

Survivorship Resource Guide for Adolescents & Young Adults



Tufts Medical
Center

Who We Are

The **Reid R. Sacco Adolescent & Young Adult (AYA) Cancer Program at Tufts Medical Center** provides long-term follow up (also known as survivorship) care to AYAs (ages 18-39 years old) who have completed cancer treatment.

Our program aims to help you monitor and/or manage potential late-effects from treatment by providing you with a personalized Survivorship Care Plan (SCP). The SCP consists of a Treatment Summary and Long-Term Follow Up Care Plan.

In addition to clinical care, we understand the importance of addressing the far reaching impact of cancer and connecting with the AYA community. We hope you find this guide useful.

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Reid R. Sacco AYA Cancer Program



We hope you will use this guide to stay educated, empowered, and supported. It includes a curated list of resource links, advice, questions to ask, and a place for notes.



Resource links and advice are provided for informational purposes, and should not replace discussions with your care team. If you are having a medical emergency please contact 911 and/or your care team. Links provided were accurate as of April 2021. No endorsement is made herein. This guide is proprietary to the Reid R. Sacco Cancer Program at Tufts Medical Center (©2021).

Teen Cancer America



Support for the creation of this booklet was provided by Teen Cancer America (TCA). TCA partners with hospitals, including Tufts Medical Center, to ensure AYAs receive the age-appropriate care they deserve.

<https://teencanceramerica.org/>

Transitioning to Post-Treatment Life

If you are not yet a patient of the [Reid R. Sacco AYA Cancer Program](#), we invite you to schedule an introductory visit to receive a personalized Survivorship Care Plan and discuss your long-term health. Here are some tips other survivors have used in their post-treatment care:

BE ORGANIZED. Managing your post-treatment care, appointments, and insurance on top of work/school can be complicated. Focus on what works best for you to stay organized (e.g., a dedicated binder for paperwork or add appointment reminders in your phone).

ASK FOR HELP. For some, adjusting to life after treatment can be emotionally challenging. We encourage you to seek help from your care team, mental health provider, and family or friends if you are having a hard time.

WRITE THINGS DOWN. Keep notes to refer back to, or write questions down as they come to you. Bring these notes with you to your next appointment. We created a 'be-prepared-online toolkit' that can be downloaded. It includes a symptom log and health checklist: www.tuftsmedicalcenter.org/ayaresources

"The AYA Cancer Program Care Team helped me understand the long-term effects and care needed...The yearly checkups are sources of consistency and stability with my healthcare that make moving forward and maintaining a healthy lifestyle more manageable."

-Jack, currently 29 years old

Keep in Mind: Hospital Resources

Tufts Medical Center

- Ask your care team about the reiki program or connecting you with a social worker.

Tufts Children's Hospital

- Check with the child life specialist team for supportive care and/or a social worker.

"I've learned that life is short, and you cannot take anything for granted. I have also learned that you cannot control everything, and some things are not a choice in life, and that can be a hard pill to swallow. Cancer at 16 with a long treatment has impacted every day of my life since, and while it is such an important part of who I am, it does not define me. It is only part of my big life story."
-Lauren, diagnosed at age 16

Notes

Sexual Health - Fertility

Cancer treatment may impact your ability to have a biological child. Here are some resources to help start these conversations with your partner and doctors.

Embracing good sexual health is important for cancer survivors as well as their partners. We encourage speaking with your care team about sexual health concerns.

"I wish I had considered [fertility] seriously earlier than I did, and saved more money...be upfront early with your spouse about how your health history may impact your ability to have children."

-Lauren, diagnosed at age 16

Resource Links: Sexual Health

National Coalition for Sexual Health

Web:

<https://nationalcoalitionforsexualhealth.org/tools/communicating-to-the-public/sexual-health-quick-tips>

- Tips and action steps to good sexual health.

American Cancer Society: Fertility & Sexual Health

Web: <https://www.cancer.org/treatment/treatments-and-side-effects/physical-side-effects/fertility-and-sexual-side-effects>

- Includes information for single and partnered individuals, tips on managing sexual problems related to cancer, and questions people have had about cancer and sex.

Additional Resources: Fertility

Alliance for Fertility Preservation

Web: <https://www.allianceforfertilitypreservation.org/fertility-preservation/post-treatment-options>

Phone: 925-290-8950

- Read about: fertility testing; third party parenting; options if you had taken fertility preservation methods prior to starting treatment.

Livestrong Fertility Program

Web: <https://prod-io.livestrong.org/what-we-do/program/fertility>

Phone: 855-220-7777

- Find a fertility clinic in your area based on zip code.

Circle Surrogacy

Web: <https://www.circlesurrogacy.com>

Phone: 617439-9900

- Information on surrogacy as an option for starting a family

Questions to Ask

1. Is there a doctor I should see or test I can take to check my fertility?
2. Is pregnancy safe for me?

Notes

Costs - Insurance

Having the best insurance plan possible is especially important for cancer survivors for ongoing health care.

As your financial responsibility is directly impacted by your insurance plan, here are tools to help get you started in understanding your insurance plan:

Resource Links

Triage Cancer

Web: <https://tragecancer.org/animatedvideos>

Phone: 424-258-4628

- Webinars and short videos covering insurance-related topics, including understanding the basics, how to pick a plan, and options when losing insurance and managing bills.
- Toolkit for navigating cancer-related finances: <https://tragecancer.org/cancer-finances>

Patient Advocate Fund

Web: <https://www.patientadvocate.org/explore-our-resources/education-resource-library/>

Phone: 800-532-5274

- Information on topics such as finding health insurance, appeals, and explanation of benefits.

Keep in Mind: Hospital Resources

1. The Financial Coordination office (617-636-6013) provides financial counseling, as well as assistance with applying for insurance coverage or setting up a payment plan.
2. Social workers can connect you with resources to help offset costs, such as transportation vouchers.

Features to know about your plan:

- What is the annual deductible that you will have to pay before your insurance provider starts sharing more of the costs?
- What is your out-of-pocket maximum each year?
- What is your cost-share/co-insurance amount for specific cost of care (e.g., specialist visit, survivorship testing)?
- Do you have/need supplemental insurance?

Notes

Financial Grants

Here are some organizations that provide financial grants for a variety of needs. Make sure to carefully check the application period for each grant, as applications are usually only open for select periods during the year.

Resource Links

Aunt Bertha Findhelp.org

Web: <https://www.findhelp.org/>

- Aunt Bertha is a social care network that links people to organizations that may be able to help.
 - Type in your zip code and click on the *Money* icon for links to financial support opportunities.

The SAMFund

Web: <https://www.thesamfund.org>

- Financial assistance grants for survivors, currently ages 21-39, within 5 years post treatment. Recipients have used funds to help pay for medical bills and fertility treatments.

Keep in Mind: Hospital Resources

1. Your care team/social worker may be able to provide assistance with transportation costs.
2. There may be financial grants to help cover prescription costs that your care team can assist with.

Notes

School - Work

Even if you continued to attend school or work during treatment, you may benefit from additional support/adjustments. Before sharing your cancer experience, it is a good idea to think about what you wish to keep private versus what you may want or need to share. Knowing your legal rights may also help you determine what to share and with whom.

Below are some resources and strategies to help you seek accommodations:

Resource Links

Cancer and Careers

Web: <https://www.cancerandcareers.org/en>

Phone: 646-929-8032

- Information on: legal rights in the workplace; resume review services; tips on sharing the 'cancer' news at work.

Triage Cancer

Web: <https://trriagecancer.org/cancer-employment-work-rights>

Phone: 424-258-4628

- Fact sheets on topics such as returning to work and requesting reasonable accommodations.

Your School

- In addition to your professors, there are (disability, counseling, tutoring) offices that provide assistance.

Your Employer

- Check with human resources for reasonable accommodations (e.g., changes that help you do your job without causing significant hardship for your employer).

Questions to Ask

1. Ask your care team if you are having problems with concentration and memory: Would they recommend neuropsychological testing?
2. Ask your school/employer: Is there a formal process in place for requesting reasonable accommodations?
3. Ask yourself: Do you want to share your diagnosis with classmates/co-workers? This is a personal decision and not required!
4. Ask yourself: Have my career priorities changed?

"I started graduate school a few years after completing treatment as I wanted to pursue a new career that was more fulfilling to me."

–Rachel, diagnosed at 25 years old

Notes

Social Connections

The young adult cancer community is full of diverse individuals who share the complex experience of adjusting to life after a cancer diagnosis as an AYA. These non-profit organizations were founded by young adults and/or their family members to link patients/survivors with others who can relate to what you may be going through.

“It took [Stupid Cancer’s] Cancer Con conference to truly understand the unresolved emotions and fears that still lived inside me...knowing it’s there and that it’s normal for cancer survivors really helped to change my mindset.”

- Megan, currently 38 years old

Resource Links

Stupid Cancer

Web: <https://stupidcancer.org/>

- Meet members of the young adult cancer community via virtual meet-ups or their annual Cancer Con(ference). Webinars and links to other AYA resources.

Elephants & Tea

Web: <https://elephantsandtea.com/>

- “The elephant in the room is cancer. Tea is the relief conversation provides.” Stories written by the young adult cancer community. Perkatory, a digital, monthly meeting offers another way to meet others.

Additional Resources

Imerman Angels

Web: <https://imermanangels.org/>

Phone: 866-463-7626

- Get matched with or become a ‘cancer mentor’ to someone of similar age/cancer diagnosis.
- This service is available for you and/or your caregiver.

Cactus Cancer Society (formerly Lacuna Loft)

Web: <https://lacunaloft.org/cactus-cancer-society/>

- 100% online, this organization offers creative writing and art workshops, a blog, book club and a weekly e-newsletter.

I Had Cancer Blog

Web: <https://www.ihadcancer.com/survivorship>

- Posts written by other cancer survivors on range of topics related to survivorship.

Notes

Wellness Activities

These organizations focus on wellness through group physical activity with programs offered online and (planned for late 2021) in person. They are dedicated to 18-39 year olds, with a consideration of a wide range of physical abilities in mind, and some programs also open to caregivers.

Resource Links

Dear Jack Foundation

Web: <https://www.dearjackfoundation.org/breatheseries21/>

- Online (on demand/live): The Breathe Series includes free yoga, meditation and breath work classes.

First Descents

Web: <https://firstdescents.org/programs/>

Phone: 303-945-2490

- Rock climbing and other outdoor adventures. Regional programs are currently planned for 2021. Participation is free on the first trip.

True North Treks

Web: <https://www.truenorthtreks.org/>

- Online: Mindfulness meditation classes throughout the year.
- Backpacking and canoeing treks. Trips in 2021 are currently planned. There is no cost upfront. Pay it forward to help the next participant.

Project Koru

Web: <https://www.projectkoru.org/>

- Surf or snow week-long adventures. Participants pay for travel, camp is free. Currently offering online virtual programming.

Questions to Ask

1. Ask your care team: Would I be 'medically approved' to participate in this activity? You will likely be asked to obtain a signed release from your care team in order to participate.
2. Ask yourself: Am I physically and emotionally ready to participate in this type of activity? These trips can be taken at a later time.

“Participating in outdoor adventure and wellness programs healed the parts of me that my doctors couldn’t. Rediscovering my body’s strength and reigniting my excitement for life while connecting with others my age who understood exactly what I was going through, gave me the support I needed to move forward.”

–Sara, diagnosed at 36 years old

Notes
