

Informed Consent and Substituted Decision-Making

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Informed consent

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"You want informed consent, I want more pudding.
Let's make a deal."



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Why consent matters



Patients have the right to decide what happens to their body and what treatment / services they receive



Treatment without consent may have legal and professional consequences



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Case example 1: HPDT

- Nurse providing continence care. Risk of care being misinterpreted
- Patient made allegations of sexual assault
- Nursing Council PCC→ HPDT
- Conflicting evidence from patient and nurse. HPDT ultimately found both credible, albeit with inconsistencies in both parties evidence
- Different (higher) level of care provided



Legal framework for informed consent in Aotearoa

Common law principles

Crimes Act 1961

New Zealand Bill of Rights Act 1990

Code of Health and Disability
Services Consumers' Rights

Nursing Code of Conduct



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HDC Code of Patients' Rights:

Right 5 - Effective Communication

Right 6 – Right to be fully informed

Right 7 – Right to make an informed choice and give informed consent

Nursing Code of Conduct:

Reflects and incorporates the above rights along with rights in the Privacy Code



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Right 7 – Right to make an informed choice and give informed consent

“Services may be provided to a consumer only if that consumer makes an informed choice and gives informed consent, except where, any enactment, or the common law, or any other provision of this Code provides otherwise.”



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Right 5 – Effective Communication

- Every consumer has the right to:
 - Effective communication and for the information to be provided in a way the consumer can understand
 - An interpreter where necessary and reasonably practicable
 - An environment that enables open, honest and effective communication.



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Right 6 – Right to be fully informed

- Every consumer has the right to the information that a reasonable consumer, in their circumstances would expect to receive
- This includes an explanation of:
 - Condition and diagnosis
 - Treatment options (including no treatment)
 - Risks, side effects, and benefits
 - Expected outcomes
 - Costs
- Every consumer has the right to honest and accurate answers to questions relating to the services



Unreasonable refusal?



Competent patients have the legal right to refuse medical treatment however irrational or unwise that may appear to the treating team or the patient's whānau



Right 7(7) of the Code – Every consumer has the right to refuse services and to withdraw consent to services



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Case Example 2: HDC

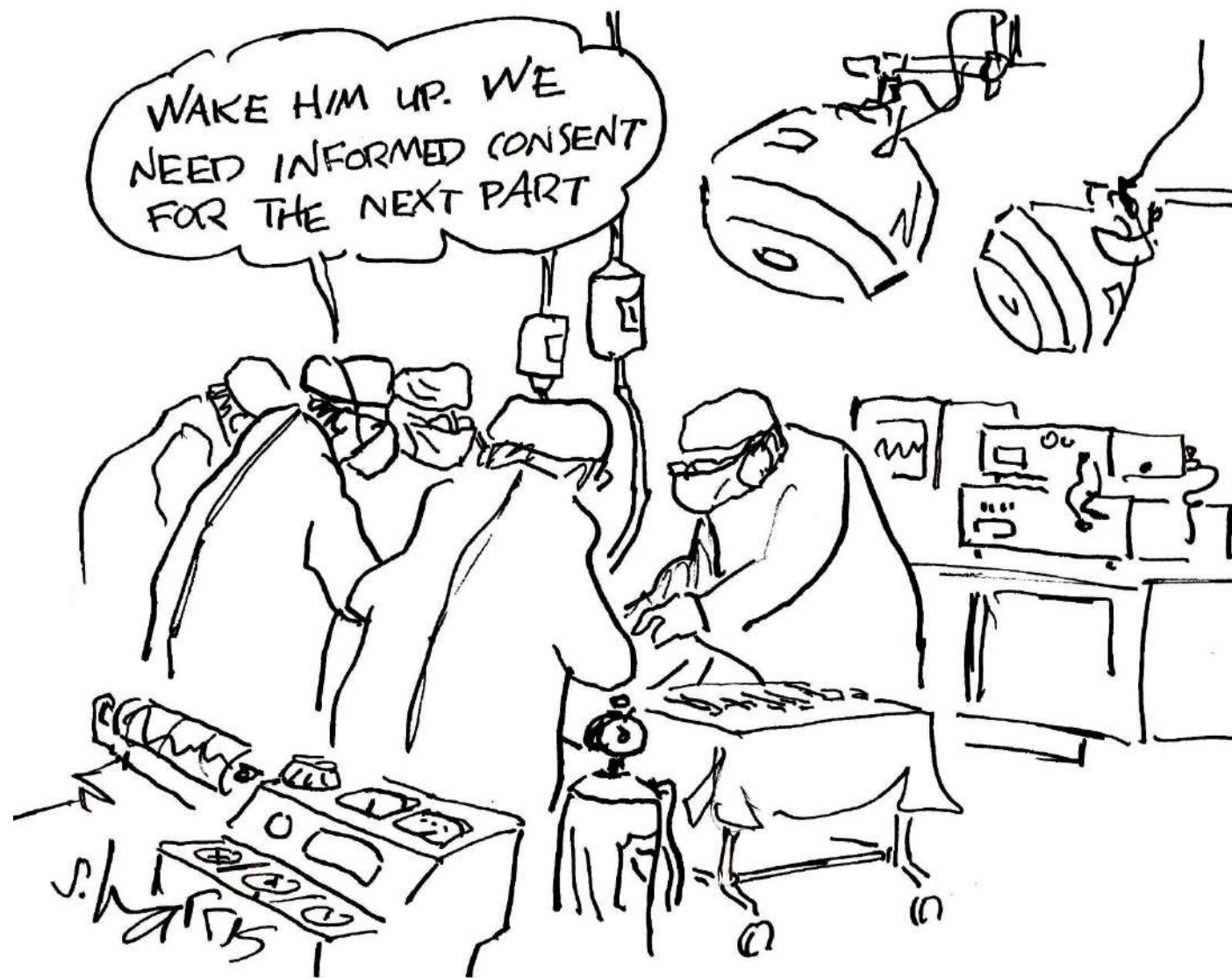
- Patient (Ms A) lives alone and receives residential support, including medication oversight, from a disability service
- Ms A was prescribed clonazepam by her GP
- Ms A preferred to take the clonazepam at night-time
- Support worker concerned Ms A was feeling anxious during the day, and raised this with RN B
- The support worker and RN B discussed the possibility of administering Ms A with her prescribed clonazepam during the day. Both RN B and support worker were aware that Ms A did not want to take clonazepam in the day-time



Case Example 2 contd: HDC

- Differing versions of events, but both accounts consistent that the RN agreed Ms A could be administered clonazepam during the day without informing her
- RN was responsible for the administration of clonazepam to Ms A, and provided direction to the support worker, that she could administer the drug without Ms A's consent
- RN found in breach of right 7(1) by providing services to Ms A when she had not made an informed choice and provided informed consent to receive the clonazepam during the day on the two occasions





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Substituted decision making



"A raise in my allowance is fine, dad. But what I'm really after is power of attorney."



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Competence and consent

Presumed competence: Assume all consumers can make informed decisions unless there is evidence to the contrary (Right 7(2))

Diminished competence: Consumers retain the right to participate in decisions as much as their competence allows (Right 7(3))



Common myths ...

Myth 1 - If someone lacks capacity, they have no say at all

Myth 2 - Next of kin automatically have the right to decide

Myth 3 – A child must be 16 years or over to be able to consent

Myth 4 – If a patient has an EPOA then the attorney is automatically the decision maker

Myth 5 - If there is no-one who can legally consent then a doctor can consent to treatment



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Consumer unable to consent – who can?

Welfare Guardian	Enduring Power of Attorney	Parent or legal guardian
Court-appointed decision-maker for an adult who lacks capacity	Appointed by the person while they have capacity	Usually the decision-maker for a child who lacks capacity
Appointed only where necessary	Authority only begins once the person loses capacity	Decision-making authority arises from guardianship under the Care of Children Act
Must promote and protect the person's welfare and act in their best interests and encourage the person to participate in decisions as far as practicable		Must act in the child's best interests and involve the child in decisions according to their age and maturity
Cannot refuse consent to standard medical treatment intended to save life or prevent serious harm, or consent to certain treatments prohibited by the PPPR Act		Authority is limited where a child is competent to make their own healthcare decisions (a Gillick competent child)



Significant vs non-significant matters

Significant matters	Non-significant matters
- Permanent change in residence - Entering long-term residential care - Undergoing a major medical procedure, treatment or surgery	- Routine or everyday decisions about personal care and welfare - Common medical treatment
Attorney may only act once mental incapacity has been formally certified (or determined by the Court)	Attorney may usually act if they reasonably believe the donor lacks capacity for the decision



Parent or legal guardian (for a child)

No fixed “age of consent” – assessed using **Gillick competence**

A child aged **16 or over** can give or refuse consent as if an adult (section 36 Care of Children Act 2004)

Under 16s: may consent if Gillick competent

Contraception may be given to children under 16 years old without parental consent

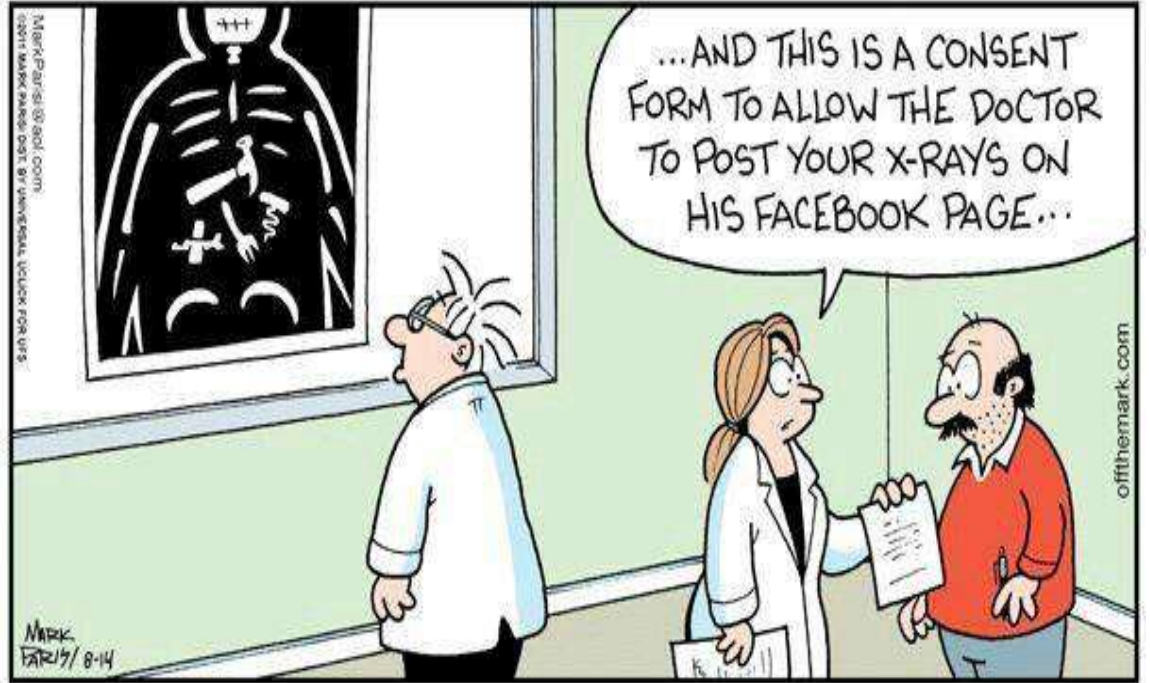


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Absence of valid consent

- Emergency situations
- Provision of services authorised by statute or ordered by court
- Right 7(4) Code of Patients' Rights



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Right 7(4)

- Consumer not competent and no person entitled to consent
- Right 7(4) sets out the legal position for providing services to the consumer:
 - Best interest of consumer
 - Reasonable steps taken to ascertain views of consumer; and
 - Having regard to views, services are consistent with views; or
 - Take into account views of other suitable persons
- Nursing Code of Conduct: Nurse must ensure care given is in best interests of patient and reasonable steps taken to ascertain views of patient / other suitable persons.



Other factors to think about

- Advanced directives
- Personal order / treatment order
- Health Information Privacy Code



High risk area for nurses

Common issues:

- Consulting and obtaining consent from an EPOA when EPOA not activated.
- Failing to obtain consent from a patient directly as not established patient did not have capacity.
- Not updating a welfare guardian / EPOA with sufficient updates about patient's condition.
- Assessing a child's capacity for individual treatment decisions
- Failing to appropriately consult if relying on right 7(4)
- Determining who is entitled to information about the person's health.



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What does this look this in practice?

- Elderly woman- 86 years old- with dementia
- EPOA in place- daughter- not activated
- Fluctuating capacity
- Admitted to hospital – confused
- Agitated and combative during cares
- Doctor wants to administer haloperidol to calm patient as is common practice with dementia patients

What steps need to be taken?



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What to do when someone claims they speak for a patient....

- Starting point - the patient is always presumed competent
- Sight the document (EPOA / Welfare guardian)
- Check for restrictions
- Verify the medical certificate
- Differentiate between significant and non-significant decisions
- Consult the patient
- Document
- When in doubt – escalate



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**"I'll remove the thorn ... but first you must sign this form
that says you won't eat me."**