



Executive Functioning and Fluctuating Capacity

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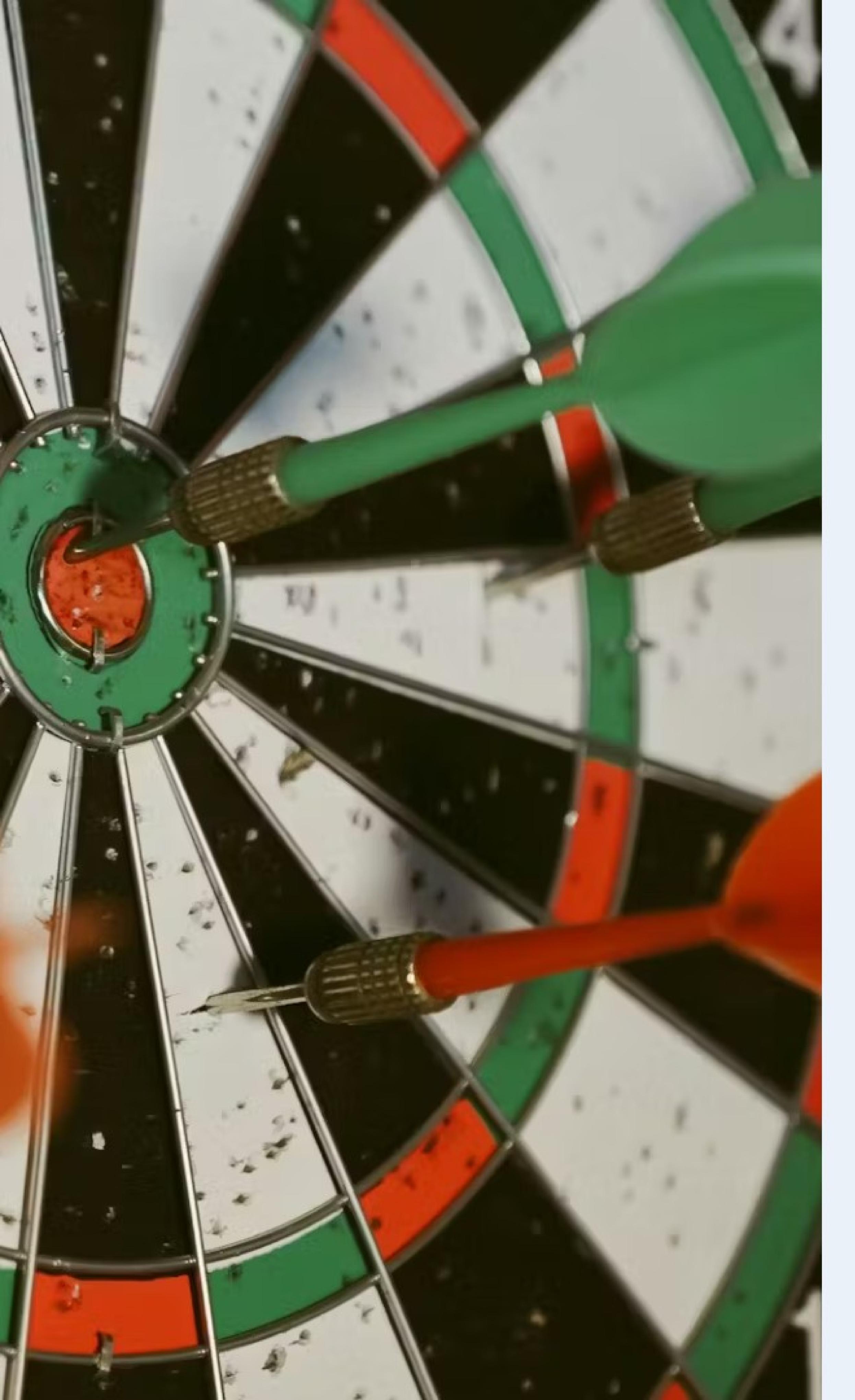


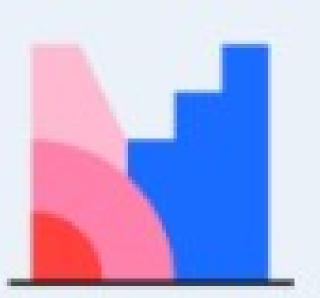


Instructions









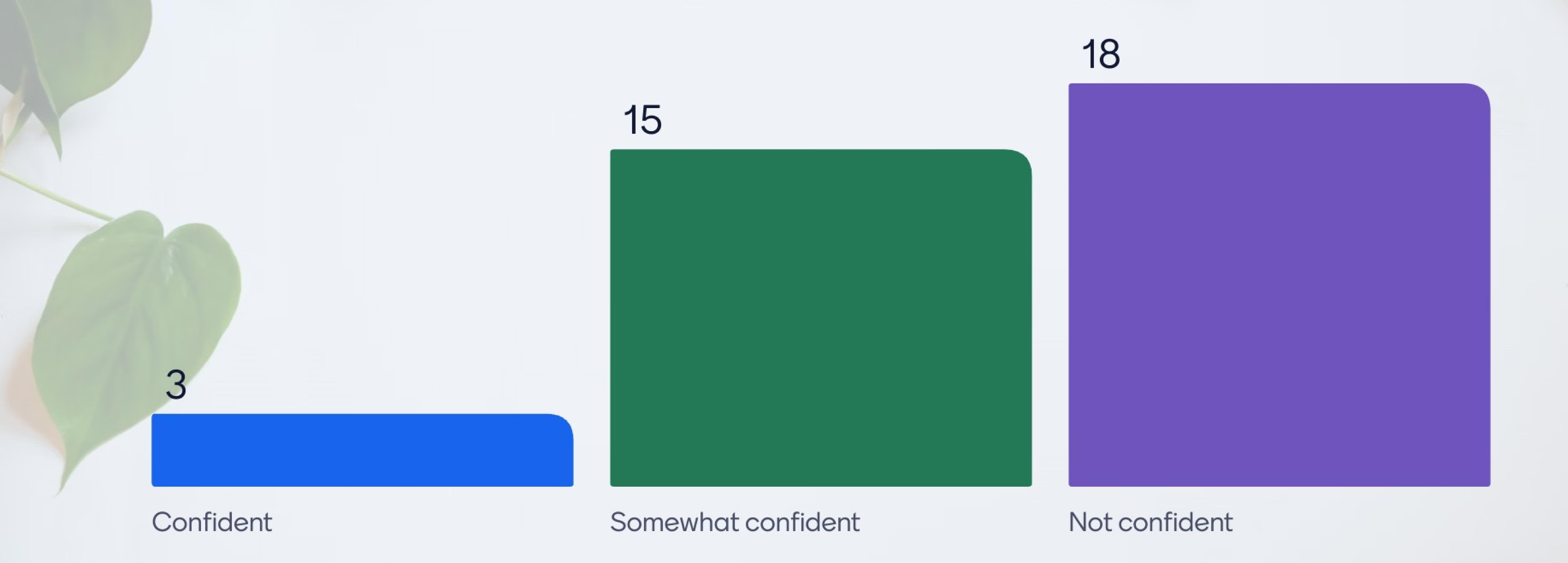
Objectives

This session will explore the dilemmas that arise from working with people who have executive dysfunction or fluctuating mental capacity and how the existing legal framework for assessments under the Mental Capacity Act can be applied

- To consider the meaning and relevance of executive dysfunction on mental capacity and the assessment of mental capacity.
- Develop an understanding of recent key Court of Protection cases involving executive dysfunction
- What is fluctuating capacity and who does it commonly affect?
- Mental Capacity Act case law on fluctuating capacity
- Macro v micro decisions

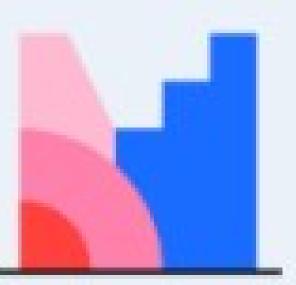


How confident are you when assessing capacity at identifying executive functioning issues?







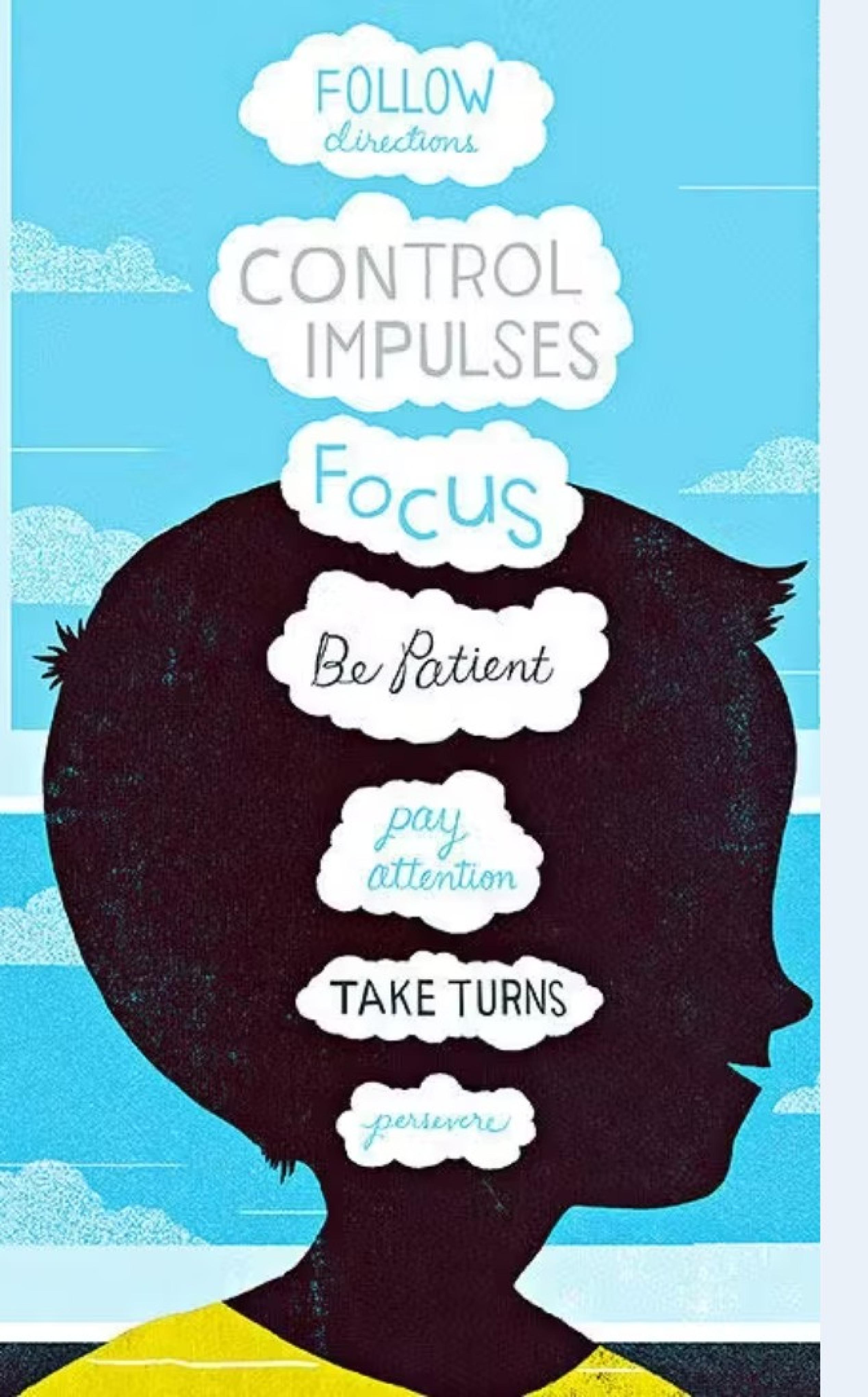


Context:

NICE Decision Making & Mental Capacity- 2018

"Structured assessments of capacity....need to supplemented by real-world observation of the person's functioning and decision-making ability"







What is it?

- Umbrella term- multiple cognitive, emotional and behavioural abilities/difficulties, primarily controlled by the frontal lobe
- Caused by a wide range of factors including, head injury, stroke, infection, tumours, MS, Alzheimer's, Huntington's, ARBD, Autism, ADHD, Tourette's, exhaustion, severe pain, severe stress, intoxication, depression, anxiety, OCD, EUPD, schizophrenia, bipolar affective disorder
- An effect, not a cause



What do you think are the 'signs' of executive dysfunction that you may observe or discuss with an individual?

49 responses







Abilities:

Self-awareness

Planning & organisation

Motivation

Flexibility of thinking

Performance monitoring

Inhibition or initiation of appropriate behaviour

Concentration & absorbing information

Learning rules

Decision making

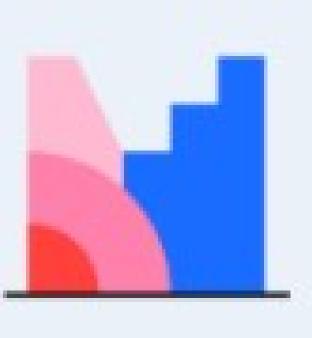
Emotional regulation

Social behaviour

Multi-tasking

Problem solving







Dysfunction

Difficulties adapting to change

Poor processing skills

Poor problem solving

Poor organisation, difficulties actioning intention, apathy

Difficulties with recall and attention

Poor motivation, start but not finish

Mood disturbance & poor control

Rigid thinking- unable to think abstractly, black & white

Difficulties in social situations- lack of filter, aimless

Impulsivity & poor control, difficulty initiating, planning & sequencing tasks

Difficulty monitoring or evaluating self

Not learning from consequences

Difficulties multi-tasking

Difficulty with time management

Considerations:

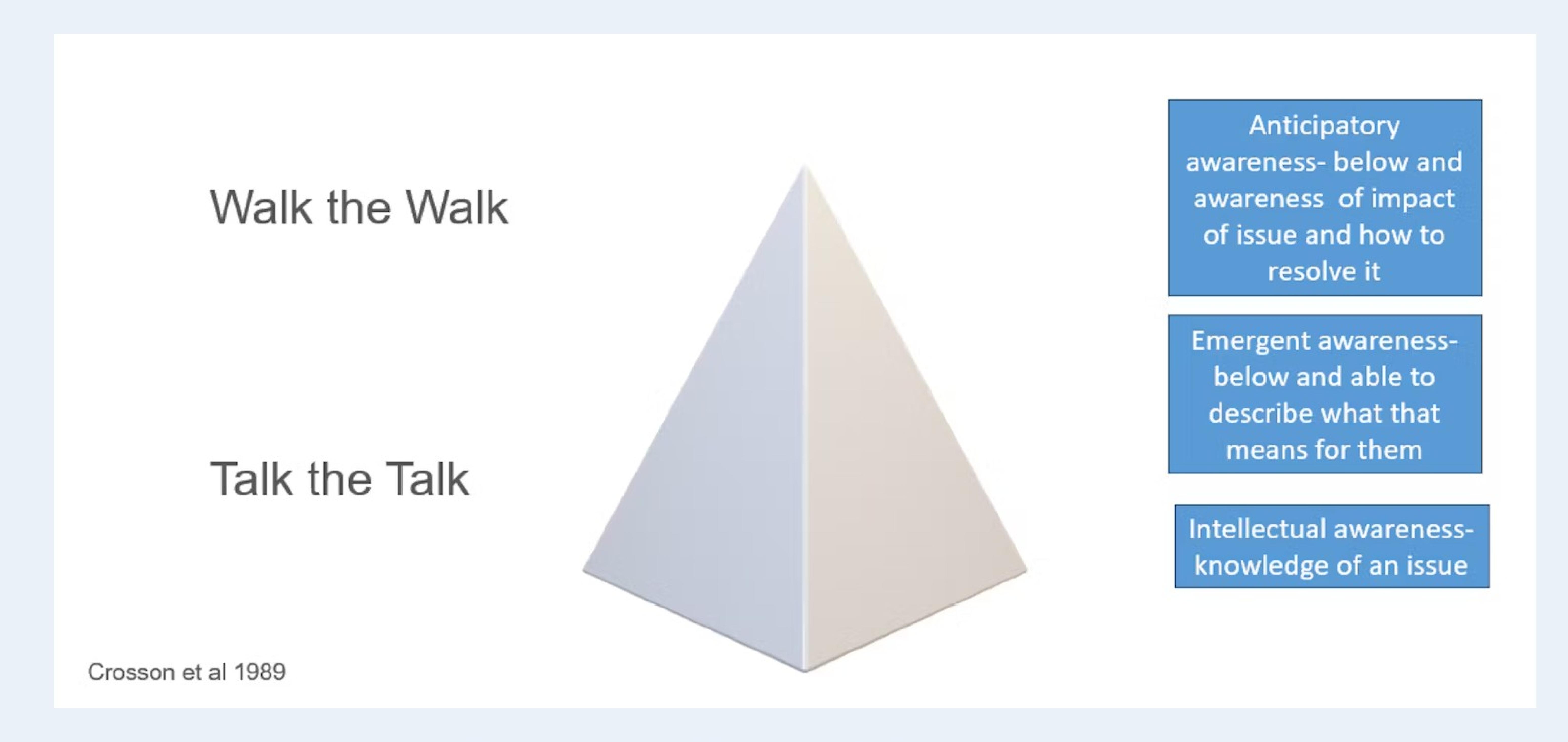
- Difference between 'decisional' decisions (i.e. immediate decisions such as whether to receive personal care) and 'decisional & performative' decisions (i.e. information is applied outside of the capacity assessment such as finances, residence etc.), Dr Emma Cameron & James Codling
- The 'Frontal Lobe Paradox'

'Talk the Talk' v's 'Walk the Walk'- the knowing/doing dissociation

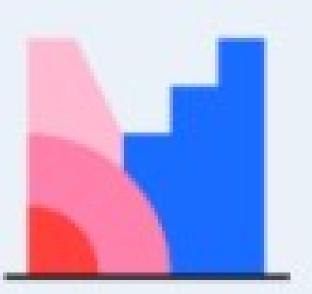
Viewing 'material time' as the time that the conversation is held is a 'falsehood and
potentially dangerous'. Observational real-world evidence from families, carers,
professional etc. needs to be considered if it is applicable to the decision being made







Pyramid Model of Awareness





Assessment

- Clock Face Drawing Test
- Focus on the 'using & weighing' part of the functional assessment
- Employ professional curiosity- What underpins decision making? Always ask WHY?





Professional Considerations & Case Law

- Belief
- Impact of impairment/dysfunction of mind/brain in the moment
- Emotional dysregulation
- Macro v's Micro decisions
- Longitudinal & fluctuating decision making
- Adaptive reasoning- repetition v's application



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Belief

Nottingham University Hospitals NHS Trust v's JM & Anor [2023] EWCOP 38

26-year-old man with autism and renal failure

Traumatic childhood

Refusing dialysis (3 times a week, 4 hours duration each time)

Received extensive support to understand the consequences of this decision- death within 8-10 days

Patient does not 'believe' their diagnosis- "nothing bad will happen" & "won't die".

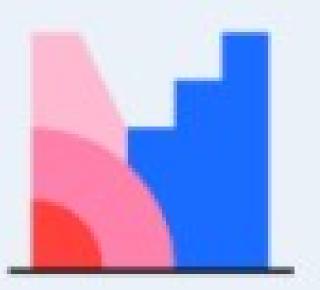
Did not want to die

Mother (diagnosis of schizophrenia) and sister of similar opinion

Trust were seeking authorisation from the Court to restrain JM to deliver dialysis







Judgement:

'The nature of JM's autism....serves to disable him from processing his thoughts and experience in an effective way. Nonetheless, JM's own reality, even though it greatly differs from ours, requires to be respected.

Reminded us of the fact that a person with cognitive impairments may be operating within a very different reality to everyone else does not mean that it is a reality which can simply be ignored.

It is not what he is saying but the executive functioning skills of processing information that is being considered and given more weight to rather than his belief system. Described as having concrete language, literal thinking, emotional dysregulation and fixating on issues.

Impact of impairment/dysfunction of mind/brain in the moment:

Wrightington, Wigan & Lee Teaching Hospitals NHS Foundation Trust and SM [2002] EWCOP 56

16-year-old looked after female

Complex PTSD, childhood trauma, anxiety and emotional dysregulation

History of sexual exploitation

39 weeks pregnant with an intense fear of giving birth-risk of still birth

Refusal of induction and C-section on multiple occasions despite initially agreeing

Wanting to be awake when baby is delivered

Trust seeking an order for declarations that SM lacked capacity to make decisions regarding her obstetric care and treatment; that the Trust could proceed with a care plan which included delivery by caesarean section if necessary; and that SM could be deprived of her liberty to achieve the safe delivery of her child



Judgement:

'When SM is lucid, she is able to articulate an optimal form of treatment....her anxiety and dysregulation disables her from being able to use and weigh relevant information in the heat of the moment....fear induced by panic may paralyse the will and thus destroy the capacity to make a decision'

Outcome:

'It is plainly in SM's best interests that she is able to exercise a high degree of autonomy over the manner in which her baby is born...I regard it as not only proportionate but also in SM's short and long-term best interests that the hospital attempts one final administration of vaginal induction of the baby......I am satisfied, however, from all that I have heard that there have been times in the last few days when SM has lost capacity in what has been described as

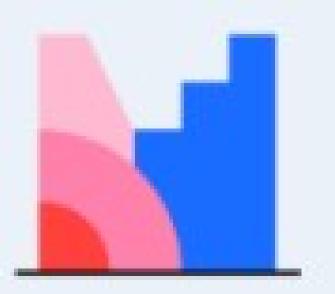


Outcome cont:

"the heat of the moment", when anxiety and stress has overwhelmed her, and she has not been able to make a capacitous decision in relation to the appropriateness of submitting to Caesarean section. Should that situation arise in the hours ahead and if, in the opinion of the treating clinicians, she loses capacity again...and if the welfare of the mother or child is compromised or is likely to be compromised such that a caesarean section is indicated as an emergency, I confirm that it is in SM's best interests for the baby to be delivered by Caesarean section performed under general anaesthetic; it will accordingly be lawful for the hospital to perform that procedure in those circumstances'







Longitudinal & fluctuating decision making

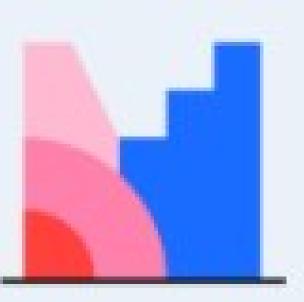
A Local Authority and H [2023] EWCOP 4

18-year-old natal male now identifying as a female

History of major trauma from neglect/abuse resulting in accommodation in multiple foster placements

Highly restrictive and effective care plan (past 3 years) due to extreme risk to self and others when dysregulated, including sexual harm to children (actual and online)

Multiple other diagnoses impacting on executive functioning abilities- global developmental delay; attention deficit hyperactivity disorder; developmental trauma disorder; possibly emotionally unstable personality disorder; traits of autism spectrum condition; extremely disordered attachment and highly disrupted emotional regulation





Judgement:

'Residence decisions need to be viewed as longitudinal, requiring a balance of the options'

'H was able to do this in a capacitious fashion when calm & engaged but unable to achieve this at times of emotional dysregulation. This is an important qualification of capacity'

Adaptive reasoning

Re A (Capacity: Social media and Internet use: Best Interests) [2019] EWCOP 2

21-year-old man with a LD living in supported living.

Unable to meet personal and domestic needs without support.

Befriended and groomed by paedophile ring to use extreme pornography and carry out acts.

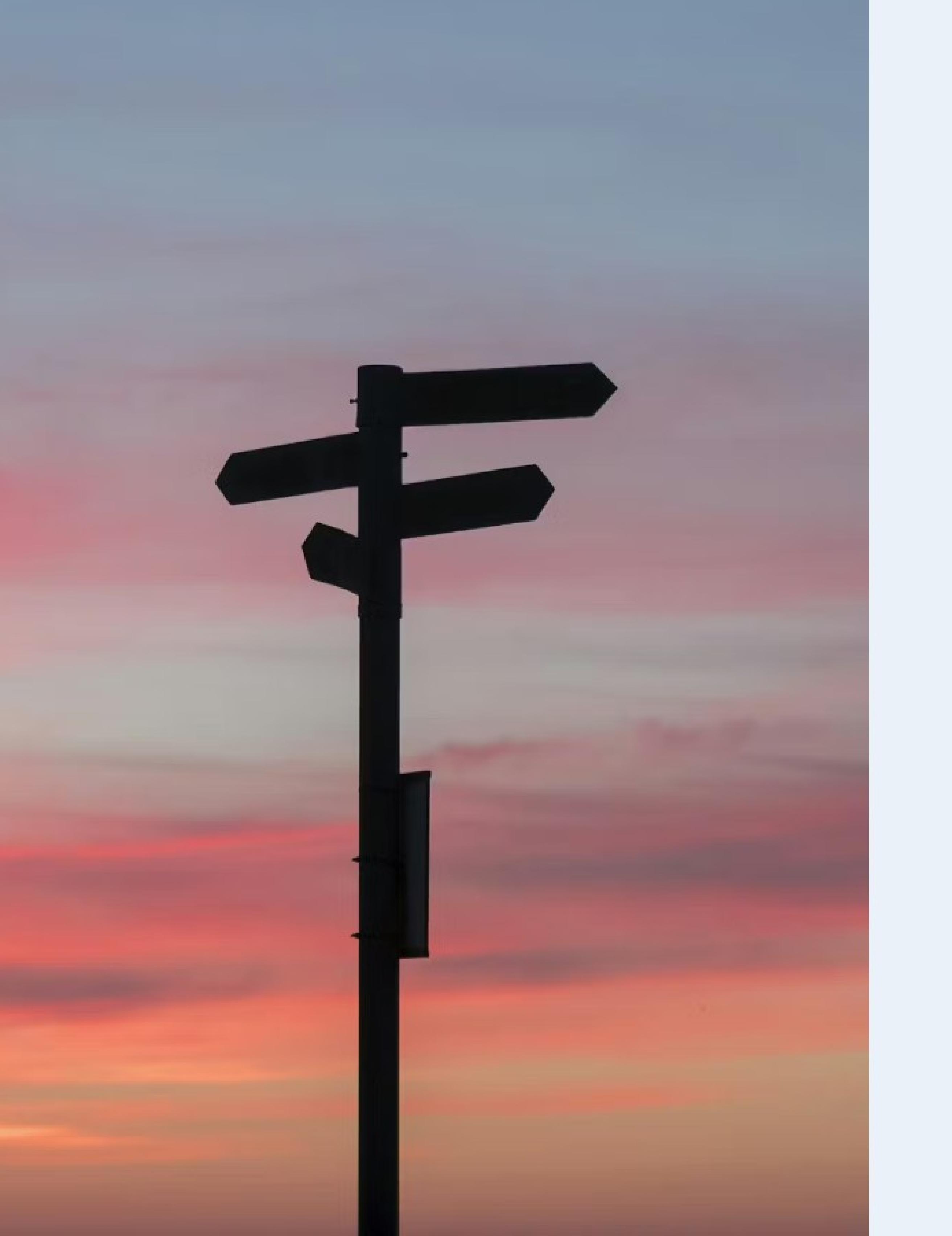
Engaged with specialist sexual exploitation worker and had lessons regarding internet/social media use with reinforcement of key messages by support workers.

Case highlighted 'difficulty with flexible adaptive reasoning- that is, while in some respects he can repeat back what he has been told, he is unable to apply it to actual situations'







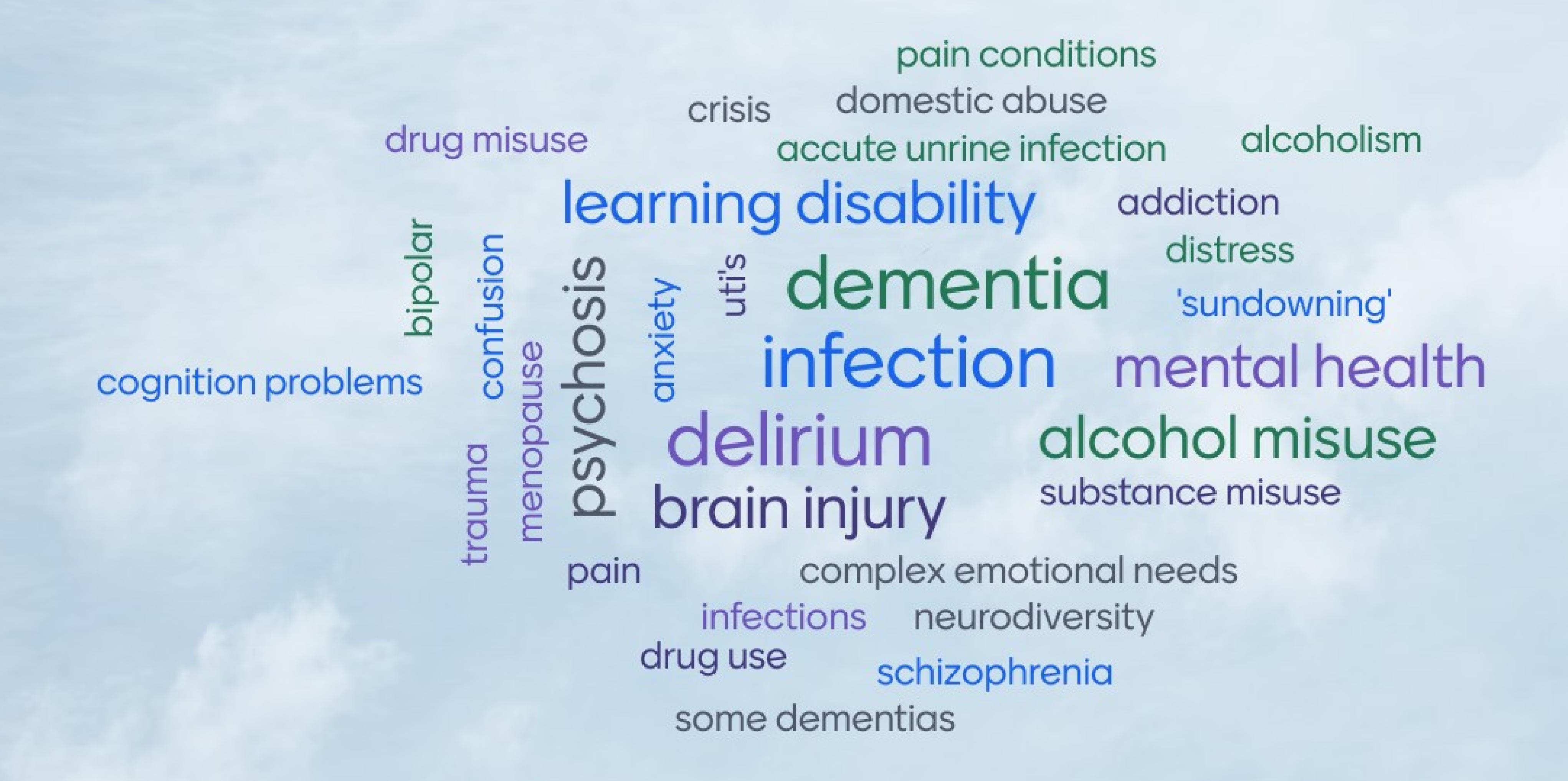


Fluctuating capacity refers to situations where a person's decision-making ability varies. The person may lack capacity at the time of one assessment, but the result may be different if a second assessment is undertaking.



What different conditions may people be living with that can result in fluctuating mental capacity?

43 responses



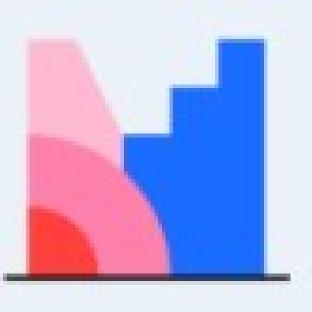




Section 2:

- This sets out the Act's definition of a person who lacks capacity. It focuses on the
 particular time when a decision has to be made and on the particular matter to which
 the decision relates, not on any theoretical ability to make decisions generally.
- It follows that a person can lack capacity for the purposes of the Act even if the loss of capacity is partial or temporary or if his capacity fluctuates.
- It also follows that a person may lack capacity in relation to one matter but not in relation to another matter.







Challenges:

Fluctuating capacity can be a major concern for health and social care professionals.

- Can the decision by delayed?
- Inconsistent and unpredictable.
- Takes up significant time and resources.
- Often a sophisticated and nuanced approach is needed.

The importance of assessing at a person's best

X v A Local Authority [2014] EWCOP 29

- Korsakoff's Syndrome and living in a care home. DoLS in place.
- Social Worker and Psychiatrist deemed he lacked capacity re residence, BIA deemed him to have capacity and noted the importance meeting him "at his best".
- The judge ruled that he had no doubt that when X entered the home, X lacked capacity to consent to accommodation and care arrangements, but that he now was able to identify the factors relevant to making the decision about where he should live. He knew what he had to do to find a rental property and what help he would need to move from the home. "He was not able to identify the precise detail, but that is not a legal requirement. He understand the salient information".







Draft Code of Practice

The draft code also has new guidance on fluctuating capacity. It distinguishes between isolated and repeated decisions. For isolated decisions, the decision should be delayed until the person has the capacity to make it for themselves. If it's not possible to delay, the minimum action necessary should be taken until the person regains decision-making capacity.

In contrast, for repeated decisions, such as the day-to-day management of finances or management of a condition such as diabetes, it may be appropriate to consider the broader time over which the decisions need to be made. This is especially so if the consequences of the decisions are serious, and the person only has capacity to make them for a very small part of the time (4.51-4.56).

The case of A v X [2012] EWHC 2400 (COP)

Man with dementia.

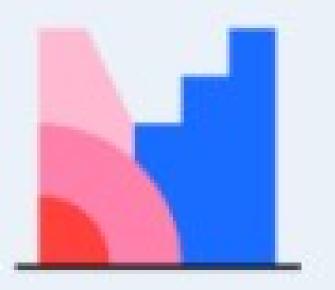
The judge considered whether X had capacity to manage his affairs.

There would be times when he would be able to manage his affairs, but the general concept of managing affairs is ongoing and unlike a specific act.

The management of affairs relates to a continuous state of affair whose demands may be unpredictable and may be occasionally urgent.







Emotional dysregulation

Royal Borough of Greenwich v CDM [2019] EWCOP 32

64-year-old female

Personality disorders

Unstable diabetes which has led to a below knee amputation

Needs insulin x 2 daily-administer by DN's

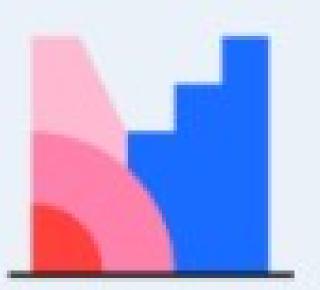
History of declining insulin or stating already having had it

Previous judgements in relation to residence (had capacity) and diabetes management (fluctuated as a result of personality disorders)

Court asked to consider further evidence regarding fluctuating capacity and macro/micro decisions







Emotional dysregulation

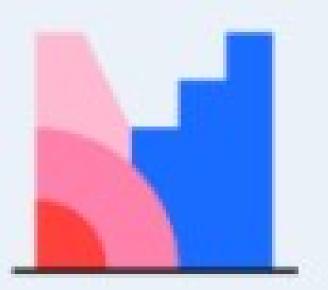
Judgement-

'there is a difference between CDM stating understanding of her diabetes and management needs and her ability to put this into practice. She becomes emotionally dysregulated so frequently that her ability to act on her decisions is compromised frequent'

CDM did not understand that she was at risk of death when her insulin levels were very poorly controlled, and her emotional dysregulation as a result of her personality disorders was frequent and affected her ability to retain and to weigh information.

This was discussed further.....





Macro v's Micro decisions

Judgement continues-

'there may be occasions when CDM has the capacity to make micro decisions (i.e. diet, blood tests, administration of insulin, hospital) in relation to her diabetes and times when she does not (due to fluctuations in capacity). However,.... logically, legally and practically it is a macro decision and CDM lacks capacity to take the macro-decision (management of her diabetes)'

The Judge viewed that diabetic care decisions should be viewed as macro decisions.

This was taken a step further.....

Fluctuating Capacity

Judgement continues-

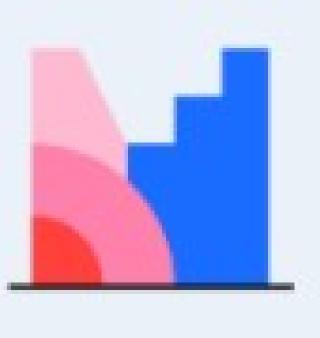
'There may be sometimes when CDM makes a decision in relation to the management of her diabetes where she understands the elements of the decisions being made, retains the information, weighs it up without the defect of a dysregulated emotional state, and communicates this effectively. However, these times, if they occur, are infrequent and unpredictable. If this is fluctuating capacity, then CDM has fluctuating capacity to manage her diabetes'



Judgement continues -

'there may be occasions when CDM has the capacity to make micro-decisions in respect of her diabetes and occasions when she does not, i.e. that her capacity does in fact fluctuate. However, if the court acceptstheir (experts) conclusions, logically, legally and practically, it is a macro-decision, and CDM lacks capacity to take the macro-decision, the issue of fluctuating capacity simply does not arise.







- Case where care packages have stabilised a situation resulting in a person regaining capacity.
- For example non compliant diabetic cases.
- Person is deemed to lack capacity in relation to diabetes management.
- They regain capacity and then make the unwise decision to disengage with treatment
- Health declines and they lose capacity.
- In these cases there needs to be robust care planning to ensure that a "regime" is put in place or "kicks in" when the person loses capacity.
- Court can make contingent declarations.



Key Messages:

- Being articulate, plausible and coherent does not = capacity
- The 'right' to make unwise decisions is dependent on if the person has capacity to do so
- Allowing people to make unwise decisions without assessing their capacity do so shows a lack of respect to protect an individual's autonomy and self determination
- The riskier the decision the increased need to explore the reasoning
- An awareness of risk needs to be explored in relation to application to own and future situations
- Always consider diagnostic overshadowing- is there another reason for the presentation
- If you are informed that someone lacks capacity when distressed be sure to see them at their best and worst



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