ARAFMI

The Future for Caring and the Law

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The Caring Cauldron



Carers are multi-talented

Spectrum

- > Supporters
- Advocates
- > Financiers
- > Event managers
- Personal assistants
- Martyrs
- > Jugglers
- ➤ Lifetime committers
- Family parents, siblings or partners

AND are getting older



The Cared For are multi-faceted

Spectrum

- Complex needs
- Immersed in a system
- Dependant
- Challenging
- Evolving
- Poor or not
- Good days/Bad days
- Impaired capacity

AND are getting older



My Agenda

- 1. The Caring Context
- 2. The Law
- 3. Carers to do list
- 4. Cared for's to do list
- 5. Scenarios



Caring Context

The Journey of Caring

- The Carer Journey
 - Parent
 - Carer
 - Decision maker
 - Impaired capacity
 - Death
- The Cared For Journey
 - A Child
 - An adult
 - A Dependant
 - Impaired capacity
 - Death



Caring Context (cont)

The Legal Landscape

- Capacity
 - ➤ Children and capacity
 - >Adults and capacity
- Who are Decision makers
- Duty and responsibilities of decision makers



The Law of Capacity

- It's complicated!
- Major regulator of:
 - the relationship between carers and cared for
 - •The relationship with regulators and bureaucrats
 - •The relationship with health professionals
 - The relationship with service providers
- Can be major restriction on individual human rights
- Doctors uncomfortable with the concept and its assessment
- Can be opportunity for abuse



Why is assessing capacity important?

It is a pre-condition for everything in life

- Legal necessity
- Professional necessity
- Moral necessity



The Great Legal Presumption

All adults are presumed to have capacity for all decisions unless there is evidence to the contrary



The Law of Capacity (cont)

What is evidence to the contrary?

- It's a legal test not a medical test
- Doctors assess it against the legal test
- Capacity is generally where a person is able to:
 - Understand the nature and effect of a decision
 - •Freely and voluntarily make the decision
 - Communicate the decision in some way
- Must satisfy all three criteria
 - If not, then can be said to be of impaired capacity for that decision
 - •Then the issue of who can make the decision instead arises
- If pass the test, then can make their own decision



The Law of Capacity (cont)

Incapacity is *not* necessarily:

- A global condition
- A constant condition
- A poor MMSE test
- Bad memory
- Being old
- Ignorance
- Low IQ
- Eccentricity
- Conventional communication failure
- Bad or silly decisions
- Mental Ilness



The Law of Capacity (cont)

It is also nuanced

- Decision specific
 - •Heart transplant –v- Flu vaccination
- Domain specific
 - •Finances –v- Health care
- Time specific
 - Morning noon or night
- Age specific
 - Children under 10 are incapable
 - Children between 10 and 14 can be incapable
 - Children between 15 and 18 are capable subject to legal restrictions



Decisions for Incapable People



The Law of Substitute Decision Makers

Where do you find them?

- They can just exist without any formal authority
 - Eg a parent of a child or an Informal Decision Maker
- You can appoint them in a document
 - Enduring Power of Attorney
- They can be deemed by law to exist
 - Statutory Health Attorney
- Specific legislation creates them
 - Nominees
- A court or Tribunal appoints them
 - Eg Administrators and Guardians



The Roll Call of Substitute Decision Makers

The Smorgasbord

- Informal Decision Maker
- Enduring Power of Attorney
- Administrators
- Guardians
- Statutory Health Attorney
- Public Trustee
- Public Guardian
- Authorised signatory on bank accounts
- Representative (Aged Care Act)



The Roll Call (cont)

The Smorgasbord (cont)

- Advance Health Directive
- Advance Health Directive for Mental Health
- Responsible Person (Privacy Act)
- Nominee (Social Security Act)
- Nominees (NDIS)
- Nominated Support Person (Mental Health Act)
- Litigation Guardian (Court proceedings)
- Interstate Decision Maker
- New Zealand Decision Maker



An Urban Myth

The Next of Kin!

- Eg spouse or parent
 - What is their power for substitute decision making because of that status?
- Yes for parents with children under 18 (mostly)
- No for financial decisions for an adult unless that adult has made an EPOA or has had an Administrator appointed by QCAT



The Capacity Spectrum

Compare the Language

Impaired Capacity

Cannot understand the nature and effect of a decision, make the decision freely and voluntarily and communicate the decision

Mental liness

A clinically significant disturbance of thought, mood, perception or memory

Dementia

An irreversible loss of cognitive functioning in thinking, remembering and reasoning to such an extent that it adversely interferes with a person's daily life and activities



Mental Ilness is a capacity challenge

- Episodic
- Fluctuating
- Unpredictable
- Lapsing
- Good days bad days
- Treatable not irreversible
- Likely life long
- Complicated by ageing
- Supportive decision making



Discrete Issues

- QCAT
- Mental Health Regime
- EPOA
- Guardians
- Nominated Support Person
- Advance Health Directive Mental Health



QCAT - Qld Civil and Administrative Tribunal

- Super tribunal with lots of jurisdiction
- One is guardianship for personal and health care decisions
- QCAT determines an adult's capacity
- If an adult (aged 18 or over) does not have an EPOA for those decisions and has impaired capacity QCAT can appoint a Guardian to make the decisions
 - can be member of family or Public Guardian
- But an advance application for the appointment of a guardian can be made when the child is 17.5 years old to take effect when child turns 18



Mental Health Regime

- Mental Health Review Tribunal and Mental Health Court
- Broadly regulates assessment of mental health and treatment
- Not an assessment of capacity (unlike QCAT)
- An assessment of mental illness may be a factor in assessing capacity or it may not



Enduring Power of Attorney

- A document appointing people to make financial and/or personal and health care decisions for a person
- The powers are usually only activated by the impaired capacity of the person (with one exception)
- Crucial for everyone to have one (provided you have the capacity to make it)



Nominated Support Person

- Involuntary patient may appoint one or more
- The person can:
 - Receive all required notices to patient
 - Discuss confidential information about the patient
 - Support patient at MHRT
- Not a decision maker
- Still need EPOA or Guardian



Advance Health Directive for Mental Health

- Discrete addition to the Advance Health Directive
- Can state in advance what health care you do or do not want if ever you can't say – an advanced consent or refusal
- A treatment authority however does not require your consent
 - However if your AHDMH is adequate to provide consent for your treatment and care needs, a treatment authority must not be made
 - Eg you can consent to receiving ECT in an AHDMH
- Can also appoint an EPOA for Health care in an AHDMH



The Cared For Legal to do list

All depends on their capacity to do a:

- Will
- EPOA
- Advance Health Directive Mental Health



The Carer Concern

What happens if you can't care anymore?

- You die
- You lose capacity
- You lose the ability

What happens if you do nothing to prepare or plan for that?

- No Will
- No EPOA
- No financial plan

Chaos and crisis!



The Carer Plan

Will

- How to provide for a cared one if you die
- Provide sufficient resources for their care
- Preserve social security benefits for them
- Devices
 - Life interests
 - Protective trust
 - Special disability trust
- Attitude of other children beware of promises, promises the "promise to look after our sister or brother"



The Carer Plan (cont)

Enduring Power of Attorney (EPOA)

- How to provide for a cared one if you lose your capacity to do so
 - or to make decisions for them
- The EPOA doesn't normally provide care but can be authorised to use your finances to ensure care is provided
- Who to appoint
- Special terms and conditions in EPOA
 - -Re the extent and type of care and accommodation
 - Conflicts of interest
- Attitude of other children beware the "the preservation syndrome"



The Carer Plan (cont)

Other Issues for Carers

- Try to ensure you have your adult child prepared and use times of lucidity to get them to do an EPOA
- If not, apply to QCAT to be their Administrator and Guardian
- How to prepare for a child about to turn 18 and become an adult
 - Applying to QCAT be administrator and guardian
 - Can do in advance ie at age of 17.5 years
- Understand your legal responsibilities you are not just a parent or carer
 - Supportive decision making
 - General and Health Care Principles
- Think about becoming other decision makers e.g., nominees re NDIS



The Cared For to do List

Good things to do

- Will
- EPOA
- Advance Health Directive for Mental Health



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Scenarios



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The Bank Query

- You care for your 43 old son with ongoing issues with schizophrenia
- You've been operating his bank account for years as his informal decision maker
- One day you get a letter from the bank querying your right to do so
- You reply by telling them what you have been doing it for years
- They respond and say not acceptable and require you to formalise your right to do so
- What are you going to do?



The Wedding

- Your 28 year old daughter is currently an involuntary patient at a psychiatric hospital
- You visit her one day only to be told by her that she went out one day on leave and got married to a fellow involuntary patient
- What are you going to do?



The Reluctant Doctor

- Your 32 year old daughter lives with you and you are her carer and EPOA
- You take a keen interest in her health and up to this point have been prepared to accept what your daughter tells you about her medication regime and her compliance
- Lately however she has been less responsive and more secretive and her behaviour is starting a downward spiral
- You ring her doctor to discuss your concerns
- The doctor tells you he cannot discuss it as it would be breach of his confidentiality obligations to your daughter as his patient
- Will you accept that



Thank you And may you care well for them and yourself



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