Doctors, patients urged to discuss advanced care plans

When Dr. Christopher (Chip) Doig's mother-in-law was hospitalized recently with a life-threatening condition, he experienced first hand the stress many patients and family members undergo with medical professionals who are reluctant to initiate conversations about advanced care directives.

"Nobody asked my mother-in-law what her wishes were or if she had an advance care directive," Doig told doctors attending an education session on advance directives at the Canadian Medical Association's 146th annual meeting in Calgary, Alberta. "In fact, she did [have an advance care directive]."

But that directive needed updating and discussing, given her current situation, said Doig, an intensive care specialist and former president of the Alberta Medical Association. During the height of the health crisis, a doctor had asked Doig's wife to talk with her mother about her wishes, but she could not at that point.

Later, the hospital organized a family care conference, so her entire medical team could be aware of Doig's mother-in-law's wishes. The family showed up, but only the physiotherapist, occupational therapist and her family doctor — who came in from vacation — turned up. The social worker, the doctor directly responsible for her hospital care, the bedside nurse or the specialist and clinical nurse manager did not attend.

"I felt very, very disappointed" in the health care system, says Doig.

Subsequently, Doig and his wife rewrote his mother-in-law's advanced care plan in consultation with her. The experience changed him. "It actually became a very intimate moment for my wife... and for me as a son-in-law," he says.

End-of-life planning and advanced care directives will be a major topic of discussion at the CMA annual meeting this week.

Many doctors are reluctant to initiate discussions about end-of-life plan-

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Advanced care planning increases the quality of life of dying patients, improves the experience of family members and decreases health care costs.

ning with their patients — or to make their own advanced care plans, Doig and experts in the advanced care field told physicians at the CMA session Aug. 18.

They are concerned that they will make their patients uncomfortable, or that they don't know enough to guide their patients, says Sharon Baxter, executive director of the Canadian Hospice Palliative Care Association. Baxter is also a member of the Advance Care Planning National Task Group, which has launched a campaign called Speak Up to encourage Canadians to discuss advanced care plans with their families and health care providers.

Advanced care planning increases the quality of life of dying patients, improves the experience of family members and decreases health care costs, Baxter told

the doctors. But although most professionals support the idea of advanced care planning, the majority do not engage in it, she said.

Not only are they uncomfortable with the topic, they are often not reimbursed for those conversations, which take time. Many doctors also fear saying the wrong thing, she says.

"I'm an expert in life-sustaining means as an ICU [intensive care unit] physician," says Doig. "The only expertise you require is a relationship with your patients and the willingness to take care of them."

Having the conversation, listening to patients and writing down their wishes is essential and avoids the moral distress — as well as medico-legal consequences — of not having the discussion, Doig pointed out.

And those conversations should not occur in the emergency room or the intensive care unit, or even in lawyers' offices, he stressed. "They should occur long before the medical setting. Please, just do it."

In Sooke, British Columbia, where Dr. Robin Saunders practises family medicine, he and six other physician colleagues who serve the community of 12 000 people try to ensure those conversations take place long before it becomes necessary for them to act on advanced care plans. Every month, family doctors lead free, two-hour long, advanced-care planning workshops. Participants are encouraged to ask

questions and voice fears as they develop their plans, which then become part of their permanent health record, Saunders says. Patients can cancel or amend their advance care directives at any time.

Patients whom the doctors believe need to have these discussions are specifically invited to the workshops, which are also open to the public.

The seven family doctors started the process by making their own advanced care plans and discussing them with their family physicians. "In my opinion, the conversations must start in the community," Saunders says. "It must be part of your routine care."

He suggested other family practices adopt the model used in Sooke. "It's about listening; it's about communities."

Once a patient is already on a ventilator, it's too late, he added. He encouraged doctors to begin the conversations by involving family and friends as well as health care providers to discuss their beliefs, values and wishes, write them down, and then ensure their doctors read the plans and know what they contain.

Those plans should also encourage discussions of organ and tissue donations, said both Doig and Saunders. — Laura Eggertson, *CMAJ*

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