



Q&A

for Young Adults
with Cancer

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College

My Story

“I was a sophomore in college and the semester had just begun. I went to the doctor for what I thought was a simple cold. She tried to help me, but none of the medications were working. I finally went to the emergency room, and that’s when I found out that I had lymphoma. My world was turned upside down. I had a hundred things to take care of, including school, and it was all so overwhelming.”

Do I need to withdraw from school?

You do not have to withdraw. Some people are able to take classes through treatment. This is a decision you should make with your family and your doctor. If you need special arrangements, contact the dean of your college. If you decide to take a leave or withdraw, review the medical withdrawal policy at your university and contact the registrar. The student disability center may be able to help with absences, as well as physical and educational needs.

Can I get any tuition money back? What will happen to my financial aid or scholarships?

This depends on a lot of factors. Speak with your school's registrar about payments or refunds. For scholarships, speak with your school advisor. Options depend on who you received the money from. The most common option is to request a deferment to receive the money later.

Will I ever be able to go back to school?

Yes! You can go back to school when you are ready. Continue to discuss your feelings and your health with your doctor. Explore enrollment options. Options may include part-time, online classes, or a temporary transfer to a local university.

Is there anyone who can help me with all of this?

There are a lot of people who can help you. Speak with a hospital social worker or vocational counselor. They provide guidance and can help plan the next steps. An advisor or dean at your university may be able to help as well. ■



Communication

My Story

“It’s devastating enough to hear you have breast cancer. Now, how do I tell my family and friends? I’m still processing everything. I’m anxious, scared and totally overwhelmed. The last thing I want is to burden anyone else or be treated differently. Fast forward a few weeks later and now I feel suffocated. All of the phone calls, pink breast cancer gifts, it’s a lot.”

When should I tell family and friends about my diagnosis?

Telling others you have cancer can be difficult. There is no “right time” so you get to decide who to tell and when to tell them.

It is helpful to make a plan. Start a list of the people who you want to share your diagnosis with.

- Who does your diagnosis affect?
- Who has noticed changes in your mood or routine?
- Who would you like help and support from?

Then consider some of the factors below.

- Does this person receive news better in groups or one-on-one?
- Do you feel more comfortable talking to this person in groups or one-on-one?
- What kind of communication (text, in person, phone, etc.) are you most comfortable with?
- When are you most likely to be at your best?
- Are there any factors that might make the conversation more complicated?

How can I prepare myself for their reactions?

You can't control how other people react. Some people may ask you detailed questions while others may be silent. Some might be empathic, while others don't seem to understand. Some may cry, while others remain fully composed.

- Think about when to tell people.
- Plan for the discussion and possible reactions.
- Try to create an environment where you will feel most comfortable.

- Think about the questions that others are most likely to ask. Then, take those questions to your medical team to make sure you have the information you need to answer them. There may be brochures or websites they can give you to share with your loved ones.
- Have some talking points written down.
- Let people know how much (or how little) communication you would like to have and how you prefer to be contacted.

Keep in mind that you will have opportunities in the future to further explore feelings and reactions. It doesn't all have to be discussed in one conversation.

What about the tough questions? Like, "Are you going to be okay?"

There may be sensitive conversations with friends and family members. Some could contain difficult questions. Ultimately, you are the only one who can decide how you want to answer those questions. Share only what you feel comfortable talking about and don't be afraid to lead or take charge of the conversation.

If you don't have the time, energy or information to answer tough questions, remember that it's okay to get back to that person at a later time. You can respond with something like:

- "I don't want to talk about that."
- "I don't know the answer to that right now."
- "I'm trying to stay positive and take things one day at a time."
- "It's been a long day and I don't think I have the energy to go into everything right now."

Also, remember that it's always okay to stop a conversation or delay a response if you become uncomfortable or emotional.

How do I ask for help?

The most important thing you can do is be honest! Tell people exactly what you need and be specific about how they can help you. Some examples might be:

- Running errands
- Making/buying food for you
- Paying for a prescription
- Driving you to appointments
- Performing housework/lawn work
- Caring for pets or children
- Sitting with you while you receive infusions
- Staying overnight on days when you know you won't be feeling well
- Watching a movie with you
- Maintaining your social media

Some patients find it helpful to redirect all offers to a "task manager" or "help coordinator." This person should be someone close to you, who is familiar enough with your wishes and with your treatment plan to coordinate support in a way that will be helpful for you.

How do I set boundaries?

Having a support system is great and people almost always means well. However, you may need to set boundaries with your family and friends. Boundaries may involve:

- **Visitation:** when, how often and how to coordinate visits
- **Communication:** how to best communicate support or requests to you
- **Caregiver involvement:** who can speak on your behalf (if anyone) and when
- **Support:** how to help
- **Topics of conversation:** how to handle sensitive topics like positivity, spirituality, nutrition, fertility, etc.

It's okay, and even encouraged, to set aside time and space for yourself. Don't be afraid to tell people "no" or "not at this time."

How should I communicate with people?

There are a lot of ways to communicate from face-to-face, to using phones and computers. People may reach out to you in any of these ways. Decide what needs an immediate response and what can wait until later. You may decide to delegate some of these communications to a task manager. Use this person to reinforce your communication boundaries. ■



Dating and Intimacy

My Story

“On my 19th birthday I was diagnosed with a malignant bone tumor on my right lower leg and a childhood form of ovarian cancer. My treatments left me with thinning hair and a prosthetic on my right leg. It’s been three years since I finished treatment and I’m ready to start dating again.”

Dating

I'm anxious about dating!

Cancer and cancer treatments can affect your health, emotions and your physical appearance. This may change your self-confidence. None of these factors should stop you from seeking companionship. In general, dating is about making a connection. It's about being vulnerable and trusting. A good partner will like you for who you are.

Are there dating groups or websites that are specific for people with cancer?

There are dating sites such as cancermatch.com specific to cancer patients/survivors. Sharing similar experiences often attracts people to one another. However, specific sites may limit your dating pool.

When is the right time to tell a love interest about my cancer history?

There is no right or no wrong time. Some people share immediately while others prefer to wait until they have made a deeper connection. Do what makes you feel most comfortable.

Are there medical precautions I need to consider before having sex?

Consult with your doctor. It will depend on your specific cancer and your treatment. Some treatments require the use of birth control as these medicines may cause birth defects. Always consider whether you need protection from sexually transmitted infections or need birth control before having sex.



My Story

“My chemotherapy ended over four months ago and I am dating a girl that I really like a lot. We are ready to take our relationship further, but I am afraid I won’t be able to perform. I’m not comfortable being intimate.”

Intimacy

Are there other ways of being intimate?

Yes. Intimacy is defined by each couple. It could be anything from hand holding, to oral sex, to intercourse.

How does cancer treatment affect your sex drive?

Cancer treatments can reduce your sex drive. In men it may cause erectile dysfunction; for women vaginal dryness. Get to know your body. If you are experiencing these changes, talk with your doctor. Your doctor can help you determine what treatment (counseling, medicine, etc.) may be helpful.

Will my partner understand my needs?

Your relationship may be tested. Every couple is different, as are the needs of each person in the relationship. Those needs change over time and circumstances. Talk to your partner. Be honest and listen to one another. Some couples find it helpful to see a counselor or therapist. ■



Emotions

My Story

“My cancer journey has been like a rollercoaster. Even though I had a great support system, at times I felt isolated, angry, and scared. I got used to living at the hospital, then all of the sudden it was time to go home. Getting back into my regular life felt like it was twice as hard as being in the hospital. There were lots of ups and downs. I felt tired and sad a lot. I realized I was depressed.”

Is this normal?

You may feel a lot of different emotions. There is no right or wrong way to feel. Some emotions might include

sadness, fear, hopefulness and even excitement. You may feel fine or nothing at all. These emotions can change over time.

Identify what you are feeling. What is the challenge and how does it make you feel? Are you handling your emotions in a healthy way? It's okay to feel bad. It's okay to feel good about bad things. Sometimes there is no need to change or act on your emotions. All emotions are normal.

However, you may not feel comfortable with your current emotions. Think about a time you felt this way in the past. What did you do to feel better? Use healthy coping techniques. Talk to your doctor or a social worker.

What are some examples of healthy coping techniques?

Below are a few examples. Try a few and see what works best for you.

- Do something physical (i.e. walk, exercise or recreational sports)
- Listen to music
- Watch a movie
- Read a book
- Journal
- Take up a new hobby
- Take a bath
- Call a friend
- Get a massage
- Light candles or create a calm space
- Take a nap
- Repeat your mantra (or work on finding one!)
- Surround yourself with people who support you

- Seek out a positive, interesting or funny story
- Follow a blog or twitter feed (unrelated or related to cancer)

Start each morning by having a goal for the day. This can be a small goal. Achieving small goals help get you get to the bigger goals. Examples of small goals include:

- Get out of bed
- Take a shower
- Read a few pages of a book
- Write a thank you note

Other coping strategies include:

- Maintain a positive attitude
- Join a support group
- Plan for the worst and hope for the best
- Embrace your emotions

Will I feel like this forever? When should I ask for help?

As your experiences change so will your emotions. Your ability to cope may change as well. Get help if your emotions become overwhelming or last more than a few weeks. ■



Exercise

My Story

“Shortly after my 21st birthday, I was diagnosed with cancer. My life changed immediately. My social life, academic studies and job became less important as I focused on my health. My appetite, mood and energy changed from day to day. I also struggled with nausea and sleeplessness. I wondered if these effects were permanent. Would the steroid medicines affect my ability to be active and play sports? Despite the hardships, I made a commitment to take care of myself. There are still days I don’t have an appetite or I don’t want to get out of bed, but my goal is to look ahead and think positively.”

What activities can I do?

Stay as active as you can. Listen to your body. You may need to adjust your activity level. Chemotherapy can cause your platelet count to drop temporarily. Low platelets increase risk of bleeding. Because of this you may want to avoid high-impact activities. Talk to your doctor about safe physical activities. A rehabilitation specialist (occupational

or physical therapist) can also work with you to tailor a workout specific to your goals and treatment plan. Most importantly, be patient with yourself.

If you aren't active, get active! A little bit of activity is better than none. Inactivity can lead to overall decreased health.

What activities will I be able to do if I get prosthesis?

If you lose a limb due to surgery, you will work with rehabilitation and prosthetic teams to develop a recovery plan. You will be able to choose prosthesis from different materials based on comfort and functionality. Your activities and level of performance may change. You will meet with these teams often to update your plan as needed.

What can I do to help with the fatigue?

The best treatment for fatigue is to maintain some level of activity, no matter how small.

What foods can I eat to help give me energy?

First, eat foods rich in nutrients such as fruits and vegetables. Then eat foods high in protein and calories, such as nuts and meats. If you have dietary restrictions or want one-on-one support, ask to see a dietician.

I am taking steroids. What can I eat to help fill me up but not gain weight?

Foods high in fiber and protein will help you feel full. Some of the side effects of steroids include muscle and bone weakness, weight gain and increase blood sugar. Talk with your dietician, care team, and exercise therapist to create a plan to maintain a healthy weight. ■



Fertility

My Story

“I was diagnosed with cancer at 18 years old. I have my whole life ahead of me! I haven’t figured out all of my dreams, but I’ve always pictured myself having children at some point. My doctors are talking about giving me chemotherapy, so suddenly it’s something I have to think about. Even scarier, it’s something I have to make decisions about. What will my future look like now?”

Will I be able to have my own kids?

Cancer and cancer treatments can impact your chance of having biological children. The risk of becoming infertile, or unable to have children, depends on many things. For example, your age, the type of cancer treatment you receive (whether it is chemotherapy, radiation therapy and/or surgery), and the amount of treatment you are given are factors that are important. Infertility caused by cancer treatment can be temporary or permanent.

Is there something I can do now so that I can have kids later?

Sperm banking is a common procedure for males. Options for females include shielding reproductive organs, taking medicine during treatment, and freezing unfertilized eggs, embryos or ovarian tissue. None of these options can guarantee that you will have children, but may improve your chances.

Preserving fertility does not mean that you have to have kids later. It just keeps your options open if you decide you want children.

How much does fertility preservation cost? Is it covered by my insurance?

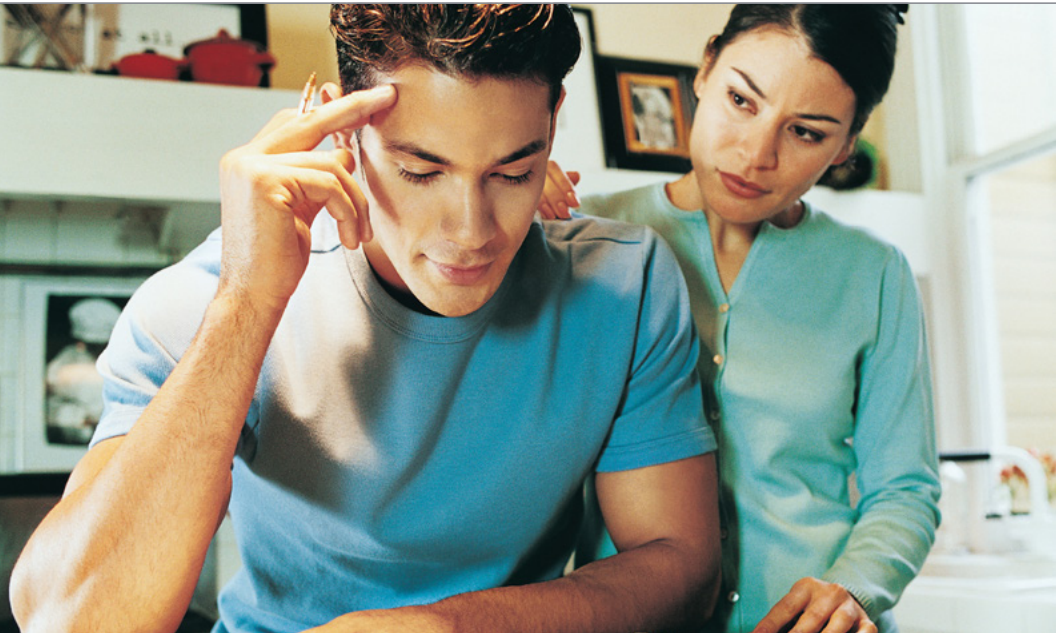
The cost of fertility preservation can vary greatly. Check with your insurance provider to see if any costs are covered. There are also grants and community programs that can decrease the costs.

What other options are there for building a family?

Options include adoption, surrogacy, and in vitro fertilization (commonly known as IVF). If you want to know more about these topics, ask your care team for more information or resources.

Who do I talk to about fertility preservation or other fertility concerns?

Talk your care team before starting any treatment, as some treatments may decrease your options. It is never too late to talk about options for family building, even if you have already started treatment. Sometimes there is not enough time to preserve fertility before starting cancer treatment. However, it is still important for you to learn about your options for building a family in the future. Ask your team for a referral to MD Anderson's Oncofertility Service. If you are not an MD Anderson patient, ask someone on your care team for a referral to a local expert. ■



Finances

My Story

“I’m so overwhelmed by my medical bills. The bills are piling up, I’ll be paying forever. Additionally, I’m from out of town and have to come to the hospital several times a month for treatment. I’m getting worried that I won’t have the financial resources to keep paying for my trips and housing.”

Who can I speak to about my bills?

Questions about charges, your portion of the charge, or payment plans should go to the billing department. They can also give you information on appealing a charge or insurance denial. If you have questions about financial assistance, contact a social worker.

How should I organize my bills?

Keep a calendar of your testing, treatment, and hospital admissions. Create a binder and file system for medical bills. Visit your insurance company's website to view claims and payments. You can compare the information on the website to the medical bills you receive. Opening a new bank account may help track bill payments and separate medical bills from other finances.

Can I deduct medical bills on my taxes?

If your medical bills for one year are more than 7.5% of your annual gross income (AGI) you can deduct them from your taxes.

What housing options are available?

Determine how long you will need to stay for treatment. Patients who are staying a short period of time (generally less than 2 weeks) typically stay in a hotel. Hotel rates can vary greatly.

Depending on the hotel, some of the benefits of staying in a hotel include:

- Discounts to people receiving medical care in the area

- Free breakfast
- Free shuttle to the hospital

If you plan to stay for more than a few nights, talk with the hotel staff about their weekly rates. Often times, the longer you stay the bigger the discount you get.

Short term housing is an option for patients who are staying for a longer period of time. You can rent through a leasing agency or through your own search. Compare short term housing rates to hotel prices. Some churches and charitable organizations may also provide housing. Talk with your social worker about what is available to you.

Are there programs to help with my transportation?

Your hospital or a community group may offer transportation assistance programs. Programs differ based on type of transportation (ground, bus or air), criteria for assistance (distance from the hospital, insurance provider, income, etc.), and limits on how often they can be utilized (yearly, quarterly, monthly, etc.).

If you are looking for local assistance, try contacting the American Cancer Society or your local United Way. For assistance with longer distances that require air travel try Angel Flight, Corporate Angels or the National Patient Travel Center.

My family and friends would like to start a fundraiser for my medical bills. What's the best way to set up an account for this?

Here are some options. Read the fine print for each as there may be fees or taxes.

1. Create your own website independently and use PayPal to collect donations.
2. Use a website already created for fundraising purposes and just make your own page.
3. Open an account at a bank where people can deposit funds.

Do I need to save all my receipts for food/parking/housing/travel?

It's a good idea to keep track of your spending. This is helpful if you are claiming the expenses on your taxes or submitting them for reimbursement. ■



Insurance

My Story

“I’ve been cancer free for the past year. Each birthday I celebrate another year of being cancer free; however, as I age and become more independent I worry about my insurance. I’ve always been covered by my parents’ plan, but that isn’t an option anymore. I’m really confused about all the different options for health insurance and disability insurance.”

What is COBRA?

COBRA (Consolidated Omnibus Budget Reconciliation Act) provides a temporary extension of benefits for people who have experienced job loss, transition between jobs, death, divorce or other life event. There are several things you should know about COBRA.

- If an employer insures fewer than 20 people, they are not required to offer COBRA coverage.
- Coverage generally lasts 18 months.
- It can be expensive since you pay for the entire cost of the insurance.
- There is a short enrollment period after the transition or life event.

If you aren't eligible for COBRA, there are still several other options.

- Apply for government insurance (Medicare, Medicaid, county).
- Purchase your own individual insurance plan (marketplace options vary by state).
- If you are a student, look into the school's insurance.

It is important to make sure you always have insurance coverage. However, plans can be more expensive based on your medical history.

What's the difference between Medicare and Medicaid?

Both are government programs. Medicare is federally sponsored and Medicaid is state sponsored. Medicare is accepted in most states. Because Medicaid is state specific, services may not be covered in other states.

For example, if you are approved for Medicaid in Texas, services may only be covered within Texas.

Medicare eligibility is based on age (over 65) or Social Security disability status (patients who have received Social Security disability for 2 years). Medicaid eligibility is based on your income. There can be exceptions and it is possible for some people to have both.

Who should I talk to?

Start with the Human Resources department at your job. Here are some points to discuss with them.

- Can you still see your same doctors at the same price?
- Are clinical trials covered?
- Are preventative screenings covered like skin and cervical cancer?
- How much do you have to pay out of pocket each year?
- How much do you have to pay for each doctor's visit?
- Is there a prescription plan?
- Are your medicines covered?

What's an HMO versus a PPO?

HMO stands for Health Management Organizations and PPO stands for Preferred Provider Organizations. They are both types of insurance plans. They differ in cost and access to care.

With an HMO, your costs tend to be lower but you may be limited on where or who provides services. A PPO tends to be more costly, but generally has more options for where or who provides services.

What is “in-network?”

“In-network” refers to a contract between an insurance company and service providers. They agree on a set cost for various services. “Out-of-network” means there is no contract between an insurance company and service provider. Out-of-network costs are typically higher.

You are able to choose between either list. Before you see a doctor, check to make sure they are on a pre-approved list of health care providers or in-network. Visit the insurance website to view your policy and find which doctors and hospitals are in-network on your plan. You can also view your medical bills online to see if you have reached your deductible or how much your co-pay will be.

What are my options for short- and long-term disability insurance?

Short-term and long-term disability plans are coordinated through your employer. Some employers offer both, some just offer short-term and others offer no disability benefits at all. The cost of disability benefits vary based on your employer.

In general, short-term disability plans provide benefits for 90-180 days and reimburse 60-100% of your income. For many cancer patients, short-term disability does not cover the length of time for treatment and recovery. Once short-term disability runs out, you may apply for long-term disability if you have elected to receive long-term disability benefits. You will not be enrolled automatically. You will need to apply. There may be a 60-180 day waiting period to qualify for long-term disability, so plan accordingly. ■



Nutrition

My Story

“I was diagnosed with AML (Acute Myeloid Leukemia) when I was 30. After initial treatment, I was in remission for four years, relapsed and had a stem cell transplant. I tried to gain weight before transplant, but I still lost 30 lbs. The hardest part has been to eat food when I have no appetite or am sick to my stomach. I thought about taking supplements but I’m not sure.”

How do I adjust my diet back to “normal” after treatment?

There is no normal diet. Your diet may be changed many times during or after treatment to help you maintain a

healthy weight. Review your weight and discuss any changes with your health care team.

Any tricks to help with the nausea?

- Eat small, frequent meals.
- Try bland foods like baked potatoes, rice and bananas.
- Drink between meals. Drink only small amounts while eating.
- Snack throughout the day.
- Avoid spicy food.
- Avoid very greasy or very sweet foods.
- Choose cold drinks and foods, over hot ones.
- Sit up while eating and for 30 minutes afterwards.
- Practice good mouth care. Gargle with salt and baking soda. Artificial saliva may also help moisten your mouth.
- Use plastic forks and spoons to minimize metallic taste.
- Avoid citrus, tomato and highly acidic foods.
- Ensure your cooking space is well ventilated as smells can trigger nausea.
- Discuss medicine options with your health care team.

Should I be taking any multivitamins or other supplements?

Eat a well balance diet. It is always best to get nutrients from food first. Supplements are meant to fill nutritional gaps. Talk with a doctor or dietitian if you think you are not getting enough vitamins.

Be sure to tell your doctor or dietitian about any vitamins, supplements or herbs you are currently taking or

considering. Take all your current medicines, including supplements, to your doctor's appointment in the original bottles. Certain foods, supplements and herbs can cause interactions with chemotherapies and other medicines. This can negatively affect your cancer treatment. Your doctor and care team can help guide you through these decisions.

What foods can I eat to help me gain weight?

To add calories, add butter and healthy oils while cooking. Add powdered milk to milk and shakes. Healthy fats like peanut butter and avocado can also help.

Should I drink protein shakes?

Getting optimal protein is an important especially if you are vegan or vegetarian. There are several ways to get more protein, but ask your health care team or dietician first. Some protein supplements can be hard on the kidneys.

Can I drink a glass of wine or beer while receiving chemo? What about after treatment?

Limit alcohol during treatment. Alcohol may interfere with normal liver functions. Your liver helps break down medicines and filter out toxins. Review your liver enzyme levels with your doctor. ■



Planning

My Story

“I’m Carlos. I’ve been admitted to the hospital several times this year for chemotherapy. Every time the check in lady asks if I have an advance directive. I have no idea what that is and I feel dumb asking her.”

What is an advance directive?

An advance directive is a collection of three documents:

- Medical power of attorney
- Living will
- Out-of-hospital do not resuscitate (DNR) order

Who needs an advance directive?

Everyone should have an advance directive. Unexpected things happen to people of all ages and to those who are both healthy and ill. The more prepared you are, the better. Take some time to think about what you want in the event that you become critically ill. Write that information down as it can help your loved ones guide your care.

What happens if I don't have an advance directive?

For people who have not completed all three parts of an advance directive, each state has its own laws stating how to handle situations.

Who do I give my advance directive to?

Keep the originals in a safe place where other people can locate them. Also give copies to each person you appointed to make medical decisions on your behalf, your family members and all of your healthcare providers. Ask that your documents be added to your medical record.

What is a medical power of attorney?

A medical power of attorney is a person you choose to make medical decisions on your behalf if you are unable to make decisions. This could be while you are sedated, in surgery or in a coma.

Who you choose to be your medical power of attorney is up to you. It can be your partner, parent, sibling or friend but there may be an age requirement. Choose someone who will keep your best interests at heart, and who you trust to carry out YOUR wishes. You can appoint a primary and up to two secondary decision makers, just



in case the primary person isn't available or isn't able to make a decision.

What happens if I don't have a medical power of attorney?

Each state has specific laws. A medical power of attorney will be appointed for you according to the laws in the state where you are currently receiving care. The person appointed could be your spouse, parents or nearest living relative.

How do I get a medical power of attorney?

Ask a social worker for the medical power of attorney form. It is also available online. You can also get a lawyer to prepare the document. You will need signatures from two witnesses to finalize the document. It may have to be notarized as well. You can cancel or change your decision maker(s) at any time by completing a new form.

What other decisions can my medical power of attorney make?

The medical power of attorney only covers medical decisions. If you want someone to make financial decisions, you will need to contact a lawyer to appoint a durable power of attorney.

What is a living will?

The purpose of a living will is to communicate how you would like to be cared for in the event of a terminal diagnosis or an irreversible condition from which you are expected to die. You can state what is most important to

you as you approach the end of your life, and if you have any specific wishes for your care.

Do my doctor and my family have to do what I say?

A living will is not a legal document that forces your health care team or family to take specific actions. It can act as a guide to help them honor your wishes. Having a critically ill loved one is a stressful time. The more your family and medical team understand what you want, the better. It is important to both write and discuss your wishes with those close to you.

How do I make one?

You can have a living will drafted by an attorney, find forms on the internet or ask someone like a social worker to help you. If you decide to complete the paperwork to make your living will legal, the final document generally requires two witnesses. Depending on what state you live in, it may also need to be notarized. You should keep the original in a place where others can locate it, and give copies of the document to all of your health care providers.

What is an out-of-hospital Do Not Resuscitate (DNR) Order?

An out-of-hospital do not resuscitate order gives medical personnel who might care for you outside of the hospital (such as EMTs or home health nurses) permission to NOT start cardiopulmonary resuscitation (chest compressions or CPR) or other emergency life sustaining procedures. If you are admitted to the hospital, a similar form is used called the "In-Hospital Do Not Resuscitate (DNR) Order".

These orders can be withdrawn at any time if you change your mind, or if your condition changes. Hospital staff can help you with both the in-hospital and out-of-hospital DNR orders as each will need to be signed by your physician.

What is a traditional will?

A will is a document that contains your final wishes, including where you want your possessions, property, money, etc. to go. If you have young children, this is also where you can suggest the name of someone who could be the children's guardian if something were to happen. A traditional will can be a simple letter or formal document drafted by an attorney.

What happens if I don't have a will?

Your belongings will be distributed based on your state laws. Your money and possessions could go to your parents, your spouse, your kids or some combination of your nearest relatives. Laws may differ by state.

Sharing Your Wishes

How do I start the conversation?

It's best to talk face to face. Be aware of the person you are talking to and how they might respond. Consider bringing up an example you saw on the news or television. You may even want to role play before meeting, or invite a family member or friend for support.

There is an advance care planning guide developed just for young adults called "Voicing my Choices." It isn't a legal document, but rather a guide. If you chose to

complete it, sharing it with your loved ones is another way to initiate the conversation.

Can I make my death easier for my loved ones?

There is no right way to prepare. The best thing to do is talk with your loved ones. Share your wishes, hopes and memories. Even sharing your burial plan can provide them with a sense of comfort when they have to make difficult decisions later on. Listen to one another, and just spend time together.

What else do I need to know or should be doing?

Don't forget about your online accounts. Consider making a list of usernames and passwords, and then give the list to someone you trust in case of emergency. For example:

- **Financial institutions** – banks, credit cards companies, investment firms, loan agencies, anywhere that has financial records
- **Medical institutions** – doctor's offices, hospitals where you have been treated, anywhere that has medical records
- **Contracts** – cable, electricity, cell phone, water, gas
- **Insurance** – health, life, house, car, disability
- **Other** – email, social media, blogs

Actively start a legacy project. This is a great way to capture memories and spend time with the people you love. Some ideas include making a scrapbook of important people in your life, writing a blog about an experience that had a huge impact on you, learning how to make a famous family recipe, or joining an organization that is dedicated to one of your passions. Think about your hobbies, interests and values, and then think about how to share them with your loved ones. ■



Survivorship

My Story

“I was diagnosed with breast cancer at 25. I had a lumpectomy, radiation, and then chemotherapy. My cancer seems to be gone and on my last visit the doctor said ‘See you in a year.’ I’m incredibly happy, but also terrified. For the last 3 years I’ve come to the clinic almost every week and was always told the next steps I had to take. Now, it’s up to me. I know they aren’t abandoning me, but this feels a lot like leaving home and living on my own for the first time.”

What's next after active treatment?

A cancer survivor is anyone with cancer, from the time of diagnosis through the remaining years of life. After active cancer treatment (surgery, chemo and/or radiation) is complete, it is time to move to the next phase of care. You will now receive survivorship care. Survivorship care helps reduce, detect and treat any problems from cancer treatment. You will also be monitored for any new cancer.

Patients are typically transitioned to a Survivorship Clinic. Others may continue to see their primary oncologist. Ask your oncologist about your survivorship care options.

The goal of survivorship care is to have a personal care plan based on specific guidelines designed for survivors. Your health care team will work with other specialists and services to address your issues and concerns.

What happens in survivorship care?

You will visit with a health care provider. This visit may include the following:

- Review of your medical history
- Physical exam
- Side effect management
- Other cancer screenings based on age and gender (like skin, breast, prostate and cervical)
- Screening for lifestyle behaviors related to cancer risk (distress, healthy eating, weight management, regular exercise and tobacco cessation)
- Follow-up care plan and treatment summary
- Routine testing to monitor your remission status
- Referrals as necessary

My Story

“I’m Andrew and three years ago when I was 24 I had radiation and chemotherapy for lymphoma. I’m in remission and I can almost forget some days that I had cancer, except for the burning neuropathy in my hands and feet. My oncologist said it would go away with time. Well, shouldn’t it be gone by now?”

Long Term Effects

What kind of health issues might I have post-treatment?

Here is a list of some possible late effects from radiation and chemotherapy:

- Heart disease and high blood pressure
- Thyroid and other hormone problems
- Infertility – the inability to have children
- Osteoporosis and fragile bones
- Decreased kidney and liver function
- Secondary cancer – a different type of cancer that occurs as a result of treatment
- Neuropathy – tingling, burning or odd sensations especially in your hands and feet (includes “phantom limb” symptoms in amputees)
- Lymphedema – swelling of lymph nodes due to radiation or surgery
- Fatigue
- Constipation, diarrhea and digestive problems
- Hearing loss
- Memory, attention and learning problems
- Anxiety and depression

Will they go away?

Treatment-related side effects may improve. Some go away, others may not. Your health care team can give you more specific expectations based on your situation.

What can I do to treat my symptoms?

Your health care team will help you manage your symptoms. Here are some additional tips:

- Talk to other survivors with similar symptoms
- Explore integrative therapies like massage and acupuncture
- Eat healthy
- Manage your stress and get plenty of rest
- Stay physically active
- Go to a counselor or support group

If your symptoms don't go away and are interfering with your life, ask questions or get a second opinion.

My Story

“Hi, my name is Laura. I am 31 and a 10-year survivor of leukemia and a bone marrow transplant. As exciting as it was to hear that I was in remission and considered to be a cancer survivor, I didn't realize the long road I had ahead of me. I experienced a lot of emotions and went through many phases as I experienced life after cancer. I ultimately discovered they were all normal, but finding my ‘new normal’ was quite a journey.”

Support

What is a “new normal?”

New normal is a term used to describe the process some patients experience as they transition from active treatment to remission. Some patients may have little to no change in their lives, while others manage physical changes, value shifts and emotional highs and lows. New normal references the fact that even if you could go back to your old life, it would feel different. So you have to learn and discover what normal means to you now.

Where can I go for more support?

Contact your social worker or health care team for support. Here are some tips to get you started:

- Find a survivors group or other support group
- Join a non-cancer related club or group
- Enjoy or rediscover a hobby
- Journal, blog or use social media
- Make wellness a priority – exercise, eat healthy, manage your stress and get plenty of rest

Where can I find resources for caregiver support?

Ask your social worker or health care team about caregiver support groups, events and other activities.

How can I use my experience to give back and help others?

Some ways might be:

- Volunteer
- Sign up for a peer-to-peer matching program (both at your hospital and in the community)
- Get involved with an advocacy organization (general health or cancer specific) ■



Work

My Story

“It was a big year for me, my 25th birthday! I just finished my first year working as an electrical engineer. The job was good and I was enjoying my new financial freedom. The pain in my calf had been there for a couple of weeks before I decided to see a doctor. I assumed I strained a muscle exercising, but little did I know that I had a tumor the size of a golf ball. Being told that I had cancer was the last thing I expected at my age.”

Do I have to quit work? Can I work and get treatment at the same time?

You don't have to quit your job. Some patients are able to work and receive treatment at the same time. Other options might be to take a leave of absence or work well you feel able. Have an open discussion with your medical team. Talk about your treatment schedule, expected side effects and the impact it may have on your ability to work. You may need to talk to your supervisor or human resources representative if you need to make special arrangements.

What are my legal rights?

You have rights as an employee. Review the Family and Medical Leave Act (FMLA) and the Americans with Disabilities Act (ADA).

What if I can't afford to take off of work?

Before you make a decision about taking time off of work, look at your finances. What are your current obligations and assets? Do you have short-term or long-term disability? Do you have family or friends that can help with your bills? Create a new budget to evaluate the impact of a reduced income. You may be eligible for employer, federal, and/or state disability benefits.

What do I tell my boss?

You will need to talk to someone at your job regarding your needs. Identify the appropriate person and share as much information as you feel comfortable with. Some people tell their entire story, while others may only discuss their case in general terms (brief diagnosis,

treatment plan, and anticipated side effects). Once you have created a plan, communicate any changes in your work status to the right person and department, document everything in writing and keep copies of everything.

Do I have to tell everyone about my diagnosis?

Sharing your diagnosis is up to you. You do not have to tell everyone. Do what makes you comfortable. You might find it helpful to create a password protected blog or social media page to relay information and updates to your loved ones. This limits access to only your family and selected friends and colleagues.

When can I go back to work?

This is an important discussion to have with your doctor. You should only return to work when you and your doctor agree that you are physically able to fulfill your work duties. Your employer may require a letter from your doctor. ■

Resources

College

Students with Disabilities Preparing for Postsecondary Education-Know your Rights and Responsibilities: ed.gov/ocr/transition.html

Collegiate Cancer Foundation: collegiatecancer.org/scholarships.html

Communication

Caring Bridge: caringbridge.org

American Cancer Society – Telling Others About Your Cancer: cancer.org/treatment/understandingyourdiagnosis/talkingaboutcancer/talkingwith-friends-and-relatives-about-your-cancer

MyLifeLine: mylifeline.org

Dating and Intimacy

MD Anderson – Sexuality and Cancer Recommended Resources: mdandersontlc.libguides.com/sexuality

Livestrong – Relationships During Treatment: livestrong.org/we-can-help/emotional-and-physical-effects-of-treatment/relationships-during-treatment

CancerCare – Dating and New Relationships: During and After Cancer: cancercares.org/publications/293-dating_and_new_relationships_during_and_after_cancer

Emotions

Individual support

- Family and friends
- Mental health professional available through the hospital (social worker, psychologist, psychiatrist)
- Mental health professional in the community (contact your insurance for covered providers)
- Patient matching programs
- Social media

Group support

- Hospital support groups
- Community support groups
- **Online groups/forums:**
 - Stupid Cancer: stupidcancer.org
 - CancerCare: csn.cancer.org/forum
- **Camps/retreats:**
 - First Descents: firstdescents.org
 - Camp Mak-A-Dream: campdream.org/programs/young-adult-conference
 - Project Koru: projectkoru.org
- **General resources for young adults:**
 - Cancer180: cancer180.org
 - Stupid Cancer: stupidcancer.org

Exercise

MD Anderson – Complementary and Integrative Medicine Recommended Resources: mdandersontlc.libguides.com/integrative

Amputee Coalition: amputee-coalition.org

Ossur prosthetics: ossur.com

Disabled Sports USA: dsusa.org

Achilles International: achillesinternational.org

Fertility

MD Anderson – Fertility and Cancer Recommended Resources: mdandersontlc.libguides.com/fertility

Livestrong – Becoming a parent after cancer: livestrong.org/we-can-help/fertility-services

RESOLVE, The National Infertility Organization: resolve.org

American Society for Reproductive Medicine: reproductivefacts.org

Finances

MD Anderson – Financial and Legal Assistance Recommended Resources: mdandersontlc.libguides.com/financial

Business Center at MD Anderson: mdanderson.org/patients-family/becoming-our-patient/planning-for-care/insurance-billing-financial-support.html

American Cancer Society – If Your Health Insurance Claim is Denied: [cancer.org/treatment/finding-and-paying-for-treatment/understanding-health-insurance/managing-your-health-insurance/if-your-health-insurance-claim-is-denied](https://www.cancer.org/treatment/finding-and-paying-for-treatment/understanding-health-insurance/managing-your-health-insurance/if-your-health-insurance-claim-is-denied)

American Cancer Society Finding and Paying for Treatment: [cancer.org/Treatment/FindingandPayingforTreatment/ManagingInsuranceIssues](https://www.cancer.org/Treatment/FindingandPayingforTreatment/ManagingInsuranceIssues)

Internal Revenue Service – Medical and Dental Expenses: irs.gov/publications/p502/ar02.html

MD Anderson – Housing Information: mdanderson.org/lodging

American Cancer Society – Find Support Programs and Services in Your Area: [cancer.org/treatment/supportprogramsservices/app/resource-search](https://www.cancer.org/treatment/supportprogramsservices/app/resource-search)

Livestrong – How to Start a Fundraiser for Medical Bills: [livestrong.com/article/32653-start-fundraiser-medical-bills/](https://www.livestrong.com/article/32653-start-fundraiser-medical-bills/)

Insurance

MD Anderson – Financial and Legal Assistance Recommended Resources: mdandersontlc.libguides.com/financial

Getting covered if you're under 30: [healthcare.gov/young-adults/coverage/](https://www.healthcare.gov/young-adults/coverage/)

Department of Labor – COBRA information: [dol.gov/dol/topic/health-plans/cobra.htm](https://www.dol.gov/dol/topic/health-plans/cobra.htm)

Department of Health & Human Services – Medicaid vs. Medicare: [hhs.gov/answers/medicare-and-medicaid/what-is-the-difference-between-medicare-medicaid/index.html](https://www.hhs.gov/answers/medicare-and-medicaid/what-is-the-difference-between-medicare-medicaid/index.html)

American Cancer Society – Understanding Financial and Legal Matters: [cancer.org/acs/groups/content/@editorial/documents/document/acsq-020183.pdf](https://www.cancer.org/acs/groups/content/@editorial/documents/document/acsq-020183.pdf)

Patient Advocate Foundation – Your Guide to the Disability Process: [patientadvocate.org/index.php?p=490](https://www.patientadvocate.org/index.php?p=490)

CancerCare – Legal assistance: [cancercares.org/tagged/legal_assistance](https://www.cancercares.org/tagged/legal_assistance)

Nutrition

MD Anderson – Nutrition Recommended Resources: mdandersontlc.libguides.com/nutrition

MD Anderson – @TheTable: <https://atthetable.mdanderson.org/>

MD Anderson – Complementary and Integrative Medicine Recommended Resources: mdandersontlc.libguides.com/integrative

National Center for Complementary and Integrative Health: nccih.nih.gov/health/integrative-health

United States Department of Agriculture: [choosemyplate.gov](https://www.choosemyplate.gov)

Livestrong – A Cancer Nutrition Guide: images.livestrong.org/pdfs/livestrong-fertility/Meals-to-Heal-Well-Nutrition-Guide.pdf#ga=2.250316047.808599202.1512512561-488419780.1512512561

Planning

MD Anderson – Advance Care Planning Recommended Resources: mdandersontlc.libguides.com/advancecareplanning

CaringInfo – Download Your State’s Advance Directives: caringinfo.org/i4a/pages/index.cfm?pageid=3289

American Bar Association – Consumer Toolkit for Health Care Advance Planning: americanbar.org/groups/law_aging/resources/consumer_s_toolkit_for_health_care_advance_planning.html

American Cancer Society – Nearing the End of Life: cancer.org/treatment/end-of-life-care/nearing-the-end-of-life.html

5 Wishes (not legal in every state): agingwithdignity.org/five-wishes

Voicing My Choices – Advance Care Planning Guide for AYAs (not a legal document): agingwithdignity.org/five-wishes/pediatric/voicing-my-choices-faqs

Legacy Project: legacyproject.org/index.html

Survivorship

MD Anderson – Survivorship Recommended Resources: mdandersontlc.libguides.com/survivorship

Work

MD Anderson – Financial and Legal Assistance Recommended Resources: mdandersontlc.libguides.com/financial

Family and Medical Leave Act (FMLA): dol.gov/whd/fmla

Americans with Disabilities Act (ADA): ada.gov

Cancer and Careers: cancerandcareers.org/en

Cancer Legal Resource Center: cancerlegalresources.org

National Cancer Legal Services Network: nclsn.org

Q&A

for Young Adults
with Cancer



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