



ADOLESCENTS AND YOUNG ADULTS AFFECTED BY CANCER: MEETING THE CHALLENGE

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Note: This handout is offered as a communication aid for patients and their providers. It is not a substitute for professional examination, diagnosis, or treatment.

This material aims to shed light on the challenges faced by the Adolescent and Young Adult (AYA) person affected by cancer and how to access resources specific to AYA challenges and navigation of the AYA cancer journey. LGBTQ+ AYA cancer journey navigation sources are included.

INTRODUCTION

Youth holds the promises of your dreams in learning, friends, career, and family. There is an organic sense of invincibility as an adolescent and young adult (AYA).

Cancer diagnosis, treatment, and the issues that might follow you into survivorship can seem like they turn your plans and your body upside down.

You may find yourself cancer-free or in remission, yet dealing with a lot of issues in treatment and survivorship that seem gargantuan to wrap your head around:

- possibly dealing with early menopause
- finding yourself unable to biologically father children
- living in a body older than that of your peers with osteoporosis of your bones from treatment, requiring caution with certain activities
- Your guts and kidneys may not work like they do for other people your age.

On the psychosocial side of things, you may find yourself dealing with:

- the financial toxicity of treatment
- social isolation

pg. 1

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- emotional and mental distress

On the sexual intimacy and dating side of things, you may find yourself dealing with:

- inability to have erections
- inability to enjoy vaginal penetration
- figuring out how to approach dating

Your cancer care team, which has worked so hard with you on beating cancer and become a significant source of support. You may find they fall away as you enter remission or the cancer-free zone.

There are a lot of milestones your peers are meeting that you may find challenged by your cancer and survivorship to meet:

- starting a career
- finishing college
- finding a romantic partner
- independence from your parents

This is A LOT.

There is help.

Finding people who share your experience and the available resources through Adolescent and Young Adult (AYA) Cancer Support organizations and groups can be a lifesaver.

SOURCES OF SOLID, REAL-LIFE ALIGNED HELP

Sources of AYA support organizations and groups can make a huge impact. Once you reach out, they make engaging with them easy. If you find you don't like one, find another.

Avoid going this alone.

Many organizations have the mission of supporting AYA people affected by cancer through the snags and barriers you never even dreamed of encountering as a young person.

[Elephants and Tea](#) is an online magazine published every three months. It is packed full of stories of young people who have shared these challenges and outline how they got help with real-life aligned organizations and other sources of support, friends with the shared experience.

[Young Adult Survivors United](#) (YASU) provides interactive, engaging, and relevant virtual cancer support activities nationwide.

pg. 2

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[Stupid Cancer](#) (scroll to the bottom of the page) and [Elephants and Tea](#) have pages full of organizations that offer various types of support to the AYA population, including:

- individual counseling
- support groups
- social activities
- outdoor adventures
- financial assistance
- legal aid
- dating
- fertility preservation and available alternative information

Consider researching online for local AYA cancer support organizations close to your home. This may enable you to connect with AYA Cancer peers more often in person.

The [National Cancer Institute](#) has a list of Adolescent and Young Adult support groups and organizations.

[CancerCare.org](#) and the [National Cancer Institute](#) have exceptional resources for adolescents and young adults. They contain guidance, well-explained paths forward, and easily accessed resources to help you navigate your journey.

These groups often offer separate forums for their younger and older members.

These sources offer insight and resources for:

- Coping with your cancer diagnosis, treatment, and journey
- Mental health considerations
- Connecting with other AYA people who are also on the cancer journey
- Fertility discussion and preservation
- Sexual health issues relative to AYA population needs
- LGBTQ+ considerations
- Dating scene insights
- Relationship navigation
- Health and well-being issues
- Career and school considerations
- Financial resources

pg. 3

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- Many other considerations and steps
- A plethora of other supports for the AYA cancer population

NAVIGATING THE DATING SCENE

The dating scene is challenging enough without having to bring cancer into the equation.

Start with [small steps](#) to help you build self-confidence and strengthen social skills. Some ways to enter a friendly social environment are activity or hobby clubs, a cancer support group, cancer support organization activities, making plans with friends, or going to a gym. Support groups have people with the shared experience of fighting cancer and can be incredibly valuable for safe social experiences and support through your unique challenges.

Once you do meet someone who is a potential date, your cancer diagnosis may feel like the proverbial elephant in the room.

MD Anderson Cancer Center Social Worker Jill Bassar recommends [avoiding surprises](#) by sharing your cancer diagnosis early in the relationship. Bassar advises not to get discouraged if the other person decides they are not interested in a relationship; it is better to understand this sooner than later.

Your cancer experience is not an easy subject to broach.

- Consider writing down talking points about how you want to share your cancer diagnosis.
- Maybe [practice with a friend](#) or family member and ask for their feedback.
- Stay true to yourself and your experience.

Find or create a relaxed and casual time with your romantic interest to bring up your experience. Being honest about your physical and emotional challenges may bring you closer together, suggests Bassar. If you have [physical alterations](#), such as an ostomy or scars, talk honestly about how these make you feel and its role in fighting your cancer.

Let the other person know you are willing to answer any questions and listen as they share a challenge they have experienced themselves.

APPROACHING SEXUAL INTIMACY

Cancer and its treatment are known to affect sexual health.

Note: If you are currently being treated, use condoms, female condoms, and dental dams to avoid your intimate partner having repeated exposure to your bodily fluids which may contain traces of your treatment agent.

Avoid unintended pregnancy while being treated with the use of birth control recommended by your treatment team.

As a young adult, you may find yourself dealing with vaginal dryness, an ostomy, an inability, or limited ability to have an erection.

These are issues you expect much older people to be experiencing, not you.

There is help.

Elephants and Tea publication has several excellent informational articles about sexual concerns, challenges, and solutions:

[The brain is the biggest sex organ](#)

[Emotional Intimacy](#)

[Erections and orgasms](#) (part 1 of a three-part series)

[Erections and orgasms](#) (part 2 of a three-part series)

[Erections and orgasms](#) (part 3 of a three-part series)

[Infertility and Dating](#)

[Orgasms](#) (part 1 of a two-part series)

[Orgasms](#) (part 2 of a two-part series)

[Self-advocacy in the bedroom](#)

[Vaginal pain with penetration](#)

[Various types of sexual health providers](#) (you can get help)

And many more (type “sexuality” in the search bar of the *Elephants and Tea* webpage)

FERTILITY PRESERVATION AND ALTERNATIVES TO FERTILITY

Cancer treatments affect fertility.

Treatment may affect eggs, the sperm, the ability to be a biological parent, or the ability to ejaculate.

Each situation is unique to the person:

- their belief system
- the individual treatment effects
- financial resources for fertility preservation
- the amount of time treatment may be delayed for fertility preservation

Sperm can be affected by chemotherapy for up to 2 years after treatment.

Discuss this important issue with your cancer care team.

pg. 5

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LONG TERM RELATIONSHIPS

Cancer and the treatment affect the dynamics of long-term relationships.

You are both different people after the diagnosis and treatment. Your dynamic may have gibe from romantic partner to caregiver and patient. It can be hard to go back to romantic partner.

It is OK to mourn what was.

To help preserve the relationship, work together to resolve the issues you each identify. Avoid placing blame. Consider journaling your thoughts to help you articulate them in a compassionate, respectful, and warm way.

After Cancer has several patient education handouts to address the topics that intersect with this issue, depending on your individual situation.

Couples therapy and or sex therapy may be helpful.

HANDLE WITH CARE

Your sexual self, body image, identity, and self-image are at a critical stage of development. Your cancer diagnosis, treatment, and the possible effects continuing into survivorship can throw roadblocks into this development.

It is imperative that you pay attention to your mental health, self-image, body image, and social relationships. It is critical that you surround yourself with support and engage in activities you enjoy.

Your body image may also be affected by your cancer or cancer treatment. Inward-facing scars of changes in self-perception can be as devastating as outward scarring. This body image alteration is magnified for you.

AYA people diagnosed with cancer have the highest risk of suicide of any cancer survivor group.

The Suicide-Crisis Lifeline: 988 text, call, chat

This means you need to pay attention to how you are doing. Strongly consider reaching out to an AYA cancer support organization.

An AYA-specific support group and organization can provide support specific to your AYA needs.

The risk of suicide can be reduced through:

- Timely symptom management through prompt reporting of symptoms and speaking up when symptoms are not well-managed
- Practicing self-care with exercise, good sleep habits, eating well, taking care of your appearance, reaching out, accepting help.
- Being honest with your healthcare providers when you are feeling down for more than a few weeks
- Reaching to support organizations and cancer institute social workers to locate resources to alleviate financial strain
- Accepting help to alleviate stressors and strains

pg. 6

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- Engaging with cancer support groups for the uplifting support of the shared experience
- Getting referred to counseling through cancer support organizations and your healthcare team

LGBTQ+ CONSIDERATIONS

For young members of the LGBTQ+ community who are affected by cancer, there are challenges of social isolation, and finding providers who are LGBTQ+ friendly and LGBTQ+ support groups can make a profoundly positive difference.

- [National LGBT Cancer Network](#) provides a wide spectrum of resources, provider information, and access to support groups.
- [Young Adult Survivors United](#) has an LGBTQ+ virtual support chat, which meets monthly.
- Elephants and Tea uses non-gender-biased language and addresses LGBTQ+ issues in many of their articles.

For young members of the LGBTQ+ community who are affected by cancer, there are often greater challenges of social isolation. Finding providers who are LGBTQ+ friendly and LGBTQ+ support groups can make a profoundly positive difference.

TAKE CHARGE

With determination, click on the provided resources and empower yourself on your unique journey.

Look up local AYA cancer support organizations to connect in person with others on the journey and discover their available resources.

Love yourself.

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