DYING AND END-OF-LIFE PROCEDURES

In a recent issue of *U.S. Catholic Magazine,* Myles Sheehan was interviewed by the editors of U.S. Catholic. **This is a great interview. I hope you take time to read it and share it with others**. Myles Sheehan is a senior associate dean and professor of medicine at Loyola University Chicago Stritch School of Medicine in Maywood, Illinois and a practicing geriatric doctor, Sheehan helped to develop the geriatrics curriculum at Harvard Medical School and at Stritch. [“Repreinted by permission of U.S. Catholic magazine (http://www.uscatholicorg) U.S. Catholic is published by the Claretians. Call 1-800-328-6515 for subscription information.”

What makes a good death?

A good death is one where you have the comfort of the sacraments, good pain control, your symptoms are adequately controlled, people who love you are nearby, and-this can be the hardest part-you can die in a place of your choosing.

Dying happily means someone sits and holds your hand. And your doctor tries to meet achievable goals and doesn’t abandon you to the experience of your illness.

What does a worst-case scenario for death look like?

When doctors don’t do anything right and there’s poorly treated pain and symptoms are not controlled. The worst deaths I’ve seen were when someone had clearly been dying for quite a while but no one had raised the issue. It was like the two-headed guest at the dinner table whom everyone politely ignores. There can be almost a delusional fixation on a cure that doesn’t exist. That fixation leads to a much worse dying process in terms of pain, family dynamics, and insanity.

How so?

I’ve seen delusional avoidance of dying and folks dying in severe pain after aggressive and excruciating treatment, while family members are fighting with each other and with the doctors.

You can’t help wondering, “What is wrong with all of you?” Why is it a news flash that someone with widely metastatic cancer that has been treated is dying now? Why did the family drive the doctor so insane about the treatment that he or she just gave up and did what the family wanted, all the while knowing it wouldn’t work?

How does this happen?

Often the family members who strongly insist on ongoing life-sustaining therapy have a disturbed relationship with their parents. They think they need to prove their love by doing everything medically available to make up for what they haven’t done during their lifetime. In many ways, “I love you” in the United States is expressed through technology, money, or power. To some, the idea that we can’t keep a person from dying seems almost absurd.

The classic situation is the mother with two children. The daughter, who cared for Mama for a million years, says, “Let’s just keep her comfortable.” The son, who’s a lawyer from California, shows up and announces he’s going to sue everybody and he’s going to show everybody how much he loves Mama by demanding ridiculously burdensome treatments. I see this kind of thing way too often.

What do you do in that situation?

I stand up and say no. I can be scary right back in the face of the lawyer from California. Of course, it helps to be senior associate dean of the medical school, and it helps to be a Jesuit priest when it’s a Catholic hospital.

What do other doctors do?

Because I have a vow of poverty, it doesn’t matter to me how much money I make. But if you’re a doctor who has to see 30 or 40 patients a day to make money, you can’t spend four hours fighting with a crazy person. So you say, “I give up. Let’s just keep your mother on the ventilator. Fine.”

There’s another situation that sometimes leads families to insist on burdensome care for a dying person. That is with people who have been poor all their lives and have not had access to health care-say, someone among the working poor who doesn’t qualify for Medicaid.

Now try to explain to that family why it’s time to stop treating that man. As a society, we didn’t let Dad have medical care throughout his whole life. Now that they’ve finally seen more health care than they’ve ever dreamed possible, the nice doctor is saying, “Oh well, I think we should stop this now.” Of course this family will be suspicious.

Do families ever try to stop appropriate treatment?

I’ve been in a couple of horrible situations where I came close to calling in the district attorney because the family said, “Do not feed this person.” I have always said no and that I would have them arrested if they tried

to stop us.

How important is it to have a living will or an advance directive about health care?

If you even think about documenting what you would like at the end of life, you're about 900 percent ahead of most people. With an advance directive, though, the most important thing is to do it in conversation with your physician. If you draw up a durable power of attorney only with your lawyer, it's like having marriage counseling with your banker.

What do you recommend?

An advance directive is any form of documentation that expresses an individual's wish in the event of a life-threatening illness in which he or she can no longer participate in the decision-making process. There are different kinds, such as the Living Will and the durable power of attorney for health care.

I find the living will very problematic because it talks of having a terminal illness and imminent death, but it's hard to define when that's actually happening. Is it when I have metastatic cancer, or when I get obstructive pneumonia from the cancer, or when I am septic from the pneumonia?

The *Durable Power of Attorney* allows me to appoint another individual who can speak with my voice if I can no longer participate in the discussion. That's a far more useful thing, provided you have a conversation with the physician to set up the ground rules.

What kind of conversation?

When I talk to my older patients, I ask them, "What if you got really sick and you couldn't answer me in the emergency room. Would you want me to treat you very aggressively?" Most of my older people say, "Oh no, just let me go."

But then I ask, "What if I could do something, and after a couple of days you'd be out of intensive care and home within a week or two?" And they say, "Well, of course, do that."

And I say, "OK, that's why I need somebody you trust whom I can talk with. I'd like to make a basic game plan with you: I'll push hard for a day or two if I think I can get you better, If after a day or two you're not getting better but getting worse and your other systems are failing, I will probably think it's time to back off and make sure you're very comfortable and allow you to die." And they'll say, "That makes sense."

You mentioned keeping your patient comfortable. Is that an accepted goal for all doctors?

During medical school I had no formal education on pain control, and many senior doctors are not good at controlling pain. It may take a while to get the right mix of pain medicines, but many patients do very well afterward.

Yet the main reason people want assisted suicide is to avoid dying in pain. Is that a misconception?

There will always be plenty of suffering attached to the dying process because you're leaving this life, which is very sweet. And not knowing what's on the other side hurts, too. As a doctor I can't take that away, and I certainly wouldn't try to take it away as a priest because it would be taking away someone's humanity. As for pain, a well-trained doctor can take care of most of that and can relieve most symptoms.

As a society, we tend to avoid facing the end of life. The call for assisted suicide is a quick fix to avoid the issue.

Why do you say it's a quick fix?

Well, look at the premise: I am very much afraid of having a bad death. I don't trust doctors. I don't think they can sustain my quality of life. Therefore, I will let a doctor kill me. There are some logic problems there.

Instead, can we think about what it means to die in the context of my life and what a good death might be? I think the increasing distance we have from a natural death leaves people not thinking clearly.

Do doctors feel pressure to assist in suicides?

Perhaps some do. But I think if they were more adequately informed about how to care for folks in a larger context, it would relieve some of the pressure they feel.

When a patient says, "Doctor, I want you to help me take my life," the first answer is not yes or no. The first answer is "Something must be going on to make you feel that way today. Can you tell me what's happening?" Often you find a context that reveals the statement's meaning.

The times I had the fleeting thought that I could help end someone's life-were it not for the fifth commandment in my soul-were it because I was uncomfortable waiting for someone to die. It's hard to be patient.

Physicians are people who want to help. It would be easy to consider assisting in a suicide as "helping" and to say, "What's the difference?" The difference is that, when you take a life, you're no longer a healer. Sometimes the most healing thing for a physician to do is say to the person or family, "Are you finding this as hard as I am?" Just to allow those emotions to be expressed is a great help.

How do you think our church can effectively counter the movement for assisted suicide?

We should not blow it, as we have done in the abortion discussion, by focusing only on the legal aspects. That doesn't mean to be naive about lawmaking, but it also means that we shouldn't react simply out of fear. Instead, let's recognize the power of our tradition to create substantial change in society by bearing witness: by taking care of people when they're old and sick, loving them, giving them reasonable medical care, and not shoving tubes down their throats when they're dying. We pray for them before they die, as they die, and after they die.

If the church would effectively and publicly witness to that, we could change the culture of dying in the U.S. But we have not adequately shared our vision of an alternative way of dying that involves the love of a believing community.

People support assisted suicide because they fear dying, and that's because of their experience of poor care. If we could emphasize pain control, symptom control, adequate care, and hospice, what a difference we could make.

Bishops should say, "I will take very seriously cases of untreated pain as a violation of Catholic ethical guidelines. Dying in untreated pain is an offense against God and against humanity."

Do you buy the studies showing that spirituality promotes health?

I'm intrigued, but I also reserve judgment for several reasons. One reason what those studies imply about God. God is ultimately beyond our control. Don't think God is going to react in a statistically significant way to influence treatment outcomes. It's heretical to think we can control God.

I fear some of these studies make us think we have ultimate control. I've seen women blame themselves for a recurrence of breast cancer: "I didn't pray right, I didn't drink enough water, I didn't meditate." What a lot of nonsense. It's not your fault.
The last time I checked, somebody who had a really good spirituality ended up executed in the most horrible way possible. So if you do everything right – the right yogurt, stand on your head and pray the right prayers, you're still going to die. But that doesn't mean God is not with you in the most profound way.

Have you ever seen a miracle?

No, I haven't. But I believe it happens.

I also believe there is an everyday miracle we fail to attend to. We look for the miracle we have decided we want rather than the one God is supplying. So you see families that have been at each others throats for years, and here they are all around the bedside praying. You see people reconciled, you see an opportunity for change or forgiveness or laughter we say, "Nah, that doesn't count."

Sometimes a family will say, "We are going to pray for a miracle." Now I've learned to say, "So you believe in God's goodness and care for your mother. They'll say yes.

Then I'll say, "Do you have enough faith to let God bring the miracle God wants rather than the one you're going to dictate to the Lord?"

One time when I said that, There were two medical students behind me. The one whispered to the other: "Closed track with a professional driver. Don't attempt on your own."

Reflection Questions

1. In your opinion, what is a good death?

2. Do you think it is wise to document what you would like at the end of your life, e.g., Living Will? If yes, have you done it?

3. If you were to die tomorrow, are all your affairs in order? Not taking care of such stuff will only leave a lot of unnecessary grief and maybe anger with your survivors.