Patient Level of Care Preferences In Stroke

“Whole Person Care”

American Heart Association.

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Dr. Gordon Kelley

Title: **Patient Level of Care Preferences in Stroke: “Whole Person Care”**

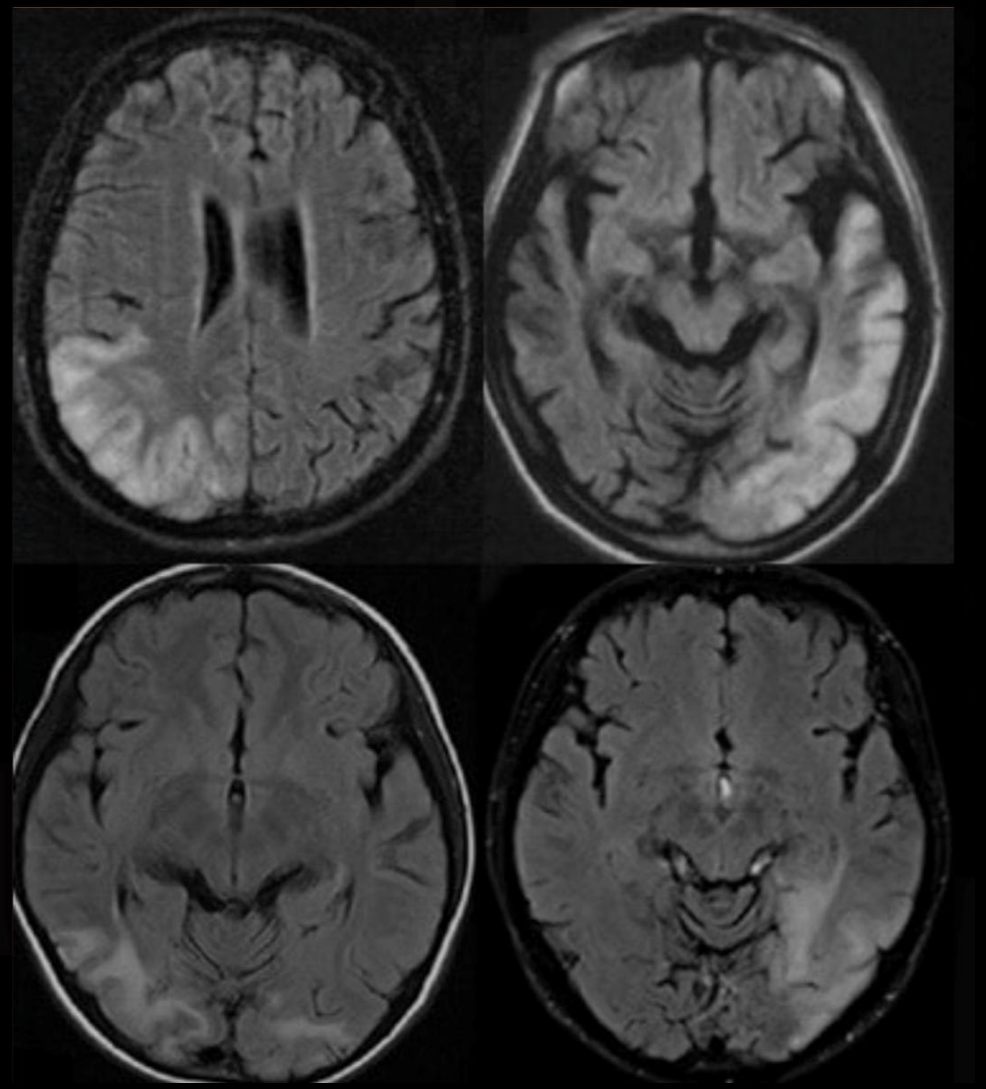
No relevant financial relationships exist.

- A 75-year-old right-handed widow who had been independent and active is seen as an ER “Stroke Code” for acute onset of confusion with left sided weakness that began 30 minutes PTA.

- She has new onset a.fib, BP 160/85. CTP shows multi focal areas of ischemia especially in the right parietal and both occipital lobes. CTA shows a right M3 branch occlusion and poor visualization of both PCA’s. She is given tenecteplase admitted and admitted to the ICU.

- The next day, she appears to have cortical blindness, a moderate left hemiparesis and anosagnosia for her deficits. She failed her swallow test.

- Her two daughters want to know:
  - what's going on?
  - What's her prognosis?
  - your recommended plan?



WHO definition of Palliative Care

An approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical,, psychosocial and spiritual.

The key aspects of the WHO definition of palliative care, and how this type of care is already provided, to some extent, by stroke units

	Palliative care	**Stroke unit care**
Approach-to improve quality of life of patients and families	Aims to improve quality of life	Clinicians consider the impact of stroke and its treatment on quality of life, and make decisions about the risks and benefits of treatment and rehabilitation.
Life-threatening illness	Is appropriate for patients with life-threatening illness	Stroke is a life-threatening illness. Stroke clinicians regularly deal with the physical, psychological, and existential distress of sudden, life-threatening illness.
Early	Needs to be considered early in the trajectory of a life-threatening illness	Admission to a stroke unit generally occurs very early after stroke onset. Thus, stroke clinicians are ideally placed to consider palliative care.
Pain Other physical problems Psychosocial problems Spiritual problems	Addresses a wide range of physical, psychosocial, and spiritual problems	Rehabilitation addresses the direct neurological consequences of stroke. Stroke unit care does address pain, physical, and psychosocial problems, but spiritual care is not considered to the same extent.

https://pubmed.ncbi.nlm.nih.gov/33949268/

Palliative and End-of-Life Care in Stroke

- In 2010 there were nearly 130,000 stroke related deaths
- >5% of all deaths in the US
- 73% ischemic; 16% ICH; 13% sequelae of stroke; 4% SAH
- 50% of deaths in hospital & acute rehab; 35% in SNF; 15% home
- Stroke is a leading cause of adult disability
  - >20% stroke hospitalizations are discharged to SNF
  - 30% stroke patients remain permanently disabled

-AHA/ASA Scientific Statement on Palliative Care and End-of Life Care 2014

https://www.ahajournals.org/doi/10.1161/str.0000000000000015

Frequency of Individual Palliative Care Needs

Most frequently recorded needs were:

- Dysphasia (96.8%)
- Death rattles (31.5-60.7%)
- Dyspnea(16.3-48.4%)
- Anxiety, confusion, delirium, agitation (7.9-25.4%)
- Constipation, dry mouth, seizures
- Pain (50%), sleep disturbance (43%), bladder/bowel incontinence (15%)
- Existential needs: hopelessness, loss of meaning, thoughts of death

https://pubmed.ncbi.nlm.nih.gov/33949268/

Palliative care needs in stroke may be difficult to assess

- Palliative care symptoms recognized in 2/3 of patients dying on an acute stroke unit; true frequency likely higher
- Cognitive impairment, aphasia, & dysarthria are barriers to communication (compared to cancer patients)

https://pubmed.ncbi.nlm.nih.gov/33949268/

Death after Stroke

- Most patients dying from stroke do not die at home
- Only half died in their preferred place (home)
- 25% dying in hospital die alone
- Stroke patients less likely than cancer patients to receive info regarding their transition to “end of life care” & their families less likely to receive bereavement care
- Healthcare providers tend to focus on physical recovery (rather than psychosocial and spiritual needs)
- Potentially futile interventions are often ongoing when specialist palliative care referrals are made, or on the day of death.
- Few physicians saw spiritual care as a significant issue.

https://pubmed.ncbi.nlm.nih.gov/33949268/

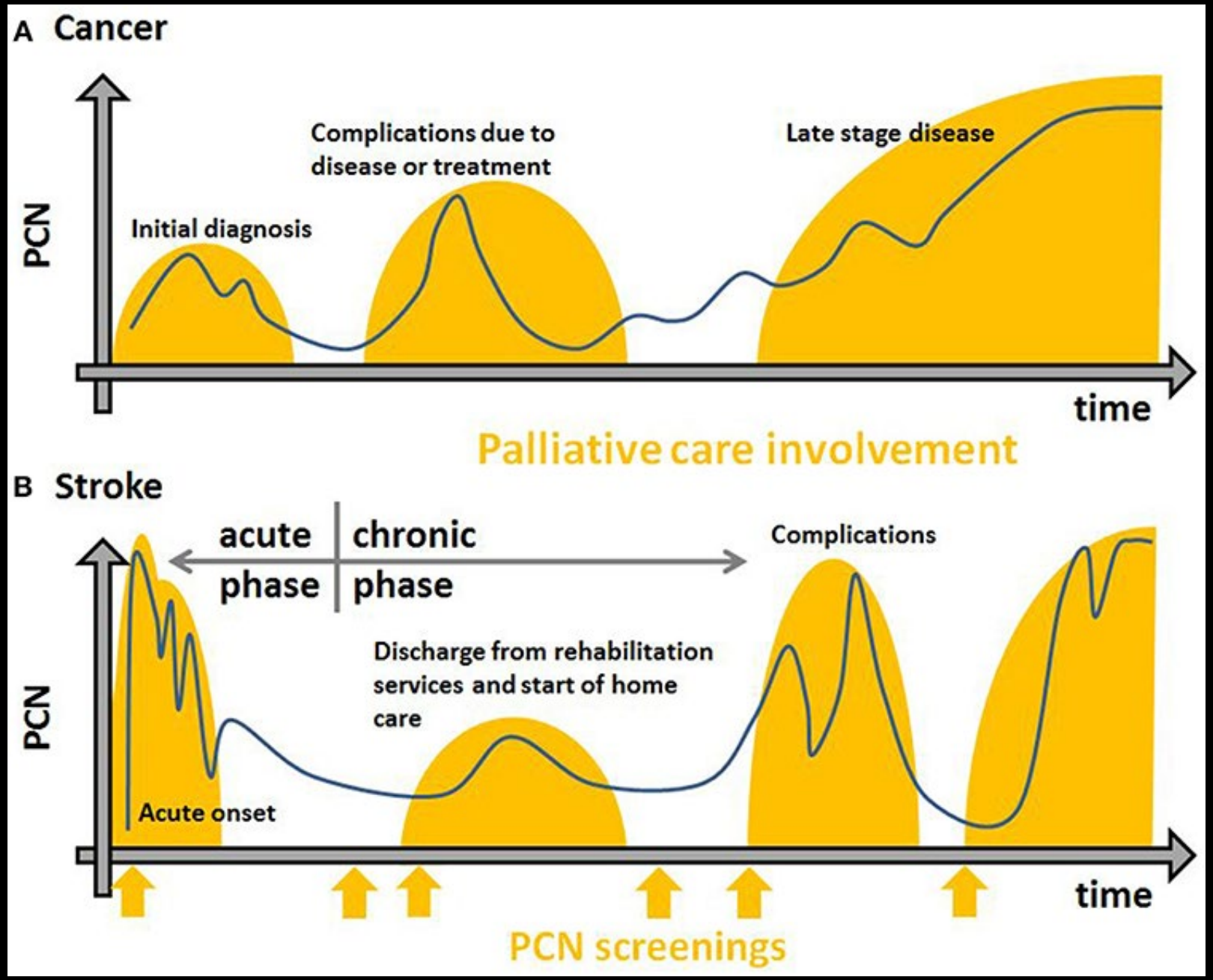
Palliative Care

- Patient and Family centered care
- Optimizes quality of life by anticipating, preventing & treating suffering
- Through the continuum of illness, palliative dare emphasizes:
  - Addressing physical, intellectual, emotional, social & spiritual needs
  - Facilitates patient autonomy, access to information, and choice
- Strong emphasis on end-of-life care, but palliative care domains are appropriate for all patients with serious illness, regardless of illness stage

Primary Palliative Care for Stroke Patients and Families

1. Promote & practice patient- & family- centered care
2. Effectively estimate prognosis
3. Develop appropriate goals of care
4. Be familiar with common stroke decisions with end of life implications
5. Assess and effectively manage emerging stroke symptoms
6. Possess experience with palliative treatments at end of life
7. Assist with care coordination including palliative care/hospice referral
8. Provide patient/family opportunity for personal growth/bereavement
9. Actively participate in continuous quality improvement & research

https://www.ahajournals.org/doi/10.1161/str.0000000000000015



https://www.frontiersin.org/articles/10.3389/fneur.2019.00164/full

Estimating Prognosis

- Some stroke syndromes (eg basilar artery thrombosis, malignant MCA infarct) have high chance of early death/severe disability
- Errors in prognostication can result in premature w/d of care or over treatment causing excessive suffering, burden & costs
- Challenge of determining what constitutes a “good” outcome for and individual patient
  - Tendency to focus on risk of short term mortality
  - Long-term functional outcome & QOL likely more important to patients/families

What is a “Good Outcome”?

- Stroke survivors can report satisfying QOL even in the face of severe handicaps
- “Disability paradox”: phenomenon of individuals with disabilities rating their QOL higher than non disabled individuals
- Patients & surrogate decision makers may need education about the capability of individuals to adapt to physical limitations and disease burden (“cognitive biases”)
- Patients with stroke may have limited capacity to understand and communicate their treatment preferences
- A palliative care consult can serve as a “second opinion” to minimize treatment biases

Communicating Prognosis

- Describe the best & worst case scenarios @ 3 or 6 months

- ASK-TELL-ASK

ASK-TELL-ASK

ASK (stroke neurologist): **Explore what the patient or family understands** about the illness and treatment and assesses their desire for information. for example:

“What have the doctors told you about what is going on with your loved one and what your loved one’s prognosis and treatment options are?”

TELL (stroke neurologist): The provider frames the information in a way the patient/family understands. Giving a warning shot (“I have difficult news for you”) allows the patient/family to prepare emotionally, for example:

“I’m concerned as well. **I would like to tell you a little more about what I see is likely to happen down the road, and then I would like to review with you some things that we can do** (pause to allow family to absorb information.) First, I am worried that she will get worse…”

ASK (stroke neurologist): The second Ask **explores how well their information was understood and which points may need more explanation**. For example:

“I know that was a lot of new information. Who are you going to talk to about this meeting today? To make sure I did a good job of explaining to you, can you tell me what you are going to say to them?”

Strategies for providers during shared decision making after severe stroke

- Acknowledge “shock” and suddenness of stroke and its profound effect on the patient and family
- Identify patient’s wishes early on; e.g. advanced directive, Power of Attorney, any previous conversations about views of living with severe disability, patient’s “values”
- Ask about, and address any guilt, e.g. “If only I’d found him sooner”
- “Truth telling:” be as honest as you can be about likely outcomes
- Showing CT brain scan may help to show extent of stroke and align family and health care professionals’ expectations about recovery and goals of care
- Try to avoid allowing the family to feel responsible for decisions about:
  - Cardiopulmonary resuscitation
  - Artificial feeding or intravenous fluids
- Let family know that dignity/symptom control are paramount whatever the decision
- Offer further meetings
- Document the discussion to ensure consistency of messaging.

(from Chest Heart & Stroke Scotland’s online Stroke Training and Awareness (STARS) training module: “Sensitive and Effective Conversations at the End of Life after Acute Stroke,”. http://chsselearning.org.uk).

ESTABLISHING A PLAN OF CARE

- “Hope for the best, plan for the worst”

- Living wills and advance directives

Advance Directive

- A witnessed, written document or oral statement in which a person indicates his/her choices regarding healthcare decisions.
- Guides healthcare treatment WHEN AND ONLY WHEN a person lacks capacity to make or communicate decisions
- 3 classic formats:
  - **Durable Power of Attorney (DPOA) for Healthcare**:
    - appoints an agent to make healthcare decisions for a patient when the patient lacks capacity or can't communicate
  - **Living Will**:
    - a document that specifies end-of life care preferences. Invoked only when when the patient is certified terminally ill by two physicians and when the person can no longer speak for themselves
  - **Health Care Directive**:
    - a more comprehensive Living Will that states additional specific directions

- The Joint Commission has made documentation of whether a patient has an Advance Directive (AD) a quality measure for over 25 years.
- At admission, patients are asked if they have an AD.
- But…
  - Yes, I think I did.
  - It’s in my safety deposit box
  - DPOA doesn’t know what choices are
  - Patient can’t state what their choices are

Obstacles to completion of Advance Directives

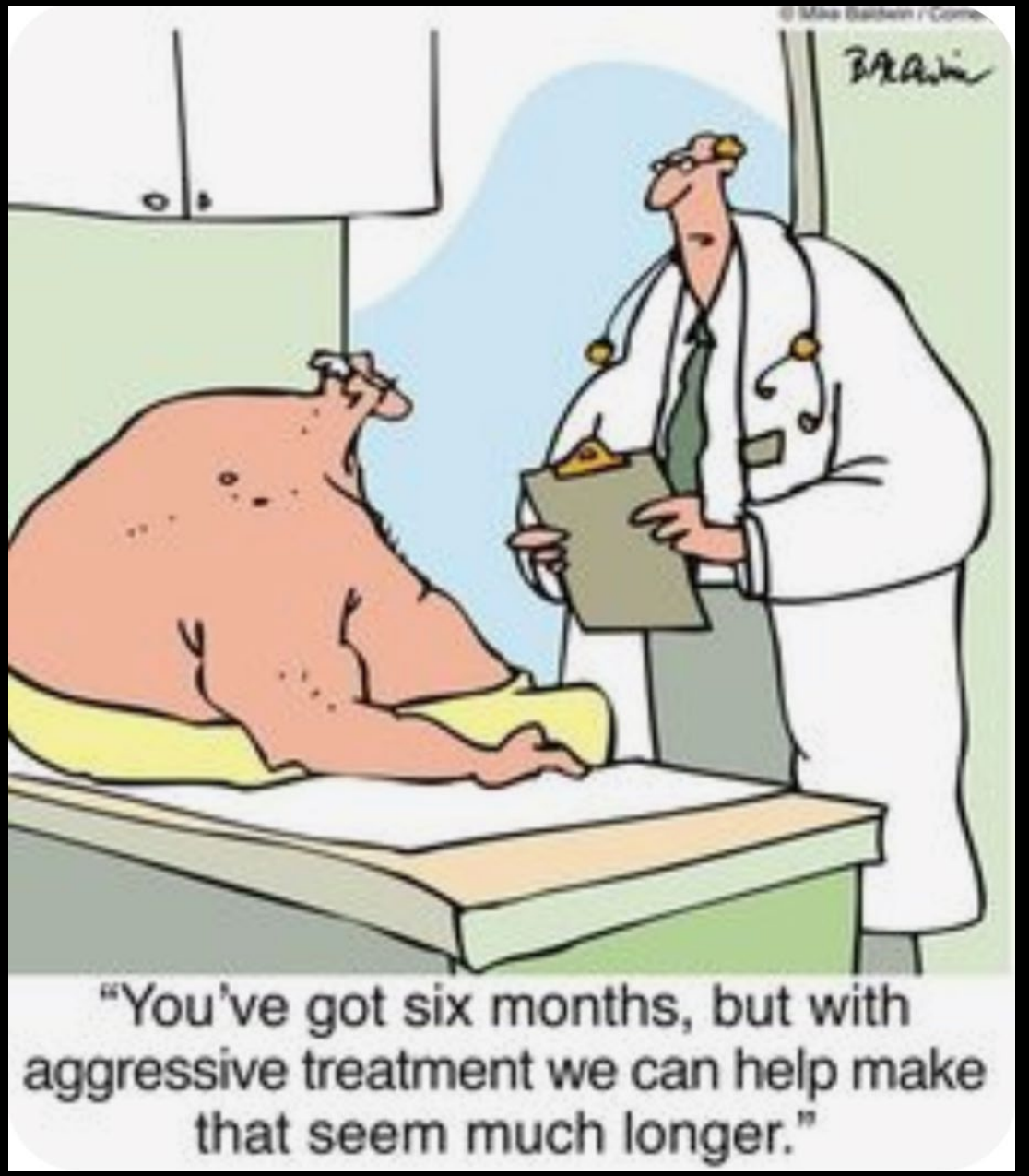
- Denial
- Many patients and doctors find discussing end of live uncomfortable
- Time consuming; “can of worms”
- Somebody else’s responsibility
- Don’t know where to start

Classic late 20th Century model of Medical care:

Fight disease, extend life at all costs.

If patient gets too sick…

…divert to “keeping them comfortable” and let them die


"You've got six months, but with aggressive treatment we can help make that seem much longer."

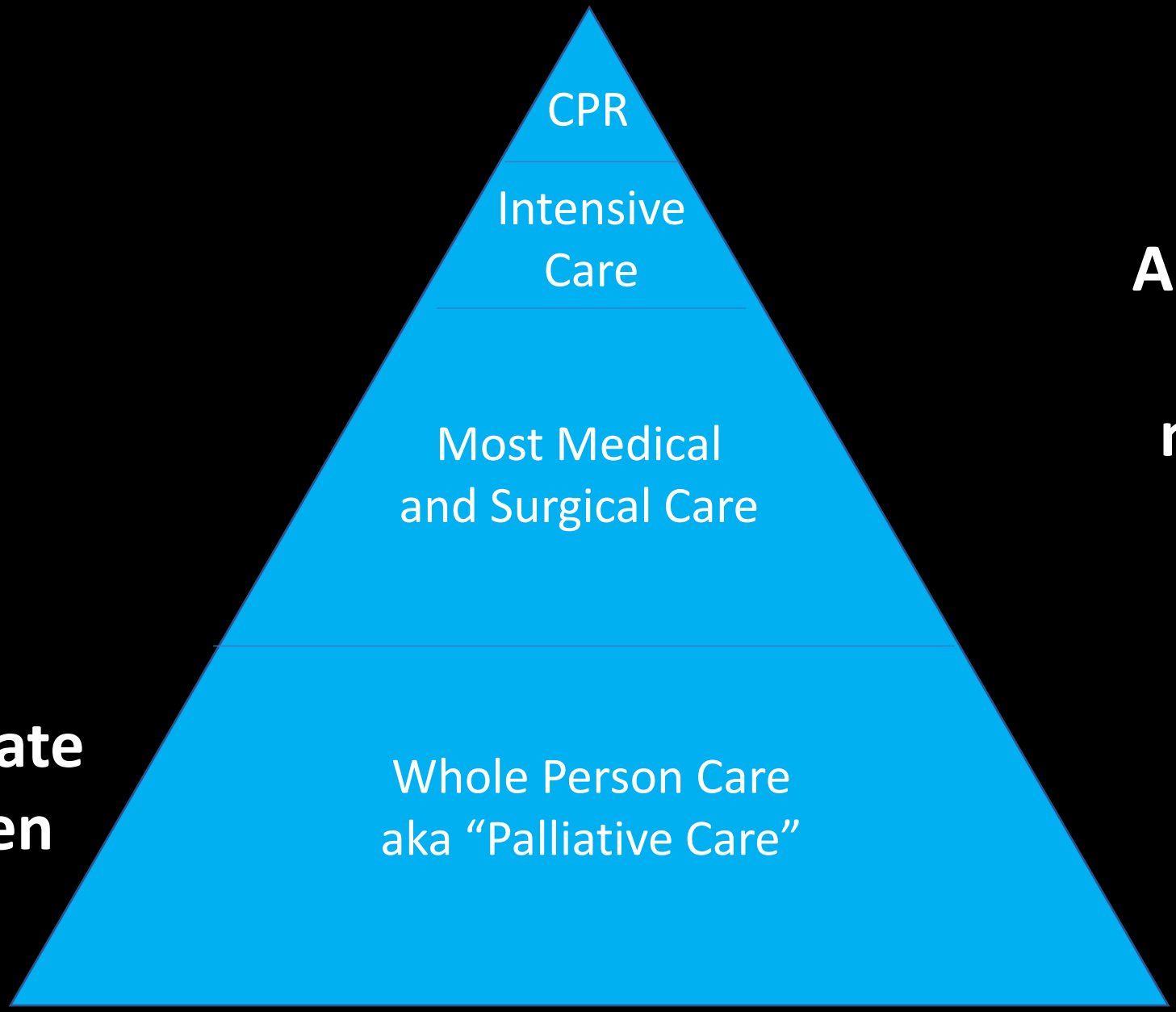
Palliative Care is Good Care

-Kathleen M. Foley MD

Newer Model of Whole Person Care:

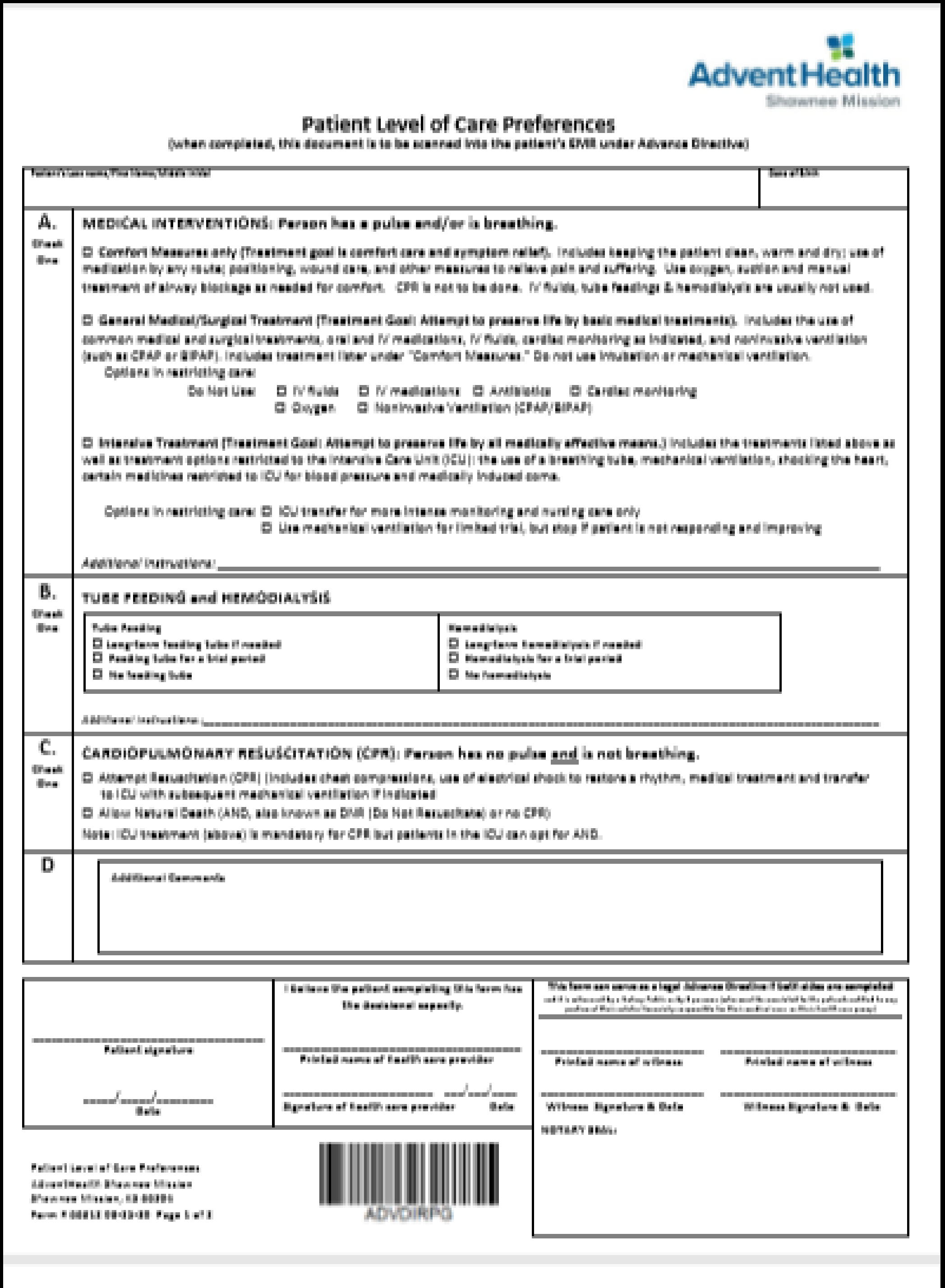
Emphasis begins with helping the patient live their life to the fullest

- With respect, dignity and comfort
- The goals of care are defined by the patient's personal goals and collaborative decision making with their physician
- All patients receive palliative care
- Medical/surgical interventions are recognized as optional (especially if they don't align with the agreed upon goals of care)



All the other stuff is negotiable

Compassionate Care is a given



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Patient Level of Care Preferences

(when completed, this document is to be scanned into the patient's EMR under Advance Directive)

A. Check One

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

☐ Comfort Measures only (Treatment goal is comfort care and symptom relief). Includes keeping the patient clean, warm and dry; use of medication by any route; positioning, wound care, and other measures to relieve pain and suffering. Use oxygen, suction and manual treatment of airway blockage as needed for comfort. CPR is not to be done. IV fluids, tube feedings & hemodialysis are usually not used.

☐ General Medical/Surgical Treatment (Treatment Goal: Attempt to preserve life by basic medical treatments). Includes the use of common medical and surgical treatments, oral and IV medications, IV fluids, cardiac monitoring as indicated, and noninvasive ventilation (such as CPAP or BiPAP). Includes treatment listed under "Comfort Measures." Do not use intubation or mechanical ventilation.

Options in restricting care:
Do Not Use: ☐ IV fluids ☐ IV medications ☐ Antibiotics ☐ Cardiac monitoring ☐ Oxygen ☐ Noninvasive Ventilation (CPAP/BiPAP)

☐ Intensive Treatment (Treatment Goal: Attempt to preserve life by all medically effective means.) Includes the treatments listed above as well as treatment options restricted to the Intensive Care Unit (ICU): the use of a breathing tube, mechanical ventilation, shocking the heart, certain medicines restricted to ICU for blood pressure and medically induced coma.

Options in restricting care: ☐ ICU transfer for more intense monitoring and nursing care only
☐ Use mechanical ventilation for limited trial, but stop if patient is not responding and improving

Additional Instructions: ______

B. Check One

TUBE FEEDING and HEMODIALYSIS

Tube Feeding	Hemodialysis
☐ Long-term feeding tube if needed	☐ Long-term hemodialysis if needed
☐ Feeding tube for a trial period	☐ Hemodialysis for a trial period
☐ No feeding tube	☐ No hemodialysis

Additional Instructions: ______

C. Check One

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

☐ Attempt Resuscitation (CPR) (Includes chest compressions, use of electrical shock to restore a rhythm, medical treatment and transfer to ICU with subsequent mechanical ventilation if indicated

☐ Allow Natural Death (AND, also known as DNR (Do Not Resuscitate) or no CPR)

Note: ICU treatment (above) is mandatory for CPR but patients in the ICU can opt for AND.

D

Additional Comments

Patient signature

Date

I believe the patient completing this form has the decisional capacity.

Printed name of health care provider

Signature of health care provider Date

Printed name of witness Printed name of witness

Witness Signature & Date Witness Signature & Date

NOTARY SEAL:

Patient Level of Care Preferences
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Patient Level of Care Preferences

- Designed to promote discussions between patients and their admitting caregivers.
- It allows a patient to put limits on the aggressiveness of medical care
- It applies not only after the patient loses capacity to communicate but helps them clarify their goals while they still are competent and can communicate
- It allows the admitting caregiver to clarify and translate patient care preferences into orders in the EMR

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Patient Level of Care Preferences

(when completed, this document is to be scanned into the patient's EMR under Advance Directive)

Patient's Last name/First Name/Middle Initial	Date of Birth

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

Check One

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D

Additional Comments

_____
Patient signature

____/____/_____
Date

I believe the patient completing this form has the decisional capacity.

_____
Printed name of health care provider

_____ ___/___/___
Signature of health care provider Date

This form can serve as a legal Advance Directive if both sides are completed and it is witnessed by a Notary Public or by 2 persons (who must be unrelated to the patient, entitled to any portion of their estate, financially responsible for their medical care or their health care proxy)

_____ _____
Printed name of witness Printed name of witness

_____ _____
Witness Signature & Date Witness Signature & Date

NOTARY SEAL:

ADVDIRPG

If completed and witnessed by two qualified witnesses, the PLCP form can serve as an Advance Directive

_____ **Patient signature** ____/____/_____ **Date**	**I believe the patient completing this form has the decisional capacity.** _____ **Printed name of health care provider** _____ ___/___/____ **Signature of health care provider Date**	This form can serve as a legal Advance Directive if both sides are completed and it is witnessed by a Notary Public or by 2 persons (who must be unrelated to the patient, entitled to any portion of their estate, financially responsible for their medical care or their health care proxy) _____ _____ **Printed name of witness** **Printed name of witness** _____ _____ **Witness Signature & Date** **Witness Signature & Date** **NOTARY SEAL:**

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Form # 66312 08-25-20 Page 1 of 2

ADVDIRPG

CONTACT INFORMATION

If I should be unable to make my own health care decisions in the future, I would trust these people to speak for me and be my Durable Power of Attorney for health care decisions:

Principal Contact	Relationship	Phone Number	Email Address
Second/Alternate Contact	Relationship	Phone Number	Email Address
Patient		Phone Number	Email Address

If completed and witnessed, this form can serve as an Advance Directive.

Competency

Essential elements of Decisional Capacity:

1) The ability to communicate choices
2) The cognitive ability to understand information relevant to the decisions
3) The ability to make choices consistent with personal values

The form includes a signature box for the health care provider that attests to the patient's decisional capacity. If the patient is not judged competent, the form should not be completed, and a notation should be made in the patient's chart. If the patient has already declared a DPOA, the form can be used to clarify the DPOA's decisions.

Eligible Witnesses

- To be considered a legal document, the form must either be witnessed by a Notary Public (MO) or by 2 qualified witnesses (KS).
- Witnesses must:
  - Be unrelated to the patient
  - Not be entitled to any portion of their estate
  - Not be financially responsible for their medical care or be their health care proxy

Talking Points

We want to maximize your quality of life. If you get sicker, our possible medical interventions may cause suffering.

You are still alive, but it's clear you are in your final chapters. We want you to be able to tell your own story.

(For families):

Any decisions we make should be gifts of love and compassion.

Advantages

- It's relatively quick
- It simplifies a complex system for overwhelmed patients & families
- It introduces the idea that medical interventions are optional; there is no stigma in choosing to limit intensity of care
- It emphasizes "Whole Person Care"

75 year old widow with cortical blindness, left hemiparesis and anosagnosia

- Family agreed that she had valued her independence and that it was highly unlikely she would be able to return to living independently, but they wanted to give her “her best shot.”
- They wanted to proceed with rehab, but if she developed new serious complications, they wanted to emphasize comfort care and made her “do not intubate” and “DNR” status.

“General” vs “Specialist” Palliative Care

- Stroke units and stroke physicians should be competent in providing “general” palliative care

- Specialized palliative care teams provide “specialist” palliative care

References & Further Reading

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