PROVIDENCE Health & Services

Dying patient care

Revised: June 14, 2019

Introduction

Death is defined as irreversible cessation of circulatory and respiratory functions or irreversible cessation of all functions of the entire brain, including the brain stem.[1] Signs and symptoms of impending death vary. (See *Signs and symptoms of impending death*.)

SIGNS AND SYMPTOMS OF IMPENDING DEATH

Signs and symptoms of impending death vary and may include:

- confusion
- decreased level of consciousness or unresponsiveness
- irregular or decreased respirations that may be accompanied by rattling and gurgling sounds
- weak or erratic pulse
- decreased blood pressure
- decreased socialization or social withdrawal
- pale, mottled, cyanotic, diaphoretic, or cool skin
- bowel and bladder incontinence
- involuntary movements
- loss of reflexes in the extremities.

A patient needs intensive physical support and emotional comfort as the patient approaches death. Emotional support for a dying patient and family most commonly entails reassurance; your physical presence helps ease fear and loneliness. More intense emotional support is important at much earlier stages, especially for patients with a long-term progressive illness who can work through the stages of dying. (See *Five stages of dying*.)

The patient's wishes about extraordinary means of supporting life must be respected. The patient may have a current signed advance directive. This document, legally binding in most states, declares the patient's wishes for end-of-life care should the patient be unable to make decisions. (See the "Advance directives" procedure.)

FIVE STAGES OF DYING

According to Elisabeth Kübler-Ross, author of *On Death and Dying,* the dying patient may progress through five psychological stages in preparation for death. Although each patient experiences these stages differently and not necessarily in this order, understanding them will help you meet the patient's needs.

Denial

After learning about the terminal illness, the patient may refuse to accept the diagnosis. The patient may experience physical signs and symptoms similar to a stress reaction—shock, fainting, pallor, sweating, tachycardia, nausea, and GI disorders. During this stage, be honest with the patient but not blunt or callous. Maintain communication so that the patient can discuss personal feelings after acknowledging the reality of death. Don't force the patient to confront this reality.

Anger

After the patient stops denying the impending death, the patient may show deep resentment toward those who will live on after the patient dies—to you, to the facility staff, and family members. Although you may instinctively draw back from the patient or even resent this behavior, remember that the patient is dying and has a right to be angry. After you accept the anger, you can help the patient find different ways to express it and can help family members understand it.

Bargaining

Although the patient acknowledges impending death, the patient attempts to bargain with God or fate for more time. The patient will probably strike this bargain secretly. If the patient does confide in you, listen.

Depression

In the depression stage, the patient may first experience regrets about the past and then grieve about the current condition. The patient may withdraw from friends, family members, the practitioner, and you. The patient may suffer from anorexia, increased fatigue, or self-neglect. You may find the patient sitting alone in tears. Accept the patient's sorrow and listen. Provide comfort by touch as appropriate. Resist the temptation to make optimistic remarks or cheerful small talk.

Acceptance

In acceptance, the last stage, the patient accepts the inevitability and imminence of death—without emotion. The patient may simply desire the quiet company of a family member or friend. If for some reason a family member or friend can't be present, stay with the patient to satisfy the patient's final need. Remember, however, that many patients die before reaching this stage.

Equipment

- Clean bed linens
- Clean gowns
- Gloves
- Warm water
- Soap
- Washcloth
- Towels
- Lotion
- Lift sheets
- Oral care supplies
- Artificial tears or ophthalmic saline solution
- Fluid-impermeable pads
- Protective barrier cream
- Lubricant
- Sponge-tipped swab
- Optional: indwelling urinary catheter insertion kit, suction equipment, vital signs measurement equipment, prescribed medications, oral fluids

Implementation

- Verify the presence of a current signed advance directive in the patient's medical record. Obtain one from the patient's family members if indicated; offer information on advance directives, as requested and required by your facility.[2][3][4][5]
- Clarify and communicate goals of treatment and the patient's values with the patient's family and multidisciplinary team.
- Gather the necessary equipment and supplies.

Meeting physical needs

- Perform hand hygiene.[6][7][8][9][10][11]
- Confirm the patient's identity using at least two patient identifiers.[12]
- Provide privacy.[13][14][15][16]
- Raise the bed to waist level before providing care *to prevent caregiver back strain.*[17]
- Perform hand hygiene.[6][7][8][9][10][11]
- Put on gloves *to comply with standard precautions.*[18][19][20]
- Whenever moving from a contaminated area to a clean one during patient care, remove and discard your gloves,[18][20] perform hand hygiene,[6][7][8][9][10][11] and put on new gloves.[18][20]
- Obtain the patient's vital signs and perform assessments, including end-of-life signs and symptoms, as indicated.
- Screen for and assess the patient's pain using facility-defined criteria that are consistent with the patient's age, condition, and ability to understand.[21][22] If administering pain and other medications for end-of-life signs and

symptoms (such as dyspnea, cough, anxiety, and delirium) as needed and prescribed, follow safe medication administration practices.[23][24][25][26]

- Treat the patient's pain, as needed and ordered, using nonpharmacologic, pharmacologic, or a combination of approaches. Base the treatment plan on evidence-based practices and the patient's clinical condition, past medical history, and pain management goals.[21] (See the "Pain management" procedure.)
- When the patient's vision and hearing start to fail, turn the patient's head toward the light, face the patient, and speak to the patient from near the head of the bed. *Because hearing may be intact despite loss of consciousness,* avoid whispering or speaking inappropriately about the patient in the patient's presence.
- Monitor skin integrity carefully, and turn and reposition the patient, as needed. Individualize turning and repositioning according to the patient's preference. Use pressure redistribution, padding, and positioning devices as needed *to promote comfort.*
- Change the bed linens and the patient's gown as needed. Provide skin care during gown changes.
- Adjust the room temperature for patient comfort if necessary.
- Observe for incontinence or anuria, the result of diminished neuromuscular control, decreased renal function, constipation, or diarrhea. If necessary, obtain an order to catheterize the patient, and place fluid-impermeable pads beneath the patient's buttocks. Provide perineal care using soap and warm water, a washcloth, and towels *to prevent irritation.* Apply a protective barrier cream as indicated.
- Elevate the head of the bed *to decrease respiratory resistance.* Provide gentle suction of the oropharynx as indicated *to remove thick, copious secretions.* As the patient's condition deteriorates, the patient may breathe mostly through the mouth.
- Offer fluids frequently and respectfully; don't force the patient to take fluids.
- Provide oral care frequently, taking care to moisturize the oral mucosa and lips as needed *to provide comfort.* (See the "Oral care" procedure.)
- Provide eye care using artificial tears or ophthalmic saline solution as ordered *to prevent corneal ulceration, which can cause blindness and prevent the use of these tissues for transplantation after the patient dies.* (See the "Eye care" procedure.)
- Reassess and respond to the patient's pain by evaluating the response to treatment and progress toward pain management goals. Assess for adverse reactions and risk factors for adverse events that may result from treatment.[21]
- Return the bed to the lowest position *to prevent falls and maintain patient safety.*[27]
- Discard used supplies in the appropriate receptacles.[20]
- Remove and discard your gloves.[18][20]
- Perform hand hygiene.[6][7][8][9][10][11]

Meeting emotional needs

- Fully explain all care and treatments to the patient and family members, even if the patient is unconscious, *because the hearing may be intact.*[28] Answer any questions as candidly as possible while remaining sensitive and respectful.
- Allow the patient and family members to express their feelings, which may range from anger to loneliness. Take time to talk with the patient and family members. Sit near the head of the bed, and avoid looking rushed or unconcerned.
- Assure family members that care will continue before, during, and after the withdrawal of life-sustaining measures as indicated, regardless of the outcome.
- Encourage appropriate affection among the patient and family members, and provide for privacy and confidentiality.
- Appreciate cultural, spiritual, and religious traditions related to the dying process.
- Notify family members, if they're absent, when the patient wishes to see them. Let the patient and family members discuss death at their own pace.
- Offer to contact a member of the clergy, palliative care team, hospice, or social services department if appropriate.
- Document the procedure.[29][30][31][32]

Special Considerations

- If family members remain with the patient, show them the location of bathrooms, lounges, and cafeterias. Explain the patient's needs, treatments, and care plan to them. If appropriate, offer to teach them specific skills *so that they can take part in nursing care.* Emphasize that their efforts are important and effective. As the patient's death approaches, give them emotional support.
- Teach family members about the signs and symptoms of impending death.

- Collaborate with the multidisciplinary team *to see whether you can discontinue procedures and unnecessary medications;* you should administer necessary medications by an alternative route when the by-mouth route becomes difficult.[33]
- Family dynamics and cultural, religious, and spiritual beliefs may all affect the grieving experience. Questions of an afterlife, unresolved social or emotional issues, and financial concerns are common matters expressed and discussed.
- Respect the patient's and family members' wishes regarding complementary and alternative medicine; refer to the National Institutes of Health National Center for Complementary and Alternative Medicine as requested.
- When appropriate, contact the Organ Procurement Organization (OPO) if the patient is being evaluated for brain death or if support is being withdrawn in anticipation of imminent death *so that an OPO coordinator can discuss possible organ donation with family members; such discussions require special knowledge, training, and experience to deliver the appropriate message to family members.*[34] Check the patient's records *to determine whether the patient has completed an organ donor card.* (See *Understanding organ and tissue donation*.)

UNDERSTANDING ORGAN AND TISSUE DONATION

Federal regulation enacted in 1998 and revised in 2004 requires health care facilities to report patients whose death is imminent or who have died at the facility. The report must be timely and must be directed to a regional organ procurement organization.[35][36][37] This regulation attempts to ensure that no potential donor goes undetected. The regulation ensures that the family of every potential donor will understand the option to donate. According to the American Medical Association, about 25 kinds of organs and tissues are transplanted. Although donor organ requirements vary, the typical donor must be between the ages of neonate and 60 years old and free from transmissible disease. Tissue donations are less restrictive, and some tissue banks will accept skin from donors up to age 75.

Collection of most organs, such as the heart, liver, kidneys, or pancreas, requires that the patient be pronounced brain dead and kept physically alive until harvesting of the organs. Harvesting some tissue, such as eyes, skin, bone, and heart valves, is possible after death. Contact your regional organ procurement organization for specific organ donation criteria or to identify a potential donor. If you don't know the regional organ procurement organization in your area, call the United Network for Organ Sharing at 804-782-4800.

For more on how to register for organ donation, go to http://donatelife.net.

Documentation

Record changes in the patient's vital signs and general status. Note the patient's pain and sign and symptom assessment, pharmacologic and nonpharmacologic pain and symptom management, and the patient's response. Document end-of-life care discussions, choices, and advance directives. Obtain all necessary signatures, consents, and required copies. Note the time of cardiac arrest and of the end of respiration, and notify the practitioner when these occur.

This procedure has been reviewed by the Academy of Medical-Surgical Nurses.

AMSN Academy of Medical-Surgical Nurses

Related Procedures

- Care of a dying patient, neonatal
- Dying resident care, long-term care
- End-of-life care, long-term care
- Mechanical ventilation discontinuation for end-of-life care, respiratory therapy
- Withholding and withdrawing life-sustaining treatments

References

(Rating System for the Hierarchy of Evidence for Intervention/Treatment Questions)

1. The President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research. (1981). "Defining death: Medical, legal, and ethical issues in the determination of death" [Online]. Accessed April 2019 via the Web at https://repository.library.georgetown.edu/bitstream/handle/10822/559345/defining_death.pdf?sequence=1&isAllowed=y (Level VII)
2. The Joint Commission. (2019). Standard RI.01.05.01. *Comprehensive accreditation manual for hospitals.* Oakbrook Terrace, IL: The Joint Commission. (Level VII)
3. Centers for Medicare and Medicaid Services, Department of Health and Human Services. (2018). Condition of participation: Patient's rights. 42 C.F.R. § 482.13(b)(3).

4. Accreditation Association for Hospitals and Health Systems. (2018). Standard 15.01.12. *Healthcare Facilities Accreditation Program: Accreditation requirements for acute care hospitals.* Chicago, IL: Accreditation Association for Hospitals and Health Systems. (Level VII)
5. DNV GL-Healthcare USA, Inc. (2019). PR.3.SR.1a. *NIAHO® accreditation requirements, interpretive guidelines and surveyor guidance – revision 18.2.* Milford, OH: DNV GL-Healthcare USA, Inc. (Level VII)
6. The Joint Commission. (2019). Standard NPSG.07.01.01. *Comprehensive accreditation manual for hospitals.* Oakbrook Terrace, IL: The Joint Commission. (Level VII)
7. Centers for Disease Control and Prevention. (2002). Guideline for hand hygiene in health-care settings: Recommendations of the Healthcare Infection Control Practices Advisory Committee and the HICPAC/SHEA/APIC/IDSA Hand Hygiene Task Force. *MMWR Recommendations and Reports, 51*(RR-16), 1–45. Accessed April 2019 via the Web at https://www.cdc.gov/mmwr/pdf/rr/rr5116.pdf (Level II)
8. World Health Organization. (2009). "WHO guidelines on hand hygiene in health care: First global patient safety challenge, clean care is safer care" [Online]. Accessed April 2019 via the Web at http://apps.who.int/iris/bitstream/10665/44102/1/9789241597906_eng.pdf (Level IV)
9. Centers for Medicare and Medicaid Services, Department of Health and Human Services. (2018). Condition of participation: Infection control. 42 C.F.R. § 482.42.
10. Accreditation Association for Hospitals and Health Systems. (2018). Standard 07.01.21. *Healthcare Facilities Accreditation Program: Accreditation requirements for acute care hospitals.* Chicago, IL: Accreditation Association for Hospitals and Health Systems. (Level VII)
11. DNV GL-Healthcare USA, Inc. (2019). IC.1.SR.1. *NIAHO® accreditation requirements, interpretive guidelines and surveyor guidance – revision 18.2.* Milford, OH: DNV GL-Healthcare USA, Inc. (Level VII)
12. The Joint Commission. (2019). Standard NPSG.01.01.01. *Comprehensive accreditation manual for hospitals.* Oakbrook Terrace, IL: The Joint Commission. (Level VII)
13. The Joint Commission. (2019). Standard RI.01.01.01. *Comprehensive accreditation manual for hospitals.* Oakbrook Terrace, IL: The Joint Commission. (Level VII)
14. Centers for Medicare and Medicaid Services, Department of Health and Human Services. (2018). Condition of participation: Patient's rights. 42 C.F.R. § 482.13 (c)(1).
15. Accreditation Association for Hospitals and Health Systems. (2018). Standard 15.01.16. *Healthcare Facilities Accreditation Program: Accreditation requirements for acute care hospitals.* Chicago, IL: Accreditation Association for Hospitals and Health Systems. (Level VII)
16. DNV GL-Healthcare USA, Inc. (2019). PR.2.SR.5. *NIAHO® accreditation requirements, interpretive guidelines and surveyor guidance – revision 18.2.* Milford, OH: DNV GL-Healthcare USA, Inc. (Level VII)
17. Waters, T. R., et al. (2009). "Safe patient handling training for schools of nursing" [Online]. Accessed April 2019 via the Web at https://www.cdc.gov/niosh/docs/2009-127/pdfs/2009-127.pdf (Level VII)
18. Siegel, J. D., et al. (2007, revised 2018). "2007 guideline for isolation precautions: Preventing transmission of infectious agents in healthcare settings" [Online]. Accessed April 2019 via the Web at https://www.cdc.gov/infectioncontrol/pdf/guidelines/isolation-guidelines-H.pdf (Level II)
19. Accreditation Association for Hospitals and Health Systems. (2018). Standard 07.01.10. *Healthcare Facilities Accreditation Program: Accreditation requirements for acute care hospitals.* Chicago, IL: Accreditation Association for Hospitals and Health Systems. (Level VII)
20. Occupational Safety and Health Administration. (2012). "Bloodborne pathogens, standard number 1910.1030" [Online]. Accessed April 2019 via the Web at https://www.osha.gov/pls/oshaweb/owadisp.show_document?p_id=10051&p_table=STANDARDS (Level VII)
21. The Joint Commission. (2019). Standard PC.01.02.07. *Comprehensive accreditation manual for hospitals.* Oakbrook Terrace, IL: The Joint Commission. (Level VII)
22. Blinderman, C. D., & Billings, J. A. (2015). Comfort care for patients dying in the hospital. *New England Journal of Medicine, 373*, 2549–2561. Accessed April 2019 via the Web at https://www.nejm.org/doi/full/10.1056/NEJMra1411746 Abstract | Complete Reference | Full Text | Ovid Full Text |
23. The Joint Commission. (2019). Standard MM.06.01.01. *Comprehensive accreditation manual for hospitals.* Oakbrook Terrace, IL: The Joint Commission. (Level VII)
24. Centers for Medicare and Medicaid Services, Department of Health and Human Services. (2018). Condition of participation: Nursing services. 42 C.F.R. § 482.23(c).
25. Accreditation Association for Hospitals and Health Systems. (2018). Standard 16.01.03. *Healthcare Facilities Accreditation Program: Accreditation requirements for acute care hospitals.* Chicago, IL: Accreditation Association for Hospitals and Health Systems. (Level VII)
26. DNV GL-Healthcare USA, Inc. (2019). MM.1.SR.3. *NIAHO® accreditation requirements, interpretive guidelines and surveyor guidance – revision 18.2.* Milford, OH: DNV GL-Healthcare USA, Inc. (Level VII)

27. Ganz, D. A., et al. (2013, reviewed 2018). *Preventing falls in hospitals: A tool kit for improving quality of care* (AHRQ Publication No. 13-0015-EF). Rockville, MD: Agency for Healthcare Research and Quality. Accessed April 2019 via the Web at https://www.ahrq.gov/professionals/systems/hospital/fallpxtoolkit/index.html (Level VII)
28. The Joint Commission. (2019). Standard PC.02.01.21. *Comprehensive accreditation manual for hospitals.* Oakbrook Terrace, IL: The Joint Commission. (Level VII)
29. The Joint Commission. (2019). Standard RC.01.03.01. *Comprehensive accreditation manual for hospitals.* Oakbrook Terrace, IL: The Joint Commission. (Level VII)
30. Centers for Medicare and Medicaid Services, Department of Health and Human Services. (2018). Condition of participation: Medical record services. 42 C.F.R. § 482.24(b).
31. Accreditation Association for Hospitals and Health Systems. (2018). Standard 10.00.03. *Healthcare Facilities Accreditation Program: Accreditation requirements for acute care hospitals.* Chicago, IL: Accreditation Association for Hospitals and Health Systems. (Level VII)
32. DNV GL-Healthcare USA, Inc. (2019). MR.2.SR.1. *NIAHO® accreditation requirements, interpretive guidelines and surveyor guidance – revision 18.2.* Milford, OH: DNV GL-Healthcare USA, Inc. (Level VII)
33. Leung, J. G., et al. (2014). Pharmacotherapy during the end of life: Caring for the actively dying patient. *AACN Advanced Critical Care, 25,* 79–88.
Abstract | Complete Reference | Ovid Full Text |
34. National Institute for Health and Care Excellence. (2016). "Organ donation for transplantation: Improving donor identification and consent rates for deceased organ donation: Approach to the those close to the patient" [Online]. Accessed April 2019 via the Web at https://www.nice.org.uk/guidance/cg135/chapter/1-recommendations(Level I)
35. Centers for Medicare and Medicaid Services, Department of Health and Human Services. (2018). Condition of participation: Organ, tissue, and eye procurement. 42 C.F.R. § 482.45.
36. Accreditation Association for Hospitals and Health Systems. (2018). Standard 14.00.01. *Healthcare Facilities Accreditation Program: Accreditation requirements for acute care hospitals.* Chicago, IL: Accreditation Association for Hospitals and Health Systems. (Level VII)
37. DNV GL-Healthcare USA, Inc. (2019). TO.2.SR.2. *NIAHO® accreditation requirements, interpretive guidelines and surveyor guidance – revision 18.2.* Milford, OH: DNV GL-Healthcare USA, Inc. (Level VII)

Additional References

- Becker, C. A., et al. (2017). Perceptions of dying well and distressing death by acute care nurses. *Applied Nursing Research, 33,* 149–154. (Level VI)
Abstract | Complete Reference |
- Clark, K., et al. (2015). The effect of a care bundle on nursing staff when caring for the dying. *International Journal of Palliative Nursing, 21,* 392–398. (Level VI)
Abstract | Complete Reference |
- Dose, A. M., et al. (2015). Dying in the hospital: Perspectives of family members. *Journal of Palliative Care, 31,* 13–20. (Level VI)
Abstract | Complete Reference |
- Raisio, H., et al. (2015). Defining a good death: A deliberative democratic view. *Journal of Palliative Care, 31,* 158–165. (Level VI)
Abstract | Complete Reference |
- Wolf, L. A., et al. (2015). Exploring the management of death: Emergency nurses' perceptions of challenges and facilitators in the provision of end-of-life care in the emergency department. *Journal of Emergency Nursing, 41,* e23–e33. (Level VI)
Abstract | Complete Reference | Ovid Full Text |

Rating System for the Hierarchy of Evidence for Intervention/Treatment Questions

The following leveling system is from *Evidence-Based Practice in Nursing and Healthcare: A Guide to Best Practice* (2nd ed.) by Bernadette Mazurek Melnyk and Ellen Fineout-Overholt.

Level I:	Evidence from a systematic review or meta-analysis of all relevant randomized controlled trials (RCTs)
Level II:	Evidence obtained from well-designed RCTs
Level III:	Evidence obtained from well-designed controlled trials without randomization
Level IV:	Evidence from well-designed case-control and cohort studies
Level V:	Evidence from systematic reviews of descriptive and qualitative studies
Level VI:	Evidence from single descriptive or qualitative studies
Level VII:	Evidence from the opinion of authorities and/or reports of expert committees

Modified from Guyatt, G. & Rennie, D. (2002). Users' Guides to the Medical Literature. Chicago, IL: American Medical Association; Harris, R.P., Hefland, M., Woolf, S.H., Lohr, K.N., Mulrow, C.D., Teutsch, S.M., et al. (2001). Current Methods of the U.S. Preventive Services Task Force: A Review of the Process. American Journal of Preventive Medicine, 20, 21-35.