

Cancer: the right to life

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On Nov. 25, 2000, 12 cancer support groups from around the country joined hands to release the Declaration of Rights for People with Cancer in India.

Such rights have now become law in many countries of the developed world. The Declaration of Rights released on that day, at the first All India Cancer Support Groups' Conference, was adapted from the Declaration of Rights drawn up by Cancer Link, United Kingdom.

The rights include basic human rights which are often violated once a person is diagnosed with cancer. These are: the right to receive equal concern and attention whatever one's gender, caste, socio-economic status or religious belief; the right to be treated with respect and dignity and to have all needs — physical, social and psychological — responded to, whatever the prognosis; the right to be told that one has cancer in a sensitive manner and to share in all decision making thereafter; The right to be fully informed about treatment options including the benefits and risks involved; the right to be asked for one's informed consent before being entered into a clinical trial; the right to refuse treatment, to ask for a second opinion or to use complementary therapies.

One too often hears of cases where information, including the diagnosis, is withheld from the person with cancer on the plea that he or she will be unable to handle it. This is by and large a specious argument as studies conducted all over the world show that most people would like to know where they stand. There is a need to train our medical students to break bad news which is both an art and a science. What you say is as important as how you say it and when you say it.

Also, assumptions are made about people based on stereotypes. This is reinforced by the fact that those who administer medical and nursing care in super speciality hospitals in our urban centres come from a particular background. As a result, villagers are often denied details about their illness as illiteracy is equated with the inability to understand.

Conversely, it is automatically assumed that an educated and well dressed person knows all that needs to be known. Add to this the paternalistic model of our medical system where the patient comes as humble supplicant to the great and wise doctor. Those who have the temerity to ask for a second opinion on a matter that concerns their life are literally shown the door. "Don't bother to come back to me," is a familiar response.

The next set of rights set out in the declaration are of a more practical but equally important nature, especially in our context. They concern the right to continue to receive quality care irrespective of the ability to afford it. The right to have one's special welfare needs acknowledged, which include claims arising out of physical disability. The right

to be considered for medical and life insurance; and the right to employment without discrimination .

The sad fact is that for many in this country cancer is simply a death sentence. They cannot afford the expensive treatments and drugs prescribed, as well as the costs involved in residing for long periods of time in a big city. On the other hand, it is a tragedy that private practitioners continue to prescribe prohibitively expensive treatments and drugs even when they know that the disease has reached a terminal stage. The desperation of the members of the family coupled with the inability of doctors to acknowledge their limits result in many people dying grotesque deaths.

This is despite the emergence of a specialised branch of medicine known as palliative care which is being used very effectively around the world to ensure that people with illnesses such as cancer continue to enjoy a good quality of life right till the end. In India, not only is palliative care not taught in the medical curriculum, but oral morphine, the cornerstone of the WHO's pain control ladder, is out of the reach of most cancer patients in India. There are only a few hospitals, again located in the cities, who have a license to dispense it.

With more and more children surviving cancer today it is time for all of us to join hands and lobby our policy makers to ensure that the rights of people with cancer are not lost sight of as HIV and AIDS capture the popular imagination. With cancer poised to engulf the developing world supporting such an effort is akin to investing in your future.

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South Asia Medical Ethics on-line

The South Asian Medical Ethics e-group is co-ordinated by members of the Bioethics Group of the Aga Khan University, Karachi, Pakistan, and the Forum for Medical Ethics Society, Mumbai, India.

SAME was set up following the development of a number of informal contacts across the sub-continent.

It is meant to respond to the need to promote discussion on issues in medical ethics in this part of the world, to exchange ideas, provoke meaningful debate, and strengthen valuable relationships between the people of our countries.

We hope that you will find this discussion meaningful, contribute with your own experiences, press reports and comments on issues in medical ethics, and forward this invitation to friends and colleagues in this region.

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