

4

Create *an* End-of-Life Care Plan

Lance writes ...

By this point, you have developed skills to deal forthrightly with the concept of death and dying. You confronted denial and probably moved toward acceptance. You considered styles of decision-making. You thought about roles to be played by various individuals on behalf of the dying patient. You analyzed myths, and considered new ways of looking at a very serious issue. Just by virtue of the fact that you made it this far is a strong indicator that you have the courage and wisdom to do an admirable job as you work through the dying process, whether it is your own, or someone else's.

The next few steps are relatively easy by comparison. Our job at this point is to simply help you organize your thoughts into a meaningful end-of-life care plan. Obviously, every situation is different, so we must

use generalities. Keep in mind what we have said many times before...the goal is to orchestrate a well-managed, peaceful, and comfortable death for the person for whom medical therapy is futile.

Rather than lengthy text, you may appreciate a clear, concise list of important considerations in your planning. In later chapters, you will find lengthy, descriptive advice on language and style that augments the following points:

- Call a family meeting. Include all appropriate people, especially the patient, if at all possible.
- Identify the surrogate, spokesperson, and leader. Often this will be the same person. If the patient is able and willing, he or she should be the leader and spokesperson.
- Clarify that medical futility has been reached and the patient or surrogate has decided to pursue comfort care as a priority.
- Relay known diagnostic and prognostic facts and opinions from the doctor, taking care to avoid speculation or elaboration.
- Give everyone a chance to voice their feelings regarding death and comfort care, in general and with regard to the dying person.
- Make sure the appropriate documents (for example, the living will, health care power of attorney, and Bedside Do Not Resuscitate order) have been filled out and signed. Place copies at the patient's bedside, at the doctor's office, and hospital and/or nursing home, as well as with the surrogate and other involved family members. It is wise to be over-prepared rather than under-prepared.
- Discuss with family and friends how much time and effort they are able to contribute to the care plan. Consider a schedule of attendants to be with the dying person. Consider bathing and hygiene: will the family handle it or will a professional, such as a nurse's aide, be hired? Identify needs and gaps to be discussed with the physician, social worker, and/or hospice people.

- Discuss funeral arrangements ahead of time to avoid confusion and angst during the turmoil and grief that may occur immediately after death.
- Make appointments with the doctor and hospice. Be prepared to make it clear that medical futility has been accepted, comfort measures are desired, and plans have been made to care for the patient as much as possible. Also be prepared to identify areas where help is needed. Do not be afraid to ask, as the professional may be aware of available resources that the layperson is not.
- By the time you have done these things, and taken some organized notes along the way, you will essentially have your plan in place. Review your notes and the situation, and write down an outline. We have provided a Notes Section at the end of this book to organize your information. This becomes the written representation of the end-of-life care plan. Everyone, from the patient to the physician, will be relieved to have addressed many of these issues ahead of time, and the patient will indeed receive much more focused and appropriate care than he or she would have otherwise. Given the nature of courts and legal challenges, it would be wise to have notes of important meetings signed and notarized as well. This adds credibility to the soundness and integrity of the plan. Also, a well-conceived narrative (either written or on audio or video tape), signed by the patient and notarized, may detail their overall views about death and describe the style of end-of-life care. This would serve to further document the patient's wishes and to relieve the burden of guilt that might eventually befall the surrogate. Remember that the living will only covers some very specific clinical situations and many possibilities are left out.
- Once all that is in place, then turn your attention back to living. Within the time and energy remaining to the dying person, start imagining trips to be taken, visits to make, and conversations to be had. The team should focus on helping the person who is dying to move through the various stages of grieving and confession that Bert gave us, as well as helping the person to have fun and pleasure.