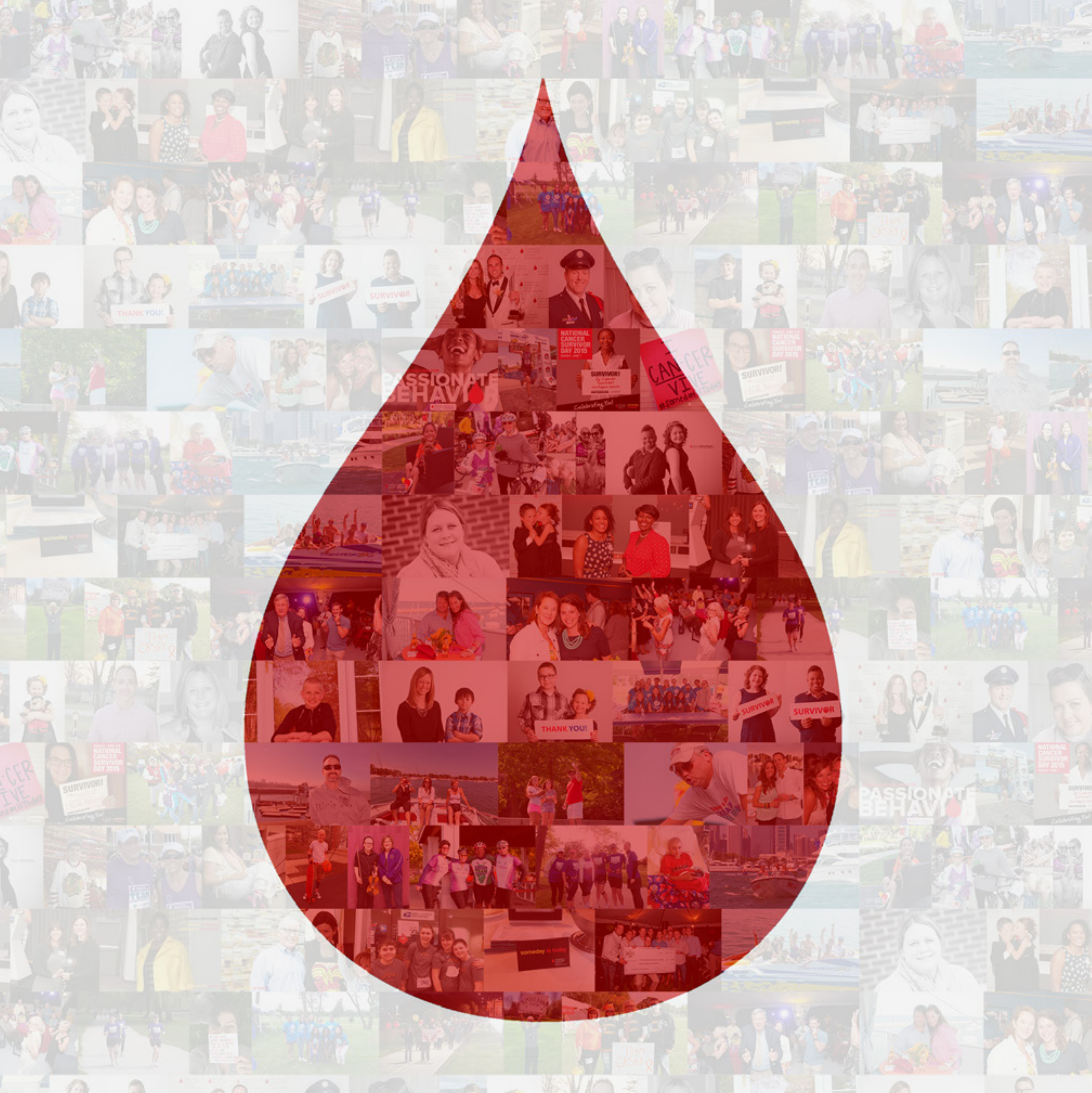
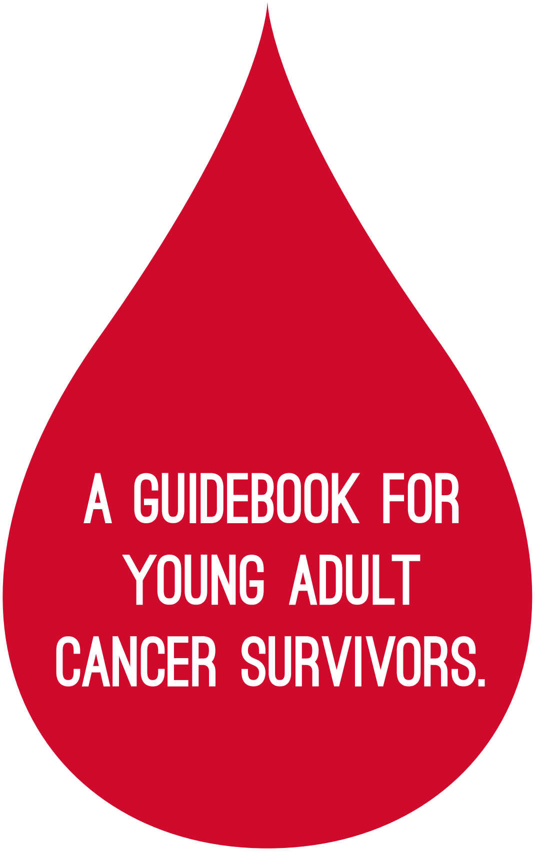


LEUKEMIA &
LYMPHOMA
SOCIETY®

Moving Forward
Adolescent & Young Adult Survivorship

The Leukemia & Lymphoma Society
Greater Illinois Chapter



A GUIDEBOOK FOR YOUNG ADULT CANCER SURVIVORS.

This guidebook does a great job in helping you figure
out the physical and psychosocial aspects of post cancer
treatment. I wish I had something like this back in the day.

Joe S.- 21 year survivor

Welcome to the Adolescent and Young Adult Survivorship Guidebook.

Like you, I am a survivor of blood cancer. I was diagnosed over 20 years ago, and at that time the survival rates were lower than they are today. I am thankful that with excellent medical attention and a supportive and loving family, today I can say I am a survivor.

But as you and I both know, being cancer-free is not the same as being free from cancer – there are residual elements of my cancer treatment that had an effect long after it ended. While no longer having cancer is a tremendous gift, as I entered survivorship there were questions that weren't easily answered. For example—is my future defined differently than it was prior to being diagnosed with cancer; are there intimacy and fertility issues to consider; will my ability to learn and excel at things change; what resources are available for me and my family?

That is the benefit of this guidebook. It will offer answers to some of your questions and point you towards resources that may help. While I didn't have access to this information when I was diagnosed, it is still beneficial to me after being cancer-free for so many years.

So welcome to the world of survivorship! It's a pretty good life–I have a beautiful wife, two delightful children, I run two businesses–and I still have that wonderful, supportive family I had when I was going through treatment. There is life after cancer. And this guidebook can make yours even better.

Yours in good health,

JCell

Joe Caltabiano

Contents

> “NOW THAT TREATMENT IS OVER
> I AM READY TO MOVE FORWARD.”

WELCOME TO SURVIVORSHIP

Surviving cancer is a great triumph. Every cancer patient looks forward to the day when the oncologist finally says that treatment is complete. That day marks the beginning of a new journey: survivorship. For many young adults (ages 15-39), who may be either starting their journey or entering the next phase of adulthood, life after treatment can present a new set of challenges.

Some survivors may have mixed emotions, from relief that treatment is over, to anxiety about the future. Others may experience long-term adverse effects from the treatments. Still others may desire practical help to get back to school, job, relationships ... or to begin a new path altogether.

This guidebook was created to provide young adult cancer survivors with the resources to meet these new challenges. Contained within this book, you will find tips for creating your own survivorship care plan, identifying late effects, re-entering school and work, coping with fertility, and living healthfully. And, because survivorship is unique for every person, we have included an extensive list of national organizations, local resources, and online communities, where you can find the tools to map your own unique journey.

> “A SURVIVORSHIP CARE PLAN WILL HELP YOU KEEP ALL OF THE MOST IMPORTANT INFORMATION CLEAR AND ORGANIZED. IT WILL PROVIDE YOU WITH CLARITY ABOUT YOUR CANCER EXPERIENCE, AND HELP YOU TO ACHIEVE YOUR BEST POSSIBLE FUTURE HEALTH.”

Treatment Summary & SURVIVORSHIP CARE PLAN

Once your cancer treatment is completed, you might be ready to take a very long break from anything medical. The reality is that having a cancer diagnosis, even when cured, means regular care is critical to protecting your long-term health.

As you move beyond your cancer treatment, your medical team should provide you with an individualized survivorship care plan–a document that spells out guidelines for monitoring and maintaining good health.

A survivorship care plan provides clarity – for you and for future health care providers. It describes your diagnosis; details every aspect of your treatment, including any radiation, medications, dosages, or surgeries; and provides a schedule for monitoring and coordinating your future care. In short, it is a description of what you have experienced in the past and what you can expect in the future. With all details of your treatment in one, organized document, any future specialists who treat you will have the right information for your specific needs.

Bring a copy of your plan to every medical visit. It is your assurance that you get the customized follow-up care you deserve.

A special note for Chronic Myeloid Leukemia (CML) patients

As treatment for CML is completed, (such as after a successful stem cell/ bone marrow transplantation) or continues long-term, (such as treatment with targeted therapy), talk with your doctor about developing a follow-up care plan. This plan may include lifelong follow-up physical exams, medical checkups blood tests, and occasional bone marrow tests to watch for signs or symptoms of recurrence or late effects. It is critically important that both you and your health care team stick to the scheduled tests.

THREE KEY PARTS OF A SURVIVORSHIP CARE PLAN ARE:

1. Record of your medical history
2. Summary of your cancer diagnosis and treatment
3. Follow-up care plan

1. YOUR MEDICAL HISTORY.

A detailed medical history will help you and your future health care providers sort out which concerns may be related to your cancer and which are not. List all your current and past health experiences from as far back as possible, including:

- Medical and dental problems
- All vaccinations and immunizations
- Full list of medications you take (prescribed and over the counter)
- Adverse effects or reactions to previous medicines or treatments

- List of past injuries and the outcome
- List of surgeries and results
- Pain problems
- Diet and nutritional concerns
- Allergies and sensitivities
- Your family medical history – blood relatives who have had diabetes, cancer, stroke, and other conditions

2. SUMMARY OF YOUR CANCER DIAGNOSIS AND TREATMENT.

As time passes, it may be difficult to remember every detail of your diagnosis and treatment plan. Because this information is critical to the specialists who will care for you throughout your life, you will need to provide them with your:

- Specific diagnosis
- Medication names and dosages
- Radiation details, if used
- Any surgical procedures
- Any unusual or especially severe or acute complications

This record (ask your oncologist for a written summary of your cancer treatment) will help you discuss post-treatment needs with your health care provider and will serve as an effective communication tool between your oncologists and primary care physicians.

3. FOLLOW-UP CARE PLAN.

As a cancer survivor, you deserve coordinated, personalized, preventive follow-up care that addresses your current concerns, provides a schedule to continue monitoring your health, and offers guidance to future clinicians. A follow-up care plan includes:

- The overall goal of your future treatments (i.e.; cure, control, or symptom relief)
- A schedule of future screenings and tests
- Aspects of your care that your primary care physician should follow
- Concerns your specialist will continue to monitor
- Signs, symptoms, and health risks you should report
- Long-term adverse effects that you may experience
- Strategies for lifestyle choices to improve your future health
- Community resources where you can get support

In summary, this plan includes recommendations for ongoing health monitoring, strategies for improving health, and information about future cancer screenings and health risks related to previous treatment.

WHAT TO DO IF YOU DO NOT HAVE A SURVIVORSHIP CARE PLAN

Every cancer survivor needs a comprehensive care plan to help improve their health, guide future health care, and improve quality of life. If your health care team has not provided you with a written survivorship care plan, download and print out the ASCO Treatment Summary and Survivorship Care Plan template (www.asco.org) and have your oncologist complete it immediately. Find a copy of the template in the appendix section of this guidebook.

WANT MORE GUIDANCE?

Many advocacy groups, professional organizations, and cancer centers have developed templates and tools for writing a survivor care plan, including:

- **American Society of Clinical Oncology (ASCO)** – provides survivor care plan templates that can be used for any cancer diagnosis. www.asco.org

- **LIVESTRONG** – has an online tool in which patients develop their own plan for review with their health care providers. A Spanish version is also available. www.livestrongcareplan.org

- **Children's Oncology Group** – developed the Long-Term Follow-Up Guidelines as a resource for health care providers. www.childrensoncologygroup.org

- **Journey Forward** – provides an electronic Medical History Builder to help patients summarize their medical history. www.journeyforward.org

- **Passport for Care® Survivorship Care Plan** – a user-friendly, web-based program guides cancer survivors and their health care providers in making decisions to maximize quality of life. https://cancersurvivor.passportforcare.org/

- **National Comprehensive Cancer Network** – a nonprofit alliance of cancer centers, offers Taking Charge of Follow-up Care to guide patients who are making formal survivorship plans. www.nccn.org

NOTES

LATE EFFECTS

Late effects – adverse effects caused by treatments that help cure cancer – may not become apparent until after your treatment is over, sometimes several years later. Although improvements in reducing late effects continue to evolve, the powerful chemotherapy, radiation, and surgeries that killed your cancer can cause late effects in some patients.

Learning about potential long-term effects is the first step to taking control of your health. Adhering to your schedule of follow-up care is the best way to monitor and manage any late effects. Your oncologist or specialist nurse will talk to you about late effects associated with the particular treatments you had.

COMMON PHYSICAL LATE EFFECTS INCLUDE:

- **Bone damage –** Chemotherapy and corticosteroid treatment can decrease bone density, which increases risk of fractures. Reduced bone density is known as osteopenia, which can lead to osteoporosis, a more severe reduction in density.

- **Fatigue –** Most survivors experience fatigue: it is completely normal. The good news – there are specific techniques for coping with it. Unfortunately, many young adults may misinterpret this symptom as a sign of recurrence. Worse, many survivors blame themselves for their fatigue, which adds unneeded guilt and frustration. Speak up about fatigue – it is the best way to get the help you need.

> “LIFE AFTER TREATMENT CAN BE BOTH AN EXCITING AND SCARY TIME. HEARING ABOUT POSSIBLE LATE EFFECTS CAN BE OVERWHELMING AT TIMES AND BRING BACK MANY EMOTIONS. IT IS IMPORTANT TO KEEP IN MIND THAT THE GOAL OF LONG TERM FOLLOW UP IN A SURVIVORSHIP CLINIC IS TO KEEP YOU HEALTHY AFTER TREATMENT. REGULAR FOLLOW UP AND OPEN CONVERSATIONS WITH YOUR DOCTOR WILL HELP TO MANAGE ANY LATE EFFECTS, SHOULD THEY APPEAR. CONNECTING WITH FELLOW SURVIVORS OR A MENTAL HEALTH PROFESSIONAL MAY ALSO HELP TO DEAL WITH ANY EMOTIONAL LATE EFFECTS AND CAN BE AS IMPORTANT AS FOLLOWING UP WITH A DOCTOR.”

-MARGARET S. GOSSEN, MA, LCSW
PEDIATRIC ONCOLOGY SOCIAL WORKER
UNIVERSITY OF ILLINOIS HOSPITAL & HEALTH SCIENCES SYSTEM

- **Development of secondary cancers –** Chemotherapy and corticosteroids have been associated with developing a secondary cancer, especially in patients who also had radiation therapy. Skin cancer is the most frequent: make sure you get an annual skin exam by a dermatologist. Young women who had radiation to the chest area are at higher risk of breast cancer later in life. Report any new or unusual symptoms to your physician, and make sure you schedule mammograms, colonoscopies, and any other routine screenings.

- **Heart problems –** Radiation to the chest and certain types of chemotherapy can result in heart muscle injury or heart failure later in life.

- **Hypothyroidism –** An underactive thyroid gland can be caused by radiation. See your primary care physician if you experience increased sensitivity to cold, weight gain, painful joints, muscle aches, or pale, dry skin, as these could be signs of hypothyroidism.

- **Infertility –** High-dose chemotherapy or blood and marrow stem cell transplant can cause premature menopause or fertility problems in women. Men may experience temporary or lasting sterility.

- **Lung problems –** Chemotherapy and radiation therapy to the chest may cause scarring of the lungs, inflammation, and breathing difficulties.

- **Lymphedema –** Swelling in the arms and legs can occur when a blockage in the lymphatic system prevents fluid from draining adequately. Lymphedema may develop immediately after surgery or radiation therapy, or it may occur months or years after cancer treatment has ended. There are solutions: if you experience swelling, talk with your physician as soon as possible to learn how to manage your symptoms.

- **Peripheral neuropathy –** Numbness, tingling, or pain in the hands and feet – can last months after therapy.

MENTAL AND EMOTIONAL LATE EFFECTS ARE ALSO COMMON:

- **Psychological effects –** Most survivors feel like they have been on an emotional roller coaster – anger toward the cancer, feeling isolated while being treated, relief it is over, grateful to still be alive, fear of recurrence … the list goes on. These are strong emotions to handle early in life. Some survivors return to life with a new, more positive outlook. Others feel down, depressed, hopeless, numb, or irritable. Some patients – even their caregivers – experience post-traumatic stress disorder – an anxiety that can develop after experiencing an extremely frightening or life-threatening situation. That is why it is so important to answer any questions about your mood as honestly as you can: your health care team should be screening for depression, PTSD, anxiety, and more.

- **Cognitive effects –** Trouble concentrating, mental fogginess, forgetting things, "just can't find … that … word … " and other mental lapses are so common. Some survivors refer to it as "chemo brain." Even survivors who never had chemotherapy can feel mentally sluggish. No need to despair: there are ways to cope. In many cases, cognitive training strategies can help increase memory performance and, simple compensatory strategies and accommodations at work or home, can be really helpful in performing your everyday tasks. Talk to your health care team, or find a counselor who specializes in treating cancer patients to help you reduce the problems and develop ways to cope with them.

If you remember nothing else, remember this: you can get help!

From clinical services to practical advice to peer support, help is available, often as close as your keyboard.

- Be as open and honest as you can about everything you are experiencing during your follow-up visits.
- Reach out to a grief counselor, pastor, or loved one to let them know how you feel.
- Connect to online survivor groups.
- Look for local support groups in your community.

Support services such as those provided by The Leukemia & Lymphoma Society, CancerCare, the Lance Armstrong Foundation, Stupid Cancer, Planet Cancer, and others, can be critical factors in healing.

Please see page 53 for information on connecting to these and additional support organizations.

STANDARD OF CARE

Meeting your emotional, practical and social needs is as important as treating your physical symptoms. In order to better meet these needs, you will be asked to complete a survivorship screening form during your medical visits. Your answers to the questions on the form will help clinicians assess your post-treatment mental, physical, and emotional health and give you the necessary information or connect you with resources to help meet your specific needs and improve your quality of life.

It is important that you take an active role in your care by letting your care team know how they can support you in managing your health and wellness, so ALL your care needs are addressed – physical, emotional, spiritual and social needs.

Print out the “Questions for your Survivorship Appointment” form at LLS.org/Patient Services and take it to future appointments along with your survivorship care plan (a copy of the form is in the appendix section of this guidebook).

> THINKING ABOUT THE LATE EFFECTS OF CANCER AND ITS TREATMENT SIDE EFFECTS CAN BE OVERWHELMING. YOUR FIRST LINE OF DEFENSE AGAINST THIS IS TO MANAGE YOUR ANXIETY. TAKE 8 DEEP, SLOW BREATHS AND REMIND YOURSELF THAT YOU ARE A SURVIVOR! NEXT, REMEMBER THAT KNOWLEDGE IS POWER-MAKE SURE YOUR ONCOLOGIST GIVES YOU A COMPLETE HISTORY OF YOUR CANCER DIAGNOSIS AND TREATMENTS. ALSO ASK YOUR ONCOLOGIST TO GIVE YOUR PRIMARY CARE PROVIDER A LIST OF ALL THE ROUTINE TESTS AND SCREENINGS YOU SHOULD HAVE GOING FORWARD. FINALLY, COMMUNICATION IS KEY. COMMUNICATE WITH BOTH FELLOW SURVIVORS ABOUT THEIR EXPERIENCES AND YOUR MEDICAL TEAM ABOUT YOUR NEEDS AND CONCERNS. A GOOD PRACTICE IS TO KEEP A SMALL NOTEBOOK WITH YOU AT ALL TIMES (OR USE AN APP ON YOUR PHONE) SO YOU CAN WRITE DOWN ANY QUESTIONS YOU HAVE OR NOTE ANY CHANGES YOU OBSERVE IN YOUR BODY. BEING YOUR OWN ADVOCATE BY USING THESE TIPS WILL MAKE MANAGING ANY LATE EFFECTS OF CANCER MUCH EASIER.

- ANA G. GORDON, AM, LSW
UNIVERSITY OF ILLINOIS HOSPITAL & HEALTH SCIENCES SYSTEM

NOTES

Blood & Marrow
STEM CELL TRANSPLANTATION

A stem cell transplant may be the best treatment option for patients with blood cancers.

While transplants can make a cure possible, the intense procedure and related treatments can impact several systems in your body and may leave additional late effects. Some may clear up in a few weeks or months. Other complications may linger for the rest of your life. If you have had a blood and marrow stem cell transplant – whether autologous (your own stem cells) or allogeneic (donor stem cells) – you need to be especially diligent in monitoring your health throughout your life.

Potential late effects after having a transplant may include:

- **Organ damage –** to the liver, kidneys, lungs, heart, or bones and joints
- **Secondary cancers –** skin cancer, oral cancer, and breast cancer are most common
- **Infertility –** caused by irradiation of the gonads or high-dose chemotherapy (fertility may persist in some patients, so when pregnancy is not desired, contraceptive measures are important)
- **Hormone changes –** such as changes in the thyroid or pituitary gland
- **Cataracts –** clouding of the lens of the eye, causing vision loss, may occur several years after the transplant

> NAVIGATING THE POST-TRANSPLANT JOURNEY MAY STILL BE FILLED WITH CHALLENGES; IT IS ESSENTIAL TO PARTICIPATE ACTIVELY IN YOUR FOLLOW-UP CARE AND TO HAVE A SUPPORTIVE ENVIRONMENT OF CAREGIVERS AT HOME AND IN THE CLINIC TO HELP YOU ACHIEVE YOUR GOALS OF OPTIMIZING YOUR POST-TRANSPLANT QUALITY OF LIFE, MINIMIZING TOXICITY AND RESTORING A HEALTHY AND PRODUCTIVE LIFESTYLE.

- W. STOCK, MD
CO-DIRECTOR ADOLESCENT AND YOUNG ADULT ONCOLOGY CLINIC
THE UNIVERSITY OF CHICAGO MEDICINE

Please know that, even though you are at risk for late effects, the impact of these complications can be reduced and managed. That is why it is so important to make sure you continue to get good follow-up care. If you are unable to return to your transplant center for yearly visits, your local oncologist should be aware of all the recommendations for monitoring your various organ systems.

You can find more information and post-transplant care guidelines at:

- The Leukemia & Lymphoma Society offers a free booklet, Blood and Marrow Stem Cell Transplantation at www.LLS.org/booklets
- The American Society for Blood and Marrow Transplantation, www.asbmt.org
- The Center for International Blood and Marrow Transplant research, www.cibmtr.org

NOTES

“I AM NOT DEFINED BY MY CANCER.”

Life After
TREATMENT

Ending treatment signifies an important accomplishment however, recovery can come with its own set of challenges. You likely feel joyful, relieved, excited ... and perhaps a little confused, maybe even worried. After spending so much time entirely focused on getting well, many young adult survivors are left wondering, "Now what?"

Figuring out how to move on after cancer treatment is one of the hardest things for any survivor to do. It is at this point when many survivors finally are able to process their feelings and think about what comes next. For many, life after cancer is a "new normal."

It is important that you give yourself time to adjust.

NOW WHAT?

Like many young adults, you are beginning life on your own: you may have expectations of finding a companion, having children, settling down, and building a career. But, while you were being treated for cancer, it might have felt like these common life expectations were put on hold. Now that treatment has ended, you may find that you can still achieve some of your goals, and perhaps need to revise others.

Cancer may have left you with changes in your body, your energy level, or your emotional state, which could slow down or prevent you from pursuing your original goals as soon as you would like. Or your goals may have changed entirely. Or you may not have any clear idea of what you want to do next. While this state of limbo can be frustrating, there is no need to feel rushed or pushed. A time will come when you feel ready to explore new opportunities.

Take some time to look into different options, and write down a few short-term and long-term plans. Talk to your family, spiritual leaders, career advisors, or social workers for advice. There is no wrong or right way to deal with survivorship. Doing what feels right for you is the most important thing.

SCHOOL AND STUDY

Many young people who have been through cancer treatment feel it is important to go back to school or college as soon as possible. If you have been away for a long time, however, you might feel nervous about things not being the same as before.

You may feel self-conscious about the changes you have experienced, or worry about how others will react to them. People at school may treat you differently … even act a bit weird at first. You might be worried about catching up on work, or having to repeat classes and being behind your friends.

HERE ARE A FEW TIPS TO CONSIDER WHEN RETURNING TO SCHOOL:

Tell your teachers what to expect. You, your parents, or someone from your medical team can talk with your teachers and guidance counselors about what to expect when you return to school. Your teachers might be able to prepare your classmates and help them understand why you might feel or look different. Or perhaps someone from the hospital or a local cancer organization can visit your school to talk to teachers and students about cancer.

Asking for help is OK! Everyone will want to help … but few will know how. People may be afraid to offer help because they are worried you will think they pity you.

Be honest with your friends about what you need and what you do not. It is best to be specific: ask for extra help in your classes and, if necessary, tutoring.

Remember, you do not have to go through this alone. **Your friends and teachers want to help – ask them!**

Talk openly about your disease. Often when things are not talked about openly, rumors can get started. You can prevent people at school from talking about you behind your back by telling them upfront about what is going on and letting them know that it is OK to ask questions. If you talk openly about your disease, it will make it easier for you and everyone else.

Coping with looking different. If you are worried about how your friends will react the first time they see you after your treatment, catch up with them before you go back to class. Invite them over or go out with them so they can get used to the way you look at the moment.

Take it easy. You might feel ready to jump right back into school and make up for lost time. Take it slowly – it could be harder than you expect.

"SCHOOL IS A PLACE FOR LEARNING AND FUN BUT RETURNING TO SCHOOL AFTER CANCER TREATMENT CAN BE A TOUGH ADJUSTMENT. YOUR PARENTS, HEALTHCARE PROFESSIONALS AND SCHOOL PERSONNEL, PARTICULARLY YOUR COUNSELOR OR SOCIAL WORKER, CAN HELP YOU TAKE STEPS TO ASSURE A SMOOTH TRANSITION FROM ACTIVE TREATMENT TO BACK TO SCHOOL."

– T. CONNELLY, SOCIAL WORKER
BREMEN HIGH SCHOOL

This might be because you were away a lot, or because your treatment has made it harder to concentrate or grasp new information. You might have to work harder than you did in the past to achieve your goals. Maybe your goals will change. That's OK. Just know who you are and what you want. The rest will follow.

Your health and getting better is the most important thing at this time, and you, your teachers, and your parents might have to adjust your expectations for now.

HIGHER EDUCATION

Your cancer treatment and adverse effects may impact your decision to enroll in, or continue with, your college or graduate school education. It might also impact your choice of courses and method of study.

You might be worried about:

- Causing more stress to your body
- Not being able to meet the academic requirements, or even failing
- Not fitting in or receiving unwanted attention
- Physical accommodations such as wheelchair access
- Not being able to complete particular types of assessments, practical work, or field trips

Depending on your treatment and adverse effects, you may want to defer your studies while your body adjusts. Remember, staying healthy is your number one priority.

If you are planning for college, here are some questions to ask:

- **Location** – Would you feel more secure attending college closer to home with support nearby, even if that is a different school than you originally intended?

- **School size –** Will you feel more comfortable in a small school with a low teacher/student ratio that provides opportunity for individualized instruction? Or, will a larger institution with an established program for students with disabilities better suit you?

- **Campus layout –** If you are experiencing fatigue or mobility issues, consider ease of getting around. Is the campus hilly or flat? Spread out or compact?

- **Transportation –** Is accessible public transportation convenient?

- **Disability services –** Are there quality disability services geared toward cancer survivors? Will they meet your specific needs? Meet with the staff before you enroll to discuss your needs and their accommodations.

- **Local hospital and medical facilities –** Talk to your oncologist about your needs for treatment or follow-up care. Will medical facilities near campus be able to provide what you need?

- **Culture –** How well dœs the administration and faculty understand the needs of people with learning and other disabilities? What is their commitment to addressing your specific needs?

- **Time frames –** As much as possible, be realistic about your energy levels and current abilities. Will you be able to meet the course requirements and completion dates?

- **Teaching styles –** Will academic advisors be able to steer you toward instructors whose teaching style complements your learning style?

- **Flexible learning venues –** If you need to leave town for treatment or cannot get to class, will the school provide online learning or other options?

- **Other students with disabilities –** Finding others who are going through similar struggles can help survivors navigate problems and know what to expect. Will you be able to find students you can relate to?

Most campuses have a student center that provides counseling, financial assistance, tutoring, career advice, health services, housing referrals, and more. Take advantage of any available services that will help you ease into campus life.

WORK

Returning to work – and a daily routine – can help you regain confidence and independence. Transitioning back to work may feel overwhelming: give yourself plenty of time to prepare.

BEFORE YOU GO BACK

Every work situation is different and every survivor's abilities are different. Of course, you will discuss your decision with your physicians and your manager, but it is up to you to decide when you are ready. Your decision could depend on your financial resources, health insurance, the type of work you do, and the nature of your recovery.

To make your transition smoother, you may want to:

- **Coordinate with your employer –** Set up a meeting with your human resources department to discuss transition plans. Get details on any options that may help you, such as a disability management program, a flexible or part-time schedule, or other accommodations. This is also a good time to review and update your insurance and benefits.
- **Know your limits –** Do not try too much too soon, and take regular breaks as needed.
- **Request modifications –** A different chair, a change in desk height, little things can make a big difference in making you more comfortable and productive.
- **Be clear –** Tell your boss about any medical appointments and treatments you need to schedule.
- **Adjust –** As much as possible, try to schedule your day so you do the most work and meetings at the times you feel the best.

- **Talk –** Decide how much and what you want to tell your colleagues about your cancer. One option: tell a few colleagues you trust and ask them to inform others.

KNOW YOUR RIGHTS

Get to know your workplace rights and responsibilities, so you can prepare appropriate responses to challenges you may face.

The **Americans with Disabilities Act** (ADA) and other regulations protect the employment rights of cancer survivors with disabilities. For example, it is required that your employer provide "reasonable accommodations" to allow you to do your job, as long as you are qualified to perform the essential duties of your position. Such accommodations may include part-time hours, reassignment to another position, leave time for medical visits, or periodic work breaks to take medications and contact your health care team. Before granting a reasonable accommodation, your employer may request documentation that verifies your limitations, such as fatigue, chronic pain, and cognitive difficulties, which ADA classifies as disabilities. Note that employers are not allowed to ask for your medical records.

GETTING A NEW JOB

Some survivors find the cancer experience reshapes their career priorities. Others consider a change in direction. Whether you are looking for your first job or have been inspired to make a change, there are many options and possibilities available to you. Take your time to think about what is really right for you.

If you are qualified for a job and are physically able to do the work, your cancer history should not affect your ability to get a job:

- An employer cannot, by law, ask questions about your health or about a medical condition.
- An employer cannot refuse to hire you because of your health history.
- It is your personal decision whether to tell a future employer about your cancer.
- Your employer must keep any information you share about your history of cancer or any other medical information confidential.
- An employer is allowed to ask you in a job interview about your abilities to perform specific tasks related to the job, such as whether you can lift up to 50 pounds or travel.
- You may find it helpful to provide a potential employer with a letter from your physician that explains your health status and ability to work.
- You may worry about how to explain gaps in your work history or the reason for leaving the position you had before your treatment. Consider talking with a career counselor or social worker for advice on interview skills and resume preparation that present you in the best light.

Keep in mind that job searching can be stressful and discouraging for anyone. Taking proactive steps can boost your self-esteem and help you stay positive while you are looking for employment.

You can find more information about workplace and cancer at: www.cancerandcareers.org

FINANCES

Whether you are a student, a young professional, or newly settled and starting a family, young adulthood is a time when finances are not always secure and when insurance coverage is not a given. In fact, young adults are much more likely to be uninsured or to have very limited health insurance when compared to children or older adults.

The cost of medical care is considerable: even with insurance, you may need to pay out-of-pocket for transportation to the medical center, co-pays, and deductibles. If you delayed education or career advancement due to your treatment, you might feel even further behind.

Although managing insurance and financial issues may seem intimidating, there are a number of ways to get help during a time of need. Check out the national and local organizations that offer financial information, advice, and support for cancer survivors listed in the Resources section.

If you are under age 26, the Affordable Care Act allows you to stay on your parents' health insurance, even if you are married, financially independent, or no longer live with your parents.

Once you reach age 26, you can continue to buy your parents' plan at your own expense for up to 36 months through COBRA, the Consolidated Omnibus Budget Reconciliation Act. This can be expensive, as you will pay the full cost of the plan, plus an administrative fee, (generally 2%). In many cases, less expensive options are available in the individual market.

Find more information on choosing a plan when you have a history of cancer at http://triagecancer.org

> “A CANCER DIAGNOSIS OFTEN CHANGES OUR ROLES WITHIN RELATIONSHIPS IN OUR FAMILY, WITH OUR FRIENDS, OR BETWEEN ROMANTIC PARTNERS. WE MAY EXPERIENCE CHALLENGES COMMUNICATING DUE TO CHANGES IN OUR SELF-IMAGE OR IDENTITY. WE MAY FEAR APPEARING WEAK, NEEDY OR VULNERABLE. FAMILY MEMBERS, FRIENDS AND ROMANTIC PARTNERS MAY STRUGGLE WITH CHANGES IN THEIR ROLES AS WELL, SUCH AS BEING THE PRIMARY CAREGIVER FOR A SPOUSE OR PARTNER, OR FRIENDS HAVING A SENSE OF VULNERABILITY THAT THEY ARE NOT IMMUNE FROM BEING DIAGNOSED WITH A LIFE LIMITING OR LIFE THREATENING ILLNESS.”

-JANINE GAUTHIER MULLADY, PHD
CLINICAL HEALTH PSYCHOLOGIST
LIFE RESET SOLUTIONS, PC

RELATIONSHIPS AFTER CANCER: FAMILY, FRIENDS, PARTNER

Cancer often changes the way you relate to your family, friends, romantic partners, peers as well as the way they relate to you. Chances are, you have noticed that some of your relationships have felt different. You may have felt alone and sad as you have seen people turn away from you or otherwise treat you differently from how they had before. Or you might have felt truly supported by those who stuck with you during your cancer journey.

Everyone close to you has been changed by your cancer experience. Navigating relationships can be challenging when transitioning to life after treatment. You may recognize some of these common scenarios

- **Changing responsibilities –** During treatment, you might not have been able to handle all the household duties you had performed before your cancer diagnosis. Now that your cancer treatment is over, your partner or other family members might be expecting you to resume those responsibilities. But you might not feel up to it yet. This can be frustrating for your family members, and you might feel pressured to do more before you are ready.

- **Changing roles –** If you were a take-charge kind of person before cancer, you may find that your partner or family had to take over that role while you were in treatment. Figuring out when, how, and whether to switch back can be confusing and awkward.

- **Withdrawing from you –** You may find that some friends and family members are avoiding you, such as when someone stops returning your phone calls. Whether subtle or overt, it hurts. People withdraw for a number of reasons. They might not know what to say or are worried about saying the wrong thing. People might not know how to offer you support. Others will not know how to react.

- **Giving you too much attention –** Rather than feeling lonely, you might find yourself being smothered with good intentions. Friends or family might baby you and insist on doing things for you, even when you don’t need it. They love you – perhaps they want to protect you – but in fact they are giving you too much attention.

- **Being nosy –** Some people ask a lot of questions — perhaps more than you are willing to answer.

- **Confusing expectations –** If your recovery is not going as well as you had hoped, or things are not getting back to "normal" as quickly as you would like, you might be frustrated. Try not to take your frustrations out on the people around you. If you do, you could push them away.

Nurturing relationships with friends and family

Before feelings of loneliness and isolation get you down, acknowledge that all of your loved ones care about you, and they each have their own way of reacting to your cancer. Tips for repairing relationships include:

- **Start the conversation –** Some people might want to ask how you have been feeling, but not know what to say. Or they may worry that they will upset you. Start the conversation yourself. Let people know whether you welcome their questions — or whether you prefer not to talk about your cancer at that time.

- **Accept help –** Friends and family are going to ask you if there is anything they can do. Plan ahead and come up with specific suggestions, from helping around the house to just being there for you when you need to talk.

- **Let others know what to expect of you –** Be honest about what you can do and what you cannot. If you are not ready to assume the responsibilities you had around the house before your cancer diagnosis, do not feel pressured to take up those duties too soon. Just tell your family what to expect so that they are not left wondering. When you are ready to take up your prior duties, let your family know that routine tasks can help you feel more normal and aid in your recovery.

- **Keep the friendships that matter –** Some people may withdraw from you: you will have to let them go. Try not to spend emotional energy patching up relationships that may not have been strong to begin with. Invest your time and energy in the friends who are closest to you.

- **Plan what you will say –** You will get questions about your cancer and your treatment – some of those questions may feel uncomfortable. Try to anticipate how you will tell someone you are uncomfortable with their questions, or how you will redirect the question, or ways to change the subject.

- **Be patient with others –** If you become frustrated, remember that the people around you have good intentions. They may not know the right things to say or do, so their words and actions may seem inappropriate or critical. That awkwardness may come from unfamiliarity with the situation. With time and patience, things will improve.

- **Stay involved when you can –** Some friends or family might not invite you to do things because they assume you are not yet ready for social activities. Let these people know when you want to be included — or ask someone else to relay your message.

- **Seek out support groups –** You will have times when you feel that people who have not had cancer cannot understand what you are going through. You are right: they cannot. Discuss your feelings with other cancer survivors who get it. Find them in community or online support groups. Support groups are also available for your friends and family. Suggest these groups to the people closest to you.

- **Get professional help –** A counselor or therapist will have ideas on ways to better communicate with the people around you. Ask your physician for a referral.

SEXUALITY AND INTIMACY

Dating and exploring your sexuality is an important part of being a teenager and young adult.

Some survivors, however, may experience changes in their sexual function or sex drive due to either the cancer or its treatments. Cancer may have affected your confidence, self-esteem, and appearance. You may worry that you are less attractive and that it will be difficult to form new relationships.

Many wonder whether, and how, they will tell future partners about their cancer, particularly if their fertility has been affected. Disclosure of a cancer diagnosis can be very difficult and requires careful consideration, planning, and support.

Issues of sex and sexuality may be uncomfortable or challenging for you or your health care providers to address directly. Still, even if it feels awkward, it is important to discuss what you are experiencing with a member of your health care team. Intimacy is very closely connected to your feelings about your relationship as well as your feelings about yourself. Find a counselor who has experience working with people with cancer and talk through some of these issues: you will help both yourself and your partner.

SPIRITUALITY AND RELIGION

You have a right to your own beliefs and about religion, spirituality, and faith. For some who have coped with a life-threatening illness, religion and spiritual practice can be an important source of comfort and support. Others may see recovery as a time of spiritual exploration. Still others might not be interested at all.

If you want explore your spirituality, here are a few options:

- Begin an ongoing dialogue with your clergy or counselor
- Join a group for meditation, prayer, and support
- Read spiritual writings
- Keep a journal to express your feelings, thoughts, and memories

Regardless of where you are right now, it is important to find whatever support that is meaningful for you. Remember, it is OK to assert your needs if your beliefs are challenged in a way that is not respectful for you.

NOTES

> “JUST REMEMBER THAT EVERY PATIENT, EVERY CANCER, EVERY TREATMENT IS UNIQUE, AND SO IS THE POTENTIAL FOR IMPACT ON FERTILITY.”

FERTILITY

Fertility and childbearing can be essential components of a young adult's life. Although unpredictable, cancer and cancer treatments may affect a person's ability to conceive. Sometimes these issues are overlooked when the patient is younger, single, or needs to start treatment quickly.

If you are concerned about your ability to conceive children – now or in the future – speak to your health care provider. Although these conversations may be awkward at first, you may find options to protect or preserve your fertility.

FOR MEN

Factors that could influence fertility include: your age at time of diagnosis and treatment, the drugs and dosages used (especially cyclophosphamide, procarbazine, or other alkylating agents), the location and dosages of any radiation, the length of your treatment time, and whether you had a blood and marrow stem cell transplant. Effects that may be temporary or permanent include:

- Reduced sperm production
- Reduced testosterone, which can delay or speed up puberty, or cause impotence

What you can do about it

The most important thing you can do: speak up! Talk to your oncologist before, during, and after treatment to take preventative steps, get a semen analysis, and schedule regular follow-up evaluations.

- **Gonadal shielding –** If your testes will be exposed to radiation, ask about external shields, which must be used for every treatment. This will not apply if the testes themselves need to be radiated.

- **Sperm banking (cryopreservation) –** The fertility preservation option with the highest likelihood of success for men. Semen is collected, frozen, and stored for future use. In most cases, semen is collected through masturbation. It can also be collected via electroejaculation where an electrical current stimulates ejaculation while the patient is under anesthesia.

- **Testicular sperm extraction –** For adolescents or adults who do not produce sperm, a surgeon can remove pieces of testicular tissue. Any mature sperm can be frozen or used immediately for in vitro fertilization.

- **Testicular tissue freezing –** Boys who have not yet gone through puberty do not produce mature sperm, so they cannot bank sperm. Testicular tissue freezing is an experimental surgical procedure where testicular tissue is removed and frozen for possible future use. This technique, however, has not yet resulted in a pregnancy. Further research is needed.

- **Donor sperm –** Men who were not able to store their sperm before treatment can use sperm donated by another man. Sperm banks screen for infectious diseases and record the physical traits of the anonymous donors.

FOR WOMEN

All women experience changes during the reproductive cycle. Because it can be so confusing to sort out which changes are "normal" and which are caused by your disease or treatment, it is important to be frank with your health care professionals about irregular menstrual cycles, hot flashes, breast tenderness, painful intercourse, trouble getting pregnant, or a history of miscarriages.

Note that chemotherapy and radiation may cause:

- **Delayed menstruation**

- **Premature ovarian failure (POF) –** Also known as early menopause, females with POF are unlikely to have subsequent menstrual periods or the ability to become pregnant naturally. There is no treatment to restore fertility for women with POF, but symptoms can be managed with hormone therapy, including estrogen, progesterone and, sometimes, testosterone.

- **Damage to the uterus –** Damage can be caused by radiation, and can increase the risk for infertility, miscarriage, or premature birth. Young girls who receive cancer treatment tend to have fewer fertility problems than teenagers and adults who do.

What you can do about it

It is important to know that, depending on how ill you are at the time of diagnosis and the time available, there may be options to preserve your fertility potential before treatment begins.

- **Egg freezing –** A series of hormone injections stimulates the ovaries to produce multiple mature eggs. While the patient is under anesthesia, the eggs are removed, frozen, and stored for possible future use without being fertilized.

- **Embryo freezing –** After eggs are retrieved, as above, they are mixed with sperm to produce embryos in a procedure called in vitro fertilization. The embryos are frozen and stored for future use. Embryo freezing is the option with the highest likelihood of success.

- **Ovarian transposition –** A minor surgical procedure where the ovaries are moved outside the radiation field to reduce exposure and potential for damage.

Experimental options undergoing further research:

- **Ovarian tissue freezing –** Girls who have not yet gone through puberty have no mature eggs, and women who must start treatment quickly do not have the two to three weeks required to produce multiple eggs for freezing. These patients may be able to have part or all of the ovary removed and frozen for possible future use. Only a small number of pregnancies have resulted from reimplanted tissue, and this may not be safe for patients with certain types of cancer.

- **Gonadotropin-releasing hormones (GnRHs) –** This is a medication used during chemotherapy to suppress ovarian function and possibly protect the eggs from damage.

OPTIONS FOR HAVING CHILDREN AFTER TREATMENT

Permanent infertility is not common after treatment: many men and women will be able to conceive naturally. In general, waiting at least two years after treatment before attempting conception is recommended. Pregnancy after treatment dœs not appear to increase a woman's risk of cancer reoccurrence and generally is safe for both mother and baby. But every case is different: check with your physician to find out how long you should wait, and whether your body can handle pregnancy safely.

If cancer treatment has made it difficult or impossible to conceive naturally, you still have options (for men, see page 39 :

- **In vitro fertilization (IVF) –** A process where eggs and sperm are fertilized outside the body, then implanted into a woman's uterus. If you were not able to freeze eggs or embryos before cancer treatment, a fertility specialist may be able to help you stimulate more eggs for IVF now. IVF treatments require a healthy uterus and taking hormones before and after the procedure.

- **Donor eggs –** If you are not able to use your own eggs, donated eggs can be fertilized in the lab with your partner's sperm, then transferred to your uterus by IVF. By law, all egg donors, whether they are a family member, friend, anonymous donor, or known donor from an agency, are screened for psychological issues, medical conditions, and potential genetic diseases before they are allowed to donate eggs.

- **Donor embryos –** Embryos are donated by couples who have undergone IVF for their own infertility and chose to donate their remaining embryos. As with egg donation, the embryos are transferred into your uterus. This procedure allows a woman with a healthy uterus to experience pregnancy. By law, the couple donating the embryos must have the same tests that are required for the egg donation.

- **Gestational carriers –** If you are unable to carry a child, or if becoming pregnant could put your health at risk, you could have embryos from your eggs and your partner's sperm implanted in another woman who will carry the baby through pregnancy. A gestational carrier is NOT related to the baby.

- **Surrogacy –** Similar to a gestational carrier, a surrogate carries the baby during pregnancy. The difference is that a surrogate provides her own eggs, and is artificially inseminated with the biological father's sperm. A surrogate is genetically related to the child she carries. Surrogacy and gestational carrier laws are different in each state: consult an attorney skilled in this area if you are considering these options.

ADOPTION

Adoption is another option for building a family after cancer treatment. In general, people who have been treated for cancer and are free of disease are eligible to adopt. At this time, adopting from the US is easier than adopting internationally. Policies vary from state to state and from country to country, so it is important to work with an adoption agency or attorney to guide you.

> “YOU GO THROUGH LOSS,
> ANGER AND DEPRESSION-AND
> EVENTUALLY YOU DISCOVER HOPE.”

OTHER REPRODUCTIVE HEALTH ISSUES

Birth Control – Some drugs can be very harmful to an unborn child and may cause birth defects. If you are sexually active, it is important to use birth control throughout your treatment and for a period of time after treatment ends.

Sexually transmitted diseases – Even if you know you cannot become pregnant or father a child, you are still at risk for sexually transmitted diseases. A barrier method of contraception, such as condoms, is recommended. Ask your health care team for more information.

Pregnancy – If cancer or treatment did not effect the ovaries or uterus, most women who are of childbearing age and able to conceive can have normal pregnancies and healthy babies. Before you try to become pregnant, talk to your oncologist to make sure that your body is medically ready to handle pregnancy.

This is especially important if you are still taking medication, such as imatinib. Although not usually associated with infertility, drugs to treat cancer are not recommended during pregnancy. You should not stop taking medication without medical advice. In addition, you may want a fertility assessment before you try to conceive.

Health of Children of Cancer Survivors – Most children born to cancer survivors are healthy. The percent of babies with birth defects born to cancer survivors is similar to that of babies born to parents without a cancer history. You may be concerned about passing on a "bad" gene for cancer. Rest assured, very few types of cancer are passed on from parent to child. If you are concerned, talk to your health care team about the risks for your type of cancer and for advice on genetic counseling.

Breast-feeding – If you have had radiation to the breast area, your ability to produce milk may be affected. Talk with your physician about whether you will be able to breast-feed after treatment.

Seek support – Whether you are the patient, partner, or parent, it can be helpful to seek the support of other people. Your health care team and The Leukemia & Lymphoma Society can help you access local or online support resources.

NOTES

> GETTING BACK TO A HEALTHY LIFESTYLE AFTER CANCER IS ONE OF THE MOST IMPORTANT THINGS YOU CAN DO FOR YOUR HEALTH. MAKING HEALTHY CHOICES ABOUT THE FOOD YOU EAT AND HOW ACTIVE YOU ARE CAN HELP YOU TO FEEL GOOD, HAVE MORE ENERGY AND IMPROVE YOUR OVERALL HEALTH AND WELLBEING.

HEALTHY LIVING

The recommendations for cancer survivors are the same as the recommendations for anyone who wants to remain healthy. Following these guidelines can improve your quality of life and smooth your transition into survivorship:

- Eat a balanced diet
- Maintain a healthy weight
- Drink water or other non-caffeinated beverages
- Move daily, such as walking
- Relax to manage stress
- Get enough sleep
- Avoid tobacco, drug abuse and limit alcohol

FOOD AND NUTRITION

Eating well can help you feel better and stay stronger during and after cancer treatment. Although no diet, food, or supplement is known to prevent, cause, treat, or cure blood cancers, most nutrition professionals agree that a good, balanced diet consists of nutrient-rich fruits and vegetables; whole grains; and low-fat proteins, such as fish, lean meats, and poultry. Good nutrition can help the body:

- Replace blood cells
- Repair tissues broken down by treatment

- Smooth your ability to tolerate adverse effects
- Support the immune system
- Reduce risk for some diseases, such as certain kinds of heart disease and some cancers

A healthy diet is especially important if your cancer or its treatment put you at increased risk of osteoporosis or heart disease.

EXERCISE

Whether you have always been active or whether activity is new to you, exercise can lower your risk of other health problems. Cancer survivors who exercise may find:

- Increased strength, energy, and endurance
- Fewer signs and symptoms of depression
- Less anxiety
- Reduced fatigue
- Improved mood
- Higher self esteem
- Less pain
- Improved sleep

Exercise can range from gentle stretching to being very active. Before you start or return to exercise, talk with your health team for ways to adapt exercise to your specific needs and limitations.

> “COMMUNICATING OPENLY WITH YOUR CAREGIVERS AND HEALTH CARE PROVIDERS IS THE FIRST STEP IN COPING WITH STRESS AFTER CANCER TREATMENT.”

MAINTAIN A HEALTHY WEIGHT

Maintaining a healthy weight is one of the best things you can do for your overall health. Some survivors find they have gained or lost weight during treatment. Now is a good time to ask your physician for a healthy weight goal and strategies for meeting that goal.

If you need to gain weight, ask your physician about ways to control nausea, pain, or other adverse effects that may be preventing you from getting the nutrition you need. You might talk to a dietitian for advice on making food more appealing and easier to eat and for advice on gaining weight safely.

If you need to lose weight, remember it is best to lose weight slowly — no more than 2 pounds (about 1 kilogram) a week. Control the number of calories you eat and balance this with exercise. If you need to lose a lot of weight, it can seem daunting. Take it slowly and stick to it.

AVOID TOBACCO

Tobacco products increase the risk of cancer: quitting is the single most important change you can make to lower future cancer risk. If you have tried quitting in the past but have not succeeded, seek help. There are many resources available, including medication and counseling that can be found at www.cancer.net/tobacco

http://www.cancer.net/navigating-cancer-care/prevention-and-healthy-living/tobacco-use

DRINK ALCOHOL IN MODERATION

Alcohol is consistently linked to cancer. If you choose to drink alcohol, do so in moderation. For healthy adults, experts recommend up to one drink a day for women of all ages and men older than age 65, and up to two drinks a day for men age 65 and younger.

BE SAFE IN THE SUN

Too much sunlight can be harmful. There are steps to limit your exposure to UV rays. Use broad-spectrum sunscreen with sun protection factor (SPF) values of 30 or higher against both UV-A and UV-B rays. Wear protective clothing and a hat when you are outdoors. Protect your eyes by wearing sunglasses that block 99-100 percent of UV-A and UV-B radiation.

REDUCE STRESS

Fear of recurrence or of new cancers can trigger anxiety, sleep disturbance, fatigue, and negatively affect health, lifestyle, and relationships with others. Other common stressors include beginning a new chapter in life, lacking energy to complete daily activities, facing the financial aftermath of treatment, and struggling with infertility.

Learning how to manage stress is extremely important for your recovery: make small changes, learn to say "no," and get help with potentially challenging issues. Other ways to manage stress include exercise, social activities, support groups, acupuncture, yoga, massages, and relaxation techniques.

> YOUR PHYSICAL AND MENTAL HEALTH IS VERY CLOSELY TIED. I AM A BIG FAN OF ROGER WALSH'S SIMPLE THERAPEUTIC LIFESTYLE CHANGES (TLCS) TO CREATE VIBRANT TOTAL HEALTH. THESE TLCS INCLUDE EXERCISE, WHOLESOME EATING, SPENDING TIME IN NATURE, POSITIVE RELATIONSHIPS, LEARNING TO MANAGE YOUR STRESS, ENJOYABLE HOBBIES, RELIGIOUS OR SPIRITUAL REFLECTION, AND GETTING INVOLVED IN YOUR COMMUNITY. THIS MIGHT SEEM LIKE A LONG LIST, BUT IT'S EASY TO COMBINE THESE FACTORS-GO ON A HIKE TO GET IN YOUR EXERCISE, NATURE FIX, STRESS RELIEF, AND SPIRITUAL REFLECTION. OR VOLUNTEER TO COOK A MEAL AT A LOCAL FOOD SHELF WITH FRIENDS SO YOU CAN PRACTICE YOUR HEALTHY COOKING SKILLS, DEEPEN YOUR FRIENDSHIPS, AND HAVE FUN CONNECTING WITH PEOPLE IN YOUR COMMUNITY. BE CREATIVE AND MAKE THESE TLCS YOUR OWN, AND YOU'LL BE REWARDED WITH BALANCED HEALTHY LIVING.

-ANA G. GORDON, AM, LSW
UNIVERSITY OF ILLINOIS HOSPITAL & HEALTH SCIENCES SYSTEM

NOTES

APPENDIX

RESOURCES

The following is a list of reputable organizations and agencies dedicated to servicing the needs of anyone who has been affected by cancer, regardless of type.

The organizations are grouped by primary focus.

Please note that the availability of some of the resources/groups mentioned in the handbook may change over time. Check directly with the organizations for the most updated information.

Leukemia & Lymphoma Society

Adolescent and Young Adult resources

www.lls.org/youngadults

The Leukemia & Lymphoma Society offers **YAconnect**, featuring programs and support for young adults facing cancer. These series include:

- Weekly online chat that provides an open forum for young adults dealing with cancer and cancer survivorship
- Blood cancer discussion boards, which features a section specifically devoted to the young adult cancer community
- Webcasts that feature experts and young adults discussing topics such as the physical, emotional and financial challenges faced by young adults with cancer
- Video Series about Cancer Survivorship in Young Adults

Patti Robinson Kaufmann First Connection Program
http://www.lls.org/support/peer-to-peer-support

Peer to Peer support: survivors and caregivers are matched to others who have shared a similar cancer experience.

Cancer support centers in the Chicago area

Local centers offer support groups, classes and activities for individuals and families touched by cancer. Most programs are free.

Cancer Support Center
2028 Elm Road
Homewood, IL 60430
708-798-9171
www.cancersupportcenter.org

Cancer Wellness Center
215 Revere Drive
Northbrook, IL 60062
847-509-9595
www.cancerwellness.org

Gilda's Club Chicago
537 N. Wells Street
Chicago, IL 60654
312-464-9900
www.gildasclubchicago.org

Living Well Cancer Resource Center
442 Williamsburg Avenue
Geneva, IL, 60134
630-262-1111
https://livingwellcrc.org
info@livingwellcrc.org

Wellness House
131 N. County Line Road
Hinsdale, IL, 60521
630-323-5150
www.wellnesshouse.org

Cancer support for young adults

Critical Mass: The Young Adult Cancer Alliance (CM: YACA)

www.criticalmass.org
Email: info@criticalmass.org

A group of non-profits, medical institutions, patient advocacy groups, government agencies, clinicians, researchers, and dedicated individuals united by a shared passion to improve the lives of young adults with cancer. They strive to ensure access to the best medical and psychosocial resources, to improve treatment outcomes, and to support adolescents and young adults through the cancer experience.

Huff Post Generation Why

www.huffingtonpost.com/news/generation-why

Read articles and posts from young adult survivors and their caregivers in the health section of The Huffington Post.

Hope for Young Adults with Cancer

www.hope4yawc.org

Hope4YAWC provides financial support, a social network, and an outlet for those battling, surviving, and living with cancer.

Lacuna Loft

lacunaloft.com
info@lacunaloft.com

Lacuna Loft provides lifestyle support for patients, survivors, and caregivers. It provides the tools and resources to empower young adults with cancer and other long-term illnesses to continue to live a vibrant life.

LIVESTRONG Foundation

www.livestrong.org

Provides patients, family, friends, and caregivers with information, education, counseling services, and referrals to other resources. The Young Adult Alliance advocates for young adults with cancer and survivors.

Planet Cancer
http://myplanet.planetcancer.org
contactus@planetcancer.org
855-220-7777
Planet Cancer, a LIVESTRONG Initiative, is an online community of young adults in their 20s and 30s. With social networking, online forums, and other programs, Planet Cancer provides a supportive community of peer support and advocacy for young adults with cancer.

Stupid Cancer: I'm too young for this! Foundation
http://stupidcancer.org
contact@stupidcancer.org
877-735-4673
Stupid Cancer is the largest US-based charity that addresses young adult cancer through advocacy, research, support, outreach, awareness, podcasts, mobile health, and social media. They support a global network of survivors, caregivers, and advocates to ensure that young adults are aware of the age-appropriate resources that can help them get busy living.

Twist Out Cancer
http://twistoutcancer.org
Provides a forum where anyone affected by cancer can share thoughts, experiences, stories, and insights, allowing for the exchange of encouragement and wisdom from one community member to another.

Ulman Cancer Fund for Young Adults
http://ulmanfund.org
info@ulmanfund.org
888-393-3863
It provides support, education and empowering opportunities to young adult cancer survivors. It also provides information about college scholarships and other education concerns.

Cancer support organizations

American Cancer Society: Cancer Survivors Network (CSN)
http://csn.cancer.org
Provides information for survivors related to being healthy after treatment, ongoing research, and local resources for help. The goal is to create a community of cancer survivors and families through online chats and message boards, the Cancer Survivors Network, and support groups.

Cancer.net
www.cancer.net
Timely, comprehensive, oncologist-approved information from the American Society of Clinical Oncology. Find resources and discussions focusing on survivorship, steps to take after cancer, information about late effects, and rehabilitation. Survivors share stories on the message board.

Gilda's Club Chicago
www.gildasclubchicago.org
537 N. Wells Street
Chicago, IL 60654
312-464-9900

Imerman Angels
www.imermanangels.org
205 W. Randolph
19th Floor
Chicago, IL 60606
877-274-5529
Imerman Angels provides personalized connections that enable one-on-one support among cancer fighters, survivors, and caregivers.

Lainie's Angels
http://lainiesangels.org
stathi@lainiesangels.org
Lainie's Angels is dedicated to helping families with a child who has cancer or a

blood disorder. By putting a network of healthcare staff, counselors and peer support in place, they help families understand complex medical information, and offer ongoing guidance and support.

MyLifeLine.org Cancer Foundation
http://mylifeline.org
The mission of MyLifeLine.org is to empower cancer patients and caregivers to build an online support community of family and friends to foster connection, inspiration, and healing through free, personalized websites.

The Leukemia & Lymphoma Society
Greater Illinois Chapter
www.lls.org/il
651 W. Washington Blvd
Suite 400
Chicago, IL 60661
312-568-7715

Triage Cancer
http://triagecancer.org
Triage Cancer is dedicated to helping survivors, caregivers, and health care professionals navigate cancer survivorship issues by connecting them to experts, information, and resources.

Education

College Board
www.collegeboard.org
212-713-8000
https://www.collegeboard.org/students-with-disabilities
Ensures that students with disabilities receive appropriate accommodations on SAT, AP, PSAT/NMSQT college entrance tests.

LD Online
www.ldonline.org
Provides information about accommodations, college preparation, legislation and policy, self advocacy and study skills for students with learning disabilities.

Learning Disabilities Association of America
www.ldanatl.org
412-478-7242 [AU: phone on web site is 412-341-1515]
Offers parents information on learning disabilities, negotiating the special education process, and other practical solutions.

Think College!
www.thinkcollege.net
Provides information for students with intellectual disabilities as they transition between high school and college.

Youthhood
www.youthhood.org
Offers decision-making tools to help young people plan for life after high school.

Employment and Insurance

Cancer and Careers
www.cancerandcareers.org
Cancer and Careers empowers and educates people with cancer to thrive in their workplace by providing expert advice, interactive tools, and educational events.

Cancer Legal Resource Center
www.cancerlegalresourcecenter.org
866-843-2572
Provides free information and resources on cancer-related legal issues

including insurance coverage, employment appeals, access to health care and more.

Patient Advocate Foundation
www.patientadvocate.org
800-532-5274
Helps patients remove obstacles to health care, including medical debt crisis, insurance access, and employment issues. Sponsors the Scholarship for Survivors program for students who have survived cancer and other serious diseases.

Fertility

Circle Surrogacy
www.circlesurrogacy.com
bhale@circlesurrogacy.com
617-439-9900
Circle Surrogacy is one of the oldest and largest surrogate parenting agencies, with extensive financial and legal information on gestational surrogacy and egg donation.

LIVESTRONG Fertility
www.livestrong.org/we-can-help/fertility-services/
855-220-7777 (English and Spanish)
LIVESTRONG Fertility is dedicated to providing educational information and access to resources that support cancer patients and survivors whose cancer and its treatment present risks to their fertility.

My Oncofertility
www.myoncofertility.org
866-708-3378
A patient education resource offers information about cancer fertility, updates from experts, and stories and advice from fellow survivors.

RESOLVE: The National Infertility Association
www.resolve.org
info@resolve.org
703-556-7172
RESOLVE: The National Infertility Association is a non-profit, charitable organization, that works to improve the lives of women and men living with infertility. The web site provides information on assisted reproductive technology, third-party donors, adoption, and more. It also offers information about local RESOLVE support groups, educational events, and facts about state insurance coverage for infertility.

Society of Assisted Reproductive Technology
www.sart.org
kjefferson@asrm.org
205-978-5000 x 109
The Society of Assisted Reproductive Technology website features information on assisted reproductive technologies with step-by-step descriptions; financial guidance; and the emotional aspects. The site's search tool can guide you to practitioners in your area.

The Oncofertility Consortium
303 E Superior Street
Suite 10-121
Chicago IL 60611
www.oncofertility.northwestern.edu
866-708-3378

The Oncofertility Consortium® is a group of researchers and medical professionals dedicated to exploring and expanding options for the reproductive future of cancer survivors. The online patient information resources include tools that will help you navigate the complex fertility issues facing patients with cancer and other serious diseases.

Legal and Financial needs

Cancer Legal Resource Center
www.disabilityrightslegalcenter.org/cancer-legal-resource-center
866-843-2572
The CLRC provides information and education about cancer-related legal issues to the public through its national telephone assistance line. The CLRC 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.

Hope for Young Adults with Cancer
www.hope4yawc.org
Hope4YAWC provides direct financial support along with a social network and outlet for those battling, surviving, and living with cancer.

The Cancer Survivors' Fund
www.cancersurvivorsfund.org
csf@cancersurvivorsfund.org
281-437-7142
Provides college scholarships for young cancer survivors and prosthetics to disadvantaged young adults.

The National Collegiate Cancer Foundation
www.collegiatecancer.org
info@CollegiateCancer.org
240-515-6262
NCCF provides services and support to young adults who have been diagnosed with cancer and are pursuing higher education, including need-based financial support.

The National GRACE Foundation
www.graceamerica.org
agallonio@graceamerica.org
401-793-6337

GRACE stands for Growing, Recovering and Achieving a College Education. This foundation provides college admission and financial aid counseling to pediatric cancer patients and survivors.

The SAMFund
www.thesamfund.org
info@thesamfund.org
617-938-3484
The SAMFund provides financial support, grants, and scholarships for young adult cancer survivors in transition to post-treatment life.

Outdoors

First Descents
www.firstdescents.org
Provides opportunities for cancer survivors to experience the excitement of kayaking, rock climbing, and other outdoor adventures.

The Wilderness Program
www.cancerwellness.org
ebyer@cancerwellness.org
The Wilderness Program (WP) addresses the unique needs of young adults in a restorative environment. WP is designed to foster personal and social responsibility, and enhance the emotional growth of individuals.

True North Treks
www.truenorthtreks.org
info@truenorthtreks.org
True North Treks is dedicated to enriching the lives of young adult cancer survivors through outdoor-based activities.

Survivorship Apps and Patient Portals

AYA Healthy Living App
www.healthysurvivorship.org
Assess your health habits and general sense of well being. The app offers personalized tips for being more active, eating better, and living a longer, healthier life. It is especially designed for adolescents and young adult cancer survivors ages 15-39. [iPhone]

Cancer Survivor Link™
http://www.cancersurvivorlink.org/Default.aspx
SurvivorLink stores your Survivor Health Care Plan in a Patient Portal, letting you see your treatment summary, risk for late effects, and screening plan online. [Web]

Mission CONTROL / Critical Mass
http://criticalmass.org/missioncontrol/
Mission Control gathers resources and services for young adult survivors in one easily searchable platform. [Web]

Thank you to the Coleman Foundation who made this program possible. With their support, blood cancer patients, survivors and their families are served in a more meaningful way.

ASCO TREATMENT SUMMARY AND SURVIVORSHIP CARE PLAN

General Information

Patient Name:	Patient DOB:	
Patient phone:	Email:	

Health Care Providers (Including Names, Institution)

Primary Care Provider:
Surgeon:
Radiation Oncologist:
Medical Oncologist:
Other Providers:

Treatment Summary

Diagnosis

Cancer Type/Location/Histology Subtype:	Diagnosis Date (year):

Stage: ☐ I ☐ II ☐ III ☐ Not applicable

Treatment

Surgery ☐ Yes ☐ No	Surgery Date(s) (year):

Surgical procedure/location/findings:

Radiation ☐ Yes ☐ No	Body area treated:	End Date (year):

Systemic Therapy (chemotherapy, hormonal therapy, other) ☐ Yes ☐ No

Names of Agents Used	End Dates (year)

Persistent symptoms or side effects at completion of treatment: ☐ No ☐ Yes (enter type(s)) :

Familial Cancer Risk Assessment

Genetic/hereditary risk factor(s) or predisposing conditions:

Genetic counseling: ☐ Yes ☐ No Genetic testing results:

Follow-up Care Plan

Need for ongoing (adjuvant) treatment for cancer ☐ Yes ☐ No

Additional treatment name	Planned duration	Possible Side effects

Schedule of clinical visits

Coordinating Provider	When/How often	

Cancer surveillance or other recommended related tests

Coordinating Provider	What/When/How Often	

Please continue to see your primary care provider for all general health care recommended for a (man) (woman) your age, including cancer screening tests. Any symptoms should be brought to the attention of your provider:

1. Anything that represents a brand new symptom;
2. Anything that represents a persistent symptom;
3. Anything you are worried about that might be related to the cancer coming back.

Possible late- and long-term effects that someone with this type of cancer and treatment may experience:

Cancer survivors may experience issues with the areas listed below. If you have any concerns in these or other areas, please speak with your doctors or nurses to find out how you can get help with them.

☐ Emotional and mental health
☐ Physical Functioning
☐ Memory or concentration loss
☐ Other
☐ Fatigue
☐ Insurance
☐ Parenting
☐ Weight changes
☐ School/Work
☐ Fertility
☐ Stopping smoking
☐ Financial advice or assistance
☐ Sexual functioning

A number of lifestyle/behaviors can affect your ongoing health, including the risk for the cancer coming back or developing another cancer. Discuss these recommendations with your doctor or nurse:

☐ Tobacco use/cessation
☐ Alcohol use
☐ Weight management (loss/gain)
☐ Diet
☐ Sun screen use
☐ Physical activity

Resources you may be interested in:

Other comments:

Prepared by: Delivered on:

- This Survivorship Care Plan is a cancer treatment summary and follow-up plan is provided to you to keep with your health care records and to share with your primary care provider.

- This summary is a brief record of major aspects of your cancer treatment. You can share your copy with any of your doctors or nurses. However, this is not a detailed or comprehensive record of your care.

Questions for your Survivorship Appointment

All patients are asked to complete this questionnaire as part of their standard of care. Please take a few minutes to answer the following questions to help us better address your needs.

Over the **last 14 days**, how often have you been bothered by the following problems?

Please mark one box per row	**Not at all**	**Several Days**	**More than half the days**	**Nearly every day**
Feeling nervous, anxious or on edge	☐	☐	☐	☐
Not being able to stop or control worrying	☐	☐	☐	☐
Little interest or pleasure in doing things	☐	☐	☐	☐
Feeling down, depressed, or hopeless	☐	☐	☐	☐
Fear of developing another cancer or a recurrence	☐	☐	☐	☐

Indicate if any of the following has been a concern for you in the **past 7 days**, please check Yes or No for each.

YES	**NO**	**Financial Concerns**
☐	☐	Paying for food and/or housing
☐	☐	Paying for my medication or medical care
☐	☐	Insurance coverage or no health insurance

YES	**NO**	**Social Concerns**
☐	☐	Concerns about my children
☐	☐	Concerns about my partner
☐	☐	Issues with work or school
☐	☐	**Spiritual / Faith / Religious Concerns**

YES	**NO**	**Nutrition Concerns**
☐	☐	Concerns about body weight
☐	☐	Concerns about diet (food) and cancer risk/incidence
☐	☐	Concerns about alternative/herbal supplements

YES	**NO**	**Treatment or Care Concerns**
☐	☐	Lack understanding about my cancer diagnosis or stage
☐	☐	Have questions about potential long term complications from my treatment
☐	☐	Developed other illnesses as a result of my cancer treatment
☐	☐	Issues with transportation to/from appointments
☐	☐	Need help coordinating my care
☐	☐	Need cancer screening

Other problems or concerns:

____

____

____

YES	**NO**	**Physical Concerns**
☐	☐	Ability to have children
☐	☐	Appearance
☐	☐	Breathing
☐	☐	Constipation or Diarrhea
☐	☐	Hot flashes and/or vaginal dryness
☐	☐	Nausea or Vomiting
☐	☐	Difficulty with chewing or swallowing due to cancer therapy
☐	☐	Pain
☐	☐	Sexual intimacy or function
☐	☐	Dry skin
☐	☐	Sleep
☐	☐	Energy level is lower than before I started treatment
☐	☐	Swollen arms/legs
☐	☐	Tingling in my hands/feet
☐	☐	Trouble remembering or concentrating

Indicate which factors may be relevant to your lifestyle, please check Yes or No for each.

YES	**NO**	**Life Style Factors**
☐	☐	I use tanning beds
☐	☐	I am often outside, in the sun
☐	☐	I use tobacco
☐	☐	I use prescription pain medication for reasons other than pain control
☐	☐	I exercise regularly
☐	☐	I drink alcohol
☐	☐	I use recreational drugs

NOTES

The Coleman
FOUNDATION

LEUKEMIA &
LYMPHOMA
SOCIETY®
fighting blood cancers

someday
is today®

The Leukemia & Lymphoma Society
Greater Illinois Chapter
651 W. Washington Blvd. Suite 400
Chicago, IL 60661
(312) 651-7350
www.lls.org/illinois