SHROPSHIRE SAFEGUARDING COMMUNITY PARTNERSHIP

SAFEGUARDING ADULT REVIEW Mrs H

2023

Report by Patrick Hopkinson

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SAFEGUARDING ADULT REVIEW - Mrs H

Shropshire Safeguarding Community Partnership

Personal information on Mrs H provided by her family

Our mother was born in 1943 with Cerebral Palsy and, as a result, had suffered significant, lifelong poor physical health and subsequently, poor mental health. In those days this was set against the backdrop of a generation of people who, at that time, didn't understand mental health let alone the enormous personal impacts that this could have on an individual, their families and friends – it was simply not recognised or appreciated in the way that it is now. Treatments weren't well understood and periodic institutionalisation, Electroconvulsive therapy (ECT) and a cocktail of medication was a routine part of mum's and ours lives.

Her mental illness was sometimes misunderstood by professionals and others, particularly as her health deteriorated so extensively in the last few years of her life. It became apparent that the ebbs and flows of her illness, which were represented by good times and bad, had finally appeared to have taken hold of her. In later years, there did not seem to be an apparent treatment pathway that could stabilise mum in a way that would maintain any sense of the life she had been able to experience in her periods of relative wellness previously, as well as keep her safe. We were informed by a clinician that mum was likely stuck in a psychotic episode of which there may be no way to come back.

The dreadfully sad manifestation of mum's illness could vary from aggression, sometimes violence, suicidal intentions and acute paranoia. This could lead to her being so exhausted that she sometimes hardly had the strength to speak properly or stay awake. She lacked insight, would frequently hear voices talking to her in her head and have random but frequent seizures. Her life with her illness was unpredictable, and as one Social Worker with more than 20 years of experience once said, our mum was the most unique and complex service user he had worked with.

Yet, despite the dreadful illness that had been inflicted on our mum and the devastating effects it could have on her health, daily function and relationships, when in good health, she was a very loving, kind, extremely protective, generous and caring person. The most important thing in our mother's life was her family. She often told us that she worshipped the ground upon which our father stood which was evident to see and she found it unbearable being parted from him for long. When he had to be admitted to hospital in later years for various operations and ailments, she would fret for him and could not wait for him to come home so that she could fuss over him. She hated being left alone in the home, so during this time, we would take it in turns to stay the night with her. She was also very proud of her children and her grandchildren. She was eager to tell people about everyone's achievements and walk them through the walls of photographs that had everyone on at home. She was a very intelligent lady who loved history and the Royal family. She was an avid reader and her ability to retain facts was most impressive. You could ask her almost anything about British history and the private lives of royalty and she would

be able to answer at length and with enthusiasm. For many years, she enjoyed visiting stately homes and National Trust properties with our dad.

She was also a very hard worker and was very proud of her home. As we were growing up, she was renowned for polishing and hoovering twice a day and she took care to see that we were well-dressed and spotlessly clean. Even as she got older and it became more physically difficult for her, she would still ensure the house was spotless, even if it meant supervising others to do it.

She was a very generous person too. She loved to shop and buy new things and she would often return from trips and excursions with thoughtful gifts for people. She regularly gave the grandchildren pocket money and would ensure they had a little extra for holidays. She would get very excited for birthdays and Christmas, and would usually have finished her shopping by October! She loved family occasions, coming round for tea or going out for lunch and she was always so appreciative of everything anyone did for her. She particularly enjoyed two family holidays to the USA with her son and his family, and when our father was no longer allowed to drive due to his illness, we would take them out on excursions to the zoo and other places like that which she loved.

We have always been a very close family and for most of her life we were able to support our mother through her times of illness. This is why it was so apparent to us in her final two years, that she was extremely unwell and sought help for her, as it became increasingly difficult to reason with her and cope with her extreme symptoms. To those that knew her, it was distressing to see that her health was deteriorating so fast and unable to be stabilised, and indeed we had feared for some time that this might become the case.

However, we could not have foreseen the lack of support and understanding, and the poor judgement of her condition that was present during her last two years of her life. In the months before her death Mum was having aggressive and violent outbursts, she was rejecting care, had isolated herself and was hearing voices. She was persistently calling the various health and care agencies, making irrational and aggressive demands. During this time our dad's health was deteriorating at an extremely rapid pace, and he was in receipt of end of life care.

Nothing could have prepared us for losing two parents within months of each other. It is our belief that our mum would still be alive today had she received the much needed specialist care that she so desperately needed and was crying out for.

There is not a single day that goes by where we don't think of our mum and dad.

1. INTRODUCTION

1.1 Mrs H was born in 1943. She had a husband, to whom she was married for almost 60 years, two daughters and a son. Mrs H's husband had been her primary carer for many years but in subsequent years, her husband's health

had deteriorated significantly due to heart and kidney failure and his strength and mobility declined rapidly due to his condition. Mrs H did not have a circle of friends or wider support network other than her husband, children and grandchildren.

- 1.2 Mrs H was partially blind and registered disabled. As well as multiple physical health problems, Mrs H suffered lifelong significant mental health issues and was sectioned under the Mental Health Act on a number of occasions, the most recent being for a period of several months during 2019/2020 when she was detained at the Redwoods Centre in Shrewsbury. In March 2020 Mrs H was transferred to a care home and in June 2020 Mrs H returned to her own home, living alone, with a care package.
- 1.3 During periods when Mrs H's mental health was poor, she would have what were described as "paranoid trust issues" which led her to be secretive about her illness with her family and to lack trust in them as well as in services and agencies. Mrs H, for example, changed GP practices on several occasions due to disagreements with them and made complaints about different agencies and individuals. Mrs H attempted to take her own life many times throughout her life, including an attempt two weeks before she died.
- 1.4 On the evening of the 21/3/21 Shropshire Fire and Rescue Service forced entry to Mrs H's home because Mrs H was not responding to her carers who had called at her house several times. The ambulance crew found Mrs H alive and conveyed her to hospital as they suspected that she had sepsis. On admission to hospital Mrs H's family were told that she "had pneumonia and aspiration, was extremely unwell and unlikely to recover. She had been lying on the floor for a long period of time and the aspiration was likely caused by ingesting her own vomit". Mrs H died in hospital on 26/3/21.

2. SAFEGUARDING ADULT REVIEWS

2.2 The Shropshire Safeguarding Community Partnership (SSCP) is the Safeguarding Adults Board (SAB) for Shropshire. Section 44 of the Care Act 2014 places a statutory requirement on SABs to commission and learn from Safeguarding Adult Reviews (SARs) in specific circumstances, as laid out below, and confers on SSCP the power to commission a SAR into any other case:

'A review of a case involving an adult in its area with needs for care and support (whether or not the local authority has been meeting any of those needs) if —

- a) there is reasonable cause for concern about how the SAB, members of it or other persons with relevant functions worked together to safeguard the adult, and
- b) the adult had died, and the SAB knows or suspects that the death resulted from abuse or neglect..., or

c) the adult is still alive, and the SAB knows or suspects that the adult has experienced serious abuse or neglect.

The SAB may also –

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

- ...Each member of the SAB must co-operate in and contribute to the carrying out of a review under this section with a view to –
- a) identifying the lessons to be learnt from the adult's case, and
- b) applying those lessons to future cases.
- 2.3 Board members must co-operate in and contribute to the review with a view to identifying the lessons to be learnt and applying those lessons to the future (s44(5), Care Act 2014).
- 2.4 The purpose and the guiding principles of this SAR are set out on the Keeping Adults Safe in Shropshire website https://www.keepingadultssafeinshropshire.org.uk/safeguarding-adult-reviews/ and in the West Midlands Regional Safeguarding Adult Review (SAR) Policy https://www.keepingadultssafeinshropshire.org.uk/media/1332/west-midlands-regional-safeguarding-adult-review-guidance.pdf
- 2.5 All SSCP members and organisations involved in this SAR, and all SAR panel members, agreed to work to these aims and underpinning principles. The SAR is about identifying lessons to be learned across the partnership and not about establishing blame or culpability. In doing so, the SAR will take a broad approach to identifying causation and will reflect the current realities of practice ("tell it like it is").
- 2.6 Mrs H's family made a referral for a SAR which was received by the SSCP on 28/4/21. This case was considered by the SSCP at an initial scoping meeting on 18/6/21 who made a recommendation to the Independent Chair of the SSCP that the case met the criteria for a SAR under S44 (1) and (2) or (3) of The Care Act 2014. On 15/7/21 the Chair of the SSCP decided that the criteria for a SAR had been met and therefore a SAR would be conducted.
- 2.7 The SAR was led by Patrick Hopkinson as the Independent Author and Lead Reviewer. Patrick Hopkinson is an Independent Consultant in Adult Safeguarding and had no previous involvement with this case and no connection with the agencies that worked with Mrs H.
- 2.8 Family involvement in this SAR
- 2.9 Mrs H's son and two daughters provided the Independent Author and Lead Officer of the SAR with information about Mrs H and concerns about her care and treatment. Mrs H's family reviewed and contributed to the report and recommendations.

3. BRIEF SUMMARY OF CHRONOLOGY AND CONCERNS

- 3.1 Mrs H was born in 1943. She had a husband, two daughters and a son. Later in life Mrs H disclosed to practitioners that she had been sexually abused as a child.
- 3.2 Mrs H had an extensive medical history, and her medical notes are dominated by mental health issues. According to her family, Mrs H was treated with electro-convulsive therapy (ECT) on numerous occasions, including a time during the 1990's when she was attended hospital for routine ECT. Episodes of overdosing on her medication dated back to 1981 and when Mrs H's mental health was poor she could be distrustful of her family and of services. Worsening physical health problems were also a major feature in Mrs H's life and these included temporal lobe epilepsy, hypertension, oesophageal problems, osteoarthritis, glaucoma, chronic airways disease, diverticular disease, knee replacement surgery, heart failure. Cerebral palsy reduced Mrs H's mobility, which in addition to epilepsy, put Mrs H at an increased risk of falls. Mrs H was assisted to move around her home by her husband or family and used a wheelchair and a walking frame
- 3.3 On 01/09/19 Mrs H was admitted to the Redwoods Centre (an in-patient facility for adults with acute mental health problems, dementia and rehabilitation needs) following a small overdose of medication. Mrs H returned home on leave on 09/09/19 and was formally discharged from the Redwoods Centre on 16/09/19.
- 3.4 On 20/09/19 Mrs H was taken to A&E after saying that she had taken an overdose and on 21/09/19, Mrs H was informally readmitted to the Redwoods Centre following attendance at her home by a member of the mental health crisis team. This was at the request of Mrs H's family who had been contacted by their father who could no longer cope with Mrs H's aggression towards him. Mr H had become extremely agitated, abusive and aggressive towards him and her family had been unable to calm her.
- 3.5 On 26/09/19 Mrs H cut her wrists while at the Redwoods and was detained at the Redwoods Centre under Section 2 of the Mental Health Act. This meant that Mrs H could be kept in hospital for up to 28 days while she was assessed. Mrs H requested to appeal to a tribunal against her detention, which was rejected.
- 3.6 On 06/10/19, while at the Redwoods Mrs H was admitted to A&E overnight because of an overdose and then returned to the Redwoods Centre. During this time, according to her family, Mrs H's behaviour was at times agitated, abusive and aggressive and Mrs H had reportedly hit another patient.
- 3.7 On 31/10/19 Mrs H's placed on Section 3 of the Mental Health Act to treat her for depression. Mrs H also appealed unsuccessfully against this Section.
- 3.8 Throughout the Christmas 2019 period home leave for Mrs H under Section 17 of the Mental Health Act was trialled. The Section 17 leave was built up incrementally with Mrs H starting with a few hours once or twice a week to overnight leave at home. Mrs H successfully spent Christmas Day at home.

- 3.9 On 17/01/20, while at the Redwoods, Mrs H attended A&E following a possible seizure.
- 3.10 On 22/01/20 Mrs H went home on two weeks further Section 17 leave, with a care package and additional support from the Hospital Avoidance Team of Midlands Partnership Foundation Trust (MPFT).
- 3.11 On 23/01/20 Mrs H's leave was revoked and she was returned to the Redwoods Centre because she had attempted to strangle one of her daughters, this was reported to have been observed by a carer. According to Mrs H's family, prior to this Mrs H had hit and kicked her husband, prevented him from sleeping and had spent all night awake washing and cleaning. Mrs H. blamed the family for her having been readmitted back to the Redwoods Centre.
- 3.12 In subsequent days Mrs H said that she did not wish to speak to her family and she told a psychologist that if she attempted suicide again, she would not be unsuccessful because she felt unloved. According to Mrs H's family, however, her daughter-in-law had managed to maintain visits to Mrs H and had established a degree of trust with her. Other family members had been rejected by Mrs H.
- 3.13 On 04/02/20 a consultant psychiatrist reviewed Mrs H and diagnosed Mrs H's condition as personality disorder, mood disorder, temporal lobe epilepsy and organic brain syndrome (OBS) with specific executive functioning impairment. The consultant suggested that returning home should not be an option for Mrs H and recommended a 24-hour care placement.
- 3.14 On 17/02/20 a mental capacity assessment was undertaken by Adult Social Care with input from MPFT and concluded that Mrs H lacked capacity to make decisions about future care needs and residence. Subsequently a best interests meeting was held which determined that it was in Mrs H's best interests to reside in a nursing home placement following discharge from the Redwoods Centre. Mrs H's family were not involved in this best interests meeting. There is no record of the meeting. According to Mrs H's family, she had begun to trust her family again and visits had resumed. Mrs H had also started to speak with her husband again by telephone in the care home.
- 3.15 On 10/03/20 Mrs H was transferred, with her agreement, to a placement with her family's involvement at a local care home, initially on two weeks' Section 17 leave and then on a permanent basis.
- 3.16 Consequently, on 23/03/20 Mrs H's detention for treatment under Section 3 of the Mental Health Act was revoked and she was formally discharged to The Care Home with Section 117 Mental Health Act aftercare. Restrictions in response to the Coronavirus pandemic meant that Mrs H's family could not visit her but had delivered personal items of furniture to her including the chair in which she had slept for several years,
- 3.17 On 6/04/20 Shrewsbury and Telford Hospital NHS Trust completed a "Recommended Summary Plan for Emergency Care and Treatment" form for Mrs H which noted that Mrs H wanted to have full hospital treatment including

- cardiopulmonary resuscitation if she became unwell and her children to be consulted should she be unable to make decisions.
- 3.18 On 29/04/20 MPFT were notified by the manager at The Care Home that Mrs H was unsettled and "obsessed" with Covid, that her husband would not answer her telephone calls and that she was refusing Lorazepam (to treat anxiety and sleeping problems). The manager at The Care Home reported that Mrs H was using her wheelchair to ram into other people when she was upset and seemed frustrated that she was not being listened to. The manager felt that Mrs H had mental capacity, and, despite suggestions that they should, had not applied for Deprivation of Liberty Safeguards to keep Mrs H at The Care Home.
- 3.19 On 05/05/20, the registered nurse on duty at The Care Home completed a Mental Capacity assessment and concluded that Mrs H had the mental capacity for future planning.
- 3.20 On 07/05/20 a multi-disciplinary team meeting involving health services, ASC and the Care Home Owners agreed to a trial period for Mrs H at home. However, concerns were expressed by MPFT at the meeting about Mrs H's capacity and return home and the Care Home Manager was advised to apply for emergency Deprivation of Liberty Safeguards to keep Mrs H in the care home, but declined this.
- 3.21 On 11/05/20 ASC received a letter from Mrs H's three children setting out their concerns about their mother's care and support.
- 3.22 On 11/06/20 a social worker reported that Mrs H had capacity and that Deprivation of Liberty Safeguards were not applied for Mrs H because Mrs H did not have short-term memory loss, was able to understand her care and support needs and was able to have a full and relevant conversation. On 14/05/20, during a multi-disciplinary meeting, involving a Consultant Psychiatrist, Ward Doctor, 2 Social workers, an Operation Lead from MPFT, a representative from the CCG and the Care Home Manager, the Care Home Manager again declined to apply for emergency Deprivation of Liberty Safeguards and the social worker agreed to pursue this further with the Care Home Manager.
- 3.23 On 15/06/20 ASC received a further letter from Mrs H's family about Mrs H's care and support, raising a concern that Mrs H's medical and mental health history were not being considered and expressing an objection to Mrs H's return home. The letter stated that, "we didn't want her to become a statistic in a lessons learnt exercise". On 16/06/20 Mrs H left The Care Home and returned home with the support of a live-in carer. Mrs H's husband had been admitted to a care home in March 2020 and so Mrs H was living alone for the first time. Within the first 24 hours of returning home Mrs H fell, resulting in an injury to her head and a broken wrist.
- 3.24 On 18/6/20 the live-in carer arrangement broke down because Mrs H found live-in care too intrusive and, following an incident where Mrs H locked the carer out of the house, left herself with access to her medication. Mrs H had

also been aggressive towards the carer, who refused to continue to provide care for her.

Following this it was felt that as Mrs H was not accepting of the lesser restrictions nor would she accept informal admission to hospital, there should be an assessment of her Mental Capacity. Mrs H was assessed by the AMHP and 2 doctors who concluded that she was not detainable under Section 2 of the Mental Health Act and that she had the capacity to make decisions about her care and treatment and where she should reside.

That evening the Emergency Duty team arranged for 2 carers to stay with Mrs H until the following day when a package of support was decided upon. 2 carers were required due to the aggression showed towards the previous carer.

- 3.25 On 19/06/20 The Domiciliary Care Agency, a local domiciliary care company, started providing a care package of four daily care visits with two carers each time to support Mrs H with medication and assess her welfare and another two carers and a car to support with grocery shopping. A locked box, to which Mrs H did not have a key but her carers did, was provided for Mrs H's medication in response to her disclosure to the Hospital Avoidance Team that she would harm herself and knew how to do it.
- 3.26 On the evening / night of 25/06/20 Mrs H refused to allow the carers from The Domiciliary Care Agency into her home.
- 3.27 On 26/6/20 Mrs H attended A&E following another fall.
- 3.28 On 29/06/20 a mental health risk assessment was completed for Mrs H jointly by health, social care and the Domiciliary Care Agency.
- 3.29 On 21/07/20, following a challenge by Mrs H disputing her dementia diagnosis, a review was conducted by a consultant psychiatrist who diagnosed that Mrs H had frontal lobe syndrome. This was recorded in ASC records as frontal lobe epilepsy with auditory hallucinations.
- 3.30 On 31/07/20 MPFT, The Domiciliary Care Agency and Mrs H liaised regarding Mrs H's request to change or stop her medication and how this could be managed safely, if at all. Mrs H did not feel that she required medication. Mrs H's consultant psychiatrist and another psychiatrist concluded that she lacked capacity to make this decision due to an impairment of executive functioning. Mrs H was told that she could not decide to stop taking the medication.
- 3.31 On 13/08/20 Mrs H attended A&E claiming that she had a seizure because she had missed her medication that evening. According to the records of The Domiciliary Care Agency a staff nurse at Shrewsbury Hospital stated that Mrs H had experienced a pseudo seizure and that it "was not a proper seizure as such". Mrs H's GP and the social worker discussed Mrs H's medication and decided that the risk to her physical health outweighed her risk of overdose. Therefore, it was decided that Mrs H would have access to her medication. Mrs H's family were not consulted about the assessment of Mrs H's capacity to manage her medication because the GP surgery followed Mrs H's

- expressed wishes that no information about her physical or mental health be shared with her family.
- 3.32 On 14/08/20, given the change in her diagnosis to frontal lobe syndrome, Mrs H was transferred from the dementia team to the Community Interventions Pathway team.
- 3.33 On 17/08/20 in consultation with MPFT, ASC discontinued the care visits by The Domiciliary Care Agency to give Mrs H her medication. From 17/08/20 care reduced to two per week of 1.5 hours on Tuesdays with two carers and 2 hours on Fridays with two carers. The care visits were to assess and confirm Mrs H's welfare as well as to support her with grocery shopping, accessing the community, social interaction and with laundry if required.
- 3.34 On 12/11/20 a s117 review was completed with The Domiciliary Care Agency, the social worker and Mrs H. During this review Mrs H agreed for the carers to continue to support her.
- 3.35 On 25/12/20 West Midlands Ambulance Service (WMAS) were called out twice to Mrs H's home. On the first occasion a family member made a telephone call concerned for Mrs H's welfare. On arrival WMAS had a conversation with Mrs H, conferred with MPFT by telephone and agreed that Mrs H was not at risk of suicide or self-harm. On the second occasion Mrs H's daughter called MPFT reporting that Mrs H was ranting and delusional and that she had told her grandson she was going to take all of her tablets at once. WMAS attended and, once Mrs H had calmed, felt that Mrs H was not at risk of suicide and reported this back to MPFT.
- 3.36 On the 28/01/21 Mrs H was admitted to hospital having attempted suicide with a mixed medication overdose. Mrs H's family said they were not informed about the admission to hospital, nor about the permanent damage to Mrs H's organs resulting from this attempt to end her life. The hospital noted that Mrs H had acute kidney injury Stage 1 (where kidneys suddenly stop working properly https://www.nhs.uk/conditions/acute-kidney-injury/)
- 3.37 Shrewsbury and Telford Hospital NHS Trust state this was mild kidney damage and there was no damage to any other organs.
- 3.38 On 11/03/21 Mrs H took a mixed medication overdose. It appears that this did not prompt a review of her needs.
- 3.39 On 16/03/21 West Mercia Police assisted Mrs H following a report from a member of the public that Mrs H was walking up and down the street disorientated, confused and unsteady on her feet. There was a concern Mrs H was going to walk into the road.
- 3.40 From 19/03/21, additional care visits were arranged for when Mrs H became agitated in order to ease her anxieties and to provide someone for her to talk to. The Domiciliary Care Agency made two visits to Mrs H on 19/03/21. The first was for shopping but Mrs H turned the carers away. On the second visit

- the carer spoke to Mrs H through the kitchen window. This was the last recorded time that Mrs H was seen.
- 3.41 On the evenings of 20/03/21 and 21/03/21 a carer visited Mrs H, but there was no answer. The Domiciliary Care Agency contacted the MPFT avoidance team and the Police.
- 3.42 The Police were unable to attend due a priority 1 call, but Shropshire Fire and Rescue Service (SFRS) arrived to gain entry to Mrs H's property. Mrs H had changed the locks and had removed keys from the key safe. Forced entry was required but the protocol for this requires the presence of a second agency and SFRS must wait for the police to attend. SFRS had to wait for just over one hour to force entry, with the permission of the police.
- 3.43 Mrs H's family were alerted and upon arrival were told that, "there were signs of tablets strewn across the worktop and an opened half empty carton of milk next to them inside the house but that there was no response from inside".
- 3.44 SFRS found Mrs H on the floor and WMAS conveyed her to the Royal Shrewsbury Hospital (RSH) as the crew suspected sepsis. Mrs H's family were told that she "had pneumonia and aspiration, was extremely unwell and unlikely to recover. She had been lying on the floor for a long period of time and the aspiration was likely caused by ingesting her own vomit"."
- 3.45 RSH considered that Mrs H would deteriorate despite medical intervention and that the outcome was likely to be poor. RSH discussed this with Mrs H's family, who asked that the antibiotics that she was being treated with be continued until Mrs H had been seen by a neurologist, who confirmed that Mrs H was profoundly unconscious. Consequently, the antibiotics were stopped and RSH noted that Mrs H's family agreed "CPR would not be in their mother's previously held views or her best interests".
- 3.46 On 25/03/21 Mrs H was reviewed by a consultant neurologist who felt she was profoundly unconscious as the result of a fall of unknown cause which might be related to a seizure or cardiac event. On 26/03/21 Mrs H passed away in hospital.

4 THE EVIDENCE BASE FOR THE REVIEW

- 4.1 Michael Preston-Shoot (2019) argues that, "Drawing on existing evidence about effective practice would mean that reviewers are not starting out with a blank canvas. What is proposed here is that SARs begin explicitly with the available evidence-base, using it as a lens with which to scrutinise case chronology and explore through panel meetings, interviews and learning events with practitioners and managers what facilitates good practice and what presents barriers to effective practice"
- 4.2 The advantage of this approach is that, "The emphasis then is less on description and more on immediate reflection and systemic analysis of facilitators and barriers, across nationally determined policy, legal and

- financial systems as well as local arrangements and staff values, knowledge and skills" (Preston-Shoot, 2019).
- 4.3 Consequently, a study was made of both the research evidence and practice evidence that provides insight and guidance when working with someone in Mrs H's situation: self-harming, with mental health needs and a history of childhood trauma, and who presented challenges to and rejected services.

4.4 Mental Capacity Act and Decisional and Executive Capacity

- 4.5 The extent to which a person who self neglects can put whatever decisions they make into effect should be considered. There were concerns about Mrs H's ability to self-care and take medication.
- 4.6 Certain neurological conditions can impact negatively on executive functioning (which includes motivation, planning, social behaviour and speech production). Mrs H had been given two diagnoses, one of organic brain syndrome with specific executive functioning impairment and, a few months later, one of frontal lobe syndrome. Both of the diagnoses involve impaired executive functioning. Chronic organic brain syndrome is associated with dementia. Symptoms of frontal lobe syndrome include weakness of one side of the body or face, falling, inability to solve problems or organise tasks, reduced creativity, impaired judgment, depression, difficultly controlling emotions and impulsive or risky behaviour https://www.verywellhealth.com/the-brains-frontal-lobe-3146196.
- 4.7 Compared with control groups, people with frontal lobe damage:
 - Are significantly slower and less accurate at problem solving when it involves planning ahead.
 - Persisted with riskier behaviours for longer and were less responsive to negative outcomes.
 - Were no different when identifying what the likely outcome of an event would be.
- 4.8 As a result, people with frontal lobe damage might have the mental capacity to predict what might happen but are less likely to be able to take action to prevent it from happening.
- 4.9 Significantly, these cognitive deficits are unlikely to be detected using the verbal reasoning tests frequently used in mental capacity assessments. It does not appear that this was considered when decisions about Mrs H's mental capacity were made.
- 4.10 Whilst the Mental Capacity Act does not explicitly recognise the difference between decisional capacity (the ability to make a decision) and executive capacity (the ability to turn that decision into action), it is an important distinction in practice, especially with people who self-neglect and feign compliance or avoid contact. Executive capacity can be explored through the assessment of a person's ability to use and weigh information in order to make a decision (see for example,

https://safeguardingcambspeterborough.org.uk/wp-content/uploads/2020/11/ADASS-Eastern-Region-Self-Neglect-and-Hoarding-2020.pdf).

4.11 The proposed revised Code of Practice for the Mental Capacity Act will, subject to consultation, include guidance on assessing mental capacity where there is an impairment in executive functioning and a mismatch between what a person says and what they do. The proposed revisions include that, "A person who makes a decision which others consider to be unwise should not be presumed to lack capacity. However, a series of unwise decisions may indicate an inability to use or weigh information" (section 4.39).

4.12 **Best Interests**

- 4.13 A best interests meeting may be needed where someone aged at least 16 years old lacks the mental capacity to make significant decisions for themselves and needs others to make those decisions on their behalf.
- 4.14 A best interests decision cannot be made for a person if they have been assessed as having capacity to make the decision or (where there is doubt about capacity) a capacity assessment has not been undertaken to confirm that they lack capacity.
- 4.15 Chapter 5 of the Mental Capacity Act 2005 Code of Practice explains the process to determining the best interests of a person who lacks capacity by reference to a statutory checklist which must always be followed.

Self-harm

- 4.16 Mrs H self-harmed as far back as 1981, there were regular occurrences when she was unwell and Mrs H attempted suicide several times in the last year of her life.
- 4.17 Self-harm is defined as "Any act of self-poisoning or self-injury carried out by an individual irrespective of motivation" (NICE 2011).
- 4.18 The Royal College of Psychiatrists has published guidance on working with adults who self-harm https://www.rcpsych.ac.uk/docs/default-source/improving-care/better-mh-policy/college-reports/college-report-cr229-self-harm-and-suicide.pdf?sfvrsn=b6fdf395">https://www.rcpsych.ac.uk/docs/default-source/improving-care/better-mh-policy/college-reports/college-report-cr229-self-harm-and-suicide.pdf?sfvrsn=b6fdf395">https://www.rcpsych.ac.uk/docs/default-source/improving-care/better-mh-policy/college-reports/college-report-cr229-self-harm-and-suicide.pdf?sfvrsn=b6fdf395">https://www.rcpsych.ac.uk/docs/default-source/improving-care/better-mh-policy/college-reports/college-report-cr229-self-harm-and-suicide.pdf?sfvrsn=b6fdf395">https://www.rcpsych.ac.uk/docs/default-source/improving-care/better-mh-policy/college-reports/college-report-cr229-self-harm-and-suicide.pdf?sfvrsn=b6fdf395">https://www.rcpsych.ac.uk/docs/default-source/improving-care/better-mh-policy/college-report-cr229-self-harm-and-suicide.pdf?sfvrsn=b6fdf395">https://www.rcpsych.ac.uk/docs/default-source/improving-care/better-mh-policy/college-report-cr229-self-harm-and-suicide.pdf?sfvrsn=b6fdf395">https://www.rcpsych.ac.uk/docs/default-source/improving-care/better-mh-policy/college-report-cr229-self-harm-and-suicide.pdf?sfvrsn=b6fdf395">https://www.rcpsych.ac.uk/docs/default-source/improving-care/better-mh-policy/college-report-cr229-self-harm-and-suicide.pdf?sfvrsn=b6fdf395">https://www.rcpsych.ac.uk/docs/default-source/improving-care/better-mh-policy/college-report-cr229-self-harm-and-suicide.pdf?sfvrsn=b6fdf395">https://www.rcpsych.ac.uk/docs/default-source/improving-care/better-mh-policy/college-report-cr229-self-harm-and-suicide.pdf
- 4.19 The guidance states that a safety plan should be drawn up in conjunction with the individual if they are at risk of suicide and there is emerging evidence of the effectiveness of such plans (Zonana et al. 2018).
- 4.20 A Safety Plan is an agreed set of activities, strategies to use and people and organisations to contact for support if someone becomes suicidal, if their suicidal thoughts get worse or if they might self-harm. The components of a safety plan are:

- Reasons for living and/or ideas for getting through tough times
- · Ways to make your situation safer
- Things to lift or calm mood
- Distractions
- Sources of support, to include anyone you trust.
- The plan should also include specific reference to the removal or mitigation of means of suicide or self-harm.
- 4.21 There is no evidence that a suicide safety plan was prepared with Mrs H.

4.22 **Self-neglect**

- 4.23 Self-neglect is one of the ten categories of abuse and neglect specified in the adult safeguarding sections of the Care Act statutory guidance.
- 4.24 Self-neglect can be defined as, "the inability (intentional or non-intentional) to maintain a socially and culturally accepted standard of self-care with the potential for serious consequences to the health and well-being of the self-neglecter and perhaps even to their community" (Gibbons et al, 2006, p.16).
- 4.25 Michael Preston-Shoot and Suzy Braye have undertaken extensive research into and guidance on working with people who self-neglect and this was available from December 2018 onwards. As this is about learning lessons it is appropriate to consider the guidance to help practitioners facing similar situations of self-neglect in the future. For the purposes of this SAR, it is sufficient to focus only on a summary of this guidance.
- 4.26 Practice with people who self-neglect is more effective where practitioners:
 - a) Seek to understand the meaning and significance of the self-neglect, taking account of the individual's life experience
 - b) Work patiently at the pace of the individual, but know when to make the most of moments of motivation to secure changes
 - c) Keep constantly in view the question of the individual's mental capacity to make self-care decisions
 - d) Communicate about risks and options with honesty and openness, particularly where coercive action is a possibility
 - e) Ensure that options for intervention are rooted in a sound understanding of legal powers and duties
 - f) Think flexibly about how family members and community resources can contribute to interventions, building on relationships and networks
 - g) Work proactively to engage and co-ordinate agencies with specialist expertise to contribute towards shared goals

In order to do this, the following approaches should be used:

- a) History taking. Explore and ask questions about how and when self-neglect started.
- b) Be proactive and identify and address repeated patterns of behaviour
- c) Try different approaches, use advocates and concerned others, raise concerns, discuss risks, maintain contact, avoid case closure
- d) Ongoing assessment and review of mental capacity
- 4.27 On a more strategic level the policy, procedural and organisational environments that foster this way of working are likely to have the following characteristics:
 - a) Agencies share definitions and understandings of self-neglect
 - b) Interagency coordination and shared risk-management is facilitated by clear referral routes, communication and decision-making systems
 - c) Longer-term supportive, relationship-based involvement is accepted as a pattern of work
 - d) Training and supervision challenge and support practitioners to engage with the ethical challenges, legal options, skills and emotions involved in selfneglect practice
- 4.28 The extent to which these approaches were applied to Mrs H, and the environment to support them existed, provide a useful analytical framework for this SAR.
- 4.29 Self-neglect, mental capacity and freedom of choice
- 4.30 Safeguarding Adults Reviews (amongst others Andrew, Staffordshire and Stoke, 2022; Harold, Brent 2022; Adults B and C, South Tyneside; Mr I, West Berkshire and W, Isle of Wight) have increasingly focused on the challenges of practicing in a way which balances the principles of freedom of choice and self-determination with the duties, public expectations and moral imperatives of public services. These take place within a legislative context that includes the Human Rights Act 1998 see Appendix 1, the Mental Capacity Act see Appendix 2, the Care Act see Appendix 3.
- 4.31 These are further complicated by confusion in the application of the Mental Capacity Act, its statutory guidance and principles when considering questions of whether or not people are able to make decisions on a specific matter at a specific time (see for example, the post-legislative scrutiny report of the House of Lords Select Committee on the Mental Capacity Act 2005 published in 2014).

- 4.32 At the intersection of these factors is the question of the extent to which adults should be left by public services to behave in a way that is objectively detrimental to their health and wellbeing or which threatens their lives. More fundamentally it can be reduced to a question of freedom of choice versus protection. The guidance (for example, Braye and Preston Shoot, 2020) on working with people who self-neglect challenges the either/ or nature of this question by asking practitioners to consider:
- 4.33 Is a person who self neglects really autonomous when:
 - a) They do not see how things could be different
 - b) They do not think they're worth anything different
 - They did not choose to live this way, but adapted gradually to circumstances
 - d) Their mental ill-health makes self-motivation difficult
 - e) They have impairment of executive brain function
- 4.34 Is a person who self neglects really protected when:
 - a) Imposed solutions do not recognise the way they make sense of their behaviour
 - b) Their 'sense of self' is removed along with the risks
 - c) They have no control and no ownership
 - d) Their safety comes at the cost of making them miserable

4.35 Trauma Informed Practice

- 4.36 Mrs H experienced trauma in childhood and this may have impacted on her adult life. Mrs H had been sexually abused as a child and, according to practitioners, would not allow her own children outside because of this. Mrs H told staff at the Redwoods Centre that she would not sleep in a bed because that is where the abuse had taken place. Mrs H's children, however, told the review writer that Mrs H' has started to sleep in a chair because of arthritis. Relations with her husband were also strained and she alleged that he was controlling of her. Mrs H related to practitioners that she had wanted to buy her children new clothes to wear to church, but her husband would not give her the money. Mrs H's children, however told the review writer that they never all went to church. Mrs H's children, considered that their mother was controlling of, and abusive towards, their father, rather than the other way around, and was abusive towards them when her mental health was poor. In the later years of Mrs H's life she said that she wanted to divorce her husband.
- 4.37 Mrs H was known to have attempted suicide on many occasions and as far back as 1981. She could become agitated and was known to be mistrustful of others including her family and practitioners when her mental health was poor. At times Mrs H became angry and shouted at practitioners. Mrs H often voiced a degree of opposition to elements of her planned care.
- 4.38 Trauma informed practice is a strengths-based approach, which seeks to understand and respond to the impact of trauma on people's lives. The approach emphasises physical, psychological and emotional safety for

everyone and aims to empower individuals to re-establish control over their lives. Having a basic understanding of how stress can affect an individual is important. Knowing this will make us less likely to fuel other people's stress levels. This means paying attention to 'how' we engage with other people, as well as to 'what' we do. It also means thinking about what may have happened to someone, rather than judging what is 'wrong' with them https://www.plymouth.gov.uk/adultsandchildrenssocialcare/childrenssocialcare/academysocialworkplymouth/informationandresourcespractitioners/traumainformedpractice.

4.39 The Blue Knot Foundation has produced guidance and resources on trauma informed practice https://blueknot.org.au/resources/blue-knot-publications/guidelines/. This guidance has been adapted for the Trauma-Informed Toolkit published by the Scottish Government https://www.gov.scot/publications/trauma-informed-practice-toolkit-scotland/pages/12/#AP2, some of which is listed below:

4.40 Understand the impacts of stress on the brain

 Under stress, we can all lose the ability to be calm, reflect and respond flexibly.

4.41 Signs of trauma can take different forms

- Trauma responses include both:
- Hyperarousal (obvious agitation, e.g. shaking, sweating, raised voice)
- and
- Hypoarousal (e.g., glazed eyes; `zoning out'; `shut down'; can be harder to detect).

4.42 Simple ways to lower arousal can restore safety

- We can all learn to do this for ourselves and others.
- Lowering arousal allows the person to return to a place where they can tolerate their feelings (`the window of tolerance') and avoid being overwhelmed from hyper- and hypoarousal.

4.43 Challenging responses and behaviours can be defences against stress

- Traumatised people develop coping strategies to protect them from being overwhelmed.
- Understanding this allows us to consider what may have `happened to' a person rather than what is `wrong' with a person.

4.44 The `way in which' we interact with a traumatised person (not just `what' we say and do) is important

• It can also either increase or decrease a person's stress levels. This underlines the importance of knowing how to interact in a trauma-informed way, not make things worse, and `do no harm'.

4.45 Understanding the stress response

Hyperarousal

- Increased heart rate
- Increased rate of breathing
- Blood flows from the arms and legs to organs and major muscle groups
- Tension in the person's muscles
- Hypervigilance i.e., being on guard (for threat)
- Problems with the digestive system
- Disturbance of sleep and energy levels

Hy*po*arousal

- Having feelings of being 'shut down' or 'cut off'
- Avoidant avoiding places, events, feelings
- Withdrawn
- Loss of humour, motivation, pleasure and connection with others
- Disturbance of sleep and energy levels

4.46 Tips to reduce stress

Hyperarousal

- Recognise being hyper-aroused is a distress/fear response
- Validate their response ('I can see you are...')
- Support the person to feel safe
- Turn the person's focus to their current need/task
- Support gentle ways for the person to release some energy
- Help the person to feel grounded, and feel settled in their body (e.g. feet firmly on the floor; some stretches)

Hy*po*arousal

- Recognise being hypo-aroused is a distress/fear response
- Support the person to feel safe
- Provide an opportunity for the person to express their current needs without pressuring them to do so
- Pay attention to the physical space (more or less proximity to others?)
- Help the person to become aware of their current surroundings and to tune into their senses
- Encourage the person to move a little, change their posture/position or practice a familiar ritual or rhythm. Emphasis should be on movement rather than sensations for hypo-aroused states.
- Direct attention outward (e.g., noticing objects in the room) rather than inward.

4.47 Family involvement, respecting choice and confidentiality and sharing information

4.48 The Care Act sets out the wellbeing principle in section 1 and states that, "the core purpose of adult care and support is to help people to achieve the

- outcomes that matter to them in their life". Section 2.18 of the Care and Support Statutory Guidance for the Care Act states that promoting a person's wellbeing, "should include consideration of the role a person's family or friends can play in helping the person to meet their goals".
- 4.49 During the last nine months of her life Mrs H was described as estranged from her family, although Mrs H's family considered that this fluctuated. Developing and maintaining family or other personal relationships is included within the Eligibility Regulations for social care: "Local authorities should consider whether the adult is lonely or isolated, either because their needs prevent them from maintaining the personal relationships they have or because their needs prevent them from developing new relationships" (s6.106 (g) of the Care and Support Statutory Guidance)
- 4.50 Consequently, supporting Mrs H to renew contact with her family would have been consistent with the duty to promote her wellbeing. Additionally, Mrs H was isolated at times during 2020 and 2021 due to the Covid-19 restrictions, although these did sometimes allow family contact. Mrs H, however, retracted consent for practitioners to share information with her family.
- 4.51 There is a clear legislative expectation that the views of adults with care and support needs are valued and that their choices are respected and followed wherever possible. The Care Act, for example, recognises the importance of "beginning with the assumption that the person is best-placed to judge their situation" and places a duty on local authorities to make sure that:
 - The person participates as fully as possible in decisions and is given the information and support necessary to enable them to participate
 - decisions are made having regard to all the person's circumstances (and are not based only on their age, appearance or other condition or behaviour)
 - any restriction on the person's rights or freedom of action is kept to the minimum necessary.
- 4.52 Section 1.14 of the Care and Support Statutory Guidance for the Care Act also states that, "Considering the person's views and wishes is critical to a person-centred system. Local authorities should not ignore or downplay the importance of a person's own opinions in relation to their life and their care. Where particular views, feelings or beliefs (including religious beliefs) impact on the choices that a person may wish to make about their care, these should be taken into account. This is especially important where a person has expressed views in the past, but no longer has capacity to make decisions themselves".
- 4.53 Practitioners often face a dilemma when balancing a person's views and wishes with the need to act to protect them from harm. S14.187 of the Care and Support Statutory Guidance for the Care Act states that "...agencies should reach an agreement about confidentiality and information sharing which is consistent with the Caldicott principles that:

- information will only be shared on a 'need to know' basis when it is in the interests of the adult
- confidentiality must not be confused with secrecy
- informed consent should be obtained but, if this is not possible and other adults are at risk of abuse or neglect, it may be necessary to override the requirement
- it is inappropriate for agencies to give assurances of absolute confidentiality in cases where there are concerns about abuse, particularly in those situations when other adults may be at risk".
- 4.54 s14.188 of the Care and Support Statutory Guidance for the Care Act states that, "Where an adult has refused to consent to information being disclosed for these purposes, then practitioners must consider whether there is an overriding public interest that would justify information sharing (for example, because there is a risk that others are at risk of serious harm) and wherever possible, the appropriate Caldicott Guardian should be involved. Confidentiality: NHS Code of Practice sets out guidance on public interest disclosure".
- 4.55 There was a risk that should Mrs H, or another party, complain to the Local Government and Social Care Ombudsman or to the NHS and Parliamentary Ombudsman about contact with her family without her consent, then the Ombudsman might reach a finding of maladministration which might also include a payment of compensation.
- 4.56 Common law, the Human Rights Act 1998 and the General Data Protection Regulations (GDPR), supplemented by the Data Protection Act 2018, regulate the processing of personal data about living individuals in the UK.
- 4.57 The GDPR defines personal data as: "any information relating to an identified or identifiable natural person ('data subject'); an identifiable natural person is one who can be identified, directly or indirectly, in particular by reference to an identifier such as a name, an identification number, location data, an online identifier or to one or more factors specific to the physical, physiological, genetic, mental, economic, cultural or social identity of that natural person" and sets out a number of principles covering its use and storage. Essentially, disclosure of confidential information is only allowed if consent to disclose is given, if disclosure is required by law or when it is justified in the public interest.
- 4.58 If Mrs H, or another party, complained about a breach of the GDPR there is risk that this would have resulted in a fine.
- 4.59 It is unlikely that Mrs H's decision to not allow information to be shared with her family posed a risk to other people. However, even where there is no public interest concern, practitioners should also consider and assess whether or not a person has the mental capacity to make a decision. In Mrs H's case

this would have included exploring the reasons why she did not want information shared with her family; and determining whether or not she understood, retained and used and weighed the information necessary to deciding that she did not want contact, in addition to her ability to communicate her decision.

- 4.60 Even if Mrs H had made a capacitous decision that there should be no information shared with her family, attempts by her family to contact services should not be rejected. The General Medical Council, for example, states that "In most cases, discussions with those close to the patient will take place with the patient's knowledge and consent. But if someone close to the patient wants to discuss their concerns about the patient's health without involving the patient, you should not refuse to listen to their views or concerns on the grounds of confidentiality. The information they give you might be helpful in your care of the patient".
- 4.61 The Royal College of Psychiatrists goes further in suggesting that professionals may initiate contact with others including family members, stating, "There is nothing to prevent you, or any other healthcare professional, from receiving information provided by any third party about the patient, as receiving information does not equate to disclosure. Indeed, provided the circumstances do not involve disclosure of confidential information, a healthcare professional may actively request information without the patient's consent. This can be an important part of the risk assessment of a patient".
- 4.62 The Consensus Statement from the Department of Health (2014) states "if the purpose of the disclosure of information is to prevent a person who lacks capacity from serious harm, there is an expectation that practitioners will disclose relevant confidential information". The document further indicates that where a person is at "imminent risk of suicide", this in itself will raise significant doubts about their mental capacity. In such cases the practitioner must record their decision about sharing information and the justification for this decision.
- 4.63 The document further adds that the duty of confidentiality in no way prevents practitioners from listening to the views of family members and friends, who may offer a vital insight into the individual's state of mind, thus aiding care and treatment. Good practice also includes providing families with non-person-specific information such as how to gain access to services in a crisis, as well as support services for carers.
- 4.64 Despite this, the GMC strikes of a note of caution and warns that, "You should, however, consider whether your patient would consider you listening to the views or concerns of others to be a breach of trust, particularly if they have asked you not to listen to specific people. You should also make clear that, while it is not a breach of confidentiality to listen to their concerns, you might need to tell the patient about information you have received from others for example, if it has influenced your assessment and treatment of the patient. You should also take care not to disclose personal information unintentionally for example, by confirming or denying the person's perceptions about the patient's health".

4.65 There is a distinction here between a practitioner disclosing personal data (which includes health information) to a person's family against the person's wishes and receiving information from a person's family. Mrs H's family did not ask that information be shared with them without Mrs H's consent but that their concerns about Mrs H were listened to.

5 ANALYSIS

- 5.1 Using this research and practice evidence base, best practice guidance and legislation it is possible to analyse the way in which the different organisations involved worked with Mrs H.
- 5.2 Mental capacity assessments and the significance of organic brain / frontal lobe syndrome in relation to Mrs H's mental capacity.
- 5.3 Mrs H was given two diagnoses which involved executive functioning. The first was on 04/02/20 when a consultant psychiatrist at Redwoods Centre reviewed and formulated Mrs H's condition as personality disorder, mood disorder, temporal lobe epilepsy and recently diagnosed organic brain syndrome (OBS) with specific executive functioning impairment. The psychiatrist highlighted Mrs H's impulsivity, lack of awareness, emotional dysregulation and poor planning and judgement with a lack of insight. Because of this the psychiatrist did not believe that Mrs H's return home was a safe option and recommended that Mrs H be found a 24-hour care placement.
- 5.4 Subsequently, on 17/02/20 a formal mental capacity assessment was undertaken by ASC, with input from MPFT, with the outcome that Mrs H lacked the mental capacity to make decisions about her future care needs and residence. Mrs H moved to The Care Home, a residential care home operated by The Care Home Owners.
- 5.5 However, a few months later, the Care Home staff questioned Mrs H's lack of capacity, based on the impression they had formed of her. On 06/05/20 a registered nurse working at The Care Home completed a mental capacity assessment (and consulted a social worker) and deemed Mrs H to have capacity for future planning (believed by The Care Home Owners to mean that Mrs H had capacity to determine where she should live).
- The care manager at The Care Home viewed their role to be that of an advocate for Mrs H and to relate Mrs H's views to other professionals. Registration with the Care Quality Commission (CQC) places wider set of responsibilities upon care managers including the duty to protect Mrs H and ensure her care needs were met.
- 5.7 The manager at The Care Home reported that Mrs H was using her wheelchair to ram into other people when she was upset. Mrs H's family believe that because Mrs H had been aggressive towards other residents, was extremely agitated and shouted and screamed, it was to The Care Home's benefit that Mrs H no longer resided with them.
- 5.8 There was no full record made of the mental capacity assessment completed on 06/05/20, nor is there a requirement for all mental capacity assessments

and their outcomes to be recorded. Consequently, it is not clear how the conclusion of capacity was reached by The Care Home Owners and whether it took into account Mrs H's impairment in executive functioning diagnosed on 04/02/20.

- 5.9 A multi-disciplinary team meeting involving health, ASC and The Care Home Owners held on 07/05/20 agreed to a trial period for Mrs H at home, and Mrs H returned home on 16/05/20. One of Mrs H's daughters told the review writer that she explained to a social worker that she felt it was not safe for Mrs H to return home but was told that returning home was an arrangement that would "most likely go wrong but it was a risk that should be taken". Whilst trials of different support and accommodation options are useful, they should at least be based on a reasonable belief that they will work over an agreed timescale, and if they do not, there should be a rapidly implemented alternative.
- 5.10 On 11/06/20 a social worker from ASC, following an assessment by telephone rather than face to face due to Covid-19 restrictions, noted that Mrs H had capacity and that deprivation of liberty safeguards were not applied for because Mrs H did not have short-term memory loss, was able to understand her care and support needs and was able to have a full and relevant conversation. There is no record that the diagnosis of conditions which effect executive functioning were considered in reaching this conclusion.
- 5.11 Mrs H was assessed again on 18/06/20 by the AMHP and two visiting doctors. They determined that Mrs H did not present with a mental disorder requiring admission or treatment. The report noted that Mrs H had mental capacity about her care and treatment and all other matters, but there is no evidence that Mrs H's diagnosis of impaired executive functioning was considered.
- 5.12 On 29/06/20 a mental health risk assessment was undertaken. Practitioners undertaking the risk assessment decided it was not necessary to assess Mrs H's mental capacity at that time because Mrs H's "mental capacity with regards to her care, support and accommodation needs, has been assessed several times over recent weeks and [she] has been assessed as having mental capacity".
- 5.13 Mrs H challenged her diagnosis of dementia and on 21/07/20 was reviewed by a consultant psychiatrist and a second diagnosis was given since there was "clear evidence of Frontal-Lobe type psychopathology...not necessarily amounting to a clear diagnosis of dementia (i.e. not neurodegenerative and progressive) but liable to cause [Mrs H] as much or more difficulty than a dementia diagnosis would". The psychiatrist noted Mrs H's emotional changeability, poor social skills and lack of empathy and that Mrs H could be easily provoked to temper, showed no room for compromise or negotiation, and had poor insight. According to the psychiatrist, these could be best explained by a diagnosis of frontal lobe syndrome.
- 5.14 On 31/07/20 Mrs H's consultant psychiatrist and another psychiatrist concluded that, due to an impairment of executive functioning, Mrs H did not have capacity to decide to stop taking her medication. It does not appear that

- this led to a review of Mrs H's capacity to make decisions about her care and support needs and where she lived.
- 5.15 On 28/01/21 Mrs H was admitted to hospital because she had attempted suicide by overdose. The mental health liaison team concluded that Mrs H was not actively suicidal and had "capacity to make her own decisions". On 12/03/21 Mrs H took another overdose.
- 5.16 Mental capacity is time and decision specific and can vary over time and decisions. It is possible that Mrs H had capacity to make a specific decision on a particular day, but not the next and that she may have had capacity to make decisions about her own self-hygiene, but not about her medication. Practitioners from The Care Home Owners cited Mrs H's ability to clean her own room, attend to her personal hygiene needs and to help prepare the dining room before meals as suggestive of her capacity to look after herself and to determine where she should live. This perhaps did not consider the wider picture and history of Mrs H's complex physical health and fluctuating mental health needs, Mrs H's executive functioning, mood and aggression.
- 5.17 Practitioners also felt that Mrs H was able give the impression that she was fully capacitous, particularly with those who were new to her and who did not have the benefit of experience working with her over any length of time. This has also been related to problems in Mrs H's executive functioning, typified by an ability to talk convincingly whilst being unable to turn decisions into action. Somewhere in Mrs H's contact with agencies, the awareness and significance of Mrs H's organic brain syndrome/ frontal-lobe disorder seems to have been lost or disregarded.
- 5.18 Thus, some practitioners treated Mrs H as if she had no condition which might lead to, in the terms of the Mental Capacity Act, an impairment in the functioning of the mind or brain. In the absence of this awareness, Mrs H's strongly expressed views were accepted as her lifestyle choice. Whilst the presence of an impairment in the functioning of the brain or mind is a necessary but insufficient component in the process of making a mental capacity assessment, the fact that Mrs H could assert her beliefs forcefully does not mean that they were capacitous. In the last year of Mrs H's life her mental capacity was assessed seven times. On two occasions it was concluded that she did not have capacity, and on five occasions it was concluded that she did. It is not clear whether the groups of professionals who reached different conclusions ever conferred. More careful attention to Mrs H's executive functioning may have led to different outcomes.
- 5.19 The lack of awareness of the effects of organic brain/ frontal lobe syndrome seemed to lead to practitioners trying to work around Mrs H at her own pace and to take decisions about her care that were acceptable to her, without realising that her views may be influenced the presence of an impairment in executive functioning and that her decisions not to let carers into her home may be based upon paranoia. Notably, Mrs H had stopped taking her antipsychotic medication at this time.
- 5.20 Between June and August 2020, the care that Mrs H received from services was incrementally reduced based on the understanding that Mrs H made

capacitous decisions. This was despite a threat of suicide in June 2020, despite Mrs H's family raising concerns in June 2020 that her presentation and agitation were significantly increasing, and despite reports that during August 2020 Mrs H made an increasing number of distressing and, at times, angry and accusatory telephone calls to her GP surgery, the out of hours service, MPFT, her family and the domiciliary care agency. Not all the details of the assessment of capacity were shared and it is not clear if all the agencies knew of Mrs H's diagnosis when making mental capacity assessments.

- 5.21 Decision points were not factored into further decision making. Assessments did not influence further assessments. There was no retrospective review of how agencies came from one decision to another. There was a tendency to consider each assessment of mental capacity as a discrete event and to only focus on Mrs H's mental capacity operationally rather than strategically (i.e., in terms of consistency, fluctuation and of deeper questions that went beyond Mrs H's ability to talk convincingly). This approach has also been described as considering mental capacity as a "video" rather than as a "snapshot".
- 5.22 In conclusion, the significance of organic brain/ frontal lobe syndrome in relation to Mrs H's mental capacity was not consistently recognised and considered.

5.23 **Best Interests**

- 5.24 After Mrs H was assessed as lacking capacity in February 2020, according to ASC a Best Interests meeting was held in March which determined that it was in Mrs H's best interests to reside in a nursing home placement once she was discharged from the Redwoods Centre. According to ASC no family members were involved in, and both ASC and MPFT state that they have no record of, this Best Interests meeting. It is not possible to determine the degree to which the process for the best interests decision followed best practice, or indeed who was involved in the meeting.
- 5.25 It should also be noted that Shropshire has its own multi-agency Mental Capacity Act Guidance https://shropshire.gov.uk/media/10915/mca-multi-agency-guidance-policy-october-2018.pdf, available from October 2018. This guidance also referred to the MCA Code of Practice 2005, best interests decisions and the statutory checklist which states "The views of other people family members, partners, carers and other relevant people are to be consulted (if it is "practicable and appropriate") as to what might be in the person's best interests". Unless Mrs H had previously instructed that her family were not to be consulted it would have been appropriate to have involved them in the best interests meeting.
- 5.26 If it had not been appropriate for members of Mrs H's family, who were not estranged from Mrs H at the time, to have been involved in the best interests meeting, as the decision was about a change in residence and there was no one else to consult with other than paid professionals, then according to the statutory checklist, an Independent Mental Capacity Advocate should have been appointed.

- 5.27 Risks of suicide, overdose and seizure and decisions relating to the administration of medication
- 5.28 During the time covered by this safeguarding adults review, Mrs H was prescribed different types of tablets, together with inhalers, eye drops and gel. These included an antidepressant, two anti-epileptics, two painkillers and a minor tranquiliser. Mrs H did not always adhere to treatment. For example, on 09/09/19 the Crisis Team discovered that Mrs H had stopped taking citalopram (a medicine that treats low mood and panic attacks).
- 5.29 Mrs H also had a history of overdose on medication and self-harm in other ways. Mrs H's family said that "Our mother attempted to commit suicide a number of times throughout her life, including multiple times within the final 18 months of her life." That Mrs H had a history of medication overdoses since 1981 was noted in a mental health risk assessment undertaken in June 2020. MPFT considered all of these overdoses to be intentional and practitioners undertaking the mental health risk assessment considered these episodes a suicide risk. Mrs H first became involved with the MFPT Crisis Team on 25/06/19 due to an overdose and took overdoses on 01/09/19 and 20/09/19. On 26/09/19 Mrs H cut her wrists whilst in the Redwoods Centre. There is also a reference made by MPFT at this point to Mrs H previously attempting suicide using a ligature. On 06/10/19 Mrs H overdosed again.
- 5.30 Mrs H spoke about her thoughts and fears of overdosing on medication. For example, in January 2020 Mrs H talked of suicide to a psychologist at the Redwoods Centre. In June 2020, during a Mental Health Act Assessment, Mrs H voiced thoughts about ending her life through overdose if she was detained and returned to hospital or residential care. On 19/06/20, shortly after Mrs H's return home from The Care Home, Mrs H told the MPFT Hospital Avoidance Team that she would harm herself and knew how to do it. Mrs H said that she felt unsafe around medication and had thoughts of ending her life through overdose.
- 5.31 This prompted a community psychiatric nurse and Mrs H's social worker to arrange for Mrs H's medication to be locked away on 19/06/20 so that Mrs H would not have unsupervised access to it. Four care visits a day were commissioned to support Mrs H with medication and to assess her welfare. There was, however, some evidence that Mrs H was not engaging with the care visits. On 25/06/20, for example, Mrs H refused to let anyone into her home. ASC were aware of this.
- 5.32 On 29/06/20 a mental health risk assessment was undertaken jointly by health, adult social care and The Domiciliary Care Agency. The assessment noted that Mrs H's medication was safely stored in a locked box to which only the carers had access and set an action for the Multi-Disciplinary Team to work collaboratively with Mrs H to develop an individualised safety plan. This was good practice and in line with the recommendations of the Royal College of Psychiatrists, but it is not clear whether a safety plan was drawn up. The risk assessment on its own did not include the components of a safety plan as described by the Royal College.

- 5.33 Mrs H continued to not always adhere to treatment and this had an impact on her health. For example, on 07/08/20 Mrs H refused to take her medication at lunchtime, and in July 2020 Mrs H told practitioners that she was no longer going to take olanzapine (anti-psychotic medication), although, according to MPFT, Mrs H did agree to continue to take it until instructed to stop. In August 2020, however, The Domiciliary Care Agency stated that Mrs H had stopped taking olanzapine and commented in their care notes that Mrs H's refusal to take anti-psychotic medication was having a detrimental effect on her mental health.
- 5.34 On 13/08/20, Mrs H attended A&E claiming to have experienced a seizure because she did not have access to her medication. Mrs H was reported to be very angry that her medication had been locked away and voiced this displeasure forcefully. Despite Mrs H's GP's concern that there was no evidence for Mrs H's seizure, on 14/8/20 the GP and the social worker decided that the risk to Mrs H's physical health outweighed the risk of overdose and that Mrs H should be given access to her medication. ASC, in consultation with MPFT, cancelled Mrs H's four daily medication and welfare assessment visits, reducing the number of visits to two a week.
- 5.35 This was a pragmatic solution but avoided the underlying matter of Mrs H's refusal to allow carers in and the context of her history of overdose and varying adherence to taking medication. The result was a fairly uncontrolled situation with no checks on how much medication Mrs H had taken. According to ASC, a Community Mental Health Nurse was monitoring Mrs H's mental health and medication, but there is no mention of any visits to do this in the chronology supplied by MPFT. The Domiciliary Care Agency were not asked to monitor Mrs H's medication intake.
- 5.36 Less than a month before, Mrs H had made a request to stop her medication and Mrs H's consultant psychiatrist and another practitioner had concluded that she lacked capacity to make this decision due to an impairment of executive functioning. Despite this background practitioners took decisions which reduced their ability to monitor Mrs H's medication intake and consequently reduced their ability to protect Mrs H from self-harm and self-neglect.
- In subsequent months, the care visits, now reduced to two per week, went unanswered by Mrs H on a more frequent basis. Although a Section 117 review was conducted on 12/11/20, ASC are unable to confirm that Mrs H was taking the correct amount of medication. There were indications of further threatened and actual self-harm by overdose. For example, on 25/12/20 Mrs H told her grandson that she was going to take more than the prescribed dose of tablets and then on 28/01/21 and 12/03/21 Mrs H took an overdose However, the decision to allow Mrs H to control and administer her medication was not reviewed, nor did there appear to be any efforts to introduce or stepup the monitoring of Mrs H's medication intake.
- 5.38 It does not appear that the mental health risk assessment was reviewed to specify how that risk of self-harm and suicide was to be managed in light of Mrs H's ability to access her medication.

5.39 On 21/03/21 Mrs H was found unconscious on the floor with tablets strewn across her kitchen worktop. Mrs H was later described by a consultant neurologist as profoundly unconscious as a result of a fall of unknown cause which might have been related to a seizure or cardiac event.

5.40 **Self-harm and self-neglect**

- 5.41 It was clear that Mrs H self-harmed and attempted suicide, but it was not so obvious that she self-neglected.
- 5.42 Mrs H did not present as self-neglecting in the terms of her cleanliness and keeping house. On 13/03/21, for example, Mrs H was visited at home by her mental health care-coordinator and her social worker who found her to be well kempt, apparently eating and drinking normally, and the house tidy. According to The Care Home Owners, whilst Mrs H was at The Care Home she cleaned her own room, attended to her personal hygiene needs and helped the care team prepare the dining room before meal times.
- 5.43 However, there was evidence of self-neglect in Mrs H's rejection of care visits (ASC state that it was not unusual for Mrs H to not answer the door to carers when they visited) and her decisions to stop taking particular medication, particularly where this was done without consultation with her GP.
- 5.44 Mrs H's decision to stop taking her anti-psychotic medication may have had an impact on her mental state, including suicide attempts, how she felt about her family, and her engagement with services. It is not clear whether the reasons for her wishing to stop taking Olanzapine were explored with her. Mrs H may have found side-effects unpleasant or the effects of the medication oppressive upon her thoughts. Further understanding of the context of Mrs H's wishes may have led to different decisions, for example, the exploration of alternative anti-psychotic medication which was more sympathetic to Mrs H's mental health needs and wishes. Drawing on Preston Shoot and Braye's work, more may have been done to seek to understand the meaning and significance of the self-neglect, taking account of the individual's life experience.

5.45 Trauma informed approach

- 5.46 It is clear from the records that at times carers from The Domiciliary Care Agency experienced Mrs H to be very angry and upset and that Mrs H shouted and swore at them and accused them of lying. There are a number of instances of carers reporting that they tried to explain matters to Mrs H (for instance, when she accused them of lying), but Mrs H would not listen. One carer reported on 13/08/20 that they asked Mrs H to "calm down" several times before ending a telephone call with Mrs H. It is possible this approach may have inflamed Mrs H's anger and distress.
- 5.47 In MPFT's professional view Mrs H's childhood trauma had as much impact on her as the other mental health and neurological conditions from which she suffered. Because of Mrs H's history MPFT carried out a sexual safety risk assessment and mental health practitioners worked with Mrs H using a trauma-informed approach. According to MPFT it was well known amongst

- agencies working with Mrs H that she had experienced trauma in childhood. The social worker who worked with Mrs H was aware of this too.
- 5.48 In light of Mrs H's childhood trauma, other agencies' ability to effectively engage with Mrs H may have been improved by the adoption of trauma-informed approaches. Some ways of working in a trauma-informed way and engaging with people who are distressed, are given in section 4 and further guidance is given in the Trauma-Informed Toolkit published by the Scottish Government https://www.gov.scot/publications/trauma-informed-practice-toolkit-scotland/pages/12/#AP2
- 5.49 The timeliness of action to be taken when carers were unable to access Mrs H's home for care visits.
- 5.50 ASC issued no specific instruction and reached no agreement with The Domiciliary Care Agency about when ASC's avoidance team should be contacted if carers had been unable to enter Mrs H's property because, for example, she refused to let them in, or did not answer the door.
- 5.51 There was no agreement about how many "frustrated" or no-contact care visits were attempted before alerting the avoidance team. Carers were sometimes able to have a discussion with Mrs H through her kitchen window, but there did not appear to be any discussion with ASC about the degree to which this form of contact met Mrs H's care and support needs. The Domiciliary Care Agency state that they counted a discussion through the kitchen window as a visit. It was not unusual for Mrs H to not answer the door, but according to The Domiciliary Care Agency it was unusual for Mrs H to not respond to two visits in a row. The last time the carers entered Mrs H's property before she was found on the floor on the evening of 21/03/21 was on 02/03/21, when a carer took Mrs H to a supermarket to buy food. Mrs H was receiving only two care calls per week at this time.
- The last time The Domiciliary Care Agency carers spoke to Mrs H was on 19/03/21, when two attempted visits were made. Mrs H turned the carers away on the first visit and spoke to them through her kitchen window on the second. Carers attempted visits on 20/03/21 and 21/03/21 with no reply, and then in the evening of the 21/03/21 they alerted the ASC avoidance team and the police. Mrs H was found on the floor.
- 5.53 Given that Mrs H was at risk of falls due to cerebral palsy and epilepsy and that she had a history of not taking the correct medication an agreement about the timeliness of the action in the event of non-contact would have been appropriate.
- 5.54 Recognition of Mrs H's psychosis and the affect this had on her behaviour and on family dynamics.
- 5.55 Mrs H's family felt that at times agencies did not fully recognise the extent of Mrs H's psychosis and delusional belief system. They considered that it took some time for agencies to recognise that Mrs H should be admitted to a mental health hospital, and stated that it was only when a nurse visited Mrs H

- at home and was frightened of her because of her behaviours that Mrs H was admitted to the Redwoods Centre.
- 5.56 Mrs H's family said that Mrs H's psychosis led her to be aggressive and to make allegations towards her husband and children. For example, Mrs H accused one of her daughters of stealing a lamp from her home, when the lamp had been removed to be repaired as it was broken. Mrs H's family supplied the SAR author with some of the recorded telephone messages that Mrs H made to them and to her husband and grandchildren. These must have been very distressing for Mrs H's family to hear.
- 5.57 Mrs H's family felt that agencies did not pay sufficient attention to these factors. For example, a small portable television from Mr and Mrs H's home had been moved to her husband's care home so that he could watch it in his room. Mrs H's family told the review writer that she made many phone calls demanding that she should have it back and that even though she could barely walk, Mrs H telephoned for a taxi and took the large flat screen television from the living room to the care home to demand that it be exchanged for the portable one. On arrival at the care home, she became threatening towards the care home staff who called for assistance from Mrs H's family and from the police. Mrs H's family said that agencies' focused on trying to resolve the matter of who should have which television and did not recognise Mrs H's behaviour as bizarre or due to mental health needs, despite there being a pattern of other irrational behaviours.
- 5.58 Mrs H had made allegations that her husband had abused her, when according to Mrs H's family, she was abusing him. There was no evidence that Mrs H was abused by her husband, who was described by their family as the "rock that held it all together". The incident with the television was an example of Mrs H's controlling behaviour over her husband. Mrs H's family felt that they and their father were portrayed as being in the wrong and that there was insufficient checking by agencies to obtain a more informed view of what was really happening. Mrs H's family also felt that Mrs H's accusations that her husband was abusing her resulted in agencies giving preference to her version of events, by moving him out of his home into a care home.

5.59 Listening to and involving Mrs H's family

- 5.60 Mrs H's family stated that they tried to do whatever they could to keep Mrs H in residential care as they did not feel it was safe for her to live at home, but they were not listened to. They felt they were not equipped to deal with Mrs H being at home, and that Mrs H was not fit and well enough to be alone. This was exacerbated by restrictions placed on carers, for example, who were not allowed to change light bulbs for Mrs H. Mrs H telephoned her family frequently asking daily for help at home, which they provided as best they could. Mrs H was not stable on her feet and her family believe that she broke the lamp in a fall.
- 5.61 It appears that Mrs H had at times given permission for her family to be involved and contacted by agencies about her, but then withdrew permission for this. For example, on 09/09/19 Mrs H gave ASC permission to speak to

- her daughter about an assessment of care and support needs but on 26/06/20 a social worker noted that Mrs H had instructed them not to contact her family.
- 5.62 Mrs H's family had expressed concerns about Mrs H to her GP in emails, but Mrs H also told her GP that she did not want her family contacted about her physical or health mental health. MPFT reported that they had multiple discussions with Mrs H in which she both consented and refused for different family members to be given information about her.
- 5.63 Consequently, practitioners faced a dilemma about contacting Mrs H's family and what to discuss with them. There is, however, a distinction between Mrs H's specific refusal to allow professionals to pass health information to family members, and the more general request for professionals to not contact her family members at all. Similarly (as outlined in section 4), there is also a difference between practitioners obtaining information from family members about their concerns or about a person's background and sharing confidential information with them.
- 5.64 Whilst the mental health risk assessment made in June 2020 does mention that information was taken from Mrs H's family, there was no contact with Mrs H's family to gather background information when capacity assessments or Best Interests decisions were made, nor when it was decided to give Mrs H access to her medication.
- 5.65 Mrs H's son said that he attended one meeting with doctors and Mrs H at the Redwoods Centre, but he was unable to express his views and concerns because when he tried to do so Mrs H became aggressive towards him.
- 5.66 No mental capacity assessment appears to have been made about whether Mrs H had the capacity to decide to exclude her family and the significance Mrs H's diagnosis of organic brain/ frontal lobe syndrome does not appear to have been acknowledged or understood.
- 5.67 Mrs H's family also wrote two letters to ASC with concerns and questions about Mrs H's care and support. According to ASC there is no record that these letters were acknowledged or responded to.
- The first letter was received from Mrs H's family by ASC on 11/05/20 and raised concerns about a perceived lack of clarity in support planning, as this had changed three times within the space of three weeks, and the effect of this on Mrs H's mental and emotional wellbeing. The letter also raised concerns that Mrs H's complex needs, her history of mental illness and how this manifested itself, were not fully understood or acknowledged within the support plan. The letter expressed a lack of confidence in the proposed plan for Mrs H to return home as the level of support provided would be insufficient and concerns over how Covid 19 isolation requirements would be managed. Mrs H's family questioned Mrs H's mental capacity and requested that a risk assessment of Mrs H's home be undertaken to assess access and other health and safety issues. Mrs H's family also expressed their frustration because their correspondence and concerns had not been responded to.

- 5.69 The second letter was received by ASC on 15/06/20. Mrs H's family related further concerns about what they saw as ASC's failure to involve them in Mrs H's care planning; concerns over a newly allocated social worker based on their knowledge of the Mrs H's history and that there was a lack of clarity as to who would be co-ordinating Mrs H's support. Mrs H's family also raised concerns that Mrs H's presentation and agitation were significantly increasing and would not be manageable in the community. Mrs H's family also asked several questions about who was responsible for various decisions.
- 5.70 ASC is unsure if these letters were responded to. Mrs H's family stated that their second letter was handled through the local authority's complaints process, which concluded that no information could be given to Mrs H's family because of data protection requirements. Mrs H's family confirmed that they did not receive a response to their first letter and stated that in general their correspondence and concerns were largely ignored. This lack of response understandably contributed to Mrs H's family's lack of confidence in those responsible for Mrs H's care.
- 5.71 ASC may not have been able to answer all of Mrs H's family's questions without disclosing information that Mrs H had not given permission to be revealed, but her family's concerns and requests that, for example, Mrs H's medical history be taken into account, should have been considered and responded to. Services should have been reviewed on the basis of concerns raised by Mrs H's family and where appropriate redesigned to meet Mrs H's complex needs. This would have demonstrated more respect for Mrs H's family's feelings and concerns and may have engendered greater confidence in services.
- 5.72 In conclusion, agencies should have assessed whether Mrs H had the mental capacity to make the decision to exclude her family and could have obtained information from her family to help inform decisions about Mrs H's care and support. This could have been done without infringing data protection legislation and the Care Act guidance. Responding to family concerns should have been given more priority.

5.73 Case leadership and coordination

5.74 There is evidence of some inter-agency consultation and decision making, including Mrs H's GP and social worker working together to make the decision to allow Mrs H access to her medication. The AMHP was involved at one stage and concerns that Mrs H was being abused by her husband were brought to a Multi-Agency Risk Assessment Conference (MARAC) (but since there was no evidence, no action was taken) but otherwise there was no multi-agency review of Mrs H's history and of the effectiveness of interventions. There was no lead agency or primary decision maker. Mrs H's allocated social worker changed over time and, according to her family, sometimes Mrs H had no allocated social worker. This is not necessarily unusual since allocation to a social worker is based on assessed and perceived risk and priority.

6. FINDINGS

- 6.1 The significance of organic brain/ frontal lobe syndrome in relation to Mrs H's mental capacity was not consistently recognised and considered.
- 6.2 Mrs H was diagnosed with organic brain syndrome with specific executive functioning impairment and subsequently with frontal lobe syndrome. Both diagnoses indicated an impairment to the functioning of the mind or brain, which is one part of the mental capacity assessment under the Mental Capacity Act.
- 6.3 The Code of Practice for the Mental Capacity Act is clear that mental capacity should be presumed unless demonstrated otherwise and that a diagnosis or a person's appearance is an insufficient basis from which to conclude a lack of capacity. Mental capacity is also time and decision specific and can vary over time but a repeated mismatch between what a person says and what they do when required to act may suggest that they lack the mental capacity to make the decision in question.
- 6.4 Two out of the seven mental capacity assessments undertaken in the last year of Mrs H's life concluded that Mrs H did not have capacity regarding decisions about her care and treatment. Knowledge and understanding of the significance of organic brain / frontal lobe syndrome for mental capacity assessments, however, either became lost or was not shared. (See Recommendations 1 and 2).
- 6.5 The rationale and process for making a best interests decision was not recorded.
- 6.6 Following the first mental capacity assessment in February 2020 which concluded that Mrs H did not have capacity to decide on her support needs and residence, a best interests meeting was held. This meeting determined that it was in Mrs H's best interests to reside in a nursing home placement once she was discharged from the Redwoods Centre. ASC and MPFT have no records of this meeting and therefore the justification for the decision is not clear. Mrs H's family was not involved in the decision and it would appear that it was appropriate for them to have been consulted. (See Recommendations 3 and 4).
- 6.7 More consideration should have been given to measures to protect Mrs H from self-harm and self-neglect.
- 6.8 Following the decision to allow Mrs H access to her medication, instead of redoubling efforts to protect Mrs H given her previous history of overdose and variable adherence to treatment, practitioners took decisions which reduced their ability to monitor Mrs H's medication intake and consequently reduced their ability to protect Mrs H from self-harm and self-neglect.
- 6.9 Despite the continued overdoses, Mrs H's access to medication was not reviewed, nor did there appear to be any efforts to introduce or step-up the monitoring of Mrs H's medication intake. (See Recommendation 5)

- 6.10 Good practice was applied in conducting a mental health risk assessment and identifying the need for a safety plan, however it is not clear whether a safety plan was developed and no actions consistent with one were undertaken.
- 6.11 The Royal College of Psychiatrists recommends that a safety plan should be drawn up for a person at risk of suicide and that it should be developed in consultation with the person. It is not clear whether a safety plan was developed for Mrs H. (See Recommendation 6).
- 6.12 Trauma informed approaches may have enabled greater understanding of Mrs H's situation.
- 6.13 MPFT used a trauma-informed approach. In light of Mrs H's complex presentation and her history, the adoption by other agencies, including The Domiciliary Care Agency, of trauma informed practice and approaches to support people who self-neglect outlined in section 4 of this report may have resulted in more effective strategies for working with Mrs H. (See Recommendations 6 and 7)
- 6.14 There was no agreement in place about the timeliness of action to be taken when carers were unable to access Mrs H's home for care visits.
- 6.15 ASC issued no specific instruction and reached no agreement with The Domiciliary Care Agency about when MPFT's avoidance team should be contacted if carers had been unable to enter Mrs H's property because, for example, she refused to let them in, or did not answer the door. There was no agreement about how many "frustrated" or no-contact care visits were attempted before alerting the avoidance team. Carers were sometimes able to have a discussion with Mrs H through her kitchen window, but there did not appear to be any discussion with ASC about the degree to which this form of contact met Mrs H's care and support needs.
- 6.16 Given that Mrs H was at risk of falls due to cerebral palsy and epilepsy and that she had a history of not taking the correct medication it would seem appropriate that there should have been some agreement about the timeliness of the action in the event of non-contact. (See Recommendation 8)
- 6.17 More attention could have been given to the legal framework in handling Mrs H's changing wishes in respect of her family and responding to family concerns should have been given more priority.
- 6.18 Agencies should have assessed whether Mrs H had the capacity to make the decision to exclude her family, and if they concluded that Mrs H did have capacity to make this decision, there were times when they could have obtained information from Mrs H's family to help inform other decisions about Mrs H's care and support, without infringing data protection legislation and the Care Act guidance. More prioritisation to responding to family concerns should have been given. (See Recommendation 9).
- 6.19 Mrs H's family feel that agencies gave more credence to Mrs H's version of events than they did her families. Professionals have to strike a balance

- between "hearing" the voice of the person they are working with and seeking verification from others, when working with individuals who have a history of Psychosis
- 6.20 Advice for families on how to support their members with mental health needs which contains information on managing behaviours, coping and who to contact for support should be developed (see Recommendation 10).

7. RECOMMENDATIONS

- **7.1 Recommendation 1.** Partner agencies should promote understanding of executive brain function in relation to the Mental Capacity Act and decide how this knowledge can be disseminated to direct care providers. This could form part of the preparation for the revised code of conduct for the Mental Capacity Act
- **7.2 Recommendation 2.** The Shropshire Safeguarding Community Partnership should issue guidance on correctly recording mental capacity assessments and on sharing health information relevant to mental capacity assessments (such as neurological conditions or impairments to the functioning of the mind or brain) with other relevant agencies to inform their mental capacity assessments.
- **7.3 Recommendation 3.** The Shropshire Safeguarding Community Partnership should amend the Shropshire Multi-Agency Mental Capacity Act Guidance to specify when bests interests' decisions should be recorded, providing the rationale and a record of those involved and consulted, and further promote the document to practitioners in partner agencies.
- **7.4** Recommendation 4. Partner agencies should ensure that key decisions about, for example, where someone should live or whether or not they want contact with their family should be accurately recorded and updated. This could be supported by training, instructions, guidance and discussion in one-to-one and case meetings.
- **7.5** Recommendation 5. Partner agencies should decide how best to ensure that decisions are reviewed, and action taken when incidents suggest that more needs to be done to protect a person from self-harm or self-neglect. ASC and MPFT should review their guidance on risk assessments.
- **7.6** Recommendation 6. Partner agencies should ensure that their staff are equipped with best practice tools for working effectively with people with care and support needs including that of Royal College of Psychiatrists (suicide and self-harm), the guidance on working with people who self-neglect and on trauma-informed approaches.
- **7.7 Recommendation 7.** Partner agencies should decide how best to ensure that commissioned services adopt best practice, including trauma-informed approaches.
- **7.8** Recommendation 8. ASC should ensure that clear instruction is given to commissioned services about timeliness of action when care calls are not

responded to, and this should be determined by the assessment of risk to the person.

- **7.9** Recommendation 9. Partner agencies should promote greater understanding of the legal framework around confidentiality and in handling a person's wishes in respect of their family.
- **7.10 Recommendation 10:** A leaflet could also be created with support from MPFT, which provides advice for families on how to support their members with mental health needs and contains information on managing behaviours, coping and who to contact for support.

APPENDIX 1: HUMAN RIGHTS ACT

All public sector bodies, whether or they are directly or indirectly funded by the UK Government have a duty under the Human Rights Act to discharge the State's positive obligations under the European Convention on Human Rights:

- Article 2 to protect life
- Article 3 to protect against torture, inhuman or degrading treatment
- Article 5 to protect against unlawful interferences with liberty, including by private individuals
- Article 8 to protect physical and moral integrity of the individual (especially, but not exclusively) from the acts of other persons

APPENDIX 2: MENTAL CAPACITY ACT

The following principles apply for the purposes of the Mental Capacity Act:

A person must be assumed to have capacity unless it is established that he lacks capacity.

A person is not to be treated as unable to make a decision unless all practicable steps to help him to do so have been taken without success.

A person is not to be treated as unable to make a decision merely because he makes an unwise decision.

An act done, or decision made, under this Act for or on behalf of a person who lacks capacity must be done, or made, in his best interests.

Before the act is done, or the decision is made, regard must be had to whether the purpose for which it is needed can be as effectively achieved in a way that is less restrictive of the person's rights and freedom of action.

The Mental Capacity Act requires a three-stage test of capacity to make decisions:

- 1. Is the person unable to make the decision? i.e. are they unable to do at least one of the following things:
 - Understand information about the decision to be made, or

- Retain that information in their mind, or
- Use or weigh that information as part of the decision-making process, or
- Communicate their decision (by talking, using sign language or any other means)
- 2. Does the person have an impairment of, or a disturbance in the functioning of, their mind or brain, whether as a result of a condition, illness, or external factors such as alcohol or drug use?
- 3. Does the impairment or disturbance mean the individual is unable to make a specific decision when they need to? Individuals can lack capacity to make some decisions but have capacity to make others, so it is vital to consider whether the individual lacks capacity to make a specific decision at a specific time.

APPENDIX 3: ADULT SAFEGUARDING

The local authority must make enquiries (or cause enquiries to be made) where an adult:

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

The local authority must make (or cause to be made) whatever enquiries it thinks necessary to enable it to decide whether any action should be taken in the adult's case and, if so, what and by whom.

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