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# Hospice Care and Planning

## Starting “The Hospice Conversation”

**H**ospice care is a great comfort and benefit to any family facing an end-of-life situation. Hospice care is available to anyone who has been identified as having a life expectancy of six months or less, and who elects palliative (comfort) care rather than curative care. Nevertheless, the average time span of hospice care is only around three weeks.

That raises an obvious question: Why do people wait so long?

One very important reason is that people involved in the situation – from doctors to family members to patients – are often reluctant to start “the hospice conversation.” Life is precious, and we don’t want to be seen as being the first to give up hope.

As understandable as that may be, it often results in the sort of situation in which, in retrospect, you hear comments like “everybody knew it was time, but nobody wanted to say anything.” And even that’s usually not a fair statement. More true is that people involved in the situation *wanted* to bring up the subject of hospice care, but were *afraid* to.

With that in mind, here are some (hopefully) helpful tips for starting “the hospice conversation.”

### Tips for Doctors

Doctors often feel in a particularly difficult position when it comes to initiating a discussion of hospice care. They are trained to cure people, occasionally hailed as “miracle workers,” and subscribe to a Hippocratic Oath that seems to define their duty as preserving life.

So what should a doctor do when he or she starts to feel that a hospice election may be appropriate? Perhaps the first rule should be, “Ease thy burden.” Talk to professional colleagues, hospital staff, your own staff, even family members. Ask if they feel that a discussion of hospice would be appropriate. Ease any potential feelings of guilt by asking if there are other steps you should first take toward curing the patient. And always remember that people are seldom, if ever, offended by being given choices.

If the possibility of hospice has crossed your mind, then it’s something you need to discuss with your patient and the family. You’ll be fine if you frame the discussion so as to assure them that you’ll do your best to help support whatever decision they make. Try something like this:

*We’ve talked about options for addressing your condition that are directed toward keeping you alive as long as possible. But your condition is such that you might also want to consider hospice care, the goal of which is to keep you as comfortable and pain-free as possible. I care about you, and I’m here to help you however you may choose to be helped. One thing I want to be sure you know about a hospice election is that you can always change your mind later, and go back to curative care. And I want you to know that I will monitor your condition, and if I feel you should go back to curative care, I’ll be sure to tell you.*

### Tips for Family Members

It’s never easy for any family to face an end-of-life situation. Emotions invariably run high, and it’s not uncommon for those emotions and the associated stress to cause strained conversations and even arguments. Sometimes we say things we later regret having said.

The statements that get us in trouble are usually made “in the heat of the moment.” So think about it for a moment – that’s almost never the case with hospice. Nobody blurts out “let’s put mom on hospice” in the middle of, or right after, a discussion with a doctor. We think about it, and agonize over it, before we say anything. That gives us time to plan out what to say.

As with doctors, if you think it may be time to talk about hospice, it probably is. You’ll be very unlikely to offend anyone if you remember a few simple guidelines. First, it’s hard to be mad at someone who just told you they love you. Second, human touch does wonders for relieving stress. Third, nobody wants to feel excluded from a discussion that affects them greatly. Fourth, patience is a virtue; you don’t need, probably shouldn’t expect, and certainly should not be offended if you don’t

## Ask the Expert . . .

### The body, mind, and spirit in rhythm...

By Mary Magill

Just as being born is an act of nature, so is dying an act of nature. It is part of everyone's journey and is something we should embrace as a "holy" happening, an honor to be part of, and a humbling experience. Hospice's presence enables a person to pass away with dignity, respect and love.

We strive to give patients and families the information and knowledge they need to make informed decisions regarding their loved ones healthcare at the end of life.

Our focus on comfort, quality of life, guidance, and emotional & spiritual support for our patients and their families.

*Alternative Hospice blends the old with the new.* Our team is seasoned in conventional healthcare, and many have experience in complementary care techniques. We offer patients and caregivers' aromatherapy, touch, massage, guided imagery, visualization, acupressure, music, reflexology, and prayer.

Dr. Joseph Flaherty with SLU Medical School is our medical director, and guides our team. His wisdom and knowledge related to end of life care, pain and symptom management, and openness to complementary care, gives our patients and families peace of mind...*the body, mind, and spirit in rhythm.*

Would you like to be added to our mailing list for *Hospice Care and Planning* or be a guest columnist? If so, please contact our

Director of Community Education and Outreach, Beth Frame, at (314) 567-9292 or (618) 659-9292, or email to [beth@coulsonlawgroup.com](mailto:beth@coulsonlawgroup.com) to be included.

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get an immediate answer to this sort of life choice. Try something like this:

*I want to talk about something that's been going through my mind after hearing what the doctors said. This is hard. First, I want you to know how much I love mom, and how much I love all of you, and as soon as I get done saying this, I'm going to give each of you a big hug. What I wonder is, is it time for us to start talking about hospice? I'd like for us to talk about that, to think about it for awhile, and then to come to a decision together as a family.*

#### Tips for Hospice Patients

If you're the hospice patient, my first suggestion is something you may be hearing a lot lately: Be brave. Don't be afraid to speak up. Chances are, if you're thinking about hospice, your family is, too, and they're waiting for you to be the one to bring up the subject. You're the only one who truly knows how much pain you're enduring.

For you, the guidelines are these. First, have no fear about raising the subject prematurely or incorrectly. If it's not time yet, or at all, rest assured that your doctor will tell you so. Second, demand honesty. You don't need or want to be patronized, even if it's well-intentioned. Third, never ever forget that you can change your mind later. You make the hospice election, and you can terminate it and go back to curative care. Try something like this:

*I've listened carefully to what the doctors had to say, and I want to find out whether I should go on hospice. I'm going to have a frank discussion with them about it. I'm in a lot of pain, and it's getting worse. I don't have a death wish, and I won't elect hospice unless I think it's the right thing. I want you to be brave with me, and for me, and when we talk about this, I want you to be honest with me, and not just tell me what you think I want to hear.*

#### Tips for Everyone

**Tip #1:** A family counselor once told me something I have come to appreciate as being profoundly wise: you can practice a conversation, just like you can practice the piano or a golf swing. If you're dreading a conversation, find someone to help you practice it. You already know, in your mind, what the toughest parts of the conversation are going to be. Role play them out, until you get to the point that you have a pretty good idea of how best to handle them. Trust me: this takes a lot less time and energy than agonizing does.

**Tip #2:** Remember that you aren't making a final decision, you're starting a conversation.

**Tip #3:** Call some hospices, and arrange for them to come talk to you about hospice. They know what you're going through, and they have lots of experience in dealing with the tough issues and decisions you're facing. And they really, really care.

**Tip #4:** If you want to learn more about the subject before you start the conversation, get a copy of our *Consumer's Guide to Hospice Care*. It's full of valuable and practical information.

We're on the web!  
[www.coulsonlawgroup.com](http://www.coulsonlawgroup.com)

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