“Empowering Yourself Palliative Care”

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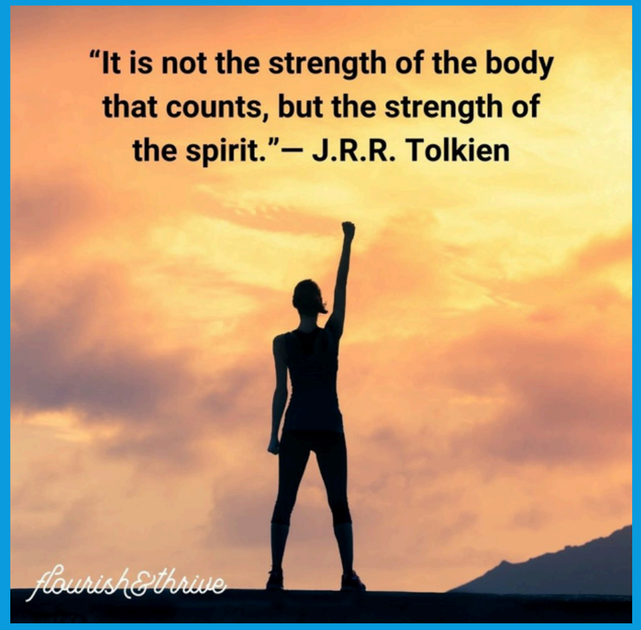
I have no relevant disclosures

Power

Resilience and Strength



Resilience Factors

Speaking a common language

- *Palliative care, and the medical sub-specialty of palliative medicine, is specialized medical care for people living with serious illness. It focuses on providing relief from the symptoms and stress of a serious illness—whatever the diagnosis. The goal is to improve the quality of life for both the patient and the family.*

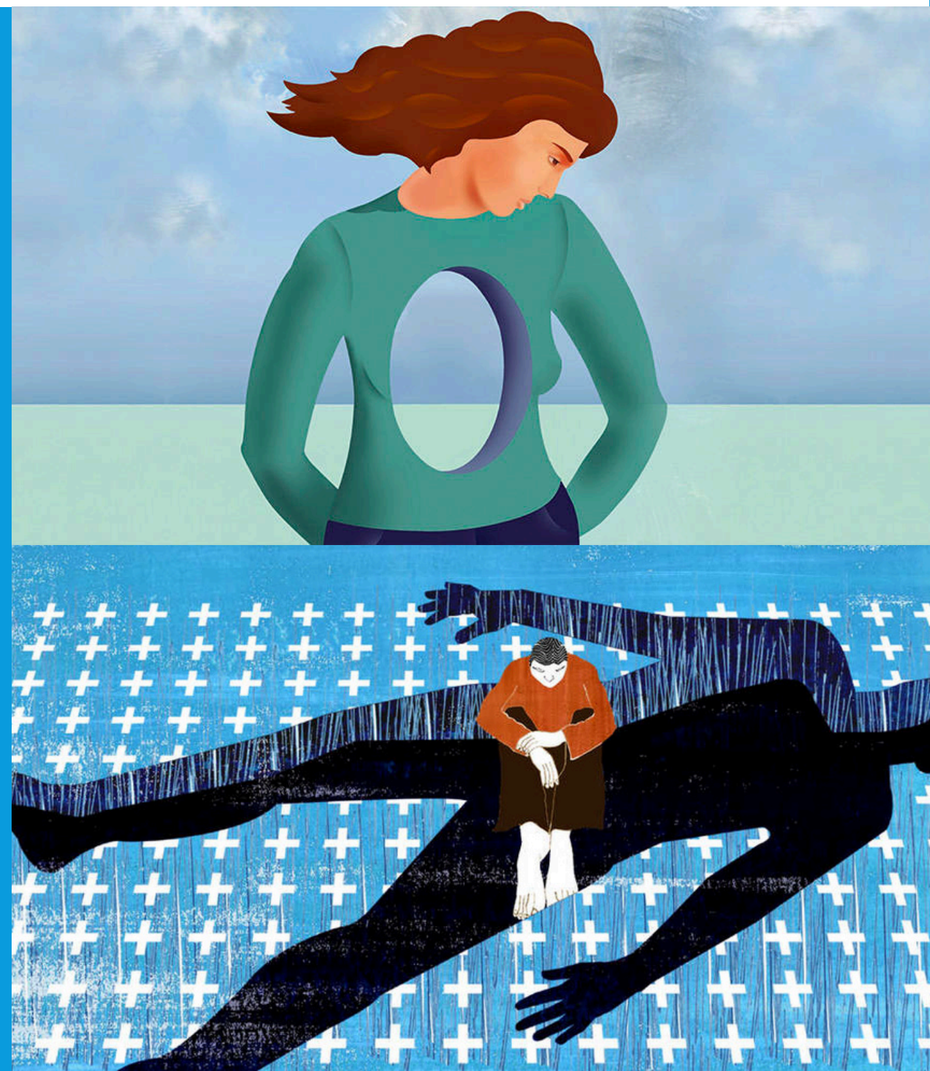
- *Palliative care is provided by a team of palliative care doctors, nurses and other specialists who work together with a patient's other doctors to provide an extra layer of support. It is appropriate at any age and at any stage in a serious illness and can be provided along with curative treatment.*

Bottom Line

- Palliative care is not to help you die, it is help you live
- Palliative care is not just to help you survive, it is to help you on your journey to thrive
- Palliative care is not to help you be resilient or strong it is to support you to be the person you are at the time
- Palliative care is not to direct your decisions, it is to:
  - Make sure you are informed
  - Honest
  - Support
  - **Accept**

What Does Illness threaten?

- Certainty
- Security
- Confidence
- Stability
- Wellbeing



What are we offering? 3H

- **Helping:** we help **people** achieve their goals and assist them with things they need
- **Hoping:** explore what **people** are hoping for and help them reframe hope with clinical conditions change
- **Holistic:** we focus on **persons** and individuals with emotional, physical, and spiritual components- value human complexity and tailor their care to them- sometimes we facilitate **healing**

What is the Philosophy?

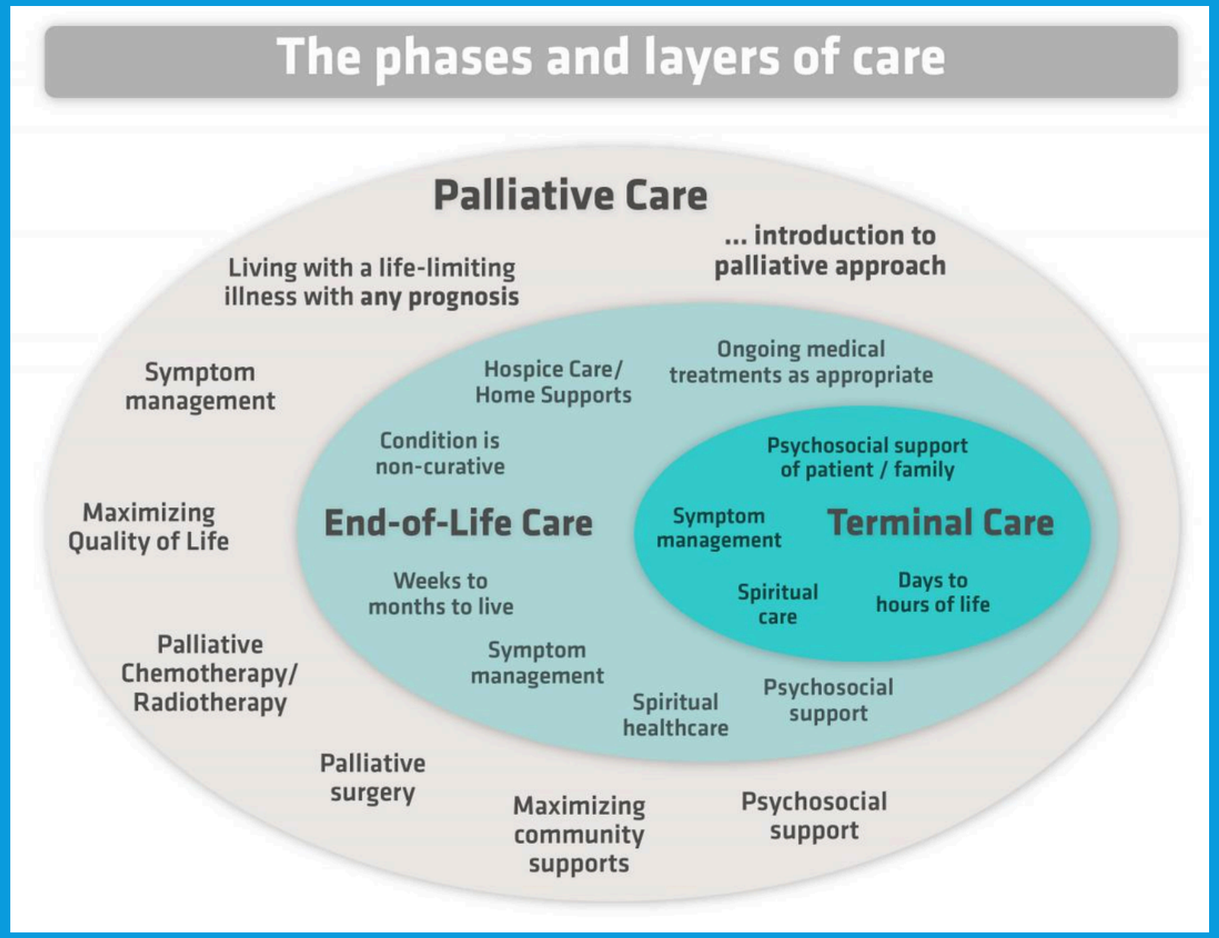
- Palliative Care is about goals
- We have health care providers who are the guides
- Willingness to allow people to set the goal
- Work through the uncertainty together

Where do we operate in the medical system?

- An area of medical uncertainty
- Evidence-based medicine fails
- Where the patients “are”

As the kids say " We get in where we fit in."

Palliative/Supportive Care



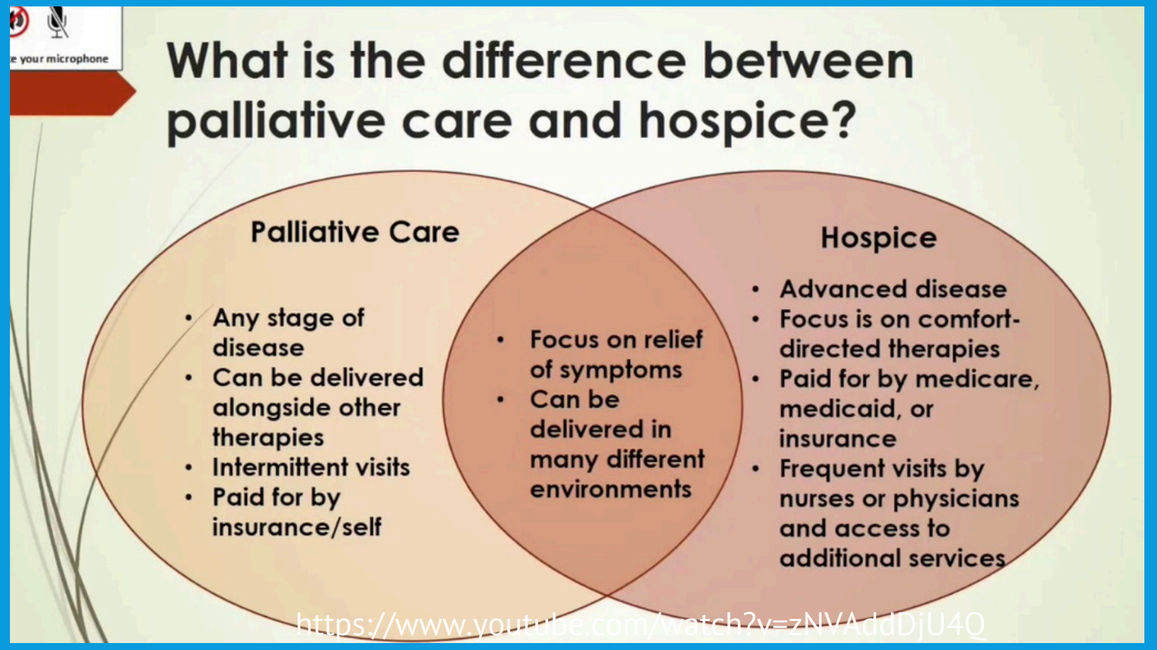
- **Palliative/Supportive care in advance cancer is standard of care – ASCO Guidelines**
- Palliative/Supportive care should be available to patients to maximize quality of life through all phases of illness
- Palliative/Supportive care is not equivalent to hospice care
- Hospice is the vehicle that delivers palliative care when a person is at the end of life

Common Language

- Supportive care is part of the larger whole of the services available to help patients and families cope with cancer
- Supportive Oncology is a vital collection of services that people with cancer may need to support them through various stages of illness

Hospice

- Hospice is an interdisciplinary program of palliative and supportive services funded by third-party payers (insurances) that is provided to patients both at home and in institutions; for people who we are concerned may have weeks to months to live.
- The intention is for them to live as comfortably as possible; and their caregivers & families to be supported. It is the vehicle by which end of life care can be provided with maximum level of support.



Where can you receive supportive/palliative care services?

Primary Palliative Care: palliative/supportive care provided by treating teams

Outpatient Supportive/Palliative Care Services: embedded in oncology teams or free-standing clinics provided by specialist

Hospital: consultative palliative care teams

Home based Supportive/Palliative care: provided in private homes or institutions by agencies/specialist

Interprofessional Teams

Palliative Care

- Provider: Doctor/Advance Practice Provider
- Spiritual Health Clinician
- Social worker / Licensed Clinical Social Worker
- Nurse/Care Coordinator
- +/- Pharmacist
- +/- Integrative therapies: child life, music, Pet therapy, art therapy psychology
- Orders medications and durable medical equipment paid for by patient's insurance

Hospice

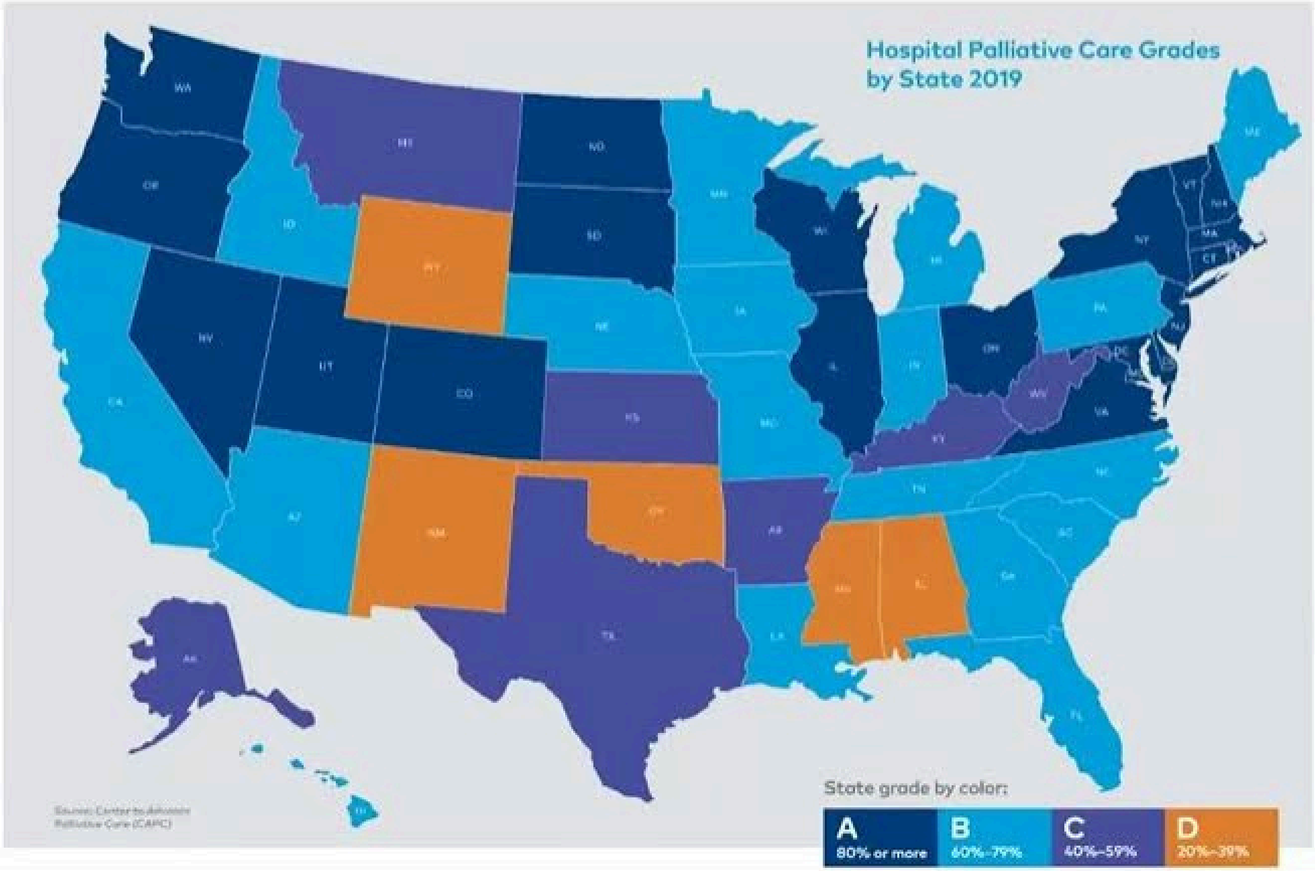
- Provider: Doctor/Advance Practice Provider
- Spiritual Health Clinician
- Social worker / Licensed Clinical Social Worker
- Nurse/Care Coordinator
- Certified Nursing Assistant
- Pharmacist
- +/- Integrative therapies: child life, music, Pet therapy, nutrition, physical therapy, psychology, art therapy
- Bereavement
- Provides medications and durable medical equipment paid for by hospice benefit

What can be offered in a Supportive/Palliative care visit?

- Symptom management 2nd to cancer and/or treatment: symptoms are treated as a primary illness
  - Pain, nausea, constipation, diarrhea, neuropathy, depression/anxiety, itching, fatigue, shortness of breath
- Define life goals: short and long-term
  - Assistance with achieving goals: (treatment, life, bucket list, relationships)
- Needs assessment for community resources: for patient and family
- Empathic and supportive listening: patient and family
- Counseling and coaching
  - Assistant with complex decision making
  - Caregiver support
- Advance care planning :
  - Discussing or clarifying prognosis
  - Discussion and/or completing advanced directive: identifying health care agents/surrogate decisions makers
  - Planning for the future

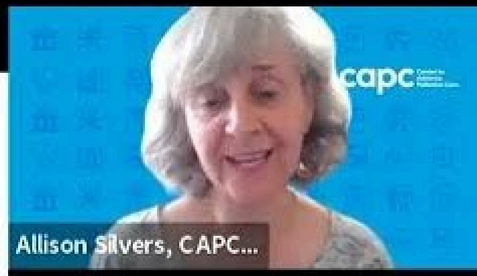
Advocacy

Access to Palliative Care: 83% of US hospitals with 50+ beds report palliative care teams



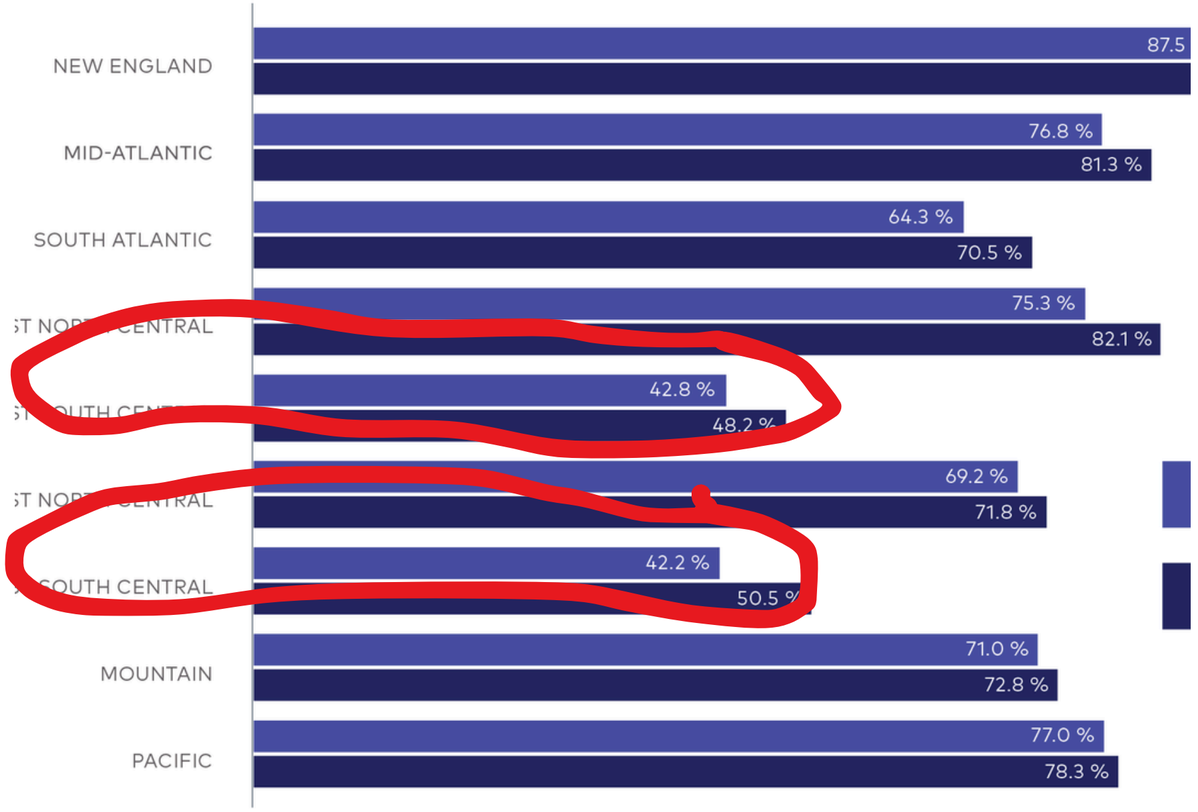
Hospital types ***less*** likely to offer palliative care:

- Southern (59%)
- For-profit (35%)
- Public (60%)
- Sole community provider (40%)
- Rural (17%) hospitals



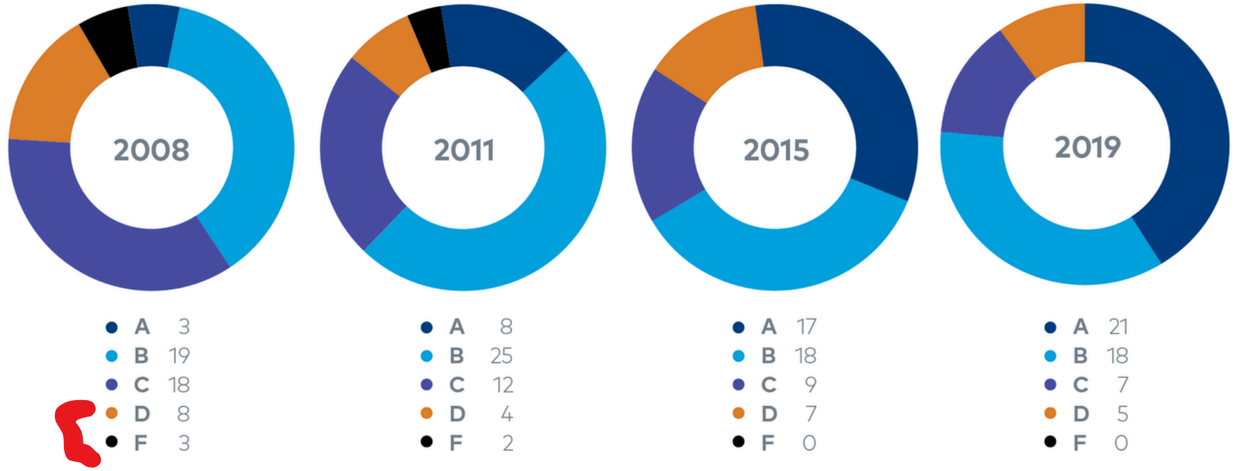
Graph A. *Growth in the prevalence of hospital palliative care by region, from 2015 to 2019*

Growth in palliative care prevalence varies greatly by region.



Graph B. *Number of states by grade (2008, 2011, 2015, 2019)*

Three-quarters of states now have a grade of A or B.



Barriers

What limits access

Systemic Barriers

- Misconceptions
- Lack of financial support
- Lack of palliative care teams (Interprofessional teams)
- Lack of trained providers

Referral Barriers

- Bias
- Fear of losing patients
- Fear patients will give up
- Belief palliative care is only end of life
- No evidence of disease

Detour: No evidence of disease

NED (no evidence of disease) should be replaced with NCCF (no current cancer found)

	Breast cancer survivors (N = 350)	Reference population (N = 350)	Univariate compari
	N (%)	N (%)	OR[a] (95%CI)
Concentration difficulties	80 (22.9)	37 (10.6)	2.5 (1.6–3.8)*
Forgetfulness	80 (22.9)	51 (14.6)	1.7 (1.2–2.6)*
Dizziness	95 (27.1)	63 (18.0)	1.7 (1.2–2.4)*
Nocturia	90 (25.7)	65 (18.6)	1.5 (1.1–2.2)*
Appetite loss	21 (6.0)	9 (2.6)	2.4 (1.1–5.4)*
Intermittent claudication	23 (7.3)	11 (3.5)	2.2 (1.1–4.6)*
Chest pain	32 (9.1)	21 (6.0)	1.6 (0.9–2.8)
Abdominal bloating	72 (20.6)	53 (15.1)	1.5 (0.98–2.1)
Cough when lying down	47 (13.4)	34 (9.7)	1.4 (0.9–2.3)
Shortness of breath after exertion	106 (30.3)	87 (24.9)	1.3 (0.9–1.8)
Fatigue after exertion	97 (27.7)	79 (22.6)	1.3 (0.9–1.9)
Palpitations	82 (23.4)	66 (18.9)	1.3 (0.9–1.9)
Edema ankles	65 (18.6)	51 (14.6)	1.3 (0.9–2.0)

OR = Odds Ratio, unadjusted.

*Significant.

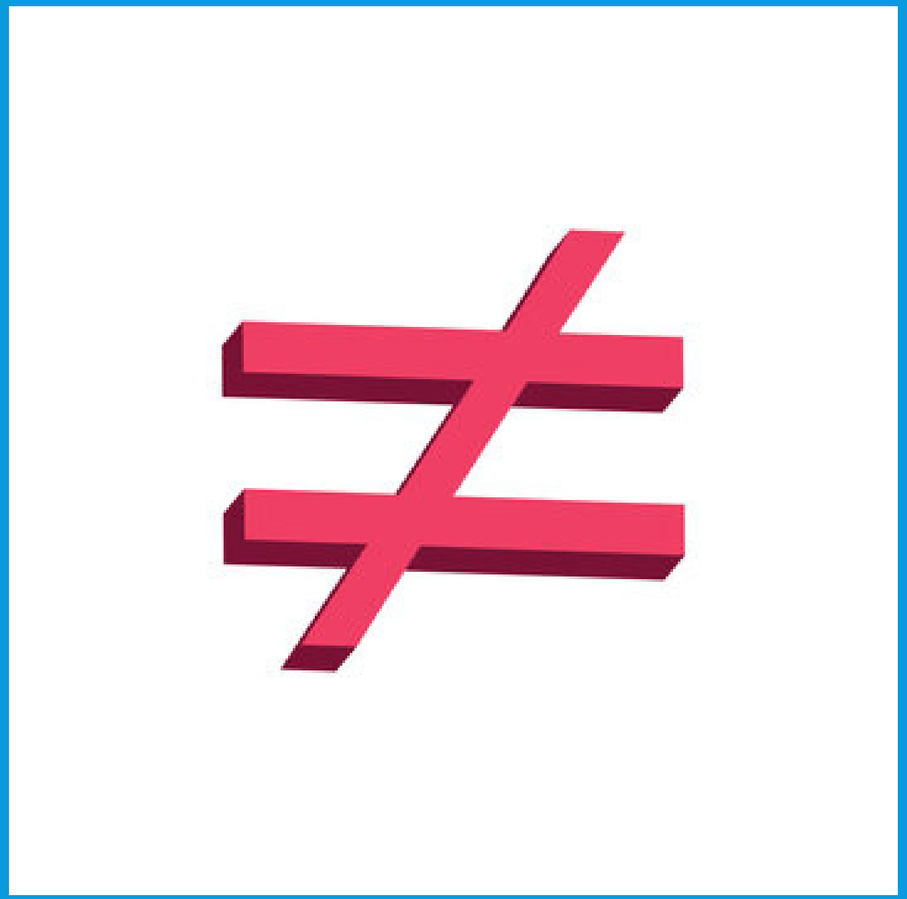
[a]The multivariate analysis only performed when the odds ratio is 1.5 or higher.

- *"305 BCS (74%), with a median of 7.4 years since diagnosis reported chronic pain, of whom 84% had moderate pain, and 97% experienced pain at least 1-3 days/week. Other symptoms were paresthesia (63%), allodynia (48%), and phantom sensations (15%). Report of pain symptoms, alone or combined, was significantly associated with poorer quality of life."*
- **When you have been treated for cancer, your whole body shows evidence of the disease whether the cancer is there or not**

Maass SWMC, Boerman LM, Brandenbarg D, Verhaak PFM, Maduro JH, de Bock GH, Berendsen AJ. Symptoms in long-term breast cancer survivors: A cross-sectional study in primary care. Breast. 2020 Dec;54:133-138. doi: 10.1016/j.breast.2020.09.013. Epub 2020 Sep 30.

Hamood R, Hamood H, Merhasin I, Keinan-Boker L. Chronic pain and other symptoms among breast cancer survivors: prevalence, predictors, and effects on quality of life. Breast Cancer Res Treat. 2018 Jan;167(1):157-169. doi: 10.1007/s10549-017-4485-0. Epub 2017 Aug 31. PMID: 28861642.

Cure or NED does not equal Wellness



Call To ACTION

Access to high-quality Palliative Care delivered by an Inter-professional team for advanced care is the standard of care

Primary palliative care delivered by your healthcare teams is not a "*bonus*" it is an expectation

Asking your healthcare team for palliative care is not "giving up", it asking for the tools you need to make it through your journey.

You are not your cancer you are a person. Treating cancer without treating what cancer is doing to you is substandard care.

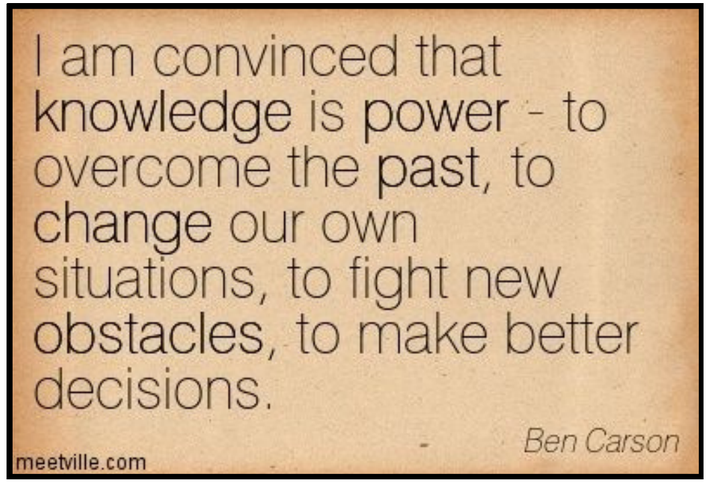
Your organizations should fight just as hard for your quality of life as they fight for access to treatment and cure.

NED (No Evidence of Disease): Cancer survivorship should include a palliative approach to care.

Summary

- Supportive Care is part of the larger whole, of the services provided by supportive oncology
- Supportive/Palliative care is not hospice. Supportive/Palliative care provides symptom management and an extra layer of support for people and families living with serious illness no matter where they are in the illness
- Supportive Care is whole person care and care is directed by a person's value
- Hospice is the medical service that provides palliative and supportive care for people and families at end of life
- Supportive/Palliative Care is provided by an interprofessional team

Thank you



Resources:

www.getpalliativecare.org
https://palliativedoctors.org