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Effective End-of-Life Care Planning in Scotland: Culture and Law

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Abstract

In the context of an ageing population, end-of-life care planning is increasingly important. The law in Scotland does not, as yet, take the active and specific steps to help address this that are evident in other jurisdictions. I contend that there are two particular issues which need to be addressed here. The first is to normalise the idea of a discussion about dying. This is important in order to allow individuals to feel entitled to discuss and plan for it by way of an advance directive, to feel that it is a valuable exercise, and to feel reassured that their plans will not falter if they lose capacity. The second is to formulate an approach which prompts and encourages that discussion, but also promotes autonomous decision-making. I assert that the law can, and should help with both of these by providing a legislative basis for advance directives in order to set out the requirements for formal validity, and by making provision for an allied, non-mandatory pro-forma to guide and assist those who wish to use it.

Delivering end-of-life care that meets an individual's needs and wishes is a difficult issue, from at least two different perspectives: one cultural, one legal. From a cultural point of view, there is clear reluctance on the part of some, perhaps many, to engage in open and frank discussions about their death, or that of a relative, and the process of dying. From the legal perspective, there have been numerous attempts across the UK and other jurisdictions to formulate an approach that both encourages and enshrines advance care planning and which seeks to allow for the use of advance directives as a means for the individual to specify refusals of particular treatments prior to losing capacity. In this context, terminology can vary but for the sake of clarity, in what follows, 'advance' or 'anticipatory care planning' is a broad term covering all aspects of planning for future illness, incapacity and death, including statements of wishes, views and specific decisions. 'Advance directive'[1] is used to denote the specific drawing up of a document to identify, in advance, which types of treatment the individual wishes to refuse and in what circumstances, and is designed to operate only when the individual is in those circumstances, and has lost capacity to communicate a refusal of treatment for themselves.

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[1] Advance directive is the term used in Scotland while other jurisdictions use 'advance decision' or 'living will' to denote the same document.

An End-of-Life Discourse: the Scottish Context

There are clear indications from government and policy indicators that advance care planning is something to be promoted and embedded in health care provision. The Council of Europe set out its Recommendation[2] in 2009, that national governments promote self-determination for capable adults by introducing legislation on continuing powers of attorney and advance directives. In 2013, Key Information Summaries (KIS) were introduced into Scottish GP practice in order to allow for advance care planning to be brought into the scope of primary care provision, and there is evidence of their increased use.[3] However, KIS are intended to be written up by GPs and shared in real time with secondary and emergency care providers. While these are a valuable contribution to advance care planning, they are not entirely within the scope of the present discussion. The Scottish Government's *Strategic Framework* for Action on Palliative and End of Life Care 2016-2021[4] specifically sets out to drive forward 'a new culture of openness about death, dying and bereavement' and to support the development of 'a national conversation which engages with this topic'.[5] The emphasis is placed on, among other things, conversations between individuals and professionals in order to plan care and support, and to ensure that this process accords with individuals' needs and preferences.[6] In tandem with this, there is a recognition of the need for professionals to engage in communication with patients, and document, review, update and share the individual's preferences and any decisions that are taken, in order to ensure that care is person-centred and reflects their needs and wants.[7] While recognising that there are challenges involved in encouraging people to have conversations about topics they would rather not discuss, and acknowledging that the feasibility of such discussions is influenced by a range of factors including information provision, culture and belief systems, and health literacy,[8] the Framework goes on to set out a number of commitments. Of particular note here are Commitments 5 and 6; respectively a recognition that there are, now, opportunities for strategic engagement to (re)frame public discourse on death, dying and loss;

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[2] Council of Europe Recommendation, CM/Rec (2009) 11.

[3] J. Tapsfield *et al.*, 'Many people in Scotland now benefit from anticipatory care before they die: an after death analysis and interviews with general practitioners', *BMJ Supportive and Palliative Care* (published online first: 13 April 2016 doi:10.1136/bmjspcare-2015-001014).

[4] The Scottish Government, *Strategic Framework for Action on Palliative and End-of-Life Care 2016-2021* (2015) (hereafter, '*Strategic Framework*').

[5] Shona Robison MSP, Foreword to *Strategic Framework for Action on Palliative and End-of-Life Care 2016-2021* (2015).

[6] *Strategic Framework*, para. 3.

[7] *Ibid.*, para. 9.

[8] *Ibid.*, para. 14.

and that the government will support greater public and personal discussion of bereavement, death, dying and end-of-life care. It is this notion of the opportunity to (re)frame the public discourse, and the encouragement of discussions on death and dying that are the starting point for this paper. In what follows, I will consider the extent to which governments and policy initiatives are promoting this end-of-life discourse, and consider the ways in which law could aid this process.

In the Scottish content, a major step in framing such a discourse was taken in late 2015 with the publication of the *Strategic Framework*. The accompanying *Supporting Evidence Summary* classifies the present period as 'inspiring times for palliative and end-of-life care in Scotland'.[9] In it, the Scottish Government expresses its adoption of the World Health Organisation's definition of palliative care, focusing on quality of life, prevention and relief of suffering. It further asserts that, as part of the human right to health, palliative care should be provided through person-centred and integrated health services, paying attention to individual's needs and preferences.[10] In realising a vision of palliative care available to all, the *Supporting Evidence Summary* identifies the need for those providing palliative care to, among other things, individualise care to patients' needs and involve people in discussions about it.[11] Three key areas are identified; autonomy, personal preferences, and honesty and openness,[12] with 'autonomy' being described in terms of a sense of control even within limited remaining options, and 'personal preferences' being envisioned as being delivered through supported forward-planning opportunities in which the individual's desires are understood. Good quality communication is therefore key, including better electronic communication to share preferences and wishes with those involved in care.[13] Anticipatory care planning is seen as something which should be an essential part of healthcare, grounded in honest and open conversations which lead to a documented, regularly reviewed and shared record of what matters to the individual patient across a wide range of end-of-life issues, which will make it more likely that the care received will reflect the patient's wishes.[14]

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[9] The Scottish Government, *Strategic Framework for Action on Palliative and End of Life Care 2016-2021; Supporting Evidence Summary* (2015) (hereafter '*Supporting Evidence Summary*'), para. 1.2.

[10] *Supporting Evidence Summary* para. 1.6, citing World Health Organisation, *Palliative Care*, Fact Sheet No. 402 (July 2015) at www.who.int/mediacentre/factsheets/fs402/en/.

[11] *Ibid.*, para. 2.1.

[12] *Ibid.*, para. 3.1.

[13] *Ibid.*, para. 3.2, including the use of Key Information Summaries (KIS) and ensuring a wider reach for that shared information.

[14] *Ibid.*, para. 4.8.

Shortly before the Government's *Strategic Framework* was published, the Health and Sport Committee also published its inquiry into palliative care[15] which had been prompted by the debate during the stage 1 consideration of the Assisted Suicide (Scotland) Bill.[16] During the debate on the legalisation of doctor-assisted suicide, it was clear that there was considerable concern among MSPs[17] that any focus on legislating for assisted suicide would take attention and resources away from palliative end-of-life care. In ultimately rejecting the Bill, the Committee took responsibility for an inquiry into the issue of access to palliative care, current barriers, and the nature of that initial conversation between individuals and those involved in their care. It also undertook to carry out research on international comparisons of the means by which data on palliative care is measured.[18] The Committee highlighted the imperative for having conversations about death, dying and also deteriorating states of health, and while they recognised that people often do not want to talk about it and that it would require a significant cultural shift, much of the evidence they gathered pointed to a perception that such topics of conversation need to become normal.[19] In their evidence to the Committee, Scottish Care highlighted the need for individuals to regain familiarity with the process of death, noting that it is no longer the norm for people to die at home with their family and so it has ceased to be a normal part of family life.[20] The emphasis which the Government has placed on open and honest discussions about death is certainly not aided by a culture in which we are often shielded from the incidence of death.

As regards advance care planning, the Committee stated an aim to set and achieve 'common goals that will ensure the right thing is being done at the right time by the right person(s) with the right outcome'.[21] The idea of setting common goals in this way can be aided by using an advance directive and the Committee noted that, inevitably, this would be more suited to individuals with long term conditions who can plan for the course of that condition.[22] They also noted that as the condition progresses, it becomes appropriate to include end-of-life planning into anticipatory care planning, so that wishes as to place of death, welcome and unwelcome interventions, and attitudes to CPR can be re-

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[15] The Scottish Parliament Health and Sport Committee, 'We Need to Talk About Palliative Care' SP Paper 836, 15th Report, 2015 (Session 4) (2015) (hereafter SP Paper 836).

[16] The Bill was introduced in December 2013 and fell at stage 1 in May 2015.

[17] Members of the Scottish Parliament.

[18] SP Paper 836, para. 4.

[19] *Ibid.*, para. 84.

[20] *Ibid.*, para. 85.

[21] *Ibid.*, para. 129.

[22] *Ibid.*, para. 129.

corded.[23] The Royal College of Nursing's evidence identified anticipatory care planning as crucial to facilitating active choices on the part of the individual while they are still capable.[24] In this regard, it was highlighted by Alzheimer's Scotland that in the case of dementia patients, it is often hard to identify when the individual enters what might be described as the end-of-life phase, particularly when they are dying of dementia itself rather than some other condition.[25] This would seem to further add to the argument that advance care planning should, wherever possible, be done at the earliest feasible stage.

The Committee did not go so far as to suggest that advance care planning can be instigated as some kind of single pro-forma, capable of being utilised by all who might benefit from it in a formulaic style.[26] All such advance planning requires to be tailored and in particular, the type of conversation required will differ (potentially widely) depending on the circumstances of the individual involved. However, it would be my contention (to which I will return later) that, in finding ways to promote healthy and open discussions of death and dying preferences, alongside prompts for professionals about the types of questions to broach with individuals, a draft pro-forma of an advance directive could also be helpful to allow discussions and decisions where the individual has clear views on treatments they wish to refuse.

An End-of-Life Discourse: the English Context

The House of Commons Health Committee also reported on end-of-life care in 2015[27] and equally highlighted the lack of experience of, and familiarity with dying and death among families, compared to previous generations.[28] It also raised an important point if the overall goal here is to improve the incidence of a timely discussion of death, and the usage of advance care planning; that the terminology frequently used in this area lacks clarity and is not well understood. The report notes that terms such as 'end-of-life care', 'palliative care', 'hospice care' and 'supportive care' are not used in a consistent way.[29] This would seem to be a small but important way in which some of the overall objectives could be achieved, in order to present the public with a clear and consistent message about the nature and value of advance care planning.

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[23] *Ibid.*, para. 130.

[24] *Ibid.*, para. 134.

[25] *Ibid.*, para. 169.

[26] *Ibid.*, para. 142.

[27] House of Commons, Health Committee Report, *End of Life Care*, HC805, 15/03/2015.

[28] *Ibid.*, para. 6.

[29] *Ibid.*, para. 9.

This is even more the case if governments are to achieve stated aims such as effecting a cultural shift in attitudes towards death and discussing it openly. The report sets out the five Priorities of Care drawn up by the Leadership Alliance for the Care of Dying People.[30] These are that, once someone is identified as being within a few hours or days of death:

- this is recognised and communicated clearly to the individual, and decisions and actions are taken which are in accordance with their wishes, and are subject to regular review and revision (this last point is particularly important in a document which may last for some time before being used – the more evidence there is of regular review, the easier it is to assert that it represents the current wishes of the individual);
- sensitive communication takes place between professionals and the individual, and those close to them;
- the individual is involved in decisions about their treatment and care, and that those close to them are also involved to the extent that the individual wishes;
- the needs of relatives and those close to the individual are actively explored, respected and met if possible;
- an individual care plan is agreed, coordinated and delivered with compassion. This includes planning around the means of provision of food and drink, symptom control, and psychological, social and spiritual support.

While this is predicated on a diagnosis of imminent death, a number of organisations gave evidence to the Committee highlighting that timing is crucial here.[31] While it is clear that advance care planning, and, within that, advance directives would play a vital part in this process, they have a wider role to play among those who are not yet at that critical point where death is imminent. Thus, subject to regular review and updating, such planning can have a valuable role among those who are diagnosed with a longer-term condition, and potentially also, even more broadly, among the wider population, as a tool to be used in the event of a future catastrophe or the advent of a terminal illness.

In responding to the House of Commons Select Committee's report, and the commissioned *Review of Choice in End of Life Care*,[32] the Government put particular emphasis on the work being done in this area. This relates in partic-

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[30] Leadership Alliance for the Care of Dying People, 'Priorities of Care for the Dying Person' (June 2015), www.nhsiq.nhs.uk/media/2485900/duties_and_responsibilities_of_health_and_care_staff_-_with_prompts_for_practice.pdf.

[31] *Ibid.*, paras 41 and 42, where both the Alzheimer's Society and Age UK note that determining the last phase of life is difficult, especially for those not diagnosed terminal or life-threatening conditions.

[32] The Choice in End of Life Care Programme Board, *What's Important to me. A Review of Choice in End of Life Care* (2015), https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/407244/CHOICE_REVIEW_FINAL_for_web.pdf.

ular to awareness-raising,[33] and educating the professionals involved so they can facilitate the necessary conversations with individuals.[34] The overall message coming from both English and Scottish Governments is that advance care planning and advance directives are useful tools which should be embedded in normal practice and facilitated through timely, open and honest discussions with the individual about current and future care as they reach the end of their lives. Alongside this, a culture shift is also required in which death and dying is accepted as a normal part of human experience and not regarded as taboo.

Relevant Legal Measures

Anticipatory care planning, while it can set common goals and lay out the individual's preferences, cannot have the force of law when it comes to determining *active* treatment, as patients cannot request a certain treatment for a later stage in their decline and expect that the doctor treating them in the future would be legally bound by that advance *request* for treatment. However an advance *refusal* of treatment is quite another matter and such a refusal can be made without the same caveats. In Scotland, there is no specific legislative force behind an advance directive refusing treatment, and instead the position relies on an oblique reference in the Adults with Incapacity (Scotland) Act 2000,[35] and an assumption in professional guidance that doctors would and should take account of previously expressed wishes.[36] Taking account of something is, however, not the same – particularly from the point of view of the individual – as requiring that a valid directive is followed. In England, such an advance refusal carries the force of law in that, so long as certain formalities are followed, an advance directive refusing certain treatment in specified circumstances, must be adhered to regardless of whether it conflicts with the doctor's clinical judgement of the patient's best interests. The Mental Capacity

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[33] *Ibid.*, para. 28.

[34] Department of Health, *Government Response to the House of Commons Health Select Committee Report on End of Life Care (Fifth Report of Session 2014-2015)*, Cm9143 (2015), at paras 15, 16, 17.

[35] Adults with Incapacity (Scotland) Act 2000, s 1(4)(a) 'In determining if an intervention is to be made and, if so, what intervention is to be made, account shall be taken of –
(a) the present and past wishes and feelings of the adult so far as they can be ascertained by any means of communication, whether human or by mechanical aid (whether of an interpretative nature or otherwise) appropriate to the adult...'.

[36] BMA guidance on the Adults with Incapacity (Scotland) Act 2000, which does not specifically mention advance directives, states that 'there is no reason to assume that the courts in Scotland would take a different approach to the English courts. The relevant code of practice states that valid advance refusals of treatment "are potentially binding", and, in the BMA's view, doctors should comply with an unambiguous and informed advance refusal when the refusal specifically addresses the situation that has arisen' BMA Ethics, 'Medical treatment for adults with incapacity', British Medical Association 2009, 9.2.1.

Act 2005 (MCA) sets out the formal requirements for a valid advance directive in England.[37] This allows advance directives refusing treatment to hold a rather different position compared with advance statements of wishes. Given they are legally binding if they meet the validity requirements, English advance directives have more force than advance statements of wishes, and indeed than advance directives made in Scotland. In opting for a statutory format to enshrine the advance directives aspect of advance care planning, the MCA sits alongside a variety of exemplars from other jurisdictions but it still cannot be assumed that, in a particular jurisdiction, legislation on its own provides an answer. There is, for example, evidence that the implementation of the MCA has fallen rather short of its expectations;[38] in contrast to assertions by the Government that public awareness of the existence of advance directives had risen, the Select Committee heard evidence of research showing a very small uptake rate (3%) in the context of findings that 82% of respondents had strong views about their own end-of-life preferences,[39] and that while there were sporadic instances of successful use of advance directives, this was a long way from consistent across the system[40] and as such, individuals who could have benefitted from such advance planning had not done so.

If legislation on its own, such as has been introduced in England, is insufficient (and evidence of current uptake rates would tend to suggest that it is), then what else can be done? Since legislation is always at the mercy of implementation, it seems sensible to look at additional measures which could be taken to help to push forward and entrench the conversation about dying and the utilisation of advance care planning in all its forms. Simply suggesting that the Scottish Government's aims here could be met by following England and numerous other jurisdictions in legislating to give advance directives the full force of law, would not in itself be of great value, although it is contended that it would be a start. A fairly straightforward approach to outlining the legal requirements for a valid advance directive in Scotland could be taken. Looking at

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[37] In brief, that it be made by a competent adult, that is it revocable at any time, that it sets out the circumstances in which it is to apply and the treatment which is being refused in advance, that the individual has done nothing inconsistent with that advance directive since, that there are no reasonable grounds to believe that circumstances have changed in ways which were not anticipated by the individual and which may have changed their view, and that it is in writing and witnessed if refusing life-sustaining treatment.

[38] House of Lords Select Committee, 'Mental Capacity Act 2005: post-legislative scrutiny – Select Committee on the Mental Capacity Act 2005' (February 2014), www.publications.parliament.uk/pa/ld201314/ldselect/ldmentalcap/139/13902.htm.

[39] Written evidence from Compassion in Dying, to the House of Lords Mental Capacity Act 2005 Select Committee, Oral Evidence vol. 1 at p. 470, www.parliament.uk/documents/Mental-Capacity-Act-2005/mental-capacity-act-2005-vol1.pdf.

[40] House of Lords Select Committee, 'Mental Capacity Act 2005: post-legislative scrutiny – Select Committee on the Mental Capacity Act 2005' (February 2014), para. 197.

the MCA, sections 24 to 26 set out the legislative basis for advance directives in England. In doing so, they set out the core requirements for validity in a succinct and unadorned fashion, covering issues such as capacity, age, requirements for writing and witnessing, and clarity. A similar approach could be adopted for Scotland whereby legislation is introduced to set out the requirements for a legally valid advance directive. That legislation need not be overly lengthy but would need to make clear what formalities were required to constitute a valid and binding directive.[41] But the implementation of such a change would be a separate issue and could well fall foul of the barriers that seem to have impeded progress in England.

Shifting cultural dynamics

The Scottish Government's *Strategic Framework* places considerable emphasis on the need for open and honest conversations about death and dying (both individually and nationally), and on the need to normalise the context around death and dying. These are difficult topics to discuss given our modern cultural sensitivity to death and dying, and how these are to become a more normal part of our shared discourse is a challenge. It appears that there are a number of things which are necessary in order to normalise this discourse around dying. These are: that individuals see having such conversations as something to which they are entitled, and not an imposition on others; that they see it as a valuable process of identifying and recording their wishes and decisions with the assurance that, if formulated validly, they will be adhered to; and that the whole process is carried out as early as their situation allows and crucially while they remain competent.

As noted above,[42] there is evidence to suggest that people in general are drawn to the idea of exercising their autonomy and being able to dictate what happens to them after they lose capacity. However, turning this expression of interest into something more concrete, and specifically into higher uptake rates for advance directives, is more of a challenge. But it is a challenge which prompts me to wonder what the law can do to help this process. Law is perhaps more often in the business of responding to cultural change than in helping to drive it (see, for example, the eventual response to society's increasing acceptance of the status of same sex relationships), but it seems to me that part of the solution may lie in convincing individuals that planning in advance for their own future

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[41] In this respect, such legislation could take a stance similar to that of the Requirements of Writing (Scotland) Act 1995, in setting out the *formal* requirements for validity of the document concerned.

[42] See note 40 above.

care and treatment is an overall worthwhile process; and in order to convince them that it is worthwhile, it further seems to me that it would be helpful to provide a means to set out those advance directives for their future care which, if done according to specified requirements for validity, will be guaranteed to be enforceable. One of the problems with the current position in Scotland is the status of any such advance directive and the lack of any firm legislative guarantee of enforceability, which makes it harder to argue for a change in public attitudes whereby conversations and autonomous decisions about dying, taken in advance, are the order of the day. However, formulating a legal approach which is capable of helping to promote a shift in culture is not going to be achieved by bare legislation. In attempting to take the public from a position of reticence and silence about death and dying, to a position where discussions and conversations about this area are commonplace (perhaps both expected, and an expectation) will require more support and guidance, as well as assurance of the legal enforceability of any subsequent document recording those decisions in respect of future care and treatment. This is where there is scope for looking into the approach to advance directives taken in some other jurisdictions, where a pro-forma style is used (or in some cases, mandated).

Statutory forms of advance directive and the question of autonomous expression

One of the difficult issues often raised in relation to advance directives, is the uncomfortable relationship between one of the standard requirements for legal validity (that it is clear and unambiguous), and the nature of the document itself (that it is an expression of a particular individual's wishes about their care and treatment in the future). In most cases, the individual wishing to draw up an advance directive is, in this respect, a lay person trying to formulate descriptions of situations which may arise in the future and, in the light of those situations, the medical treatment they would refuse. In particular, they are trying to formulate such advance directives in a way which will be clearly and unambiguously referable to their condition at that future point in time. It can be argued that lay individuals simply lack the vocabulary and range of experience necessary to formulate such an unambiguous medical instruction. In order to try to alleviate this particular criticism, some jurisdictions have opted for a statutory formula for advance directives; sometimes a form with boxes to tick to itemise what they would or would not want, or with gaps to fill in. Examples vary, and not all are mandatory, but to give a brief selection;

- Manitoba[43] has a one page form as a non-mandatory guide which, in respect of advance treatment directives, provides a blank space for the individual to write out their instructions and the circumstances in which they are to apply, and reminds users that they will only be carried out if they are clear and precise;
- the New Zealand Medical Association has two sample forms, one of which lists conditions and circumstances with no space for input from the individual, while the other takes a much more open approach, providing space for the individual to write in their own wishes in their own words;
- the Department of the Attorney-General and Justice for the Northern Territory of Australia provides an Advance Personal Plan document incorporating a combination of tick boxes and space for the individual to write out their own instructions, as specified by the Advance Personal Planning Act 2013;
- South Australia similarly sets out their provisions on advance directives in legislation (the Advance Care Directives Act 2013) which also provides that it must be made by way of a mandatory form issued by the Minister, although that form allows the individual to specify their instructions in their own words;
- *5 Wishes*,[44] a style valid in the majority of US states, adopts more of a combination approach, using blank spaces for the individual to write out their own additional instructions, but using predetermined language to set out the conditions in which certain types of treatment might be refused, with tick boxes to be filled by the individual;
- and in Alberta, the Personal Directives Act 2000 sets out a non-mandatory standard form which provides a template for individuals to complete, supported by the Office of the Public Guardian who provides information and education to encourage the uptake of these directives.[45] The template itself is fairly short, and provides the option to appoint an agent to make decisions on all matters, or some delineated matters, or to appoint no agent at all but rather give instructions to service providers. The form leaves a blank section for these instructions to be completed in the individual's own words.[46]

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[43] Under the provisions of the Health Care Directives Act 1992 (as amended), although s. 11 notes that the form is available to use but not mandatory.

[44] See www.agingwithdignity.org.

[45] J. Simon *et al.*, 'Evidence of increasing public participation in advance care planning: a comparison of polls in Alberta between 2007 and 2013', *BMJ Supportive and Palliative Care* (published online first: 27 January 2016 doi:10.1136/bmjspcare-2015-000919).

[46] See s. 5 of the pro-forma, available from Alberta Human Services, www.humanservices.alberta.ca/documents/opg-personal-directives-form-opg5521.pdf.

Such a pro-forma can have its benefits (it raises a range of issues for the individual which they may not have covered had they been left to write it purely by themselves and can be drawn up in a way which is technically precise in terms of the language and terms of art used), but there are also detractions. Some are very lengthy which, in the context of a drive to normalise conversations about one's own mortality and increase awareness of, and use of advance care planning tools, could be seen as potentially off-putting to some individuals. However, in encouraging individuals to have what will be admittedly difficult conversations – difficult for both them, their families and health professionals – there is an argument for saying that any legislation should guide and assist, as well as enable and enforce. It is in this context that a pro-forma attached to a legislative instrument has its value; the individual knows that their advance directive will be valid because it follows the prescribed format; that format will have guided them through the 'things to think about'; it will have acted as a prompt to, and rubric for, that open and honest conversation; and it will have acted as a means to facilitate autonomy. However, there is a note of caution to be sounded here, and it relates to the ever-present, underlying principle of autonomy.

At a more conceptual level, the point behind an advance directive is that it allows the individual, while they still have capacity, to take and record decisions in the expectation that they will be followed should the envisaged situations arise. They are thus being utilised as a means of projecting individual autonomy forward into the future, as the individual in question will necessarily be unable to express their decisions when the time comes. If the individual comes to a point in the future where particular treatment is proposed while they have capacity, there is no role for an advance directive as the individual would make and communicate a contemporaneous autonomous decision. This raises a more philosophical question about the scope of an advance directive. Can one written in another's words ever stand as the equivalent of the individual's own autonomous decision?

The advantage of writing an advance directive in one's own words is clear. It is personal and descriptive; it provides a narrative of one's wishes as derived from conversations engaged in. While it may lack the clarity required by law, it enshrines the personal autonomous decisions of the previously competent individual. Leaving aside for the moment the issue of legal validity, it is clear that drafting one's own advance directive is preferable as an expression of autonomy. Should it be used at a later date, it will be turned to as the equivalent of a contemporaneous statement by the individual. Thus, in a very literal sense, it stands as their voice. And in that context, it is a deeply personal document. It therefore remains a point of contention whether advance directive can, at a conceptual level, have a role in upholding autonomy, while couched in predetermined language, tick boxes or gaps to be filled in existing sentences. An expression of autonomy is about personal self-expression, not about ticking the option that 'most' applies to you, or filling in a blank section in the context and rubric of a predetermined form.

A Better Approach?

So, rather than requiring that an advance directive is set out in a prescribed pro-forma (as is the case in some jurisdictions), or leaving the entirety of the drafting of the directive up to the individual (helped, if they so choose, by the guidance and styles available online from numerous groups and charities), perhaps the better option is to have a single pro-forma, endorsed by legislation and available as a non-mandatory guide. Something which can be a point of reference to allow individuals to think about what they need to cover, something to suggest how to express particular decisions in ways which will be clear, but something which is still an intrinsically personal and individual narrative of their wishes and decisions for their own future treatment. Referring to a single, endorsed pro-forma would also allow those professionals involved in implementing and assessing advance directives to become familiar with them, and more conversant and comfortable with implementing them.[47]

The provision for advance directives in Alberta is instructive in this respect, particularly as section 6.1 of the Personal Directives Act 2000 clearly states that regulations may be used to establish a documentary form for such a directive, but that using such a form is not mandatory. Part 2 of the Act sets out formal requirements for validity, covering the expectable issues including when a directive would come into effect and how it could be revoked, and the need for it to be in writing, signed and witnessed. Section 7 goes on to set out, in a permissive way, what might be in the directive, and the Act also covers issues such as assessing whether the individual has regained capacity.[48] Part 4 sets out the requirements on service providers to follow the terms of a valid directive which has come into effect. The associated pro-forma from the Office of the Public Guardian, as referred to in section 6.1, is available online.[49] It can be seen that it allows for a style in which the individual either appoints an agent, or sets out their own instructions in section 2 of the form. These instructions can then be specified, in their own words, in section 5 of the form.

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[47] If such an approach were adopted, professionals would, of course, also come across individual advance directives written up entirely by the person involved, but there would be scope for increased confidence and familiarity with the statutory version in those cases where the individual chose to use it.

[48] Personal Directives Act 2000, s. 10.

[49] https://cfr.forms.gov.ab.ca/form/OPG5521.pdf.

A non-mandatory style guide attached to legislation which enshrines the enforceability of a validly executed advance directive would, in my view, move the Scottish position forward and help to make some inroads into achieving the Scottish Government's objectives in this area. It would do so in two distinct ways.

1. Having legislation setting out requirements for validity for an enforceable advance directive would give an increased sense of the important role that such documents can have, and would give greater confidence to those seeking to use them, giving them a greater sense of assurance that (so long as valid), it would be enforceable and would be followed at the relevant future date. It would give individuals who chose that route a means to express their autonomous decisions about their future treatment, and a degree of comfort in knowing that they had put their decisions on record and that the directive would be followed in the event that they had lost capacity and were in the situation envisaged.
2. A pro-forma which went along with that legislation would allow for the open and honest conversation envisaged in the *Strategic Framework* to be guided (although not dictated or trammelled). A pro-forma could be drafted so as to prompt individuals to consider relevant issues which they might otherwise overlook, but would allow them the option to either adopt the rubric of the pro-forma itself, or adapt it to their own phrasing, or to use it as a prompt to thought and conversations with others as part of the process of devising a document entirely of their own construction.

This latter option, where individuals draft their own, or adapt the statutory pro-forma advance directive, would of course be potentially more vulnerable to a lack of clarity that affected its validity, but allowing for individuals to draft their own document if they so chose would give them the option of making that very personal statement of their decisions for future treatment in a personalised fashion, and would preserve it as a genuine exercise of autonomous decision-making, rather than an exercise in selection of pre-determined phrases. It would allow those inclined to do so to ensure that their own autonomous voice came through the documentation of their decisions, and did so loud and clear. Moreover, as part of its role as an extension of individual autonomy, the advance directive would amount to an exercise in decision-making by the individual and as such, when it is activated at a future date, would take the burden of decision-making away from professionals and family members, and leave them (particularly the latter) with the comfort of knowing that the individual achieved the outcome they desired, sought, and chose for themselves.

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