

Issues in the Provision of End-of-Life Care: An Overview for General Staff Education

Optimum end-of-life care requires not only the expertise of palliative specialists but the sensitivity of all involved staff. Caring for dying patients can be deeply rewarding, but it still can be difficult at times for many of us in health care. These patients can stir in us our personal struggles with dying and death. They can remind us of the limits of medicine, and seek from us solutions that we may not be able to provide. They—and their families—can express powerful emotions and raise strong feelings in us. They can draw us into conversations that make us uneasy about what to say, or simply ask time from us when we feel pressed by a busy workday. Yet, in the hospital we frequently meet people who are facing death and who need our help in doing so. Encountering these patients usually turns out not to be so daunting after all, but rather to be quite manageable. The following basic points may be valuable for staff to keep in mind about end-of-life care:

- 1) Patients should feel free to make known their questions or concerns about dying and end-of-life care, and members of the care team should invite patients to express what is on their minds. Discussions should be in an atmosphere that patients find "safe." Privacy is often key. Also, requests to speak with particular physicians, nurses, or other care team members may be of timely importance to patients as they process their own needs and act upon them. Patients' questions about their illnesses and care plans should be answered as quickly as possible, as the very idea that "time is short" can make waiting burdensome.
- 2) A specific concern shared by many patients is pain management, and staff should be especially attentive to any question about pain.
- 3) At every possible point, patients' rights to make decisions about their medical care should be affirmed. The subject of Advance Directives should be raised by appropriate staff in such a way as to be part of this affirmation. Issues of personal control are frequently crucial to patients.
- 4) Organ donation may be a sensitive topic, but many patients see in it a validation of their capacity to help others—indeed, to accomplish the high ideal of saving another's life—and family members may find comfort in the enduring legacy of such a noble gift. Any discussion of donation should emphasize the honoring of patients and their values and not merely the potential use of their organs. Questions should be addressed by specially trained staff or by representatives from the Delaware Valley Transplant Program.
- 5) Patients and their families should be aware of specific resources for support in the hospital, including Social Work, Pastoral Care, and the hospital's Ethics Committee. If the patient is enrolled in hospice care, that will provide additional resources. Patients should also be encouraged to involve their own networks of support, including friends and clergy.
- 6) Religious and cultural needs may be keenly felt, especially regarding rituals of forgiveness, blessing and affirmation of one's value and identity. Patients may request sacred objects, music, or a specific diet following religious or cultural traditions. They may need to discuss issues of spirituality and meaning, often with religious authorities.
- 7) Relationships may be much on patients' minds, and every effort should be made to facilitate communication with friends and family members, if this is requested, especially those at some distance and those with whom reconciliation is a concern. Visiting hours may need to be modified to accommodate patients' contact with certain people. Conversely, some patients may request more privacy—they may want time to "think by themselves," or they may feel the need to be shielded from conflict with or between family members.
- 8) Patients may wish to have familiar items from home, including photographs or a favorite blanket.
- 9) Expect that emotions can run strong when touching upon dying and death, including feelings of fear and sadness and anger. Expression of these feelings is normal and generally healthy. Staff should try to hear these expressions—without taking them personally—in terms of the needs of the patient.
- 10) As a patient nears death, the family can have difficulty interpreting the changes happening in their loved one's body. Appropriate members of the care team should ask if there are questions about the dying process and offer a medical understanding.
- 11) All staff should be attentive to their own emotional stress while working with the dying. Staff should consider how their network of personal support may include colleagues, Pastoral Care, and Health System resources like the Employee Assistance Program. Health professionals often need to grieve the death of patients for whom they have cared.