Pediatric Palliative Care and Communicating with Grieving Families

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Objectives

- Participants will be able to define Pediatric Palliative Care
- Participants will be able to describe how to have *goals of care* and *quality of life* discussions and the SPIKES method for breaking bad news
- Participants will be able to identify three types of communication and report an increase in comfort in communicating with grieving families

WHO Definition of Palliative Care

"Palliative care is an approach that improves the quality of life of patients and their families who are facing problems associated with life-threatening illness. It prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual."

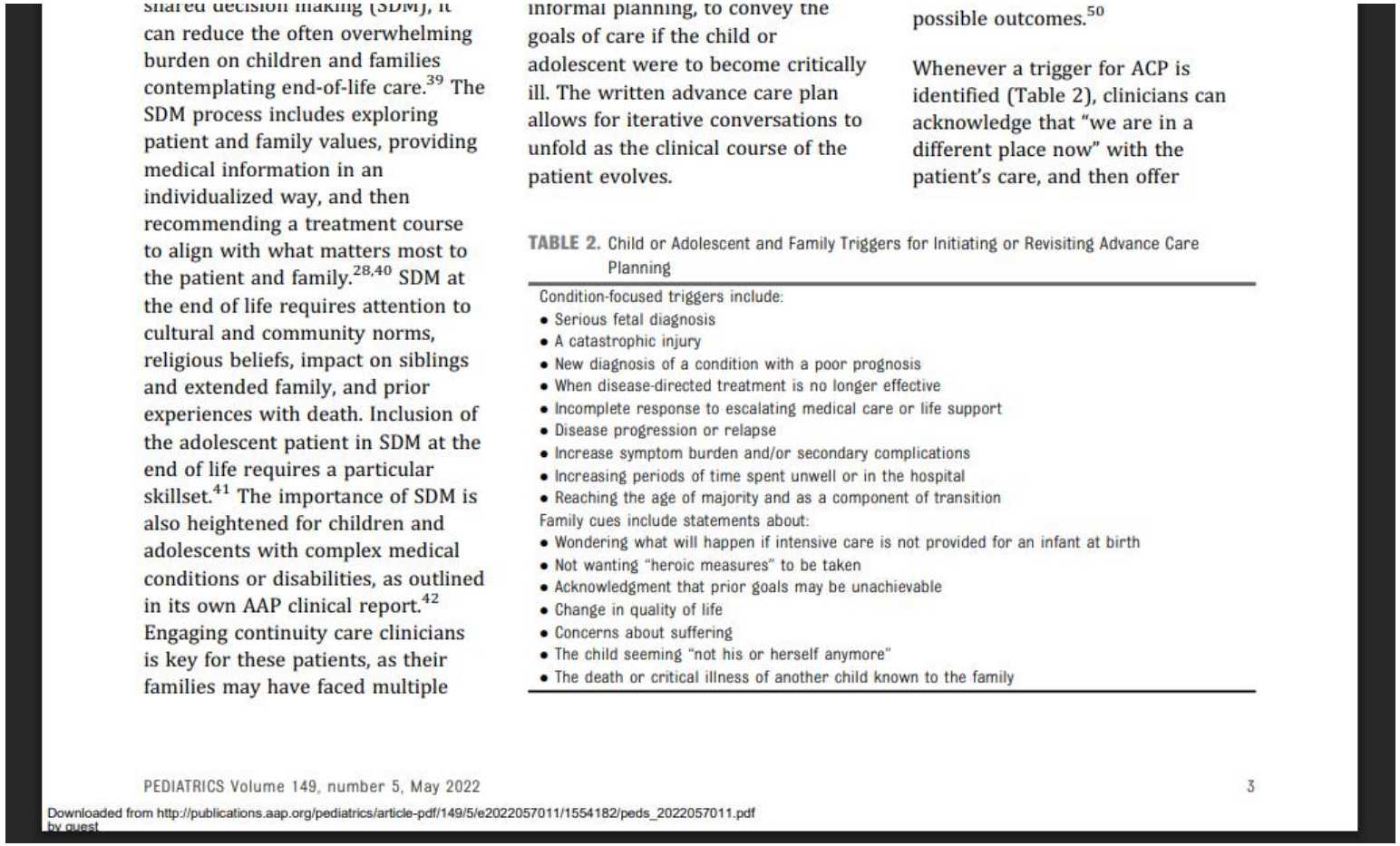
(World Health Organization, 2020)

Why Consult Palliative Care

"The AAP recommends specialty PPC 'should be consulted for advanced clinical treatments and complicated decision making and for social and spiritual needs beyond what the primary care team can provide.' Palliative care teams can help to optimize complex pain and symptom care, quality of life, appraisal of prognosis, conversations about shifting goals, and family and care team support."

(Linebarger, Johnson and Boss, 2022)

When to Consult Palliative Care



shared decision making (SDM), it can reduce the often overwhelming burden on children and families contemplating end-of-life care.[39] The SDM process includes exploring patient and family values, providing medical information in an individualized way, and then recommending a treatment course to align with what matters most to the patient and family.[28,40] SDM at the end of life requires attention to cultural and community norms, religious beliefs, impact on siblings and extended family, and prior experiences with death. Inclusion of the adolescent patient in SDM at the end of life requires a particular skillset.[41] The importance of SDM is also heightened for children and adolescents with complex medical conditions or disabilities, as outlined in its own AAP clinical report.[42] Engaging continuity care clinicians is key for these patients, as their families may have faced multiple

informal planning, to convey the goals of care if the child or adolescent were to become critically ill. The written advance care plan allows for iterative conversations to unfold as the clinical course of the patient evolves.

possible outcomes.[50]

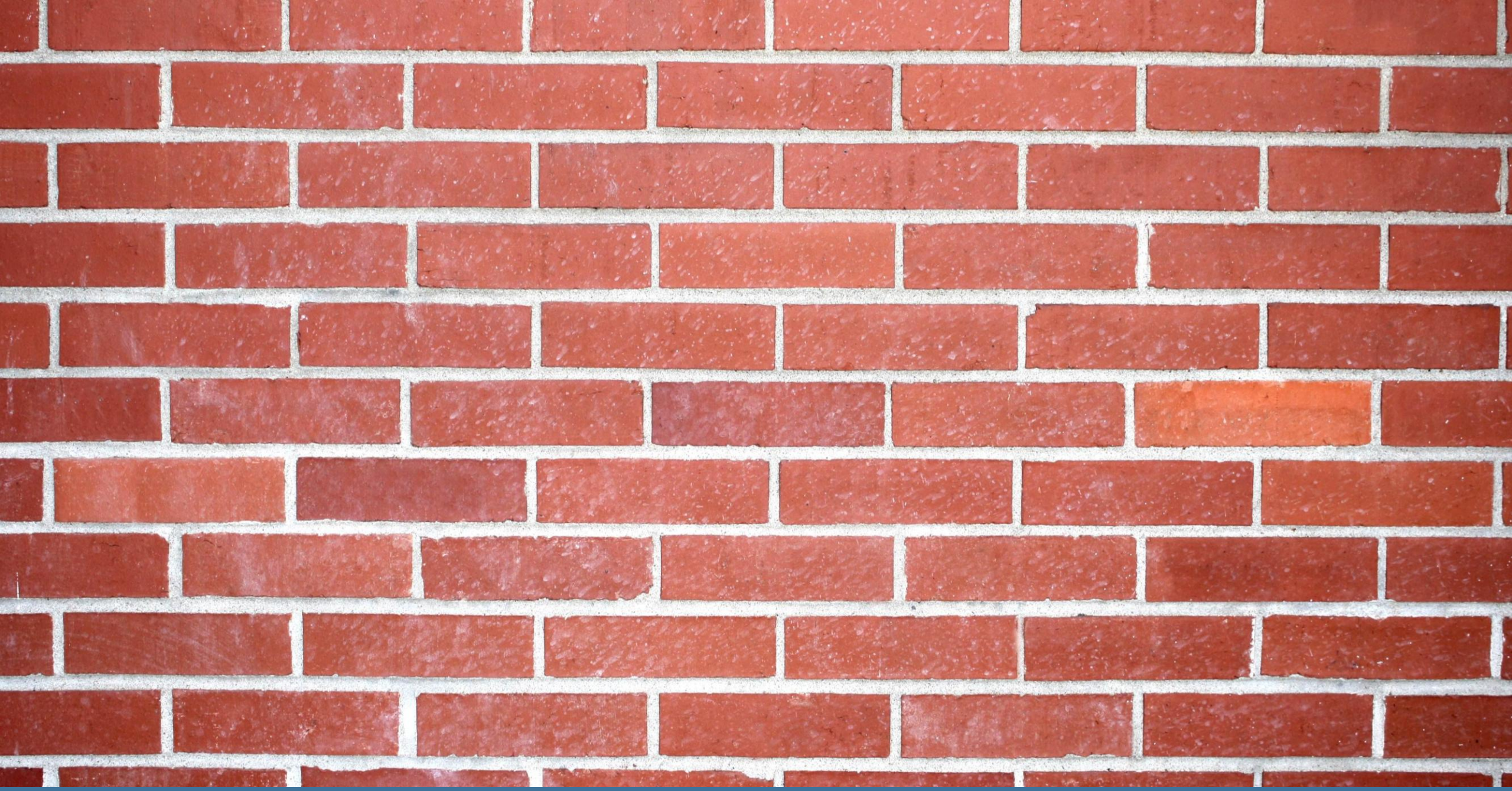
Whenever a trigger for ACP is identified (Table 2), clinicians can acknowledge that "we are in a different place now" with the patient's care, and then offer

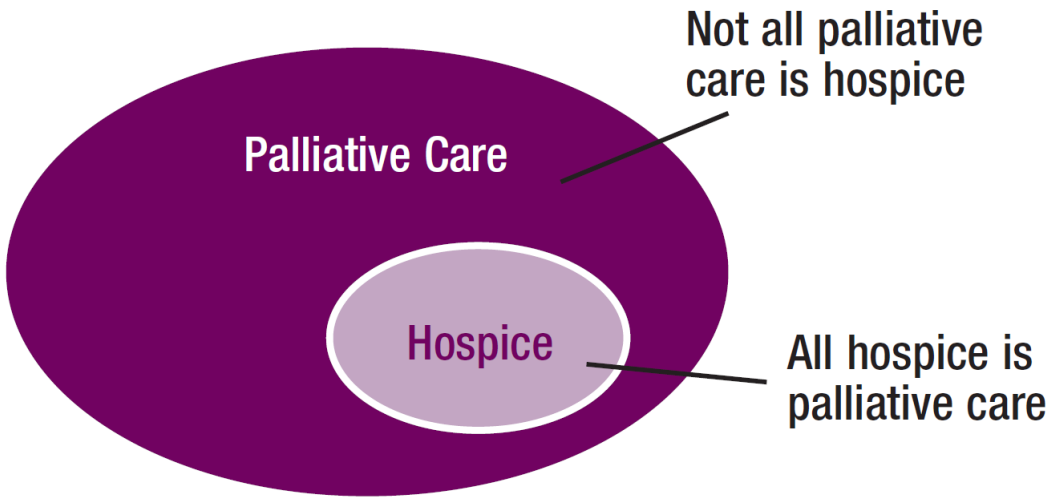
TABLE 2. Child or Adolescent and Family Triggers for Initiating or Revisiting Advance Care Planning

Condition-focused triggers include:
• Serious fetal diagnosis
• A catastrophic injury
• New diagnosis of a condition with a poor prognosis
• When disease-directed treatment is no longer effective
• Incomplete response to escalating medical care or life support
• Disease progression or relapse
• Increase symptom burden and/or secondary complications
• Increasing periods of time spent unwell or in the hospital
• Reaching the age of majority and as a component of transition
Family cues include statements about:
• Wondering what will happen if intensive care is not provided for an infant at birth
• Not wanting "heroic measures" to be taken
• Acknowledgment that prior goals may be unachievable
• Change in quality of life
• Concerns about suffering
• The child seeming "not his or herself anymore"
• The death or critical illness of another child known to the family

AAP Guidance for Pediatric End-of-Life Care

(Linebarger, Johnson and Boss, 2022)





What is Hospice?

Medical, psychosocial, and spiritual care.

Focus on comfort and quality of life.

Eligibility Criteria:

- Terminal illness with a prognosis of 6 months or less to live if the illness runs its normal course.
- Election of hospice benefit, including waiving further disease-directed treatment.

Bereavement support.

Goals of Care & Quality of Life Discussions

In best case scenarios, initial discussions center around rapport building and involve more listening than talking.

Ask if it is a good time to talk, are there others that need to be present, sit

Identify where the family is now

- What has the medical team told you about what is going on with your child?
- What are the next steps for your child?
- What questions do you have?
- What are you most concerned about?

Identify sources of strength/support for the family

- Where does your strength come from?
- Who do you lean on for support as you make these decisions?

Identify hopes/goals

- What are you most hopeful for right now?
- I carry that hope alongside of you but, I am worried. If the worst-case scenario were to present, are there other things you are hoping for?

Identified what defines Quality of Life

- What does a good day look like?

Breaking Bad News: SPIKES

- Setting the Environment
- Perception
- Invitation
- Knowledge
- Emotions and Empathy
- Summary/Strategy

(Rosenzweig, 2012)

Breaking Bad News: SPIKES

Setting the Environment

Perception
- *Tell me what you understand about your child's illness.*

Invitation
- *Would it be okay if we talk about some changes/serious concerns regarding your child's care?*
- *We have the results of ___. Can we talk about them?*

Knowledge
- Warning Shot
  - *The situation is more serious than we originally hoped…*
  - *Unfortunately, I have some bad news to share with you…*
  - *Things are not going in the direction we had hoped…*
- Simply and directly deliver the new information that needs to be shared and potential pathways forward / next steps / decisions to me made

Emotions and Empathy
- Appropriate and kind response (more on this to come)

Summary/Strategy
- Summarize the new information and where things are in the present
- Give space for hope
- Establish that the family has a clear understanding of the pathways forward / next steps / decisions to be made

Example:

In summary, we now know {new diagnosis/lab/result of intervention/etc}. While we continue to join you in your hope, we will be closely monitoring {vitals/labs/intervention/etc} over the next {specify time} to determine how your child is responding to the interventions. Signs the situation is improving would be { } and signs that the situation is getting worse would be { }. I will plan to reconvene with you {specify time…in an hour, later this afternoon, tomorrow} to reevaluate. I am hopeful we might see improvement, but I am worried we may not in which case, we will need to have a hard conversation about our next steps.

Remember…

Just because it isn't what I would do, doesn't mean it isn't right → least amount of regrets

Normalize what can be normalize

- Other families I've met in similar situations have shared…
- I don't know if it something you are interested in but, sometimes families ask about XYZ. I want you know those are available if you would like to talk more about them

"Your child <u>needs</u>…"

"Withdrawing Care"

"Giving up" → honoring what the child is telling us

Decision Making

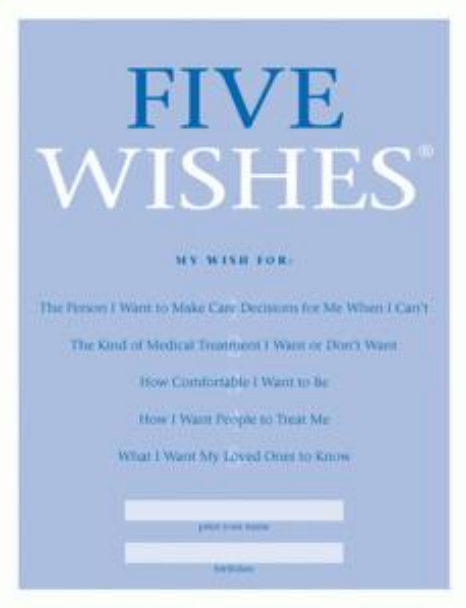
Fully Informed

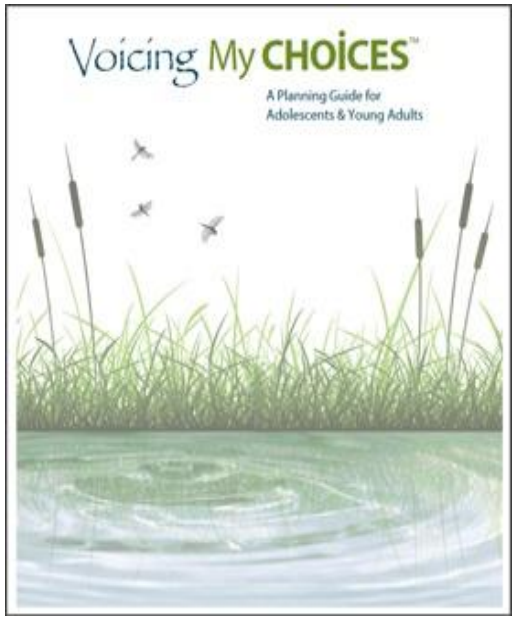
- Understanding of potential pathways
  - Decision making not just for today but what does it mean for the future
  - *If we follow this pathway, we could anticipate….*
- Benefit versus burden (risk)

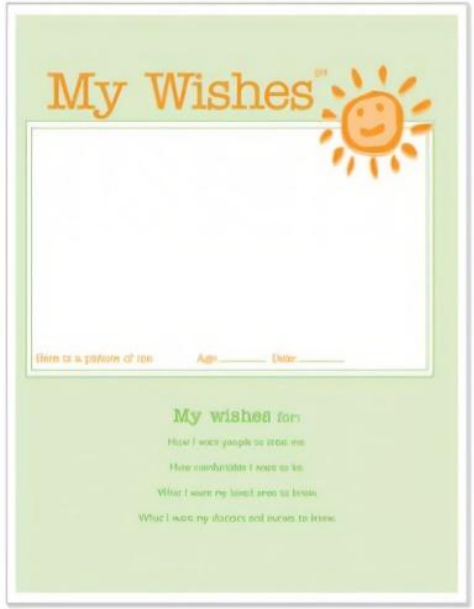
Shared Decision Making

- Medical Recommendation
- Plan of care most consistent with goals of care

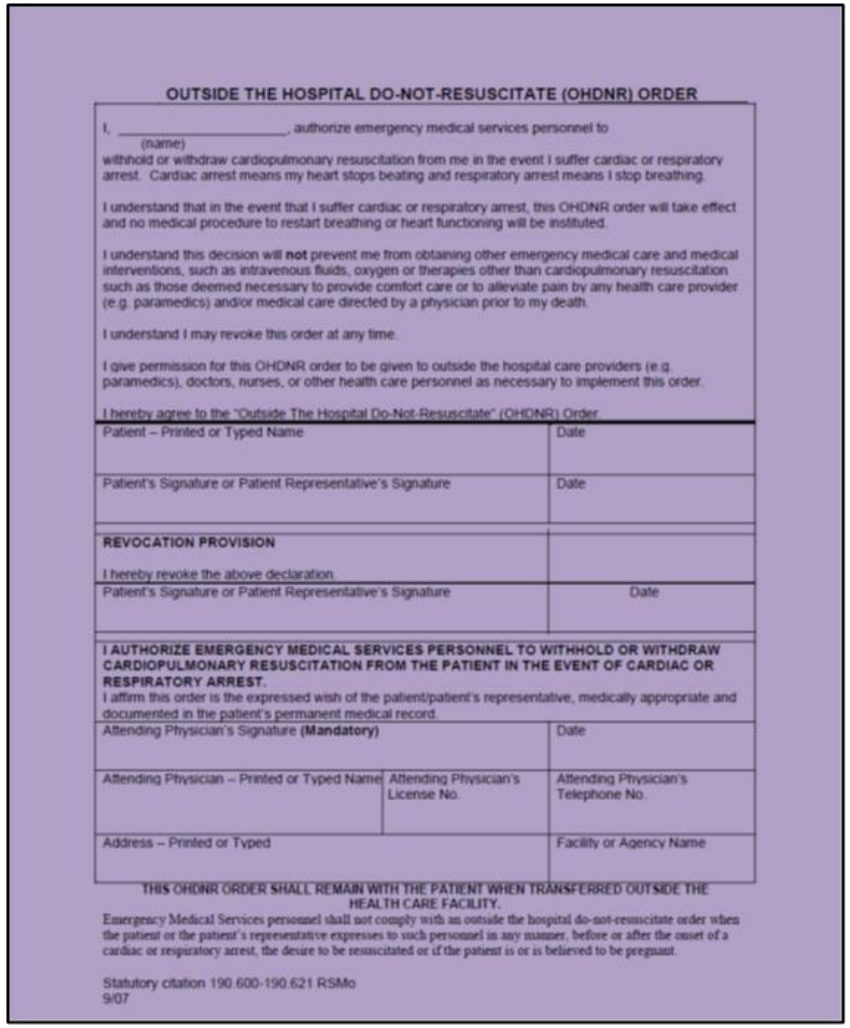
Advance Care Planning Tools







(Aging With Dignity, 2025)



OUTSIDE THE HOSPITAL DO-NOT-RESUSCITATE (OHDNR) ORDER

I, _____, authorize emergency medical services personnel to
(name)
withhold or withdraw cardiopulmonary resuscitation from me in the event I suffer cardiac or respiratory arrest. Cardiac arrest means my heart stops beating and respiratory arrest means I stop breathing.

I understand that in the event that I suffer cardiac or respiratory arrest, this OHDNR order will take effect and no medical procedure to restart breathing or heart functioning will be instituted.

I understand this decision will **not** prevent me from obtaining other emergency medical care and medical interventions, such as intravenous fluids, oxygen or therapies other than cardiopulmonary resuscitation such as those deemed necessary to provide comfort care or to alleviate pain by any health care provider (e.g. paramedics) and/or medical care directed by a physician prior to my death.

I understand I may revoke this order at any time.

I give permission for this OHDNR order to be given to outside the hospital care providers (e.g. paramedics), doctors, nurses, or other health care personnel as necessary to implement this order.

I hereby agree to the "Outside The Hospital Do-Not-Resuscitate" (OHDNR) Order.

Patient – Printed or Typed Name		Date
Patient's Signature or Patient Representative's Signature		Date

REVOCATION PROVISION

I hereby revoke the above declaration.

Patient's Signature or Patient Representative's Signature		Date

I AUTHORIZE EMERGENCY MEDICAL SERVICES PERSONNEL TO WITHHOLD OR WITHDRAW CARDIOPULMONARY RESUSCITATION FROM THE PATIENT IN THE EVENT OF CARDIAC OR RESPIRATORY ARREST.
I affirm this order is the expressed wish of the patient/patient's representative, medically appropriate and documented in the patient's permanent medical record.

Attending Physician's Signature **(Mandatory)**		Date
Attending Physician – Printed or Typed Name	Attending Physician's License No.	Attending Physician's Telephone No.
Address – Printed or Typed		Facility or Agency Name

THIS OHDNR ORDER SHALL REMAIN WITH THE PATIENT WHEN TRANSFERRED OUTSIDE THE HEALTH CARE FACILITY.

Emergency Medical Services personnel shall not comply with an outside the hospital do-not-resuscitate order when the patient or the patient's representative expresses to such personnel in any manner, before or after the onset of a cardiac or respiratory arrest, the desire to be resuscitated or if the patient is or is believed to be pregnant.

Statutory citation 190.600-190.621 RSMo
9/07

Out of Hospital Do Not Resuscitate (OHDNR)

Empathetic Communication

- Avoidance
- Moralizing Statements
- Supportive Statements

Avoidance

Often misperceived

Can make families feel as though

- they or their loved one does not matter
- the loss is diminished
- the situation is insignificant if not talked about.

Moralizing Statements

Said more for (or to the benefit of) the person commenting rather than for the grieving

Can come across as non-supportive, an attempt to “fix” or make the grieving “feel better”

Examples:

- I know how you feel
- It is for the best
- It is going to be okay
- Silver lining statements; at least…
  - She is not suffering anymore
  - The death was quick
  - He had a full life
  - You are young and can have more children

Supportive Statements

Acknowledges the grief without trying to fix it

Opens the door for discussion but also allows for listening

Support aligning with the patient while recognizing the reality of the circumstance

Examples:

- I am not sure what to say…(I want to know that I see you/I am here)
- I wish … (the scans would have been better/the chemo was effective/we were able to have a different conversation)
- I can only imagine what you are experiencing...

Questions

References

Aging with Dignity. (2025). Five Wishes. https://store.fivewishes.org/ShopLocal/en/start-page

Jennifer S. Linebarger, Victoria Johnson, Renee D. Boss, THE SECTION ON HOSPICE AND PALLIATIVE MEDICINE; Guidance for Pediatric End-of-Life `Care. *Pediatrics* May 2022; 149 (5): e2022057011. 10.1542/peds.2022-057011

Rosenzweig, Margaret Quinn PhD, FNP-BC, AOCNP. Breaking bad news: A guide for effective and empathetic communication. The Nurse Practitioner 37(2):p 1-4, February 12, 2012. | DOI: 10.1097/01.NPR.0000408626.24599.9e

World Health Organization. (2020, August 5). *Palliative Care*. World Health Organization; World Health Organization. https://www.who.int/news-room/fact-sheets/detail/palliative-care

Resources:

Resolve Through Sharing: https://www.resolvethroughsharing.org/

VITAL talk: https://www.vitaltalk.org/