Safeguarding Adults Review (SAR)

Overview Report

‘Pauline’

Commissioned by

West of Berkshire Safeguarding Adult Board

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Independent Safeguarding Consultants, Safeguarding Circle

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1. Introduction

1.1 West Berkshire Safeguarding Adults Board ['WBSAB'] commissioned this Safeguarding Adults Review ['SAR'] following the death of an adult with care and support needs, who will be known for the purposes of anonymity within this report as 'Pauline'. Pauline died at home in November 2021, having fallen and fractured her neck. Prior to this, she had several known conditions that impacted on her ability to manage daily living activities, including a diagnosis of Alzheimer's disease, cataracts and arthritis. Concerns had been raised by her neighbours and a number of professionals over recent years that, as she had grown increasingly frail with age, behaviours which may have been present throughout her life (e.g. non-concordance with medication, hoarding out of date foods) posed increased risk to her health. WBSAB believed, on the information available following initial enquiries, this case may meet the criteria for a review under s44 Care[1] and wished to explore if known risks or needs had been properly considered in line with relevant legal duties. Those concerns, whilst reasonably held, proved on closer examination of case files unfounded and as such this is a discretionary SAR.

1.2 Pauline lived alone in her own home. She was described by practitioners who knew her as a local well-liked character. She was friendly, chatty and cooperative, but fiercely independent and someone who, despite increasing frailty associated with aging and degenerative illness, remained very active and physically able. She walked everywhere and was very proud of her ability to manage. She was resistant to accepting support, especially social care services. Her home, which she had bought in her 60s following a divorce, was much more than bricks; it symbolised regaining and retaining control over her life. Her neighbours carried out regular checks (often daily). One neighbour also acted as keyholder and emergency contact and facilitated access to Pauline including passing key messages from professionals to Pauline regarding medication management, health appointments etc.

1.3 The reviewers wish to commend all those offering support to Pauline. It was apparent within case records and throughout the discussions undertaken in this review, that a wide network of practitioners and neighbours carefully considered not only Pauline's needs, but also her deeply held desire to remain independent when determining how to best support her. The kindness shown to her not only by practitioners, but her wider community, was very moving.

2. Scope of Review

Purpose of a Safeguarding Adult Review and parallel processes

2.1. Prior to this review a police investigation concluded there was no third-party involvement in her death and that this was an accident. The Inquest into Pauline's death is scheduled to take place following the completion of this review.

2.2. The purpose of undertaking a Safeguarding Adult Review (SAR) is not to apportion blame, undertake human resources duties or to establish how someone died. It is to establish whether there are lessons to be learned from the circumstances of the case about the way in which local professionals and agencies work together to safeguard adults, review the effectiveness of procedures (both multi agency and those of individual organisations) and inform and improve local interagency practice by acting on learning.

Methodology

2.3. The SAB commissioned independent reviewers to conduct this SAR using the Social Care Institute for Excellence Learning Together methodology and tools from the SAR In Rapid Time

[1] A review must be completed where an adult with care and support needs dies or experiences serious harm as a result of abuse or neglect and there were concerns about how agencies worked together to protect against the abuse or neglect.

method. The learning produced concerns 'systems findings'. This may include looking beyond whether agencies have met their individual statutory duties, to exploring whether there were any social and organisational factors that make it harder or easier for practitioners to proactively safeguard, within and between agencies. It is then for the Safeguarding Adult Board, together with its partner agencies, to decide how to act on any recommendations for improved practice.

2.4. Pauline was estranged from her family, but a respected member of her local community. Because her neighbours and friends played an active role in monitoring her wellbeing, particularly during the Covid Pandemic lockdowns, WBSAB and the reviewers agreed they would likely have valuable insights into the issues considered within this review, so they were invited to contribute to this review.

2.5. Multi-agency learning events also took place, both with front-line practitioners who worked with Pauline and the leaders who oversaw the services involved in supporting them. The following agencies provided chronologies to support the SAR:

- Reading Borough Council's adult social care department ['RBC ASC']
- Berkshire Healthcare Foundation Trust ['BHFT']
- Pauline's GP
- Royal Berkshire NHS Foundation Trust ['RBFT']
- South Central Ambulance Service ['SCAS']
- Thames Valley Police

Themes

2.6. The period under review is from 01.03.2020, shortly before the national 'lockdown' to prevent further spread of Covid-19 was announced, until Pauline's death in November 2021. WBSAB asked that the following themes be examined through this SAR:

- Are the care management and safeguarding pathways used to support adults with dementia suitable for adults who are, or are at risk of, self-neglecting?
- What legal frameworks could have been applied in this case, what were the challenges in agencies applying them?
- What are the barriers facing professionals when considering Mental Capacity and best interest decisions in risk management?
- Was the engagement between front line staff and Pauline's neighbours appropriate?
- What was the impact Covid had on this case and what lessons can be learnt in the event of any future pandemics?

3. Narrative Chronology

3.1 In March 2020, following receipt of a safeguarding concern from Age UK in respect of Pauline wandering in Reading town centre, Reading Borough Council's adult social care department ['RBC ASC'] requested Berkshire Healthcare Foundation Trust ['BHFT'] older people's mental health team ['OPMH'] bring forward a planned 6-month review to ascertain Pauline's mental state and well-being. This information was shared with the Memory Clinic Nurse who arranged to visit Pauline on the 24.3.20 at home. By this time, the Covid-19 pandemic meant that anyone over the age of 70 and those clinically vulnerable had been advised to self-isolate. She was assessed and the nurse noted a cognitive decline since the last contact a couple of years ago. The nurse also spoke to a neighbour, who did not express any concerns regarding Pauline. She was assessed as at low risk; her GP was updated regarding the cognitive decline and it was noted for the memory clinic to review in 12 months or earlier if needed.

3.2 A further concern was raised to RBC ASC in April 2020 by a neighbour prompting three telephone welfare calls to Pauline over the next 36 hours. She was reported to be open, talking '*freely and in much detail about her daily life, her activities and her eating routine. She spoke of the Covid restrictions and said that she "felt like a prisoner in her own house" whereas she was used to regularly going out [Pauline] was articulate, humorous and reasonably lucid throughout the calls'*[2] Pauline consented to receiving welfare calls and was contacted two days later by RBC's ASC emergency duty service commenting '*everyone was being so nice, she was receiving food parcels and a neighbour was checking she was safely 'stretching her legs'*.

3.3 Following a further concern raised by a neighbour that Pauline may not be taking her medication, RBC ASC carried out a welfare check on the 29.04.20. They were reassured by Pauline that she could manage her self-care, she appeared clean and well and confirmed she was taking her meds but liked to be '*independent and do her own thing'*. RBC ASC followed up with the community hub and with her neighbour who confirmed 4 members of the street were looking out for her. To address concerns that her cognitive decline might prevent her regularly taking her medication, RBC ASC purchased and installed a memory clock. They also arranged for a keysafe to be installed and requested (via GP) District Nurses visit to address 'weeping leg'. At a further welfare check (on 06.05.20) reported she looked well and refused assistance as wanted to go for a walk. The district nurse carried out home visit on 07.05.20 noting no pressure sores, but that her legs were swollen, and she had high blood pressure so the referral was then allocated to the community matron as that service is able to offer more comprehensive support. Her GP visited on 13.05.20 and was satisfied Pauline was managing. There was further communication between RBC ASC and her GP on the 20.05.20 in response to a safeguarding referral raised by community matron who had been treating her swollen legs, re concerns of self-neglect. The GP receptionist offered to collect her prescription and drop it to her that evening. It appears that Pauline then returned that medication to the pharmacy and, following notification by RBC ASC that she was still without medication, the GP receptionist agreed with the pharmacy to deliver weekly medication to enable Pauline to manage this.

3.4 RBC ASC remained concerned and carried out another home visit on the 22.05.20 speaking at length with Pauline and her neighbour. They attempted to remove out of date food, but this upset her, she complained '*that's my money in the food you are throwing away'*. At a subsequent home visit on the 05.06.20 social workers reminded her of the importance of taking her medication after she confirmed that, though these were delivered weekly, she wasn't taking them. She responded to their prompts '*don't teach me to take my medication, I have been taking them before you were born*".[3] Despite the telling-off, the practitioner reminded Pauline to take her medication when the memory clock alarm sounded. Given the concerns that she may not act on advice, they advised Pauline that they would return.

3.5 On the 09.06.20 her treating consultant psychiatrist requested a memory clinic nurse notify the LA that she '*probably lacked capacity'* but remained at low risk. He confirmed he believed she would be safe to remain in her home providing a package of care was in place. It was agreed that a formal assessment of her capacity should be completed and best interest meeting should be set up.[4] There is evidence that RBC ASC tried to arrange a multi-disciplinary meeting, between 17-25.6.20, spoke with her GP on 26.6.20 and carried out a further home visit on the 30.06.20 during which they were able to persuade Pauline to accept social care assistance despite her concerns that this would impact on her independence. It was evident from the clear records kept of the conversation that Pauline understood the measures in place to reduce Covid-19 infections. It was also clear that, despite concerns regarding her not wishing to take medication, she was managing activities of daily living.

[2] Taken from the combined chronology prepared for this review from electronic case notes
[3] Taken from the combined chronology compiled for this review from electronic case notes
[4] The merging of the separate duties under the Mental Capacity Act 2005 to assess capacity in an issue and time specific manner with the subsequent duty (which arises only if a person lacks capacity) to make decisions in their best interest is considered in more detail later in this report.

Unfortunately, on the 10.07.20 Pauline refused to let carers in, so it was agreed with her that the Community Reablement Team would provide this.

3.6 The Best Interest meeting, scheduled for 22.07.20, was cancelled to enable an assessment of the twice daily visits from reablement carers, but the community matron, allocated Community Psychiatric Nurse and social worker agreed on 23.07.20 to reschedule. A joint visit was undertaken that day. Given the clear record of the conversation reported within the case notes, practitioners reasonably concluded '*there were no concerns around [Pauline's] capacity as she clearly understood/aware of her home environment and her care/support needs... [Pauline] is managing her personal care and daily living domestic task independently. She has supportive neighbours who check on her at regular intervals. The main concern is around her not taking her meds, however, she displayed a clear understanding that meds come under health and stated that it is not the job of the Social Service to manage this thus declined to show us her meds. …We advised [Pauline] that we will be closing her case to ASC and provided her telephone details to contact if her circumstances change. [Pauline] was pleased with this and thanked for trying to help her.*'[5] It was also noted that Pauline had paid privately to have the keysafe removed as she felt this was intrusive. The decision to close the referral to RBC ASC was discussed on 11.08.20 with the Community Matron who agreed that, despite it being foreseeable that Pauline would 'hit crisis' at some point her neighbours were aware of who to contact, so services would be alerted and could respond then. The Community Matron also confirmed they had discharged her and asked RBC ASC to notify GP of their concerns regarding Pauline's non-concordance with medication. Her GP practice confirmed they were aware of her situation and would continue to monitor, re-referring if they have further concerns.

3.7 On the 14.08.20 her GP requested BHFT's older adults' community team memory clinic nurse conduct a home visit. This was done on 21.08.20. The nurse believed Pauline '*lacked insight and understanding for the concerns professionals have for her, and on the balance of probability lacks capacity to make reasoned informed decision regarding her environment, extra help and care planning due to the progressive nature of her dementia which had declined since her last review*.' She planned to '*arrange an MDT to determine care pathway. [Social worker], OPMH Team Lead and [community matron] have been emailed with outcome of the visit*.' It does not appear that this the meeting took place.

3.8 Pauline suffered an injury in October 2020 and called 111 for advice. On the 18.11.20 she attended the civic centre, but it was closed due to lockdown. A duty social worker called her on the 19.11.20 and (having not received a response), arranged a home visit for the following day. She was reported to be '*smartly dressed, the house was clean and warm. She showed staff she had fresh food and was aware of the lockdown restrictions. No concerns were noted*.' There is evidence within the case notes of good practice by paramedics ['SCAS'] who referred Pauline to the BHFT's fall clinic after she had tripped on a curb and refused further hospital assessment in January 2021.[6] She was treated by paramedics and returned home. They also raised a safeguarding referral. Her GP also raised concerns to BHFT's Older Adults Home Treatment Team ['HTT'] on the 21.01.21 as she was refusing support. The HTT carried out a joint home visit with consultant psychiatrist and community psychiatric nurse ['CPN'] on the 21.01.21 checking with a neighbour and (using her spare key) entered the house to ensure she was not at home. Her GP later confirmed she was in A&E at Royal Berkshire Hospital. The consultant and nurse returned on the 25.01.21 finding that she '*appeared well, reasonably well kept and pleasant. [She] declined practitioners to enter the house, although she let them into the house once he informed [Pauline] he may have to complete Mental Health Act assessment. Mental Health Assessment completed and Consultant to complete a report plan*.' Her GP confirmed that, whilst they did not have a copy of the assessment or plan on their records, they did receive verbal feedback from the memory clinic.

[5] Taken from combined chronology RBC's case notes

[6] However, this referral was declined and closed on the 31.01.21 by the falls clinic, without communication to the Older Adults Mental Health team

3.9 Pauline contacted RBC ASC on the 02.02.21 for a conversation, this may have been triaged as a safeguarding concern as s.42 enquiry was subsequently closed with advice that an RBC ASC complete an assessment. On the 11.03.21 there was a multi-disciplinary meeting with BHFT Community Mental Health team, older people's mental health team (Memory clinic nurse and CPN), RBC ASC and her GP in attendance. It was agreed that '*the least restrictive option at this time will be for Pauline to have a care package at home*'. The social worker agreed to allocate to the Community Reablement Team ['CRT'] so they could complete a formal capacity assessment. She was assessed via telephone on the 30.03.21 which recorded *'[Pauline] is insistent she can do all her shopping, sometimes daily this keeps her active & catches the bus to the village or into town. She did request not to have this taken away from her as she enjoys this task. Medication: Pauline collects the prescription from the doctor's surgery & takes to the chemist to be dispensed - unsure if Pauline takes correctly? Laundry: Pauline said she had a line full of washing out when we were chatting this afternoon & she will get this in before its damp. Conversation: some was repeated during the telephone call about shopping & laundry tasks… Neighbour: Pauline praised her good neighbour for any support Pauline needs. Mobility: Pauline didn't reflect on her mobility & claims she was also doing the garden earlier today.* A subsequent face to face assessment on the 22.4.21 noted '*observations: Pauline was appropriately dressed, but clothing was lightly stained and grubby in places (the latter could be from clearing activity today). She was able to communicate her views and wishes, but it was difficult to ascertain whether she was evading discussion of her health conditions or does not wish to enter into discussion about them. All areas of the home were cluttered; numerous photographs, greetings cards, trinkets and ornaments; in the hearth (fire boarded up) were candles, some of which had been lit. There was clear access through the rooms however, though the floors were in need of cleaning*.' The memory service also carried out a home visit on 26.04.21 and on 04.5.21, but received no answer.

3.10 In May 2021 the RBC ASC (Hub and Wellbeing Team) supported Pauline to carry out a welfare benefit check and applied for attendance allowance to maximise her benefits. They also confirmed her utility bills were paid via Direct Debit. Her social worker from the short-term team visited again on the on the 11.06.21 and again identified trip hazards, she explained within her case notes that she hadn't challenged Pauline as it was evident Pauline was trying to clear items (including hoarded out of date food) and didn't wish to undermine the trust built with Pauline, which was understandable given Pauline's reluctance to accept interventions from social care. Her case was then transferred to the localities team as it was recognised (in line with the local self-neglect guidance[7]) that long-term work under the care management framework was what was needed. Her newly allocated social worker carried out home visit on the 10.08.21 and 25.08.21 offering Pauline a home safety fire visit and befrienders. Unfortunately, Pauline declined to let this social worker in and closed the door. On the 09.10.21 she attended her GP surgery for a covid vaccine.

3.11 On the 6.11.21 the police were contacted when she was found in a confused state in the street. The officer who attended correctly conveyed Pauline home, despite her saying she was happy to get the bus. This provided the officer with an opportunity to assess Pauline's home environment and identify any family members or support that Pauline had. The officer checked Pauline's home and documented that the house was mostly in order but was a little cluttered and unclean. The officer showed good practice by carrying out enquiries with neighbours to try and establish if Pauline had any family members or support. The officer identified a neighbour, who informed them that Pauline has Alzheimer's and that her condition had deteriorated over the last few months. Her neighbour stated that Pauline was isolated from her family and had no other means of support apart from various neighbours, who all keep an eye on her. She confirmed she had contacted RBC ASC regarding her concerns. Thames Valley police subsequently made a referral to RBC ASC. The officer also completed an

[7] https://www.sabberkshirewest.co.uk/media/1494/self-neglect-a-5-minute-update-v20.pdf

ABCDE[8] vulnerability assessment tool and deemed the risk as B grade (risk of harm, but not imminent). This was triaged by the Multi-Agency Safeguarding Hub and a referral was made to RBC ASC. He also spoke to the local Police Community Support Officers to see if they knew Pauline and requested that they attend her home address to check on her whilst they were out on patrol within the area. This is good practice by the officer.

3.12 On the 12.11.21 the memory clinic nurse carried out home visit (having returned to work from extended leave). A subsequent review by the social worker on the 15.11.21 indicated that her cognition had deteriorated. Before undertaking the visit, the social worker had spoken with neighbour who confirmed her condition had got worse in last few months. Pauline was offered one daily call to help with food preparation, but became angry.

3.13 Pauline was again found wandering by a social worker (not known to Pauline) and taken home on the 22.11.21. BHFT's OPMH team (the allocated CPN) attempted a home visit on the 24.11.21 but there was no answer. Her CPN also spoke with her social worker on the 29.11.21 to arrange a joint home visit for the 01.12.21. Sadly, before this visit could take place Pauline was found dead by her neighbour, who had become concerned because Pauline had not taken in her bins that morning.

4. Case Analysis

Are the care management and safeguarding pathways used to support adults with dementia suitable for adults who are, or are at risk of, self-neglecting?

4.1 Alzheimer's disease is the most common cause of dementia in the UK, it is estimated that 5,430 people over 65 are living with dementia in the West Berkshire area, of those 3616 have a formal diagnosis.[9] It affects multiple brain functions with symptoms becoming more severe as the condition progresses, usually over many years. In 2009 a national strategy 'Living well with dementia'[10] was published, prioritising action to ensure a wider understanding of the causes of dementia, better mechanisms for diagnosis and the development of a range of services for people with dementia and their carers which meets their changing needs over time. The West Berkshire Dementia Action Alliance has published an action plan to deliver on the those aims, including a commitment to '*work towards necessary improvements to enable people with dementia and their carers to live independently in their community for as long as possible*'. [11] To achieve such aims, health and social care practitioners will need to confidently apply relevant legal frameworks and navigate pathways to assess and review needs, offer support and when necessary provide effective interventions to treat symptoms, prevent an escalation of needs and safeguard an adult from harm, including harm arising from self-neglect.

4.2 Whilst symptoms remain manageable most people will primarily be supported by their GP and primary care (under powers conferred by s3 National Health Service Act 2006) to commission services for the prevention of illness, care and after-care for persons suffering from illness. Pauline was well known to staff at her GP practice, who were responsive to Pauline whenever she attended the surgery. Her GP explained they were frequently involved in capacity and risk assessments and maintained a welcoming and responsive approach, even during periods of Pandemic lockdowns, because it actively reduced the risks of self-neglect as it encouraged

[8] Airway, Breathing, Circulation, Disability, Exposure – please see https://www.resus.org.uk/library/abcde-approach
[9] Taken from data published by NHS Digital (https://app.powerbi.com/view?r=eyJrIjoiM2Y0ZTUzMDUtMmYzOC00MDUxLWE1YTUtMjRhYzVkZjVlODRjIiwidCI6IjUwZjYwNzFmLWJiZmUtNDAxYS04ODAzLTY3Mzc0OGU2MjllMiIsImMiOjh9) on 12.10.22
[10] 'Living well with Dementia: A national strategy' 2009, HMSO available at: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/168220/dh_094051.pdf. Since the publication of this strategy, the DHSC's Dementia policy team have also published an implementation plan to make the UK the best place in the world for dementia care. Available at: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/507981/PM_Dementia-main_acc.pdf
[11] Available at: https://www.dementiaaction.org.uk/local_alliances/5166_west_berkshire_dementia_action_alliance

her to attend whenever she had concerns about her health, enabling them to monitor her health and wellbeing.

4.3 As symptoms progress, BHFT's OPMH team provide services for patients (referred either by their GP or RBC ASC) who have been diagnosed with memory problems and older adults with other mental health issues such as psychosis, anxiety and depression. The service comprises of the HTT, Community Mental Health Team, Psychology and Memory Clinic. The Memory Clinic is responsible for assessment, diagnosis and initiation of treatment in respect of dementia. Pauline was also well known to the memory clinic and community mental health teams. She had been under the care of the same psychiatrist since 2014. The service knew Pauline well; at the time of her diagnosis and since staff explored her wishes regarding treatment options (medication) available to slow the condition. Her treating psychiatrist explained that Pauline had expressed some doubts as to whether the medication would have an impact but had agreed to take this if it would assist her to remain independent and living in her own home for as long as possible. They were also responsive when asked by partner agencies to review Pauline's health. For example, in March 2020 they overrode their usual practice to bring forward a review in light of the fresh concerns and tried on 5 further occasions during the 20-month review period to visit her at home, checking with neighbours if they had any concerns regarding her deterioration.

4.4 Statutory duties to assess social care needs under the Care Act 2014 are triggered on the deliberately low threshold of an appearance of need for care and support (s9 Care Act). There is also an enduring duty to assess (s11(2)) even if an adult refuses an assessment if the adult does not have capacity to refuse an assessment or is experiencing, or at risk of, abuse or neglect. Prior to the review period, in 2018, Pauline had been referred to RBC ASC for an assessment by the Police. She had refused an assessment and, satisfied she had capacity to refuse and was managing her care needs, RBC ASC fairly concluded they had no further duty. Throughout the review period RBC ASC responded quickly to requests by neighbours or other professionals to complete welfare checks, they demonstrated empathetic, but persistent interest in her wellbeing in the face of Pauline's reluctance to agree to social care and worked closely with other professionals to ensure risks they had identified were explored in line with the statutory obligations.

4.5 In addition to the assessment duties, statutory guidance accompanying the Care Act 2014 confirmed that concerns regarding self-neglect can trigger safeguarding duties (under s42 Care Act). The term covers a wide range of behaviours including neglect of one's personal hygiene, health or surroundings. Whilst the guidance does not require every case of self-neglect will require a safeguarding enquiry, it does stress the importance of determining the adult's ability to protect themselves by regulating their behaviour and recognising that '*there may come a point when they are no longer able to do this, without external support*.'[12]

4.6 Research findings[13] warn practitioners against too readily taking a person's willingness to continue self-neglecting at face value, without further exploring their ability to protect themselves, ascertaining their reasons for behaviours and discussing with them other options to best manage health and care needs. This was not a feature in Pauline's care. For example, as practitioners became aware Pauline was not taking her medication because her memory was failing, they provided weekly trays and a memory clock to reduce the risk of inadvertent overdoses or, conversely, a more rapid deterioration in her overall health from not taking her medication. In conversations with the reviewer, medical practitioners confirmed that whilst it would have been beneficial to her to take her medication regularly (as it would have slowed the deterioration in her health), there was no imminent risk to her life of non-compliance. The

[12] pg.14.17 Care and Support guidance
[13] Bray, Orr and Preston-Shoot (2015) 'Serious case review findings on the challenges of self-neglect: Indicators of good practice' Journal of adult protection 17,2, 75-87

practitioners felt the only effective way to secure total medication compliance would be to provide 24-hour supervision within a residential setting, however panel members and senior managers felt this review provided opportunities to highlight the wide range of less restrictive options that should always be considered, e.g the use of assisted technology, as used to support Pauline to remember to take her medication. For the reasons explored below, practitioners correctly concluded they did not have legal powers to compel Pauline to accept that level of care.

4.7 Even by November 2021, Pauline's presentations were not unique or particularly severe. Throughout the review period, Pauline's neighbours and practitioners working across partner agencies (including within the voluntary sector) responded in line with obligations to report concerns. For example, Age UK staff and neighbours reported concerns in at the start of the first lockdown. Likewise in November 2021 a police officer and, later that month, a social worker demonstrated excellent safeguarding practice after Pauline had become confused whilst in her local community.

4.8 Practitioners responded promptly when concerns were raised and gave appropriate proper consideration to duties to prevent needs escalating (under s2 Care Act 2014, e.g. by providing her with a memory clock) and to provide advice and information (s4 Care Act 2014 e.g. by working with her to help her manage finances). As detailed above, they worked collegiately[14] on capacity and needs assessments, both of which took account of the risks associated with Pauline's cognitive decline and unwillingness to accept social care support. As noted above, agencies concluded in August 2020 they should close active case work given Pauline's polite, but persistent refusal to accept support, her presentations that suggested she was managing daily living and indications that she had insight into her health needs (as she would attend her GP whenever she had health concerns). Her GP was notified and understood they could re-refer as soon as her needs or position changed. Subsequently, as her symptoms became more pronounced, there was evidence of an escalation in the multi-agency risk management planning. For example, in January 2021 her GP requested BHFT's HTT conduct an assessment. This is a crisis service for people who may require intensive monitoring and support within their home environments to prevent hospital admissions. The HTT attempted a joint visit with Pauline's treating psychiatrist and CPN from the Community Mental Health team (responsible for long-term monitoring of her mental health and wellbeing) and, during the subsequent visit, her psychiatrist completed a mental health assessment concluding that she did not meet the threshold for detention under the Act.

4.9 Whilst her social worker had identified trip hazards in June 2021 and the police recorded her home environment was 'a little cluttered and unclean' a fatal fall could not have been predicted with the required level of certainty that would have made it necessary and proportionate to override her refusal to accept support. Her home conditions did not amount to hazardous or raise issues of public nuisance that would justify interventions under either the Housing Act 2004 or Public Health legislation. Those legislative powers exist to manage wider issues of public safety so do not, on the face of the Acts, require consideration of the person's capacity.

4.10 During the review senior leaders and practitioners reflected on whether more could have been done to explain to her options for assistive technology that might enable her to continue to live independently for longer. RBC reported they had recently overhauled their offer of Technology Enabled Care ['TEC'] and now have a small team [the 'NRS'] who use the trusted assessor model to complete needs assessments, recommend and install equipment designed to assist activities of daily living and/or alert nominated people if the adult requires urgent assistance, e.g. because of a fall or fire. BHFT's staff also confirmed that their Older People's teams are able to access this service. Practitioners highlighted that they sometimes still face resistance

[14] In line with duties under s6-7 Care Act 2014

to this offer particularly if there is a cost attached to the purchase or maintenance of those technologies. Clearer guidance on when a person may be able to use a direct payment or personal health budget to fund those costs might overcome some of that resistance and provide cost efficiencies for health and social care agencies. It was accepted that, whilst TEC is widely offered when adults are first referred through RBC's front door, familiarity with the range of support available and processes for instructing NRS may not be as well known in locality or community mental health teams. They believed a renewed awareness campaign across RBC, Integrated Care Board ['ICB'] and BHFT's care management and review teams, especially if this focused on practical examples of how those services could resolve complexities that arise when an adult is at risk of self-neglect, may lack the capacity to recognise that risk but it is not in their best interests to require a more intrusive offer of domiciliary care or residential placement. It is understood that RBC will be launching an awareness campaign in November 2022 and they already circulate a TEC newsletter.

4.11 Whilst it is apparent from the case notes that Pauline was pleased with decisions to close her case. However, practitioners questioned whether it was prudent to maintain a level of frequent but low-level social care support, given the likelihood of further deterioration in her cognition and the risks for adults with dementia who live alone. Practitioners talked of the high level of anxiety they feel about such cases and the impact on their own wellbeing when deciding they must close a referral, but believed their systems were such that this was a requirement. Conversely, senior managers spoke of the flexibility within the system that would enable such an approach. It is understood that previously RBC had an in-house carer service (available before the austerity measures) that could be responsive- working with adults at their pace and in line with their interests to develop trusted relationships and further mitigate risks of self-neglect. It appears from the case records that this was the approach intended for Pauline as her case was transferred to the long-term localities team. It should also be noted, Pauline was offered a referral to a befriending service, but declined this offer. Practitioners commented she seemed more reluctant to engage with the newly allocated long-term worker than she had with the social worker from the short-term team. They speculated as to whether this coincided with a deterioration in her cognition or if her engagement would have been better if the change in worker had not occurred. Senior managers confirmed they are exploring ways to provide a consistent worker for adults who are considered 'difficult to engage'.

4.12 Practitioners mused whether guidance to staff on how to apply discretion and refer (even against a person's wishes) for a wellbeing service that could provide frequent checks might assist practitioners to meet their duties under s11(2) Care Act. Certainly, where there is evidence of risk, powers under s42(2) Care Act should also be considered to facilitate a balanced, gradual or stepped approach.

What legal frameworks could have been applied in this case, what were the challenges in agencies applying them?

4.13 As set out above, the principle legal frameworks relevant to Pauline were the duties to provide health services, assess social care needs and, where there is a risk of abuse or neglect to work together to safeguard. Whatever legal framework is applicable, all public bodies must exercise legal powers in a way that complies with overarching obligations enshrined within the Human Rights Act 1998. While Article 2 of the European Convention on Human Rights (ECHR) places a duty on public bodies to prevent avoidable deaths, this must be balanced against the right to freedom from inhumane treatment (Article 3), the right to liberty (Article 5) and respect for private and family life (Article 8). The right to life is not an absolute right and a series of high-profile legal cases, such as the sad decision to turn off life support for Archie Battersby,[15] show how the courts weigh these different, and at times competing human rights, to take decisions in the individual's best interest.

[15] *Barts Health NHS Trust v Dance & Ors (Re Archie Battersbee)* [2022] EWFC 80 (15 July 2022) (bailii.org)

4.14 As noted above, the multi-disciplinary team supporting Pauline complied with their duties under the NHS Act and the Care Act. It was agreed that the risks to her would be well-managed were she to accept a care package of regular support. RBC ASC were in agreement to arrange that care, but her opposition to accept support in her own home made it necessary to consider if she had the requisite mental capacity to understand her needs and any risks of not meeting these. Thereafter, given the duties to promote wellbeing and uphold rights protected by the ECHR, practitioners must also explore if it would be proportionate and necessary in the circumstances to require an individual to accept support and, if an intervention requires an element of compulsion, identify the most appropriate legal power to provide that support.

4.15 There are two primary pieces of UK legislation that provide a legal framework to provide care or treatment to someone of 'unsound mind' namely, the Mental Health Act 1983 (MHA) and the Mental Capacity Act 2005 (MCA). Powers and duties under the MCA are considered below in response to the third theme of this review. Under the MHA, a person can be detained for the purpose of assessment for up to 28 days (s.2 MHA) if an application for admission is made by an Approved Mental Health Practitioner ['AMHP'] or the patients nearest relative. Two doctors must confirm that a) the patient is suffering from a mental disorder of a nature or degree that warrants detention in hospital for assessment (or assessment followed by medical treatment) for at least a limited period; and b) he or she ought to be detained in the interest of his or her own health or safety, or with a view to the protection of others. If they are assessed as needing to remain in hospital for treatment, a further application can be made under s3 MHA. In addition, s7 MHA permits for a patient to be received into guardianship on similar grounds. The powers of a guardian are set out within s8 MHA and include the power to determine a person's residence, require they attend for medical treatment and provide access to medical practitioners or other person so specified. As noted above, any exercise of these powers must demonstrate due consideration have been given to the duties to prevent avoidable deaths (Article 2 ECHR) as well as the right to freedom from inhumane treatment (Article 3), the right to liberty (Article 5) and respect for your private and family life (Article 8).

4.16 In conversation with the reviewers, practitioners unequivocally agreed that whilst there were risks to Pauline remaining within her own home, they were satisfied (given her presentation) that it was unnecessary and disproportionate to use powers to compel her to receive treatment in hospital under the MHA or be received into guardianship. They did not believe that she would have had the capacity to understand and retain the terms of any guardianship order, so questioned whether those powers would have had any practical application to reducing risks for Pauline. They also commented that guardianship powers were very rarely used, in part because this required a willing guardian to take on the responsibility. For Pauline, this would have meant the Local Authority assuming that role. Practitioners reported that was extremely unlikely because the legal mechanisms to impose care for someone in their best interests under the MCA were better understood and likely to have proved more beneficial in practice.

4.17 Staff spoke of the pervasiveness of the issues identified in this case. All had high levels of case experience where the adult lacked capacity to understand the risks faced by their degenerative condition but was not yet at high risk of harm to warrant close supervision of the nature that is available within a residential setting. They sometimes perceived the legal frameworks as a barrier to providing a proportionate, gradual approach to interventions. Examples were given of usual pathways into care for adults who resist lower-level social care interventions of being as a result of a crisis or critical event, such as a fall necessitating hospital admission or frequent police interventions requiring the use of powers under s2, s135-136 of the MHA to enable a period of in-patient assessment and thereafter to facilitate a move into residential care. Practitioners, particularly those who worked primarily under the MHA framework, believed this was because of the lack of resources- specifically delays in allocation

of Best Interests Assessors (under the Deprivation of Liberty procedures[16]) and availability of supported, sheltered accommodation or residential care. This may also be because there is a protocol between health practitioners and Thames Valley Police to support best practice when interventions for people in mental health crisis.[17]

4.18 Senior leaders accepted there were exceptional pressures in the local supported accommodation and residential care market, particularly during the Covid-19 pandemic. However, they also queried whether responding when someone has reached a crisis results in overreliance on MHA powers to facilitate admissions. There was concern that professionals may not be confident when interpreting legislation or case law or misunderstand the local pathways and resources to support a de-escalation of risks. They highlighted that urgent assessments under the MHA are resource heavy for the AMHP team and that there are mechanisms for RBC's operational and Deprivation of Liberty team to make available skilled assessors for urgent assessments of capacity and best interest, including where this might require authorisations under the Deprivation of Liberty Procedures.

4.19 All staff were keen to explore how systems could be better designed to provide clearer guidance on the pathways to support or escalate concerns where a person, particularly someone living alone with dementia, was refusing support. It was noted that, although practice in this case was very clearly person centred and respectful of her right to private life, it did provide an opportunity to explore how embedded that practice is. Staff spoke of opportunities that should be explored to improve information sharing between teams when urgent assessments are undertaken under MHA or MCA so that community-based teams have access to crucial records available to RBC and BHFT teams. They also stressed that a greater focus on the principles enshrined in the Mental Capacity Act 2005 from the point of a dementia diagnosis right through someone's journey may enable people to remain safe in their home environment for longer.

What are the barriers facing professionals when considering Mental Capacity and best interest decisions in risk management?

4.20 Outside of treatment under the MHA, the provision of care and treatment is only lawful if the person receiving the care/treatment has either given capacitated consent or, if the person lacks capacity, acts are done in accordance with legal obligations under the Mental Capacity Act 2005 and the Human Rights Act 1998. "*Every adult capable of making decisions has an absolute right to accept or refuse medical treatment, regardless of the wisdom or consequences of the decision. The decision does not have to be justified to anyone. Without consent any invasion of the body, however well-meaning or therapeutic, will be a criminal assault*"[18]

4.21 The MCA provides an arrangement for the assessment and, if necessary, the provision of care and treatment. A person lacks capacity in relation to a matter if at the material time he is unable to make a decision for himself in relation to the matter because of an impairment of, or a disturbance in the functioning of, the mind or brain. A person is unable to make a decision for himself if he is unable to understand, retain, and weigh the information relevant to that decision, or to communicate this. The fact that a person is only able to retain the information for a short period does not prevent them from being able to make the decision. There is a presumption of capacity unless otherwise evidenced and a person cannot be treated as lacking capacity, merely because someone else considers their decision to be unwise.

4.22 The second limb of any duty under the MCA, following a determination that the person lacks capacity, is to determine what care or treatment should be provided in according to the best

[16] s4 and sch.A1 of the MCA, shortly to be replaced by the Liberty Protection Safeguards
[17] 'Management of Mental Health Crisis Interagency Partnership Agreement' BHFT, April 2015, document ref CCR018
[18] *Aintree University Hospitals NHS Trust v James* [2014] AC 591

interest principles set out in s4 MCA. These are not defined in the MCA, rather it sets out a checklist of factors to be considered when making a Best Interests decision. This is not just the person's medical best interest, but rather the person's welfare in the widest possible sense, and considers the individual's broader wishes and feelings, and values and beliefs. All decisions should follow careful consideration of the individual circumstances of the person and focus on reaching the decision that is right for that person – not what is best for those around them, or what the "reasonable person" would want. Critically, a person's best interest is *'not an academic issue, but a necessary protection for the rights of people with disabilities. As the Act and the European Convention make clear, a conclusion that a person lacks decision-making capacity is not an 'off-switch' for his rights and freedoms. To state the obvious, the wishes, feelings, beliefs and values of people with a mental disability are as important to them as they are to anyone else, and may even be more important. It would be wrong in principle to apply any automatic discount to their point of view.'*[19]

4.23 The MCA Code of Practice is clear that those two separate limbs much be carefully distinguished. This was not always apparent in the inter-agency communication throughout Pauline's care. In particular, concerns regarding her capacity to reliably take her medication were not fully explored in multi-agency discussions which led to misperception about legal powers and responsibilities to mitigate the risk. The assumption by practitioners that she 'probably lacked capacity' so it was in her best interests to receive a care package at home meant that there was a lack of clarity about how that assessment had been reached. The issue and time specific nature of capacity issues are such that it is possible for subjective interpretations of presentations to influence professional judgements. The MCA code of practice advises that, before determining that a person lacks capacity on a specific issue care must be taken to ensure the salient information has been explained in a manner they can understand. It is highly probably that social care staff may not have sufficient medical knowledge to fully explain to Pauline the importance to her of taking her medication and therefore would find it difficult to adjudicate on whether she was adequately weighing this up. Conversely, social care practitioners are well placed to decide (based on their presentations and discussions with an individual) if they understand the risks of not accepting support. In Pauline's case, had a multi-agency formal capacity assessment carefully explored those two separate issues and determined (and subsequently recorded) which, if either, issue she had lost capacity to decide, it would have reduced the risk of seemingly conflicting views of her capacity (as alluded to above in 3.7 and 3.8) and enabled practitioners to have then more clarity on the legal consequences for each service to then determine what action they might proportionately take to provide necessary medical and/or social care support in her best interest.

4.24 A person who lacks capacity should still be involved in best interest decision-making process as far as possible. Those people who do not have family or friends who can represent them have a right to the support of an Independent Mental Capacity Advocate (IMCA) during the assessment process. Practitioners must also demonstrate that before deciding any action or inaction, the least restrictive options were considered. Practitioners working to support Pauline concurred that during the period under review she was probably unable to understand and weigh up her need for some support due to the extent of her dementia. Equally, as the case records demonstrate, they knew the importance she had placed on remaining independent at home for as long as possible and how distressing she found intrusions into her home. As such, they were cognisant of their responsibilities to make decisions regarding her care and treatment in her best interests in line with s4 Mental Capacity Act 2005 and of prioritising the least restrictive approach. They spoke eloquently of the need to build trust, offer alternative services (such as the befriending services, reablement care or assistive technology) to mitigate risks and of the benefits of multi-agency collaboration to monitor any deterioration.

[19] Peter Jackson in *Wye Valley NHS Trust v B* [2015]

They identified factors usually taken into account when determining when and how to put in place care and support against someone's wishes and explained that, though there were early indicators that she was growing frailer, she had not yet exhibited any changes in behaviours such as increased aggression, she was still very mobile, nor had she lost significant weight or shown poor self-care posing imminent risk to health. She had been found a few times confused, but there were not yet frequent missing episodes or police notifications. As such, whilst they anticipated (had she not fallen in November 2021) considering more restrictive care arrangements, it was commendable that in order to respect her wishes to remain independent they provided a high level of care. In the words of one professional during discussions with the reviewers, anything else at this stage of her illness '*would have been cruel, it would have felt like torture to her*'.

4.25 In *Westminster City Council v Manuela Sykes* [2014][20] the Court of Protection explored carefully the ethical and legal issues pertinent in Pauline's case. Like Pauline, Ms Sykes had dementia and had a history of not accepting care. Her illness had progressed beyond that recorded in Pauline's case, she was reported to have had altercations with others, was neglecting herself (with unhygienic and hazardous living conditions, weight loss to 41 kg), she was also at risk from wandering and lack of awareness of personal safety. As such she had been compulsory admitted to hospital (under s2 MHA) and thereafter placed in a nursing home. The issue before the Court was whether, given her distress, the Local Authority should fund a trial period of care at home. Ruling that it should, DJ Eldergill highlighted *"the importance of individual liberty is of the same fundamental importance to incapacitated people who still have clear wishes and preferences about where and how they live as it is for those who remain able to make capacitous decisions. This desire to determine one's own interests is common to almost all human beings. Society is made up of individuals, and each individual wills certain ends for themselves … has distinctive feelings, personal goals, traits, habits and experiences. Because this is so, most individuals wish to determine and develop their own interests and course in life, and their happiness often depends on this. The existence of a private sphere of action, free from public coercion or restraint, is indispensable to that independence which everyone needs to develop their individuality, even where their individuality is diminished, but not extinguished, by illness. It is for this reason that people place such weight on their liberty and right to choose."*

4.26 This judgment serves as a warning too against public bodies becoming too risk averse at the expense of the person's best interests. "*Risk cannot be avoided of course. All decisions that involve deprivation of liberty or compulsion involve balancing competing risks, of which the risk that others may suffer physical harm is but one. For example, detention and compulsory care or treatment may risk loss of employment, family contact, self-esteem and dignity; unnecessary or unjustified deprivation of liberty; institutionalisation; and the unwanted side-effects of treatment."*

4.27 Reflecting on the good practice demonstrated in this case, practitioners were mindful of how this could be further improved and what might ensure that such careful practice is embedded throughout WBSAB partner agencies. They noted that, despite consensus that she lacked capacity regarding the impact of non-compliance with her medication or refusing additional support may have, there was no formal capacity assessments recorded or shared by those responsible for assessing and providing her care. It is understood that the delay in formally assessing her capacity was because social care staff believed staff from the memory clinic or CMHT would need to complete this and she was often out when they visited.[21] There is no presumption within legislation or the Code of Practice that capacity assessments must be undertaken by a qualified medical practitioner, in fact even the assessment document for an application to the Court of Protection (a COP3 form) confirms this can be completed by a GP,

[20] Available at: https://www.bailii.org/ew/cases/EWHC/COP/2014/B9.html
[21] This was despite evidence that practitioners would have contacted her neighbour to remind Pauline of any scheduled visits.

psychiatrist, Approved Mental Health Professional, social worker, nurse or occupational therapist. In Pauline's case this did not materially adversely impact of the quality of interventions or shared risk management. However, all those involved in this review understood the benefits of complying with good practice expectations to record and carefully document capacity assessments across the multi-disciplinary teams. They noted that it might improve practice and certainly ensure that capacity assessments were completed in a timelier way if a protocol could be agreed locally confirming the range of disciplines that were well placed to assess care or residence matters, what issues would require specialisms (e.g. medication management) and when it would be prudent to have multi-agency joint assessments on complex, specific issues. This is the basis for recommendations, particularly recommendation 2, set out below.

4.28 Practitioners remain steadfast in their assessments that it was in Pauline's best interest to still be living in her own home at the time of her death, they accepted that if Pauline had not fallen, she would have inevitably required more support as her illness progressed. There are a number of initiatives designed to upskill RBC's practitioners on MCA practice, including having MCA champions within locality teams. During discussions, it was suggested that developing those roles so that each team also had access to safeguarding champions might encourage broader discussions of the legal and ethical issues that this case raises. Staff were able to point also to multi-disciplinary risk enablement panels, such as the monthly Reading Integrated Care Network which is attended by social care and health professionals (including GPs) to discuss what support can be explored with an adult and to check that all options have been offered. Staff accepted that not all practitioners will be aware of that forum. They may also not have the confidence to approach legal teams for advice when initially facing complexities in care planning due to resistance from someone who lacks capacity. Again, whilst senior leaders spoke highly of the accessibility and excellent advice provided by their legal teams, they recognised for many practitioners it almost felt like they were forsaking their own social work skills by turning to legal for 'permission' to use more interventionalist approaches. This misperception should be addressed through effective staff and case supervision.

4.29 It was almost inevitable, as Pauline's condition and ability to live safely alone deteriorated, that the matter would have to be considered by the Court of Protection. As such, the lack of formal capacity assessments and risk management plans could have made it more difficult to justify urgent interventions or look to restrict her liberty (e.g. including a change in residence) as they may not have been able to demonstrate the less restrictive actions to mitigate risks had been exhausted. It is also notable, despite agreement Pauline lacked capacity regarding care decisions, that an Independent Mental Capacity Advocate or Care Act Advocate had not been appointed to support her within those assessment, care planning and safeguarding discussions. There are, therefore, opportunities to improve recording and monitoring systems to ensure improved compliance with important procedural safeguards embedded within the MCA and Code of Practice and these too are addressed within the recommendation set out below.

Was the engagement between front line staff and Pauline's neighbours appropriate?

4.30 Research[22] shows that people with family or friends and neighbours who hold in a positive regard they remain at home for as long as possible have the easiest course with dementia. Sadly, many people within the UK do not have strong relationships with neighbours, so become very isolated which in turn impacts on their physical and mental wellbeing, often resulting in dependency on residential based care faster than might otherwise have been necessary. This was not Pauline's experience. As reported above, Pauline's neighbour had

[22] https://www.ageuk.org.uk/information-advice/health-wellbeing/mind-body/staying-sharp/looking-after-your-thinking-skills/social-connections-and-the-brain/

for many years acted as a protective factor. The paid attention to her comings and goings, often checked in with her and acted as a link between her and practitioners, reminding her of appointments and the need to take her medication. If alerted that she had become confused whilst out shopping, they were available to help her return home.

4.31 Practitioners spoke of the importance of regular contact with Pauline's neighbours when seeking to mitigate risks for Pauline given her reluctance for formal support. They also explained the importance of maintaining important professional standards, for example Pauline's confidentiality. Case records suggest care was taken to ask only pertinent information from her neighbours to enable a dynamic evaluation of risks. For example, the memory nurse during one failed home visit (as Pauline had gone out) checked if neighbours felt she was coping, whether they felt she may have lost any weight, dressed appropriately for the weather, left home at night when the risks might be greater for her. In asking these questions, she provided guidance on changes in behaviour or presentation her neighbour might want to look out for as that would prompt more detailed enquiries by professionals.

4.32 It was also clear from the case records that practitioners respected that there were boundaries to the level of support her neighbours felt able to provide, for example understanding that whilst one neighbour was happy to have a key and pass messages, she did not wish to be more closely involved in Pauline's care plans. It was reasonable, therefore, that her neighbours were not offered carer assessments or involved more closely with care planning responsibilities.

4.33 Shortly before Pauline's death one neighbour commented that they had raised concerns to RBC ASC, but felt nothing had been done. Senior leaders in discussion with the reviewers noted that because it is not always possible to share the outcome of a query or safeguarding concern with members of the public, out of respect for the person's right to a private life, this is perceived as not having been acted on. Hopefully, this review provides reassurance that those concerns were shared and acted on to the full extent that the statutory bodies' legal powers. It also offers an opportunity to widen the understanding of the considerations that must be given by public bodies when seeking to support adults living with dementia and the importance, stressed by the West Berkshire Dementia Action Alliance, of necessary improvements. A starting point, one that the WBSAB may wish to be involved in, might be to raise awareness of what a community based, first response might look like. Building on public health messaging during the Pandemic, messages about how to offer safe, supportive assistance, when and how to raise concerns should enable proportionate risks. Such a campaign, particularly over the coming winter months when the cost of living will be most keenly felt by adults with care and support needs, particularly those on fixed incomes, will have wide benefits for adults living with dementia, their carers and for society at large.

What was the impact Covid had on this case and what lessons can be learnt in the event of any future pandemics?

4.34 In 2020 the Covid 19 pandemic placed extraordinary strain on health and care professionals, who had to balance the need for individuals with serious health conditions to receive care in the community, with the need to keep them safe from coronavirus infection. At the start of this review period the Government had not yet introduced the Coronavirus Act 2020 or associated guidance and personal protective equipment was not widely available outside the NHS. At that time, many people refused care and home visits due to fear of infection and, as deaths within residential care rose, there was widespread reluctance to take up support within those settings.[23] The Office for National Statistics report into care home deaths reveals risks continued throughout this review period, as a consequence of second and third waves of the

[23] ONS report is available at: https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/articles/deathsinvolvingcovid19inthecaresectorenglandandwales/deathsregisteredbetweenweekending20march2020andweekending21january2022

virus. This additional risk, therefore, had to also be considered when balancing if it would be necessary and proportionate to require Pauline, against her stated wishes, to receive domiciliary or residential care.

4.35 Pauline's dementia limited her capacity to understand her need to accept some support, but case records demonstrate that she was aware of the measures imposed to limit social interaction and the risks posed by the Pandemic. It was also documented that arrangements were quickly in place to ensure she received food, medication and regular welfare checks. As noted above, whenever concerns were raised, staff from across relevant agencies provided prompt responses - often involving home visits to ensure her needs and wellbeing could be assessed face to face, albeit with necessary safety measures to prevent the spread of the virus.

4.36 It is possible that the enforced isolation, necessary to prevent the spread of the Coronavirus during the pandemic, hastened Pauline's cognitive decline. However, what is clear from the case files and discussions with those involved in this review was that at the time of her death she was still well nourished and mobile. She also still valued her independence and wished to remain at home and that this was made possible by the close attention paid to her wellbeing by practitioners and a committed network of neighbours. Studies[24] highlight the '*myriad negative physical and mental health outcomes that are linked to the older adult experiencing loneliness and/or social isolation*'[25] but also the opportunity that arises from the lessons learnt and ingenuity employed by practitioners during the pandemic who found creative ways to engage and stay connected to older adults. The pandemic was undoubtedly a very difficult time to have additional vulnerabilities, but there was also remarkable effort from volunteers and key workers to reduce harm to adults with care and support needs. WBSAB may wish to build on the community engagement work at neighbourhood levels with practical advice on providing compassionate, safe opportunities for social interaction for adults with dementia who wish to retain their independence but, like Pauline, truly value their place within their community.

5. System findings and recommendations

5.1 There is evidence of appropriate multi-agency referrals, information sharing and shared risk assessment in line with duties under s3 NHS Act and the Care Act. Practitioners demonstrated persistent, compassionate concern particularly with regards to her ability to take her medication and manage her nutrition, given her practices of keeping out of date food. The approaches adopted by agencies were in line with the local self-neglect policy and reflect the aspiration that practitioners understand the person beyond the self-neglect.

5.2 There was also evidence of multi-agency cooperation to address the complexity and uncertain of managing foreseeable risks given Pauline's reluctance to accept support.

5.3 However, practitioners found their ability to offer solutions that '*connect relevant legal rules with the professional priorities and objectives of ethical practice*'[26] was at times thwarted by misperceptions of how legal frameworks operate and cumbersome processes for multi-agency assessment and risk management. Developing clear guidance for staff across the partnership and particularly for first responders, GPs and trusted assessor within the acute hospital discharge process to assess of the availability and suitability of TEC will support the application of a least restrictive approach within best interest decision making for adults living with dementia.

5.4 Just as important will be to raise awareness within RBC ASC of when and how to utilise existing legal powers[27] to provide protective, low-level interventions (such as befriending

[24] Berg-Weger M, Morley JE. Loneliness in older age: An unaddressed health problem. J Nutr Health Aging. 2020;24(3): 243–245 8
[25] Berg-Weger, M., Morley, J.E. Loneliness and Social Isolation in Older Adults during the COVID-19 Pandemic: Implications for Gerontological Social Work. *J Nutr Health Aging***24**, 456–458 (2020). https://doi.org/10.1007/s12603-020-1366-8
[26] Bray and Preston-Shoot [2016] Legal Literacy: Practice tool' Darlington: Research in Practice for Adults
[27] Under s2, 18-20 and s42(2) Care Act 2014 and in accordance with s4 MCA 2005

services or technology enabled care) for those who lack capacity but are experiencing or at risk of self-neglect. This would provide increased opportunities to monitor changes in needs over time and prevent overreliance on re-referrals at times of crisis.

Recommendation 1: WBSAB should consider raising awareness of the good practice and compassionate care shown to Pauline.

Recommendation 2: WBSAB and relevant partners, in collaboration with the West Berkshire Dementia Action Alliance should review the local dementia strategy to ensure there are clear pathways between voluntary, community and faith sector organisations, primary care, specialist services provided by BHFT and adult social care. This should provide guidance on:

- Holistic needs assessments and risk mitigation at the point of diagnosis and at regular intervals as the condition progresses. Processes should ensure the adults wishes are clearly recorded, respected and correct legal processes followed to bring together multi-agency risk plans, care plans and health management plans.
- The availability and range of assistive technology, including links to local direct payments and personal health budget policies as possible mechanism to fund that support and maintain independence for as long as possible;
- The availability of temporary respite, step up/ down[28] and supported living options and guidance on the use of MCA and Deprivation of Liberty Safeguards (soon to be Liberty Protection Safeguards) legal frameworks to prevent an overreliance on s2 MHA powers.
- Access to local sources of information, advice and assistance for adults living with dementia and their carers that support with appointing lasting powers of attorney and advanced decision making;
- Raise awareness across partner agencies of the relevance of s42(2) powers to empower practitioners to provide, preventative low-level support or monitoring and befriending services.
- Provide guidance, modelled on the local MHA protocol, of the steps agencies with health and social care assessment, care planning and safeguarding responsibilities should take when they are unable to make contact with an adult living in the community with dementia. This should include guidance on wider powers of entry and what level of risk would trigger the necessity to use police powers under the Police and Criminal Evidence Act 1984 ['PACE'].

Recommendation 3: WBSAB should consider a public awareness campaign that provides practical advice on providing compassionate, safe opportunities for social interaction for adults with dementia who wish to retain their independence value their place within their community.

Recommendation 4: WBSAB should provide guidance to first responders, primary care, trusted assessors and community health and social care review teams on availability of TEC and application of a least restrictive approach within best interest decision making for adults living with dementia.

Recommendation 5: WBSAB should seek assurance from the relevant partners agencies (e.g RBC, ICB and BHFT) that they have effective procedures to monitor compliance with duties to carry out and record capacity assessments for those with known cognitive impairments.

Recommendation 6: Consideration should be given to whether the 'connected care' system should be adopted more widely across RBC and health partners to enable greater information sharing between health and social care is enabled to flag key documents such as capacity assessments.

[28] Practitioners were keen to explain that due to a lack of resource, currently temporary placements are reserved for those on pathway 2 of the 'Discharge to assess' model. There is no resource to provide a temporary placement for respite or to stabilise someone with a view to helping them to avoid admission to hospital and thereafter return home. This is likely to be costly on a financial, legal and reputational basis and so should be a high priority for the ICB and Local Authority.

Appendix A: Glossary

AMHP	Approved Mental Health Practitioner
ASC	Adult Social Care
BHFT	Berkshire Healthcare Foundation Trust
CMHT	Community Mental Health Team
CPN	Community Psychiatric Nurse
CRT	Community Reablement Team
ECHR	European Convention on Human Rights
GP	General Practitioner
HTT	BHFT's Older Adults Home Treatment Team
ICB	Integrated Care Board
IMCA	Independent Mental Capacity Advocate
MCA	Mental Capacity Act 2005
MHA	Mental Health Act 1983
OPMH	Older People's Mental Health team
OT	Occupational Therapist
PACE	Police and Criminal Evidence Act 1984
RBC	Reading and Berkshire Council
RBFT	Royal Berkshire NHS Foundation Trust
SAR	Safeguarding Adults Review
SCAS	South Central Ambulance Service
TEC	Technology Enabled Care
WBSAB	West Berkshire Safeguarding Adults Board