

# Improving Engagement With Your Primary Care Provider As a Cancer Survivor

**Amber Brown Keebler MD**  
Assistant Professor  
Internal Medicine and Pediatrics  
Department of General Internal Medicine

University of Nebraska Medical Center Nebraska Medicine

1

## Objectives

- Describe the epidemiology of cancer survivorship and the future projections about cancer survivor' healthcare service
- Identify potential long-term effects of cancer treatment and what resources or management strategies are available to develop healthier lifestyles and/or improve quality of life
- Discuss the roles and responsibilities of the cancer survivorship healthcare team in shared decision-making for post-cancer treatment plans and care decisions as well as advancing health equity in cancer survivorship

2

## Cancer Survivorship At A Glance

- 16.9 million Americans in 2019
- Expected to exceed 22 million by 2030
- Demand for survivorship care is rising rapidly
- Access limited by current work force and specialists
- 2004 Institute of Medicine Report
  - Prevention
  - Surveillance
  - Intervention
  - Coordination



Tara Winstead, Pexel

3

## The Face of Cancer Survivorship

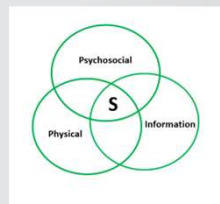


Breston Kenya, Pexels

4

## Complex Care Needs

- Needs of person receiving cancer treatment vs. Needs AFTER
- Needs of Oncologist – Cancer Care Delivery
- Needs of PCP – Knowledge
- Communication



5

## Oncology Barriers



Phone: chepte cormani, Pexel; Stethoscope: Karolina Grabowska, Pexel; Nurse: Laura James, Pexel

6

## Primary Care Barriers



Karolina Grabowska, Pexel

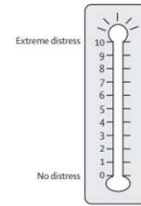
- Communication
- Care Delivery
- Limited Knowledge

7

## NCCN Distress Thermometer

Distress is an unpleasant experience of a mental, physical, social, or spiritual nature. It can affect the way you think, feel, or act. Distress can make it harder to cope with having cancer, its symptoms, or its treatment.

Instructions: please circle the number (0-10) that best describes how much distress you have been experiencing in the past week, including today.



[nccn\\_distress\\_thermometer.pdf](#)

8

## Problem list

Have you had concerns about any of the items below in the past week, including today? (Mark all that apply)

### Physical concerns

- ☐ Pain
- ☐ Sleep
- ☐ Fatigue
- ☐ Tobacco use
- ☐ Substance use
- ☐ Memory or concentration
- ☐ Sexual health
- ☐ Changes in eating
- ☐ Loss or change of physical abilities

### Emotional concerns

- ☐ Worry or anxiety
- ☐ Sadness or depression
- ☐ Loss of interest or enjoyment
- ☐ Grief or loss
- ☐ Fear
- ☐ Loneliness
- ☐ Anger
- ☐ Changes in appearance
- ☐ Feelings of worthlessness or being a burden

### Social concerns

- ☐ Relationship with spouse or partner
- ☐ Relationship with children
- ☐ Relationship with family members
- ☐ Relationship with friends or co-workers
- ☐ Communication with health-care team
- ☐ Ability to have children

### Practical concerns

- ☐ Taking care of myself
- ☐ Taking care of others
- ☐ Work
- ☐ School
- ☐ Housing
- ☐ Finances
- ☐ Insurance
- ☐ Transportation
- ☐ Child care
- ☐ Having enough food
- ☐ Access to medicine
- ☐ Treatment decisions

### Spiritual or religious concerns

- ☐ Sense of meaning or purpose
- ☐ Changes in faith or beliefs
- ☐ Death, dying, or afterlife
- ☐ Conflict between beliefs and cancer treatments
- ☐ Relationship with the sacred
- ☐ Ritual or dietary needs

### Other concerns:

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

[nccn\\_distress\\_thermometer.pdf](#)

9

## Long Term Concerns of Cancer Survivors

- Cardiac dysfunction
- Treatment induced metabolic syndrome
- Lymphedema
- Pain
- Treatment induced neuropathy
- Bone Health
- Immune related effects
- Anxiety and Depression
- Fear of Recurrence
- Cognitive Impairment
- Fatigue
- Sleeping problems
- Sex and Intimacy
- Returning to Work
- Financial Toxicity



Andrew Neel, Pexel

10

## Treatment Related Cardiac Dysfunction

### Conditions:

- Cardiomyopathy
- Valve Disorders
- Abnormal Heart Rhythms
- Coronary Heart Disease



Orlano Ortiz, Pexel

### Risk Factors:

- Treatment
  - Anthracycline
  - Trastuzumab
  - Radiotherapy
- Age > 60
- Baseline cardiovascular risk

### Screening and Treatment Guidelines:

- Echocardiogram
- Cardiology Referral
- Medications

11

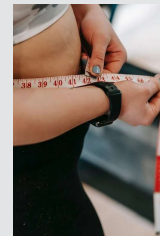
## Treatment Induced Metabolic Syndrome

### Conditions:

- Central obesity
- Insulin resistance
- High triglycerides
- High Blood Pressure

### Screening and Treatment Guidelines:

- Routine surveillance
- Lifestyle interventions
- Medications



Andres Ayrtton, Pexel

### Risk Factors:

- Surgery
  - Pituitary/Hypothalamic
  - Orchiectomy
  - Salpingo-oophorectomy
- Radiation
  - Brain
  - Pituitary
  - Whole Body
- Hormone blocking therapies
- Chemotherapies
  - Anthracycline
  - Platinum

12

## Treatment Related Lymphedema

### Condition:

- Swelling and sensation of heaviness
- Difficulty with speech and swallowing



Anna Shvets, Pexel

### Risk Factors:

- Types of Cancer
  - Breast
  - Gynecologic
  - Prostate
  - Head and Neck
  - Melanoma
- Previous surgery or radiation

### Screening and Treatment Guidelines:

- High suspicion
- Referral to Lymphedema Specialist
- No activity limitations
- Monitor for signs or symptoms of infection

13

## Treatment Related Chronic Pain

### Conditions:

- Recurrence
- Disease Progression
- Chronic Pain Syndrome
- Osteoporotic Fractures
- Cystitis/Proctitis
- Neuropathies
- Post-surgical Pain

### Risk Factors:

- Radiation therapy
- Surgical Therapy
- Chemotherapy

### Screening and Treatment Guidelines:

- Screen at every visit
- Comprehensive assessment
- Realistic goal setting

14

## Bone Health Considerations

### Conditions:

- Osteopenia
- Osteoporosis



Tina Miroshnichenko, Pexel

### Risk Factors:

- Hormone Blocking Chemotherapy
- Radiation
- Bone Marrow Transplant

### Screening and Treatment Guidelines:

- Calcium and Vitamin D in diet
- Stop smoking
- Limit alcohol intake
- Exercise
- Bone mineral density testing

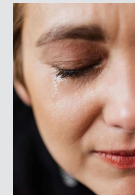
15

## Psychosocial Effects

### Conditions:

- Anxiety
- Depression
- Fear of Recurrence
- Fatigue
- Sleeping Difficulties
- Sex and Intimacy
- Return to Work
- Financial Toxicity

### Screen EVERYONE



Karolina Grabowska, Pexel

16

## Managing Other Chronic Diseases

### Be aware of:

- Baseline chronic diseases
- Risk factors for new onset or progression
- Potential for drug interactions
- Continued importance of lifestyle modification



Nataliya Vaitkevich, Pexel

17

## Strategies to Improve Survivorship Care

- Risk stratification
- Surveillance of recurrence
- Management of late and long-term treatment Effects
- Health living recommendations
- Chronic disease management
- Community involvement
- Online and virtual tool development

### Survivorship Care Plan

18

## Resources

[Cancer Survivorship Program | Nebraska Medicine Omaha, NE](#)

For Providers:

[American Society of Clinical Oncology \(ASCO\) Guidelines](#)

[Centers for Disease Control and Prevention Information for Health Care Providers](#)

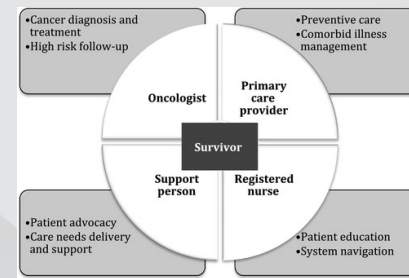
[GW Cancer Center's Online Academy](#)

[National Comprehensive Cancer Network](#)

[OncoLink Survivorship Care Plan Tool](#)

19

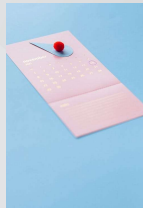
## Survivorship Care Model



20

## Cancer Survivorship Team: Survivor Responsibilities

- Continue to follow oncology team recommendations
- Communicate needs with entire care team
- Transition focus from acute to chronic healthcare
- Know your Survivorship Care Plan

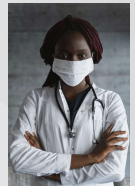


Nataliya Vaitkevich, Pexel

21

## Cancer Survivorship Team: Primary Care Provider Responsibilities

- Know the details of cancer history
- Review Survivorship Care Plan
- Know Family History
- Surveillance of recurrence
  - Risk assessment and screening guidelines
  - Physical Exam
- Management of late and long-term treatment effects
- Healthy living recommendations
- Chronic disease management
- Communication and Coordination with Survivor and Healthcare Team

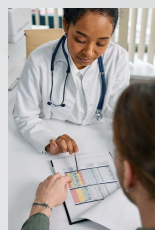


Tina Miroshnichenko, Pexel

22

## Cancer Survivorship Team: Oncology Responsibilities

- Surveillance of Recurrence
- Management of late and long-term treatment effects
- Education of patient and care team
- Communication clearly with PCP and the Survivor
- Survivorship Care Plan



Cotton bro studio, Pexel

23

## Example: Self Management Shared Care Model

- National Health Service in the UK
- Breast, Prostate, Colorectal Cancer Survivors
- Tested a Risk Stratified Follow Up Care Model
- Foundation of self management
- Recovery Care Package
- Success
  - 50% Colorectal and Prostate Cancer Survivors
  - 80% Breast Cancer Survivors

### Results:

- Increased efficiency during visits
- Reduced hospitalizations
- Reduced costs

### Factors for Success:

- Systems to support remote monitoring
- Routine whole person needs assessment
- Access to critical services
- Adequate support for PCPs

24

## What's next?

- Adaptive healthcare systems
- Standardized referrals
- Survivorship care plans
- Including support person/caregiver
- Promoting comprehensive healthcare models
- Advocacy and Policy Making



Fauxels, Pexels

25

## Future Research

- Patient Centered Outcomes Research Institute
- Cancers other than Breast Cancer
- Long Term Survivors
- Late effects of new therapies
- Identifying factors for recurrence and adverse effects
- Adolescents and young adult adults
- Survivorship models of care



Lukas, Pexel

26

## Take Home Points to Improve PCP Engagement

Know the Stakeholders in Survivorship Care  
 - Needs, Barriers, Roles and Responsibilities  
 Identify and treat concerns of Survivors  
 Develop and Participate in an Appropriate Model of Care  
 Research is needed to maximize Quality of Care

27

## References

1. Emery J, Butow P, Lai-Kwon J, Nekhlyudov L, Rynderman M, Jefford M. Management of common clinical problems experienced by survivors of cancer. *The Lancet*. 2022;399(10334):1537-1550. doi:10.1016/S0140-6736(22)00242-2
2. Hebden M c., Abrahamson K, Griggs R r., McComb S a. Shared mental models of cancer survivorship care. *European Journal of Cancer Care*. 2018;27(2):e12831. doi:10.1111/ecc.12831
3. Jefford M, Howell D, Li Q, et al. Improved models of care for cancer survivors. *Lancet (London, England)*. 2022;399(10334):1551. doi:10.1016/S0140-6736(22)00306-3
4. Love M, Debay M, Hudley AC, et al. Cancer Survivors, Oncology, and Primary Care Perspectives on Survivorship Care: An Integrative Review. *J Prim Care Community Health*. 2022;13:21501319221105250. doi:10.1177/21501319221105248
5. National Academies of Sciences, Engineering, and Medicine, Health and Medicine Division, Board on Health Care Services, National Cancer Policy Forum. *Long-Term Survivorship Care After Cancer Treatment: Proceedings of a Workshop*. National Academies Press (US); 2018. Accessed May 30, 2023. <http://www.ncbi.nlm.nih.gov/books/NBK499470/>
6. *From Cancer Patient to Cancer Survivor: Lost in Transition*. National Academies Press; 2005. doi:10.17226/11468

28



Anna Shvets, Pexel

29



30

University of Nebraska  
 Medical Center

Nebraska  
 Medicine