Postmortem Care: Pediatric (Hospice and Palliative Care) – CE

ALERT

Don appropriate personal protective equipment (PPE) based on indications for isolation precautions.

Immediately after death and before postmortem care activities, place the patient’s body in the supine position and elevate the head of the bed to decrease livor mortis.

OVERVIEW

Experiencing a pediatric patient’s death following a prolonged illness and hospice care is emotionally and psychologically draining for the family and caregivers. Even when death is expected, being ready for a pediatric patient’s death is impossible. The hospice nurse should help the family develop a plan for making the death and postmortem care a time that includes rituals or participation that is meaningful and special to them.

Caring for a deceased child’s body with sensitivity and in a manner consistent with the child’s and family’s religious or cultural beliefs is essential. Culture and beliefs are different and personal for every pediatric patient and family. The hospice team should plan ahead with the patient and family, being mindful of important cultural and religious rituals and practices at the end of life. Avoiding assumptions that all individuals from the same ethnic group handle death in the same manner and considering the family’s unique needs when performing postmortem care are important.

After death, the body undergoes many physical changes, including loss of skin elasticity; algor mortis, which causes a drop in body temperature to room temperature; livor mortis, which causes a purple discoloration of the skin from blood pooling in dependent areas; and rigor mortis, which is the stiffening of the body. Postmortem care should be provided as soon as possible to prevent tissue damage or disfigurement. Immediately after death and before beginning postmortem care activities, the hospice team member should elevate the head of the patient’s bed and place a clean pillow under the child’s head to prevent livor mortis of the face.

The 1986 Omnibus Budget Reconciliation Act (OBRA) requires that a patient’s survivors be made aware of the option of organ and tissue donation.[1,2] For patients in hospice care, the option for donation is limited to skin, tissue, bone, and cornea. These are organs and tissues that do not require a beating heart donor. The hospice team should contact the organ procurement organization (OPO) to have the discussion about organ donation with the pediatric patient and family before the end of life to ensure that their wishes will be followed.[2] The hospice team must honor the family’s cultural and religious practices concerning organ and tissue donation and support their final decision. Many donor families report that donating organs helped them in their grief and that they felt positive about the experience.

Aside from the legal requirements regarding a pediatric patient’s death, the hospice care team member should discuss with the family the possibilities of mementos (e.g., lock of hair, handprint), which family members they would like present (e.g., extended family, friends, others in the case of divorce), important rituals (e.g., bathing, dressing), disposition of the body (e.g., funeral home, coroner, cremation center), whom to contact for the

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pronouncement of death, and which hospice care team member will sign the death certificate.

EDUCATION

- Consider the pediatric patient's and family's values and goals in the decision-making process.
- Assist the family to develop plans to notify extended family members, friends, the patient's school, play groups, community groups (e.g., scouts, sports teams), and church or other religious groups.
- Explain the purpose and process of postmortem care to the family, as appropriate.
- Educate the family and caregivers regarding bereavement care and counseling for survivors, including the pediatric patient's siblings.
- Provide individualized, developmentally appropriate education to the family and caregivers based on the desire for knowledge, readiness to learn, and overall neurologic and psychosocial state.
- Instruct the family and caregivers on the safe and proper handling and disposal of medication and medical waste, as needed.
- Establish a rapport with the family and caregivers that encourages questions. Answer them as they arise.

ASSESSMENT

1. Perform hand hygiene and don PPE as indicated for needed isolation precautions.
2. Introduce yourself to those present.
3. Verify the correct patient using two identifiers.
4. Assess the need for social work, counseling services, and spiritual care for the family and caregivers.
5. Confirm that death has been determined and whether there is need for an autopsy.
6. Determine the pediatric patient's and family's desire for organ donation.
7. Discuss the family's plans or requests for preparing or viewing the body (e.g., position of the body, special clothing). Determine whether they wish to take the lead, assist with, or be present for care of the body.
8. Perform appropriate steps depending on whether the patient died in the home or in an inpatient hospice setting.

    a. Home hospice: Ask the family whether there are others they want to notify or to have come to the home (e.g., extended family, clergy).
    b. Inpatient hospice:

        i. Determine whether family members or other caregivers are present and if they have been informed of the death.
        ii. Give family members and friends a private place to gather. Allow them time to ask questions and to grieve.

PREPARATION

1. Make the appropriate hospice care referral (e.g., spiritual care, social work) or ask the family's spiritual leader to stay with and support the family members who are not helping prepare the body.
2. Create an environment of trust that allows conversation regarding the management of the survivors' expectations.

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3. Create an environment that advocates for family needs using a holistic interdisciplinary team.
4. Prepare an area in a clean, convenient location, and assemble the necessary supplies.
5. Review the plan for postmortem care of the patient's body. Ensure that all requested supplies (e.g., holy oil, special clothing) are available for the family.
6. Discuss the planned cultural, spiritual, or personal rituals or practices with the family or caregivers.

PROCEDURE

Postmortem Care in the Home Setting

1. Perform hand hygiene and don PPE as indicated for needed isolation precaution.
2. Explain the procedure to the family and caregivers and ensure that they agree to postmortem care.
3. Help the family notify extended family, friends, and others of the death.
4. Per the organization's practice, assist the family with notifying their chosen funeral home regarding the transfer of the patient's body.
5. Perform hand hygiene and don gloves, gown, mask, and eye protection.
6. If tissue is being donated, follow the organization's practice for care of the body.
7. Assess the general condition of the body, paying attention to the presence of dressings, tubes, and medical equipment.
8. Facilitate the pronouncement of death and the death certificate per the organization's practice.
9. Follow the organization's practice regarding body preparation.

    a. If it is a medical examiner's case, do not remove indwelling tubes and lines (e.g., feeding tubes, urinary catheters, IV catheters). Clamp tubes and send them with the body. The medical examiner may also want to examine devices and IV solutions.
    b. If this is not a medical examiner's case, disconnect and cap IV lines, if present.

        Rationale: Removing IV catheters allows fluids to leak out. Funeral home personnel remove lines after embalming.

10. Place a small pillow under the pediatric patient's head or position it according to cultural preferences.
11. If culturally appropriate, close the patient's eyes by gently pulling the eyelids over the eyes.

    Rationale: For some cultures, closed eyes convey a more peaceful and natural appearance, whereas other cultures prefer that the eyes remain open.

12. Wash the body. If family members are participating in washing the body and providing postmortem care, assist them with donning PPE, as available, for protection from bodily fluids.

    Rationale: Some cultural practices require that family members cleanse the patient's body.

13. Remove soiled dressings and replace them with clean dressings, using paper tape or circular gauze bandaging.

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Rationale: Paper tape minimizes skin damage when the tape is removed.

14. Place an absorbent pad under the patient's buttocks or apply a diaper or brief, if available.

    Rationale: Relaxation of the sphincter muscles at the time of death causes the release of urine and feces.

15. Place clean clothing on the patient's body. The family may have clothing selected for this time. Ensure that it is not the clothing the family wishes for the funeral, wake, or viewing.
16. Brush and comb the patient's hair. Remove any clips, hairpins, or rubber bands.

    Rationale: Hard objects damage and discolor the face and scalp.

17. Identify which of the pediatric patient's belongings are to stay with his or her body and which are to be left with the family (e.g., toy, watch, jewelry).
18. Allow the family time alone with the child's body.

    a. Provide tissues and water for the family.
    b. Allow the family ample time and encourage them to say goodbye with their chosen religious, cultural, or personal rituals and in their preferred manner.

       Rationale: Compassionate care provides family members with a meaningful experience during the early phase of grief.

    c. Encourage the family to hold the child if they wish. Assist them with this as needed.

       Rationale: If the patient still has tubes, picking up and holding him or her without dislodging them may be difficult.

    d. Obtain a memento that the family determined before the child's death (e.g., lock of hair).
    e. Remain accessible to address needs and answer questions.

19. When the family has finished their time with the child's body, identify and tag the body, leaving the identification on the body per the organization's practice.
20. Ensure that prompt transportation of the pediatric patient's body to the funeral home has been arranged.
21. Obtain the name and contact information of the funeral home's representative to whom the body is being released.
22. Follow the organization's practice for disposal of supplies (e.g., tubing, needles, and syringes, soiled dressings or linens, and medications).
23. Contact the company for retrieval of durable medical equipment (e.g., ventilators, IV pumps, feeding pumps) if they are not requested by the medical examiner.
24. Discard supplies, remove PPE, and perform hand hygiene.
25. Document the procedure in the patient's record.

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Postmortem Care in an Inpatient Setting

1. Perform hand hygiene and don PPE as indicated for needed isolation precautions.
2. Explain the procedure to the family and caregivers and ensure that they agree to postmortem care.
3. Help the family notify extended family, friends, and others of the death.
4. Per the organization’s practice, notify the morgue or the family’s chosen funeral home regarding the transfer of the child’s body.
5. Perform hand hygiene and don gloves, gown, mask, and eye protection.
6. If tissue is being donated, follow the organization’s practice for care of the body.
7. Assess the general condition of the body, paying attention to the presence of dressings, tubes, and medical equipment.
8. Facilitate the pronouncement of death and the death certificate, per the organization’s practice.
9. Follow the organization’s practice regarding body preparation.

    a. If it is a medical examiner’s case, do not remove indwelling tubes and lines (e.g., feeding tubes, urinary catheters, IV catheters). Clamp tubes and send them with the body. The medical examiner may also want to examine devices and IV solutions.
    b. If it is not a medical examiner’s case, disconnect and cap IV lines, if present.

        Rationale: Removing IV catheters allows fluids to leak out. Funeral home personnel remove lines after embalming.

10. Place a small pillow under the patient’s head or position it according to cultural preferences.
11. If culturally appropriate, close the pediatric patient’s eyes by gently pulling the eyelids over the eyes.

    Rationale: For some cultures, closed eyes convey a more peaceful and natural appearance, whereas other cultures prefer that the eyes remain open.

12. Wash the body. If family members are assisting with washing the body and providing postmortem care, assist them with donning PPE for protection from bodily fluids.

    Rationale: Some cultural practices require that family members cleanse the pediatric patient’s body.

13. Remove soiled dressings and replace them with clean dressings, using paper tape or circular gauze bandaging.

    Rationale: Paper tape minimizes skin damage when the tape is removed.

14. Place an absorbent pad under the patient’s buttocks or apply a diaper or brief, if available.

    Rationale: Relaxation of the sphincter muscles at the time of death causes the release of urine and feces.

15. Place a clean gown on the patient’s body.

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16. Brush and comb the patient's hair. Remove any clips, hairpins, or rubber bands.

    Rationale: Hard objects damage and discolor the face and scalp.

17. Allow the family time alone with the child's body.

    a. Provide a private space for the family to spend time with the child's body.
    b. Provide tissues and water for the family.
    c. Remove unneeded medical equipment from the room.

        Rationale: Removing medical equipment provides a more peaceful, natural setting.

    d. Allow the family ample time and encourage them to say goodbye with their chosen religious, cultural, or personal rituals and in their preferred manner.

        Rationale: Compassionate care provides family members with a meaningful experience during the early phase of grief.

    e. Encourage the family to hold the child if they wish. Assist them with this as needed.

        Rationale: If the patient still has tubes, picking up and holding him or her without dislodging them may be difficult.

    f. Obtain a memento that the family determined before the child's death (e.g., lock of hair).
    g. Remain accessible to address needs and answer questions.

18. When the family has finished their time with the child's body, identify and tag the body, leaving the identification on the body per the organization's practice.
19. Remove the linens per the organization's practice.
20. Follow the organization's practice regarding securing the hands and feet. Position the hands in an elevated position on the abdomen.

    Rationale: Some organizations require securing appendages to prevent tissue damage when the patient's body is moved. Swelling of the hands and wrists commonly occurs after death, which worsens when the hands are placed in a dependent position beside the body.

21. Place the patient's body in a shroud provided by the organization.

    Rationale: The shroud protects against injury to the skin, avoids exposure of the body, and provides a barrier against potentially contaminated bodily fluids.

22. Place an identification label on the outside of the shroud per the organization's practice.

    Rationale: Labeling ensures proper identification of the body.

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23. Follow the organization's practice for marking a body that poses an infectious risk to others.

    Rationale: Marking the body reduces morgue and funeral home staff exposure to contamination.

24. Identify which of the patient's belongings are to stay with his or her body and which are to be given to the family (e.g., toy, watch, jewelry).
25. If prompt transportation of the body to the funeral home is delayed or the patient's death is a medical examiner's case, transfer the body to the morgue.
26. Obtain the name and contact information of the funeral home's representative to whom the body is released.
27. Discard supplies, remove PPE, and perform hand hygiene.
28. Document the procedure in the pediatric patient's record.

MONITORING AND CARE

1. Observe family's, friends', and caregivers' responses to the loss, and provide support as needed.
2. Assist the family and caregivers with resources to support emotional, psychosocial, and spiritual needs. Encourage them to use available community resources and volunteers.

EXPECTED OUTCOMES

- Body is cared for with dignity and respect and per the child's and family's wishes.
- Body is prepared properly for autopsy, if required.
- Body is prepared properly for tissue donation, if applicable.
- Body is transported to the funeral home per the family's wishes.
- Family and caregivers have the opportunity to say goodbye.
- All legal requirements are carried out as needed (e.g., death certificate).
- Spiritual, cultural, and personal wishes are recognized or honored.

UNEXPECTED OUTCOMES

- Family and caregivers are not adequately prepared for the postmortem care of the body.
- Body is not prepared properly for tissue donation, if applicable.
- Body is not properly prepared for autopsy, if required.
- A delay in transportation to the funeral home or coroner occurs.
- Spiritual, cultural, and personal wishes are not recognized or honored.
- Legal requirements are not carried out as needed.

DOCUMENTATION

- Time of death
- Name of the hospice care team member pronouncing and certifying the death and signing the death certification
- Any special preparation of the body for autopsy or organ and tissue donation
- Individual who was called and individual who made the request for organ and tissue donation
- Postmortem care provided and who participated in the care
- Name of funeral home and individual accepting the body
- Names of family members notified at the time of death and their relationships to the child

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- Personal articles left on the body (e.g., prosthetics, glasses, jewelry) or tubes and lines left in place
- Time body was transported and its destination
- Location of body identification tags
- Education
- Complications and related interventions

REFERENCES

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- Level II - At least one well-designed randomized controlled trial
- Level III - Well-designed controlled trials without randomization
- Level IV - Well-designed case-controlled or cohort studies
- Level V - Descriptive or qualitative studies
- Level VI - Single descriptive or qualitative study
- Level VII - Authority opinion or expert committee reports

Supplies

Ensure that all necessary supplies and durable medical equipment are available.

- PPE (gloves, gown, mask, eye protection)
- Plastic bag for hazardous waste disposal
- Absorbent pad or diaper
- Washbasin
- Washcloth
- Warm water
- Bath towel
- Clean clothing
- Shroud kit with name tags, if applicable
- Syringes for removing urinary catheter
- Scissors
- Small pillow
- Paper tape, gauze dressings
- Paper bag, plastic bag, or other suitable receptacle for patient's belongings, to be returned to family members, if appropriate

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