Decision-Making Capacity: Legal Considerations

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New England Dementia Forum – 9 August 2023

TOPICS

1. Key principles

- Capacity, supporting capacity, capacity assessment

2. Planning for future incapacity

- Health and financial matters

3. Decision-making when a person can't make their own decision

- Substitute decision-makers

CAPACITY AND ITS LEGAL SIGNIFICANCE

- Capacity – the ability to make a decision for oneself

- Legal significance 
  - How we exercise autonomy and self-determination
  - Necessary for legally valid consent to healthcare
  - We have legal rights to plan in advance for loss of capacity

ASSUME CAPACITY

- The law assumes adults are able to make their own decisions

  "[e]very 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 (1914) 211 NY 125, Cardozo J

But what about a diagnosis of dementia?

NATIONAL DECISION-MAKING PRINCIPLES

- Everyone has an **equal right** to make decisions and to have their decisions respected.
- Persons who **need support** should be given access to the support they need in decision-making.
- A person's **will and preferences** must direct decisions that affect their lives.
- There must be **appropriate and effective safeguards** in relation to interventions for persons who may require decision-making support.

Australian Government

Australian Law Reform Commission

A PERSON HAS CAPACITY IF THEY ARE ABLE TO:

- ☑ understand the facts or information about a decision
- ☑ understand the choices available
- ☑ understand what will or could happen from making a decision
- ☑ use reason to weigh the risks and benefits of a decision
- ☑ clearly communicate consistent decisions

Judge capacity by the process of decision-making, not whether you agree or disagree with the decision.

CAPACITY CAN BE SUPPORTED

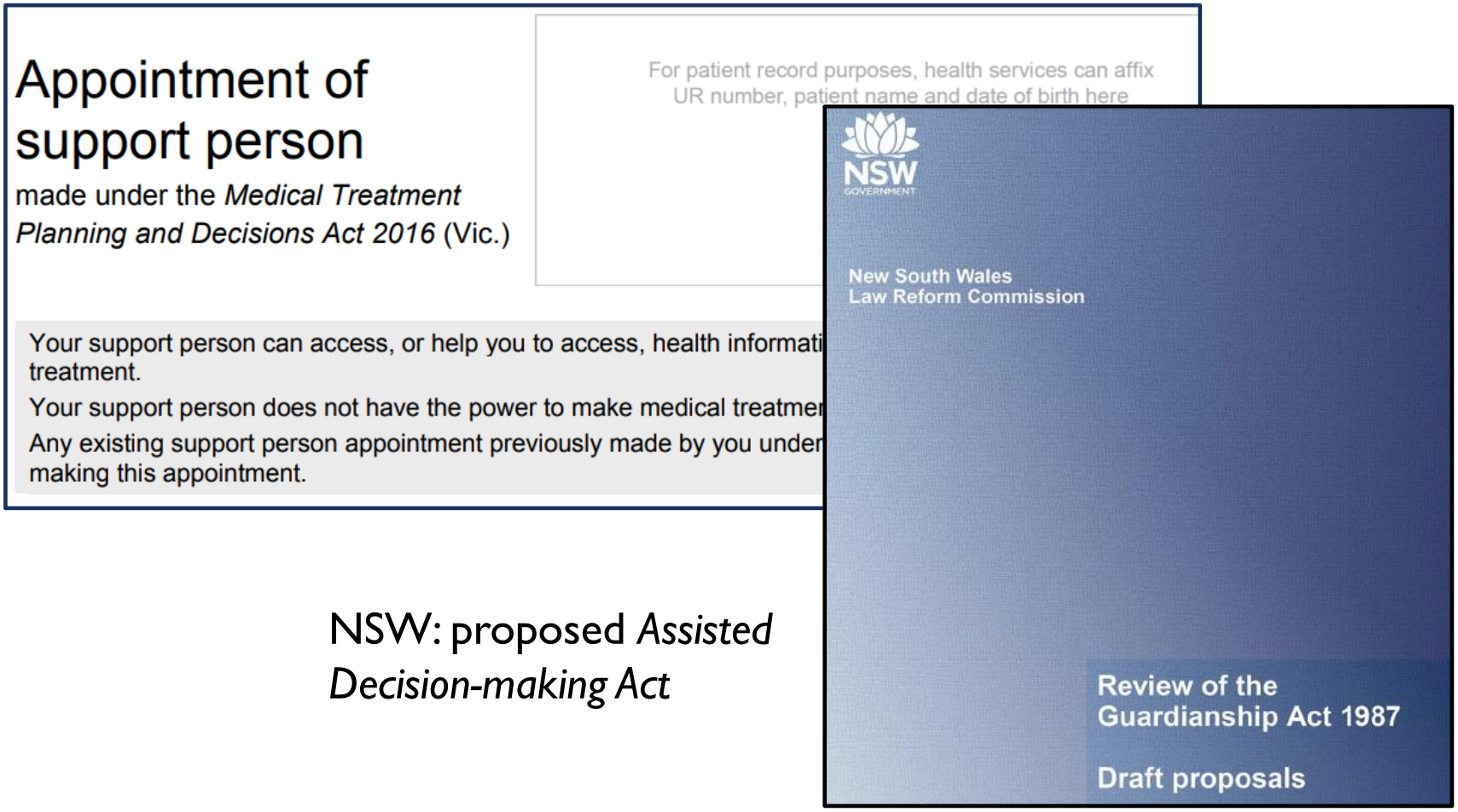
- ☑ Information
- ☑ Time
- ☑ Physical environment
- ☑ Stressors
- ☑ Physical health
- ☑ Trusted support person(s)

BEING A SUPPORT PERSON

- **helping someone make their own decisions** so they have control over things that are important to them
  - gather information
  - help person understand options and express decision
  - advocate for implementation

https://cdpc.sydney.edu.au/research/planning-decision-making-and-risk/supported-decision-making/

THE LEGAL POSITION IN NSW AND VICTORIA



Appointment of support person

made under the *Medical Treatment Planning and Decisions Act 2016* (Vic.)

For patient record purposes, health services can affix UR number, patient name and date of birth here

Your support person can access, or help you to access, health informati
treatment.

Your support person does not have the power to make medical treatmer

Any existing support person appointment previously made by you under
making this appointment.

NSW GOVERNMENT

New South Wales
Law Reform Commission

Review of the
Guardianship Act 1987

Draft proposals

NSW: proposed *Assisted Decision-making Act*

DIFFERENT KINDS OF DECISIONS

In-the-moment decisions

- healthcare
- money or property
- accommodation
- other day-to-day decisions

Future-oriented decisions

- making a will
- making an advance directive
- appointing an enduring representative

"This person lacks capacity."

Capacity for what specific decision?

How has capacity been supported?

Is it likely capacity will be regained?

CAPACITY REQUIRES CASE-BY-CASE ASSESSMENT

Capacity is:

- domain specific
- decision specific
- time specific

Assessment may be:

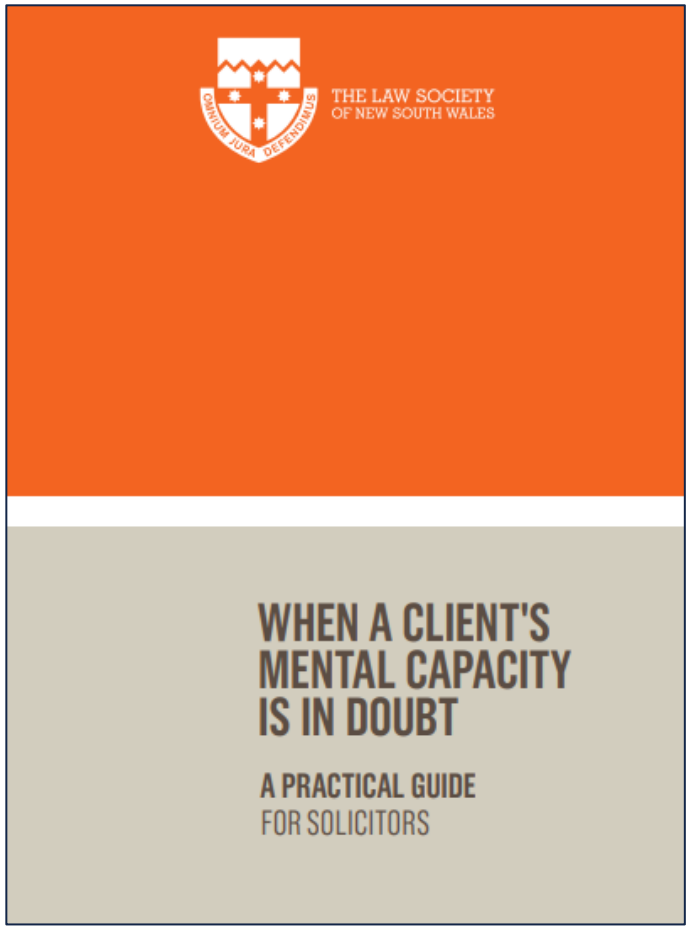
- Informal – by family, carer
- Formal – health and/or legal professional

Specific legal 'tests' may apply to assessing capacity for certain kinds of decisions.

LEGAL TESTS

Scott v Scott [2012] NSWSC 1541: "the concept of mental capacity must be assessed relative to the nature, terms, purpose and context of the particular transaction" or decision

- example: making a will (testamentary capacity)
  - understand nature and effect
  - extent of assets
  - possible beneficiaries
  - not a deluded or poisoned mind



FORMAL CAPACITY ASSESSMENT

- Assessment by medical / health specialist
- Information to guide the assessment:
  - Person's background
  - Decision or activity for which capacity needs to be determined
  - Relevant medical information
  - Information about person's social or living circumstances
  - Person's values and preferences

UNWARRANTED ASSESSMENT REQUESTS?

Psychosomatics 2017:58:483–489

Original Research Report

Capacity Evaluation Requests in the Medical Setting: A Retrospective Analysis of Underlying Psychosocial and Ethical Factors

Stephen Pesanti, M.D., M.B.A., Brandon Hamm, M.D., M.S., Bryn Esplin, J.D., Matt Karafa, Ph.D., Xavier F. Jimenez, M.D., M.A.

OVER 50% OF REQUESTS ARE UNWARRANTED

Background: *Psychosocial and ethical variables influence physicians in requesting decision-making capacity (DMC) evaluations. Previous authors have classified certain DMC evaluation requests as "unwarranted" when there is no explicit suspicion or evidence that the patient might lack DMC.* **Objective:** *To explore psychosocial and ethical reasons motivating both "warranted" and "unwarranted" DMC evaluation requests by physicians in the medical setting.* **Methods:** *A retrospective electronic health record review was approved by the institutional review board. All psychiatric consultation requests identified as DMC evaluation requests between January 1, 2012 and December 31, 2012 were assessed independently by 2 reviewers. Each reviewer identified each DMC evaluation request as "warranted" vs "unwarranted." Unwarranted DMC evaluation requests were defined as those lacking explicit suspicion that the patient might lack DMC or those with explicit evidence of a patient with blatantly impaired DMC. We hypothesized that most (over half) DMC evaluation requests would be deemed unwarranted. Descriptive statistics, chi-square/Fisher exact tests, and t-test/ANOVA were used.* **Results:** *A total of 146 DMC evaluations were reviewed, and 83 (56.8%) of these were deemed unwarranted. Of these, most were likely driven by a previous neuropsychiatric disturbance ($p < 0.001$). Various other psychosocial and ethical patterns were identified (i.e., the practice of defensive medicine and guardianship concerns).* **Conclusion:** *Over half of DMC evaluation requests in a general medical setting were unwarranted. Many such requests were motivated by unarticulated psychosocial and ethical factors. DMC evaluation requests appear to serve as a means for indirectly resolving various psychosocial and ethical dilemmas beyond assessing DMC itself. Implications and future directions are discussed.*

(Psychosomatics 2017; 58:483–489)

INTERNAL MEDICINE JOURNAL

RACP Specialists. Together

doi:10.1111/imj.15916

ORIGINAL ARTICLE

Waiting for guardianship in a public hospital geriatric inpatient unit: a mixed methods observational case series

Joanna Connolly [1] and Carmelle Peisah [2,3,4]

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- 45 older hospital patients where capacity was in question; guardianship order made in 44/45
- delays in or absence of appropriate capacity assessment
- factors contributing to impaired capacity
  - dementia
  - falls, dehydration, malnutrition, delirium
  - medication mismanagement
  - lengthy hospital stay
  - family discord, abuse of older person

HOW DO PEOPLE EXPERIENCE CAPACITY ASSESSMENT?

Developing and Piloting the Consumer Experience of Capacity Assessment Tool (CECAT)

Karen Sullivan & Kelly Purser *Psychiatry, Psychology and Law*, 2022

- Benefits: helpful, a relief, revealed the truth, united everyone
- Harms: demeaning, made the situation worse, caused disharmony
- Justice: fair, voluntary, involved trickery, coercion
- Process: clearly explained, thorough, confusing, intimidating

Need for clear explanation about capacity assessment process and what to expect.

PLANNING FOR FUTURE INCAPACITY

HEALTH AND FINANCIAL MATTERS

ADVANCE PLANNING

- A process of thinking about, discussing and documenting your **values and preferences**.
- Focused on **future situations** when you are unable to make and communicate your own choices.
- **Healthcare**: What types of care would you want to receive? What outcomes would you consider acceptable?
- **Financial**: How do you want your finances managed? For what purposes do you want your money used?

LEGAL ASPECTS

- Appointing an **enduring representative**
  - **Enduring guardian** – health and personal decisions
  - **Enduring power of attorney** – financial and property decisions

- Preparing an advance directive

End of Life Planner

An interactive guide that helps you to prepare for end of life tasks.

What's in the planner?

The planner will assist you in preparing for the following:

Will preparation

Begin planning which assets to include in a will.

Learn more

Enduring Power of Attorney

Consider nominating someone you trust to manage your financial affairs.

Learn more

Enduring Guardianship

Consider nominating someone you trust to make health related decisions if you're not able to yourself.

Learn more

Funeral wishes

Create a plan for your funeral to share with family and friends.

Learn more

Find a professional advisor

Book an appointment with NSW Trustee & Guardian or find a solicitor to prepare formal legal documents.

Learn more

Downloadable PDF

Once you complete the planner, you can download a summary to share with your family and professional advisor.

https://www.nsw.gov.au/family-and-relationships/end-of-life-planner

ENDURING GUARDIAN

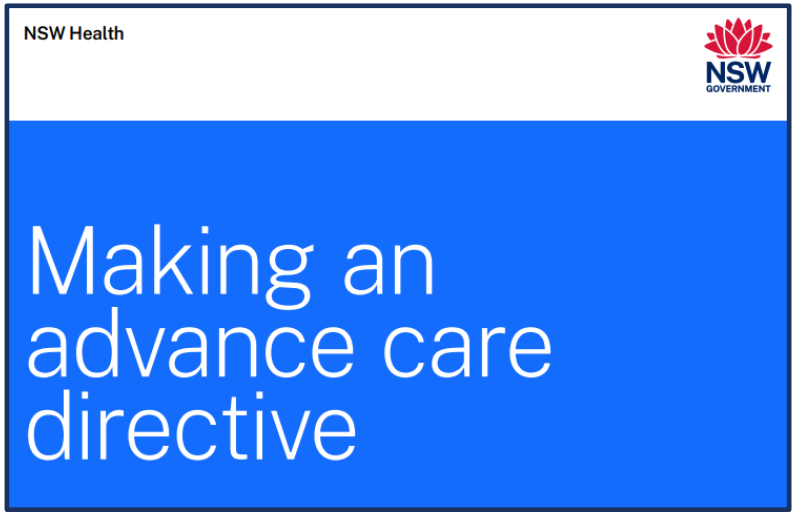
- An Enduring Guardian has the legal authority to make **health** and **lifestyle** decisions
- May be one or more people
- Can specify the types of decisions the Enduring Guardian can make

APPOINTING A GUARDIAN

- Complete Appointment of Enduring Guardian form
- Specify the decisions the Guardian can make
- Give other directions
  - consult with specific people before making a decision
  - follow Advance Healthcare Directive
- Form must be signed by Guardian and witnessed

ADVANCE CARE DIRECTIVE

- States values, wishes and preferences for care
- Records directions about specific treatments
- Comes into effect when person not able to make and express decisions



CASE SCENARIO – MR A

- A man completes a 'worksheet' provided by his Jehovah's Witness congregation
  - he indicates that he refuses blood transfusions and dialysis
- One year later, he is admitted to hospital suffering from septic shock and respiratory failure
- Doctors put him on mechanical ventilation and kidney dialysis to sustain his life
- The worksheet is subsequently brought to their attention

NSW SUPREME COURT DECISION

"A person may make an 'advance care directive': a statement that the person does not wish to receive medical treatment, or medical treatment of specified kinds. If an advance care directive is made by a **capable adult**, and is **clear and unambiguous**, and extends to the **situation at hand**, it must be respected. It would be a battery to administer medical treatment to the person of a kind prohibited by the advance care directive."

Hunter and New England Area Health Service v A [2009] NSWSC 761

PRINCIPLES

- "right of a capable adult to refuse medical treatment"
  - "not concerned with any such notion as 'the right to die'" [para 4]
- "common law recognises two relevant but in some cases conflicting interests:
  - a competent adult's right of autonomy or self–determination: the right to control his or her own body; and
  - the interest of the State in protecting and preserving the lives and health of its citizens." [para 5]
- "a medical practitioner confronted with a clear choice made by a competent adult on the basis of social, religious or moral values must respect that choice, even though the practitioner does not share the values underpinning it" [para 14]

INTERPRETING A DIRECTIVE

"…if there is any real doubt as to the sufficiency of an advance refusal of medical treatment, the court should undertake a careful analysis. But the analysis should start by **respecting the proposition that a competent individual's right to self-determination prevails over the State's interest in the preservation of life** even though the individual's exercise of that right may result in his or her death. An over-careful scrutiny of the material may well have the effect of **undermining or even negating** the exercise of that right.

It is necessary to bear in mind that not all those who execute advance care directives are legally trained. Their words should not be scrutinized with the care given to a particularly obscure legislative expression of the will of Parliament. On the other hand, particularly bearing in mind the likely consequences of upholding an apparent exercise of the right of self-determination, the court must **feel a sense of actual persuasion that the individual acted freely and voluntarily, and intended his or her decision to apply to the situation at hand.** … It cannot be correct to recognise, on the one hand, an individual's right of self determination; but, on the other, effectively to undermine or take away that right by over-nice or merely speculative analysis."

Hunter and New England Area Health Service v A [2009] NSWSC 761, para 36, 37

REALITY CHECK

- Low uptake of advance care directives
- Someone else making a directive for a person
- Directives disregarded
- Variable quality and uncertain validity

Australian Health Review, 2018, 42, 89–92
http://dx.doi.org/10.1071/AH16205

Case Study

Advance care directive documentation: issues for clinicians in New South Wales

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Abstract

Objective. The aim of the present study was to assess the characteristics of documents presented as advance care directives (ACDs) at a public health organisation in New South Wales (NSW). It was envisaged that the findings would inform the refinement of locally developed educational strategies.

Methods. All ACD documents provided during hospital admissions and entered into the electronic medical record system over a 12-month period were reviewed. An audit tool was developed and used to identify whether key requirements for ACDs in NSW had been addressed.

Results. Of the 100 ACDs that were reviewed, only 50 were assessed as being valid to inform future clinical scenarios. Multiple templates with different designs and of varying length had been used.

Conclusions. Documents identified as ACDs may carry doubt about their validity. Clinicians require education about differences in template formats, the application of content to clinical decisions and associated legal responsibilities.

POWER OF ATTORNEY

- A legal document appointing a person or organisation to manage your **financial** and **legal** affairs while you are alive
  - e.g. money, bank accounts, shares, real estate
- You can give instructions
- **Does not** cover health or lifestyle decisions

- **Ordinary Power of Attorney**
  - acts on your behalf for specific times or situations
    - e.g. during an overseas trip or a hospital stay
  - ceases if you lose capacity
- **Enduring Power of Attorney**
  - continues to apply if you lose capacity

DECISION MAKING FOR A PERSON WHO CAN'T MAKE THEIR OWN DECISIONS

WHO DECIDES?

SCENARIO

A middle-aged woman with a life-limiting disease, taken to hospital unconscious, with a consequent need for health decisions to be made

WHO IS THE DECISION-MAKER?

A middle-aged woman with a life-limiting disease, taken to hospital unconscious, with a consequent need for health decisions to be made by others. She had not completed an AD nor appointed a substitute decision-maker. The following potential decision-makers were present at the hospital: the patient's husband (from whom she has been separated for many years); her son (who is also her attorney for financial matters); her daughter (who is currently her full-time carer); and the patient's same-sex partner of 5 years.

PERSON RESPONSIBLE (NOT 'NEXT OF KIN')

1. Guardian – appointed by person or NCAT
2. Spouse – wife, husband, de facto partner; where more than one person fits definition, most recent person
3. Person who provides care (not paid)
4. Close friend or relative

BECOMING A SUBSTITUTE DECISION-MAKER

Ideally, the substitute decision-maker should be:

- available (live in the same city or region) or readily contactable
- willing to discuss and understand the person's values and wishes
- able to support decision-making where possible
- comfortable talking to doctors, other health professionals and family members
- able to advocate for the person
- prepared to make decisions clearly and confidently on the person's behalf, based on their own values and preferences

Do our risk preferences change when we make decisions for others? A meta-analysis of self-other differences in decisions involving risk

PLoS ONE 14(5): e0216566.

Eleonore Batteux[1]*, Eamonn Ferguson[1], Richard J. Tunney[2]

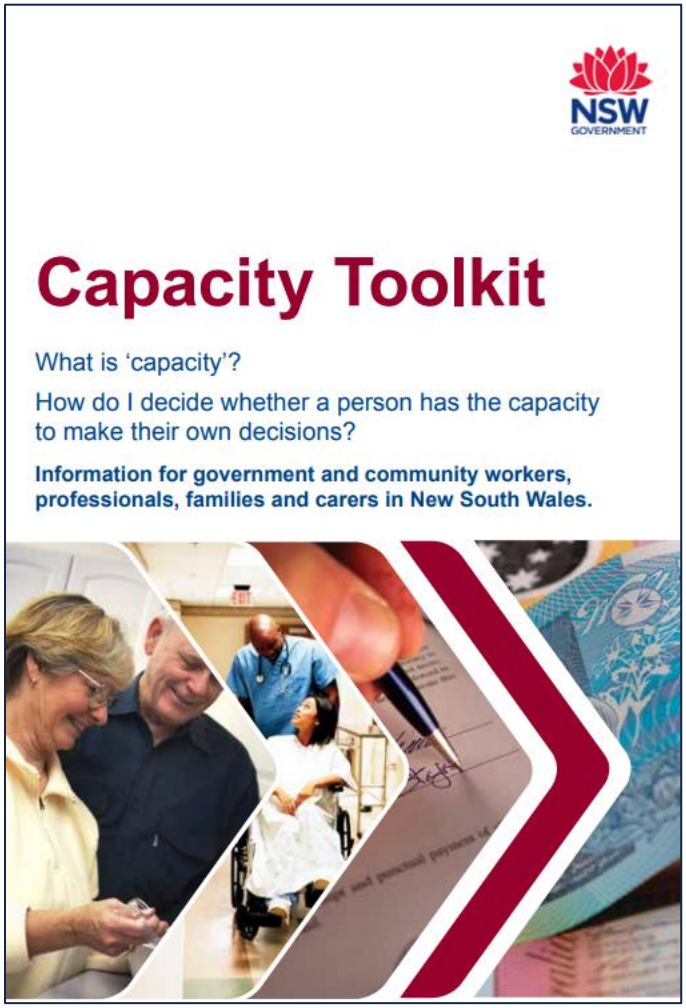
Exploring How Accountability Affects the Medical Decisions We Make for Other People

Front. Psychol. 10:79.

*Eleonore Batteux[1], Eamonn Ferguson[1] and Richard J. Tunney[2]**

Being a substitute decision-maker

SUMMING UP



Capacity Assessment	→	Presumed Capacity
Substitute Decision Making		Supported Decision Making
Best Interest	→	Will and Preference
Capacity is fixed		Capacity can be built
Decisions are made independently	→	Decisions are made with support

HNE COMMUNITY HEALTHPATHWAYS

Community HealthPathways

Hunter New England

https://hne.communityhealthpathways.org/

Username: hnehealth

Password: p1thw1ys

patient info HUNTER NEW ENGLAND

http://patientinfo.org.au/

No password required

Decision-making Capacity

See also Consent.

Background

About decision-making capacity

Assessment

It is not necessary to assess capacity in a life-threatening emergency, however, if there is an advance care directive (ACD), this is a legally binding document.

1. Prepare for the assessment:
   - Determine what has prompted a capacity assessment. Consider common triggers.
   - Identify the particular decision the patient is seeking to make. Capacity is decision-specific.
   - Gather information to inform assessment.
   - Determine whether a substitute decision-maker e.g., enduring guardian or power of attorney/financial manager has already been appointed.
   - Allocate sufficient time with the patient and support people.
2. Check understanding:
   - Explore with the patient their understanding of the decision being made and choices available.
   - Where possible, provide education and support about the available options. Do not mistake a lack of knowledge for incapacity.
   - Arrange an interpreter, if necessary.
   - Use the teach-back technique.
3. Check decision-making:
   - Consider personal beliefs and values that may impact on decision-making.
   - Ask specific questions relating to the decision being made. Capacity is domain-specific:
     - Financial matters
     - Medical treatment consent
     - Legal matters
   - Determine if there are any risks of impaired decision-making.
   - Assess for any impaired decision-making capacity as a result of a treatable condition. Capacity, or lack of capacity, is time-specific and not necessarily permanent.
4. Check communication – Consider whether the patient:
   - Has a TOP5.
   - Requires an interpreter.
   - needs assistance to communicate their thoughts about the choice.

Management

> Practice point
>
> **Beware decision-making capacity can change**
>
> Decision-making capacity can change over time. A person's capacity should be assessed at the time a treatment decision is needed. A person may have capacity for some decisions but not others, and their capacity to make decisions can change over time.

1. Communicate the outcome of the assessment to the patient, and its implications for them.
   - Specify the domains and decisions where capacity is intact and where it is impaired.
   - Encourage decision-making in matters where capacity is intact, even when many decisions will require a substitute decision-maker.

   If there is inadequate evidence that capacity is impaired, no further action is required.
2. If uncertainty remains, request an appropriate specialist assessment, e.g. geriatrician referral, neuropsychiatrist or neuropsychologist referral.
3. For testamentary capacity concerns, advise patient and/or person responsible to seek legal advice.
4. If urgent clinical decisions are required:
   - Check the patient's advance care directive (ACD) for guidance, if available.
   - If a guardianship order is in place, attempt to contact the appointed guardian.
   - If none of the above are available, seek direction from the person responsible.
   - If there is no person responsible, an application to the NSW Council & Administrative Tribunal (NCAT) is necessary for consent. Where a person objects to treatment, the NCAT may authorise a guardian to give consent, if it is satisfied the person's objection is due to them not understanding the nature of or reason for the treatment.
5. If impairment in capacity may be related to mental illness, manage according to the relevant Mental Health pathway. Consider using Easy to Read Information Sheets on Mental Health Services in NSW.
6. Discuss with the patient and carers the legal mechanisms to allow substitute decision-making in financial, welfare, and health matters:
   - Activation of financial management order (formerly known as enduring power of attorney) or guardianship order, if in place.
   - Application to the NSW Civil & Administrative Tribunal (NCAT) for:
     - financial management order (formerly known as enduring power of attorney) – for financial decisions.
     - guardianship order – for managing personal welfare and health decisions.
   - General practitioners can phone the NCAT Guardianship Division **1300-006-228**.

   See NSW Trustee & Guardian – Information for Medical and Healthcare Practitioners.
7. Document contact details for any appointed attorneys or legal guardians in the patient's medical record.

Referral

- If uncertainty remains, request a geriatrician referral, neuropsychiatrist or neuropsychologist referral.
- For testamentary capacity concerns, advise the patient and/or person responsible to seek legal advice.

Consent

This page provides a general summary of consent principles only. See also:

- Advance Care Planning (ACP)
- Decision-making Capacity

Background

About consent

Management

> Practice point
>
> **Encourage shared decision-making**
>
> The discussion you have with your patient is fundamental to the consent process. This is an ongoing process and more than just the signing of a form.

1. Determine that the patient has the capacity to consent to the treatment or procedure – see the Decision-making Capacity pathway.
2. Ensure that the patient has given their consent voluntarily after discussion of risk.
3. Encourage shared decision-making – the discussion you have with your patient is fundamental to the consent process. This is an ongoing process and more than just the signing of a form.
4. Disclose sufficient information to allow the patient to make an informed decision.
5. Discuss risk in general, specific, and particular terms. A known risk should be disclosed when:
   - an adverse outcome is a common event, even though the detriment is slight.
   - an outcome is severe, even though its occurrence is rare.
6. Check patient understanding:
   - Explore with the patient their understanding of the decision being made and choices available.
   - Where possible, provide education and support about the available options. Do not mistake a lack of knowledge for incapacity.
   - Use the teach-back technique.
7. Document the discussion in the patient's notes.
8. Consider the following specific situations:
   - Emergency treatment
   - Implied consent
   - Minors and consent
   - Impaired capacity to provide fully informed consent, including patients with intellectual or cognitive disability
   - Patients from a culturally and linguistically diverse background – consider if an interpreter is required
   - Challenging situations
   - Informed refusal
9. Where people lack capacity to consent:
   - If the patient doesn't object, seek consent from the person responsible, who can consent for major or minor treatment.
   - For minor treatment, if there is no person responsible, or the person responsible cannot, will not, or is unable to consent, you may treat without consent. However, you must note on the patient's record that the treatment is necessary to promote the patient's health and well-being and that the patient isn't objecting. [5]
   - An application to the NSW Civil & Administrative Tribunal (NCAT) is necessary if consent is required for:
     - special medical treatment.
     - the use of psychotropic medications outside accepted use i.e., chemical restraint.
     - treatment that the patient indicates, or has previously indicated, that they do not want carried out.
     - participation in a clinical trial.
     - major treatment if there is no person responsible or the person responsible is unwilling to provide consent.

Information

For health professionals

For patients

QUESTIONS?

- Thank you