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## Making Treatment Decisions for the Future: Advance Directives and the Question of Legislative Clarity?

Sarah Christie

*Reader in Law, The Law School, Robert Gordon University, Aberdeen.*

Maggie Anderson\*

*Lecturer in Law, The Law School, Robert Gordon University, Aberdeen.*

### Abstract

*This article sets out to consider the extent to which advance directives can be used as an effective means to entrench personal autonomy, and, in the light of their statutory form in numerous other jurisdictions, consider the various approaches which are currently used abroad to determine whether Scotland, which at present has no legislation entrenching their use, would benefit from such an approach.*

### Introduction

Making our own decisions about the type of medical treatment we are to receive, or perhaps more crucially, not receive is a core aspect of the exercise of personal autonomy. It is now abundantly clear that the concept of autonomy has become the driver behind contemporary medical practice and that the exercise of that autonomy is of fundamental importance. For competent, capable patients, such an exercise is fairly unremarkable. For incompetent, incapable patients, it is an impossibility (unless other measures have already been taken) and the best interests test provides a mechanism for determining their treatment. However, an advance directive can constitute such an 'other measure' and provide a means by which incompetent and incapable patients can enforce their autonomous choice to refuse a particular treatment, notwithstanding their inability to convey their choices at the time of treatment.<sup>1</sup> 'An advance directive

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<sup>1</sup> The terminology here is somewhat varied; advance 'directives', 'decisions', and 'statements' are all used, although 'directives' tend to refer to advance refusals while 'statements' tend to be more general. 'Directives' is used more commonly in Scotland, while 'decisions' is used in England. This article will use the term 'advance directives'.

is, after all, nothing more or less than the embodiment of the patient's autonomy and right of self-determination.<sup>2</sup>

But to exercise autonomy, individuals must be able to show that they are legally competent to make that decision. Decisional competence in the context of end-of-life healthcare, where continuing capacity may be in question, has long proved difficult, whether in relation to immediate or future treatment choices. Individ-

uals with capacity who are about to undergo treatment will be able to refuse that treatment, even if doing so threatens their life. However, not all such decisions are made in the immediate face of treatment. In certain situations, individuals may be able to predict loss of capacity due to the progression of their illness, or may foresee it as a possible eventuality and wish to make decisions about their future, rather than imminent treatment. The role here of an advance directive is one which seems initially attractive. It allows individuals to state that they do not want certain treatment in specified future circumstances. If those circumstances subsequently arise, after they have lost capacity, then the directive is intended to stand as their voice and determine the course of action. This is important because decisions about appropriate treatment still need to be made despite loss of capacity, and one of the eternal questions is who is best placed to decide; is it best in the hands of a third party, paternalistic decision-maker operating on the basis of best interests, or the individual themselves via a prior expression of his or her wishes? The situations where advance directives could prove useful all share the same core characteristics; they revolve around someone losing the capacity to make decisions about their own treatment, either as a result of a major catastrophic incident, or the inevitable progression of a disease, or for some other reason. Doctors need to look beyond the physical individual in order to find someone capable of making that treatment decision. In the face of loss of individual capacity, a traditionally-accepted route is to look to the best interests of the patient.<sup>3</sup> However, if individuals have previously contemplated their loss of capacity, there is another option. If they had, while competent, decided that they did not want certain types of treatment, they may have drawn up an advance directive as a means of communicating that decision into the future, so that it could stand as their voice if they became incapable of communicating their wishes.

The usefulness of a valid advance directive has been illustrated recently in *Re M (Adult Patient) (Minimally Conscious State: Withdrawal of Treatment)*,<sup>4</sup> a

<sup>2</sup> *HE v. A Hospital NHS Trust* [2003] EWHC (Fam) 1017, at para. 37.

<sup>3</sup> See, for example in the context of PVS patients, *Airedale NHS Trust v. Bland* [1993] 1 All ER 821 and *Law Hospital NHS Trust v. Lord Advocate* 1996 SLT 848.

<sup>4</sup> [2012] 1 WLR 1653.

case involving the withdrawal of artificial nutrition and hydration from a minimally conscious woman because it was no longer in her best interests. Although she had made informal statements about being kept alive artificially, there was no formal advance directive in place. The Court of Protection specifically noted that, *had* the patient executed an advance directive refusing artificial nutrition and hydration in the circumstances she was now in, the court would have been required to follow it. However, in the absence of such a directive, the court was unable to authorise its withdrawal from a minimally conscious patient.<sup>5</sup> However, the importance of capacity at the time of making any advance directive is fundamental, as is well illustrated by *A Local Authority v. E*,<sup>6</sup> where the Court of Protection declined to find that E had demonstrated capacity at the point when she had attempted to execute a valid advance directive. This can be contrasted with *X Primary Care Trust v. XB*,<sup>7</sup> where a patient with motor neurone disease was found to have had capacity at the time that his advance directive was made. He had been on ventilation for some time and was latterly only able to communicate by moving his eyes. He had indicated his desire to refuse life-prolonging measures, even if that resulted in his death, once his disease progressed to a certain point, and his wife had sourced an advance directive form from the internet. This had been read to him and he had indicated his agreement to each of the points. Given that the judge was satisfied that XB had capacity and that the directive complied with all the requirements of the relevant legislation, it was upheld as valid. As we will see, the common law has developed to allow for both contemporaneous and advance refusals of treatment at the instance of the patient, and further developments have taken place in some jurisdictions to specify the formalities for a valid advance directive under statute.

While the common law provided for advance refusal of treatment,<sup>8</sup> the introduction of sections 24 to 26 of the Mental Capacity Act 2005 has put advance directives onto a statutory footing in England and Wales. With them has come further evidence of the continuing dominance of personal autonomy in the area of planning for age and future illness. Some of the rationale behind the introduction of a statutory basis for advance directives in England can be found in the remarks made at the bill's second reading.

... under the common law, any one of us could take an advance decision to refuse treatment now. All of us can do that and we believe that it is right to es-

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<sup>5</sup> The patient's minimally conscious state here distinguished the court's approach from that as regards a PVS patient.

<sup>6</sup> [2012] EWHC 1639 (COP).

<sup>7</sup> (2012) 127 B.M.L.R. 122.

<sup>8</sup> See below.

tablish a framework and to set out the criteria for people who want to take such a decision.<sup>9</sup>

Other issues which were felt to justify the introduction of these measures included a need to present medical staff with a greater degree of certainty about a patient's genuine wishes when faced with decisions to withdraw or withhold life-sustaining treatment, and a desire to alleviate the burden on relatives at a distressing and difficult time. The GMC also requires doctors to consider advance care planning with those patients whose gradual loss of capacity is an unavoidable, or at least reasonably foreseeable, aspect of the progression of their disease.<sup>10</sup> Advance care planning is envisaged here as a wider issue than simply encouraging the use of an advance directive, and encompasses issues such as spiritual needs, the place in which patients will be cared for, and the nature of emergency treatment that may become necessary, as well as discussions about individuals' wishes in relation to future treatment.

However, this legislative position is not to be found in Scots law. During consultation on the Adults with Incapacity (Scotland) Act 2000, the Scottish Executive took the view that there was no general support to warrant legislating for advance directives, and that it would be impossible to devise legislation that covered all eventualities.<sup>11</sup> The 2000 Act restricts itself to requiring that the past and present wishes of the incapable adult be taken into account in any treatment decision made by medical staff,<sup>12</sup> without providing any further measures to deal with making advance directives. While 'taking account' of something under the provisions of the 2000 Act may well mean that the course of action taken does accord with the patient's wishes, it does not mandate that a patient's wish to refuse particular types of treatment will be acceded to. That refusal would simply be something taken into account alongside the wishes of relatives, guardians or attorneys. The only area in which advance directives are specifically mentioned in Scottish legislative provisions is in respect of mental health treatment.<sup>13</sup> This article sets out to consider the extent to which advance directives can be used as an effective means to entrench personal autonomy, and, in the

<sup>9</sup> David Lammy, Parliamentary Under-Secretary of State for Constitutional Affairs, Hansard, HC Vol. 425, col. 31 (11 October 2004), with reference to the then Mental Capacity Bill.

<sup>10</sup> General Medical Council, 'Treatment and Care towards the End of Life: Good Practice in Decision-making', 2010, paras 53, 60, 67-74, [www.gmc-uk.org/guidance/ethical\\_guidance/end\\_of\\_life\\_care.asp](http://www.gmc-uk.org/guidance/ethical_guidance/end_of_life_care.asp).

<sup>11</sup> Scottish Executive, *Making the Right Moves: Rights and Protection for Adults with Incapacity* (*Scottish Executive Papers*), (Edinburgh: Stationery Office Books, 1999), 6.14.

<sup>12</sup> Section 1(4) Adults with Incapacity (Scotland) Act 2000.

<sup>13</sup> The Mental Health (Care and Treatment) (Scotland) Act 2003 s. 276 requires the Mental Health Tribunal to have regard to the patient's wishes in respect of their mental health treatment if those wishes are expressed in a valid advance statement.

light of their statutory form in numerous other jurisdictions, assess the various approaches which are currently used abroad. These range from provisions which amount to little more than bare enactments giving statutory authority for the validity of directives (England), to more extensive legislation explicitly dealing with a broad range of issues and sometimes including a pro forma template directive (Queensland). These alternate approaches will be considered in order to determine whether similar legislation would be of benefit to Scotland, or whether the current position, where any such expression is one of the factors taken into account, is a more realistic solution.

### Refusal of treatment at common law

Patient autonomy is perhaps most noticeable when competent individuals exercise their rights to refuse particular treatments there and then, against the recommendations of their medical team. Refusal of treatment cases have a lengthy, albeit not initially auspicious, history. One particular context which has given rise to such issues is the treatment of an adult Jehovah's Witness who refuses to consent to procedures that involve the possibility of a blood transfusion. *Re T (adult) (refusal of treatment)*<sup>14</sup> saw the Court of Appeal uphold a decision to override the patient's refusal of a blood transfusion on the grounds that, while a *competent* adult had the right to refuse treatment on any basis, those whose mental capacity was in doubt should be treated to best ensure the preservation of life. Here, T's condition following an emergency caesarean section had deteriorated further and this, coupled with evidence of misinformation and outside undue influence, allowed the court to determine that her refusal was invalid. The state's compelling interest in the preservation of life was only required to cede in favour of an individual's unequivocal decision to refuse treatment, and any ambiguity had to be construed in favour of life.

This situation gives rise to a conflict between two interests, that of the patient and that of the society in which he lives. The patient's interest consists of his right to self-determination – his right to live his own life how he wishes, even if it will damage his health or lead to his premature death. Society's interest is in upholding the concept that all human life is sacred and that it should be preserved if at all possible. It is well established that in the ultimate the right of the individual is paramount. But this merely shifts the problem where the conflict occurs and calls for a very careful examination of whether, and if so the way in which, the individual is exercising that right. In case of doubt, that doubt

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<sup>14</sup> [1993] Fam 95.

falls to be resolved in favour of the preservation of life for if the individual is to override the public interest, he must do so in clear terms.<sup>15</sup>

However, while denying T the right to refuse treatment given that the circumstances cast doubt on the validity of that decision, Lord Donaldson did set out criteria under which an advance refusal of treatment would be valid; the individual must have been competent and free from external influence when the advance decision was taken, must have anticipated the circumstances they are now in and intended the refusal of treatment to apply to those circumstances.<sup>16</sup> This was set out as an absolute right to choose, with one caveat; that it might not apply in cases where that choice could encompass the death of a viable foetus. Cases such as *Re C (adult: refusal of medical treatment)*<sup>17</sup> further entrench the general position taken in *Re T*, that a competent adult can refuse treatment for any reason, no matter how apparently unusual. The patient was a paranoid schizophrenic who refused a life-saving amputation, but was held to be competent to make such a refusal, despite the fact that many would have disagreed with his decision. The case goes further still in that his refusal was not simply a refusal of consent for the immediate situation and proposed amputation, but for any future interventions as well, and in granting the injunction sought by C, the judge effectively achieved what the Mental Capacity Act has subsequently brought in. In *Re B (adult: refusal of medical treatment)*<sup>18</sup> the right of a competent patient to refuse treatment, even where that refusal will lead to his or her death, was affirmed and this approach has since been further extended to cover the competent pregnant woman who, despite the existence of her foetus, is as entitled to refuse treatment as any other competent adult so long as she has capacity.<sup>19</sup> Although robust statements are made by the court about the primacy of autonomous choice, competence is the barrier on this particular road, and while *St George's Healthcare NHS Trust v. S*<sup>20</sup> establishes her right to refuse treatment, it follows a number of earlier cases where that right had been overridden by the courts on the grounds that the woman lacked capacity, particularly in those cases where the foetus had yet to be delivered. The difficulty faced by the courts in these cases has been in accepting the notion that a competent woman would refuse life-saving treatment in the face of a threat to *both* herself and her foetus. However, the current position for pregnant women is

<sup>15</sup> [1993] Fam 95 at p112, *per* Lord Donaldson.

<sup>16</sup> It is worth noting here that these criteria are exactly those which, when translated into a legislative provision, cause difficulties in terms of ensuring the continuing validity of the directive into the individual's future.

<sup>17</sup> [1994] 1 All ER 819.

<sup>18</sup> [2002] 2 All ER 449.

<sup>19</sup> *St George's Healthcare NHS Trust v. S* [1999] Fam 26.

<sup>20</sup> [1999] Fam 26.

the same as for anyone else. The competent pregnant woman is allowed to refuse treatment, in just the same way as any other competent adult, no matter how bizarre that decision may seem to others. The question, as in all cases, is whether the individual has capacity to make the decision.

### Contemporary v. advance refusal

While it is clear that the competent adult, pregnant or not, can refuse treatment proposed in the immediate or short term for any reason, there remains a separate issue; whether such a refusal can hold for the future, specifically for a point in the future when the individual is incapable of either taking or communicating a decision on treatment. There has been some debate as to whether the concept of an advance directive can be valid in these circumstances, where a previous 'self' seeks to exercise its autonomy to bind a future 'self' with different priorities and interests,<sup>21</sup> but the common law does provide situations where the law has upheld an advance refusal of treatment. In *Re C*, the patient refused both the immediate proposed treatment and any future attempt to amputate the limb in question. The judgment is recognised as the first to uphold the validity of, and indeed use the term, advance directive. In *Re AK (medical treatment: consent)*<sup>22</sup> the patient made an advance refusal of treatment by the only means of communication left to him,<sup>23</sup> to the effect that artificial ventilation should be withdrawn a fortnight after he had lost all means of communication. It was held that, although emergency situations gave doctors the right to treat patients who could not consent, that did not apply if it was already known that the patient did not want such treatment to be provided and had been competent at the time to take that decision. The judgment in *AK* recognised the potential difficulties in ascertaining that the advance wishes were still reflective of the patient's views, but determined that to ignore *AK*'s clear refusal of treatment when the time came would have been unlawful. Using an advance directive to set out a statement of individual choices for future healthcare is a clear move to extend that individual's autonomous choices into a phase of his or her life where it would not otherwise operate, although it does proceed on an assumption that the individual's values and beliefs remain as they were when the directive was made. It comes fraught with difficulties of specificity; ascertaining whether the individual, who can no longer be asked to

<sup>21</sup> On this, see for example A. Maclean, 'Advance Directives, Future Selves and Decision-making', *Medical Law Review* 14(3): 291; S. Holm, 'Autonomy, Authenticity or Best Interest: Everyday Decision-making and Persons with Dementia', *Medicine, Health Care and Philosophy*, 4 (2001): 153.

<sup>22</sup> [2001] 1 FLR 129.

<sup>23</sup> By blinking to indicate 'yes' and 'no'.

clarify issues, actually wanted a particular provision of the directive to apply to the precise situation he or she is now in. However, numerous other jurisdictions have drawn up legislation setting out the parameters of a valid advance directive, and it is to these that we now turn. While it is notable that attempts to legislate in this area are sometimes criticised as misguided, given that legislation cannot possibly cover all the eventualities involved,<sup>24</sup> as long ago as 1995 the Law Commission acknowledged that legislation could not be expected to resolve all the difficult questions inherent here. In doing so, it pointed to the role of codes of practice and model forms in providing guidance.<sup>25</sup> The statutory formulations found elsewhere all focus on the same core issues (clarity, competence, applicability) but take quite different approaches as to how to formulate such a framework. These differences in approach fall into two distinct groups; those where legislation is sparse in terms of detail and the individual's voice is a much stronger force, and those where the directive follows a template in which the individual's voice is (somewhat) lost.

### Existing Statutory Approaches to Advance Directives

A variety of jurisdictions have legislated to provide for the enforceability of valid advance directives and illustrative examples can be found in England, Australia and the United States.<sup>26</sup> These include, respectively, the Mental Capacity Act 2005 (MCA), the Powers of Attorney Act 1998 (PAA), and the relevant provisions of the Missouri Revised Statutes, the Illinois Living Will Act and the Alabama Natural Death Act. Through these measures it can be seen that various approaches are taken to drafting legislation that is designed to cover the issues, with some core elements being reproduced across legislative regimes, whereas other issues are alternately dealt with explicitly or left to implication. Differences are also evident in attitudes towards the drafting of such a document, with some jurisdictions favouring templates while others leave the issue entirely to the individual. While there is obvious merit in allowing the individual's voice to carry through the advance directive (that is, after all, the point), leaving choice of language and terminology to the individual does raise

<sup>24</sup> For example, Scottish Executive, *Making the Right Moves*, 6.14 (note 11).

<sup>25</sup> 'Statutory provisions cannot resolve the problems and questions which may arise in relation to the validity and applicability of advance refusals. The development of a code of practice and model forms which direct patients towards making the terms of any refusal clear will help to address the most likely problems', Law Com No 231 on Mental Incapacity (London: HMSO, 1995) para. 5.22.

<sup>26</sup> Forms of advance directives in use may also include provisions on the appointment of health care proxies to make decisions on behalf of the individual, but these are not the focus of this article.



the inherent difficulty of ensuring clarity and applicability. This is particularly the case, given that a lay person will be setting out their wishes for future treatment decisions, in a document intended to apply to specific clinical circumstances, and to be applied by medical professionals.

### England and Wales

The MCA specifies a minimum age of eighteen coupled with a need to show that the individual was legally competent at the time the directive was made.<sup>27</sup> It defines incapacity very broadly, as an inability to make the decision in question because of a temporary or permanent functional impairment or disturbance of the mind or brain.<sup>28</sup> The explanatory notes to the section list psychiatric illness, learning disability, dementia, brain injury or toxic confusional state as possible causes and classifies this as the 'diagnostic test'. However, while this appears to be a decidedly clinical definition of incapacity, section 3 goes on to set out the circumstances in which the individual will be deemed unable to make a decision; where they lack the ability to understand or retain information relevant to the decision, use or weigh that information as part of the process of making that decision; or communicate that decision using any available means. This fits broadly with definitions of capacity under common law as exemplified by Munby J. in *R (on the application of Burke) v. General Medical Council*,<sup>29</sup> identifying capacity as grounded in the ability to exercise rational thought and to process and weigh relevant information in coming to a decision. It is not necessary that individuals can retain the information long term, and 'information relevant to the decision' is defined to include the reasonably foreseeable consequences of deciding to undergo or reject the treatment, or of making no decision at all. Equally, since the purpose of an advance directive is to allow the individual themselves to dictate treatment decisions in the future, should he or she have lost capacity, any subsequent valid conferral of decision-making authority in respect of those same decisions on another person will render the directive invalid.<sup>30</sup> The subsequent granting of, for example, a lasting power of attorney is clearly inconsistent with the underlying purpose of an advance directive and invalidates it. Conversely, it is worth noting that, since an advance directive is to be viewed as the equivalent of a contemporaneous refusal by a competent person, it invalidates any previously granted power of attorney. Similarly, subsequent inconsistent actions will also affect the validity of the di-

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<sup>27</sup> Mental Capacity Act (MCA) 2005 s24(1).

<sup>28</sup> MCA 2005 s2.

<sup>29</sup> [2005] QB 424 at 440.

<sup>30</sup> MCA 2005 s25(2)(b).

rective,<sup>31</sup> such as where an individual effects a change of faith which imposes, or removes, restrictions on treatments but has not revised the directive to reflect this.<sup>32</sup>

One of the fundamental aspects of an advance directive is that it is designed to apply to a future situation in which the individual is no longer capable of making his or her own contemporaneous decision. Thus, while capacity at the time of making the directive is vital, the incapacity of the individual at the time when the directive is to apply is also a key element in assessing applicability.<sup>33</sup> Further, the patient's advance directive is only applicable if the treatment decision under discussion is specified in the advance directive.<sup>34</sup> A further caveat is introduced to the effect that subsequent changes in circumstances of which the individual was not aware at the time of making the directive and which would have affected the decision if the individual had known of them, also invalidate the directive.<sup>35</sup> The longer ago the directive was written, the more likely it is that circumstances now differ from those envisaged. These would include new treatment options, but also significant changes in the individual's personal<sup>36</sup> or spiritual life. Directives that purport to refuse future administration or continuation of life-sustaining treatment must be supported by clear written, signed and witnessed statements that the directive is to apply even where the consequences of complying with it will be fatal to the individual.<sup>37</sup> The directive must also be specific as to what treatment is to be refused; a general refusal of any and all treatment at some future point in time will not be sufficient, although descriptions of what types of treatment are being refused may be couched in lay language. However, as noted in the Code of Practice,<sup>38</sup> some forms of treatment are excluded from the ambit of advance directives. Thus, basic essential care, which covers measures including provision of food and hydration by mouth, cannot be refused; by contrast, artificially administered hydration and

<sup>31</sup> MCA 2005 s25(2)(c).

<sup>32</sup> For an example of this type of situation which arose prior to 2005, see *HE v. A Hospital NHS Trust* [2003] EWHC (Fam) 1017, where a woman, born into Islam who had then converted to become a Jehovah's Witness, had effected a directive refusing blood products. At the relevant time, she had, however, become engaged to a Muslim, agreed to revert to her former religion and ceased attending services as a Jehovah's Witness. It was held that her decision to abandon her beliefs as a Jehovah's Witness was clear and undeniable and that the directive, which she had not altered, was invalid in the face of her clear and contrary act of reverting to a faith which did not require the refusal of blood products.

<sup>33</sup> MCA 2005 s25(3).

<sup>34</sup> *Ibid.* (4).

<sup>35</sup> *Ibid.*

<sup>36</sup> This would also include a subsequent and unenvisaged pregnancy, on which see later.

<sup>37</sup> MCA 2005 s.25(5) and (6).

<sup>38</sup> Mental Capacity Act 2005 Code of Practice (Department of Constitutional Affairs, 2007), para. 9.28, referring to s.5 of the Act.

nutrition are classified as life-sustaining treatment and can therefore be rejected under a written advance directive.

Where valid, an advance directive in England takes effect as if the individual had made the decision contemporaneously.<sup>39</sup> However, no liability attaches if treatment is carried out or continued after the doctor has taken all reasonable measures to ascertain whether there is a valid, applicable and contrary advance directive and either does not know or is not satisfied of the existence of any such directive.<sup>40</sup> Doctors are not 'satisfied' that a valid and applicable directive exists if they have genuine doubts about its validity and applicability.<sup>41</sup> Equally, there is no liability if treatment is withdrawn or withheld on the basis of a reasonable belief that there is a valid and applicable advance directive in effect which requires such withdrawal or withholding.<sup>42</sup> However, as noted when the Mental Capacity Bill went through its second reading,<sup>43</sup> there is a difference in how this protection is applied. Doctors who decide that there is a valid directive in place and so withdraw or withhold treatment must do so on the basis of a reasonable belief. Doctors who instigate or continue treatment will only incur liability if they know or have satisfied themselves that a directive is in place, but continue nonetheless. It was felt that the greater burden placed on the doctor who withholds or withdraws treatment meant that the preservation of life was more effectively enshrined in the legislation.

Under the MCA, a written advance directive is only necessary where the individual seeks to refuse life-sustaining treatment,<sup>44</sup> and thus any other form of advance refusal of treatment may be constituted in writing or verbally, as can any withdrawal or alteration.<sup>45</sup> However, the Code of Practice recommends that those treating the patient record any verbal advance directive to avoid potential confusion at a later date when it is sought to be relied upon.<sup>46</sup> It may well be that those caring for the patient have a fundamental objection in conscience to honouring the terms of the directive, particularly if the directive envisages the refusal of life sustaining treatment, which would necessarily involve those treating the patient in providing basic and palliative care only, while watching

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<sup>39</sup> MCA 2005, s.26(1).

<sup>40</sup> *Ibid.* (2).

<sup>41</sup> Mental Capacity Act Code of Practice (note 38) para. 9.58.

<sup>42</sup> MCA 2005, s.26(3).

<sup>43</sup> Lammy, Hansard, HC Vol. 425, col. 31 (note 9). See also S. Michalowski, 'Advance refusals of life-sustaining treatment: the relativity of an absolute right', *Modern Law Review* 68, no. 6 (2005): 958 at 960.

<sup>44</sup> MCA 2005 ss25(5) and (6).

<sup>45</sup> MCA 2005 s.24(5), unless the alteration is such as to make the directive applicable to life-sustaining treatment.

<sup>46</sup> Mental Capacity Act Code of Practice (note 38), para. 9.22-9.23.

a medically avoidable death ensue. No right of conscientious objection exists *ex facie* under the MCA but the Code of Practice, which sets out how the Act should be implemented, allows for an exercise of conscience on the part of the treating clinician, so long as the patient is transferred to the care of a colleague.<sup>47</sup> This accords with an interpretation of the right to autonomy, which includes a caveat that it cannot be exercised in such a way as to harm others, and mirrors the position in, for example, abortion cases. Giving those with principled objections to withholding treatment which could otherwise extend the patient's life the right to pass the patient's care to a colleague, rather than be faced with a choice between illegal action and subjectively immoral action, avoids a situation where the patient's autonomous right to determine treatment harms those in charge of providing that treatment.

### The United States

It is, perhaps, not surprising that American jurisdictions can field some of the most comprehensive legislative exemplars in this field, given that the concept of an advance directive has its origins there.<sup>48</sup> Missouri<sup>49</sup> adopts the pro forma approach, providing a template, should individuals wish to use it, which can be added to with further specific (and severable) instructions at the granter's discretion. It is formulated to cover the withdrawal or withholding of death-prolonging measures when individuals are suffering a terminal condition and unable to make contemporaneous decisions, thereby allowing individuals to specify circumstances in which they do not wish their life to be extended further. Treatment designed to be palliative is not encompassed in any such refusal, and neither is the provision of artificial hydration or nutrition, or any deliberate course of action which hastens death. Instead, the refusal envisaged here is an advance refusal of treatment that is purely designed to hold off death which would otherwise occur. The pro forma directive itself is short; a single paragraph, which is to be signed, dated and witnessed, and provides a section to allow for its later revocation by the granter. The legislation goes on to deal with other issues, requiring that those treating the patient do not act contrary to the directive unless they have a 'serious reason ... consistent with the best interests' of the patient.<sup>50</sup> What these 'serious reasons' might be is not specified, and this appears to allow a best interests (paternalistic) determination to overrule the autonomous advance decision of the patient. It further specifies the need for competence on the part of the individual at the time of making the directive,

<sup>47</sup> *Ibid.*, paras 9.61-63.

<sup>48</sup> L. Kutner, 'The Living Will: A Proposal', *Indiana Law Journal* 44 (1969): 539.

<sup>49</sup> Missouri Revised Statutes, ss459.010-055.

<sup>50</sup> S459.025.

and that 'advanced age' *per se* will not be sufficient to dislodge the presumption of competence.<sup>51</sup> Although Missouri adopts the statutory recognition approach taken by England, the scope of a Missouri directive is quite different. Most notably, it only applies when the individual is terminally ill, and only allows for a direction to withhold or withdraw death-prolonging procedures. This makes it considerably more restrictive in approach and, arguably, far less of a means of upholding the broader concept of individual autonomous choice.

The Illinois Living Will Act<sup>52</sup> again refers to the advance refusal of death delaying procedures in the context of terminal conditions. Death delaying procedures are defined as those which will do no more than put off the inevitable moment of death (as opposed to palliative measures), and a non-exhaustive list of procedures is identified, which includes artificial ventilation and intravenous feeding.<sup>53</sup> Artificial nutrition and hydration may not be withdrawn or withheld if that would, in itself, cause death by starvation or dehydration, rather than as a result of the terminal condition. Again, a short pro forma version of the directive is included. This too is fairly restrictive in comparison with the MCA, although in contrast to the Missouri provisions, it does allow patients to state in advance that they wish to have artificial feeding measures withdrawn. The Alabama Natural Death Act<sup>54</sup> applies in cases where the individual is terminally ill or permanently unconscious and covers advance refusal of medical procedures, life-sustaining treatment and artificial nutrition and hydration (where this is set out specifically). It also provides a considerably longer pro forma directive to be signed, dated and witnessed. The pro forma sets out each of the applicable conditions (terminal illness or permanent unconsciousness) separately, and specifically includes a section for other directions to be added by the individual, as well as including a section dealing with the appointment of a proxy decision-maker. These provisions go markedly further than those in Missouri or Illinois, to the extent that they apply beyond situations of terminal illness. However, their scope is only extended to cover permanent unconsciousness, and thus they are still significantly more limited than the MCA. The operation of a directive is also nullified for the duration of a patient's pregnancy.

Alongside legislative pro forma, Aging with Dignity<sup>55</sup> provide a template for an advance directive ('Five Wishes') which can be used in the majority of states. This is much more detailed. It allows for both the appointment of a proxy and advance refusals of treatment, and incorporates elements of explanation of the

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<sup>51</sup> S459.035.

<sup>52</sup> 755 Illinois Compiled Statutes 35/1.

<sup>53</sup> *Ibid.* 35/2(d).

<sup>54</sup> Code of Alabama, s.22-8A-1.

<sup>55</sup> [www.agingwithdignity.org](http://www.agingwithdignity.org).

decisions being made, in lay terms. It details specific types of situations in which the individual may wish to refuse treatment and allows individuals to specify the nature of comfort and personal care they wish to receive, as well as how they wish to be treated and how much they want relatives to be told about their condition. It is, in comparison to even the longer legislative pro formas, an extensive document which deals with the social, psychological and spiritual side of approaching death, as well as the medical. In practical terms, the feasibility of complying with all the specific elements which the individual may have set out is relatively burdensome on hospital staff, but as a means of allowing individuals to express their autonomous choices in advance of their incapacity, it is a thorough and determined attempt to enhance autonomous choice.

### Queensland

While the English legislation sets out a broad framework but leaves the responsibility for content and phrasing to the individual, Queensland presents a quite different approach to providing for advance directives. In terms of statutory provisions, as well as enabling legislation, a non-mandatory pro forma advance directive is provided under section 44(2) of the Powers of Attorney Act 1998.<sup>56</sup> Its scope is wider than that found in other pro formas, in that it applies to both future refusals of treatment and to the giving of prospective consent to future treatment,<sup>57</sup> but as noted on the pro forma itself, while there is an entitlement to refuse treatment, there is no guaranteed entitlement to insist on specific treatment despite having already consented to it. It also takes precedence over any power of attorney. Capacity is defined under schedule 3 of the PAA as encompassing the ability to understand the nature and effect of a decision, freely make that decision and communicate it in some way,<sup>58</sup> and thus requires broadly the same core elements for validity as a common law directive. Statutory advance directives take effect once the adult granter has lost capacity in a relevant respect, but any refusal of life-sustaining treatment can only take effect if either the granter has an incurable, irreversible, terminal condition and death is expected within a year, or is in a persistent vegetative state, or permanently unconscious, or is suffering such a severe illness or injury that he or she is not expected to recover sufficiently to be able to have the life-sustaining treatment withdrawn. This represents a significant limitation compared with the English approach which allows treatment to be refused regardless of the individual's underlying condition. It is also acceptable to withdraw artificial

<sup>56</sup> Directives not following this format remain valid under the common law, so long as capacity and voluntariness are established, following basic principles from English common law.

<sup>57</sup> PAA 1998 s.35(2).

<sup>58</sup> This bears some similarity to the test set out under s.3 of the MCA in England.

nutrition and hydration, where providing such would be contrary to good practice.<sup>59</sup> The Act goes on in later sections to provide for relief from liability where the health care provider did not know about the directive, or where it failed to act in accordance with the directive because it had good reason to believe it was uncertain, inconsistent with good practice or that circumstances had changed in ways which made compliance with the directive inappropriate.<sup>60</sup> This last caveat raises interesting questions; it is phrased in ways resonant with the MCA, except that the MCA would invalidate a directive where circumstances had changed in ways which the granter of the directive had not envisaged (therefore making the change in circumstances relevant where it would have affected the subjective viewpoint of the granter). Here, the PAA envisages the directive becoming invalid where compliance with it had become inappropriate, through a change in circumstances, which specifically includes developments in medical technology. This presupposes that a decision that the directive is no longer to be complied with could be based on the assessment of its continued suitability as made by persons other than the granter. This in turn raises questions about the statutory form of a directive in Queensland and the extent to which it is genuinely a vehicle for continued patient autonomy. The availability of a (fairly lengthy) pro forma is an interesting alternative and potentially addresses at least some of the issues around clarity and ambiguity, if a largely standardised format is employed. If, however, the purpose of an advance directive is to allow the individual to 'speak' through it, then a document in a specified format where the individual has filled in the blanks could detract from its role as a genuine expression of individual choice.

### The United Nations

The United Nations Convention on the Rights of Persons with Disabilities (CRPD) was ratified by the UK Government in 2009. Article 12 asserts equal recognition before the law for persons with disabilities, and recognises their equal right to legal capacity. It further sets out that appropriate measures shall be taken to allow persons with disabilities to access whatever support mechanisms might be necessary to allow them to exercise that legal capacity. In doing so, it puts the focus on individual autonomy with the addition of what might be termed 'assisted autonomy', in place of the more paternalistic 'best interests' approach. As Dinerstein notes: '...supported decision making, which Article 12 embraces, retains the individual as the primary decision maker, while recognising that the individual with a disability may need some assistance

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<sup>59</sup> PAA s.36(2)(b).

<sup>60</sup> PAA 1998 ss102 and 103.

– and perhaps a great deal of it – in making and communicating a decision’.<sup>61</sup> It is clear that what is envisaged for persons with disabilities is access to a range of whatever support is necessary for them, given their specific disability. While that range could encompass all manner of practical issues and the provision of support or assistance by other people, it seems clear to us that a further way of envisaging such support would be to encourage the use of advance directives by those who can envisage disability at a future point. For those persons facing a diagnosis of an illness which will, at a later date, render them disabled and incapable of communicating a decision, an advance directive can be seen as a way of providing support to their future selves by communicating in advance their decisions about treatment. However, the ambit of Article 12 is much more extensive. It applies to all persons with disabilities. In the context of our discussion here, the individual we posit is one who has capacity but foresees at time when that will be lost, and wants to plan in advance for that eventuality. However, the CRPD has much greater significance for those persons who are currently disabled, for whom it establishes a right to exercise capacity that will require a root and branch change in how capacity and autonomy are currently conceptualised. The UK’s initial report on its implementation of the CRPD<sup>62</sup> talks in terms of those measures which have already been set out in the existing legislation. While these measures do indeed provide assistance to those who need supported decision making, it seems to us that what is still lacking is the more explicit and fundamental recognition of the equal right to exercise legal capacity which will require a re-envisioning of how we understand the notion of capacity and autonomous choice. While this, and the allied notion of what we understand about identity when tied to autonomy, is a highly significant issue, it is beyond the scope of our discussions for this article.

However, in respect of the situations under discussion, where individuals who currently have capacity can contemplate a future disability, advance directives do seem to us to have a role in assisting them to make decisions in the future by setting out their wishes in advance. To have a role as a support measure in this way, advance directives need to be placed on a clear footing, and be made easy and accessible to individuals. This again turns us back to the issue of the approach to their formulation. In terms of the various approaches to the statutory formulation of advance directives, the English approach is one of the most flexible, allowing for the individual to refuse, in advance, any proposed treatment so long as the requirements of the MCA are followed. Other approaches limit

<sup>61</sup> R. Dinerstein, ‘Implementing Legal Capacity Under Article 12 of the UN Convention on the Rights of Persons with Disabilities: The Difficult Road from Guardianship to Supported Decision Making’, *Human Rights Brief* 19, no. 2 (2012): 8 at 10.

<sup>62</sup> Available at [www.ohchr.org/EN/HRBodies/CRPD/Pages/SPReports.aspx](http://www.ohchr.org/EN/HRBodies/CRPD/Pages/SPReports.aspx). Accessed 25 July 2013.



the individual's ability to refuse in one or more ways, by limiting the types of condition which the patient must be in (terminal, permanently unconscious, not pregnant) before the directive will take effect, or the types of treatment that can validly be refused. If a more flexible model were to be sought for Scotland, the MCA offers a clear example of such an approach which upholds the individual's autonomous right to choose in all circumstances, so long as the directive is valid. However, the MCA does lack the standardised statutory *pro forma* found in numerous other jurisdictions. While such *pro formas* have their limitations, there is something to be said for a standardised form. It has the benefit of being easily accessible, which may encourage uptake, and of being consistent, which would make it increasingly familiar to clinicians who come across it at the bedside. It also avoids the problems inherent in allowing lay individuals to draw up directions themselves, without understanding the technical language.

### Scotland

There is as yet no specific enabling legislation in Scotland that covers the use of advance directives by individuals who want to direct the future course of their treatment themselves. The Adults with Incapacity (Scotland) Act 2000 sets out guiding principles for any intervention in the life of an incapable adult and states, in section 1(4), that the present and past wishes and feelings of that adult shall be taken into account. These may be ascertained by any method. This allows for a previously drafted advance directive to be taken into account in determining the nature of a medical intervention at a later date, but it requires that such wishes are taken into account alongside the views of relatives, guardians, welfare attorneys and such like, without stating any order of priority and thus does not allow the previously expressed wishes of the individual to necessarily *determine* the course of action. The 2000 Act has an accompanying Code of Practice<sup>63</sup> which classifies an advance statement refusing specified treatment as an advance directive and indicates that such a document is potentially binding. It notes that an advance statement would be a 'strong indication' of the patient's past wishes but should not be taken in isolation, without consideration of other factors including its age, relevancy to the patient's current situation, medical advancements that may have affected the patient's view, and the patient's current wishes (presumably if able to express them). This is reflective of many of the points raised in the MCA, but the Code itself notes that it is not mandatory.<sup>64</sup> Further reference to the concept of an advance

<sup>63</sup> Adults with Incapacity (Scotland) Act 2000 Part 5 Code of Practice, 2nd ed. (Scottish Government, 2008), para. 2.30.

<sup>64</sup> Codes of Practice are authoritative statements in their field, offering guidance on good practice but are not generally legally enforceable. Here, part 2 of the Code (para. 2.1) states that it sets out the relevant statutory rules followed by guidance on good practice and para. 2.30 falls under the latter.

directive can be found in NHS Scotland's policy on non-resuscitation<sup>65</sup> which allows a valid advance refusal of CPR to establish circumstances under which it should not be undertaken. It also contemplates discussion with the patient about the role of a directive if it is anticipated that the patient could go into arrest. Thus, while there is some recognition of the relevance of a patient's prior expressed wishes in Scotland, the law is considerably less formalised than in other jurisdictions. The question, then, is whether this is a better position, and whether, given some of the problematic issues – to which we now turn – Scots law would benefit from a legislative framework.

### Some Problem Areas – The Pregnant Woman and the Intention that the Directive should Apply to Subsequent Circumstances

Directives are only valid if they are applicable to the circumstances which have subsequently arisen. This is evident through both common law and statutory formulations and allows medical staff to treat in accordance with the best interests of the incapax, on the grounds that the patient's prior expressed wishes do not cover the current situation. It is clear that, if the circumstances are genuinely not those which appear in the directive (for example where certain treatments have been refused if the individual is terminally ill, but in fact that individual is brought into hospital unconscious but not terminal), the directive should not apply. However, there are situations which raise issues of greater complexity. An issue of particular difficulty is whether the existence of a foetus at any particular stage of development should invalidate the individual's advance directive. This takes us back to the fraught issue of foetal rights and the extent to which a developing but unborn foetus can impact on the rights of the autonomous woman who carries it. Identifying pregnancy as a change in circumstances which is sufficient to invalidate a directive is a means of ensuring that the duty to preserve life is upheld, but would involve disregarding advance directives refusing life-sustaining treatment made by any woman of childbearing age, should they come to be relied upon at a future date when she is pregnant.

In some jurisdictions, while the legislation does not *ex facie* provide that an advance directive is automatically invalidated by virtue of a subsequent pregnancy, it would be possible for a doctor to regard that subsequent pregnancy as a change in circumstances which the individual had not contemplated and

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<sup>65</sup> NHS Scotland 'Do Not Attempt Cardiopulmonary Resuscitation Integrated Adult Policy', 2010, [www.scotland.gov.uk/Publications/2010/05/24095633/7](http://www.scotland.gov.uk/Publications/2010/05/24095633/7).

which could have made a difference to her advance refusal of treatment, thus giving grounds to disregard the directive and continue or initiate the life-sustaining treatment.<sup>66</sup> Indeed the English Code of Practice specifically recommends that individuals include directions on possible future circumstances, citing the issue of a future pregnancy as an example. However, the position in England does not go so far as to say that a subsequent pregnancy automatically voids an advance directive, and thus, if a woman had contemplated it as a possibility for her future, and specified that her refusal of life-sustaining treatment should apply notwithstanding any future pregnancy, that would amount to a valid directive. The woman in question needs to state that she is rejecting life-sustaining treatment even in circumstances where its removal would put 'life' at risk (specifically defined to cover both her and her foetus' life).<sup>67</sup> In contrast, many US states specify in their advance directive legislation that any directive refusing life-sustaining treatment is not to apply if the individual is pregnant at the relevant later date or, in some states, if that pregnancy has passed the point of viability.<sup>68</sup> The first of these two approaches raises an interesting problem. If the pregnant woman is competent to take her own decisions, reaches a particular stage of pregnancy and decides to abort, then providing that the jurisdiction in question allows abortion at that stage, she has a right to access abortion services, and the foetus' 'right' to life is automatically defeated by her autonomous choice exercised within those legislative limits. However, imagine a woman who had previously drawn up a valid advance directive stating that she no longer wanted life-sustaining treatment if she had been comatose on life support for eight weeks. If at a future date she lapsed into a coma, required life-sustaining measures but was also discovered to be pregnant, the situation would be quite different. The existence of her foetus would, under jurisdictions that disapply directives on evidence of pregnancy, defeat her earlier directive. Thus, while competent, she could choose to undertake an autonomous course of action which would result in the termination of the life of her foetus, but while incompetent, even after having drawn up a directive, those wishes in respect of her own life would be defeated by the existence of the foetus. That foetus would suddenly gain a standing and a level of protection, by virtue of its mother's incompetence, which it would not otherwise have had. While measures that limit access to abortion as pregnancy advances are evidence of the interplay and shifting balance between female autonomy and the state's obligation to

<sup>66</sup> Mental Capacity Act Code of Practice (note 38) para. 9.16.

<sup>67</sup> MCA s.25 Explanatory Notes s.89.

<sup>68</sup> See, for example, Missouri (Revised Statutes Title 31 §459.025) and Alabama (Code §22-8A-4(e)) and where pregnancy invalidates the directive. In Oklahoma (Code §63-3101.8C), the directive is similarly invalid unless the individual has specified that life-sustaining measures should be withdrawn notwithstanding any future pregnancy. Colorado (Revised Statutes §15-18-104(2)) and Illinois (Compiled Statutes Chapter 755, §35/3(c)) both view a pregnancy which has passed the point of viability as invalidating the directive.

protect life, a measure which defeats the operation of her autonomy simply by virtue of the foetus' existence, at a point when it is not afforded legal protection against being aborted, is a curious measure. Of the three options (that pregnancy, or post-viability pregnancy invalidate a directive or that, in contrast, a directive overrides any consideration of the foetus), the middle ground at least has some congruity with the position on the protection of the foetus in the context of abortion.

The MCA does not specifically state that pregnancy overrides any existing directive but does, as noted, allow for an unanticipated chance in circumstances to do so. Thus the English courts faced with a pregnant woman could classify the existence of her foetus as an unanticipated circumstance which would have made her rethink her directive. However, the concomitant Code of Practice for England and Wales specifically recommends that individuals specify circumstances which they can envisage arising, and that they state in the directive whether it is to apply. This implies that they have the freedom to assert that a particular circumstance is not to affect the applicability of the directive. So, for example, the woman here could write into her directive, which refused life-sustaining treatment, that it was to apply notwithstanding any subsequent pregnancy and thus defeat attempts by the courts or her doctors to override her autonomous choice by appealing to her changed circumstances. The woman who did not make provision for such future possibility might lose the autonomous rights she had striven to protect by virtue of her advance directive. Pregnancy is perhaps a unique change in circumstances, as women making advance directives while of childbearing age would be more likely to consider the possibility that, whether at present they do or do not wish to conceive, pregnancy will remain an ongoing possibility until they reach the menopause and thus would be more likely to deal with that possibility in drafting their directive. However, subsequent pregnancy is not the only situation that can give rise to an unanticipated future circumstance.

#### Further Problem Areas – Other Unanticipated Changes in Circumstances

It has been stated consistently that one of the purposes of an advance directive is to extend autonomy beyond the reaches of an individual's capacity. However, the issues which surround the acceptance and application of a directive cast doubt on how firmly this extension of autonomy is entrenched in practice. Patients may only exercise their right of autonomy if they were competent at the time to make the directive, and if the directive remains valid at the point of its subsequent implementation. The more courts are able to use either statutory or common law frameworks to find either of these missing, the easier it is (hollowly) to trumpet the patient's right to autonomy, because in the

circumstances, the duty to preserve life will win in any case. Since the English legislation has yet to be relied on in respect of subsequent changes in circumstances, it remains to be seen how the courts might approach implementing the statutory framework they have been given. Provisions such as section 25(2)(c) of the MCA, which specify that the directive is not valid if the patient has done anything 'clearly inconsistent' with the view that the directive continues to represent their wishes, allow an element of subjective assessment to be brought in, whereby courts could interpret actions as invalidating the directive without evidence of actual revocation by the individual. Section 25(4)(c) allows for the directive to be overridden where 'there are reasonable grounds for believing that circumstances exist which [the patient] did not anticipate at the time of the advance decision and which would have affected his decision had he anticipated them'. The classification of a circumstance as one which would have affected the individual's decisions had he or she known about them is difficult. The explanatory notes which accompany the MCA mention significant changes in available medications and treatments for particular conditions which, since the time the directive was drafted, have fundamentally altered the prognosis for the individual and made continued treatment less of a burden. This could establish that there were reasonable grounds to believe that unanticipated circumstances now existed which would have affected the individual's decisions. However, the nature of 'reasonableness' in this context is unclear. While a doctor or judge may feel that a particular new drug clearly makes living with a particular condition bearable and 'worthwhile', it is exactly that determination made for an individual by others, and the usurpation of personal autonomy, which the concept of an advance directive seeks to avoid. This issue – of whether a directive can or should apply if circumstances have unfurled in ways which the individual did not contemplate – is one which has been raised in the philosophical literature on this subject.

A criticism of advance directives put forward by Dresser is that the content of the directive will necessarily be insufficiently informed (given that it will play out in the future) and that the context in which the incapax is now situated may be very different from that initially envisaged.<sup>69</sup> Autonomous choice exercised contemporaneously by the competent individual requires that the decision be made in the light of all the relevant information, even if the decision once taken is open to being viewed by others as irrational in that context. If directives are to be relied upon as *prior* expressions of autonomous choice, then they too should be informed decisions. However, there is an obvious temporal problem here. The directive would have been made some time previously – anything

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<sup>69</sup> R. Dresser, 'Precommitment: A Misguided Strategy for Securing Death with Dignity', *Texas Law Review* 81 (2003): 1823 at 1839.

from a few days to many years. The shorter the time period between drafting and implementation, the more likely the directive is to be sufficiently informed. However, Dresser argues that, at the date at which the directive is to be implemented, relevant factors may be very different from how they were at the point when it was drafted, and that this diminishes the moral weight of the directive. This would then suggest that other decision-making factors should be brought into play, such as best interests, in order to protect the now vulnerable and incompetent patient. Her argument is that the patient's own prior and well-intentioned decisions may turn out to be harmful to the patient in the future when they come to take effect, such as when a treatment refused at the time of drafting now turns out to have clear benefits for the patient. 'Just as an advance directive may not bind physicians to perform active euthanasia, because this choice is contrary to existing medical conventions, a directive should not bind physicians to decisions that would clearly harm incompetent patients.'<sup>70</sup> In effect, her argument envisages a situation where patients need protection from the terms of their advance directive because they have become their own worst enemies.

Looking at the English formulation in the light of the above criticism, it can be seen that provision is made in section 25(4)(c), whereby one of the statutory reasons for overriding a directive is that 'there are reasonable grounds for believing that circumstances exist which [he] did not anticipate at the time of the advance decision and which would have affected his decision had he anticipated them'.<sup>71</sup> The Explanatory Notes to the Act go on to elucidate this and cite new medications or treatment for a condition which significantly alter the patient's outlook or reduces his or her burden. Thus, under English law, any directive drafted at a time when treatment was unavailable or ineffectual and burdensome in itself, would be invalid if, at the point when it was to be implemented, some new treatment had become available which would dramatically improve the patient's condition. This answers Dresser's concern that patients' own prior decisions could end up depriving them of the best clinical care at a later date, when medicine has moved on. In this respect, the two variants above strike a balance between allowing the patient's autonomous voice to be heard and accepting that, in some circumstances, the passage of time will have rendered that prior decision a less clear indication of what the patient would have wanted had he or she been able to make a contemporaneous decision. Inevitably, this means blurring the picture and generating a situation where, in some cases, best interests will defer to autonomous choice, whereas in others (although perhaps less often) best interests will rule the day because the directive will be invalidated by subsequent developments. This could be seen as a necessary evil

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<sup>70</sup> *Ibid.* 1847.

<sup>71</sup> MCA s.25(4)(c).

in recognition of the fact that the exercise of autonomy is a process by which individuals who are *informed* of their situation makes decisions about the course of their lives. On the other hand, this approach (disapplying the directive if future advances mean it is – in medical opinion – no longer valid) denies the very expression of autonomy that directives are intended to enshrine.

### **What, Then, Can be Said for the Current Scottish Approach?**

As noted at the outset, the legislative regime in Scotland does not provide statutory recognition for advance directives, although there is an assumption that common law acceptance as demonstrated through the English courts would hold sway. Section 1(4) of the Adults with Incapacity (Scotland) Act 2000 states that the past and present wishes of the patient must be taken into account in making any treatment decision. Beyond that, the accompanying Code of Practice states that advance directives are potentially binding and that a doctor should take legal advice before proceeding to treat in the face of a contrary directive.<sup>72</sup> However, none of this goes as far as the advance directive legislation considered above. The question then becomes whether the current Scottish position is sufficient for the needs of both patients and medical staff. Under the provisions of the MCA in England, a patient with a progressive neurological condition, who felt that there were situations where life would not be a blessing, could draw up an advance directive specifying certain future scenarios in which he or she would not want treatment to be continued. If validly executed, such patients would be able, in most cases, to rely on the future implementation of their wishes, were they no longer competent to refuse treatment at the time. In Scotland, those same patients could still draw up advance directives but would have no assurance that these would necessarily be followed. It is perfectly possible to argue that it would be rare for a doctor to continue to treat their patient in the face of a clear expression of the patient's prior contrary wishes. However, the value of advance directives can be identified at two separate points in time. They have value at the point when treatment is being considered, as the means of providing clear and convincing evidence of patients' own wishes and allowing the extension of their autonomous choice beyond their capacity to communicate those choices. But they also have value at the point when they are drawn up, potentially years in advance of their implementation, when they give the patient the reassurance and comfort that comes from knowing that

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<sup>72</sup> Adults with Incapacity (Scotland) Act 2000 Part 5 Code of Practice para. 2.30 (2008).

they have done what is necessary to ensure their wishes are fulfilled, and the sense of control that is achieved by this extension of autonomy.

While advance directives have an intuitive appeal, and certainly appear to satisfy the increasing demands of individual autonomy, significant questions remain about their feasibility as a solution to the problem of deciding treatment in the face of a loss of capacity. There certainly leave a number of core problems in their wake. At a prosaic level, are they capable of being stored safely enough to remain intact for as long as they may be needed? Are they capable of being stored somewhere, or somehow, that will ensure that medical staff have access to them at the relevant time (particularly when that could be in an emergency, many decades in the future)? At a more substantive level, are they ever capable of being drafted sufficiently precisely to meet the legal requirements imposed on them? Given that an advance directive is intended to be projections of the individual's voice, thrown out into his or her own incapacitated future, it may seem sensible to allow that individual to speak for themselves. Yet legal tests that require the future situation and proposed treatment to match that postulated in the directive require a degree of precision, not to say crystal ball gazing, that is hard to achieve. And at the conceptual level, is it ever possible to bind a future version of yourself? If, in the future, you have lost capacity, rational ability, the faculty of memory and experience, are you still sufficiently the same person to allow the earlier directive to be viewed as granted by you, and binding on you? And as a corollary to that, are 'you now' actually well placed to know what is best for 'you in the future'? While 'you now' can – in at least some situations – be said to be best placed to decide what is in your current interests (and indeed this is the crux of the autonomy argument), who is to say that 'you now' know what will be best for 'you in the future'? Given that 'you now' cannot know what situation that 'future you' will be in, or what interests or values 'future you' will have, can 'you now' decide in the present what will be for the best in some indeterminate situation which has yet to arise?

There are, however, broadly two different broad of situation that a doctor presented with an incompetent patient and an advance directive could face. At one end of the spectrum are terminally-ill individuals who are aware of the nature and course of their disease, and have put in place measures to deal with the final phase of their lives and their imminent death. At the other end are individuals who was suddenly struck down but have previously drawn up directives to cover future events that they have envisaged might happen to them. The problem of current and future versions of yourself are much less significant in the former case. While there may be a place for advance directives for those whose death is more imminent and whose prognosis more predictable, they perhaps fail, in the light of the difficulties already outlined, to have a more generic place as a tool through which future care planning can be *absolutely pre-determined* by the individual. As such, it is argued that, while it would be possible



to put directives on a statutory footing in Scotland, it could not then be assumed that all individuals who used that legislation and sought to formalise their views on future treatment would be able to rely on a guarantee of its future applicability. Just as in other jurisdictions, the passage of time and advent of unexpected circumstances will defeat any attempt, under any legal framework, to ensure the future applicability of current wishes. Advance directives cannot hope to cast out far into a speculative future and still guarantee their applicability regardless of the passage of time and the mutability of circumstances. It may well be that, despite valiant attempts to set out legislative frameworks for advance directives, for some patients they will always promise rather more than they are capable of achieving.