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Cancer Center

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Kathleen Foley, Neurologist -- "Death is inevitable, but severe suffering is not. We must look to the day when compassionate and skilled end-of-life care becomes a part of the fabric of the American healthcare system, and we won't need to request it — it will simply be offered as needed."

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Memorial Sloan Kettering Cancer Center neurologist Kathleen M. Foley focuses on the assessment and treatment of pain in cancer patients, as well as on developing policies for pain and palliative care worldwide. She is the incumbent of The Society of Memorial Sloan Kettering Cancer Center Chair and former Chief of the Pain and Palliative Care Service. Dr. Foley chairs the International Association for Hospice and Palliative Care and is a member of the Institute of Medicine of the National Academies.

In the early 1970s, I trained at Memorial Sloan Kettering Cancer Center and became chief resident in neurology both at Memorial Sloan Kettering Cancer Center and at Cornell. In 1974, Jerry Posner [who then headed neurology at Memorial Sloan Kettering Cancer Center] offered me a fellowship to study pain. I'd done basic research in genetics in medical school but was eager to do clinical research. However, when I took the job I warned Dr. Posner that I knew nothing about pain. His reply was, 'Don't worry, no one else does either.'

At the time, cancer patients were inadequately treated for pain. Medications were not given in anticipation of pain, as they are today. Instead, patients often had to wait until they experienced pain to receive medications, which were only given by injection.

Also at about that time, the modern pharmacology of treating pain was just beginning, with the new understanding that morphine-like receptors were present in the brain. At Memorial Sloan Kettering Cancer

Center, a medical pain clinic had started, and there was an informal pain consultation service. By 1981 we'd formalized a pain service as a designated service within the Department of Neurology. I was given the task of bringing together the programs that worked on pain — clinical analgesics, which was run by Memorial Sloan Kettering Cancer Center physician Raymond Houde and nurse Ada Rogers; clinical pharmacology, which was directed by Charles Inturrisi, professor of pharmacology at Weill Cornell Medical College; and the clinical neurology program — and it was the first designated pain service in a cancer setting in the United States. Other physicians joined us, including [Memorial Sloan Kettering Cancer Center neurologist] Gavril Pasternak, who was developing a laboratory to study opiate receptors in the brain. Working with Dr. Pasternak and others, we developed a program at Memorial Sloan Kettering Cancer Center that combined basic and clinical research, along with a training program. And together with Nessa Coyle [a PhD nurse practitioner at Memorial Sloan Kettering Cancer Center], we developed a supportive care program for patients with complicated pain.

In recent years, the most important change for patients is that pain is now recognized as another vital sign, like blood pressure, and is monitored every day. In 1974, pain was not being monitored any day. Now, at Memorial Sloan Kettering Cancer Center, patients who report pain can have a specific pain consultation, and medications will be ordered. These may vary from a patient-controlled analgesic pump to a wide range of different drugs. Then our patients are followed both in an outpatient clinic and at home until their pain abates.

Memorial Sloan Kettering Cancer Center has a strong commitment to pain management. From its inception, our service has worked closely with the departments of nursing, psychiatry, social work, and anesthesiology.

While I remained on staff at Memorial Sloan Kettering Cancer Center, I gave up heading the Pain and Palliative Care Service in 1995 to devote more time to running the Project on Death in America (PDIA). The project, of which I was an originator, was funded by [financier and philanthropist] George Soros for nine years. [The project officially concluded at the end of 2003.] The focus was to transform the culture of death in America through initiatives in science, the humanities, education, and professional training.

The PDIA focused on the quality of life for a very vulnerable population — patients with life-threatening illnesses. These patients must know that pain relief is available and should be able to obtain this relief. Minority populations should be able to have access to pain and palliative care in the same way that rich white Americans do. And we need to have systems in place so that government funding for this care is provided to children as well as to adults.

The PDIA also recognized that we had to focus on the development of leaders and palliative care experts if we were going to be able to change the care of patients. We created leadership programs for physicians, nurses, and social workers. For example, over the years, we awarded grants to 87 faculty scholars, many

of whom now hold positions at leading academic institutions around the country, including at Memorial Sloan Kettering Cancer Center. These professionals were to be the Trojan horses within our institutions to lead pain and palliative care services.

The scope of the projects the PDIA funded was extraordinary. There are community hospitals around the country, for instance, that received funding, which now have pain and palliative care services to both enhance patients' quality of life as well as provide end-of-life care. Another PDIA project focused on how to improve the care of the dying in prisons. We also supported two Institute of Medicine (IOM) reports that identified problems in the profession and made recommendations for change. A report that I edited from the National Cancer Policy Board and the IOM, published in 2001, *Improving Palliative Care for Cancer*, is now the accepted standard for what the role of palliative care within cancer centers should be.

The Project on Death in America was catalytic. Mr. Soros is now funding a project that focuses on the development of palliative care globally. We help governments develop pain and palliative care initiatives and policies. For example, one of our grantees has worked with the government of Romania to change their narcotic drug laws to facilitate access to pain medication for cancer patients.

We work closely with the World Health Organization (WHO). For many years Memorial Sloan Kettering Cancer Center was a WHO collaborative center. Now I'm on the expert panel and serve as the chair of the group developing the palliative care standards for the WHO Cancer Control Program.

In this country, there have been encouraging and significant changes in Medicare policy. Bridging programs between palliative care and hospice care have been developed. Such bridging programs allow patients to receive palliative care concurrently with active therapy for cancer. That's a very big step, reflecting the recognition that there should be simultaneous care for patients at any stage in their illness. It shouldn't be either/or: you get either pain relief or active cancer treatment. At any stage in his or her illness, a patient with cancer should be a candidate for good symptom management. There should also be full support of their psychological state and attention to their quality of living. Patients need to be able to access palliative care in the same way they access chemotherapy. In our enthusiasm for cure, we have often forgotten about care.

However, the good news is that there is a growing interest in research and in developing a research agenda. The public is increasingly sophisticated about the subject; and baby boomers, especially, are coming to these discussions with experiences of what they don't want to have happen to them. So, between burgeoning awareness and engaging a larger population to talk about the issues and not to view end-of-life care as a taboo topic, I think there is great reason for optimism.

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