

Survivorship Care Planning: What's Next in Your Journey?

Dr. Tamika Turner, DNP, NP-C, AOCNP
 Dr. Ina L. Wilson, DNP, APRN-BC, BMTCN

Objectives:

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

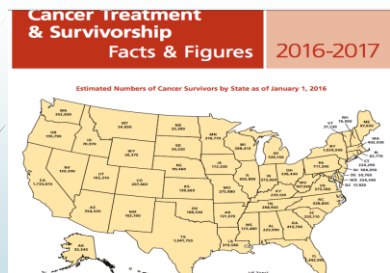


Why Survivorship Care?

- 15.5 million survivors of cancer in the US today
- The number of survivors are predicted to increase significantly over the next 10 years due to:
 - Improved early detection
 - Improved treatments
 - Aging baby boomers-there will just be more of us!
 - Longer life expectancies
- Cancer survivors often experience a higher burden of illness and self reported health outcomes than matched controls who have never been diagnosed with cancer

American Cancer Society. Facts and Figures, 2016.
 Yabroff KR, Lawrence WF, Clauser S, Davis WW, Brown ML. Burden of illness in cancer survivors: findings from a population-based national sample. *J Natl Cancer Inst.* Sep 1 2004;96(17):1322-1330

Cancer Survivors By State



American Cancer Society, Surveillance and Health Services Research, 2016

Cancer Survivors By Diagnosis and Gender

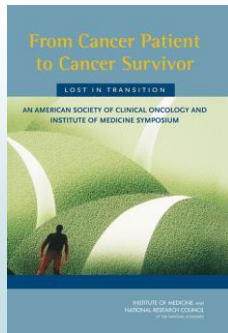
Figure 1. Estimated Numbers of US Cancer Survivors

As of January 1, 2016

Male		Female	
Bladder	8,306,760	Bladder	4,521,970
Cervix & neck	724,695	Uterine corpus	970,190
Colon & rectum	614,460	Cervix & neck	885,540
Esophagus	574,250	Thyroid	811,490
Non-Hodgkin lymphoma	381,480	Non-Hodgkin lymphoma	436,370
Kidney & renal pelvis	701,340	Leukemia	958,990
Testis	268,550	Lung & bronchus	398,790
Lung & bronchus	278,200	Esophagus	378,430
Leukemia	270,020	Liver & biliary	341,980
Oral cavity & pharynx	278,880	Chovy	292,540
Total survivors	12,971,600	Total survivors	8,981,620

NOTE: Beginning with the 2016-2017 edition, estimates for specific cancer types now take into account the potential for a history of more than one cancer type. Estimates should not be compared to those from previous years. See Source of Statistics, page 24, for more information.
 Source: Surveillance Research Program, Division of Cancer Control and Population Sciences, National Cancer Institute.
 American Cancer Society, Surveillance and Health Services Research, 2016

Survivorship Movement



American College of Surgeons Commission on Cancer

- Standard 3.3** - The development and implementation of a process to disseminate a comprehensive care summary and follow-up plan to patients with cancer who have completed treatment

Commission on Cancer (2016). Cancer Program Standards: Ensuring Patient Centered Care.

When Should Survivorship Care Begin?

Definition of a Cancer Survivor:

- An individual is considered a cancer survivor from the time of diagnosis, through the balance of his or her life.
- Family members, friends, and caregivers are also impacted by the survivorship experience and are therefore included in this definition.

NCI Office of Cancer Survivorship
<http://dccps.ncti.nih.gov/ocs/definitions.html>

What Should Survivorship Care Include?

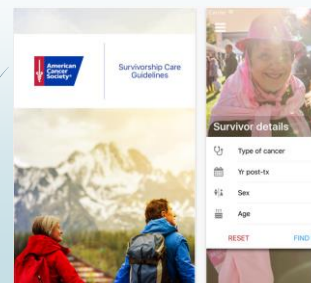
- Survivorship care plan, psychosocial care plan and treatment summary
- Screening for new cancers and surveillance for recurrence
- Care coordination strategy which addresses care coordination with PCPs and primary oncologists
- Health promotion education
- Symptom management and palliative care

THE ESSENTIAL ELEMENTS OF SURVIVORSHIP CARE: A LIVESTRONG Brief, Ruth Rechis, Ellen B. Beckjord, Sarah R. Avey, Kerry A. Reynolds, Devon McGoldrick December 2011

American Society of Clinical Oncology

<http://www.cancer.net/survivorship/follow-care-after-cancer-treatment/asco-cancer-treatment-and-survivorship-care-plans>

American Cancer Society Survivorship Care Guidelines App



Practical Issues of Survivorship

- Difficulty working due to physical and/or emotional after effects
- Changes in relationships with loved ones, friends or co-workers
- Problems getting or retaining health or life insurance coverage
- Financial stressors
- Employment discrimination



Financial Impacts During and After Treatment

- Treatments not covered by insurance
 - Clinical trials
 - Unable to work due to illness
 - Difficulty finding employment with benefits
 - Expenses that occur from traveling to and from treatments

Financial Distress Options

- Medical Coverage
 - Medicare
 - Medicaid
 - State Health Coverage Marketplace
- Income Alternatives
 - Supplemental Security Income (SSI)
 - Social Security Disability Insurance (SSDI)

Financial Distress Options

- Life Insurance
- Retirement Plans
- Contact AAMDSIF to connect you with organizations that may be able to financial assist you (financial resource list will be on our education materials table)

Financial Resource Sites

- <https://www.canceradvocacy.org/resources/cancer-survival-toolbox/>
- <https://www.canceradvocacy.org/shop/>
- <https://www.medicare.gov/sign-up-change-plans/decide-how-to-get-medicare/whats-medicare/what-is-medicare.html>

Financial Resource Sites

- <https://www.medicaid.gov/medicaid/eligibility/index.html>
- <https://www.healthcare.gov>
- <http://patientadvocate.org/>

National Cancer Survivor Tools

https://smhs.gwu.edu/gwci/sites/gwci/files/NCSRC_Toolkit_Patients_FINAL.pdf?src=GWCIwebsite

National Cancer Survivorship Resource Center Toolkit Provider Tools

Implementing Clinical Practice Guidelines for Cancer Survivorship Care



You may encounter many defeats, but you must not be defeated. Please remember that your difficulties do not define you. They simply strengthen your ability to overcome.

Maya Angelou



Living Well During and After Treatment



Living Well During and After Treatment



TOO BUSY
LOOKING GOOD



- ▶ Collaboration with healthcare providers
- ▶ Support groups
- ▶ Physical activity
- ▶ Nutrition
- ▶ Managing stress
- ▶ Look good-Feel good
- ▶ Embrace the new normal

Living Well During and After Treatment

- Collaboration with providers:
 - Treatment summary/survivorship care plan
 - Support groups
 - Symptom tracker

Living Well After Treatment

- ▶ Physical activity
 - ▶ Start slow... 5minutes and work your way up
 - ▶ Be consistent... so that it becomes a habit
 - ▶ Join group exercise
 - ▶ Get your family and friends on board
 - ▶ Make it part of your lifestyle
 - ▶ One step in from of the other
 - ▶ Cancer Harbors" YouTube page



Nutrition

- ▶ Eating well before, during and after treatment
 - ▶ Small frequent meals
 - ▶ Preplanned meals
 - ▶ Add protein to each meal
 - ▶ Avoid/limit processed foods
 - ▶ Limit intake of "white foods"
 - ▶ Limit caffeine intake
 - ▶ Limit sugary drinks
 - ▶ Drink water

Coping with the Emotional and Social Side Effects

- ▶ "Chemo brain"- memory, attention and focus problems
- ▶ Depression/Anxiety
- ▶ Role changes/body image changes
- ▶ Occupational disability

Side Effects That Impact Nutrition

- ▶ Loss of appetite
- ▶ Sore mouth or throat
- ▶ Dry mouth
- ▶ Dental and gum problems
- ▶ N/V/D
- ▶ Fatigue
- ▶ Weakened immune system

Caring for Your Appearance

- ▶ Keep up with your regular grooming habits
- ▶ Pamper yourself
- ▶ Manicured nails
 - ▶ Keep them short, filed
- ▶ Protect your skin
 - ▶ SPF 30 higher
- ▶ Get enough rest
- ▶ Exercise



Working During & After Treatment

Factors that impact ability to work

- Type of treatment
- Stage of your cancer
- Overall health
- The kind of work you do

Working During & After Treatment

Tips for working

- ▶ Timing of treatments
- ▶ Talking with friends/co-workers about cancer
- ▶ Keep your supervisor up to date regarding treatment
- ▶ Legal protections

Working During & After Treatment

- ▶ American with Disabilities Act
- ▶ Family and Medical Leave Act
- ▶ www.cancer.org



Coping with Emotional & Social Side Effects

Emotions.... So many emotions



Coping

- ▶ Healthy coping
 - ▶ I look for more information when problems come up or when I get bad news
 - ▶ I talk with others and share my concerns when I face a problem
 - ▶ I use humor to get through tough situations
 - ▶ On some days, I try not to think about my illness
 - ▶ I keep busy as a form of distraction
 - ▶ Cancer has made me re-examine my life, but there are still people and activities I enjoy

Coping

- ▶ Engage in activities that you enjoy, that replenish you emotionally & spiritually




Caregivers Role

- ▶ Caregivers role is vital
- ▶ Ask for help
- ▶ Be prepared for some people not to help
 - ▶ Be prepared to receive help from unexpected people
- ▶ Self-care
 - ▶ Find time to relax
 - ▶ Don't neglect your personal life




Resources

- ACS Cancer Survivors Network
- Patient Distress Checklist
- Look Good Feel Better Program (ACS)
- Road to Recovery (ACS)
- Reach To Recovery (ACS)
- Little Red Door Cancer Agency

Thank you!!!!

Questions?



SURVIVORS




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