Executive Functioning and Self Neglect 11th June 2024

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.Extracts from other presentation have been used and referenced

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What is Self Neglect?

'Self-neglect is defined as ‘the inability (intentional or non-intentional) to maintain a socially and culturally accepted standard of self-care with the potential for serious consequences to the health and well-being of the self neglecters and perhaps even to their community.’ (Gibbons, S. 2006. ‘Primary care assessment of older people with self-care challenges.’ Journal of Nurse Practitioners, 323-328.)

The Care Act statutory guidance defines self-neglect as; "a wide range of behaviour neglecting to care for one's personal hygiene, health or surroundings and includes behaviour such as hoarding".

When is S42 not triggered?

The Care Act 2014 (statutory guidance updated March 2016) included self neglect as a category of abuse and neglect, and so the adult safeguarding duties outlined in the Care Act apply equally to cases of self-neglect.

However, in relation to self-neglect, the Care Act statutory guidance acknowledges:

“This covers a wide range of behaviour neglecting to care for one’s personal hygiene, health or surroundings and includes behaviour such as hoarding. It should be noted that self-neglect may not prompt a section 42 enquiry. An assessment should be made on a case by case basis.

A decision on whether a response is required under safeguarding will depend on the adult’s ability to protect themselves by controlling their own behaviour. There may come a point when they are no longer able to do this, without external support.”

If not S42 then what?

The Care Act 2014 places specific duties on local authorities in relation to abuse and neglect, including self-neglect:

(i) Assessment- (Care Act Section 9 and Section 11)

The Local Authority must undertake a needs assessment, even when the adult refuses, where-

- it appears that the adult may have needs for care and support,

- and is experiencing, or is at risk of, abuse and neglect (including self-neglect).

This duty applies whether the adult is making a capacitated or incapacitated refusal of assessment.

Making Safeguarding Personal

The Care Act and Making Safeguarding Personal have set out guiding principles to consider when engaging with individuals who may self-neglect or hoard:

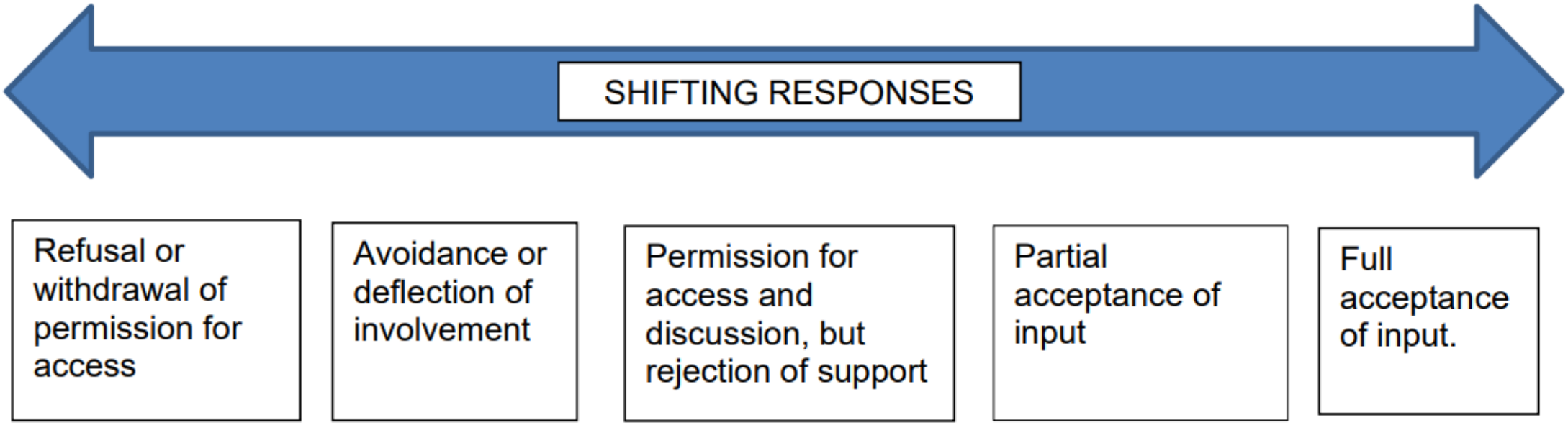
- Start with the assumption that the individual is best placed to judge their wellbeing

- Pay close attention to individual's views, wishes, feelings and beliefs

- Preventing or delaying development of needs for care and support and reducing needs that exist

- The need to protect people from abuse and neglect.

Utilising the above principles enables practitioners to work in line with Making Safeguarding Personal. This ensures that any enquiry completed in relation to self-neglect is outcome focused, is in line with the adults wishes rather than process driven, and puts involvement of the adult at the heart of intervention; 'Nothing about me, without me.'


SHIFTING RESPONSES
Refusal or withdrawal of permission for access
Avoidance or deflection of involvement
Permission for access and discussion, but rejection of support
Partial acceptance of input
Full acceptance of input.

Mental Capacity

Mental capacity is a key determinant of the ways in which professionals understand self-neglect and how they respond in practice.

One of the statutory principles of the Mental Capacity Act 2005 states that “a person is not to be treated as unable to make a decision merely because he makes an unwise decision”4; a person who makes a decision that others think is unwise should not automatically be labelled as lacking the capacity to make a decision. Efforts should be made to build and maintain supportive relationships through which services can in time be negotiated.

For adults who have been assessed as lacking the mental capacity to make specific decisions about their health and welfare, the Mental Capacity Act allows for agency intervention in the person’s best interests. In urgent cases, where there is a view that an adult lacks mental capacity (and this has not yet been satisfactorily assessed and concluded), and the home situation requires urgent intervention, the Court of Protection can make an interim order and allow intervention to take place.

Assessment of capacity

A Local Authority v JB [2021] UKSC 52:

'…the *first* question to be asked is whether P is unable to make a decision for himself in relation to the matter. If so, the *second* question is whether than inability is "because of an impairment of, or a disturbance in the functioning of the mind or brain"'.

'The causal nexus'

The assessment **process**

- **Specific decision** – what is the decision you are asking the person to make?
- **Relevant information** – what key things does the person need to understand, retain and use and weigh to make the decision?
- **Stage 1 – Functional Test** – Can the person make the decision?
  - **Understand** the information provided to them.
  - **Retain** the information long enough to make a decision.
  - **Use and Weigh** the information provided.
  - **Communicate** their decision to you.
- **Stage 2 – Diagnostic Test** – Is there a disturbance / impairment in the functioning of the mind or brain?
- **Stage 3 – Causative Nexus** – If the person cannot make a decision, is this because of an identified disturbance / impairment of the mind or brain?

Mental Capacity Act 2005, *s.2-3*
PC v City of York Council [2013] ECWA Civ 478
Re JB [2021] UKSC 52

The **Presumption**

Berkshire Healthcare NHS Foundation Trust

The presumption of capacity is important; it ensures proper respect for personal autonomy by requiring any decision as to a lack of capacity to be based on evidence. Yet the section 1(2) presumption like any other, has logical limits. ***When there is good reason for cause for concern, where there is legitimate doubt as to capacity [to make the relevant decision], the presumption cannot be used to avoid taking responsibility for assessing and determining capacity.*** *To do that would be to fail to respect personal autonomy in a different way.*

Royal Bank of Scotland Plc v AB [2020] UKEAT 0266_18_2702 at [26]

For further discussion see: Astrachan, Keene and Kim (2023) Questioning our presumptions about the presumption of capacity

Unwise Decisions

Berkshire Healthcare NHS Foundation Trust

The principles are only “for the purposes of [the Mental Capacity Act]”, the statement on unwise decisions is therefore not a general statement about a ‘right’ to make unwise decisions in all contexts.

Further, the word ‘merely’ means that an unwise decision cannot be the **only** reason for concluding that a person lacks capacity, **however** unwise decisions could be a reason to question the presumption of capacity, unwise decisions may also contribute to a conclusion that a person lacks capacity.

There may be cause for concern [and therefore a need to assess their capacity] if somebody:

- **repeatedly makes unwise decisions** that put them at significant risk of harm or exploitation or
- makes a **particular unwise decision** that is obviously irrational or out of character

Mental Capacity Act Code of Practice, 2.11

Michael Preston-Shoot and Mike Ward (2021) How to use legal powers to safeguard highly vulnerable dependant drinkers in England and Wales, 9

Assessing mental capacity in connection to hoarding

When assessing capacity, it is important to remember this is an assessment of whether the adult has capacity to understand the risks associated with the hoarding behaviour. The pertinent points being;

- is the adult able to weigh up the alternative options, for example being able to move around their accommodation unhindered, being able to sleep in their bed, take a bath, cook in their kitchen, sit down on a chair/sofa (this list is not exhaustive);
- can the adult retain the information given to them (e.g. if the accommodation is cleared, you would be able to move around your accommodation);
- can the adult communicate their decision.

It is essential that any capacity assessment is clearly documented on case records.

Emerging Themes

The perceptions of people who neglect themselves have been less extensively researched, but where they have,

- pride in self-sufficiency
- connectedness to place and possessions and behaviour that attempts to preserve continuity of identity and control.
- Traumatic histories and life-changing events are also often present in individuals' own accounts of their situation.

Differentiation between **inability** and **unwillingness** to care for oneself, and **capacity** to understand the consequences of one's actions, are crucial determinants of response.

Executive dysfunction

- A person gives coherent answers to questions, but unable to put into effect the intentions expressed in those answers
- Colloquially, described as the person being able to ‘talk the talk’, but unable to ‘walk the walk’
- Associated with brain injury, autism, Prada-Willi syndrome, obsessive compulsive disorder and hoarding
- Umbrella term used to identify difficulties with a wide range of cognitive functions commonly thought to be situated in the frontal lobes of the brain

Executive Dysfunction

The inability to perform activities of daily living, even though the need for them may be understood – is seen as significant, and when this is accompanied by an inability to recognise unsafe living conditions, self-neglect may be the result.

Let be clear Executive Dysfunction is not a new or replacement for a Mental Capacity Assessment . It may provide evidence to support a MCA. Ans support suport autonomy.

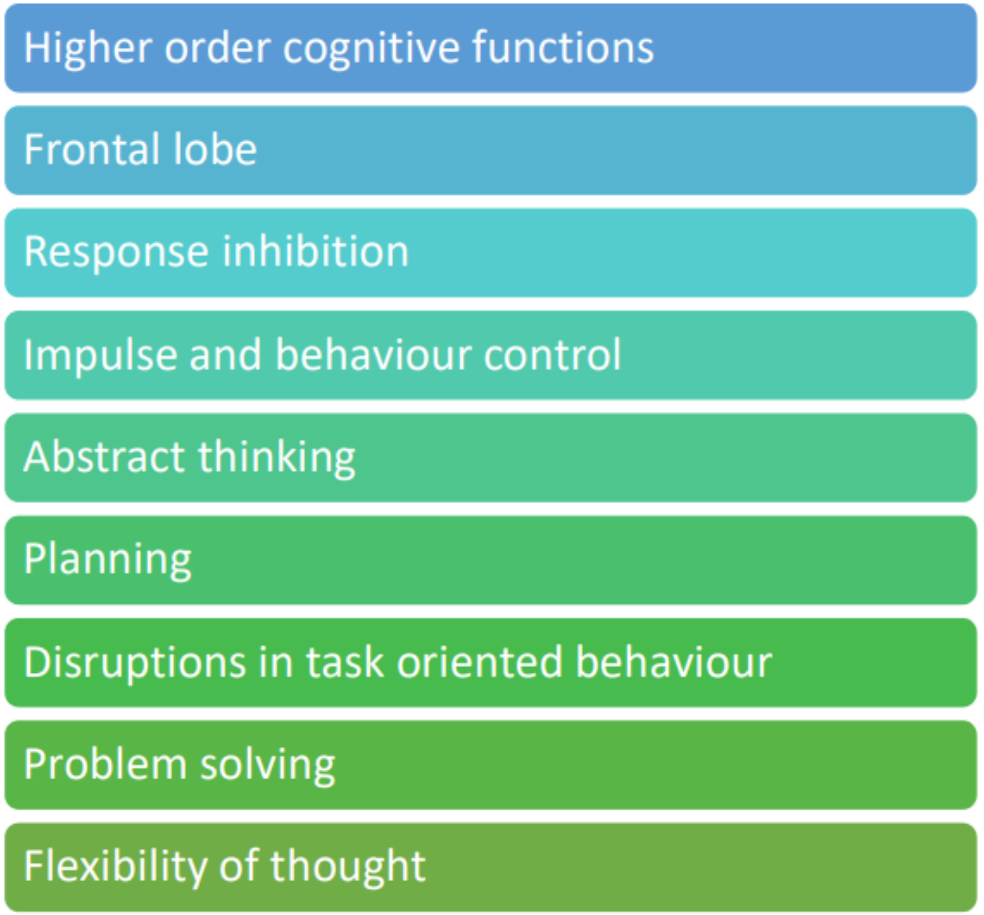
Neil Allen (39 Essex street) describes Mental capacity as legal concept MCA 2005 and Executive Dysfunctioning as a clinical concept test.

It is about a divorce mismatch between saying and doing and how the person explains that mismatch Real world evidence triangulation of information and conversations.

Executive Function let's hear about it from an expert with experience …

Executive Function (youtube.com)

Mental Capacity Act and DoLs | West of Berkshire Safeguarding Adults Board (sabberkshirewest.co.uk)



Executive Dysfunction what is it ?

Did you recognise any of these in the video ?

(with thanks to James Codling Mental Capacity Act and Deprivation of Liberty Safeguards Training and Development Manager Cambridgeshire County Council)

1. Working Memory

Being able to keep information in mind and then use it in some way.

2. Flexible Thinking / Cognitive Flexibility

Being able to think about something in more than one way.

3. Self-control / Inhibitory Control

Being able to ignore distractions and resist temptation. This is how people regulate their emotions and keep from acting impulsively

Executive function is responsible for these 5 skills:

- Paying attention
- Organising and planning
- Initiating tasks and staying focused on them
- Regulating emotions
- Self-monitoring (keeping track of what you are doing)

Beware a Diagnostic Approach

- It’s important to note that impaired executive function does not automatically lead to a conclusion that a person lacks capacity.
- Many patients with executive dysfunction can make capacitous decisions, especially with support.
- It is however an important issue to be aware of, particularly in relation to decisions that are performative in nature.
- Executive dysfunction does not change the approach to the assessment of capacity, the test set out in sections 2 and 3 MCA must still be applied.

Dr Emma Cameron and James Coding (2020) *When mental capacity assessments must delve beneath what people say to what they do*.

Talk the talk, **walk the walk…**

- You can form a reasonable belief that someone lacks capacity to make a decision **if they cannot implement what they say they will do** in the abstract because, for example, they cannot bring to mind the information needed to implement the decision.
- However, you can only reach this conclusion where there is a clearly documented **evidence of repeated mismatch**. More than one assessment is therefore likely to be required.
- And, you must be able to explain how the inability to perform the decision is **linked to the functional and diagnostic tests** (remembering the requirement to provide all practicable support to the person to be able to make the decision themselves).

39 Essex Chambers (2022) *Carrying out and recording capacity assessments* at [62-4]
Capacity Guide (2023) The person seems to say one thing and to do another

Talk the talk, **walk the walk…**

- Baseline information and triangulating this with what the person says in the assessment and what others who know the person report is essential (where possible).
- This is particularly important in patients who are able to give a response quickly, and with conviction, but are in fact confabulating.
- A lack of ‘probing’ questions when assessing capacity can be a barrier to identifying a person’s inability to understand or use and weigh the relevant information (for example, simply asking ‘do you understand’, rather than asking further exploratory / probing questions like ‘what practical issues do you need help with’, ‘who will provide this’, what the pros and cons of a decision are).

Dr Emma Cameron and James Coding (2020) *When mental capacity assessments must delve beneath what people say to what they do*.
Alex Ruck Keene (2023) Alcohol Related Brain Damage and capacity – in conversation with Ken Wilson and Julia Lewis

Neglect example

This example could be replaces by a personal care/ pressure relieving equipment / example or alcohol use.

- There is a concern raised that Person A is not taking their medication (could be insulin or other medication)
- When Person A is seen by professional and due to concerns about A undiagnosed cognitive impairment they have undertaken a mental capacity assessment at different points over the last few months
- Each assessment the outcome is that Peron A had capacity (51%)
- Person A seem to fully understand the reason why they need the medication and how to take the medication and what may happened if they don't. They retain and summarise back and they communicate clearly they want to take the medication and plan to do so.
- **What could be considered ?**

Neglect example

This example could be replaces by a personal care/ pressure relieving equipment / example or alcohol use.

- The professional reflects in supervision that they are concern and curious that Person A is not a person who is just disorganised or has a chaotic lifestyle that affects their concordance with medication. They want to discuss the approach to assessing capacity because they think something isn't right !!
- They discussed Person A doesn't take the insulin as prescribed and keeps having admission or episode of being unwell is able to "walk the walk"
- This lead to discussion re their executive functioning the supervisor asked have you seen this repeatedly with person A ? How may time ? What have family /friend seen observed ?
- The clinician went away reviewed notes and used this to record their reasonable belief 51% that Person was unable to make a decision at the **material time** and thus assessed to lack the capacity to take the diabetic medication to manage condition and this was caused by an currently undiagnosed condition. (He was awaiting a memory clinic assessment)

Case study **‘David’**

- David is alcohol dependent. His mother had looked after him and when she died his father hired a cleaner. When his father died, David moved home and was self-neglecting. He had lost job and had mental health and mobility issues. He has multiple long-term health conditions, including leg ulcers, osteoporosis and diabetes.
- Practitioners often found human dirt covering the walls of his flat and clothes lying around which appeared to be wet through urination or covered in faeces. He consistently declined care assessments and help, stating that he is able to manage and there is nothing to be concerned about.
- He has no hot water, no shower, toilet, or food in the house and his lights were not working. He says he will get on top things ‘soon’.

Discuss the above, what could be considered?

Alex Turner (2019) Safeguarding study reveals knowledge gaps in applying MCA to cases of alcohol-based harm

Case study **‘David’**

- David agrees to go into a respite facility while his property was deep cleaned but doesn’t appear to fully understand why this is being done, reporting that he is agreeing to this to ‘keep the authorities off his back’.
- After the deep clean, David returns to his property and the condition of the property quickly deteriorates. He also continues to decline care and treatment for his physical health conditions.
- His home care package advise they are going to withdraw support due to David’s alcohol-fuelled verbal abuse directed at their staff.
- He gets an informal carer, who is also drinking and suspected to be financially exploiting him.
- There are concerns that he is not properly caring for his leg ulcers, which are deteriorating.

Discussion, what are the next steps?

The importance of identifying the **decision(s)** and **relevant information**

- The question of whether or not a person has capacity to make decisions about drinking is not, in and of itself, likely to be of critical importance.
- Instead, it is likely to be the **impact** of the person's dependence on alcohol (or substances) on their capacity to make other decisions (for example, in relation to care and support needs).
- The approach is therefore likely to be, can the person understand, retain, use and weigh relevant information for purposes of another decision, the **consequences** of their alcohol dependence (for instance breakdown of the placement, homelessness or even death) being part of that relevant information.

39 Essex Chambers (2020) *London Borough of Tower Hamlets v PB*

Case study **‘David’**

Care and Support	Residence
(a) With what areas the person under assessment needs support; (b) What sort of support they need; (c) Who will provide such support; (d) What would happen without support, or if support was refused. (e) That carers may not always treat the person being cared for properly, and the possibility and mechanics of making a complaint if they are not happy.	(a) The two (or more) options for living. (b) Broad information about the area. (c) The difference between living somewhere and just visiting it. (d) The activities that the person being assessed would be able to do if he lived in each place; (e) Whether and how the person being assessed would be able to see friends and family if he lived in each place; (f) The payment of rent and bills. (g) Any rules of compliance and/or the general obligations of a tenancy. (h) Who they would be living with at each placement; (i) The sort of care they would receive in each placement; (j) The risk that a family member or other contact may not wish to see the person being assessed should they choose a particular placement against their family’s wishes.

Case study **‘David’**

- David is assessed to lack capacity to make decisions about his care and support needs and residence. It is assessed to be in his best interests to need a placement at a specialist care home who can provide support to people with challenging behaviours and to be supported to reduce his alcohol intake.
- He is moved to a specialist care home that specialises in caring for people with substance misuse difficulties. David’s care plans are updated, and his alcohol intake monitored, with support from alcohol services to reduce the risk of withdrawal.

University of Bedfordshire (2023) Alcohol Management in Care Homes A Good Practice Guide for Staff
Alex Turner (2019) Safeguarding study reveals knowledge gaps in applying MCA to cases of alcohol-based harm

Questions

Hoarding, capacity & best interests

AC and GC (Capacity: Hoarding: Best interests) [2022] EWCOP 39

- AC, 92-year-old woman with Alzheimer's & alcohol-related brain damage
- Lived at home with son who had Asperger's, anxiety, OCD & depression
- Both AC & son diagnosed as having a hoarding disorder
- Council had become concerned that AC's care needs not being met due volume of items in the property & ongoing court proceedings
- AC admitted to hospital & whilst there, a suitable nursing placement was identified by the local authority & son
- Court declared that AC lacked capacity on residence and care, & it was in her best interests to move from hospital to a care home
- Also appointed an independent deputy

The relevant information for making decisions as to items & belongings

1) Volume of belongings & impact on use of rooms
2) Safe access & use
3) Creation of hazards
4) Safety of building
5) Removal/disposal of hazardous levels of belongings

The judge's decision

- AC lacked capacity to make decisions about managing her property and affairs & her items and belongings
- Trial care at home was not without risk but, on the evidence, it was a 'manageable risk' & in AC's best interests
- Conditions placed on the son eg to give access to care workers, work with the deputy, continue to see therapist & store shopping appropriately

… the aim of the court should not be to remove all risk but to create manageable risk and the court should not ignore the risk of institutional care failing by providing a sad and less than ideal outcome for AC.

MCA, inherent jurisdiction & self-neglect

London Borough of Croydon v CD [2019] EWHC 2943 (Fam)

- CD was diabetic & epileptic, poor mobility, incontinent of urine/faeces & unable to maintain his home environment
- Also, excess alcohol use & often inebriated at home
- Frequent incidents of falling in his flat, non-compliance with medication, severe self neglect, inability to manage personal care, activities of daily living & health
- His home environment deteriorated & care agency were unable to access the flat due to fears of cross contamination & infection
- Frequently called emergency services
- CD lives alone and socialises with friends in the same block of flats who equally have alcohol misuse problems

Key issues

- CD's flat was soiled with human waste, putting him & visitors at high risk of infectious diseases
- He was continuing to drink alcohol and soil himself
- Carers unable to access his flat to provide the personal care CD required
- CD was not willing to change his ways or be moved to a safe environment where he could be supported with his personal care
- Local authority proposed a ‘20 point care plan’ to the court which allowed its staff to gain access to CD’s flat (1) to provide appropriate care for CD himself & (2) make his accommodation safe for human habitation

The judge's decision

- All agreed care plan was in CD's best interests but disagreed over jurisdiction (local authority sought orders under IJ but OS suggested MCA)
- Judge held that he was both a vulnerable adult for the purposes of the inherent jurisdiction & lacked capacity to make decisions about his care
- The relevant impairment / disturbance being his psychiatric background of depression and/or dysthymia and/or his chronic alcohol abuse
- It was also noted that CD's capacity fluctuated
- Judge therefore made an order under the MCA, while also including in the order the finding that CD was vulnerable & so the IJ was an alternative route available to the local authority on the particular facts of the case

Some case law references you may like to read
A Local Authority v AW **Judge** Cobb J [2020] EWCOP 24

- Although Cobb J modestly suggested that the judgment did not establish any or new great legal principle, it is – as Sherlock Holmes would have said – not without points of interest. Some of those points arise out of the careful recitation and analysis of the evidence going to capacity, serving as a model of the resolution of a complex – finely-balanced – case. Others arise out of the fact that this is another in a small (but slowly growing) body of case-law relating to executive functioning, described (at paragraph 39) as "*the ability to think, act, and solve problems, including the functions of the brain which help us learn new information, remember and retrieve the information we've learned in the past, and use this information to solve problems of everyday life*" – crucially, and properly, linked to one of the MCA criterion (in this case, his problems with executive functioning being such as to prevent AW being able to understand the information relevant to residence and care).
- https://www.39essex.com/information-hub/case/local-authority-v-aw

Useful link to BW SAB Case Law and Articles

- Mental Capacity Act and DoLs | West of Berkshire Safeguarding Adults Board (sabberkshirewest.co.uk)

- "An awful state": Self-neglect and mental capacity – Promoting Open Justice in the Court of Protection (openjusticecourtofprotection.org)
- When mental capacity assessments must delve beneath what people say to what they do - Community Care

Case law :London Borough of Croydon v CD [2019] EWHC 2943 (Fam) High Court (Family Division (Cobb J))

- *CD is diabetic and also epileptic and has poor mobility, incontinent of urine and faeces and unable to maintain his home environment. CD's condition is further complicated by excess alcohol use and he is mostly inebriated at home. This has led to frequent incidents of falling in his flat, non-concordant with medication, severe self neglect, inability to manage his personal care, activities of daily living, his health and wellbeing. Recently his home environment deteriorated to a stage that a care agency commissioned via Croydon Council were unable to access the flat to support him with his care needs for fear of cross contamination and infection*
- A Local Authority v BF | 39 Essex Chambers
- BF was a 97 year old man who suffered from diabetes, osteoarthritis and as blind in both eyes. At the time of the appeal he was residing in residential care against his wishes, rather than at home with his son KF. The history of the case is long and involved, but in short BF lived in a bungalow with his son KF following the death of his wife. KF suffered with drug and alcohol addiction and was noted to intimidate visiting care staff such that all ultimately refused to provide BF with care at home.
- The person seems to say one thing and to do another - Capacity guide
- 2023-04-25 NMCF S2E4 Exec Dysf FINAL (essex.ac.uk)