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What is Palliative Care?

There are formal definitions of palliative care, but another way to understand it is to hear about a friend.

PATRICIA

Patricia was a widow in her mid-70's. She was petite, frail, a smoker and living alone in an apartment. She didn't eat well. When she was taken to a Toronto hospital, she was diagnosed with kidney failure. Given her health and lifestyle, they told her that she had 3 months to live. But she could not go home because she could not care for herself properly. She was parked in a hospital bed. If she were to die as projected, her stay would cost the healthcare system over \$100,000. For the rest of her life she would stare at a hospital room.

If our hospice had existed, Pat could have gone home with assistance from our **hospice home services**. These services would help her eat and drink properly, give her some socialization with visiting volunteers and her health could be monitored so that if and when she needed medical intervention, she could receive care. Eventually, she would spend her last weeks at the **residential hospice**. The cost for the home hospice services, at about \$80 per day, so this scenario would save the system a lot of money.

But the hospice was not there to help Pat. So here is what happened.

My wife and I had known Pat for years because as she was a friend of my in-laws. Seeing her situation, we invited her to come and live with us until the end. We were assured that Pat had only 90 days of life left.

World Health Organization Definition of Palliative Care

*Palliative care is an approach **that improves the quality of life** of patients and their families facing the problem associated with life-threatening illness, through the **prevention and relief of suffering** by means of early identification and impeccable assessment and treatment of **pain and other problems, physical, psychosocial and spiritual.***

Palliative care:

- 1. provides relief from pain and other distressing symptoms;*
- 2. **affirms life** and regards dying as a normal process;*
- 3. integrates the psychological and spiritual aspects of patient care;*
- 4. offers a support system to help patients live as actively as possible until death;*
- 5. offers a support system to help the family cope during the patients illness and in their own bereavement;*
- 6. uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;*
- 7. intends neither to hasten or postpone death;*
- 8. will enhance quality of life, and may also positively influence the course of illness;*
- 9. is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.*

When she was home, my wife, a registered nurse, suggested that maybe she did have a choice not offered at the hospital and that we should get a second opinion. The new doctor explained that if she was to continue being a smoker, he was not interested in helping because it was a sign that she was not caring for herself. If she quit, he would consider surgery, but her chances of surviving were about 50%.

Pat quit smoking that day and had the surgery. She recovered well. She then lived with us on one kidney - **for 8 years** - until she eventually died of lung cancer. Although palliative, Pat's life changed considerably - for the better. She was able to live well with one kidney, her diet improved, and she now had a family.

Consider Pat's story and ask, what is palliative care?

One could argue that the removal of the kidney was not palliative care because it certainly helped prolong her life. The next 8 years, however, were years of palliative care. There was no effort to cure whatever ailed her, and she had other complications. Pat was never going to get back out and play sports, but she was able to go to our cottage for weeks in the summer and enjoy the beauty and peace of the Georgian Bay region. She was able to enjoy a socialization that she had missed during her years of decline.

Palliative care was us thinking about Pat having a life. It was not us sitting around thinking about death. From the WHO's definition of palliative care:

- We provided relief from pain and other distressing symptoms;
- we affirmed life. We treated dying as a normal process; and
- Pat's quality of life was definitely enhanced, and this positively influenced the course of illness.

I hope Pat's story can give new meaning to hospice-palliative care.

Hospice-palliative care is about care, not cure.

Hospice-palliative care is about life!

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