

TERMINAL CARE: TREATING THE WHOLE PERSON

Buchholz, WM. Terminal Care, Part 2: Treating the Whole Person.
J Am Acad Phys Assist . 6: 203-9, 1993.

ABSTRACT

TERMINAL CARE: TREATING THE WHOLE PERSON, William M. Buchholz, MD
Terminal Care is not a subspecialty but the logical extension of caring for the whole person throughout a chronic mortal illness. Quality of life rather than length of life becomes the goal. The whole person includes a physical body, emotional and spiritual concerns, and complex relationships as part of a family and community. Consider the crisis of a terminal disease from the perspective of therapeutic positivism. With the dangers lie opportunities. As symptoms develop they should be treated with skill and creativity. As physical function declines, more outside resources such as HOSPICE are required. The patient's loss of control and loss of identity requires the reestablishment of a sense of security. The family must simultaneously bond with and let go of the patient and still keep their own lives going. There is no greater opportunity for the PA to be a whole person, developing intellectual skill in symptom control, growing in interpersonal skills, and experiencing the awe that comes from participating so intimately in another's life.

WHO DIES?

"Who dies?" asks Stephen Levine in his book of the same name¹. It is as easy or difficult to ask, "Who lives?" The answer to "Who are you?" is complex. People have bodies and identify with this highly visible part. As cognitive creatures people have thoughts and beliefs which constitute an ego they identify as "the real me." They experience emotions and when in the grip of a powerful emotion like anger or fear they may become that feeling and identify with that as in "I am angry."

People have role-identities as mothers, lawyers, doctors, brothers, etc. When asked who they are, most commonly people reply, "I'm a PA." "I'm a doctor." "I'm a mother." Only when pressed will they go on with their other identities. There are the myriad relationships and roles of family, business, friends, classmates and so forth. These relationships constitute the other realms that define us in our society.

Regardless of religious belief, most people have some sense of themselves as spiritual beings. This may be a highly organized belief as is found in many religions. It can be less structured and exist as a faith that somehow the universe is benign. For some it is a moment of awe at a sunset or at the birth of a child. Like birthing, dying is a transition in state and status. When a person becomes a patient and that patient becomes terminal all of these identities become fragile, subject to destruction and change as the person grows sicker and dies.

Acute problems and chronic non-malignant diseases are different from terminal illnesses. With the former it is sometimes possible to "get away with" treating the disease process alone, trusting that the patient will handle the rest of the problems himself. In terminal care the family-and-patient are the unit of care. It is impossible to ignore the emotional, spiritual, and social issues that are an inherent part of the dying process. The Physician Assistant (PA), or any other professional caregiver, must be able to provide

both technical medical care and recognize and treat (or refer) the companion problems of mortality.

EXERCISE

To get a more vivid experience of what is involved try the following exercise. List the 10 most important things, people, relationships, events, etc. in your life on index cards. Rank them from 1 to 10 in importance to you. Put them face down in order on the table in front of you. One at a time take the 5 "least important" cards, look at them, and slowly tear them in half. Shuffle the rest and let someone draw them one at a time, show them to you, and tear them in half until only one card remains. (This is an emotionally powerful exercise and should be done with someone you trust and can talk with openly.)

WHAT IS TERMINAL?

All definitions of terminal refer to the end of the body and change in status. Webster's dictionary refers to it as a boundary at the end of something, a concluding, closing or final period.² Patients use the word terminal to mean either near death or having a disease that cannot be cured. Some patients may consider themselves terminal because, out of fear or depression, they cannot imagine any outcome but death. From the physician's perspective, terminal may refer to the point where efforts to prolong life seem unwarranted. This decision may be colored by his inability to reverse the disease with his techniques and be quite subjective. It may not mean that life cannot be prolonged by other skills and other physicians.

Dr. Ernie Young, a bioethicist at Stanford University, describes terminal as "that point X in a person's life that there is a conscious understanding that the person is dying. That point may be noted by the patient, the family, or the physician." (personal communication) Sometimes people just "know" that they are dying, and may be able to predict the moment of death. There may be conflict, however, when patient, family and physician have different perspectives on when the patient is "terminal." In reality "terminal" is a process that occurs over a time measured in days, weeks or months and awareness may be delayed until after the biological events have become obvious.

Medicare has defined "life expectancy of 6 months or less" as terminal for the purpose of Hospice certification.³ There are studies that show how difficult it is to predict when people will die⁴ and recently Medicare has revised its requirements to recognize that uncertainty.

For practical purposes the following definition of terminal is offered. The patient has a chronic disease that is progressive in spite of efforts to prolonging life. Unchecked, the disease process will kill the patient. The patient and family are aware at either conscious or subconscious level of the likelihood of death. Patients have at least some symptoms and some decrease in functional capacity.

ASSUMPTION

For many medical practitioners there is a sense of defeat if the efforts to cure or prolong life fail. This results in **therapeutic nihilism** and a sense of "there is nothing we can do anymore" when it becomes clear that the patient is terminal. Too often the patients are told, "nothing can be done," in the mistaken assumption that the physician has

considered all the options. For this paper I am making the assumption of **therapeutic positivism**: there is always something constructive that can be done.

The Chinese word for "crisis" is wei djie and is comprised of two ideograms, "danger" and "opportunity." Before becoming terminal, the patient has faced many crises. In this final crisis are both the very real dangers of death and suffering and the opportunities for completing a life journey in a way that is satisfying and meaningful. In considering the events that the patient, the family and the PA must face one can consider both the problems to be overcome and some of the opportunities present. I encourage the reader to examine these problems and find the opportunities inherent in them for himself.

(insert **Table 1 Tasks of the Patient**)

TASKS OF THE PATIENT

Patients with terminal illness have an enormous job. They must deal with increasing physical symptoms and decreasing physical function; the psychological stresses of loss of control, loss of hope, fear, anger, depression and grief; and social disruption as family and economic roles change. Throughout this patients face the often conflicting expectations of their families and the medical system. No wonder nobody volunteers for this job!

Physical Tasks of the Patient

To a greater or lesser degree physical symptoms can be controlled.⁵ Depending upon the type of cancer and the site of metastases, from 65 to 85 % of patients will have significant pain.⁶ Pain can be controlled in up to 91% of cases.⁷ Unrelieved, chronic pain results in depression, fatigue, insomnia, anorexia and decreased physical functioning. These same symptoms may result from the disease itself. Only by successfully treating the pain can these two etiologies be separated. Patients often fear pain and can be reassured ahead of time that their pain can and will be effectively treated. Nausea and dyspnea can likewise be ameliorated if not eliminated. Decubiti and wound infections can often be prevented. Anorexia, weakness and loss of energy are harder to treat.

Side effects of treatment arise and must be addressed. Radiation proctitis may need cortisone enemas. Opioid induced constipation can be prevented or effectively treated. Some treatments may be avoided because of their potential side effects. Patients often refuse palliative chemotherapy or surgery because they do not want anything else to disturb their sense of control, preferring to forego potential benefits to avoid any new symptoms from the treatment.

The loss of physical function and independence that comes from progressive weakness is sometimes more distressing than any physical pain. The Karnofsky index is a commonly used objective rating system that gives a percent score to different levels of activity. (See table 2) On a personal level, a score of 60% means that simple activities like getting in the car and driving to the store become difficult if not impossible. At 50% bathing, shampooing hair, dressing or cooking may leave patients so tired or breathless that they must rest ten minutes after each task. The motions required to put on stockings or lace up shoes may be physically impossible or too painful to do. If help is not available at that time patients may not get dressed and hence, be unable to get out. Patients who take pride in their appearance may be unwilling to be seen publicly because

they are ashamed of how they look. The physical weakness is emotionally draining so that neither flesh nor spirit is willing and functional level drops further.

It is just as important to ask about and address the problems of physical functioning as to treat physical symptoms. Find out what patients actually do and how long it takes them. Specific questions like "When was the last time you went out for dinner?" or "How much time do you spend outside the house?" may be required to get useful information. Vague answers like, "I'm doing ok" may reflect a much lower functional state than implied. Invite family to be present during examinations to corroborate and expand upon patient responses. This will often elicit their help in solving some of the problems.

(Insert **Table 2 Karnofsky Performance Scale**)

Psychological tasks of the patient

As devastating as the physical symptoms and deterioration are, the psychological tasks are even greater. Furthermore these issues must be addressed at a time when patients are physically weakened and their usual support systems are already taxed. The most prominent issues are those of hope, control, and loss.

HOPE

Hope has three components: The individual hoping, the projection into the future (expectation) and the object, event or state desired.⁸ There are both cognitive and emotional components to hope, both a belief and a desire. Hope is the creation of a desired future reality and the projection of oneself into that future. Hope acts as a coping mechanism, a filter to diminish the impact of events and an energy that can overcome resistance or inspire activity.

If Hope were a medicine that could be prescribed, the Physician Desk Reference entry describing its mechanism of action would read: "Depression is characterized by the inability to imagine anything different from the present. HOPE, because of the component of Expectation, relieves the inability to project into the future. HOPE allows such individuals to create a possible future, thereby relieving the onus of living in the present. The anticipation of pleasure relieves pessimism. Anxiety, characterized by a sense of loss of control, is alleviated by predicting a desirable future event, thereby providing an anchor for the individual in the midst of free-floating anxiety. The sense of aloneness is relieved by anticipating allies or help. Fear, which consists of projecting into the future an undesirable event (helplessness, pain, etc.) is redirected by the expectancy of a positive rather than negative outcome. Motivation to accomplish goals and compliance with medical treatment are increased by a sense that the goal is attainable."⁸

What happens when patients are told that "there is no more hope" and they are terminal? The future ceases to exist. Patients lose the will to live, often stop eating, withdraw and then die. At the minimum their fundamental defenses against depression and anxiety are disabled. There is no motivation to continue treatment or to be engaged in any future oriented task. Sometimes all the information is rejected and a state of denial or "false HOPE" arises.

The definition of false hope depends upon the perspective of the person. From the patient's point of view, no hope is untrue and he may ask, "How can it be false when I

truly want it?" From the perspective of the PA or physician it is an "unrealistic" view that a low probability outcome is likely. Medical personnel are particularly careful to avoid giving false hope and may inadvertently give "false despair" instead.⁸

A practical definition of "false hope" is "the creation of a reality that is inhabitable only by the patient." As long as there is no harm to the patient or family then the unrealistic but hopeful statements can go unchallenged. If, however, the actions based upon such beliefs would be harmful (e.g., an unrefundable deposit on a cruise) then the PA can gently point out the consequences of such actions on the family and on the patient himself.

The conflict between the patient's need to maintain hope and the caregiver's need to be honest generally can be resolved if the emotional component and future projection are preserved and the object of hope (goal) is redefined. When asked, "Is there any hope?" it is appropriate to support the patient's ability to look into the future with some sense of optimism. If cure is not possible, then comfort can be promised. If one year is unlikely, then one month may be guaranteed. If walking unaided is too difficult then independence using a wheelchair and limited walking can be offered. It is a process of looking into the glass and finding what is still there.

CONTROL

Cancer, like AIDS or a progressive neurological disorder is a disease of control. On a cellular level the neoplastic cells are out of control. They no longer respond to environmental signals that limit their growth. On a personal level, patients feel out of control. Their bodies are unpredictable. Their schedules are disrupted by office visits or symptoms. The feeling of being out of control filters their experiences and often determines their responses.

As a rule of thumb consider patients' requests and conversation as coming from people who feel out of control. When possible, enable patients to resume as much control as they can in their lives. Symptoms that disrupt their function should be treated. Arbitrary treatment schedules can be changed. The environment can be modified. Cordless telephones, intercoms, remote controls for equipment all make it easy to extend ones presence beyond limited physical boundaries. If nothing else, the feeling of being out of control can be acknowledged. Once shared, it becomes less terrifying.

When examined very closely most of our beliefs about control are illusions. Ultimately, particularly in life-death situations, we have very little control. When we realize that our illusion of control is just that, an illusion, then there can be the beginnings of trust. Most people put considerable effort into controlling their environment and the events in their lives. Some become very skilled at this under "normal" circumstances. When confronted with a terminal illness the circumstances are different and the previously developed skills no longer work. The executive accustomed to giving orders finds that she can no longer instruct her body to carry out her commands. Even her demands of the medical system cannot be satisfied. The metaphysically oriented writer, used to invoking his "spiritual guides" for life decisions begins to lose faith when they seem to abandon him. His imagery, prayers, herbs and healers appear to be powerless to stay the advance of his cancer and he becomes weaker. The engineer whose faith in science and medicine as secular deities questions the foundations of his world as they, too, seem unable to help.

When feeling out of control patients revert to their most basic and often primitive coping mechanisms. Since the basic problem is lack of trust, it is difficult for them to be flexible enough to try something new. Often it is a matter of waiting for the right time to change, when it becomes clear that their present method of controlling is not working and they don't know what to do next. Under these circumstances, when the patient "knows that he doesn't know," there can be an opening for something new and creative.

In this situation the nature of control can shift, just as the focus of hope can shift. Instead of the individual exercising control himself or through his immediate environment, control ceases to be important and they can strive instead for a sense of peace. It is like being on a bus speeding down a narrow mountain road, being unable to take control of the wheel. At some point there develops a trust that Someone is in charge and driving the bus or at least the faith that no matter what happens one will cope. Both Judeo-Christian and Eastern traditions emphasize that spiritual development requires letting go of control. It can range from an apocalyptic vision of "God as Ruler of the Universe" to a simple "ah ha, so that's how it is." Regardless of the intellectual form, letting go of control brings with it a sense of peace and relief that the struggle is unnecessary.

A sense of humor is likewise important. This is true for both the PA and patient. A moment of lightness when trapped in a heavy struggle can often give just enough perspective to show a way out of the battle. It is not a time for jokes or gallows humor but rather a pause to look for the ridiculousness of the situation. When faced with a demanding patient caregivers may feel frustrated. If viewed with some chagrin as a battle for control, a chuckle can replace the growl with the realization that there are no winners in such a battle.

LOSS

Terminal patients are faced with losing everything. They are losing their sense of immortality as they see their bodies deteriorate. They lose their social identity as they can no longer work. They lose their independence as they can no longer function. As illustrated in the brief exercise in the beginning of this paper, this leads to a profound emptiness all the way to one's core.

Shock, Bargaining, Anger, Depression, Acceptance--the stages of loss described by Kubler-Ross--are neither sequential stops on a bus line nor a work plan to complete.⁹ These are common human responses to any kind of loss and are part of the grieving process. Each part of the person that is lost elicits these responses and they may not be synchronized. The patient may feel angry about one thing, depressed about another and shocked by a third. For some losses there may be no resolution or acceptance in that person's lifetime.

This lack of completion can be distressing for caregivers, especially when it does not meet with their needs or expectations. When confronted with patients experiencing loss, caregivers may either try to "fix it," accelerate the adjustment to it, or feel impotent and withdraw. Under some circumstances any of these responses may be appropriate. In other situations the only correct response is a compassionate ear and a willingness to share their grief.

If it is possible to prevent deterioration and maintain function then corrective measures should be applied. The loss of mobility from a pathological hip fracture can be

treated with hip pinning and radiotherapy. It is more difficult to accelerate another person's emotional adjustment. Sometimes reframing the loss offers a fresh perspective. It can be helpful to point out that letting go of what is no longer useful can provide an opportunity for something new to take its place.

When confronted with another human being's suffering it is easy to be overwhelmed by its enormity. A natural defense mechanism is to withdraw and shut off emotionally from that other person. This can be necessary when the caregiver is drained and has no resources left. Withdrawal is not, however, the only answer to being unable to change another's grief. The hard part of loss is feeling alone. What the PA can do, regardless of anything else, is agree to be there and not abandon the patient when they just need someone to share with.

Social tasks of the patient

If a family is disrupted when mother has the flu and can no longer drive carpool and fix dinner what kind of chaos develops when she is dying at home and will never resume her duties? Her sense of self-esteem as a productive member of the family and community is shattered. There may be a sense of shame that she has "failed." The problems she handled before her illness accumulate and cause more stress for her and the family. The income drops at a time when it is most needed since most in most families today all adults contribute economically. The support she received from her professional and social activities is curtailed. Both social roles and activities change with a terminal illness.

The patient's job is to redefine himself or herself, reestablish a sense of worth and maintain relationships. For people used to "doing something" as their identity it can be difficult to shift to "being something." Yet this is the role that is most open to them as their physical condition deteriorates. As the center of attention the patient may find a catalytic power previously undeveloped. It seems quite natural for the elderly to become "consultants" and repositories of wisdom rather than physically doing chores. Through introspection the terminal patient can cultivate an understanding that the rest of the family may be too busy with their "doing" to do. It is very common for patients threatened with a mortal illness to become much more aware of the beauty of life. This wisdom, gained at considerable cost, may be valuable enough for some patients to remark, "it is worth it."

Although social relationships may change they do not stop. Concerns about "what will they think?" may sometimes be replaced by "so what?" More intimacy may develop. Love can be expressed more freely. Deep friendships blossom. Unproductive relationships can be left behind. People used to being "givers" become "receivers." Patients may have to be guided to redefine their generosity as "creating an opportunity for others to feel the warmth of giving."

At the same time responsibilities must be delegated and turned over to others. The attorney who has been accustomed to handling all the home finances and taxes must relinquish these jobs to other family members, sometimes in the face of their resistance. His style may have been to "keep things tidy" and it is difficult for him to see a more casual approach. It may be necessary to compromise on certain issues, holding firm on others.

Facilitating these social tasks may not be part of the PA's role but left unattended can complicate overall management. Involving social workers, counselors, family and

friends, and pointing out that these are active problems can elicit solutions that will make terminal care much smoother.

(insert **Table 3 Tasks of the Family**)

TASKS OF FAMILY

The family's job is just as hard as the patient's, perhaps more so. The patient is the center of attention and all efforts are directed toward him. It is easy to ignore the family's "dis-ease." They may feel it is selfish to call attention to their own needs. The family may think, "Dad is so sick and dying, our problems aren't as important as his." The medical system may reinforce this belief by ignoring family unless they make a fuss, giving oil only to "squeaky wheels." Depending upon who is the patient, the makeup of the family, and the nature of family dynamics certain problems arise.

Growing closer to patient and completing unfinished business.

With the realization that "it is just a matter of time" families often try to crowd into that time what had been left previously undone. They recognize there is no limit on how much love that can be shared. Regardless of how good the relationship there is always the possibility of growing closer, of loving a bit more. There is yet another chance to heal a wound, to give or receive forgiveness, to clarify a misunderstanding, to repay a debt. There seems to be a natural drive for completion and there are regrets if such opportunities are irrevocably missed.

Such completions cannot be forced and there is a hazard of imposing one's own agenda upon the patient and family. It may be enough simply to point out opportunities and make it easy for them to happen.

Dealing with one's own and the patient's emotions.

Just as the patient is experiencing the psychological fluctuations of the illness, so do family members feel anger, denial, depression and anxiety. They are experiencing a loss, too. They have their own feelings as well as those of the patient to deal with. Often family members may have to put aside their feelings to cope with those of the patient whose needs seem to have priority. This may be true for the moment but unless dealt with constructively, the family's emotional needs will ultimately weaken the system.

It is common that when the diagnosis of cancer is first made either the patient will say, "don't tell my family," or the family say, "don't tell the patient." Each tries to protect the other. When patients become terminal this same conspiracy resurfaces in efforts to protect the other from the news. In neither situation (at least in Western cultures) can the sham be maintained. Eventually, if only covertly, everybody finds out and the lack of acknowledgment only hinders resolution. In Asian cultures and to some extent in Mediterranean cultures it is standard practice not to share this information. Because the culture supports this practice it may work there. Because of the the widespread value of informed consent it is more difficult to conceal such information in the United States.

It is my practice to encourage dealing with emotions openly in proportion to the coping skills of the patient and family. Some families may not want to share their feelings with each other, much less with strangers. Be sensitive to the emotional state of the family as well as of the patient and offer help without insisting.

Conflict between family and patient.

The needs and adjustment of the family and patient may not be coordinated. Arenas of conflict and disputes about control that existed before the patient became ill still exist and can be magnified by the disease. Families may still want/need the patient to recover even though the patient may know that is not possible. Food and eating can become a battleground as the patient grows more anorectic and loses weight. Unfinished meals can be perceived as a rejection of love. Patients can control the family by choosing when and what they will eat. Families may want more treatment and patients submit even though they do not truly wish it.

The PA can become a "fair witness" under these circumstances rather than a judge deciding what is right. It is legitimate to point out both that advanced cancer often makes it difficult for patients to eat and that food is necessary to maintain enough strength to interact with the children.

Gathering support for oneself when feeling unworthy.

Too many times "helping the helper" seems legitimate only when the helper is near collapse. Because of the visible and dramatic needs of the patient it seems harder to justify getting specific help for the spouse or children unless there is some obvious physical problem. There may be the expectation that since the patient is such a saint or hero that the family should do likewise. Invisible needs for emotional support and help with unfamiliar tasks (e.g., cooking, managing insurance billing, fixing a leaky sink, etc.) are just as important as learning to operate an oxygen tank or administer complicated medication schedules.

Although some families do manage to cope without outside help, having additional resources available makes the system much more flexible. Having the number of a Hospice nurse by the telephone acts like a panic button and may let the family cope better even without calling for help. It is useful to encourage but not insist that families contact the local Hospice at least to see if their services might be useful.

Disruption of family routine and roles and taking on new responsibilities

Having a sick person at home or in the hospital disrupts family routine. Whatever the patient did before and cannot do now must be done by someone else. This extends from bathing and changing someone who is bed-bound and incontinent to doing the dishes and taking out the trash. Ambivalence is likely. The person(s) stuck with the new job may feel resentful at the interruption of their lives even while being grateful that they can serve a loved one in need. In any event, the family's life is different because of the patient's illness. They may respond to this as a problem or as a challenge. As the PA gains experience in terminal care, he or she can help by sharing the solutions that other families have found to be effective.

Anticipatory grief: letting go of dreams and the unrealized future.

The greatest pain is letting go of dreams. The years of planning for retirement and traveling in an RV visiting the children are shattered by the realization that one's spouse is dying. An anticipated reality is snatched away and nothing is left in its place. In silence the question arises, "What will I do when they're gone?" In order to protect oneself some distance must be created and there is a gradual withdrawal from a future with the patient to imagining one without them. This process is simultaneously the source of depression and tears and the seed of a new future.

It seems a paradox that the family must both grow closer to the patient in the brief time that remains and yet become independent of them, anticipating their loss. The

answer lies in concentrating on the present, focusing only on what is happening now. This avoids looking into the darkness of the future and allows a greater intimacy in the present. Letting go of the future is done in small increments to limit the pain. The best counsel comes from a Chinese proverb. "You can't prevent the birds of sorrow from flying over your head. You don't have to let them make a nest in your hair."

Continuing with life after the patient dies.

Life goes on for the family even while the patient is dying. There is homework to complete, the garden to weed and meals to cook. These jobs will continue after the patient has died. The future must be planned for. Because the future had been so carefully dreamed to include the person who is now dying it lies open now with little structure. It is easy for family members to be overwhelmed with both the jobs to be done now and the future to be created later. Like the man who ate the elephant, even the biggest jobs are done one bite at a time. When overly stressed, family should be encouraged to delay solving problems that do not need solutions right now. Circumstances may change to eliminate these problems (perhaps bringing on new ones) and they will grow stronger and more experienced as a result of solving previous problems.

(insert **Table 4 The PA's Task**)

The PA's TASK

The PA has a challenging professional and personal job. Perhaps nowhere else is there such an opportunity to be of service where there is great need. The properly trained person who is sensitive to the opportunities available can make an enormous difference in the lives of both the patient and the family. In addition to the customary tasks of a PA in caring for patients there are some special jobs that are almost unique to terminal care.

Competence

In order to provide competent medical care the PA must be familiar with the techniques of pain control and recognize the complications of treatments and the disease process. There must be both an understanding of the common events that occur in dying patients and an appreciation for the breadth of variation between individuals and between different diseases. Competence requires knowing the limits of one's training and a commitment to expanding one's knowledge base. Because much of terminal care is empirical, one of the best sources of training is the experience of other caregivers. Competence is gained by close and conscious observation of patients and families as they go through the dying process.

Carefulness

Just as critical care requires careful monitoring of physiologic measurements so does terminal care require careful clinical assessments. Patients change quickly and in order to take advantage of opportunities the PA must maintain a high level of awareness. It is important to follow up on intuition or hunches for the unconscious mind is often a keen observer. Often I have been spared the mistake of complacency when I followed my intuition and checked on the patient before a major problem developed.

Compassion

There is a difference between compassion and sympathy. Sympathy is a feeling for the patient, often a feeling of pity. This maintains a distance between individuals.

Compassion is feeling with the patient and serves to bring the two together. It makes both more human. There is no injunction to "fix" the patient, often they simply wish to be seen and heard for what they are. Part of compassion is to be a witness, "And take upon's the mystery of things, As if we were God's spies."¹⁰ When approached with compassion, patients and families feel safe to be angry or sad, true to whatever they are feeling at the moment.

Communication

A telephone call initiated by the PA or physician is worth ten return calls, no matter how promptly they are returned. Communication is more than a method of exchanging information. It is one of the most powerful medicines available, probably equal to morphine in its ability to bring comfort. Sensitive listening and careful observation of body language can be more effective than CT or MRI scans for finding out what the patient is experiencing. It is important to learn how to give negative information tactfully, with a respect for the impact of the news. When asked directly, the truth must be told. Not everyone, however, wants all of the truth in one overwhelming dose. Just as radiation therapy has to be delivered in fractions, so must information be given in portions that can be assimilated and used constructively. Even though the caregiver can see the entire picture and can anticipate what will be needed later doesn't mean that the patient can deal with it at this moment. Give them time to digest what they need now.

There are frequent occasions when silences develop and a sense of awkwardness appears. Before responding to break the silence, ask yourself, "What would a Wise Man do?" When I have done that the reply is usually, "be silent, you don't have to do anything." The nonverbal communication of a touch, a hug, or moving the box of tissues closer is often quite enough.

Catalyst

A catalyst is an agent that allows or speeds a reaction without being changed in the process.² The PA can act as a catalyst when there is conflict between the patient and family by clarifying issues and facilitating discussion. This facilitation must be done without judgment of good and bad, but only a view of what will work or not work to further the expressed goals. Similarly the PA acts as a guide in making important decisions, not imposing values but outlining the best strategy to achieve the stated goal.

Rather than trying to force issues or do too much the best policy seems to be to "make it easy for miracles to happen." Alan Watts said of Zen, that with study "one might become the kind of person who, without actually intending it, is the source of marvelous accidents."¹¹ Great practice is required to cultivate such a presence. In the mean time it takes boldness to act on intuition when you are uncertain and courage to remain silent when you have nothing to say.

Keep Cool

Harry Truman is credited with saying, "If you can't stand the heat, get out of the kitchen." As professional caregivers we may be required to stand close to the heat of patients and families in the crisis of terminal illness. If done on an occasional basis there is time to cool down between emotionally draining situations. If terminal care is a sizable part of one's practice it is imperative to develop coping mechanisms that dissipate the heat and prevent burnout. Regular de-stressing is needed, either with time off or a regular practice of meditation, exercise, etc. An image that has helped me is to picture

myself as a clear piece of glass. My job is to allow light from the source to pass through me unimpeded to an area of darkness. Occasionally I may bend the light a little to illuminate an area that seems darker than others. It is not my job to be the source of light, just to keep myself clean and not to get in the way. Ram Dass, one of the founders of the Boston AIDS Hospice, suggested that caregivers acknowledge that the work that is done in not so much for the patient as work on oneself. When terminal care becomes a method of one's own enlightenment and growth in compassion it becomes less of an effort and more of a blessing

Suggested Readings

There are many excellent books available on Hospice and terminal care. The following is not intended as an exhaustive list but rather a few of the ones I have found useful. The ones by Stephen Levine have meditation scripts that can be read to patients by family members and address issues of pain, fear, and loss of control.

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Table 1

TASKS OF THE PATIENT

Physical Tasks

Increasing physical symptoms

Side effects of therapy

Decreasing physical function

Psychological Tasks

Anger, anxiety, depression
Loss of Hope
Loss of Control
Grieving
Social Tasks
Changing roles
Changing relationships

TABLE 2

Karnofsky Performance Scale	
100%	Normal
90%	Able to carry on normal activity
80%	Normal activities with effort, some signs or symptoms of disease
70%	Cares for self, unable to carry on normal activity or do active work
60%	Requires occasional assistance but is able to care for most of needs
50%	Requires considerable assistance and frequent medical care
40%	Disabled, requires special medical care and assistance
30%	Severely disabled, hospitalization indicated although death not immanent
20%	Very sick, hospitalization necessary, active supportive RX needed
10%	Moribund
0%	Dead

Table 3

Tasks of the Family

Growing closer and completing unfinished business
Dealing with one's own and the patient's emotions
Conflict between family and patient
Gathering support for oneself when feeling unworthy
Disruption of family routine and roles and taking on new responsibilities
Anticipatory grief: letting go of dreams and the unrealized future
Continuing with life after the patient dies

Table 4

PA's TASK
Competence
Carefulness
Compassion
Communication
Catalyst
Keep Cool