



Dear Friend:

8 April 2008

A Flood of Anger

They had doodled in an apparent moment of abandon all kinds of things—birds, women and abstract or half-formed figures—on the walls of that camp in Majdanek, Poland. They were all children. The day after they drew those pictures, they were sent to the nearby gas chamber.

Their experience, or, what Elizabeth Kubler Ross imagined could have been their end-of-life experience was to become an underpinning of her philosophy of death and dying. When she clamoured for a new deal to the dying, Ross had those final flights of fancy etched on her mind.

A correspondent has invoked not only Ross but those anonymous child painters who were made to inhale a heavy dose of killer gas sixty five years ago. He was commenting on an unusually usual story we had reported in our e-letter. It was the story of the distress of a doctor who had to wait upon his dying father outside an intensive care unit.

Death was round the corner, but the dying man would be allowed no clasp of a loving hand or a glance of affection. He was to go, segregated from everything he loved, out of sight of everyone who had a prayer for him on their lips. The doctor-son was naturally restless, and not so naturally, helpless. He ranted incessantly and, of course, ineffectually, about the virtual torture of a dying man within impregnable medical custody.

This was, our correspondent said, worse than whatever eerie vision is conjured up by that term, custody. In raging words, he spoke of the children who had a day to paint their mind before they were gassed. This doctor's father had no such luxury. There are many like him who are given no time or space to express themselves before their final exit. They are released from medical custody only when the omnipotent keepers of the intensive care units are convinced that what lies inside is cold, unalterable death. Our correspondent has given it a name, suitably latinized: *intensive care-itis*.

His anger has found expression in many and various ways. This is how Dr David Brumley put it: "What an impassioned description of the doctor's distress. I'm sure everyone will read it and hopefully it will help to make change. Never think, however, that this kind of behaviour is

anything but geographically universal! We can tell such similar stories. I suppose it is all the more poignant because of the ever present issue of lack of resources. When this kind of thing happens here, I am always thinking of the waste at all levels, and spending such scarce resources for such inappropriate behaviour makes me so mad.”

This is a measure of the silent anger against the medical unconcern with which death and dying is dealt with in many if not most of our supposedly august institutions of health. We are flooded with mail which makes this point in distressingly similar tone. The shortest of it was from Dr Raji Suresh: “I could see his agony through your words. It was a reminder for all of us stating that we need to do a lot for spreading the message of supportive care.”

An Unsurprising Award

We were not exactly surprised when the American Pain Society announced the Kathleen Foley Journalist Award for 2008. The winner could not have been anyone other than Donald McNeil after what he did in the columns of the New York Times. His coverage of pain care, if you like, lack of it, was described as “superb.” The letter of nomination went on to say that Donald’s article was

Donald’s work was recommended by Dr Karin Westbund High of the University of Kentucky. In her nomination, Karin said his articles were To that nomination, Mr Chuck Weber, communication consultant of the American Pain Society lent more strength by presenting another report of Donald. Those additional credentials were a report on the palliative care scene in India. The report appeared in NYT on September 11, 2007 under the title, "In India, A Quest to Ease the Pain of the Dying." In it Donald said some things about Pallium India that made us ever more humble.

The APS award was created in 2002 to recognize excellence in reporting pain-related topics. It is named for Dr. Foley in recognition of her contributions to furthering professional and public understanding about the need for effective cancer and end-of-life pain management.

Now there is some twist in the tale. Donald has won the award but can’t accept it. NYT conduct rules do not permit him to accept. Rules are rules, and rules should be respected, especially when awards, award-givers and award-winners proliferate. It does not quite matter whether he accepts the award. What matters is that he has been chosen for it. What matters is also that he has been chosen in recognition of his work on what we have done or not done in palliative care.

Palliative Policy for Kerala

Kerala is well on its way to score another first rank. This small state in south India may soon be the country’s first to have a State Palliative Care Policy. Many countries in the world have palliative care policy as part of the country’s health care policy. But most of them are in the developed world.

In 2005, Pallium India submitted to the Government of Kerala a proposal for formulation of a palliative care policy. Following preliminary meetings, we prepared a draft document. Since then many meetings followed in which the government’s representatives and palliative care

workers sat together and went through the draft document in great detail. The group decided on a final draft which went through the government machinery. We hear that the departments of Law and Finance have cleared the proposal and that it is in the final stages of approval.

We see this as a great advance. For the last decade and a half of significant palliative care development in the state, it has been predominantly an activity of Non-Government Organisations. All of us have always realized that it is essential that palliative care becomes part of main-stream health care. This we declaration of a governmental policy for “Pain and Palliative Care” will pave the way for such integration of palliative care into general health care.

We have a lot of people to be grateful for. We particularly recognize the support of the Health Secretaries, Dr Vishwas Mehta, Dr Rajan Khobragade and Dr Usha Titus. We must also mention the efforts by Dr Mathews Numpeli. The Indian Association of Palliative Care (IAPC) had moved the Supreme Court of India seeking intervention for the formulation of a National Palliative Care Policy. Now that Kerala is showing the way, the nation cannot lag behind, whether the apex court gives a directive or the Union Government takes a decision in the matter.

Visitors from “Human Rights Watch”

The Constitution of India guarantees life with dignity.

What dignity is there in the life of a man with unrelieved pain who cannot sleep for nights together, who cannot attend to his basic needs because of pain, who cannot feel any human thoughts because of extreme pain! It is indeed distressing to think that most such suffering is unnecessary. If only the existing medical knowledge were used effectively! If only the World Health Organization’s three-step analgesic ladder—it has been there for 22 years—were taught to doctors and nurses and used effectively!

Is not such apparent disregard for human suffering a gross violation of human rights? To answer the question, we should have a human rights watch report. To draft such a report, we had two visitors from “Human Rights Watch” for a few days, Mr Diederik Lohman and Ms Rebecca Schleiffer. They had an active stint with us, joining us on home visits, seeing the work in our clinic and interviewing patients, doctors and officials. They are now visiting other parts of the country. We await their report at once with hope and torment.

Faculty Development Workshop

On April 24 and 25, we have a faculty development workshop for the EPEC-India project at Manipal. Dr Raj Warriar, vice-chancellor of the Manipal University, and the team from Manipal will host it. Dr Linda Emanuel (Chicago), Dr Vivek Khemka (New Jersey) and Dr Suresh Reddy (Houston) are expected to attend, representing the EPEC program of the Northwestern University.

The objective is to empower potential teachers to use the EPEC-India curriculum for our training programs. The curriculum includes four plenaries and 21 modules. Most have trigger videos, and all have powerpoint presentations and supportive word documents.

On 26 and 27, there will be a training program for 100 doctors. This training program will use the EPEC-India curriculum.

The Indo-American Cancer Association (IACA) has sanctioned a grant for the conduct of the program at Manipal. As mentioned in the association's home page, "IACA is an organization of cancer specialists of Indian subcontinent heritage with a mission to advance cancer care wherever its members live and work." We thank IACA for this grant.

Dialogue with Death

Nachiketas was perhaps not known to Dr Elizabeth Ross, Swiss psychiatrist who, in a manner of speaking, made a movement of death, enhancing information and empowering people to face it, ridding them of fear. If she had known about him, she would have heavily drawn on the wisdom of Nachiketas who was perhaps the first known mortal to block death in its way and wrest from it the ultimate wisdom of life. His dialogues with death animate and sustain the great Indian book of wisdom, Kathopanishad.

Death is introduced as life's great metaphor. There is first its fear which hardly impedes Nachiketas's pursuit of knowledge. There is then death's attempt to deflect Nachiketas from his path with boons and blandishments. And finally death appears as the giver of ultimate wisdom, interpreter of the meaning of life. To death this saying is attributed: *Perennial joy or passing pleasure?/ This is the choice one is to make always./ The wise recognize these two, but not the ignorant./The first welcome what leads to abiding joy, though painful at the time./ The latter run, goaded by their senses,/ After what seems immediate pleasure.*

Editor