

THIS NEW NORMAL ISN'T NORMAL AT ALL: LIFE AFTER A CANCER DIAGNOSIS

Agenda

- What does it mean to be a "Cancer Survivor"
- The psychosocial impact of survivorship
- Questions and answers



WHAT DOES IT MEAN TO BE A "CANCER SURVIVOR"



The New Normal

What Is "Normal" After Cancer Treatment?

- "Those who have gone through cancer treatment describe the first few months as a time of change. It's not so much "getting back to normal" as it is finding out what's normal for you now. People often say that life has new meaning or that they look at things differently now. You can also expect things to keep changing as you begin your recovery.
- Your new "normal" may include making changes in the way you eat, the things you do, and your sources of support. "

(NCI Facing Forward Life after Cancer Treatment)

PATIENT PERSPECTIVE

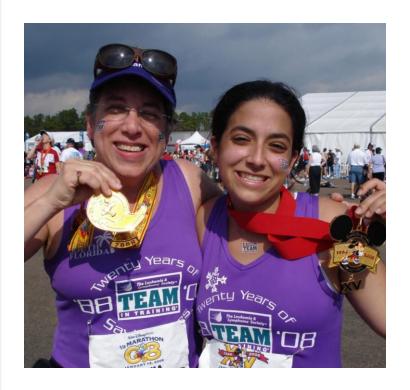




"I had a hard time adjusting to life after cancer treatment. My well peers and family did not understand me or what I was going through. They were all in a different place in life, I was ahead of my well peers in some ways and behind them in others. It took me several years to adjust" – Patient diagnosed with AML when he was 12 and continued treatment through age 14 including a stem cell transplant.



WHAT DOES IT MEAN TO BE A "CANCER SURVIVOR" FAMILY/CAREGIVER PERSPECTIVE



"My husband had a hard time after my cancer treatment. I had to reassure him that everything would be ok every time scans and follow-up visits were scheduled. It took him longer to adjust to the new normal than me. He had a harder time transitioning to survivorship and the new normal than I did" – Lymphoma Survivor and retired nurse.





PSYCHOSOCIAL EFFECTS

SURVIVOR CONCERNS MAY INCLUDE:

- FEAR OF RECURRENCE
- FEAR OF DEATH
- SURVIVOR'S GUILT
- TRANSITIONING OUT OF THE ROLE OF CANCER PATIENT
- EMPLOYMENT ISSUES AND RETURNING TO WORK
- FINANCES
- HEALTH AND LIFE INSURANCE COVERAGE

19% survivors meet criteria for PTSD

DEPRESSION & ANXIETY

common psychological effects





THE IMPACT OF SURVIVORSHIP

Psychological Effects

There can be significant psychosocial effects of a cancer diagnosis, especially amongst patients with a pre-existing mental health condition.

According to The National Cancer Institute:

- One in three people with cancer experience mental or emotional distress. It is most common in breast cancer (42%) and head and neck cancer (41%) patients.
- Up to 25% of cancer survivors experience symptoms of depression and up to 45% experience anxiety.
- Many cancer survivors also experience symptoms meeting the criteria for Post-Traumatic Stress Disorder (PTSD).
- Cancer survivors are twice as likely to die by suicide than the general population.



FAMILY ISSUES

Common concerns with loved ones

- **People expect you to do what you did before your cancer.** For instance, if you used to take care of the house or yard before your treatment, you may find that these jobs are still too much for you to handle. Yet family members who took over for you may want life to go back to normal. They may expect you to do what you used to do around the house.
- You may expect more from your family than you receive. They may disappoint you, which might make you angry or frustrated. For example, you may get less attention and concern than you did during treatment.
- You may still need to depend on others during this time. Even though you want to get back to the role you had in your family before, it may take a while to get into a routine.



FEAR OF RECURRENCE



- AS MANY AS 70% OF POST-TREATMENT CANCER SURVIVORS REPORT HIGH LEVELS OF FEAR OF RECURRENCE.
- CAREGIVERS MAY ALSO EXPERIENCE FEAR OF RECURRENCE.
- THIS CAN LEAD TO INCREASED ANXIETY AND DEPRESSION



HEIGHTENED SENSE OF MORTALITY AND SUSCEPTIBILITY

Includes mental health issues

CANCER SURVIVORS
MAY HAVE A
HEIGHTENED SENSE
OF MORTALITY AND
SUSCEPTIBILITY TO
OTHER ILLNESSES.





COPING WITH GUILT

Some survivors feel guilty that they survived while others with a cancer diagnosis did not.

This is called "survivor's guilt."

Other sources of feelings of guilt may include

- Blaming themselves for the diagnosis because of lifestyle choices or habits prior to diagnosis
- Worry about being a burden for a caregiver or loved ones
- Cost of treatment

Caregivers may also experience guilt because they are healthy and/or were not able to help more.

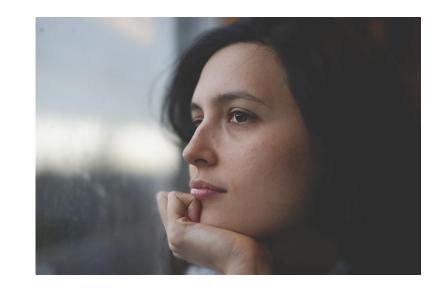


TRANSITIONING OUT OF THE ROLE OF CANCER PATIENT

After cancer treatment, survivors may

- Struggle to find new routines that don't center around treatment and doctor appointments
- Want to return to life before cancer, but this may not be possible
- Wish to make lifestyle changes or pursue new goals
- Move on and put the experience behind them

This time is sometimes referred to as a "new normal." It's different for all cancer survivors.





EMPLOYMENT CONCERNS

Unemployment rates for survivors are higher than for the general population.

Survivors may encounter difficulties when returning to work

- Physical or cognitive limitations
- Fatigue
- Depression
- Anxiety
- Perceived or real discrimination.

Certain flexible work arrangements are allowed under the Americans with Disabilities Act (ADA).





FINANCIAL CONCERNS

From the Livestrong 2012 Survey, approximately **33%** of working age survivors went into debt and **3%** filed for bankruptcy.

Financial stress may increase if unable to return to work after finishing treatment.

Financial concerns can also contribute to difficulty maintaining adequate health and life insurance coverage.

Coping Strategies

- Investigate other sources of income if unable to return to work
- Organize bills and rank them in order of importance
- Make appeals to insurance company
- Talk to creditors to create payment plans
- Contact organizations that offer financial help to cancer survivors









WE ARE ALL HUMAN



Natural disasters strike, medical emergencies happen, and accidents occur. We cannot always prevent emergencies, but we can prepare for them. Advance care planning can provide peace of mind. Begin advance care planning by thinking about and gathering information for future medical care.

This process will help you to set your priorities and formulate your preferences about the care you receive if you become incapacitated, are unable to make decisions or are approaching the end of your life. Share your preferences for medical care with your family and caregivers. If the people close to you understand what you want and your reasoning, they will be better able to support your choices.

