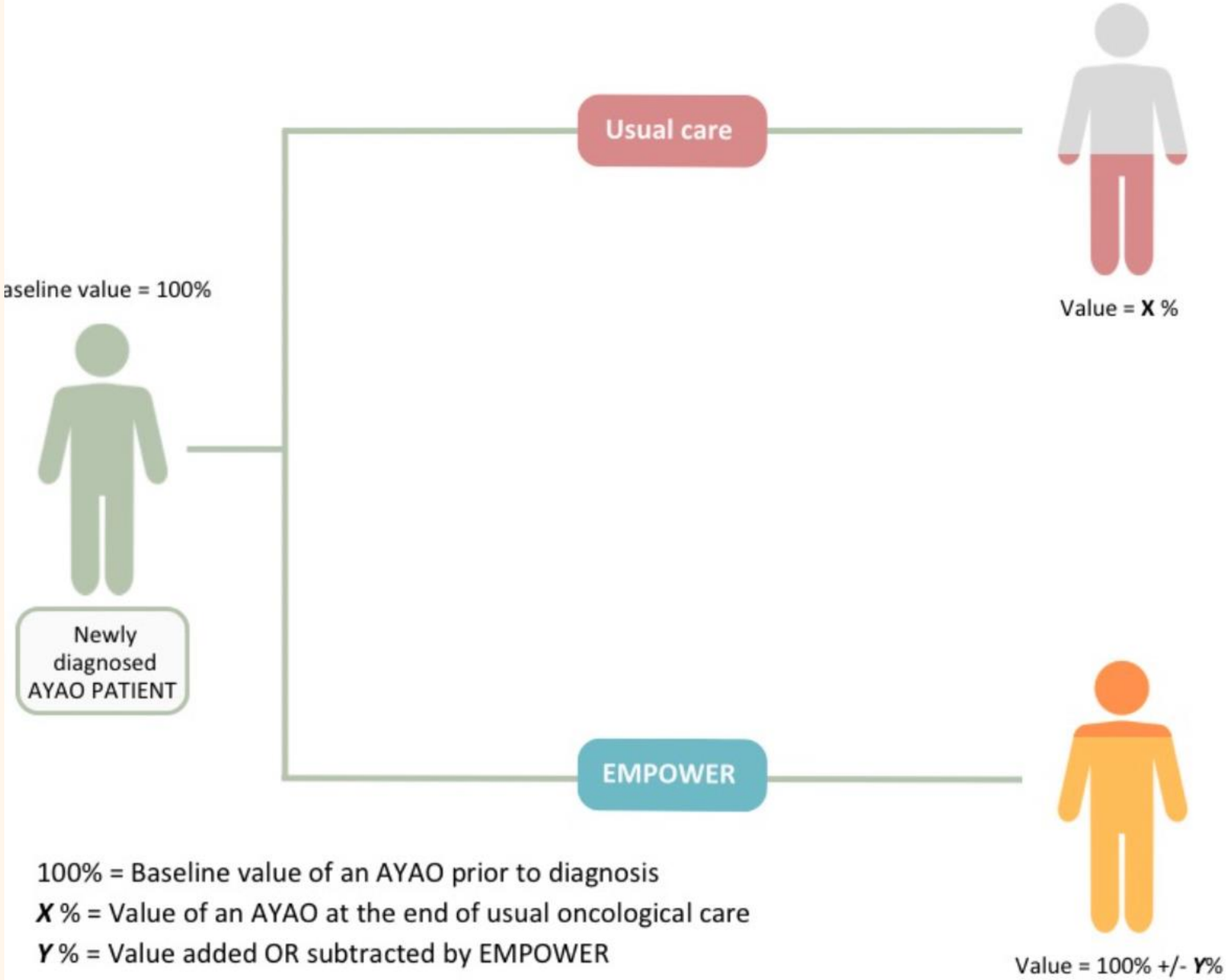
Age-appropriate info-education, interventions and activities

Become

Asia's leading centre for AYAO Care

Empower

Our patients and HCWs in AYAO Care




100% = Baseline value of an AYAO prior to diagnosis
***X*** % = Value of an AYAO at the end of usual oncological care
***Y*** % = Value added OR subtracted by EMPOWER

**Hypothesis:** EMPOWER will add on to the growth of an AYAO. The value of an individual in this case is assumed to include but is not limited to their individual, economic, social, societal and physical values.

# COMPONENTS


**First AYA consultation:**
(By AYAO doctor & Patient Navigator)

- Service and support introduction
- Comprehensive assessment (LYFE &DT)
- Distress interventions
- Provide point of contact

Within 2 weeks
of first consult

**Second AYA consultation:**
(By Nurse/ Patient Navigator - Virtual consult)

- Info-education
- Introduce support group/ Buddy system
- Counselling for fertility preservation

3 days - 1 week
after first treatment

**Third AYA consultation:**
(By Nurse/ Patient Navigator - Virtual consult)

- Opportunistic consult
- Comprehensive assessment (LYFE &DT)
- Distress interventions

**Fourth/ Subsequent AYA consultation:**
(By Nurse/ Patient Navigator)

- Arrange for physical/virtual consultation midway through treatment
- Comprehensive assessment (LYFE &DT)

**End of treatment AYA consultation:**
(By Nurse/ Patient Navigator)

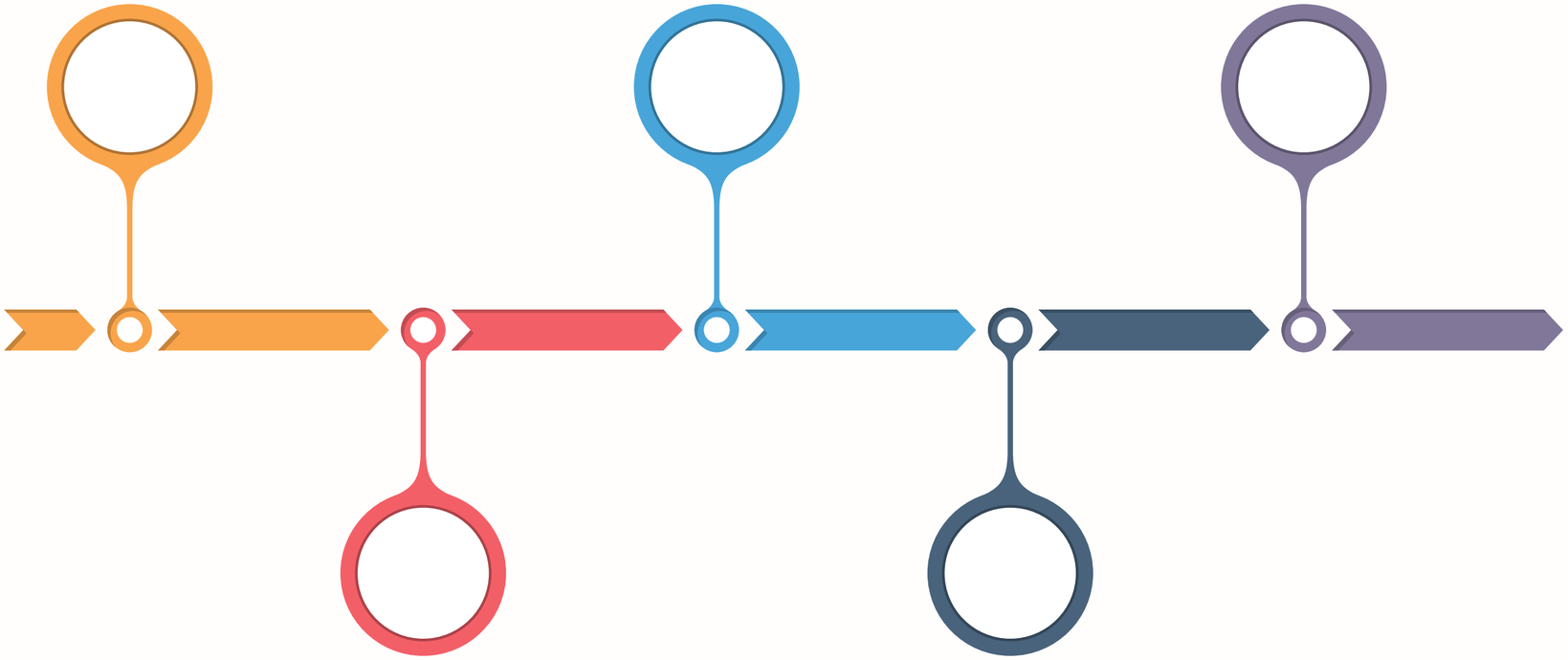
- Assess for new issues
- Assess for toxicities
- Comprehensive assessments (LYFE &DT)

# Mr B

- 22yo with relapsed ALK-ALCL
- Relapsed after 1st line treatment
- Repeat relapse resulting in need for autologous BMT

- Youngest of 3 children
- Lives with parents
- Dad retired, Mum is a principal in child care centre
- Studied in ITE College West

- Feb'19 presented with non-healing left buttock ulcer
- s/p RT
- July '19 relapsed
- July '19 - Nov '19 chemotherapy



- Dec'19 - May '23 : Surveillance
- May '23: restarted school , developed mood issues
- Aug '23: Saw AYAO Clinic

- Found to have low mood/suicidal

- Depression being managed
- Sept '23: 2nd relapse
- Sept - Oct '23: multiple discussions re: treatment, initially declined
- Oct '23 - Jan '24: salvage chemo
- Transplanted March '24

- Was on follow-up
- Found to have some new rash, being monitored for recurrence

# Mr B

Bad Disease

Financial concerns

Emotional Concerns, depression


Isolation

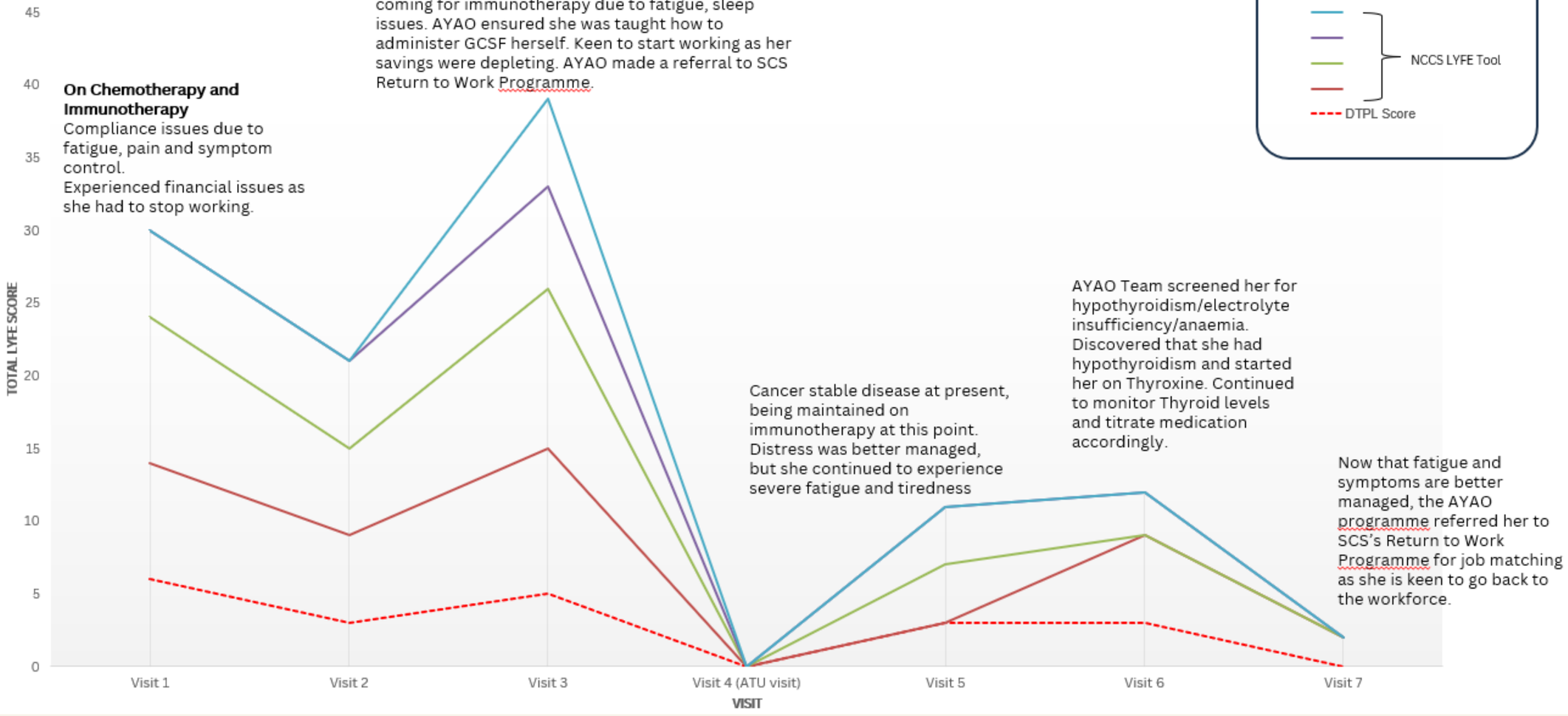
Suicidal attempts

Had to Stop School

# 03 Follow-up visits

**On Chemotherapy and Immunotherapy**
Compliance issues due to fatigue, pain and symptom control.
Experienced financial issues as she had to stop working.

Compliance issues with GCSF administration and coming for immunotherapy due to fatigue, sleep issues. AYAO ensured she was taught how to administer GCSF herself. Keen to start working as her savings were depleting. AYAO made a referral to SCS Return to Work Programme.



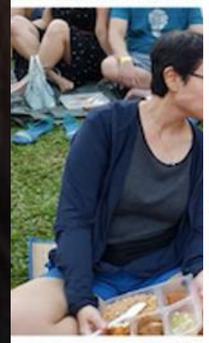

Cancer stable disease at present, being maintained on immunotherapy at this point. Distress was better managed, but she continued to experience severe fatigue and tiredness

AYAO Team screened her for hypothyroidism/electrolyte insufficiency/anaemia. Discovered that she had hypothyroidism and started her on Thyroxine. Continued to monitor Thyroid levels and titrate medication accordingly.

Now that fatigue and symptoms are better managed, the AYAO programme referred her to SCS's Return to Work Programme for job matching as she is keen to go back to the workforce.

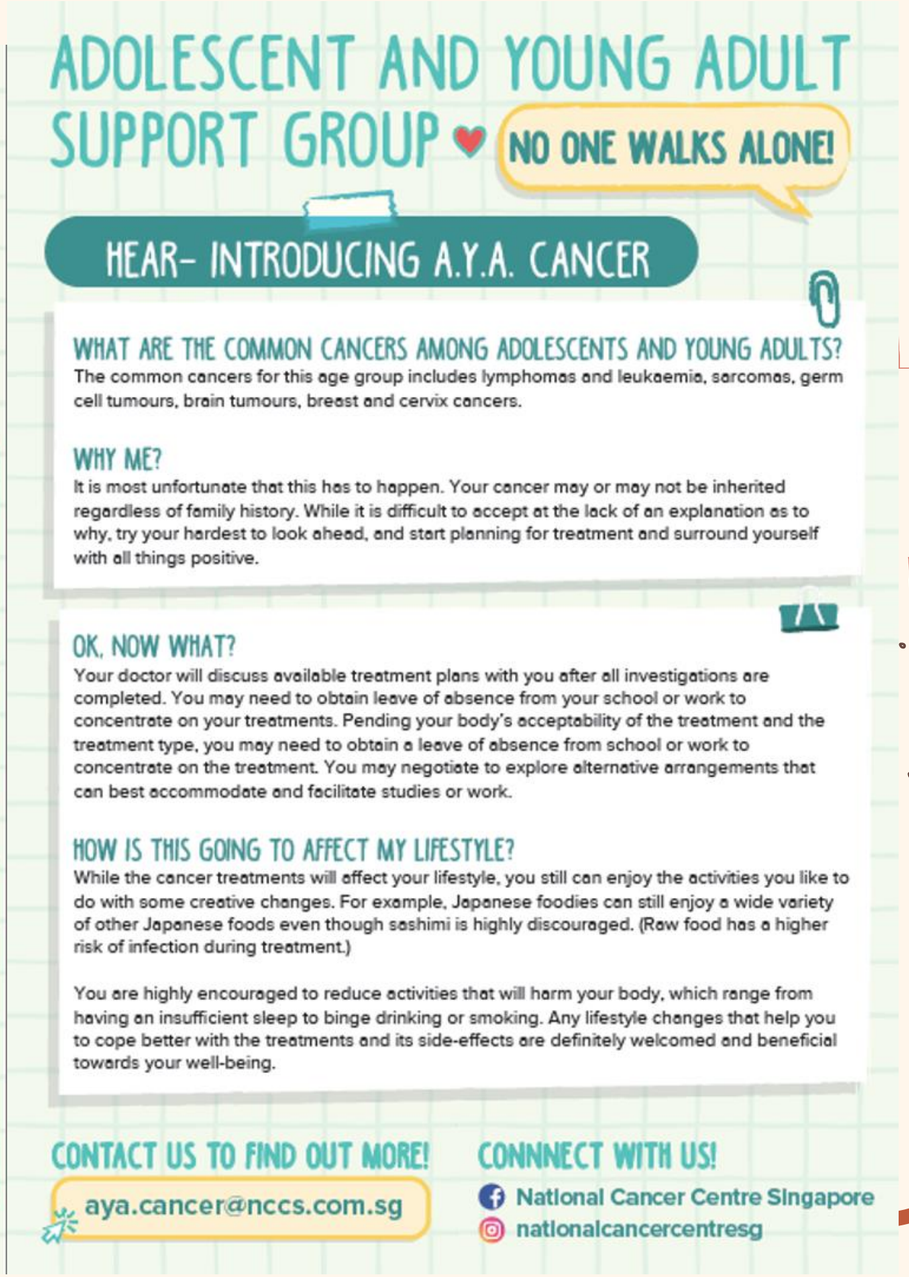
# COMPONENTS





# COMPONENTS

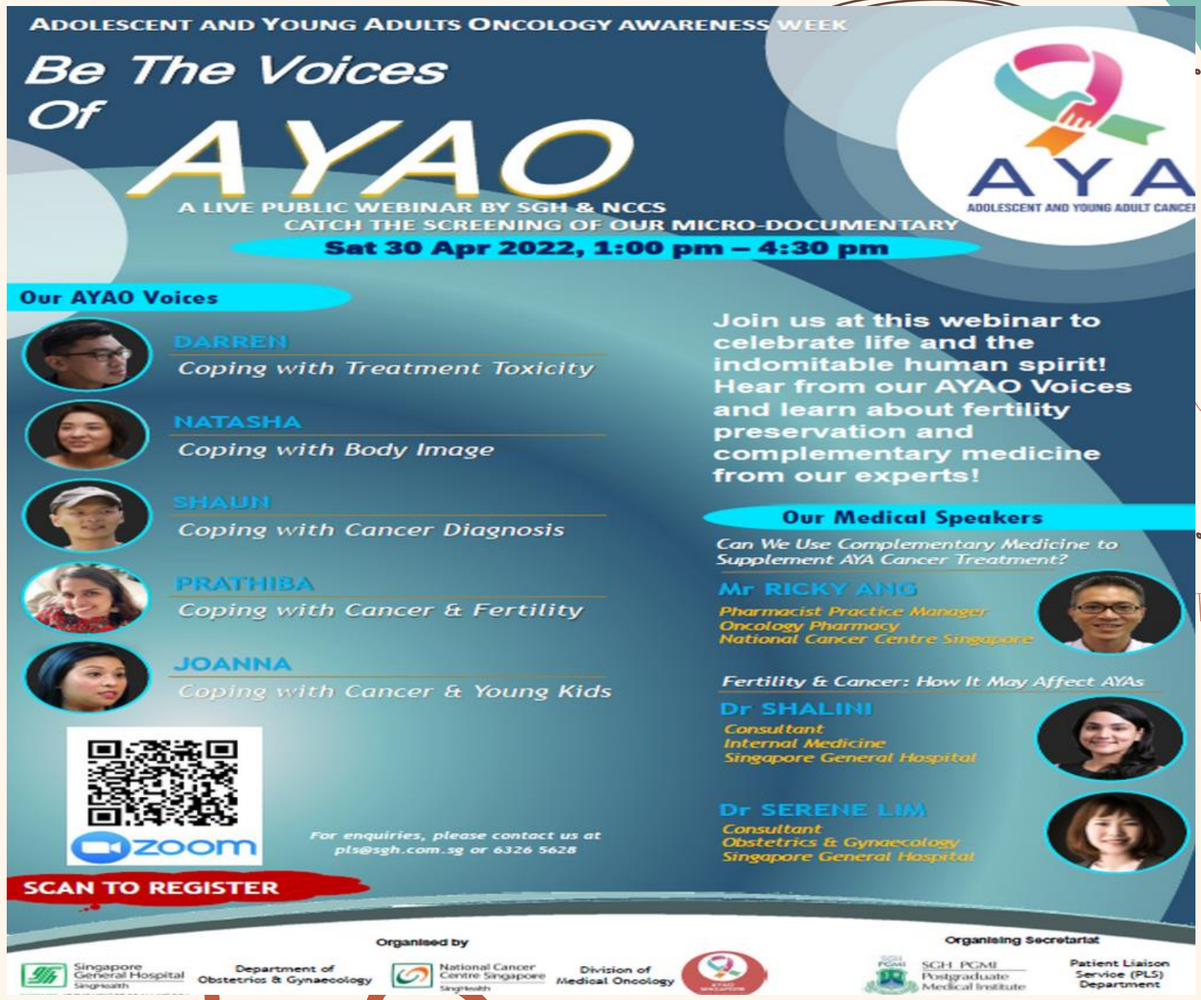

H.E.A.R.T
WE YOU
National Cancer Centre Singapore
SingHealth
HEAR
Living with cancer by myself feels annoyingly uncomfortable..
He is the worst type of company to be with..
And he loves to talk and plant all sorts of negativity in me..
Everything became a little bit brighter when I met people at the support group who are dealing with the same crappy situation as me..
All of a sudden, my world became less lonely.. Cancer also stopped having that negative grasp on me.
And I wonder.. Why did I ever think that it was a good idea to keep this to myself!


ADOLESCENT AND YOUNG ADULT SUPPORT GROUP
NO ONE WALKS ALONE!
HEAR- INTRODUCING A.Y.A. CANCER
WHAT ARE THE COMMON CANCERS AMONG ADOLESCENTS AND YOUNG ADULTS?
The common cancers for this age group includes lymphomas and leukaemia, sarcomas, germ cell tumours, brain tumours, breast and cervix cancers.
WHY ME?
It is most unfortunate that this has to happen. Your cancer may or may not be inherited regardless of family history. While it is difficult to accept at the lack of an explanation as to why, try your hardest to look ahead, and start planning for treatment and surround yourself with all things positive.
OK, NOW WHAT?
Your doctor will discuss available treatment plans with you after all investigations are completed. You may need to obtain leave of absence from your school or work to concentrate on your treatments. Pending your body's acceptability of the treatment and the treatment type, you may need to obtain a leave of absence from school or work to concentrate on the treatment. You may negotiate to explore alternative arrangements that can best accommodate and facilitate studies or work.
HOW IS THIS GOING TO AFFECT MY LIFESTYLE?
While the cancer treatments will affect your lifestyle, you still can enjoy the activities you like to do with some creative changes. For example, Japanese foodies can still enjoy a wide variety of other Japanese foods even though sashimi is highly discouraged. (Raw food has a higher risk of infection during treatment.)
You are highly encouraged to reduce activities that will harm your body, which range from having an insufficient sleep to binge drinking or smoking. Any lifestyle changes that help you to cope better with the treatments and its side-effects are definitely welcomed and beneficial towards your well-being.
CONTACT US TO FIND OUT MORE!
aya.cancer@nccs.com.sg
CONNNECT WITH US!
National Cancer Centre Singapore
nationalcancercentresg


BURGERS
LAD
GRILLED BUN
TOMATO
ESE
MEAT 100%
CUTLET
HOT AND FRESH

# COMPONENTS


ADOLESCENTS AND YOUNG ADULTS ONCOLOGY
AYAO WEEK WEBINAR
HOSTED ON ZOOM
APRIL 5–8, 2021, 5PM TO 6PM (GMT +8)
Fads and Facts (5th April)
Dr Eileen Poon
Consultant, Division of Medical Oncology, NCCS
Program Director, AYAO
Misinformation, cancer facts, and screening needs in AYAO
Caregiver and Families (6th April)
Dr Victoria Wong
Associate Consultant
Division of Supportive and Palliative Care, NCCS
Supportive and Palliative Care Lead, AYAO
Difficulties that caregivers face
It is a Personal Journey (7th April)
Ms Chong Hui Min
Osteosarcoma Survivor and AYA Ambassador
Sharing her personal journey of survivorship
Care to Go Beyond (8th April)
Ms Selene Chan
Assistant Nurse Clinician, Nursing Division, SGH
Caring for AYAO patients in hospitals
REGISTRATION:
bit.ly/AYAOWebinar21
or scan QR Code:
FOLLOW US AT:
@ayao.singapore
Details of the programmes may be subjected to changes without prior notice.
Organised by:
In partnership with:
National Cancer Centre Singapore
National University Cancer Institute Singapore
Powered by


ADOLESCENT AND YOUNG ADULTS ONCOLOGY AWARENESS WEEK
Be The Voices Of AYAO
A LIVE PUBLIC WEBINAR BY SGH & NCCS
CATCH THE SCREENING OF OUR MICRO-DOCUMENTARY
Sat 30 Apr 2022, 1:00 pm – 4:30 pm
AYA
ADOLESCENT AND YOUNG ADULT CANCER
Our AYAO Voices
DARREN
Coping with Treatment Toxicity
NATASHA
Coping with Body Image
SHAUN
Coping with Cancer Diagnosis
PRATHIBA
Coping with Cancer & Fertility
JOANNA
Coping with Cancer & Young Kids
Join us at this webinar to celebrate life and the indomitable human spirit! Hear from our AYAO Voices and learn about fertility preservation and complementary medicine from our experts!
Our Medical Speakers
Can We Use Complementary Medicine to Supplement AYA Cancer Treatment?
Mr RICKY ANG
Pharmacist Practice Manager
Oncology Pharmacy
National Cancer Centre Singapore
Fertility & Cancer: How It May Affect AYAs
Dr SHALINI
Consultant
Internal Medicine
Singapore General Hospital
Dr SERENE LIM
Consultant
Obstetrics & Gynaecology
Singapore General Hospital
zoom
For enquiries, please contact us at pls@sgh.com.sg or 6326 5628
SCAN TO REGISTER
Organised by
Singapore General Hospital
Department of Obstetrics & Gynaecology
National Cancer Centre Singapore
Division of Medical Oncology
Organising Secretariat
SGH PGMI Postgraduate Medical Institute
Patient Liaison Service (PLS) Department

# COMPONENTS

## AYAO Video – Voices of AYAO

Videos

The Voices of AYAO: Adolescents and Young Adults Oncology

YouTube · National Cancer Centre Singapore
8 Apr 2022

3 key moments in this video

Why choose to be alone when you can build stories with people, your loved ones. Then eventually.... there would be meaningful memories with them

NATASHA

We cannot control the things that happens to us on the outside. We can control with how we choose to react and deal with it, emotionally, mentally and spiritually

SHAUN

Dont be afraid of the whole treatment process. Go through it and you will come out stronger and a better version of yourself

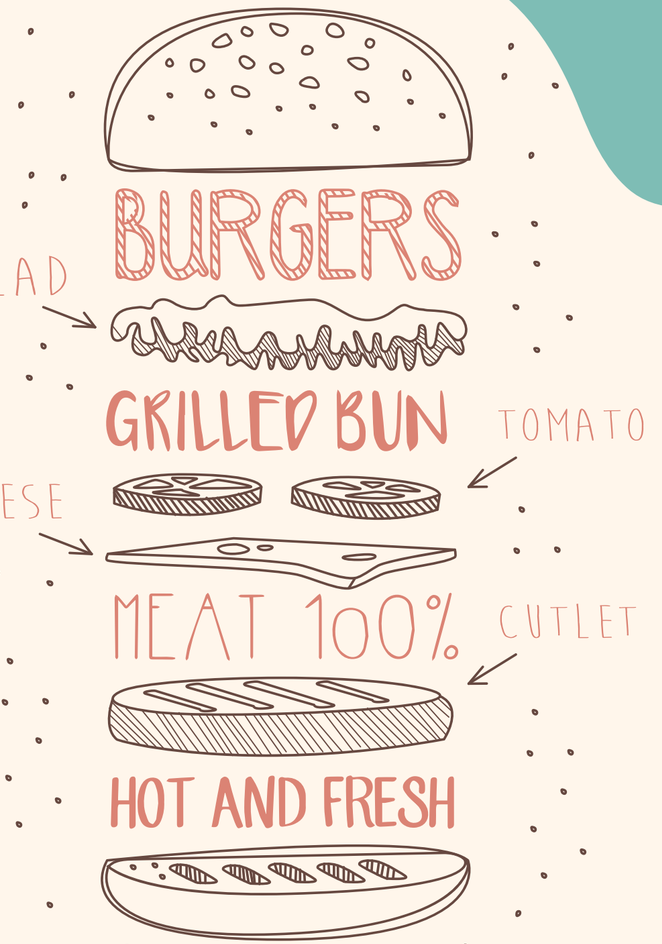
DARREN

https://youtube.com/clip/UgkxU4flbUR4X67I1ph-3e44BPcYCejobORL

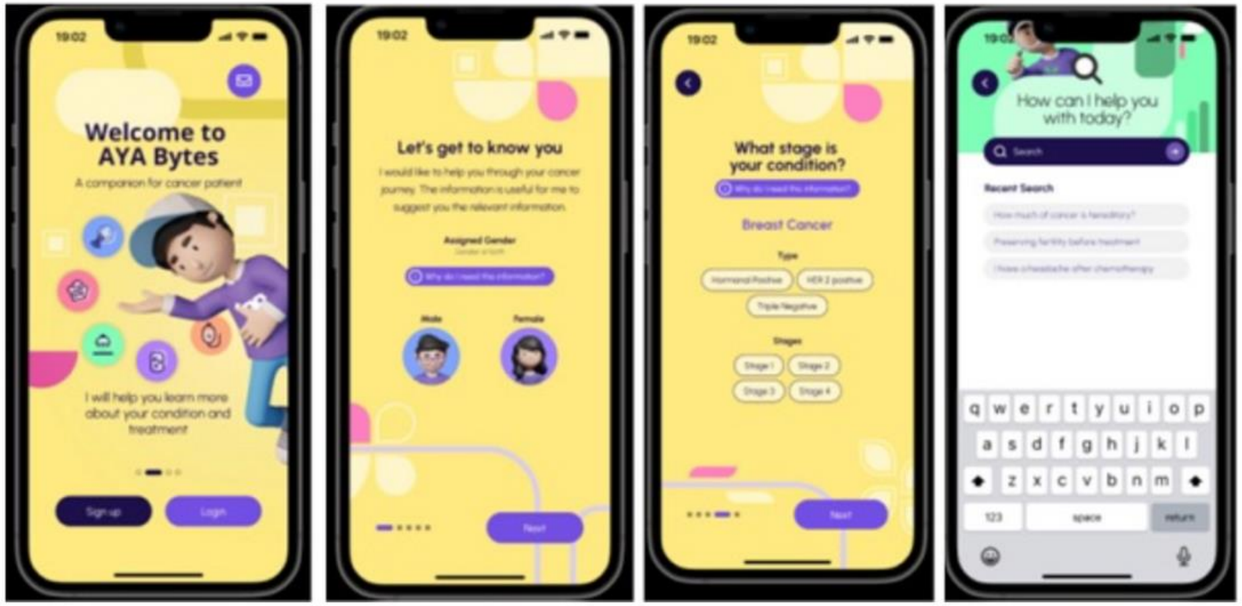
Don't put yourself in statistics, we are not just numbers. If a doctor were to tell you that you have 50% chance of survivability, why define yourself to this 50%. You are a whole, you are 100%.

https://youtube.com/clip/UgkxO7rgbnakd0RAPRTPxpDJIVKVtEut4o_N

SingHealth DUKE-NUS ACADEMIC MEDICAL CENTRE



# COMPONENTS


Welcome to AYA Bytes
A companion for cancer patient
I will help you learn more about your condition and treatment
Sign up
Login
Let's get to know you
I would like to help you through your cancer journey. The information is useful for me to suggest you the relevant information.
Assigned Gender
Male
Female
Next
What stage is your condition?
Why do I need this information?
Breast Cancer
Type
Hormonal Positive
HER 2 positive
Triple Negative
Stages
Stage 1
Stage 2
Stage 3
Stage 4
Next
How can I help you with today?
Search
Recent Search
How much of cancer is hereditary?
Preserving fertility before treatment
I have a headache after chemotherapy


Mood Tracker
How are you feeling today?
You are doing really well
Positive
Good
Reason
Exercise, Complete therapy
Thank you for sharing your mood. I understand what you are going through, here is some inspiration to help you improve your mood.
Cancer fatigue: Why it occurs and how to cope
Managing Fatigue or Weakness
Shaun: I have recorded your mood
Symptoms Tracker
What symptoms are you having?
What symptoms are you having?
Symptoms
Appetite loss, Diarrhea
Your symptoms is common when you are going through treatments. Here are some articles to help you with
Cancer fatigue: Why it occurs and how to cope
Shaun: I have recorded your symptoms


SALAD
BURGERS
GRILLED BUN
TOMATO
CHEESE
MEAT 100%
CUTLET
HOT AND FRESH


The
CANDID
CANCER
Podcast

# THE ROAD AHEAD

## KEY PARTNERS

- AYA Team
- Medical Oncologists
- Surgical Oncologists
- Radiation Oncologists
- Palliative Care Physicians
- Sub-Specialties
- Social Workers
- Psychologists
- Allied Health
- Nursing

## VALUE PROPOSITIONS

- Provide holistic, individualized, age-appropriate care
- Complementary care that value-adds to oncologists that is time-efficient for doctor and patient
- Become Asia's leading centre for AYAO care
- Development of world's first AYA psychosocial distress tool

AYA

ADOLESCENT AND YOUNG ADULT CANCER

## AYAO ISSUES

- Late Diagnosis and High rates of defaulting
- Lack of age-appropriate info-education, guidelines
- Sexuality & Fertility Preservation
- Increased levels of psychosocial distresses
- Survivorship issues (Toxicities, 2nd Cancers, reintegration)
- Palliation and Death in AYAO
- Lack of AYA-specific support

## KEY DIFFERENCES

- Complementary care alongside primary treatment
- Regular check-ins/follow-ups to decrease risk of patients defaulting
- Better identification of distresses/issues earlier
- Better care coordination
- Survivorship clinics + clear survivorship guidelines to facilitate proper right-siting in future
- Better psychosocial support

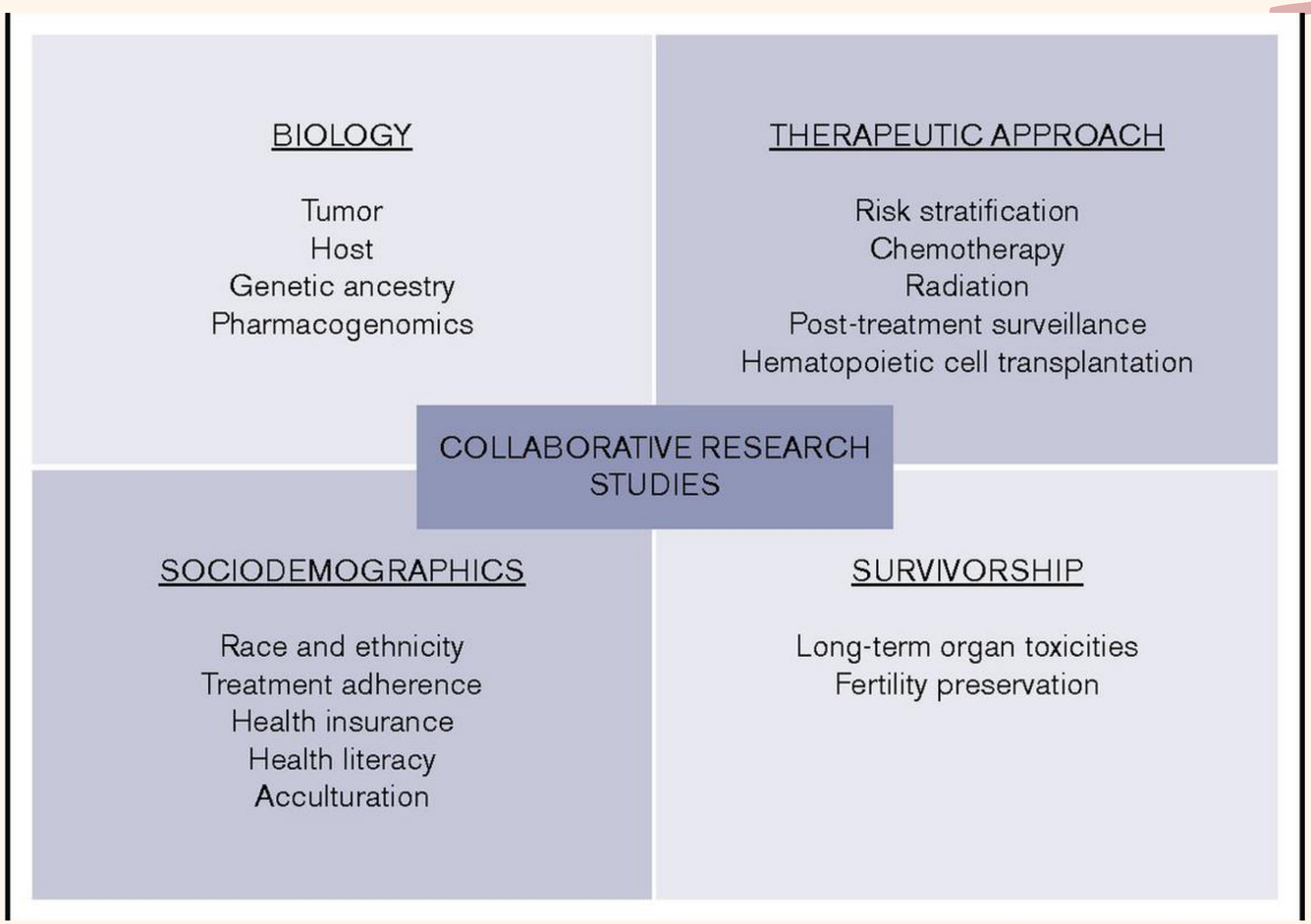
## HOW BIG IS THE PROBLEM

5-7% of cancer population (Childhood cancers 1%)
2018-2021: >6000 AYA patients seen in NCCS
400-500 NEW AYAO patients seen per year
>80% expected to have longer survival/cure
* AYAs = economically viable part of the society

## REVENUE SOURCES

Subvention by MOH
Grants from Health Service Research/NCCRF/Onco-ACP
Philanthropy and Funders

# THE ROAD AHEAD




Justine M Kahn et al. 2017 Blood advances 1(22): 1945-1958

# CONTACT

www.nccs.com.sg

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NationalCancerCentreSG
AYAO Singapore

NationalCancerCentreSingapore