

Promoting a Healthier Wyoming Conference  
**Current Challenges and Insights  
of Adult-Onset Cancer Survivorship**

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# Objectives

1. Explore professional perceptions of cancer survivorship and recognize how they match or differ from the patient's actual experiences, including the language we use.
2. Identify common and unique challenges of cancer survivorship from the perspective of patient, family, caregivers and clinicians
3. Identify gaps in clinical and supportive services available to people with cancer and their caregivers; consider ways to bridge those gaps.

## Statistics:

15.5 million cancer survivors in 2016  
>20 million by 2026  
>26 million by 2040

# Disclosures and Contributions

- Nothing to disclose
- Grateful for shared expertise from my colleagues in AOSW and the oncology care community, among them are:
  - Christina Bach, MSW, MBE, LCSW, OSW – OncoLink
  - Carlin Callaway, DNP – University of Colorado Cancer Center, ASCO Survivorship Committee
  - Susan Hedlund, LCSW, OSW-C, FAOSW – Knight Cancer Institute (OR), CoC Advisory Committee
  - Barbara Martin, MSSW-CSW, IIC – Louisville, KY

# Through your eyes and experience:

C =

A =

N =

C =

E =

R =

## Activity / Discussion:

- Use the letters in one or both of these words to describe in your understanding of the cancer experience – one word per letter
- Determine your viewpoint beforehand:
  - Person with **direct cancer experience**: as a patient or immediate family member (spouse/partner, parent, sibling, child, caregiver)
  - Someone with more **indirect cancer experience** through your connection with a colleague, friend, neighbor, extended family (grandparent, aunt, uncle)

S =

U =

R =

V =

I =

V =

O =

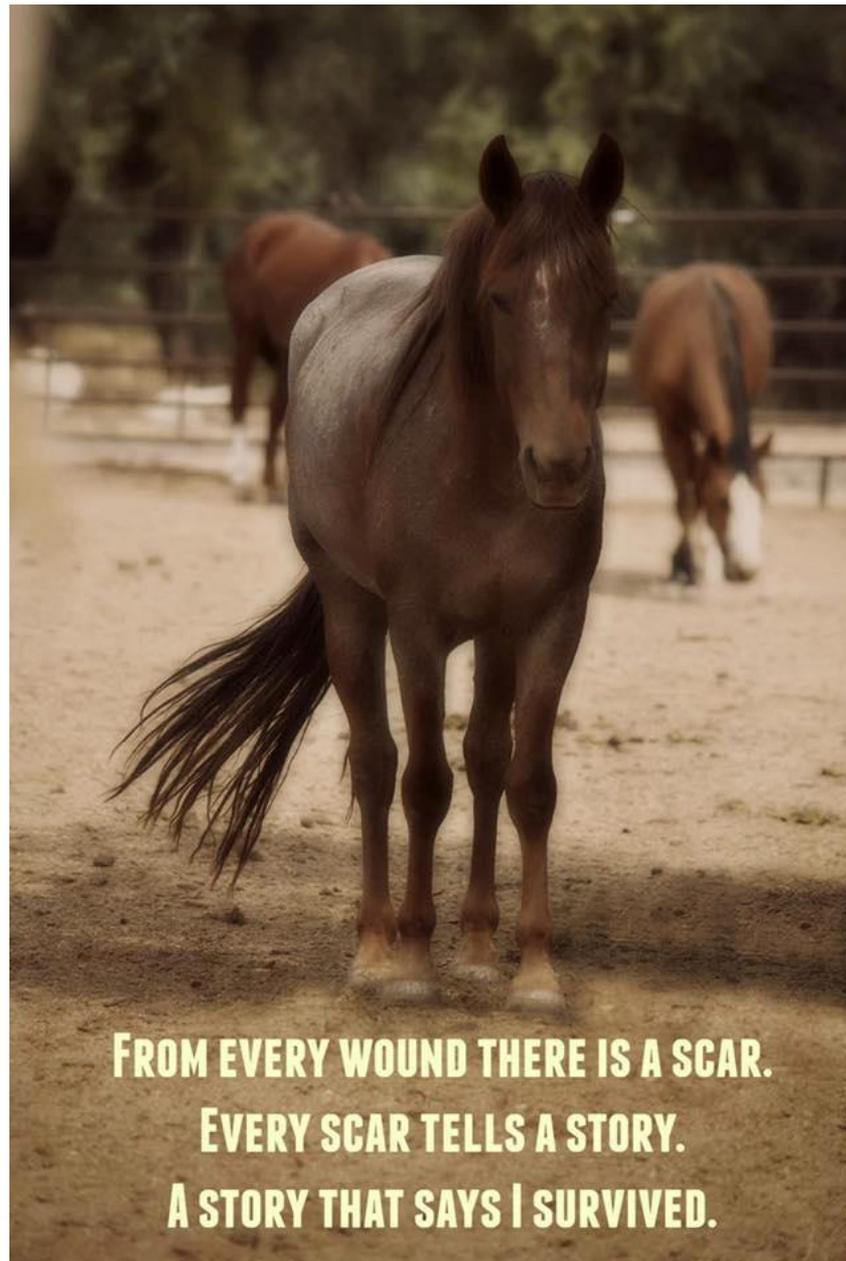
R =

*Our perception is our reality*

# “Survivorship” Defined

- **NCCN:** “An individual is considered a cancer survivor from the time of diagnosis, *during and immediately after treatment*, through the balance of his or her life. Family members, friends, and caregivers are also affected by cancer. (Version 2.2019)
- **NCCS/NIH:** physical, psychological, financial, emotional, spiritual, and social challenges – the broad experience on the cancer continuum *living with, through, and beyond a cancer diagnosis*.
- **Patients: What it is like to live or die with cancer**
  - *My meaning* - How did it change me?
  - What fits the individual’s experience?
  - What language do we use when we talk to patients?
  - Hold a “Beginner’s mind”

Individuals  
define their  
experience



**FROM EVERY WOUND THERE IS A SCAR.  
EVERY SCAR TELLS A STORY.  
A STORY THAT SAYS I SURVIVED.**

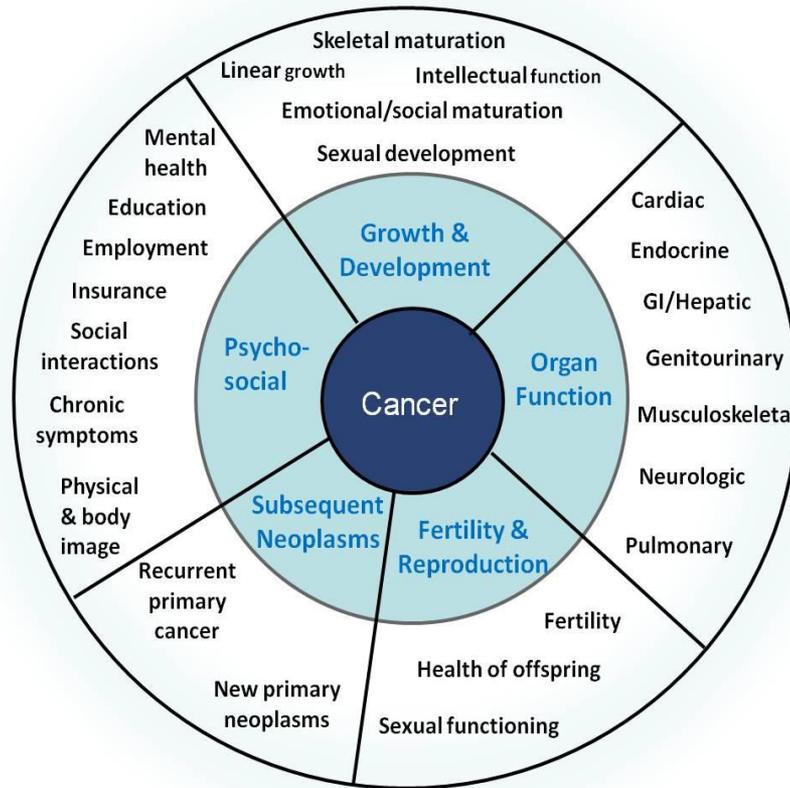
# Common & Unique Survivorship Issues

- Patient
  - Grief/loss
  - Anxiety, Depression (hx)
  - Vulnerability
  - Recurrence/progression
  - Risks of another cancer
  - Anticipation, vigilance, worry, waiting
  - Side effects: pain, fatigue, sleep, lymphedema, menopause, etc
  - Self-image
  - Pre-existing conditions / co-morbidities
  - Work / Family / Life
  - Cognitive changes
  - Late-effects/Long-term
  - Caring for other family members
- Family
  - Self-care
  - Competing priorities
  - Compassion Fatigue
  - Depression
  - Fear of recurrence, too!
- Friends
  - How can I help?
  - What can I say?

**How do I keep  
HOPE alive?**

**Where can I find  
the support and  
guidance I need?**

# Health Concerns after Cancer



Presented by Melissa Hudson at 2016 Cancer Survivorship Symposium

# What do people facing cancer want/need?\*

Physical	Psychological	Practical	Social
Diet	Fear of Recurrence	Cognitive changes	Support
Exercise/ Movement	Appropriate Threat Monitoring Practices	Financial / Insurance Assist	Connection
Chronic pain	Values-clarification	Community Resources	Compassion
Sexual Health / Fertility	Coping strategies	Healthcare/System Navigation	Healthy Lifestyles

- Improved continuity of care when treatment ends
  - SCPs they can read/understand – a plan for the future
  - Shared responsibility with oncologist – the handoff
    - RCT: PCP vs. oncologist survivorship care
  - Genetic counseling – assessing and managing family risk

# What do NCCN, CoC, and Clinicians want?

- CoC no longer requiring SCPs
  - What about treatment summaries?
- NCCN Guidelines (modified 2019)
  - Standards for Survivorship Care
    - including Survivorship Care Planning
  - General Principles of the Survivorship Guidelines
    - across the continuum of care
- Enrollment in clinical trials
- Improved multi-disciplinary care coordination
  - PCPs responsible for care after treatment
    - More OVs and need for survivorship follow-up guidelines
    - Integrate recommendations into PCP workflow
    - 9X more likely to have survivorship discussions if received SCP
    - Prefer shorter, concise versions
- ASCO statement – “need for standardized, evidence-based practice guidelines for the management of treatment effects and health promotion of survivors.”

# Survivorship Care Plans / CoC - evolving

- Inspired by the 2005 IOM report – *From Cancer Patient to Cancer Survivor: Lost in Transition*
- Treatments and experience changing rapidly – no “best practice” established
- SCP Research:
  - no differences in patient-reported outcomes or distress – may be more satisfied with care
  - increase in symptoms, concerns about illness and emotional impact
  - Latina breast cancer survivors – greater PCP implementation of and patient adherence to recommended survivorship care
  - Mailed SCP and telehealth follow-up: reduced distress, improved mental health
- Detailed and derailed by unfunded mandate
- SCP templates/formats
- What now?
  - Each institution appoints person/committee to define survivorship effort for that institution
  - Create own metrics
  - Demonstrate programs and services for survivors

# Advice from a Cancer Survivor

- Do it now!
  - Be grateful, cherish
  - Prioritize (passions vs. obligations)
  - QOL matters!
  - Heal more than my body
- 
- **Advice for Clinical Caregivers**
    - Listen!
    - Be mindful of the language you use to describe my experience
    - Include me in decisions
    - Be informed about survivorship issues I raise
    - Share info and resources, but don't overwhelm me
    - Help me coordinate my aftercare – become a bridge to my PCP
    - Help me celebrate and find joy
    - Take care of yourself, so you can take care of me



**“Cancer survivorship is so individualized – patients should all have a living Survivorship Plan of Care.**

**Some things remain, other things show up from time to time, but patients should be able to speak with someone who understands survivorship issues so that patient-centered care happens.**

**That way, survivors can stay on their own path and not get caught up in anyone else’s path.”**

- KY stakeholder/provider interview

# How will YOU apply what you learned today?



**"What you do makes a difference, and you have to decide what kind of difference you want to make."**

**Jane Goodall**



# Thank you!

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