

**SURVIVORSHIP CARE PLANNING:
WHAT'S NEXT IN YOUR JOURNEY**

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LEARNING OBJECTIVES

- ❖ Understand the physical, social & emotional impact of your journey, post diagnosis
- ❖ Understand the importance of follow-up care & your survivorship treatment plan
- ❖ Learn about the legal & financial impact and your rights as a survivor
- ❖ Learn how to find a survivorship program

SURVIVORSHIP-DEFINITION

Living **with, through, and beyond** a diagnosis of cancer or bone marrow failure disorder.

“Anyone who has been diagnosed with cancer from the time of diagnosis through the balance of his or her life.”
Julia H. Rowland, PhD, Director, Office of Cancer Survivorship, NCI

SEASONS OF SURVIVAL

Acute Survivorship Period of initial diagnosis & treatment	Transitional Survivorship The difficult time when celebration is blended with worry & loss as you complete treatment.	Extended Survivorship You may be living with cancer or a bone marrow failure disorder as a chronic disease or may be in remission because of ongoing treatment.	Permanent Survivorship You may be in remission & asymptomatic. Or, you may be cancer-free but not free of cancer because of chronic late & long-term health or psychosocial problems.
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Your needs may be different at different times.

SURVIVORSHIP STATISTICS

- ❖ As of January 2016, estimates include 15.5 million cancer survivors in the US
 - ❖ This represents 4.8% of the population
- ❖ This number is projected to increase by 31% to 20.3 million by 2026
- ❖ In 2016, 67% of survivors have lived 5 years or more from diagnosis, 44% 10 years or more, and 17% 20 years or more
- ❖ 62% of survivors are 65 years of age or more

<https://cancercontrol.cancer.gov/ocs/statistics/statistics.html>

COMPONENTS OF SURVIVORSHIP CARE



**SURVIVORSHIP GOAL:
PROMOTE AND MAINTAIN A HEALTHY LIFESTYLE**



DIET

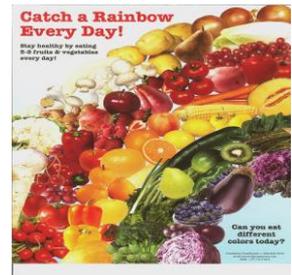
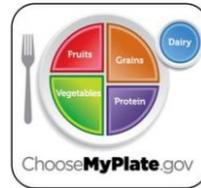
Goals:

- ❖ Maintain a healthy body weight.
- ❖ Aim for a diet high in vegetables, whole grains, fruit & low in sugars & fats.
- ❖ Limit red meat and avoid processed meats.

THE NEW AMERICAN PLATE

What you eat: Proportion

Aim for meals made up of 2/3 (or more) vegetables, fruits whole grains or beans and 1/3 (or less) animal protein.



DIET: AVOID "PORTION DISTORTION"

TURKEY SANDWICH

20 Years Ago

Today



320 calories

820 calories

Calorie Difference: 500 calories

National Heart, Lung, and Blood Institute
Obesity Education Initiative

Maintaining a Healthy Weight is a Balancing Act
Calories In = Calories Out



How long will you have to ride a bike in order to burn those extra calories?*

*Based on 160 pound person

MAINTAINING HEALTHY BODY WEIGHT

Calories In = Calories Out



If you ride a bike for 1 hour and 25 minutes, you will burn approximately 500 calories.*

*Based on 160 pound person

National Heart, Lung, and Blood Institute
Obesity Education Initiative

DIET TIPS



Limit how much processed meat and red meat you eat.

Minimize your intake of processed meats such as bacon, sausage, lunch meats, and hot dogs.

Choose fish, poultry, or beans instead of red meat (beef, pork, and lamb).

If you eat red meat, choose lean cuts and eat smaller portions.

Prepare meat, poultry, and fish by baking, broiling, or poaching rather than by frying or charbroiling.

DIET TIPS



Eat at least 2½ cups of vegetables and fruits each day.

Include vegetables and fruits at every meal and for snacks.

Eat a variety of vegetables and fruits each day.

Emphasize whole fruits and vegetables; choose 100% juice if you drink vegetable or fruit juices.

Limit your use of creamy sauces, dressings, and dips with fruits and vegetables.

DIET TIPS



Choose whole grains instead of refined grain products.

Choose whole-grain breads, pasta, and cereals (such as barley and oats) instead of breads, cereals, and pasta made from refined grains, and brown rice instead of white rice.

Limit your intake of refined carbohydrate foods, including pastries, candy, sugar-sweetened breakfast cereals, and other high-sugar foods.

DIET TIPS



Choose foods and drinks in amounts that help you get to and maintain a healthy weight.

Read food labels to become more aware of portion sizes and calories. Be aware that "low-fat" or "non-fat" does not necessarily mean "low-calorie."

Eat smaller portions when eating high-calorie foods.

Choose vegetables, whole fruit, and other low-calorie foods instead of calorie-dense foods such as French fries, potato and other chips, ice cream, donuts, and other sweets.

Limit your intake of sugar-sweetened beverages such as soft drinks, sports drinks, and fruit-flavored drinks.

When you eat away from home, be especially mindful to choose food low in calories, fat, and added sugar, and avoid eating large portion sizes.

Get Your MyPlate Plan
The MyPlate Plan shows your food group targets – what and how much to eat within your calorie allowance. Your food plan is personalized, based on your age, sex, height, weight, and physical activity level. The MyPlate Plan is also available in Spanish.



<https://www.choosemyplate.gov/MyPlatePlan>

FOOD TIPS IF YOU ARE HAVING TROUBLE EATING

- ❖ Fill the refrigerator, cupboard, and freezer with healthy foods.
- ❖ Stock up on foods that need little or no cooking, such as frozen dinners and ready-to-eat cooked foods.
- ❖ Cook foods ahead of time and freeze in meal-sized portions.
- ❖ Ask friends or family to help you shop and cook during treatment.
- ❖ Create a grocery list of items you usually buy so that it is easy for friends and family to shop for you

<https://www.cancer.gov/publications/patient-education/eatinghints.pdf>

FOOD TIPS IF YOU ARE HAVING TROUBLE EATING

- ❖ Eat small, frequent meals.
- ❖ Eat plenty of protein and calories when you can.
- ❖ Eat when you have the biggest appetite. For many people, this is in the morning.
- ❖ Eat the foods that sound good until you are able to eat more.
- ❖ Drink plenty of liquids but limit fluids at mealtime.
- ❖ Add calories and protein to meals.
- ❖ Avoid smells that make you feel sick.
- ❖ Cold foods or room temperature foods may be more appealing than hot food.

<https://www.cancer.gov/publications/patient-education/eatinghints.pdf>

ADDING CALORIES TO MEALS

- ❖ Add butter or oils to foods.
- ❖ Spread peanut butter or other nut butters — which contain protein and healthy fats — on toast, bread, apple or banana slices, crackers, or celery.
- ❖ Use croissants or biscuits to make sandwiches.
- ❖ Add powdered creamer or dry milk powder to hot cocoa, milkshakes, hot cereal, gravy, sauces, meatloaf, cream soups or puddings.
- ❖ Add sliced avocado or guacamole to salads and sandwiches.
- ❖ Add seeds, such as sunflower and pumpkin seeds, to salads, stir-fries and casseroles.
- ❖ Add ground flaxseeds to yogurt, smoothies, hot cereals and casseroles.
- ❖ Top hot cereal with brown sugar, honey, dried fruit, cream or nut butter.
- ❖ Make a shake using ice cream, fruit, whole milk.

FOOD TIPS FOR THOSE WITH A COMPROMISED IMMUNE SYSTEM



- ❖ Keep hot foods hot and cold foods cold.
- ❖ Put leftovers in the refrigerator as soon as you have finished eating.
- ❖ Scrub all raw fruits and vegetables with a brush and water before you eat them.
- ❖ Soak berries and other foods that are not easily scrubbed in water, then rinse.
- ❖ Scrub fruits and vegetable that have rough surfaces and peels, such as melons, oranges, and avocados, with a brush and water before you cut or peel them.
- ❖ Make sure your juices and milk products are pasteurized.
- ❖ Eat nuts that are shelled and roasted.

FOOD TIPS FOR THOSE WITH A COMPROMISED IMMUNE SYSTEM



- ❖ Wash your hands, knives, and counter tops before and after you prepare food. This step is most important when preparing raw meat, chicken, turkey, and fish.
- ❖ Wash your hands each time you touch raw meat, chicken, turkey, or fish.
- ❖ Use one cutting board for meat and another one for fruits and vegetables.
- ❖ Thaw meat, chicken, turkey, and fish in the refrigerator or defrost them in the microwave.
- ❖ Do not leave meat, chicken, turkey, or fish sitting out to thaw.
- ❖ Cook meat, chicken, turkey, and eggs thoroughly. Eggs should be hard, not runny. Meats should not have any pink inside. To be sure meat, chicken, turkey, and fish is safe, use a meat thermometer and cook to the safe temperature.

FOOD TIPS FOR THOSE WITH COMPROMISED IMMUNE SYSTEM

- ❖ Do not eat raw fish or shellfish, such as sushi and uncooked oysters.
- ❖ Do not eat raw nuts.
- ❖ Do not use foods, condiments, or drinks that are past their freshness date.
- ❖ Do not buy foods from bulk bins.
- ❖ Do not eat at buffets, salad bars, or self-service restaurants.
- ❖ Do not eat foods that show signs of mold, including moldy cheeses such as bleu cheese and Roquefort.
- ❖ Do not eat any perishable foods that have been sitting at room temperature longer than 2 hours.
- ❖ Do not eat leftovers that have been in the refrigerator longer than 3 days.

DIET



- ❖ Routine use of dietary supplements is not recommended for cancer/disease control
- ❖ Talk to a healthcare provider before taking dietary supplements

MAINTAIN A HEALTHY LIFESTYLE

- ❖ Avoid tobacco products
- ❖ Limit alcohol intake
- ❖ Follow up with your primary care doctor at least once a year
- ❖ Receive age-appropriate vaccines
- ❖ Practice sun safety
 - ❖ Use water-resistant sunscreen with UVA and UVB protection with an SPF of at least 30
 - ❖ Apply generously and reapply every 2 hours throughout day and after swimming
 - ❖ Use physical barriers whenever possible
 - ❖ Long sleeves, hat, sunglasses
 - ❖ Avoid direct sun exposure during peak activity
 - ❖ Do not use tanning beds



PRIORITIZING PHYSICAL ACTIVITY: THE BASICS

<https://www.cancer.org/healthy/eat-healthy-get-active/healthy-eating-active-living-videos>



EXERCISE

- ❖ At least 150 minutes of moderate or 75 minutes of vigorous activity per week—spread out over the course of the week
- ❖ Strength or resistance training at least twice a week
- ❖ Avoid prolonged periods of inactivity



EXERCISE



Light exercise = no noticeable change in breathing

- Leisure biking
- Video game activity
• (ex: Wii)
- Light housework
- Bowling
- Tai chi

Moderate exercise=can talk but not sing

- Dancing
- Biking on level ground
- Gardening
- Tennis
- Brisk walking
- Yoga

Vigorous exercise=can say a few words without stopping to catch a breath

- Aerobics class
- Biking faster than 10 miles/hour
- Hiking uphill
- Jumping rope
- Martial arts
- Race walking, jogging, running
- Swimming
- Stair climbing

REDUCE THE TIME YOU SPEND SITTING

- ❖ Limit time spent watching TV and using other forms of screen-based entertainment.
- ❖ Use a stationary bicycle or treadmill when you do watch TV.
- ❖ Use stairs rather than an elevator.
- ❖ If you can, walk or bike to your destination.
- ❖ Exercise at lunch with your coworkers, family, or friends.
- ❖ Take an exercise break at work to stretch or take a quick walk.
- ❖ Walk to visit coworkers instead of phoning or sending an e-mail.
- ❖ Go dancing with your spouse or friends.
- ❖ Plan active vacations rather than only driving trips.
- ❖ Wear a pedometer every day and increase your number of daily steps.
- ❖ Join a sports team.



STRATEGIES TO INCREASE PHYSICAL ACTIVITY

- ❖ Join a supervised exercise program or classes (ex. Livestrong at YMCA)
- ❖ Telephone counselling
- ❖ Accountability coach or personal trainer
- ❖ Schedule exercise like an appointment that you can't miss
- ❖ Set short and long term goals—identify what motivates you
- ❖ Use a pedometer or fitness tracker to monitor activity
- ❖ Get an exercise buddy or join a class/group



TIPS FOR COMBATTING FATIGUE

- ❖ Balance periods of activity and rest
- ❖ Do high priority activities when you have the most energy
- ❖ Exercise will help decrease fatigue
- ❖ Avoid medications that may make you drowsy
- ❖ Avoid alcohol
- ❖ Take short naps (no longer than 30 minutes)
- ❖ Get enough sleep at night



EXERCISE PRECAUTIONS

- ❖ Talk to your health care provider before starting a new exercise program
- ❖ Listen to your body
- ❖ If your platelets are low, avoid high risk activities (including contact sports, rollerblading, etc)



“LOOK GOOD, FEEL BETTER”

- ❖ Make time to care for yourself
- ❖ Maintain your routine
- ❖ Pamper yourself
- ❖ Join a “Look good, feel better” program near you

<https://youtu.be/Hv3ex7DO9uY>

Lookgoodfeelbetter.org

SOCIAL & EMOTIONAL IMPACT OF SURVIVORSHIP



“
I was afraid and not prepared. Everyone said it would be fine, but it was not very reassuring. I was terrified. I got so familiar with people at the doctor’s office, and then I realized I would not see them anymore.”

American Cancer Society

TIPS FOR COPING



<https://youtu.be/ti0kEycRMd8>

THEMES IN SURVIVORSHIP

- ❖ The “New Normal”
- ❖ Fear of recurrence
- ❖ Expectations
- ❖ Survivor’s Guilt
- ❖ Anxiety and depression
- ❖ Post-traumatic stress disorder



ADJUSTING TO THE “NEW NORMAL”



- ❖ Making changes in diet and activity
- ❖ Identifying new or different sources of support
- ❖ Adjusting to changes in your physical appearance or abilities
- ❖ New routines and habits
- ❖ You may see yourself differently or find that others see you differently
- ❖ Whatever your new normal may be, give yourself time to adapt to the changes. Take it one day at a time.

COPING WITH FEAR OF RECURRENCE

- ❖ Be informed: Understand what you can do for your health now, and find out about the services available to you.
- ❖ Talk to your health care team; share your concerns. Be honest
- ❖ Know that it's common for cancer survivors to have fears about every ache and pain. Keep notes about any symptoms you have.
- ❖ Keep your follow up appointments and stay on track with your follow-up plan
- ❖ Talk to a counselor. Make sure you have a follow-up care plan. Having a plan may give you a sense of control and a way to feel proactive with your health after treatment.

COPING STRATEGIES



- ❖ Find comfort and meaning
- ❖ Read uplifting stories about the human spirit.
- ❖ Use humor, laugh
- ❖ Pray or meditate
- ❖ Take part in community or social gatherings for your own support and to support others.
- ❖ Talk with others who have had similar experiences.
- ❖ Find resources at a place of worship for people dealing with chronic illnesses like cancer.
- ❖ Grieve for your losses. Recognize that you have been through a lot, and it's normal to be sad over the way life was before cancer.
- ❖ Finding Support: Talk with your hospital, health care team, or social worker. They may know about faith-based organizations in your community that provide specialized services for cancer survivors.
- ❖ Keep a journal. Write down your thoughts about what gives meaning to your life now.
- ❖ Think about helping others

ROLE OF THE CAREGIVER

- ❖ To care for others, you must care for yourself-be mindful of your own health and needs
- ❖ All of these strategies apply to you too!
- ❖ Find a support system
- ❖ Ask for help and then, use the help.
- ❖ Prioritize activities and needs.
- ❖ Gather information and identify resources.



THINGS TO CONSIDER ABOUT WORKING

- ❖ How will treatment affect work and schedule?
- ❖ Can treatment schedule be adjusted to meet work needs?
- ❖ How flexible is my work environment?
- ❖ How stressful physically and mentally is my job?
- ❖ Can accommodations be made?
- ❖ How is my identity connected to work?
- ❖ Have priorities changed?
- ❖ If returning to work, consider a transition plan.



Cancerandcareers.org

REASONABLE ACCOMMODATIONS

- ❖ Outlined in the Americans with Disabilities Act (ADA)
- ❖ Modification to job, schedule or environment to make it possible for you to perform job duties
- ❖ Identify challenges and needed modifications
- ❖ Modify work schedule
 - ❖ Work from home
 - ❖ Adjust hours
 - ❖ Schedule breaks

Cancerandcareers.org

RESOURCES REGARDING WORK QUESTIONS

The screenshot shows the Triage Cancer website with a navigation bar at the top. Below the navigation bar, there is a section titled "WHERE TO START" with a sub-header "Need guidance navigating the world of work? We'll help you think through next steps, including things that may not have crossed your mind." Below this is a "LEARN MORE" button. To the right is an icon of an open book. Below the "WHERE TO START" section are two columns: "LEGAL & FINANCIAL" and "BACK TO WORK AFTER CANCER". Each column has a brief description and a "LEARN MORE" button.

TIPS REGARDING COSTS OF HEALTHCARE



- ❖ Take the time to understand your medical benefits and insurance options
- ❖ Explore Medicare, Medicaid, and state health coverage marketplace
- ❖ Triage Cancer has tools to compare plans and options
- ❖ Explore income alternatives including: Social Security Disability Insurance and Supplemental Security Income to see if you qualify
- ❖ Explore life insurance and retirement plans as a source of cash

Triagecancer.org

TIPS REGARDING THE COSTS OF HEALTHCARE

- ❖ Take the time to read & understand your bills
- ❖ Organize your bills and medical records (Example: cancer101.org planner)
 - ❖ Keep records of medical bills, explanation of benefits (EOB), claims filed, preauthorizations, medications, results
 - ❖ Copies of correspondence with insurance companies
 - ❖ Meals, lodging, travel expenses related to medical care
- ❖ If you are having trouble paying your healthcare bills:
 - ❖ Contact your provider before the bills are sent to collections agencies
 - ❖ Ask for more time to pay
 - ❖ Negotiate a payment plan
- ❖ Appeal denials of coverage (39-59% of appeals are won)
- ❖ Ask your healthcare facility about patient assistance programs
- ❖ Many drug companies have patient assistance programs
- ❖ Contact AAMDSIF for resources

Triagecancer.org

FINANCIAL TOOLKITS

The screenshot shows the Cancer Finances website. At the top, there is a navigation bar with the Triage Cancer logo, the name "Cancerfinances.org", and several menu items. Below the navigation bar is a large image of US dollar bills with a green arrow pointing upwards. Overlaid on the image is the text "CANCER FINANCES" and "A Toolkit for Navigating Finances After Cancer". Below the image is a "GET STARTED" button.

Cancer101.org

The screenshot shows the Cancer101 website. At the top, there is a navigation bar with the Cancer101 logo and several menu items. Below the navigation bar is a large image of a desk with a laptop, a smartphone, and a notebook. The notebook has "CANCER A PLAN" written on it. Below the image is a "GET STARTED" button.

SURVIVORSHIP CARE

- ❖ Goal for all survivors to receive a survivorship care plan
- ❖ Ask your healthcare provider
- ❖ Refer to a Survivorship Clinic



SURVIVORSHIP CARE PLAN COMPONENTS



- ❖ Treatment summary—what were you treated with and when
- ❖ The care plan should include, at a minimum:
 - ❖ Likely course of recovery from treatment and need for ongoing health maintenance and ongoing therapy needs
 - ❖ Recommended cancer screening and other testing and the schedule on which they should be performed
 - ❖ Possible late or long term effects of treatment and symptoms
 - ❖ Signs of possible recurrence and secondary cancers
 - ❖ Possible effects on partner relationships, sexual function, work, parenting, and need for psychosocial support

EXAMPLES OF SURVIVORSHIP CARE PLANS

- ❖ Journey forward (<https://www.journeyforward.org/>)
- ❖ Oncolife (<https://oncolife.oncolink.org/>)
- ❖ American Society of Clinical Oncologists (ASCO) (<https://www.cancer.net/survivorship>)



RESOURCES

Financial & Legal

- ❖ Cancer and Careers (cancerandcareers.org)
- ❖ Triage Cancer (trriagecancer.org)
- ❖ Cancerfinances.org
- ❖ Canceradvocacy.org (National Coalition for Cancer Survivorship)

Lifestyle

- ❖ choosemyplate.gov
- ❖ Livestrong.org
- ❖ American Cancer Society (Cancer.org)
- ❖ American Institute for Cancer Research (aicr.org)

AA•MDS
INTERNATIONAL FOUNDATION

