Safeguarding Adults Review (SAR) of the circumstances concerning P

Overview

Claire Crawley, Author, on behalf of the
West of Berkshire Safeguarding Adults Partnership Board
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Table of Contents

1. **Introduction**
2. **The Review Methodology**
3. **P- the person**
4. **Overview**
5. **Pressure ulcers**
6. **Postural management**
7. **Safeguarding**
8. **Analysis**
9. **Findings**
10. **Learning themes emerged that address the terms of reference for the Review**
11. **Conclusions**
12. **Changes in practice connected to this case**
13. **Recommendations for all agencies**
14. **Recommendations for individual agencies**
15. **What next?**
16. **Appendix 1: ACRONYMS USED IN THIS REPORT**
17. **Appendix 2: P Family's view to the SAR**

1. Introduction

1.1. Overview of the circumstances that led to this review

1.1.1. P was born on 4th August 1955. She was diagnosed with secondary progressive Multiple Sclerosis (MS) in 1998 when she was living with her husband K. K assumed the role of carer, but he later became ill himself and sadly died in September 2014.

1.1.2. P was admitted to the Royal Berkshire Hospital (RBFT) on 6th March 2019 with infection, site unknown, and high temperatures that were not controllable by oral antibiotics. She died 6 weeks later on 20th April 2019. She was 63 years old. Her death certificate states the cause of death as 1a) sepsis 1b) infected pressure ulcers and 1c) Multiple Sclerosis.

1.1.3. P had a number of health issues including MS and Scoliosis. Over time P developed severe contractures that were to prove significant in the development of her pressure ulcers. Her poor health was compounded by a history of very heavy smoking and a poor diet.

1.1.4. In January 2016, unable to manage at home, P moved to Y, an extra care sheltered housing facility. Although this facility had its own in-house care team, that team did not have capacity to take on P's care whilst she was a tenant there. Instead P received care from external home care providers; both of whom were reported to the commissioners Reading Borough Council (RBC) for failures in P's care.

1.1.5. In 2018, following a safeguarding section 42 Enquiry, P moved to X, a nursing home, on 14th June that year. This move was recorded as the outcome of the safeguarding enquiry.

1.1.6. Whilst P was in hospital and before she died, members of P's family raised safeguarding concerns with both the hospital and Reading Borough Council about the care X gave P. Her family were particularly worried about P's worsening contractures and severe pressure ulcers; they felt that the services meant to protect her, had failed her.

1.2. Statutory duty to conduct a Safeguarding Adults Review

The Care Act 2014 gave SABs a statutory duty[1] to undertake a Safeguarding Adult Review (SAR):

a) An adult with care and support needs has died and the Safeguarding Adults Board (SAB) knows or suspects that the death resulted from abuse or neglect, or an adult is still alive, and the SAB knows or suspects that they have experienced severe abuse or neglect, and

b) There is reasonable cause for concern about how the Board, its members or others worked together to safeguard the adult.

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[1] Sections 44[1]-[3], Care Act 2014

1.3. West Berkshire’s Safeguarding Adults Board decision to conduct a review

1.3.1. RBC considered that the circumstances surrounding P’s care should be put to the SAB as meeting the criteria for a SAR. This was discussed at the SAR Panel of the SAB on 11th July 2019 when it was agreed that a SAR was required and that the author should be independent and external and commissioned by RBC.

1.3.2. The terms of reference were agreed by the SAR Panel as its meeting of August 2019. The SAB and RBC gave administrative support to the SAR and a senior member of RBC ASC was appointed as the liaison point between the family and SAR author.

1.4. Terms of Reference

1.4.1. The SAR panel identified the areas of concern were in relation to the transfer of P’s care from the community to nursing home. Some areas were identified for particular attention:

- Assessment and care coordination
- The processes for provision and transfer of equipment.
- Communication between the family and services throughout the care.
- Whether the Section 42 Enquiry dealt adequately with the concerns raised and, more broadly, wider risk.

1.4.2. The time period for the SAR to consider was stated as the period covered by the Section 42 Enquiry, 14th March-12th April2019; the SAB request for information from the involved agencies called for chronologies from January 1st 2018 until 20th April 2019.

2. The Review Methodology

2.1. The model for the Review

2.1.1. To help inform the SAR, the SAB requested chronologies of involvement from all the agencies involved with P’s care from 1st January 2018 until her death in April 2019. This also gave them the opportunity to evaluate their own practice, citing any good practice, highlighting gaps and suggesting / implementing improvements.

2.1.2. A significant amount of information was available to the SAR from a range of services, reflecting P’s considerable and multi-faceted needs. I visited X and read P’s care records held there. I conducted more than 20 interviews with professionals and managers who had either been involved in P’s care directly or had insight into or overall responsibilities for safeguarding and quality assurance. These were across agencies and mostly in person although some were telephone calls. I followed up with further discussions as the SAR progressed where I concluded that I needed further information.

2.1.3. There were a number of people that I was unable to see as they no longer worked for the agencies. This was particularly true of those employed by RBC.

2.1.4. Overwhelmingly, those interviewed adopted a reflective and non-defensive approach and many had already learnt from events or were committed to doing so.

2.2. Involvement of P’s family

2.2.1. At the outset of the review I contacted members of P’s family via the liaison arrangements put in place by RBC. It had previously been agreed that one of P’s sons would act as point of contact and communication between members of the family and the Review.

2.2.2. I offered family members a range of options as to how they might participate in and inform the Review, in addition to the information and concerns that they had already presented.

2.2.3. P's two sons and daughters-in- law chose to meet me together in one of the family's homes. All live in Reading.

2.2.4. P's two sisters communicated separately with me and chose to have a telephone conversation. I also had email correspondence provided to me between one of P's sisters and RBC. Both sisters live in Oxford.

2.2.5. P's family were provided with a draft copy of the report in order to discuss the findings with them. This was done via a telephone conference call due to the social distancing restrictions in place at the time. P's family agreed to delete this report after discussions with me had concluded. P's family have provided a statement to go to the SAB alongside this SAR. The statement can be found in Appendix 2.

2.3. Agencies contributing to the Review

Berkshire Healthcare Foundation Trust	BHFT provided community healthcare services to P, including from the neurorehabilitation team.
Royal Berkshire Foundation NHS Trust	RBFT is the hospital that treated P in the last two months of her life.
Reading Borough Council Adult Social Care	RBC is the local authority responsible for arranging social care services for P.
West Berkshire Clinical Commissioning Group	WBCCG is responsible for commissioning health care services for its local population.
X	X is the nursing home where P lived from June 2018-March 2019.
2 GP Surgeries	These were P's local surgeries, one when she lived in the community (including at Y) and another at X.
Care Quality Commission	CQC received complaints about care in X from P's family following P's admission to RBFT

3. P- the person

3.1. Pen picture

3.1.1. P was born 4th August 1955. She married and had two sons, A and D with her first husband. At some point P remarried to K, K was her third husband; they were married prior to P's diagnosis of Multiple Sclerosis.

3.1.2. It was difficult to form a picture of P from her records. From the people I spoke to, including family, P was remembered as "not the easiest of women" and "her own worst enemy"; and at times she seemed to acknowledge this herself. This element of her character predated the onset of her long-term condition. Nevertheless, professionals who persisted were able to get her views and involvement in care planning. P was known to have been a very heavy smoker.

3.1.3. P used a wheelchair from 2005. She stopped independently transferring after K's illness; his subsequent death in 2014 resulted in greater involvement from P's children and their spouses. They worked with adult social care to create a support package for P now that she lived alone. P received support from carers in the bungalow that she had shared with K.

3.1.4. During the period that this Review covers, P was visited regularly by both sons and their wives. There had previously been periods when relationships between P and her sons had been strained and when there was minimal contact.

3.1.5. P's mobility declined further after K died. Despite having carers in to help, her family observed P being "unable to cope" and not taking care of herself. P was having a lot of falls and the ambulance service was receiving frequent calls. At this stage P was still smoking, neglecting her diet (which had been a long-standing issue) and putting herself at risk by leaving the flat in her wheelchair, often not properly dressed, trying to buy cigarettes. When she became unable to do this, she persuaded carers to buy her cigarettes, giving them her bank card and security details to use. P was also letting strangers in, putting herself further at risk

3.1.6. P always preferred to eat sweets, sandwiches and cakes, again persuading carers to give her these rather than hot food with more nutritional value. However, P's family were concerned that P was putting herself at risk and did not understand the potential consequences of her actions. Her sons said that P had not appeared to understand or remember that K was dying, despite this being explained to her. By 2015 P's weight had fallen, she had had several falls and caused burns to herself with her cigarettes.

3.1.7. P lived in the bungalow that she had shared with her late husband until she was hospitalised in 2015 for a range of concerns, including malnutrition. She was discharged from hospital in January 2016 when she moved into Y, an extra care facility. P was supported here by care agencies commissioned by RBC. P lived here until she moved to the nursing home X in June 2018. P was admitted to RBFT on March 6th, 2019.

4. Overview

4.1. Introduction

4.1.1. The chronologies that individual agencies submitted have been brought together by the SAB to enable an examination of the overall period under Review. Where possible gaps in records have been addressed by talking to individuals involved in P's care.

4.1.2. Although her care package had minor changes over the time she lived in Y, essentially P was scheduled to receive 5 2-person calls 7 days a week. At one point there was an, unsuccessful, attempt by RBC to reduce this to 4 visits.

4.1.3. P's sons expressed their appreciation of the staff at Y. However, the lack of capacity of the in-house care service to support P contributed to the fact that P could not be adequately supported here in the longer term. The in-house service was managed on-site, was available on call 24 hours a day, including night-time toilet calls and offered continuity of staff and care. This was very different from the service P experienced from the agencies that RBC commissioned externally. Although untested, it seems to me highly likely that P could have benefited significantly from being supported by the in-house service.

4.1.4. Two different agencies provided care to P during the time she lived in Y. She experienced significant problems with both which were reported to adult social care. I have not seen evidence that RBC took any action of substance in regard to failures of care. P had significant input from health and social care agencies during her time here. Health services were largely focused on prevention and treatment of pressure ulcers although she also received input and treatment with regards to her contractures and everyday health needs.

4.1.5.I have taken as my starting point the beginning of the chronologies that agencies provided, January 2018, as these provide some detail about the early and growing concerns about P's care.

4.1.6. P’s family are particularly unhappy about the management of and communication about P’s contractures and pressure ulcer care, the latter are cited on the death certificate as a contributory cause of death.

4.1.7.The hospital care given to P after her admission to the Royal Berkshire on March 6th, 2019 until her death on April 20th 2019 is detailed and well-documented. Neither the family nor others have questioned the care and treatment given in hospital and the records demonstrate an appropriate and thorough clinical response that involved many disciplines and professionals. The records show clear explanations and communication with the family throughout, allowing time for family discussion prior to any decision-making.

4.1.8. I have examined the chronologies and records agencies provided in relation to P’s care. I subsequently explored the significant themes that emerged with a range of staff involved in P’s care.

4.1.9. Although this Review has a focus on P’s transfer to X it was necessary to examine this move in its wider context and consider the care P received in the months leading up to her move into X.

4.1.10. P’s health had deteriorated over a much longer period of time and I found gaps in the earlier periods of care that arguably contributed significantly to what came later.

5. Pressure ulcers

5.1. Context

5.1.1. Pressure ulcers can have a major impact on the health and quality of life for individuals. Prevention is the best option as treatment of pressure ulcers is not always successful. Pressure ulcers can be serious and lead to life-threatening complications such as blood poisoning or gangrene. Pressure ulcers are graded with increasing severity from category 1-4 and identification followed by treatment at an early stage reduces the likelihood of them progressing further.

5.1.2. Whilst the provision and correct use of pressure relieving equipment can assist in prevention and treatment, equally the provision of the wrong seating and sleeping options can increase the chances of someone developing pressure ulcers.

5.1.3.The following is extracted from the National Institute for Health and Care Excellence (NICE) guidelines on the prevention and treatment of pressure ulcers:[2]

Risk assessment

Carry out and document an assessment of pressure ulcer risk for adults:

- being admitted to secondary care or care homes in which NHS care is provided
- or receiving NHS care in other settings (such as primary and community care and emergency departments) if they have a risk factor, for example:
    - significantly limited mobility (for example, people with a spinal cord injury)
    - significant loss of sensation
    - a previous or current pressure ulcer
    - nutritional deficiency
    - the inability to reposition themselves
    - significant cognitive impairment.

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[2] https://www.nice.org.uk/guidance/cg179/chapter/1-Recommendations#prevention-adults

5.2. January-June 2018; Y.

5.2.1.This was a critical period in the development of P's pressure ulcers.

5.2.2. On January 2nd2018 the DN (district nurse) visited P to check a moisture lesion on her sacrum and discovered pressure ulcers on P's heels. One was a category 4, the severest classification and should have immediately raised serious concerns.

5.2.3. The A agency carers had known of, but not reported these, despite inter-agency guidance to the contrary. To compound this, carers had not used the gel pads the DN prescribed to help prevent this.

5.2.4. The DN immediately agreed with P the provision of a ToTo (lateral turning system for the bed) to be used in conjunction with gel heel pads. This was delivered on January 4th, 2018.

5.2.5. The DN also referred P to podiatry and she completed a Datix record (health online incident reporting system) about the non-reporting of the pressure ulcers. I would have seen expected to see evidence that RBC thoroughly and robustly challenged the agency about this but did not seen anything that suggested this was the case.

5.2.6. Now the DN was aware of the pressure ulcers, she devised a clear management plan. But there are a number of entries in the records that show that agency carers' adherence to the plan was variable over the next six months. Only a week later, on 10th January, a week after DN knew of pressure ulcers, she again found that the left heel pad was not in place and P was complaining of the pain. This should have sounded warning bells and prompted an escalation of action and concern

5.2.7.Over the next 2-3 months there were incidents of the carers turning off the ToTo, not using the gel pads and using Kylies (an absorbent sheet with waterproof backing) and DN advised that these should not be used as they tend to become bunched up and have the potential to worsen skin.

5.2.8. Nevertheless, P's skin improved sufficiently that the district nurse was able to reduce her visits to weekly. During this period care was transferred from agency A to B, a different home care agency; a change had been agreed some months previously following dissatisfaction with A but had taken time to implement due to lack of availability of an alternative provider.

5.2.9. However, by April the DN was visiting P daily again as she had category 4 pressure ulcers on her sacrum and foot; over the next weeks there were also more DN reports of the carers switching off the ToTo to give personal care but not turning it back on again. Again, concerns should have been escalated about this agency's capacity to adequately care for and support P.

5.2.10. On April 26th DN noted an increase in pressure damage. There was lots of pressure on the category 4 pressure ulcer on P's foot when she was in bed. She also had a small blanching blister on top of her big left toe.

5.2.11. The category 4 pressure ulcer was recorded by a podiatrist as caused by P's foot positioning in the wheelchair, her foot was dropped and was resting heavily on the foot plate. P also had a moisture lesion under her right breast and under her left arm. The DN changed P's mattress to an Elite air mattress to try and improve matters. The absence of a named care coordinator and effective multi-disciplinary working limited the care improvements that might have been made at this stage.

5.2.12. By May 15th the moisture lesion under P's breast had healed. The sacral sore (mentioned in 5.2.8) was noted to have reduced in size. However, now the wound on P's ball of the foot that had previously been recorded as a blister had deteriorated. It was noted that P's foot was pressing against the wheelchair. The DN requested another Podiatry review.

5.2.13. Following a telephone call with the Podiatrist it was agreed to recommend P be on bedrest and to consider an x-ray to rule out Osteomyelitis if still concerned. The DN's discussed this in a team meeting and agreed to ask the GP to organise an X-ray as delay was risky.

5.2.14. Osteomyelitis is an infection of the bone, a rare but serious condition. Bones can become infected in a number of ways: Infection in one part of the body may spread through the bloodstream into the bone or an open fracture or surgery may expose the bone to infection.

5.2.15. The DN advised the care agency that P should be on bed rest and subsequently followed up to check that the advice was being followed.

5.2.16. On May 21st, 2018, P had an x-ray of her heel that found no evidence of osteomyelitis or fracture.

5.2.17. Two days later the GP visited to review P's wound and prescribed antibiotics for the infection. Because of the deterioration in P's left foot, DN made daily visits to dress it.

5.2.18. By June 1st the wound was larger, and the GP was again consulted, who prescribed more antibiotics.

5.2.19. By June 3rd, 2018 the DN noted new category 2 pressure ulcers to top of P's left foot and carried out daily visits to dress her wounds.

5.2.20. PA was admitted to X 14th June 2018. At this point she already had pressure ulcers to both legs and heels and a pressure sore to the sacrum.

5.3. X June -December 2018

5.3.1. X requested a Podiatry review shortly after P's admission and this took place on 28th June. This noted that a pressure-relieving mattress and heel pad were in place and P's feet had generally improved.

5.3.2. By 11th October the picture was quite different. A Podiatrist noted: "P was in a fixed contracted position in bed, screaming and crying when her leg was moved. Doesn't like to be turned by staff and will move herself back into her 'normal' position." The podiatrist recommended "conservative treatment" as no further intervention was available as pressure was the cause of the deterioration with advice to refer back to podiatry if further deterioration was observed.

5.3.3. The podiatrist was unable to fully assess as P became very distressed when her legs were touched but she noted the presence of 2 x Cat 4 pressure ulcers on P's heels.

5.3.4. The GP visited the next day and prescribed antibiotics. By 26th November the pressure ulcer on P's sacrum had deteriorated; she was seen by the GP, antibiotics were again prescribed.

5.3.5. X requested another Podiatry review on 28th November. This took place the next day and multiple pressure ulcers were recorded. The podiatrist noted that there had been considerable deterioration in skin integrity of the foot since the previous visit in June and observed that P's nails were long and curving. The podiatrist was querying a systemic infection and the possible need for IV antibiotics and requested an urgent GP review.

5.3.6. The GP visited and continued antibiotics. The GP visited P a total of 14 times whilst she lived in X.

5.3.7. P was seen again by podiatry on 4th December who advised continuing with redressing and monitor for infection and continue course of oral antibiotics.

5.3.8. X nurses were using a shaped cushion to prevent P from putting her legs into a contracted position. The podiatrist advised dressings twice weekly by nursing staff at the home, there was no planned podiatry follow-up, but P's referral was "live" so that the home could quickly refer back directly to podiatry with any further concerns.

5.3.9. On December 15th 2018, P was seen by the GP, the wound on sacrum was described as "offensive" in records and the GP visited and prescribed antibiotics. I could find no reference (response)to the request to consider IV antibiotics or why oral antibiotics were not proving effective.

5.4. January-March 2019

5.4.1. The GP saw P on January 4th 2019 when there was no change to her sacrum. The GP visited again on 7th January and prescribed Icthopaste. This is normally used in the treatment of leg ulcers.

5.4.2.On January 17th X sent a referral sent to the Tissue Viability Nurse (TVN) service and notified the Care Quality Commission (CQC) of pressure ulcers on 21st January. The results of a swab were received on 22nd January and antibiotics again prescribed.

5.4.3. The Tissue Viability Nurse saw P on January 24th and made recommendations for the dressing of P's sacrum wound and noted an appropriate mattress was in use. P had already been seen by the Dietetics department. X was to ensure that prescribed food supplements were available to P as she needed protein to help heal the ulcers. The TVN also contacted the Occupational Therapy service (OT) in regard to re-positioning equipment due to contractures.

5.4.4. TVN reviewed P again on 25th January and recorded a category 4 pressure ulcer to P's sacrum. The GP reviewed P on 12th and 19th February.

5.4.5. On March 6th X called podiatry and TVN about deterioration of P's wounds. The same day X contacted the out of hours GP who visited and arranged for P to be admitted to Royal Berkshire Foundation Trust (RBHFT). By this time P had been receiving oral antibiotics consistently, albeit not quite continually, for six months.

6. Postural management

6.1. The term "postural management" is a term that is now frequently used by the Berkshire professionals I talked with but was relatively unknown outside of the allied health professions during the period that this Review covers. Essentially it is about achieving good positioning for an individual who is unable to do this for themselves.

6.1.1. P's access to appropriate pressure relieving and positioning equipment is one of the questions that this Review was asked to look at. It was quite difficult to establish an accurate picture as various professionals ordered equipment at different stages of P's life and these were not always recorded in the same place.

6.1.2.The NRS system that tracks equipment was described to me by an OT (in relation to P's equipment) as "vague and inaccurate" so the chronology here has been established by reference to P's notes on the Adult Social Care database the clinical notes of a number of individual professionals and the NRS (equipment store) records.

6.2. November 2017-June 2018: Y

6.2.1. P had taken a specialist reclining chair with her to Y, one that she had been provided with before the involvement of RBC Adult Social Care (ASC). From August 2017 she was supplied with Symmetrikit cushions to help position her in bed.

6.2.2. An RBC Care Coordinator (CC) visiting in November 2017 (to gather information about a safeguarding referral) noticed that P looked very uncomfortable, her head facing downwards because of the positioning of the chair and realised she needed to involve the council's OT service.

6.2.3. It transpired that P was slumped in her chair because the back of the chair was now too upright, P was unable to position herself and there was not enough support to stop her leaning over (her scoliosis meant that she leant to the right). This badly affected her ability to eat, drink and swallow. The OT assessed P as needing a tilting chair, which would also help to prevent further curvature of the spine. The seat of the chair remained suitable, but the back rest needed changing.

6.2.4.During the assessment process the OT and CC found old food stuck on the inside and outside of chair and covering the control box when changing the back of chair (from a Sorrento to Phoenix), which apart from being unhygienic could have caused it to malfunction. The chair was described as filthy, months and months of spilt food that had never been cleaned up. It was said to be impossible to get completely clean. This suggests a consistent lack of appropriate hygiene procedures on the part of the care agency; care agencies' responsibilities in this area are contained in the regulations governing registration.

6.2.5. Meanwhile, the DN had prescribed pressure relieving equipment for P's bed. One was the ToTo, a system that moves the person and is electronically operated on a timer to gradually turn the person.

6.2.6. In March 2018 an OT from the Community Based Neuro Rehabilitation Team West Berkshire Community Hospital (WBCH) prescribed Symmetrikit cushions. The Symmetrikit sleep "system" is a series of brackets that prevents a person's posture from pulling them further out of line and is not electronically operated. It relies on each individual care worker to place the brackets or positioning cushions in the right place every time. Symmetrikit cushions can also be used without the brackets.

6.2.7. In February 2018, the OT responsible for reassessing P's seated positioning requirements ensured that the new equipment was trialled before it was purchased, to ensure that it was suitable and fit for the intended purpose; the changes included a different chair back to be used with wedges and cushions to relieve pressure and promote comfort.

6.2.8. Once the new equipment was in place the OT arranged a demonstration for the carers on the use of the chair and positioning equipment. The OT sent laminated photographs of P in her chair demonstrating the moving and positioning of equipment (taken and shared with P's permission) to the home care agency so that all carers visiting the home would understand how the equipment was to be used to ensure P's comfort and, importantly, to relieve pressure that might led to pressure damage. These photographs were supposed to be displayed in P's home straightaway, but it was later discovered that they were never placed in her home but kept in the agency office for the next four or five months and were still there when P was admitted into X.

6.2.9.The OT discussed with P the possibility of installing a ceiling track for use with a particular hoist that could reduce the number of transfers she would have to undergo but P refused, saying that didn't want her flat to be over-medicalised.

6.2.10. There were access hoists in P's flat that the OT removed (because of the risk of carers using them) as they were now considered unsafe for P. P retained her bespoke equipment until she was admitted to X.

6.2.11. On June 18th2018 the management of Y arranged for P's positioning and pressure relieving equipment to be collected and returned to the store, including equipment bespoke to P. The records state that this was at the request of the DN service. No-one realised, noted or requested that some of the equipment was specifically prescribed and provided for P and should have transferred with her. The social worker, care home and district nurse all shared a duty of care to ensure that P took the equipment to the care home that she needed but there seems to have been no communication between them on this subject.

6.3. X

6.3.1. The identification of postural management by the Integrated Care Home Service team (ICHS) as a general issue led to a pilot project to address postural management education in nursing and care homes. This included holding learning events for care staff and other professionals that highlighted the importance of postural management equipment.

6.3.2. P was admitted to X in June 2018. On admission, P was cared for on a standard pressure-relieving NOVA Alternating Air mattress without the benefit of additional specialist equipment such as that which had been prescribed and provided for her at home and at Y.

6.3.3. P was in bed at all times after her admission. She did not use the chair customised for her use that her son brought from her previous home. However, the Review notes that given the severity of her pressure ulcers and contractures there was a doubt that she would improve enough to use it although this was never communicated to the family.

6.3.4. In January 2019, as part of the work that led to the pilot mentioned above, P was seen in X by a member of the ICHS team, approximately seven months after her admission to X.

6.3.5. The ICHS team initially had to defer the postural assessment as P wasn't considered able to be moved from bed at that time as her contractures were too severe and moving would have caused her considerable pain. The team's first step was to review P's pain relief and prescribe the use of positioning cushions in the bed.

6.3.6. At the same time, Botox injections that P had received in the past were also being reconsidered to give P some relief from the contractures and allow her some movement.

6.3.7. The ICHS team arranged to visit P with a representative from one of the specialist equipment companies to decide whether a KomfiTilt turning system would help P, essentially similar to the ToTo mattress P had once used at home but a more gentle and simpler system with only on / off controls. By this stage the OT considered it highly unlikely that P would use her chair again and agreed with P for it to be removed as it took up a lot of space in her room and had things piled upon it making what was already a small room feel smaller and it also restricted the space available to care for P.

6.3.8. On February 28th Symmetrikit cushions were supplied and the placement of cushions discussed by the ICHS with home staff: P had been referred to a bed at WBCH for Botox treatment. The OT completed a positioning profile for staff to use until a reassessment in WBCH following her planned Botox.

6.3.9. The ICHS team visited P again in February and by then the GP had prescribed pain prevention patches. However, the Komfitilt could not be fitted under P's mattress as she needed another bed to move into whilst that happened. The fitting was rearranged for a couple of days later and a spare bed temporarily put in place that P was moved to, allowing the new equipment to be fitted. This was only in place a short time before P was admitted to hospital.

6.3.10. Following this a sleep system of cushions was constructed. Laminated sheets showing the correct placement were left for X staff. This was to be kept under review by the ICHST in case changes needed to be made. Botox was again discussed at the end of February but before a hospital bed became available at the WBCH, P was admitted to the RBFT with an uncontrollable temperature and infection.

6.3.11. The ICHS team kept in regular touch with RBFT after P's admission. The OT contacted the physiotherapist working with P in RBFT and advised about the specialist cushions which had been ordered prior to P's admission to hospital and that they may aid good postural positioning, it was agreed that the OT would contact P's son and ask if he would collect the equipment from X and bring them to the ward at RBH, he said was happy to do this which he did.

6.4. RBFT March 6th-April 21st2019:

6.4.1. On admission to hospital P was nursed on a Hybrid mattress before being upgraded to a Climatic mattress.

6.4.2. P was recorded as having sepsis with pressure ulcers as a possible source. She had extensive pressure damage to both her feet, sacrum and buttocks with other areas of pressure observed including her left hip.

6.4.3. The hospital noted that pressure damage was already well known to DN in the community and had previous input from TVN and so it did not meet the criteria for the hospital to raise a safeguarding concern about care at the home. A safeguarding concern should have been raised, although this patient was safe and receiving appropriate care, the safeguarding of others in X needed to be considered.

6.4.4.The hospital started a course of treatment to manage and try to reverse the contractures including Botox injections, which P had received before. Members of the healthcare team formed the opinion that the development of pressure ulcers was almost inevitable given the severity of P's contractures. There was difficulty re-positioning throughout P's admission due to the contractures, even with pre-emptive analgesia.

7. Safeguarding

7.1. Context

The Care Act 2014 put adult safeguarding on a statutory footing for the first time. [3]

7.1.1. Multi-agency SABs had to be created [4] and are responsible for adult safeguarding in their area. Local authorities were able to join together in one SAB and this is what happened in Berkshire. The West Berkshire SAB local authority members are: Reading, West Berkshire and Wokingham. The local authority responsible for P's social care was Reading Borough Council.

7.1.2. One of the functions of the SAB is to ensure that policies and procedure for adult safeguarding are effective and workable in practice. Whilst procedures rightly do not prescribe one process for all safeguarding concerns, nevertheless they do remind agencies, managers and practitioners of the principles underpinning safeguarding and of the primary focus of any enquiry, that being the wellbeing of the individual. Professionals are encouraged to exercise judgement and seek guidance from others, including line managers. The Pan Berkshire adult safeguarding guidance on managing risk makes a helpful distinction, encouraging staff to adopt "defensible decisions" rather than "defensive actions." [5]

7.1.3. There were a number of safeguarding concerns raised in relation to P's care over the years, going back to at least 2016, so some predate the scope of this Review. Quite how many is difficult to establish as not all led to a formal section 42 Enquiry and the recording of both concerns and responses is not consistent nor always informative.

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[3] https://www.gov.uk/government/publications/care-act-statutory-guidance/care-and-support-statutory-guidance#safeguarding-1

[4] https://www.gov.uk/government/publications/care-act-statutory-guidance/care-and-support-statutory-guidance#safeguarding

[5] https://info.westberks.gov.uk/CHttpHandler.ashx?id=37406&p=0

7.2. Safeguarding 1 Y 2017

7.2.1. The safeguarding referral date nearest to the beginning of the time period used here was November 2017 when a DN raised a safeguarding concern about agency A's mismanagement of P's pressure ulcers. This was allocated to an RBC CC to gather information in relation to the concern (not a section 42 Enquiry at this stage as those were only progressed by social workers and OTs with additional training). She contacted family and visited P, including when P's family were present.

7.2.2. She was still involved on 10th January when the DN raised another safeguarding concern about the care agency with the local authority, via Datix. "Carers were not following DN guidance in regard to use of gel pads or equipment (ToTo) and were not reporting new pressure areas to the DN. Again, this was not allocated to a Section 42 Enquiry and the overall outcome is recorded as:

- DN to monitor pressure sores and re-dress regularly.
- Provider to investigate further as to why pressure ulcers hadn't been reported sooner.
- QPM (Quality and Performance Management team) alerted to follow up with care provider to be more vigilant with monitoring the pressure sores and report appropriately.

7.2.3. The care coordinator emailed QPM to advise of the above. It appears to have been left to the care agency to decide what if any action should be taken, both in relation to failures in care and going forwards.

7.2.4. The care coordinator (CC) remembers it being difficult to engage P in discussion at first, but she persevered and remembers P chatting and also showing a sense of humour. The CC couldn't verify the neglect the family alleged herself (as P was in too much pain to be moved) but saw photographs that the family had taken.

7.2.5. At this time P talked of wanting to die, was low in mood, saying her life was spent just waiting for carers, but felt that they didn't listen to her when they did come, for example when they were undertaking personal care. This meant that when P roused herself to speak to the carers it was usually because she was in severe pain and then was often verbally abusive, swearing and shouting.

7.2.6. The CC recalled a discussion about care homes and that P was adamant that she did not want to go into one. However, the family were keen for this to happen as they were "desperate" to get P proper support. The family felt that they had tried the alternatives, had consistently raised detailed concerns about P's care but that P's health and overall well-being continued to deteriorate.

7.2.7. After this "gathering of information" stage the CC's line manager was approached for decisions which are summarised above. As well as the concerns the DN had originally notified, and which were added to by the family, the CC observed a number of errors and omissions. The moving and handling risk assessment on the file in P's home; as with the rest of the Care Plan available was out of date by two years, dated 12/01/16 – with a review date of 12/04/16, that had not been completed. The Medication Administration Record (MAR) sheet was not completed accurately with no mention of what medication had been given. These are serious omissions.

7.2.8. RBC records state that the care provider responded with proposed actions to address the gaps, but the allocated worker noted: *"Visited today (1 February) records are still not update, no new information in file, no manual handling assessment, despite Occupational Therapist having completed and sent through two in 2017."* The recorded "outcome" was that the DN would continue to dress pressure ulcers and "monitor" the situation. Additionally, it was agreed to commission an alternative care provider but in the meantime: *"Current carers know P well and are able to meet her needs until new package can be put in place. OT visiting next week."*

7.2.9. This was despite the fact that the agency was being changed because P's needs were in fact not being adequately met. In response to the other care concerns that the family had raised, the CC contacted the care provider. The latter responded that up to date care plans were in the office, as were the detailed instructions for positioning, moving and handling P. The CC stated that the plans were still out of date when she ceased to work with P some months later.

7.2.10. P's family agreed to a change of care provider but were unconvinced that there would be significant improvement, indeed were worried that it might be worse. The CC approached the Y in-house team again, but they still lacked the capacity to take over P's care. The QPM team was again alerted to concerns about agency A.

7.3. Safeguarding 2 Y April 2018

7.3.1. The next significant safeguarding referral was made in April 2018 in relation to the care agency B (that later transferred and became C care agency) that RBS commissioned to replace A. This was designated as a Section 42 Enquiry.

7.3.2. P's son reported alleged neglect of his mother and this was mirrored with yet another set of concerns raised by the DN.

7.3.3. P was made aware of the Safeguarding referrals and the reason for them and she was recorded as agreeing that they should be explored. P's family's concerns:

- *The client being left in bed after morning calls.*
- *The client being left in uncomfortable position, knowing that the client is at high risks of pressure sores,*
- *Carers continuously resetting Toto mattress. There are no signs of carers supporting the client with having breakfast.*
- *Client`s hair is not being washed and brushed, resulting in clumps forming and needing to be cut out.*
- *Client`s home environment is being neglected by the carers (food left out overnight, bins overflowing.*

P was made aware of the Safeguarding referrals and the reason for them and she was recorded as agreeing that they should be explored.

7.3.4. The referral from the district nursing service:

"P is being visited by the District Nurse because of a moisture lesion. There has been significant deterioration and the lesion has turned into a pressure sore. The reason for deterioration seems to be that the carers were not using the equipment designed to reduce the moisture lesion. There was a 'ToTo' in place, which the care agency were not turning on and using, and also they have a 'Kylie' in place which decreases the effectiveness of the Toto. [D/Nurse] would like to report the incident as a Safeguarding due to the Care Company not using the equipment provided and not following recommendations as to its use."

7.3.5. P's family detailed serious concerns included the carers not staying for their allocated time, sometimes not visiting at all and falsifying the call log. Her family had found P in bed at 5.30pm one day but the carers had already completed the call log for 8pm. On one occasion it was allegedly found that P had been left in the same incontinence pad and without calls between 6pm until 8.50am the next day. The DN had also alleged that P was not being given her Baclofen, medication that was important to relax P' s muscles to allow movement and reduce pain. Extremely worrying was the allegation that the DN had witnessed carers forcing food into P's mouth. I can see no evidence of action by RBC on this last very serious allegation.

7.3.6. The allocated Social Worker (SW) took over a month to follow up the referral. She did not discuss these allegations with the DN that had made the referral nor the home carers providing hands-on care although she did belatedly email the agency asking for some information. Following her visit, the SW asked the provider to investigate the alleged failures of care, but a week later, before the provider had responded, the decision was taken to move P into a care home. The information the provider gave was inadequate and was provided after P had gone into hospital. The decision to move P seems to have been taken by a few professionals and family and although the SW records P's agreement, it is hard to reconcile this with her previous opposition to moving to a care home. The SW's contract at RBC was terminated due to poor performance, including in relation to P.

7.3.7. Because of P's known opposition to moving to a care home, RBC should have offered P an independent advocate or provided an IMCA (if she were assessed as lacking capacity to make the decision) appointed to support her in coming to a decision. [6]

7.4. Safeguarding referral 3 Y April 2018

7.4.1. In what seems to have been a "counter" allegation, on 16th April, the agency carers alleged that the DN was not dressing P's heels and had tried to dress pressure ulcers on P's buttocks when P was trying to open her bowels, risking infection. The information was passed from the Safeguarding Adult Team to RBC locality team, to incorporate onto the existing Section 42 Enquiry. On 16th April a different district nurse SM and a district nursing sister did a joint visit for a scheduled dressing. The sacral dressing was noted to be falling off. The sacral wound was cleaned with Proshield spray and a new dressing was applied. A photograph was taken with consent. There is no mention in the record that the dressing was soiled or that there was any sign of infection or worsening of the pressure sore. It would be normal practice to record in the record if a pressure sore had worsened or become infected or if a fouled dressing was removed. Had a dressing been applied when a patient was defecating the dressing is likely to have been soiled and for the wound to have worsened and be red and infected, but photographs taken at the time show that this was not the case. The wound was recorded as improving the next day, 17th April.

7.4.2.The social care records state that referrals 2 and 3 above were incorporated into one S42 Enquiry.

7.4.3. In June 2018, RBC's record (Mosaic) states the agency sent a response through to RBC about the allegations of failure in care but the document was not attached to the RBC system. The C care agency manager has searched their archived files but cannot find a copy of their response to give me.

7.4.4. On May 21st, 2018 RBC records that C transferred P's care needs onto the rota system (people planner) and "identified that calls were not being completed at the correct times and for the correct length of time. Daily care notes were audited, and this confirmed our concerns. This was discussed with the Care Manager and care workers who supported P". I consider this to be a light-touch approach to such serious concerns.

7.4.5. Although the provider accepted that the failures in care happened and did suspend the staff in question, the latter were allowed to leave the agency without any action being taken or any recorded consideration given to making referrals to DBS. The same is true of the agency registered care manager who was responsible for overseeing P's care package; she also left; I was told that she was working elsewhere in the care sector.

7.5. Safeguarding 4 January 25th, 2019 X

7.5.1. This referral came about as a result of a TVN's review of a category 4 pressure ulcer. The TVN completed a Datix entry and raised a safeguarding concern about the lack of postural management service for P.

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[6] 6 https://www.gov.uk/government/publications/care-act-statutory-guidance/care-and-support-statutory-guidance#safeguarding-1

7.6. Safeguarding 5th March 2019 X

7.6.1. The RBHFT notes tell us: "Son thinks that a safeguarding concern should be raised against the care home; he's been assured that we will do it". The hospital has no record of concern raised internally or externally at this time as the son was unsure whether he wanted to pursue. He decided to discuss with family before deciding if they wanted to take it any further.

7.6.2. On March 14th, 2019 D (son) called the Lead Nurse Adult Safeguarding at hospital saying he wished to raise some safeguarding concerns about the care P was receiving in X prior to coming to hospital; the concerns were about the pressure damage, that the pressure damage has been getting worse. The hospital raised a safeguarding concern with RBC and agreed that P could not be discharged until this was investigated.

7.6.3. On the same date CQC received (on their on-line "share your experience" form) and passed on to RBC the following concern from P's sister: *"4 bed sores. She was kept in bed at X for them to heal. However last week she was taken to Royal Berks hospital with a temperature & remains in hospital with Sepsis & a new water infection. She now has sores on her ankles & inside of her knees. Along with this the skin around her private area is compromised - she is incontinent. This all suggests that having been transferred to X for the purposes of healing she is in fact worse. Her lips are all broken out due to dehydration & her teeth have clearly not been kept clean. the hospital staff are raising concerns of neglect I'm assuming with Social Care at Reading Borough Council. Everything that has happened to her is preventable & I'm appalled at the level of neglect clearly visible when you see her. She is only 63 with early dementia & MS."*

7.6.4. RBC began a Section 42 Enquiry in relation to the family's concerns, which were also in a letter P's sister emailed to the Director of Adult Social Services (DASS) on 12th March.

7.6.5. A lead worker was allocated, an Assistant Team Manager (ATM) in the hospital social work team independent of P's care.

7.6.6. The ATM carried out the Enquiry promptly, but it was somewhat hampered initially by the closure of the ward, where P was a patient, to visitors because of an infection. So, it was not until 5th April that he was able to visit P and ask for her views, although he had by then spoken to P's sons, the home and hospital staff, ascertained that there were no concerns about the care P was receiving in hospital and that she was in a safe place.

7.6.7. On April 5th P was able to communicate with the ATM (ward staff saying that she was having a good day) and he considered that P had the capacity to do so. P was aware of where she was, where she had been living prior to admission and was content to return to X when better. However, she also thought that her pressure ulcers were caused by lying in bed because the staff did not have enough time to get her up. As the conversation went on P became drowsy. He intended to visit again the following week but did not do so as her condition by then had deteriorated.

7.6.8. The hospital staff told him and P's family that medical staff considered the pressure ulcers were unavoidable given P's advanced contractures. P's family thought that more could have be done to prevent the worsening of P's contractures and that keeping P in bed at all times in X exacerbated the situation.

7.6.9. On April 11th, the ATM visited X to see P's room, examine P's care notes and talk to staff. He saw her room and found it to be neat and tidy, having been unused for a month.

7.6.10. The ATM then arranged a meeting with P's sons and X on April 12th to discuss the concerns. The focus of the meeting was an opportunity to put the family's concerns directly to the home's managers and hear their response. The meeting is recorded as providing some reassurance for the family that P had been receiving significant and appropriate input from a range of professionals during her time there, despite that not being communicated to the family at the time. The family was still concerned about the cleanliness of P's room and her ability to reach her table but no conclusions on these areas were recorded.

7.6.11. The ATM concluded that the information shared at this meeting and reassurances from X about future communication resolved the safeguarding issue and agreed P would return to X once well enough for discharge. It is unclear if the family agreed with the conclusions although they are recorded as "feeling better now they had a good understanding of professionals that have been involved and the appropriate action that has taken place".

7.6.12. At this stage there was clearly a shared expectation that P would recover and be discharged.

7.6.13. The enquiry was signed off on 30th by the OT lead within RBC.

7.6.14. The notes and the conclusion of the Enquiry was not shared in writing with the family, so we do not know if they felt at that time that it reflected the discussion.

7.6.15. My subsequent discussions with P's sons discovered that they were unaware that this meeting was held in relation to the Section 42 Enquiry but thought that it was held to facilitate a safe return for P to X when discharged as there appeared to be no other available placement and P herself said she was not opposed.

8. Analysis

8.1. Introduction

This section looks at the factors that may have impacted on the care provided to P, including how well a multitude of agencies and individuals worked together to support P.

8.1.1. The Safeguarding Adults Team (SAT) accepts and screens initial safeguarding referrals where there is not an allocated social worker. If a referral requires further action it is sent to the appropriate operational team unless it is deemed "organisational" in which case the SAT is responsible. In P's case it could be argued that organisational abuse or perhaps a joint approach with the appropriate team should have been explored given the concern was about RBC commissioned services. There seems to be no evidence that QPM acted.

8.1.2. The SAT team has a role in giving advice to providers where care workers are being investigated but I did not see anything that suggested that this happened with either home care agency that delivered P's care.

8.2. Assessment of risks and needs

8.2.1. The guidance to the Care Act 2014 describes at some length the need to involve people in their own assessment and care planning, with support as necessary; that assessments should be carried out by appropriately trained workers and should be holistic in order to promote the individual's overall well-being. The guidance emphasises the benefit of joint assessments where a range of professionals can contribute their knowledge and expertise to develop the best possible plan for the individual.

8.2.2. I heard more than once that there were staff that had misinterpreted the Care Act (2014) and the Making Safeguarding Personal personalisation approach (MSP) and that one result was that the use of Multi-Disciplinary Team (MDT) meetings had declined notably since its introduction.

8.2.3. MDT meetings (whether termed strategy meetings or not) can be remarkably effective in sharing information, identifying and managing risk thereby ensuring improved outcomes for individuals. P's care plan suffered as a result of the absence of these.

8.2.4. P's notes accurately referred to her as having MS and scoliosis; P had secondary progressive MS which has a prognosis of increasing spasticity and cognitive impairment. The assessment of needs in the social care records were largely focused on P's need for support with activities of daily living rather than a broader, holistic assessment of P as a person. This may be a deficit in recording or practice but my conversations with professionals and P's family suggest it was a combination of the two.

8.2.5. The social care records that I saw did not set out the wider potential impact of the disease, neurological, psychological as well as physical that would have been well known to the specialist health services that were involved with P. There were no alerts on file that MS can cause cognitive impairment, memory loss, or that it can manifest itself in confusion and problems with word finding. If these matters were discussed it is not evident in the social care file.

8.2.6. The risk of MS causing contractures is well-known within the neurology service and some allied professions but was much less familiar to other professionals.

8.2.7. P's social care records did not describe the link between contractures and the prevention and management of pressure ulcers. Nor did they reflect any understanding of the preventative and positive role that equipment could play. This highlights the gaps that are exacerbated by a lack of a multi-disciplinary joint approach and sharing of information.

8.2.8. P's risk of developing pressure ulcers was high, well known and documented throughout her care history. Although, not included in her social care assessment, P was at added risk of developing them not only because she had MS but also a history of poor nutrition and heavy smoking, both delaying collagen production, which can also make MS worse.

8.2.9. It is clear from the NICE guidelines that P was at very high risk of developing pressure ulcers as a number of the risk factors highlighted in NICE guidelines were present.

8.2.10. The development of pressure ulcers pre-dated P's admission to X by some considerable time, at least six months (the period for which I have information). Over time P suffered both from moisture lesions (on fleshy parts of the body) and pressure ulcers on more bony places, particularly her ankles and feet.

8.2.11. Despite appropriate equipment being provided for P at Y, alongside instructions for its use, there are repeated instances of the equipment not being used properly, in particular the pressure relieving equipment and dressings. There are several instances of the ToTo being turned off despite repeated instructions to the contrary.

8.2.12. In addition, carers at times were found to be using items that were potentially worsening P's skin integrity such as Kylie sheets.

8.2.13. I saw no evidence that assessors and providers of care considered the impact pain and immobility can have on mood and "compliance" with care or developed a management plan to deal with this.

8.2.14. P was a young woman when she was diagnosed with MS and was still relatively young when she died. Consideration of the loss of independence and all that goes with it hardly features in P's social care records. The support plan also paid scant attention to P's hearing impairment and her need for carers to explain what they were going to do slowly and clearly and offer reassurance. The assessment of risks and needs was poorer as a result of these omissions.

8.2.15. So, although P's notes health and social care notes occasionally have some references to P's mood and possible depression, these concerns did not make a significant appearance in her care plans or in the tasks assigned to care workers. Not only were these aspects of her health important in their own right but also are likely to have had a major impact on her perception and experience of the physical care that she was receiving, including her willingness to undergo the discomfort and pain that she knew would happen as a result.

8.2.16. There is some consensus that P screamed and shouted (a common response from her) not only when she was moved but before she was moved as she was anxious, anticipating the pain to follow. This may have accounted for the view that I heard that P didn't want to be "interfered with" and that she treated professionals and carers as a bit of a nuisance, seemingly not wanting to engage or interact, although she was able to communicate should she choose. However, professionals who persevered, and there were a small number of these, were able to get P to talk and open up about her views on her situation.

8.2.17. P's experience of pain was a recurring theme throughout her P's health and social care notes, but where the care agencies' notes mentioned this it was largely in relation to her ability to tolerate care and treatment rather than the overall impact on her emotional and mental well-being and quality of life. It is also unclear if the information about pain that carers held was systematically communicated to nurses and then GPs for further investigation / treatment.

8.2.18. Overall, RBC safeguarding practice in relation to P displayed a lack of professional curiosity with little to demonstrate that P was at the heart of the work. Records did not demonstrate reflective practice and discussion, either within or outside formal supervision.

8.2.19. In X, at P's review undertaken on July 2nd, 2018 the focus remained on P's pressure ulcers (that were improving since her admission) rather than her wider social and psychological needs, despite the Deprivation of Liberty Safeguards (DoLS) process that was undertaken, drawing attention to the latter.

8.2.20. RBFT, By the time P was admitted to the Royal Berkshire Hospital, her contractures were so severe that although pain relief was administered it was not enough for P to consistently tolerate movement or physiotherapy. Towards the end of P's life one of the community allied health professionals recalled P saying that she was in so much pain that she just wanted "my legs cut off".

8.3. Mental Capacity

8.3.1.The Mental Capacity Act 2005 (MCA) provides the legal framework for acting and making decisions on behalf of individuals who lack the mental capacity to make particular decisions for themselves. The same rules apply whether the decisions are life-changing events or everyday matters.

8.3.2. The Act tells us that it must be assumed that an adult has full legal capacity to make decisions for themselves unless it can be shown that they lack capacity to decide for themselves at the time the decision needs to be made. This is known as the presumption of capacity. The Act also states that people must be given all appropriate help and support to enable them to make their own decisions or to maximise their participation in any decision-making process.

8.3.3. The underlying philosophy of the Act is to ensure that any decision made, or action taken, on behalf of someone who lacks the capacity to make the decision or act for themselves is made in their best interests.

8.3.4. For most of P's involvement with services it was tacitly assumed that P had capacity to make the decisions in question. This presumption of capacity reflects the first principle of the MCA.

8.3.5. However, brief recorded references to P’s mental capacity in relation to her care decisions, with reservations expressed, date back long before the period that this Review covers.

8.3.6. As early as 2014 and 2015, P’s GP notes referred to P having possible dementia and cognitive impairment.

8.3.7. P’s family told me that her awareness of risk was much reduced even three to four years before K died. At times she did not remember family visiting. At other times she seemed unable to understand or remember how ill K was and, following his death, that he had died.

8.3.8. A GP who assessed P’s mood and cognition in 2015, concluded P did not have dementia but was depressed and recorded “They feel that she has cognitive impairment caused by MS and previous drinking”. No further action was taken at this time. She had been prescribed medication for mood in the past but had proved erratic at taking them.

8.3.9. As early as 2016 some professionals recognised that P was likely to have some cognitive impairment and recorded that it was wise not to accept P’s acceptance at face-value but to dig deeper to ensure her understanding. There was also mention of a referral to a memory clinic, but I saw no evidence that this was followed up.

8.3.10. In February 2018 a dietician visited P to review and offer support and advice around diet and stated that P was “confused” as the information P gave differed from information given by the carers when they arrived. I could not find evidence that this “confusion” was explored further.

8.3.11. Following a home visit in March 2018, the Consultant in Neurorehabilitation wrote to P’s GP confirming Botox injections and asking for follow-up by the Community Physiotherapy Service to maximise the effectiveness of the injections. He also noted P "has cognitive decline and seems to be quite forgetful, although can communicate effectively”.

8.3.12. I found references in GP’S notes to possible Alzheimer’s Disease, confusion and short-term memory loss in May 2018 but again no record of follow up.

8.3.13. I was told that other concerns were raised in 2018 about P’s capacity but some professionals I spoke to thought that there was a worry that they would be seen as “assuming” lack of capacity because of P’s diagnosis of MS. They told me that there had been a culture of capacity being assumed unless “glaringly otherwise”.

8.3.14. One professional remembers that P had very strong views about how she wanted to receive her care and refused a ceiling track and a hoist that she could be changed in; this would reduce the numbers of transfers she would have to undergo. I was told that these would have been preferable but would not have made enough of an impact on P, to consider her refusal as reason for doing a formal assessment of capacity. Reassuringly, P did accept the Symmetrikit cushions reinstated as part of a sleep system but without the brackets.

8.3.15. The OT involved in prescribing specialist seating for P when she lived at Y found P able to engage and tell her what she needed / wanted but she concluded that, although P’s responses were generally plausible, in asking follow-up questions found that there appeared to be some cognitive impairment. For example, although P could volunteer that she didn’t like the food she was given, her recall of events was poor. P would also suddenly make a request “out of the blue”, for example for cigarettes, even though she no longer smoked and had not done so for a considerable time.

8.3.16. The OT observed that although P was vocal in a reactive way (often shouting and swearing in pain when she was moved) she was not necessarily assertive on her own behalf, didn’t complain about feeling generally uncomfortable or initiate conversation about her care. This view of P is also held by her family and other professionals.

8.3.17. I did not find any recorded discussion that P may have had fluctuating capacity or that steps should be taken to support her in decision-making. This is of particular importance for several reasons: P's refusal of personal care was frequently cited by providers as a reason for care not being given as per the care plan, she refused some equipment and she had expressed strong opposition to moving into a care home.

8.3.18. I was told that P didn't always appear to understand that there were ways of reducing her discomfort, for example she initially refused bed rails. However, when given clear information in a way that she could understand, P was supported to make the decision to have them installed.

8.3.19. In May 2018, DN discussed having a catheter with P, to reduce the risk of her skin breaking down but P declined. DN also discussed the nursing home option with P; who said she wanted to go but not permanently. P requested that the nurse discuss these things further with her son which the nurse did. The DN broached the use of a catheter again in order to assist healing of ulcers, P declined.

8.3.20. On 23rd May the DN met the with family and the social worker to consider next steps in relation to the Section 42 Enquiry. The meeting lost focus on the failures of care and moved to focussing on P's needs and the original purpose of the meeting, failure of home care, was not addressed. The professionals present and the family agreed that P's capacity fluctuated, and that a move to X nursing home would be in her best interests. P should have been provided with an Independent Mental Capacity Advocate to represent her wishes in this process as she had previously stated clearly that she did not wish to move permanently into a care home.

8.3.21. The only formal and recorded mental capacity assessment I found on record was dated September 2018, this was an assessment for a DoLS authorisation and was after P was admitted to X. This found that P was disorientated in time and place and did not see herself as having care needs but thought that she needed help cutting the grass at her bungalow. P was unable to remember living in Y, and the assessor noted her as having fluctuating capacity, although she did say that she was happy at X, "I like it here…the staff are nice…..I wouldn't want to move." Neither the social worker or mental health assessor recorded concerns about P's room or care.

8.3.22. In February 2019 an ICHS nurse assessed P as having severe impairment in cognition and felt that her low mood was linked to her loss of independence. The nurse was planning to discuss this with memory clinic staff, but P was admitted to hospital before this could be arranged.

8.3.23. P was very unwell when she was admitted to RBFT and was described as having "possible short-term memory loss" but I found no other reference to her mental capacity during her stay. She was considered to have capacity to be involved in the RBC led Section 42 Enquiry that followed.

8.3.24. For major decisions hospital staff liaised closely with P's family, who were involved in decision-making, including the eventual extremely difficult decision to stop on-going active treatment (IV antibiotics) and keep P comfortable.

8.4. Multi-disciplinary working and accountability

8.4.1. Following on from her diagnosis of MS, P received interventions from a wide range of professionals for the rest of her life; these included the community neurological team, occupational therapists, physiotherapists, dieticians, podiatrists, social workers, district nurses, MS specialist nurses and Tissue Viability Nurses. P was under the care of neuro-rehab consultants from 2004-2018.

8.4.2.Whilst P’s files contain numerous examples of bilateral conversations between professionals or professionals and the care providers, there is almost no evidence of multi-disciplinary meetings or coordinated risk assessment and care planning.

8.4.3. Given the severity of P’s needs, she was a prime candidate for continuing oversight and coordination of her care from a lead professional. In P’s case a social worker would seem to be a good choice. Instead her case was opened to different individuals as situations arose and closed before issues were fully resolved. This was particularly, but not only, true of adult social care, contributing to an ad hoc approach to practice that was pre-occupied with firefighting. Effective care coordination would have provided a more holistic and personalised experience for P.

8.4.4. There are good examples of professionals looking beyond the immediate concern to try and improve P’s overall quality of life, for example the safeguarding intervention that led to P being provided with a replacement back for her specialist chair.

8.4.5. Regular, although not necessarily frequently, multidisciplinary meetings would have ensured that all involved with P’s care discussed and were aware of the latest care concerns, plans to meet them and any risks arising. Such a forum could have acted as holding providers of care to account in a way that seems in P’s case to have been absent in any meaningful way.

8.5. Pain management

8.5.1. I was concerned that P’s refusal of care when living in Y was at times accepted without appropriate follow-up and usually put down to her pain and discomfort, often expressed by her shouting and swearing. However, there is no evidence that the carers talked to their own managers or visiting professionals about the possibility of additional or alternative pain management. I was told that carers felt unsupported and isolated and lacked confidence and adequate training. It is possible that they also did not understand just how uncomfortable P was and how fatigued she would become being hoisted.

8.5.2. One professional observed P as being “shattered” following her morning routine. This professional had a conversation with P explaining that they were trying to get the balance right, moving P no more than was necessary but enough to ensure she received essential care, but this reassurance and explanation needed to be a feature of the delivery of P’s care every day and was absent.

8.5.3. When P was prescribed bed rest, she did not always want to go back to bed after her personal care, partly because it would involve another move and carers felt unable to insist as they felt they would be forcing her against her wishes. Not all carers were able to communicate clearly in English and this hampered their ability to explain and reassure P, particularly given her hearing impairment that seems to have received scant acknowledgement or resulted in appropriate adjustments.

8.5.4. P’s experience of pain was to prove an on-going issue. Once she was resident in X the ICHS team was unable to carry out a full postural assessment in January 2019 due to PA’s level of pain. X contacted the GP at the request of the team to request extra pain control and consider use of Botox; to enable the assessment to be done. The GP prescribed a Fentanyl pain relief patch and co-codamol which P took regularly.

8.5.5. The hospital staff tried a wide variety of pain relief and techniques to ease her pain but nothing made her able to regularly tolerate physiotherapy.

9. Findings

9.1. Introduction

There were some examples of good practice, both within and between agencies.

9.1.1. The DN team informed RBC (who commissioned P's social care) when care agencies failed to implement the care plan. The team also made efforts to coordinate visits with the carers' visits to minimise the disruption and discomfort for P. I saw evidence of team discussion and reflection to establish next steps, such as requesting the GP to arrange x-ray, prescribe anti-biotics.

9.1.2. The RBC care co-ordinator, observing the need for OT involvement, used her own initiative to refer on and then arrange joint visits. She also made a point of taking the time to build a rapport with P to ensure that she was able to participate in the assessment and decision-making process.

9.1.3. The community OTs working with P came in for particular praise and appreciation from her family. I found their records were well set out, actions were clearly recorded with the decision-making process laid out and evidence of good consultation with P, her family and other professionals. The records demonstrate a holistic approach to P's situation that appropriately balanced and managed risk whilst respecting P's right to control her home environment.

9.1.4. X referred to TVN, podiatry and the GP. The TVN who saw P in January 2019 in X had recently undergone awareness training in postural management; she made a prompt and appropriate referral to the ICHS team that had recently commenced its pilot project on postural management.

9.1.5. The ICHS responded promptly to referrals and worked well with P, X and GPs. Team members discussed / arranged further Botox treatment with P, her family and WBCH. Following P's admission to RBFT the ICHS liaised closely with the ward / hospital to provide continuity of care and prepare for P's discharge.

9.1.6. When P lived both in Y and X, GPs responded promptly to requests for visits and referrals.

9.1.7. RBC initiated a Section 42 Enquiry that focused on X and the possibility that the care it delivered constituted organisational abuse.

9.1.8. However, there is evidence of a significant number of failures in communication between agencies that, taken together, detracted from P always receiving optimal care.

10. Learning themes emerged that address the terms of reference for the Review.

10.1. Assessment and care coordination (TOR1)

10.1.1. P's range of needs, her involvement with many agencies, perceived reluctance to engage with carers and professionals and the frequency of concerns raised by family and professionals made her an excellent candidate for on-going care co-ordination by one named individual.

10.1.2. An experienced SW would have been a good choice for this role, given the different elements of health and social care risks and needs that needed assessing. Given that P's degenerative condition was clearly deteriorating, it was predictable that she would have changing needs and that any care plan would need regular adjusting to remain relevant. If overall care co-ordination had been in place, I would, for example, have expected to see up to date care plans in P's home.

10.1.3. P should have benefited from a named individual able to bring together the understanding and expertise of a range of professionals to create a care plan that took account of her as a complete person, where risk was evaluated and managed. There was no one professional for P or her family to look to provide continuity, and effective resolution of the problems they encountered in her care provision. A number of individuals attempted to take this responsibility, but none were resourced to provide long-term support and too often they moved on before reaching a satisfactory conclusion. This was either because they were locum staff, were changing roles or simply fire-fighting cases.

10.1.4. A named accountable individual would have identified the need to pull together MDT/ agency meetings where information could be shared, risks identified, and action agreed and assigned to named professionals. As it was there were some meetings described as MDT, but these tended to be within but not across agencies which is what was actually needed. For example, in hospital and community health settings very often a social worker would not be involved. Any involved professional could have initiated such a meeting, but none did, other than an ICHS OT, towards the end of P's residence at X.

10.1.5. P's voice is rarely heard in her records. The employment of an effective caseworker and or advocate should have been considered in order to make her voice heard. Her family did their best but all work full-time and their views may not always have been those of P herself.

10.1.6. A named worker should have regularly reviewed P's situation with Y managers to determine criteria / timescale for P to receive support from the in-house care staff that many professionals told me would have provided a more reliable, accessible and quality service.

10.1.7. No one person had the responsibility for on-going holding to account of care providers, although a number of professionals attempted this at various points. The overall responsibility seems to have rested with the QPM team of RBC, but I have seen no records of follow-up to concerns logged with them or feedback to those who raised them.

10.1.8. Agency responses needed to be better coordinated and aligned. It is not until P is in hospital that we learn that P was "lost" to follow-up services after her previous Botox treatment.

10.1.9. Despite serious concerns, agency A remained providing care for some months as the Personal Budget Support Team (PBST) attempted to find a replacement. The first two weeks of the replacement agency, B, seem to have been somewhat of a "honeymoon" period, after which family again raised concerns about P being neglected. In mid-April 2018 safeguarding concerns were also raised by the district nurse; the family's and these were incorporated into one Section 42 Enquiry, apparently discussed with P and allocated to a SW. This SW failed to visit P for over a month, unbeknownst to her line manager.

10.1.10. P was referred by the TVN to the ICHS team in late January 2019, towards the end of her stay at X. The team responded quickly, carrying out joint assessments, ordering and fitting equipment. However, it appears that between P's 6 weekly review in July 2018, when her pressure ulcers were noted as improving, and October 2018 there was a significant deterioration in P's pressure damage. I am not aware of what attempts were made to prevent recurrence. X then involved the GP and Podiatry but in November the pressure ulcers had deteriorated once again.

10.1.11. It was not until mid-January that X referred to the TVN again and the records show that this was the first reference to postural management since P's admission to X. Although the home's notes of that visit state that the TVN had no safeguarding concerns, the TVN's notes state that she raised lack of postural management as a safeguarding concern by telephoning a social worker at RBC. I assume the involvement of the ICHS was the response, but this is not explicitly stated, and I can see no other reference to the safeguarding referral. The DATIX record completed by the TVN does not record this episode as a safeguarding referral.

10.2. The processes for provision and transfer of equipment (TOR 2).

10.2.1. A range of equipment was available to improve P's health and comfort.

10.2.2. P had specialised seating for some time before the period this Review covers. She took this with her from home to Y. I could not identify the provider of the chair but there did not appear to be an arrangement in place for servicing and reviewing its suitability.

10.2.3. As P's MS deteriorated, the chair's positioning ceased to be helpful for P, by November 2017 it was causing her problems and directing her head downwards. This was spotted in late 2017 by an observant RBC care coordinator who took immediate steps to have P's needs reassessed by an OT.

10.2.4. The OT undertook a thorough review of P's postural needs and arranged trial periods for a replacement chair back and additional cushions / wedges to retain P in the correct position. The OT was thorough, arranging a training session for carers and also supplying detailed laminated photographs showing how to move, handle and position P; these were to have been left in her home. Unfortunately, these were never taken from the care agency to P's home and as the care coordinator's and OT's involvement was now over, this deficit was not picked up or dealt with.

10.2.5. Different professionals are responsible for different elements of an individual's care needs and then for addressing them, including the provision of equipment. This is dependent on a professional's training and area of expertise and responsibility. For example, in P's case, the district nursing service dealt with pressure relieving equipment for the bed, the OT with help with postural management but that also has an impact on prevention of pressure damage. Physiotherapists assist with exercises, to relieve contractures and optimise mobility, including following Botox injections. In addition, P had essential input from a range of other professionals such as Dieticians, Podiatrists, TVNs, MS specialist nurse and neurorehabilitation.

10.2.6. In P's case, when she was living at Y, the DN service supplied appropriate pressure relieving equipment for her bed. However, this then had to be used consistently and there is clear evidence that it was not. We have examples from when the DN team found and recorded this, but we do not know about the many other occasions when the DN was not visiting. There are DN recorded incidents of carers turning off the ToTo system, an essential component of P's pressure care.

10.2.7. The DN prescribed gel heel pads which were not always used; the carers had decided that they weren't working, although they were not qualified to make that decision and they did not go back to the DN for advice. There are examples too of equipment used that should not have been and exacerbated the breakdown of P's skin, such as the Kylie pad that became creased and created a pressure risk. In the process of carers moving P her sacral dressing sometimes became creased causing additional problems.

10.2.8. P's move to a care home was precipitated by concerns of family and professionals that the care she was receiving at home was inadequate.

10.2.9. Whether or not P's move to a nursing home was inevitable, necessary or desirable is impossible to assess with hindsight. What is clear however is that poor care at home was a key consideration behind this decision and that many professionals involved in P's care were not consulted. The records state only that P agreed this outcome but there is no detail recorded about her views or assessment of her capacity to make this decision, a significant gap.

10.2.10. Nursing homes are required to provide a certain amount of "standard" equipment, including pressure relieving mattresses. However, when P moved to X she had been using a number of bespoke pieces of equipment, specifically prescribed for her, critical for maintaining her comfort and skin integrity as well as counteracting the progression of her contractures. When P moved none of her equipment, other than her chair which her son transported, was transferred with her. And at this stage she was not using the chair as she was being cared for in bed. She was, however, nursed on a NOVA Alternating Air mattress that was standard use in X for individuals with, or at high risk of developing, pressure ulcers.

10.2.11. X identified P's severe risk of pressure ulcers in her care plan dated July 4th 2018. She was then provided with a profiling bed, slings, hoists and pressure relieving mattress supplied by the home. The home was not informed about the additional equipment P had used at home although its staff did visit P at home prior to admission to assess whether the home could meet her needs they did not make a note of the equipment that needed to transfer with P and the other professionals present did not bring it to the home's attention.

10.2.12. There appears to have been a serious omission in X's failure to identify the specialist equipment that P was using and that was available to her in Y Providers are required to provide person-centred care, providing safe and appropriate equipment to ensure that individuals are protected from harm. No-one in X identified P's specialised equipment during her assessment in her home. It was not until P had been living in X for over 6 months that this failure was recognised and it was fortunate that the TVN visiting X had had the benefit of recent ICHS training in this area.

10.2.13. P continued to be cared for in bed on admission to X. From visiting professionals' records, it was clearly intended to be short-term (until) in the hope that her pressure ulcers healed, which may or may not have been realistic. One of the two conditions that the BIA recommended to be attached to her DoLS authorisation stated that the home was "to enable P to regularly access the communal areas of the home for more social stimulation once her pressure sores have improved and it is safe for her to be transferred from her bed to her specialist chair". This is also stressed in the consultant psychiatrist's report who undertook P's mental capacity assessment on 27th June 2018. This condition was not met and I could find no evidence of it's appropriateness being challenged by X at the time.

10.2.14. Although P was admitted to X with pressure ulcers, by July 30th the dietic department noted that both the ulcers on the sacrum and heels were (nearly healed) improved.

10.2.15. (It is not clear what preventative care X did or did not put in place in the intervening months but) In October a podiatrist recorded that deterioration of P's pressure ulcers was due to pressure on the areas and accelerated by P's position in bed, where she was not being turned sufficiently. X sought more medical advice in November due to further pressure deterioration. X then made a new referral to TVN on 16th January 2019 as the sacral ulcer had (reoccurred) deteriorated.

10.2.16. The TVN visited promptly and immediately referred to the ICHS. The team's involvement resulted in assessment and provision of bespoke equipment This included the installation of a Kommfifit sleep system that is gentler than the ToTo and has a simpler control system, either on or off, so less to "fiddle" with. The equipment is designed to improve comfort and quality of life as well as mitigate against pressure damage. However, it proved difficult to fit to the bed due to P's pain on being moved.

10.2.17. I was told that P's contractures were too advanced for seating to be an option when the ICHS saw her. One described them as "the worst she had ever seen". I understood this to be a factual statement rather than a judgement on P's care.

10.2.18. In late February, at the request of an OT, the X manager organised a multi-disciplinary meeting at X. The purpose was recorded as a discussion about on-going care. This meeting discussed P's significant cognitive impairment and concerns about her low mood but agreed that P could consent to the Botox treatment suggested.

10.2.19. However, P's health continued to deteriorate further despite regular visits from the GP and on-going treatment with anti-biotics. By 6th March 2019, X records show that P was very unwell, not communicating, confused with a very high temperature. The out of hours GP was called, and he ordered an ambulance to take P to hospital.

10.3. Communication between the family and services throughout care. (TOR 3)

10.3.1. P's family found the lack of continuity of a named RBC worker frustrating and problematic. This resulted in them having difficulty in knowing who to contact when they were worried about P and her care, as they frequently were. At times they phoned the last worker they had contact with only to find they had moved on.

10.3.2. The absence of planned care reviews meant there was no regular opportunity for family to feedback to agencies on how the care package was working. It is not clear that they were notified when professionals made safeguarding referrals on behalf of P. However, there was one example of P asking the DN to discuss the options that she was suggesting (catheter and care home) with her son, D, and this she did.

10.3.3. The family complained that lack of communication was an issue throughout P's stay at X. P's sons and their wives all work fulltime and so mainly visited P during the evening. They reported finding it difficult to find qualified members of staff to ask about P's condition or inform of their concerns. I found little evidence in X's care notes for P of communication with family. This was backed up by X acknowledging their failure in communication when meeting with RBC and family in April 2019 to discuss the final Section 42 Enquiry (although the family dispute that they were told that this meeting was held about the Enquiry).

10.3.4. P's family state that P's admission to a hospital came as a shock as they were not aware of the deterioration in P's health or the steps that the home and GP were taking in response, specifically the giving of antibiotics.

10.3.5. The information that X sent with P to hospital was nine months out of date (04/07/2018) and this appears indicative of a larger problem with the home's communication, although the (erroneous) out of date information did not affect P's treatment in hospital. Later the home informed the Review that this information was sent with P to hospital to demonstrate that P already had pressure ulcers when admitted to X's care, although this was not clear to the hospital staff.

10.3.6. Communication between the hospital and family during P's admission provides a marked contrast with very proactive discussions taking place between the hospital staff and the family, starting with the day after admission. These are recorded in some detail in the ward notes. They include discussions about some very sensitive subjects including resuscitation and end of life care.

10.3.7. D chose to share his concern about P's care in X with the hospital staff on a number of occasions and that resulted in the hospital making a safeguarding referral to RBC. One member of medical staff concluded that the pressure ulcers were going to be difficult to manage and likely to be inevitable given the severity of P's contractures and that the care home could not have reduced the chances of pressure ulcers because of the contractures. This view was shared with the family by a Dr on 25th March as part of a broader discussion on P's condition and what the hospital was doing in response.

10.3.8. D explained that it was the lack of communication by X about the deterioration of P's pressure ulcers that he was most upset about because as far as he was aware, they were improving. He was also upset that P had been in bed for all the time that she had been in X and felt that this led to a decline in her mobility, worsening contractures and subsequent deterioration in pressure ulcers.

10.3.9. There is a long ward note recording a telephone conversation that Dr had with D on April 2nd, going into some detail about the challenge that P's condition was presenting, how they were responding and the options for treatment, including palliative care. The Dr considered that family were not yet ready for discussion about the last point. However, P continued to become more and more unwell with spiking temperatures and by April 19th the Drs considered that her prognosis was very poor and explored this with D. D was able to go away and talk to his brother, with a clear understanding of the clinical picture and they agreed to stop on-going active treatment whilst keeping P comfortable. P passed away the next day.

10.3.10. The detail of the ward notes presents a picture of on-going clear and sensitive communication with P's family by the medical and other staff.

10.4. Whether the Section 42 Enquiry dealt adequately with the concerns raised and, more broadly, wider risk. (TOR 4)

10.4.1. A range of safeguarding concerns were raised during the period I looked at, including one that purported to represent a full Section 42 Enquiry prior to P's admission to X.

10.4.2. The Enquiry that this SAR was asked to focus on was the one raised in March 2019 dealing retrospectively with the care that P received at X. The concerns the family had focused on were on P being nursed in bed for eight months, resulting in worsening of her contractures and severe pressure damage.

10.4.3. Although the record of the Enquiry details the actions that the home took, particularly in involving other professionals some fundamental questions remained unanswered. There is no clear explanation of why P was in bed for her whole time at X when she had been using her specialised chair only a short time before her admission. I could not find whether the Enquiry gave any consideration to the possibility of P sitting out in her chair as her pressure ulcers improved, which they did at first.

10.4.4. The reliance on X's own notes about professionals' interventions did not reveal the safeguarding concern about postural management that the TVN allegedly raised in January 2019. I did not see anything that suggested the Enquiry talked directly to the various external professionals involved in P's care at X.

10.4.5. The Enquiry restated that members of the healthcare team appeared to have formed the opinion that the development of pressure ulcers was inevitable given the severity of P's contractures and that had been explained to the family. However, the Enquiry did not consider a challenge to this view or explore the context. The Enquiry did not engage directly with the hospital medical staff but relied upon a file note included in the hospital chronology.

10.4.6. The Enquiry focused on the care P received at X, understandably given the family identifying that as the source of concern. There was reference to P having pressure ulcers on admission; but there was no further exploration of this, the focus being entirely on X's care.

10.4.7. The Enquiry did not consider the postural management interventions P had previously received in Y or what they had been designed to achieve, presumably because there was no one involved in the Enquiry who had that knowledge. The family did know about the chair, but they had no real reason to question if P should have taken any other equipment to X; as they told me they viewed the staff at X to be the "experts" and should be trusted to provide necessary care. They would not have been aware that the bed P had in the home was using a standard pressure relieving mattress rather than the bespoke positioning and turning systems that she had at home. The home had not been made aware of the bespoke equipment that had been provided to P at home but nor was it pro-active in this regard.

10.4.8. My understanding is that at the time period that this SAR is looking at any Section 42 Enquiry in Reading was reviewed and signed off by the line manager of the social worker. In this case it was the OT lead who considered it concluded and signed it off.

10.4.9. The governance arrangements for Enquiries in RBC have changed since then and the manager of adult safeguarding now reviews all Enquiries with the responsibility for final decision-making resting with her.

10.4.10. The family expressed concern about the lack of on-going involvement of the Coroner's Office about the circumstances leading up to P's death. I am unable to provide much insight about the thinking here but would observe that the Coroner's Office appear to have accepted reassurance from RBC that the Section 42 Enquiry had been resolved to the family's satisfaction.

11. Conclusions

11.1. Organisational matters RBC seemed to be affected more than its partners by difficulty in recruiting staff, particularly social workers. This was connected to a number of issues the Review identified, including pressure to close cases, lack of continuity of worker and short-term task-focused practice.

11.2. Management oversight and adherence to Pan Berkshire-wide agreed inter-agency adult safeguarding protocols

11.3. There were examples across all the community agencies of gaps in both of these areas. These would include lack of notifications of concern, delayed and incomplete safeguarding enquiries, missed care calls, missed follow-ups, lack of communication with family, poor recordkeeping, unclear decision-making and absence of clear risk-management.

12. Changes in practice connected to this case

12.1. My conversations with professionals across agencies reflected increased understanding that P's case was not unique and that it had highlighted deficiencies in a number of areas including gaps knowledge and skills in the workforce and inadequate inter-agency working. There was also an awareness that as people live longer with long-term conditions the issues P's care raised will become more common and that some services as currently commissioned and configured may not be able to meet changing needs.

12.1.1. The CCG commissioned ICHS pilot on posture management is proving to be successful in raising overall awareness in the care homes as well as having a positive impact on some individuals. As well as visiting professionals, homes are able to refer to the ICHS team directly. The team received 250 referrals in nine months.

12.1.2. There are now postural management champions in every care home in West Berkshire. The ICHS estimates that between 10% and 20% of people in care homes have contractures. Given the significance of immobility (and there are many different causes not only neurological conditions) in the development of contractures it is important that this learning is applied more widely, for example to home care providers.

12.1.3. To support this the ICHS has produced a leaflet and a short video summarising the most important information and contacts: https://www.youtube.com/watch?v=_2K1t2pTDTs

12.1.4. The team has emailed it to all the care home managers, relevant teams in BHFT and the local authority OT leads. It will appear in the CCG newsletter to the GPs and on the CCG website. The team has also shared it with the safeguarding leads in the GP surgeries.

12.1.5. X sent 75% of its staff on the postural management training.

12.1.6. Previously Section 42 Enquiries were signed off by the "investigating" professional's line manager. These now receive more independent scrutiny by the lead safeguarding manager in RBC, who also checks that all the relevant information is completed. This should result in improvements in the undertaking of and recording of Enquiries.

12.1.7. The manager of the SAT considers that the ability to use the Adult Social Care recording system thereby sharing 2-way information with localities would shine the spotlight on providers causing concern more quickly. This is in discussion.

12.1.8. C care agency has implemented a live call monitoring system that alerts managers to missed, late and curtailed care calls.

12.1.9. RBC has established a monthly Risk Enablement Panel chaired by RBC's Principal Social Worker for adults.

Purpose:

- To provide a forum for RBC employees to discuss people with complex and challenging support needs, and shared learning from these.
- To provide professional guidance and management oversight of high-risk situations.
- To access support from managers of partner agencies where input is required.
- To provide a documented escalation pathway, ensuring practitioners have access to appropriate oversight.
- To ensure agencies have complied with their legal, national and local policy requirements.
- To sign off ongoing and unmanaged risks as held by the organisation. RBC has established a monthly Risk Enablement Panel chaired by RBC's Principal Social Worker for adults.

12.1.10. RBC 's establishment of a "rag-rating" system for monitoring deadlines in individual safeguarding cases is intended to ensure that any drift is alerted to line managers quickly and can be dealt with.

12.1.11. A more vigorous approach to achieving high quality services is being pursued within RBC QPM. This should be evaluated for impact.

12.1.12. The RBFT is reviewing its policy that specialist equipment for contracture management is only usually available to neuro rehabilitation or those who have new contractures and are going to be in-patients for a significant length of time.

12.1.13.The DN management team plans to consider a process for ensuring that care homes are aware of any specialist equipment being used by patients in the community when they move to residential care.

12.1.14.Additional learning has been put in for the community nurses around pressure ulcers and escalation:

- The learning from previous SARS involving pressure ulcers has been shared in "Learning Curve", this is a briefing which shares learning and good practice for nurses, this was recently shared in the 7-minute learning summary sent out from the SAB.
- The safeguarding team had further training on pressure ulcers in October 2019 and how they can support the teams when they have concerns. Pressure ulcers have become part of the supervision discussions.
- Learning from incidents and the importance of escalation when nurses have concerns about other providers regarding safeguarding has been raised in team meetings and is part of the patient safety and quality agenda for localities.
- The Rapid Response and Treatment team have done a big piece of work and training around postural management, contractures and pressure ulcers for internal and external teams. (They would be happy for this to be shared further).

13. Recommendations for all agencies

13.1. Professional practice

13.1.1. There needs to be a stronger culture of "professional curiosity" and shared accountability

13.1.2. Families' views and contributions should be acknowledged and recorded

13.1.3. Families and professionals making safeguarding referrals should receive feedback on outcomes of Enquiries

13.1.4. Promote person-centred practice that recognises that individuals are more than the sum of their health and social care needs

13.1.5. Decision-making needs to be collaborative, transparent and “defensible”

13.1.6. Supervision needs to incorporate an improved reflective approach in contrast to task-focused

13.1.7. Mental capacity needs to be explicitly addressed, particularly where someone’s behaviour compromises their health, at every stage of decision -making.

13.1.8. RBC should have a mechanism for ensuring that conditions attached to DoLS authorisations are reviewed and implemented

13.1.9. Individuals should receive appropriate support where they experience difficulty in participating in decision-making, for whatever reason

13.2. Care coordination and accountability

13.2.1. RBC should work with partners to establish criteria and responsibility for the appointment of an on-going lead professional in complex cases. This will often, but not always, be a social worker.

13.2.2. All support plans should contain clarity on roles and responsibilities of the agencies involved, preferably with a named contact

13.2.3. The responsibility for overall case coordination should always be made clear

13.2.4. All professionals are reminded of their duty of care to escalate concerns whether or not they are the lead professional

13.2.5. The particular need for any equipment should be identified and reviewed at any time responsibility for an individual’s care is transferred between providers

13.3. Pressure ulcer care

13.3.1. The SAB should review, update and relaunch its pressure ulcer pathway and obtain confirmation from SAB members and providers that teams have discussed and updated local protocols where necessary.

13.4. Safeguarding

13.4.1. Review overall workforce capacity in relation to safeguarding and address any gaps

13.4.2. Consider inadequate agency responses and lack of feedback to safeguarding referrals being included in data returns to the SAB

13.4.3. Safeguarding Enquiries should always involve the individual, their family and adopt a holistic approach and be regularly audited

13.4.4. Ensure that managers in all services know how and when to refer individuals to DBS and relevant professional regulatory bodies.

14. Recommendations for individual agencies

14.1. Reading Borough Council-adult social care

14.1.1. Commissioning and quality assurance of services

14.1.1.1. RBC should review and update its commissioning strategy, involving front-line practitioners, partner agencies and feedback from users and carers

14.1.1.2. RBC should implement a robust assurance system so that failures in commissioned care should be challenged robustly and followed up immediately by QPM

14.2. West Berkshire Clinical Commissioning Group

14.2.1. Commissioning and quality assurance of services

14.2.1.1. WBCCG should consider the evidence for continuing the ICHS work on postural management and arrive at a commissioning decision about this.

14.2.1.2. WBCCG should have an action plan for ensuring widespread knowledge of the relationship between postural management and pressure ulcers, including family carers and home care agencies.

15. What next?

15.1. The SAB should develop an action plan that is practicable, measurable and can be evaluated for impact.

15.2. All agencies should take responsibility for disseminating the learning from this SAR to its own workforce and reflect it in arrangements with partners.

16. Appendix 1: ACRONYMS USED IN THIS REPORT

- Adult Social Care, ASC
- Assistant Team Manager, ATM
- Berkshire Healthcare Foundation Trust, BHFT
- Extra care sheltered housing provider, Y
- Care Coordinator, CC
- Director of Adult Social Services, DASS
- District Nursing, DN
- Integrated Care Home Service, ICHS
- Making Safeguarding Personal, MSP
- Mental Capacity Act, MCA
- Multi-disciplinary Team, MDT
- Multiple Sclerosis, MS
- National Institute for Health and Care Excellence, NICE
- Personal Budget Support Team, PBST
- Royal Berkshire Foundation Trust, RBFT
- Reading Borough Council Adult Social Care, RBC
- Safeguarding Adults Board, SAB
- Safeguarding Adult Review, SAR
- Safeguarding Adult Team, SAT
- Social Worker, SW
- Tissue Viability Nursing, TVN

SAR of the circumstances concerning P

- West Berkshire Clinical Commissioning Group, WBCCG
- Care home provider, X
- GP Surgery, GP
- West Berkshire Community Hospital, WBCH
- Care Quality Commission, CQC

Appendix 2: P Family's view to the SAR

The review carried out by Claire Crawley albeit it thorough the family believe it is only the start of exposing the failings of many professionals involved in the care of P. In the report it is stated that P's voice was not heard, and she was not given an advocate. This appendix is P's voice.

P was angry at with the cards that life had dealt her and was unable to argue her just cause. Her family tried hard to get her voice heard her sons and daughter-in-law. It seems clear from the report that no one was listening and if they were, they took no action, action which could have mitigated the damage done to P's body which lead to the hellishly painful end of her life and untimely death.

In light of the report and as a Section 42 was in place at the time of P's death:

- We would like the case referred back to the coroner for a full inquest in light of the report's findings

In particular it is felt:

- that the report should have gone back to when K died. It is known that P in trying to get to the toilet (she was not incontinent and knew when she needed the loo) fell frequently and ambulances were called. At this time alerts were raised and should have been responded to. The family believed that alerts had been raised by South Central Ambulance because of the number of times they were called out. In the space of a month they were called on 27 separate occasions. A senior politician was also alerted to P's Care and said she would look into it and commented that "this could be the canary in the mine".

- The report does not address all the failings/findings and issues raised by the family whilst in X, Y and prior to this when she was living independently with a care package. It should be remembered that whilst at Y P could feed herself, drink unaided and was in a chair.

- That the report only gives 1 paragraph in the analysis section to X. As P was sent to X for healing and improvement in her overall situation both physically, emotionally and psychologically we would have expected to see more written here.

- In terms of the Sec 42 raised in March 2019 (when P was admitted to RBH) the belief at that time of all the family but primarily A& D was that the meeting they had in X was in line with a belief that P would "recover" and be discharged back to X where her recovery could continue. Although they were deeply concerned about their Mother going back to X they attended the meeting in the hope that X would address their failings as they were told that there was no other accommodation for their Mother at that time. Although communication was discussed no other concerns that had been raised were discussed and at NO time were A or D informed that the meeting was a Sec42 investigation. The Coroner was not informed that there was at the time of P's death there was an open Sec42 Safeguarding Investigation. The family believe that apart from the major issues in relation to the reporting, treatment and on going monitoring of P's pressure ulcers outlined in this review an inquest could have considered if the lack of consistent care over a long period contributed to her death.

- RBC talk about P's named social worker. We know that when she was admitted to RBH that there was "no named SW" albeit P was an open and current case and they swiftly named the SW in RBH as P's named Social Worker.

There are further Questions concerning the report.

1.1.5 – Original Sec 42- moving to X conclusion, how was it ascertained that at X P's situation would improve. What checks were in place? We know that X visited P in Y (this is noted further on in the report) and would have seen and assessed the equipment she was using yet didn't raise a concern once admitted as to why it hadn't been moved with her.

5.2.9 – DN notes category 4 pressure sore (Jan 2018). These had not been raised with CQC as is required under the legislation. The DN did complete an online record of the non-reporting. The report hasn't investigated thoroughly the trajectory from when these sores were category 1 – 3 or indeed what happened following the DN alert as it is evidenced that P's situation seemed to get worse.

5.3.5 – A podiatry review on 28th November 2018 asked for an urgent GP review (bearing in mind she had been having antibiotic meds since October) and although the GP visited all he did was again prescribe antibiotics. Why the GP was not concerned enough at that point bearing in mind P had received several courses of antibiotics to admit to hospital for intravenous antibiotics? Was the GP interviewed? This continued until P was admitted to RBH in March! The family don't know if GP even visited or if consultations were carried out on the phone.

7.1.3 – Although the report acknowledges that a number of safeguarding alerts were raised as far back as 2016 because there is inconsistency in recording, we cannot establish what the outcome of any of these were. We would ask that when so many were raised why didn't RBC and the Safeguarding Board not undertake an enquiry at any time on both Y & X? It would be usual for the Safeguarding Team Manager to know about alerts raised- what did they do?

7.2.7 – What sanctions were placed, or improvement measures required on the Care Agency following findings around Care Plans, MARS sheets not accurately completed etc. Did RBC address these failings and what was the outcome?

7.3.6 – A SW had their contract terminated due to poor performance in relation to P but there is no evidence that this was notified to the DBS Service.

7.4.5 – Why was no consideration given to referral to the DBS Service? This has left a Reg Manager free to continue working in this sector with the most vulnerable people.

10.1.10 – 10.1.11 – between July 2018 & October 2018 P's ulcers deteriorated and again in November. Why then did X not refer to Tissue Viability Nurse until mid-January 2019? At that time, they stated there was a safeguarding concern, yet once again this referral and how it was dealt with cannot be found. Why? Who is responsible?

10.2.15- ICHS stated the contracture of P's muscles was the worst ever seen- One has to then ask "why" were they the worst ever seen- how did they get this bad **IF** P had been receiving the correct and proper care at all times both in her own home, Y & X. As a sufferer of MS it was important that she was kept mobile and wasn't kept in a bed in the same position for the whole time she was in X and also at the end of her time in CCC. No person's body should have been allowed to get contorted to the extent P's did. This needs to be tested at inquest.

12.1 – P's case was not "unique". This is unrepresentative of dealing with the most vulnerable and does not embrace the individuality of the patient. This statement suggests that the professionals that were spoken to would not deliver holistic, person centred care but that people would be treated very similarly.

Additionally, we would ask that consideration should be given to the following:

- Detailed analysis of when and what was communicated to the CQC in relation to P's bedsores
- What actions the CQC took when they knew P had Grade 4 bedsores and that the number pf sores over time was increasing
- Why was the Manager of Y not interviewed?
- There appears to be no "Impact Report"
- Who "signed off" the earlier Sec 42 as resolution using P's move to X as conclusion, why did they not keep this "live" until they ascertained there was overall improvement in P's primary and secondary care and support needs.
- As there was further deterioration well documented in the report in P's condition(s) we would have expected further analysis of what happened in X and why.

SAR of the circumstances concerning P

- It is also known following our meeting with CC that P had received medication for depression, neither the depression nor the usefulness of the medication were ever reviewed.

P was 63 when she died, she leaves behind 2 sons and 3 grandchildren. The family accepts that P struggled accepting some of the card's life had dealt to her and this manifested itself at times in anger and frustration. However, complex an individual may be services are expected to always work in the best interests of their clients. P had a DOLS in place which meant she wasn't always able to articulate her feelings, fears and pain in the same way the rest of us can. Staff should have been able to manage P's complexities in line with her DOLS status, instead time and again they failed her and RBC was inadequate in delivering correct and proper care to P from when she became widowed.

The ToR for the SAR states that particular attention be paid to:

- Whether the Sec 42 enquiry dealt adequately with the concerns raised and more broadly, wider risk – P's family are not satisfied that the report has adequately answered this in full
- Communication between family and services throughout the care – P's family do not believe this has been fully investigated and cite the Sec 42 (although P's sons didn't know it was a Sec 42 meeting) meeting in X as the only time communication was addressed
- The processes for provision of and transfer of equipment- P's family don't feel this has been fully and adequately investigated. We know X visited Y and saw the equipment but never raised a question as to where it was when TX to X took place. Why? Who was responsible?
- Assessment and care co-ordination- P's family don't accept this has been fully answered. Why did P not have a named SW until she was in the last weeks of life? What were the failings of the SW who had her contract ended due to performances, why did the SW's Manager not know P hadn't been seen, what supervision was happening, when, how? Lack of records on P's care- who was responsible? Care Agency staff falsifying care records and MARS sheets, who was responsible for this, what actions were taken, what happened to these staff

Conclusion:

In as much as we fully appreciate the work Claire has undertaken to get somewhere on what happened to P this report in no way goes far enough and leaves a monumental amount of both unanswered and stimulates asking further questions.

The family believe this to have been and avoidable death given P was only 63 and although had MS, had she at all times been given the appropriate care she:

- Wouldn't have had the ghastly contractures she did which can only have resulted in extraordinary pain
- Wouldn't have had several Grade 4 bed sores which resulted in Sepsis likely in her bones which couldn't be diagnosed in full due to the contractures and RBH not being able to do an MIR.

Without both of these problems P would likely still be in her chair, getting out with her family, watching The Chase and in her own inimitable way shouting at her sons!!

P's Family

May 28th 2020