

# Withholding and Withdrawing Life-Sustaining Medical Treatment

## Case Study



### Renata's story

Renata is a resident at the Calypso Aged Care Home. Two years ago, she was diagnosed with advanced bowel cancer and received three intensive cycles of chemotherapy treatment after undergoing a bowel resection to create a permanent colostomy. Renata was aware that her cancer was incurable but with the help of her husband, she remained well and enjoyed a reasonable quality of life.

At the end of last year Renata's husband passed away suddenly. Following his death she became socially isolated and found it increasingly difficult to care for herself. With her children's support she moved into Calypso.

Not long after settling into Calypso, Renata began experiencing right-sided chest and upper abdominal pain. Following further investigations, Renata's oncologist, Rajesh, advises that the cancer has metastasised to her right lung, liver, and bones. He advises Renata to consider palliative chemotherapy as it may manage her disease symptoms and possibly prolong her life. Renata's son, Alejandro, is at the consultation and tells Rajesh he wants his mother 'to do everything possible and keep fighting'. Renata reluctantly agrees to schedule chemotherapy for later that week.

After the appointment, Renata returns to Calypso and reflects on her diagnosis. She is fatigued, and feels that her strength is deteriorating due to her age and conditions. She previously experienced severe side effects from chemotherapy and understands the palliative treatment will only temporarily extend her life but not cure her condition.

Later that week, Alejandro takes Renata to her appointment where she advises Rajesh that after much careful thought she does not want chemotherapy, and would prefer to focus on spending the time she has left with her family. Alejandro becomes distressed and demands that Rajesh 'make my mother have the chemo!'.

## Points for reflection

1. Is it lawful for Renata to refuse chemotherapy, even if she may die sooner without that treatment?
2. Does Rajesh have to follow Renata's decision?
3. Can Alejandro demand that Renata have the treatment?
4. What if Renata did not have capacity to decide about chemotherapy?

## 1. Is it lawful for Renata to refuse chemotherapy, even if she may die sooner without that treatment?

The law presumes that all adults have capacity to consent to or refuse treatment, unless it is shown otherwise.

A person with decision-making capacity may refuse medical treatment, even if it is needed to keep them alive. This is because **capacity relates to a person's ability to make a decision, not what decision they make**. However, unwise or unusual decisions may be a prompt to check a person's capacity.

Renata will have capacity if she:

- is able to comprehend and retain the information needed to make the decision, including the consequences of the decision; and
- can use and weigh that information when deciding.

If Renata has capacity, provided her consent has been given freely and voluntarily (and relates to the proposed treatment) she can lawfully refuse the chemotherapy.

Renata appears to understand the proposed treatment, and the consequences of having or refusing the chemotherapy (she knows that if she does not have it the cancer will spread and cause death). She has considered the information provided by Rajesh and has weighed it.

For example, she has considered that the chemotherapy may prolong her life, but also its other implications including the potential for side effects and diminished quality of life. She has used and balanced that information against the consequences of refusing treatment, as part of her decision-making process.

Learn how to determine if a person has capacity to consent to medical treatment in the **End of Life Law Toolkit's Capacity and Consent to Medical Treatment resources**. (<https://www.eldac.com.au/Toolkits/End-of-Life-Law/Capacity-and-Consent-to-Medical-Treatment>)

## 2. Does Rajesh have to follow Renata's decision?

A health professional must follow a decision to withhold or withdraw treatment made by a person who has capacity. In fact, a health professional who provides treatment contrary to a refusal will have committed an assault on the person, and may be subject to civil, criminal or disciplinary action. Therefore, if Renata has capacity Rajesh should accept her decision not to have chemotherapy.

## 3. Can Alejandro demand that Renata have the treatment?

No. If Renata has capacity, her decision to refuse treatment must be followed, even if Alejandro or others disagree with her decision.

## 4. What if Renata did not have capacity to decide about chemotherapy?

Where a person does not have capacity, a decision to withhold or withdraw life-sustaining can still be made:

- in a valid Advance Care Directive (made when the person had capacity); or
- by a person's substitute decision-maker, provided they have the power to do this under the law of their State or Territory.

Learn more about substitute decision-makers' powers 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>)

When deciding to withhold or withdraw life-sustaining treatment from a person without capacity, a substitute decision-maker needs to consider the principles for decision-making set out in State or Territory laws. These differ between States and Territories but generally require the decision-maker to consider:

- what decision the person would have made, based on the person's views, wishes and conduct when they had capacity; and
- the person's interests and wellbeing (sometimes referred to as the person's 'best interests') after considering such things as potential risks, burdens and benefits of treatment.

Renata does not have an Advance Care Directive refusing treatment, so if she did not have capacity her substitute decision-maker would need to consider whether or not to consent to the chemotherapy. If Alejandro is her lawfully recognised substitute decision-maker, he would need to consider Renata's values and preferences, and apply the decision-making principles in Renata's State or Territory, in order to reach a decision.

Learn about:

- how decision-makers make 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>)
- substitute decision-making in the **End of Life Law Toolkit's *Substitute Decision-Making resources***. (<https://www.eldac.com.au/Toolkits/End-of-Life-Law/Substitute-Decision-Making>).

## Final legal observations

After further discussion, Rajesh considers that Renata understands the proposed treatment, and the consequences of having or refusing the treatment (e.g. that she will die). He believes she has considered the information provided and weighed it to arrive at her decision e.g. she has considered that the chemotherapy may prevent the cancer, but may also cause side effects; that it may prolong her life only temporarily; and that her preference is to spend time with her family. The law recognises Renata's choice not to have chemotherapy, which Rajesh must respect.