Safeguarding Adults Review

Executive Summary

‘Sam’

Prepared by: Jem Mason
Making Connections IOW
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1. Introduction

Sam died at Ashford St Peter's Hospital on 13th November 2021. Sam presented at the Accident and Emergency department emaciated and not meeting his oral and nutritional needs. Sam died before a gastrostomy procedure could be carried out.

An inquest into Sam's death recorded the medical cause of death as Bronchopneumonia, Motor Neuron Disease (Facial Onset Sensory and Motor Neuropathy) and malnourishment.

The Coroner indicated that opportunities for inter-agency communication were missed which could have allowed the issue of weight loss and malnourishment to be addressed at an earlier stage.

2. The Review and Methodology

The methodology adopted is a review of extant health and social care records; communications; and safeguarding adults enquiries; and the production of an overview report by an independent author.

The agencies involved in this review are:

- A2Dominion Housing Association
- AlpenBest Care (Home care provider)
- Ashford and St Peter's Hospital
- Central Surrey Health
- Surrey and Borders Partnership NHS Foundation Trust
- Surrey County Council (Adult Social Care)
- Surrey Heartlands Integrated Care Board (ICB) – Primary Care/General Practitioner
- Surrey Police
- Woking and Sam Beare Hospice

The period under review is from August 2020 to November 2021. This represents the final fifteen months of Sam's life. The review panel convened on 30th November 2023 the review completed on 19th September 2024

The review panel have sought the views of an independent practitioner with specialist knowledge of Motor Neuron Disease from Surrey Downs Health & Care

All activities in setting up the review, running the review, and delivering outputs have been carried out with reference to the Safeguarding Adult Review Quality Markers (SCIE March 2022).

3. Family Involvement

The lead reviewer has consulted with members of Sam's family. Sam's sons requested a personal statement be included in the review:

Sam was one of you, he had worked in the care sector for over 30 years. He was a good person, full of kindness and with the biggest heart. He was the best dad in the world and, was loved and admired by all those who knew him.

He knew what was happening but didn't think you cared about what really mattered to him, which was to be near to us and to be cared for with the support he needed, just as he had provided the same to 100s and 100s of people with care needs.

We get MND is complex but when you're working with a deteriorating condition with an indeterminate longevity, please know time is really of the essence, knowing what's the priority is essential, keeping to your promises, invaluable and the most important person in an MDT is the person themselves.

Please imagine our dad was your dad, your husband or son and think about how you would have wanted their support to work and their end of life to be the best it could be. It was truly terrible for our dad and us but knowing you care what happened, you'll learn from it and share this with others to make a real difference now, to those who you work with will give us some meaning and comfort. So, please, please keep our dad's story alive so that there is an authentic and tangible worth for others you are there to help.

(Sam's sons, aged 15 and 18 when he passed.)

4. Summary Background

Sam was 60 years old when he died

Sam first experienced difficulties chewing in October 2018. Following an extended period of assessment the diagnostic picture of Sam's condition was confirmed in January 2021. First identified as an atypical Motor Neuron Disease, later identified as Facial Onset Sensory and Motor Neuropathy.

Sam was first referred to Adult Social Care in August 2020. After initial contact with the Spelthorne Locality Team there was no further action until Sam contacted them again in December 2020, reporting a speech impairment, difficulty eating, reduced mobility, falls and difficulty with personal care. Sam contacted Spelthorne Locality Team a third time in January 2021 saying he was struggling and feeling low. Sam was offered a personal assessment and listed for allocation.

Sam indicated to his GP he was depressed and drinking a high level of alcohol. Sam requested from Adult Social Care support to enable him to relocate nearer to his family, particularly his sons.

In early 2021 there was a high level of contact between Sam and an array of professionals (Neurologist, GP, Spelthorne Locality Team, OT, Physiotherapist, SaLT, Dietician, Specialist Palliative Care Team; Respiratory Care Team, Podiatry). Sam was also commissioned a package of care to include support with personal care, meal preparation and shopping.

Throughout 2021 Sam's level of engagement with professionals and acceptance of support declined. Sam spoke regularly about his desire to be near his children and of his fluctuating mental health and low mood. Sam said he was living in physical pain and feeling isolated. Sam opted not to have a gastrostomy at this time but did not rule it out for the future. Substantial weight loss was recorded across this whole period.

In the middle of 2021 after an altercation with a visiting carer, Sam cancelled all commissioned care. For a brief period, Sam was cared for by an ex-partner. This support ended when Sam was refused a direct payment to pay for this care and the ex-partner was unable to continue without it. An alternative personal assistant was not found. No interim care was put in place.

By autumn Sam was turning away health professionals as he found them morbid. Sam had lost significant amounts of weight and was finding it difficult to feed himself. Sam had been without formal care arrangements for several months, his neck collar had worn out and had needed replacing leaving his jaw without effective support. No progress had been made in relocating Sam to be nearer his sons.

A visit from his Specialist palliative Care Nurse at the beginning of November identified significant self-neglect and resulted in the advice for Sam to present at the Accident and Emergency Department as soon as possible. Sam was admitted to hospital the next day.

Sam remained in Hospital until he died on 13th November 2021. Sam was in the end unable to have the gastrostomy tube fitted, because by the time he was admitted to hospital he was too unwell for the procedure. Sam contracted pneumonia and was physically unable to recover from this.

5. Findings

Coordination of Person-Centred Support

From the earliest contact there was a pattern of divergence between Sam's view of his situation and that of the professionals around him. By June 2021 interactions had settled into this characteristic rhythm, which laid the foundation for the deterioration in Sam's condition to be noted but continue unabated.

A personal assessment under the Care Act (20014) was not carried out early enough. It is likely that early statutory assessment would have reduced the risk of missed opportunities to address self-neglect at a later stage. It also seems probable that the later trajectory could have been interrupted at any point had there been a recognition of the divergence between Sam's own support agenda and those of the professionals around him.

Although there is a great deal of recording of Sam's condition and his communication with professionals, there was insufficient coordination to ensure Sam was receiving the right support and the support he wanted.

The multi-disciplinary meeting involved only health professionals, there was no representation by Adult Social Care or of Sam himself.

Being able to form a holistic view of Sam's treatment, care and support needs would also have enabled other global issues to be identified. Questions may perhaps have arisen regarding Sam's Mental Health and Mental Capacity, both of which were important to the context in which services were being offered.

Mental Capacity Act (2005)

At several points practitioners recorded that they had assumed Sam had capacity. It is not apparent from practitioner notes that this was called into question or that reasonable steps were taken to determine capacity.

A better knowledge of MND may have prompted practitioners to question Sam's mental capacity. Regardless of this, the evidence that Sam was delaying or struggling to make important decisions in this context should have prompted a formal assessment of capacity with regards to care and support needs. Likewise, the critical consequences of what was seen as Sam's lifestyle choice to 'self-neglect' should have prompted practitioners to seek greater clarity in respect of his mental capacity to manage those risks.

In short, a vulnerable person, with growing health, care and support needs, accompanied by visible signs of and an articulation of low mood; should have been the subject of more curiosity on this matter. A clearer picture of Sam's mental capacity not only would have enabled robust risk assessment and management it would likely have shaped the way services were offered to Sam.

Communications

The confirmed diagnosis of MND appeared to act as a trigger for a number of services.

Across the first four months of 2021 the activity recorded in the various chronologies can only be described as intense. Sam was a man who had just received a terminal diagnosis that could also have an impact upon his mind and executive function. A variant of MND that begins in the area of the face and makes communication a struggle. Living alone in a period when COVID19 restrictions place additional barriers on personal contact. Finding it increasingly difficult to hold a telephone, type a text message or an email. Feeling the effects of low mood and fatigue.

Given the indications that communication and contact was overwhelming Sam, the question arises as to whether it was necessary to have such an intensity. The prognosis Sam had was of years rather than months. Some of the support required was urgent or immediate, such as adaptations and equipment, respiratory checks and dietician input. Other aspects were potentially less urgent e.g. advance care planning.

In this instance, the push to complete all the necessary planning early may have defeated its own end. Consideration could have been given to a structured and coordinated approach to communications and the tasks that needed to be completed at various stages.

A truly person-centred approach would start with this from Sam's perspective and construct a personal plan with timelines that start from the present time, prioritise tasks through a listening approach and then utilise the time available. Sam likely needed support in managing all the support that was being offered to him. This is probably true

of any individual with a serious and terminal diagnosis and is likely to fall somewhere in the combined roles of the Specialist Palliative Care Team and the Adult Social Care Team.

Section 42 Referral and Enquiry

The criteria for a S42 enquiry are straightforward:

- has needs for care and support (whether or not the authority is meeting any of those needs),
- is experiencing, or is at risk of, abuse or neglect, and
- as a result of those needs is unable to protect himself or herself against the abuse or neglect or the risk of it.

Professionals displayed thought processes suggesting Sam's mental capacity was being assumed, any disengagement must be a choice, and no further enquiry was warranted.

Were the criteria applied correctly it would be evident that the first two criteria were met. Sam was already in receipt of care and support and was already showing signs of neglect.

The third criteria is Sam able to protect himself against neglect should at least have been in some significant doubt. Even had Sam's capacity been assessed and confirmed; his growing physical disabilities and relative isolation meant he was likely unable to protect himself against weight loss and poor personal care. The idea that simply because someone makes their own decision, they can no longer meet the third criteria is simply not valid. A robust capacity assessment may also have highlighted that Sam could not execute decisions either and lacked both the mental capacity and the physical ability to protect himself from harm.

Sam's disengagement from some services, his lack of formal care arrangements, his rapid weight loss, concerns about drinking excessive alcohol, low mood and thoughts of self-harm could have and should have prompted a safeguarding concern to be raised by any of the practitioners. This is particularly true of those working closely with Sam and able to see the absence of care and support and the impact of it.

A multi-disciplinary approach including both Health and Social Care representatives could then have identified some of the issues raised in earlier findings e.g. a determination of Mental Capacity.

Other Findings

COVID19 - With respect to COVID19 and the impact upon Sam's care and support, the findings are minimal. The pandemic caused some delays in offering Sam health appointments, but these were not excessive, and Sam was fast-tracked upon full diagnosis.

Direct Payments – The direct payments scheme itself cannot be held responsible for the extended period Sam was without formal care. It was not some failing in the scheme that prohibited him from receiving support. Delays in arranging the direct payment extended this period, this was accompanied by a deflated employment

market making it difficult to recruit a PA, even when the Direct Payment had been agreed. In Sam's instance there was a further delay both in the offer of a Direct Payment and the recruitment of a PA because he was informed, he could not employ his ex-partner as an assistant. The Local Authority could have explored its discretionary powers. Escalation by the Social Worker to a Team Manager under the Direct Payments Policy should have occurred.

6. Recommendations and Questions for the Board and Agencies

Question 1: How can agencies assure the Board that multi-agency meetings in relation to life-limiting conditions, identify and have meaningful representation from all appropriate agencies and consider the views and involvement of the person and their representatives?

Question 2: How can specialist support for MND be made available in Surrey to allow equal access across all neighbourhoods and places?

Question 3: How can individual agencies and the Board improve understanding across the workforce of the presence of FTD within MND patients? How can the agencies assure the Board that patients with MND receive a regular review of both their mental health and levels of cognition?

Question 4: How can agencies assure the Board that individuals, particularly those known to be living alone, have effective and accessible communication plans that can be referenced and followed by practitioners and agencies? How can agencies assure the Board that consideration will be given to the person's available support network and the need for advocacy where appropriate?

Question 5: How can agencies assure the Board that individual practitioners understand and will take action in accord with their legal duty to refer where there is self-neglect or a pattern disengagement from care and/or treatment offers? How can agencies assure the Board that practitioners will cooperate and share information to meet their combined duty to safeguard the welfare of those at risk through self-neglect?

Question 6: How can Surrey County Council assure the Board that in line with the Care Act (2014) an assessment of need (s9) will always be undertaken where such a legal duty exists with a correct understanding of the provisions of s11 (assessment refusal)? How can SCC assure the Board that s42 enquiry; assessment under the Mental Capacity Act (2005); and coordinated safeguarding action will follow as appropriate under the Care Act (2014) and the Mental Capacity Act (2005) in cases of self-neglect?

Question 7: How can agencies assure the Board they are making available guidance to practitioners regarding MND and the recommended approaches to care, treatment and safeguarding?

Question 8: Should the Local Authority and Board reconsider local policy and the role of S42 enquiry where individuals are deceased.

Question 9: How can Surrey County Council assure itself that their policy relating to Direct Payments is understood and adhered to by all relevant practitioners?