Adults with Incapacity (Scotland) Act 2000

Proposals for Reform

This submission is made on behalf of the Christian Medical Fellowship (CMF), an association with over 4,500 medically qualified members throughout the UK. 452 of our members (about 10%) reside in Scotland and there are 93 student members at five different Scottish medical schools.

CMF has a particular interest in the care of dying persons. A significant proportion of our members are involved in palliative medicine and hospice care, and we recently produced a booklet, entitled Facing Serious Illness, in collaboration with colleagues in the Lawyers' Christian Fellowship. It is available from our bookshop:
(https://www.cmf.org.uk/resources/bookstore/?context=book&id=258)

Submission provided by Dr Rick Thomas (Researcher)

This is a limited submission, responding only to the issues raised in Chapter 11 of the consultation guide.

Chapter 11 – Advance directives

Question: Should there be clear legislative provision for advance directives in Scotland or should we continue to rely on common law and the principles of the AWI Act to ensure peoples' views are taken account of?

No. In our opinion there does not need to be any change to the current legal provision for advance directives in Scotland.

Our view, and that of our members, is shaped, first and foremost, by the belief that every human being is made 'in the image of God'[1] and that as such every human being, no matter how old, frail, ill, physically or intellectually disabled, has built-in value and significance. Nobody has the right to say of another that their life is 'not worth living'. Indeed, God calls us to treat the most vulnerable people with special respect.[2] But it is not just Christians who take such a view; many of different faiths and none also hold that all human life has inherent value. Decisions about treatments should therefore focus on a consideration of the benefits and burdens of any medical intervention, rather than viewing some states of existence as being excessively burdensome in themselves.

We recognise the potential usefulness of advance directives for some situations:

[1] Genesis 1:27
[2] Exodus 22:22-23

- They can support the autonomy of the individual patient against what some see as a self-serving medical profession;
- They may relieve the fear of a degrading and drawn-out death, being kept alive by extraordinary or disproportionate means, and help people achieve 'death with dignity';
- They could help release scarce healthcare resources that would otherwise be tied up in prolonged and ultimately futile treatment.

However, we believe the potential downsides of statutory advance directives are more compelling:

- **Unpredictable**
  Advance directives often state that 'in the event of 'x' medical condition occurring with no chance of recovery, I would not want 'y' to be done'. In practice, it can be very difficult to predict outcomes accurately. People can make extraordinary recoveries. Sometimes a diagnosis turns out to have been wrong. One study showed that about half of the cases of Persistent Vegetative State are incorrectly diagnosed.[3] Requiring two or more doctors to agree on a prognosis may reduce the error, but does little to eliminate the problem. People's attitudes and wishes frequently change with the onset of serious illness. It appears that life often seems more precious when it is more precarious, and most patients when confronted with a choice between death and seriously disabled life, choose life.

  A study of 21 people who were paralysed from the neck down and needed ventilators to help them breathe, found that only one person wished that she had been allowed to die. Two were undecided, but the remaining 18 were pleased to be alive.[4] It is reasonable to believe that while healthy, they would have said they would rather die than live in this highly-dependent state.

- **New developments**
  When writing an advance directive, a person will make assumptions based on current abilities of technology to control pain or other symptoms. However, developments in medical practice are constantly increasing our ability to make life comfortable, and an advance directive may not be able to take these changes into account.

- **New Circumstances**
  Many events in life can influence one's attitude to disability. For example, the arrival of a grandchild can give an elderly person a new reason for wanting to continue living, and a change in religious conviction can revolutionise a person's attitudes to life, death and disability. Even without religious convictions, many people come to see real meaning and purpose in their suffering that could not have been anticipated when considering an advance directive.

[3] Andrews K, Murphy L, Munday R & Littlewood C. Misdiagnosis of the vegetative state: retrospective study in a rehabilitation unit. BMJ 1996;313:13-16.
[4] Gardner BP, Theocleous F, Watt JW & Krishnan KR. Ventilation or dignified death for patients with high tetraplegia. BMJ 1985;291:1620-22.

Doctors need to do everything possible to check that a patient hasn't changed his or her mind, rather than simply relying on an advance directive. A study of 150 competent persons, with advance directives, concluded that 61% thought there could be times when their best interests would be served if clinicians ignored their directive.[5]

- **Coercion of the vulnerable**
  There is also the concern that vulnerable people will be coerced into signing advance directives, and unscrupulous carers or potential beneficiaries may exploit the feeling of 'I don't want to be a burden to my family or carers'. Even without overt coercion vulnerable patients may feel an internal sense of duty to sign, so this pressure can be both real and imagined.

- **Autonomy is not absolute**
  Advance directives are seen as a way of letting a person assert their 'rights'. However, patients have no legal right to demand treatments that are not in their best interests. This means that if in an advance directive a patient refuses a treatment, and the exact situation arises in which the advance refusal is applicable, then a doctor has a legal duty to respect that refusal. However, even if the advance directive requests specific treatments, a clinician is not obliged to provide them if in his or her judgement it would be clinically unnecessary or inappropriate.

- **Trust is better than control**
  Legal documents will always be poor substitutes for good doctor-patient relationships. A discussion with a trusted family doctor, summarised in a **Note of Wishes** that is included in the patient's notes, enables a patient to clearly express their hopes and fears without running the risk that, years later, an advance directive that may no longer be fit-for-purpose be applied inflexibly to a situation that could not have been foreseen when it was drafted.

  A person concerned lest treatments may be withdrawn inappropriately, or that doctors may consider their life no longer worth living, can record these concerns as part of a Note of Wishes. For example, it may state that they wish to be provided with clinically-assisted nutrition and/or hydration where these have a reasonable chance of sustaining life or easing symptoms.

  A Note of Wishes is not legally binding and can be changed or updated, without legal fuss of cost, as circumstances or perspectives change over time. It will be sensible to include family and friends in discussions about both the original content and any subsequent updates. It is then less likely that uncertainty or disagreement will arise in implementing a person's wishes when the time comes.

- **Power of Attorney**

[5] Sehgal A et al. How strictly do dialysis patients want their advance directives followed? JAMA 1992;267:59-63.

The appointment by a person (known in Scottish law as the 'Granter') of one or more people with legal power of attorney to make decisions later in life, on the behalf of that person, should they later lose capacity, is preferable to an advance directive. It gives control to those who, over years, have earned a place of trust in the eyes of the person now incapacitated, rather than giving it to those in a professional capacity who may have to rely on a dated directive written years previously by someone of whom they have no personal knowledge. In particular, it gives the attorney(s) authority to give or refuse consent to life-sustaining treatment, which is something that requires careful thought and an understanding of what the patient would have decided had they had capacity. The rigidity of an advance directive can prevent a doctor helping a patient, when there might be a reasonable chance of recovery, if that form of treatment had previously been refused.

The Power of Attorney is a more flexible, more natural and more robust solution. It calls for trust rather than offering control. It is commonplace, cost-effective and easily understood. It enables a person to choose an attorney(s) who understands their values and will later be able to act on their behalf in keeping with those values and in relation to treatment and circumstances that may not have been foreseen at the time the LPA was drafted.

As the above provisions are already permitted under the principles of The Adults with Incapacity (Scotland) Act 2000, CMF does not support a change to legislative provision for advance directives.

CMF Public Policy Department, April 2018