

PERSONAL FINAL PLANNING

edmontonjournal.com/homes

EDITOR: SHELLEY BINDON, 780-429-5356; sbindon@edmontonjournal.com

EDMONTON JOURNAL / SUNDAY, MAY 15, 2011

Volunteers offer comfort in final days

Caring for the dying is rewarding duty for special caregivers

MELANIE COLLISON
Journal Special Reports Writer

After lunch each day, Tom Johnston makes his way to Ward 9Y of the Edmonton General Continuing Care Centre.

That's the palliative-care unit, where social workers and chaplains join physicians and nurses in easing patients' symptoms and supporting their quality of life once a cure is no longer possible.

Over the past five or six years, Johnston has spent nearly 1,300 afternoons there.

"I make coffee, run errands, pick up and deliver mail, just whatever is necessary," Johnston says in his matter-of-fact way.

He knows the place so well he also does orientation for the families of patients coming in, reassuring them their loved ones will be cared for 24 hours a day so the exhausted caregivers can rest and recover their own health.

"I take patients out in their wheelchairs in the summertime if anyone is well enough to go out," he says, and relates a couple of joyful stories about people who'd thought they were dying but got well and went home once they'd had a spell of caring attention and good nutrition.

When patients are not well enough to go out, or winter clings on in its unforgiving way, Johnston just sits with them.

They might talk a little about any of a thousand subjects, including death, which is all right by him.

"I never really had a fear of death," he says, perhaps because he had to come to terms with it when he served as a tail gunner on a Lancaster bomber during the Second World War.

The patients don't really talk a great deal about dying, anyway, Johnston says, because, "when it comes right down to the end, most of them are ready to go."

They might just watch TV together. He won't understand a word of, say, Chinese TV, but he holds the patient's hand and she knows she is not alone.

"People think it must be depressing to work in a place where people are dying, but it's not," Johnston



BRIAN GAVRILOFF, THE JOURNAL

Tom Johnston volunteers in the palliative-care ward at the Edmonton General. He runs errands for or simply attends to those living out their final days.

says. "The staff work there because they want to. This gives us a fantastic group of people. It's a happy place."

Johnston knows 9Y from the other side because that's where his first wife died.

"In 1983, my wife had cancer, and in the couple of last months she was with us, the doctor insisted she go into palliative care.

"I got to know their procedures and appreciated how well they looked after everybody. I decided when I retired I would volunteer there."

His late wife's physician was Helen Hayes, member of the Alberta Order of Excellence, whose concern for people facing chronic pain and terminal illness led to the palliative-care programs Alberta has today.

When Johnston was finally ready to retire 20 years later, he did some volunteering at Pilgrims Hospice and attended courses at the Cross Cancer

Institute to prepare for 9Y.

"I'd kept it in mind because they looked after my wife and me so well," he says.

"Families become part of the (larger) family there. They have a tea every Tuesday afternoon run by volunteers and get the families together to talk to one another. Families come back to the teas after their loved one has passed on."

Johnston has remarried, to a woman who nursed at the Royal Alexandra Hospital. She now volunteers at the General, too.

"It takes a special volunteer to visit a palliative unit, more than continuing care," says Bernadette DeSantis, manager of corporate communications for CapitalCare in the Edmonton area. A wholly owned subsidiary of Alberta Health Services, CapitalCare is the largest organization in Canada providing continuing care. "We have over 1,000 volunteers in

continuing-care centres. The people in continuing care are dying, but we don't know when, whereas the people in palliative care are staring at death at close range. They have a lot of issues they need to confront, so these volunteers help them face death," DeSantis says.

In the last decade, family members of people in continuing care have become part of the care team, she says.

"A lot stay on as volunteers after they lose their own family members."

CapitalCare organized a conference this winter that included a presentation and workshop by Amy Levine, director of a formal palliative volunteer group in New York City, called the Doula to Accompany and Comfort Program.

While the word "doula" is generally associated with supporting a woman through the birth process, it

can equally mean being a companion through the process of dying.

While there was enthusiasm for the workshop, there's no plan afoot to create a formal death doula program in Edmonton.

"The same principles and ideas are being used already in our centres," DeSantis says.

"It probably keeps me young," Johnston, 87, says. "If I sat down, I'd be long gone. I've known so many people in jobs they hated for years and years. Along comes their 65th birthday, they soon tire of playing golf, they haven't any other interests and they drop dead."

"Volunteering certainly keeps people feeling a lot better as they get older, if they're doing something useful."

■ 'Death doulas' listen, ease fear and loneliness / F3

Role of personal representative can be demanding

RAY TURCHANSKY
Special to The Journal
SHERWOOD PARK

Know what you're getting into before saying yes to responsibility

speaking about the job of personal representative.

"People may have had a relative or father go through it and have some sense what it's about, but you never see movies about it, you never see television programs about it, you never read books about it.

"So people come into this role with a very limited understanding of what it is."

Generally, power of attorney gives one person legal authority to act for another; a guardian assumes responsibility for minor children in the case of their parents' death or disability; a trustee takes legal title to property and administers it for the benefit of beneficiaries.

You can have either a springing power of attorney, which springs into effect if a person becomes incompetent, or an enduring power of attorney, which endures after they become incompetent.

In one recent case, a financial adviser was unable to designate a



LARRY WONG, THE JOURNAL

Paul McLaughlin, left, and Andrew McLaughlin are partners at Turning Point Law firm in Sherwood Park. Paul teaches a course for executors.

beneficiary when a registered retirement savings plan was converted to a registered retirement income fund, because the holder was incompetent and hadn't provided appropriate powers in the enduring power of

attorney.

For the most part, people are earnest, diligent and want to do a good job, said McLaughlin, but "a lot of people have appointed attorneys who aren't trained or capable of

doing the work, and have misguided ideas of their powers under the power of attorney."

Many firms write into the power of attorney the permission to give beneficiaries a disclosure of assets at any time, and disclosure can be required at least once a year.

"The only mechanism that we've got to deal with this is the courts, which is an awful, awful way to deal with it.

"There should be a registry of power of attorney, and part of the process of registering for power of attorney should involve an educational program. The problem is giving notice to the attorneys of what they are accountable for."

Different roles, different responsibilities

Personal representative is the generic Alberta term used to include a male executor or female executrix, an administrator or administratrix, and a trustee.

See BENEFICIARIES / F2