

Resource Guide for Adolescents & Young Adults with Cancer



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.

While we know that you are in excellent hands with your current care team, we also know that having cancer as a young adult is a unique and difficult experience. This guide contains resources dedicated to improving the AYA cancer experience.

We hope you find this guide useful and hope to hear from you if we can provide supportive assistance during this time.

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Reid R. Sacco AYA Cancer Program



We hope you will use this guide to stay educated, empowered, and supported through your cancer care experience. 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 March 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/>

Tips for Treatment

Your care team has likely discussed potential side effects that result from cancer treatment. We encourage you to share your concerns as they arise so the care team can recommend interventions or make referrals to other specialists. Here are some suggestions from other young adult patients of strategies that they found useful during their treatment experience:

ADVOCATE FOR YOURSELF. This could mean asking for clarification if you don't understand a procedure, submitting an insurance appeal (p.7) or requesting work accommodations (p.11).

BRING A COMPANION. Have a 'second pair of ears' to help you remember the details of what was discussed at appointments. A companion can also provide support and help make long days at the hospital less stressful.

BE ORGANIZED. Managing your 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. Going through treatment can be hard, it is okay to ask for help from your care team, mental health provider, family and friends.

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

"Wear something comfortable that is easy to remove for blood draws or IVs."

-Rachel, diagnosed at 25 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.

Questions to Ask

1. Is there a clinical trial that I could be a part of?
2. Who should I call if I have a question or concern between appointments?
3. How will the potential side effects impact my daily life/ability to work/socialize?
4. Are there things I shouldn't do during treatment?

"If you're going through or about to start chemo, put a peppermint candy in your mouth...it diminishes the salty saline taste."

-Jack, currently 29 years old

Notes

Fertility - Sexual Health

Now is the time to discuss how cancer treatment could potentially impact your fertility (ability to have a baby in the future). Whether you see yourself having a biological child in future or not, it is important to understand your options for fertility preservation. We also encourage speaking with your care team about sexual health concerns. If you're worried about these conversations, please use this guide to help get you started.

Resource Links

Alliance for Fertility Preservation

Web: <https://www.allianceforfertilitypreservation.org/index.htm>

Phone: 925-290-8950

- Overview of options
- Patient stories

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
- Reproductive information and financial support

Save My Fertility (the Oncofertility Consortium)

Web: <https://www.savemyfertility.org/pocket-guides/patients>

Phone: 866-708-3378

- Pocket guides: What to ask your doctor and overview of options

Questions to Ask

1. Will the cancer or treatment affect my fertility?
2. Is there anything I can do to preserve fertility before treatment starts (e.g., female egg preservation; male sperm banking)?
3. If I take steps to preserve my fertility now, will this impact the effectiveness of my treatment?
4. Females only: Will my menstrual period be affected by cancer treatment? If so, for how long? Could I go into early menopause?
5. Can I have sex (or get pregnant) while receiving treatment for cancer?

“Fertility was the farthest thing from my mind at that moment. But, I wish I had asked more about impact on fertility, and egg preservation/freezing, [especially], as I arrive at a time to have children.”
-Lauren, diagnosed at age 16

Notes

Costs - Insurance

Cancer care can be expensive. If you have concerns about the cost of treatment don't hesitate to bring this up to your care team.

Your financial responsibility is directly impacted by your insurance plan. Therefore, having the best plan possible and understanding what it covers is very important!

Features to know about your insurance 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 for in-network care?
- What is your cost-share/co-insurance amount for specific cost of care (e.g., specialist visit, blood work, scan)?
- Do you have/need supplemental insurance?

Resource Links

Triage Cancer

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

Phone: 424-258-4628

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

Patient Advocate Fund

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

Phone: 800-532-5274

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.

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

Family Reach

Web: <https://familyreach.org/ftp/>

Phone: 857-233-2764

- In addition to providing grants, this Boston-based organization has a 'Financial Guidebook for Young Adults with Cancer' and offers a Financial Treatment Program to help overcome 'financial side effects.'

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.

Dear Jack Foundation

Web: <https://www.dearjackfoundation.org/life-list/>

- LifeList: A wish-grant program that aims to create positive experiences to individuals undergoing treatment.

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

Cancer treatment may impact your ability to attend school or complete your work tasks in the ways you were previously able to. Below are some resources and strategies to help you seek accommodations (additional support/adjustments).

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://tragecancer.org/cancer-employment-work-rights>

Phone: 424-258-4628

- Fact sheets, webinars and videos on: tips for working through treatment; employment rights; family and medical leave act (FMLA).

Your School

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

Your Employer

- Check with human resources for time off/leave policies, employee assistance program, and disability paperwork.

Questions to Ask

1. Ask yourself: Do you need to consider a leave from school/work? Are you able to do this?
2. Ask yourself: Do you want to share your diagnosis with classmates/co-workers? This is a personal decision and not required!
3. Ask your care team: Will cancer treatment impact my ability to attend school/work?
4. Ask your school/employer: Is there a formal process in place for requesting reasonable accommodations?
5. Ask your school/employer: Can I take a medical leave of absence? (If you take a leave of absence from your job, make sure to ask if this will have insurance coverage implications).

“You have to do what is best for you. That might be taking time off school and focusing on treatment. But it could also be keeping yourself mentally engaged by continuing your studies.”

–Maria, diagnosed at 26 years old

Notes

Social Connections

The young adult cancer community is full of diverse individuals who share the complex experience of going through cancer as an AYA. These non-profits 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.

“Let yourself grieve. This is a big change. It often feels like a loss of the best part of your life. Don’t give up hope...One thing I didn’t do, but now wish I had, was to find a community of people my age who totally understood what I was going through.”

- 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 a ‘cancer mentor,’ 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 weekly e-newsletter.

“For me, talking to others who have experienced the hard thing you are going through is really helpful and makes you not feel so alone...A healthy mix of humor and sarcasm worked great for me.”

-Lauren, diagnosed at age 16

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 are available year round.
- Build connection with nature, your peers and yourself through backpacking and canoeing treks. Trips in 2021 are currently planned. No cost upfront, pay it forward to help the next participant.

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/post treatment.

“I finally met kindred spirits—other young adult cancer survivors who knew what it was like to face your mortality so young. I felt so comfortable with them. Nothing I said would freak them out or make them uncomfortable. We could air our frustrations without guilt. We tend to only focus on the physical toll of cancer, but it’s just as important to heal the emotional toll.”

–Maria, diagnosed at 26 years old

Notes
