



San Diego Hospice  
& Palliative Care

**Excerpts from  
A Personal View of the Volunteer's Role  
Expectations and Realities of Hospice Work**

**Malcolm C. Rich**

**Adapted from  
The American Journal of Hospice Care, May / June 1985**

I became a patient care hospice volunteer in 1981 because I wanted to serve as an objective listener for the dying and for the family and friends of the terminally ill. After three years, I am writing this article to share with other volunteers my opinions about the role of the hospice volunteer. After contact with 15 hospice families, I am still not absolutely sure of the meaning of the term hospice volunteer. But I have experienced enough hospice situations to have formed opinions about the effectiveness of volunteers, and about the myths concerning dying and hospice that cause volunteers to have faulty expectations – with resulting anxieties and frustrations.

What we all read about the hospice movement and what we hear on television documentaries may not be what we will find as volunteers entering the homes of the dying. The sanitized public view does not include the nuances that volunteers need to know. This article looks at the importance of training, the multiple roles served by the volunteers and what we as volunteers might expect. The opinions I express are mine, and the reader may disagree with some or all of them. The important point is that we should be discussing these nuances, which include feelings and issues of practical strategies that volunteers may use to maximize their effectiveness and prevent burnout from stress, anxiety and emotional intensity.

### **Training and Continuing Education**

Without question, hospice training programs are useful endeavors. However, they do not nor should they be expected to be a cookbook course on how to be the perfect volunteer. Aside from the fact that there is no such thing as the perfect volunteer, training courses are designed to introduce volunteers to the

hospice concept, give some examples as to what we might do and help the trainees acquire useful skills. Volunteers who admit that they leave these courses not knowing exactly what it is to be a volunteer are being honest. We draw upon what we learn in our training as we deal with our families so that a volunteer really begins to appreciate the training course only after he or she begins to visit families. As far as I am concerned, it is volunteers' gut level reactions as caring and resourceful human beings that make them good volunteers; training, continuing education and experience with hospice families sharpen and mold these reactions over time. It is little wonder that it is hard to define the term hospice volunteer.

## **The Role of Volunteer**

*Role as Listener.* As trained listeners, we listen to the dying person and his or her family rather than tell them what they should be saying. The topic of conversation might be the philosophy of life and death, but more likely it will be about the weather or a discussion of what the various family members have done throughout their lives. Volunteers with the expectation that they will sit for hours and listen to dying people philosophize about life and dying are likely to be disappointed. The dying process does not turn people into philosophers. It does make the dying person and surrounding caregivers anxious, fearful and sometimes mistrustful. It is our job as volunteers to use the art of listening to allow the families to talk through their problems.

The volunteer's role as listener should not be confused with that of a social worker. We are in the homes of the dying as friendly visitors to provide comfort and support, not to resolve long-standing problems within the family unit. This is a distinction that is often difficult to make and one of the reasons that volunteers need to consult with their supervisors when it is not clear-cut whether or not intervention is appropriate.

*Role as Back-up Resource.* The role of the volunteer as listener is a role often discussed in hospice training programs. But what happens when the patient cannot talk or chooses not to talk, and the family says it does not need to talk to volunteers? If this is the case, the role of the volunteer may become that of back-up resource – a role not to be taken lightly.

In one of my cases, the family brought in enough relatives and friends to be with the patient 24 hours a day. We were told at the beginning that we should be assigned to another case. However, we stayed with the case, checking regularly with the patient and caregiver to see if we could be of assistance. Ultimately, we were asked by the caregiver to become active participants when gaps occurred in the 24-hour coverage.

In another case, my partner and I were able to report an emerging pain control problem to the medical director because we had monitored a situation where we had been asked by a family to take a secondary role.

Thus, the role as back up is important for two reasons. The first is that volunteers should not underestimate the value of the security provided to the family by the mere availability of the volunteer. If something goes wrong, hospice volunteers may be called upon. The peace of mind provided to the family by this role is intangible and cannot be measured. Second, the role of the back up allows the volunteer to monitor the situation and to be prepared to take action if they discern a problem that hospice can be instrumental in resolving. Volunteers should not be lulled into inactivity because the family is not allowing them to take a primary role. The back-up role can be just as important, although more frustrating to the volunteer.

While there is nothing wrong with the back-up role, the volunteer should keep a question in mind: "Does the patient and family understand the role of the volunteer?" It is easier for the family members to understand the role of the hospice medical staff. Families can understand easily that the hospice medical director is present to assist in pain management. The role of the hospice nurse is equally clear. But the volunteer role is more amorphous. This discussion may be painful because the family members may not want to make any more decisions at a time when they are anxious and fearful; but to avoid problems later in the case, it is very important that the volunteer explain hospice to the family and discuss the volunteer role with them. Too often, families do not realize the potential of having volunteers available or make unrealistic demands on us. The chances of these unfortunate events can at least be reduced with some early straight talk. Therefore, it is important for the volunteer to sit down with the patient and family at the

outset of the case and discuss the options available. No, we do not do windows; and no, we do not provide nursing services, even if a volunteer happens to be trained as a nurse. Yes, we can do simple errands; and yes, we can stay with the patient while the family members take a needed rest.

## **Role of the Volunteer: What to Expect**

We, as volunteers, enter a case at a time when the family's emotional well-being may be at a low ebb. They may have already tried numerous approaches aimed at a miracle cure, and the miracle has not happened. The family may also be troubled financially and overwhelmed by all the nurses, doctors, medications and equipment. Yet, sometimes we find wonderful families who accomplish almost superhuman tasks as they face the dying process with courage, realistic

expectation and dedication to allowing the patient to die without pain and with as much dignity as the disease will allow.

We also meet families who cannot cope with the stark reality of dying. Their stress and fear may affect every step of their lives during what they consider to be life in a dark tunnel with no light at the end. They may even have trouble making decisions, and calm, usually rational, people may become abrupt and even rude, making statements that seem irrational, unfeeling or mean under the circumstances.

We will, in all likelihood, experience both types of families and many in between as well. Our responsibility is to comfort the patient and family without expecting tranquility. The idealized version of hospice about which we read in books and see on television occurs at times, but not as often as we would like. There is no one type of hospice family, and there is no one way to die properly. In fact, the hospice volunteer may not even like the patient, family members or any one associated with the particular case. Just because a person is dying does not mean that he or she will suddenly become introspective, considerate of others and a pleasure to visit. An ornery, demanding and unpleasant person may not change personality when they get sick.

As volunteers, we must bring large dosages of patience and caring for even the best person cannot be expected to be pleasant when they are suffering. Hospice patients become bedridden and often suffer the humiliation of incontinence. They may endure callous feelings and statements from friends and relatives. People under stress and suffering may act differently than if everything were well. It is important to remember that while it is understandable for volunteers to not always like their families, they must continue to serve and never allow feelings to get in the way of the amount of attention paid to the family. If there are serious problems in the relationship, then the volunteer can be replaced, but once the assignment is in place we must serve out our role to the best of our abilities.

## **General Considerations**

An important issue for any volunteer is how to become involved enough with the family that they will trust us, but to remain objective enough that we do not burn out from the stress and emotional strain. It is necessary for any volunteer who wants to be active within hospice for a long period of time to develop a network of persons to discuss cases, to discuss ideas and strategies and in which to confide feelings. The use of friends and acquaintances may be a breach of confidentiality and inappropriate in light of the sometimes gruesome details and depressing situations. Hospice interdisciplinary team members can be a source of information within hospice situations that seem pervaded by confusion.

In addition, it is critical to the volunteer role that the appropriate people have the right information, and keeping other interdisciplinary team members up to date on cases will reduce the likelihood that an issue will fall between the cracks. Each volunteer should find the appropriate hospice interdisciplinary team member to listen to his or her stories and *debrief* thoroughly after each case. It is one way to both defuse the strain and improve hospice effectiveness.

The issue of volunteer burn out should be addressed. Some volunteers burn out very quickly, and I believe the cause can be found, at least in part, in faulty expectations. There is not a way that a hospice training course can discuss every situation that a volunteer will encounter. Notwithstanding the sanitized version of death and dying being taught in college courses, the dying process may be humiliating and ugly or beautiful and inspiring. Hospice volunteers must expect and cope with both situations. We should not, as volunteers, underestimate the hard work involved, but be sure that we do not bear the burden alone.

## **Conclusions**

The volunteer will, over time, develop realistic expectations of what he or she will find when they enter the home. The volunteers at the outset should discuss their role and its limits with each of the family members and the patient. To help minimize volunteer anxiety, the volunteer should know where to reach a caregiver in case of emergency – particularly if the volunteer is staying alone with the patient.

The volunteer follows the difficult path of being close enough to the family to be useful but remain objective enough to provide support to the family at the time of death and thereafter. We are told that we will grieve along with the family. Many times this is the case, and we must utilize our support network to remain objective. How to do this comes with experience and is a critical component of the staying power of a volunteer.

I have attempted to discuss the multiple roles of the hospice volunteer. They range from active involvement to being a back-up resource, but the common link is that our goal is to make the dying process as comfortable for the patient and family as possible. Just as there is no hospice way to die – no singular best way to end one's life – there is no one way to be effective as a volunteer. The gut level reaction of volunteers, trained by programs and experience, is our greatest asset. As we slowly begin to rely on our reactions, there is corresponding reduction in the amount of anxiety associated with being a volunteer.

Hospice volunteering is rewarding and difficult. We, as volunteers, should not underestimate the level of difficulty. We must enter each case with realistic expectations and do the necessary communicating to reduce anxiety and thereby to reduce the possibility of burn out.