

Appendix 1

THE ADVANCE DIRECTIVE

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Patient autonomy is one of the guiding ethical principles of modern medicine, and is encountered daily in negotiations with patients about diagnostic tests to which they are willing to submit and medications they are willing to take, and through the process of informed consent, which is intended to assure that the patient is aware of the risks and benefits of potentially harmful interventions. These expressions of autonomy are based on a patient's ability to understand and to make reason judgements as a partner in their health care. There may come a time when the patient is incapable of decision making, and, under these circumstances, there are two ways in which the patient's autonomy may be expressed: a living will and a durable power of attorney.

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An Advance Directive is a written or oral directive given by a competent person in order to govern and to control medical decision making for future situations of incapacity (Sass, 1998). It is also called a 'Living Will' because in effect it is a will, which the person writes for himself for actions to be taken on his or her behalf when he or she is still alive (Welie 2001). One has to distinguish therefore between wills which indicate what the person wishes after his or her death, for example organ donation, or the use of his or her body for research, and what that same person wishes to be carried out on his or her behalf when not in a position to take decisions any longer. A living will, however, is more specific. By definition it is itself an advance directive refusing or requesting specific types of medical intervention in the event of future incapacity (Sass, *op.cit.*).

Advance directives are an indispensable and essential part of medical practice today. They give the power to a patient to make an informed choice, within the law of the country, about him or her when mentally incapacitated, dying or in palliative care. A patient may designate a trusted person or family doctor to be his or her health care representative and take decisions on his or her behalf. In this case the advance directive is a written statement addressing who this 'power of attorney for health care' is. The power of attorney, that is, the person acting on the patient's behalf, obviates the problem that living wills are not legally binding and therefore may be challenged by relatives and the medical team. The word of the person designated by the patient to act on his or her behalf is almost as binding as the word of the patient.

Naturally there comes a time in many people's lives where difficult decisions need to be taken. Should we strive to keep the person alive at all costs, even compromising what many would feel is the dignity of the person? Or should the person be allowed to die quietly? Doctors, facing patients without explicit directives, are obliged to resuscitate people and to try to keep them alive as long as is reasonably justified. Whilst in the past it was the medical team to decide a DNR order, nowadays this decision is taken with the family (Welle, 2001: 170). The family is in the best position to know what the patient would have wished. An advance directive makes things easier. A person may thus express a wish that he wants to live as long as possible and that all the powers of modern medicine should be used to keep him alive. Another may express a wish not to be resuscitated if terminally ill but to be kept comfortable at all times, or not to be given any form of extraordinary treatment. However the qualifier 'within the law of the country' is important in this respect - no one is obliged to carry out a directive which is morally questionable or illegal, such as assisted suicide.

There are problems however both with the directive itself and with implementing it. Consider a person suffering from dementia. There is a bioethical debate of whether a previous written old directive should take precedence over the present wishes of the person (Vollman, 2001). The person may be having gaps when memory functions rather well stating he wishes all to be done to keep him alive, forgetting the advance directive he had written a couple of years earlier should he be demented. Naturally the family and the particular situation come into place in upholding or not the directive. But it is not all that easy. Clinicians may be aware that when confronted with death or with a severe disease, the wishes expressed by the person previously may change. As long as patients are competent there is no problem in changing the directive. The issue arises when competence, which may be compromised by the pain someone has, is doubtful. The second problem, that of advance directives not being available, can be tackled by educating people on these issues and having them discuss with their doctor what can be done.

The local scenario

Advance directives are by necessity subject to cultural and legal restrictions. In a country where euthanasia is not legal, an advance directive indicating that the person would wish to be put to death in case of dementia or severe pain would be invalid. But the culture of a country can dictate where these written directives can be extremely useful. Advance directives need not be restricted to medical decisions only but to decisions taken beforehand for a time when the person is no longer competent because of medical conditions or old age. In Malta, advance directives are still unpopular. Usually the medical team converses with the family to find out the wishes of the ill person. More frequently, decisions are taken on their behalf without the ill having made any explicit requests.

Whilst the family doctor can play an important role in keeping written advance directive for patients (Christie, 1986: 172), the problem is that people are not registered with specific doctors. Hence if two doctors turn up holding divergent wishes of patients, this would be a confusing issue, unless one is simply to take the last wish written assuming that the previous one is void. The law would have no way of knowing which doctor is the 'legal' attorney for health care of the patient. But this problem aside, responsible people can abide by a family doctor and have written documents, which can take the form of a questionnaire, kept in their files (Daly 1995: 128). Of course the system does not call in the family doctor should this patient be taken to hospital without the latter's knowledge and the hospital team would have no way of knowing about such directives. Such is the importance to have patient registration and to enhance the co-operation between secondary and tertiary with primary care (Mallia, 2001), and the role of the GP in hospital (Christie, 1986:161).

There may be sound reasons for people wishing their family doctors to keep advance directives. Old people in particular are afraid of decisions being taken on their behalf to which they are not consenting, such as being put in a home, hospitalization, or worse still being made to sign wills that go against their previous ones. Old people are often put in embarrassing and coercive positions to write testimonials to which they may have reservations. Naturally for fear of being abandoned they sign documents presented to them by notaries they have never seen before (usually brought in by the particular member of the family in whose interest it is that the will be signed) and consent to being examined by doctors who are not their family doctors. Of course it goes without saying that professional ethics would still dictate that notaries and family doctors do not cheat in this process. It is not the first time I was called to sign a document for a notary stating that the person was capable of making informed choice, only

to find that the person fails badly the mental examination test. The family may find another doctor, who was not the family doctor of the patient, but who can still legally issue documents, who is ready to express a different opinion.

Legislation requiring people to register with a family doctor will create the legal framework to avoid abuses, which unfortunately may be found in every profession. The family doctor is the ideal person to intervene on behalf of the patient who does not wish to give power of attorney to a relative or friend, and to entrusted with his or her wishes (Rakel, 1995: 151). The doctor would be in a position to help with DNR orders and other end-of-life decisions, even if no specific written document was available. Since advance directives can also be oral, physicians are culturally and objectively the ideal candidates to be trusted with advance health care directives.

However, the legal framework is useless unless people are instructed in the powerful potential of this tool. Whether written in legal or religious language, an advance directive that gives a clear indication of the person's wishes vis-à-vis health care choices, is a powerful tool. Yet the power of this tool must come at the expense of regulations in the National Health Care system which allows the hospital team to know who is truly the family doctor. In our system there may be more than one doctor involved in the family; moreover the 'usual' doctor may not have been found at the time of admission, and another doctor been used to refer the patient to hospital.

In a country where one still may wait up to three weeks to receive a discharge letter from hospital and where family doctors are not part of the national health services, it seems ambitious to be speaking about advance directives. Yet our patients deserve no less than the rest of European countries. An advance directive allows physicians to continue giving compassionate care whilst respecting the wishes of patients

even when they are no longer capable of communicating. Any guidelines for patient rights should include the right to give advance directive and the right to have them recognised.

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