



Survivorship Care Plans: Being an Empowered Patient

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Fred Hutch Cancer Center

Moving Beyond Cancer To Wellness
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Today's Topics

- **Understanding survivorship**
- **Common late and long-term effects of cancer and cancer treatment**
- **Cancer treatment summaries and care plans**
- **Survivorship Consult visit**



Who is a “Cancer Survivor”?

- NCI definition

“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 and included in this definition.”



National
Comprehensive
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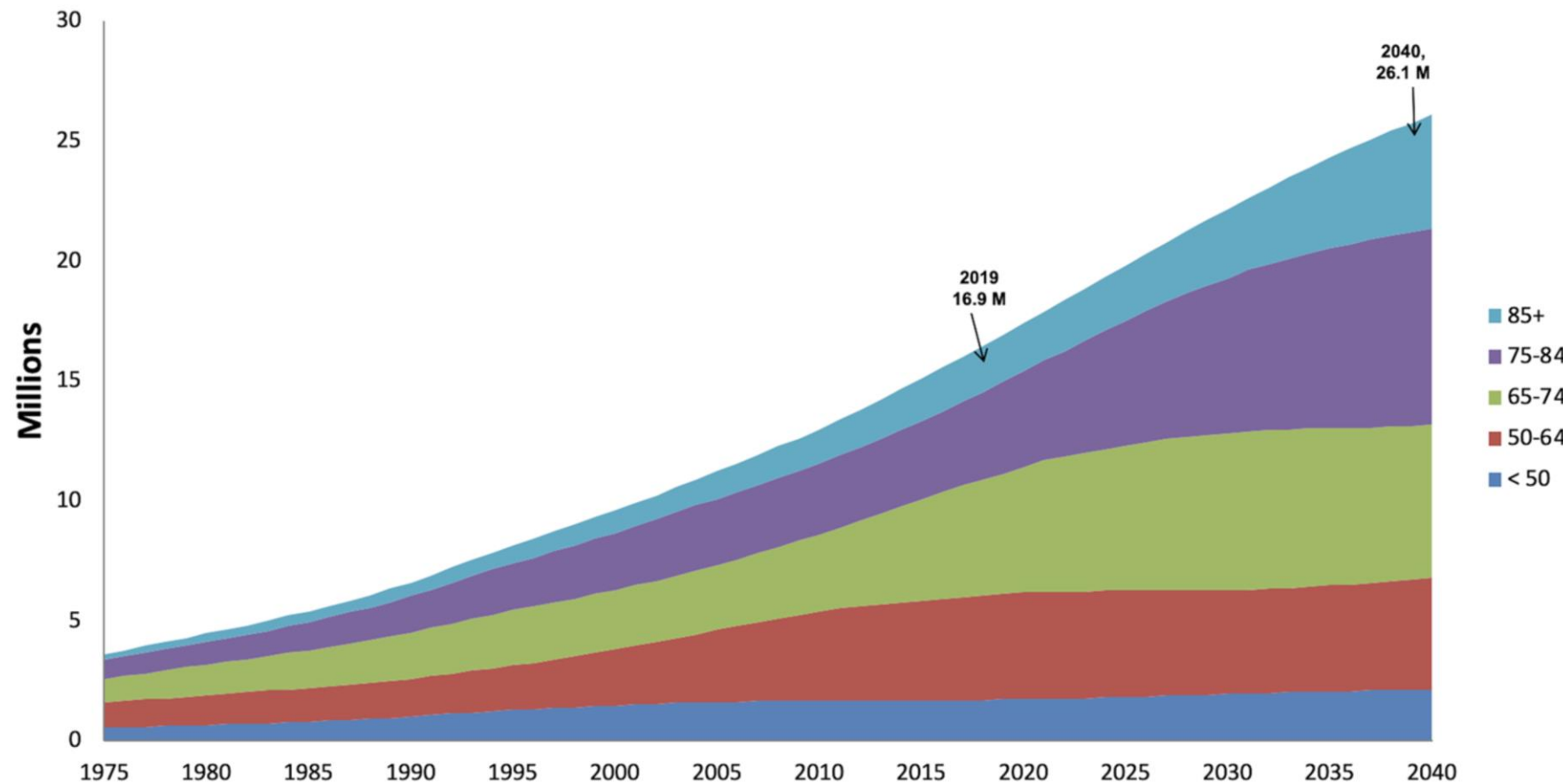
NCCN Guidelines Version 2.2020 Survivorship

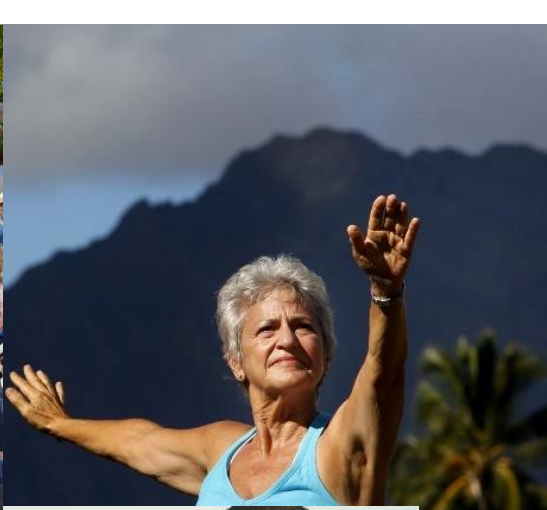
[NCCN Guidelines Index](#)
[Table of Contents](#)
[Discussion](#)

DEFINITION OF SURVIVORSHIP

- **An individual is considered a cancer survivor from the time of diagnosis, during and immediately after treatment, and through the balance of his or her life. Family members, friends, and caregivers are also affected by cancer.^a**
- **These guidelines focus on the vast and persistent impact both the diagnosis and treatment of cancer have on the adult survivor. This includes the potential impact on health, physical and mental states, health behaviors, professional and personal identity, sexuality, and financial standing.**
- **These guidelines are applicable to survivors across the continuum of care, including those on endocrine therapy, with chronic cancers (eg, metastatic disease), and long-term survivors.**

Growth in the number of cancer survivors over time in the United States





Surviving and Thriving:
Comes in many shapes, sizes, needs and capabilities



Cancer Survivors are ALL OF US.

We will have cancer

or people we love will have cancer.

Survivorship is about living life as healthy as

possible and as well as possible

with and beyond cancer.

The Good News!

- **Most cancer survivors describe themselves as having good-excellent health (60-80%)**
- **Most cancer survivors are psychologically healthy before and after treatment**



Those who function well may have needs that are not observable.



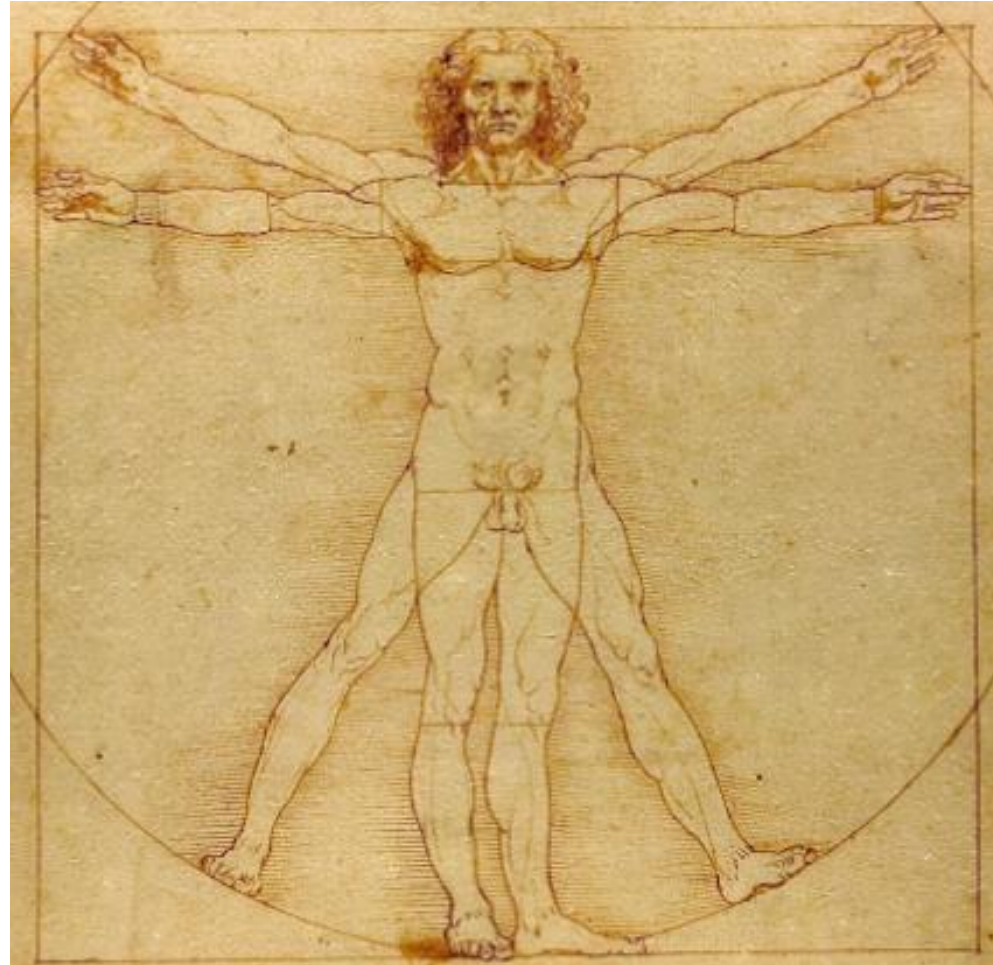
Cancer Survivor Challenges

Wellness & PsychoSocial

- Mental health
- Employment
- Education
- Social interactions/support
- Chronic symptoms:
 - Fatigue, Cognition,
 - Insomnia, Neuropathy
- Lifestyle
- Physical function

Environment & Finances

- Family / Caregiver function
- Access to health & resources
- Insurance
- Financial toxicity



Organ Function

- Cardiac
- Endocrine
- Musculoskeletal
- Genitourinary
- GI/Hepatic
- Neurologic
- Pulmonary

Subsequent Malignancies

- Recurrent cancer
- New cancers

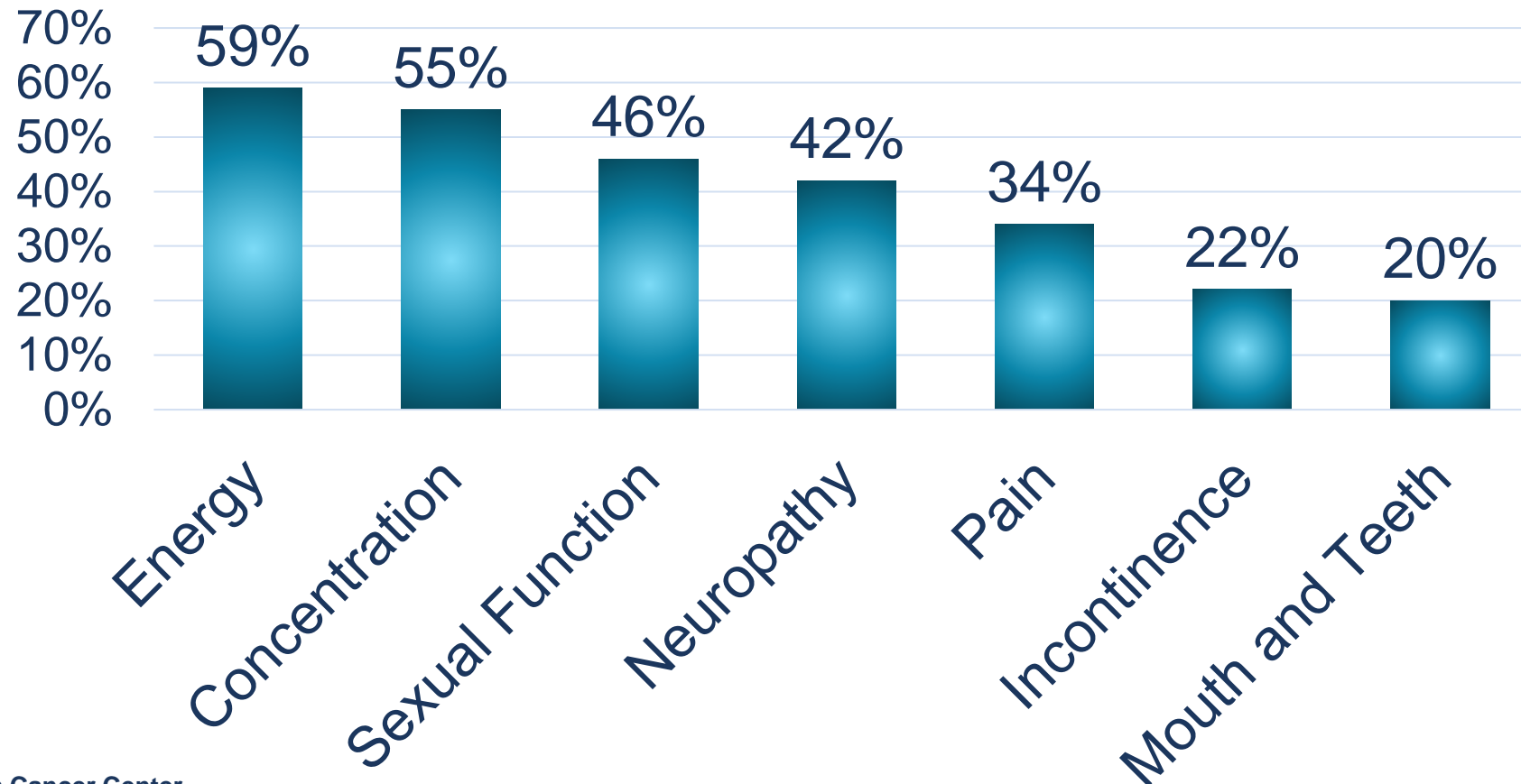
Fertility & Reproduction

- Sexual functioning
- Health of offspring
- Fertility



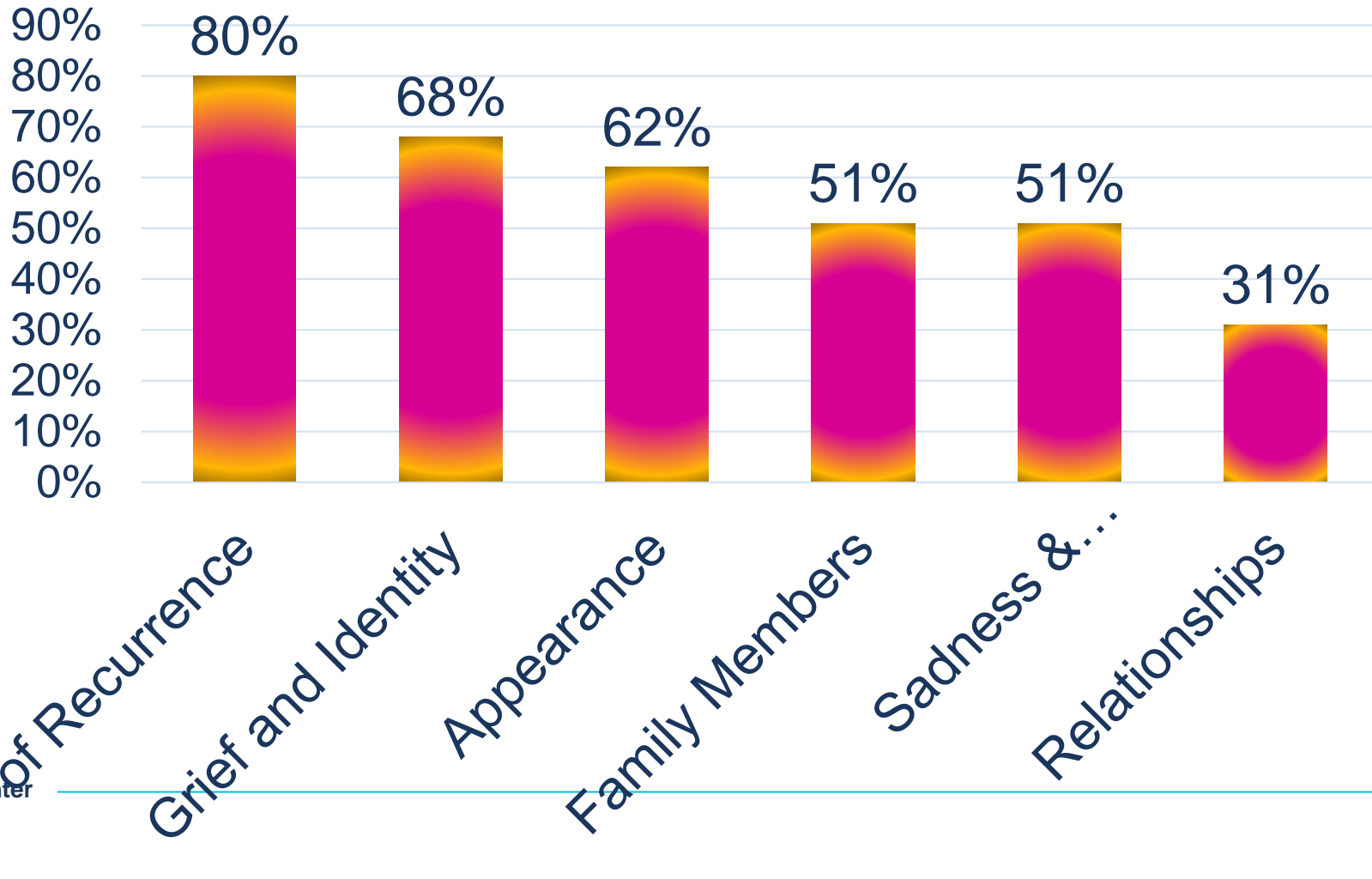
Percent of survivors who report

Physical Concerns



Percent of survivors who report

Emotional Concerns



Distress Reactions of Survivors

Uncertainty

- * Not knowing what the future will bring
- * Thoughts and feelings about recurrence

Grief and Loss

- * What will never be (fertility/pregnancy)
- * What is changed forever (hair, work, energy)
- * Includes body image, self-esteem

Fear of

Recurrence

- * Intrusive thoughts about cancer recurring
- * Worry encroaches on activities, sleep, enjoyment
- * Afraid to rebuild life - disappointment



In the Words of a Non-Hodgkin's Survivor

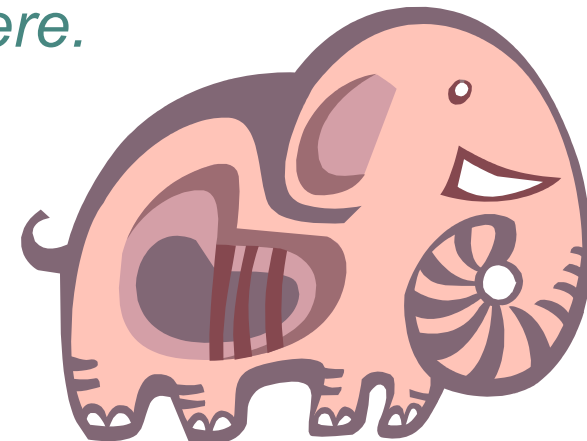


“After I was in remission a few years, I was told to call my doctor if I had a problem. But after cancer, you starting imagining the worst with every little twinge: is this something I should watch for or be concerned about?”

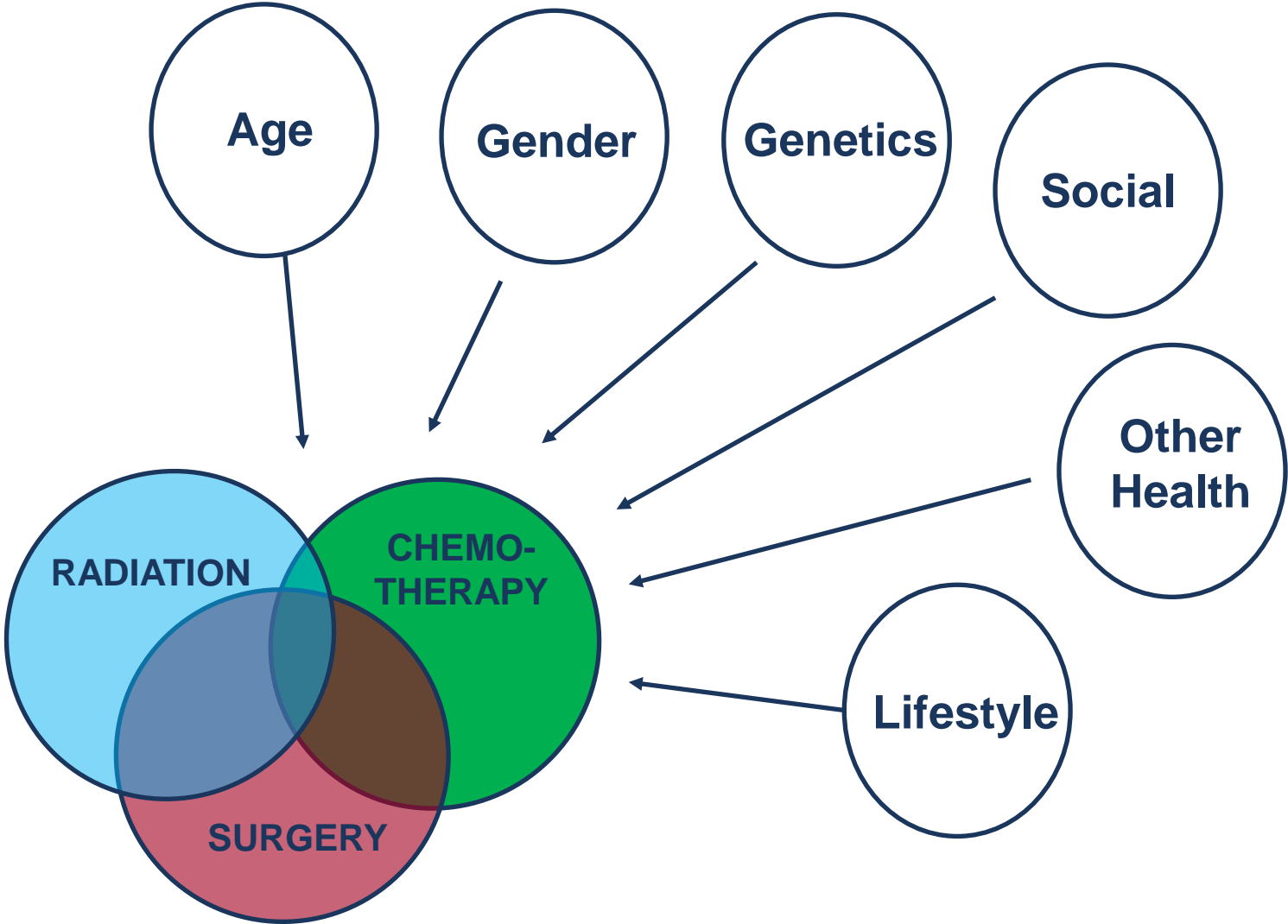


Fear of Recurrence

“Someone likened cancer to a pink elephant, and the pink elephant initially is right there in front of your face, you know... and then as you get better, the pink elephant maybe goes to another room. And then as you get much better, the pink elephant goes down the street, but it’s always there and you always know it’s there.”



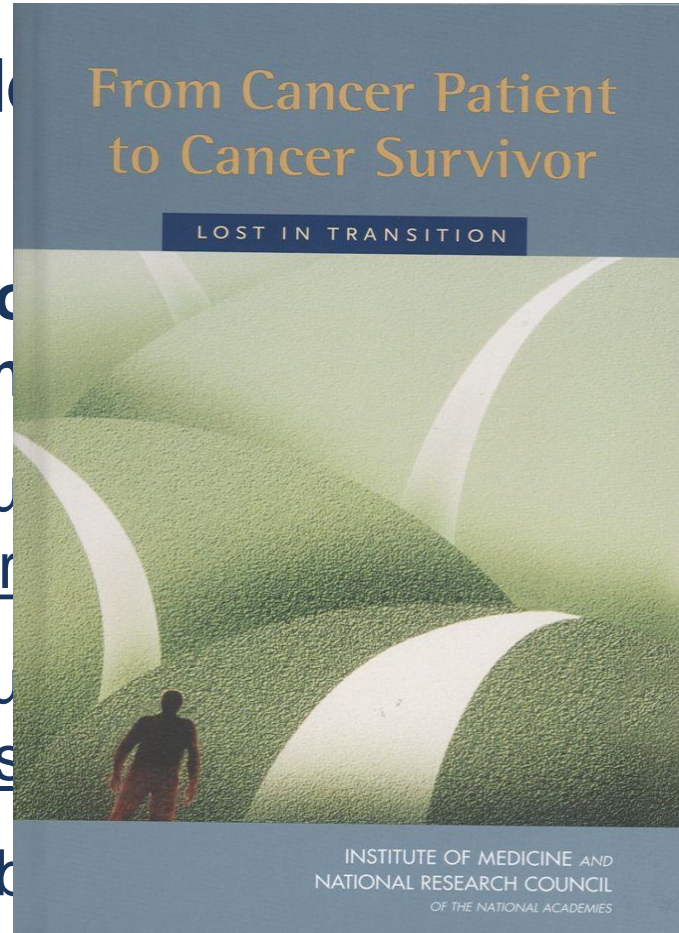
Assessment of Risk



From Cancer Patient to Cancer Survivor: Lost In Transition (2006)

IOM Report Identifies Key Needs:

1. Every survivor needs a comprehensive treatment summary and care plan.
2. Prevention, surveillance, and management of new and recurrent cancers.
3. Prevention, surveillance, and management of long-term consequences of cancer and its treatment.
4. Coordination between primary care providers to ensure that survivor health needs are met.



Survivors do not know what they do not know

- Many survivors do not know what they need: what is 'normal'
 - Unaware of what tests and follow up visits they should have
 - Unsure which physician specialists they should continue to see, or see for what
 - Unsure how they 'should feel'
- Care Coordination is unclear
 - Oncologist may think primary care is doing monitoring beyond cancer surveillance
 - Primary care may think oncologist is doing cancer monitoring and preventive care
 - Survivors may not know who to see when and for what
 - If survivors look fine and are not complaining, assume all is well
- Lack access to survivorship care
 - Services are not available or survivors do not know about services



Survivorship Treatment Summary and Care Plan Goals

- Summary of cancer history/treatment
- Primary cancer surveillance plan
- Cancer/cancer treatment health risks
- Subsequent cancer/late effects screening
- Promote a healthy lifestyle to reduce cancer risks and maximize wellness
- Screening for/management of health conditions
- Definition of roles of involved providers
- Resources to address medical/psychosocial needs

i Systemic Therapy (Chemotherapy, Biotherapy, Adjuvant Therapy, Other)				
Agent:	Route:	Cycles:	Date Start:	Date Stop:
Cumulative Anthracycline Dose Administered: i				
Blood Products:		Growth Factors:		
Radiation Therapy				
Date Start	Date Stop	Total Dose (cGy)	i	
Fields included: i				
Complications of therapy:				
Dose reduction:				
Complications (from which modality if known):				
Providers				
General Medical Care:		Oncologic Care:		

Long term effects and Follow-Up care	Recommendation
Cardiac Health	Heart problems can occur after certain chemotherapy drugs (anthracyclines) or after chest
Lung/Respiratory	<p>Recommendations driven by:</p> <p>Specific Exposure:</p>
Musculoskeletal	
Cognitive	e)
Fertility	
Hormonal Changes	<p>Diagnosis</p> <p>Age</p>
Secondary cancers	<p>Gender</p>
	<p>exposure. Notify your health care provider...</p>

2. CARE PLAN

WELLNESS Recommendations	
✓ Health Maintenance	Make sure you keep up to date on vaccinations and routine health maintenance screening (cholesterol, blood pressure, skin
✓ Exercise and Physical Activity	The SCCA encourages breast cancer survivors to adopt a physically active lifestyle. Try to engage in at least 30 minutes of moderate
Lymphedema	Review lymphedema prevention education. Consider a referral to physical therapy for lymphedema, range of motion...
✓ Nutrition	The SCCA supports the nutrition guidelines of the American Cancer Society to optimize health and reduce cancer risk.
Genetic counseling and testing	If there is a history of cancer in your family, or if you were diagnosed with breast cancer at a very young age,
Fear of Recurrence	Develop and strengthen coping skills. Talk to friends and family. Request a referral to a therapist and information on...
✓ Heart Health	Low fat diet, regular aerobic exercise and maintaining weight and blood pressure. Know what your cholesterol level is.
✓ Bone Health	Regular weight bearing exercise. Daily Calcium and vitamin D,
Pain	Regular exercise both aerobic and resistance training, stretching,
Fatigue	Adequate sleep, regular exercise and good nutrition will facilitate recovery and reduce fatigue after treatment.
✓ Sexual Health/Body Image	Communicate with your partner. Suggest vaginal lubricants/ moisturizers and plan time for intimacy.
✓ Memory/ cognitive concerns	Look into organizational strategies such as establishing a routine
Plan	

FOLLOW-UP CARE				
TEST	LAST DONE	FREQUENCY	PROVIDER TO CONTACT	NEXT DUE
Complete Physical Exam		Yearly		
Oncology Follow-up		As per oncologist		
Surveillance for Risk of Recurrence		Set by your Oncologist		
Bone Density Test (DEXA)		Every 2-5 years		
Colonoscopy		Every 10 years		
Screening Labs				
Gynecological Exam		Yearly		
Pap Smear		Every 3 years		
Mammogram		Every 2 years		
Breast MRI				
Skin Exam		Yearly		
Cardiac Screening		TBD		
Vision Exam		Yearly		
Dental Exam		Twice a year		
Immunizations		Yearly		
CONTACT/RESOURCES				
Education		Survivorship Notebook provided		
Contact Survivorship Clinic		survivor@seattlecca.org or 206-288-1021		
Resources				

Prevention Works!

Control the things you can control...

- Keep blood pressure, cholesterol, blood sugar and weight under control
 - Nutrition is vital
 - Exercise
 - Addressing emotional needs
 - Manage stress
 - Alcohol and substance use
 - Quit smoking
 - Sleep is critical for physical and emotional well-being, immune function, and coping



Benefits of Survivorship Care

Cancer survivors are best served when they have the support of both primary care and their oncology team after they complete treatment.

The TS/SCP is shared with the patient, patient's primary care provider, oncologist and other specialists in order to:

- Improve communication and collaboration of health care team
- Empower the patient and entire care team
- Educate community providers, limiting fear of accepting survivors as patients
- Support patient self-advocacy through knowledge of surveillance, prevention, early detection and wellness needs



And, It's What Our Patients Need

A treatment summary and survivorship plan are the pieces that have been missing in my care since finishing treatment.

A survivorship care plan is the formerly missing step to help us survivors regain our dignity and confidence moving forward with a plan with our eyes open.

After my cancer treatment, I knew there were tests I needed and illness I was at an increased risk for, but I didn't know the specifics. Now I know exactly what I need to do to be as healthy as possible in the future.



Fred Hutch Cancer Center Survivorship Program

•The **mission** of the Fred Hutch Survivorship Program is to improve the lives of cancer survivors through integrated research, education and advancements in clinic care.

- Clinical care
- Research
- Outreach



Fred Hutch Survivorship Clinic

- 60 minute visit in person or telehealth
 - **Eligibility:** Any one with a history of cancer treatment, does not need to have received treatment at Fred Hutch Cancer Center.
 - Recommended after treatment has been completed and before surveillance visits are completed to assist transition to primary care.
 - Can be referred by oncology team, primary care or **self-refer**.
- Evaluation and assessment of your Survivorship needs
- Review individualized Treatment Summary and Survivorship Care Plan
- Most insurance plans consider this a necessary visit for individuals who have received treatment for cancer; prior to appointment, patients are counseled about contacting insurance provider to review coverage





[NCCN Survivorship Panel Members](#)
[NCCN Survivorship Sub-Committee Members](#)
[Summary of the Guidelines Updates](#)

General Survivorship Principles

- [Definition of Survivorship \(SURV-1\)](#)
- [Standards for Survivorship Care \(SURV-2\)](#)
- [General Principles of the Survivorship Guidelines \(SURV-3\)](#)
- [Screening for Subsequent New Primary Cancers \(SURV-4\)](#)
- [Principles of Cancer Risk Assessment and Counseling \(SURV-5\)](#)
- [Assessment by Health Care Provider at Regular Intervals \(SURV-6\)](#)
- [Survivorship Assessment \(SURV-A\)](#)
- [Survivorship Resources for Health Care Professionals and Survivors \(SURV-B\)](#)
- [Principles of Screening for Treatment-Related Subsequent Primary Cancers \(SURV-C\)](#)

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 \(SLYMPH-1\)](#)
- [Pain \(SPAIN-1\)](#)
- [Hormone-Related Symptoms \(SHRS-1\)](#)
- [Sexual Health \(SSH-1\)](#)
- [Fertility \(SF-1\)](#)
- [Sleep Disorders \(SSD-1\)](#)
- [Employment and Return to Work \(SWORK-1\)](#)

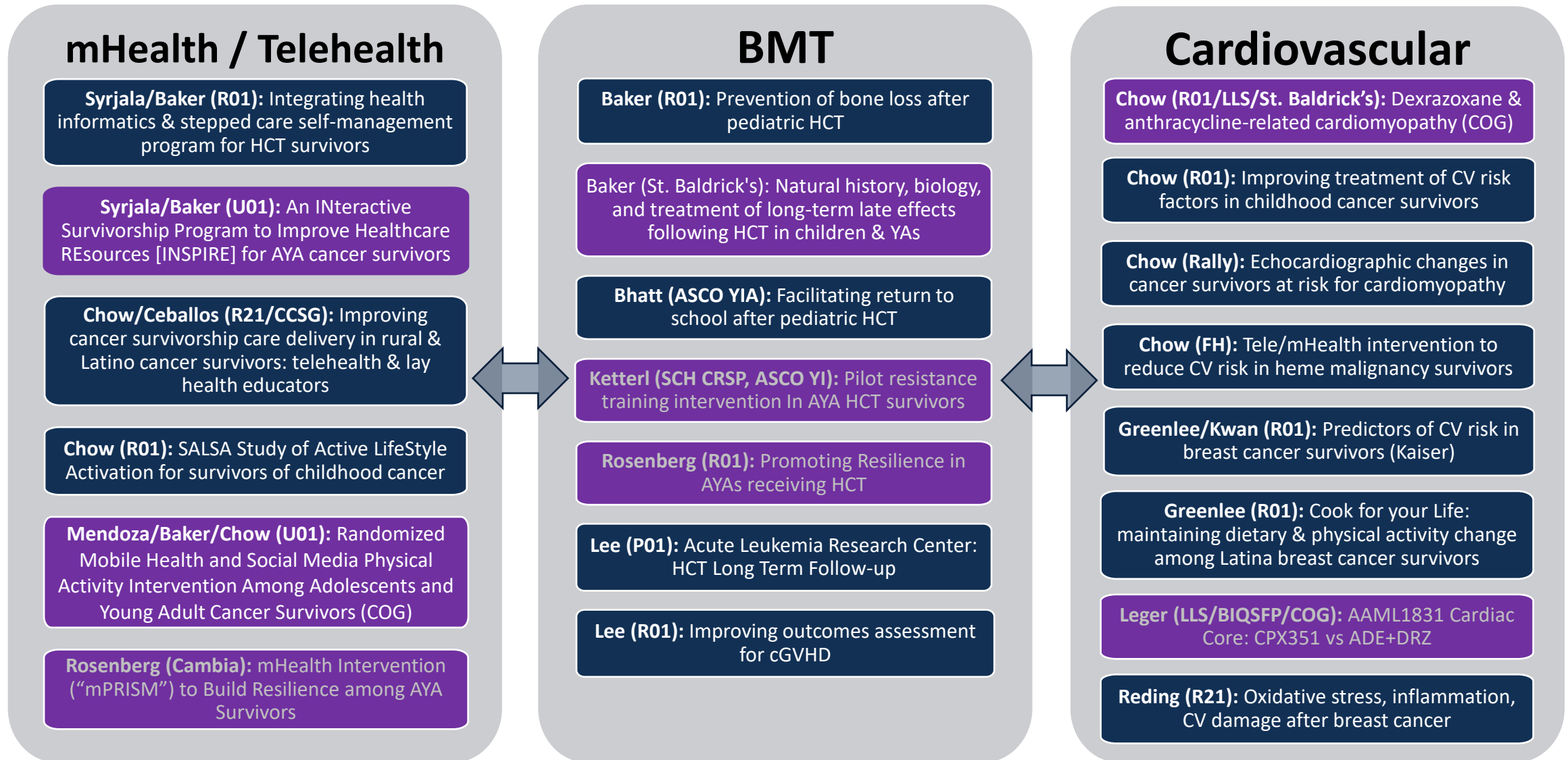
Clinical Trials: NCCN believes that the best management for any patient with cancer is in a clinical trial. Participation in clinical trials is especially encouraged.

Find an NCCN Member Institution:
<https://www.nccn.org/home/member-institutions>.

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

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

Major Research Domains (Current / Recent Grants)





Thank you