End of Life Care in NC

Introduction to Hospice and Palliative Care Services

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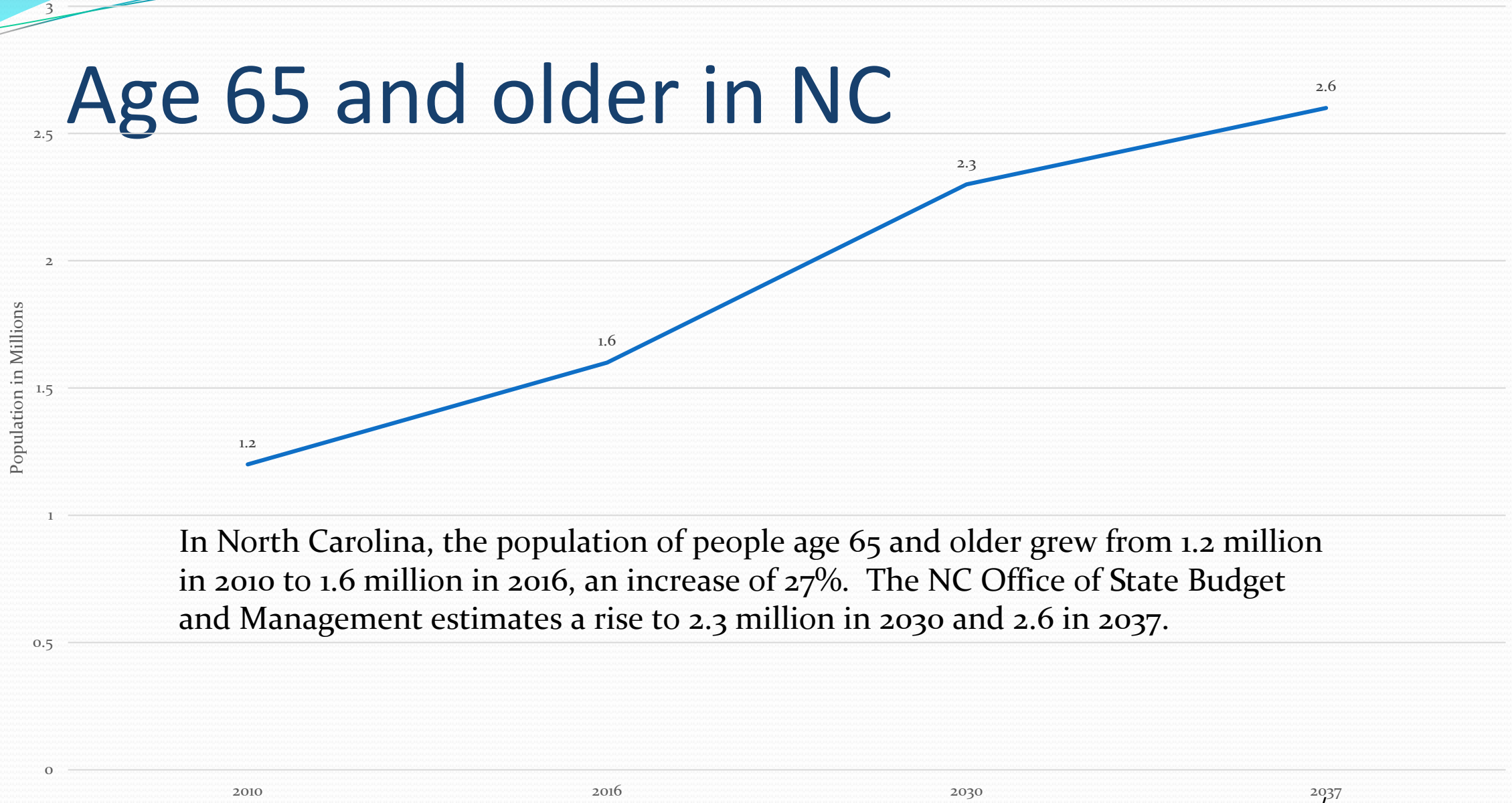
We'll touch on…

- Lay of the land- some demographic changes
- Cost and Quality imperatives
- Services provided
- Room for improvement

Age 65 and older in NC



In North Carolina, the population of people age 65 and older grew from 1.2 million in 2010 to 1.6 million in 2016, an increase of 27%. The NC Office of State Budget and Management estimates a rise to 2.3 million in 2030 and 2.6 in 2037.

NC in Focus: Fast-growing older population also growing more diverse | Carolina Demography. https://demography.cpc.unc.edu/2017/06/28/nc-in-focus-fast-growing-older-population-also-growing-more-diverse/. Accessed October 26, 2018.

- In 2016, 15.5% of North Carolina's population was 65 or older.

University of Virginia, Weldon Cooper Center for Public Service for Public Service

Projected NC population proportions 65 & older

- 2020: 18%
- 2030: 21%
- 2040: 22%

https://demographics.coopercenter.org/national-population-projections

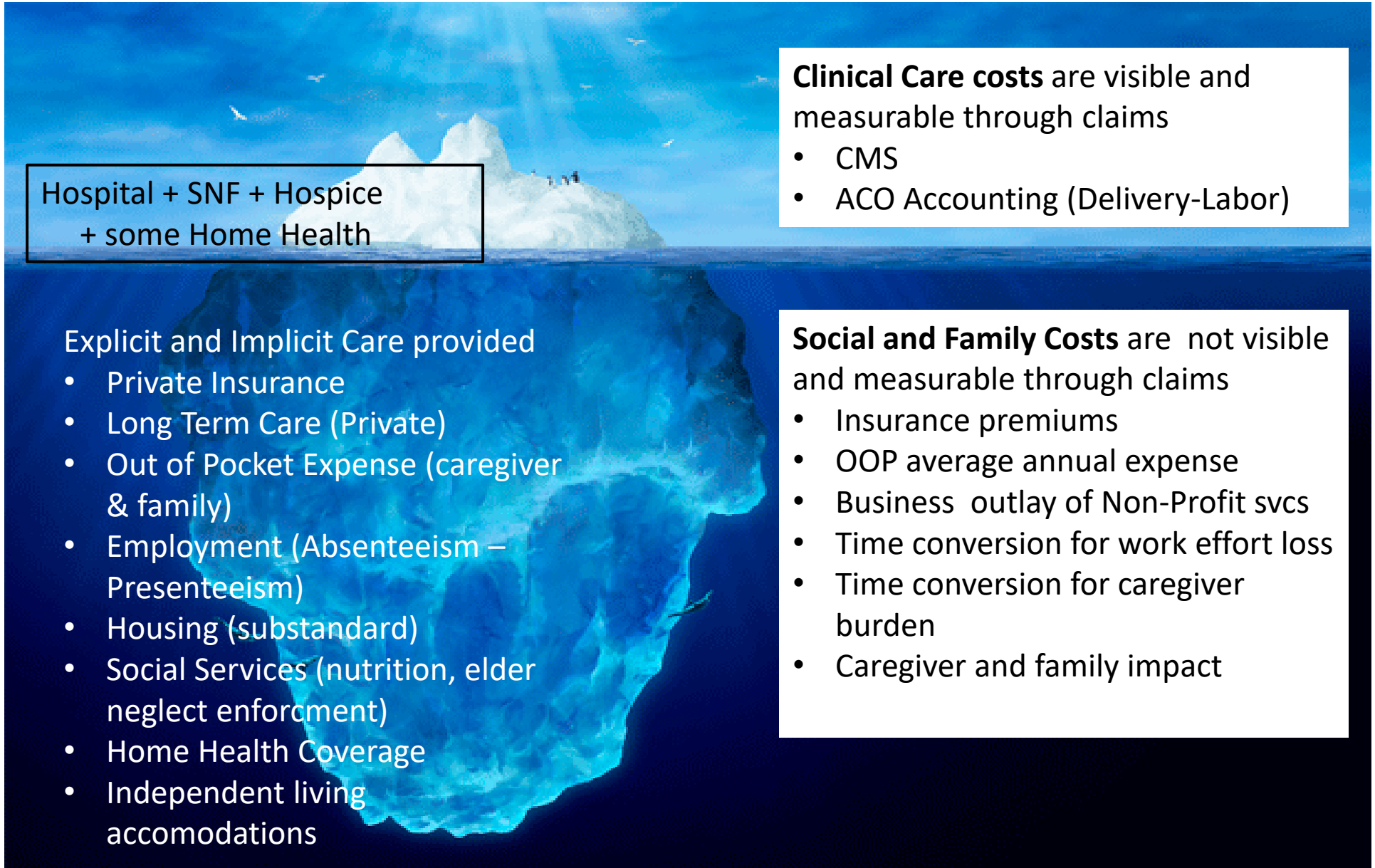
Aging and Cost of Care in NC

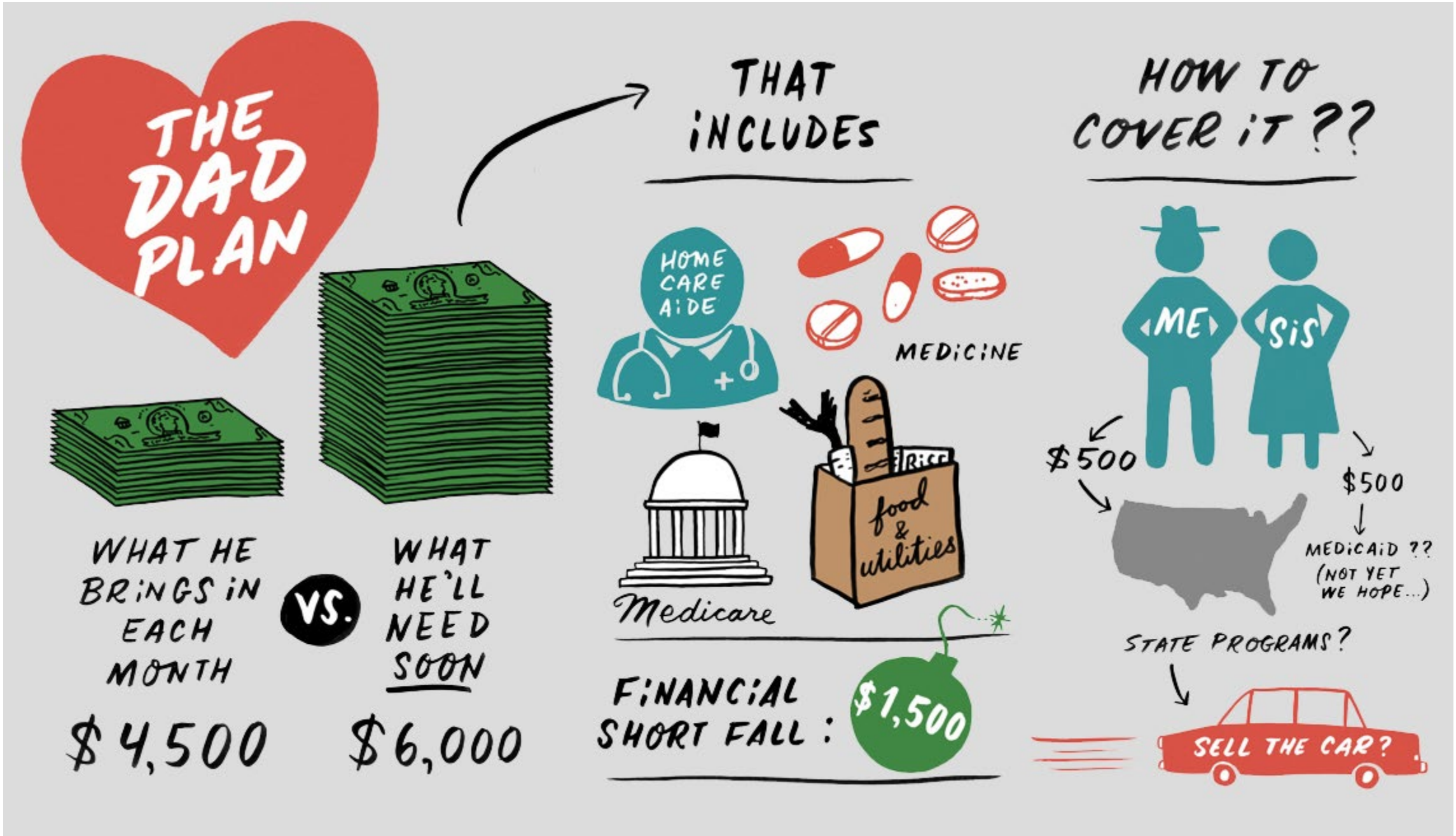
- In 2012, the cost of health care for North Carolinians 65 & older was $25 billion
- In 2037, the projected cost will be $69 billion
- 180% increase

http://www.ncmedicaljournal.com/content/79/1/66.full

Iceberg at End of Life with Advanced Life Limiting Illness

Capital and Social Costs need system change




THE DAD PLAN
WHAT HE BRINGS IN EACH MONTH
$4,500
VS.
WHAT HE'LL NEED SOON
$6,000
THAT INCLUDES
HOME CARE AIDE
MEDICINE
Medicare
food & utilities
FINANCIAL SHORT FALL :
$1,500
HOW TO COVER IT ??
ME
SIS
$500
$500
MEDICAID ??
(NOT YET WE HOPE...)
STATE PROGRAMS?
SELL THE CAR?



Nearly **one quarter of adults in North Carolina provide regular care** or help to an older adult with a disability or illness. Of these caregivers, more than half are employed and **balance work and caregiving**. (AARP) In addition, in 2015, the ratio of potential caregivers—people aged 45-64—to those over the age of 80 was eight-to-one. By 2030, there will **only be 4 potential caregivers for every older adult in the state.** (NCIOM)



Today

There are about **7 caregivers** for each person 80+

2030

There will be about **4 caregivers** as boomers reach 80

2050

There will be about **3 caregivers** as Generation X hits 80

By the Generations

Older generations now have lots of boomers to care for them. But with lower rates of marriage and fewer children, the baby boom generation (born 1946 to 1964) and Generation X (1965 to 1979) will have smaller pools of caregivers.

Cost & Quality as Motivators

- High cost of end of life care.
- Small numbers of patient with high utilization

Almost one-third of Medicare expenditures are attributable to the 5 percent of beneficiaries who die each year.

About one-third of expenses in the last year of life are spent in the final month

- End of life care is 21% of Medicaid costs in North Carolina (2.6 billion out of $12.4 billion)

  http://www.ncmedicaljournal.com/content/79/1/43.full

- System in “default”- we will do everything to everyone

Quality of Care Imperative

- 70% die in hospitals or long-term care
- Aggressive and often futile therapeutic interventions in the last weeks of life
- 40% have severe pain prior to death
- Unmet needs for symptom management and support
- 31% families report major financial hardship because of terminal care costs

Quality deficit

- The average patient has 3 care transitions in last 90 days of life
- 30% of Medicare decedents have at least one ICU stay in the last month of life
- Mismatch between what health care provides and what seriously ill people need
- Family dissatisfaction with end-of-life care received by their loved ones

PALLIATIVE CARE

An added layer of support

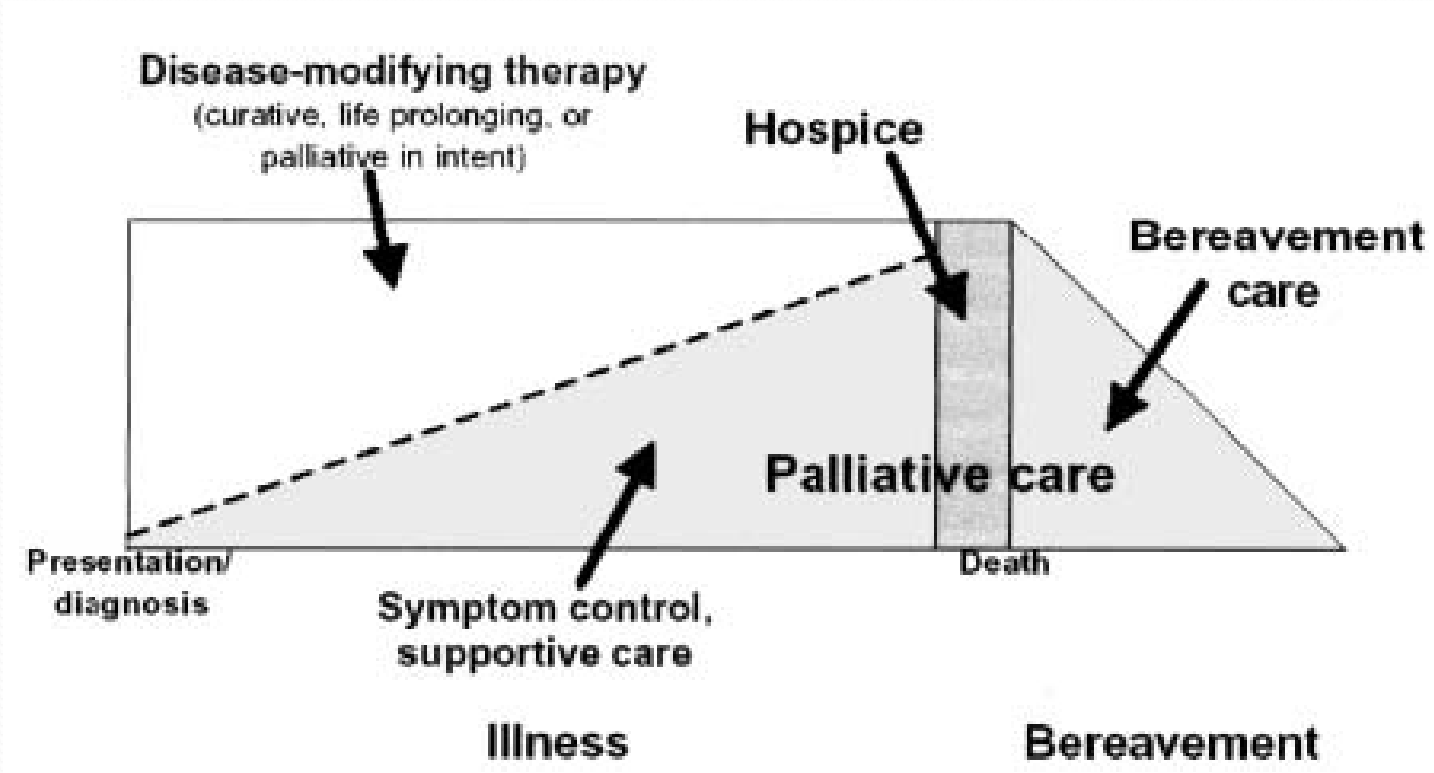
- Care to improve the quality of life for patients with serious illness
- Focus:
  - ⇨ Symptom management
  - ⇨ Communication & Decision-making facilitation
  - ⇨ Support for patient and family
- ***Co-exists with disease-based evaluation and treatments***

All hospice is palliative care, but **not all** palliative care is hospice.

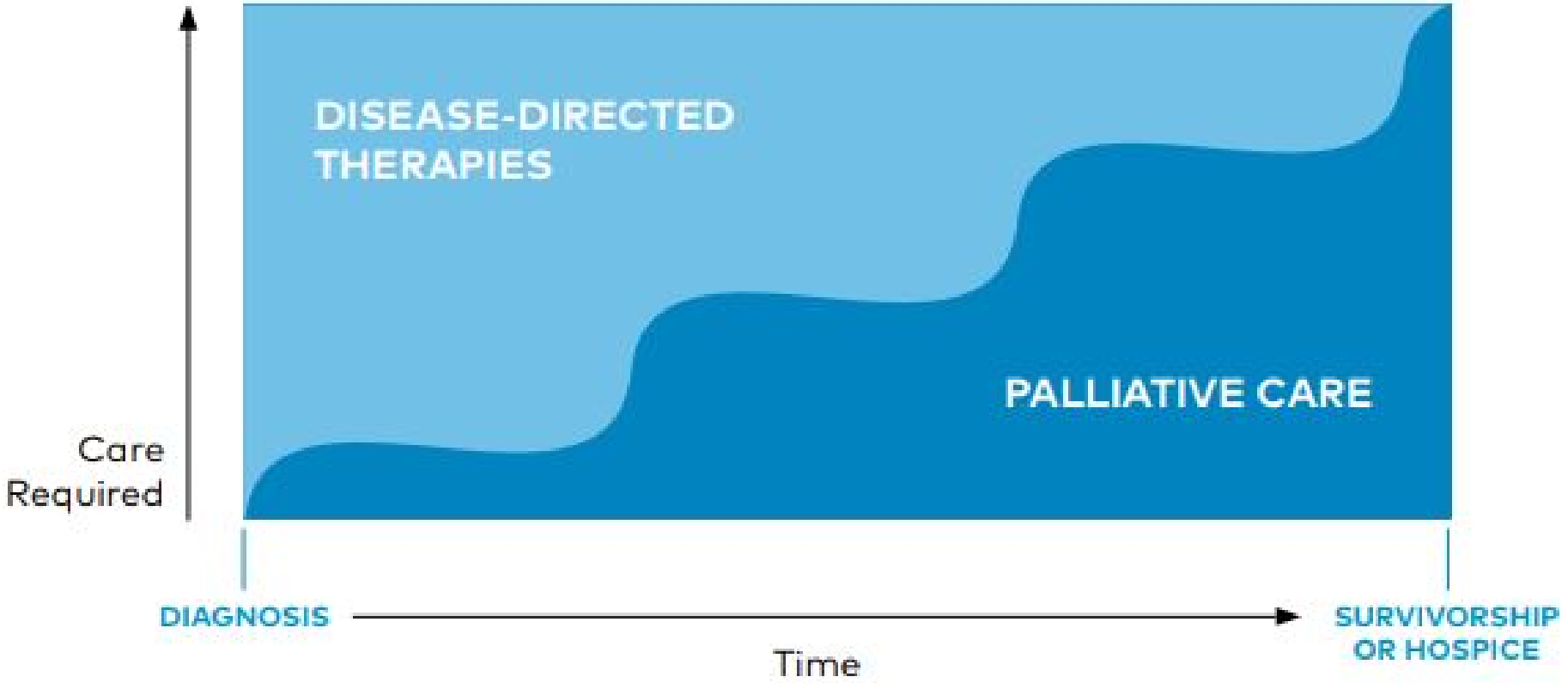
Hospice is a model of palliative care restricted to terminal illness.

Palliative care is appropriate at any age and at any stage in serious illness.

Palliative Care – Hospice Intersection



Education in Palliative and End-of-Life Care (EPEC): www.epec.net


DISEASE-DIRECTED
THERAPIES
PALLIATIVE CARE
Care
Required
DIAGNOSIS
SURVIVORSHIP
OR HOSPICE
Time

Palliative Care=Best Care

The NEW ENGLAND JOURNAL of MEDICINE

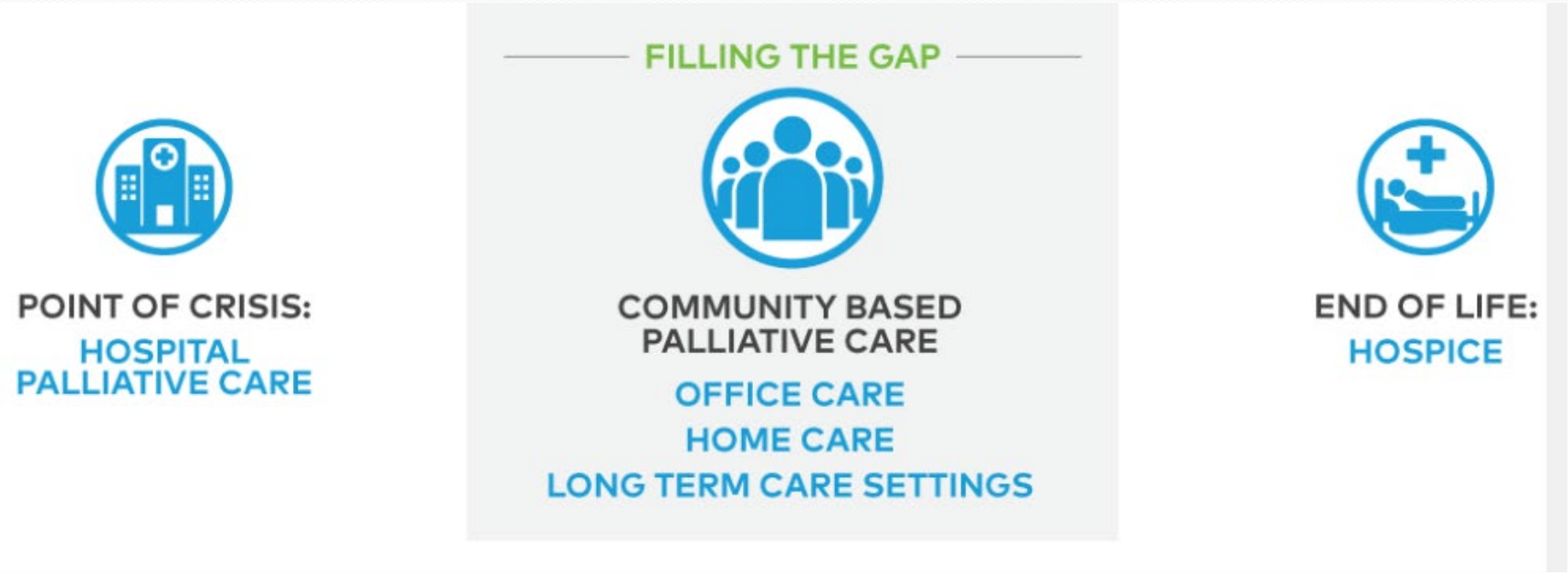
- 151 patients with metastatic lung cancer randomly assigned to get either oncology treatment alone or oncology treatment with palliative care.
- Palliative care group reported less depression and happier lives as measured on scales for pain, nausea, mobility, worry and other problems.
- Substantially fewer of them opted for aggressive chemotherapy as their illnesses worsened and many more left orders that they not be resuscitated in a crisis
- **They typically *lived almost three months longer* than the group getting standard care, who lived a median of nine months.**

Temel et al. Early Palliative Care for patients with Non-Small-Cell Lung Cancer. NEJM 2010; 363: pp.733-42

Palliative Care Consultation

- Primarily hospital based
  - 70% of mid/large sized hospitals in NC
  - Some outpatient or nursing home programs
  - Consult service: MDs, NPs, SW, Chaplain
- Reasons for Consult:
  - Symptom assessment & management
  - Patient and family support
  - Facilitate communication & decision making
    - Information needs
    - Establish, clarify goals of care

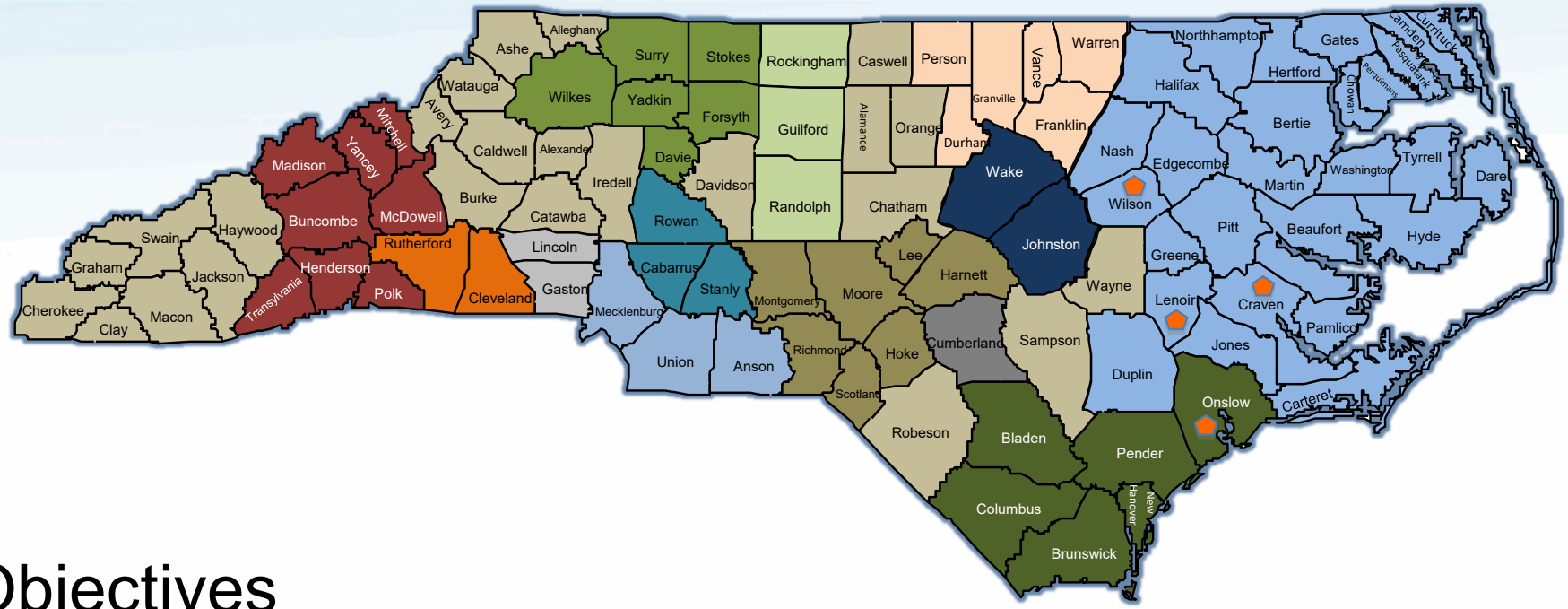
Palliative care has historically been provided in the inpatient hospital setting or in hospice under the Medicare hospice benefit.



Palliative care historically has not been provided in other community settings, where the majority of patients living with serious illness would benefit from its availability.

community-based palliative care models

- “bridging programs”; Advanced Illness Management
  - Providing longitudinal, community-based PC
  - comprehensive medical/psychosocial assessment
  - coordination, advance care planning, communication of preferences to providers
  - palliative care, focusing on comfort as well as the psychological, social and spiritual well-being of patients and families.
- In concert with standard care to assess and address multidimensional symptoms
- Coordination of care, streamlining the transition from palliative to end-of-life care



Initiative Objectives

1. To enhance patient autonomy through advanced care planning communication in primary care
2. To enhance access to hospice, palliative care and other supportive care services for seriously ill patients

CCNC Palliative Care Initiative Strategies

- Identific
  - PC indi ity score
- STAFFI
  - PC Coc
  - PC 101
  - Telepho
  - Statewi
- Provide rdize)
  - *Would you be surprised?* The longer you have known the patient…
  - Sensitize clinical judgment (providers and care management staff)
  - MOST form (POLST paradigm)

Develop systems to support the PCMH

- **Communication Tools**
  - Palliative care questions in CMIS
  - Respecting Choices / VitalTalk – communication skills
  - Goals of care discussions (Longevity, Function, Comfort)

- Coordination of QI efforts with community resources

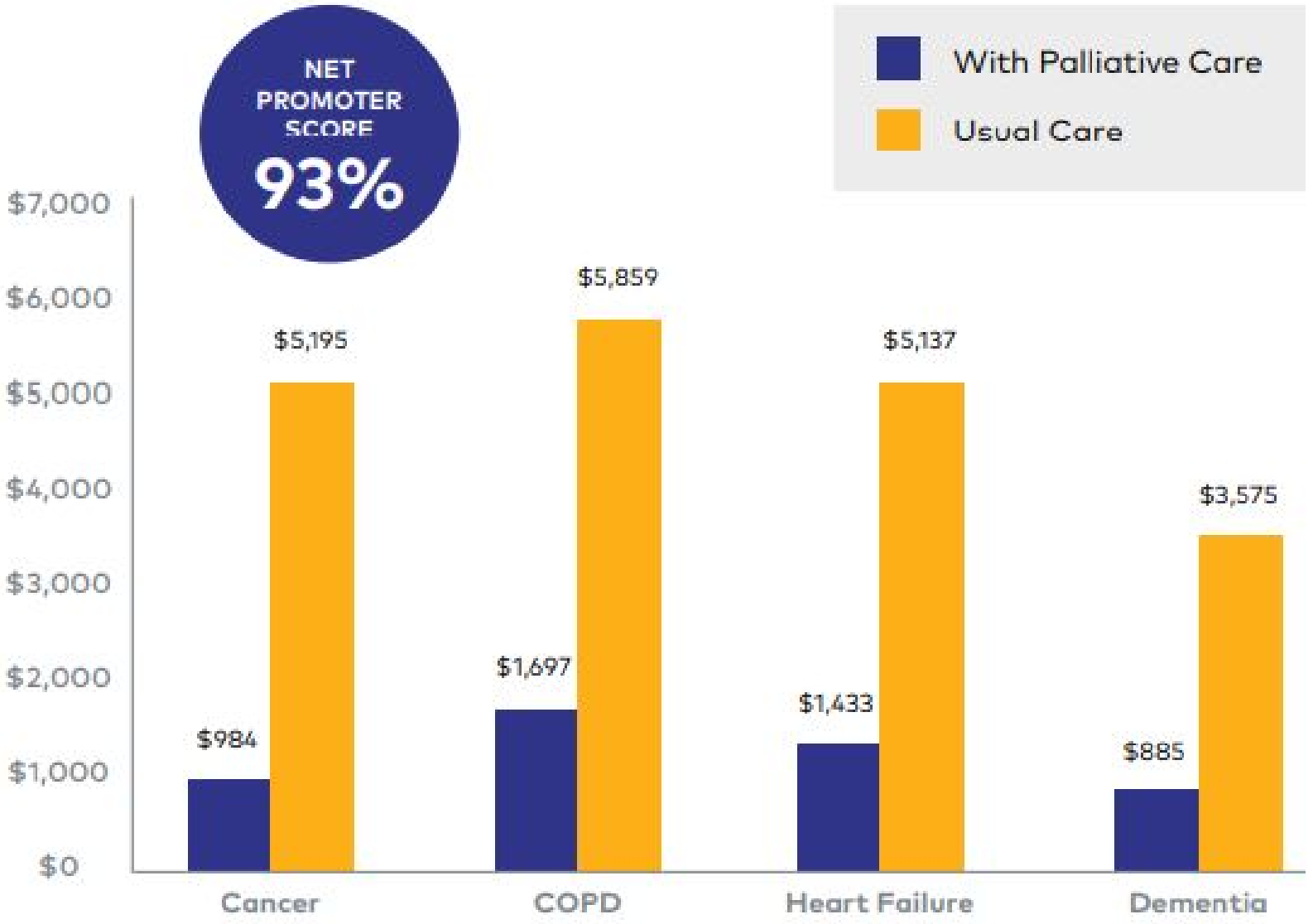
- **Comprehensive Care Team- partnerships with local HH&H**
  - *meet the complex needs of patients who were not yet eligible or not yet ready to accept hospice - aka "home based palliative care"*
  - *Leveraging the local expertise*

ROI

- In nearly every quarter leading up to their death date, patients in the intervention group had *fewer inpatient days, more hospice days, and lower costs.*
- Average cost savings were $1,661 per patient, per month. Overall, there was an estimated $2.0 million in savings among the 207 patients receiving PC intervention.

Fischer J, Thomas J, and Jackson C. (November 2015). *Effect of CCNC's Palliative Care Initiative for Non-Dual Medicaid Recipients.* CCNC Data Brief No. 6, Community Care of North Carolina, Inc.: Raleigh, NC

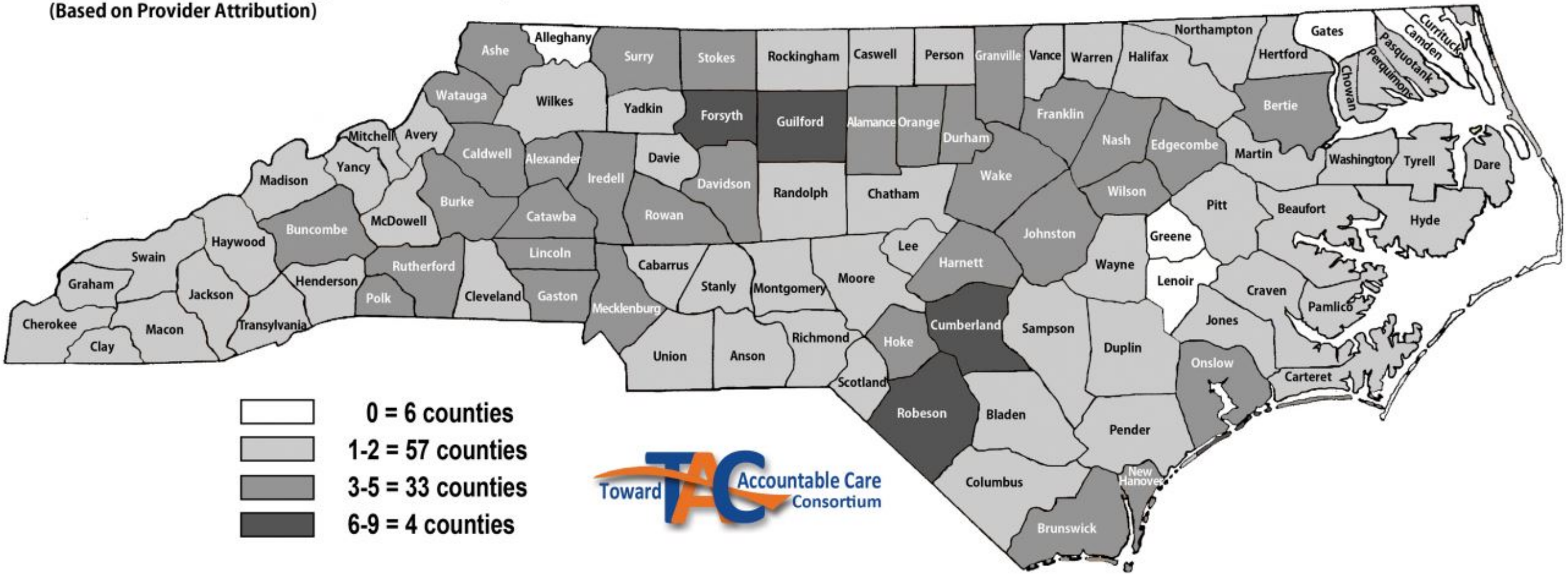
Palliative Care Program Hospital Costs per Month and Satisfaction Score



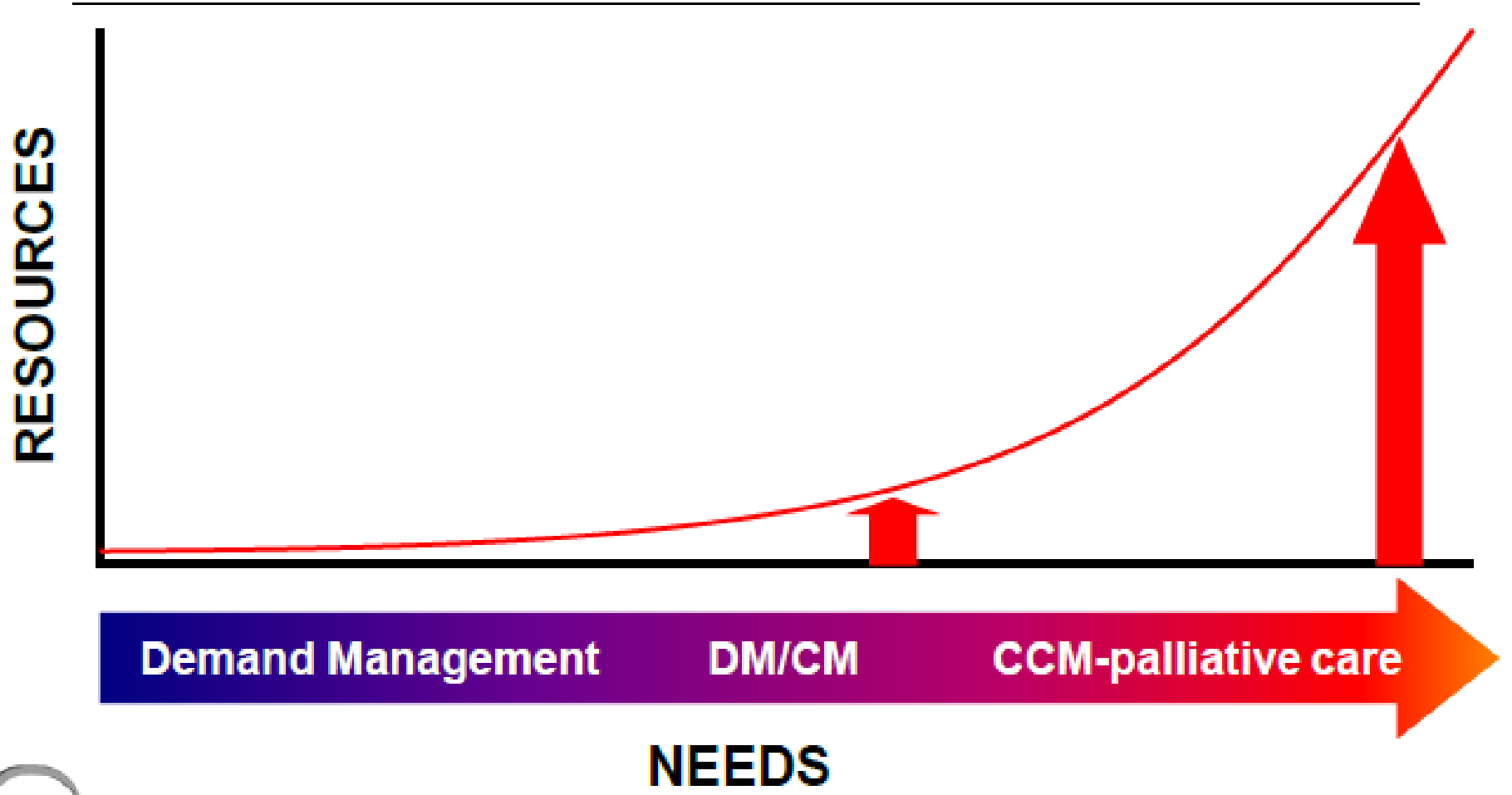
Sources: Cassell, JB, et al. "Effect of a Home-based Palliative Care Program on Healthcare Use and Costs." *J Am Geriatr Soc*, (2016).
Boehler, A. NICHM Foundation Webinar, "Prioritizing Super-Spenders: Coverage and Care for High-Need Patients." (May 19, 2017).

Accountable Care Organizations Represented in North Carolina (MSSP & NextGen)

(Based on Provider Attribution)



Matching (Payer) Resources to Needs

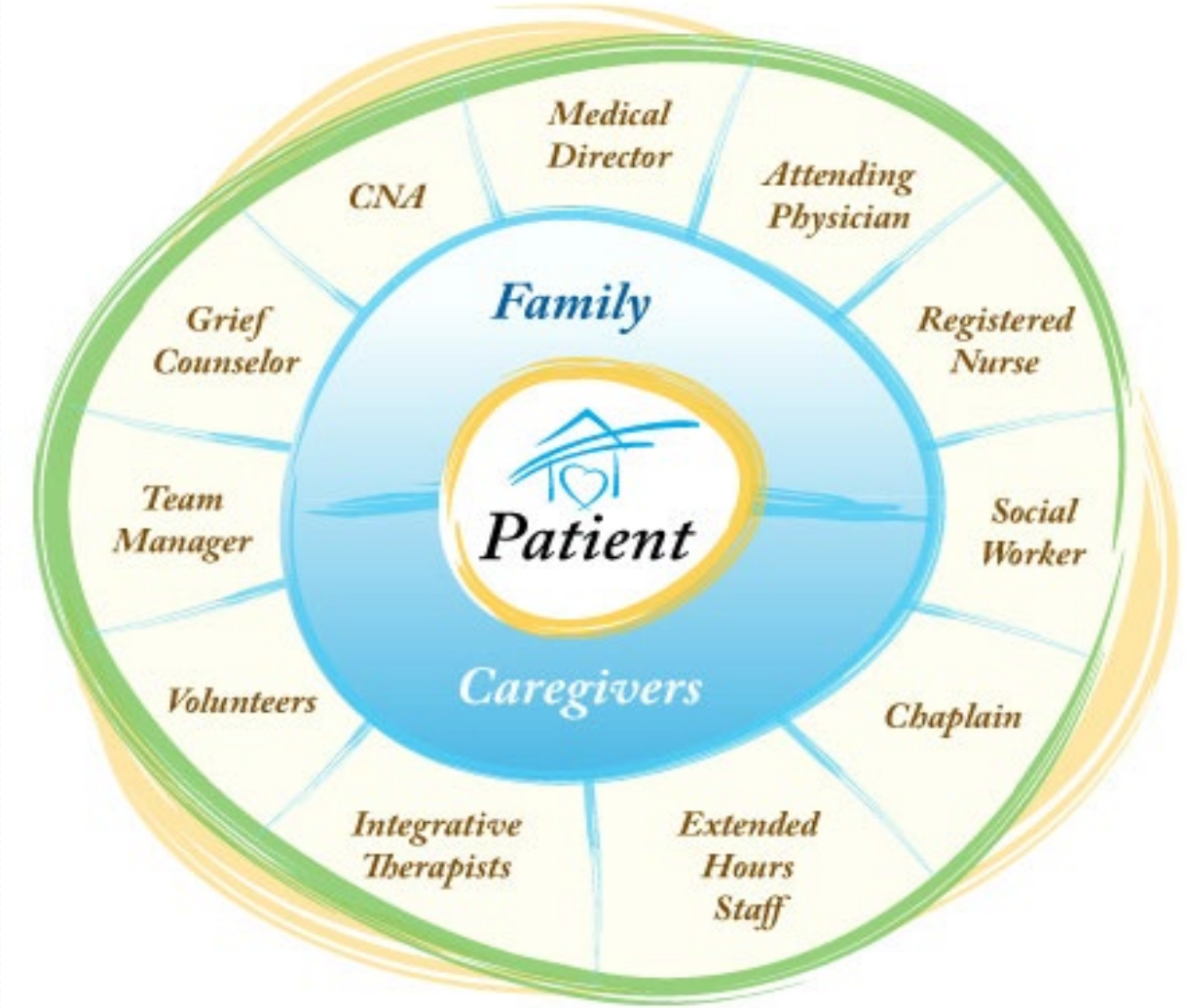


CENTER TO ADVANCE PALLIATIVE CARE

Hospice

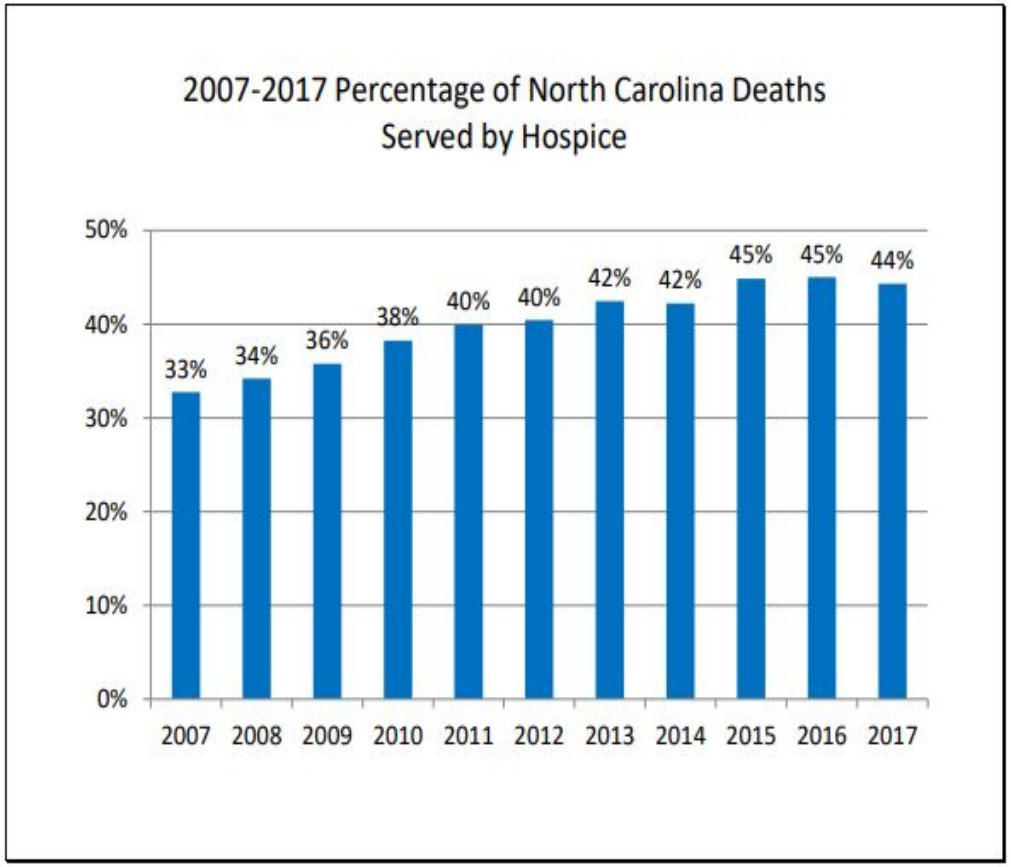
- ✓ Philosophy
- ✓ Home Care Program
- ✓ Insurance Benefit
  - Life limiting illness
  - Focus on care not cure
  - Unmet needs
  - Intensive pain and symptom management
  - Spiritual & social support
  - Desire to remain at home

Hospice team - INTERDISCLIPLINARY



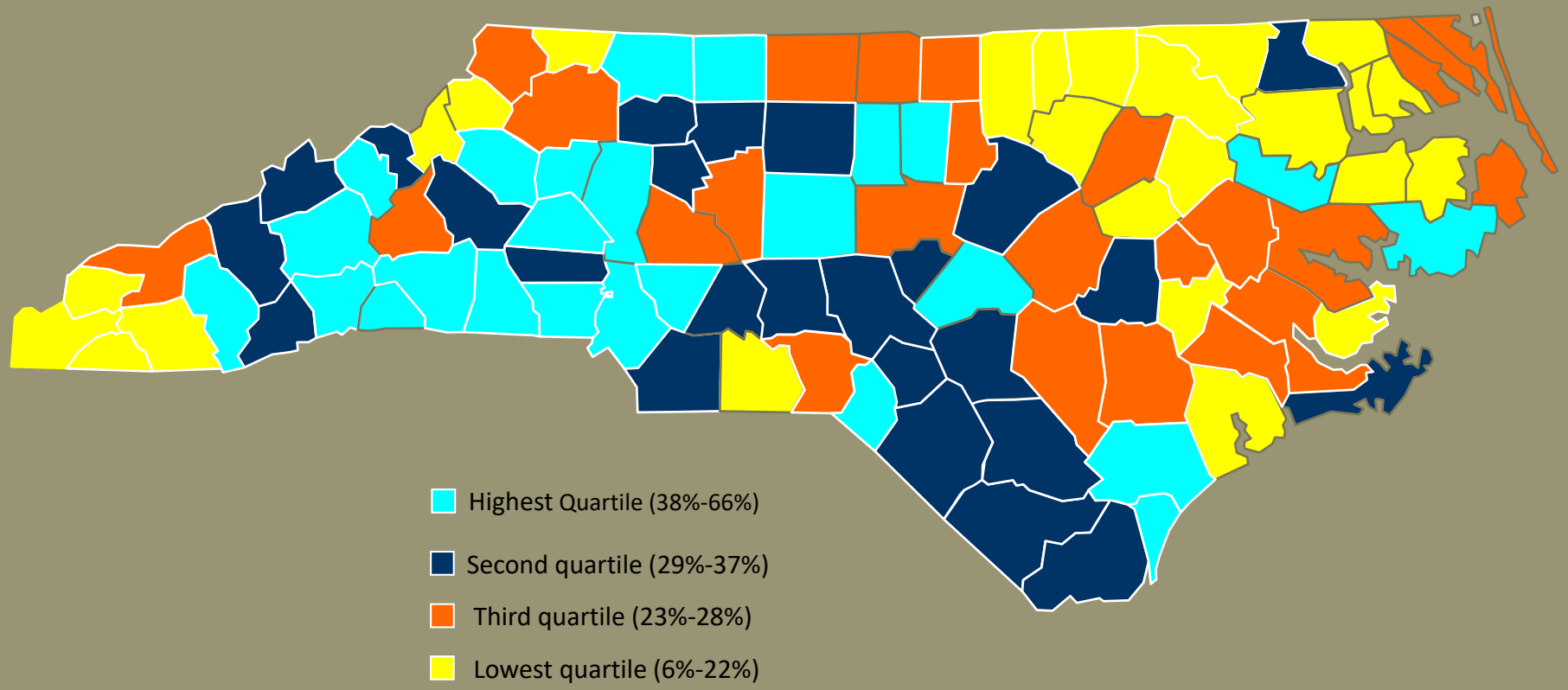
2017 Hospice- North Carolina Data

- 44% of decedents received hospice in NC (up from 30% in 2006)
- 48% nationally -NHPCO 2017
  - **22% NC Medicaid**
- high of 58% UT and low of 23% PR
- Davie, Yancey, Polk (95%, 88%, 87%)
- Orange, Pitt, Hyde (25%, 24%, 21%)



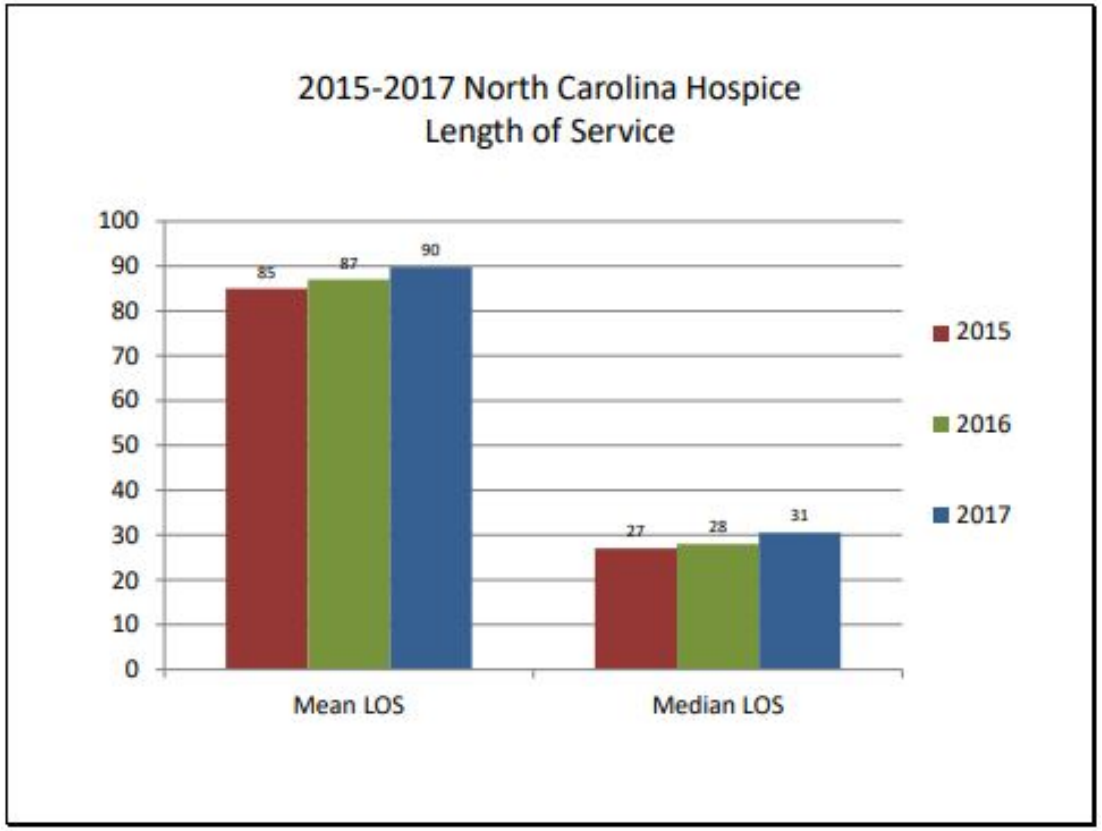
Hospice Utilization Rates

Counties designated by quartile

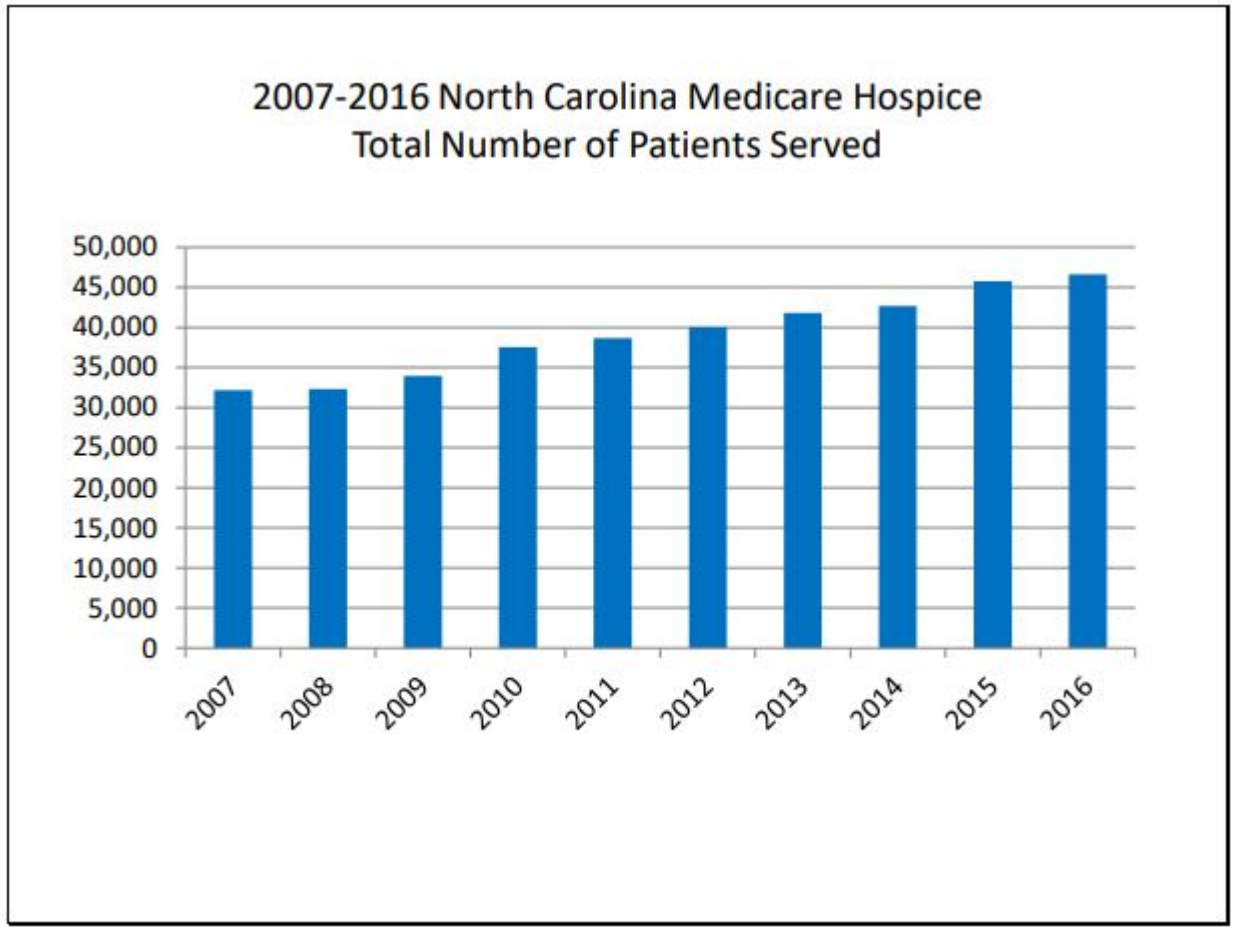


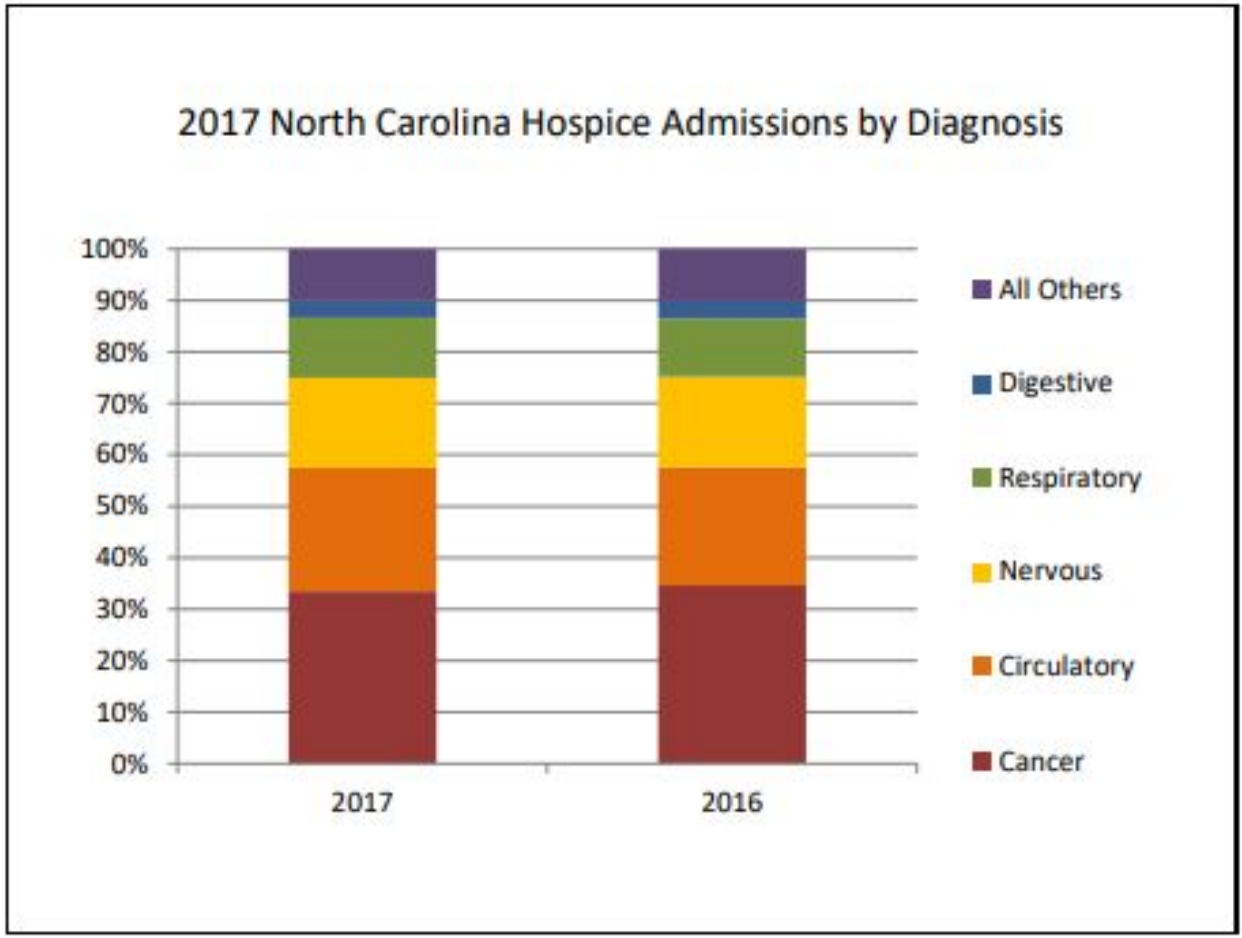
Deaths by Length of Stay	2017 NC Data Count of Patients	2017 NC Data % of Patients	2016 NC Data % of Patients	2016 Medicare NC	2016 Medicare National
% Died < 7 Days	16,147	38.2%	37.2%	35.5%	36.4%
% Died > 180 Days	3,693	8.7%	8.7%	5.0%	5.4%

Comment: Having such a high number of patients die in less than 7 days impacts the hospice team's ability to deliver the full range of services to a patient to provide the best hospice experience. Use this information in education to referral sources, including a renewed emphasis on Advance Care Planning discussions between providers, patients and their families.



the carolinas CENTER FOR HOSPICE AND END OF LIFE CARE





the carolinas CENTER FOR HOSPICE AND END OF LIFE CARE

In 2000 60% of hospice admissions were Cancer

Hospice Improves Quality

- Higher family satisfaction compared to terminal care in hospital or nursing home
- Decreases hospital transfers and improves pain control
- Improves family satisfaction with pain control, care for emotional and spiritual needs

Sources:
J Pain Symptom Manage 2003;26:791-9.
J Am Geriatric Society 2002;50:507-15.
JAMA 2004;291:88-93.

Determining Prognosis

- **Major barrier to hospice referral and discussions**
  - Physicians afraid of being wrong
  - Data indicates that physicians overestimate prognosis (as much as by a factor of 5) - consistently!
- Best prognostic data exists for cancer
- The longer you have known the patient and the more recently that you have seen them….
- Most (but not all) patients want to discuss
- Palliative care consultations are NOT dependent on prognosis

Source: EPERC, Medical College of Wisconsin

General Predictors: applicable to all diagnoses

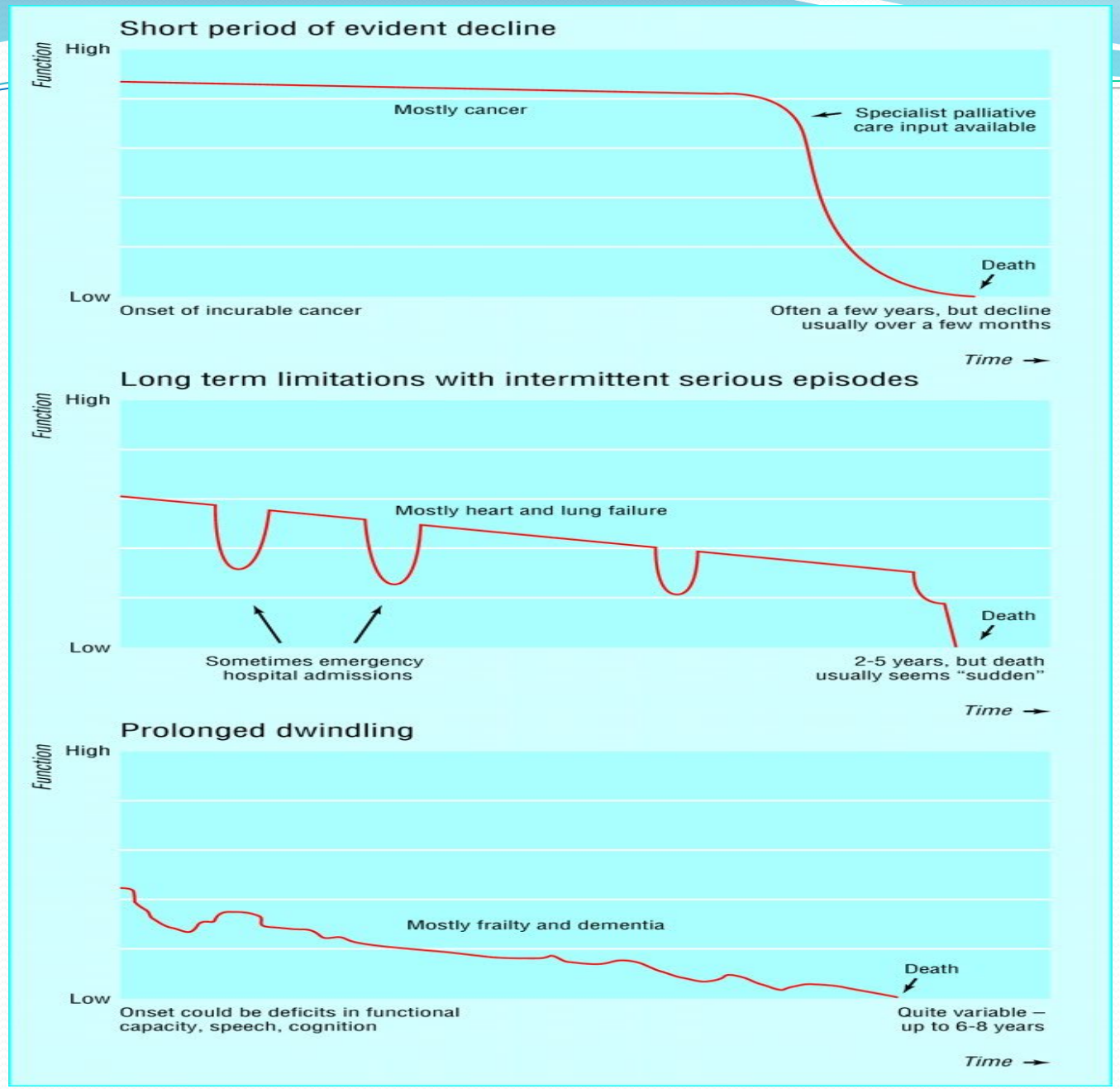
- Underlying chronic life-limiting disease

+

- Progressive loss of function (ADLs)

+

- Increasing frequency of hospitalization with no improvement in function



Typical Chronic Illness Trajectories

Murray S A et al. BMJ 2005;330:1007-1011

BMJ

Who is “at risk”?

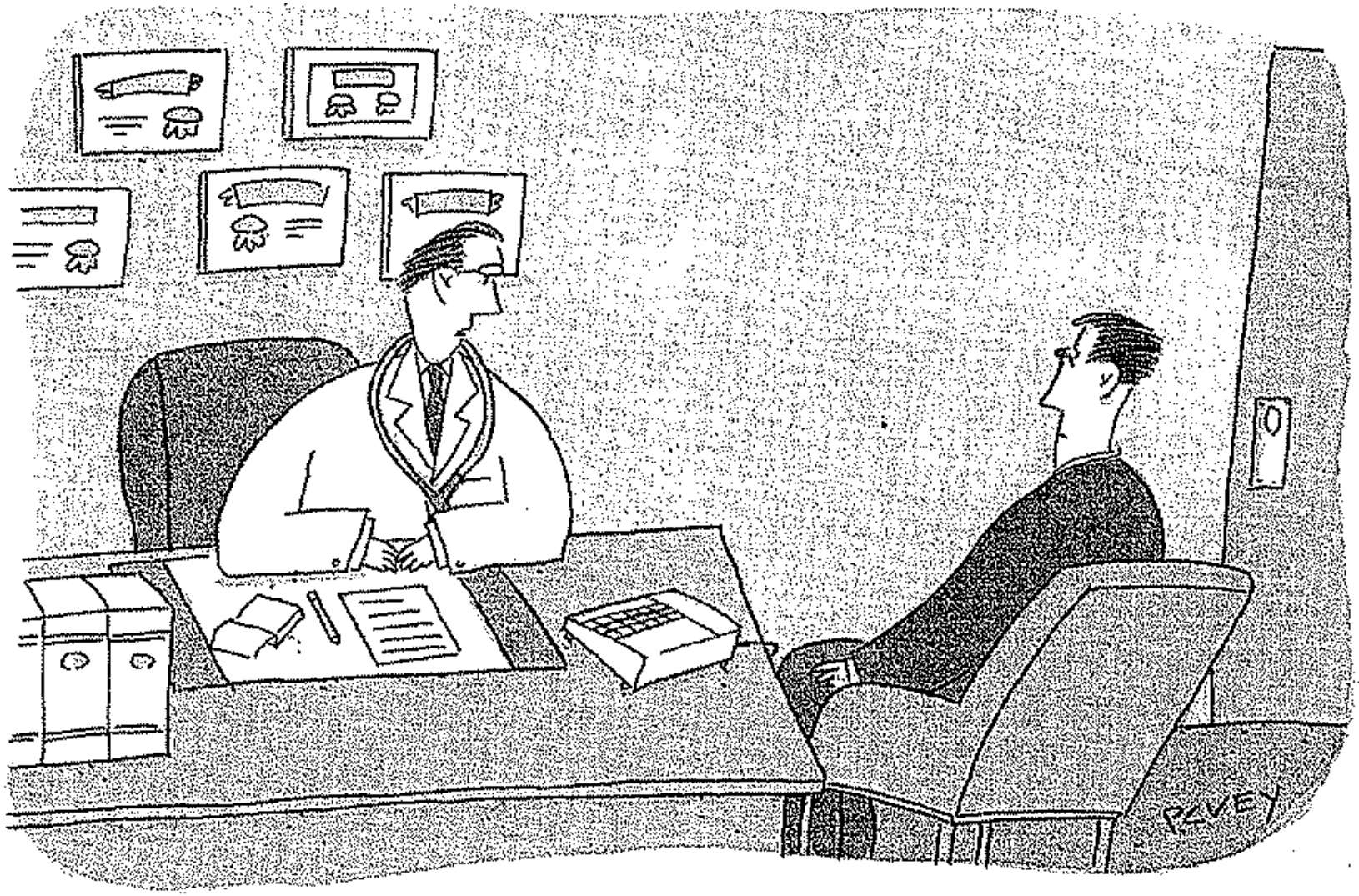
Patients with advanced serious illness:

- ✓ Incurable cancer,
- ✓ Advanced chronic organ system failure (COPD, CHF, renal failure, liver failure)
- ✓ Progressive neurologic conditions (dementia, Parkinson’s, ALS, major stroke)

Who else is “at risk”?

Patients with:

- ✓High risk of death during the coming year – *“Would you be surprised if this patient died in the next year?”*
- ✓Who prioritize goal of comfort
- ✓Frequent hospitalizations
- ✓Recent functional decline



"There's no easy way I can tell you this, so I'm sending you to someone who can."

Comparison

Hospice	Palliative Care
Pain & Symptom Management	Pain & Symptom Management
Patient & Family Support	Patient & Family Support
Communication/Decision Making	Communication/Decision Making
Comprehensive insurance benefit: Meds/Equipment/Home supports	Limited insurance coverage for physician consultation
Prognosis < 6 months if natural course	Independent of Prognosis
Goal: exclusively comfort. Avoid hospitalizations	Co-exists with disease-based evaluation/treatment, hospitalizations
Where: Home, long-term care, inpatient facility beds	Where: primarily hospitals, long-term care, outpatient clinics

Watch our Language

To remove barriers to good care, we need to talk about palliative care with language that has relevance to patients, families, and health professionals:

Added layer of support;

Work with patient's doctors;

Relieve pain, symptoms, stress of serious illness;

Any age, any stage, any dx;

Alongside curative/life prolonging Rx

Putting it in writing….

- Health Care Power of Attorney

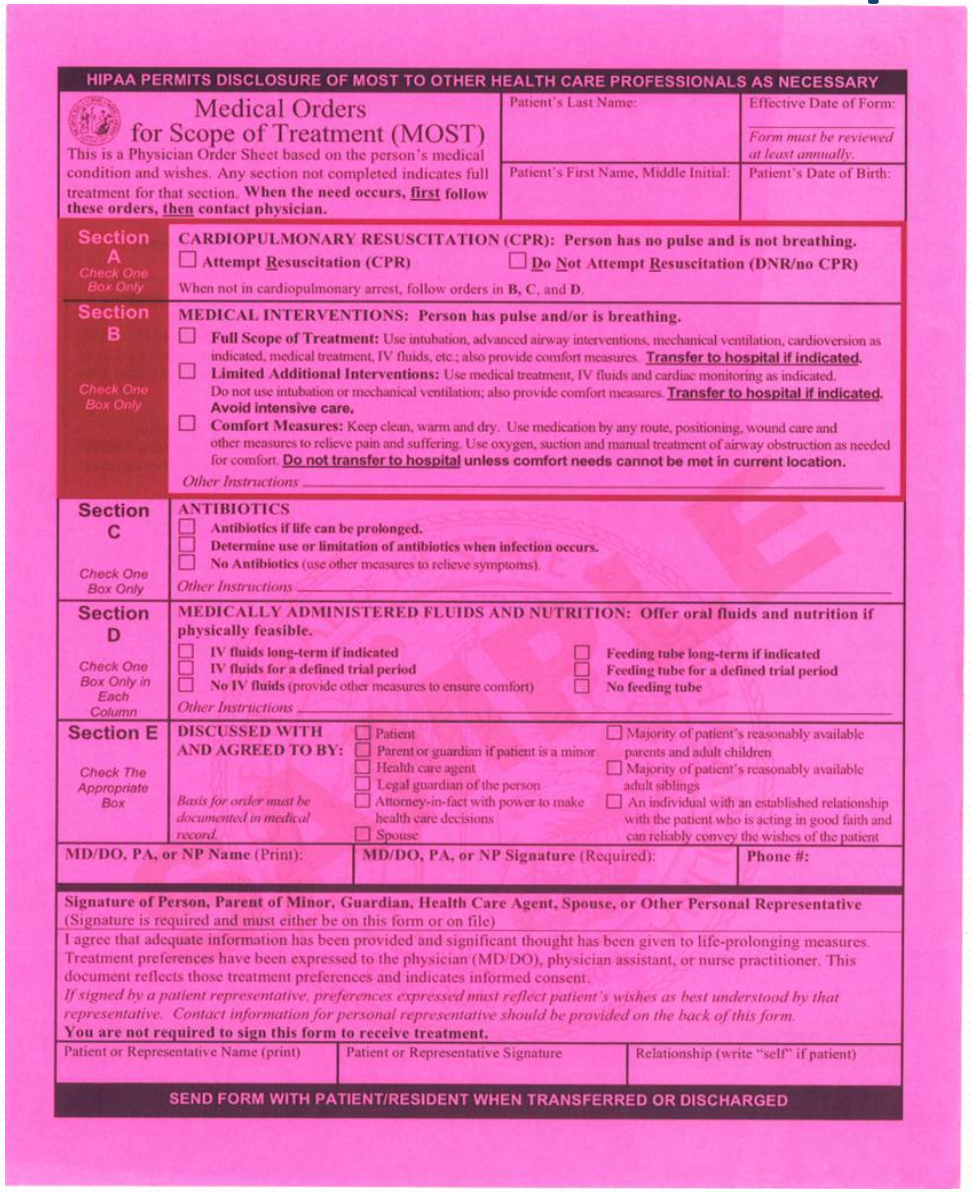
  - who would make a good surrogate

  - do they know how you feel, what is important to you or how you would make decisions?

- Living Will

- Medical Orders for Scope of Treatment (MOST)

Medical Orders for Scope of Treatment (MOST)



HIPAA PERMITS DISCLOSURE OF MOST TO OTHER HEALTH CARE PROFESSIONALS AS NECESSARY

Medical Orders for Scope of Treatment (MOST)

This is a Physician Order Sheet based on the person's medical condition and wishes. Any section not completed indicates full treatment for that section. **When the need occurs, first follow these orders, then contact physician.**

Patient's Last Name: | Effective Date of Form: *Form must be reviewed at least annually.*

Patient's First Name, Middle Initial: | Patient's Date of Birth:

Section A *Check One Box Only*

CARDIOPULMONARY RESUSCITATION (CPR): Person has no pulse and is not breathing.

☐ **Attempt Resuscitation (CPR)** ☐ **Do Not Attempt Resuscitation (DNR/no CPR)**

When not in cardiopulmonary arrest, follow orders in **B, C,** and **D.**

Section B *Check One Box Only*

MEDICAL INTERVENTIONS: Person has pulse and/or is breathing.

☐ **Full Scope of Treatment:** Use intubation, advanced airway interventions, mechanical ventilation, cardioversion as indicated, medical treatment, IV fluids, etc.; also provide comfort measures. **Transfer to hospital if indicated.**

☐ **Limited Additional Interventions:** Use medical treatment, IV fluids and cardiac monitoring as indicated. Do not use intubation or mechanical ventilation; also provide comfort measures. **Transfer to hospital if indicated. Avoid intensive care.**

☐ **Comfort Measures:** Keep clean, warm and dry. Use medication by any route, positioning, wound care and other measures to relieve pain and suffering. Use oxygen, suction and manual treatment of airway obstruction as needed for comfort. **Do not transfer to hospital unless comfort needs cannot be met in current location.**

Other Instructions _____

Section C *Check One Box Only*

ANTIBIOTICS

☐ **Antibiotics if life can be prolonged.**

☐ **Determine use or limitation of antibiotics when infection occurs.**

☐ **No Antibiotics** (use other measures to relieve symptoms).

Other Instructions _____

Section D *Check One Box Only in Each Column*

MEDICALLY ADMINISTERED FLUIDS AND NUTRITION: Offer oral fluids and nutrition if physically feasible.

☐ **IV fluids long-term if indicated** ☐ **Feeding tube long-term if indicated**

☐ **IV fluids for a defined trial period** ☐ **Feeding tube for a defined trial period**

☐ **No IV fluids** (provide other measures to ensure comfort) ☐ **No feeding tube**

Other Instructions _____

Section E *Check The Appropriate Box*

DISCUSSED WITH AND AGREED TO BY: *Basis for order must be documented in medical record.*

☐ Patient
☐ Parent or guardian if patient is a minor
☐ Health care agent
☐ Legal guardian of the person
☐ Attorney-in-fact with power to make health care decisions
☐ Spouse
☐ Majority of patient's reasonably available parents and adult children
☐ Majority of patient's reasonably available adult siblings
☐ An individual with an established relationship with the patient who is acting in good faith and can reliably convey the wishes of the patient

MD/DO, PA, or NP Name (Print): | **MD/DO, PA, or NP Signature** (Required): | **Phone #:**

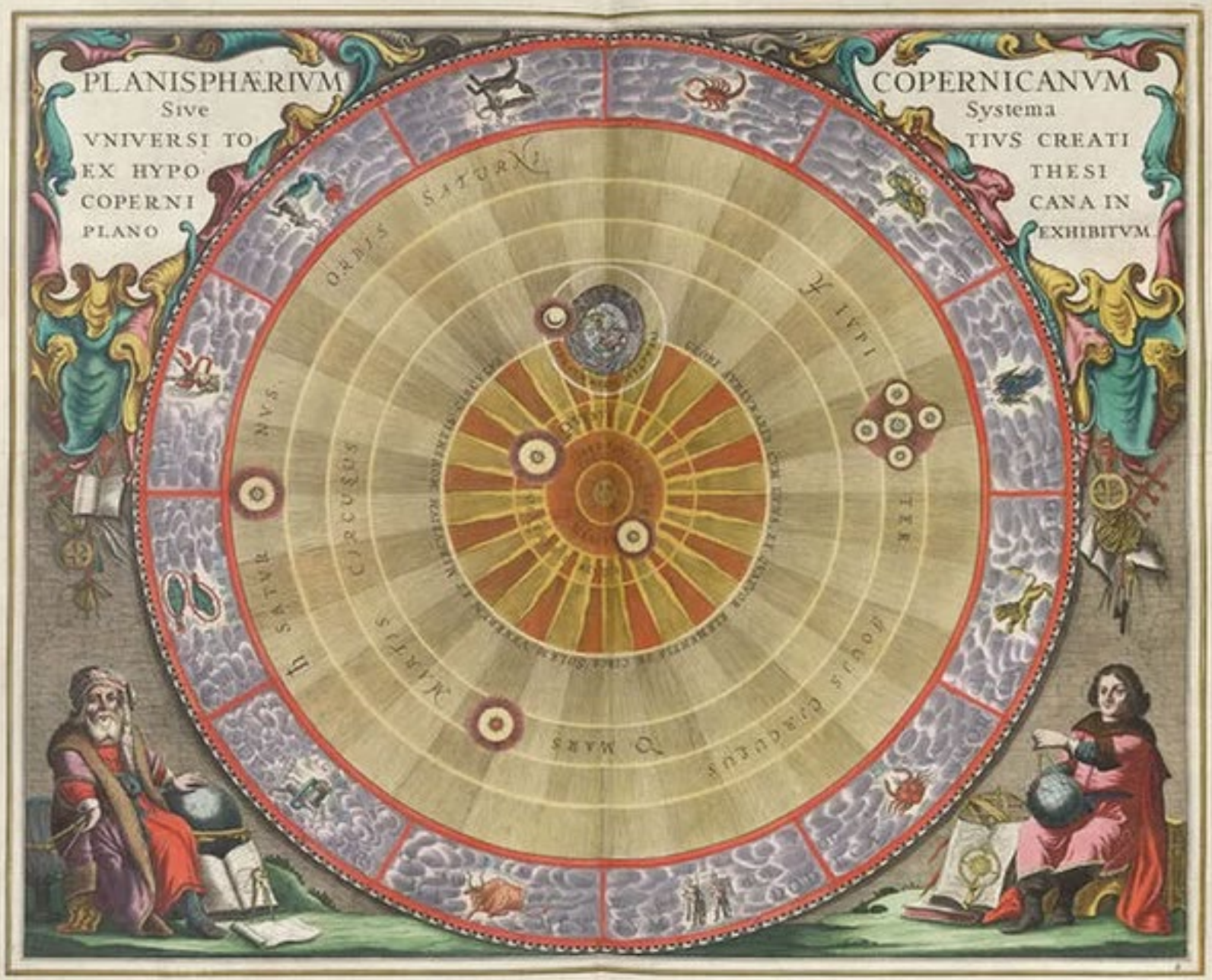
Signature of Person, Parent of Minor, Guardian, Health Care Agent, Spouse, or Other Personal Representative
(Signature is required and must either be on this form or on file)

I agree that adequate information has been provided and significant thought has been given to life-prolonging measures. Treatment preferences have been expressed to the physician (MD/DO), physician assistant, or nurse practitioner. This document reflects those treatment preferences and indicates informed consent.
If signed by a patient representative, preferences expressed must reflect patient's wishes as best understood by that representative. Contact information for personal representative should be provided on the back of this form.
You are not required to sign this form to receive treatment.

Patient or Representative Name (print) | Patient or Representative Signature | Relationship (write "self" if patient)

SEND FORM WITH PATIENT/RESIDENT WHEN TRANSFERRED OR DISCHARGED

- More than a DNR order
- Guide care even when patient has not arrested
- Options to receive or withhold treatments
- Avoid inappropriately limiting or providing other types of treatments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ORBIS CIRCULUS
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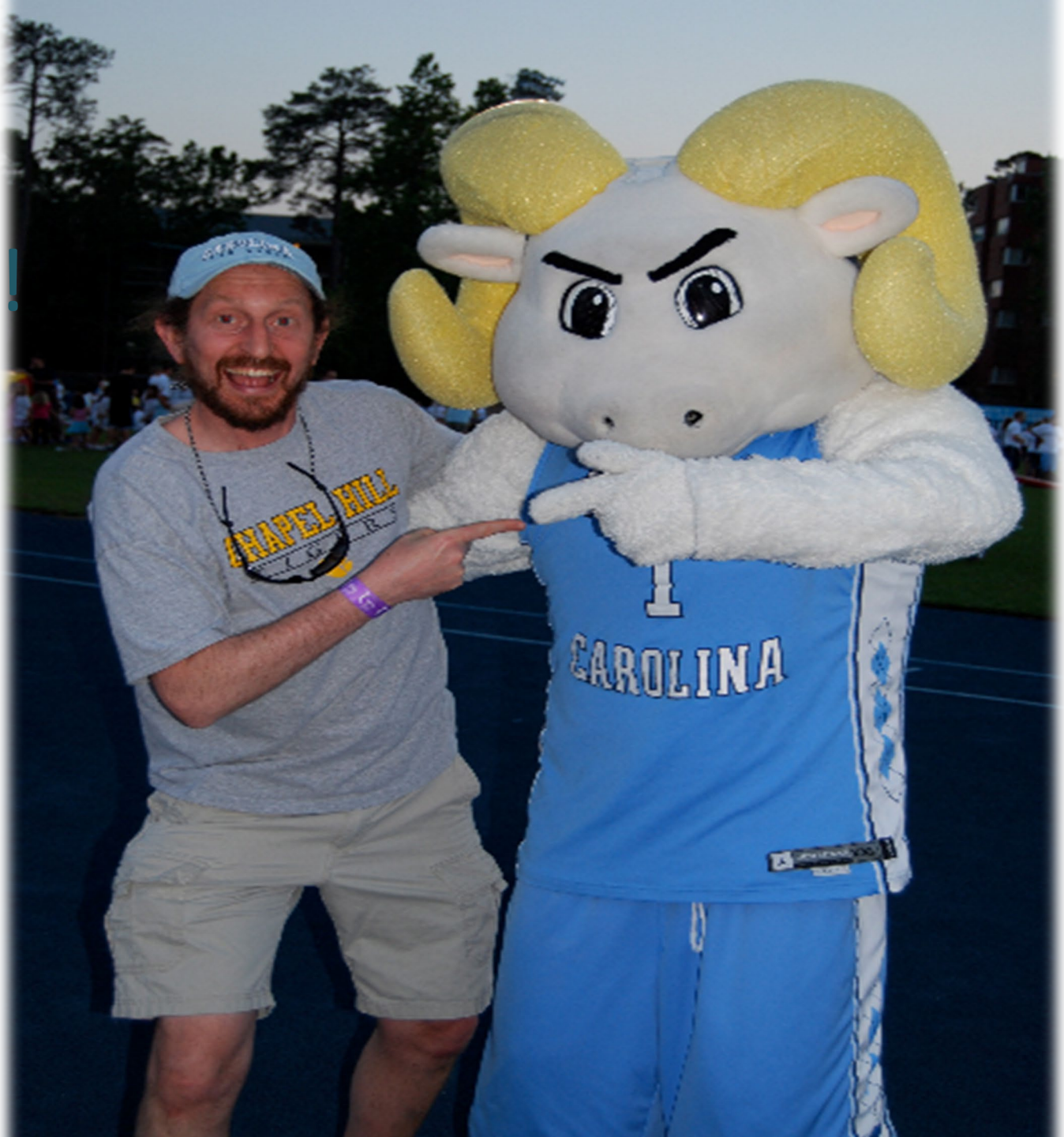
Thank you!



Go Heels!