Response to Question on Notice – Adjunct Clinical Professor William

Excerpt from transcript:

The Hon. TREVOR KHAN: Sure. Professor, you are probably presuming where my question is going and your assumption may be wrong. So let me just work it through a little bit. You have come across advance care directives. That is correct, is it not?
Adjunct Clinical Professor WILLIAM: Correct.
The Hon. TREVOR KHAN: And you know that an advance care directive can be a very simple document that only needs to be executed by the patient—that is correct, isn't it?
Adjunct Clinical Professor WILLIAM: Correct.
The Hon. TREVOR KHAN: And indeed they are established under common law. In New South Wales there is no legislative framework around them—you know that?
Adjunct Clinical Professor WILLIAM: Yes.
The Hon. TREVOR KHAN: And do you know that at common law, when dealing with an advance care directive, there is a presumption of capacity? Did you know that?
Adjunct Clinical Professor WILLIAM: Yes.
The Hon. TREVOR KHAN: And there is no requirement for a patient, prior to executing an advance care directive, for instance, to have consulted their doctor with regards to the treatment options that are available. Did you know that?
Adjunct Clinical Professor WILLIAM: Yes.
The Hon. TREVOR KHAN: And did you know also that there is no requirement for an advance care directive that a patient has received advice with regards to palliative care? Did you know that?
Adjunct Clinical Professor WILLIAM: Yes.
The Hon. TREVOR KHAN: And there is no framework in any way with regards to advance care directives to, for instance, penalise a relative who may have convinced a patient to execute an advance care directive. Did you know that?
Adjunct Clinical Professor WILLIAM: Yes.
The Hon. TREVOR KHAN: And did you know that an advance care directive can extend to such things as not only DNRs but, for instance, in the case of a loss of capacity, to the patient not being hydrated or fed in any way? Did you know that?
Adjunct Clinical Professor WILLIAM: Well, I think there are a couple of issues to consider here. Much like a birthing plan, when someone who is going to deliver will have wishes about what they would like, that needs to be taken into consideration. But when that person comes into hospital in a certain clinical situation, the doctrine of necessity might mean that we would have to act in a certain way which would be against the wishes of that person because of the risk to the baby. In a similar circumstance, I have seen people with advance care directives that have been very well put together and very clear, but the doctor has not considered them and acted in the interest of the doctrine of necessity to treat that person because of the information they had with them.
The Hon. TREVOR KHAN: Putting aside the doctrine of necessity, do you understand that to act contrary to an advance care directive—for instance, with regards to issues of feeding and hydration—would be to commit an assault upon the patient?
Adjunct Clinical Professor WILLIAM: Well, I have never seen any advance care directives that have had that detail in them, because often they are more vague—
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Adjunct Clinical Professor WILLIAM: I would say that with any advanced care directive, whenever it was made, the approach of shared decision-making would occur because we do not know what that person has said in the interim and we also do not know when necessarily the advance care directive was made and whether it was an inappropriate time and needed to be reviewed as other circumstances have come about. The shared decision-making process that Professor Kissane discussed previously is something that exists, where we talk about what the trajectory of the illness is and how the wishes of the patient are married with what the clinical management will be going forward.
The Hon. TREVOR KHAN: I will just end by saying this: Professor, can I invite you to look at such cases as *Hunter and New England Area Health Service v A*, a 2009 decision dealing with a schizophrenic patient who

sought to refuse care. The Supreme Court there made pretty clear what the law is in regards to this matter, and I suggest it is not consistent with your description.

Response – Adjunct Clinical Professor William

I have reviewed the summary of this case as detailed at this website:

https://www.caselaw.nsw.gov.au/decision/549ffbac3004262463c78daf[1]

The "Summary of principles" from the case is listed here:

- There does not appear to be a great body of authority in Australia dealing with the relevant principles. (The decision of Ambrose J in Re Bridges [2001] 1 Qd R 574 focused on relevant Queensland legislation, and on its application on the facts of that case.) Accordingly, to assist those faced with emergency care decisions, I summarise my understanding of the relevant principles (whilst acknowledging that what I say will not apply in every conceivable circumstance):

    1. except in the case of an emergency where it is not practicable to obtain consent (see at (5) below), it is at common law a battery to administer medical treatment to a person without the person's consent. There may be a qualification if the treatment is necessary to save the life of a viable unborn child.
    2. Consent may be express or, in some cases, implied; and whether a person consents to medical treatment is a question of fact in each case.
    3. Consent to medical treatment may be given:
        - by the person concerned, if that person is a capable adult;
        - by the person's guardian (under an instrument of appointment of enduring guardian, if in effect; or by a guardian appointed by the Guardianship Tribunal or a court);
        - by the spouse of the person, if the relationship between the person and the spouse is close and continuing and the spouse is not under guardianship; by a person who has the care of the person; or
        - by a close friend or relative of the person.
    4. At common law, next of kin cannot give consent on behalf of the person. However, if they fall into one or other of the categories just listed (and of course they would fall into at least the last) they may do so under the Guardianship Act .
    5. Emergency medical treatment that is reasonably necessary in the particular case may be administered to a person without the person's consent if the person's condition is such that it is not possible to obtain his or her consent, and it is not practicable to obtain the consent of someone else authorised to give it, and if the person has not signified that he or she does not wish the treatment, or treatment of that kind, to be carried out.
    6. A person may make an "advance care directive": a statement that the person does not wish to receive medical treatment, or medical treatment of specified kinds. If an advance care directive is made by a capable adult, and is clear and unambiguous, and extends to the situation at hand, it must be respected. It would be a battery to administer medical treatment to the person of a kind prohibited by the advance care directive. Again, there may be a qualification if the treatment is necessary to save the life of a viable unborn child.

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[1] https://www.caselaw.nsw.gov.au/decision/549ffbac3004262463c78daf

7. There is a presumption that an adult is capable of deciding whether to consent to or to refuse medical treatment. However, the presumption is rebuttable. In considering the question of capacity, it is necessary to take into account both the importance of the decision and the ability of the individual to receive, retain and process information given to him or her that bears on the decision.
8. If there is genuine and reasonable doubt as to the validity of an advance care directive, or as to whether it applies in the situation at hand, a hospital or medical practitioner should apply promptly to the court for its aid. The hospital or medical practitioner is justified in acting in accordance with the court's determination as to the validity and operation of the advance care directive.
9. Where there is genuine and reasonable doubt as to the validity or operation of an advance care directive, and the hospital or medical practitioner applies promptly to the court for relief, the hospital or practitioner is justified, by the emergency principle, in administering the treatment in question until the court gives its decision.
10. 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.
11. What appears to be a valid consent given by a capable adult may be ineffective if it does not represent the independent exercise of persons volition: if, by some means, the person's will has been overborne or the decision is the result of undue influence, or of some other vitiating circumstance

It is difficult to state the specific question being asked, but I will attempt to summarise the question from the transcript:

Advance Care Directives (ACDs):

- Can be a very simple document that only needs to be executed by the patient.
- Are established under common law.
- Do not have a legislative framework around them in NSW.
- Possess a presumption of capacity under common law.
- Do not have a requirement for a patient, prior to executing an ACD, to have consulted their doctor with regards to the treatment options that are available.
- Do not have a requirement that a patient receives advice with regard to palliative care.
- Do not have a framework with regard to an ACD, to penalise a relative who may have convinced a patient to execute an ACD.
- Can extend beyond DNR orders, to the patient not being hydrated or fed in any way.
- That are contravened in any way, would be considered an assault upon the patient.

The above would imply that ACDs need to be respected without question, and involve an assumption of capacity and appropriate information, without medical consultation. There is no framework to consider and penalise someone for coercion in the formation of ACDs.

Points for consideration

- Firstly, the case cited for review states the following (see https://www.caselaw.nsw.gov.au/decision/549ffbac3004262463c78daf[2]):

  What this case does and does not involve
  This case is concerned, at the level of principle, with the right of a capable adult to refuse medical treatment; and, at the particular level, with the question of whether the advance care directive prepared by Mr A was a valid exercise of that right. It is not concerned with any such notion as "the right to die". That is so even if (as it appears is the case) the likely consequence of giving effect to Mr A's wishes, as expressed in the advance care directive, is that he will die.

- Secondly, for clarity, the case involved Mr A who did not have schizophrenia as far as I can ascertain (as described in this document https://law.anu.edu.au/sites/all/files/users/u9705219/jlm_lawrep-withdrawing_treatment_brightwater.pdf[3]):

  The patient in Hunter and New England Area Health Service v A [2009] NSWSC 761 (Mr A) was a disabled adult male Jehovah's Witness who, on 1 July 2009, was admitted to the emergency department of a hospital run by the Hunter and New England Area Health Service (HNEAHS). He was suffering from septic shock and respiratory failure and showing a limited level of consciousness.

- Thirdly, I am not a legal expert in NSW legislation. However, if I am correct in my interpretation of the case under review, there are some concerns to raise from a medical perspective. If ACDs do not require medical or legal consultation in their formation, then there is a risk of avoidable harm both in their formation and in their expression. Given the right information, support and guidance people can change their decisions after due consideration. Is the suggestion being made that healthcare professionals accept every ACD on face value? In my career, I have seen many examples of futile treatment being provided to people who consented to "please their family" or under the impression of "false hope". I have also seen cases of ACDs being over-ruled by clinicians on the basis of the "emergency principle". So how will this be monitored and how will accountability be maintained?

- We have moved from "paternalistic decision-making" in healthcare, to one of "shared decision-making". The doctor-patient relationship is vital in this discussion but needs to be as impartial as possible. Other relationships can bias the decision-making process, e.g., family, friends, and society.

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[2] https://www.caselaw.nsw.gov.au/decision/549ffbac3004262463c78daf

[3] https://law.anu.edu.au/sites/all/files/users/u9705219/jlm_lawrep-withdrawing_treatment_brightwater.pdf

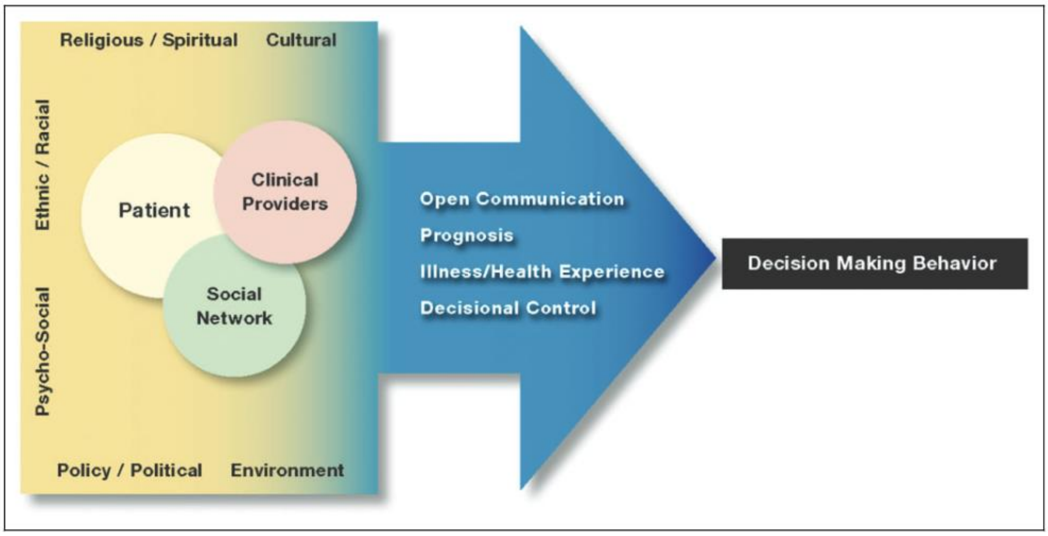

Figure 1. Decision-making process at the end-of-life.

Our decisions are influenced by so many factors and rarely occur in a vacuum (see diagram above).[4] It is important that we ensure people understand the relevant information and the subsequent decisions that emanate from their choice of action – whether that is consent to treatment, or the refusal of treatment. It should be noted that informed consent should include, but often does not, the option of not having the intervention in question.

- Finally, healthcare professionals and public health have an important educational role in society. Many people have misperceptions about palliative care and hence make decisions based on misinformation. Health literacy in our population needs to be addressed. How do we support people who do not speak English? Should they have a translator helping with their ACD? How should we best support people who do not know how to navigate the healthcare system in a particular State? What may be legal, may not always be practical or consistent with best medical practice. In this case, permitting an ACD to be upheld without understanding the reasoning behind it, or trying to correct any misinformation or misperceptions, seems contrary to best medical care. Advance Care Planning (ACP) has its problems and has been of questionable benefit, as described in a recent article[5]:

  During the last 25 years, studies have evaluated ACP with various methods and across large groups of patients. Despite the intrinsic logic of ACP, the evidence suggests it does not have the desired effect. Many clinicians may be disappointed that promoting conversations with patients well in advance of needed medical decisions has not improved subsequent care as hoped. New research focused on training clinicians and preparing patients and families to engage in high-quality discussions when actual (not hypothetical) medical decisions must be made is needed to achieve the outcomes that ACP has not. The clinical and research communities should learn from the evidence that does not support prior hypotheses and proceed with different approaches to improve care for seriously ill patients.

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[4] Romo RD, Wallhagen MI, Smith AK. Viewing Hospice Decision Making as a Process. Am J Hosp Palliat Care. 2016;33: 503–510

[5] Morrison RS, Meier DE, Arnold RM. What's Wrong With Advance Care Planning? JAMA. 2021;326: 1575–1576

The lack of a framework or appropriate legislation to mitigate against avoidable harm is a matter for the legal system to correct. It should not be an argument to perpetuate the problems into further legislation involving end-of-life care.