Cambridgeshire and Peterborough Safeguarding Adult Board

Safeguarding Adult Review

Joe

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Contents

1. Introduction

Joe was a 54-year-old White British man with a chronic alcohol use disorder. He had a history of serious physical health problems and extreme self-neglect. He died at home in squalid circumstances in July 2023.

A referral for a Safeguarding Adult Review (SAR) was made by Cambridgeshire Adult Social Care due to:

- Concerns about Joe's self-neglect and alcohol addiction and the management of the associated risks.
- The adequacy and appropriateness of mental capacity assessment.
- A possibly inappropriate discharge from Hospital a fortnight before his death.
- The management of refeeding risk.

This request for a mandatory SAR was agreed by the SAR Panel in September 2023, with a focus on the period from 1st July 2022 until his death.

2. Purpose of the Safeguarding Adults Review

The purpose of SARs is to gain, as far as possible, a common understanding of the circumstances surrounding the death of an individual and to identify if partner agencies, individually and collectively, could have worked more effectively. The purpose of a SAR is not to re-investigate or to apportion blame, undertake human resources duties or establish how someone died. Its purpose is:

- To establish whether there are lessons to be learnt from the circumstances of the case about the way in which local professionals and agencies work together to safeguard adults.
- To review the effectiveness of procedures both multi-agency and those of individual agencies.
- To inform and improve local inter-agency practice.
- To improve practice by acting on learning (developing best practice).
- To prepare or commission a summary report which brings together and analyses the findings of the various reports from agencies in order to make recommendations for future action.

There is a strong focus on understanding issues that informed agency/professional's actions and what, if anything, prevented them from being able to properly help and protect Joe from harm.

3. Independent Review

Mike Ward was commissioned to write the overview report. He has been the author of twenty-five SARs as well as drug and alcohol death reviews and a member of a mental health homicide inquiry team. He worked in Adult Social Care for many years but in the last decade has worked mainly on developing responses to change resistant dependent drinkers. Mike co-authored the report with Jane Gardiner who is being mentored to become a SAR author. She has a background in alcohol misuse, domestic abuse and professional boundaries.

4. Methodology

A multi-agency panel of the Cambridgeshire and Peterborough Safeguarding Adults Partnership Board was set up to oversee the SAR and commissioned the authors to complete the review. Initial information was sought from agencies involved with Joe using the SAB's Individual Management Report form. This seeks information on the individual, a chronology and analysis of agency involvement.

Some of the information provided included information from outside the time period enabling a fuller picture of Joe to be developed.

The following agencies were involved in the process:
- ICB / Primary Care (GP)
- East of England Ambulance Service
- Cambridgeshire Constabulary
- Cambridge University Hospitals NHS Foundation Trust
- Care agency
- Adult Social Care, Cambridgeshire County Council (ASC)
- Cambridgeshire and Peterborough NHS Foundation Trust
- Department for Work and Pensions

In June 2024, a Practitioners' Workshop was held to consult those who had worked with Joe or had other insights into his life. All of this information was analysed by the authors and an initial draft of the report was produced and went to the Review Panel in August 2024. Further changes were made over the next two months, and a final draft was completed in September 2024 following a SAR sub-group meeting. This was then submitted to the SAB.

5. Family contact

An important element of any SAR process is family contact. Joe had an ex-wife who continued to be involved in his care and a son and daughter who were adults at the time of his death. They were contacted to engage them in the process; and the authors held an online conversation with them. The family also provided other background material. The authors are profoundly grateful for their powerful insights into Joe's life. These have greatly informed this process.

6. Parallel processes

There were no parallel processes such as Police or Coronial inquiries that coincided with the review process.

7. Background and personal Information

7.1 Joe's history

Joe was a 54 year old man who was found dead at home by a carer at the end of July 2023. He had an ex-wife who had continued to be involved in his care and two adult children (both in their early twenties in 2023). He was also survived by his mother, but his father sadly died of a stroke the day after Joe's death.

His family reported that Joe's official cause of death was

- alcohol related liver disease
- chronic pancreatitis
- malnutrition.

He had had an alcohol use disorder for most of his adult life. He also used drugs. At points, he grew cannabis and his daughter recalled Joe taking her to visit drug dealers. In 2001 Joe overdosed on methadone, despite not being known to have been a heroin user. Nonetheless his family viewed alcohol as his main problem.

He was a successful children's entertainer for much of his adult life. His children provided a picture of a very colourful character. He kept a menagerie of exotic pets including snakes, scorpions, an iguana, spiders and ferrets. He would carry his snake in public. He loved music and painting and was very creative e.g. making puppets out of milk cartons to entertain his children. In Hospital he fashioned a pair of slippers out of cardboard. The family said he always "needed a project".

A particularly fond childhood memory for the children was going to a Festival and following a mysterious green man playing a flute and letting off fireworks only to discover in adulthood that that had been Joe. A picture was painted of a fun and vibrant dad who enjoyed spending time with his children. He was clearly much loved, and is missed, by his children.

However, chronic alcohol use took its toll. He met his ex-wife in 1992 and she quickly became aware of his pattern of heavy drinking. He told her that he went to AA for help, but he seems to have been lying about much of his attendance. By 2011, she describes him as having become "unliveable with". At that point, there was violence towards her and she fled with the children. Joe served two weeks in prison as a result of this assault. Although she continued to help care for him, they never lived together again.

Over the years, Joe has had many referrals to Alcohol Services, he also reported to professionals that he attended AA meetings. However, his engagements with such services was inconsistent, with periods of poor engagement. Notably, he declined Alcohol Service contact during 2021/22.

During the last 12 years of his life, he deteriorated severely. By this point his career as an entertainer had ended. He sexually assaulted a Police Officer in London when intoxicated on one occasion. His family said he was often shoplifting alcohol and, as a result, he was banned from Marks and Spencer.

In 2014 he was diagnosed with bi-polar disorder. His family suggest that this was accompanied by schizo-affective elements. They described how he would contact the family saying things like *“Amy Winehouse is coming over!”* or *“The Russians are invading our house and won’t get out”*. On another occasion, he hallucinated that an alien was coming through the window. He was possibly using alcohol to self-medicate.

He was largely non-compliant with help for this. He was started on Lithium in 2014 and stopped it in August 2016 because he found that it made him feel worse, i.e., drowsy and more inclined to drink. It is unclear what impact this condition was having in the latter part of his life.

However, his main problems were physical. A Department for Work and Pensions report summarised Joe’s health conditions as alcohol misuse and chronic pancreatis which resulted in the removal of his spleen, pancreas and stomach, and a colectomy. He had a stoma and colostomy bag fitted. Joe viewed the bag as a big problem and found it very embarrassing if it burst. He also had a diagnosis of type 2 diabetes mellitus (very likely secondary to his pancreas disease) made in May 2017; therefore, he had insulin for a short while.[1]

The Covid restrictions impacted on Joe. His family said that Joe seemed to take Covid personally. He didn’t appreciate the impact of the pandemic on the wider world, and instead was upset because no one was visiting him. His son recalled Joe being very offended when someone in Tesco asked him to stand two metres away, not understanding the context, and being unaware that this was a government requirement.

This led to a further period of physical decline. He ended his life living alone in a very squalid environment. His son described him as living like *“a hermit in a cave.”* In May 2022, a safeguarding concern was raised by a dietician within her Trust, stating that Joe was “at a high risk of self-neglect due to not eating.”

7.2 The review period

During the last year of his life, Joe’s physical condition meant that he was involved with a number of agencies: Carers, Occupational Therapist (OT), Nutritionist, Adult Social Care and his GP. In March 2023, his ex-wife had a phone conversation with the OT, expressing concern regarding Joe’s capacity to make decisions.

In April 2023, the Care Agency raised concerns saying that Joe “is skeletal, and that you can see his bones and is very unwell”. The GP was contacted to relay these concerns and a safeguarding concern was raised. The Multi-agency Safeguarding Hub (MASH) advised that this was *“not safeguarding but case management.”* Advice was given to contact the GP and District Nurse.

In May 2023, the GP stated that there were no concerns about Joe’s ability to understand the situation or regarding capacity. However, the next day a safeguarding referral was made due to “*significant self-neglect including malnourishment; possible*

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[1] About 1 in 4 people with type 2 diabetes take insulin.

mental health affecting decision-making; and Joe providing different information to multiple professionals involved." The risk was stated as potentially life threatening.

Guidance was given by MASH regarding self-neglect and Joe's capacity to understand the risks. They advised that a time/decision specific capacity assessment with emphasis on executive function should be carried out at any time that Joe's capacity was in doubt. On 24th May, the GP and Social Worker conducted a joint home visit. The GP felt Joe had capacity to make health-related decisions, but the Social Worker was less confident that this was the case. A multi-disciplinary team (MDT) meeting was arranged for 7th June 2023. A section 42 assessment and a social care assessment were added to the Community Team waiting list.

Joe was admitted to Hospital on 30th May 2023. Paramedics identified *"hypotension hypothermia and confusion, then becoming unresponsive with a Glasgow Coma Scale score of 3"* (the most serious score). He was known to agencies as being at risk of serious self-neglect and an MDT was planned.

On the 7th June 2023, the MDT meeting was held and significant concerns were raised regarding his discharge home. Refusals to engage were noted and mental capacity assessments regarding his medication use and alcohol intake were requested. His mental capacity regarding care and support was to be assessed as needed. On the 16th June, a Hospital Social Worker completed a revised care and support plan ahead of discharge as Joe had requested a new care agency.

A deep clean of his flat was undertaken during this stay. His flat was so filthy that a traumatic cleaning company used eight people in hazmat suits. His son stated that there was *'literally sh*t all over the walls.'* Joe was reported to have been very upset at this intervention, as he considered it completely unnecessary. He stated: *'you've raped my flat'* and could not believe that his flat had been in such a bad state.

On 19th June 2023, Joe was discharged from Hospital and then re-admitted 3 weeks later on 12th July when he was described as *"unable to mobilise, appears severely malnourished. Maggots & flies found under patient when moved & pressure sores seen to both elbows. Query faeces on patient's hands."*

From the 20th June to the 12th July, the Care Agency reported that Joe did not engage with care and was uncooperative or told them to leave because he wanted to sleep. The Carers say that they did what they could with regard to emptying urine bottles, putting rubbish out, putting things within easy reach of Joe and preparing food and drink if asked. The Care Agency reported that his care was *"going well"* and that they *"cannot force Joe to accept support."* They said that Joe often cancelled calls or asked the Carer to leave, even threatening to call the Police, and as the care plan stated Joe had capacity, if the Carer is asked to leave, they did so.

Between the 29th June and 3rd July, a Social Worker twice attempted a home visit. Joe refused to engage and, on each occasion, a later call was agreed.

On 4th July Joe's ex-wife found him 'conscious but very drunk' and reported the property to be *'covered in faeces and stinks and he shouldn't be living like this.'* The Social Worker visited shortly after and recorded Joe to be extremely low weight and *"covered in what looked like dried faeces."* Joe refused to engage in conversation and asked the Social Worker to leave. As noted, the care agency reported that things were *"going well"* and that they "*cannot force Joe to accept support."*

His family, on the other hand, said that they felt that his Carers were not fulfilling their role. They said the: "*Carers didn't do things. There was food in the fridge that was off. They put clothes in the machine that went mouldy because they were not hung up. They did the bare minimum. They didn't alert others when things went wrong. They treated him like a dog in a kennel."*

On the 6th July, an MDT meeting was held. His GP *'felt Joe had mental capacity in terms of understanding risk of death and had met with him on two occasions. It was noted that malnutrition and self-neglect concerns had been present for "years"*.'

Between 7th – 12th July, there was a period of quite intense multi-agency working, with differences of opinion regarding his capacity, and efforts to ascertain a picture of what was happening with Joe's care.

The Social Worker discussed the MDT with a Team Manager who escalated it to the Head of Service. A "Need to know" form was shared with the MASH. A request was made to the GP for evidence of the impact on skin integrity, a mental capacity assessment around his health needs, consideration of a Mental Health Act assessment and an NHS Continuing Healthcare Fast Track application. The Social Worker was also asked to revisit to complete a mental capacity assessment around accepting care and support. Other risks were highlighted: falls, other health concerns, equipment needs, food and fluid intake, sufficient care capacity and whether adequate plans were in place. Updates were requested from all agencies and a Multi-Agency Risk Management (MARM) meeting was scheduled for 13th July.

The Social Worker undertook a joint home visit on 10th July with the GP. The Social Worker queried Joe's capacity, but *"the GP assessed Joe as having mental capacity in relation to physical health."* Advice was, therefore, sought regarding mental capacity and the risks were escalated by Adult Social Care and advice was given to contact ICB safeguarding.

His family provided a summary of his situation in the last two months of his life. They said that: *"his flat smelt like a sewer and, therefore, delivery companies banned him. There was sh*t on the walls of his flat. Before his first return home he paid for this to be cleaned and eight people in hazmat suits had to clean it. Then it got worse and he went into Hospital."* His ex-wife then said with irony: *"But he had capacity."*

This verbal picture was accompanied by an actual picture of Joe at the end of his life. This is a visceral image of a near naked man wrapped in a stained duvet: his hair is matted and unkempt. He was under five stone in weight at his death.

On the 12th July, Joe was readmitted to Hospital. The Ambulance Service noted that Joe was *"unable to mobilise, appears severely malnourished. Maggots & flies found under patient when moved & pressure sores seen to both elbows. Query faeces on patient's hands."* On 14th July, he was assessed by Liaison Psychiatry as lacking capacity and requiring an urgent DoLS application. However, the next day, Joe was assessed by two Doctors as having capacity regarding discharge. "*both Doctors felt that Joe could understand, retain, use and weigh information and made the decision to go home without waiting for support*."

On 16th July, Joe was discharged home. This swift discharge meant that little preparation had been made for his return. On the 28th July, the family report that the Carers took alcohol away from him. On 29th July, Carers arrived at Joe's home to find that he had died.

8. The family perspective

Joe's ex-wife and two children are very angry and distressed about the decisions made by professionals in the last weeks of his life, and specifically about his mental capacity.

In talking about this to the authors, his ex-wife essentially shouted that all she heard from practitioners was that *"he apparently had capacity."* She said *"I want to understand why we can't do things? He put his family through hell…If some intelligent person had looked at this, they would have done something."*

His daughter has written that: "*My dad was not an easy person to deal with but the care he received and the lack of understanding from psychiatrists was appalling - if they had taken his case seriously perhaps there would be a slight chance that he'd still be here?! Or even if he'd still passed away at least his quality of life would've been much better…My dad was a stubborn man, who wanted no help - that of course was not easy for his carers or psychiatrists but he was LESS THAN 5 STONE with schizophrenia and bipolar and they let him just be free in his decision making and free to live a destructive life…Something HAS to change, I can't live knowing other people may be in similar situations to my dad and aren't getting the help that they need."*

Separately she has written: *Something I keep thinking about is (a professional from the Hospital) calling us 2 weeks before my dad passed away and informing us that there was nothing wrong with him mentally. His physical state was a reflection of his mental state but she refused to believe that because she'd spoken to him and he seemed "fine"…She wouldn't let us even tell her our sides, I took the phone and got extremely angry (which is unlike me) and told her that his mental state is the reason he is so ill…She even said if he leaves Hospital and drinks himself to death that's on him, now this isn't wrong as it was his choice to drink, but if they had taken his capacity away from him he would still be here as he would've been put in a place where he wouldn't have been allowed to drink. But they refused to take his capacity away from him because he was "fine" according to the* (professional)*. I just feel so angry. I wake up everyday feeling angry. I can't think like this, I have to just shake it off because there is nothing I can do, I can't go back in time.*

In the meeting with the authors, his daughter said: *"He should have been in Hospital. He was left on his own to rot. I struggle because of the guilt. I struggle with my own mental health as a result."*

His ex-wife felt that the notion that Joe had capacity to make decisions about his care was at this point *"the most ridiculous thing."* She felt that his death was *"painful"* and “*unfair,”* while his son argued that the way in which Joe was allowed to live would *“be considered torture if he (Joe) were doing this to someone else.”*

Beyond mental capacity, the family talked about other aspects of the discharges in the last year of his life. His son also felt that there was poor communication from the Hospital: *“the last 3 months were the worst. No one told the family about discharge and no care plan was in place. He didn’t want any carers, he went back to a flat without food, heating, light etc.”*

9. Analysis

The central theme in Joe’s care is the use of the Mental Capacity Act in the last weeks of his life and the decision-making around the discharge home from Hospital. This will be explored in section 15. However, his care raises a number of separate issues that will be explored in other sections:

- People that services find difficult to engage
- Alcohol interventions
- Motivational interventions
- Safeguarding and other Adult Social Care Interventions
- Smoking.

Joe’s ultimate decline occurred relatively swiftly and he was an individual with very serious health problems. It is fair to acknowledge that given this, it may have been difficult to prevent him dying in the subsequent months. Nonetheless, it is vital best practice is considered. Particularly because, as his family suggest, this might have provided a more dignified end to his life.

10. People that services find difficult to engage – the need for a policy

Joe had a number of aspects to his presentation – his substance use disorder, possible mental health concerns, health problems and self-neglect. However, one issue underpins all of these – services found him very difficult to engage into the care that would have benefited him.

Joe consistently stated that he did not wish to engage with medical care, personal care or nursing care. He is noted to have repeatedly told visitors, especially Carers to leave; to *‘f*** off’*; and had threatened to call the Police if people did not go. While he did on occasion allow some personal care or nursing tasks such as wound management to be carried out, the overwhelming picture is one of refusal.

This situation highlights the need for a specific published procedure to guide professionals on dealing with client non-engagement. The local Multi-Agency Risk Management (MARM) Guidance fulfils that role.

This Guidance would benefit from accompanying guidance on what techniques work with hard to engage clients. This is an under-developed field. The SAR authors looked for national guidance on this issue as part of the drafting of the report but could not find an overarching guidance document. Reports such as “The Keys to

Engagement" (mental health)[2] and "The Blue Light Project" (alcohol misuse)[3] have addressed this issue with specific client groups but there is no single guidance document. Whether at a local or a national level, such guidance will be a vital support to those working with vulnerable and difficult to engage clients.

Joe is not unusual in presenting difficulties of engagement. The Manchester Safeguarding Partnership *Carers Thematic Learning Review 2021* identifies: *a sense that…persistent refusal of offers of care and support were perhaps too readily accepted, perceived and interpreted by practitioners as 'non-compliance' rather than as a form of self-neglect, which was a product of the adults' adverse life experiences, poor quality of life and very challenging day to day living*.

Another review from Manchester, the *Homelessness Thematic Review,* comments that: *When faced with service refusal, there should be a full exploration of what may appear a lifestyle choice, with detailed discussion of what might lie behind a person's refusal to engage; loss and trauma often lie behind refusals to engage. Contact should be maintained rather than the case closed, in an effort to build up trust and continuity.*

Ongoing "marketing" of the local guidance would support this, and it would be enhanced by more specific training and guidance on what works to engage and motivate individuals like Joe who refuse services.

11. Alcohol use disorders

Joe had an alcohol use disorder which, undoubtedly, had a significant impact on his life and on the problems that led to his death. This section considers the specific responses to his alcohol use.

The GP report notes that *"Joe has been known as a heavy drinker since the 90s. Alcohol abuse has been a big `part of his life…Alcohol has been the main reason for his co-morbidities."* There are differences of opinion on whether Joe was physically dependent on alcohol. However, the notes reference Joe consuming alcohol at home while also informing professionals that he was abstinent. Alcohol's role in his life can be seen in the last weeks of his life:

- 1st June 2023 - A Liaison Psychiatry Nurse assessed Joe's alcohol abuse and whether he had alcohol withdrawal syndrome. A referral to Alcohol Services was considered.
- 4th July - Joe was found by his ex-wife to be 'conscious but very drunk'.
- 16th July - Joe reported to a Hospital medical practitioner that he had no access to alcohol and that his admission was not alcohol related.
- 22nd July - he was described as intoxicated with one empty wine bottle, another half full and eight empty cans of Guinness having been consumed since the previous day's visit.

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[2] https://www.centreformentalhealth.org.uk/sites/default/files/keys_to_engagement.pdf

[3] https://alcoholchange.org.uk/help-and-support/get-help-now/for-practitioners/blue-light-training/the-blue-light-project

- 24th July - Carers reported to Adult Social Care that Joe appeared to be consuming large amounts of alcohol and advice was requested from Alcohol Services as Joe had not given consent for a referral to be made.
- 27th July - Alcohol Services accepted a referral to support Social Care in managing Joe's alcohol consumption.
- 28th July - Joe was visited by a Community Nurse and a Carer and noted to be very intoxicated. He had three bottles of vodka next to him, one being almost empty, and these were moved out of his reach.

His family reported that Joe was accessing alcohol via home deliveries. He seems to have left the key safe code for delivery drivers so that they could leave it for him. Three bottles of wine had been seen in a Deliveroo bag. Consideration was given as to whether the key safe number could be changed in Joe's best interest to prevent alcohol delivery and consumption. However, it was reported that some delivery companies banned him because of the state of his property.

This history raises a number of questions about the response to alcohol use disorders.

11.1 Alcohol screening and identification

At the very least, Joe's case is a reminder of the importance of robust alcohol screening processes to ensure that alcohol-related risk is identified and highlighted by all the agencies that are working with an individual. In accordance with NICE Public Health Guidance 24, professionals working with the public need to be alert to the possibility of alcohol use disorders and should ensure that the AUDIT alcohol screening tool[4] is routinely being used by all relevant professionals, whether in Primary Care, Mental Health Services, Adult Social Care, Housing or any other adult service.

Beyond meeting NICE guidance, encouraging earlier intervention would also help fulfil the Prevention duty in Section 2 of the Care Act. Perhaps more importantly, it would encourage practitioners to become used to talking about alcohol.

11.2 Home delivery

Joe's care raises an issue which may become a more regular concern – the home delivery of alcohol. At the most basic level, home delivery drivers should not leave alcohol without seeing the person who has ordered it. Even at a familiar address they do not know whether the person who has ordered it this time is over 18. Even with someone like Joe, he could be the victim of a "home invasion" where young people are using his address. They should also not be selling alcohol to people who are intoxicated. Deliveroo, for example, acknowledge this on their website.

This should be discussed with the Licensing Team in the Council. Beyond this, there is the ethical issue of whether it is right for delivery companies to be routinely selling alcohol to people who are living in self-neglecting circumstances. This might be something that could be addressed through conditions on licences. Again, this needs to be discussed with the Licensing Team.

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[4] Alcohol Use Disorders Identification Test (AUDIT) (auditscreen.org)

11.3 Restricting access to alcohol

At a couple of points, practitioners appear to have considered removing, or actually removed, alcohol from Joe. While this may have been done for the best of reasons, it is clearly misguided because of the risk of physical withdrawals. All practitioners should be regularly reminded of this risk as part of training or agency communications.

11.4 Community interventions – assertive outreach

In October 2023, the Office for Health Improvement And Disparities published the *UK clinical guidelines for alcohol treatment.* These set out the standards that can be expected from Alcohol Treatment Services. Any assessment of the work undertaken by local Alcohol and Drug Services needs to be seen in the context of this guidance.

Joe appears to have been referred to local Alcohol Services on a number of occasions. However, there does not appear to have been a recent successful engagement with services.

It is not possible, therefore, to comment on existing services. However, this does raise questions about what else might be required to meet Joe's needs. A range of evidence now identifies "what works" with difficult to engage chronic dependent drinkers. This is most clearly summarised in Alcohol Change UK's Blue Light project manual.[5] However, the Clinical Guidelines endorse this approach, as do the Carol SAR from Teeswide SAB and the Alan SAR from Sunderland SAB.

At its core is:

- A care package centred on intensive assertive outreach.
- A co-ordinated multi-agency management approach to guide and support the work.
- The willingness to be consistent and persistent and to allocate time to the task

Joe could well have benefited from an assertive outreach approach which would have attempted to build a relationship with him in order to understand what lay behind his challenging behaviour. Is it cognitive impairment? Is it shame about the way he is now living? Is it fear that intervention might interrupt his supply of alcohol or cigarettes? Is it concern that he may lose his independence?

An assertive outreach approach is built on the recognition that, with complex individuals such as Joe, agencies are going to need to sustain the relationship rather than expecting him to be able to do that. This will require an approach that is:

- Assertive – using home visits
- Focused on building a relationship
- Flexible – client focused – looking at what the client wants
- Holistic – looking at the whole person
- Coordinated – linking with other agencies
- Persistent and consistent.

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[5] Again it needs to be noted that the author of this review is a co-author of the Blue Light manual.

Once professionals have a better understanding of what is behind this pattern of non-engagement, they can begin to think about ways in which his needs can be better addressed. Joe is likely to have benefited from the availability of specialist assertive outreach staff who could have worked with him. This may be an area for local service development.

11.5 Detoxification and residential rehabilitation

It is likely that the best pathway for Joe would have been detoxification and residential rehabilitation. This would have enabled:

- A time away from his home situation in a protected environment;
- A chance to properly assess him and consider any possible cognitive impairment; and
- A chance to address the substance use disorders and develop an appropriate care plan.

This would not have been an easy answer to his problems. The fundamental problem is that Joe would almost certainly have refused such an offer. His family confirmed this in conversation. In addition, it is probable that there would have been problems finding an appropriate placement.

Nonetheless, this review suggests that, given the range of possible care packages, a detoxification followed by some form of “dry” residential rehabilitation would have been the best option. Therefore, it is important that:

- persistent efforts should have been made to “sell” this approach to him by all professionals;
- funding should have been available via commissioners for this approach without unreasonable barriers if he expressed interest in this option; and
- commissioners should support and encourage the development of residential facilities that will work with more complex alcohol use disorders including those with possible cognitive impairment.

12. The refeeding syndrome

Refeeding syndrome is a metabolic disturbance which occurs as a result of reinstitution of nutrition in people who are severely malnourished. When too much food or liquid nutrition supplement is taken during the initial four to seven days following malnutrition, the consequent electrolyte imbalance may cause neurologic, pulmonary, cardiac, neuromuscular, and hematologic symptoms: many of which, if severe enough, may result in death.

Joe was at severe risk of this syndrome in the last two months of his life. By the end of his life his body weight was below five stone. Dietetics (in conjunction with the GP) expressed concern that it was not feasible to safely and closely monitor refeeding risk in the community. This was considered in the mental capacity process that led to his discharge on 16th July; but Joe rejected feeding in the Hospital setting.

13. Approaches to self-neglecting dependent drinkers

13.1 Professional attitudes / lifestyle choice

The needs of dependent drinkers can easily be viewed as "self-inflicted" or a "personal choice". The Leanne Patterson Safeguarding Adult Review (Northumberland) comments that: *A number of agencies identified in their contact with Leanne that she was 'making choices' around lifestyle that were increasing her risk and made her difficult to engage…*[6] This report cannot prove that such attitudes impacted on the care of Joe, but it is a possibility. Therefore, it is important to ensure that professional training and management challenges such beliefs. Whilst it is true that people begin by choosing to drink, at the later stage in a drinking 'career', choice may have disappeared.

Chronic dependent drinkers are often at the centre of an almost "perfect storm" of physical conditions that will challenge the idea that their drinking is a self-determined choice. The most obvious of these is that they are dependent on alcohol. The origin of the word "addiction" is a Latin word that implies enslavement. It can be argued that "addiction" is by definition a loss of the ability to make choices.[7] At the very least, addiction will remove an element of choice about drinking because of the serious risk of unmanaged withdrawals.

Beyond addiction, many other physical conditions impair the ability of dependent drinkers to make choices about their lives:

- 60-70% will be depressed due to the chronic depressant effect of alcohol.[8]
- They may have alcohol related brain damage due to the effects of alcohol on the body (which effects at least 35-40% of this client group).[9] [10] [11]
- They may have frontal lobe brain damage due to injuries from fits, fights or falls. This is commonplace in dependent drinkers and will also make capacity harder to assess. [12] [13]
- They may have physical health problems which impair judgement e.g. the low energy levels that result from liver disease or the confusional states that result from pancreatitis and urinary tract infections.[14]
- They may have poor sleep patterns due to alcohol misuse (or lifestyle) which again will lead to depression, low mood and lack of energy.[15]
- Poor nutrition will lead to depression.[16]
- Foetal alcohol damage before birth may have led to learning disabilities or behavioural disorders which are still impacting in adulthood.

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[6] Northumberland SAB – Leanne Patterson – Safeguarding Adults Review - 2019

[7] Rosenthal R. – The etymology and early history of "addiction" – Addiction Research and Theory – February 2019

[8] Davidson K. – Diagnosis of depression in alcohol dependence – British Journal of Psychiatry (1995) 166, 199-204

[9] Wilson K. - *Alcohol related brain damage in the 21st century* Br J Psychiatry. 2011 Sep;199(3):176-7.

[10] http://www.youtube.com/watch?v=Joe_3uou6nyQ&index=2&list=PLSEhy70YpU5tZyaoHxz5UTuOUyJokMdFD

[11] Information provided to the author by Drink Wise Age Well

[12] https://www.basw.co.uk/resources/repairing-shattered-lives-brain-injury-and-its-implications-criminal-justice

[13] Professor Ken Wilson provides invaluable insights into the impact of alcohol related brain damage and mental capacity in this video: https://vimeo.com/259124220

[14] E.g. http://www.britishlivertrust.org.uk/liver-information/living-with-liver-disease/looking-after-yourself/

[15] Alcohol and Sleep | Sleep Foundation

[16] E.g. http://www.nchpad.org/606/2558/Food~and~Your~Mood~~Nutrition~and~Mental~Health

The barriers to self-determination are not just physical. In the Ms. H and Ms. I SAR (Tower Hamlets), the partner of a woman who had died having experienced multiple exclusion homelessness[17], commented that she had been unable to maintain abstinence because past traumas and adverse life experiences "*kept bubbling up.*"

That SAR goes on to comment that: "*This captures quite graphically how individuals can be governed by impulses to distance themselves from emotional distress. She was caught in a life-threatening double-bind, driven to avoid suffering through ways that only deepened her suffering.*"[18]

In working with individuals like Joe, it is important to ensure that professional attitudes are not impeding responses through training and professional development.

13.2 Professional curiosity

The various barriers highlighted in the previous section mean that practitioners will need to use professional curiosity to understand the individual's situation. Many of them are likely to have applied to Joe: e.g. depression and poor sleep. It is unclear how emotional trauma might have applied to Joe, but the loss of his stomach, his need to use a colostomy bag, the associated potential for embarrassment and limitations on his life can be seen as trauma, indeed his son described it as such.

Most importantly, consideration needs to be given to the impact of cognitive impairment. There is growing concern that cognitive impairment, particularly acquired brain injury (ABI), is a factor in the presentation of many of the people who are subject to SARs. In 2022, Mark Holloway and Aly Norman published an article on this: *"Just a little bit of history repeating: the recurring and fatal consequences of lacking professional knowledge of acquired brain injury"*[19] Since then they have found another 20 more SARs about people with an ABI, where the SAR identifies that the impact of the ABI upon functioning was not picked up and responded to.

Questions were raised about Joe's cognition and there was a suggestion that a neuropsychology referral should be made to better understand his cognitive function. At no point was Joe diagnosed with a cognitive impairment, therefore, it is hard to take this theme too far. However, Joe did experience seizures (on one occasion he bit a chunk of his tongue off), very poor nutrition which impacts on cognition, and chronic heavy drinking which leads to Wernicke Korsakoff Syndrome.

This review cannot re-diagnose Joe, so the impact of cognitive impairment is unknown; however, this is a reminder of the importance of considering cognitive functioning with individuals who require safeguarding, especially those that services find hard to engage.

Given the life-threatening impact of the decisions that were being taken about Joe, it is vital that practitioners exercise professional curiosity to determine what exactly is happening with Joe before taking capacity decisions which were likely to have the

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[17] "multiple exclusion homelessness" comprises extreme marginalisation that includes childhood trauma, physical and mental ill-health, substance misuse and experiences of institutional care.

[18] Preston-Shoot, M. (2020) Ms H and Ms I: Thematic Safeguarding Adults Review. Tower Hamlets SAB

[19] *The Journal of Adult Protection*, Vol. 24 No. 2, pp. 66-89. https://doi.org/10.1108/JAP-10-2021-0036

most serious consequences. This would seem to be a key lesson from his care. This will require professional training, managerial supervision and challenge as well as ongoing messaging about this issue. Workers and managers must ensure that a thorough exploration of needs is undertaken before capacity decisions are taken.

13.3 Motivational interventions

Given the challenge of engaging Joe, consideration needs to be given to specific work to motivate him into structured care. With people like Joe, professionals will need to build motivation rather than expecting the individual to have their own motivation. This will require a range of professionals to have had training in motivational interventions and, in particular, motivational interviewing.

Motivational interviewing was developed by William Miller and Steve Rollnick in the 1980s and 1990s. It is now widely used in behaviour change settings e.g. smoking cessation or diet compliance. However, it has its origins in the alcohol and drug treatment sector. It recognises that approaches to dependent drinkers based on persuading, challenging or confronting people are unlikely to be successful and may actually entrench the person in their defences. Instead, professionals need to change the way that they understand "denial". It says that denial is only a surface presentation, behind that denial is someone who is more ambivalent and uncertain about their desire and ability to change. Therefore, workers need to identify and work on that ambivalence to encourage forward momentum.

It may be unreasonable to expect Carers to have these skills but other practitioners should have training in these approaches and be using them with this client group.

13.4 Multi-agency management

Clients like Joe benefit from regular multi-agency discussion. This will support clear and positive inter-agency liaison and multi-agency working. This should be a part of any guidance on working with engagement issues, i.e. there should be an escalation pathway into multi-agency management.

This could be addressed in a number of ways: as part of a safeguarding process; by having a clear policy on dealing with clients that services find difficult to engage; by having a specific policy on calling multi-agency meetings; through referral to an existing multi-agency group; or through individual initiative by another professional. Whichever way this is approached, clients like Joe will benefit from a group that can step back from the day to day interventions and see the overall picture of the problems he presented and consider ways in which these could have been better addressed.

In Joe's care, multi-agency meetings and joint working took place, and there was communication about concerns and risks. Regular joint visits took place, for example, the GP and Social Worker attended jointly. The question is whether there was sufficient multi-agency discussion of Joe's capacity. It is noticeable that a planned MDT meeting for 13th July was cancelled because Joe was admitted to hospital. To ensure good planning for his next steps, this would seem to be precisely the point at which multi-agency planning should have been stepped up.

14. Safeguarding and other Adult Social Care interventions

At the centre of Joe's care in the last months, is the concern that he was discharged from Hospital with inadequate social support. His ex-wife spoke of her *"incredulity"* on one occasion that no family members were informed when he was discharged and to a flat with no gas, no electricity and no food, where she found him shivering with cold.

In the last year of his life, Joe was an adult with care and support needs and the Care Act should have provided a framework for addressing the challenges he posed, as well as protecting him from further harm. In May 2022, a safeguarding concern was raised by a dietician stating that Joe was *"at a high risk of self-neglect due to not eating"* Three other safeguarding concerns were raised about him during the review period.

On 19th April 2023, a Section 9 Care Act assessment was completed. It was recorded that there was no reason to doubt Joe's ability to understand and be involved in the assessment process. He was assessed as being eligible for care and support as defined by the Care Act 2014. Care and support planning took place and two daily care calls were thought to be required and the care agency started on 25th April.

In the subsequent weeks, Joe made very poor use of these Carers and often restricted their activities. It is easy to see Joe as "difficult" or even "ungrateful for" the care. However, it does raise an important question: was the care package appropriately designed with Joe in mind? Joe, like many self-neglecting individuals, may struggle to engage with Carers. Therefore, is work required to support and motivate Joe to accept the care? Simply expecting him to accept the care may be naïve and may also waste resources. Does he need some assertive input to focus on him and build up his willingness to accept this service?

On 25th April, his Care Agency reported that Joe was *"skeletal…that you can see his bones and is very unwell."* The GP was contacted and a safeguarding referral was made. MASH advised that this was *"not safeguarding but case management."* Advice was given to contact the GP and District Nurse. It has to be asked whether this was a missed opportunity to explore his situation further and begin a multi-agency care planning process? It is also noted that advocacy was not considered to support him to make decisions in regard to his health, mobility and nutrition. This is the only mention of the provision of advocacy for Joe in the notes and raises the question of whether more consideration should have been given to this?

Another safeguarding concern was raised on 22nd May. This time the MASH practitioner provided an in-depth summary/analysis and recommendations, specifically highlighting consideration around capacity and executive functioning, and the possibility for MARM referral.

On 26th May, Section 42[20] and social care assessments were added to the Community Team waiting list. An MDT was also arranged. Given the serious concerns around

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[20] Section 42 of the Care Act – the safeguarding section

Joe, it is unclear why the decision to place this case on the waiting list was made. There is no evidence to rationalise how this decision balanced waiting versus the risks involved.

On 16th June, whilst Joe was an inpatient, the Hospital Social Worker completed a revised care and support plan ahead of discharge as Joe had requested a new care agency. This indicated that there was informal support available from his ex-wife and children, which in reality appeared to have stopped. On 19th June, Joe was discharged from Hospital but was re-admitted three weeks later on 12th July: *“unable to mobilise, appears severely malnourished. Maggots & flies found under patient when moved & pressure sores seen to both elbows. Query faeces on patient’s hands.”* This indicates a rapid decline in health despite ongoing multi-agency involvement and a s42 inquiry. It does raise questions about the adequacy of the work undertaken pre-discharge to ensure that Joe was appropriately cared for in the community. Was this a missed opportunity to undertake a more thorough assessment and review?

On 4th July, Joe was found by his ex-wife to be *‘conscious but very drunk’* and reported the property to be *“covered in faeces and stinks and he shouldn’t be living like his”.* A Social Worker visited at 12:45 and recorded Joe as extremely low weight and *“covered in what looked like dried faeces.”* The Social Worker recorded Joe’s refusal to engage in conversation and asked him to leave. Nonetheless, the Care Agency reported that things were *‘going well’* but also that they *‘cannot force Joe to accept support.’*

On 13th July, following admission the Hospital Safeguarding Lead raised a safeguarding concern, around severe self-neglect. Three days later Joe self-discharged, and went back to very poor circumstances and died just over two weeks later.

Some work was clearly undertaken to safeguard Joe and to meet his care and support needs. Concerns were raised, an assessment was undertaken under section 9 and a care plan was initiated. The key questions are about:

- the decision to view the first concern in 2023 as a care management rather than a safeguarding issue;
- the speed of response to a case of serious self-neglect i.e. the decision to place his case on a waiting list;
- the intensity of work done to support him post-discharge; and
- the type of support provided - as was said above, the provision of care may require work to help people to accept and engage with the care.

Nonetheless, the key issue in his care concerns decisions about his mental capacity. These impacted on all aspects of the Adult Social Care response and are considered in the next section of the report.

15. Mental Capacity

15.1 Background

At the centre of Joe’s care is a debate about the use of the Mental Capacity Act. His care raises a number of questions about the use of the framework and, ultimately, the adequacy of the legislation or Code of Practice for this client group.

During the last two months of his life there were differences of opinion between Medical Staff and Adult Social Care about his mental capacity. Broadly, Medical Personnel assessed Joe as having capacity while adult social care services considered that he did not, albeit largely for different decisions. For example:

- 24th May 2023 - GP felt Joe had capacity to make health related decisions, but the Social Worker is on the record as being less confident about this.
- 4th July – He was visited by a Social Worker but a comprehensive assessment of capacity was not possible because Joe ceased to engage.
- 6th July – An MDT meeting was held and his GP felt he had mental capacity in terms of understanding risk of death. The Senior Social worker involved said that the only mental capacity decision the Social Workers can consider was related to care and support needs and that decisions regarding medication, nutrition and respect are for medical professionals.
- 10th July – Joint Social Worker and GP visit. The Social Worker felt that 'on balance of probability' Joe *"lacks capacity re how his care and support needs should be met."* It is stated that the *"GP assessed Joe as having mental capacity"* in relation to his physical health needs i.e., health planning, diet and nutrition and Hospital treatment.
- 13th July 2023 – It is noted that Joe has bi-polar disorder and is not medicated for this. There was a query about this affecting his capacity.
- 14th July 2023 – A note was recorded by Liaison Psychiatry, stating that: *"Joe lacks capacity and requires an urgent DoLS application, and including information regarding refeeding safety, as well as information regarding cognitive baseline and suggestion for a neuropsychology referral to better understand cognitive function. A recommendation was made that multi agency assessment regarding self-neglect and complex discharge is required, particularly around capacity and any objection to remaining in Hospital. A recommendation to contact Safeguarding with a referral should Joe persist to leave the Hospital when cognitive impartment persists."* It subsequently transpired that this assessment was based on a previous mental capacity assessment and that Joe was not seen face-to-face on that occasion.

On 16th July, a decision was taken, involving two Doctors, that Joe had capacity to discharge himself. At this point he was still very physically unwell, with concerns about the impact of the refeeding syndrome. This is seen in the Section 44 referral as a key stage in his care process and highlights the need to consider carefully the use of mental capacity legislation. Therefore, details from the Doctors' notes on that decision are included:

"We found him to be significantly cachectic[21] and malnourished and at serious risk of refeeding complications…He is adamant he will not accept any form of tube feeding, whether transnasal, transabdominal or intravenous. He does not want to be in hospital and wants to go home...Patient wished to self-discharge with once daily care only...Patient feels he can manage his stoma independently and he uses urine bottles

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[21] Cachexia is a complex syndrome associated with an underlying illness, causing ongoing muscle loss that is not entirely reversed with nutritional supplementation.

to pass urine which he states he disposes down the toilet. He does not wish to have assistance with personal care. He was very clear throughout admission that he did not wish to be in hospital and wished to be at home, mentioning self-discharge on a number of occasions. We had significant concerns over his capacity due to extremity of BMI and likely impact on his brain... However he was able to meet all the criteria for capacity, a second consultant was asked for independent opinion on this and was in agreement that he could understand, retain and weigh up information and communicate his wishes. We were very clear to patient that he is at severe risk of complication (both medical and due to lack to strength and mobility) and these are very likely to lead for further admissions and even death. We were clear that we felt he would be better off in a hospital environment medically in order to increase his BMI safely and that we felt he needed a substantial package of care currently. Patient understood our concerns and recommendation but on balance felt the level of depression he experiences in hospital outweighed benefit and he would choose to go home despite significant risk to himself. Patient was very clear he did not wish for any family to be contacted on his behalf - despite friends/family requesting updates and inclusion in discharge planning."

At this point Joe was discharged home and just under two weeks later was found deceased. Adult Social Care comment that:

- *"Joe should not have been discharged home on the 18th July without care in place or the property cleaned – he was unable to do this himself.*
- *The refeeding risk was not robustly planned and managed in the community.*
- *The mental capacity assessments hospital completed in July 2023 only related to his discharge and not care and treatment in the community."*

His family also expressed very serious concern about the decision to discharge him home.

This scenario highlights the challenges posed by the use of this legislation with this complex client group. The following sections attempt to chart a way through these complexities, including, ultimately, a recognition that the current legislative framework may be inadequate.

15.2 A humane response

Professor Michael Preston-Shoot, a leading expert on Safeguarding and author of many SARs, has talked about the importance of a "humane" response to this client group. It is very easy to become lost in the minutiae of legal frameworks and the specifics of diagnoses. Above all, Joe needs practitioners who can step back and recognise that his life is swiftly spiralling out of control and that he appears unable to protect himself. He needs workers who recognise a "duty of care" and persistently and consistently pursue their "professional responsibility" towards him. Moreover, those workers need managers and agencies that will support their staff to provide an assertive and flexible approach to meet his needs.

This must surely be professionals' main goal. This does not mean professionals should ignore the legislation; however if the legislation clashes with the fundamental professional role of caring for the individual, then that must be a red flag for further discussion and action.

15.3 Professional attitudes to the family

Of particular concern in this context is that Joe's daughter stated that during this period, a professional called and told her that: "*there was nothing wrong with him. If he goes home and dies then that is on him".* The authors have no separate corroboration of this, nonetheless it is indicative of both a possible training need around professional attitudes to this client group and a need for training on communication with families. This appears to be an unacceptable way to talk to the daughter of a man who may be dying.

15.4 Assessing Joe's capacity

As has been said, a number of assessments were made of Joe's capacity, both by Health and Social Care practitioners. These focused on different decisions and there were differing outcomes. At the very least these differences, while potentially appropriate, suggest the need for multi-agency reflection. His care needs a far more robust and considered discussion of his mental capacity. This could have happened at the MDT meeting scheduled for 13th July, but this was cancelled as a result of his admission.

We have to acknowledge that in the case of *Kings College NHS Foundation Trust v C and V*, the Court of Protection determined that a woman, C, had the capacity to decide not to consent to life-saving treatment that her Doctors wished to give her following an attempted suicide. This had left a legacy of kidney damage that required renal dialysis. This suicide attempt was because the woman, who was described as a "socialite" and had lived an unconventional and "sparkly" lifestyle, felt that all of that was now in her past and she did not want to live in a world where she could not have that lifestyle. She took an overdose but did not die. Given the option of dialysis she refused it. Her Doctors felt that she lacked the capacity to take that decision. The Court of Protection disagreed and endorsed her capacity to refuse.

It could be argued that Joe is in an analogous situation. He refused to stay in Hospital acknowledging that if he returns home he risked death. However, this section sets out a number of reasons for arguing that the assessment could, and possibly should, have had a different outcome.

The depth and breadth of consideration – The Kings College decision was reached after exhaustive consultation, multiple assessments, input from the family and, of course, legal challenge. This did not happen with Joe. At the very least there should have been further multi-agency discussion and family input before this serious decision was reached. The day before, a colleague of the assessing Doctors had decided that Joe did not have capacity and required a DoLS. This would have allowed both Doctors to have a "reasonable belief"[22] that Joe lacked capacity to take the decision to discharge himself, pending a more detailed review.

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[22] This is the required standard in the Mental Capacity Act

Assistance with decision making - Is he being helped to make this decision? The Act states that people must be given all appropriate help and support to enable them to make their own decisions or to maximise their participation in any decision-making process. The MCA Code of Practice repeatedly highlights the need to assist capacitous people with their decision-making e.g. *people must be given all appropriate help and support to enable them to make their own decisions*[23]; *it is important to take all possible steps to try to help them reach a decision*[24]; *it is important to provide appropriate advice and information*[25]; *providing relevant information is essential in all decision-making.*[26]

Perhaps more relevantly the Code of Practice comments that:
2.11 There may be cause for concern 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.
These things do not necessarily mean that somebody lacks capacity. But there might be need for further investigation…[27]

Given the timeframe around this decision, it is questionable whether this standard was met with Joe.

Compulsion – The key difference between Joe and the Kings College case is his addiction. The Code of Practice recognises that "compulsion" can be a factor that impacts on capacity. It states at 4.22 that: "*For example, a person with the eating disorder anorexia nervosa may understand information about the consequences of not eating. But their compulsion not to eat might be too strong for them to ignore."* The reference to anorexia is simply an example and it is not hard to see how this extends to Joe's alcohol dependence. He may have a compulsion to drink that impacts on his capacity to make key decisions.

It is interesting to note that in the debate in Parliament on the proposed smoking ban, the then Conservative Health Secretary, Victoria Atkins, stated that there was *"no liberty in addiction".* The Times leader article the next day echoed that view, stating: "Free choice does not exist when addiction drives desire" (Fake Freedom, 17 April 2024). The idea that compulsion may prevent reasonable choice has high level support.

The decision that is the focus of the MCA assessment - The decision that is focused on when Joe is in Hospital is whether he has the capacity to decide to discharge himself. It is worth considering whether the correct decision to focus on should have been whether he can go home and maintain his health, body weight and engage with medication regimes?

Understand his values – In discussing the Kings College case, Alex Ruck Keane KC highlights the importance of understanding whether the decision is consistent with the

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[23] Mental Capacity Act 2005: *Code of Practice 1.2*
[24] Mental Capacity Act 2005: *Code of Practice 2*
[25] Mental Capacity Act 2005: *Code of Practice 2.8*
[26] Mental Capacity Act 2005: *Code of Practice* 3.7
[27] Mental Capacity Act 2005: *Code of Practice 2.11*

individuals' values.[28] Both his son and daughter believed that Joe did not wish to die. His daughter highlighted a conversation with Joe in which he specifically said that he didn't want to die. They highlighted that he had a lot of spiritual books about understanding self, for example about dealing with depression, which suggested that he wanted to find a way forward. Moreover, neither recall professionals asking them about whether they thought their father wanted to die. Indeed on 16th July Joe told medical staff that he would ideally like his stoma reversed but appreciated that this was too risky with his current body mass. This is not obviously the statement of someone who wished to die. His son speculated that perhaps because Joe had been so very ill so often but was still alive, he simply did not believe the medical opinions; he may even have considered himself invincible. Questions about whether Joe wanted to die are not central to the specifics of a mental capacity decision but again they would have provided important background and context.

Family involvement – The discussion with his ex-wife and children suggests that they were not consulted about key mental capacity decisions. They would have had valuable insights into what was happening and Joe's attitudes and motivations. The MCA Code of Practice (4.52) states that: "*Professionals can get background information from a person's family and carers"*. It needs to be acknowledged that the Code then says: "*But the personal views of these people about what they want for the person who lacks capacity must not influence the outcome of that assessment".* This principle, which is repeated at other points in the document, may make professionals hesitate about family input. However, it does not and should not deter professionals from consulting the family in order to understand what is happening.

Executive capacity - Possibly the key issue in assessing capacity with vulnerable and self-neglecting individuals like Joe is the need to consider executive function / executive capacity. The Teeswide Carol SAR (about a chronic dependent drinker) talks about the need to look at someone's "executive capacity" as well as their "decisional capacity". Can someone both *make* a decision and *put it into effect* (i.e. use information)? This will necessitate a longer-term view when assessing capacity with someone like Joe. Repeated refusals of care, as happened with him, should raise questions about the ability to *execute* decisions. The draft Code of Practice to the Mental Capacity Act now specifically highlights the need to consider executive function.

Moreover, the existing (and draft) Code of Practice supports this stating that: *4.30 Information about decisions the person has made, based on a lack of understanding of risks or inability to weigh up the information, can form part of a capacity assessment – particularly if someone repeatedly makes decisions that put them at risk or result in harm to them or someone else.*

On the 24th May, the MASH advised that there should be an *'emphasis on his executive functioning (A structured assessment of capacity may need to be supplemented by real world observations of Joe's functioning and decision-making ability in order to provide a complete picture).'* It is unclear whether this was able to take place. However, the last three months of his life highlight the importance of

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[28] CoProduce Care • A podcast on Spotify for Podcasters

considering executive capacity. This was supported by the Practitioners' Workshop and clearly represents a professional development issue.

A more robust multi-agency discussion would have allowed practitioners to professionally challenge each other over the use of the concept of executive capacity.

The need for ongoing work - Ultimately, even if it is argued that Joe is capacitated, this should not be the end of his care. The report of *The 2013 Mental Capacity Act 2005: Post-Legislative Scrutiny*, criticises the use of the Act in this way: *The presumption of capacity…is sometimes used to support non-intervention or poor care, leaving vulnerable adults exposed to risk of harm.*[29] The MCA Code of Practice repeatedly highlights the need to assist a capacitous person who *"repeatedly makes repeated unwise decisions"*[30] or to undertake *further investigation in such circumstances.*[31]

A more relevant legal judgement - LB Croydon vs CD [2019] EWHC 2943 (Fam) - Relatively few legal judgements have been made about the care of dependent drinkers during the era of the Mental Capacity Act. The most relevant to Joe is the *London Borough of Croydon vs CD*.

CD was a 65 year old man with chronic alcohol use disorder who suffered from a range of other problems including depression, epilepsy diabetes and physical disabilities. He was frequently falling, not taking medication, self-neglecting, unable to manage his personal care, activities of daily living, his health and wellbeing. He was frequently calling 999 and attending A&E regularly. He was unable to safely complete most activities of daily living without help from his carer.

His flat had been 'blitz cleaned' on many occasions and a support care package commissioned but this had failed on all occasions. By the time the matter came before the Court, CD's flat was soiled with human waste, putting him and anyone who accesses his flat at high risk of infectious diseases. He was continuing to drink alcohol and soil himself. His entire house from the hallway, lounge, bedroom and kitchen, including all his furniture, had faecal and urinal stains making it odorous and uninhabitable to live and preventing Carers from going to his flat to provide the personal care CD required.

The Judge found that CD was disinclined to change his ways and was not willing to be moved to a safe environment where he could be supported with his personal care. The applicant local authority commended a twenty-point care plan to the court.[32]

The Judge said that: *Given the finding that there is reason to believe that he lacks capacity in relation to decisions concerning his care…I take the view that it is in CD's best interests that I should give directions and/or make orders without delay which enable the Local Authority to gain access to his accommodation in order, first of all to provide appropriate care for CD himself and secondly to make his accommodation safe for human habitation. Were I not to do so there is in my judgment,*

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[29] Mental Capacity Act 2005: Post-Legislative Scrutiny 2013 105

[30] Mental Capacity Act 2005: *Code of Practice 1.2*

[31] Mental Capacity Act 2005: *Code of Practice 2.11*

[32] London Borough of Croydon v CD | 39 Essex Chambers

from the evidence that I have seen and read, real cause to believe that his well-being would be very significantly impaired indeed.

Escalating the Mental Capacity decision – Given that there were differing views from professionals about Joe's capacity to make decisions, should this decision have been escalated? No evidence has been found that this was escalated to legal teams in the Acute Trust or the Local Authority. Ultimately, an application should probably have been made to the Court of Protection to determine Joe's mental capacity. (The Local Authority have subsequently acknowledged the importance of this potential step.)

15.5 What action might flow from a decision about his capacity

Unlike the Mental Health Act, the fact that someone lacks capacity does not lead to a specific pre-determined set of actions. The next steps need to be in someone's best interest but will vary dependent on the decision involved and the circumstances of the individual. The question is: what would have been In Joe's best interest?

Given his health problems and the need to understand what lies behind this presentation he probably needs a longer period in Hospital for detoxification and physical recovery. Ideally this would have been accompanied by motivational work to encourage him to agree to a move into residential care for longer term recovery. If not, then developing a package of care in the community that was acceptable to him.

15.6 The impact of the concept of "Mental Capacity" on the Carers

A contributory factor in Joe's decline is that he failed to make best use of the care he was offered. In particular, he often rejected the help of his Carers. This rejection of care appears to have been accepted because Joe was understood to have the mental capacity to make this decision. Therefore, his choice to sit in clothes soaked with urine or faeces should be accepted as the final word. This is clearly a misunderstanding of the mental capacity framework.

The report of *The 2013 Mental Capacity Act 2005: Post-Legislative Scrutiny*, specifically highlighted the challenges posed by clients like Joe: *The presumption of capacity…is widely misunderstood by those involved in care. It is sometimes used to support non-intervention or poor care, leaving vulnerable adults exposed to risk of harm. In some cases, this is because professionals struggle to understand how to apply the principle in practice. In other cases, the evidence suggests the principle has been deliberately misappropriated to avoid taking responsibility for a vulnerable adult.* [33]*…Such points were echoed in the submissions from family carers who expressed frustration at the misappropriation of the assumption of capacity by health and social care staff to justify poor care.* [34]

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[33] Mental Capacity Act 2005: Post-Legislative Scrutiny 2013 105

[34] Mental Capacity Act 2005: Post-Legislative Scrutiny 2013 64

15.7 The adequacy of the Mental Capacity Act

The ultimate message from this case may well be that the Act is very challenging to apply to people with compulsive and dependent behaviours and that the point of discharge from Hospital, where decisions are being taken very swiftly, poses a particular problem with this group.

It is worth reflecting on "what would the public think about the need for intervention with someone self-neglecting to such an extent that he was sleeping on a maggot-infested sofa, covered in faeces and flies, but deemed to have capacity?" It is the view of the authors of this SAR, and certainly of Joe's family, that lay people would expect public bodies to be taking assertive action to protect Joe and probably to believe that they were able to do that legally.

The challenges posed by this situation are even greater when one turns to the guidance on the legislation. The Code of Practice on the Mental Capacity Act mentions alcohol and drugs just three times. (The Guidance on the Care Act mentions alcohol and drugs just twice.) Practitioners are working in the absence of any clear statutory guidance on how to negotiate the type of challenges posed by Joe. This is not an isolated issue, for example, at least 25% of SARs feature people with significant alcohol use disorders.[35]

Therefore, beyond further training in this area, there ought to be a local workshop / task and finish group to consider how to use the Mental Capacity Act most appropriately with this and similar client groups and develop local procedures. This will need to involve, at the least, health, social care, SAB and legal services staff.

If this workshop and the SAB shares the view of this report that there is a tension between the Act and professional duties of care and public expectations, then it is legitimate for the SAB and other professional bodies to raise these concerns with the Department of Health and Social Care. The SAB may want to consider pressing national government, at the least, for better guidance on how to use the existing legislation most effectively with this client group.

15.8 Beyond the Mental Capacity Act

The notes mention that a Mental Health Act assessment was considered at one point. Joe may well not have had a mental disorder in terms of the Act; therefore this is an unlikely pathway forward. However, it is positive that workers were considering other options.

It might also have been possible to move beyond the Mental Capacity Act / Mental Health Act and to build a case for action on the need to preserve his Article 2 rights under the Human Rights Act – the right to life? (Or indeed Article 3 – freedom from degrading treatment). This is not a widely used approach in the substance misuse field, but, in Manchester, the Substance Misuse Social Work Team is using the Human Rights Act to drive intervention with individuals where other frameworks have not proven viable. This is a route that may have been worth consideration in Joe's case.

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[35] Preston-Shoot M. et al. - National SAR Analysis: April 2017-March 2019 – LGA / ADSS (2020)

Ultimately, this raises questions about use of Inherent Jurisdiction; however, whether Joe would have satisfied the articulated standard that he is both 'of unsound mind' of a nature and degree warranting confinement and lacks the relevant decision-making capacity is a moot point.[36]

16. Smoking

Joe was a smoker. This is a minor issue in this SAR, but it is important to explore smoking and smoking cessation with dependent drinkers Smoking contributes not only to the worsening of lung disease but also liver disease, pancreatitis and cognitive damage. It also raises the risk of fire hazards. Reducing smoking among people with mental health problems is an Office for Health Improvement and Disparities priority. There has also been a governmental focus on smoking among people with substance use disorders. Therefore, it is important that professionals recognise the need to address this issue with people with alcohol use disorders. (NB It is positive that the Fire and Rescue Service received a referral for a “safe and well” visit to Joe’s property in 2023. This could not be completed due to non-engagement).

17. Key Learning Points

Joe died at home in squalid circumstances in July 2023. Behind this lay a history of a chronic alcohol use disorder, serious physical health problems and extreme self-neglect. He was undoubtedly a difficult man to help. His ex-wife described Joe as *“hard work”* to care for. However, she thought that because his care had been *“handed over to professionals,”* that he would be safe and cared for appropriately. This was not the case.

Therefore, his care highlights a number of key learning points that will improve care for others in similar circumstances. The central theme in Joe’s care is the use of the Mental Capacity Act in the last weeks of his life and the decision-making around the discharge home from Hospital. However, other themes also emerged.

People that services find difficult to engage - Joe had a number of aspects to his presentation – his substance use disorder, possible mental health concerns, health problems and self-neglect. However, one issue underpins all of these issues – services found him very difficult to engage into the care that would have benefited him.

This highlights the need for a specific published procedure to guide professionals on dealing with client non-engagement. The local Multi-Agency Risk Management (MARM) Guidance fulfils that role. This Guidance would benefit from accompanying guidance on what techniques work with hard to engage clients. It is important that there is ongoing “marketing” of the local guidance and more specific training and guidance on what works to engage and motivate individuals like Joe who refuse services.

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[36] London Borough of Croydon v CD | 39 Essex Chambers

Alcohol use disorders - At the very least, Joe's case is a reminder of the importance of robust alcohol screening processes to ensure that alcohol-related risk is routinely identified and highlighted by all the agencies that are working with an individual.

Joe's care raises an issue which may become a more regular concern – the home delivery of alcohol to vulnerable people. At the most basic level, home delivery drivers should not leave alcohol without seeing the person who has ordered it. They should also not be selling alcohol to people who are intoxicated. There is, however, the wider issue of delivering alcohol to vulnerable people. These points should be discussed with the Licensing Team in the Council.

At a couple of points, practitioners appear to have considered removing, or actually removed, alcohol from Joe. All practitioners should be regularly reminded that this risks potentially life-threatening alcohol withdrawals.

Joe could well have benefited from an alcohol assertive outreach approach which would have attempted to build a relationship with him in order to understand what lay behind his challenging behaviour. This may be an area for local service development.

Professional attitudes - In working with individuals like Joe, it is important to ensure that professional attitudes are not impeding responses. The needs of dependent drinkers can easily be viewed as "self-inflicted" or a "personal choice". This report cannot prove that such attitudes impacted on the care of Joe, but it is a possibility. Therefore, it is important to ensure that professional training and management challenges such beliefs.

Professional curiosity - Given the life-threatening impact of the decisions that were being taken about Joe, it is vital that practitioners exercise professional curiosity to determine what exactly is happening with him before taking capacity or other decisions which were likely to have serious consequences. This would seem to be a key lesson from his care.

Cognitive impairment – In particular, practitioners will need to use professional curiosity to understand whether cognitive impairment is a factor in his presentation. With chronic dependent drinkers this will often be the case, and this was mentioned with Joe.

Motivational work - Given the challenge of engaging Joe into structured care, consideration needs to be given to specific work to motivate him. Simply expecting him to accept the care may be naïve and may also waste resources. Professionals will need to build motivation rather than expecting the individual to have their own motivation. This will require a range of professionals to have had training in motivational interventions and motivational interviewing.

Multi-agency discussion - Individuals like Joe benefit from regular multi-agency discussion. This should be a part of any guidance on working with engagement issues – i.e. there should be an escalation pathway into multi-agency management. This is the case locally and in Joe's care multi-agency meetings and joint working took place, and there was communication about concerns and risks. The question is whether there was sufficient multi-agency discussion of Joe's capacity in the period around his final admission.

Safeguarding and Adult Social Care - At the centre of Joe's care in the last months, is the concern that he was discharged from Hospital with inadequate support. His ex-wife spoke of her incredulity on one occasion that no family members were informed when he was discharged and to a flat with no gas, no electricity, and no food, where she found him shivering with cold.

Some work was clearly undertaken to safeguard Joe and to meet his care and support needs. Concerns were raised, an assessment was undertaken under section 9 and a care plan was initiated. The key questions are about:

- The decision to view the first concern in 2023 as a care management rather than a safeguarding issue;
- the speed of response to a case of serious self-neglect i.e. the decision to place his case on a waiting list;
- the intensity of work done to support him post-discharge; and
- the type of support provided - the provision of care may require work to help people to accept and engage with the care.

However, the central question with Joe is the use of the Mental Capacity Act.

Mental Capacity - At the centre of Joe's care is a debate about the use of the Mental Capacity Act. His care raises a number of questions about the use of the framework and, ultimately, the adequacy of the legislation or Code of Practice for this client group. Joe's care suggests a tension between a professional duty of care and the application of the legislation. The former must surely be the professionals' main goal. This does not mean practitioners should ignore the legislation; however, if the legislation clashes with the fundamental professional role of caring for the individual, then that must be a red flag for further discussion and action.

Mental Capacity and professional attitudes - Joe's daughter stated that, two weeks before her father's death, a Doctor called and told her that: "*there was nothing wrong with him*. *If he goes home and dies then that is on him".* This is indicative of both a possible training need around professional attitudes and a need for training on communication with families.

The depth and breadth of consideration – In mid July 2023, two Doctors determined that Joe had the capacity to discharge himself from Hospital to a home that was in a poor state wand with inadequate support. At the very least there should have been further multi-agency discussion and family input before this serious decision was reached. The day before, a colleague of the assessing Doctors had decided that Joe did not have capacity and required a DoLS. This would have allowed both Doctors to have a “reasonable belief”[37] that Joe lacked capacity to take the decision to discharge himself, pending a more detailed review.

Assistance with decision making - The Act states that people must be given all appropriate help and support to enable them to make their own decisions or to maximise their participation in any decision-making process. This does not seem to have been the case with Joe.

Compulsion – The Code of Practice recognises that “compulsion” can be a factor that impacts on capacity. It states at 4.22 that: “*For example, a person with the eating disorder anorexia nervosa may understand information about the consequences of not eating. But their compulsion not to eat might be too strong for them to ignore.”* The reference to anorexia is simply an example and it is not hard to see how this extends to Joe’s alcohol dependence. The fact that he may have had a compulsion to drink should have been considered in assessing his capacity to make key decisions. In particular, whether he can use or weigh information.

The decision that is the focus of the MCA assessment - The decision by the two Doctors focused on whether Joe had the capacity to decide to discharge himself. Is the correct decision not rather whether he can go home and maintain his health, body weight and engage with medication regimes i.e. the reasons he was brought into Hospital?

Understand his values – consideration should be given to understanding whether mental capacity decision are consistent with the individual’s values. Both his son and daughter believed that Joe did not wish to die. Questions about whether Joe wanted to die are not central to the specifics of a mental capacity decision but again they would have provided important background and context.

Family involvement – The discussion with his ex-wife and children suggests that they were not consulted about key mental capacity decisions. They would have had valuable insights into what was happening and Joe’s attitudes, values and motivations.

Executive capacity - Possibly the key issue in assessing capacity with vulnerable and self-neglecting individuals like Joe is the need to consider executive function / executive capacity. Can someone both *make* a decision and *put it into effect* (i.e. use information)? This will necessitate a longer-term view when assessing capacity with someone like him.

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[37] This is the required standard in the Mental Capacity Act

The impact of the concept of mental capacity on his Carers - His Carers appear to have accepted Joe's refusals of care because he was understood to have the mental capacity to make this decision. This means that decisions to sit in clothes soaked with urine or faeces should be accepted as the final word. This is clearly a misunderstanding of the mental capacity framework.

The adequacy of the legislation – All of this suggests the need for reflection on the adequacy of the Mental Capacity Act with this client group. There should be a local workshop / task and finish group to consider how to use the Mental Capacity Act most appropriately with this and similar client groups at the point of Hospital discharge and to develop local procedures. This will need to involve, at the least, Health, Social Care, SAB and Legal Services staff.

If this workshop and the SAB shares the view of this report that there is a tension between the Act and professional duties of care and public expectations, then the SAB (and other organisations) should raise these concerns with the Department of Health and Social Care. The SAB may want to consider pressing national government, at the least, for better guidance on how to use the existing legislation most effectively with this client group.

Smoking - There needs to be a focus on addressing smoking in this client group and Alcohol and Drug Services, as well as other professionals, should recognise the importance of smoking cessation with this client group.

18. Recommendations

Recommendation A

Cambridgeshire and Peterborough SAB should ensure that there is ongoing "marketing" of the local Multi-Agency Risk Management (MARM) Guidance and should develop more specific training and guidance on what techniques work to engage and motivate individuals who refuse services.

Recommendation B

Cambridgeshire and Peterborough SAB should ensure there is training and professional development to ensure that professional's beliefs that severe alcohol use disorders are "self-inflicted" or a "personal choice" are challenged and do not impede responses to this client group.

Recommendation C

Cambridgeshire and Peterborough SAB should reassure themselves that the local Public Health Teams are working to ensure that all frontline services are aware of, and are able to use, robust alcohol and drug screening tools such as the AUDIT tool or Assist-Lite to identify and record the level of substance related risk for clients.

Recommendation D

Cambridgeshire and Peterborough SAB should work with local Licensing Departments to ensure that the ethics and legality of home delivery of alcohol to vulnerable people are carefully considered.

Recommendation E

Cambridgeshire and Peterborough SAB should reassure themselves that all practitioners understand the dangers of restricting access to alcohol to people who are currently dependent.

Recommendation F

Cambridgeshire and Peterborough SAB should ensure that guidance or protocols are available to support professionals to consider the use of the Mental Capacity Act in the context of clients that agencies find difficult to engage generally and people with alcohol and drug use disorders specifically. This should include reminders about the importance of multi-agency discussion, professional challenge, family involvement and the use of executive capacity.

Recommendation G

Cambridgeshire and Peterborough SAB should set up a local workshop / task and finish group to consider how to use the Mental Capacity Act most appropriately with this and similar client groups at the point of Hospital discharge and to develop local procedures to support professionals. This will need to involve, at the least, Health, Social Care, SAB and Legal Services staff.

Recommendation H

Cambridgeshire and Peterborough SAB, in conjunction with other local agencies and professional bodies, may wish to consider lobbying national government for either improved guidance on using the Mental Capacity Act; or new legislation to better meet these needs.

Appendix 1 Terms of reference

- Accessing Joe’s voice:
    - (a) When, and in what way, were Joe’s wishes and feelings ascertained and considered?
    - (b) How was Joe supported to make decisions for himself?
    - (c) Were the needs and voices of his family considered?

- Self-neglect: Was there evidence of Joe lacking self-care or lacking care of the home environment to the extent that it endangered his safety and wellbeing? Did agencies respond appropriately to these concerns?

- Risk: Was risk identified and appropriately addressed?

- Substance misuse: Were appropriate steps taken to address his alcohol use? What challenges and barriers exist for people experiencing alcohol use disorders? In particular, please consider the potential role of unconscious bias and also comment on whether any reasonable adjustments are made for people experiencing alcohol use disorders.

- Clients who are difficult to engage: are there procedures and pathways for the management of individuals who are difficult to engage in services?

- Joint working concerns: Was information sharing and communication between agencies and services appropriate and timely?

- Multi-agency management: To what extent did consistent multi-agency management feature in his care?

- Safeguarding: Were safeguarding needs considered and addressed appropriately and were there missed opportunities to raise a safeguarding concern at any stage?

- Mental capacity: Was the Mental Capacity Act 2005 appropriately considered and implemented in practice? Was Joe’s voice actively listened to in any mental capacity considerations?

- Other legal options: Does it appear that all legal options, including seeking legal advice where appropriate, were explored to safeguard Joe?

- Systemic issues: Did any systemic issues impact on Joe’s care / service delivery, including, for example, agency resource / capacity issues, austerity, the COVID pandemic, workforce knowledge and training in relation to supporting people with substance/alcohol use disorder?

- Escalation: Were senior managers involved at points where they could have been?

- Good practice: Was there any good or notable practice with Joe that should be flagged?