# Cancer Survivorship

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Life after cancer can be anything but ordinary.  Survivorship is a broad term that includes not only people who have been diagnosed with cancer at some point in their life, but also the friends and family members of people who have been diagnosed with cancer.  Following the treatment period, during which cancer patients have an abundance of support and helpful information, survivors may feel at a loss for this support, with many unanswered questions. It is important that survivors know it takes time to recover and readjust to life.  It may not be possible to immediately return to their previous version of "normal".  They may need to take some time to determine what is normal for them at the current time.

Quality of life is usually measured with a survey taken by a person about their general situation and feelings. If a cancer patient or survivor is not happy with their condition, they are said to have a low quality of life. This may lead the patient's doctors to change the treatment or follow up program in order to make the patient feel better. Having a high Health Related Quality of Life (HRQoL) is important to cancer patients and survivors because they tend to receive more consistent care and follow through with the suggested treatments. Some recent studies have shown that patients with a higher quality of life may live longer.1, 2

Because there are so many things that can decrease quality of life, doctors are still working on the best ways to improve this important aspect of cancer care.1, 3

Subjects included on this page:


- Follow-up Care
- Palliative Care
- Diet and Exercise
- Financial Aspects
- Job Discrimination
- Physical Problems
- Survivorship Resources


You may also want to see our information for Caregivers.

# Follow-up Care

. Click here to watch the full interview with Ned Crystal.

Download the list below as a PDF file.385.81 KB

## Talking with Your Primary Care Doctor After Cancer Treatment

1. ***Before*** Leaving the Care of the Oncology Team
    a. **Get a treatment summary**. Should provide a detailed list of all treatments you received.
    b. **Make sure you have a copy of all of your cancer-related medical test results** and/or get a copy of all medical test results sent to your primary care provider (PCP). You may need to talk to your team to find out how to request all information for your PCP.
    c. **Get a 'long term care plan'**. Your cancer care team should provide you with this before you are discharged from their care. The plan should describe the types of things you need to look out for in the

near and distant future. It may also include recommended screenings and other information specific to patients with your type of cancer/types of treatment.

2. Items to Discuss with Your Primary Care Doctor

To best serve you, your primary care provider will need access to all of your cancer-related medical information. It is a very good idea to make sure that you and your PCP are 'on the same page' with respect to your follow-up care. The list presented here includes some of the most common things that patients should consider discussing with their doctors.

a. **How and when will you be screened for a recurrence of your cancer?**

You should have a plan in place for regular checkups and relevant screening exams.

b. **How and when will you be screened for secondary cancers?**

Because some cancer treatments raise the risk of other, *new* cancers (secondary cancers), it is important to know what to look for.

c. **How will you be treated for long-term side effects?**

Some cancer treatments can lead to side effects that can last a very long time. An example is the pain/burning (neuropathy) caused by nerve damage due to some kinds of chemotherapy.

d. **How will you be checked for late effects?**

Some cancer treatments may cause side effects that do not show up for months or years after the treatment stops. An example is heart damage caused by some chemotherapy drugs.

e. **Sexuality**

Some cancer treatments can impact sexual performance and/or desire. These include hormonal treatments for breast and prostate cancer, and surgery that impacts sexual functioning. Body image is also a major concern for some cancer survivors, as surgery can leave them feeling unattractive. Sexuality is part of the human experience, and it is important to address any issues, psychological or physical.

f. **Lifestyle changes**

Items to consider include diet, exercise, alcohol consumption, and cessation of tobacco usage. If you do not currently exercise regularly, a plan should be created to maximize the benefits and minimize any risks.

g. **Fertility**

Cancer treatments can impact the ability of a survivor to have a child. If this is something that you are considering, you should talk with your physician about any concerns or risks.

h. **Integrative Oncology**

Many cancer survivors utilize integrative oncology treatments/practices. These include yoga, Tai Chi, herbal supplements, 'food therapy', and acupuncture. Unfortunately, most patients do not discuss these practices with their doctors. That is a mistake!

It is important that all supplements and other treatments are documented and discussed. There is good evidence that some treatments can have beneficial effects, but some herbal remedies can interfere with medications or have other effects that need to be addressed. Natural does *NOT* mean safe.

If you are using or considering a complementary medicine approach, discuss this with your physician.

i. **Emotional and psychological issues**

Cancer is stressful!!! The impacts can last a lifetime. It is very common for cancer survivors to

suffer from depression and anxiety. Make sure that you discuss this with your physician and seek appropriate counseling/medication when it is warranted. Addressing psychological concerns is as important as dealing with physical issues.

j. **Clinical trials in survivorship**

Although not as common as treatment trials, there ARE clinical trials that are designed to address challenges faced by cancer survivors. You should consider identifying and joining these types of trials in your area.

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Young cancer survivors may face different challenges than adults. The U.S. National Cancer Institute has compiled information specifically for childhood cancer survivors.4

**Barriers to Treatment**

There are different reasons why patients do not get the care they should. Some of them are listed here:

- Structural barriers: inadequate health insurance, complexities of the health care system, treatment facility hours of operation, appointment wait times, and access to transportation.6
- Physician factors: attitudes, beliefs, preferences, and biases.6
- Cost of cancer care is a possible burden for many patients and their families. For information to help compare insurance plan coverage visit the American Cancer Society Cancer Action Network (ACS CAN).

Getting the proper care is essential for cancer survivors, so if problems arise, it is very important that the patient reach out to their healthcare team, family, and friends to find ways to get the care they need. Don't wait!

**Palliative Care**

Palliative care improves the quality of life of patients with cancer. While this service is not yet available to all in need, there are many professionals in this growing specialty area.

To learn about and find palliative care professionals see the Resources section of this page.

**Diet**
Due to the physical and emotional stresses of cancer treatments, cancer survivors may be at an increased risk for other health problems including obesity, heart problems, osteoporosis, high blood pressure, and diabetes. Because of this, it is imperative that cancer survivors maintain a healthy diet, a regular exercise plan, and work to manage their stress in order to optimize their health. The American Cancer Society recommends eating plant-based foods like fruits, vegetables, grains, and foods low in fat in their Nutrition Guidelines.

people riding bikes

**Exercise**
Exercise may play an important role in controlling fatigue, improving cardiovascular fitness, losing or maintaining weight, improving mood, and stress management. Finding motivation to exercise can be hard due to the side effects of cancer treatment, like fatigue, that may interfere with a survivor's positive lifestyle decisions; however, it is possible. The American Cancer Society recommends exercising as soon as possible after treatment because of the association between physical activity and reduced risk of cancer recurrence.5

Exercise Suggestions:

- For those who have been inactive for a while, it is helpful to begin with about 10 minutes of walking per day.
- Combine exercise with other daily activities, i.e. taking the stairs, walking to the store rather than driving, parking further from an entrance, or exercising while watching television.
- If you suffer from insomnia, consider yoga, which can improve sleep quality.6 Yoga can be a gentle option because individual poses can be tailored to patient abilities. To read more about the role of yoga and Tai Chi

in therapy, visit our CAM section.
- Finding an exercise partner or group can help to provide motivation and friendly support.
- If you suffer from fatigue, try scheduling exercise during times of the day when you expect your energy levels to be highest.
- It is important to speak with your doctor before beginning a new exercise routine.

Healthy Lifestyle Suggestions:

- After treatment, it is important to continue contact with the healthcare team.
- Don't smoke and avoid secondhand smoke.
- Taking measurements to manage stress will help the recovery process to move along more quickly.
- Making more time for fun activities will help improve mood.

# Financial Aspects

***Understanding the Costs Related to Cancer***[7]

Types of cancer-related cost

- Medical: medical office visits, tests, treatments, drugs and caregiving
- Lifestyle: transportation, travel, legal help and financial services

Talk to your health care team

- While many people are hesitant to ask about their financial concerns, it is vital to talk to your health care team.
- One study has shown that while more than half of the patient participants wanted to talk to their doctors about costs, only 19% actually did. 57% of the patients who had conversations with their doctors about financial concerns felt that it helped significantly decrease their costs, and even more felt it decreased their anxiety during the course of treatment

Seek financial assistance

- Resources that provide financial assistance include child care, personal items (wigs, mastectomy bras, ostomy supplies), counseling services, legal help, transportation.
- Those who can refer you to helpful organizations include: social workers, advocates, financial counselors, and patient navigators at your medical center.
- Federal laws offer benefits, health insurance protection, and discrimination protection.

***Healthcare Costs***

As a cancer survivor, it is very important to be aware of the financial and legal matters related to cancer diagnosis and treatment. Knowing the specifics of healthcare insurance policies is very important. Some types of diagnostic and treatment procedures may not be included in a patient's coverage plan. It is important to speak with hospital financial counselors about hospital bills to determine if reduced rates or monthly payments are available/suitable. The U.S. Federal government has produced guidelines for the treatment of patients.

**Financial Support for Disabled Individuals**

Patients who are unable to work because of a serious medical condition are often eligible for disability support from the U.S. federal government (Social Security Administration). The process can take some time (6. months or more), so it will not work for immediate payment of medical expenses, but it is very worthwhile.

Learn about disability support via the Social Security Administration

Call Social Security at **1-800-772-1213** (You'll need your SS # handy)

***Pharmaceutical Company Patient Assistance Programs***[9]

If you do not have prescription medication coverage, have limited prescription insurance, or have a number of prescriptions, you may be having a difficult time paying for them. Some of these Patient Assistance Programs, located in the Resources section, may be able to help with the medications they manufacture.

# Job Discrimination

It is important for a cancer survivor to be aware of their rights under the Americans with Disabilities Act. Employers may be reluctant to hire cancer survivors because they are afraid they may not be able to handle the workload of physically demanding jobs; however, **it is unlawful for an employer to discriminate against someone with a**

**disability**.

Even though having cancer can be disruptive, it may be possible to continue working. Survivors may find that working provides a sense of normalcy to everyday life. Patients and survivors should talk with their employers about what options are available, whether part-time or full time. Many employers are willing to work out alternative work schedules and locations.

Learn more about the Americans with Disabilities Act

## Physical Problems

Cancer can significantly affect the human body on many levels, both physically and emotionally. Problems may arise as a result of the cancer itself or as a result of cancer treatment. The impact can be minor or severe. In the worst cases, side effects can be debilitating for the patient and their healing process. It is important for cancer survivors to speak with their doctors about any changes or concerns.

Some physical changes that a cancer survivor may experience include (*Note: these links will take you to the Side Effects section*):

- Anemia
- Anorexia (inability to eat)
- Blood Clots
- Chemotherapy Induced Tissue Damage
- Diarrhea
- Fatigue
- Fertility Problems
- Hypercalcemia
- Low Blood Counts
- Lymphedema
- Mastectomy/Breast Reconstruction
- Memory and Concentration Problems
- Menopause Symptoms
- Nausea
- Neutropenia
- Oral Health
- Pain
- Swelling
- Weight Loss and Changes in Eating Habits

Watch an interview with Dr. Michael Burke, a psychiatric oncologist

*If you find the material useful, please consider linking to our website.*

## Survivorship Resources

### Healthy Lifestyle

SurvivorLink

Smokefree (US Government site)

iTHRIVEplan

Nutrition Services (Winship Cancer Institute

Adult Survivorship (Winship Cancer Institute)

Cancer Survivorship Guidelines

### American Cancer Society Programs

Cancer Survivors Network

Hope Lodge

I Can Cope

Look Good...Feel Better

Reach to Recovery

Road to Recovery

"TLC" Direct

**Financial Resources**

American Cancer Society Cancer Action Network (ACS CAN)

Rights as a U.S. Healthcare Patient

Social Security Administration Disability Services

Health Insurance Benefits (Winship Cancer Institute)

Family Reach - a non-profit organization with the mission of assisting cancer patients with financial challenges

Vivor - a healthcare company that works with providers to reduce cancer care costs for patients.

**Pharmaceutical Company Patient Assistance Programs**

Abraxane Financial Support

Amgen Safety Net Foundation

AstraZeneca Affordability Programs

Boehringer Ingelheim CARES Foundation

Bristol-Myers Squibb Patient Assistance Foundation

Celgene Patient Support

Genentech Access Solutions

GlaxoSmithKline Commitment to Access

Johnson & Johnson Patient Assistance Foundation

Lilly & Company Cares Foundation

Merck Patient Assistance

Novartis Oncology Patient Assistance Now

Pfizer RxPathways Assistance

Purdue Pharma Cost Savings

Sanofi Patient Connection™

**Choosing a Doctor**

How to Choose a Doctor (ACS)

Find a Cancer Specialist

Find a Hematologist

Find a Surgical Oncologist

DoctorFinder

Find a Surgeon

Find Your Doctor of Osteopathic Medicine

**Choosing a Treatment Facility**

NCI Cancer Center List

Association of Community Cancer Centers

Listing of Children's Oncology Group Locations by State

## Choosing Among Recommended Treatments

Prepare for Your Care

American Cancer Society's Treatment Page

## Palliative Care

ACS CAN Quality of Life

Patient Quality of Life Coalition

Palliative or Supportive Care (ACS)

Get Palliative Care

## Employment

Cancer and Careers

Patient Advocate Foundation

U.S. Equal Employment Opportunity Commission

## Georgia Survivorship Resources

Winship Cancer Institute - Living With Cancer

Georgia Center for Oncology Research and Education (CORE)

Georgia Cancer Information

Georgia Cancer Survivorship Connection

Cancer Patient Navigators of Georgia

Georgia Society of Clinical Oncology

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