Advance care planning for pregnant patients

Does pregnancy change a person's medical values and preferences?

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The concept of autonomy, which prioritises bodily integrity and free will, is widely recognised and upheld in health care.[1] One way autonomy is operationalised is by respecting the choice of adults with decision-making capacity to consent to, or refuse, medical treatment. This includes respecting advanced consent in the form of advance care planning (ACP).

ACP allows individuals to specify their values and preferences for medical treatment in advance so they can be relied on in the event they lose decision-making capacity. ACP may be undertaken at any stage of adult life, and early engagement is encouraged, particularly for individuals with ongoing illnesses. However, ACP is typically reserved for end-of-life diagnoses when an individual has an impending terminal illness and is at imminent risk of losing decision-making capacity.

In this article, we draw on relevant ethical, legal and medical frameworks and use clinical vignettes to highlight the importance of early engagement in ACP, and present arguments for its use in the context of pregnancy.

The position of Australian law

Despite a degree of jurisdictional variation, every Australian state and territory, whether in common law or legislation, recognises the right of an adult with decision-making capacity to document their medical values and preferences in an advance care directive (ACD) and appoint a substitute decision maker to help guide treatment decisions in the event they lose decision-making capacity.[2] The position in Australian law is that pregnant patients, like any other adults, will generally be presumed to have decision-making capacity unless there is evidence to the contrary, and accordingly will have their ACD upheld, insofar as permitted by law.

This position contrasts with the approach of some United States jurisdictions where the contents of a pregnant patient's ACD may be overlooked because of laws that prioritise the preservation of the fetus over patient autonomy. A recent review revealed that 31 US states restricted the choices of pregnant patients to withhold or withdraw life-sustaining therapies, 26 of which invalidate an ACD during pregnancy.[3] Three states mandate doctors to test female patients of childbearing age for pregnancy before withholding life-sustaining treatments, and 12 states require life-sustaining therapies to continue until the delivery of the fetus.[3]

While this level of restriction does not exist in Australian law, Australian jurisdictions do put some restrictions on medical decisions regarding termination of pregnancy. Most jurisdictions will treat termination of pregnancy as a special medical procedure, resulting in ACD preferences not being treated in the same way that other preferences may be. Some jurisdictions expressly preclude substitute decision makers from consenting to a termination of pregnancy on the patient's behalf and require tribunal authorisation for the procedure to be lawfully performed. Health practitioners are also bound by jurisdictional termination of pregnancy legislation.

The importance of ACP during pregnancy

A patient's medical decision making may be affected by the presence and gestation of their pregnancy, particularly in situations where a person has a chronic medical condition or a past medical condition that may be impacted by the pregnancy. Decisions about continuing a pregnancy or pursuing medical treatments, including termination of pregnancy, involve profound individual value systems and are usually made between a patient, their loved ones and health practitioners. In the event a patient loses decision-making capacity during pregnancy, having access to previously expressed preferences relevant to the pregnancy are useful for guiding medical decisions. ACP should be considered as part of pre-conception counselling for patients with complex medical conditions, as part of the multidisciplinary care recommended by the Royal Australian and New Zealand College of Obstetricians and Gynaecologists.[4]

The importance of ACP in the context of pregnancy was highlighted by a 2021 qualitative study,[5] which identified an important role for ACP during pregnancy but noted several challenges for implementation.[5] Although the legal framework in Australia is not necessarily a barrier to facilitating ACP during pregnancy, such a practice is far from routine. Our hypothetical clinical vignettes (Box 1), and the discussion that follows, highlight difficulties that arise when pregnant patients lose decision-making capacity and explore how ACP may have mitigated some of these challenges. Although these vignettes were developed by the authors, they represent scenarios that are possible in an Australian context.

Unpacking the clinical vignettes: ethical and medical challenges

Although the Australian legal framework is relatively permissive, the clinical vignettes raise several ethical and medical challenges, some of which could be mitigated by context-specific ACP. Context-specific ACP may not always be possible, but if an individual has an illness with a predictable disease trajectory, the treating clinician should have open conversations with the person about what to expect throughout the course of their illness. This will enable the person to document specific treatment preferences relevant to the different stages of their disease. When challenging cases arise in practice, clinicians should seek advice

1 Hypothetical clinical vignettes

Vignette 1

A 35-year-old woman with a known inborn error of immunity has an advance care directive specifying her wishes not to have children. The patient becomes encephalopathic following an infection at 15 weeks' gestation. The woman was without a partner and had planned for a termination of pregnancy, but this was not documented in the medical record. She becomes unwell in the interim and requires admission to intensive care, intubation and sedation. The neurological prognosis is unknown, and the woman's family expresses the desire to continue the pregnancy.

Vignette 2

A 31-year-old woman living in a remote Australian community with end-stage renal failure has an advance care directive specifying her wishes not to be maintained on artificial ventilation or extracorporeal life support. She develops severe SARS-CoV-2 infection at 19 weeks' gestation after a late diagnosis of pregnancy. She was awaiting specialist advice regarding the health implications of pregnancy continuation, which was delayed due to the pandemic. Before admission, the patient had not updated her advance care directive and is now in cardiorespiratory failure, which necessitates immediate intubation, ventilation and possible extracorporeal membrane oxygenation.

Vignette 3

A 38-year-old woman experiences a catastrophic stroke in the setting of unexpected recurrent astrocytoma, resulting in no possibility of neurological recovery. She is found to be 16 weeks' pregnant with a live fetus. This is an unplanned pregnancy. She has expressed a desire to be an organ donor. During her tumour diagnosis she had an advance care directive which has been withdrawn after initial treatment. Maintenance of pregnancy would require a further 16–20 weeks in the intensive care unit and may impact the ability to donate organs. The donation of organs following or during pregnancy has been reported[6] and is possible for patients with diffuse astrocytoma.[7]

from their health service's legal and clinical ethics team, particularly when specified preferences (and the context in which they apply) are unclear.

Clinical vignette 1

This case highlights the importance of clarifying a person's pregnancy wishes in their ACD. With an unknown neurological prognosis, it is understandable that the family, owing to the prospect of losing the patient, may hold on to the hope of a child. This would be an extremely challenging situation.

The reasons behind this person's planned termination of pregnancy are of relevance. They may relate to their own health concerns, risk of pregnancy itself or desire not to have a child. Ethically, unless additional preferences were divulged by the patient to their family, invoking substituted judgement principles, the preservation of the patient's autonomy should be prioritised by the treating team.

From a medical perspective, continuing the pregnancy during a prolonged intensive care unit admission may affect treatment decisions and the person's physical condition as the pregnancy continues. In an alternative scenario pertaining to a wanted pregnancy, consideration of how treatment may impact fetal viability would play a large role.

Clinical vignette 2

This case highlights the difficulties in enacting a person's pre-specified ACD wishes about artificial ventilation in the context of a periviable pregnancy. In this case, there is a conflict between the person's clear preferences not to be maintained on life support and their unclear preference to continue the pregnancy. It raises the ethical challenges of defining medical futility and justifying withdrawal of care based on grounds of patient-dependent qualitative futility.[8] Box 2 contains a summary of the reviews relating to outcomes for life support measures in pregnancy.

Pregnancy is a known risk factor for poor outcomes with COVID-19[12] and concurrent end-stage renal failure, and respiratory failure results in a high likelihood of stillbirth or extreme prematurity, creating a significant burden in caring for the patient and the child.

Patients with chronic conditions may incorrectly assume they cannot become pregnant, and the diagnosis may be delayed. In all females of reproductive age with chronic medical conditions,

2 Summary of evidence on outcomes for pregnant patients maintained on life-sustaining therapies

Article	Summary	Maternal outcomes	Fetal outcomes
Esmaeilzadeh (2010)[9]	• Literature review identifying 30 cases over 28 years of continuation of life support measures for the purpose of fetal benefit after maternal neurological death/brain death	• Not applicable	• 12 viable infants born alive, 1 neonatal death • Mean gestational age at time of neurological death, 22 weeks • Mean gestational age at delivery, 29.5 weeks
Moore (2016)[10]	• Literature review of 332 publications containing 45 patients treated with extracorporeal life support or extracorporeal membrane oxygenation • Median duration of life support, 12.2 days (range, 1–57 days)	• 78% survival rate	• 65% survival rate
Naoum (2020)[11]	• Systematic review of outcomes for extracorporeal membrane oxygenation during pregnancy • 221 publications containing 358 cases	• 75% maternal survival at 30 days • 13% severe maternal haemorrhage requiring surgical intervention • 5% brain death	• 65% fetal survival • 49% preterm delivery • 28% neonatal intensive care unit admission

family planning remains essential to avoiding difficult situations. Support networks including primary care teams play an important role in supporting pregnant people in remote areas. Even with an ACD, clinicians must consider clinical practice standards relating to futility of treatment. Upon diagnosis of pregnancy, the person's ACD should have been reviewed to consider all possible situations that may have arisen.

Clinical vignette 3

This case is made difficult by the absence of a current ACD. Clinicians should investigate if the patient expressed recent preferences relating to termination of pregnancy (eg, to a substitute decision maker). Without this information, it is difficult for the patient's care team to decide on any course — terminating the pregnancy to facilitate organ donation, or continuing pregnancy knowing the patient's wishes for organ donation may not be honoured and chances of a live birth are small but medically achievable.[9]

Recommendations and conclusions

In focusing on ACP and pregnancy, this article highlights the benefits of ACP beyond the end-of-life context and the importance of reviewing a patient's values and preferences as their circumstances change.

For ACP to become part of mainstream practice, health practitioners must effectively educate colleagues and patients, and take practical steps to implement ACP systems.[13] Clinicians should familiarise themselves with the applicable forms, laws and processes in their jurisdiction (Box 3). Document management systems should be in place that enable access to a patient's most up-to-date ACD and details of their substitute decision maker.

Health practitioners should look for opportunities to engage in the ACP process with pregnant patients, particularly those diagnosed with chronic conditions. Where possible, the contents of the patient's

3 Relevant current legislation and resources for clinicians, by jurisdiction

Jurisdiction	Current legislation and case law	Resources
Australian Capital Territory	*Medical Treatment (Health Directions) Act 2006* *Powers of Attorney Act 2006* *Guardianship and Management of Property Act 1991*	https://www.health.act.gov.au/services/advance-care-planning
New South Wales	*Guardianship Act 1987* *Hunter and New England Area Health Service v A* [2009] NSWSC 761	https://www.health.nsw.gov.au/patients/acp/Pages/default.aspx
Northern Territory	*Advance Personal Planning Act 2013* *Guardianship of Adults Act 2016*	https://nt.gov.au/law/rights/advance-personal-plan
Queensland	*Powers of Attorney Act 1998* *Guardianship and Administration Act 2000*	https://www.qld.gov.au/health/support/end-of-life/advance-care-planning
South Australia	*Consent to Medical Treatment and Palliative Care Act 1995* *Advance Care Directives Act 2013* *Guardianship and Administration Act 1993*	https://www.sahealth.sa.gov.au/wps/wcm/connect/public+content/sa+health+internet/conditions/end+of+life+care/advance+care+directive
Tasmania	*Guardianship and Administration Act 1995*	https://www.health.tas.gov.au/health-topics/palliative-care/about-palliative-care/planning-and-decisions-about-end-life#what-is-an-advance-care-directive-acd
Victoria	*Medical Treatment Planning and Decisions Act 2016* *Guardianship and Administration Act 2019*	https://www2.health.vic.gov.au/hospitals-and-health-services/patient-care/end-of-life-care/advance-care-planning/medical-treatment-planning-and-decisions-act
Western Australia	*Guardianship and Administration Act 1990*	https://www.healthywa.wa.gov.au/Articles/A_E/Advance-care-planning
National resources		National framework for advance care planning documents are available at https://www.health.gov.au/resources/publications/national-framework-for-advance-care-planning-documents For information about advance care planning including education for health practitioners and a free national support service, visit Advance Care Planning Australia's website at https://www.advancecareplanning.org.au/ For a comprehensive review of the law, see Haining C, Nolte L. Australian advance care planning laws: can we improve consistency? Austin Health, Advance Care Planning Australia, 2021, revised 2022 (available on request by emailing acpa@austin.org.au) For further guidance (including online modules) on advance care planning law including capacity, advance care directives and treatment decisions, visit Queensland University of Technology's End of Life Law Australia website: https://end-of-life.qut.edu.au/

ACD should be revisited regularly during pregnancy to reflect any change in preferences or clinical context.

Clinicians should also capitalise on opportunities to discuss patients' reproductive preferences and engage in ACP before pregnancy. ACP could form part of pre-conception counselling for patients with chronic or significant past medical conditions that may worsen in pregnancy, and a Medicare Benefits Schedule billing item could be considered. For females of childbearing age creating an ACD for the first time, the possibility of pregnancy and family planning options should be considered.

ACP in pregnant patients warrants further attention from the profession. To become part of routine practice, active efforts from medical providers to engage in early and targeted ACP relevant to pregnancy are imperative.

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