



# Young Adult Toolkit

Information and resources for 15 to 39-year-olds with cancer



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# About the AYA Toolkit

The AYA (adolescent and young adult) Toolkit is a collection of helpful information for AYA patients and their families. Some information is specific to City of Hope, like the resources listed at the end of every chapter. However, much of the information is more general and relatable for any young adult at any stage of cancer treatment. At the end of the toolkit is a long list of community resources organized by subject. We encourage you to spend some time reading each chapter and utilize any resources that might benefit you!

Sincerely,



City of Hope's Adolescent and Young Adult Team aya@coh.org



City of Hope's Adolescent and Young Adult Team

# Important Phone Numbers

Appointments	800-826-HOPE (4673)
To Schedule, Change or Confirm a Medical and/or	Lab Appointment:
Appointment Line	
Billing Questions:	
Questions About Your City of Hope Medical Center	er Bill800-270-HOPE (4673)
Questions About Your Medical Bill (Medical Group	o)
Blood Donor Center Appointments	
Case Management	
Clinical Social Work	
Diagnostic Radiology	
Doctorand as	Please dial 626-256-HOPE sk the operator for your doctor's office.
Two Guest Service Desks:	
City of Hope Helford Clinical Research Hospital	
Main Medical	
Medical Records (Health Information Management Service	es)626-218-2446
Nursing Triage Call Center	
Patient Advocate	
Patient Financial Counseling	(Ask at any appointment registration desk. This is based on your doctor.)
Sheri & Les Biller Patient and Family Resource Cen	ter626-218-2273
Spiritual Care Services	
Pharmacy	
Positive Image Center <sup>SM</sup>	
Positive Image Center Satellite (near the Women's Ce	nter)626-218-9105
Radiation Treatment	
Surgery Waiting Room	
Tram Escort and Security Services	

### Having Cancer as a Young Adult

About 90,000 adolescents and young adults (ages 15 to 39) are diagnosed with cancer each year in the United States. The challenges of cancer are different for AYAs because your age group has specific needs. You're in a distinct developmental phase that includes a lot of important changes and social milestones (like school, dating, college or career choices, starting a family, etc.) It is typical for AYAs to feel invincible and believe that serious illnesses happen only to older people; the reality is that most people your age are likely to be healthy. Your healthy peers' concerns and problems may seem far less serious and important than your own. Many AYAs are frustrated by the sudden lack of control and change that a cancer diagnosis can bring, especially since there may be a lot of change you're already facing.

Here are some things you can do to help yourself cope while you are being treated for cancer and once treatment has ended:

**Learn.** Obtain reliable information about your diagnosis and treatment from your medical team. One important example: Ask about the impact that treatment may have on your fertility. See the "Fertility" section on page 18 for additional information. Knowledge is a source of power and can help you feel more in control. Some helpful resources to have on your team may include doctors, nurses, social workers, patient navigators and insurance case managers. See the "Communication" section on page 6 for helpful questions to ask your medical team and more.

**Care for yourself.** Whether you listen to calming music, do yoga or simply spend time with friends, caring for yourself is important in maintaining good health. Cancer is a part of your life, but having a sense of normalcy is helpful, too. Think about what gave you joy prior to your diagnosis, and find ways to do those things in your new routine. Do pleasant activities and doctor-approved exercise as much as possible, too. Information about caring for yourself is incorporated into many sections of this toolkit, but the sections about "Symptom Management," on page 10 and "Coping With Psychological Stress" on page 25 may be particularly helpful.



**Reach out to family and friends.** Your family and friends are part of your support team, but they may need more information about cancer to help them understand what you're going through. The educational tools and websites you turn to for information can also help those closest to you. Keep in mind that others may have different reactions and views about cancer than you do, but education and communication are important starting places to get the support you may need. Check out the section called "Cancer's Impact on Relationships," on page 13, for more insight about sharing all of this with your loved ones.

**Keep in mind that schedule changes are temporary.** Sometimes cancer treatments change your normal work or school schedules. Some people are able to shift their daily routines by working or going to school part time. Others may think about short-term disability or taking a leave from school. Talking with health care professionals can also help you find a treatment schedule that meets your individual needs and works around prior commitments. Find out what options may work for you and, if needed, meet with any professionals who may be able to help, such as a social worker, financial counselor, etc. The "Managing Work, School or Home Life" section in this toolkit, on page 28, is a good starting point as well.

**Seek professional support.** Joining a support group offers a place for you to compare your experiences and solutions with other young adults. One-onone counseling gives you the chance to talk about how cancer may affect dating, career goals and life priorities. Some organizations offer networking events and workshops that bring you together with peers in a similar situation. Many of these services are now easy to access over the phone and online. More information is provided in the next section, "Connecting With Peers," on page 5, and the "Coping With Psychological Stress" section on page 25.



# **Connecting With Peers**

Feeling alone and lonely is common for adolescent and young adult (AYA) cancer patients and survivors. This isolation can be physical as well as emotional. Because cancer is relatively rare in teens and young adults, you may not meet many (if any) patients your age in hospitals and doctors' offices. There's often some separation from peers because many facilities have pediatric and adult services, with some AYA patients in either. Treatment may also mean that you stay at the hospital, sometimes far from home, which keeps you away from normal social activities.

Emotional isolation can result from being unable to spend time with your friends and missing school, work and important milestones, such as graduations, transition to college or the workforce, dating, parenting, etc. To keep things feeling normal, you might not tell others about your cancer experience, adding to the sense of isolation. AYAs with cancer can have changes in the body and appearance that can make you feel different from your peers. You may feel like you can't relate to your friends like you used to. At the same time, your friends may not know how to ask you about your experience, or may not know what to say when you talk about it.

For these reasons, it can be incredibly helpful to connect with peers who share the cancer experience. You're not alone! You aren't the only one having a hard time or learning how to cope, and sometimes it helps to hear that what you're feeling is normal.

### Resources for Peer Support at City of Hope

#### City of Hope AYA Instagram and Facebook page

Follow us on Instagram @COH\_AYA where we post resources and social events. "Like" our Facebook to get updates about on-campus programs and social events, community announcements or interesting articles at **facebook.com/cohayaoncology**.

#### ConnectU at City of Hope

ConnectU is our AYA peer support program. Once you're enrolled, you'll be paired with another patient, and you can talk to this same-age peer about life during or post-treatment. Email **aya@coh.org** for more info or to start the enrollment process.

#### "Empowering Young Adults" psychoeducational group at City of Hope

This eight-week class is run two to three times each year by the Division of Psychology.

#### The AYA section of the Sheri and Les Biller Patient & Family Resource Center

There is a section of the Biller Patient and Family Resource Center that is dedicated to AYA information and resources, including upcoming events and groups at City of Hope. Check it out for upcoming opportunities for peer interaction!

# Communication

How well you and your health care team communicate is one of the most important ways of getting good health care. Unfortunately, talking to your medical provider isn't always easy. It takes time and effort on both parts. Good communication improves the quality of care that you receive and it consists of giving information as well as getting information.

- Giving good information means sharing honest and accurate information about yourself regarding matters that affect your care.
- Getting information requires active listening and asking questions.
- Have a clear idea about what you want to know and how much you want to know about your treatment.
- Everyone likes to receive and process information differently. It is important for you to understand how you like to receive information. It's also important for you to share that with your health care team so that they can tailor the information given to you.



### Communication Tips

#### Be assertive when you need to be.

If you don't know ... ASK. If you don't understand ... ASK. If you're not sure ... ASK.

- 2 Keep asking until you understand the answer.
- **Repeat back what you think you heard.** This gives you and your health care provider the chance to make sure you understand what is going on and what to expect.
- 4 Make sure you understand what you need to do. This includes follow-up appointments, labs and tests, treatments to follow, forms to turn in, medication instructions, procedures and more.

- Make a list of your questions before each appointment. Write down your questions so you don't forget them. (You can also keep a notepad with you at all times so you can write down questions as you think of them during the day.) Bring your list of questions with you to all your appointments and tell your provider at the start of the appointment that you have questions. Many patients find it helpful to say something like, "I have a few questions for you today. Please let me know when it's a good time to ask them."
- 6 **Bring someone with you to your appointment.** This person can help you take notes, remember and understand what your medical provider says, and talk with you after the appointment is over.
- 7 Take notes and make sure every question is answered in a way that you can understand. You can write them down or ask your medical provider if it is OK to record the conversation. Later, you can review your notes and remember what was said.
- 8 Have a clear idea about how much you want to know. Some people want to learn all that they can, others only want a little information at a time. It is also important to tell your medical provider how you like to receive information and when you have heard enough the choice is yours.
- **9** Find out how to contact your medical team if you have problems or have further questions. This includes when to call, who to call and where to go.

Ask for additional resources for information, education and support. You might want printed information about your type of cancer and treatment, or you may want to attend classes, workshops or support groups. Ask about what is available at City of Hope and in the community. The Sheri & Les Biller Patient and Family Resource Center offers resources for information, education and support for patients and caregivers. The center is located near the entrance to the Main Medical building, or you can call at **626-218-2273**.

### Common Questions to Ask Your Health Care Provider

About My Cancer	<ul> <li>What kind of cancer do I have?</li> </ul>
About Chemotherapy	<ul> <li>Why do I need chemotherapy?</li> <li>Are there other ways to treat my type of cancer?</li> <li>What is the goal of this chemotherapy?</li> <li>What are the benefits and the risks of chemotherapy?</li> <li>How is my type of cancer usually treated?</li> <li>Are there any clinical trials for my type of cancer?</li> </ul>
About My Treatment	<ul> <li>How many cycles of chemotherapy will I get?</li> <li>How long is each treatment? How long between treatments?</li> <li>What types of chemotherapy will I get?</li> <li>How will these drugs be given?</li> <li>Where do I go for this treatment?</li> <li>How long does each treatment last?</li> <li>Should someone drive me to and from treatments?</li> </ul>
About Side Effects	<ul> <li>What side effects can I expect right away?</li> <li>What side effects can I expect later?</li> <li>How serious are these side effects?</li> <li>How long will these side effects last?</li> <li>Will all the side effects go away when treatment is over?</li> <li>What can I do to manage or ease these side effects?</li> <li>What can my doctor or nurse do to manage or ease these side effects?</li> </ul>
Who to Contact if Problems Occur	<ul> <li>When should I call my doctor or nurse about these side effects?</li> <li>Who should I call?</li> </ul>
More Information	<ul> <li>Where can I get more information?</li> <li>— National Cancer Institute cancer.gov</li> <li>— American Cancer Society cancer.org</li> <li>— Cancer Care cancercare.org</li> </ul>

*Reference: Tips for meeting with your doctor or nurse. Chemotherapy and you. National Cancer Institute at* **cancer.gov/cancertopics/coping/chemotherapy-and-you** 

### Communication Tips for Caregivers: How Can I Be Supportive?

#### Feel free to share this section with your caregiver!

Going with the patient to medical visits is an important part of your role as a caregiver. Being ready for a medical visit helps you and the patient get the most out of the appointment and get the information you need, which may also ease your stress.

Sometimes, patients diagnosed with cancer find it hard to ask for help or even talk about the disease. When this happens, you may feel frustrated not knowing how the patient is doing, if they are having trouble or what they may need. Here are some tips to help improve communication and show you care for someone diagnosed with cancer:

- Be a good listener. Sometimes, all a patient needs is someone to simply listen to him or her.
- Be comfortable with the patient's silence. Silence gives space for the patient to think deeply without interruption. This may help the patient express their thoughts and feelings more easily.
- Never underestimate the power of a warm and loving touch. A touch may communicate more than words can say.
- Talk to the patient about topics other than cancer. This can help a patient feel more normal and make cancer seem less overwhelming.
- At times, patients may find it hard to feel positive. Sadness, anger and fear are normal emotional reactions to cancer. You can encourage your loved one to share how he or she is feeling, even if it seems negative.
- Instead of saying, "Let me know if you need help," be specific with the help you can offer. Patients may not know how to ask for help or what help is available for them. Being specific with the help you can give sends a message that you are interested and genuine with your offer. Some suggestions for helping may include cooking a meal, picking up some groceries, giving a ride to and/or from appointments, helping with household chores or caring for the patient's child(ren).
- Keep visiting, and stay in touch. People with cancer can feel very lonely and isolated. Just being there can be comforting and reassuring.

Adapted from the American Cancer Society and Cancer Care

# Symptom Management

Symptoms and side effects of cancer treatment can range significantly based on cancer type and treatment course. Sometimes it is hard to know if symptoms are from cancer treatments or from the cancer itself. Either way, remember that there are ways to help you deal with these symptoms. Always make sure to tell your medical team about your symptoms, and let them know how the symptoms are impacting you.

#### Common physical symptoms and ways to manage them

#### FATIGUE

- Get plenty of rest (eight hours at night and one to two short naps during the day).
- Be active when you're awake, but also try not to overdo it.
- Ask for help when you need it.
- Keep a diary or record of your symptoms, including fatigue. This will help you better communicate your symptoms with your health care team.
- Eat a well-balanced diet. Refer to the Food Safety Guidelines at the end of the toolkit for recommendations.
- Meditation, yoga, guided imagery and prayer are other ways to be mindful and focused.

#### **APPETITE CHANGES**

- Eat five to six small meals per day.
- Set a schedule.
- Drink high calorie shakes or smoothies.
- Use plastic forks or spoons to help with any changes in taste. (Some people become sensitive to metal due to tastebud changes related to treatment.)
- Increase your activity level, if you can.
- Change your routine by eating in new places (like a picnic in the park or in your backyard).

#### CONSTIPATION

- Drink eight cups of water or other liquids throughout the day.
- Be active.
- Eat foods high in fiber (whole grains, raw vegetables, beans, nuts, seeds, dried fruit).
- Take fiber supplements and stool softeners.
- Keep a diary or record of symptoms.

#### DIARRHEA

- Eat five to six small meals per day.
- Drink eight to 12 cups of clear liquids per day.
- Eat food low in fiber.
- Stay away from:
  - Very hot or cold drinks
  - Alcohol
  - Milk or milk products
  - Spicy foods
  - Greasy and fried foods
  - Drinks with caffeine
- Keep a diary or record of symptoms.

#### MOUTH AND THROAT CHANGES

- Clean your mouth, teeth, gums and tongue.
  - Brush after each meal and at bedtime.
  - Use toothettes if brushing is too painful.
  - Don't use mouthwashes that have alcohol.
  - Gently floss.
- Eat foods easy to chew and swallow.
- Soften foods with gravy, broth or yogurt.
- Eat foods at room temperature.
- Suck on ice chips or popsicles.

#### NAUSEA AND VOMITING

- Eat a bland diet.
- Plan when it is best to eat or drink based on when your symptoms tend to be less intense.
- Eat small meals and snacks.
- Avoid foods with strong smells.
- Stay calm and relaxed before treatment (you can utilize deep breathing, distraction, acupuncture and more).
- Take nausea medications as prescribed and when needed.
- Keep a diary or record of symptoms.

#### PAIN

- Keep a diary or record about the details of your pain its location, type, what makes it worse/better, whether or not medications help.
- Talk with friends and family about your pain so they can help distract you.
- Don't skip medications! (Follow your doctor's recommendations.)
- Deep breathing, meditation, guided imagery and distraction may also help to reduce muscle tension, anxiety and pain.

#### SEXUAL CHANGES

- For men this could include:
  - Inability to climax
  - Impotence
  - Feeling too tired or disinterested in sex
  - Feeling worried, stressed or depressed
- For women this could include:
  - Symptoms of menopause hot flashes, vaginal dryness,
    - irritability, irregular menstrual cycles
  - Infections
  - Feeling too tired or disinterested in sex
  - Feeling worried, stressed or depressed
- Ask your doctor or nurse if it is safe to have sex.
- Be open and honest with your partner about how you are feeling.
- Explore new ways to show love.

#### **SKIN AND NAIL CHANGES**

- Itching, dryness, redness, rashes and peeling
  - Take short, cool showers.
  - Pat dry with a towel after bathing.
  - Use mild-moisturizing soap.
  - Use unscented creams or lotions right after showering.
  - Do not use perfume, cologne or aftershave that has alcohol.
- Sun sensitivity
  - Stay out of direct sunlight.
  - Use sunscreen.
  - Keep lips moisturized.
- Nail problems
  - Wear gloves when cleaning.
  - Use products to make nails stronger.
  - Keep nails clean and short to help prevent infections.

# Cancer's Impact on Relationships

Cancer can feel like something you have to deal with on your own. You may feel the need to isolate yourself from others. On the other hand, confronting a cancer diagnosis may bring you and your loved ones closer together. Keeping the lines of communication open with the people in your life can allow you to feel more connected to a network of support. The following are ways cancer can impact your relationships with your.

#### Parents

After a cancer diagnosis, young adults who have lived on their own sometimes choose to move back into their parents' home temporarily. Do not think of moving in with your parents as giving up your independence, but as a way to ensure that your emotional, practical and financial needs will be met during this difficult time. Be honest about your need for privacy, and share your feelings and thoughts 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 may be difficult for siblings of any age. They may want to help you in practical ways, such as taking you 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

It's important to note that young adulthood is often a time of change in friendships, even without a cancer diagnosis. Plus, your peers may not have experience with cancer and may not know how to respond. Do not be afraid to take the lead in reaching out to them. Be honest about what you need and what you feel like talking about. If your friends want to help, ask them to help you in specific ways, such as running errands, giving you rides or making meals. Some friendships may change during this time in your life, so focus on friends who are able to listen to you and support you.

#### **Spouses and Partners**

Most young adults do not expect their spouse or partner to be diagnosed with cancer. The fear of losing a loved one can be overwhelming. Sometimes this fear can drive an emotional wedge between partners. 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 a sense of normalcy back to your lives, too. Consider attending City of Hope's "Couples: Essential Skills for Overcoming the Challenges of Cancer Together" group. (More information is provided at the end of the toolkit in the section titled "Sheri & Les Biller Patient and Family Resource Center Ongoing Programs.")

#### Children

Among the many questions and concerns parents face when they (or another family member) are diagnosed with cancer is how to talk to children. How you talk to the children or what you tell them depends on many things, such as their ages, personalities and what you know about the treatment. By being open and honest with children, you are helping them express their feelings or concerns. You are also letting them know that it is OK to talk about the diagnosis and what they might be thinking or feeling. We have child life specialists here who work with children and teens and can help explain what you are going through in a developmentally appropriate way. For Child Life Services or additional information, ask your health care provider for a referral.



# LGBTQIA+ Cancer Patients and Survivors

Since 2017, City of Hope has been named a "Leader in LGBTQ Healthcare Equality" on the Health Equality Index by the Human Rights Campaign.

#### Health and Health Care Considerations

- LGBTQIA+ (lesbian, gay, bisexual, transsexual, queer/questioning, intersex and asexual) patients may experience heightened stress because of pre-existing disparities or stressors prior to cancer diagnosis.
- Among other risk factors, LGBTQIA+ individuals are less likely to have adequate health insurance, more likely to have experienced discrimination based on sexual orientation or gender identity, and more likely to experience alienation from their family of origin.
- Research indicates that LGBTQIA+ individuals experience higher rates of psychological distress than heterosexual individuals, even without a cancer diagnosis.
- The LGBTQIA+ community is also more likely to use tobacco and alcohol, which increases risk for certain cancers and/or other medical conditions.

#### Disclosure

A national survey of LGBT cancer survivors by Margolies and Scout (2013) revealed that most patients chose to share their sexual orientation/gender identity with their medical team on their own, rather than on a form or in response to a provider's question. Sharing one's LGBT identity (and being accepted by the medical team) has been correlated with better patient health outcomes. If you choose to disclose information about your sexual orientation or gender identity with the medical team, it is considered confidential information and will be treated as such. Every patient deserves to feel comfortable and respected.

City of Hope does not discriminate against any person on the basis of race, color, sex, religion, national origin, age, disability, sexual orientation, gender identity or gender expression. We believe in respecting the dignity of each human being.

### Resources at City of Hope

#### City of Hope: Pride in the City

Pride in the City exists to create an accepting and inclusive environment that serves the needs and interests of all City of Hope LGBTQIA+ employees, patients and their families, and the surrounding community.

#### **Patient Navigation**

City of Hope has a trained patient navigator for LGBTQIA+ patients. You can reach the patient navigators by calling the Sheri & Les Biller Patient and Family Resource Center at **626-218-2273**.

#### **Social Work**

If you would like to speak to someone about additional resources, please contact the Division of Social Clinical Work at **626-218-2282**.

# Sexuality

Some types of cancer treatments can cause changes that affect your sexuality. Whether you have sexual changes during cancer treatments may depend on other factors, such as age, other illnesses or conditions, etc. Sexuality is an important part of everyday life, and it is important that you talk to your medical team if your treatment affects your sexuality.

Sexuality may also be uncomfortable to talk about openly and honestly. You may not like talking about it, but hopefully some of this information is helpful, and it can empower you to talk to your medical provider about any concerns.

#### **Overview of Sexual Health During Treatment**

- When a patient's blood counts are low, sexual intercourse and oral-genital stimulation should be avoided to decrease the chance of infection. When blood counts return to normal, these activities can be resumed. Discuss this with your care provider, too.
- If there is a chance of pregnancy, birth control should be used. Chemotherapy can cause changes in the female eggs and sperm that could lead to birth defects. (Males may wish to use a sperm bank before the start of therapy since some types of treatments may cause sterility. Read more about this in the "Fertility" section on page 18.)
- Plan your sexual activity for when the side effects of chemotherapy are the lowest.
- Use personal lubricants when needed (use water based products, such as K-Y jelly or Astroglide.) The Positive Image Center<sup>SM</sup> at City of Hope has some of these products available. See the resources on the next page for more information.

#### There are some factors that may affect your sexual desires:

- Stress related to your disease, treatment or financial concerns
- Anxiety or depression
- Body image changes, such as hair loss or surgery
- Side effects from treatment, such as nausea, diarrhea, skin changes, fatigue and hormonal changes

#### **Potential Treatment-Related Symptoms**

Most of the side effects that affect your sexuality are temporary and may go away after treatment. Always talk to your medical provider about the side effects your treatment may cause.

#### WOMEN

- Menopause symptoms, such as hot flashes, vaginal dryness, feeling irritable, and irregular or no menstrual periods
- Increased risk of bladder infections
- Increased risk of vaginal infections (which may include discharge and/or itching)
- Lack of sexual desire (do not feel like having sex)
- Pain with sexual intercourse

#### MEN

- Cannot get or keep an erection
- Cannot reach climax
- Lack of sexual desire (do not feel like having sex)

#### What you can do:

- Talk to your medical team about your sexual health, including birth control, family planning and if it's OK to have sex.
- Talk to your partner about your feelings.
- Engage in other pleasurable and important intimate behaviors with your partner, including touching, holding hands and physical closeness.
- Explore new ways to show your love.

#### What not to do:

- Do not keep your feelings to yourself.
- Do not isolate yourself from your partner.
- Do not make assumptions about your sexual health or fertility before speaking to your medical team.

### Resources at City of Hope

#### Positive Image Center<sup>SM</sup>

This center is a resource for some personal care items that target symptoms outlined in this chapter. Ask the Information Desk for directions to the Positive Image Centers on campus, call **626-218-3842 or** email **positiveimagecenter@coh.org**.

#### **Occupational Therapy**

- If you're admitted to the hospital at City of Hope, you may attend the sexuality group that occupational therapists organize for inpatients approximately twice each month. Call Occupational Therapy at 626-218-0040 for more information.
- Occupational therapists can also meet with you individually (on both an inpatient or outpatient basis) to provide more information about sexuality. Call Occupational Therapy for more information, or ask your medical team to create a referral to an occupational therapist.

#### Social Work

You may want to contact your social worker for more resources or recommendations by calling **626-218-2282**.

#### "Chemotherapy and You"

You will find more information in the "Chemotherapy and You" booklet, located in the chemo packet you received before your first treatment.

References: This information was adapted from the following sources: Dana Farber Cancer Institute, City of Hope (2008) Sexuality (handout)

# Fertility

Radiation therapy and chemotherapy treatments may cause temporary or permanent infertility. Infertility means you cannot have a child. These side effects can depend on the patient's sex, age at time of treatment, the specific type and dose of radiation therapy and/or chemotherapy, the use of single therapy or many therapies, and length of time since treatment.

#### MEN:

- Not all cancers and cancer treatments will affect your ability to have a baby. Ask your oncology team about your risks and consult a male reproductive specialist, if you can.
- Sperm banking is the most successful and least expensive way to keep your fertility. It should be done before cancer treatment starts, even if you have very low sperm count. Sperm can be frozen for many years and still used later to try to have a baby.
- Due to possible genetic damage to sperm from treatments, doctors usually recommend waiting six to 12 months after the end of chemotherapy or radiation before trying to get pregnant naturally.
- Sperm production may return right away or many years after cancer treatments. If you do not want to become a parent, you should use birth control (even if you think you are infertile).

#### WOMEN:

- Not all cancers and cancer treatments will affect your ability to have a baby. Ask your oncology team about your risks and consult a reproductive specialist, if you can.
- Even if your period returns, damage to your ovaries from certain treatments may put you into menopause five, 10 or 20 years earlier than the average age.
- Eggs, embryos and ovarian tissue can be frozen for many years and still be used to try to have a baby.
- Your medical team may tell you that you need to wait anywhere from six months to five years after cancer treatments to try to get pregnant.
- The return of your period does not always mean that you're fertile and not having a period does not always mean that you're infertile. If you're not ready to become a parent, you should use birth control (even if you think you're infertile).
- Some cancer treatments may cause long-term damage to your heart and lungs. This damage can sometimes complicate pregnancy. Ask your medical provider if pregnancy is safe for you.
- Children born to cancer survivors are not at higher risk for birth defects or cancer, unless the cancer involved is caused by a known genetic mutation. If this is the case, it may be possible to use genetic screening methods to help keep from passing the gene mutation to your children.

#### Chemotherapy

For patients getting chemotherapy, age is an important factor and recovery improves the longer the patient is off chemotherapy. Chemotherapy drugs that have been shown to affect fertility include: busulfan, melphalan, cyclophosphamide, cisplatin, chlorambucil, mustine, carmustine, lomustine, vinblastine, cytarabine and procarbazine.

#### Radiation

For men and women getting radiation therapy to the abdomen or pelvis, the amount of radiation that goes to the testes or ovaries is an important factor. Fertility may be preserved by the use of modern radiation therapy techniques and the use of lead shields to protect the testes. Women may undergo surgery to protect the ovaries by moving them out of the field of radiation.

#### **Procreative Alternatives**

Patients who are concerned about the effects of cancer treatment on their ability to have children should talk about this with their medical team before treatment. Your doctor can recommend a counselor or fertility specialist who can share options and help patients and their partners decide what is best for them. Options may include freezing sperm, eggs or ovarian tissue before cancer treatment.

#### **Financial Considerations**

Although some insurance companies will often pay for infertility treatments, procedures such as sperm banking, egg freezing and embryo freezing are usually not covered. Since insurance coverage varies widely, please discuss these options with your insurance company.

Financial assistance programs are available through organizations such as Livestrong Fertility. Please review fertility resources at the back of the toolkit as well.

### Resources at City of Hope

#### Talking to your medical team

It is important that you talk with your medical provider about your concerns and your options. They may also provide a referral to a specialist, if needed.

#### Sheri & Les Biller Patient and Family Resource Center

You may find helpful information, education and support in the Biller Patient and Family Resource Center located near the entrance to the Main Medical building, or you can call **626-218-2273**.

References: This information was summarized or adapted from the following sources:

LiveStrong Fertility

Cancer.gov

# Cancer and Body Image

Cancer and its treatment can change how the body looks, feels and what it can do, and these changes can affect your self-image. Body image is how you feel about your looks, while self-image is how you view your personality, abilities, potential, values, interests and how you relate to others. It is normal to feel distressed and anxious about the changes that take place in your body.

#### Depending on your treatment, physical changes may include:

- Skin changes
- Weakness or loss of energy
- Swelling of the face, arms or legs
- Changes in your sexual functioning, such as infertility (inability to have a child), early menopause, loss of sex drive or difficulty getting an erection
- Weight changes
- Hair loss from radiation treatment or chemotherapy
- Decrease in physical skills, such as athletic skills, balance and speed
- Scars from surgery
- Loss of body part(s)

#### How Physical Changes Can Affect Body Image

Body image is important to most people. Some changes from cancer treatment can be seen by others and make a patient feel self-conscious. Changes that cannot be seen by others can also make a person feel different (such as fatigue, early menopause, acquiring a new scar or infertility). Some people feel a loss of confidence in their body image and its abilities if these changes happen. You may feel like your body is weak or feel a loss of control over your body/health.

On the other hand, some patients experience positive changes, such as a sense of pride in the resilience of their body. Others may feel that issues about body appearance matter less to them during or after treatment. Cancer treatment can also lead some people to treat their body better than they did before by eating healthier and focusing on things like exercise.

Body and self-image are unique to each person and may change with time. Cancer treatment can alter your body image, but you can also practice some behaviors that will help you cope with these changes in a healthy way.

#### Coping With Changes to the Body

Your unique self-image and/or physical appearance can be very important parts of your self-concept. It is normal to feel distressed, sad or frustrated over changes to your body.

Ways to cope:

- Allow yourself time to grieve physical losses, prepare for psychological challenges and make adjustments to your new body.
- Talk or meet with other young adults with cancer about how they cope and what adjustments they made due to bodily changes.
- Be ready for questions and/or comments that may come up about your appearance, and think about how you'd respond. If you prefer not to talk about it, then say it's a private matter to anyone who asks.
- While you may look and feel different, remember that you are the same person on the inside. Your character traits, personality, interests and values are not taken away by cancer. You may even find new strength you didn't know you had.
- Take care of your body with healthy eating habits, tolerated exercises and enough sleep. Acquiring a new physical skill can help you feel better about your body and its changes. Ask your medical provider how much activity you can do.
- Make this a time when you can try a new fashion or look, such as a different style of clothes, hair color or accessories that help you feel more confident and proud of your changing appearance.
- If you are not able to do some of the physical activities or sports you did before, try to find new activities that interest you.
- Ask for a referral to a rehabilitation therapist to help you in managing any physical limitations you may have. (Always remember to check with your medical team first.)
- Let members of your health care team know about your concerns, so they can assist you in the best way possible.

### Resources at City of Hope

#### "Look Good ... Feel Better" Class

Trained cosmetologists teach about how to overcome appearance-related side effects of treatment. More information on the class can be found by contacting or visiting the Sheri & Les Biller Patient and Family Resource Center or in the back of this toolkit in the "Sheri & Les Biller Patient and Family Resource Center Ongoing Programs" section on page 39.

#### Positive Image Center<sup>SM</sup>

Oncology-trained, licensed cosmetologists can work one-on-one with patients to help minimize the visible side effects of cancer treatment. Services provided include: free haircuts and head shaves, custom wig fittings and cuts, pre/postmastectomy fittings, product consultation and retail, demonstration of eyebrow application, head wrap and scarf tying techniques. Ask the Information Desk for directions to the Positive Image Centers on campus, or call **626-218-3842**.



#### **Physical Therapy**

Your medical team can create a referral to Physical Therapy to assist with increasing activity/reducing pain, restoring functioning and preventing disability.

#### **Occupational Therapy**

Occupational therapists can address concerns related to body image, facilitate independence with activities of daily living, address lifestyle factors to promote health and well-being and more. Your medical provider can create a referral to Occupational Therapy.

### Dependency vs. Autonomy

#### What Is "Normal?"

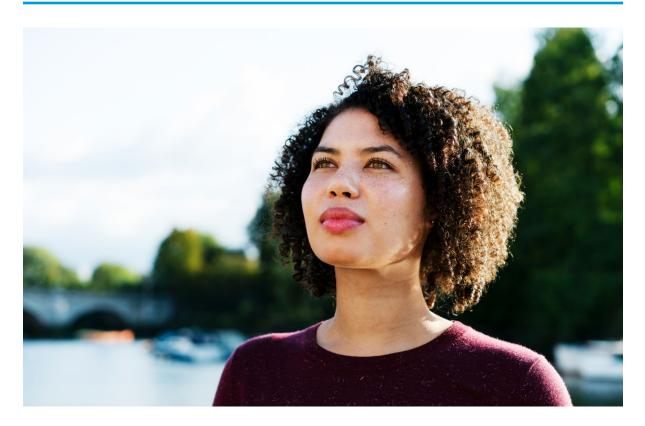
For young adults, normal means moving from the dependent world of a child who is cared for by others to the world of an adult who cares for himself or herself. This is often characterized by an individual's development of their own identity, establishment of interpersonal relationships, formation of close-knit peer groups, determination of a sense of values and beliefs, and pursuit of educational and career goals.

This stage of development is also marked by an increased investment in relationships, commitment and intimacy, and a focus on creative and meaningful work. Oftentimes, when an adolescent or young adult (AYA) is diagnosed with cancer, many of these tasks or developmental goals are put on hold. As a result, patients can often feel a loss of control and that they are stuck within their current circumstances.

What Life May Look Like	What Life May Look Like
Before a Cancer Diagnosis	After a Cancer Diagnosis
<ul> <li>Hopes and dreams for the future</li> <li>Focus on friends, dating, family</li> <li>Sense of security (safety)</li> <li>Focus on school or work</li> <li>Stable overall health</li> <li>Hobbies</li> <li>Plenty of leisure time</li> <li>Optimism</li> </ul>	<ul> <li>Feeling a loss of control</li> <li>Increased anxiety, anger or depression</li> <li>Fear or uncertainty</li> <li>Different view of mortality</li> <li>New financial considerations</li> <li>Learning new medical terminology</li> <li>Adjusting to "hospital life"</li> <li>Appointments, including scans, tests and procedures</li> </ul>

#### The Struggle for Independence

Because of the unique developmental goals and needs of AYA cancer patients, there is often a struggle to figure out where one fits in the "cancer world." Some patients easily walk the line between independence and dependence by learning how to manage their care and ask others for help when it's needed. More often, though, AYAs have challenges because they were more independent before their diagnosis and then have to rely more on family and friends for emotional, financial and physical support during treatment.



All of this can be very overwhelming and difficult to manage, but here are a few tips that can help. Remember, **asking for help does not mean you've lost your independence!** 

- Don't be afraid to ask for help.
- Be specific when people ask how they can help you.
- If you'd like, consider the use of online programs, such as Caring Bridge or Care Pages, to communicate medical status and support needs with loved ones. (More information is provided in the "Resources" section on page 45 at the back of the toolkit.)
- Have an open and honest discussion with your family and friends about your needs and how people can help you. Try using the statement, "I need your help, but I still want to be independent" as a starting point.
- Be involved in talking about your treatment with your medical team.
- Talk with your medical provider about what to expect regarding time away from work and/or school.
- Stay connected with your friends and family as much as you can.
- Try to keep some sense of normalcy by doing as many of the things that you used to enjoy as possible.

# Coping With Psychological Stress

Psychological stress alone has not been found to cause cancer, but psychological stress that lasts a long time may affect a person's overall health and ability to cope with cancer. People who are better able to cope with stress have a better quality of life while they are being treated for cancer.

#### What Is Psychological Stress?

Psychological stress is what people feel when they are under mental, physical or emotional pressure. It is normal to experience some psychological stress from time to time, but people who have high levels of psychological stress or who have it repeatedly over a long period of time may develop health problems. When people feel that they cannot manage or control changes caused by cancer or normal life activities, they are in distress. This can include symptoms of depression, anxiety and panic.

#### What Happens to the Body During Stress?

The body responds to physical, mental or emotional pressure by releasing stress hormones (such as epinephrine and norepinephrine) that increase blood pressure, speed up the heart rate and raise blood sugar levels. These changes help a person act with greater strength and speed to escape something that seems like a threat.

Research has shown that people who have intense and long-term (chronic) stress can have digestive problems, fertility problems, urinary problems and a weakened immune system. People who have chronic stress are also more likely to get viral infections, such as the flu or common cold, and to have headaches, trouble sleeping, depression and anxiety.

#### How Does Psychological Stress Affect Young Adults Who Have Cancer?

Young adults who have cancer may find the physical, emotional and social effects of the disease to be stressful. Those who try to manage their stress with risky behaviors (such as smoking or drinking alcohol) or those who become more sedentary (move and exercise very little) may have a poorer quality of life after cancer treatment. People who are able to use healthy coping methods to deal with stress (such as relaxation and stress management techniques) have lower levels of depression, anxiety and symptoms related to the cancer and its treatment. Common times that cancer-related distress can happen include: when you're first diagnosed, before treatment starts, if you're anticipating unwanted side effects, after you finish your first round of treatment, during follow-up visits with your doctor (once treatment is done) and if you're worrying about the cancer coming back or getting worse.

#### How Can Young Adults Who Have Cancer Learn to Cope With Psychological Stress?

Emotional and social support can help patients learn to cope with psychological stress. It can reduce a patient's experience of depression, anxiety and disease and treatmentrelated symptoms. Here are some ways of getting emotional and social support:

- Training in relaxation, meditation or stress management
- Counseling or therapy
- Cancer education sessions
- Social support in a group setting
- Medications for depression or anxiety
- Exercise

# When Should You Contact Your Medical Provider for More Assistance With Psychological Stress?

If you're experiencing:

- Sadness that keeps coming back or "empty" mood
- Lack of motivation or despair
- Loss of interest in family, friends, hobbies
- Panic, loss of control
- Sweaty palms, racing pulse, trouble breathing, trembling or shaking that's not caused by a known medical condition
- Frequent loss of appetite or overeating
- Cannot sleep or sleeping too much
- Cannot cope with pain or fatigue

### Resources at City of Hope

#### Social Work

It is important that you talk with your health care team if you are feeling distressed. You may find that talking with your social worker can help. You can reach your social worker by calling the Division of Social Work at **626-218-2282**.

#### **Psychology or Psychiatry**

If you're having symptoms of depression or anxiety, your medical team can refer you to additional support services available at City of Hope, such as the divisions of Psychology and Psychiatry.



Sheri & Les Biller Patient and Family Resource Center

#### Sheri & Les Biller Patient and Family Resource Center

You may also find helpful information, education and support in the Biller Patient and Family Resource Center. Programs such as support groups, yoga, education classes, music therapy, art therapy and more may help you to cope with your feelings. The center is located near the entrance to the Main Medical building, or you can call **626-218-2273**.

#### References:

This information was summarized or adapted from:

- National Cancer Institute. Adjustment to Cancer: Anxiety and Distress (PDQ) at cancer.gov/cancertopics/pdq/supportivecare/adjustment/Patient/page2
- Psychological stress and cancer. National Cancer Institute at cancer.gov/cancertopics/factsheet/Risk/stress

### Managing Work, School or Home Life

Managing your work, school or home life may become difficult during and after cancer treatment. It is normal for your relationships with family members, friends, co-workers or classmates to change as you go through cancer treatment. Also, you may find that you need to take time off work, reduce your hours or not work at all. If you are in school, you may not feel well enough to fully participate in school life. Talk to your social worker about helpful communication tips and ways to handle any changes with work, school or home life.

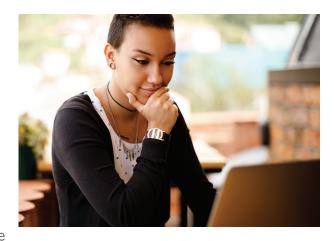
#### Working while in treatment

- Talk to your employer about making schedule (or workplace) changes.
- Ask your employer about working at home or using special equipment to make it easier for you to do your job.
- During any discussions about workplace or schedule changes, document each request and the outcome of your discussion.
- Talk to your medical provider or nurse about scheduling follow-up visits that do not conflict with your work responsibilities.
- Get your doctor to write a letter to your employer about how, if at all, cancer may affect your work or work schedule.

#### **Concerns about school**

- Let your school advisor know about your progress.
- Find out about school resources to make it easier for you to return to school. These may include:
  - Student health services
  - Financial aid resources
  - Career planning services
  - Student health insurance
- Ask classmates or friends to let you know about any changes.
- Talk to your instructor about getting more time to finish homework/projects or getting copies of lecture notes.
- You may choose to take some time off from school for a little while. Contact your school's administration and ask who can explain your options regarding taking medical leave from classes.

Were you unable to finish high school and want to take the General Equivalency Development/Diploma (GED) test? (If you pass this test, it shows that you have United States or Canadian high schoollevel academic skills. Passing the test often means you can apply for college or certain jobs even if you didn't complete high school.) Information is available at **cde.ca.gov/ta/tg/gd,** or check out City of Hope's helpful booklet, "How to Take



the General Equivalency Diploma Test in California," at **CityofHope.org/academicadvocacy** or on campus at the Sheri & Les Biller Patient and Family Resource Center.

City of Hope's Academic Advocacy Program coordinator can assist with many of these concerns; see the "Resources" section on the next page for more information.

#### **Home Life**

- Ask for help when needed.
- Talk to your family about what you are able to do and what not to expect.
- Give yourself more time to finish tasks.
- Openly talk about any changes that cancer treatment may cause to your routine at home.
- Follow a good sleep hygiene routine (try to go to sleep and wake up around the same time every day, try not to use your bed for activities other than sleep, stop using technology 30 minutes before bed, etc.)
- Be aware that your recovery may take longer than expected.
- If you have children:
  - Be honest with them.
  - Speak directly and openly with them.
  - Allow them to become informed about your cancer, and get them involved in your recovery.
  - Spend quality time with them as much as possible.
  - Ask your medical team about Child Life Services. A child life specialist can help speak with your children about your cancer and help them adjust.
- Talk to your health care team about any additional services you may need.

### Resources at City of Hope

#### Academic Advocacy Program

The Academic Advocacy Program helps you with resources, information and educational planning so you can achieve academic success during and after treatment. Educational advocacy can include:

- Helping a patient obtain modifications/accommodations if he or she is attending school
- Assisting in withdrawal or deferment of college courses
- Facilitating the process of home teaching or independent study
- Individual/family counseling related to educational options, school re-entry and psychosocial adjustment in the school, college or university environment

Ask your doctor or social worker to submit a referral to the school program coordinator for assistance in navigating school-related concerns. (The school program coordinator can be reached directly at **626-218-8125**.) Learn more at **CityofHope.org/academicadvocacy**.

This information was summarized or adapted from:

• National Cancer Institute. Facing Forward: Life After Cancer Treatment-social and work relationships. 2010. Retrieved from cancer.gov/cancertopics/coping/life-after-treatment/page7#f

### Cognitive Changes in Cancer Care

Some patients may experience changes in the way they think, focus or remember. This can be caused by stress or as a result of treatment (such as chemotherapy, radiation, surgical resection, etc.). Here are some signs of cognitive changes and how to get support for them.

#### Signs to watch for

Have you noticed that some of the things you do every day are harder than they used to be? Review the list below and speak to your doctor if you feel these issues are impacting your day-to-day life.

- Lose things like keys
- Forget things like appointments
- Can't complete routine daily tasks
- Feel like I'm in a fog
- Can't connect the dots
- Get distracted easily
- Feel one step behind all the time
- Can't keep up with school/work
- Can't focus on a whole conversation
- Struggle to learn something new



#### Why Am I Having Trouble With My Thinking?

As a cancer patient, you may notice changes in how much you can remember, how long you can stay focused or how well you can do normal daily tasks. This may be due to changes caused by:

- The cancer itself
- Chemotherapy or radiation treatment
- Emotional stress

#### Who Can Help Me?

If you feel that changes in your memory and thinking skills are making it hard to complete everyday tasks, there are people who can help. Talk to your doctor about the things you have a hard time doing on a daily basis.

Based on the discussion with your doctor, you may be referred to an occupational therapist to improve day-to-day function, a neuropsychologist to assess your ability or a neurologist to provide medical treatment. Each expert has a different way to help patients do the things they need to do every day.

#### How Will Specialists Help Me?

#### **Occupational Therapist**

- · Recommends ways to improve your thinking and memory skills
- Helps with multitasking and balancing responsibilities (work, school, etc.)
- Works with you to improve your quality of life
- Provides guidance to help you take care of your daily tasks on your own
- Gives you tools and strategies to work through these changes

#### Neuropsychologist

- Conducts in-depth cognitive and psychological assessments to discover the problem
- Works with an Academic Advocacy Program coordinator to plan for your school needs during or after treatment
- Helps you transition back to work
- May refer you to other specialists or resources for your needs

#### Neurologist

- Assesses for medical issues
- May suggest further testing based on symptoms you have
- May give you medicine or nonmedicinal treatments

#### How Can I Connect With a Specialist?

#### To get support from any of these specialists, ask your City of Hope doctor for a referral.

\*This information is from the City of Hope "Cognitive Changes in Cancer Care" booklet, which can be found in the Sheri & Les Biller Patient and Family Resource Center and on City of Hope's website.

### Parenting With Cancer

Cancer can be exhausting on its own, but balancing cancer treatment or recovery with parenting can be particularly exhausting. The following are some ways you can try to adapt to the demands of treatment and still have meaningful time with your loved ones.

#### **1** Seek out (and accept) support from family, friends and the community.

- If you have a partner, talk about how household responsibilities might need to change temporarily. Added responsibilities can feel overwhelming and lead to frustration, so it's helpful to talk openly about how you're coping and how you can help each other.
- Friends, family members and acquaintances may offer to help, but don't know how. Try to make a list of specific tasks you could use some help with, such as picking your child up from school/activities, hosting your child for a play date, getting groceries, making meals, etc. When someone offers to help, choose a task from the list that seems appropriate for that person. Online services like Caring Bridge or Lotsa Helping Hands can also create shared calendars/ webpages for coordinating loved ones' offers to help.
- Local community resources may be helpful, such as school guidance counselors or psychologists, after-school programs and other charitable organizations. (Social workers, case managers and other members of the health care team may be able to provide helpful referrals.)

#### 2 Establish (or continue) daily routines and quality time.

- Try to maintain some normalcy in your child's life. Keeping a daily routine as much as possible can help your son or daughter feel comforted.
- Plan and keep some time of the week for family time together. Connection is an important element to helping a child feel secure. Play games, read, go for a walk, etc.
- Encourage them to continue participation in enjoyable activities (spending time with friends or family, sports, clubs) as much as possible.

#### $\exists$ Practice healthy communication with your children.

 Talk to them about your cancer in clear, developmentally appropriate terms. Many people think they can "protect" children by not telling them about cancer, but it's helpful to name it clearly because vague descriptors like "sick" or "owwie" can be confusing for children. (Note: Most children ages 0 to 3 are unable to understand cancer or its terminology. But it's helpful to still try to explain upcoming events in clear, simple ways, with lots of reassurance.)

- Every child is different in the way they prefer to receive information and be involved in a parent's care. Some children ask questions and want lots of detailed information. Others may want to come to doctor appointments whenever possible. Try to notice how your child wants information and reassurance, and allow them to participate in the way that seems helpful for their developmental age and personality.
- If you're in the hospital, having your child visit (if possible) can help them worry less. Try to arrange transportation so that they can visit you on a regular basis. (Note: There may be more limited visitation options during flu season depending on your child's age.)
- Track the family's activities on a shared calendar or one that is displayed so everyone can see it. Talk about plans together at the beginning of the week or the night before each day.

#### Ask your children for help, if they're old enough to do so.

Children can feel powerless when a parent is sick. Asking them to do developmentally appropriate chores may help them feel like they're helping. (But be careful about setting unrealistic expectations — remember, these duties should be appropriate for their age and not too stressful.) Chores could include picking up their toys, clearing the dinner table, washing dishes, folding laundry, feeding a pet, etc.

#### 5 Reconsider your priorities.

- It is important (and healthy) to accept that you can't do everything, especially during cancer treatment. Try to make a list of everything that needs to be done. Which items are most important to you? Which can be left undone? What could be done by someone else?
- Spend less time in the kitchen if it simplifies life for you. You don't have to feel guilty about keeping meals simpler. For example, sandwiches can take the place of a more involved meal. If you like to cook, you can also do so in bulk and freeze some for later.
- There are plenty of services that can help you save time and energy if you're willing to pay a fee. Major stores such as Target and WalMart offer free two-day delivery, free in-store order pick-up or even free drive-up options at online checkout. Services like UberEats or Instacart can bring food right to your door. (Note: These services charge you, so be sure you know the fees and estimated total when you order.) Some laundromats offer wash and fold service for a set price per pound. Is there a service that might be worthwhile to make your life easier?

#### **6** Take care of yourself.

It can be easy to overlook your own feelings and needs when you're a parent. Make sure that you're taking care of yourself, too, because you can only help your family when you're physically and emotionally healthy. Talk with your medical provider if you're struggling with physical or emotional symptoms. Try to engage in activities you enjoy and spend time with loved ones. Time spent resting and enjoying yourself helps renew your energy, which gives you strength to support your family.



### Resources at City of Hope

#### Child Life

Child Life Services can help you communicate with your child about cancer. For Child Life Services or additional information, ask your health care provider for a referral.

#### Social Work

Your social worker may also know of more resources for parents in the community. You can reach the Division of Social Work by calling **626-218-2282**.

## Strengthening the Spirit

Life changes in many ways when you have cancer. You might find yourself turning to your spiritual side more often to help you cope, or you may question your faith. Both of these are normal as you try to reorient your life during a time of crisis. It's important to remember that you're not alone at this time — many people have taken this spiritual journey before you.

#### **Everyone Has a Spiritual Dimension**

Whether or not you attend a church, synagogue, mosque or temple, you are a spiritual person. Everyone holds certain beliefs and values about what makes life worthwhile, and many people have experienced moments when they have felt connected to a deeper meaning or reality.

Spiritual moments can happen at any time — for example, when you feel close to nature, look into the face of a loved one, enter a house of worship or sense a greater power. Spiritual beliefs and experiences are nurtured in different ways. For some, participation in a religious tradition is important. Others draw spiritual understanding from philosophy or the arts. Whatever your spiritual beliefs, remember that spirituality is a part of your life and that it can stay that way or grow stronger.

#### Tips for Strengthening Your Spirit

- Read spiritual writings. These can include the Bhagavad Gita, Bible, Quran or other faith-based texts. Delving into sacred texts can put you in touch with ancient traditions of wisdom and give you a sense of connection with a more divine reality. Recently published books on spirituality can also give new insights.
- Seek the help of others. You might connect with your clergy or counselor, or join a group for meditation, prayer and support.
- Retreat to spiritual spaces, natural settings, concerts and museums. Going to such places may help you feel a sense of peace.
- Keep a journal to express your feelings, thoughts and memories. This can add to your process of self-discovery and development.

### A Strong Sense of Spirituality Can Help

A sense of meaning, purpose and connection beyond yourself can help you to have a better quality of life during cancer. Some studies show that people with cancer have less anxiety, depression and pain when they feel spiritually connected.

Spirituality can also help you to put your problems in perspective. Practices such as prayer, meditation and worship can help you to calm and restore yourself. Many people also find the support of other members of spiritual communities to be a great source of practical and emotional help.

A diagnosis of cancer can start a process of looking inward for a stronger connection to what is most meaningful and sacred. Out of the turmoil of this crisis, you can find strength and deeper meaning in your life.

### **Finding Support**

It is also common for people to have both negative and positive feelings about their cancer experience. Speaking to someone about your feelings may be helpful. Your hospital chaplains can offer spiritual care and support in whatever way best serves you, no matter what your faith or spiritual path may be.



#### What do chaplains do?

- Offer compassion and presence.
- Listen to your concerns.
- Address spiritual or religious concerns.

### Resources at City of Hope

#### Spiritual Care Services/Chaplains

City of Hope's Division of Spiritual Care Services can be reached at **626-218-3898**.

#### Social Work

Talking to your social worker can help you to understand your feelings. You can reach the Division of Social Work by calling **626-218-2282**.

#### **Psychology or Psychiatry**

Talk to your medical team if you still have concerns. Your medical team can refer you to other services or health care professionals who can help, such as a psychologist or psychiatrist.

#### Childhood, Adolescent and Young Adult Survivorship Program

Patients are seen in a clinic designed to meet their long-term follow-up needs. As part of the program, patients will see a physician or nurse practitioner, psychosocial team member and a dietician. Patients will also learn about their treatment and receive a personal treatment summary, survivorship care plan and information about resources and services. The goal is for each survivor to stay as healthy and informed as possible. This program works in partnership with each patient's primary health care team and is part of the research program here at City of Hope.

#### **Eligibility**

Diagnosis of cancer before 40 years of age

Types of cancer can include leukemia, lymphoma, sarcoma, germ cell tumor, brain and spinal tumor or other types of childhood cancers.

Patients with sickle cell disease or other blood disorders requiring a bone marrow transplant before 40 years of age

At least two years since completion of cancer treatment and currently in remission

Patients can participate in this program regardless of current age.

For more information or to schedule an appointment, email survivorship@coh.org.

#### Breast Cancer Survivorship Program

Our Breast Cancer Survivorship Program provides personalized follow-up care to support our breast cancer survivors after treatment. At your first visit, you will receive your personalized Survivorship Care Plan. This plan includes a written record of your cancer treatment and follow-up recommendations based on your treatment history and specific circumstances. The survivorship nurse practitioner will go over your plan in detail, address any questions or concerns you may have, and make any necessary referrals.

## Sheri & Les Biller Patient and Family Resource Center Ongoing Programs

Note: Schedule and availability of classes and groups are subject to change. Please call the Sheri & Les Biller Patient and Family Resource Center for current availability. (Last updated May 2023)

#### **Couples: Essential Skills for Overcoming the Challenges of Cancer Together**

Join this group to learn and gain tips and tools on how to strengthen relationships, enhancing open and honest communication, problem solving skills and more.

Who: Patients and significant others When: Third Tuesday of the month, noon to 1:30 p.m. Where: Conference Room Y9 Contact: Lynne Thomas at **626-218-8406** or **Lythomas@coh.org** 

#### Discharge Planning Class for BMT (Bone Marrow Transplant) Caregivers

Drop-ins are welcome. Who: Patients and caregivers When: First and third Wednesday of the month, 11 a.m. to 1 p.m. Where: City of Hope Helford Clinical Research Hospital, Fifth Floor Conference Room H-5154 Contact: **HCTdischargeclass@coh.org** 

#### **Express Yourself Through Art**

Discover your inner artist and express yourself through the creative process of art. Explore drawing, collage, crafts and more. No previous art experience is necessary.

Who: Patients and caregivers When: Second and fourth Tuesday of the month, 1:30 to 3 p.m. Where: Virtual Contact: **626-218-2273** or **BillerResourceCenter@coh.org** 

#### **Inpatient Arts Program**

Learn how to paint with acrylics. No previous art experience is necessary. Class is led by an instructor and all supplies are provided.

Who: Patients and caregivers When: Second and fourth Thursday of every month, 1:30 to 3:30 p.m. Where: City of Hope Helford Clinical Research Hospital, Sixth Floor lobby Contact: **626-218-2273** or **BillerResourceCenter@coh.org** 

#### Look Good ... Feel Better Class

Experienced cosmetologists will teach women how to overcome the appearance-related side effects of treatment.

Who: Women currently being treated with chemotherapy or radiation When: Various dates and times Where: Sheri & Les Biller Patient and Family Resource Center Activity Room Registration required: **626-301-8874** 

#### **Metastatic Breast Cancer Education and Support Group**

Join us for education, support and the opportunity to connect with others.

Who: Patients only When: Second Wednesday of the month, 5:30 to 7 p.m. Where: Virtual Contact: 626-218-3842 or BillerResourceCenter@coh.org

#### Prostate Cancer Support Group

Stop by to obtain educational information, share experiences and more.

Who: Prostate cancer patients and their spouses/partners When: Last Tuesday of the month, 6 to 7:30 p.m. Where: Virtual Contact: **Kaburns@coh.org** 

#### Scalp Care Workshop

Experts from the Positive Image Center<sup>SM</sup> educate about hair loss in cancer treatment and ways to manage it.

Who: Patients When: Select dates and times throughout the year Where: Virtual and in person Contact: **626-218-9105** or **BillerResourceCenter@coh.org** 

#### **Tobacco Cessation Support Group**

Learn strategies to overcome withdrawal symptoms and to break habits that link to and trigger tobacco use.

Who: Patients When: Mondays, 3 to 5 p.m., and Tuesdays, 6 to 9 p.m. Where: Virtual and in person Contact: **626-218-9114** or **smokingcessation@coh.org** 

#### Yoga Classes

This course includes various hatha yoga postures and development of daily home practice and relaxation techniques, including meditation and deep breathing.

Who: Patients and caregivers When: Mondays 10 to 11 a.m. Where: Virtual Registration required: **626-218-2773** 



#### Now That I'm a Patient, What Do I Need to Know? Patient and Family Orientation (In English and Spanish)

Join us and learn who to call for answers and support, discover helpful resources and more.

Who: Patients and caregivers

When:

Tuesdays, 10a.m. to noon Wednesdays, 11 a.m. to noon Fridays, 10 to 11 a.m. Where: Virtual and in person Contact: **626-301-8913** or **patienteducation**@**coh.org**. Registration is encouraged.

Virtual Registration: event.cityofhope.org/patientorientation/home

## Food Safety Guidelines

Type of Food	Foods Allowed	Foods to Avoid
Meat, Deli and Poultry	<ul> <li>Meat or poultry cooked to safe minimum internal temperatures</li> <li>Hot dogs, lunch meats or deli meats reheated to steaming hot or 165 F</li> </ul>	<ul> <li>Raw or undercooked meat or poultry</li> <li>Hot dogs, deli meats and luncheon meats that have not been reheated</li> </ul>
Fish and Seafood	<ul> <li>Previously cooked seafood heated to 165 F</li> <li>Canned fish and seafood</li> <li>Fish cooked to safe minimum internal temperatures</li> </ul>	<ul> <li>Any raw or undercooked fish or shellfish, or food containing raw or undercooked seafood, e.g., sashimi (found in sushi, ceviche, etc.)</li> <li>Refrigerated smoked fish</li> <li>Partially cooked seafood, e.g., shrimp and crab</li> </ul>
Milk	<ul> <li>Pasteurized milk</li> </ul>	<ul> <li>Unpasteurized (raw) milk</li> </ul>
Cheese	Cheeses that are clearly labeled "made from pasteurized milk," such as: • Hard cheeses • Processed cheeses • Cream cheese • Mozzarella • Soft cheeses	Soft cheeses made from unpasteurized milk, such as: • Feta • Brie • Camembert • Blue • Queso fresco (Mexican cheese type)
Eggs	<ul> <li>At home:</li> <li>Use pasteurized eggs/egg products when preparing recipes that call for raw or undercooked eggs.</li> <li>All other unpasteurized eggs need to be fully cooked.</li> <li>When eating out:</li> <li>Ask if pasteurized eggs were used.</li> </ul>	<ul><li>Foods that contain raw or undercooked eggs, such as:</li><li>Homemade Caesar salad dressings</li><li>Homemade raw cookie dough</li><li>Homemade eggnog</li></ul>

Type of Food	Foods Allowed	Foods to Avoid
Fruits and Vegetables	<ul> <li>Washed, fresh fruits and vegetables, including salads</li> <li>Cooked sprouts</li> <li>Cooked, frozen or canned fruits and vegetables</li> <li>Canned or pasteurized fruit or vegetable juices</li> </ul>	<ul> <li>Raw sprouts (alfalfa, bean or any other sprout)</li> <li>Unwashed fresh fruit and vegetables, including lettuce/salads</li> <li>Fruits or vegetables that have bruises, visible mold and/or soft spots</li> <li>Unpasteurized fruit or vegetable juices</li> </ul>
Pâtés	<ul> <li>Canned or shelf-stable pâtés or meat spreads</li> </ul>	<ul> <li>Unpasteurized, refrigerated pâtés or meat spreads</li> </ul>
Honey	<ul> <li>Honey that clearly states that it has been pasteurized</li> <li>Baked goods, cereals, snacks and other foods containing honey that have been pasteurized</li> <li>Cooked, nonpasteurized honey</li> </ul>	• Nonpasteurized honey



#### **Essential Food Safety Guidelines**

- 1 CLEAN: Wash hands, utensils and cutting boards before and after contact with raw foods.
- 2 **SEPARATE:** Keep raw meat and poultry apart from foods that won't be cooked.
- 3 COOK: Use a thermometer and refer to the temperature chart (below).
- 4 CHILL: Chill leftovers and takeout foods within two hours and keep the fridge at 40 F or below.

#### USDA RECOMMENDED SAFE MINIMUM INTERNAL TEMPERATURES



IsItDoneYet.gov

## Resources

## Apps for your smartphone

Headspace (meditation)
MindShift (anxiety)
Cancer Distress Coach (distress, coping skills)
Take a Break! Guided Meditations for Stress Relief
T2 Mood Tracker (track stress, anxiety, depression)
Virtual Hope Box (emotion regulation, coping)
Breathe2Relax (breathing exercises, stress tracking)

### Body Image

Beauty Bus beautybus.org

#### Self-Image and Cancer

cancer.net/patient/Coping/Emotional+and+Physical+Matters/Self-Image+and+Cancer/Self-Image+and+Cancer

#### Look Good Feel Better

**lookgoodfeelbetter.org (women) lookgoodfeelbetterformen.org (men)** This program is dedicated to improving self-esteem and quality of life, including appearance-related side effects.

#### **Cancer in Young Adults**

cancer.net/navigating-cancer-care/young-adults-and-teenagers

#### LIVESTRONG: Body Image

livestrong.org/we-can-help/emotional-and-physical-effects-of-treatment/body-image

#### Tender Loving Care (TLC) by the American Cancer Society

**tlcdirect.org** Affordable with Find affordable wigs, hair loss products, mastectomy products and more.

## Cognitive Changes or "Chemo Brain"

Articles by the National Institutes of Health's National Cancer Institute: "Preventing Chemo Brain? Study Identifies Potential Approach for Common Problem" cancer.gov/news-events/cancer-currents-blog/2022/chemo-brain-prevention-s1p

E-brochure by the American Cancer Society: "Getting Help for Chemo Brain" cancer.org/content/dam/cancer-org/cancer-control/en/booklets-flyers/ getting-help-for-chemo-brain.pdf

## College Scholarship Information

#### **Cancer for College**

#### cancerforcollege.org 760-599-5096

Cancer for College awards national scholarships and financial aid to cancer patients and survivors, as well as amputees under the age of 35.

#### **FinAid**

#### finaid.org

FinAid offers scholarships for patients, survivors, children of cancer patients or survivors, students who lost a parent to cancer and students pursuing careers in cancer treatment.

#### The Samfund

#### thesamfund.org | 617-938-3438

The Samfund helps young adult cancer survivors with a successful transition into their post-treatment life by providing financial support through grants and scholarships.

#### **Ulman Cancer Fund For Young Adults**

#### ulmanfund.org | 888-393-FUND

The Ulman Fund supports, educates and connects young adults affected by cancer through online resources, college scholarships, advocacy and awareness.

# Connecting With Other Young Adults and Emotional Support

#### 13Thirty Cancer Connect

#### 13thirty.org

This national nonprofit is dedicated to helping teens that live with cancer. It contains teen-oriented resources designed to help them cope with cancer and treatment, as well as connect with other teens who are going through the same experience.

#### **Cactus Cancer Society**

#### cactuscancer.org

Cactus Cancer Society is a nonprofit organization providing online support programs to young adult cancer patients, survivors and caregivers.

#### **Cancer Care**

#### cancercare.org | 800-813-4673

Cancer Care provides telephone, online and face-to-face counseling, support groups, education, publications and financial assistance to cancer patients and survivors.

#### Cancer Hope Network

#### cancerhopenetwork.org | 877-467-3638

This nonprofit organization matches adult cancer patients with trained volunteers who have undergone and recovered from a similar cancer experience.

#### **Cancer Support Community, Benjamin Center location (Los Angeles)** cancersupportla.org | 310-314-2555

The Cancer Support Community in Los Angeles offers multiple support groups, including those for blood cancers, brain tumors, breast cancer (Stages 0 to 2), breast cancer (Stages 3 and 4), gay men with prostate cancer, Spanish-speaking patients, children, pancreatic cancer, prostate cancer, post-treatment breast cancer, general support, wellness connection and young adults.

#### **Cancer Support Community, Pasadena location**

#### cscpasadena.org | 626-796-1083

The Cancer Support Community in Pasadena, California, offers multiple support group opportunities, including meetings for bereavement, children, family and friends, Spanishspeaking patients and caregivers, a general support group, breast cancer patients, survivorship and young adults.

#### **Elephants and Tea**

#### elephantsandtea.com

Elephants and Tea is a media company with a mission to help AYA (adolescent and young adult) patients, survivors and caregivers know they're not alone in their fight with cancer.

#### GRYT

#### grythealth.com | 844-487-4798

Our mission is to amplify more voices to improve health outcomes. We do this by relentlessly focusing on the patient voice. We support and learn from lived experiences of people with a diagnosis and those that assist them, co-creating authentic connection and education that help people advocate for themselves and others.

#### **Imerman Angels**

#### imermanangels.org | 877-274-5529

Imerman Angels matches cancer patients with survivors of their same age, gender and cancer type.

#### Little Company of Mary Hospital

#### lcmh.org | 708-422-6200

Little Company of Mary Hospital has two available support groups currently, including one for breast cancer and another for metastatic breast cancer.

#### LIVESTRONG

#### livestrong.org

LIVESTRONG provides free, confidential, one-to-one support to anyone affected by cancer, whether you have cancer or are a loved one, friend, caregiver or provider.

#### Long Beach Memorial Medical Center

#### memorialcare.org/long-beach-memorial | 562-933-0900

Long Beach Memorial Medical Center provides a few support group opportunities, such as a general cancer patient support group, Healing through Creativity Workshop, Writing through the Cancer Journey workshop and a Young Survivor Support Group.

#### Magnolia House by Tower Cancer Research Foundation

#### magnoliahouse.towercancer.org

Magnolia House is a free, integrative wellness program offering online mind and body classes, workshops and individual services.

#### **Mission Control**

#### missioncontrol.com

Mission Control is an excellent database where you can search for resources near your location, including groups, transportation, professional services and more.

#### **Northridge Hospital Medical Center**

**dignityhealth.org/socal/locations/northridgehospital | 818-885-8500, ext. 5668** Northridge Hospital Medical Center offers a Breast Cancer Support Group on the second and fourth Tuesday of the month from 7 to 8:30 p.m.

#### San Antonio Regional Hospital

#### sarh.org | 909-579-6700

San Antonio Regional Hospital offers a few support group options, including a breast cancer group, general support group for any type of cancer and a caregiver support group.

#### **Stupid Cancer**

#### stupidcancer.org

Stupid Cancer is a nonprofit organization that empowers young adults affected by cancer through innovative and award-winning programs and services. It is a go-to hub for resources, support, education, peer-to-peer connection and advocacy.

#### **Thrive to Survive Los Angeles**

#### thrivesurvive.org

Thrive to Survive aims to create a portal community to enable real-life meetups (support groups and seminars) of young adult cancer survivors in addition to clear, concise access to information, such as understanding medical practitioner, financial resources and lifestyle information. They offer a monthly support group every second Wednesday of the month.

#### **Torrance Memorial Health System**

#### torrancememorial.org | 310-517-4711

This group facilitates a number of support group options, including head and neck cancer, lung cancer, mastectomy/breast reconstruction support, men's cancer and women's cancer groups.

#### **Young Survival Coalition**

#### youngsurvival.org | 877-972-1011

This organization supports young adults affected by breast cancer through peer connection and education.

### Communication Tools for Family and Friends

#### CarePages

#### carepages.org

This resource center offers tips for you and your loved ones on how to communicate during a health crisis, articles and inspirational stories, discussion forums and helpful blogs written by experts. CarePages also has a gift shop powered by Amazon.com that offers gift suggestions listed by recipient or situation.

#### CaringBridge

#### caringbridge.org

CaringBridge has free personal webpages for people fighting illness. Keep a personal online journal, post photos and allow friends and family members to sign your guestbook. CaringBridge also offers a service that turns your online journal into a bound book for a small fee.

#### **Five Wishes**

#### fivewishes.org

Five Wishes offers advanced care planning for patients and an easy to understand advanced directive form in many languages that is legal in 42 states.

#### My Life Line

#### mylifeline.org

This group connects cancer patients and caregivers with family and friends in order to reduce stress, anxiety and isolation.

## Voicing My Choices Planning Guide for Adolescents and Young Adults

This planning tool is designed to help AYAs (adolescents and young adults) living with a serious illness to communicate preferences to friends, family and their caregivers.

## Disability, Work Information and Legal Help

#### **Cancer and Careers**

#### cancerandcareers.org

This resource on cancer in the workplace includes tips for interviewing, what your employer can and can't do, fashion and beauty tips, and career coaches to help you through work-related transitions.

#### **Cancer Legal Resource Center**

#### thedrlc.org/cancer/

#### 866-843-2572 or 213-487-2106 (Los Angeles location)

This group provides information and education about cancer-related legal issues to the public through its national telephone assistance line. It also conducts national education and outreach programs for community groups, employers and health care professionals and is actively involved in community activities to raise public awareness of cancer-related legal and public policy issues.

#### **National Cancer Legal Services Network**

#### nclsn.org

This network promotes increased availability of free legal services programs so that people affected by cancer may focus on medical care and their quality of life.

#### **Patient Advocate Foundation**

#### patientadvocate.org | 800-532-5274

The Patient Advocate Foundation is a national nonprofit organization that seeks to safeguard patients through effective mediation, assuring access to care, maintenance of employment and preservation of financial stability. It serves as an active liaison between patients and their insurers, employers and/or creditors to resolve insurance, job retention and/or debt crisis matters relative to their diagnosis through professional case managers, doctors and health care attorneys.

#### **Social Security Administration**

#### ssa.gov | 800-772-1213

Here, you can apply for Social Security Disability Insurance online, check the state of and manage your disability application, answer questions about disability, appeal your denied claim, check your eligibility for benefits using the online screening tool and more.

#### **Triage Cancer**

#### triagecancer.org | 424-258-4628

This site provides free education on the practical and legal issues that arise after a cancer diagnosis.

#### **United States Department of Labor**

Employee Benefits Security Administration — Health Plans dol.gov/agencies/ebsa

This site provides consumer information and links on health coverage, COBRA, HIPAA and much, much more, including how to file claims and appeals with your insurer.

### Fertility

#### **American Society of Clinical Oncology**

#### asco.org

This site offers recommendations on fertility preservation in people treated for cancer.

#### California Cryobank

#### fertile-future.com | 866-477-3762

California Cryobank helps those facing potential infertility from medical risks with fertility preservation, including egg, embryo or sperm banking. Financial assistance and long-term storage options are available.

#### **California Fertility Partners**

#### californiafertilitypartners.com | 310-828-4008

This Los Angeles fertility clinic is dedicated to the evaluation and treatment of male and female reproductive issues and to helping people build families.

#### **Care Fertility**

#### carefertility.net | 818-230-7778

This innovative fertility center offers fertility preservation and reproductive treatments. Free consultations are provided. Office locations are in Glendale, Arcadia and Upland, California.

#### **Center for Fertility and Gynecology**

#### center4fertility.com | 818-514-1184

This center offers comprehensive services, including evaluation, diagnosis and preservation techniques. Office locations are in Tarzana, Bakersfield, Thousand Oaks, Torrance and Encino (lab), California.

#### Hope for Two: The Pregnant With Cancer Network

#### hopefortwo.org

Hope for Two offers free support for women diagnosed with cancer while pregnant.

#### **HRC Fertility**

#### havingbabies.com | 866-472-4483

One of the largest providers of advanced fertility treatments in the United States, HRC Fertility offers fertility testing and a wide range of reproductive treatments. Offices are in Encino, Fullerton, Laguna Hills, Newport Beach, Oceanside, Pasadena, Westlake Village and West Los Angeles, California.

#### **Innovative Fertility Center**

#### innovativefertility.com | 310-648-2229

From advanced reproductive technology to minimally invasive therapies, Innovative Fertility Center offers a comprehensive array of treatment plans surrounding fertility preservation and reproductive treatments. The center is located in Manhattan Beach, California.

#### Loma Linda University Center for Fertility and IVF

#### lomalindafertility.com | 909-554-3003

Loma Linda offers comprehensive fertility preservation and treatment for cancer patients and survivors.

#### **OC Fertility**

#### ocfertility.com | 949-706-2229

OC Fertility provides complete reproductive medicine and infertility services, including infertility evaluation, ovulation induction, intrauterine insemination, in vitro fertilization, minimally invasive surgery and more. The center is located in Newport Beach, California

#### The Oncofertility Consortium

#### oncofertility.northwestern.edu

The Oncofertility Consortium represents a nationwide interdisciplinary network of medical specialists, scientists and scholars who are exploring the relationships between health, disease, survivorship and fertility preservation in young cancer patients.

#### **Pacific Reproductive Center**

#### pacificreproductivecenter.com | 866-423-2645

Pacific Reproductive Center offers a wide range of infertility treatment options. Their infertility treatment processes include consultation and evaluation, testing, initial treatments and, if necessary, assisted reproductive technologies. Locations include Torrance, Irvine, Glendale and Corona.

#### **Reproductive Fertility Center**

#### reproductivefertilitycenter.com | 949-438-1524

Reproductive Fertility Center is a leading fertility practice dedicated to helping people fulfill their dreams of family by providing them with the most technologically advanced solution possible. Services include diagnostic procedures, fertility preservation and assisted reproductive technologies. Locations include in Irvine, Alhambra, Corona and Diamond Bar, California.

#### SaveMyFertility.org

#### savemyfertility.org

This site offers online fertility preservation toolkits for patients and their providers.

#### **UCLA's Fertility and Reproductive Health Center**

#### obgyn.ucla.edu/fertility | 310-794-7274

The UCLA Fertility and Reproductive Health Center manages complicated problems related to infertility. It also provides counseling and treatment regarding the risk of transmitting genetic disorder to offspring.

#### **USC Fertility**

#### uscfertility.org | 213-975-9990

USC Fertility offers state-of-the-art clinical care in a personalized and supportive environment, including fertility testing, egg freezing, IVF, surrogacy and more.

#### Verna's Purse

#### reprotech.com/vernas-purse

Verna's Purse is a financial assistance program for those in need of fertility services.

#### Western Fertility Institute

#### westernfertility.com | 888-261-4574

Western Fertility Institute is a Los Angeles-based fertility clinic providing a supportive and comfortable environment using the latest technology and equipment on the path to achieving a healthy pregnancy. It is located in Encino, California.

## Financial Assistance and Insurance

#### CancerCare

#### cancecare.org | 800-813-HOPE (4673)

CancerCare provices free, professional support services to individuals, families and caregivers to help them cope with and manage the emotional and practical challenges of cancer. CancerCare can help with costs, such as home care, child care, pain medication, lymphedema supplies and copay assistance.

#### **Cancer Financial Assistance Coalition**

#### cancerfac.org

The Cancer Financial Assistance Coalition is a group of financial assistance organizations joining forces to help cancer patients experience better health and well-being by limiting financial challenges. Users search a national database for organizations that help with a specific cancer diagnosis or find resources for a specific type of assistance or need.

#### **Family Reach Foundation**

#### familyreach.org | 857-233-2764

Family Reach helps cancer patients and caregivers with nonmedical expenses such as financial assistance, resource navigation and more.

#### **Good Days**

#### mygooddays.org | 871-968-7233

Good Days provides prescription copay assistance and therapy management for underinsured patients with certain cancer diagnoses.

#### **HealthWell Foundation**

## healthwellfoundation.org 800-675-8416

HealthWell Foundation provides financial assistance to eligible individuals to cover coinsurance, copayments, health care premiums and deductibles for certain medications and therapies. Eligibility requirements are based on medical, financial and insurance situation.

#### The Leukemia & Lymphoma Society

#### Patient Financial Aid Program and Co-Pay Assistance Program

#### lls.org | 800-955-4572

The Leukemia & Lymphoma Society's financial assistance programs provide a limited amount of financial assistance to help patients who have significant financial needs. Their Co-Pay Assistance Program offers financial support toward the cost of insurance copayments and/or insurance premium costs for prescription drugs. Patients must qualify both medically and financially for this program.

#### Life List by Dear Jack Foundation

#### dearjackfoundation.org/programs/lifelist

Life List is a wish-granting program that offers hope to AYA (adolescent and young adult) patients currently in treatment for life-threatening cancer diagnoses. Visit the website for an application and to see sample Life Lists.

#### **Modest Needs Foundation**

#### modestneeds.org | 800-955-4572

Modest Needs Foundation provides short-term financial assistance to families and individuals in temporary crisis due to an unexpected financial setback related to a medical condition.

#### **My Hope Chest**

#### myhopechest.org | 727-488-0320

My Hope Chest provides breast reconstruction surgery assistance to uninsured women who meet eligibility criteria: must be younger than 69, free of medical complications that would preclude safe surgery and be a citizen or legal resident of the U.S.

#### National Children's Cancer Society

#### thenccs.org | 314-241-1600

This society provides financial assistance for families who have a child with cancer. Eligible applicants must be diagnosed prior to the age of 18 and treated prior to the age of 21.

#### **Needy Meds**

#### needymeds.org | 800-503-6897

Helps consumers fill in the individual pharmaceutical applications in search of free medications for their particular illness. You can see if your medication is available from this program at its website. Needy Meds also offers a database of free or low-cost clinics by state.

#### Net Wish

#### netwish.org

This program helps requests for immediate and pressing financial aid every month. The specific focus of Net Wish is on how the aid will help children, older adults and other vulnerable members of our community. Request a wish online, with a maximum request of \$500. The more specific the request, the better chance of a helping hand.

#### Medication Assistance Tool

#### Medicine Assistance Tool (mat.org)

This site is a single point of access to more than 400 public and private patient assistance programs, including more than 150 programs offered by pharmaceutical companies, and provides assistance to the uninsured.

#### **Patient Access Network Foundation**

#### panapply.org | 866-316-7263

This national nonprofit organization is dedicated to helping insured people living with chronic, life-threatening and rare diseases with out-of-pocket costs for their prescribed medications.

#### Patient Advocate Foundation — Co-Pay Relief Program

#### copays.org | 866-512-3861

This group provides direct copayment assistance for pharmaceutical products to insured patients who financially and medically qualify. The program offers assistance for breast cancer, colon cancer, head and neck cancers, lung cancer, lymphoma, kidney cancer, malignant brain tumors, multiple myeloma, pancreatic cancer, prostate cancer, sarcoma and secondary issues related to cancer treatment.

#### **Patient Services Incorporated**

#### patientservicesinc.org

#### 800-366-7741

Patient Services Incorporated assists patients with locating health insurance policies, and provides health insurance premium assistance and copayment assistance. They offer help for bone metastases, cutaneous T cell lymphoma, chronic myeloid leukemia, chronic myelocytic leukemia and gastrointestinal cancer.

#### **RX** Assist

#### rxassist.org

This resource center has information about patient assistance programs, primarily those administered by the drug companies themselves.

#### **RxHope**

#### rxhope.com

This web-based patient assistance resource helps patients complete assistance applications and processes, and fulfills and tracks requests for patient assistance programs for people needing help paying for their medications.

#### The Samfund

#### thesamfund.org | 617-938-3484

The Samfund supports young adult survivors of cancer in the U.S. as they recover from the financial impact of cancer treatment. Through direct financial assistance, in-person and online support, they help young adults move forward toward their personal, professional and educational goals.

### LGBTQIA+Resources

#### Cancer Care, "Coping With Cancer as an LGBT Person"

cancercare.org/publications/209-coping\_with\_cancer\_as\_an\_lgbt\_person Cancer Care's webpage specifically talks about coping with cancer as an LGBT individual.

#### **National LGBT Cancer Network**

#### cancer-network.org

This network educates the LGBT community about cancer risks, trains health care providers on culturally competent care and advocates for LGBT survivors.

#### National LGBT Cancer Project

#### lgbtcancer.org

This national nonprofit for LGBTQ cancer survivors provides support and advocacy, including "Out With Cancer," the organization's online support group community.

## Parenting

#### American Cancer Society book: "Cancer in Our Family"

#### acs.bookstore.ipgbook.com/cancer-in-our-family-products-9780944235959.php

This book can be purchased in electronic version (for approximately \$10) or in print (for approximately \$15). It helps parents understand how to talk to children about cancer and calm many of their fears.

#### American Cancer Society page: Helping children when a family member has cancer

**cancer.org/treatment/children-and-cancer/when-a-family-member-has-cancer.html** This is a helpful webpage that includes subjects such as how to cope with diagnosis, how to cope with treatment, understanding support services, dealing with recurrence or progressive illness, dealing with a parent's terminal illness and when a child has lost a parent.

#### **Bright Spot Network**

#### Brightspotnetwork.org

This network provides young cancer survivors who are parents of small children with a safe space for individual and familiar healing, recovery and reconnection.

#### Cancer.net article: "Parenting While Living with Cancer"

## cancer.net/coping-with-cancer/talking-with-family-and-friends/parenting-while-living-with-cancer

This short article contains tips about how to cope with cancer while taking care of yourself and your family.

#### Livestrong YouTube video: "Cancer Education Class: Parenting with Cancer"

#### youtube.com/watch?v=pA-mFE4K3Dw

This free video from Livestrong is about how to promote resiliency in your children while you're going through cancer treatment.

### Research Your Cancer

#### **American Cancer Society**

#### cancer.org 800-227-2345

The American Cancer Society provides help with all aspects of cancer, from call centers to assistance with clinical trials and everything in between.

#### Cancer.net

#### cancer.net

The American Society of Clinical Oncology's site has oncologist-approved cancer information. It offers disease-specific information and resources on coping, survivorship and advocacy, and includes a wealth of information for young adults with cancer.

#### **National Cancer Institute**

#### cancer.gov 800-422-6237

Cancer.gov is the National Cancer Institute's (NCI) website, a comprehensive resource of cancer information, including the basics on disease types and all NCI-sponsored clinical trials. The site also has phone assistance and live chat for online help.

#### National Institutes of Health

#### clinicaltrials.gov

This registry and results database has publicly and privately supported clinical studies.

## Retreats and Camps for Young Adults

#### Camp Mak-A-Dream

## campdream.org 406-549-5987

Camp Mak-A-Dream offers weeklong programs for young adults with cancer, siblings and young adult survivor advocate training.

#### Dear Jack Foundation | Breathe Now Retreats

#### dearJackFoundation.org

Open to young adult survivors and their partners who are one to three years removed from their day of treatment, Dear Jack Foundation's Breathe Now Wellness Retreats harness the transformational powers of yoga, meditation and psychosocial breakout sessions to help couples renew, learn and grow as they live their lives together postcancer.

#### **Epic Experience Beyond Cancer**

#### epicexperience.org

Through its week-long adventure camps, regional meetups, and educational programming, Epic Experience empowers adult cancer survivors, thrivers and caregivers to live beyond cancer.

#### **First Descents**

#### firstdescents.org 970-926-2444

First Descents offers young adults free outdoor adventure experiences designed to empower them to climb, paddle and surf beyond their diagnosis, defy their cancer, reclaim their lives and connect with others along the way.

#### **Project Koru**

#### projectkoru.org | 904-441-0495

Project Koru's programs harness the healing power of the elements and focus on renewing, rebuilding and restarting lives after cancer through outdoor adventure.

#### **True North Treks**

#### truenorthtreks.org

True North Treks is dedicated to supporting young adult cancer survivors by connecting with other survivors and oneself in beautiful, remote wilderness areas.

### Sexuality and Intimacy

## The American Association of Sexuality Educators, Counselors and Therapists aasect.org

#### National Cancer Institute: Self-Image and Sexuality

#### cancer.gov/about-cancer/coping/self-image

This National Cancer Institute webpage examines sexuality and reproductive issues as affected by cancer.

#### **Sexual Health Network**

#### sexualhealth.com

The Sexual Health Network is dedicated to providing easy access to sexuality information, education, support and resources.

## Contributors

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## Notes and Questions


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