



A Field Manual for Palliative Care in Humanitarian Crises

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Care of the Dying Patient FREE

Chapter: Care of the Dying Patient

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Introduction



Care of the dying patient generally refers to care in the last days or hours of life. The goals of care during the last hours and days of life are to ensure comfort and dignity. Good palliative care does not hasten death.

In humanitarian settings, where healthcare providers may not have expertise in palliative care, identifying when patients are at this stage of life can be challenging. In addition, during this time, physical symptoms can be difficult to control; the best way to ensure they are well managed is to anticipate the symptoms and develop a management plan.

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This chapter will discuss the key physiological changes, communication, and symptom management considerations required to provide care of the dying patient in humanitarian-crisis situations. While providing optimal care for dying patients in these situations may be challenging, a clear understanding of key components of good care can guide clinicians to prioritize their efforts.

Recognizing When Death Is Imminent



When death is approaching, most individuals look quite similar, despite their underlying medical condition. Observations that may help to identify patients who are approaching end of life include the following:

- Very tired and weak, spending the majority of time sleeping or lying down
- Little or no oral intake and difficulty swallowing
- Altered level of consciousness—confused, agitated, restless, or drowsy
- Changes in pulse, blood pressure, and breathing, cool and mottled extremities
- Decreased urine and stool output

Children are often more resilient and may survive what appears to be the imminently dying phase, because they have less age-related degeneration of vital organs. Patients with malnutrition will have a more rapid progression to end of life.

Predicting how long a patient will live is very challenging; changes in the patient's condition should guide prognostication. If changes are:

- Hourly, death is expected in hours to several days.
- Daily, death is expected in days to several weeks.
- Weeks, death is expected in weeks to months.

Ensuring a Good Death



Research indicates that patients and family members feel that a “good death” includes the following^{1,2}:

- Communication and clear decision-making from healthcare providers
- Adequate pain and symptom management
- Strengthening relationships with loved ones (resolving conflicts, saying goodbye)
- Preparation for death

Completing these actions may be challenging for clinicians in humanitarian crises. In these settings, when staff might be limited,

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having a nonmedical member of the healthcare team (such as a patient guide, community health worker, or other staff member) stay with the family can be critical and reduce the family's demands on the healthcare team.

Communication



It is important to provide clear and prompt information about prognosis to the patient and family. When speaking about how much time is left, one should provide a time range, since a precise answer is likely to be wrong and may cause families to lose trust in the clinical team (Box 9.1). Box 9.2 provides suggested language for these conversations.

Box 9.1 Respiratory Pattern Changes

- When talking to families about how long the patient is expected to live, acknowledge uncertainty and always give a time range, for example: “It can be difficult to predict, but I expect that he will live for hours to a few days.”
- Be honest about the situation, since this helps families to plan appropriately. For example, ensure that loved ones are present or are aware of the situation.
 - Clear and honest information is valued and preferred.³
 - Honesty does not lead to a loss of hope but instead demonstrates your team's honesty and transparency.⁴
 - Avoid saying, “There is nothing more that can be done,” as there are always things that can be done, such as treatment of pain and other symptoms.
- Use the checklist in Box 9.2 to guide the conversation when you expect that death is expected soon (adapted from Serious Illness Conversation Guide).^{5,6} This sequence follows evidence about the best structure for delivering difficult news and discussing goals of care.

Box 9.2 Key Steps for Conversation to Inform Family that Death is Expected and to Establish Plan of Care

1. Set up the conversation by introducing yourself and asking permission to proceed: “Can I talk to you about what is happening to your loved one?”

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2. Assess the family's understanding of the illness: "What is your understanding of where your loved one is at with their illness?"
3. Share the prognosis: "I wish it were different, but I am worried that your loved one is very sick and will not be able to recover from this illness. We do not have any treatments that can cure this problem, and I am worried that your loved one is not going to live for very long."
4. Assess goals and wishes: "What are your goals, given the information I have shared with you?"
5. Establish a plan: "I recommend that we focus on providing care that ensures that your loved one is comfortable, and they can be with those they love."
6. Close the conversation: "We will be here to treat and support your loved one and your family."

Family Meeting Tips

- Sit down and give the patient and family your undivided attention for 5 to 10 minutes, in the most quiet and private location possible and practical for the setting.
- Be honest about how much time you have: "I would really like to spend more time with you, but unfortunately, I only have 10 minutes, so what are the most important questions you have for me at this time?"
- Tell the family when you will be able to return to see them.
- If possible, involve a nurse and psychosocial counselor in the meeting, who can continue to provide support after the meeting.

Symptom Management Considerations in the Last Hours and Day

Guidelines and standardized order sets are recommended to ensure consistent treatment with appropriate doses of medications and to enable bedside clinicians to initiate care. See Box 9.3 for an example.

Box 9.3 Suggested Guidelines for Management of Escalating Pain, Dyspnea, and Agitation

Escalating Pain, Dyspnea, and Agitation

No ceiling dose exists for symptom management in the last hours or days of life (end-of-life phase). The correct dose is the dose that

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relieves the patient's symptoms. Titrate the medications rapidly (over minutes to few hours).

Loading Dose

For patients already on opioids: Administer loading dose of opioid equal to 10% of total dose in past 24 hours

For patients not already on opioids: Administer IV or SC loading dose as follows:

Morphine 5 mg, children <12 years: 0.1 mg/kg

Subsequent Dosing

Doses may be given every 10 minutes PRN for end-of-life symptoms.

Escalate dose as follows (note: 5 mg is given as an example, actual dose may vary):

First dose: 5 mg, if ineffective after 10 minutes, then give

Second dose: 5 mg, if ineffective after 10 minutes, notify prescriber,

Third dose: 7.5 mg (1.5× starting dose), if ineffective, after 10 minutes, then give

Fourth dose: 7.5 mg (1.5× starting dose), if ineffective after 10 minutes, then give

Fifth dose: 10 mg (2× starting dose)

Once good pain relief is achieved, provide the total dose administered during the titration phase SC or IV q4h regularly and as a PRN/SOS dose.

Do not use only PRN doses, as this will allow the symptoms to return and will lead to more distress.

Pain assessment may be by use of pain scale or observations of verbal and nonverbal behavior (crying, grimacing, and moaning either at rest or when moved).

Continuous Infusion Instructions

Recommended hourly rate = total opioid administered in the steps just outlined, divided by 4.

Recommended 24-hour amount of medication = total opioid administered in the steps just outlined, multiplied by 6.

Adjuvant Therapy for Symptoms that May Accompany Pain or Dyspnea

See Chapter 13 for dosing.

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For agitation

Recommended starting dose:

PO//IV/SL/PR lorazepam or PO/SC/IV midazolam: PRN for anxiety or agitation

SC/IV/PO haloperidol: PRN for hallucinations or agitation

For Excess Respiratory Secretions

Oral atropine 1% eye drop solution, SC glycopyrrolate or SC hyoscine butylbromide

Adapted from *Textbook of Interdisciplinary Pediatric Palliative Care*.⁸

Ensure that the healthcare team (or family) has the following medications available to be given immediately for severe symptoms (such as pain, dyspnea, and agitation or restlessness) at the end of life.

- Subcutaneous/Intravenous (SC/IV) morphine (or another opioid, if available)
- Rectal (PR) diazepam (or midazolam SC/IV if available)

The goal at this stage is comfort, not to reverse the underlying cause of the symptom. Discontinue vital sign assessments, pulse oximetry, nonessential medications (including IV fluids), and laboratory and radiological tests.

If symptoms are not well managed, this suffering may be the family's final memory of their loved one, which can cause further distress and complicated bereavement.

Do not be afraid to rapidly increase the dose of morphine or other medications in order to achieve symptom control. For patients who experience refractory symptoms, palliative sedation can be considered (full details are beyond the scope of this chapter).

The SC route is useful in this phase of illness in order to manage symptoms quickly, without the trouble of needing to maintain IV access. Insert a butterfly needle and secure it in place. This can be kept for up to 7 days (provided the SC site does not have any significant redness or tenderness). Medications that can be given SC (same dose as IV) include the following. See also Chapter 13 for complete details and a compatibility chart.⁷

- **Opioids:** morphine, hydromorphone, fentanyl, methadone, oxycodone, diamorphine
- **Sedative-hypnotics:** midazolam, clonazepam, phenobarbital

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- **Antiemetics:** haloperidol, metoclopramide, levomepromazine (methotrimeprazine)
- **Antisecretory agents:** hyoscine butylbromide, hyoscine hydrobromide, glycopyrrolate, octreotide
- **Antihistamines:** cyclizine, promethazine
- **Miscellaneous:** dexamethasone, methylalantrexone, naloxone

Escalating Pain, Dyspnea, and Agitation



These are three common symptoms that often require intensive treatment near the end of life. The use of rapidly escalating doses of opioids is appropriate to manage pain or dyspnea and, when used by trained providers, will not cause respiratory depression or addiction or hasten death (see Box 9.3).

To facilitate rapid titration of medications, ensure that clinicians are readily available and that medications, including opioids, are available at the bedside for rapid administration. Refer to Chapters 4, 5, and 7 for complete management.

Confusion, Disorientation, and Delirium



Delirium at this stage is generally due to multiple conditions, which are generally irreversible, such as the underlying disease process, metabolic and electrolyte imbalances, liver and renal failure, infection, and hypoxia. Urinary retention is a potentially reversible cause, which can be managed with insertion of a Foley catheter. Refer to Chapter 7 for guidelines in treating delirium.

Counsel the Family

Patients may still be able to hear, so encourage family members to speak to and reassure their loved one.

Weakness and Fatigue



This condition is expected and will increase as the patient gets closer to death. Do not give stimulants (methylphenidate, steroids) to try “to wake the patient up” at this stage of illness. Ensure that the patient is gently turned and repositioned, to avoid pressure ulcers (if death is imminent, this is not relevant).

Counsel the Family

Allow the patient to rest, as weakness and fatigue are a normal part of the dying process. The patient will have a limited amount of energy, so help the patient prioritize how they want to use their energy.

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Some patients may experience a brief period of increased energy and mental alertness prior to their death. If this occurs, it should be used for quality interaction with loved ones.

Decreased Oral Intake



Reduced oral intake is a normal part of the dying process; patients who are close to dying do not feel hunger or thirst. Fluids and foods should be provided if desired by the patient. Do not provide parenteral fluids since research shows that this does not improve symptoms, quality of life, or survival for palliative care patients who cannot drink.⁹

Counsel the Family

Forcing a patient to eat or drink may be dangerous because of the risk of aspiration. Providing IV fluids will not prolong life or improve comfort, but it can cause distress from edema and dyspnea. Providing oral care by swabbing the mouth with water and keeping the lips moist with petroleum jelly (Vaseline) or lip balm is recommended.

For families who are struggling with stopping (or not starting IV fluids), a trial of 24 hours of IV/SC fluids may be offered. Discuss with the family and agree on the goals of the therapy. Prior to starting fluids, reassess daily; if the patient is not improving, then discontinue fluids.

Respiration Pattern Changes



Breathing will change as the patient approaches end of life, with breathing becoming slow and shallow or rapid and shallow. Periods of apnea or increased work of breathing are common but do not necessarily indicate dyspnea, and need not be treated unless it is distressing to the patient.

Counsel the Family

Advise the family that breathing changes may occur, but generally do not cause distress in the patient.

Respiratory Secretions



Patients often have impaired ability to swallow at the end of life and cannot clear secretions. These secretions can accumulate and lead to gurgling or rattling sounds. This most often occurs when the patient is only minimally conscious or unconscious and does not cause the patient any distress.

Position the patient on their side with the upper body elevated to allow secretions to passively drain out of the mouth. Reduce or stop artificial (IV) fluids or nutrition (IV or NG), since this will worsen this symptom.

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Suctioning is not usually helpful and may be distressing to the patient. Consider suctioning only if thick mucus or blood is present in the mouth and can easily be removed with a soft catheter.

Medications

- Atropine 1% (eye drop solution), glycopyrrolate, hyoscine butylbromide, or hyoscine hydrobromide

The following medications will not work for secretions deep in the lungs (i.e., pulmonary edema or pneumonia) and are not always effective for upper airway secretions. See Chapter 13 for dosing.

Counsel the Family

Convey to the family that the patient is unaware of this symptom and it is not causing them discomfort.

Incontinence and Urinary Retention



Incontinence of urine, stool, or both is common. Keep the patient clean and dry. A Foley catheter may be helpful but is not always needed, since urine output is minimal and absorbent pads or cloth and plastic can be used.

Urinary retention may occur and should be suspected in a restless patient with a distended bladder. In this case, a Foley catheter should be inserted.

Urinary retention can be a side effect of opioid medication, which is more commonly seen in infants and young children. A Foley catheter or intermittent catheterization may be needed.

Seizures and Convulsions



Seizures can be caused by cancers (primary or metastatic), drug toxicity (e.g., pethidine/meperidine), metabolic or electrolyte abnormalities (hypoglycemia, hyponatremia, hypercalcemia), hypoxia, severe liver failure, infections of the central nervous system (CNS), or epilepsy. Treatment is comfort focused, and a full investigative workup is not necessary.

For children with a history of epilepsy, if the child can no longer swallow medications, SC midazolam or another benzodiazepine should be started.

Management

See Chapter 13 for dosing. Corticosteroids can be considered for seizures secondary to brain metastasis, to reduce peritumoral edema.

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Acute Treatment (Status Epilepticus)

- **Diazepam, lorazepam, or midazolam**, repeat after 5 or 10 minutes if needed.
- If these are ineffective, consider doubling the dose of midazolam or diazepam or give **phenobarbital**.
- This should be followed with regular phenobarbital, to prevent further seizures.

Prophylactic Management

- This should only be considered for patients with brain metastasis who have already had a seizure or malignant melanoma with brain metastases and in children with epilepsy.
- Phenytoin, carbamazepine, or valproate can be considered.

Pediatric Treatment Considerations

Parents should be trained in the use of sublingual (SL) lorazepam or rectal (PR) diazepam as abortive medications if a child is likely to have a prolonged seizure at home. Box 9.4 provides guidance on PR administration as an alternative route.

Box 9.4 Rectal Administration of Medications for Children

Administer medication rectally in children using a syringe attached to a small feeding tube cut to 5 cm in length. Insert the feeding tube 4 to 5 cm beyond the anal margin for an older child and less for an infant.

Home-Based Palliative Care



Families should be asked about their preferred location for death. Providing home-based palliative care in a humanitarian crisis is possible and, indeed, preferable, as it may relieve the burden on healthcare facilities. Several home-based palliative care services have been developed in refugee camps and other humanitarian crisis situations.^{10,11}

For patients who wish to go home, it is very important to provide a 24-hour contact number for a clinician, since families frequently need advice about symptom management. Without telephone support, patients frequently return to the hospital when pain or other symptoms are not well controlled or they die at home with significant suffering.

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Providing home visits from trained community health workers enables families to stay at home. Counseling and training for family caregivers prior to discharge is important. Box 9.5 shows a checklist for counseling caregivers preparing for death at home.¹²

Box 9.5 Counseling Checklist for Family Caregivers

Physical Care

- Moisten mouth with ice chips or a damp cloth soaked in water or fruit juice.
- Keep lips moist with balm or petroleum jelly (Vaseline).
- Keep the person clean and dry; use cloths or pads for urinary incontinence.
- Give the medications to control symptoms, at the correct times.
- Do not wait until the symptoms are severe, as this will lead to symptoms that are more difficult to control.
- Do not force the person to eat or drink. If they do not want to eat, this is okay.
- Assist the person to change position or turn every 2 hours to prevent pressure ulcers.
- Contact the home palliative care team (or whoever is providing 24-hour telephone support) if pain or other symptoms are not controlled.

Emotional and Spiritual Care

- Tell the person that they are loved and will be remembered.
- Ensure that the person has opportunities to discuss any feelings of guilt, worry, or regret.
- Connect with spiritual or religious leaders if the person wishes this.
- Sit with the person, hold their hand, and talk to them.

Home palliative care team members should include the following:

- Community health workers (CHW) with training in basic home-based palliative care
- Physicians and nurses with training in palliative care who supervise and provide guidance to the CHWs and visit patients who are having significant uncontrolled symptoms

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An emergency symptom management kit, kept at the patient's home, can be used by CHW or trained family members to provide relief for acute distress in a patient at the end of life. The kit should contain the following medications:

- Morphine (or other opioid)—for pain and dyspnea
- Haloperidol—for nausea and delirium
- Hyoscine butylbromide (or other agent for oral secretions/congestion)—for secretions
- Midazolam, diazepam (or other benzodiazepine)— for seizures, catastrophic bleeding, and acute respiratory distress

Special Situations



Unsuccessful Resuscitation

During resuscitation, allowing the family to be present is preferred, as this can lead to less anxiety, depression, and second-guessing about the care provided and the competence of staff.^{13,14}

A member of the healthcare team should be assigned to stay with the family to update them about what is happening, answer their questions, and provide emotional support.

Discontinuing Fluids and Nutrition

In patients who have hours or days to live, it is considered standard of care to discontinue medically administered fluids and nutrition (see section Decreased Oral Intake).

Medically provided fluids and nutrition can ethically be withheld or withdrawn if they are no longer in the best interest of the patient—for example, if they only prolong and add morbidity to the process of dying.¹⁵ Fluids and nutrition may be withdrawn from a child who permanently lacks awareness and the ability to interact with the environment, such as a child in a persistent vegetative state or children with anencephaly.

It is important to counsel patients and families that this does not mean clinicians are “giving up” on a patient or abandoning the patient but rather focusing intensely on comfort and support.

Discontinuing Ventilatory Support

It may be ethically appropriate to discontinue intensive respiratory support (e.g., noninvasive or invasive ventilation) in certain circumstances. These supports are often started when a patient's prognosis or illness trajectory is unclear or when the patient is believed to have a reversible condition.

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It may become clear that the underlying cause of ventilator dependence is irreversible. In these situations, continued ventilatory support will not provide meaningful quality of life and may prolong suffering. This act of discontinuing ventilator support (or other life-sustaining treatments) is not the same as euthanasia or medical assistance in dying.

It is essential to involve the family in the decision to discontinue ventilatory support. Involving religious or cultural leaders may also be necessary.

After discontinuation of ventilation, most patients live only minutes or hours; however, there are some patients who may live for a few days or longer. Clinicians must prepare the family for the possibility that the individual may breathe on their own, especially in pediatrics, where this is more common.¹⁶

Management: Before Withdrawing Ventilator

- Ensure that family are present, if desired.
- Turn off all monitors and alarms.
- Discontinue all other life-sustaining treatments (e.g., artificial nutrition and hydration, antibiotics, dialysis).
- Remove all unnecessary medical paraphernalia (NG tubes, IV lines, etc.).
- Allow any neuromuscular blocking agents to wear off.
- Ensure that a rapid-acting opioid (e.g., morphine), benzodiazepine (e.g., midazolam or lorazepam), and an agent to manage secretions (e.g., glycopyrrolate) are available and drawn up at the patient's bedside.
- Give a dose of opioids and benzodiazepine prior to withdrawing the ventilator, to ensure the patient does not feel any discomfort or dyspnea.¹⁷

Process of Withdrawal

- Ensure that the patient appears comfortable.
- Withdrawal by immediate extubation is recommended.¹⁸

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After Ventilator Withdrawal

- If the patient appears distressed, symptoms should be immediately and aggressively controlled, by giving morphine and midazolam, every 10 minutes, until distress is relieved.
- A clinician should be easily available to answer questions and manage symptoms.

Memory Making



While this is especially relevant parents when a child dies, it can also be meaningful for families of an adult who dies. Having tangible objects to remember their loved one supports the family in their grief. This is especially important with a pregnancy or infant loss, as parents have few tangible memories of their child's short life.

In many cultures, parents are encouraged to try to quickly forget that a child has died, but this is not recommended, as it leads to more complicated grief for parents.

Having tangible objects to remember their loved one supports the family in their grief. This is especially important with a pregnancy or infant loss, as parents have few tangible memories of their child's short life.

Common memory-making activities that can be easily offered to families include the following:

- Photographs or videos.
- Prints or molds of hands and feet, locks of hair
- Linking objects, which provide a physical reminder of the connection between the child and loved one (e.g., a pair of special necklaces or bracelets, one of which is placed with the child and the other with the parent).
- Personal items: clothing, baby blanket, small toys, hospital bracelet, birth certificate, bassinet card.
- Memory boxes: items can be stored and looked at when desired.

Some parents may not want to keep any memory items, which should be respected. All parents should be offered memory making, since in all cultures, there are some parents who will desire this.¹⁹

After-Death Care



It is important to express empathy with a simple statement, such as "I am sorry for your loss." Confirm the death by physical examination (absence of heart sounds, palpable pulse, or respirations for 60 seconds). Document the date and time of death in the medical record and the cause of death.

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Allow the family as much time as they desire to say goodbye and to perform any religious or cultural rituals, as permitted within the limitations of the setting.

During an epidemic (e.g., Ebola), it may not be possible to release the body to the family, so assistance from a psychologist or spiritual support person is important to support the family's bereavement.

Supporting Staff Who Provide End-of-Life Care



Witnessing frequent suffering and death can cause staff burnout, compassion fatigue, and moral distress. Chapter 17 provides more details about how to address this.

Regular support meetings create a safe space for staff to reflect and express their emotions on providing end-of-life care. Staff can reflect on the care that was delivered—what went well, what could be improved. Senior staff members should attend to demonstrate the importance of seeking support.

Commemorating the patient is also important for healthcare providers. This can be done by having memorial services, attending funeral services, or having follow-up contact with families. Letters, phone calls, or text messages from staff are deeply valued by families who often treasure the memories of this small act of kindness by staff.²⁰

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