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2025 WILLS AND ESTATES CONFERENCE

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CAPACITY ASSESSMENT: HOW TO DETERMINE WHO CAN DECIDE

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LEGAL CAPACITY

A legal construct which impacts upon medical decision making

"Capacity is a legal construct, it is fluid, decision specific, and context dependent"*

Capacity is assumed unless lack of capacity has been established

* O'Neill, N. K. F. & Peisah, C. (2012) *Capacity and the law*. Sydney University Press, Sydney

CAPACITY TO MAKE DECISIONS: GENERAL PRINCIPLES

For health professionals, assessing a patient's decision-making capacity is a part of every patient encounter.

For the most part, the process is spontaneous and straight forward.

Through dialogue, the clinician is able to confirm that the patient understands their health situation and options for treatment or care.

CAPACITY TO MAKE DECISIONS: GENERAL PRINCIPLES

Important to distinguish a **decision outcome**, what a person has decided, from the **decision-making process**, how the person came to that decision or choice.

Concept of **decisional relativity**: decision making is fluid, and decision-making capacity can vary according to different situations and different tasks.

HOWEVER..

Cognitive and physical changes in our older adult population can be linked to decline in everyday functioning that includes loss of decision-making skills

As a result, there are times when there is a need to assess a patient's decision-making capacity more thoroughly and in keeping with legal standards

Neglecting to assess capacity when necessary may result in physical or legal harm by the client continuing to make decisions that are not in their best interest

TRIGGERS FOR ASSESSMENT OF COMPETENCE

From a **medical perspective,** triggers can include:

- patients behave in a manner that is out of character and carers/family raise question about competence

- patients refuse treatment that is deemed to be clearly beneficial

From a **legal perspective,** triggers may include:

- disputes over a deceased's will and estate

- perceived coercion or undue influence by one party over another person

LEGAL STANDARD FOR COMPETENCE

Legal standard for competence addresses one of or more of the following:

1. Ability to communicate choices – involves ability to maintain and communicate stable choices for long enough to be implemented.

2. Understanding information relevant to the choices – involves ability to understand causal relations and likelihood of various outcomes.

3. Appreciating the situation and its consequences – understand the specific implications it carries for one's future.

4. Manipulating information in a rational manner – ability to use logical process to compare risks and benefits. Examine patient's chain of reasoning.

Appelbaum PS, Grisso T (1988) *Assessing patients' capacities to consent to treatment*. **NEJM** 319 (25): 1635-1638

DOCTRINE OF INFORMED CONSENT

A client or patient must be adequately informed prior to undertaking a capacity assessment.

Sufficient information on which to base a decision must be given. This may outline:

- nature of illness/disorder

- details of treatment

- risks and benefits of treatment in the longer term

Appelbaum PS, Grisso T (1988) *Assessing patients' capacities to consent to treatment*. **NEJM** 319 (25): 1635-1638

SIX STEP CAPACITY ASSESSMENT PRINCIPLES

1. Always presume capacity
2. Capacity is decision specific
3. Don't assume a person lacks capacity based on appearances
4. Assess a person's decision-making ability, not the decision they make
5. Respect a person's privacy
6. Substitute decision making is a LAST resort

NSW Government Capacity Toolkit (2020)
https://dcj.nsw.gov.au/documents/resource-centre/capacity-toolkit/capacity-toolkit.pdf

"Your grandma and I have decided to live together"

CASE STUDY 1

Mrs X is an 86 year old patient admitted to hospital with falls secondary to urinary tract infection

She lives alone and has a son B and daughter in law M who state that mum has not been looking after herself and needs to go into a residential aged care home

Mrs X wants to go home. She is lying in bed most of the day, refusing to have physiotherapy. An occupational therapist assessment deems her at high risk for falls if she were to return home

Her Mini Mental State Examination score with a Polish telephone interpreter is 18/30

CASE STUDY 1

1. Does Mrs X have decision-making capacity in relation to her discharge destination and long-term accommodation?

2. What other information do you need to gather?

CASE STUDY 1

There is no Enduring Power of Attorney

Mrs X has two sons M and L (lives overseas in Morocco)

L arrives in Canberra and explains that although his mother was born in Poland, she was brought up in France and her main language is French

A French interpreter is booked and a formal capacity assessment is undertaken on two separate occasions.

Mrs X is deemed to have decision making capacity. Her Rowland Universal Assessment Scale was 28/30

CASE STUDY 1: LESSONS LEARNT

Information gathering including social, family, functional and cognitive history are important prerequisites to a capacity assessment

Always involve an interpreter if the assessment can not be done adequately in English. And make sure it is the correct interpreter!

Maintain some scepticism when interpreting assessments of other clinicians (doctors, nurses, allied health) in the hospital setting

ASSESSMENT OF CAPACITY

Domain/decision specific - at the point in time when a particular decision is made, does the individual understand the nature and effect of the decision?

Emphasis on optimal communication and circumstances

- Use of interpreter
- Defer until acute episode resolved in case of delirium or depression
- Should be done independently without family, carers, or lawyers present. Support person may be required if the client is anxious but this person should not influence the assessment process

OUTCOME OF CAPACITY ASSESSMENT

Capacity is difficult to measure

May fail to prove decision-making capacity because:

1. It is not present
2. The process used was inadequate
3. The person applying the process did not apply it properly

ASSESSING CAPACITY

Cognitive assessment scores cannot be used alone

- Important to assess other cognitive domains such as judgement, executive function, not just memory

Functional tests should be domain specific (different for finances or personal care decisions)

- Ability to handle finances
- Ability to undertake personal activities of daily living (e.g. showering, toileting, dressing)

CAPACITY: SIX C'S

A capable person:

1. knows the **Context** of the decision at hand (is not making choices based on delusional constructs)
2. knows the **Choices** available
3. appreciates the **Consequences** of specific choices
4. applies logical reasoning to **Compare** between choices
5. is **Consistent** in their choice (and there is no undue influence or coercion)
6. is able to **Communicate** their choice

WHO CAN ASSESS CAPACITY?

No stipulation in Australia - courts/tribunals decide whose evidence to accept

Generally, is the responsibility of the person accepting the decision (lawyers for legal documents, doctors for healthcare matters, bank managers for loans etc)

Expertise usually sits with professionals who make such assessments on a regular basis and have some understanding of the impact of cognitive impairment or psychiatric illness on decision-making capacity.

Psychiatrists, psychogeriatricians, psychologists, aged care nurse practitioners, geriatricians:

- Appreciate “grey areas” such as multimorbidity, illness complexity, frailty
- Comprehensive assessment of the whole person in a social context and plan for future care needs
- Ability to assess a person in their own home (“home visit”)

MENTAL CONDITIONS AFFECTING CAPACITY

Acute stress disorder

Bipolar affective disorder

Depression

Schizophrenia

Dementia

Delirium

Intellectual disability

Any condition that causes **cognitive disability** – a level of cognitive function that can lead to difficulty with day-to-day tasks such as decision making and communication

COGNITIVE DISABILITY VERSUS COGNITIVE IMPAIRMENT

Cognitive disability arises from interaction between a person with cognitive impairment and attitudinal and environmental barriers that hinder their full and effective participation in society on an equal basis with others.

People with **cognitive disability** may include those with intellectual disability, learning disability, dementia, acquired brain injury and some people with autism.

Cognitive impairment is a term that encompasses actual or perceived differences in cognitive domains including concentration, processing, memory, learning, communication, awareness and decision-making.

https://disability.royalcommission.gov.au/publications/final-report-executive-summary-our-vision-inclusive-australia-and-recommendations

DELIRIUM AND CAPACITY

A. A disturbance in attention (i.e., reduced ability to direct, focus, sustain, and shift attention) and awareness (reduced orientation).

B. Is acute in onset - develops over a short period of time (usually hours to days), represents a change from baseline attention and awareness, and tends to fluctuate in severity during the course of a day.

C. Additional disturbance in cognition (e.g. memory deficit, disorientation, language, visuospatial ability, or perception)

D. Not better explained by a pre-existing, established or evolving neurocognitive disorder and do not occur in the context of a severely reduced level of arousal, such as coma.

E. Disturbance is a direct physiological consequence of another medical condition, substance intoxication/withdrawal, or exposure to a toxin, or due to multiple aetiologies.

DSM-5, *Diagnostic and Statistical Manual* fifth edition. (American Psychiatric Association, 2013)

DELIRIUM SCREEN – 4AT

https://www.the4at.com/

4AT

Assessment test for delirium & cognitive impairment

(label)

Patient name:

Date of birth:

Patient number:

Date: **Time:**

Tester:

CIRCLE

[1] ALERTNESS

This includes patients who may be markedly drowsy (eg. difficult to rouse and/or obviously sleepy during assessment) or agitated/hyperactive. Observe the patient. If asleep, attempt to wake with speech or gentle touch on shoulder. Ask the patient to state their name and address to assist rating.

Normal (fully alert, but not agitated, throughout assessment)	**0**
Mild sleepiness for <10 seconds after waking, then normal	**0**
Clearly abnormal	**4**

[2] AMT4

Age, date of birth, place (name of the hospital or building), current year.

No mistakes	**0**
1 mistake	**1**
2 or more mistakes/untestable	**2**

[3] ATTENTION

Ask the patient: "Please tell me the months of the year in backwards order, starting at December." To assist initial understanding one prompt of "what is the month before December?" is permitted.

Months of the year backwards	Achieves 7 months or more correctly	**0**
	Starts but scores <7 months / refuses to start	**1**
	Untestable (cannot start because unwell, drowsy, inattentive)	**2**

[4] ACUTE CHANGE OR FLUCTUATING COURSE

Evidence of significant change or fluctuation in: alertness, cognition, other mental function (eg. paranoia, hallucinations) arising over the last 2 weeks and still evident in last 24hrs

No	**0**
Yes	**4**

4 or above: possible delirium +/- cognitive impairment
1-3: possible cognitive impairment
0: delirium or severe cognitive impairment unlikely (but delirium still possible if [4] information incomplete)

4AT SCORE ☐

DELIRIUM AND CAPACITY

Ensure that attention is not impaired.

- Is the client able to direct, focus, sustain and shift attention?

Following a hospital admission or acute illness, give at least 6 weeks for a delirium to resolve.

Check with partner, family, or carers whether the client has returned to previous level of physical and cognitive function if there is a history of delirium.

DEMENTIA AND CAPACITY

Dementia is a neurocognitive disorder where there is progressive deterioration in cognitive function.

Most common forms of dementia, Alzheimer's dementia and Vascular dementia (or Mixed dementia) are slowly progressive over years.

Loss of short term memory alone does not determine a person's decision-making capacity in people living with dementia.

Neuroimaging is usually unhelpful in determining decision-making capacity but is part of routine clinical care in diagnosing dementia.

Neuroimaging may identify specific parts of the brain which correlate with areas associated with decision-making capacity but behavioural or interview testing is more accurate.

Darby RR, Dickerson BC. Dementia, decision-making, and capacity. *Harv Rev Psychiatry* (2017) 25)6): 270-278

OTHER DEMENTIA SUBTYPES

Frontotemporal dementia is the second most common form of dementia in younger adults. It affects executive functions, decision-making capacity early

Lewy Body dementia can be associated with fluctuations in cognitive function and attention. Delusions and visual hallucinations are prominent features.

DEMENTIA AND CAPACITY

Main cognitive domains affecting decision-making capacity are:

1. Executive functions – the ability to select a goal, have the motivation to achieve this goal, and the mental processes involved in achieving the goal. Enables goal-directed behaviours but at the same time, inhibiting other competing goals.

2. Determining expected reward or punishment associated with different choices. Incorporates expected value for a given choice, the amount the rewarding experience differed from what was expected, determination of choice with greatest reward.

3. Meta-cognition – awareness of one's cognitive limitations including emotional and motivational limitations. Important skill which allows people to adapt behaviour to avoid events where poor decision-making might occur.

Darby RR, Dickerson BC. Dementia, decision-making, and capacity. *Harv Rev Psychiatry* (2017) 25)6): 270-278

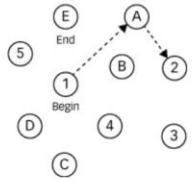
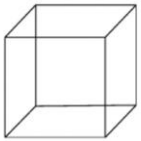
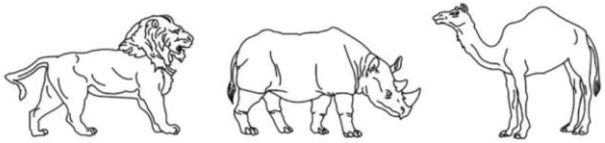
ASSESSING COGNITIVE FUNCTIONS

Executive function: trail making task, Stroop effect test

Memory function: episodic memory (short–term recall, digit span), working memory, semantic memory (general knowledge), verbal memory, visual memory (Ray-Osterrieth Complex Figure)

Meta-cognition assessment: can be assessed by comparing self-ratings with carer ratings of cognitive ability or self-rating versus actual performance on cognitive testing

MONTREAL COGNITIVE ASSESSMENT

Question number	Task/question
1. Executive functioning – alternate trail making	 Join the numbers and the letters in the order they ascend.
2. Visuospatial abilities – cube task	 Copy the cube.
3. Visuospatial abilities – clock task	Draw a clock with the time showing ten past eleven.
4. Language – naming	 Name each of the three images.
5. Memory – anterograde	Repeat and remember the words face, velvet, church, daisy and red.
6. Attention – digit span	Read one list of digits in a forward order and another list of digits in a backword order.
7. Attention – vigilance	Read a list of letters and tap your hand each time the letter A appears.
8. Attention – serial 7s	Take away 7 from 100 and keep taking 7 away from the new number for five trials (serial 7s).
9. Language – repetition	Repeat the sentences 'I only know that John is the one to help today' and 'The cat always hid under the couch when the dogs were in the room'.
10. Language – fluency	List as many words as you can starting with the letter F in 1 minute.
11. Abstraction	Identify the similarity between 'a train and a bicycle' and 'a watch and a ruler'.
12. Memory – recall	Repeat the word remembered in Question 5. Memory – anterograde.
13. Attention – orientation	Answer what date, month, year, and day, it is and which place and city.

STROOP EFFECT TEST

SET D

red	green	blue	yellow	blue
red	blue	red	yellow	red
green	yellow	yellow	green	red
blue	yellow	green	blue	yellow
green	green	red	blue	green
blue	blue	yellow	blue	red

https://teach.genetics.utah.edu/content/memory/Stroop-Test.pdf

SIX STEP CAPACITY ASSESSMENT (DARZINS, MOLLOY, STRANG)

1.Trigger

2. Assent

3. Information gathering

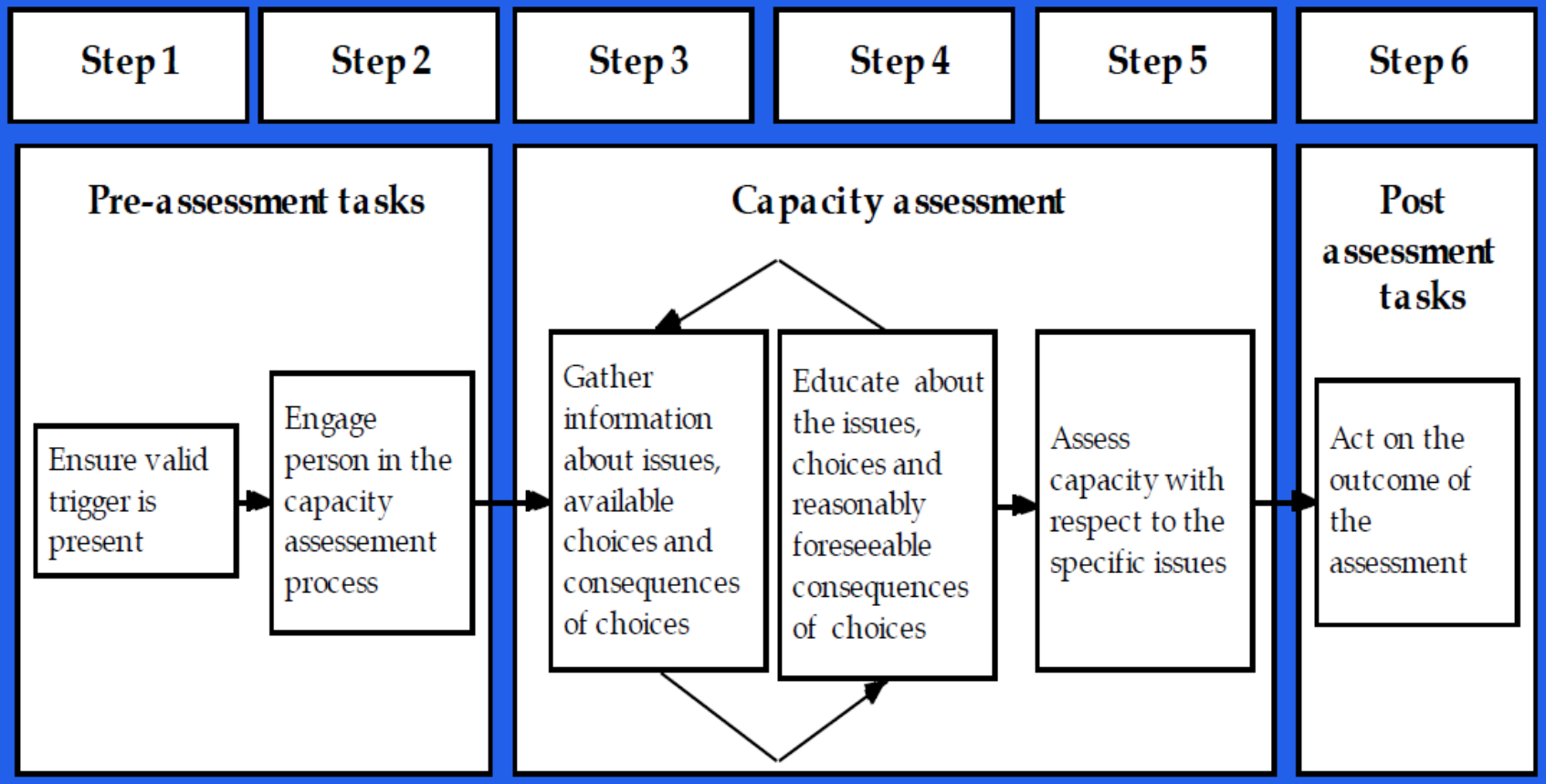
4. Education

5. Assessment

6. Action

Darzins, Peteris, D William Molloy and David Strang (2000)
Who Can Decide? The Six Step Capacity Assessment Process (Memory Australia Press).

The six step Capacity Assessment Process



TRIGGERS AND RED FLAGS

Client or others at risk

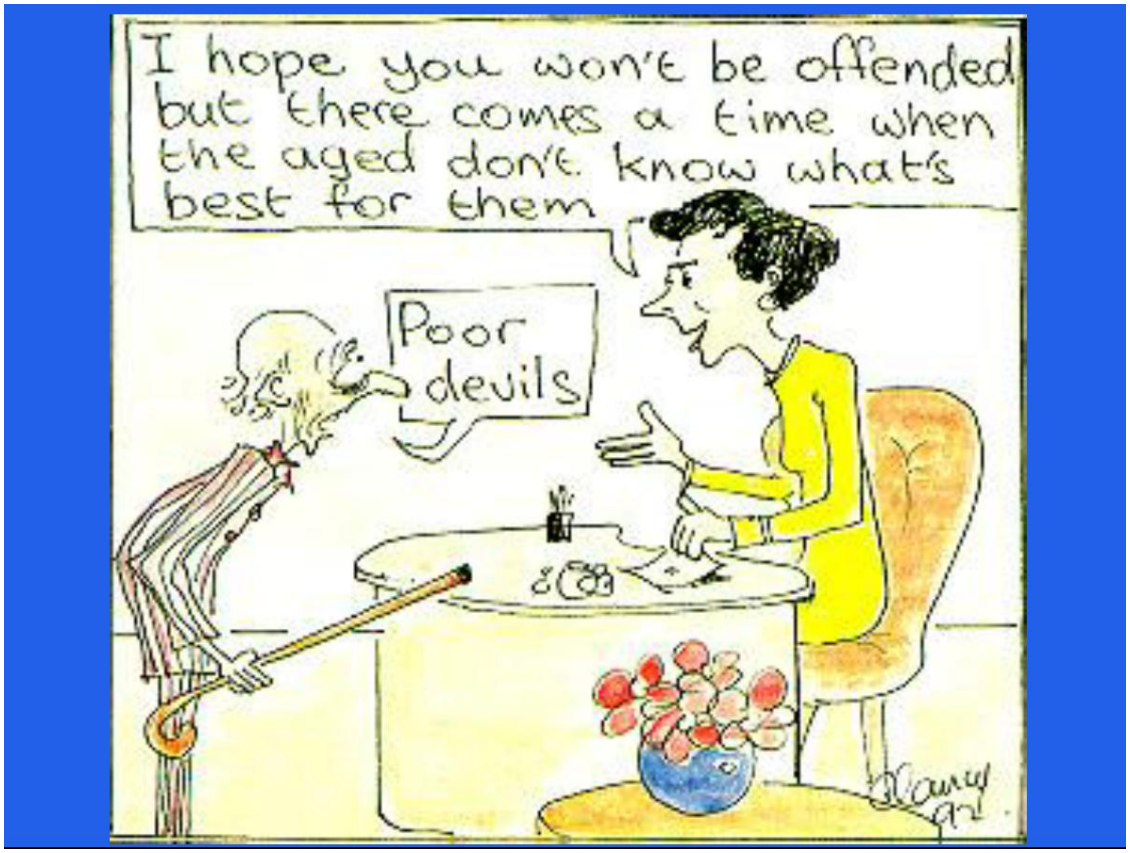
Known or suspected impaired decision making

Choices “out of character”

Cognitive change including memory loss, impaired comprehension or communication, mental inflexibility

Change in character, mood, personal presentation

Previous attempts to solve a problem have failed and appointment of substitute decision makers may solve problem


I hope you won't be offended but there comes a time when the aged don't know what's best for them
Poor devils

ASSENT

Need to gain co-operation (not “consent”)

Explain process, why and possible outcomes

INFORMATION GATHERING

Information from others helps define trigger, circumstances, choices available and possible consequences

This is where the whole team comes in to play: family, friends, carers, GP, social worker, occupational therapist, physiotherapist, pharmacist

EDUCATION

Need to ensure that patient has received enough information about trigger, choices and consequences to be able to make a rational decision

Aged Care Assessment Team assessment may be part of this education

REQUISITE CONDITIONS

Interview patient alone

Use an interpreter if not English speaking

Use vision aids and hearing aids

Establish rapport with patient

Spend sufficient time!

ASSESSMENT

Does individual understand and appreciate decisions they face?

1. able to understand Context of problem
2. able to understand Choices
3. able to appreciate Consequences
4. able to Compare and rationalise decision
5. is Consistent in their decision
6. able to Communicate decision

Assessment process should be well documented

ACTION

Help competent make and act on decision

Appoint substitute decision makers if necessary (best interests)

Appreciate loss of self-esteem, depression etc following loss of decision making ability

CASE STUDY 2

Mr Smith, a 78 year old Professor of Physics, has been admitted to hospital with an infected leg ulcer

His daughters who live interstate express concern that he is not looking after himself and is neglecting his health

He has been non-adherent with his antihypertensives and diabetes medications

A CT brain shows a large meningioma in the frontal lobe

He has a skin cancer on his leg but is refusing further treatment

CASE STUDY 2

1. Does Mr Smith have decision-making capacity in relation to his health and discharge destination?

2. What other information do you need to gather?

CASE STUDY 2

Cognitive assessment:

- MMSE 30/30
- Montreal Cognitive Assessment 28/30 (two points lost in recall)

His daughters have Enduring Power of Attorney (jointly and severally) and it comes into effect when Mr Smith lacks decision making capacity

His GP confirms history of self-neglect and non-compliance with medical treatment

CASE STUDY 2

A 6 step capacity assessment is completed and Mr Smith is deemed to have decision making capacity

He is discharged home but 6 weeks later, presents to the clinic in state of further deterioration in his health

Deemed to lack decision making capacity

- Unable to show understanding of consequences of health and lifestyle decisions
- Lacks logical reasoning when comparing choices
- Lacks consistency in health decisions

Enduring Power of Attorney is made effective due to patient's incapacity

His family move Mr Smith interstate to residential aged care

CASE STUDY 3

Mr Z is a 79 year old architect. He was diagnosed with Parkinson's disease in 2021. He lives with his wife Mrs Y.

In March this year, his neurologist commenced Mr Z on pramipexole (trade name Sifrol) for tremor and slowing of his gait.

Since then, he has been gambling at the pokies, soliciting prostitutes and ordering medication on the internet to improve his sexual performance. He has moved to an apartment and changed his mobile phone number so that Mrs Y is unable to contact him.

Mr Z would like to "update" his will. He plans to change the beneficiary of his estate to X, a lady he has met on Tinder who is about to arrive from overseas.

CASE STUDY 3

Impulse control disorders (ICDs) can occur in Parkinson's disease.

ICDs refer to pathological gambling, hypersexuality, binge eating, and compulsive buying. The core features of ICDs include repetitive or compulsive behaviour, reduced control over these behavior, and gaining pleasure while carrying out the behaviour.

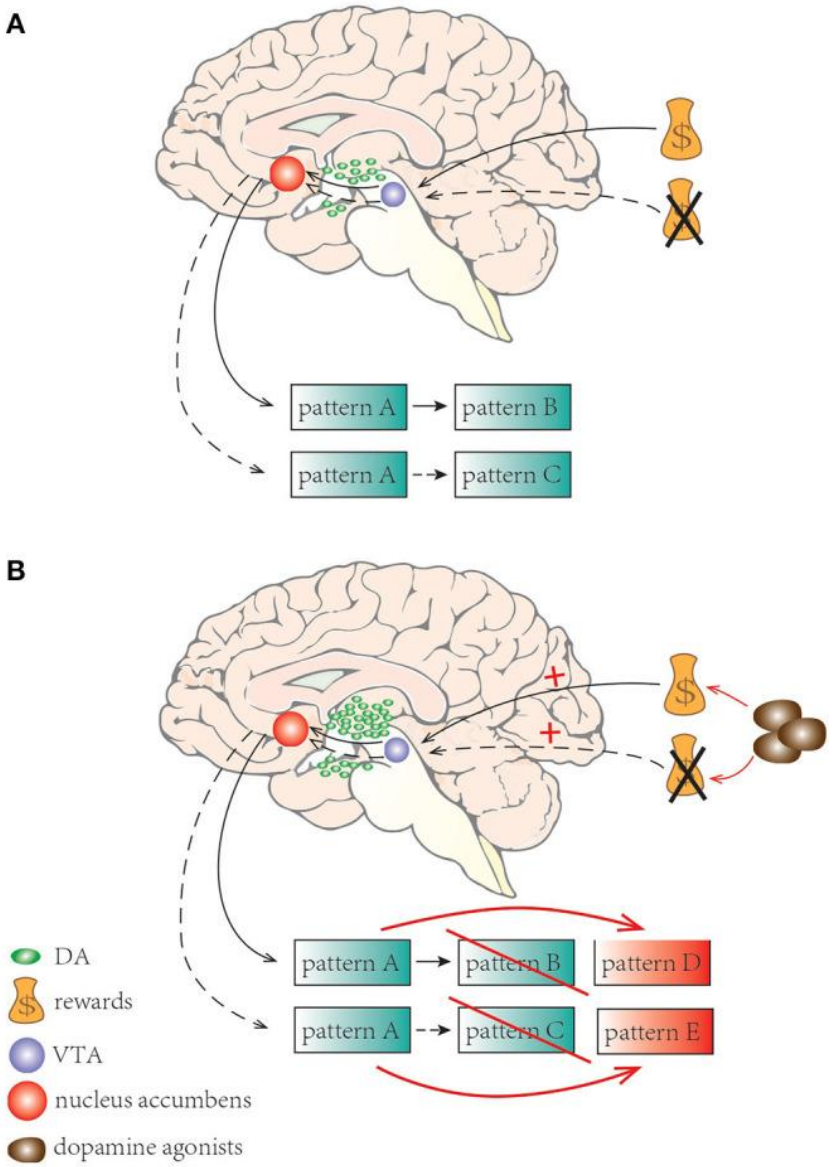
ICDs occur more commonly with chronic use of dopaminergic therapies including dopamine agonists (e.g. pramipexole).

Recognition of pramipexole as the cause of Mr Z's ICD and cessation of this medication can result in complete resolution of his impulsive behaviour.

IMPULSE CONTROL DISORDERS

Zhang et al. Impulse Control Disorders in Parkinson's Disease: Epidemiology, Pathogenesis and Therapeutic Strategies

Frontiers in Psychiatry (2021);12:635494.



CAPACITY ASSESSMENT

Capacity assessment – the 6 C's: Context, Choices, Consequences, Compares (using logical reasoning), Consistent, Communicate

Medical conditions affecting decision-making capacity.

Screening cognitive tools used as an adjunct to assess capacity.

Red flags when referral to a health professional may be required.

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