THE BLOG 10/03/2010 10:08 am ET Updated Nov 17, 2011 How to Handle Family Dynamics Around a Dying Loved One



By Judith Johnson

While there are times when the motivations of family members for asserting their particular point of view regarding the "well being" of a critically ill loved one are self-serving at best, more often the motivation is love. Yet, terrible things are done in the name of love and the dynamics of power and influence that can develop among family and loved ones can be shocking. All too often, tensions escalate as judgments and discord fester, while no one knows how to step forward and lance the family wound by talking honestly and respectfully about differences of opinion and differing styles of response to the situation. Frequently, childhood politics surface and you suddenly find yourself the seven-year-old kid who used to be bullied by her older sister.

While everyone might sincerely believe that they all have the patient's best interest in mind, they may have diametrically opposed views about what that would look like and how it is to be accomplished. Unfortunately, all too often family members polarize against each other behind the scenes rather than uniting in support of the patient.

Here are some guidelines to help families navigate these stressful and emotionally challenging times.

Respect the patient's right to make his or her own decisions as long as deemed mentally competent.

Recently, a client shared her family's drama around their terminally ill mother. Behind the scenes, some family members are under the impression that mother is depressed and needs antidepressants and have emailed her doctor urging him to prescribe them. Others are concerned about drug interactions and over-drugging mom and perhaps masking feelings that she needs the opportunity to process. When I asked what the mother wanted, my client didn't know — no one had asked her. They were too busy campaigning for their point of view behind her back.

Be sure that the patient designates a health care proxy before being deemed mentally incompetent.

The person who is appointed as the patient's health care proxy is charged with the responsibility to make all decisions on his or her behalf regarding health care. A client told me that her father was the health care proxy for her mother. However, he was terribly uncomfortable dealing with death and dying. The choice of who to appoint should not be primarily governed by the person's rank in the family pecking order. Rather, the patient should thoughtfully decide based upon who is most able to communicate comfortably with the patient about his or her health care situation and to advocate for the patient with doctors, nurses and caregivers. If, for example, a family member holds a strong personal or religious belief that would prevent him or her from following the patient's wishes, they should not serve as health care proxy.

No matter how strong your opinion, that doesn't make you an expert.

If you are a family member with concerns about the treatment protocol and care being given to your loved one, address it either with the patient and/or the family member who is managing the patient's care. Feel free to express your point of view, but respect the right of the person who is making the decisions. Be careful not to make others wrong for not agreeing with you.

Clarify, agree upon and respect a pecking order for the flow of information and influence.

Whoever is primary caregiver and/or health care proxy should be respected as the one who has the most up-to-date knowledge about the patient's condition and needs. If you really want to demonstrate your love for the patient, than do everything you can to support this person in caring for your loved one and in keeping communications clean and above board within the family. Avoid the temptation to judge and talk about each other behind backs. If you have a problem, address it directly with the person(s) involved. Having a loved one who is critically ill is stressful enough. Do not make matters worse by bringing your personal animosity toward another family member into the situation.

Handle your emotional needs on your own. Don't act them out around the patient.

It is not uncommon for relatives who live at a distance to try to overcompensate for their absence and perhaps guilty feelings by playing the hero or making a larger than life impact on the situation. It is important to be ruthlessly honest with yourself about how you feel and to be, first and foremost, respectful of the patient's needs and the normal routine that has been established for the patient's care.

For example, don't take it upon yourself to feed the patient two big bowls of oatmeal because that used to be his or her favorite breakfast. Find out what the patient is eating now and stay with that. Also, consider the possibility that if you did manage to feed him or her that much oatmeal it wouldn't necessarily mean that it was a good idea. They may be fully aware of your need to feel helpful and be eating it to please you even though it will cause digestive distress later.

In most cases, an in-law should focus on supporting his or her spouse in handling the emotions, tensions and concerns regarding the situation and not try to be a major player in decision-making.

There are exceptions. For example, if an in-law is the primary caregiver and/or supervising the day-to-day care of the patient, then his or her knowledge of the patient's needs should be highly regarded and other family members who visit should seek his or her guidance and insight about what is and is not in the best interest of the patient. This is especially important if the patient is living in the home of this in-law and his or her spouse or in a nearby facility while other family members are not local to the situation.

Remember that you are writing family history through your behavior. Consider giving the patient a wonderful experience of loving, united family support.

As always, your comments, stories, wisdom and insights are always welcome in comments below or by email to me at: judithjohnson@hvc.rr.com



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