

# WHEN CURING IS NOT AN OPTION... CARING MEANS COMFORT

SUZANNE KAREFA-JOHNSON, MD HMDC  
FAMILY HOSPICE CARE,  
OCTOBER 19, 2019

# HIPPOCRATES- the father of medicine

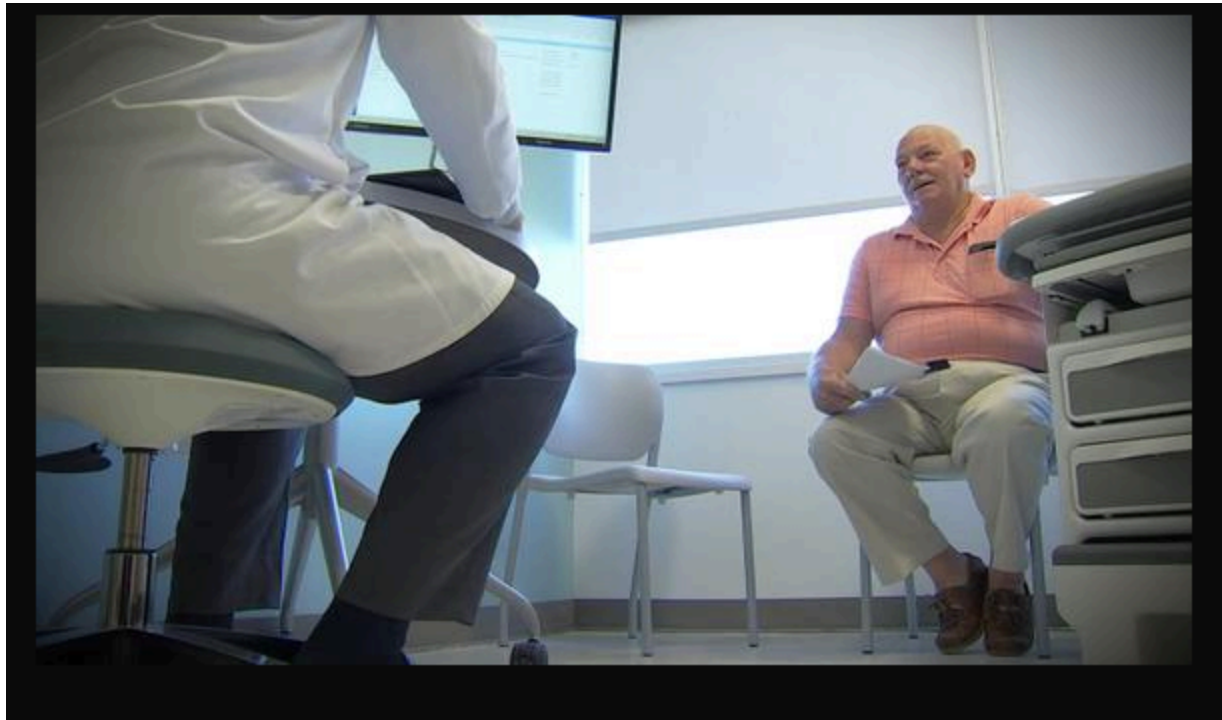


Cure sometimes, treat  
often, comfort always.

Hippocrates



# THE VISIT TO THE DOCTOR



# THE GRAYING OF AMERICA

- ▶ 10,000 Baby boomers are turning 65 each day
- ▶ Every minute 7 Baby boomers turn 65
- ▶ In 2035, people age 65 and over will number 77.0 million. Children under age 18 will number 76.5 million. OLDER ADULTS WILL OUTNUMBER CHILDREN





# LEADING CAUSES OF DEATH IN AMERICA

- ❖ HEART DISEASE
- ❖ CANCER
- ❖ UNINTENTIONAL INJURY
- ❖ CHRONIC LOWER RESPIRATORY TRACT DISEASE ( asthma, COPD, pulmonary hypertension, occupational lung disease)
- ❖ STROKE AND CEREBROVASCULAR DISEASE ( stroke, TIA, subarachnoid hemorrhage, vascular dementia)
- ❖ ALZHEIMER'S DISEASE

# WHERE DO CALIFORNIANS PREFER TO DIE?

- ▶ 70% OF CALIFORNIANS SAY THEY WOULD PREFER TO DIE AT HOME
- ▶ IN 2009, 42% DIED IN A HOSPITAL, 18% DIED IN A NURSING HOME
- ▶ IN 2009, ONLY 32% DIED AT HOME!





DYING IN THE ICU



DYING AT HOME



# FINAL WISHES OF CALIFORNIANS

- ▶ FACTORS THAT WERE IDENTIFIED AS MOST IMPORTANT AT THE END OF LIFE WERE:
- ▶ NOT BURDENING FAMILIES FINANCIALLY
- ▶ NOT SUFFERING WITH PAIN. BEING “COMFORTABLE”

# HOW ARE THESE FINAL WISHES COMMUNICATED?

► OR ARE THEY....





# COURAGEOUS CONVERSATIONS

- ▶ 56% OF CALIFORNIANS HAVE NOT SHARED THEIR WISHES FOR END OF LIFE WITH THEIR LOVED ONES
- ▶ 80% SAY THEY WOULD TALK TO THEIR PHYSICIAN ABOUT END-OF-LIFE CARE, BUT ONLY 7% HAVE ACTUALLY DONE SO






# ADVANCE DIRECTIVES

- ▶ DEFINITION: A WRITTEN STATEMENT OF A PERSON'S WISHES REGARDING MEDICAL TREATMENT
- ▶ WRITTEN TO ENSURE THAT THOSE WISHES ARE CARRIED OUT SHOULD THE PERSON BE UNABLE TO COMMUNICATE THEM TO A DOCTOR
- ▶ IN CALIFORNIA, THERE IS THE OPTION OF THE **POLST** FORM

# POLST- PHYSICIANS ORDER FOR LIFE SUSTAINING TREATMENT

HIPAA PERMITS DISCLOSURE OF POLST TO OTHER HEALTH CARE PROVIDERS AS NECESSARY							
 EMSA #111 B (Effective 1/1/2016)*	<b>Physician Orders for Life-Sustaining Treatment (POLST)</b> <small>First follow these orders, then contact Physician/NP/PA. A copy of the signed POLST form is a legally valid physician order. Any section not completed implies full treatment for that section. POLST complements an Advance Directive and is not intended to replace that document.</small>						
	<table border="1"><tr><td>Patient Last Name:</td><td>Date Form Prepared:</td></tr><tr><td>Patient First Name:</td><td>Patient Date of Birth:</td></tr><tr><td>Patient Middle Name:</td><td>Medical Record #: (optional)</td></tr></table>	Patient Last Name:	Date Form Prepared:	Patient First Name:	Patient Date of Birth:	Patient Middle Name:	Medical Record #: (optional)
Patient Last Name:	Date Form Prepared:						
Patient First Name:	Patient Date of Birth:						
Patient Middle Name:	Medical Record #: (optional)						
<b>A</b> Check One	<b>CARDIOPULMONARY RESUSCITATION (CPR):</b> <i>If patient has no pulse and is not breathing.</i> <i>If patient is NOT in cardiopulmonary arrest, follow orders in Sections B and C.</i> <input type="checkbox"/> Attempt Resuscitation/CPR (Selecting CPR in Section A <u>requires</u> selecting Full Treatment in Section B) <input type="checkbox"/> Do Not Attempt Resuscitation/DNR (Allow Natural Death)						
<b>B</b> Check One	<b>MEDICAL INTERVENTIONS:</b> <i>If patient is found with a pulse and/or is breathing.</i> <input type="checkbox"/> <b>Full Treatment</b> – primary goal of prolonging life by all medically effective means. In addition to treatment described in Selective Treatment and Comfort-Focused Treatment, use intubation, advanced airway interventions, mechanical ventilation, and cardioversion as indicated. <input type="checkbox"/> <i>Trial Period of Full Treatment.</i> <input type="checkbox"/> <b>Selective Treatment</b> – goal of treating medical conditions while avoiding burdensome measures. In addition to treatment described in Comfort-Focused Treatment, use medical treatment, IV antibiotics, and IV fluids as indicated. Do not intubate. May use non-invasive positive airway pressure. Generally avoid intensive care. <input type="checkbox"/> <i>Request transfer to hospital <u>only</u> if comfort needs cannot be met in current location.</i> <input type="checkbox"/> <b>Comfort-Focused Treatment</b> – primary goal of maximizing comfort. Relieve pain and suffering with medication by any route as needed; use oxygen, suctioning, and manual treatment of airway obstruction. Do not use treatments listed in Full and Selective Treatment unless consistent with comfort goal. <i>Request transfer to hospital <u>only</u> if comfort needs cannot be met in current location.</i>						
Additional Orders: _____							

# FIVE WISHES

## FIVE WISHES®

### MY WISH FOR:

The Person I Want to Make Care Decisions for Me When I Can't

The Kind of Medical Treatment I Want or Don't Want

How Comfortable I Want to Be

How I Want People to Treat Me

What I Want My Loved Ones to Know

print your name

for home



# GOWISH CARDS



*the*  
**GoWish**<sup>™</sup>  
*game*



Coda Alliance  
[www.codaalliance.org](http://www.codaalliance.org)

# FOR THE MORE ADVENTUROUS

What are you #dyingtoknow?

**DEATH CAFÉ**

Where you just pay for the coffee  
'cause the cake and conversation are free!

BEACH HUT COFFEE - 2 Beach Road, Ulverstone  
2pm till 3.30pm

RSVP: Email [projectnorthwest@tahpc.org.au](mailto:projectnorthwest@tahpc.org.au)  
Or phone 0408.628.573

8th August 2014  
[www.dyingtoknowday.org](http://www.dyingtoknowday.org)

**Dying To Know day**  
an annual day of action bringing to life  
conversations and community actions  
around death, dying and bereavement.



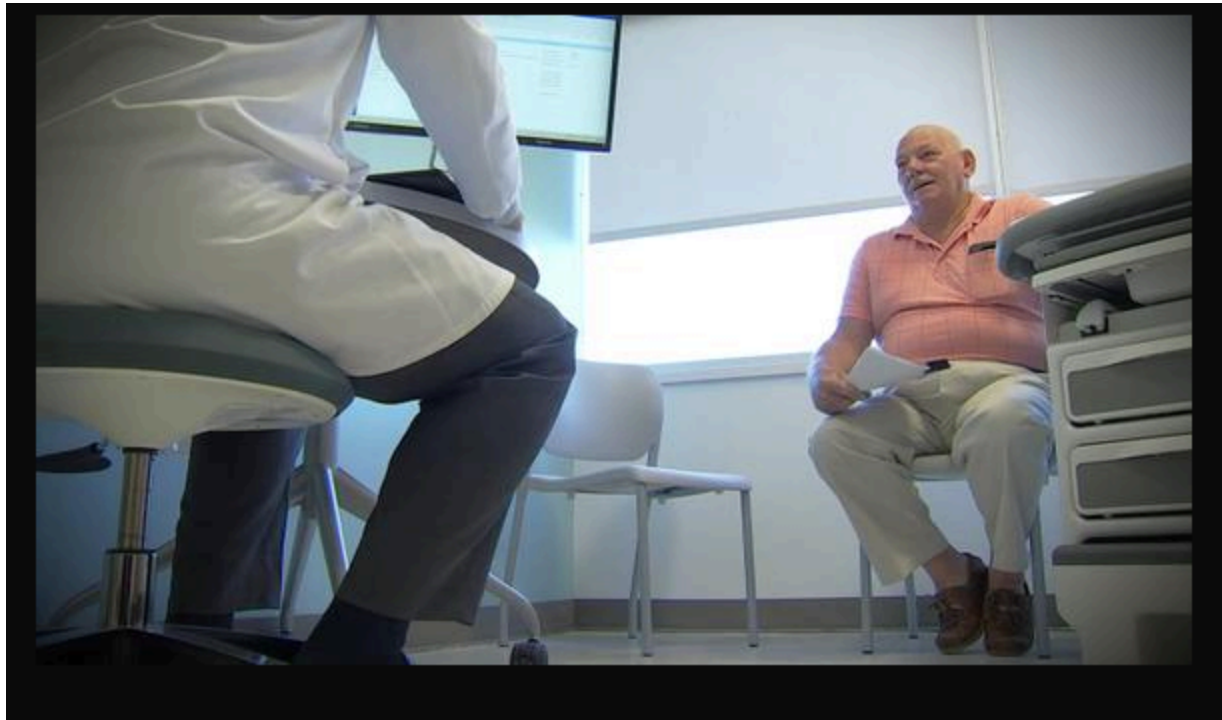
  

# DEATH PHOBIA

- ▶ IN AMERICA WE ARE AFRAID TO SPEAK ABOUT DEATH
- ▶ IN MEDICINE IT IS OFTEN VIEWED AS THE ULTIMATE FAILURE
- ▶ WE ARE OBSESSED WITH YOUTH AND CONQUERING EVERY CHALLENGE
- ▶ THERE IS ONE THING THAT EVERYONE IN THIS ROOM SHARES, OTHER THAN OUR HUMANITY.... WE WILL ALL DIE



# THE DOCTOR'S OFFICE



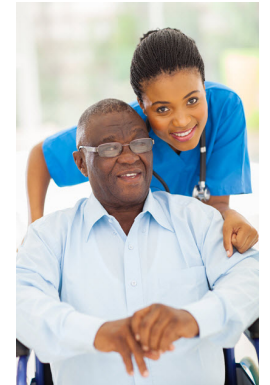
IF NO “HOPE” OF CURE....

- ▶ HOSPICE
- ▶ PALLIATIVE CARE – “relief of suffering” from latin ‘**palliare**’- TO WRAP ONE’S ARMS AROUND
- ▶ PALLIATIVE CARE IS GIVEN AT ANY POINT ALONG THE ILLNESS TRAJECTORY- PATIENTS DO NOT HAVE TO BE TERMINALLY ILL
- ▶ HOSPICE- PALLIATIVE CARE AT END OF LIFE ( 6 MONTHS OR LESS PROGNOSIS)
- ▶ HOSPICE FOCUSES ON SYMPTOM MANAGEMENT  
/ COMFORT CARE



# THERE IS ALWAYS “HOPE” FOR COMFORT AND QUALITY OF LIFE- HOSPICE

- ▶ INTERDISCIPLINARY CARE GIVEN WHEREVER THE PATIENT “LIVES”
- ▶ HOME, ASSISTED LIVING, BOARD AND CARE, NURSING HOME
- ▶ MEDICARE HOSPICE BENEFIT – COVERS ALL CARE RELATED TO THE TERMINAL PROGNOSIS ( 1986)





# QUALITY OF LIFE- HOSPICE

- ▶ PATIENTS <65 COVERED BY THEIR COMMERCIAL INSURANCE
- ▶ MEDICAL COVERS HOSPICE
- ▶ INITIAL TWO 90 DAY BENEFIT PERIODS FOLLOWED BY UNLIMITED 60 DAY BENEFIT PERIOD AS LONG AS PATIENT IS CLINICALLY ELIGIBLE

# HOSPICE

- ▶ “CARE” COVERS:
- ▶ NURSING, PHYSICIAN, SOCIAL WORKER, SPIRITUAL COUNSELOR, HOME HEALTH AIDES
- ▶ ALL MEDICATIONS RELATED TO THE TERMINAL PROGNOSIS
- ▶ ALL DME NEEDED ( hospital bed, walker, bedside commode, oxygen)
- ▶ SUPPLIES ( incontinence products, body washes, chucks, gloves)
- ▶ UNIT OF CARE IS THE PATIENT AND THEIR “FAMILY” ( HOWEVER THEY DEFINE THAT)



# CORE HOSPICE TEAM

- ▶ NURSE ( USUALLY RNs)- CASE MANAGERS- AT LEAST ONCE /WEEK VISITS
- ▶ SOCIAL WORKER- ASSISTANCE WITH FINDING COMMUNITY RESOURCES; PLACEMENT, APPLICATIONS FOR IHSS, MEDICAID, LIAISON WITH RCFE STAFF
- ▶ SPIRITUAL COUNSELOR- ADDRESS EXISTENTIAL ISSUES AROUND END-OF-LIFE, COUNSELING



# CORE HOSPICE TEAM

- ▶ BEREAVEMENT- SUPPORT OF ANTICIPATORY GRIEF, INDIVIDUAL AND GROUP SUPPORT, OUTREACH TO SURVIVING FAMILY/CG/FRIENDS
- ▶ PHYSICIAN-INITIAL VISIT AND FOLLOW UP VISITS AS NECESSARY; CLARIFICATION OF GOALS OF CARE: AGGRESSIVE PAIN AND SYMPTOM MANAGEMENT TO MAXIMIZE QUALITY OF LIFE, EDUCATION ON DISEASE PROGRESSION/ EOL SYMPTOMS ; EOL COUNSELING AND SUPPORT; LIAISE WITH COMMUNITY PHYSICIANS



# ADDITIONAL TEAM MEMBERS

- ▶ HOME HEALTH AIDES- PROVIDE HANDS ON CARE WITH ACTIVITIES OF DAILY LIVING ( BATHING, TOILETING, DRESSING, BED CARE)
- ▶ VOLUNTEERS- PATIENT ENGAGEMENT/SOCIALIZATION, CAREGIVER RELIEF
- ▶ BEREAVEMENT COUNSELORS



# HOSPICE SERVICES

- ▶ “UNIT OF CARE” – PATIENT AND FAMILY
- ▶ PLAN OF CARE IS DRIVEN BY PATIENT AND FAMILY’S “GOALS OF CARE”
- ▶ HOSPICE IS “ON CALL” AS NEEDED, 24 HOURS/DAY, 7 DAYS?WEEK
- ▶ BENEFIT EXTENDS 13 MONTHS AFTER DEATH OF PATIENT TO PROVIDE BEREAVEMENT CARE TO SURVIVING FAMILY/CAREGIVERS

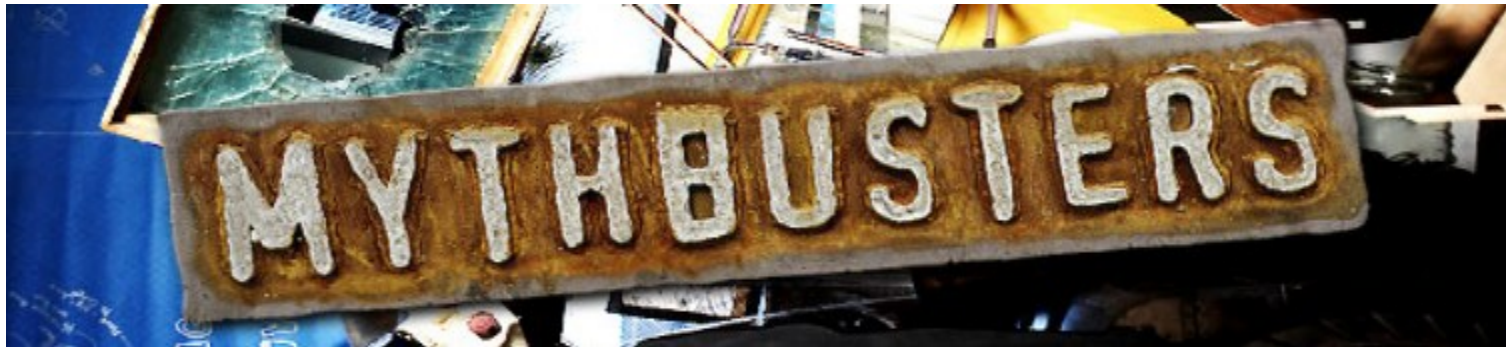


# HOSPICE LEVELS OF CARE

- ▶ MOST PATIENTS ARE AT THE **ROUTINE** LEVEL OF CARE
- ▶ **SHORT-TERM INPATIENT CARE** AVAILABLE FOR SYMPTOMS THAT CANNOT BE MANAGED AT HOME ( GENERAL INPATIENT CARE)
- ▶ **SHORT TERM CONTINUOUS CARE** AT HOME FOR AGGRESSIVE SYMPTOM MANAGEMENT
- ▶ **RESPIRE CARE** IN NURSING HOME TO PROVIDE RESPITE FOR CAREGIVER(S)

# HOSPICE MYTHS

- ▶ HOSPICE MEANS YOU HAVE GIVEN UP
- ▶ HOSPICE CARE HASTENS DEATH
- ▶ HOSPICE ONLY LASTS FOR 6 MONTHS
- ▶ HOSPICE MEANS YOU HAVE TO GIVE UP YOUR OWN PHYSICIAN



# HOSPICE MYTHS

- ▶ HOSPICE IS ONLY FOR THOSE WITH DAYS OR WEEKS TO LIVE
- ▶ HOSPICE IS A PLACE AND YOU HAVE TO LEAVE YOUR HOME
- ▶ HOSPICE MEANS YOU HAVE TO GIVE UP CONTROL
- ▶ HOSPICE IS ONLY FOR PATIENTS WITH CANCER
- ▶ HOSPICE HASTENS DEATH THROUGH USING MORPHINE





# HOSPICE FACTS AND FIGURES- TOP FIVE DIAGNOSES

- ▶ CANCER – 30%
- ▶ HEART – 17.6%
- ▶ DEMENTIA – 15/6%
- ▶ RESPIRATORY- 11.0%
- ▶ STROKE – 9/4%

**TAKE AWAY- 70% OF HOSPICE PATIENTS DO NOT HAVE A CANCER DIAGNOSIS**

- ▶ 27.8% OF HOSPICE PATIENTS ARE ENROLLED IN HOSPICE FOR SEVEN DAYS OR LESS!

**TAKE AWAY- PEOPLE SPEND UP TO A YEAR PLANNING THE “VACATION OF A LIFETIME”!**

# DAME CICELY SAUNDERS 1918-2005

- ▶ GRANDE DAME AND FOUNDER OF THE MODERN HOSPICE MOVEMENT
- ▶ NURSE, SW AND PHYSICIAN
- ▶ INTRODUCED CONCEPT OF “**TOTAL PAIN**”



# TOTAL PAIN

- ▶ PHYSICAL/SOMATIC
- ▶ PSYCHOLOGICAL
- ▶ SOCIAL
- ▶ SPIRITUAL
- ▶ FINANCIAL





- ▶ SUFFERING- ESSENTIAL PART OF LIFE –LOSS, GRIEF, HEARTBREAK
- ▶ SUFFERING- THAT WE CAN IMPACT
- ▶ HOSPICE/PALLIATIVE CARE- MISSION TO RELIEVE SUFFERING
- ▶ BEING ALIVE IS A FATAL CONDITION- ATUL GAWANDE



- ▶ HOPE SPRINGS ETERNAL- ALWAYS SOMETHING TO HOPE FOR
- ▶ ATTEND TO END OF LIFE PLANNING WAY BEFORE ITS NEEDED ( ADVANCE DIRECTIVES/COURAGEOUS CONVERSATIONS)
- ▶ IF YOU OR SOMEONE YOU KNOW HAS BEEN DIAGNOSED WITH A TERMINAL ILLNESS, DISCUSS THE POSSIBILITY OF HOSPICE WITH YOUR PHYSICIAN(S)

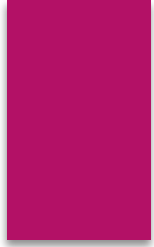


# THE HOSPICE PROMISE

- ▶ **“YOU MATTER BECAUSE YOU ARE YOU, AND YOU MATTER TO THE END OF YOUR LIFE. WE WILL DO ALL WE CAN NOT ONLY TO HELP YOU DIE PEACEFULLY, BUT ALSO TO LIVE UNTIL YOU DIE” - CICELY SAUNDERS**







THANK YOU FOR YOUR GIFT OF  
PRESENCE