

Living before Leaving Can Make a Real Difference!

By Dr R Akhileswaran

World Hospice and Palliative Care Day is celebrated on the second Saturday of October every year.

There is a general belief, which has been borne out by a few studies, that a patient with a life-limiting illness would like to spend the final days of his life in the comfort of his own home with the people he loves. Is this always possible? If the answer is yes, then what are the factors that make this happen and if the answer is no, what prevents it from happening? Let us consider some of the issues involved in both the scenarios.

The home is considered a safe haven when one finds love in it. Everyone believes this is true, and to a large extent it is so, until unexpected demands come up. A loving elderly couple may have spent many years together and have numerous fond memories of their life at home. When one of them is diagnosed with a life-limiting illness and has to be given round the clock care at home, the love between the couple can really be tested. The demands of care can be high enough to break the determination of a loving caregiver to look after the spouse at home.

Appropriate care at home also comes with a few costs. Economic cost is only part of the problem. Social, psychological and emotional costs can be equally burdensome. Some of us are born with a caring attitude, some of us “learn” to become caring and some of us have “caring” thrust upon us. It is the third group who will find caring for the patient at home the most challenging.

Compassion becomes a very important trait if one becomes a caregiver for a dying patient at home. Apart from dealing with the physical pain of the patient with the help of home hospice teams in the community, one has to be prepared for a number of personal “losses” that come with it. Sometimes the caregiver has to give up his job to become a full time caregiver at home. This also leads to a change of lifestyle and the personal “loss” that accompanies it. Filial piety and a sense of responsibility of doing the right thing often helps compassionate caregivers look after their loved ones at home till they die.

Love, care and compassion can lighten the burden of caregiving at home to a great extent. This would be challenged by the day to day vagaries of the patient due to his deteriorating condition. With adequate support from the home hospice teams, the challenge can be overcome within a home setting. Helping the patient live well in his own home before his ultimate and inevitable exit can make a big difference to him. This will also make a real difference to the caregiver as the “good death” invariably carries with it memories which last a lifetime. **SMA**

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