

B&NES, Swindon & Wiltshire (BSW) Self-Neglect Virtual Conference

"Don't judge me by the chapter you have walked in on. I have a past and a future and not defined by my current situation".
Quote from Swindon Experts by Experience.

Please put your name and role in the chat



Lunch Break

30 minute lunch break



Instructions



A top-down view of a white medical surface. A silver stethoscope with a blue tube is positioned on the left. A hand is visible in the lower right, holding a clear syringe. The text is overlaid on this background.

SAR Robert

Including overview of when to make a safeguarding adult referral
Dr Michelle Sharma

Any Questions:

Emily's story




Where the
magic happens

Welfare and Safety Plan

Faith Margle & Kati Wood

Your
Comfort
Zone



“Don't judge me by  the chapter you have walked in on. I have a past and a future, I am not defined by my current situation”

– Swindon experts by experience



Welfare and Safety Plan

“Don’t judge me by the chapter you have walked in on. I have a past and a future, I am not defined by my current situation” –
Experts by experience

Top Tips on using this tool from experts with experience:

- Do not judge me
- Using the word 'risk' can make me feel judged. Talk to me about my safety, welfare and wellbeing. Please ask me my preferred terminology (for example not everyone is comfortable with the word hoarding)
- Be honest with me about what this conversation is about. It is okay to tell me you are concerned and why – this makes me feel cared about.
- Listen to my experience, don't start the conversation with your own idea of what I need. Give me time.
- Ask me what is going well for me. Celebrate all my wins for you and me, however small they may seem

How the plan was developed

- We worked with people who have experienced self-neglect and/or hoarding behaviour
- How to make it valuable for different people?
- It is a living document for the person, breathing the persons perspective into the document
- We were mindful of language and approach

Welfare and Safety Plan

"Don't judge me by the chapter you have walked in on. I have a past and a future, I am not defined by my current situation" – Experts by experience

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Person Centred Welfare and Safety Plan - To be completed with the Person

Title & Name	
Preferred Name	
Address	
Why we are talking about my Safety and Welfare	1.
People involved (Family/ friends/ people/ agencies/ services already involved)	
My communication needs/reasonable adjustments	

Pronouns	
Date of birth	
Personal reference number:	

After this conversation, is an assessment or review of mental capacity needed?

Does the person appear to understand the concerns?	Yes	No	Unsure
Please explain your rationale			
Is an assessment or review of the persons mental capacity required?	yes	No	Unsure
Please explain your rationale			

Negligible	Minimal	Moderate	High	Extreme
There are no significant concerns for my welfare and safety.	There are examples of me not coping with some aspects of daily living. These can be managed with minimal support.	Occasional episodes of self-neglect that give cause for some concern.	There are serious concerns about my ability to manage and for my wellbeing and safety.	There are very serious current concerns. My welfare and safety are currently at risk to the extent that the situation will need to be addressed immediately.

Consequences

	0	1	2	3	4	5
Likelihood						
1						
2						
3						
4						
5						



Examples of areas of concern (Please use blank boxes at the bottom for additional concerns)

	Past			Present			RAG Rating
	Yes	No	Don't Know	Yes	No	Don't Know	
Lack of self-care							
Managing nutrition and fluid intake							
Supportive friends/relationships (social support network), is the person experiencing isolation?							
Dressing appropriately for weather and/or activity							
Managing physical health including medication and sharps.							
Managing mental health and wellbeing, including medication							
Managing and maintaining hygiene							
Does the person have suitable accommodation? suitable/ working adaptations or equipment							

What are the benefits of these behaviour(s) of concern?
Explore these benefits through transparency, be open and honest. Draw comparisons between my views and the professionals views.

What are the dangers of these behaviour(s) of concern?
Explore these benefits through transparency, be open and honest. Draw comparisons between my views and the professionals views.

Views of other people involved in the assessment
Consider the positives and challenges for me.

What could be the consequences of these concerns or continuing this behaviour?
If nothing changes what could happen?



I've learned that people
will forget what you
said, people will forget
what you did, but
people will never forget
how you made them
feel.

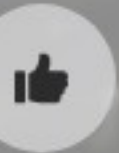
Maya Angelou



Any Questions:

coffee break

15minute break



Legal Literacy - Mental Capacity Act

Tim Shearn & Leona McCalla



If a person lacks capacity to make a decision about health and social care needs, professionals can ask their next of kin to make it on their behalf?

0 
True

0 
False

The MCA has 5 key principles that should be followed by all professionals?

0 ✓
True

0 ✗
False

The MCA is primarily concerned with preventing those we work with from harming other people?

0 
True

0 
False

In order to be assessed as lacking capacity under the MCA a person must have a mental disorder that falls within the scope of the Mental Health Act?

0 
True

0 
False

If a person is making an unwise decision, we must always allow them to do so?

0 
True

0 
False



Professional Curiosity: What is it and why it's important?

- Professional Curiosity is an approach that should underpin all our interactions in health and social care.
- Ask questions rather than accept all at 'face value'.
- Respectfully challenge when appropriate.
- Question what you observe.
- Challenge our own professional assumptions about what we see.
- Consider information from a variety of sources.

How can I be professionally curious?

- **Don't presume** you know what is happening with an individual – ask questions and seek clarity.
- **Be open** to assimilate information into your assessment that does not support your initial assumptions.
- **Seek clarity** from others – family and professionals.
- Be open to having your **assumptions challenged** and to **challenging others**.
- Be open to **what you see** – what visual clues are there as to how life is for the individual.
- **Use supervision** to explore professional curiosity and seek alternative views.

What are some of the barriers to being professionally curious?

- **Lacking the confidence** to appropriately challenge and ask difficult questions.
- Being **overly optimistic** about a person's situation – not wanting to see the problems.
- **Making assumptions** and not allowing challenge to occur.
- **Unconscious bias** e.g. all people who misuse alcohol are making a choice to do so.
- **Lack of time** and **heavy workloads** to fully assess and develop an engaging professional relationship.

Professional curiosity, self-neglect and the MCA

- Professional curiosity is a vital component of good MCA practice.
- This is especially true when considering principles 1 and 3 of the MCA
- People who self-neglect may present as individuals who are making competent decisions or following a so-called 'lifestyle choice'.
- How do you differentiate between an individual making an 'unwise decision' and one who lacks capacity?
- You demonstrate an enquiring mind and professional curiosity!



Use of the MCA in self-neglect cases

Research from the University of Bristol found:

Assessments of capacity were **not being carried out** in cases of self-neglect even when professionals were observing concerning behaviours or where there was an existing diagnosis which may have impacted on their decision-making ability.

Capacity assessments were often **not recorded** or, when they were, **they lacked detail and clarity** about who completed it and what the conclusion was.

Such practice exposes practitioners, their employers and those individuals in their care to **unnecessary risk**.

There was a fundamental lack of confidence on the part of practitioners to undertake capacity assessments and incorrect assumptions that it was **not their responsibility** to do so.

MCA Principles

The MCA introduces 5 key principles:

1. A person must be assumed to have capacity unless it is established that he/she/they lack capacity.
2. A person is not to be treated as unable to make a decision unless all practicable steps to help him/her/they to do so have been taken without success.
3. A person is not to be treated as unable to make a decision merely because he/she/they makes an unwise decision.
4. An act done or decision made under this act for, or on behalf of, a person who lacks capacity must be done or made in his/her/their best interests.
5. Before the act is done, or the decision is made, regard must be had as to whether the purpose for which it is needed can be as effectively achieved in a way that is less restrictive of the person's rights and freedom of action.



MCA – Principle 1

S1(2) 'A person must be assumed to have capacity unless it is established that he/she/they lacks capacity'

- There is often a misinterpretation of this key principle, something which is not new. It was highlighted by the House of Lords select committee on the MCA as far back as 2014;

*'We were told of a worrying tendency among local authorities to use the presumption of capacity to avoid taking responsibility for a vulnerable person'.

'In some cases, the evidence suggests the principle has been deliberately misappropriated...'*

(House of Lords post legislative scrutiny – paragraph 63)

MCA – Principle 1: key messages



- Whilst principle 1 of the MCA is fundamental to good MCA practice and protecting people's rights to make their own decisions, it cannot be used as a justification for non-intervention.
- It cannot be used as a justification for not engaging your brain and using your professional curiosity as to whether the person has capacity to make the decisions that are leading to self-neglect behaviours.
- Whilst you always start from a presumption of capacity, if you have cause to doubt an individual's ability to make a decision, it would be negligent not to undertake an assessment of their capacity.
- Remember, it is your responsibility to prove the person lacks capacity, not the other way round.
- Some cases may be 'borderline' – it is the balance of probabilities.

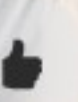
MCA – Principle 1

- SARs have highlighted that practitioners with excessive workload pressures may be at risk of using the presumption of capacity as a tool for 'disposing' of cases, be that consciously or subconsciously.
- Promoting a person's decision-making autonomy and protecting people from the risk of self-neglect should not be a mutually exclusive exercise and should be carefully balanced to support those experiencing self-neglect.
- In many cases there is a need to step into the MCA arena rather than put them away in the file marked 'too difficult to open'.

Final word on principle 1

'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, when there is legitimate doubt...the presumption cannot be used to avoid taking responsibility for assessing and determining capacity'

The Honourable Mr. Justice Swift – Royal Bank of Scotland PLC
v AB: UKEAT/0266/18/DA



MCA Principle 3

S1(4) A person is not to be treated as unable to make a decision merely because he/she/they makes an unwise decision'

Like principle 1, the so-called 'right' for us all to make unwise decisions cannot and should not be used as a justification for not being professionally curious and potentially questioning capacity when there is cause to do so.

MCA Code of Practice para 2.11:

'There may be cause for concern if somebody repeatedly makes unwise decisions that put them at significant risk of harm...or makes a particular unwise decision that is obviously irrational or out of character. These things do not necessarily mean that somebody lacks capacity but there might be need for further investigation.'

MCA- Principle 3

When interpreting principle 3:

- Remember the guidance in the Code of Practice.
- Be aware of your own values and the decision you would have made in the same circumstances and how this may be influencing your judgement.
- Is there anything that suggests that the person may be struggling to make the decision? Again, use your professional curiosity.
- Has the person previously been assessed as lacking capacity to make other decisions? Have they an established impairment or diagnosis BUT be mindful of diagnostic over-shadowing...

MCA - Principle 3

- In cases of self-neglect, when risks are high, consideration of, and an assessment of the person's capacity will be important.

Particularly so in the face of evidence.

- If you decide not to proceed with a capacity assessment, then there should be a clear rationale recorded in the individual's care record as to why you have decided that this was the correct course of action. **You should be prepared to justify this decision.** This may include evidence as to why the decision is unwise rather than indicating a lack of capacity.

An exploration of the difference between an inability to protect oneself from the effects of self-neglect (lack of capacity?) and unwillingness to seek help (unwise decision?) may need to be demonstrated.

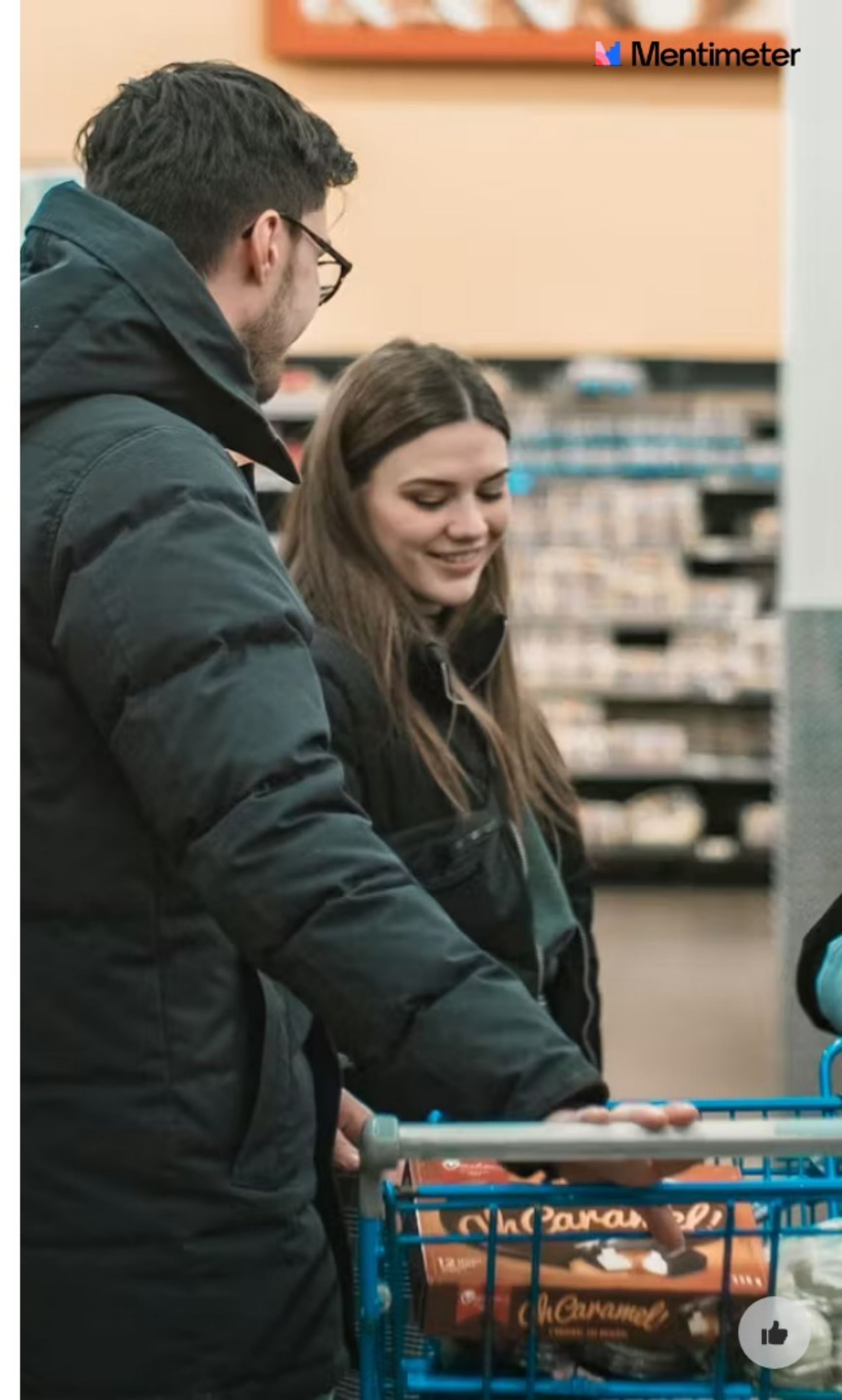
MCA - Principle 3

- If in any doubt, proceed with an assessment.
- Any decision taken should be kept under review.
- When considering whether a person lacks capacity to make a decision, it may be necessary to consider their executive functioning

MCA - Principle 3

LGA – Analysis of Safeguarding Adult Reviews (SARs):

- Highlighted that, in a number of SARs, when faced with what could be seen as 'unwise decisions, practitioners sometimes relied on the assumption that the person was following a 'lifestyle choice' rather than exploring (being curious!) about whether an individual had the ability to carry out the decisions when they had stated the intention do so – **their executive functioning.**



Mental Incapacity Defined: Section 2 (the 'diagnostic test')

"A person lacks capacity in relation to a matter if at the material time he is unable to make a decision for himself in relation to the matter because of an impairment of, or a disturbance in the functioning of, the mind or brain"

What does this mean?



Assessing Capacity

- Incapacitated only in relation to a particular decision at a particular time
- It does not mean that a person lacks all capacity to make any decisions at all. A blanket approach
- Only the smallest area of decision making necessary should be identified
- Contrasts with approach that states that because a person has a particular medical condition, they lack general capacity



What are we assessing capacity for? This is always the starting point!!



- Does the person have the mental capacity to make a decision about receiving a package of care?
- Can the person decide regarding the provision of a hospital bed?
- Can the person decide about wound care/ pressure care?
- Does the person have the mental capacity to manage their diabetes?
- Can the person make the decision regarding hospital discharge?
- Can the person make a decision about taking prescribed medications?
- Does the person have the mental capacity to decide about accessing support with hoarding?
- Can the person make the decision regarding NG tube insertion?
- Does the person have the mental capacity to make a decision regarding continence care?



Mental Incapacity Defined: Section 3

- **Stage 1:** The functional test: URWC
- Can the person **understand** the relevant information?
- Can the person **retain** the relevant information?
- Can the person **use** or **weigh** the relevant information?
- Can the person **communicate** that decision?
-
- **Stage 2:** Does the person have an impairment or functioning of the mind or brain?
- **Stage 3:** Is it because of that impairment they cannot make decision? (Causative Nexus)

Stage 1

- Salient Factors: Asking the right questions for the decision to be made!!



What could be the salient factors for determining whether the person has capacity to access help for their hoarding ? (Tick all relevant)

- 0% a) Does the person know their date of birth?
- 0% b) Does the person understand they have a problem with hoarding?
- 0% c) Does the person know whether they are able to move around their accommodation unhindered?
- 0% d) Does the adult know how many children they have?
- 0% e) Does the adult know whether they can access their kitchen to make a meal?
- 0% f) Does the adult know if they can access their bath to bathe?
- 0% g) Does the adult know what support is available to them?

What could be the salient factors for determining whether the person can manage their care and support needs ? (Tick all relevant)

- 0% a) Does the person know that they need support to make a meal?
- 0% b) Does the person know that their weight has been declining?
- 0% c) Does the person know where they were born?
- 0% d) Does the person know that they experience incontinence of urine?
- 0% e) Does the person know that they have not bathed and showered for several months?
- 0% f) Does the adult know if who the prime minister is?
- 0% g) Does the adult know what support is available to them to meet their needs?

Conducting Assessments:

- **Be transparent**- completing a capacity assessment/outcomes, ask the question you are trying to obtain consent for
- **Do your homework**- be clear what the salient info is that is relevant to the decision being made, including the **'reasonable foreseeable consequences'**.
- Salient info needs to be delivered in a way that **"the man on the street can understand"**- *Montgomery v Lanarkshire Health Board* [2015] UKSC11
- Need to **not set 'the bar too high'** for understanding or be overly influenced by the **'protection imperative'**- *CC v KK & STCC* [2012] EWCOP 2136



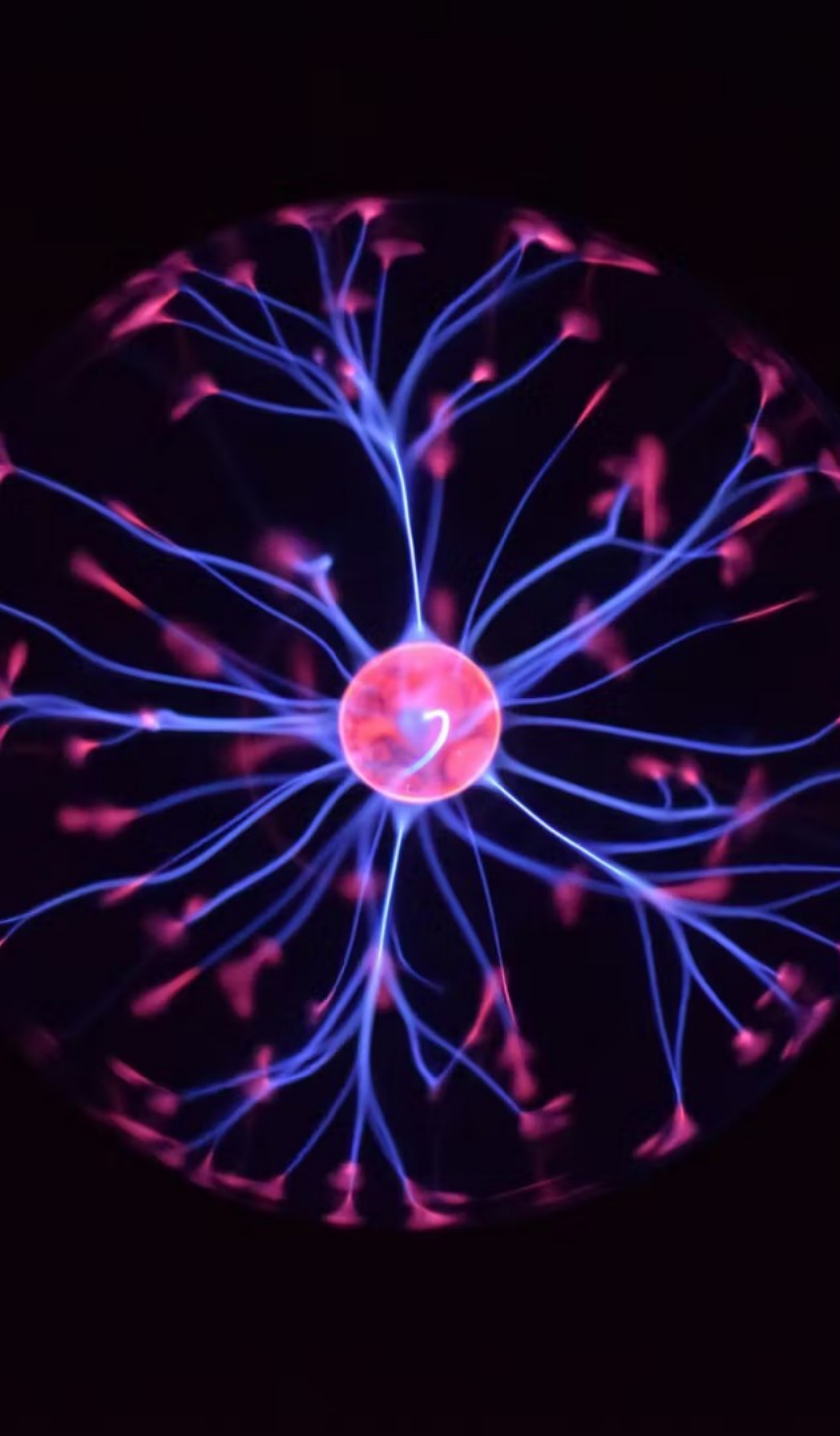
Conducting Complex Assessments:

Repeat assessments: This might be required to ensure that professional curiosity and appropriate challenge is embedded within an assessment. It is important than when undertaking the assessment that the practitioner does not accept the first, and potentially superficial, response rather than exploring more deeply into how a person understands and can act on their situation.

Sharing information: It is important to collect and share information with a variety of sources, including other agencies, to complete a picture of the extent and impact of the self-neglect and to work together to support the individual and assist them in reducing the impact on their wellbeing and on others

MDT Discussion: Triangulating of information

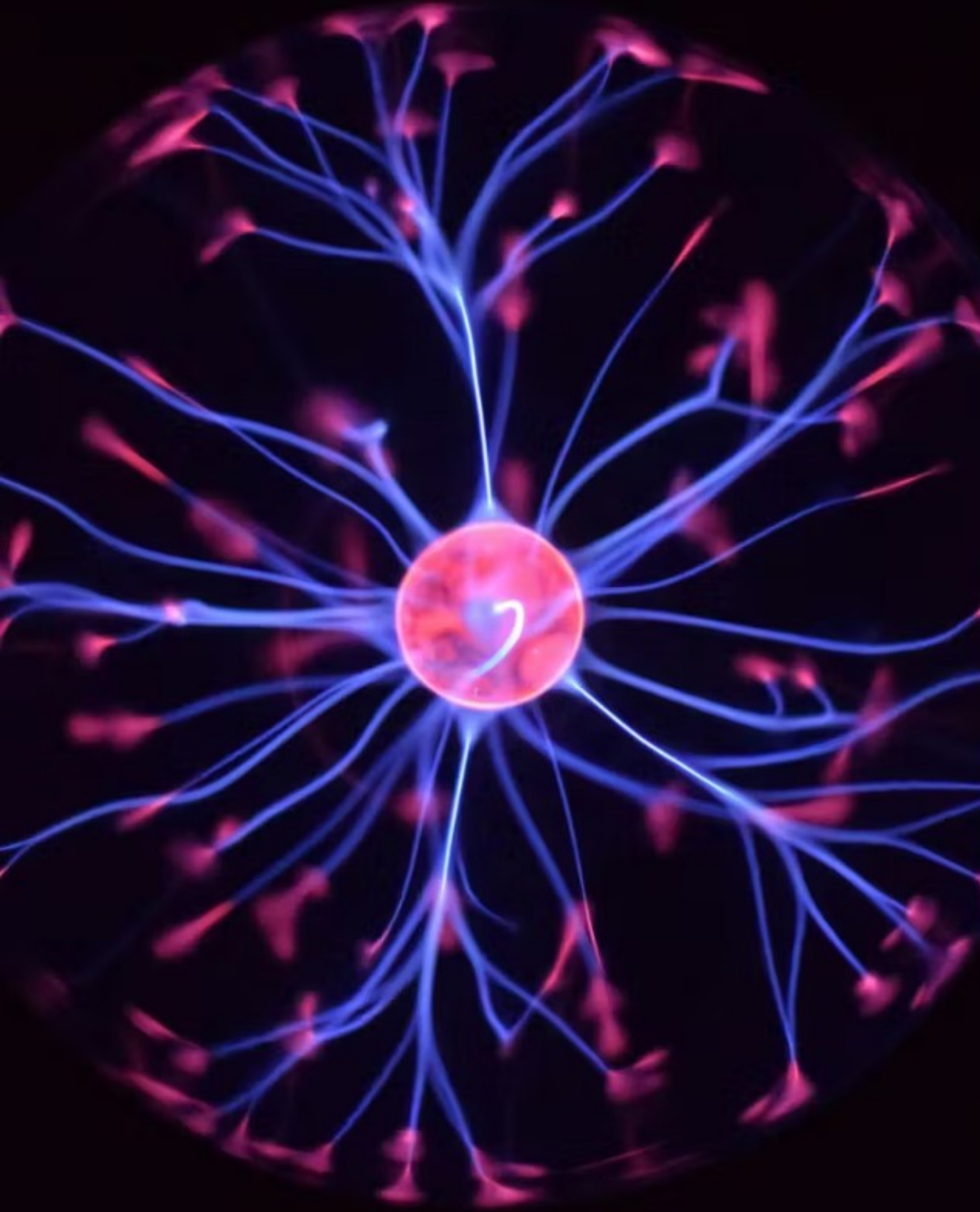




Mental Impairment & Causative Nexus

Cognitive Impairment: Dementia, Parkinson's, Huntington's, Autism etc

Complex and traumatic life experiences: Consider the long term impacts of trauma on cognition, interpersonal relationships, and people feeling overwhelmed in moments of crisis, and the possible implications for mental capacity. Some research has shown that events such as the loss of parents as a child, childhood abuse, traumatic wartime experiences, and struggles with alcohol or other substance misuse have preceded the person self-neglecting. Relatively recent grief and loss may also tip a person into self-neglect, particularly if the loss is of a figure who has previously cared for the person or their environment, e.g. a parent or partner.



Mental Impairment & Causative Nexus ... *Continued*

Impact of substance misuse and alcohol misuse / dependency: Is there an Alcohol Acquired Brain Injury or Korsakoff's diagnosis? Has this been explored?

Executive Capacity:

Executive capacity is “the planning, initiation, organization, self-awareness, and execution of tasks”.

Mental capacity involves the ability to understand and reason through the elements of the decision (decisional capacity) and the ability to realise when that decision needs to be put into practice and execute it at the appropriate moment (executive capacity).

The Mental Capacity Act 2005 states that a person is unable to make a decision if they are unable to “use or weigh” the relevant information, which could be interpreted as inclusion of consideration of executive capacity.



Executive Capacity... *continued*

However, assessment of executive capacity could be promoted much more clearly and explicitly in the Act. Existing research on the connections between executive capacity and self-neglect is limited.

Executive functioning- **'talk the talk'** v's **'walk the walk'**, responses do not align with actions

Is the patient able to identify their deficits and the mismatch between their response in the abstract and their actions in the concrete (i.e. not able to bring to mind the required information to implement what say when they need to)

Requires documented evidence of the mismatch and repeated assessment in most cases



Executive Functioning:

'If the person cannot understand (and/or use/weigh) the fact there is a mismatch between what they say and what they do when required to act, it can be said that they lack the capacity to make the decision in question BUT

This conclusion can only be properly reached when there is clear evidence of a repeated mismatch between what the person says and what they do. This means that in practice it is unlikely to be possible to conclude that the person lacks capacity as a result of their impairment on the basis of one single assessment'

Draft MCA Code of Practice para 4.38



Best Interests Decision Making

- **Principle 4:** Acts and decisions on behalf of the person lacking capacity must be in their best interests
- **Principle 5:** Acts and decisions must be the least restrictive

Section 4 Checklist for decision maker:

- Consider all relevant information
- Persons wishes, feelings, beliefs, values (past & present) and other factors the person would consider if able to
- Consult appropriate people who have an interest in persons welfare
- Consider least restrictive options
- Can the decision be delayed?
- Involve the person as much as reasonably practicable
- Do not discriminate; age, appearance, behaviour or condition
- Not motivated by desire to bring about persons death (Life sustaining treatment)

Best interests Considerations:

- Is there a **Lasting Power of Attorney for Health & Welfare?**
- Appoint an **Independent Mental Capacity Advocate**
- Hold a **Best Interests Meeting**
- Consider the **welfare balanced approach** to decision making to reach a decision
- Make an application to the **Court of Protection**
-
- Example of welfare balanced approach document



Proportionality and Best Interests

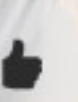
- Best interests interventions are made where appropriate and take full account of the individual's wishes, feelings, beliefs and values.
- To build a relationship that enables small steps to lead to larger ones, while monitoring risk, capacity and wellbeing.
- To find and understand the person behind the behaviour.
- To support the person to find safe ways of managing the risks in their situation.
- To ensure intervention takes account of all relevant powers and duties: Autonomy is respected where decisions are made with capacity.
- To find a balance between the moral mandates: Respecting autonomy whilst fulfilling a duty of care. To support the individual in achieving the outcomes they value
- To formulate an inter-agency plan with shared goals and clear roles

Hoarding Capacity and Best Interests

In the case of Re: AC and GC [2022] EWCOP 30 In contrast,

Mrs Justice Theis took a 'holistic' approach and considered X's capacity to make decisions about her items and belongings alongside residence, care & support. She identified the relevant information as:

- The obligations under the tenancy agreement
 - What areas X needed support with
 - What type of support
- The consequences if X did not have that support or she refused it
- The volume of belongings and the impact on use of rooms
 - Safe access and use
 - Creation of hazards
 - Safety of the building
- The removal or disposal of hazardous levels of belongings



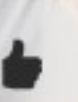


The judge concluded,

X was unable to use or weigh the relevant information due to the symptoms of her mental health conditions. She also lacked capacity to make decisions about her property & financial affairs due to impulsive purchasing of items and the impact this had on the health and safety concerns

Hoarding Capacity and Best Interests:

- In relation to the best interests, the judge was faced with a binary choice – either X remained in the property with no prospect of change, or steps were taken to enforce change. There was no middle ground.
- X 'strenuously' objected to the proposed plan which would cause her significant distress and could make her suicidal. The proposed plan was also a very significant interference with her Article 8 rights. Conversely, the risks would remain very high if not action was taken.
- The judge ultimately concluded that it was in X's best interests to be removed from her home (using restraint if necessary) and placed in a supported living placement to enable her property to be cleared.





Hoarding Capacity and Best Interests:

'...In doing so I readily accept the considerable risks that are being taken in overriding X's expressed wishes and the consequences for her of such a step being taken, bearing in mind her mental disorder and the suicide threats she has made. Those matters weigh heavily in the balance. Having said that, I consider the balance is tipped the other way by what I regard as the substantial and increasing risks X would be left exposed to if this order was not granted. They are serious risks that would have a direct impact on X's health and safety. There is no prospect of any other step being taken that would bring about out any meaningful change...'

Final Thoughts !!!

It is noted that in such cases of serious self-neglect, it can be very challenging to professionals / agencies / organisations involved to balance the individual's rights and agencies' responsibilities.

All individuals have the right to take risks and to live their life as they choose. These rights, including the right to privacy, must be respected and weighed when considering duties and responsibilities towards them.

Even where a person may lack the mental capacity to make this decision!

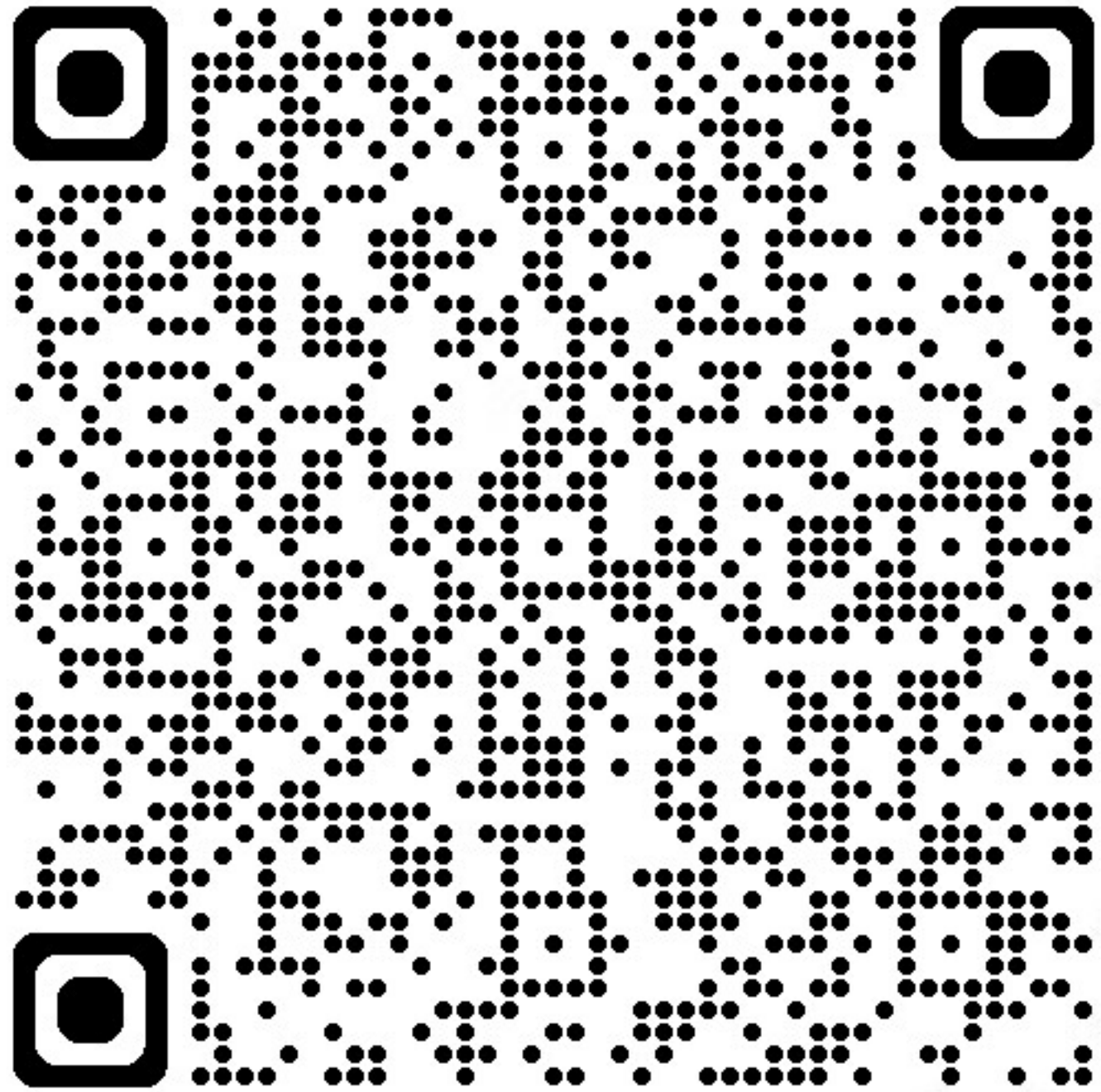


Any Questions:

Closing comments and reflections

0 responses





Thank you!

Please complete a feedback form using the QR code or link in the chat.

Once complete you will be able to download your certificate of attendance.

