

About Hospice

Category : End of Life Care

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The Philosophy and Practice of Hospice

No aggressive treatment.

Hospice care is what is known as palliative care. It has to do with palliation or relief of symptoms. Hospice care is begun when a patient and/or family has come to the recognition that a cure is impossible (apart from the working of a miracle). Those of us who really believe in hospice believe that life and death are sacred. Death is as much a part of the developmental life cycle as birth.

The fundamental prerequisite to hospice care is the recognition by patient and family that the time for aggressive care is over. You cannot be on hospice care and choose aggressive treatment measures, unless they are for management of a particular set of symptoms. If you decide while on hospice that you do want to seek treatment, you will have to revoke your hospice benefit. If a patient and family are not together on these decisions, it will generally only end up increasing the emotional pain and anxiety of the patient or family. PLEASE, don't assume you know what is best for the patient.

Main Goal.

The main role of hospice is to keep the patient comfortable. Comfort involves many dimensions, not just physical. It involves emotional and spiritual well-being also. Indeed, by law (in the US, at least) a federally reimbursed hospice must be able to provide you with resources that address all aspects of your care: physical (a physician or nurse), a social worker, and a spiritual counselor. In addition, physical comfort involves more than just pain control. It often involves control of bowel symptoms, sleep regulation, breathing difficulty, sexual matters, and many other issues. Nonetheless, one of the biggest reasons why people choose hospice is because of their belief that it offers the promise of pain relief while promoting as much independence as possible. Indeed, one of the major reasons people consider physician-assisted suicide is because of fear of intractable pain.

The hospice team. Hopefully, you live in an area where there is a large hospice. A large hospice will be more likely to provide a full complement of resources. While it is a requirement that hospices have certain disciplines available (physician, nurse, social worker and spiritual counselor, and some sort of bereavement system in place), many of them only utilize part-timers or volunteers for some of these positions. In addition, hospice has become more competitive, more business oriented, and less patient oriented in recent years. Also, as in all areas of health care, government has greatly cut benefits to hospice providers. Thus, the staffing is frequently far below optimal levels, especially in the psychosocial components of the team. You should look for the smallest patient to staff ratio and a full complement of team members. Finally, please don't make the assumption that the chaplain is always out to convert you. There are many of us who'd like to do nothing more with you than make friends and chew the fat (as long as its at least occasionally meaningful fat!). Okay, okay, one more

thing: You can change your primary care physician to the hospice physician. This is often very helpful because hospice physicians are generally especially skilled at pain control.

Location.

Hospice care serves patients in homes, in hospitals, and in nursing homes. I have even had patients in rescue missions and motels. Some hospices even have their own wing of a hospital and, in some large cities, their own freestanding building. Hospices are very useful in helping families to place a loved one in need of long term care. They will generally be reluctant to recommend a particular nursing home. But if you make an effort to do some good homework on your part, they will often give you a feel for what may be the better choice.

The Focus of Care.

The primary focus of care should always be the patient. Not the family. Not the care providers. The patient. If the patient is made comfortable, then the family can and should get the attention. But the symptoms of the patient must come first and must be controlled.

Pain Control. If you choose hospice care, you should expect relative control of pain. There will likely be some pain episodes, especially as you, your nurse, and your physician seek to balance out the medications (meds). Pain management follows a certain routine, an increasingly higher ladder. Your physician must first assess your pain and then prescribe medications equal to his assessment. In general, she will start by prescribing the least strong meds that she/he assesses you need. She WILL NOT start off with stronger meds unless, in her view, they are appropriate to your circumstances. Second, your physician will monitor your pain. Over time, if necessary, pain meds will become stronger or will be increased in size, frequency, or change in kind.

The biggest request of families is that hospice "keep my father comfortable." It is strange then, that families sometimes fall into one of two extremes: they either want the patient snowed (heavily medicated) or they want the patient alert, even if it means a reduction or withdrawal of pain medications. When these extremes occur, it often has many reasons:

â€¢ The family is so focused on their own anticipatory grief that they fail to understand the nature of the patient's pain. They are either ignoring the pain or minimizing it.

â€¢ The patient/family does not understand/does not want to understand/is afraid of the use of pain medicines.

â€¢ There may be some religious concern about the use of pain medicines ("Will that make him stop breathing?").

It is essential that patient/family and hospice caregivers work together to be clear about what the goals are for the patient. Those goals should be as unambiguous as possible (a Care Plan).

Finally, there is much confusion about the role of morphine in hospice care. It is not only helpful for pain but for some breathing difficulties as well. You should ask for clarification, resources, and help from the hospice staff if you have any questions about this.

[The Hospice Patient's Alliance](#) - There is much information that is very helpful on this site.

Unfortunately, for all the helpful information on this site, we cannot continue to recommend it. While

we are grateful for their much-needed mission of consumer advocacy, we are deeply troubled by their methods (litigious) and their positions. In a recent [press release](#) entitled Angels of Death Flourish In Hospice - Four Families Report. Hospice Advocacy Group Initiates Letter Writing Campaign 1/25/01, the Hospice Patient's Alliance asserts that "Research summarized in medical journals (see below) suggests that many hundreds and possibly thousands of patients in the U.S. may be euthanized without their consent." There are many changes occurring in hospice care that are deeply disturbing to me: poor staff to patient ratio; occasional incompetence; bureaucracy; and corporatization, among other things. But the assertions and implications of this site's management concerning hospice care in general are false.

In fact, many patients improve after coming on to hospice care and have to be taken off until they requalify.

I have read the case histories noted in the release and am concerned that this organization has chosen these cases to raise as examples of "involuntary euthanasia." These families seem/seemed incapable of 1) taking responsibility for their own care, 2) communicating with each other about their concerns and wishes, and 3) understanding the treatment protocol and either following it or changing providers. In fact, in the day to day practice of hospice care, these are the main difficulties that patients, families and staff encounter. (Hint, Hint! If you want to make sure that your loved one does well on hospice, make sure you address these issues.) There is NO DOUBT that poor communication and lack of respect for patient wishes was a significant factor in these cases. But this is a far cry from involuntary euthanasia. If the management of this site had spent more time providing hands-on hospice care, they would spend less time looking for "Angels of Death" and invest their time in more meaningful interventions for patients and families. This site risks destroying what it seeks to improve.

- Mike Davis, Th.M.