DECISIONS, DECISIONS, DECISIONS – WHERE THE FRONTAL LOBES MEET THE MENTAL CAPACITY ACT

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My frame of reference.....

- As a Consultant Clinical Neuropsychologist, my primary focus is on brain changes and their impact on behaviour.....
- repeatedly shown that no matter where the brain lesion is, whether subcortical gray matter, subcortical white matter, cerebellum, brainstem, or even parietal and occipital lobe, a greater or lesser degree of frontal systems syndrome is present (Hoffman, 2013)



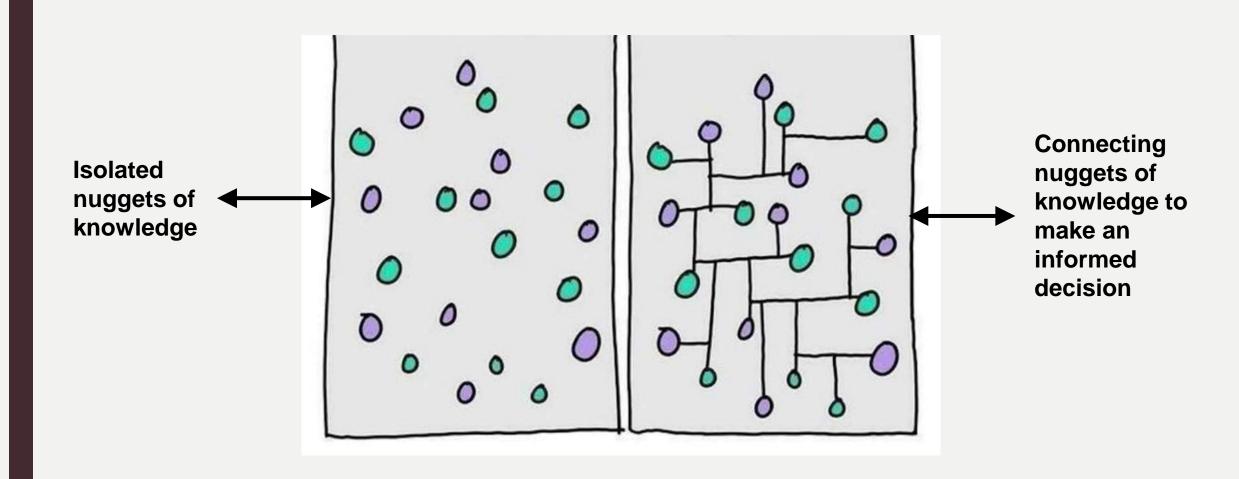
What is the "frontal lobe paradox"?

■ Patients with Frontal Lobe Paradox, first described by Walsh (1985), typically present as,

"proficient within clinical interviews and perform normally on traditional office-based assessments....at the same time, however, they exhibit marked limitations within the domain of adaptive functioning" (George & Gilbert, 2018).

- This has also been referred to as the "knowing-doing dissociation" (Teuber, 1964)
- Such patients are "good in theory but poor in practice" (George & Gilbert, 2018)

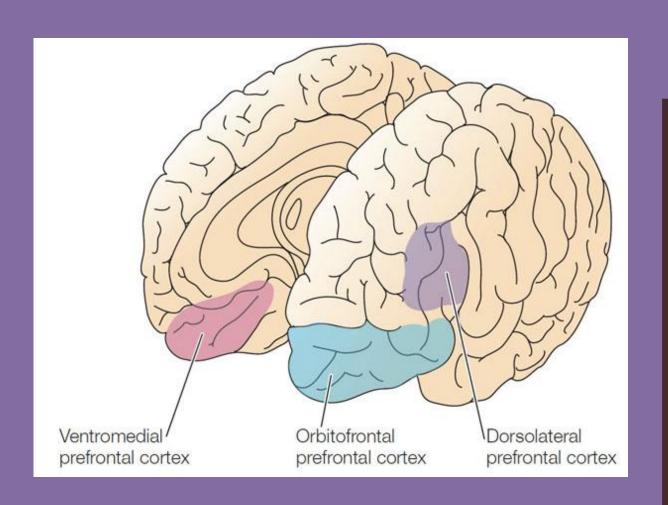
Dissociation between "knowing" & "doing"



Let's meet our frontal lobes.....

- Frontal lobes are considered to be the seat of higher order functions the substance of what makes us human and different from other mammals.
- This part of the brain is the largest and helps us with:
 - Attention, concentration, working memory
 - Weighing up, evaluating, forming judgements, selecting solutions based on past experience
 - Monitoring and regulating our own behaviour including inhibiting ourselves based on context and consequences
 - Connecting to our mid-brain emotional control system



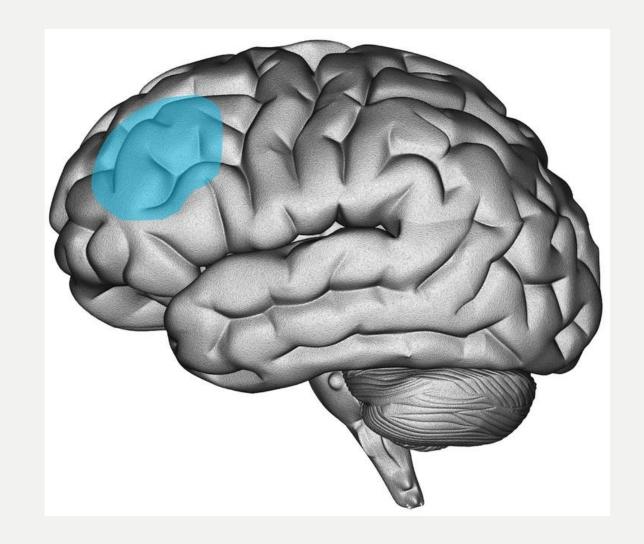


PREFRONTAL CORTEX:

THESE AREAS ARE
FUNCTIONALLY BUT NOT
ANATOMICALLY DISTINCT

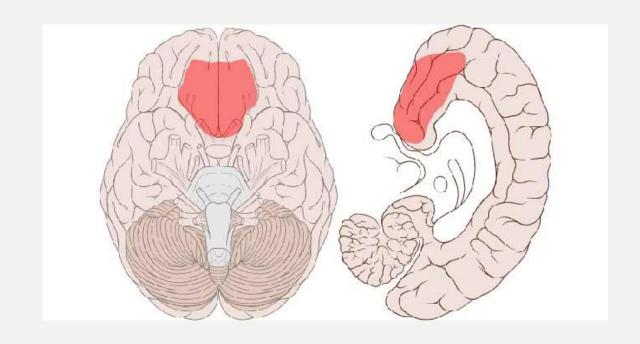
Dorsolateral Prefrontal Cortex (DPFC)

- Mediates planned,purposeful, prioritised,goal-directedbehaviour
- Working memory



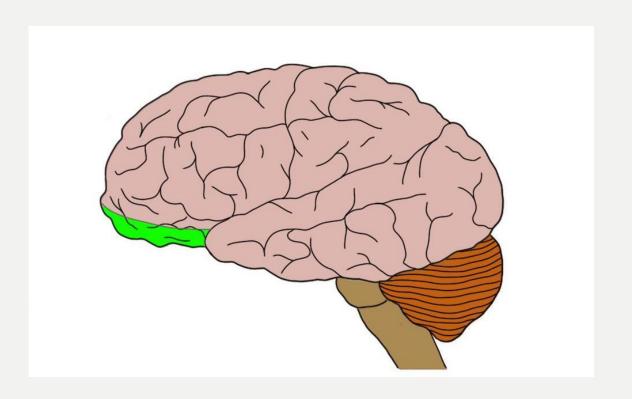
Ventromedial Prefrontal Cortex (VMPFC)

- Attentional Control
- Mental Flexibility
- Analysis of potential threats
- Facilitates rapid shifts in behaviour
- Appraises emotional significance of events



Orbitofrontal (prefrontal) cortex

- Responsible for impulse control (inhibition)
- Compares relative value of options (in decision-making)
 costs v benefits What is this worth for me? Linking drive to reward
- Facilitates moral development through learning of social values
- Acts as the 'cerebral brake'.



Clinically the picture is confusing....

"Patients with ventro-medial prefrontal lesions had remarkably preserved intellect, as measured by conventional neuropsychological instruments, and an equally remarkable defect of emotional behaviour" (Damasio, 2009).

"Decrements in executive and adaptive functioning are often masked by preserved language and verbal reasoning skills, so much so that an individual may appear remarkably unimpaired...(they) may grossly overestimate their adaptive skills and consequently, underestimate their need for support or supervision" (George & Gilbert, 2018) How can we assess "frontal lobe paradox" in practice?

Real life vs Measured ability

"It is unwise, even negligent, to form opinions on how test performance is likely to influence everyday behaviour, without carefully interviewing those with direct experience of the person's real-world behaviour over a period of time" (Wood & Bigler, 2017, p.93)

Worthington (2019) is eloquent on the point that most of the Neuropsychometric tests that we rely upon are focused on only one of four prefrontal cortical areas that all contribute to functional, executive, behaviour thus ensuring only an incomplete picture at best, or an inaccurate one at worst.

Decisionmaking under ambiguity or under risk?

- Recent research (Ouerchefani et al, 2019) studied the different roles played by the VMPFC and DLPFC in terms of decision-making.
- They used a well-known test called the Iowa Gambling Task. Individuals are presented with four decks of cards characterised by different punishment-reward profiles. Those without a brain injury usually take up until card 40 before they fully work out how to obtain the best outcome. The object of the task is to earn as much money as possible.
- The findings indicate that the **DLPFC** group also work out the rules by this point but that there is individual variance in terms of moving from decision-making with uncertain outcomes (ambiguity) to probable outcomes (known risk) known as "strategy application disorder"
- The findings also show that <u>even when</u> the <u>VMPFC</u> patients work out the rules, they fail to integrate the knowledge with their decision-making. This has been explained in terms of *insensitivity to punishment* (or hypersensitivity to reward)

How do such patients behave?

- OK with familiar tasks but unable to cope with novelty.
- Unable to translate intentions into actions.
- Full of promises & plausible.
- Inability to initiate, plan, organise, or sequence, activities.
- Behaviour can be aimless, impulsive, and fragmented.
- Jobs started but not finished.
- Lacking a "filter"
- Poor time perspective when trying to meet deadlines.
- Unable to monitor and evaluate own actions.
- Behaviour is impulsive.
- Unable to think flexibly or abstractly.
- Less able to adapt behaviour to changing circumstances.
- A dichotomous style of thinking everything seen as black or white

When Frontal Lobe Paradox meets the Mental Capacity Act (2005)

- Starting point is to assume capacity unless there is evidence to the contrary
- Stage 1 legal test: evidence of impairment in functioning of mind or brain, whether temporary or permanent, at the material time that the decision is to be made
- Stage2 legal test: person must be able to:
 - Understand the relevant information
 - Retain the relevant information
 - Weigh up and use the information as a basis for decision-making
 - Communicate their decision (by whatever means)

Case study:

- Female (AA) unwitnessed fall downstairs whilst intoxicated (frequently drunk)
- On arrival at A&E –
 GCS 7 (intubated for a week with ICP bolt fitted)

Positive Neuroradiology

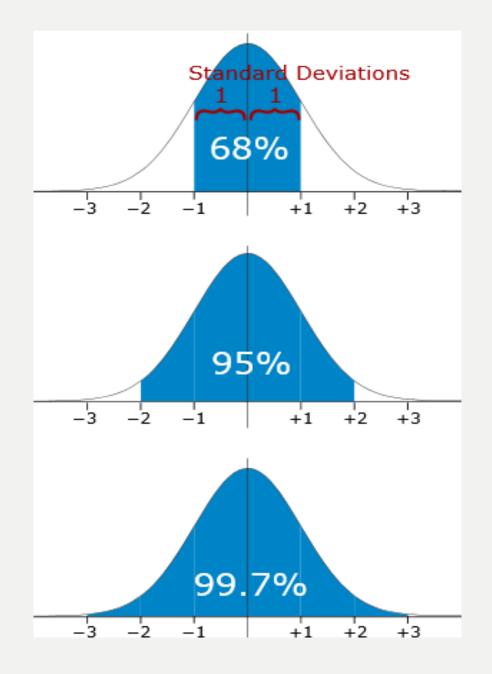
- Right Fronto-Temporal haematoma
- Bilateral Temporal haematoma
- BiTemporal contusions
- # Left Temporal bone
- # Left Sphenoid bone
- #Left Orbital bone

AA – BEHAVIOUR

- verbose & repetitive,
- highly distractible,
- impulsive,
- lacking insight,
- verbally plausible but behaviourally impaired,
- unable to follow instructions,
- fatigues very easily
- Sociable, warm & engaging

AA - COGNITION

- Grossly impaired memory (functioning in bottom 0.4% of peers at her best)
- Extremely poor attention (functioning in bottom 2% of her peers)
- Extremely slowed processing (more than two standard deviations below the mean for her age)
- Executive function tests within normal limits



This is the normal distribution curve.

68% of us lie within one standard deviation of average.

95% of us lie within two standard deviations of average

99.7% of us lie within three standard deviations of average

To DoLS or not to DoLS

- DoLS acid test is based on Cheshire West judgement:
 - Is the person under continuous care and supervision?
 - Is the person "not free to leave"?

If the answer to either of these questions is YES then a DoLS has to be applied for – WHETHER OR NOT THE PERSON IS ASKING TO LEAVE

- Ward-based DoLS assessment took into account AA lack of insight, her lack of awareness of financial and personal safety and her lack of ability to find her way around if she left the hospital.
- A DoLS was applied for and the views of all clinical staff and the Social Worker was that this was appropriate.
- A DoLS Assessor attended without notice, did not read the clinical notes, did not introduce themselves to staff or interview any of the clinical team about AA. After a brief interview, they rejected the DoLS application and recommended its removal
- The Ward staff appealed and submitted robust evidence
- A second DoLS assessor attended, on a Sunday morning, again without notice and without reference to staff or notes, following a brief chat with AA recommended that the DoLS be removed.
- The Ward staff appealed and submitted robust evidence, including from the family.

What was she like?

Capacity to decide discharge destination:

- Completely lacked insight into the level of support and prompting she received in the ward environment and, therefore, no grasp on what help and support she would need on return to living alone (were she to return home)
- "failed" real-life tasks such a meal preparation, shopping and money management (failure to integrate knowledge)
- Absence of awareness of risks of alcohol on return home which faced a local off-licence – (insensitivity to punishment)
- However, Consultant Social Worker (who had not met AA beforehand) held a discharge planning meeting on the ward and disagreed with all clinical staff and family members. She recommended that AA be discharged home with telephone "safe and well" calls......

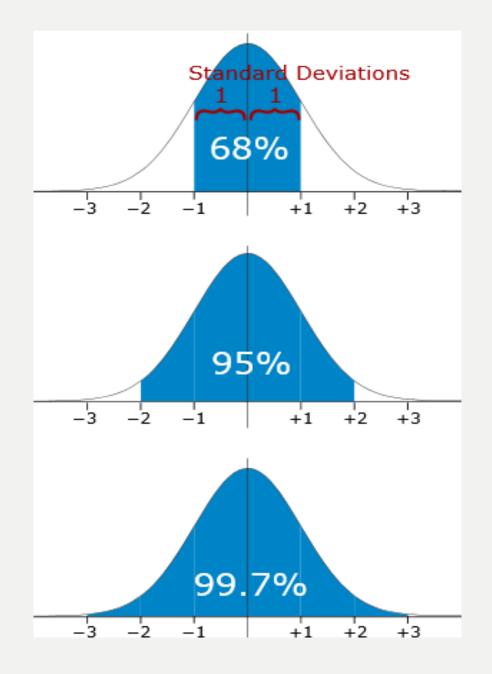
Case Study : BB

- **BB** RTC at high speed (unrestrained & ejected)
- GCS 4 at scene
- Intubated and sedated for 3 ½ weeks
- ICP bolt fitted
- Diffuse Axonal Injury, blood in occipital horns of lateral ventricles, haemorrhagic contusion in corpus callosum and left Parietal area (parasagitally)

- Rigid thinking
- Distractible
- Poor insight into injury or needs
- Highly fatigued
- Disorientated (still in PTA months later)
- Slowed processing noted
- lacksquare non-compliance
- Softly spoken & charming
- Preserved intellect
- Verbally plausible

BB: neurocognitive test results

- Preserved general cognitive function (high average – IQ range 110-119)
- Extremely impaired attention function (bottom 1% of peers)
- Grossly abnormal memory function (bottom 0.1% of peers)
- Massively slowed processing (four standard deviations below the mean)
- Performed "plausibly" on executive tests!



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What was he like?

- Frequently absconded from ward (he watched staff and learned the door exit code) picked up by police running up local dual carriageway against traffic flow (insensitivity to punishment)
- Asked to have his PEG removed and on morning of elective surgery he ate a doughnut he had hidden in his locker because he was hungry. He also fully understood that he needed to be NBM (failure to integrate knowledge)
- Softly spoken and charming until thwarted when he would fly into a rage and physically assault those in his vicinity (lack of cerebral brake)
- Convinced a DoLS assessor that he did not need to be under continuous supervision and should be free to leave the ward. Asked his mate to bring a car so that he could drive around the local area (whilst under a driving ban and still in PTA).....

Case Study: CC

- Knocked off his bicycle by a car that failed to stop for police
- Bifrontal decompressive craniotomy – followed by cranioplasty
- Poorly controlled posttraumatic seizures (status epilepticus) requiring emergency intervention on every occasion
- Able to converse "normally" and give plausible account of self

Positive Neuroradiology:

- Bilateral acute subdural haematoma
- Vault fracture, complex displaced fracture to left temporal petrous bone and left greater wing of the sphenoid
- Multifocal haemorrhagic contusion associated with cerebral oedema

CC: neurocognitive test results

- Generally preserved cognitive function (IQ range 100-109)
- Extremely impaired attention function
- Impaired working memory
- Slowed processing
- Verbal dyspraxia
- Executive tests within normal range

What was he like?

- Anosognosia (complete lack of awareness of injury)
- Frequent uncontrollable seizures (status epilepticus) which distressed him greatly yet.... Non-compliance with $\mathbf{R}_{\!\!\mathbf{X}}$ (Strategy application disorder)
- Impulsive decision-making and actions extremely poor perception / analysis of risk to self
 - crossing busy road outside front door without looking;
 - jumping from first floor window to leave hospital when request to self-discharge was challenged (insensitivity to punishment)

Capacity to make informed decisions about compliance with medication

- CC had post-traumatic epilepsy each seizure developed into status epilepticus (without exception)
- His seizure threshold was reduced by several factors all of which were known to him (underlying infection, smoking cannabis, alcohol, missing meals, missing sleep, over-exercising)
- He was aware that his medication regime was carefully designed and titrated to reduce his seizure frequency – an outcome that he wanted above all else
- He was distressed by having seizures as each required an emergency admission to A&E by ambulance and could only be managed in resus
- He had all of this concrete knowledge verbally and in writing which was reinforced with each admission (approximately every six to eight weeks)
- He was aware that he was at risk of SUDEP
- He was provided with alarm reminders and support worker prompts to take his medication at the appropriate times of dayt
- He failed to apply any of this information (knowledge) to the required behaviour to take his medication regularly
- Consideration was given to a programme of covert medication administration (with CoP advice)

Case Study:

- Male had only been in UK for one month at time of accident
- RTC pedestrian v lorry at high speed on side of motorway
- GCS 8 at scene
- PTA for almost 3 months

- Diffuse axonal injury
- Frontal and temporal contusions
- Sub Arachnoid Haemorrhage (SAH)
- Bilateral skull fractures

How did he behave?

- Difficulty following routine (unable to cope with novelty)
- Lowered frustration tolerance
- Impulsive actions
- Verbally disinhibited
- Restless and agitated at times
- Lack of insight into high levels of fatigue
- Socially inappropriate (disclosed personal information to strangers)
- Motivated to engage in rehab by wife & daughter
- Socially respectful of team but frequently argumentative
- Verbally plausible to others

Cognitive difficulties

- Easily distracted
- Difficulty following conversation (not attributable to English as a second language)
- Word finding problems in first language and English
- Impaired ability to learn new information and to remember to do something (prospective memory)
- Poor organisation and problem-solving skills

From behavioural records (OAS-MNR & SASBA)

- Triggers to behaviour including extreme fatigue / poor sleep; drinking too much strong coffee; being asked to do something he did not want to do (or could not see the point of; over-stimulated environment)
- Verbally aggressive (arguments were perceived as something that had to be won at all costs – targeted wife and daughter)
- Physically aggressive (held wife by throat, followed wife through house holding knife; would storm off threatening to end his own life; blocking doorway and holding handle to prevent others leaving or coming in; punching self)

Rehab strategies

- Was able to learn self-control strategies, information about anger management....but absolutely unable to apply these in the moment. If prompted this would cause him to escalate further.
- Always remorseful after an outburst when mood would plummet and suicide risk would increase
- Put wife and child at risk (emotionally and physically) – resulted in 2 x safeguarding referrals – led to breakdown in relationship between family and MDT.
- Crisis plan drawn up with "standing" referral to challenging behaviour unit

KEY MESSAGES FROM TODAY:

- 1. Wherever the injury in the brain, frontal lobe systems are <u>always</u> affected
- 2. Frontal lobe systems mediate awareness, self-regulation, applying knowledge in the moment and the ability to apply reasoning
- 3. Frontal lobe paradox is real
- 4. Don't assume that the person has preserved insight or awareness <u>no</u> <u>matter what they say</u>
- 5. Don't rely on interview / tests alone: measure / observe in real-life situations; speak to those that know the person
- 6. This is particularly pertinent when considering the third limb of the second stage of the legal test of mental capacity: the ability to weigh up information in the process of arriving at a decision

THANK YOU!

