

Coping With Cancer as a Young Adult

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Coping With Cancer as a Young Adult

The CancerCare Connect® Booklet Series offers up-to-date, easy-to-read information on the latest treatments, managing side effects and coping with cancer.

Founded in 1944, CancerCare® is the leading national organization providing free, professional support services and information to help people manage the emotional, practical and financial challenges of cancer. Our comprehensive services include case management, counseling and support groups over the phone, online and in person, educational workshops, publications and financial and co-payment assistance. All CancerCare services are provided by master's-prepared oncology social workers and world-leading cancer experts.

CancerCare relies on the generosity of supporters to provide our services completely free of charge to anyone facing a cancer diagnosis. If you have found this resource helpful and wish to donate, please do so online at www.cancercare.org/donate. You may also mail a check, payable to CancerCare, to CancerCare, Attn: Donations, 275 Seventh Avenue, New York, NY 10001.

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CancerCare®
National Office
275 Seventh Avenue
New York, NY 10001

Toll-free 800-813-HOPE (4673)
Fax 212-712-8495
Email info@cancercare.org
Web www.cancercare.org

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TABLE OF CONTENTS

Introduction	2
Managing Your Treatment	3
Insurance Matters	6
Find Financial Help	8
School and Work: Adjusting Your Schedule	10
Cancer's Impact on Relationships	12
CancerCare Can Help	15
Frequently Asked Questions	18
Resources	21

EDITOR

Marlee Kiel, MSW, LCSW

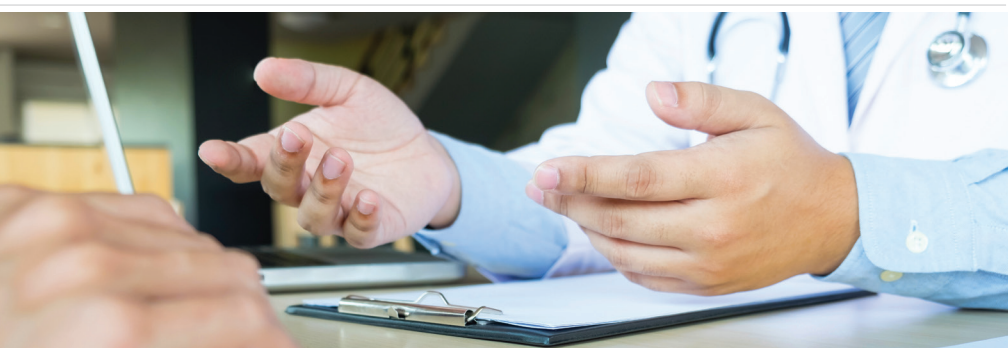
Young Adult Program Manager, CancerCare

Young adults coping with cancer face challenges that are unique from other age populations.

A cancer diagnosis is most often unexpected. This is especially true for young adults in their twenties or thirties. At this age, it's normal to feel invincible and to believe that serious illnesses like cancer can happen only to older people. Also, young adults are often misdiagnosed due to the misconception that cancer is an "older person's disease."

Young adulthood is a time when most people are focused on their education, career, dating and starting a family. However, as a young adult with cancer, you may feel as if your life has been upended. New concerns may arise such as where to get the best medical care or how to pay for treatment-related expenses.

While there may be an adjustment period where you may delay goals related to your life plan, a cancer diagnosis does not have to keep you from living a full life. This booklet offers helpful guidance and support for how to cope with many of the changes, challenges and adjustments related to cancer, along with places to find support.



Managing Your Treatment

After hearing the words "You have cancer," you may feel scared and overwhelmed. Learning as much as you can about your diagnosis may help you feel more in control. The relationship you have with your medical team can also make a huge difference in helping you cope in a positive way.

Here are some tips for managing your treatment and communicating with your health care team:

Get informed. The members of your health care team can provide accurate information about your diagnosis and treatment options along with referrals to valuable resources. Ask them to recommend reliable websites, organizations, books or brochures that describe your diagnosis and your treatment. However, there is such a thing as too much information. Avoid using Google to inform treatment decisions; each individual will respond differently to treatment even with the same diagnosis. While credible information can help you feel more in control, too much information has the potential to cause anxiety.

The resources listed in the back of this booklet are also excellent sources of information. If you feel overwhelmed with the amount of research you need to do, ask a friend or a family member for help.

Prepare for your medical appointments. If you have questions about your care, you may find it helpful to write down your questions in advance. Prioritize them so that the most important questions are answered first. Write down your doctor's answers or bring someone with you to take notes or serve as a second set of ears. If having someone attend appointments with you is

not an option, ask if you are able to record the conversation using your cell phone. With the technology available, many young adults find it helpful to process the information at a later time or listen to the information again with a friend or a family member. Remember, you can also ask for copies of your medical records.

Don't be afraid to ask questions. If you are unsure what something means, let your doctor know. Make your questions specific and brief. Use “I” statements whenever possible—saying “I do not understand” is more effective than “You are being unclear.” Try repeating the information back to your doctor to make sure you understand what they are saying. If you are a visual learner, ask to see the X-rays or slides. Remember, this is your medical team and they are here for support, education and guidance. Sometimes it may feel as if you do not have enough time with your doctor or oncologist. It is okay to advocate for your needs as a patient. Read CancerCare’s fact sheet titled “The Value of Assertiveness When Talking to Your Doctor” for more tips.

Bring up fertility concerns. Cancer treatments can have a variety of long-term and short-term side effects on a person’s ability to conceive or carry a child to term. Discuss fertility concerns with your doctor before, during and after treatment. If your medical team has not addressed your concerns, be a self-advocate and continue to ask questions about possible side effects of treatment. If family planning is a priority, make sure your health care team understands this. Your health care team may refer you to a fertility preservation specialist so that you can explore options such as sperm or egg harvesting (storing for later use). Some of these options are costly and few are covered by insurance at this time, but financial assistance programs are available for those who qualify. For comprehensive information about fertility preservation, contact LIVESTRONG Fertility (www.fertilehope.org)

or The OncoFertility Consortium (www.savemyfertility.org). You can also read CancerCare’s fact sheet titled “Coping With Fertility Concerns: Finding Resources and Support” for more information.

Discuss what treatment plan is best for you. Your lifestyle and daily activities may influence treatment recommendations. Talk with your health care team about treatment goals and your preferences about treatment. For example, find out if treatment will interfere with your ability to continue working or going to school. If you have an important event coming up, ask if you can reschedule an appointment or round of treatment so you can attend. Scheduling adjustments may not always be possible, but you won’t know unless you ask.

Be your own advocate. Because you know yourself and your needs better than anyone, you are in the best position to talk with your health care team about any issues. You may have to take the lead in bringing up certain topics, such as fertility preservation or how much your treatment will cost. Do not hesitate to bring up any concerns so that you get the help you need. Read CancerCare’s fact sheet titled “Doctor, Can We Talk?: Tips for Communicating With Your Health Care Team” for more information.



Insurance Matters

Whether you are the primary insured or on another person's insurance policy, talk to your insurance company about any concerns that you may have. Many companies will assign a case manager to help you clarify benefits and suggest ways to get other health services. You can also ask for help from an insurance broker or from the human resources staff at your workplace. CancerCare's professional oncology social workers can also help you navigate the world of insurance policies and paperwork.

COBRA. If you recently left a job and were covered by an employer's health insurance, you may be eligible to continue receiving insurance coverage under COBRA (the Consolidated Omnibus Budget Reconciliation Act). COBRA requires employers to make health insurance under their plan available to former employees up to 18 months after employment has ended. For more information, visit the website for the U.S. Department of Labor (www.dol.gov).

Disputing a claim. If you feel you have been denied a claim even though you are entitled to coverage, HealthCare.gov has a helpful guide on how to dispute claims with your insurer, along with other helpful information. Also, consider arranging a meeting with someone from the hospital's financial office or billing department. You may be able to work out a monthly payment plan or get a reduced rate.

Organizing Your Health Information

After a cancer diagnosis, it's normal to feel overwhelmed trying to keep track of medical appointments, test results and treatment information. Keeping records together in one binder or accordion folder can help you stay organized and feel in control of your care. Retain a copy of every document you receive from your health care team, as well as every bill, statement and payment you receive or make.

Information you may want to collect:

- A contact list of your medical providers
- Dates of appointments and any discussion notes
- Medications you are taking
- Bills and billing inquiries
- Insurance provider information
- Copies of medical records

Some centers that provide reduced-cost health care, such as Hill-Burton facilities, administer care for free or on a sliding scale based on your income. These facilities are available in most states. To find a Hill-Burton facility near you, call 800-638-0742 or visit the website of the U.S. Department of Health and Human Services (hhs.gov). Uninsured young adults may also be eligible to receive financial help for medical expenses through Medicaid. Read CancerCare's fact sheet titled "Coping with Cancer When You're Uninsured" for more information.

Find Financial Help

A cancer diagnosis can magnify any financial burdens you are already facing. Fortunately, there are many financial assistance programs that help young adults affected by cancer. Talk to your health care team about your financial needs and referrals to resources.

Financial help for young adults with cancer exists in the forms of:

- Insurance reimbursement
- Co-payment relief
- Discounted or free medications
- Grants to cover practical costs such as child care and transportation to and from treatment
- Educational grants and scholarships

Visit CancerCare's website (www.cancercare.org) and read our fact sheet "Sources of Financial Assistance" to learn more about finding financial resources.

Another resource is CancerCare's Online Helping Hand at www.cancercare.org/helpinghand. This is a searchable, online database of financial and practical assistance available to people with cancer. This comprehensive online tool features up-to-date contact information and descriptions for hundreds of national and regional organizations offering financial help to people with cancer.

Tips for Taking Control of Your Finances

When you or a loved one has received a cancer diagnosis, money may be the last thing you want to think about, but taking control of your finances from the start may be the best way to prevent a crisis later on.

Get a handle on your income and expenses. Figure out how much money is coming into your household, how much you spend and what you spend it on. Do you have money saved for an emergency? Do you have assets (a home, other property, a retirement plan, life insurance) that you can use to obtain cash?

Stay on top of medical bills. The consequences of medical debt are staggering and unfortunately all too common. Medical debt can be a major burden and a source of continuing stress for many living with cancer. If you find yourself behind on paying medical bills, there are resources that can help. View the Resource Section on page 23 of this booklet.

Get help. Oncology social workers are licensed professionals who counsel people affected by cancer, providing emotional support and helping people access practical assistance.

School and Work:

Adjusting Your Schedule

A cancer diagnosis as a young adult may require making adjustments to educational or career-related goals. Young adults with cancer are often able to continue with work or school by modifying their routines and schedules. Your teachers and co-workers may prove to be excellent sources of guidance and support should you choose to disclose your diagnosis.

Before returning to school, make an appointment with your school's office of student affairs to discuss the transition back to student life. The office's administrators can refer you to the appropriate health and financial resources, as well as discuss your school's health services and student health insurance policy. Consider meeting with the staff in your student health center to make them aware of your medical history.

Many young adults are able to return to the workplace during or after treatment. However, some may need to limit the number of hours they work per week or choose to leave their job entirely. Tell your doctor about your typical workday, along with your treatment history, to help form a recommendation on whether you can return to work.

The Americans with Disabilities Act (ADA) helps protect the civil rights of people with a disability, which includes facing a cancer diagnosis. Talk to your supervisor or your human resources department and discuss accommodations that may help ease your transition, including a flexible work schedule or a re-evaluation of your job's responsibilities and duties. Read CancerCare's fact sheet titled "Cancer and the Workplace" for more information on laws that protect patients.



Cancer's Impact on Relationships

A cancer diagnosis can be isolating, especially for this age group. You may feel that your diagnosis is yours alone to cope with, and perhaps feel the need to withdraw from others. This is normal; however, finding your support network is important. Allowing open communication with family, friends and loved ones may help you feel more supported in the long-term.

Parents. After a cancer diagnosis, young adults who have previously lived on their own sometimes choose to move back into their parents' home temporarily. While this may feel like you are giving up your independence, remember that it is temporary. You will want to make sure that your emotional, practical and financial needs are being met during this time period. Be honest about your need for privacy and share your feelings and emotions with your parents. You may find them to be a strong source of emotional and practical support.

Siblings. Watching a brother or sister face a cancer diagnosis is difficult for siblings of any age. They may want to help you in practical ways such as providing transportation to and from treatment or helping with household tasks. Encourage your siblings to talk openly with you. Let them know that they can support you by just taking the time to listen. Spend time together talking about subjects other than cancer.

Friends. Oftentimes, you will find that friends and peers will not know how to respond to the news of your cancer diagnosis. While this may feel discouraging, do not be afraid to take the lead in reaching out to them. Be honest about what you need and what you feel like discussing. If your friends want to help, ask them to help you in specific ways such as running errands,

providing transportation or preparing meals. Although some friendships may change during this time in your life, focus on the friends who are able to listen to you and support you.

Spouses and partners. Most young adults do not expect their spouse or significant other to be diagnosed with cancer. The thought and fear of losing a loved one can be overwhelming. Sometimes this fear can drive an emotional wedge between partners and negatively affect communication. It is important for each of you to talk openly and honestly about your thoughts, feelings and fears. Remember, you do not need to always talk about cancer. Discussing day-to-day topics can help bring back a sense of normalcy to your lives. If you find yourself needing further support, CancerCare can help by offering individual case management and counseling to patients and to caregivers.



Talking to Your Children

Young adults who have children may be concerned about how much information they should share with them about their diagnosis. Parents often do not want to share information as a way to protect their children from worrying; however, speaking honestly with your children can help them to feel safe and secure.

Give your children accurate, age-appropriate information.

Explain your treatment plan and how it may affect your lives. Encourage your children to share their feelings, even those that are uncomfortable. You may also want to speak with an oncology social worker about support groups or events for children who have a parent diagnosed with cancer. More tips for communicating with your children can be found in CancerCare's booklet titled "Talking to Children When a Loved One Has Cancer."

Intimacy in relationships. The way you feel about your sexuality may change as a result of your cancer. There are side effects to treatment and surgeries that may cause a decrease in self-esteem and sexual libido. Discussing sexuality with your partner may feel uncomfortable at first, but it can lead to a greater sense of emotional intimacy. Be honest about your feelings and encourage your partner to be open about their feelings as well. Communication will become increasingly important as your relationship grows. Read CancerCare's fact sheet titled "Intimacy During and After Cancer Treatment" for more information.

CancerCare Can Help

Receiving a diagnosis of cancer can be very difficult as young adult, and adjusting to the necessary changes in your life can be challenging.

CancerCare can help. We are a national nonprofit organization providing free, professional services to anyone affected by cancer. Our licensed oncology social workers can provide support and education, help in navigating the complicated health care system and provide information on support groups and other resources.

To learn more about how CancerCare helps, call us at 800-813-HOPE (4673) or visit www.cancercare.org.

You will likely also build your own personal support network, composed of family and friends. In doing so, it's best to take some time to think about the people in your life and how they are best suited to help. Match the task to their strengths—ask a family member who loves to shop to pick up something for you at the store; ask a friend who's a good listener to come over for a chat.



The Value of Oncology Social Workers

Oncology social workers are professionals who counsel people affected by cancer, providing emotional support and helping people access practical assistance.

Oncology social workers can provide individual case management and counseling, facilitate support groups, locate services that help with home care or transportation and guide people through the process of applying for Social Security disability or other forms of assistance.

Seek individual counseling with a professional. You may feel that the diagnosis is yours alone to cope with, and perhaps feel the need to withdraw from others. Oncology social workers, psychologists and psychiatrists can help you sort through complex emotions. CancerCare provides free individual case management and counseling to people with cancer and caregivers across the country.

Join a support group. Support groups provide a safe environment where members can relate to each other through a shared, similar experience. Joining a support group can help decrease isolation and emotional distress. In addition, support groups can also be sources of valuable information and resources. Not surprisingly, members find that sharing resources and coping skills can be highly rewarding, whether on the giving or the receiving end of support. CancerCare provides free, professionally led support groups over the telephone, online and face-to-face in New York City, Long Island and New Jersey.



Frequently Asked Questions

Q: My diagnosis was so sudden and serious that I did not have time to undergo fertility preservation before beginning treatment. Is it too late for me to ever have a child?

A: A cancer diagnosis can sometimes leave little time to consider long-term implications of treatment. Ultimately, the options for conceiving after cancer depend very much on your type of cancer and its treatment. Speak to your oncologist and a fertility expert to find out what options may be available for you. Generally, most oncologists recommend that women wait a minimum of six months after cancer treatment has ended before trying to get pregnant and that men wait two years after finishing cancer treatment. Visit www.fertilehope.org or read CancerCare's fact sheet titled "Coping With Fertility Concerns: Finding Resources and Support" for more information.

Q: I am continuing to work while receiving chemotherapy. I am still able to do my job, but I often feel extremely tired from side effects. I don't want to be let go from this job. Should I tell my supervisor about my fatigue?

A: The Americans with Disabilities Act (ADA) prohibits employers from discriminating against people who have been diagnosed with cancer. You are not required to share your experience with your supervisor or any of your co-workers unless you are requesting accommodations that will allow you to do your job. Work with your supervisor to create a work schedule that suits your needs. Your supervisor may allow you to reduce your work hours or allow you to work from home so that you won't experience increased fatigue from your commute. You may also explore being temporarily reassigned to a new position that is less taxing for you.

Q: I have been working with my oncologist for about a month now, but I still do not feel comfortable with them. Am I allowed to ask to see a different oncologist?

A: It is important to feel comfortable with your health care team and satisfied with your care. Do not hesitate to ask any member of your health care team to recommend a different physician. You can contact your insurance provider to find another oncologist in your community under your insurance plan. You might also ask others for recommendations or contact diagnosis-specific foundations.





Resources

General Cancer Organizations

CancerCare

800-813-HOPE (4673)
www.cancercare.org

American Cancer Society

800-227-2345
www.cancer.org

Cancer and Careers

www.cancerandcareers.org

Cancer Support Community

888-793-9355
www.cancersupportcommunity.org

LIVESTRONG

877-236-8820
www.livestrong.org

National Cancer Institute

800-422-6237
www.cancer.gov

National Coalition for Cancer Survivorship

877-622-7937
www.canceradvocacy.org

Young Adult Resources

CancerCare's

Young Adult Services
800-813-HOPE (4673)

Camp Mak-A-Dream

406-549-5987
www.campdream.org

Fertile Action

877-276-5951
www.fertileaction.org

First Descents

303-945-2490
www.firstdescents.org

LIVESTRONG Fertility

855-220-7777
www.fertilehope.org

The Samfund

617-938-3484
www.thesamfund.org

Stupid Cancer

877-735-4673
www.stupidcancer.org

Ulman Cancer Fund

888-393-3863
www.ulmanfund.org

Young Survival Coalition

877-972-1011
www.youngsurvival.org

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