

# PALLIATIVE CARE *matters...*



*because everyone deserves a good death.*

*Palliative Care...* is care that relieves the suffering and improves the quality of life for persons who are living with or dying from advanced illness and their families. It helps people with life-threatening illness live as fully and as comfortably as possible by providing services that ensure their physical, psycho-social, spiritual and practical needs are being met.

*Palliative Care...* is comprehensive. It draws on the expertise of many health care professionals including doctors, nurses, social workers, pharmacists, volunteers, spiritual leaders, etc.

*Palliative Care...* is collaborative. Patients, families and the team providing care support each other and make decisions together.

We don't have a province-wide system of palliative care in Nova Scotia. Unfortunately, that means patients and their families are suffering...

- 80% of us want to die at home, but 70% are forced to die in hospital because there aren't enough home care services.
- Medications are covered if you die in hospital, but not if you die at home. This means the last choice people ever make is often based on their pocket book and not their preference.

- Palliative care is only available in certain communities at certain times of day. Where you live and when you die determines the level of care you do or don't receive.
- In some parts of Nova Scotia people are dying on palliative care waiting lists.

## *A Good Death is ...*

- ... as free from pain as possible.
- ... surrounded by the people you love.
- ... in a setting of your choice.
- ... with physical, emotional, social, practical and spiritual support.
- ... caring, dignified and peaceful.

## *A Bad Death is ...*

- ... no pain relief or over-medicated.
- ... alone in an institution away from the people you love.
- ... you want to die at home but are forced to go to hospital.
- ... no physical, emotional or spiritual support.
- ... isolated, angry and traumatic.

## PALLIATIVE CARE *matters...*



*On February 19th, Tony Morris' 64-year-old wife Marilyn died of cancer. After two long battles with the illness, the hospital told the family it was time for palliative care. Unfortunately, there was no room on the Palliative Care Unit and she had to stay on the cancer ward.*

*"This means oncology nurses trained in saving lives looked after Marilyn, instead of palliative nurses trained in helping people's lives end with peace and dignity. There was inconsistent proactive pain management, which meant Marilyn, who would not complain, suffered in excruciating pain before she asked for relief. One day I came in and she was lying in her own feces. When I went for help I was told the nurse was on break. Often, when I arrived, Marilyn was lying on soiled bedding and had remains of sterile swab packets in her bed. Another day her oxygen bottle was changed and it didn't work. Marilyn could not breathe properly and no one noticed until I pointed it out a couple of hours later. I was so angry that her suffering was being made worse by the system that was supposed to help."*

Finally, Tony had had enough, and despite the fact that his wife did not want him to complain, he went to the doctor and as he puts it "raised a fuss" and had Marilyn moved to the Palliative Care Unit.

*"The difference was abundantly clear. On the oncology floor I was fighting for her care all the time and had no time for*

*Marilyn herself. Once she moved I had time to focus on her. It was a totally different environment – quiet, soothing and safe. The nurses checked-in regularly and they managed her pain. They looked after Marilyn and the whole family in all ways – physical, emotional and spiritual. Marilyn was very heavily sedated by this point, but she seemed to relax more on the palliative unit and seemed more at ease. I think she would have fought death on the cancer unit, but she accepted it on the palliative unit. At the end, I was able to lay with her and hold her in my arms as she slipped away."*

Unfortunately, the excellent palliative care Marilyn received at the end was not enough to undo the damage.

*"I lost her and I lost my faith. The system let Marilyn down. I wasn't able to say a proper goodbye because I was too busy fighting to get her proper care. We never even got to talk about her dying. We didn't get to have so many conversations that we would have, had she been in a proper palliative care environment from the start. I am left with so many questions. People like Marilyn have devoted their lives to bringing up children, building their communities, improving the lives of their neighbors, working hard at their jobs. They deserve the dignity of proper care during their final days on this earth."*

All Tony says he can do now is hope that something good can come from Marilyn's death. He is telling her story to try to convince the provincial government to increase funding for palliative care so no one else will ever have to suffer like Marilyn did.