

Survivorship 101:

A Quick Course on What Happens *Next* for People with Cancer



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Leslie Heron, RN, BSN, MN, APRN, FNP-BC, NC-BC

Survivorship Clinic, Seattle Cancer Care Alliance

Survivorship Program, Fred Hutchinson Cancer Research Center



Objectives

- Describe what might be expected *along the road* after cancer treatment is completed.
- Increased awareness of *common hazards* – the long term and late effects of cancer and cancer therapies.
- How to *be in the driver's seat* on the survivorship journey.

Who are Survivors?

“...anyone who has been diagnosed with cancer from the time of diagnosis through the balance of his or her life”

American Cancer Society

What is Survivorship?

Addressing the unique needs of survivors after active treatment ends

Lingo: What's the Difference Between Long Term and late Effects?



- **Long Term Effects**

Effects or complications that begin during treatment and persist

Examples – fatigue, peripheral neuropathy, sexual problems, worry

- **Late Effects**

Effects from treatment that may not show up for months or years after treatment ends

Example – secondary cancers, heart disease, lung fibrosis, infertility, early menopause

Late and Long Term Effects Seen in Survivorship

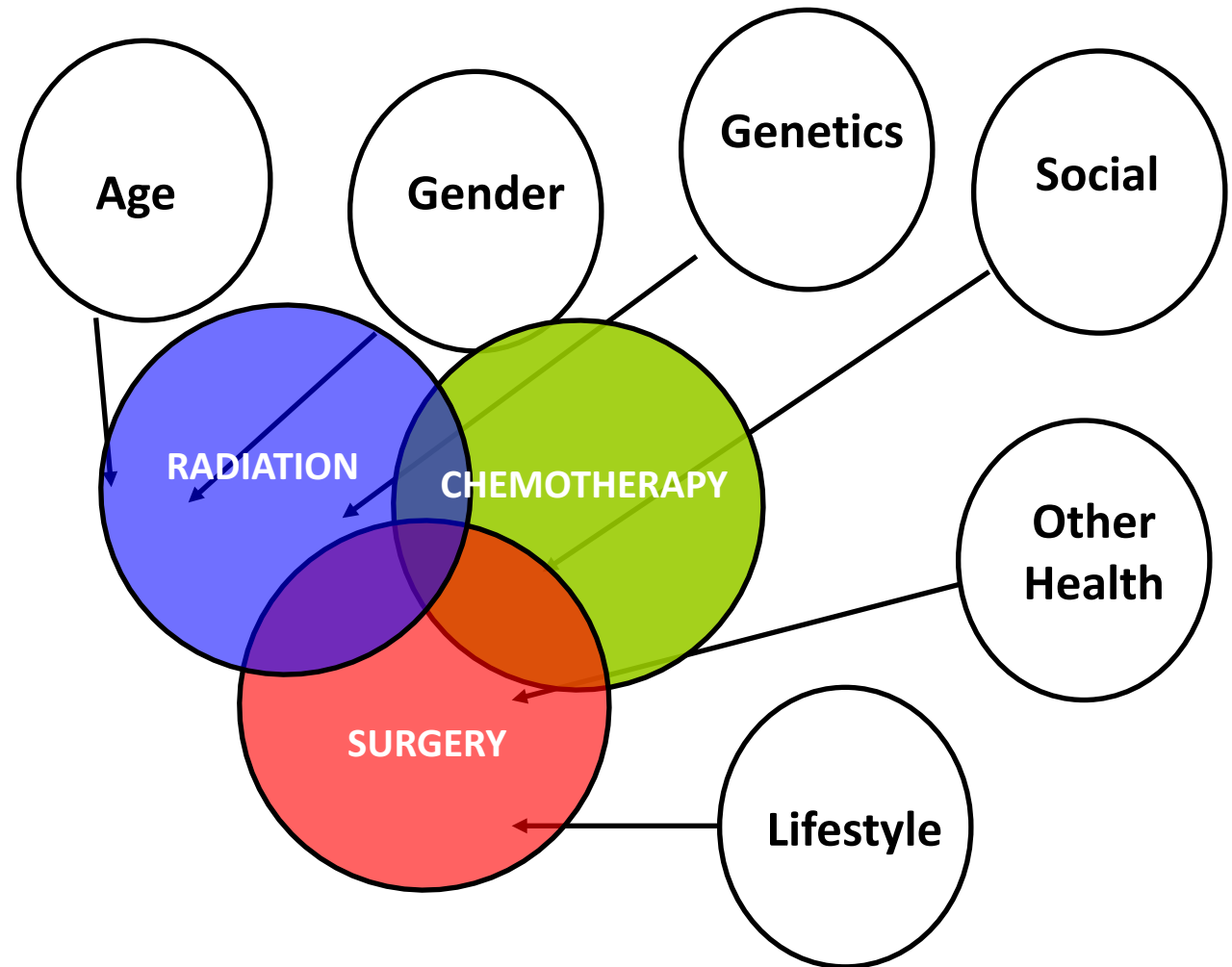
Medical Problems:

- ✓ Cardiovascular disease and cardiac failure
- ✓ Fatigue
- ✓ Pain
- ✓ Osteoporosis / osteopenia
- ✓ Hypothyroidism
- ✓ Premature menopause
- ✓ Pulmonary function
- ✓ Lymphedema
- ✓ Urinary incontinence
- ✓ Infertility
- ✓ Neurologic problems (balance, neuropathy, memory)
- ✓ GI (bowels, bloating, acid reflux)
- ✓ Dental impairments
- ✓ Recurrence
- ✓ Increased risk of 2nd cancers
- ✓ Accelerated aging

Emotional and Functional Concerns:

- ✓ Memory loss
- ✓ Restricted social and physical activities
- ✓ Fear of recurrence/living with uncertainty
- ✓ Muscle and joint stiffness, weakness, cramps or pain
- ✓ Sexual dysfunction
- ✓ Intimacy/relationship issues
- ✓ Distress and worry
- ✓ Job loss/Job lock
- ✓ Role changes at home
- ✓ School concerns
- ✓ Insurance problems
- ✓ Financial concern or crisis
- ✓ Sleep disorders
- ✓ Cognitive processing disruption

What Effects Risk After Treatment?





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

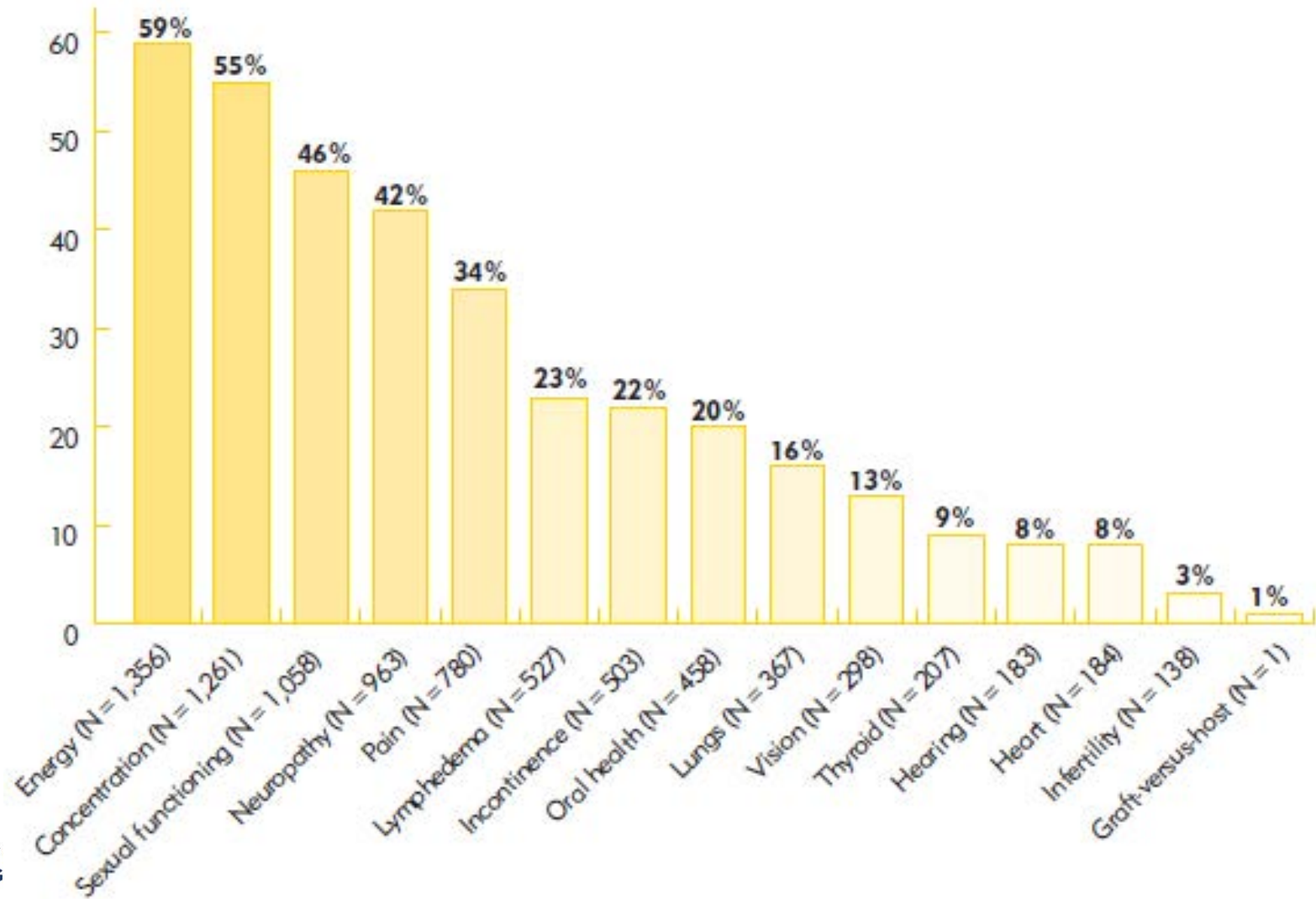
LIVESTRONG



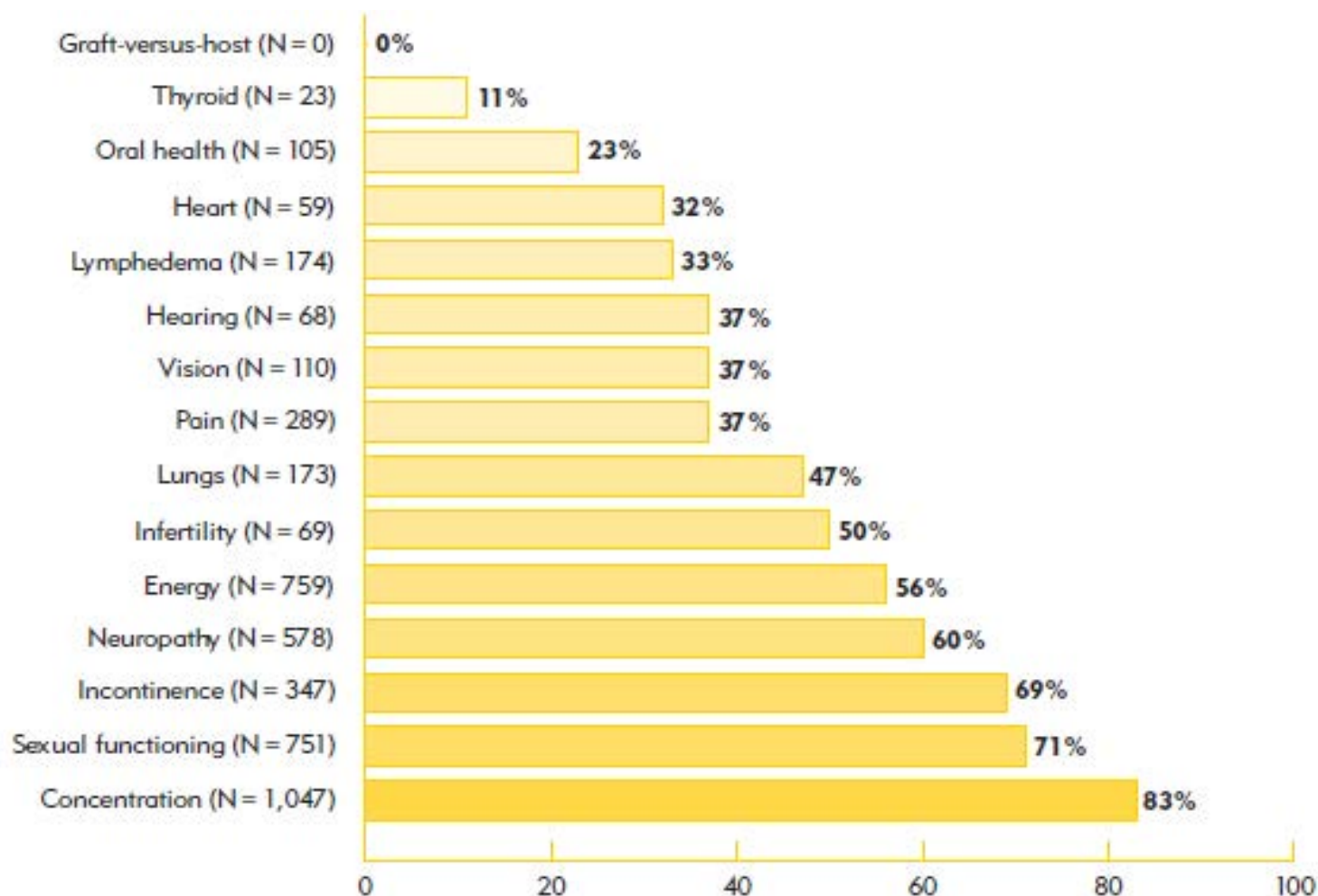
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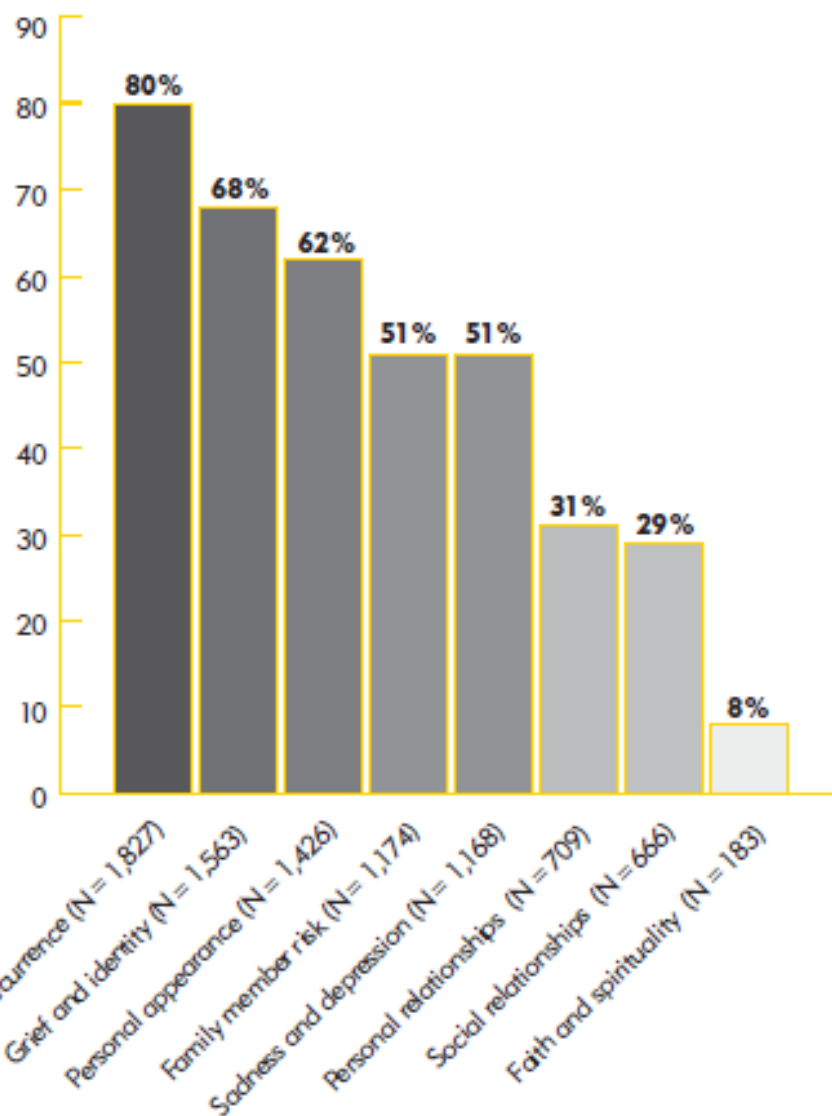
Percentage of Respondents who report physical concerns



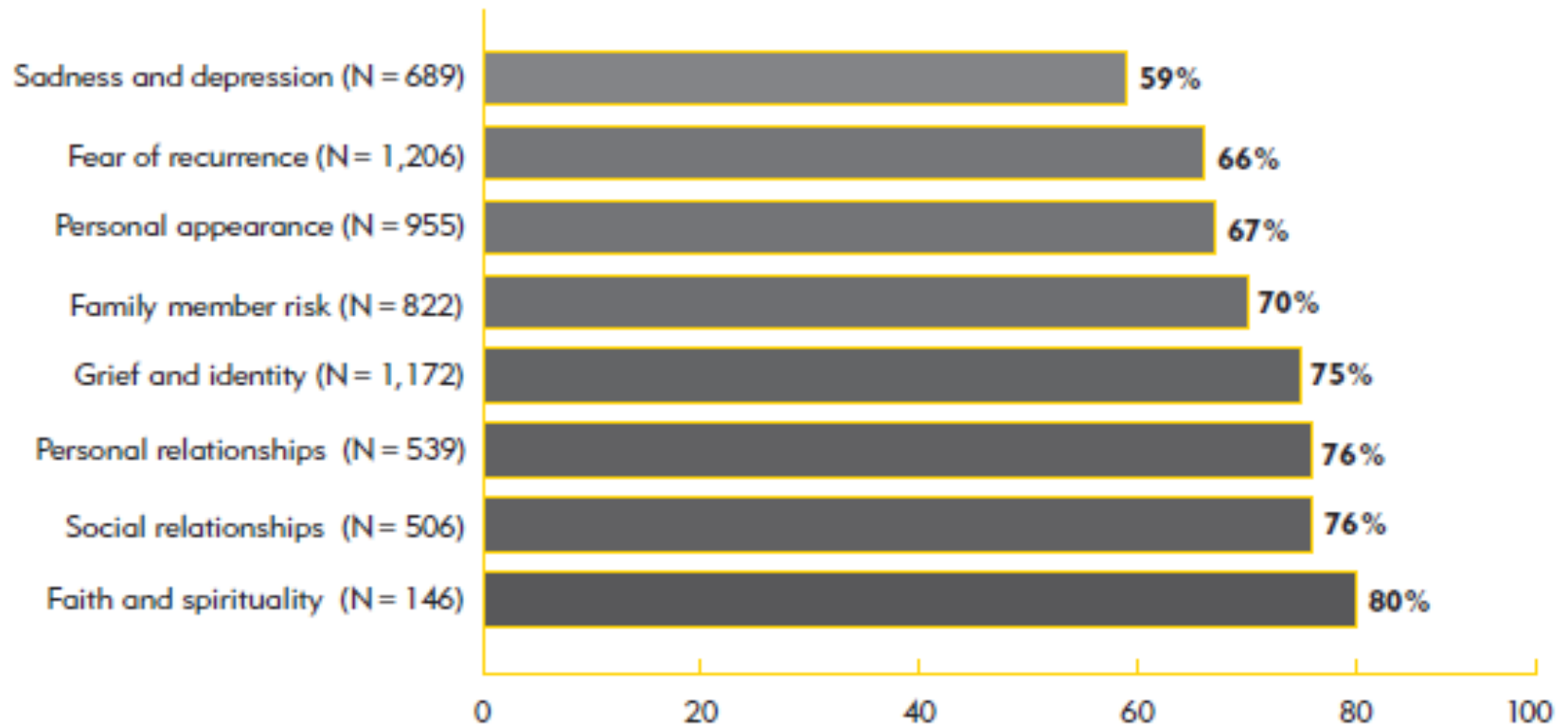
Percentage of respondents who report they did not receive help for their concerns



Percentage of respondents who experienced emotional concerns



Percentage of respondents who report they did not receive help for their emotional concerns



What's a Survivor to DO?

Who's supposed to keep track of my risks?

Who do I call?

What is important?

When do see my PCP?

Is this normal?

Will this improve?

When do I come in?

How can I stay healthy?



Quality of Life in Survivorship:

4 Areas of Focus (Ferrell, 1996)

- **Physical:** Symptom relief and function
- **Psychological:** Sense of control, positive life changes, addressing fear and distress
- **Social:** Roles and relationships
- **Spiritual:** Finding hope and meaning



Physical



- **Fatigue**

- For some people, this improves but does not go away. It can come and go, but should not get dramatically worse over time.
- Check with your healthcare provider to rule out a physical cause (anemia, thyroid, heart, etc.)
- **Exercise** is actually the ‘treatment’ for fatigue!
- *Livestrong at the Y, Team Survivor NW, walk with a friend, yoga, water walking, bands or weights, Physical Therapy, and more. **GET MOVING!**

Physical



- **Sexual Function**

- It is **normal** to have a loss of interest and function with increased stress and physically feeling ill
- Cancer treatments **can** affect sexual function
- Many changes in sexual function can be **improved**
- *Read books, ask questions, seek information from healthcare providers, support groups, and stores, experiment (products, toys, touch, positions), and **TALK** about it!

Psychological



- **Fear of recurrence**
 - **Normal** to have multiple psychological reactions to a life threatening event!
 - **Common:** Fear, worry, guilt, anger, depression, anxiety, post-traumatic stress, being hypervigilant, and more.
 - ***Control** what is in your control, make **healthy** choices, make a bucket list and work through it, do “**legacy work**”, seek reliable information and support, **ask for what you need**.

Social



- **Return to work (or social activities)**
 - There are *physical and psychological* changes that effect the **roles** we hold throughout our lives.
 - It is **normal** to feel differently about what is important to us over time.
 - **Physical changes** can affect endurance, strength, and the actual ability to perform tasks: typing, sitting, lifting, organizing, listening, etc.
 - *Be honest about WHAT you can/can't do and WHY.
 - *Seek **reasonable solutions** with work re-training, work release, disability assistance, information on physical and psychological support and assistance.

Spiritual



- **Finding Meaning**

- **Common** to feel overwhelmed, like giving up, stuck, misunderstood, and helpless
- Tendency to withdraw, isolate, feel fearful, sad, or angry
- **Resilience** helps meaning finding: *Being able to experience both positive and negative emotions in distressing situations*
- *Being willing to learn from hardship
- *Participating in kindness (both receiving and “giving back”)
- *Practicing self care (physical and mental)
- *Finding humor
- *Self-kindness (not self-indulgence)
- *Recognizing our common humanity (resist isolation)
- *Mindfulness (acknowledging the current moment)

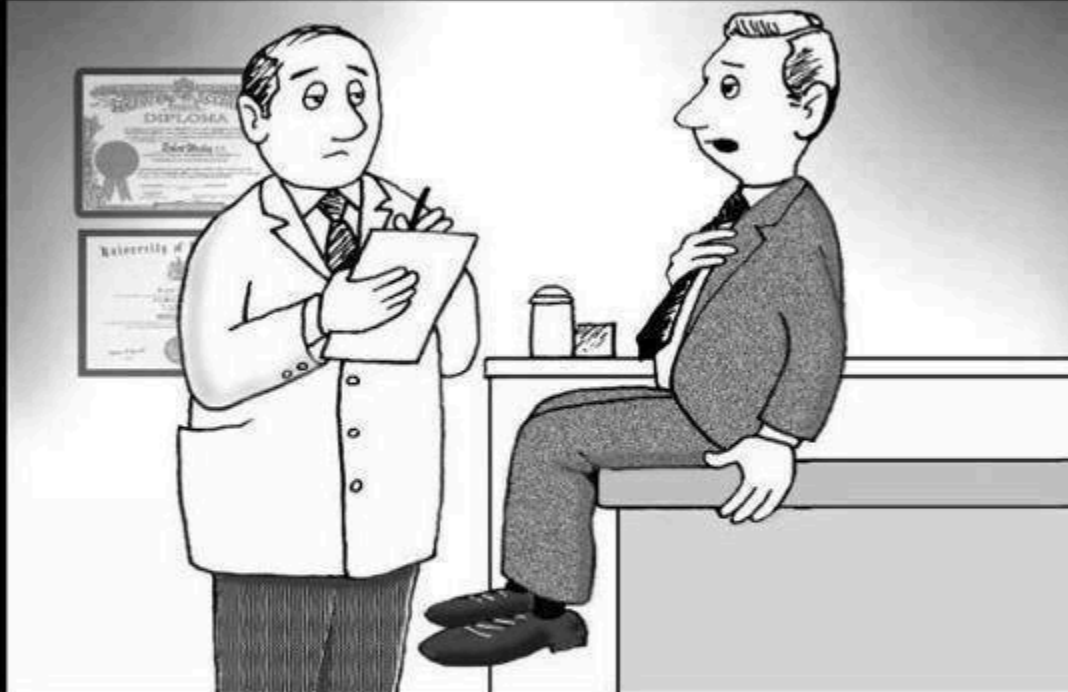
Prevention Works!

Control the things that can be controlled...

- *Keep blood pressure, cholesterol, blood sugar, weight, chronic illnesses and stress under YOUR control*
 - Relationships are important
 - Exercise is actually **prevention**
 - Address physical AND psychological needs
 - Actively manage stress and distress
 - Limit alcohol and substance use, quit smoking
 - Participate in activities that bring you joy
 - Sleep is critical for physical and emotional well-being, immune function, and **coping**.
 - Ask for help!



Patient: Doctor, I don't feel well and I'm not sure why.



Doctor: I want you to meditate for 20 minutes, twice a day, exercise for at least 30 minutes a day, avoid processed foods, eat plenty of organic fruit and veg, spend more time in nature and less indoors, stop worrying about things you can't control and ditch your T.V. Come back in 3 weeks.

What Cancer Survivors Need

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

Survivorship care 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.

Thank You!

You don't have to go navigate this road on your own...
survivorship resources can help you be in the drivers seat!

