ELDAC

End of Life Directions for Aged Care

Substitute Decision-Making

Case Study

Vivian's story

Vivian is an 80-year-old resident of the Sapphire Peaks Residential Aged Care home. She is generally well. While boarding the shuttle bus to do her weekly shopping, Vivian missed her footing and fell backwards, hitting her head on the pavement. She rapidly became unresponsive and was rushed to the closest Emergency Department.

Vivian is unconscious and does not have capacity to make decisions about medical treatment. The medical team discuss Vivian's treatment options with her children Amy (aged 47) and James (aged 45), their father Ed (Vivian's ex-husband who she divorced 15 years ago, and who is visiting with Amy from interstate), and Vivian's sister Rachel, who has a close relationship with Vivian. Amy and James are also close to their mother and visit her often.

The neurosurgical specialist team advise that due to her severe head injury, Vivian requires urgent surgery to relieve intercranial pressure caused by the bleeding around her brain. The surgery is needed for Vivian to survive, but it is an invasive procedure, and given her age and the extent of the trauma there is a risk that she may not survive the anaesthesia or operation.

Vivian does not have an Advance Care Directive, or a guardian or attorney, so a substitute decision-maker's consent is needed to proceed with the surgery. Amy recalls a recent conversation with her mother, following a friend's death, where she told Amy that she would not want to have any major operations or medical treatment at this stage of her life, and would not want to be kept alive if she were dying. Ed remembers Vivian having similar conversations with him when they were married. Amy and James want to respect their mother's wishes and although devastated, they decide not to consent to the operation. Rachel is horrified and cannot bear the thought of Vivian dying if there is a chance she might survive. She begs Amy and James to reconsider.

Points for reflection

1. Who is Vivian's legally recognised substitute decision-maker?
2. What happens if there is a disagreement among Vivian's family members about her treatment?
3. Can Vivian's substitute decision-maker/s refuse consent to the operation?
4. What factors should Vivian's substitute decision-maker/s consider when making the decision?
5. Does the clinical team have to follow the decision?

1. Who is Vivian's legally recognised substitute decision-maker?

As Vivian does not have an Advance Care Directive, or appointed guardian or attorney, the laws in all States and Territories set out a hierarchy of 'default' substitute decision-makers (known as a person responsible, Statutory Health Attorney, medical treatment decision-maker or health attorney, depending on the State or Territory). The appropriate decision-maker is usually someone who has a close and continuing relationship with the person e.g. the person's spouse or another family member.

As Vivian is divorced from Ed, he is no longer her spouse and cannot be her decision-maker. Applying the law in each State and Territory, Vivian's decision-makers are as follows:

- In **Queensland, South Australia, Tasmania, the Australian Capital Territory and New South Wales** Vivian's relatives who have a close and continuing relationship with her can make the decision. Therefore, **Amy, James and Rachel** can be her decision-makers. In the **Australian Capital Territory**, the health professional may ask the decision-maker they believe is best able to represent the person's views to give consent.

> Learn more about the law in the **Australian Capital Territory** at *End of Life Law in Australia*. (https://end-of-life.qut.edu.au/treatment-decisions/adults/state-and-territory-laws/australian-capital-territory)

- In **Victoria**, Vivian's adult children who have a close and continuing relationship with her (Amy and James) are higher on the list of decision-makers than an adult sibling (Rachel). Where there are two or more adult children, the eldest can make the decision, in this case, **Amy**.
- In **Western Australia**, Vivian's nearest relative who maintains a close relationship with her is her decision-maker. In the order of priority among relatives, a person's children (Amy and James) are higher in the list than a sibling (Rachel). Therefore, **Amy and James** can be Vivian's decision-makers.
- In the **Northern Territory** default decision-makers do not exist. Consent would need to be provided by the **Northern Territory Civil and Administrative Tribunal**.

2. What happens if there is a disagreement among Vivian's family members about her treatment?

When disputes arise, it is rare for the guardianship and other legal systems to become involved, and for cases to be decided by courts or tribunals. Most conflicts are managed within the treating hospital or health service using internal dispute resolution policies or procedures. These seek to facilitate open communication and achieve consensus among decision-makers through processes such as clinical reviews, obtaining an independent second medical opinion, family or case conferences, and mediation. Legal advice may also be sought from the health services' legal team.

In some States and Territories, guardianship and medical treatment legislation sets out how disagreements can be resolved. This may involve referring the disagreement for dispute resolution (e.g. through the Public Advocate or Public Guardian in some jurisdictions), and, as a last resort, applying to tribunals or courts to make the decision.

> This area of law is different in each **State and Territory**. Learn more at ***End of Life Law in Australia***. (https://end-of-life.qut.edu.au/treatment-decisions/adults/state-and-territory-laws)

In this case, Rachel disagrees with Amy and James and wants Vivian to have the surgery. In practice the hospital would most likely hold a family meeting to attempt to reach consensus among them.

> Learn more about how to manage medical treatment decision-making disputes in the **End of Life Law Toolkit's *Managing Disputes about Medical Treatment Decision-Making* resources**. (https://www.eldac.com.au/tabid/5281/Default.aspx)

3. Can Vivian's substitute decision-maker/s refuse consent to the operation?

A substitute decision-maker can make most medical treatment decisions for a person who has lost capacity, including decisions about whether life-sustaining treatment should be provided, withheld or withdrawn.

The law on what decisions can be made varies by State and Territory. In all **States and Territories except the Northern Territory**, Vivian's decision-maker/s is able to refuse consent to the operation. In the **Northern Territory**, the Northern Territory Civil and Administrative Tribunal has power to refuse consent.

This area of law can be complex, especially in relation to stopping life-sustaining treatment once it has started.

Learn more about what decisions a substitute decision-maker can make in your **State or Territory** at *End of Life Law in Australia*. (https://end-of-life.qut.edu.au/treatment-decisions/adults/state-and-territory-laws)

4. What factors should Vivian's substitute decision-maker/s consider when making the decision?

When making the treatment decision, Vivian's substitute decision-maker/s should consider:

- what Vivian would have wanted if she had capacity; and
- whether treatment would be in Vivian's best interests, after considering the potential risks, burdens and benefits of the treatment.

The laws in each State and Territory also set out principles to guide substitute decision-makers e.g. decision-making principles, health care principles.

The principles in most jurisdictions require substitute decision-makers to consider the person's:

- interests and welfare
- views, preferences and wishes (if known); and
- treatment options, risks and alternatives.

Here Vivian's decision-maker/s should take into consideration Vivian's previous statements about her treatment preferences e.g. that she does not want any major operations or medical treatment, and does not want to be kept alive if she is dying. The risks of the surgery (e.g. death); other available treatment options (here, there are none); the benefits of future treatment (she may survive) and the burdens (including what her prognosis would be if she does survive); and other decision-making principles in her jurisdiction should also be considered.

Learn more about making substitute decisions in your **State or Territory** at *End of Life Law in Australia*. (https://end-of-life.qut.edu.au/treatment-decisions/adults/state-and-territory-laws)

5. Does the clinical team have to follow the decision?

Generally a substitute decision-maker's decision should be followed, even if refusing treatment will result in a person's death. If the clinical team undertakes the surgery without first obtaining consent from a substitute decision-maker, they could be liable under criminal or civil law or be subject to disciplinary action.

If a clinical team is concerned about the decision a substitute decision-maker makes (e.g. they believe it is not in the person's best interests), they may seek advice from the hospital or health service's legal team, or a medical defence insurer. In some State and Territories, the Public Guardian or Public Advocate's office may be able to provide information or assistance.

Final legal observations

Vivian's legally recognised substitute decision-makers (which vary depending on which State and Territory Vivian is in) must decide whether or not to consent to the operation. In doing so they must take into consideration the factors discussed in reflection point 4. If there is disagreement among Vivian's decision-maker/s, a meeting could be held with the clinical team to reach consensus. In this scenario the clinical team should follow the substitute decision-maker's/s' decision about Vivian's treatment, unless they have concerns about the decision, in which case legal advice should be sought.