ATTENTIVE CARE: WORKING WITH THE DYING PATIENT

Judith Lief

When working with the dying patient, there is a tremendous temptation to ignore one’s own relationship to death, and to immediately assume the role of the helper. However, from a contemplative perspective, the starting point for being truly able to help another person is the willingness to approach the relationship with as little personal and professional baggage as possible. That is, we must be willing to enter the room of a dying person without preconceptions, ideologies, roles, or strategies. This means entering in a rather naked fashion: we have not prepackaged our approach, and therefore we are willing to allow ourselves to be vulnerable and to feel the quality of not quite having figured the whole thing out. In fact, in any intense situation, we discover that we cannot rely on the memory of what we have learned in the past. If we are about to have a car accident, it won’t help to refer back to the driver training manual. In such circumstances, we can only rely on our present quality of being or state of mind.

When we walk through the door of a dying person’s room, it is important to take the time to allow ourselves to see what is actually going on. We will find that we can learn much more from the situation itself than from what we bring into it. This involves letting the situation find its own pace. We need to guard against the impulse to rush to conclusions because of our nervousness that we might not know what to do. So often we find ourselves driven by some kind of subtle discomfort: we have to keep busy in order to show ourselves and others that we are doing our job and being helpful. But if we are willing to enter cold and to allow ourselves to feel discomfort, a natural receptivity and insight will develop. In the Buddhist tradition, this is called prajna. It is the kind of insight that comes from letting the world speak for itself.
I was with my father just before his death, and it was interesting and sometimes painful for me to watch how the various nurses related to him. Everyone knew that he was dying. Some of the nurses were very ordinary in their manner and could talk to him in a relaxed way. Others were obviously using their routines to avoid the situation. The most extreme case was a nurse who literally barged into the room, dashed over to the bed, and declared, "It's time for your vitamins." I looked at her and said, "You've got to be kidding! Vitamins?" It was almost humorous that she was so out of touch with the fact that he was about to confront his death.

Having entered someone's environment mindfully and with sensitivity, we can then provide "attentive care," which simply means providing what is needed. This could involve offering a sip of water, engaging in a conversation, or opening the drapes. It might not involve doing very much at all; perhaps we would just sit with the patient, and share the space with them. Attentive care is the kind of action that comes from responding directly to the need at hand and recognizing at the same time that our actions are not necessarily going to provide a cure or solution for the "problem." Instead, our basic intention is to enter the patient's world. We are willing to feel the person's confusion, if that is their experience, or their pain and fear, or their sense of injustice. We are not bringing in our world and imposing it on them. We may discover that their world is very different from ours. They may be responding to their death in a way with which we totally disagree. We may encounter tremendous confusion and emotionality surrounding the dying person, their family, the hospital staff, and whoever else is present. But still we are willing to step in and share that swirling, confusing realm, rather than standing back and protecting ourselves.

Having entered the patient's environment, the next step is to cultivate warmth, or empathy, in our relationships. Assuming that we have already begun to relate to our own fears about death, we are then prepared to loosen the dualistic
perspective of, "I am helping you." Entering the patient's world means being willing to die with him or her. This may seem like a shocking statement. It represents a reversal of the usual tendency to protect ourselves and to refer everything back to our own personal perspective. In this case, we now try to see from the perspective of the other person and to actually put their perspective before our own. In the Buddhist tradition, this reversal is usually referred to as "exchanging self for other."

The habitual tendency is to always look after one's own interests first, even at the most mundane level. When we cut pie for dessert, we may think, "Well, maybe I'll put that one on my plate." With children, the bias is more obvious. As adults we usually manage a degree of subtlety; still, there is a pervasive and often unconscious attitude of placing one's own interests first. Fundamentally we feel glad that the patient is the one who has cancer and we are the ones looking after them. It is hard not to feel that way, even while sincerely and earnestly trying to help someone. "Exchanging self for other" is a practice of reversing that perspective by having the intention of giving the patient one's own credentials, so to speak, and taking on their illness. This kind of compassion has a radical quality: we are giving away our sense of health, peacefulness, and clarity.

As a starting point, we could notice and acknowledge the inclination to look out for ourselves and to find security in the fact that we are not the one who is sick. It isn't all that helpful to pretend to be benevolent. We have to begin at the beginning, by simply being aware of how we enter a room, what concerns come up in our minds, and how we view the other person. How much are we really willing to identify with the patient's situation? What are our limits? We observe that process and notice the points of holding back. If we are naive about our motivations, we face the danger of developing a patronizing attitude. The desire to be of help can be diverted into the self-satisfaction of the "helping" role, which may not be in the best interest of the patient at all.
Being honest about our limitations naturally lightens our self-image and gives rise to sense of humor. This could be a valuable contribution to our perspective, since it is easy to lose one’s sense of humor in extreme situations. People often feel that humor is particularly inappropriate for the deathbed: death should be preserved as a solemn occasion. But often so much valuable ordinariness, richness, and warmth are lost because of the false solemnity which patients feel from others. They begin to feel excluded from the ordinary human realm. They think, “I used to be a regular human being doing regular human things, but now I am sick and I am about to die, so I have been assigned to a special category.” Then they feel they should try to live up to that category. At that point you may be doing someone a great favor simply by treating them as an ordinary human being.

Attentive care begins with a willingness to step into someone’s world with an open and vulnerable attitude. Through *prajna*, or the natural intelligence which then arises, we see both what is needed in the environment as well as our own resistances to empathizing with the patient more completely. Our next topic is action, or *upaya* in Sanskrit. *Upaya* is often translated as “skillful means.” In Mahayana Buddhism, the idea is to join *prajna* and *upaya*, so that action is based on intelligence, rather than on preconception and self-preservation. *Upaya* is divided into five aspects, known as *paramitas*: generosity, discipline, patience, exertion, and meditation. The *paramitas* are helpful reference points in our aspiration to cultivate tenderness, friendliness, and empathy as we work with dying people.

Generosity, in this case, is the willingness to share. In working with a dying person, we are sharing their pain and confusion, and we are offering whatever healthiness we feel. The most effective act of generosity is to share our fearlessness and confidence. Those qualities in ourselves don’t need to be expressed with any sense of smugness. Instead, we can acknowledge a mutual potential for confidence in the midst of pain and anxiety. It is also important to appreciate the
generosity of the patient. Sometimes people experience an embarrassment about continually being on the receiving end of generosity. It can be frustrating for a person who is ill when no one cares to receive what they offer—even if it is just a gesture, or a word. So it is very important that generosity includes the acceptance of the wisdom and human kindness offered by the one who is sick.

Discipline, the second paramita, fundamentally means being with what we’re doing, while we’re doing it. This can be difficult when relating to one patient after another, but it is important to hold together one’s presence, as it were, in order to be as fully there as possible for each person. Discipline also has a quality of not indulging in one’s own confusion. We needn’t deny our confusion; it is simply not helpful to bother others with it. Another aspect of discipline is acknowledging and respecting the other person’s path. Whether it is a path of illness or aging, the circumstances of each person’s life have their own logic and integrity. Particularly in stressful situations, people need the support and encouragement to be fully present throughout their experiences.

A third aspect, which is extremely important and also difficult to cultivate, is patience. Again, we begin with our own patience: not trying to be what we are not, and not becoming exasperated with ourselves. We need to give ourselves time to work with difficult situations. We need to know when we are overwhelmed. We can relax our state of mind on the spot by being kind to ourselves. We are who we are, and we can only do so much. We do not have to feel badly about our limitations. Patience is not laziness; it is allowing room for a realistic assessment of ourselves, as well as some humor about our pretentions. Patience is the most powerful force for overcoming the aggressive drive to achieve something or other. Then we also allow others to express their emotions, because we provide an atmosphere where no one needs to prove anything. Resistances, denial, and
resentment can all be allowed to surface and be worked through.

The fourth paramita is exertion. Exertion is energetic hard work. It is not the blind exertion of a worm digging through a tunnel, nor is it the compulsive speediness that comes from trying to confirm that we are hard-working. It is a steadiness of energy, like the gait of an elephant. The elephant moves along imperturbably, while covering great distances. True exertion is also necessarily far-seeing. When we are narrowly focused, we find ourselves working harder and harder, until we burn out. We speed along with our agenda until we deplete our energy. But the paramita of exertion is based on constantly tuning in to humor and to the moments of open receptivity which are always available to us. As for our patients, dying involves enormous exertion. It is not a passive process. The body is struggling back and forth between life and death: there are cycles of resistance, relaxation, and confusion. We can appreciate and acknowledge that a tremendous amount of energy and attentiveness is required.

Finally, there is the paramita of meditation, which is the cultivation of a state of mindfulness, particularly in our interactions. It is a sense of ordinary composure, of being aware beyond our preconceptions, ideas, and thoughts.

All these aspects of upaya, or skillful means, are ways of working with the tendency toward self-centeredness. When we are willing to expose ourselves to the fears and anxieties we encounter in ourselves and our patients, our inherent intelligence is uncovered. It is said that the action of skillful means—generosity, discipline, patience, exertion, and meditation—and the intuitive directness of intelligence are like two wings of a bird. When they are balanced, we are able to be genuinely helpful, to whatever extent is possible within the limits of our working situation.

When we have a contemplative perspective, the process of working with others becomes a constant reflection of our own state of mind. It is a powerful and revealing process which vividly reflects our current relationship with uncertainty,
death, and impermanence. Humor is a critical aspect of this process. We must be able to not take ourselves too seriously. We may think that we are going to be the one who steps in and, just in the nick of time, helps the dying person to realize his or her human potential. I doubt if any of us is going to be able to accomplish that very often. We should have some humor about ourselves and realize that we are involved in a slow process of growth. We are working with our own states of mind, just as our patients are working with theirs. And we are also dying, just as they are. We are all in this together.