End-of-Life Care for Children

Pediatric Project ECHO

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February 11, 2026

Disclosures

- Financial/Conflicts of Interest
  - None
- Medications
  - Some medications discussed are ‘off-label’
- Will not be discussing ACP or symptoms already covered in other CC sessions
- Will not discuss medication doses

Acknowledgement

- Dr. Megan Doherty and Dr. Stephanie Van Zanten for use of some of their slides

Objectives

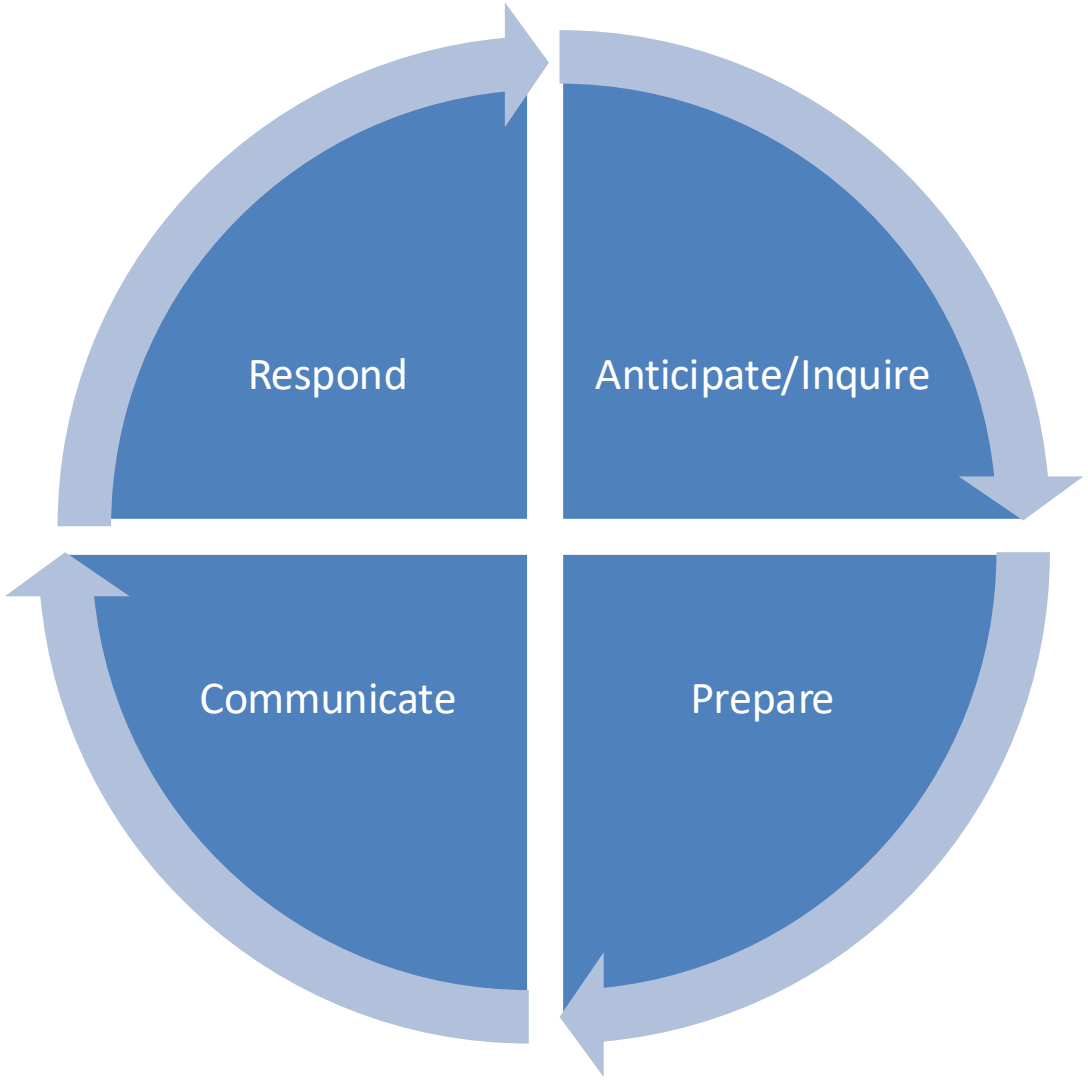
To identify and communicate when end of life is approaching

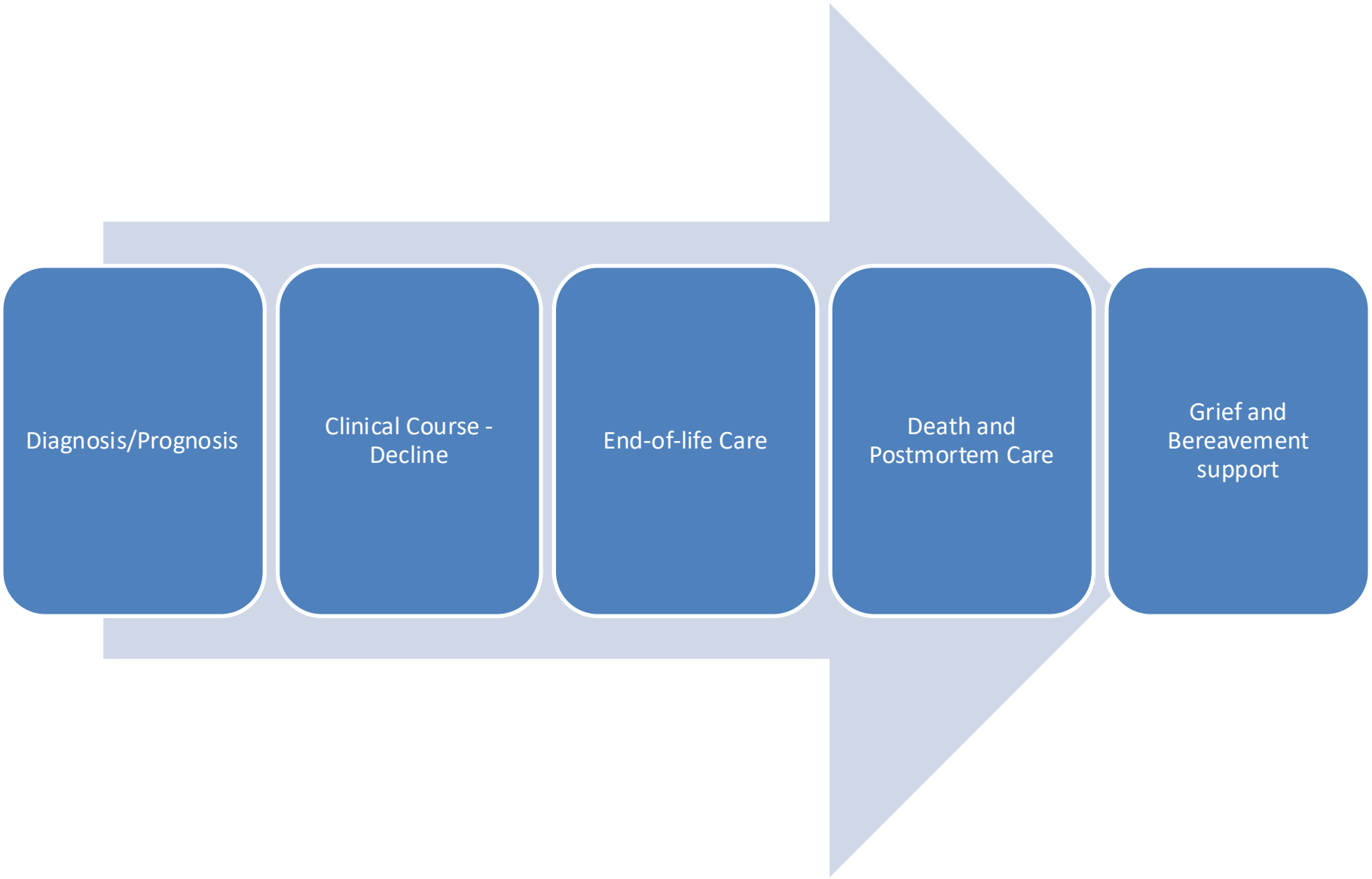
To anticipate and prepare for care at end-of-life including location of care

To develop an approach to pain and symptom management

To develop an approach to emergencies at end of life

The “Process” in Palliative Care



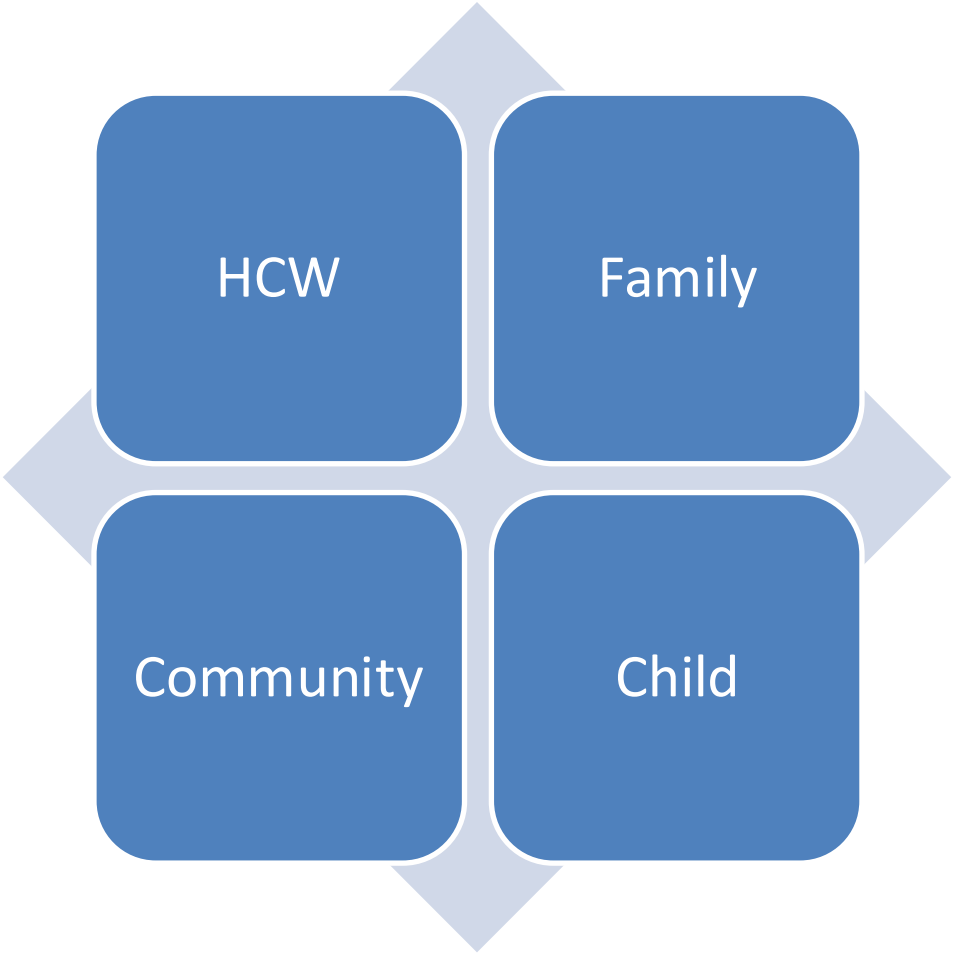

Diagnosis/Prognosis
Clinical Course - Decline
End-of-life Care
Death and Postmortem Care
Grief and Bereavement support

Physical Aspects
Legal and Ethical Aspects
Spiritual/Cultural Aspects
Palliative Care
Wishes and Hopes
Social/family Aspects
Psychological aspects

Death of a Child

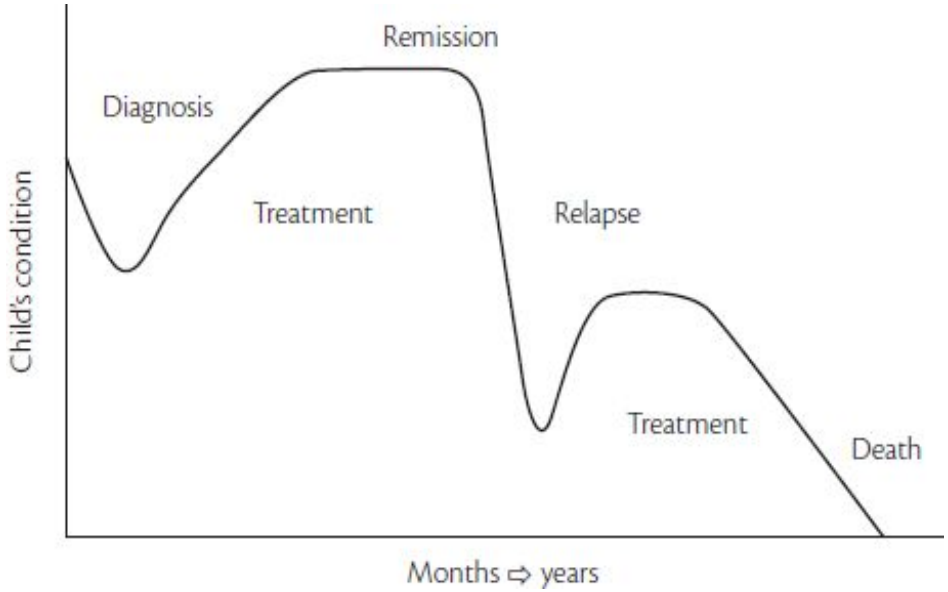
- Implications for parents (and other family members)
- Implications for siblings
- Implications for health care system (and HCW)
- Implications for the society and culture

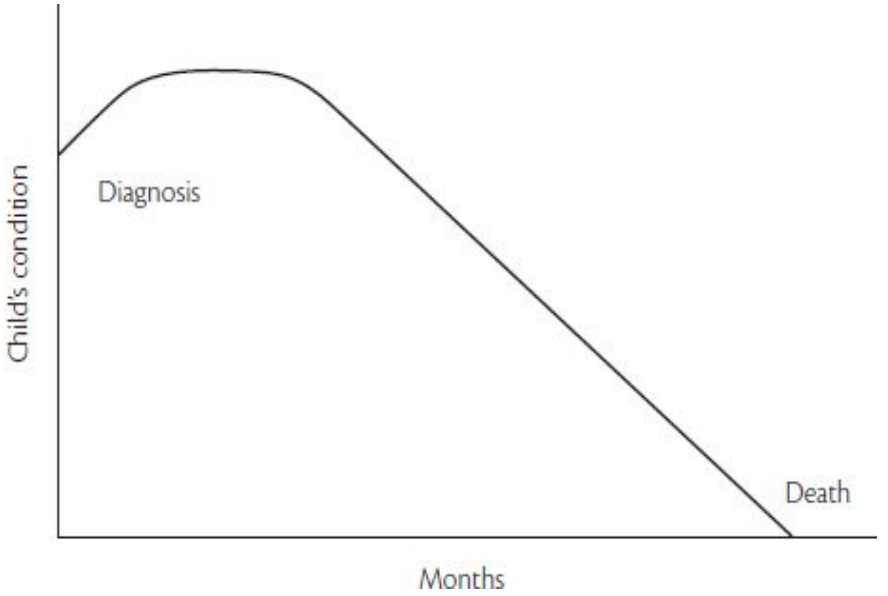
Team!

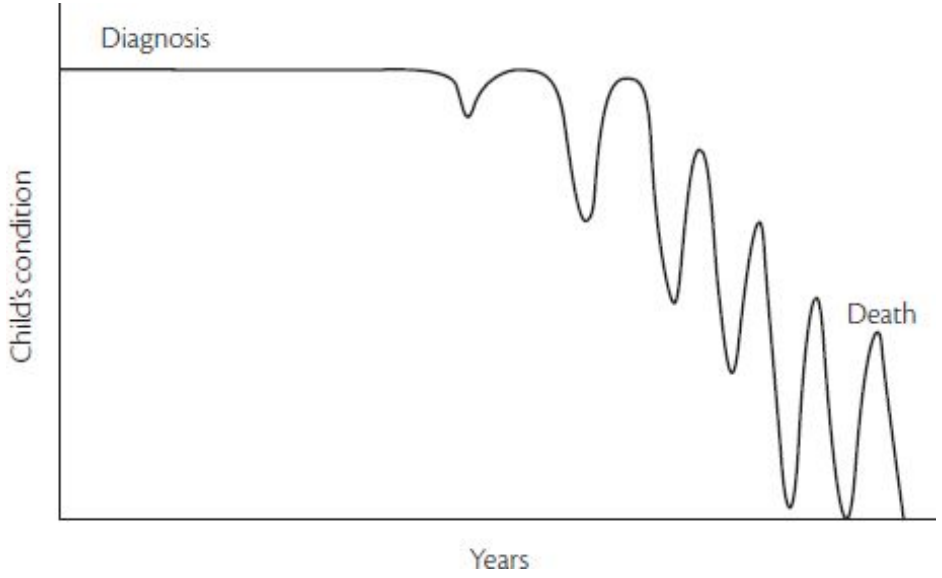


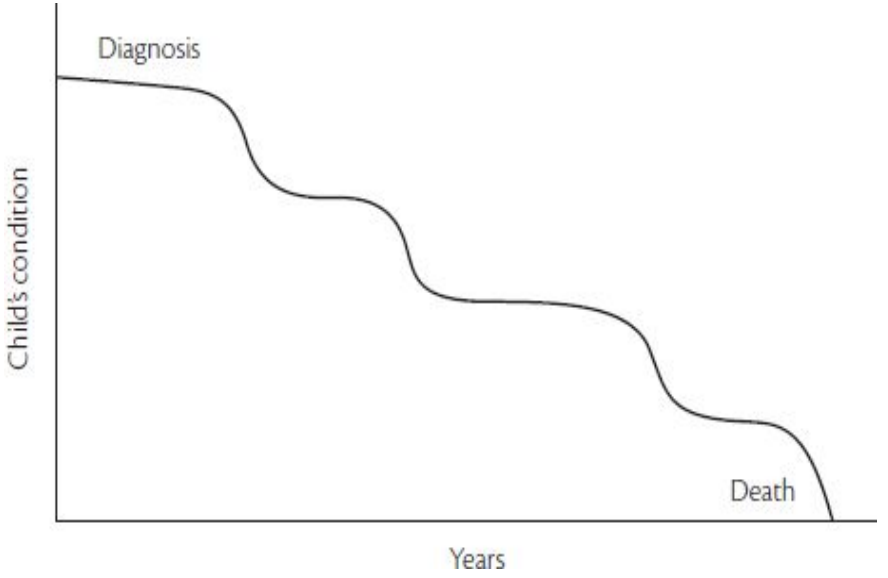
The End-of-Life Period

- The period of time when the child has no realistic hope for cure
- Timing varies
- Dependent on the disease and circumstances
- Trajectory of decline and death









Oxford Textbook of Palliative Care for Children

Anticipate

- Anticipate a timeline
- Anticipate symptoms and signs
- Anticipate supports
- Anticipate challenges

Prepare

- Have a sense of resources and tools at disposal
- Know and prepare your team
- Plan how and when to communicate

Communicate

- Communicate timeline
- Communicate signs and symptoms
- Communicate supports
- Communicate challenges

Communication re Prognosis

- Clear, compassionate communication
- Involve key staff members and family
- Be direct
- Be honest (Don’t be weird)
- Be inquisitive (Ask why?)
- Uncertainty
- Cure no longer possible
  - Quality > quantity of life

Question - Poll

- Most parents who talked about death with their child who had a life-limiting illness regretted it.
  - True
  - False

Communication with the Child

- Dependent on age, developmental stage, family communication style, culture
- Evidence suggests no parent who talked to their child regretted it but some (27%) who did not, wish they had (Kriecbergs et al. 2004)
- Encourage open communication but do not force
- Be truthful and direct at appropriate developmental level
- Allows for legacy building, memory making

Involvement of Siblings

- Encourage parents to ask siblings what they understand
- Encourage involvement in EOL care
- Prepare parents for divergent reactions
- Use your allied health resources

Physical Aspects
Legal and Ethical Aspects
Spiritual/Cultural Aspects
Palliative Care
Wishes and Hopes
Social/family Aspects
Psychological aspects

Wishes and Hopes

Goals of care based on values

Important events/celebrations/milestones

Memory and legacy

Location of care

Location of care

- Majority of US children die in hospital (56%) and >85% of those die in an ICU (Field et al. 2003; Feudtner et al 2007)
- More children die in hospital than is desired by parents and families
    - Evidence shows children with underlying complex chronic conditions are increasingly dying at home (Feudtner et al 2007)

Oxford Textbook of Palliative Care for Children

Locations of care

- Hospital
- Home
- Hospice
- Other

- No clear medical contraindication to care at a desired location as long as limits to what can be provided is clear

EOL care at home

- Is it possible?
- Written care plan with contingencies
- Must have 24-hour coverage to HCW
- Medications and Equipment
- Legal implications (e.g. provincial laws and regulations)

Social/Family Aspects

- Support for parents and siblings
- Support for additional family members
- Identify supports in community
- Financial implications (job, funds, funeral costs etc.)

Spiritual/Cultural Aspects

- FICA
- F: Faith or Beliefs
- I: Importance and Influence of beliefs
- C: Community
- A: Address Care Issues

FICA

- Do you consider yourself spiritual or religious? Both? Neither? What things do you believe in that give meaning to your life?
- How have your beliefs influenced in your behavior during this illness?
- Are you part of a spiritual or religious community?
- Are there ways in which we can support you in your faith/spirituality/religion? Would you like to talk to someone about these matters? Would like us to arrange for a member of your faith community to come and see you?

Psychological Impacts

- Depression/Anxiety
- Grief and Bereavement
- Trauma, PTSD and Stress Response
- Attachment and Detachment
- Transference and Counter-Transference

Legal and Ethical Aspects

- Beneficence and Non-maleficence
- Justice and Equity
- MAID
- Code Status
- Hastening death
- Death Certificate
- Autopsy
- Organ Donation

Physical Aspects

- Decline
- Dying Process
- Declaration of Death

Decline

- Request for Further Treatment?
- Evidence suggest that children who receive cancer-directed therapy during EOL period suffered from a greater number of symptoms than those who did not receive treatment (Heath et al. 2010)

Decline

- Symptom management is key!
- Constipation, pain, anemia, bedsores, etc
- Builds trust and support system
- Provides opportunities to understand the multidimensional components of care delivery and goals

Decline

- Changes in energy level and appetite
- Weight loss
- Changes in ADL

Decline

- Timeline is variable
- Disease dependent
- Treatment dependent
- Location dependent (no evidence to support this claim)

Dying Process

- Characterized by
  - Decreased oral intake
  - Diminished awareness of thirst or hunger
  - Diminished consciousness level
  - Natural progression towards coma and death

Dying process

- Neonates and young children do not always present this way
- Can be a sudden decline
- Continue to be awake till the very end
- Continue to be interested in food

The dying process

- Prognostication is imprecise
- The shorter the time left, the more accurate estimates tend to be
- Ask permission if would be helpful to know what to expect

EPEC Pediatrics
Textbook of Interdisciplinary Pediatric Palliative Care
Oxford Textbook of Palliative Care for Children

Signs of Impending Death

- Profound progressive weakness
- Sleeping much of the time
- Little interest in food and drink
- Difficulty swallowing
- Oliguria or anuria
- Dropping BP
- Changes in respiratory rate and pattern, may include Cheyne-Stokes breathing
- Noisy breathing, airway secretions
- Mottling and cooling of the skin
- Mental status changes, such as delirium, restlessness, agitation and coma

- *these signs may not be present in the case of brain death and child is on a ventilator (e.g. MVC)

Textbook of Interdisciplinary Pediatric Palliative Care who adapted from Bicanovsky L. Comfort Care: symptom Control in the Dying

Interventions when Death is Approaching

- Consider discontinuing things that are no longer helping the child
- When death imminent do not need to aggressively treat same symptoms as previously
  - Constipation
  - Bedsores
  - Anemia

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If you have ever been involved in a case where ANH has been discontinued, please share in the chat how this made you feel as a HCP.

Artificial Nutrition and Hydration

- If able and wish to eat and drink this should be offered
- ANH are medical interventions not a comfort measure
- Anorexia common at EOL
- Can be withdrawn “when such measures only prolong and add morbidity to the process of dying.” (AAP)
- Clear consensus that little if any discomfort when ANH withdrawn
- Be mindful of regulations if practicing in certain States in US

AAP – Forgoing Medically provided nutrition and hydration in Children, 2009
Textbook of Interdisciplinary Pediatric Palliative Care

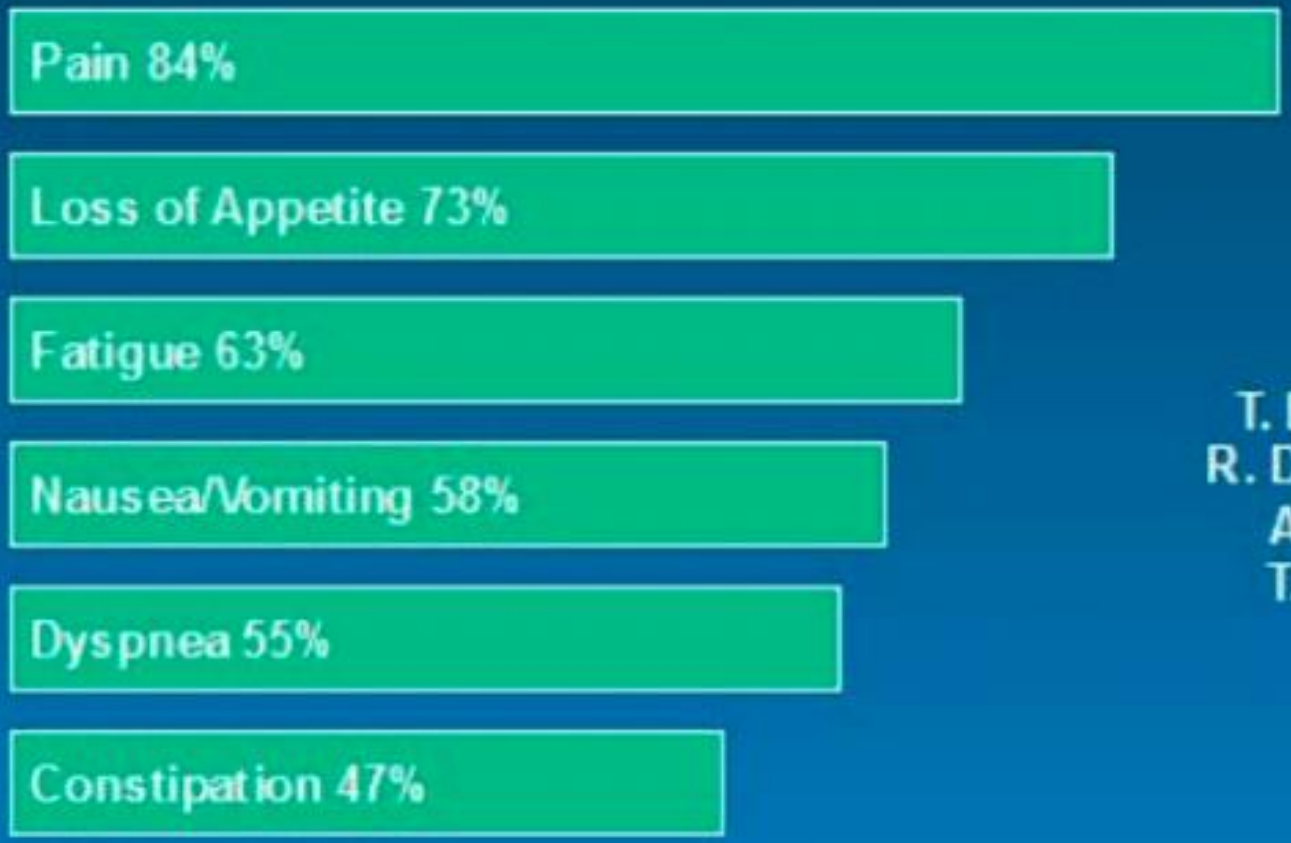
Artificial Nutrition and Hydration

- Contribution to symptom burden
- Natural death

Symptom Management during EOL Care

- Pain
- Dyspnea
- Seizures
- Delirium
- Fatigue
- Nausea/Vomiting
- Fever
- Constipation
- Emergencies

Symptoms during the last week of life in pediatric patients



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T. Dangel (Poland)
R. Drake (Australia)
A. Goldman (UK)
T. Hongo (Japan)
J. Wolfe (USA)

Symptom Management during EOL Care

- Do not forget the Non-pharmacological interventions
- Music therapy, Rec Therapy, Play Therapy
- Massage
- Fan, changes in temperature/humidity
- Being indoor/outdoor
- Photographs, family time

Pharmacological Management

- May involve intensification of current care
  - Higher doses
  - More frequent doses
  - New symptoms
  - Worsening of previously controlled symptoms
- Discuss ahead of time and have a plan
- Ensure alternate route for PO medications is available

Oxford Textbook of Palliative Care for Children

Pain

- Common symptom in cancer patients
- Sores/fractures
- History and clinical exam
- Parent/Caregiver report
- Nurses!

Pain Medications

- Non-opioids
  - Acetaminophen
  - Ibuprofen and other NSAIDs
- Opioids
  - Morphine
  - Hydromorphone
  - Oxycodone
  - Fentanyl
  - Methadone

Opioids

- Common concerns and barriers
- Consider:
  - Choice of drug
  - Route
  - Dosing needs
  - Scheduled + prn
  - Side effects
  - Ceiling effect
  - Tolerance

Adjuvants

- TCA/SNRI
- Gabapentin/Pregabalin
- Steroids
- Ketamine
- Topical agents
- Bisphosphonates
- Radiation
- Regional nerve blocks
- CBD?

Intractable Pain

- Considered an emergency
- Rapid titration of opioids may be required
- Need to be experienced
- Some published protocols
- Opioid-induced hyperalgesia (Extremely rare in children)
- Palliative Sedation

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Dyspnea

- Very common symptom
- Depends on etiology
- Not the same as breathing changes at end-of-life

Dyspnea

- Non-pharmacological interventions
- Low dose opioids
- Procedures/interventions
- Palliative Sedation
- Oxygen

Delirium

- Disturbance of consciousness, change in cognition, and perceptual disturbance that develops over a short period, usually hours to days and fluctuates over time (DSM definition)
- Under recognized
- May miss it if you don’t assess it

Delirium

- Up to 85% of adult palliative care patients experience delirium (Massie, Holland, 1983)
- Possible causes: often multifactorial
- Untreated pain, anxiety, sepsis, electrolyte imbalance, iatrogenic, natural process
- Pediatric tools for delirium screening
  - Pediatric Confusion Assessment Method for the ICU (pCAM-ICU)
  - Preschool Confusion Assessment Method for the ICU (psCAM-ICU)
  - Cornell Assessment of Pediatric Delirium (CAPD)

Delirium Management

- Correct the correctable
  - Within treatment goals
- Familiar people or toys present
- Low lighting (or allow exposure to day light)
- Soothing music
- Orient patient with clock, calendar
- Maintain correct sleep-wake cycle

Pharmacological management

- Only if patient is at risk of harm to self or others or experiencing hallucinations that are distress
- Manage Hallucinations with Antipsychotics (Typical vs Atypical)
- Harm reduction with sedation (Benzos, Thiazine, Atypical with strong sedative effect)
- Palliative Sedation

Textbook of Interdisciplinary Pediatric Palliative Care
McMaster Children's Hospital Pediatric Palliative Care Medication Dosing Guide

Seizures

- Escalate AEDs
- IV/IM/SC
- Infusions
- Palliative Sedation

Constipation

- Common
- Iatrogenic
- Low food intake
- Treat when symptoms and signs suggest discomfort
- PEG – Volume dependent
- Rectal Supp
- Naloxegol/Methylnaltrexone

Nausea/Vomiting

- Iatrogenic
- Obstructions
- Ondansetron
- Ativan
- Benadryl
- Metoclopramide
- Dexamethasone

Fever

- Non-Pharmacological
- Tylenol (IV!)
- NSAIDS (IV/IM)
- Dexamethasone

A Word on Dexamethasone

- Great drug for multi symptom management
- Pain, nausea, fever, dyspnea
- Increases anxiety, hunger
- Behavioral changes
- Long term use with significant adrenal issues
- Body changes
- Fluid retention
- Avoid during the dying process if possible
- Rapid titration or discontinuation

Palliative Care Emergencies

- Pain crisis
- Bleeding
- Hypercalcemia
- Intestinal obstruction
- SVC obstruction
- Spinal Cord Compression

Oxford Textbook of Palliative Care for Children

Declaration of Death

- Exam
- Explain what you are about to do
- (Be aware of any state/provincial regulations)
- Declaration (Use the D word!)
- Pause
- Support

Postmortem Care

- Ideally a plan in place
- If not – after declaration, pause and support, discuss with the caregivers
- Pay attention to cultural/religious needs and requests
- Do not judge
- Share concerns and anticipated challenges (Be honest)

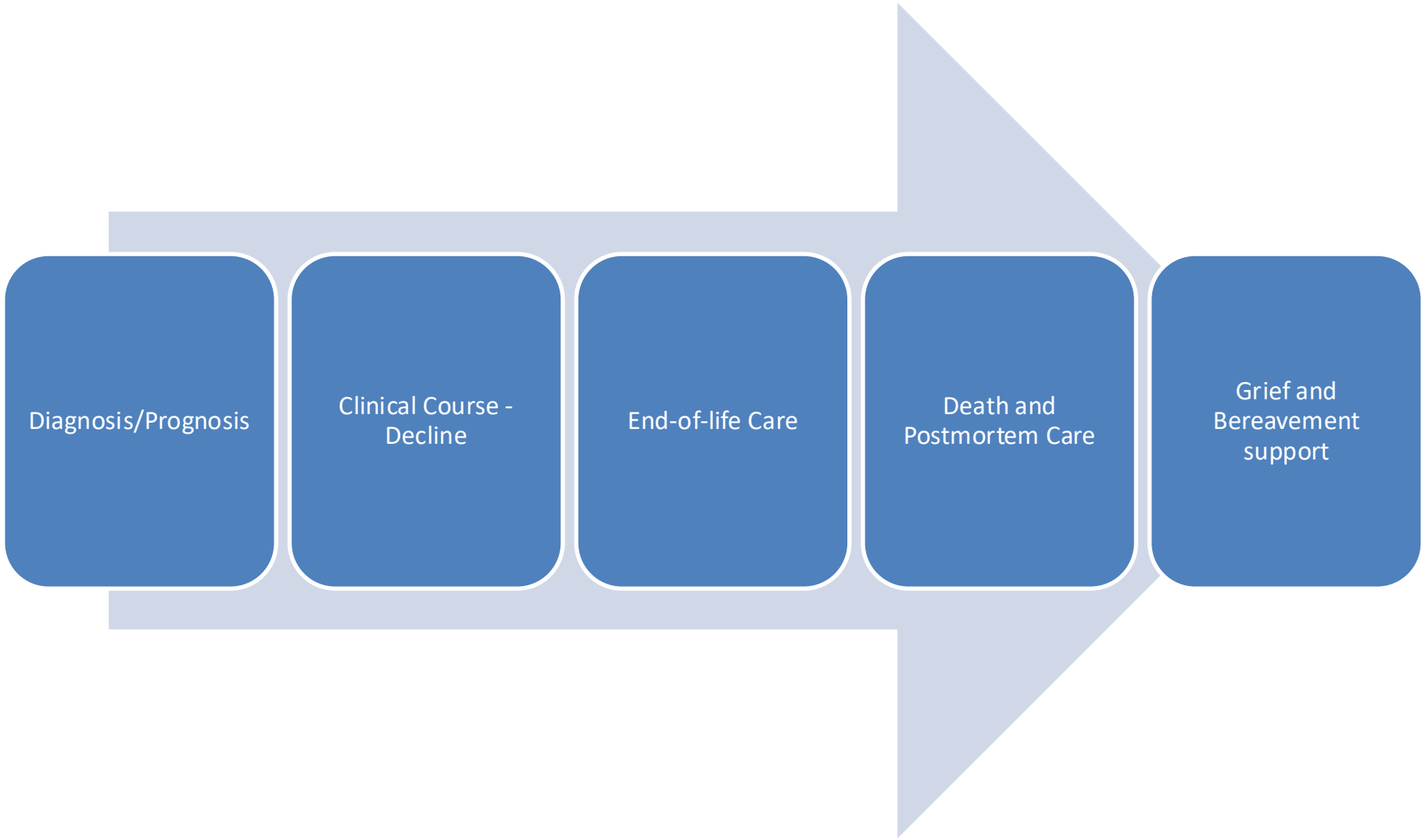
Celebration of life/Funeral

- No obligations to attend
- Personal preference

Self-Care

- Engage in a hobby
- Talk to someone
- Seek help
- Closure and connection

Summary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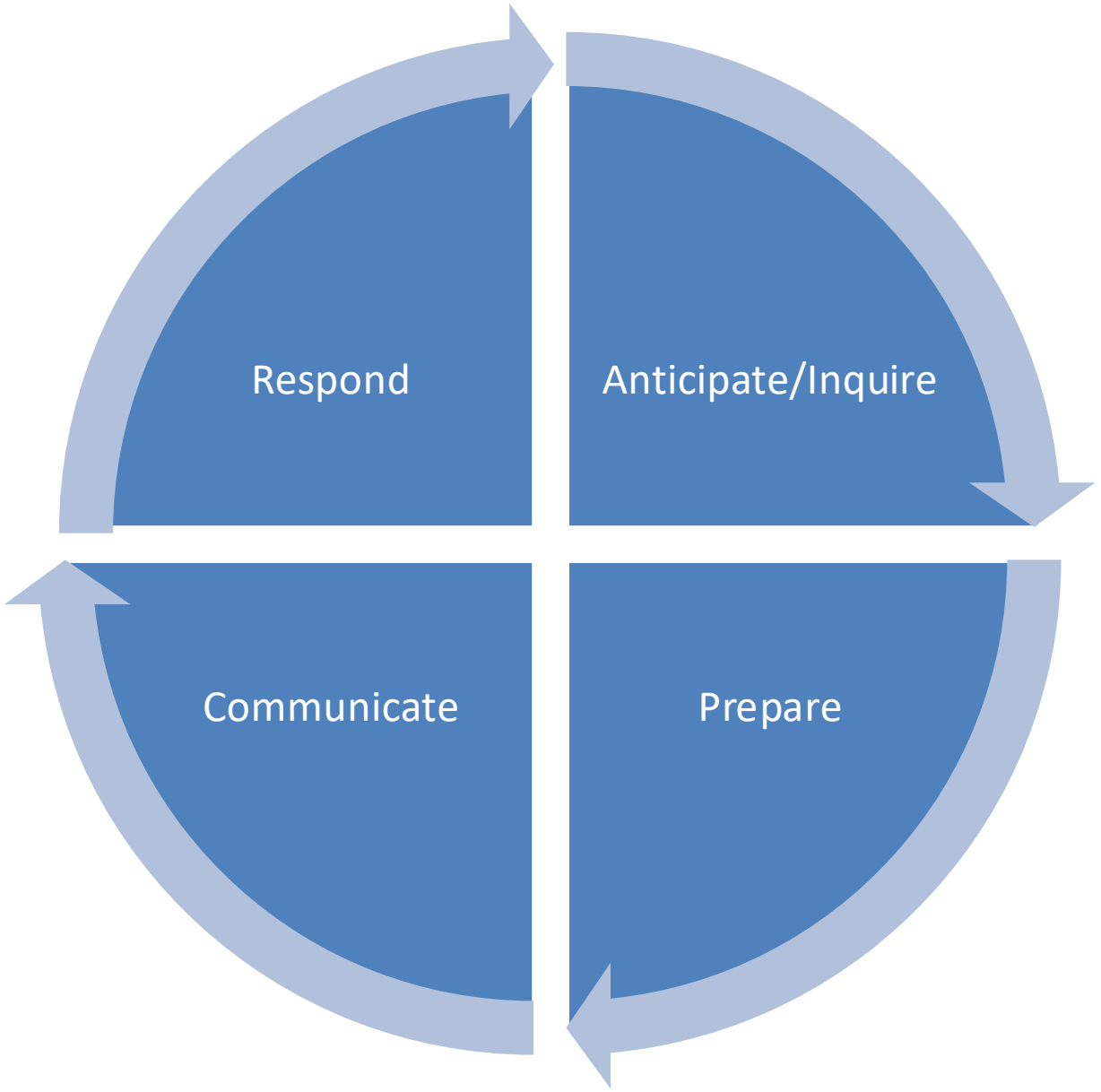
Respond
Anticipate/Inquire
Communicate
Prepare

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Questions and Discussion