



Survivorship Care: *Empowering you*

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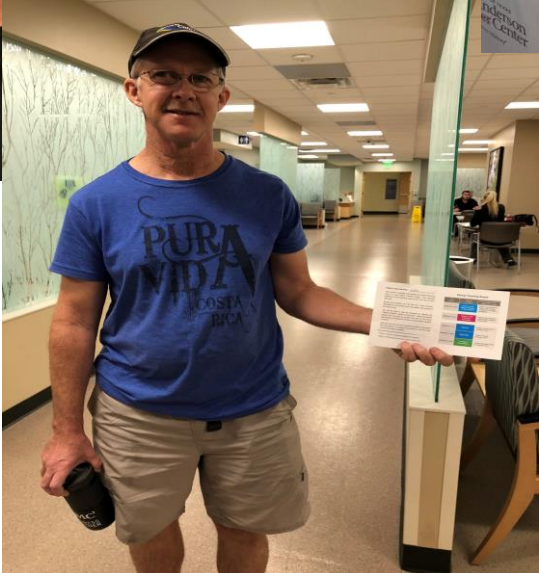
Survivorship Program
Fred Hutch Cancer Center

MM Fighters Presentation
March 16. 2024

March- Multiple Myeloma Awareness Month



My Story: Amelanotic Melanoma Stage 3 C Diagnosis date: 4/8/2018 Recurrence July 4th, 2020. Currently NED continuing Surveillance



Today's Topics

Understanding Survivorship

Challenges affecting us all

Diving into Distress Reactions-
living the day to day

Operation Thrive

The 4 Ps

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
Cancer
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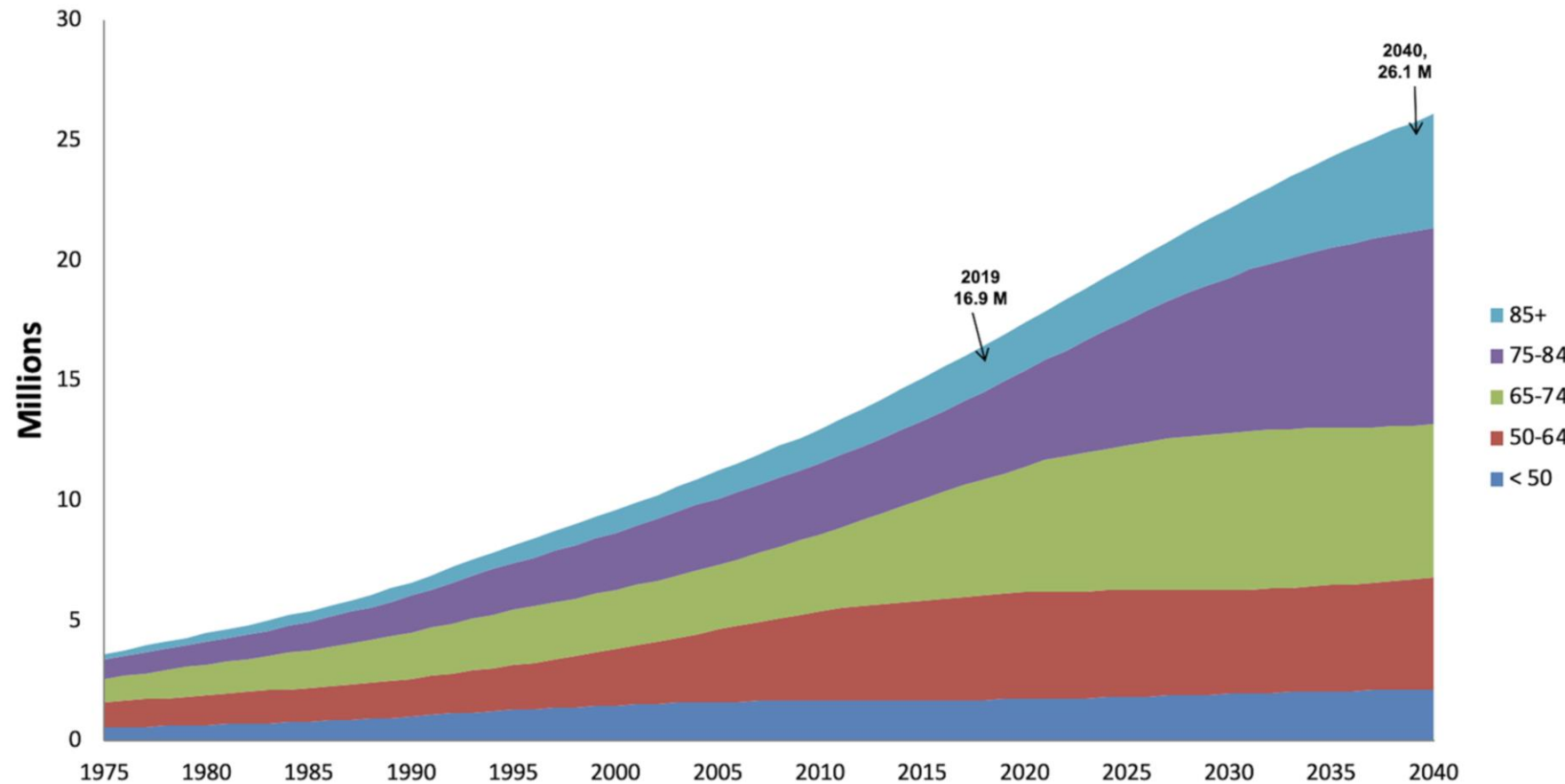
NCCN Guidelines Version 2.2020 Survivorship

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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



What is the life expectancy of a person with myeloma?

Can you live 20 years with myeloma?

Yes, it is possible for individuals with multiple myeloma to live 20 years or even longer, especially with the advancements in treatment options and supportive care that have been made in recent years . Cancer.net Aug 23, 2023

Latest statistic

58% of those diagnosed with Myeloma are living greater than 5 yrs.

MULTIPLE MYELOMA

BY THE NUMBERS

1/132

Lifetime risk of developing multiple myeloma (just 0.76%)

65+

Most MM cases occur in people who are 65 and older

130k

Number of Americans living with multiple myeloma

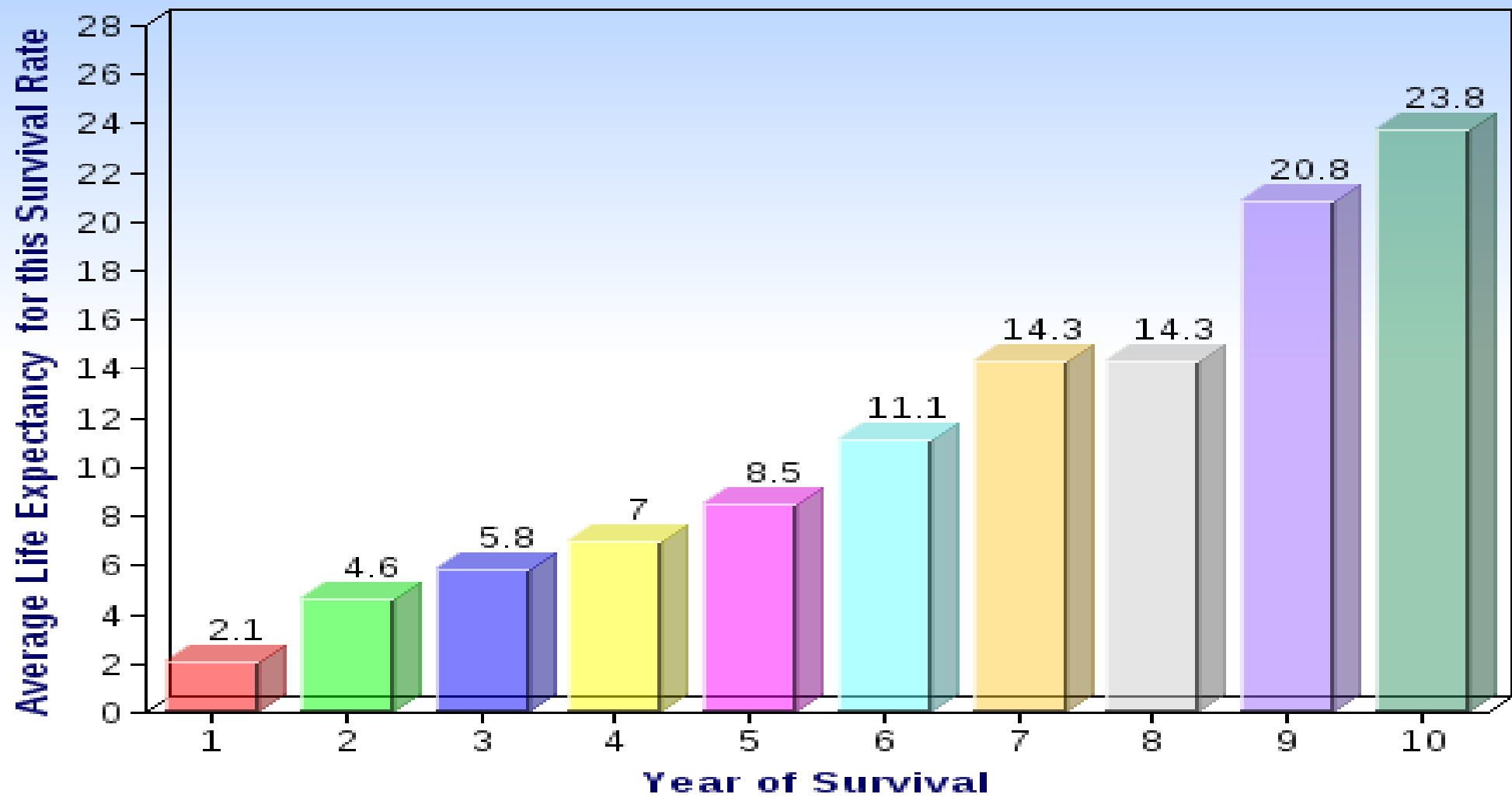
50%

Percentage of people who live at least five years after diagnosis

30k

Number of new cases diagnosed every year in the United States

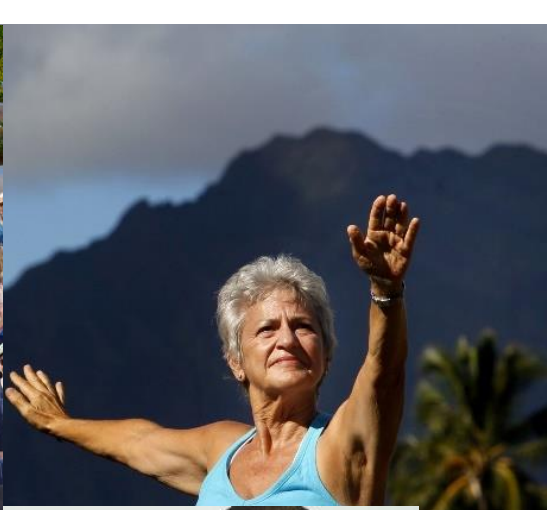
Life Expectancy Rate by Year of Survival



How quickly does myeloma progress?

The risk of myeloma progressing is highest in the first 5 years after diagnosis. About 50 out of 100 people (50%) with smoldering myeloma develop symptoms and need treatment within the first 5 years. However, after 5 years this risk decreases, and some people never develop symptoms or need treatment.

Given this and where each person lives their survivorship needs may look a bit different.



Surviving and Thriving:

Comes in many shapes, sizes, needs and capabilities



Cancer Survivors are *ALL OF US*.

We, or the people we love may be affected by a cancer diagnosis.

***Survivorship* is about living our best life physically and emotionally during and beyond any cancer diagnosis.**

The Good News in Overall Survivorship!

- Many cancer survivors describe themselves as having good-excellent health (60-80%)

Many cancer survivors state they feel psychologically healthy before and after treatment. (60-75%)

I wonder if we surveyed Multiple Myeloma patients would the Percentages would be higher or lower?



Those who appear to be functioning 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,**

Lifestyle

Physical function

Environment & Finances

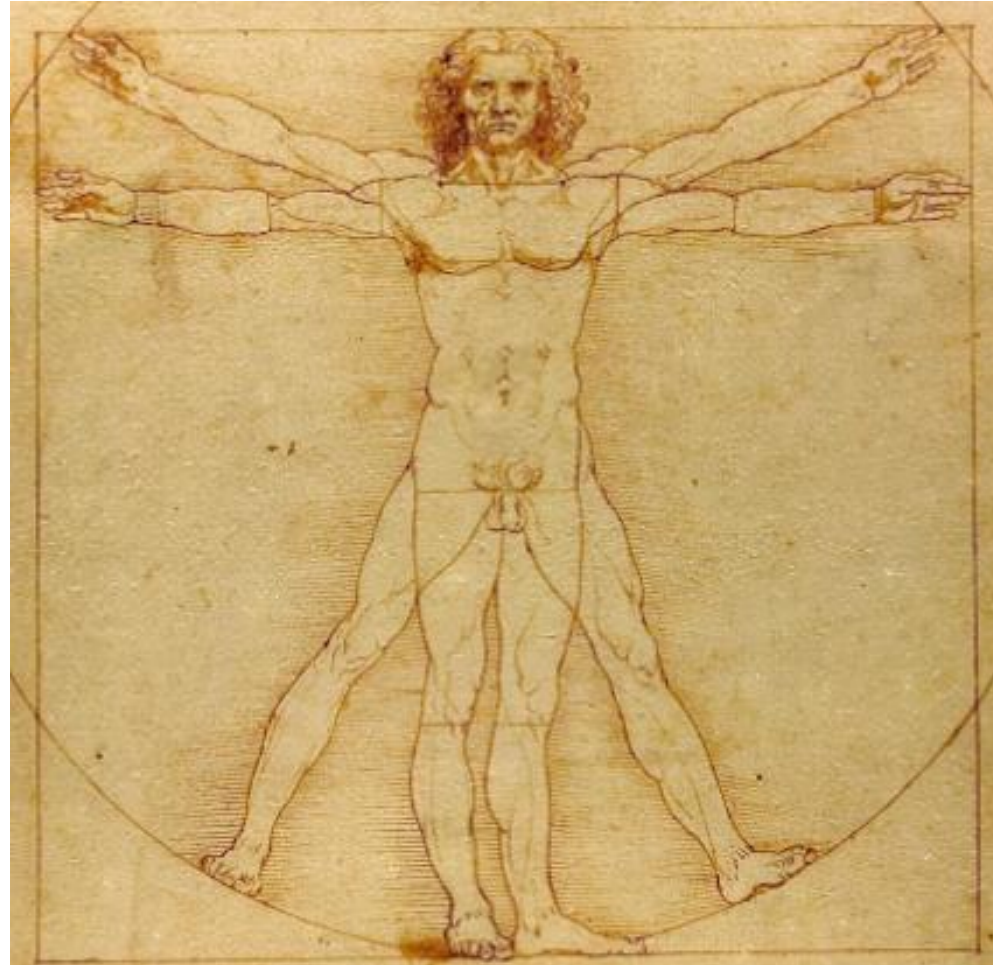
Family / Caregiver function

Access to health & resources

Insurance

Fred Hutchinson Cancer Center

Financial toxicity



Fertility & Reproduction

Fertility

Health of offspring

Sexual functioning

Organ Function

Cardiac

Endocrine

Musculoskeletal

Genitourinary

GI/Hepatic

Neurologic

Pulmonary

Subsequent Malignancies

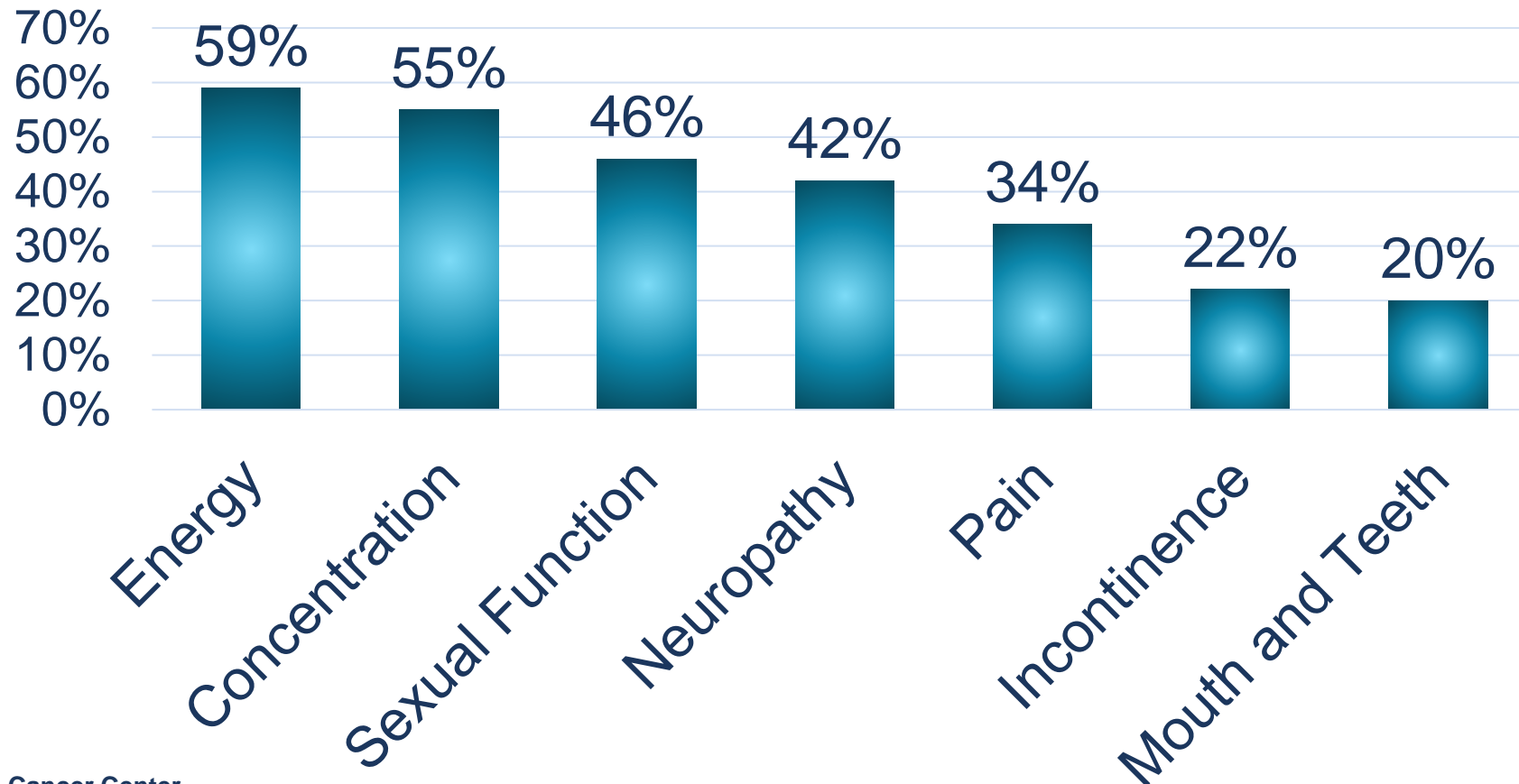
Recurrent cancer

New cancers



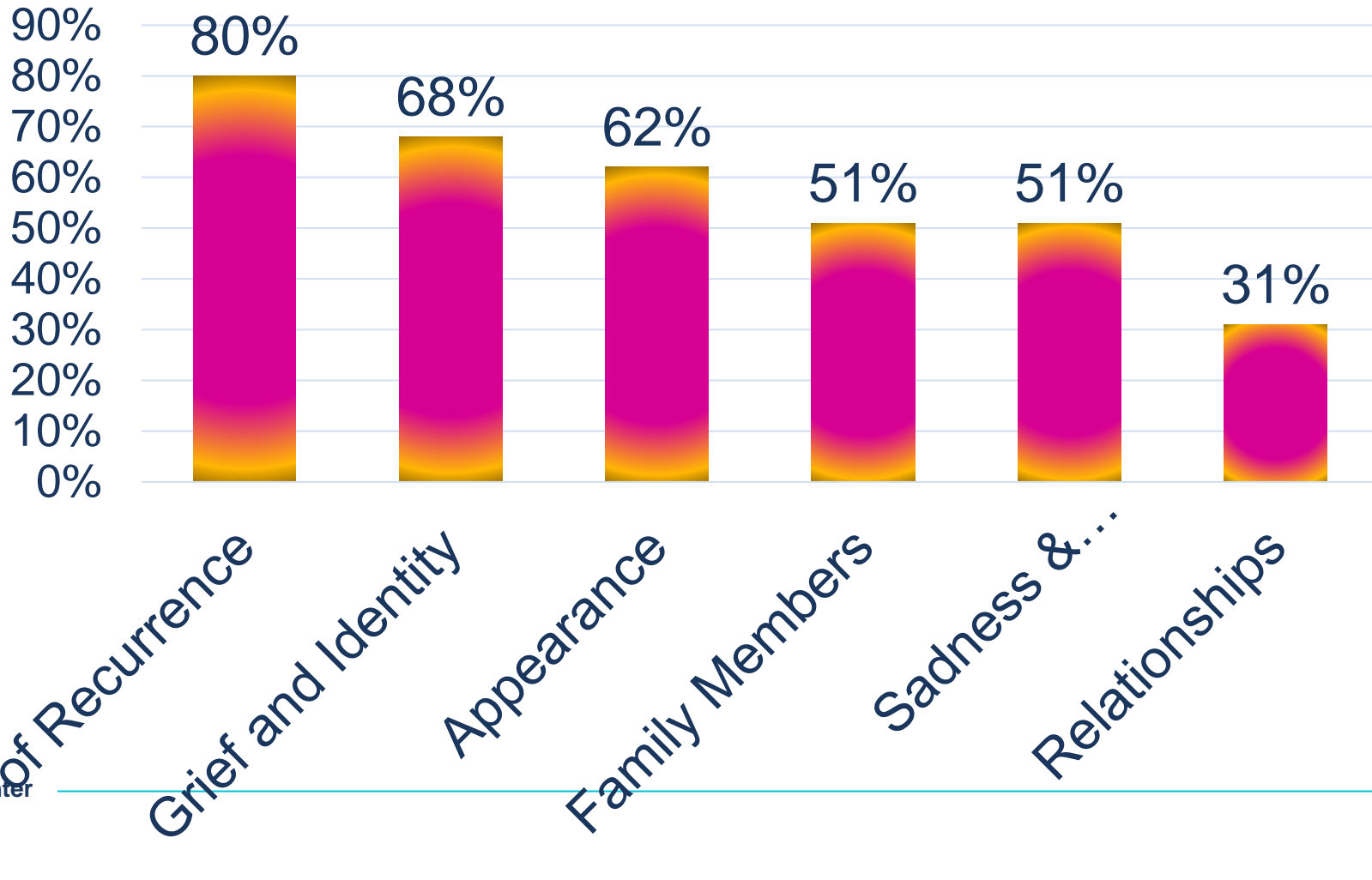
Percent of Survivors Report:

Physical Concerns



Percent of Survivors Report:

Emotional Concerns



Distress Reactions of Survivors

Uncertainty

Grief and Loss

What will be my new Norm?

Fear of Recurrence



Distress Reactions of Survivors

Uncertainty - so many questions and no concrete answers

- * Not knowing what the future will bring
- * Thoughts and feelings about how to move on
- * Feeling insecure about how this will change the family dynamic.
- * work and home responsibilities- continuing work, caring for family, finances, health insurance



Distress Reactions of Survivors

Grief and Loss

- * What is changed forever (work, physical stamina)
- * Includes body image, self-esteem
- * Independence /Identity



Distress Reactions of Survivors

What will be my new Norm?

When people see me:

- * Will I be thought of as Barb, the cancer patient
- * Will I be able to adapt to my new challenges and feel a sense of being whole.
- * Will I finally be able to accept my life as is and embrace my challenges?

Can I truly be “Living not Existing?”



Distress Reactions of Survivors

Fear of Recurrence

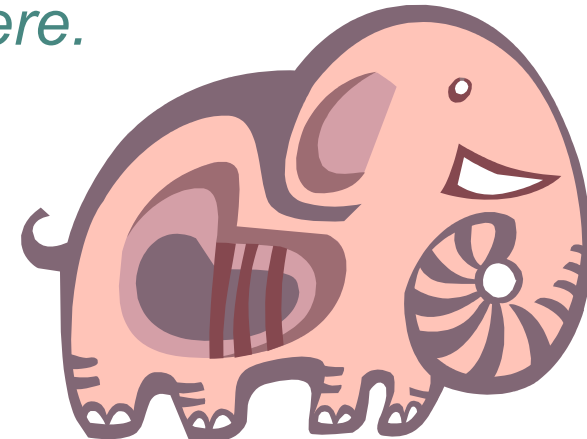
- *Intrusive thoughts about cancer recurring
- *Worry encroaches on activities, sleep, pleasure
- * Afraid to rebuild life – disappointment

The What Ifs.....



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.”



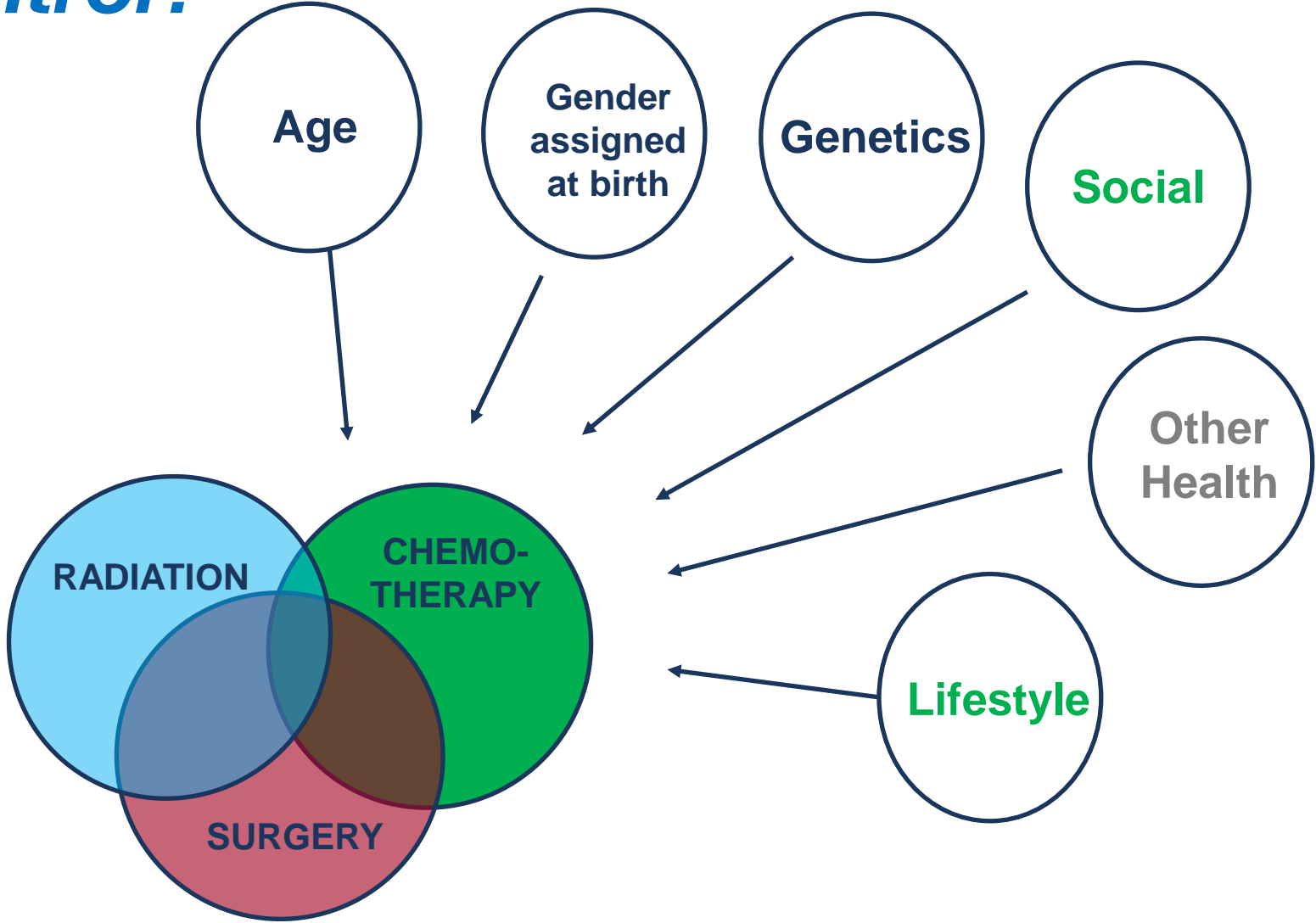
In the Words of a Melanoma Survivor



“ Everyday I would ask myself why me and then one day I realized **Why not** me? At that moment I knew that I had to figure out how to live my best life knowing it would never be the same” Barb Regis



Operation Thrive: *What we can and cannot control?*



What each of us can do..... Prevention Works!

Lifestyle Control the things you can!

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



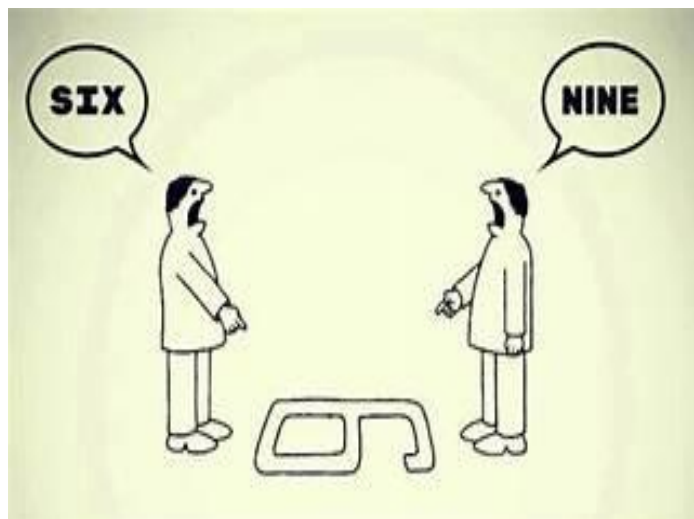
What each of us can do..... Prevention Works!

Social Control the things you can!

- Do not Isolate
 - Let others help
 - Focus on self care
 - Address emotional needs/focus on the positive
 - Manage stress
 - Pets can be amazing therapy
 - Don't be hard on yourself.



Perspective



Perspective

One's viewpoint, sentiment, point of view, mindset.

A particular attitude toward or way of regarding something;
Perspective is the way that one looks at something.

Influenced by personal experiences

- Positive or negative
- We have a choice.
- Time of reflection

Permission



Field Trip
Permission Slip

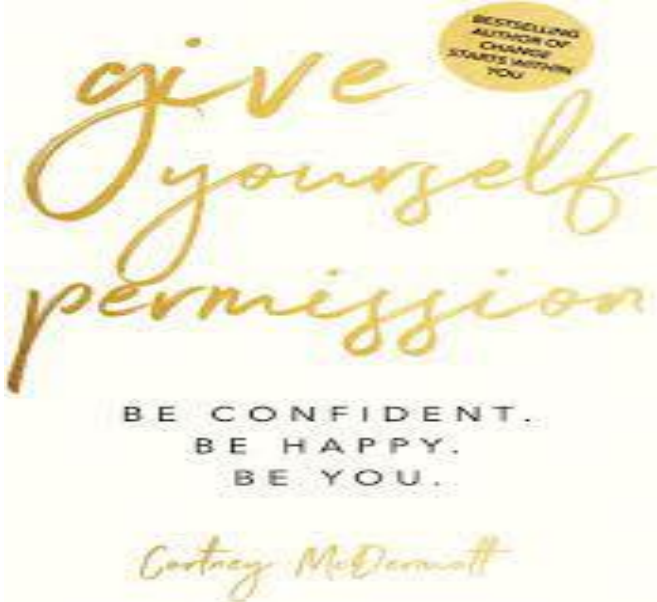
Destination: _____
Date: _____ Cost: _____

Time Leaving: _____ Returning: _____
Parent Chaperone Volunteer: _____

Lunch: Provided Pack Lunch N/A

Student: _____
Parent Signature: _____

Icons: A bear, a bird, a lunchbox with a cat, and a school bus.



Permission

Consent, grant, license, green light, ok, acceptance

Giving approval to someone or *Yourself* to do something or feel a certain way.

- Rest
- Take time to heal
- Feel a certain way
- Change something you do not like

The only Permission that liberates us and at the end of the day truly matters is:

That which you give to yourself.

Perseverance



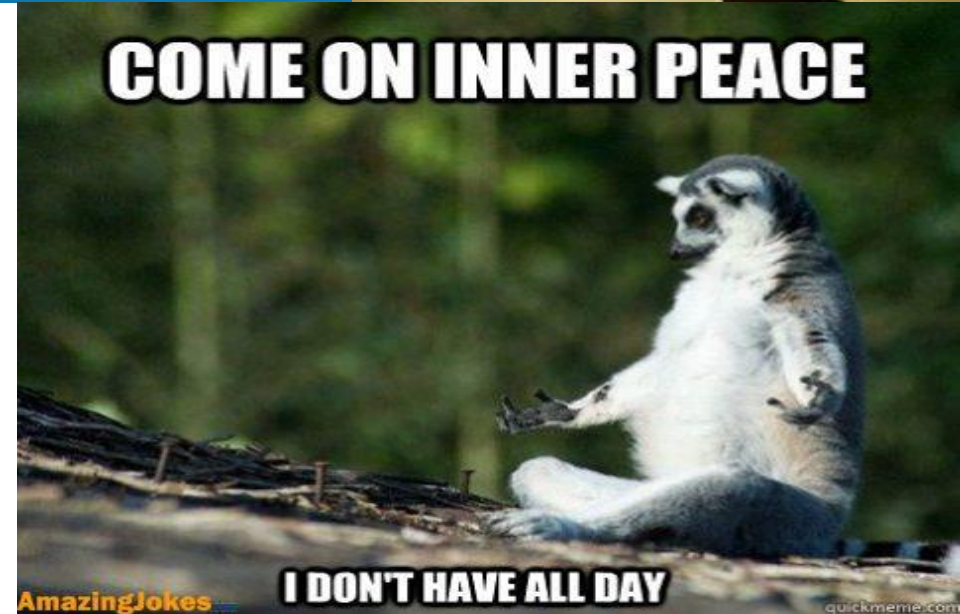
Perseverance

One's continued effort to achieve something despite difficulties or opposition.

A quality that allows someone to continue to try despite obstacles that arise along the way.

- dealing with setbacks
- working through the side effects of therapy
- it's a marathon with at times an unknown end game.
- persistence to continue a path that can be difficult

Peace



Peace

Across all cultures, and throughout all human time, we share the same six emotions – sadness, anger, fear, joy, love, and peace.

One's state of physical, emotional and spiritual calm

Influenced by personal experiences

- gratitude
- contentment
- feeling relaxed
- silence



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.



What Our Patients Say

The treatment summary and survivorship plan are the pieces that assure continuity of care and identify any preventative recommendations needed.

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.





[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](#).



Are you Living or Existing



Thanks so much for your time!