

Helping each Other

If you share my tears,
If you take the first merciful step toward me,
If you walk bravely into what I am feeling,
Then we begin to bring down the power of despair.

*Molly Fumia
Safe Passage*



WinterSpring

We're not afraid to be with loss

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A time to cry

Tears are wordless messages,
A vital part of grieving:

Pain can be eased
when people are able
to weep together.

Friends and family
may believe that
crying in front of
or *with* a dying person
will be upsetting to the loved one.

Not true

A dying child said to her parents:
“Aren’t you sad that I’m so sick?
Don’t you care?
How come I’ve never seen you cry?”

A time to touch

Sickness can make a person
feel very lonely and apart.

A dying person needs more than ever
to be close to the living.

The sense of touch
reduces the bleakest of all feelings –
abandonment.

Holding your loved one communicates:
“No matter how serious the illness,
feelings toward me have not changed:
I am not rejected.
I am not untouchable.”



Could You Just Listen?...

As caregivers we often want to “fix” the pain, to make the person feel better. The following requests emphasize the importance of being “responsive to” rather than “responsible for” each other.

When I ask you to listen to me and you start giving me advice, you have not done what I asked.

When I ask you to listen to me and you begin to tell me why I shouldn't feel that way, you are trampling on my feelings.

When I ask you to listen to me and you feel you have to do something to solve my problem, you have failed me, strange as that may seem.

Listen! All I asked was that you listen, not talk to or do- just hear me.

Advice is cheap; 20 cents will get you both Dear Abbey and Billy Graham in the same paper.

I can do for myself; I'm not helpless- maybe discouraged and faltering, but not helpless.

When you do something for me that I can and need to do for myself, you contribute to my fear and inadequacy.

But when you accept as a simple fact that I do feel what I feel, no matter how irrational, then I can quit trying to convince you and can get about this business of understanding what's behind this irrational feeling. When that's clear, the answers are obvious and I don't need advice.

Irrational feelings make more sense when we understand what's behind them.

Perhaps that's why prayer works, sometime, for some people- because God is mute, and He/She doesn't give advice or try to fix things. “They” just listen and let you work it out for yourself.

So please listen and just hear me.

And if you want to talk, wait a minute for your turn- and I'll listen to you.

- Author Anonymous



Practical Tips to Help the Seriously Ill

1. Don't avoid me. Be the friend...the loved one you've always been. Touch me. A simple squeeze of my hand can tell me you still care.
2. Call me to tell me you're bringing my favorite dish and what time you are coming. Bring food in disposable containers, so I don't have to worry about returns.
3. Take care of my children for me. I need a little time to be alone with my loved one. My children may also need a little vacation from my illness.
4. Weep with me when I weep. Laugh with me when I laugh. Don't be afraid to share this with me.
5. Take me out for a pleasure trip, but know my limitations. Call for my shopping list and make a special delivery to my home.
6. Call me before you visit, but don't be afraid to visit. I need you. I am lonely
7. Help me celebrate holidays (and life) by decorating my hospital room or home, or bring me tiny gifts of flowers or other natural treasures.
8. Help my family. I am sick, but they may be suffering too. Offer to come stay with me to give my loved ones a break. Invite them out. Take them places.
9. Be creative. Bring me a book of thoughts, taped music, a poster for my wall, cookies to share with my family and friends....
10. Let's talk about it. Maybe I need to talk about my illness. Find out by asking me: "Do you feel like talking about it?"
11. Don't always feel we have to talk. We can sit silently together.
12. Can you take my children or me somewhere? I may need transportation to a treatment, to the store, to the doctor.
13. Help me feel good about my looks. Tell me I look good, considering my illness.
14. Please include me in decision-making. I've been robbed of so many things. Please don't deny me a chance to make decisions in my family or in my life. Talk to me about the future. Tomorrow, next week, next year. Hope is so important to me.
15. Bring me positive attitude. It's catching! What's in the news? Magazines, photos, newspapers, verbal reports keep me from feeling the world is passing me by.
16. Could you help me with some cleaning? During my illness, my family and I still face dirty clothes, dirty dishes and a dirty house. Water my flowers.
17. Just send a card to say, "I care."
18. Pray for me and share your faith with me.
19. Tell me what you'd like to do for me and, when I agree, please do it!



The Horse on the dining room table

I struggled up the slope of Mount Evmando to meet the famous guru of Nepsim, and ancient sage whose name I was forbidden to place in print. I was much younger then, but the long and arduous hike exhausted me, and despite the cold, I was perspiring heavily when I reached the plateau where he made his home. He viewed me with a patient, almost amused look, and I smiled wanly at him between attempts to gulp the thin air into my lungs. I made my way across the remaining hundred meters and slowly sat down on the ground, propping myself up against a large rock just outside his adobe.

We were both silent for several minutes, and I felt the tension in me rise, then subside until I was calm. Perspiration prickled my skin but the slight breeze was pleasantly cool and soon I was relaxed. Finally I turned my head to look directly into the clear brown eyes which were bright within his lined face. I realized that I would need to speak.

“Father,” I said, “I need to understand something about what it means to die before I can continue my studies.” He continued to gaze at me with his open, bemused expression. “Father,” I went on, “I want to know what a dying person feels when no one will speak with him, nor be open enough to permit him to speak about his dying.”

He was silent for three, perhaps four, minutes. I felt at peace because I knew he would answer. Finally, as though in the middle of a sentence, he said: “It is the horse on the dining room table.” We continued to gaze at each other for several minutes. I began to feel sleepy after my long journey and I must have dozed off. When I woke up he was gone, and the only activity was my own breathing.

I retraced my steps down the mountain – still feeling calm, knowing that his answer made me feel food but not knowing why. I returned to my studies and gave no further thought to the event, not wishing to dwell upon it, yet secure that someday I should understand.

Many years later I was invited to the home of a casual friend for dinner. It was a modest house in a typical California development. The eight or ten other guests, (people I did not know well) and I sat in the living room drinking Safeway Scotch and bourbon and dipping celery sticks and raw cauliflower into a watery cheese dip. The conversation, initially halting, became more animated as we got to know each other and developed points of contact. The drinks undoubtedly also affected us.

Eventually the hostess appeared and invited us into the dining room for a buffet dinner. As I entered the room, I noticed with astonishment that a brown horse was sitting quietly on the dining room table. Although it was small for a horse, it filled much of the large table. I caught my breath but didn't say anything. I was the first one to enter so I was able to turn to watch the other guests. They responded much as I did: they entered, saw the horse, gasped or started, but said nothing.



The host was the last to enter. He let out a silent shriek, looking rapidly from the horse to each of his guests with a wild stare. His mouth formed soundless words. The in a voice choked with confusion, he invited us to fill our plates from the buffet. His wife, equally disconcerted by what was clearly an unexpected horse, pointed to the name cards which indicated where each of us was to sit. The hostess led me to the buffet and handed me a plate. Others lined up behind me, each of us quiet. I filled my plate with rice and chicken and sat in my place. The others followed suit.

It was cramped sitting there, trying to avoid getting too close to the horse while pretending that no horse was there. My dish overlapped the edge of the table. Others found other ways to avoid physical contact with the horse. The host and hostess seemed as ill-at-ease as the rest of us. The conversation lagged. Every once in a while someone would say something in an attempt to revive the earlier pleasant and innocuous discussion, but the overwhelming presence of the horse so filled our thoughts that talk of taxes or politics or the lack of rain seemed inconsequential.

Dinner ended and the hostess brought coffee. I can recall everything in my plate and yet have no memory of having eaten. We drank in silence – all of us trying not to look at the horse, yet unable to keep our eyes or thoughts anywhere else.

I thought several times of saying: “Hey, there’s a horse on the dining room table,” but I hardly knew the host and I didn’t wish to embarrass him by mentioning something that obviously discomfited him at least as much as it discomfited me. After all, it was his house. And what do you say to a man with a horse on his dining room table? I could have said that I did not mind, but that was not true – it’s presence upset me so much that I enjoyed neither the dinner nor the company. I could have said that I knew how difficult it was to have a horse on one’s dining room table, but that wasn’t true either; I had no idea. I could have said something like: “How do you feel about having a horse on your dining room table?” ; but I didn’t want to sound like a psychologist. Perhaps, I thought, if I ignore it, it will go away. Of course, I knew that it wouldn’t . It didn’t.

I later learned that the host and hostess were hoping the dinner would be a success in spite of the horse. They felt that to mention it would make us so uncomfortable that we wouldn’t enjoy our visit; of course we didn’t enjoy the evening anyway. They were fearful that we would try to offer them sympathy, which they didn’t want, or understanding, which they needed, but couldn’t accept. They wanted the party to be a success so they decided to try to make the evening as enjoyable as possible. But it was apparent that they (like their guests) could think of little else than the horse.

I excused myself shortly after dinner and went home. The evening had been terrible. I never wanted to see the host and hostess again, although I was eager to seek out the other guests and learn what they felt about the occasion. I felt confused about what had happened and extremely tense. The evening had been grotesque. I was careful to avoid the host and hostess after that and I did my best to stay away altogether from the neighborhood.



Recently I visited Nepsim again. I decided to seek out the guru once more. He was still alive, although nearing death, and he would speak only to a few. I repeated my journey and eventually found myself sitting across from him. Once again I asked: "Father, I want to know what a dying person feels when no one will speak with him, nor be open enough to permit him to speak about his dying."

The old man was quiet, and we sat without speaking for nearly an hour. Since he did not bid me leave, I remained. Although I was content, I feared he would not share his wisdom, but finally he spoke. The words came slowly.

"My son, it is the horse on the dining room table. It is a horse that visits every house and sits on every dining room table – the tables of the rich and the poor, of the simple and of the wise. This horse just sits there, but its presence makes you wish to leave without speaking of it. If you leave, you will always fear the presence of the horse. When it sits on your table, you will wish to speak of it, but you may not be able to.

However, if you speak about the horse, then you will find others can also speak about the horse – most others, at least, if you are gentle and kind as you speak. The horse will remain on the dining table, but you will not be so distraught. You will enjoy your repast, and you will enjoy the company of the host and hostess. Or, if it is your table, you will enjoy the presence of your guest. You cannot make magic to have the horse disappear, but you can speak of the horse and thereby rend it less powerful."

The old man then rose, and motioning me to follow, walked slowly to his hut. "Now we shall eat," he said quietly. I entered the hut and had difficulty adjusting to the dark. The guru walked to a cupboard in the corner and took out some bread and some cheese which he placed on a mat. He mentioned to me to sit and share his food. I saw a small horse sitting quietly in the center of the mat. He noticed this and said: "That horse need not disturb us." I thoroughly enjoyed the meal. Our discussion lasted far into the night, while the horse sat there quietly throughout our time together.



Sequence of Reactions after Diagnosis of Life Threatening Illness

When the person becomes aware of his diagnosis and prognosis, whether he is told directly or learns by advancing through the stages of awareness discussed elsewhere, he and his family usually go through a predictable sequence of reactions described by Kubler-Ross

Denial and isolation are the initial and natural reactions when the person learns he is terminally ill: "It can't be true. I don't believe it's me." The person may go through a number of rituals to support his denial, even to the point of finding another doctor. He needs time to mobilize his own outside resources. Denial serves as a necessary buffer against overwhelming anxiety.

The person is denying when he talks about his future; avoids talking about his illness, death of self or others; or when he persistently pursues cheery topics. Recognize his need, respond to this behavior, and let him set the pace in conversation. Later, he will gradually consider the possibility of his prognosis; anxiety will lessen; and the need to deny will diminish.

Psychological isolation occurs when he talks about his illness, death, or mortality intellectually but without emotion, as if these topics were not relevant to him. Initially, the idea of death is recognized, although the feeling is repressed. Gradually, feelings about death will be less isolated, and he will begin to face death but still maintain hope.

If the patient continues to deny for a prolonged time, in spite of advancing symptoms, he will need much warmth, compassion, and support as he gets close to death. Your contacts with the patient may consist of sitting in silence, using touch communication, giving meticulous physical care, conveying acceptance and security, and looking in on him frequently. If denial is extensive, he cannot grieve or face the inevitable separation. Yet Kubler-Ross found that few persons maintain denial to the end of life.

Anger, the second reaction, occurs with acknowledgement of the reality of the prognosis. It is necessary for an eventual acceptance of approaching death. As denial and isolation decrease, anger, envy and resentment of the living are felt. In America, direct expression of anger is unacceptable, so this stage is difficult for the patient and others around him. Anger is displaced onto things or people, for example: "The doctor is no good;" "the food is no good;" "the hospital is no good;" "the nurses are neglectful;" and "people don't care." The family also bears the brunt of the anger.

Anger results when the person realizes life will be interrupted before he finishes everything he had planned. Everything around him reminds him of life while he is dying, and he feels soon-to-be-forgotten. He may make angry demands, frequently ring the bell, if he is hospitalized, manipulate and control others, and generally make himself heard. He is convincing himself and others that he is not yet dead and forgotten.



Don't take the anger personally. The dying person whose life will soon end needs empathy. The person who is respected, understood, given time and attention, will soon lower his angry voice and decrease his demands. He will realize he is considered a valuable person who will be cared for and yet allowed to function at his maximal potential as long as possible. Your calm approach will lower his anxiety and his defensive anger.

Bargaining, the third reaction, occurs when the person tries to enter some kind of agreement which may postpone death. He may try to be on his best behavior. He knows the bargaining procedure. He hopes to be granted his special wish – an extension of life, preferable without pain. Although he will initially ask for no more than one deadline or postponement of death, he will continue his good behavior and his promises to devote his life for some special cause if he lives.

Bargaining may be life-promoting. As the person continues to hope for life, to express faith in God's willingness to let him live, and to actively engage in positive, health promoting practices, the body's physical defenses may account for those not-so-uncommon cases where the person has a prolonged, unexpected remission during a malignant disease process. Hope, which is involved in bargaining and which you can support, gives each person a chance for more effective treatment and care as new discoveries are made.

Depression, the fourth reaction, occurs when the person gets weaker, needs increasing treatment, and worries about mounting medical costs and even his necessities. Role reversal and related problems add to the strain. Depression about past losses and his present condition; feelings of shame about his illness, sometimes interpreted as punishment for past deeds; and hopelessness enshroud the person and extend to his loved ones.

Preparatory depression is the next stage and differs from the previous depressions. Now the person realizes the inevitability of death and he comes to desire the release from suffering that death can bring. He wishes to be a burden no more; he recognizes that there is no hope of getting well. The person needs a time of preparatory grief to get ready for this final separation from the world. The depression he feels now comes with the realization of impending loss – not only are loved ones going to lose him, but he is losing all significant objects and relationships. He reviews the meaning of his life and searches for ways to share his insights with the people most significant to him, sometimes including the staff. Often the fact that he cannot share aspects of his life or valued material objects with people of his own choosing will cause greater concern than the diagnosis of a terminal illness or the knowledge of certain death. As the person thinks of what his life has meant, he begins to get ready to release his life, but not without feelings of grief.

Honor the patient's request while at the same time promoting optimum physical and emotional comfort and well-being. Explain the feelings and needs of the patient to the family and other members of the health team so that they can better understand his behavior. The family should know that this type of depression is beneficial if the patient is to die peacefully and that it is unrelated to their past or present behavior.



Acceptance, the final reaction, comes if the person is given enough time, does not have a sudden, unexpected death, and is given some help in working through the previous reactions. He will reach a point, where he is neither angry nor depressed about his fate, nor envious or resentful of the living. He will have mourned his loss of many people and things and will contemplate his end with a certain degree of quiet expectation. Now we see the ultimate of ego integrity described by Erikson. Acceptance is difficult and takes time. It depends in part on the patient's being aware of the prognosis of his illness so that he can plan ahead – religiously, philosophically, financially, socially, and emotionally. This last stage is almost devoid of feeling.

The healthy aged person will also go through some aspects of the previously discussed reactions, for as the person grows old he contemplates more frequently his own mortality and begin to work through feelings about it.



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