

Advance Care Directive Case Study



Alistair's story

Alistair has Coronary Heart Disease (CHD) and Parkinson's disease. After experiencing a Cerebral Vascular Accident last year, Alistair's cognition and functional ability has significantly deteriorated. Upon routine review, Alistair's GP Elizabeth believes his Parkinson's disease is entering its later stages.

Until now Alistair and his wife Mary have lived independently while receiving occasional help from their daughter, Helen. Due to worsening arthritis, Mary can no longer care for him, and they reluctantly decide that Alistair should move into Hilltop Grove, a residential aged care home.

By the time Alistair transitions to Hilltop Grove his Parkinson's disease has deteriorated significantly and he no longer has capacity to make medical treatment decisions. Mary provides the Nurse Manager with Alistair's Advance Care Directive. It was made when Alistair had capacity, and refuses life-sustaining treatment, as well as antibiotics.

Two months later, Alistair contracts severe Community Acquired Pneumonia and Elizabeth attends Hilltop Grove to review his condition. She observes that his vital signs are unstable and that he is deteriorating due to the severity of the infection. Hilltop Grove's Manager contacts Mary and Helen to advise them of Alistair's condition.

Elizabeth reviews Alistair's Advance Care Directive and, in accordance with his refusal of life-sustaining treatment, does not call an ambulance or administer antibiotics. She instructs the Hilltop Grove nursing staff to focus Alistair's care on ensuring his comfort, and charts medications to adequately manage his symptoms.

Helen arrives at Hilltop Grove alone as Mary is unwell. She becomes distressed when she speaks to a nurse attending to Alistair and learns that no treatment other than medication for pain and symptom relief has been provided. She is unaware of Alistair's Directive and believes that Elizabeth should be providing medical interventions to save his life.

Points for reflection

1. Was Elizabeth's decision not to provide antibiotics lawful?
2. Are there any circumstances in which Elizabeth would be justified in not following Alistair's Advance Care Directive?
3. If you were Elizabeth, how would you approach your discussion with Helen about Alistair's care? Is there anything Elizabeth could have done differently?

1. Was Elizabeth's decision not to provide antibiotics lawful?

Generally, a valid Advance Care Directive must be followed by a health professional, even if it refuses life-sustaining treatment that is needed for the person to live.

In States and Territories which have **Statutory Advance Care Directives** governed by legislation (all jurisdictions except New South Wales), Alistair's Advance Care Directive will be valid if it is:

- **in writing** (usually using an approved form outlined in State and Territory legislation). In the Australian Capital Territory and Tasmania, it can also be made verbally or in another way,
- **signed by Alistair** (who must have made the Directive voluntarily when he had decision-making capacity),
- **witnessed**, and
- **applicable to the medical situation.**

The Directive must also comply with any other legislative requirements e.g. receiving information or medical advice before completing it.

In States and Territories which have **common law Advance Care Directives (all States and Territories except Queensland)**, Alistair's Directive will be valid, regardless of whether it is verbal or in writing, so long as it was **made voluntarily, when Alistair had capacity.**

In **Queensland**, an Advance Health Directive which refuses life-sustaining treatment will only apply if certain conditions are met.

Learn more about Queensland's law on Advance Health Directives at *End of Life Law in Australia*. (<https://end-of-life.qut.edu.au/advance-directives/state-and-territory-laws/queensland#547671>)

Here, there is no reason to suggest that Alistair's Directive is not valid. It applies to Alistair's medical situation as it refuses life-sustaining treatment and antibiotics. Elizabeth acted lawfully by following Alistair's Directive and treatment refusal. If Elizabeth had provided Alistair antibiotics, she may be liable under criminal or civil law for committing an assault.

2. Are there any circumstances in which Elizabeth would be justified in not following Alistair's Advance Care Directive?

There are **limited circumstances where an Advance Care Directive does not need to be followed**. These differ in each State and Territory. Some common examples are:

- Where a Directive is too uncertain or ambiguous to guide medical decision-making.
- Where the person's circumstances have changed to such an extent since the Directive was made that it should not be followed.
- Where a Directive requests treatment that the health professional believes is non-beneficial, futile or not in the person's best interests.

In **Queensland**, a health professional does not have to follow a direction in an Advance Health Directive that is uncertain or inconsistent with good medical practice.

As none of these circumstances exist in Alistair's situation, there is no reason why Elizabeth should not follow Alistair's Advance Care Directive.

The law on following Advance Care Directives varies across Australia. Learn about the law in each **State and Territory** at *End of Life Law in Australia*. (<https://end-of-life.qut.edu.au/advance-directives/state-and-territory-laws>)

3. If you were Elizabeth, how would you approach your discussion with Helen about Alistair's care? Is there anything Elizabeth could have done differently?

Elizabeth should communicate openly with Helen about Alistair's Advance Care Directive and treatment preferences. This could involve discussing:

- The purpose of an Advance Care Directive e.g. to record a person's decisions, preferences or values around their medical treatment and care where they lack decision-making capacity, and that it enables Alistair's treatment choices to be respected.
- That a person can refuse life-sustaining treatment in their Advance Care Directive even if following that request will result in their death.
- That a Directive is a legally binding document that health professionals are obliged to follow.

It would also be helpful for Elizabeth to listen to Helen's concerns and answer any questions about Alistair's condition and future management.

Better practice in this scenario may have been for Elizabeth or her colleagues to have met with Helen immediately on her arrival to discuss Alistair's prognosis and the implications of his Advance Care Directive. This approach may have enabled early, proactive management of the situation and reduced Helen's distress.

For further tips on managing end of life conversations with the people you care for and/or their families, refer to:

- the End of Life Law Toolkit's: *Managing Disputes about Medical Treatment Decision-Making* resources (<https://www.eldac.com.au/tabid/5281/Default.aspx>)
- *End of Life Essentials education modules* (<https://www.endoflifeessentials.com.au/tabid/5195/Default.aspx>)
- *CareSearch Patients' and Families' Experience of End-of-Life Care* (<https://www.caresearch.com.au/caresearch/tabid/740/Default.aspx>)

Final legal observations

Alistair had a valid Advance Care Directive that was made voluntarily when he had the capacity to do so. It refused life-sustaining treatment and antibiotics, and was relevant to the medical situation. Elizabeth therefore acted lawfully in following the Directive and complying with Alistair's refusal of treatment.