LET ME DECIDE

DEMENTIA AND DECISION MAKING
The big Ds

- Dread
- Diagnosis
- Dementia
- Doom
- Decline
- Discounted

“At diagnosis we are immediately discounted—our views are discredited because of dementia….you become invisible in most conversations.”

Bill 85
We dread losing our mental capacity

Even though:

- Adults are presumed to have “capacity” until proven otherwise (Australian Law)

- A person is able to make a decision if they can:
  1. Understand the facts and choices involved
  2. Weigh up the consequences
  3. Communicate the decision

- Adults including people living with dementia have the right to make decisions which may put them at risk of a poor outcome.
Capacity to make decisions

- Is domain specific (financial vs health vs lifestyle etc)
- Recognises a hierarchy of decision complexity
- May depend on the complexity and implications of a decision
- May fluctuate with time and context
- "The vast majority of irrational choices are made by competent people"
“Even when we are losing the capacity to maintain the legal control over our lives, we can still make decisions about how we wish to live our lives.”

Trudy 91
Things don’t get much worse!

MEDICAL CERTIFICATE

This is to certify that

Mr N

is a long term patient of this medical practice. He is receiving ongoing medical treatment.

He does not have capacity either now or in the future, to sign any documents, make a new will or initiate any legal proceedings.

This Certificate was completed on 31/8/2010
We need to change the discourse

This requires:

- The **attitude** and belief that people understand what is said
- The **expectation** that people can participate in making decisions
- Appropriate **support** to ensure maximum participation in all decisions.
Aim of the Dementia Advocacy Service

To support people with memory loss and dementia to make their own decisions and continue to manage their lives so they can remain living successfully in the community for as long as possible.

Helping you stay in control
Advocacy

- **Is a process** of standing by, speaking and acting on behalf of and upholding the rights of an individual or group who have limited ability to exercise choice or their rights. Advocates act at a person’s direction to empower them.

- **Advocates work with a person to assist with a specific issue** or problem such as access to care or services, abuse etc. The advocate provides support until the problem is solved. Contact is usually short term.

- **Ongoing or linked advocacy** - As a consequence of an individual’s vulnerability or lack of family or other support an individual may choose to have ongoing support from an advocate.
Critical features of the person-centred advocacy approach

- Person centred support
- Empowerment
- Continuity of approach and support
- Providing information
- Recognising triggers for planning opportunities
- Documentation of decisions
- Revisiting ideas, options and choices/decisions made
- Ongoing strategy
- Independence of the advocate
- Client directed
- Watching brief regarding rights & safety
- Building trust through acceptance and practical assistance
- Attitude of capability
- Build on strengths
- Effective communication through supportive listening
- Minimise stress
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Client decision-making

- Encourage dialogue
- Understand priorities
- Provide information
- Ensure opportunities to revisit
- Support action
Michael has now decided & chosen to:

- Revoked his Enduring Guardianship
- Chosen his home
- Made a new Will
- Filed for a divorce
- Contacted 2 of his 3 sons
Joe

- 84 year old widower living alone
- Only family was 92 year old brother
- Extremely independent and resourceful
- Had refused medical treatment and support into his home
- Has very complex finances
Challenges for Joe

A reality that makes him vulnerable

- Joe has no problems but accepts his failing memory
- He fears dementia and thinks his memory will get better
- Resists future planning and had a complex financial situation
- Struggles with new systems and concepts (Webster Pack)

His view of the future

- Joe focuses on how well he is managing and wishes to retain control of decision making about his life
- He resists change & is angered by people saying he is not coping.
Joe’s choices

- Acceptance of medication for his medical conditions
- Referral to a specialist to investigate his memory loss
- An ACAT assessment and support through the process
- The introduction of a level of in-home support that he is happy with and which increased over time to 24 hour care
- A referral to Alzheimer’s Australia Tasmania for their Creative Well Group
- To stay living at home for as long as possible
- The advocate to attend medical, legal and other significant appointments
- Continuing to make decisions regarding his future.
- Accepting the need for alternate decision making to manage his complex finances
- His decision to move to residential care
Successful Supported Decision Making

Person-centred approach combines with rights-based advocacy

- Documentary evidence and prior instructions
- Past and present wishes
- Knowledge of client – values, communication, priorities

Successful Supported Decision Making
Living well with dementia is the new discourse. So we must recognise that:

- If we provide advocacy services it will be possible for individuals living with dementia to make their own choices & decisions
- But it is important to educate the community that individuals with dementia are able to participate in decision making
An Advocate is a good thing! Helping people if they have no family. She rings me. Sometimes people are hard to get & when they ring back you can’t remember what you needed to talk to them about.

Joe 84

“*The advocate thinks of things to help me.*”
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Thank You
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