ADVANCE CARE PLANNING IN PEDIATRICS

BILLIE WINEGARD, MD MPH

47TH ANNUAL PEDIATRICS IN THE RED ROCKS CONFERENCE

JUNE 2024

SOMETIMES WE CAN OFFER A CURE, SOMETIMES ONLY A SALVE, SOMETIMES NOT EVEN THAT.

BUT WHATEVER WE CAN OFFER, OUR INTERVENTIONS, AND THE RISKS AND SACRIFIES THEY ENTAIL, ARE JUSTIFIED ONLY IF THEY SERVE THE LARGER AIMS OF THE PERSON'S LIFE.

WHEN WE FORGET THAT, THE SUFFERING WE CAN INFLICT CAN BE BARBARIC.

WHEN WE REMEMBER IT, THE GOOD WE DO CAN BE BREATHTAKING.

ATUL GAWANDE, MD

BEING MORTAL

DISCLOSURES

I HAVE NO FINANCIAL INTEREST OR OTHER RELATIONSHIP WITH ANY MANUFACTURERS OF ANY COMMERCIAL PRODUCTS

OBJECTIVES

- DEFINE ADVANCE CARE PLANNING
- DISCUSS THE BENEFITS OF ADVANCE CARE PLANNING FOR CHILDREN AND FAMILIES AFFECTED BY COMPLEX MEDICAL CONDITIONS
- DESCRIBE AN APPROACH TO ADVANCE CARE PLANNING WITH CHILDREN AND THEIR FAMILIES

A BRIEF LOOK BACK AT MEDICINE'S HISTORY

EARLY 1900s

- PENICILLIN DISCOVERED – 1928
- IRON LUNG (NEGATIVE PRESSURE VENTILATOR) INVENTED – 1929
- SULFONAMIDE DRUGS DISCOVERED – 1935
- PHENYTOIN AVAILABLE – 1938
- POSITIVE PRESSURE VENTILATORS INVENTED – 1940S
- FIRST SUCCESSFUL REMISSION IN CHILDHOOD LEUKEMIA – 1947

1950s AND 60s

- FIRST INTENSIVE CARE UNIT – 1953
- FIRST KIDNEY TRANSPLANT – 1954
- MOUTH-TO-MOUTH RESUSCITATION INVENTED – 1956
- MODERN CPR DEVELOPED - 1960
- FIRST NEONATAL INTENSIVE CARE UNIT – 1961

SO…

BEFORE THE 1960s, WHEN YOUR HEART STOPPED BEATING, ***THERE WERE NO CHOICES TO MAKE***

ADVANCES IN MEDICINE DURING THE 1960 - 1970s CREATED A NEW WORLD. IT OFTEN BECAME DIFFICULT TO TELL - ARE WE:

SAVING A LIFE OR ***PROLONGING SUFFERING AND DEATH***

ADVANCE CARE PLANNING

DEFINITIONS

- **PEDIATRIC PALLIATIVE CARE:** SPECIALIZED MEDICAL CARE FOR CHILDREN WITH SERIOUS ILLNESSES, GOALS ARE TO MATCH TREATMENT TO PATIENT GOALS AND IMPROVE QUALITY OF LIFE FOR THE CHILD/FAMILY
- **ADVANCED CARE PLANNING:** PROCESS OF DISCUSSING **LONG-TERM GOALS** AND THE **TREATMENTS TO SUPPORT THESE GOALS**
- **ADVANCED DIRECTIVE:** A PATIENT'S HEALTH CARE PLAN FOR THE FUTURE IN CASE HE OR SHE IS UNABLE TO MAKE MEDICAL DECISIONS – IT CAN ONLY BE USED IN THIS SITUATION
- **LIVING WILL:** WRITTEN INSTRUCTIONS THAT EXPLAIN HEALTH CARE WISHES, ESPECIALLY ABOUT END-OF-LIFE CARE, SHOULD THE PATIENT BE UNABLE TO SPEAK FOR HIM OR HERSELF
- **HEALTHCARE PROXY:** LEGAL DOCUMENT THAT LETS ONE NAME A HEALTHCARE AGENT – SOMEONE TRUSTED TO MAKE HEALTHCARE DECISIONS IF THE PATIENT IS UNABLE TO MAKE DECISIONS FOR HIM OR HERSELF IN THE FUTURE

Advance care planning for paediatric patients. Paediatr Child Health. 2008 Nov;13(9):791-805.

A BRIEF LOOK BACK AT ADVANCE CARE PLANNING'S HISTORY

THE BIRTH OF ADVANCE CARE PLANNING

- LATE 1960s: "THE LAW PROVIDES THAT A PATIENT MAY NOT BE SUBJECTED TO TREATMENT WITHOUT HIS CONSENT"
  - BUT, WHAT ABOUT PATIENTS WHO WERE – BUT ARE NO LONGER – CAPABLE OF MAKING HEALTH CARE DECISIONS?

- 1976: CALIFORNIA ADOPTED THE FIRST LIVING WILL STATUTE: OFFERED A STANDARDIZED TOOL TO EXPRESS THEIR WISHES ABOUT LIFE-SUSTAINING TREATMENT

Sabatino CP. The evolution of health care advance planning law and policy. Milbank Q. 2010 Jun;88(2):211-39.

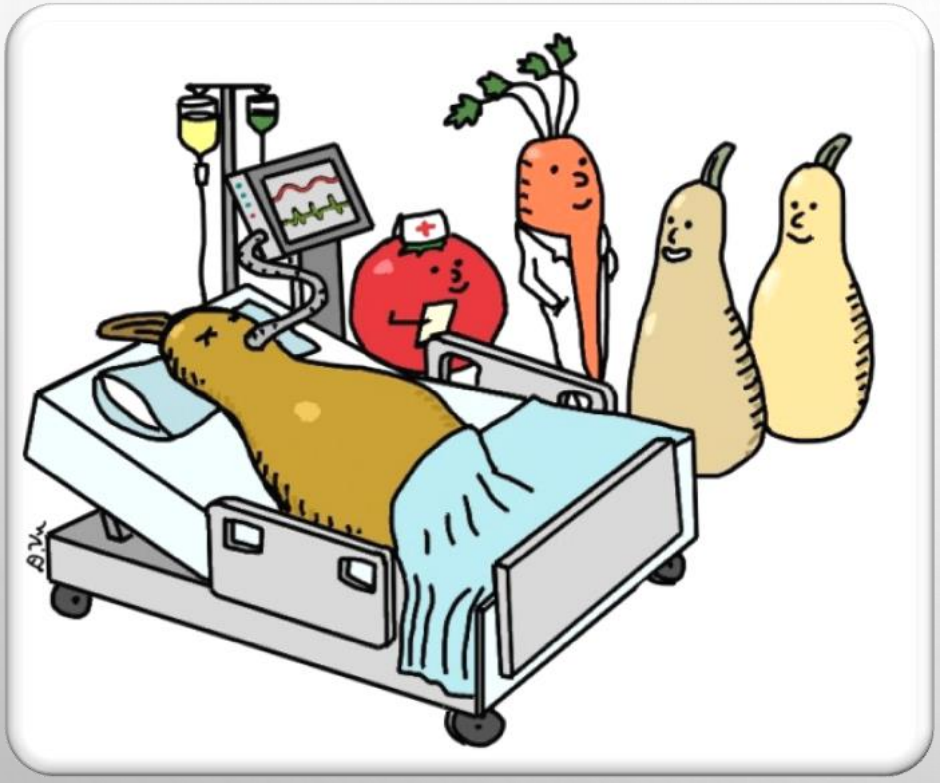
KAREN ANN QUINLAN – 1975
THE FIRST RIGHT TO DIE CASE

- "MANY DOCTORS, AFTER ALL, ARE TAUGHT TO REGARD **DEATH AS AN ENEMY AND TO DO ALL THEY CAN TO DEFEAT IT** – OR AT LEAST TO KEEP IT AT BAY FOR A WHILE. MANY REGARD 'PULLING THE PLUG' AS AN ACT AKIN TO EUTHANASIA, WHICH IS FORBIDDEN BY BOTH LAW AND THE MEDICAL CODE."

- "FOR ALTHOUGH THE QUINLAN CASE CONCERNS MAINLY THE MAINTENANCE OF LIFE BY ARTIFICIAL MEANS, IT COULD, IF CARRIED TO ITS LOGICAL CONCLUSION, BE APPLIED IN STATE HOSPITALS, INSTITUTIONS FOR THE MENTALLY RETARDED AND FOR THE ELDERLY… [AND] COULD PROMPT NEW SUITS BY PARENTS SEEKING TO END THE AGONY OF INCURABLY AFFLICTED CHILDREN, OR BY CHILDREN SEEING TO SHORTEN THE SUFFERING OF AGED AND TERMINALLY ILL PARENTS."

Sabatino CP. The evolution of health care advance planning law and policy. Milbank Q. 2010 Jun;88(2):211-39.

AMERICAN MEDICAL ASSOCIATION POSITION



"He looks so happy! He's wanted nothing more than to be in a persistent vegetative state."

- "IN 1975 THE AMERICAN MEDICAL ASSOCIATION (AMA) EQUATED WITHDRAWING A RESPIRATOR IN ORDER TO ALLOW DEATH TO OCCUR (LETTING DIE) WITH 'EUTHANASIA' (MERCY KILLING) – AND EQUATED EUTHANASIA WITH MURDER."
- "AT THE TIME, THE OFFICIAL POSITION OF THE AMA WAS THAT IT WAS PERMISSIBLE NOT TO PUT A PATIENT ON A RESPIRATOR; BUT ONCE A PATIENT WAS ON A RESPIRATOR, IT WAS NOT PERMISSIBLE TO TAKE THAT PATIENT OFF IF THE INTENTION WAS TO ALLOW DEATH TO OCCUR. THE JUSTICES FOUND THIS LINE OF REASONING 'RATHER FLIMSY.'"
- WHEN DID THE AMA CHANGE ITS POSITION ON WITHDRAWAL OF VENTILATOR SUPPORT FROM AN IRREVERSIBLY COMATOSE PATIENT?

1986

Pence, Gregory. Classic cases in medical ethics (3rd ed). Boston: McGraw Hill, 2000.

1980s AND 90s

- BY END OF 1986, 41 STATES HAD ADOPTED LIVING WILLS
- WITH SHORT-COMINGS OF LIVING WILLS, IN THE 1980S, POLICYMAKERS TURNED TO THE POWER OF ATTORNEY FOR HEALTH CARE
- BY THE END OF 1997, EVERY STATE HAD ENACTED SOME VERSION OF A HEALTH CARE POWER OF ATTORNEY STATUTE

Sabatino CP. The evolution of health care advance planning law and policy. Milbank Q. 2010 Jun;88(2):211-39.

1990: THE PATIENT SELF-DETERMINATION ACT

ALL MEDICARE AND MEDICAID PROVIDER ORGANIZATIONS ARE REQUIRED TO:

1. PROVIDE WRITTEN INFORMATION TO PATIENTS CONCERNING THEIR RIGHT UNDER STATE LAW TO MAKE DECISIONS ABOUT THEIR MEDICAL CARE AND THE RIGHT TO FORMULATE ADVANCE DIRECTIVES
2. MAINTAIN WRITTEN POLICIES AND PROCEDURES REGARDING ADVANCE DIRECTIVES AND MAKE THEM AVAILABLE TO PATIENTS UPON REQUEST
3. DOCUMENT WHETHER OR NOT THE PATIENT HAS EXECUTED AN ADVANCE DIRECTIVE
4. COMPLY WITH THE REQUIREMENTS OF STATE LAW RESPECTING ADVANCE DIRECTIVES
5. EDUCATE STAFF AND COMMUNITY ON ADVANCE DIRECTIVES

Sabatino CP. The evolution of health care advance planning law and policy. Milbank Q. 2010 Jun;88(2):211-39.

THE 90s: OUT OF HOSPITAL

- IN EARLY 1990S, THERE BECAME A GROWING AWARENESS OF UNWANTED RESUSCITATION OF TERMINALLY ILL PATIENTS LIVING AT HOME OR IN A HOSPICE WHEN AN EXPECTED MEDICAL CRISIS AROSE AND SOMEONE ON THE SCENE CALLED 911
- IN THIS SITUATION, EMERGENCY MEDICAL SERVICES PERSONNEL ARE OBLIGATED TO DO EVERYTHING POSSIBLE TO RESUSCITATE A PATIENT WHOSE HEART OR BREATHING HAS STOPPED
  - AN ADVANCED DIRECTIVE NORMALLY DOES NOT TRUMP THAT OBLIGATION
  - STATES BEGAN ENACTING LEGISLATION OR REGULATIONS IN THE EARLY 1990S TO PERMIT SERIOUSLY ILL PERSONS IN THE COMMUNITY TO AVOID UNWANTED RESUSCITATION THROUGH THE USE OF OUT-OF-HOSPITAL DNR ORDERS

Sabatino CP. The evolution of health care advance planning law and policy. Milbank Q. 2010 Jun;88(2):211-39.

THAT WAS INTERESTING, BUT WHY SHOULD I CARE? I TAKE CARE OF KIDS – IT'S ALL ABOUT SUPERHEROES AND PUPPIES

MYTH:
THE DEATH OF A CHILD IS A RARE EVENT

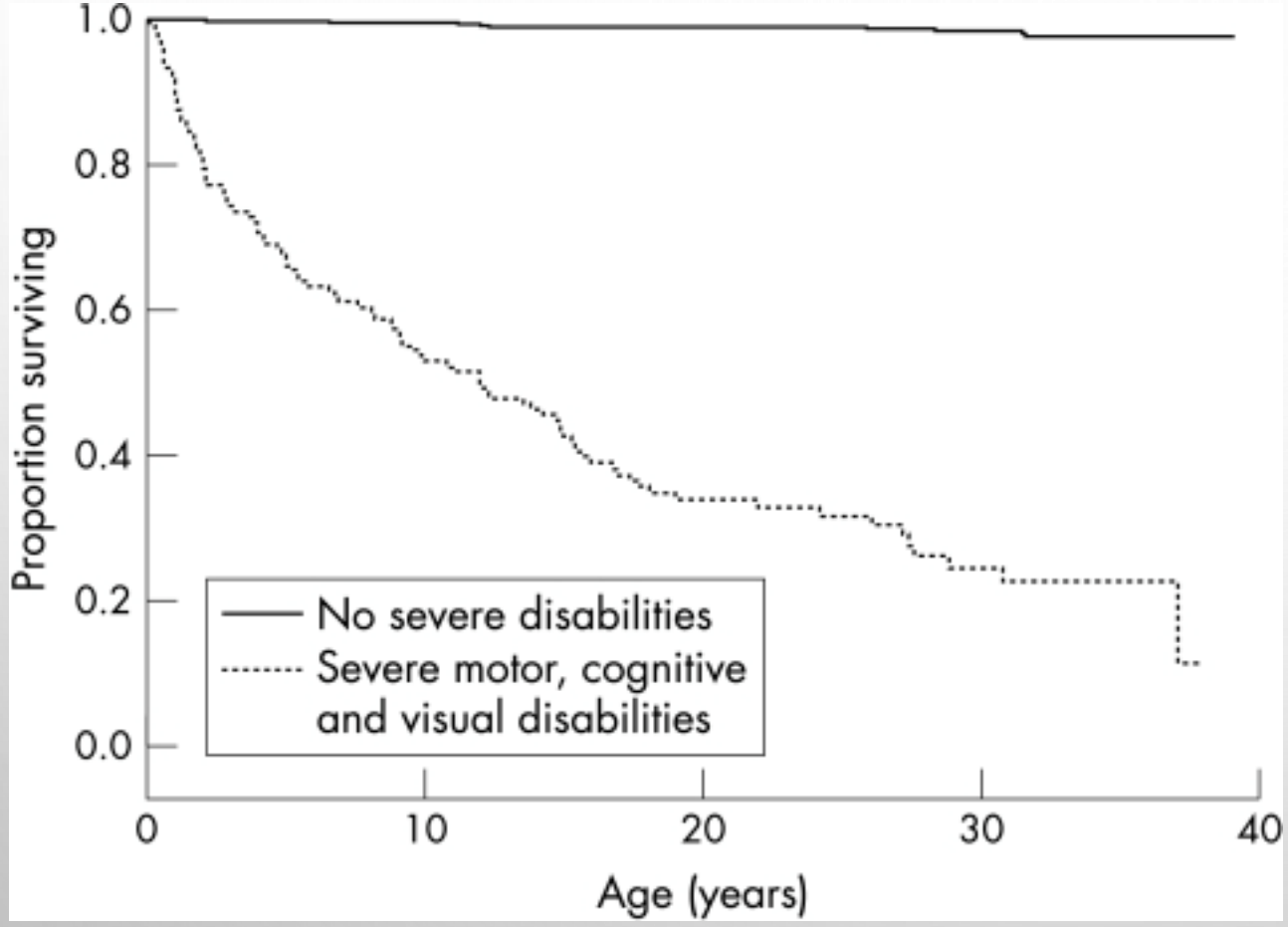
- 60,000 – 70,000 CHILDREN HAVE DIED ANNUALLY IN THE U.S. (AGE 0-24, 2018-2022)
- MORE THAN 3 MILLION OF THE 76 MILLION CHILDREN LIVING IN THE U.S. LIVE WITH MEDICAL COMPLEXITY, CHRONIC, LIFE-LIMITING AND LIFE-THREATENING CONDITIONS
  - WITH MEDICAL ADVANCES, CONDITIONS THAT WERE PREVIOUSLY FATAL ARE NOW CHRONIC
  - THE NUMBER OF CHILDREN WITH THESE ILLNESSES IS INCREASING AT A RATE OF 5% PER YEAR
  - CARE IS BECOMING MORE COMPLICATED (AND COSTLY)
  - DEATH RATE IS HIGHER (BUT DECREASING SLIGHTLY)

Centers for Disease Control and Prevention, National Center for Health Statistics. National Vital Statistics System, Mortality 2018-2022 on CDC WONDER Online Database, released in 2024. Data are from the Multiple Cause of Death Files, 2018-2022, as compiled from data provided by the 57 vital statistics jurisdictions through the Vital Statistics Cooperative Program. Accessed at http://wonder.cdc.gov/ucd-icd10-expanded.html

Agostiniani R, Nanni L, Langiano T. Children with medical complexity: the change in the pediatric epidemiology. *J Pediatr Neonat Individual Med*. 2014;**3**(2):e030230.

AN ESTIMATE:

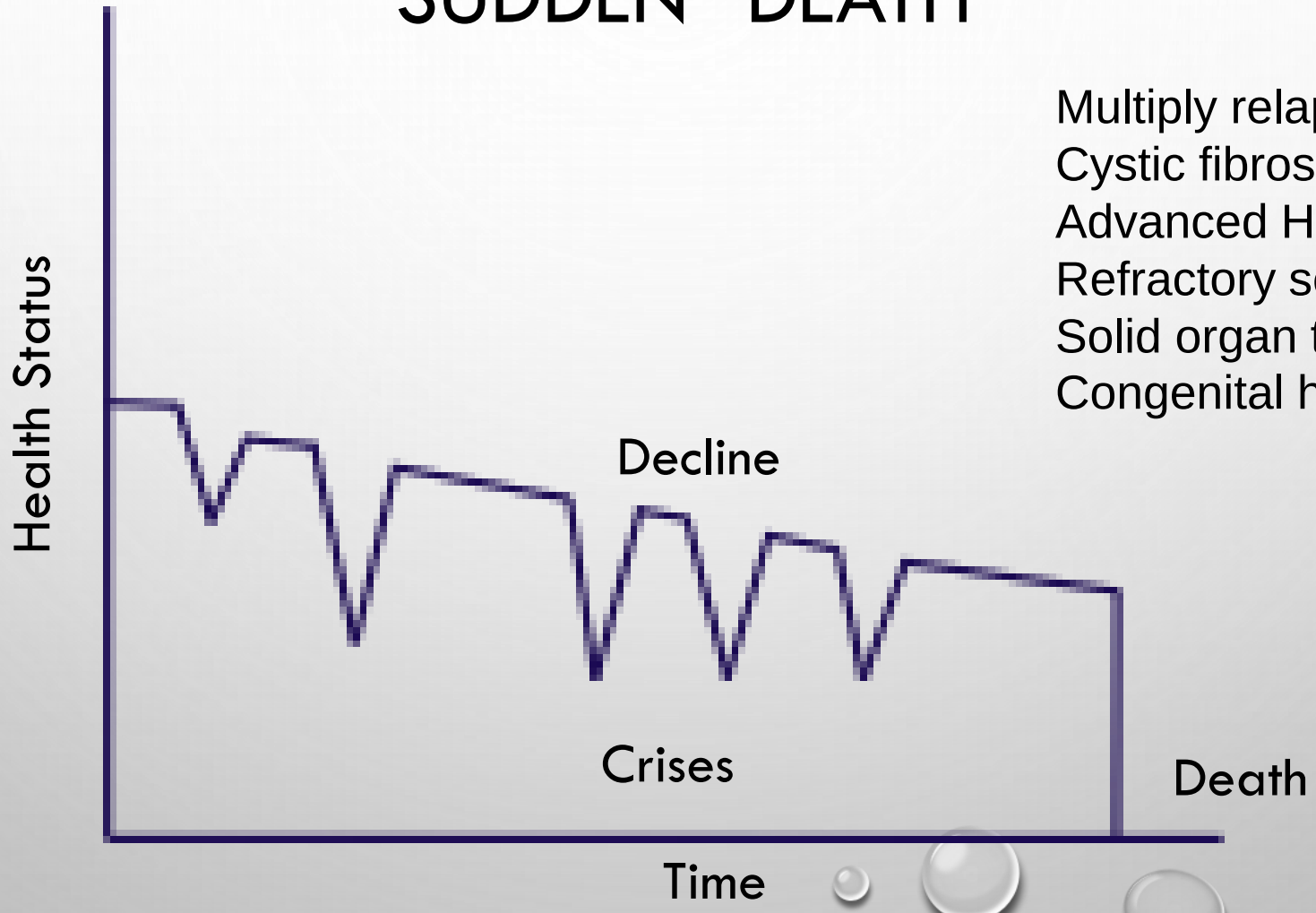
- 237,000 CHILDREN IN THE U.S. LIVE WITH LIFE-LIMITING CONDITIONS
  - EQUIVALENT TO #570 BOEING 747s
- 10,800 – 13,800 CHILDREN 0-17 YEARS OLD DIE DUE TO LIFE-LIMITING CONDITIONS EVERY YEAR
  - EQUIVALENT TO #26-33 BOEING 747s = 1 CRASH every 11-14 days



PROGNOSIS: THE CHILD WITH SEVERE COGNITIVE AND PHYSICAL IMPAIRMENT

Hutton JL and Pharoah POD. **Life expectancy in severe cerebral palsy.** Arch Dis Child. 2006 Mar; 91(3): 254–258.

MYTH:
"SUDDEN" DEATH



Multiply relapsed cancer
Cystic fibrosis
Advanced HIV
Refractory seizure disorder
Solid organ transplant recipient
Congenital heart disease

CAUSES OF DEATH

All Infants	Infants with Complex Chronic Conditions	All Children 1-19 Years	All Children 1-19 Years with Complex Chronic Conditions
Congenital malformations	Cardiovascular	Accidents	Malignancy
Short gestation / low birth weight	Congenital / genetic	Suicide	Neuromuscular
Maternal complications	Respiratory	Assault	Cardiovascular
SIDS	Neuromuscular	Malignancy	
Accidents / unintentional injury		Congenital malformations, deformations and chromosomal abnormalities	
Complications of placenta, cord, or membranes		Heart disease	

Feudtner et al. Pediatric Palliative Care Patients: A Prospective Multicenter Cohort Study. Pediatrics June 2011; 127(6): 1094-101.

DESIRED OUTCOMES OF ADVANCED CARE PLANNING

- NOT ABOUT FILLING OUT PAPERWORK / CREATION OF A DOCUMENT

- TO KNOW AND HONOR A PATIENT AND FAMILY'S **INFORMED** PLANS BY:
  - CREATING AN EFFECTIVE PLAN
  - MAKING THESE PLANS AVAILABLE TO THE TREATING HEALTH PROFESSIONALS
  - ASSURING THAT PLANS ARE INCORPORATED INTO AND USED TO GUIDE MEDICAL DECISIONS

HOPE IN THE FACE OF SERIOUS ILLNESS

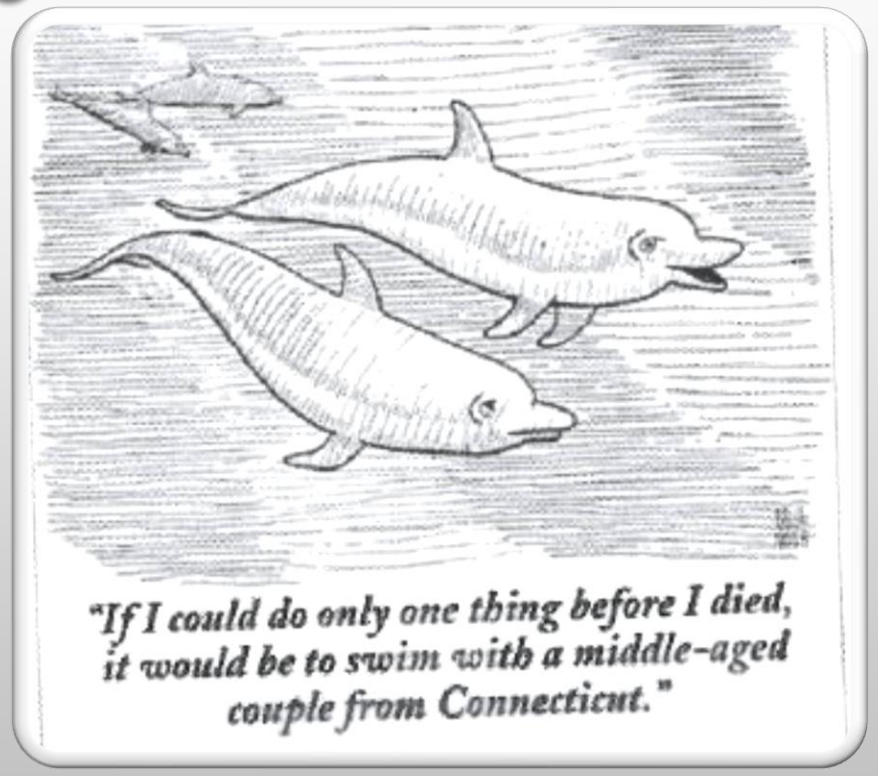
- ENGAGING IN ADVANCE CARE PLANNING **INCREASES KNOWLEDGE WITHOUT DIMINISHING HOPE, INCREASING HOPELESSNESS, OR INDUCING ANXIETY**
- DISCLOSURE OF A TERMINAL PROGNOSIS DOES NOT MEAN LOSS OF PATIENT HOPE. INSTEAD, HOPE WAS REDEFINED ON A GOAL OTHER THAN CURE
- MANY PEDIATRIC PROVIDERS FEEL PREPARED TO PARTICIPATE IN ADVANCE CARE PLANNING, BUT THAT DOES NOT ALWAYS TRANSLATE INTO ACTION
- MAY BE CHALLENGING FOR MEDICAL CAREGIVERS TO CONSIDER INTEGRATION OF ADVANCED CARE PLANNING BECAUSE IT MAY BE PERCEIVED AS 'GIVING UP'

Green, MJ, et al., Advance Care Planning Does Not Adversely Affect Hope or Anxiety Among Patients With Advanced Cancer. J Pain Symptom Manage, 2015. 49(6): 1088-96.

Coulourides Kogan, A, M Penido, and S Enguidanos, Does Disclosure of Terminal Prognosis Mean Losing Hope? Insights from Exploring Patient Perspectives on Their Experience of Palliative Care Consultations. J Palliat Med, 2015. 18(12): 1019-25.

Sanderson,A.,A.M. Hall, and J.Wolfe,Advance Care Discussions: Pediatric Clinician Preparedness and Practices. J Pain Symptom Manage, 2016. 51(3): 520-8.

GOALS OF CARE



- FAMILIES MAY HAVE MANY DIFFERENT GOALS:
  - DISEASE PREVENTION
  - CURE
  - PROLONGATION OF LIFE / SLOWING OF DISEASE PROGRESSION
  - RELIEF OF SUFFERING
  - OPTIMIZING QUALITY OF LIFE
  - ACHIEVING A GOOD DEATH
  - "THAT THE DOCTORS ARE WRONG."
- NONE OF THESE GOAL IS INHERENTLY MORE VALID THAN ANOTHER
- MULTIPLE GOALS MAY APPLY SIMULTANEOUSLY
- **OVER TIME AND NEAR END-OF-LIFE, GOALS FOR CARE AND TREATMENT PRIORITIES WILL CHANGE**
- ***GOALS MAY APPEAR TO BE CONTRADICTORY***
- SOME GOALS TAKE PRIORITY OVER OTHERS

GOALS OF CARE

PEARLS

- SET GOALS BEFORE DETERMINING THE TREATMENT PLAN:
  - **"JUST BECAUSE WE CAN DOES NOT MEAN WE SHOULD."**
  - **"LET THE GOALS DRIVE THE TREATMENT."**
- ASK EARLY IN THE RELATIONSHIP HOW THE PATIENT / FAMILY WOULD LIKE TO HANDLE INFORMATION SHARING AND DECISION MAKING
- ALWAYS EXPECT HOPEFULNESS—THE OBJECT OF HOPE CHANGES WITH TIME
- MAKE A PARTNERSHIP WITH YOUR PATIENT AND THE FAMILY CAREGIVER; DRAW THEM INTO THE INTERDISCIPLINARY TEAM AND FOSTER THEIR ACTIVE PARTICIPATION IN THE CARE PLAN

GOALS OF CARE

PITFALLS

- FAILING TO DISCUSS EXPECTATIONS
- PROVIDING UNWANTED INTERVENTIONS. MOST PATIENTS WILL BECOME ANGRY AND LOSE TRUST IF THINGS ARE DONE TO THEM THAT THEY DO NOT WANT
- THINKING THAT THE “PROBLEM-ORIENTED” APPROACH IS THE SAME AS SETTING GOAL
- USING LANGUAGE WITH UNINTENDED CONSEQUENCES
- OFFERING A FALSE SENSE OF HOPE
- MAKING EXCESSIVELY OPTIMISTIC ESTIMATES OF PROGNOSIS

GOALS OF CARE: HOPE LANGUAGE

- "TELL ME ABOUT LITTLE _____ ON A GOOD DAY. DO YOU HAVE ANY PICTURES?"
- "CONSIDERING WHAT _____ IS UP AGAINST, **WHAT ARE YOU HOPING FOR?**"
- "I AM HOPING FOR A MIRACLE, TOO, BUT JUST IN CASE THE MIRACLE DOESN'T HAPPEN, WHAT ELSE ARE YOU HOPING FOR?"
- "WE WANT TO MAKE SURE THAT _____ LIVES AS LONG AS POSSIBLE AND AS WELL AS POSSIBLE."
  - "WE ARE HOPING FOR THE BEST, BUT SOMETIMES WE HAVE TO PREPARE FOR THE REST."
  - "HE IS NOT DYING BECAUSE HE IS NOT EATING… HE IS NOT EATING BECAUSE HE IS DYING…"

GOALS OF CARE DEFINE ADVANCE CARE PLANNING:

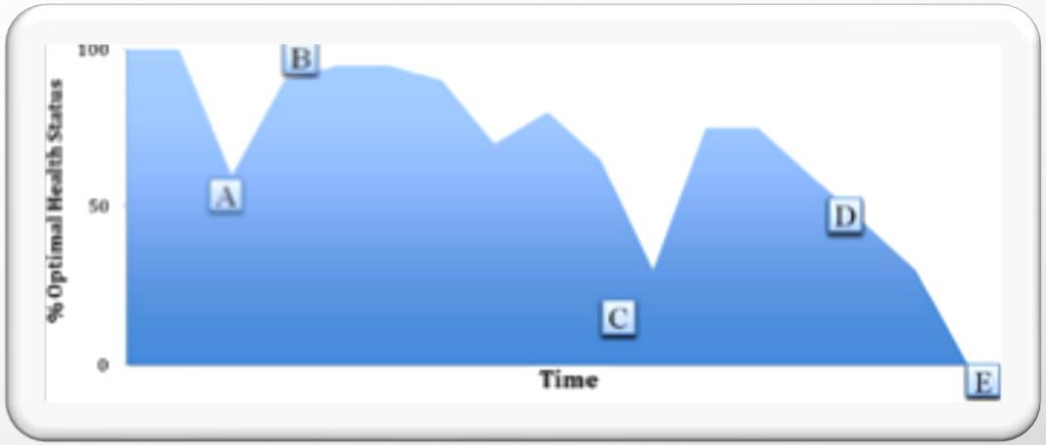
"SO, WHAT I HEAR YOU SAYING IS THAT THE IMPORTANT THINGS ARE…"

GOALS OF CARE → DISCUSSION OF LIMITATIONS (IN PALLIATIVE CARE, WE CALL THEM PROTECTIONS)

- AT TIMES, THESE CONVERSATIONS LEAD TO DISCUSSIONS OF LIMITATIONS OF TREATMENT
- PARENT: "WE KNOW THAT WE DON'T HAVE MUCH TIME WITH HIM."
  - "IN SIMILAR CASES, PARENTS START TO THINK ABOUT WHAT THEY WANT THAT TIME TO LOOK LIKE, WHAT THEY MIGHT OR MIGHT NOT WANT FOR THEIR CHILD. IS THAT SOMETHING THAT YOU HAVE DONE?"
  - "WE'RE NOT FACING ANY DECISIONS RIGHT NOW, BUT IS IT IMPORTANT TO YOU TO HEAR ABOUT SOME OF THE DECISIONS THAT YOU MIGHT BE FACED WITH IN THE FUTURE?"
  - "GIVEN WHAT YOU'VE SAID IS IMPORTANT TO YOU, I WOULD RECOMMEND….
    - "HAVING (OR NOT HAVING) A MEDICAL PROCEDURE"
    - "STARTING (OR STOPPING) A MEDICATION OR TREATMENT"
    - "PUTTING IN AN ORDER TO **PROTECT YOUR CHILD** FROM EXPERIENCING PAINFUL THINGS, SUCH AS CHEST COMPRESSIONS OR INTUBATION IF HE DIES AND HIS HEART STOPS OR HE STOPS BREATHING."

WHEN SHOULD ADVANCE CARE PLANNING OCCUR?

- AT DIAGNOSIS!
- AND THEN AGAIN:
  - ADVANCED ILLNESS WITH COMPLICATIONS
  - FUNCTIONAL DECLINE
  - CO-MORBIDITIES
  - FREQUENT HOSPITAL OR EMERGENCY DEPARTMENT VISITS



- AND AS WE NEAR END-OF-LIFE: "WOULD YOU BE SURPRISED IF THIS CHILD DIED IN THE NEXT YEAR?"
- AND EVEN AS WE'RE PROVIDING END OF LIFE CARE
- GOAL-DIRECTED DECISION MAKING IS AN ONGOING PROCESS THAT IS **BEST INITIATED DURING TIMES OF CALM INSTEAD OF CRISIS** AND REVISITED OVER TIME AND AS THE CHILD'S CONDITION EVOLVES

Friebert S, KA Bower, B Lookabaugh. Caring for Pediatric Patients: Unipac 8 A Resource for Hospice and Palliative Care Professionals. Glenview, IL: AAHPM, 2012.
Klick, Jeffrey C. et al.. Pediatric Palliative Care. Current Problems in Pediatric and Adolescent Health Care , Volume 40 , Issue 6 , 120 – 151.

ETHICAL AND LEGAL CONSIDERATIONS

- BECAUSE OF THEIR DEVELOPMENTAL STAGE OR THEIR MEDICAL CONDITIONS, DECISIONS ARE MADE USING THE BEST INTEREST STANDARD:
  - THE DECISION MAKER (USUALLY THE PARENTS) MUST DETERMINE "THE NET BENEFIT FOR THE PATIENT OF EACH OPTION…. THE COURSE OF ACTION TO BE FOLLOWED, THEN, IS THE ONE WITH THE GREATEST NET BENEFIT TO THE PATIENT."
- AAP ENDORSES WITHDRAWING OR WITHHOLDING OF BURDENSOME THERAPIES IN THE INTEREST OF MAXIMIZING A CHILD'S QUALITY OF LIFE
- WHO IS ELIGIBLE FOR LIMITATIONS?

Michelson KN, D Steinhorn. Pediatric End-of-Life Issues and Palliative Care *Clin Pediatr Emerg Med*. 2007 September ; 8(3): 212–219.

LIMITATIONS

FAMILIES MIGHT CONSIDER:

- DO NOT RESUSCITATE (DNR) OR DO NOT ATTEMPT RESUSCITATION - IF YOUR CHILD'S HEART STOPS (I.E. THEY HAVE DIED), DO NOT DO CPR, ALLOW THEM TO HAVE A PEACEFUL DEATH
- DO NOT INTUBATE (DNI) - DO NOT PUT A BREATHING TUBE IN YOUR CHILD'S THROAT
- DO NOT ESCALATE (DNE) – CONTINUE CURRENT TREATMENTS BUT DON'T ADD MORE
- DO NOT HOSPITALIZE (DNH) - IF YOUR CHILD BECOMES SICKER AT HOME, DO NOT BRING HER BACK TO THE HOSPITAL

- FULL ARREST
  - FULL CODE: "DO EVERYTHING"
  - NO CPR
    - DNR: DO NOT RESUSCITATE
    - DNAR: DO NOT ATTEMPT RESUSCITATION
    - AND: ALLOW NATURAL DEATH

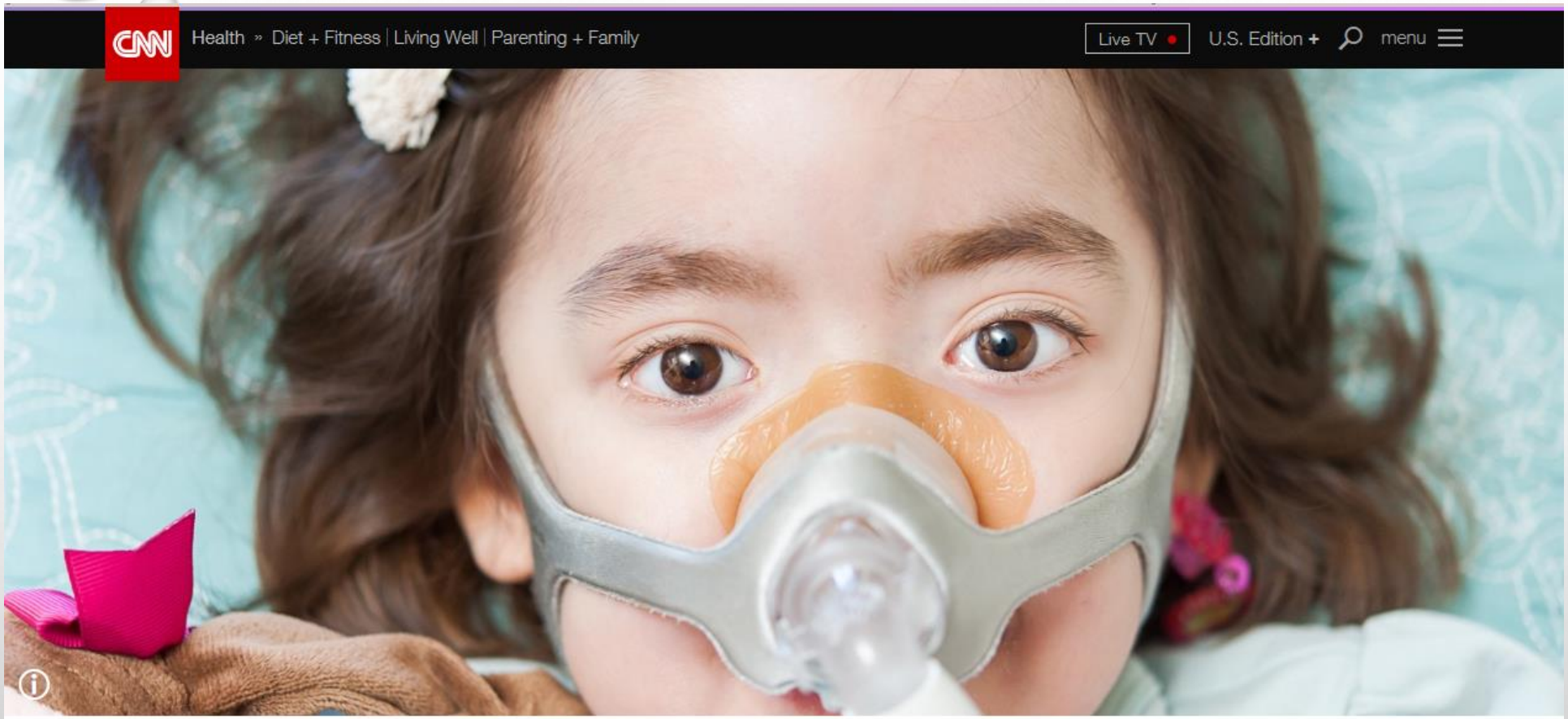
CODE STATUS ORDERS

- FOR THOSE WHO HAVE OPTED TO **NOT** HAVE CPR, IN A PRE-ARREST SITUATION:
  - **FULL TREATMENT**: PRIMARY GOAL OF SUSTAINING LIFE BY MEDICALLY INDICATED MEANS
    - INTUBATION/VENTILATION
    - CARDIOVERSION
  - **SELECTIVE TREATMENT**: PRIMARY GOAL OF TREATING MEDICAL CONDITIONS WITH SELECTED MEDICAL MEASURES
    - MEDICAL TREATMENT
    - IV FLUIDS AND IV MEDICATIONS
    - LESS INVASIVE AIRWAY SUPPORT (CPAP, BIPAP)
  - **COMFORT FOCUS**: PRIMARY GOAL OF MAXIMIZING COMFORT

INVOLVING THE PATIENT

- BY VIRTUE OF THEIR AGE, CHILDREN YOUNGER THAN 18 YEARS DO NOT POSSESS COMPETENCY (LEGAL TERM)
- BUT, THEY MAY HAVE THE CAPACITY TO PARTICIPATE IN ADVANCE CARE PLANNING
  - THOSE WITH CAPACITY SHOULD ACTIVELY PARTICIPATE IN THEIR OWN HEALTHCARE DECISION MAKING AND HAVE THEIR DECISIONS RESPECTED
  - TYPICAL INTELLECT: 14 YEARS AND OLDER
  - MANY CHILDREN WHO HAVE LIVED WITH A CHRONIC OR SEVERE ILLNESS THAT HAS CONFERRED HEALTH-RELATED MATURITY BEYOND THEIR CHRONOLOGICAL AGE CAN PARTICIPATE AS WELL

Friebert S, KA Bower, B Lookabaugh. Caring for Pediatric Patients: Unipac 8 A Resource for Hospice and Palliative Care Professionals. Glenview, IL: AAHPM, 2012.



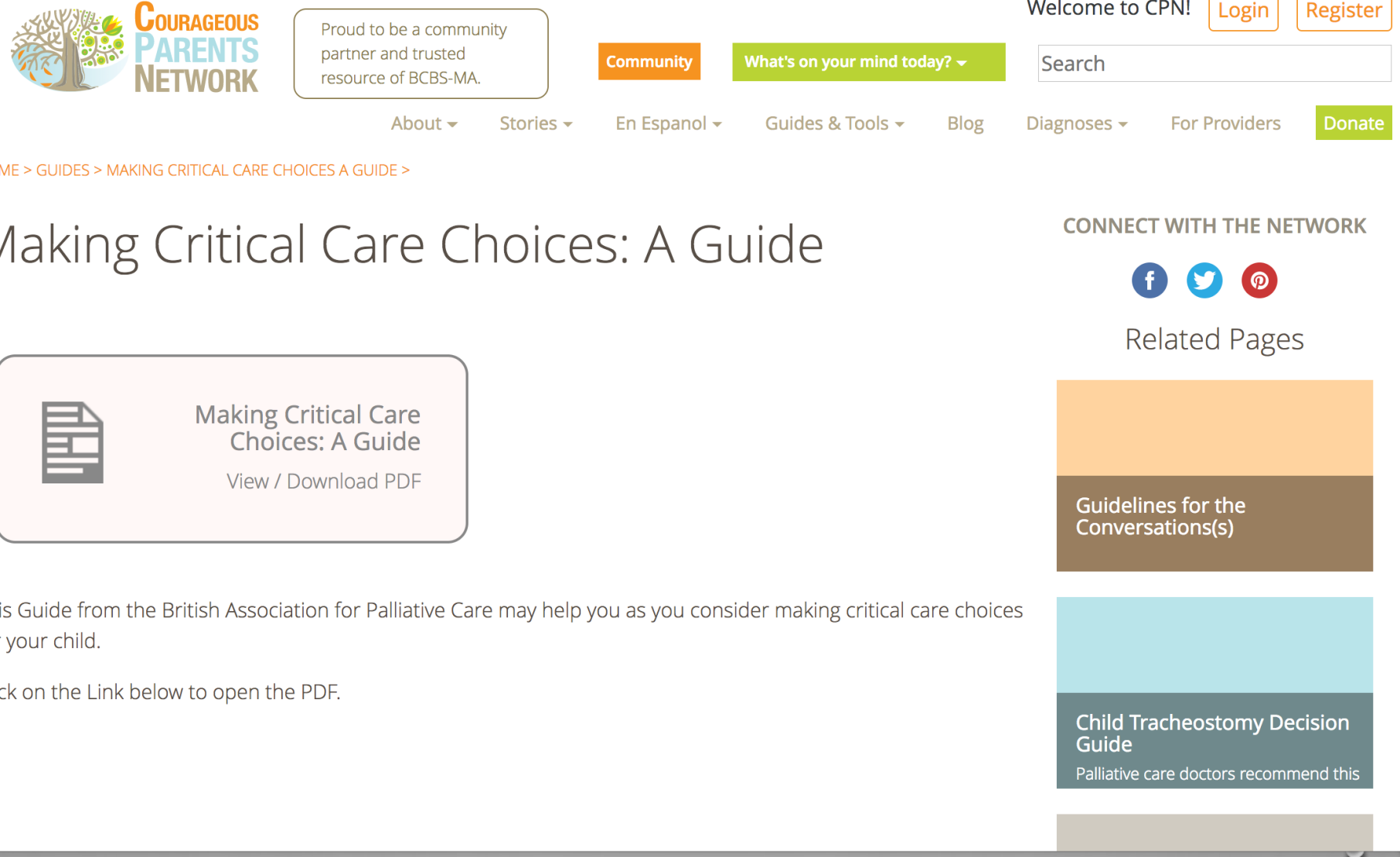
Heaven over hospital: Dying girl, age 5, makes a choice

By Elizabeth Cohen, CNN Senior Medical Correspondent

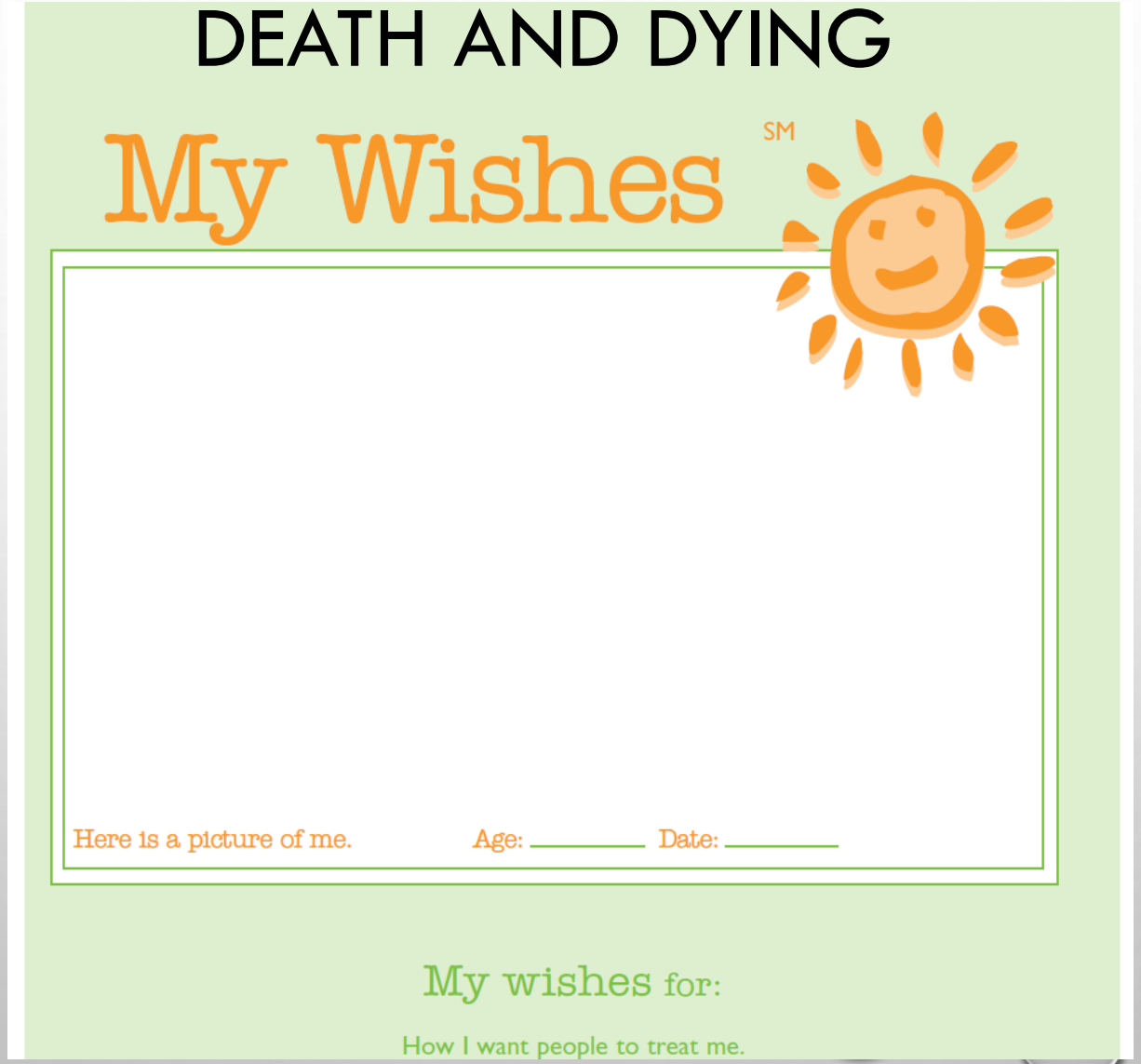
Updated 2:39 PM ET, Tue October 27, 2015

BUT, AREN'T THERE FORMS OR SOMETHING THAT I CAN USE TO HELP WITH THESE CONVERSATIONS?

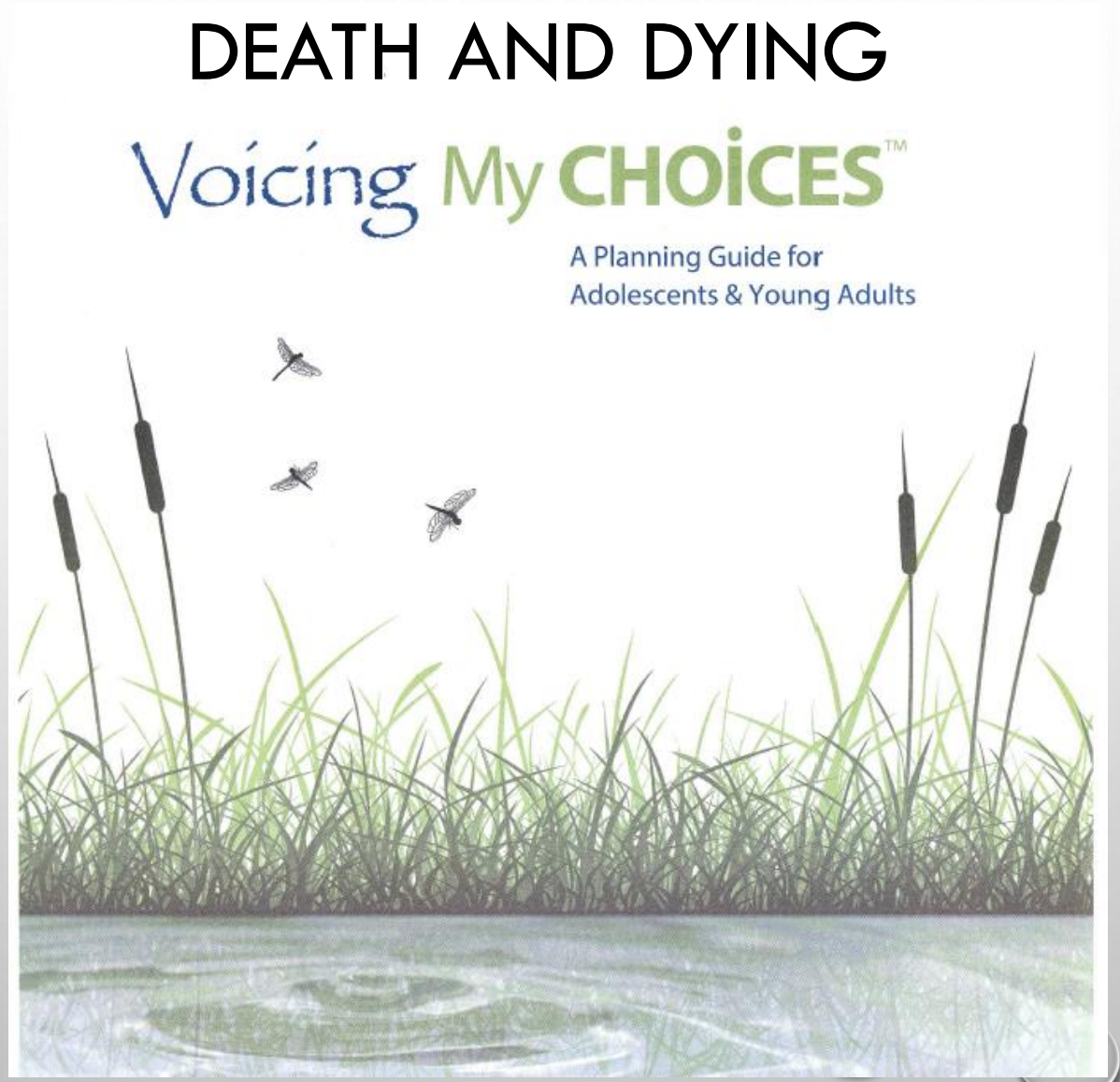
COURAGEOUS PARENTS NETWORK

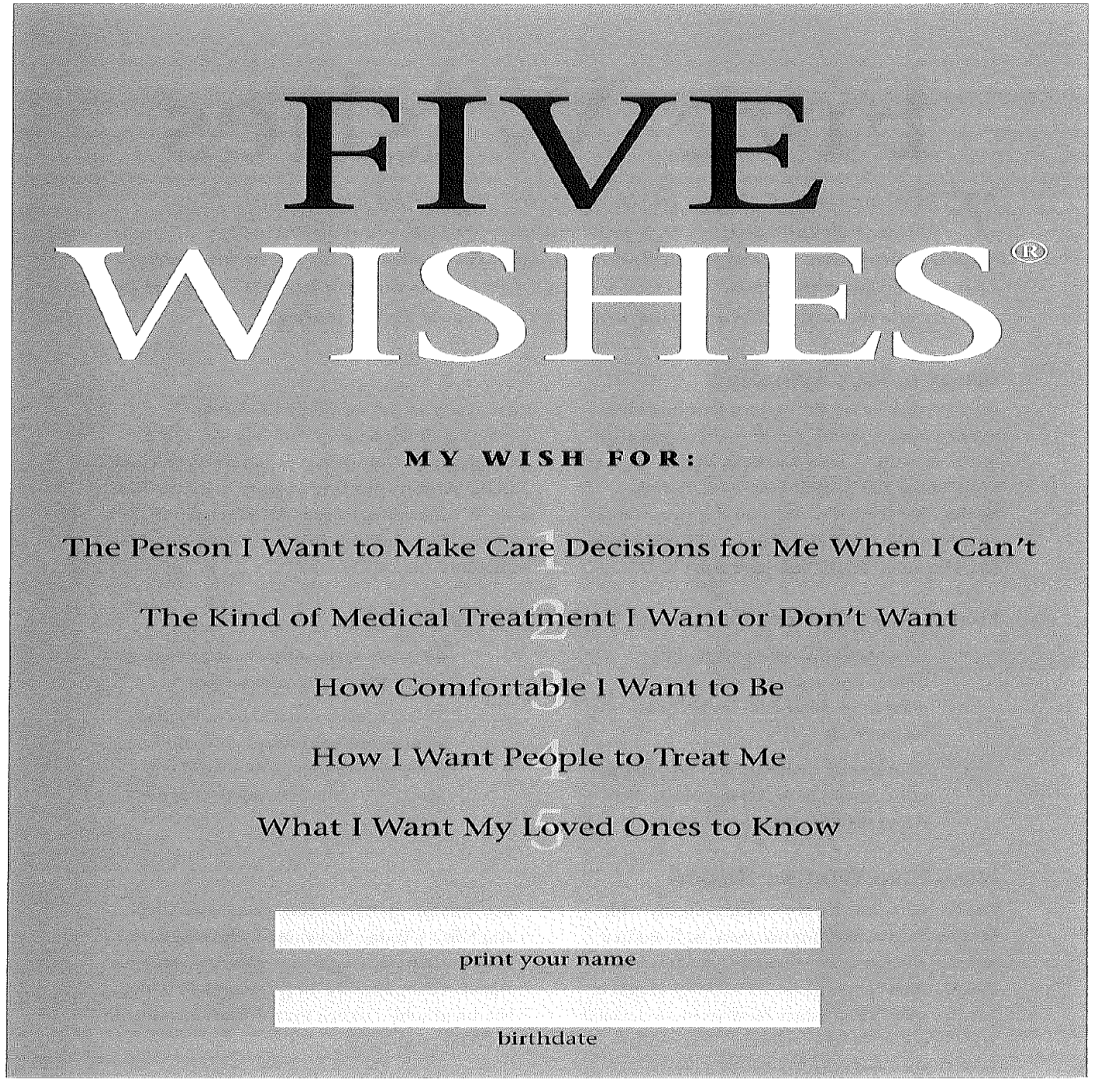


DEATH AND DYING



DEATH AND DYING




FIVE
WISHES®
MY WISH FOR:
1 The Person I Want to Make Care Decisions for Me When I Can't
2 The Kind of Medical Treatment I Want or Don't Want
3 How Comfortable I Want to Be
4 How I Want People to Treat Me
5 What I Want My Loved Ones to Know
print your name
birthdate

THE CONVERSATION PROJECT

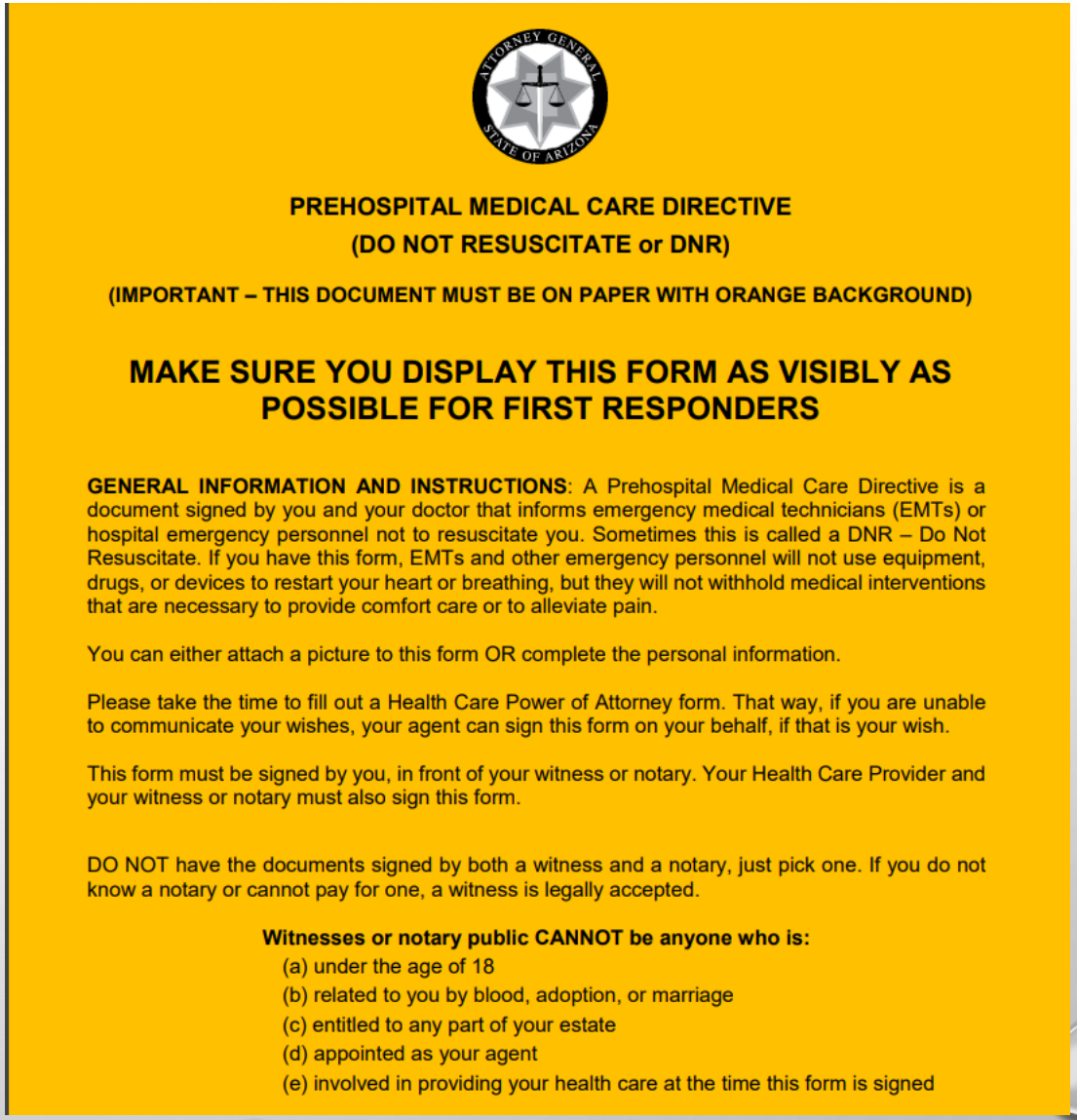
Your Conversation Starter Kit

When it comes to end-of-life care, talking matters.

THE FORMS

ARIZONA PREHOSPITAL MEDICAL CARE DIRECTIVE "THE ORANGE FORM"

- IF YOU DO NOT WANT TO BE RESUSCITATED BY FIRST RESPONDERS
- IF YOU STOP BREATHING OR YOUR HEART STOPS BEATING, THEY ARE NOT TO:
  - START CPR
  - USE EQUIPMENT, DRUGS OR DEVICES TO RESTART YOUR HEART OR BREATHING
- SIGNED BY:
  - PATIENT/LEGALLY AUTHORIZED REPRESENTATIVE
  - LICENSED HEALTHCARE PROVIDER
  - WITNESS OR NOTARY
- OFFICIAL FORM FOR ARIZONA



PREHOSPITAL MEDICAL CARE DIRECTIVE
(DO NOT RESUSCITATE or DNR)

(IMPORTANT – THIS DOCUMENT MUST BE ON PAPER WITH ORANGE BACKGROUND)

MAKE SURE YOU DISPLAY THIS FORM AS VISIBLY AS POSSIBLE FOR FIRST RESPONDERS

GENERAL INFORMATION AND INSTRUCTIONS: A Prehospital Medical Care Directive is a document signed by you and your doctor that informs emergency medical technicians (EMTs) or hospital emergency personnel not to resuscitate you. Sometimes this is called a DNR – Do Not Resuscitate. If you have this form, EMTs and other emergency personnel will not use equipment, drugs, or devices to restart your heart or breathing, but they will not withhold medical interventions that are necessary to provide comfort care or to alleviate pain.

You can either attach a picture to this form OR complete the personal information.

Please take the time to fill out a Health Care Power of Attorney form. That way, if you are unable to communicate your wishes, your agent can sign this form on your behalf, if that is your wish.

This form must be signed by you, in front of your witness or notary. Your Health Care Provider and your witness or notary must also sign this form.

DO NOT have the documents signed by both a witness and a notary, just pick one. If you do not know a notary or cannot pay for one, a witness is legally accepted.

Witnesses or notary public CANNOT be anyone who is:

(a) under the age of 18
(b) related to you by blood, adoption, or marriage
(c) entitled to any part of your estate
(d) appointed as your agent
(e) involved in providing your health care at the time this form is signed

https://www.azhha.org/tlc_forms#prehospital-medical-directive

PREHOSPITAL MEDICAL CARE DIRECTIVE

In the event of cardiac or respiratory arrest, I refuse any resuscitation measures including cardiac compression, endotracheal intubation and other advanced airway management, artificial ventilation, defibrillation, administration of advanced cardiac life support drugs and related emergency medical procedures.

Patient's Printed Name: _____

Patient's Signature: _____Date: _____

***If I am unable to communicate my wishes, and I have designated a Health Care Power of Attorney, my elected Health Care agent shall sign:**

Health Care Power of Attorney Printed Name: _____

Health Care Power of Attorney Signature: _____

PROVIDE THE FOLLOWING INFORMATION OR ATTACH A RECENT PHOTO:

Date of Birth_____
Sex_____
Race_____
Eye Color _____
Hair Color _____

INFORMATION ABOUT MY DOCTOR AND HOSPICE (if I am in Hospice)**:**

Physician:_____Telephone: _____
Hospice Program, if applicable (name):_____

SIGNATURE OF DOCTOR OR OTHER HEALTH CARE PROVIDER

I have explained this form and its consequences to the signer and obtained assurance that the signer understands that death may result from any refused care listed above.

Signature of a Licensed Health Care Provider: _____
Date: _____

SIGNATURE OF WITNESS OR NOTARY (NOT BOTH)

I was present when this form was signed (or marked). The patient then appeared to be of sound mind and free from duress.

Witness Signature:_____Date: _____

NOTORIAL JURAT:

STATE OF ARIZONA) ss
COUNTY OF _____)

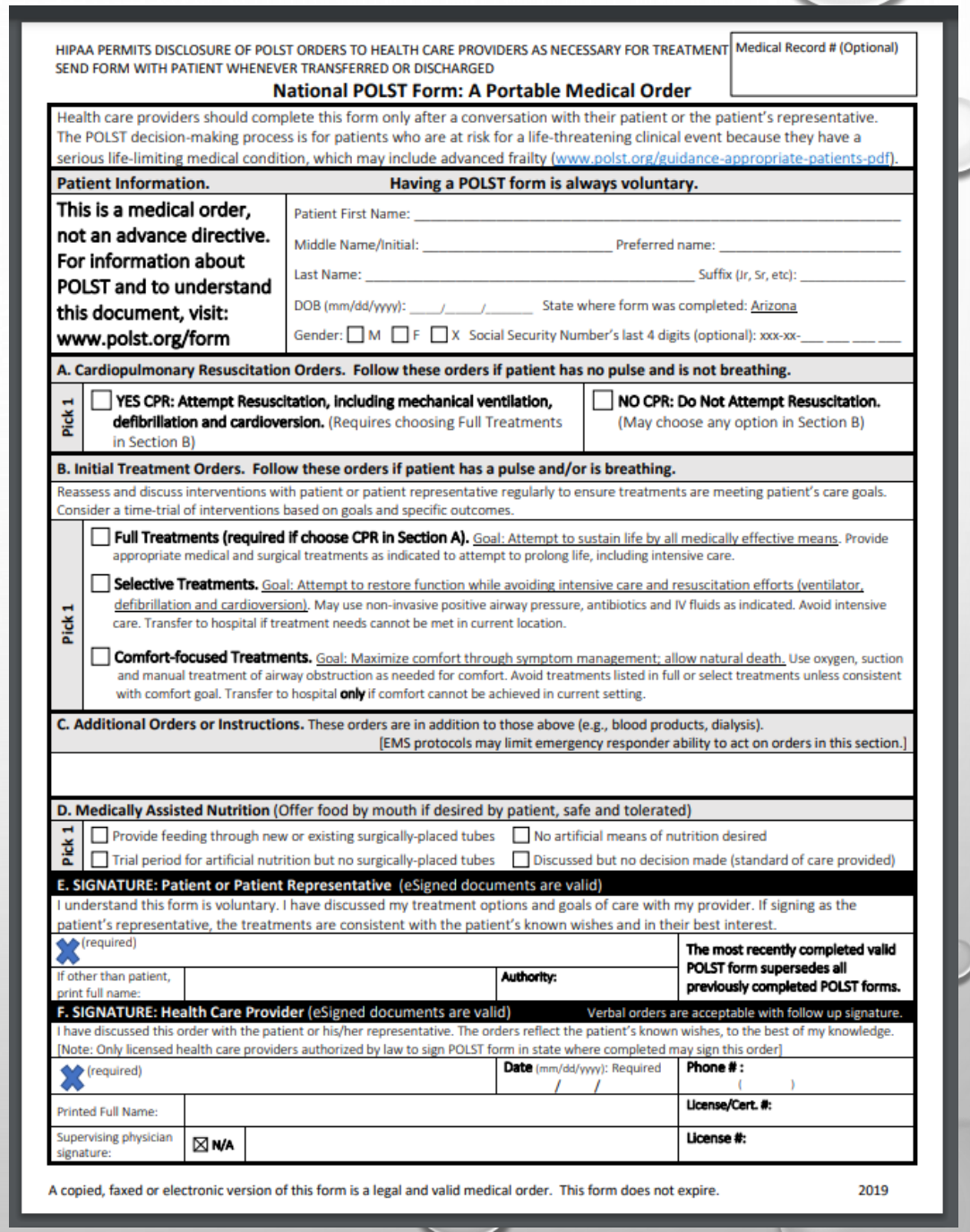
_____
Patient's Name/Health Care Power of Attorney Name

Subscribed and sworn (or affirmed) before me this _____ day of _____, 20 _____

Notary Public Signature: _____My Commission Expires: _____

POLST

- IS INTENDED FOR PERSONS OF ANY AGE FOR WHOM DEATH WITHIN THE NEXT YEAR WOULD NOT BE UNEXPECTED (THE "SURPRISE QUESTION")
  - THIS INCLUDES PATIENTS WITH ADVANCED ILLNESS
  - POLST IS NOT INTENDED FOR PERSONS WITH CHRONIC, STABLE DISABILITY, WHO SHOULD NOT BE MISTAKEN FOR BEING AT END OF LIFE.
- NOT THE OFFICIAL FORM FOR ARIZONA



HIPAA PERMITS DISCLOSURE OF POLST ORDERS TO HEALTH CARE PROVIDERS AS NECESSARY FOR TREATMENT
SEND FORM WITH PATIENT WHENEVER TRANSFERRED OR DISCHARGED

Medical Record # (Optional)

National POLST Form: A Portable Medical Order

Health care providers should complete this form only after a conversation with their patient or the patient's representative. The POLST decision-making process is for patients who are at risk for a life-threatening clinical event because they have a serious life-limiting medical condition, which may include advanced frailty (www.polst.org/guidance-appropriate-patients-pdf).

Patient Information. **Having a POLST form is always voluntary.**

This is a medical order, not an advance directive. For information about POLST and to understand this document, visit: www.polst.org/form

Patient First Name: _____

Middle Name/Initial: _____ Preferred name: _____

Last Name: _____ Suffix (Jr, Sr, etc): _____

DOB (mm/dd/yyyy): ____/____/_____ State where form was completed: Arizona

Gender: ☐ M ☐ F ☐ X Social Security Number's last 4 digits (optional): xxx-xx-____ ____ ____ ____

A. Cardiopulmonary Resuscitation Orders. Follow these orders if patient has no pulse and is not breathing.

Pick 1

☐ **YES CPR: Attempt Resuscitation, including mechanical ventilation, defibrillation and cardioversion.** (Requires choosing Full Treatments in Section B)

☐ **NO CPR: Do Not Attempt Resuscitation.** (May choose any option in Section B)

B. Initial Treatment Orders. Follow these orders if patient has a pulse and/or is breathing.

Reassess and discuss interventions with patient or patient representative regularly to ensure treatments are meeting patient's care goals. Consider a time-trial of interventions based on goals and specific outcomes.

Pick 1

☐ **Full Treatments (required if choose CPR in Section A).** Goal: Attempt to sustain life by all medically effective means. Provide appropriate medical and surgical treatments as indicated to attempt to prolong life, including intensive care.

☐ **Selective Treatments.** Goal: Attempt to restore function while avoiding intensive care and resuscitation efforts (ventilator, defibrillation and cardioversion). May use non-invasive positive airway pressure, antibiotics and IV fluids as indicated. Avoid intensive care. Transfer to hospital if treatment needs cannot be met in current location.

☐ **Comfort-focused Treatments.** Goal: Maximize comfort through symptom management; allow natural death. Use oxygen, suction and manual treatment of airway obstruction as needed for comfort. Avoid treatments listed in full or select treatments unless consistent with comfort goal. Transfer to hospital **only** if comfort cannot be achieved in current setting.

C. Additional Orders or Instructions. These orders are in addition to those above (e.g., blood products, dialysis).
[EMS protocols may limit emergency responder ability to act on orders in this section.]

D. Medically Assisted Nutrition (Offer food by mouth if desired by patient, safe and tolerated)

Pick 1

☐ Provide feeding through new or existing surgically-placed tubes ☐ No artificial means of nutrition desired

☐ Trial period for artificial nutrition but no surgically-placed tubes ☐ Discussed but no decision made (standard of care provided)

E. SIGNATURE: Patient or Patient Representative (eSigned documents are valid)

I understand this form is voluntary. I have discussed my treatment options and goals of care with my provider. If signing as the patient's representative, the treatments are consistent with the patient's known wishes and in their best interest.

✖ (required)

If other than patient, print full name: **Authority:**

The most recently completed valid POLST form supersedes all previously completed POLST forms.

F. SIGNATURE: Health Care Provider (eSigned documents are valid) Verbal orders are acceptable with follow up signature.

I have discussed this order with the patient or his/her representative. The orders reflect the patient's known wishes, to the best of my knowledge. [Note: Only licensed health care providers authorized by law to sign POLST form in state where completed may sign this order]

✖ (required) **Date** (mm/dd/yyyy): Required ___/___/_____ **Phone #:** (___)

Printed Full Name: **License/Cert. #:**

Supervising physician signature: ☒ N/A **License #:**

A copied, faxed or electronic version of this form is a legal and valid medical order. This form does not expire. 2019

SOUNDS GREAT, BUT WHY DO I CARE?

THE EFFECTS OF ADVANCE CARE PLANNING IN PEDIATRICS

- MEDICAL TREATMENT IN THE ICU SETTING MAY BE MODIFIED AFTER IMPLEMENTATION OF AN ADVANCE DIRECTIVE
- MAY PROMOTE HOME DEATHS FOR CHILDREN
- TRIGGERS POSITIVE EMOTIONAL EXPERIENCES FOR ADOLESCENT PATIENTS AND THEIR SURROGATES
- REDUCED PARENTS' DIFFICULTIES IN MAKING TREATMENT DECISIONS
- IMPROVED SURROGATES' UNDERSTANDING OF THE PATIENT'S TREATMENT PREFERENCES
- DID NOT CAUSE DEPRESSION OR ANXIETY IN PATIENTS, DID NOT CHANGE THEIR QUALITY OF LIFE

PROFESSIONAL GUIDELINES FOR ADVANCED CARE PLANNING

- AMERICAN ACADEMY OF PEDIATRICS AND THE INSTITUTE OF MEDICINE
  - BEGIN AT DIAGNOSIS
  - BE SHARED
  - INDIVIDUALIZED
  - ROUTINE AND STRUCTURES

American Academy of Pediatrics, Committee On Bioethics And Committee On Hospital Care. (2000). Palliative care for children. Pediatrics 106, 315-357.
Institute of Medicine. (2002). When children die: improving palliative care and end-of-life care for children and their families. (eds). Field MJ, Behrman RE. Washington, DC, National Academy Press.

“**HOW PEOPLE DIE** REMAINS IN THE MEMORIES OF THOSE WHO LIVE ON.”

- CICELY SAUNDERS

“THAT TOOK A LONG TIME AND WASN’T EFFICIENT, BUT IT FELT LIKE CARING.”

- 3RD YEAR MEDICAL STUDENT

BILLIE WINEGARD, MD MPH

BWINEGARD1@PHOENIXCHILDRENS.COM

O: (602) 933-7255

THANK YOU!