Briefing into the case of John

Who was John?

John was a 51 year old man when he died in December 2018. His cause of death is recorded as sudden unexpected death in epilepsy, a previous traumatic brain injury and alcohol dependency syndrome

John had an extensive history with agencies and was described in agency records as "presenting with significant cognitive impairment due to his repeat brain injuries and excessive alcohol consumption" (Fen House, clinical psychologist). Over a period of years he suffered from recurrent falls, unintentional weight loss, fractures, social isolation and a long term seizure disorder.

Records indicate that John was employed until early 2016, when he was made redundant. He appears to have been employed in industries that involved regular international travel. These roles also included an element of networking that often involved drinking. John's view was that the travelling prevented him making friends or forming romantic relationships.

John had a long history of significant alcohol abuse that appears to have commenced during his time at University. Agencies records indicate that he did not consider himself to be alcohol dependent or that his health problems were as a result of his drinking. He maintained that his drinking was habit not addiction, and that he drunk because he was lonely and isolated.

John had sustained more than one brain injury, records suggest that the first brain injury was caused as a result of regular seizures that he suffered possibly, as a result of alcohol

withdrawal. The time scale for this review goes back to 2017, but records supplied by agencies to inform this review evidence that he was suffering from seizures from at least 2016. The second brain injury occurred in July 2017, John was hit by a car and then hit by another car two days later and admitted to Addenbrookes Hospital. The reason for his admission was recorded as acute on chronic subdural haematoma. A CT scan was undertaken which showed left subdural haematoma and right frontal extradural haematoma. There was also haemorrhagic contusions in his left temporal lobe and an intraventricular haemorrhage with a midline shift. He has also sustained right frontal and parietal fractures and required evacuation of subdural haematoma, left craniotomy and triple bolt insertion.

Throughout John's story there were instances where he was an inpatient at hospital and other health settings, during these periods he would not have access to alcohol and his health improved and he was deemed to have capacity. Throughout these periods of time, he was consistent and clear that he wished to return home and he was aware that alcohol was having a significant detrimental effect on his health. However, on discharge from the health settings he would recommence drinking heavily. Often his levels of intoxication meant that he was putting himself at harm and levels of safety within his home were minimised. This case clearly demonstrates the tensions that professionals face when dealing with people with fluctuating capacity and the grapple of balancing a person's human rights – v- harm that they may be causing themselves.

Records show that he suffered alcohol related seizures dating back to 2009. John continually refused services saying "resources should not be wasted on him" and he was consistently described in agency records as "not engaging with services".

John's Family

John had some family members but none lived close to him. His mother lived in the southern hemisphere and made numerous trips back to the UK to assist with his care. He also had two sisters, one who died 10 years ago and another sister who lived in Gloucestershire.

Both his mother and sister were extremely concerned about John and his level of alcohol dependency. His mother had legal power of attorney for his health and wellbeing and his sister had legal power of attorney for his finances.

They were concerned about him living alone, which was his wish, and with his consent installed CCTV so that they could monitor him in his home environment. Records show that they regularly called emergency services when they observed he had passed out or was unsafe in his home environment.

Good Practice Areas

There were several positive areas of practice identified within the case;

Hospital discharge planning was well thought out and multi agency in its approach. There were several examples of good practice around multi agency working and MCA assessments. This included extension of funding to ensure that an assessment could be concluded. It was also considered good practice that John was discharged to Fen House '*a neurorehabilitation centre that offers community-based rehabilitation for people with an acquired brain injury (ABI)'*.

Mental Capacity was a central theme of this review and there was evidence within agencies records that assessments were made at appropriate times. However, the assessments showed fluctuating capacity which made it difficult for professionals to work with him. When John was not drinking he was deemed to have capacity but when he resumed drinking, capacity ceased to exist. John's story clearly evidences the constant tensions around working with cases of fluctuating capacity. Any mental capacity assessment that was undertaken could only relate to a particular incident, at a particular time. As a result, multiple assessments were required and capacity was constantly changing. This proved challenging for agencies to work with and was further exacerbated by John's reluctance to accept help and support. There was good evidence of multi-agency input into the MCA assessments and evidence that CHC

returned a capacity assessment as it did not have the correct signatures on it. It was also recognised that John may benefit from an advocate and one was appointed.

It is clear that professionals from a range of agencies found it difficult to help John when he was adamant that he did not want support. Throughout the case the tenacity of professionals is reflected in case records, they did not give up and continued to try and work with him. At the time, there was not a process for professionals to follow if an individual had care and support needs but was not engaging with services. If John was alive today, when he had capacity, he would have met the criteria for the Multi Agency Risk Management process. This process was introduced in 2019 and is specifically aimed at individuals who have care and support needs, have mental capacity and are not engaging with services. The Multi-Agency Risk Management (MARM) process provides professionals from all agencies with a framework to facilitate effective multi-agency working with adults (aged 18+) at risk of harm who are deemed to have mental capacity for specific decisions that may result in serious harm/death through severe self-neglect or risk taking behaviours and refuses or is unable to engage with services. The process provides a structure for professionals to come together and discuss how best they can support an individual who does not want the support of agencies. This process would have been particularly helpful when John was living back in the community and there was a lack of multi agency oversight of his wellbeing.

The Deprivation of Liberty Safeguards (DoLS) are part of the Mental Capacity Act 2005. The safeguards aim to make sure that people in care homes and hospitals are looked after in a way that does not inappropriately restrict their freedom. The safeguards set out a process that hospitals and care homes must follow if they believe it is in the person's best interests to deprive a person of their liberty, in order to provide a particular care plan.

Agencies had recognised that John would benefit from a DoLS and this was put in place. There was also legal power of attorneys in place that applied to John’s health/ wellbeing and finances. The Office of the Public Guardian was contacted by agencies in relation to the legal powers of attorney and this was considered good practice

Key learning areas for professionals

Self-neglect was a recurrent theme throughout John's story, this became increasingly evident through the periods of John's sustained drinking. However, it appears from records that there was a tendency for agencies to focus on John's drinking and brain Injuries and there was very little consideration of self-neglect and its impact. As a result, agencies did not follow the self-neglect policy and support around self-neglect was not offered. It should be noted that John had a history of not wanting to engage with agencies and based on previous patterns of behaviour he may not have engaged with services around self-neglect but this option was never explored. Whilst it is recognised that John did not want to stop drinking, agencies could have explored what steps could be taken to try and keep John safe in his home. For example, spare keys to his home being kept somewhere so that agencies could gain access to his home, a lower sofa so that he was less likely to fall when he sat down or got up from the sofa, carpet rather than hard flooring so he was less likely to injure himself if he fell. There is no evidence that of any of these enabling factors were considered by agencies and there was a lack of professional curiosity.

There is clear evidence that when John was an inpatient at the various health settings, agencies came together to agree a multi-agency approach to his care and discharge. However, when he was discharged, the multi-agency element of planning appears to have stopped. There is clear evidence that agencies continued to visit John in his home but this was undertaken in isolation. There is a pattern throughout the case of agencies coming together during John's stays in healthcare settings, forming a multi-agency "helicopter view" of care followed by discharge. John then returned home, continued drinking and not engaging with agencies. He then became ill and was readmitted to a health setting. During this stay there was another helicopter view formed followed by discharge, drinking, non-engagement and silo agency working. This pattern continued. There is nothing to suggest that agencies came together to agree a multi-agency plan when he was within the community.

The pattern of multi-agency working when John was in health settings followed by agency silo working when he was discharged home is further reflected in the multi-agency information sharing. When John was an inpatient there was some good examples of information being shared across agencies and shared risk assessments, however when John was discharged home there is a lack of information sharing. This pattern of inconsistency is apparent throughout John's story.

Records indicate that John had suffered from at least two separate brain injuries, but there is little evidence that agencies considered the impact that this may have had on his behaviour. Research indicates[1] that injuries to the frontal lobe can affect an individual's preponderance to impulsiveness. John had a known history of alcohol abuse, but it appears that agencies did not recognise or consider how his brain injury may have affected his need to drink or act impulsively. As a result, the effect of his brain injury and the impact on his drinking was not included within assessments of risk. Records indicate that members of staff from the brain injury unit were not regularly invited to the multi-disciplinary discharge meetings, consequently the opportunity to consider John's brain injuries and alcohol abuse holistically was missed. Whilst, agency records suggest the staff within the brain injury unit had started to consider the effect of damage to John's frontal lobe and the subsequent effect on his behaviours, there is no evidence that this was communicated to the wider partnership. As a result, partner agencies were not informed of this risk and did not take this into account when they undertook assessments.

There were a number of organisations, and individuals working within them, who worked very hard to support John but he often did not accept the support available or was unable to due to his alcohol dependency and inability or unwillingness to abstain from alcohol. NICE guidance recommends that all new cases referred to alcohol treatment services should have

[1] https://www.headway.org.uk/about-brain-injury/further-information/research/health-and-social-care/frontal-lobe-paradox-and-the-mental-capacity-act/

an assessment of cognitive function. However, despite a number of requests John declined any support from these services.

It was recognised in a report by Alcohol Change UK (2019) from findings of SAR's with alcohol dependency as a factor, that both the Mental Capacity Act (2005) and Care Act (2014) offer little guidance on how to support people with alcohol issues who might need care and support. The report concludes 'At the national level, work is required to clarify how the Mental Capacity Act and the Care Act should be intelligently applied to vulnerable adults who are misusing alcohol. In particular, the challenges of applying the concept of self-neglect to substance misusers and applying the Mental Capacity framework to people with fluctuating capacity need to be urgently addressed if more unnecessary deaths are to be avoided.'

Professionals need to have greater understanding of the long-term effect of alcohol misuse on an individuals' mental capacity. When undertaking assessments,

- professionals need to be aware of Alcohol Related Brain Damage as a mental health condition and
- how this may impact on an individual's behaviour

Mental capacity can be a complex area for practitioners to understand and assess. At the time of John's death this was further exacerbated by a lack of consistent language and understanding across the partnership. In recent years, there has been significant progress in this area and a movement towards a nationally defined approach to mental capacity. The Mental Health & Justice research initiative, which is '*A multi-disciplinary research initiative, addressing a cluster of public policy challenges that arise at the complex interface where mental health and mental healthcare interact with principles of human rights*' launched its new guidance on - **Capacity Guide: Guidance for clinicians and social care professionals on the assessment of capacity** in January 2022, this guidance is viewed as national practice. In addition, there are now dedicated websites, https://capacityguide.org.uk/ to assist people in

understanding mental capacity, particularly where the capacity fluctuates as in John's case. These resources were not in place at the time of John's death.

Locally, there is still further work required to ensure that the partnership has a consistent understanding of mental capacity, a shared language and a recognition of each agency's role and responsibilities around mental capacity and assessment. Whilst, it is acknowledged that this work is taking place within some agencies, further action is needed to ensure that it is comprehensively developed and embedded across the partnership. To facilitate this work, the Cambridgeshire and Peterborough Safeguarding Adult Board have identified mental capacity as a key priority for 2022 -2024.

John's family, in particular his mother was seen as a protective factor. Although his mother lived in the southern hemisphere she regularly returned to the UK. When she was staying in the UK agencies relied on mother (who had LPA for Health and wellbeing) to help support John. As a result, there became an overreliance on his family to support him. When they returned to their homes, their support was withdrawn and the gap that was left was not filled by any agency. This was further evidence of the lack of holistic multi agency planning when John was living in the community.

Recommendations;

1. The Cambridgeshire and Peterborough Safeguarding Partnership Adults Board should seek to ensure that there is greater awareness of the long-term effect of alcohol misuse on mental capacity and the recognition of Alcohol Related Brian Damage and physical damage.

2. The Cambridgeshire and Peterborough Safeguarding Partnership Adults Board should ensure that there is continued training, understanding and use of the Multi Agency Risk Management Guidance (MARM).

3. The Cambridgeshire and Peterborough Safeguarding Partnership Adults Board should ensure that there are training opportunities for practitioners to consider the impact of self neglect.

4. The Cambridgeshire and Peterborough Safeguarding Partnership Board Practitioner Briefing on Professional Curiosity / Opportunities to be curious should be refreshed and recirculated to agencies.

5. The Cambridgeshire and Peterborough Safeguarding Adults Board should ensure that there is a consistent partnership approach to mental capacity which includes a shared understanding of MCA and agencies roles and responsibilities. This will be facilitated by mental capacity being identified as a key priority for the partnership (2022-2024)

6. All agencies must ensure multi agency planning and information sharing is in place to inform assessments and ensure that there is a holistic understanding of risk.

Further Information

Adult Safeguarding Partnership Board Website:
https://www.safeguardingcambspeterborough.org.uk/adults-board/

Multi-Agency Safeguarding Training:
https://www.safeguardingcambspeterborough.org.uk/availabletraining/

Safeguarding Adult Reviews: https://www.safeguardingcambspeterborough.org.uk/adults-board/about-the-adults-board/sars/

Multi-Agency Risk Management Guidance (MARM):
https://safeguardingcambspeterborough.org.uk/adults-board/information-forprofessionals/cpsabprocedures/multi-agency-risk-management-guidance/

Leaflets, Resource Pack, Training slides, Virtual training and Useful Information: https://www.safeguardingcambspeterborough.org.uk/adults-board/resources-for-practitioners/

Multi-Agency Policies and Procedures: https://www.safeguardingcambspeterborough.org.uk/adults-board/information-forprofessionals/cpsabprocedures/

Self Neglect: https://safeguardingcambspeterborough.org.uk/adults-board/information-for-professionals/selfneglect/

Mental Capacity Act: https://safeguardingcambspeterborough.org.uk/adults-board/information-for-professionals/deprivationof-liberty-safeguards-dols/

Social Care Institute for Excellence: https://www.scie.org.uk/self-neglect/at-a-glance

References

Alcohol Change UK – Learning from Tragedies 2019: https://alcoholchange.org.uk/publication/learning-from-tragedies-an-analysis-of-alcohol-relatedsafeguarding-adult-reviews-published-in-2017