Another in a series: Matters of Life and Death

Doctor teaches how to explain the unfixable

By Eileen M. Carlton
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Dr. Cameron Muir

Terri Schiavo's ashes were buried Monday, but the debate over the lingering death of the Florida woman goes on.

Dr. Cameron Muir is caught up not in the debate but in the real medical world, where people decide whether they would like to be kept alive in a persistent vegetative state or would want all life support systems removed.

In Schiavo's case, her family was torn apart over whether to pull the plug as she lay in a vegetative state after collapsing in 1990. An autopsy revealed that her brain damage was irreversible.

About the time the Schiavo case was playing out, firefighter Donald Herbert, of Buffalo, N.Y., regained consciousness after being in a coma for almost 10 years. Not only was Herbert conscious, he appeared to have no loss of memory, no loss of cognitive ability. Does Herbert's recovery argue that there was hope for Schiavo? Does this muddy the waters for making an informed decision about one's fate?

Not necessarily, say Muir and medical definitions that dictate decisions made by the most reputable medical agencies.

Muir is vice president for medical services for Capital Hospice and is also with Capital Palliative Care Consultants. He has seen it all and has chosen to see it all.

A bioethicist, Muir explains to other doctors how to tell patients and families that some things are unfixable.

He knows the face of mortality all too well. In Loudoun, Muir finds himself spending significant amounts of time at Heritage Hall Nursing and Rehabilitation Center, Falcons Landing and Sunrise at CountrySide. He also provides hospice consultation to Inova Loudoun Hospital.

"Many people believe that bioethics is more theory than practice. I believe that hospice and palliative medicine is bioethics in practice," Muir said.

"We are constantly being asked to see families struggling with serious illness; to help make them physically comfortable so they can think straight; and then be able to talk with them about about the big picture of their disease, and what options there are for them, and help them navigate through the systems and the choices."

Muir emphasizes that the person must be allowed to have the final say in his or her own fate.

Muir has been helping doctors and patients deal with this enormously demanding task for 10 years.

"Mostly what I saw was the look in people's eyes that just said that there was a lot more to what they were thinking and struggling with than most physicians address," Muir said. "So I sought training to better understand how to deal with these issues."

The first step, Muir said, is to find out how the patient wants to get the news, how to begin the process.

Some patients want the doctor to be direct. Others ask that a relative or friend be the one to explain the situation.

The protocol is one Muir learned at Northwestern when he was involved with EPEC, or Education in Palliative and End-of-life Care, a project to develop a national curriculum of core competencies – what every physician should know. One of the 12 major modules is breaking bad news.

The immediate aftermath is perhaps the most emotionally charged of all the stages. According to Muir, three different approaches are available to doctors and patients.

"The first is preventive palliative care, which is to encourage everyone to have discussions about their

wishes long before something bad ever happens," Muir said.

That calls for a living will in which the individual lays out desires for the end of life.

The second solution, Muir said, is to lay out the options to the family. "Then identify who is the best person to make decisions, which would speak to what the patients would say if they could sit up and tell you," Muir said.

The third part is often the most difficult: Build consensus at a family meeting.

"You sit down, go over the medical facts, try to make sure what the treatment options are," Muir said, "and 99.9 percent of the time people come to a consensus, agree as to what the patient would have wanted and move forward with whatever that plan would be."

The outcome: The family – not some outside group like an ethics committee or the courts – would settle the matter.

How big is the problem?

The Health Talk Web site http://www.healthtalk.ca reports that on any given day in the United States, between 10,000 and 15,000 patients are in a coma and a similar number are in a persistent vegetative state. In part, this "epidemic of unconsciousness" is a result of advances in doctors' abilities to save severely injured bodies having outstripped their ability to rescue the brain.

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