

Too Young for This! Facing Cancer Under 40

*Sarah Sciortino, MSW, LSW
University of Chicago Medicine*



YOUNG ADULT-ING WITH CANCER

Sarah Sciortino, MSW, LSW
University of Chicago Medicine Comer Children's Hospital
ssciortino@peds.bsd.uchicago.edu

What does it mean to be a YA?

- In the context of oncology, defined as ages 15-39
- During this Young Adult era, many critical processes occur:
 - Formation of coping skills
 - Solidifying and enhancing self-esteem
 - Self-esteem in various realms: Relational, sexual, career, etc.
 - Increasing independence, autonomy and self-efficacy
 - Developing identity:
 - Being comfortable with who you are and who you want to become

Now let's throw the big C in there...

- YA patients and survivors are challenged to:
 - Remain active and independent
 - Cope with treatment related adverse effects
 - Manage stress
 - Seek and understand information
 - Manage emotional responses (of both self and others)
 - [50/50 Sharing the news](#)
 - Seek social support
 - Maintain a positive attitude while also accepting diagnosis/prognosis



The 5 domains of YA cancer-related stress

1. INFORMATIONAL

2. PRACTICAL

3. EMOTIONAL

4. INTERPERSONAL

5. EXISTENTIAL

Informational stress

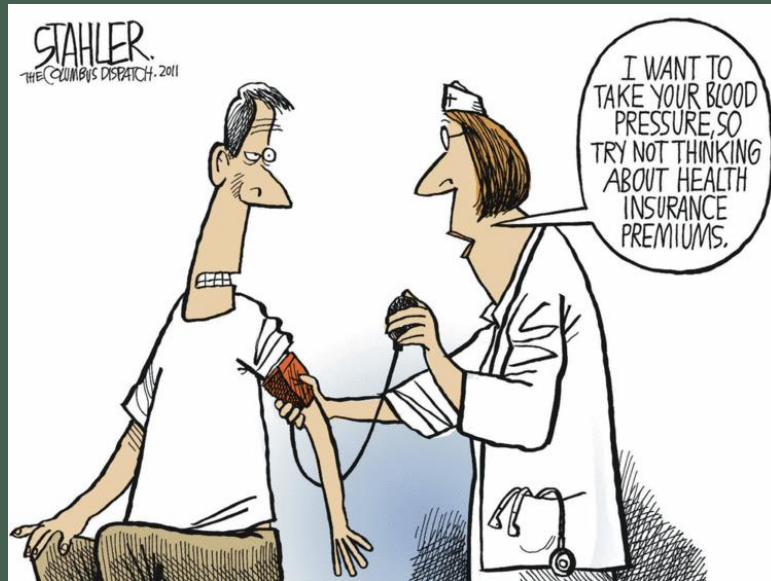
- Information overload!
 - Treatment/surgery and Late Effects
 - Fertility Preservation
 - Diet and Nutrition
 - Mental Health
- THE INTERNET
 - Statistics
 - Conflicting information
- Communicating information
 - From doc → patient → parents/spouse/friends
 - Parenting a YA



How to cope with informational stress

- Have open, clear, honest discussion with loved ones about how you want to handle incoming information
- Limit internet time and stick to reputable sources
 - And make sure you're looking at AYA-specific sites
 - What to do if you find yourself in the "rabbit-hole"?
- Take notes at significant appointments and don't be afraid to ask questions of your providers
- Stay organized!
 - Simple organizational techniques can help lessen stress around information overload
- Stay attuned to yourself: Is this information distressing or empowering?
- If you still find yourself stressed by the sheer amount of information....

Practical stress



- Health insurance
- Financial burden
- School/work disruptions
- Transportation issues
- Social life disruptions

How to cope with practical stress

- Stay informed and know your rights (see informational stress)
 - A feeling of competency can alleviate distress
- Work closely with your Social Work team and utilize their services
- And if you still feel stressed...



Emotional stress

SADNESS

ANGER

HELPLESSNESS

GUILT

GRIEF

FEAR/WORRY/ANXIETY

TRAPPED

SHAME

DESPAIR

ENVY

CONFUSED

How to cope with emotional stress

- Peer support is important!
 - Offers YAs opportunity to build interpersonal and problem-solving skills
 - Sharing of life experiences creates sense of community and thus reduces feelings of shame and social isolation
 - Evidence demonstrates significant improvement in psychologic well-being
- Programs like Mindfulness-Based Stress Reduction (MBSR) can help to alleviate emotional distress
 - Mindfulness meditation, breathing and relaxation techniques
 - Movement/exercise
- Utilize your psychology and psychiatry teams
- Or utilize community therapy providers:
<https://www.psychologytoday.com/>
- And if you still feel stressed...

Interpersonal stress



Interpersonal Stress

- Friends falling away and friends stepping up
- Intimate relationship stress, flirting, dating, sex
- Parenting vs Being Parented
- Your own changing identity, self-esteem, and perspective
- Making medical decisions



How to cope with interpersonal stress



- Clear lines of communication
- If moved back in with parents, maintain independent space
- Seek safe guidance from family therapist, couple's therapist, sex therapist, or sexual health clinic
- Outdoor adventure programs
- Seek peer support from other YAs
- And if you still feel stressed...

Existential stress

(aka “I am pissed at the universe”)

- Asking the big questions:
 - Why has this happened to me?
 - Is there a reason?
 - What is my purpose?
 - Is there a purpose?
- Feeling alone, different, isolated, rare
- Feeling like a speck in the universe
- Facing mortality at a young age



How to cope with existential stress

“The root of suffering is resisting the certainty that no matter what the circumstances, uncertainty is all we truly have”

“Sticking with uncertainty is how we learn to relax in the midst of chaos, how we learn to be cool when the ground beneath us suddenly disappears. We can bring ourselves back to the spiritual path countless times every day simply by exercising our willingness to rest in the uncertainty of the present moment—over and over again.”

~Pema Chodron, *Comfortable with Uncertainty: 108 Teachings on Cultivating Fearlessness and Compassion*



QUESTIONS?
COMMENTS?

Break-out discussion

- Groups of 4-5
- Introduce yourself and share what brought you to this conference
- After introductions, go around and discuss the following:
 - If you're a YA patient, survivor, or caregiver:
 - Which realm of stress has impacted you the most? How so?
 - What have you done or what would you like to do to help cope with that stress?
 - If you're an advocate or provider:
 - Which realm of stress do you witness most or feel most impacted by in working with YA patients?
 - How do you try to assist patients in alleviating that stress?
- I will ring the chime when it is time to bring it to a close.
- Try to make sure everyone has a chance to speak. You do not have to share anything that feels too personal. Please commit to maintaining confidentiality of what is spoken here.

AYA Cancer Support Resources

AYA Cancer Patient Advocacy Organizations:

- **Young Adult Cancer Connection** :: <http://yacancerconnection.org/>
 - Offers emotional and clinical resources, workshop recaps, and peer connection
- **Stupid Cancer** :: <http://stupidcancer.org/>
 - Offers programs and services, such as its annual conferences, to young adults with cancer
- **Ulman Cancer Fund for Young Adults** :: <http://ulmanfund.org/>
 - Raises awareness of unique YA needs and provides resources
- **Critical Mass** :: <https://criticalmass.org/>
 - An alliance of organizations dedicated to enhancing services for YAs impacted by cancer
- **SeventyK** :: <http://seventyk.com/>
 - Educating patients, caregivers, and healthcare providers about the unique needs of the AYA cancer patient
- **Society for Adolescent and Young Adult Oncology** :: <http://www.sayao.org/>
 - Advancing AYA cancer care through research, education, and interdisciplinary collaboration with health professionals
- **Livestrong** :: <https://www.livestrong.org/we-can-help/young-adults>
 - Provides resources and guidance on unique issues of AYA population

Emotional and Peer Support Organizations:

- **Lacuna Loft** :: <https://lacunaloft.org/>
 - Provides online wellness support programs and resources as well as a peer support community
- **I Had Cancer** :: <https://www.ihadcancer.com/>
 - Offers peer connection and discussion forums to young adult cancer patients and survivors
- **Imerman Angels** :: <http://imermanangels.org/>
 - Provides one-on-one mentorships and support for individuals affected by cancer
- **CancerCare: Young Adults** :: http://www.cancercare.org/tagged/young_adults
 - Offers phone counseling, online support groups and workshops for young adults affected by cancer
- **Cancer Hope Network** :: <http://www.cancerhopenetwork.org/>
 - Matches individuals with cancer and their caregivers with trained volunteer survivors
- **Spero** :: <http://speroforcancer.com/>
 - An app that connects people with cancer with others who have a similar diagnosis
- **Instapeer** :: <http://instapeer.org/>
 - An app that provides peer-matching for people with cancer who are of similar age and diagnosis
- **CaringBridge** :: <https://www.caringbridge.org/>
 - Provides an online platform to keep family and friends informed of healthcare updates

Financial Assistance and Scholarships, part I:

- **SAMFund :: <http://www.thesamfund.org/>**
 - Provides grants for 21-39 year olds post-treatment or on maintenance therapy and offers financial education webinars and toolkits
- **SAMFund and Triage Cancer – Finances 101 :: <https://cancerfinances.org/>**
 - Finances toolkit for young adults
- **DAM Cancer :: <http://www.dam-cancer.org/>**
 - Provides financial assistance to young adults (age 18-35) who have cancer
- **Cuck Fancer :: <http://cuckfancer.org/>**
 - Provides financial assistance to young adults (18-29) within five years of diagnosis
- **Allyson Whitney Foundation :: <http://allysonwhitney.org/>**
 - Provides grants to young adults (ages 15-36) currently undergoing or within 8 months of treatment of rare cancer
- **Hope for Young Adults with Cancer :: <http://www.hope4yawc.org/>**
 - Provides resources and funds for young adults (18-40) in or up to 5 years out of cancer treatment for everyday expenses. Also coordinates with Stupid Cancer for meetups
- **The Nicki Leach Foundation :: <http://www.nickileach.org/>**
 - Provides financial grants to young adults (18-30) in cancer treatment
- **The Simon Cancer Foundation :: <http://www.thescf.org/>**
 - Provides scholarship to cancer patients and survivors enrolled in a 4 year university or college

Financial Assistance and Scholarships, part II:

- **Patient Advocate Foundation** :: <http://www.patientadvocate.org/>
 - Provides co-pay assistance and scholarship program for survivors under age of 25 who have been diagnosed with or treated for cancer, a chronic or life-threatening disease within the past 5 years
- **My Hometown Heroes** :: <http://www.myhometownheroes.org/>
 - Provides college scholarships for young adult cancer survivors (17-39)
- **Cancer for College** :: <http://www.cancerforcollege.org/>
 - Provides college scholarships for those affected by cancer
- **Cancer Survivors' Fund** :: <http://www.cancersurvivorsfund.org/>
 - Awards four levels of scholarships to assist with college expenses for young cancer survivors. Provides financial assistance for prosthetic limbs as well
- **Sy's Fund** :: <http://sysfund.org/>
 - Provides funding for ages 18-39 in treatment or with a chronic condition designated for individuals to pursue creative passions and application of integrative therapies
- **Brian Morden Foundation** :: <http://www.brianmordenfoundation.org/scholarship.htm>
 - Awards a scholarship to student pursuing major in either music, technology, or medicine – cancer survivors given special consideration.
- **National Collegiate Cancer Foundation (NCCF)** :: <http://collegiatecancer.org/>
 - The General Scholarship Program supports young adult cancer survivors and current patients between 18-35 pursuing an associate, bachelor, master's, doctorate or certificate at an accredited college, university or vocational institute

Career and Legal Assistance Resources:

- ***Cancer and Careers*** :: <https://www.cancerandcareers.org/en>
 - Providing tools and resources for those working during and post cancer treatment
- ***Disability Rights Legal Center*** :: <http://drlcenter.org/>
 - Provides information and education about cancer-related legal issues to the public through its toll-free national telephone assistance line and webinars
- ***Patient Advocate Foundation*** :: <http://www.patientadvocate.org/>
 - Provides legal counseling regarding access to care, job retention, and medical debt for those with cancer

Fertility Support:

- **Fertile Action** :: <http://www.fertileaction.org/>
 - Educates those affected by cancer about fertility preservation options, offers peer support, and provides grants to reduce costs
- **Livestrong Fertility** :: <https://www.livestrong.org/we-can-help/fertility-services>
 - Provides gender and age specific fertility information for those affected by cancer as well as a discount program
- **MyOncoFertility** :: <http://www.myoncofertility.org/>
 - Educates patients and caregivers about cancer's impact on fertility and provides self-advocacy tips
- **Hope for Two** :: <http://www.hopefortwo.org/>
 - Provides resources and peer-to-peer mentorships for women pregnant while dealing with cancer diagnosis and treatment decisions

Camps, Retreats and Adventure Programs:

- **First Descents** :: <http://firstdescents.org/>
 - Free adventure trips for young adults (18-39) affected by cancer
- **True North Treks** :: <http://www.truenorthtreks.org/>
 - Offers wilderness treks for young adult survivors and caregivers
- **Athletes for Cancer** :: <http://www.athletes4cancer.org/>
 - Adventure trips for young adults affected by cancer
- **Send It Foundation** :: <https://www.senditfoundation.org/>
 - Provides outdoor adventures for young adult cancer fighters and survivors
- **Camp Mak-A-Dream** :: <http://www.campdream.org/>
 - Offers Montana-based retreats for children, teens, young adults and siblings of those affected by cancer
- **The Cassie Hines Shoe Foundation** :: <https://www.cassiehinesshoescancer.org/>
 - Provides a weekend-camp and social support for those who received cancer diagnosis between 16-30. Connects to other camps as well.
- **Camp Simcha** :: <http://www.campsimcha.org/>
 - Offers a free program to people between the ages of 6-20 in or out of treatment for cancer
- **Survive and Thrive Cancer Programs** :: <http://survivethrive.org/>
 - Offers adventure expeditions to young adults affected by cancer. **Cost associated with this program

Cancer Information:

- **American Cancer Society :: <https://www.cancer.org/>**
 - Cancer-specific information, resources and support
- **Journal of Adolescent and Young Adult Oncology :: <http://www.liebertpub.com/jayao>**
 - Latest research in the new AYA-oncology field – Not all articles are available to the public, but some are fully available at no cost
- **NCCN Guidelines for Patients: Caring for Adolescents and Young Adults :: <https://www.nccn.org/patients/guidelines/aya/index.html>**
 - Comprehensive guidelines for young adults diagnosed with and navigating cancer

Free Gifts and Services:

- **Brushes with Cancer** :: <http://twistoutcancer.org/brushes-with-cancer>
 - A program that matches artists with those touched by those touched by cancer to creatively portray their story
- **3 Little Birds 4 Life** :: <http://3littlebirds4life.org/>
 - Grants wishes to young adults ages 18-40 with any type of cancer at any stage
- **Wish Upon a Wedding** :: <http://wishuponawedding.org/>
 - Grants weddings or vow renewals for couples facing terminal illness or serious life-changing circumstances
- **Craig Willinger Fund** :: <http://cwfund.org/>
 - Grants trips to see soccer matches for teens and young adults (10-25) with a cancer diagnosis
- **Phil's Friends** :: <http://philsfriends.org/>
 - Sends care packages to individuals with cancer
- **Good Wishes** :: <http://www.goodwishesscarves.org/>
 - Provides one free scarf or wrap to anyone experiencing hair thinning or loss due to illness and/or treatment
- **The Why? Foundation** :: <http://www.thewhyfoundation.org/fighter-bags/>
 - Provides "fighter bags" with donated products to anyone with a cancer diagnosis on a first come first serve basis

AYA Books and Blogs:

- ***Terminally Illin'*** :: <http://www.cancercomicbook.com/>
 - Kaylin Andres artistically depicts her experience with cancer as a 23-year-old in this clever comic book
- ***Everything Changes: The Insider's Guide to Cancer in your 20's and 30's***
 - Kairol Rosenthal offers advice and stories from 25 young adults with cancer
- ***Blog: Texting with Cancer*** :: <http://www.textingwithcancer.com/>
 - Natalie Sun documents her breast cancer diagnosis at age 25 through an optimistic and pessimistic texting conversation
- ***Planet Cancer: The Frequently Bizarre Yet Always Informative Experiences and Thoughts of Your Fellow Natives***
 - Compilation of essays by young adults impacted by cancer. Planet Cancer is now a Livestrong initiative.
- ***The Courage Club: A Radical Guide for Audaciously Living Beyond Cancer***
 - Katie Campbell describes her own young adult cancer experience and presents ways in which she found meaning in life with cancer.