

END-OF-LIFE: DIFFICULT CONVERSATIONS

“Human life is purely a matter of deciding what's important to you.” - Anonymous

Working in the health care field presents many challenges, and one especially difficult challenge for all involved is having conversations about the end-of-life care. Unfortunately, our society is a death denying society that avoids the issues surrounding our own death and the death of friends and family members. We avoid discussing the inevitable outcome for all of us and the practical issues that need to be addressed at this difficult time. No doubt, talking to someone who is dying can be difficult, but it can also be therapeutic and a caring exercise that can benefit all involved. We may not know what to say or are afraid to say the wrong thing but our relationship demands that we attempt this interaction. Initially it may be easier for us to avoid the topic and the person than to engage in the conversation. Whether you are the patient or the caregiver having an open conversation with your loved ones will give you and your family a sense of peace that outweighs the initial anxiety.

A little over two years ago “The Conversation Project,” which seeks to facilitate end-of-life conversations, collaborated with the Institute for Healthcare Improvement, a not-for-profit organization and a leader in health and health care improvement world wide. These groups are committed to reframing the patient-provider relationships and encourages individuals to talk about their wishes for end-of-life care before patients are in a health care crisis. While many caregivers, patients and families find conversations about end-of-life wishes and end-of- life care difficult they surely must take place.

There are many fears that surround the discussion of end-of-life care. Some of these may include fear of having invasive feeding tubes and ventilators, fear of ending up in a nursing home, fear of dying in a hospital or institution, fear of being incapable of making decisions and fear of loss of independence. The best way to address the end-of-life fears is to communicate clearly, having these conversations with the person about their end-of-life wishes in advance!

The Conversation Project developed an effective tool called the “Where I Stand Scale” that may help initiate the conversation. The “Where I Stand Scale” assists in determining a person’s preference for end-of-life care. In brief, after reading two statements the person rates their feelings about a given scenario on a scale of 1 to 5, five being most important. Some examples of the statements are:

- I want to live as long as possible, no matter what. - or - Quality of Life is more important to me than quantity.
- I want my doctors to do what they think is best. - or - I want to have a say in every decision.
- When the time comes I want to be alone. - or - I want to be surrounded by my loved ones.

An additional Conversation Project suggestion is to write down a “What Matters To Me” statement in the presence of your loved ones, which could be a big help down the road. It could help to communicate to the medical caregivers what abilities are most important, what’s worth pursuing treatment for and what isn’t in the event the person is not capable of communication.

If you are having difficulty starting the conversation be sure to pick a time when you have the attention of the person(s) you want to share your planning and preferences with or with whom you want to help determine their preferences. Most likely there will be more than one conversation required as you and your family become more comfortable formulating a plan. Depending on the stage of life, and stage of illness, choices may change overtime. Be sure the choices and decisions discussed are shared with your physicians, family members, friends and caretakers.

Being able to identify preferences and making them known to caregivers, friends and family is very empowering to the patient. As always, caregivers should be sensitive and open in understanding their patient's desires and reasoning behind their wishes. Making sure all involved are knowledgeable of the patient's wishes is an important part in providing the desired and appropriate care. Being able to openly discuss with family members their wishes and to reminisce together about past experiences is a beautiful way to honor the individual and provide a loving connection.

Knowing about your loved one's wishes is incredibly important as death nears. It can also be a comfort to the bereaved knowing they have carried out the wishes of their loved one. By planning ahead and having these difficult conversations the goals of improving patient-provider relationships, and partnering with patients to develop appropriate goals of care within the desires one wishes of the patient can be successfully accomplished.

Marilynn W. Allemann, LCSW, CPC
Executive and Personal Coach
Masters Executive Coaching
www.MwaExecCoach.com
www.MwaExecCoach.wordpress.com