

# Give the gift of your presence



A tear traced the top of her cheek. "I just thought I came in here for respite care but it looks as though I won't be leaving."

Unexpected words from my friend and colleague lying in the hospital palliative care bed. She battled cancer for more than a decade. A warrior who acted fiercely as her own advocate, she and her medical team could battle the rampaging disease no more.

Emails had flashed across computer screens telling her cadre of comrades it was time to bid goodbye.

As I stood by her bedside, I watched the tear. And stayed silent.

Good that I did, because my dying friend turned to me and talked about my life, what she thought of my writing and character and what I must do.

"You deserve the very best. Never forget that Dear heart."

A valiant goodbye and a good visit . . . for both of us.

But not all visits to dying family or friends go as well. In fact, it's the fear of saying or doing the wrong thing that too often keeps us from visiting the mortally ill.

The key to unlocking this door of fear, says Louise Kashuba, "is meeting the patient where they are at. There is not one single way to approach someone who is dying."

The medicine patient care manager at Grey Nuns Community Hospital, Kashuba says, "One of the things I personally learned as the daughter-in-law of someone who was dying is I had to listen to what my mother-in-law wanted. And it stopped becoming what I might think might be the right thing, was the right thing, and who I think should be there.

"It took me back to what did she need in those last days. What did she want in those last days? So we certainly took our cues from her. I might have needed

something different, but if I didn't listen to what she was saying, then I was remiss."

#### **INITIAL AWKWARDNESS**

Psychologist Cheryl Nekolaichuk assures that it's quite normal to feel that initial awkwardness or worry about saying the wrong thing.

"That can occur with people who are well experienced in the field, myself included."

She will often ask relatives or the patients themselves for permission to come to visit, depending on where the patient is at.

Sometimes it's actions, not words, that bespeak that caring. Nekolaichuk had a relative she liked and they always talked of getting together for lunch.

"But we never got around to it," said Nekolaichuk. "Then she became quite ill."

That is when their lunches began.

"I would bring something special that she had asked for," said Nekolaichuk. "It was a wonderful way of recreating that special time. It wasn't so much as what I said as what I was able to do."

Kelley Fournier, unit supervisor at the Grey Nuns Tertiary Palliative Care Unit, knows that ability to do something for a patient is her calling card.

"With a nurse's role it is made a little easier. We don't wait to be invited in; we need to go into the room. We help them in a lot of task-oriented ways that help facilitate the conversation."

She tries to find something in common with either the visitor or the patient that she can talk about rather than the seriousness with what is going on with the patient.

"That will often lead us to conversations about how I can support them."

That support can simply mean being present, says chaplain Bonnie Tejada.

Being present can take many forms. Simply sitting with someone in silence matters.

"We underestimate how valuable that is, how much it can minister and comfort the person you are sitting with – just your physical presence," says Tejada.

Remember too the person's physical reality. They may be tired, fall asleep, have periods of confusion.

"So take their lead as to what type of interaction is possible," counsels

Tejada.

“It might not be a lot of conversation with a lot of dialogue. It might just be a few comforting words, holding their hand – just following their lead on what they want to talk about, taking your direction from them.”

#### **MANY OPTIONS**

Don't depend on just conversation. Maybe you can read to them, listen to music, watch an old movie together.

Remember too there are two people that need caring in this relationship.

“Taking care of yourself as a visitor is critical,” says Tejada.

This means seeking out a counsellor, close friend, a clergy member, “someone who is a support to you, to walk through that journey with you,” says Tejada.

You are carrying – consciously or unconsciously – baggage of anticipatory grief.

“If you can have a supporting conversation with someone even before you go on a visit – what am I afraid of, what feelings are coming up for me – to be able to look at that on your own before you go in for a visit, allows you not to bring all that with you and lets you be present to the person you are visiting.”

Know that walking with someone as they make this sacred journey to the end of their life is a privilege, says Tejada. “To walk alongside in a gentle way, I think changes the person who goes with the one who is dying.”

#### **BEING THERE MATTERS**

The thing to remember, says Dr. Robin Fainsinger – is being there matters.

“Often people think there is nothing I can do,” says the clinical director of palliative medicine at the Grey Nuns. “We hear that commonly at the bedside . . . family members, friends, feeling powerless.”

But they are forgetting one crucial thing.

“What people minimize or do not value is the fact that they showed up,” underlined Fainsinger.

“They stayed. People worry so much about what they might say and what might be wrong, they forget about the value of their presence. Even if the person is too tired to have them stay very long, they took the time to show up. It is way more important than anything they might ever say.”

That watchful presence benefits the medical staff too.

“They have spent 24 hours there – the importance of their presence, the extra assistance it gives the health care team by having those extra eyes to identify things and help guide us in things we might otherwise miss. . . . I have to remind them of that,” says an impassioned Fainsinger.”