



iSURVIVE
SERVICE MANUAL FOR CANCER SURVIVORSHIP

YOUR DASHBOARD | TABLE OF CONTENTS

A MESSAGE FROM MCA, KPPEPR AND PIVOT.....	4
A MESSAGE FROM THE COMMUNITY ADVISORY COUNCIL (C.A.C.).....	5
TAB ONE: INTRODUCTION TO YOUR SURVIVORSHIP SERVICE MANUAL	
TAB TWO: THE CANCER SURVIVORSHIP CREW	
SURVIVORS: AT THE WHEEL OF CANCER SURVIVORSHIP.....	15
CAREGIVERS: RIDING SHOTGUN ON YOUR LOVED ONE’S CANCER JOURNEY.....	17
PROVIDERS: “MECHANICS” OF SURVIVORSHIP.....	19
TAB THREE: INTRODUCTION TO CANCER SURVIVORSHIP	
CANCER SURVIVORSHIP IN AMERICA.....	24
CANCER SURVIVORSHIP IN KANSAS.....	26
CANCER SURVIVORSHIP IN RURAL COMMUNITIES.....	26
TAB FOUR: SCHEDULED MAINTENANCE: FOLLOW-UP CARE	
THE MILEAGE LOG.....	30
GUIDELINES FOR THE MAJOR TYPES OF CANCER.....	33
TAB FIVE: THE CHECK ENGINE LIGHT: PHYSICAL EFFECTS DOWN THE ROAD	
PHYSICAL AND MEDICAL SIDE EFFECTS.....	38
TAB SIX: BLUE HIGHWAYS: PSYCHOSOCIAL HEALTH AND SURVIVORSHIP	
TAB SEVEN: MAINTENANCE LOGS: WHAT TO ADDRESS AT VISITS	
THE MAINTENANCE LOG.....	58
TAB EIGHT: GOING THE EXTRA MILES: S.M.A.R.T. GOAL SETTING	
TAB NINE: ACTION PLAN TEMPLATE: USING S.M.A.R.T. GOALS TO TAKE ACTION	
ACTION PLAN TEMPLATE TOOL.....	69
MY STEPS FOR ACTION.....	70
TAB TEN: SURVIVORSHIP CARE PLANS (SCPs)	
EXAMPLE OF A CANCER TREATMENT SUMMARY.....	78
BLANK TEMPLATE FOR A CANCER TREATMENT SUMMARY.....	81
TAB ELEVEN: PIT STOPS AND PASSENGERS: LEARNING TO TALK ABOUT CANCER	
TAB TWELVE: CONNECTING SURVIVORSHIP JOURNEYS: COMMUNITY NETWORKING	
TAB THIRTEEN: RESOURCES	
TAB FOURTEEN: GLOSSARY, END NOTES AND PHOTO CREDITS	



Questions



Info for Primary Care Providers



Info for Caregivers

REGISTRATION | MY CANCER SURVIVORSHIP SERVICE MANUAL

Fill out the following information to the best of your ability. Remembering certain details from your treatment may be difficult. Don't be afraid to call your oncologist or other providers to ask for help locating any forgotten details.

• Name _____

• Cancer Information

Date of Diagnosis (MM/YY) _____

Type _____

Stage _____

Treatment _____

End of Treatment Date (MM/YY) _____

• Cancer Care Team _____

• Primary Care Provider's (PCP) Name _____

• Locations of Care

Address _____

Phone (_____) _____

Address _____

Phone (_____) _____

NOTES:

This survivorship manual was created by a Colorado-based team in 2015 and then updated and adapted from 2017-2018 by a team at The University of Kansas for the needs of Kansas communities.

Created by:

High Plains Research Network Community Advisory Council
Joy Batt, RN, Kaitlyn Bennett, Fred Crawford, Maret Felzien, Martha Flores, Rafael Flores, Mike Hernandez, Colby Jolley, DO, Verleen Karney, Ned Norman, Marc Ringel, MD, Mary Rodriguez, Sergio Sanchez, Norah Sanchez, Kathy Winkelman, Steve Winkelman, Chris Bennett, JC Carrica, EdD, Lori Jarrell, RN, Leslie Hall-Huz, RN

University of Colorado Department of Family Medicine
Matthew Westfall, Linda Overholser, MD, Linda Zittleman, MSPH, Susan Gale, Christin Sutter, Jack Westfall, MD

Version 1.0 | March 2015 | Supported with funding from the National Cancer Institute

Adapted by:

Members of The University of Kansas Cancer Center's PIVOT (Patient and Investigator Voices Organizing Together)
Julie Crotts, Kristine Darnell, Neil Maune

Masonic Cancer Alliance/Kansas Patients and Providers Engaged in Prevention Research
Kyla Alsman, RN, BSN, K. Allen Greiner, MD, MPH, Jennifer Klemp, PhD, MPH, MA, Susan Krigel, PhD, Trish Long, PA, Becky Lowry, MD, Danielle Peereboom, MPH, Ashley Spaulding, MA

Version 2.0 | May 2018 | Supported with funding from the Centers for Disease Control and Prevention

Version 3.0 | Updated May 2024 | Ellie Brent, MPH, Karin Denes-Collar, LCSW, LCSW, Catie Knight, MPH, Jennifer Klemp, PhD, MPH, MA, K. Allen Greiner, MD, MPH

Kansas Patients and Providers Engaged in Prevention Research (KPPEPR)
Contact: 913-945-6873; kppepr@kumc.edu

A MESSAGE FROM MASONIC CANCER ALLIANCE (MCA), KANSAS PATIENTS AND PROVIDERS ENGAGED IN PREVENTION RESEARCH (KPPEPR) AND PATIENT AND INVESTIGATOR VOICES ORGANIZING TOGETHER (PIVOT)

We are pleased to be able to offer this resource to cancer survivors in Kansas. Our friends in Colorado created this survivorship manual in 2015 and, with their guidance, we have adapted it to fit the needs of Kansas communities. We invite you to read the letter below from the original creators: a group of cancer survivors, caregivers, health educators and providers in Eastern Colorado. When we set out to adapt this manual, we knew that we also needed a team that represented diverse perspectives: primary care providers, oncology providers, clinical psychologists, survivorship experts and - most importantly - cancer survivors from various communities in rural Kansas.

We hope that you find this resource helpful in navigating your survivorship journey along with your care team.

Sincerely,
Members of MCA, KPPEPR and PIVOT

A MESSAGE FROM COMMUNITY ADVISORY COUNCIL (C.A.C.)

Hello,

Most of us have been where you are now—a cancer survivor—or know someone who is. A cancer diagnosis is typically surprising and more than a little bit scary. The time after treatment can bring uncertainty and newfound fear. Treatment probably felt manageable because you had an established support system of caregivers, doctors, nurses, and counselors. However, in the time period after treatment, a lot of that support system disappears after treatment. We recognize this transition may be a difficult and anxious one as parts of your support system fade away.

We are a group of Colorado community members, patients, health educators, and physicians. We created this service manual to help our friends, family members, and coworkers to live long and fulfilling lives after cancer diagnosis and treatment. Cancer and cancer survivorship are serious business. Advancements in screening, prevention, and diagnosis mean more people are living longer after a cancer diagnosis. This growing population of cancer survivors demonstrates the resiliency and fight of patients and doctors, and highlights areas for future research and attention.

Unfortunately, there really is no such thing as a cancer-free life. Even if your treatment is considered “curative,” cancer is a long-term, chronic health concern. A cancer diagnosis may affect your day-to-day activities, even in small ways, for the rest of your life. But stories of survivors living long and healthy lives for many years after diagnosis are becoming the norm. This is a hopeful time for cancer survivors and their loved ones.

Transitioning back to “normal” life after treatment can be overwhelming. Support, communication, and “straight talk” from your health care team is very important. We encourage you to work closely with your medical team to create a long-lasting relationship. Don’t be afraid to ask questions and expect answers.

Our goal is to provide clear messages and tools to help you transition back to day-to-day life and manage your cancer-specific needs over time. Survivorship is an ongoing process that may require changes in your lifestyle habits—changes that may not happen overnight. Remember, even small steps can make a big difference in your health.

We hope this service manual helps you, your caregivers, and your medical team to gain knowledge, develop relationships, and take action as a thriving cancer survivor.

Sincerely,

Members of the High Plains Research Council
Community Advisory Committee

The Community Advisory Council (C.A.C.)
Joy Batt, RN • Kaitlyn Bennett
Fred Crawford • Maret Felzien • Martha Flores
Rafael Flores • Mike Hernandez • Colby Jolley, DO
Verleen Karney • Ned Norman • Marc Ringel, MD
Mary Rodriguez • Sergio Sanchez • Norah Sanchez
Kathy Winkelman • Steve Winkelman • Matthew Westfall Jack
Westfall, MD • Linda Zittleman, MSPH
Susan Gale • Christin Sutter • Chris Bennett
JC Carrica, EdD • Lori Jarrell • Leslie Hall-Huz





INTRODUCTION TO YOUR SURVIVORSHIP SERVICE MANUAL

The iSURVIVE Service Manual was designed to be a resource for cancer survivors who are navigating the “open road.” What defines a cancer survivor? A cancer survivor is anyone with any history of cancer. Survivorship begins at diagnosis and continues for the rest of the person’s life. If you are a survivor, you may feel like the “only one” who is on this journey—but, in fact, you are one of millions of people in the United States who are cancer survivors.² And that number is growing.

Early detection and diagnosis, along with improved treatments, are increasing the number of cancer patients that are living with or through their disease. Because more people today survive after diagnosis, health care providers often have difficulty managing survivors and their cancer-related needs. The iSURVIVE Service Manual supports cancer survivors, caregivers and health care providers (specifically primary care providers or PCPs) as they create strong, lasting relationships that manage cancer survivorship needs and ensure safe travels on the roads ahead.

Remember these important messages while on your survivorship journey. You can:

- LIVE a full and healthy life all along the roads of survivorship.
- LEARN all about survivorship, including fitness and nutrition, long-term effects and necessary follow-up.
- EXPECT your oncologist to provide you with a survivorship care plan, including a summary of your treatment, risks from treatment and next steps for screening and lifestyle. This will help you and your PCP stay on course with/navigate your long-term survivorship care.
- START your survivorship journey using this service manual as a guide.



© Jody Gragg
Barber County



WHY A “SERVICE MANUAL?”

There are many helpful and comprehensive cancer survivorship resources available. What makes this resource different? A lot of survivorship resources are difficult to access and understand because they contain too much information and are very technical. Many resources are specific to certain types of cancers and do not cover survivorship in general. The iSURVIVE Service Manual intentionally does not cover the technical details of every type of cancer— instead it focuses on the common elements of all cancer survivors.

The iSURVIVE Service Manual is modeled after a car service manual. A “service manual” organizes information in an easy-to-access format for cancer survivors across the cancer journey. The work and effort you invest to take care of your car is similar to the work and effort you need to invest in taking care of your body. If you are a car owner, you bring it to a mechanic for scheduled maintenance. Similarly, as a cancer survivor, you need to visit an oncologist and PCP for checkups.

You also take certain precautions at home to maintain your car warranty — just as you need to take personal responsibility to maintain your health and avoid complications down the road. The iSURVIVE Service Manual has information that will help you keep your “check engine light” off and your “battery charged.” Think of this resource like an owner’s manual, not a mechanic’s manual.



For long-term survivors, there is information in this manual for you as well. Cancer survivorship care is a rapidly developing field, and guidelines are regularly being updated. Many resources on long-term cancer survivorship are emerging. There is no better time than the present to confidently take the wheel on your cancer survivorship journey.



IF I'M ALREADY A LONG-TERM SURVIVOR, SHOULD I BE WORRIED THAT I'M ONLY NOW RECEIVING THIS RESOURCE?

No—don't worry! Long-term cancer survivorship represents a broad spectrum from the recently diagnosed, to 30-year survivors, to individuals who will remain on treatment for extended periods of time. Some people have received comprehensive survivorship care while others have received very little. Cancer survivorship care is a rapidly emerging field, and new recommendations and guidelines are updated regularly. Much of what we know about long-term cancer survivorship are recent developments. Wherever you are on your cancer journey, there is no better time than now to take more control and "ownership" of your health. We hope this service manual will help you take the wheel, whether it is your first year of survivorship or your fiftieth.



CAREGIVERS

You play a critical role in assisting your survivor on the survivorship journey. As a "go-to" partner, you can encourage use of the iSURVIVE Service Manual as a resource to help them take the wheel on their journey to long-term health. At this stage, think of yourself as a navigator, air traffic controller, or advocate. As your loved one travels along his/her cancer journey, you can remind him/her about his/her qualities of strength and resilience and encourage a continued focus on reaching the destination of good health.



PRIMARY CARE PROVIDERS

Primary care providers (PCPs) have an important role to play in long-term cancer survivorship care. Our understanding of cancer survivorship care continues to grow as research provides new insights and recommendations. Many recommendations and guidelines are available in the resources section at the end of this manual. Regardless of your current survivorship care practices, don't be afraid to have a candid conversation with your patients. Talking through concepts and ideas of long-term survivorship care will help dissipate anxiety they may feel after receiving this resource. Long-term survivorship care requires communication and partnership between providers and patients.





THE CANCER SURVIVORSHIP CREW

SURVIVORS: AT THE WHEEL OF CANCER SURVIVORSHIP

At some point in the past, you were handed the keys to a brand new “pickup truck”—the life of a long-term cancer survivor. Whether it was 30 years ago, 10 years ago, or yesterday, this transition back to the open road may have been, and may still be, difficult. You are not alone if you feel anxious, angry, or sometimes confused, regardless of where you are along the survivorship journey. Navigating your “new vehicle” may feel like the first time you got behind the wheel. You have an idea of what life is like after cancer treatment, just as you may have had an idea how to drive a stick shift for the first time when you were a teenager. Even if you are already an expert navigator on the roads of cancer survivorship, your journey likely hasn’t been without its share of speed bumps and potholes.

The iSURVIVE Service Manual will help keep your “motor” running and help you to become an expert navigator on the roads of survivorship. Through every mile of your journey, remember that you are not alone. Your family and friends, cancer care team, and primary care provider (PCP) will be there as part of your service team.

This manual outlines required maintenance and screenings as part of your well-person and survivorship care plan and will help you to become an active, engaged patient. It can also help you build a survivorship partnership with your caregivers and health care team.

You are not alone in your cancer survivorship journey.

Your family and friends, cancer care team and PCP will be there as part of your service team.

You’ll find background information on cancer and long-term survivorship. Health maintenance logs and template action plans will help you monitor possible cancer-related issues and incorporate healthy habits. Just as with your vehicle, responsibility for maintenance is up to you. Refer to the iSURVIVE Service Manual frequently in order to ensure worry-free travels.

CREATE A PARTNERSHIP WITH HEALTH CARE PROVIDERS

Cancer survivorship care can be complicated because it requires action and vigilance by both you and your health care providers. Often, many survivors get lost between their transition from treatment to long-term survivorship.

This can happen when patients and doctors have inadequate communication or instructions. As with a mechanic, creating a partnership with your health care providers, in particular your PCP, is critically important.

Take this manual to all your appointments and use it as a tool for coordinating with your providers. Make sure to take notes, ask questions, fill out the maintenance logs, and follow the action plans.

Creating a partnership with your providers is key to successful long-term survivorship.

Engage with your doctors and tell them your needs and priorities. Remember that doctors can only help if you are willing to actively communicate with them and take steps to improve your overall health.

COMMUNICATION—A TWO-WAY STREET

It's always a good thing to have a mechanic or two on call for a journey. Establishing communications with your health care team may seem challenging, but don't be intimidated!

To help, there is information in this iSURVIVE Service Manual for both health care providers and caregivers to help them establish a relationship and "rules of the road." As you are taking steps to

improve communication with your cancer care team, your doctor will be taking similar steps to improve communication with you! We have provided information for all service team members because we know communication is a two-way street.

Here are a couple of communication tips to keep in mind when you meet with members of your health care team:

- Discuss health needs, goals, and priorities using maintenance logs (see page 58).
- Develop an action plan with your doctor using the provided template (see page 69).

Make sure you follow your action plan and take agreed upon steps to work towards improved health and quality of life.



CAREGIVERS: RIDING SHOTGUN ON YOUR LOVED ONE'S CANCER JOURNEY



CAREGIVERS

Family and friends often play a critical role in supporting survivors—as caregivers. Throughout this iSURVIVE Service Manual there are specific call outs, like this one, that provide information to assist you in supporting your survivor.

The cancer survivorship journey may be difficult for caregivers. Watching a loved one struggle through physical and emotional hardship can take its toll. It is important that you take active steps to maintain your own physical and psychosocial health, to be able to provide the best support possible.

A few “do’s:”

- Do seek help and support for yourself. Taking care of yourself is essential for supporting your survivor.
- Do utilize outside resources for support.
- Do keep channels of communication open with your family, friends and others who are there to support you.

It may be difficult to talk to your survivor about your personal concerns and issues, but it is important to communicate about realistic expectations and limitations. Navigating the caregiver-survivor relationship is different for everyone and it is helpful to work through it with understanding and grace.

RESOURCES FOR SELF CARE

National Cancer Institute (NCI)

<https://www.cancer.gov/publications/patient-education/caring-for-the-caregiver>

American Cancer Society (ACS)

<https://www.cancer.org/cancer/caregivers.html>

Triage Cancer

This website has a list of webinars on a variety of topics that are helpful for both survivors and caregivers.

<http://trriagecancer.org/webinars>

Cancer Support Community

<https://www.cancersupportcommunity.org/caregivers>

Kansas Cancer Partnership

<https://www.kscancerpartnership.org/cancer-survivor-resources/>

CAREGIVER SUCCESS CHECKLIST

- Act as a support system for your survivor.
- Help facilitate a relationship between your survivor and his/her health team.
- Take care of yourself.
- Make sure your survivor is attending regular checkups and appointments.
- Assist in recognizing or addressing any treatment side effects.
- Gauge psychosocial health and seek professional help if necessary.
- Facilitate conversation and establish comfort between survivor and care team.
- Hold your survivor accountable to his/her goals and action plan.
- Ensure the primary care team receives a survivorship care plan and other important documents.
- Help your survivor learn to talk about cancer and advocate for themselves.

iSURVIVE SERVICE MANUAL CONTENT FOR CAREGIVERS

Introduction	21
Blue Highways: Psychosocial Health and Survivorship	43
Maintenance Logs.....	51
Action Plan Templates: Using S.M.A.R.T. Goals to Take Action.....	65
Pit Stops and Passengers: Learning to Talk About Cancer	85
Connecting Survivorship Journeys: Community Networking	89



PROVIDERS: “MECHANICS” OF SURVIVORSHIP



PRIMARY CARE PROVIDERS

Health care providers, especially those in primary care, must communicate and partner with patients who are cancer survivors in order to help them maintain healthy habits and minimize the risks and impacts of cancer. Cancer survivors have specialized and unique care needs. Throughout the iSURVIVE Service Manual there are specific call outs, like this one, that provide information to help you provide the best possible care to your survivor patients.

CREATING A LONG-TERM PARTNERSHIP

In 2005, the Institute of Medicine (IOM) published “From Cancer Patient to Cancer Survivor: Lost in Transition.” This work outlined the deficits of long-term cancer survivorship care. Cancer survivors often describe feelings of abandonment and being “lost in transition” after their primary treatment ends and long-term survivorship begins.

These feelings often result from less frequent follow-up care by cancer care teams and lack of familiarity with cancer survivorship-specific care by PCPs. Cancer survivors need cancer care providers and PCPs to communicate and coordinate their cancer survivorship care.

Health care providers should build a strong and successful relationship with patients who are cancer survivors. Resources are identified throughout the iSURVIVE Service Manual that

will educate and facilitate improved survivorship care and build partnerships.

Take time to review maintenance logs and action plans (pages 58 and 69) with patients as one way to enhance relationships and help patients begin to take ownership of their survivorship and lifestyle decisions.



PROVIDER SUCCESS CHECKLIST

- Take ownership of your cancer survivors' care.
- Recognize their unique long-term care needs.
- Create a strong partnership with survivors for long-term survivorship.
- Address treatment side effects, especially less obvious issues such as psychosocial or sexual health concerns.
- Review maintenance logs with survivors during visits.

iSURVIVE SERVICE MANUAL CONTENT FOR PROVIDERS

Introduction	21
Blue Highways: Psychosocial Health and Survivorship	43
Maintenance Logs.....	51
Action Plan Templates: Using S.M.A.R.T. Goals to Take Action.....	65
Survivorship Care Plans (SCPs)	73
Pit Stops and Passengers: Learning to Talk About Cancer	85
Connecting Survivorship Journeys: Community Networking	89





INTRODUCTION TO CANCER SURVIVORSHIP



WHO IS A CANCER SURVIVOR?

A “cancer survivor” is anyone who has any history of cancer starting from the time of diagnosis until the end of his/her life. After treatment, some cancer survivors live cancer free while others live with cancer as a chronic disease.

WHY DO WE CARE ABOUT CANCER SURVIVORSHIP?

Cancer was once considered a death sentence. Today, many cancer patients are living well beyond their diagnosis and treatment. Long-term cancer survivorship is a relatively modern concept.

WHY ARE SURVIVORSHIP RATES INCREASING?

There are millions of cancer survivors in the United States and the number keeps growing. Survivorship rates are increasing for three main reasons:

1. Earlier detection/diagnosis/screening

Improved cancer detection means people are often diagnosed at earlier stages of the disease. This means their cancer is less severe and treatment is often more successful.

2. Improved treatments

Treatments are getting better and are helping to save and extend many lives. Researchers and doctors continue to find new ways to treat patients.

3. Aging population

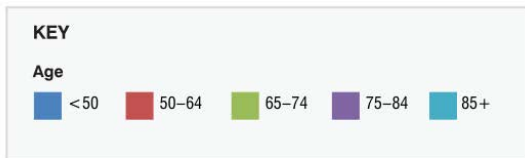
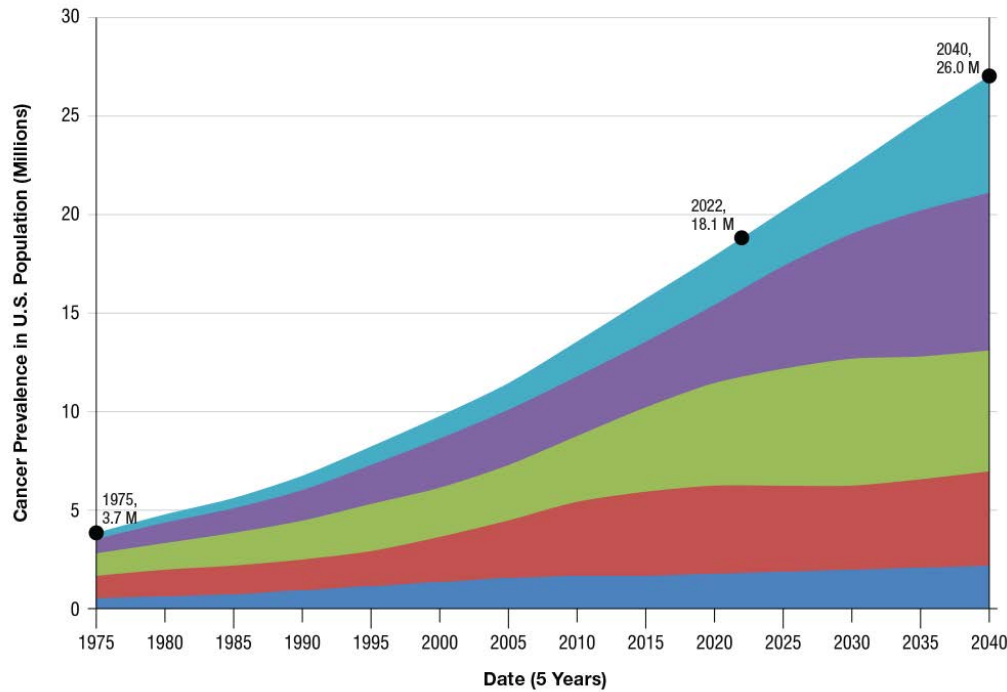
The older people become, the higher their chances are of getting cancer. On average, the U.S. population is becoming older as baby boomers age and subsequent generations have fewer children. The number of older Americans will only continue to increase.



CANCER SURVIVORSHIP IN AMERICA

As of January 2022, there were over 18 million cancer survivors in the United States². That number is projected to increase to 22.5 million, by 2032, and 26.0 million by 2040².

Cancer Prevalence and Projections in U.S. Population from 1975–2040



REFERENCES

Bluethmann SM, Mariotto AB, Rowland JH. Anticipating the "Silver Tsunami": Prevalence Trajectories and Comorbidity Burden among Older Cancer Survivors in the United States. *Cancer Epidemiol Biomarkers Prev.* 2016 Jul;25(7):1029-36.

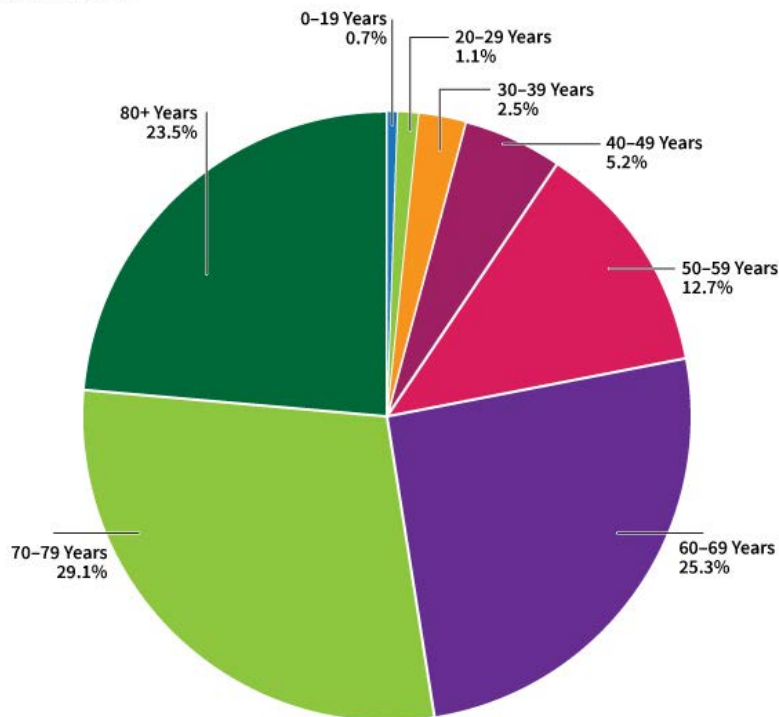
Miller KD, Nogueira L, Devasia T, Mariotto AB, Yabroff KR, Jemal A, Kramer J and Siegel RL. *Cancer Treatment and Survivorship Statistics.* CAA Cancer J Clin. 2022.

CANCER SURVIVORSHIP IN AMERICA

- Approximately two thirds of survivors are currently 65 years or older.²
- Most cancer survivors (about 69 percent) were diagnosed more than five years ago.²
- The number of survivors is growing. In the next 10 years, the number of cancer survivors is predicted to increase by about 31 percent.¹
- Many cancer survivors have medical problems other than just cancer:
 - About 18 percent have cardiovascular disease.³
 - About 17 percent have diabetes.³
 - About 11 percent have asthma.³
 - About 33 percent are obese.¹⁵
 - About 15 percent are current smokers.¹⁵
 - About 33 percent described activity limitations because of health problems.³
 - Adult cancer survivors are more likely to have psychological distress and depression.⁴

Estimated Number of Cancer Survivors in the U.S., by Current Age – More Detail

JANUARY 1, 2022



REFERENCE: *Cancer Treatment & Survivorship Facts & Figures 2022-2024*. Atlanta: American Cancer Society; 2022.

CANCER SURVIVORSHIP IN KANSAS

- There are more than 15,000 Kansans diagnosed with cancer each year. Due to advancements in medical care, more Kansans are living with cancer. In 2019, 7.7% of Kansas adults reported having been diagnosed with cancer (excluding skin cancer).⁶
- As of 2020, there were an estimated 126,655 people living with cancer in Kansas who were diagnosed with cancer in the past 19 years.⁷
- The most commonly diagnosed invasive cancers in Kansas are prostate, lung, and colorectal among men; and breast, lung, and colorectal among women.⁶



CANCER SURVIVORSHIP IN RURAL COMMUNITIES

- In the United States, there are 2.8 million cancer survivors living in rural areas. The proportion of cancer survivors in rural areas is similar to the proportion of cancer survivors in the general population.⁹
- Compared to those living in urban areas, rural cancer survivors, in general, report poorer health status (36.7 percent) than those in urban areas (26.6 percent).⁹
- Compared to urban areas, survivors in rural areas may be more likely to:
 - have additional chronic health issues⁹
 - report more emotional cancer-related distress⁹⁻¹²
 - report higher rates of unemployment for health reasons^{9,13}
 - use tobacco¹³
 - be physically inactive¹³
- Many of these differences cannot be explained by differences in health insurance or education status.⁹



SCHEDULED MAINTENANCE:
FOLLOW-UP CARE

YOUR 100,000 MILE WARRANTY

Just like your truck, you have a long-term “100,000-mile” warranty. Consistent follow-up visits with your oncologist and primary care provider will serve as your “health warranty” as you navigate the roads of cancer survivorship. These dedicated health professionals will be there to help you with concerns and issues that arise along your journey. Your oncologist, in particular, is an especially important “mechanic” following diagnosis.

Several years after your diagnosis, your oncologist may send you back to the open road. Your PCP is there for you. Always remember that you are more than capable and a strong, proactive, and engaged patient. Work to cultivate a lasting relationship with all your health care crew to keep them available wherever your survivorship road leads.

THE THREE PHASES OF CANCER CARE

1. Active treatment

Your oncologist is your primary medical provider during this time period. You will have frequent appointments, anywhere from a couple times a year to weekly, depending on your treatment plan. Do your best to clarify your treatment plan with your oncologist so you know which doctors (Radiation Oncology, Surgery, and so on) are engaged in your treatment.

You need to continue to communicate with your PCP. This includes sharing general health information. The active treatment phase generally lasts one to two years, but this time frame may vary.

2. Transition from treatment to survivorship

Transitioning from treatment to survivorship also involves transitioning care from your oncologist back to your PCP.

You should have a survivorship-oriented appointment and conversation with your PCP following release from treatment. This conversation should focus on creating a long-term survivorship care plan and relationship. You may want to ask questions about surveillance, testing, and appropriate long-term follow-up. Additionally, you should discuss your Survivorship Care Plan/Treatment Summary. This phase often occurs in the three to five year range, though this time frame may also vary.

3. Long-term survivorship

PCPs are now the most important part of your care crew. Continue to see your PCP annually or for any worrisome symptoms. Continue to cultivate a long-term survivorship relationship.



THE MILEAGE LOG

PHASE OF TREATMENT	APPROXIMATE YEARS AFTER DIAGNOSIS	ONCOLOGIST FOLLOW-UP	PRIMARY CARE PROVIDER (PCP) FOLLOW-UP	MISC FOLLOW-UPS TO CONSIDER
ACTIVE TREATMENT	1	Likely regular appointments depending on treatment and for any specific worrisome symptoms	Annual appointment	<ul style="list-style-type: none"> • Counselors • Psychologists • Spiritual leaders • Check in with family, close friends, partners • Physical therapists • Financial advisors • Nutritionist
	2	Continuing regular appointments depending on treatment and for any specific worrisome symptoms	Annual appointment	
END OF ACTIVE TREATMENT AND TRANSITION TO LONG-TERM SURVIVORSHIP	3 to 5	Less regular appointments, annual/multi-annual depending on treatment	Annual appointment and for any specific worrisome symptoms. Once your oncologist has released you, all care questions should go to PCP unless otherwise indicated.	<ul style="list-style-type: none"> • Counselors • Psychologists • Spiritual leaders • Check in with family, close friends, partners • Physical therapists • Financial advisors • Nutritionist
LONG-TERM SURVIVORSHIP	6 to 10	Possible annual checkups depending on treatment	Annual appointment	<ul style="list-style-type: none"> • Counselors • Psychologists • Spiritual leaders • Check in with family, close friends, partners • Physical therapists • Financial advisors • Nutritionist
	11 to 20	Possible annual checkups depending on treatment	Annual appointment	
	20+	Possible annual checkups depending on treatment	Annual appointment	



TRANSITIONING FROM ONCOLOGY TO PRIMARY CARE

At some point, your oncologist will see you less frequently. This may be within a few years of completing treatment but will vary based on your diagnosis, treatment, and other factors. It is common when transitioning between care teams that you may feel anxious and worried. There are several important things to focus on as you are “changing lanes”:

1. You can manage this transition! Your care team has been, and will continue to be, with you through every curve and turn of your survivorship journey.
2. Make a long-term action plan that will be used as a guide for follow-up between your Cancer Care Team and PCP. Think of your PCP as the “Service Manager” who will guide your well-person visits and cancer screenings and address your questions. Now that your PCP is your main point of contact, it is important that you talk with him/her about the things you need to do into the future. From this point on, unless otherwise advised, all health-related questions should be brought to the attention of your PCP before other providers. The iSURVIVE Service Manual includes resources that will help you cover important topics at visits and create action plans (pg 69).
3. It is important that members of your service team are aware of your diagnosis, treatment and follow-up recommendations. This will ensure that your “car” is maintained and tuned up according to “manufacturer guidelines” (evidence-based guidelines). If you switch your PCP, make sure you update your new provider on the details of your

survivorship journey. It is important he/she knows the specifics of your treatment in order to provide you with the best possible care.

4. If you are currently a long-term survivor and are just now receiving the iSURVIVE Service Manual, it is a great time to tune-up!

- If you have not been in consistent contact with your PCP, schedule a visit.
- If you have not been filling out your action plans or have not told your PCP about your survivorship history, now is the time.

Recommendations made in this manual are general and may not be a perfect fit given your unique cancer situation. For more detailed guidelines on follow-up care, the National Comprehensive Cancer Network (NCCN) offers detailed recommendations specific to different types, stages, and treatments of cancer.

MAINTAINING YOUR WARRANTY

When you own a car, you are responsible for following through on scheduled maintenance outlined in your dealership warranty. Similarly, you must be proactive about your survivorship scheduled “maintenance” in order to keep your “health warranty.” A number of guidelines, resources, and tools that will help you take steps towards healthier lifestyle habits are included throughout this manual.



CLINICAL TRIALS

Have you ever been asked about or considered participating in a clinical trial? Clinical trials save lives by 1) leading to new and improved treatments, and 2) helping identify better ways to prevent or diagnose cancers. Each study answers scientific questions and tries to find better ways to prevent, screen for, diagnose, or treat a cancer. Yet, very few people participate in clinical trials.

Many people are unaware of the option of clinical trial participation or are misinformed about the clinical trial process. There are many safeguards built into clinical trials so that volunteering individuals benefit from being involved directly or indirectly and are not exposed to unsafe or harmful new treatments or procedures. Sometimes participants will be randomized to one of two pathways in a clinical trial but that often guarantees the person is either getting the best known treatment or a new treatment enhancement that is expected to be even better. Please consider talking to your health care providers and team members about clinical trials as they may have specific examples of trials they helped facilitate.

You can also browse clinical trials that might be available to you using the two sites below.

University of Kansas Cancer Center Clinical Trials Finder:

<https://www.kucancercenter.org/cancer-clinical-trials/find-trial>

Frontiers Trials Today:

<https://kumc.trialstoday.org/>

WHAT IS THE NCCN?

The National Comprehensive Cancer Network® (NCCN®) is a not-for-profit alliance of 27 of the world's leading cancer centers. The network is dedicated to improving the quality, efficiency, and effectiveness of care for patients with cancer. Through the leadership and expertise of clinical professionals at NCCN® Member Institutions, NCCN® develops resources that provide valuable information to the numerous stakeholders in the health care delivery system. The tables on the following pages include information for accessing the patient treatment guidelines for the top most common cancers in Kansas. A website link is provided for each.

Finally, you can always search for NCCN recommendations using a traditional web search engine. Type "NCCN" into a Google search and select the top entry. This will take you to the NCCN main page. Hover your mouse over the "Guidelines" drop down menu bar at the top left and then select "Guidelines for Patients" option.



PATIENT GUIDELINES FOR TREATMENT OF MOST COMMON TYPES OF CANCER IN KANSAS

GUIDELINE: CANCER TYPE		URL
Adolescent and Young Adult		https://www.nccn.org/patients/guidelines/content/PDF/aya-patient.pdf
Bladder		https://www.nccn.org/patients/guidelines/content/PDF/bladder-patient.pdf
Breast		Use link to then scroll down to find the specific breast cancer type of interest: https://www.nccn.org/patientresources/patient-resources/guidelines-for-patients#category_1
Colon		https://www.nccn.org/patients/guidelines/content/PDF/colon-patient.pdf
Kidney		https://www.nccn.org/patients/guidelines/content/PDF/kidney-patient.pdf
Leukemia		Use link to then scroll down to find the specific leukemia cancer type of interest: https://www.nccn.org/patientresources/patient-resources/guidelines-for-patients#category_1
Melanoma		https://www.nccn.org/patients/guidelines/content/PDF/melanoma-patient.pdf

GUIDELINE: CANCER TYPE		URL
Oral		https://www.nccn.org/patients/guidelines/content/PDF/hn-oral-patient.pdf
Pancreas		https://www.nccn.org/patients/guidelines/content/PDF/pancreatic-patient.pdf
Prostate		Use link to then scroll down to find the specific prostate cancer stage of interest: https://www.nccn.org/patientresources/patient-resources/guidelines-for-patients#category_1
Thyroid		https://www.nccn.org/patients/guidelines/content/PDF/thyroid-patient.pdf
Uterine		https://www.nccn.org/patients/guidelines/content/PDF/uterine-patient.pdf
All Others*		For a complete list of all available NCCN guidelines for patients, visit the following: https://www.nccn.org/guidelines/patients



THE CHECK ENGINE LIGHT:
PHYSICAL EFFECTS DOWN THE ROAD

IN IT FOR THE LONG HAUL: TREATMENT SIDE EFFECTS

If you have a copy of this iSURVIVE Service Manual, you have likely completed your cancer treatment. We commend you for your courage and strength during the treatment process.

Completing treatment is a reason for celebration! You have successfully navigated the most difficult stretch of the survivorship journey.

We cannot overstate the importance of viewing survivorship as a long-term proposition. While the most challenging part of your journey is over, you should not simply put the truck back on cruise control. As a cancer survivor, you need to take extra care to make sure you stay healthy. This starts with monitoring and managing possible side effects from your treatment. As always, your care crew will be with you.

This section highlights some of the potholes you may encounter along your survivorship journey. While this section has a lot of very helpful information on many possible side effects, it is not a comprehensive resource. We decided to include only a selected group of potential side effects for a number of reasons:

1. We have included only the most common and minor side effects. More severe side effects are generally less common.
2. Remember, side effects are possible but not guaranteed. Many survivors have very few issues after treatment completion while a few have some minor side effects.
3. Side effects from cancer treatment are unique. The best plan is to consult with your doctor and care team.

All that said, the goal of this section of the manual is to provide general information. Ultimately, your care team should address your symptoms and diagnoses... so keep building a strong, long-term relationship with your care team.



PHYSICAL AND MEDICAL SIDE EFFECTS

In general, the late and long-term effects you may experience are related to the type of therapy you received during treatment.

LATE EFFECT

A symptom that starts after causative exposure/therapy has been completed. Essentially, a late effect is some symptom which you experience after your treatment is complete that is a result of that treatment.

Example:

- Osteoporosis—some cancer treatment methods, such as steroids and high dose methotrexate, can weaken your bones down the road.

LONG-TERM EFFECT

A symptom that starts during treatment and persists. A long-term effect is one that you start experiencing during treatment as a result of the treatment. A long-term effect is one that will not go away after treatment is complete. The distinction between late and long-term is that late effects don't manifest until well after treatment.

Examples:

- Fatigue—You may experience fatigue during and after your treatment is complete.
- Neuropathy—Damage to the nerves that run information from the brain/spinal cord to the rest of the body. This may result in impaired muscle movement or sensation in the limbs, and pain.
- Cognitive dysfunction—This is a symptom in which parts of the brain aren't functioning at "optimal speed." Some cancer therapies can harm decision-making skills and result in some minor memory loss.

RADIATION

Late and long-term effects resulting from radiation therapy generally correspond with the radiated body region. For example, if you received radiation therapy in the chest region for breast cancer, that radiation could cause late or long-term symptoms in the chest region. This impacted region is often referred to as the "radiation field."

Examples:

- Basal cell skin cancer in radiation field. Radiation therapy can lead to basal cell skin cancers. These small skin cancers are not a significant issue if addressed in a timely manner.
- Scarring
- Premature menopause



SURGERY

Similar to radiation, late and long-term symptoms resulting from surgery generally correspond with the part of the body where the surgery occurred.

Examples:

- Pain
- Physical/mobility impairment
- Lymphedema—A condition related to the functioning of the lymphatic system. Surgery can harm lymph vessels/nodes and result in blockages or interruptions of lymph flow. When vessels or nodes don't function properly, lymph fluid builds up in abnormal amounts resulting in swelling. This swelling generally occurs in the arms or legs. Lymphedema is often associated with surgery for breast cancer.

However, many types of surgery and some radiation treatments can cause significant swelling associated with lymphedema.

Special Note: Many cancer patients who only require surgical treatment feel they “got off easy.” Radiation therapy and chemotherapy cancer treatment plans are often considered much more grueling and taxing on the body and mind than surgical options. Surgery is no less serious than other treatment therapies. Although risks for side-effects are fairly minimal, you should remain vigilant in your survivorship journey and continue to take steps to improve your health.

CHEMOTHERAPY

Unlike radiation and surgery, chemotherapy late and long-term effects do not necessarily correspond with specific areas of the body. For example, someone receiving chemotherapy for colon cancer may have resulting heart issues.

Examples:

- Anemia—A condition in which blood has a decreased number of red blood cells or hemoglobin. This lowers the ability of blood to carry oxygen throughout the body. Symptoms of anemia include fatigue, weakness, shortness of breath, or the inability to do strenuous exercise.
- Sensory changes—It is possible the senses of smell and taste may change slightly after chemotherapy. These changes may go away.
- Body aches and pains
- Fertility—Chemotherapy can have long-term detrimental effects on fertility. Survivors should see fertility specialists during the family planning process if they have any related concerns.
- Osteoporosis—This is generally characterized by a decrease in bone density. Bones become more fragile, brittle and more likely to fracture.

ANTI-ENDOCRINE/HORMONAL THERAPY

This treatment therapy is used to block hormone levels. Similar to chemotherapy, hormonal therapy late and long-term effects do not necessarily correspond to the part of the body being treated for cancer. Possible side effects are highly dependent on the gender of the survivor.



Examples:

Women: Anti-estrogen drugs can lead to some of the following late/long-term effects:

- Joint pain
- Depression
- Hot flashes and premature menopause
- Risk for osteoporosis
- Vaginal dryness or pain

Men: Androgen deprivation therapy for prostate and other cancers can lead to some of the following late/long-term effects:

- Anemia
- Depression
- Bone thinning
- Increased risk for diabetes

PHYSICAL SYMPTOMS NOT SPECIFIC TO ONE TYPE OF THERAPY

Examples:

- Fatigue
- Pain
- Memory/cognition issues - Treatments can cause brain function to be compromised for periods of time. These cognitive issues are often referred to as “chemo-brain.”
- Insomnia - Difficulty falling asleep or staying asleep
- Dyspnea - Shortness of breath
- Sexual dysfunction



RISK FACTORS FOR LATE AND LONG-TERM EFFECTS

Late and long-term risk factors can be broadly grouped into two main categories: treatment-based risk factors and lifestyle risk factors.

Treatment-based risk factors

Specific aspects of a treatment plan can contribute to an increased risk for late and long-term effects. The following risk factors are specific to childhood survivors. Childhood cancers are more thoroughly studied relative to many other cancers. Although such recommendations may be true for non-childhood cancer survivors, definitive research is currently lacking.

Examples:

- Cumulative dosage received during treatment
- Age during treatment
- Duration of exposure to chemo or radiation therapy
- More specifically, chest radiation may be associated with increase risk for cardiovascular disease, particularly if combined with a chemotherapy regimen.

Lifestyle risk factors

Lifestyle may play a large role in determining risk for cancer treatment late and long-term effects. People who practice healthy lifestyle choices have a diminished risk for late and long-term effects. Lifestyle risk factors are considered modifiable because survivors have some control over decreasing their risk.

Examples:

- Regular physical activity, a healthy diet, and maintaining a healthy body weight can all decrease your risk of developing health problems like diabetes.

- Smoking, especially if combined with radiation therapy, multiplies risk for secondary lung cancer or cardiovascular disease.

WORSENING COMORBIDITIES

A comorbidity is any chronic, non-cancer condition that a survivor might have at any point during his/her survivorship journey. Late and long-term effects are comorbidities that develop during, or as a result of, cancer treatment. Many survivors have chronic health conditions prior to diagnosis and treatment for cancer. These non-cancer related comorbidities can occasionally worsen during or after treatment as a result of the emphasis placed on cancer care. The following are a few common comorbidities that can worsen as a result of cancer treatment.

Examples:

- Diabetes
- Blood pressure



ADDITIONAL RESOURCES

The National Comprehensive Cancer Network (NCCN) resources provided in the warranty coverage section of this manual contain significant information on late and long-term effects of various cancers and treatment plans.

The American Cancer Society (ACS) website also includes many comprehensive resources similar to those found on the NCCN website. Click on the url below to visit the ACS website:

<http://www.cancer.org>



BLUE HIGHWAYS: PSYCHOSOCIAL
HEALTH AND SURVIVORSHIP

WHY BLUE HIGHWAYS?

We titled the psychosocial health section of this service manual “Blue Highways” because, like the side country roads printed in blue on maps, psychosocial health may be overlooked. The title “Blue Highways” also conveys that psychosocial health is “off the beaten path.” Unlike purely medical cancer-related concerns, psychosocial health interventions are not part of the “fast-track” or “interstate” system of survivorship care. Particularly in rural communities, psychosocial health care is at risk of being “the small, forgotten, out-of-the-way dirt roads of survivorship care.” (William Least Heat-Moon)

Psychosocial health may be overlooked for several reasons including:

- Embarrassment or discomfort on the part of either the survivor or the care team
- Fear that taking time to focus on psychosocial concerns may take away from addressing physical concerns
- Fear of judgment
- Attempts to remain stoic
- The belief that psychosocial concerns aren't as important to address
- Lack of resources to address concerns
- Particularly in rural areas, the possibility that the survivor and therapist might know each other outside the patient-provider relationship.

Many survivors fail to receive needed care because they are too uncomfortable bringing up psychosocial concerns with their providers. If you have psychosocial concerns that your care team does not specifically assess (either on paper or

in conversation), don't hesitate to bring it up. For instance, you might start by saying, “Lately I've noticed that I've had trouble sleeping. I can't stop worrying about my cancer coming back.”

Psychosocial health is a critical part of survivorship care and overall quality of life. Untreated psychosocial health issues can result in adverse health effects.

Negative emotions are an expected part of the survivorship journey. When they become difficult to manage, it may be time to seek professional assistance.

If you feel stuck and can't seem to move forward, please reach out to your care team for help.

PSYCHOSOCIAL OR EMOTIONAL CONCERNS

Depression and anxiety during treatment

It is very common to feel depressed or anxious throughout cancer survivorship, particularly during active treatment. You are dealing with a life-altering and possibly threatening condition. You are not alone if you feel down in the dumps.

These negative feelings may persist even after you finish active treatment. Each person's emotional well-being is unique and deserves unique attention.

Fear of recurrence

Almost all cancer patients have a low to moderate level of fear of recurrence. In fact, a low level of fear of recurrence can actually be beneficial because it can motivate survivors to follow recommendations regarding follow-up care, such

as going to screenings and taking medications. In addition, this motivation may encourage survivors to improve their overall health by sticking to a healthy diet, exercising, and quitting smoking.

But some survivors have such high levels of fear of recurrence that it robs their daily life of joy. A high level of fear of recurrence comes with a cost, as it can decrease cancer survivors' social, emotional, and physical functioning. In fact, studies have shown that compared to survivors with a low level of fear of recurrence, survivors with high levels of fear of recurrence generally have a lower overall quality of life.

So how can you balance the benefits of a low level of fear of recurrence with the negative consequences of a high level of fear of recurrence? The recommendations listed below can help you:

1. Get an accurate understanding of your risk of recurrence from your oncology team.
2. Have a plan: learn the signs of recurrence and what to do if you have symptoms.
3. Ask your oncology team what you can do to decrease your risk of recurrence, including recommendations for diet and exercise.
4. Focus on wellness: put your energy into improving your overall health.
5. Start low and go slow: take small steps, and set realistic goals. Be patient with yourself when making changes.
6. Do something that brings you joy daily. Sing in the shower! Watch a silly TV show!
7. Be social. Strengthen and create meaningful relationships with others.

8. Learn to live with uncertainty.

9. Think about what gives your life meaning and what your values are, and live your life accordingly.

10. Know when to reach out for help: if you are thinking of harming yourself or someone else, or if your anxiety is impairing your quality of life and you are unable to make changes on your own, ask your healthcare team for a referral to a therapist.

Try to adopt the philosophy of putting your cancer experience into perspective. Strive to make your cancer experience serve as the motivation to make your future life as meaningful and rich as possible.

Perhaps it may seem odd, but some cancer survivors say their life is better after cancer! They may talk about the perception that major personal growth has occurred as a result of facing a challenging life event.



General survivorship stress

The term “cancer-free” is a bit complicated. Survivors, even after active treatment has concluded, are never “finished” with cancer because of the ongoing nature of survivorship. Concerns about cancer may persist for the rest of a survivor’s life.

There may be a disconnect between cancer survivors and those without any cancer experience. Cancer survivors may experience situations where they feel out of sync compared to those who have no cancer experience.

It is not unusual for cancer survivors to experience changes in relationships. Perhaps you are focusing more on meaningful relationships and letting some casual relationships go by the wayside. It is important to have these meaningful relationships because chronic loneliness has significant consequences on quality of life. If you feel lonely and disconnected, reach out for professional help.

It is important to stay on top of your own psychosocial needs just as you would stay on top of car maintenance items like oil changes or bulb replacements.

SEXUAL HEALTH CONCERNS

Psychosocial health can also be linked to sexual health concerns. There can be discomfort for both the survivor and the care team in identifying and managing sexual health concerns. Concerns surrounding sexual health and intimacy may be difficult to address for both survivors and providers because they are multifaceted; they combine physical and psychological health. For example, sexual health issues can result from radiation to sexual organs, chemotherapy, or emotional concerns related to intimacy and quality of life. Both providers and survivors may find it difficult to talk about sexual health concerns because these conversations can be awkward and uncomfortable. However, it’s the responsibility of both the care team and the survivor to engage in discussions, which may include: intimacy, body image, possible infertility, libido (sexual drive) and/or symptom management (vaginal dryness, erectile dysfunction, pain during intercourse, etc). Don't hesitate to bring up your concerns with your primary care team and ask for a referral to a specialist if symptoms do not improve.

SPIRITUAL CONCERNS

Cancer survivors sometimes struggle with issues related to mortality, the meaning of life, and other spiritual concerns. Spirituality and spiritual health can be important components of a survivor’s overall quality of life. Resources should be identified to assist with spiritual concerns, including spiritual/religious leaders, support groups, or family and friends.

PRACTICAL AND SOCIAL CONCERNS

The transition from cancer treatment to long-term survivorship represents a change in the significance of cancer in an individual's life.

- Missing work - may cause anxiety for financial and professional reasons. The focus during this transition should be on getting healthy. Cancer survivors are protected by various pieces of legislation, most specifically the Family and Medical Leave Act. This legislation entitles survivors to up to 12 weeks of job-protected leave in a given year for "a serious health condition that makes the employee unable to perform the essential functions of his or her job."
- Health insurance and costs - Unfortunately, long-term cancer care costs will persist many years into the future. While "small" relative to acute treatment, the costs of long-term care, whether it's follow-up visits, screening measures, or management of late and long-term effects, will not be zero. Consider these long-term survivorship costs when making decisions regarding insurance coverage and personal finances. Consider discussions with:
 - Family
 - Employers about employer-based insurance options
 - Insurance assistance consultants/sites
 - Insurance navigators

- Family planning/child-rearing - Childhood and adolescent cancer survivors often face issues with premature ovarian failure and family planning. Many cancer treatment therapies can have detrimental effects on sexual and reproductive health. In some rare cases, treatments can lead to infertility. These issues should be discussed with PCPs, as they can assist survivors with treatment options or referrals to a specialist. There are many treatment and therapy options for survivors with sexual or reproductive health concerns.



PRIMARY CARE PROVIDERS

Help survivors by actively addressing psychosocial health issues during visits. Cancer diagnosis, treatment, and transition to survivorship are potentially challenging experiences. Psychosocial issues can include fear, anxiety or depression. Take time to assess whether survivors are emotionally and psychologically healthy during this transition and refer them to psychosocial professionals if needed.



CAREGIVERS

Help your survivor get the help they need. You are uniquely positioned to assist your survivor with psychosocial concerns because you are so close to them. Ask questions and take the time to listen to make sure they are in a good place emotionally and psychologically as they enter long-term survivorship. Also make sure you are addressing your own psychosocial concerns. Being a caregiver can be emotionally and psychologically taxing. You may develop some psychosocial concerns yourself as you work to support your survivor. Don't put your own psychosocial health on the back burner as you focus on assisting your survivor. Get the help you need as soon as such concerns arise in order for you and your survivor to stay healthy.



MAINTENANCE LOGS: WHAT TO ADDRESS AT VISITS

QUESTIONS TO ASK DURING CLINIC VISITS

You may be unsure of what questions to ask your doctor during follow-up appointments. You've been given so much information, how are you supposed to know what to ask? Don't worry! The table on the next page is your maintenance log, with lists of various topics, concerns, and priorities to cover at appointments.

You should also review the suggested questions, which may prepare you for a discussion with your provider. Not only will this help you cover all your cancer-related questions, it is also a way to cultivate a long-term relationship with your care team. The maintenance log can be a helpful tool for both you and your care team as you address survivorship.

Remember to keep your maintenance log safe inside the iSURVIVE Service Manual so you can refer back to it when needed.



PRIMARY CARE PROVIDERS

Your patient may have many questions. Use the maintenance log to guide discussions and evidence-based recommendations with your patients as you help them confidently navigate survivorship.



CAREGIVERS

Help your survivor think through concerns prior to their appointments. Support them during appointments by taking notes and encouraging them to ask difficult - but important - questions. At the same time, be willing to leave the room if it will make your survivor more comfortable.



MONITOR FOR RECURRENCE

Worry about your cancer coming back is the most common cause of anxiety in cancer survivors.

- Monitoring for recurrence is a shared responsibility between you (informing your care team about symptoms or concerns you experiencing), and your primary and cancer care teams.
- A survivorship care plan can be a good tool for mapping out your follow-up schedule of appointments and follow-up recommendations. Make sure you are aware of and scheduled for any follow-up tests.
- Discuss this plan with your primary care provider.

Questions to ask your cancer care team:

1. Ask your team for a plan, including a schedule or timeline for follow-up care such as appointments and testing (blood tests, x-rays or scans, genetic testing, etc.).
2. What specific signs and symptoms should I watch for based on my specific type of cancer? This may include new or lingering symptoms and things you need to pay attention to that might indicate additional testing or assessment is necessary.

MANAGEMENT OF LATE/LONG-TERM EFFECTS

A diagnosis and treatment of cancer may lead to side effects (also known as late/long-term effects). It is often difficult to know who is the best provider to discuss risks and management, since some issues may overlap with pre-existing health concerns you might have or will develop with time and age. Managing late/long-term effects is a shared

responsibility between you, your primary care provider and your cancer care team.

Questions to ask your primary care provider:

1. How does my history of cancer impact my current health issues or risk for other chronic health issues? (examples may include cardiovascular concerns, diabetes, weight management, bone loss)

2. Are there specific tests or recommendations for prevention or treatment if I am at risk or currently have developed a late effect secondary to my cancer? (examples may include fasting blood tests, bone mineral density, low-dose CT scan, stop smoking, weight loss)

Questions to ask your cancer care team:

1. What are the most common late/long-term effects of my type of cancer and the treatment I received?

2. Is there any special monitoring that would be recommended? (examples may include bone density test, eye exam, visit with a cardiologist)

SURVEILLANCE FOR NEW CANCERS

Every cancer survivor is at risk for developing another cancer. This may be higher if you have a family history of cancer or a genetic mutation increasing your risk or are just slightly at increased risk due to age, gender, radiation exposure or other treatment-related risks. Understanding your risk, surveillance strategies, and follow-up is a shared responsibility between you, your primary care provider and your cancer care team.

Questions to ask your primary care provider*:

1. Did my cancer care team share with you my current risk assessment for specific cancers, types of cancer screening and frequency, and prevention strategies that are best for me? If not, here is a copy of my plan.

2. Are there other cancer screenings that I should have based on my age, gender, and exposures? (examples include colonoscopy, skin cancer screening, mammogram, MRI)

3. Who will continue to order my cancer screenings going forward? Will you let my cancer care team know?

Questions to ask your cancer care team*:

1. Based on my family history, genetic status, cancer type and treatment, am I more at risk of developing certain cancers?

2. What screenings (type and frequency) or preventive strategies are best for me and my level of risk? (examples include colonoscopy, skin cancer screening, mammogram, MRI, diet and exercise, stop smoking)

3. Will you order these tests for me or should my primary care provider do so? Will you let him/her know?

4. Do I qualify for genetic testing? If I had genetic testing, are there any update tests that are appropriate for me or my family?

*Please note that you are ultimately the link between your primary care provider, cancer care teams, and other specialists. You might have to help facilitate communication among everyone. Always remember that you are your best advocate!

HEALTHY BEHAVIORS AND LIFESTYLE

Every cancer survivor has room for improvement when it comes to healthy behaviors and lifestyle. This may include weight loss, managing your psychosocial health, stopping smoking, and/or wearing sunscreen, to name a few.

To improve long-term health and enhance survival it is recommended that cancer survivors:

- Keep a healthy body weight throughout life.¹⁴
- Move more and sit less. Engage in at least 150-300 minutes of moderate-intensity physical activity each week.¹⁴
- Follow a healthy eating plan that includes more vegetables, fruit, and whole grains, and less processed foods, red meat, and added sugars.¹⁴
- Limit alcohol intake. It's best not to drink alcohol but when you do limit it to 1 drink per day for women and 2 drinks per day for men.¹⁴

Questions to ask your primary care provider:

1. Based on my health status, how much should I be exercising? What types of exercise are best for me?

2. What is the recommended amount of sleep for someone like me?

3. What is the best strategy or plan to improve my diet?

4. Have you received information from my cancer care team on specific lifestyle recommendations based on my cancer diagnosis and treatment?

5. Would meeting with a specialist be helpful in addressing my lifestyle? (examples may include dietician, psychologist/social worker, cancer certified exercise specialists, cancer rehab)

6. Will you let my cancer care team know my risks? Will you or my cancer care team refer me?

Questions to ask your cancer care team:

1. Due to my type of cancer and treatment, do I have any limitations for incorporating lifestyle changes (diet and exercise) into my daily routine? (An example might include having lymph nodes removed and precautions with certain types of exercise.)

2. Would meeting with a specialist be helpful in addressing my lifestyle? (Examples may include dietician, psychologist/social worker, cancer certified exercise specialists, cancer rehab.)

3. Will you let my primary care provider know my risks? Will you or my primary care team refer me?

MANAGING MY COMORBID HEALTH CONDITIONS

Based on your unique healthcare needs, you may have or be at increased risk for other common chronic diseases (diabetes, cardiovascular disease, hypertension, obesity, elevated cholesterol, decreased bone mineral density, genetic risk, etc.). It is important to know what your risks are and how your cancer diagnosis, treatment, and family history may increase this risk. Understanding your risks and management strategies is a shared responsibility between you, your primary care provider and your cancer care team.

Questions to ask your primary care provider:

1. Based on my risks and/or comorbid conditions, what types of follow-up or preventive strategies are recommended?

2. Do I need to see a specialist?

3. Who will order or manage my follow-up care? Have you communicated this with my cancer care team?

Questions to ask your cancer care team:

1. Have my diagnosis and treatment increased my risk for other comorbid conditions?

2. Are there any specific follow-up recommendations based on my risk*?

3. Do I need to see a specialist?

4. Who will order or manage my follow-up care? Have you communicated this with my primary care team?

*Genetic testing is recommended for many types of cancers, even if you are a cancer survivor. Genetic testing is constantly changing as researchers learn more information about the human genome.

Even if you had cancer many years ago, if you meet criteria for genetic testing, you should consider it to inform your risk as well as to inform your family members of their risk.

If you had genetic testing before 2014, talk with your cancer care team to see if updated genetic testing is needed.



THE MAINTENANCE LOG

CORE CATEGORY	TOPICS FOR DISCUSSION WITH MY PCP
Monitoring for recurrence	<ul style="list-style-type: none"> • Who is primarily responsible for monitoring possible recurrences? My oncologist? My PCP? Is it someone within the oncology team? • Are you receiving records/test results from my oncologist? • Have you received a Survivorship Care Plan from my oncologist's office? • What steps should I take at home to self-monitor for recurrence? • What symptoms should I be watching for?
Management of late/long-term effects	<ul style="list-style-type: none"> • Who is primarily responsible for helping me manage my late/long-term effects? My oncologist? My PCP? Do they communicate with each other? • What steps should I take independently to manage my late/long-term symptoms? • Are there symptoms you're aware of that I should be watching for? • What can you tell me about which side effects to expect? • Could symptom X,Y, or Z be from cancer treatment? • I'm feeling anxious. What can I do?
Surveillance for secondary cancers	<ul style="list-style-type: none"> • Who is primarily responsible for helping me with surveillance for secondary cancers? My oncologist? My PCP? Do they communicate with each other? • Are there new recommendations for follow up? • Do my cancer history and treatment affect the possibility of second cancers? • What symptoms should I be watching for?
Addressing preventive care / Lifestyle interventions	<ul style="list-style-type: none"> • In general, are my current lifestyle choices healthy? • How is my diet? • Am I exercising enough? • What are other ways I can change my everyday lifestyle, even in small ways, to improve my overall health and decrease my chances of secondary cancer?
Managing comorbidities*	<ul style="list-style-type: none"> • Who is responsible for helping me manage my comorbidities*? • What resources can I access for help with managing comorbidities? • What can I do on my own to manage comorbidities? • Am I happy? Do I have any emotional or psychological concerns? • Are my relationships with coworkers, friends, and family healthy? • Is intimacy with my partner a problem? • Who should I see to address any of these concerns? • What can I do on my own to address these concerns?

*Comorbidities encompass any physical, psychosocial, or sexual health issues you may have. Don't be afraid to ask about any of these issues, as they are important in addressing your overall health.



GOING THE EXTRA MILES:
S.M.A.R.T. GOAL SETTING



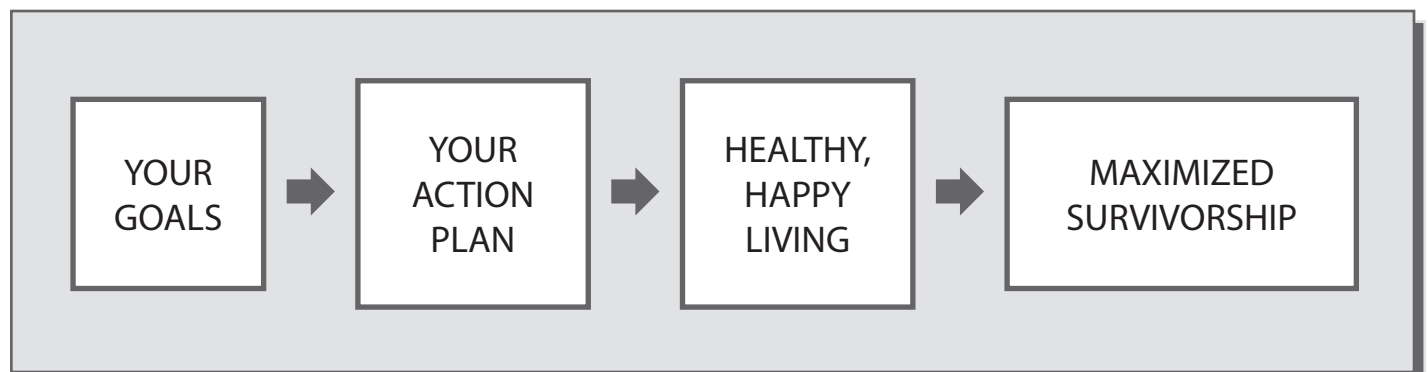
WHAT IS THE POINT OF MAKING GOALS?

The best way to maximize survivorship is through healthy living. Goal setting can be the basis from which you can improve your lifestyle habits and overall health. We encourage you to make goals because we believe they will help you live a healthier and happier life.

The previous sections of the manual have provided a lot of information on what to expect in cancer survivorship and how to deal with potential complications. You may feel overwhelmed by all the recommendations. Remember, cancer survivorship is a lifelong process. There may be some lifestyle changes, even small ones that will be important for maximizing your health.

Change can be hard, but working with your care team and utilizing available resources can help make these changes manageable.

“Going the Extra Miles: Goal Setting” provides guidelines to help you, with the assistance of your care team and caregivers, to create goals that can work for you. Goals can be anything from increasing your exercise, working towards or maintaining a healthy weight, increasing your fruit and vegetable intake, addressing your psychosocial well-being, wearing sunscreen on a regular basis, keeping appointments with your care team, or taking medications as instructed. Your goals can be about more than your physical or medical issues. Set your own personal goals.



S.M.A.R.T. GOALS

The S.M.A.R.T. goal method is a way of creating goals that are reasonable and achievable as opposed to those that are unrealistic or undefined.

S.M.A.R.T. stands for:

Specific

Goals that are clearly defined.

Measurable

Goals for which you can measure progress.

Achievable

Goals that are reasonably attainable.

Results-focused

Goals focused on achieving some desirable end.

Time-bound

Goals clearly defined within a certain time-frame.

You might say, "My goal is to exercise more." While an important goal, it is too vague. There is no way of determining if the goal has been met because it doesn't follow the guidelines of being specific, measurable, achievable, results-focused, and time-bound.

Setting S.M.A.R.T. goals will help you reach your goals:

Specific: Goals should be straightforward and focused on a specific behavior. Your goals should clearly define what you are going to do. Your goal should answer, "What? When? How Much?"

Example: A general goal would be, "I will get in shape," while a specific goal would be, "I will walk 30 minutes 3 days a week."

Measurable: You should be able to measure your progress as you stay on track toward reaching your goals. If your goal is measurable, you should be able to answer, "How much? How many? When will

the goal be reached?" Example: If your goal is to walk 30 minutes three days a week, you can keep track of your physical activity minutes using the weekly exercise charts provided in the binder.
Attainable: The best goals require you to stretch yourself a bit, but they aren't so extreme that you will give up. Example: Setting a goal of exercising 60 minutes five days a week when you haven't been exercising at all may be too extreme. Instead, set a smaller goal of 30 minutes three days a week. As you reach smaller goals, you can slowly work up to the larger goal.

Realistic: Your goal is probably realistic if you actually believe it can be achieved. It should be something that you are both willing and able to do. Only you can decide if your goal is realistic. Example: A goal of never again eating sweets may not be realistic for someone who really enjoys cake, cookies and ice cream. Instead, set a goal of eating fruit in place of one sweet each day.

Time-bound: If you don't have a set time for reaching your goal, you will be tempted to postpone working on it. It's important to have both short-term (daily or weekly) and long-term (monthly or yearly) goals. Example: Instead of saying, "I am going to eat more fruits and vegetables," say, "I am going to eat five servings of fruits and vegetables every day starting tomorrow."

Here's another example of a goal that is not specific: "My goal is to lose some weight."

Here is a S.M.A.R.T. version of the goal:

- "My goal is to lose 10 pounds by the end of next month by riding my bike twice a week, taking the stairs instead of the elevator, and not eating seconds at dinner."



WHY USE THE S.M.A.R.T. GOALS APPROACH?

The S.M.A.R.T. goals approach provides accountability by making goals realistic and achievable. Often, people take an “all or nothing” approach to goal setting. A survivor might make an unrealistic exercise goal of working out for at least an hour everyday, 365 days a year. This survivor, realizing he or she will never be able to do that, will likely become discouraged and give up. Unattainable, undefined, and unreasonable goals discourage people from taking even small steps. The S.M.A.R.T. goal approach encourages survivors to take consistent small steps towards living a healthier life.

You are your most important asset. Take care of yourself as you do those you love.

~Joy Batt

Your goals will be unique to your situation, and that’s the way they should be! Take the time to make effective goals for yourself and do your best to stay accountable to these goals and begin to live a healthier life.

In the next section of the manual, you will use your S.M.A.R.T. goals to create an action plan for healthier living. Action plan tools will help you keep track of your provider’s recommendations and your goals. We hope these tools will help you successfully describe and implement life goals.





ACTION PLAN TEMPLATE: USING S.M.A.R.T. GOALS TO TAKE ACTION

MAKING AN ACTION PLAN PART OF YOUR LIFE

This section focuses on setting priorities and creating an action plan. The following list gives examples of different areas that you may choose to focus on. It's important to prioritize so that you don't get overwhelmed. During visits, your doctor will likely give you a lot of information on how to manage your cancer-related medical issues. Information can include different surveillance measures, ways to manage late/long-term effects, and important lifestyle recommendations about diet or exercise. You may need a system, or plan, to help you keep track of all of the information.

An action plan has two purposes:

1. To help you keep track of recommendations and information shared by your PCP and health team.
2. To serve as a means for achieving healthy living and maximizing survivorship using S.M.A.R.T. goals as a starting point.

Filling out an action plan with your provider can help to organize steps you can take to live a healthier life while facilitating conversations and relationship-building at the same time.

Use the action plan template tool on page 69 to organize the general recommendations of your care team along with your own S.M.A.R.T. goals.

CREATING YOUR ACTION PLAN

There are two different parts of the action plan template. In the first part, you'll find various lifestyle topics that suggest action areas to improve your health. In each of these areas, there



are examples and a spot for you to fill in your own goals. Think of the first part of the action plan template as a "menu" for lifestyle improvements. There are many different options and routes you can take towards improved health.

In the second part, you can specify action steps that you will take to achieve your goals and details about how you will track progress.

Complete both parts. The first part will help you keep track of your provider's recommendations and your goals. The second part will help you keep track of the details of each goal.

DON'T BE OVERWHELMED

You don't have to make a goal in each lifestyle category. Different categories are provided to give you choices. Remember, improving your health will require many small steps. We suggest you try to set three goals - two that you set and one that your PCP or caregiver helps you create.

You may have your own action plan method and should use whatever works best. Making goals and implementing them into your life is the intent,

and the process will come in different forms for different people. Create your own system of goal setting and action planning if you feel it will help you improve your lifestyle habits.



PRIMARY CARE PROVIDERS

Take the time to work with patients on completing a comprehensive action plan. Doing it together will help them engage in their care decisions and give them guidelines for improving their health. Encourage survivors to be accountable to the recommendations defined in the action plan.



CAREGIVERS

If you are attending appointments with survivors, take part in helping to create their action plan. Your input as an invested third party is valuable. Additionally, help survivors review the action plan once they return home. Ask them how you can help them implement their action plan and get into a new routine after they finish treatment. It can be hard to find a way back to old routines or to make new ones, and support from caregivers can be helpful.



ACTION PLAN TEMPLATE TOOL

LIFESTYLE CATEGORY	EXAMPLES OF ACTION PLAN GOALS (WHAT CAN YOU DO TO IMPROVE YOUR HEALTH?)	ACTION (WHAT GOALS HAVE YOU CREATED?)
Management of Late/ Long-Term Effects	I will sleep at least eight hours each night to manage fatigue.	
Management of Comorbidities	I will try to monitor and manage my blood pressure with a home blood pressure kit.	
Nutrition	I will eat more vegetables. I will drink fewer sugar-sweetened beverages.	
Fitness	I will try to exercise four days a week for 30 minutes.	
Psychosocial Health	I will talk to a counselor about my anxiety.	
Sleep Management	I will sleep at least eight hours each night to manage fatigue.	
Spiritual Health	I will have lunch with my spiritual leader to talk about my cancer survivorship.	
Social Support	I will attend a support group for long-term cancer survivors.	
Smoking/tobacco cessation	I will use the next six months to quit smoking.	
Alcohol/ substance use	I will try to minimize my alcohol consumption to a drink or less each day.	

MY STEPS FOR ACTION

Note: This action plan template was adapted from the WIN Patient booklet intervention.

Identify what goals are most important to you and your overall health. We suggest working with your primary care provider, caregivers, and other trusted family and friends to track goals over time. Make sure to develop specific steps to achieve your goals and discuss ways to overcome barriers.

EXAMPLE: I will eat more vegetables.

How important is this goal to me? 1 2 3 4 5 6 7 8 9 10

How confident am I that I can achieve this goal? 1 2 3 4 5 6 7 8 9 10

Challenges or hurdles: I often forget to eat vegetables because I eat at restaurants and fast food frequently.

Action steps to make the goal happen:

I will cook dinner more often and eat a mixed green salad with dinner four times per week.

I will eat baby carrots, celery, and/or broccoli for snacks three times per week.

Goal A: _____

How important is this goal to me? 1 2 3 4 5 6 7 8 9 10

How confident am I that I can achieve this goal? 1 2 3 4 5 6 7 8 9 10

What are my challenges or hurdles?

1) _____

2) _____

3) _____

Action steps to make this goal happen:

1) _____

2) _____

3) _____

MY STEPS FOR ACTION

Goal B: _____

How important is this goal to me? 1 2 3 4 5 6 7 8 9 10

How confident am I that I can achieve this goal? 1 2 3 4 5 6 7 8 9 10

What are my challenges or hurdles?

1) _____

2) _____

3) _____

Action steps to make this goal happen:

1) _____

2) _____

3) _____

Goal C: _____

How important is this goal to me? 1 2 3 4 5 6 7 8 9 10

How confident am I that I can achieve this goal? 1 2 3 4 5 6 7 8 9 10

What are my challenges or hurdles?

1) _____

2) _____

3) _____

Action steps to make this goal happen:

1) _____

2) _____

3) _____

MY STEPS FOR ACTION

My plans to track progress:

1) _____

2) _____

3) _____

The action plan pit crew: who will keep me accountable to my goals?



SURVIVORSHIP CARE PLANS (SCPs)

WHAT ARE SURVIVORSHIP CARE PLANS (SCPs)

Doctors are increasingly required by hospitals and cancer centers to provide survivorship care plans (SCPs), which include a summary of treatment, a review of possible late effects, and a schedule of recommendations. Your SCP will address your personal cancer survivorship needs based on your specific “series, make, and model” of cancer.

Survivorship care plans help both survivors and primary care teams track cancer history details and serve as a starting point for long-term follow-up.

It is very important that you have an SCP and make sure your PCP gets a copy. He or she will use this information as a roadmap in order to provide you with the best possible long-term cancer survivorship care.

SURVIVORSHIP CARE PLANS ARE NOT PERFECT

Survivorship care plans are rarely uniform from hospital to hospital, and they vary in length. It may be helpful to review and update your SCP periodically as changes arise or if you are on extended treatment for your cancer. Your SCP will be most helpful if it is used with other survivorship resources - like this iSURVIVE manual. Bring your SCP and manual to your appointments to help build a stronger relationship between you and your care team.

INFORMATION TO LOOK FOR IN AN SCP

Survivorship care plans should contain certain pieces of information including:

- Diagnosis
- Dates of diagnosis and end of treatment

- Summary of treatment (surgery, type and cumulative dose of chemotherapy, immunotherapy, radiation therapy)
- Recommendations for follow-up visits and evidence-based screening and testing
- Potential late effects of treatment and management
- Other preventive screenings and recommendations
- Resources

A sample treatment summary can be found on page 78.

A DEEPER LOOK INTO PARTS OF THE SCP

Resources

The SCP will often include resource information about specialists. Survivors can use the contacts provided or can ask their oncologist, PCP, or care team members for additional contacts such as psychologists, spiritual leaders, and financial counselors.

Comorbidities and lifestyle interventions

The SCP includes additional lifestyle recommendations that may be cancer-specific recommendations or independent of your cancer. Addressing comorbidities (diseases or conditions that coexist with a primary disease) or unhealthy lifestyle habits may decrease risk for late or long term effects. National experts and organizations have summarized lifestyle recommendations, which can be personalized by your care team. Maintenance logs and S.M.A.R.T. goal-oriented action plans will also help with applying recommendations to unique situations.



The Masonic Cancer Alliance (MCA), the outreach network of The University of Kansas Cancer Center, serves the entire state of Kansas and western Missouri. MCA has staff that can provide various support and resources to cancer survivors.

If you are interested in learning more about how MCA can assist you in your survivorship journey, please contact MCA via email at **kucc-mca@kumc.edu** or by phone at **1.877.253.4477**.

Psychosocial well-being

Addressing psychosocial concerns requires open dialogue between a survivor and their care team. During times of transition, such as completion of initial treatment, you may experience more psychosocial concerns. Take the initiative and bring up any concerns with your care team.

The care team

The example SCPs summarize the care team. Survivors are rarely alone on the roads of survivorship.

WHAT IF YOU DO NOT HAVE AN SCP?

You may not have an SCP for a number of reasons. Perhaps you finished your treatment phase before SCPs were widely used and standard of care in practice. If you don't have one, talk to your oncologist about creating one for you (see blank template on page 81).

You or your oncologist can also use one of several templates available for creating your SCP. In order to develop the most accurate plan of care, you may need to talk to your cancer care team or collect your medical records to have some details of your cancer therapy.



PRIMARY CARE PROVIDERS

Many hospitals and practices have started delivering the SCP to meet new national accreditation standards by the American College of Surgeons and other accrediting agencies. Despite this emerging standard, there may be inconsistencies in the appearance and delivery of SCPs. However, they may be helpful for coordinating care between oncologists and PCPs and have the potential to be an important resource for patients.

Contact your patient's cancer care team to coordinate shared care, and ask for their SCP or for one to be created (see blank template on page 81).

Psychosocial concerns may not be emphasized in an SCP. Assess your patient's current psychosocial status.



EXAMPLE OF A CANCER TREATMENT SUMMARY

Cancer Treatment Summary

Provided by Kristin Leonardi-Warren RN CNS on 4/13/2014

General Information

Patient Name:	Joe
Patient ID:	1111111
Phone:	
Date of Birth:	1/1/1990
Age:	24
Support Contact:	

Care Team

Medical Oncologist:	Onc Ology, MD, Children's Hospital
Surgeon:	N/A
Radiation Oncologist:	Brad Onc, MD
Primary Care Physician:	John Smith, MD

Cancer Diagnosis Information

Diagnosis	Hodgkin's Lymphoma
Diagnosis date:	2002
Staging Information:	Stage II
Tumor Markers:	
Molecular Markers:	
Tumor type/histology/grade:	
Additional Comments:	Received blood products

Background Information

Family history/predisposing conditions:	@FAMCANCERHX@
Major co-morbid conditions:	@PROB@
Tobacco use:	Yes; 1 pack per day of cigarettes
Alcohol use:	Yes; occasional
Genetic Counseling/Screening:	Not indicated
Genetic Test Results:	Not indicated

Treatment Summary				
Cancer Surgery Information				
Date of Surgery:	6/1/2002			
Surgical procedure:	Excisional biopsy of lymph node			
Surgical location:	left supraclavicular area			
Surgical Findings:	Nodular sclerosing Hodgkin's lymphoma			
Additional Comments:	N/A			
Medication Therapy				
Chemotherapy /Biologic Drug name	Dose	Route	# of Cycles Administered	Cumulative dose
Cyclophosphamide	600 mg/m ²	IV	4	2.4 mg/m ²
Vincristine	1.4 mg/m ²	IV	4	Not indicated
Procarbazine	100 mg/m ²	PO	4	2.8 g/m ²
Doxorubicin	35 mg/m ²	IV	4	140 mg/m ²
Bleomycin	10 units/m ²	IV	4	40 units/m ²
Prednisone		IV/PO	4	N/A
Start Date:	6/5/2002			
End Date:	10/2002			
Dose Reduction?	no			
Treatment Goal:	Curative			
Treatment on Clinical Trial?	No			
Radiation Therapy				
Radiation Therapy:	Total dose: 2100 cGy Site: neck and mantle			

Survivorship Care Plan:

Below is a summary of our recommendations from your visit. These recommendations are based on the most currently available Children's Oncology Group (COG) and United States Preventative Services Task Force (USPSTF) guidelines. Please share this with your primary care provider(s) and any other health care providers of your choosing.

Cancer Survivorship/Late Effects

- Anthracyclines can lead to heart dysfunction and can lead to coronary artery disease (CAD). Per review of your records, you were exposed to Doxorubicin at a dose totaling 140 mg/m². As this is a low dose but combined with chest radiation, we recommend a baseline echocardiogram and B-type natriuretic peptide (BNP) level, followed by an echocardiogram every 2 years. Pending the results of this initial study, further cardiac recommendations should be made. If abnormalities are noted, consultation with a cardiologist is recommended.
- Additionally we recommend you avoid heavy lifting or other isometric exercises that place extra strain upon your heart. Pregnancy can precipitate decompensation.
- Alkylating agents can result in secondary leukemias up to 15 years following their administration. As a 12 year survivor, your risk of secondary leukemia is slightly elevated; a complete blood count was done at the time of your visit and was normal. This should be repeated annually for another 5 years
- Alkylating agents are known to have potential ill effects on spermatogenesis. Your total cyclophosphamide dose was 4.8 g/m², leaving your long term risk of infertility slightly elevated. We would recommend a semen analysis when you are ready to explore fertility. In the meantime, if you

are sexually active and not ready to father a child, you should assume you are fertile and use proper precautions. Dr. X is a fertility specialist who works primarily with patients who have been through cancer treatment. Her office phone is xxx-xxx-xxxx.

- You received bleomycin at a total dose of 40 units /m². Bleomycin can increase the risk for fibrosis or scarring in the lungs. You should have a yearly lung exam. Additionally, due to the fact that high oxygen exposure can worsen this risk, you should seek pulmonary consultation prior to any surgery in which general anesthesia or any activity such as scuba diving is planned. If you should experience any shortness of breath or respiratory changes, you should see your primary care provider for a pulmonary referral.
- Treatment with steroids can increase your future risk for osteoporosis, which can in turn increase your risk for bone fractures. You received Prednisone and therefore you should have a baseline bone density evaluation to determine if you have any bone thinning. You should also discuss therapies that can potentially help to reduce your risk for osteoporosis or treatment for osteoporosis with your adult primary care provider.
- Because you received corticosteroid therapy your risk for cataracts could be increased. You should have a yearly eye exam.
- As skin cancers are more common in childhood cancer survivors, we encourage you to perform monthly skin checks and consider a baseline evaluation by a dermatologist. Additionally we highly encourage you to use sunscreen of SPF 30 or greater and to reapply frequently.

General Health Maintenance/Preventive

- Current recommendations for routine reproductive health include monthly self-testicular exams.
- We encourage you to keep up to date with your immunizations, which include yearly influenza vaccination and a tetanus booster every 10 years.
- We strongly encourage initiation of an aerobic exercise regimen of at least 30 minutes at a time 3-5 times a week. Walking is a very acceptable and inexpensive form of exercise which we urge you to consider.
- We want to emphasize the importance of smoking cessation as an important component of improving your overall health, this includes all kinds of smoking.
- We recommend a baseline screen for diabetes with a fasting blood glucose, and a fasting lipid profile to evaluate cardiac risk factors.
- We recommend avoidance of excessive alcohol. No more than 1 to 2 alcoholic drinks per day.
- Furthermore, we reiterate the benefits of weight management on long-term health. A healthy BMI is between 19 and 24; your BMI is 22.5.

Mental Health/Well-Being

- Overall, you appear to be coping well with your status as a pediatric cancer survivor. We have no further specific recommendations for you at this time.

We encourage you to share this letter with your primary care provider(s) and any other providers of your healthcare to assist in following these recommendations.

Sincerely,

Dr. Onc Ology

BLANK TEMPLATE FOR A CANCER TREATMENT SUMMARY (SHARE WITH YOUR PROVIDERS)

Cancer Treatment Summary

General Information

Patient Name:	
Patient ID:	
Phone:	
Date of Birth:	
Age:	
Support Contact:	

Care Team

Medical Oncologist:	
Surgeon:	
Radiation Oncologist:	
Primary Care Physician:	

Cancer Diagnosis Information

Diagnosis	
Diagnosis date:	
Staging Information:	
Tumor Markers:	
Molecular Markers:	
Tumor type/histology/grade:	
Additional Comments:	

Background Information

Family history/predisposing conditions:	
Major co-morbid conditions:	
Tobacco use:	
Alcohol use:	
Genetic Counseling/Screening:	
Genetic Test Results:	

Treatment Summary Cancer Surgery Information				
Date of Surgery:				
Surgical procedure:				
Surgical location:				
Surgical Findings:				
Additional Comments:				
Medication Therapy				
Chemotherapy /Biologic Drug name	Dose	Route	# of Cycles Administered	Cumulative dose
Start Date:				
End Date:				
Dose Reduction?				
Treatment Goal:				
Treatment on Clinical Trial?				
Radiation Therapy				
Radiation Therapy:				

Survivorship Care Plan:

Below is a summary of our recommendations from your visit. These recommendations are based on the most currently available guidelines from _____.
Please share this with your primary care provider(s) and any other health care providers of your choosing.

Cancer Survivorship/Late Effects

General Health Maintenance/Preventive

Mental Health/Well-Being

Care Team Members:



PIT STOPS AND PASSENGERS: LEARNING TO TALK ABOUT CANCER

PEOPLE ARE NATURALLY CURIOUS

You may encounter people along your cancer journey who are curious about your story. For those who have never had cancer, it can be a scary, complex, and confusing topic. People may ask some inappropriate or awkward questions or start intrusive conversations about your cancer survivorship experience. Here are a few examples:

- “Is cancer contagious?”
- “So, what’s your prognosis?”
- “Is it genetic?”
- “Have you tried yoga? I hear it’s great for preventing cancer.”

CANCER SURVIVORSHIP CONVERSATIONS

You are empowered to take ownership of your journey by preparing to talk about cancer on your own terms. This does not mean you have to discuss your experience. Your willingness to talk about your cancer experience might even vary from day to day.

Because you are the survivor and expert navigator of the roads of cancer survivorship, you have the power to drive the conversation. Maybe you are comfortable describing your entire experience. Or maybe you don’t want to talk about it at all. Either end of this spectrum - and everything in-between - is okay.

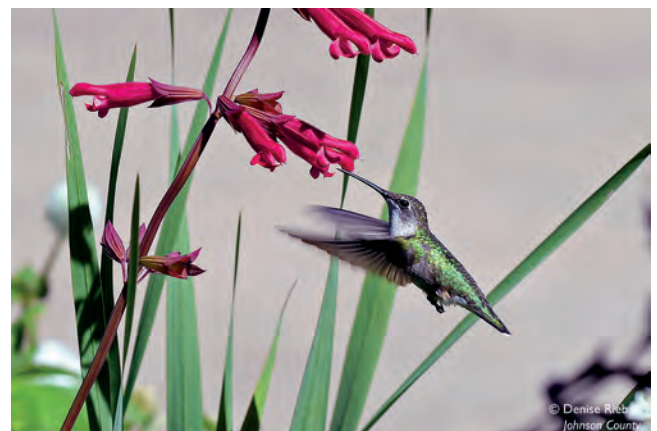
SUGGESTIONS FOR TALKING ABOUT CANCER

- Talk things out with family members and close friends. Practice conversations that you might have with acquaintances and colleagues.

Everyone’s treatment and survivorship is their own journey. There are commonalities, but journeys are unique.

~Fred Crawford

- Get help from counselors or other professionals.
- Attend support groups or reach out to other survivors.
- Write and practice a short “elevator speech” version of your survivorship journey.
- Delegate a caregiver to be your “cancer assistant.” That person can share information through Facebook or patient journey websites like CaringBridge (<https://www.caringbridge.org>) or he/she can set up a phone tree to share information you want friends and family to know.



PRACTICING YOUR SURVIVORSHIP

“SHORT STORY”

During and post-treatment, many survivors have difficulty answering questions like, “How are you?” or, “Are you okay?” Family members and friends who are not as familiar with your cancer experience may not know other questions to ask. You may feel like telling them all the details of your survivorship journey, or you may choose to keep them private. Instead of treatment specifics, they probably want to know how you are coping and how they can support you.

Think through and practice a short version of your story that has minimal treatment and care details and includes information about how you are doing and help you might need.



CAREGIVERS

While talking about their experience can be a healthy activity for survivors, it can be difficult and may not be appropriate for everyone. Instead of “scripting” what to talk about and how, encourage loved ones to talk about cancer in whatever way feels helpful and healthy. Support them in talking about cancer on their own terms and help prepare them for insensitive questions.

Hints for talking about cancer with survivors:

Ask open-ended questions.

Open-ended questions will give survivors a chance to express how they are feeling and coping. Many survivors are reluctant to share feelings; asking open-ended questions can help them do so.

Ultimately, as a cancer survivor, you don't really remember what people said, you just remember that they were there.

~Fred Crawford

Listen.

Listening goes hand in hand with the first helpful hint. If you prompt survivors with an open-ended question, you must actively listen and receive their feelings and thoughts. Allowing survivors to talk through things as you listen closely can help improve their emotional and psychosocial health.

Don't make assumptions.

Everybody is different, and the way each individual copes with cancer survivorship will be unique. Don't jump to conclusions; instead, allow survivors to explain how they feel.

Offer to coordinate communication and outreach.

Friends and family want to provide support but might need a little direction. As a caregiver, work with “your” cancer survivor to get a list of whom he/she wants to stay in touch with and what information he/she wishes to share. Set up a phone tree or web-based patient journey page (Facebook or www.caringbridge.org) and keep this information updated. Set up a sign-up for meals, rides (for the survivor or his/her children), running errands, etc. This allows friends and family to help and stay engaged.



CONNECTING SURVIVORSHIP
JOURNEYS: COMMUNITY NETWORKING

PATIENT NAVIGATORS

A patient navigator is a professional or lay health worker who helps survivors connect to providers and resources. They can be an excellent resource in navigating the cancer journey and the health care system.

Not sure whether you should have additional follow-up visits or if your fatigue is cancer-related? Or maybe you have questions related to insurance or billing. Patient navigators can advise you about whether or not you should consult the care team. Patient navigators can help survivors sift through information and navigate sometimes complex and confusing systems.

CONNECTING TO PATIENT NAVIGATION NETWORKS

Soon after your diagnosis, you may have been connected to a patient navigator. Patient navigators are particularly helpful during the first stage of survivorship, when survivors must cope with a new diagnosis and prepare for their treatment plan. However, survivors can seek help from patient navigators during any part of the survivorship journey.

Cancer survivors in your community may also be helpful in pointing you in the right direction and connecting you with additional resources. Community-level networks are informal, and you may need to ask around to get in contact with navigators in your area. However, once you have connected with the right people, you will likely find that community members are very welcoming and want to support you across your journey.

In our community, you can almost always find someone who has gone through the same thing a new cancer survivor is navigating. In this way, long-term cancer survivors can serve as a helpful and insightful resource to newer survivors.

~Verleen Karney

BECOMING A CANCER SURVIVORSHIP CHAMPION

If you are a long-term cancer survivor, you may want to give back by helping others through their journey. If you are comfortable playing this role, you have an opportunity to smooth the roads of someone else's survivorship journey.

If a peer mentor network already exists in your community, you can connect and contribute. If a peer mentor network doesn't exist in your community, maybe it's time to get the ball rolling. As a long-term survivor, you have the opportunity to serve as an important resource and give back to your community. Because you are a champion of cancer survivorship, community members will respect and seek your advice. For cancer patients still in treatment, you are a beacon of hope. If you are comfortable talking about survivorship, allow your care team to share your contact information as a survivorship resource.



PRIMARY CARE PROVIDERS

You can be a guiding intermediary who helps connect patients with peer navigation networks. Some patients may actively tell you to give out their contact information to new survivors. You may know of others who are outspoken survivors in the community who would obviously be open to providing assistance. You can even ask patients if they would be willing to allow you to give out their contact information to other survivors.

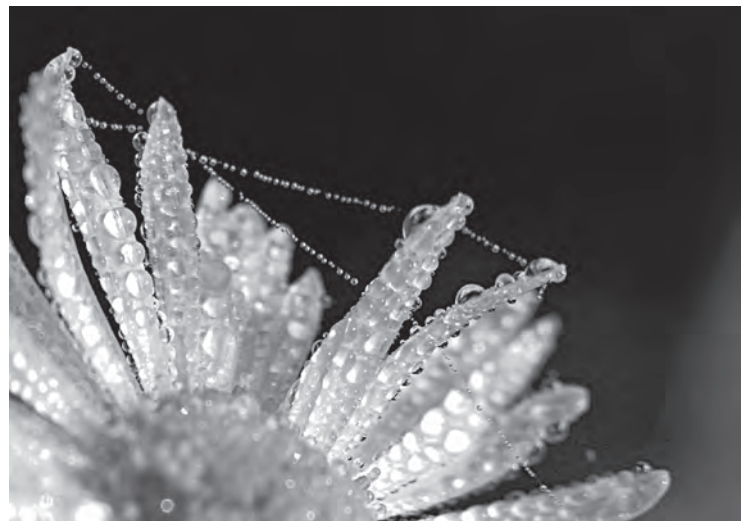


CAREGIVERS

As a caregiver of a cancer survivor, you undoubtedly know a lot about cancer and the different stages of the survivorship process. Just like your survivor, you could be a very helpful resource to a newer survivor and his/her family and friends. Just like your survivor, you are capable of being a local cancer survivorship resource and further contributing to a patient navigation community network. Your perspective as an experienced caregiver is very valuable.

Community navigators have a calm, empathetic demeanor that a primary care provider and the speed of his/her office may not be able to provide.

~ JC Carrica





RESOURCES

RESOURCES

RESOURCE	URL
American Cancer Society	http://www.cancer.org/
Guidelines	National Comprehensive Cancer Network: https://www.nccn.org/patientresources/patient-resources/guidelines-for-patients Children’s Oncology Group Long-Term Follow-Up: http://www.survivorshipguidelines.org/
Kansas Cancer Partnership	https://www.kscancerpartnership.org/resources/
Triage Cancer Webinars	http://tragecancer.org <i>Resources and webinars with help for practical, legal and financial issues impacting people beyond diagnosis</i>
National Cancer Center Institute	https://cancercontrol.cancer.gov/ocs/resources/survivors
American Society of Clinical Oncology Survivorship Care Compendium	https://old-prod.asco.org/news-initiatives/current-initiatives/cancer-care-initiatives/survivorship-compendium
American Institute for Cancer Research	https://www.aicr.org <i>Great resource for physical activity and nutrition information for survivors</i>

Do You Have a Personal or Family History of Cancer?

Some people are at higher risk for cancer than others. If you know which family members have had certain cancers and the ages they were diagnosed, our genetic experts can better define your risk and the risk of your family.

Options may include more frequent screenings, preventive medications, surgery or lifestyle changes.

Use this tool to identify your risk of certain cancers. Record the number of relatives affected by each cancer type and their age at diagnosis, if possible.

Include only blood relatives.

	Breast	Colon/Colon Polyp	Uterus	Kidney	Melanoma	Ovarian/Peritoneal	Pancreas	Prostate	Stomach	Thyroid	Adrenal Gland	Brain/Spine	Eye	Skin	Age at cancer
You															
Sister(s)															
Brother(s)															
Mother's Side/Maternal															
Mother															
Aunt(s)															
Uncle(s)															
Cousin(s)															
Grandmother															
Grandfather															
Great Aunt(s)															
Great Uncle(s)															
Father's Side/Paternal															
Father															
Aunt(s)															
Uncle(s)															
Cousin(s)															
Grandmother															
Grandfather															
Great Aunt(s)															
Great Uncle(s)															
Your Children															
Daughter(s)															
Son(s)															
Your Grandchildren															
Granddaughter(s)															
Grandson(s)															

© 16010107Z

Give this completed tool to your provider, and discuss how personal and family history might influence your cancer risk and/or options for genetic testing.



GLOSSARY AND END NOTES

GLOSSARY

ACS

American Cancer Society

ANEMIA

A condition in which blood has a decreased amount of red blood cells or hemoglobin. Essentially, this lowers the ability of blood to carry oxygen within the body. Generally, symptoms of anemia are fatigue, weakness, shortness of breath, or the inability to do strenuous exercise.

BASAL CELL SKIN CANCER IN RADIATION FIELD

Radiation therapy can lead to basal cell skin cancers. These small skin cancers are not a significant issue if addressed in a timely manner.

CANCER

The uncontrolled growth of abnormal cells that can invade other organs. Oftentimes, this uncontrolled growth is caused by damage to the DNA, further resulting in the production of more abnormal cells.

CANCER NAMING

Cancer is always named for the organ/cell type where the abnormal cancerous cells started to grow. If the cancer started in the pancreas, it is called pancreatic cancer. If it started in the colon, it is called colon cancer. Categories like carcinoma, sarcoma, leukemia, lymphoma, etc. further characterize where the cancer started.

CANCER STAGING

Cancer diagnoses include a “stage.” The stage describes the degree to which the cancer has spread and helps guide treatment and predict the prognosis. Cancer can be staged anywhere from stage I to stage IV. Generally speaking, the lower the stage number, the less distant the spread and - thus - the better the diagnosis.

CARE TEAM

This includes any health care professional involved in your primary care or specialty care, including cancer care.

CAREGIVER

A close friend or family member of a cancer survivor who assists a survivor throughout their survivorship journey.

COGNITIVE DYSFUNCTION (CHEMO-BRAIN)

This is a symptom in which parts of the brain aren’t completely functioning. Some cancer therapies can harm executive decision making skills and result in minor memory loss.

COMORBIDITY

The simultaneous presence of two chronic diseases or conditions in a patient. A comorbidity is any chronic non-cancer condition that a survivor might have at any point during their survivorship journey. Late and long-term effects are comorbidities that develop during - or as a result of - cancer treatment. Conditions like diabetes or heart disease, which a survivor might have had prior to their cancer diagnosis, also count as cancer comorbidities, even if they were not side effects of the cancer treatment.

iSURVIVE

The grant through which this service manual was constructed. This manual is a patient-centered resource that supplements the resources given to providers in practice on cancer survivorship.

LATE EFFECT

A symptom that starts after therapy has been completed. It is a result of the treatment you received.

LONG-TERM EFFECT

A symptom that starts during treatment and persists. A long-term effect is one that you start experiencing during treatment as a result of the treatment. A long-term effect is one that will not go away after treatment is complete. The distinction between late and long-term is that late effects don't manifest until well after treatment.

LYMPHEDEMA

This is a condition related to the functioning of the lymphatic system. Surgery can harm lymph vessels/nodes and result in blockages or interruptions of lymph flow. When vessels or nodes don't function properly, lymph fluid builds up in abnormal amounts, resulting in swelling. This swelling generally occurs in the arms or legs. Lymphedema is often associated with surgery for breast cancer. However, many types of surgery and some radiation treatments can cause significant swelling associated with lymphedema.

METASTASIS

Cancer cells can spread throughout the body if not treated. Such cells can spread through blood, the lymph system, nerves, and direct invasion of other organs. The process of cancer spreading is called metastasis.

NCCN

National Comprehensive Cancer Network

NCI

National Cancer Institute

NEUROPATHY (COGNITIVE NEUROPATHY)

Damage to the nerves running information from the brain/spinal cord to the rest of the body. This may result in impaired muscle movement/sensation in the limbs and pain.

OSTEOPOROSIS

A disease in which bones become weak and brittle due to loss of bone density.

PRIMARY CARE PROVIDER (PCP)

The term primary care provider encompasses both physician and non-physician providers who provide care at the point of first contact. Primary care providers serve as the entry point for patients into the health care system.

PRIMARY AND SECONDARY CANCER

A primary cancer is the initial cancer with which you might be diagnosed. A secondary cancer is one that may have been caused by the treatment of a primary cancer. For example, women who receive chest radiation for lymphoma might end up being diagnosed with breast cancer as a secondary cancer.

RECURRENCE/RELAPSE

A recurrence or relapse occurs when the primary cancer returns.

REMISSION

A decrease in or disappearance of signs and symptoms of cancer.

S.M.A.R.T. GOALS

Goals that are specific, measurable, achievable, results-focused, and time-bound.

SURVIVOR

A cancer survivor is anyone who has any history of cancer starting from diagnosis until death.

SURVIVORSHIP CARE PLAN (SCP)

A report, generally compiled by your oncologist following active treatment, that outlines the specifics of your treatment, possible late and long-term effects, and general recommendations for long-term survivorship care. The SCP is a useful communication tool between oncologists and PCPs.

TUMOR

Cells in our bodies are always growing. When cell growth is out of control, it may develop into a growth known as a tumor. Tumors can be benign or malignant. Malignant tumors, or cancerous tumors, are those that spread into other tissues. Benign tumors are non-cancerous tumors.

CLINICAL TRIALS*

Clinical trials test how new medications or treatments work. Patients who participate have access to these new drugs and treatments. By joining a clinical trial, individuals can contribute to the medical knowledge that may improve their cancer care and help future patients battle the disease.

GENETIC TESTING*

Also called DNA testing, it involves examining your DNA to look for changes (mutations) in your genes that may cause illness or disease. It is frequently ordered to better understand a person's risk for developing cancer.

*Additions made with the May 2024 update.



END NOTES

iSURVIVE Kansas Service Manual Version 1 (May 2018) Updated May 2024

1. Bluethmann SM, Mariotto AB, Rowland, JH. Anticipating the “silver tsunami:” Prevalence trajectories and comorbidity burden among older cancer survivors in the United States. *Cancer Epidemiol Biomarkers Prev.* 2016;25:1029-36.
2. American Cancer Society. *Cancer Treatment and Survivorship Facts & Figures 2022-2024.* Atlanta, GA: American Cancer Society; 2022.
3. Underwood JM, Townsend JS, Stewart SL, Buchannan N, Ekwueme DU, Hawkins NA, et al. Surveillance of demographic characteristics and health behaviors among adult cancer survivors: behavioral risk factor surveillance system, United States, 2009. *MMWR CDC Surveill Summ.* 2012;61(1): 1-23.
4. Li C, Li C, Forsythe L, Lerro C, Soni A. Mental health services utilization and expenditures associated with cancer survivorship in the United States. *J Cancer Surviv.* 2015;9(1):50-8.
5. Miller KD, Siegel RL, Lin CC, Mariotto AB, Kramer JL, Rowland JH, et al. Cancer treatment and survivorship statistics, 2016. *CA Cancer J Clin.* 2016 Jul;66(4):271-89.
6. Kansas Department of Health and Environment. *Burden of Cancer in Kansas, March 2021.* <https://www.kdhe.ks.gov/DocumentCenter/View/6478/2021-Burden-of-Cancer-in-Kansas-PDF?bidId=>
7. U.S. Cancer Statistics Data Visualizations Tool, based on 2022 submission data (1999-2020): U.S. Department of Health and Human Services, Centers for Disease Control and Prevention and National Cancer Institute; <https://www.cdc.gov/cancer/dataviz>, released in November 2023.
8. Kansas Cancer Registry. *Cancer Incidence in Kansas, 1999-2014.* https://www.kumc.edu/kcr/CancerStats/01_KCR_MYR_1999%20-%202014_Intro.pdf
9. Weaver KE, Geiger AM, Lu L, Case LD. Rural-urban disparities in health status among US cancer survivors. *Cancer.* 2013 Mar 1;119(5):1050-7.
10. Andrykowski MA, Burris JL. Use of formal and informal mental health resources by cancer survivors: differences between rural and nonrural survivors and a preliminary test of the theory of planned behavior. *Psychooncology.* 2010;19(11):1148-55.
11. Andrykowski MA, Steffens RF, Bush HM, Tucker TC. Disparities in mental health outcomes among lung cancer survivors associated with ruralness of residence. *Psychooncology.* 2014;23(4):428-36.
12. Burris JL, Andrykowski MA. Disparities in mental health between rural and nonrural cancer survivors: a preliminary study. *Psychooncology.* 2010;19(6):637-45.
13. Weaver KE, Palmer N, Lu L, Case LD, Geiger AM. Rural-urban differences in health behaviors and implications for health status among US cancer survivors. *Cancer Causes Control.* 2013;24(8):1481-90.
14. Rock CL, Thomson CA, Sullivan KR, Howe CL, Kushi LH, Caan BJ, et al. American Cancer Society nutrition and physical activity guideline for cancer survivors. *CA Cancer J Clin.* 2022. <https://doi.org/10.3322/caac.21719>.
15. Gregory K, Zhao L, Felder TM, Clay-Gilmour A, Eberth JM, Murphy EA, Steck SE. Prevalence of health behaviors among cancer survivors in the United States. *J Cancer Surviv.* 2024 Jun;18(3):1042-1050. Epub 2023 Mar 18.

