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Hospice Care or Caring Friends?

When my friend entered nursing home care, I was relieved to hear that he would receive hospice care. As it turns out, it is not as simple as that. When you attend a team meeting, you may meet the person in charge of making decisions for hospice care. However, you may not meet the individual providing the hospice care. It is extremely important that you meet that individual. You have a choice here. Just as you can choose your primary care physician or your oncologist you have a voice when it comes to your hospice care individual provider.

If unsatisfied, it is very important that you meet with the team of social worker, psychologist, and hospice care manager to discuss your concerns. Just as you want a good match with a therapist, you want and need a good match with the hospice provider. Perhaps that person is just right for someone else, but perhaps not for you.

The experience with my friend involved making a decision on this hospice care situation. Actually, he was forced to make a decision. He needed to choose. That choice, as it turns out, was quite easy. The young woman who was providing hospice care appeared to be very uncaring, and emotionally unsympathetic. She seemed emotionally unavailable. We, my friend and I and his best friend, were just beginning to consider requesting another person for his hospice care, when we were hit with yet another surprise. This journey has been filled with surprises!

We discovered that he was not allowed to see his one and only physician, his oncologist. The nursing home explained that he could not see an oncologist while receiving hospice care. (Go figure!)

I cannot help but recall the experience of my friend many years ago who was suffering with cancer and while her intention was one of positivity, she refused hospice care. Her children were left unprepared for her death. Not that we can truly and completely prepare children, or anyone at any age, for the inevitability of facing and accepting death of a loved one, but talking about it allows for some of that horrible, scary truth to sink in, to see the reality that is on its way, marching ever closer with each day.

Once presented with the choice that a patient who is considered in the category of hospice care, could not see an outside physician, their decision was easy. The nursing home physician had become my friend's primary care physician.

Again, this was not by choice. It is just the way it is done. That physician sees, or rather, oversees, everybody at the nursing home. It was not the same as a personal relationship with his own primary care physician. And so, my friends decided to skip the “hospice care” and continue to see the oncologist who cared so deeply and so compassionately about my friend.

This one decision was one of so many needing to be made when approaching the end of your loved one’s life. Nursing home physician or your own? Cremation or burial? Hospice or no hospice? Die at home or in a nursing home? Receive physical therapy to improve strength and mobility even though that therapy will not save the life?

These are not easy choices and the right choice varies with each individual and his or her circumstances. Having good friends and family who know you and support you is the best gift one can receive, while alive and when facing death.

Small things still matter while big things are happening. A friend offers to hang pictures on the walls of the nursing home. Friends help to clean out the house, finding homes for sheet music, books and furniture. Friends dig up plants, transferring them to friends’ homes in memory of our loved one. The peonies were kept in place for now, to enjoy their final bloom before moving on to another growing place.

The thread holding this unfolding narrative together, seems to be the involvement of loving friends. Of course, the category of friends includes family. And the thread holding the threads together? Love. To love and be loved creates a tightly knit weave strong enough to hold what life, and death, brings. Caring friends make all the difference in the world, even when we don’t know what in the world is going to happen.

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