



Survivorship resource guide for adolescents & young adults



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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.

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.

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 March 2023. No endorsement is made herein. This guide is proprietary to the Reid R. Sacco AYA 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



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

Keep in mind: hospital resources

Ask your care team about the reiki program or connecting you with 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

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

trinecancer.org/animatedvideos

T 424.258.4628

- 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: <https://trinecancer.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.

Features to know about your 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, tests)?
- 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

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 Expect Miracles Foundation/SAMFund

expectmiraclesfoundation.org/samfund

T 617.938.3484

Financial assistance grants for survivors, currently ages 21–39 when application is submitted. Recipients have used funds to help pay for medical bills, rent/mortgage supplementation and fertility treatments.

- Applications open twice a year. See website for verification.

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.

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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

cancerandcareers.org/en

T 646.929.8032

- Resume review services, as well as information on your legal rights in the workplace and protecting your online image.

Triage Cancer

tragecancer.org/cancer-employment-work-rights

T 424.258.4628

- Fact sheets on topics related to returning to work, such as 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***

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

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 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.

I Had Cancer Blog

ihadcancer.com/survivorship

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

Notes

Wellness activities

These organizations focus on wellness through group physical activity. They are dedicated to 18–39 year olds, 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.
- Backpacking and kayaking canoeing treks are planned. There is no cost upfront. Pay it forward to help the next participant.

Project Koru

projectkoru.org/

- Surf or snow week-long adventures. Participants pay for travel, camp is free.

Ulman Foundation

ulmanfoundation.org/cancerto5k/

- Starting in March, a 12-week run/walk training program takes place in Boston offering a chance to get in better physical shape with other members and supporters of the AYA cancer community.

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

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

Resource links: sexual health

National Coalition for Sexual Health

nationalcoalitionforsexualhealth.org/tools/communicating-to-the-public

- Tips and action steps to address common sexual concerns, with tips for talking to a health care provider or therapist.

American Cancer Society: Fertility & Sexual Health

cancer.org/treatment/treatments-and-side-effects/physical-side-effects/fertility-and-sexual-side-effects

- Information on managing sexual problems, with suggested questions to ask your care team about sexual problems or side effects related to treatment.

Resource links: fertility

Alliance for Fertility Preservation

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

T 925.290.8950

- Read about post treatment fertility options including fertility testing, using previously stored eggs/sperm, and third party parenting (use of donated eggs, sperm, or embryos).

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.

Circle Surrogacy

circlesurrogacy.com

T 617.439.9900

- 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

Mental health

Your emotional well-being, including managing stress and the psychological impact of cancer is an important a part of survivorship 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.

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
- 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 received, 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 post-treatment.

Resource links

American Institute for Cancer Research

aacr.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.

Helpful websites, apps and books for weight loss

tuftsmedicalcenter.org/patient-care-services/Departments-and-Services/Weight-and-Wellness-Center/Patient-Resources/Helpful-Websites-Applications-and-Books

- Recommendations from Tufts Weight and Wellness Center. Includes links to resources to track calories & exercise as well as online support groups.

Additional resources

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.

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, though, and beyond cancer to regain strength and connect with other survivors.

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