Safeguarding Adults Review

Sam

September 2024

Making Connections IOW
Lead Reviewer: Jem Mason

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1. Introduction

This safeguarding adults review (SAR) has been commissioned by the Surrey Safeguarding Adults Board (SSAB) to gain an understanding into the events and actions of health and social care agencies prior to Sam's death on 13th November 2021.

Sam died at Ashford St Peter's Hospital. Sam had presented at the Accident and Emergency department on 2nd November 2021 on the advice of professionals having been described as emaciated and not meeting his oral and nutritional needs. A gastrostomy procedure was already scheduled for 16th November 2021. Sam died before the procedure was able to be carried out.

An inquest into Sam's death was heard on 9th and 10th January 2023. The Coroner recorded the medical cause of death as Bronchopneumonia, Motor Neuron Disease (Facial Onset Sensory and Motor Neuropathy) and malnourishment. The Coroner concluded, after detailed consideration, that the threshold for criminal neglect was not met. A verdict of this kind would depend upon a direct causal link being established between a gross failure in a duty of care and the cause of death. The Coroner made this finding on the understanding that in the absence of sufficient evidence to the contrary, Sam had the mental capacity to make his own decisions around treatment, care and support and that his own reluctance to accept certain treatments was a contributing factor. Matters concerning Sam's mental capacity, or lack of, will be revisited in this review.

It was acknowledged at inquest 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. This indicates the potential for further learning as to how the agencies could coordinate their interactions and provide improved care and support for individuals like Sam.

A referral was made by Surrey County Council (SCC) to SSAB for consideration of a Safeguarding Adults Review under Section 44 of the Care Act (2014). A decision was made on 24th April 2023 to proceed with a SAR on the grounds that Condition 2 at Section 44(3) of the Care Act (2014) had been met.

The Care Act (2014) section 44 provides two conditions under which a SAR must be carried out and states:

Condition 1 is met if—

(a)the adult has died, and

(b)the SAB knows or suspects that the death resulted from abuse or neglect (whether or not it knew about or suspected the abuse or neglect before the adult died).

Condition 2 is met if—

(a)the adult is still alive, and

(b)the SAB knows or suspects that the adult has experienced serious abuse or neglect.

In the case of this referral Condition 2 cannot have been met because Sam has died. I believe the reliance on Condition 2 may have arisen from confusing wording in the SSAB decision form which states “the person has not died as a result of the abuse or neglect” rather than simply “the person has not died”.

Where a person has died the SAB must proceed on a basis of Condition 1 if it suspects that the adult has experienced serious abuse or neglect, and the death was as a result.

In this case, where the Coroner has indicated death was not caused by neglect, I can understand why SSAB would not wish to proceed on the basis of Condition 1 even were it to suspect some neglect has occurred and contributed to an earlier death. This SAR can still proceed on a discretionary basis under Section 44(4).

(4) A SAB may arrange for there to be a review of any other case involving an adult in its area with needs for care and support (whether or not the local authority has been meeting any of those needs).

The Care and Support Statutory Guidance (2014) in paragraph 14.126 indicates a SAR should *“seek to determine what the relevant agencies and individuals involved in this case might have done differently that could have prevented harm or death”*

Any SAR should keep in view six key principles as laid out in CaSSG (2014) para. 14.4: Empowerment; Prevention; Proportionality; Protection; Partnership; and Accountability.

At its heart, this SAR considers the final months and days of a man with a progressive terminal condition. Considerations arise from the actions of individuals and agencies, and whether they were effective in delivering the six principles for Sam.

- Empowerment – Did individuals and agencies support a ‘*person-led*’ approach understanding Sam’s needs and wishes throughout the progression of his MND?
- Prevention – Did individuals and agencies act in a timely way given what was known or could have been known at the time, and ‘*take action before harm occurs*?’
- Proportionality – Did individuals and agencies provide the right level of intervention, getting involved ‘*as much as needed*’
- Protection – Did Sam receive the right ‘*support and representation’* when he was in ‘*greatest need?’*
- Partnerships – Did professionals ‘*work together to get the best result*’ for Sam?
- Accountability – Did individuals and agencies act with ‘*accountability and transparency*’ in responding to their visible concerns about Sam?

2. Terms of Reference

Full terms of reference can be found at Appendix A.

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 from the point of first referral to St Georges Hospital for definitive diagnosis and to Adult Social Care (SCC) for personal assessment of care and support needs.

A review panel with representatives from each organisation convened on 30th November 2023 the review completed on 19th September 2024

A specialist practitioner for rare neurological disorders from Surrey Downs Health & Care attended the panel on 12th April 2024.

3. Methodology

The methodology adopted is a review by an independent author and the production of an overview report.

In choosing a methodology, the panel and lead reviewers took into consideration the elapsed time from Sam's death to the start of the review, a period of two years. Changes of personnel and the challenges for memory would likely make a direct engagement with the relevant professionals challenging.

There is a large amount of documentation available to the review. Three Section 42 reports have been produced by Adult Social Care (SCC) in 2022, the year following Sam's death. A Coroner's inquest took place early 2023. These reports and findings are available to the review.

There is a body of contemporaneous notes held electronically by each agency. Summary chronologies have been supplied to the lead reviewers. A single chronology has been produced by the review to help understand agency contact from Sam's perspective and to identify where crossover communications and actions did and did not happen.

The review panel have sought the views of an independent practitioner with specialist knowledge of Motor Neuron Disease. The purpose of this is to increase understanding of the condition and support potential learning for practitioners when working with individuals living with MND.

The lead reviewer has undertaken an analysis of key events and contacts, explored through a framework of key issues set out in the terms of reference.

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).

4. Family Involvement

The lead reviewer has consulted with members of Sam's family. Sam's family shared their own experiences of supporting him up to and during the last months of his life. Sam's family have provided significant details and insight into Sam's state of mind, his wishes and feelings and his views of the support offered. Sam's family have been consistent champions for Sam and have continued to add their views in a measured way to section 42 enquiries, the Coroner's inquest and latterly this review.

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.)

5. Summary Background

Sam was 60 years old when he died. His family described a big man both in strength and personality. Sam was a family man and devoted to his family; he was hard-working, thoughtful, artistic and musical. Working in the care sector Sam had first-hand experience of offering person-centred and compassionate care to others.

In October 2018 when he was 57, Sam saw his GP as he had been experiencing difficulty chewing and was referred to a maxillofacial clinic. A few months later Sam was referred by his GP to a TIA (transient ischaemic attack) clinic after experiencing left-sided weakness in his face. The TIA clinic perceiving no evidence of a stroke suggested further neurological review. Further tests were undertaken at Ashford and St Peter's Hospital (ASPH) across 2019 as Sam started to experience weakness in his neck and his left arm. By March 2020 Sam had shoulder pain that was affecting his quality of life and a first referral for Physiotherapy was made. It should be noted that this coincided with the introduction of national restrictions in response to the Covid19 pandemic. The precautionary measures taken by all clinics had an impact upon waiting times for appointments and perhaps delayed investigations by a few months. By August 2020 Sam's difficulty with chewing was beginning to cause weight loss. A referral was made by a consultant neurologist at ASPH to St George's Hospital for the purpose of obtaining a definitive diagnosis. The events that follow come within the period for review.

6. Key Events

As can be seen from the summary background Sam had some contact with health agencies via his GP prior to August 2020 and at this point was unknown to Adult Social Care. Increased contact with agencies occurred following a review meeting with his Consultant Neurologist on 6th August 2020. Sam was accompanied to this review meeting by his ex-partner. Sam's Consultant Neurologist took the following actions:

- A referral to St Georges Hospital to pursue a definitive diagnosis
- A referral for a Speech and Language Therapist (SaLT) at Central Surrey Health (CSH) with reference to chewing difficulty.
- A referral a Dietician (CSH) with reference to weight loss as a consequence of chewing difficulty.
- A referral to Orthotics (CSH) to obtain a neck collar/brace.
- A referral to the Mental Health Team for 'Talking Therapies' with reference to signs of depression.
- A 'to whom it may concern' letter outlining the physical and emotional impact of the symptoms to support housing applications for Sam to be nearer his children.
- A 'to whom it may concern' letter for Sam's employer to support the need for reasonable adjustments in the workplace.

Following this meeting on 17th August 2020 Sam's ex-partner made a referral to Adult Social Care (Spelthorne Locality Team) services on Sam's behalf, requesting a personal assessment. A follow-up telephone conversation from the duty worker to Sam's ex-partner ascertained Sam's deteriorating health condition, that he had not come to terms with the current diagnosis, that he was experiencing weight-loss, and he was struggling to wash himself. An introductory email was sent to Sam offering support for those who cannot manage personal care and daily living. Sam responded by email to say that he could complete personal care with some struggle, would welcome intervention if things changed and would notify the team. No further action was taken by the Spelthorne Locality Team at this time.

Sam commenced medication for depression and pain relief. The initial referral for talking therapies to Surrey and Borders Partnership Trust (SABP) was rejected due to insufficient information. A new referral was not made as Sam felt the medication was beginning to work. At this time Sam was placed on a non-urgent waiting list for the Community Reablement Team and SaLT at CSH with advice indicating longer waiting times due to Covid19.

From October 2020 to December 2020 the diagnostic picture of Sam's condition became clearer, first indicated as an atypical Motor Neuron Disease, later identified as Facial Onset Sensory and Motor Neuropathy.

On 17th December, four months after the initial email contact with Spelthorne Locality Team, Sam contacted them again to request help. At this time, he reported that he had a speech impairment, difficulty eating, had reduced mobility leading to several falls and had difficulty getting in and out of the bath. A follow up phone call was made by an Occupational Therapy Assistant. Sam indicated he could shower but only when well enough, otherwise he would strip wash. Sam was advised to continue to strip wash and a referral for grab rails in the shower was made. No other action was recorded at this time.

There followed a period of more intense activity in the second and third weeks of January 2021.

Sam had an initial telephone assessment by a Physiotherapist from (CSH) followed by a home assessment shortly afterwards. This assessment recorded significant difficulties with personal care, food preparation, eating and drinking for which several adaptations were recommended. Sam reported to be of low mood and tearful and he was advised to contact his GP and the Spelthorne Locality Team.

Sam contacted Spelthorne Locality Team, this was a third contact following those in August 2020 and December 2020. Sam said he was struggling with his personal care, felt very low and couldn't get through to his GP. Sam was offered a personal assessment, was advised to keep trying his GP and if he had thoughts of self-harm to call emergency services. Sam was listed for allocation.

Sam spoke with his GP and spoke of his low mood and occasional suicidal thoughts. Sam also said he was drinking four bottles of wine a week. Wanted to stop anti-depressants and try counselling instead. Sam received GP advice and planned a review two weeks later.

Sam's ex-partner was contacted by the Spelthorne Locality Team and recommended to contact the housing department in relation to Sam relocating nearer to his family. Advice was also given that matters regarding falls and low mood should be referred back to Sam's GP for onward referral to the falls team and the Community Mental Health Team.

Sam's diagnosis was confirmed to him in the third week of January by his Consultant at St Georges Hospital. Sam didn't want to talk about the prognosis but was asked to consider medication that could slow the progress of the disorder. The neurologist appraised Sam's GP that a frontal-lobe component of the condition could affect executive decision making and might account for any difficulty in making decisions such as where to live and accessing counselling support.

Referrals to Occupational Therapy, Dietician and for SaLT input were accelerated, with particular consideration to be given to a Gastrostomy procedure. Further referrals were made to the respiratory care team, Woking and Sam Beare Hospice and the Adult

Social Care Team for inclusion at Multi-disciplinary Team discussion. It was noted Sam was wearing a temporary neck brace and was awaiting a collar from Orthotics.

Spelthorne Locality Team arranged an appointment for a personal assessment and commissioned twice daily care for an interim period of two weeks. The personal assessment was completed on 25th of January. Sam confirmed the support was helping. It was noted his mobility was poor, he had experienced falls and lack of dexterity meant he could only prepare snacks and drinks and not a full meal. Sam's weight loss and lack of appetite was noted. Sam said his diagnosis had 'hit him hard', his mental health had deteriorated, and he discussed his desire to be near his children. Sam confirmed his ongoing need for support twice a day and his desire to maintain his independence. Sam's care and support package was increased to include shopping and domestic support.

Across this period and carrying on through February and March 2021 there was a high level of contact between Sam and professionals (Neurologist, GP, Spelthorne Locality Team, OT, Physiotherapist, SaLT, Dietician, Specialist Palliative Care Team; Respiratory Care Team, Podiatry).

The SaLT records at this time dysarthria reducing the movement of Sam's lips and tongue impacting intelligibility something made worse by his fatigue. The neck brace was also mentioned as necessary to aid with jaw closure. The SaLT noted that Sam was working from home and reliant on the telephone to keep in contact with work and with his family and friends. While it was getting increasingly difficult to make himself understood, Sam's main method of communication with his ex-partner and his children was by video call. Sam said he felt isolated. A referral was made for Specialist Augmentative and Alternative Communication (AAC).

Referrals were made by the OT to 'Neater Eater' and an appointment for a joint visit with a representative and a trial period with Mobile Arm Support was arranged. A further referral was made by ASPH for a replacement neck brace as the one Sam had was worn out. Sam met with a Physiotherapist and discussed his home exercise programme and began trialling walking with a walking stick. Sam trialled the Mobile Arm Support and felt it would help his ability to eat and drink independently. Sam was discharged by the Physiotherapist.

A review of Sam's support plan was carried over the telephone at the beginning of March 2021. Sam asked for care to be removed from Sundays as he wanted a lie in and would also have support from family members, otherwise care and support was going well. The provider reported no issues either and Sam's care was marked to be reviewed annually.

When Sam was reviewed at home on 30th March 2021 by a dietician significant weight loss was noted. Sam's normal weight had been around 88 to 95 kilograms. By January 2021 this had fallen to 69 kilograms. Sam had lost a further 2.3 kilograms from January to March 2021. Sam himself reported that the weight loss was caused by a reduced appetite and because eating was 'hard work'.

Sam still spoke of wanting to move to be near his children and said his mental health was up and down, attributing this to fatigue, medication and loss of the ability to do previously basic tasks, such as dressing. Sam was blending food to make it easier to swallow but wanted more textured foods to maintain quality of life. Sam could have Complan as a nutritional supplement but hadn't had this for a few days because he had run out of milk. Undertaking food shopping and making Complan were included in the tasks assigned to carers.

Sam and the dietician discussed Gastrostomy, but Sam remained of the mind that he didn't want this procedure at that time but wouldn't rule it out for the future. Sam was advised to consider this early; at that time Sam said he 'wants to do all he can to stay unchanged' because his independence is important to him. The dietician agreed a plan with Sam for regular meals and Complan. The dietician would then review again after three months (which would be the end of June 2021).

At the beginning of April 2021 an OT reviewed Sam at home. Noted he was self-medicating with CBD oil and reported improvements. Sam was advised to discuss this with his GP and Neurologist. The application for a grant for Mobile Arm Support was still in progress, however Sam was observed to be managing with the help of the package of care. Further contact and updates occurred across April regarding the Mobile Arm Support.

At about the same time a home visit was made by two social care assistants from the Spelthorne Locality Team to confirm the removal of Sunday care as requested the previous month.

21st April 2021 a SaLT visited Sam at home. They reported that Sam felt fatigued but ok to meet. They noted he did not wear his neck brace as it had become too uncomfortable, he instead supported his jaw with his index finger throughout the meeting. Sam said there had been no progress with the move to be nearer his children. The remainder of the visit concerned familiarisation with the AAC device and a discussion about 'voice banking' using technology supplied by the MND Association. A number of telephone contacts by the SaLT to further arrange voice banking then took place.

SaLT visited again a month later (21st May) Sam said he did not wish to pursue voice banking. Sam said he had low mood and lacked motivation because even daily tasks had now become daunting and exhausting. Sam said he was living in physical pain and feeling isolated. The SaLT accepted Sam's choice not to voice bank and said that there were alternatives that could construct a voice, or he could come back to banking later. Sam said that he wasn't feeling pressurised to voice bank it just 'was not his priority at the moment'. The SaLT recorded Sam as saying he is 'receiving lots of support but not the support he wants.' Sam wanted to move close to his family and would think about voice banking after that. Sam was not interested in social/support groups as it was hard to connect with new people and he was getting some visits from his neighbours, friends and family.

SaLT visited again two weeks later. Sam isn't using his AAC device but feels he is managing well and enjoying visits from his family. Sam reported that he would be moving to be near his children in a few weeks to stay in a friends flat while he awaited a social housing offer. The SaLT recorded that Sam was eating foods with a high risk of choking, he has to hold his jaw shut to swallow. This was discussed with the SaLT and Sam indicated he understood the risks but ‘wants to have a quality of life’. Sam’s weight loss was continuing, Gastrostomy was again discussed but Sam said he didn’t want to make unnecessary choices. Sam was no longer using his neck brace because it was too uncomfortable. When he was not eating, he was using a chin strap to support his jaw. Notes from this visit were shared with Sam’s GP and with the Multi-disciplinary Team (MDT)

14th June 2021 notes are produced from an MDT meeting with contributions from the Dietician, SaLT and Specialist Palliative Care Nurse. It is noted that Sam’s prognosis is likely to be a few years. That Sam is choosing to ‘risk feed’ for quality of life and has decided not to continue with voice banking. Sam has declined Gastrostomy at present. That the Specialist Palliative Care Nurse should begin discussing Advanced Care Planning (ACP) with Sam.

On 24th June Sam had a visit from an Occupational Therapist. They record that Sam has stopped his commissioned package of care and has a friend, ex-partner(Y) staying with him and helping with care duties. Sam feels he has put on weight and has enough mobility in his hand that he is only occasionally using the mobile arm support. Sam is still using the chin strap that a friend provided and has stopped using the worn-out collar. Throughout the meeting Sam supported his jaw with his finger. Sam is still intending to move to his friends flat near his children. The OT’s conclusion was that with the support of this ex-partner (Y) Sam was managing at home. Sam was discharged from OT services.

On the same day the Care Provider AlpenBest Care (ABC) contacted Spelthorne Locality Team to report an incident from three days earlier. Sam’s carer had arrived, and Sam was delayed in opening the door for them. The delay prompted ABC to switch Sam’s carer. When Sam opened the door, he was unhappy because he didn’t know this second carer and became angry. Sam then declined any care from ABC saying he could be supported ‘at the moment’ by his ex-partner who confirmed the same. Sam’s ex-partner indicated she would contact Spelthorne Locality Team to review the care as Sam’s condition was deteriorating. Sam cancelled all care calls from that point on and this was communicated by ABC to the Spelthorne Team.

Four days later Spelthorne Locality Team allocated a social worker. Sam’s other ex-partner contacted the allocated worker on that day to raise concerns at the cancellation of care and suggested a Direct Payment may suit Sam’s needs better. The allocated worker then followed up with a phone call to Sam who confirmed he did not need commissioned care at that time as his ex-partner was staying with him. The worker obtained some advice from Housing about timescales for social housing and emailed the advice to the ex-partner who had made the call.

On 30th June the dietician visited Sam again and recorded weight as 59.5 kilograms a loss of around 8 kilograms over the quarter, compared to 2.3 kilograms lost the previous quarter. A total loss of 10.4 kilograms (15.1%) weight loss in six months. Sam was presenting as happier and more motivated with his ex-partner staying and cooking his meals. Gastrostomy was discussed again and Sam indicated he did not want this procedure unless incapable of oral nutrition. Sam was encouraged to maintain his regime of regular meals. The supplemental Complan was discontinued in favour of Fortisip compact nutritional drinks. The dietician would review again in two months.

On 1st July 2021 Sam's GP phoned him and his ex-partner and consulted with them separately. The GP felt Sam was struggling to make decisions about his future care such as ceilings of care and place of death. GP felt advanced care planning is needed and contacted Sam's Specialist Palliative Care Nurse to request support with helping Sam accept his diagnosis and prognosis, which was understood by the GP to be months. The Specialist Palliative Care Nurse responded by email indicating he was having discussions about a 'ReSPECT' emergency care plan, memory boxes for the children and the need for Sam to update his will.

Sam's allocated Social Worker visited Sam on 5th July 2021 and updated his personal assessment. Sam indicated that he was unhappy with commissioned care and would like a Direct Payment, he welcomed the idea of employing an assistant of his choosing and wanted to employ the ex-partner who was staying with him as a Personal Assistant.

Two weeks later Sam's Social Worker telephoned to inform him he would not be able to employ his ex-partner using a Direct Payment, the reason for this is not recorded. It seems likely this advice was given based on provisions within the Direct Payment Regulations (2014) that place restrictions upon the employment of relatives, albeit with some Local Authority discretion available. It is far from certain that an ex-partner staying with Sam primarily for the purposes of providing care would have met the definition of a 'close relative' to preclude them from the arrangement. It should also be noted the SCC Direct Payments Policy in effect at the time stated, "If it seems likely that employing a close family member living in the same household is necessary, this must be agreed by a Team Manager and discussed at Consistent Practice Meetings (CPMs)." There is no record of such an escalation occurring. Sam was upset at the advice he had been given by his Social Worker and said he didn't want a Direct Payment. Sam was asked if he wished to accept commissioned care again, Sam declined and ended the call. After discussion between the Social Worker and their line manager, Sam was assumed to be making an unwise decision with mental capacity. The follow-up plan was to provide Sam further advice about how he could employ another personal assistant. Sam's Social Worker contacted Sam's ex-partner (X) to enlist help in encouraging Sam to accept a Direct Payment. Ex-partner (X) confirmed at that time Sam's other Ex-partner (Y) had returned home and could no longer support Sam and he was being supported by a neighbour instead. Sam was willing to consider a Direct Payment.

6th August 2021 Sam's dietician contacted him to arrange a home visit. Sam replied by email declining the home visit and said he wanted to reduce home visits as he feels this will be productive for him. Sam's Dietician responded with an open offer to visit on request, but otherwise planned to contact again in two months to offer input.

25th August Sam's Social Worker visited Sam at home to discuss Direct Payments and agreed an offer of 16 hours support per week. On the same day Sam's OT and SaLT telephoned him. Sam confirmed his ex-partner (Y) was no longer staying and he was being supported by a neighbour. Sam was still hoping to move nearer his children.

Sam was not really using the AAC device but felt his speech and swallowing were unchanged. The SaLT noted Sam was less intelligible than in previous contacts with an estimate that 40% of his communication could be understood. Sam had not given any more thought to Speech Banking or Gastrostomy. The SaLT agreed a plan to contact Sam for a further review in two months' time.

Sam was discharged from CSH service for Physiotherapy and Speech and Language Therapy at this point.

On 9th September a further MDT meeting was held. It was noted that Sam was turning away health professionals as he found them morbid. The following disengagement was recorded:

- Sam's refusal of the dietetic review in the face of significant weight loss.
- Sam not wanting to discuss advanced care planning with his neurologist.
- Sam cancelling his carers because they were unhelpful.

An action was recorded that Sam's GP would be asked to discuss with Sam the consequences of declining interventions. A few days later Sam's GP received notification from ASPH that Sam did not attend a respiratory appointment, there had been no further contact. Sam was discharged from the respiratory team and his GP should re-refer if needed. Six days later Sam's GP received a further notification from ASPH that Sam had now missed a neurology appointment. Notification of a 2nd missed neurology appointment came a month later. Further appointments continued to be offered by the Neurology team.

At the end of September, the Consultant Neurologist and Specialist Palliative Care Nurse had a video call with Sam. They discussed the slow progression of his disease, and the prognosis was in terms of "years rather than months." Sam's continuing weight loss was discussed. At this point there was a change in Sam's view, and he agreed to a Gastrostomy. This was based on new information to him that despite this procedure he would still be able to 'risk eat and drink'. The GP made the referral that evening.

By the middle of October Sam had been made redundant from his job. Sam's social worker referred him for financial assessment. SCC assessment team provided him with information and contact numbers to claim benefits. Sam's Direct Payment had been agreed a month earlier and his Social Worker contacted Surrey Independent Living Council (SILC) to enquire on progress finding suitable candidates to become Sam's personal assistant. At this time the market place was depressed and there had been no response to the advert. SILC were unable to give a timeframe for recruitment. It should be noted that Sam had been without a formal care arrangement since 21st June 2021, a period of four months. Sam's ex-partner (Y) had been unable to provide in person support beyond the end of July. Sam had been relying on informal support from his neighbour and visiting family for a period of three months.

Sam's Specialist Palliative Care Nurse contacted Sam's GP and Dietician on 25th October 2021 to notify that he had visited Sam at home:

- Sam had lost further weight.
- The appointment for Gastrostomy was 16th November 2021.

- Sam had run out of Fortisip drinks and needed a new prescription. Although Sam was noted as having limited movement and may find it challenging to lift them to his mouth.
- Sam has no regular carers (through choice) and is relying on neighbours and family.

The nurse then contacted his social worker on the same day to raise the following issues:

- Sam needed OTs to provide a replacement neck collar (Aspen Vista type).
- Sam needed specialist crockery and cutlery.
- To give an update on the informal care arrangement with a neighbour and a feeling that a formal care arrangement was now needed.
- Sam had continued to lose weight, but had now agreed to a Gastrostomy, scheduled three weeks later (16th November 2021).

The nurse also updated Speech and Language Therapy of both of these contacts.

The nurse received a response from a social care assistant redirecting him to the Community Reablement Team (CRT) for equipment. The Social Worker then contacted the nurse and advised Sam had not wanted commissioned care and a Direct Payment arrangement was in place instead and Sam had the mental capacity to make that decision.

Sam's SaLT learning of his increasing difficulty followed up the referral for assistive technology made in April 2021 and discovered the referral had been closed in May 2021 because Sam had declined equipment at that time. The SaLT arranged a home visit to Sam for 2nd November 2021 to review swallowing, communication and assistive technology needs.

The Specialist Palliative Care Nurse visited Sam on 1st November 2021. Sam was dehydrated and the nurse felt emergency admission to hospital was needed for fluids and Gastrostomy. Sam declined admission that day saying he would go the following day. The nurse assessed Sam as having the capacity to make this decision. A plan was made for Sam to present at A & E the following day with contingency plans for if he should deteriorate in the meantime. These plans shared with his neighbour and a visiting friend of Sam's.

As planned the SaLT visited Sam early the following day. They noted that Sam was 'significantly emaciated' and unkempt. The Fortisip nutritional drinks that had been delivered by the pharmacy were seen on the living room floor. The property was in a 'significant state of disorder'. This included a number of bowls of food on the floor that were uneaten and signs that Sam had been sleeping on of the sofa. Sam's ex-partner (X) was present at the visit and later supplied pictures of the property to SCC.

The SaLT remained with Sam while he had a Fortisip drink and observed the difficulties Sam had with raising the drink to his mouth, with swallowing; and with retaining the liquid in his mouth after drinking. The SaLT offered Sam assistance, but he declined and said he wanted the SaLT to leave so he could be alone.

As planned, Sam was admitted to ASPH later that day, his friend having called an ambulance to take Sam to Accident and Emergency.

The following day the SaLT sought advice from CSH safeguarding team as to whether a safeguarding concern should be raised. The SaLT was advised to raise an internal incident report and contact the Spelthorne Locality Team, which they did. In the communications that followed there was some discussion between the SaLT, the Specialist Palliative Care Nurse and Sam's Social Worker regarding self-neglect. The Nurse's recorded view was that Sam had mental capacity and had chosen to self-neglect and the Multi-Agency Safeguarding Hub would not be able to respond. Sam's Social Worker expressed a similar view. While they were fully aware of concerns surrounding 'self-neglect', it was Sam's wish to remain independent and the Social Worker was unsure what other support could be offered if Sam did not accept services. It appears a safeguarding concern was not raised at this point and future actions were to be considered after discharge.

Sadly, Sam remained at ASPH 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.

The period of time from Sam's significant meeting with his Consultant Neurologist in August 2020 to his death in November 2021 is fifteen months. The view from both Neurologists was that Sam's variant of MND would progress slowly and the prognosis even a few months before his death was that he had years rather than months left. After Sam's diagnosis emerged at the start of 2021 there was a period of intense activity from all agencies lasting some six months. In the latter half of 2021 contacts became less frequent and Sam began to disengage from the support offered. In the last five months of his life Sam lived alone and had no formal care package of care. Sam's rapid weight loss, difficulty eating, and problems supporting his jaw were evident to all professionals who visited him across 2021. There is no record of Sam obtaining a replacement neck brace. Sam never achieved his primary aim to move closer to his children.

7. Findings

Coordination of Person-Centred Support

The most impactful statement regarding the support and care received by Sam is recorded in his own comments to the SaLT in mid-2021. After a period of intense activity with multiple practitioner visits and contacts Sam summarised it this way, "I have had lots of support but not the support I want".

From the earliest contact there is a pattern of divergence between Sam's view of his situation and that of the professionals around him.

The frequency with which professionals encounter medical and social care needs means they can be incredibly familiar with them. For Sam this was a new experience, one with which he was unfamiliar. Even with a background of working in social care, it is unlikely Sam understood the options available to him, the nature of treatments, the risks, likely outcomes, and the options for funding care. These things are every day for the professional, they were all relatively new concepts for Sam to relate to his own circumstances.

An illustration of this can be seen in Sam’s first contact with Adult Social Care. The information provided to Sam suggested that care and support is for those who ‘cannot manage’ personal care and activities of daily living. In Sam’s own assessment, he might be struggling, but ultimately, he was managing and so he discounted support at that time. The practitioner who regularly deals with offers of support focuses on the transactional part of the conversation and hears ‘I don’t want support at this time’. The emphasis that has been placed by agencies on individual practitioners to respect person-centredness and personal-autonomy may also be a factor here, creating a reluctance to push back to individuals.

Professional curiosity at the simplest means taking a pause for thought, to listen and see beyond the presenting words. A referral had been made by Sam’s ex-partner (X) indicating he had a health condition and was struggling, Sam himself said he was struggling. These words should have been given equal weight and a simple push-back to Sam was needed. It is likely that a s9 Care Act assessment should have been offered and undertaken at that point, affording more time for Sam to grow accustomed to talking and thinking about his care needs.

Interactions such as this can undermine a sense of co-production, setting independence and the receipt of care and support as opposing forces at an early stage i.e. you will only need care and support when you can no longer be independent.

This kind of oppositional thinking was certainly evident in Sam’s interactions in the following year. The gap widened between the priorities Sam had for himself (relocation, spending time with family and having familiar people around him) and the priorities of professionals (mobility, nutritional needs, voice banking, advance care planning). Eventually Sam appeared to find the interventions of practitioners invasive and fruitless. From a practitioner viewpoint, Sam was entrenched in resisting care and support and was making unwise decisions which simply needed to be respected.

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.

It should be recognised at this point the failure to carry out a s9 assessment does not just indicate a lack of professional curiosity but more importantly indicates a poor understanding of the legal duty to assess needs. Sam should not have been presented with an offer of help for ‘those who cannot manage’, he should have been offered an assessment to determine his needs. What Sam declined at that stage was an offer of care and support. This does not amount to a refusal to be assessed for need. Furthermore, the potential questions around Sam’s mental capacity and emerging signs he was at risk of self-neglect would mean the duty to assess remained regardless of any refusal, see s11 Care Act (2014).

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.

With the benefit of hindsight and a global view of professional communications it is easy to reconstruct a holistic view of Sam’s situation and struggles and likely outcomes. It is too simplistic to ask the question ‘why did nobody see this?’ The challenge for agencies is how to place themselves in a position of foresight and gain a coordinated person-centred view. There is no doubt that a s9 assessment carried out by Adult Social Care and a fulfilment of the welfare duty and duty for cooperation between agencies should have gone a long way to achieving this.

Hearing and recording Sam’s words appears to have been done very effectively and practitioners have been diligent in recording their concerns and Sam’s concerns. It is unlikely that the Dietician, SaLT, Physiotherapist, OT, Specialist Palliative Care Nurse, Neurologists and GP; diligent as they were in their recording, could identify a complete picture.

The multi-disciplinary meeting seems to have been convened for this purpose and had the means to establish and respond to a complete picture were it not for two significant omissions. Adult Social Care were not represented meaning the focus was largely on therapeutic services and social care considerations were largely absent. Sam’s own views were not adequately represented at this forum. His actions in declining different forms of support were noted in the characteristic vein of ‘unwise decisions’ and risk-taking behaviour. In a person-centred approach it is not sufficient for a person simply to be central to the discussion, they must be central in the dialogue and decision making. Sam had stated many times that the most important thing to him was to be close to his children and to be able to communicate effectively with them. Sam was not averse to receiving support, he was just not receiving the support that was most important to him. Had his voice been heard here, it is possible he would have been more amenable to addressing what he saw as secondary support needs. It is also possible that he would not have become disenchanted with services and practitioners. Sam’s characterisation of practitioners as ‘too morbid’ shows the growing propensity to think about what Sam would want and need at the very end of his life, rather than what he wanted and needed today. This mismatch went undetected.

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)

Section 2 of the Act states that “*a person lacks capacity in relation to a matter if at the material time he is unable to make a decision for himself in relation to the matter because of an impairment of, or a disturbance in the functioning of, the mind or brain*.”

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

Early discussion between the Consultant Neurologist and Sam's GP identified that a characteristic feature of MND is an impact upon the frontal lobe of the brain. This has an impact upon executive function. It was identified that this could account for some difficulty Sam was having in making decisions about his treatment, care and support.

Practitioners seemed largely unaware that MND, even though it is a neurological condition would constitute an impairment or disturbance of the mind or brain.

There is common acceptance following the judgement in PC & NC v City of York Council [2013] EWCA Civ 478, that assessment of mental capacity should begin with a question of whether a person is unable to make a particular decision and then proceed to a question of the impairment.

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.

The Coroner's finding that Sam had not been subject to neglect rested in part on the determination that there was no evidence of a lack of capacity. In the absence of such evidence a coroner has no choice but to assume capacity. It may be that a failure to collect such evidence led to this inevitable outcome.

This is a very serious point. In this report I have until now placed 'self-neglect' in quotation marks. This is because it is the term that has been used by practitioners when referring to Sam's decisions to decline support.

Whether this is an accurate description hinges upon whether Sam lacked capacity. If Sam lacked the mental capacity to decide and execute actions to safeguard himself, then it would be appropriate to refer to the lack of safeguards simply as 'neglect' and not 'self-neglect' as Sam cannot be held solely responsible for it.

Irrespective of the outcome of any determination of mental capacity, the indicators were that Sam was not fully identifying his level of need and was disengaging from the support available. The safeguarding duties pertaining to any kind of neglect, including self-neglect are clear with section 42 of the Care Act (2014) and the related guidance. These duties are not contingent upon mental capacity, but a determination of capacity may have a significant impact upon them. The absence of a safeguarding response under section 42 will be explored as a separate finding.

That a mental capacity assessment should have been undertaken is almost beyond question in the circumstances. As it did not occur, or occurred but was not recorded, it is difficult to comment on the approaches to such an assessment. However, it's worth noting the previous finding where holistic professional curiosity rather than transactional approaches are encouraged. The same approach would have needed to be applied to the capacity assessment, considering the whole raft of presenting evidence as to whether Sam was able to weigh and use information and not merely Sam's polite refusals.

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.

Sam's disengagement from services is a recurring theme. In the context of someone struggling with their executive function, the volume of practitioner contact, and communication could easily be (and likely was) overwhelming and unmanageable.

I will turn to this now.

Communications

The confirmed diagnosis of MND appeared to act as a trigger for a number of services. It is clear Sam would be in need of support from all of these services and the speed in which they responded should be commended. The communications and referrals within health services appeared to flow well and Sam soon began to receive contact from a variety of different professionals.

Across the first four months of 2021 the activity recorded in the various chronologies can only be described as intense. As a reviewer I sometimes found myself breathless reading of the number of letters, emails, texts, phone calls and visits that were involved.

Place this in the context of a man who has just received a terminal diagnosis that he is struggling to come to terms with. A diagnosis that could have an impact upon 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.

There is also the added dimension, as has been previously noted, that much of this communication addressed areas of support that were not Sam's primary concern at that time.

It was noted in Sam's GP record that a reasonable adjustment was needed, and Sam was finding it increasingly hard to hold a mobile phone. Despite this, Sam carried on receiving important communications by text for many months.

Against this backdrop it is unsurprising, was perhaps even guaranteed that Sam would disengage from at least some of the communication. There is a repeated pattern of missed telephone conversations, emails and texts not responded to and missed appointments. The standard response to these often appeared to be a closure of a referral with a request for re-referral where necessary.

Much of this communication was directed to Sam's GP and it raises the question as to whether it were possible for the GP to identify repeat patterns of missed appointments and communications. Where communication needs, disengagement and possible self-neglect had been identified, it would seem prudent to have a regular review of the patient’s notes for a view across time. It is not clear that this happened.

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.

It is undoubtedly the case that any kind of planning is improved if it is done at an early stage. In Sam’s case some of this momentum for early planning was clashing with his needs and feeling in the moment. This is illustrated by Sam’s approach to voice banking. Where it had been recorded that Sam declined voice banking this suggested a refusal by someone who doesn’t wish support. Sam’s actual view was more nuanced, “I will be able to think about voice banking after I have moved.”

The finding is something of a paradox, in that the pressure to make so many decisions and have so much support in a short space of time, drove Sam’s increasing disengagement from services and ultimately shortened the time he had available to put plans in place. Sam’s death was untimely given his prognosis; he died without a robust advance care plan; he did not achieve the aims that would have assured him a good quality of life to the end and allow him to die peacefully. Sam ran out of time for the organisation of an orderly death with preparations for the provision for his family.

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 discussions between the SaLT, CSH Safeguarding team, the Specialist Palliative Care Nurse and Adult Social Care regarding a referral for self-neglect or neglect, reveal a level of confusion for practitioners in this area.

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.

Given these criteria it should be evident that not all apparent self-neglect will lead to a section 42 enquiry. It is possible for an adult without care and support needs who is very capable of attending to their personal welfare to engage in self-neglectful behaviour. This is perhaps true self-neglect, because the locus of the decision making is with the individual.

On the other hand, the argument that someone does not meet the criteria for enquiry because neglecting themselves is their choice would be self-defeating and remove self-neglect from safeguarding enquiries completely.

This appears to have been the thought process employed in Sam's instance, i.e. that because his capacity was assumed, disengagement was a choice and warranted no further enquiry.

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. Current practice in Surrey is that SCC will determine if this criteria has been met. Other agencies only need consider if the first two criteria have been met.

The criteria for making a safeguarding referral, although based on section 42 is probably in practice a little lower than the criteria for enquiry, on the basis, 'if in doubt, refer'.

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 concern to be raised by any practitioner. This particularly true of those working closely with Sam and able to see the absence of care and support and the impact of it.

It is likely the section 42 criteria were met, and an enquiry ought to have followed.

A multi-disciplinary approach including both Health and Social Care representatives could have identified some 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. Communications were marginally increased with the need for pre-screening calls before a home visit. COVID19 also increased Sam's sense of isolation and had a negative impact on his mental health. On the whole it is unlikely the outcomes for Sam would have been different if COVID19 were removed from the equation, the other findings have much more bearing.

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. Undoubtedly the 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.

It is evident thought should have been given as to Sam's care and support needs in the interim period. Agreeing to have a direct payment is not the same as having the arrangements under the DP in place. Any practitioner agreeing a Direct Payment should give some thought to the logistical care questions that follow and the likely time it will take for the DP to be fully operative.

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 (Y) as an assistant.

It has already been noted that the practitioner advice around this was not contained in the notes seen by the reviewer. However, it is not clear to me how an ex-partner is necessarily included in the exclusion list in paragraph (3) of regulation 3 of the Care and Support (Direct Paments) Regulations 2014. Likewise, paragraph (2) allows a local authority discretion:

(2) Except that, if the local authority considers it is necessary to do so, direct payments may be used to pay a person mentioned in paragraph (3)—

(a)to meet the care needs of the adult; or

(b)to provide administrative and management support or services for the purpose of enabling a person to whom the direct payments are made to—

(i)comply with legal obligations arising from the making of and use of the direct payment, or

(ii)monitor the receipt and expenditure of the direct payment.

Given that Sam and his ex-partner (Y) had clearly not been together for some time, that the current arrangement was for the purpose of providing support and would necessarily come to an end if there were no remuneration; the local authority could have explored its discretionary powers further. Escalation by the Social Worker to a Team Manager under the Direct Payments Policy should have occurred. Sam had visibly improved with this care and the alternative was an absence of formal care for over four months. There is no record of any further consideration being given under the policy.

8. Recommendations and Questions for the Board and Agencies

1. Following an initial diagnosis Sam received a high level of support from a range of practitioners. That support was appropriate and reflective of the NICE guidance on assessment and management of Motor Neurone Disease. Although the support given was valuable to Sam, in his own words it was ‘not the support I want’. The support Sam wanted was to keep him connected to his family and enable the full enjoyment of his remaining life. The coordination of Sam’s support by means of a multi-agency team meeting lacked representation by Adult Social Care. As a result, there was a focus upon Sam’s clinical needs. Many of Sam’s social needs, while regularly acknowledged, were left to Sam to address himself.

   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?

2. Specialist input to the review highlighted some common responses by individuals to a diagnosis of MND. The desire to prioritise living rather than focussing upon end of life was a key theme. This is reflective of Sam’s experience and his characterisation of professionals as ‘too morbid’. Support from a professional with a good understanding of both the clinical and personal journey of individuals with MND can enable an improved self-management of the disease and its effects. Such support includes explanations of treatment options available; the setting of realistic expectations; helping with preparation for the future, symptom management and how to achieve a good quality of life. Specialist MND support was not available to Sam, and this was reflected in his gradual disengagement from and disenchantment with the support offered.

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

   Action already taken prior to the review:
   Woking and Sam Beare Hospice have confirmed the establishment of a MND Link Nurse within the Hospice with an associated MND caseload. Multi-agency meetings in respect of MND have improved links with specialist MND practitioners for neighbouring areas giving greater coverage. The introduction of an electronic patient record (EMIS) with sharing agreements in place has improved collaboration and communication between Central Surrey Health and the Hospice at practitioner level.

3. The review learned that Frontotemporal Dementia (FTD), while not present in every individual with a diagnosis of MND, is likely to factor in around 50% of cases. In Sam’s case it was identified and recorded very early that this could be a contributing factor to his difficulty with decision making and executive

function. Despite this, no clear assessment of mental capacity was recorded by any practitioner. Sam displayed a pattern of behaviour in which appointments were being missed, available treatments were declined, social care cancelled, and assistive technology returned. When Sam appeared regularly to be making choices that could be detrimental to his own care and disease management. In addition, there was recognition and record by professionals of Sam's declining mental health and increasing depression. This appears to have been understood as a conditioned response to his disease rather than a symptom indicating the progression of FTD.

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?

4. The progression of MND in those types affecting the face and speech are going to have an increasing impact on the ability to communicate verbally. In addition to this, modern communication methods rely heavily upon the use of smart phones, telephones and email, all of which can become increasingly difficult for a person with MND. This may not be a significant limiting factor for people who live alongside others and who have regular daily support. In Sam's circumstances, living alone and receiving a high volume of communications there are indicators that this became too difficult and overwhelming such that disengagement was employed as a coping mechanism. How much this was impacted by FTD and the difficulties with executive function is not known.

   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?

5. The three criteria outlined in Section 42 of the Care Act (2014) were likely to have been met four to six months before Sam's eventual admission to hospital. Sam had care and support needs, these were well known and documented but not formally assessed under the Care Act (2014). Sam was at risk of self-neglect or neglect, indicated by the fact that he lived alone, began to decline care and treatment offers at a low level, culminating in the cancellation of care. Sam was known to be living without any formal care arrangements for several months and had experienced significant weight loss. Sam was known to have MND with a decreasing physical ability to meet his own care needs. Had it been recognised or assessed he may also have lacked capacity and executive function to organise the care and support he needed. Although the three criteria for further enquiry were very likely to have been met, and Sam was in contact with a considerable number of practitioners, no safeguarding referral has been recorded in individual agencies or with the multi-agency safeguarding hub.

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?

Action already taken prior to the review:
Since April 2022, Woking and Sam Beare Hospice have undertaken joint caseload reviews between Clinical Nurse Specialists and Palliative Care Doctors. These are undertaken monthly or more frequently if required and are documented clearly in the medical record. For patients with greater complexity more frequent (two weekly) formal reviews are undertaken and documented.

Surrey County Council (Adult Social Care) have indicated an intention to review the ‘levels of need’ documentation giving guidance in this area.

6. Within this review there have been several instances where a greater understanding of MND by professionals may have improved the responses, care and treatment Sam received. A better understanding of Sam’s limitations arising from his condition and an appreciation of the timescales relating to that condition, may have prompted improved and more timely responses. For example, a more flexible approach could have been sought in terms of a direct payment arrangement; the sudden changes in care delivery that precipitated the cancellation of care could have been avoided; alternative housing could have been more actively pursued on his behalf.

   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?

7. Three S42 enquiries were undertaken after Sam had died. Given that a key purpose of enquiry is to drive immediate action to safeguard the individual, this would not have been relevant at the time the enquiries were undertaken. Other frameworks likely exist for addressing critical incidents and ensuring learning and remedial action. It is important that any enquiry or management review leads to a meaningful action plan. Consideration ought to be given to the whether S42 enquiry is the best use of resource to achieve the outcome.

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

Action already taken prior to the review: Adult Social Care guidance is currently being prepared for issue by July 2024 indicating there is no S42 duty in relation a deceased person.

8. Sam was offered a Direct payment and had a carer who was willing and able to provide care. The arrangement ended and Sam was left without formal or informal care arrangements because he was told he could not have a Direct Payment to employ his ex-partner. Under SCC policy, discretion could have been given to allow and monitor the use of this Direct Payment if the practitioner had escalated to their team manager for consideration.

   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?

9. Glossary

A2D Housing	A2D Housing
ABC	AlpenBest Care
ASPH	Ashford and St Peter's Hospital
CaSSG (2014)	Care and Support Statutory Guidance – Care Act (2014)
CRT	Community Reablement Team
CSH	Central Surrey Health
GP	General Practitioner
MND	Motor Neuron Disease
SABP	Surrey and Borders Partnership NHS Foundation Trust
SAR	Safeguarding Adults Review
SCC	Surrey County Council
SH-ICB	Surrey Heartlands Integrated Care Board
SILC	Surrey Independent Living Council
SSAB	Surrey Safeguarding Adults Board
WSBH	Woking and Sam Beare Hospice
TIA	Transient ischaemic attack or 'mini stroke'

10. Appendix A: Terms of Reference

The purpose of the Review is to establish whether there are lessons to be learnt from the circumstances of the case about the way in which relevant professionals and agencies have or are working together to safeguard adults at risk to inform inter agency and multi-agency practices as they relate to safeguarding adults at risk. The Terms of Reference will include:

1. The review is in respect of Sam, who **died on 13th November 2021** aged 60.

2. Sam's circumstances were first notified to Surrey County Council (Adult Social Care) in August 2020. Sam's primary contact with agencies prior to this had been through health professionals in the early stages of his illness. Sam had a rare form of Motor Neurone Disease (MND) which led to his death a little over a year after his first contact with Adult Social Care. Across this period Sam experienced a worsening in his upper body movement including severe head drop prompting the use of a collar. Sam consequently had difficulty eating and difficulty speaking. There was a significant period in the months before his death when Sam had no formal care and support in place. At the time of his death Sam was malnourished and this was a combined cause of death with bronchial pneumonia and the effects of MND. Safeguarding enquires made by three agencies concluded that Sam had experienced neglect and/or organisational abuse.

3. The Safeguarding Adult Review will include the specific areas listed below. In addition, the review will address any other areas that the reviewers believe have the potential to contribute to the stated purpose:
    - The impact of a deterioration in Sam's physical health upon his mental health and wellbeing and other matters or events that may have contributed.
    - The actions taken in respect of care and support needs following Section 9 Care Act (2014) assessment, including the operation of the Direct Payments Scheme.
    - Continuity of care provided by agencies as a whole and individuals within those agencies, including systematic safeguarding responses where an assault may have occurred.
    - Communication and contact with Sam and his family alongside professional assumptions and the opportunities to apply further professional curiosity.
    - The experience of Sam's family and their views in relation to his care.
    - The balance between the welfare duty of agencies and the personal wishes of Sam in providing person-centred care.
    - What actions were taken with respect to the Mental Capacity Act (2005).
    - What other assessments and approaches to assessment were used or considered, including Carer's assessment.
    - Whether there was sufficient understanding of Motor Neurone Disease in its different forms and the impact this may have had upon Sam's care. Views will be sought from a relevant expert in this field to support the review.

- The impact that the Covid19 pandemic may have had upon the care provided to Sam.

4. The Safeguarding Adult Review will initially consider the period from **17th August 2020** (the point of first contact with Adult Social Care) up until Sam's death on **13th November 2021** a period of **one Year and 88 days**. An earlier period may be considered should interim review findings suggest this is appropriate.

5. Three Section 42 Care Act (2014) enquiry reports have been produced by the Local Authority. These reports will form the basis for this review. Given the elapsed time since Sam's death and the intervening Coroner's inquest, contact with individual members of agencies may be limited. The three enquiry reports contain significant chronological data. Additional chronologies will be requested. For the purposes of the review a summary chronology will be produced by the lead reviewers and any inconsistencies clarified or noted. A complaint response relating to home care provision will also be reviewed.
   - Section 42 Report (19th May 2022) - Ashford and St Peter's Hospital
   - Section 42 Report (6th October 2022) - Woking and Sam Beare Hospices
   - Section 42 Report (6th October 2022) – Surrey Adult Social Care
   - St George's UHFT – Chronology
   - Surrey Heartlands Integrated Care Board – General Practice Chronology
   - Central Surrey Health – Chronology
   - A2Dominion Housing Association – Complaint Response

6. The following agencies will be represented in the Safeguarding Adult Review Panel:
   - 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

7. There are no advocacy requirements or duties currently identified for this review. Independent representation from Sam's family members meets the standard set out in Section 68 (4) of the Care Act (2014)

8. Sam's family members will be offered the opportunity to speak with the lead reviewers if they so wish. When planning any learning events, consideration will be given by the panel as to whether Sam's family wish to be and could be involved where appropriate. Any involvement must be clearly indicated to participants ahead of the event.

9. The circumstances surrounding Sam's death have been referred to the coroner and examined at inquest. The Coroner's verdict is that Sam did not die as a result of abuse or neglect. The Coroner noted concerns regarding missed opportunities for agencies to work together. Reference will be made to the Coroner's investigation in this review. Consideration will be given as to whether the definition of abuse and neglect applied by the Coroner's Court differs from that applied by Section 42 of the Care Act (2014). There are no other investigations outstanding.

10. The Safeguarding Adult Review will commence on 30th November 2023 and is anticipated to take four to five months but will be completed no later than 31st May 2024.