Common principles

https://end-of-life.qut.edu.au/
“[e]very human being of adult years and sound mind has a right to determine what shall be done with his own body”

Schloendorff v Society of New York Hospital (1914) 211 NY 125, Cardozo J
Principle

Where a person is able to make and express their own decisions, their wishes must be respected ...

- including a refusal of life-sustaining interventions
- “a medical practitioner confronted with a clear choice made by a competent adult on the basis of social, religious or moral values must respect that choice, even though the practitioner does not share the values underpinning it”
"To my doctors, nurses and staff and all the people caring for me. I am writing this letter to address a very difficult and upsetting topic which I have thought about for many months now. ... let me be absolutely clear, it is my wish that the life sustaining mechanical ventilation which has kept me alive for the last nineteen years be ceased soon at an agreed time and place. Please give me the control over the care that I receive that every other patient is afforded, and I know is my right."

Re JS [2014] NSWSC 302
"I hereby direct [facility] that immediately upon the witnessing of my signature on the within document:

That I **not be provided with any nutrition or hydration** by mouth or medical administration except for such incidental hydration as may be indicated in conjunction with oral hygiene or the use of mouth swabs to palliate pain and discomfort; 

That I **not be administered** insulin or any other medication except for medication to palliate pain and discomfort."

*H Ltd v J* (2010) 107 SASR 352
The law gives people the right to plan in advance for future incapacity...

- *(further in)* advance directives
- substitute decision-making
- supported decision-making

**Advance care planning in your state or territory**
Find forms and information about advance care planning requirements, relevant to your state or territory.

https://www.advancecareplanning.org.au
• “public policy’s choice for championing patient autonomy in the face of incapacity”
  C Sabatino. The evolution of health care advance planning law and policy. *Milbank Quarterly* 2010;88(2):211

• low uptake
  White et al. Prevalence and predictors of advance directives in Australia. *Internal Medicine* 2014;44(10):975
  Rainsford et al. Personal advance care planning uptake amongst Australian and New Zealand palliative care medical and nursing professionals. *Progress in Pall Care* 2016;24:153

• variable quality and uncertain validity
Delegalizing Advance Directives — Facilitating Advance Care Planning
Joshua A. Rolnick, M.D., J.D., David A. Asch, M.D., M.B.A., and Scott D. Halpern, M.D., Ph.D.

When Luis Kutner, a human rights lawyer, first proposed the idea of the “living will” in 1969, he conceptualized it as a document establishing a trust, with the patient as the beneficiary and physicians as trustees. Kutner expected that such a document would be signed by two witnesses, notarized, and carried in the patient’s pocket at all times. In 1976, California became the first state to create a living-will statute; today, 47 states have similar laws. States have also codified the ability to choose a surrogate decision maker — a right modeled after a legal construct, the power of attorney. The advance directive has now come to denote a legal document designating a health care decision maker, a living will, or both.

Although many legal documents don’t require formal witnessing, notarization, or specific templates, most states’ advance-directive statutes require witnesses or a notary, and some stipulate use of a statutory form. Perhaps "the legal model diverts important health care planning from doctors’ offices to lawyers’ offices”

Lawyers and advance care and end-of-life planning: Enhancing collaboration between legal and health professions
Nola M Ries* J Law & Med 2016;23:887

In Australia and internationally, advance care planning (ACP) is emphasised as an important means by which individuals can express their wishes for health care during future periods of incapacity. ACP has mainly been promoted in health care settings and very little is said about the role of lawyers, despite the fact that some people are more likely to discuss their health care wishes with a lawyer than with a doctor. This article addresses this significant gap and
Improving professional practices

A Medical–Legal Partnership as a Component of a Palliative Care Model

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Abstract

Introduction: A medical–legal partnership (MLP) is a model that addresses unmet social and material needs for patients. The MLP and quantifies the benefits of the program for both patients and providers.

Methods: The legal services program, an MLP, reviewed legal needs for 270 residents of a long-term care institution reported on the revenue reimbursed.

Results: The Legal Services Program received 270 referrals from multiple legal issues. Seventeen beneficiaries had cases that resulted in savings of $25,346 for current and past health care costs described in-depth.

Conclusion: This MLP demonstrates the ability to be effective in addressing the needs of patients with cancer and is an integral part of the care model.

Substitute decision making ... 
...should be a last resort

United Nations Convention on the Rights of People with Disabilities
  - right of people with disability to dignity, autonomy, equal recognition before the law
  - access to supports to enable decision-making
Authority means the law says the person can do things like

- get information you need to make a decision
  For example, your medical information

- talk to people and organisations about you and decisions you need to make

- tell people and organisations the decisions you have made

- go to meetings with you

- help you to say what you want when you are sick.
Principle

- decision-making should respect the **will and preferences** of the person
  - values-based directives
  - statutory principles to identify and guide substitute decision-makers

- but no right to compel “extraordinary, excessively burdensome, intrusive or futile medical treatment, sustenance and support” *Messiha v South East Health* [2004] NSWSC 1061
Gap between principle and practice

"not simply channels or psychic mediums for applying [person’s] values and preferences” to medical issues (p 30)
Wendler’s question: At a more fundamental level, what if the end of a human life tends to be characterized by a combination of uncertainty over what is in the person's medical interests and difficulty identifying which course of treatment is consistent with the individual's preferences and values? What should we do then? Might reality force us away from a strongly patient-centered approach? And, if so, what should we prioritize instead?