



Assisting Children Whose Family Member is Sick or Dying of COVID-19

Opportunities for Nurses to Provide best Practices at the bedside

Objectives

- Discuss the role of the bedside nurse during the COVID-19 crisis with caring for children of dying patients
- Describe the developmental stages of children
- Discuss communication strategies to provide optimal emotional support for grieving children and to promote best practices
- Identify a variety of legacy building activities appropriate for different developmental stages



Case Study

- 45-year old male with history of diabetes, hypertension, COPD, and now with newly diagnosed COVID-19 who is in the Intensive Care Unit (ICU) on a ventilator. He is married, his wife is in the emergency room being checked for fever and cough. The patient's mother contacts the ICU team to ask how to best assist her grandchildren who are at home upset and afraid, ages 5 and 14 years old.
- *Where does the bedside nurse begin with providing support for this family?*

Supporting the Children



The quality of communication with children about life-threatening illness and death has a long-term effect on their psychological wellbeing and family functioning (Rapa, Dalton, Stein, 2020)

- Dad is sick, no one can visit him
- Mom is not here
- Grandma is not telling us anything
- I can't go to school
- I can't see my friends
- I am scared

Key Questions to Consider

- What is the meaning of illness to the family?
- What is the child's prior experience with sickness/death? (family member, pet(s), friend?)
- What is the child's developmental stage?
- How does the family typically communicate difficult news?



What Children of Dying Family Members May Ask: The 3 C's

- “Can I catch it?”
- “Did I cause it?”
- “Who's going to take care of me?”



Librach et al, 2011



Role of the Primary Palliative Nurse

Assess

Educate

Advocate

Delegate

Plan

Follow-up

Infants

- Understanding of death
 - No formal understanding of death
 - Fear of separation
 - Responsive to emotions, the environment, anxiety level of others
- Reactions to death
 - More irritable, clingy
 - Cry more
- Strategies to maximize coping
 - Keep routine as consistent as possible
 - Positive touch
 - Prioritize child over chores, ask for help
 - Assign a regular support person(s)



(Knefley, 2019)

Toddlers and Preschoolers

- Understanding of death
 - Not permanent
 - Seen as punishment
 - Egocentric- caused by or related to self
 - Magical thinking
 - Fear of dying
- Reactions to death
 - May show little concern
 - Regression
 - Fear of separation
 - Repeatedly discuss death, may play out death scenes
- Strategies to maximize coping
 - Prepare them for what to expect
 - Be consistent in wording used, use concrete language
 - Address need for security
 - Address misconceptions
 - Allow them to play, including playing out death themes

(Knefley, 2019)



School-aged Children

- Understanding of death

- Progression of understanding from possible for others to possible for themselves
- Irreversibility
- More interest in biological aspects of death

- Reactions to death

- Increased crying, anxiety
- Headaches, stomach aches
- Denial, hostility
- Guilt, blame
- Inattention, withdrawn

(Knefley, 2019)

- Strategies to maximize coping

- Explore possible reactions with child
- Give permission to show (or not show) emotions
- Honest explanations for death
- Provide legacy opportunities
- Listen, validate



Adolescents

● Understanding of death

- Many have achieved a mature understanding of death
- Able to think more abstractly
- Better understands the implications of death
- Can acknowledge that life is fragile
- Still some invincibility

● Reactions to death

- Assume more adult role
- Preoccupation with death
- Regression
- Practice denial by risk-taking
- More critical of parents

(Knefley, 2019)

● Strategies to maximize coping

- Explore possible reactions with child
- Give permission to show (or not show) emotions
- Honest explanations for death
- Provide legacy opportunities
- Listen, validate
- Music therapy, if desired



Preparing the Words

- Be concrete
 - Dead, died
 - Body stopped working
 - Heart stopped beating
 - Lungs stopped breathing
 - He/she does not feel pain
 - Not able to talk, eat, walk
- Avoid confusing terms and clichés
- Allow for silence
- Prepare answers for questions- both existential and concrete

(Knefley, 2019)



Tips for the Discussion

- Discuss the facts while paying attention to the child's developmental level
- Identify the best person to provide the disclosure
 - May or may not be the parent
- Remember, it's okay to show/express emotion if you are speaking to the child or family via video call or telephone
- Seek to partner with Child Life Specialists and Clinical Social Workers.



After the Disclosure

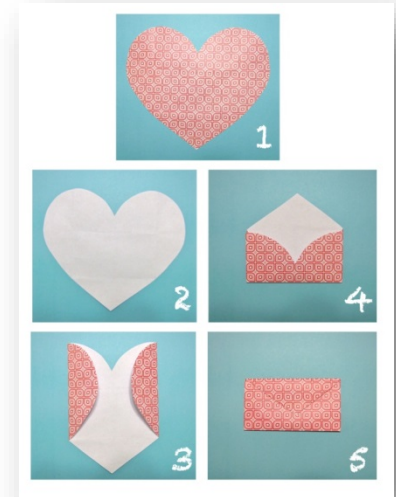
- Communicate language used for consistency
- Allow for play opportunities
- Identify ongoing support person/ people
- Offer legacy building opportunities





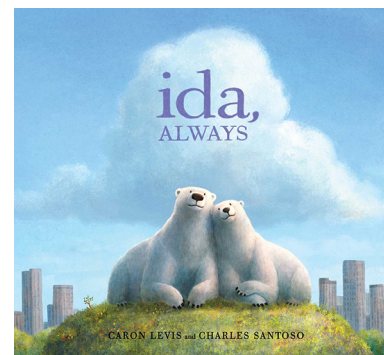
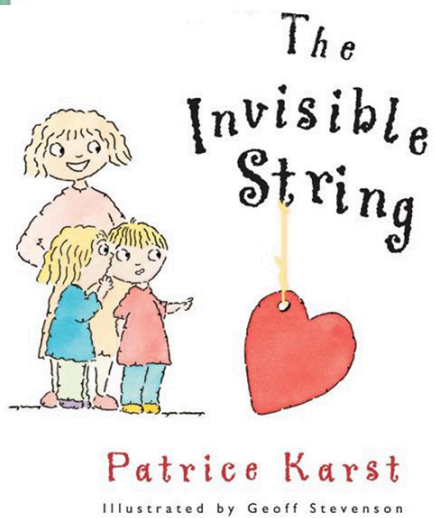
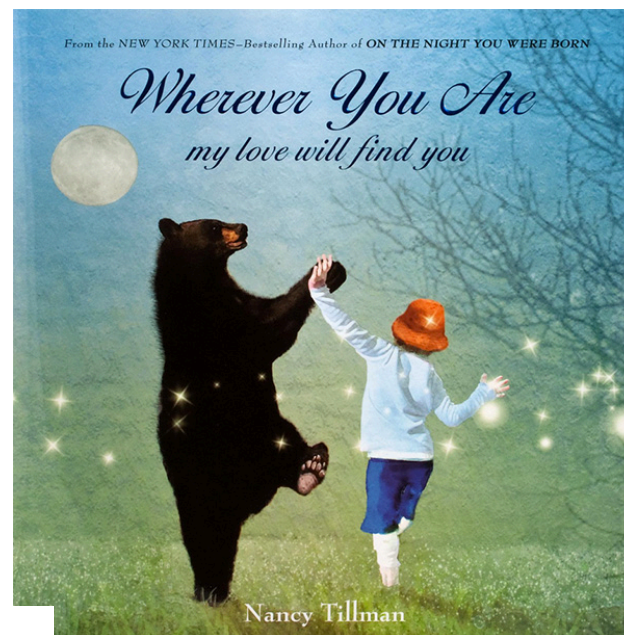
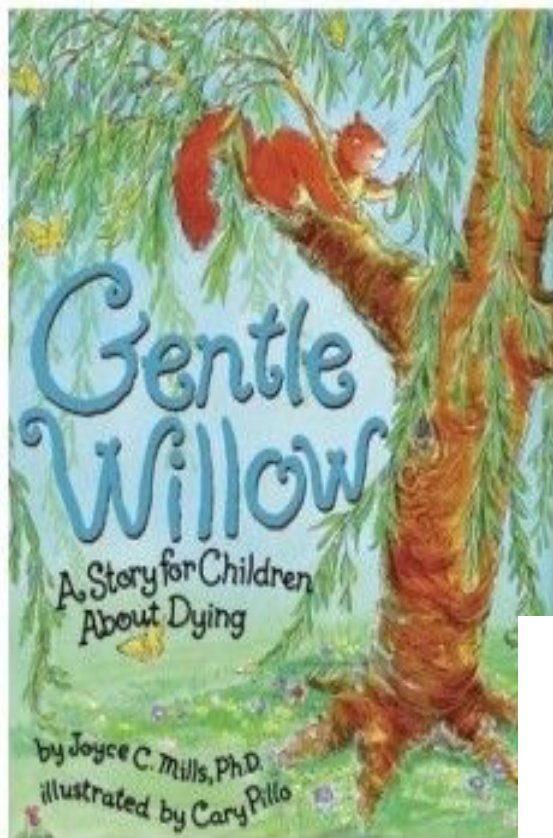
Legacy Activities

- Farewell Messages
 - Opportunity to say good-bye
 - Opportunity to share feelings
 - Can be shared or private



(Knefley & Thaxton, 2019)

Resources





Conclusion

- The nurse must utilize a developmental approach when caring for children whose family member is sick or dying of COVID-19
- The nurse must assess, educate, advocate, delegate, plan, and follow-up while providing support to children whose family member is sick or dying of COVID-19
- The nurse should seek to partner with Child Life Specialists and Clinical Social Workers.



References

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- Rapa, E., Dalton, L. & Stein, A. (2020). Talking to children about illness and death of a loved one during the COVID-19 pandemic. *Lancet Child Adolescent Health Journal*. Retrieved from: [https://doi.org/10.1016/S2352-4642\(20\)30174-7](https://doi.org/10.1016/S2352-4642(20)30174-7)
- <https://www.nebraskamed.com/patients/child-life/resources>
 - Kids Worry, Too- addresses hospitalization of a loved one
 - What Will I Tell the Children- developmental information on death