Consultation on the Proposed Reform of the Adults with Incapacity Act

Response from Scottish Partnership for Palliative Care

About Scottish Partnership for Palliative Care (SPPC)

The Scottish Partnership for Palliative Care (SPPC) brings together health and social care professionals from hospitals, social care services, primary care, hospices and other charities, to find ways of improving people's experiences of declining health, death, dying and bereavement. We also work to enable communities and individuals to support each other through the hard times which can come with death, dying and bereavement.

Sometimes our field is described as "palliative care" but depending on what people understand by this term, this language can cause confusion. One way of thinking about "palliative care" is to talk in terms of providing "good care" to people whose health is in irreversible decline or whose lives are coming to an inevitable close. However, the work of the SPPC is not synonymous with death – it is about life, about the care of someone who is alive, someone who still has hours, days, months, or years remaining in their life, and about optimising wellbeing in those circumstances.

SPPC was founded 26 years ago and has grown to be a collaboration of over 50 organisations involved in providing care towards the end of life. SPPC's membership includes all the territorial NHS Boards, all the hospices, a range of professional associations, many national charities, local authorities, social care providers and universities.

Focus of this Response

The scope of the proposed reforms is broad but this response focusses on issues relating primarily to end of life care.

Delirium

The Scottish Palliative Care Guidelines define delirium as

> *"disturbed consciousness and inattention with cognitive impairment; acute onset and fluctuating course as a physiological consequence of disease or treatment."*

Other terms used to describe delirium include acute confusional state, agitation, and terminal restlessness, but the terms terminal restlessness and terminal agitation should be used only once reversibility has been excluded.

Around 57,000 people die each year in Scotland, of these around 46,000 will do so following a period of poor and deteriorating health. Delirium presents in around 30% of palliative care inpatient admissions and as the very end of life approaches this increases to around 80-90%. Very large numbers of people will therefore experience delirium and consequent incapacity in the context of end of life.

Delirium is often reversible and people with delirium in palliative care can rapidly move from normal cognition to incapacity and back to normal cognition within hours, days and weeks. Delirium can therefore create potential for uncertainty for families and carers. Delirium also creates challenges and uncertainty for healthcare professionals - the Adults with Incapacity Act is currently insufficiently clear as to how clinicians are required to manage loss of capacity in the context of fluctuating delirium and in respect of loss of capacity and delirium at the very end of life.

Currently, practice in palliative care is inconsistent across Scotland in relation to implementation of the Adults with Incapacity (Scotland) Act 2000 for patients with delirium. In some areas of Scotland, clinicians are in receipt of legal advice which recommends the use of a Certificate of Incapacity under Section 47 of the Act (section 47 forms) for everyone who loses capacity in the last days of life. The advice states that without this in place, healthcare practitioners are not legally allowed to treat the patient under the Act. However, in other areas in Scotland this is not standard practice and loss of capacity is seen as a normal part of the dying process.

We believe that the Act should be reformed so that the requirements and responsibilities of clinicians are clear when they are managing situations involving incapacity due to delirium, whether that is fluctuating delirium or delirium experienced at the end of life.

We believe that any reform to the Act, whilst continuing to protect the human rights of individuals, should not require processes which may cause distress for families or detract in any way from care processes at the end of life.

Advance Directives

An advance directive is a way of trying to ensure that practitioners respect the wishes of the person, should they become incapable of making such decisions themselves. During our consultation we received legal opinion that there can be little doubt as to the legal validity of advance directives. However, incorporating advance directives in the ACT should help to address the perception that because there have been no Scottish legal cases confirming their status that there is some doubt about their enforceability.

We believe that the Act should be reformed so that it contains legislative provision for advance directives in Scotland, and this should not be left to common law as is currently the case. The revised Act should also include clarification of what constitutes a legal advance directive. Consideration should be given to the adoption of common terminology across the UK to refer to such directions (currently termed Advance Decisions to Refuse Treatment under the Mental Capacity Act 2005 in England).

Context for Reform

In developing this response we received many comments, which whilst not referring directly to the content of the Act, provide important context and which should be taken into account in any reform of the law:-

Public Awareness and Uptake

Generally public awareness and/or uptake of power of attorney and advance directives is low, and this needs to be addressed.

There is also a need to ensure good accessible information and advice for people when they are deciding the content of their advance directive or power of attorney. For example, generally helpful clauses in a power of attorney are sometimes omitted (eg appointing substitute attorneys, allowing the attorney to make a decision as to the incapacity of the grantor etc). With advance directives the attempt to envisage future medical scenarios needs good advice (and may be difficult even with this advice) and should recognise that future treatment options may evolve over time.

More information and support for people to whom POA has been granted is also required.

Access to end of life planning instruments generally

Reform of advance directives should pay regard to the development and promotion of anticipatory care planning in general, and specific instruments such as ReSPECT and DNACPR. There is a need to consider how all these instruments (including advance directives and power of attorney) can be accessed rapidly via electronic registers so that clinicians can be clear about what is the most up to date and valid documented expression of a person’s wishes.

Professional Awareness and Training

There remains a need for professional awareness and training to underpin the Act.

Other Comments

SPPC would be happy to work with Government to contribute to the development of detailed proposals addressing the issues which are raised in this response.

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April 2018
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