

Survivorship Care Planning in YOUR Real World: Promoting YOUR HEALTH and WELLNESS

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Topics:

1. Context: the big picture of cancer survivorship
 - ✓ Who are survivors, what needs to they have?
2. How does survivorship care planning meet these needs?
3. What can YOU DO to meet your survivorship needs?

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Cancer Survivors in the United States

41% lifetime cancer risk

1 in 2 men

1 in 3 women

5-year relative survival rate:

➤ 80% of children

➤ 69% of adults

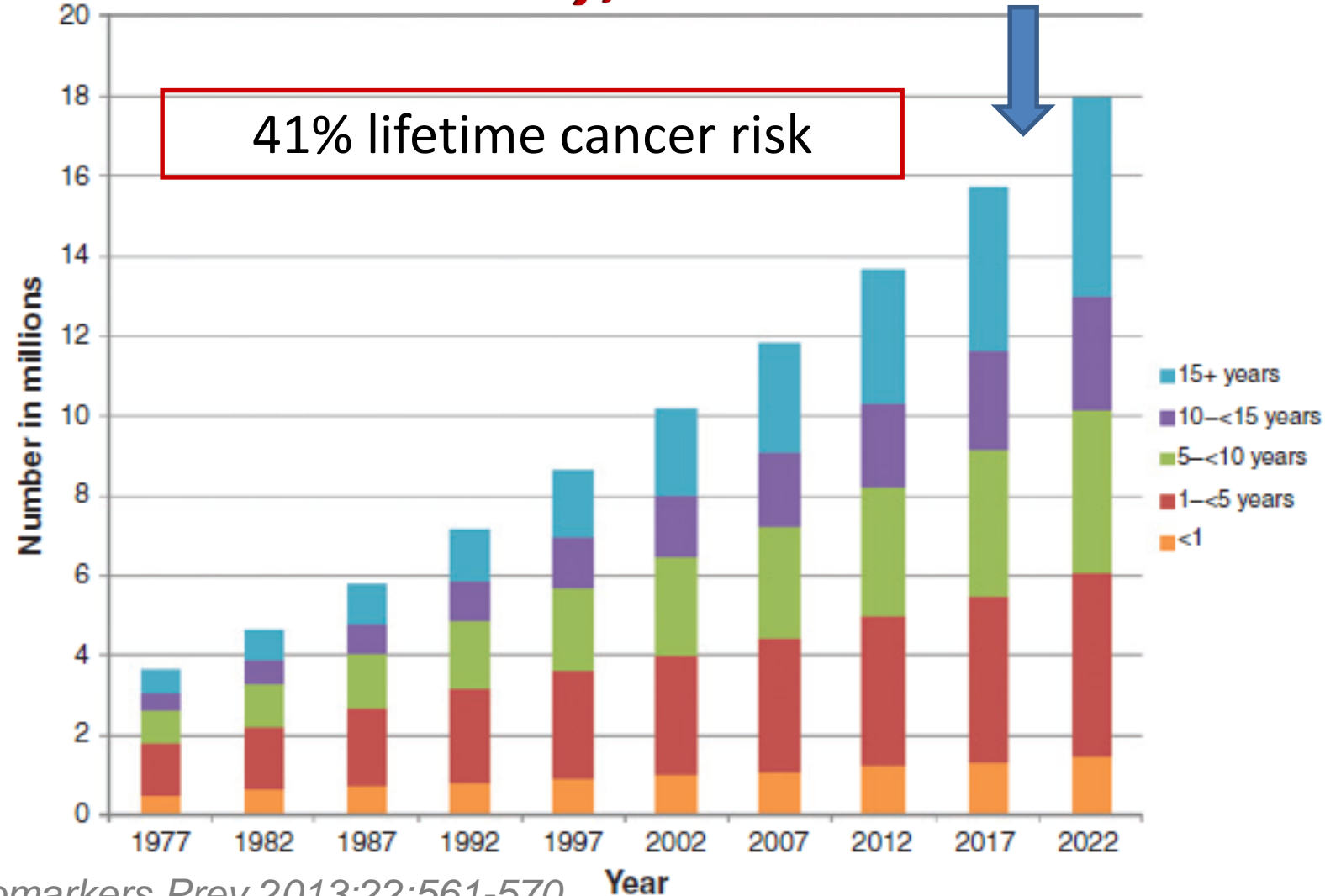
if diagnosed 2006-2012

Cancer Survivors in the United States

16.9 million in January, 2019

USA:

- 67% diagnosed 5 or more years ago
- 45% diagnosed 10 or more years ago
- 5 year survival:
 - 90% for breast cancer
 - 97% for prostate cancer



de Moor J S et al. *Cancer Epidemiol Biomarkers Prev* 2013;22:561-570

American Cancer Society. *Cancer Treatment & Survivorship Facts & Figures*. Atlanta: ACS; 2017 & 2018

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.**



Surviving and Thriving:

Comes in many shapes, sizes, needs and capabilities



Cancer Survivor Challenges

Wellness & PsychoSocial

Mental health

Employment

Education

Social interactions/support

Chronic symptoms:

Fatigue, Cognition,
Insomnia, Neuropathy

Lifestyle

Physical function

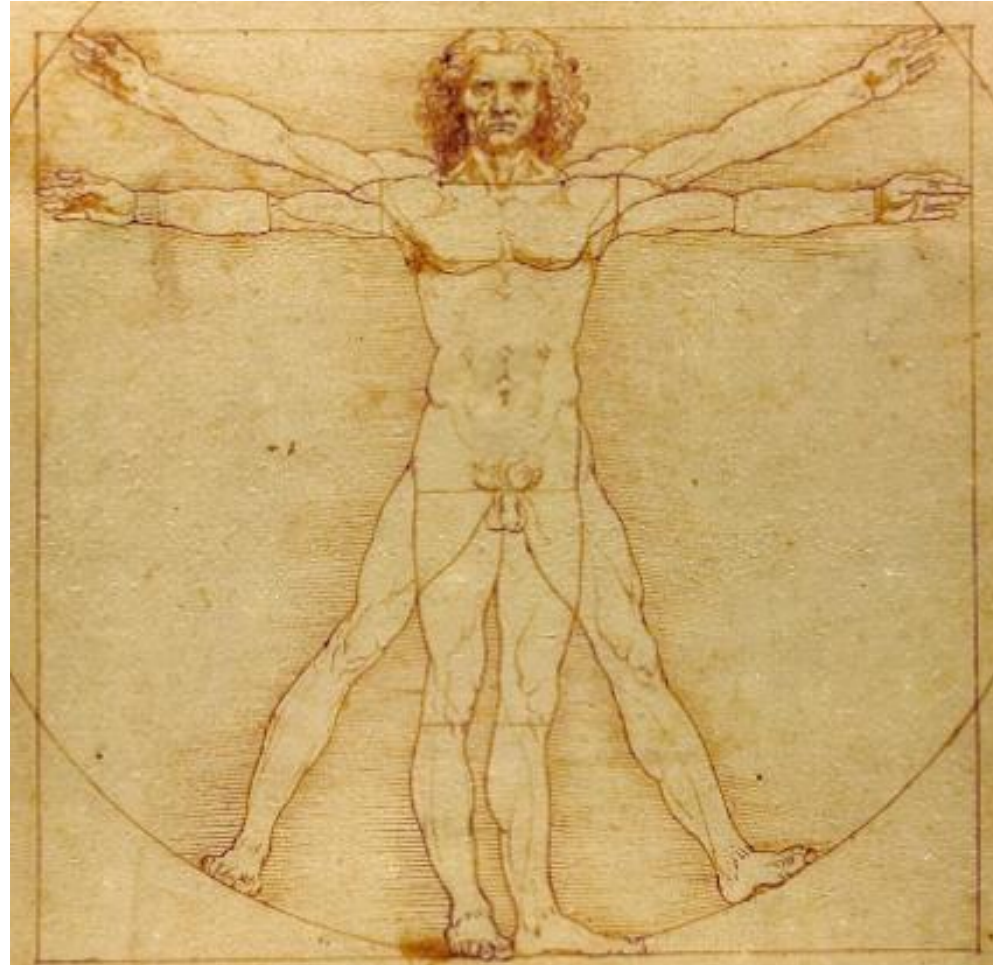
Environment & Finances

Family / Caregiver function

Access to health & resources

Insurance

Financial toxicity



Fertility & Reproduction

Fertility
Health of offspring
Sexual functioning

Organ Function

Cardiac

Endocrine

Musculoskeletal

Genitourinary

GI/Hepatic

Neurologic

Pulmonary

Subsequent Malignancies

Recurrent cancer

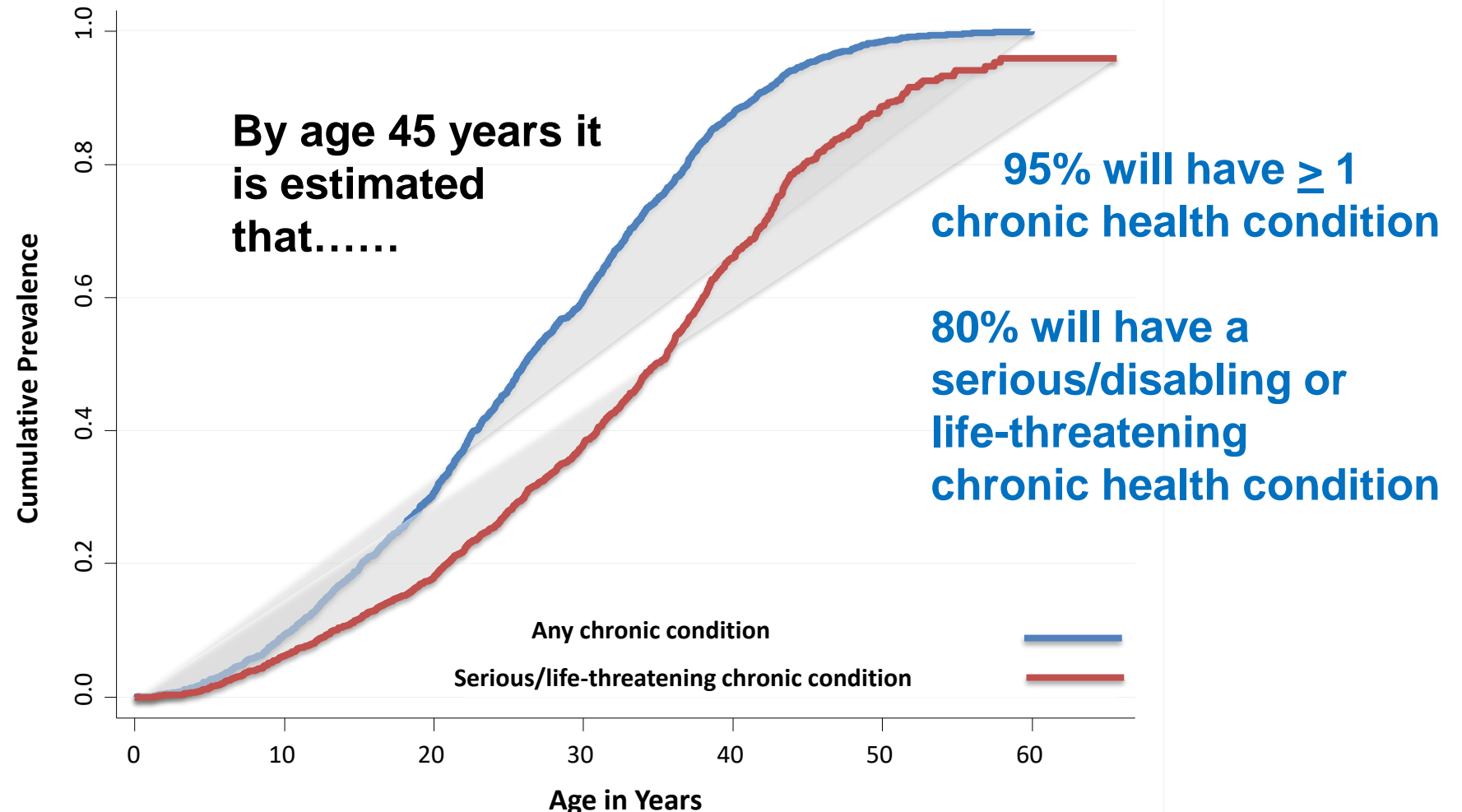
New cancers

Clinical testing of late effects in 1713 adult survivors of childhood cancers

Median age at diagnosis: 6 yrs (range, 0-24)

Median age at study: 32 yrs (range 18-60)

Median time from diagnosis: 25 yrs (range 10-47)





HOW CANCER HAS AFFECTED POST-TREATMENT SURVIVORS: A LIVESTRONG REPORT
FINAL REPORT

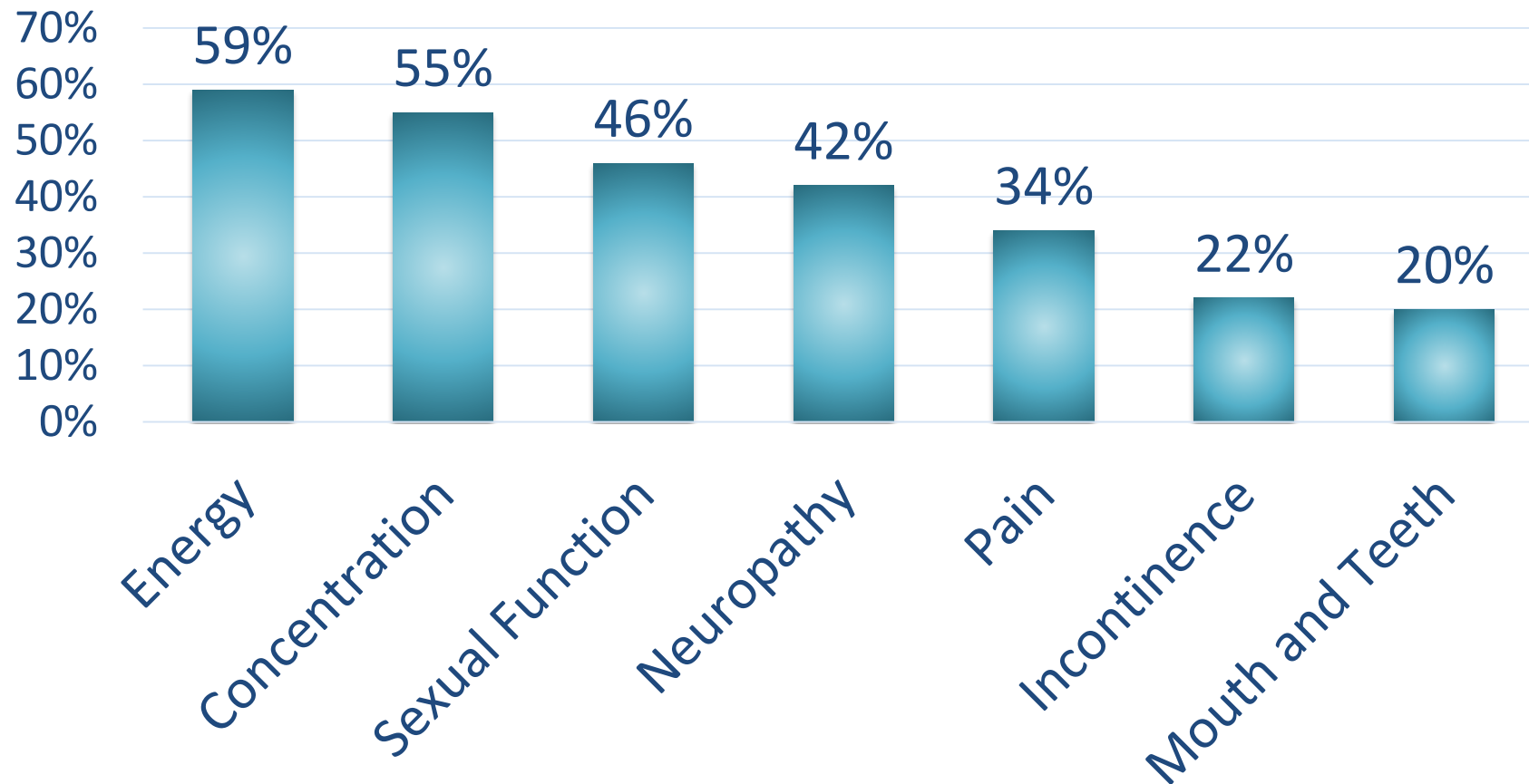
Surveyed > 3000 cancer survivors

LIVESTRONG

Rechis et al. LIVESTRONG Survey Report, 2012

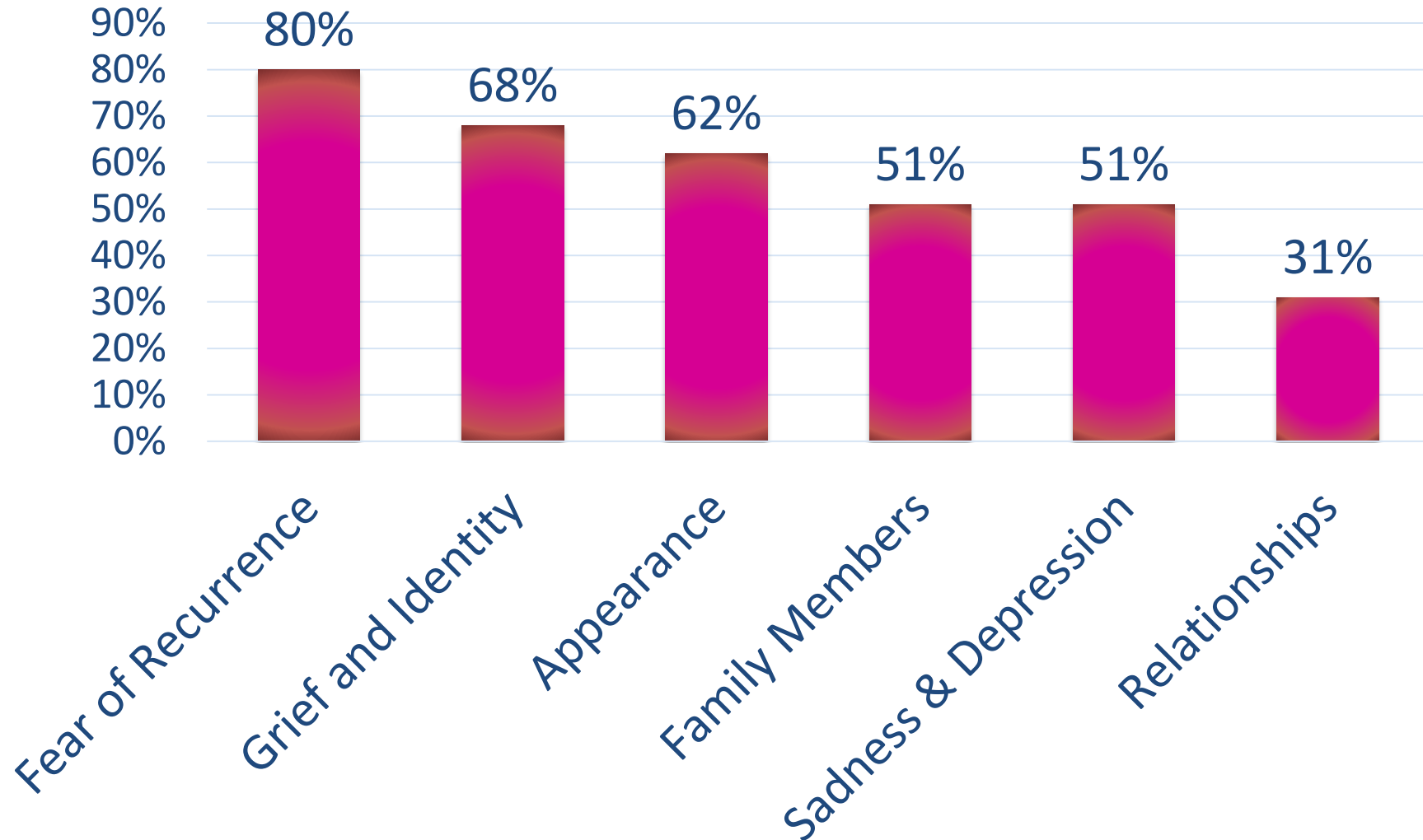
Percent of survivors who report

Physical Concerns



Percent of survivors who report

Emotional Concerns



Fear of Recurrence

- Persists at least up to 9 years after treatment Mishel et al. *Psychooncology* 2005
- Fear of Recurrence can impair clinical care and quality of life
 - Avoidance of health care visits
 - Increased health care use and emergency room visits
 - Impairs quality of life

Lebel et al. *Supportive Care Cancer*, 2013

- Cognitive strategies (5 sessions) improve multiple symptoms related to fear
 - Attention training: it is safe to not think about worries all the time
 - Acceptance: it is ok, I can tolerate having fears and worries and still live my life
 - Mindfulness: relaxes and eases mind and body
 - Values-based goal setting Butow et al. *J Clin Oncol*, 2017

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Survivorship Care Plans

- Half of survivors do not get their recommended health care to reduce their risks of cardiac events, cancer, or other health problems
- Survivors often do not understand their health behavior risks and benefits
 - Tobacco risk is well known
 - Alcohol risks are becoming clearer
 - Healthy eating - many misconceptions
 - Exercise: CLEAR BENEFIT, need to know how to get started, how to stay motivated
 - How to manage emotions after treatment
- Survivorship care plans are mandated for all survivors:
 - Many do not get them, Many do not address healthy behaviors

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

Fred Hutch / SCCA Survivorship Program

- Established in 2006 through a grant from LIVESTRONG Foundation
- Mission is to provide:
 - Clinical Care
 - Outreach & Education
 - Research

Fred Hutch / SCCA Survivorship Clinical Care:

- Nurse prepares a Treatment Summary and Care Plan
- Patient eligibility
 - Off active treatment, without active cancer
 - All ages, all diseases
- 60-90 min Survivorship Clinic Treatment Summary and Survivorship Care Plan reviewed with nurse practitioner or doctor
 - Visit billed and reimbursed as oncology follow-up

Survivorship Care Plan Goals

Personalized document from oncology clinician:

- 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

Fred Hutch / SCCA Survivorship Clinical Care:

Emphasis of the Survivorship Clinic visit is on review of the care plan, identification of referral needs and accessing community resources

Most Common Referrals after Evaluation:

PT

OT

Vocational Rehab

Specialty Consult Clinics

Psychology / Psychiatry

Social Work

Intimacy/Sexuality

Fertility

Chaplaincy

Pain

Nutrition

Acupuncture

Sleep Medicine

Cardiology

Endocrinology

Other Specialty Consult Clinics

Patient Comments

When you go through the experience that I have been through with cancer, you feel kicked to the ground and then dropped into the wilderness once the treatment is over. A treatment summary and survivorship plan are the pieces that have been missing in my care since finishing treatment.

I appreciate the Survivorship Clinic's willingness to listen to me and add pragmatic steps to help me on my quest for a bit of my old life back!

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

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Your Personal Survivorship Care Planning

1. Get your Personalized care plan from a Survivorship Provider

- Primary cancer surveillance plan

2. Take Charge

- Decide what you NEED for your health and wellness: Make a List
- Decide on a plan for what YOU CONTROL
 - ✓ What you can do
 - ✓ What you need help to do – and Who Will Help
- Decide what steps you will take to manage your HEALTH
 - ✓ Put your health care needs on your calendar;
 - ✓ keep track of your screening plan and results
- Decide what steps you will take to manage your WELLNESS

3. 3 Ps: Prioritize, Plan, Pace

Take Charge: What do I Value? (Prioritize these)

What do I value that keeps me motivated:

- My kids: I want to be there to see them have kids
 - Get pictures of your kids in your wallet and
 - When you are tempted, take them out and look at them!
- Life! There are still a lot of things I want to enjoy:
 - I want to sky dive!
 - [*be specific, what do you want to do*]
 - I'm going to schedule a sky dive today for my next birthday and start getting ready

These are my Priorities, I'm going to make certain I make the time and plan the actions I need for these

My Plan for my Health and Wellness

What do I need and
What are my concerns?

1. Cancer coming back
2. Worry about my future
3. What health problems should I keep track of
4. My wellness:
my lack of energy
my activity level
my eating habits

My Plan for my Health and Wellness

What do I need and

Do I control it?

What are my concerns?

or does someone?

- | | |
|---|--|
| 1. Cancer coming back | No, but there are things I can do |
| 2. Worry about my future | Yes, I can control my worry
No, I do not control all my future
Yes, I can do something about my future |
| 3. What health problems should I keep track of | Yes, I can find out what health tracking I need |
| 4. My wellness:
my lack of energy
my activity level
my eating habits | Yes, I control this but I might need some help |

My Plan for my Health and Wellness

**What do I need and
What are my concerns?**

**Do I control it?
or does someone?**

What Steps will I take?

1. Cancer coming back

No, but there are things I can do

Make sure I do my follow-up
plan from my oncologist
Get a Survivorship Care Plan

2. Worry about my future

Yes, I can control my worry
No, I do not control all my future
Yes, I can do something
about my future

Call my doctor about a referral -
talk to about my worries
Focus on my wellness -
take charge of what I can

3. What health problems
should I keep track of

Yes, I can find out what
health tracking I need

Call and schedule an appointment
for a Survivorship Care Plan

4. My wellness:
my lack of energy
my activity level
my eating habits

Yes, I control this but
I might need some help

Talk to my doctor about fatigue
Get a physical therapy evaluation
Make an activity plan, join the gym
Talk to my spouse, make a plan

My Plan for my Health and Wellness

What do I need and What are my concerns?	Do I control it? or does someone?	What Steps will I take?	DONE!
1. Cancer coming back	No, but there are things I can do	Make sure I do my follow-up plan from my oncologist Get a Survivorship Care Plan	<input type="checkbox"/> <input type="checkbox"/>
2. Worry about my future	Yes, I can control my worry No, I do not control all my future Yes, I can do something about my future	Call my doctor about a referral - talk to about my worries Focus on my wellness - take charge of what I can	<input type="checkbox"/> <input type="checkbox"/>
3. What health problems should I keep track of	Yes, I can find out what health tracking I need	Call and schedule an appointment for a Survivorship Care Plan	<input type="checkbox"/>
4. My wellness: my lack of energy my activity level my eating habits	Yes, I control this but I might need some help	Talk to my doctor about fatigue Get a physical therapy evaluation Make an activity plan, join the gym Talk to my spouse, make a plan	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>

Survivorship Care Plan Visit

A Survivorship Care Planning visit can take care of a lot of this!

Who will support my Plan for Taking Charge?

- What health care providers can you see and discuss your plan?
- What family or friends can you share your plan with who will talk with you when you are frustrated, worried, tempted?
- Who will exercise with you?
- Who will have fun with you without tempting you to break your eating or drinking plan?

Pace

- Be realistic, what can you do in a day or a week (and still enjoy life)?
- Be Certain your Priorities are in your daily plan!
- It takes time to achieve goals
 - when things are going in the right direction you feel better and are more likely to keep going

3 Ps: The Main Idea for Taking Charge of Your Health

- Prioritize

- Know what you value most!
 - In the big picture
 - Every day

- Plan

- Make sure what you value/prioritize happens, don't leave it to chance
 - Big things
 - Every day
- List your plans so you can track when you've done them

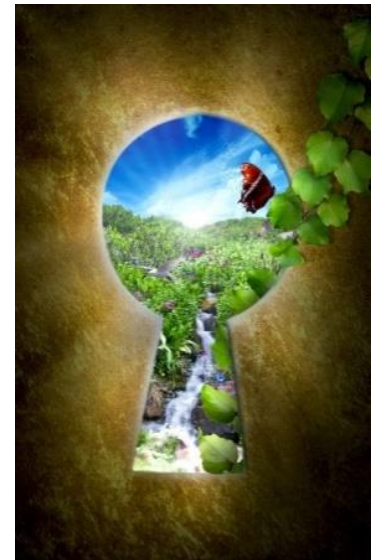
- Pace

- Be realistic, what can you do in a day or a week?
- Be Certain your priorities are in your daily plan!

KEY POINTS



1. Survivorship Care has come a long way
 - One plan does not fit all needs
 - You need your own Survivorship Care Plan for Health and Wellness
2. You are the expert on your wellness needs, use the 3 Ps
 - Identify your values / Priorities – these keep you motivated
 - Plan your health and wellness needs
 - Make sure you connect to those who can help – you don't have to do it alone
 - Pace – you don't have to do it all this week
3. Survivorship care planning can ease your mind and improve your health and wellness



THANK YOU

Questions?

Discussion



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