

I Don't Know What to Say, What Can I Do?

Supporting Children and Their Families At the End of Life



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Family Needs During Palliative Care

- Need for info
- Individualized assessment and careplanning
- Assessing emotional and behavioral problems
- Enhancing the QOL for the child
- Support for the family (psychological, social and spiritual)
- Assistance with practical and financial concerns
- Seamless transition between care settings
- Respite care
- Care at the time of death
- Bereavement

What Families Want Us To Know...

- How special and unique their child is
- That we won't forget their child
- That their child is a great teacher; things we learned from them
- Hope is important
- Honesty is important even if it's difficult

- That they have done everything possible
- That we have done everything possible
 - No regrets
- That their child is a “fighter”
- That they are good parents who have made good decisions for their child (Hinds, et al, 2011)
 - even if you don't agree with their decisions, try to find something...

Remembering the Circumstances of Their Child's Life and Death

- Comfort: physical, emotional, spiritual
- Peaceful, non-judgmental presence
- Knowledgeable, compassionate, professional caregivers who demonstrate competent caring and caring competence and ... kindness



Role of the Nurse

- The importance of presence
- Maintaining a realistic perspective
- Giving bad news
- Anticipating
- Preventing
- Treating
- Promoting
- Advocacy

Education about What to Expect

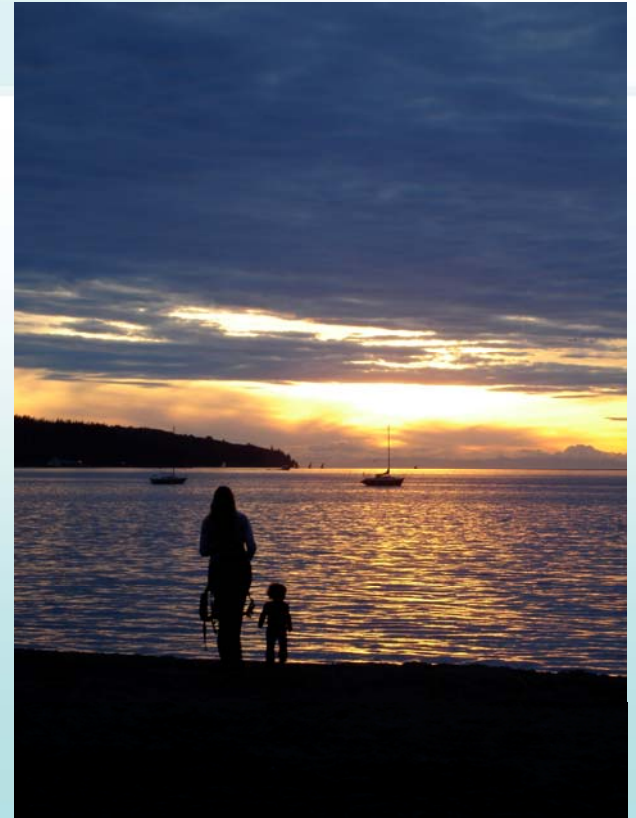
- Education creates empowerment
- Keep instructions simple - verbal and written
- Signs, symptoms of dying
- Care management

The Imminently Dying Child

- Estimating prognosis
- Signs/symptoms only a guideline
- Dying process

Psychological and Spiritual Interventions

- Fear of dying process
- Fear of abandonment
- Fear of unknown
- Nearing death awareness
- Withdrawal; spiritual care
- Elicit desired goals/rituals
- Drifting in and out of “present”



Johnston-Taylor, 1999; Morse, 1990

Suffering and Spiritual Care Issues

- Consult with Spiritual Care Department
- Ask the family re their spiritual and/or religious beliefs
- Do a spiritual assessment

“In your worst moment, what gives you strength?”

- Kathy Perko

Physical Symptoms of Approaching Death

- Confusion, disorientation, delirium
- Turning inward; withdrawal
- Weakness and fatigue
- Drowsiness, sleeping
- Decreased intake; anorexia; unable to swallow/dysphagia
- Changes in breathing
- Changes in pain and symptoms

Physical Symptoms of Approaching Death, cont'd

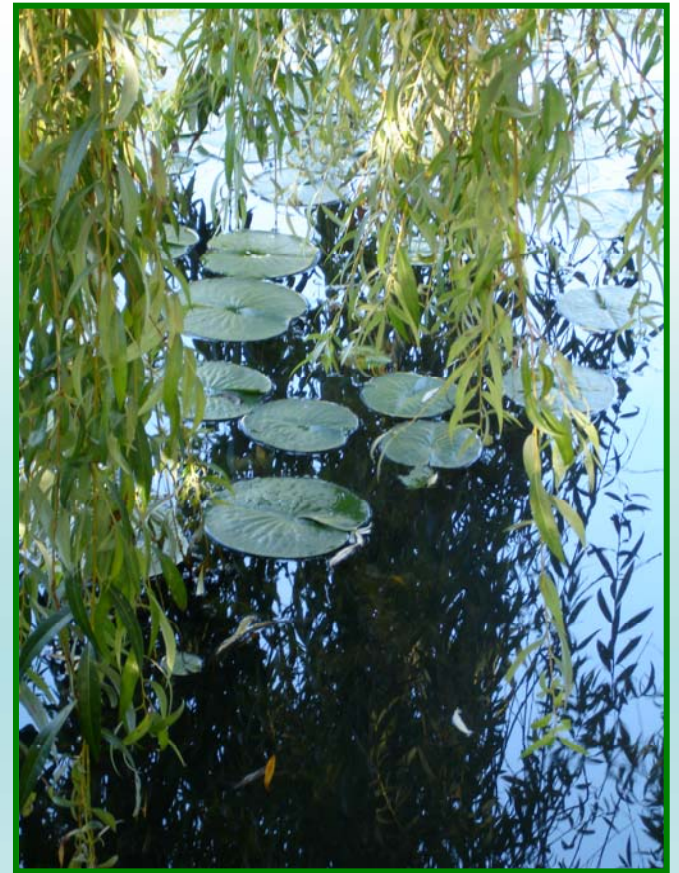
- Changes in pain
 - Fears
 - Other medications
 - Alternate routes

Principle of Double Effect

- An action that has one good (intended) and one bad (unintended but foreseeable) effect is permissible if the following conditions are met:
 - The action itself must be good or indifferent. Only the good consequences of the action must be sincerely intended.
 - The good effect must not be produced by the bad effect
 - There must be a compelling or proportionate reason for permitting the foreseeable bad effect to occur.

Sedation

- Communication with family
- Goal of sedation
- Treatment
- Comfort Measures



Physical Symptoms, cont'd

- Surges of energy
- Restlessness/agitation
- Fever
- Bowel changes
- Incontinence
- Nausea/vomiting
- Seizures
- Changes in behavior
- Changes in appearance

Signs and Symptoms of Imminent Death

- ↓ urine output
- ↓ bowel sounds
- Respiratory changes
 - Irregular breathing
 - Cheyne-Stokes
 - Pulmonary congestion
 - “Moaning” respiration
 - Agonal breathing
- ↓ periods of wakefulness
- Inability to maintain temperature
- Mottled/cold extremities
- ↓ LOC
- Coma

The Death Vigil

- Family presence
- Common fears
 - Being alone with the child
 - Painful death
 - Time of death
 - Giving “last dose”
 - Supporting siblings

Nursing Interventions

- Collaboration with team
- Reassurance and education
- Role model comforting
- Physical comforting
- Spiritual care; honor culture
- Rituals, memory making

Practical Matters

- “Can I just sit here with you?”
- “Would you like me to talk with your other family members, or be there with you when you talk with them?”
- “Is there anyone I can call for you?”
- “How can I help?”
- “Would you like some time alone?”
- “Would you like me to put a sign on the door advising visitors to check with us before entering?”

Role-Model Comfort Care

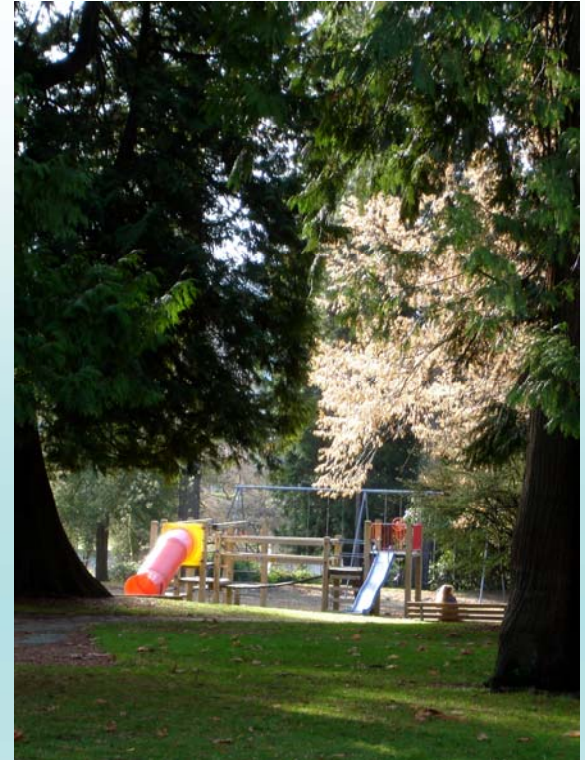
- Physical comfort:
 - Manage pain and other symptoms; perception
 - Relieve muscular tension: massage, stroking, patting
 - Relieve thirst/dry mouth
- Create a comfortable environment:
 - Indirect lighting, ie: lamp
 - Warm, brightly colored quilt
 - Music
 - Aromatherapy
 - Dark towels

Role-Model Comfort Care

- Talk to the child
- Create memories:
 - Life review; remembering the good times
 - Hand/foot molds or prints
 - Video/audiotaping
 - Photographs
 - Memory book/box
- Use humor*
- Do for vs support them
to do for themselves

Death: When the Time Comes

- Signs of death
- Holding the child
- Communicate the death
- Inform the family – next steps
- Death pronouncement
- Professional presence:
 - to be present or not
 - Calming, compassionate manner
 - Calm voice



Respect Culture

- Pay attention to specific tasks, rites at time of death
- Use Culture Clues™
- Consult a cultural interpreter
- Find out about rituals
 - Before & after death

Care Following Death

- Preparing the family
- Organ donor procedures
- Other support



Care Following Death

- Laying out the body:
 - Removal of tubes, equipment
 - Bathing and dressing the body
 - Care in moving the body: settling of fluids
 - Family participation



Care Following Death

- Compassionate/sensitive removal of the body
 - “I’ll make sure to tuck her in and give her an extra blanket”
- Livor mortis: 1-4 hrs after death
- Rigor mortis 2-12 hrs after death
- Respect cultural preferences
- Assist with calls, notifications
- Assist with arrangements
- Initiate bereavement support

At the time of death...

- Being With
- Staying After
- Walking Out

May you be free from pain
May you be free from suffering
May your heart be filled with peace.

Madeline Ko-I Bastis (2000) Peaceful Dwelling



I share with you the agony of your grief. The anguish of your heart finds echo in my own. I know I cannot enter all you feel, not bear the burden of your pain. I can but offer what my love does give; the strength of caring, the warmth of one who seeks to understand the silent storm-swept barrenness of so great a loss. This I do in quiet ways, that on your lonely path, you may not walk alone.

Thurnam, H (1953). Meditations of the heart.



What you are
accomplishing may seem
like a drop in the ocean.
But if this drop were not
in the ocean, it would be
missed.

-Mother Teresa

Consider the team...



CONCLUSION

We are here not to fix what's broken, but to be with people through the brokenness that can't be fixed, but can sometimes be healed.

- Steven Liben