



Resource guide for adolescents & young adults with cancer



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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 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 2023. No endorsement is made herein. This guide is proprietary to the Reid R. Sacco Cancer Program at Tufts Medical Center (©2023).

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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.

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.4) or requesting work accommodations (p.6).

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 (p.10).

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: tuftsmedicalcenter.org/ayaresources

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

— Rachel

Keep in mind: hospital resources

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

Questions to Ask

1. Is there a clinical trial that I could be a part of?
2. What is the best way to reach you 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

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 starts sharing in the payment of bills?
- What is your out-of-pocket maximum each year?
- What is your cost-share/co-insurance amount for specific services (e.g., specialist visit, lab work, scan)?
- Do you have/need supplemental insurance?

Resource links

Triage Cancer

triacancer.org/cancer-health-insurance-finances-cost

T 424.258.4628

- Guides, webinars and short videos covering insurance-related topics. Topics include an explanation of health insurance basics, instructions on picking a plan, options if you have lost your insurance at work, and managing bills.
- Toolkit for navigating cancer-related finances: triacancer.org/cancer-finances

Patient Advocate Fund

education.patientadvocate.org

T 800.532.5274

- Information on topics such as finding and selecting a health insurance plan, insurance appeals and denial training, and how to understand your explanation of benefits document.

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 may only be open for select periods during the year.

Resource links

Family Reach

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

T 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

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

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:

Resource links

Cancer and careers

cancerandcareers.org/en

T 646.929.8032

- Information on your legal rights in the workplace, resume review services, as well as tips on sharing the ‘cancer news’ at work.

Triage Cancer

triagecancer.org/work-and-cancer

T 424.258.4628

- Fact sheets, webinars and videos on tips for working through treatment, employment rights, as well as the 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

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

Resource links

Stupid Cancer

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

elephantsandtea.com/

- “The elephant in the room is cancer. Tea is the relief conversation provides.”
- Stories written by the young adult cancer community.
- Ongoing virtual events page provides links to book clubs, social meet ups, yoga classes and much more.

Additional resources

Imerman Angels

imermanangels.org/

T 866.463.7626

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

Cactus Cancer Society (formerly Lacuna Loft)

cactuscancer.org

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

Notes

Wellness activities

These organizations focus on wellness through group physical activity. They are dedicated to 18–39 year olds (and sometimes through early 40s), and take into consideration the wide range of physical abilities of participants. Some programs are also open to caregivers.

Resource links

First Descents

firstdescents.org/programs/

Phone: 303.945.2490

- Rock climbing and other outdoor adventures are planned. Age eligibility is from 18–45 years old. Participation is free on the first trip.

True North Treks

truenorthtreks.org/

- Online: Mindfulness meditation classes are available year round.
- Build connection with nature, your peers and yourself through backpacking and kayaking/canoeing treks. 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

Notes

Sexual health & Fertility

Now is the time to discuss how cancer treatment could potentially impact your fertility (ability to have a biological child in the future). It is important to understand your options for fertility preservation. We also encourage you to speak with your care team about sexual health concerns.

If you're worried about these conversations, please use this guide to help get you started.

"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

Resource links

Alliance for Fertility Preservation

allianceforfertilitypreservation.org/fertility-preservation/post-treatment-options

- Overview of options to protect or preserve your reproductive potential, with patient stories.
- Information on insurance coverage and financial assistance programs.

Livestrong Fertility Program

prod-io.livestrong.org/what-we-do/program/fertility

T 855.220.7777

- Find a fertility clinic in your area, based on zip code.
- Reproductive information and financial support.

Questions to ask

1. Will the cancer or treatment affect my fertility?
2. Is there anything I can do to preserve my fertility before treatment starts (e.g., egg preservation; sperm banking)?
3. If I take steps to preserve my fertility now, will this impact the effectiveness of my treatment?
4. If applicable, 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

Notes _____

Mental health

Your emotional well-being, including managing stress and the psychological impact of cancer is an important part of cancer care. Remember, you are not alone.

Ask for help

Psychological trauma resulting from a cancer diagnosis and treatment has been well documented in the medical literature, especially in young adults.

To help you work through any new or ongoing concerns, there are licensed and trained individuals who can help, such as:

- A **social worker** provides counseling, therapy, and can help with problem solving. Some social workers have their own private practice, while some work within the hospital setting.
- A **psychologist** works with people who may have short-term or chronic illness; they can treat mental, emotional, and behavioral conditions.
- A **psychiatrist** is a clinician who can diagnosis mental health conditions, and if mutually agreed upon, can prescribe medication.

Find the help you need

Finding a therapist can be challenging. It may require motivation and persistence to reach out for help and schedule an appointment. It may also be challenging to find someone whom you feel comfortable with, don't give up!

Tips for finding a therapist include:

- Talk to your Primary Care Provider (PCP). They may suggest coping strategies or recommend a therapist.
- If you're comfortable, ask friends or family who may have a therapist to recommend.
- Log into your insurance provider's website or call the number on the back of your insurance card to find a therapist within your insurance network.

Actions you can take

Making small changes in your daily activities can have a positive ripple effect in improving how you feel. Here are some actions you can take:

- Connect with a family member, friend, co-worker, or peer in the AYA community (see the Social Connections page)
- Enhance your bedtime routine to make sleep a priority
- Get outside in the sunshine (but don't forget to wear sunscreen)
- Find a creative outlet: Draw, Write, Dance, Sing, Cook
- Listen or participate in webinars about stress management and mental health. Many organizations mentioned in this guide (e.g., Triage Cancer, Stupid Cancer) host events on these topics throughout the year.

Notes

Nutrition & Physical activity

A healthy lifestyle combined with a good diet can help you maintain a healthy weight and ensure that you are providing your body with vital nutrients. While you can't control the potential toxicity of treatments you receive, diet and physical activity are modifiable lifestyle factors that can help mitigate late-term treatment effects, in addition to improving your mood. Just keep in mind that changing your palate, dietary habits, and physical stamina may take time.

See the below links for some resources and ideas to get you started on your own wellness journey.

Resource links

American Institute for Cancer Research

aicr.org/

T 800.843.8114

- Information on the importance of a nutritious diet and a healthy lifestyle: Diet tips; food facts; healthy recipes.
- Research on the anti-cancer properties of specific foods and nutrients with tips on how to read a nutrition label.

Triage Cancer

triagecancer.org/cancer-exercise-nutrition

T 424.258.4628

- Webinars on cancer, exercise, and nutrition to help you sort out fact from fiction.
- Other information includes research and tips for cancer prevention and survivorship.

Additional resources

YMCA and Livestrong at the YMCA

livestrong.org/ymca-search

- Check out your local YMCA for in-person or virtual classes.
- Learn more about the Livestrong at the YMCA program. Livestrong assists those living with, through, and beyond cancer to regain strength and connect with other survivors.

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