



**NCCN Virtual Nursing Program:
Advancing Oncology Nursing™**

**Wednesday, March 17, 2021
4:10 PM – 4:55 PM EDT**

Advancing Survivorship Care through Program Development

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Fred & Pamela Buffett Cancer Center

NCCN.org – For Clinicians | **NCCN.org/patients** – For Patients

Objectives

- Describe several different survivorship care models for the long-term follow-up of cancer survivors.
- Discuss ideas to address special areas of survivorship care including fertility, post allogeneic stem cell transplant care, and the transition of survivors of childhood cancer from pediatric to adult survivorship programs.
- Explain how educational programs for survivors and providers can help promote optimal survivorship care.



Who is a Cancer Survivor?

A *survivor* is anyone living with a history of cancer – from the moment of diagnosis through the remainder of life.

American Cancer Society (2019)



What is Cancer Survivorship?



Why is Survivorship Important?



American Cancer Society (2019)

Survivorship Care Models

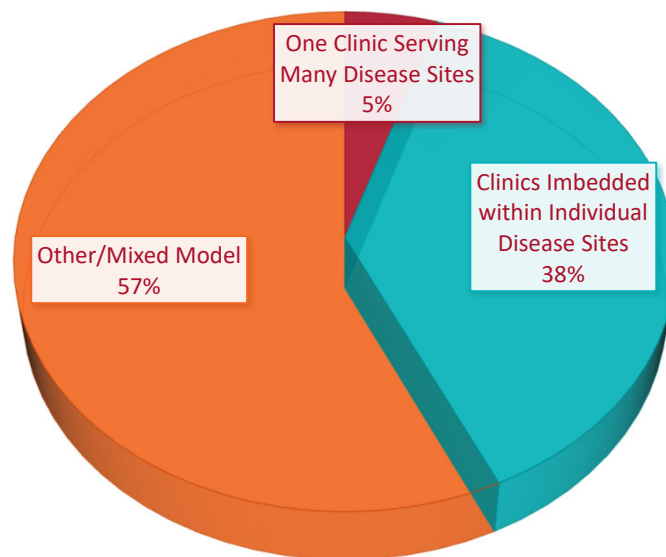


Survivorship Models

Oncology Specialist Care	<ul style="list-style-type: none"> + Continuity of care - Not focused on late/long term effects or wellness; lack of time
Multidisciplinary Clinic	<ul style="list-style-type: none"> + Expertise in late/long term effects; multiple services in one location - Resource and time intensive; not needed by all survivors
Disease Specific Survivorship Clinic	<ul style="list-style-type: none"> + Expertise in one particular area; simple to pilot service and apply guidelines - Limited to survivor populations with large numbers
General Survivorship Clinic	<ul style="list-style-type: none"> + Provides survivorship services for all groups; financially more efficient - Difficult to have expertise in one clinic across all survivor groups
Consultative Survivorship Clinic	<ul style="list-style-type: none"> + Continuity oncologist, fewer resources, provides post treatment plan - One time visit with no follow up; limited time; requires a billing provider
Community / Shared care with Primary Care	<ul style="list-style-type: none"> + Focus is on wellness and co-morbid conditions; promotes independence - Limited knowledge on late/long term effects; roles not clearly delineated



NCCN Member Institutions Survivorship Programs (n=21)



Mixed Model Example

Nebraska Medicine Survivorship Program

General
Survivorship
Clinic

Disease
Based
(Thyroid and
Gyn Onc)

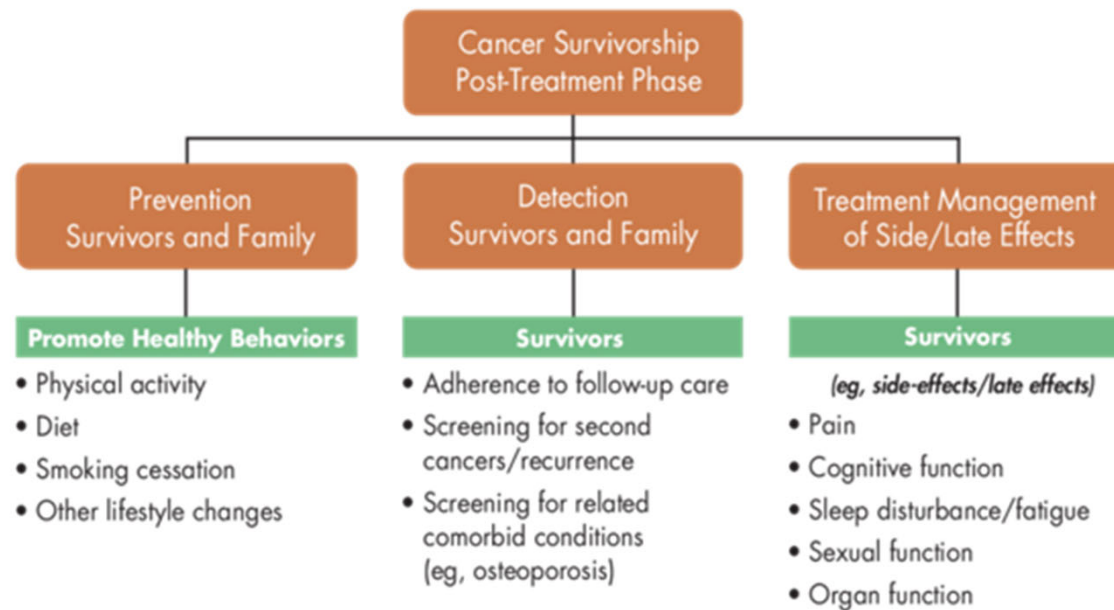
Allogeneic
PSCT Long
Term Follow
Up Clinic

Adult
Survivors of
Childhood
Cancer Clinic

PSCT, peripheral stem cell transplantation



Survivorship Visit Components



Survivorship Care Plan

- Key survivorship component
- Road map for post-treatment care
- Tool for care coordination and communication



Survivorship Care Plan

Cancer Treatment Team Members	
Pediatric Oncologist:	Bruce G Gordon, MD
Cancer and Pathology Information	
Diagnosis	Hodgkin disease
Diagnosis Date:	April 2012 (age 16)
Staging Information:	Staging form: Hodgkin Lymphoma (Pediatrics), COG - Clinical: IIA
Treatment Summary:	
Surgery:	None
Chemotherapy:	ABVE-PC x 4 cycles per COG AHOD0031 completed 7/2012 A = Doxorubicin B = Bleomycin V = Vincristine E = Etoposide P = Prednisone C = Cyclophosphamide
Radiation:	bilateral neck and mediastinum 8/2012 - 9/2012, total 2100cGy



Survivorship = Supportive Care Services

Nutrition

Psychiatry /
Psychology

Physical /
Occupational
Therapy

Support
Groups

Social Work

Smoking
Cessation

Genetic
Testing

Oncofertility

Massage

Acupuncture

Mindfulness

Yoga



Survivorship Research

Assessment and management of symptoms and toxicities

Psychosocial behavioral interventions designed to promote quality of life and reduce symptom burden

Associations between stress, psychosocial factors and symptom burden

Disease activity and survival

Caregiving

Adaptations of survivorship interventions

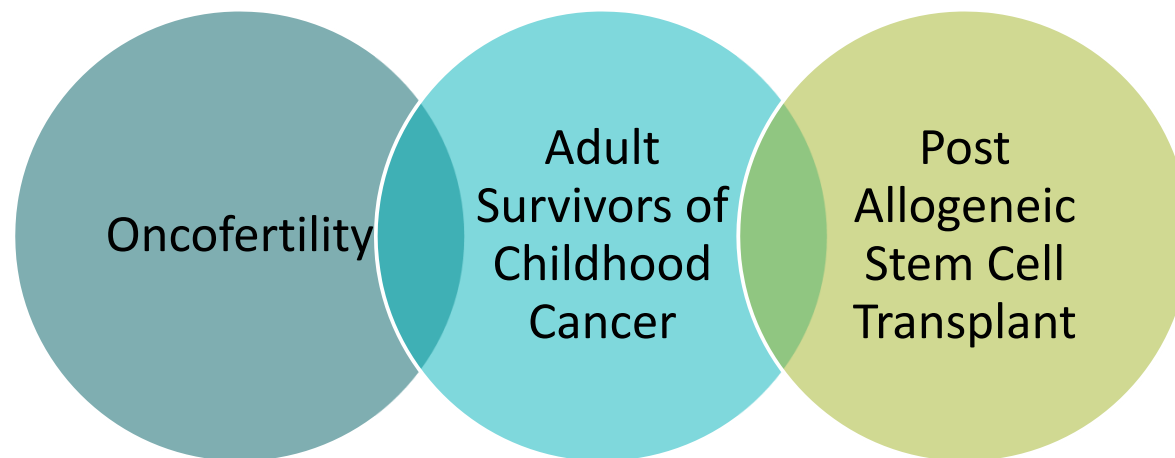
eHealth programs that target symptom management, healthy lifestyle, and care delivery in cancer survivors



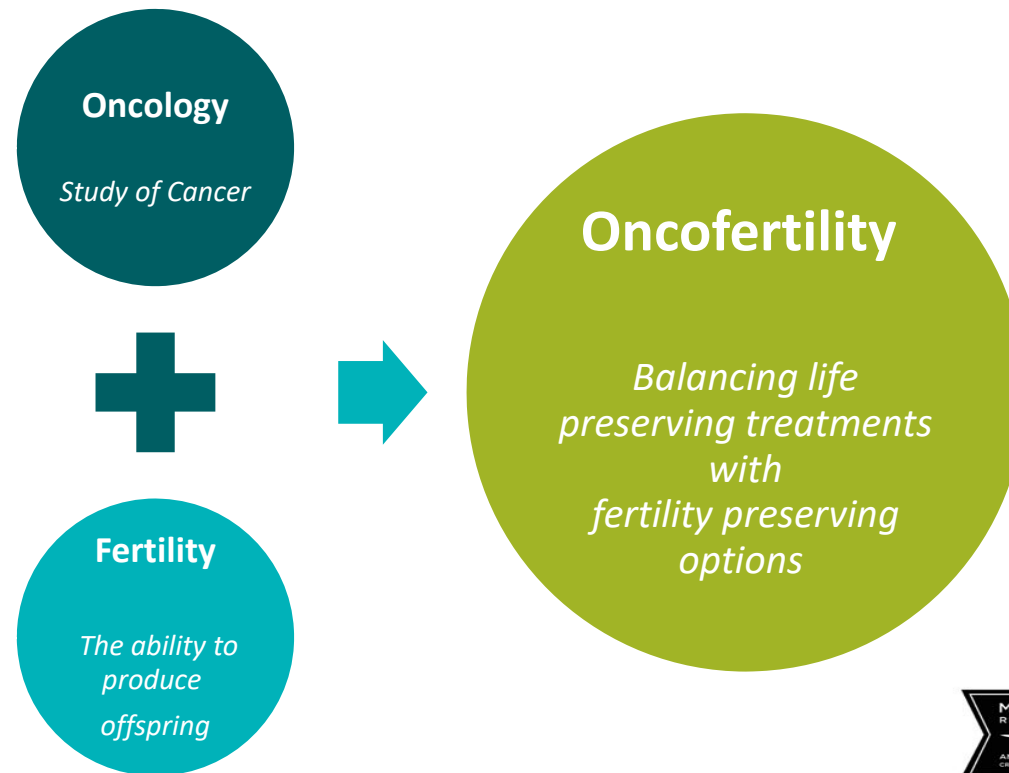
Special Areas of Survivorship



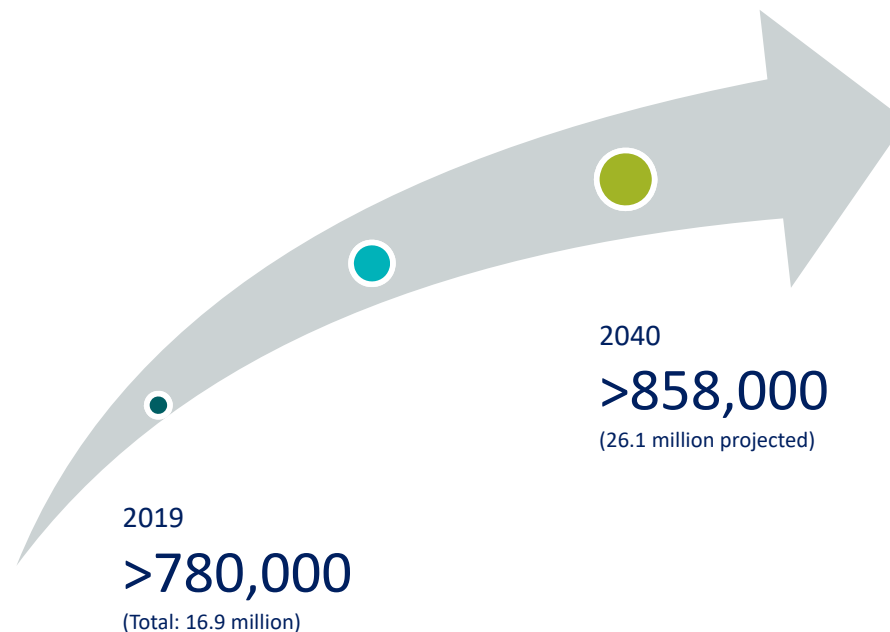
Special Areas of Survivorship



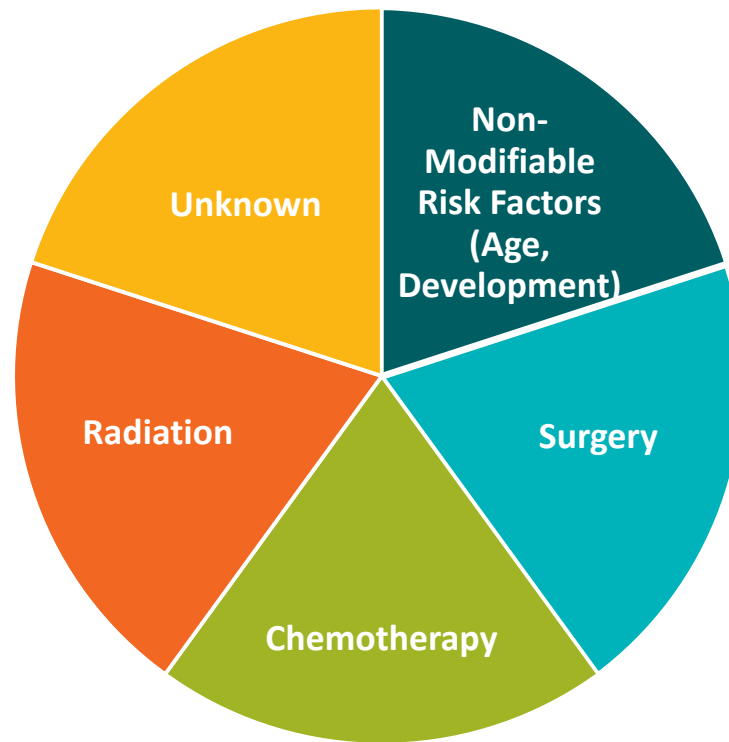
Oncofertility



Oncofertility Significance AYA Cancer Survivors in the US



Oncofertility Significance Infertility Risk Varies



Oncofertility Significance



Oncofertility Significance – Areas to Improve

Documentation

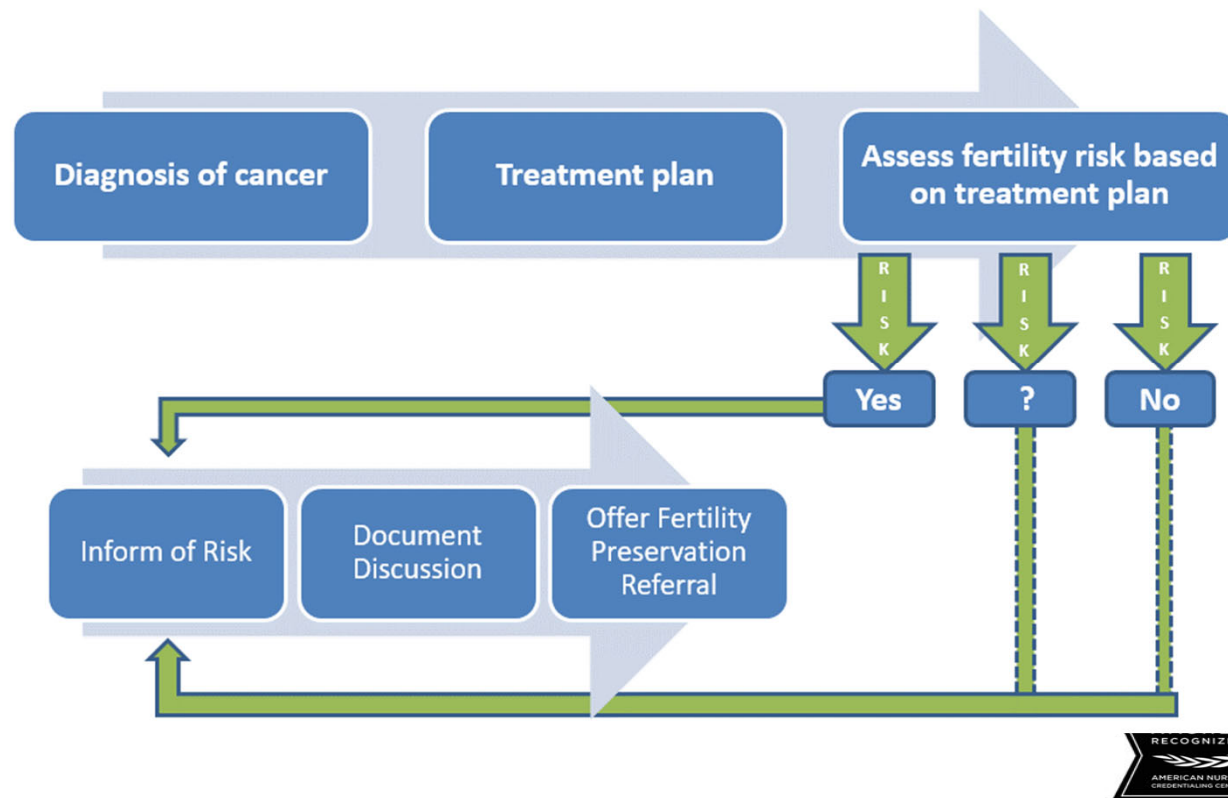
Provider Knowledge
– Infertility
Risk/Options for
Fertility preservation

Patient/Provider
Education materials

Coordination of
Referrals/Financial
assistance



Fertility Preservation



Best Practices to Implement

Discuss infertility risk and fertility preservation with all pts ages 15-45, Parent/Guardian if younger

Refer all interested and ambivalent patients

Address fertility preservation before treatment starts

Document discussion

Answer basic questions about impact on cancer treatment

Refer to psychosocial providers if they experience distress

Encourage registries and clinical trials

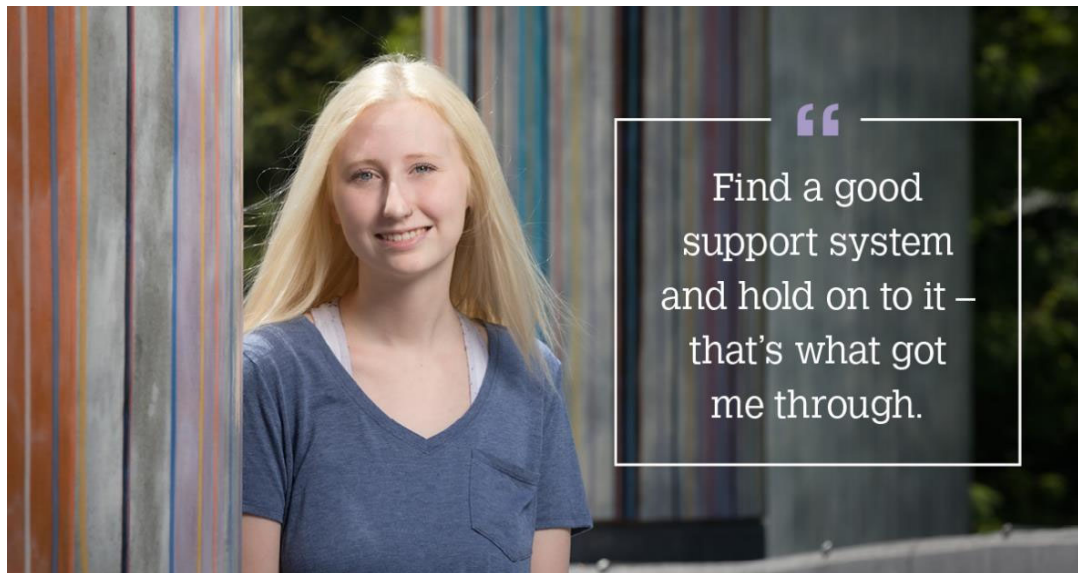


Key Points:

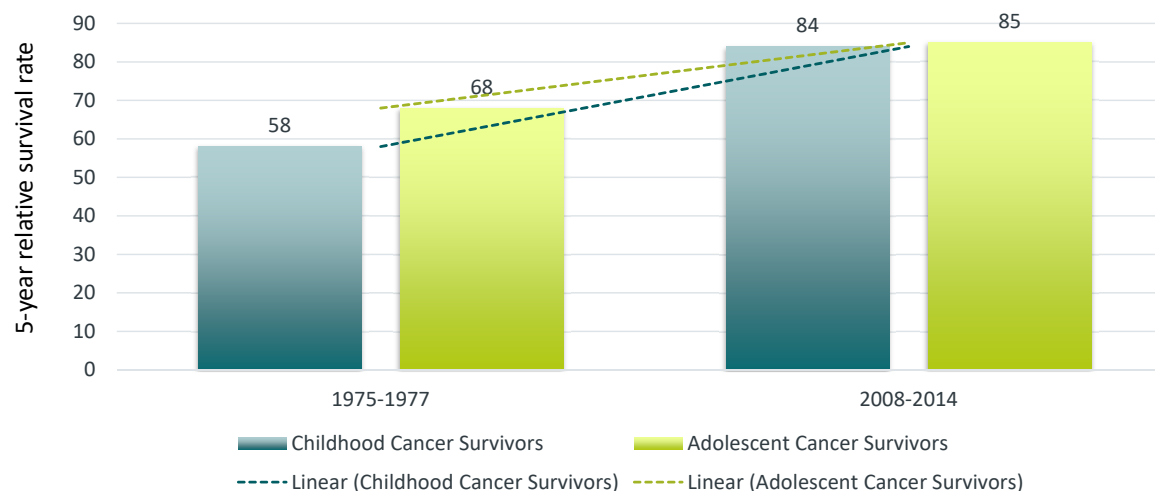
- Don't ask: Do you want a family later on?
- Instead ask: Do you want the choice to have a family later on?
- Document your conversation



Adult Survivors of Childhood Cancer



~400,000 Adult Survivors of Childhood Cancer



American Cancer Society (2019); Sayed (2020)



Two Types of Transition:

Acute Care to Long Term Follow Up

- Varies between institutions
- Focus on late effect screenings and health promotion
- May cause mixed emotions (not seeing staff as frequently)

Pediatric Care to Adult Care

- Occurs as adolescents and young adults “age out” of pediatric healthcare system
- Focus on preparation of survivor and family to assist in successful transition
- May cause mixed emotions while transitioning from familiar to unfamiliar setting with new providers



Areas for Improvement

Adolescent and young adult (AYA) childhood cancer survivors (CCS) should be empowered to continue their survivor-focused care as they transition into adult medicine.

However, the majority of AYA-aged survivors (~60%):

- Have deficient health-related knowledge
- Not engaged in recommended health promotion and screening practices that could improve their long-term outcomes
- Become lost to follow up around the age of typical transition to adulthood



Transition Process

Pediatric Oncology Team

- Followed by pediatric oncology team for ideally 5 years following treatment (varies depending on age)
- Surveillance for disease

Childhood Survivorship Clinic

- Transitions to survivorship when 2-5 years off therapy
- Focuses on late effects
- Prepares patients and families for adult transition starting at age 16-18

Adult Survivors of Childhood Cancer Clinic

- Transitions to adult survivorship between ages 19-25 (2 years off therapy)
- Demonstrates readiness
- Focuses on late effects, refers to adult specialty services as indicated



Adult Survivors of Childhood Cancer Clinic



Children's
Hospital

Nebraska
Medicine
Pediatric BMT

Self Referral



Unique Needs for Young Adult Transition

Knowledge Deficit of Survivor	Psychological Factors	Healthcare System Issues
Knowledge Deficit of Provider	Financial Issues	Insurance Issues

Freyer (2010) ; Mouw (2017)



Themes of Transition Clinic

Emphasize risk-based screening and health promotion

Bridge the knowledge deficit of primary care providers on screening guidelines and health risks

Reinforce the importance of ongoing follow up for asymptomatic survivors

Create a plan and provides ongoing education

Provide up-to-date resources for survivors as they mature

Discussion of infertility risk, assessment, and available options after treatment

Facilitate survivorship research



Key Points:

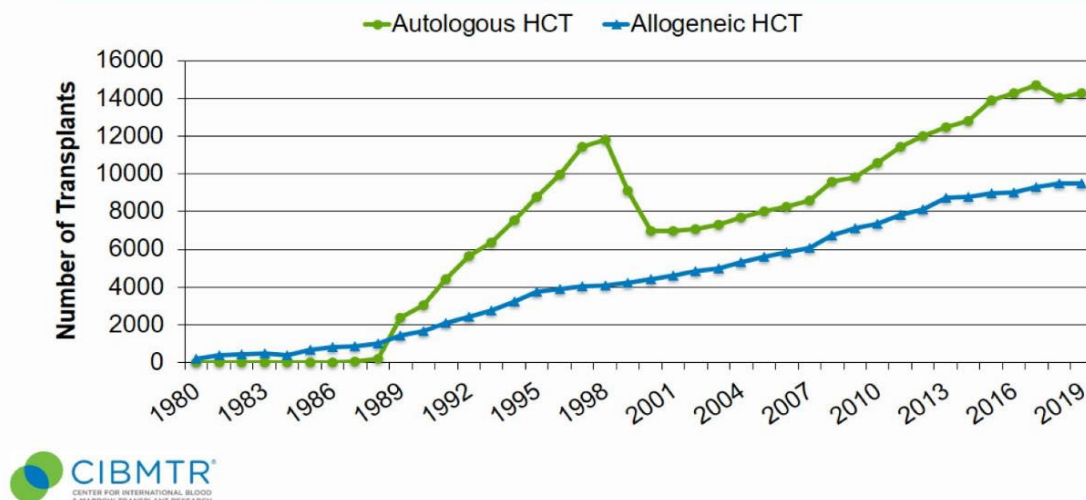
For the adult survivors of childhood cancer, how can we:

- Lower attrition rates
- Improve adherence to care
- Improve relationships (continuity, longitudinal follow-up)



Allogeneic Transplant Survivors

Estimated Annual Number of HCT Recipients in the US by Transplant Type



Phelan, R., Arora, M., Chen, M. Current use and outcome of hematopoietic stem cell transplantation: CIBMTR US summary slides, 2020.



Allogeneic Transplant Survivors

- Patients disease-free at 2 or 5 years have > 80% 10-year survival rate
- Late effects have adverse effects on
 - Morbidity
 - Mortality
 - Working status
 - Quality of life



Allogeneic Transplant Survivors

- Retrospective study (n=1087)
- Cumulative incidence at 5 years post SCT
 - Any non-malignant late effect at 5 years 79%
 - 3 or more late effects 26%
- Life expectancy among 5 year survivors remains 30% lower than general population

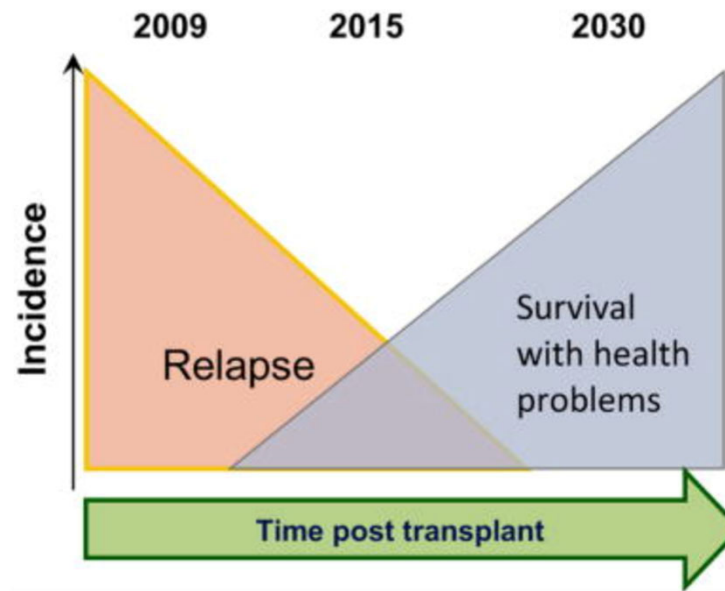
Khara et al. J Clin Oncol. 2012; Martin et al. J Clin Oncol. 2010



Transplant Survivor Continuum

Early Concerns:

- Graft Failure
- Relapse
- Transplant-related complications
- Immunodeficiency



of potential problems increase with time from transplant:

- Metabolic
- Pulmonary
- Bone loss
- Delayed immune reconstitutions
- Renal complications
- Cognitive problems
- Second malignancies

(Battiwalla, M., Tichelli, A., & Majhail, N. S., 2017)



Late Effects

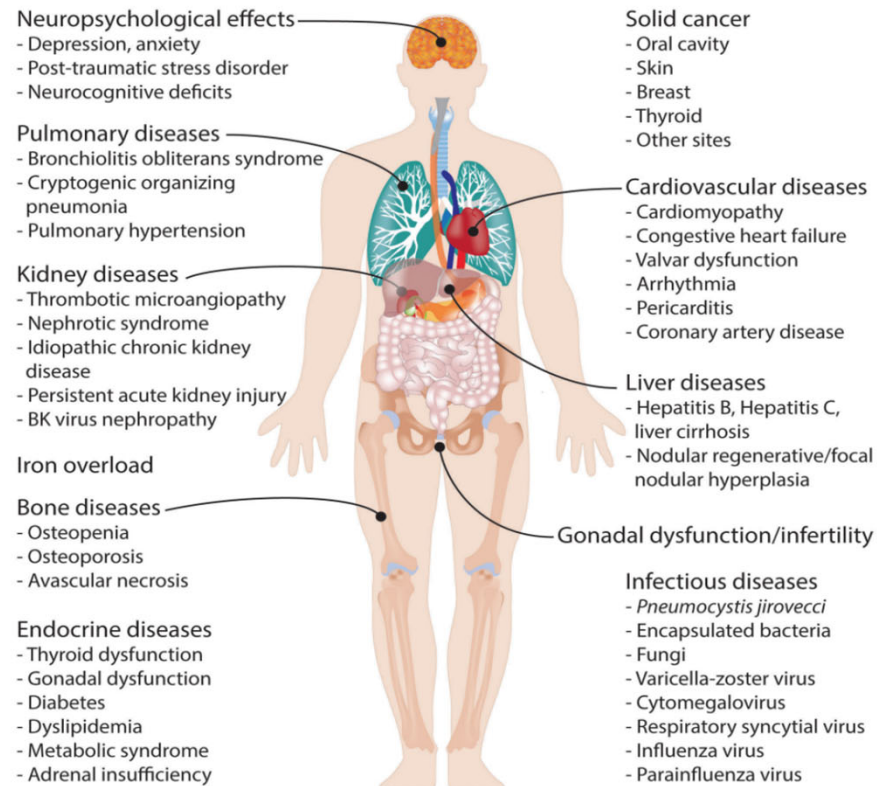


Figure 1. Late effects of blood and marrow transplantation.

Inamoto et al. Haematologica 2017; 102(4)



Long Term Follow Up

Specialized Long Term Follow Up Clinic

- Coordinate long-term management of BMT survivors, offering risk-based screening for early detection of long-term complications.

Dedicated Primary Care Providers

- Special interest in cancer survivorship issues to take on the responsibility of managing such a patient.

Hybrid Approach

- Specialized clinics partner with PCPs in the community to optimize the long-term care of the transplant survivors.



Educational Programs for Survivors and Providers





National Comprehensive
Cancer Network®

NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines®)

Survivorship

Version 1.2021 — February 24, 2021

NCCN.org

NCCN Guidelines for Patients® available at www.nccn.org/patients

Continue

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National
Comprehensive
Cancer
Network®

NCCN Guidelines Version 1.2021 Survivorship

[NCCN Survivorship Panel Members](#)

[NCCN Survivorship Sub-Committee Members](#)

[Summary of the Guidelines Updates](#)

General Survivorship Principles

- [Definition of Survivorship & Standards for Survivorship Care \(SURV-1\)](#)
- [General Principles of the Survivorship Guidelines \(SURV-2\)](#)
- [Screening for Subsequent New Primary Cancers \(SURV-3\)](#)
- [Familial/Genetic Risk Assessment Considerations For Subsequent Primary Cancers \(SURV-4\)](#)
- [Assessment By Health Care Provider at Regular Intervals \(SURV-5\)](#)
- [Survivorship Assessment \(SURV-A\)](#)
- [Survivorship Resources For Health Care Professionals And Patients \(SURV-B\)](#)
- [Principles of Screening for Treatment-Related Subsequent Primary Cancers \(See SURV-C\)](#)

Preventive Health

- [Healthy Lifestyles \(HL-1\)](#)
 - ▶ [Physical Activity \(SPA-1\)](#)
 - ▶ [Nutrition and Weight Management \(SNWM-1\)](#)
 - ▶ [Supplement Use \(SSUP-1\)](#)
- [Immunizations and Infections \(SIMIN-1\)](#)

Late Effects/Long-Term Psychosocial and Physical Problems

- [Cardiovascular Disease Risk Assessment \(SCVD-1\)](#)
- [Anthracycline-Induced Cardiac Toxicity \(SCARDIO-1\)](#)
- [Anxiety, Depression, Trauma, and Distress \(SANXDE-1\)](#)
- [Cognitive Function \(SCF-1\)](#)
- [Fatigue \(SFAT-1\)](#)
- [Lymphedema \(SLYMPH-1\)](#)
- [Hormone-Related Symptoms \(SMP-1\)](#)
- [Pain \(SPAIN-1\)](#)
- [Sexual Function \(SSF-1\)](#)
 - ▶ [Female Treatment Options \(SSF-2\)](#)
 - ▶ [Male Treatment Options \(SSF-3\)](#)
- [Sleep Disorders \(SSD-1\)](#)
- [Employment and Return to Work \(SWORK-1\)](#)

The NCCN Guidelines® are a statement of evidence and consensus of the authors regarding their views of currently accepted approaches to treatment. Any clinician seeking to apply or consult the NCCN Guidelines is expected to use independent medical judgment in the context of individual clinical circumstances to determine any patient's care or treatment. The National Comprehensive Cancer Network® (NCCN®) makes no representations or warranties of any kind regarding their content, use or application and disclaims any responsibility for their application or use in any way. The NCCN Guidelines are copyrighted by National Comprehensive Cancer Network®. All rights reserved. The NCCN Guidelines and the illustrations herein may not be reproduced in any form without the express written permission of NCCN. ©2021.

Clinical Trials: NCCN believes that the best management for any patient with cancer is in a clinical trial. Participation in clinical trials is especially encouraged.

To find clinical trials online at NCCN Member Institutions, [click here: nccn.org/clinical_trials/member_institutions.aspx](#).

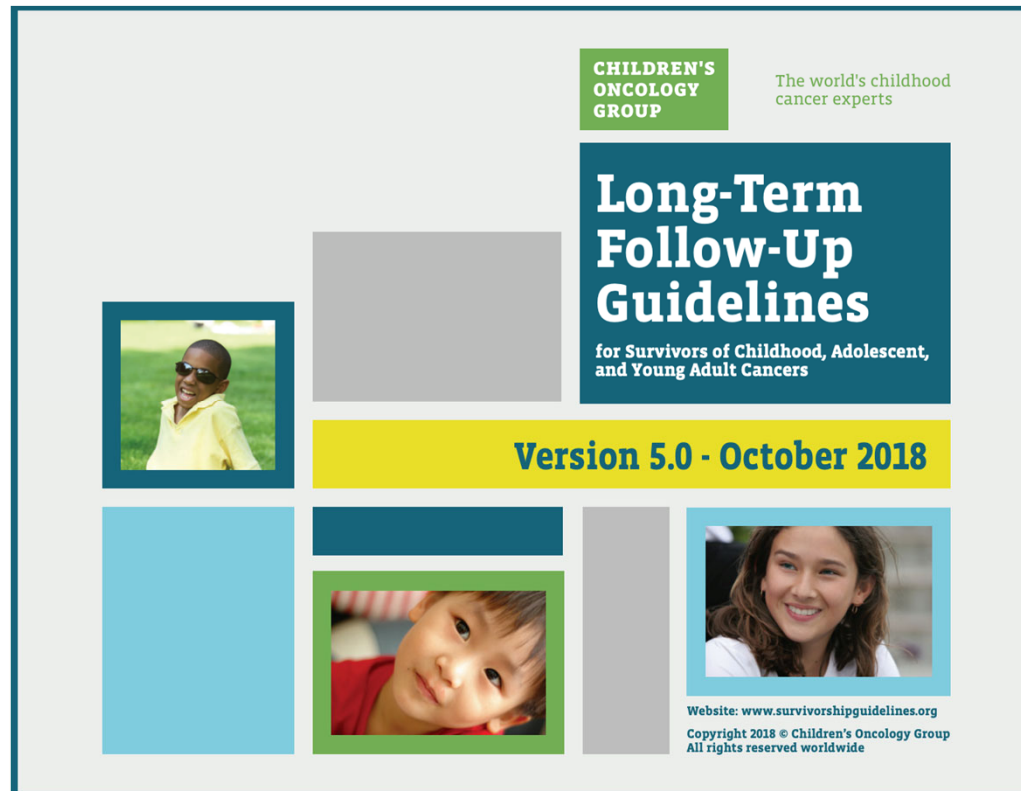
NCCN Categories of Evidence and Consensus: All recommendations are category 2A unless otherwise indicated.

See [NCCN Categories of Evidence and Consensus](#).

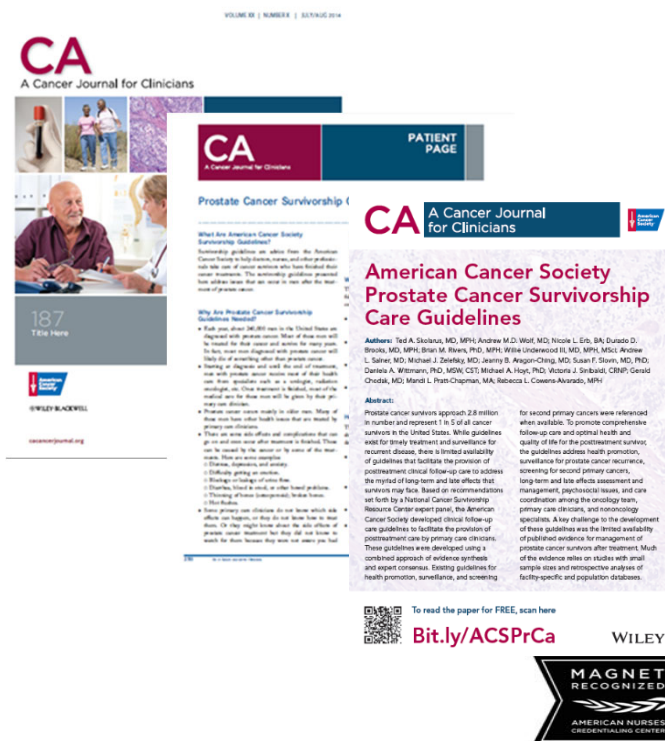
Nearly 300 pages

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Children's Oncology Group



American Cancer Society Survivorship Care Guidelines





CANCER SURVIVORSHIP E-LEARNING SERIES FOR PRIMARY CARE PROVIDERS

Module 1: The Current State of Survivorship Care and the Role of Primary Care Providers

Module 2: Late Effects of Cancer and its Treatments: Managing Comorbidities and Coordinating with Specialty Providers

Module 3: Late Effects of Cancer and its Treatments: Meeting the Psychosocial Health Care Needs of Survivors

Module 4: The Importance of Prevention in Cancer Survivorship: Empowering Survivors to Live Well

Module 5: A Team Approach: Survivorship Care Coordination

Module 6: Cancer Recovery and Rehabilitation

Module 7: Spotlight on Prostate Cancer Survivorship: Clinical Follow-Up Care Guideline for Primary Care Providers

Module 8: Spotlight on Colorectal Cancer Survivorship: Clinical Follow-Up Care Guideline for Primary Care Providers

Module 9: Spotlight on Breast Cancer Survivorship: Clinical Follow-Up Care Guideline for Primary Care Providers

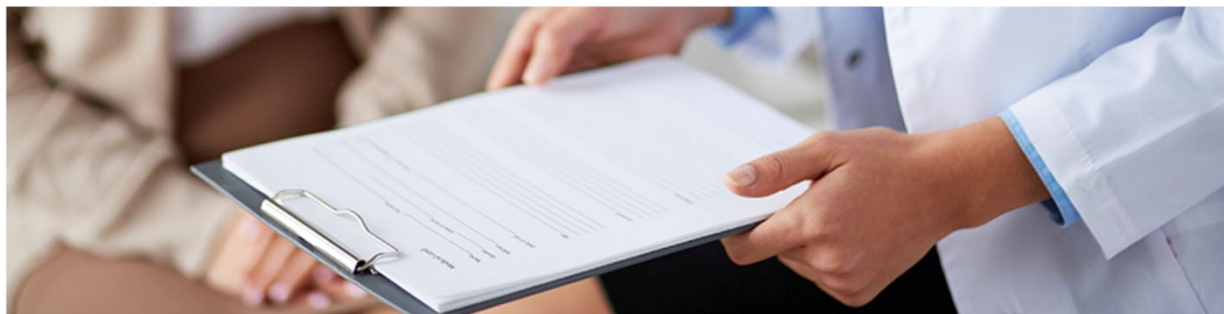
Module 10: Spotlight on Head and Neck Cancer Survivorship: Clinical Follow-Up Care Guideline for Primary Care Providers





School of Medicine
& Health Sciences

National Cancer Survivorship Resource Center Toolkit



- **Implementing Clinical Practice Guidelines for Cancer Survivorship Care**
- **Cancer Specific Checklists**
- **Provider Tools**
- **Patient Tools**



Survivorship Compendium

Key Components of
Survivorship Care →

Building a Survivorship
Care Program →

Models of Long-Term
Follow-Up Care →

Determining the Best
Model for You:
Conducting a Needs
Assessment →

Challenges to
Implementing a
Survivorship Program →

Providing Survivorship
Care in Practice →

Measuring the Quality
of Survivorship Care →



Survivorship Clinical
Tools & Resources →

Coverage &
Reimbursement for
Survivorship Care
Services →

Survivorship Care
Educational
Opportunities →

Survivorship Patient &
Family Resources →



[Home](#)[Courses](#)[The Program](#)[Contact Us](#)

Welcome to ECHO

ECHO is a web-based training program that includes psychosocial, biological, clinical and skill building modules to help oncology allied health professionals (nurses, physician assistants, social workers, and psychologists) communicate timely and relevant information regarding reproductive health to their adolescent and young adult (AYA) patients. This program and course materials provided at no cost to participants.

The 2021 ECHO Training Program will begin on January 14th, 2021 and end on March 19th, 2021.

Interested in participating in ECHO?

Thank you for your interest in the ECHO Training Program! We are not accepting applications at this time. If you would like to be informed of future ECHO opportunities, please fill out this brief form.



[Yes I'm Interested](#)

Enriching Communication Skills for Health Professionals in Oncofertility (ECHO)

Virtual Course

Topics focused on:

- Risk of infertility
- Fertility preservation
- Sexual functioning
- Body image
- Ethical, social, cultural considerations





American Institute for
Cancer Research®

Healthy Living Tips For Cancer Survivors

The same evidence-based guidelines that help prevent cancer also **help reduce**
risk of cancer recurrence and other non-communicable diseases.

ITHRIVE PLAN

Personalize Your Health and Wellness

Many cancer survivors talk about the challenge of facing a “cliff” after the activity of medical treatment has ended. There’s a new normal to navigate, and new health concerns to consider. **Use the Access Code [aicr](#) when joining.**

JOIN NOW





Get Started

This free and easy to use program provides cancer survivors with information regarding the health risks they face as a result of cancer therapies.

[Develop My Cancer Survivorship Care Plan](#)



Programs for Survivors

How are you celebrating your survivors?

Despite the challenges of short-term and long-term effects of treatments, cancer survivors are resilient.

Cancer Survivors' Month is celebrated in June. This is a time to celebrate milestones and serves as a reminder of our mission.



Virtual Events

- Virtual events offered June 1- 7th
- Online cooking demo
- Virtual Yoga Mindfulness and stress reduction
- Exercise at home



June 1 through 7

Brought to you virtually by Nebraska Medicine. Learn more about each activity listed below and register at NebraskaMed.com/Survivorshipweek.

Downloadable frame to place around your Facebook profile picture to show your support



Online cooking demo and overview of nutrition guidelines for survivors offered by Fred & Pamela Buffett Cancer Center specialized dieticians, Karen Overman, MMN, RDN, LMNT, and Sam Nessetti, MMN, RDN, LMNT



Virtual yoga class provided by One Tree Yoga

Presentation on mindfulness and stress reduction by Steven P. Wengel, MD, assistant vice chancellor for Campus Wellness for UNO and UNMC



Check out Facebook.com/NebraskaMed to learn more from cancer survivors throughout this special week



Online presentation on exercise for cancer survivors (discuss why it is so important, research, and what you can do from home to start) by Diane Ehlers, PhD, and Lindsey Hanson, MS, ACSM-CEP



Nebraska Medicine

Sponsored by Nebraska Medicine Guild



References

American Cancer Society. *Cancer Treatment & Survivorship Facts & Figures 2019-2021*. Atlanta: American Cancer Society; 2019.

Battiwalla, M., Tichelli, A., & Majhail, N. S. (2017). Long-Term Survivorship after Hematopoietic Cell Transplantation: Roadmap for Research and Care. *Biology of blood and marrow transplantation : journal of the American Society for Blood and Marrow Transplantation*, 23(2), 184–192. <https://doi.org/10.1016/j.bbmt.2016.11.004>

Flores, T., Glaser, K. M., McDaniel, D., Rokitka, D., Amato, K. A., & Reid, M. E. (2019). Building a comprehensive cancer survivorship program. *Ecancermedicalscience*, 13, 992. <https://doi.org/10.3332/ecancer.2019.992>

Freyer D. R. (2010). Transition of care for young adult survivors of childhood and adolescent cancer: rationale and approaches. *Journal of clinical oncology : official journal of the American Society of Clinical Oncology*, 28(32), 4810–4818. <https://doi.org/10.1200/JCO.2009.23.4278>

Mouw, M. S., Wertman, E. A., Barrington, C., & Earp, J. A. (2017). Care Transitions in Childhood Cancer Survivorship: Providers' Perspectives. *Journal of adolescent and young adult oncology*, 6(1), 111–119. <https://doi.org/10.1089/jayao.2016.0035>

Phelan, R., Arora, M., Chen, M. Current use and outcome of hematopoietic stem cell transplantation: CIBMTR US summary slides, 2020.

Sadak, K.T., Gameda, M.T., Grafelman, M. *et al.* Identifying metrics of success for transitional care practices in childhood cancer survivorship: a qualitative interview study of survivors. *BMC Cancer* 20, 898 (2020). <https://doi.org/10.1186/s12885-020-07360-9>



Questions?

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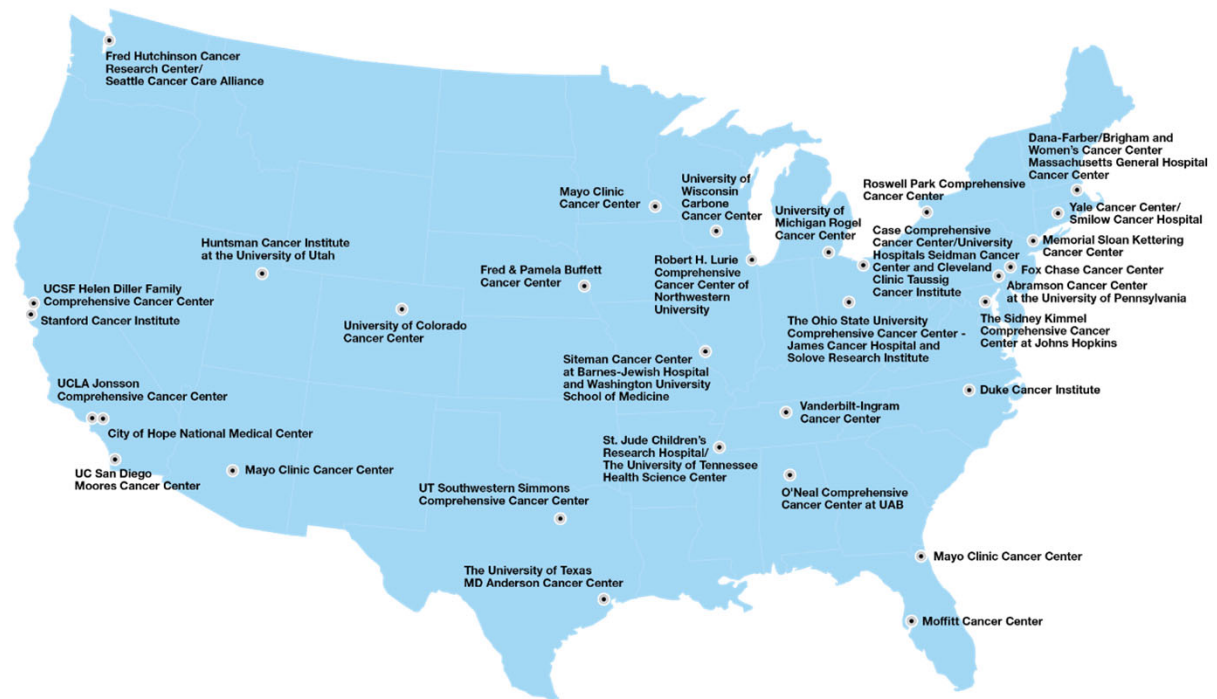




National Comprehensive
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- **Who We Are**
An alliance of leading cancer centers devoted to patient care, research, and education
- **Our Mission**
To improve and facilitate quality, effective, efficient, and accessible cancer care so patients can live better lives
- **Our Vision**
To define and advance high-quality, high-value, patient-centered cancer care globally

NCCN Member Institutions



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