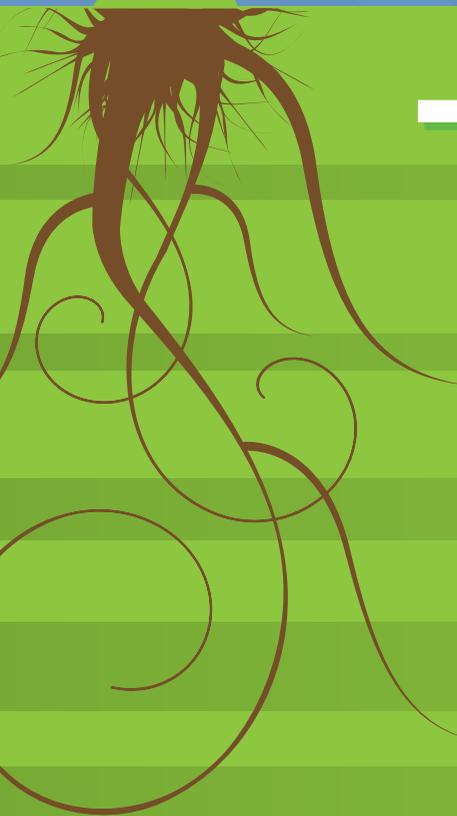




10
to



thrive

A comprehensive, easy-to-read guide
to life after cancer for young adults.

2nd Edition

Brought to you by Thrive/Survive Los Angeles in partnership with Well Beyond Ordinary



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to life after cancer for young adults

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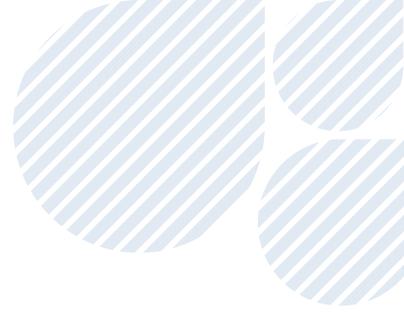
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And most importantly, you, the young adult survivors who dare to seek out the resources, tools and support you need to continue your journey through survivorship so that you can thrive.



Introduction

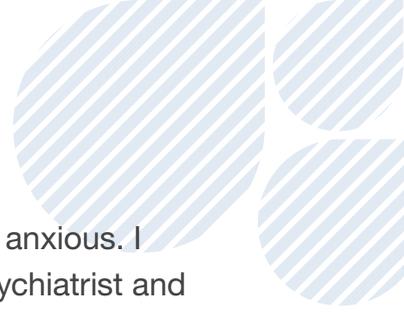
Nico Juber, Cancer Survivor
Co-Founder of Thrive/Survive Los Angeles

This is the book I wish someone had given me in November of 2002, right when I finished my cancer treatment.

I was 19 years old and my body had been through a war zone due to my Non-Hodgkin's Lymphoma treatment. I was lucky, all signs pointed to remission. The doctors gave me the thumbs up and sent me on my way with instructions to check in after a few months.

Suddenly, I was back in college, wearing a short blonde wig, trying to once again find my center given everything that had happened to me over the past six months. Treatment was over.

Great.



Now what?

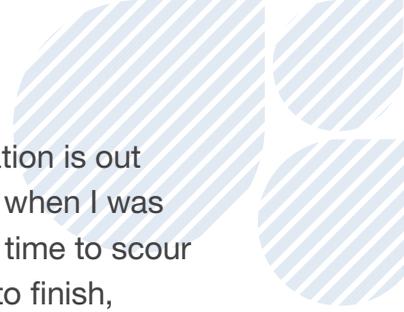
Then the vertigo hit. I was spinning, dizzy and anxious. I didn't know why. I was sent to the campus psychiatrist and handed a prescription for anti-anxiety medication but given no explanation for what was happening to me.

Every little bump and lump was now cancer. Once you've had cancer, there is a distinct sense of waiting for the other shoe to drop. It's happened once — why not again? I was the pillar of mental strength on my way through treatment itself. It wasn't until afterwards I allowed myself to fall apart, and subsequently had to find a way to put the pieces back together over the next few years.

No one had prepared me for the other side of survivorship — the part that lasts the rest of your life.

Fourteen years later, the anxiety has quieted. When I find a little bump on my arm, the “cancer!” reaction has diminished. It doesn't go away, but it gets better. I realize, as I hope you will, the actual cancer treatment can be a blip on your radar compared to the rest of your life as a cancer survivor. I now understand the importance of long-term survivorship care planning and routine checks, and was very fortunate to find the folks at the UCLA Livestrong Center of Excellence to do my annual appointments and testing. But I had to stumble onto this information. This made me determined that no other survivor should go without a plan.

As young people, we have a very different set of circumstances than others on the other side of treatment. We're just building our lives, our credit, our education, our



families and our careers. Support and information is out there for young survivors, much more so than when I was 19. It's amazing. But young people don't have time to scour through pages of research. We've got school to finish, careers to grow and families to raise. Just give us the main pieces of information we need to know. That's how 10 to Thrive was born—this is meant to be your practical, go-to guide with key nuggets of information for living as a young person after cancer.

Over the past ten years, I've been asked the following two questions a remarkable number of times (don't be surprised if you're asked them as well!):

“Weren't you lucky to survive?” Nothing about cancer is lucky. Cancer treatments are radical and our bodies are amazingly resilient, but that doesn't mean side effects can't pop up down the line.

Don't let people trivialize the ongoing issues of survivorship. It sucks that I have to get echocardiograms, EKGs, bone scans, breast MRIs, mammograms and a host of other tests done every year. Just because you survive, you are not lucky to have had your physical, mental and financial health impacted.

“Don't you feel grateful for your cancer experience?” I never hoped to be diagnosed with cancer one day so that I could grow up and start a nonprofit in Los Angeles for other post-treatment young survivors. I'm not grateful for having had cancer. No one wants cancer. I long for the innocent days of when I felt implicit trust in my body, didn't have scars and radiation tattoos and never had fatigue.



I am grateful, however, that we live in a world that was equipped to treat my cancer. I'm grateful for the others survivors I've met and friends I've made. I'm grateful surviving has given me the opportunity to hopefully make things better for the next generation of young people going through a really crappy experience and spending as much of the rest of their lives thriving as possible.

Most of all, I am grateful that you found your way to this book.

Nico Juber is a 15-year survivor of Non-Hodgkin's Lymphoma and co-founder of [Thrive/Survive Los Angeles](#), a project of The Giving Back Fund. As a young adult survivor, she found that the community in the post-treatment phase of survivorship is a growing population with documented special medical and psychosocial needs. Access to real, relevant, practical information is hard to come by and the community in Los Angeles had been disjointed. Many young adult survivors feel alone, too young for most post-treatment services and too old for pediatric services, often never having met another person who has been through what they have been through. Thrive/Survive aims to create a portal community to enable real-life meet-ups of young adult cancer survivors, in addition to clear, concise access to information such as understanding local medical practitioners, financial resources and lifestyle information.

A Project of The Giving Back Fund:

<http://www.givingback.org>

The Giving Back Fund (GBF), established in 1997, seeks to cultivate and nurture a new group of philanthropists within the sports and entertainment communities and to help establish role models who will inspire others to give back. GBF provides philanthropic consulting, management and programs to athletes, entertainers, entrepreneurs, and other high net worth individuals aimed at increasing the impact of their philanthropy. GBF is launching several new programs to help ensure that new generations of sports and entertainment professionals learn how to be effective and powerful philanthropists. The Giving Back Fund is a 501(c)(3) organization. Donations to Thrive/Survive, A Project of The Giving Back Fund are tax-deductible to the fullest extent of the law.

Survivorship Care Planning

Top 10 Quick Steps to Survivorship

Pamela Goetz

*Oncology Survivorship Navigator at
Sibley Memorial Hospital, Johns Hopkins Medicine.*

1. You aren't alone if you're asking yourself: "What now?"

This is frequently the question cancer survivors like you may ask when active treatment has been completed. A cancer diagnosis can be a shock, raising challenging questions about where to go for care, treatment choices, prognosis, financial costs, psychosocial issues, and the list goes on. You rely on and see your health care providers as a life-line to explain all the options available, help you make treatment decisions, provide patient-centered clinical care, and refer you to other specialists when necessary. The ongoing support of a health care provider — whether a surgeon, medical oncologist, radiation oncologist, receptionist, social worker, dietician, or nurse navigator — provides direction, support, guidance, hope, and hopefully, the very best outcome. Then, suddenly when the last day of treatment comes, you walk out the door, leaving behind the care team whom you have relied on, often daily for your diverse needs across the continuum of your care. A survivorship care plan (SCP) can help.

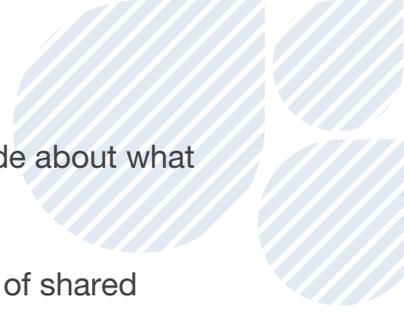
2. What exactly is a survivorship care plan?

A survivorship care plan is a written or electronically conveyed document that a health care provider discusses with you, the patient, and shares with other providers at the completion of cancer treatment or when transitions in current treatment occur (e.g., cancer recurs or current treatment fails to produce the desired result). The best practice of implementing a care plan is found in good doctor/patient communication and coordination with other health care providers. A SCP typically includes:

- Diagnosis & treatment summary
- Best schedule for follow-up tests
- Information on late and long-term effects of cancer treatment
- List of symptoms to look for
- List of support resources

3. When does survivorship care begin?

In 1986, the founders of the National Coalition for Cancer Survivorship formed an organization that would change the terminology from cancer “victim” to cancer “survivor,” addressing the range of survivorship issues related to living with, through and beyond a cancer diagnosis. NCCS’s definition of a survivor, from the time of diagnosis and for the balance of life, is now the accepted standard for those who work in the cancer community. While some health care professionals focus on the distinct elements of post-treatment survivorship care planning, NCCS understands that the benefits of a shared written plan extend back to



the diagnosis when the first decisions are made about what treatment is most suitable.

A cancer care plan should reflect the process of shared decision-making, based on a discussion between you and your providers. It's important that you understand your options and the goals of treatment before you start that treatment. The treatment plan can help guide you as you talk with doctors and other members of the health care team about what is important to you and any concerns you may have. A planning document will help when talking about treatment options and possible side effects and other implications of the treatment. The plan can easily be shared with other doctors you might see for cancer treatment or for any other health care needs.

Interesting fact: Of those who did not receive a written care plan outlining their treatment before it began, 78% said having one would have helped them ask appropriate questions about what side effects to expect from treatment (from a 2007 Harris Interactive study conducted by NCCS and Sanofi-Aventis).

4. When else do you need a plan and why?

In 2005, survivorship care planning became a topic of interest among physicians who treat cancer and among primary care doctors who often see patients once treatment ends. The Institute of Medicine (IOM) published the report, **From Cancer Patient to Cancer Survivorship: Lost in Transition** and in its opening paragraph, it recognized that cancer and its treatment has an effect on health, function,



sense of security and well being, with long-lasting impact on survivors. The report goes on to say that a coordinated follow-up plan is essential to a survivor's long-term health.

The coordinating provider should create a treatment summary which can be given to you as well as shared with other doctors and health care providers. A summary includes information about the cancer pathology and diagnosis, all treatments received, and the follow-up care guidelines that address potential late effects caused by the cancer treatment.

Only one third (35%) of survey participants received a written summary of treatment when care ended (from the 2007 Harris Interactive study conducted by NCCS and Sanofi-Aventis)

Once active treatment is completed, you may experience some relief while also feeling insecure about the future and fears of recurrence. Many survivors commonly question how they'll know if they're having a recurrence, what symptoms should be of concern, what kind of tests and monitoring are needed, which doctor will provide ongoing care, and whether life will ever get back to normal.

So, just as you would plan a cross-country trip, you are better prepared to take the next step in your journey of survivorship if you have a written plan that serves as a personalized roadmap. Cancer survivors like you have different health care needs than before they were diagnosed and need to be monitored for the rest of their lives. The survivorship care plan helps to ensure that you and everyone



involved in your care knows what follow-up is needed, when it is needed, and what providers will administer that care. The plan also lists any late or long-term effects that may result from your treatment. Since many survivors worry about their ongoing health, the plan also details what symptoms might be a concern and which provider should be contacted.

5. Who cares for you?

The terms “patient-centered” and “coordinated care” are often heard as measures of quality care. But for newly diagnosed patients unfamiliar with the cancer world, it may not be obvious that they play a critical role in the quality of care they receive. Patient-centered care, by definition, places the patient in the center of the care team. When empowered to participate in decisions about their own care, patients feel more in control and can help their providers know what care best meets their needs and preferences. Effective communication between you and your providers is critical. Care plans are tools that can improve the communication between you and your providers, by making sure that everyone understands the post-treatment goals and your long-term survivorship care needs.

The plan includes a list of the numerous health care professionals involved in your care emphasizing the need for team coordination, as well as defining whom you should see for follow-up care.



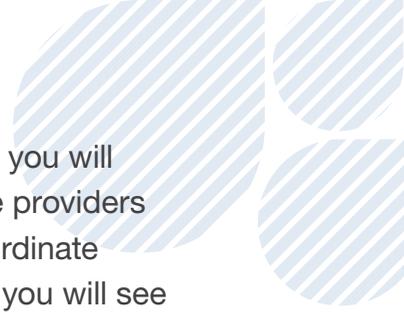
6. If you are an adolescent or young adult done with cancer treatment, what do you need to keep in mind?

A cancer diagnosis interrupts the usual routine and outlook on life, and for young adults this is especially true. While many of your peers are looking forward to new opportunities, such as college or a new job, you may have had to put some of those developmental steps on hold. Post-treatment, young survivors like you may have to address issues like fertility preservation, early menopause, insurance coverage, employment issues, and a curtailed social life.

Once active treatment is over, you may just want to get on with life. However, it's important that you too understand the need for ongoing follow-up care and are aware of potential late effects from your treatment. Follow-up care helps to monitor changes in health, prevents or provides early detection of other cancers, and manages any physical or psychosocial effects. Specialized online, national and local resources are available to help connect you with survival information and a community of peers also facing the future after a diagnosis.

7. How can I help myself?

Ask your provider for a survivorship care plan and treatment summary when your course of treatment ends. If you completed treatment a while ago, contact your coordinating provider and ask for one. A consolidated summary will be useful to you, your primary care doctor or other specialists; and getting it now will be helpful if you move or your provider retires.



Get a plan to understand what follow-up tests you will need to have and how often. Your cancer care providers should communicate that plan to you and coordinate your care with other health professionals who you will see when treatment ends (e.g., your primary care physician, gynecologist, urologist, etc.). You can reduce your risk of recurrence or secondary cancers through screening, diet, exercise, smoking cessation, and sun safety. Ask your health providers to include information in your survivorship care plan about how to minimize your risk.

8. What do I do if I am having issues?

Talk with your providers about any problems you might have with pain, side effects (lymphedema, sexual dysfunction, pain and fatigue, etc.), paying for care, or coping with personal and physical changes related to your cancer.

Ask your provider where you can get help with psychosocial issues, spiritual needs, employment and, fertility counseling, questions about genetics and family history.

9. What can I do to help others?

Get involved at the local or national level to help others facing a cancer diagnosis. There are many opportunities to improve the experience others have facing a cancer diagnosis. You can help newly diagnosed patients one-on-one, raise awareness about prevention, screening and self-advocacy at local health fairs, or provide the patient voice in policy-related issues, whether at the state or national level.

10. What resources are available to me?

American Childhood Cancer Organization

<http://www.acco.org>

<http://www.acco.org/Information/TreatmentandSurvivorship/LateEffects.aspx>

Founded by parents of children with cancer, the ACCO site offers information, support, and advocacy, including information about late effects and an extensive resource list.

Association of Oncology Social Work (AOSW)

www.aosw.org An organization of oncology social workers and others who specialize in helping cancer survivors and their families with the emotional and practical impact of cancer.

CancerCare

www.cancer.org A national organization that provides a toll-free counseling line and educational programs. All services are free of charge.

Cancer.Net

www.cancer.net A patient education website from the American Society of Clinical Oncology that provides information on cancer, treatments, clinical trials and survivorship guidelines. Includes live chats, message boards and links to support groups.

The Children's Oncology Group

<http://www.childrensoncologygroup.org/> Online information regarding cancer in children, adolescents, and young



adults, including information about follow-up care, written by experts from the Children's Oncology Group, a network of more than 200 hospitals that form the world's largest pediatric cancer research organization.

**Children's Oncology Group
Long-term Follow-up Guidelines**

www.survivorshipguidelines.org

Journey Forward®

www.journeyforward.org Easy-to-use software for oncology professionals to create treatment summaries and customized survivorship care plans to guide survivors in follow-up care after active treatment. Includes information about potential late and long term effects of treatment, future symptoms to watch for, checklists of psychosocial needs, relevant articles, and local resources. Includes a Medical History Builder for survivors to create an electronic record of their medical history in one place, eliminating the need to recreate it for each doctor's visit.

Keene, N, Hobbie, W, Ruccione, K. (2012)

<http://www.childhoodcancerguides.org/our-books/childhood-cancer-survivors/>

Childhood Cancer Survivors: A Practical Guide to Your Future. Bellingham, WA.

LIVESTRONG

www.livestrong.org Created by the Lance Armstrong Foundation, this website offers information about dating, relationships, infertility, sexual dysfunction, and survivorship care planning, and more resources addressing AYA issues.

National Association for Continence

www.nafc.org A national organization dedicated to improving the quality of life of people with incontinence, voiding dysfunction and related pelvic floor disorders. Provides a database of professionals specializing in the diagnosis and treatment of incontinence.

National Cancer Institute

www.cancer.gov Offers many educational resources for cancer survivors. NCI Cancer Bulletin, July 26, 2011, Volume 8/Number 15 specifically addresses AYA issues.

National Coalition for Cancer Survivorship

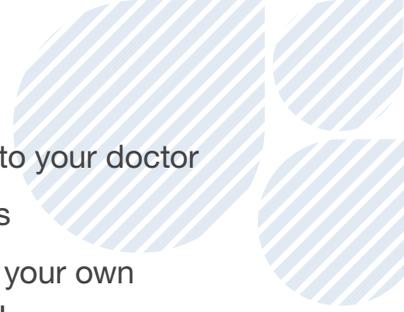
www.canceradvocacy.org A national cancer advocacy organization that advocates for quality cancer care for all people touched by cancer and provides tools that empower people to advocate for themselves.

Cancer Survival Toolbox[®] - an award-winning, self-learning audio program to help people develop important skills to better meet and understand the challenges of their illness, from diagnosis and beyond treatment. The audio programs address scenarios for many topics and issues cancer survivors face and are inspired by true stories. Available at no cost in English and Spanish.

Pocket Cancer Care Guide iPhone app

A free iPhone app to help survivors prepare for visits with health care providers.

- Browse hundreds of questions in categories relevant to stages of your cancer diagnosis, including transitioning off of active treatment

- 
- Build lists of questions to use when talking to your doctor
 - Record and playback your doctor's answers
 - Can't find the right question to ask? Create your own custom questions and add them to the app!
 - Explore the extensive glossary to learn more about medical terminology your doctor uses
 - Link doctor appointments to your lists and automatically add it to your calendar

Self-Advocacy: A Survivor's Handbook

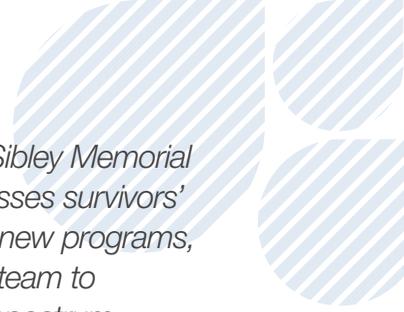
NCCS believes that cancer becomes a much lesser foe when faced by informed and knowledgeable health care consumers who know how to communicate their needs to those who can be helpful to them as they experience cancer. This handbook focuses on self-training steps and tools to assist and empower individuals dealing with cancer. Up to 10 copies available at no cost from NCCS. In English only.

National Comprehensive Cancer Network (NCCN)

www.nccn.com/ A nonprofit alliance of 21 of leading cancer centers. The NCCN has a consumer website that includes information about follow-up care for cancer (*Taking Charge of Follow-up Care*). National Comprehensive Cancer Network (NCCN)

Stupid Cancer

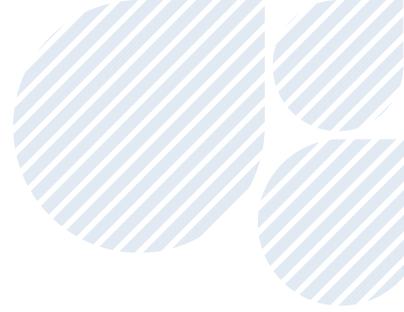
www.stupidcancer.org A nonprofit organization that empowers young adults affected by cancer through innovative and award-winning programs and services, such as their annual OMG Summit, Stupid Cancer Radio Show and online forums.



Pam Goetz is the Oncology Survivorship Navigator at Sibley Memorial Hospital, [Johns Hopkins Medicine](#). In this role she assesses survivors' needs and gaps in services, develops and implements new programs, and coordinates with other members of the healthcare team to provide patient-centered care and services across the spectrum, from diagnosis through long-term survivorship. As a navigator, she works with patients and caregivers to identify barriers and concerns and connects them to services and programs that may help alleviate physical, psychosocial, and spiritual issues. She has introduced integrative health services and classes to empower patients and caregivers to achieve a better quality of life during and after treatment. Pamela provides support to the administrative director in hospitals' compliance with ACOS and other authoritative guidelines and standards. She collaborates with physicians and other providers to define the content and process for the delivery of survivorship care plans to patients completing primary treatment.

Pam previously worked at the National Coalition for Cancer Survivorship (NCCS). As Director of Survivorship programs, she oversaw the development of survivors' resources, including the award-winning Cancer Survivors Toolbox[®], represented the organization on the Journey Forward[®] partnership, which developed an electronic tool to create survivorship care plans, and worked with a team to deliver continuing education training to oncology health care professionals. While at NCCS, Pam represented the organization at the Commission on Cancer.

Prior to her work at NCCS, Pam coordinated education and outreach activities in the Cancer Care program at Suburban Hospital. While there, she led the hospital's effort to implement a no-smoking policy on the campus grounds, for which she received the Key Contributor Award. Pam also facilitated prostate cancer and skin cancer screenings, introduced Tai Chi classes for cancer patients, and managed a number of other survivorship programs, including National Cancer Survivors Day events. She served as Suburban Hospital's Cancer Care program to the Montgomery County Cancer Crusade.



Coaching Strategies

Top 10 Coaching Strategies: The Other Side of Survivorship

Tambre Leighn, MA, PCC, ELL-MP

Treatment is over — for some of you, recently. For others, it ended years ago. Either way, you now live in a part of the cancer continuum commonly referred to as long-term survivorship. The label is a convenient way to identify the post-treatment journey.

But cancer isn't a one-size-fits-all kind of experience and neither is how you negotiate the landscape of life after treatment. There may be common ground or similar areas of challenges, however the impact is different for each person depending on many factors.

From a life coaching perspective, we explore the challenges that come with finding your way forward to a life beyond cancer. As it is with treatment, the post-treatment experience also varies widely depending on the individual. Some of you may make a relatively smooth transition, experiencing few to no treatment side effects or psychosocial implications. Others may face significant challenges physically, emotionally and/or in practical life areas such as finances, career and social. A litany of factors contribute to the picture of what your post-treatment life looks like, unique to you. This is why the coaching model focuses on supporting survivors to create their own approach to survivorship.



Working with a coach helps you move from overwhelming feelings of confusion and stress to clarity, ease and peace so you can quickly make decisions and choices that support not only your physical wellbeing but also help you design a life where you feel like you're thriving again.

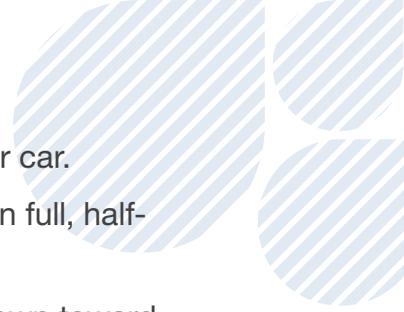
Like Nico, I wished for more support and resources while I was caring for my late husband who was diagnosed with Hodgkin's lymphoma when he was just 34 years old. He and I both struggled with the implications of his cancer. Some of our concerns and issues were shared. Others were unique to the different roles we were cast in. I chose to walk away from a successful twenty-year career in Hollywood to become a coach so others going through the cancer experience would have access to tools and support that we did not have. I have no regrets and though, of course, I wish Gary had survived, he lives on as the inspiration in the work I do to help survivors and their families access the highest quality of life possible. So, I've created my top ten coaching strategies to help you with some of the common challenges experienced by young adult survivors

Tambre's Top 10 Coaching Strategies for Young Adult Survivorship Challenges

1. Create awareness of your physical energy level.

Fatigue, during, after and long into survivorship can be a lingering challenge. Think of your body being like a car. You have to fill it with gas to get it to run.

There is a simple way to begin consciously monitoring your available energy:

- 
- Imagine you have a gas gauge, just like your car.
 - Start regularly checking in to see if you're on full, half-empty or bone dry.
 - If you notice the needle starting to cruise down toward half-empty or below, check in to see if you need to add sleep, better nutritional choices or exercise to your routine. Check out the upcoming section [Top 10 Foods, Exercise and Strategies for the Rest of Your Healthy Life](#) by Carolyn Katzin for more information, changes and choices that can support increased physical energy.

Becoming an expert in monitoring your energy will help you to begin to make choices that add fuel to your tank.

It's also important to look at your expectations and thoughts surrounding how much energy you feel you "should" have. Then get educated as to whether these expectations are realistic. Your doctor can help you determine if there are any medical causes for low energy, so be sure to speak up if you find yourself struggling consistently with this.

I encourage my clients to use a 1 to 10 scaling model to report concerns to their medical team. Spend a few minutes throughout your day checking in and asking yourself, on a scale from 1 to 10 with 10 being the most energized and 1 being the least, how much energy do you feel you have access to in that moment. Tracking these scores for several days and up to a week can give you and your medical team valuable information and help you set a baseline. Work with your doctor to determine what a normal energy is for you.

If, at any point, you find yourself consistently struggling to get out of bed in the morning or unable to complete the

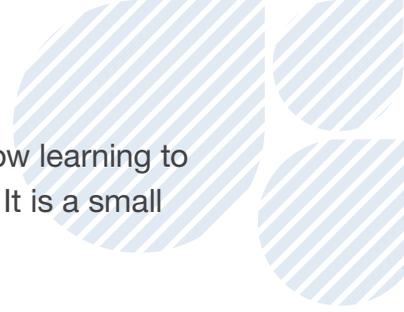


basic tasks and daily goals you set for yourself, be proactive and ask your doctor for a psychosocial screening to be sure depression isn't a factor. Coaching tools and approaches are not a replacement for therapy. Check out the [International Coach Federation website](#) for clarification on the distinction between therapy and coaching. Your wellbeing is your responsibility.

2. Your secret energy stash.

Physically, most people are well aware of how to fuel our bodies. What most of us don't realize is that our thoughts can also drain us of valuable energy.

- Begin to build awareness by noticing what thoughts increase or decrease your energy. Anything that increases your energy is something you'll want to continue focusing on.
- Thoughts that feel like they drain you of energy are areas where we work in coaching to either help you eliminate them or reframe how you experience them.
- A great way to start working in this area on your own is to notice the word choices you make. Is your inner dialogue or external communication with others littered with low energy or negative words? How often do you find yourself saying you should or have to do something? Check out [Tip #4](#) below.
- Create a reminder that makes you feel good which you can use to replace thoughts that drain your energy. Some people call them mantras. One effective approach is to reword the draining thought into a positive. For example,



transforming “I am always tired” to “I am now learning to monitor and increase my available energy.” It is a small thing that can make a big difference.

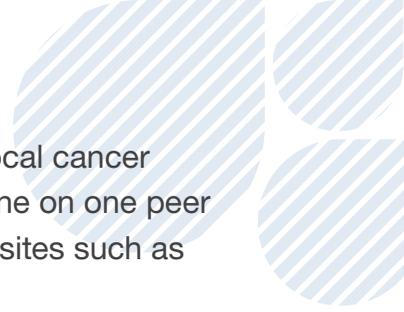
3. You are not alone.

One of the most common complaints I hear from my clients, second to low energy, is how isolated they feel when treatment ends and they are told to move forward with their lives. Most people go from being surrounded by their medical team, family and friends from diagnosis through the end of treatment then find themselves stepping back into a world where they struggle to relate to others.

This can be particularly challenging for young adults who may have had to take a leave from school or early career positions. While your peers were busy graduating, getting married, starting families or working their way toward major career goals, you were facing side effects, medical bills, financial impacts and the difficulty of maintaining a social life. While the cancer experience can move you to a place of emotional maturity, this sometimes creates a relatability issue in your social life.

Thanks to the Internet and social media, there is no reason to sit in isolation. You have many options available; one is sure to fit your schedule, budget and personality type. If you prefer anonymity, online young adult cancer communities such as [I Had Cancer](#) and chat rooms on young adult survivor sites like [StupidCancer.com](#) are a great option.

Looking to connect in person? In Los Angeles, you can check out [Thrive/Survive Los Angeles'](#) group or [weSPARK](#).



Check with your treatment center, doctor or local cancer community resource for recommendations. One on one peer connection is another popular option through sites such as Jonny Imerman's [Imerman Angels](#).

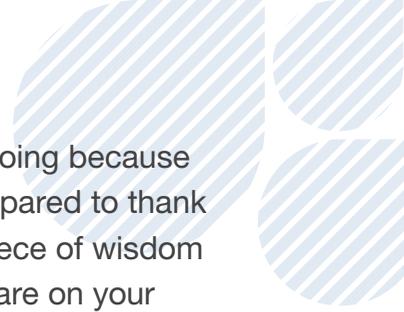
Group experiences, including group coaching, not only arm you with new tools and approaches but also offer the opportunity to connect with other group members facing similar challenges. Though logically it may seem like you should “get” that you’ve got access to support and you’re part of a larger community, emotionally it’s natural to feel all alone when you spend most of your time with others who have not had to deal with cancer.

4. Don’t should on yourself.

There is nothing inspiring when we generate an action out of feeling obligated. Guilt as a motivator isn’t energizing. When others have been there for us through challenging times or offer advice with their best intentions, it can be challenging to turn down their invitations or take a pass on their well-meant advice. Refer back to [#1](#) above — if an invitation or suggestion doesn’t add fuel to your energy tank, you have the right to graciously take a rain check.

Some quick ways to eliminate the “[shoulds](#)” include asking yourself:

- Is the action or choice actually supporting you in a way you will feel great before, during and after or do you imagine you will possibly regret it? Going through cancer gives most survivors an intimate and intuitive sense of their physical limits. Use this to choose wisely.

- 
- Is the action or choice something you are doing because you feel obligated to someone else? Be prepared to thank someone for their thoughtful invitation or piece of wisdom while letting them know that for where you are on your healing journey right now, it's not the best fit for you to choose that action or approach.
 - Is the “should” worth the energy it will cost you when you act out of obligation? This is your “bottom-liner.” If the answer to this question is no, you now have great clarity about the decision that will be in your best interest.
 - When you catch yourself saying you “should” do something, it is an opportunity to stop and reassess. For more insights on this, check out [The S Word](#).

5. Give yourself permission.

You've handled a lot more than many of your peers. Life's thrown you a serious curveball. Honor and respect the courage and strength you've learned to tap into from that moment you were diagnosed until now. If you struggle with:

- feeling guilty asking for help, give yourself permission by remembering how good it feels to help others and that you're creating an opportunity for them to feel that way when you invite them to make a difference for you.
- lightening up, give yourself permission to play, enjoy life and laugh. Being joyful is a gift to yourself and the world. Cancer is serious but becoming overly focused on this is draining. Humor is an important part of healing. Do something that fits your character and personality and your energy level. Small things make a big difference.

- criticizing yourself on days your feel down, give yourself permission to simply be in this space and feel crappy. My late husband and I put a lot of effort into being as positive as possible however, at one point on a particularly rough day, I shared with him that sometimes we just had to be honest and say, “this sucks.” A tool I share with my clients to help ensure they don’t get stuck there is to make an agreement with themselves as to how long they would like to stay in that space and just feel those feelings. Then they would put on a favorite upbeat song, or go for a walk or watch a comedy to help shift out of it.

6. You have a choice.

How you choose to live your life after cancer is completely up to you. Very few people go through the experience without a shift in priorities and a greater focus on investing in what matters to them. You can focus on what cancer cost you or you can focus on what you want to do to get back in the driver’s seat. Every action you take and decision you make writes the story of what you will make of going through cancer. If you aren’t proactive, it can define you — but you are not your cancer.

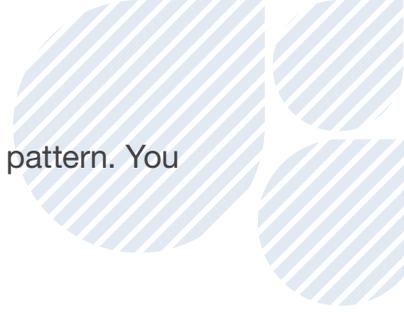
Going through cancer forces you to make a lot of decisions. There is a process you most likely developed for yourself to do this. You often didn’t have time to waste being unclear or confused. Use this skill to help you now choose to build a life that is meaningful and inspiring to you. Don’t let cancer dictate the next chapters of your story.

7. Practice patience.

Changing your thoughts and actions can take time and practice. We are creatures of habit. The good news is this means you know how to create one. If you can create a bad habit based on choices that don't support your survivorship plan or wellbeing, you can create new habits that do. When you've identified the change or changes you want to make, first practice patience. Set your goals and a time period to experiment with the new thoughts or behaviors. Observe (not judge) how you do, then patiently notice where you can generate some improvement and go for it again.

Sometimes sliding into an old thought pattern or habit triggers a feeling of "oh, no — not THIS again." The feelings and emotions around cancer can be complex and often involve experiencing a sense of loss or grief. Even when you've gone through therapy, coaching or a support group, you may find yourself facing sadness, anger, etc. At the moments where the pattern or struggle re-presents itself, you can support yourself by truly understanding and acknowledging something I call [The Spiral Effect](#).

- The reality is that when you have experienced growth and gained insight into a situation, you can never actually go back to that old place. You are actually coming back around at it with a new level of understanding or new tools. You are not be as likely to get stuck in for as long or experience the same depth of suffering as in the past. You have the awareness to recognize the feelings that are coming up and the chance to choose how to act/re-act.
- Life is not lived in a linear fashion. As you learn and grow you are spiraling upward, ascending, transcending. You



are becoming something more than the old pattern. You are living beyond the past.

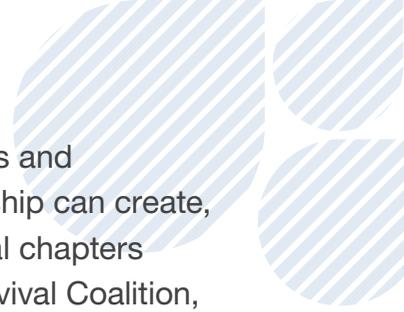
8. Transform a complaint into an action.

Sometimes going through an experience like cancer can significantly impact what you see as important. Often people seek out a new career path aligned with making a difference in the world. Many cancer survivors have taken a complaint they had about their own experience and created a solution to help other survivors. Thrive/Survive Los Angeles and this eBook are great examples of turning something from a complaint into a positive outcome that can make a difference for others.

9. Be of service to others.

When you put others first and do something to contribute to someone else in need, it often works to boost your own energy. There is something magical about it. Keep it simple if you don't have a lot of time, energy or resources. You can sign up as a peer-to-peer volunteer for an organization like [Imerman Angels](#). They match people with similar cancers together — someone who is further along with someone newly diagnosed.

Find a young adult website that speaks to you and contribute regularly on message boards with information you may have learned that has helped you. Run an Internet campaign to fundraise for your favorite cancer nonprofit. Start a blog and feature the stories of other survivors that inspire you. Ask yourself, if you could be of service to others once a week, what difference could you make?



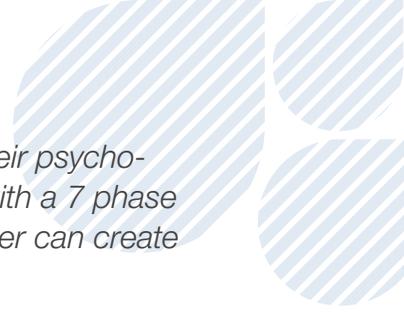
If you are challenged to find practical solutions and resources in your area for the issues survivorship can create, check in with non-profit organization with local chapters such as American Cancer Society, Young Survival Coalition, and Stupid Cancer.

10. Be extraordinary.

You survived cancer — now do whatever it takes to thrive. You deserve it. You have gifts and wisdom to share in your own way. What does an extraordinary life look like to you? How do you define success for you? What will it take to experience at least one extraordinary moment each day? It can be enjoying a sunrise, creating something, coffee with a friend, dancing in public, sharing with someone what it is they mean to you. It doesn't have to mean taking a hot air balloon ride (though it can).

If you need some inspiration, check out Randy Pausch's [“The Last Lecture: Really Achieving Your Childhood Dreams”](#), watch my interview with [Kurt Yaeger](#), a former top BMX competitor, on recreating his life after losing his leg in a motorcycle accident or simply read through the other chapters of this book and notice all the extraordinary moments, experiences, organizations and services created by people whose lives have been affected by cancer.

Tambre Leighn, MA, PCC, ELI-MP is a certified professional coach trained through [iPEC](#) trained certified professional coach and a leading expert in the field of cancer survivorship coaching. She is also the co-creator of [Well Beyond This](#), a coaching based,



digital platform for cancer survivors that supports their psycho-social needs. Well Beyond This provides survivors with a 7 phase process to address the overwhelm and fatigue cancer can create so they have the energy to thrive again.

Tambre has been published in Coping With Cancer Magazine, Breast Cancer Wellness and was recently invited to be a Stakeholder Grant Reviewer for the American Cancer Society. Through her company, [Well Beyond Ordinary](#), Tambre offers coaching as well as a large number of free resources and library of blog articles.

As a sought after speaker, Tambre has delivered cancer survivorship, caregiver and wellness workshops, coaching and leadership training to top organizations including: Young Survival Coalition, Atlantic Healthcare Systems, USC Phillip Norris Cancer Center, Emory University, Mattel Inc., Keep A Breast Foundation, Thrive/Survive Los Angeles, UCLA's Healthy Lives After Cancer, StupidCancer, Pink Link, and more.

She has also published two eBooks available on Amazon.com, "Just Diagnosed: Practical Tips for Cancer Survivors and Caregivers" and, specifically for caregivers, "Self Care isn't SELF-ish: Taking Care of You IS Caring for Your Loved Ones." Tambre is also co-creator of this eBook project.

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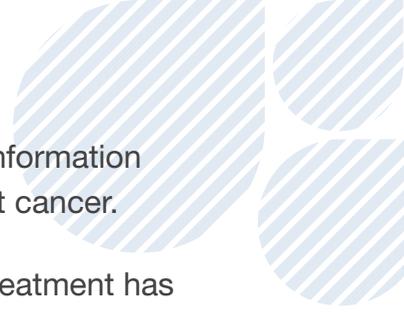
Emotional and Psychological Issues Top 10 Psychological Issues to Consider when Treatment Ends

*Kauser Ahmed, Ph.D. and Belinda Sangrat, M.A.
Simms/Mann UCLA Center for Integrative Oncology*

Cancer and cancer treatments impact our bodies both physically and mentally. Finally hearing the news that you are cancer-free can put you on top of the world for a little while, but — then what? Many young adult survivors like you find that it's not always easy adjusting to a “new normal.” Feelings of sadness, anger, worry and frustration are to be expected during survivorship and can come and go over time. Read on to understand what's normal and what signs to look for when it's time to seek help.

1. Why can psychological/emotional issues come up at different times during a survivor's development and life, long after treatment has ended?

Being a cancer survivor is part of someone's life. There are times when it can feel like a small, or not very important part of your identity, and other times when it plays a greater role. As a young survivor, your challenges can include issues related to your cancer history. Periods of transition — such as leaving home for college, getting a job, a first significant relationship or contemplating parenthood — are all milestone events that come with their own unique obstacles. For example, you might meet someone new and decide to make them an intimate part of your life. When this happens,

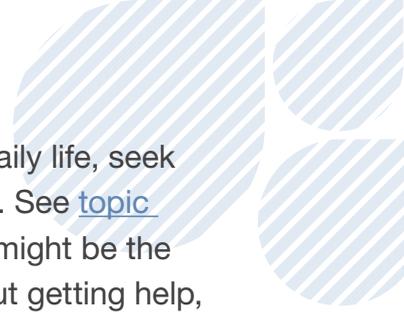


you might think about how or when to share information about your medical history or your fears about cancer.

You may also have concerns about whether treatment has affected your fertility and ability to have a biological child. Another example might be when you start looking for a job. One of the first things you might consider could be health benefits or the amount of time the company lets you take off to go to medical appointments. These challenges can re-introduce feelings of sadness or frustration about being a cancer survivor or they can generate new feelings about what it means to have reached these milestones. Having these feelings does not mean that something is “wrong” ; they are simply signals that this part of your identity needs some time and attention — so that you can continue to make sense of what being a cancer survivor means to you, on your terms.

2. Is it common for young cancer survivors to feel anxious or depressed?

Yes. Although estimates can vary, research indicates that up to 25% of cancer survivors experience symptoms of depression and up to 45% report feelings of anxiety. Compared to older adult cancer survivors, young adults who have gone through cancer treatment experience a greater number of difficult social and emotional challenges. Feelings of sadness, anger and fear of recurrence are normal and to be expected, especially in your first year of survivorship. Later in this chapter ([topic #7](#)), we list common signs and symptoms that can point to clinical anxiety and depression. If you are experiencing these symptoms and they last longer



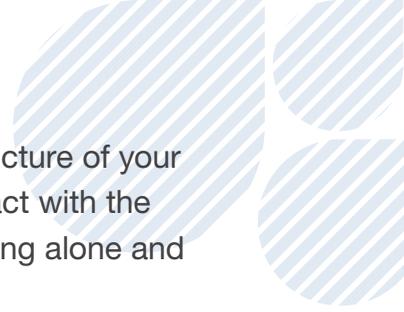
than two weeks or if they interfere with your daily life, seek help from one or more of the resources below. See [topic #9](#) below to find out which type(s) of support might be the best fit for you. To see how you might go about getting help, check out [topic #10](#).

3. Do cancer survivors think about suicide?

A significant number of cancer patients report that they have thoughts of hurting themselves or feel like they would be “better off dead.” When compared to the general population, someone with a cancer diagnosis is almost two times more likely to commit suicide. Studies have shown that cancer survivors have high rates of suicide and that rates of suicide may remain elevated many years into survivorship, particularly if there are ongoing late effects of treatment. This means that many survivors struggle with suicidal thoughts but do not openly talk about it. If this is you, seek support so that you are not struggling with these feelings on your own. If these thoughts persist, or you begin to think of ways you might act on these feelings, it is definitely time to tell someone and get their help in finding professional assistance. See [topics #9](#) and [#10](#) for more details on what types of help are available and ways in which you could go about getting help.

4. What can make psychological issues harder in survivorship than during treatment?

When you are in treatment, you may feel like fighting cancer is a full-time job. You are doing your “job” to keep cancer away just like the rest of the medical team is doing



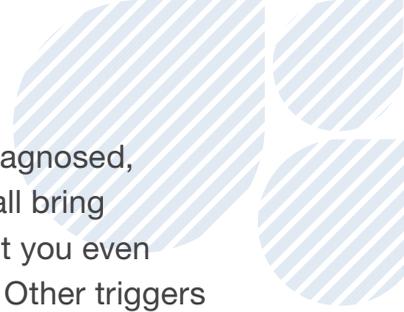
theirs. When treatment ends, much of the structure of your appointments, as well as the supportive contact with the medical staff is gone and you may be left feeling alone and vulnerable.

Many survivors note that it is not until AFTER all the difficult physical aspects of treatment ended that they are able to pay any attention to the emotional toll of the experience. This can be especially complicated when the people around you — family, friends, coworkers — are excited and celebratory about you “being done.” You may feel like the only one not celebrating and it is common to feel reluctant about sharing how you feel for fear of bringing others down.

It can also feel difficult to ask for more support when you perceive that everyone wants you to be “back to normal.” These feelings can be most acute in the first several months after treatment and during the transition phase of figuring out what it means to have survived cancer, but these feelings can also continue for quite some time afterwards. Sometimes you may even find that these feelings get triggered by new or unexpected events.

5. What are the most common triggers for psychological distress?

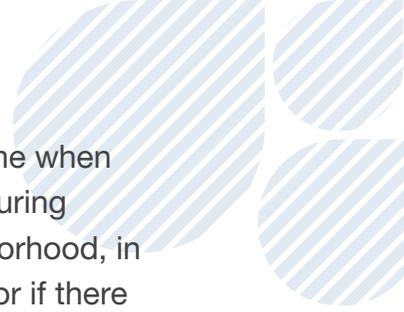
As survivors, the most common triggers for emotional distress are related to reminders that the experience of cancer may not be over or that cancer may come back. These triggers include any physical symptoms that were present when you were first diagnosed or any new symptoms that bring on worry about another



cancer. Anniversaries of the date you were diagnosed, date of surgery, or the end of treatment can all bring on unexpected feelings — sometimes without you even realizing that a significant date has come up. Other triggers include ongoing late effects of treatment that linger or are identified at a later point. These can bring on feelings of sadness, frustration and even anger about not being able to put the experience behind you. They can also cause worries that having had cancer may always compromise your quality of life or your ability to achieve all the goals you set for yourself. And lastly, triggers can come from sources completely outside of your own life. News reports of celebrities with cancer or even research news about advances in cancer can suddenly inject thoughts about your own diagnosis and treatment history into a day that had been normal and happily cancer-free.

6. What are “normative” emotional responses and what feelings that suggest it is time to seek help?

Just like in everyday life, there are good days and bad days. Feelings of sadness, frustration, anger and worry will undoubtedly be part of your survivor experience and you will find that these emotions come and go over time. You may also feel isolated, or different from your peers. You may find, initially, that you no longer have as much in common with good friends whom you knew before your cancer diagnosis. Many survivors say that they feel older than their friends in some ways, with a greater sense of life perspective, and at the same time, they feel more anxious about random social things like dating or being in loud, crowded social settings.



It certainly makes sense to have periods of time when survivors feel more difficult emotions — like during transitions from the end of treatment to survivorhood, in the weeks leading up to a scan or screening, or if there has been some other difficult experience related to being a cancer survivor. But when these feelings continue on for more than two weeks at a stretch, pay attention and see if they are accompanied by other changes. These include changes in appetite, sleep, energy, concentration or more feelings of irritability, tearfulness or agitation. If you have these kinds of feelings as well as a general sense that it is hard to enjoy things you used to care about or if you feel like everything in your life is just harder than it should be, it is time to consider seeking help. And of course, if you begin to have persistent thoughts about harming yourself or you can't stop thinking about how you would carry out plans to harm yourself, don't wait! Get help immediately by contacting your doctor, therapist or dialing 911.

7. What can clinical depression or anxiety look like for someone who is a young cancer survivor?

Listed in the [table on page 43](#) are characteristics or criteria used to diagnose adults with clinical depression and/or anxiety. It is important to keep in mind that young cancer survivors may be more likely to express their distress in other ways, too.

As a young cancer survivor, your anxiety may also focus on feelings of disappointment in yourself for not living up to your own high standards or worries about letting others down. Although you may express less overt emotions



such as tearfulness or sadness, it is probably more likely that you'll describe stresses or frustrations. Young male survivors, in particular, may have more feelings of helplessness that get expressed in angry or impulsive outbursts. If you are experiencing these symptoms and they last longer than two weeks or if they interfere with your daily life, seek help from one or more of the resources below. See [topic #9](#) below to find out which type(s) of support might be the best fit for you. To see how you might go about getting help, check out [topic #10](#).

8. What are some of coping mechanisms that young survivors develop that make it difficult for them to seek help?

Nearly everyone who goes through a cancer diagnosis is told by others how “brave” and “strong” they are. But young cancer survivors, in particular, can receive these kinds of messages throughout their treatment from doctors, nurses, parents, teachers — basically, every person who knows what you're going through. It can be hard to watch your parents in distress, and it's very easy to take on the role of “protecting” them from feeling worse by being a good soldier and not complaining. There can be real benefits to this way of getting through really hard procedures, and it might help you cope during treatment to just focus on what you have to do. This strategy can also motivate you to get through other challenges in your life after cancer by being persistent or determined. The downside, however, can be that when it is all done, you can have a hard time acknowledging any difficult feelings to yourself and it can be especially hard for you to talk about them with others. This



way of coping could leave you feeling that it is wrong to be struggling or to ask for any kind of emotional help because you might feel that you should be strong or capable enough to deal with everything on your own. There are lots of ways to be strong, and different ways of coping make sense at different times in your life. Think about what have been the strengths and limitations of the way you got through cancer treatment — and think about what new ways you want to cope with challenges or express yourself to others now that you are a survivor. These are choices you get to make to keep growing.

9. What are some of the different forms of help (e.g., peer support groups, therapists, psychiatrists) and when can they be useful?

There are many kinds of support available to survivors. Peer support, whether on internet chat sites or in live group meetings, can be a great place to go when you are feeling alone in your experience or unsure if others are going through similar struggles. Just hearing others' stories and sharing ideas about how different survivors manage their stresses can be a great relief and can help you to feel less isolated. Seeing a psychologist or other licensed mental health clinician who is familiar with oncology can also be beneficial when you would like to talk about some of the more personal aspects of what you have gone through and focus on better understanding how your cancer experience has intersected with other experiences in your life — dynamics with your family or partner or aspects of yourself you had noticed even before the diagnosis. Meeting with a knowledgeable therapist can give a safe space in

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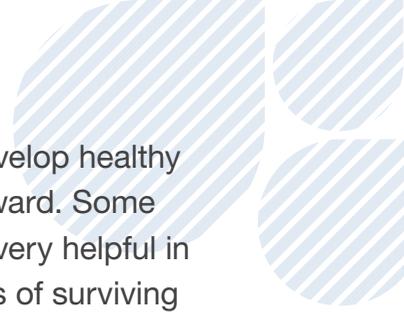
Common Symptoms of Depression

- Feeling sad, empty, depressed, irritable or tearful most of the day, nearly every day
- Inability to enjoy or diminished interest in nearly all or almost all activities/hobbies that you used to find pleasurable
- Changes in sleep pattern such that you have difficulty falling asleep, difficulty staying asleep or sleeping too much
- Decrease or increase in appetite nearly every day
- Fatigue or loss of energy
- Feelings of worthlessness or excessive guilt
- Excessive difficulty thinking, concentrating or making decisions
- Feeling really agitated or sluggish
- Suicidal ideation with or without a plan or recurrent thoughts of death

Common Symptoms of Anxiety

- Excessive anxiety and worry occurring most days that is difficult to control
- Feeling restless, keyed up, irritable or on-edge
- Changes in sleep pattern such that you have difficulty falling asleep, difficulty staying asleep or restless, unsatisfying sleep
- Excessive difficulty thinking, concentrating, making decisions
- Physical symptoms include fatigue, fidgeting, headaches, nausea, numbness in hands and feet, muscle tension, muscle aches, difficulty swallowing, bouts of difficulty breathing, trembling, twitching, sweating, insomnia, hot flashes, and rashes

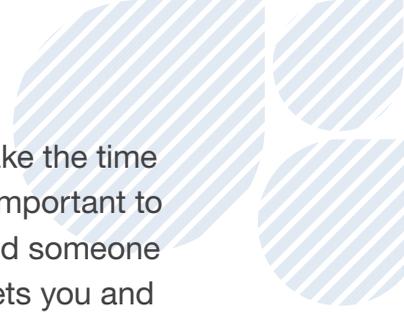
Adapted from: American Psychiatric Association. (2000). Diagnostic and statistical manual of mental disorders (4th ed., text rev.). Washington, DC: Author.



which to examine these issues and also to develop healthy ways of dealing with them now and going forward. Some survivors find that meeting with a therapist is very helpful in assisting them to manage the unique anxieties of surviving cancer and can help them in defining what they want from their “new normal.” Psychiatrists are a specific kind of medical doctor who help people manage difficulties with depression, anxiety or other psychological issues when they require more than therapy. Usually with the referral from someone else on your health care team, a survivor could see a psychiatrist to assess their symptoms of depression, anxiety or other conditions and to then come up with the appropriate medication that can help put those symptoms back into balance. Often, it is helpful to see a psychiatrist and a therapist at the same time.

10. How do I go about getting help?

There are different resources available to help you gain access to the right kind of support. The internet has many websites specifically for young people who have gone through cancer including: www.stupidcancer.com and www.ulmanfund.org. You can also contact your local American Cancer Society office at www.acs.org to get information about face- to-face support groups for young survivors in your area. You should consult with your healthcare team — your oncologist, nurse or primary care doctor — for referrals to knowledgeable therapists and/or psychiatrists. If they are not able to assist, or you would like to find someone who accepts your insurance, contact your insurance company and they will refer you to a website that lists mental health specialists on your insurance panel. You can typically have



initial appointments with several therapists. Take the time to meet with different therapists because it's important to choose one that you are comfortable with. Find someone who is a good fit for you — a therapist who gets you and can help you to make the best of where you are headed!

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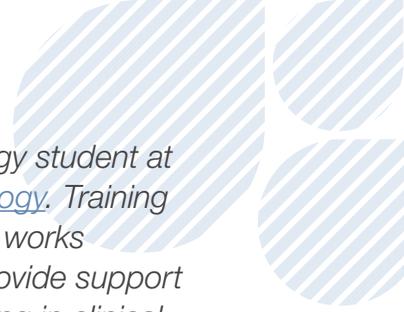
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4

Eat Well, Live Well

Top 10 List of Foods, Exercise and Strategies for the Rest of Your Healthy Life

*Carolyn Katzin, MS, CNS, MNT Certified Nutrition Specialist
President of Fountain Resources, Inc.*

1. Start and end each day with a thought of gratitude for the food and other sustenance that has brought you to this moment.

Ideally, starting and ending each meal with such a moment of gratitude — also called grace — helps trigger healthy digestive secretions, too.

2. Have breakfast.

Whole grain cereals or yogurt with wheat germ, flax or chia seeds or egg whites with spinach or poached egg on whole grain toast are great ways to start the day. Add a cup of blueberries for added antioxidants. Your attention will be better focused in the morning when you have some high fiber food within a couple of hours of getting up. This is also an important meal for getting dietary fiber into your diet.

3. Eat high fiber foods throughout the day.

Fiber is found in foods that don't come from an animal source so beans, vegetables, nuts and seeds as well as fruit have fiber, unless it has been refined away. Fiber provides

nourishment for the microorganisms that live in our digestive tract and enhances a healthy balance of probiotics.

4. Choose at least one of the cruciferous family of vegetables each day.

A good one to have raw is watercress, which is full of health benefits, low in calories and high in fiber. Another good choice is steamed broccoli. Others include kale, Swiss chard, cauliflower, brussels sprouts, cabbage, bok choy and mustard greens.

5. Choose at least one of the Allium family of vegetables at least three times a day, preferably more often.

Examples include garlic, scallions, onions, shallots (ideal for those who find onions difficult to digest), chives and leeks.

6. Choose fish at least twice a week for easy to digest protein and omega-3 fats.

Canned sardines or salmon are rich in calcium as the bones are softened in the canning process so you can eat them.

7. Cook from scratch often so you know what you are actually eating.

If you have a farmers' market nearby select organic produce when you can and add lots of fresh culinary herbs and spices to your home made dishes. Soups are a wonderful way to eat vegetables and you can season them with lots

of culinary herbs like rosemary, oregano, thyme, etc. which have lots of nutritional benefits.

8. Berries and more berries.

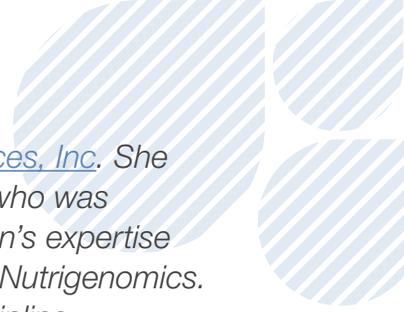
Berries of all sorts provide color, nutrients and flavor. They are low calorie, low sugar and high fiber; they also make wonderful garnishes, toppings and desserts. Black raspberries are especially beneficial in maintaining healthy cells that line the upper airways. Eat at least once a day.

9. Get up and move often.

Instant recess or brief activity breaks make for better overall health and get your metabolism and circulation moving. Dance, stretch, breathe deeply and simply enjoy being alive. This is so important if you are in a sedentary type of job or find yourself feeling unmotivated. You don't have to embark on a huge exercise program to get the benefits of movement. Ten minutes several times a day is just as beneficial.

10. Don't smoke and avoid exposure to all types of airborne carcinogens.

Tobacco smoke contains more than 250 chemicals and at least 4 are radioactive and more are known carcinogens. There is nothing good about smoking, chewing or inhaling tobacco products.



Carolyn Katzin is the President of [Fountain Resources, Inc.](#) She is a nutritionist with twenty-five years of experience who was educated at University of London and UCLA. Carolyn's expertise includes the emerging field of nutritional genetics or Nutrigenomics. Her graduate degree involved research into this discipline.

Carolyn is a lead volunteer with the American Cancer Society. She is a member of the national nutrition, physical activity and cancer control advisory group and a member of the California Division Board. Her work with cancer patients began in 1985 at The Cancer Support Community Benjamin Center, formerly The Wellness Community in Santa Monica and she remains on their professional advisory board.

Visit www.carolynkatzin.com or www.cancernutrition.com to learn more about Carolyn's related nutrition and health-related services.

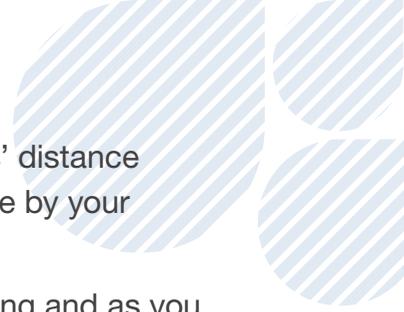
10 Tips for Young Cancer Survivors Creating a Sustainable Yoga Practice

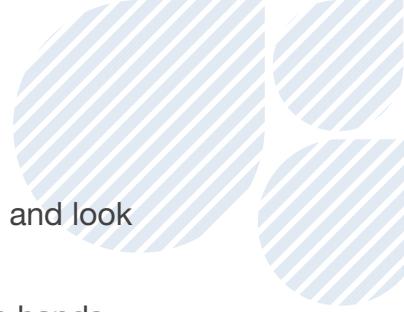
*Sara Zuboff, Certified Yoga Teacher and Massage Therapist
Founder of The Spirit Mechanic*

1. I like to move it, move it.

Boiled down to the essentials, yoga is the union of the body and mind using the tools of breath and movement. After undergoing treatment, the mind/body connection may feel severed or even unattainable. Yet in seeking the path to wellness it becomes obvious that this connection is vital to the journey and yoga is an accessible vehicle to jumpstart that connection. And perhaps the easiest way to begin the creation of a yoga practice is simply to do that: begin. As with any physical activity and exercise, please make sure to check with your doctor for clearance to begin your yoga practice and to discuss any physical limitations you may have.

Start where you are by beginning to breathe through the nostrils. Notice the breath as it comes into and out of the body. Notice the chest as it rises and falls and the sensation felt at the nostrils. Practice this way for several moments, allowing your breath to deepen into the lower abdomen. Once you feel connected and centered to the breath we will add a series of movements called Sun Salutations in order to feel the immediate effect of uniting breath and movement.

- 
- Stand in Mountain pose, with your feet hips' distance apart, thighs lifting, chest open, hands loose by your sides and palms facing in.
 - As you inhale, circle the arms up to the ceiling and as you exhale circle the arms down to the floor, hinging forward from the hips in order to bring the fingertips to the floor (bending the knees as needed). We are now in Standing Forward Bend.
 - From here, inhale and look up with the head, bringing fingertips to the shins. As you exhale lower back down to Standing Forward Bend.
 - Inhale in and as you exhale take a large step back with your right foot (Runner's Stretch).
 - Inhale in and as you exhale take a large step back with your left foot, coming into Plank pose. (Lower your knees to the ground if needed).
 - Inhale in and as you exhale bend the elbows in by your sides and lower yourself all the way to the floor.
 - As you inhale, place your hands by your chest, elbows bent by the sides.
 - As you exhale, press into the hands lifting your torso and head up toward the ceiling creating a mild back bend (Upward Facing Dog).
 - Take and inhale and as you exhale bring your toes underneath your feet (putting the feet into a flexed position).
 - Inhale and as you exhale lift the hips high towards the ceiling, making a triangle with your hands and feet as the base (Downward-facing Dog).

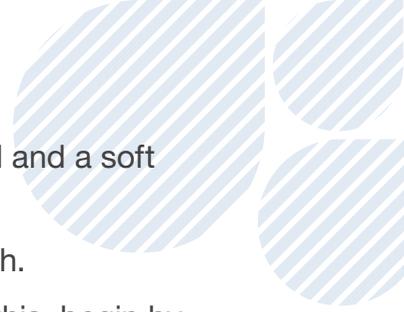
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- Take three breaths here.
 - Then on the third inhalation, lift the right leg and look towards your hands.
 - As you exhale, swing the leg up towards the hands (Runner's Stretch).
 - Inhale and as you exhale bring the left foot towards the hands in Standing Forward Bend.
 - Inhale and as you exhale circle the arms all the way up towards the ceiling, coming up with a flat spine.
 - Inhale and as you exhale lower the arms down by your sides.
 - Repeat the entire sequence 3 to 5 times.

2. Stoke your inner fire.

One of the great benefits of yoga is an increase of energy or inner fire. One of the biggest complaints I hear from clients who have undergone treatment is that their energy feels lacking, so much so that sometimes a physical practice can seem daunting. Luckily there are other tools to increase energy. One of the most accessible ways to do this is through breathing exercises that are designed not only to increase energy but to calm the nervous system. A popular breathing technique called Ujjai breathing can be used as a stand-alone exercise or as you do your yoga poses, which will create a powerfully energetic response within the body.

Ujjai breath

- Breathing deliberately in and out through the nose, raising the back of the tongue up to touch the soft palate of the



mouth. This will create a soft rushing sound and a soft vibration at the back of the throat.

- Keep the inhales and exhales equal in length.
- If you're having trouble getting the hang of this, begin by making a drawn-out "HA" sound. After several breaths this way, close the mouth, but continue to make the HA sound at the back of the throat.

3. Kundalini rising.

I remember my first yoga class. It was full of foreign phrases like "Kundalini rising" and "inner shakti." I enjoyed the physical aspect of the practice, but I had no idea what they were talking about. After sticking with my practice, I learned that having my kundalini rising was actually a good thing. Kundalini rising is the idea of moving energy up from the base of the spine up through the chakras (or energy centers) located along the spine. Having this energy move up allows for greater vitality and vibrancy. In order to free up the energy that can sometimes get stuck in the body and free up the flexibility of the spine, try the following exercises.

Sufi Circles

- Sit in a comfortable cross legged position. Move your torso in a big circle imagining that you are drawing a giant circle with your navel.
- Continue for 1 minute and then switch directions, performing the movement for another minute.
- Remember to arch from your low back as you move forward and round the spine as you come back. The head can gently follow the movement of the spine.

Spinal Flex

- Begin in a comfortable cross-legged position.
- As you inhale, arch your back, bringing your sternum forward.
- As you exhale, bring the sternum in, arching your back out (rounding the spine).
- The breath can be as fast or as slow as you like.
- Remember to allow the head to gently follow the movement of the spine. Perform for 1 to 3 minutes.

4. Balance in an unbalanced world.

Finding balance is a buzz phrase in our culture. As our worlds become fuller it becomes essential, but even more challenging to find balance. The interesting thing about balance is it is not static. Balance is actually a dance of give and take, doing and letting go. The next time you're feeling out of balance, try this yoga balancing pose to remember the challenging, yet attainable goal of finding balance in an unbalanced world.

Tree Pose

- Start by standing in Mountain pose, legs should be hips' distance apart, arms down by the sides palms facing in, and chest open. Shift your weight slightly onto the left foot, keeping the inner foot firm to the floor, and bend your right knee. Reach down with your right hand and clasp your right ankle.
- Draw your right foot up and place the sole against the inner left thigh; if possible, press the right heel into the



inner left groin, toes pointing toward the floor. The center of your pelvis should be directly over the left foot.

- Rest your hands on the top rim of your pelvis. Make sure the pelvis is in a neutral position, with the top rim parallel to the floor.

Lengthen your tailbone toward the floor. Firmly press the right foot sole against the inner thigh and resist with the outer left leg. Press your hands together in front of the chest in prayer position. Gaze softly at a fixed point in front of you on the floor about 4 or 5 feet away.

Stay for 30 seconds to 1 minute. Step back to Tadasana with an exhalation and repeat for the same length of time with the legs reversed.

5. Inner strength, inner peace.

Core strengthening is all the rage in fitness regimens and for good reason. Yogis have always understood that core strength not only creates toned abs, but also fosters an inner reserve of accessible power. I love to incorporate core strengthening poses into my yoga practice, especially when I'm feeling overwhelmed and stressed as it allows me to immediately experience my own strength and further empowers me to face my challenges. Core poses were my secret weapon as I navigated my own diagnosis and treatment. To increase core strength, try the following pose called Boat Pose.

Boat Pose

- Sit on the floor with your legs straight in front of you. Press your hands on the floor a little behind your hips, fingers pointing toward the feet, and strengthen the arms. Lift through the top of the sternum and lean back slightly. As you do this make sure your back doesn't round; continue to lengthen the front of your torso between the pubis and top sternum. Sit on the "tripod" of your two sitting bones and tailbone.
- Exhale and bend your knees, then lift your feet off the floor, so that the thighs are angled about 45-50 degrees relative to the floor. Lengthen your tailbone into the floor and lift your pubis toward your navel. If possible, slowly straighten your knees, raising the tips of your toes slightly above the level of your eyes. If this isn't possible remain with your knees bent, perhaps lifting the shins parallel to the floor.
- Stretch your arms alongside the legs, parallel to each other and the floor. Spread the shoulder blades across your back and reach strongly out through the fingers. If this isn't possible, keep the hands on the floor beside your hips or hold on to the backs of your thighs.
- While the lower belly should be firm, it shouldn't get hard and thick. Try to keep the lower belly relatively flat. Press the heads of the thigh bones toward the floor to help anchor the pose and lift the top sternum. Breathe easily. Tip the chin slightly toward the sternum so the base of the skull lifts lightly away from the back of the neck.
- At first stay in the pose for 10-20 seconds. Gradually increase the time of your stay to 1 minute. Release the legs with an exhalation and sit upright on an inhalation.

6. Get your Zen on.

Meditation can seem intimidating at first, but mainly due to the misconception that you have to be able to stop thinking in order to meditate. Our brains are made for thought.

Meditation's aim is to simply widen the space and lessen our attachments to our thoughts so we don't feel run by them.

This can be particularly useful during stressful times when our minds have run amok as it will give a sense of distance and freedom from painful thoughts. An easy way to begin a meditation practice is to start simply. Here's a wonderful technique to use and my suggestion is to set a reasonable practice time and set a timer if needed.

Mindfulness Meditation

- Begin either in a comfortable seated position or lying on the floor. (If you tend to fall asleep easily, consider using a seated position) Close your eyes and inhale and exhale several times through the nose. Allow the breath to occur naturally, without trying to force it into a pattern. Just notice what it feels like to breathe, in this moment. When you are ready, bring your focus to the sensation of air as it moves in and out of the nostrils or to the gentle rising and falling of the chest as you breathe. Simply notice these sensations for several moments and as you inhale, silently say to yourself “inhaling” or “rising” and as you exhale say to yourself, “exhaling” or “falling.” Continue in this way for as long as you feel comfortable. If your mind wanders into thought simply observe this also, labeling the thoughts as “thinking.” See if you can label the thoughts without getting drawn into them, allowing yourself to come back to observing the breath. You may practice this way for as

long as you feel comfortable. If you need to change your position, do so gently and mindfully. When you are ready to complete your meditation session, simply open your eyes, allowing your connection to the present moment continue as you move about the rest of your day.

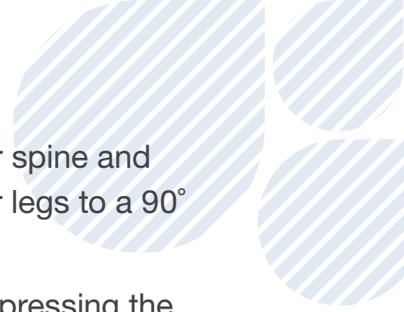
7. Change your perception.

Have you ever felt stuck in a negative emotion or situation? Or, there may be an event in your past that you can't seem to get over or let go. It can be difficult to change our minds once they've been set in a certain direction. Sometimes it's easier to practice changing our perception in our bodies first to remind us of the freedom that can come with changing our minds. Practice a yoga inversion pose to help connect with this concept.

Shoulder Stand

Warning: If you have wrist, neck or shoulder pain, please consider using a modification. If you have high blood pressure, heart disease, stroke or a hiatal hernia, please consult a doctor before performing this pose.

- Begin by lying on your back, lengthening your whole body. If you would like to work in full shoulder stand, try placing a folded blanket under your shoulder along the shoulder line, allowing your head to rest off of the folded blanket, keeping your neck in a neutral position.
- Lay your arms with palms facing down, along the floor by your sides.

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- Gently draw the belly up and in toward your spine and keep your shoulders relaxed as you lift your legs to a 90° angle to your body.
 - Place your hands on the backs of the hips, pressing the elbows into the floor, allowing your hands to support the pelvis.
 - Engage your stomach as you roll the hips gently up and off of the floor.
 - Maintaining the hips off of the floor, by positioning the hands under the pelvis (the base of the palms will cup your iliac crest).
 - Lengthen the legs out, allowing them to move to an approximate 70° angle with the ankles directly above the face.
 - Now, align the forearms so they are parallel in order to distribute the weight evenly. If this is too much pressure on the arms or hands, move the legs to an angle more towards the head (Half Shoulder Stand).
 - If you feel comfortable, you may come into full shoulder stand by continuing to come upright with the legs, by walking the hands toward the shoulder blades.
 - Come onto the tops of the shoulders by walking the elbows towards each other.
 - Stay here, breathing deeply for as long as you feel comfortable.
 - To come out of this pose, engage your belly and roll down slowly. Once you are out of the pose, lay on your side with your knees slightly bent, breathing deeply, and when you are ready, slowly come into a seated position.

Modifications

- ◆ Use the wall for support with one leg bent, foot on the wall. (This will help take strain off the wrists and shoulders)
- ◆ Use a folded blanket under the shoulders to maintain the natural curve of the neck.

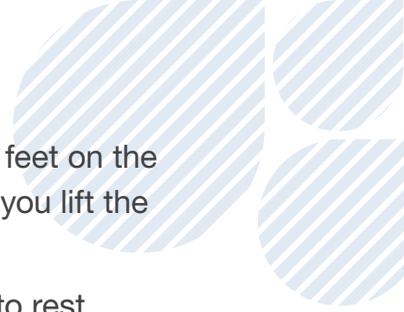
8. Trading depressed for deep rest.

We are a go-go-go society. Sometimes all that doing can create a feeling of malaise as our to-do lists reach never ending proportions. A good antidote to all that doing is to take time out of our day to create a period of deep rest. Restorative poses are a powerful addition to any yoga practice and a wonderful way to counteract the stress of day-to-day living. An added and somewhat unexpected benefit is the energy boost restorative poses can give.

Legs-up-the-wall pose

Warning: Contraindicated if you have serious eye problems, such as glaucoma.

- With a folded blanket, pillow or bolster, start 5-6 inches from the wall.
- Sit sideways on one end of your support. On an exhale, in one movement, swing your legs up the wall as your shoulders and head come to rest on the ground.
- Your sitting bones should be in the space between the support and the wall, allowing a gentle lowering of the tailbone.

- 
- If you need to adjust the support, place the feet on the wall with bent knees. Press into the wall as you lift the hips up and move the support as needed.
 - Keep the legs vertical and allow your arms to rest naturally at your sides or shoulder height.
 - Stay in the pose for 5 to 15 minutes. (This would be a good pose to practice one of the healing meditations)
 - To come out of the pose, slide off the support onto the floor and then turn onto your side. Stay on your side for a minute or two before coming up slowly.

Modifications

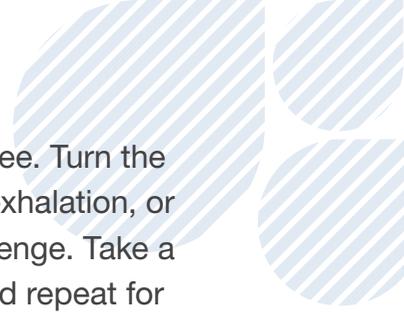
- ◆ If your cervical spine feels flat, place a small folded towel under the neck.

9. Stand your ground.

As life continues to move at a dizzying pace, the ground underneath our feet and our decisions can feel uncertain. A sense of feeling grounded is essential as we navigate life's challenges. The standing poses in yoga are not only designed to increase strength, but to create an energy and feeling of true connection and support. Warrior 1 is a wonderful introduction to standing poses and will give you a feeling of power and connection. After treatment, I remember feeling very vulnerable, physically and emotionally. Standing poses allowed me to connect to a deep well of strength and support not only within myself, but in the world around me.

Warrior 1

- Start by standing in Mountain pose, with legs hip-distance apart, arms down by the sides, palms facing in, and chest open. With an exhale, step or lightly jump your feet 3 1/2 to 4 feet apart. Raise your arms perpendicular to the floor (and parallel to each other), and reach actively through the little-finger sides of the hands toward the ceiling. Firm your scapulas against your back and draw them down toward the coccyx.
- Turn your left foot in 45 to 60 degrees to the right and your right foot out 90 degrees to the right. Align the right heel with the left heel. Exhale and rotate your torso to the right, squaring the front of your pelvis as much as possible with the front edge of your mat. As the left hip point turns forward, press the head of the left femur back to ground the heel. Lengthen your coccyx toward the floor, and arch your upper torso back slightly.
- With your left heel firmly anchored to the floor, exhale and bend your right knee over the right ankle so the shin is perpendicular to the floor. More flexible students should align their right thigh parallel to the floor.
- Reach strongly through your arms, lifting the ribcage away from the pelvis. As you ground down through the back foot, feel a lift that runs up the back leg, across the belly and chest, and up into the arms. If possible, bring the palms together. Spread the palms against each other and reach a little higher through the pinky-sides of the hands. Keep your head in a neutral position, gazing forward, or tilt it back and look up at your thumbs.
- Stay for 30 seconds to a minute. To come up, inhale, press the back heel firmly into the floor and reach up



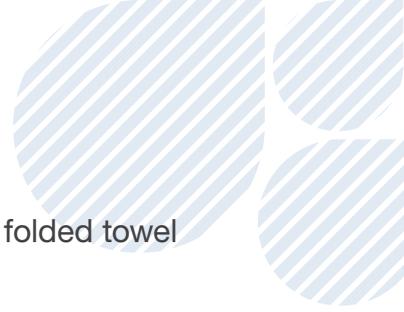
through the arms, straightening the right knee. Turn the feet forward and release the arms with an exhalation, or keep them extended upward for more challenge. Take a few breaths, then turn the feet to the left and repeat for the same length of time. When you're finished, return to Mountain pose.

10. Invitation to being.

At the end of every yoga session we end in a pose called Savasana or corpse pose. At first blush the pose seems simplistic, but it will probably be one of the most challenging poses you do. While you lay on the floor in the pose the aim is to let go of your identification with your body. As you do, you are immediately confronted with questions, "If I am not my body, what am I? What is left?" Deceptively simple, corpse pose is a true invitation to being rather than doing.

Savasana (Corpse pose)

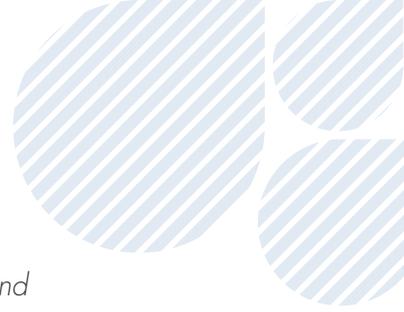
- Lie down in a neutral position, with your legs and arms out and relaxed along the floor.
- Allow yourself to become aware of the breath, the gentle rise and fall of the chest as you breathe.
- Soften the face and with each exhale allow your body to sink further into the floor.
- Continue for as long as you feel comfortable, using the rhythm of the breath to allow you to sink further and further into relaxation.



Modifications

- ◆ If you have low back pain, place a small folded towel under the knees.
- ◆ If you become chilly lying on the floor, place a light blanket over you before you begin.

Sara Zuboff is a certified yoga and massage therapist who started *The Spirit Mechanic* out of her devotion to helping people achieve a healthier lifestyle. She has worked in physical therapy for seven years, creating health programs for people recovering from a myriad of ailments; Guillain Barre, Breast Cancer, Rheumatoid Arthritis, Multiple Sclerosis, & Pelvic Dysfunction. Diagnosed with Thyroid Cancer in 2010, Sara became even more passionate about sharing the life enhancing tools that yoga therapy can provide. Sara received her massage education from LAVI and is licensed in the state of California. She continues to pursue her yogic studies, but currently has been certified to teach Hatha Yoga from Santa Monica Yoga, Pre-Natal and Yin Yoga from Santa Barbara Yoga and a children's certification from Mini Yogis.



Survivorship Care: Exercising and Health

*Carol J. Michaels, Cancer Exercise Specialist and
Creator of Recovery Fitness®*

At least 20 observational studies have shown that physically active cancer survivors have a lower risk of cancer recurrence and improved survival compared with those who are inactive, according to the newly released American Cancer Society 2012 Nutrition and Physical Activity Guidelines for Cancer Survivors.¹

In spite of this, as noted by Dr. Demark-Winfried, associate director for cancer prevention and control at the University of Alabama at Birmingham, “We know that after a first diagnosis of a potentially life-threatening cancer, many cancer survivors are primed to re-evaluate lifestyle behaviors; however, the data are beginning to accrue that this often is a short-term change, and without reinforcement, they tend to drift back to previous lifestyle habits the farther they are from diagnosis”.²

What often gets in the way between survivors knowing they “should” exercise and actually doing it is an incorrect assumption. I have observed that many people assume

1 Rock, C. L., Doyle, C., Demark-Wahnefried, W., Meyerhardt, J., Courneya, K. S., Schwartz, A. L., Bandera, E. V., Hamilton, K. K., Grant, B., McCullough, M., Byers, T. and Gansler, T. (2012), *Nutrition and physical activity guidelines for cancer survivors*. CA: A Cancer Journal for Clinicians, 62: 242–274. doi: 10.3322/caac.21142 <http://onlinelibrary.wiley.com/doi/10.3322/caac.21142/abstract>

2 *Encouraging Lifestyle Modifications, Personalizing Surveillance Strategies Improves Risk of Second Cancer*, ASCO Daily News, <http://chicago2012.asco.org/ASCODaily-News/Survivorprevention.aspx>



exercise has to be intense and high impact. An effective exercise program for cancer survivors, however, will start gently with slow progression. A good program should take into account:

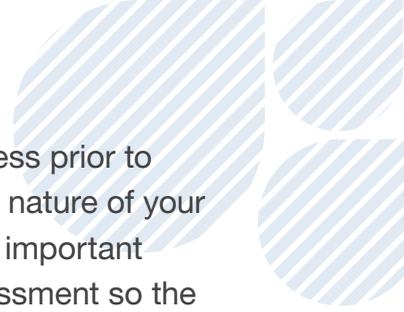
- what exercises you already do
- your limits
- what you can do now and
- meeting your interests and needs.

There are many types of cancers, treatments and late-term side effects with each one affecting survivors in different ways.

It is important, therefore, to work with an exercise specialist or possibly a physical therapist in order to develop the correct program for each unique situation. Check with your primary physician or other specialists tracking your survivorship care for recommendations to qualified exercise providers.

1. Getting started.

It is never too soon or too late to implement an exercise program. Just be sure you have received clearance from your doctor. A cancer exercise specialist can recommend a program to fit your unique needs. One of the best ways to find an exercise specialist is by contacting the American College of Sports Medicine (ACSM). Use the following link to find someone in your area: <http://members.acsm.org>.



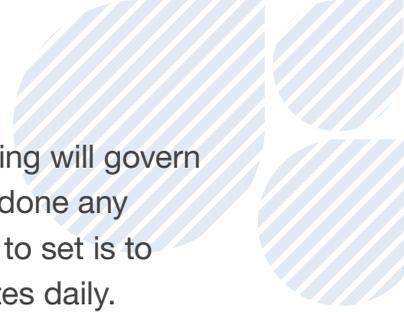
Your program will depend on your level of fitness prior to diagnosis, the type of cancer you had and the nature of your treatment. Before beginning any exercise, it is important that your specialist conduct a full fitness assessment so the program takes into account your unique health issues and treatments. Be aware of balance problems or weakness, and do not exercise if you become dizzy, anemic, or have an irregular heartbeat.

Deep breathing is a good way to begin each session. You can do this while lying down. Breathe in through the nose for 5 seconds and out of the mouth for 5 seconds. On the exhale press your navel to your spine. Deep breathing is a great way to reduce anxiety and has a deep calming effect.

If you have or are at risk for lymphedema, deep breathing can aid lymphatic flow. Lymphedema is an accumulation of lymphatic fluid, which can cause swelling. It can develop at any time so use judgment when exercising. A lymphedema specialist, physical therapist or cancer exercise specialist can review this with you. <http://lymphnet.org> is a great source of information on this topic.

2. Aerobic exercises.

Aerobic exercise gets the heart rate up. It includes activity like walking, biking and running. The American Cancer Society recommends adults “... get at least 150 minutes of moderate intensity or 75 minutes of vigorous intensity activity each week (or a combination of these), preferably spread throughout the week.”

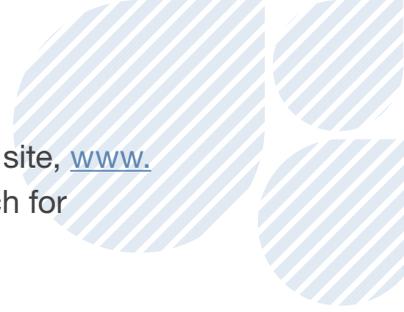


Your conditioning at the time you start exercising will govern your program. For those of you who have not done any exercise, walking is a good start. A good goal to set is to eventually build it up to at least 30 to 60 minutes daily. You can do it all at once or break it up in small amounts done throughout the day. Pay attention to your heart rate, breathing and muscle fatigue. It may be counterintuitive but if you suffer from fatigue, exercise may help. So set up a routine for when you have more energy and note that it is not necessary to go past moderate intensity to gain the benefits.

Aerobic exercise is a good way to burn calories to keep your weight under control. Being overweight can exacerbate other medical conditions a cancer survivor may have. The benefits of exercise to your lungs, heart and other organs are well established. There is growing evidence that the amount of time spent sitting is also important, regardless of your activity level. Our lifestyle is causing us to be less active. Too many of us sit in front of a computer or TV for hours at a time. So try to get up and walk around or stretch every half hour, if possible.

3. Posture and balance.

Surgery and radiation can result in muscle tightness, which causes poor posture. Poor posture can cause aches and pains and lead to orthopedic issues. Some of the chemotherapies used in certain cancer treatments are known to potentially affect balance and can cause neuropathy. Begin with neck, shoulder and upper back stretches. Simple exercise like walking on a straight line as if it were a tightrope and doing calf raises can improve



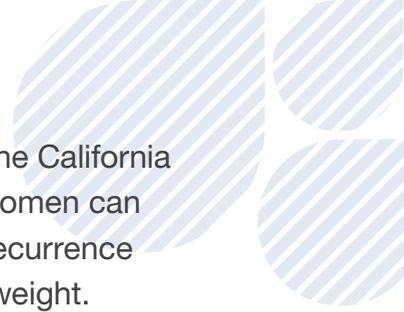
balance. The American Cancer Society's web site, www.cancer.org, is a good place to start your search for information.

4. Flexibility.

Lack of flexibility is another important concern. It is recommended that survivors learn appropriate stretches and continue to perform them long after surgery and treatments are finished. Surgery and treatments often result in a decrease in range of motion. Begin a stretching program to stay and maintain flexibility as soon as you can. If you did not start right after treatment, don't use this as an excuse not to start now. You can start a stretching program at any time and improve your flexibility. Scar tissue will continue to form and must be stretched regularly to prevent adhesions. Survivors find they need to continue to stretch long after their surgery and treatments. A good way to get started is to go to my website, www.recoveryfitness.net, where you can find a DVD which covers essential stretches to regain your flexibility.

5. Strength training.

Strength training can increase muscle mass. It can be performed with weights, bands, machines, or your own body weight. Some of the treatments can cause sarcopenia, which is a change in the fat muscle ratio. Strength training is important because it can increase your muscle mass and decrease fat.



Some research (like the recent findings from the California Teachers Study) has shown that overweight women can have a higher risk of certain types of cancer recurrence compared to women who maintain a healthy weight. Estrogen receptor positive breast cancer is fed by estrogen, which thrives in fat. Dr. Jennifer Ligibel, a medical oncologist at the Dana Farber Cancer Center, found that BMI can be related to survival.

Strength training can also help decrease the risk of osteoporosis, which can be an issue after certain chemotherapies. Strength training will not only potentially increase your muscle mass, it can also help to strengthen your bones. Reconstructive surgeries usually require special strength training exercise programs.

6. Overall health benefit.

An exercise program may improve your overall health along with benefitting your long-term survivorship. It can also help reduce many long-term late side effects of the treatments and can help your heart and bones while potentially decreasing your risk of diabetes. Starting an exercise program can be a challenge – even for people who never faced a cancer diagnosis. To get motivated, consider all of the benefits of exercise, which can include:

- improving the chance of being there for your loved ones
- becoming a healthy lifestyle role model for your family
- increasing your energy and concentration so you can perform better at work and in your life
- improving your overall quality of life

- allowing you to participate in the sports and other activities you enjoy
- feeling better physically and emotionally

7. Weight control.

Exercise can help you control your weight. Many people actually end up gaining weight from the cancer treatments. This is a health concern for all survivors, however it can be a particular concern for breast cancer patients with estrogen positive cancers. Exercise, combined with proper nutrition, can help you reduce your weight and rebuild muscle to increase metabolism.

For those of you who need to gain weight, exercise can help increase your appetite. Gastro-intestinal cancers and head and neck cancer can cause loss of muscle mass and weight loss.

Cancer can also take a toll on how you feel about your body. A lot of the surgeries and therapies required to treat a cancer can alter the body and give one a poor self-image. Exercise can make you fitter, which can help improve body image. When you start to see the benefits of exercise it serves as positive reinforcement. Write down all the possible reasons to start a program: less fatigue, better mood, improved energy, feel better, etc. Scheduling your exercise in the morning and making that your priority before you start your day is a strategy that works for many of my clients. If you leave it for later in the day something might come up to interfere with your program. A good approach is to have an exercise friend. You will both reinforce each other and you will be accountable to each other.

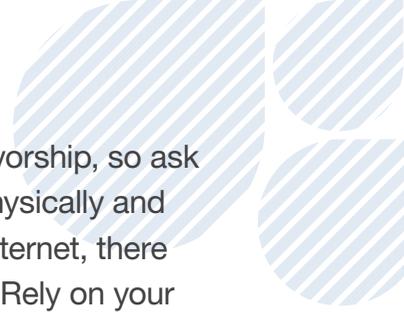
8. Reduce stress.

Exercise can often decrease stress, anxiety and depression. Regular exercise can have a powerful effect on one's mood by releasing pain-relieving endorphins. Always start slowly and listen to your body, eventually increasing the frequency, length, and intensity of your program. Exercise training is emerging as a therapy to address the negative psychological side effects associated with cancer survivorship. Make sure your exercise program is fun. Exercising with friends builds a social camaraderie. Group exercise classes provide friendship and support and motivate you to stick to a program.

9. Commitment to start.

Starting an exercise program can be challenging, but also rewarding. All types of moderate exercise are beneficial. Think about the activities or sports you enjoyed before your diagnosis (or even back when you were a child) and do them. Do you like to walk, ride a bicycle, or dance? If so, you can build your exercise program around the activity that engages you. Notice if you start making excuses for not exercising.

We often use excuses to hide our fear of failure, which then becomes a barrier to achieving our goals. Women with a breast cancer history or survivors who are uncomfortable with the physical changes caused by cancer or treatment, may have unique concerns about their appearance and may be uncomfortable when changing in locker room or wearing certain kinds of workout gear or bathing suits. If you need a private changing area, request one. Self-advocacy is an



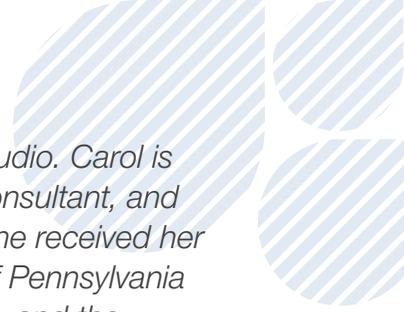
important part of empowering yourself in survivorship, so ask for what you need. Choose clothing you feel physically and mentally comfortable wearing. Thanks to the Internet, there are many websites to help you with resources. Rely on your inner strength to exceed self-imposed limitations. A fear of believing you won't achieve goals can prevent you from trying.

10. Maintaining your exercise program.

How can you stick with your exercise program? It is a good idea to set goals. Some people derive great satisfaction in setting and then achieving goals. You can record your daily progress. This can be done with charts and graphs to record your progress and reward achievements. You will feel good about yourself when you achieve your goals. Cancer survivors show tremendous progress when participating in a consistent well-designed exercise program. Keep in mind that just like everyone else, you will have days when you exercise easily and others when it is more challenging, so be patient with yourself. Keep as active as possible, be safe and have fun.

There is a very important message for cancer survivors and patients - stay active. Research has continued to show a correlation of physical and emotional improvement after participation in exercise.

Carol Michaels is the founder of the Recovery Fitness® a cancer exercise program, developed to improve the recovery from cancer surgery and treatments. She has worked with physicians and other health professionals to develop her Recovery Fitness program,



which is currently offered at her West Orange, NJ studio. Carol is an award winning Cancer Exercise Specialist and consultant, and is on the board of numerous health organizations. She received her degree from the Wharton School of the University of Pennsylvania and is certified by the American Council on Exercise, and the American College of Sports Medicine.

*Carol is a speaker for corporate wellness programs, fitness organizations, community events, and cancer related organizations on fitness and health issues. She has appeared on health related radio and television programs, and is published in numerous magazines, newsletters, blogs and medical journals. Carol developed and produced two DVD's called **Recovery Fitness -Simple Stretches and Recovery Fitness-Strength Training**. She created the Cancer Specialist Recovery course in partnership with the National Federation of Professional Trainers. Her book, *Exercises for Cancer Survivors*, is a fantastic resource for anyone undergoing cancer surgery or treatments. The book and DVDs can be found on her website www.carolmichaelsfitness.com. Carol is the IDEA Fitness Personal Trainer of the Year.*



Your Financial Health

10 Steps to Building Your Financial Future

Joanna Morales, Esq. & Monica Bryant, Esq.
Triage Cancer

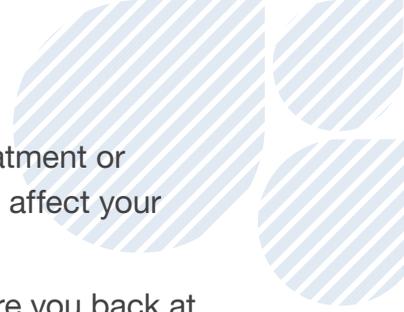
When you have a history of cancer which may have kept you from working for a period of time, which may have left you with medical bills that have affected your credit, and which may continue to pose a financial burden for you, it can seem overwhelming to find your way out of that maze.

Here are a few tips for building a foundation for a healthy financial future:

1. Look at your financial picture.

Even if you had a financial plan prior to your cancer diagnosis, it can be helpful to review where you are financially after completing treatment. Figuring out what your financial picture looks like can help you decide which of the steps below you should take, if any. It can also help you identify priorities (e.g., do you need to find a job, do you have a stack of bills that you have been too afraid to open, or are you ready to start thinking about building your savings or contributing to a retirement plan?). Figuring out what your next steps might be is entirely personal to your situation. To get a clear picture of your situation, consider these questions:

- What is the current status of your finances?

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- Were you able to keep working through treatment or did you need to take time off? How did that affect your financial situation?
 - Now that you are finished with treatment, are you back at work, able to go back to the same job or type of work, or because of side effects do you need to look for another career path?
 - Do you have a stable income?
 - What are your recurring and potential expenses?
 - What assets do you have? These can include homes, savings bonds, retirement plans, etc. Some of these may be assets that can help you to access cash if necessary (e.g., 401K retirement plans or life insurance policies that you can withdraw money from early because of a serious medical condition).
 - What secured and unsecured debt do you have? Secured debt includes things like a car loan or home mortgage. Unsecured debt includes student loans, personal loans, and credit card debt.

2. Check your credit score.

If you have already had a challenging financial picture, then you may be less concerned about a drop in your credit score from working with a debt solutions agency or filing for bankruptcy. However, it is important to [learn about your credit score](#) and to check your credit report. Your credit may be checked when you rent an apartment, lease or buy a car, buy a home, or even get cable television. In addition, some employers conduct background checks that include looking at your credit score or full report.

- Each of the three national credit bureaus ([Equifax](#), [Experian](#), and [TransUnion](#)) is required to provide you with a free copy of your credit report once every twelve months, if you ask for it. To order a copy of your credit report, visit www.annualcreditreport.com or call 877-322-8228.
- Once you receive your credit report, check to make sure that the information they have about you is correct. If not, you can ask the credit bureaus to fix the information.
- A credit bureau is permitted to report most accurate negative information for seven years and bankruptcy information for 10 years.
- The [Federal Trade Commission](#) is a good source of information about credit scores and reporting.

3. Create a budget.

After you have assessed your financial picture, create a budget that includes that new information, including any expenses you might have remaining, related to your medical care.

- Consider talking with a [financial planner](#). Financial planners work with people of all income levels so don't feel like you don't have enough money to utilize one.
- Consider contacting a [consumer credit counseling agency](#), which can provide you with practical tools, such as financial calculators, budget worksheets, and other resources. They may also be able to help you negotiate payment plans or settlements with your creditors. As a consumer, you still have rights. Be aware that some [debt solutions](#) may negatively affect your credit score.

4. Take steps to rebuild your credit report.

It can be challenging to [raise your credit score](#) if it drops, but it is possible.

- Moreover, just because you have a low credit score does not mean that you cannot get credit. Each creditor sets their own standards and some may only look at your recent credit history. If your bill-paying history has improved, they may offer you credit. It may be worthwhile to contact potential creditors informally to discuss their credit standards.
- There are some ways to build a [better credit report](#). For example, if you have one or more credit cards, make sure that the balances on each card are not more than 30% of your available credit on that card.
- There are also some other ways to demonstrate fiscal responsibility, including:
 - ◆ Filing your taxes. Even if you cannot pay the whole amount that is due, file your return and work out a [payment plan](#) with your state tax entity and the IRS.
 - ◆ Paying down your bills with the highest interest rates first.
 - ◆ Look into secured credit cards. These are credit cards that require you to put a certain amount of money into an account and they will give you a credit card with that spending limit. There are lots of credit card scams out there, so make sure that you go a reputable credit institution, such as a large bank or local credit union. Make sure to get all of the information before getting



a secured card. Avoid cards with fees or ones that require you to buy insurance.

- ◆ Building your savings by paying yourself first each month, even if it is a small amount.
- ◆ Retirement might seem far off in the future, but building your retirement assets is important, especially if you had to dip into your retirement plan while in treatment to help pay bills. If your employer matches your contributions to a 401k plan or another retirement plan, don't leave money on the table. Try to contribute the maximum amount to your plan that your employer will match.

5. Review your medical bills.

Medical bills may keep arriving long after your treatment is over. It is important to stay diligent and check that your bills are accurate, dispute them if there are problems, and if you believe a procedure or treatment should have been covered, and it wasn't, know that you have the right to appeal that decision.

- Most insurance companies have an internal appeals process. Check your policy or contact your insurance company for more information on their internal appeals process. All states also have an [external appeals process](#).
- If you have extensive bills, consider talking with a professional bill reviewer or medical claims organization (e.g., [MedClaims Liaison](#)).

6. Contact your creditors.

Talking with your creditors before they turn over your unpaid bills to collections agencies can help to protect your credit. If you can't make a payment, ask for more time. Check to see if they would be willing to negotiate a payment plan or accept a lower lump sum payment. This also applies to your landlord, student loan companies, and health care providers.

- However, be careful when considering paying medical bills by credit card. Most credit cards have high interest rates and you may end up spending more than necessary. It is also not recommended that you take out a loan on your home (e.g., a second mortgage or home equity line of credit) to pay your medical bills, because you then turn unsecured debt into secured debt and risk losing your home if you cannot make the payments.
- Some health care providers may be willing to discount your medical bill, so it can be worthwhile to ask.
- Paying [student loans](#) might also be challenging for you. Some private student loan companies will allow you to change payment plans or postpone payments through a loan deferment or forbearance process. Federal student loans also have a system to forgive loans if you qualify as having a [permanent and total disability or meet other criteria](#).

7. Look at financial assistance programs.

Although the bulk of your cancer treatment is over, there may still be medications you need to help manage side-effects from treatment or other long term medical conditions that you may experience. Some financial assistance

programs may help with medical expenses and some may help with insurance or other bills.

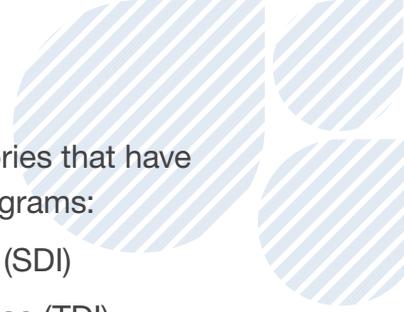
- There are cancer specific and healthcare organizations that may provide financial assistance, such as the [American Cancer Society](#), [Patient Services Incorporated \(PSI\)](#), [Patient Advocate Foundation](#).
- In addition, [The SAMFund](#) is a nonprofit organization that specifically provides young adult cancer survivors with a successful transition into their post-treatment life by providing financial support through grants and scholarships.
- Organizations such as [NeedyMeds](#), [Patient Access Network Foundation \(PAN\)](#), and [RxHope](#) may be able to help you pay for your prescription drugs. Additionally, many pharmaceutical companies have programs to provide people who are having financial difficulties with their medications.
- As a cancer survivor, you may be eligible for certain scholarships to help pay for higher education. Several Divisions of the [American Cancer Society](#) offer scholarships, as well as organizations such as [Cancer for College](#) and the [National Collegiate Cancer Foundation](#). To find an extensive list of scholarship opportunities, visit www.finaid.org/scholarships/cancer.phtml.
- Your friends, family, neighbors, and co-workers may be sources of financial help. They may not realize that just because your treatment has ended you may still need financial assistance. Consider setting up an online fundraiser through a website such as [GiveForward](#) or [MyLifeLine](#) to raise money to help pay for medical bills or

living expenses, while you are still getting back on your feet after treatment.

8. Look at your insurance portfolio for potential sources of income.

There are different types of insurance coverage that you may currently have through your employer or that you purchased on your own, which can provide some financial assistance.

- Disability Insurance is insurance that provides employees with some income while they are unable to work due to a medical condition. There are private, employer, state, and federal disability insurance plans. Keep in mind that each type of disability insurance has a different definition of “disability.” Even if you have completed treatment, you may be experiencing side effects from treatment or have other medical conditions that are keeping you from being able to work. If you have one of these plans, you may be entitled to some retroactive benefits, if you are already back at work.
 - ◆ If you are back at work or have finished treatment, you may not be eligible for the two federal long-term disability programs: [Social Security Disability Insurance \(SSDI\)](#) or [Supplemental Security Income \(SSI\)](#). However, you may find yourself needing to take a short period of time off from work for follow up medical care. For more information about disability insurance, visit <http://tragecancer.org/QuickGuide-DisabilityInsurance>.

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- ◆ There are only six U.S. states and territories that have short-term state disability insurance programs:
 - California State Disability Insurance (SDI)
 - Hawaii Temporary Disability Insurance (TDI)
 - New Jersey Temporary Disability Insurance (TDI)
 - New York Disability Benefits Law (DBL)
 - Rhode Island Temporary Disability Insurance (TDI)
 - Puerto Rico Disability Insurance

 - ◆ Do you have a disability or supplemental health care policy through your employer or a private policy that you bought yourself (e.g., Aflac or MetLife)?
 - Some of these plans pay for certain benefits, which can provide you with additional sources of income. Even if you have completed treatment, you may be able to get reimbursed for things that you paid for while in treatment. Contact your insurance company or your employer's human resources representative for more information.

 - ◆ Life insurance is insurance that you can purchase to provide a beneficiary of your choosing a preset amount of money in the event of your death. If you already have a life insurance policy and you need financial assistance, consider:
 - Does your policy allow you to borrow money from the policy if you have a disability?
 - Does your policy contain a waiver that pays your premiums for you while you are unable to work because of a disability?

- Could a viatical settlement be beneficial to you?

A viatical settlement is when you sell your life insurance policy to a third party, typically for less than the full policy amount. This may be a useful option because you get access to needed funds; however, your original beneficiary will not receive anything from the life insurance policy.

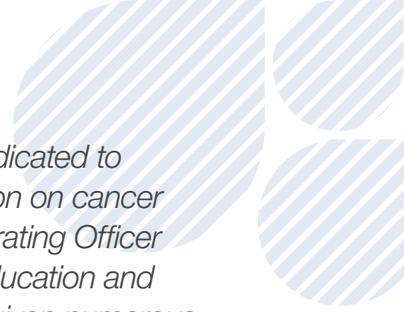
9. Consider talking to a bankruptcy attorney.

If you have already worked with a credit counseling agency and you still are unable to pay or negotiate a payment plan for your medical or other bills, you may want to talk with a bankruptcy attorney. It is critical to become informed about the bankruptcy process and its effects on your credit report. Also, there are rules that make it more difficult to completely eliminate medical debt through the bankruptcy process than it has been in the past.

- You can find a bankruptcy attorney by contacting your local bar association for a referral or visit www.lawhelp.org. The American Bar Association also has a [Guide to Credit & Bankruptcy](#).

10. Remember that you are not alone.

Engage your family and friends to help you through these steps. There is nothing to be ashamed about when it comes to your financial health. Getting assistance from your support network, professionals, and other resources can help you build a foundation for a healthy financial future.



Monica Fawzy Bryant is a cancer rights attorney dedicated to improving access to and availability of quality information on cancer survivorship issues. She currently serves as Chief Operating Officer for [Triage Cancer](#), a nonprofit organization providing education and resources on cancer survivorship issues. Monica has given numerous educational seminars, written articles and blogs, and appeared on community television and radio channels discussing healthcare-related legal issues. Monica is an Adjunct Law Professor at John Marshall School of Law in Chicago, teaching a class on Cancer Rights Law. Prior to relocating to Chicago, Monica served as Legislative Counsel for U.S. Congresswoman Linda T. Sánchez and Law Clerk for U.S. Senator Dianne Feinstein. During her time in Congress, Monica focused on health, justice, civil rights, and women's issues. She can be followed on Twitter @NavSurvivorship.

Joanna L. Fawzy Morales is a cancer rights attorney, author, speaker, and Chief Executive Officer of [Triage Cancer](#). Joanna has spent twenty three years working on behalf of individuals with cancer. She also served as an Adjunct Professor of Law at Loyola Law School, teaching a groundbreaking seminar in Cancer Rights Law for five years. Joanna has presented hundreds of educational seminars throughout the country for patients, survivors, caregivers, health care professionals, advocates, lawyers, employers, and the general public. In addition, Joanna serves on numerous cancer community committees and boards, including on the Board of Directors for the California Division of the American Cancer Society and on the National Advisory Board of CancerForward. Joanna has received awards and recognition for her service to the cancer community and her work in the area of legislative advocacy, such as the 2009 Susan G. Komen for the Cure® Public Policy Advocate of the Year. She was also recognized by the Los Angeles Daily Journal as one of the Top 20 Attorneys in California Under the Age of 40 in 2010. Joanna can be followed on Twitter @CancerRights.

6

Your Legal Rights 10 Cancer-Related Legal Issues to Consider

Joanna Morales, Esq. & Monica Bryant, Esq.
Triage Cancer

1. Know what type of health insurance you have.

If you have an employer-sponsored health insurance plan it is important to figure out if your plan is insured or self-insured (also called self-funded). A self-insured plan is one where your employer pays for the costs of your health insurance directly, rather than contracting with an insurance company to provide you with health insurance. Often, self-insured plans will hire a third party administrator to manage their employee claims. That third party administrator may be a health insurance company. It can be confusing because you may have an insurance card that has an insurance company logo on it, but that company is only administering your employer's self-insured plan.

- It is important to know if you have a self-insured plan because some of the rights in the Patient Protection and Affordable Care Act (ACA) and other laws may apply differently to you.
- If you are unsure what type of plan you have, you can contact your human resources representative at work or call the phone number on your insurance card.

2. Investigate your health insurance options.

Having and keeping health insurance after a cancer diagnosis is critical. It may be vital for your access to follow up cancer care and treatments for long term side effects. However, our health care system and the health insurance options that might be available to you are constantly changing. To find the latest information about your personal health insurance options, visit www.CancerFinances.org.

3. Compare your health insurance options

- Whether you are uninsured, have an individual insurance policy, or coverage from your employer, it is worthwhile to compare your options for health insurance coverage. You may find that some options offer better coverage for lower costs.
- There are three things that you want to compare when comparing your health insurance options: 1) costs; 2) are your providers covered by the plan; and 3) are your prescriptions drugs included on the list of covered drugs (formulary).
- When comparing prices for different plans, do the math. You don't want to just look at the cost of the monthly premium. You also want to look at how much the annual deductible is and what the out-of-pocket maximum is on each plan. The out-of-pocket maximum is the most that you will pay out-of-pocket each year for your medical expenses. So, when you are comparing the annual cost of plans you multiply the monthly premium times 12 and add that amount to the out-of-pocket maximum amount, then compare the total cost for the year.

4. Know your health insurance rights.

- It is important that you understand your health insurance rights so that you can make educated choices, meet deadlines, and not miss out on opportunities.
- For example, under the ACA, insurance companies can no longer set lifetime or annual limits on essential health benefits in your policy and they cannot cancel your policy unless they can show that you committed fraud or intentionally lied on your application.
- In addition, if an insurance company denies coverage for your medical care, you have the right to complete an internal and external appeals process. In some states, you may have the right to a second medical opinion paid for by your insurance company or to have your insurance company pay for infertility treatments or cover the routine costs of participating in a clinical trial. For more information about your state health insurance protections, contact your state insurance agency, which can be found here <http://trriagecancer.org/resources/stateresources>.

5. Know your employment rights.

- You are not required to [disclose](#) information about your health to an employer or potential employer. However, if you want to access protections under federal and state fair employment or leave laws (as an employee or a job applicant), then disclosure of some health information may be required. This does not necessarily mean that you have to share your actual diagnosis. For more information about your employment rights, visit <http://trriagecancer.org/employment>.

6. You may have the right to reasonable accommodations at work.

- Individuals who have completed cancer treatment may continue to experience side effects that qualify them for protections and benefits under the Americans with Disabilities Act (ADA). Under the ADA, an employee with a disability may be entitled to [reasonable accommodations](#). Reasonable accommodations are changes in an employee’s work environment or position, so that the employee can “enjoy equal benefits and privileges of employment as are enjoyed by its other similarly situated employees without disabilities.” Reasonable accommodations can include leave time, job restructuring, telecommuting, additional rest breaks, or changes in the physical work environment.
- The [Job Accommodation Network \(JAN\)](#), is a government resource that can help you figure out if there are reasonable accommodations that would work for you in your workplace. You can find a guide on reasonable accommodations here <http://tragecancer.org/QuickGuide-ReasonableAccommodations>.

7. You may have the right to take time off work.

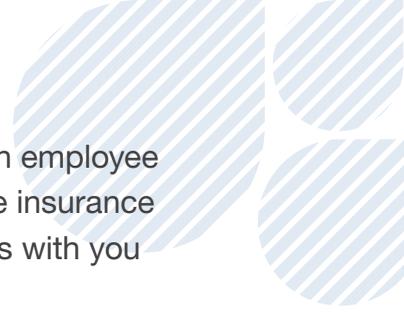
- Even after your cancer treatment is completed, you may still experience side effects from treatment or have follow up medical appointments.
- Under the [Family and Medical Leave Act \(FMLA\)](#), if you have worked for the same employer for a total of 12 months (and during those 12 months worked more than 1,250 hours), and your employer has more than 50 employees (within a 75 mile radius of your work site), you



may be eligible to take up to 12 weeks off work. FMLA leave can be used intermittently, meaning that you can take one day off or one week off at a time, for a total of 12 weeks within a twelve month period. Click here for more information about the FMLA <http://tragecancer.org/QuickGuide-FMLAExtended>.

8. Carefully review your employee benefits package.

- If you have been at your current job for a while, it can be helpful to review your employee benefits. Knowing your benefits can allow you to effectively use your benefits when you need to, but it can also be a great alternative bargaining tool with current employers if you are seeking a promotion or raise. It is also helpful to [review your benefits](#) when there are changes in your family or you experience other life changes, such as marriage.
- When starting a new job, consider the benefits package that you are being offered. A well-rounded benefits package will provide you with benefits beyond the standard health, dental, and vision insurance coverage. Good packages will also include short and long term disability insurance, life insurance, long-term care insurance, retirement plan (e.g., 401K or 403b plans), and vacation, sick time, or other paid time off. Other things to consider: will your employer fully or partially pay for the cost to cover you and your dependents, can you buy additional coverage for your dependents, and does your employer offer supplemental insurance coverage that you can purchase on your own.
- Once you have a pre-existing condition, such as cancer, it can be difficult to purchase life, disability, or long-term



care policies, so having these included in an employee benefits package is very helpful. Also, some insurance companies will allow you to take the policies with you when you leave your employer.

9. Understand the legal implications of genetic testing and your genetic information.

- [The Genetic Information Non Discrimination Act \(GINA\)](#) forbids employers and health insurers from improperly using genetic information. GINA has two parts, one regulates the use of genetic information in health insurance and the other regulates the use in employment the employment context.
- However, GINA does not protect you in the disability, life, or long-term care insurance arenas. There may be state laws that provide additional protections in these areas. For more information, contact your state insurance agency. You may want to think about your portfolio of insurance coverage prior to taking any genetic tests.

10. Consider completing an estate plan and medical-decision-making documents.

- If you are over 18 years old, it is important to consider completing a will and advanced health care directive. Many people think that you have to be wealthy to create these documents, but that is not the case.
- Each state has different requirements to create a will. You can designate a guardian for your children, decide who will receive cherished possessions, and make other plans in your will. Expressing your wishes in writing can

be very helpful to your loved ones. <http://tragecancer.org/estateplanning>

- An Advanced Health Care Directive is a way to have your medical wishes honored if you are unable to communicate them at the time. Advanced health care directives are called by different names in different states. For more information, visit (<http://www.caringinfo.org/i4a/pages/index.cfm?pageid=3289>). Some states also recognize Physician Orders for Life-Sustaining Treatment (POLST) forms to document your medical decisions. For more information about POLST, visit www.polst.org.

Monica Fawzy Bryant is a cancer rights attorney dedicated to improving access to and availability of quality information on cancer survivorship issues. She currently serves as Chief Operating Officer for [Triage Cancer](#), a nonprofit organization providing education and resources on cancer survivorship issues. Monica has given numerous educational seminars, written articles and blogs, and appeared on community television and radio channels discussing healthcare-related legal issues. Monica is an Adjunct Law Professor at John Marshall School of Law in Chicago, teaching a class on Cancer Rights Law. Prior to relocating to Chicago, Monica served as Legislative Counsel for U.S. Congresswoman Linda T. Sánchez and Law Clerk for U.S. Senator Dianne Feinstein. During her time in Congress, Monica focused on health, justice, civil rights, and women's issues. She can be followed on Twitter @NavSurvivorship.

Joanna L. Fawzy Morales is a cancer rights attorney, author, speaker, and Chief Executive Officer of [Triage Cancer](#). Joanna has spent twenty three years working on behalf of individuals with cancer. She also served as an Adjunct Professor of Law at Loyola Law School, teaching a groundbreaking seminar in Cancer Rights Law for five years. Joanna has presented hundreds of educational seminars



throughout the country for patients, survivors, caregivers, health care professionals, advocates, lawyers, employers, and the general public. In addition, Joanna serves on numerous cancer community committees and boards, including on the Board of Directors for the California Division of the American Cancer Society and on the National Advisory Board of CancerForward. Joanna has received awards and recognition for her service to the cancer community and her work in the area of legislative advocacy, such as the 2009 Susan G. Komen for the Cure® Public Policy Advocate of the Year. She was also recognized by the Los Angeles Daily Journal as one of the Top 20 Attorneys in California Under the Age of 40 in 2010. Joanna can be followed on Twitter @CancerRights.

Get to Work

10 Ways to Make Balancing Survivorship and Work Easier

Rebecca V. Nellis

Chief Mission Officer, Cancer and Careers

1. Arm yourself with facts.

Nearly 50% of cancer survivors are of “working age”.

- More than 63% of cancer survivors return to work after treatment.
- 73% of employed survivors surveyed reported that working during treatment helped them cope.

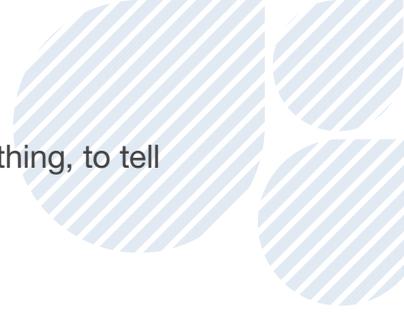
2. Back to work after cancer — easing back into the routine.

Make sure to take care of yourself physically and mentally.

- Remind yourself of past accomplishments — these will help you to feel more confident as you get back into the swing of things.
- Forget multi-tasking: keep a notebook, prioritize and do one thing at a time.

3. What they don't know can hurt you.

The Americans with Disabilities Act applies only if your employer knows that you have (or had) a medical condition. But before you say or do anything at work consult with a legal service organization to understand your options and



make an informed decision about what, if anything, to tell and when.

4. Study your options.

Know your company's policies on medical conditions, flex time, telecommuting, etc. before you disclose your cancer history.

- Learn more about the health insurance laws that might protect you (HIPAA, COBRA, GINA, PPACA) and job-protected leave laws (FMLA, state laws) so you are prepared for anything that might come up.

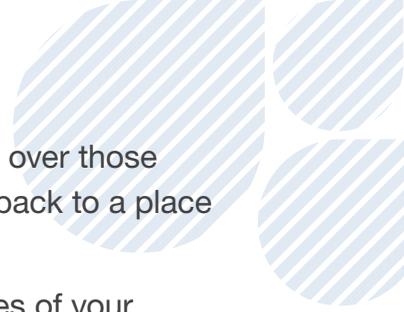
5. People want to be supportive, but don't know how. Tell them.

Your boss, co-workers, and human resources team won't know how to address your cancer history without your input. Be clear with them about any limitations (or lack thereof) so you can address them and move forward.

6. Understand that you may be seen as the "cancer girl" or "cancer boy" in the office for longer than you'd like.

People may assume you can't do your job in the same capacity you could before treatment. You can show them they are wrong without overworking yourself.

- It's up to you what you want to discuss at work. Take a cancer-related comment (e.g. "My dad had cancer too") and spin it back to work (e.g. "Thanks for sharing that.



Also, do you think now is a good time to go over those meeting minutes?”). Shift the conversation back to a place where you feel comfortable.

- It may take time to recast yourself in the eyes of your workplace; don't get frustrated. Just remember the more you focus on work the more they will follow your lead.

7. Prepare a response for the resume gap question in an interview.

If you have a gap in employment due to cancer treatment, a prospective employer may ask why you were out of work at that time. Having a succinct and clear response will help to direct the conversation back to the task at hand. One example: “There was a health issue in my family at the time, but everything is fine now and I can't wait to get back to work. Could you also talk to me a bit about the office environment here?” Or if you are changing industries or roles you can use the career shift as a reason why you have a gap, something like “I realized that I was much more suited to writing than to sales so I stepped out of my job to rethink my career. This opportunity is exactly what I am looking for because of X, Y, Z.”

- Steering the conversation can help put the focus back on your strengths and the needs of the prospective employer.

8. Cancer is often an impetus for career changes.

You've gone through a life altering experience — and now your job doesn't fulfill you in the same way. You're not alone! It may be time to start looking for a new job.

- If you're hesitant to get back in the job market immediately, try volunteering at an organization doing work you believe in or at the hospital where you received treatment.

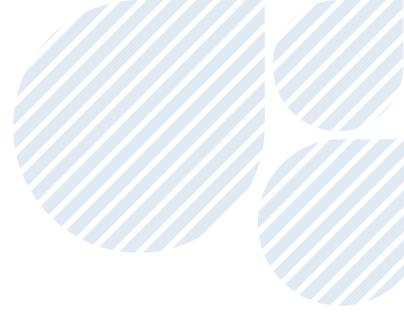
9. Be mindful of what you say online.

You may think you are safe posting on your social networks about your cancer history, but with privacy settings changing every day you may not be as protected as you think. Whatever you do and say online becomes part of your online brand — so be aware that employers may be able to access the things you post and consider the short and long-term effects of what you say and do.

10. Contact Cancer and Careers.

A national nonprofit dedicated to empowering and educating people with cancer to thrive in their workplace by providing FREE expert advice, interactive tools and educational events. Through a comprehensive website (www.cancerandcareers.org), free publications, career coaching, and a series of conferences and educational seminars for employees with cancer and their healthcare providers and coworkers, Cancer and Careers strives to eliminate fear and uncertainty for working people with cancer.

Rebecca V. Nellis *has worked for more than 15 years in the nonprofit sector and spent the last 13 years designing, developing and overseeing the programming and strategy for [Cancer and Careers](#). She speaks nationally on the wide-ranging issues that people with cancer face as they try to balance treatment, recovery and work. Rebecca holds a Bachelor's of Fine Arts from New York University and a Master of Public Policy from Georgetown University.*



Dating After Cancer

Jonny Imerman of [Imerman Angels](#)

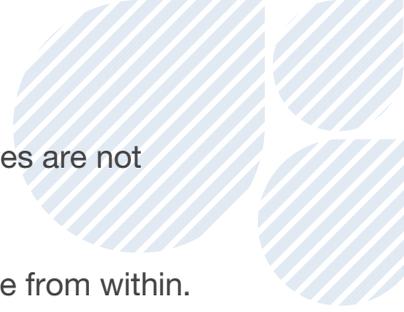
Tamika Felder and [Cervivor](#)

Dating after cancer can be one of the most challenging experiences. Let's face it; dating before cancer probably wasn't without its unmet expectations, disappointments and difficulties in meeting someone who shares your same values and priorities in life. Now that you're a young adult survivor, getting back in the dating game presents its own unique issues. In this "He Said/She Said" dialogue, young adult survivors Tamika Felder and Jonny Imerman get personal with their —

Top 10 Tips for Dating After Cancer

1. **Fall in love with yourself first!**

Tamika: You have to love yourself first, you can't move on to having a relationship with someone else unless you're datable. If you can date yourself and if you have confidence, you're up to doing it. You have to love and believe in yourself first. When you're just coming out of the experience of cancer, you don't know who you are. Exploring questions like "what are my priorities in life? what has changed? what, if anything, do I need to grieve and let go of so I can embrace this next phase of my life?" can help. Some people use journaling to do this, others blog and others turn to a professional such as a therapist or a coach. Each person needs to create an emotional recovery plan that aligns with



who they are. With survivorship, past challenges are not one-size-fits-all. It's got to come from you.

Jonny: I agree with that 100%. It's got to come from within. The initial phase we're speaking about here is something I call the refraction period. After people like Tamika and I survive cancer, they've got to build back up. It's not like constructing a new house; it's rebuilding. You were going in a certain direction in your life and it was looking a certain way. Now it's refracted, like when a beam of light shines through a prism. It is still that beam of light but it is no longer going in the same direction as it was before. This change of direction can result in a momentary loss of identity. Your confidence can be rattled. My body wasn't the same — I looked like shit. My energy level wasn't the same. You feel off, socially.

Add to that the challenge of dating and it can be hard. It's got to come from within — your confidence that you are a good person and that you care about other people. That's where I drew my confidence from — knowing this about myself. When I first started dating after cancer, I couldn't believe a girl wanted to go out with me. After cancer, you are rebuilding emotionally and physically. You build it back slowly over time — so allow yourself that refraction period of emotionally and physically rebuilding.

2. There is no rush.

Tamika: Take time. Work on yourself first before you dive in. There is no rush. Work on the issues, find out who you



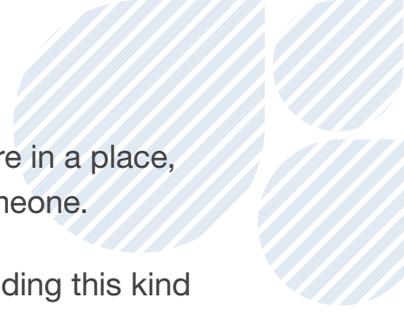
are. Then you'll be much healthier in a whole, fulfilling relationship.

Jonny: Going through the cancer experience forever changes who you are in life. You need to feel whole, healthy. To do this requires getting back into a relationship with you and not rushing as if to fill some void. Expectations are best left at the curb. They are usually something we're placing on ourselves and they can make us feel like we need to get back out there sooner than maybe we are ready. I learned this the hard way, forcing myself before I was ready and I went straight into the deep end. It was a hard lesson and it hurt but it also gave me the chance to readjust my expectations and ease off on myself.

3. One doesn't have to be the loneliest number.

Tamika: I see a lot of people who are lonely after cancer. They become obsessed with thoughts like "I wish I'd had a partner through treatments, I'm all alone, no one will date me." But when you're just coming out of it, you don't know who you are. I hate the term "new normal", as there is nothing normal about it, and it may be normal for other survivors — but if you're not talking to other survivors it is hard to see it is normal.

Knowing yourself and loving yourself is key. You have to have the confidence to move forward in a relationship. It is an opportunity to get to know who you are and what's important to you now that you have been through this experience. When you're in a healthy relationship with



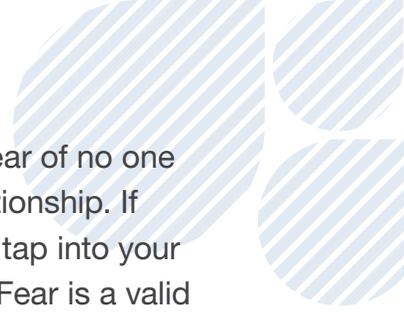
yourself, you don't need someone else. You are in a place, instead, where you can choose to be with someone.

Jonny: THAT's sexy — that's attractive — exuding this kind of confidence and not coming from a needy place. When you develop an intimate relationship with you, you are no longer lonely, nor are you dependent on someone else for company. There is an independence that is possible out of this experience. You'll be more likely to attract a relationship and one that is in your highest good when it isn't a salve for loneliness.

4. When, When and When?

Jonny: When is it right to start dating again? Take time post-treatment to go from feeling vulnerable to feeling whole. It's going to happen, you're going to get better. Patience is definitely something to bring to the process of dating. Even when you are ready, a relationship may not magically appear in front of you. So, again, living from a whole life where you are fulfilled in other areas and connecting with family, friends and other survivors is where to look to in times of needing to be patient. Just be open to the possibility that as you move forward on this new refracted life path, if you are available and authentic, you will eventually attract someone who shares a similar vision for life.

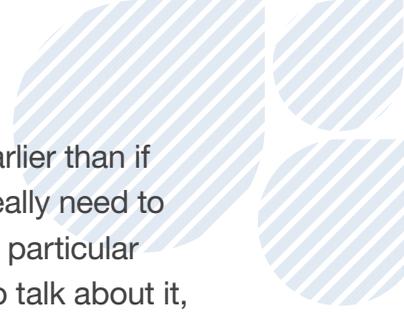
Tamika: There is no right answer. Sometimes we start dating before we're really ready and this can be painful. Check out [#10](#) below for a Dating Readiness Inventory from Jonny to help you assess where you are. Also, check in with your heart and your intuitive self. Often what comes up when



we think about dating is fear of being alone, fear of no one loving us again with regard to an intimate relationship. If you lovingly ask fear to step aside so you can tap into your intuition, our inner truth often shines through. Fear is a valid part of ourselves whose goal is to keep us safe — but when we are confident and feel safe, then we don't need our fear to protect us. We're ready to open ourselves up to the experience of dating knowing that whatever happens, we're there for us. It's a process you have to prepare yourself and realize just because you're ready to date doesn't mean it will happen instantaneously.

Another “when” also involves a how much — when do I reveal I have had cancer and how much do I reveal? Again, this is going to be a personal choice impacted perhaps by how obvious, or not, what you've been through is to someone on a first date. One of the common tendencies that may not get us the results we would like is TMI: too much information. When I first started dating, I tended to just say it all up front, almost like a challenge. “Here — see if you can deal with I've had cancer and I can't have kids.” Later I realized this wasn't the thing a guy wanted to know first and foremost about me. It was just too much information but you're trying to find your way in the dating world so you don't know that at first.

Jonny: There is a point where you do need to talk about things you can or can't do, how you feel, or maybe you're sterile or have a colostomy bag. Who isn't going to be self-conscious about that? It's about coming to terms and being at peace with how you are going to have these important conversations. If you have a visible scar, prosthesis or have



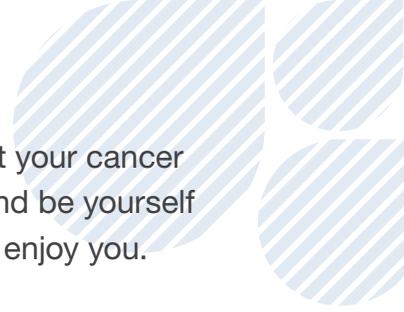
lost your hair, you may be bringing things up earlier than if these physical signs weren't so obvious. You really need to consciously decide what is best for you in your particular circumstance. And if you don't know or need to talk about it, reach out to those of us in the young adult survivor world who can help you find the support you need. It's really important for you to know you are not alone and you don't have to do this alone.

5. When is it time to play the cancer card?

Tamika: Never in dating. No one wants to spend time with a whiny person. This is where the piece about being in love with you really comes in. If every time you go out with someone and you're bitching about life, no one wants to be around that kind of negative thinking. They may not dump you because you have cancer but because you are in a negative space.

If you find yourself in a pattern of negative talk about your cancer or life, it is a great sign it's time to go back and attend to yourself. Where are you creating the focus on your dates? Playing the cancer card is more about feeling like a victim of the experience. Do a check in with yourself and just ask where is my energy right now? Am I feeling excited about enjoying this time getting to know someone or am I worrying about whether or not it will work out, will they accept me once they know I've had cancer, how will I handle conversations about intimacy, body image or fertility?

The more you can be in the moment and be comfortable in your own skin, allowing things to unfold and trusting that

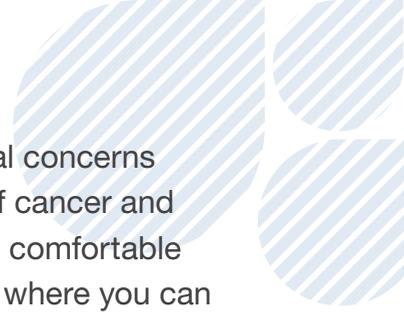


you'll know when the right time is to talk about your cancer experience, the more likely you'll be relaxed and be yourself so you can enjoy dating and so your date can enjoy you.

Jonny: Certainly, dating after cancer can be challenging and there is a time when you will want to bring up the fact that you've had cancer. When may be different depending on how visible or obvious the physical evidence is. For example, with women who lose their hair, it is more obvious and may require earlier disclosure. Dating bald you may feel different about yourself; you certainly look different. You may feel self-conscious but hair is a good analogy in that it does grow back over time. Hair grows and it continues to grow. It is a sign that things are changing and that it does get better. Disclosing about your cancer is different than playing the cancer card. It depends on how you say it — if you say it like it's a downer, then that's the experience you're creating for the person but if you come from a place of hey, I had this experience that had a big impact on my life but I'm doing great now, I have my energy back. It's all about the energy you're giving the conversation. So how you say it is just as important as when and what you say.

6. What are you afraid of?

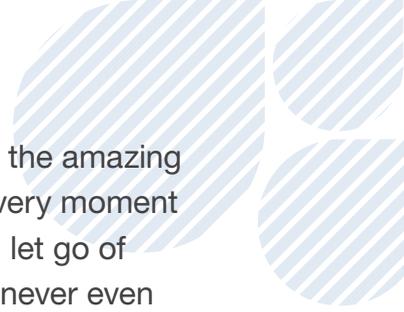
Jonny: If you're afraid to bring something up, it's probably a good sign you're not ready to date yet. There may be more places to go back and do some self-work. What blows me away is when young adult survivors start talking about these issues; they are very open about what they are afraid of and what they're self-conscious of. There are a variety of fears because every one is an individual and has their



own unique experience of cancer. The physical concerns can be very different depending on the kind of cancer and treatment you had. But it is only when you get comfortable with you that you will find the emotional piece where you can connect with someone else and see this person loves you for everything you are, the good, the bad, the scars. Dating is going to bring up whatever your fears are, so it's really just an opportunity to get even more clarity on where you have a little more growing to do.

Tamika: Trust. Trust is a great combatant of fear. When everything is lined up and it is perfect, you will know. Sometimes, unfortunately we want things to happen before their time but everything has to happen at its own time. When we trust that everything has its own divine timing and it will get easier with time and with testing ourselves by getting out there when we have done our work, then we get the chance to show up in an authentic, available way not needing to be fixed — because we were never broken. We just had this tough thing we went through that is now an expression of our strength.

Jonny: Practice gratitude. When fear about dating or disappointment because a relationship didn't work out comes up, you have to live life and be grateful. The key is to think about gratitude, don't think about desires. To me, desire is what makes people unhappy. You want the perfect job, to make more money, find the perfect girl or guy to be in a relationship with. When we're focusing on the future and feeling like we don't have something right now, it creates conflict for us. Instead, just being grateful in the moment for all you do have is a true expression of living life now —

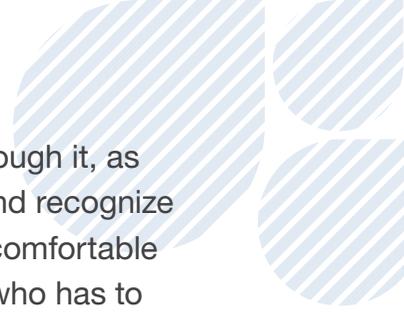


not wishing or wanting or hoping but by being the amazing person you are and celebrating it. Don't live every moment trying to match desires. Gratitude allows us to let go of expectation and when we do, possibilities we never even considered have the chance to show up.

7. Be comfortable with your body.

Tamika: Whether it is dating or sex, have a sense of how you look at yourself. Look in the mirror and tell yourself what you love about yourself every day because you have to prepare yourself for the experience of intimacy and sex. And dating is intimacy of not only the body but also of the mind. So really understanding the thoughts you are having about your body will help you know when you are ready. You may need to relearn what feels good to you. Along with mirror work, I also used positive affirmations to become more comfortable with my body.

Jonny: Be able to look in the mirror and be comfortable with how you look. This is a big part of moving from feeling broken to whole. It's a part of that internal confidence. Find a way to feel sexy and feel like you look good. When you have internal confidence in your external appearance, it shines through. Both Tamika and I have gone through this; me, with my ball and Tamika, with her vagina. What has helped us is to find people who are real and deep, not overly focused on the physical but who care about more about connection, friendship, shared values and who embrace everything about us.



And also, talking to others who have been through it, as the more you open up about it, talk about it and recognize you're not alone in this experience, the more comfortable you become. Feeling like you're the only one who has to bring up conversations about the impact cancer has had on your body is isolating. Knowing how others have used humor or being open or authenticity or integrity to frame these conversations can really help you find what fits for you when it comes to talking about any special intimacy issues.

8. Don't quit.

Tamika: It does get better. If a relationship doesn't work out, pick yourself up and dust yourself off and try, try again. As young adult cancer survivors we have faced much tougher moments than this. Draw on the strength and courage you uncovered when you went through your treatments and everything you've put into rebuilding your life and keep going. What kept me going when relationships didn't work out was my amazing supportive group of friends and family.

Jonny: Yes, don't quit. I don't think any of us would still be here if we gave up easily. This is just another opportunity to tap into our inner strength and our support system. It really is a chance to learn where we are with our relationship with ourselves. If we truly are living a more whole life, while we may be disappointed when dating doesn't work out with a particular person, we can allow ourselves to feel that disappointment but we're not rocked to the core by it. It wasn't a life raft to begin with — that is something we built within ourselves and we still have it. Connect with others who share similar values and belief systems. Other young

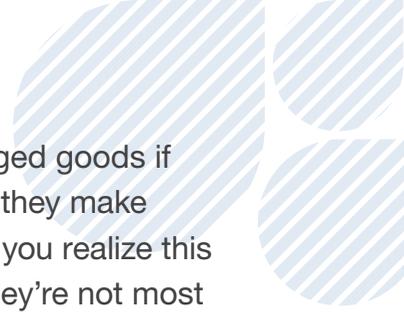
adult survivors don't judge you so take advantage of this community.

9. Diving in head-first.

Tamika: Executing the dating process is not an easy thing to do. You will be rejected. This is true for anyone going through the dating process, not just someone who has had cancer. There will be someone you're interested in who isn't interested in you. What's different for young adult survivors dating after cancer is that someone may be not interested in dealing with you because you had cancer. You need to be ready to deal with this. You're going to have to kiss some frogs (or whatever the male version of that is) and it's all not going to be perfect. Someone is going to hurt your feelings but realize if you dated and you didn't have cancer the same thing would most likely happen at some point. You still find people who like you and who don't like you.

Personally, I dated people who had issues with me not being able to have children. It can really help to connect with other young adult survivors who share similar challenges or issues, which is why I started Tamika & Friends. I wanted to create an organization so people facing this kind of conversation didn't feel like they were the only ones.

Jonny: It does get better. Build up your confidence first. There is no rush. Take your time. You have your whole life ahead of you. It's not about being hard or calloused or having a tough skin but you do have to be okay with who you are — scars and all whether those are physical or emotional or both. When you're raw in the beginning and



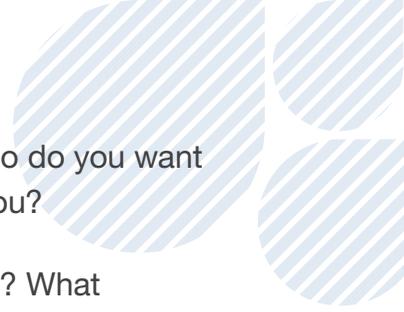
just coming through it, you can feel like damaged goods if someone rejects you. This is especially true if they make clear it is because you had cancer. Eventually you realize this isn't someone you want to be with because they're not most likely going to be there when shit gets bad.

In the end, it actually helps you find someone who is real and deep. Someone who loves you for who you are, what you've been through and someone who respects this about you. It helps you find someone who is in it for the best reasons. It is a filter in a positive way as it helps you find the people who aren't superficial and who are going to stay through the challenging times in life. This kind of partner is worth going through the dating challenges to find.

Building friendships with others who are alike and are going through the same things is another great tool. Know it does get better and you do gain your confidence back. Look at other young adult survivors like Tamika and myself. We do what we do to help you build relationships with role models and peers so you have a network of support. That's why, like Tamika, I started a nonprofit to help others connect. Use the resources like my Imerman Angels out there. You don't have to do this alone.

10. Single & ready to mingle.

Tamika: First of all, are you truly ready? This is the time where you find out what you want in a mate or a partner. Be very clear about what you are looking for because you've had cancer. It's not a time to play around and let just anybody come into your life. Be conscious about the kind of

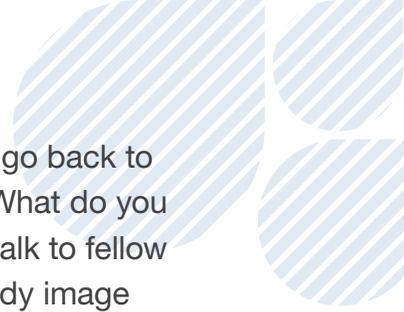


person and relationship you are choosing. Who do you want to be with and what values are important to you?

And then how do you want to go about dating? What process is a better fit for you? Maybe you want to let your network know. Maybe you're interested in online dating? Or maybe it is a better fit for you to be involved with an activity or group being open to the possibility you may meet like-minded people through a shared common interest.

Jonny: Tamika raises some great questions here. One way to see if you're truly ready is to take a Dating Readiness Inventory. Some questions you can ask yourself are:

- Am I comfortable with the changes cancer has created in my life in all areas — physical, emotional, career, financial or am I hoping that meeting someone will fix one or more of these areas?
- Do I clearly understand that if it doesn't work out, it's not necessarily about my cancer or me? That it could be some "less than" thinking on the other person's part?
- Am I strong enough to handle what may feel like "rejection" if a relationship doesn't work out?
- Do I have a sense of how and when I will want to share with someone that I've had cancer?
- Have I considered how to handle any conversations that need to be addressed regarding being intimate with someone to prepare them for scars, missing body parts, areas of my body that are painful or numb or other special needs or circumstances?



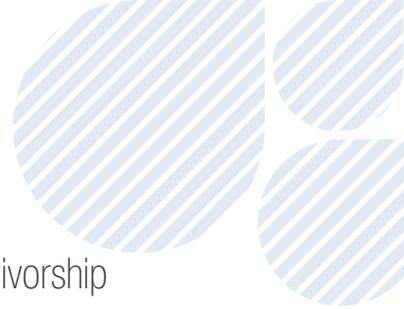
If you answered no to one or more questions, go back to [Tip #1](#) about falling in love with yourself first. What do you need to turn a no into a yes? Do you need to talk to fellow survivors and get some of their insights? A body image coach? A sex therapist? No one expects you to do this on your own but it is up to you to identify what you need and who can provide you with the support you need to get it.

Jonny Imerman is a young adult cancer survivor who strives to make sure no one fights cancer without the support of someone who has already triumphed over the disease. After being diagnosed with testicular cancer at the age of 26, Jonny decided to found [Imerman Angels](#), a nonprofit organization, which carefully matches a person touched by cancer (a cancer fighter or survivor) with someone who has fought and survived the same type of cancer (a Mentor Angel). Imerman Angels now has more than 4,000 cancer survivors and more than 1,500 caregivers in its network, and has been featured by dozens of news organizations including The Wall Street Journal, Harpo Radio's "Oprah and Friends" with Dr. Oz, Men's Health, NBC5 Chicago, CBS2 Chicago, ABC7 Chicago, ESPN Radio Chicago, Chicago Sun-Times, Detroit Free Press, LIVESTRONG Quarterly, and Clinical Journal of Oncology Nursing. Jonny received the 2012 CNN Hero Award, 2012 Lincoln Park Young Professionals 'Chicago Best of The Best' Award; 2011 Twilight Foundation Detroit's Civic Leadership Award; 2011 Chicago Social Magazine's 'Who is Chicago' Award; the 2010 Jefferson Award for Public Service; 2010 University of Michigan Humanitarian Service Award; 2009 Ulman Cancer Fund For Young Adults 'Hope Award'; and 2007 Daily Candy 'Sweetest Thing' Award. Jonny has been invited to speak at cancer centers such as MD Anderson, Memorial Sloan-Kettering, Mayo Clinic, Dana-Farber, City of Hope, Northwestern, Rush, and Children's Hospital Los Angeles. Jonny grew up in Bloomfield Hills, MI and lives in Chicago.



Tamika Felder is the Founder & CEO of [Cervivor](#). After a diagnosis of advanced cervical cancer in 2001 at the age of 25, Tamika Felder triumphed in her fight against this deadly disease, and now uses her experience to help educate other women about ways to prevent it. She is the founder and CEO of Cervivor, a national nonprofit organization dedicated to cervical cancer awareness through a network of survivors and their friends. Her inspiring story and message have been featured in numerous media outlets. Since 2009, Tamika & Friends has served as the lead U.S. partner of the global Pearl of Wisdom Campaign to Prevent Cervical Cancer. Tamika is a former board member of the Ulman Cancer Foundation for Young Adults, is a survivor spokesperson for the Lance Armstrong Foundation and has served as community representative for the President's Cancer Panel (2003).

Tamika was honored in 2006 with a Presidential Leadership Award at the Kennedy Center, given by Women in Government, for her efforts in helping to eliminate cervical cancer. In 2009, Tamika received the Appreciation Award from the National Cervical Cancer Coalition; the Spirit Foundation's Cervical Cancer Survivor Champion Award; and the Maryland Healthcare Volunteer Hero Award. In 2010, she received the 1st annual "Be That Woman" Award from the Washington Area Women's Foundation. In 2011, the Ulman Cancer Fund for Young Adults presented her with the "Young Adult Fight" Award. She currently resides in the Washington, D.C. area and is an award-winning television producer and TV host.



Intimacy & Sexuality: Getting Real About Feeling Sexy & Creating Vibrant Intimate Relationships in Survivorship

Barbara Musser

Intimacy and Sexuality Coach and CEO of Sexy After Cancer

Often an unexpected consequence of treatments is the opportunity and the challenge of rehabilitating our intimacy and sexuality. Losing hair during chemo can torpedo our sense of feeling attractive and sexy, and how about the instant menopause that can result from some chemo and hormonal therapies? The good news is that your sex life isn't over — it just may be temporarily asleep. The question is, how to wake up the inner Sleeping Beauty or Handsome Prince of your libido, intimacy and sex life?

There are a lot of facets to intimacy and sexuality, beyond the mechanics of inserting some skin and exchanging fluids. Emotions, thoughts and beliefs, our spiritual balance, and how our bodies are NOW, all come into play. Your sex life may not have been stellar before cancer, and then it takes a hit. [What's a girl or guy to do?](#) Don't give up hope, because there's lots you can do to build bridges from where you are now to where you want to be, so that you can have a vibrant, healthy and satisfying intimate and sexual life.

Top 10 Tips for Getting Your Sexy and Mojo On

1. Mirror, mirror, on the wall.

First, accept, forgive and make peace with your body as it is now. Take 5-10 minutes a day to stand naked in front of a full-length mirror and look at your body through the eyes of love. Tell yourself out loud, “I love you. You are beautiful/ attractive/sexy/handsome.” Use the words you most need to hear. Doing this practice daily for 30 days will create a new neuronal pathway in your brain, and you will have a completely different experience of yourself.

How we feel about ourselves is what we transmit to others, so doing this foundation piece will have a big payoff, in terms of how you feel and how others experience you.

2. It's an inside job.

If you have “head trash” about your attractiveness or about cancer, it's time to take out the trash. Working with your mindset is a powerful and direct way to empower yourself. There are some great books and recordings (<http://godworksthroughfaithaudio.com/>) that can help with this. I also highly recommend Ellen Langer's work: <http://www.npr.org/2012/08/02/157809852/mindfulness-using-your-brain-to-beat-stress>. The essence is to visualize what you want to experience in terms of intimacy and sexuality, and then feel the feelings that go along with those experiences. It's the feelings that go along with the thoughts that make the difference here. The brain doesn't distinguish between what's happening and what we think/feel is happening, so

use your brain to create the experiences you want to have. I've created a special report for how to work with your mindset in 7 areas to thrive in your intimate and sexual life: <http://tinyurl.com/10tothrive>.

3. What is sexy?

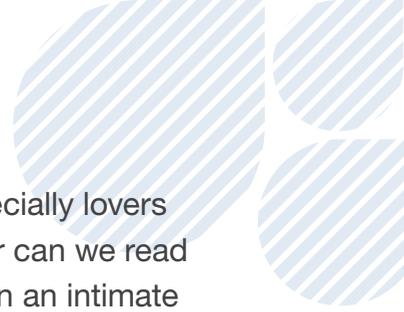
Think about the people who are sexy to you, and it's probably not just about the physical package. Studies show that hands down, confidence is the biggest component of being sexy.

Make a list of all the things you love about yourself, then put them on index cards. Pick one card each day and really "live" that quality. As you begin to embody it, people will be attracted to that quality in you, and the confidence they sense in you will be magnetic. For example, "I love my smile that can light up a room. Whenever I walk into a room and smile that smile, people start to flirt with me, every time!"

4. Learn to flirt!

Flirting is much more than having a series of great lines to say. It's how you look at someone, how you respond when they look at you, before you say a word. It's that look across a room that says, "Wow! I see you and I want you!"

Flirting with no agenda is not only fun, but it's a great gift that you give to yourself and to whoever you're flirting with. It doesn't have to go any farther than this, and if it does, have fun.



5. Ask for what you want.

No matter how much we want it, people, especially lovers or potential lovers, cannot read our minds, nor can we read theirs. Being willing to ask for what you want in an intimate or sexual situation can be a real turn on, and you're much more likely to experience it.

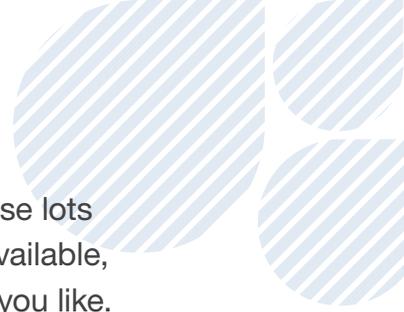
You may not feel ready for intercourse. So tell your partner and ask for something you do want, like a make-out session. Remember when you first began to kiss and how “hot” that was? How your body responded, how big the energy of that felt and how you might not have wanted that to end? Try it again and see what happens.

6. Take your time!

There's no rush here. It may take your body longer to respond, so take whatever time you need to allow that to happen. Going slow, being patient, and listening to your body's wisdom, can be very erotic.

7. Strengthen your pelvic floor muscles.

Surgery, radiation, chemo and hormonal therapies can all weaken the pelvic floor muscles, which have a great deal to do with how genital sex feels. This is true for men as well as women! Beyond Kegel exercises, try perineal massage and squatting, which will help stretch and strengthen the pelvic floor, leading to increased flexibility and elasticity of the tissue.



8. Lube, lube and more lube.

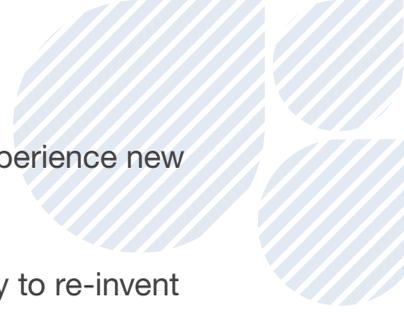
When your sex play will include the genitals, use lots of lubricant. There are lots of different lubes available, so try several until you find one (or more) that you like. Lubricants not only help reduce friction, but can also help to moisturize delicate and dry genital tissue and help prevent uncomfortable pulling and tearing.

9. What is sex, really?

Play with this idea: sex is an acronym for Sacred Energy Exchange or Spiritual Energy Exchange or Sensual Energy Exchange. When you take the focus off genitals and orgasm, a whole new universe of possibilities opens up. Our entire bodies are erotic and filled with erogenous zones, so take some time to explore and learn what feels good, what turns you on, what not so much, and what you like. Then you can ask your partner for a variety of pleasures and expand your sex play.

10. Beginner's mind.

In Zen and other spiritual traditions, the advice is to operate from the place of beginner's mind, where everything is new, and it's as if this time is the first time you've ever had the experience, even if it's the thousandth time. It enables us to free ourselves from thinking we know how it's supposed to be, where it will lead, or expecting something specific. This practice opens the doors to delight in ways we haven't imagined, because we know how it's supposed to be. This is a key, especially with a body, mind, heart and spirit changed by the experience of having cancer. It won't be like it was



before, and beginner's mind really helps to experience new possibilities.

Here's the bottom line: you have the possibility to re-invent yourself in the ways you experience desirability, intimacy, and sexuality. This can be one of the biggest gifts of cancer. Allow yourself to expand the horizons and you just may be surprised at what you discover.

Barbara Musser *is a respected intimacy and sexuality educator, coach, facilitator and author. She was diagnosed with breast cancer in 1989 at age 37. She had a child after treatment. She has worked with hundreds of women, couples, and health care professionals to create programs to help heal the trauma of cancer treatments to intimacy, sensuality, sexuality and relationships. Barbara is the founder and CEO of [Sexy After Cancer](#). She has written a book, **Sexy After Cancer ~ Meeting Your Inner Aphrodite on the Breast Cancer Journey**, and she leads retreats for women with cancer, for couples, and for partners of those with cancer.*

10

Fertility & Parenthood

Top 10 Items to Discuss with a Fertility Specialist

Dr. Tina Koopersmith M.D.

West Coast Women's Reproductive Center

Many young adult cancer survivors have to deal with the reality that it may not be quite as straightforward to build a family as it is for other people who never faced a cancer diagnosis. Arming yourself with the key information and the right questions to ask your doctor will empower you on your journey to maintaining your health and making the right decisions for you.

1. Did my treatment affect my eggs or my sperm?

Many medicines used as chemotherapy are damaging to the eggs and sperm. Just like the drugs may have been toxic to the linings of the intestines causing nausea and diarrhea, these drugs often are toxic to the ovary and gametes. Sometimes this is not obvious until years after the treatment. Radiation therapy aimed at the ovaries or the testicles may also harm egg and sperm development, respectively.

During chemotherapy, it is not uncommon for the menses to stop. This may be temporary during the treatment and the menses (periods) may restart after the chemo is finished. This stoppage of menses, called amenorrhea, may be from the stress of the chemotherapy, both physically and mentally or it may be directly due to damage from the chemo drugs themselves. Most likely it is due to a combination of both



these factors. When under severe stress or malnutrition, the endocrine system may shut off the ovaries and periods may stop, but it also may be due to the toxic effects of the chemo on the growing eggs. The younger you are during your treatment, the more likely that the menses will return. However, the return of periods is not always synonymous with undamaged ovaries and eggs. Many, but not all, gametes may have been destroyed, so there may be fewer eggs left in the ovary. This means menopause may come earlier than expected. It also means fertility may be adversely affected — and at a younger age than expected in the general population.

For men, chemotherapy can damage their sperm. Some men have no sperm or markedly reduced sperm counts after chemotherapy is finished. When treatment is completed, a patient can get a semen analysis/sperm count to check if there are still sperm. The analysis should check sperm count (how many sperm?), motility (are they moving forward?) and morphology (do the sperm look normal?). It would be best to wait 6-12 months after chemotherapy or radiation is finished before the analysis can be considered accurate. For men, they can easily collect sperm after treatment and be told if there are sperm or not. A survivor can find out if the sperm look normal or not. However, they won't know for sure if the sperm will work until they try to use the sperm and it makes a baby (or not). For men, time does not affect sperm count or motility.

2. I am sexually active. What are my options for birth control?

In young survivors who are not ready to conceive and start a family, contraception is essential once they are past puberty and sexually active. There are many options for birth control for women but sometimes there are contraindications to certain hormonal contraceptives, depending on your cancer history. Consider how effective a birth control method is, but also ask yourself the following:

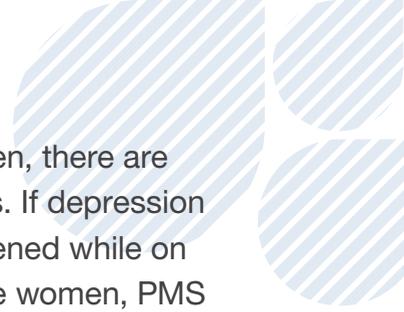
- What are the possible side effects?
- Will I use this according to the directions?
- Do I need my partner's cooperation?
- How will my health or other medical conditions affect this method?
- How often do I have sex/will I need this?
- Do I want to have children later?
- Does this protect against human immunodeficiency virus (HIV) and other sexually transmitted diseases (STDs)?
- Are there additional health benefits to using this form of birth control?

Barrier Methods:

Condoms are highly effective methods of birth control when used correctly. The diaphragm and the cervical cap are other possibilities. For detailed information on all of these barrier methods, go to www.acog.org.

Hormonal Contraception:

The oral contraceptives on the market today are low dose formulations of synthetic hormones: estrogen and progestin. Combined oral contraceptives or COCs have both an estrogen and a progestin; progesterone only contraceptives have only the progestin hormone. According to acog.org: “With typical use, 8 women out of 100 will become pregnant during the first year of using birth control pills.” Use of oral contraception increases the risk of blood clots—the risk is now quoted as 4-10/20,000 women per year. This compares with a risk of 6-20/10000 women during a pregnancy. Other risk factors for blood clots include cancer, surgery and immobility, so these should not be used during active treatment for the cancer when the odds of a deep venous thrombosis (blood clot) may be increased from the malignancy. A major surgery also increases the odds of a thrombosis, so COCs should be stopped 6 weeks before a major surgery (if that is possible), or as soon as the major surgery is planned/scheduled. If there is a family history of a blood clot or a family history of a syndrome that predisposes you to a blood clot, then COCs may be contraindicated. If a young woman has survived a hormonally dependent cancer such as a breast cancer, then COCs are contraindicated. Since the pills are metabolized in the liver, if there is liver damage, then COCs are contraindicated. Recent studies suggest use of the pill may increase the risk of heart attacks and stroke, hence if there is significant vascular disease or hypertension or diabetes, these are relative contraindications to pill use and the risks and benefits and alternatives need to be discussed at length with your doctor.



Most women tolerate pills, but for some women, there are associated mood changes while on hormones. If depression or anxiety (or other mood disorders) are worsened while on the pill, pills should be discontinued. For some women, PMS symptoms are improved while on the pills. For some women, headaches are worse with pill use, and for others menstrual migraines can be eliminated.

The benefits to the pill include lighter menses, less anemia, less ovarian cyst formation, a lowered risk of future ovarian and uterine cancers, and control of irregular menses. Frequently, there are also less severe menstrual cramps.

The NuvaRing and the OrthoEvra patch are similar to the pill. These both contain synthetic estrogen and progestin like the Combined Oral Contraceptive pill. The difference is how the drug is delivered into the body: oral pills, through the skin from the patch, and through the vaginal tissue from the ring. They have the same risk/benefit profile as the pill.

Women using the pill need to remember to take a pill daily; users of the ring need to change the ring monthly and of the patch, weekly. This may determine which system they choose to use.

Progestin-only Hormones:

There is a pill with only progestin it also is quite effective and has a similar risk profile to the COCs. There may be less risk of a blood clot, although the package insert still includes this as a contraindication.

Progestin-only methods include Depo-Provera, a shot in the arm every 3 months, or an implant placed under the skin in



the doctor's office and changed every 2 years (Implanon). According to acog.org: "With typical use, 6 women out of 100 will become pregnant within the first year of using the injection and less than 1 woman out of 100 will become pregnant within the first year of using the implant." Menstrual cycles are usually changed with these methods: no menses is common or sometimes there will be light, unscheduled bleeding. Some women complain of weight gain (5-10 lbs or so) with Depo-Provera. Most women tolerate this method well, but mood changes are also associated with these hormonal methods of contraception. Long-term use of Depo-Provera may lead to some reversible bone loss. This appears to be temporary, but in cancer survivors who may have already had treatments toxic to bone such as radiation, this may be an added insult to bone health and may be a relative contraindication to its use.

For more information: <http://www.acog.org/Patients/FAQs/Progestin-Only-Hormonal-Birth-Control-Pill-and-Injection>

Emergency Contraception

Emergency contraception that prevents pregnancy after sex is sometimes called "the morning after pill." Emergency contraception or the morning after pill involves taking pills after unprotected intercourse or the insertion of an IUD after intercourse.

To learn more, visit:

<http://www.acog.org/Patients/FAQs/Emergency-Contraception>

or

<https://www.plannedparenthood.org/learn/morning-afterpill-emergency-contraception>

Intrauterine Devices

The IUD (intrauterine device) is a good method of contraception. The IUD is a small device around 3 cm long that is placed into the womb by a trained healthcare professional. All IUDs are over 99% effective. The IUD is very safe. There is a small increased risk of a pelvic infection within the first 3 months after insertion and then the risk is equivalent to the risk of a woman not using any contraception. It is inserted in the doctor's office and needs to be changed infrequently: the Paragard brand is changed every 10 years, the Mirena brand every 5 years.

The Paragard brand is made from plastic with a T-shaped frame and a copper wire. It is associated with a few extra days of bleeding per month, perhaps more anemia and more cramps. The only contraindication is Wilson's disease (an inherited disease of copper metabolism), or an allergy/intolerance to copper. There are no hormones in the Paragard. Women will continue to get a period monthly with this IUD.

The Mirena brand is a plastic T shape with a small amount of progesterone hormone on it. The Mirena is associated



with lighter menses or no menses (50% of users say their menses are nonexistent). The Mirena protects the uterine lining from the effects of estrogen — extra natural estrogen in women with irregular cycles and also extra estrogen from women taking estrogen to treat menopause symptoms. Some oncologists feel it is safe for breast cancer survivors, but ask your oncologist first. For more information about IUDs, see:

- www.paragard.com
- <http://www.mirena-us.com>
- www.acog.org

Sterilization

For those done with childbearing, sterilization is a good option. A tubal ligation can be performed during the hospitalization after a delivery or as an outpatient procedure. The tubes are cut during an outpatient laparoscopy and surgery is performed through the navel under a general anesthesia.

ESSURE is a newer procedure: a gynecologist can insert metal coils into the tubal openings as seen from the inside of the uterus. This is done via a hysteroscopy: a surgery is performed through the cervix without any cuts on the abdomen. It is also done as an outpatient procedure and sometimes done in the doctor's office under twilight or local anesthesia. An x-ray needs to be done 3 months later to ensure the tubes have scarred closed around the coils.

Alternatively, men can be sterilized via vasectomy; this is a surgery usually done in the urologist's office. Follow up tests



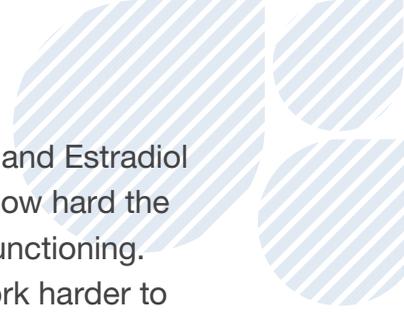
need to be done 3 months later to ensure no sperm remain in the ejaculate. Click here for more info on vasectomies:

<http://www.acog.org/Patients/FAQs/Sterilization-for-Women-and-Men>

3. What is my ovarian age and why does it matter?

Women are very different from men and all women have a biological clock. That means at a certain age, there are no more eggs in the ovary, there are no more monthly periods and a woman can no longer get pregnant. That means that time significantly affects egg count and egg quality. For most women, menopause occurs close to age 51, but it can happen at earlier or later ages. An ovary may age faster or slower than the “average” woman. A woman may go through menopause at age 30 or 40, many years earlier than the average; her ovarian age would then be older than her chronological age. At each age then, her fertility potential is different from other women. There is no way to assign an exact “age of the ovary” but there are ovarian aging markers which can be used to check the ovary and assess its fertility potential. These include pituitary hormones, ovarian hormones and an assessment of the quantity of eggs in the ovary.

Reproductive endocrinologists using the Antral Follicle Count (AFC) to determine ovarian age. AFC is the number of small follicles/eggs seen and counted in the ovary during a transvaginal ultrasound. “Younger” ovaries have more follicles. Pituitary hormones instruct the ovary to grow eggs and ovulate while the ovary makes eggs and hormones.



We measure the pituitary hormones: FSH, LH and Estradiol while you are on a period and we can check how hard the brain/pituitary is working to keep your ovary functioning. A high FSH suggests the brain is having to work harder to keep up — it is showing signs of aging. A high estradiol may also be an ominous sign on day 3 of your cycle. AMH is another ovarian hormone made by the eggs that are in the ovary that haven't yet started to grow. The more eggs still in the ovary, the higher the AMH and conversely the lower the AMH level, the closer to menopause a woman is. A recent analysis used age and AMH levels to accurately predict the age of menopause.

Asymptomatic cancer survivors with normal menses, especially those who were exposed to toxic chemotherapy and radiation therapy, may consider testing these ovarian aging markers on a routine or yearly basis. If a young cancer survivor begins to have changes to her menstrual cycle, these tests should be obtained immediately as well. These markers do not predict fertility or infertility but they are aids in assessing the health of the ovaries. If any of these tests are abnormal, a consult with a reproductive endocrinologist should be quickly obtained.

See:

<http://womensreproduction.com/fertility-preservation.php>

<http://womensreproduction.com/egg-freezing.php>

4. What do I do if I don't get my period again after treatment is all over?

Amenorrhea means no menses. This is very common during chemotherapy but menses often resume after chemotherapy. The stress of treatment may lead to endocrine shut-down: no menses from lack of input from the stressed out brain/pituitary. The largest follicles, usually those visible on ultrasound, also known as the gonadotropin dependent oocytes in the ovary, are the most susceptible to cell death from chemo. Ovulation and periods usually cease during cancer treatments. However, the smaller follicles that have not yet been recruited to grow are more resistant to damage from chemo and radiation treatment. These are the follicles that begin to grow again post-treatment and lead to cycling later. The younger the patient is when she receives chemo, the more small eggs that were in the ovary before treatment and, the more likely she is to resume cycling once treatment is over. However, in a number of survivors, amenorrhea persists long after treatment is over. It is essential to find out why the periods have stopped. It could be due to either pituitary failure (the organ in the brain that controls the hormone system) or to ovarian failure.

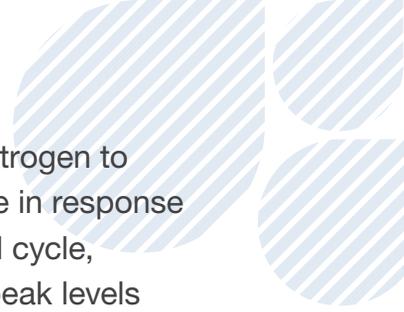
Total body irradiation or radiation to the head (the eye, the head, or nasopharynx) as well as brain surgery may increase the risk of damage to the pituitary (an endocrine gland that is in the head behind the eyes). If menses stop, pituitary hormones should be checked to differentiate the cause of amenorrhea. If there is damage to the pituitary, then puberty may be affected. Growth hormone is also made in the pituitary, so if growth hormone levels are affected, there may be an affect on total height attained. Thyroid



function can also be affected if the pituitary stops making thyroid stimulating hormone (TSH) because the pituitary was damaged. If the pituitary has stopped working, replacement with hormones is necessary. The ovary may still have eggs and can still produce eggs or hormones if stimulated.

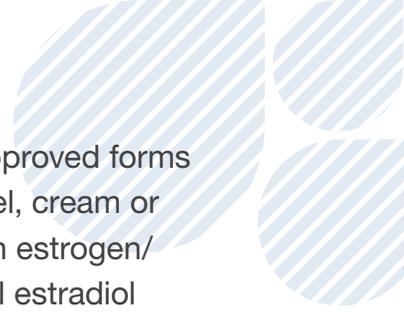
Alternatively, the ovary may be damaged by the treatments and premature menopause may ensue. Menopause before age 40 is also premature ovarian failure (POF). By definition there are low estrogen (estradiol) levels. Low estradiol is associated with bone loss. It may also affect the cardiovascular system adversely. Heart disease and atherosclerosis may develop earlier than expected. During the transition to menopause, hot flashes, night sweats, insomnia, joint aches and mood changes have been described. The vagina may become dry and narrow and irritated. A retrospective study revealed that the premature removal of ovaries in premenopausal women decreased the risk of ovarian cancer but increased the morbidity (sickness) and mortality (death) rates in these young women. This suggests that exposure to normal premenopausal hormone levels in young women is important for their overall health. In a cancer survivor whose ovaries have stopped making eggs and hormones, replacing the missing hormones estradiol and progesterone is recommended.

- For survivors with POF, a DEXA bone scan should be obtained at baseline to check bone density; how often it is repeated should be guided by initial results, body size, hormone use and any other risk factors for osteoporosis.
- Estrogen replacement/therapy should be considered. This should replace the body's own natural estradiol.



Progesterone also needs to be added to estrogen to protect the uterus from overgrowth of tissue in response to estrogen. In the normal female menstrual cycle, estrogen is produced all month long, with peak levels mid-cycle, and progesterone is made after the mid-cycle estrogen peak for two weeks. Estrogen and progesterone replacement can be taken cyclically to mimic the natural cycle and then the patient may continue with menses. Alternatively, the hormones can be given in a fashion similar to the combined oral contraceptive pill: the estrogen and progesterone are taken together daily. In the former scenario, menses are expected. With daily combined therapy, there may be no menses; this is safe. If a couple is not interested in fertility, and perhaps not completely post-menopausal, then an alternative is for the survivor to take combined oral contraceptives to help with both menopause symptoms and contraception.

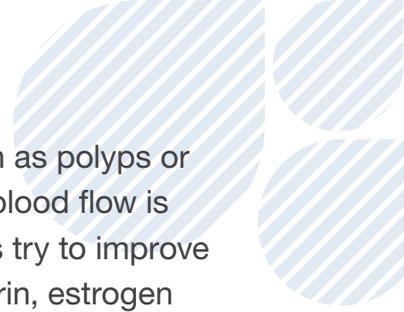
- There are a number of different hormones on the market for the survivor to choose from. Estrogen comes as micronized estradiol (this is the closest to natural estradiol made by the ovary). There are also pills that are a combination of different estrogens: estradiol as well as other metabolites of estradiol: estrone, estrone sulfate, estriol, estradiol glucuronide and more. There are different forms of estrogen: pills, gels, creams and adhesive patches. For progestins, there are three types of pills: synthetic progestins medroxyprogesterone acetate, norethindrone acetate or micronized progesterone. Only the latter is a natural progestin. The other available natural progesterones are vaginal preparations: crinone 4% and 8%. Some pharmacies will compound the progestin into a



gel or cream but so far there are no FDA approved forms of natural progesterone as a transdermal gel, cream or patch. There are two brands of combination estrogen/progesterone patches — these have natural estradiol but a synthetic progestin. Synthetic means the chemical formulation differs from that made by the human body. Another way to have endometrial protection from the effects of estrogen is with the Mirena IUD. This is inserted into the uterus, providing effective contraception, and ensures the uterine lining doesn't grow when exposed to estrogen either naturally from the ovary or from estrogen medications.

5. Was my pelvic/uterus harmed by my treatment?

Radiation treatment may damage the pelvis. There is an increased risk of miscarriage as well as pre-term labor and delivery after radiation to the pelvis. The uterine blood vessels can be examined by ultrasound to ensure there is adequate blood flow and normal resistance in the arteries. The inside of the uterus, the endometrial cavity, needs to respond to ovarian hormones and develop a tissue lining that is receptive to the developing embryo. Prior to a pregnancy, the doctor can do an ultrasound mid-cycle to check the inside of the uterus (the lining). Growths such as polyps or myomas can grow inside the cavity and may adversely affect conception or pregnancy. A special ultrasound with water instilled into the uterus can be done to check the lining and ensure there are no growths in the cavity. A telescope can be inserted through the cervix to look at the lining/cavity to make sure it looks normal and is not scarred closed.



If there are scars in the cavity or growths such as polyps or myomas, these can be removed surgically. If blood flow is compromised and the lining is thin, specialists try to improve the lining. Sometimes medicines such as aspirin, estrogen given vaginally or Viagra are used to enhance blood flow. Acupuncture and herbs have been used to help improve the uterine lining as well.

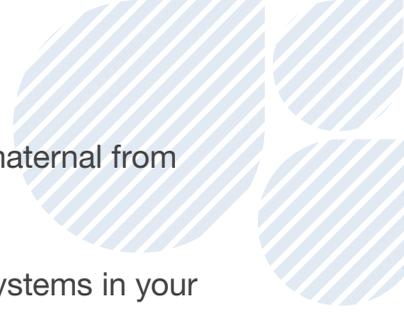
During a pregnancy, the fetal growth needs to be monitored closely. If there is suboptimal blood flow to the uterus, this may affect the baby's growth. Uterine muscle contractility and the ability to grow and stretch easily may be compromised. Monitoring the baby with serial ultrasounds and later with additional fetal heart rate monitoring and testing is recommended during a post-radiation pregnancy.

6. Can I be pregnant?

Will cancer affect my pregnancy?

Pregnancy is always possible if you are having spontaneous menses and cycles. Pregnancy may be low risk without any significant problems but there may be reasons to consider you at higher risk.

If you have agents that damaged your ovaries and eggs, then the incidence of miscarriage may be higher than expected for your age. Although not often offered with a first pregnancy loss, cancer survivors should request a chromosomal analysis to better analyze the products of conception and the cause of the miscarriage. It should be done by someone well-trained in getting adequate tissue for

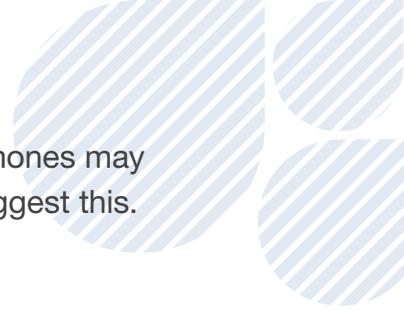


analysis or sent to a lab that can distinguish maternal from fetal tissue.

The chemotherapy may have affected other systems in your body, and pregnancy may put added demands on these systems. It is wise to have a consult with a maternal fetal medicine specialist prior to conception to ensure that there are no specific tests to be done prior to pregnancy. Baseline kidney, lung and cardiac function should be tested if chemotherapy or radiation therapy may have adversely affected these organ systems. For instance: Adriamycin may have led to heart damage which may make the pregnancy high risk and you may need to be followed by a cardiologist in addition to the OB and/or the perinatal specialist. Toward the end of pregnancy, serial ultrasounds and weekly non-stress testing may need to be done to check the baby's growth and heart rate. This is especially important if you had radiation to the pelvis or if there is underlying vascular disease like high blood pressure.

Will cancer affect my pregnancy? Will a pregnancy affect my cancer survival? Will pregnancy affect my prognosis?

Most of the time pregnancy does not affect long-term cancer prognosis. It is usually recommended that the cancer survivor wait a reasonable amount of time after cancer diagnosis and treatment before conception. This allows the patient to process the disease and illness in advance. Also this ensures adequate time to evaluate the effects of the cancer medicines and treatment on body systems such as heart, blood vessels and kidney. There are no studies to suggest cancer adversely affects a pregnancy. Theoretically for breast cancer, since the tumor may be hormonally



responsive, there is fear that a change in hormones may affect the prognosis but the data does not suggest this.

Will my baby be normal?

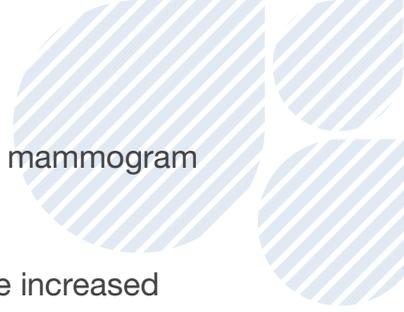
The rate of birth defects in the general population is stated 3-5%. This includes structural defects such as heart defects, spinal cord defects and other malformations noted in the baby. The use of chemotherapy, radiation therapy or surgery for cancer in the past does not change this statistic. However, it is not recommended to expose an ongoing pregnancy to these treatments.

The risk of a baby with Down Syndrome or other chromosomal anomaly is most related to a woman's age but not directly with her chemotherapy. It is possible that this risk changes somewhat if her ovarian age (see above) is adversely affected by her treatments. Similarly, many miscarriages are due to chromosomal errors and this may be related to ovarian age as well as chronological age. The cause of some abnormalities in children, such as Autism or Attention Deficit Disorder, is unknown and it is not believed to be affected by cancer treatments.

7. Do I have an increased risk for another cancer?

Radiation therapy may increase the odds of a second malignancy, so screening is recommended:

Chest: If you received chest radiation > 20 cGy or total body irradiation, then mammograms should be started 10 years after the treatment ended or at age 35, whichever comes first. Breast MRIs are now also recommended, especially at the young premenopausal ages when the breast tissue is



still dense. The MRI is more sensitive than the mammogram with dense breast tissue.

Neck: Thyroid dysfunction or malignancies are increased if there was neck radiation therapy. Yearly thyroid function should be checked by laboratory values. Examination of the thyroid for nodules should also be done yearly, an ultrasound can always be done if the exam is equivocal.

Other: Certain site-specific radiation therapy increases the odds of certain cancers: skin cancer, brain/spinal cord cancers, thyroid cancer, and bone cancers. Close observation and continued surveillance is recommended in all survivors.

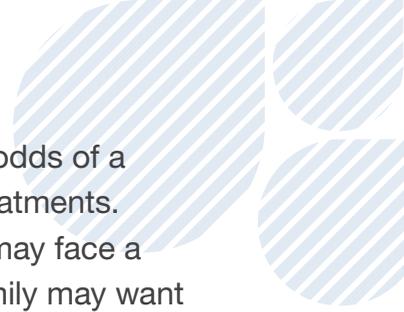
Certain chemotherapies increase the odds of acute myeloid leukemia. These include cyclophosphamide, nitrogen mustard, etoposide, teniposide, anthracyclines and the hematopoietic stem cell transplant. Consequently, yearly blood counts should be obtained on all survivors especially if they received chemotherapy. Additionally, a blood count should be obtained immediately if survivors are symptomatic — excess fatigue or shortness of breath to suggest anemia, frequent infections or a serious infection to suggest abnormal white cell function, and/or easy bruising to suggest platelet dysfunction.

Most cancers are random events but a few cancers are associated with inherited genes that increase the odds that any individual with that gene will have a cancer. An individual with that gene mutation may have an increased risk of several types of cancer. Which brings us to the question below.

8. Did I inherit a gene that increased my chance of a getting a cancer? Can I be tested for this gene?

Genes are pieces of DNA that we inherit from our parents. Some families have several family members with the same type of cancer. Once the human genome had been mapped, scientists began to examine the genome for specific genes. They have identified certain genes that increase the predisposition to a cancer. Individuals with these genes have an increased risk to get a cancer when compared with the general population. Individuals inherit these genes from their parents.

Knowing if you have one of these genes may affect the frequency of surveillance for a second malignancy. Also young individuals with one of these genes may choose to surgically remove nonessential organs that are at increased risk for a cancer. Some individuals who carry a gene may choose to proactively choose offspring (using genetic diagnosis of embryos created in an in vitro fertilization lab) that do not carry the affected gene. A consult with a geneticist who specializes in the genetics of cancer is recommended if you were diagnosed at a young age with a cancer. It is recommended that you complete an extensive family history of diseases/deaths prior to meeting with the geneticist. As research into the human genome progresses, there are likely to be more genes identified that are involved in the development of cancers and more tests to offer patients in the future. This makes it important to continue to ask your oncologist at each yearly visit if there is any new test to be offered.

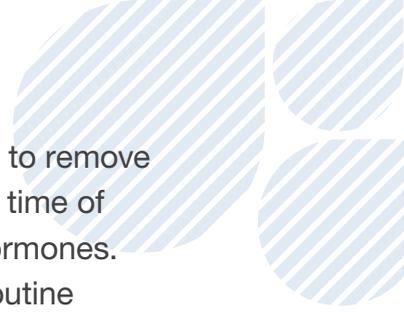


Getting screened for genes that increase the odds of a malignancy may help you decide on future treatments. It may also help family members before they may face a cancer diagnosis. If you have a gene, your family may want to be screened to see if they carry the same gene. Perhaps this will lead to better surveillance for them and a cancer avoided or found at an earlier stage with better outcomes. It is presently illegal for insurance companies to discriminate based on results of gene tests. For more information, please see: <http://www.myriad.com/>

BRCA gene mutation

The most common cause of hereditary breast cancer is an inherited mutation in the BRCA1 or BRCA2 gene. BRCA 1 and BRCA 2 are two genes that have been well characterized. They are named because they confer an increased risk of breast cancer. They are inherited as autosomal dominant genes; this means that you only need one copy of the gene (from one parent) to have an increased risk of cancer. Having a BRCA 1 or 2 gene increases the odds of breast cancer from 11% (the general population) to 40-80% lifetime risk. This gene also increases the odds of ovarian cancer: 33% and 10% lifetime risk for BRCA 1 and 2 gene, respectively. Having this gene also confers an increased incidence of male breast cancers, pancreatic cancers and prostate cancers.

This gene can be screened for with a simple blood test. If you have a gene, you may want an intervention, meaning prophylactic removal of the breasts and plastic surgery reconstruction. MRI of the breast is also recommended



as an additional screening test. You may want to remove the ovaries after having your children or at the time of menopause, when the ovaries stop making hormones. BRCA 1 cancers can be hard to detect with routine mammograms, so MRI of the breast is very helpful in this syndrome. Presently we can screen for BRCA1 and 2 mutations or screen a panel of genes (the panels now have 26-28 genes and their mutations, all which confer an increase in cancer risk either breast cancer or other cancers). To learn more: <http://www.myriad.com/> or <http://www.bracnow.com/>

Lynch Syndrome

Hereditary nonpolyposis colon cancer syndrome (HNPCC or Lynch syndrome) is caused by an inherited mutation in any one of several genes that help to repair DNA damage. About 3 to 5% of all colorectal cancers occur in people with HNPCC, with most of these cancers occurring before the age of 50. The lifetime risk of colorectal is estimated to be as high as 80% in people with HNPCC. People with HNPCC may develop polyps at the same rate as others, but these polyps are more likely to become cancer and in a shorter period of time. It is important that people with HNPCC begin having colonoscopies at age 20-25 and that colonoscopy is repeated every 1-2 years because cancer can occur so early and quickly in this population. Since Lynch syndrome also entails a higher risk of endometrial cancer, screening of the uterus can be done with biopsies of the uterus and/or hysterectomy after childbearing. Any abnormal uterine bleeding should also be evaluated immediately. For more

information:

http://www.myriadtests.com/index.php?page_id=14

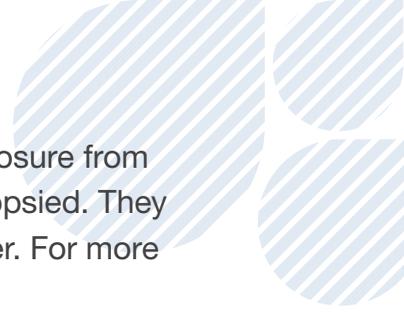
Familial Adenomatous Polyposis (FAP)

FAP is caused by a mutation in the APC gene, which is most often inherited from a parent. In 30% of cases, however, it occurs without a family history. About 1% of all colorectal cancers are diagnosed in people with FAP. People with FAP typically develop hundreds or thousands of polyps in their colon and by age 40, almost all people with FAP will have developed colorectal cancer. For more information, see: https://www.mysupport360.com/mission/hereditary-cancer.php?page_id=14.

Hereditary Melanosis

Risk factors for melanoma that arises in the skin include fair skin, a history of sunburns and/or prolonged exposure to ultraviolet light (both sun and artificial UV light), multiple moles, older age, a personal or family history of non-melanoma skin cancer and a personal or family history of melanoma. Melanoma rates are 20 times higher in Caucasians than in Blacks. As we age, our years of sun exposure increase, and therefore the risk of melanoma increases.

Researchers have found that the risk of melanoma is 2.24 times higher in people with a first-degree relative with the diagnosis; therefore it is important to be aware of your family history. Hereditary melanosis syndrome can also be detected with a gene test. Those affected have a higher risk of melanoma and should receive frequent skin exams. These



individuals should be careful to avoid sun exposure from 10 am to 2 pm and have any atypical mole biopsied. They are also at increased risk for pancreatic cancer. For more information, see:

https://www.mysupport360.com/mission/hereditary-cancer.php?page_id=80

Li Fraumeni Syndrome

The Li Fraumeni syndrome results from a defect in the p53 tumor suppressor gene. These individuals have an increased risk of breast cancers and sarcomas.

9. If I had cancer, will my children also have cancer?

If I have an inherited syndrome, does that mean any child of mine will also have this syndrome? Can I do PGD to prevent transmission of the increased risk of cancer? How much does it cost?

Inherited syndromes do confer an increased risk of cancers. Many inherited cancer syndromes are dominant syndromes: this means only one copy of the gene is needed to increase the risk. However, this means that you, the affected individual, probably only have one affected gene. Any child of yours would have a 50% chance of inheriting that gene. Said another way, 50% of your children will not carry the gene. Moreover, having the gene doesn't guarantee a cancer; it only increases the risk. In addition, since gene testing is now available, some patients choose to intervene medically to decrease their risk of a future cancer.



PGD stands for pre-implantation genetic diagnosis. PGD is a procedure designed to be done during an in vitro fertilization cycle. The embryos are created in the lab after mixing the sperm and the eggs. The embryos are grown in culture for several days. On the 3rd or 5th day in culture a needle is inserted into the embryo and one or more cells is removed from the embryo. The DNA from the cells' nucleus is then prepared and tested with DNA probes to see if the embryo carries the gene of interest. The embryos are reported as free of the gene, or carriers of 1 or 2 copies of the gene. If a gene confers disease with only one copy of the gene it is considered a dominant gene. Having one copy of the gene means the embryo is affected. Some other genes only cause significant disease with two copies of the genes: embryos with one or no genes will be free of disease.

Limitations:

- PGD requires in vitro fertilization (IVF). PGD is not 100% accurate; there is an inherent but small error rate. Also, it is not a guarantee of pregnancy. IVF pregnancy rates range from a high of 60% with egg donation to a low of 3% in women over 43. Even in fertile women, IVF does not guarantee a pregnancy.
- Most cancers are sporadic, even in young people. PGD is only applicable when cancer-causing genes have been identified. In addition, specific probes to identify the DNA in the embryos must be available.
- This never is a guarantee that the offspring won't develop a cancer or that the offspring doesn't have another birth defect. Birth defects after IVF is quoted at 4% of all births,

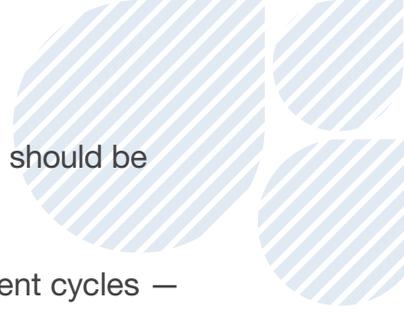
in the general population birth defects affect 3% of the population.

- IVF and PGD are expensive technologies. In the future, these costs may change as technologies change. Presently, an IVF cycle with pre-implantation genetic diagnosis may cost \$15,000-20,000 per cycle, If there are surplus embryos made and frozen, the cost of a second try is considerably less.

10. The doctors told me my eggs (or sperm) don't work anymore. Can I still be a parent?

What if I don't have a uterus?

Egg donation is an option for women whose ovaries have stopped functioning. It has a very high success rate. A known or anonymous egg donor, who undergoes medical, psychological and STD screening, takes fertility medications to develop eggs. At the same time, the oocyte recipient (cancer survivor) would take estrogen to prepare the uterus for a pregnancy. Once the egg donor's eggs were mature, the physician removes them from her and the eggs are identified and then inseminated with sperm. The sperm is usually from your partner but could be from a sperm donor as well. The embryos are made and grown in culture for several days. The oocyte recipient would then take estrogen and progesterone. Five days later, the embryos would be transferred back into the recipient uterus (cancer survivor). Two weeks later, a pregnancy test would be done. Usually, only 1 or 2 embryos are transferred back to you and any surplus embryos could be frozen for later use. Pregnancy rates are as high as 60% per cycle. You would take hormones for the first 12-14 weeks of pregnancy, but then the placenta takes over and supports

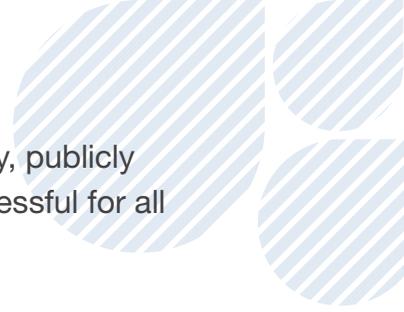


the pregnancy. Once the baby is delivered, you should be able to breast feed, as well.

Presently, most egg donation — oocyte recipient cycles — are done by syncing the cycles and using fresh eggs, but the fertility experts are starting to freeze eggs as well as sperm. This may become more common and then you would be able to purchase frozen eggs from an egg bank. The oocyte recipient would still take estradiol and progesterone and have an embryo transfer. With frozen eggs, the eggs would be thawed and the sperm injected directly into the egg (ICSI) to encourage fertilization. Frozen egg cycles will likely be more cost effective.

For some women, the ovaries are still functioning but the uterus may have been removed or damaged by radiation or surgery. For these women, parenthood is possible via gestational surrogacy. In this instance, the cancer survivor takes fertility drugs to grow her eggs. Her partner (or a sperm donor) supplies the sperm. In vitro fertilization is performed after removal of the eggs from the ovary. A gestational carrier who has received estrogen followed by progesterone then undergoes the embryo transfer and pregnancy. A pre-birth adoption can be obtained, which confirms the parental identity of the child and ensures the genetic parents are on the birth certificate and have full custody and rights.

Some women have lost both their uterus and their ovaries. These women can choose to use both an egg donor and a gestational surrogate so that their partner has a genetic tie to the child. Alternatively, these women can choose to



adopt a child. Adoptions can be done privately, publicly or internationally. Adoptions can be very successful for all parties involved.

Men are also at risk for damage to their gametes from surgery, chemotherapy or radiation therapy. If the cancer survivor was counseled about this complication, he may have stored sperm before treatment was administered. Sperm will survive frozen in a sperm bank for many years. Thawed sperm can be used to inseminate a woman, placing the sperm in the woman's uterus. This is a simple office procedure. This can be done in a natural cycle. The only requirement is that the woman monitor her cycle for ovulation (using urinary LH kits available in the pharmacy). If the sperm count is low, if there are limited vials of sperm, if there are other factors affecting the woman's fertility — including advanced age — then the sperm can be used in an in vitro fertilization cycle. With an in vivo cycle using insemination, 5 million motile sperm are needed for significant success. With an in vitro cycle, much fewer sperm are needed to make embryos; if there are 20 eggs, then only 20 mature sperm are needed.

If, after cancer treatment, there are no sperm in the ejaculate, then donor sperm can be used to inseminate your partner. The donor can be anonymous or a known donor — perhaps a brother, father or cousin. Sometimes, a urologist specializing in fertility may also offer to microscopically dissect the testes to look for sperm. If sperm are found, these sperm can be used to inseminate eggs in the lab via in vitro fertilization. Since it is possible that there won't be sperm, it is recommended to have a back-up plan with donor sperm during an in vitro cycle. Or the biopsy can be done prior to an in vitro cycle, and any sperm

frozen with the testes tissue. However, in this later scenario the sperm may not survive the thaw.

Some couples elect to adopt embryos. These embryos usually have been stored in an in vitro fertilization lab. As in vitro fertilization cycle success rates improve, there are instances when surplus embryos have been created and stored. A couple may have completed their family and have extra embryos. Rather than destroy these embryos, they may be willing to allow another couple to adopt the embryos. Legal documents are required and then the recipient can have the embryos placed back into her uterus. The new baby will genetically be related to the couple who created them, but the recipient will be the legal parent and again, breast feeding is possible.

Table 1: Toxins for the gamete

Risks of ovarian failure according to the chemotherapeutic agent drug specific and dose dependent

High risk

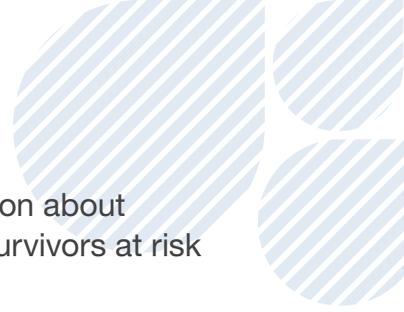
- Cyclophosphamide
- Chlorambucil
- Melphalan
- Busulfan
- Nitrogen mustard
- Procarbazine

Intermediate risk

- Cisplatin
- Adriamycin
- Taxanes (relative risk unknown)

Low or no risk

- Methotrexate
- 5-Fluorouracil
- Vincristine
- Bleomycin
- Actinomycin B



For more about fertility, see Fertile Hope

www.fertilehope.org, which provides information about reproductive options to cancer patients and survivors at risk for infertility due to cancer treatment.

Dr. Tina Koopersmith is a board certified physician in both Obstetrics and Gynecology and Reproductive Endocrinology and Infertility at the [West Coast Women's Reproductive Center](#). Her clinical areas of expertise include recurrent loss, fertility, premature ovarian failure and polycystic ovaries. In addition to providing fertility services, she specializes in gynecologic disorders, especially hormonal disturbances in young girls with difficulty during puberty and reproductive age women with irregular cycles. In recent years, she has begun to focus on the reproductive needs of young women newly diagnosed with cancer as well as those survivors of childhood cancers. She offers fertility preservation treatments, fertility treatments and long-term management of their reproductive health.

She attended medical school at Duke University School of Medicine and subsequently completed her residency in Obstetrics & Gynecology and her fellowship in Reproductive Endocrinology & Infertility at the University of Southern California Keck School of Medicine. Following her fellowship, she began practicing in the San Fernando Valley where she continues to practice today.

In fellowship, Dr. Koopersmith researched the metabolism of vaginally administered progesterone, the effects of misoprostol on early pregnancy, and the outcomes of multiple pregnancies in women over age 45. She has presented her research at national meetings and published in peer-reviewed journals. Dr. Koopersmith is a member of the American College of Obstetrics and Gynecology. She is an active member of the American Society for Reproductive Medicine since 1990 and a member of the Society

of Reproductive Endocrinology and Infertility since graduation in 1993. She is fully trained in minimally invasive surgery techniques, including use of the daVinci robotic system with laparoscopy.



Notes





