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Balancing rights and needs of older people living at home

NASCA Forum 2015

Objectives

- To provide an opportunity for people to discuss their own experiences around concerns about the safety of an older person at home, and the ways in which such concerns were addressed
- To outline the legal framework that applies



Case Study 1: Brian

Case Study

Brian is 93 years old and lives at home. He has always lived what could be described as an eccentric lifestyle. He does not believe in using electricity, and eats only organic food, much of which is from his own garden. He receives home support, but his carers believe his health is deteriorating, and are concerned about their ability to continue to care for Brian at home. When these concerns are raised with Brian, he accepts that things are getting more difficult, but says he will never agree to go into a rest home.



Over to you

- What options are available to the carers?
- What legal and ethical principles need to be taken into account?



Starting principle -
it's your road...

It's your road.....



It's your road and yours alone.
Others may walk it with you,
but no one can walk it for you.



Autonomy and
self-determination

Autonomy and self determination

"Every human being of adult years and sound mind has a right to determine what shall be done with his own body"

(Schloendorff v Society of New York Hospital 105 NE 92 (NY, 1914), p93)



But – you have to
be competent

Competence

- Presumption of competence:
 - the Code of Rights (Right 7(2))
 - PPPR Act (ss5 and 93B)
- Age is not determinative of decision making capacity
- Suffering from a particular condition (e.g. dementia), or being subject to orders under the Mental Health (Compulsory Assessment and Treatment Act) 1992, are not determinative of decision making capacity



Assessment of capacity

- Based on work by Dr Greg Young, C&C DHB

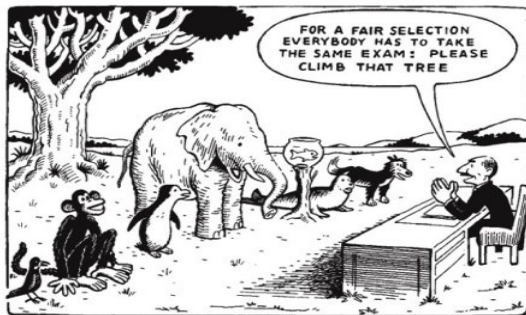


So when do we assess for competence?

- Suspected impairment of cognition
- Decision that is out of character
- Decision that is causing contention
- Decision with very serious consequences



Competence assessment methods



Competence assessment methods

- Intuitive Assessment
- Vignette Method or structured interview
- Semi-structured Interview
 - MacArthur Competence Assessment for Treatment



Competence Assessment

- **Problem:** Why is there an issue about this person's competence to make this decision? Is there a reversible factor affecting the person's competence?
- **Situation:** What does the person know about the facts of the current situation? Does the person know why the decision needs to be made now?
- **Options:** Does the person know the options available to him/her – what decisions could be made?



Competence Assessment

- **Consequences:** Does the person know the consequences of not making a decision, or of the available options?
- **Consistency of choice:** Is the decision consistent from one day to the next, and is the decision consistent with the person's previously expressed wishes?
- **Undue influence:** Is the person able to express a decision without being excessively influenced by other people?
- **Reasons for choice:** What is the person's reason for the decision? Is the reason based on a delusion, profoundly abnormal mood, misrepresented information, or is it the product of pathological impulsivity?

"Play SOCCUR"



What happens if a
person lacks
capacity?

Other ethical principles apply

- Beneficence (a group of norms pertaining to relieving, lessening, or preventing harm; and providing benefits and balancing benefits against risks and costs)
- Nonmaleficence (a norm of avoiding the causation of harm)



So, simply put....

Capacity is the gatekeeper of autonomy

- If you have capacity:
- If you don't have capacity, someone else determines what is in your best interests



So who decides..?

- Person lacking decision making capacity
 - Advance Directive
 - Enduring Power of Attorney
 - Statutory authority
 - Mental Health (CAT) Act
 - IDCCR Act
 - ADA Act
 - Right 7(4) Code of Rights
 - Doctrine of necessity
 - Court Order
 - Welfare guardian
 - Property manager
 - Personal order
 - Parens patriae (High Court inherent jurisdiction)



Case Study 2:
Ulma

Case Study

Ulma is 79 years old. She is suffering from dementia. She owns her own house, and has lived there much of her life. Her son also lives with her. Ulma was admitted to hospital amidst concerns that she was not being cared for properly at home, and arrangements were made for Ulma to live in a rest home. Ulma's son has turned up saying that he is going to take her back home. There are serious concerns about Ulma's son's motivations, and the provider believes it is not in Ulma's best interests to go back home.

What should be done?



Does Ulma have capacity?

- Just because Ulma has dementia does not automatically mean that she does not have capacity to decide where she wants to live
- Even if she has diminished capacity, she may still be able to indicate her preferences, which should be taken into account



LIKE



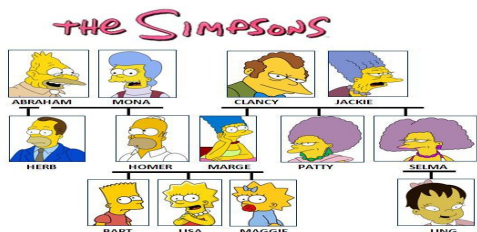
DISLIKE

- If Ulma lacks capacity to make this decision, someone else will need to make the decision



Legal status of Ulma's son

- No lawful entitlement to consent on behalf of an incompetent adult simply because you are next of kin, family or a close friend



Another person
lawfully entitled to
consent

Another person lawfully entitled to consent

- The people who may be lawfully entitled to consent on behalf of an incompetent adult are:
 - An **enduring power of attorney ("EPOA")** for personal care and welfare or an enduring power of attorney for property (depending on the type of decision to be made)
 - A **welfare guardian** or **property manager**, depending on the type of decision to be made
 - Another person appointed under a **court order**



What is an
Enduring Power
of Attorney?

What is an EPOA?



What is an EPOA?

- The purpose of an EPOA is to enable a person to grant someone else the power to act on their behalf in relation to their personal care and welfare and/or their property
- There is a difference between a power of attorney and an EPOA
- The prime characteristic of an EPOA is that it continues to have effect after the donor becomes mentally incapable



Personal care and welfare – and - property

EPOA for personal care and welfare

- Appointed to make decisions relating to personal care and welfare
- **Only** comes into effect when donor is **mentally incapable**
- May only be **one** EPOA for personal care and welfare
- EPOA deed can restrict attorney's powers and can put conditions on decisions
- Statutory limitations on exercise of powers



Welfare guardians

- Effectively the same as an EPOA for personal care and welfare but are **court appointed**
- To appoint a welfare guardian the Court must be satisfied that:
 - The person **wholly** lacks capacity to make or communicate decisions relating to any particular aspect(s) of their personal care and welfare; and
 - Such an appointment is the **only** satisfactory way to ensure the appropriate decisions are made
- Statutory limitations on exercise of powers



EPOA for property

- Can come into effect when the donor is mentally capable and/or after the donor becomes mentally incapable
- May allow the EPOA to act generally in relation to the whole or a specified part of the donor's property
- May impose certain conditions and restrictions
- The EPOA's actions will be accepted as those of the donor if the EPOA does not include any conditions or restrictions



Overarching obligations

- “The paramount consideration of the attorney is to **use the donor's property in the promotion and protection of the donor's best interests**, while seeking at all times to encourage the donor to develop the donor's competence to manage his or her own affairs in relation to his or her property.” s 97A(2) PPPRA
- “The paramount consideration of the attorney is the **promotion and protection of the welfare and best interests** of the donor, while seeking at all times to encourage the donor to develop and exercise his or her capacity...” s 98A(2) PPPRA
 - Encourage independence
 - Facilitate integration into the community “to the greatest extent possible”



Ask for a copy

Ask for a copy

- Always check the official document empowering the EPOA and WG
- A copy of the document (and any certificate of mental incapacity) should be kept on file
- The EPOA or WG can only consent to treatment that falls within the ambit of the empowering document



Case study 3:
Beth

Case study

- Beth is 85. She is living in a rest home. Every morning she goes out for a walk.
- One morning, she falls when out walking, and can not get up by herself. She has to wait until a passer by is able to help her. She is a bit shaken and bruised but otherwise OK.
- Beth's daughter is EPOA for personal care and welfare. She thinks that it is no longer safe for Beth to go out walking, and wants to put a stop to it.
- **Can she do so?**



When does an
EPOA for
personal care and
welfare come into
effect?

Activating an EPOA for personal care and welfare

- **No formal 'activation' is required**

- An EPOA for personal care and welfare is activated when the person becomes **mentally incapable**
- Special requirements if EPOA acting in relation to a **"significant matter"**



'Significant matters'

- Specific requirements must be met before an EPOA can act in regard to a **"significant matter"**
- A significant matter is one that **has a significant effect on health, wellbeing or enjoyment** (e.g. permanent change in residence, entering residential care, undergoing a major medical procedure)



Insignificant matters

- **For any matter that is not significant the EPOA must reasonably believe a person is mentally incapable:**

- Belief must be based on reasonable grounds
- Where there is doubt it may be prudent to seek a medical certificate even on matters that are not significant
- Remember Right 7(3) - a person with diminished competence retains the right to make an informed choice and give informed consent to extent appropriate to his or her level of competence



Before an EPOA can act on a 'significant matter'

- A relevant health practitioner must have certified, or the Court must have determined that the person is mentally incapable
- A "relevant health practitioner" is a registered health practitioner whose scope of practice includes the assessment of a person's mental capacity
- **A certificate in the prescribed form is required for each significant matter** (except where certification is indefinite or relates to a specified period)



Mentally incapable

- The person will be "mentally incapable" if he or she **lacks capacity to:**
 - Make a decision; or
 - Understand the nature of decisions; or
 - Foresee consequences of decisions or foresee consequences of failure to make decisions; or
 - Communicate decisions (about matters relating to personal care and welfare)



(Section 94 of the PPPR Act)



Mentally incapable

- **Recognises incapacity as relevant to individual decisions rather than 'global incapacity'**



What is the role of the EPOA?

EPOA/welfare guardian = consumer

- **"Consumer"** in the Code of Rights means a health consumer or a disability services consumer
and
- **Includes** a person entitled to give consent on behalf of that consumer for the purposes of:
 - Right 5 – Right to effective communication
 - Right 6 – Right to be fully informed
 - Right 7(1) and 7(7) to (10) – Right to make an informed choice and give informed consent, right to refuse or withdraw consent to services, removal of body parts
 - Right 10 – Right to complain



What this means in practice...

- The **consent** of the EPOA or WG must be obtained before carrying out any medical treatment on the person for whom the EPOA or WG is acting



What this means in practice...

- The EPOA or WG:
 - Must be kept **informed** about the person's condition
 - Must be **involved** in decisions about the person's care
 - Is **entitled to the information** the person themselves would require to make an informed decision
 - Must be given **accurate answers** to questions about the person's care and condition
 - May **refuse services and withdraw consent** (subject to the statutory restraints)



Case study 4: David

Case study

- David suffers from a condition that has resulted in slow cognitive and physical decline. He remains at home, where his partner, Yvonne cares for him. David also receives home support services. Yvonne is David's EPOA for personal care and welfare and property. David's carers have noticed that he has started to suffer from pressure sores. He also has a cough that has started to sound chesty. Yvonne refuses recommendations that David be seen by his GP. David's carers have had a discussion with his GP, who says it is likely David needs antibiotics. While Yvonne accepts wound care, she refuses to agree to antibiotics.
- *What should be done?*



Limits on the powers of EPOAs and WGs

Limits on powers of EPOAs and WGs

- EPOAs and WGs **cannot consent to:**

- The administration of ECT
- Surgery designed to destroy any part of the brain for the purposes of changing behaviour
- Medical experimentation, other than an experiment to be conducted for the purpose of saving the person's life or preventing serious damage to the person's health

(Sections 98(4) and 18(1) of the PPPR Act)



claro

Limits on powers of EPOAs and WGs ...

- EPOAs and WGs **cannot refuse consent to standard medical treatment/procedure** intended to save a person's life or prevent serious damage to the person's health

(Sections 98(4) and 18(1) of the PPPR Act)



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Back to David

- Possibility of social admission to hospital
- Provision of antibiotics if considered to be standard medical treatment
- But – is it standard medical treatment?



claro

Back to David

- Assuming the collective view is that the provision of antibiotics is standard medical treatment, the EPOA has no power to refuse consent
- Provision of antibiotics can be given pursuant to right 7(4)

claro

Case study 5: Elise and Louise

Case study

- Elise and Louise are sisters and live in their own house
- Both suffer from advanced dementia
- Both have appointed their friend, Anna to act as their EPOA for personal care and welfare
- There are concerns by home support staff that the sisters can no longer cope at home with the maximum funded support
- Anna refuses to consent to their admission to a residential care facility, saying they were much better off at home
- **What should be done?**

EPOA



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Elise and Louise

- Social admission and then refusal to discharge home/negotiated outcome?
- If no social admission or longer term issue – court orders?



Doubts or
concerns about
the actions of an
EPOA/WG?

Doubts or concerns about the actions of an EPOA/WG?

- Decisions of an EPOA or WG may be reviewed by the Court
- Advice should be sought if:
 - There is genuine doubt as to whether the person's own instructions should be relied on or those of the EPOA or WG
 - There are concerns that an EPOA or WG is not acting in the best interests of the person

(Sections 89 and 102 of the PPPR Act)



What are the roles of the various agencies?

**WHAT IS
YOUR
ROLE?**



Back to Right 7(4)

Right 7(4) of the Code of Rights

- Under Right 7(4) services may be provided if:
 - A consumer who is not competent to make an informed choice AND
 - There is no person entitled to consent AND:
 - Services are in the **best interests** of the consumer; **and**
 - Reasonable steps to ascertain **consumer's views**; and
 - Views of consumer or other suitable person** taken into account



What are the limits of right 7(4)?

- There is a lack of clarity about the competence of the person to make decisions relating to their personal care and welfare
- There is an EPOA/welfare guardian in place
- The person is violently opposed to what is proposed and restraint may be necessary
- The family have differing views from the staff involved in providing care with respect to what is in the best interests of the incompetent person



Long term detention?



Remember Ulma?

Case Study

Ulma is 79 years old. She is suffering from dementia. She owns her own house, and has lived there much of her life. Her son also lives with her. Ulma was admitted to hospital amidst concerns that she was not being cared for properly at home, and arrangements were made for Ulma to live in a rest home. Ulma's son has turned up saying that he is going to take her back home. There are serious concerns about Ulma's son's motivations, and the provider believes it is not in Ulma's best interests to go back home.

What should be done?



Back to Ulma

- If Ulma does lack capacity to make her own decisions, there is an obligation to take steps to ensure Ulma is safe
- Any decisions made on behalf of Ulma must be in Ulma's best interests
- It may be necessary to obtain a court order that Ulma reside at the rest home
- If the son has EPOA, it may be necessary to apply to the court for a review of the son's decision to take Ulma back home



What are the roles of the various agencies?



Court orders

Orders and powers under the PPPR Act

- The PPPR Act provides for the Court to make:
 - Personal orders** that deal with the care and welfare of the person in question
 - Property orders** appointing a property manager or administrator to look after the person's property affairs



Personal Orders

- Where a person **lacks mental capacity** to manage his or her affairs the Court may make personal orders authorising certain actions or allowing others to manage those affairs, for example:
 - Particular medical advice or treatment
 - Rehabilitative, therapeutic, or other services of a specified kind
 - Living arrangements specified in the order
 - That the person shall enter, attend at, or leave an institution specified in the order (but not a psychiatric hospital)
 - Appointing a welfare guardian to make decisions about the person's care and welfare
 - To administer property
- Court may make further orders as is considered necessary to give effect, or better effect, to a personal order
- Personal Orders expire on the date specified in the order or after 12 months or sooner where the effect of the order is spent



Case study 6: Georgina

Case Study

Georgina is 66 years old. She lives with her daughter and her son in law, and their adult children. She suffers from early stage dementia. She is admitted to hospital due to a fall. She has marks on her wrists, and appears to not be eating and drinking properly. When asked whether everything is OK at home, she confirms that it is. She says that she wants to go home as soon as possible.

On a follow up visit by a community social worker, one of the adults at the house mentions that from time to time, they tie Georgina to a chair to "keep her safe".

What should happen next?



Who is a vulnerable adult?

- A vulnerable adult = a person unable, by reason of detention, age, sickness, mental impairment, or any other cause, to withdraw himself or herself from the care or charge of another person



The duty

- Everyone who has actual care or charge of a person who is a vulnerable adult and who is unable to provide him or herself with necessities is under a legal duty to:
 - Provide that person with the necessities
 - To take reasonable steps to protect that person from injury (Crimes Act, s151)



Ill treatment and neglect

- Section 195 of the Crimes Act sets out an offence
- The offence focuses on:
 - Ill-treatment or neglect of a child or a vulnerable adult
 - Previously focussed only on children
- If found liable under section 195 there is now a maximum penalty of 10 years imprisonment



When will a person be liable under section 195?

- Must be a person who:
 - Has actual care or charge of a child or vulnerable adult ("the victim"); or
 - A staff member of any hospital, institution or residence where the victim resides; and
- Must:
 - Either intentionally harm the person; or
 - Omit to discharge a duty (and the omission was likely to result in the victim being harmed); and
- Major departure from standard of care expected



The new section 195A

- Section 195A is entirely new
- Imposes a duty on particular people to take reasonable steps to protect vulnerable adults or children (victims) from a risk of:
 - Death;
 - Grievous bodily harm; or
 - Sexual assault; and
- As well as setting out the duty, it also sets out that a failure to take such steps is an offence
- Maximum penalty of 10 years imprisonment



Who will be liable under section 195A?

- Persons who:
 - Reside in the same household as the victim or are a staff member of any hospital, institution or residence where the victim resides; and
 - Have frequent contact with the victim; and
 - Know that the victim is at risk; and
 - Fail to take reasonable steps to protect the victim from the risk



Back to Georgina

- If the issue of possible abuse and/or neglect became apparent while Georgina was in hospital = obligation to take reasonable steps to protect Georgina from injury. This may simply involve speaking with Georgina if she has capacity or arranging an assessment if there are concerns about her capacity
- If Georgina lacks capacity, further steps will need to be taken
- If the issue of possible abuse and/or neglect becomes apparent when Georgina is home, there is likely to be a professional obligation to take reasonable steps, but there is unlikely to be criminal liability in relation to a failure to do so



Final points

These are tricky situations



How to bridge the gap?



The problem is - there may only be you



Questions?

