## Last Days at Home ....preferred, but not necessarily better.

## Comments from a blog:

... I am very clear that there comes a time to accept the inevitability of death. But patients don't just "die." They often linger in distress, and the care that can be provided at home may not be enough (although hospice care is wonderful). Nursing homes are expensive for many, and if I understand the system, patients need to be admitted from the hospital for costs to be covered. So the alternative is to have a family member who is in the last stages of dying admitted to the hospital, not to be saved, but to be helped through the process of dying. Dying at home sounds wonderful, but some family members can't handle that. I know that we need to change that admission to the hospital in order to save costs, but I also know that families often need the help that a hospital can provide at those final days.

... As an RN for 38 years and a home hospice nurse for 7, I have seen both sides of the medical model. The main reason most people die in institutions is that there is no alternative care model in our society. Unless a person has a family with enough willing and able members or enough money to hire private caregivers there is no system to care for people in their home at end of life. While dying in an institution is sad if you wish otherwise at least you receive care.

... Even when the appropriate talks are held, and the family and patient are all accepting the prognosis and a suitable comfort care plan, most places do not have appropriate support for home care. Family are often either old and frail and unable to provide care (such as turning patient, toileting and skin care) or are working full time (often in order to support the family and keep the insurance) and unable to provide 24/7 care. Home nursing support is often limited to a couple hours a day maximum, and live in care is not inexpensive, and is often TOTALLY unavailable. Much of the issues therefore are actually quite practical issues that need to be resolved for decent end of life care, even if the emotional and philosophical issues have been resolved.

... I agree with the comments of "by your side" and Catherine Butler MD. Most families just cannot meet the 24/7 care demands that institutions can provide to terminally ill patient. Elderly frail couples, working spouses often are not able to cope with the constant, daily demands of a debilitated patient that need assistance for bathroom, toilet, feeding, medications, etc. We have not developed a practical societal alternative model to meet that demand. Hospice care level is an alternative that requires intense family participation and often resources that few families have.

... I run a community hospice in a developing country in Asia. Agree with most of what have been said, and would like to add .... In a universal system where most of the best (doctors and nurses) are assigned or opt to work in hospitals, it is not wrong for patients and care- givers to hope that the hospital would be the better option than at home. This hope is not necessarily for longer life, but just for better care! The best are in the hospitals, the need is greatest in the homes. This is a problem which we are facing in the development of palliative care in our country – more are being trained and almost all will be working in the hospitals. It not only the patients who want to be in the hospitals!