WOLVERHAMPTON SAFEGUARDING BOARD

SAFEGUARDING ADULTS REVIEW

EDITH

Died 2018 – 80 years of age

OVERVIEW REPORT

AUGUST 2019

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1. THE REVIEW PROCESS

Circumstances leading to the Review

1.1 This Safeguarding Adults Review (SAR) [1] was commissioned following the death of Edith in July 2018 who was 80 years of age. She had been admitted to hospital following a 999 call from the family who reported that Edith was slouched in her wheelchair, and had been hallucinating. Paramedics found her in an unkempt state, with pressure ulcers on her right ankle (Grade 3) and buttock (Grade 4).

1.2 Edith died 5 days later – the cause of death being sepsis, community acquired pneumonia, and frailty of old age. A death certificate was issued by the Coroner and a decision made that an inquest was not required.

1.3 Edith had been living for the previous 8 years with her elderly nephew, Mr A, in his 1 bedroom flat. Safeguarding concerns around possible self neglect and / or neglect had previously been raised a year earlier when she was admitted to hospital. She was discharged home with a high level of home care support, but this was ended at Edith's request in February 2018.

Parallel Processes

1.4 Enquiries carried out by West Midlands Police after Edith's death established that the nephew had been struggling to meet Edith's personal care needs, and no criminal charge was considered because there was no evidence of deliberate harm.

Time Period Covered by the Review

1.5 The Review covered the period from July 2017 to July 2018. This start date was selected because that was when the concerns about possible neglect / self neglect were identified.

Agencies Involved

1.6 The following agencies and services contributed to this Review:-

City of Wolverhampton Council

Royal Wolverhampton NHS Trust
- New Cross Hospital
- District Nursing Service
- Occupational Therapy / Physiotherapy Service
- Tissue Viability Nursing Service
- Dementia Outreach Team

University Hospitals Birmingham NHS Foundation Trust
(Queen Elizabeth Hospital)

Wolverhampton Clinical Commissioning Group (CCG)

West Midlands Police

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[1] *Section 44 of the Care Act 2014 requires a Review to be carried out where "An adult with care and support needs (whether or not those needs are met by the local authority) in the Safeguarding Adult Board's area has died as a result of abuse or neglect, whether known or suspected, and there is concern that partner agencies could have worked together more effectively to protect the adult"*

West Midlands Ambulance Service

Woodford Home Care

Wolverhampton Homes

1.7 A SAR Panel comprising senior representatives of most of the above agencies was independently chaired by Chris Brabbs, who was also the Independent Overview Report Author. Specialist advice was provided by the WSB Board Manager. Practitioners and managers involved in Edith's case participated in 2 learning events with the SAR panel to explore the key issues and identify the learning.

Involvement of Family Members

1.8 Letters were sent to Mr A's 2 daughters, Mrs D and Mrs G, to provide them with information about the SAR process and an invitation to contribute their perspectives. These letters included a request for their advice as to how best to approach their father. This was because the Review Team was mindful of Mr A's age and the importance of avoiding the possibility of distress being caused through a direct approach. There was no response to these letters and it was agreed that a further approach should be made prior to publication in order to try and share the review findings.

2. TIMELINE OF KEY EVENTS

West Midlands Ambulance Service (WMAS) Attendance – July 2017

2.1 WMAS received a 999 call from Mrs D, Edith's great niece, as she had noticed that a wound on Edith's foot and she had a pressure ulcer on her buttock. The history provided was that Edith had been confined to chair or bed for the past 6 weeks, and Mrs D had been trying to support her father Mr A in providing personal care. She claimed to have tried to contact the GP and district nurses during that period but there was no evidence of this in the GP notes.

2.2 Paramedics found Edith lying in bed soaked to her waist in urine. She had a pressure ulcer on her buttock with the bone exposed, and also pressure ulcers between her toes, on her heel, and necrotic tissues [2] on her foot. There was evidence of encrusted dirt and dried faeces on various parts of her body. The paramedics' observation was that the house appeared dirty and cluttered. Edith was transferred to hospital. Safeguarding concerns were submitted to the Multi-Agency Safeguarding Hub (MASH) by both the paramedics (WMAS) and the hospital. The latter referred to Edith's frail and unkempt condition and raised the possibility of self neglect and / or neglect through acts of omission.

Care and treatment in hospital

2.3 Edith remained in hospital for a month during which time all appropriate clinical investigations and treatment were carried out including the involvement of a dietician, occupational therapists, physiotherapists, and tissue viability nurses. The pressure ulcer on her buttock was judged to be more grade 3 than 4 as there was no bone or tendon visible. Dementia screening and a CT scan showed only expected age related degeneration. Throughout the admission, Edith was consistently deemed to have mental capacity to make decisions about her care and treatment, and her decisions to

[2] *Necrotic tissue consists of an accumulation of dead cells, tissue and cellular debris.*

sometimes not engage with the therapists to practice use of the transfer equipment was respected.

Outcome of Safeguarding Concerns

2.4 The outcome of the exploration of the safeguarding concerns by the hospital social worker was that the suspected abuse was not substantiated because Mr A and his family explained that Edith had refused personal care from them.

2.5 A subsequent Care Act assessment established that Edith was eligible for support because she was entirely reliant on others to meet all her personal care and social needs, and transfer to and from her bed. Edith told the social worker when she was on her own, that she did not want the family to care for her but would allow carers to meet her personal care needs. Edith and Mr A accepted the plan for 4 x 30 minutes calls daily. Both the social worker, and a therapist picked up from Edith that she was anxious about Mr A's reaction towards her if he was approached to discuss her future care needs, and that she would be in trouble, and he would shout at her, if he thought she had spoken to them.

Hospital Discharge Planning

2.6 A home visit by an occupational therapist (OT) established that there was a hospital bed already in situ, but arranged for this to be replaced with the appropriate bed and pressure relieving mattress together with a molift [3], wheeled commode, table with wheels and a replacement pressure cushion. Mr A was asked to move the settees to create space for these, and to purchase a suitable chair. The suggestion of a key safe was declined as Mr A preferred to let the home carers in.

Agency involvement after Edith returned home in early August 2017

2.7 District nurses visited Edith immediately following discharge and recorded that Edith was at high risk of potential pressure damage (Waterlow [4] score of 25) and of malnutrition (MUST [5] score of 2). The personalised management plan (PMP) established twice weekly visits and a referral was made to the community dietician. With the benefit of the regular daily care provided by the home carers, the original grade 3 pressure ulcer healed 3 weeks after discharge and the district nurses were able to end their involvement at the end of August 2017.

2.8 However, just 2 weeks later in mid September, the district nurses resumed involvement following a referral from the GP Practice who had been informed by the home carers that Edith had a new pressure ulcer on her right buttock, and had slept in her wheelchair overnight. This was assessed by a Tissue Viability Nurse as grade 3 but healing.

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3 *A molift is a raiser platform is designed to safely move the user from a sitting to standing position*

4 *The Waterlow pressure ulcer risk assessment tool covers seven items: build/weight, height, visual assessment of the skin, sex/age, continence, mobility, and appetite, and special risk factors, divided into tissue malnutrition, neurological deficit, major surgery/trauma, and medication. a score of 10-14 indicates 'at risk': 15-19 high risk: 20+ very high risk*

5 *The Malnutrition Universal Screening Tool (MUST) is a five-step screening tool to identify adults, who are malnourished, at risk of malnutrition or obese. It also includes management guidelines which can be used to develop a care plan.*

2.9 Meanwhile, the home care agency informed the Adult Social Care (ASC) duty worker that Mr A wanted to cancel the home care package of support because he was unable to go out. The home care agency shared their concerns that the home conditions were declining; Edith was always asking for the care to be provided quickly so she could go outside to smoke with her nephew; she was not always using the commode; and dry towels and clothes were not always available. The agency was advised by the allocated ASC assessor to reduce the visits to just the morning and evening call pending a social care review visit the following week.

2.10 The reduction was confirmed at that visit, on the basis that Mr A would provide the day time care including helping Edith to bed for an hour's bed rest as advised by the district nurses. The offer of Telecare was declined partly because of cost and also because the family said that Mr A did not have a landline or mobile telephone. [6] [7]Although Mr A agreed to the offer of a carer's assessment, this was never carried out. The Care and Support Plan was updated with the conclusion that Edith's needs were still being met and the support would be reviewed annually unless her needs changed.

Developments – October to December 2017

2.11 The home care agency informed the district nursing service that the reduction meant they would not be able to turn Edith as frequently as had been recommended. Despite this, the pressure ulcer had healed by mid October a month after treatment commenced.

2.12 However, just 2 weeks later towards the end of October, a further referral was made to the District Nurses after the home carers thought there was a new pressure ulcer, and reported that since the reduction to 2 calls a day Edith was often very wet on arrival for the evening call. On this occasion, no wounds were found.

2.13 After this, there was a three month period when the situation appears to have settled down given that the home carers did not identify any concerns about Edith's care and presentation which they considered needed to be raised with either the GP or Adult Social Care.

Developments – January to February 2018

2.14 In late January 2018, the home carers contacted the GP Practice to chase a referral to the continence team and request a referral be made to the district nurses to check some sore areas they had found. The home carers recorded that this was believed to be due to Edith wearing soiled pads. Edith had asked to have a lower body wash on both calls that day which she had been declining – preferring just a "freshen up" and change of pad. Edith was also complaining of back discomfort and swollen feet which the carers thought was possibly due to her not mobilising enough as she appeared to be in her wheelchair most of the day.

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6 *A phone or internet connection is necessary to connect the base unit to a call centre which monitors the alarm and responds when the alarm within the home is activated*

7 *During the review, the home care agency confirmed that Mr A did have a mobile telephone but their observation during visits was that Mr A did not answer this*.

2.15 The referral was declined by the district nurses until Edith had been assessed by the GP to identify if there were other possible causes for the soreness such as an infection. The nurses also advised the GP receptionist to contact either the out of hours GP service or the Rapid Intervention Team [8] but the latter also declined the referral as the situation did not meet the criteria.

2.16 The home care agency then contacted the continence team direct to ask for a visit to advise Edith on the continence management options, and pointing out that she had not received any continence products from the continence team. The home care agency's concern was that the continence products Mr A was buying may not have been suitable and could be the reason for Edith being found to be wet and experiencing soreness which could increase the risk of pressure ulcers again developing. However, although the agency was informed that this referral would be followed up, the SAR did not receive any evidence that this happened. The agency also informed the ASC duty officer that the district nurses had refused to visit, and shared their concerns about Edith's skin integrity and well-being. There is no record that either the GP or ASC followed up on the referrals made by the home care agency.

2.17 Two weeks later, in early February, Mr A, told the home carers that he wanted Edith's profile bed [9] removed as it was taking up too much space in the lounge and he intended to get Edith a divan bed instead. When advised that the involvement of an occupational therapist would be required in case the equipment to transfer Edith might not fit under a divan, Mr A said that he would be taking it down in 3 days time. The agency then spoke to Mr A's daughter, Mrs D, who said that the profile bed had spoilt Christmas as there was no room for a tree.

2.18 When the risks were explained, Mrs D agreed to ask her father to wait until the OT could provide advice. However, it does not appear that the home care agency informed the ASC Access Team of the bed issue which meant that no referral was made to the OT service for an assessment visit. The bed was collected by the supplier a few days later who recorded "client refused". It does not appear that the supplier made any enquiries with the OT service to check that removal had been agreed with them.

Cancellation of all Home Care Support

2.19 A week later, in mid February, Mrs D rang the home care agency to query the latest bill and stated that it was too much for Edith who was said to have requested that all care stopped immediately, and that the family would provide all the care. The Home Care Deputy Manager expressed her concerns about the added pressure this would bring the family and the possible risks to Edith.

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8 *The Rapid Intervention Team is a team of nurse practitioners from the Royal Wolverhampton Trust who are independent prescribers. They have a limited number of slots each day, to conduct home visits for GPs on a 'first come first served' basis. There are strict criteria on what type of patients can be referred. They will see patients with suspected cellulitis (skin infection), chest infection or urinary tract infection. They don't re-visit; i.e. if a patient has been treated for a condition but not improved, or has deteriorated, then the GP needs to visit these patients.*

9 *an electric care bed used to assist elderly and disabled users with mobility and their carers with nursing with side rails that can be raised and lowered to help prevent falls from the bed.*

2.20 The Deputy Manager informed the Adult Social Care duty officer of her concerns, including that Edith may not have been involved in the decision. She was advised that the family were required to give a week's notice, and the service should continue during that period, pending a review visit by a social care assessor. However, Mrs D did not accept this requirement and refused any further visits being made.

2.21 When the social care assessor visited 2 weeks later at the end of February, it was recorded that Mr A initially tried to prevent her from seeing Edith but relented because of the assessor's persistence. The risks were explained to Edith but she was insistent that she did not want home care support although the assessor's perception was that Edith's responses were prompted by Mr A. The assessor immediately discussed the situation with her manager which resulted in a decision to end the care package and close the case. There is no record that this decision was shared with any other agency other than the home care agency.

2.22 There was no further agency involvement until mid June 2018 when WMAS attended following a report from a neighbour who believed that Edith was unconscious in her wheelchair. However, on attendance, Edith was asleep and upset that an ambulance had been called. She declined all assessments offered.

Re-admission to Hospital July 2018

2.23 In early July, WMAS responded to a 999 call from the family who reported that Edith was slouched in her wheelchair more than usual and had been hallucinating. Paramedics found Edith's trousers were soaked in urine and the bedding was soiled. Mr A said that he could not cope any more and his view was that Edith would benefit from being in a care home. The hospital noted that on admission, Edith appeared very unkempt. She had a grade 3 pressure ulcer on her right ankle and a grade 4 ulcer on her left buttock which were entered on the DATIX system. [10]

2.24 On admission, Edith was noted by hospital staff to be emaciated, dirty and had discharging pressure ulcers. She was transferred to the Assessment Medical Unit (AMU) where she was noted to be alert but lethargic and confused. The following day she was diagnosed as having sepsis. During a dementia screen, Edith expressed her concern about her forgetfulness over recent months. Her oxygen saturation level was 90 per cent but she refused to have oxygen. On the third day the diagnosis was confirmed as sepsis secondary to community acquired pneumonia and infected pressure ulcers. It was agreed that there was a high risk of deterioration and a decision made that Edith was not suitable for escalation and resuscitation would be futile.

2.25 During the first 3 days, there were problems in identifying who was next of kin because the name and contact number in their records was that of the home care deputy manager. The latter was not at work when the hospital first tried to contact her and it took several calls before she was able to provide the hospital with contact details for Mr A and Mrs D.

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10 *Datix is a type of incident reporting software that is used across much of the NHS. It is used to log adverse events, and can be accessed by all employees of the Trust, including those in the community, via the intranet.*

2.26 In a discussion with Mr A and Mrs D, a doctor recorded that Mr A had cancelled the care package because it was not convenient for him as he had to be at home at certain times and he could not get the shopping and washing done. He again stated that he could not cope any longer. Mr A and Mrs D informed the doctor that Edith's brother was the next of kin, and explained that they could not participate in end of life decisions, or visit due to their own disabilities.

2.27 On the day Edith died, the hospital made 4 unsuccessful attempts to ring Mrs D to ask if the family wanted to visit. When contact was eventually made, the hospital recorded that the previous explanations were given that they were unable to visit because of their circumstances and disabilities. The home care deputy manager received a text message from Mrs G, Mr A's other daughter, saying that they were pre-occupied dealing with her mother's cancer. Edith died later that day.

3. KEY FINDINGS AND LEARNING

3.1 The Review findings and learning cover the following themes:-

- gathering accurate information relating to home circumstances, informal carers, and GP;
- hospital discharge arrangements;
- primary care services engagement following hospital discharge;
- processes for responding to safeguarding concerns raised around self neglect;
- assessments including assessment of risk of self neglect / unintentional neglect / possible domestic abuse
- safeguarding considerations when services are declined;
- working with hard to engage service users;
- assessment of mental capacity where this may be being impaired by coercion or controlling behaviour;
- arrangements for escalation of concerns in high risk cases.

4. INFORMATION ABOUT EDITH

4.1 The starting point of the SAR findings is to provide a brief profile of Edith, her home circumstances and lifestyle so that the SAR maintains a focus on her situation, needs and experiences.

4.2 The July 2017 ASC assessment established that Edith had lived in the local area all her life. She was a widow and did not have any children. Prior to her retirement she worked at a social club issuing entrance tickets.

4.3 Edith had a long history of back pain caused by cord compression, which caused her to stoop, and severe arthritis in her hands affecting her grip. When her mobility and dexterity deteriorated, Edith asked Mr A if she could move in with him to avoid having to go into residential care.

4.4 Edith had very little independence and was reliant on others to meet all her personal care and support including transfer in and out of bed, dressing, washing, pad changes, oral care, grooming and meals. Edith used a wheelchair that required somebody to push her. She also had hearing difficulties due to a perforated left ear drum and classed herself as deaf. She chose not to wear a hearing aid but was able to communicate without assistance.

4.5 Edith enjoyed being out of the flat whenever possible, and would often be found sitting outside with Mr A having a cigarette. The home carers commented that in a morning she was always wanting to get the care over and done with as quickly as possible so she could be taken outside. She and Mr A enjoyed their daily trips to the nearby shops and cafes with visits to charity shops being a regular port of call as Edith liked shopping for clothes, handbags and jewellery, Mr A was said to take great care in making sure Edith was nicely dressed. The clothes buying was partly to cut down on laundry which was proving a challenge because of the limited space in the flat. Later they acquired a tumble drier to make this easier.

4.6 Most of the above factual information comes from the ASC assessment carried out in July 2017. It is a concern that the GP records, which are very brief, do not give an impression of Edith as a person, her home and family circumstances, or how she managed with everyday life, other than she needed a wheelchair to come to appointments. There is also no mention of her mental health or general demeanour. It appears that on the occasions she was seen, little attempt was made to establish more information about her circumstances, the reasons for the conditions she presented with or the occasions she did not re-attend as advised.

4.7 None of the agency records, including the hospital records provide any insights into Edith's personality and relationships. The only observations about these were provided by the home care agency during the SAR who got to know Edith well. Their experience was that she was strong minded, and was not afraid to express her views, although generally she seemed to defer to Mr A's wishes. At times, her hearing difficulties may have been a factor for her fairly short replies when spoken to which gave the impression that she did not want to engage in conversation.

Knowledge about Edith's family / informal carers

4.8 A major concern is the inaccurate and contradictory information in agency records about the status of Mr A and his 2 daughters in relation to Edith. Even at the stage the SAR was carried out, there was uncertainty as to whether, and how, Edith and Mr A were related.

4.9 It was ASC's understanding from the information gathered during the first assessment in September 2017 that Mr A was Edith's nephew. However, the record made by the GP Practice, hospital and community tissue viability nurse variously referred to him as her nephew, husband, or partner. Similarly there were contradictory records about the relationship of Mr A's daughters to Edith with references to step-daughter, niece, or great niece.

4.10 One hospital doctor did pick up the discrepancy in the hospital records that described Edith as living with her husband and nephew, because Edith told him that her husband had died in the 1990s. However, this does not appear to have resulted in action to update her hospital record.

4.11 No agency held any information about the circumstances of Edith's elderly brother, her immediate next of kin, which would have been important to take into account when deciding how he should be approached to inform him of the SAR and offer the opportunity to contribute his perspectives.

4.12 Although not affecting the timeliness and quality of the care provided the lack of accurate information and contact details within agency records proved a problem when hospital staff needed to have urgent discussions about her condition and end of life care.

Delays in information being received by Edith's GP

4.13 The Review heard that standard hospital practice is to check GP details with patients at the point of admission. However this does not appear to have happened when Edith was admitted to hospital in July 2017. One problem in identifying the correct GP is that Edith's GP practice is one of three within the same building and it appears that some professionals may treat the building as one site and do not always make sufficient enquiries to distinguish which of the 3 practices is the relevant one. In Edith's case, the documentation completed by the paramedics when she was taken to hospital in July 2017 included the name of a GP in one of the practices she had never been registered with.

4.14 The lack of checking meant that the hospital records were not updated and resulted in the discharge letter in August 2017 being sent to her previous GP Practice, and it was not received by the correct GP practice until mid September, over a month later. This meant that her GP did not immediately receive information about her treatment which might require GP follow-up. Although the 2 GP Practices are in the same building, the previous practice would not have known who the current GP was, and in line with normal practice, returned the letter to the hospital with a note confirming Edith was not their patient.

4.15 It is clear from the letters sent by the Tissue Viability Service and Dementia Service in September and October 2017 that they had the correct GP information. However, neither service updated the central Clinical Web Portal system. The GP information was only changed on the portal after Edith's death.

4.16 Although some staff in the GP practice were aware of Edith's death from the enquiries made by the police, it was 6 weeks before the formal notification letter was received from the hospital. This appears to have been related to the time gap before the enquiries requested by the Coroner had been concluded and the death certificate being issued. Unfortunately, in the intervening period, the GP sent a standard letter to Edith inviting her to attend for chronic disease monitoring. The arrival of this letter in these circumstances had the potential to cause considerable upset for the family.

4.17 In exploring why this error occurred, the SAR heard that GP practices would normally trigger a process when notified of a death which would make it clear to anyone accessing the records that the patient is deceased. In the case of patients who die in hospital, this is usually triggered when formal notification is received. Changes are then made to the electronic record, and paper copies of the notes are sent to NHS England.

Learning

4.18 Agencies were unable to provide any information about Mr A during the SAR to supplement the brief references in the records that Mr A's ability to care for Edith was impaired by his own health needs, age and frailty. This lack of basic information gathered by professionals about Mr A and the involvement of his daughters is a concern as it is an important element in building up a full picture to ensure a well rounded assessment which takes into account the extent of any family and informal support networks.

4.19 In addition, it is essential that agencies have contact information in the event of an emergency, or where they may need to be involved in best interests' processes where a person lacks capacity to make a decision about their care and treatment. Where an agency has doubts about whether it holds the correct information, a way forward is to cross check the information with other agencies known to be involved.

4.20 It will be important therefore that WSB is assured that each agency has taken steps to ensure that they have clear systems in place to ensure that their records are updated to reflect changes in the home circumstances, contact details for the person the service user wishes to be contacted when circumstances require this, and the correct GP information.

4.21 For hospitals, it is important that this information is gained while the patient is in A&E because of the increasing frequency of patients being seen there by a consultant physician who organises follow up without them having to be admitted to hospital. Where patients are moved to a ward, steps should be taken to re-check the information with the patient, and relatives if they are visiting. As Edith's case demonstrated, it is important to clarify the GP information precisely given that there are several GP surgeries in the same building.

4.22 The SAR identified updating presents a challenge for those GP practices which use a touch screen for patients to log in their arrival for an appointment, and do not require them to routinely speak to a receptionist. Given the time involved in editing the record, placing the onus on GPs or nurses to do this may not be an approach which can be relied on given the time constraints of the 10 minutes allocated for each consultation.

4.23 The SAR heard that some practices have notices up asking patients to let reception know if they have changed their contact details, but this is an approach which is patient-dependant and they may not remember if they have previously provided their latest details.

4.24 One possible option which was identified through the SAR discussions is whether there is scope to add additional questions to the check-in screen, which might include the house number and the last 3 digits of the telephone contact number. If the patients answer no, the screen would then direct the patient to reception to check in for the appointment when the details can be updated. However, this would not overcome situations where patients who have moved are reluctant to share this information if it could lead to their having to switch to another practice. The SAR was also informed that some patients use a relative's address in order to stay registered with the practice. It was agreed that further discussions will need to take place with GPs to identify viable solutions.

Access to Medical Information

4.25 During the SAR discussions, it was noted that there is already some facility for sharing essential medical information with other healthcare providers being able to access the GP Summary Case Record. [11] This is a summary profile of the patient's medical history and includes different levels of information dependent on what the patient has agreed can be included. It was also noted that the possibility of creating a shared health and social record is being piloted nationally.

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My Care Passport

4.26 The SAR Review Team explored a further possible way of sharing essential information through the use of "care passports" which the home care agency has started to complete with each of its current service users. This is in an electronic format which means that it can be shared quickly and easily. It was agreed that this initiative by the agency was good practice.

4.27 "My care passports", or "my healthcare passports", which have been introduced in several areas of the country, are proving an effective way of gathering information about the service user, and sharing this when the service user presents in any health, hospital or care setting. Although there are variations in format, they generally include coverage of the following:-

- information about the person's history that it is important to be aware of;
- details about family members to contact;
- names and contact numbers of services / professionals involved;
- care and support being received;
- ability to understand and communicate;
- abilities and needs in relation to personal care and mobility;
- preferences in terms of how care and support is provided;
- preferred support when upset or with behaviours that may challenging or cause risk
- medications
- likes and dislikes

Some areas have also seen the introduction of "carer passports" which helps to improve and embed identification, recognition and support for carers in the day-to-day life of an organisation or community. [12]

4.28 Given the findings from this SAR, it is recommended that there is further exploration of the benefits which might flow from extending their use by all health and care providers.

5. HOSPITAL DISCHARGE PLANNING

5.1 There was effective joint work to plan the discharge once the occupational therapist (OT) had identified that all the necessary equipment was not in place. Prior to that, it appears that hospital doctors were pressing ahead with plans for Edith to go home without an appreciation that a care package and equipment needed to be organised for a safe discharge. Once the appropriate equipment was identified, hospital therapists attempted to work with Edith to try this out, although sometimes she declined to engage.

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[12] *Carers UK have been working in partnership with the Carers Trust, with funding from the Department of Health and Social Care, on a project designed to help local areas introduce Carer Passports in five key settings - hospitals, employment, community, education and mental health trusts.*

Discharge Summary

5.2 The guidance issued by the British Medical Association (BMA) [13] advises that discharge letters should contain a brief summary of what has happened to the patient, and include all investigations, new diagnoses, and why medications have been started or stopped.

5.3 Edith's discharge letter did detail all the clinical findings, including the dementia investigations, and the practical assistance she would require to transfer at home. It also referred to self neglect being a factor for the pressure ulcer which resulted in her admission, but did not include any further details about the conclusions reached in respect of the safeguarding concerns raised.

5.4 Although there was reference to social care being involved, and the family's request for district nurse and chiropody referrals, the letter did not include any details of the home care package of support. Nor was there any reference to the original intention which had been mooted to include a recommendation that the GP carry out a follow up visit to see how Edith was managing at home with the package of care, and consider whether further memory assessments were required.

Learning

5.5 In addition to clinical matters, it is essential that discharge letters contain clear information about care support arrangements, any safeguarding issues, and recommended follow up action by GPs. While it is reasonable for hospitals to expect that GPs will apply accepted best practice and routinely arrange for their patients to be followed up, research has shown that this does not always happen. One study published in 2016 [14] found that failures occurred in the processing of requested actions in almost half of all discharge summaries, and in respect of all types of actions requested. [15] There may be value in exploring the option of including a separate "GP action plan" with discharge letters which is a practice adopted by some consultants following outpatient appointments.

EDITH'S ENGAGEMENT WITH PRIMARY CARE SERVICES

6.1 The above issue leads into consideration about the degree of GP involvement with Edith. Although outside of the SAR time period, a summary of the contact prior to July 2017 provides some helpful context when considering issues that were to arise in respect of her engagement with assessments and acceptance of support offered.

6.2 Although not a frequent attender prior to 2014, Edith did engage with routine monitoring. However, the lack of any contact between September 2014 and December 2016 represented a definite change in the pattern particularly as she no longer even attended for an annual review. This lack of contact resulted in her being exception reported for the blood pressure and smoking quality indicators.

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13 *"Hospital discharge: the patient, carer and doctor perspective" – The British Medical Association (BMA) – January 2014*

14 *Processing of discharge summaries in general practice: a retrospective record review - Rachel Ann Spencer, Simon Edward Frank Spencer, Sarah Rodgers, Stephen M Campbell and Anthony John Avery – British Journal of General Practice 2018;*

15 *Overall failure rate 46%; medications changes not made 17%; Tests not completed 26%; 27% of requested follow-ups not arranged*

6.3 Edith was seen towards the end of April 2017 for a medication review when a small leg ulcer was identified which was dressed. However, she did not return for this to be changed regularly as advised until 3 weeks later when a large scab was found over the right ankle which needed debriding. [16] When Edith returned a second time 6 days later, 2 open wounds were noted on the top of her right foot, which looked like burst blisters. The nurse explained the risk of infection, the need for regular dressing changes, and replacement footwear. She also documented the issue of poor hygiene. Edith did not return as advised which resulted in her wounds deteriorating significantly as found by WMAS and the hospital 2 months later.

6.4 The issue here is whether the GP Practice could have taken a proactive approach in checking with Edith the reasons for her not returning. Practice staff were aware that Edith was dependent on other people to bring her to the practice, and therefore it would have been important to check if there was an issue about her not being able to organise help when it was required. If that was the case, a home visit could have been considered. However, as highlighted earlier, the GP records contained no mention about her home circumstances or whether the need for additional help was ever explored.

GP contact with Edith after July 2017

6.5 The delay in the discharge letter reaching the GP appears to have been a contributory factor for no medicines reconciliation taking place. This resulted in Edith continuing to be prescribed Ramipril [17] for another 2 months after discharge. This had been stopped in hospital because it was causing low blood pressure which could cause her to collapse. If the deputy home care manager had not picked this up and alerted the GP, there is a possibility that Edith would have remained on the drug even longer with potentially serious consequences.

6.6 A concern is that there had been previous issues in terms of GP oversight of the prescribing of the Ramipril. The GP records show that Edith did not have a blood test until April 2017, 5 years after she was started on the medication. Accepted clinical practice is that these should be done before and after starting the medication, and after any increase in the dose. Although Edith had been advised at some appointments to arrange a blood test, she did not book to have this done.

6.7 During the review period, Edith only had one physical contact with the practice in early October 2017 when she wished to have her ears syringed following a hearing test. This could not be done as they were full of hard wax, and she did not re-attend as advised once she had had chance to loosen this at home with olive oil drops.

6.8 Later that month, she was invited to attend for a memory review as recommended by the dementia service. However, the GP letter was couched in non specific terms, and did not explain that the reason for Edith being asked to attend was to follow up the initial tests carried out in hospital. Had the letter made this clear, it would have enabled Edith to make an informed choice whether to take up the appointment.

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16 *Debriding involves cutting away dead tissue*

17 *Ramipril is a blood pressure tablet*

6.9 There were also attempts to telephone Edith, first after Mr A had called at surgery to ask about medications, and second a follow up call after she did not respond to a letter to check her smoking status. [18] On both occasions the phone number was unobtainable and was removed from her record. There is no record of any attempts being made to try to find out if there was a new number, or an alternative means of making telephone contact via a relative.

6.10 It does not appear that the GP picked up on the frequency of district nurse involvement which might have prompted consideration of the need for a health review. This may have been because the receptionist was pro-active in taking responsibility for making the referrals to the district nurses the same day and it is possible that this may not have been flagged up in a conversation with the GP to supplement her entry in the patient notes.

Learning

6.11 The above analysis leads to a number of learning points around the following issues:-

- processes to ensure safe prescribing and medication reviews;
- processes to engage patients who fail to respond to invitations for routine reviews or follow up appointments which have been advised as important;
- exploring the social circumstances of adults who are unable to attend appointments independently;
- administrative processes following notification of a patient's death to ensure further correspondence is not sent inappropriately.

6.12 While patients must take some responsibility for their own health, it is the clinician signing the script who must take responsibility for safe prescribing, and blood tests are one essential element in achieving this. It is acknowledged that this can be a difficult situation for GPs when patients do not attend reviews as requested, but safe practice would be to prescribe a shorter supply of medications and not issue a further prescription until a patient has been reviewed.

6.13 It will also be important that the CCG assures itself that GP practices have a robust system in place to ensure that the patient record is updated in terms of diagnosis and medications. The Review was informed by the GP representative for the CCG who was the IMR author, that there are varying approaches adopted by GP Practices to achieve this. Some rely on this being done by administrative staff, or pharmacists where practices have these, or by the GPs themselves. The particular arrangements are not important as long as the updating is carried out.

6.14 The SAR also discussed the issue of the national GP contract which requires each patient to have a named GP who is responsible for overseeing their care. While for ongoing problems, it is generally considered better for the patient to be seen by the same GP to provide continuity of care, in reality this government policy objective is difficult to achieve. In part this is because many GPs work part-time. In addition, patients often do not want to wait for the next available appointment with their

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18 *This was to enable the GP to submit information for the quality and outcomes framework (QOF) which is part of the General Medical Services (GMS) contract for general practices and was introduced on 1 April 2004.The QOF rewards practices for the provision of 'quality care' and helps to fund further improvements in the delivery of clinical care.*

preferred GP and opt to see the first available GP. Notwithstanding these constraints, the SAR recommends that GP practices should aim wherever possible to facilitate continuity of care by booking appointments with the same GP particularly for patients with complex co-morbidities.

7. THE RESPONSE TO SAFEGUARDING CONCERNS IN JULY 2017

7.1 The review has concluded that there was insufficient assessment of both the possibility of self neglect and / or unintentional neglect by a third party through acts of omission. This raises the question as to how confident professionals are in picking up the possible indicators, and the extent to which use is being made of the regional self-neglect guidance adopted by WSB and published on its website. The guidance on self neglect first published in 2015, [19] draws on research carried out by the Social Care Institute for Excellence (SCIE). [20] Guidance on neglect/acts of omission and self-neglect is contained within the overall adult safeguarding adults procedures. [21]

7.2 During the July 2017 hospital admission, there were repeated references to Edith having the appearance of self neglect but without any explanation of the basis for those observations. Health professionals do not appear to have gathered a more detailed history to explore further the reasons for her poor presentation to supplement the initial history provided to paramedics by the family.

7.3 The conclusion reached by the hospital social work team was that the original safeguarding concerns were not substantiated and the criteria for further enquiries were not met. In reaching this conclusion, there appears to have been little professional curiosity and probing of the family's explanations that Edith had refused personal care and these were accepted without cross checking with all relevant staff.

7.4 It does not appear that ward staff were spoken to which may have revealed the information picked up by the therapist that Edith was fearful of Mr A's reactions, and that on occasions she had to wait for her needs to be attended to when Mr A went out.

7.5 Although the SA2 form [22]referred to discussion having been held with the GP, the SAR established this was not strictly accurate because the conversation had been with a GP receptionist who provided the information that Edith's last attendance had been in May 2017 for the leg dressings. A discussion with the GP would have been important in building up a full background history, and may have revealed that Edith had not been brought back for the dressings to be changed. While it is possible that this may have been Edith's decision, the questions which needed to be probed further was why Edith was not willing to accept the personal and medical care her deteriorating presentation clearly required, and why the family did not seek advice or help earlier. The lack of direct contact with the GP raises the question as to whether GPs are sufficiently integrated into local safeguarding arrangements.

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19 *Adult Self-Neglect Best Practice Guidance - Responding to self-neglect concerns and enquiries for adults with care and support needs in the West Midlands – published October 2015*

20 *Self-neglect policy and practice: key research messages - Written by Suzy Braye, David Orr and Michael Preston-Shoot – Social Care Institute for Excellence (SCIE) March 2015*

21 *Adult Safeguarding: Multi-agency policy and procedures for the protection of adults with care & support needs in the West Midlands – first published 2012 – updated September 2016*

22 *An SA2 form is a record of a strategy discussion and also an enquiry plan (if progressing to a Section 42 safeguarding enquiry*

Unintentional Neglect

7.6 There is a clear difference between deliberate or wilful neglect and acts of omission which can be seen as unintentional harm. Acts of omission may or may not result in harm. The latter may be due to a lack of knowledge or because the carer's own physical or mental health needs render them unable to provide the necessary care. The carer may also be an adult with care and support needs of their own.

7.7 The rationale for carrying out a Care Act assessment rather than initiating further safeguarding enquiries was that this was proportionate and the least restrictive way of addressing the concerns. This approach was consistent with one of the options suggested in the Care Act Statutory Guidance for responding to such situations. The key factor influencing the decision was that both Edith and the family were requesting help, therefore it was considered unnecessary to talk to them about abuse and neglect given that Mr A and his daughter Mrs D had explained that they had been trying to care for Edith and had not previously sought or received advice and support.

8. ASSESSMENTS INCLUDING ASSESSMENT OF RISK

Care Act Assessment – July 2017

8.1 In contrast to the approach when the safeguarding concerns were considered, hospital social worker 2 adopted a more inclusive approach through consultation with a range of professionals to supplement information gained from Edith, the family, and the hospital records. Contributions were obtained from the ward sister, a senior occupational therapist, and the consultant for the care of the elderly who had overseen her treatment. This comprehensive assessment led to agreement to the high level of home care support. One issue which emerged from the assessment, which appears to have had a bearing on subsequent events, was that Mr A expressed his concern that Edith would be required to use her attendance allowance to contribute to the cost.

Reduction in Home Care Support – September 2017

8.2 The decision made by Edith and Mr A to reduce the home care support was clearly a significant development, and raised the possibility of Edith's personal care needs not being met sufficiently with the consequent risk of further pressure ulcers developing.

8.3 The concerns raised by the home care agency were understandable given the discovery 2 days earlier that Edith had slept in her wheelchair overnight, her breasts were sore, and there was evidence of a new pressure sore. This was subsequently assessed as grade 3 by the district nurses following an urgent referral made to the GP by the home care agency. In addition, when the district nurses had recently ended their involvement because the original pressure ulcer had healed, they commented on the important contribution the home carers had made to the healing process.

8.4 The interim decision taken by ASC, in discussion with the home care agency, to reduce the support to 2 calls a day, appears to have been a pragmatic compromise to avoid the support being cancelled in its entirety. However, the downside was that the reduction would become an established change before the implications and risks could be explored with Edith through a reassessment visit. Arranging a more immediate follow up visit might have been a more proportionate response given the level of concerns raised, and importantly to check that this potentially significant reduction in support was Edith's wish given that the request had been made by Mr A

who had no legal authority to make decisions on her behalf. [23] Until then, there had been no reason for professionals to question the assumption that Edith had mental capacity to make decisions about her care.

8.5 Although during the re-assessment Edith said she understood the risks of further pressure ulcers developing, a key factor which needed to be taken into account was Mr A's ability, not just his willingness, to provide the required level of care.

8.6 In accepting Mr A's reassurances about his ability to meet Edith's needs during the day, insufficient consideration was given to the information previously provided by Mr A and his daughter Mrs D. During the original July assessment in hospital, Mr A had reluctantly acknowledged that he was no longer able to continue to care for Edith due to his own health needs, age and frailty. An observation made by hospital social worker 1 in the SA2 form which appears to have lent weight to this, was that Mr A's presentation suggested that he did not change his clothes often because there was dried food spillage, and his skin appeared to have areas of grime. In addition, he had explained that Edith would not accept his help with personal care.

8.7 Mrs D had also experienced the same problem and shared her opinion that her father could no longer continue to provide the care. Another important factor which needed to be taken into account was that Mr A would not be able to draw on much practical support from Mrs D because she could not visit very frequently because she worked fulltime, had small children, and also was caring for her own mother.

8.8 Given all the above factors, a comprehensive assessment of both Edith's and Mr A's needs was essential. It was positive that the offer of a carer's assessment was made and accepted by Mr A given that the extra responsibilities he was taking on. However, the SAR discussions clarified that the purpose and potential benefits of such an assessment were not explained in detail, which might have included exploring how his need to go out could be balanced with Edith's personal care needs. In the event, although a referral was made to the local authority's carer support team, the assessment was never carried out although the reason for this could not be established. It is a concern that there was no progress checking by ASC after the referral was made, or when the reassessment visit was carried out in February 2018.

8.9 The conclusion in the updated Care and Support Plan was that Edith's needs were still being met despite the reduction in support. However it appears that there was no further discussion with the home care agency which raises doubts as to whether the risk assessment gave sufficient weight to their view that the situation would most likely deteriorate. The home care agency has identified its own learning from this episode that it might have asserted its concerns more robustly.

8.10 In addition, no approach was made to the district nurses who by then had become re-involved, to both gain their perspectives about the risks, and inform them of the reduction of home care support. This would have been important information for the nurses to take into account in terms of their frequency of monitoring. In the event, the district nurses were alerted to the implications of the reduced care by the home care agency which was good practice.

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[23] *A person is only empowered to make decisions on someone's behalf through the arrangements for lasting power of attorney*

Cancellation of all home care support

8.11 When the home care agency alerted ASC to the family's request, a more urgent visit might have been expected given the home care agency's suspicion that Edith may not have been involved in the decision. The record of the visit made 2 week later suggests that there was some basis to this concern given that Mr A initially seemed to want to prevent the assessor from seeing Edith, and the assessor's perception that throughout the visit, Edith appeared anxious and her responses seemed to be prompted by Mr A.

8.12 While recognising the difficult situation the assessor faced in being able to talk to Edith in private, the question arises as to what further steps might have been considered to probe further as to whether Edith was making the decision to terminate the home care support of her own free will. This would have been particularly important in the light of previous disclosures from Edith during her time in hospital that she was anxious about Mr A's reaction if he found out what she had shared with professionals, or the issues that they might raise with him.

Edith's apparent anxiety about Mr A's reactions

8.13 The first indication of this was Edith's response when a hospital therapist sought her permission to ring Mr A to discuss her need for equipment at home. Edith said "No, he will shout, I will get in trouble". Although this was reported back to the ward sister and the senior physiotherapist, this was not shared further with either the hospital social worker, or the hospital's safeguarding lead to seek advice on whether this suggested the possibility of a safeguarding or domestic abuse issue which needed to be pursued further.

8.14 The second was the record made by ward staff of the feedback provided by hospital social worker 1 about her meeting with Edith the following day to consider the safeguarding concerns raised by WMAS and the Hospital. This noted that Edith had been very reluctant to engage and she stated "Mr A will shout at her". When asked if she wanted carers at home, Edith stated "Mr A looks after me, there's nothing wrong with that". When Edith agreed to the social worker speaking with Mr A to establish if he needed support, she said "yes, but be careful what is said - I will be in trouble if Mr A thinks I have been talking to you".

8.15 There was no further attempt to explore the reasons for Edith's apparent fear of Mr A's anticipated reaction. Applying greater professional curiosity at this stage should have led to the social worker checking with health staff whether they had picked anything up regarding this anxiety, which may have revealed what Edith had said to the therapist.

8.16 It would appear that there was some basis for Edith's fear of Mr A's reactions when considering some professionals' experiences of the manner in which Mr A showed his dissatisfaction about the service provided. In August 2017, the GP receptionist recorded that he had shouted at her when he called for a prescription which was not ready. There were also several instances of his criticising the home carers if he disagreed about the way they did their work, for example:-

- his unhappiness that a home carer wore a face mask because of cigarette smoke;

- criticising the home carers for encouraging Edith to drink more which he claimed had frightened her, because she might end up having to be admitted

to hospital. This was an embellishment by Mr A of what the home carers had actually said;

- the home carers ringing Mrs D when they could not gain access to the house one morning which he said would have upset her. He continued to complain about this at length despite efforts by the deputy manager to de-escalate the situation.

8.17 A possibly significant observation shared by the home care agency during the SAR was that while they were carrying out their duties, Edith rarely wanted to be closed off from Mr A. This extended to her always wanting the door between the lounge and kitchen being kept open even when intimate personal care was being carried out. In the light of her disclosures at hospital, this may have been because she was fearful of his reaction if he was to suspect that she had been speaking to the carers privately.

Learning

8.18 This case reinforces the guidance that to ensure person centred care, professionals must ensure that at all times they try to "hear the voice" of the service user as well as their families. That can only be done if opportunities are created to see the person on their own while also taking into account whether this could put them at risk of increased threatening or controlling behaviour.

8.19 In this case, Edith was only seen on her own twice by social care professionals, first when the safeguarding concerns were being explored in July 2017, and the final re-assessment visit in February 2018. However, on both occasions, she was only seen alone for a very short period because she did not appear to want to talk. It is acknowledged that in the February visit, the assessor would have been in a difficult situation in not being able to explore the reasons for this with Edith given that Mr A was close by.

8.20 Where there are difficulties in securing engagement, being allocated the time to building a relationship is essential to empower the service user to explore the implications of their actions, and lead them to accept, or continue to accept, support. However, it is recognised that allocating the required time for this level of input is a challenge for local authorities given the high demand set against a background of overall financial pressures.

8.21 It is also important that professionals are prepared to challenge family members where their wishes could have a negative impact on the care provided or plans being made. Leadership and support from managers is a vital ingredient for this to happen.

Response to refusal of services

8.22 The decision by Adult Social Care to close the case following the February re-assessment did not reflect the regional guidance on self neglect [24] which explains the actions which should be taken when a service user and / or informal carer declines support. These are not situations which professionals should walk away from, and as the regional guidance stresses, respecting the wishes of an adult does not mean passive acceptance.

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[24] *Adult Self-Neglect Best Practice Guidance - Responding to self-neglect concerns and enquiries for adults with care and support needs in the West Midlands – published October 2015 – re-issued in 2018*

8.23 Where further involvement is declined, or cannot be achieved without putting the service user in a difficult situation, consideration should be given to how some monitoring of the service user's circumstances might be achieved where the risks are judged to be high. In Edith's case, options which might have been considered could have included asking the GP to carry out a home visit given that an annual review was due, and asking if the housing agency could find a pretext to make a review visit.

8.24 In cases where high risks of abuse and/or neglect cannot be managed adequately or monitored through other processes, the guidance is clear that consideration should be given to carrying out safeguarding enquiries under Section 42 of the Care Act, and where necessary draw up a multi-agency safeguarding plan. If this plan is still rejected, and the risks remain high, a further meeting should be convened to discuss a review plan. Again, the case should not be closed just because the adult is refusing to accept the plan, and legal advice should be sought in these circumstances.

8.25 In situations where there is on-going refusal, whether this is a capacitated choice or not, either to accept an assessment, or the support offered, it is important that a detailed record is maintained of all the steps taken to evidence that practitioners and managers have acted reasonably and proportionately in all the circumstances. This audit trail should document what options were considered, and why certain actions were, or were not, taken.

Domestic Abuse

8.26 The finding that professionals did not consider the possibility of domestic abuse in Edith's case provides a reminder that a significant proportion of people needing safeguarding support do so because they are experiencing domestic abuse. This is recognised in the Care Act as one of the types of abuse that require protection and prevention regardless of whether the abuse or neglect is deliberate or unintentional. Consequently, domestic abuse approaches and legislation can be considered safeguarding responses in appropriate cases. These are set out in the Wolverhampton Over-Arching Domestic Violence & Abuse Protocol and Guidance.

8.27 In 2013 the cross-government definition of domestic abuse was extended to include controlling and coercive behaviour. [25] One significant national statistic when considering cases like Edith's is that older women and those with disabilities, who are reliant on family members and carers, are twice as likely to suffer domestic abuse. However, victims may not realise that they are subject to domestic abuse, or find it hard to talk about this, which confirms the need for professionals to probe further to help them open up and assist them to seek help.

8.28 When Edith shared her fear of Mr A' reaction, an assessment should have been carried out by the hospital staff using the Safe Lives (DASH) risk assessment tool. [26] The SAR was informed that the hospital continues to encourage a proactive approach by their staff in checking whether there are possible domestic abuse issues and this is included in their safeguarding training. It will be important that WSB seeks

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25 *Controlling behaviour is a range of acts designed to make a person subordinate and/or dependent by isolating them from sources of support, exploiting their resources and capacities for personal gain, depriving them of the means needed for independence, resistance and escape and regulating their everyday behaviour.*

Coercive behaviour is an act or a pattern of acts of assault, threats, humiliation and intimidation or other abuse that is used to harm, punish, or frighten their victim.

26 *Domestic Abuse, Stalking and Honour Based Violence (DASH) Risk Identification, Assessment and Management Model.*

assurance that all agencies are ensuring their staff are applying a proactive approach and are drawing on the local guidance.

Pressure Ulcers and Safeguarding

8.29 As pressure ulcers were a recurring issue in Edith's case, and an infected ulcer was a contributory factor to the cause of death, it may be helpful to clarify the current national approach to the question of when these require a safeguarding as well as a clinical response.

8.30 The incidence of pressure ulcers would not in themselves usually warrant a safeguarding concern being raised with the local authority. Guidance was issued by the Department of Health and Social Care (DHSC) in January 2018 which clarified that pressure ulcers should normally be approached as an issue for clinical investigation rather than a safeguarding enquiry led by the local authority.

8.31 However, it also provided a decision-making framework [27] to assist professionals in considering whether safeguarding concerns should be raised. This addressed the previous lack of national consensus around this issue. The guidance was updated in October 2018 to reflect the recommendation from the National Stop the Pressure Programme [28] that the definition of "avoidable" or "unavoidable" should no longer be used because the focus on this was resulting in too much professional time being expended on trying to prove which of these definitions applied.

8.32 The guidance provides a reminder that pressure ulcers may occur as a result of neglect, whether deliberate or unintentional, and advises that where this is one of a number of safeguarding concerns, then there should be a multi-agency approach coordinated by the local authority, with health taking the lead for the clinical investigation.

8.33 This appears to have been the situation in Edith's case given the possibility of Edith being a victim of domestic abuse from the controlling behaviour by Mr A and his family, and the possibility of financial abuse / exploitation given that they had raised concerns about the financial costs of the care, and the information that Edith did not appear to have control over her own money.

Response to cancellation of support due to financial issues

8.34 Although a major reason for the family wanting to reduce, and then end the home care support was that this was restricting Edith's and Mr A's lifestyle, finance also seems to have been a significant factor with Mrs D saying that Edith could not afford to pay for her care. Cost implications had also been one reason for the family declining Telecare services in September 2017 and February 2018. [29]

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27 *This includes six key questions and the threshold for raising a concern is 15 or above. However, the guidance stresses that this should not replace professional judgement.*

28 *National Stop the Pressure Programme*

29 *The other reason recorded in the September assessment was that the family did not have a landline or mobile phone although the care plan listed a mobile number for Mr A. the home care agency confirmed that Mr A did have a mobile phone but chose never to answer it while they were there*

8.35 Edith's financial contribution [30] towards the cost of the home care was covered by the higher rate of Attendance Allowance [31] she was already receiving. However, the difficulty experienced by many service users is that they become used to, or reliant on, the allowance to fund their daily living costs and / or chosen lifestyle. This can then have a considerable impact in terms of how to make the necessary changes in managing their overall budget when the allowance has to be used to pay for care costs. An early indication that this might become an issue had been telegraphed when at the outset Mr A expressed concerns that Edith would need to use her Attendance Allowance to pay for care.

8.36 Where service users and families say they are unable to afford care offered, or intend to cancel existing support, it is essential that practitioners explore the reasons for this, and check that they are in receipt of all possible financial entitlements. In Edith's case, this had been confirmed through the benefit maximum check carried out as part of the original September assessment. The purpose of the attendance and / or carer's allowance needs to be explained, and strenuous efforts made to explore why these cannot be used for their intended purpose, and challenge any reluctance or resistance from the service user or their family to discuss this.

8.37 This question does not appear to have pressed sufficiently in Edith's case. This was reflected in the explanation provided by the ASC IMR author during the SAR Learning Events that the emphasis had been on explaining the risks of cancelling the service, rather than the exploring the issues around ability to pay, and trying to help Edith and the family to find a solution.

8.38 The SAR also identified 2 further issues in relation to situations where support is declined or cancelled. As well as checking that service users and their families have a clear understanding of the assessed financial contribution, it is also crucial to explain if this will alter if there is a change in the level of support. During the SAR, the home care agency shared their experience that a lack of understanding was a recurring issue in their discussions with service users who are raise concerns that they may have to cancel the service. An issue in Edith's case was that under the charging system, her original contribution remained the same from November 2017 onwards despite the ending of the daytime calls. Despite the hospital social worker explaining the charging policy during the July 2017 assessment, it is possible that Edith and Mr A may have expected the charges to reduce because of this, and when this was not the case, led to the decision to cancel all support.

8.39 The second is the importance of practitioners satisfying themselves that the decision to cancel for financial reasons is one being made by the service user, and to rule out the possibility of financial abuse by a partner, relative or other third party. This was a potential safeguarding issue which should have been given greater consideration in Edith's case given that the concerns about charges, the inability to pay, and Edith's wish to cancel support, were always initially raised by Mr A or Mrs D.

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30 *The weekly cost of the home care support in 2018 was £197.68 and Edith's assessed contribution towards the cost was £75.84.*

31 *Attendance Allowance is a non means-tested benefit for people aged 65 to help with the extra costs of long-term illness or disability where a person needs help to look after herself. It is paid at 2 rates – the higher rate is paid where the criteria for assistance both during the day and at night are satisfied. In 2018, the higher rate was £85.60.*

Accommodation Issues

8.40 The SAR has highlighted the importance of professionals including issues around accommodation when carrying out assessments.

8.41 As time went on, it became more evident that the limited space was creating practical difficulties and ultimately led to Mr A's ultimatum in February 2018 that the profile bed be removed or he would dismantle it. This led to it being taken back into stock soon afterwards with the consequence that Edith slept in the bedroom and Mr A on the sofa which is not ideal on a long term basis particularly given his age.

8.42 However, although the limitations of the accommodation would have been fairly obvious, at no stage did any professional, including the housing agency, explore with Mr A and Edith the issue of whether the accommodation was able to meet their respective needs on a long term basis, and whether they had considered applying to move to larger accommodation. Seeking Edith's views about this would have been important as this had become her permanent home for the past 7 years and the possible adverse implications for her health and mobility.

8.43 In May 2018, an application for re-housing was submitted for Mr A via the Wolverhampton Homes website with his daughter Mrs G given as the contact person. It is not known whether this was made with Mr A's agreement. There was no supporting information provided other than Edith being listed as Mr A's carer. This application did not progress any further because under the Wolverhampton Homes choice based lettings policy, the onus is on applicants to express an interest in particular properties which are advertised on the website or in the local office. However, no bids were made by or on behalf of Mr A.

8.44 The SAR heard that potential applicants can seek advice about the re-housing options, and explain their circumstances, either through their central office or local offices. Where there are more complex health issues, the application can be allocated to the vulnerabilities officer who will make the necessary enquiries with other agencies to gather information which will lend support to their application. During the SAR, the housing agency confirmed that they are exploring how they can be more proactive in picking up the issues which occurred in this case, both through the routine audit visits to tenants, and also information provided by applicants to support their application.

9. ISSUES AROUND MENTAL CAPACITY

9.1 Throughout the SAR time period, Edith was deemed to have mental capacity to make decisions about her treatment and support, and on occasions, professionals noted this in the records.

9.2 However, during the 2017 hospital stay doctors did have concerns that Edith may have undiagnosed dementia given the circumstances related to her admission. The result of the initial memory test, [32] and Edith's concern about forgetfulness in recent months, identified the need for further investigation. A subsequent CT scan showed only expected age related deterioration, and there was no evidence that her cognitive impairment was impaired to any significant degree. The attempt by a Dementia Outreach Service practitioner to follow this up proved unsuccessful because Edith

[32] *Edith scored 4/10 on the Abbreviated Mental Test (AMT). This is offered to all patients aged 75 or over who are an emergency admission. Any score below 8/10 would require further investigation)*

was described as being withdrawn and not wanting to talk. Consequently, the service later wrote to the GP to check if further memory assessments were required

9.3 The fact that Edith was judged to have mental capacity in respect of her care was a key issue in the decision by Adult Social Care to close the case in February 2018. Having regard to Section 1(4) of the Mental Capacity Act 2005 that a person is not to be treated as unable to make a decision merely because he/she makes an unwise decision, the view taken was that her decision to cancel the home care support needed to be respected.

9.4 The SAR finding is that there was a lack of robustness in ASC's approach to this issue. The key issue here was whether the practitioner had any reason to call into question Edith's mental capacity. The key requirement of the Mental Capacity Act [33] is that a person must be assumed to have mental capacity unless it is established otherwise. This statutory principle states that every adult has the right to make their own decisions – unless there is proof that they lack capacity to make a particular decision at the time when it needs to be made.

9.5 Having regard to the stage 2 functional assessment test set out in the Mental Capacity Act Code of Practice, it would appear that Adult Social Care staff were satisfied that Edith had capacity to make a decision about her care arrangements i.e. Edith was able to understand and retain information, weigh up and was able to communicate her decision. However, upon closer examination, the SAR finding is that there was a lack of robustness in evidencing Edith's ability to "use and weigh up" the information which should have included her ability to understand and weigh up the risks to her health and well-being, not only in making a decision, but also the ability to ensure her choices could be acted on by Mr A to maintain her health and personal hygiene.

9.6 The validity for raising this doubt about Edith's mental capacity stems from information provided by Edith in the original social care assessment in July 2017 that not only she was slightly forgetful, but more significantly, she struggled with making complex decisions.

9.7 There is also a question around whether Edith's decision making about her care was affected either because of actual coercive control by Mr A and his family, or because of her fear of criticism from Mr A, if she made a decision which she knew he would disapprove of because it would restrict their freedom to go out. The indications that this might be occurring from Edith's behaviour and comments made to professionals were previously covered in the previous section. The fact that the intention to cancel the home care support was communicated by first Mr A, and then his daughter Mrs D, raised doubts as to whether this was a decision which Edith was making of her own free will, or was actually theirs. This required more robust exploration than the social care assessor was able to achieve.

Learning

9.8 The SAR has identified three key areas of learning around issues relating to mental capacity. The first is the importance of robust risk assessment in cases of possible self neglect when professionals consider a person's decision to be unwise.

[33] *Section 1(2) of the Mental Capacity Act 2005*

9.9 The second is around the issue of coercive control, particularly when this is hidden, given that throughout the case, the possibility of this was not considered or explored sufficiently. The discussions at the SAR Learning Events confirmed the need for further training around recognition and possible courses of action when this type of abuse is suspected.

9.10 The third is the options available to the local authority where a person is considered to be at serious risk of abuse and/or neglect but the person has not lost mental capacity for reasons set out in the Mental Capacity Act. In these cases, the local authority may wish to explore with Legal, the powers of the High Court in exercising its inherent jurisdiction to make orders to protect the person.

9.11 Following a recent domestic homicide review (DHR), some action has already been taken to address this. The CCG has embedded the learning from the DHR into the Safeguarding Adults Level 3 training for primary care professionals, and also featured in 2 bespoke training sessions provided by a drama group commissioned by the CCG in 2018.

9.12 The Domestic Violence Forum provides free training on coercive control. This was a local project which the CCG has supported to facilitate the GP Domestic Violence Training and Support Project, with funding secured from the Safer Wolverhampton Partnership [34]. At the last count over 200 GP practice staff have been trained over 42 practices, and the impact has seen referrals being made by GPs for consideration at Multi-Agency Risk Assessment Conference (MARAC) meetings. [35]

Response to unwise decisions

9.13 Respecting a person's right to make what appears to be an unwise decision is at the heart of Article 8 of the European Convention on Human Rights, [36] the empowering ethos of the MCA, and the principles of Making Safeguarding Personal (MSP). However, professionals face challenges in balancing this with their professional duty of care to keep people safe where the consequences of the decision could have serious adverse effects on a person's health, and in this case, ultimately be life threatening. The Government's response to the House of Lords report [37] acknowledged that these inter-dependencies need to be built into the safeguarding discussion. In Edith's case, however, this balance was not achieved, and Adult Social Care placed too much weight on respecting Edith's autonomy.

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34 *The Safer Wolverhampton Partnership is the name for the statutory Community Safety Partnership*

35 *MARAC meetings consider the risk of future harm to people experiencing domestic abuse and if necessary their children, and draw up an action plan to help manage that risk.*

36 *Article 8 states:- 1. - Everyone has the right to respect for his private and family life, his home and his correspondence. 2. There shall be no interference by a public authority with the exercise of this right except such as is in accordance with the law and is necessary in a democratic society in the interests of national security, public safety or the economic well-being of the country, for the prevention of disorder or crime, for the protection of health or morals, or for the protection of the rights and freedoms of others.*

37 *Government response "Valuing Every Voice" June 2014*.

9.14 Where it appears that an unwise decision is being made, good practice requires a robust risk assessment of the situation including the person's analysis of the risk and that of significant others including the assessor. A detailed record should be made of the steps taken to consider whether a person has capacity and the reasons for the conclusion reached. It is also important to include a reminder here that Section 11 (2) of the Care Act 2014 requires the local authority to carry out a needs assessment if either the person lacks capacity to refuse the assessment and the authority is satisfied that carrying out the assessment would be in the adult's best interests, or the person is experiencing, or is at risk of, abuse or neglect.

9.15 It is also important for the local authority to consider whether it needs to exercise its duty under Sections 67 and 68 of the Care Act 2014 to appoint an independent advocate to support and represent the person if it appears that a person with care and support needs may have substantial difficulty in being involved in decisions about their care, or where there are safeguarding concerns, in situations where there is not an appropriate individual to support them.

9.16 Equally, where there are doubts as to whether a person has mental capacity, and there appears to be a potential conflict of interest between the service user and the family, involving an independent advocate may need to be considered.

9.17 From the contemporaneous record of the re-assessment visit in February 2018, the decision to cancel the home care seemed to be driven more by Mr A rather than Edith. This subsequently became more apparent from the explanation provided by Mr A when Edith was re-admitted to hospital in July 2018.

9.18 It is recognised that securing the involvement of an Independent Mental Capacity Advocate (IMCA) may not be easy to achieve because the IMCA provider may decline to get involved where the service user is deemed to have capacity and the family are involved. It is also important to consider whether it would make the situation more difficult for the service user, particularly in cases like Edith's where she was living with Mr A.

10. ESCALATION OF CONCERNS

10.1 The home care agency demonstrated good practice by notifying the GP practice immediately when they noticed pressure ulcers or other sores developing, and also in raising their concerns with Adult Social Care about the possible consequences of the reduction in their support, citing the issues that they had encountered in providing all aspects of Edith's personal care. This is all the more commendable given that the agency had not been given any directions from Adult Social Care as to what they should report and when.

10.2 As covered earlier, the home care agency has identified its own learning that it might have asserted its concerns more robustly. However, in exploring this issue during the SAR, it was established that they were unaware of how they might have escalated their concerns. It is a concern that neither the home care agency nor some other professionals involved in the SAR, were aware of the joint multi-agency escalation policy first adopted by the Adult and Children's Safeguarding Boards in June 2016 and updated in May 2019.

Learning

10.3 A key finding from the SAR is that no consideration was given to arranging a multi-agency meeting when the home care was ended in order to consider the potential risks and the concerns about Mr A's apparent influence on Edith's decision. During the time period covered by this SAR, it was identified that there were no agreed multi-agency procedures in place for professionals to meet to share information, and formulate multi-agency support, unless these met the criteria for being considered within the formal adult safeguarding procedures. The SAR was informed of several developments which are designed to address this gap.

10.4 The first is that there are much closer working relationships between social care staff and district nurses, which are resulting in early discussion of cases and more joint visits. In one district, this has been enhanced through co-location of staff, and the possibility of replicating this in other districts is being explored. Second, there are now monthly multi-disciplinary meetings in each district with a core membership of social care staff, district nurses and the community matron. The Learning Event discussions confirmed that cases such as Edith's would now be raised at these meetings. Third, some GP practices have introduced multi-disciplinary meetings. The SAR heard that discussions are taking place as to whether these should continue as separate arrangements or whether there might be advantages in these being merged.

10.5 Although the SAR was informed that other professionals are able to attend, the home care agencies reported that they are not routinely invited to the meetings. The importance of valuing their contribution was recognised by the SAR panel and that ways must be found to harness their experience and insights, preferably through attendance, or at a minimum through some discussions prior to the meeting and feedback afterwards. Facilitating their involvement has become all the more important because with the reduction in ongoing care management by social care staff because of the volume of work, home carers have increasingly become the "eyes and ears" for statutory agencies in monitoring a service user's situation and reporting any changes in levels of functioning and risks. In addition, it was agreed that there should be exploration of how referral pathways might be simplified so that home care agencies can make direct referrals to other professionals such as district nurses in order to achieve the most rapid response to service user needs.

Concern Meetings

10.6 In addition, while this SAR was being carried out, a report was considered by WSAB in March 2019, setting out arrangements for convening "concern" meetings which would also enable cases to be considered that do not meet the criteria for raising formal safeguarding adults concerns. The objective of this proposal is to:-

- encourage partners, professionals and services to deliver co-ordinated, early responses to issues and concerns about adults, in a proactive and preventative way;

- agree an early multi-agency offer of advice, assistance and support to adults where there are escalating concerns about their well-being and safety.

10.7 The draft proposal explains that the option of convening a "concerns meeting" is open to any professional or agency when it is perceived that risks are escalating, or prevention is required. The proposal purposely does not set out any specific guidance or flowchart on the process to be followed, which is intended to avoid the possibility of professionals not convening meetings because of uncertainty as to whether the criteria are met. It will be important however to reinforce the message that convening

a meeting is a step which can be taken by home care agencies and community health professionals, such as district nurses, who in the past, might not have seen this as a legitimate step they can take.

10.8 Within the hospital, there are daily multi disciplinary meetings, referred to as “team huddles”, which look at the next steps required to progress patients though their stay in hospital and facilitate discharge. These “huddles” include the consultant, doctors, occupational therapist and/or physiotherapist, ward manager, sister-in-charge and the social worker if available, Each patient is discussed with actions and deadlines identified to address all relevant issues which might include:-

- whether the patient is medically fit or needs further intervention;
- estimated date of discharge;
- any physiotherapy or occupational therapy needs, including the need for OT home visits to identify any equipment required;
- assessments that are required to meet any social care needs;
- any possible safeguarding concerns which have been picked up.,
- any referral needed for input from tissue viability nurses, district nurses or community matrons;

10.9 The “huddle” is also a process which is now being used within district social work teams to provide an opportunity for practitioners to discuss cases where people have complex needs or situations where workers feel they have reached an impasse and want to pull on the expertise and experience within the team to find creative solutions. These discussions always include managers, and take place at least twice a week with “mini huddles” being arranged as necessary in emergency situations.

10.10 It will now be important for WSB to receive assurance that these developments are making a difference, and the SAR heard the intention of WSB to include examination of a sample of “prevention” cases within its annual multi-agency audit programme and through its arrangements for “dip sampling” carried out by the Multi Agency Safeguarding Hub (MASH).

10.11 Although all the above arrangements provide a wide range of mechanisms to discuss situations which are causing concern, the SAR identified that there also needs to be an agreed mechanism to escalate cases where there are continuing concerns about high risk cases where action either has not been, or cannot be, resolved at a local level. These high level multi agency meetings could be organised along the lines of the MARAC meetings used in cases of domestic violence. In addition, practice guidance could usefully describe what situations might be viewed as high risk, and what best practice would look like in terms of a co-ordinated multi-agency response.

11. FINAL CONCLUSIONS / SUMMARY OF KEY LEARNING

11.1 The SAR has identified the following good practice:-

- the clinical care provided by health professionals in hospital and in the community which met all expected agency standards;

- the first Care Act assessment carried out by hospital social worker 2 which identified Edith’s support needs and designed the care package;

- the alertness of the home carers in spotting the signs of possible deterioration in Edith’s skin integrity, and immediately reporting this to the GP practice to request referrals to the district nurses;

- the efforts made by the home care agency to raise concerns with both Mr A, and Adult Social Care about the possible risks that would flow from the reduction and then ending of home care support, and the removal of the pressure relieving bed;

- the persistence of the social care assessor in insisting that she saw Edith on her own when carrying out the February re-assessment.

11.2 However, a recurring issue throughout the case was the difficulty professionals experienced in securing the necessary level of engagement with Edith to gain insights into how she experienced her situation, and to be confident that her wishes and feelings about her care had been explored fully and taken into account. There were several references to Edith appearing unwilling to talk when she was in hospital in July 2017, and once she returned home, the opportunities to talk to her alone were hampered by the limited space in the flat, and Edith being aware that Mr A was never far away.

11.3 One factor, which the SAR learning events identified as making this case quite unusual, was the vagueness and evasiveness of Mr A and his family when professionals were seeking to gather information about the home circumstances. As a consequence it was never confirmed if, and how, Edith and Mr A were related. It would have been important to have established the nature of their relationship because this might have had a bearing in understanding the reasons for Edith's poor physical condition in July 2017, and her reported refusal to decline the personal care offered by Mr A and his daughters.

11.4 The fact that health and social care professionals did not probe this sufficiently during the hospital stay in 2017 affected the later reassessments carried out by Adult Social Care. A more in depth understanding of the reasons for the previous problems might have brought sharper focus to consideration on the history and the likely future risk with the ending of all home care support. The request to cancel the service effectively put Adult Social care in the position of being asked to accept Edith being put back into the same situation that existed in July 2017 which had led to her poor physical condition and admission to hospital.

11.5 With hindsight, the decision to address the original safeguarding concerns through only an assessment of Edith's care needs may have been a contributory factor to the insufficient consideration focus later on the possible safeguarding issues in respect of self neglect, unintentional neglect, financial abuse, and coercive control.

11.6 The need for greater awareness of how to recognise and respond to the possibility of coercive control, particularly when it is hidden, and its potential impairment on a victim's mental capacity when making decisions about their care and treatment, is one of the most important areas of learning from this SAR.

11.7 A key issue highlighted by this SAR is the importance of early prevention and multi-agency consideration of cases which give cause for concern. This report has earlier described a number of positive developments in terms of joint working and multi-disciplinary meetings which provide the opportunities for this to happen. It will now be important for WSB to receive evidence that these are making a difference, and they are picking up potential safeguarding issues through dip sampling of cases and multi-agency audits. These should also check that all relevant agencies have been invited to contribute, particularly home care providers.

11.8 Where prevention work is not providing the necessary safeguards, this case has reinforced the importance of applying existing guidance for initiating formal safeguarding enquiries, and the development of a safeguarding plan as necessary, where it is identified that the service user's physical and / or mental health is likely to be at risk as a result of the refusal or termination of support.

12. MULTI-AGENCY RECOMMENDATIONS

12.1 The above summary of the key findings and learning leads to the multi-agency recommendations set out below. In addition to these, the actions identified by individual agencies to address their own learning are attached at Appendix 1.

1. WSB should seek assurance that where it is known or suspected that neglect or self neglect may be placing a service user at risk, but assessments or services have been refused or prevented, professionals always:-

   (a) consider whether there is a need to initiate formal safeguarding enquiries and where necessary, draw up a safeguarding plan;

   (b) make a detailed record of the reasons for any decisions not to initiate safeguarding enquiries.

2. WSB should be assured that where it is identified that a person may be experiencing unintentional neglect by an informal carer:-

   (a) the reasons for this are explored fully with an assessment of the carer's circumstances, willingness and ability to meet the person's needs;

   (b) a carer's assessment is offered to identify their own health and care support needs.

3. WSB should seek assurance that there is evidence that multi-disciplinary meetings, and multi-agency "concern" meetings are:-

   (a) securing the involvement of all relevant agencies;

   (b) enabling home care agencies to contribute their knowledge and perspectives;

   (c) proving effective in co-ordinating early intervention to reduce risk, and are identifying potential safeguarding issues.

4. Wolverhampton Safeguarding Board (WSB) and the Safer Wolverhampton Partnership should seek assurance from its statutory partners that across the partnerships that:-

   (a) professionals are equipped through guidance and training to recognise the indicators of possible coercive control and where this may be affecting a person's ability to make significant decisions such as those about their care and treatment;

   b) there are quality assurance processes in place to support effective and consistent practice in the use of trigger questions and the multi-agency risk assessment tool for cases involving domestic abuse, and in particular cases involving coercive control;

c) that relevant professionals have access to updated legal guidance, including reference to current case-law, on the different legal options which are available to protect adults at risk who may be victims of coercive control.

5. WSB should seek assurance that where time constraints allow, all relevant agencies are approached when additional information is being gathered to inform the response to formal safeguarding concerns that have been raised, and are informed of the decisions made.

6. WSB should seek assurance from the relevant statutory partners that they are satisfied that agencies are applying robust systems and processes to maintain up to date information about a service user's GP, and contact numbers / email addresses for family members or informal carers to be contacted when circumstances require this.

7. WSB should request a report from the relevant statutory partners on the options, such as the use of health and care passports, to enable essential information about a service user and agency involvement, to be accessible to professionals making home visits, or when the person is seen in a clinical setting.