

Very few of us will die in our sleep.

Welcome to SBH Bronx Health Talk, produced by SBH Health System and broadcast from the beautiful studios at St. Barnabas Hospital in the Bronx. I'm Steven Clark.

It's not easy talking about end of life issues. Yet, being in a hospital, unable to express yourself, and not having previously communicated your wishes to loved ones, is much worse.

This is why, according to Maureen Eisner, Vice President of the Patient Experience and Bioethics at SBH Health System, most people will spend far more time in end of year holiday planning than they will in end of life planning.

(24:05 – 24:28) Unfortunately, not enough people do because a lot of the issues in end-of-life could really be avoided if they did. I think it's an unpleasant topic so sometimes families don't want to talk about it, but it really is a very necessary topic because it really does help in the future. And these conversations need to be had.

This means, says Eisner, those medical interventions routinely performed to keep patients alive – cardiopulmonary resuscitation, feeding tubes, intubation, surgery – could be avoided for those who don't wish their lives prolonged through such means.

A legal form, called an advanced directive, can make one's wishes clear and will communicate them to family or friends. This includes a living will, which tells doctors and loved ones what kind of care you want at end of life, and a health care proxy, which names your health care agent. A MOLST form (which stands for Medical Orders for Life Sustaining Treatment), is recommended for patients with serious health conditions to discuss with their physicians.

Experts say that an advanced directive is important for all people, regardless of age. And, the best time to do it is when you're generally healthy.

(1:37 – 54) Yes, actually that's the best time to do an advanced directive because you're not stressed. You're not dealing with the illness and most importantly you have capacity to do that. Lots of times we see a lot of issues where patients now lose capacity and we never knew what they wanted to while you're healthy is the best time to do it.

Providers like Dr. Steven Reichert, director of palliative care at SBH, often see what happens when the wishes of the patient are not known or followed and how it can create conflict within families.

(Reichert podcast, 10:26 – 11:26) To begin with, just the shock and the process of dealing with bad news, and I break a lot of bad news, so the family is working with denial or anger or bargaining as they work through the process before they can accept what's going on. For many in this community especially their strong spirituality and religious beliefs become very challenged and tested when they're in an ICU environment and their belief and faith that God will heal and restore sometimes can become very much challenged as their loved ones get sicker and suffer. So then you also have the families that unfortunately are in disagreement or sometimes even fight about life support machines and whether to stop them or not and sadly sometimes there's disagreement among families and I have to kind of allow them to go through their process as they each come to their own accord.

Conveying your feelings to loved ones will make sure your wishes are carried out, says Eisner, and will enable the five ethical principles of end of life: autonomy, beneficence, non-maleficence, justice and fidelity to be fulfilled.

(0:14 – 0:55) Autonomy is important in end of life because you want to make sure that you're doing what the patient wants and that's their autonomous decision as to what happens to them. Beneficence – we always want to do good and the least amount of harm so and actually to do no harm actually trumps doing good so most of all we never want to make a situation worse. Certainly justice we want to make sure people are all treated equally, resources are distributed equally, and fidelity, we want to have that relationship with our patients where they trust us so these are really the basic tenants of medical ethics and we make decisions and we do ethical consultations around those principles.

Providers must play an important role in this.

(12:30 – 12:50) I think the provider needs to respect what the patient's wishes are and of course, although we're putting the patient first, they need to have empathy for the family and what they're going through with patients permission to have information about you know sometimes being too aggressive with care at end of life is not a good thing. It's just prolonging suffering and prolonging the dying process and I think the family needs to understand that as well.

People live longer today and medical technology has the power, in many cases, to keep people alive indefinitely. Has that raised the stakes on end of life planning? Ruth Diones, the interfaith chaplain at SBH, weighs in.

(5:15 – 6:25) So my first response to that is not necessarily as a chaplain but as someone who is witnessing the advances in medicine that can keep someone alive almost indefinitely, especially someone who's young and has had something catastrophic happen and they're on life-support and completely unresponsive and that is what their life is, so it becomes more and more important as we can accomplish more and more medically. Spiritually it is always an issue for patients and family that what they do is aligned with spiritual values, with their heart, what they think is most important, what will bring them to God at the end of their physical life, so it's critical to think about these things not only from the perspective of law, but from spirituality and from one's own faith to perspective.

Spirituality, adds Chaplain Diones, is an important component, even among those who don't consider themselves religious, or don't necessarily believe in a supreme being.

(6:36 – 7:15) Spirituality is so much more than a particular faith group and membership in a particular congregation. Spirituality can be simply, and it's not simply of course, what matters most to you, what gives you meaning in life, the reason to get up in the morning, and for anybody that could be being a good person, being kind, those kinds of things are spiritual.

The role of the chaplain, she says, is to listen and be a calm presence at an emotionally turbulent time.

(8:57 – 9:35) I listen to what they value, so again if they are a person of spirituality, faith, I will say "What's your personal theology? How does that help you get through this? What helps you cope? If it's a person who does not look towards a greater being or a particular faith group, I will talk about what's important to them and what's important. Usually, it's family. Family is almost a constant of what's important to people. How would you like to be remembered? What is your legacy? And all of these things can be addressed from your perspective as a chaplain.

Patients and families must understand the terminology that often gets discussed at this time. While all of hospice care is palliative care, for example, not all of palliative care is hospice care, says Dr. Reichert.

(Reichert tape 1:42 – 2:44) Hospice care is a very specific discipline doctors and nurses and social workers that are trained in managing patients who are truly at the end of life, but also in those situations patients have already made a decision or their families. They've decided to forego aggressive life-sustaining care. These are patients that have given up on chemotherapy or their oncologists has said "I'm sorry there's nothing we can do" These are patients who have decided not to pursue artificial life support so the hospice population is various. In palliative care I deal with a much broader range of patients, patients who face certainly very serious illness and life-threatening but patients who may have months or even years to live but face serious challenges either because of emotional issues or social issues or physical issues or also just helping them with medical decision-making, understanding some of the really complex choices that are available to them and what might fit their own personality, their own lifestyle best as they move forward.

There is also a public misunderstanding about hospice care, he says.

(Reichert tape 2:52 - 3:36) Even hospice care itself has an understandably negative connotation, but many people when they think of hospice care they think "Oh a hospice as a place you go to die. They send you somewhere and you go there to die." and hospice care is also that living it's about helping you live as best you can for the remaining time of your life. By estimation, most hospice patients have less than six months to live many are only in hospice care for a few weeks but some hospice patients can live for much longer than six months. Palliative care is even broader and more diffuse and that's why when I introduce myself I now say "I'm a comfort care doctor I'm here to try and make things better" in a very broad sense.

Education about end of life is not only critical for providers, patients, and families, but even clergy. This is part of the reason why SBH recently scheduled an end of life workshop with interfaith leaders. The benefits of such an event, says Chaplain Ruth, work both ways.

(15:33 – 17:00) The first thing is they need to know the perspective of the hospital and the laws that exist. They need to understand that so they can understand how best to help themselves and their congregation. However, I think there's a part of it that's we're beholden to understand as well, which is the religious and cultural beliefs that different faith groups approach end-of-life with and without us being sensitive to that we may not be able to communicate well at all and there can be disharmony at a very important moment in life. Some faiths have very specific ways of doing things at the end of life and we need to know some of them. So, for example, if the patient is Muslim and a woman it's only men who are taking care of her, there might be an

issue in terms of needing to have a nursing attendant who is female who takes care of person at death. Things like that are really important. Another thing is even though these people are faith leaders, they may not know that different faiths have taken positions, have written documents in terms of what can occur, what is a natural death at the end of life. So they define what is a natural death and what is permitting someone to die naturally vs. killing them. Some people think that if they withdraw life support they're killing them, they're actively killing them, whereas these major faiths do believe that it is permitting a natural death.

Maureen Eisner expounds on the importance in understanding these differences.

(18:58 – 19:25) An example would be sometimes in the Catholic religion, it's a myth that if you withdraw care that somehow you're killing the patient and really the religion doesn't look at it like that. It looks at it as though it's ending suffering and it's allowing a natural death for the person to die, so you know sometimes families have guilt and signing a "do not resuscitate" order and it's really the most sensitive thing to do and their religion does support it."

All things being considered, even in the best of circumstances, admits Chaplain Ruth Diones, this is a uniquely stressful, anxious and disturbing time.

(29:46 – 30:40) It's not a chaplain's job to fix things, to be God, and tell them what God's answer is or make decision or offer advice. The chaplain's job is to be a presence, a listening presence and to open their thinking. So that's what I try to do when I'm with people is really hear what their concerns are. Sometimes if you really listen it may not be something so complicated that they're looking for and it can be addressed, and sometimes it's intractable and I am faced with feeling a little bit helpless and not knowing how to be of service other than listening and being a presence for them.

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