

Sharing the Boardroom with Chronically and Terminally ill People

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VERY ROUGH Draft

Courage is being scared to death and saddling up anyway.

John Wayne (1907-1979)

Dedication: This paper is in memory of Adam Minsky, Chris Pitkin and Roger Merritt. You are not forgotten.

It is 1977. New York. The office of the National Hemophilia Foundation. Ben Letterman, a sprightly little man who looks like he just walked off a Walt Disney set, is explaining in great detail the work he has been doing on behalf of the Foundation to Dr. Margaret Hilgartner. Margaret, a pediatric hematologist from Cornell listens attentively. At almost 6' tall the blond, statuesque Hilgartner looks down to take in every word. Ben Letterman has hemophilia. He doesn't know if he will be attending the next board meeting. He never knows. Some mornings he will wake up to realize he has had a bleeding episode into a joint and not be able to walk. He goes to the hospital, not to a board meeting.

All diseases are thieves. Some rob you of your youth, some your childhood, your beauty, your sense of hope, your dignity and even your life. No disease is a gift, and yet some people with chronic and terminal illnesses go beyond their own sense of loss and make a commitment to give to others so as to make meaning of their lives.

Time, strength and pain are the great unknowns. Looking at a limited future, management styles change. Some are able to empower others with their knowledge. They become mentors. They are visionaries beyond their own lives. They look into the future and want to see a piece of themselves still there. And yet the clock is always ticking. The sense of immediacy is palpable.

Many boards will have a member with a terminal or chronic illness, whether their organization supports medical research, a school or dance troupe or environmental program. Sensitivity to the issues involved in sharing the board room with chronically and terminally ill people can enable people to choose to devote time without impeding the mission of the organization they care about.

Removing Power

Perhaps the most difficult aspect of sharing the board room with chronically and terminally ill people is knowing when it is the right time to remove power, whether as a committee chair or an officer or simply as a member of the board.

There are two obvious fears. One is that the member will never be well enough again to serve, and the other is that it brings some board members in touch with their own vulnerability to illness and ultimately death. This is particularly difficult for the board member who has the same disease or is in the same age group. Watching a peer deteriorate can be a frightening experience.

Denial is the worst possible way to deal with the continued ill health of a member. The work does not get done and the mission of the agency is not advanced. The person who is ill feels not only sadness about his/her condition, but guilt at not being about to participate fully.

There are two practical ways to handle these situations. One is a sabbatical system that is built into the bylaws, the other is a form of a living will giving a board member the responsibility to make the judgment when it is time to resign from active service.

A sabbatical system can be of value for any board member. It would provide up to a six-month leave of absence. During this period, all mailings would continue to arrive but no responses would be expected. Leadership positions would be turned over to another member. This can work for a corporate member going through a merger, acquisition or strike, the expected arrival of a new baby, a prolonged period out of town or any other personal reason which would prohibit one from participating fully in the organization.

There are several advantages of the

sabbatical system. The first is that it is not necessary for committed board members to resign when work, health or other needs keeps them from regular meeting attendance and committee involvement. It also alerts the rest of the board not to count on this person for a specific period of time. How specific the announcement should be to the rest of the board should be discussed in advance of any public statement. Any information should be cleared with the person taking the leave.

Another advantage of this system is that the reputation of the member stays intact. Many years ago I served on a board with a woman who did not attend a meeting in over a year. I called her on numerous occasions regarding various committee issues and she did not return my call. My assumption was that she was irresponsible. Ten years later I found out the truth: her Mother died during that year and she had surgery and chemotherapy. Having never met this person, I had a very negative view of her commitment to this agency. Had someone taken the initiative to give her a sabbatical, her actions would not have been misunderstood.

A second way of dealing with the transfer of power is a type of living will. I once met a man who had a debilitating illness that could eventually impede his mental abilities. He told me he had asked a close friend on the board to make the decision for him to resign if his mental capacity prevented him from fulfilling his duties. He told me it was the only way he could stay involved. He said he cared too much for the vulnerable children his agency served to risk their well being because of his ego. This gentleman had also let the board know the agency was in his will and suggested they do the same. His wife and children had been informed of his wish that in lieu of flowers, contributions should be made to this charity. He was a true visionary who was able to see and plan for a future without his presence.

This was a rare individual. But boards are made of rare people who give time, energy, money, thought and caring to the causes they believe in.

Approaching the subject of removing power should be done in private, with kindness and caring. "We appreciate all you have done over the years for our agency. I particularly remember the way you always.... Because of your leadership we are where we are today. We are concerned about your health. We wondered if you might want to take a short sabbatical to regain your

strength." Then you need to listen carefully to both the words and the feelings behind them.

Perceptions of Time

At times people who are ill have chosen to finish a specific piece of work. They can find themselves overwhelmed and frantic with small delays. One friend who was terminally ill told me long term planning meant next week. When something was promised on Friday and not delivered until Monday, he went ballistic. He told me he knew he was being totally unreasonable, but he couldn't help it. He just felt powerless.

Both board and staff can bear the brunt of this. Obviously, staff and other board members may have different priorities than the person who is ill. It is up to board colleagues to run interference when unrealistic time expectations are made. A partner, friend or co-chair can assume this role. This can either mean pitching in and making sure the work is done in an expedited fashion, or helping the person who is making the demands to understand the time, work and personal commitments of staff and colleagues so as to give them some relief.

Staff and colleagues who are the brunt of this kind of anger have a difficult time coping. They get angry at the insinuations and attacks and then feel guilty about their anger. Unless a third party intercedes a vicious cycle of avoidance and anger can pollute the atmosphere of an agency.

Reconnecting

People deal with death as differently as they deal with life. Everyone is different. It is important to check with survivors as to what kind of involvement they want. Some wives, lovers, mothers, fathers, friends and siblings want a break. Others want to proceed with volunteer work with a renewed commitment or at times a driven quality.

The decision should be made in conjunction with the leadership. A private meeting needs to be set up and the simple question asked, "what would you like your involvement to be at this time?" Grieving people might not know, but it is a place to begin talking.

To stay in touch and let someone know they are welcome back is always helpful. Again, should the member who has lost a sibling, spouse child, friend or parent desire it, a board

sabbatical can be offered.

I recently spoke to a woman whose son had died fourteen months before. She told me it was her first meeting since his death. I commended that it must be very difficult to return after such a short time. She said I was the first person who thought it was a short time. But it was obviously a short time...for her.

Mentoring

I met a young man of 23 who said that three older men in a disease related group took him out to lunch and said, "it's going to be up to you. We need to teach you everything we know and you'd better be a quick learner." All three died within a year. Luckily, he was a quick learner and recently represented his chapter at a national meeting. His year of learning was invaluable. Through their mentoring, they empowered another, left a bit of themselves and saved an organization.

In this case, they found each other. Sometimes, it needs to be more contrived. People who serve organizations have incredible skills, knowledge, wisdom and gifts. A closely connected person can ask the ill person who they see on the board with real leadership potential, and then pair them up to co-chair a committee or work on a project together. Sometimes, the person who is ill might want to nominate someone from the outside with whom to share their knowledge of the organization.

If the person who is ill has a very long association with the group, a memoir or oral history can be invaluable. The process can be both informative and healing.

Nate Smith wrote the History of the National Hemophilia Foundation before he died. I loved the section where the bank note paying off a major debt was burned on a silver tray at the Waldorf Astoria. I would have never known this marvelous bit of history had he not taken the time to write a memoir.

Saying Goodbye

When a group has lost a member, saying goodbye is always difficult, especially when it is a national or regional board and the funeral or memorial service is far away. A group that has

lost hundreds of constituents has an even bigger problem. The National Hemophilia Foundation now has a memorial service at every National meeting to say goodbye and celebrate the lives of those who have died. Conference attendees write the names of those they want recognized in a book. In addition to music and sometimes words of comfort, the list is read. In the midst of decisions, agendas and meeting and greeting old friends, the loss of what are often called "blood brothers" is acknowledged.

The more difficult problem at times is to decide whether it is more respectful to continue a project after a death or to plunge ahead. There is no "right" answer. I once had a board member die unexpectedly of a heart attack in his fifties. We went to his company and his wife outlined the commitments he had made. They made the decision to honor his wishes and sponsor a large event. Had they chosen not to, it would have been absolutely all right? What is important is to have an open and frank discussion and not push for an immediate answer.

While dealing with death, celebrating a life can be healing for an entire community. The life of a person needs to be celebrated as it was lived.

I have been to several truly great, healing and joyous funerals. One funeral was of a friend's elderly grandfather who loved to shoot craps. We were all given dice to leave on the grave. Sam would have loved it. His funeral was irreverent and filled with warmth and humor, as was his life.

The other was of a six-year-old boy who died of a brain tumor. His favorite songs, including Puff the Magic Dragon and the theme from Mighty Mouse were played. His favorite story was read and the children in his Church choir sang. I left feeling incredibly sad, and yet, in his six years, he had such a full life. A stranger could have attended and known who Kevin was.

Saying goodbye should be an act of acknowledgment and celebration. I particularly appreciated a board meeting when after a moment of silence we were asked to share any stories about our colleague who had died. I didn't know this woman well, but when people had finished, I appreciated and understood her better. I also had a real desire to recommit myself to the work of the agency and to move forward.

Summary

There are two goals to sharing the boardroom with chronically and terminally ill people. They are to provide a kind, loving and accepting environment while forwarding the mission of the agency. Neither goal need be sacrificed for the other. Planning, mentoring, an occasional sabbatical, facing issues squarely and saying goodbye in a fashion appropriate to the individual will provide a place where all know they can contribute beyond their own mortality and leave a legacy to benefit generations to come.