

*Friends at the End*  
*Promoting end of life choices*



## Consultation Response

### Adults with Incapacity Reform

April 2018

## Overview

For over 18 years, Friends at the End has worked to promote knowledge about end of life choices and campaigned to see a change in the law to allow Assisted Dying.

We have supported hundreds of people through the end of their lives and been involved with the preparation of two parliamentary Bills in Scotland.

Our long term aim is to see the passing of Assisted Dying legislation, until this happens we work to ensure that every UK citizen has a Good Death within the current legal framework.

We sponsor the Cross-Party Group on End of Life Choices in the Scottish Parliament working with MSPs to raise awareness of issues at the end of life and to grow a coalition of stakeholders who are supportive about making improvements to peoples end of life choices. Assisted Dying is only one focus and we work to better inform individuals of all end of life choices currently available to them. These include the promotion of sensible forward planning tools such as Powers of Attorney, Advance Directives, Wills etc. We provide information and leaflets on advance directives and help individuals to complete these documents and file them appropriately. Please see our website for more information.<sup>1</sup>

We support our members to raise awareness of end of life issues with their parliamentarians and the wider public through the provision of e-bulletins & newsletters, local group meetings, training, lectures and conferences. We share information about practice and research from around the world. Our ultimate goal is for all UK citizens to have a good death, whatever that means to each person.

We welcome the opportunity to consider and respond to the Scottish Government's consultation on Adults with Incapacity Reform and have the following comments to put forward for consideration.

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<sup>1</sup> <https://www.friends-at-the-end.org.uk/publications/advance-directives-decisions/>

## Consultation questions

### Chapter Eleven

**1. 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?**

Yes, there should be clear legislative provision for advance directives (AD's) in Scotland.

The Scottish Law Commission's 1995 Report recommended that advance directives be included in the original Adults with Incapacity Act, but they were subsequently omitted.

In Scotland, the law in this area cannot be said to have developed, or further developed, adequately, meaning that AD's have no clear and authoritative statement in the current law.

Upon advice from academics and solicitors, Friends at the End concluded that advance directives are only 'potentially binding' in Scotland by way of common law.

Meanwhile other jurisdictions are considering the whole issue of end-of-life decision-making in a modern way and are implementing integrated regimes, which include full use and promotion of advance directives.

A helpful comparison highlighting successful reform can be seen in the approach taken by France. Until 2016, advance directives only had advisory value in French law. Similarly, to Scotland, the law stated that physicians may take these documents into account but is not obliged to respect them. The French president François Hollande set up a consultation to review the law. This resulted in a new report being published by a parliamentary committee in 2012. This report, entitled, 'Reflections on the End of Life from a Perspective of Solidarity' made suggestions on how to improve the law on end-of-life treatment.

The report suggested granting greater value to advance directives to strengthen patient autonomy. As a result of further debates and another parliamentary report in 2015, a new law on end of life issues came into force in early 2016. The 'law creating new rights in favour of patients and persons at the end of life' grants binding value to advance directives.<sup>2</sup>

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<sup>2</sup> <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5167768/#CR57>

We believe it is time that Scotland kept pace with these positive international developments.

The Scottish Government is committed to patient centred care and affording statutory basis to advance directives is central to this.<sup>3</sup> Many people are sure they would not want to be kept alive in a long-term coma-like state. According to a recent YouGov poll, 82% of people have strong views about their end-of-life treatment but very few (about 4%) have made an advance directive.

One of the reasons for this is that many people wrongly believe that family members would be able to make health care decisions on their behalf, if they were unable to do so themselves. An AD frees your loved ones from the pressure of having to make critical medical care decisions for you while they are under stress or in emotional turmoil. If your health takes a turn for the worse, it provides peace of mind to know that your doctors have a blueprint in place to guide them.

It is not easy for families and medical professionals to withhold or withdraw treatment and an AD helps them to come to terms with this by giving reassurance that they are respecting your wishes. An AD empowers individuals to determine how the end of their life will happen and empowers the family and healthcare team with guidance on how to ensure capacious decisions are respected. Research shows that patients and their families report significantly less stress, anxiety and depression when an AD is in place.

**2. If we do make legislative provision for advance directives, is the AWI Act the appropriate place?**

Yes.

**Further comments**

Registration and distribution via a central repository is particularly important, as well as wider clinician/public education. The office of the public guardian could be the repository for advance directives, in the same way that they current hold powers of attorney etc.

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<sup>3</sup> [http://www.healthcareimprovementscotland.org/our\\_work/person-centred\\_care/person-centred\\_programme.aspx](http://www.healthcareimprovementscotland.org/our_work/person-centred_care/person-centred_programme.aspx)

The Scottish Government should aim to ascertain how many people in Scotland currently have AD's or similar instructions, increase uptake of AD's and comparable measures and identify ways to promote AD's as a means of sensible life planning for all ages.

A medical crisis can occur at any time (even when young or healthy), and individuals may lose the ability to state their wishes or make decisions. Some of these decisions could be regarding end-of-life care, and research has shown that those types of decisions are not best made under the pressure of a crisis. It is important to make healthcare plans in advance to ensure individuals get the medical treatment they do and do not want. Putting plans down in writing, in the form of advance directives, is ideal but people will only be motivated to do this if they are sure that the document is legally binding and will be respected.

Research suggests that many adults haven't thought about or put off advance planning and only a tiny percentage haven't documented their wishes for end-of-life care. Preparing for a time when you may be too ill to make your own medical decisions is an important step—especially since many people lack the capacity to make their own medical care decisions at the end of life. These measures need to be evaluated rationally, during normal times, and while individuals are able to effectively communicate their wishes.

Raising awareness of forward planning tools is imperative to Scotland's long-term health strategies. As an expert organisation, Friends at the End has the potential to create learning materials and provide training for healthcare professionals to provide greater familiarity with Advance Directives. Existing links with organisations such as ADAssistance could be leveraged to ensure that an authoritative voice was provided. There are approximately 961 GP practices in Scotland. Creating a learning pack for each surgery would likely be cheaper than a full public education campaign but would require considerable investment in time and expertise. The expertise of the Cross Party Group on End of Life Choices could be drawn upon for this project, particularly given the participation of individuals, who have experience as training providers.

NB: Whilst encouraging individuals to respond to this consultation we have had feedback that the process is not user friendly, especially if one wishes only to respond to individual questions and not the entire consultation. The wording of Chapter Eleven's questions could also be construed as presupposing and a better approach would have been to simply ask **Should there be clear legislative provision for advance directives in Scotland?**

**For further information please contact:**

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