

PART II: WHEN DEATH OCCURS

Dying in Institutions The discussion that follows about preparation for expected death and what to do when the patient dies is relevant to patients dying in any setting (e.g., at home, in hospital, in nursing homes, other extended care facilities, jails, etc). However, a few remarks are warranted regarding the particular challenges of ensuring a comfortable death in an institution whose culture is not focused on end-of-life care.

1. Create a home-like environment

- Institutions should make the environment as home-like as possible
- To help ensure privacy, move the patient to a private room where family can be present continuously and intimate with the patient if they would choose to do so
- Encourage the family to surround the patient with a few personal things or photos

2. Facilitate continuity of care

- Prepare the professional staff and encourage continuity of care plans across nursing shifts and changes in house staff
- Avoid changing settings abruptly simply because the patient is dying as this can be very disruptive and distressing to everyone (e.g., transferring from a nursing home to hospital or vice versa)
- As many patients approach the end of their lives, they prefer to remain with the caregivers they know, rather than be transferred to another facility

3. Consider a specialized unit

- Priorities and care plans at the end of life differ considerably from those for life-prolongation and cure
- It is frequently challenging for physicians and other health care professionals to incorporate both into a busy hospital or skilled nursing facility
- If the provision of end-of-life care proves to be difficult in these settings, consider a specialized unit where patients and families can be assured of the environment and the skilled care they need

As Expected Death Approaches No matter how well families and professional caregivers are prepared, they will often find a prolonged death to be draining, particularly if the patient is intermittently restless or agitated. To help family members through this difficult time as death approaches providers can:

1. Be available to review the status of the patient and answer questions

- Families may need to hear gentle repetition and clarification of:
 - the goals of care
 - the futility of life-prolonging therapies, and
 - the irreversibility of unfolding events
- Throughout the last hours of life, particularly as death approaches, families will benefit from repeated contact the their physicians and/or other members of the interdisciplinary team
 - To minimize confusion and unnecessary telephone calls, clarify the role of the physician and members of the interdisciplinary care team and their contact information in advance
 - Families will settle best if questions are answered calmly and their concerns addressed promptly
 - To be effective, ensure that a knowledgeable physician, or other health care professional, is available by telephone 24 hours per day, 7 days per week
 - Delays in communication only heighten anxiety and may leave families frustrated that the care provided was not the best that was possible

2. Encourage plans for rites, rituals, and funerals

- Advance discussion should ensure that everyone is aware of personal, cultural, and religious traditions, rites, and rituals that may dictate:
 - How prayers are to be conducted
 - How a person's body is to be handled after death
 - When/how the body can be moved
- To expedite arrangements for the funeral, memorial services, burial, or cremation, suggest that the patient and/or family contact the funeral home in advance

3. Review the Signs That Death Has Occurred

- As expected death approaches, answer questions and review the signs and potential events that may occur as the patient dies
- Signs that death has occurred include:
 - The heart stops beating
 - Breathing stops
 - Pupils become fixed
 - Body color becomes pale and waxy as blood settles
 - Body temperature drops
 - Muscles and sphincters relax
 - Urine and stool may be released
 - Eyes may remain open
 - The jaw can fall open
 - Observers may hear the trickling of fluids internally

What to Do when Death Occurs

- If the patient dies at home, remind families and caregivers that there is no need to call 911
- If a home hospice program is involved, have the family call the hospice
- If a home hospice is not involved, determine in advance, who should be notified
- Make certain that family and professional caregivers understand that there are no specific "rules" that govern what happens when the patient dies (in any setting)
- Unless death is unexpected, or malice is suspected, involvement of the coroner's office is usually not required (local regulations may vary)
- If the patient has not requested organ donation or made an anatomic gift to a medical school (for which there will be specific protocols prearranged), the physician or other health professional need not attend quickly to witness what has occurred
- Presence may be helpful if family members are distressed and need immediate support with their acute grief reactions

After Expected Death Occurs

1. Shift Care to Family and Caregivers

- When expected death occurs, the focus of care shifts from the patient to the family and those who provided care
- Everyone present will have a different experience and a different sense of loss
- Even though the loss has been anticipated for some time, no one will know what it feels like until it actually occurs, and indeed it may take hours to days to weeks or even months for each person to realize the full effect
- Encourage all who are present, including caregivers, to take the time they need to realize what has happened and say their good-byes
 - There is no need to rush, even in the hospital or other care facility
- Encourage everyone to touch, hold, and even kiss the person's body as they feel most comfortable (within the limits allowed by personal, cultural or religious practices, while maintaining universal body fluid precautions)
 - The time spent with the body will help people through their acute grief
 - It will help them to develop a new sense of awareness of what has happened
 - It will benefit everyone as the event becomes more distant and family members start to adapt to the absence of their loved one

2. Create an environment that will facilitate the acute grieving process

- To facilitate the acute grieving process, professional caregivers may wish to create a visually peaceful and accessible environment when family members are ready
- A few moments spent alone in the room positioning the patient's body, disconnecting any lines and machinery, removing catheters, and cleaning up any mess will allow the family closer access to the patient's body
- If eyes remain open, eyelids can be manually held closed for a few minutes and will usually remain closed once they dry
 - If they remain open, a small amount of surgical tape or a short Steri-strip will hold them closed for longer without pulling on eyelashes when they are removed
- If the jaw falls open as muscles relax, a rolled up towel placed under the chin of an elevated head will usually hold the jaw closed until muscles stiffen some 4 to 6 hours later

3. Assess grief reactions

- Caregivers who have not been present for the death can assess how family members are handling their loss by listening to a recounting of how things went leading up to the death and afterward
- Spiritual advisors or other interdisciplinary team members may be instrumental in orchestrating events to facilitate the transition that those present are experiencing
- Grief reactions beyond cultural norms suggest a risk of significant ongoing or delayed grief reactions

4. Facilitate additional visitors

- When the immediate family is ready, invite others who have been close to the patient, including caregivers, to come to the bedside to witness what has happened before the person's body is moved
- When letting people know what has happened, follow the guidelines for communicating bad news
 - Try to avoid breaking unexpected news by telephone, as communicating in person provides much greater opportunity for assessment and support
- As additional visitors arrive, spend a few minutes to remind them of the changes in body color, temperature, and the scene they will see. This can reduce the surprise and make the transition a little easier for everyone

Moving the Body

1. Beginning Preparations

- Preparations for burial or cremation and a funeral or memorial service(s) can begin once family members have had the time they need to:
 - Witness what has happened
 - Deal with their acute grief reactions
 - Observe their customs and traditions
- Some family members may find it therapeutic to help bathe and prepare the person's body for transfer to the funeral home or the hospital morgue
 - For many, such rituals will be their final act of direct caring

2. Arranging transfer of the body

- Once ready, family members or professional caregivers (at the request of the family) may call a chosen funeral service provider and arrange to move the person's body
- Most funeral services are available to transfer the body 24 hours per day, 7 days per week, and will attend at home within a short time of the call
- If the patient is in a health care institution, the funeral home will deal directly with the institution

3. The death certificate

- Depending on local regulations and arrangements, some funeral directors will insist on the completed death certificate being present before they pickup the body
- All will require a completed death certificate to proceed with any body preparation and registration of the death
- To avoid delaying the process, ensure that the physician who will complete the certificate has ample warning that one will be required (though the physician does not need to be called at the moment of the death just to do this)

4. Addressing family concerns

- Families who have not discussed funeral arrangements in advance may have many questions about burial, cremation, embalming, and/or different types of services
 - If the funeral director is not available, a little time spent by the physician answering their questions will ease the anxiety of the surviving family members
- For many, the arrival of the funeral directors to remove the body is the next major confrontation with reality, particularly if the death has occurred at home
 - Some family members will wish to witness the removal
 - Others will find it very difficult and will prefer to retire to another place and allow professional caregivers to handle things discreetly
- For some, the thought that the person's body will be enclosed in a body bag is intolerable
 - Ensure that professional caregivers and funeral directors have the sensitivity to recognize when this is an issue and negotiate a suitable alternative (e.g., not closing the bag until it has been removed from the vicinity of the home)
 - Institutional caregivers should be aware that there may be similar reactions by family members when professionals prepare the body for transfer to the morgue

Other Tasks after Death Occurs At home, once the body has been removed and family members are settled, professional caregivers can offer to assist them with some of their immediate tasks

- They may notify other physicians and caregivers that the death has occurred
- They may notify health care service agencies so that services can be stopped and equipment removed from the home when it is convenient for the family
- They may suggest how to secure valuables
- They may dispose of medications, particularly opioids, in the toilet, and they may dispose of biological wastes (caregivers should be clear about local regulations governing ownership of medications after a death and waste disposal)
- When family members are ready, professional caregivers can let the family know how to reach them, then leave them to have some privacy together

Bereavement Care

- Immediately after the death, those who survive will need time to recover from their stress and fatigue, and restore their environments back to normal
- A bereavement card and attendance at the patient's funeral may be appropriate
- For many physicians and members of the professional team, encouraging follow-up visits from family members is part of their professional duty of care. During these visits, providers can:
 - Assess the severity of grief reactions to the recent loss
 - Assess coping strategies
 - Provide support
- When ready, professional members of the interdisciplinary team can also offer to assist family members to:
 - Deal with outstanding practical matters
 - Secure documents to redeem insurance
 - Find legal counsel to execute the will
 - Meet financial obligations
 - Close the estate

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