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In borderline cases, what are the options and best practice advice when distinguishing a client's wish from a valid Advance Decision to Refuse Treatment and a valid will?

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Advance Decisions: History and Practice and Distinctions

- Creation of a school of thought that people can bind their futures by expressed wishes; even when they lose capacity
- How the MCA treats such wishes
- What recent cases tell us about how such wishes are not sustained
- Further comments about the development of the doctrine (if it is a doctrine) in light of growing focus on autonomy

History

- *Cruzan v Director, Missouri Department of Health*, (SCt 1990), 497 US 261,110 SCt 2841,1990.
- Society's interests and the presumption in favour of intervention
- United States Supreme Court upheld the Missouri Supreme Court's ruling that the State has an interest in preserving life which, without *'clear and convincing evidence*' of the incompetent patient's previously expressed wishes should override any supposed right of the incompetent patient to decide in advance that life-sustaining treatment should be withheld or withdrawn.
- This ruling established a 'default view' of society (in the USA at least) the assumption that citizens would wish their lives to be sustained in any event, even where there is no prospect of that 'life' supporting consciousness and hence constituting the sort of life that can in any meaningful sense be led and hence of any value to the individual whose life it was.

“'Living will' and 'advance directive' are terms whose meanings are often conflated. Whether this is a serious problem is a moot point: where the meanings of each coincide is in the notion of the anticipatory decisions of a competent person being recorded in advance of certain contingencies in the expectation that those decisions will be given weight upon those contingencies”.

“So it is not the autonomy of the unconscious we are protecting but their critical interest in having their autonomous decisions respected, even when they are no longer capable of making any such decisions or of being aware of whether or not they are being respected. How important is it to respect critical interests as opposed to conscious interests, particularly when the conscious critical interests of some are in competition with the bare critical interests of others (as where my conscious critical interest in receiving a life-saving organ transplant is in competition with your advance directive not to have your organs used after your death”? Reviews in Clinical Gerontology1994; 4: 269-275

How are wishes dealt with?

"My central claim is that mental capacity law has been devised with a commitment to achieving patient-centred care; care that honours where possible the patient's own, reflectively endorsed values, whether or not she has decision making capacity. This position is consistent with dominant themes in medical ethics and law, and prevailing national and international discourses. I will demonstrate how, all things equal, if a patient's reflectively endorsed view on her interests is known, legally this should hold equal weight regardless of whether she has capacity or not".

Coggon, J. (2016). Mental capacity law, autonomy, and best interests: An argument for conceptual and practical clarity in the Court of Protection. Medical Law Review, 24(3), 396-414. https://doi.org/10.1093/medlaw/fww034

- Someone’s wishes and feelings are not automatically given precedence over other factors.
- It depends upon the circumstances – with some features having “magnetic importance” in some cases.
- The test of best interests is not solely a test of substituted judgement : i.e. what someone would do if they still had capacity. It is about taking account of the past wishes and the present wishes and feelings and what they now view as important.
- If the decision concerns care and treatment – physical safety is not always the important consideration: the competing factors, such as their attachment to their home, their privacy and sense of security at home, their attitude towards institutional life and the importance to them of their freedom.

Decision making by way of advance decisions

24Advance decisions to refuse treatment: general

(1)“Advance decision” means a decision made by a person (“P”), after he has reached 18 and when he has capacity to do so, that if—

(a)at a later time and in such circumstances as he may specify, a specified treatment is proposed to be carried out or continued by a person providing health care for him, and

(b)at that time he lacks capacity to consent to the carrying out or continuation of the treatment,

the specified treatment is not to be carried out or continued.

(2)For the purposes of subsection (1)(a), a decision may be regarded as specifying a treatment or circumstances even though expressed in layman's terms.

(3)P may withdraw or alter an advance decision at any time when he has capacity to do so.

(4)A withdrawal (including a partial withdrawal) need not be in writing.

(5)An alteration of an advance decision need not be in writing (unless section 25(5) applies in relation to the decision resulting from the alteration).

25Validity and applicability of advance decisions

(1)An advance decision does not affect the liability which a person may incur for carrying out or continuing a treatment in relation to P unless the decision is at the material time—

(a)valid, and

(b)applicable to the treatment.

(2)An advance decision is not valid if P—

(a)has withdrawn the decision at a time when he had capacity to do so,

(b)has, under a lasting power of attorney created after the advance decision was made, conferred authority on the donee (or, if more than one, any of them) to give or refuse consent to the treatment to which the advance decision relates, or

(c)has done anything else clearly inconsistent with the advance decision remaining his fixed decision.

(3)An advance decision is not applicable to the treatment in question if at the material time P has capacity to give or refuse consent to it.

(4)An advance decision is not applicable to the treatment in question if—

(a)that treatment is not the treatment specified in the advance decision,

(b)any circumstances specified in the advance decision are absent, or

(c)there are reasonable grounds for believing that circumstances exist which P did not anticipate at the time of the advance decision and which would have affected his decision had he anticipated them.

(5)An advance decision is not applicable to life-sustaining treatment unless—

(a)the decision is verified by a statement by P to the effect that it is to apply to that treatment even if life is at risk, and

(b)the decision and statement comply with subsection (6).

Formalities

Can be expressed in layman's terms but needs to be sufficiently clear what treatment is being rules out and the circumstances in which it is not be be given.

• It need not be in writing unless it relates to life sustaining treatment. If it relates to life sustaining treatment it must be in writing and include a statement that it is to apply to that treatment even if life is at risk.

• It must be signed by the person, or by someone in their presence at their direction.

• It must be witnessed by someone wo then signs as a witness.

• This document can be withdrawn at any time if someone has capacity.

• The withdrawal of a decision relating to life sustaining treatment need not be in writing.

Where a registered LPA is in place, that must be looked to and consent given to those nominated to make decisions on behalf of the person lacking capacity – known as the donee.

• This can include consenting to or refusing medical treatments and other aspects of care , social life, save for life sustaining treatment (which can only be authorized if the LPA expressly permits this).

• An LPA can be revoked by the court if a donee has contravened their authority or acted contrary to their best interests.

• The existence of an LPA, unless it expressly deals with the treatment, does not prevent an advance decision being applicable and valid.

Checklist to effective advance decisions

Capacity

Ensuring compatibility with an LPA [if AD made before LPA, AD take priority]

Consultation with medical professions: to ensure it is tailored to likely events

Drafting in line with the Code of Practice [*X Primary Care Trust v XB* [2012] EWHC 1390 (Fam), 127 BMLR 122, [2012] WTLR 1621, Theis J gave specific judicial endorsement (at 34) to the guidance and suggestions for best practice at paragraphs 9.10–9.23 of the Code of Practice as to what should be included in an advance decision].

Explanations to clients, signature and storage

Exceptions

An advance decision to refuse treatment is not applicable if:

• the maker still has capacity to give or refuse consent to the treatment in question at the time the treatment is proposed (s 25(3));

• the proposed treatment is not the treatment specified in the advance decision (s 25(4)(a));

• the circumstances are different from those set out in the advance decision (s 25(4)(b)); or

• there are reasonable grounds for believing that circumstances have now arisen (such as the development of new treatments or changes in personal circumstances) which were not anticipated by the person when making the advance decision and which would have affected the advance decision had s/he anticipated them at the time (s 25(4)(c)).

Determining applicability

- *Re PW (Jehovah's Witness: Validity of Advance Decision)* [2021] EWCOP 52
- An 80-year-old woman who was a Jehovah's Witness and was at risk of dying if untreated with a blood transfusion. She had made a valid advance decision in 2001 which included a decision to refuse blood or blood products even if her life was in danger.
- Determined that her actions since that decision was made were inconsistent with the advance decision and came within the provisions of the MCA 2005, s 25(4)(c).

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