

Appendix 2

THE RIGHTS OF THE DYING PATIENT

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At no time in our history have we been so reluctant to face death and discuss it. Death, which is such an intrinsic part of life, has become a taboo for today's culture. In actual fact, it is not death itself that people dread, but the manner, time and even place of death. As a result of this fear to talk about death, today's culture is facing the danger of leaving the dying to approach their end unsupported not only by their relatives, but even by health carers.

In order to provide the best possible care and treatment for dying patients, nurses, doctors and other health care professionals who come in direct contact with terminally-ill patients need to be trained in those attitudes and dispositions which enable them to approach the dying patient with skills and confidence with which they treat other patients. Training in palliative care, or care of the dying, needs to feature more prominently in the curriculum of all health care professionals.

It is a fact that illness of any serious kind wounds our capacity to express fully our humanity. When we are ill, we lose our freedom to do things we are accustomed to do; we lack knowledge to heal ourselves; and we are in pain, suffering or disabled, anxious, fearful, and dependent. In that state of vulnerability, we seek out those who profess to be healers. Along with our bodies and our minds, illness wounds our very humanity. To be healed, as humans, we need therefore healing not only of minds, and bodies, but also of our whole humanity. When patients know that their illness is incurable and that death is inevitable, the usual wounds illness inflicts on their humanity become more and more painful. Vulnerability, dependence, and the need for compassion become overwhelming.

The relationship between the terminally ill patient and the healthcare professional who undertakes the obligations to treat and care for that person involves more than a medical dimension. What obligations do health carers assume when they promise to help someone who is suffering, dying, and in pain? First and foremost, doctors, nurses and other healthcare professionals have the moral obligation to respect the dying patient as a person right up to death. Good quality terminal care must be patient-centred and accordingly must respect the patient as person. Health care professionals must remember that they are caring not for a dying patient, but for a person who is dying. Respecting the dying patient as a person means in practice respecting the patient as a subject of rights. This approach conforms with the spirit of Hippocrates.

It is a well-known fact that where there is staff shortage, it is the patient with a good chance of recovery who absorbs much of the staff's attention. There is the danger, that for convenience, the dying patient is moved to a corner or a side ward and is thereby isolated from other patients and neglected by health carers. Such an attitude is demeaning to the dignity of the dying patient who has the right to humane care and treatment. A dying patient will sometimes apologise for being such a trouble for health professionals, feeling embarrassed and guilty perhaps for taking time from others. The breathless speed of a busy ward is definitely ill-suited to the dying patient's need for tranquillity and peace.

Respecting the dying patient as a person means to offer holistic care for that patient. A holistic view of health care for patients comprises not only a physical aspect, but also emotional, spiritual and social dimensions. The healthcare team is expected to fulfil multiples roles, providing not only medical or nursing skills, but also psychological and emotional support. Moreover, patients may have the need for spiritual care. The dying person may wish to discuss personal, moral or spiritual problems. Dying patients are seen and treated as whole

individuals only when all these dimensions of care are provided for by healthcare professionals.

It is essential for health carers to master techniques to control pain and distressing symptoms. However, in addition to the technical skills required, health carers need to be able to develop a caring relationship with the dying patient. Since dying patients show a wide range of emotions and feelings, doctors and nurses must possess those qualities and dispositions which enable them to respond appropriately. In many cases their care tends to require more emotional involvement than technological skill.

Traditionally doctors have been taught to concentrate on the mechanisms of treatment. They have found it easier and safer for their emotional survival to distance themselves from the emotional issues surrounding the process of dying. While distancing oneself may be helpful for the health carer, it is not helpful for the patient or relatives. Dying patients want reassurance that their doctor is interested in them as individuals right up to death. Doctors and nurses should approach the dying patient with a deepened sense of conviction that they have a noble vocation of responding with sensitivity and feeling to patients' needs.

Many patients fear that their rights may be compromised at the end of life. Due to the widespread consciousness that under certain aspects, medicine can easily be dehumanising, various attempts have been made to construct a bill of rights for patients. Since those approaching the end of life are envisaged as being particularly vulnerable, such statements make specific references to dying patients. The language of rights presupposes that others have corresponding duties to see that rights are respected. In what follows I shall attempt to mention briefly some of the most fundamental rights of the dying patient:

1. Right to caring environment

In her famous book *On Death and Dying*, Elizabeth Kubler-Ross attributes modern man's flight from death to the fact that today, death takes place in an environment that is gruesome, lonelier and many ways mechanical. Kubler-Ross contrasts this modern way of dying with what she called the "old fashioned ways", where the dying person usually passed away at home, surrounded with his/her relatives. This contrast indicates the importance of a caring environment that makes a lot of difference to the dying patient.

Care of the dying must be founded on the same ethical principles as the treatment of all other patients. Health carers should be aware that their relationship with patients may change when there can be no longer any expectation of restoring the patient to health. As the patient moves into a terminal stage, the focus will shift to support, ensuring the best quality of life and coming to terms with the situation. When death becomes inevitable, the aim of treatment alters, but this does not affect adherence to fundamental ethical principles.

It is unacceptable for a health carer to make remarks, such as, "There is nothing more I can do". At no point in the patient's dying process can one say, "There is nothing more that I can do". It all depends on how you define 'doing'. It may be 'no further surgery, 'no further treatment', 'no new drug therapy', but that is still not the end of the line. There still remains relationship, caring, the comfort of the presence of a person whom the patient trusts. It is here that the roles of the doctor and the nurse are entirely interchangeable, but not mutually exclusive.

Caring for the dying patient requires separating out how much of the patient's distress is due to pain mechanisms, and how

much to suffering caused by other causes like anxiety and fear, guilt and the feeling of being punished and abandoned by the family, friends, or medical attendants. To deal adequately with these sources of suffering demands discernment of the causes of suffering, its effect on pain, and its meaning to this patient. It is obvious that the treatment for some of the varied sources of suffering is not analgesia. Rather, it is necessary to take the time needed to know the patient, to enable him/her through compassionate understanding, psychological or emotional assistance.

Health carers must extend themselves emotionally not only to the patient but also to his/her family who are in need of information, comfort and support.

2. Rights to autonomy and choice

The patient has the right to make decisions about his or her medical treatment. Respecting the autonomy of the dying patient means to acknowledge the patient's right to informed consent. There are three basic prerequisites for informed consent: the patient must have the capacity to reason and make judgements, the decision must be made voluntarily and without coercion, and the patient must have a clear understanding of the risks and benefits of the proposed treatment alternatives or non-treatment, along with a full understanding of the disease and the prognosis.

Fulfilment of the third condition requires that the physician takes the time to discuss the issues fully with the patient and outline the differences among alternatives, which are sometimes very difficult to estimate. In addition to being thoroughly informed, the patient must also understand clearly his or her right to make choices about the type of care to be received - a right many patients are not aware of. The pre-eminence of the patient's choice does not preclude the

physician's responsibility to make and to share with the patient a personal judgement about what the patient should do.

Dying patients have the right to exercise their autonomy and control to the fullest possible extent at the end of their lives. Doctors provide patients with information to enable them to do this but, particularly at the end of life, the doctor-patient relationship demands more than the simple provision by the doctor of a list of options. The physician has a special obligation to listen to the doubts and fears expressed by patients who are hopelessly or terminally ill. Advanced directives must be respected.

3. The right to information

Caring for the dying patients demands ongoing communication with the patient, his/her relatives and with other health care professionals. Doctors should seek to be as frank as possible with patients. In the past, information was withheld on the grounds that it would distress the patient. This argument is still valid in those circumstances in which the doctor feels that information would harm the dying patient. But this is the exception not the general rule. Respecting the autonomy of the patient requires truth-telling and keeping promises.

Doctors should avoid being paternalistic with dying patients by withholding all information. Doctors often find it easier to talk to those close to the patient rather than to the actual patient. For a long time, physicians held that knowledge of a fatal disease should be withheld from the patient or communicated to the family only. This is a further degradation of the person of the patient. The principle of patient's autonomy requires the empowering of patients through the provision of information.

The dying patient has also the right not to be informed, when this is his or her expressed wish.

4. The right to confidentiality and privacy

The patient has the right to have his sickness and information related to it in confidence. Illness intrudes into the person's privacy. This calls for confidentiality and modesty in any examination and treatment of the dying patient.

5. The right to a good death

Dying patients have a right to be looked after by caring, sensitive and experienced professionals who will attempt to understand their needs and support them facing the process of their own death. What is sought, however, by some who defend this right, is not simply a right of access to the best available terminal care, but also the acknowledgement that the patient has a right to choose to die by "voluntary euthanasia". Rather than helping the dying patient to terminate his/her life, dying patients need to be cared for to continue to live while dying. The Hippocratic tradition gives pre-eminence to the doctor's responsibility to benefit and not harm the patient.

6. The right to support

Dying should not be an event suffered in isolation. When the patient's symptoms have been adequately controlled and communication is a possibility, the crisis of dying, like the other crises of life, can become an opportunity for reconciliation and growth. Ideally, support for the dying patient should come from family members and other people close to the patient.