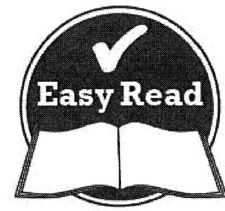




Justice
Law Reform
Commission



Review of the Guardianship Act

Question Paper 5: Medical and dental treatment and restrictive practices

Easy Read version



How to use this document

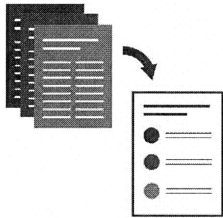


This information is written in an easy to read way. We use pictures to explain some ideas.



This document has been written by the Law Reform Commission.

When you see the word 'we', it means the Law Reform Commission.



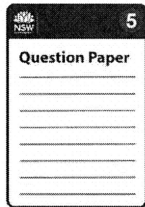
This Easy Read document is a summary of another document.



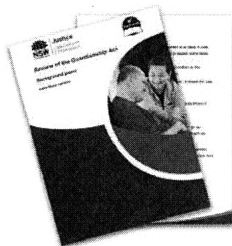
You can find the other document on our website at lawreform.justice.nsw.gov.au



You can ask for help to read this document. A friend, family member or support person may be able to help you.



This is the fifth question paper. There are other papers as well.



We suggest that you read our Easy Read Background Paper. It explains many of the ideas in this question paper in more detail.

What's in this document?

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What we are trying to do



At the moment, we are reviewing the law about guardianship.



Guardianship is when another person makes decisions for you. This is usually because you can't make decisions on your own.



The law we are reviewing is called the *Guardianship Act 1987*.



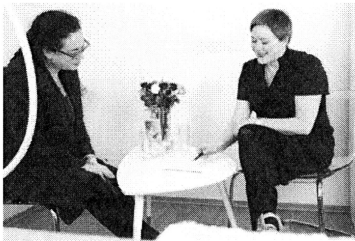
We want to make sure that the law is fair.



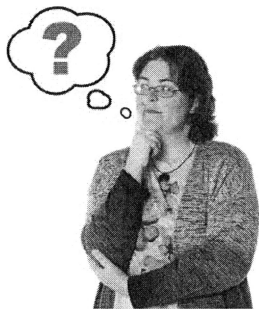
We also want to make sure it is right for the community today.



Our community has changed a lot since the law was written in 1987.



We'd like to know what you think about our ideas for new laws.



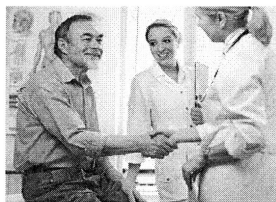
This document has some questions for you to think about.

What this paper is about

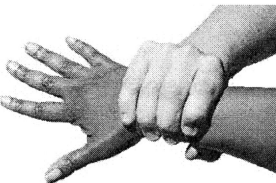
This paper covers 3 important topics:



1. Who can make decisions about medical and dental treatment.

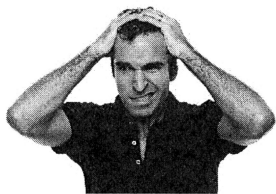


2. Who can make decisions about taking part in medical research.



3. Who can make decisions about the use of **restrictive practices**.

Restrictive practices are used to stop a person from:



- hurting themselves



- hurting others



- damaging something.

These practices include things like:



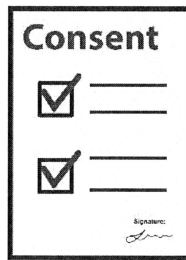
- using medication to calm someone down



- removing someone from the room and keeping them on their own for a while.

We discuss restrictive practices in more detail on page 32.

Who can give consent?



If you give **consent** you say it is ok for somebody to do something.



If you consent to medical or dental treatment, it means you agree to have the treatment.

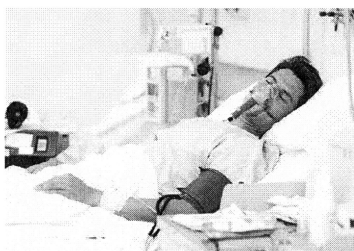
Consent can be given by:



- you
- someone who can make decisions for you.



Some people can't give their consent.



This might be because they have:

- a severe disability
- trouble explaining what they think.

→ Relies on the knowledge and diligence of the doctor

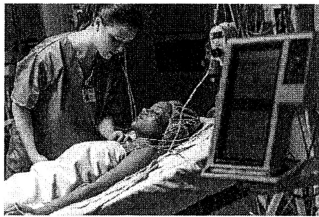


How do we know when someone can't give their consent?

The law currently says people can't give consent if they can't show:



- they understand the type of treatment and any effects it may have



- whether or not they consent – they can't speak, nod or use some other way to show if they agree with the treatment.

Question 1: What do you think about who can give consent?

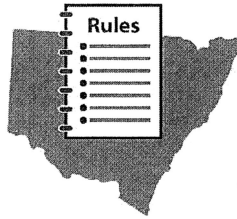
1

Should these things mean that someone can't give consent?

You can use the space below to share your thoughts.

- This can be a problem for people who speak English as a second lang. & people with intellectual disability,
Maybe doctors will assume the ~~patient~~ ^{patient} has someone to
support them with the decision but they might not.
They need permanent staff - not casual. This relies on
doctors explaining things well, which they might not do
They Yes/No approach to consent is not right its more
complicated. Some people with disability say 'yess'
b/c they don't know what will happen if they don't.
The hierarchy for person responsible needs to be
better defined, in partic ^{partic} in case of the patient.

Question 2: Which types of treatment need consent?



In NSW the law has different rules depending on the type of treatment you need.



This includes treatment from a doctor or dentist.



For some treatments, the person treating you must get consent from someone else if you can't give it yourself.



This includes treatments that are:

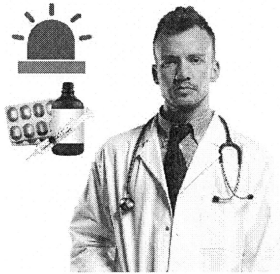
- risky – they could be dangerous
- intrusive – they can be unpleasant for the patient.



For example, consent is needed for an operation.



And consent is needed to have a cast put on a broken leg.



Consent isn't needed for:

- emergency first aid
- some types of medicine.

What do you think?

What do you think about these rules? Should there be any other rules?

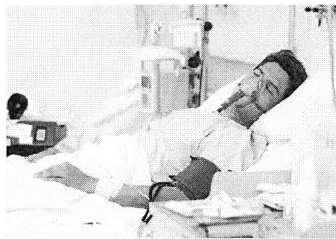
You can use the space below to share your thoughts.

Happy with this.
It is good if that you don't need
to give consent for emergency first
aid.

Question 3: Who can make decisions about stopping treatment?



At the moment, a doctor can say that medical treatment being used to keep someone alive should be stopped.



This usually only happens in some situations – if someone is dying and is in a lot of pain.



If the person can't say yes or no about this, someone else can make that decision for them.



Some people think this should never happen.



They think that the treatment should continue, no matter what, to keep the person alive.

What do you think?

You can use the space below to share your thoughts.

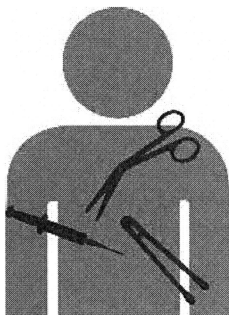
Doctors have a lot of power and need more education.
All lives matter. If someone is ill we don't discriminate -
address bias against disability.

- Relies on the honesty & accuracy of family
members

- People in accommodation services - it needs to be
talked about and have it written down - less contact with
friends & family - Sometimes dis don't want to pursue
active care

Question 4: Who can make decisions about parts of our bodies?

4

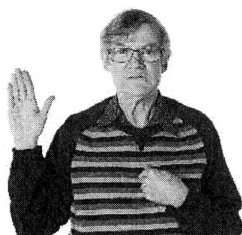


There are some medical treatments that involve removing small parts of our bodies.



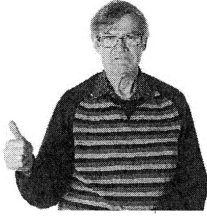
For example, sometimes people need to have a small piece of their body removed to:

- treat a sickness they have
- help someone else who is sick.



At the moment, the law says that, sometimes, someone else can make a decision for another person about these kinds of operations.

If someone is going to make a decision for someone else, they need to think about:



- Is it the best thing for the person?



- How risky is the operation?



- Will the operation help the person be healthy?

What do you think?

Should these rules be different? You can use the space below to share your thoughts.

Two very different issues: removing a body part to benefit another person, so has the potential to exploit people with disabilities.

There should be 2-3 people involved - almost like a tribunal!

For the operation to remove a body part to benefit their health, the guardian should still be involve the patient as much as possible in the decision.

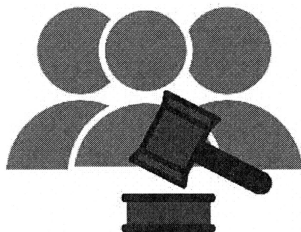
Question 5: Who can say yes or no to treatment?



At the moment, if you can't consent to treatment yourself, different people can give consent for you.



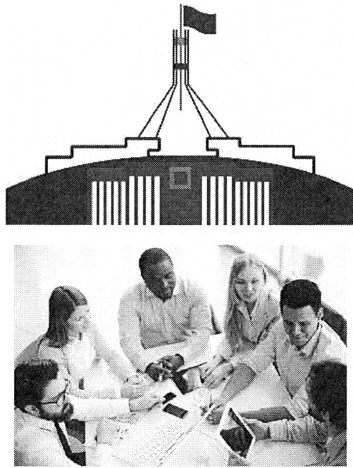
There are different types of treatment, and different people who can give consent.



A **tribunal** can give consent to all types of treatment.



In NSW we have the Guardianship Division of the NSW Civil and Administrative Tribunal (the Tribunal).



The Tribunal is a group of people appointed by the Government who work together to make decisions about guardianship.

Type of treatment	Examples of this kind of treatment	Who can give consent
Special treatment	This might be an operation to change whether or not you can have a baby, or it might be an abortion.	Only the Tribunal or your guardian.
Major treatment	Being given a drug that might become addictive. Having a tooth removed.	<ul style="list-style-type: none"> • the Tribunal • your guardian • your husband, wife or partner • your carer • a close friend or relative
Minor treatment	Having a cast put on a broken leg	<ul style="list-style-type: none"> • the Tribunal • your guardian • your husband, wife or partner • your carer • a close friend or relative

What do you think?

Do you agree with the types of people who can make decisions about treatment?

You can use the space below to share your thoughts.

Sterilisation - consent should be from the tribunal - not the guardian

Decisions can be based on preconceptions eg people with disabilities aren't interested or are too interested in sex.

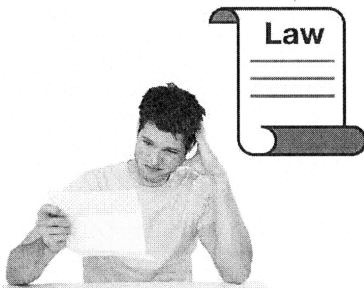
Major & minor treatment - we're happy with that.

Question 6: What if you say no to treatment?

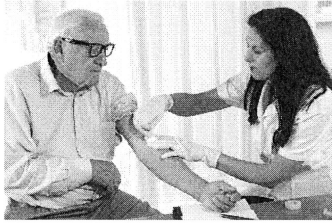
6



Sometimes, people with a disability say that they don't want to receive treatment.



At the moment, the law says that there are times when their wishes can be overruled.



This means that someone can say that you must have the treatment, even if you don't want it.

This can happen when the doctor says:



- You don't understand enough about the treatment.



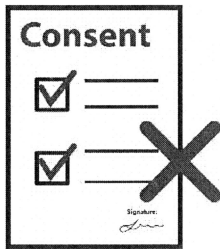
- The treatment won't cause you harm, pain or distress.

What do you think?

You can use the space below to share your thoughts.

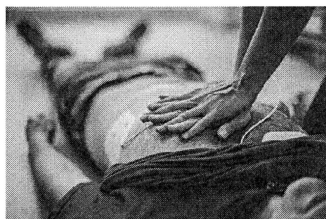
Whilst it is important to make sure the patient understands the consequences; how do you really be sure about capacity. People may still reject treatment even when they don't fully understand consequences. Some docs might dismiss refusal as a temper tantrum. Operations can bring back trauma for a customer; the patient is the expert on their distress - not the dr. A person's beliefs, eg religious beliefs should be respected even if they have a disability. Should always flesh out why a patient is refusing.

Question 7: Is consent always needed?



At the moment, the law says that there are times when consent for treatment is not needed.

This includes when urgent treatment is needed to:



- save your life



- stop your health being damaged



- help reduce pain or distress.



It can also happen when no one is available to give consent and the doctor says the treatment needs to happen anyway.

What do you think?

You can use the space below to share your thoughts.

They need to better define min. treatment because at the moment the definition is anything that is not for major or part of a clinical trial.

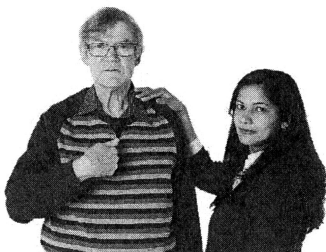
Question 8: Who is the 'person responsible'?

8

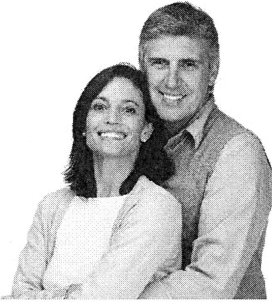


Someone who the law says can give consent for someone else to be given major medical or dental treatment, is called the **person responsible**.

This person might be:



- your guardian



- your husband, wife or partner



- your carer



- a close friend or relative.

List	
1	_____
2	_____
3	_____
4	_____

The law says that the order of the list is important.



A guardian is chosen first.

If they are not available, a husband, wife, carer, friend or relative will be chosen.

What do you think?

Is this a good list?

Do you agree with the order?

Should anyone else be on the list?

You can use the space below to share your thoughts.

What is a "career"? Can this be a paid
worker. If not, how is it different to close
friend / spouse / relative.

We feel close / friend / relative is
more important than career.

Every item on the list needs
to be tightly defined.

Question 9: What should people think about before making a decision for someone else?

9



Making a decision about someone else's medical or dental treatment is a big deal.

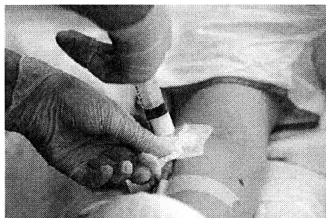
The law says that the person needs to think about the following things when doing this:



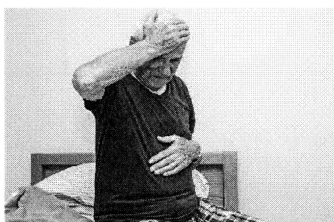
- Why the person can't give consent themselves.



- The type of medical or dental problem that needs treatment.



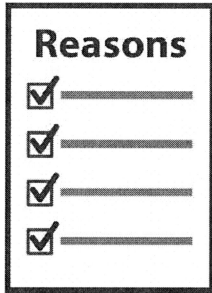
- If any other types of treatment are available.



- The effects that the treatment might have on the person.



- The risks of the treatment.



- The reasons why the treatment is needed.

What do you think?

Are these the right things to think about?

Is there anything that people need to think about?

You can use the space below to share your thoughts.

How would you involve the patient?
What would the patient choose?
We'd put 'What is the medical decision?' at the top because capacity is decision specific.

Question 10: When is it ok to make a decision about sterilisation?

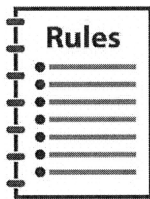
10



Sterilisation is when someone has an operation that prevents them from having a baby.



Both men and women can be sterilised.

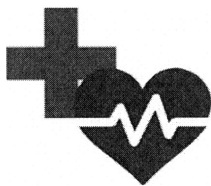


If you can't make a decision yourself, there are special rules about consent for sterilisation.



Only the Tribunal can make a decision about sterilisation.

The Tribunal must think about:



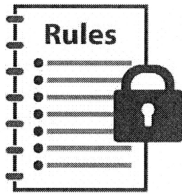
- the person's health and wellbeing



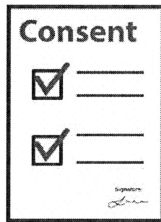
- if the treatment will save the person's life



- if the treatment will stop damage to the person's health.



Some people think that these rules are too strict.



Others think that sterilisation should never happen without the person's consent.

What do you think?

You can use the space below to share your thoughts.

Do ~~of~~ Sterilisation should not happen without a person's consent. Patients should always be involved and given appropriate support. Maybe patients need skills; support to develop the skills.

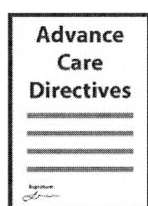
Sterilisation to save your life is more important.
Sexism is sterilising women and not men.

Question 11: Should you be able to write down what should happen about your health in the future?

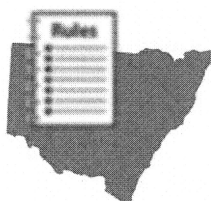
11



In some parts of Australia, you can write a document to explain what should happen about your health in case you can't consent in the future.



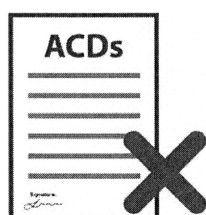
These documents are called **advance care directives**.



In NSW at the moment, the rules about advance care directives are unclear.



In some other parts of Australia, the law says that you can write in an advance care directive who it is that you trust to make decisions for you in the future.

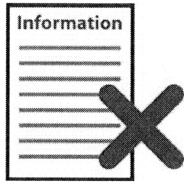


In some other parts of Australia, the laws also say that there are some situations where the advanced care directive should not be followed.

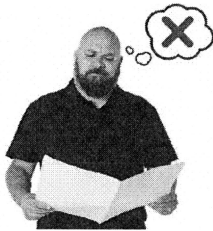
This includes:

- If the person was forced to agree to the document.





- If the person used incorrect information to make their decisions.



- If the document does not match their current wishes.

What do you think?

Should you be able to write down what should happen about your health in the future?

You can use the space below to share your thoughts.

The advanced care directive should be reviewed regularly and this should be easy to do.
Agree with those circumstances where it would not apply.

Clinical trials

Question 12: Who should decide whether or not you can take part in a clinical trial?



Clinical trials are a way of testing new medicines or medical treatments.



Sometimes, people who can't give consent take part in a clinical trial.



In NSW, only the Tribunal can give consent for them.



In other parts of Australia, a person's guardian, husband or wife can decide.



Some people think that people who can't give consent should never be allowed to take part in clinical trials.



Others think this isn't fair.



For example, what if the medicine being tested was a cancer drug that could save your life?



There may be benefits to taking part in trials that people don't know about.

What do you think?

Who should be able to decide if you can take part in a clinical trial?

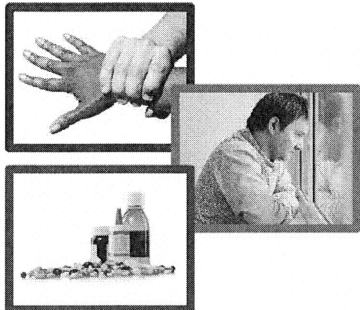
You can use the space below to share your thoughts.

The Person Responsible should give consent (presuming the cost is fixed up if consent is defined & the order is changed)

Restrictive practices

13

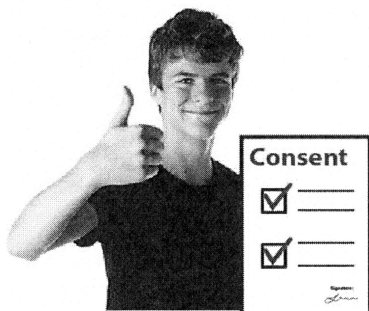
Question 13: Should there be laws about restrictive practices?



Restrictive practices are sometimes used to stop someone harming themselves or others.



At the moment, there is nothing in the law about restrictive practices.



A person is supposed to give consent before restrictive practices are used on them.

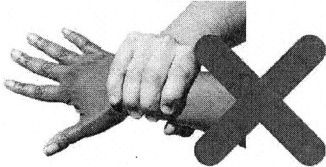


If the person can't give consent, someone else can say that it's ok to use restrictive practices.



Carers are sometimes unsure:

- if they can use restrictive practices
- who to ask about this.

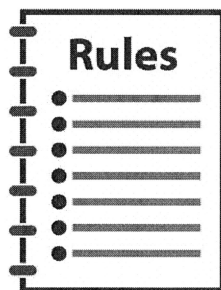


Sometimes restrictive practices are used when they shouldn't be.



Some people think that restrictive practices should not be allowed at all.

Others think there should be:



- clear rules



- penalties for people who break the rules.

What do you think?

You can use the space below to share your thoughts.

Question 14: Are there any other issues or ideas that you would like to share with us?

14

Without consent is can be assault or false imprisonment.

If the government approved it, they would have a good overview. People with disabilities are at heightened risk.

We need legislation - if the government should manage & monitor that. To provide safeguarding - possibly until the national framework comes in.

There needs to be a state-wide senior practitioner

Legislation is particularly important within the NDIS, where "extra services" can't be funded within not-for-profits.

What's next?



Thank you for taking the time to answer our questions.



We will think about all the answers that you and other people give us.

We will do this when we write down our ideas for making changes to the law.

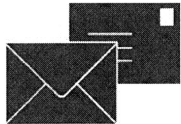
If you'd like more information, please contact us. Our contact details are on page 39.

How to tell us what you think

You can send your answers to us by email or post.



nsw-lrc@justice.nsw.gov.au



GPO Box 31

Sydney

NSW 2001



We need to receive your answers by
Friday 12 May 2017.



We may publish your answers on our website,
or include them in things that we write.



If we do this, people will be able to read
your answers.



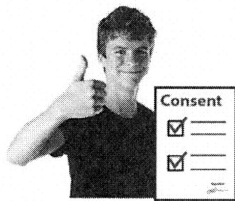
Please tell us if you don't want us to publish some,
or all, of your answers.

Word list



Advance care directives

Documents that are used to explain what should happen about your health in the future.



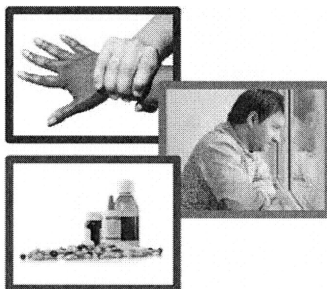
Consent

Saying it is ok for somebody to do something.



Person responsible

Someone who makes a decision for someone else about major medical or dental treatment.



Restrictive practices

Techniques that are used to stop a person from:

- hurting themselves
- hurting others
- damaging something.



Sterilisation

When someone has an operation to prevent them from having a baby.



Tribunal

A group of people appointed by the Government who work together to make decisions about guardianship.

Contact us



(02) 8346 1284



nsw-lrc@justice.nsw.gov.au



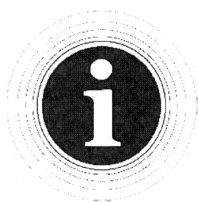
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