

SOME GUIDANCE NOTES ON COMPLETING YOUR LIVING WILL

(These notes do not form part of the living will document)

NOTE: If you are admitted to hospital with a serious illness you are strongly advised to ask for your living will so that you can review it, update it, or affirm that it still represents your current wishes.

Examples of Additional Instructions

It is not necessary generally to insert any additional instructions on your living will, but the following are exceptions that certain people may wish to consider. If you are adding any wording in the "additional instructions" section, it is advisable to discuss it thoroughly with a doctor first.

Example 1: Dementia declaration.

Your living will already recognizes the extreme forms of senile dementia - situations where you do not recognize your nearest relations, no longer know the time in which you live, and are no longer capable of performing the activities of daily life such as eating, drinking, washing, going to the toilet. If you also want to emphasise that you refuse treatment in the *initial* phase of senile dementia, which is characterised by periods of extreme confusion, interspersed with periods of extreme lucidity, you can add: "In the event that I find myself in the situation of the beginning of senile dementia and also have a life-threatening physical condition, I refuse all further life-sustaining treatment."

Example 2: Declaration of non-resuscitation.

One of the natural ways by which a lasting suffering can be ended is a cardiac arrest. A person to whom this happens is unconscious immediately. If no immediate action is taken, the patient will die within a short time, dying a fairly mild death. When a cardiac arrest occurs however, health care teams would generally make attempts to resuscitate the patient as soon as possible. These can take the form of heart massage, mouth-to-mouth resuscitation, or more sophisticated measures.

Resuscitation however is undesirable if you consider cardiac arrest as a relief or if in view of your age or medical condition consider the chances of complete recovery after resuscitation to be very small. Your doctor should be able to give you information about the eventual consequences of resuscitation in your situation.

If you do not want resuscitation, you will have to talk this over in good time with your doctor, your family, social workers or those close to you. You will have to consider very carefully if your wish for non-resuscitation applies to all circumstances. The following text, which also includes accident and drowning, could be added to your living will for non-resuscitation, but should *only* be included after discussion with your doctor: "I refuse all life-sustaining treatment in case I find myself in a situation of unconsciousness caused by cardiac arrest, accident or drowning. I also refuse any draining of my stomach."

Example 3: **Pregnancy waiver/non-waiver.**

If you are a woman of child-bearing age, you may wish to consider whether your wishes about non-treatment should apply if you were carrying a viable foetus. You could then add one of the following texts:

a) "This living will is to be temporarily overruled if I am pregnant and, to a reasonable degree of medical certainty, the foetus may develop to the point of live birth."

OR

b) "My advance refusal of treatment, as stated in this document, is to be carried out even if I am pregnant and carrying a viable foetus, and even if this means that the foetus will not develop to the point of a live birth."

Example 4: **Refusal of specific treatments.**

If you have a condition such as AIDS or multiple sclerosis, where the prognosis involving incapacity is known with some certainty, as are the available treatment options: you may wish to make advance refusals of specific treatments, such as chemotherapy, where there is likely to be a choice between benefits and burdens. If this is the case, suitable wording should be devised with your doctor and added to your living will.

WHAT TO SAY TO YOUR DOCTOR

When you approach your doctor or medical consultant in order to lodge your living will in your medical records, you may be unsure as to his or her reaction. If your doctor has not come across a living will before, he or she may need some reassurance from you as to what it is. Bear the following points in mind, or take a photocopy of the following paragraph with you:

(You could say...) *"The purpose of the living will document is to minimize the indignity or suffering that might ensue in the event of certain irreversible conditions, and to spare doctors and relatives the problem of trying to make difficult decisions on my behalf. "*

It does not ask the doctor or nurse to do anything contrary to existing law - in fact the law fully upholds the right of any patient to decline treatment, including life-sustaining treatment, and to receive analgesic drugs in quantities to relieve intolerable distress.

If the doctor has personal objections to accepting the document or making its existence known at such times as may be appropriate, then an alternative doctor should be recommended who may not have the same reservations.

If at all possible, it is extremely desirable to discuss the living will with your doctor. Ask for the medical terms and the implications of refusing treatment to be explained so that you fully understand what you are signing. This will also mean that your doctor will be more fully aware of your wishes if he or she has to make difficult decisions at a time when you are no longer able to speak for yourself.

If you still have further queries about your living will, you can send a large stamped addressed envelope and small donation to VESS, 17 Hart St, Edinburgh EH1 3RN (UK) requesting a LIVING WILL INFORMATION PACK which provides further answers to common questions, as well as guidance on some of the difficult areas of law and medical ethics concerning such documents. Members of VESS can also obtain Living Will stickers for medical files, a document carrying case, a medical alert card to carry in a wallet, and update stickers to indicate that the document has been renewed every few years. Subscription to VESS costs £15 per year (Overseas residents: £30) and includes a regular and comprehensive newsletter, which keeps you informed of any changes in the law or practice of living wills.