

Death teaches US doctors lessons in art of living

December 24 2010, by Kerry Sheridan

Farrah Daly is a doctor who helps people die. The 33-year-old neurologist spends most of her days on the road. Her car's GPS is filled with the addresses of people who may have only days to live.

On one frigid day in December, her day off, she heads to see a patient she has been treating for eight months, Alton Hlavin, 74.

As she drives cautiously along the jam-packed highway, allowing other cars to cut in front of her without complaint, she thinks about how much pain he may be in, and whether he will tell her the truth about it.

Hlavin suffers from an incurable disease called cortical basal degeneration. Similar to Parkinson's disease, it gradually attacks [nerve cells](#), causing debilitating [muscle pain](#) and shrinking parts of the brain until the patient can no longer walk or talk.

"The disease is progressing, damn it," he told her on her last visit.

When Daly arrives at his home this time, the former State Department consultant who has written two books and traveled to more than 70 countries is seated in a recliner, his right arm twisted at an odd angle by his waist. He is quiet and pale.

She exchanges kisses and hugs with Hlavin's wife Martha, and their hospice nurse Linda before sitting down next to Hlavin.

"So um, how much are you hurting today?" Daly asks.

Hlavin answers slowly, haltingly. His wife answers for him whenever a pause goes on too long.

As recently as a few weeks ago, Hlavin was going to church on Sundays and he even managed to vote in November's election. But lately he needs more [pain medication](#). His steps are getting smaller. He swallows his pills with applesauce and he has a hard time releasing the bottle of water in his left hand after taking a drink, his wife explains.

"I have difficulty expressing myself sometimes," Hlavin says, then sighs. "It's a real pain, You want to say something and you're..." he stops.

"You can't find the word?" Martha asks.

"Yeah," he says.

Daly writes a new prescription and advises Martha and Linda of some slight changes to his drug regimen which includes morphine, methadone, and a steroid. After nearly an hour and half, she leaves.

Though there were no tears on this visit, it was clear to Daly that Hlavin's condition has declined since her last visit two months earlier. A single event -- an infection, or a fall, or a pill that gets stuck in his airway -- could take him at any time, she says.

"I think that to do this work well, you really have to be engaged with your patient," Daly says on the drive home. "The risk is, you get really engaged with your patient."

-- They eased my fears of death --

Those who choose this line of work see it as a calling, even if they are not religious people. Like Daly, they see a need for helping people in the gap that exists between accepting that a condition is terminal and coping with the pain that follows. They are doctors whose mission is to care, not cure.

But they also face stress and depression, and some areas of the field including home care aides and social workers, can see high turnover rates.

"Burnout is a common problem because it is very, very stressful," said Andrew Putnam, a palliative care expert at Georgetown University.

Capital Hospice, a 15-bed inpatient facility outside Washington, hosts weekly bereavement sessions so that staff, clergy and volunteers can have a safe place to share their grief.

"It's not an easy job but it's one that has meaning," explains supervising nurse Stacey Ishag, who has worked at Capital Hospice for 11 years.

Ishag left work as a cancer nurse more than a decade ago, after she could no longer bear to see people suffer and waste away from the ravages of chemotherapy.

"I felt like I was causing them harm," Ishag says. "I had some counseling and people explained to me that it was their choice." But soon afterward she decided to do hospice work full time.

"I had to say goodbye to the chemo," she says.

But even in hospice, there were moments when she admits the exposure

to dying became almost too much, including one year early in her career when she bore witness to 400 deaths.

"It really hit me then," says Ishag. She began keeping a journal which helped her realize she was learning something from her patients.

"They have actually eased my fears about death," she says.

"Number one, that we don't have to suffer. Our end of life can be dignified. We have medications. Our end of life can be managed for our own comfort.

"Also I think a big part for me is seeing what's important in life -- it's not what's ahead, the unknown, but mending relationships here, trying to right some of the wrongs."

A recent study of palliative and hospice care professionals in Canada found that constant exposure to dying actually had a positive effect on their outlook.

"Although Western society has been described as a death-denying culture, the participants felt that their frequent exposure to death and dying was largely positive, fostering meaning in the present and curiosity about the continuity of life," writes Shane Sinclair of the University of Manitoba.

For her part, Daly admits that her toughest times have been when treating patients her own age. It can easily become too personal.

She says there have been times when she has had to "abruptly" take a day or two off, and that her employers have always been supportive of those requests.

She is grateful that her husband, a software engineer, does not work in the same profession. And she moonlights as a fitness instructor, teaching combat and kickboxing at a gym where no one knows her day job.

"Use your arms, they're not permanent!" she shouts to the class, half-wondering if they find her a bit odd. "Feel how your body feels right now!" she cries. "This is what it feels like to be alive!"

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