

YOUNG ADULT AND TEEN CANCER POCKET GUIDE

Coping with cancer between 15 and 39

FAST FACTS

- In 2020, there were approximately 89,500 new cases of cancer among people aged 15–39.¹
- Teens and young adults are more likely to be diagnosed at later cancer stages than older people. Reasons include not having insurance, not having routine tests to look for cancer, and being younger than the age when most people develop cancer.

WHEN TEENS AND YOUNG ADULTS HAVE CANCER

For the most part, cancer happens in older adults. According to the American Cancer Society, only about one in 20 people with cancer is a young adult aged 20–39.² The broader category called “adolescents and young adults” includes people who are diagnosed with cancer between the ages of 15 and 39. So, if you feel like you wandered into the wrong waiting room at your oncologist’s office, you’re right—most people with cancer are older. Help and support are available, but you may need to look for it. This pocket guide and the tools that go with it are designed to help you do just that.

THE BEST CARE STARTS WITH YOUR QUESTIONS AND NEEDS

Health-care providers and researchers know that adolescents and young adults, or AYAs, face unique challenges. These are mostly related to dealing with a disease during the life stages where you would normally focus on building your adult life through school or training, work, relationships, and family.

Jennifer Bires, MSW, LICSW, OSW-C, is a certified oncology social worker who specializes in working with adolescents and young adults. She is executive director of life with cancer and patient experience for the Inova Schar Cancer Institute in the Washington, D.C., metropolitan area. She suggests each person ask the following questions of their health-care providers:

- How will treatment impact my ability to work or go to school?
- What side effects should I expect, and how will they impact my quality of life?
- Will any of the treatments I am being prescribed impact my fertility?
- How can I reduce the risk of long-term side effects from treatment?

It can be hard to find information about prognosis since so few people are diagnosed as young adults, which may mean the statistics you can find online represent a group of patients who are typically diagnosed at a later stage in life. If this information is important to you, don’t be afraid to ask your doctor for more information or help in understanding how the statistics you can find in the literature might apply or not apply to your situation.

Other questions that might be on your mind:

■ How will my parents, siblings, boyfriend, girlfriend, or spouse cope? What about my young children?

■ How can I relate to staff and other patients at the hospital or cancer clinic? If my cancer is common in children, I might be seeing a pediatric cancer specialist (pediatric hematologists/oncologists). If it is more common in older adults, I could be the youngest person in the waiting room. Where is my peer group?

■ Should I choose a doctor who specializes in my cancer/cancer subtype?

■ How can I reduce the risk of long-term side effects from treatment?

■ How will cancer and treatment affect my ability to find a partner and have children (if desired)?

“It’s important to bring up topics that are important to you, otherwise your treatment team may not know they are on your mind,” says Bires.

You may want to reread the list above and place a check mark by any questions you have. Then feel free to share them with your health-care provider or a social worker on your cancer care team.

Integrative health solutions for AYA challenges

Feeling isolated

No matter where you are in life—a college athlete, pregnant mom, or a young professional—all face the challenge of isolation in dealing with cancer. Cancer can put you out of sync with the people around you. Friends, neighbours, and co-workers don't understand the fear, fatigue, and hours of appointments. And because of their ages and differing life stage, they probably know few other people your age with cancer. Who can you talk to?

Social connection is the solution for this AYA cancer challenge. You can:

- Ask your health-care team to refer you to a support group for people your age.
- Join an online group, search a hashtag on social media that relates to your cancer (i.e., #BreastCancer) or visit a website specifically for younger people with cancer. See the Resources section below for a list of organizations.
- If you don't have online access, talk with a social worker on your health care team. They can help you find resources for equipment, Wi-Fi connections, or in-person support.

Want to engage your friends but don't know how to start the conversation?

- Consider writing a journal online or creating a blog that outlines your cancer journey. You can simply share a link without having to verbally tell people how you are and where you are in treatment again and again.
- Identify needs such as meals, help with housework, and other areas where friends and family can help. Appoint a close friend to communicate these areas of need with your social circle.

Read our blog post [How Emotional Connections Can Help You Heal](#).

Planning your family

Bires says cancer specialists may not bring up the fact that for adolescents and young adults, cancer treatment could affect their ability to have children in the future. "They may not feel comfortable talking about it, there may not be time to do anything because treatment needs to start right now, or finances may be a concern," says Bires.

However, simply talking about cancer treatment's effects on future fertility can be reassuring, even if no practical steps (like banking sperm or freezing eggs) are possible. Asking specific questions about your fertility can help you get the information you need to know what's ahead. You can ask:

- Will my cancer treatment affect my ability to have children?
- I want the option of having children later. How can we protect my body during treatment or preserve eggs, ovarian tissue, or sperm for the future?
- How much does it cost to freeze eggs, ovarian tissue, or sperm? Who can help me learn more about these procedures, costs, and timing?
- What are my options if biological children are not possible?

Jenny Leyh, a breast cancer survivor who was diagnosed in 2016 while pregnant with her daughter, worried about the health of her baby and wondered how treatment may affect her ability to have more children once treatment ended.

"The diagnosis alone was terrifying, but I also worried that the treatment would make me infertile," said Leyh, who was 33 years old at the time of diagnosis. "My doctors brushed it off, saying 'you're young, there's no reason to think your body won't bounce back.' But the fact is many women go into early menopause after treatment for breast cancer. I was lucky that I was able to naturally conceive another baby a few years after cancer treatment ended, but not everyone has this experience. I wish my doctors had listened to my concerns and included a fertility specialist in my care team. Because of the aggressive nature of my cancer (triple negative breast cancer) treatment could not wait, and there wasn't time to discuss options, and that just added to an already high level of stress."

Dealing with sex and relationships

The book and movie *The Fault in Our Stars* include physical intimacy between two teens with cancer. Having sex, marrying, and having children are important emotional and physical milestones that many teens and young adults with cancer worry about missing. Depending on your beliefs and wishes, this can be a worry or regret.

You may also wonder, "Who will ever want to be with me if I have these scars, look like this after treatment, or have a permanent medical device attached to my body (such as a colostomy bag)?" Education and talking with peers can both help. You will likely be surprised at how many people live active lives and meet new partners even when they have colostomies and scars. We created a free, downloadable [Cancer and Sexuality Pocket Guide](#) to point you to educational resources and options for supporting this important part of your body, mind, and spirit.

Risky behavior

Having a life-threatening illness can lead to risky behavior, especially for teens. The desire to escape reality can also lead to overuse of alcohol and other substances—but some of these can cause severe side effects when taken with cancer medications.

Acknowledging that you might want to take physical risks or use substances is important. So is asking, "Why?" An organization like [First Descents](#) or [Epic Experience](#) can help you find adventures

and activities that boost your mood and provide excitement and meet other young adults with cancer with fewer negative consequences.

Talk with your health-care team about whether drinking alcohol or using marijuana or other substances is safe and how much. “There’s ‘completely unsafe, not recommended, but safer, and possibly safe,’” says Bires. Having the information can help you make better choices.

Insurance

Teens and young adults are often without the same insurance coverage as older or younger people with cancer. Before the Patient Protection and Affordable Care Act was passed in 2010, as many as 1 in 3 young adults with cancer did not have health insurance coverage.³ The age range of 15 to 39 includes people who still use a parent’s insurance coverage, those who may not have coverage through a job or spouse, and those with job- or school-related insurance that can change if the job ends or they graduate.

Looking at all your potential sources of health insurance coverage can be helpful. Also, talk to your health-care team. Most hospitals and clinics have financial counselors who can work with you to meet the cost of care even if you have a high-deductible insurance plan or need to apply for state insurance coverage. They can also connect you with many discount programs from drug manufacturers.

Work

Can you work when you have cancer? Will you keep your job during treatment? Having cancer can affect your job prospects and earnings for many years.⁴ If possible, plan what to do ahead of time. Options include:

- Using long-term disability insurance.
- Staying with a friend or family member.
- Applying for Social Security disability income if you cannot work.
- Simply taking time off, if you have financial support from someone in your household.

Being a survivor

When you start cancer treatment, you may be concerned with possible health issues that may arise later in life due to effects of chemotherapy, surgery, or radiation. Survivors of adolescent and young adult cancer can face “late effects” including:

- Reduced ability to have children.
- Health problems, including later cancers and problems caused by cancer treatment, such as heart problems from radiation therapy.
- Hormone problems.
- Nerve damage.

Ask your health-care team about what late effects your cancer and its treatment can cause. It’s never too early to say you want a “survivorship” plan, with appointments, tests, and preventive medicine in order to thrive after cancer.

Resources

Most of these resources are free or low-cost.

- [Camp Kesem](#) – Support for children of cancer survivors during and beyond cancer treatment.
- [Colontown](#) – An online community for people living with colon or rectal (colorectal) cancer, their caregivers, friends, and family members. Apply to join.
- [Dana-Farber Cancer Institute Websites for Young Adults with Cancer](#) – Links to many websites, including support for college students with cancer, career support, information on fertility, and more.
- [For the Breast of Us](#) – For women of color diagnosed with breast cancer, many of whom are younger than age 40.
- [Stupid Cancer](#) – *Welcome to the club you didn’t ask to join.* Many types of support, from groups to how to be your own advocate and more. Specifically for teens and young adults.
- [Teen Cancer America Resources](#) – From financial and educational help to wigs and outdoor adventures, Teen Cancer America provides a huge list of organizations offering support.
- [Young Survival Coalition](#) – For young adults facing breast cancer, with many resources, workshops, and opportunities to connect with fellow survivors and thrivers.

Fertility Support

Looking for an onco-fertility specialist in your area? The [OncoFertility Consortium](#) includes a search option on their website where you can locate specialists in your state.

For the AYA cancer patient, this fund specifically addresses that population: <http://www.thesamfund.org/get-to-know-us/about-us/>

More Pocket Guides and Tools

- [The Pocket Guide to Nutrition and Cancer](#)
- [The Pocket Guide to Movement and Cancer](#)
- [An Integrative Approach to Your Reproductive Health](#)
- [Your Healing Journey: A Patient Guide to Integrative Breast Cancer Care](#)
- [Your Healing Journey: A Patient Guide to Optimal Healing Environments](#)
- [How Healing Works: Get Well and Stay Well Using Your Hidden Power to Heal](#) [book] by Dr. Wayne Jonas

