Should medical involvement be required in completion of advance care directives?

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Introduction

- Advance care directive (ACD) = a binding directive intended to stand in place of refusal of or consent to medical treatment if the maker loses capacity to make or communicate decisions in future (no substitute decision-maker required)
- "Medical involvement" – deliberately vague

- Principle underpinning common law and legislation on ACDs is respect for individual autonomy and right to self-determination – enables people to express preferences for future treatment in advance of losing capacity

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Some background

- *Medical Treatment Planning and Decisions Act 2016* (Vic) permits making of binding ACDs providing refusal of or consent to treatment, without a current condition.

- ACD must be witnessed by two people, one of whom must be a registered medical practitioner. Both must certify the maker:
  - Had capacity in relation to each statement in document
  - Freely and voluntarily signed in presence of 2 witnesses
  - Appeared to understand the nature and effect of each statement in the ACD

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Some background

- The Bill originally included broader category of ‘authorised witness’, including people authorised to take affidavits, as well as medical practitioners.

- Amended during debate to restrict authorised witnesses to medical practitioners, “as a strong safeguard to ensure that advance care directives will only be made by people who understand the potential consequences”.

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Medical involvement in ACD making in Australian jurisdictions

Jurisdiction	Medical involvement required?	Medical involvement optional and/ or encouraged?	Additional comments
Common law	No - explicit	N/A - no witnessing requirements	*Hunter and New England Area Health Service v A* [2009] NSWSC 761
ACT	No	Optional: any two witnesses	Advance refusal of life-sustaining treatment only
NSW	No	N/A – common law	No legislation
NT	No	Encouraged in prescribed form Health practitioners in list of authorised witnesses	
QLD	Yes – to certify as to capacity	Strongly encouraged in prescribed form	Person's treating clinician cannot witness
SA	No - explicit	Health practitioner in list of authorised witnesses Prescribed form – mentions "may want" legal or medical advice	Person's treating clinician cannot witness ACD not invalid because person not fully informed/didn't receive advice

Medical involvement in ACD making in Australian jurisdictions

Jurisdiction	Medical involvement required?	Medical involvement optional and/or encouraged?	Additional comments
TAS	No	N/A – common law	No legislation
VIC *MT Act 1988* *MTPD Act 2016*	Yes – certify informed Yes – as witness	N/A - required	Broader ACDs from 2018 Parliament rejected requirement for information provision
WA	No	Encouraged in legislation (confusingly)	*Guardianship and Administration Act 1990* (WA) S 110Q(1)(b): ACD not valid unless maker encouraged to seek legal or medical advice; S 110Q(2) - validity not affected by failure to comply with 110Q (1)(b).
National Framework	No – very clear	Mixed – depends on person's circumstances	Recommends checking with HP terms used actually reflect preferences and goals of care, particularly if providing specific medical directions, to ensure "directions are clear, unambiguous and more likely to achieve the outcomes they are seeking."

Why is medical involvement encouraged?

- To enhance autonomy, by promoting informed decision-making
- ACDs that do not reflect the maker's preferences will not enhance their autonomy
- Medical involvement should increase the probability that a person's ACD will reflect their preferences and be applicable

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Why is medical involvement encouraged?

- Evidence ACDs often do not reflect preferences and/or too vague or too specific to apply
- Evidence that discordance can be due to misinformation and misunderstandings
- Several studies show people change their treatment preferences in response to medical information, including about life-sustaining treatments e.g. people more likely to refuse CPR when better informed
- Low health literacy is an obstacle to articulating preferences
- Professional duty of care to support informed decision-making

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Why is medical involvement not required?

To enhance autonomy, by respecting people's decisions:

It is not necessary, for there to be a valid advance care directive, that the person giving it should have been informed of the consequences of deciding, in advance, to refuse specified kinds of medical treatment. Nor does it matter that the person's decision is based on religious, social or moral grounds rather than upon (for example) some balancing of risk and benefit. Indeed, it does not matter if the decision seems to be unsupported by any discernible reason, as long as it was made voluntarily, and in the absence of any vitiating factor such as misrepresentation, by a capable adult.

***Hunter and New England Area Health Service v A* [2009] NSWSC 761**

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Why is medical involvement not required?

… a 'mentally competent patient has an absolute right to refuse to consent to medical treatment for any reason, rational or irrational, or for no reason at all, even where that decision may lead to his or her own death.' If the right to refuse treatment for any or no reason at all is qualified by a requirement to be sufficiently informed, how does that sit with the principle of bodily integrity that underpins the right? (White, Willmott and Howard (2006))

Requirement to receive medical information described as an illegitimate barrier to ACD completion (Willmott (2010))

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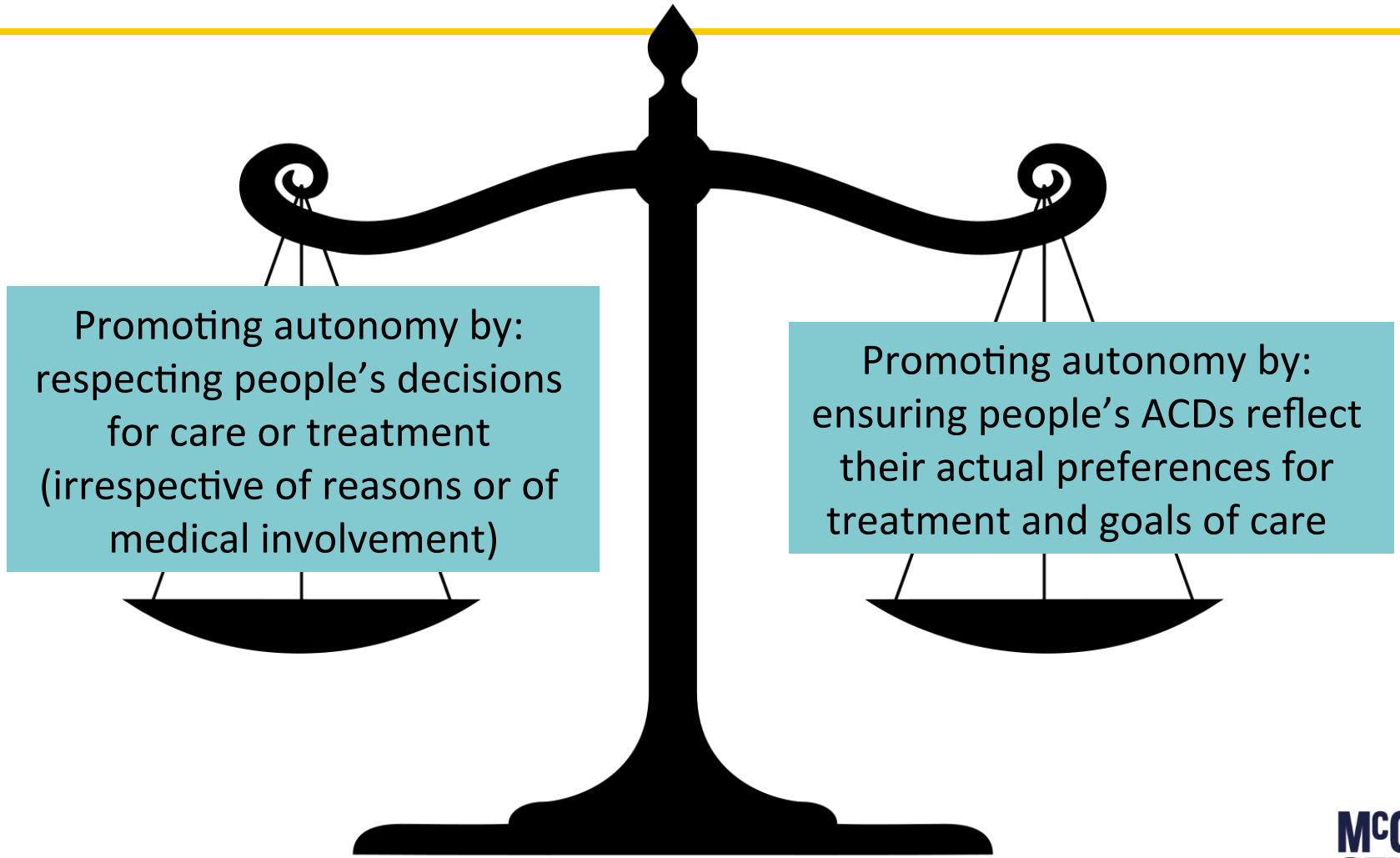
Key challenge



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What requirements ensure ACDs reflect actual preferences?

Requirement for capacity (validity)

- Presumed
- Ability to understand and weigh information doesn't require actually having or using the relevant information

Voluntariness (validity)

- Limited safeguard only insofar as requires that preferences expressed weren't unduly influenced by another

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What requirements ensure ACDs reflect actual preferences?

Witnessing (validity), varies from

- No req't (common law)
- Witnessing signature only (ACT, WA)
- Certifying as to capacity (Qld)
- Certifying as to voluntariness and/or that the maker understands nature and effect of ACD (NT, Vic, SA)
  - whether maker needs to understand medical or legal effect appears to differ across authorities

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What requirements ensure ACDs reflect actual preferences?

Maker intended ACD to apply in the circumstances (applicability)

Maker may not have intended ACD to apply if:
Change in circumstances so that the maker would not have intended it to apply: medical or other circumstances
Decision based on incorrect information or assumptions
Uncertainty/ambiguity as to meaning of ACD
No decision has been made (in respect of circumstances)

Ref: Willmott, White and Howard (2006) *MULR*

What requirements ensure ACDs reflect actual preferences?

How can a doctor ascertain whether the maker intended the ACD to apply to the circumstances that have arisen?

- Presumption unless reason to suspect otherwise
- If it is obvious from the ACD – clearly written and specific OR too vague or uncertain to apply
- If family or treating clinicians are sure the maker would/would not have intended it to apply

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What requirements ensure ACDs reflect actual preferences?

Maker may not have intended ACD to apply if:	Likely to benefit from medical involvement at time of ACD making?
Change in circumstances so that person would not have intended it to apply: medical or other circumstances	Yes – medical circumstances ? – change in personal circumstances
Decision based on incorrect information or assumptions	Yes
Uncertainty/ambiguity as to ACD meaning	Yes
No decision has been made (in respect of circumstances)	?

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Are there relevant differences between consent and refusal?

- History of ACDs lies in refusal of life-sustaining treatments
- Recent legislative developments incorporate consent also, while recognising treatment can't be demanded.
- Parameters for refusing treatment are the same, whether doing so contemporaneously or in advance – there is no requirement to be medically informed.

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Are there relevant differences between consent and refusal?

Medical practitioners are required to provide information as part of contemporaneous medical decision-making:

- Valid consent: "informed in broad terms of the nature of the procedure", to protect bodily integrity from unwanted interference/assault (autonomy)
- Duty of disclosure: advised of "material risks", so that people can determine for themselves the extent they are willing to accept potential risks/negligence (autonomy).

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Are there relevant differences between consent and refusal?

- 'Informed consent' is not possible in ACD making, but should the underlying principles of informed decision-making and the requirements of valid consent be abandoned also?
- People can waive the right to information, but to what extent?
- Need to understand in broad terms the nature of the procedure for valid consent.
- Waiving the right to information is generally not encouraged (particularly at the public policy level), and generally needs to occur within a doctor-patient relationship.

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Relevant differences between contemporaneous and advance decision-making?

- Increasing emphasis on informed decision-making
- Consent requirements are relaxed for advance decision-making – no requirement for person consenting to treatment to be informed even in broad terms about the nature of the procedure.
- Yet, a person making a contemporaneous medical decision will generally (not always) already be in a more informed position than a person making a decision in advance, particularly in advance of having a medical condition

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Discussion

Two arguments for not requiring an informed refusal:

1 – the principle of autonomy requires that a person cannot be treated against their will regardless of the reasons for their decision; and

2 – there should be consistency in the law relating to contemporaneous refusal and advance refusal.

May yield different conclusions for advance consent

1 – the principle of autonomy underpins informed decision-making requirements so that people understand the nature and effect of a procedure before consent is obtained.

2 – if we aim for consistency in law/legal principles then requirements for advance consent should match requirements for contemporaneous consent.

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Discussion

If we don't accept requirement for medical involvement:

- Accept ACD makers provide valid if not informed consent
- Who obtains and is protected by the consent?
- Specificity of particular acts consented to
- Accept non-valid consent for advance decisions

If we do accept requirement for medical involvement:

- Require medical involvement for consent **and** refusal
- Have different requirements for refusal vs consent
- Do not permit legally effective consent via ACDs – permit preferences or requests but SDM required

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Does the Victorian legislation strike the right balance?

- Witnessing role but with very specific instructions
- Supported by professional obligations and duty of care
- Provides opportunity but not requirement for information - retains ability for people to demonstrate understanding and refuse further information
- Lay and professional witness have same responsibilities
- Unreasonable barrier?
  - Witnessing provisions in all jurisdictions (not common law)
  - More onerous to see a doctor than a lawyer or other authorised witness? See Rolnick, Ash and Halpern (2017) *NEJM*

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