A typical seven-step model scenario with living wills:

1. A patient in good health makes an appointment with the GP to discuss living wills. A simple style of document can be taken to open discussion. The GP discusses possible health care situations, including sudden accidents or trauma. She explains some of the options and the sort of decisions which might have to be taken, and listens to the patient’s preferences should such circumstances arise. The GP discusses these preferences with the patient and assures herself that the patient understands what would be involved.

2. The patient completes a fairly basic living will form outlining preferences for non-treatment in the event of incapacity. It may also include a statement of values (desired outcomes) such as the patient’s feelings about things such as quadriplegia, unrelievable pain, or lasting mental impairment. Beyond the limits of exact and enforceable instructions, these values can form a guide, an aid to decision-making when there are ‘grey’ areas. This process may be assisted by the use of clinical vignettes (see Values Section of the longer Living Will document), or could just be fairly general.

3. The patient makes photocopies of the living will for personal safekeeping (possibly keeping one with the driving license, bus pass or other documents usually carried on one’s person). The patient gives a copy to the family or significant others, and possibly a solicitor, and instructs the GP to put the original in the medical file.

4. The patient reviews the living will approximately every three years, or in the event of serious changes in health (whichever is earlier), to see if it still reflects the patient’s current wishes. (A person’s lawyer is more suited to issuing reminders than the GP, but it is not essential to involve your lawyer.) If the patient’s wishes change, the patient replaces any old copies with new copies, but otherwise simply updates the existing document with the date and a signature in the margin.

5. If the patient’s health changes dramatically, the GP or consultant discusses future scenarios with the patient in some detail, so that relevant choices can then be incorporated in the living will. At this point, or in the elderly (who may reasonably envisage more serious health problems than the young), the patient may feel that a more comprehensive style of document is appropriate if only the simple one has been used so far. If the patient is forewarned of a hospital admission, then a copy of the living will is taken with personal effects. A copy should also be given to the hospital health care team (as medical records may take some time to be transferred from the GP). If a new, more comprehensive document is completed, it should be photocopied, distributed, and placed in the medical records in the same way as the basic one.

6. The patient is admitted to hospital and stabilised (ambulance teams generally are legally required to “save life”). The living will is then reviewed by the health care team. If the patient regains consciousness, the future choices in the living will are reviewed by giving the patient further information on likely scenarios and options. These should be discussed. Clinical vignettes (imaginary but typical scenarios) may again be helpful in discussing outcomes, especially where there are a large number of treatment options or where the

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1 Such as the blue form provided by EXIT. Any properly designed form is OK, but it is often easier to start off with a simple one.

2 The EXIT buff-coloured document

3 See the dark yellow ‘Extended Values History’ form.
patient has a limited capacity/desire to absorb relevant information. It may also, for instance, be necessary to correct patients’ misunderstanding of certain techniques. For instance, studies have shown lay persons typically view tube-feeding as “very serious and probably painful and undignified” and dialysis as “not very serious” whereas medically trained people would probably take the opposite view of these two procedures (Tube-feeding is relatively minor: dialysis is not.)

Similarly, CPR (resuscitation) may be a more serious procedure in an elderly, frail patient, since survival rates are low and the procedure may cause further damage; whereas in a comparatively young, healthy person, it is more likely to be completely successful without after-effects. Popular beliefs about CPR may well be based on misleading media portrayals. Hospital staff can ensure that the patient understands what is involved so that informed decisions for the future can be made.

The final choice should always rest with the patient or based on the patient’s wishes where these can be ascertained with any reasonable degree of certainty. The patient’s choices may be influenced by the information given them – some studies have suggested that patients who think they are going to live for at least six months are more likely to favour life-extending care over comfort care, compared to patients who think there is a considerable chance they will not last six months. Good care includes giving the patient enough information to make considered choices.

7. **Health care decisions are triggered** by a patient’s new condition, when the patient cannot speak for him or herself. The living will is consulted. Where specific refusals have been made that apply to present circumstances that have arisen, or to treatments being offered, those refusals are honoured (they are legally binding).

If there is evidence that such refusals were invalidly made (for instance, under pressure) then they may be over-ruled, but there is a presumption of competence. If there are no specific instructions that apply to the circumstances that have now arisen, then the living will is taken into consideration together with other factors, including clinical judgement on the treatment in question, and professional judgement of the patient’s best interests, before reaching a treatment / non-treatment decision. Verbal indications are important and may be uncovered by discussion with the patient’s relatives or significant others. It may be that the patient had expressed a strong desire to avoid certain treatments but not put it into writing.

The patient may also have expressed a strong desire to revoke the living will. The health care team are responsible for evaluating such information before reaching a decision. Contrary to popular belief, family members have no authority to make such decisions (exceptions to this include decisions for minors, and also the Scottish system of proxies which can give limited authority to specific persons.) If the patient is pregnant and carrying a viable fetus, application to a court is desirable although not essential. It should be noted that the weight of valid and applicable refusals of treatment continue to apply in emergency situations and in the operating theatre.

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4In *Re AK* (2000) 58 BMLR 151, the court stated that, in an emergency, a doctor is entitled in law to treat by invasive means if necessary a patient who by reason of the emergency is not able to consent, on the grounds that the consent can in those circumstances be assumed; but that it was also clearly the law that doctors are not entitled so to act if it is known that the patient, provided he was of sound mind and full capacity, has let it be known that he does not consent and that such treatment is against his wishes.