



Queensland
Aphasia
Research
Centre

Deciding in Dementia: Balancing Supported Decision-making with Precedent Autonomy?

Michelle King, Bridget Burton, Asmita Manchha, Zheng Yen Ng, & Sarah J Wallace

Michelle King

michelle.king@uq.edu.au

 @nellBot73

A research centre of the



**STARS Education and
Research Alliance**

CREATING KNOWLEDGE | TRANSFORMING CARE



THE UNIVERSITY
OF QUEENSLAND
AUSTRALIA

Metro North
Health

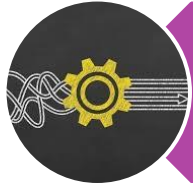


Queensland
Government

The Problem...



Precedent Autonomy (such as advance healthcare directives and powers of attorney) = common form of future planning by people with dementia.



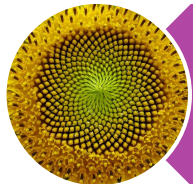
However, the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) Article 12 provides for **legal personhood and supported decision-making** for everyone with disabilities, including dementia.



This can **create a conflict** between a person's previous wishes and their right to be supported to make a new decision.



Should we respect the decisions a person made earlier (precedent autonomy), or should we support them to decide **now** (supported decision-making)?



Which “self” should decide?

What does supported decision-making mean for precedent autonomy?

Precedent Autonomy?

Form 2
Powers of Attorney Act 1998 (section 44(2))
Version 4, approved for use from 30 November 2020.

For patient record purposes, health services can affix identification label here

**Enduring power of attorney
–short form
(Queensland)**

This form allows you to appoint someone you trust (an ‘attorney’) to make decisions for you during your lifetime. Use this form to appoint:

- attorney(s) for personal (including health) matters only
- attorney(s) for financial matters only
- the same attorney(s) for both personal (including health) matters and financial matters.

Before you complete this form, read [Form 9 – Enduring power of attorney explanatory guide](#), consider who you want to appoint and talk to them.

This is a legal document that can significantly affect your legal rights. It is recommended that you seek independent legal advice before completing this form.

Forms and explanatory guides are available at www.qld.gov.au/relationships/planahead

ENDING POWER OF ATTORNEY – SHORT FORM | Version 4, approved for use from 30 November 2020. Queensland Government

- **Precedent Autonomy** is where we use what someone told us they wanted in the past to make decisions in the present
- Formal precedent autonomy is where someone writes down what they want in future (like a direction for health care) or appoints someone as a power of attorney / decision-maker to act for them in the future
- Often used by people who have dementia to make provision for what family and others should do if they “**lose capacity**”
- It specifies **now** how a person thinks they would like to decide **in future**
- Nearly all effectively act as forms of **substitute decision-making in practice**

But... The UNCRPD?

Able2L

UNCRPD Article 12 - Legal Personhood

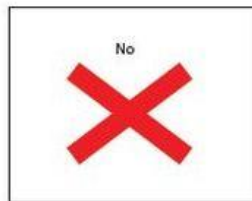
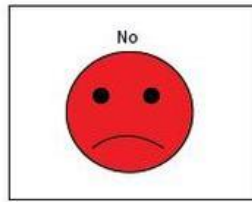
Merges legal standing with legal agency = all people have **legal 'capacity'**

Therefore = Supported Decision-making

- New Aged Care Act + Charter of Aged Care Rights (etc)

However

- Precedent autonomy is recommended to people with dementia as a way to be “included” in future decision-making
- Substitute decision-making (including precedent autonomy) is preferred (and sometimes, enforced) in aged care
- People with dementia in residential aged care are routinely excluded from decision-making in practice
- If we should support all people to make their own decisions, are there legal problems with relying on / requiring precedent autonomy and similar formal documents when decisions are being made?

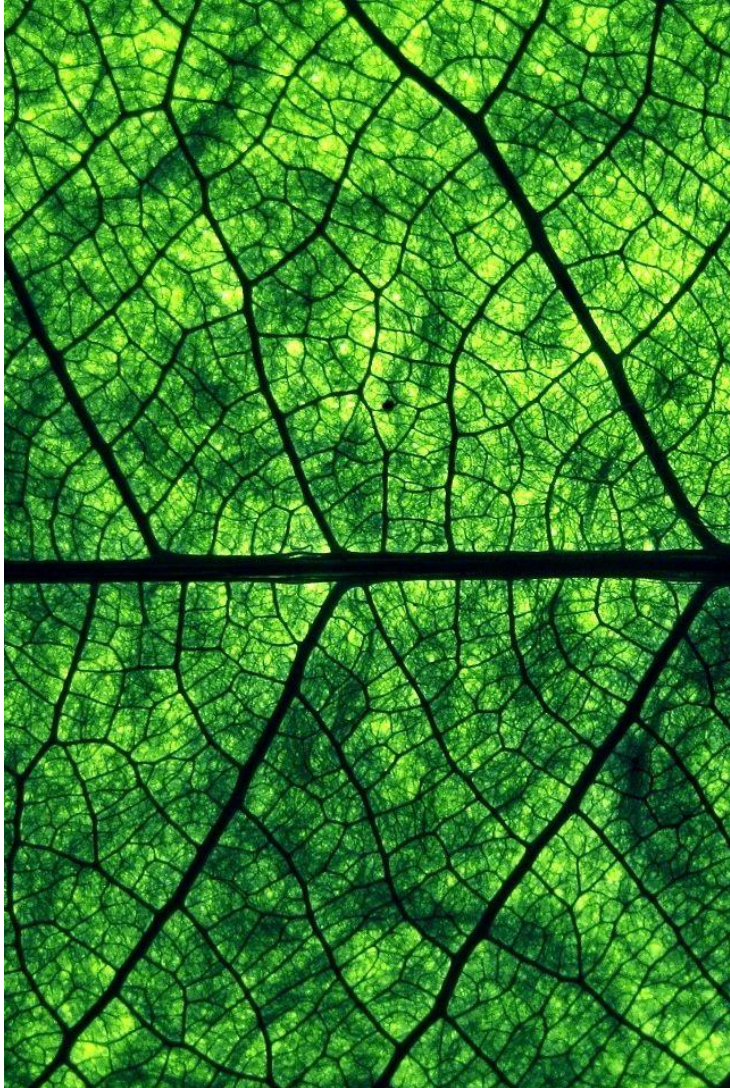


Precedent Autonomy as ‘Will and Preferences’?



- If a person can't communicate clearly about a decision, we need to make that decision based on their “**will and preferences**”
- This is **not** “best interests” (except in very limited circumstances)
- How do we determine someone's **will and preferences**?
- Precedent documents can indicate will and preferences **when the document was made**
- They may only be one part of interpreting a person's current will and preferences **when the decision is made**
- What if someone **disagrees with their own previous decisions**? When should we listen to them?
- Most future planning documents are based in forms of **substituted decision-making** and do not include requirements to use supported decision-making at all – so what then?

So... Which 'Self' Decides?



- Should we respect the decisions a person **made earlier** (precedent autonomy), or should we support them to **decide now** (supported decision-making)?
- Current preferences may be (seen as) incompatible with the previous 'self': what about the **dignity of risk**, or just changing your mind?
- What about "**best interests**" and issues of **safeguarding**?
- What about people who can no longer express will and preferences (the "**Hard Cases**")?
- What about what our **systems** require? Current practices **privileges substitute** decision-makers.
- How does this **work in practice now**? How should it work in future?
- **What should the law do?**

Conversations about Care
(MRFF)

+

Dementia Centre for Research
Collaboration Pilot Grant (2022)

+

UQSHRS ECR Startup Grant
(2024)



Queensland
Aphasia
Research
Centre

A research centre of the



**STARS Education and
Research Alliance**
CREATING KNOWLEDGE | TRANSFORMING CARE



THE UNIVERSITY
OF QUEENSLAND
AUSTRALIA
CREATE CHANGE



Metro North
Health



Queensland
Government

QARC's goal is to improve the lives of people with aphasia.

 **Website:** shrs.uq.edu.au/qarc



Interviews with:

14 people living with dementia

+

26 significant others of people
living with dementia

+

Aged care staff

(n 27 = 12 interviews and 2 focus
groups)

Decision-making and Dementia in Practice



Home Types of care ▾ Assessment ▾ Find a provider ▾ Manage my services ▾ Contact us

Legal information

If you are thinking about accessing aged care, you may want to think about who will manage your affairs as you age.

You may choose to give someone you know and trust powers to make decisions for you. You can arrange to give someone power of attorney over your affairs.

Powers of attorney, enduring powers of attorney, and enduring guardians

- Most *significant other* participants made decisions *for* a person by basing them on "what the person [would have] wanted" and/or using formal precedent autonomy documents
- *Participants with dementia* discussed precedent autonomy documents as the main way to represent "themselves" and their wishes NOW "for the future"
- *Staff* wanted formal documents and clear 'chain of command' of who can make a decision 'for' someone
- Decisions were discussed as in a person's "best interests", especially when this conflicted with that person's expressed or previous preferences
- Very few people mentioned supported decision-making or support for a person to make decisions

Powers of Substitute Decision-makers



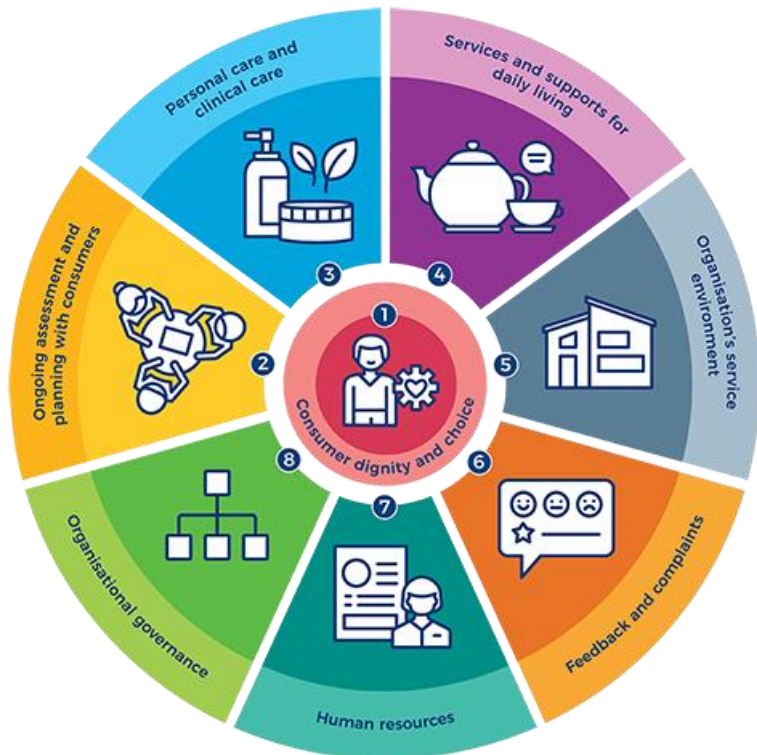
And say that according to the paperwork, or according to the statement of choice, that the resident wishes to stay in the facility for comfort care, shall we honour her wishes? **Although you're the EPOA, you can change that decision**, but shall we respect the resident's wishes to – to let her go peacefully and pain free and just make the best of what's left?

CAC 30 Staff

Best Interests Decision-making

The main issues for participants around decision-making was what to do when a person “can’t make good decisions” anymore. Key events triggering “best interests” concerns were:

- Diagnosis of dementia
- Driving
- Independence (leaving home alone)
- Daily life skills like shopping, eating and meal prep, bathing and dressing, and medication
- Money and finances (including Wills)
- Moving to residential care facilities
- Access to the person, usually when there was family conflict
- Health care decision-making
- End-of-life care



“Best Interests” Decision-making



I had to make some difficult decisions with her. uh, you know, **I had to get her licence revoked.** We had to get her car removed from the property. There are a few other difficult things we had to do with her. And with the poor short-term memory, she found it very hard to go through the process of having those things withdrawn from her life. *DCaC Staff 3*

The doctor would see her for 20 minutes and, you know, ask all the memory questions they ask and, you know, can you figure out this problem, and so they would see her for 20 minutes where she was really, really trying to prove that she was capable, but at home like she wouldn't shower for eight days, she wouldn't eat for three days, she would forget to take her meds for days, and so it was extremely frustrating. *CAC 35 SO*

If they're later stages of dementia and can't go home alone, but **they just want to go home alone?** Um, yeah [...] They don't have the capacity to make decisions. *DCaC SO12*

But...Safeguarding?



He was starting to wander out of the house looking for his childhood home, and he wouldn't, couldn't return to the house. [His wife] would have to go out for walking with him to keep safe. They were both in their late eighties walking around at two o'clock in the morning in the neighbourhood. It wasn't safe. And then he got out by himself and someone found him wandering, called the police. [...] Then the daughter then decided it was time for him to go into residential care. *DCaC Staff 2*

...because it became evident that Mum was making poor decisions. She actually ended up homeless for a short while and, like, just, you know, wanting her independence but not being able to think of the consequences or rationally think of the consequences of her choices. ... it became evident she couldn't care for herself. *CAC 32 SO*

Will and Preferences?



Once he... they were in the shops and he stole, he shoplifted. He stole a bottle of whiskey and put it under his coat [...] Um, anyway, the shopkeeper was really kind. And my family took that as 'well, we're obviously not giving him enough whiskey!' *DCAC SO9*

So, Mary would go and knock on the door of the neighbours and say that Andrew, which is the, um, make believe person, is in her roof and if [the neighbour] could come out – come and, you know, get him out. Yeah. Or she'd lock herself out [...]. Then, she started going to the Police every day.

Last week she was more and more paranoid, and she talks, talks about killing Andrew. [And we said to her neighbour] "It's dementia, it's hallucinations, delusions. It's not something – she would act upon." Um, but I think [the neighbour] is worried about her children, which is fair enough I suppose. *CAC 20 SO*

Supported Decision-making?



And I say that – oh, looking back now, with all the changes in perception, I now know about supported decision making. But I didn't even have support for decision making - to make any decision! In fact, I look back now, and **I can see how bullied I was by the system, and I in turn coerced my mother that this was “the best thing for her”**.

I said I'm a perfect example of **what not to do for supported decision making**. Because I can see back that there was, you know, we all were concerned about Mum's living, you know, staying alive, and not roaming and not hitting her head again, and not doing this and not doing that, but nobody was listening to what she really wanted. **And what she wanted to do was stay there in her own home and do her gardening, and not fall over. CAC 9 SO**

The 'So What'?



- How does precedent autonomy interact with federal and state decision-making regimes increasingly based in “supported decision-making”? **What are the legal and practical issues?**
- We need better guidance and practical frameworks for:
 - The role and duties of decision-makers/supporters
 - Dealing with decisions that place a person a real risk of harm
 - Changing your mind / support for the “current self”
 - People where there may be no meaningful capability to participate in decision-making
 - Practical + systemic realities of decision-making on the ground
- Can/should we rely on precedent autonomy documents based in substituted decision-making to “solve” decision-making for older Australians?
- **We need legal frameworks to think differently about these issues and practice frameworks to DO differently in practice**



Queensland
Aphasia
Research
Centre



If you support a person with dementia to make decisions – I'd love to interview you!
Scan the QR Code for the project EOI and fill in your details!

If you are interested in being part of a Roundtable on decision-making and aged care - email me!

michelle.king@uq.edu.au



@ShellBot73 (Bluesky)



<https://www.linkedin.com/in/michelle-king/>

A research centre of the



**STARS Education and
Research Alliance**

CREATING KNOWLEDGE | TRANSFORMING CARE



THE UNIVERSITY
OF QUEENSLAND
AUSTRALIA

Metro North
Health



Queensland
Government