

### A Case in Point:

This story is about Raj, a 66 year old physicist born in India. An Oakland Tribune reporter wrote an article about Raj concerning the fact that he was dying and had no family. Lisa, his love of 30 years had died just a few years earlier. Raj had prostate cancer and was on the waiting list to enter a skilled nursing facility. Frank Ostaseski, then director of the Zen Hospice Project (ZHP), invited Raj to come and spend his final days at the ZHP Guest House (GH).

Raj spent 5 months at the GH. When he arrived he immediately felt its warmth. "It felt as though someone immediately put their arms around me and gave me a big hug. It was a wonderful feeling. I think I really have died and gone to heaven. I am surrounded by angels here."

Within weeks of his arrival, his disease sufficiently paralyzed him from the chest down so that he had no control over any of his lower body functions. While he could still move his arms, his hands were also affected. The ZHP volunteers and nursing attendants became his arms and legs.

Even though Raj was paralyzed, he still was experiencing significant pain in his back and chest. The hospice staff recommended oral morphine and morphine skin patches which soon brought him comfort. Raj's disease progressed much slower than he would have liked. He wanted to be free of his ailing body.

A week before his death Raj was having difficulty swallowing. The only food he ate was apple sauce to help his pills to go down more easily. He was sleeping more and each word he spoke took nearly all the effort he could muster. We would often sit in silence for hours and I would hold his hand to comfort him.

Raj was ever so grateful for the care he received at the GH. I was able to be with Raj the entire day before he died. We parted with tears and vowed to see each other again. The next morning Raj died very peacefully.

Greg Schneider  
Director, HEAL Project

### *Caring for a Terminally-Ill Loved One: Understanding the Dying Process*



Every one of us will die. A few of us (<10%) will die suddenly. Most of us (>90%) will die after a long period of illness with gradual deterioration until an "active dying" phase at the end. The last hours of our lives may be some of our most inspiring. They provide one last opportunity to heal relationships, say our good-byes, give final gifts to those we love, and find spiritual peace.

Caregivers, friends and family can approach an imminent death of a loved one as an experience that will be inspiring and forever life-changing. Those who do so, often find this to be true. This time can bring the family renewed strength and unity. If the impending death is considered as something to avoid because of fear, anger or regret then unnecessary suffering may occur for the dying and their life closure may be incomplete. The resulting grief of survivors may be elongated beyond that which would have occurred otherwise.

Most of us have little or no experience with the dying process or death. Based on media dramatization and our vivid imaginations, most people have developed an exaggerated sense of what dying and death are like. Therefore caregivers have an opportunity to play a critical role in helping their dying loved one and others through this journey into the unknown. This facilitates a calm and peaceful death for the person who is dying.

**Knowledge of the dying process** – just confronting the topic of death is a major challenge for most of us. Discussing the physical details of the process is even more of a challenge. This topic is included here briefly for one reason...having such knowledge as the caregiver will help reduce one significant element of uncertainty in your caregiving journey. This will also allow you to be the *compassionate and reassuring presence* for others who may be completely unfamiliar with the dying process.

There are other reasons why this is important. It is our natural instinct to want to feed someone we love if we know they have not been eating as a result of their illness. In most cases, the dying will lose their appetite and reduce food intake long before they reach the last hours of their lives. As death nears, their fluid intake will also be significantly reduced. This is a natural process. Insistence on feeding someone who is unwilling to eat may cause problems such as aspiration, nausea and increased tensions. Another reason to be aware of the stages of the dying process is that an opportunity may be missed to have final closure with your loved one. Having some idea of when death may occur will help caregivers to prepare themselves and others to have adequate time for saying good-byes.

**Physical signs of approaching death** – weakness and fatigue; increased sleep; reduced food and fluid intake; loss of ability to swallow; withdrawal or detachment from others; reduction in urine output from loss of kidney function; restlessness; confusion; incontinence; congestion in the lungs or throat that leads to noisy breathing; noticeable breathing changes such as shallow breaths and/or long periods between breaths; lowered or elevated body temperature; cool hands and feet from reduced circulation; loss of ability to close eyes.

Many of these symptoms will occur at different times and to varying degrees in each individual, however the general order as listed is somewhat representative.

With faith in immortality, it is easy to hold to the optimistic view that no day is wasted though it is wrought with mistakes.

It is used in the journey and when twilight comes, you are one day nearer home.

Betty Ryder  
Died May 27, 2003