

*Hospice and Palliative Care ...*

for *Care* near/at the End of Life ...

... lessons from a Hospice House ...

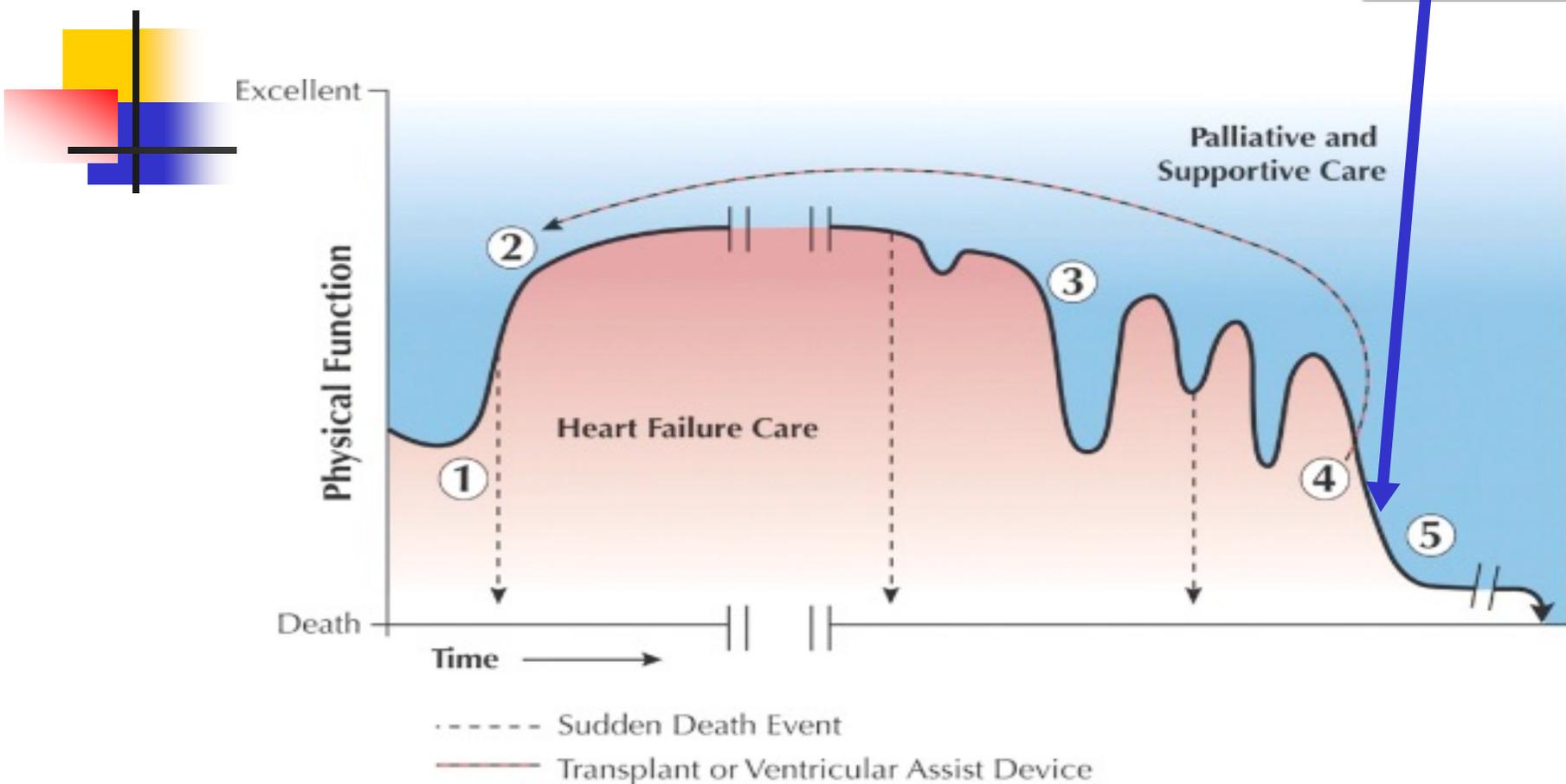
JOHN FORSYTH, M.D.  
FOR ASANTE MENDED HEARTS GROUP  
MAY 17, 2022

# First, *before* we begin ....

- a brief review of last month ...
- an addendum (about dementia) ...
  - a little recent history ...

Common Trajectories (80%) of:

# Function in the final years of Heart Patients / *“Final Chapter”*



Goodlin, S. J. J Am Coll Cardiol 2009;54:386-396

# A little HISTORY :

- Most People CHOSE:
- Death at home –
- comforted by
- loved ones (>90% still do!)



(before 1950)

1950 –  
1990



Many people ended their lives in **INTENSIVE CARE:**

- when chose to “**Do Everything Possible**”
- → intubated, sedated, restrained ...
- **DEPERSONAL**, **ISOLATED** (~15-40%; ave 33%)



Current Era:

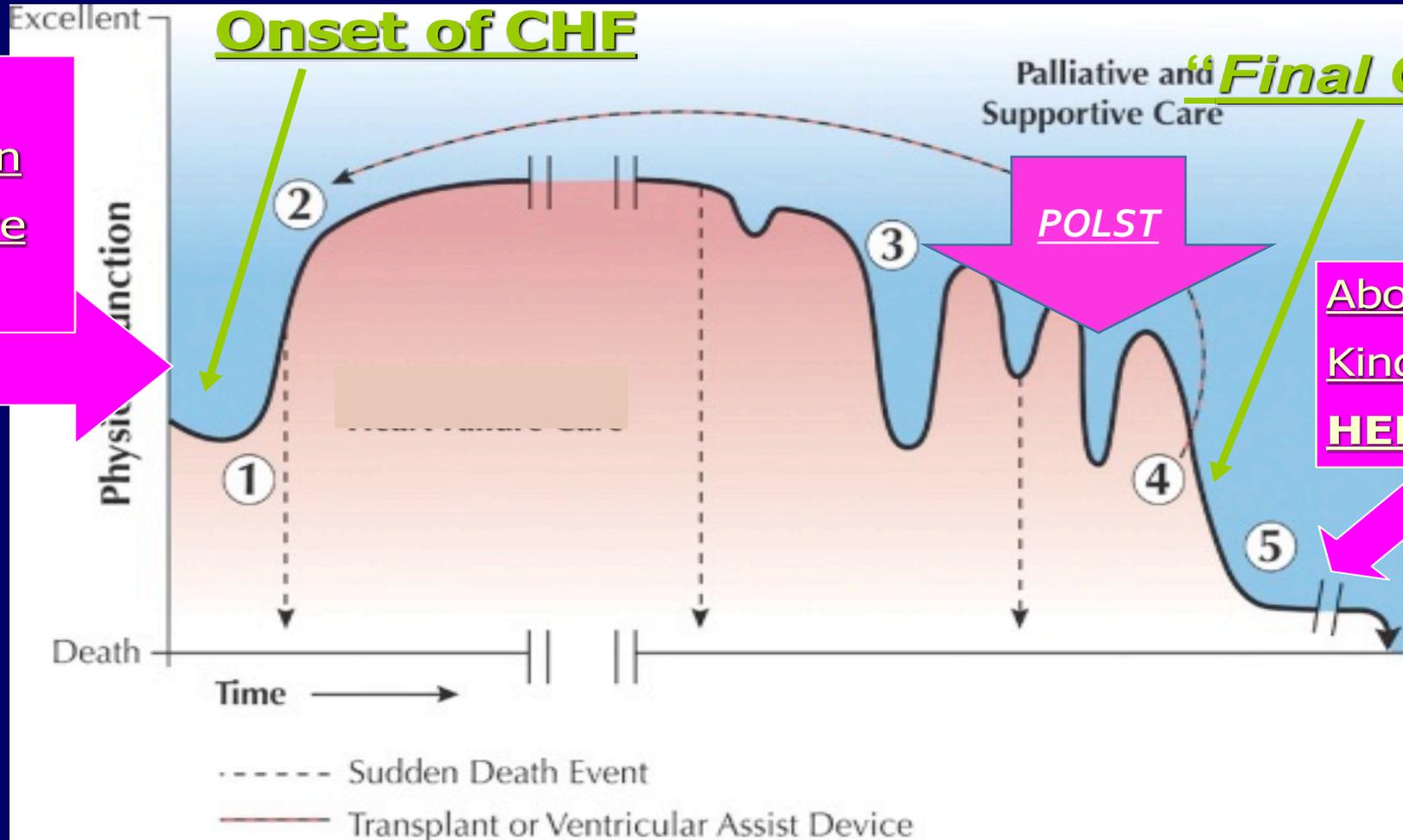
Since 1984

Increased Acceptance of **Hospice and Palliative Care** Near/At End-of-Life

# Time Course of Functional Decline in Late Life – HEART/CHF

## Adv. Care Planning – WHEN to BEGIN?

Begin the Conversation  
Adv Directive  
HERE !

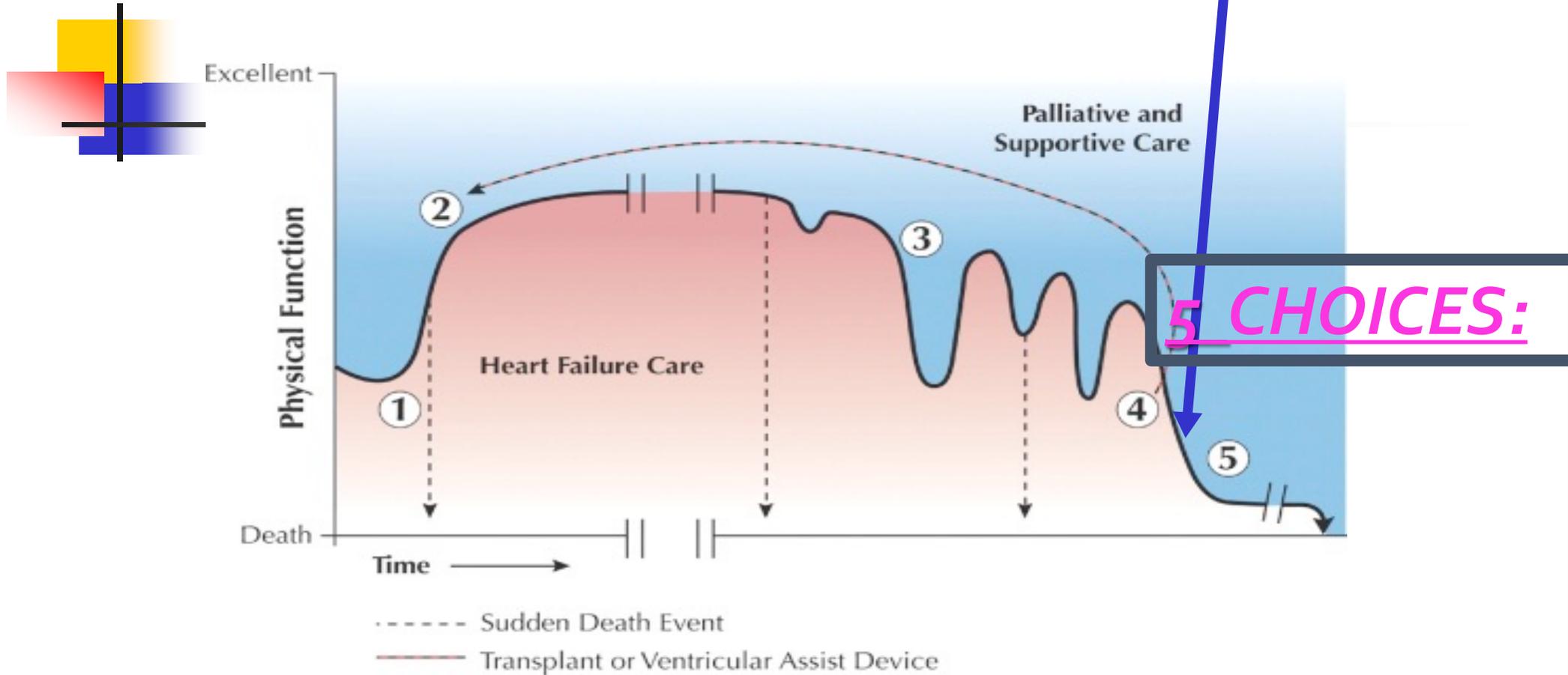


About the Kind of Care  
HERE !!

Goodlin, S. J. J Am Coll Cardiol 2009;54:386-396

Common Trajectories (80%) of:

# Function in the final years of Heart Patients / *“Final Chapter”*



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# 5 Choices (Possibilities) re Care in Stages 4 and 5: (first 3 in POLST form)

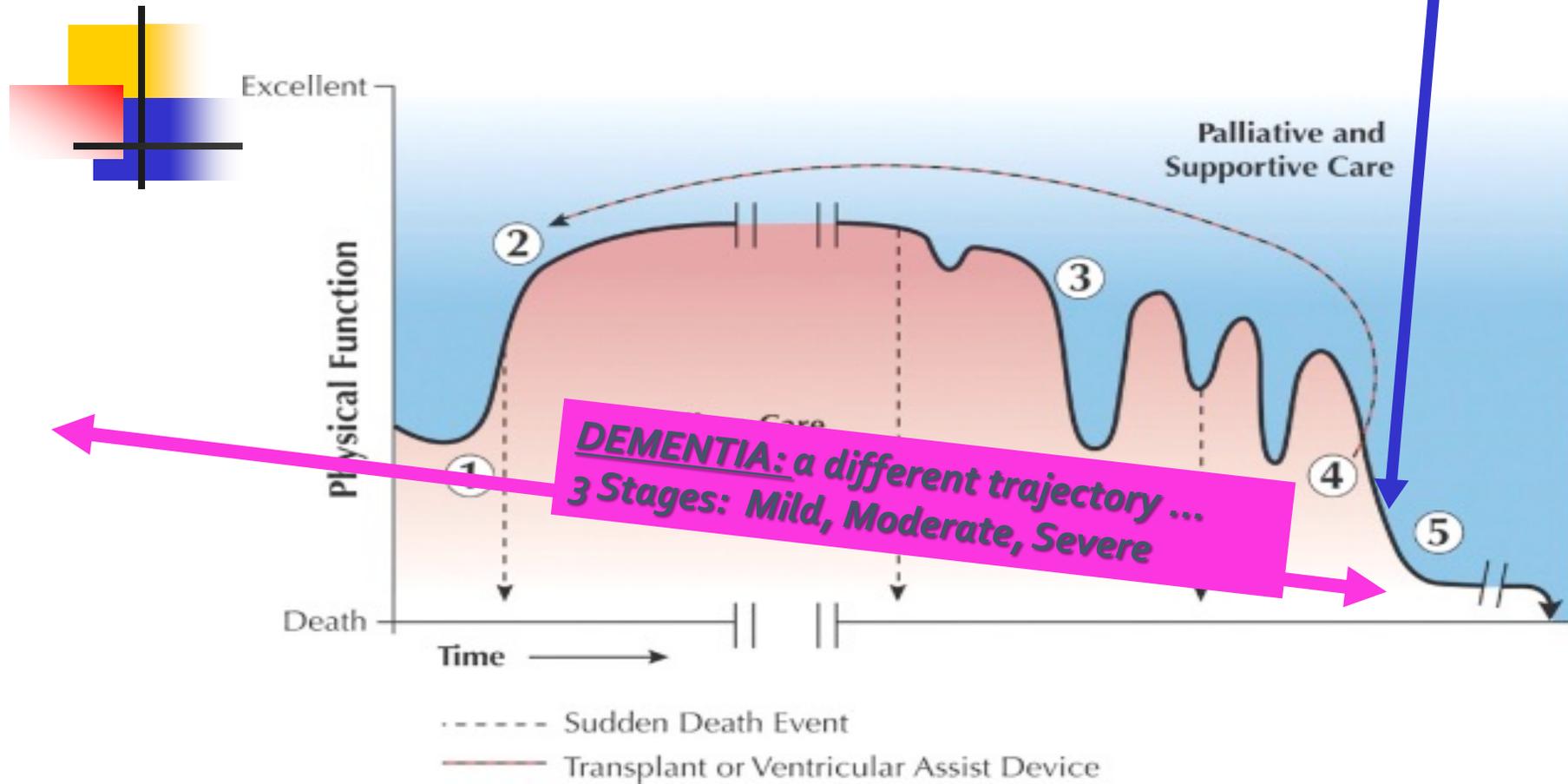
- 1. "FULL" Treatment: including ICU, respirator, etc.
- 2. "LIMITED Treatment" OK hospital, but NO ICU/respirator, etc
- 3. "COMFORT " Measures ONLY HOSPICE preferred +/- C.House
- 4. VSED ( Voluntary Stop Eating and Drinking)
- 5. DWD/MAID (Death with Dignity/ Medical Aid in Dying)

## 2... a possible Addendum ... re DEMENTIA ...

- An add-on to your Advance Directive re choices of care IF ....
  - DEMENTIA is a *possibility*:
    - **3 stages**
    - **3 choices** (for each stage, same as POLST)
- [www.dementia-directive.org](http://www.dementia-directive.org)

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### 3. recent HISTORY re Hospice...

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Current Era:

Since 1984

Increased Acceptance of Hospice and Palliative Care Near/At End-of-Life

since 1984:

# HOSPICE AND PALLIATIVE CARE FLOURISHED !

... IN U.S. AND OREGON!

OREGON HAS LED OUR COUNTRY (!) IN BOTH ...

1984 – U.S. (MEDICARE) → Hospice Benefit = pal care @ home by TEAM;  
1984 → present: Hospice GROWS (!)... Slowly at First, now RAPIDLY:

<u>Year</u>	<u>% U.S. Deaths on Hospice</u>
<b>1980</b>	<b>&lt; 1%</b>
<b>2000</b>	<b>21.6%</b>
<b>2015</b>	<b>&gt; 50%</b>

NOW ... 53% DEATHS IN OREGON supported by HOSPICE

CAVEAT: ~40% of Hospice patients CANNOT support good Hospice care in their own homes !!!

( establishes great need for facilities dedicated to hospice care ... Celia's House !!! )



Today's main focus:

## II. Hospice and Palliative Care

*as told by the story of ...*

*Celia's House*

*a legacy of ...*

*an embodiment of ...*

*the long and storied tradition of  
hospice and palliative caregiving ...*

## 4 Examples:

... that make EOL CARE at Celia's House "SPECIAL" ...

- 1. Its Heritage ... in Hospice and Palliative Care ...
- 2. Celia's House: a collaborative Community affair (!)
- 3. Our Heart ... in Three Words (Present, Kind, Real) and a Poem
- 4. Our Essence ... A Story: "A Chair Close By" ...

# 1. "An Image":

The Story of  
Our HERITAGE in ...  
Hospice

London, ~1600

*Let's take a closer LOOK:*



# 1. "The Image":

Our Heritage in ...

## Hospice

London, ~1600

1) So similar to NOW...  
at Celia's House ...EXCEPT:

**TWO Essential Presences:**

WOMEN and SOUND!!!

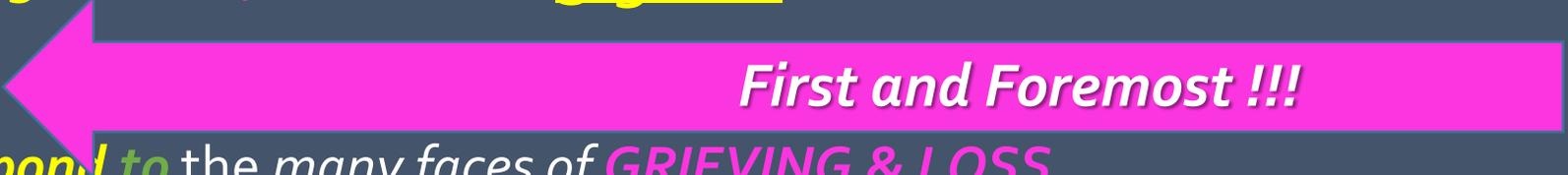
2) Captures the Essence of:

COMFORT,  
CARING,  
BEING PRESENT  
COMMUNITY  
SPIRITUAL  
CONTINUITY

"Palliative Care "



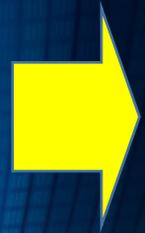
# So, what IS Palliative Care ?

- An ancient concept: "relief of suffering" ...
- Modern era focus: "Well Being" (CARE, not CURE) - 5 goals:
- - COMFORT CARE !!!  *First and Foremost !!!*
- - to recognize and respond to the many faces of GRIEVING & LOSS
- - to honor and help CLOSE Meaningful Personal relationships;
- - to support each person's Spiritual Journey - "what makes life meaningful"
- - to respect & honor each person's Goals re end-of-life care
- - ALL of Above !!!
- And so, What then is Hospice ?
- it IS Palliative Care ... in last 6 months of Life ...
- (since 1984 in U.S. = the Medicare benefit)

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## 2. Celia's House ... Independent Non-profit **Community** Affair:



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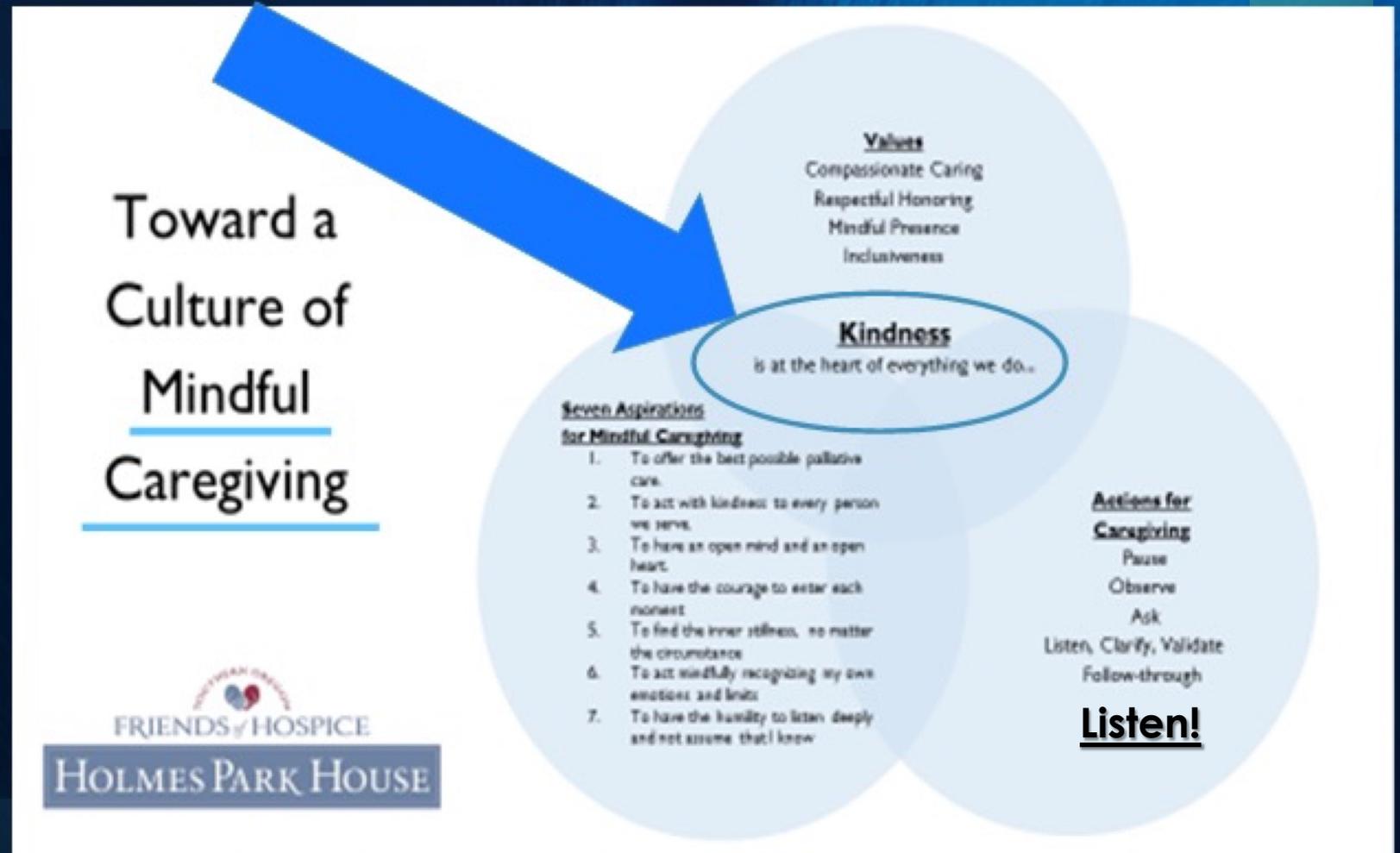
### 3. “Mindful Caregiving”

*(Hospice and Palliative Care at Celia’s House)*

- a) What is it?
  
- b) Where did it come from?
  
- c) What is its Essence?

Beginning in 2017, over a year before Celia's House opened:

What  
Kind  
of  
Care  
At  
Celia's  
House?



... overall, a COMPLEX concept !!!

Three Years Later:

*Essence* of "Mindful Caregiving":

( in Three Words )

Being Present

Being Kind

Being Real

*And in the cold dark hours  
when the earth smells  
of human dust  
and is so sad,  
I want to knock on every door  
and bake fresh bread  
for All who dwell therein ...  
Here,  
in the Oven of my heart ...*

*Cesar Vallejo*

## 4 Examples:

... that make the EOL CARE at Celia's House "SPECIAL" ...

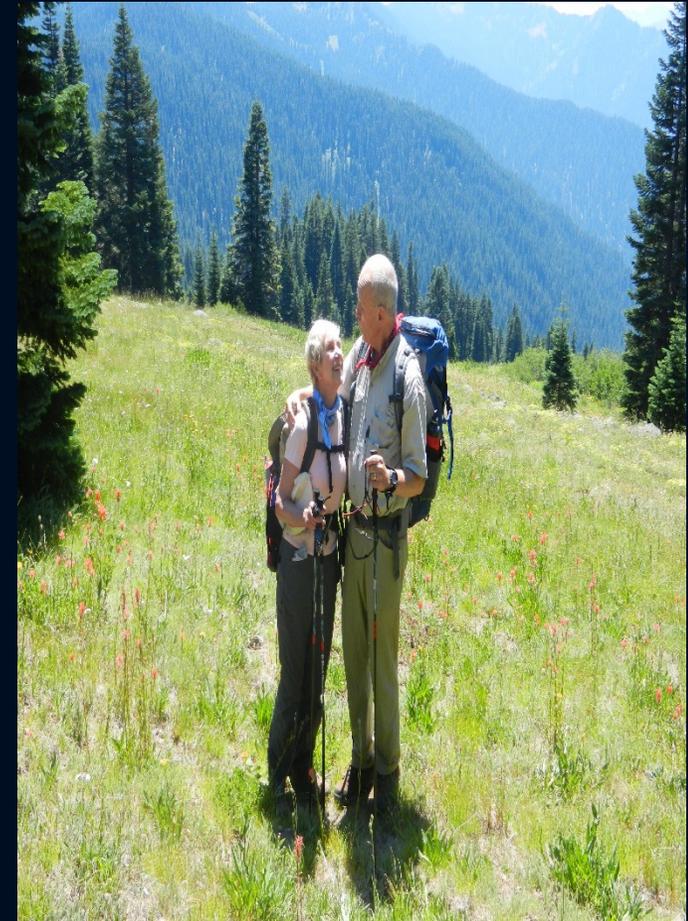
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4. .... *a story* .... "A Chair, Close By" ...

• ... "it's the little things" (that often count the most)....



- a chair, close by ...
- a gentle touch ...
- a favorite music ...
- a sip of water ... or of wine ...
- an hour with the night sky ...
  - a poem ... or a prayer ...
- silence ... and memories .....
- ... **"moments of Grace"** ...



• when we care ... mindfully ... with kindness ...

In this Introduction to Hospice & Palliative Care...  
... the Story of Celia's House .... as told by:

An Image:



Three Words:

*Be Present*

*Be Kind*

*Be Real*

Poem & Story:

“ Here, in the Oven  
of my heart” ..

and

“A Chair  
Close By ...”

But, the true **Story of Celia's House** does **NOT** end here ...

➤ Celia's House ...

... a *model* to be shared with southern Oregon ...



... Welcoming ... Peaceful ... Quiet ... Natural ... Mindful ... Caring ...  
... *for the final journey* ...

# Thank you!

for

- *Your* *Thoughts, Questions,*
- *and*
- *Stories!*