

# Adult Decision Making in NZ

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# Current Law

- Current law is based on informed consent of treatment offered by a provider, to individuals with capacity
- If the patient lacks capacity the decision is made by the Enduring Power of Attorney or the Welfare Guardian unless the decision relates to serious or life-threatening illness when the clinician decides based on the patient's best interests.
- Little ability to resolve disagreement (apply to the Court)
- Well suited to consenting for surgical procedure. Not suited for consenting for Residential Care.
- Determines who has power to decide,
- Limited focus on quality of decision



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# Case Study

Joan and Harry 80's in family home. Living spaces on the upper floor. Both drive, annual overseas cruise. Regular walkers, both have mental capacity. Son John 15-minute drive away, Susan and Emily live overseas.

Joan falls fractures 6 ribs and a collar bone. Healing well transferred to rehab ward. Can she go home?

Physio unhappy difficulty walking up a full flight of stairs.

The nurses are worried can she manage personal cares. The doctor is worried that she is inflating her capabilities

Harry is quite worried. Joan wants to go home, she hates it in the hospital.

Susan has come back to visit and is happy to stay with them at home and help until Joan is better.

John and his family have been providing meals for Harry and are happy to continue with that and provide further support as needed.

Emily has zoomed into family meetings and thinks she should not go home until she is much better, because she is worried about another fall.

Joan is eligible for home support twice a day.

When Joan can walk up full flight stairs, can go home,

Home support will be going in,

Susan will be staying with them.

support from John and his family.



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# Problems with the chain of decision making

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Informed Consent

Implies decision is rational

Treatment offered by provider

Is this negotiated, can the patient choose a treatment

Individual has Capacity

Some decisions will affect more than the individual. Capacity Assessment problematic

# Informed Consent

- Dunedin Study. 15% of patients vaccine refusers, high likelihood of >4 Adverse Childhood Experiences.
- ACE people make decisions more on the basis of emotions
- What if the patient does not trust the information from clinicians?
- What is the clinician's role in caring for a person who is making a decision that has a high chance of causing harm?
- Manson and O'Neill "Consent" versus agreed management plan.
- Rethinking informed consent in bioethics N. C. Manson and O'Neill Onora Publisher: Cambridge University Press 2007



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# Individual

- Is this just Joan's decision?
- Would it be OK if Susan was not staying?
- What if the physio really thinks it would be unsafe to go home?



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# Treatment offered by provider

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- Patients only have a choice between treatments offered by the provider; cannot choose opiates for back pain.
- What happens if the provider does not offer the treatment that the patient wants how is difference resolved?
- What if Joan wants to go home with district nurse support, against our advice, do we have to provide it?



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# Capacity

- Capacity assessment done well requires time and training
- In theory it is done in relation to a particular decision, in practice it is often global.
- What difference does Joan's capacity make to this decision?
- Serious issue for disabled community who have their rights taken away.
- A significantly mana-diminishing activity
- Open to abuse, with little ability to contest the judgement



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# Case Study

- Joan went home, Susan lived with them until Joan's pain abated, and her fitness returned.
- Joan developed dementia, gradually less able with household tasks. Susan moved in again to prepare meals and manage the household.
- Harry had macular degeneration and his sight was significantly impaired.
- Both managed the stairs and walked daily but more frail.
- Susan tired of living with them always being "on call" and moved over to stay with John and his family, daily visits. Harry bought Susan a car to facilitate this.
- Emily visited twice yearly, unhappy with standard of care, state of house and unfair Harry had bought a car for Susan.
- Both had episodes of falling down the internal stairs, fortunately without serious injury.
- When Joan first started to deteriorate, the family discussed the option of moving to an Aged Care Facility. Joan was amenable to the idea, but not now.
- Harry said that the only way he would want to leave the house was in a box.

# Case Study continued

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- Joan began to get up in the night and go walking. On one occasion she went down the drive.
- Harry stressed from not sleeping worrying about Joan and wanted Susan to move back in.
- John was getting late-night phone calls from Harry wanting help. Things were becoming bad.
- Susan was doing as much as she could and relying on John and family to support her. Not eligible for funded support and could not afford to self-fund it even if they could find someone willing to do it.
- Emily; Harry's wish not to move should be honoured and the family would just have to provide more support.
- Harry agreed to go and look at a villa in a nearby Aged Care Facility. Joan was happy to go along without really understanding. Harry decided that it was the best option.
- The GP was approached and did a capacity assessment for Joan and found her to have capacity.
- Harry, Joan, Susan and John went to the lawyer's office and the contract to move to the Aged Care Facility was signed by Joan and Harry.
- The family helped the move. Susan moved into the family home.
- Two weeks after moving in Harry declared that he wanted to move back home. John told him that he was welcome to do that but that no support would be provided. They stayed in the villa.

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EPOA or Welfare Guardian

Cost to get EPOA many do not have one

Best Interests

Culture bound concept...length of life vs quality of life

No effective mechanism for resolving conflict

Abuse of EPOA power, relatives disagreeing with doctor's plan at end of life...

# Individual

- Is this just Joan's decision, or Harry's decision?
- Does Susan get a say? Does Emily get a say?



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# Capacity

- What if the lawyer believes Joan does not have capacity for this decision?
- Is the presence of Susan and John coercive?



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# EPOA or Welfare Guardian

- Many people do not have this.
- No register of EPOA's
- Without one, patient with dementia can be stuck in public hospital for lack of someone to consent to going to rest home
- Undermines the role of “next of kin” ...all practices collect next of kin data and frequently use it for contacting the patient or informing family of death etc. (HDC Code no next of kin HIPC allows for this)
- What if Emily had the EPOA and refused to sign contract with Rest Home?



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# Best Interests

- Culture bound inevitably reflects the unconscious bias, values and beliefs of clinician. For example balance between quality and quantity of life.
- For decisions at end of life why is it just a decision made by the clinician after consulting?
- Emily thinks “Best interests” is to stay at home, John and Susan disagree What do we do?



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# Complaint Mechanisms

- For disagreement only available mechanism is the Courts which cannot hear things urgently unless life is at stake.
- John and Susan could apply to the court to rescind the EPOA for Susan and Susan be appointed instead. The cost of proceedings is problematic.
- Cases of EPOA taking all the funds for themselves hard to contest
- Cases of EPOA deciding to take patient home against advice with bad outcome.



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# Conclusion

- Current law does not reflect clinical process.
- Focusses on who should have power to make a decision not on reaching a good decision.
- Informed Consent vs Reaching an Agreed Management Plan



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# Discussion



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